“KNOWING MY STATUS” AND THE PMTCT PROGRAM

"KNOWING MY STATUS" AND THE PMTCT PROGRAM: PRESERVATION OF LIFE STRATEGIES POST HIV DIAGNOSIS

By

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ABSTRACT

In this thesis, I focus on the health-seeking experiences of women diagnosed with HIV in a prevention of mother-to-child transmission (PMTCT) program in Lilongwe, Malawi. Based on ethnographic research, which included participant observation, in-depth interviews, and focus groups with women participating in the program, I explore women's motivations for HIV testing, capacity to engage in health interventions, and the meaning they give to life with HIV. While the PMTCT program is delivered at a local site, it is produced at a local-global intersection where local actors and international processes converge. I utilize critical approaches to medical anthropology to examine the global political and economic context of local life and the PMTCT program. The program is one where lives are at stake; where women learn of their HIV status, available medical interventions, and work to prolong their lives. Women engage in this program because nurses communicate messages of hope in the face of HIV. These messages are the new benefits of HIV in countries with growing opportunities for therapeutic intervention. This thesis contributes to an emerging health/social science literature that seeks to develop successful HIV interventions by focusing on patients' experiences of HIV and HIV therapies newly available in Africa. Yet, as reported in this study, women experience barriers to the purported benefits because of the dominant health-delivery paradigm. Specifically, its verticality; human resources, counselling, and education limitations; and structural constraints that prevent women's full participation in the program. Successful PMTCT programs will need a more comprehensive approach to health and disease treatment, to provide more than just techno-medical solutions. Successful therapeutic interventions need to not only provide drugs, but also address other barriers to health maintenance.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE – INTRODUCTION

This thesis is fundamentally about HIV diagnosis at a particular point in the lives of a group of women, and as part of a distinct HIV intervention, a prevention of mother-to-child transmission (PMTCT) program in Lilongwe, Malawi. Moreover, as I will demonstrate throughout this thesis, HIV diagnosis is complex: individual lives intersect with therapeutic narratives, and global processes manifest locally. Thus, multiple paths lead to and from HIV diagnosis. In this thesis I explore many of these. Principally, I focus on the salient narratives that emerged from my ethnographic research in Malawi and those illuminated by my position as a medical anthropologist. In this chapter, I introduce the thesis and the main theoretical propositions that inform it. However, instead of a comprehensive literature review here, I integrate references to literature throughout the thesis when they are relevant to the thesis argument and narrative.

The exploration of HIV diagnosis has temporal and spatial qualities, and my research takes many paths of inquiry from the point of entry of a PMTCT program. First, I examine the creation and delivery of a PMTCT program, including the therapeutic interventions offered and not offered, the messages communicated, the program's relationship to other health services in Lilongwe, and its location within national and international health policy. Second, I research how women understand and make sense of the program and the communicated medical information. Third, I focus on women's decision making about participation and engagement in the program, including decisions about testing and drug uptake, and barriers to their participation. Forth, I look at HIV diagnosis within women's life course, focusing on how women make sense of HIV diagnosis within their life stories. Fifth, I consider the relational meaning of HIV and women's negotiation of their HIV status with their husbands, families, and friends. Finally, I situate the PMTCT program in a macro political economic context, which includes donor funding, patent agreements, and pharmaceutical pricing (see Figure 1.1 for a diagram of these multiple paths of inquiry). In this thesis, therefore, I investigate women's past and present realities at the intersection of the local and the global. The PMTCT program can be thought of as a "global assemblage" – a global form articulated in a specific situation (Collier and Ong 2005). Global assemblages are "domains in which the forms and values of individual and collective existence are problematized or at stake, in the same sense that they are subject to technological, political, and ethical reflection and intervention" (Collier and Ong 2005:4).

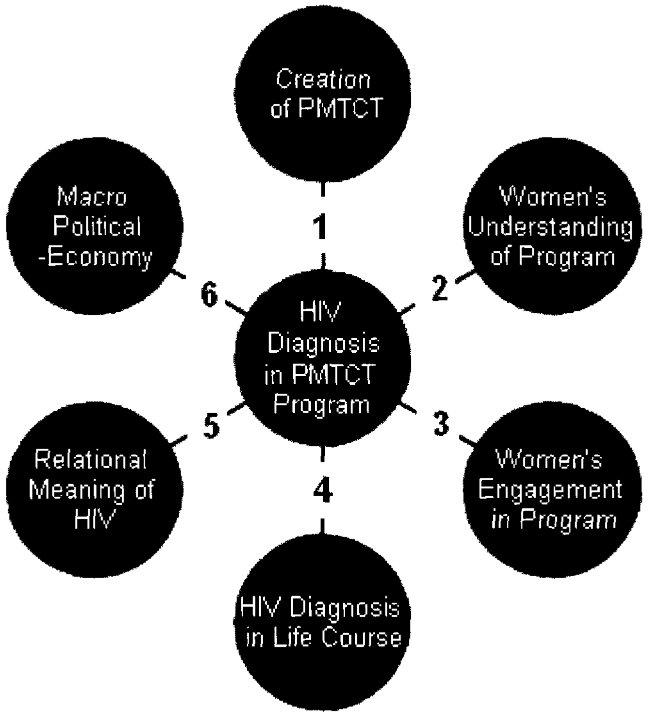

Figure 1.1-Paths of Inquiry

I draw on critical approaches to medical anthropology, political economy of health, and elaborations of structural violence to investigate the way in which health and illness are intertwined in global processes. As Baer (1982:1) describes, the political economy of health "is in essence a critical endeavour which attempts to understand health related issues within the context of the class and imperialist relations inherent in the capitalist world system." For example, both the prevalence of infectious diseases, including HIV, and the poor distribution of treatments for them reflect other global disparities and social inequities (Farmer 1999). For this reason, the political economy approach has often been adopted in anthropological studies of HIV (see for example Baer et al. 2003; Doyal et al. 1994; Farmer 1999; Farmer et al. 1996; Kim et al. 2000; Nguyen and Peschard 2003; Parker 2001; Schoepf 1998; Schoepf 2001; Schoepf et al. 2000; Singer 1998).

Political economy influences the theoretical orientation of this thesis. I believe that the life possibilities and opportunities of the women in my study, and indeed of all of us, are shaped by fundamentally global economic and political processes. The fabric of women's everyday lives in Malawi is, indeed, bound up in both the local and the global. Importantly, each illuminates something that would be obfuscated in examining only the other; therefore, analyses of both are necessary.

In giving analytical importance to the global, I do not seek to diminish individual action in local life worlds; in fact, I return to that subject below.

However, I do wish to avoid a sole focus on individual volition. Too often in HIV commentary individual agency has been exaggerated and “choice” overly emphasized (Farmer 1999:9). This has been particularly devastating in the history of AIDS prevention programs, which have promoted individual behaviour change. Indeed, one of the strengths of the political economy approach to HIV has been its challenge to reigning epidemiological risk-exposure categories and individualized prevention models. The political economy approach focuses, instead, on the manner in which “risky” behaviour is shaped by the cultural, gendered, social and economic contexts of people’s lives. The scientific community, with its knowledge of risk probabilities, expects individuals to follow communicated advice about risk, in accordance with scientists’ philosophy of risk management. They believe in the “rational actor”: “A creature from the imaginations of risk experts, who manages risks on the basis of the experts’ judgment about how a rational optimizer would, and should, act if in possession of all relevant scientific information” (Adams 1999:10). Scientific risk managers simplify individuals’ complex lives and believe that communicating risk is sufficient for individuals to manage their personal risk in ways that are acceptable to scientific risk managers. Medical anthropologists demonstrate that competing risks and benefits influence individual action (Green and Sobo 2000) and that people negotiate risks and benefits in light of socio-economic structures.

In the life stories women shared with me, they talked about their poverty, food insecurity, and their inadequate access to (and poor quality of) education and health. These limited life possibilities are rooted in colonialism, neo-colonialism, and global economic marginalization. The women's relationships intertwine with local structures, including gendered and cultural expectations about womanhood, to make women vulnerable to a range of risks. While everyday talk naturalizes gendered subjectivities, these are cultural constructions of what it means to be male and female. Women's subordinate role creates vulnerability, including to HIV. Sadly, this is not extraordinary.

> Millions of women living in similar circumstances – but with very different psychological profiles and cultural backgrounds – can expect to meet similar fates. Their sickness is a result of structural violence: neither culture nor pure individual will is at fault; rather, historically given (and often economically driven) processes and forces conspire to constrain individual agency. (Farmer 1999:79)

For the women in my study, structural factors that lead to their HIV infection become again important after diagnosis, as they try to preserve their lives despite their HIV infection.

The capacity of Malawi to adequately address citizens' lives with HIV is a global issue. That Malawi can now provide some HIV treatments is the result of concerted international advocacy and activism, notably by Stephen Lewis, former UN Special Envoy for HIV/AIDS in Africa, and South Africa's Treatment Action Campaign. However, some HIV services and drugs are offered in the absence of others. This is the result of specific international health policies, donor funding agreements, pharmaceutical pricing, and the World Trade Organization (WTO) Agreement on Trade-Related Aspects of International Property Rights (TRIPS). Therefore, HIV treatment and care seeking by people living with HIV in resource-poor countries is also affected by global issues. Increasingly, discussions of global HIV treatment inequalities have focused on the uneven distribution of techno-medical solutions. Where it is available (mostly in the northern hemisphere), antiretroviral therapy (ART) has reduced AIDS deaths. Where techno-medical treatments are available in the South, there is insufficient coverage and access primarily to first-line therapies.

Those involved in medical care do more than provide treatment, they also define problems and construct solutions within the politics, culture, and economics of biomedicine. They thus have the power not only to diagnose and treat but to stake claims on meanings. The critique of epidemiological risk, above, is part of medical anthropologists strength in destabilizing the presumed objectivity of scientific investigation and biomedical practice. Anthropologists have produced rich investigations into the cultures of science and biomedicine. They have uncovered the social construction of scientific and medical epistemologies. While scientists may claim that their research is culture free, anthropologists have shown how this process, as all life ways, is steeped in culture (Comaroff 1993; Foucault 1994; Good 1994; Marshall 2005; Martin 1989; Scheper-Hughes and Lock 1987; Vaughan 1991).

Science and medical care are also bounded by politics and economics. In this context, the meaning of HIV diagnosis has shifted, in part, due to the need to make testing attractive to people who now have access to some treatment, and also to meet treatment targets. While HIV testing used to be seen as risky, it now has been recast as having specific benefits that motivate people to get tested. For example, pregnant women decide to be tested to reduce the risk of transmitting HIV to their babies if found positive, and the promise of positive living. The PMTCT program gives priority to preventing vertical transmission. Women, however, prioritize the benefits of "knowing your status" for their own health, as preventing vertical transmission is only relevant after women test positive. Women participating in the PMTCT program, therefore, anticipate greater attention to their own health status than is provided.

While in this thesis I use a broad political-economic framework, one that has been criticized for abstracting beyond the lives of individuals, I am also very much interested in local life worlds and individual experience. I seek women's narratives and want to know how they work out and give meaning to their life problems and illness. HIV diagnosis is one such individual problem; at the same time as it is a global issue. Not only is this true because lives are at stake, but also because dominant cultural constructions of HIV make particular claims about HIV and the lives of those infected. These claims illuminate the importance of looking at dominant cultural themes of illness in individual's narratives. At the local level, after HIV-diagnosis, women deal with the multiple popular, community, and personal meanings of HIV. They also work to make sense of HIV within their own life courses, and to negotiate the meanings they give to their diagnoses with those they choose to tell about their status. They construct HIV in purposeful, yet contradictory, ways that navigate both dominant cultural claims and new therapeutic narratives.

To be sure, a great deal of what is to be worked out after HIV diagnosis takes place outside the PMTCT program. Women still have only limited access to treatments for HIV, in spite of the promise that HIV testing can prolong one's life. Therefore, I am interested in how women negotiate individualized interventions in order to prolong their lives and live positively with HIV. Focusing on individual action and agency, even in the face of devastating circumstances, is important. Women work extremely hard at sustaining life after diagnosis. However, over and over again, I must return to the structures that create violence in women's lives. For example, "positive living" entails individualized bodily monitoring and regulation. Rather than supporting women in every possible way to achieve the benefits of HIV testing for themselves and their children, PMTCT program staff provide women with disarticulated information.

Here, again, biomedicine's power includes defining the problem and proposing appropriate interventions – in this case those directly related to the medical prevention of vertical transmission. Women's capacity to navigate the PMTCT program and other health services is hampered by the vertical delivery of multiple programs. For women to achieve the communicated benefits of the PMTCT program and prolong their lives post-diagnosis, HIV programs must move beyond narrow definitions of therapy and access to it. To be sure, drugs must be available. However, a broader definition of therapy and therapeutic access would, for example, address food insecurity and transportation barriers to accessing care. Without a broader definition of health, responsibility for health maintenance is downloaded from the state to those who have the least capacity to ensure health. Thus, women often talk of their frustration in following treatment regimes due to poverty, food insecurity, and lack of control over their sexual and reproductive health. Without adequate resources, including counselling and education, women may not respond to the PMTCT program in the way that those who deliver its services expect.

Lock and Kaufert's (1998) description of women's engagement with biomedicine is relevant to women in Malawi. The authors found that women's responses to medicalization "may range from selective resistance to selective compliance, although women may also be indifferent...Ambivalence coupled with pragmatism may be the dominant mode of response to medicalization by women" (1998:2). For women in Malawi, ambivalence toward the possible reduction of vertical transmission makes sense in the face of uncertain possibilities and definite structural barriers. For HIV-positive women who have decided to participate in the PMTCT program, pregnancy is inevitably medicalized. Such a process, however, is not a primary concern to them. The vulnerability of women's bodies to HIV is given immediate bearing by the diagnosis. Fittingly then, Kaufert (1998) describes breast cancer activists, like AIDS activists, as wanting "more rather than less science" (Kaufert 1998:306).

This is true of women in Malawi who seek medical resources to prolong their lives.

OVERVIEW OF CHAPTERS

In the next three chapters, I present background information and the context for the remaining five chapters. In Chapter Two, I offer an introductory sketch of Malawi. I focus on the political and economic context of my research and ground the critical approach laid out in Chapter One in the Malawian setting. In Chapter Three, I outline the methods I used to collect data in Lilongwe, Malawi. As my research largely focuses on the stories that women told me, in Chapter Three I also position my methodological use of narratives and delineate the relationship I see between *experience* and *narrative*. In Chapter Four, I draw on women's life stories to situate HIV diagnosis within the life course. First, I attend to women's socio-economic and gendered experiences of childhood, young adulthood, relationships, and marriage. Second, I move general theory and the political economy of Malawi from the abstract level to the personal and intimate.

In Chapter Five, I focus on the PMTCT program and women's diagnoses of HIV within it. I describe the PMTCT program's components and its delivery. I also situate the PMTCT program within a shifting HIV-intervention policy framework in the developing world. I focus in particular on the shift in meaning of and discourse about HIV testing from "risky endeavour" to "opportunity." I explore the benefits communicated by PMTCT program nurses of HIV testing.

Women's motivation for accepting HIV testing illuminate that they have clear expectations of benefits.

In Chapter Six, I examine the social construction of HIV and the way in which dominant meanings of HIV in the community impact on HIV-positive women. I focus on risks of HIV transmission communicated in public health campaigns through which the prevailing discourses on HIV are constructed. These discourses focus on HIV as a signifier of deviance, immoral behaviour, and risk-taking. While HIV epidemiology has moved beyond classification of risk groups, these groups still frame popular understandings of HIV infection. Women make sense of their own HIV diagnoses in light of these discourses. Women with HIV must also negotiate these meanings in their everyday lives as they confront stigma and decide to communicate their HIV status to others.

In Chapter Seven, I turn to women's experiences of health care within the PMTCT program and in the health system more generally. I focus on barriers that women face in achieving the PMTCT program's benefit. These include variable uptake of nevirapine and adherence to infant feeding advice. I found that inadequate time for counselling and low-quality counselling hinder women's full participation in the PMTCT program. This is particularly important, as women have their own understandings of HIV transmission. Other barriers that I discuss include the vertical organization of the program, food insecurity, poverty, and transportation.

Beyond the PMTCT program's immediate goal of reducing vertical transmission, staff also promote HIV testing as an avenue to individual-level health regulation. In communicating health information nurses emphasize that knowledge of HIV status can allow individuals to safeguard their health, maintain the strength of their immune systems, and prolong their lives. This discourse on "positive living" is the focus of Chapter Eight. Positive living entails eating a balanced diet, reducing stress, using condoms to prevent reinfection, and limiting future child bearing in order to keep the body strong. While women are motivated by the benefits of this HIV post-testing advice and place great importance on body monitoring and regulation, I explore the challenges that women face in changing their health behaviour.

In Chapter Nine, I conclude by synthesizing and consolidating four groups of themes in my research findings. The first group comprises the intersection of local and global within daily life in Malawi, risk of infection with HIV, and creation and communication of therapeutic possibilities. The second is a continuum of life protecting actions that crosses women's before/after-HIV-diagnosis divide. The third is subjunctive narrative, which I use to delineate multiple possibilities, yet to be realized, that are communicated by all actors in the PMTCT program. The fourth is the impact of individualized interventions, which also span the before/after-HIV-diagnosis divide and impede success in HIV interventions and the PMTCT program.

CHAPTER TWO – RESEARCH SETTING

BACKGROUND

I carried out this study at a health centre in a peri-urban area of Lilongwe, the capital city of Malawi. Malawi is a relatively small, landlocked country in sub-Saharan Africa. It is bordered to the north and northeast by Tanzania; to the east, south, and southwest by Mozambique; and to the west by Zambia. The Rift Valley spans the length of the country and encompasses Lake Malawi, which extends along the eastern border for 475 kilometres (NSO and ORC Macro 2005:1). Malawi is divided into three regions – Northern, Central, and Southern – as well as 27 districts. The district of Lilongwe is in Malawi's Central region. Lilongwe became the capital of Malawi in 1975, and between then and 1980 surrounding rural areas and villages were incorporated into the city (Rohregger 2006:1155).

Lilongwe has three climatic seasons: wet, dry, and cold. The wet season begins during November or December. Malawians wait anxiously for the rains to begin so that they can plant their new crops and be relieved of the heat and dust. The wet season lasts until April and is followed by a cold, dry season when temperatures dip below ten degrees Celsius. From August to the start of the rains it is dry and increasingly hot, with temperatures climbing above 30 degrees Celsius. The climatic seasons also correspond to cycles mapped on the body and its well-being. Malawians talk of the hungry season, the months preceding the harvest, when food stores from the preceding year are dwindling. During the cold

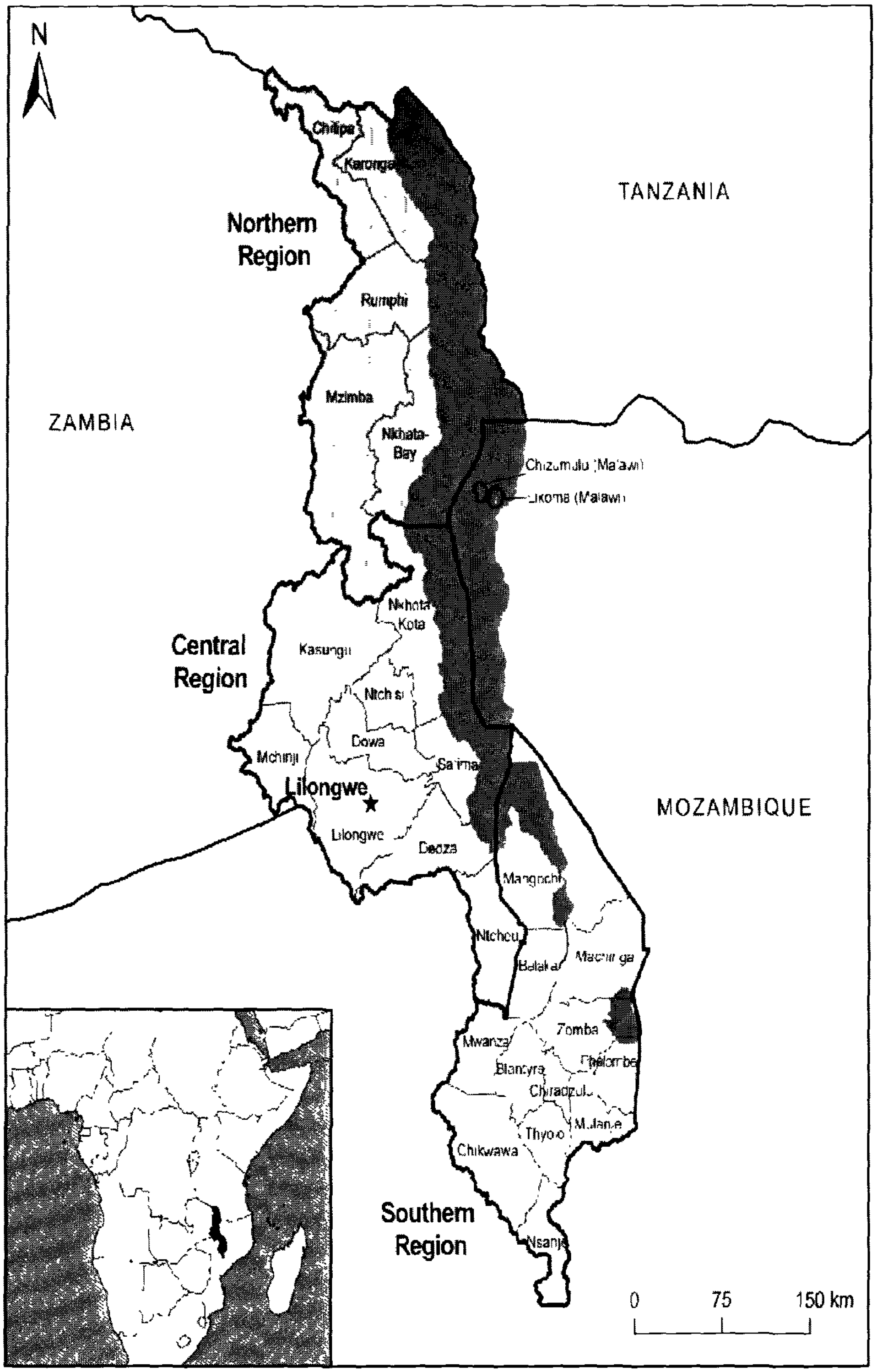

Figure 2.1-Map of Malawi (NSO and ORC Macro 2005:xxviii)

season people feel most susceptible to colds and chest infections, and the dry and dusty season is associated with diarrhea.

Malawi has a culturally and linguistically diverse population of 12.6 million people (UNDP 2006). Archaeologists and oral historians estimate that Malawi was occupied by ancestors of its present-day inhabitants in waves of migration between the 13th and 19th centuries (Ott 2000:151-153). The Chewa are Malawi's largest ethnic and linguistic group, with close to 70 percent of the population. The rest of the population is composed of the Yao, Tumbuka, Sena, Lomwe, Tonga, Nkhonde, Ngoni, Senga, Nyakyusa, and Lambya, as well as Asian and European descendents (NSO 2002:62).[1] Malawians are predominantly Christian (80 percent) and Muslim (13 percent) (NSO 2002:63).

While there are specific differences between the various groups in terms of culture, belief, and tradition, a long history of migration, inter-marriage, and living side by side illuminates the flexibility of cultures. Missionization, colonialization, economic change, and increased migration may have accelerated cultural change, but ethnographers illustrate that the cultures of Malawi, as elsewhere, were never static (see, for example, Mair 1951; Ott 2000; Phiri 1983). The flexibility of culture was manifest in my study in women's occasional uncertainty about what traditions they would follow. For example, when it was a

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[1] These are the linguistic and cultural groups listed in *Malawi, An Atlas of Social Statistics* (NSO 2002). However, as Kaspin (1995) notes, there is little agreement on how many ethnic groups live in Malawi. She cites Mary Tew's 1950 ethnography, which indicated as many as 25 groups. The reduction of ethnic categories in more recent surveys, Kaspin suggests, has to do with the "manipulation of language categories by colonial and post-colonial administrators, and the politicisation of ethnic consciousness during this period" (Kaspin 1995:601).

woman's first pregnancy with her husband, she would often say that she was unsure which practices they would follow because she and the husband are from different cultures. Similarly, women who considered themselves "modern" or religious often described not following "traditional" practices. For example, in relation to the traditional practice of not using salt when cooking during menstruation, one woman described, "My mother is a very religious person, so she doesn't really follow most traditional practices. So, she told me to start putting salt, saying it doesn't have any significance. It's just a tradition." The flexibility of cultural practices has particular importance in health development and HIV intervention, where cultures have too often been viewed as static and rigid. The fight for health and against HIV has too often been cast as a fight against culture (for critiques of this approach see Fassin 2001; Gausset 2001; Hunt 1996; MacDonald 1996; Oppong and Kalipeni 2004; Sacks 1996; Schiller et al. 1994; Schoepf 1995; Schoeph 2004; Treichler 1999; Watney 1989; Wilton 1997). Such an approach often fails to recognize that cultural practices are flexible and people open to change if health providers suggest culturally compelling and appropriate modifications.

Health intervenors also fail to recognize that it is unsafe aspects of cultural practices that create risk of HIV infection, not the practices themselves. Moreover, focusing on cultural practices diverts attention from other explanations for high prevalence and regional variation in HIV infection (Oppong and Kalipeni 2004). Intervenors often look to culture as an explanation for why people are not taking up health promotion, rather than focusing on structural barriers that may impede individual capacity (Fassin 2001). I present this discourse not to deemphasize cultural beliefs and practices, but to highlight the ongoing process of cultural change in Malawi, the diversity of cultural practices, and to problematize the reification of culture in health development.

Malawi is still primarily rural, although internal migration and urbanization are increasing. Migration during the colonial period was mostly out of the country to provide cheap labour for agricultural estates and mines of Zambia, Zimbabwe, and South Africa. This drew 40 percent of able-bodied men each year (Rohregger 2006:1155). At Malawi's independence in 1964, 95 percent of the population was rural; by the 1998 census, the urban proportion had increased to 14 percent (Englund 2002:138). The economy is primarily agricultural and includes estate farms, smallholders who farm their land primarily for subsistence, and agricultural labourers who work for estate farms and more prosperous smallholders (Harrigan 2001:1). Urbanization has brought people to Lilongwe from all over Malawi, often to unplanned settlements. Under the rule of the former dictator, Banda, these areas were often cleared. Since the early 1990s, however, they have been legalized and incorporated into the city (Rohregger 2006:1156). The area served by the Area 25 Health Centre is thus made up of planned and unplanned urban settlements and rural villages.

Poverty and Social Indices

Malawi is an extremely poor country, which is reflected in the country's health, social, and economic indicators. On the United Nations' Human Development Index, a broad indicator of well-being, Malawi ranks 166 out of 177 countries. Indeed, Malawi is one of the poorest countries in the world. It has a high infant mortality rate of 110 per 1000 live births, and another 65 children per 1000 die before their fifth birthday. Maternal mortality rates are also among the highest in the world: 1,800 women per 100,000 die in childbirth. Life expectancy in Malawi is less than 40 years, and 56.3 percent of children born will not survive to age 40. The per capita Gross Domestic Product (GDP) was higher in 1979 than it is today at US$169 (UNDP 2006). Moreover, there is unequal income distribution. Malawi ranks highest in Africa on income inequality (Harrigan 2001:1). Poverty is widespread: in 1998, 64.2 percent of Malawians lived in poor households where daily consumption and expenditure fell below the poverty line, and 36.3 percent lived in ultra-poor households where expenditure was less than 60 percent of the poverty line (NSO 2002:27).[2] Deriving from poverty, food insecurity is also widespread (Harrigan 2001:1). Public expenditure on health is just 3.3 percent of GDP and expenditure on education is six percent of GDP. Until recently, Malawi spent more servicing its debt than on health and education combined (UNDP 2006). (Debt-relief programs for Malawi are discussed below.)

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[2] These poverty lines are regionally specific and were developed from the "cost of minimum recommended daily calorie requirements plus some additional basic non-food items" (NSO 2002:27).

These statistics represent Malawi's marginal status. In Chapter One, I situated my study within critical approaches to medical anthropology. In the next few pages, I elaborate on and contextualize the above-cited indicators within Malawi's colonial and post-colonial history.

Political History

The country that is today Malawi was colonized by the British. It officially became the British Central African Protectorate on May 14, 1891. This, however, was preceded by exploration and by Portuguese, Arab, German, and British interest in the area from 1616 (Sindima 2002:15-26). The British changed the colony's name in 1907 to Nyasaland, the name given to the area by David Livingstone in 1859 (Sindima 2002:1). To the British, Malawi was a reservoir of cheap raw materials and labour but not valuable because it lacked exploitable minerals. Therefore, the British mostly neglected it and relegated it to a "colonial slum" (Mhone 1992:3). They did little to enlarge the economic or physical infrastructure of the country (Sindima 2002:32-34).

Malawi's peripheral position in the global political and economic order continues today, despite gaining independence in 1964. Independence followed a long transition period of political protest and civil disturbances, but was primarily peaceful. Up to 1994, Malawi was ruled by dictator Dr. Hastings Kamuzu Banda, the "president for life." From independence, Malawi's policies were market oriented and emphasized development of economic infrastructure and growth rather than strong social goals and policies.[3] While some development was funded through bi-lateral donations, other projects, including the presidential palace in Lilongwe and the Kamuzu Academy,[4] an elite educational institution, was funded by loans from private banks overseas (Sindima 2002:141).

Until 1980, Malawi's economic strategy was hailed by international financial institutions (IFIs) as an African success and attributed to its market policies. Economic growth was in line with or ahead of other countries in the region (Sindima 2002:67-73). However, Banda's policies oppressed the poor majority and benefited only a small elite (Peters 2006:326). Although gains were made in social programs, they were not as Malawians expected at independence. For example, enrolment in primary education increased from 20 percent at independence to 70 percent in 1987. However, even though Banda presented himself as dedicated to the education of children, schools were grossly inadequate and underfunded. Between 1970 and 1980, spending per pupil dropped by almost half, student-teacher ratios worsened, and only 3.4 percent of primary school graduates were able to go on to secondary (Lwanda 1993:177-179; Sindima 2002:123-125). Health spending was also a low priority. Only modest gains were made on health indicators. For example, between 1970 and 1981, life expectancy increased from 40 to 44 years and infant mortality declined from 199 to 158 per

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[3] The "cabinet crisis" after independence in 1964 concerned Malawi's economic path. Ministers who opposed Banda's capitalist path were ousted. This was the beginning of a growing concentration of power; ultimately constitutional changes in 1966 made Malawi a one-party state (Sahle 2001-108).

[4] Up to 40 percent of all public expenditure on education went to running the Kamuzu Academy (Lwanda 1993:178).

1000 live births (Chipeta 1992:92). Banda's political shortcomings and poor human rights standards led to growing dissatisfaction, protests, strikes, and violence (Sindima 2002:130).

In 1993 "foreign and domestic economic, social, religious, political and other factors had forced Dr. Banda's hand" (Lwanda 2006:525-526), and he called a referendum that decided on a multiparty system. He stepped down in 1994, and Malawi made an again-peaceful transition to a multiparty democracy. For the next ten years Malawi was led by Bakili Muluzi, who had gained power through "old guard" and business networks, and promised patronage without any concern for the socio-economic needs of the poor (Lwanda 2006). After taking power President Muluzi siphoned off state funds and capitalized on International Monetary Fund (IMF) and World Bank policies, whereby he ground down state corporations before selling them off. He "rapidly built up a business empire that came to include coal mining, fuel distribution, transport, real estate in Malawi and Europe, retail, broadcasting and aspects of the service industry" and became the "third-richest president" in Africa (Lwanda 2006:539-540). At the end of his second term, Muluzi attempted to thwart the constitution and maintain power. These attempts failed, and Malawi's second democratically elected president, and Muluzi's chosen successor Bingu wa Mutharika, took office in 2004. While observers of Malawian politics believed that he would be a puppet of Muluzi, after his election, President Mutharika renounced Muluzi's corruption and formed a new party (Lwanda 2006). This fracture has led to political crises, including an impeachment bid and alleged attepts to assassinate Mutharika. However, he has followed through charging members of his old party with corruption, successfully worked with international donors, and achieved Malawi's completion point for debt relief. Nonetheless, there have been ongoing accusations of patronage and misuse of government funds by opposition members and the media.

Macro-Political Economy

Newly independent African governments, lacking capital, funded social improvements and less legitimate infrastructure projects through loans from private international banks guaranteed by the banks' home governments. Consequently, debt in the developing world rose in the 1960s and even more dramatically in the 1970s. The 1970s oil crisis and the prerogative of banks to earn interest on banked "petro-dollars" made banks eager to lend money to the developing world at low interest rates (Kanji et al. 1991:987; Schoepf et al. 2000:97-98). For Malawi, crisis came in the late 1970s and early 1980s. Malawi's economic development policy had focused primarily on the export of agricultural cash crops. This policy was particularly vulnerable to drought, as occurred in Malawi in the 1979/1980 growing season, and to exogenous shocks. In 1979 oil prices doubled, commodity prices fell, interest rates rose, and importing of agricultural inputs into Malawi and agricultural exports were hindered by instability in Mozambique (Harrigan 2001:2; Sindima 2002:115). Malawi's economic collapse was exacerbated, because the first round of its loan repayments to private overseas banks coincided with this downturn. Between 1978/1979 and

1980/1981, debt servicing costs increased from 15 percent of the total recurrent budget to 40 percent (Sindima 2002:115).

The international financial crisis was not confined to Malawi and Africa; the IMF saw potential for defaults on debt repayment, as occurred in Mexico and Brazil, as a threat to the international financial system. Kanji et al. (1991) describe the situation:

> Although it was the private banks' imperative for higher rates of profits that led them to this critical situation of losing out on their "investments," the US, the IMF, the World Bank and the OECD [Organization for Economic Cooperation and Development] countries stepped in to bail them out (in the interest of the economic and financial *status quo*). In the face of this unstable situation, the interests of the IMF and the World Bank, reflecting those of the OECD countries that effectively control these institutions, were to ensure debt servicing by the developing countries so that the profits of the Western financial institutions could be maintained. (Kanji et al. 1991:988)

It was in this climate that the World Bank engineered Structural Adjustment Programs (SAPs). Its *Berg Report*, released in 1981, set the framework. This report also provides the "standard interpretation" of the causes of the African financial crisis: African governments undermined development through too much state involvement, which left little room for free markets to flourish (Arrighi 2002:7; Kanji et al. 1991:988).

African policies were thereafter oriented to earning foreign exchange in order to pay debts, and future loans were conditional on acceptance of policy reforms. These included substantial currency devaluation to make exports more competitive; removal of price controls and subsidies for food crops to stimulate local production; privatization of government-owned enterprises and public services, and implementation of user fees for health and education to recover costs; new investment policies, including tax incentives, free repatriation of profits, and elimination of tariff protection; and, removal of minimum wage and labour protections (Arrighi 2002:7; Kanji et al. 1991:988; Schoepf et al. 2000:99). As Harrigan describes,

> The Washington institutions placed the onus of adjustments squarely on the shoulders of developing countries, who were expected to introduce liberalised export-oriented policy regimes to pay back debt and overcome balance of payment deficits...Little attempt was made to adjust the hostile global environment facing developing countries. (Harrigan 2001:6)

Between 1980 and 1986, 75 percent of sub-Saharan African countries implemented IFIs' structural adjustment programs (Kanji et al. 1991:988). Malawi, under President Banda, was first forced in 1981 to negotiate with the IMF and World Bank for structural adjustment loans to bail it out of its crisis (Peters 2006:323). From the World Bank's perspective, Malawi's past economic success made the country a good testing ground for these new macro-economic policies, and it was expected to rebound quickly (Harrigan 2001:5). In reality, structural adjustments were as damaging to Malawi as to other African countries.

Impact of Structural Adjustments

The SAPs imposed by IFIs have had devastating effects on African countries. The gains that they made in health, mortality reduction, and adult literacy in the 1960s and 1970s were subsequently lost (Arrighi 2002:5). Africa, once the recipient of donor aid and loans from the North, now pays out more than it receives. "Whereas in 1979 there was a net flow of $40 billion from the north to the south (the balance of new money over debt service), today that flow has been reversed so that approximately $60 billion a year is transferred from poor to rich countries" (Kanji et al. 1991:985). By the mid-1980s, the purported benefits of SAPs had not been achieved, while debt had increased and economies had stagnated. By this time, debt was so high that non-oil-producing countries in sub-Saharan Africa were using between 30 and 70 percent of their export revenues to service debt (Schoepf et al. 2000:99). In 1985, debt in sub-Saharan Africa was 76 percent of Gross National Product (GNP); by 1997 this had grown to 108 percent of GNP (excluding South Africa) (UNICEF 1997:31). As UNICEF (1997:3) reports, such disproportion fails to stimulate growth, hampers economic vitality, and drains resources from the social sector.

Between 1983 and 1990, developing countries repaid US$1,000 billion of debt. However, due to debt-service arrears and new borrowing, debt grew from US$800 billion in 1983 to US$1,500 billion in 1990 and nearly US$2,000 billion in 1997. Although a problem of all developing countries, it has been an impossible drain in sub-Saharan African countries, which owed US$84 billion in 1980 and now owe US$200 billion (Ramphal 1999:28). In the most heavily indebted countries, including Malawi, governments have allocated up to 40 percent of national budgets to debt servicing. This has had a devastating impact on social spending. Moreover, a large percentage of bilateral aid to poor countries goes back to donors as debt repayment (Ramphal 1999:28; UNICEF 1997:30-31).

SAPs have had a particularly negative impact on the agricultural sector in Malawi, the basis for economic and food security in the country. Loan conditions led to liberalized agricultural policies; a push to diversify crops and prioritize export crops; and a reduction in maize input subsidies and credit schemes. These policy changes led directly to the 1987 famine (Peters 2006:323). IMF pressure to reduce grain stores, in addition to climatic factors and corruption within Muluzi's government, again led to famine in 2001-2002 (Peters 2006:325). Beyond these severe crises, Malawi's policies have left the poor absolutely and relatively poorer, as they have not been able to capitalize on export-crop production, as have farmers with more resources (Peters 2006). Exports have also been vulnerable to international price shocks, which have reduced Malawi's foreign-exchange earnings.

In summary, scarce resources are drained from food security, health, and education by debt servicing (Ramphal 1999:27). Within structural adjustments, social services are no longer seen as basic needs or human rights but as sellable commodities (Kanji et al. 1991:989). At the local level, SAPs have resulted in lower incomes, higher costs of living, deteriorated living conditions, and poorer health. Moreover, structural adjustments do not impact all members of society equally. Evidence suggests that the deleterious effects have been most marked among women (Kanji et al. 1991:990; Manjate et al. 2000; Schoepf et al. 2000:102). In particular, SAPs diminish women's resources, because they require user fees for health care, schools, and transportation (Moss 2002:650; Schoepf

2001:344). The devastating impact of SAPs led UNICEF to call for "adjustments with a human face." Accordingly, the World Bank focused on gender in its recent anti-poverty strategy (Kanji et al. 1991:990; Moss 2002:650).

Poor governance, corruption, the burden of debt, and structural adjustment programs have devastated the health and well-being of Malawians. Increased awareness of the unjust legacy of dictators and debt has led to growing pressure on IFIs and world leaders to redress global inequalities and given momentum to debt relief. A poignant example of this international activism is Nobel Laureate Wangari Maathai's address to the 2007 World Social Forum in Nairobi:

> It is no secret that a number of the loans were given to many dictatorial, unaccountable and irresponsible leaders in Africa and elsewhere, and the money never benefited those that it was meant for…How can you punish the poor citizens, who were never consulted about the loans, which were used to oppress them, strengthen the ruling and cooperating elites, and exploit resources at the expense of the health, environment and welfare of the people? These debts were not only poorly transacted but are illegitimate. (Mulama 2007)

International pressure has resulted in initiatives to address poor countries' debt burdens. The Highly Indebted Poor Country (HIPC) Initiative (later the Enhanced HIPC Initiative) is one such program. Countries are eligible for the HIPC Initiative if they have unsustainable debt, a satisfactory track record of IMF and World Bank reforms and adjustments, and a Poverty Reduction Strategy Paper (PRSP). Decisions on eligibility ("decision point") are made entirely by the IMF and World Bank. At each decision point, IFIs reduce debt to "sustainable" levels (Jubilee Research 2007). Malawi reached its decision point in December of

2000; however, it took longer than expected to achieve the targeted strategies set out for the completion point. This, however, occurred in 2006 when HIPC and the G8's Multilateral Debt Relief Initiative (MDRI) relieved Malawi of 90 percent of its debt (US$3.1 billion). This relief immediately freed US$110 million annually from debt servicing (World Bank 2006), but it is, however, only a partial success. Malawi still has high domestic debt and bilateral debt[5] (Hurley 2006). Moreover, Malawi's economy is still marginal and vulnerable to export shocks; it has unequal access to markets and will have to take on new debt. These realities thus necessitate a more radical realignment of the world financial system if the citizens of the poorest countries in the world are to move out of poverty and achieve basic health and well-being.

The HIV Epidemic

Schoepf et al. (1991:189) assert that "disease epidemics generally erupt in times of crisis and AIDS is no exception." AIDS erupted in Africa during the crisis of structural adjustments and quickly spread "along the fault lines of...society" (Baer et al. 1997:159). SAPs have been particularly damaging for the poor. As I discussed above, structural adjustments have led to social upheaval that precipitates the spread of HIV: user fees for health,[6] labour migration, and

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[5] The Kuwait Fund, the Arab Bank for Economic Development (BADEA), the Organisation for Petroleum Exporting Countries (OPEC), and South Africa have not provided debt relief for Malawi (Munthali 2006).

[6] The privatization of health services and the implementation of user fees limit the ability of poor women to use health services (Manjate et al. 2000:51). In relation to the spread of HIV, this is particularly important, as untreated sexually transmitted infections increase the probability of HIV infection (Parker and Patterson 1996).

urban unemployment. Women face growing poverty, economic choices become limited, and sex increasingly becomes a survival strategy.

In 2006, 63 percent of all people living with HIV were in sub-Saharan Africa, and 72 percent of AIDS deaths occured in the region. Malawi's National AIDS Commission (2004) estimated that 760,000 adults between the ages of 15 and 49 were living with HIV in Malawi. This represents an overall adult prevalence of 14.4 percent, a range from 12.4 percent in rural areas to 23 percent in urban areas. Of the adults living with HIV, 440,000 are women. A breakdown of these statistics shows that women are acquiring HIV at younger ages than men, illustrating the increased vulnerability of girls and young women.

Table 2.1-HIV Prevalence in Malawi by Age and Sex
(NSO and ORC Macro 2005:230)

Age	Percentage HIV Positive	
	Women	Men
15-19	3.7	0.4
20-24	13.2	3.9
25-29	15.5	9.8
30-34	18.1	20.4
35-39	17.0	18.4
40-44	17.9	16.5
45-49	13.3	9.5

The first hospital case of HIV was reported in Malawi in 1985, but President Banda was reluctant to acknowledge the disease and silenced public discussion. Initial response to AIDS in Malawi was thus slow (Conroy and Malewezi 2006:139; Lwanda 2004:35). However, in the following years, AIDS slowly moved onto the national agenda. The capacity of African countries and Africans to deal with the AIDS crisis, though, has been limited by available infrastructure and economic resources, notably ground down by SAPs (Schoepf et al. 2000:108). While many have argued for local solutions to HIV, Schoepf counters that this is inadequate. For those that cannot afford HIV care, this local solution does not meet basic human rights standards.

> It will not do to allow public health services to be ground down and then declare that locally offered care meets human rights standards. Today, many people are unable to afford simple antibiotics, the prices of which have skyrocketed with SAP-imposed devaluation...Only the wealthy can afford AIDS drugs even at sharply reduced prices. Moreover, administration of antiretrovirals requires effective health care systems. (Schoepf 2001:352)

Treatment of people infected with HIV not only alleviates their suffering but contributes to the prevention of HIV transmission. Where antiretroviral drugs are accessible to people living with HIV, voluntary HIV testing increases, there is less transmission of the virus due to lower viral loads, and vertical transmission of HIV drops.

In recent years, international treatment activism has mobilized the international community, and donor support is improving. For example, in 2002 the Global Fund to Fight AIDS, Tuberculosis, and Malaria approved Malawi's grant application for US$196 million. The grant has provided increased funding for anti-AIDS services, including the roll-out of antiretroviral therapy. However, more concerted action is still required. Still less than five percent of Malawians have access to HIV services: voluntary counselling and testing (VCT), antiretroviral therapy, and prevention of mother-to-child transmission programs (Conroy and Malewezi 2006). Given new resources, Malawi has an ambitious scale-up plan. By the end of 2005, 37,635 people had started free ART. This is expected to increase to 245,000 by 2010; just 50 percent of those in need of treatment however (Harries et al. 2006).

