Access to Healthcare by Pregnant and Lactating Women Living with HIV and AIDS in Kenya

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy

Dalla Lana School of Public Health, Social and Behavioural Health Sciences
University of Toronto

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Abstract

Maternal deaths are the second biggest killer of women of reproductive age. High maternal deaths in sub-Saharan Africa reflect inequities in health services. This study explored how intersecting factors such as gender, class, and other social relations shape access to healthcare among a selected group of HIV-positive Kenyan.

Guided by a postcolonial feminist perspective, the study employed semi-structured interviews to elicit the perspectives of key institutional actors on the challenges and constraints of the health services landscape and in-depth interviews to gain insight into the lived experiences of individual women’s access to healthcare within the healthcare and social context of a purposively selected large Kenyan town.

Key institutional actors’ perspective indicated that the healthcare system is complex, in flux, and homogenized women. They acknowledged that a lack of adequate healthcare funding resulted in unmet needs for people living with HIV, gaps in training of health practitioners and shortage of medical equipment and supplies. Women’s narratives revealed the complexities of their lives. Women’s diversity and agency were reflected in their stories about how they accessed healthcare within this complex healthcare system and within the existing social constraints in this setting.
Women engaged with patriarchy and employed various strategies to access healthcare and strive for positive living. Positive social interactions such as social support were instrumental in motivating women’s access to healthcare. Negative social interactions, such as stigma, blame and social obligations, worked to both hamper and motivate women to access healthcare. Women’s social class intersected with gender and these other social relations to determine their access to healthcare.

A lack of consideration of women’s heterogeneity results in a failure to account for how structures of oppression and gendered inequities translate into diverse material risks for women and impact their ability to access healthcare. A postcolonial feminist perspective, that listened to silenced and homogenized voices, is an effective tool to unmask the circumstances and conditions that affected women’s access to healthcare. This study contributes to the research on maternal health in countries with high maternal mortality and provides the basis for planning and implementing equitable care at local and national levels.
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<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal Care</td>
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<tr>
<td>APHIA Plus</td>
<td>AIDS, Population and Health Integrated Assistance (USAID, NGO)</td>
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<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>CBO</td>
<td>Church-Based Organization</td>
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<tr>
<td>CCC</td>
<td>Comprehensive Care Clinic</td>
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<tr>
<td>CHW</td>
<td>Community Health Worker</td>
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<tr>
<td>CSO</td>
<td>Civil Society Organization</td>
</tr>
<tr>
<td>DASCO</td>
<td>District AIDS/STI Control Office</td>
</tr>
<tr>
<td>FBO</td>
<td>Faith-Based Organization</td>
</tr>
<tr>
<td>FHOK</td>
<td>Family Health Options of Kenya (NGO)</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>KAIS</td>
<td>Kenya AIDS Indicator Survey</td>
</tr>
<tr>
<td>KEMRI</td>
<td>Kenya Medical Research Institute</td>
</tr>
<tr>
<td>KNASP</td>
<td>Kenya National AIDS Strategic Plan</td>
</tr>
<tr>
<td>KNBS</td>
<td>Kenya National Bureau of Statistics</td>
</tr>
<tr>
<td>LE</td>
<td>Life Expectancy</td>
</tr>
<tr>
<td>LMIC</td>
<td>Low- and Middle-Income Countries</td>
</tr>
<tr>
<td>MDG</td>
<td>Millennium Development Goals</td>
</tr>
<tr>
<td>MEGEN</td>
<td>Men for Gender Equality (NGO)</td>
</tr>
<tr>
<td>MMR</td>
<td>Maternal Mortality Rate</td>
</tr>
<tr>
<td>MoGCASD</td>
<td>Ministry of Gender, Children and Social Development</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>MOMS</td>
<td>Ministry of Medical Services</td>
</tr>
<tr>
<td>MOPHS</td>
<td>Ministry of Public Health and Sanitation</td>
</tr>
<tr>
<td>NACC</td>
<td>National AIDS Control Council</td>
</tr>
<tr>
<td>NALEAP</td>
<td>National Legal Aid Program</td>
</tr>
<tr>
<td>NASCOP</td>
<td>National AIDS &amp; STI Control Program</td>
</tr>
<tr>
<td>NCST</td>
<td>National Council for Science and Technology</td>
</tr>
<tr>
<td>NEPHAK</td>
<td>National Empowerment Network for PLWHA in Kenya (NGO)</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
</tr>
<tr>
<td>NHIF</td>
<td>National Health Insurance Fund</td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
</tr>
<tr>
<td>PASCO</td>
<td>Provincial AIDS/STI Control Office</td>
</tr>
<tr>
<td>PCEA</td>
<td>Presbyterian Church of East Africa (CBO)</td>
</tr>
<tr>
<td>PGH</td>
<td>Provincial Government Hospital</td>
</tr>
<tr>
<td>PGHN</td>
<td>Provincial Government Hospital of Nakuru Municipality</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Healthcare</td>
</tr>
<tr>
<td>PLWH</td>
<td>People Living with HIV</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living with HIV and AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child Transmission</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WLWHA</td>
<td>Women Living with HIV and AIDS</td>
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Preface

I start the story of my journey by reflecting on how I first became interested in this area of research. My interest developed during my master’s research project, “Support and Barriers to Exclusive Breastfeeding (EBF) among Women in Nakuru, Kenya,” where I became privy to and sympathetic towards the experiences of accessing healthcare by women living with HIV and AIDS. Participants recruited for my master’s research study were pregnant and lactating women receiving services from the provincial hospital. During my time spent at the hospital, I was able to build relationships with the health professionals at the hospital, in particular, a nurse and a nutritionist who worked closely with women living with HIV and AIDS. I was invited to attend the monthly meetings held by the Mothers’ Club, a support group for women living with HIV and AIDS, at the provincial government hospital.

While the focus of my master’s research was infant feeding, interviews with health professionals and participant observation of these peer support groups revealed that women living with HIV and AIDS in this community faced a number of challenges, including issues of poverty, stigma, and fear of disclosure. In interviews with several different health professionals, I was told that most of the women in the support group at the hospital were of lower socioeconomic status. I was also told that “some of them are very poor … [and have] no food in the house … so we really want to uplift their economic status.” I learned that “disclosure is a very big problem … if [you are] HIV positive, you cannot disclose … you can get blamed and that is the fear, and maybe they will be chased away … or the man abandons the home and goes away.” Many women were afraid of being stigmatized: “they don’t want anybody to know … just want to sit alone … suffer alone.” It was evident that the support counselling these women received from the health professionals and the peer support in the group provided social support, which helped them to live positively.

Through my affiliation with the Department of Nutrition at Egerton University, I was also invited to attend meetings held by a support group for people living with HIV and AIDS, the Badili Mawazo. A faculty member from the Department of Nutrition was working on a livelihood research project, “Small-Scale Income Generation through Poultry Keeping and Farming” with the Badili Mawazo. All members of this group were people living with HIV and AIDS and were clients of an NGO, the Love and Hope Centre, who were participating in its home-based care
program. The Love and Hope Centre provided counselling, medical care, spiritual care, nutritional care, and educational programs on behavioural change. The group’s objective was to restore the dignity of people infected with and affected by HIV and AIDS. They aimed to alleviate suffering through socioeconomic empowerment, capacity building on self-reliance, empowering everyone to cope with HIV and AIDS, and promoting positive living through behavioural change.

Members of the Badili Mawazo were of lower socioeconomic status. The group developed cooperative activities that provided them with food and income. They initiated a number of livelihood projects, where food production was the core activity. The group also made and sold a variety of craft goods, and participated in a microfinance project that allowed some members to save money and set up small businesses.

The insights I gained from my interviews and observations led to the question, “How does poverty and stigma influence the experiences of access to healthcare by pregnant women living with HIV and AIDS?” I had also developed personal relationships with two pregnant women, both of whom were master’s students. Both women were of higher socioeconomic status; one was employed with the Ministry of Public Health and Sanitation. These women were financially secure, and sought and received monthly antenatal care from a private physician and delivered at private facilities. My relationship with these two women led to a second question, “How do the experiences of access to healthcare by women of lower socioeconomic status compare to those of women of higher socioeconomic status?”

My topic evolved as I investigated the literature on access to healthcare in low- and middle-income countries. Much of the literature suggests that patriarchy is a significant factor impacting women’s access to healthcare in low- and middle-income countries. However, most of the literature is based on non-African countries. I reflected on the patriarchal assumptions and on various social relations related to access to healthcare that inform my doctoral work. Kenya is a patriarchal society (Makayoto, Omolo, Kamweya, Harder, & Mutai, 2013); however, I had observed that women in this setting appeared to be very resourceful and resilient. Women of lower socioeconomic status actively looked for and engaged in informal employment, and proactively sought maternal care. Women in the HIV support groups actively sought HIV treatment, care, and support. While there was evidence that patriarchy was a factor in access to
healthcare, socioeconomic status seemed to play a significant role in access to healthcare by women living with HIV. Is the influence of patriarchy different for the three women of higher socioeconomic status with formal employment whom I met and formed relationships with at the university than for the members of the support group who were of lower socioeconomic status? Two of these higher status women had never married; one had adopted a child and owned her own home. A third woman with two children divorced her husband because he was unfaithful and an abusive alcoholic. After her divorce, she purchased land and built a house for her and her children. I postulated that patriarchy might not be the most significant factor impacting women’s access to healthcare in this setting, and that the influence of patriarchy could be different for women of lower socioeconomic status compared to women of higher socioeconomic status.

As I reflected on my experiences and the emerging questions, I realized that my outlook and assumptions come from my social and political location, which determined the questions that I was drawn to investigate and how I engaged in the process of knowledge production (Anderson, Khan, & Reimer-Kirkham, 2011, p. 17). My personal, professional, and social experiences “played a crucial part in the construction and representation of knowledge in my work” (Joseph, 2009, p. 12). I was born and grew up in a country that had been colonized and subsequently gained independence from “foreign rule.” I now make Canada my home, but I am among those referred to as “immigrant women of Colour” (Anderson, et al., 2011, p. 17).

I was born in Trinidad and immigrated to Canada when I was twenty years old. Having lived in Canada for several years now, I have developed a sense of belonging, but still retain my identity as a woman of colour and an immigrant from a postcolonial, developing country with a traditional patriarchal culture. Part of my identity is also that of a full-time employee for many years, first with TD Canada Trust and later with the University of Toronto, before resigning to work on my PhD. I am financially independent, own my own home, and divorced. Reflecting on my own positioning allowed me to become aware of several assumptions I held. I assumed that I would be able to identify with women in Kenya because of a shared postcolonial patriarchal culture, but I found that this was not entirely the case. While I did have some shared identity with women at the university, I did not identify with women of lower socioeconomic status in this setting. I also assumed that as a woman of colour I would not be seen entirely as an “outsider,” but I found that for most people, I was a “muzungu” from Canada. This journey has allowed me to be reflexive about both my personal and academic experiences, which constitute the reflexive
background for my efforts to articulate what I want to understand about access to healthcare by women living with HIV and AIDS in an urban town in Kenya. My experiences have played a critical role in drawing me to this substantive research area. By reflecting on my journey, I am able to lay bare my personal and academic assumptions about this phenomenon, and begin to articulate factors that impact and shape access to healthcare for women living with HIV and AIDS.

As I have outlined above, my journey began in my research with Kenyan women, many of whom lived in poverty. Through women’s narrative interviews, I learned that although culture is important to these women and shaped their breastfeeding practices, “culture intersects in powerful ways with a complex set of social relations, located in women’s histories and their position in the labour market” (Anderson et al., 2011, p.17). The following excerpts from my master’s research (Gayapersad, 2009) provide evidence of complex and intersecting issues:

My mother advised me to give the baby [from birth] cow’s milk and add water and two spoons of sugar in the morning. There are some situations where some children are born hungry and you have to give them other foods like uji [millet flour porridge] before six months. [participant 1]

I was told that I wasn’t on the maternity delivery list and to wait … I was too tired, so I went home. My husband was sick [AIDS] and the other children were at home suffering, so I decided to go home. I gave birth that night at 3 o’clock; I had medicine that I was to give the baby at birth [for PMTCT] … I decided to give formula [for PMTCT]. My husband went to get it – 2 tins, it was ksh.540 then, and that’s how it continued until my husband died. Then it stopped because I couldn’t afford the formula. [participant 2]

The women’s narratives highlighted the harsh realities of their everyday existence. I came to understand that their “life circumstances, not static cultural beliefs,” shaped their breastfeeding practices and that their “positioning in the workforce reflect[ed] deep structural issues” (Anderson et al., 2011, p. 18). This new understanding led me to postcolonial feminist scholarship. Rather than focusing on essentializing women’s culture, my interpretive lens shifted to the material context of these women’s lives. I became concerned with gaining a contextual
understanding of women’s lives, and with how to address structural inequities and ensure equitable access to healthcare (Anderson et al., 2011, p. 18; Anderson et al., 2009, p. 289).

I offer this preface to provide the reader with the context for my academic inquiry. In the following introductory chapter, background information, objectives and research questions will be presented.
Chapter 1
Study Rationale and Goals

The child was tested and the results were HIV positive. When I was tested I was also found HIV positive. My husband was found negative and deserted us in hospital; he reacted very negatively towards me. He gave me some money ... If he had not given me I would have strained I would not have started [ARVs] that particular time. I moved back home with my mother and I was working. I have since then been struggling with my children. My mother helped me to get the courage to accept my situation when I found out I was positive ... I myself started encouraging people who looked weak so that they could go for tests and take drugs.

This is a brief excerpt of one woman’s story in this present study. This is how some women are living their lives in a specific urban setting in Kenya and it is necessary to understand the context of these women’s lives and the social relations that determine their access to healthcare.

According to the World Health Organization (2014a) the high number of maternal deaths in some areas of the world reflects inequities in access to health services and highlights the gap between rich and poor, both among and within countries. In sub-Saharan Africa, where maternal mortality ratios are the highest, a trained midwife, nurse, or doctor attends fewer than fifty percent of women during childbirth. While approximately ninety-one percent of women in Kenya have at least one antenatal care visit, only forty-seven percent have four antenatal care visits, and most women do not receive antenatal care early in their pregnancy (KNBS & ICF Macro, 2010). Forty-four percent of births are delivered in a health facility, while fifty-six percent are delivered at home (World Health Organization, 2013c; KNBS & ICF Macro, 2010).

This study seeks to identify social factors that influence women’s access to healthcare in an urban setting in Kenya. The aim of the study is to explore the intersections between social factors (gender, class, and other social relations) and women’s access to healthcare. Specifically, the
study examines access to healthcare by pregnant or lactating women living with HIV and AIDS in Kenya,\(^1\) one example of many countries in the global south. For the purpose of this study, I use “global south” to refer to developing or low- and middle-income countries\(^2\) (World Bank, 2014); the terms will be used interchangeably. The term “global south” is also used in this dissertation because of its significance in the postcolonial feminist perspective (Mohanty, 2003). This study is not investigating the differentials between men’s and women’s access to healthcare or health outcomes, for example, mortality rates in low- and middle-income countries (LMIC). The study is also not seeking to measure women’s HIV knowledge and its correlation to healthcare access. While the study recruits pregnant and lactating women living with HIV and AIDS, it is not interested in the differences between these two groups. The study concentrates on exploring the experiences of both these groups of women to examine the individual variations in access to maternal and HIV healthcare among women, in their reproductive years and expecting or caring for babies, in one low-income country, Kenya. It asks the question: What accounts for the gaps in women’s access to healthcare across social strata within one area of this diverse and dynamic country?

This study documents and conveys contextual knowledge of twenty-three women’s lives that explored the social relations that determined respondents’ access to healthcare. A set of qualitative methods was appropriate to gather rich contextual stories of respondents’ lives. Employment of a postcolonial feminist perspective illuminated the intersection of complex social relations in their lives (Nayaran, 1998; Mohanty, 2003; Anderson et al., 2009; Kako et al., 2012; Mkandawire-Valhmu et al., 2013).

Contextualized knowledge (local frames of meaning) obtained through qualitative methods as proposed in this study illuminated the “complexity of the intersectionalities among problems such as poverty and suffering, and people’s inability to access appropriate healthcare, and thus provide the basis for planning and implementing equitable care at local and national levels” (Anderson et al., 2009, p. 289). Contextualized knowledge also helped to appreciate the strength

\(^1\) Sub-Saharan Africa is classified as “developing only” by the World Bank, and Kenya is classified as a “low-income” country: http://data.worldbank.org/country/kenya

\(^2\) The World Bank’s definition of a country as a low- or middle-income country (LMIC) is based on gross national income (GNI) per capita.
and agency that individuals possessed in relation to their health and healthcare (Anderson et al., 2009; de Souza, 2010).

An examination of women’s lived experiences through a postcolonial feminist lens (Narayan, 1998; Mohanty, 2003) can provide a more nuanced view of women’s access to healthcare in Kenya (Anderson et al., 2009; Kako et al., 2012). This perspective is useful because the multilayered analysis offered gives insight into how classed and gendered identities, among others, determine the social and material conditions of women’s lives. It exposes classed and gendered inequities and makes explicit how complex intersectionalities organize an individual’s experiences (Collins, 1990; Brewer, 1993; Crenshaw, 1994; Nayaran, 1998; Mohanty, 2003; Anderson, 2004; McCall, 2005; Mkandawire-Valhmu et al., 2013).

Joan Anderson built on both postcolonial feminist (Narayan, 1998; Mohanty, 2003) and intersectionality perspectives (Crenshaw, 1994; McCall, 2005) and extended their application to health and healthcare research. Since Anderson’s work is grounded in health and healthcare, it provides the most useful postcolonial feminist perspective for this study. My scholarly aim is to shed light on the gaps in access to healthcare, and to generate knowledge concerning the context of respondents’ daily existence in response to Anderson’s (2009, p. 289) call for action to address everyday reality as it pertains to pregnant and lactating Kenyan women living with HIV in an urban setting in Kenya. In addition, I am aiming to extend Anderson’s work on health and healthcare by applying a postcolonial feminist perspective in an African setting rather than in a Canadian setting. Recognizing and fully comprehending the poverty and suffering of pregnant and lactating Kenyan women living with HIV would help to better understand, and support, their access to healthcare. Specifically, understanding these women’s experiences accessing antenatal services, facility-based delivery services, and HIV treatment and care may shed light on classed and gendered inequities and other social relations of oppression.

Postcolonial feminism, which allows for complex intersectional analyses of gender, class, and other social relations (Narayan, 1998; Mohanty, 2003; Anderson et al., 2009), will be used as a framework to explore the social possibility and individual ability of women living with HIV and AIDS to access healthcare in an urban setting in Kenya. To my knowledge, this study is the first to employ a theoretical perspective that considers the intersection of a number of social factors and its impact on women’s access to healthcare in Kenya. Knowledge generated in this study
provides information that could be useful to healthcare providers, particularly those working in antenatal and ARV clinics where they come into frequent contact with women living with HIV, and the various strategies discussed here might prove helpful to women in different geographic spaces who are living in similar contexts to those of the women who participated in this study.

1.1 Women’s Health – Globally

Women play a crucial role in development, and women’s health is important for building stable, peaceful, and productive societies (United Nations Secretary-General, 2010, p. 6). There are conditions that only women experience which have a potentially negative impact only they suffer. Some of these conditions, such as pregnancy and childbirth, are biological and social processes that carry health risks and require healthcare (World Health Organization, 2009).

One of the key indicators of women’s health is the number of maternal deaths. Maternal deaths are the second biggest killer of women of reproductive age (World Health Organization, 2013c). The largest proportion of maternal deaths are caused by obstetric hemorrhage during or just after delivery, followed by eclampsia, sepsis, complications of unsafe abortion, and indirect causes such as HIV (World Health Organization, 2014a).

Limited or differential access to healthcare has been identified as a key problem to target in order to reduce maternal mortality (McNamee, Ternent, & Hussein, 2009, p. 42; World Health Organization, 2005, p. 21). The high number of maternal deaths in some areas of the world reflects inequities in access to health services and highlights the gap between rich and poor, both among and within countries (World Health Organization, 2014a). The World Health Organization (WHO) argues that “to improve maternal health, barriers that limit access to quality maternal health services must be identified and addressed at all levels of the health system” (World Health Organization, 2014a, p. 4).

The WHO, the directing and coordinating authority for health within the United Nations system, summarized much of the literature on women’s health. While others such as the World Bank, the International Money Fund, and the academic community shape the health agenda, the WHO plays a significant role in determining this agenda and articulating policy options. A WHO report titled Make Every Mother and Child Count (2005) indicated that the health of mothers in many countries is not making the progress it should because of complex issues such as poverty and
HIV/AIDS, which leave many mothers excluded from healthcare (e.g., antenatal care) to which they are entitled (World Health Organization, 2005). In high-income countries, virtually all women have at least four antenatal care visits, are attended by a skilled health worker\(^3\) during childbirth, and receive postpartum care (World Health Organization, 2014a). In low-income countries, just over a third of all pregnant women have the recommended four antenatal care visits. Only 46 percent of women in low-income countries benefit from skilled care during childbirth (World Health Organization, 2014a).

The Millennium Development Goals (MDGs) all influence health and the health agenda. World leaders committed to “promoting gender equality and empowering women” (MDG 3), and “combating HIV, malaria and other diseases” (MDG 6). MGD1 and MGD5 demand attention to poverty and women’s health. To improve maternal health (MDG 5), countries committed to reducing by three-quarters the maternal mortality ratio and providing universal access to reproductive health (United Nations, 2011). To achieve this goal by 2015, it was recommended that “developing countries governments should adopt development strategies bold enough to meet the MDG targets” and that one of those strategies should include a “focus on women’s and girls’ health (including reproductive health) and education outcomes, access to economic and political opportunities, right to control assets, and freedom from violence” (United Nations Development Program, 2005).

Another WHO report, *Women and Health: Today’s Evidence, Tomorrow’s Agenda*, argues that women’s health is “profoundly affected by the ways in which they are treated and the status they are given by society as a whole” (2009, p. 4). Women’s health is critically affected by social and economic factors such as access to education, household wealth, and place of residence. Women’s lack of access to and control over resources, primary responsibility for care work, restricted mobility, and limited decision-making power may also have an impact on their health (World Health Organization, 2009).

\(^3\) A skilled attendant as defined by the World Health Organization (WHO) is “a health professional – such as a midwife, doctor, [clinical officer –ed.] or nurse – who has been educated and trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the immediate postnatal period, and in the identification, management and referral of complications in women and newborns” (World Health Organization, 2005).
The report also mentions that many women face higher health costs than men due to their maternal and reproductive healthcare needs, yet they are more likely than their male counterparts to be poor, unemployed, or engaged in part-time work or work in the informal sector that offers no health benefits (World Health Organization, 2009). Where there are user fees for maternal health services, households pay a substantial proportion of the cost of facility-based services, and the expense of complicated deliveries is often catastrophic (World Health Organization, 2009).

1.2 Health Policy and Real Women

Health policy set forth by international health organizations to provide guidelines for countries such as Kenya, indicates that “[a]ll families should have access to care that extends from pregnancy, through childbirth and on into childhood” (World Health Organization, 2005, p. 1). Healthcare during pregnancy is vitally important for detecting and managing conditions that may complicate pregnancy and childbirth. International health organizations recommend basic antenatal care that provides women with a package of preventive interventions, including nutritional advice (World Health Organization, 2014a). A minimum of four antenatal care visits is recommended to ensure that pregnant women receive the interventions they need to prevent and manage complications. However, as pointed out earlier, the proportion of women attending antenatal clinics for the recommended number of visits in developing regions remains low (World Health Organization, 2014a).

The WHO has provided guidelines for “special considerations for the care and management of pregnant women living with HIV” (2013c, p. 14). The guidelines recommend minimizing the risk of HIV transmission during labour and delivery by following several key principles and practices, including reinforcing recommended antenatal clinic visits, especially for high-risk management in the late third trimester, and promoting facility-based delivery by trained skilled birth attendants (World Health Organization, 2013c).

An examination of the research literature, including international health policy on maternal health and women’s access to healthcare in the global south, demonstrates that the concepts of “Third World women” (Mohanty, 2003) and “women’s health” have been essentialized, which has implications for determining women’s access to healthcare services (McCormick, Kirkham, & Hayes, 1998). For example, international health policy states that all women need access to
antenatal care in pregnancy and skilled care during childbirth (World Health Organization, 2005, p. 41), a measure, which would reduce maternal mortality ratios. While this statement can be read as emphasizing equity and equality and universalizing access to antenatal care, this policy, when adopted at national levels, may essentialize women’s health by assuming “all women” share the same experiences of healthcare access. By emphasizing antenatal care at the expense of other selective care, such as postnatal continuous maternal healthcare, international health policy while a targeted approach further essentializes women’s health.

While its health policies essentialize women’s health, the WHO recognizes that women’s health and healthcare experiences differ among and within countries (World Health Organization, 2014b). In almost all countries, girls and women living in wealthier households experience lower levels of mortality and make higher use of healthcare services than those living in the poorest households (World Health Organization and UNICEF 2013, 2013).