The challenges of HIV primarily relate to lack of adequate financial and human resources, and infrastructure. The human resource crisis in the health system is exacerbated by doctors and nurses leaving the country for better-paying jobs. The capacity of Malawi's government to address the crisis is constrained by IMF limits on pay levels and hiring strategies. Stephen Lewis writes,

> We're talking about a sovereign government, fighting the worst plague in history, with but a handful of professionals: according to the Minister of Health, Malawi has one-third of the nurses it needs (four thousand instead of the necessary twelve thousand) and perhaps 10 percent of the doctors (three hundred rather than three thousand) for a population of twelve million. And they weren't being allowed – I repeat, this sovereign government wasn't being allowed – to hire more staff and pay better salaries because it would breach the macroeconomic straitjacket. (Lewis 2005:14-15)

International patent agreements and exorbitant pharmaceutical prices also limit the capacity of governments to provide HIV care. Presently, Malawi procures a generic, first-line antiretroviral drug combination from the Indian company Cipla, but it has no capacity to supply free second-line treatments. This is a major problem for those who are resistant to, develop resistance to, or experience side effects from the existing drug combination. One of my interviewees described,

> There are huge challenges ahead; it's not just turning a spindle and then it just happens. What are we going to do about second- and third-line treatment? Enough people have taken trimune that they need to be switched, and there are drugs they could be switched to... [But,] we only have trimune as a free drug in government centres. And, they've got all of this pressure coming out of Washington, DC about patents...But, if we make it impossible for people, for countries to buy drugs from India, we have a huge

> crisis on our hands, because there's no way Malawi can afford to go on the market, even at deeply discounted, humanitarian prices and purchase these drugs. And there's no way people could afford them.

HIV treatments, including ART and PMTCT services, are delivered in Malawi in ways reflective of Malawi's marginal status. They do not meet international best-practice standards, because resource constraints make adherence to standards impossible. Moreover, although more affordable and better treatments are needed, the situation might worsen, as developing countries are under increasing pressure to adhere to international patent laws. Another systemic problem in tackling HIV, and the one addressed throughout this thesis, is the narrow focus of HIV services on biomedical aspects of treatment and drugs. These are necessary and much desired by Malawians, but programs need to expand to achieve true success. This means striving for quality health services and breaking down barriers to access. It also means looking most broadly at health, at food security, and psychosocial well-being.

CHAPTER THREE – RESEARCH METHODS

METHODS

The primary data in this thesis derives from anthropological fieldwork I conducted in Lilongwe, Malawi between May and July 2003 and between August 2004 and July 2005 – a total of 14 months.

I used May to July 2003 to become acquainted with Malawi and build connections for the full research program. As I was interested in researching the experiences of women living with HIV, and hoped to look specifically at PMTCT programs as sites of HIV diagnosis and the creation of HIV-positive women, I wanted to build connections with organizations through which I could meet women living with HIV. More specifically, I hoped that I could gain access to a PMTCT program where I would be able to recruit women into the research and learn about the delivery of PMTCT programs and HIV services. Therefore, I spent my preliminary research period meeting with individuals at various AIDS service organizations. Through these meetings, I learned how the government and various local and international organizations were addressing the HIV epidemic in Malawi. I also became familiar with the organizations providing PMTCT programs in Malawi at various locations. In Lilongwe, I learned that an organization, hereafter called the Lilongwe HIV Program, delivered the PMTCT program at three government health centres, Kawale Health Centre, Area 18 Health Centre, and Area 25 Health Centre, and at Bottom Hospital, a division of Lilongwe Central Hospital. While in Malawi, I was able to make initial e-mail contact with the Lilongwe HIV Program and learned more about how its staff delivered the PMTCT program.

Over the course of the next year, I communicated with Lilongwe HIV Program staff about the research I wanted to undertake. During these exchanges, I purposefully communicated the flexibility of my research plan. My hope was that their research needs could be incorporated into my research project so that the research could be mutually beneficial. In mid-March 2004, the Lilongwe HIV Program granted me access to the PMTCT program at Area 25 Health Centre, which they chose because it was the only one with space to accommodate my research (other health centres were over capacity in building space and nurses). Although Lilongwe HIV Program staff felt that my research would be beneficial and valuable, they did not provide any research directions that they felt would be useful for their own work. Moreover, they wanted my research not to consume any of their resources, to be confined to the Area 25 Health Centre, and not to include any of their other sites or medical research programs. While I agreed, these restrictions minimized any potential for collaboration with the Lilongwe HIV Program and limited my access to their multiple medical research projects.

Program staff facilitated my research prior to my arrival in Lilongwe by telling me what approvals I would need for my research: from the Lilongwe District Health Officer (obtained in May 2004) and the National Health Sciences Research Committee (NSHRC) within the Malawi Ministry of Health and Population. I submitted my research protocol to the NHSRC for ethical and scientific approval in June 2004 and it was approved in principle, pending my clarification. I did so in July 2004 and received final approval in September 2004. I also obtained approval from McMaster University's Research Ethics Board.

Upon my arrival in Malawi, Lilongwe HIV Program staff were very helpful in acquainting me with the PMTCT program protocol, Lilongwe HIV Program and government staff at the Area 25 Health Centre, and familiarizing me with Area 25. They also introduced me to the main AIDS Support Organization (ASO) there, which provides home-based care and programs for orphan and vulnerable children. The staff also recommended a research assistant, who had worked with them on research projects in the past.

Language

Chichewa and English are both official languages in Malawi; however, other languages are regionally important. In the central region of Malawi, Chichewa is the most common language and is the day-to-day language of communication for the women who participated in my study. However, depending on where they were born and grew up, they may also speak one of the other languages. More educated Malawians working in health, education, government, and international organizations are most often fluent in English. Official documents and daily newspapers are also in English.

Although I had hoped to learn it, my very limited Chichewa at the beginning of the study made a research assistant/translator essential. Conducting research without full comprehension of the local language is a less than ideal way to engage in anthropological research. The nuance of language can be lost in translation, and eavesdropping on multiple ongoing conversations is impossible. To a large extent these challenges can be overcome with a proficient translator, by deliberately seeking out information, or asking to be let in on a joke or story.

The research assistant I hired, Cynthia Zulu, was a Malawian in her early 30s. She lived near the health centre and was familiar with the area and the health centre staff. Cynthia met me at the health centre each morning and translated printed and verbal health information communicated to women by health centre staff. She also translated my questions and participants' responses during interviews and focus groups. While translation during interviews was sometimes lengthy, it provided a real-time check of the translation quality, as an answer would often differ from what I expected if the question had not been translated properly. Such situations were infrequent, but when they occurred, I could immediately ask Cynthia for clarification and she could rephrase the question. In situations where Chichewa was not a participant's first language or where she spoke Chichewa from another area of Malawi (which Cynthia sometimes called "deep Chichewa"), Cynthia also needed clarifications.

Participant Observation

Over the research period, I spent weekday mornings and early afternoons at the health centre. This was when it was most active. I would arrive at the health centre by 8:00 a.m., when women gathered for antenatal care, family planning services, and brought children to the under-five clinic, and when men and women lined up for outpatient health care. This time at the health centre allowed me to see the day-to-day functioning of the health centre and the movement of people through the various health services. I joined women in their long waits for antenatal care and often left the health centre after the last woman had received her HIV test results, sometimes after 3:00 p.m. I was also able to witness less frequent events: groups of silent women accompanying a woman and her miscarried or stillborn child for burial, groups of wailing mourners collecting the body of their loved one, and ox-carts and wheelbarrows bringing the sick from more distant villages.

My presence at the health centre also allowed me to build relationships with nurses and other health centre staff. The many informal conversations were perhaps as informative as the formal interviews I conducted with these people. For clients, I became a regular part of the health centre scene; I would often see people repeatedly and get to know them. Being there on a regular basis also allowed me to stay connected with participants in my research. Women often missed our scheduled interviews, but came to know that they could find me at another time. They would often check in with me between interviews to let me know how they were or what ailments were affecting them or their children. I also was at the health centre for the delivery of many participants' babies and held several within hours of birth.

I also became familiar with the community and participated in the activities of two AIDS service organizations that operated in Area 25. With one, I went to a number of villages with volunteers as they provided home-based care to the sick. This gave me the chance to see some of the community support available for individuals living with AIDS and their affected families. I also attended some of their Saturday morning programs for orphans and vulnerable children. This ASO was founded by, and continues to be run largely by, people living with HIV. In keeping in touch with this ASO throughout my stay, I gained a broader perspective on the experiences of many people who had been living openly with HIV for several years and were actively engaged in community support and mobilization against HIV. Another group with which I became familiar was the clinic and support group run by the Catholic diocese in St. Francis Parish, next to the Area 25 Health Centre. I visited their Wednesday-morning clinic on a number of occasions and met with their support group for people living with HIV. I also introduced to this group a number of participants of my research project.

Figure 3.1-Home Based Care Visits with an AIDS Service Organization around Area 25, Lilongwe

Figure 3.2-Catholic Diocese Support Group, St. Francis Parish, Area 25, Lilongwe

Interviews

During the recruitment phase of my research, the nurses informed all the women attending antenatal health talks about my research. In the post-HIV-test counselling sessions, the nurses asked women who tested positive whether they would be willing to meet with me; most agreed. Those who did not primarily cited time constraints. When a woman agreed, I tried to meet with her immediately to explain the research and what would be involved if she decided to participate. When a woman was interested in participating, Cynthia read her the Chichewa consent form. We emphasized that my research was distinct from the health services at the health centre, that we were not doctors or nurses, that we were not employed by the health centre or the Lilongwe HIV Program, and that participation would not influence their health care. This emphasis was important, as the interviews took place at the health centre. We also emphasized the voluntary nature of the research and that interviews were confidential. We then answered any questions about the research and asked the woman if she would like to participate. We also asked about expectations from participation. This allowed us to clarify any misunderstandings and to ensure that women had appropriate expectations. All women who could write signed the consent form. Those who could not gave oral consent.

At this time we asked women how they felt about what had happened in the PMTCT program that day. Thus we heard women's initial reactions to their HIV positive diagnosis. However, because the women had already been at the health centre for a long time, sometimes up to seven hours, we did not want to delay them further. We made an appointment for the first interview within the next week. A few women decided not to participate or said that they would like to discuss the research with their husbands. We gave all women who met with us initially, whether they decided to participate in the research or not, a small gift (a bar of Sunlight soap and a 500-gram bag of salt) to thank them for their time.

The interview schedule was arranged to coincide with processes in the PMTCT program, with six interviews in total for each participant. I tried to combine interviews with women's regular visits to the health centre to minimize disruption. Sometimes, due to the length of the life history interview, it was divided into two parts anytime after the second interview and was used to fill in an otherwise lengthy gap between interviews. Interviews lasted approximately one hour each. All were tape recorded and simultaneously translated and transcribed by Cynthia Zulu.

Table 3.1 outlines the number of women who participated in each interview. During the interview process 14 women did not continue for various reasons: eight could not be found for follow-up, two moved, one was sick and being looked after in her home village, one had stillborn twins and had been sent back to her village by her husband, and two withdrew from the study. One withdrew as she felt that she could no longer attend interviews because her new baby was very fussy. The other did not explain why she was withdrawing, but it seemed that she was concerned that people might find out about her HIV status.

Table 3.1-Summary of Interviews

Interview	**Topic Summary**	**Number of Women Interviewed**
1	Background and demographic data, decisions about first antenatal care visit and HIV testing, coping with HIV status and disclosure, meaning of HIV diagnosis, understanding of PMTCT program	34
2	Follow-up and catching up, coping with HIV status, disclosure, beliefs and practices about pregnancy	30
Life History	Childhood, adolescence and coming of age, relationships and first sexual experience, marriage, motherhood, household economics	23
3	Follow-up and catching up, labour and delivery, beliefs and practices about birth, coping with HIV status	21
4	Follow-up and catching up, infant health and feeding, meanings and beliefs about HIV	20
5	Follow-up and catching up, infant's HIV test (PCR) results and meanings of those results	20

Focus Groups

At the end of January 2005, two separate interests in furthering the research led me to add focus groups. First, I wanted to create a research forum for conversation between women. Second, I wanted to learn more about women who had a lengthier experience of HIV and participation in the PMTCT program than the women I had interviewed. I therefore did not include the women I had interviewed in the focus groups. The Lilongwe HIV Program runs a postnatal support group for women in the PMTCT program. Through this group I recruited women for the focus groups. These women already knew each other's HIV status, alleviating my concern about initiating disclosure.

Originally I planned two focus groups of six women each. As I wanted to avoid long sessions and had a number of topics I wanted to discuss, I planned for each group to meet three times. At the end of January, I presented my research to the support group and explained that I was looking for participants in group discussions on gender relationships, HIV and AIDS, and the PMTCT program. There was an overwhelming response; 24 rushed forward for Cynthia and me to take their names. I decided to double the number of focus groups, begin with two sets of sessions in February and a further two in March. Of the 24 women who signed up, 21 came to the sessions. In the end, I met with each group of women four times. The first meeting was taken up with explaining the research, the consent process, and discussing the questions and concerns women brought to the meeting. The focus groups each lasted approximately two hours. All were tape recorded and then translated and transcribed by Cynthia.

Following the compensation guidelines used by the Lilongwe HIV Program, all participants in interviews and focus groups were given 200 Malawi Kwacha (MWK), approximately CAN$2.25 at the time, for each meeting, a drink and a snack.

Figure 3.3-Focus Group, Area 25 Health Centre, Lilongwe

Contextual Interviews

I also conducted interviews with informants who could provide context for the PMTCT program and other HIV interventions in Malawi. At the Area 25 Health Centre, I interviewed four Lilongwe HIV Program nurses, two Lilongwe HIV Program community nurses, three government nurses, the government medical assistant, as well as the government clinical officer, the most senior medical staff person at the health centre. At the Lilongwe HIV Program, I also interviewed the PMTCT program manager and two staff members from overseas overseeing research and other programs. At the National AIDS Commission and the Reproductive Health Unit of the Ministry of Health and Population I interviewed three policy makers, two of whom focused on the PMTCT program. I also interviewed four stakeholders in multilateral and bilateral aid agencies, including the head of the Joint United Nations Program on HIV/AIDS (UNAIDS) in Malawi. Countless informal conversations with local and expatriate health care providers and development workers also informed my understanding of Malawian and international responses to HIV.

Data Analysis

I began initial data analysis during research by identifying themes that emerged in interviews and focus groups and when rereading the transcripts. This grounded research allowed me to probe emergent themes in future interviews. On completion of data collection, I systematically identified further thematic codes by rereading all interview and focus group transcripts. I used an inductive approach to ensure that research findings emerged from women's own communicated experiences. I entered all interview and focus group transcripts into QSR N6, a qualitative data analysis program. Then, I manually coded all interview and focus group data line by line into designated themes and sub-themes. Additional themes emerged as I coded data, and I incorporated these into my thematic scheme. When I identified new codes, I reviewed previously coded data and recoded data if new themes were relevant. In total, I coded the data into 97 themes and sub-themes. After all data was ordered thematically, I read and analysed each theme, paying attention to the data's provenance and context within specific interviews, as well as the relationships between different themes and sub-themes. I organized the thesis by developing a coherent narrative flow between the many themes that emerged from research and data analysis.

Research Ethics

Repeatedly over the course of my research, situations reminded me that the role of the researcher, and the research design, ought to be equally determined by participants and the researcher. Post-modern and feminist anthropologists have destabilized the previously assumed authority of the ethnographer and challenged anthropologists to critique and redress the representation of "the other" in ethnographic writing (Behar and Gordon 1996; Clifford and Marcus 1986). Also problematic is the unequal relationship between the researcher and researched; feminist and other activist anthropologists call for a similar politicization of the research encounter (Nelson 1996). In part, this requires removing the researcher's control over the research process and recognizing that participants also have research goals (Scheper-Hughes 1995). "Qualitative, ethnographic research methods can be empowering in themselves, to the extent that they open up a space for previously silenced women to speak about their suffering and gain affirmation of their efforts – often secret, dangerous, and subversive – to abate it" (Petchesky 2001:279).

Throughout the course of my research it was clear that women had specific goals in participating and it was important to me to address these, to respond. Being responsive influenced my research; for example, in focus group meetings I added two focus groups to avoid turning women away. I recognized that women can gain from participation in research financially and socially: they can have their views heard and questions answered. Being aware of the potential benefits also meant recognizing that participants would be unsatisfied just answering my questions; they wanted to ask their own questions and receive answers. In the consent process, when I asked women if they had any questions about the research, they often responded with questions about their health, their fears, their worries, and the PMTCT program. They asked how they could protect themselves from the virus, if there was any way to protect their babies, how long someone could live with AIDS, etc. These questions confronted me with confusion over my authority to answer and the reality that I might be the women's best source for a timely answer. Although I knew the answer to most of the questions and could draw on printed material from the PMTCT program, I was unsure whether I should do so or arrange for a nurse to meet with the women again. In wanting the women to receive the best information possible, I worried about causing friction with the nurses by questioning their counselling and increasing their workload. I decided to consult with the PMTCT program manager. She felt that it was fine for me to answer such questions myself.

The women continued to ask me questions throughout the research, and I became more comfortable with answering. I came to think of it as one way in which the research could be mutually beneficial. However, answering questions did create some difficulties: I wanted to understand how women thought about and understood HIV, its transmission through labour, delivery and breastfeeding, and antiretroviral drugs. In answering questions, I did not want to construct myself as an expert, inhibiting women from answering questions or reflecting them back. This did happen occasionally, but overall I was still able to find out how women understood these things. The focus groups were particularly good for discussing competing belief models, as one woman would ask a question and the others would give their own explanations. However, this presented another problem: what to do when women presented medically "wrong" beliefs in their explanations without asking for the "right" answer. As a medical anthropologist, I found this a particularly acute conundrum, because I respect different ways of knowing and recognize that medical information is contingent. At the same time, however, the women were acting within the medical model to preserve their lives and prevent transmission of HIV to their children. Thus, in such cases, I tried to share information with women not as an expert, but as a friend. In the end, I felt that this was ethically correct, particularly in light of the frustrations some women felt about the medical system and their care seeking efforts. This I elaborate in Chapters Seven and Eight.

WOMEN AS ETHNOGRAPHERS OF THEIR LIVES: NARRATIVE AND EXPERIENCE

My participation in the lives of the women in my study was more marginal than in traditional anthropological research. I focused on one site, a health centre, and women's engagement at that site. I decided not to extend my study beyond the health centre due to the sensitive topic, HIV, and an ethical imperative to do no harm, to be sensitive to participants' rights to safety and privacy (AAA 1998).

When women did invite me to visit their homes, I was sure to discuss stigma and safety with them in advance. Women's life experiences outside the health centre thus primarily came to me through their stories in interviews. They therefore can be seen as ethnographers of their own lives (Mol 2002:15).

Figures 3.4-Visit to Participant's Home for Lunch

Taking a narrative approach within anthropology means that anthropologists' knowledge of life worlds increasingly comes through narrative, rather than participant observation. Some authors have been critical of this shift. Wikan (2000) opines, "I have deplored the downplayed role of *observation* in making sense of a person's experiences, arguing that we need observation of real-life events to anchor and also offer *resistance* to person's telling-it-as-it-was" (Wikan 2000:220-221). Indeed, I found my daily participant observation at the health centre vital to grounding and understanding women's descriptions of their experiences in the health care system. Wikan's comment, however, also raises methodological questions about the nature of narrative and its association with experience. Questions about this association have led to a profusion of approaches to narrative. It is polarized as either experience-near or a construction with no real foundation in experience, as well as everything between these poles (Csordas 1994; Good 1994; Mattingly 1994, 2000; Peacock and Holland 1993).

I see narrative as both the communication of life experiences and as a fundamental way of making sense of the world, engaging with others, and directing future action. This closely follows Peacock and Holland's (1993) proposal of a dialectical approach, which they term "processual," to the study of narrative. Narrative, they posit, is about more than the communication of stories about experiences. Ochs and Capps (1996:19) describe narrative as a "fundamental genre in that it is universal and emerges early in the communicative development of children" (see also Linde 1993; Monks 1995; Price 1995). Proponents of the processual approach equally emphasize narrative as a culturally mediated phenomenon important in psychological processes and self-formation. They also approach narrative as important in the "formation and maintenance of social relationships and collective identity" (Peacock and Holland 1993:372); a product of interaction between narrators and interlocutors; an outcome of cultural and collective dynamics and a "gripping formulation of beliefs, values, and ideas basic to a cultural tradition" (Peacock and Holland 1993:373). In the processual view, narrative is never static; rather, it is an active process central to human development. Practically, this means that stories change – not that the events communicated are necessarily different, but that the meanings given to the events reflect the narrators' different vantage points throughout their life courses. One element of this is the subjunctive quality of narrative, in which narrators both imagine alternate possibilities and leave multiple possibilities open for future engagement (Good 1994:146).

Illness, in the anthropological study of narrative, is a paramount example of a life event that can fundamentally reorient the meanings given to life experiences. "Almost every illness story," says Frank (1995:54), "carries some sense of being shipwrecked by the storm of disease, and many use this metaphor explicitly." In confronting illness, therefore, narrative helps people reconstruct themselves. Narrative creates continuity between past, present, and future, and maintains connections with others. If, as Frank describes, illness is the loss of destination and map, then "stories have to *repair* the damage that illness has done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of drawing new ways and finding new destinations" (Frank 1995:53).

Storytelling during illness engages the narrator immediately in the world; it challenges discontinuity and the lost sense of self created by illness (Becker 1994; Becker 1997; Price 1995). To achieve continuity narrators restructure their life stories in light of new circumstances. This process involves reorganization of the story and a change in emphasis between the foreground and background. This is necessary to maintain connection between the past, the present, and the future, an exercise in what psychoanalyst Donald Spence calls "narrative truth" (Frank 1995:60-51). This process of "emplotment" "draws a configuration out of a simple succession. Emplotment brings together heterogeneous factors such as agents, goals, means, interactions, and unexpected results and renders the story's contents intelligible" (Becker 1997:27). Emplotment is performative, insofar as people learn their stories by telling them and hearing the reactions of others (Becker 1997:153, Frank 1995:1). Telling stories may create a range of possible interpretations rather than certain truths and thus leaves open diverse possibilities for future action (Migliore 1994). While the creation of self is continual and ever evolving, when illness calls for radical revisions the need for new meanings is particularly acute. This may be especially true for women with HIV who see a contradiction between the dominant discourse on HIV and their own life experiences (discussed in Chapter Six). The narrator, therefore, seeks to create a continuous sense of self, as well as to convey and negotiate this self with others (Linde 1993).

Narratives are not exclusively individual, but outcomes of collective, and sometimes political, meaning making. For example, Ochs and Capps (1996:33) illustrate how institutionalized storylines, dominant narratives in education, religious, legal, and medical settings, give moral voice to particular world views. Studies of illness experiences and narratives illuminate how people come to tell particular, and often similar, stories about their illnesses. Individual perspectives on illness often come from, or are influenced by, local cultural systems (Kleinman 1988:27). In times of crisis, people draw on their cultural resources. For Migliore, these consist of

> (1) a number of verbal and nonverbal cues people can use to express their suffering, (2) various cultural concepts that provide individuals with a basis for interpreting and explaining their experiences or the experiences of others, and (3) various preventive and therapeutic rationales people can employ to guide them in their attempts to deal with illness and misfortune.
>
> (Migliore 2001:103)

Frank (1995), for example, identifies three narrative types, drawn primarily from written accounts of illness in North America and Europe, that dominate in individual accounts of illness. Davies' (1997) and Ezzy's (2000) analyses of narratives by people living with HIV also use plot types. For Frank, "narrative types are the most general storyline that can be recognized underlying the plot and tensions of particular stories" (1995:75). While Frank is clear that people tell their own stories, he is also aware that people draw on cultural resources when doing so.

Prevailing themes to address illness, however, should not be viewed as either fixed or overly deterministic. When prevailing cultural themes cannot help individuals make sense of their lives, new cultural themes emerge. As I expound throughout this thesis, women with HIV draw on the theme of "living positively," which challenges dominant constructions of what it means to have HIV (see also Levy and Storeng 2007). This is consistent with the literature, which shows that therapeutic communities often have specific narratives about illness. One site where this plays out is self-help groups (Cain 1991; Janzen 1982; Steffen 1997). "Groups amend normalizing ideologies to reflect their particular views, and because these amended ideologies carry particular moral force for group members and buffer them from more generalized ideologies of normalcy, they facilitate agency" (Becker 1997:202). Self-help groups often also have their own powerful narratives that shape the experiences of members. As Garro and Mattingly point, out "Narratives offer a powerful way to shape conduct because they have something to say about what gives meaning, what is inspiring in our lives, what is dangerous and worth taking risks for" (Garro and Mattingly 2000:12).

Narratives, including group narratives, however, are problematic. For example, Good (1994:160), drawing on Turkish narratives of epilepsy, finds that who tells stories and what stories get told are influenced by power relationships based on gender, age, and family position (see also Garro and Mattingly 2000). Ochs and Capps (1996:33) refer to the silencing of alternative stories as "linguistic oppression." "Narrative asymmetry" is apparent in the privileging of certain versions of stories and ways of recounting experience. The construction of illness experiences is thus political and relates to specific relations of power. While there is a general perception that illness stories are empowering, this is not necessarily the case.

> Is such storytelling (finding its contemporary manifestations predominantly in self-help groups, therapy, everyday life and social science interviews), just another of Foucault's 'technologies of the self,' one of the ways in which power operates by convincing people to seek certain parts of themselves and institute

> practices (e.g. confession, diet, physical/spiritual exercise, therapy) to effect a transformation of self? (Crossley 1999a:1686)

While individuals may be able to resist normative role constructions, agency can be supplanted by dominant ideals about the life course and moral predilections for "healing." For example, Price's (1995) study of the use of life history among terminally ill patients warns that medical personnel can reify, commodify, and standardize life stories if such stories become part of formal therapy. Moreover, we must attend to the relationship between narrative and experience. Narratives of illness may promise empowerment that cannot be fully actualized because of structural barriers to well-being and the best care.

In the positive-living narratives I elaborate, empowerment has a relational quality; that is, context is important for understanding what narratives do. For women living with HIV, the "living positive" narrative can empower them to challenge the dominant construction of HIV as a death sentence associated with moral deviance. The narrative thus legitimates women's experiences and provides hope that they will live, and indeed live well. However, what seems to be a productive, powerful narrative in one context invokes discipline and control in another when it masks injustice. In the Malawi case, it downloads responsibility onto those without adequate health, nor psychosocial and economic support to safeguard their health.

In recognizing that narratives are not solely individual, I do not seek to obliterate storytellers' agency. Indeed, narratives do have strength: I see them as not simply stories about the past, but as changing current situations. Narratives project future possibilities on which narrators can act (Mattingly 2000), in part through their orientation toward social relationships (Hunt 2000; Migliore 2001). Women with HIV maintain relationships with their husbands by presenting themselves and their HIV status in particular ways.

I understand women's stories of their lives after HIV diagnosis as part of how they make sense of their illness. I see these narratives as not only being about their lives but influenced by prevailing discourses about HIV in the community and the discourse of "living positively" promoted by health care providers. I also see women's narratives as oriented toward the future, in their hope, and mine, that in telling these stories they will address their struggles in life with HIV: struggles with service providers, health systems, international health policy, and international political economy – the other narratives interwoven in this thesis.

CHAPTER FOUR – SITUATING HIV DIAGNOSIS IN WOMEN'S LIFE STORIES

INTRODUCTION

As an anthropologist, my point of entry into women's lives was at the time of their HIV diagnosis; however, HIV diagnosis occurred in the middle of women's stories. From diagnosis their stories went backward and forward. In this chapter, I look at the factors in women's lives that led to HIV infection.

Authors within anthropology and other disciplines have well documented the local and global determinants of the HIV epidemic among African women. This political-economic approach, often referred to within anthropology as an analysis of structural violence, sees individual risk factors for disease as structured locally, nationally, and internationally (Brummelhuis and Herdt 1995; Doyal et al. 1994; Farmer et al. 1996; Nguyen and Peschard 2003; Parker 2001; Schoepf 1995; Singer and Clair 2003). In so doing, the structural violence approach moves beyond individual psychological and behavioural prevention interventions.

Here I continue the discussions of critical approaches to medical anthropology, political economy, and structural violence in Chapters One and Two. However, I refocus my lens from the macro context of global and national political economy, to everyday social, economic, and gendered structures that create risk for women. HIV has been described as just one among many problems in women's lives that need to be addressed (see Connors 1996; Ward 1993). In focusing on the structural determinants of risk, I acknowledge these other problems, as well as the limited control women have over the perpetuating factors.

I examine the economic, cultural, and gender inequalities that put women at increased risk of HIV infection:[7] poverty, low educational status, and poor job opportunities. In Malawian reality, economic security comes to women through relationships with men and marriage, limiting women's capacities to negotiate safe sex (see Maman et al. 2000b). Women's poverty translates into uncertainty, where basic needs are fulfilled with difficultly and unexpected events can create severe crises.

I also consider the cultural construction of women and their sexuality, which restricts what is permissible for women and makes it extremely difficult for women to navigate both expectations and negotiate safe sex or lifestyles that will protect them from HIV. The flow of power between the sexes, bounded by culturally prescribed masculinities and femininities, contributes to the spread of HIV. While I focus on women, HIV equally endangers men's lives through the cultural construction of manhood.[8] The National AIDS Commission (1999) describes this gendered epidemic:

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[7] In addition to socio-economic factors that increase women's risk for HIV, they are also biologically more vulnerable through heterosexual contact than men. The virus is transmitted more effectively from males to females than from females to males (Buzy and Gayle 1996:190).

[8] Gupta (2000:19) describes men's vulnerability to HIV as caused by their greater power. Expectations of men mean that they are supposed to be more knowledgeable about and experienced with sex. These norms prevent men from accessing information about sex, thereby admitting their lack of knowledge, and coerce them into proving their manhood by experimenting with unsafe sex at a young age. The norms also perpetuate the belief that multiple partners are essential for men's survival (Campbell 2003). Finally, the cultural expectation that men be invulnerable makes it difficult for them to acknowledge their risk of HIV infection.

> Most Malawian men and boys view pre- and extra-marital sex as a demonstration of manhood. This is basically because the Malawian cultural values regarding sex and sexuality tend to emphasize and strengthen the dominance of men and boys and subordination of women and girls. Some of these views are entrenched by initiation ceremonies and the whole process of socialization.

The salient themes in the literature on women's disproportionate risk for HIV infection are lack of knowledge and silence about sex, expectations of wife- and motherhood, and lack of power to negotiate the terms of relationships. These burdens define women's situation in many parts of Africa; I will discuss how they affect women in Malawi.

Of course, the gendered and economic components of structural violence do not operate separately. They interweave and compound each other in creating vulnerability. As with women's life stories, I will deal with them together; in the following paragraphs I tack between them.

A STRUCTURAL VIOLENCE READING OF MALAWIAN WOMEN'S LIFE STORIES

Women's life stories bring out the pervasive poverty of life in Malawi, not solely in descriptions of what happened but in the matter-of-factness of the telling. These are ordinary, rather than extraordinary, stories.

Early Disadvantage

The poverty, in which most of the women in my study live, began in childhood. For example, women describe that they initiated labour at a young age to help provide necessities in their parents' homes.

> Interviewer: Growing up, how do you think your family was managing in terms of money?

Participant: When I was growing up, I used to do a lot of piecework because of poverty. I grew up in problems.
I: What sort of piecework did you do?
P: Working in the fields and also selling firewood in the plots. My parents were very poor – I should not lie – and we were suffering even before my father died. He used to make baskets, so sometimes he would return home without selling. We were very poor.
P: Did you and your family have enough to eat?
I: Sometimes it was scarce, such that we would sleep on empty stomachs, and sometimes it was available.

The majority of Malawians are subsistence farmers; in good years this provides sufficient food for most of the year.[9] Hunger, however, is common prior to the harvest, when most families have exhausted their grain stores.[10] Poor families, who do not have land to farm, must find money through work for others and business, as the woman quoted above describes. For families who subsistence farm, food is most often available; however, earning money for household necessities, such as clothes and soap, is still a challenge.

I: Did you and your family have enough to eat?
P: Food was readily available because, after harvesting, it would go up to February the other year. But things were difficult in terms of clothing, school fees, soap, etc.

Unattainable education is one of the major impacts on women of their families' poverty. The women in my study had between zero and 12 years of education; the average was 5.8 years. Although Malawi introduced free primary

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[9] Even in Lilongwe, subsistence farming is still common. As adults, most of the women in my study do some subsistence farming. Some women owned land in their home villages (either within or away from Lilongwe), which they farmed. Others rented land around Area 25 to farm.

[10] In recent years, regional and nation-wide famines have recurred in Malawi due to drought and inconsistent rainfall, exacerbated by mismanagement of government grain stores and the HIV epidemic.

education in 1994, many women told me that they had left school prior to that time due to unaffordable school fees.

> I: What specifically do you remember as the problems growing up?
>
> P: In terms of food, it was just fine. But in terms of clothing there was a problem, because I could admire some friends that they were well dressed but as a child I just said, "That's life." For example, for me to stop school when I was going into Form Three[11] it was because of MWK50. And, because of this, I really felt there were problems in our family.

Even women who did benefit from free primary education often faced other education costs, such as exam fees and secondary school fees. One woman says, "I failed to sit for my Standard Eight exams, because I was required to pay MWK1,000, and that time I was staying with my aunt and she couldn't produce that money. So I failed to continue with school."

Losing parents compounded women's poverty. Children who had lost one or both of their parents often moved around within their extended families and sometimes faced abuse and neglect, or had to care for siblings. This situation curtailed their education.

> When I was going to Form One it's when my mother died and she left me with a small baby of about seven months. My relatives refused to take care of the baby. And, as a result, I failed to continue school because I was taking care of the baby, taking her to the hospital when sick and also under-five services. I stayed with the baby for a year and later she passed away. I never went back to school despite the baby dying, because there was no one to pay my school fees and I was not getting any support from anywhere.

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[11] In Malawi, primary school goes from Standard One to Standard Eight, and secondary school goes from Form One to Form Four.

Overall, the women in my study lamented that they were unable to continue their education, and described futures thus lost.

The literature on HIV in Africa describes women's lack of educational opportunity as gendered. In Ghana, Mills and Anarfi (2002:327) report that girls are less likely to attend school than boys and more likely to be withdrawn from school due to the family's inability to pay for school fees, books, and uniforms. In South Africa and Zaire, Jewkes et al. (2003:126) and Schoepf et al. (1991:191) found that girls are vulnerable to sexual harassment and coercion by teachers in exchange for passing grades. In my study, women described preference for boys over girls when money was insufficient to pay for the education of all the children.

> I: When did you stop school?
> P: I stopped in Standard Five.
> I: What happened that you stopped then?
> P: Nothing, you know that time we were paying something, so my parents couldn't afford to pay fees for all of us.
> I: Were any of your brothers or sisters able to continue with school?
> P: Yes, like the males they continued, and others are now working as teachers.
> I: How did you feel that your brothers kept going to school and you didn't?
> P: I felt bad, but as I was that time I just thought of getting married, what else could I do?

Literacy statistics in Malawi confirm the priority of boys in education. In 1998, 54 percent of women and 74.9 percent of men over 15 reported being literate in at least one language (NSO 2002:46). Moreover, men outnumbered women in their attainment of primary, secondary, and post-secondary school certificates.

Education statistics, however, suggest that free primary education may be reversing priority of boys in education, at least at the primary level. There is now a slight female majority in primary-school enrolment (NSO 2002:49). The increase in primary enrolment has, however, overwhelmed the education system. There are too few teachers and too many students. Stories of students having to exchange sexual favours for basic education and extra lessons abound in the popular press and grey literature.

Relationships and Marriage

As women reach adolescence, socio-economic disadvantage combines with cultural meanings of womanhood to create risk of HIV infection. Gupta (2000:18) describes a "culture of silence" surrounding sex in many societies that makes it difficult for women to discuss and access information about sex. In Malawi, this is certainly the case. When girls start menstruating, elder women in the community give them advice. Generally, the extent of advice on sexuality is that young women are told to stay away from boys or else they will become pregnant (see also Wood et al. 1998). Some women in my study also describe being told that they should stay away from boys, because "nowadays there are a lot of diseases." Although limited communication on sex increases women's vulnerability to HIV, in that women are less knowledgeable about sex and less free to communicate their terms in sexual relationships, some women describe the advice as protective, at least prior to marriage. Some women describe being encouraged by the elders' advice and refusing to have sex before marriage.

> I: When did you start having boyfriends?
> P: It took time. In fact, I never had boyfriends, because my mother told me that it is not good to play with boys. But other girls had relationships. The time I got into the marriage, I had problems because I never knew anything about what happens.

Another woman describes having boyfriends but waiting to have sex until she was married: "I used to end the relationships because, when they asked for sex or something, I would just end the affair. So, I started when I got married."

Women in my study, however, also describe a peer expectation that, once they reach a certain age, they will begin to have boyfriends. This social pressure works against elders' advice. More often than not, relationships with boyfriends include sex (see also Wood et al. 1998). As one woman describes, "When one reaches the adolescent stage, people start having relationships, and I had been one of that sort. My relationships never used to last; as a result I changed partners, and I never used to use condoms that time. This year, in January, it's when I got married." Another woman describes her first sexual encounter:

> My friends used to laugh at me, saying that I was stupid, and they started telling me that I need to have a boyfriend. So my friend, who had a boyfriend, took me to see her boyfriend at his house. Then, I didn't know what happens between boyfriend and girlfriend. They said I should sleep with my friend's boyfriend's friend.

This woman describes being forced to have sex but staying in the relationship to gain acceptance from her peer group: "We became good friends, and we started moving together. And they no longer used to laugh at me." This woman's story also speaks to women's vulnerability to HIV in that boyfriends are often older than girlfriends and may have previously been exposed to HIV. This woman further said that the man she first had sex with was a seasonal worker and she later heard that he had a wife.

Economic necessity exacerbates social pressure and led many of the women early into relationships with men.

> I: When did you start having boyfriends?
> P: I started having boyfriends after I became matured [started menstruating]. And maybe it's just that I got carried away and I didn't know what a relationship is. And that was in Form One. But when I was in Standard Eight, I only used to hear from people that people are in love, but I didn't know what happens between lovers.
> I: Did you have your first sexual experience with your first boyfriend?
> P: Yes. And I can say I was somehow forced to do that because I thought that, maybe if I sleep with him, he will give me money, as people say. But it didn't happen that way, and I thought, ooh, I have failed myself.
> I: So you were forced to have sex the first time?
> P: Yes. Because it was him who wanted sex and, as for me, childish, I just gave in, thinking it was part of life.
> I: What were other girls saying about money and sex at that time?
> P: What I used to hear is what I have said. That is why I attempted sex that time. So I don't know whether it's true or not, because it didn't work for me.
> I: Why did you need money?
> P: Because there was poverty, and that time I was in school. I used to lack body lotion and laundry soap. All I could manage was a small bottle of Vaseline and one tablet of soap. But, when I see my friends they had all sorts of things. And I used to ask myself, are those things my friends have here in this world? So, that's why I indulged myself in a relationship.

Malawian women are often forced to rely on sex throughout their lives. Moreover, it is clear that sexual exchange extends beyond prostitution; it is widespread and seen in terms of reciprocity (Jewkes et al. 2003:126; Lugalla et al. 1999:395). The term *survival sex* foregrounds that women depend on sex for economic survival (de Zalduondo 1999; Preston-Whyte et al. 2000; Wojicicki 2002). However, such relationships differ from prostitution because, whereas condoms may be acceptable in casual relationships, they are largely unacceptable in stable relationships (couples may consider even a few non-exclusive, sexual interactions a stable relationship) (Gysels et al. 2002:182). In all cases, where women depend on men for economic survival, they will have less success at negotiating condom use.

In addition to initiating relationships for economic stability, Malawian women also turned to marriage for the same pragmatic reason.

> I: How did you feel your family was managing in terms of money?
> P: They weren't managing. That is why I failed to continue with my education. Sometimes I would do some piecework to buy clothes and soap for myself, because the people who raised me up couldn't provide.
> I: Did you have enough to eat, or were there times when food was scarce?
> P: Food was very available, but the problem was in terms of buying clothes for me. In order to do away with my problems, I thought it was time to get married.

Of the women who describe seeking marriage, particularly early marriage, because of economic need, a significant proportion had lost one or both parents or were living away from them. Thus, parental loss was another reason to seek marriage. "I was not on [good] terms with my mother, and most times she used to shout at me. When I would ask for something from my mother, she would tell me to dig open my father's grave for assistance. So, I thought that was too much. That is why, when somebody proposed to me, I just accepted so that I could be assisted." Women who were not living with their immediate families but relied on extended families were also driven to early marriage.

> When I was staying with my mother things were readily available. But, when I was staying with my aunt, I lacked a lot of things. There was poverty. I had no clothes, no money. There was a lot missing. And on top of that, she favoured her children in everything and showed less love to me. That is why I decided to get married, thinking that I will be at peace. Otherwise my getting married was not intentional.

Some women report extremely early marriages, often with much older men. Women's poverty and men's power to choose women often leads to relationships between younger women and older men. The changing demographic of the HIV epidemic in Africa gives light to the power of men to choose sexual partners. Older men increasingly choose younger women as sexual partners whom they, in part, believe are less likely to be infected with HIV. In Malawi, the prevalence of HIV is significantly higher among women in their teens and twenties than men (see Table 2.1). Men's attempts to reduce their own risk has increased the risk of infection for young women (see also Mill and Anarfi 2002:327). As one woman in my study relates, "When I was 12 it's when I became matured. At 13 years old somebody proposed marriage to me. So, because of the bad relationship with my brother's wife, I just accepted this man, thinking that if I had my own home then some of these problems would finish. I would have peace." Another woman says,

> I: So how did you decide that you would marry this guy?
> P: In fact, it wasn't my intention to marry this man because he is much older than me. And he was once married and he has three

> children with his other wife. One child lives with me, but it was my aunt who forced me to marry him and also because of problems. Otherwise, I feared also to hear that he is big and was once married, but now I am used to him and the relationship is just good. And he does everything for me, he buys some clothes, *chitenje* materials [lengths of printed fabric], etc.

Social norms also lead women to early marriage. In Malawi, like elsewhere in Africa, being single and childless compound the low status of women. Jewkes et al. (2003:126) say that the social worth of women is determined by their ability to get and keep a man. Women in my study describe womanhood as something achieved by attaining cultural standards of womanhood: "The foundation of being a woman is coming of age, seeing periods. Secondly is getting married. After getting married is falling pregnant. After she delivers a baby, it's when there comes the name of 'woman'." This is women's expected life course: "Somebody who is not married, we expect that she is going to get married and bear children." This expectation often competes with women's own life desires, including education.

> I: Why didn't you want to get married?
> P: Even though I had become matured, that time I still felt I was young, not ready for marriage. I wanted to continue with school to see how far I could go with school, but my parents said that how long am I going to continue with school? Saying that, when one grows up she must get married. So, because my parents forced me, I ended up accepting. Otherwise my wish was to continue with school. I really did not want to get married. I even reached a point of wanting to run away or look for some piecework, but it didn't happen. I just decided to obey them.

Limited communication to girls about acceptable behaviour in marriage, advice from elders that women must respect their husbands and not cause a fuss, and women's economic position, often leave women vulnerable to abuse. Cultural expectations to be good women and proper wives structure their relationships with men. The advice at puberty and at the *chinkhoswe*[12] also emphasizes respect for elders and husbands (see also Gysels et al. 2002). Women in my study describe "good women" as those who selflessly care for their families, do not make "noise in the house," are quiet, patient, and reasonable. They say that being a good wife also means ensuring their husband's sexual fulfillment (see also Jewkes et al. 2003). Women, however, say that they would never initiate sex, because they might be seen as prostitutes and too interested in it. The silence about sex between husbands and wives includes lack of communication about husbands' and wives' sexual needs. One woman says that she would like to entice her husband away from prostitutes, who she feels have some special knowledge about sex, but feels that she cannot discuss her husband's sexual needs with him nor can she try anything new, for fear that he will accuse her of extramarital affairs.

Childhood poverty and disadvantage, derived from the low status of women and their limited access to resources, continue throughout women's lives.

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[12] A *chinkhoswe* is the traditional marriage ceremony, where the families of the woman and man gather to formalize the union of the couple and the families. Most women in my study had a *chinkhoswe* for their first marriage. Traditionally it would occur before the couple began living together. Now, however, some couples begin living together before their *chinkhoswe* and some never have one. In subsequent marriages, a *chinkhoswe* is much less common. "White weddings," following European wedding customs, are increasingly popular, but the women in my study said that these were too expensive. A few had a white wedding in addition to, or instead of a *chinkhoswe*.