Within the health sector, the Kenya Health Policy Framework has been the basis for the country’s health agenda. Kenya’s 2010 Constitution and Vision 2030 development agenda guided the Kenya Health Policy 2012 – 2030 (MOMS & MOPHS, 2012). The aims of the health agenda were to provide an efficient, high quality healthcare system where special attention would be paid to lowering HIV incidence and maternal mortality, reducing inequalities in access to healthcare, and providing access to those excluded from healthcare due to financial reasons (Government of the Republic of Kenya, 2007, p. 18).

The Kenya Health System Assessment 2010 report (Luoma et al., 2010) stated that Kenya has implemented important health sector reform measures, and has prioritized strengthening of the health system. But despite this commitment to prioritize health, Kenya’s expenditure on health remains low. The private sector, including households, remains the largest contributor of health funds, at 37 percent of the total health expenditure (THE), while public sector financing has remained constant over the last decade, at about 29 percent of THE. The contribution of donors to THE has more than doubled, from 16 percent in 2001/02 to 34 percent in 2009/10 (Luoma, et al., 2010, p. 17). In Kenya, low government expenditure “compromises the quality of care in the public sector, evident in the shortage of medical supplies, inadequate human resources, and poorly maintained infrastructure” (Luoma et al., 2010, p. 18). Also, overreliance on external resources for key programs such as HIV prevention and care threatens the sustainability of
programs in Kenya. High out-of-pocket (OOP) expenditures limit access to care, especially for poor Kenyans. It has been estimated that 16 percent of sick Kenyans do not seek care due to financial barriers, while 38 percent must liquidate their assets or borrow to pay for medical bills (Luoma, et al., 2010).

Maternal, sexually transmitted infection (STI), and reproductive health services, with 24-hour facility-based delivery service, was available at only 16 percent of all Kenyan facilities. The report also noted that the availability of 24-hour delivery services did not correlate with higher delivery by health professionals. Factors other than availability of health services in Kenya, such as education levels, transportation, cost and other factors, may be significant (Luoma, et al., 2010).

Exploring women’s diversity in access to healthcare is essential in order to address the inequalities in access to healthcare among women in an urban setting in Kenya. Also important is an exploration of the complex and intersecting social factors that influence access to healthcare by women living with HIV in this specific setting (Anderson, 2004). An understanding of these issues may prove useful to health providers and policy makers to help curb the alarming trend in maternal mortality in Kenya.

1.3 Study Setting

The purpose of this study is to explore and analyze the intersecting factors that shape access to healthcare by pregnant women living with HIV and AIDS in an urban setting in Kenya. In order to achieve this goal an understanding of the urban Kenyan setting is necessary. The setting, a large town, located in the South Rift Valley, is among the five largest urban centres and one of the fastest growing towns in Kenya. It is an important agricultural city, trade centre, and transportation corridor to the western agricultural region for the whole of Kenya. As a result, this urban centre has become a migrant town and is home to many of Kenya’s ethnic groups.

From my own experience and observations, this setting in Kenya is a vibrant and thriving town. The town centre is a vibrant hub for small and large businesses, including several major banks, grocery chain stores, restaurants, retail clothing stores, competing telecom outlets, as well as a large outdoor food market, numerous street hawkers, and several matatu (mini-bus) stages. The
town has several major hotels to service a busy tourist industry due to its close proximity to a national park and easy access to several other attractions located in the vicinity.

It is also an important educational centre, with a large public university, and is fast becoming a centre for academics, with many satellite campuses from various Kenyan universities. Many of the official government offices are located in the town, including the Ministry of Public Health and Sanitation, and the district and provincial AIDS and STI offices. Also located in the town are several non-governmental organizations (NGOs), churches and faith-based organization (FBOs), private hospitals, private health practitioners, and the provincial government hospital.

The central business centre is surrounded by residential areas: large luxury homes where the wealthy live, smaller homes and low rise apartments where the middle class lives and a number of surrounding slums where the urban poor live. The town seemed very cosmopolitan, with diverse ethnic African groups, East Asians, Western tourists, and Chinese development workers. My primary interaction was with my Kenyan friends and colleagues, many of whom were Kikuyu, Kalenjin, Luo, and Luhya. Through them I learned that this town was a political hotbed, and I heard first-hand accounts from a number of them of the 2007 post-election violence between ethnic groups. Many Kikuyus were displaced, including the families of a number of my friends, during this period. More recently, during the 2012 election, there seem to be greater awareness among my friends of the politics of ethnicity. Because of this awareness, they agreed that violence would not be part of the 2012 election. The 2012 election in Kenya took place without ethnic violence.

Due to the many months I spent in this setting, I became very familiar with the town and the transportation network, so I was able to navigate my way around town and the surrounding areas quite easily. Much of my work was conducted in town, at the hospital, and in the surrounding slums. I do acknowledge my class privilege and that it creates its own biases. I point this out in case it is not obvious in my writing. My personal vision stems from my Indo-Caribbean heritage and though participants’ perspectives were different from my own one commonality we shared was that we were all born and raised in so-called “Third World” countries.
1.4 Research Questions

A qualitative study was conducted and drew on a postcolonial feminist perspective to examine the contextual, social, and material issues associated with access to healthcare for this specific group of women. The following research questions guided my exploration of this research subject:

(1) How do patriarchy and agency shape experiences of access to and utilization of healthcare for HIV-positive pregnant and lactating women in an urban setting in Kenya?

(2) How does the intersection of gender and class structure access to and utilization of healthcare?

(3) How do other social relations shape these women’s ability and willingness to access healthcare?

These questions guided the study to gain an understanding of the everyday experiences of pregnant women living with HIV and the activities they engaged in to ensure their healthcare needs were met. These questions are important for Kenya today and also for countries facing similar situations. A qualitative approach employing narrative in-depth interviews was used to explore these experiences. Through this type of exploration, I examined issues of agency and patriarchal oppression, and the intersection of gender and class and other social relations.

Using an interpretative analysis of the data, this study aims to provide an understanding of these and other social relations, which constrain or empower pregnant women living with HIV and AIDS when they are negotiating access to healthcare. The present study sought respondents who all had some access to healthcare, but aimed to understand how access varied based on their socioeconomic status. The aim was to analyze women’s narratives to reveal the complexities of their lives and question if they are a homogeneous sociological group characterized by common dependencies or powerlessness. The present study explored whether a lack of consideration of women’s heterogeneity results in a failure to account for how structures of oppression and gendered inequities translate into diverse material risks or crises for women and impact their ability access to healthcare.
Contextual knowledge from women and key institutional actors in this urban setting in Kenya can inform the management of maternal conditions and health policy and practice. It can inform the Kenyan government and healthcare system when they are considering the issue of equity and targeting vulnerable population subgroups during the development of strategies for increasing interventions and reaching national health goals (World Health Organization and UNICEF 2013, 2013).
Chapter 2
Women's Access to Healthcare in Low- and Middle-Income Countries

This chapter highlights the risks that some women face due to the lack of access to maternal healthcare in LMIC. It examines the literature on women’s access to healthcare in LMIC. The literature reviewed indicates that international health policy essentializes women and women’s health in LMIC because it fails to account for women’s diversity or for the structures of oppression and gendered inequities these women experience. Patriarchy is the predominant theoretical concept used in the literature to describe women’s access to healthcare in LMIC. This patriarchal framework has essentialist overtones (Crompton, 1998; Acker, 1989; Pollert, 1996) and fails to adequately capture women’s experiences of access to healthcare in an LMIC setting such as Kenya.

2.1 Pregnancy Is a Disproportionate Health Risk for Poor Women

In contrast to rich countries, maternal deaths and HIV and AIDS are leading causes of death for women of reproductive age (15 to 44 years) in LMIC (World Health Organization, 2013c) (Figure 2.1). Ninety-nine percent of all maternal deaths (289,000 worldwide) occurred in the global south (Table 2.1). More than half these deaths (56 percent) occurred in sub-Saharan Africa (World Health Organization, 2014b). The most dangerous place for a woman to have a baby is sub-Saharan Africa, where 1 in 40 women is at risk of dying during pregnancy and childbirth compared to 1 in 3,300 women in Europe (World Health Organization, 2014).
The WHO (2014b) suggests that most maternal deaths can be prevented through skilled care at childbirth and access to emergency obstetric care. In sub-Saharan Africa, where maternal mortality ratios are the highest, a trained midwife, nurse, or doctor attends fewer than 50 percent of women during childbirth. Women who do not receive the necessary check-ups miss the opportunity to detect problems and to receive appropriate care and treatment. Care also includes immunization and prevention of mother-to-child-transmission of HIV and AIDS (World Health Organization, 2014b).

The WHO 2005 report *Make Every Mother and Child Count* (World Health Organization, 2005) highlighted that women with HIV have a greater risk of pregnancy and childbirth complications. AIDS is also a major indirect cause of maternal mortality through increased rates of malaria and opportunistic infections such as tuberculosis. In Rakai, Uganda, for example, maternal mortality was 1,687 per 100,000 live births among HIV-infected women compared to 310 per 100,000 live births among non-infected women (World Health Organization, 2005). Children of an HIV-positive mother have a higher mortality risk than children of HIV-negative mothers. HIV

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infection in children, almost always acquired through mother-to-child transmission, causes high mortality rates, and some 60 percent of infected children die before their fifth birthday (World Health Organization, 2005).

### Table 2.1: Estimates of Maternal Mortality Ratio, Number of Maternal Deaths, and Maternal Deaths Attributed to HIV/AIDS, by United Nations MDG* Region, 2013

<table>
<thead>
<tr>
<th>Region</th>
<th>MMR†</th>
<th>Number of maternal deaths</th>
<th>AIDS-attributed MMR</th>
<th>Number of AIDS-related maternal deaths</th>
<th>Percentage of AIDS-related indirect maternal deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>World</td>
<td>210</td>
<td>289,000</td>
<td>5</td>
<td>7,500</td>
<td>2.6</td>
</tr>
<tr>
<td>Developed Regions</td>
<td>16</td>
<td>2,300</td>
<td>0</td>
<td>65</td>
<td>2.8</td>
</tr>
<tr>
<td>Developing Regions</td>
<td>230</td>
<td>286,000</td>
<td>6</td>
<td>7,400</td>
<td>2.6</td>
</tr>
<tr>
<td>Sub-Saharan Africa</td>
<td>510</td>
<td>179,000</td>
<td>19</td>
<td>6,800</td>
<td>3.8</td>
</tr>
<tr>
<td>Kenya</td>
<td>400</td>
<td>14,700</td>
<td>Not available</td>
<td>Not available</td>
<td>5.4</td>
</tr>
</tbody>
</table>

* MDG = millennium development goals
† MMR = maternal mortality ratio: maternal deaths per 100,000 live births

Source: World Health Organization.5

#### 2.2 Defining Access to Healthcare

Within healthcare, access is a complex concept with many different definitions; its meaning has changed over time and according to context. A conceptual definition of access posed by the WHO (1978) in the Alma-Ata declaration is as follows:

> Accessibility implies the continuing and organized supply of care that is geographically, financially, culturally, and functionally within easy reach of the whole community. The care has to be appropriate and adequate in content and in amount to satisfy the needs of people and it has to be provided by methods acceptable to them. (p. 58)

Based on this definition offered in the Alma-Ata declaration (WHO, 1978, p. 58) access, or “accessibility”, is about the availability of healthcare services. For healthcare utilization

individuals must have geographic, financial, culturally, and functional access to healthcare. The Alma-Ata declaration states that societies at different stages of development should define access in different ways based on their stage of development (p. 59). The Kenya Ministry of Public Health and Sanitation Strategic Plan, 2008–2012 defines access as “a prerequisite to high utilization of health services as it brings the services closer to the people. Access is influenced by geographical, economic and socio-cultural factors” (MOPHS, 2008). This definition was adapted from the Alma-Ata Declaration (WHO, 1978) definition. Here, access to health services has been described as a supply-side phenomenon, whereby the emphasis has been laid on the availability of services and the opportunity to use them (Mooney, 1983). The World Health Organization (2000) defines access to health care as the possibility of obtaining care when it is needed.

An adequate supply of health services needs to be available in order to “have access.” The availability dimension of access to healthcare is concerned with the opportunity to obtain healthcare when it is wanted or needed; it is measured “traditionally using indicators such as the numbers of doctors or hospital beds per capita” (Gulliford et al., 2002, p. 186). According to Michael Thiede (2005), health policy in many countries has been guided by a focus on the supply-side factors of healthcare access: availability and physical provision of health services. He argues that assessing the number of individuals per doctor or the distance to the nearest health facility does not take into account individual or societal-related factors (Thiede, 2005).

Penchansky and Thomas (1981, p. 139) proposed that “access is a measure of the ‘fit’ between characteristics of providers and health services and characteristics and expectations of clients, and that this concept includes five dimensions: availability, accessibility, accommodation, affordability and acceptability.” This approach proposed by Penchansky and Thomas “extended the concept of access beyond service availability, to consider the personal, financial and organizational” aspects of access (Gulliford et al., 2002, p. 187). Service availability is a rather limited measure of access to healthcare, because people in need may often have access to services and yet encounters various difficulties in utilizing services (Gulliford et al., 2002, p. 186).

Thiede defines access as the “social possibility and individual ability to use health services” (2005, p. 1453). The approach is based on the “doings and beings,” described by Sen (as cited in Thiede, 2005, p. 1454) as “functionings”. These “functionings”, central to well-being, vary from
elementary ones, such as escaping morbidity and mortality, to more complex ones, such achieving self-respect. Capability is a person’s functions or ability to achieve well-being (Sen, 1993). This concept of capability is closely related to Thiede’s (2005, p. 1454) paradigm of access. Thiede (2005) suggests that access across health systems is a precondition for health services utilization where services are needed. Access to healthcare, therefore, is not an objective concept that can be measured solely on availability. Thiede’s definition informs this study.

There is much ambiguity regarding the term “access”; having access to healthcare does not automatically lead to utilization. The various definitions of access in the literature often emphasize one or more of the dimensions of access. I propose that access as it pertains to this study is whether women, who can potentially benefit from effective and comprehensive healthcare, have the individual ability and the social possibility to access healthcare. This study investigated the relational factors that may limit women’s subjective experiences or ability to access health services. Understanding the issues that constrain or empower pregnant women living with HIV and AIDS and their access to healthcare in Kenya is salient to improving maternal health (World Health Organization, 2014b).

2.3 Essentialist Perspectives to Women’s Health

2.3.1 Policy approach to women’s health

Essentialism is the view that categories of living things (in this case, women) have an underlying reality or true nature that cannot be observed directly but which gives the object or member of the category its identity (Gelman & Taylor, 2000). Essentialism legitimizes dominant interpretations and definitions, and suggests unproblematic, ahistoric, and universal characteristics. As it pertains to women, it suggests that there is an “essential female nature that is universal and unchanging or they have a common trait that links all women as women” (McCormick et al., 1998, p. 497). Chandra Talpade Mohanty (2003, p. 22) points out that the category “women” is inherently problematic because it assumes that all women, across classes and cultures, are socially constituted as a homogeneous group.

Like the concept of “women,” the concept of “women’s health” is also essentialized (McCormick et al., 1998). Definitions of women’s health perpetuate a medical or disease model and limit the vision of women’s health. Biological essentialism has led to a focus on women as
reproducers, so that women’s health is primarily considered in terms of reproductive capacity and function. Biological essentialism marginalizes women’s health issues that are not related to biological aspects of reproduction. The focus on women as reproducers has led to gender blindness with regard to other health problems that have important sex and gender dimensions, including HIV and AIDS (Rogers & Ballantyne, 2008, p. 51). This blindness or bias has profound political implications for determining which programs are supported and for facilitating women’s access to healthcare services (McCormick et al., 1998).

International health policy tends to essentialize women’s health (Varcoe, Hankivsky, & Morrow, 2007). Essentialism in this regard assumes that all women (as a category) share the same experiences, views, and priorities regardless of cultural background, geographical location, economic status, or other differences (Hankivsky et al., 2010). It is argued that traditional conceptualizations of women’s health have been limited by the failure of policy to take the diversity of women into account (Varcoe et al., 2007).

HIV policy and practice tend to reinforce essentialisms about women. There are two essentialized and contested assumptions of women in the HIV literature: rational neoliberal agents and vulnerable victims. The biomedical narrative makes assumptions about women’s agency (health related social action) (Popay et al., 2003), while the social narrative emphasizes women’s vulnerability. According to Kippax and Stephenson (2012, p. 789), the biomedical dimension of HIV prevention focuses on an individualistic view, where women living with HIV are seen as “rational neo-liberal agents who, when counseled by experts, adopt the prevention technologies advocated or change their behaviour to reduce HIV transmission” (Kippax & Stephenson, 2012, p. 789).

Although it has been recognized that HIV is a disease of the poor, and that poverty and developmental schemes have resulted in specific groups being exposed to occupations like sex work, “interventions simply involve a search for biomedical cure and behaviour modification of individuals or risk groups” (Yadavendu, 2013, p. 172). The biomedical model is both reductionist and problematic. Fee and Krieger outline this biological individualism as follows:

The biomedical model is also premised on the ideology of individualism. Adopting the notion of the abstract individual from liberal political and economic theory, it considers individuals ‘free’ to ‘choose’ health behaviours. It treats
people as consumers who make free choices in the market place of products and behaviours, and it generally ignores the role of industry, agribusiness, and government in structuring the array of risk factors and individuals are supposed to avoid. There is little place to understand how behaviours are related to social conditions and constraints or how communities shape individuals’ lives. From this perspective, populations and subgroups within populations – including ‘risk groups’ – consist merely of summed individuals who exist without culture and history. (Fee & Krieger, 1993, p. 1481)

The dominant focus of HIV-related discourse and policies has always been biomedical, with a particular emphasis on treatment. According to the Treatment 2015 framework (UNAIDS, 2012, p. 4) a “recent review of prevention intervention trials noted that among the biomedical prevention tools evaluated to date, effective antiretroviral therapy provides the greatest prevention effect.” This increased attention to antiretroviral (ARV) therapy to prevent HIV infection comes from large randomized control trials such as the phase 3 clinical trial HPTN 052, conducted by the HIV Prevention Trials Network and funded by the US National Institutes of Health. This clinical trial provided clear evidence of reduced HIV transmission and acquisition when antiretroviral drugs are provided immediately to HIV-infected individuals in serodiscordant relationships (Cohen et al., 2011).

The HPTN 052 study (Cohen et al., 2011) and others such as the PARTNER study (Rodger et al., 2014) have led to the endorsement of treatment as prevention (TasP) by USAIDS (2012) and the World Health Organization (World Health Organization, 2012; World Health Organization, 2013a). The underlying principle of TasP is to reduce the risk of HIV transmission with antiretroviral therapy to suppress viral load to undetectable levels in people diagnosed with HIV, in turn reducing the transmission risk to uninfected partners and also “reducing community viral load, that is, the aggregation of individual viral loads of people infected with HIV in a specific community” (Newman et al., 2015).

Kulkarni, Shah, Sarma, and Hahajan (2013) completed a systematic review of the clinical rationale, operational feasibility, and ethical appropriateness of the test-and-treat strategy being promoted to prevent and eliminate new HIV infections. Concerns were raised with regards to the clinical uncertainties of drug toxicities and ARV resistance from early treatment. Concerns were
also raised about healthcare systems or healthcare workforce capacity to deal with higher patient volumes and sustainable funding to scale up HIV care systems to ensure lifelong treatment, especially in low- and middle-income countries. Prioritizing public health benefits of TasP over individual-level clinical benefits and risks also raised ethical concerns (Kulkarni et al., 2013).

While people living with HIV have recognized the potential benefits of Treatment as Prevention (TasP), they have also expressed concerns (Newman et al., 2015). It was found that “many participants felt that TasP messages overlooked the potential diversity of needs and situations of individuals, who each have a unique story to tell, live in a particular social context, and have a specific health and social history which they feel must be taken into account when making decisions about treatment” (Newman et al., 2015, p. 830).

Treatment 2015 (USAIDS, 2012, p. 5) has three fundamental pillars:

1. **Demand.** Creating demand for HIV treatment – led by people living with HIV, as well as by key populations heavily affected by HIV, and sustained by civil society and the international community.

2. **Invest.** Mobilizing sustained investment, giving priority to innovation, and using the available resources as strategically as possible.

3. **Deliver.** Ensuring that health and community systems, infrastructure, enabling laws and policies, as well as community systems are in place to deliver treatment to all people living with HIV who are eligible.

The Treatment 2015 framework (USAIDS, 2012) leverages international and national guidelines on HIV testing and treatment. However, limited resources may result in the provision of antiretroviral therapy (ART) to asymptomatic individuals in one setting, but a significant number of individuals who meet current World Health Organization guidelines for therapy may not receive treatment. Also scarce resources may be redistributed, which will divert resources away from other forms of HIV prevention and other diseases and conditions (Kulkarni et al., 2013, p. 20).

The main component of the Treatment 2015 framework is to continue and expedite scale-up towards universal access to treatment for all people worldwide who need antiretroviral therapy.
The primary focus is therefore on the supply side and availability of access to HIV treatment. However, as recognized, international and national guidelines adopting the TasP approach do not account for the diversity and social context of people living with HIV (Newman et al., 2015).

In the 1990s, UNAIDS and the World Health Organization adopted a vulnerability approach (Kippax, Stephenson, Parker, & Aggleton, 2013, p. 1368). UNAIDS’ description of vulnerability is as follows:

Vulnerability refers to unequal opportunities … and other social, cultural, political, and economic factors that make a person more susceptible to HIV … Factors underlying vulnerability may reduce the individuals’ ability to avoid HIV risk. Factors include: accessibility, quality, and coverage of services; and social and cultural norms. Norms can include practices, beliefs, and laws that stigmatize and disempower certain populations, limiting their ability to access or use HIV prevention, treatment, care, and support services. These factors, alone or in combination, may create or exacerbate individual and collective vulnerability to HIV. (USAIDS, 2011, p. 24)

In the social narrative, “vulnerability” (Mann, Tarantola & Netter, 1992; Ayres, Paiva, & França, 2011; Kippax, Stephenson, Parker, & Aggleton, 2013) is conceptualized as social structures or social barriers such as gender or poverty. Vulnerability is seen as an attribute that similar individuals (female) possess. Women are seen to constitute a vulnerable population where they are positioned separate from the social; their actions and behaviours are “acted on and driven by the social, but are unable to act upon it” (Kippax et al., 2013, p. 1369). For example, a study conducted in South Africa indicated that women’s greater biological susceptibility to HIV accounted for higher HIV prevalence among women than men and that “a host of sociocultural and economic factors rooted in gender power inequities exacerbate women’s vulnerability to infection” (Pettifor, Measham, Rees, & Padian, 2004, p. 1996).

Edstrom (2010) argues that vulnerability “fails to capture intention, desire, agency and dynamics between people, or how those interactions are shaped by and also influence structural contexts” (p. 217). This notion of vulnerability also essentializes gender by reinforcing an equation between femininity with women and masculinity with men (Edstrom, 2010, p. 217). Women are framed as vulnerable, disadvantaged, and unfortunate victims; they are seen as mothers, faithful
and domestic, passive and powerless (Edstrom, 2010). These narratives and frames ignore women’s agency and initiative. Women are not seen as resourceful, opportunistic, and empowered. Women’s sexual relationship choices to supplement their livelihoods with direct sex work are seen as “lack of choice” rather than as “distress response” to poverty and hunger (Edstrom, 2010). These essentialisms fail to account for how structures of oppression and gendered inequities translate into diverse material risks or crises for women (Edstrom, 2010).

Despite the critique of vulnerability having negative implications for women’s agency, the concept has had it benefits. HIV activists tapped into the concept of vulnerability to develop declarations that provided a framework for their demands for HIV and sexual and reproductive health and rights specific to women living with HIV (Bell, Mthembu, O’Sullivan, & Moody, 2007; Edstrom, 2010). In 2002 the first charter, the Barcelona Bill of Rights, was initiated by the International Women’s AIDS Caucus of the International AIDS Society and the International Community of Women Living with HIV/AIDS (ICW). The Bill highlighted “elements of rights of particular relevance to HIV-positive women, including the right to live with dignity and equality, to bodily integrity, to health and healthcare, including treatment, to safety, security and freedom from fear of physical and sexual violence, to be free from stigma, discrimination, blame and denial, to human rights regardless of sexual orientation, to sexual autonomy and sexual pleasure, to equity in our families, to education and information and to economic independence” (Bell et al., 2007, p. 115).

Another charter, the HIV-Positive Young Women’s Sexual and Reproductive Rights Charter, organized by the ICW declared that HIV-positive women have the same rights as other women but also need access to HIV-specific information and services. Sexual rights such as the right to say “no” to sex and to practice safer or protected sex were outlined in the charter. The charter included reproductive rights such as the right to decide whether and when to conceive without being judged, and the rights to safe delivery and breastfeeding, to quality antenatal care, to equal access to reproductive healthcare, regardless of social, economic or political status, and to access HIV-preventive methods (Bell et al., 2007, p. 114).

In many studies in the HIV literature, as outlined above, assumptions are made of women’s agency without consideration of their diversity and the social context in which they live; others emphasize vulnerability, which robs women of their identity and individuality. I wanted to
interrogate these polarized views and address the issue of women’s agency and vulnerability in this urban setting in Kenya as it pertains to pregnant and lactating women living with HIV and their access to healthcare.

As mentioned in the “Preface” my previous work (Gayapersad, 2009) in Kenya revealed that women in this setting appeared to be very resourceful and resilient. Women of lower socioeconomic status actively looked for and engaged in informal employment and proactively sought maternal care. Women in the HIV support groups actively sought HIV treatment, care, and support. While there was evidence that patriarchy was a factor influencing access to healthcare, socioeconomic status seem to play a significant role in access to healthcare by women living with HIV (Gayapersad, 2009).

The framing of women as active agents or as vulnerable victims informs policy; these polarized views have policy implications. For example, HIV health policy recommend that pregnant women living with HIV should access and adhere to HIV care and treatment, seek antenatal care, and have a facility based delivery, to prevent mother to child transmission of the disease. Policy is based on the assumption that women are rational neo-liberal agents who are able to access these services (Kippax & Stephenson, 2012). A significant challenge is the operationalization of HIV and sexual and reproductive health policies to address the inequities in access to healthcare. The global challenge is how to implement policy and health system support practices within local contexts in populations that are fundamentally heterogeneous. Health policy makers and healthcare workers need to consider wider social and structural challenges faced by women, including patriarchy.

2.3.2 Patriarchy and women’s health

A review of the literature suggests that “developing countries” have been homogenized, in many academic analyses, with little effort made to differentiate sub-Saharan African countries from south Asian countries. These developing countries have been essentialized as patriarchal. For example, a study on women’s autonomy and their involvement in decisions related to their own healthcare makes comparisons between countries such as Bangladesh and Kenya (Ahmed, Creanga, Gillespie, & Tsui, 2010).
The claim that women in developing countries lack autonomy is prevalent in the literature. It has been concluded that patriarchy is the ideological foundation for gender inequity, which limits women’s access to health resources in many low-income countries (Ahmed, Adams, Chowdhury, & Bhuiya, 2000; Nikiema, Haddad, & Potvin, 2008; Okojie, 1994; Ojanuga & Gilbert, 1992; Vlassoff, 1994; Zaidi, 1996). Christiana Okojie (1994) defines patriarchy as “the sum of institutional mechanisms that serve to limit women’s economic autonomy relative to men’s” or as “a set of social relations with a material base that enables men to dominate women” (p. 1237). Women’s subordination to men translates into all aspects of life in society, including access to resources and decision-making power. Many women in low-income countries cannot make decisions regarding when to seek healthcare; a spouse or senior member of the household makes healthcare decisions on behalf of women in these countries (Okojie, 1994; Ahmed et al., 2010). Researchers, for example, indicate that “dependence on men for economic survival has been a principal barrier to women’s control over their reproductive behaviour in developing countries” (Sharma, Sawangdee, & Sirirassamee, 2007, p. 674) and that raising women’s status will empower them to make decisions about their healthcare.

Gender inequities in the modern healthcare system are manifested largely through lack of access to healthcare for women and girls, including limited access to health facilities (Ahmed et al., 2000; Okojie, 1994; Ojanuga & Gilbert, 1992; Puentes-Markides, 1992; Vlassoff, 1994; Zaidi, 1996). According to Ojanuga and Gilbert (1992), gender analyses of health and healthcare utilization in developing countries reveal that women suffer poorer health and face various sociocultural factors which negatively impact their physical well-being and their access to appropriate healthcare services. A study that examined the gender inequities of health in Third World countries, including Bangladesh, Ghana, India, Korea, Nigeria, Rwanda, and Senegal, found that a woman’s limited decision-making autonomy restricts her access to transportation and leads to discrimination in healthcare utilization, resulting in high maternal mortality rates and morbidity from various gynecological problems (Okojie, 1994). There is a tendency in the literature to support the claim that women in “developing countries” lack autonomy with regards to their healthcare (Ahmed et al., 2010). Based on my experiences in Kenya, I believe we have not done enough work in this area.

The link between gender asymmetry and disadvantage in access to healthcare has been established mainly for South Asia, where strong patriarchal social structures are prevalent.
Evidence of this link is provided by women’s health-seeking behaviour in Bangladesh (Ahmed et al., 2000). In their study, Ahmed et al. (2000) found persistence of gender differentials in health-seeking behaviour; although women of reproductive age appeared to suffer equally from the burden of illness as men, they sought treatment significantly less often. The researchers suggest that these gender differentials in treatment seeking most probably reflect the powerful influence of patriarchy in rural Bangladeshi society (Ahmed et al., 2000).

A Kenyan study (Fotso, Ezeh, & Essendi, 2009) argues that the growing body of knowledge concerning women’s autonomy and their access to healthcare in developing countries offers little empirical evidence from sub-Saharan Africa, where “the patterns of women's status and social position have been shown to differ from those observed in Asia and other parts of the developing world” (Fotso et al., 2009, p. 2). The study demonstrates that the influence of women’s autonomy on the utilization of maternal health services among poor women in Nairobi is weak on average, while women’s household wealth and education were identified as strong correlates (Fotso et al., 2009).

A study in Burkina Faso, “Women Bargaining to Seek Healthcare,” did not detect an obvious gender gap in healthcare utilization, but suggested that traditional norms and mechanisms of intrahousehold resource allocation continue to influence women’s access to healthcare in sub-Saharan Africa (Nikiema et al., 2008). In the groups studied, gendered norms pointed to women’s subordination to their husbands, and a woman’s ability to mobilize resources for healthcare depended on her right to benefit from joint resources (Nikiema et al., 2008). These researchers acknowledged that sociocultural heterogeneity is particularly relevant in the pluralistic context of sub-Saharan Africa, where these sociocultural factors significantly shape women’s access to healthcare (Nikiema et al., 2008).

A “gender paradox” exists in the HIV research data, which indicate that more women access antiretroviral treatment (ART) than men (Bila & Egrot, 2009). A particularly relevant study, “Gender Asymmetry in Healthcare-facility Attendance of People Living with HIV/AIDS in Burkina Faso” (Bila & Egrot, 2009), offers an anthropological analysis focusing on gender and the organization of the health system in an African context. The study found that the social values attached to female gender create conditions that favour women’s attendance at care facilities for people living with HIV (PLWH). The high cultural value placed on maternity; the
social representation of the role of women in children’s survival, upbringing, and education; and the status of wife in the husband’s lineage are factors that encourage women to go to care facilities. Health policy and the promotion of women’s empowerment within the healthcare system for PLWH add to the previously mentioned cultural factors in maintaining and strengthening women’s facilitated and privileged access (Bila & Egrot, 2009).

Scholars argue that patriarchy has essentialist overtones and effectively overrides the complexities of contemporary gender relations (Crompton, 1998; Acker, 1989; Pollert, 1996). According to Rosemary Crompton (1998), the concept “patriarchy” is essentialist in that it is “predicated on men’s oppression of women which remains the most significant causal explanation of gender relations” (p. 132). Crompton suggests that this essentialist view allows little room for change, and that gender relations should be viewed as structured in the context of employment, families, and state institutions, where these structures are negotiated and interpreted by changing and flexible gendered subjects (Crompton, 1998).

Patriarchy does not account for the consequences of poverty; neither does it determine relations of production and reproduction that exploit the lives and labour of African women (Madison, 2008). In the 1960s and 1970s, patriarchy provided the essential focus and the identification of the theoretical object for thinking about the subordination of women (Acker, 1989). Patriarchy was seen as a “universal, trans-historical, and transcultural phenomenon; women were everywhere oppressed by men in more or less the same ways” (Acker, 1989, p. 235). This notion of patriarchy, according to Acker (1989), tended towards a biological essentialism that provided no strong basis for theorizing the vast historical and contemporary variations in women’s situations.

Anna Pollert (1996) argues that patriarchy, as an analytical tool does not adequately allow for analysis of gender and class; because it has a one-dimensional focus on gender, patriarchy neglects class dynamics (pp. 655–656). Pollert also claims that the use of the concept “patriarchy” does not allow for the “possibility of struggle for change among both women and men as gendered subjects” (p. 641).
2.3.3 Moving beyond essentialisms

While gender-based analysis in health is often concerned with demonstrating how the differences between genders affect health status, access to, and interaction with the healthcare system, its complexity and interaction with other determinants has been inadequately investigated and understood (Hankivsky & Christoffsen, 2008). Hankivsky and Christoffsen (2008) argue that “[t]he lack of attention to how gender interacts with or is modified by other determinants of health or in fact may be less relevant than other factors wrongly essentializes the experiences of women, reifies existing inequities among different groups of women and arguably leads to the production of faulty and incomplete knowledge” (p. 273). Postcolonial feminism allows for a complex intersectional analysis of gender, class, race/ethnicity, and other social relations (Collins, 1990; Brewer, 1993; Crenshaw, 1994; Nayaran, 1998; Mohanty, 2003; Anderson, 2004; McCall, 2005). A postcolonial feminist perspective departs from the construction of African women as powerless victims of patriarchy (Mohanty, 2003), and provides a more explicit examination of the inequities in women’s access to healthcare (Anderson et al., 2009). Chapter 3 presents a more in-depth review of postcolonial feminism.
In this chapter, I will discuss the theoretical framework that was employed to explore access to healthcare by pregnant and lactating women living with HIV in an urban setting in Kenya. First, I will discuss the premise of postcolonial feminist scholarship relevant to my work. Second, I will examine the primary postcolonial feminists who informed my approach. Postcolonial feminism played a central role in this research study from conceptualization and data collection to data analysis. In this qualitative inquiry, working with a postcolonial feminist lens meant data collection and analysis employed an interpretive perspective concerning the lived experiences of women in LMIC and their access to healthcare that recognized the material (access to food, safe housing, adequate income) and social (race, class, gender and other social relations) circumstances of women living with HIV and AIDS.

Arthur Frank (2013) argues for theory-grounded research. The following is his perspective on the role of theory:

Theory presents a vision of society that is grounded in empirical observation but is more than the sum of observations alone. Theory understands observations within the framework of specific concerns about how collective life is assembled. Thus, theory both derives from observations and informs understanding of what is observed. (Frank, 2013, p. 19)

Theory helps orient the researcher in the field to observe particular activities and to identify patterns within the data (Hammersley & Atkinson, 2007), and should be “inclusive of the voices that will interrupt the taken for granted structures inscribed upon us through relations of power” (Anderson, 2000, p. 225). Joan M. Anderson (2004, p. 244) further indicates “[o]ur analytic tools must enable us to unmask the circumstances and conditions that affect individual lives.” The analytic tool, postcolonial feminism, employed in this study is described in the following sections of this chapter.
3.1 Postcolonial Feminism

Before delving into postcolonial feminism it is worthwhile to briefly discuss postcolonial theory as it provides a historical context of the emergence of postcolonial feminism perspectives. Postcolonial theory developed from the work of Edward Said, the colonial discourse theorist. Said (2000) defines colonization as

the expansive force of a people; it is its power of reproduction; it is its enlargement and its multiplication through space; it is the subjugation of the universe or the vast part of it to that people’s language, customs, ideas, and laws. (p. 135)

Said (2000) analyzed how Europeans in the nineteenth century represented various cultures they came into contact with through imperial expansion. According to Said (2000), the West presented these other cultures as an “Other” to a Western norm. A central tenet of postcolonialism is to “create alternative discourses that challenge established, dominant discourses by giving voice to those who have been marginalized and viewed as Other” (Khan et al., 2007, p. 231). Anderson (2002) suggests postcolonialism provides

a window for understanding how conceptions of ‘race’, notion of the racialized ‘Other’ (written with an initial capital to denote a specific category and space to which ‘non-western’ people, constructed as inferior through the process of racialization and cultural essentialism, have been assigned), fluid identities, and hybrid cultures, have been constructed within particular historical and colonial context. (p. 8)

Of particular significance, postcolonialism illuminates the process by which “concepts such as ethnicity, race, and culture have been constructed and used to create binaries by locating non-European peoples as the essentialized, inferior, subordinate Other” (Khan et al., 2007, p. 230). Reimer-Kirkham and Anderson (2002) note that ethnicity, race, and culture are often used interchangeably to convey “difference.” The process of “Othering” reaches into the everyday and the structure of human relationships (Anderson, 2004, p. 240).
Race is not a neutral category; race has been used to support colonization of a socially constructed “Other” and to legitimize exploitation over others (Anderson, 2004). Rather than the discredited generalizations of race, the term “ethnicity” has been increasingly employed since the 1960s to “account for human variation in terms of culture, tradition, language, social patterns and ancestry. The nature of any ethnic group is based on composite shared values, beliefs, norms, behaviours, and experiences” (Ashcroft, Griffiths, & Tiffin, 2013, p. 98). Studies have shown that while ethnic groups are not necessarily marginalized cultural groups, all ethnic groupings exert powerful political function; the ethnic group is a salient formation in the bid for political power within a society (Ashcroft et al., 2013, p. 101).

Bhabha (1995, p. 206) posits that we rethink our perspective on culture; it is fluid, ambiguous, and partial. He suggests “cultures are never unitary in themselves, nor simply dualistic in relation of Self to Other” (Bhabha, 1995, p. 206). Bhabha’s (1995) conceptualization of culture challenges a culturalist perspective that views social behaviours of the Other as determined by fixed cultural characteristics (as cited in Khan et al., 2007, p. 231). According to Reimer-Kirkham & Anderson (2002) the construct of culture draws on colonial and historical notions of race reinforcing longstanding patterns of domination and inequities. Classification of people into cultural and ethnic groups is evidence of a racialized application of culture (Reimer-Kirkham & Anderson, 2002, p. 5). Anderson (2002, p. 15) also argues, “the difficulties people face in accessing and utilizing healthcare may be due not to their ‘culture’ but, instead, to historical processes that have produced systemic inequities and oppression.” Current global and economic trends have resulted in increasing wealth and income for some and poverty for others, and “can be read as extensions of colonizing processes” (Anderson, 2002, p. 13).

Dirlik (1999) argues that postcolonialism has sidelined categories such as class (p. 150), while ethnicity and race have moved to the centre of the discourse (p. 153) and become the central organizing principles of postcolonialism. Postcolonialism allow for productive analyses to be carried out on issues of race and difference (Mills, 1998, p. 99) and focus our attention on the processes of dehumanization and human suffering throughout history, providing the context for understanding health inequalities (Anderson, 2004, p. 240). However, this focus on the concept of race has resulted in “problems and inequalities that do not have their origins in ethnicity or race [becoming] neglected or else misunderstood, while these categories [have] become inflated
in their reach, sometimes even reinforcing the ethnic essentialisms that postcolonial critics in fact intend to deconstruct” (Dutton, Gandhi & Seth, 1999, p. 123).

Another important analytic dimension, gender, has been lacking in mainstream postcolonial theory (Mills, 1998; Anderson, 2004). Feminist scholars have added this missing component and have reacted against the universalizing tendencies within Western feminist thought (Mills, 1998; Mohanty, 2003; Anderson, 2004). Feminist scholars such as Collins (1990) and Brewer (1993) maintain that not all women have similar struggles or experiences, that women’s historical positioning, constructions of race and racialization, and class relations are intersecting and interlocking systems of oppression (as cited in Anderson, 2002, p. 17). Along with this recognition of difference, black feminism critically examines these differences as historicized within colonial relations. This more inclusive analysis draws attention to the context of each person’s suffering and illuminates how these differences determine the social and material conditions of people’s lives.

Narayan (1998, p. 86) argues that issues of gender need to be thought of in conjunction with, and not in isolation from, issues of class, and race/ethnicity, and emphasizes that differences among women must be understood and theorized in order to avoid essentialist generalizations about women’s problems. An important task for a postcolonial feminist perspective, then, is to depart from essentialism about the universalist categories “woman” and “cultures” (Narayan, 1998; Mohanty, 2003).

A postcolonial feminist perspective provides a theoretical lens that enables the unmasking of processes such as globalization, colonialism and neocolonialism, racialization, gender and class relations, and their intersections, which structure life experiences, human suffering, and health (Anderson, 2000, p. 225). In addition to revealing how social inequalities are located and constructed within a political, historical, cultural, and economic context, postcolonial feminism also focuses on patriarchy as a source of oppression (Racine, 2003, p. 96).

Anderson (2004, p. 242) argues that globalization, along with transnational corporatism, has resulted in “shifting power relations and new forms of colonialism,” which “has had devastating consequences on the lives of the poor, especially working class women of the South.” Mohanty (2003, p. 234) states that transnational institutions such as the World Trade Organization (WTO), the World Bank, and the International Monetary Fund (IMF), banking and financial institutions,
and cross-national governing bodies like the Multinational Agreement on Investments (MAI) have had devastating effects on poor people around the world, and that girls and women, especially in the Third World/South, bear the brunt of globalization.

3.2 Application of Postcolonial Feminism to Women and Health in a Specific Context

It is important to examine these key intersections as they pertain to pregnant and lactating women living with HIV and their access to healthcare in an urban setting in Kenya. The intersection of race/ethnicity, gender, class, and other social relations impacts human suffering and health (Anderson, 2000). This multilayered analytic perspective illuminates how these processes determine the social and material conditions of people’s lives (Reimer-Kirkham & Anderson, 2010; Anderson, 2004; Anderson, 2000). It provides a window into analyzing how these intersecting social relations shape health and illness meanings, and organizes our ability to manage illness (Anderson, 2000).

A postcolonial feminist perspective can be used to explore the “intersectionalities between problems such as poverty and social suffering and people’s inability to access appropriate healthcare, within different geographical contexts” (Anderson et al., 2009, p. 283).

3.3 Theorists Informing the Study and Issues Underpinning the Framework

As evident from the above discussion, the work of postcolonial feminist theorists Joan M. Anderson and Chandra Talpade Mohanty underpin this study. I drew on Mohanty’s (2003) argument against an essentialist construction of “Third World” women as Other and powerless victims of patriarchy. I also employed Mohanty (2003) suggestion that postcolonial feminism “emphasizes the agency of third world women who have been characterized in discourses of colonialism and development as passive victims of oppressive religious and cultural traditions”. In addition, I utilized Anderson’s (2004, p. 244) suggestion that postcolonial feminism aims to hear voices of those viewed as Other. To hear these historically silenced voices, postcolonial feminism “creates space in a constructive manoeuvre for agency of subaltern and subjugated knowledges” (Narayan, 1998; Mohanty, 2003; Anderson et al., 2011, p. 21).
My use of a postcolonial framework to underpin this study was motivated by a desire to address the essentialism and homogenization of women in this specific urban setting in Kenya and to engage in an interpretive analysis that emphasizes their agency and their capacity to deal with the difficult circumstances related to HIV and illuminate their strategies to access healthcare. Furthermore, I drew on the other central tenets of postcolonial feminism outlined by Anderson (2002), historical relations that contribute to structural inequities along the axes of race/ethnicity, class, gender, and other social relations. Anderson (2002) uses Smith’s (1999) definition of “social relations,” which suggests the following:

Social relations directs attention to, and takes up analytically, how what people are doing and experiencing in a given local site is hooked into sequences of action implicating and coordinating multiple local sites where others are active. (p. 7)

Social relations organize everyday experiences; people are active in specific local settings as participants in social relations concerted with those of others in multiple local settings. Social relations “constitute subject positions organized at a level transcending particular local settings and organizing sequences of action across multiple local sites. Subjectivity as well as agency are constituted in these relations; people’s capacities to act arise within them” (Smith, 1999, p. 81).

As noted, social relations are factors such as gender and class that coordinate people’s activities (Smith, 1999). However, scholars also see social relations as interpersonal relations (Due, Holstein, Lund, Modvig, & Avlund, 1999; Fuhrer & Stansfeld, 2002). “Social relations” is a multifaceted term; it has also been defined as a “diverse set of interpersonal relationships and exchanges that people engage in both within and between families, friendships and group affiliation” (Fuhrer & Stansfeld, 2002, p. 812). According to Due et al. (1999, p. 663), the function of social relations is to be found in the interpersonal interactions within their structure. Studies have shown that social relations influence health (Due et al., 1999; Fuhrer & Stansfeld, 2002). Specifically, it has been shown that supportive social relations enhance the ability to cope with stressful events and improve well-being, while non-supportive social relations increase the potential impact of stressful events and thus exacerbate ill health (Rook, 1984; Rook, 2015). In other words, there are both positive and negative social relations; while most peoples’ social interactions may be positive, other social interactions may be “negative social exchanges which are least as potent, and often more potent, than the effects of positive social exchanges” (Rook,
This research study requires that a broader conceptualization of social relations be employed to examine access to healthcare by pregnant and lactating women living with HIV in Kenya, and therefore both these perspectives or definitions of social relations by Smith (1999) and Due et al. (1999) will be utilized.

Another reason for my use of postcolonial feminism in this study is consistent with Smith’s (1999) examination of social relations that organize everyday experiences. Anderson et al. (2009) recommend an analysis that “begins from the particular to the general, starting from the voices of the marginalized subject, connecting the micro- to macro levels, and using subjugated narratives and knowledges to inform us of inequities and injustices” (p. 286).

Thus the core tenets of postcolonial feminist scholarship added to context relevant scholarship are crucial to this study in order to gain an understanding of access to healthcare by pregnant and lactating women living with HIV within this specific geographical context, Kenya. The knowledge that is constructed “in context” will inform us of how social relations and other intersectional factors shape individual experience and provide insights into how inequities are manifested in access to healthcare.
In this chapter, I will provide the historical, postcolonial, and neocolonial Kenyan context in which pregnant and lactating women living with HIV access healthcare. I will also describe the current healthcare system and the health status of women in Kenya.

According to the county’s development plan (Republic of Kenya, 2013, p. 57), low access to health services in this urban setting is due to the long distances that must be covered to access the nearest health facility. In addition, some patients face major challenges in “accessing health facilities due to poverty and impassable roads. Majority of the health facilities lack adequate infrastructures, drugs and trained personnel to attend to some of the chronic illnesses. There is therefore need to address poverty, inadequate medical facilities, high cost of medical services and inadequate medical personnel in order to promote healthy living in the county” (Republic of Kenya, 2013, p. 57).

4.1 A Brief Historical Narrative: Kenya

The imposition of British colonial rule in Kenya, which began in 1895, entailed the process of Westernization and capitalist penetration of African economies (Ochieng & Atieno-Odhiambo, 1995). Capitalist mode of production replaced the indigenous mode of production and integrated the African economies into the Western capitalist system of market relations. Traditionally, the majority of African Kenyans were peasants who lived by subsistence farming in rural areas, but other social classes emerged during the colonial period (Ochieng & Atieno-Odhiambo, 1995).

Ochieng and Atieno-Odhiambo (1995) suggest that Kenyans were compelled to work for the Europeans to gain access to commercial credit and cash crop production. They were also compelled to pay taxes. With the introduction of taxes, an urban “petty bourgeoisie” was created; these people held positions such as clerks, nurses, teachers, and translators, and enjoyed job security and a decent level of income. A large sector of urban “labouring poor,” such as artisans, street hawkers, kiosk holders, and casual labourers, also arose. During the colonial period, a
large number of peasant households, many of whom held the title to their land and produced food for their own subsistence, began to produce cash crops for sale. These peasants became the rural “petty bourgeoisie.” Those who were only able to produce food for subsistence became the middle peasantry, while those who were landless became the poor peasantry. The urban and rural petty bourgeoisie played an important role in Kenyan society and greatly expanded its economic, political, and social influence after independence. These people further enhanced their class position through accumulation of greater resources and education (Ochieng & Atieno-Odhiambo, 1995).

Women’s roles were subordinated to those of men during the colonial period; women were confined to subsistence economy and domesticity, while men were socialized into capitalism as wage earners and cash crop producers (Nasong’o & Ayot, 2007). Women became the primary producers of food and cash crops at the subsistence level, but were not paid for their productive and reproductive labour. They became the chief subsidy of capitalist production and were pushed into low status jobs and relegated to the private, domestic sphere (Nasong’o & Ayot, 2007).

After independence in 1963 the Kenyan government did not fundamentally change the colonial system and its structures, and the new constitution was insensitive to gender (Nasong’o & Ayot, 2007; Wipper, 1971).

Much of the literature on social class in Kenya written in the 1970s and 1980s was based on a Marxist form of class analysis with little discussion of women’s position in the class structure (Kitching, 1980). House-Midamba (1991) defined class as stratification rather than as a place in the production process. A class system largely based on socioeconomic criteria of education, income, occupation, language skills, and the allocation of residential space has emerged in Kenya, where a woman’s class position is intertwined with that of her husband or father, even if the woman is employed (House-Midamba, 1991).