Limited access to jobs in the formal economy lead women to unstable, poorly paid jobs in the informal sector (Karim and Frohlich 2000:76). Forster (2001:247) describes how men in Malawi participate in the wage-labour market to a greater extent than women. Although women get jobs in certain industries, domestic and clerical work, most earn income from the erratic sale of agricultural produce. Indeed, this is the experience of the majority of women in my study. Those who have waged work earn income in the informal sector, through what they call "piecework," and small-scale businesses where they primarily sell produce. Despite their limited income, they report considerable control and autonomy over household finances. Moreover, they often make substantial contributions to the household through subsistence farming.[13]

Marriage does not protect Malawian women against HIV, because extramarital affairs are common; it is culturally permissible, and even expected, that men will have multiple sexual partners. While women may protest this behaviour, social norms, as well as their economic dependency on men, keep them married. As one woman says, "I have lived a very pathetic, difficult life because I didn't have parents. But now I can say life is better because I am now married." This often-expressed need for marriage, however, leads women to tolerate behaviour that they otherwise would not. The women in my study discuss the commonness of men's affairs outside marriage. In the focus group discussions, one woman said, "As we are talking here, they are already in bars at

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[13] Land ownership in the Central and Southern regions of Malawi is predominantly matrilineal.

Nsungwi. Most men here are very unfaithful to their wives, more especially those who drink beer and even those who look quiet." Their husbands' affairs are a major concern for women and a major problem within their marriages. However, they simultaneously excuse such behaviour by describing men as biologically needing multiple partners, being unable to control their sexuality. One woman's husband spends long periods working away from home: "Men can't endure [without sex], but women can endure and abstain." Overall, women astutely observe their husband's behaviour; they know when their husbands are having affairs and confront them: "Most men do that behind their wives' backs, but women know about that because the man's behaviours change in the home." However, even without any evidence of an affair, a woman may not dismiss the possibility that her husband is having one. For example,

> I: Does your husband have any relationships besides you?
> P: You cannot know men, because where they go we don't go with them.
> I: But do you think he is having affairs?
> P: I have never heard anything like that, but again I cannot praise him that he doesn't have girlfriends.

Although this woman has never heard any rumours or seen any behaviour that signals an affair, their commonness and the belief that men are predisposed to them makes women constantly aware of the possibility. Therefore, this woman would not dismiss the possibility that her husband is having an affair.

Women describe the multiple impacts of their husband's affairs on their lives, families and marriages. One of the major problems is that husbands often provide financial support to the other women:[14] "When the husband has a girlfriend, he supports her so much and gives no support at all to his own house and wife." This also impacts the children: "When a man is having an affair outside marriage, he doesn't leave food at home. The children and the wife suffer." Women also talk of the dangers of men's affairs for their own health and the well-being of the family: "If they have other relationships, the end result is contracting STIs for the wife." The tactics that women use to address men's affairs and protect themselves from HIV are discussed next.

Women's actions against their husbands' multiple partnerships, including second wives, are limited by the acceptance of this behaviour within women's networks, including elders and marriage advocates. The majority of women in my study who were presently, or had been, in polygamous unions[15] describe entering such unions because their husbands had decided to marry their girlfriends.

I: Your first husband, did he have another wife?
P: At first, it was me alone and he later married another wife.
I: How did you feel about that when he took another wife?

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[14] The extramarital affairs of women are also discussed by women in my study and seen by them to be common. While women in my study do not discuss having affairs, it is likely that some of them did. They talk, however, about women being driven to outside relationships in order to provide for themselves and their children when their husbands give money to their girlfriends. However, other research finds that women also seek affairs for consumer and luxury items, such as lotion, and for sexual satisfaction or revenge (Watkins 2004:686). Indeed, many women in my study did mention these reasons for affairs, and especially non-necessity items.

[15] In Malawi, 16 percent of women are in polygamous marriages (NSO and ORC Macro 2005:94). In my study, many of the women in polygamous unions became co-wives by accident. For example, one woman describes marrying a man whom she thought had divorced his wife. However, a few months into the marriage and after she was already pregnant, the first wife returned from her village asking the husband if they could continue the marriage. The second wife then became a co-wife, had on-going disputes with the first wife and the husband, and was trying to negotiate her own divorce.

> P: I did feel bad, my heart pained. When he took a second wife, I didn't want to stay with him. But, after the elders spoke to me, saying that is how men behave, I changed and accepted.

Facing such cultural acceptance, many women acquiesce to their husbands' marrying a second wife. Another woman tells how her husband decided to get married a second time because she failed to produce a child.

> I: What was the impact of the miscarriages and stillborn baby on your marriage?
>
> P: My husband started blaming me for the deaths of the children, saying he can't just be wasting his energy for nothing. He married a second wife, but unfortunately during delivery the second wife had a stillborn. So I asked him who has a problem, because he left me for a second wife accusing me of having a problem. So he said maybe we women were not moving well [i.e. having affairs]. The second wife fell pregnant again and miscarried, and that's the time I had my son. That was in 1998. So he left the second wife and came back to me.
>
> I: How did you feel when he said he was going to take a second wife?
>
> P: I gave him a go-ahead since he is a man…I told him to go ahead as long as he made sure he cared for me. I never bothered him…I packed my things and went back to the village. So, while there, it's when my family told me to go back…I refused, saying he will end up killing me, because I am innocent but he goes out to other women. After we resolved the issue in the village, I think he has changed because, even if he goes to the field for three months, he still comes back to check on us. So, since that time, he has changed.

One of the issues that emerges from this woman's story is the vulnerability of women unable to bear children. Throughout sub-Saharan Africa, women's social status depends on their ability to produce children (Gupta 2000:19; MacDonald 1996; Mill and Anarfi 2002). Moreover, and in relation to HIV, when having children is a goal of marriage, advocating condom use will fail.

Gender-Based Violence

Gender-based violence is a major determinant of women's risk of HIV infection in sub-Saharan Africa. It includes physical, sexual, psychological, and economic abuse and has evolved in part from the subordinate position of women in society (Heise et al. 1999:1). The growing literature on violence against women in Africa examines how it increases women's risk for HIV (Gupta 2000; Maman et al. 2000a; Moss 2002; van der Straten et al. 1998; Wojicicki 2002; Wood et al. 1998). Maman et al. (2000b:461) outline three ways that it does so: (1) through forced or coerced sexual intercourse, (2) by limiting women's ability to negotiate safe sex; and (3) through the association between childhood sexual abuse and high sexual risk-taking in adulthood. Researchers thus recognize violence against women as both a major public health concern and a human rights issue. Researchers have also examined the way in which HIV-prevention campaigns that do not take into account violence against women fail to achieve their goal, because women victims of violence may not be able to negotiate partner reduction or condom use (Maman et al. 2000b:461).

The women in my study describe gender-based violence in their marriages, including physical, sexual, and emotional abuse. Several women report severe physical violence, including threats to the lives of both them and their children. As one woman describes it,

> Yes, indeed, men beat up their wives saying the woman is talkative. But this is not the exact problem. It is because they have found girlfriends who they feel are more beautiful than their wives. So, whenever they come home, they just start beating up

> their wives. And people get surprised saying, "Did you quarrel"?
> No, I am also surprised.

Women feel vulnerable to violence when they try to address their husbands' extramarital affairs or discuss household finances.

> This problem is common here in Malawi, because most people are jobless. And when you try to reason with the husband about lack of clothes or other things, he ends up beating you because he thinks you are troubling them. That, indeed, is common here in Malawi. The person I got married to is from my home area. I stayed with him for one year, but I ran away from him because he used to beat me a lot.

The woman quoted above describes having two miscarriages induced by her husband's violence and running away to save her third pregnancy. Like affairs, women find men's violence unacceptable: "Mostly men who behave in that manner lack some love." Another woman says, "Most men who behave like that were just born cruel. They take you as their slave, forgetting that they married you as a wife. This is lack of love." They explain violence as resulting from the power difference between men and women: "It happens because it is taken that women are powerless against men." Indeed, women often do feel powerless against domestic violence: "In Malawi men beat up their wives. They were just born cruel. We don't feel good when such things happen, but what can we do?" As is discussed below, women do manage to leave abusive husbands, and many describe being supported by their families in these decisions.

WOMEN'S AGENCY AND THEIR STRATEGIES AGAINST AND WITHIN STRUCTURES

As the preceding discussion illustrates, many social, economic, and gender factors limit women's life possibilities and create vulnerability to HIV.

Proponents of the structural violence perspective, however, in addressing and contextualizing the burdens of women's lives often represent women as wholly powerless. They fail to account for women's agency, even when it occurs within the structural constraints of their lives (Schoepf 1998:99-100). Butt (2002) criticizes medical anthropology activists for presenting truncated accounts of individual lives – "the suffering stranger" – to promote theoretical arguments for structural violence. Within such accounts, Butt argues, anthropologists create typologies – "the hungry" or "the poor" – while neglecting the rich personal and cultural contexts of these individuals' lives. Anthropologists thus perpetuate the construction of "third world people," particularly "third world women." Such representations homogenize people. As Mohanty (1991:56) argues, they produce the image of an "average third world woman" who "leads an essentially truncated life based on her feminine gender (read: ignorant, poor, uneducated, tradition-bound, domestic, family-oriented, victimized etc.)." On the other hand, the strength of the structural violence perspective is in how it attends to the ways in which the world system and local gender, social, and economic factors create individual suffering and risk of HIV infection. Unfortunately, it often also portrays these factors as limiting *any* individual agency.

The life stories told by women in my study, however, illuminate a diversity of experience that does not cohere neatly to presumed intractability of structures. For example, women do address negative life situations. They do not accept men's power absolutely. They have clear expectations for their husbands and take action if men do not fulfil their roles or harm them or their children. The women's life stories specifically illuminate how women try to discuss problems with their husbands and work to change their relationships. Failing this, women seek divorce.[16] In many cases, women's efforts are directly related to their perceived vulnerability to HIV. With reference to HIV, researchers may not notice women's preventive actions, because researchers approach prevention from the dominant risk reduction framework. The dominant ABC approach (Abstain, Be faithful, and use Condoms) overshadows other more locally appropriate prevention approaches (Schantz 2005).[17]

In interviews and focus groups in my study, women describe their actions against their husband's extra-marital affairs. Moreover, they see themselves able to exert power. One strategy that women use is discussing problems with the husband and trying to convince him to change his behaviour.

> As for me, I have been married for ten years now but we have been living nicely. Though my husband drinks beer a lot, and sometimes he even comes in the morning [after sleeping out]. But when we sit down to discuss, he accepts that he is wrong and I also forgive him, and things continue moving. So, even now, we live nicely without problems. So the most important thing is patience and talking whenever there is a problem. And, in this way, some men do change their behaviour.

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[16] In rural Malawi, Schantz (2005) and Smith and Watkins (2005) also noted these strategies.

[17] For married women, whose rate of HIV infection is higher than that of unmarried women, abstinence and condom use are inappropriate. Moreover, married women may themselves be faithful but cannot guarantee that their husbands will be (Schantz 2005:480). One woman in my study says that, for married women, the major risk of HIV infection is marriage: "It's [HIV] something which finds you at home. Because, myself, I have never been promiscuous nor gone to bars, but I have just been innocent."

Women draw on men's obligation to their families to support their claims for behaviour change: "We sit them down to tell them that, by doing that [affairs], they will not be able to care for their families. Instead, they will concentrate on girlfriends." To prevent men's misuse of money on girlfriends, the women feel capable of controlling the household money. "We do have the powers, more especially when it comes to money. When your husband is misusing the money, just take the money without telling him. And you can tell him later on with some advice on how he should spend money. So, him being your husband, you must be free to advise him on some things." Women also talk about affairs with husbands to protect themselves against HIV and other STIs.

> I: Have you ever discussed HIV with your husband?
> P: Yes.
> I: What sort of things did you discuss?
> P: Like abstaining from having multiple sexual partners, not being promiscuous, and being faithful to one another.
> I: When did you start discussing HIV with your husband?
> P: I started long time ago, advising him on his movements. Saying he should change, nowadays there is this pandemic. But he wouldn't listen, and sometimes he would end up insulting me. So, maybe because he is a man and he has money, he doesn't want to listen to my advice. But I try to talk to him most times.

While this woman states that her strategy has not succeeded, she evinces women's perception that talking to husbands about the dangers of HIV is an on-going process. Another woman describes feeling that she could not discuss rumours of her husband's affairs with him, because she did not have any proof and they might end up fighting. She chose, instead, to discuss condoms and succeeded. However, using condoms is not common among the married women in my study.

> I: Why did you decide to discuss condoms with your husband at that time?
> P: When I started hearing rumours that he had a girlfriend. That's the reason.
> I: And what did you talk about?
> P: I just told him that, nowadays, there are a lot of diseases. So it's better to use condoms to avoid spreading these diseases.
> I: Did you mean using condoms when sleeping with other women or at home?
> P: I meant with me.
> I: And how did he respond when you said this?
> P: He accepted without problems.

Women even feel that it is their duty to discuss problems with their husbands, not solely to protect their own well-being, but also their husbands'.

> A woman's responsibility to her husband is to protect the husband's life by being jealous for him. You have to tell him that where he is going it's not good. Yes, of course, sometimes he is stubborn but with time he listens, saying that, "If my wife is telling me this, that means she loves me." And same with the woman. The man tells her that, "My wife, I fell in love with you so we could live together for long, but what you are doing will not help you." So, a woman has a responsibility to her husband, and her husband also has a responsibility to his wife. And that responsibility is to protect each other's life.

As discussed above, women believe that men are biologically inclined to take multiple partners. They feel, however, that as wives they must encourage their husbands to be faithful in order to protect themselves and their families. Of course, discussing extramarital affairs with husbands is an imperfect strategy. To a large extent, women's success depends on the temperament of their husbands: "If the man is understanding, you can, you have the power. But there are other men who say they are the heads of the family." However, some women feel that, often, men do not listen, and the end result is fighting.

> It is possible we have no success, because most men don't want to accept or be told something or what to do. For example, my own husband, he was born cruel. There is nothing that I tell him that he will listen to, only when he is the one who has started the story. But, when I tell him that I wanted to talk to you about something, that's when I see him going out. And, when I insist, he just tells you that, "Ee woman, you are used to commanding [literally, you want to take my trousers] but not with me. You took your ex-husband's trousers, but not mine. You are not going to get them." So there is no success. It's difficult.

Women's attempts to discuss problems with their husbands sometimes result in domestic violence: "We cannot allow our husbands to have relationships outside marriage. It's unacceptable. But, when it reaches this point, men become aggressive and they are very angry. So we can't stop them, because they can't listen."

Unsuccessful discussions can lead to women being "sent home" to their home villages or initiating divorce. Divorce is common in Malawi,[18] and there is evidence that the institution of marriage has historically been unstable because of matrilineal kinship patterns dominant in the Central and Southern regions of Malawi (Kaler 2001; Vaughan 1983). Moreover, divorce in Malawi may be initiated equally by men or women. It is justified by women, their families, and marriage advocates, when there is domestic violence or extra-marital affairs.

> I: What was your relationship like with your first husband?
> P: I don't know how to explain this, because he was just born cruel. Because what I saw in him was something like a dictator life. Always imposing things on me or demanding. Once I try to make a point or clarify a thing, he used to beat me up. So it's

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[18] In my sample, 19 women had married for the second time, and four for a third time. Of course, a few women had been widowed, not divorced.

> because of that I ran. Because, as a human being, I had a right to be heard, too.

If husbands and wives fail to reach an acceptable solution, divorce is likely. A woman describes how divorce from her first husband followed repeated attempts to talk to him and returning to her parents' house.

> I: Did your husband have other relationships beside you?
> P: Yes, he had girlfriends outside.
> I: How did that make you feel?
> P: I used to feel bad, and I used to advise him that what he was doing was bad. But he used to refuse, saying, It's not true, I just drink beer. When I insisted that I have heard you have girlfriends, he would chase me away. So I would go to my parent's house, because I was thinking it was not right for him to be sleeping with me and other women, for fear of these sexually transmitted diseases. While at my parent's house, I would hear that my husband has married another wife.
> I: What would happen when he married another wife?
> P: Nothing, I would just stay at my mother's house. But, after, he would come to pick me up to go and stay with him. He would plead for me to go back. The reason why I never bothered to leave his house [permanently] for my parent's house was because I fear these diseases of nowadays.
> I: Did you discuss the diseases with him?
> P: I used to talk to him, saying, 'Why don't you just stick to one woman? Because, if you continue sleeping with me then you sleep with another woman, later that other woman sleeps with another man, then you are being unfair on my part. Because I am just innocent and, in the end, we will all die, leaving our children to suffer.' But his response would just be like, 'That's your own thinking,' and off he would go. I would just say to myself that, 'Why don't I find myself a man who will be faithful to me, other than live with somebody who may end up killing me because of changing women and later leave my children to suffer?' It's better to stay at my mother's house.
> I: So how did it finally end with this husband?
> P: For me to know that the marriage has finally ended was that he had a *chinkhoswe* with another woman.

This exchange shows that, for many women, divorce is less ideal than continuing in the marriage. They must balance the perceived risk of HIV from their husbands with the knowledge that they will most likely remarry. Remarriage, as this woman's story shows, is also risky; moreover, women worry about supporting themselves and their children after divorce.

Divorce can be a successful way to move out of dangerous relationships; however, it is also an imperfect strategy. Moreover, it is not seen as viable for all women. One of the problems that women in Lilongwe face if they want to leave their husbands is that money for transportation to their home villages is unavailable. Women stay in relationships because of other economic reasons as well. One woman, who is unhappy in her relationship, says that, nonetheless, "this marriage is going to continue because of the children. I cannot afford to be getting married everyday, because men are not happy to look after somebody else's children." One of the problems in women's use of divorce as an HIV prevention strategy is that they are likely to remarry because of economic and cultural pressure.

The women in my study had varied success in supporting themselves after they divorced or were widowed. One says, "Even if you are alone, you try to do business and life goes on. There is a saying that God doesn't leave his people."

While this woman is determined to stay on her own,[19] others tried but found it impossible.

> I: How did you feel when your husband died?
>
> P: I felt very bad. I grieved and it affected me a lot, because he left me with a small baby who was just sitting down. You know death is something painful which you cannot easily get used to. Because of that I decided to stay for some time without getting married. So, because of the hardships I was coming across in the village, I decided to remarry so that I can be assisted in caring for the children. So, unfortunately, I got married last year, and just after a month I fell pregnant.
>
> I: If it were not for financial problems, would you have still married?
>
> P: No, I wouldn't have married. I would have continued with my business and started a much bigger one so that it could help me with some things which I lacked.
>
> I: Why would you have preferred to stay on your own?
>
> P: I would have stayed on my own because of the problems women face in marriages. Like, in my case I am married, fine, but I have found myself in this situation [HIV positive]. So, maybe before I married this man he was promiscuous. Because, after my husband died, I went for a test and I was negative. So you can see, because of such things, one can decide to stay on her own as long as she has the resources.

To a large extent, women's capacity to survive alone depends on support from parents or other family members: "When my first marriage ended, I went home to stay with my grandparents because I thought it's not good to rush into another marriage. Because women just sit at home innocently, but it's men who bring in diseases. So it's last year I decided to remarry." Women describe surviving alone through piecework and small business.

> I: How were you managing after you divorced?

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[19] As I will discuss in Chapter Eight, this woman's determination to stay on her own relates to her HIV status and her desire not to be reinfected or to weaken her immune system through pregnancy.

> P: After my first husband left me, I was just doing business, selling cassava.
> I: Did you feel you were able to support yourself and children?
> P: Yes. And also my parents live near, so they were able to assist me, too.

Assistance from parents or other relatives, however, is no guarantee that women will be able to stay on their own. Even women who live with their parents may need additional support, when their parents are also poor: "I was staying with my parents and doing some piecework in people's fields. Still, I was suffering a lot and sometimes would sleep without eating." Moreover, women describe business income as erratic. While it may be a good business at one point, it can easily turn bad.

Women who cannot sustain themselves after marriage often remarry quickly, in order to stabilize.

> I: How was your life after your marriage ended?
> P: I just decided to find another man.
> I: Was that immediately after your marriage ended?
> P: It took a bit of some time, but, again, what forced me to get married quickly was that we didn't have a permanent place to stay. We were just begging for accommodation. So I just thought of remarrying, so that the problem can be lessened. So that's why I decided to get married to my current husband.
> I: So, you're saying that because of economics you needed to have another husband?
> P: Yes, I felt that way because that time I had just lost my child and was not strong. And, also, I lacked a lot of things. That's why I just decided to find myself another man to help me with some problems I was facing.
> I: Why did you marry this man particularly?
> P: I didn't consider those things to say whether he was good or bad, but I just wanted to because of the problems and the way we were staying.

The necessity, often urgency, of women's decisions to remarry often leads them into relationships that are no better than the ones they left. One woman describes her lack of success in protecting herself through divorce:

> As for me, I tried on my part, because I divorced the man who used to marry yearly. But unfortunately, I landed in the worst, because the present husband marries also and has many relationships. So, the reason for leaving the first husband was trying to protect myself from being infected with the virus. But, alas, I landed in the real AIDS.

This woman is confident that it was, in fact, her second husband who infected her with HIV, relaying that her first husband is healthy.

Women also discuss the cultural expectation that women marry, as well as marriage being a source of respect.

> I: Why did you remarry?
> P: People who are not married are not respected. That is why I just decided to marry him.
> I: Why do you think people who are not married are not respected?
> P: When these married men don't sleep in the house, their wives just suspect that they have slept in the house of the person who is not married.

Unmarried women are also the target of rumours and gossip.

> P: It's good to get married, because if you over stay without getting married, people stop giving you respect. And I used to hear rumours saying that I will snatch people's husbands. But my life, I have no interest in other people's men, and I have always been hardworking in my fields. I was saying, why are they jealousy of me? Why don't they mind their business?
> I: Why do you think it's good to get married for the sake of respect?
> P: Respect is needed for any human being because, even if you stay for quite a long time on your own, the moment you get married people start respecting you.

For women, cultural pressure to marry equals poverty in leading them to remarry.

> I: If it weren't for poverty, would you have still married your second husband?
> P: Yes, I would have still married. Because we still need a man in our lives for a lot of things.
> I: What are those things?
> P: There are a lot of things which force women to get married. One, to have sex and, when you are not married, people accuse you of sleeping with their husbands.

As seen above, women are the ones who pressure each other to marry and remarry. Therefore, in examining their HIV-risk factors, the role of women as cultural-norm enforcers, through gossip and rumours must be addressed. Women in my study relate how, on many occasions, their efforts to gain economic independence through small business or wish to stay unmarried (which unfortunately ultimately failed) were challenged not by men, but by women. They do, however, try to protect themselves from HIV and the strategies they use should be recognized and fostered in prevention programs at the same time as larger socio-economic structures are broken down.

In the next chapter, I focus on women's HIV diagnosis within the PMTCT program. In this chapter I laid an important foundation. As I will demonstrate, the same factors that hinder women protecting themselves from HIV infection hinder their attempts to maintain their health and seek care for HIV.

CHAPTER FIVE – BECOMING A PERSON LIVNG WITH HIV

INTRODUCTION

In this chapter, I discuss the way in which pregnant women, in routine antenatal care, in the normal course of their everyday lives, receive an HIV diagnosis within a PMTCT program. While not all of the women in my study learned of their HIV diagnosis this way, it was the avenue of diagnosis for most. I link the diagnosis of HIV in pregnancy, and thus the creation of HIV-positive pregnant women, to a discourse on the communicated benefits of HIV testing.

The high rates of HIV infection among women in Africa and the significant risk of vertical transmission, make pregnant women a suitable target for HIV prevention programs.[20] The advent of prophylactic antiretroviral therapy to reduce vertical transmission, as well as the increasing availability of both prophylactic and therapeutic ART in Africa, has led to a discourse about the benefits of HIV testing. This discourse involves not only the individual benefits, but broader public health and health systems benefits. These benefits, however, hinge on concerted efforts to create them and are not guaranteed. Nonetheless, they contributed to the expansion of testing and are also used to promote it.

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[20] A great deal of the literature on HIV and pregnancy focuses on women's decisions to terminate their pregnancies or not, and the influence of health care providers and other interests on these decisions (Amaro 1993; Arras 1990; Bedimo et al. 1998; Jemmott and Miller 1996; Kline et al. 1995; Levine 1990; Pivnick et al. 1991; Squire 1993; Van Hollen 2007). I do not discuss that topic here, because it never emerged in my interviews or discussions, for two possible reasons. First, abortion is illegal in Malawi. Second, although traditional and medical abortions do occur, women are usually diagnosed with HIV late in their pregnancies, and the health care staff emphasize the greater probability of giving birth to HIV negative babies.

Within this policy context, pregnant women are increasingly, and routinely, offered HIV tests. Moreover, because of communicated benefits, pregnant women accept HIV testing, even though they are not guaranteed treatment. PMTCT program staff see women accepting HIV tests and prophylactic treatment as doing so on behalf of their children. I find, however, that pregnant women are instead motivated by the other promoted benefits of HIV testing, risk evaluations, and pre-existing desires for testing. Preventing HIV in their children becomes a concern after a positive test result, when their own HIV status becomes relevant to their child's health.

The promoted benefits of HIV testing both encourage it and facilitate coping after diagnosis. They ease women's transition to their new HIV identity. Although distraught about their test results, women still find comfort in the possibility of positive living. Even though comforted by these messages, they are equally concerned about their capacity to achieve the benefits of HIV testing.

VERTICAL TRANSMISSION OF HIV AND THE PMTCT PROGRAM

Globally, vertical transmission of HIV is the most common cause of HIV infection in children under 15 (UNICEF 2006b). While UNICEF uses the term "parent-to-child transmission" to remove blame from mothers and recognize that it occurs within the context of reproductive relationships, "mother-to-child transmission" (MTCT) is the more common term. PMTCT programs also exemplify the fragmentation of health services over holistic or comprehensive approaches. Women often get care only on behalf of their children (Denenberg 1997:329).

> The view of women as vessels and vectors of transmission fits well into a historical context where women have been identified through their reproductive function. We see this in public health and in medicine, where women's health is almost exclusively seen as "maternal and child health"; that is, those aspects of health related to reproduction, childbearing and childrearing. In fact, "maternal and child health" often refers exclusively to maternal behaviour that may adversely affect neonatal growth, infant development or child health, rather than to the mother's (woman's) health. (Amaro 1993:21)

Where PMTCT programs are available in the developing world, women themselves are diagnosed with HIV, making these tests unlike other antenatal screening (Sherr 1993:52). However, they are offered treatment within PMTCT programs only to reduce vertical transmission, not for their own infection.

Without any intervention, there is a 35 percent probability that a pregnant woman will transmit HIV to her child.[21] Of infections, 15-20 percent occur during pregnancy, 50 percent during labour and delivery, and 33 percent through breastfeeding (UNICEF 2006b).

Programs to prevent vertical transmission of HIV were first available in Malawi in 2001. By the time of my research, they were available at 36 sites in 21 of 27 districts. They are all operated by what the Malawian government calls

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[21] Risk of vertical HIV transmission reported in scientific studies varies considerably. WHO (2006) reports a 25 to 50 percent rate, UNICEF (2006b) a 35 percent rate, and UNAIDS (2006) a 30 to 45 percent rate. The reported range of risk of transmission of HIV through breast milk is particularly wide due to a number of factors: whether breastfeeding is exclusive or mixed, maternal viral load, maternal CD4 count, co-infection with malaria, vitamin A deficiency, duration of breastfeeding, presence of infant oral thrush, and breast problems (mastitis, fissures, abscesses, etc.).

"NGO partners," three quarters of the sites by UNICEF. Throughout my research, I repeatedly heard that the government has been slow to expand PMTCT programs, concentrating rather on their priorities: voluntary counselling and testing, and antiretroviral therapy. Despite this, the government has a clear target, in line with international policy, of reducing vertical transmission by 50 percent by 2010:

> The overall goal of the program is to improve the health status of all women of child bearing age and children in the country and to contribute to the fulfillment of the UN General Assembly Special Session (UNGASS) Declaration on HIV/AIDS (June 2001) and the Abuja Declaration (December 2000) of reducing the incidence of HIV in infants by 20 percent in the short term (by 2005) and by 50 percent in the long term (by 2010), through accelerated expansion of services to reduce mother-to-child transmission of HIV. (Ministry of Health 2004a:7)

In addition to a clear policy, the government also has funding to expand PMTCT programs through a Global Fund to Fight AIDS, Tuberculosis and Malaria grant.

At the Area 25 Health Centre, as well as at three other government antenatal care sites within Lilongwe, the PMTCT program is delivered by Lilongwe HIV Program staff within their larger biomedical research program. The PMTCT program is funded through an international paediatric AIDS foundation, which supports such programs in a number of countries. While the Lilongwe PMTCT program is delivered strictly as a service, it is seen as providing a pool of HIV-positive pregnant women who can be recruited into other biomedical research programs. Women participating in the PMTCT program often refer to it as a study, because such studies are ubiquitous in Lilongwe.

PMTCT interventions in Lilongwe resemble those in other resource-poor settings: HIV education for all pregnant women, HIV counselling for pregnant women and testing,[22] a single dose of the antiretroviral drug nevirapine to each HIV-positive woman and the baby, and infant-feeding counselling. Program staff also treat of minor illnesses and refer women to tertiary medical facilities, either the central hospital or to Lighthouse, the main HIV treatment facility in Lilongwe. Women can also attend a support group once they have given birth. The program cares for women diagnosed with HIV and their infants until the infants are 18 months of age, when women are discharged.

In the West, with more expensive and complex HIV treatments, the rate of vertical transmission of HIV is now less than two percent (WHO 2004). In the developing world, PMTCT program standards differ. While this is often attributed to feasibility and affordability, questioning macro-political and economic commitment to offer the most effective interventions in all settings would be more appropriate. In the absence of such commitment, the antiretroviral drug most often used in resource-poor settings, including the PMTCT program in Lilongwe, is nevirapine. When Guay et al. reported, in 1999, that nevirapine was effective and safe as a short-course antiretroviral it was seen as a breakthrough in affordable and safe PMTCT treatment for pregnant women. Guay st al.'s (1999) study showed that a single dose of nevirapine given to a mother in labour to reduce

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[22] During the course of my research, the PMTCT program switched from an opt-in to an opt-out system of HIV testing.

maternal viral load and a single dose to the child within 72 hours of birth could cut the risk of transmission of HIV in labour and delivery by half.

In addition to nevirapine, women in the Lilongwe PMTCT program receive infant-feeding advice to reduce post-partum HIV infection. The WHO/UNICEF/UNAIDS policy guidelines on infant feeding and HIV state, "When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-positive mothers is recommended; otherwise, exclusive breastfeeding is recommended during the first months of life" (UNICEF 2006c). The majority of women attending the PMTCT program do not meet the conditions for replacement feeding in that replacement feeding is neither an acceptable, feasible, affordable, sustainable nor safe alternative to breastfeeding. Therefore, the program staff advocate exclusive breastfeeding for six months and rapid weaning. The guideline derives from a South African study that found that mixed feeding increases HIV transmission (Coutsoudis et al. 1999).[23]

The Area 25 PMTCT program is delivered as a vertical program and is separately staffed and geographically distinct from government health services within the health centre. Nurses refer women to the PMTCT program at their first antenatal health visit. After the initial visit at the PMTCT program, all HIV-positive and HIV-negative women receive their antenatal health services from the

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[23] Mixed feeding, where breast milk is combined with other foods, has been shown to be riskier than exclusive breastfeeding. Researchers hypothesize that infants given food have less healthy gut linings and thus the HIV virus is more easily transmitted through breast milk.

government health system. HIV-positive women, however, must return to the PMTCT program at various stages for additional services. As one public health researcher at an NGO told me, this is indicative of Malawi's HIV programs, "This is an old epidemic, and we're only seeing a better response now. However, one problem is that HIV is fragmented into PMTCT, TB, home-based care, etc. These are vertical programs which are not talking to each other. There is no holistic response." Poor integration between health services erects barriers for women; they get lost in the gaps between various services. However, although PMTCT program staff have pressured the government to expand PMTCT programs and to take over their delivery of the PMTCT program, the government argues that infrastructure and human-capacity limitations prevent them from adding new maternal and child health components.

THE DISCURSIVE SHIFT OF HIV TESTING: FROM RISK TO BENEFIT

Increased availability of HIV interventions in resource-poor settings, including counselling and testing, antiretroviral therapy, and PMTCT programs, has resulted in a discursive shift in international and local public health policy on HIV testing from the risks of testing to benefits. While HIV interventions are far from universally accessible in Africa, their availability, and the perceived public-health advantages of testing, have led to promotion and encouragement of HIV testing for individual benefit. More broadly, testing is seen as beneficial to the health systems.

From the first recognition that HIV is responsible for AIDS, public health policies around HIV have been characterised by "HIV/AIDS exceptionalism" (Bayer 1991; DeCock and Johnson 1998; DeCock et al. 2002; Flowers and Church 2002). This exceptionalism derives from the socially constructed meanings given to both people living with AIDS and the epidemic, what Treichler (1988) calls "an epidemic of signification." People with HIV were concerned that normal infection-control procedures could infringe on their human rights and civil liberties (DeCock and Johnson 1998; Epstein 1995). With HIV/AIDS exceptionalism, public health officials apply different standards for testing, surveillance, and contact investigation than would be normal for other infectious agents (DeCock et al. 2002).[24] Currently, however, there seems to be a shift away from this exceptionalism, particularly with HIV testing in the developing world. Testing is now seen more as a benefit than a danger, and international agencies and local governments in the developing world are promoting testing outside the traditional parameters of voluntary counselling and testing.

The increasing availability of HIV interventions in the developing world has led to this policy shift to health-care-provider initiated testing. Concomitantly, in order to reach HIV treatment targets, such as WHO's "3 by 5 initiative,"[25] increased uptake of HIV testing is required (Kippax 2006; Rennie and Behets 2006). Therefore, WHO considers HIV counselling and testing a fundamental

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[24] For example, HIV testing has commonly been voluntary, and the names of those infected have not been registered (Bayer 1991).

[25] WHO sought to increase the number of people on ART to 3 million by 2005.

component of its Initiative, and of enabling access to available services. "Testing and counselling services must become commonplace in settings where those most likely to benefit from knowledge of their HIV status can be reached, such as services for tuberculosis, sexually transmitted infections and acute medical care as well as antenatal care services" (WHO 2005). The *UNAIDS/WHO Policy Statement on HIV Testing* (2004) stresses the importance of diagnostic and routine testing. This involves routinely offering HIV tests in such contexts as sexually transmitted infection clinics, and antenatal care services where PMTCT services are available, and in health care settings in high-prevalence communities where ART is available (UNAIDS/WHO 2004). In all cases, the policy states, HIV testing must be confidential, accompanied by counselling, informed, and voluntary.

Increased availability of HIV interventions has led not only to encouraging more comprehensive testing services, but also produced a discourse on the benefits of HIV testing, as clearly described to me by the head of UNAIDS in Malawi:

> Because there was no antiretroviral treatment at that time and the cost was prohibitive, most people found that they couldn't answer the question, Even if I get tested, then what? The other dimension is people associate testing with risks: risks of stigmatization, risks of losing your job, and the discomfort of knowing that you have this life-threatening disease. So, I think at that time it was seen that the risks of knowing your status outweighed your personal benefit. I think the international community, plus NGOs, human rights organizations, everybody really, by necessity played up the risks associated with knowing. But those same organizations, the same entities that participated in doing that, now realize that times have changed. HIV testing now becomes gateway to benefits. You

> know, even in a poor country like Malawi, you can be treated. So, I think the international community is now making the transition from HIV testing as risk to HIV testing as a gateway to benefits.

International public health policy makers conceptualize the benefits of HIV testing as two-levelled. Individual's knowledge of their HIV status is seen to reduce the spread of the virus, engage people in positive health choices, and facilitate health seeking behaviours, including accessing antiretroviral therapy. At a broader level, the increased visibility of HIV, and particularly healthy people living with HIV, breaks the silence and stigma of HIV, engenders prevention, and recasts HIV as a "normal" disease. Some of the these benefits are articulated in the book *Voluntary Counselling and Testing: Site Counsellors' Handbook for Malawi* (see Figures 5.1 and 5.2). As shown in the next section, such benefits are also communicated by health educators at local HIV testing sites, and form a compelling message for women contemplating HIV testing.

Benefits of VCT

VCT is an essential component of a comprehensive HIV/AIDS program. VCT is also a link to care and support services. VCT is also a cost-effective prevention intervention and has the potential to benefit individuals, families and communities.

Benefits of VCT to the individual

The benefits of VCT to the individual include:

- Helps people who test negative to protect him/herself from HIV
- Helps people who test positive to protect others and to live positively
- It links the individual to medical care and support services including antiretroviral drugs (ARVs)

Benefits of VCT to the couple and family

The benefits of VCT to the couple and family include:

- Supports safer relationships and enhances faithfulness
- Encourages family planning and PMTCT
- Allows the couple/family to plan for the future

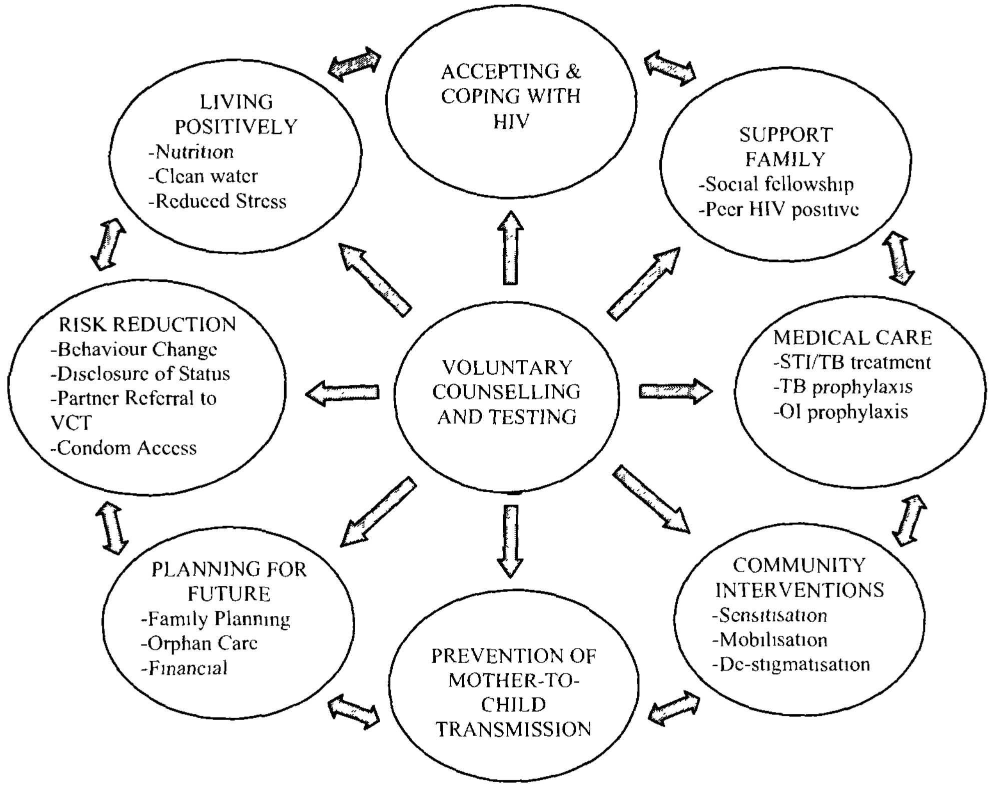
Benefits of VCT to the community

The benefits of VCT to the community include:

- Generates optimism as the majority will test HIV negative
- Influences community norms (testing, risk reduction, discussion of status, condom use)
- Reduces stigma and normalizes HIV in the community
- Serves as a catalyst for the development of care and support services
- Reduces transmission and changes the tide of the epidemic

(Ministry of Health 2004b:69)

Figure 5.1–The Benefits of VCT Testing



(Ministry of Health 2004b:70)

Figure 5.2–VCT as the Entry Point into Prevention and Care Services

Beyond direct benefits of HIV prevention and care, policy makers think of HIV interventions, particularly PMTCT services as a way to strengthen entire health systems.

> Cost effective interventions exist and can be tailored to specific local situations to prevent mother-to-child transmission of HIV and to reduce the mortality rates of children under five. Additionally, strategies and interventions to prevent mother to child transmission of HIV are an important means to strengthen health systems, reduce the impact of AIDS, and mobilise societies to combat HIV/AIDS. (UNICEF 2006a)

Similar to the health systems benefits in the UNICEF statement, Lilongwe HIV Program staff also see its PMTCT program as strengthening the health system, not only by improving it, but by creating "health citizens" who will demand better health services.[26] The director of international programs in the Lilongwe HIV Program told me,

> Well, we think it [PMTCT program] is fitting in, and certainly hope it's fitting in. Because it's improving the quality of care that women get who come to the antenatal clinic. They get what they are supposed to get. We make sure they get everything in the government health rhythm of services and medication. And vaccines, vitamins and whatever they are supposed to get. We hope it's also creating higher expectations from the women. Because you're not on the PMTCT program and you see your friend got her vaccination and you didn't you know. We're hoping that people will speak up. We're hoping it raises the standard of care and the expectation. We're hoping it's making antenatal clinics themselves more efficient generally. We hope that, because we're there and because we're doing things and conducting HIV tests and syphilis tests and other things and diagnosing tuberculosis and referring people, that there's sort of a higher standard of care available in clinics where we operate or where anybody operates PMTCT. That's the theory.

The director believes in a two-way process where health systems are strengthened and patients take on an active, consumer driven approach to health care, in which they demand services that might not yet be available.

The multiple benefits of HIV testing, however, are far from realized in Malawi's health systems. Indeed, Rennie and Behets (2006:52) critique these purported benefits, saying that the question is more how to achieve universal treatment access in ways that are "swift, affordable, feasible, efficient *and* ethically sound in the resource-poor countries most burdened by HIV/AIDS."

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[26] Scholars are increasingly analyzing the way in which citizenship is imposed, contested and sought on the basis of biology, therapy, and pharmaceutical interventions (Ecks 2005; Nguyen 2005; Rose and Novas 2005).

The argument that HIV testing is the "gateway to prevention" rests on a premise that "if you know you are HIV positive then as a responsible rational autonomous agent you will not engage in unsafe sex and if you know you are HIV negative then you will act to remain so" (Kippax 2006:232). However, the claim that HIV counselling and testing leads to behaviour change, and thus prevention, is contentious (Flowers and Church 2002; Kippax 2006; Matovu et al. 2005; Painter 2001). Indeed, it seems that, for counselling and testing to be beneficial, it must address the context of sexual interactions, not simply deliver clients their serostatus. Painter (2001:1398) argues that such interventions can impart HIV-prevention information in a much more focused way than broad-based media campaigns. However, Painter finds that the potential benefits of HIV counselling and testing are limited by both their rapidity in clinical settings and the way in which HIV prevention and care are decontextualized from client's lives. As Painter (2001:1399) says, VCT "discussions are disarticulated from the everyday realities of communicating, much less negotiating, protective actions with their partners who are absent from VCT sessions." Partners do, however, influence the capacity of clients to prevent HIV and seek care.

Beyond this interpersonal negotiation, access to services to prevent or address HIV infection is not guaranteed. The head of UNAIDS in Malawi told me that he sees HIV testing as necessary, but insufficient to achieve the purported benefits:

> Testing is knowledge from which any kind of intelligent control or any kind of behaviour modification would have to be based. If you

> don't know, it's difficult for us to talk about behaviour modification, because it's theoretical. Ignorance of a problem can never be a solution…Now what happens after you've known your status, whether positive or negative? People must bear that in mind…So, I ask my colleagues, can you help people living with HIV/AIDS in Malawi? What program do you have to support them to live positively? And tomorrow you want them to safeguard humanity by not transmitting the virus? What attention are you giving them? What support are you giving them to make sure that they don't transmit?...We know the virus will eventually go from somebody who has it to somebody who doesn't, so it boils down to appropriate interventions. If you're negative, society is to put in place mechanisms to support you adequately. But, if you're positive, society needs to be very clear in the support mechanisms. You must not lack anything you need to live positively.

While this belief is laudable, it is distant from reality in Malawi.

The Malawian Government initiated a national, antiretroviral therapy scale-up plan at the beginning of 2004, which includes free ART in the public sector. Although access has improved, at the time of my research only 6.5 percent of Malawians in need of ART were receiving it (Libamba et al. 2005). HIV support and care was also extremely limited, especially outside major centres.