More recently, Orchardson-Mazrui’s (2006, p. 162) examination of the cultural perceptions of gender issues in Kenya outlined the hierarchy of class construction in modern Kenya. Kenyan society has an elite, wealthy class with political and economic power. Next, there is a middle class with aspirations to belong to the elite, wealthy class. They are those working in formal jobs such as the civil service. Finally, there is a working class, which can be subdivided into various categories such as factory workers, semi-skilled labourers, self-employed people engaged in
small businesses, and domestic workers (Orchardson-Mazrui, 2006). Orchardson-Mazuri refers to the lowest social class as the “bottom of the heap” (p. 162); they are the most oppressed and impoverished members of Kenyan society. These people often dwell in slums with mounds of garbage, poor infrastructure, abject poverty, and joblessness (Orchardson-Mazrui, 2006).

According to USAID Kenya (2014) women in Kenya currently make up the vast majority of agricultural workers, and produce and market most of the food. Yet they earn only a fraction of the income generated and own just a nominal percentage of assets. Only 20 percent of those earning a formal wage throughout the country are women, leaving a huge percentage of women to work in the informal sector without any federal support. The effect is severe, with nearly 40 percent of households run solely by women. Because these households lack a fair income, nearly all these homes suffer from poverty or extreme poverty (USAID Kenya, 2014). Women social status and women’s health has been significantly influenced by global economic conditions as will be discussed in the following section.

4.2 Globalization and Neocolonialism

Navarro (2007) maintains that a trademark of our times is the “dominance of neoliberalism in the major economic, political, and social forums of the developed capitalist countries and in the international agencies they influence, including the International Monetary Fund (IMF), the World Bank, the World Trade Organization (WTO), and the technical agencies of the United Nations, such as the World Health Organization (WHO), Food and Agriculture Organization, and UNICEF” (p. 9). According to Navarro (2007) the tenets of neoliberalism is as follows: The state needs to reduce its interventions in economic and social activities; labour and financial markets need to be deregulated in order to liberate the enormous creative energy of the markets; and commerce and investments need to be stimulated by eliminating borders and barriers to allow for the full mobility of labour, capital, goods, and services. Adherence to these tenets has led to the development of a globalization of economic activity that has generated enormous economic growth associated with social progress (Navarro, 2007). Globalization then is defined as “the internationalization of economic activity according to neoliberal tenets” (Navarro, 2007, p. 10). Collins (2003, p. 98) mentions that globalization has been redefined many times, and has come to describe a complex process occurring unevenly across the different spheres of human lives, not only in the economic sphere.
According to Prasad (2005, p. 269), postcolonialists have concluded that old colonial empires have transformed themselves into a demarcated group seen as “the West,” and that it is the West’s affiliation with global institutional power which has resulted in the “continued economic dependence of former colonies on their colonial masters.” Prasad (2005) refers to this state of affairs as neocolonialism, which has come to imply the continuation of colonial rule by economic and other means. Prasad (2005) characterizes the mechanism of neocolonialism in the following way:

Neocolonialism is orchestrated in and through various world organizations such as the World Bank, the IMF, and the WTO that enact trade and monetary policies ensuring that old global asymmetries remain in place. (p. 270)

Some scholars such as Dollar (2001) celebrate the expansion of globalization, but others (Cornia, Rosignoli, & Tiberti, 2009; Navarro, 2007; Weisbrot, Baker, & Rosnick, 2007) regard globalization as the cause of the world’s growing inequalities and poverty. The debate over globalization’s positive or negative impact on the health status of nations has made international public health an issue of global concern.

According to Dollar (2001), globalization has a positive impact on health due to the benefits of global economic integration of different economies and societies resulting from the greater flows of goods, capital, people, and ideas. He indicates that economic integration is a powerful force for raising the incomes of poor countries, and that in the past twenty years large developing countries have grown faster than rich countries due to the opening up of their economies to trade and investment (Dollar, 2001). Dollar also claims that the higher growth, which generally accompanies globalization in developing countries, benefits poor people, and that income inequality does not tend to increase in countries which open up their economies. Therefore, Dollar’s (2001) study concludes that globalization has indirect positive effects on nutrition, infant mortality, and other health issues related to income.

Other authors (Cornia, Rosignoli, & Tiberti, 2009; Weisbrot, Baker, & Rosnick, 2007) have shown that while the world’s economic product quadrupled in the period from 1981 to 2005, progress towards poverty reduction was limited and uneven. Data on economic growth and social indicators such as health outcomes and education indicate that the past twenty-five years have seen a slower rate of economic growth and reduced progress on social indicators for the vast...
majority of low- and middle-income countries (Weisbrot et al., 2007). According to Weisbrot et al. (2007) along with the reduced economic growth in recent years, progress on health outcomes has also slowed. The data on health outcomes, life expectancy, infant and child mortality, and adult mortality indicate a significant drop in the rate of progress for the majority of low- and middle-income countries in the period 1980–2002, compared to the previous period 1960–1980 (Weisbrot et al., 2007). Globalization has created an environment of poverty and greater inequality for many people worldwide, but especially in developing countries (Cornia et al., 2009; Weisbrot et al., 2007). Furthermore, women are the main victims of neoliberal policies, whether in production or in the sphere of household and community reproduction (Bond, 2007). Available evidence also indicates that few countries in Africa have the productive capacities to achieve the economic growth rates to deal effectively with mass poverty and deprivation (Mbaku, 2007).

According to Collins (2003, p. 99), the “relationship between globalization and economic growth, income distribution and poverty provides the general background for discussing health outcomes.” Collins (2003) argues that health status tends to improve when economic growth includes poverty reduction, and that higher household incomes lead to improved access to healthcare and health-related goods and services. Economic growth also provides societal resources, including government revenues, to supply those goods and services (Diaz-Bonilla, Babinard & Pinstrup-Andersen, 2002; Collins, 2003). Collins (2003) also points out that the translation of the economic benefits of globalization into health benefits requires economic growth to be sustainable and targeted towards the poor. To realize health benefits, resources generated through the globalization process should be used to strengthen national health systems to ensure access to essential health services and to improve other health-related services, such as education, nutrition, water and sanitation, and environment. However, rising within-country inequalities of income distribution has a significant impact on access to healthcare (Collins, 2003; Cornia et al., 2009).

Economic reforms have been implemented with the active support of the International Monetary Fund (IMF) and the World Bank. Of major significance is the structural adjustment programs (SAPs) imposed on many African economies; by the mid-1980s in an effort to deal with demands for public goods and services, many African countries sought assistance from these institutions (Bond, 2007). The increasing debt burden and the servicing of these debts have
become one of the most important constraints to economic growth and human development in Africa (Mbaku, 2008). In Africa, debt service to foreign creditors is carried out in hard currency derived from the export of goods and services, which could be used to increase national spending on social services, especially in critical areas such as education, healthcare, and HIV and AIDS prevention. One Africanist scholar (Mbaku, 2008) suggests that these “selective and capriciously” imposed programs have benefited members of the ruling class, while levying significant social, political, and human costs on the rest of society. Evidence from several African countries which implemented SAPs, he points out, has shown that populations groups, especially children, women, and rural inhabitants, have been further impoverished and marginalized by these programs (Mbaku, 2008).

Bond (2007) suggests that the draining of African wealth by the North have reduced the available resources for Africa’s development and increased its countries’ dependency on the North. He asserts that Africa’s debt crisis worsened during this current era of global restructuring; African countries have repaid more than they received, with outflow in the form of debt repayments equivalent to three times the inflow of loans and exceeding export earnings. During the 1980s and 1990s, Africa repaid US$255 billion or 4.2 times the original 1980 debt. For some countries, servicing debt far exceeded government health servicing (Bond, 2007).

According to Lister and Labonte (2009) stringent conditions imposed by the IMF and the World Bank on countries such as Kenya forced to borrow during the economic crisis in the 1980s involved privatization of public services, opening up of markets for private providers, and tighter restrictions on government spending on social programs, including health and education. Lister and Labonte (2009) mentioned that focus has been placed on cost recovery in the form of user fees, private sector providers, and an explicitly two-tiered system in which only a minimal package of essential care would be available to the world’s poor. Cutbacks in government expenditure on health and infrastructure meant that access to and the quality of healthcare would be affected (Lister & Labonté, 2009).

Globalization also affects health status, particularly in low-income countries, through the impact of international trade agreements such as Trade-Related Aspects of Intellectual Property Rights (TRIPS) (Cornia, 2001). The TRIPS agreement has in effect made “access to essential life-saving drugs difficult for low-income countries, regardless of their level of public health
expenditure” (Cornia, 2001, p. 837). According to Cornia (2001, p. 837), international trade rules provide twenty years of protection for new discoveries and restrict the possibility of producing or importing essential drugs. In addition, even in cases where TRIPS allows parallel imports of cheap generic drugs, trade pressures by the large countries where the major pharmaceutical companies are based limits access to affordable drug imports (Cornia, 2001, p. 837).

4.3 Globalization and Women’s Health in Kenya

Parsitau (2008) notes that Kenya, when it won its independence, introduced populist health policies, which served to discontinue African experiences of the colonial past and to make the government popular. From independence in 1963 until the 1980s, healthcare was free, and Kenya expanded healthcare facilities and the training of health professionals. The new postcolonial government abolished user fees that had been in place under colonialism and made universal healthcare a major policy goal (Chuma & Okungu, 2011; Parsitau, 2008). Health services were funded primarily through general taxes until 1988 (Chuma & Okungu, 2011, p. 2). Improvement in health status was reflected in declining mortality rates, including reduced infant mortality rates (Parsitau, 2008).

The situation changed with the debt crisis of the 1980s (Parsitau, 2008). High inflation, slow rates of economic growth, and declining earnings from exports in the early 1980s created a difficult economic climate for many low-income countries, including Kenya (Parsitau, 2008; Chuma & Okungu, 2011). National incomes were affected, government deficits increased, and the standard of living for families in Kenya declined (Parsitau, 2008; Chuma & Okungu, 2011).

In Africa, economic restructuring, the policy recommendations by international financial institutions (such as World Bank and IMF) aimed at restructuring the public institution themselves through privatization, decentralization, public expenditure cuts, retrenchment and new structures of incentives to make the state leaner and fitter, was a major component of the globalization process (Bangura, 1994). Stabilization and adjustment packages, promoted by the World Bank and the IMF, were introduced to stop further deterioration in living standards. Structural adjustment programs (SAPs), the promotion and reinforcement of a market-oriented concept of health sector reform (HSR) that favoured private provision and financing, including reductions in public sector health spending, introduction of user fees, and other cost recovery
measures aimed at making health systems financially self-sustaining, were an important component of this process. Economic restructuring, coupled with SAPs, had a significant impact on the provision of social services such as healthcare and education (Karingi & Siriwardana, 2008). According to Bond and Dor (2007) the effects of SAPs included disincentives to health-seeking behaviour, and the ability to meet major healthcare expenses dwindled, as did nutritional status. Additional healthcare costs imposed as a result of SAPs placed further burdens on household incomes and on food consumption (Bond & Dor, 2007).

The Kenyan government yielded in the late 1980s to pressure from the World Bank and International Monetary Fund to introduce user fees and other major reforms in the health sector (Chuma & Okungu, 2011). Parsitau (2008) notes that in Kenya the economic crisis and SAPs undermined people’s health in a number of ways: first the removal of farming subsidies and the resultant rise in food prices threatened families’ ability to feed themselves and remain healthy and the increasingly harsh socioeconomic conditions affected people’s access to healthcare services; second, the reduction of government expenditure in the public health sector reduced the quantity and quality of available healthcare services; and third SAPs introduced user fees or cost sharing in Kenya’s social services and transferred the cost of healthcare services to those who were already too poor to afford it (Parsitau, 2008).

According to Parsitau (2008, p. 194), “women in Kenya [as compared to men] have less access to medical care, are more likely to be malnourished, poor, illiterate, and even work longer and harder. The lack of services to meet health needs related to sexuality and reproduction during pregnancy and childbirth is among the leading causes of mortality and morbidity of women of reproductive age in Kenya” (Parsitau, 2008). In Kenya, women dominate the less skilled workforce, and, as a result of retrenchment policies from the implementation of SAPs, many women found themselves cut from formal sector employment (Parsitau, 2008). Cost-sharing policies in the education and healthcare sectors also affected women adversely, as did the removal of agricultural subsidies, which effectively lowered the living standards of women and children in Kenya (Parsitau, 2008). This is supported by a World Bank working paper on a health sector assessment in Kenya (Barnes et al., 2010) that indicates that twenty-three percent of Kenyan women have no education at all and that poverty levels exacerbated by high unemployment, affect almost thirty-eight (37.9) percent of Kenyan women.
4.4 Kenya’s Healthcare System

Health service providers in Kenya are wide ranging and include government, faith-based, and other not-for-profit organizations, profit-making service providers, and traditional healers. A relatively large proportion of health services are provided by the private sector. Public services, multi-tiered organization comprising various levels, the lowest being the village dispensary and the Kenyatta National Hospital at the apex, cater mainly to the poor, are generally inadequate, in terms of insufficient skilled human resources and shortage of medical supplies, at the lower levels (Danida, 2011).

At national level, the Ministry of Health (MOH) provides health leadership (MOMS & MOPHS, 2012). Kenya has decentralized its health management system to increase decision-making power for resource allocation and service delivery at the county level to allow for greater community involvement in health management (MOMS & MOPHS, 2012). Following the promulgation of the new Constitution of Kenya in August 2010 the country is now administratively divided into forty-seven counties. Through this decentralized national health-care system, there is devolution of funds and decision-making to county level, where the counties are responsible for delivering health services and implementing health programs; this decentralization is a central element of the public health system (MOMS & MOPHS, 2013).

Kenya’s service delivery system is now based on the devolved system organized in a four-tiered system:

1. Community health services: This level is comprised of all community-based demand creation activities, that is, the identification of cases that need to be managed at higher levels of care, as defined by the health sector;
2. Primary care services: This level is comprised of all dispensaries, health centres and maternity homes for both public and private providers;
3. County referral services: These are hospitals operating in, and managed by a given county and are comprised of the former level four and district hospitals in the county and include public and private facilities;
National referral services: This level is comprised of facilities that provide highly specialized services and includes all tertiary referral facilities (MOMS & MOPHS, 2012).
Table 4.1: Responsibilities of the National and County Governments

<table>
<thead>
<tr>
<th>National ministry responsible for health</th>
<th>County department responsible for health</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Health policy</td>
<td>• County health facilities and pharmacies</td>
</tr>
<tr>
<td>• Financing</td>
<td>• Ambulance services</td>
</tr>
<tr>
<td>• National referral hospitals</td>
<td>• Promotion of primary health care</td>
</tr>
<tr>
<td>• Quality assurance and standards</td>
<td>• Licensing and control of agencies that sell food to the public</td>
</tr>
<tr>
<td>• Health information, communication and technology</td>
<td>• Disease surveillance and response</td>
</tr>
<tr>
<td>• National public health laboratories</td>
<td>• Veterinary services (excluding regulation of veterinary professionals)</td>
</tr>
<tr>
<td>• Public-private partnerships</td>
<td>• Cemeteries, funeral homes, crematoria, refuse dumps, solid waste disposal</td>
</tr>
<tr>
<td>• Monitoring and evaluation</td>
<td>• Control of drugs of abuse and pornography</td>
</tr>
<tr>
<td>• Planning and budgeting for national health services</td>
<td>• Disaster management</td>
</tr>
<tr>
<td>• Services provided by Kenya Medical Supplies Agency (KEMSA), National Hospital Insurance Fund (NHIF), Kenya Medical Training College (Kemto) and Kenya Medical Research Institute (KEMRI)</td>
<td>• Public health and sanitation</td>
</tr>
<tr>
<td>• Ports, borders and trans-boundary areas</td>
<td></td>
</tr>
<tr>
<td>• Major disease control (malaria, TB, leprosy)</td>
<td></td>
</tr>
</tbody>
</table>

Source: Constitution of Kenya, 2010

The health sector mandate is to ensure that access to basic health services is and continues to be given priority, with strong emphasis on reaching the poor. Additionally, in order to ensure that the poor have access to quality healthcare, the sector emphasizes the importance of allocating more resources to health promotion and prevention, while at the same time strengthening hospitals so that they can adequately serve as referral centres for primary health services. Some of the challenges facing the health sector (MOMS & MOPHS, 2010, p. 4) include the following:

• Insufficient skilled human resources, exacerbated by poor distribution of available health personnel, with some rural dispensaries left unstaffed
• Inadequate budgetary allocations
• Inadequate and poorly maintained infrastructure
• Widespread poverty (MOMS & MOPHS, 2010, p. 4).

A working paper by the World Bank assessing the private health sector in Kenya indicates that this sector has grown significantly in the last two decades (Barnes, O’Hanlon, Feeley, McKeon, Gitonga, & Decker, 2010). Private sector healthcare is often defined to include all the providers outside the public sector: the private sector includes for-profit and not-for-profit entities, such as faith-based organizations (FBOs) and non-governmental organizations (NGOs) (MOMS &
The private sector covers a wide range of healthcare providers, such as doctors, nurses, midwives, clinical officers, and pharmacists. These providers practice in a variety of settings, including commercial clinics and hospitals, nursing and maternity homes, university hospital and academic centres, pharmacies and drugstores, and private laboratories and other diagnostic services. Table 4.2 gives a breakdown of public and private facilities, and human resources, in various categories. As indicated in Table 4.2, the private sector is larger in terms of the number of facilities and personnel than the other sectors and growing (Barnes et al., 2010). The private sector delivers approximately 33 percent of outpatient care and 14 percent of inpatient care in the country (Luoma et al., 2010). NGOs are largely involved in capacity building of systems that support service delivery at the community and primary health facility levels, testing and scaling up service delivery models, and advocacy for better access and equity (Danida, 2011).

Table 4.2: Kenya’s Health Service Delivery System: Facilities and Human Resources

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>Public</th>
<th>Private*</th>
<th>Total Private</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>For-profit</td>
<td>Not-for-profit, NGO or Unknown</td>
<td>FBO</td>
</tr>
<tr>
<td>Tertiary Hospitals (level 6)</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Secondary Hospitals (level 5)</td>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Primary Hospitals (level 4)</td>
<td>225</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>Other Hospitals (level 4)</td>
<td>22</td>
<td>41</td>
<td>59</td>
</tr>
<tr>
<td>Health Centers (level 3)</td>
<td>473</td>
<td>21</td>
<td>88</td>
</tr>
<tr>
<td>Dispensaries (level 2)</td>
<td>2393</td>
<td>74</td>
<td>380</td>
</tr>
<tr>
<td>Nursing Homes (level 3)</td>
<td>3</td>
<td>89</td>
<td>54</td>
</tr>
<tr>
<td>Clinics (level 2)</td>
<td>20</td>
<td>1126</td>
<td>693</td>
</tr>
<tr>
<td>Laboratory – Stand alone</td>
<td>0</td>
<td>52</td>
<td>2</td>
</tr>
<tr>
<td>Stand-alone VCT clinics</td>
<td>7</td>
<td>2</td>
<td>29</td>
</tr>
<tr>
<td>Dental Clinics</td>
<td>0</td>
<td>10</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Registered Medical Personnel**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
</tr>
<tr>
<td>Clinical Officers</td>
</tr>
<tr>
<td>Nurses</td>
</tr>
<tr>
<td>Pharmacists/Pharmaceutical Technologists</td>
</tr>
<tr>
<td>Public health Officers/Public Health Technicians</td>
</tr>
</tbody>
</table>

Source: MOMS & MOPHS 2010
The Kenya National Accounts document (MOMS & MOPHS, 2010) identifies several modes of financing health services:

- Government funding through taxation
- User fees, through direct client out-of-pocket payments
- External sources from bilateral, multilateral, or philanthropic sources
- Health insurance, either through social or private insurance mechanisms (MOMS & MOPHS, 2010).

The health sector continues to be financed predominantly by private sector sources (including households’ out-of-pocket [OOP] spending), although the private sector share of the total health expenditure (THE) has decreased from a high of 54 percent in 2001/02 to 37 percent in 2009/10 (MOMS & MOPHS, 2010). Government financing has remained constant over the last decade, at about 29 percent of THE, while the contribution of donors to THE has more than doubled, from 16 percent in 2001/02 to 35 percent in 2009/10 (MOMS & MOPHS, 2010).

According to the National Health Accounts document (MOMS & MOPHS, 2010) the total health expenditure on HIV has doubled since 2001/02, from $188.6 million to $397.5 million in 2009/10. In 2009/10, the total health expenditure on HIV accounted for 25 percent of THE. Donors continue to finance the bulk of HIV and AIDS expenditures, although their contributions as a percentage of the total health expenditure on HIV declined from 70 percent in 2005/06 to 51 percent in 2009/10 (MOMS & MOPHS, 2010). The total health expenditures on reproductive health increased from $170.4 million in 2005/06 to $225.2 million in 2009/10. The government is the major source of reproductive health spending, contributing 40 percent in 2009/10 compared to 34 percent in 2005/06 (MOMS & MOPHS, 2010). The private sector’s contribution to the THE declined from 41 percent in 2005/06 to 38 percent in 2009/10 (MOMS & MOPHS, 2010). Figure 4.1 shows the breakdown of health expenditure by source.

Currently, about 25 percent of the population is covered by the national health insurance fund (NHIF). The majority of those covered are formal sector salaried employees and their dependents (MOMS & MOPHS, 2010). Approximately 46 percent of the population lives below the national poverty line, and 30 percent of the population is considered to be indigent. Health insurance coverage for this segment of the population is challenging (MOMS & MOPHS, 2010).
Figure 4.1: Breakdown of Total Health Expenditure by Financing Source

Source: MOMS & MOPHS 2010

As evident from the above data, in Kenya, low government expenditure “compromises the quality of care in the public sector, evident in the shortage of medical supplies, inadequate human resources, and poorly maintained infrastructure” (Luoma et al., 2010, p. 18). Also, overreliance on external resources for key programs such as HIV prevention and treatment threaten the sustainability of programs in Kenya. High OOP expenditures limit access to care, especially by poor Kenyans (Luoma, et al., 2010). It was estimated that 16 percent of sick Kenyans do not seek care due to financial barriers, while 38 percent must liquidate their assets or borrow to pay for medical bills (Luoma, et al., 2010).

According to Luoma et al. (2010) maternal, STI, and reproductive health services, with 24-hour facility-based delivery service, was available at only 16 percent of all Kenyan facilities. The report also noted that the availability of 24-hour delivery services did not correlate with higher delivery by health professionals. Factors other than availability of health services in Kenya, such as education levels, transportation, cost and other factors, may be significant (Luoma, et al., 2010). Based on the OOP data, it is clear that class status matters. One could expect that women’s social class will be an important factor in access to healthcare.
4.5 Insufficient Progress towards Improving Maternal Health

Driven by the global statistics on maternal mortality, this research study contextualizes a specific case. Because half of all maternal deaths worldwide occur in sub-Saharan Africa (World Health Organization, 2012), Kenya was selected for this case study. Although Kenya is one of the most developed economies in sub-Saharan Africa, with a new constitution and health policies designed to make the universal right to health a reality and to reduce maternal mortality, data on women’s health in Kenya is not encouraging. The WHO (2014) report, Trends in Maternal Mortality: 1990 – 2013, confirms that Kenya has made “insufficient progress” towards improving maternal health over this period. Evidence will be provided below regarding Kenya’s lack of progress on maternal health (Table 4.3).

Table 4.3: Sub-Saharan African Countries’ Progress in Reducing Maternal Mortality

<table>
<thead>
<tr>
<th>On Track</th>
<th>Progress</th>
<th>Insufficient Progress</th>
<th>No Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Egypt</td>
<td>Algeria</td>
<td>Malawi</td>
<td>Central African Republic</td>
</tr>
<tr>
<td>Eritrea</td>
<td>Angola</td>
<td>Mali</td>
<td>Djibouti</td>
</tr>
<tr>
<td>Benin</td>
<td>Mauritania</td>
<td>Gabon</td>
<td>Chad</td>
</tr>
<tr>
<td>Burkina Faso</td>
<td>Morocco</td>
<td>Guinea-Bissau</td>
<td>Congo</td>
</tr>
<tr>
<td>Cape Verde</td>
<td>Mozambique</td>
<td>Kenya</td>
<td>Lesotho</td>
</tr>
<tr>
<td>Comoros</td>
<td>Niger</td>
<td>Sierra Leone</td>
<td>Namibia</td>
</tr>
<tr>
<td>Côte d'Ivoire</td>
<td>Nigeria</td>
<td>Sudan</td>
<td>Somalia</td>
</tr>
<tr>
<td>Democratic Republic of the Congo</td>
<td>Rwanda</td>
<td>Zambia</td>
<td>South Africa</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>Senegal</td>
<td></td>
<td>Zimbabwe</td>
</tr>
<tr>
<td>The Gambia</td>
<td>Tanzania</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ghana</td>
<td>Togo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guinea</td>
<td>Tunisia</td>
<td></td>
<td></td>
</tr>
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<td>Liberia</td>
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<td>Madagascar</td>
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</table>

Source: United Nations Report, 2013.6

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The Countdown to 2015 Maternal, Newborn, and Child Survival provided evidence on progress for each of the 75 countries where more than 95 percent of all maternal and child deaths occur (World Health Organization & UNICEF, 2013). Figure 4.2 provides specific mortality and maternal health data for Kenya.

**Figure 4.2: Kenya: Maternal Mortality Ratio and Coverage along the Continuum of Care**

![Graph showing maternal mortality ratio and coverage along the continuum of care for Kenya](image)


As the data above indicates Kenya has not made sufficient progress towards improving maternal health. Economic constraints appear to be responsible for this lack of progress.

### 4.6 Economic Constraints

Kenya is a centre for trade and finance in the East Africa region, and is considered to be one of sub-Saharan Africa’s most developed economies (Ministry of Medical Services & Ministry of Public Health and Sanitation [MOMS & MOPHS], 2010). Agriculture accounts for 21.4 percent of Kenya’s gross national product (GDP) and employs 75 percent of its labour force. The economy also includes a large service sector, representing 62.3 percent of Kenya’s GDP, as well as a variety of other industries, including consumer goods, plastics, textiles, metals, oil refining, and tourism, which together comprise 16.3 percent of the GDP (MOMS & MOPHS, 2010).

Despite its relatively diverse economy, Kenya’s economic growth over the past decade has been hindered by electoral violence, severe droughts, and weak investment. Nearly half the country’s
population is living below the poverty line, with 20 percent of the population living in absolute poverty (i.e., living on less than one dollar per day) (World Health Organization, 2013b). Poverty levels are exacerbated by high unemployment, affecting 38 percent of Kenyan women and 23 percent of men (MOMS & MOPHS, 2010). The majority of Kenya’s poor are women (MOMS & MOPHS, 2012; Kimani & Kombo, 2010).

The Kenya National Health Accounts 2010 report (MOMS & MOPHS, 2010) indicates that Kenya spent approximately 5.4 percent of its GDP on health (equivalent to 42.2 USD per capita), with government health expenditure equivalent to only 4.6 percent of general government expenditures. Government health expenditures as a percentage of total government expenditures declined from 8 percent in 2001/02 to 4.6 percent in 2009/10 (MOMS & MOPHS, 2010). As a signatory to the Abuja Declaration in 2001, Kenya made a commitment to increase health allocations to 15 percent of total government allocations. However, the data indicates that Kenya has not been able to meet the Abuja target (MOMS & MOPHS, 2010).

4.7 The 2010 Constitution of Kenya

In 2010, the government of Kenya enacted a new constitution that addressed some of the issues surrounding healthcare. As the Kenyan Ministry of Medical Services and Ministry of Public Health and Sanitation, in their strategic plan Kenya Health Policy 2012 – 2030, state:

The Constitution of Kenya 2010 provides an overarching conducive legal framework for ensuring a more comprehensive and people driven health services delivery. It also seeks to ensure that a rights-based approach to health is adopted and applied in the delivery of health services. The Constitution provides that every person has the right to the highest attainable standard of health. It further outlines that a person shall not be denied emergency medical treatment and that the State shall provide appropriate social security to persons who are unable to support themselves and their dependents. (MOMS & MOPHS, 2012, p. 1)

The constitution focuses on improving access to services for rural areas and targets healthcare for children and persons living with disabilities. The constitution guarantees underlying
determinants the right to health, such as adequate housing, food, clean safe water, social security, and education (MOMS & MOPHS, 2012).

The Constitution of Kenya 2010 sets out the legal rights and obligations for the state in terms of the promotion of and respect for women’s rights (Amukowa, 2013). All forms of discrimination, including violence against women, are explicitly prohibited. Under the new constitution, women can own and inherit land, matrimonial property is protected during and after termination of marriage, and customary law inconsistent with the constitution is void. Thus personal law that is discriminatory to women, if in contradiction with the constitution, is invalid (Amukowa, 2013; Kramon & Posner, 2011).

According to Kramon and Posner (2011) the constitution recognizes an extensive set of rights, including such “second-generation” rights as healthcare, food, education, and housing, in order to address the issue of socioeconomic inequality. The new constitution, in addition to making provisions to address gender inequities by improving marriage, inheritance, and land-ownership rights for women, legislates that there should be a certain minimal level of female representation in national and county assemblies (Kramon & Posner, 2011).

Kramon and Posner (2011) argue that the constitution’s provision to address socioeconomic inequality is aspirational, since it cannot be easily enforced. In contrast, the provision to address gender inequities can be enforced, and therefore is more likely to have an impact (Kramon & Posner, 2011).

4.8 Kenya’s Health-related Policies

Kenya Vision 2030 is the national development agenda covering the period 2008 – 2030. The development agenda aims to transform Kenya into a “middle-income country” that provides a “high quality life to all its citizens by the year 2030” (Government of the Republic of Kenya, 2007, p. 1). The national health sector strategic plan for Kenya indicates that Kenya’s Vision 2030 for health is “to provide equitable and affordable healthcare at the highest affordable standard to all citizens” (Ministry of Public Health and Sanitation [MOPHS], 2008, p. 4). In 2012, the Kenyan government adopted a new Kenya Health Policy (2012–2030). It is aligned to the 2010 constitution and the country’s long-term development agenda, Vision 2030 (MOMS & MOPHS, 2012). Through Vision 2030, Kenya aims to transform itself into a middle-income
nation. The health policy embraces this long-term vision and uses the primary healthcare (PHC) approach to focus on achieving the goal of the right to health for all citizens as provided for in the constitution (World Health Organization, 2013b). One of the objectives of the national health policy framework is to “provide essential medical services that [are] affordable, equitable, accessible and responsive to client needs,” with “adequate finances mobilized, allocated and utilized, with social and financial risk protection ensured,” by establishing “a national social health insurance mechanism that includes the employees, employers and the informal sector for universal coverage” (MOMS & MOPHS, 2012, p. 16).

The Ministry of Health (MOH) formally approved and adopted the 2007 National Reproductive Health Policy with the theme “Enhancing the Reproductive Health Status for all Kenyans” (Ministry of Health, 2007). This reproductive health policy outlines priority actions for improving maternal health, reducing neonatal and child mortality, reducing the spread of HIV and AIDS, and achieving women’s empowerment and gender equality (Ministry of Health, 2007). The policy provides a framework for equitable, efficient, and effective delivery of quality reproductive health services throughout the country, and emphasizes reaching those in greatest need who are the most vulnerable (Ministry of Health, 2007). According to Kenya Demographic and Health Survey 2008–2009 (Kenya National Bureau of Statistics [KNBS] and ICF Macro, 2010), the new policy will allow the government to incorporate and address key issues such as security of reproductive health commodities, prevention of mother-to-child transmission of HIV, emergency obstetric care, adolescent reproductive health issues, gender-based violence, reproductive health needs of persons with disabilities, and integration of reproductive and HIV healthcare. This policy emphasizes the millennium development goals (MDGs) of improving maternal health, reducing neonatal and child mortality, reducing the spread of HIV/AIDS, and achieving women’s empowerment and gender equality (Kenya National Bureau of Statistics [KNBS] and ICF Macro, 2010).

In 2000, the government of Kenya launched a national population policy for sustainable development, outlined in its report Kenya Demographic and Health Survey 2008–2009. The report explains that the national population policy addresses the issues of environment, gender, and poverty. Goals of the population policy (KNBS & ICF Macro, 2010, p. 4) included the following:
• Improvement of the health and welfare of the people through provision of information and education on how to prevent illness and premature deaths among risk groups, especially among mothers and children

• Promotion of stability of the family, taking into account equality of opportunity for family members, especially the rights of women and children

• Empowerment of women and the improvement of their status in all spheres of life and elimination of all forms of discrimination (KNBS & ICF Macro, 2010).

The National AIDS Control Council (NACC) launched the third Kenya National AIDS Strategic Plan (KNASP III) in 2009 to address the challenges posed by HIV infection. The KNASP III aims “to achieve Kenya’s universal access targets for quality integrated services at all levels to prevent new HIV infections, reduce HIV-related illnesses and deaths, and mitigate the effects of the epidemic on households and communities” (National AIDS Control Council, 2009, p. 23).

4.9 State of Women’s Health: Slow Progress

Despite the government’s commitment to the health agenda, Kenya has lagged behind in meeting most of the targets set in the international and regional declarations (MOPHS, 2008) (Figure 4.3).

A WHO (2009) report confirms that maternal mortality is the leading cause of death in women of childbearing age in Kenya, representing 15 percent of all deaths in this population. A report by WHO Regional Office for Africa (2009) estimate 14,700 women die annually due to pregnancy and its related complications and that the HIV/AIDS pandemic has compounded this problem. Other indirect causes of death during pregnancy include malaria and tuberculosis (WHO Regional Office for Africa, 2009). In 2013, the maternal mortality rate in Kenya was 400 maternal deaths per 1,000 live births (World Health Organization, 2013c).
Life expectancy (LE) at birth in Kenya was reduced to a low of 45.2 years during the 1994–2010 policy period, but was estimated to have risen up to 60 years by 2009 – a trend that was reflected across all age groups (MOMS & MOPHS, 2012). Women’s life expectancy at birth is low at 55 years. The root causes of the weak values of impact indicators are closely linked to high levels of poverty and underdevelopment (WHO Regional Office for Africa, 2010). It is well established that maternal deaths are avoidable if women receive antenatal and delivery care from skilled health personnel.

**Figure 4.3 Health Impact in Kenya, Compared to Africa and the Rest of the World**

![Health Impact in Kenya, Compared to Africa and the Rest of the World](image)

**Source:** World Health Organization, 2009

According to *Kenya Demographic and Health Survey 2008–2009* while 91.5 percent of women in Kenya have at least one antenatal care visit, only 47.1 percent have four antenatal care visits. Most women do not receive antenatal care early in their pregnancy. The survey (KNBS & ICF Macro, 2010) also noted that only 15 percent of women obtain antenatal care in the first trimester of pregnancy, and only about half (52 percent) receives care before the sixth month of pregnancy. Overall, the median number of months of pregnancy at first visit is 5.7 months (KNBS & ICF Macro, 2010).

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Two out of five births (44 percent) are delivered in a health facility, while 56 percent are delivered at home (World Health Organization, 2013c; KNBS & ICF Macro, 2010).

The 2009 Kenya National AIDS Strategic Plan 2009/10 – 2012/13 indicates that in terms of treatment, care, and nutrition, only 38 to 45 percent of those in need of HIV treatment are being reached at present, with coverage for children much lower at 15 percent. Up to 300,000 people living with HIV (PLWH) therefore remain at risk of dying due to lack of access to treatment (National AIDS Control Council, 2009).

4.9.1 Women’s health studies in Kenya

Studies indicate, not withstanding a rich and diverse cultural heritage encompassing many different ethnic traditions, languages and practices, that Kenya is a patriarchal society where common forms of gender-based violence include rape, domestic violence, assault, early marriages and female genital mutilation for girls, and deprivation of opportunities and property (Kimani & Kombo, 2010; Makayoto Omolo, Kamweya, Harder, & Mutai, 2013). According to Kimani and Kombo (2010) under traditional beliefs and practices, women have little or no ownership, access, and control of family assets and resources.

Studies suggest that the majority of Kenyans living in poverty are women Barnes et al., 2010). These women often suffer from hunger and malnutrition, lack shelter, and fail to access essential social services such as basic education and health (Barnes et al., 2010; Kimani & Kombo, 2010). Other studies, which explore the utilization of maternal health services, confirm that low socioeconomic status is among the major barriers to health seeking (Fotso, Ezeh, & Oronge, 2008; Ochako, Fotso, Ikamari, & Khasakhala, 2011). It was found that availability of services did not translate into increased utilization by women because of the financial constraints (Fotso et al., 2008). Education and household wealth of respondents were associated with the frequency and timing of antenatal care and a large percentage of pregnant women do not seek antenatal care during their first trimester (Fotso et al., 2008; Ochako et al., 2011). Socioeconomic and demographic factors also had significant influence on use of skilled professional assistance at delivery. The economic vulnerability of urban poor women is a factor that contributes to non-institutional deliveries (Ochako et al., 2011).
A study examining factors that influence decision-making regarding HIV care access found that HIV partner influence, knowledge, stigma, and lack of disclosure were major barriers (Otieno et al., 2010). Men exerted considerable influence on how female partners accessed healthcare, and, in some cases, became violent upon learning of their partner’s HIV status. Stigma was overwhelmingly mentioned as a barrier to access. Financial constraints were also a barrier to accessing HIV healthcare (Otieno et al., 2010).

4.9.2 Variations among women: Socio-economic diversity and access to health care

As evident from the studies mentioned above, there is differential access to healthcare among Kenyan women. It has been suggested that women from “rich households” are more likely to seek early maternal care; poor women are less likely to deliver at institutional facilities; and patriarchy and partner influence is a major barrier to healthcare access (Fotso et al., 2008; Kimani & Kombo, 2010; Makayoto et al., 2013; Ochako et al., 2011).

It is important to recognize that these studies paint a global picture of Kenyan women. In doing so, the studies contribute to essentialist arguments that Kenyan women are victims of a patriarchal culture, mostly poor, and uneducated. These studies ignore women’s diversity, agency, and initiative. Women are not seen as resourceful, opportunistic, and empowered (Edstrom, 2010).
Chapter 5
Research Design and Data Collection

This chapter describes the methodology and the data collection strategy and procedures used in this study. The methods employed in the study included focus groups and interviews. Focus groups were used to validate the research tools; semi-structured interviews with health providers and other government and non-governmental organizations involved in healthcare were used to obtain information about available health services in this setting; and in-depth interviews were used to obtain participants’ narratives about their access to healthcare. The same sampling procedures and data collection techniques of other qualitative research were employed. The samples were collected from a clinical setting and from the community. The data collection strategy used to obtain participants’ narratives on access to healthcare, which is found in other qualitative research, was the audiotaped and transcribed in-depth interview, a method that works particularly well for exploring individuals’ subjective experience of illness (Muller, 1999). The resulting protocol is described in this chapter and includes the sampling strategy, sample size, recruitment, data collection, data analysis, and ethical considerations.

5.1 Methods

5.1.1 Setting

The study was conducted in a town in South Rift Valley in 2010. Interviews and focus groups were conducted at private physicians’ offices, a private location close to participants’ home, and the provincial general hospital. The county where the study was conducted has roughly 300,000 inhabitants, and is currently the fourth largest urban centre in the country.
The Provincial Government Hospital in the county (PGHN) serves the South Rift Valley. Each month the facility provides antenatal care to approximately 1,900 women, largely representative of urban Kenyan mothers of lower socio-demographic status, approximately 30 percent of whom subsequently give birth at home. According to the *Kenya Demographic and Health Survey*, poverty in the Rift Valley is estimated at 47.9 percent of the population (Kenya National Bureau of Statistics [KNBS] and ICF Macro, 2010).

### 5.1.2 Study design

To explore and analyze the intersecting factors that shape access to healthcare by pregnant women living with HIV and AIDS in an urban setting in Kenya a qualitative study was conducted. The following research questions guided this research subject:

1. How do patriarchy and agency shape experiences of access to and utilization of healthcare for HIV-positive pregnant and lactating women in an urban setting in Kenya?

2. How does the intersection of gender and class structure access to and utilization of healthcare?

3. How do other social relations shape these women’s ability and willingness to access healthcare?

For the formative phase of the study, the first objective was to validate and modify research instruments through focus group discussions (see Appendices A, C, and D). The second objective of the formative phase was to complete a document analysis of Kenya’s health policy and the Rift Valley Provincial General Hospital, Nakuru, guidelines to determine the national and local policies and provisions for the healthcare of pregnant and lactating women living with HIV and AIDS. The study was amended to include semi-structured interviews with several government officials and healthcare professionals from the Provincial General Hospital (PGH) and from non-governmental organizations (NGOs) to supplement the document analysis (see Appendix B).
For the second phase of the study, the in-depth interview phase to obtain participants’ narratives, the objective was to explore the experiences of pregnant and lactating women living with HIV and AIDS and their access to healthcare. After reviewing my initial data, I made an analytic commitment to conduct follow-up interviews with a number of participants to obtain clarification on several issues.

5.2 Ethical Oversight

In addition to applying for and receiving ethics approval from the University of Toronto (Protocol ID: 26003), I applied and received ethics approval from KEMRI (NON-SSC Protocol No. 283) and the Rift Valley Provincial General Hospital, Nakuru. I also applied and received a research permit from Kenya National Council for Science and Technology (NCST) (Research Permit No. NCST/5/002/R/113). To obtain the NCST research permit, I had to be affiliated with a university in Kenya and be recommended by the institution of affiliation. Once I was approved for the NCST permit, the Rift Valley Provincial General Hospital, the District Commissioner, Nakuru District, the District Education Officer, Nakuru District, and the local Chief’s Office were notified that I had been granted permission to conduct research in the district.

The Kenya Medical Research Institute (KEMRI) recommended that a counsellor be retained for the study due to participants’ vulnerability. An HIV counsellor was present for the focus group discussions and for the in-depth interviews except when participants requested that only the primary researcher be present in order to maintain confidentiality.

5.2.1 Ethical considerations

Ethical and moral dilemmas abound in the social research enterprise (Hertz, 1996; Guillemin & Gillam, 2004). While feminist qualitative researchers recognize and discuss ethical issues such as privacy, consent, confidentiality, deceit, and deception, they also aim to avoid causing harm to the people they study (Olesen, 2005; Hertz, 1996). Researchers try not to cause undue stress, loss of reputation, and invasion of privacy throughout the research process of negotiating access, gathering and analyzing data, and writing text (Olesen, 2005).

Conducting research with women living with HIV and AIDS meant that I had many ethical concerns to consider. As mentioned earlier, ethics approval to undertake research involving
human subjects was sought and received from all relevant research ethics committees. My research assistant and I successfully completed the US National Institutes of Health (NIH) Web-based training course “Protecting Human Research Participants” to ensure that we were aware of and could address ethical issues if they arose. I believed that my study would not cause harm because the research risks in this study were minimal as no invasive procedures were planned. I acknowledged that participants might experience emotional distress during data collection, and KEMRI, upon review of my ethics application, recommended that a counsellor be retained for the study.

I gave my participants written consent sheets explaining the reasons for my study, the proposed interview procedures, and what would happen to the interview data once the interviews were completed. I was aware of the assumption that if providing consent is “voluntary,” “coercion” is deemed not to have occurred. Yet such an assumption ignores “the potentially complex power dynamics that can operate around access and consent” (Miller & Bell, 2002, p. 63). At the hospital and at the physician’s office, a clinical officer and the physician recruited participants. Both were more powerful than the other women in terms of their perceived social class and status. Miller and Bell (2002, p. 62) questioned situations where those in more powerful positions are asked to act as gatekeepers for potential respondents, and asked whether these respondents would subsequently be able to resist taking part. Miller and Bell suggested that when powerful gatekeepers are used, notions around access, coercion, and, more importantly, consent can become very difficult for the researcher and study participants to disentangle (Miller & Bell, 2002). I had been advised about the difficulty of accessing and recruiting participants in field, so I was gratified that these two individuals facilitated my access to potential participants. The fact that none of the participants seemed reticent during the interview reassured me that they had not been coerced. However, their participation might not have been entirely voluntary; most of the women would not have refused the clinical officer and the physician, individuals they held in high regard.
5.3 Project Activities: Summary of Data Collection Procedures

The study employs a qualitative approach to data collection. To address the study objectives, this research project included two phases: formative research and In-depth interview (Figure 5.1).

Formative Research

I. Focus group discussions with pregnant and lactating women living with HIV and AIDS receiving services at PGH to validate and modify research instruments

II. Document analysis of national and local policies, supplemented with semi-structured interviews with healthcare professionals, government officials and non-government officials involved in healthcare, to determine the national and local policies and provisions for healthcare for pregnant and lactating women living with HIV and AIDS

In-Depth Interview: Women’s Narratives

III. In-depth interviews with pregnant and lactating women living with HIV and AIDS who: (a) were receiving antenatal or perinatal services from the Rift Valley Provincial Government Hospital; (b) did not seek or receive services at a healthcare facility/had given birth or planned to give birth at home, (c) were seeking and receiving services from a private healthcare professional/facility

IV. Follow-up in-depth interviews to address recurring patterns in participant data and to ask participants to give more information on categories
### Figure 5.1: Project Activities

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<tr>
<th>Activities</th>
<th>Sampling</th>
<th>Objectives</th>
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<td><strong>A. Formative Research</strong></td>
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<tr>
<td>- Document Analysis</td>
<td>✤HCWs (hospital &amp; NGOs), Government Officials</td>
<td>1. To document Kenya’s health programs, services, and policies pertaining to access to healthcare by HIV-infected women</td>
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<tr>
<td>- Interviews with healthcare professionals and government and non-government officials</td>
<td>*WLWHA (FGDs with 15-20♀♀)</td>
<td>2. To finalize research instruments and assess, and to determine the national and local policies and provisions for healthcare for pregnant and lactating women living with HIV</td>
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<tr>
<td>- Focus groups with WLWHA</td>
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| **B. In-depth Interview: Women’s Narratives** | | 3. To describe HIV-infected pregnant and lactating women’s experience accessing comprehensive healthcare |
| - In-depth Interviews | *WLWHA (IDIs with 9 - 12 ♀♀) | |
| - Pregnant/Lactating WLWHA | | |
| o Delivering at the following: Provincial Hospital/Private/None (home) | | |

| **C. Data Analysis: Follow-up Interviews** | | 4. To follow up on recurring patterns in participant data and asking key participants to give more information on categories that seem central to the emerging theory |
| - In-depth interviews with WLWHA | *WLWHA (IDI with 7 – 10 participants previously recruited for the narrative IDIs) | |
| - Focus group with HCWs, government officials | ✤HCW (FG with 7 – 10 HCWs previously recruited for formative IDIs) | |
5.3.1 Theoretical basis for data collection methods and analytic approach

A postcolonial feminist lens “frames how questions are formulated, who is included in the study, how data are interpreted, the meanings derived from the data, and how research findings are communicated and applied” (Reimer-Kirkham & Anderson, 2002, p. 15). Using this lens, research questions are framed from a particular epistemological perspective; this perspective always takes into account the context in which each life is situated, and analyzes how the intersections of processes organize experience (Reimer-Kirkham & Anderson, 2002).

Postcolonial feminism lends itself to a methodological process, which has been extended and operationalized; Khan et al. (2007, p. 231) drew upon the papers of Anderson (2002), Reimer-Kirkham & Anderson (2002), to put forward four broad elements essential to postcolonial feminism as methodology:

(1) An analytical framework that allows for the simultaneous examination of gender, race/ethnicity, class, culture, and history

(2) An analysis that moves from the particular to the general and connects micro and macro levels of analysis

(3) A construction of knowledge beginning from the worldviews of those who have been marginalized

(4) A use of subjugated knowledge to correct inequities and injustices

This research uses a methodology related to the postcolonial feminist approach as outlined above by Khan et al. (2007). I was not aware of this methodological approach at the start of this study, but through further readings on postcolonial feminist scholarship in preparation of the dissertation I concluded that it was an appropriate guide for the reader of my analytic strategy. Analysis began with everyday realities and experiences of people, which were then examined within the larger social, political, economic, and historical context to make visible the intersecting factors that organize access to healthcare by pregnant and lactating women living with HIV in an urban setting in Kenya (Anderson, 2002; Reimer-Kirkham & Anderson, 2002; Khan et al., 2007). The ultimate aim of postcolonial feminist scholarship is to translate this knowledge into practice and policy (Khan et al., 2007, p. 231).
A postcolonial feminist perspective offers no prescribed techniques for data collection or data analysis. Different techniques can be utilized depending on the focus of the inquiry, as long as they meet the criteria for scientific adequacy and rigour (Reimer-Kirkham & Anderson, 2002). Qualitative research methods, including in-depth interviews, were employed in this study. In-depth interviews were used to obtain detailed narratives from pregnant and lactating women living with HIV regarding the context in which their lives were situated and their experiences accessing healthcare. Such experiences and perspectives translated into narratives. Narratives were appropriate for a postcolonial feminist framework because narrative “highlights the uniqueness of each human action and event rather than their common properties” (Chase, 2008, p. 657), thereby enabling researchers to identify uniqueness in women’s experiences (Anderson, 2002; de Souza, 2010).

5.4 Gaining Access

Gaining access to sites and individuals to study has its own challenges. As Creswell (2007) notes, convincing individuals to participate in the study, building trust and credibility at the field site, and getting people from a site to respond are all important access challenges. Researchers with “insider status” may benefit from some amount of mutual experience with research participants not available to other researchers (Creswell, 2007). However, there are also other factors that differentiate them and shape participants’ perceptions of them as not similar (i.e., professional/class status, gender, marital status, and religious and cultural history). I recognized that my position as an outsider, “mzungu,” might have had consequences for gaining access to the research setting and for beginning recruitment.

Gaining access to sites and individuals also involves several steps. Regardless of the approach to inquiry, permissions need to be sought from a human subjects review board, a process in which various institutions review research studies for potential harm and risk to participants (Creswell, 2007). I ensured that I met institutional ethical requirements and developed strategies that were attentive to the ethical and practical implications for recruitment.