Policy makers also claim that increased testing and treatment access will reduce stigma and discrimination and recast HIV as a "normal" disease. Kippax's (2006) review of the literature suggests, rather, that stigma and discrimination are still major concerns for people with HIV, particularly women. Indeed, clinics and antenatal services prioritize women in HIV testing (Csete et al. 2004). Nonetheless HIV testing for women may lead to stigma, violence, and abuse (Gielen et al. 2001; Kippax 2006:231; Maman et al. 2000b; Rennie and Behets 2006; Temmerman et al. 1995; van der Straten et al. 1998; Watts and Garcìa-

Moreno 2000). In contrast to this argument, Castro and Farmer (2005:53) criticize the emphasis on stigma in media and public health literature and caution that it is often an excuse to stall HIV interventions. I suggest, rather, that an awareness of stigma should influence the design and delivery of programs and that protective measures for women, currently absent, should be integrated into all testing programs (Csete et al. 2004; Rennie and Behets 2006:55). I discuss the specific challenges that women face in achieving the benefits of the PMTCT program, thus truly living positively, in Chapters Seven and Eight and the impact of stigma in the next chapter.

WHO/UNAIDS policy makers acknowledge these multiple criticisms and the argument that testing benefits are not guaranteed.

> The cornerstone of HIV testing scale-up must include improved protection from stigma and discrimination as well as assured access to integrated prevention, treatment and care services. The conditions under which people undergo HIV testing must be anchored in a human rights approach which protects their human rights and pays due attention to ethical principles.
>
> (UNAIDS/WHO 2004)

UNAIDS/WHO policymakers elaborate that the purpose and benefits of testing must be clear to individuals, that access to treatment and care for those testing positive must be guaranteed, and that health care infrastructure must be adequate to sustain it (UNAIDS/WHO 2004). However, the last requirement is not necessarily developed in tandem with the expansion of HIV testing. McCoy et al. (2005) argue that treatment expansion is occurring without the necessary health systems strengthening in sub-Saharan Africa (SSA), and that additional HIV funding cannot cover the increased burdens of HIV and ART on the health systems.

> The additional funding to combat HIV/AIDS and increase access to ART will not change the fact that most SSA health systems have inadequate resources. In Malawi, for example, the projected addition of $40 million per annum from Global Fund grants would increase total per capita health care expenditures about $10 short of the estimated $30 required to provide full coverage for a package of essential health services, excluding ART. (McCoy et al. 2005:18)

The result, McCoy et al. (2005) caution, may be compromised care. They draw particular attention to how donor-delivered, vertical programs (see also Pheiffer 2003) both detract from comprehensive health systems and limit continuity of patient care. Moreover, efforts to strengthen the health systems to address HIV, must address the social, economic, and political determinants of the epidemic in addition to technological solutions.[27]

The drives to expand HIV testing and communicate testing benefits increased the number of people accessing counselling and testing in Malawi each year since 2002. That year, 91,690 people were tested for HIV, 5,059 of them women in PMTCT programs. In 2004, 221,071 people were tested for HIV, 43,345 of them women in PMTCT programs (National AIDS Commission 2005). There was an eight-fold increase in antenatal testing in PMTCT programs. Despite these increases, it is not clear that individuals, society, and the health systems are achieving the claimed benefits of HIV testing. Critiques that benefits

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[27] I deal with the ways in which women negotiate health systems and are served or not more extensively in Chapters Seven and Eight.

are not being achieved have often been interpreted by AIDS activists and others as stalling points to delay universal treatment. That is not my intent here; rather, I draw attention to the reality that benefits are not guaranteed; resources must be in place to provide them. In particular, PMTCT program staff see women as undergoing testing to prevent HIV transmission to their children. While they claim various benefits for mothers themselves, there is no guarantee within vertically delivered PMTCT programs. Moreover, in 2004 in Malawi most women did not even achieve the direct benefit of the PMTCT program, because they did not receive the drugs. Of 6,069 women who tested positive for HIV in Malawian PMTCT programs, only 2,719 received take-home nevirapine (National AIDS Commission 2005). Information was not available on how many women actually took it or how many babies received it. Similarly, at the PMTCT programs in Lilongwe, fewer than half the women who tested positive in 2004 received nevirapine. At Area 25 Health Centre, 470 women tested positive in 2004, 208 received nevirapine, and 164 babies received it.[28] As I stress throughout this thesis, it is largely based on claimed benefits that women undergo HIV testing; however, how well they achieve the benefits and avert the risks depends on their understanding of briefly communicated medical information, and on their economic and social relationships.

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[28] PMTCT program staff do try to follow up with women who miss appointments. However, most do not have addresses, so they are difficult to find. Some women also falsify their directions because they fear that their status will be disclosed. Finally, there are too few community nurses to find all of the people who have missed appointments.

ANTENATAL CARE AND COMMUNICATION OF HEALTH INFORMATION

By 8:00 in the morning, the Area 25 Health Centre is already active. People have begun to arrive for outpatient services, where early arrival sometimes lessens the long wait. Women who have come for antenatal care and family planning gather in the roofed area of the courtyard. They place their bags or health passport books (an individual health record book) in a row to mark their place in line and wait on the concrete benches for the health talk. On busy days, there are over a hundred – more than the benches can accommodate, so they sit on the ground.

Malawi has a high rate of antenatal care attendance. According to the 2004 Malawi Demographic and Health Survey (NSO and ORC Macro 2005:134), 93.1 percent of women in Malawi and 91.7 percent of women in Lilongwe District received antenatal care from a doctor, clinical officer, or nurse-midwife during their last pregnancy. At the Area 25 Health Centre, antenatal care attendance is equally high (Lilongwe District Health Office 2004). One of the government nurses told me that, in addition to providing antenatal care, nurses explain the benefits:

> When the women come, we give them education, many things about their health. Ah, they should know why they come to the antenatal care. What is it for? Why is it important for them to come to the antenatal care? And we teach them about the family planning, why they should come for family planning. And, in the antenatal, we teach them about HIV/AIDS, why it is important for them to get tested. And not HIV/AIDS only, but sexually transmitted diseases. They should know, because part of getting the HIV comes from the sexually transmitted diseases, like syphilis, gonorrhea, and the others. They should know about that.

Figure 5.3-Women Waiting at Under-Five Clinic, Area 25 Health Centre, Lilongwe

Although nurses clearly communicate the benefits of antenatal care, not all women in Lilongwe District receive complete health care due to supply and staff shortages. For example, at Area 25 Health Centre in the 12 months prior to June 2004, 42 percent of women received an adequate tetanus dose, 18 percent adequate iron supplements, and 98 percent malaria prophylaxis (Lilongwe District Health Office 2004).

While antenatal care attendance is high, most women only start in their second trimester. On average, women in my study began when they were five and a half months pregnant. The earliest a woman started was at three months and the latest at eight months. Most women say that this is because they want to make sure that it is a "real pregnancy." Although nurses try to encourage women to start antenatal care earlier, it seems that their message competes with other beliefs. Women believe that they will be sent away if they come to the clinic too early, because it would be difficult for the nurse to feel the pregnancy. Several women fear witchcraft: "Most Malawians, we don't love each other, so I think if somebody could reveal that she's pregnant at one month, that pregnancy could go missing because some evil-thinking people use charms. So that's why people decide to keep it a secret" (see also Chapman 2003). There are also material constraints. One woman reports that she thought that she would have to buy the health passport book so she waited until she had saved enough money. A couple of women who work in factories did not want to be absent from work, either because they would not get paid or feared being fired.

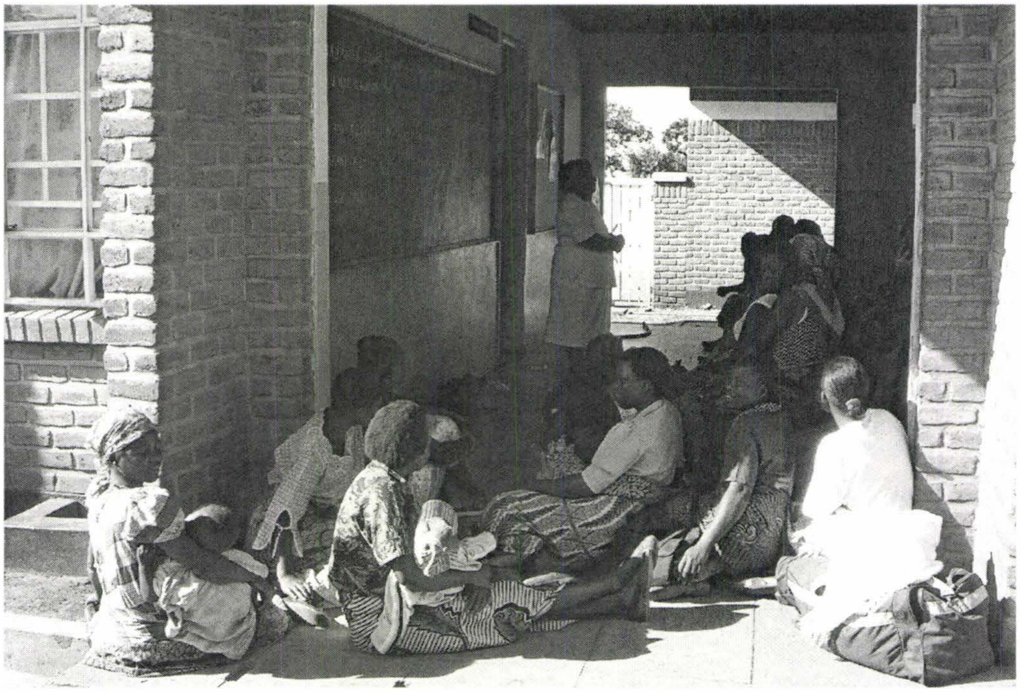

Figure 5.4-Antenatal Health Talk, Area 25 Health Centre, Lilongwe

Women in my study say that they attend antenatal care because they feel that the health centre staff will help if they have a problem during pregnancy or delivery. About half of the women began antenatal care because of illness or discomfort. One woman explains why she first came: "I was having backaches, and I said to myself that, why am I suffering as if there is no hospital?" Women who come to the outpatient department are directed to the antenatal service. As another woman describes, "When I left home, I thought I was just coming to the outpatient department according to how I was feeling in my body – I had body pains and cough. But when I got there, they told me as a pregnant woman I need to go to antenatal care, because that's where I can be assisted accordingly." In these situations, women may not have decided to start antenatal care at that point but end up there.

Despite high rates of antenatal care in Malawi, many women in my study experience or perceive opposition to it either from relatives of friends. For example,

> Friends see you going to the hospital for antenatal. They ask you "Why go to the hospital? We your friends go to TBAs [traditional birth attendants]." So I ask them that, "Can a TBA know that one doesn't have enough blood or tell you if the baby is not lying well in the womb?" They say, "Yes." But, when there's a problem, the TBAs or traditional healers still come to the hospital. So, I follow the advice from the hospital because at the hospital it's where they will help me. But, if something went wrong today, like in labour, my friends won't help me. So it's better to follow advice from the hospital.

Women also confront resistance from relatives, who point out that they managed to have children without antenatal care and vaccines. In response to this, women often explain that the modern health centre will help them. In contrast to these stories, other women often come in groups with their neighbours or fellow villagers: "It's my friends who used to encourage me to start antenatal early because it's my first pregnancy, so that I can learn more on how things work." Likewise, another woman describes being scared to attend antenatal care during her first pregnancy but being encouraged by her friends: "I was scared at first because I was childish. But then I thought, if they are insisting, that means they know what they are talking about. They have gone through this. Let me just go and start."

Women also feel that, if they attend antenatal care, they will get better care at the health centre during a birth crisis than if they did not attend. Women support this feeling with stories of friends who were left to deliver without help or were not attended to in a crisis because they did not have antenatal-care information written in their health book. In contrast to high antenatal care rates, the proportion of deliveries in biomedical health facilities is much lower. In the last five years, 57.1 percent of births in Malawi and 54.9 percent of births in Lilongwe District occurred at biomedical facilities (NSO and ORC Macro 2005:141). This pattern predominates elsewhere in Africa; African women see biomedical care as curative, not for normal birth (Amooti-Kaguna and Nuwaha 2000; Magadi et al. 2000:558).

How Health Information is Communicated

Each day at the Area 25 Health Centre, antenatal care and family planning begin with a health talk delivered by one of the nurses, most often from the PMTCT program. In these talks, nurses communicate a wide range of health information, including disease prevention and hygiene, care of common illnesses such as fever and diarrhea, and child spacing. The content of the health talk changes each day, but delivery, HIV, and the PMTCT program are always covered. For example, women are told that, if this is their first pregnancy, if they are tall or short, very young or over 30, they should deliver at Bottom Hospital (a division of the government-run tertiary-care facility in Lilongwe), where there are more resources to deal with high-risk deliveries than at the Health Centre. Women are also advised on what to bring to delivery: plastic sheets to cover the labour bed, and wool to tie and a razor to cut the umbilical cord. This list is incorporated into the educational message on HIV prevention as infection prevention measures.

Nurses usually discuss the PMTCT program at the end of the talk; the following excerpt represents a typical exchange:

> Nurse: Okay, now let's talk about blood testing. Why do we have our blood tested?
>
> Woman1: To see how we are in the body and also to know our status. After we know our status, if we are found positive we are counselled and we are also given a drug to prevent our baby from being infected with HIV.
>
> N: Thank you very much. This woman has said it all, but is there anyone who wants to add on?
>
> Woman2: Yes, you also check our Hb [haemoglobin] and, if it is low, you give us some drugs to boost up our blood.
>
> N: Thank you very much. That is what we do. We test blood, and in the blood we test to check for syphilis, HIV and Hb. We also treat visible STIs. And we also give a drug called nevirapine to those who are found HIV positive to prevent the baby from being infected. We also offer counselling and we provide fansidar for malaria and iron tablets for blood. So all those who have come for the first time must follow me on the veranda there. And also those who haven't had a test before, you can do that today. Any question?
>
> Women: No.

Through multiple visits, women become versed in the information communicated at the health talk and are able to answer questions posed by the nurses. At the time I was recruiting participants for my study, women heard the educational messages about the PMTCT program three times prior to HIV testing.

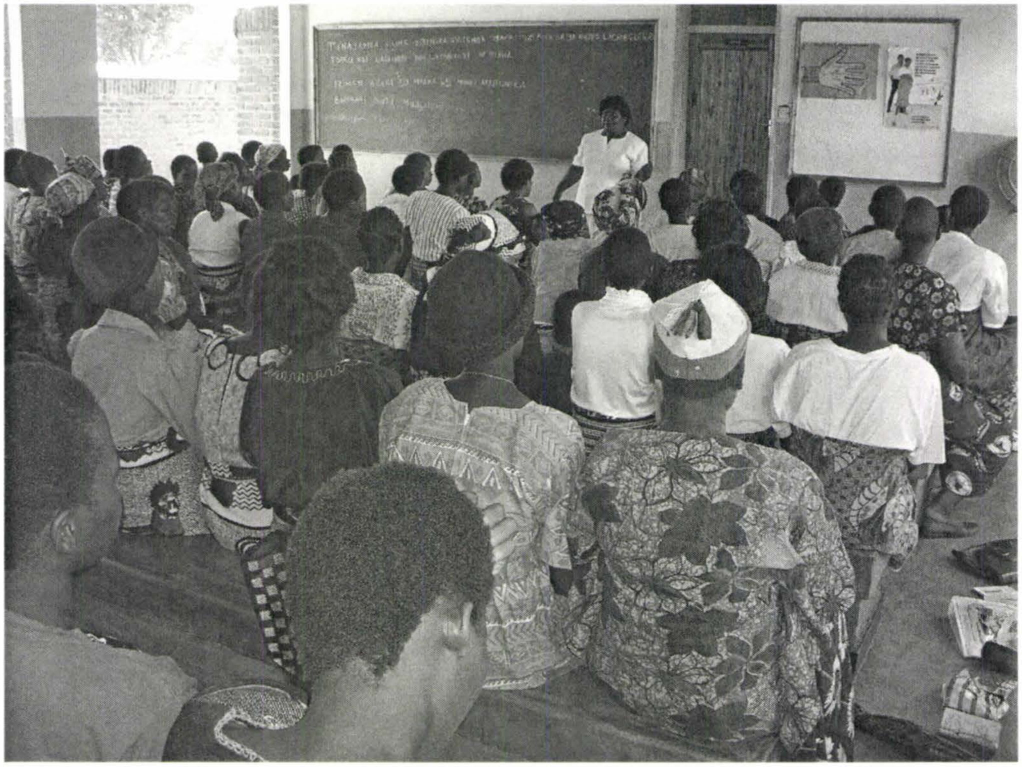

Figure 5.5-Communicating Health Information, Area 25 Health Centre, Lilongwe

In all of the education and counselling sessions, nurses provide not only practical information about HIV, tests, and the PMTCT program, but also the benefits of HIV testing. The following exchange is from a PMTCT health talk:

Nurse:	What is the benefit of having a test?
Woman:	The goodness is you know how you are in your body.
N:	What else?
Women:	[Quiet].

N: The benefit is you know your status and you receive counselling on how to prolong your life: what foods to eat, what to do in order not to increase the virus, how you can protect others and also how you can prevent your unborn baby. Those found negative are also advised on how to live so that they don't catch the virus. So, all those starting will follow me on the veranda there. Today you are going to receive all your antenatal care services there, but the next visits you will do it here. And those found HIV positive, they will be given an appointment for the drug. Any questions?

Antenatal Care Rhythm

At the PMTCT program, women's visits have a set rhythm. Between the medical components, women wait for long periods. They enter the PMTCT program space after the general health talk. First-time attendees and others who want an HIV test rush towards the benches on the PMTCT veranda. Often, there is not enough space for everyone, even though they squeeze in close together. A nurse then delivers an additional group talk on the PMTCT program. Women are then asked if they would like to have an HIV test. Those who do not, rejoin the regular antenatal program. Those who do, stay at the PMTCT program for antenatal care and individual counselling.

The nurses ask each woman's name, age, and area of residence, writing these on a piece of paper. The women line up to be weighed and kick off their shoes before stepping on the scale. They sit down again and the nurse takes their blood pressure. These too are written on the piece of paper. The nurse goes around and transfers the information from the paper to a new health passport book. The women are sent to the examining room.

They cross the courtyard, enter the main building, and crowd the hallway outside the examining room. They enter it two at a time, unwrap their *chitenjis*,[29]and remove their skirts. On the examining table, the nurse listens to foetal heartbeats with a foetal stethoscope and palpates for the size of the uterus and foetal position. She asks the women how many months pregnant they think they are. Normally they are very accurate, but sometimes the nurse corrects them. The women dress and leave and another two women enter. Exams are always extremely fast. The women cross to the other side of the building and line up for their tetanus vaccinations. Then they cross the courtyard back to the PMTCT veranda, where they are given a plastic cup for urine and go behind the Health Centre to the patient toilet block. They return, plastic bottles hidden in the cloth of their skirts and set them down on the floor in the lab.

Women then wait for pre-test counselling to begin. One or two nurses take groups of women back to the examining room to be counselled. They also stay on the benches, to be counselled in the lab or the other consultation room. Women are called in for counselling one at a time, and then called into the lab for HIV testing. In the small lab, all of the tests are laid out and identified with the women's patient numbers. A nurse does three tests for each woman: two HIV rapid tests and one syphilis rapid test. The nurse pricks each woman's index finger with a small lancet and then draws up blood in a pipette. After the woman

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[29] *Chitenjis* are lengths of fabric that women wrap around their waists on top of or in place of a skirt. Pregnant women sometimes wrap the cloth above their breasts to show modesty and conceal their pregnancy. While women say that this is how they are "supposed" to dress when pregnant, it is not popular because it is not comfortable.

leaves the room, the nurse places a drop of her blood on each test strip. After the reagent is added, it takes only a few minutes for the result to be clear. One stripe means negative and two, positive. A dipstick is used to test the urine, and the hemoglobin is checked if there is electricity.

As women wait for counselling and testing, they are given pills to treat malaria and iron supplements. After all women have been tested, program staff give them each a soft drink and a bread roll. The women often complain about the long wait for results, becoming restless. They also chat, nap in the heat, and buy from street vendors seasonal snacks, such as groundnuts or roasted corn. Finally, they are called one at a time to receive their test results. Usually those who are HIV negative are given their results first, then those found positive.

Figure 5.6-Women Waiting for HIV Test Results

TESTING AND INFORMED CONSENT

During the recruitment phase of my research project, counselling and testing was voluntary at the PMTCT program. They were routinely offered to all pregnant women and women had to opt in, (agree to participate), giving their informed consent with either a thumbprint or signature. In early 2005, this system changed from opt in to opt out. Women now have to formally decline if they do not want to be tested. Individual pre-test counselling has been replaced by group pre-test counselling, and written informed consent has been eliminated. The rationale for these changes is to reduce workload and make HIV testing of pregnant women a normal component of antenatal care, thus moving toward the policy goals of expanding HIV testing of pregnant women. Even with these changes, women still seem to have control over the decision of whether or not to be tested for HIV; however, a number of authors question whether this decision is voluntary where the test is routine.

Often, women learn of the PMTCT program for the first time at the Health Centre from the health care providers. In such situations, as Rennie and Behets (2006) describe, health care professionals must objectively communicate the clinical benefits of testing *and* the right of women to refuse. “Trained to promote health, health professionals may (consciously or unconsciously) be tempted to “sell” the clinical and public health benefits of HIV testing while playing down the right to refuse and glossing over the possible negative consequences of receiving a HIV positive test result” (Rennie and Behets 2006:54). With the shift to opt-out testing in the PMTCT program, the nurses did come under pressure from their manager to increase the rate of testing and account for women who refused. The nurses told me about their displeasure, saying that they could not force anyone. Policy makers and funding targets, however, are likely to increase pressure for testing. At sites where HIV test results are not given the same day, the non-voluntariness of testing is thought by some researcher to be evidenced in women's low return rate for their results (Cartoux et al. 1998; Rennie and Behets 2006). In the Lilongwe PMTCT program, where results are given the same day, this effect may have moved on in the process; a high number of women and babies miss their nevirapine doses.

Nurses may not intend to influence women's testing decisions; nevertheless, their medical authority and persuasive message are compelling (de Paoli et al. 2002; Rennie and Behets 2006:54). Karim et al. (1998:640) found in their South African study of informed consent for HIV testing as part of research that, despite assurance that participation is voluntary, 88 percent of women feel compelled to participate. They also found that over a quarter of women feel that refusing will compromise their medical care. Likewise, in another South African study, 45 percent of women believe that those who agree to HIV testing in a PMTCT program receive better care in the general clinic (Etiebet et al. 2004). Indeed, in the Lilongwe PMTCT program, the comprehensive medical care offered there is used explicitly to encourage women to consent to testing.[30] While nurses cite multiple benefits of HIV testing, they do not mention possible costs or consequences. Moreover, within the discourse of testing, HIV testing decisions are confined to the biomedical realm. Fittingly then, Rapp (1999) describes antenatal genetic counsellors as "revealing and creating some meanings, which mask or silence others" (Rapp 1999:62). Similarly, in Malawi, nurses talk about risk factors to explicitly encourage women to evaluate their risk within their lives. One PMTCT program nurse told me,

> You ask about the behaviour of the client – maybe, how many sexual partners have you had? Have you ever used a condom? What is your occupation? Education? Qualification? Things like that. Have you ever suffered a sexually transmitted disease? Have you ever been involved in an accident? Have you ever been transfused [blood transfusion]? That's risk assessment, in order to prepare the client to think of all those things. If they are positive you have already prepared the client. Maybe you could have someone say, "No, I cannot be HIV positive." But, if you do your risk assessment properly, then the client can know, "Maybe I contracted this virus at this stage." That's why we ask the client all this.

Through risk assessment, women, therefore, come to think of their lives as risky, where they might not have before counselling. How and what information nurses present and the context of that delivery, in health centres, limit the capacity of women to make truly voluntary decisions.

However, voluntariness itself may be inadequate. Williams et al. (2002), in researching prenatal genetic counselling, found that non-directive counselling

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[30] In the Lilongwe PMTCT program, refusing testing does limit the care provided, as these women do not receive care from the PMTCT program, which has greater capacity to provide all elements of the antenatal care rhythm than the government.

is neither practical nor ideal. Clients may find the non-directive approach confusing when they are accustomed to more authoritative, directive health care practitioners. They also may find it difficult to make decisions, asking counsellors, "What would you do?" Alternatively, women may believe that prenatal testing is not necessary because, if it were, it would be mandatory (Browner et al. 2003:1938; Williams et al. 2002:392). Finally, the emphasis on choice in prenatal testing masks the decisions that women have to make to be tested or not and what they will do if faced with a positive diagnosis (Rapp 1999:227).

TESTING DECISIONS

In 2004, in the PMTCT program at the Area 25 Health Centre, 82 percent of the 4,517 women who attended antenatal care agreed to be tested for HIV. Of the women in my study, only one communicated a non-decision to be tested. She got tested, because she believed it was part of the antenatal care process: "The doctor just told us to put some urine in the bottles for examination. And, after that, it's when they took us blood from the fingers. So I just said that maybe that's the hospital procedure." The other women gave me reasons for being tested, which I present in this section. While I present discrete categories, most women had multiple reasons for undergoing HIV testing. All but three learned of their HIV status in the PMTCT program. However, a number had previously tested and been found negative. Women's motivations for previous testing included partner's unfaithfulness, to provide a blood transfusion for a child, because of their own illness, and the death of their husband.

Most women in my study decided to be tested, and were tested, at their initial antenatal-care visit. HIV testing, therefore, does not always conclude long deliberation; it often occurs on a whim: "When I was at home I did not know that they do testing here so, when I heard about VCT and the program, I was carried away and I decided to have a test." Another woman, who had previously thought of getting an HIV test but had not made a firm decision prior to her antenatal-care visit says, "When we came yesterday, we were told during the health talk that those who want to have their blood tested can do so. So, I had long wanted to know my status, but then I doubted. Then I made up my mind to be tested." The spontaneity of decisions was sometimes quite obvious. The nurse would ask the women, "Who would like to be tested?" and then hand out a piece of paper to all those who said yes. Women would sometimes waver before taking the paper or ask for it later. The women decided on the spot but might come up with rational explanations while waiting for the test, the test results, or even as they make sense of their HIV diagnosis.

Certainly, for some women, the decision is deliberate. This is most apparent in the stories of women who return for testing at a later time. One, for example, did not stay for a test at her initial antenatal-care visit both, because she did not have adequate time to think and her two small children were fussing. However, at her next antenatal care visit, she was prepared to have the test: "I had prepared food for the kids, because I really wanted to have a test that day such that I wouldn't have minded finishing in the evening." Other women have to reconcile their desire to have the test with the beliefs and expectations of their friends. As women often come to antenatal care together, when one refuses a test, the others might also refuse. Friends also supply contradictory knowledge on HIV testing. One woman explains why she returned for the test another day: "Because people were giving me different information about the test. So I just decided to come on my own without letting them know, so I could see for myself."

In accepting HIV testing, women act against popular beliefs in Malawi. These both discourage HIV testing and provide ready excuses for people who do not test. One of the most common is that a person will not be able to cope with positive diagnosis and will poison themselves: "People don't want to know their status, fearing that, once they know they have the virus, they can take poison." Another is that people will worry, not be able to eat *nsima*, and will therefore grow thin.[31] Related to this is the belief that knowledge of test results, rather than the virus, brings on worry, continuous sickness, and AIDS. These multiple beliefs lead many Malawians to conclude that it is best not to know or to know only after falling sick.

Fear of stigma and discrimination also prevents people from having HIV tests. For example, one woman told me about a conversation that she had with her

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[31] *Nsima* is the staple food in the central and southern Malawi. It is a thick porridge made from corn flour or from cassava flour. In most of northern Malawi, rice is the staple food. It is eaten with "relish," any dish made from vegetables, legumes, eggs, fish, or meat.

neighbour, who was afraid to be tested because she thought that, if she was positive, everyone would know. Her specific concern was about the World Food Program (WFP) food supplement for HIV-positive women. Aware of this fear of stigma, nurses emphasize that HIV test results are confidential. They believe that this promise of confidentiality will encourage people to be tested. However, it does not address the reality that attending the PMTCT program after the first antenatal-care visit and receiving the WFP supplement do identify women as HIV positive. This issue I further address in Chapter Six.

Pre-Existing Desire for HIV Testing

For some women in my study, HIV testing in the PMTCT program fulfills their pre-existing desire for a test. Some women know that the health centre provides HIV testing for pregnant women and intend to have a test. One woman, who had decided to have a test before arriving for antenatal care, explains, "I heard from the women whom I stay with on the same plot. They said that, 'When you are starting antenatal, you are asked to undergo VCT, but it's voluntary.'" Other women describe wanting to have a test and being happy when they find it available at the health centre: "As for me, I was just asking myself that, what should I do to know about my status? Lucky enough, when I came to start antenatal for this baby, they said all beginners should come here. So, after, I went, and I didn't object, because I wanted to know how I was in my body." Another woman explains that she had a test but had never returned for the recommended second one.

> I had long wanted to have a test, because last year I had a test at MACRO [Malawi AIDS Counselling and Resource Organization], and I was found negative. And that test was because of my husband's promiscuity. Because sometimes you don't know that you will fall pregnant. I first of all wanted to know how I am in my body. But now since things have happened [pregnancy], I am not worried.

While this woman received her desired second test in the PMTCT program, she failed to achieve her ultimate goal in HIV testing of changing her future reproductive plans.

HIV testing and life decisions connect to pre-existing desires for testing among other women, especially the young and newly married. Some of these women intended to have an HIV test prior to marriage but did not, due to disputes with their husbands over testing.

> I: Why did you think it was a good idea to go for HIV testing before getting married?
> P: The one I was staying with [brother] is the one who advised me that, saying his [husband's] job is not a good job. I told him [husband] that we should go for a test together, but he refused.

For these women, the PMTCT program enables the test, but neither information on HIV testing nor its purported benefits influenced their decisions to be tested. As one says, "Even if I had not fallen pregnant, I would have still found a chance to go for a test, because I was scared with my first husband's behaviour. He married twice while he was still with me."

Knowing is Better than Not Knowing

Explicit within all women's stories of HIV testing is the belief that it is good to know one's HIV status:

> I wanted to know how I am in my body.[32]
>
> I just wanted to know, so that I could know how to live my day-to-day life.
>
> I just wanted to know how I am, how my body is.
>
> I wanted to know how my blood is.

Moreover, "It's better to know, rather than living in doubt not knowing where you stand. Because it can be possible that you don't have the virus. And, in the process, you can get it. Or, if you have it, it can keep multiplying." Women say that, with knowledge, people can make decisions. "Nowadays, people will just be staying not knowing that there is something in their body – which will make them sick sometime. So I decided to have my blood tested to see what to do later."

Some women who had been worrying or thinking about their HIV status decided to have certainty: "I wanted to know whether I had the virus or not, because I was troubling myself. I suspected that I could have the virus." Moreover, they find not knowing more stressful than knowing: "I just wanted to know one thing: whether I had it or not. Because I kept debating within myself to have a test or not. That is why I just made up my mind to have a test."

Women believe if they know their status, they can act accordingly in the future: "When they announced there that, if people are willing to have a test they should do so, I was very touched. Because in my whole life I had never had a test.

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[32] Throughout this thesis, I use the literal translation from the Chichewa "*Ndimafuna kudziwa zam'mene mtupi mwanga munalili*:" "knowing how I am in my body." This is synonymous with, but much more common than, "knowing my status" or "knowing my HIV status." It is understood that this is what is meant when people talk about knowing how they are in their body. People prefer to speak about difficult or embarrassing subjects, such as sex and HIV, using euphemisms (see also Moto 2004; Whyte 1997:217-218).

So I volunteered to have a test to know my status, so that I can know what to do in the future." Women explain that they thought knowing their HIV status would encourage their husbands to remain faithful: "If you know, you can advise each other in the home on what things to do, other than just staying without knowing." Knowledge of HIV status is also important in women's reproductive decisions: "I just wanted to know my status, because I may have been thinking that I am fine, not knowing that I am infected. And maybe I would have continued bearing children and leave them to suffer in the end." Finally, knowing HIV status is important in illness management:

> I wanted to know, because sometimes nowadays people just suffer from different diseases like malaria, cough, pneumonia, diarrhea – all sorts of diseases. And you will find that you are accusing people of witchcraft, not knowing that you have HIV. That's why I just wanted to know. So every time I fall sick, I will always rush to the hospital to receive treatment.

Simply wanting to know is an important motivator in women's decisions to have HIV tests; however, it overlaps with other motivators discussed below.

Feeling Vulnerable

Many women report feeling vulnerable when they decided to be tested for HIV, because of their awareness or lack of awareness of their husbands' lives outside the home: "I decided to participate in the program, because normally I'm at home and I don't know my husband's movements. That's why I wanted to know my status. And, if I know, I can listen to what the nurses say to me." Living away from their husbands is also seen by women as a risk factor and reason for testing: "Because my husband and I were far apart. He was here, and I was staying in Dedza." As well, women feel vulnerable to HIV if their husbands work away from home: "I used to think that my husband is a businessman. And sometimes he goes away for three days, so I used to think that, does he sleep alone when he is out? That's why I decided to have a test."

Many women, therefore, feel generally vulnerable: "I just wanted to see how I am in my body, because, ever since I got married to my husband, I have been faithful to him. But I feel that sometimes he is not faithful to me." Women may also be unaware of their husbands' sexual history: "My first husband was promiscuous. And this one I have just married, and I don't know about his past life. So that's why I wanted to know my status. My second husband also had a wife before, so I can't know the status of these men." The feeling of being at risk because of their husbands, reflects dominant gender relations and the acceptability of extra-marital sex.

In addition to generally feeling at risk of HIV infection, other women feel that specific conditions or situations make it likely: "Because they say that one can get the virus if they have had STIs. So, because I once had some STI with my first husband, that's why I thought I should have a test. That's what I was thinking of." Women also give deaths within their sexual networks as reasons to have a test: "This year, I learned that one of his [husband's] previous wives had died. And, the way she suffered, she must have died of AIDS. So, from that time, it's when I started thinking that, in that case, we are all infected." Another woman gives a similar situation as her motivation for wanting an HIV test: "Before I had this child here, when I was pregnant, he had two girlfriends who died. One just grew thin, and the other one had tuberculosis. So, because of this, I used to tell him that, see how your girlfriends have died? Let's go for a test. But he used to refuse." These stories may appear to make women passively fearful of HIV risk. However, as I discussed in Chapter Four, women do try to minimize risk; indeed, HIV testing is one such effort. One of the women who knew her HIV status prior to the PMTCT program, says,

> I personally caught him having sex with another women, and this forced me to go for a test at MACRO. I asked him to accompany me for a test. And I also told him that, if he was found positive and me negative, the marriage will end here. But, if both of us are to be found positive, then we shall continue staying together as long as we are faithful to each other. And no one should be found going out and that's how I knew about the virus.

While some women enter the PMTCT program feeling vulnerable, others confront risk within the PMTCT program. As part of the counselling, nurses conduct risk assessments to encourage women to think about HIV risk factors in their lives. Nurses believe that risk assessments help prepare women for possible positive test results. However, risk assessments recreate the dominant discourse of HIV risk, as discussed in the next chapter.

Health Concerns and Health Benefits

Women say that health concerns or benefits motivate them to be tested for HIV. Some feel that there is something wrong with their health or that somehow their bodies have changed: "I just decided to see what is wrong in my body, because it's different now as compared to before." Another woman says,

> Why I decided to have a test was I wanted us to know how we are in our bodies and how we were staying in our family. We were surprised, because we used to fall sick more often from malaria but the children were just fine. So that's why I told myself not to fear to come for a test – whether I was going to be found positive or not.

Other women feel physically different in their current pregnancies than in previous ones: "When I came, and after listening to the advice by the nurse, I said, 'Let me have a test, because this pregnancy is different from the rest. I'm experiencing some back pains and painful legs.'"

Most women talk about a general desire to protect the health of their babies, and some connect this to preventing vertical transmission of HIV. On general health care available in the PMTCT program, one woman says, "I wanted them to check me if I had diseases, like warts or syphilis, because they say the baby comes with stuff in the eyes. So that's why I had a test." Another says,

> I was motivated to have a test because of what the nurse said. She said that it is important for pregnant women to have a test because, once found positive, there is a prevention for the baby and because, at home, we hadn't been discussing HIV. I just thought this is good news. Since I am also pregnant, let me have a test. And, if I have the virus, my baby will be prevented from the virus.

For most women, though, preventing vertical transmission is not the main reason to have an HIV test. It only becomes relevant after one is found positive.

Women also say that they are motivated by the health benefits of knowing their HIV status communicated in the PMTCT program. One woman explains, "I wanted to know if I had the virus, and that, if I have it, I should receive counselling on how I can prolong my life." Another woman describes the availability of antiretroviral therapy as a factor in her decision to have a test: "I went there to have my blood tested, because on the radio they were announcing that there is help to people found with that problem [HIV]. So I wanted to be tested so that, if there was a problem, I should be assisted as others have been assisted." A couple of women report being motivated by nurses' advice that childbearing will weaken the immune system of HIV-positive women. "When I heard that we should have our blood tested, I was very touched, because I thought, if I knew my status, then I was going to change my programs in terms of child bearing. Because I had heard from people that HIV is an enemy of child bearing. So, when you know how you are, you change some of your programs." Implicit in women's decisions to test is a belief that they will benefit from the HIV test, that they will be counselled and receive advice specific to their HIV status, and that they will be able to live positively.

Husbands' Involvement in Decision Making

At the Area 25 Health Centre, nurses would often tell me that women refuse HIV testing because they have to ask their husbands. My research, in contrast, shows that most women do not seek approval from their husbands prior to testing and that many explicitly go against their husbands in order to have an HIV test.[33] Half of the women I interviewed had never discussed HIV testing with their husbands. Nine women had done so at some point prior to testing, and their

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[33] Given this finding, it is possible women use the need to ask their husbands as a culturally compelling excuse to not be tested, a decision they know will not be challenged by the nurses.

husbands had agreed. Seven had discussed HIV testing with their husbands prior to testing and their husbands had refused; however, these women underwent HIV testing anyway.

For women who discussed testing with their husbands, it was most often a general discussion; for example,

> I: Did you discuss it with your husband before being tested?
> P: Yes, we had been discussing that.
> I: What sort of things had you been discussing?
> P: Like when we were listening to the radio and this topic came up, we were saying that we should go and have a test together. Maybe we should go to MACRO.
> I: Did you ask your husband before being tested?
> P: No, because when I left home, I just said I was coming to the hospital. And it was when I was here when they tested my blood.

Moreover, it is clear that for a number of women, general discussions often do not lead to an HIV test, even when both agree. One newly married, 18 year old woman describes her efforts:

> I: Did you discuss HIV testing with your husband before being tested?
> P: We had discussed, and my husband said we would go for a test.
> I: Okay, what sort of things did you discuss?
> P: We were discussing according to how things are nowadays [HIV prevalence]. In fact, I had asked him if we could go for a test before we started having sex. But he used to hesitate, saying we will go, until we failed that time. We kept discussing about HIV, saying it is important to know our status, so that we can know how to take care of ourselves. He just said we will go. So that day I came for antenatal, I found a chance to at least know my status for myself.

Although it is not clear whether general discussions would have led to couples being counselled and tested, these women are bolstered by the discussions in their own acceptance of HIV testing.

With knowledge that the clinic offers HIV testing, other women report a specific plan: "I told him that I want to go for VCT when I start antenatal, and he asked me why. I told him that I just want to know, and he agreed. And, when I returned home after VCT, I told him the results."

Some women purposefully decide not to discuss HIV testing with husbands: "I did not tell him, because I thought he may not have agreed. And maybe he would have stopped me from having a test. That's why I decided to do it on my own." This woman avoided going against her husband by not discussing HIV testing. Other women, however, decide to be tested for HIV against the explicit wishes of their husbands: "When I just got married to him [husband], I used to ask him if we could go for a test. But he used to refuse me. He even warned me not to have a test myself. But then I decided to do it behind his back [at the PMTCT program] and, when I did, I was positive." Another woman describes wanting to be tested specifically because her husband did not want to be.

> I: Did you ask your husband before being tested?
> P: I told him, but he used to refuse.
> I: Why did you decide to be tested after your husband refused?
> P: Maybe he knew why he was refusing things. I don't know.

Overall, women feel that they control decisions about their bodies and knowing their HIV status. They make autonomous decisions with the intention that, in knowing their HIV status, they can act to prolong their lives. Although, I found that women do not seek their husband's approval prior to the HIV test, men's involvement is still important to a successful PMTCT program. When husbands are not involved, women have difficulties achieving various aspects of the program and following the positive living advice.

COMMUNICATING TEST RESULTS AND A SPECIFIC WAY OF LIVING WITH HIV

Women receive their test results from the nurses in individual post-test counselling sessions. In these sessions, nurses first confirm that women are ready to know their results and then explain the results of the blood and urine tests. It is then that healthy pregnant women become women living with HIV. HIV testing during antenatal care brings a disease into view; it becomes knowable. HIV differs from other conditions, as it is not diagnosed when symptoms break out. It, therefore, creates a different type of patient. Since 1984, when the first tests for detecting HIV were developed, healthy people have been aware that they carry the virus. Pierret (2000:1590) compares the situation of healthy individuals living with HIV to that of healthy carriers of testable genetic conditions.

Traditionally, medical anthropologists have distinguished illness from disease (Eisenberg 1977). They have understood "disease" as biological processes that create ill health and delineated ways in which diseases are known and understood by doctors, and defined in medicine and biology. By "illness," on the other hand, medical anthropologists have referred to individual and social experiences of being unwell. First, illness and disease may thus emerge independently. Illness can exist without disease, and disease without illness. Second, illness is presumed to have a constructivist quality not generally extended to disease; individuals may experience and give meaning to illnesses that are not scientifically verifiable. Medical anthropologists, however, have destabilized the latter claim in drawing attention to biomedicine's social production and construction. They see it then not as beyond, but within, culture. Biomedical knowledge is seen now as contingent on the political, economic, cultural, social, and historical processes implicated in its production (Foucault 1994; Martin 1989). HIV science is an excellent example of the social construction of disease (Marshall 2005; Treichler 1999). Although illness and disease are both now seen by medical anthropologists as socially and culturally constructed, the illness-disease dichotomy persists for its ability to explain the experiences of individuals suffering from illness and/or disease vis-à-vis the medical establishment. At the point of HIV diagnosis in the PMTCT program, women are diseased but not yet ill. Their condition has been revealed to them (and to the medical system) by science through HIV testing, rather than through any experience of being unwell or sick.

Labeling the women in my study as "healthy," however, is problematic. Primarily, I use the word to communicate that these women are not diagnosed with HIV during a severe health crisis and do not fit the stereotypical image in the western press of Africans with AIDS. At the time of my study, these women were living with HIV, not dying from AIDS. Health, however, is relative. Although these women do not appear any more or less healthy than any others in antenatal care, they nonetheless have a high disease burden. Malaria, diarrhea, fevers, untreated STIs, and malnutrition are common among poor Malawians. Despite this, they are primarily viewed as healthy by the PMTCT program staff. However, in a Canadian prenatal clinic, these women would surely be considered unhealthy. Moreover, neither I nor the nurses in the PMTCT program knew their actual health status; generally healthy appearance may mask severe problems. For example, one seemingly healthy woman in a focus group said that, the previous year as part of screening for a biomedical study, she was found to have a CD4 count of 154, denoting a severely compromised immune system.

In addition to delivering test results, during counselling nurses give women information on the PMTCT program and living with HIV. The possibility of life for the mother and child is created. Nurses remind women about nevirapine and give them appointments to return to the PMTCT program in their 36th week of pregnancy to receive the drug and to receive counselling on infant feeding. They advise women on how they should live, living positively (see Figure 5.7). Nurses also communicate the importance of following the positive-living advice in preventing vertical transmission, particularly by not increasing viral load. One of the nurses describes the advice she gives in counselling session:

> We tell them that being HIV infected is not that they already have AIDS. So now they are HIV infected. The viruses they have today they should be the same viruses, they shouldn't increase. The virus must not multiply in their body. So we give them the ways they can live so that those HIV infections that they have should be the same. They shouldn't add more, by using condoms or if they can

> live without having sexual intercourse at all, if they want. They should eat a balanced diet, and they should stay happy. They should mix with other people because, when they are lonely, they think a lot. But in a group of friends they have little time to think of their condition.

In counselling, nurses emphasize the importance of using condoms to prevent reinfection, good nutrition, and eating a balanced diet (see Figure 5.8), reducing stress and worry, and the cost of childbearing for the immune system.

Living Positively – from the VCT Site Counsellors Handbook for Malawi

People can live longer more healthily and more happily, if they have a positive attitude towards themselves and the people around them. Living positively involves having a positive outlook in life. It also means living responsibly with HIV. People with HIV infection can prolong their lives by making positive choices to care for their own mental and physical health.

This might include:

1. ***Avoiding re-infection*** – Re-infection can be avoided by either using a condom consistently when having sexual intercourse or abstaining from sexual activities. Using a condom or abstaining will avoid infecting others as well.

2. ***Seeking early medical treatment*** – Keeping healthy involves visiting the nearest health facility as soon as possible symptom occurs. People with HIV can have a health book for continuity of prescriptions. Prescribed dosages should always be completed.