My experience with the various institutions in Kenya was extremely positive, due in large part to my two previous exploratory visits to Kenya, where I was able to gain access to and become formally affiliated with Egerton University, Njoro, Kenya, through my academic supervisor and
his ongoing research with faculty members in the Department of Human Nutrition. This affiliation was useful in my obtaining campus housing and for identifying me as a student in the community. Through this affiliation, I was able to network with key individuals at the hospital, the community, and NCST, and to become very familiar with the research ethics approval process in Kenya. At all levels, key officials were kind, respectful, and very accommodating. I received ethics approval from KEMRI and the hospital before my arrival in Kenya for my field research and the research permit from NCST within two weeks of my arrival.

Hammersley and Atkinson (2007) acknowledge that gaining access, or entry, is a difficult task that must take into account contextual, ethical, and practical considerations. The ethics approval process, for KEMRI in particular, was similar and as rigorous as that for the University of Toronto. From my experience navigating the system for this study, it was evident that there were multiple institutional and community levels of protection for people living with HIV and AIDS to minimize researchers causing harm and risk to this vulnerable population.

Also, because of my affiliation with Egerton University and my previous networking at the hospital and with community members, I was able to enlist recruiters who could help me gain access to potential participants. A faculty member at Egerton University introduced me to private physicians who helped me recruit participants seeking their services. My contacts at the hospital helped to recruit participants seeking care at the hospital, and a community health worker recruited participants in the community. The ease of gaining access to participants was facilitated by my ability to build rapport and by gaining the respect and trust of gatekeepers involved in providing care and support to women living with HIV and AIDS in this urban setting. Because of this ease, I was able to modify my research design to include key informants from various levels of government coordinating HIV and AIDS care to supplement the document analysis and interviews with healthcare professionals at the hospital.

5.5 Sampling Procedures

Purposive, snowball, and theoretical sampling were used to recruit key informants who not only had knowledge and experience with the phenomenon, but also were also willing to speak with the researcher. My overall aim in using purposive and other sampling strategies, as opposed to probability sampling, was to include information-rich cases for in-depth study. However, this
strategy approach also required me to think critically about the parameters of the population in which I was interested and to choose my sample carefully on this basis (Silverman, 2011). The concept of “purposeful sampling” is often used in qualitative research. According to Creswell (2007), selection of participants and sites for study is done so that they can purposefully inform an understanding of the research problem and central phenomenon in the study. Theoretical sampling include follow-up on recurring patterns in participant data (Draucker et al, 2007). This was important to the present study so that participants could provide more information on those categories that seem central to the emerging theory (e.g., stigma, social support, and the sick role).

Sandelowski (1995, p. 180) suggest that sample size in qualitative research may refer to numbers of persons, but also to numbers of interviews and observations conducted. An adequate sample size permits results in a new and richly textured understanding of experience Sandelowski (1995, p. 183). Participants were selected based on their availability and eligibility for the study. For the in-depth interviews, individuals who were willing to tell their stories and lived experiences were interviewed. Purposive sampling was employed to recruit focus group participants who were pregnant and lactating women living with HIV seeking antenatal care or HIV treatment and care services at the provincial hospital. These women had knowledge and experience with the phenomenon being researched and were available and willing to participate in the study.

Purposive sampling was employed to recruit expert key informants, healthcare professionals at the provincial hospital, to determine the national and local policies and provisions for healthcare for pregnant and lactating women living with HIV. Through snowball sampling, other expert key informants were identified from government, non-governmental organizations, civil society, and church-based organizations. These informants had knowledge of health policies and provisions available for women living with HIV in the district and province.

Purposive sampling was employed to recruit in-depth interview participants who were pregnant and lactating women living with HIV and met the inclusion criteria. Theoretical sampling was used to recruit participants from the original sample for follow-up interviews to obtain clarification on a number of issues.
5.6 Inclusion and Exclusion Criteria

As outlined above the study included a formative and an in-depth interview phase. The formative Research phase included focus group participants as well as healthcare providers and government and non-government officials involved in healthcare. The in-depth interview phase included participants who were pregnant or lactating women living with HIV. Table 5.1 provides the inclusion and exclusion criteria employed when recruiting participants for the study.
Table 5.1: Participant Inclusion and Exclusion Criteria

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<tr>
<th>Data Collection Activities</th>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
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<td>Focus group</td>
<td>- Female and self-identified as HIV positive</td>
<td>- &lt; 17 years</td>
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<td>- Pregnant or have a child 6 to 18 months of age</td>
<td>- Do not belong to Swahili language group</td>
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<td>- Enrolled for antenatal/perinatal services or participating in the mothers’ support group at the PGH, Nakuru</td>
<td>- Women with serious health problems that require them to be under special surveillance</td>
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<td></td>
<td>- Of consenting age (17 years in Kenya)</td>
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</tr>
<tr>
<td>Semi-structured Interviews with H/C providers &amp; government officials involved in H/C</td>
<td>- Healthcare professionals, government officials, and non-government officials</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Have knowledge of the healthcare and support services in the South Rift Valley and employed at one of the following: provincial general hospital, Nakuru; various levels of government, non-governmental organizations, church-based organizations, and civil society groups</td>
<td></td>
</tr>
<tr>
<td>In-depth Interviews with women living with HIV to obtain narratives</td>
<td>- Female and self-identified as HIV positive</td>
<td>- &lt; 17 years</td>
</tr>
<tr>
<td></td>
<td>- Pregnant or have a child 6 to 18 months in age</td>
<td>- Do not belong to Swahili language group</td>
</tr>
<tr>
<td></td>
<td>- (a) Receiving antenatal/perinatal services; deliver/plan to deliver at the PGH, (b) not seeking or receiving services from a healthcare facility/ have given birth or plan to give birth at home, and (c) seeking and receiving services from a private healthcare professional/facility</td>
<td>- Women with serious health problems that require them to be under special surveillance</td>
</tr>
</tbody>
</table>
5.7 Recruitment

The study was advertised through verbal messages delivered by the researcher, healthcare workers, and community health workers, i.e. “word of mouth” through the following facility- and service-based networks.

Women who were receiving antenatal and community health counselling from the provincial government hospital were consecutively recruited and enrolled for participation in the focus group discussions using a non-random, purposive, service-based sampling and recruitment strategy. Hospital staff facilitated identification of potential study participants who met study criteria. Potential participants were referred to the research assistant by hospital staff to be screened for study eligibility. A fully bilingual research assistant helped with recruitment and obtained consent on behalf of the investigator.

Healthcare workers were recruited for semi-structured interviews using purposeful non-random sampling. I approached senior administrators at the clinic to obtain consent to facilitate the study and recruit healthcare providers at the clinic. All healthcare professionals spoke English, and therefore a translator was not required for recruitment. As I became immersed in the field and came into contact with providers in various positions at the hospital, I was provided with contact information for several key informants from various levels of government and NGOs. Therefore, subsequent key informants were recruited through snowball sampling. I contacted these informants either by telephone or dropping by their offices to make an appointment for an interview. These participants were provided with an explanation of the study, and informed consent was obtained prior to interviews.

Women were consecutively recruited and enrolled for participation in the in-depth interviews using a non-random, purposive, service- and community-based sampling and recruitment strategy. A community health worker (CHW) was employed to recruit pregnant or lactating HIV-infected women from the community who either delivered or planned to deliver at home, or delivered or planned to deliver at the hospital. The research assistant described the study in detail, and individuals who were willing to participate and eligible for participation were asked to provide informed consent for study participation. I approached two private physicians in this urban setting to recruit participants who sought their services and delivered at a private facility or
planned to deliver at a private facility. These participants were provided with an explanation of the study, and informed consent was obtained prior to interviews.

For follow-up, in-depth interview participants were recruited using theoretical sampling. Data analysis was concurrent with data collection, which allowed me to cycle back and forth between thinking about the existing data and generating strategies for collecting new and more detailed data on issues identified that required further clarification. The same community health worker was employed to recruit participants for follow-up interviews.

5.8 Formative Research for Tool Development

5.8.1 Focus group procedures

Focus groups were conducted with pregnant and lactating women living with HIV who were seeking healthcare from the provincial hospital to validate the research instruments: Information and Informed Consent Forms, and Interview Guides. A qualified Kenyan research assistant provided information on the study, obtained consent, and conducted the focus group discussions in Kiswahili. A note-taker and an HIV counsellor were present at all focus groups (KEMRI recommended that a counsellor be retained). This information was useful in ensuring that participants understood the details of the study, what they were consenting to, and the interview questions. Amendments were made to the research instruments accordingly, and the research assistant and primary investigator made adjustments to their interview strategy.

5.9 Data Collection

5.9.1 Interview procedures

Semi-structured interviews were conducted with expert key informants from the hospital, government, and non-governmental organizations (Table 5.2) to supplement document analysis so as to obtain information on the healthcare and support services available in this setting. I conducted these interviews, as all individuals were fluent in English. This information was useful in describing the healthcare setting in this urban setting. These interviews were conducted at a time and place convenient to the key informants.
The primary data collection to address the objectives of the study took place in the in-depth interview phase of the study. In-depth interviews were conducted with women living with HIV across social strata within this urban setting (Table 5.3). One interview was conducted with each of the 23 participants recruited. Follow-up interviews were conducted one year later with 10 of the participants from the original sample. All interviews were conducted in a private location in the community away from participants’ homes. Those who either delivered at home or at PGH were interviewed in a private location close to their homes. Women seeking care from a private physician were interviewed in a private room in the physician’s office. For the follow-up interviews conducted one year later, theoretical sampling was used to recruit the participants. They were also interviewed in a private location close to their homes.

Initially, all in-depth interviews were to be conducted by a male research assistant with the primary researcher and a female note-taker present. However, the first participant of higher social class recruited at the physician’s office specifically requested that “no other Kenyan” be present during the interview. She wanted her identity kept confidential from the local research team members because she was a healthcare professional and was concerned that she might be recognized. Therefore, a decision was made that the primary researcher would interview all higher social class participants recruited by the private physicians in order to protect their privacy and maintain confidentiality. Participants recruited by the physicians were fluent in English and were comfortable being interviewed by the researcher in English. One higher social class participant sought healthcare at the provincial general hospital and was interviewed by the research assistant. The research assistant, with the researcher present, interviewed all other participants, who were of lower social class, in Kiswahili. The interviews lasted between 60 and 90 minutes. Interviews were digitally audio-recorded and then professionally transcribed for data analysis.

Kenyan transcribers were provided with a flash drive containing the Kiswahili interview data; they were asked not to store this data on their personal computers and to return the data storage device with the raw data and transcribed files to the primary investigator. Data files with the English interviews were uploaded to a secure website for transcription by a credentialed Canadian transcription agency. All transcribers were asked to remove all data files from their computers and to keep each participant’s identity, participation, and remarks confidential (See Appendix E: Research Assistant Contract Agreement).
These in-depth interviews were face-to-face interviews using an open-ended interview guide. For this study, I wanted to elicit stories through interviews, knowing that storytelling in interviews can occur at unexpected times, even in answer to fixed-response questions (Riessman, 2008). As Riessman (2008, p. 24) asserts, if the study is to learn about an experience in all its complexity, details count because they include specific incidents and turning points, not simply general evaluations.

5.9.2 Achieved sample

To modify and validate draft instruments, four focus groups with a total of twenty HIV-positive pregnant and lactating women receiving services at the provincial general hospital were conducted in a private room at the hospital. The instruments used were the Information and Informed Consent Forms (English and Kiswahili), and Interview Guides (see Appendices B, C, and D).

To document HIV healthcare and support services in the South Rift Valley, 22 interviews were conducted with healthcare professionals from the provincial general hospital, government and non-governmental organizations, civil society, and church-based organizations (see Table 6.1).

For the in-depth interview phase of the study, 23 pregnant and lactating women living with HIV and AIDS were interviewed (see Table 7.1). Variation was sought in socioeconomic status, education level, and if and where they obtained healthcare services. This number of interviews was conducted to include deviant cases or negative instances as defined by the theory with which I am working (Silverman, 2011).
5.10 Transcription and Translation

Transcription is a deeply interpretive process. Tilley (2003) argues that a transcriber’s interpretive prints become visible on close examination of the transcription process and the texts constructed. Riessman (2008) contends that transcribers do not stand outside in a neutral objective position, merely presenting “what was said,” but rather are implicated at every step along the way in constituting the narratives that are then analyzed. For this study, credentialed transcribers transcribed interviews completed in English: one person did transcription, and quality check performed by another person. Having completed these interviews myself and listened to the audio recording a number of times, I was confident of their accuracy. The research assistant who participated in the interviews and an Egerton University language and linguistics professor independently transcribed and translated each interview completed in Kiswahili. I was unable to conduct an accuracy check for missing words and meaning as I am not fluent in Kiswahili. I compared the transcripts, and some words were interpreted differently. In one instance, one transcriber/translator used the word “perseverance” to refer to a participant’s coping skills, while the other transcriber (the university professor) translated the same text using a metaphor, “soldering on.” When I questioned the professor, he indicated that it was his “interpretation.”

Translation further complicates the transcription process. Esposito (2001) thinks the translator is actually an interpreter who processes the vocabulary and grammatical structure of the words while considering the individual situation and the overall cultural context of the source language (Kiswahili). He also argues that the interpreter “conceptualizes the meaning and, using vocabulary and grammatical structure appropriate for the target language (English), reconstructs the meaning of the statement in a new cultural context” (p. 570). As Bogusia Temple (as cited by Riessman, 2008, pp. 49–50) notes, the use of translators and interpreters has epistemological consequence as it influences what is found; translators are active in the process of constructing accounts and add another layer in the process of knowledge construction.
5.11 Data Analysis

5.11.1 Analysis of interview data from providers: Thematic analysis

The in-depth interview data, obtained from 22 expert key informants/providers, were analyzed using thematic analysis described by Braun and Clarke (2006). Accordingly, thematic analysis is a “summary and analysis of qualitative data through the use of extended phrases and/or sentences rather than shorter codes” (Saldana, 2009). “A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p. 82). That is, the process of coding and categorization leads to an outcome (Saldana, 2009). The data were categorized according to repetitions (Ryan & Bernard, 2003) and recurrent themes (Green & Thorogood, 2009).

Interview data included were from healthcare providers, government officials, and other non-government officials involved in healthcare. Key analytic findings were linked to services provided to pregnant and lactating women living with HIV, challenges the providers’ had in providing healthcare, and “barriers and facilitators” of women’s access to healthcare in this urban setting.

5.11.2 Analysis of narrative data from pregnant and lactating women living with HIV: Narrative analysis

Narratives obtained through in-depth interviews with 23 pregnant and lactating women living with HIV were analyzed as a form of data. Muller (1999, p. 222) indicates that “narrative analysis is an approach to research that takes as its focus narratives – or stories – as a means of representing and interpreting human action and individuals’ lived experience.”

There is no simple, clear definition of narrative, but it has some essential ingredients (Riessman, 2008). Catherine Kohler Riessman (2008) claims that the “term narrative in the human sciences can refer to texts at several levels that overlap: stories told by research participants (which are themselves interpretive), interpretive accounts developed by an investigator based on interviews and fieldwork observation (a story about stories), and even the narrative a reader constructs after engaging with the participant’s and investigator’s narratives” (p. 6). Suzanne E. Chase (2008) suggests that a narrative may be a short topical story about an event or specific character, an
extended story about a significant aspect of one’s life, or the story of one’s entire life (p. 652). A narrative communicates the narrator’s point of view and is an active creation that emphasizes the narrator’s voice (p. 657). Chase also asserts that by treating narratives as an active creation and emphasizing the narrator’s voice, researchers “move away from questions about the factual nature of the narrative and highlight the versions of self, reality, and experience” of the narrator. Researchers view stories as conditioned by social context. They use this lens to attend to “similarities and differences across narratives”, and treat narratives as “socially situated interactive performances”, and a “joint production of narrator and listener” (p. 657).

Scholars assert that women’s personal narratives are essential primary documents for feminist research because they present and interpret women’s life experiences, in particular, the impact of gender roles on women’s lives (Chase, 2008; Personal Narrative Group, 1989). Women’s personal narratives shed light on the course of a life over time and allow for its interpretation in its historical and cultural context (Personal Narrative Group, 1989). According to Riessman (1993), an individual’s story can reveal her social life, and as such, it is “possible to examine gender inequalities, racial oppression, and other practices of power that may be taken for granted by individual speakers” (p. 5). Riessman also suggests that human agency and imagination is given prominence in narrative analysis (p. 5).

Narratives are stories that relate the unfolding of events, human action, or human suffering from the perspective of an individual’s lived experience (Muller, 1999). A narrative is “grounded in qualitative traditions and emphasizes individuals’ lived experiences, the importance of multiple perspectives, the existence of context-bound, constructed social realities, and the impact of the researcher on the research process” (Muller, 1999, p. 223).

Since narratives functions to emphasize lived experiences and provide an understanding of the constraints of social structure and the power of women’s agency, this approach is well suited to a postcolonial feminist methodology and to addressing the proposed research questions:

(1) How do patriarchy and agency shape experiences of access to and utilization of healthcare for HIV-positive pregnant and lactating women in an urban setting in Kenya?
(2) How does the intersection of gender and class structure access to and utilization of healthcare?

(3) How do other social relations shape these women’s ability and willingness to access healthcare?

A postcolonial feminist methodology guided the data analysis. My analytical framework examined the intersection of gender, class, patriarchy and other social relations. I began my analysis from the particular (participants’ lives) and moved to the general (context in which they were situated), connecting micro and macro levels of analysis. Knowledge construction began from the worldviews of this specific group of “Third World women” in the “global south.”

First, I used Clarke’s (2005) situational mapping strategy to organize my data and think about key elements. The data were then analyzed according to two analytic schemes (Boyatzis, 1998; Crabtree & Miller, 1999).

5.11.3 Situational mapping

Clarke’s (2005) situational mapping strategy helped me to organize my data and to articulate the components of my study and think about these elements in relation to other elements on the map (Figure 5.2). The mapping provided a visual of the key elements of my data: what participants were saying in relation to healthcare access. Clarke’s (2005) messy working version of a situational map allowed me to write down elements of my research situation, which helped me gain some insight into the problem and permitted my analysis to proceed.

Situational maps include those who are involved in the broader situation. They also demonstrate the significance of structural and material conditions, even in a situation where the researcher focuses on small-scale intimate human interaction (Clarke, 2005). As Clarke (2005, p. 96) states, “all human interaction is constituted in and through the properties and conditions of this broader situation.” Certainly HIV-infected pregnant and lactating women from different socioeconomic backgrounds and healthcare professionals from the government hospital were included in this study. But also included were other key informants from different levels of the Ministry of Public Health and Sanitation (MOPHS), key church-based organizations (CBOs), non-governmental organizations (NGOs), and civil society groups. Structural factors included the
National AIDS Control Program (NASCOP), which is a technical arm of the Ministry of Public Health and Medical Services. Issues identified in the data were patriarchy, class, and gender. Other potential discourses that seemed especially important to my project were the sick role, stigma, and social relations. Clarke’s (2005) situational mapping indicated that there were intimate human interactions, such as the issues of the sick role, stigma, and social support, constituted in the broader situation.

Follow-up interviews were conducted with a number of participants to obtain clarification on several issues. This step is in keeping with the framework that Clarke (2005) endorses in situational mapping. Follow-up interviews included follow-up on recurring patterns in participant data and asking key participants to give more information on those categories that seemed central to the emerging theory (Draucker et al, 2007). Therefore, analysis was concurrent with data collection, which allowed me to move back and forth between thinking about the existing data and generating strategies for collecting new and more detailed data on issues I identified that required further clarification.
### Figure 5.2: Abstract Situational Map

#### Messy/Working Version

<table>
<thead>
<tr>
<th>Individual Human Elements/Actors</th>
<th>Non-Human Elements/Actants</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV-infected pregnant/lactating women, HCWs, AIDS and STI ministry officers</td>
<td>HIV treatment and care, knowledge</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Collective Human Elements/Actors</th>
<th>Implicated/Silent Actors/Actants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital, HCWs, Private physicians, NGOs, CBOs, PLWHA Support Groups, Mothers’ Support Group, Ministry of Public Health</td>
<td>HIV-infected pregnant/lactating women, low SES</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Discursive Constructions of Individual and/or Collective Human Actors</th>
<th>Discursive Constructions of Non-Human Actants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses as harsh Patients stigmatized because of HIV status; promiscuous, unfaithful, survival sex as easy option</td>
<td>Integrated care as more effective for treating pregnant women who are also HIV-infected</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Political/Economic Elements</th>
<th>Sociocultural/Symbolic Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital cost sharing NHIF (national insurance), Poverty, Survival sex, Prioritizing household needs, children’s school fees, informal employment, unemployment, class</td>
<td>Spousal/In-law/Alcohol abuse Gender, Patriarchy, Agency, Living positively, Traditional roles of “good” wife and mother</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Temporal Elements</th>
<th>Spatial Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long wait times, delay in receiving HIV treatment due to lack of funds for baseline tests</td>
<td>Hospital design issues: HIV Comprehensive Care Clinic open to public; lack of privacy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Related Discourses</th>
<th>Other Key Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Globalization, neoliberal policies</td>
<td>Interpersonal relationships</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Related Discourses</th>
<th>Other Key Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal relationships</td>
<td></td>
</tr>
</tbody>
</table>
5.12 Code Development

The method of analysis chosen was a hybrid approach of qualitative methods of thematic analysis: it incorporated both the data-driven inductive approach of Boyatzis (1998) and the deductive a priori template of codes approach outlined by Crabtree and Miller (1999). Key analytic findings were organized and linked to significant theoretical concepts (Crabtree & Miller, 1999). I also analyzed the women’s narratives inductively using psychological (McAdams, 1988) and biographical (Denzin, 1989) techniques. The codes were used to develop a bottom-up approach to the derivation of categories from the content of the data. Therefore, codes were created from both theory (theory-driven) and data (data-driven).

5.12.1 Codes constructed a priori: Codes in template

The method of analysis in this phase used the deductive a priori template of codes approach outlined by Crabtree and Miller (1999). Deductive coding comes from the conceptual framework or theoretical perspective or is created on preliminary scanning of the text (Crabtree & Miller, 1999; Miles, Huberman, & Saldana, 2014). Crabtree and Miller (1999, p. 166) describe the template organizing style as one that immerses the researcher in extensive data with the purpose of identifying “chunks” of text to facilitate future data retrieval and analysis. The analysis process involves (1) developing a code manual, (2) coding the text, (3) sorting segments, and (4) reading the segments and making the connections. Completion of this interpretive process is the “telling of the story or representing the account” (p. 166).

As noted, the template approach outlined above involved creating a template in the form of codes from a codebook to be applied as a means of organizing text for subsequent interpretation. Using a template, I defined the codebook before commencing an in-depth analysis of the data. Also noted, the codebook was developed a priori.

**Step 1: Developing the code manual**

Crabtree and Miller (as cited by Fereday & Muir-Cochrane, 2006, p. 84) suggest that the choice of a code manual for this phase of the analysis was important, because it served as a “data management tool for organizing segments of similar data or related text for ease in
interpretation.” According to Fereday & Muir-Cochrane (2006) “the use of a template provided a clear trail of evidence for the credibility of the study” (p. 84).

The template was based on theoretical concepts, and broad categories formed the code manual: gender and class, and other social relations. Themes related to other social relations were identified: negative and positive social interactions. These in turn were related to broader themes as characterized by issues of stigma, sick role, and social support. It was difficult to reduce intricate theories to a few words, but I tried to develop these theory-driven codes by reviewing and revising the codes in context of the nature of the raw information (Boyatzis, 1998). This process meant that I determined the appropriateness of the code labels and how they were to be applied to the data (DeCuir-Gunby et al., 2011).

First, the themes were generated from reading and contemplating the theory. Second, I reviewed and rewrote the themes and code emerging from the first step. Because theory was driving the creation of the themes, it was essential to determine the applicability of the codes with the raw data (Boyatzis, 1998). Thematic code, for example, gender and class, was developed from theory (see Chapter 3). I reviewed the theory and the data to determine the possible labels that might be relevant. For example, I needed to decide if I should code for formal/informal work as a separate category to reflect class status. I decided that this category could be included in another category “distribution through wages/salaries.” Code were written with reference to Boyatzis (1998) and identified by (1) the code label or name, (2) the definition of what the theme concerns, and (3) examples. See Table 5.4 for the list of theory-driven codes used in this study. Boyatzis’ (1998) coding process was modified to include a “family” of themes with “child” and “grandchild” subcodes or subthemes (Creswell, 2007, p. 153).

**Step 2: Coding the text and sorting segments**

Using the template analytic technique (Crabtree & Miller, 1999), I applied the codes from the codebook to the text with the intent of identifying meaningful units of text (Fereday & Muir-Cochrane, 2006). The transcripts had previously been entered as project documents into the N-Vivo computerized data management program. The codes developed were entered as nodes, and I coded the text by matching codes with segments of the data selected as representative of the code. The segments of text were then sorted, and a process of data retrieval organized the codes or clustered codes for each narrative (Fereday & Muir-Cochrane, 2006).
Step 3: Reading segments and making connections

Connecting codes is the process of discovering themes and patterns in the data (Crabtree & Miller, 1999). Similarities and differences between separate narratives were emerging at this stage. Themes within each narrative were beginning to cluster, with differences identified between the responses for varying demographics; for example, participants of lower socioeconomic status and those of higher socioeconomic status expressed differences (Fereday & Muir-Cochrane, 2006).

One approach to connecting the data is “chunking” (Crabtree & Miller, 1999), which refers to examining chunks of related texts together. Chunks are segments of text, several paragraphs or pages in length, which are vignettes or chunk summaries. Vignettes are “compact sketches that can be used to introduce characters, foreshadow events and analyses to come, highlight particular findings, or summarize a particular theme or issue in analysis and interpretation.” According to Ely, Vinz, Downing, and Anzul (1997, p. 70), vignettes are “composites that encapsulate what the researcher finds through the fieldwork.” These authors also suggest that the function of the vignette can be seen as “narrative investigations that carry within them an interpretation of the person, experience, or situation that the writer describes” (p. 70).

An immersion/crystallization organizing style was used to develop the vignettes and to search for further connections (Crabtree & Miller, 1999; Borkan, 1999). This technique involved a systematic review of the data. I committed substantial concentrated time to reading, rereading, and immersing myself in the data. I reviewed all the material from multiple horizontal passes (Borkan, 1999). I first read the data without any preconceptions, and looked at key themes. On my second reading, I read for those themes and looked for evidence in support of or against them. For the third reading, I went back again to see if there was anything I had missed (Borkan, 1999).

By using data from each case, I constructed exemplar vignettes that illustrated the layered, entangled, and complex nature of access to healthcare for participants. These vignettes were structured similarly to the “analytic abstractions” (Creswell, 2007) that I had used previously to provide outlines of participant’s life stories. Vignettes, more specifically moving vignettes, were constructed as “portraits” to represent participants’ character and experience (Ely et al., 1997). By writing vignettes based on interview data, the data became more accessible for a reader. Also,
vignettes constructed from primary data are trustworthy and representative (Spalding & Phillips, 2007).

The purpose of these vignettes was to accentuate interpretations and findings. I used these vignettes specifically to convey something of my analysis (Ely et al., 1997). The vignettes offered a way to present a cohesive and coherent rendition of the themes by avoiding the fragmentation that may come with only presenting quotes from multiple participants’ narratives to support an analytical point. I used the data from one case to compose an exemplar vignette that would convey a sense of the complex issues which influence participants’ access to healthcare. The vignettes were then used to search for further connections, patterns, and other associations (Crabtree & Miller, 1999).

5.12.2 Developing data-driven codes

These incidents “define who we are, who we were, and who we are to become” (p. 133). He also notes that we construct our identities through narratives and make certain experiences central and salient (p. 133). McAdams believes these experiences or incidents may be positive or negative, and “may mark perceived transformations of self (identity turning points), or may affirm perceived continuity and sameness” (p. 133). He termed these special incidents “nuclear episodes” (p. 133).

De Souza (2010) used these “points” to analyze her data to pinpoint where women expressed heightened emotion, where there was a sense of something having changed, and where an important moment or point in their illness journeys was revealed. At these “points” in their lives, de Souza’s (2010) participants may have been expressing agency through articulations of “who they are, who they want to be, and how they see themselves relative to the larger socio-cultural context” (p. 246).

Also informing this phase of the analysis was Boyatzis’s “Developing Themes and a Code Using the Inductive Method: An Example Using Life Stories,” a chapter in his book Transforming
<table>
<thead>
<tr>
<th>Parent Code</th>
<th>Child Codes</th>
<th>Grandchild Codes</th>
<th>Definitions</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Relations: Macro-level structures</td>
<td>Class</td>
<td>Distribution through wages/salaries</td>
<td>Economic transfers through formal/informal production work. A component of class structuring.</td>
<td>I work in the [employer]. I take home around $19,000 KES…</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Distribution through marriage/other intimate relations</td>
<td>Economic transfers through marriage/other intimate relations.</td>
<td>… I usually remind the husband early in advance about the clinic dates so during that time he gives me the money.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Distribution through family</td>
<td>Economic transfers through family/kin.</td>
<td>…she [mother] asked me what she could do for me. I told her that if she gave me a job life will continue well. I sell blouses…</td>
</tr>
<tr>
<td>Gender</td>
<td>Caring work</td>
<td>Unpaid domestic production (or reproduction) that includes bearing and caring for children and others, subsistence production for household.</td>
<td>I take care of household food. Mostly I take care of the household chores and my child. When this baby is born I will get a househelp (maid).</td>
<td></td>
</tr>
<tr>
<td>Social Relations: Interpersonal Relationships</td>
<td>Non-supportive or Negative Social Interactions</td>
<td>Social obligations</td>
<td>Support network fail to provide support. Life circumstances, chronic stressors, and loss or disruption of social network ties create unmet needs. An individual may not be able to relinquish social duties and obligations such as employment and domestic duties.</td>
<td>To say the truth life is sometimes hard but you have to work hard so I picture out the way life is and ensure we have not slept hungry and we have eaten something.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Labelling and stereotyping</td>
<td>A “label” affixed by others usually links a person to a set of undesirable characteristics that form a stereotype.</td>
<td>I had fear at that time again to say such a thing… people could associate it to sin.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Status loss</td>
<td>Status loss is seen as the consequence of successful negative labelling and stereotyping where</td>
<td>They alleged that now that I had killed their brother that I should go and engage fully in prostitution…</td>
</tr>
<tr>
<td><strong>the person connected to the undesirable characteristics suffers a downward placement in a status hierarchy.</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Discrimination</strong></td>
<td>Discrimination is seen as practices that work to disadvantage persons who have been labelled and stereotyped which lead to social inequalities in life circumstances. Like the one we work with she told the customers that I remove blood and put it in the sauce and that I have HIV. She loved talking about me and I lost customers.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Selective disclosure/concealment</strong></td>
<td>Manage information and mediate the stigma process. I was hopeless but as I started going to a support group. My neighbours don’t know. You will be ashamed when they know...when one knows he (she) tells another...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Disavow dominant perspectives</strong></td>
<td>Resistance strategies. Women in different class contexts can mobilize different resistance strategies because social class carries with it privilege that affects the experience of stigma, strategies, and resolution. I decided to come here (private clinic) because being in the public, working as a [professional position], many people in the [field of employment] know you so with stigma all around...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Blame</strong></td>
<td>HIV is typically viewed as the responsibility of the sick person, and as a result individuals are treated punitively as forms of moral deviance. After knowing my status we started having issues and he started accusing me of being unfaithful.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Positive Social Interactions</strong></td>
<td>Consensus information Sharing problems with others, especially with others who have similar problems, should decrease the perceived severity and threat value of that problem. This is referred to as “consensus information” and may facilitate help seeking. My mother helped me to get the courage to accept my situation when I found out I was positive. She was also positive... She challenged me to soldier on because she herself had done that for three years.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Informational support</strong></td>
<td>When problems cannot be resolved If you go the clinic first of all they educate you first</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
easily and quickly, people often seek information and guidance. Social network members may provide informational support by providing information, advice and guidance. and even when you are stressed they will teach you and you can even stay for three months without even thinking about it.

<table>
<thead>
<tr>
<th>Material support</th>
<th>Instrumental or material support include a wide range of activities such as providing assistance with household chores, taking care of children, lending or donating money, and providing transportation. Particularly relevant to low-income individuals.</th>
<th>When I had been hospitalized at PGH (provincial hospital) the bill had risen to 4000 KS and some hundreds which was too much by then so church members came and held a fundraising and cleared the bill.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motivational support</td>
<td>Perception is that participant is unable to overcome ongoing difficulties and things are not going to get better. Social networks play an important role by providing motivational support.</td>
<td>I went there first clinic and they made me join an HIV support group and from there I knew those women was good because they opened me up slowly until now I am able when I find someone else who is down and I can talk to her and help her be uplifted.</td>
</tr>
</tbody>
</table>

*Source: Adapted from Boyatzis (1998) and modified to incorporate a “family” of codes (Creswell, 2007, p. 153).*

I used Boyatzis’s (1998) framework to demonstrate the steps that I followed to create the data-driven codes. The steps to inductively create data-driven codes for a codebook based on Boyatzis’s (1998) framework are as follows: (1) reduce raw information; (2) identify subsample themes; (3) compare themes across subsamples; (4) create codes; and (5) determine reliability of codes.

**Step 1: Reducing raw information**

For step 1, Boyatzis (1998) recommends selecting subsamples. My study included participants (a) receiving antenatal/perinatal services; delivering/planning to deliver at the PGH, (b) not seeking or receiving services from a healthcare facility/have given birth or planning to give birth at home, and (c) seeking and receiving services from a private healthcare professional/facility. I selected subsamples from each of these groups as the basis for developing my codes (Boyatzis, 1998).

To reduce raw information into smaller units such as categories or themes, I coded using the “level of meaning,” where a code could be made up of a line, sentence, or paragraph as long as the essence was the same (DeCuir-Gunby, Marshall, & McCulloch, 2011). The objective of this step was to understand the raw information by internalizing the data through careful reading and rereading, and to reduce it to a manageable size. Reducing the raw information provides an “outline” that is easier for comparison across units of analysis, in this case, individuals (Boyatzis, 1998).

Outlines can take many forms (Boyatzis, 1998), and examples of these outlines or abstractions will be provided in subsequent chapters. Key activities, affect, thoughts, and emotions will be considered as potential themes in the outline of these life stories (Boyatzis, 1998). I followed recommendations by Frank (2012) and Creswell (2007) to select the subsamples and to form my outlines. Frank (2012, p. 43) suggests that for a truly narrative analysis, each story must be considered as a whole, and only a few stories from the original collection should be discussed in the research report. He recommends that the stories selected for focused attention should be done on the basis of phronesis, the analyst’s cultivated capacity to hear, from the total collection of stories, those that call out as needing to be written about. The stories selected should also speak...
to the original research interest (Frank, 2012). Frank suggests that analysis concerns the constant decisions being made about what belongs in the written report, what should be set aside, and how the stories fit together (Frank, 2012). I began my analysis by selecting the stories that were illustrative of the themes identified in the data, and wrote analytic abstractions of each case selected.

The data collected in this study were analyzed for the story they had to tell, a chronology of unfolding events and turning points or epiphanies (Creswell, 2007). I isolated narrative segments and categories within the interview-story, and determined larger patterns and meanings. I reconstructed individuals’ biographies and identified factors that have shaped the participants’ lives. I wrote an analytic abstraction of each case that highlighted (a) the processes in the individual’s life, (b) the different theories that relate to these life experiences, and (c) the unique and general features of the life (Creswell, 2007).

**Step 2: Identifying themes within subsamples**

To develop data-driven codes, I identified themes from abstractions of the reconstructed biographies that I had selected for my subsample. I looked at the major themes that “emerged” during an interview, and I completed codes per interview. It is important to note that a content analysis was not the aim of the data analysis, and, consequently, a single comment was considered as important as those that were repeated (Fereday & Muir-Cochrane, 2006). Specifically, I used McAdams’s (1998) concept of nuclear episodes to identify high points, low points, and turning points in the narratives, in conjunction with Denzin’s (1989) biographical approach, which focuses on epiphanies in the data. I identified these various points based on what was said; I analyzed the transcripts for instances where the women expressed a sense of something having changed and where they narrated an important moment or point in their stories.

The first subset of life stories (outlines or abstractions), which included participants who delivered at home and those who delivered at the provincial hospital, was reviewed, and the following themes were identified:

- Traditional roles of motherhood and wifehood important
• Patriarchy, a set of social relations with a material base enabling men to dominate women, which limits women’s autonomy and their involvement in decisions related to their own healthcare

• Sensitivity to others in family, mention of marriage, or divorce and children

• Obstacles in life encountered that forced changes in life or activities, such as dropping out of school early due to financial constraints, early marriages, unemployment, low-income/informal employment, HIV status, spousal/in-law abuse, disinheritance, abandonment

• Dependent on others for financial support such as spouse or family, NGOs, CBOs, engage in survival sex

• External locus of control – others have key role in shaping life and determining fate, experience stigmatization and discrimination, sense of rejection by family

• Turning points such as spousal death, spousal abandonment, accessing healthcare, seeking employment, disclosing status and seeking social support, refocusing on importance of being healthy to take care of children

The second subset, which included participants who delivered or sought care at the provincial hospital, was examined, and the following themes were identified:

• Traditional roles of motherhood and wifehood important

• Patriarchy, a set of social relations with a material base enabling men to dominate women, which limits women’s autonomy and their involvement in decisions related to their own healthcare

• Sensitivity to others in family, mention of marriage, or divorce and children

• Obstacles in life encountered that forced changes in life or activities, such as dropping out of school early due to financial constraints, early marriages, unemployment, low-income/informal employment, HIV status, spousal/in-law abuse, disinheritance, abandonment

• External locus of control – others have key role in shaping life and determining fate, experience stigmatization and discrimination
• Reflective about actions of self and others – seeks to understand HIV status, the relative impact of HIV status, open to new information that improves knowledge and ability to live positively, acknowledges reliance on others for emotional and material support
• Role models that taught others about HIV, getting tested, and treatment
• Turning points such as being abandoned by spouse/spousal death, accessing healthcare, disclosing status, living positively, seeking support and counselling, being role models to others

The third subset, which included participants who sought and received services from a private healthcare professional/facility, was examined, and the following themes were identified:

• Traditional roles of motherhood and wifehood important
• Patriarchy, a set of social relations with a material base enabling men to dominate women, which limits women’s autonomy and their involvement in decisions related to their own healthcare
• Sensitivity to others in family, mention of marriage, or divorce and children
• Obstacles in life encountered that caused introspection or commitment to improve, such as HIV status
• Reflective about actions of self – seeks to understand HIV status, open to new information to improve knowledge and live positively
• Seeks private healthcare and avoids disclosure to minimize stigma and discrimination, equates HIV with chronic illness
• Turning points such as divorcing abusive spouse, accessing healthcare, disclosing status, living positively

**Step 3: Comparing themes across subsamples**

After looking at the potential themes within each subset of life stories as described above, step 3 began. I compared the themes identified as similar within each subsample. I rewrote the potential themes. I returned to the original life stories selected for my subsets to see if the story included the theme. This step generated the several possible themes for comparison of the outlines (Table 5.5).
Table 5.5: Comparing Themes across Subsamples: Potential Themes

<table>
<thead>
<tr>
<th>Traditional values</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Wifehood</td>
</tr>
<tr>
<td>- Motherhood</td>
</tr>
<tr>
<td>- Adherence to traditional values</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patriarchy</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Spousal/partner control of household finances/access to healthcare</td>
</tr>
<tr>
<td>- Women’s autonomy/decision-making ability in the household</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sensitivity to others</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Mention of marriage, divorce, abandonment, children, family members, others with same illness</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Obstacles encountered that forced a turning point/change in life or activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>- HIV status</td>
</tr>
<tr>
<td>- Spousal abuse/In-law abuse</td>
</tr>
<tr>
<td>- Disinheritance</td>
</tr>
<tr>
<td>- Abandonment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Obstacles encountered that caused introspection, insight, or commitment to improve</th>
</tr>
</thead>
<tbody>
<tr>
<td>- HIV status</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Locus of control</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Others have key role in shaping life and determining fate</td>
</tr>
<tr>
<td>- Participants seem in control of their lives</td>
</tr>
<tr>
<td>Code</td>
</tr>
<tr>
<td>-------------------------------</td>
</tr>
<tr>
<td>Traditional values</td>
</tr>
<tr>
<td>Patriarchy</td>
</tr>
<tr>
<td>Sensitivity to others</td>
</tr>
<tr>
<td>Turning points/epiphanies</td>
</tr>
<tr>
<td>Reactions to adversity – Problems</td>
</tr>
<tr>
<td>Reactions to adversity – Causing introspection or growth</td>
</tr>
<tr>
<td>Reactive attitude towards life</td>
</tr>
</tbody>
</table>
describes life as a series of events over which she does not have control.

hospital. I have since then been struggling with my children. He had run away and so I called him and told him you left me in the hospital and the bill...

| Proactive attitude towards life | Participant mentions taking action in situations that reflect agency. Takes initiative, describes self as agent of change. | I encouraged myself I said I would make it. In this community in which I live I am actually the one who helps them...they know themselves but they live in fear because of stigma. So it is big support I give them so that even if it is a man I will take him up to there [hospital] then I leave them there so that he can access counselling… |

Step 4: Creating a code

The list of themes identified in the last step was reviewed. The themes showing a distinction between the subsamples were rewritten for maximum clarity (Table 5.6).

Step 5: Using the codes

I then coded the remaining narrative stories. The transcripts had previously been entered as project documents into the N-Vivo computerized data management program. The codes developed were entered as nodes, and I coded the text by matching codes with segments of the data selected as representative of the code. The segments of text were then sorted, and a process of data retrieval organized the codes or clustered codes for each narrative (Fereday & Muir-Cochrane, 2006). I used the information gained through identifying and comparing participant interviews to establish a way to capture their agency within a patriarchal society.

5.13 Establishing Credibility

Creswell (2007, p. 205) notes that some scholars have little use for validation as it neither guides nor informs. For example, Sandelowski (1991, p. 161) asserts that it is problematic to impose validity testing on qualitative research. In her opinion, efforts to impose validity testing are “inherently contradictory” because validity is “conditioned by empirical rather than narrative or biographical standards of truth and by a preoccupation with obtaining information at the expense of understanding expression” (p. 162). Green and Thorogood (2009) contend that validity is
problematic because “truths” in the interpretative and constructionist traditions are socially situated, and they reject a positivist idea of one fixed and essential truth. However, these authors do concede that this argument does not mean that qualitative researchers should dispense with all considerations of validity (p. 20).

Despite the debates and lack of consensus discussed above, these scholars do provide various and useful strategies for establishing credibility in qualitative research. I address some of the strategies that I undertook during my own research to ensure credibility, specifically methodological coherence (Morse, Barrett, Mayan, Olson, & Spiers, 2002); validity, specifically, triangulation, deviant, or negative cases (Green & Thorogood, 2009; Silverman, 2011; Patton, 1999); and credibility of the researcher through reflexivity (Patton, 1999).

Establishing methodological coherence entails ensuring that the research question matches with the methodologies, including types of data collected, process of analysis, and theoretical underpinning (Morse et al., 2002). In designing the research, I was conscious of making the link between qualitative methodology and postcolonial feminism. I collected interview data to answer my research questions because that process is a fundamental aspect of qualitative research, which aims to understand meanings and everyday practices. However, collecting data through interviews is also important in terms of postcolonial feminists’ inclination to generate knowledge from participant experiences. Thus I maintained methodological coherence by adhering to the principles of both qualitative research and postcolonial feminism.

I employed triangulation of sources (Patton, 1999) by comparing the perspectives of people from different points of view. I interviewed key informants from the hospital, NGOs, and CBOs to document healthcare services, conducted focus groups to validate the research tools, and conducted in-depth interviews with pregnant and lactating women living HIV. Although triangulation of my data sources did not lead to a single, totally consistent picture, the consistency in overall patterns of data from different sources contributed significantly to the overall credibility of my findings (Patton, 1999). Triangulation is not a way of obtaining a “true” reading, but is a strategy to add rigour, breadth, complexity, richness, and depth to any inquiry (Silverman, 2011).

Looking for and explaining negative or deviant cases in datasets are important for establishing credibility (Patton, 1999; Silverman, 2011). Negative cases may help develop alternative
explanations or explanations of why certain cases do not follow the main patterns seen in other cases (Patton, 1999). During analysis, I was mindful of being open to negative cases. The data did not explicitly identify negative cases. Instead, the results, following a postcolonial feminist lens, contextualized the respondents’ different social and material resources, and shed light on the variability in their experiences of accessing healthcare.

Patton (1999) sees the credibility of the researcher as intrinsically linked to the credibility of the study itself. The researcher is an instrument of the qualitative inquiry process; it is therefore critical that the researcher demonstrate reflexivity to enhance credibility of the study (Patton, 1999).

5.14 Reflexivity

I am aware of the asymmetrical or exploitative relationship between the researcher and those being researched. To counterbalance this hierarchical relationship I adopted the role of the supplicant in my fieldwork. Usually feminists assume the role of supplicant, seeking reciprocal relationships based on empathy and mutual respect, and often sharing their knowledge with those they research (England, 1994). Therefore, in my role as the researcher, I explicitly acknowledged my reliance on the research participant to provide insight into the oppressive social structures that shape their everyday lives and their experiences accessing healthcare. I unequivocally accepted that in fieldwork I am the researcher-as-suppliant and that the knowledge of the participant, in relation to this study, is greater than my own. In this way, I could potentially deal with asymmetrical and potentially exploitative power relations by shifting power over to the study participants.

Another approach to addressing this unequal power relation between myself the participants was to acknowledge my positionality as a Canadian PhD student, a woman of colour, from a postcolonial country. I recognized that being sensitive to the power relations did not mean that I could remove them. That despite some commonalities, gender and postcolonial history, I was differently positioned from the research participants. I understood that my biography and my tendency toward supplication gained me access to participants’ response, even as their responses may have been mediated by my presence. Most women in the study provided quite intimate details about their lives, such as their HIV status, their intimate partner relationships, and
engaging in survival sex. Their responses might have been different for a differently positioned researcher; positionality directly affects the fieldwork and the fieldwork is a dialogical process structured by the researcher and participants (England, 1994).

My positionality, Indo-Caribbean Canadian, social class, also exposes the partiality of my perspective and understanding of my participants’ experiences. In an effort to conceptualize women’s diversity I was concerned this partial understanding would lead to “appropriation” (England, 1994) of participants’ voice. To avoid appropriation and misrepresentation I try to give voice to participants by presenting lengthy quotes in the result chapters. However, I acknowledge that I cannot fully present participants’ voices by including lengthy quotes from their interviews because the published text is ultimately my construction and responsibility.

Engaging with reflexive inquiry raised insight into the ethical nature of my research question, especially with regard to the dialogical relationship between myself - the researcher - and participants living with HIV. I also reflected on if it was ethical to specify the place of study because the detailed narratives may reveal participants’ identities. Anonymizing participants’ data and the location of the study addressed this ethical issue. Being aware and sensitive about ethical concerns of the dialogical relationship in this fieldwork does not easily resolve the issue. However, without participants there is no research and without approval of my research protocol by Kenyan authorities, KEMRI, there would be no fieldwork to address this research question.

5.15 Limitations

While the final analysis of the data for my dissertation was discussed with my supervisor and thesis committee, the data were coded and themes were identified only by me. This process failed to provide multiple perspectives from a variety of people with differing expertise in terms of the coding. When using this method for a collaborative study, the coding of data could involve several individuals with themes developed using discussions with other researchers, a panel of experts, and/or the participants themselves.

With a finite amount of research funding, I was only able to plan a brief five-week trip for the follow-up interviews. This limited time in the field meant that not all participants were available for the follow-up interviews or could be reached by the recruiter to arrange the interview within that time frame.
Esposito (2001) indicates that during the data collection process, the researcher processes the meaning of the participant’s comments and is able to adjust questions and comments in response to unanticipated answers. Some research projects directed by monolingual researchers rely on trained bilingual facilitators to interview research participants. Although this can produce accurate information, the dynamic flexibility of the data collection process is inhibited (Esposito, 2001). With the help of the note-taker, I was able to participate and guide the interviews conducted by the research assistant. While the interviews generated were rich and detailed narratives, relying on a facilitator to conduct the interviews may have had some impact on the dynamic flexibility of the data collection process.

I depended on and had full confidence in my research assistant and another independent transcriber to translate the women’s voice.
Chapter 6
The Health Services Landscape

6.1 Key Institutional Actors

In order to understand the journeys that these women took to access healthcare in this urban setting, it is necessary to know and convey the institutional landscape. It is important to hear the institutional perspective, because it intersects with the lived experiences of the end users.

This chapter presents the findings from semi-structured interviews with twenty-two key informants, K1 – K22 (Table 6.1), regarding the healthcare services and other provisions available to pregnant and lactating women living with HIV in this urban setting in Kenya. The responses provided by these selected informants together provided an overview of the availability (supply/quality) of healthcare services in order to provide the context for healthcare services in this urban setting. Descriptions of the function of and services offered by the various government and non-governmental organizations involved in healthcare as well as insights from key actors working in the respective organizations will be presented in this chapter. These highlight both gaps in healthcare services provided and a variety of exogeneous factors that hamper women’s access, as perceived and identified to me by these key informants. Key institutional actors helped to contextualize women’s experiences and to convey the gaps in healthcare services, and their insights made it easier to map intervention/practice responses.