3. ***Practicing good hygiene*** – Good hygiene is a broad term for cleanliness, which includes:

- Taking regular baths, washing hands, shaving, cleaning teeth, wearing clean clothes, etc.
- Using clean utensils for serving food and drinking water.
- Clean living environment (e.g., sweeping inside and outside houses), well ventilated houses, clean beddings and toilets built away from kitchens.

4. ***Avoiding smoking and drinking alcoholic beverages*** – Smoking is hazardous to health. It destroys the lungs and other body organs. Alcohol destroys the liver and weakens the immune system. It also impairs rational judgments. Both smoking and alcohol are expensive habits; the money can better be used for buying bodybuilding, energy giving foods and foods with vitamins.

5. ***Doing regular exercises*** – Walking and jogging are examples of good regular exercises. Some daily chores like housework or fieldwork are also good. However, very strenuous work can put pressure on a weakened immune system.

6. ***Having enough rest and enjoying leisure*** – Enough rest is good for health. Sleeping at least eight hours over night, having relaxing weekends and resting when tired will improve health. Watching TV, soccer, sports, reading papers, journals and novels can be relaxing and enjoyable.

7. ***Avoiding stress and worry*** – Worry can affect health. Stress can even cause weight loss. Being occupied with activities can reduce stress. Sharing concerns with others can also reduce stress.

8. ***Spiritual beliefs*** – can significantly support people in times of difficulty.

9. ***Planning for the future*** – Every individual has responsibilities in life. A person living with HIV can make plans for the future including how children will be cared for, resolving problems and writing a will. (Ministry of Health 2004b:65-66)

Figure 5.7 – Living Positively

Nutrition for a Person Living with HIV/AIDS – from the VCT Site Counsellors Handbook for Malawi

Nutrition is important for people living with HIV/AIDS. Nutrients are the part of food that the body uses to produce energy for growth and movement, to build and repair tissue, and to protect the body from infections. It is usually possible to obtain all the nutrients that the body needs in everyday, inexpensive food. Food is important because it:

> *Enables the immune system to work at its best capacity.*
>
> *Provides the body with all the essential nutrients required for good health.*
>
> *Maintains weight.*
>
> *Improves strength and energy.*
>
> *Helps prevent illness.*
>
> *Can and should be enjoyable.*

A well balanced diet is essential for people living with HIV/AIDS. Meals should ideally contain food from each of the following groups.

Energy-giving foods – These are foods like rice, maize or millet, porridge, bread, cassava, plantain or yam. They should be unprocessed to give the most benefit. These foods provide the main part of the meal and most of the energy.

Animal fats, vegetable oils and nuts are a concentrated form of energy but may make diarrhea worse.

Bodybuilding foods – These include foods like chicken, fish, eggs, dairy produce, beans, lentils, peas or nuts. They contain protein, minerals such as iron, zinc, calcium, and some vitamins. Red meat and pork have the same benefits but are thought to have levels of toxins so take longer to digest.

Vitamin-rich foods – These are foods like vegetables, especially dark green and orange vegetables, and fruits. (Ministry of Health 2004b:66-67)

Figure 5.8-Nutrition for a Person Living with HIV

DISCUSSION

HIV is not simply diagnosed at a clinic; it is created through shifts in international policy, increased funding for HIV interventions, scientific research, and treatment advocacy. One woman's test is part of a decision-making system that not only creates the local possibility of an HIV test but shapes the way that test is understood and the meaning given to an HIV diagnosis. A discourse of optimism about HIV and growing possibility after an HIV test changes the meaning of having an HIV test from risky endeavour to opening possibilities for treatment and care. At the same time, increased opportunities for treatment and care create a need for HIV-positive individuals to know their status.

To a large extent, however, the discourse on benefits of HIV testing has preceded their availability. Women diagnosed with HIV in the PMTCT program can reduce vertical transmission; however, they do not decide to know their HIV status solely for their children. The communicated benefits of HIV testing are largely individualized. Positive living requires women to take control of their future health; however, it does not take into account whether they have resources to live positively: adequate food, health care, and understanding spouses or resources to live independently.

In many ways, the positive-living discourse resembles individualized HIV prevention programs. We, as medical anthropological researchers working from a critical approach, reject this model, which purports that teaching people how HIV is transmitted can prevent transmission (Obbo 1995; Schoepf 1995; 2001; Waterston 1997). We also reject discourses of responsibility and blame that follow from such a model. Researchers who study HIV within a political economy approach contextualize behaviour in relation to social factors such as gender, age, and class. We are aware of inequality built into the system and hegemonic constructions of HIV: “It is not surprising that the disease and those who suffer it are put to good ideological use in obscuring structural inequality” (Waterston 1997:1381-1382). According to positive-living advice, responsibility for healthy living with HIV is on the individual, not on structures that promote or impede such possibility. This I elaborate in the remainder of the thesis.

In Malawi, and elsewhere in Africa, expansion of services to prevent vertical transmission of HIV mean that women are increasingly offered HIV tests. They have various reasons for agreeing; however, all of the women I met see some benefit in knowing their HIV status while they are healthy. While HIV diagnosis may come unexpectedly, insofar as women may not have intended to have a test, they find comfort in the promised benefits of testing and the possibility of living positively. However, greater and more specific efforts must be made to ensure that these promised benefits are achievable.

CHAPTER SIX – IDENTITY MANAGEMENT AND CONCEPTIONS OF SELF

INTRODUCTION

The social sciences literature describes illness, particularly diagnosis with life threatening and chronic illness, as a life-changing occurrence, that turns all assumptions about the way one is in the world on their head (Becker 1997; Frank 1995; Garro 1994; Good 1994; Kleinman 1988). Many researchers, however, even suggest that, with adequate support, individuals find renewed purpose in life after illness diagnosis (Frank 1995; Mattingly 1998; Mattingly 2000). With HIV, diagnosis seems to be an even more severe crisis because of the social meanings of the disease, such as its association with deviance, promiscuity, immorality, and contamination (Clatts and Mutchler 1989; Lawless et al. 1996; Pierret 2000; Sacks 1996; Schiller 1992; Schiller et al. 1994; Treichler 1999). Despite this, authors in the literature on living with HIV, primarily focused on North America and Europe, suggest that individuals do adjust to HIV diagnosis (Davies 1997; Ezzy 2000; Green and Sobo 2000). Indeed, researchers of HIV have even reported personal "growth" among individuals post diagnosis (Crossley 1999b; Dunbar et al. 1998; Gatter 1995; Gielen et al. 2001; Siegel and Schrimshaw 2000). Similarly, researchers of HIV in Africa suggest that individuals do cope with their positive status and move on with their lives, although their capacity to address HIV is related to the health and economic resources available to them (Levy and Storeng 2007; Nguyen 2005; Phaladze et al. 2005; Plattner and Meiring 2006).

Resource availability is important to women's experiences of living with HIV; so, too, are prevailing discourses of HIV. Steeped in meaning, illness and disease are much more than biological processes (Scheper-Hughes and Lock 1987). This is particularly true for HIV. It is with a discussion of the meanings of HIV that I begin this chapter. Women negotiate their HIV identity within the social and cultural context of HIV. This begins after diagnosis, as they seek explanations for their status from their past and their knowledge of risk factors. Risk, however, is perhaps an exemplary element of the non-linear life story. In women's life stories and how they interweave with their HIV status, it becomes clear that women primarily observe risk retrospectively. This is because their positive HIV status elucidates risks in new, personal ways. Women's descriptions of risk parallel theoretical understandings, which illustrate that people do not always distinguish risk in lived time, nor can they always mitigate risk even when they are aware of it.

To live with HIV is about more than attending to the body; it is also about mediating social relationships in light of the social meanings of HIV. Women manage their HIV-positive identity carefully, as they worry about potential stigma from disclosure. In this chapter, I examine stigma around HIV in Malawi and women's experiences of it. While most women have not yet experienced stigma, because their HIV status is masked, it still influences the way in which they live with HIV. They expect stigma, because they witness it in their community and anticipate that they will be targets when they begin to show symptoms. Despite women's determination to reject the stigma, it still causes worry and impedes women from living positively with HIV.

At the end of this chapter, I focus on women's decision making about disclosing their HIV status. Women in my study most often do tell someone; however, they weigh the costs and benefits before telling. Through disclosure, women manage their HIV-positive identity and counter the prevailing discourse on HIV. Particularly, in disclosing to their husbands, they deal with duty, responsibility, and blame. Through careful decision making, most women receive positive reactions. Indeed, disclosure often facilitates emotional comfort and support providing a foundation for women's endeavours to live positively. Women also disclose to engage and educate their friends and family about HIV.

CONSTRUCTIONS OF HIV: DISCOURSES OF RISK AND BLAME

AIDS has been imbued with meaning since its beginning. When, everyone looked for bodily differences to explain why some people got AIDS and not others. That AIDS came to the attention of the West first through the bodies of American gay men led to the attribution of AIDS to differences in bodies or behaviour. After several false starts, AIDS was ascribed to an infectious agent spread sexually. However, that it primarily affected gay men, it was the specific nature of their sexual interactions, anal and promiscuous, in opposition to the presumed norm, vaginal and discriminate, that was imputed with the contagion. The early construction of HIV has a legacy today; it is still associated with difference, promiscuity, and immorality. There is, thus, a discourse on HIV and

AIDS, albeit shifting and locally different, that pervades understandings, thoughts, communications, and actions. In this section, I elaborate on this discourse, which lays an important foundation for the ethnographic discussions below.

The accounts of Malawian women of their HIV experiences are situated within this discourse. However, they also reject it because of its implications for their own experience and behaviour. Thus, a contradiction pervades women's narratives: between their frequent perpetuation of the dominant discourse and their resistance of it.

Wilton (1997) describes the cultural significance of AIDS as "social dis/ease, contamination, exclusion, discrimination, hostility, economic/material inequalities, religious doctrine, political expediency, moralism/morality, sexuality, deviance, criminality, risk, blame, disfigurement and death" (Wilton 1997:xii). There are discourses on HIV and AIDS at many levels, from the popular to the academic and scientific. Popular constructions of HIV developed hand in hand with public health campaigns about the risks of this new virus. The name change of the disease in 1982, from GRIDS (gay related immune deficiency syndrome) to AIDS, reflected its changing epidemiology. Also at this time the "4-H" risk populations were defined: homosexuals, haemophiliacs, heroin addicts, and Haitians (Treichler 1988:192). As Green and Sobo (2000:33) say, "these epidemiological categories, by which behaviour is reduced to easily measurable, decontextualized units, were accepted by researchers, largely without question…in part due to the cultural hegemony of the industrial-scientific modes of thought." The demarcation of risk groups created the perception that AIDS was also restricted to these groups. Anyone in a high risk-group was labelled at risk, whether or not he or she engaged in activities that transmitted HIV. Consequentially, those in other groups were seen as free from risk.

The growth of the epidemic beyond these groups led to a shift from risk groups to risky behaviour. This recognized that it is engagement in specific, unsafe activities rather than a specific identity that is the risk. However, this new categorization still failed, in that risky behaviours are still decontextualized from the social, cultural, economic, and political context within which they occur. In reality, infection comes not from specific behaviours but from the presence and transmission of a virus (Schiller et al. 1994).

HIV in Malawi, like Africa generally, has also been attributed to certain risk groups and behaviours (Lwanda 2004). In the early years of the epidemic, epidemiologists underestimated the threat that AIDS would pose to Africa. It was viewed as an urban disease limited to "core transmitters," people with multiple sexual partners: prostitutes and their clients, the military, and truck drivers (Schoeph 2004:16). In fact, HIV spread beyond these groups. However, promiscuity and immoral behaviour gained particular force in the discourse on HIV following the early delineation of risk groups and the focus on sexual transmission. This rhetoric has been taken on by African churches, politicians, and intellectuals (Lwanda 2004; Schoeph 2004), who perpetuate it.

Campaigns to educate individuals on the risks of transmission have therefore focused on risk groups and behaviours with the goal to change behaviour. This placed responsibility for infection with HIV on individuals. "Infection is a clear – and usually terminal – marker of individual risk taking, of engaging in behaviours typically held to be deviant or criminal. According to this view, those who are infected are *responsible* for their plight. AIDS is *caused* by a moral failure of the individual" (Brandt 1997:69). In the popular imagination, AIDS, unlike many other modern diseases, has clear "moral ontologies" (Brandt and Rozin 1997:3). Individuals diagnosed with HIV must thus come to terms with, and negotiate, their HIV status within the dominant discourse of HIV and AIDS.

BECOMING A PERSON LIVING WITH HIV

Women diagnosed with HIV in the PMTCT program confront both the physical and social meanings of their diagnosis. Women come to the health centre and to their HIV diagnosis with a reservoir of meanings about HIV. Physically, a diagnosis means multiple illnesses, long suffering, and death. Socially, HIV means deviant behaviour, promiscuity, infectivity, wan appearance, economic and social loss and devastation, illness, suffering, and death. In counselling, nurses work against these meanings to create new and hopeful understandings of HIV.

Immediately post diagnosis, women seem to struggle to reconcile their feelings about test results and nurses' advice to be optimistic. Furthermore, women want to believe in the benefits of HIV testing. While some women feel comforted by the counselling and transcending the worry, others say that the advice does not address their concerns, answer their questions, or present viable suggestions on how to live positively. Some women are comforted not by the counselling, but by alternative ways to make meaning of their diagnoses.

Women respond to their HIV diagnoses in a number of ways. For the majority, post-test counselling and the hope delivered in positive-living advice facilitate coping.

> I received my results well without any problems. I was counselled on how I can prolong my life, saying, because I have been found HIV positive, it's not the end of everything. I can live for many years, and maybe I can die with another disease and not HIV. As long as I follow the advice I was told. And I am following that advice now.

While women do report worrying about their diagnoses, they are also comforted by the advice: "After I had a test, they told me to be strong and reduce worrying. Because, if I continue worrying, I will just end up being weak." The authority and persuasiveness of the advice is the consequence of not following it. Worry will lead to weakness, sickness, and death. Another woman elaborates on the need to reduce worry and connects it to prolonging life. "I just accepted and reduced worrying. Because, if I continue worrying, I can just reduce my days to live on earth. If I was to live for 40 days, I can only live for maybe 20 days because of worrying. When it's time to start suffering I will start, but I shouldn't induce the suffering." The nurses' intention is to empower women through the positive-living advice. "I am glad that they have found me with the virus, because I know how I am in my body other than just falling sick and not know what you are suffering from. And also, nowadays, there are drugs which can prolong one's life as long as one follows the advice." The nurses communicate that women themselves have control over their health and their lives. However, in women's descriptions of their feelings about HIV diagnosis, they say that they do not permit themselves to come to terms with their HIV diagnosis. To think too much about HIV, the message goes, would be injurious and go against their life-prolonging goal.

Alternative forms of meaning making take precedence in some women's stories of their HIV diagnosis. Instead of adopting the empowering positive-living advice, they fatalistically accept HIV as a part of life: "No, I didn't expect to be diagnosed HIV positive. But, according to how things are nowadays, you can't assume that you are okay unless you are tested. It's when you can know your status." Women are comforted by both the commonness of HIV and their lack of control or blame for their infection. "I just accepted, and I said, that's how things are...I wasn't disappointed, because this thing has been happening to many people because of their unfaithful husbands. So I just said, anyway it happens." A common refrain is "AIDS is a disease that came for people, and we will all die one day." There is thus no point in worrying. In fact, worrying seems particularly pointless: "I was, of course, disappointed. But then I said, This is something which has already happened. What can I do?" Immediately following diagnosis, only one extremely religious woman sought explanation in a higher power: "When I came here on the 14th, I went for VCT, and my results showed positive.

And I am not worried. I am just leaving everything in Gods hands, because it's God who guides."

Counter to positive-living advice and in contrast to most women, some are clearly devastated: "I was thinking that my life is doomed, and the future of my children has been doomed, too." Women express loss in relation to their HIV diagnosis:

> As you can see, I am still young. I haven't enjoyed life to the maximum and, in addition to that, I have children. You know, it's very painful to be an orphan. The point I have reached now is that I am already dead. And, to make matters worse, I am pregnant. Maybe it would have been better if only I had these two children. I just wish there could be a drug that could help to cure. That would have been better.

For some women, despair over diagnoses seems to break through their positive intentions: "I can't hold my heart, I worry a lot." Multiple worries run together in women's descriptions:

> My concerns are that I feel pity for myself, knowing how people with this disease suffer. And I don't have a mother. If I had a mother, she would take care of me when I fall sick. My other concern is suffering, because you suffer for a very long time with this sickness. It doesn't go away; it just continues. Even if you have diarrhea, it will not stop, but go on and on. I am very disappointed.

Women worry about the future, which they cannot control or plan and about their marriages: "I was so scared such that I stayed for a week before disclosing. I was so scared that I thought of going home [to parents]. And, that time, I was seven months pregnant." Women worry about their children: "I worry, because somebody can't care for my children the way I can myself." Several women say that HIV has affected too many people in their families, that the family future is uncertain: "What is going to become of us?...I cannot fail to worry for myself."

In response to these very real fears, concerns, and worries, positive-living advice fails women. Moreover, women express concerns about its practicality:

> I: When you were told about your test results, did you have any questions or concerns?
> P: I didn't have any questions, but I had some concerns.
> I: What were your concerns?
> P: I was thinking of the things they told me to be eating, balanced diet foods. Since these things demand money and, at the moment, I am not working nor am I doing any business. So, when I think of this, I worry because balanced-diet foods can prolong my life, and I cannot afford them. Better for water, because I was also told to drink a lot of water.

Other women find the imprecision of the advice frustrating. In addition to knowing that they can still live for some time, they want to know how long: "I wanted to know whether I am going to die quickly or live a bit longer...I wasn't satisfied, because they didn't tell me whether I am going to live longer or how many days am I going to live." While these women ask questions and are unsatisfied with the answers, other women were too preoccupied with the test results to hear the information or ask questions:

> I: When you were told about your test results did you have any questions or concerns?
> P: I did not ask anything.
> I: But was there anything that you wanted to know?
> P: Yes.
> I: What were the things that you wanted to know?
> P: What I wanted to know is that, since I have been found positive, what can I do to at least live for some time?
> I: Did the nurses address that topic?
> P: No.
> I: Why didn't you ask about it?

> P: I forgot, because there was a lot in my head...You think, even if you know that you have the virus can you just accept that it has happened? It's okay? So that is why you can't ask there and then, because questions can't come, I couldn't remember to ask.

For women who do not receive the information on the PMTCT program or positive living, there is not necessarily another opportunity. Indeed, the many questions that women asked me suggest that most do not receive all of the information. I will address this issue further in Chapter Seven.

Over time, most women come to terms with their HIV diagnosis in ways that are consistent with the positive-living advice. Nonetheless, questions on its practicality and possibility of achieving its benefits persist. This I elaborate in Chapter Eight.

WOMEN'S UNDERSTANDINGS OF RISK AND MAKING SENSE OF HIV

Individual experiences of HIV occur within discourses that shape how individuals comprehend the world. In Chapters Four and Five I addressed some of the ways women understand risk and seek to mitigate it. In this section, I examine more extensively how women understand their vulnerability to HIV and what possible action they believed would avert infection. Risk understood retrospectively differs from risk evaluated in lived life. Women diagnosed with HIV think about the risks in their lives that led to their infection as they make sense of their HIV status. "Risk perceptions may form afterwards, as part of an ex post facto rationale for one's own behaviour" (Slovic 1987:281). From this new and fundamentally different vantage point, women consciously look for and find risks in their past. This is part of making meaning of a fragmenting life event and reconstructing a coherent life story to take into account a new situation.[34] Women's retrospective explanations of risk may or may not be the same as they were in lived life. Women are applying their new knowledge of risk to past events.

As I discussed in Chapters Four and Five, some women clearly thought that they were vulnerable to HIV prior to their diagnosis: "As for me, I had no doubt at all. I know I was vulnerable, because my husband used to marry yearly. And he never cared whether it was his friend's wife or not." Another woman says that she thought she was vulnerable to infection: "Yes, I did, I thought I was vulnerable because of my husband's promiscuous behaviour. He used to sleep with bar girls, sleepover. And the rate at which he was taking beer, I thought he never used to use condoms."

Some women did not feel vulnerable to HIV infection. In some cases, this lack of vulnerability related to women's beliefs about HIV transmission and what types of people acquire HIV. These are rooted in community stereotypes as well as prevention campaigns at the beginning of the epidemic: "As for me, I used to think that HIV is only for prostitutes or promiscuous people." As another woman describes, such beliefs are widespread: "Most people do have misconceptions, thinking that people who have HIV got it through immoral behaviours – not knowing that there are different ways that people catch the virus." Such

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[34] Recall the discussion of narrative in Chapter Three.

stereotypes freed some women from contemplating their risk: "As for me, I never thought that even normal people who just sit at home contract this virus. I used to think that only prostitutes are the ones who contract this virus. But, after I had a test, it is when I knew that even people who are innocent can catch the virus." Not only do the misconceptions around HIV make some people, who do not see themselves at high risk, feel safe, but, they exacerbate the stigma of HIV, as I discuss in the next section.

Women in my study also did not feel vulnerable to HIV if they thought that their husbands were faithful: "I ask myself that, how is it possible to have the virus in my body, because my husband and I trust each other so much." Another woman says, "I never thought I was vulnerable, because, when my husband is at home, he is very good. But when he goes to the field, maybe it's where he sleeps with other women." For these women, their risk of infection only emerges after their HIV diagnosis, as they seek explanations:

> When I came here, I met the man who is now my husband. His background was like, after he finished school, his uncle took him to work in a bottle store/bar. But I didn't know about that. And now, because of this virus, I am not surprised. Because that means, with his job, He was promiscuous. And now what he's doing, he's having a lot of money, which is confusing him.

Finding the cause of infection seems to be important in making sense of and coming to terms with HIV. Some women, however, see multiple possible causes and maintain ambiguity.

These explanations for infection are not uncontested and are often an area of disagreement between women and their husbands:

> I: If you think about your HIV status, how do you think you contracted it?
>
> P: I think it's him [husband] who infected me, though he refuses, saying I got it myself. He says he never slept plain with his girlfriends. He says he always used condoms with them.

One woman, whose husband tested HIV negative on multiple occasions, was especially seeking an acceptable explanation for her HIV:

> As for me, since I got married to my husband, I have never slept with any other man apart from my husband. Maybe it's because I was once raped by my uncle when I was a young girl and infected with bombs.[35] Otherwise, I am also surprised. And my husband is surprised too, such that he has said that we go for a test for a second time if I am serious that I have never slept with any other man since we got married. And it's true, my husband is the only man I have ever had sex with. So I wonder that could it be that I contracted the virus long time ago when I was 12 years old?

This woman and her husband both expected that the husband would also be HIV positive, because he is often away for work. In fact, there is a significant rate of serodiscordance in Malawi.[36]

While women primarily believe they were infected through sex, they also present alternative explanations, either in parallel or as substitutes: "The coming in of this virus is difficult, because others it's through injections. And others through sharing razor blades, and others it's through promiscuity." Even women who seem convinced that they contracted the virus from their husbands leave open the possibility of multiple infection routes:

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[35] *Mabomu* [bombs] is an STI characterized by swelling of lymph nodes in the groin. It is one of the STIs most mentioned by women in Malawi.

[36] A recent study of Malawian couples attending VCT found that 19.8 percent were serodiscordant. In 65.5 percent of discordant couples the woman was HIV positive and the man negative (Killam et al. 2005). This reflects the higher rate of HIV infection in women and physiological factors that create greater risk of transmission from men to women during intercourse.

> My father used to make us tattoos in the family. So I wonder, because I heard that one can contract the virus through a razor blade and also unprotected sex. So I ask myself that, Is it not possible that maybe I got the virus through the razor which my father was using on us? Or is it because of having sex? Sometimes I even think that maybe it's through the injections that I got the virus.

Medical routes of infection are prominent in women's explanations of HIV: "What I know is that others get it through having sex, and others get it through using one needle at the hospital which has also been used on an HIV-positive person." Women also mention delivery wards as a possible place for transmission: "I can't just blame my husband, but sometimes it's during delivery. Where we lie down sometimes there's a lot of blood. And sometimes in the hospitals they boil the syringes and use them on us. So those also can be contributing factors." Leaving open multiple possibilities for infection not only attends to the reality of medical infections and infections through traditional medicine and tattoos, but also removes blame from the women themselves and their husbands. Thus, although women describe feeling bad that their husbands have brought HIV infection to them ("sometimes I feel bad, but I try to control my temper because I have already fallen in the trap"), they see worry and blame as pointless, as they have already been infected.

Looking back on their lives before diagnosis, some women feel that there was nothing they could have done to prevent themselves from infection: "There was not any other way we could have protected ourselves." Most, however, explain that, had they known that they would contract HIV, they would have gone further in their prevention efforts. Women explain that they would have remained unmarried: "If I had known that he was going to infect me, I would have just remained unmarried. But, because the nose doesn't dream [you don't know the future], it's how he got me infected." They would have gone for testing prior to marriage: "Had I known in the first place, I would have asked him to go for a test." They would have used condoms: "If I had known, I would have been coming to the hospital for condoms for prevention." And, finally, they would have divorced their husbands: "If I had known that he was going to infect me, then I would have said we divorce, so I'd be on my own." Women, thus, retrospectively wish that they had done more to protect themselves from infection. However, they also feel that knowing about the HIV infection is a more informed position: "There is nothing we could do to avoid catching the virus, because we thought that maybe we didn't have the virus. We were thinking two things: a yes and a no." Moreover, women describe their diagnosis as making HIV more real. "We used to hear on the radio, but we didn't know what it meant. After we had a test, it's when we said that, so what they were saying in the radio is reality. Let's take care." It is not that women were previously unaware of HIV, but they did not connect to HIV in a significant or personal way. As I discuss in Chapter Eight, when threats are seen as real, women make significant efforts to prolong their lives after diagnosis, exceeding the gender and socio-economic constraints on women discussed in Chapter Four.

STIGMA

The stigma of living with HIV is pervasive in many women's stories and is often explicitly mentioned as a consideration as they try to negotiate life with the disease. The stigma derives not from one component of the disease but is related to both the pathways of HIV infection and the havoc that HIV wreaks on bodily integrity. This fits into the first two categories in Goffman's (1963:14) classic description of the roots of stigma: (1) bodily abnormalities, (2) character blemishes, and (3) tribal stigma, race, religion, etc. Stigmatization, however, also occurs within specific power and cultural dynamics. Drawing on the works of Goffmann, Foucault, Bourdieu, and Gramsci, Parker and Aggleton (2003) find that "stigma is deployed by concrete and identifiable social actors seeking to legitimize their own dominant status within existing structures of social inequality" (Parker and Aggleton 2003:18). Thus, in the rumours and gossip described in Chapter Four, women aim to maintain social order. The dominant discourse on HIV also aims to maintain social order. Stigma sanctions those who do not comply with social norms and legitimizes the social status of those who stigmatize.

HIV, Malawian women say, is stigmatizing because it is linked to immoral behaviour, such as prostitution and having multiple partners. As one woman describes it, "There is stigma towards HIV because, mostly, this disease is spread through sex. So they think that anyone who has HIV was promiscuous. But it's not like that." HIV stigma also relates to its visible and embarrassing destruction of the body through weight loss and diarrhea: "It's because people who have the virus lose weight in an embarrassing way." Another woman describes some of the bodily stigma of HIV: "Discrimination comes in when an HIV person starts having diarrhea, spoiling his or her pants, falling sick. And also our bodies develop sores." Moreover, HIV is stigmatized because it is a certain death sentence, and, therefore, people are seen as already dead: "They consider that person who has HIV as dead. So they say they see no reason why they should classify that person as a human being. They say it's finished for him or her." The burden of HIV on families and the length of suffering, women explain, also creates stigma: "There is stigma, because diseases claim a lot of things when one is sick: money, food, and people fail to go to work. They say you did that deliberately." Another woman adds: "Because this disease takes a longer time of suffering and your relatives suffer too before you die, that's why there is stigma." People are afraid of the spread of HIV; those with HIV are both infectious and signifiers of the spread of HIV through the community.

Stigma disrupts social experience in local, moral worlds where something is at stake. "Daily life matters, often deeply. People have something to gain or lose…This feature of life can be regarded as the 'moral mode' of experience. *Moral experience* refers to that register of everyday life and practical engagement that defines what matters most for ordinary men and women" (Yang et al. 2007:1528). In Malawi, stigma matters and infringes on the experience of local life. The majority of women with HIV feel stigma or the potential for it. Even though the majority do not recall any examples of being stigmatized, they know that there is stigma against people living with HIV in their communities and they feel vulnerable to it. "As for me, I have never been stigmatized; that has never happened to me. Maybe it's because I haven't started falling sick. But I believe that, when I start falling sick, people will discriminate me." Another woman describes her expectation: "The greatest challenge [of living with HIV] are insults, discrimination, and stigma. Because, as I am, I will not breastfeed my child, and they will just conclude that I'm HIV positive. With time, they will get used to the idea that this person is living with HIV, but at the beginning it is difficult and painful." This woman believes that her decision not to breastfeed her child will signal to her community that she is HIV positive, and, as a result, she expects to have a difficult time.

Women's belief that they will be stigmatized is based on witnessing stigma in their communities, having themselves stigmatized others, or having experienced stigma directly: "As for me, I anticipate stigma in the future, because I experienced this when my relative was sick. Most people used to say a lot about her, saying, 'That girl is suffering from AIDS, she was a prostitute.' And this went on until my relative died." Other women describe stigma that they have witnessed in their communities: "Yes, there is stigma. Because I have seen people laughing or talking bad about sick people saying, 'Ha, look she has grown thin like a small child.' But that is not good." Another woman adds, "People say, look at her. She contracted that disease which has no cure. And, when you are moving, they start pointing fingers at you and even discriminate against you. They even laugh at you." Women's anticipation of stigma also comes from the media: "I have never come across that [stigma], but I just hear from the radio that people are shouted at or not being talked to nicely. And some people say that they fear to come to the hospital to have a test or to collect medicine because of how they are talked at." Based on women's experiences living in communities that stigmatize HIV, they are fearful that they will be stigmatized.

Women who do not experience stigma living with HIV relate this to their careful management of their HIV-positive identity and their relatively good health. In contrast to the experience of most women, some women also experience stigma related to their HIV status. One woman describes her experience with her neighbour:

> Like my husband and my child, they fell very sick, and my neighbour started spreading the rumours that my husband is dying – we are going to bury him before January. I didn't say a thing. I just kept quiet. I just said to myself she doesn't know what she is talking about and how she is in her body. It would have been better if she had her test result forms in her hand. My baby opened bowels [diarrhea], so I took her to Kamuzu Central Hospital. The neighbour started telling people not to visit me, because if they did they would contract the virus – telling them that I know that an AIDS person has such symptoms. But, I have never told her anything, but she keeps spreading that rumour.

This woman describes stigma as coming with illnesses, associated with HIV. She also describes being stigmatized by her aunts: "Whenever I fall sick my aunt asks me, 'Are you not opening bowels?' And when she is inside the house she will be talking with my other aunt, 'Is this not AIDS?' Soon she is dying. And, the time I was sick, they were wearing my clothes, saying I am dying soon. But luckily enough I got well." Within families, women describe their HIV status as being used against them in arguments with those to whom they have disclosed. For example,

> When I have a misunderstanding with my sister, she calls me an AIDS person and discriminates against me. But with time we come to terms, just like that. So sometimes I tell her that, "Fine, I have AIDS then we shouldn't be using the same utensils, or maybe we shouldn't be staying together." So I just encourage myself by answering that we shall see who is going to live longer, since you wish me dead quickly.

In her own home, this woman is able to defend herself. Interestingly, she does this by drawing on the language of stigma, which she turns around and uses to threaten her sister. She also gains strength in challenging her imminent death by drawing on everyone's vulnerability to death.

Participation in the PMTCT program is itself stigmatizing for many women. Because of its distinct location in the health centre, the program clinic and women's presence on its veranda identifies them as HIV positive: "When you sit there [PMTCT program veranda] people laugh at us." As another woman similarly says, "People stigmatize us. You will see them laughing saying, 'see this woman and her child? They are both HIV positive.' They really laugh at us." The stigma of the PMTCT program is recognized by program nurses to contribute to women not returning for further health services after HIV diagnosis:[37]

> I: For women who are lost to follow-up by the program, what do you think happens to them. Why don't they continue?
>
> P: Most of them, they are very shy because the community now knows that every women who is going to that building on the veranda is HIV positive. So some women are being shy: "Everybody will know that I'm HIV positive if I go there." So, some of them don't come because of that feeling, most of them.

The World Food Program supplement given to women in the PMTCT program is particularly stigmatizing, because it has become known that only HIV positive women leave the health centre with that food: "When we come to collect flour they insult and stigmatize us, saying we have HIV." As is elaborated below, many women deflect stigma by drawing on the benefits of their participation in the program. However, stigma is a very real problem that needs to be addressed by PMTCT programs and considered in the design of HIV services.[38]

Stigma, of course, is not benign. However, it may be difficult to think about the damage it does to individuals when it primarily takes the form of gossip

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[37] We interviewed one woman the same day that she was to receive her take-home dose of nevirapine. At the end of the interview, we asked her whether she was going to see the program nurses for the nevirapine. She said she could not go, because she was too shy, because people would know that she is HIV positive. We were able to arrange for a PMTCT program nurse to come to the room where we were conducting the interview. There she received the information on nevirapine and her dose. More often, women are lost to the program without receiving any of the interventions.

[38] Indeed, a number of researchers have found that stigma is the major barrier to Africans' access to HIV services (see Mshana et al. 2006; Wolfe et al. 2006)

and rarely extends to discriminatory actions.[39] HIV stigma is often accepted and internalized by those living with the disease because it is a part of the dominant order (Parker and Aggleton 2003:18). The recipients of stigma, therefore, feel its effects very strongly and see it as detrimental:

> People talk a lot of bad things about you, to say, "Look at her. She is HIV positive." And, because of this, you who is infected, you feel bad. Because it's like you are being reminded of something you long forgot. And, because of this, you start to worry and lose weight – not because you have started suffering, but because of worries about your status.

Worry, as I illustrate in Chapter Eight, is seen as particularly damaging: "When people start thinking that someone is HIV positive, you, the person who is suffering, you start having concerns and worries. And, by so doing, your life now shortens." Stigma, thus "is not just a discursive or interpretive process but a fully embodied, physical, and affective process that takes place in the posture, positioning, and sociality of the sufferer" (Yang et al. 2007:1530). As a result of stigma, or as a way to avoid it, women may change their day-to-day lives: "When people know that one has HIV, they discriminate against that person. And also that person who is infected doesn't feel free to mix with friends because of discrimination and stigma." Such experiences impede women's capacity to cope with HIV and make it difficult to follow positive-living advice that emphasizes reducing worry and seeking comfort and distraction in friends.

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[39] Green (1995) distinguishes "felt" and "enacted" stigma. Women in Malawi, therefore, feel the effects of stigma very strongly, even though, for the most part, they have not yet been stigmatized. Alonzo and Reynolds (1995:305) suggest that this may be due to women's location on the disease-stigma trajectory. They found that stigma follows "biophysical changes in the HIV disease trajectory." Women in my study believe that they will be more stigmatized as the signs of HIV begin to show on their bodies.

Women comfort and console themselves when confronted by stigma in a variety of ways. They also resist it.[40] For example, women draw on everyone's risk of infection.

> People run away from people who are HIV positive. They stigmatize them, laugh at them, saying, "Look at them they are sick. Soon they will die, leaving their children." As for me, I have heard on the radio how they encourage people that, if you have HIV, you will not die today. I will just be staying until when it's time for me to die. And, if people will be laughing at me, I will just be saying in my heart that, ok, it doesn't matter. You are also married. One day you will also catch the virus.

This helps women deal with stigma: "Like where I stay, I see people pointing fingers at a certain woman who is sick and stigmatizing her. But the people who do that don't know how they are in their bodies." Women reason that some of the people who stigmatize have not been tested for HIV and are themselves HIV positive: "It is because they have not had a test yet. Because they haven't had a test, that is why they think it's only us who are infected. But, even if they laugh at us, we received counselling." Women believe that the advice that they received, better positions them to prolong their lives than those who have not been tested and counselled. For example, "I do collect [the WFP food supplement] myself. I can't not do that. I can't fear anyone, because the problem is with me, and

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[40] Women are not solely passive recipients of stigma; they also resist and reject it, however weakly. In so doing, they challenge both their own stigmatized identity and stigma itself. This is evinced in women's rejection of damaging explanations for their HIV status and their emphasis on multiple possible causes of infection, including their husbands. In disclosure, women present themselves in ways that reject stigma. In this section, I show that women reject stigma and their construction as different by emphasizing everyone's vulnerability to HIV and others' unknown HIV status.

thinking of other people is a waste of time." Women often feel that stigma cannot stand in their way of doing things that will help them live positively.

Women also hope that stigma will decline in their communities: "I don't think stigma can continue because of how many people are falling sick." Women also hear on the radio that the situation is changing: "I used to hear that people would discriminate against people who have the virus. But now I have heard on the radio that people are changing. They have come to accept the situation about the pandemic." Women hope that the construction of HIV is shifting and that HIV will be seen in the same way as any other disease. Indeed, HIV services staff, like those in the PMTCT program, see themselves as contributing to this shift by increasing public awareness of HIV and increasing HIV testing. However, at the same time, programs must address current stigma. Indeed, doing so could improve outcomes. Women might be more likely to continue in a program that does not publicly signify their HIV status, one that integrates HIV services into other health services.

DISCLOSURE

In general, women feel that knowledge of their HIV-positive status is private – a sensitive subject and potentially damaging if disclosed. Thus they carefully weigh the benefits of disclosure against the possible negative outcomes. Despite the latter, most women in my study, 43 out of 55 (78 percent), have already told their husbands. Some also have chosen to tell members of their immediate and extended families, and friends.[41] Disclosure is best understood as an evolving process, whereby women share their HIV status with more people over time. In most cases, women framed decisions not to share their HIV status in terms of stigma, as elaborated above.

Not Telling

One of the major reasons for non-disclosure or delay is women's belief that problems will then arise in their relationships. Women who did not discuss HIV testing with their husbands prior to having tests, or whose husbands did not agree, face challenges in sharing test results:

> I: Do you think that you are going to tell your husband?
> P: I think I will not manage to explain it. Because, when I came, I didn't tell him that I was going to have a test. It's going to be difficult. Because, if I am positive, then he is HIV positive.
> I: How do you think your husband would react if you told him?
> P: Ah, I think there would be a quarrel.

Women who worry that they will be blamed for the infection often choose not to disclose. They also anticipate questions about the root of HIV infection:

> I: Have you told your husband?
> P: No
> I: Why have you decided not to tell him?
> P: He is very difficult indeed, in the sense that, with this issue, he would have tortured me to tell him how I got the virus. It is possible that, when I got the STIs, I got it. It is also possible that I may have got it from my first husband. And it's also

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[41] Medley et al. (2004), in reviewing the literature on HIV-status disclosure in sub-Saharan Africa, found that disclosure rates vary between 16.7 percent and 86 percent. Interestingly, they found lower disclosure rates among women in antenatal-care settings than at voluntary counselling and testing sites. They report that most researchers found positive outcomes to disclosure. Varga et al. (2005) and Maman et al. (Maman et al. 2003) support this conclusion. They found both high rates of disclosure, including among women at antenatal-care sites (Varga et al. 2005) and positive outcomes in the majority of cases.

> possible that I may have got it from him. So, because he is a very difficult man, I found it difficult to tell him.

In deciding whether or not to disclose, women evaluate their husbands' past views of HIV: "I have never told anyone as of now. Because there was this other day I was chatting with my husband, so I asked him that, what if one went for a test and was found positive, what would happen? So my husband told me he would divorce that woman. So, because of his response, I fear to disclose to him." Similarly, another woman describes waiting to tell her husband because of his previous attitude towards HIV.

> When I got home [from having a test], I didn't say a thing, because my husband threatened that, if I took part in the program and was found positive, he would commit suicide. So I disclosed to him after the baby was born and, when I told him he just accepted saying, "Since we are still healthy, people won't know that we have the virus. What is important is to take care of ourselves."

Women who have not yet told their husbands often discuss the need to eventually disclose, because they find the secret difficult to keep. They try to prepare by talking about HIV with their husbands, using broadcasts about HIV to initiate discussion and gauge their husbands' reactions. Other women try to convince their husbands to go for HIV tests either alone or as a couple.

> I: Have you told your husband that you are HIV positive?
> P: No.
> I: Why did you decide not to tell him?
> P: My husband is very difficult, so I wanted us to come together to the clinic for a test. Otherwise, for me to just tell him, he cannot listen.

Several women feel that convincing their husbands to go for an HIV test will lead to better outcomes than disclosing their own test results. However, this is not easy, as husbands resist going for tests and, even if they agree, often do not actually follow through.

While most women feel that they will eventually tell their husbands their HIV status, they feel much more freedom in keeping their HIV status from other people, including other family members and friends, because of the stigma of HIV. To them HIV is sensitive and embarrassing. Moreover, they worry that people will gossip about them, which will cause pain and worry and damage their health:

> I: Why have you decided not to tell anyone?
> P: I keep it to myself, because people talk a lot. So, when you tell people about your status, they gossip a lot and they can be stigmatizing me. And, because of these factors, I can start worrying a lot which is not good for my health.

Women also see not disclosing as a way to maintain control of the information. They worry that, if they tell even one person, knowledge of their status will spread in unintended ways: "I decided to keep it to myself, because I can tell my best friend that I was found positive. And that friend of mine will also tell her friend. So the news will spread, which can make me feel uncomfortable because of my HIV status. And also I wouldn't feel good to know that people are discussing me." Information management and the potential for gossip is a particular concern for women who have not disclosed to their husband.

> I: Have you told anyone that you are HIV positive?
> P: No.
> I: Why not?
> P: Because people are talkative. They can destroy my marriage by telling my husband. Since it's not long that we got married and my husband will start wondering that, "Is it me or her that

> brought the virus?" I didn't tell anyone because, even if I told my closest friend, one day we will have a misunderstanding. She can tell my husband, and my marriage can break. And for me to go to the village, I will have no support.

Not disclosing is also a form of identity management. By disclosing, women feel that they may be associated with prostitution and promiscuity and that people will not want to associate with them because they are HIV positive. By not disclosing, they can maintain their image, at least in the near future, as good and healthy women.

Some women, however, want to share their HIV status more broadly, but do not or cannot disclose for circumstantial reasons; for example, distance from family and protecting their families from the stress and worry of knowing their HIV status. One woman says, "I didn't tell other people, because, if I did, my relatives would just be crying. Like, if I told my sister, she would be crying, because I am the one who supports her. But I have a brother who stays here whom I plan to tell." Another woman has also chosen not to share her HIV status with her mother because "my mother has high blood pressure. You know this disease [HIV] is very sensitive, so when she hears something alarming she falls sick. It's not like I won't tell her, but I want to see how she is doing first. Because recently my dad was sick, and he died. I just want things to cool down a bit. It's a good idea." In one focus group, women also discussed whether it is appropriate to tell their children about their HIV status. They feel that disclosure can be educational and prepare children for the future, but they are also concerned that children might worry about their future.

Telling

Despite real and anticipated challenges with disclosure, most women do tell their husbands and many additionally share their HIV status with other people. Therefore, women see benefits in telling. Disclosure is also sometimes necessary, less a decision to be made than something that must be done.

Many women describe sharing their HIV status with their husbands as the natural course of events, rather than something that they deliberate about. They simply tell their husbands because they are the ones with whom they live, with whom they are intimate:

> I: Have you told your husband?
> P: Yes.
> I: Why did you decide to tell him?
> P: My husband and I are one body, so, even if I hide it from him, I wouldn't have achieved anything.

Since women believe that they share the virus, and in many cases that it came from the husband, not telling seems senseless. They also feel a duty to disclose, because they are informing the husband of his potential health status. Since women's HIV status will eventually be revealed as their health declines makes hiding seem futile. The uncertain health of their unborn children also makes women inclined to disclose:

> I: Why did you decide to tell your husband about your HIV status?
> P: I thought that, even if I hide, it will not help. And maybe I will have a weakling, sick baby. And to tell him that I was found HIV positive then wouldn't be good. That's why I decided to tell him now.

Most women see more to gain than lose in disclosing.

The need that women feel to tell is compounded by other goals and benefits that they feel they can achieve. Many disclose as part of a discourse of blame. They, thus, inform husbands of the consequences of their past actions: "You have to let your husband know, because they are the ones who bring these things." Another woman elaborates: "I only told my husband about my status. And the reason I told him was because of what he did in the year 2000 [he had an affair]. It doesn't matter that it only happened for a few months. I wanted him to know the result of his actions." Disclosure can thus be seen as the conclusion of an on-going narrative within marriage. In this narrative, women have warned their husbands of the harm of having affairs and have tried to persuade them not to. In disclosure, women are able to confirm that they were not being difficult, but had accurately assessed the potential consequences of their husbands' actions

For most women, decisions to tell also relate to their desire to live positively. Encouraging their husbands to use condoms, terminate affairs, and not have any more children are all reasons for disclosing. One woman describes why she told her husband: "My husband knows. And the reason for telling him was that, if he was not moving well, he should change after listening to the advice, so that we can care for ourselves in terms of this disease." Disclosure can also facilitate appropriate response to illnesses: "I disclosed, so that, when there's a problem, he should be able to help according to the problem, and same applies to me. If he has a problem, I can know how to handle it. Also, I told him because he is my husband and the one who infected me." Many women tell so that their husbands know how to live according to the positive-living advice. In some cases, women tell because they need the husband's involvement in caring for the babies. "I disclosed to him, because we were given options on how to care for the baby: either breastfeed for six months or not breastfeed at all. I couldn't afford to care for the child alone, so that's why I decided to disclose to him. Hiding it from him would have affected the baby's care." Women also disclose to other relatives and friends to insure appropriate care in the future: "The benefit is that, when you disclose and you start falling sick, people will know about your problem and what type of food to give you. And also they will rush you to the hospital for treatment." Specifically, women want their relatives to get them biomedical care rather than use traditional healers in future illnesses: "The benefit is that somebody will not be alarmed by your sickness and also that person will not waste money taking you to the traditional healers. Instead people will just take you to Lighthouse to receive the drugs, because they were told." Uncertainty about the cause of future illnesses, women feel, will cause more distress and panic for their relatives. This in part relates to potential accusations of witchcraft as the cause for undiagnosed, incurable illnesses: "In my own capacity, I said I will disclose to them. Because, if I didn't, it's possible that they can start hating other people, thinking that they have bewitched me. So I want them to know that I have that problem [HIV]." Witchcraft also influences women not to share their status widely, as they believe that people may use their HIV status to bewitch them with impunity.

Disclosure is also an opportunity to educate and provide advice to family and friends about HIV: "I told my young sisters – reason being that it was a piece of advice and warning that they should be careful in whatever they do. They shouldn't be in problems like the ones I found myself in." Strongly emerging from these stories is women's desire to use their experience to warn others: "I also disclosed to my relative. Even now, I still tell her saying she must be careful with men. They shouldn't fool you; otherwise, you will find yourself in my situation."

As well as educating, women also talk about using their HIV status to comfort people they think may also be HIV positive: "I disclosed to a friend in the village, because she is in a marriage and also her husband is fond of marrying. So I was just shedding light to her not to have concerns [if she should be found HIV positive]." Finally, women fight stigma in their communities through their disclosure:

> I: How did you decide to tell your friends about your status?
> P: There is somebody in our area who is sick, so they were saying all sorts of things. So, they were surprised that I wasn't commenting or laughing, and they asked me why I wasn't joining in the gossip. So I told them that it's not good for them to laugh at that person, because I too have the virus. At first they didn't believe me saying, "How can an HIV person say it for herself?" I told them that it's true. So they heard that, at the hospital, they are giving Likuni Phala to people who have HIV. They believed me, because they saw me bringing the Likuni Phala. That's when they started encouraging me.

While this woman was brave to disclose even in the face of stigma, her story reflects most women's experience of disclosure, in that friends were supportive.

While women are free to tell or not, they sometimes feel that they must disclose or are "outed." Such disclosures often relate to aspects of the PMTCT program. One woman describes why she decided to tell her husband: "I decided to tell him, because I will receive a drug [nevirapine]. And maybe the time I will take the drug, he will wonder what the drug is for. So that's why I wanted him to know in advance so that he shouldn't be surprised the time I will be taking the drug." Women also describe disclosing as a way to explain where they go when they are at the health centre or support group, or the money and soap they receive through the support group: "I said that I have children, and it so happens that sometimes I leave the house with nothing, no money. So after I go home, my children ask me where I got the things. And I don't have an answer to that." In these situations, women disclose to explain certain aspects of the program. In other situations, people deduce women's HIV status by their engagement in certain activities or their presence in certain geographic locations associated with HIV. Women describe their early cessation of breastfeeding as a signifier of their HIV status to the community. "Like now, most people in our communities are aware that, when one stops breastfeeding early, she has the virus. So they say, 'You see, she has stopped breastfeeding her baby. That means she has HIV'." In some cases, women can and do create alternative stories to counter assumptions about their HIV status or to explain components of the PMTCT program. However, such stories cannot challenge community-level beliefs about their HIV status.

Responses: Support, Denial, Problems

Disclosure is most often a careful choice, based on women's assessment of the reaction of their interlocutors. One woman describes deciding to tell her aunt:

> I: Have you told anyone that you are HIV positive?
> P: I only told my husband and my mother's elder sister.
> I: Why did you decide to tell your mother's elder sister?
> P: It was my wish to let her know, because she is one of the people who encouraged me to have a test because of what she called my husband's bad behaviour and his job.
> I: And what did she say when you told her?
> P: She just told me that it happens. And it's when she started encouraging me that this is not the end of life. I should be strong, just like what I was told here at the clinic.

Because women make their decisions carefully, they anticipate comfort and support: "The reason for telling them [family] was that I panicked. So I wanted to tell somebody for relief, because I could have committed suicide if I kept to myself. Even the time I came back from MACRO, I didn't eat *nsima*. And also, when I see what people who have HIV go through, I used to worry a lot." Most women in my study were not disappointed by reactions to their disclosure and did receive the support they anticipated:

> I: What did your husband say when you told him?
> P: I told him that I went for an HIV test though you refused me. And I have been found HIV positive. And he asked me if I was disappointed about that. I said I wasn't. And it's when he started encouraging me, just like I was told at the clinic, that I shouldn't be worrying, because life goes on, I am not dying today. He keeps encouraging me everyday, and now I have gotten over it and no longer worry about my status.

Moreover, women sometimes feel that they have accomplished other goals for disclosure. One woman describes her husband's response: "He just said that I have done well, because we have known how we are. Because, even when I was leaving this place that day, I was given condoms to use with my husband. Saying we should use when making love, skin to skin no, but that we should use condoms until I deliver." Another woman reports that her friends were receptive to her revelation and advice: "Since I told my friends, they have appreciated, saying I did well to know my status. And I have shed light to them, so that they can also have a test."

Reports of positive response to disclosure were the norm, but some women do face problems. Denial is one, and it has many roots. One is unwillingness to accept blame for infection:

> I: You had said that you told your husband, but he didn't believe you. Has that situation changed since we last spoke?
> P: Up to now, he still thinks that I am lying. Whenever I try to talk to him he tells me to stop, saying I am making noise.
> I: Why do you think he responds that way?
> P: I think it's because I warned him against marrying another wife, saying nowadays there are diseases. So maybe it's a way of defending himself, that's why he answers like that.

Other women say that husbands denying their wives' HIV status because of the assumed implication for the husbands' HIV status. One woman describes her husband's response: "He didn't understand that we could be found HIV positive. He doesn't believe it, and he's refusing to go for a test." This refusal is quite common. For some husbands, this is grounded in their denial that they maybe HIV positive. Others assume that they are also HIV positive and see a test as pointless. Convincing husbands to have a test is difficult, but some women do succeed:

> I also told my husband. But the time I told him he refused, that it's not possible that we can have the virus. He was saying, "Which doctor is that, as healthy as we are, to have the virus?" So I forced him to go for a test in town, at MACRO. We boarded a minibus up to MACRO, and there we had a test and we were told the results. So now he knows that we do have the virus.

Even when women fail, and the issue remains unresolved, relationship problems do not necessarily occur:

> I: Does your husband know about your HIV status?
> P: I did tell him, but, because he never came here for a test, he doesn't believe me.
> I: Have you tried to talk to him again?
> P: I tried to talk to him, but he told me not to tell him any lies, because he's not the one who told me to have a test. So I tell him that I just wanted to know how I am in my body. It doesn't interest him. But, as for me, I'm happy because I know my status.
> I: Has this created any problems between you and your husband?
> P: There are no problems, despite him not believing that I had a test. But I keep telling him about it.

Denial of disclosed HIV status is one challenge that women face after diagnosis. Although it is frustrating, it does not necessarily cause any problems in the relationship.

A few women report more severe problems after disclosure. Some are damaging, but ultimately reconcilable. One woman reports the reaction of her family:

> When I disclosed at home, they were angry with me even though it is not my fault, but something which just happened. I was innocent. So, after they got angry at me, I started having concerns that, if my own parents are behaving like that, what then? So with

> time they started encouraging me, saying that they overreacted, that it can happen to anyone, even themselves, only that they haven't gone for a test yet.

Other women report more severe problems in their relationships after disclosure. One woman whose husband tested HIV negative describes her situation:

> P: There are always quarrels in the home; there is no cooperation. Whenever I try to ask for something from him [husband], he tells me that I am a dead person. When I try to say something, he says, "Do dead people talk?" When I need him to buy me something, he tells me that it's better he buys that thing for the living, not the dead. So I tell him that, "Have I already started falling sick?" But it is always the same thing. There is no cooperation at all.
> I: ...What about your children?
> P: I just feel pity for my children. I think that will he be able to look after my children properly as it used to be in the past, since now he has changed? And now he keeps saying that, when we go for another test and the results are the same, he is going to marry another wife. You, no, we will just be looking at each other. So that's why I have concerns about the welfare of my children.

This woman is living out a common fear among women in the study, that relatives will neglect them because they will be an economic burden. Disclosure can lead to the termination of marriages. Women are both sent home and decide to leave their husbands because of their poor response to the disclosure of HIV status. Women's stories of failed disclosure have embedded in them the ongoing reality of the stigmatization of people living with HIV in Malawi.

DISCUSSION

My research suggests that women adjust to their HIV diagnoses and come to terms with life with HIV. In this chapter, I elaborated the way in which women experience life with HIV within the dominant discourse on HIV. Women must negotiate their social relationships and manage their identities in terms of both the meaning and stigma of HIV. This shapes their understandings of their HIV diagnoses and the way in which they communicate it to others.

Stigma stands in women's way of living well with HIV. It derives from community beliefs about HIV, specifically how it is contracted and by what kinds of people. Stigma can enforce community norms and sanction perceived transgressions, such as promiscuity. While women living with HIV do not see themselves as deviant, they still feel stigmatized, regardless of whether or not they have been. They anticipate stigma in the future. They fear that it will damage their health, as it causes worry. They try to deflect stigma and comfort themselves by drawing on alternative discourses, emphasizing that they were innocently infected by HIV, that those who stigmatize are equally at risk of infection and, indeed, may already be infected but do not know their status. Despite these coping mechanisms, perceived stigma has real world implications. Some women are reluctant to access services that mark them as HIV positive. Stigma, therefore, must be taken into account by HIV service providers.

The meaning and stigma of HIV also impact women's communication of their status to others. Overall, they feel that knowledge of their HIV status is private and embarrassing, and assess very carefully to whom they will disclose it. Although not keen on disclosing, they see benefits: receiving support and planning for the future. However, other narratives also play out in disclosure: identity management, blame, and education. Careful evaluation generally pays off for women, and they receive support from their husbands, family and friends when they choose to disclose. Disclosure, however, is not universally successful. Some women get negative reactions and others choose not to disclose.

CHAPTER SEVEN – ENGAGEMENT IN THE PMTCT PROGRAM AND HEALTH SYSTEM

INTRODUCTION

In this chapter I discuss women's experiences in the PMTCT program and the health system more generally, as they attempt to address their HIV status and prevent transmission of HIV to their children. I discuss women's understandings of, and questions about, medical information, their capacity to prevent vertical transmission, and their ability to address their health and HIV status within the Malawian health systems. As I discussed, I followed the women who adhered most to the PMTCT regimen. For the most part, they received and took nevirapine themselves and received it for children and had their children tested for HIV at six weeks and at 18 months. The PMTCT program staff thus see these women as successes, in that they continue with the program after learning their HIV status and attend all or most of their appointments. Their success is unusual because, as I discussed in Chapter Five, less than half of women diagnosed with HIV in the PMTCT program take home nevirapine for themselves and bring their children for their dose.

While the women in my study can be seen as successful participants of the program, they nonetheless experienced challenges in the PMTCT program and in the medical management of their HIV status. This, therefore, suggests more general problems with the process of HIV diagnosis and the program. These women's stories may give clues why most women do not receive all components of the PMTCT program. Indeed, the women in my study express a number of problems with and suggest improvements in the PMTCT program. My observations and data analysis illuminate both fissures in the Malawian health systems and ways that these might be addressed by the PMTCT program administers and Malawian health policy makers to improve outcomes.[42] These have relevance beyond the PMTCT program, as HIV testing is increasingly routine. Counselling, follow-up, and integrating testing into comprehensive treatment and care are paramount if the desired outcomes of expanding testing are to be achieved and the promised benefits of HIV testing delivered.

Women's loss to follow-up in the PMTCT program is surprising given their motivation and expectations of HIV testing, which I discussed in Chapter Five. Women not following-up is a lost opportunity to reduce vertical transmission of HIV, provide health interventions to women to address their HIV status and opportunistic infections, and provide psychosocial support that will facilitate their adjustment to HIV. Program staff and administrators attribute non-follow-up in the Lilongwe PMTCT program to factors seen as external to the program – something about women, their culture, beliefs, practices, and gender relationships, rather than something about the program, causes women to be lost. Some of these factors are certainly important and are discussed in this thesis. However, focusing on external factors avoids an examination of the provider side of the equation, primarily the medical management of HIV. I discuss women's

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[42] My purpose was not to evaluate the PMTCT program, and I do not systematically employ evaluation concepts or draw on the evaluation literature. However, my research fits into a constructivist approach to evaluation that focuses on the way in which actors "make sense" of situations at particular junctures (Guba and Lincoln 1989).

ability to manage their own health through adherence to the positive living advice in the next chapter.

Challenges to delivering successful HIV interventions are, of course, complex and multifaceted. And, they extend beyond the architecture and delivery of the specific program I examined. In this chapter, therefore, I am mindful of the PMTCT programs' location within specific historically mitigated relations between centre and periphery, as elaborated in Chapters One and Two, which includes: the drain of African health workers and international monetary policies that have crippled the capacity of health systems to address the HIV epidemic. However, there is now justified international pressure to address HIV and, indeed, HIV programs are significantly expanding as supranational organizations and international donors increasingly focus resources on HIV. Therefore, policy makers and program deliverers need to reframe both the design and the goal of HIV interventions to achieve true success. As well, there is a need to recast measures of meaningful success. It cannot be exclusively measured in terms of access; for example, how many women have access to PMTCT services or how many women are tested for HIV. These are, too often, the measures program administrators use to demonstrate success. Instead it ought to be measured in terms of what happens to women after they test positive for HIV. Do they receive interventions to prevent transmission to their children? Are they, themselves, well cared for medically and socially? To achieve these kinds of success, even with limited resources, HIV interventions must move beyond the dominant biomedical framework, which marginalizes and externalizes political, economic, gender, and socio-cultural factors contributing to disease. Instead, program designers must attune themselves to the experiences and needs of the women using their programs. Only when these elements are attended to will we achieve truly successful health outcomes for people living with HIV.

PREGNANCY AND DELIVERY IN THE CONTEXTS OF HIV AND THE PMTCT PROGRAM

Counselling, Education, and Multiple Ways of Knowing

In the PMTCT program, women receive their test results at a post-test counselling session aimed at facilitating adjustment to HIV diagnosis and educating women on HIV and the PMTCT program. Nurses must transmit a great deal of medical and practical information during this session. Of course, this session is part of an education and counselling process that began earlier in the health talk and pre-test counselling, and will continue at follow-up appointments and in a postnatal support group. It is only after HIV diagnosis, however, that information on PMTCT becomes relevant to women's lives. The post-test counselling session is additionally important, because it is the last guaranteed contact nurses have with women. If they do not understand the PMTCT program well or do not know that they must return at a particular time, women risk being lost to the program (see also Painter et al. 2004). This is particularly important, as the PMTCT program is delivered vertically. Nurses tell women that they will continue to receive their regular government antenatal care, but must return to the

PMTCT program when they are eight months pregnant to receive their take-home dose of nevirapine.[43]

The post-test counselling session is thus very important, but too brief. Nurses have to give test results to many women, several of whom will receive positive results. Usually three nurses provide counselling and testing, as well as cover follow-up visits by other HIV-positive women. On busy days, more than 40 women may undergo HIV testing, and nurses are therefore limited in the amount of time they can spend with each woman. Post-test counselling sessions are, in practice, only about ten minutes long. One of the PMTCT nurses describes the challenge in counselling adequately:

> I: What do you think are the challenges in delivering the PMTCT program?
>
> P: One, there is a challenge of shortage of staff, because the turn up is very good…I have a lot of clients I want to see. Now you have 40 clients and three nurses that are counselling, and the quality of counselling is not good at all. Every nurse should have maybe four clients, and you sit with them and you have time with them. Then the quality of care would be better.

Quality counselling and education, which means adequate time for quality communication and care as well as delivery of appropriate information, is important, because a significant amount of information must be transmitted. Moreover, the information nurses give challenges the local commonsense way of

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[43] Near the end of my study, the PMTCT program protocol changed. In the new protocol, nurses give each woman a dose of nevirapine to take home at the post-test counselling session. While this may enable women to receive nevirapine even if they do not return to the program, it does not guarantee that they will understand how to take it or its benefit. Moreover, women may not return to receive the infant-feeding counselling or for their infant to receive nevirapine. Further on, women may fall into a gap between HIV testing and other HIV services. Giving nevirapine in the post-test counselling session does, however, improve program uptake, as now 100 percent of women testing HIV positive in pregnancy receive take-home nevirapine.

thinking about the vertical transmission of HIV (discussed below). Moreover, significant rumours about HIV transmission, frequently deriving from biomedical studies, must be challenged. Finally, beyond the PMTCT program, women's own care requires attention and is not given adequate consideration.

My research suggests that even women who continue in the PMTCT program have significant questions about PMTCT, HIV, their health, and health seeking. So do the women I recruited from the support group for the focus groups. Some of these women had delivered their last child over a year before, and, therefore, have had prolonged contact with the PMTCT program. They ought to have had ample opportunity to have their questions answered, either in follow-up appointments or in the support group sessions. Existing education and counselling thus needs to be enhanced, with more time for counselling and appropriate communication, to ensure that women have all of the information they need to make informed choices about their participation in the program, fully participate in it if they choose, and know how to attend to their own and child's health now and in the future.

Women suggest that, at the time of diagnosis, they are overwhelmed by their HIV status and not able to listen to or process medical information or ask questions: "The moment I was told my results, I wasn't myself, because I couldn't talk nor ask anything." Another woman says, "That time I was being told, my head was confused." My research suggests that women do not always have the opportunity to ask questions and do not always feel that questions are welcome.[44] When I asked women in a focus group if there were things about the program that they found confusing, one replied, "Yes, there were things which used to confuse us, but we were not free to talk." In the interview component of my research, I met with women shortly after they received their test results. My experience suggests that, even after this short period, women have had time to process their HIV diagnosis and will ask questions, given the opportunity. When I asked women if they had any questions about my study, they often asked me questions about HIV, the PMTCT program, and available treatment. Some women's questions suggest that they are so overwhelmed by the diagnosis that they missed information transmitted about the PMTCT program altogether. Women asked, Does the baby get HIV at conception? Is there anything to prevent transmission to the baby? How do you feed the baby? Is there treatment for HIV? Women are unclear whether they are to return to the PMTCT program or do not always know when to return. Some want to know when they will be given nevirapine. Women have questions about disclosure and what to do with the condoms they are given, because they worry that condoms will ignite their husbands' suspicions. The short time between the post-test counselling session and my interviews with women was enough to bring these questions and concerns to the surface.[45] But, what if

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[44] Some women begin antenatal care because of a specific health concern or after referral by staff at the outpatient clinic. Women describe getting lost in the process of antenatal care, HIV testing, and then diagnosis without having the opportunity to ask about or have their initial complaint addressed.

[45] I discussed the methodological and ethical issues around women asking questions during my research, and how I addressed these in the methods section in Chapter Three.

women leave the health centre with questions and concerns? Will they return to the PMTCT program?

The PMTCT program serves women who have pre-existing understandings about the vertical transmission of HIV, with which the program competes. These alternative understandings, are not fixed, of course, but require sufficient and compelling explanations to challenge. Most women believe that the vertical transmission of HIV is inevitable when the mother and the father are HIV positive. For example,

> I: Have your expectations for this pregnancy and baby changed since you found out that you are HIV positive?
> P: Yes.
> I: How have they changed?
> P: Because I am going to have a baby who will also be HIV positive.

Given this understanding, women find the advice on nevirapine confusing: "There were things which I found confusing. And what was confusing was that I was surprised to hear that it's possible for the mother not to transmit the virus to her baby. So, I was getting confused as how possible can that be because the baby is coming from my body." Women's commonsense understandings of conception and pregnancy, therefore, counter the possibility of preventing transmission with nevirapine: "What is confusing is that the baby has already been formed with the infected blood, but the nurse tells us to take the drug." Women also believe that the foetus can be infected through sex:

> I want to know what happens, because as for me, I think, if somebody is HIV positive and pregnant and she is sleeping with somebody who is HIV positive too, they can infect the baby during

> the time they are having sex. But, I heard that it doesn't happen like that, but that the baby can catch the virus during delivery. So what happens?

As this quote shows, the contradiction between women's knowledge and the nevirapine advice is not one that they accept. Rather, they do seek answers and a definitive explanation to these questions. In discussing such misunderstandings of medical information, I do not suggest that they are universal. Indeed, many women do understand much of the information relayed in the PMTCT program. However, there are significant gaps, and most women bring to interviews at least something that they find confusing or about which they are unsure.

Traditionally, barriers to the uptake of medical services in the developing world have been assumed to be demand-side problems, something specific about individuals, or their cultures. Predominantly these barriers are explored by researchers in the context of knowledge, attitudes, and behaviours (Fassin 2001; Petchesky 2001). Rapid assessments of these factors have frequently been carried out to more effectively market health services in the developing world. But, women's experiences of participation in the PMTCT program I studied illuminate that the greatest barriers to their uptake of services are on the supply side. "User perspectives" thus emerge as an important component of policy making and program monitoring, especially as women's perspectives significantly differ from those of policy makers and service providers (Inhorn 2006; Obermeyer 2000; Petchesky 2001).

The PMTCT program nurses realize that they are dealing with medical information that most likely cannot be understood by women in all its complexity, so they communicate it in simple terms that they believe women will understand. However, in simplifying the information, explanations often become vague. For example, nurses will explain that the vertical transmission of HIV can be prevented, but do not explain how this is possible; women are left confused. Constraints on nurses' time help explain the impossibility of extensive information. Unfortunately, partial explanations often obscure more than they enlighten. One nurse explains how she addresses women's belief in the inevitability of vertically transmitted HIV:

> Others, they underestimate [the efficacy of nevirapine]. No, I won't take this nevirapine. Because it's not going to assist me, because I'm HIV positive, my husband's HIV positive. And the baby we are making will be HIV positive, because both of us are HIV positive. So, they underestimate the use of nevirapine. So we sit down and discuss with them that the sperms and the ova do not contain the virus. If the virus is to be transmitted it will be transmitted through you, the mother.

When a woman at a focus group introduced this same topic, it became clear that the nurses' explanation is more confusing than insightful. Women see the nurses' information as competing with educational material on the sexual transmission of HIV:

> They [PMTCT program] said that it's not like men transmit HIV to the baby when producing sperms. They said that sperms don't have HIV. So, if the baby is born with HIV, it is because maybe you have hurt each other during pregnancy. But, if they are saying there is HIV in the sperms [i.e. HIV prevention information] that means, in short, we are saying that the baby can easily get the virus because the baby is made with sperms.

In this example, the nurses' explanation of the difference between sperm and semen would also be essential for women's understanding. The development of proven counselling tools and standardized communication techniques would help nurses deliver complex information in accurate, comprehensible, complete, and clear ways, and would also be time efficient for nurses.

Of course, as I have said, misunderstandings are not universal and some women's understandings align more precisely with the medical information. One woman says, "I have heard that the baby stays in a certain bag when it's in the womb, and there is no contact with our blood. Contact is only during delivery and not naturally like that." Significant misunderstandings, though, limit the program's capacity to convince women to participate and take nevirapine.

Experiential knowledge[46] repeatedly emerges as the fundamental and most compelling way women understand the world. That is to say, women come to know about the world through their experiences, rather than through the transmission of theories or empirical facts. As I illustrate below, women grasp information through their participation in a process. Thus, they find their own experience of giving birth to an HIV-negative child more persuasive than hearing of this possibility at the health centre. Equally, women privilege the knowledge of others gained through experience. To combine women's need for ongoing education, counselling, and support with important experiential knowledge, a peer

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[46] In a different anthropological context, Ketler (2000:153) describes experiential knowledge as "knowledge that is either embodied, based in one's own daily practices, or based in the daily practices of other local, familiar persons." This definition fits the way in which I use experiential knowledge in this chapter.

counselling and education program should be considered for PMTCT programs. Peers can provide ongoing counselling, education, and support, to improve women's adjustment to life with HIV, their understanding of the medical components of the PMTCT program, and their capacity to seek timely and appropriate care (Aunt et al. 2006).

A final important component of women's understanding of the PMTCT is their expectations. Misunderstanding the information nurses give and the efficacy of the program components leads either to inflated or deflated expectations (see also Etiebet et al. 2004); both are problematic. While deflated expectations may make women leave the program, inflated expectations cannot be met. Many women believe that adherence to nevirapine will always prevent transmission. One woman says: "I expect, that by participating in the program, I will have my baby, and my baby will be protected. If I didn't join, my baby would just die right away." This woman overestimates the risk of HIV transmission to her child, the immediate impact of HIV on her child's health, and the potential of the PMTCT program to prevent transmission. What will she believe about the program if her child is, unfortunately, infected? Rumours deriving from both misunderstandings and previous clinical trials, discussed below, show how information circulates in the community and its long legacy. Misunderstandings, thus, can limit program success now and in the future.

Despite women's confusion about prevention of transmission and their belief in its inevitability, they do decide to take the drug nevirapine. One woman describes her reason for participating: “I decided to participate in the program, because I’m one of the people who has HIV. And I thought at least my baby should survive, other than both me and my child dying. I heard that the baby can be born without HIV, and that’s why I decided to join.” Women’s inclination to avail themselves to the biomedical model and take nevirapine despite their own understandings indicates the persuasiveness of biomedical knowledge. Jordan’s concept of “authoritative knowledge” (1983; 1997) shows that, while many systems of understanding may exist, one gains authority either because it offers better efficacy or has structural superiority (see also Davis-Floyd and Sargent 1997). The women in my study are oriented towards the biomedical management of pregnancy, delivery, and child health, as evidenced in their high attendance at antenatal care, their preference for delivery at the health centre, and attendance at the under-five clinic. These women thus trust that the nurses’ advice is correct, even if they do not understand its logic. Moreover, they believe that any help with HIV is better than none. Women often say that they participate in the program, because they want to learn something about how to care for themselves and their families, and because they want help: “By participating in the program, I hope that the program will help to keep my life and that of my friend [friend in the house, i.e. husband] and baby. Because, if I don’t participate in the program, I can’t learn much about my life.” Women’s expectations of the PMTCT program and HIV testing, discussed in Chapter Five, are important, because it is against these expectations that women evaluate the program.

As women suspend their commonsense understandings and join the program based on the communicated medical information, they also overestimate the efficacy of the program. Most understand that nevirapine exclusively assists the infant, but a few also believe that it will help them:

> I: Why have you decided to take the drug?
> P: So that the drug should protect me.
> I: How is it that the drug protects you?
> P: It will protect me from being weak at delivery.

Nevirapine works by reducing a woman's viral load prior to delivery and, therefore, reducing the risk of transmission. Nurses explain that the drug is "reducing the number of viruses in your blood" or "making the virus sleep." As women see the virus as weakening the body, some women see fewer viruses or sleeping viruses as making the body strong at delivery.

Based on women's beliefs in the benefits of participation, women have clear expectations of their participation in the PMTCT program: "If I take the medicine [nevirapine], then the baby will be protected. But, if I do not, I will just know that my baby and I we both have the virus." Most women thus overestimate the risk of infection without nevirapine. They also overestimate the efficacy of nevirapine, believing that nevirapine prevents all vertical transmission:

> There is no way the baby can catch the virus, because we were told at the hospital that a study was done and there is no way a mother can transmit the virus to the child with nevirapine. No way through breastfeeding until six months. After six months, it is possible, because the time limit is six months and after this it expires.

Women's understanding of nevirapine as a "very strong" drug, which "makes the virus sleep" illustrates their knowledge of what nevirapine is and how it works.

However, the nuance of its efficacy, left unexplained, leads women to believe that the drug is stronger and more efficacious than it is.

Women also have misconceptions about delivery. These primarily derive from rumours in the community, which cause women worry about what will happen to themselves and their children at delivery. Some rumours directly relate to nevirapine: "I want to know about the drug [nevirapine]. Some women where I stay were saying that, once you take the drug you have complications during delivery or you stop conceiving completely." Worry that nevirapine causes infertility is also relayed as a concern of women's husbands. Furthermore, many women believe that nevirapine hastens labour. One woman describes waiting to take nevirapine until she was at the labour ward, ready to deliver.

> I: Did you take the drug nevirapine?
> P: Yes. I did, but I took it as I was entering the labour ward.
> I: So how long was that before you actually delivered?
> P: It didn't take time.
> I: Why was it that you took it at that time?
> P: They [friends] told me that, when one takes that drug, it speeds the delivery. So, thinking that if I took it here [at home], Likuni is far, I would have delivered on the way. That's the reason.

Beliefs about nevirapine need to be addressed within the PMTCT program. Rumours can make women reluctant to participate in the program and take nevirapine. Beliefs can also lead to women taking it incorrectly: for example, too late for it to be maximally effective.

Women's belief that they will die soon after delivery is supported by nurses' information that pregnancy and delivery weaken the immune system and HIV capitalizes on this weakening.

> I: What does it mean to be pregnant and HIV positive?
> P: It is very difficult for one to be pregnant and HIV positive because, when you deliver, it's the time you start suffering from AIDS. And sometimes you also transfer the virus to the baby.
> I: Why do you think the disease will come out when you deliver?
> P: Because when you deliver, you lose a lot of blood, and the body is weak at that time. So maybe that's why the disease can come out.

Some women also relate deterioration right after delivery to specific rumours about the PMTCT program.

> P: My friends said that, "They say in the program they provide all that is needed for the child. But this program you joined they take your placentas after delivery."
> I: What did the person say happens after?
> P: She said the woman suffers, falls sick for a week, and the other week she dies.
> I: Did you believe her when she told you this?
> P: Yes because I have never attended the program before. This is my first time, and they said this is what killed somebody. Up to now I still hear rumours, that is what happens. That's why I am scared.

After hearing this rumour from many women, I asked the nurses in the PMTCT program if they had heard it. They told me that it derives from a study that had been completed a year before, during which they took placenta samples. Nurses attributed the belief that women will die at delivery to some women who were tested for HIV while already symptomatic with AIDS and who died shortly after delivery. While a lot of rumours circulate, some women find them more compelling than others: "People like threatening people saying, if you take that drug you have complications during delivery. But, as for me, I have never had any complications during delivery." Women's experiences and those of others around them are influential, as they evaluate the information communicated by the program. Women also seek reassurance in their decisions to participate and confirmation of the validity of the information they receive from various sources. An opportunity to talk freely to women who have been through the program, within a support group, would be a powerful way for women to do this, would help dispel rumours, and would strengthen the messages communicated in the PMTCT program. Misinformation, a constant and universal problem, requires more attention from program deliverers and continuous education to dispel myths and rumours.

Barriers to Participation: Access and Integration

The counselling and educational barriers discussed above are only a few that women face in participating in the PMTCT program and taking nevirapine. There are also geographic constraints and system problems. The women in my study received, and for the most part, took the drug; however, accessing nevirapine for their children was more problematic: women who deliver away from the health centre do not have ready access. Women deliver away from the health centre for a variety of reasons. For a couple of women, trips to funerals in their home villages took women away to districts without PMTCT programs. One woman, who delivered prematurely, did not receive nevirapine for herself, and, in both cases, the women did not return to Lilongwe in time for their children to be given nevirapine. Women frequently travel to their home villages to farm, some women go there to deliver because, in Lilongwe without family, they do not have anyone to care for them. Therefore, while women may still receive antenatal care and deliver at health centres, with few PMTCT programs in Malawi, they will most likely not have access to PMTCT interventions.

Women who deliver at their homes in Lilongwe or at a traditional birth attendant's home may also not return to the health centre within the prescribed timeframe of 72 hours for their child's dose of nevirapine.[47] Indeed, to do so, many women must travel far soon after delivery, with a newborn. This is equally a problem for women who deliver at private clinics or mission hospitals. One woman who chose to deliver at a mission hospital did not receive nevirapine for her child, because she had stitches and could not manage the walk to the health centre. I also heard that some women are reluctant to leave the house with a newborn baby, as newborns are seen to be vulnerable to witchcraft and disease. While the women in my study told me that they do not follow the practice of keeping newborns at home, it could help to explain why many other women do not return to receive nevirapine for their babies. PMTCT program staff are now experimenting, providing mothers with take-home nevirapine syrup to administer to their babies. Moreover, including traditional birth attendants in PMTCT programs could increase access for women who deliver with their assistance (Manzi et al. 2005).

A second problem is integration of the PMTCT program into labour wards. At the time of my research the onus was on women to identify themselves

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[47] In Lilongwe District, 44.8 percent of women deliver at home or at the home of a traditional birth attendant (NSO and ORC Macro 2005:141).

as HIV positive to nurse-midwives, who were then to ensure that mother and baby received nevirapine. Some women describe themselves as hesitant:

> I: Did the baby take nevirapine too?
> P: No, but he was dosed when I came here the day before yesterday.
> I: Do you know why the baby didn't receive the nevirapine after birth?
> P: I think the nurse who was on duty didn't see the card for receiving nevirapine.

A new system, introduced while I was conducting my research, identifies women as HIV positive in their health book, rather than on a separate card. This will make women's HIV positive status clearer to nurse-midwives. Surprisingly, many women do not know whether or not they and their children received nevirapine. There is poor communication between nurse-midwives and the women. Women report being given pills but not knowing whether they are nevirapine. One woman says, "I can't know [if child received nevirapine] because, after I delivered, I rushed to take a bath. So I don't know whether they gave her or not, but the nurses from there [PMTCT program] said they would find out for me from the nurses who delivered me. But they never came back to me." While babies should be given nevirapine when they are delivered, some women relay that they had to go to the PMTCT program to receive nevirapine for their children. Other circumstances prevent babies from receiving nevirapine. One woman describes how she feels after her baby did not receive nevirapine because of a strike at Bottom Hospital, where she was referred because of prolonged labour: "I have just accepted that I will care for my baby. Maybe it's possible that, even if I could have received the drug for him, he would have still been positive. So, I just leave everything in God's hands. It's God who cares for everyone." Women who do not receive nevirapine for themselves or their children draw on the inevitability of infection as a comfort for frustration that something could have been done to prevent transmission.

Experience of PMTCT Interventions

As I discussed above, women avail themselves to interventions and believe the advice from the PMTCT program even though it is not fully understood and competes with other ways of understanding the vertical transmission of HIV. Because experiential knowledge is the most powerful way of understanding for women, it is through their successful experience of the PMTCT interventions that they come to truly believe the medical advice they receive.

Prior to their participation in the program, women describe that not knowing about it or the drug, because this is their first time being HIV positive and also their first time being HIV positive and pregnant. As such they do not *know* what happens even though they have been told about the program:

> I: Do you know by how much the risk of transmission is reduced by the drug nevirapine?[48]
> P: I don't know, because I have never taken the drug.

The exchange I had with one pregnant woman gives insight into experiential knowledge:

> I: When you are thinking that you are HIV positive, are there particular things that you think of?
> P: Yes, I think that, after delivery how many days or months is my baby going to live? I don't know, so I wanted to ask you this question.
> I: What do you think will happen in your situation?
> P: I think that after delivery the baby will just be falling sick.
> I: What do you think about nevirapine?
> P: The drug helps prevent the baby from being infected with the HIV virus during delivery.
> I: Are you planning to take that drug?
> P: Yes. Maybe it can help me. But, because I have never taken that drug before, I don't know. But I hear that, during delivery, the baby is prevented from being infected with the virus.

This woman expresses a common ambivalence towards the drug. She has heard that it can help but is yet unsure whether this is true, because her knowledge does not derive from experience.

The experience of giving birth to a healthy baby challenges the belief that babies born by HIV positive mothers are sickly. Such an experience is not

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[48] Information on the probability of HIV transmission and the percentage by which nevirapine reduces it is explained in the PMTCT program consent form, which women must sign prior to testing. Most, however, do not, and indeed cannot, read the consent form, and nurses do not read it to them. This is unfortunate, because the consent form contains most of the information on the PMTCT program. When women asked us questions about the PMTCT program, Cynthia and I often read the PMTCT program consent form to ensure that the information we were transmitting was accurate and consistent with the information they received in the PMTCT program. As women receive the consent form to take home, it was a source of problems for several. Unaware of what the consent form said and its implications, many give it to their husbands to read and, therefore, unwittingly tell their husbands that they had an HIV test. One woman relayed to us that she then had to lie to her husband about her test results. She told him that she was HIV negative, because she was unprepared to disclose her status at that time.

necessarily tied to the PMTCT program. Some women believe that they contracted HIV prior to birthing previous children.

> I: Have your expectations for this pregnancy and this baby changed since you found out your HIV status?
> P: Nothing has changed. It's just the same as for my other babies, because I had been thinking that I got the virus even before I had this child I am with. But I am taking care of him, and he is very healthy. So it wouldn't be good to change expectations for this pregnancy and baby.

For women who believe this is their first delivery as HIV-positive women, their beliefs that they and their child will be sick or die after delivery are challenged immediately after they deliver when they assess their own and their child's health:

> When I was pregnant, I used to worry a lot, because I heard that, when HIV has stayed long in one's body and the immune system drops, you start falling sick. So I thought, after I deliver, I will start falling sick and that maybe my child will not be healthy. But, after I delivered and seeing how healthy I was and my baby, I am just fine. And, the baby born from a person who has not had a test yet and my baby look the same, so I no longer have concerns.

That women survive delivery and stay healthy challenges their beliefs that they will become symptomatic after delivery: "I was worried. I was asking myself that, will I live? Or maybe I will die immediately after delivery. So I now know that God has mercy." Equally, seeing their newborn alive and healthy after delivery confirms that the information they received about nevirapine is true:

> I: How did you feel about the birth of your child?
> P: I was very happy also because of how the baby's health was, because at first I used to think that, when people have HIV, they deliver sick babies.

Despite a healthy delivery, women worry that their babies may still be HIV positive:

> I think about a lot of things. Like, I think of the baby, that she is innocent and, if she contracted the virus, it's bad...Sometimes I feel that the baby didn't contract the virus, but sometimes I feel as if she did. But I have the hope that nevirapine prevented her. I wish my baby could just grow up well without contracting the virus.

Women view HIV as a horrible disease for a baby, because their bodies are too soft and fragile to endure and because the suffering would be too much: "I just feel pity, if she can be positive and to undergo the ailments which HIV people go through." Women also hope that their children will be able to help and support them in the future: "I just wish they don't find her with the virus because, when she grows up, she can be my walking stick."

The majority of women see PCR testing[49] at six weeks as an opportunity to know their babies' HIV status and get further information on how they can best care for the baby, particularly in terms of infant feeding. Only two women in my study hesitated to have their babies tested for HIV. One was concerned that she would be disappointed if her baby was HIV positive. The other wanted to give equal love to all her children, regardless of HIV status.

> I think I got the virus in 1999, because that's the time my husband was promiscuous. So, from that time to now, I have had two children. So if I think of having my child tested, then the love may be less from the love that I have given to the other children. So it's better I don't have him tested and keep him the way I have cared for the other, ignorantly. But I will be receiving drugs for him, but I don't want to know his status.

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[49] PCR testing detects the presence of HIV, rather than antibodies to the virus. It is, therefore, used at this stage, as babies still have maternal HIV antibodies in their blood, making antibody tests inaccurate.

Women guarded against the possibility of discrimination against HIV-positive children. Prior to delivery one woman said:

> My expectations haven't changed. Like now, I asked somebody to knit for me [blanket and baby clothes]. It's just the same. If I hadn't been found positive, the baby could die anyway, and I would still have those things. And, for this reason, it's not good for me to discriminate against this baby. And only God knows. I just have to wait and see what God has in store for me.

Most, however, see having their babies tested for HIV as opening up more opportunities for proper care[50] and alleviation of worry.

All the women in my study whose babies test negative for HIV at six weeks are happy and relieved: "I was so happy. As you know, I was found HIV positive, so I was happy to learn that my child is negative. Because, as for me, I have eaten a lot of *nsima* and he hasn't [she has enjoyed life, but the baby has not]." Another woman describes her relief:

> At first I was thinking that, since I was found HIV positive, that means that my baby may also be HIV positive. But, after my baby was tested, she was found HIV negative. So that was a relief to me, because I was thinking that a baby's body is soft, they have diarrhea. And, if she is positive, she can start falling sick more often and quickly.

Such results also confirm that the information transmitted in the PMTCT program is true: "At first, I used to think it's a lie [that nevirapine reduces the risk of vertical transmission], but because, during delivery my baby had a cut on the leg, I now think it's true in terms of my baby." This woman's experience confirms for

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[50] HIV-positive babies are referred to a pediatrician at the tertiary-care facility for care and the treatment of opportunistic infections. However, at the time of my research, pediatric ART was not available.

her the efficacy of nevirapine. She believes that, without nevirapine, her child would have been infected with HIV through the cut. The importance of experience was consistent in women's stories: "I never used to understand how it can be possible that the mother and the husband are both infected with HIV and the baby is negative, but I believed and understood this after my baby was tested and found negative."

While women find that their children's HIV-negative test results confirm that the drug works, children's HIV-positive results put this into question. One woman who took nevirapine herself but did not obtain it for her son, who was born at home, says, "They told us that, when the labour pains start, we should take the drug. But, as for me, I didn't see the use...The way I see things, I think, even if he could have taken the drug, he would have still been found positive." Another woman whose child tested positive feels equally ambiguous about nevirapine and the PMTCT program. On the one hand, she describes expecting the result because they share the same blood, but, on the other hand, she says, "They say nevirapine helps prevent transmission, and I was surprised that she was found positive." More comprehensive education and counselling about PMTCT would help women understand how nevirapine works, its efficacy, and also the potential for transmission even with nevirapine use. This is important, given the dynamic relationship between biomedical and experiential knowledge that I found. In other ethnographic studies, Abel and Browner (1998) and Ketler (2000) similarly found that experiential knowledge can either extend the authority of biomedical knowledge or call it into question, depending on the convergence or divergence of the two ways of knowing, of communication between care providers and clients, and between clients.

INFANT FEEDING

Women's adherence to the nurses' infant feeding advice is important in preventing the vertical transmission of HIV.[51] HIV-positive women are advised to exclusively breastfeed their children for the first six months and then rapidly wean them to provide the greatest reduction of postnatal HIV transmission.[52] Exclusive breastfeeding is defined as "giving the infant no other food or drink, not even water, apart from breast milk (including expressed breast milk), with the exception of drops or syrup consisting of vitamins, mineral supplements or prescribed medicines" (Hairu et al. 2005). Exclusive replacement feeding, providing no breast milk, is not an option for the majority of women in Malawi

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[51] I deal with infant feeding at length in this chapter, because it is a contentious issue in reducing vertical transmission of HIV. HIV transmission through breastfeeding has threatened the position "breast is best," and has destabilized the success of breastfeeding advocates in countering unethical marketing by international formula manufacturers (see Van Esterik 1989; WHO 1981). Breastfeeding advocates want the risk of HIV transmission to be weighed against the risks of replacement feeding and the benefits of breastfeeding. Moreover, they are concerned that any infant feeding recommendations to HIV-positive mothers will spill over into the general population and reverse advances in the promotion of breastfeeding (Van Esterik 2002; WABA 2006). Indeed, while the PMTCT program where I conducted my research does not give women free infant formula, many PMTCT programs in Africa and elsewhere in the developing world do. In such cases, the onus is on women themselves to weigh their capacity to properly prepare formula against the benefits of breastfeeding. These are difficult and complex decisions for women to make, based on population statistics and contingent medical information (Levy and Storeng 2004). However, as I explore in this chapter, even when women do not receive free formula, difficult decisions still arise, which require a nuanced analysis in order to move towards appropriate, feasible infant feeding recommendations and support for HIV-positive women.

[52] As I discussed in Chapter Five, this is the best way to minimize the risk of postnatal HIV transmission in settings where adequate resources to successfully replacement feed are inaccessible to most. Exclusive breastfeeding maintains the integrity of the infant's gut lining thus reducing the risk of infection. At six months of age, when supplementary food is introduced, cessation of breastfeeding is recommended because mixed feeding increases the risk of HIV transmission.

because of the prohibitive cost of formula and fuel needed to prepare it correctly. Moreover, all Malawian women see breastfeeding as the natural, best way to feed their children.[53] Yet, exclusive breastfeeding does not predominate in Malawi or elsewhere in Africa (NSO and ORC Macro 2005:163-168; Ssenyonga et al. 2004; Taha et al. 2006; Vaahtera et al. 2001). Non-exclusive breastfeeding, or "mixed-feeding" is the most common infant feeding pattern, and is defined as "giving a baby some breast milk and also any other fluid or feeds, even a teaspoon of water" (Hairu et al. 2005). Without adequate education, therefore, many women do not exclusively breastfeed. Moreover, it is significantly harder for women to adhere to the weaning advice because of resource difficulties, which may indeed make early cessation of breastfeeding inadvisable.[54] Infant feeding is thus a vexing issue for women, because they feel guilt over potentially transmitting the virus and frustrated that they are unable to follow the best advice on how to feed their children.

Women's belief that breastfeeding is the best way to feed their infants is confirmed by the advice that they receive from the PMTCT program:

I: Why have you chosen to exclusively breastfeed?

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[53] Ninety-nine percent of children in Malawi are breastfed for at least one year (NSO and ORC Macro 2005:165).

[54] As the median duration of breastfeeding in Malawi is 23.2 months (NSO and ORC Macro 2005:165), early cessation of breastfeeding poses a new challenge for HIV-positive mothers. High rates of malnutrition and micronutrient deficiencies in Malawian children suggest that nutrition counselling and support should be at the forefront of PMTCT interventions. In Malawi, 48 percent of children under five are stunted; 60 percent are vitamin-A deficient; and 60 percent of children under three have iron deficiency anemia (NSO and ORC Macro 2005:171-179).

> P: That is how it is supposed to be. Formula milk is not very good for the baby until six months, when you can even give the baby porridge and other things.

Two women, who reported being unable to breastfeed because of problems with their breast health and shortage of milk, understood replacement feeding as a less than ideal way to feed their infants in the early months of life.

While most women breastfeed, mixed feeding is common. Women's choice of exclusive or non-exclusive breastfeeding in the first six months relates to their understanding of the infant-feeding advice, and competing beliefs about infant feeding. Those who receive adequate explanation and understand the advice well do succeed in exclusively breastfeeding their children: "I will follow the advice which I have been given, that I shouldn't give the baby any other foods until six months, then stop breastfeeding." Many women see adherence to such advice as preventing HIV transmission:

> I: How are you feeding your baby?
> P: I am only breastfeeding.
> I: Do you give her anything else?
> P: No. Not yet.
> I: Why have you chosen to exclusively breastfeed?
> P: That's the advice I was given at the health centre when I was being discharged [after delivery]...Because I was found HIV positive, so if I give the baby other foods, then the baby can contract the virus.

These women, even when I probed, say that they do not feed their babies anything other than breast milk. More common, however, is confusion about postnatal transmission (elaborated below) and other definitions of exclusive breastfeeding, whereby women describe themselves as exclusively breastfeeding but mention giving their babies water or gripe water to relieve what the mothers perceive as babies' stomach pain.

> I: I see you are breastfeeding. Do you give your baby anything other than breast milk?
> P: I only give gripe water, because she cries a lot, so I think that she cries with stomach pains.

Some women also give their babies water, which they believe is important for the intestines and stomach to grow and to prepare their babies for their future diets:

> I: Why do you give water?
> P: So that the intestines can open up, I give her warm water...That is to prepare her for the future. Because, if the baby doesn't take water now, then when she grows she will be refusing even to receive porridge.

These women do think of themselves as exclusively breastfeeding and therefore believe that they are reducing the risk of HIV transmission. A clear definition of exclusive breastfeeding is therefore an important component of the advice.

My research also demonstrates that the rationale for the advice is also important to achieving exclusive breastfeeding. Some women describe giving their children other foods, knowing that they are not exclusively breastfeeding, without realizing the importance of exclusive breastfeeding for the reduction of HIV transmission:

> I: Did they tell you why it is important to exclusively breastfeed for six months?
> P: No they just told me to exclusively breastfeed for six months, but they didn't tell me the reason why.

One woman in a focus group describes her experience:

> When I delivered, they told me that I shouldn't give my child anything apart from breast milk until I wean him. But I didn't

> understand the reason why. So sometimes, when the baby was crying, I used to buy him yogurt. Then one day when I went there [PMTCT program] and they asked me, "Why is your baby growing fat like that?" "I told them that it's breast milk and yogurt. So they told me to stop giving yogurt." But, again, I didn't know the reason why. So, this other day, it was a certain nurse who told me that my child has sores in the mouth because of the yogurt and in the milk there is HIV. So, if I continue, my child can contract the virus through breast milk and the sores. So I thought they wronged me, because they didn't explain to me very well in the first place. But, luckily enough, when I had him tested for the second time he was negative. But I had worries that I had breastfed him while giving other foods.

Exclusive breastfeeding advice must be well explained and sufficiently compelling to compete with alternative beliefs about infant feeding, such as the need for gripe water to soothe stomach pain, water to help the intestines grow well, and other foods to ease hunger. My research shows that, when women understand the advice well, they do succeed in exclusive breastfeeding. Problems emerge, however, when there are misunderstandings. As postnatal transmission of HIV is significant and malnutrition equally so, good infant-feeding counselling is vital in a comprehensive PMTCT program (Doherty et al. 2006). This is especially important, given Chopra et al.'s (2005) finding that inadequate infant-feeding counselling frequently leads to mixed feeding.

Misunderstandings about the exclusive breastfeeding advice and the risk of transmission seem significant. Many women assume that the baby can contract HIV through breast milk. "I keep asking myself that I will breastfeed. Can't the baby catch the virus through the milk? Maybe, in the near future, they will tell me what is going to happen." Being told to exclusively breastfeed to prevent transmission leads some women to believe that there is no chance of HIV transmission during exclusive breastfeeding. They do not necessarily understand how this is possible, because of the presence of HIV in breast milk. Significantly, many women attribute the prevention of HIV during this period to drugs, rather than exclusive breastfeeding. They believe that nevirapine expires at six months, and that is why they are to wean the babies at that time. One woman says, "When the mother and child are taking nevirapine you can breastfeed, and the baby will be fine. Yes, there is a chance of transmission, but it's only possible if you exceed six months of breastfeeding. At six months the nevirapine expires." Women also attribute prevention of HIV during the first six month to co-trimoxazole, an antibiotic given to babies to prevent chest infections:

> I: How do you feel about the possibilities that your baby can still catch the virus through breastfeeding?
> P: As of now it's difficult but they have given me the medicine which they said can prevent her from being infected. But, after six months, I will follow the advice which I will be told. Because, if I don't, after six months the baby can contract the virus.
> I: Which medicine is that you were given?
> P: Bactrim [co-trimoxazole].

This belief may make women place less emphasis on exclusive breastfeeding.

The other advice on infant feeding is for women to wean their babies at six months when other foods are introduced. Women well understand this information and the risk of HIV transmission after six months of breastfeeding: "We heard the advice that we should stop breastfeeding our babies at six months, and the message is in our ears. But I think that to stop breastfeeding the baby at six months is difficult." The difficulty is that most women do not feel that they have adequate alternatives to sustain their babies after six months. They must thus balance the infant-feeding advice from the PMTCT program with their knowledge of breastfeeding's importance to overall child health and nutrition.[55] Women must thus evaluate what is possible within their lives.

> P: It's difficult to stop breastfeeding the baby when he is still small.
> I: What makes it difficult to stop breastfeeding when the baby is still small?
> P: They say breast milk is the best food for the baby. Porridge is nothing, so the baby starts swelling because of lack of food.

Another woman says,

> I: I don't want to stop breastfeeding at six months, and I don't think I will manage to stop breastfeeding at six months.
> P: Why don't you want to stop at six months?
> I: Because, at six months, the baby is still small, and if I can stop breastfeeding at six months, the baby will not be healthy.

The above women were unusual. Most women recognize two health threats: HIV transmission and malnutrition. The threat of HIV is more dominant. Therefore, most women intend to cease breastfeeding at six months. One relays: "I plan to continue breastfeeding, but at six months I will start buying formula milk." One woman whose husband recently died communicates women's determination to terminate breastfeeding at six month:

> I: What are you planning to do about breastfeeding?
> P: I am planning to stop breastfeeding when the baby turns six months and introduce her to other foods.
> I: How do you think that you will manage?

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[55] Increased morbidity, infection, diarrhea, and malnutrition are all potential outcomes of poorly managed weaning, this is referred to as the "weaning dilemma" (Abiona et al. 2006) and indicate that proper counselling and education as well as support for weaning must accompany nurses' advice to rapidly wean at six months (Doherty et al. 2006).

> P: I cannot say I will manage fully/properly, but I will still do it, though with problems.
> I: What problems are those?
> P: I am saying that, because as of now, I am alone and I cannot manage. But, had it been that my husband was alive, he would have been managing all. But now I have to wait for other people to do things for me, and they cannot manage everything.

Women, therefore, at least attempt to follow the advice, even though they are aware that they may have to return to breastfeeding. As my study finished before this woman's baby was six months old, I cannot relate how her story played out.

Stopping breastfeeding early in the context of poverty and inadequate food is in the end impossible for most women, despite their initial intentions. One woman in a focus group says: "I have been in the program for quite a long time, and we were advised to stop breastfeeding our babies at six months. But I failed to wean my baby that early, because I can't afford to buy formula milk for the baby for the whole month, because I don't have money." Lack of money to buy formula is their major barrier to terminating breastfeeding: "I had decided to breastfeed for six months but, because of lack of money to buy formula milk, I have continued to breastfeed him." Women's exclusive focus on formula milk suggests that counselling does not properly assist women to assess locally available, affordable alternatives, including properly prepared animal milk. Such education is important regardless of the age at which women wean. Many women thus delay weaning until they believe that their children can survive without breast milk or formula: "I will soon wean him, because I was waiting for him to grow a bit. Because, if I wean him now, then he would need formula milk and other things. So I just want to wait a bit, so that he wouldn't even need formula milk. Soon he will stop." One woman whose child is 15 months old says, "As for me, I think I am going to stop breastfeeding my baby this coming March, because fresh maize is going to be ready for eating." Women's resources determine when they are able to stop breastfeeding: a few stop at six month, most continue beyond that.

Women are convinced that, given enough money they could terminate breastfeeding at six months. "As for me, it's support that I don't have. I can stop breastfeeding my child today, but I will not have food to feed my baby." Although women discuss the cultural norm of breastfeeding for two years, they say that, as HIV positive women, it is better to stop earlier even if they are stigmatized because of the association with HIV: "Stigma can be there, because people ask a lot of questions about why you are not breastfeeding. But you know how to answer yourself." Women have ready responses to inquiries about why they have stopped breastfeeding: "I can lie to them that I have fallen pregnant," "I will be telling them that there is no milk in my breasts," "I will tell them that the baby was refusing to suck breast milk." Another woman says that she would simply tell people the truth: "I would tell them the truth that I have a disease that I don't want to infect the baby with, for her betterment." Some women explain that protecting their child's health is more important, even if they will be stigmatized: "No doubt, stigma would be there. But the most important thing is that you and your baby are healthy." That some women do successfully wean their children early is further evidence that money, rather than stigma or specific beliefs about infant feeding, is the greatest barrier. One woman describes this as difficult, but possible:

> As for me, I stopped breastfeeding my child, because I wanted to follow the advice that we are told at the PMTCT program. Not that I have a lot of money to feed the baby. They told us to breastfeed only for six months because, that time, chances of being infected are slim. Because sometimes the baby can be infected through milk...Sometimes I feel bad [about not breastfeeding], more especially when the child is crying uncontrollably. But, because I wish my child good health, I just leave everything in God's hands. Because he is the one who cares for everyone.

Women who decide to cease breastfeeding early and have the resources to do so report that they are able to achieve exclusive replacement feeding.

Infant feeding decisions are worrisome for HIV-positive women because of their knowledge that breastfeeding increases the risk of transmission. This is true even when women are primarily or exclusively breastfeeding and becomes more worrisome as the child ages:

> I worry, because I am breastfeeding my baby. And I feel bad that maybe I may infect her with my HIV. And I feel that I am ruining her future and infringing on the baby's rights. Because a baby has the right to grow up and go to school. But, because I am feeding her infected milk, she can die quickly, since another way of transmitting HIV is through breast milk.

Worry and frustration turns to guilt after six months for women who are unable to cease breastfeeding: "We feel bad thinking that, as the baby is being breastfed, he or she can contract the virus in the process." Women also blame the PMTCT program for their undue burden: "I feel this advice is very painful, because they are asking us to stop breastfeeding our babies at six months. But we don't have money or milk to give to our babies, so this really is very painful to us." More help is needed to actualize the infant-feeding advice: "I think there is unfairness because, if they know that the baby is to stop breast milk, then they should find us an alternative solution. Because, on our own, we can't manage." Women see the advice as inappropriate to their situation: "This advice which we were given by the doctors is good, but only somebody who has money can manage to follow the advice, not us." PMTCT program staff are aware of the dilemma. The program manager says,

> We counsel these women to stop breastfeeding their babies at six months of age. But, if we look, the socio-economic status of our country, the baby needs to have some supplementary foods after six months. But, at the same time, we counsel that mother to stop breastfeeding. She doesn't have something to give the baby, so some babies also develop malnutrition because they have nothing. So, as a program, the challenge is that we have nothing to supplement these women but, at the same time, we are giving them the information that, if they continue breastfeeding at the same time as supplementary feeding, they increase the chances of HIV infection in the babies. So that's also the main challenge.

PMTCT program staff thus advise on infant feeding regardless of the inappropriateness of the advice, without adequate education or nutritional help for women to use the best possible method of infant feeding, to both reduce malnutrition and risk of HIV infection. Moreover, they download responsibility to women who have the least capacity for appropriate and sustainable infant feeding from international and national health systems that have much greater capacity. Support to mothers must be a vital component of comprehensive PMTCT programs, to maximize the reduction of HIV transmission and safeguard infant health.

HEALTH SEEKING AND HEALTH SYSTEMS INTEGRATION

Preventing vertical transmission of HIV is not the only health concern of women in my study. They also have to address their own general health and that of their children. Accessing adequate care is often frustrating. Although the PMTCT program is part of women's health seeking, their efforts extend beyond it. This is necessary in part because the PMTCT program is not integrated into the wider health systems and thus narrowly defines its health concerns. Distance to the government health centre, service availability, quality of care, and drug and staff shortages mean that women often seek health care at multiple public and private health clinics.

Although women diagnosed with HIV in the PMTCT program are primarily seen as asymptomatic and therefore not referred for further care and antiretroviral therapy, they are often sick with coughs, diarrhea, fevers, malaria, skin rashes, and other concerns for which they must seek care.[56] Most women accept the PMTCT program staffs assessment that they do not yet have AIDS; however, some are dissatisfied, illustrating the primacy of embodied knowledge over authoritative knowledge:

> P: When I came for antenatal, I was told that the virus hasn't yet started in my body, but it will start.
> I: What do you think they meant by that?
> P: As for me, in my own thinking, I think the virus has already started but, because of my condition [pregnancy], maybe they didn't want to disappoint me. But the way I feel myself, I

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[56] A recent study at another site in Malawi found that one-third of women who test positive for HIV in antenatal and post-natal care are eligible for ART, based on CD4 counts and WHO staging (Fitzgerald et al. 2006). This rate emphasizes the need for greater health assessment of women in PMTCT programs, so that they can be referred for ART if needed.

> continuously get ill – diarrhea two to three times a month – so I just feel they have hidden it from me. But I told them just to tell me the truth.

Women's care seeking is often prolonged. Many describe first seeking care at the PMTCT program when they are sick. Indeed, this is the care-seeking rhythm communicated by PMTCT program staff: that PMTCT program staff will attend to the health complaints of women and babies registered in the program. In reality, however, women often wait to see nurses there only to be referred to the government outpatient clinic. This indicates that services may be poorly integrated, even when they are at the same facility. One woman in a focus group says,

> As my friend has already said, there is no assistance. When you go there with a problem [PMTCT], they tell you that you should go to the government side, saying the problem is beyond their capacity. And, when you go to that [government] side, you will find a long queue and you are not assisted. So I feel it's not good for them to be telling us to come to the program. It is better we go there [government out-patient clinic] as ordinary people. They told us that, after we were found with this problem, they will take care of us, but they don't meet our needs. So it's better they don't tell us to go there, because there is no help at all.

Women find this process frustrating and time consuming. Given their HIV status and pregnancy, they feel it is too laborious to stand in long lines and crowded hallways waiting for care. "We people are already weak so, if we stand in a queue for a long time, we can easily fall or be pushed."

Drug shortages are a significant problem for women without money to buy them on their own. Some women say that PMTCT program staff give them drugs if the government clinic is out of stock. Other women travel to multiple clinics seeking care:

> There was a time I came and was sent back. The other day, I came again with my child. They told me to stop coming here [PMTCT program], saying I should be going to that side [government]. I felt bad, because there were no drugs. I came again, but still it was the same thing. So, I just decided to go to Area 18 Health Center myself, and there I was assisted.

Women find it equally problematic to receive vaccines for their children; the health centre was often out of stock. When women's attempts to access care take them to multiple clinics, transportation and the cost of services at private hospitals is burdensome: "If you stay far away from the health centre, you have to go to a private hospital. But if you don't have money, you will continue falling sick, and normally these government hospitals don't assist you." Women who are referred to the government-run tertiary-care facility for more specialized treatment also have to pay for transportation: "Everything needs money. To go to the hospital, Kamuzu Central, we need transport. Because we cannot go by foot to central hospital, so that also is a problem." Transportation costs also hinder women's access to ART.

The poor integration of health services, continuity of, and quality of care seriously limit women's access to ART. Since July, 2004, ART has been freely available in the public health system at a limited number of sites. In Lilongwe, at the time of my research, it was freely available at Lighthouse, a tertiary-care facility for patients with HIV. ART is available to those who have evidence of advanced HIV.[57]

Women in my study, however, had countless questions about drugs to treat HIV, how to access them and where. Many asked what they could do to prolong their lives: "What I want to know is that, since I have been found positive, what can I do to at least live for some time?" Another woman asks, "My question is, between now and the time of taking nevirapine, can't we take other medicines?" Many women are not aware that ART is available in Malawi: "My only hope is that life-prolonging drugs can be available. Then I will be able to care for my kids." Some women do not know that they are freely available, or think that the CD4 test must be paid for and is expensive:

> P: We need drugs so that we can live longer before we start falling sick.
> I: Do you think those drugs are accessible to you now?
> P: I have heard that these drugs are very expensive, and a person like me cannot access them.

Confusion about the availability and affordability of ART is widespread. Another woman says, "People are saying that you have to pay something to have a blood test [CD4 test]. So some of us we have money problems, and I heard that even the drugs you buy." With such misinformation, women are unlikely to actively seek ART. This is significant because, as I discuss below, they may fall through service gaps if they do not request referral to or go to Lighthouse on their own.

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[57] The criteria for access to free antiretroviral therapy in Malawi is a CD4 count below 200 (if asymptomatic) or a clinical classification in stage 3 or 4 of WHO's clinical-staging guidelines.

Even women who are aware that ART is available are not sure how to access it or are confused about why they have not been offered it. "I have heard on the radio people asking questions on how they can be assisted on the issue of HIV. And I also hear that, in the hospitals, there are drugs which are allowing people to live a bit longer. So my question is, how can I be assisted?" Information on free access to ART is spreading throughout Malawi, but individuals are still unsure how to get it: "I was wondering that, what is the hospital assistance? Can't they give us the drugs? Even at home, people were asking me that, I am HIV positive but I am not on drugs – what's happening?" Women want to safeguard their health and receive the best possible care but are not sure how to get it: "I wish I could be assisted medically, but I have never gone there. And I don't know where to start from." In interviews and focus groups, women actively seek information: "I just want to know that, what way should we take when we start falling sick and becoming weak?" Such questions are surprising, as they come from women active in the PMTCT program who ought to have gotten this essential information.

Women classified as still healthy wonder why they cannot yet receive treatment: "They are giving drugs to people who have started showing signs of AIDS, not people like me who have just been diagnosed HIV positive. So I just wonder that, how can I get access to these drugs?" For women trying to safeguard their health, the provision of ART to those with advanced HIV counters their preventive efforts: "I understand that those drugs can only be given to people when they start falling sick. So I was just wondering that, why not give us now, rather than waiting for us to start falling sick? Why not now so that we can live longer?" Adequate information on ART – how women get it, and when they must ask for it – is essential. Assumption that pregnant women are healthy and do not need ART must also be questioned. The ability to manage one's own health with HIV is promoted as a benefit of testing and, indeed, motivated women to test.

Knowing how to get ART is important, as it is unclear whether the existing referral system effectively allows women who need it to get it in time. PMTCT program nurses or the clinical officer in the outpatient clinic are responsible for referring women to ART; however, few women in my study have ever been referred. Women who leave the PMTCT program without referral to ART have even grimmer prospects than those in the program, as they are more likely to be lost in gaps between services. The director of international programs at the Lilongwe HIV Program says,

> When a woman at the end of her program or involvement with us, if she has not reached the point where her clinical symptoms indicate she should be referred, you know there is a risk that she won't recognize or may not have regular contact with the health care system and may not be referred appropriately and may not seek care in a timely manner. That's clearly a risk. It's not something we can directly do something about, other than to continue to work with the district health centres and the DHO [District Health Office] and the Ministry to work with the scale-up program, which we're doing.

PMTCT program staff narrowly define their mandate. They understand that vertical programs result in limited care, especially given poor integration between services and deficiencies in the whole health systems. However, they see these as systems issues beyond their direct purview.[58] In part, PMTCT program administrators explain how they draw boundaries in terms of resource limitations. The director of international programs continues, "The reality is, every now and then, you run into a limit. You can do this, but not more than that." However, women, left in the gaps between patchwork services, who view their bodies holistically and not as disconnected parts, feel abandoned when their care finishes and they have no clear prospects for continuous comprehensive care elsewhere.

This is equally a problem for women in the postnatal support group, where women gain support and share how they live with HIV.[59] One woman says, "In the support group, we are teaching each other how we can live positively, how we can care for ourselves, our bodies, and also our families." Another woman says, "This support group is important, because it helps us to reduce concerns, as opposed to when we are just at home worrying, whereby you end up falling sick and losing weight." First, benefits of the support group are limited because women may only join after they have given birth. Immediately following HIV diagnosis, women could also gain substantially from participating in a support

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[58] The MTCT-Plus initiative, a discrete PMTCT program currently operating in 13 countries, aims to address poor integration among health services by offering women, as well as their partners and children, comprehensive care within PMTCT programs, including care not traditionally part of HIV care. "The concept of MTCT-Plus was shaped by the recognition that early programs to prevent mother-to-child transmission (PMTCT) of HIV often provided minimal care or no care to HIV positive mothers, missing an obvious opportunity to promote women's health and prolong their lives, repeating similar shortcomings found in maternal and child health programs" (Myer et al. 2005:138). Replication of this model in Malawi would benefit women there, would address the poor integration of health services, and capitalize on women's participation in PMTCT programs to give them comprehensive health care, psychosocial, and nutritional support.

[59] The support group meets monthly and is facilitated by two community nurses. Its mandate is to focus on infant feeding counselling; however, the support group members discuss a variety of topics.

group. Second, women must leave the support group (and the PMTCT program) when their children are 18 months old.[60] The program staff's expectation is that women will receive support from community organizations. However, in this area of Lilongwe, there are few support services and women face the prospect of no further support. This is an additional concern as support services are an important way for women to receive current information. Making adequate support available could facilitate women's timely access to ART, as has been evinced elsewhere in Africa (Besser et al. 2006). PMTCT programs could also utilize Farmer's (2001) *accompagnateur* model of community-based care to bridge gaps between services.[61]

While resource constraints are certainly one challenge in providing PMTCT services, the biomedical definition of HIV and its vertical transmission compound staffing resource constraints. In defining HIV as a medical issue, the PMTCT program staff focus on medical treatments. There are, however, no clear boundaries between distributing nevirapine, attending to the psychosocial and educational needs of women, addressing transportation and other barriers, and poverty, particularly food insecurity. These are interrelated problems and the success of PMTCT and other HIV interventions will depend on their capacity to address them all. Moreover, nurses do not need to provide all services, as is the current practice. Pre- and post-test counselling, the support group, and community

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[60] Women whose babies die are discharged from the program and the support group. This causes stress for women in that situation, who feel that they still have to cope with their HIV status: "I thought that is discrimination. I did not choose that my child should die."

[61] Importantly, Farmer (2006) is clear that community-based-care providers must be paid, so as not to put a burden on poor communities and families by seeking volunteers.

outreach can be successfully accomplished by trained counsellors, as Malawi does in other VCT centres. This would cut costs, allow more staff to be hired, and make desperately needed nurses more available for biomedical care.

Malawi's health systems are under strain from inadequate funding and staff shortages, which impact on the quality of care. At the Area 25 Health Centre, between 300 and 400 patients visit the out-patient department each day. The clinical officer and medical assistant report that they are only able to spend a few minutes with each patient. They describe the stress and burnout that results and their frustration at not being able to provide better care. The head of UNAIDS in Malawi at the time of my research describes Malawi's health system:

> There is a crisis situation within the Ministry of Health. Health centres are closing, because there are no people to staff the facilities. Vacancies in some category of workers within the Ministry range from 50 percent to 100 percent and, if you're going to be able to scale-up testing and treatment to 50,000 Malawians, you need health workers. It's very simple. And, if you continue to lose your health workers to competitors in the country such as civil society, the UN, the donors, the bilateral missions, and you also lose some to outside of the country to the UK, you will not have the health workers that you need. So, I think one of the biggest challenges that must be addressed, and is being addressed, is the business of human resource.

In Malawi, as elsewhere in Africa, donor-funded vertical programs operate in the midst of a crumbling public-health-care system (Palmer 2006). Indeed, they often contribute to the deterioration of the public health system insofar as they divert financial and human resources from the government health system rather than feeding funds through it (Pfeiffer 2004; Schneider et al. 2006).

Staff shortages impact the quality of care that people living with HIV receive and the capacity to provide ART. Even once individuals are referred for the therapy, congestion from the great demand causes significant delays in initiating treatment. At the time of my research, people had to wait several months before they could be evaluated for ART eligibility. The director of international programs of the Lilongwe HIV Program describes the situation:

> You're talking about these gaps. These gaps are everywhere; it certainly creates a gap while someone's waiting. People get sick very quickly, you know, and don't have time to wait...Evidence shows that...those who are lost are lost within the first three months. And that suggests that people are presenting for treatment when it's too late. That's going to be a huge challenge, because the district doesn't have the kind of resources that everybody would like for them to have – and be able to follow women and do the staging (the WHO staging of HIV disease) and recognize clinically when someone needs further evaluation. It's not going be flawless, I'm afraid.

The Malawi government is working to address its health systems and human resource crisis, and, in 2004, launched the Essential Health Package, including a major investment in HIV services. Moreover, donors have committed to better coordination and a basket-funding agreement for health, the Sector Wide Approach (SWAp), to support the government in its health systems development, particularly the human resources shortage (Conroy and Malewezi 2006; Palmer 2006).

Offering ART at only a few sites also impacts women's ability to access it.[62] Lighthouse, in the centre of Lilongwe, takes one or two minibuses to reach. This costs women significantly in time and money. Moreover, they visit Lighthouse many times: for initial assessment, CD4 testing, antiretroviral therapy education, and then regularly to receive the drug. For many who are poor, free ART may still be too costly (see also Zachariah et al. 2006).

DISCUSSION

Focusing on women's experiences of health interventions illuminates the way in which users view services. Drawing on women's experiences of health services after diagnosis in a PMTCT program, I delineated barriers they experience in attending to their health, HIV status, and preventing transmission to their children. Following the salient themes of women's discussions, I focused on supply-side barriers. The program's achievement of its goals is limited, as evidenced by low follow-up rates, which I attribute to the narrow mandate of the program and its biomedical definition of health and illness. Moreover, for women diagnosed with HIV in the PMTCT program, poor education, psychosocial support, integration with the health systems, and holistic care means that they do not realize the benefits of HIV testing and the PMTCT program. Nor are their own health needs met.

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[62] In Lilongwe, 70 percent of women identify problems in accessing health services. Over 50 percent identify getting money for treatment, distance to health facility, having to take transport, and cost of transport as barriers they face (NSO and ORC Macro 2005:159).

Comprehensive counselling, support, and education are needed and must become core components of the program, not luxuries to be added on if money, time, and resources allow. Women need extensive information on the risks and probability of transmission and how interventions, including nevirapine and the infant-feeding advice, can reduce them. While this information is complicated, women do want to understand. In fact, inadequate communication of information reduces women's participation in the program. Although nursing resources are limited, the PMTCT program can employ trained, lay, health care staff, such as peer educators and community health workers. The over utilization of nurses to date reflects the program's dominant biomedical view. Peer counselling and education are a particularly fruitful avenue, given the importance of experiential knowledge to women. Beyond education, good psychosocial support for adjusting to life with HIV, dealing with poverty, microcredit and income-generating programs, and attention to nutrition and food insecurity must be mainstreamed. These factors impact women's ability to fully engage in the program and address their overall health.

Addressing the health of women living with HIV in the broadest sense also means integrating existing vertical programs to form a comprehensive, seamless health system. The current patchwork of services places an undue burden on those requiring care to seek it at multiple sites. Women's own health is particularly marginalized within the existing PMTCT program. Thus, they frequently fall into gaps between services. Adding support services and integrating with other health services would move the PMTCT program beyond its focus on infants. Women's health should not be viewed exclusively as an avenue to ensure the health of their children, although, ultimately, ensuring women's good health will improve infant health.

Importantly, even with existing barriers, women who continue in the PMTCT program report achieving specific health goals. They do also have favourable appraisals of the program:

> The program is really helping a lot, because, in the past, people used to fall pregnant without any help. But now they provide nevirapine, which prevents the baby from being infected by the virus. And also, after the baby is born, it is given the drugs to prevent it from pneumonia. And, for me, I can say that it has really helped me, because, had it been I didn't take part in the program in the first place, maybe by now my child would have the virus.

This statement reflects women's desire to concretely address HIV within their lives and their perception that the PMTCT program is an avenue to that end. Women availing themselves of these interventions cannot, however, be taken for granted. Program staff must strive to meet the expectations of all women who decide to be tested for HIV. Moreover, PMTCT programs hold much promise beyond their direct mandate to reduce vertical transmission of HIV (as I discussed in Chapter Five): to improve women's health, strengthen health systems, confront stigma, and recast HIV as a "normal" disease. Narrowly delivered PMTCT programs fail to meet these goals and thus leave their full potential unrealized.

CHAPTER EIGHT – BODILY MONITORING AND REGULATION: PRESERVATION OF LIFE STRATEGIES

INTRODUCTION

The multiple ways women self-monitor and regulate to prolong their lives and live well with HIV are the focus of this chapter. These are primarily based on the positive living advice given by nurses in the PMTCT program: eating a balanced diet, reducing stress and worry, using condoms, and not reproducing. Based on women's knowledge of the symptoms of AIDS, they engage in reflexive practice, constantly assess their own health, and look for indications that they have begun suffering from AIDS. To ward off AIDS they adhere to the positive-living advice, which is intended to empower women by giving them control over their illness. Women, however, struggle to live positively because of economic and gender realities (Levy and Storeng 2007). The individualized view of health at the base of the positive-living advice cannot produce the promised outcome, because its promoters do not recognize the structural context of health. In this chapter, I critique current regimes of living with illness as products of neoliberal economics, with their predilection for health promotion and "morally correct" health monitoring through self regulation, even of chronic disease.

In this chapter, I also demonstrate that women's prevention efforts continue after HIV diagnosis. In using the term "prevention," I incorporate women's language to describe how they try to maintain their lives and postpone death after an HIV diagnosis. Moreover, I emphasize how certain strategies, such as encouraging husbands' faithfulness and condom use, are more successful after

HIV diagnosis. While women may not immediately be able to convince their husbands to use condoms, their dialogue on condom use and work towards this goal is ongoing. Women feel that strategies to prevent re-infection, accompanied by other recommendations for positive living – not bearing more children, eating a balanced diet, and reducing worry – will prolong their lives. Women interpret "knowing your status" as a means of preventing imminent death from HIV and safeguarding the remainder of their lives for themselves and their children. As I discussed in Chapter Five, this is an explicitly communicated goal of HIV testing.

MONITORING OF BODILY HEALTH

Women see monitoring their health post diagnosis as one of the advantages of knowing their HIV status: "When I think of my HIV status, I think that I should be coming to the hospital more often so that I can be told what to do – like do ABC – so that I can live a few more years." This is the informed position women seek through HIV testing: "People who don't have the virus, they don't want to listen to the advice. But those who have the virus try to listen, so that maybe they can live a bit longer." Women often communicate the importance of experience for true understanding. After diagnosis, therefore, they monitor their bodily health and compare it with both their previous health and their knowledge of HIV progression. Monitoring allows women to be proactive; however, it is also a source of worry as women are constantly assessing each illness against their expectation of imminent health degeneration – the onset of AIDS: "The problem is worrying, because if you have malaria you start worrying thinking you have started falling sick." Women describe this constant worry as the downside of knowing their HIV status.

Women's knowledge of the illnesses of HIV comes from experiences in their families and communities, where they have all known people that they suspected had AIDS. This knowledge, and multiple public health campaigns, has created significant awareness of AIDS symptoms: "It's the sicknesses or the ailments the HIV positive people pass through. They have severe diarrhea, so that people easily notice them, that they are HIV positive, and soon they develop AIDS." Women in my study describe the symptoms that they attribute to AIDS:

> P: Signs can tell that this one has the virus, this one doesn't.
> I: Which signs are those?
> P: Hair becomes very light, lips too, thinness and some sores.

In Malawi, being fat is a sign of good health and demonstrates the body's capacity to ward off infections (see also Bentley et al. 2005). Weight loss, thus, has significance as a sign of AIDS. Those who are wasted with AIDS are called "hangers," because they are all bones, and their clothes look like they have been hung on a wire hanger. It is with such images that women compare their own health:

> It all depends on the sequence of the illnesses. For example, today headache, sore legs, malaria, etc. That way you may think you have started falling sick. But, if it can be after a month, then you can't worry. I hear that, when you start falling sick more often, say everyday, that and you suffer from different diseases. And this time your immune system is weak. That's when you start worrying.

While women find illness a more acute marker of possible deterioration, they also monitor more subtle changes. One woman considers her weight loss, despite her health, as a sign of advancing AIDS. She remembers always weighing 65 kilograms before her last pregnancy, and now she weighs 60. Of equal concern to her is that others have noticed this change: "They [friends and neighbours] are even telling me that I have deteriorated in terms of weight as compared to before. So I am just telling them that it's because I am breastfeeding." Other women point to skin rashes, numbness, and cessation of menstruation as initial signs of AIDS.

Pregnant women expect that they will begin to suffer when they give birth, that the virus will capitalize on their blood loss and weakness: "What I personally feel is that, the moment I deliver, it is the time the disease will come out and I will start suffering." Women are thus waiting for the beginning of AIDS: "I know that I have the virus, I am just waiting for the time to start the journey [death]." Illnesses lead women to worry that they have begun to suffer, while recovery provides them with renewed hope: "I do have concerns, such that I feel scared and discouraged. Because, when I have malaria, it is very serious. But with time, when I start receiving food then I say, okay it was just mere malaria." Women describe such constant worry contributing to deterioration in their health: "As I have already said, I am not strong any more. I am weak, because I worry each day."

Women also try to ward off worry; for example, by emphasizing the normalcy of common illnesses: "If I fall sick, I know that it's just like any other person falls sick. I will die when God wants. If it's diarrhea, anybody can have diarrhea. And death will come when it's time, not because I have been diagnosed with HIV." Similarly, women seek multiple possible explanations:

> P: With this pregnancy, I am experiencing backache and heart palpitations more especially when I am working. It's like I climbed a mountain or walked a long distance. But, when I look at the work done, it is just little. Or, sometimes, I feel like the pregnancy is very big and nearing delivery.
> I: Do you think that has anything to do with the HIV virus or age or something?
> P: I don't know what is really happening, because I have two things in my body, one the HIV virus and two the pregnancy. So, I don't know between the two, which is causing these.

While this woman's experience of pregnancy differs from her previous four, she does not attribute this difference to HIV alone, but to normal variation among pregnancies. Women also reassure themselves by drawing on positive-living advice and the hope it provides for a long life. Moreover, the most forceful confirmation of the possibility of living with HIV is their own survival. It challenges their previous notions of HIV and builds confidence that they can live for some time. This is relevant to women's common belief that they will begin suffering once they deliver their babies. Finally, women gain comfort by emphasizing the inevitably of illness and death for everyone, even those without HIV.

While bodily monitoring usually leads women to conclude that their health is deteriorating, some women see improvements:

> As for me, there is a change in my body because, before I had a test, I used to fall sick more often. I used to have malaria, diarrhea, things like those. But, ever since I had a test, that problem doesn't

> come again in my house. I take almost a year without having malaria, six months not having diarrhea, and three months no general body pains.

Many women tie health improvements to adherence to positive-living strategies; for example, women feel that their health is better if they do not worry about HIV, and this is confirmed by health measurements, like gaining weight.

> I: How has the thinking changed from when you were first diagnosed to now?
> P: It has been reduced. When I was being checked weight, the weight increased, showing that I have reduced my thinking. At first I used to think a lot.
> I: What do you think has contributed and helped you to think about it less?
> P: What I learn here [health centre] and also, when you ask God, he gives you.

Another woman attributes her health improvements to consistent condom use.

> P: I had told you before that, when having sex, my body becomes weak. So, when I was advised by the doctors here to use condoms, I feel better and strong now.
> I: So do you think you feel better, because you use condoms?
> P: Yes, I can feel the difference. Since I started using condoms, and I didn't know that people use condoms. And also, when I come here to receive drugs, I feel better.
> I: What drugs are these?
> P: Iron tablets and the other tablets. I don't know.

Women's improving health, which they attribute to positive-living advice, give force to that advice. Women thus find it even more persuasive as a beneficial way to live with HIV.

Eating Well

Positive living entails multiple forms of self-regulation; two are good nutrition and stress reduction.[63] The medical establishment credits both for maintaining the strength of the body, warding off disease, and halting the advancement of HIV and AIDS. Nurses communicated the benefits of these lifestyle factors, and they are adopted by women living with HIV, who see them as ways to preserve their lives and challenge HIV. However, although the discourse of bodily control empowers women as they actively combat the virus, their capacity to self-regulate is limited by their social and economic realities.

Women describe the advice that they receive on how to prolong their lives as the major benefit of knowing their HIV status: "The benefit of knowing one's status is that you can know how to live your life positively. You can know how to care for yourself, and you also know what type of foods to eat." Women see food as giving their body energy to fight the virus: "They say, when you eat balanced diet foods, the virus struggles. But, if you don't, then it starts eating up the body" At the same time women are sceptical of the practicality of the advice: "I read in

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[63] Nurses specifically promote good nutrition for people living with HIV. Evidence shows that "HIV infection affects nutrition through increases in resting energy expenditure; reductions in dietary intake; nutrient malabsorption, and loss; and complex metabolic alterations that culminate in weight loss and wasting common in AIDS. The effect of HIV on nutritional status begins early in the course of the infection, even before an individual may be aware that he or she is infected with the virus" (Piwoz and Bentley 2005). Stephen Lewis (2005:56) with reference to food security and nutrition writes, "The question of hunger becomes so much more critical in the presence of AIDS. Treatment is much more difficult, sometimes impossible, if the patient has nothing to eat: the body can't handle the drugs without food. And the further bitter truth is that full-blown AIDS can sometimes be forestalled for a considerable period of time if the body is receiving nutritious foods. When I was in Malawi, I kept repeating the defining mantra: If the body has no food to consume, the virus consumes the body." For the women in my study, the need to eat well was not a matter of science nor a mantra, it was the embodied reality of life with HIV and not enough to eat.

the pamphlets, they say that people who have HIV must eat balanced-diet foods. They normally show things like chicken, nuts, rice, eggs, pineapples, etc. Can a poor person afford to get these things?" Most women in my study could not: "Balanced diets need money, and where can I get the money to buy meat or even tea? Because, in the village, it's vegetables throughout, so that way the body will become weak fast." In line with the advice, this woman sees her economic incapacity to eat balanced diet foods as directly harming her health and believes that she will quickly become sick.

Women's powerlessness to follow the balanced-diet advice is thus a major cause for concern:

> Mainly, my concerns come when I want something to eat, and I can't get it. And you think, had it been I had money, I would have bought something. And, if I can't find it, I begin to worry and ask myself, that, am I going to live longer. So I sit down quietly, and my husband asks me, "Are you thinking of your HIV status?" I say no, nothing...I think it's not good for me to be gloomy, lonely, isolated because of my status. If I do that, it can be harmful to my life.

With knowledge of the importance of eating well and worry about not being able to do so, women in one focus group started to brainstorm, offering each other suggestions on how they could eat good, "body-building" foods even with their limited resources. "You can try to buy some foods like rice, milk for MK20, sweet potatoes and also avocado. And, in the afternoon, you can try to buy beans, vegetables, or *mgaiwa nsima*.[64] That means it's different food types and what they

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[64] *Mgaiwa nsima* is corn flour ground directly from the entire corn kernel without additional processing. It is considered the most nutritional form of *nsima*, but is not very popular.

[positive-living advice] show is just an example of balanced-diet foods." This woman also challenges the prescribed food groups and examples presented in materials on positive living, focusing on the importance of eating diverse foods. Another woman continues, "Just to add on, for breakfast you can cook porridge with groundnut flour. Because the tea that we take has no vitamins, because it's just water and nothing else." Another woman adds, "You can buy vegetables and fry them with a lot of tomato, because you can't afford to buy a chicken. And also you can buy *matemba* [small dried fish]; just fry them with vegetables. That's what I thought of." Such solutions make women feel that they can, indeed, capitalize on the health benefits of positive-living advice. While women work to eat well with their limited resources, they still face food insecurity and limited nutrition.

A nutritional supplement introduced by the WFP during my study does address food insecurity and women's nutrition.[65] However, more such programs are needed. Many women want microcredit loans to start small businesses, and, indeed they reported discussing this in the support group as something the PMTCT program would provide. Women, however, are disappointed that this has not yet happened. They also want programs that combine skill development with income generation. They believe that the money they earn will allow them to eat

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More processed forms of *nsima*, where the corn is soaked and bleached, are more popular but less nutritious.

[65] Women in the PMTCT program are given a monthly food supplement, *Likuni Phala*, a nutritionally fortified soy and maize meal and one litre of vegetable oil. While this food is supposed to be for women themselves, and some women report hiding from the rest of their families to eat, most share it. Moreover, women describe that, even if they eat *Likuni Phala* alone, once a day, it finishes before the end of the month.

well and stave off the deterioration of their health. Women feel that they are missing an opportunity to pull themselves out of their current situations, improve their standard of living, and sustain their health. My research shows that women seek pragmatic solutions based on their own experiences and possibilities.

In addition to being dissatisfied with their current capacity to eat well, women anticipate that this will become a major problem in the future, when they start suffering from AIDS: "The sick can't work, so definitely there can be poverty, so we'll need food and clothes." Women elaborate that it is not just they who will suffer, but also their children: "When I start falling sick I can't have means of looking for food for both the children and myself." Moreover, women emphasize that lack of food increases sickness, leading to further difficulty in acquiring food: "If we aren't eating a balanced diet, that contributes to the problem. Because we're sick, we can't work, can't get money. It's then difficult to get the right foods."

Coping, Moving On, Worry, and Stress Reduction

Reducing worry, particularly from HIV diagnosis and eliminating stress are life-prolonging strategies that women adopt. In line with this positive-living advice, women believe that if they think and worry about their HIV status, they will lose weight and die more quickly: "When you worry so much you can die quickly, because you can lose weight." Concomitantly, not worrying about HIV is a way to stay strong and prolong life:

I: Do you think about your HIV status?

> P: I do think of that, but not much. Because, if I think about that a lot, I can grow thin and die quickly.

Women discuss reducing and eliminating stress as one way of slowing the advancement of HIV: "The change is that, now that I know I am HIV positive, I will avoid falling pregnant, reduce worrying, and control anything which can stand in my way to cause me stress." While women try not to, they also do worry about their futures and the futures of their children, as I elaborate below.

One component that facilitates women's coping with HIV, and therefore helps stop worry, is time since HIV diagnosis. Women come to terms with HIV, although this seems to be accelerated by the advice not to worry. One woman says, "When I first heard that I had the virus, I worried so much. But now I am able to cope with the virus. I am ready for death anytime, but I don't worry or have concerns. It's like I am used to it." Women perceive a change between how they felt when they were first diagnosed and their current feeling on life with HIV:

> I: Has your thinking about your HIV status changed from the time you were first diagnosed to now?
> P: Yes it has changed because, when I just received my test results, I had worries and concerns. But now I am just normal, the way I used to live before.
> I: What do you think has contributed to coping with your status?
> P: I just decided that I should stop thinking. Because if I kept thinking, I would end up not eating, thus inviting other diseases. So, I just leave everything in God's hands.

Women relate a number of strategies that help them cope with their HIV status; they often draw on their religious faith:

> I: Where do you turn for comfort and emotional support to address HIV?
> P: I just go to church to pray on Sundays, that's all.

Women find their faith comforting, because they believe that God will answer their prayers for ways to address their difficulties: "People used to tell me that, if I have a problem, I must pray to God; he answers prayers. So, whenever I pray, I feel relieved." Church is also a social time and an opportunity to be with friends, and women seek comfort in their friendships.

Being active and busy keeps women from thinking about their HIV status: "When I'm busy doing something, I don't think of that, but, when I'm not doing anything, I start thinking. Otherwise, I just live like normal, like anybody else. I try not to think about it." Spending time with friends helps: "Instead of thinking, you chat with your friends. You laugh, and by so doing, you pass time. And soon it's time to cook, eat, and sleep, rather than just sitting by yourself and thinking. If you do that, people may think that you are sick, not knowing that it's worries that are making you to lose weight." A few women disclose their HIV status to friends in order to receive support and encouragement:

> There are people who I chat with who I've told my status. So these people encourage me to accept that I have the virus, that I should reduce worrying and live the way I was living before I knew my status. And also my husband keeps encouraging me that, of course I have the virus, but I should brush away that thinking and just live like any other person. So I make use of those encouraging words from my friends and husband, because, if I don't reduce worrying, I can die quickly.

Support from husbands is an important source of comfort for many women:

> I: What do you think has helped you to feel better about your HIV status?
> P: We keep encouraging each other, my husband and I.

Several women point to radio programs on HIV, including diaries of people living with HIV, as facilitating their coping: "As for me, what made me change my thinking, it's because of the programs I hear on the radio about HIV, how one can live positively. And, also, after I had my baby tested for the first time, I was told to join the support group where we encourage each other. So now I don't have concerns." Many women find comfort in knowing that other women are in the same situation: "When I see that there are a lot of women, I feel relieved that I am not the only one. We are many." In the support group for HIV-positive women, women meet, encourage, and support each other. One woman in a focus group says,

> I shouldn't lie. When I was first told that I had the virus, I felt pity for myself, and I cried a lot in my heart. And, on that day I was just quiet at home. They asked me what was the matter, but I couldn't say it. It took me some time to reveal. I didn't even eat *nsima* that time. I had concerns that, what has happened to me? So, with time, I started getting over it and, when I started mixing with my friends here [support group], they advised me not to have concerns. So now I no longer have concerns, only when I fall sick. Otherwise I am used to it.

The support group also enables information sharing on how to live with HIV: "When I was just told about my status, I had concerns such that I didn't even sleep that night. It took me almost a week to come back to normal. And also, when I started coming here [support group], and teaching each other on how we can live longer with the virus, I started reducing concerns." The emotional benefits of the support group further emphasize that support programs should be expanded and offered to women immediately after their HIV diagnosis to mitigate its impact.

Feeling power over their illness and living through is a powerful component in women's efforts to come to terms with the virus. Women are also empowered by their knowledge of HIV and what to do when they are sick. "I know my status, and I'm comforted by the fact that I'm not the only one who has the virus in this world. And also I'm happy that, whenever I fall sick, I can rush to the hospital for assistance. Other than, if I hadn't known, I would be thinking that I have been bewitched." This feeling of power over the illness extends to women's care of their children. Women describe the medical intervention to prevent vertical transmission as a comfort. "I am encouraged because of the nevirapine I was given, which I took during delivery. And the baby, too, was given. That gives me comfort." As another woman says,

> When I was first told about my status by the nurse, I had a lot of concerns. But, when I hear from the radio and also when I see these women, I get encouraged. But I felt more relieved when I came the day before yesterday and was told about the baby's results [HIV negative]. So, I no longer worry saying, that means there is still time.

Even when transmission to the children is not prevented or another child is found HIV positive, mothers feel better because they know how to care for their children: "Now that I know that my kids are both HIV positive, I will be rushing to the hospital whenever they fall sick. Other than if I hadn't known, I would have been having difficulties with them."

While coping strategies and the advice to reduce stress help women, aspects of their lives are still worrisome. For example, although the majority come to terms with their HIV status, worry and unhappiness may persist: “As for me, there is a change [since diagnosis] because, ever since I was told of my test results, I always have concerns.” Another woman says, “The HIV diagnosis had a bad impact on my life, because I am not happy since I knew of my status. And also I have cancelled all my plans I had for the future, because maybe I will not even get there. So, really, I am not happy.” Greater uncertainty about the future and the overwhelming imminence of death after HIV diagnosis makes planning for the future difficult for these women. Most women, however, feel that they must continue with their plans regardless of their HIV status: “My plans are that, if I can source some money in the future, I plan to continue business in order to help my family. And maybe in the future there can be a drug for curing HIV. Going back would mean going down in development.” The potential for a cure drives women’s hope and supports their will to continue with their plans, despite their HIV status. Unfortunately, the bodily realities of HIV also stand in women’s way, regardless of their psychological outlook.

The poverty that women in my study face is also a major source of worry and is compounded by their HIV status. I discussed this previously in terms of food insecurity. Poverty also makes it difficult for women to plan for the future of their children. Most worry about their children’s bleak future as orphans and prospects for care: “My heart pains a lot thinking that, surely, my children will suffer because of the pandemic." Such worry comes from women's observations of orphans within their communities: "When I look at how orphans are suffering in the communities, I feel pity for my children that maybe they will be suffering the same way when I die." Another woman elaborates the plight of orphans: "I worry, because a child is well cared for by his or her parents. Because some people shout at the orphans, reminding them of the late parents, and most people are cruel. So with this kind of treatment, beating them, etc., the children don't forget their parents, and the pain of being an orphan increases." Women worry because their children's prospects for education will diminish when they die. Some are also unsure of who will take care of their children and give them a home.

Finding solutions for future problems or being hopeful that they will live to see their children grow provides women relief from worry.

> I: What are the things that you think about your HIV status?
> P: When I am thinking, I think of my children, that they will become orphans and suffer because this pandemic claims both people in the family [mother and father]. But then I encourage myself not to worry, because my parents are still alive. If I die, they will look after my kids.

Some women have more resources with which to plan for their children's futures. "These ones [children], even though they are small, their father built them houses, so that they can be able to assist themselves and go to school." Even with uncertain prospects, women attempt to hope. "I just consoled myself that the virus stays a long time in one's body. And, when the baby's born we shall be able to enjoy with the baby for at least some time." Again, women's faith comforts them:

"My hopes for my baby are that he should grow up and become independent. Because nobody can take care of the baby the way the mother does. So, if I could start suffering now and die, it's not good. But I hope God guides the future." With no resources with which to address worry or plan for the future, women's stories switch between worry and hope that some good grace will befall them and their children.

Condom Use

Condom use is another component of positive-living advice. Beyond safeguarding sexual partners from HIV infection, condoms prevent reinfection. Women advised to use condoms also consider the advice one of the benefits of knowing their HIV status: "When you are found positive, you are assisted, because you are advised to stop sleeping with your husband, or else you should be using condoms." Women see condom use as a health-maintaining strategy: "Condoms help to protect our immune system but, if we're not using condoms, then viruses multiply in our bodies. All that is needed is to talk to each other [in the marriage] nicely." As well as a general health-maintaining strategy, condom use is also an illness prevention strategy: "I feel, if we can follow the advice that we are told at the hospital like using condoms, I think we can reduce falling sick. Maybe once a month or once in four months, or even in a year, falling sick from malaria only once." Women understand that using condoms is particularly important during pregnancy to prevent HIV transmission to the child: "Other advice is that, when my husband wants to have sex with me, he should use condoms in order to protect the baby." Women see condom use as more important if they suspect that their husbands are unfaithful.

While women feel very strongly about following the advice from the health centre to reduce re-infection with the virus, their ability to use condoms depends on disclosing to their husbands. As many husbands are reluctant to use condoms, my research shows that, for most women, condom use becomes an on-going negotiation with husbands. Women, however, are motivated to take drastic measures to protect their lives and therefore talk to their husbands about condom use more frequently and forcefully than they did before HIV diagnosis. Indeed, a few women attribute improvements in their health to condom use. Although all of the women in my study understand condom use as important and try to work towards that goal, some see it as an inadequate solution: "They say that, when you have this problem, you have to avoid having sex more often, because even condoms sometimes do burst. So really it's not good to have sex more often, but maybe once a week." Therefore, women often attempt condom use in combination with other life-prolonging strategies, such as encouraging their husbands to be faithful and having sex less often. Additionally, a few women report that they themselves are allergic to condoms: "I got some condoms, but I am allergic to them. I develop sores whenever I use them. So we agreed to be having sex only three times a month." For this woman, limiting sex, cuts the number of times she must suffer through her allergy.

Most women report a number of challenges to condom use; however, a few report that their husbands immediately accepted condoms. This seems to be related to their understanding of condoms as a life-prolonging strategy. "As for me, since I explained to him [husband], I come here every month to collect condoms, because he said it's good for us to prolong our lives by using condoms." As I discuss below, inadequate understanding of the medical information on reinfection and condom use contributes to men's resistance.

Disclosure is most often necessary before women discuss condom use with their husbands. However, some do manage to use condoms without disclosing their HIV status:

> I: Before, you had said that you hadn't disclosed to your husband. Have you disclosed to him now?
> P: Not yet.
> I: So, how did you start using condoms before disclosing to him?
> P: I just lied to him and said that's what I was told at the hospital. So he just accepted.

Another woman, who has not disclosed her status to her husband, also succeeded with condoms by presenting them as a family-planning method. However, the easy agreement of her husband led her to believe that he must also have been for an HIV test and received counselling: "I think that he went for a test and was found HIV positive, and he was advised to use condoms. Because at first he used to refuse to use condoms, but now he has agreed."

A divorced woman in my study discusses how free she is to insist on condom use, as an unmarried woman having primarily casual sex. "It would be difficult for me to meet a man who will tell me to sleep with him without using a condom. I don't have a husband, so, when having sex, it's strictly with a condom." This woman finds her situation empowering. Her freedom to use condoms in casual relationships also strengthens her desire not to remarry. Within marriage, she believes, she could not insist on condoms. Moreover, she sees a second advantage to her situation; her ability to refuse sex, which might not be possible within marriage, where sex is an intrinsic part of the relationship.

In contrast to this woman's beliefs on sex within marriage, others succeed in abstaining or reducing the frequency of sexual intercourse as an additional prevention strategy: "Sometimes, there are other men who are so loving, who will just tell you that, let us just be sleeping without having sex." For serodiscordant couples, where the husband is HIV negative, it seems that he is more willing to protect himself than in relationships where the husband is also HIV positive, or does not know his status but assumes that he is HIV positive:

> The moment I was diagnosed with HIV, I told him that he has to use condoms with me. That's what I was advised. Since then, he fears to have sex with me. Sometimes, when he wants, I tell him to use condoms. But he just says that it's better to just stay rather than having sex with me. So now we just look at each other, saying that sometimes the condoms burst.

Sexual abstinence may have been a particularly successful strategy for women in the individual-interview component of my study, as there is a cultural prohibition on sexual intercourse during the late stages of pregnancy and in the post partum period.[66] While couples do observe this prohibition to varying degrees, women can draw on it to refuse sex with their husbands.

Although some women easily convince their husbands to use condoms, most women's husbands reject the idea, at least initially. This is part of a cultural norm against condom use: "Most people don't use condoms, saying sweets are never eaten in the paper." One woman describes her husband's immediate rejection of condom use:

> When I went home to tell my husband about the advice that I was told in the counselling, like using condoms, my husband refused and got angry at me. So, in the morning, it's when he answered me that there is no way he is going to use condoms. After all, I am not the first person to be diagnosed with HIV, saying there were people who were diagnosed HIV before, so I shouldn't worry about that. But, for me, I thought he didn't answer me well because, when I think of what I was told on how to prolong my life and his response, it's difficult. And, most of the time, I keep worrying.

All the women talk about their frustration and worry about not being able to use condoms. Like this woman, they all feel that condom use is integral to maintaining their health and that they are shortening their lives by not using condoms. Most women's continued attempts to use condoms, often result in disputes: "As for me, it's true I came here, and I collected some condoms. But my husband refuses to use condoms, and that results in quarrels in the house." Despite

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[66] The life cycle in Malawi moves between periods of wet and dry, hot and cold, warm and cool. In the last months of pregnancy, couples traditionally abstain from sex to allow the baby to dry out. At birth, babies are cold and endangered by contact with those who are hot (sexually active). Parents must thus abstain from sex until the child is ritually warmed through a ceremony where the child is put in place, welcomed into the family and community (see also Kaspin 1996; Ott 2000:184-189).

this, many women are determined to continue demanding condom use and, as shown below, some will go to great lengths to achieve condom use.

Condom use is impossible for most women who have not disclosed their HIV status to their husbands.

> I: Have you ever discussed condoms with your husband?
> P: I tried to talk to him this other day that, why don't we start using condoms? So he asked why I brought up that topic. I told him that we hear people talking of condom use. So he said that I wasn't open enough. I should be straight as to why I said that. I just said nothing; I didn't continue.

As condoms are generally unacceptable within marriage, most women will not succeed in using them without disclosing their HIV status.

Husbands also reject condom use, because they do not understand the rationale for the positive-living advice, especially given that they are HIV positive or at least assume themselves to be so: "Where I didn't understand, together with my husband, was the time I was pregnant and we were told to use condoms. So my husband was saying that, why should we use condoms when we have the virus?" When the women also have poor understanding of the rationale behind condom-use, it is difficult for them to adequately explain to their husbands.

My research suggests that most women accept condom-use advice without fully understanding the reasons for it: "What was confusing to me is that they said that, if you continue having sex, that means the viruses multiply. So I was wondering that, where are those additional viruses coming from if the husband is now faithful?" More information could help women to better understand the advice and explain it more compellingly. This situation is also a result of men's marginalization from the PMTCT program: "Most men refuse to use condoms. So it's a concern to us, because it is us women who volunteered to have a test to know how our bodies are. So really, there is need for them to take part in this program, because they refuse to use condoms." Men's participation in counselling and testing would ensure that they, as well as women, receive the advice on positive living, including condom use.

Another problem is that women do not know how to start dialogues on condom use with their husbands:

> I: Why did you decide not to discuss condoms with your husband?
> P: I didn't know how to start.

Most women do not have experience, and are uncomfortable with starting discussions with their husbands about sex. In the focus groups, women spontaneously role played and offered each other convincing arguments that could be used to encourage husbands to use condoms. A number of women advised one woman, Sarah, who was having difficulty with her husband. As one woman offered, "It is very difficult. There is a problem, because we are given advice on how to prolong our lives. So, if somebody is refusing to follow the advice, it is difficult, because you will die quickly without even looking after your children." Drawing on her personal experience, this woman was convinced that, by sitting and talking nicely with her husband Sarah could convince him to use condoms. Other women were also convinced that husbands would not refuse condom use if they had adequate knowledge:

> They should tell their husbands that condoms are not only meant for child spacing but for prevention of diseases, like in their situation. If they continue having sex without condoms, then the viruses will multiply, because they will be re-infecting each other. And the end result is that they will start falling sick soon. And, the most important thing is to tell them the truth about your status. They can't refuse.

Another woman, suggested a more extreme solution: "It's better to take separate ways than to die quickly in order to praise the man because here [at the health centre] they say that we must follow the advice so that we can live for two or three years in order to see our children grow." These women's experiences suggest the need for programs to provide concrete strategies that move beyond the imperative for condom use, to actually illustrate how women might achieve it in their relationships.

At the next focus group, Sarah reported, "When I went back home, I spoke to my husband again about condom use. But he refused, saying that, if I insist, we should stop having sex. So, as I am talking now we no longer sleep together, and we no longer have sex." This was true for other women who I spoke with: "I did take the condoms, but he refuses to use condoms. As such, I have stopped having sex with him. I refuse." Women believe that, given the choice between no sex and sex with a condom, husbands will choose sex with a condom. For a number of women this strategy was successful: "At first he was refusing when I told him. But, with time it's when he wanted to have sex, so he told me to bring the condoms." For most women, therefore, husbands' refusal of condom use initiates ongoing negotiation. For Sarah, however, this negotiation broke down when she was later forced to have sex without a condom. A couple of women who were refusing to have sex with their husbands without condoms reported being rape by their husbands.

Many women discuss possibly divorcing their husbands over their refusal to use condoms; however, as was the case prior to HIV infection, they seem divided on the practicality of divorce to address husband's unacceptable behaviour: "It is not good for you to divorce your husband because of that problem. But you should find a way to convince him to start using condoms, because, if you divorce him, you will suffer together with the child. And, once you start suffering, you will want to get married again. So that is creating another problem." On the other hand, some women are convinced that they can successfully stay on their own as a life prolonging strategy.

> I: If you leave your husband, do you imagine yourself remarrying?
> P: I can never get married again.
> I: Why not?
> P: Because of my status. I can't, because, if I marry again, I will lessen my days to live, because men refuse to use condoms. So it's better I stay on my own and live longer. He may even want more children.

In other women's marriages men make the decisions: "I tried to talk to him about the advice I was given here. And he said that he can't manage to be using condoms everyday in the house and that if I insisted, I would leave his house." Ultimately, women like Sarah often decide that it is preferable to stay in the marriage and acquiesce to sex without condoms.

Overall, it seems that most women have mixed success with condom use: "If we talk about condoms, sometimes he accepts to use condoms maybe for a month. But sometimes he refuses, saying he is tired of using condoms." Again, however, the importance that women give to condom use makes them persist:

> I: They told us to be using condoms, so I knelt down to my God. So, with time, he accepted. And I just said, thank you God that he has now accepted to use condoms.
> P: Do you know why he changed his mind?
> I: I believe God's power was great because, after I prayed, the next morning he just told me that we could use condoms. There is power in prayer.

Therefore, by repeating the importance of condoms, some women report that they eventually win their husbands over: "At first, he was refusing, but I kept telling him that the condoms will help prevent the baby in the womb [from contracting HIV]. So now he remembers on his own, because he knows it's to protect the baby."

In the focus groups, women brought up female condoms: "I just hear on the radio that there are female condoms because, if men are refusing to use condoms, we can just use ourselves without them noticing." Following this discussion, I tracked down a source of free female condoms supplied by the United Nations Population Fund to a nearby reproductive health clinic. When I brought a female condom to the next focus group meeting and told the women where they could get them, they were very enthusiastic. I was able to follow up with Sarah later about the female condoms. She reported that her husband had agreed to use them and she was happy that she was finally able to use a preventive strategy.[67]

Future Reproduction

Women, diagnosed with HIV are told by PMTCT program nurses that future childbearing will negatively impact their immune systems. Moreover, adhering to the advice on condoms negates any future reproduction. Following such advice, most women discuss their intention not to have any more children. For some women, this is a departure from their pre-diagnosis plan. Other women wanted to stop having children anyway. As with condom use, some women experience or anticipate resistance from their husbands. Women also face barriers in accessing reproductive health services, particularly if they want a tubal ligation.

Based on positive-living advice, women understand childbearing as detrimental to their health: "The problems can come in if you are continuing [to bear children], because you can die quickly." Women are also motivated by their desire to care for the children they already have and not risk having children born with HIV: "It's because I want to prolong my life. And, again, it's because, if we continue, the children will be born with the virus. So it's like no work done." For these reasons, many women decide to change their reproductive plans: "I have heard that HIV is an enemy of child bearing. So, when you know how you are, you change, you remove some of your programs."

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[67] Female condoms are tricky to use. That is why the reproductive health centre does not provide them before demonstrating their proper use. Indeed, research shows that women can and do successfully use female condoms when available (Mantell et al. 2006).

Of course, for women who had already reached their reproductive goals, the advice to stop bearing children fits their plans: "When it comes to childbearing, I have fulfilled, because I have four children, who I feel are enough." Other women's stories of unwanted pregnancy add conviction to their renewed decisions to stop; however, they also illustrate that plans sometimes go awry: "Three children are enough. In fact, I had wanted to have only two children, but I was forced to have this one because it's a new marriage. Otherwise, if it were my first husband, I wouldn't have had another child. It was an appeasement." In addition to pragmatic decisions about childbearing, other women's stories also describe accidental pregnancies:

> This pregnancy was an accident, because he [husband] had asked me to go for family planning. So because I had problems with the injection [depo provera], I fell pregnant. He asked me to abort, and I tried to take different types of medicines, but I was unsuccessful for two months. So he just said that I should let it be, but it should be the last one.

One woman, who had known her HIV status for three years before participating in the PMTCT program, describes how her intention not to have any children failed: "We used to use them [condoms] always, but this time we only realized that the condom had burst after finishing, when removing it." Women's past experiences with failed contraception help to explain why women layer multiple contraceptive methods or opt for tubal ligation.

For women who have not had all the children they had wanted, HIV diagnosis and advice on non-reproduction, lead to more difficult decisions. While they are nonetheless committed to not having any more children, they feel sad and disappointed: “Like me, I don’t feel good, because I had wanted to have three or four children. But, because of the problem that I have, I can’t manage to have four children.” One woman, pregnant for the first time, speaks about the incompatibility of future pregnancies and condom use: “Now we are using condoms, and, after the baby is born, we will still be using condoms. That means this is going to be the only child.” Another woman says, “After being found HIV positive, plans have been drawn back, because we received advice that we shouldn’t continue having children.” The disappointment that women feel, however, is moderated by their commitment to the advice and their confidence that not having any more children is the right decision: “It has changed, because I had wanted to have four children. But let it be only the ones I have already, so that, the time I will start falling sick, my children will have grown a bit…I don’t really feel bad, because it’s better I take care of my children so that they can grow a bit, other than dying leaving, them young.” To successfully avoid pregnancy, women also need the agreement of their husbands, the support of their families and communities, and the necessary contraceptive technologies. Most husbands whose wives have disclosed their HIV status agree that they should not have any more children: “Yes, we did [discuss] and, in fact, he told me that, after I deliver, I must go for tubal ligation – as if he knew that these things [HIV] don’t go together with bearing children. So I thought, if I go for tubal ligation, I may just add more problems. Instead, I use a string [traditional birth control method].” Some women’s husbands, however, disagree. They either want more children or do not agree with particular birth-control techniques. "I think it is going to be difficult, because he [husband] refuses to use condoms. And he refuses also to use any child spacing methods, such that I do things on my own, and I was even planning to go for traditional medicine." It is their uncertain future that makes her husband resist tubal ligation:

> When I discussed with him, the response he gave me was that you never know how long your life is. You may be surprised that you conduct tubal ligation or use traditional medicine to stop having children, and you will find that God has kept you alive until that child grows. And maybe you may even start thinking of having more children.

Women report that opposition can lead to divorce or to husbands' marrying a second wife in order to have more children: "Sometimes, other men, even if you tell them that you don't want to continue having children because your immune system is low, they still insist that they want a child. As a result, they marry another wife." Women, though, place their own health above the possibility that their husbands will marry a second wife: "It's up to me to choose to have a long life and let him marry another wife."

In addition to their husbands' childbearing expectations, women must also negotiate the expectations of their extended family and community. Women who have only one or two children anticipate the most difficulties. They worry most about their in-laws, but feel that they can challenge questions, rumours, and gossip by drawing on alternate discourses: "I believe I can have problems from my mother-in-law. She can tell her son that, 'Why have you stopped having children when you know that in our family we didn't bear a lot of children? So leave this woman and marry another one.' I expect this to happen." Despite potential disputes about childbearing, most women believe that a husband and wife alone make such decisions: "It's true, people ask that, 'Why have you stopped bearing children?' You just answer them that, it was an agreement between me and my husband to stop having children. Marriage is between two people, as long as the two people in the house agree, there is no problem." Moreover, women draw on modernity: "Nowadays, there is what they call 'modern childbearing,' whereby people have maybe only two children. And, when they listen from the radio, they will just assume it's modern childbearing."

As I laid out in the preceding section, condoms are seen as the best way to avoid reinfection and prevent pregnancy. However, many women are unable to use condoms or feel that they are inadequate and thus turn to other contraceptive methods. In response to alternative propositions, one woman in a focus group insisted: "If you can start family planning, let's say pills, that means you have agreed to allow viruses in your body. What do you think about your life?" Despite the ideal of condom use, many women turn to alternative methods and backups:

> I: What do you think you will do in terms of childbearing?
> P: I have stopped here. I will not continue, because, if I continue bearing children, I will induce the virus to start weakening me quickly. It's better I concentrate on caring for this child, which came before I knew my status.
> I: Are you doing anything to ensure that you don't fall pregnant?
> P: Yes, we use condoms, and I am also on depo, but my husband doesn't know. He thinks we are using condoms for prevention of the virus as well as contraceptive.

Many women point to potential failure of birth-control methods: "He [husband] encouraged me to go for child spacing, saying that, 'If we have another child, that is going to be accidental.' since sometimes it happens that you fall pregnant while on family planning." Due to lack of confidence in most family planning methods, women view tubal ligation as the best contraception. However, in contrast to temporary contraceptives, available free at the health centre, women have more difficulty accessing tubal ligation. It is available from a reproductive-health NGO, Banja La Mtsogolo (BLM), a short walk from the health centre. The price is very reasonable with a referral letter from the government health centre. Obtaining a referral letter is difficult, however, because health care providers are reluctant to refer young women with few children for tubal ligation. They believe that these women or their husbands might want more children or that women will need another child to cement a future marriage. One government nurse at the health centre says,

> I: I've heard from some of the HIV-positive women who I talk to, they say, 'I want a tubal ligation, but I don't think they'll let me have it, because I'm too young or have had too few children.'
>
> P: Yeah, but we also think of the other side, of divorces. Mostly these young women these days, marriages are just breaking anyhow. So we ask them to discuss deeply, so they come with a concrete conclusion, so they don't regret later.

One HIV-positive woman, therefore, determined not to have any more children, found accessing tubal ligation challenging:

> The issue here is about tubal ligation, I was told to stop bearing children, and I was advised to go to BLM for tubal ligation. When I got there, they sent me back, saying they don't do that. So, I

> came back here to ask. So, because I want to have a tubal ligation, what am I going to do? Because, if I continue bearing children, I will die.

Not all women are aware of the referral process for tubal ligation, which adds another barrier. Moreover, rumours circulate that health problems result from tubal ligations in young women: "It's true what they told us, that we should not continue having children. But sometimes the pregnancy comes by accident, even if you are on depo. And to conduct a tubal ligation, they refuse us, saying our blood is still strong and we can have problems." Young women interpret health care providers' reluctance to refer for tubal ligation as an indication that the procedure is dangerous. Nonetheless, they still want tubal ligations if they can get referrals.

Women's reproductive decisions after HIV diagnosis rest on medical information within positive-living advice. Most women prefer not to have any more children to prolong their lives. However, their capacity to exercise their decisions is limited by their husbands and their access to medical services, particularly tubal ligation. Facilitating HIV-positive women's reproductive decisions needs to be integral to PMTCT programs (see also Myer et al. 2005). Support to women ought to extend giving advice to translating advice into action for women who do not want any more children. Mindful of the history of forced sterilization, any program for HIV-positive women must include adequate counselling on contraception, emphasize women's reproductive choice, and involve husbands where possible.

DISCUSSION – LIVING POSITIVELY: CHALLENGES AND CRITIQUE

Living positively has the potential to improve health, prolong life, and empower individuals in their lives with HIV. The philosophy of positive living and the practical advice offered challenge many of the collectively held beliefs about HIV in Malawi. Living positively promotes a happy, healthy, and long life. It promotes individual power over the illness and encourages individuals to work towards their own health goals by adopting specific health-maintaining strategies. Blind, however, to the economic, gender, and health systems realities of Malawian women the positive living philosophy fails. This is not to say that women never accomplish any of the goals of positive living, because they do. Nor do I argue that women are not empowered by the possibilities that positive living offers, because they certainly communicate power over their illness through self-regulation. These, however, are partial successes; positive living has much greater potential. Moreover, it is part of a disturbing trend, whereby, even when barriers to health are acknowledged at theoretical, political, and policy levels (as they are for women and HIV in Malawi), such acknowledgement does not translate into programs and services. They operate, instead, within the dominant theoretical, political, and policy milieu, which emphasizes individual autonomy and control over health. They present a morally correct way to be HIV positive. By assuming that individuals are free to live positively, they are in fact compelled to choose productive, healthy, and responsible lives.

The rise of health promotion began with the *Canadian Lalonde Report* of 1974 and its extension of health beyond biology to individual lifestyle and behaviour (Galvin 2002). The leadership of Western countries drew on this report to justify neoliberal policies, which favoured withdrawal of the state from social programs, including illness prevention and health maintenance (Galvin 2002) and shifting to individual responsibility for health and its maintenance (Anderson 1996:698) This trend continued throughout the developing world, as structural adjustment programs mandated fiscal conservativism to repay loans.

This privatized and depoliticized model of health fails to address socio-economic factors that shape health and illness (Singer and Baer 1995:76-77). Within neoliberalism, health is "an enterprise of the autonomous, rational self" and emphasis is on "the entrepreneurial, autonomous individual who possesses the capacity and rational agency to care for him or herself" (Persson and Newman 2006:1591). Neoliberals believe that lifestyles are freely chosen and that ill health derives from wrong choices (Galvin 2002). This echoes the dominant construction of HIV risk, as I discussed previously. Even once ill, neoliberal discourse claims, individuals can manage disease through health-maintaining behaviours. Therefore, if their health declines further they are not properly managing illness.

Empowerment emerged out of health promotion. Empowerment entails individuals taking responsibility of their own health, acting to maximize it through health-promoting behaviours (Anderson 1996). Empowerment and living positively are therefore examples of Foucault's "technologies of the self" – as

Crossley (1999a:1686) writes, "one of the ways in which power operates by convincing people to seek out certain parts of themselves and institute practices (e.g. confession, diet, physical/spiritual exercise, therapy) to effect a transformation of the self." Without adequate government resources to address the social structures that contribute to poor health, individuals are compelled to take on health-seeking behaviours and blame themselves when their efforts fail. Failure, as I have demonstrated, is inevitable for poor Malawian women living with HIV. They have limited food resources to eat a balanced diet, real stress and worry about their own and their children's future, inadequate control over their sexuality and reproduction, and poor health services, including poor access to antiretroviral therapy. True empowerment, therefore, is not solely knowledge of how to "live well" but "the process of challenging existing power relations and of gaining greater control over the sources of power" (Batliwala in Petchesky 2001:278). Living positively may provide comfort to both those who diagnose and those who are diagnosed, but it is a wholly inadequate way to address HIV. It is blind to the realities of life in Malawi and the impossibility of *real* positive living. Moreover, it is unconscionable to transfer responsibility for health to those who have the least capacity to achieve it.

The philosophy of positive living gives emotional strength to women with which to address HIV. It tells women that life with HIV is possible and makes them agents of their health maintenance. Women forcefully take on this responsibility, even as they are frustrated by the impossibility of attaining positive living. Women are committed to prolonging their lives and see knowing their HIV status as a more informed position from which to do so. For example, my research suggests that women are more willing to persist in insisting on condom use when they are trying to prevent a certain, rather than a hypothetical, death from HIV. However when money for food, transportation, and drugs is not always available, women often fail to attain positive living. Nonetheless, women make determined efforts to prolong their lives, action that is bound up in their desire to secure their own and their children's futures.

CHAPTER NINE – CONCLUSION

In this thesis, I began at a particular point of entry, women's HIV diagnosis in a PMTCT program, and ran with it in multiple yet inter-related directions. Indeed, the strength of anthropological research is the potential breadth of analysis. My analysis here was informed, first, by the narratives of women diagnosed with HIV and their interlocutors in the creation and delivery of the PMTCT program and, secondly, by my lens of analysis. In this conclusion I synthesize and consolidate my multiple propositions into four broad themes. While these overlap, I make a particular point through each one and emphasize what I see as important currents running throughout this thesis. I end by bringing together the key recommendations I have presented.

LOCAL-GLOBAL INTERSECTIONS

I draw on local-global intersections for two related strands of the thesis. First, I use a macro-political economic analysis to illuminate the influences of global history and economic policies on everyday life possibilities in Malawi. Manifest locally, women's situations in Malawi are also structured by the global economy, through structural adjustment programs that have worsened the situation of women. This macro-economic policy is part of historic continuum, implicating both Malawian leaders and the international financial system.

Malawians are amongst the poorest people in the world, and Malawian women are disproportionately disadvantaged. Their life stories illuminate the intersection of global processes with local cultural constructions – woman, wife, mother – as well as limited economic possibilities. From their early lives growing up in poor households women have limited opportunities, including education. Poverty requires girls to earn money for basic household requirements. Coming of age in such circumstances, social pressure on girls to have boyfriends and marry often colludes with economic necessity. Gender expectations limit women's capacity to negotiate the terms of their relationships, including protection from HIV.

Poverty in Malawi is embodied in poor nutrition, and high disease and mortality rates throughout the lifespan. Liberal market practices, reduced social services, mandated by international financial systems have worsened the health of Malawians. Such policies have also crippled the capacity of Malawi's government to mobilize adequate resources to address HIV. Local possibilities for the care and treatment of HIV relate to international processes, including the availability and conditions of donor funding, international patent agreements that make international standards of care impossible to achieve because of exorbitant pharmaceutical prices, and the creation of international health policy at distant locales.

The latest policy juncture has seen efforts to increase demand for HIV testing through communicating its benefits. Significantly, this relates to new international health and treatment targets that are predicated on individuals knowing their HIV status. One site of the elaboration of this policy is in PMTCT. Following on from previous health initiatives, women's health is again subsumed into their children's health. Women's own health goals are marginalized within the delivery of the program. Donor PMTCT programs are vertically delivered and thus require individuals to negotiate a patchwork of available services. Moreover, donor programs divert financial and personnel resources from the government health system, which is crumbling. The human-resource crisis is exacerbated by the "African brain drain" of Malawian health care providers to the United Kingdom, which further stretches limited staff and reduces the quality of care available.

Yet, again, new "fixes" for Malawi and commitments to funding HIV interventions are played out at local-global intersections, where countless multilateral and bilateral interests, as well as national governments and local NGOs, create health policy. Although health decisions are made at these complex intersections, health is ultimately experienced locally and personally. We need, therefore, to focus on the experiences of individuals affected by health policies.

THE PREVENTION CONTINUUM

Local-global intersections limit women's abilities to protect themselves from HIV; however, as I showed, women do try to protect themselves. The dominant prevention paradigm – abstinence, partner reduction, and condom use – ignores the dominant HIV risk factor for women in Malawi, and indeed throughout Africa. For these women, it is marriage that constitutes the major risk of HIV infection. Within marriage, abstinence messages sound ridiculous and undesirable. Moreover, women, for the most part, are faithful but cannot ensure the faithfulness of their husbands. Indeed, there is a cultural expectation that men seek multiple partners, particularly if they are away from their wives for long periods. Men are constructed as not being able to live without sex. Condoms are not always practical within marriage, as they negate reproduction. Accordingly, women use other prevention strategies, encouraging faithfulness by emphasizing their husbands' duties to their families and the threat of disease. Sometimes, women are able to negotiate condom use, although this is rare. In extremely unsatisfactory situations, women divorce. Women say that these strategies are protective as well as feasible.

HIV testing is another component of women's HIV-prevention efforts. Women see HIV testing as confirming their own health status and makes behaviour change possible. HIV-negative results may encourage husbands to protect that status. HIV-positive results open possibilities for women to protect themselves. Indeed, in the face of a certain rather than a hypothetical threat, women consolidate their efforts to preserve their lives. This is true even for condom use, which seemed impossible before diagnosis. The potential for condom use post diagnosis is particularly insightful with regard to prevention possibilities pre-infection. It suggests that when threats are evaluated as real and imminent extraordinary efforts will be made.

Women's efforts to protect their lives after diagnosis are consistent with the communicated health information on positive living. PMTCT program nurses deliver advice on lifestyle modification, which if adhered to, can keep the immune system strong, ward off infection, and postpone death. The possibility of a good life post diagnosis is a shift from previous risk discourses on HIV testing. Women rigorously monitor their bodily health after diagnosis. They take strength from signs of good health, but are worried when illness or weight loss point to possible degeneration. Women forcefully adopt the communicated health advice. They attempt as much as possible to eat well, reduce stress, and use condoms to prevent reinfection. HIV testing opens up real possibilities for health-seeking and self-care behaviours, which women explicitly refer to as prevention, prevention-of-death and preservation-of-life strategies. Moreover, they work hard at these strategies, and face considerable anguish when the circumstances of their lives prevent them from achieving their health goals.

SUBJUNCTIVE NARRATIVES

To speak in the subjunctive tense is "to be trafficking in human possibilities rather than in settled certainties" (Bruner 1986:26). When we think of roads not taken, we are speaking in the subjunctive tense. Subjunctive narratives run through this thesis, in both individual and institutional discourses. They create certain contradictions between narrative and experience but also elucidate the work of narrative in moving from the present to the future.

On a personal level, HIV diagnosis brings into relief risk factors in women's past lives. In part, their understandings of risk come from popular discourses of HIV and risk assessments that nurses carry out prior to testing. These shape women's understandings of their pasts and the possible routes of their HIV infection. HIV diagnosis leads women to contemplate risk; however, it takes on new meanings after diagnosis. From the certainty of HIV diagnosis, women describe that, if they had known they would contract HIV, they would have done more to protect themselves. But, not knowing, they could not have done anything more. We all would like to be able to apply knowledge retrospectively.

In negotiating their HIV-positive status, women also trade in the subjunctive. Although popular discourse on HIV emphasizes promiscuity and connect this with women's own behaviours or that of their husband, women leave open other possible routes of infection, such as medical procedures. Women utilize multiple infection possibilities to negotiate stigma and disclosure so as to come through with untarnished reputations. HIV diagnosis, thus, does not need to be a crisis of self. Women also traffic in subjunctive narratives to protect themselves against present or future stigma. They draw comfort from the uncertain HIV status of others, especially those who have not yet had a test, and from the unpredictability of everyone's lives.

The institutionalized narratives of HIV and PMTCT programs also trade in possibilities. The discourse on HIV testing has shifted from a focus on risks of HIV testing to benefits. The expansion of HIV interventions in Africa has led to a focus on the possible benefits that individuals can achieve. Specifically, testing is seen as the avenue to access benefits and relevant services. For example, HIV testing in the PMTCT program creates the potential to prevent vertical transmission, but also to safeguard women's own health from demise caused by HIV. More generally, expansion of HIV testing has broader possibilities. It is hoped that expanding HIV services will recast it as a "normal" disease, that funding for more HIV services will lead to health systems strengthening, and that individuals will become biological, therapeutic, and pharmaceutical citizens (Ecks 2005; Nguyen 2005; Rose and Novas 2005), demanding adequate health care. Presently, there is still a disconnection between hopeful discourses on benefits of HIV testing and individual's reality. But, it is only once greater possibilities have been imagined that they can be achieved. These institutional narratives create a path to that future, consolidate international and nation action against HIV, and potentially transpose, in some future time, imagined potentialities into realities.

Individuals, too, engage in HIV testing because of the communicated benefits in the positive living dictum. Women take up positive-living behaviours with great enthusiasm because they believe in the promise that specific bodily monitoring and self-regulation will prolong their lives. Indeed, the promise of controlling the virus helps women cope with their HIV status, which is no longer associated with certain demise. Women's narratives thus engage them actively in health maintenance when the most is at stake. However, knowing that they cannot fully achieve the medical recommendations leads women to subjunctive narratives of unfulfilled life-prolonging potential. If only they had adequate resources to wean their babies at six months of age, eat well themselves, control their sexual and reproductive health, and more easily access health services they could prolong their lives. These possible lives are infinitely better, for themselves and their children, than other narrative paths that lead to their own demise, orphaned children, broken families, and wrecked communities.

INDIVIDUALIZED HIV INTERVENTIONS

Subjunctive narratives communicate possibility, but are divergent from immediate lived experience. Thus, while HIV programs have great individual and collective promise, I must conclude with the realities of today. And, indeed, a great deal is at stake for women living with HIV, their children, families, and communities. HIV interventions have not moved beyond the focus on the individual and the belief in the rational actor who, when provided with prevention information, will act on it accordingly. But, information is not sufficient for women to safeguard their lives when they are limited by economics and gendered relationships.

The failure of interventions to protect the women in my study from HIV began before diagnosis. Indeed, HIV-prevention interventions have in Africa been declared, by and large, a failure.[68] The life stories of women in my study illuminate how HIV-prevention programs failed to address the conditions that created risks within their lives. Women's poverty, cultural expectations, and their gendered relationships make it difficult for them to avoid the risk of infection with HIV. Although most women are aware of the risk, competing demands, including

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[68] See, for example, the debate between Green (2003) and Farmer (2003) on how to address the HIV epidemic. They only agree that the "global model of HIV/AIDS prevention…has been largely ineffective in Africa."

sustaining life, often take precedence. This is not to say that women do not try to curtail risk in their lives. As I have shown, they do. Successful interventions ought to foster these prevention efforts, as well as address broader structures that have largely been ignored. They must move beyond the individual.

RECOMMENDATIONS: BEYOND INDIVIDUALIZED INTERVENTIONS

For women diagnosed with HIV in the PMTCT program, the interventions offered do not go beyond the biomedical paradigm to prevent vertical transmission. Here again, the failures of programs, suggested in the low follow-up rates, illustrates the need to move beyond this model. I now consolidate the key recommendations I made throughout this thesis and reiterate possible avenues for capitalizing on the potentials of the PMTCT program and HIV interventions in general.

Systematic problems in communication of medical information and competing ways of thinking about vertical HIV transmission are barriers to women's achievement of the full regimen to prevent vertical transmission. My research demonstrates that women have many questions about the PMTCT program, the process and probability of vertical transmission, the efficacy of nevirapine, and breastfeeding advice given in counselling session. Women who have been participating in the PMTCT program for some time still have questions. Most immediately, misunderstandings about the PMTCT program, including when women are to return, increase the likelihood of not continuing in the program. The program's vertical delivery and its lack of integration with routine antenatal care make it possible for women to continue with their routine antenatal care without returning to the PMTCT program. Further on in the program, women may not access nevirapine for themselves and their children and may not follow advice on breastfeeding because of poor understanding of the program protocol. To address these problems, enhanced education and comprehensive, on-going counselling are needed to answer women's emerging questions and ensure their understanding. To be sure, women want to understand the program and are frustrated when comprehensible, timely information is not available. One of the PMTCT program's challenges is insufficient staff to cope with the overwhelming uptake of HIV testing by pregnant women. I suggested that, when program components do not require the medical expertise of a nurse, other workers can be hired and trained. Given the importance of experiential knowledge in the community, these could include peer counsellors who have been successfully utilized elsewhere. This would also be beneficial in the creation of an avenue for financial support for some of the women in the program.

Other barriers contribute to a significant loss of the PMTCT program's potential. The scope of what is considered relevant for program success needs to be broadened. The vertical delivery of the program and its poor integration with other health services creates a number of problems. The program's delivery at a distinct geographic location identifies those who return there as HIV positive. The stigma of HIV in the community and desire to conceal their HIV status prevent some women from returning to the program. Women also have difficulty accessing nevirapine for their babies if their status is not noted when they deliver, if they deliver at a health centre without a program, or if they deliver with a traditional birth attendant. Steps have already been taken to better identify HIV-positive women at delivery and to give them nevirapine syrup to administer to their children. However, TBAs have not yet been involved in the prevention of vertical transmission; this would reach more women in delivery. Finally, directives on infant feeding are delivered without focused counselling on how women can achieve weaning their babies and then prepare locally available foods for them. Existing food-support programs target HIV-positive women's nutrition. Not only should such programs be expanded, they could also be developed as a resource for women who are about to wean. Postnatal HIV transmission through breastfeeding is significant in the case of mixed feeding, which is universal amongst women unable to wean their babies by six months.

Women meet equal constraints in achieving their own health goals. Living positively is an ideal; women in my study are still trying to figure out how to achieve it. This is significant, because it was based on the promised benefits of HIV testing that women decided to know their status. A shift to decentralized HIV interventions, possible through peer counselling and education, and community-based care is one way to provide services to women on their terrain and to bridge poorly integrated services. Moreover, access to biomedical health services needs to be improved, including ART, as well as more comprehensive psychosocial support, including food security. Substantial resources are now flowing into HIV interventions. However, dominant paradigm and policy frameworks determine how programs are designed and delivered. These frameworks have proven ineffective in preventing HIV and should not be repeated in the treatment of women living with HIV. Life-sustaining recommendations are of little use if they are unachievable within the individual lives and local worlds.

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