There were commonalities in the key institutional actors’ perspective. The main themes identified were the lack of adequate healthcare funding, which meant that, AIDS response activities were underfunded resulting in unmet needs for people living with HIV. Inadequate funding also resulted in gaps in training of health practitioners and shortage of medical equipment and supplies. Other institutional response commonalities were that exogeneous factors such as stigma and poverty influenced women’s access to healthcare in this setting.

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8 The women’s stories will be presented in subsequent chapters
Table 6.1: *9 Expert Key Informants’ Institute/Organization (n = 22)

<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Institute/Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>K1 – 5</td>
<td>Provincial General Hospital</td>
</tr>
<tr>
<td>K6</td>
<td>National AIDS &amp; STI Control Program (NASCOP), Ministry of Health</td>
</tr>
<tr>
<td>K7</td>
<td>USAID/APHIA Plus - NGO</td>
</tr>
<tr>
<td>K8 – K9</td>
<td>Provincial AIDS/STI Control Office (PASCO)</td>
</tr>
<tr>
<td>K10</td>
<td>District AIDS/STI Control Office (DASCO)</td>
</tr>
<tr>
<td>K11 – K12</td>
<td>South Rift, National AIDS Control Council (NACC)</td>
</tr>
<tr>
<td>K13</td>
<td>Constituency AIDS Office, NACC</td>
</tr>
<tr>
<td>K14</td>
<td>Ministry of Medical Services</td>
</tr>
<tr>
<td>K15</td>
<td>Nakuru District, Ministry of Gender, Children and Social Development (MoGCASD)</td>
</tr>
<tr>
<td>K16</td>
<td>Rongai District, MoGCASD</td>
</tr>
<tr>
<td>K17</td>
<td>National Legal Aid Program (NALEAP), Nakuru</td>
</tr>
<tr>
<td>K18</td>
<td>Family Health Options of Kenya (FHOK) - NGO</td>
</tr>
<tr>
<td>K19</td>
<td>Presbyterian Church of East Africa (PCEA) – Church-Based Organization (CBO)</td>
</tr>
<tr>
<td>K20</td>
<td>Hurricane Nakuru Women’s Right Centre – Civil Society Organization (CSO)</td>
</tr>
<tr>
<td>K21</td>
<td>Men for Gender Equality (MEGEN) - NGO</td>
</tr>
<tr>
<td>K22</td>
<td>National Empowerment Network for PLWHA in Kenya (NEPHAK) - NGO</td>
</tr>
</tbody>
</table>

The analysis draws on the reports from key actors involved in healthcare provision for institutional insights. As Green and Thorogood (2009) suggest, “truths” are socially situated in interpretative and constructionist traditions. As such, this study is not looking for “truths” but rather to obtain various perspectives through triangulation to add rigour, breadth, complexity, richness, and depth to this inquiry. These institutional perspectives may be challenged or corroborated by the women’s accounts and will contribute to the overall credibility of my findings.

* Roles/positions of key informants are not presented to protect identities
6.2 Government Services

Under the overall supervision of the Office of the President, the Ministry of Medical Services, and the Ministry of Public Health and Sanitation, various government bodies coordinate the healthcare services available to pregnant and lactating women with HIV in this Kenyan urban setting. These organizations include the National AIDS Control Council (NACC), the National AIDS & STI Control Program (NASCOP), the Provincial AIDS/STI Control Office (PASCO), and the District AIDS/STI Control Office (DASCO).

6.2.1 National AIDS Control Council

The National AIDS Control Council (NACC) provides policy and a strategic framework for mobilizing and coordinating resources for the prevention of HIV transmission and provision of care and support to the infected and affected people in Kenya. Since NACC is a National Coordinating Authority, its mandate includes the development of policy and a strategic framework, and mobilization and coordination of resources.

Since its inception, NACC has made some notable achievements, including the coordination, development, and implementation of the Kenya AIDS Strategic Framework (KASF) and the National HIV and AIDS Strategic Plans (KNASP I, KNASP II and KNASP III); the development of policies in key areas, such as provision for orphans and vulnerable children; mainstreaming gender into the Kenya AIDS Strategic Framework (KASF); and engaging with key sectoral ministries to mainstream HIV and AIDS in the context of the Medium Term Expenditure Framework (MTEF) budget process.

An NACC official explained that NACC coordinates resources for prevention of HIV transmission and provision of care and support in the study setting district:

NACC come up with these policies … Women are brought together to discuss the issues, [and] then those issues will come with our framework … The Ministry of Health then implements the framework … [T]he ministries implement on behalf of NACC at the facility level. Then, we [field office] coordinate it in the community level. As coordinators, we bring those women together. We
coordinate the implementation of the framework. NACC make sure that whatever has been done is in line with the Kenya National Strategic Plan.

The negative impact of HIV is particularly severe and has overburdened much of the community, where approximately 50 percent of the population lives in poverty (World Health Organization, 2014b; Kenya National Bureau of Statistics [KNBS] and ICF Macro, 2010). NACC channels funds to the communities, thus empowering them to mitigate the social and economic impacts of HIV and AIDS, and prevent further infections. NACC disburses funds to registered NGOs, CSOs, FBOs, and private sector and public sector organizations. The NACC official further described NACC’s role in the following way:

So, as NACC, we also mobilize resources for responding to HIV and AIDS disaster. But in this strict term of “the stakeholder,” we have community-based organizations, the civil society groups … These civil society groups are the ones that mobilize for example women at the community level. They get registered. Once they’re registered, they respond to a call for a proposal, which NACC have put forth … If it is found worthy of funding, we give them the resources.

NACC coordinate those organizations, CSOs, NGOs, to make reports of what they are implementing on the ground to National AIDS Control Council, where we use it to source for funds now to sort of enhance the community-based organizations’ activities. We are coordinating those organizations and we supervise their activities to make them to be in line with the strategic plan on HIV and AIDS.

The NACC official indicated that the majority of the financing for HIV and AIDS in Kenya comes from international partners. The official also mentioned that funding is limited, which makes it difficult to mitigate the impact of HIV:

But the government does not fund a lot. You cannot fight a disaster with borrowed funds [donor funding]. The community, one, for example when you do a call for proposal, you find so many groups are responding, but our services are limited for HIV and AIDS interventions.
The NACC Constituency AIDS office (lowest branch of NACC) works directly with the community organizations and links them with NACC. The NACC constituency office also vets funding applications submitted by community organizations, and forwards qualified applications to the national level for final approval. The funds are given directly to the organizations, and the constituency office supervises the organizations’ activities. An NACC constituency official described who benefits:

They have a project … maybe like they can keep chicken, they can rear goats and all that. Which is going to benefit the group and the other community members who are near them, the target group. Another … there is an organization, which has received some funds from Global Fund … They have been given the responsibility of PMTCT awareness.

Therefore it is through NACC’s mobilization and coordination of resources that community organizations are empowered financially to combat the AIDS pandemic. However, according to NACC officials, with limited funding constituent’s AIDS response activities remain under or unfunded, possibly resulting in unmet needs for people living with HIV.

6.2.2 National AIDS and STI Control Program

The National AIDS and STI Control Program (NASCOP) is mainly involved with technical coordination of HIV and AIDS programs in Kenya. NASCOP oversees the implementation of the Kenya National HIV and AIDS Strategic Plan III (KNASP III) and runs its programs. These programs include prevention of mother-to-child transmission of HIV (PMTCT); HIV Testing and Counselling (HTC); basic education and dissemination of information about HIV; communication about behavioural change and mass media campaigns. In addition, NASCOP is spearheading efforts to increase access to male circumcision, antiretroviral therapy, and treatment for sexually transmitted infections. An official from NASCOP described the program’s role:

NASCOP is a technical arm of MOMS & MOPHS that spearheads the health centre response to HIV/AIDS and other STIs. Our role at NASCOP is to advise the government on policy issues on guidelines. Whatever happens at the global level comes back to us. And we have to translate that into workable guidelines
that are relevant to the country. So, our job is: one, to translate international guidelines, especially from WHO … And then advise the government this is what we need to do … And, also, go ahead with implementation of the guidelines. So, in summary, NASCOP does health systems strengthening.

NASCOP develops guidelines and disseminates these guidelines to the health sector for a number of programs. NASCOP builds capacity for healthcare workers to be able to respond effectively to the epidemic, through training and mentorship. It is also tasked to ensure that commodities are available and to improve the quality of service delivery. While community activities are coordinated by the NACC, NASCOP coordinates activities at all health facility levels.

NASCOP draws its objectives and activities from the Kenya National Strategic Plan, which envisions having an HIV-free generation. In order to achieve that vision, NASCOP has implemented a wide range of strategies from print media and electronic media to ensuring that hospitals are ready to offer services. NASCOP is “creating demand” and sensitizing the facilities, district management teams, and provincial management teams to be prepared for the increased demand for HIV programs. The NASCOP official spoke about his work in this way:

For PMTCT, our vision is to have an HIV-free generation so to speak. And by doing so, we need to reduce pediatric HIV infections acquired through mother-to-child transmission to levels that are comparable to developed countries. And if you want to be specific to PMTCT, we are talking about the behaviour to go to the clinic … The behaviour to deliver in a health facility or not to deliver at home … Knowledge gaps – and the way we do it, we are doing it in phases. The first phase was introduction, introducing the topic. So, we hope by doing so, Kenyans will be able to understand their role as clients.

International donors fund much of NASCOP’s implementation activities, as the NASCOP official explained:

And we are also glad that we are receiving the Global Fund Grant. Which is a huge grant for us because it has lots of PMTCT activities in there. PMTCT and RH activities … for the next five years to provide subsidized antenatal care,
waiver of labour and delivery charges. And we also got another grant from UNICEF to support the community health workers do the follow-up. And, recently, we had received about 10 million dollars to support, procure the commodities. Then PEPFAR has committed support for commodities for the next five years.

Some donors are implementing partners. These implementing partners, along with the district health management teams (DHMTs), implement the programs set out by NASCOP and the Kenya National Strategic Plan.

Reportedly NASCOP’s aim is to “achieve elimination of HIV over the next four – five years” through messaging to address knowledge gaps, encourage behavioural change, create demand for services, and get “Kenyans to understand their role as clients.”

These national level actors are not the only key government actors involved in providing and overseeing healthcare services in Kenya. The following are the provincial and district actors’ perspectives.

6.2.3 Provincial AIDS and STI Coordinator (PASCO) Office

The Provincial AIDS and STI Coordinator (PASCO) office oversees the Prevention of Mother-To-Child Transmission of HIV services in all health facilities with an antenatal clinic in the Rift Valley province. The PASCO office also coordinates the ART services in South Rift. KEMSA or Kenya Pharma supplies the central sites, such as the level five hospitals or district headquarters. In this particular district, the Nakuru Central Stores serves as the central site for the health facilities within the district.

One of the main focuses of the PASCO office is to ensure all pregnant women are tested and counselled on their first visit to the ANC. A PASCO official discussed the rationale for universal testing and counselling:

We want them to be counselled and tested. For those who are found negative and they’re also told how to remain negative. For those who are positive, then what interventions do we put in place to prevent the transmission from the mother to
their baby … Others come when it’s already too late. Okay, others come early enough for us to be able to put the interventions.

Reportedly many pregnant women still deliver at home, often without a skilled health professional in attendance. According to one official, the PASCO office tries to minimize risks to pregnant women living with HIV by creating awareness through community mobilization strategies:

We do a lot of community mobilization, so that they understand that these mothers need to deliver in a facility with skilled attendant instead of just running to a TBA who may not know other problems that may arise. So, we’re also putting a lot of our strength there just to try and see whether we can strengthen this because it has been a problem for quite a long time. They come for the ANC but delivery … They sneak off to their TBA’s.

PASCO is responsible for training all staff involved in providing antenatal care and PMTCT services. Staff is trained in WHO staging and how to use laboratory results to make HIV treatment decisions. An official described staff training thus:

We are training healthcare staff who provide the services to the ANC mothers. If they are able to stage this mother using the WHO staging – if the mother is in stage one and two – fine for prophylaxis. If the mother is in stage three and four, then they need to start this mother on HAART [highly active antiretroviral therapy]. So, of course, they need their reference for the lab. Then, of course, they have to know the combination to start the first line. And then of course, we’re taking care of this mother and linking her to the CCC. So that, soon after, she can continue with her normal care.

PASCO coordinates staff training offered by NASCOP and its partners, such as AMPATH or Walter Reed Project and Mission for Essential Drugs and Supplies (MEDS). For example, NASCOP sponsored a “mentorship” program for healthcare staff. The mentorship program is a six-day curriculum where healthcare staff receives training and mentoring in the antenatal clinic, maternity ward, and postnatal clinic. The following is a description of the mentorship training offered by the PASCO office:
Sponsored directly by NASCOP … the mentorship is a new system of training – the curriculum takes 6 days where the participants come and they stay around. And, every morning, we’re able to see them. Then we’re able to distribute them to their different mentors in ANC and in the maternity unit. And then they change over and we ensure that they rotate in all those areas. They also go through the DBS, the pricking of the babies and doing the early infant diagnosis … Instead of the classroom setting, we go to the field and hospital has been a very good site for our training, and they very intensive training. They’re given the modules … they read on their own during the day; during working hours, they go and stay with the mentors in their clinical areas. So, they see one patient after another with the mentor.

Mentors include most of the staff at the PASCO; the hospital matrons (senior nurses), doctors, pharmacists, and nutritionist staff come “from as far as Samburu, Loitokitok, and other areas in the South Rift region” for training.

PASCO officials recognized that there were gaps in training offered to ANC, PMTCT, and maternity healthcare providers. The officials attributed these gaps to the lack of funding for training, which reportedly hampers delivery of services:

There’s also a gap in training, a lack of skills. Training has been done but not hundred percent, of course. We only do it when we have the funding. And that is just like a drop in the ocean. You see, you’re pulling one person from a district for training. We are still very far from achieving … that everybody is PMTCT compliant … [I]t’s my wish that at one time everybody working in MCH is trained, everybody working in Maternity is trained so that there are no gaps. But now with this kind of a situation, you find that sometimes a mother delivers and maybe there’s nobody to give her the drugs and she has to wait until tomorrow, which is not very good. And unless that person is trained enough to see it – to realize that this mother needs this service more than these other people … And we need to do something … then she may even decide this is not a sick mother. I think what is missing is to empower those midwives to be able to put them on HAART right from the ANC. And that actually empowers these midwives to be
able to prescribe the ARVs. So, she can be able to put this mother on HAART even without the help of a clinical officer. Yeah, much training hasn’t been done yet.

Reportedly the smaller “level two dispensaries” do not have ART services; they can enroll patients into care but cannot provide HIV services because staff personnel lack appropriate training and qualifications. The dispensaries often have only one or two staff members. The larger health facilities with comprehensive care clinics have a greater number of trained healthcare providers. As described by one official, the following is the extent of services offered at the different facilities:

We have trained personnel in the health facilities who are trained, they are either clinical officers or they’re nurses and they are trained on ARTs or ARVs. So, they’re the ones who are able to assess a patient, whether is medically eligible for ARTs that is going by CD4 count or WHO staging. We also have social workers and we have adherence counsellors also. So, it is actually a whole team in the comprehensive care centre … who is there will do the adherence counselling person, will also initiate this patient on ARTs and link this patient to a support group, or community worker. So, in such a facility you see all those personnel are there, but in smaller units they may not be available. But in a place like PGH, you know, they’re advantaged because they have the doctors. They have the clinicians … But when you go to the places where it’s purely run by the nurses, there’s a bit of problem.

It was noted that often there was a shortage of trained staff and a high turnover, and that many staff suffered from burnout. The PASCO officials also recognized that there was a shortage of equipment and HIV testing kits at health facilities:

Plus, some facilities, they always complain of workload. Yeah, apart from the turnovers, the workload. Maybe one person in the facility doing everything… Many of them will complain of burnouts.
I wish it was possible for all ANC, especially in the county hospitals, to have a CD4 count machine. It would be easier to monitor these mothers. You may find that sometimes they are not available and they don’t have test kits.

CD4 we have some hospitals but they’re very few. And also the turnaround time, from the time I take the specimen to the time I receive back the results. They go to Kericho and you can also imagine now the workload at Kericho, also. But now, since we have the CD4 counts in a few other level four – five hospitals, then it becomes a bit easier.

As documented above, the PASCO office is responsible for coordinating ARV/ART services and oversees the prevention of mother-to-child-transmission of HIV services in all health facilities, with an antenatal clinic in the South Rift Valley region. However, as reported by PASCO officials, due to lack of funding not all healthcare staff are fully trained to provide HIV services to women seeking antenatal care. Not all facilities are able to provide appropriate healthcare to pregnant or lactating women living with HIV due to lack of trained healthcare professionals at lower-level facilities. Also reported was the lack of sufficient equipment to ensure an efficient and quick turnaround of medical test results.

6.2.4 District AIDS and STI Coordinator (DASCO) Office

The office of the District AIDS and Sexually Transmitted Diseases Coordinator (DASCO) coordinates the HIV and STI activities in the District. The DASCO is also a District Health Management team member. The District Health Management team oversees all health-related services within the district, including HIV-related services. The DASCO, together with the other district health management team (DHMT) members, coordinates the HIV programs in the district. A number of key HIV services that the DASCO and the DHMT coordinate include the following:

- HIV Testing and Counselling (HTC) sites integrated into health facilities
- Voluntary Counselling and Testing (VCT) at stand-alone sites
- Provider-initiated testing and counselling (PITC)
- Prevention of Mother-To-Child-Transmission (PMTCT)
- Antiretroviral therapy (ART)
The DASCO, the DHMT, the Reproductive Health Coordinator, and the Antiretroviral Coordinator and others oversee services in all the government facilities, the faith-based organization facilities, and the NGO facilities (public and private sectors). They provide support to these facilities in order to ensure a high quality standard of healthcare is being provided by these facilities. The district officers ensure that the national guidelines are being implemented. The District AIDS and STI official described the situation in this way:

This NGO has a comprehensive care centre, have PMTCT services, they have laboratory, they have pharmacy … they have all the services. They also target matatu touts to be able to do activities and educate the matatu – create awareness and whatever. They also work with sex workers. They work with the people living with HIV. For us (DASCO & DHMT) we’ll go there and look at what kind of services are you doing. We are able to support them to be able to do these services appropriately. We are supposed to oversee these services, because we have somebody who is at the district level who oversees laboratory services. We have a pharmacist who oversees pharmacy services and then we go and support them to ensure that they are providing appropriate services.

To ensure services reach the community, the district officers help to build capacity through community health extension workers. Community health extension workers are public health officers or nurses who work at the community (level one), at the dispensary (level two), or at a health centre (level three); they are in charge of building a community of community health workers. Community health workers are selected by the community, and are trained to provide health education to the community. The community health workers link individuals to the different levels of facilities depending on the services required.

The DASCO official and management team in partnership with community-based organizations and non-governmental organizations coordinate educational activities to create awareness at the community level. At the community level, pregnant women are encouraged to seek antenatal care, and emphasis is placed on HIV testing for all pregnant women to prevent mother-to-child transmission. The DASCO official mentioned that despite awareness at the community level not all pregnant women seek antenatal care:
The community is educated; all pregnant mothers are supposed to go for ANC services. At community level, we want to encourage that mothers should go for ANC services. Because you find there’s a number that does not reach. If we identify them, we are able to give them prophylaxis, so that we can be able to reduce the infection to the child. Those who are HIV positive, they’re given prophylaxis at 14 weeks and they’re also given infant prophylaxis to be able to carry it home because we are not sure whether they’ll be able to deliver in a facility or not.

There are twelve comprehensive care clinics (CCC) in the district, which are responsible for providing continuity of care such as ART services, counselling, family planning, and prevention with positive education and services, and peer support groups. As described by the DASCO official, the services provided by the CCC are as follows:

Those who are identified to be positive, they’re linked to the comprehensive care centres for continuity of care, counselling … so that the client can be able to accept the situation, live positively, and change their lifestyle. Then we also have prophylaxis to prevent opportunistic and to treat the opportunistic infections in the comprehensive care. We are also, able to integrate family planning services. Then we also, have what we have what we call prevention with the positives to be able to give them prevention messages, yeah because anyone who is HIV positive is the one who can be able to infect another person and also to prevent themselves from getting re-infections. So, these services are ongoing at the comprehensive care. We also have support groups within the CCCs, So, that they can be able to have education and they’re able to support one another and they’re able to encourage one another.

The DASCO and district health management team essentially provide supportive supervision at the various levels of public health facilities to address the gaps in service provision and ensure that quality health services are being provided. They ensure that individuals are linked to the appropriate public health facility or to community-based organization or non-governmental organizations based on the services they require. They coordinate educational activities to create awareness at the community level. However, the coordinator reported that although it is
recommended that all pregnant women seek antenatal care and deliver at a health facility with a skilled professional in attendance, the percentage of women complying with these recommendations remains low.

6.2.5 Reproductive Health Official

An official from the Reproductive Health (RH) department, Ministry of Medical Services, advised that this department oversees RH services in all health facilities in the district. RH includes key issues such as antenatal care, PMTCT, family planning, reproductive tract cancers and infections, and obstetric care and complications like obstetric fistula. RH also includes a component that addresses issues of intimate partner violence, sexual abuse, post-rape care, and female genital mutilation.

The RH official mentioned that a major challenge in the district is increasing the percentage of women attending antenatal clinics for care and delivering in a health facility with a skilled healthcare professional in attendance. The ministry has a program intervention to promote at least four antenatal clinic visits by pregnant women to address obstetric complications, HIV testing, PMTCT, and other medical conditions. The RH official mentioned that many women do not receive at least a minimum of four antenatal visits and still have non-facility deliveries:

Women should attend four visits minimum in this – for PMTCT again. They need to come to the clinic early so that you can identify and put interventions early. Because, if they came late, chances are that the interventions would not work for both HIV care and also other medical conditions in pregnancy. And then, when obstetric complications are rising, we need to pick them early. So, the challenge has been most women come in their third-fourth trimester which – it has been a problem but, as a country, we put that as a performance indicator to ensure that women – those who start the first visit at least complete four recommended visits. Deliveries by unskilled attendants is still quite high. We are not even yet 50 percent delivering at the health facilities.

The RH official mentioned that the majority of pregnant women came for at least one ANC visit and that healthcare workers used this opportunity to encourage these pregnant women to continue with antenatal care and to plan with them to deliver in a healthcare facility.
While the Ministry’s program intervention promotes at least four antenatal care visits and facility delivery, reportedly, this remains a major challenge in Kenya; a significant percentage of pregnant women do not attend the recommended four ANC visits or have a facility delivery.

6.3 Public Health Sector

6.3.1 Provincial General Hospital

In this urban setting, there were two municipal hospitals in close proximity to the provincial hospital. The provincial general hospital is a referral hospital in the South Rift Valley region. One of the municipal hospitals had a comprehensive care clinic (CCC) staffed with clinical officers and nurses to provide HIV treatment and care. Often, HIV patients from this municipal hospital were referred to the provincial hospital if there was a shortage of HIV drugs. The other municipal hospital provided maternity services. However, women pregnant with their first baby and women considered at high risk were referred to the provincial general hospital in case of complications.

Interviews with key informants at the provincial general hospital described the healthcare services provided to pregnant and lactating women living with HIV. These services were based on four pillars: preventing HIV among women of reproductive age; meeting unmet family planning needs of women living with HIV; preventing HIV transmission to infants; and treatment, care, and support. According to one healthcare professional at the hospital, the hospital provided “comprehensive care for pregnant women living with HIV with a focus on antenatal care.” Care included a discussion of the “danger signs” during pregnancy and the importance of proper diet and nutrition, and counselling on appropriate breastfeeding practices, specifically the benefits of exclusive breastfeeding, for women living in a low-income setting and women living with HIV. Also included was treatment for tuberculosis and malaria.

Women tested and found to be HIV positive are sent to the lab at the hospital for a CD4 T-cell count test and are counselled on HIV treatment. Based on their CD4 T-cell count, women are placed on opportunistic infection prophylaxis or highly active antiretroviral therapy (HAART). In the absence of the CD4 T-cell count, test “staging” is done to assess the clinical stage of the disease progression. The World Health Organization “Disease Staging System for HIV Infection and Disease in Adults and Adolescents” is an approach designed for resource-limited settings.
and is widely used in Africa and Asia. This staging system has been a useful research tool in studies of progression to symptomatic HIV disease.

Healthcare professionals discussed individual birth plans based on each woman’s personal circumstances. Pregnant women were advised of the importance of delivering at a healthcare facility and told they should be prepared financially to pay for their transportation costs and hospital fees. Pregnant women living with HIV were counselled on how to prevent mother-to-child transmission of HIV. Nevirapine was given to women to take home with them in the event they were not able to deliver at a healthcare facility; this measure was to reduce the risk of HIV transmission to the child.

The provincial general hospital provides integrated comprehensive healthcare to HIV pregnant women “because we want to take care of the mother and the baby up to eighteen months postnatal.” If the baby tests HIV positive, both mother and baby are referred to the comprehensive care clinic after eighteen months to continue HIV treatment and care. Reportedly, the focus was on antenatal care, where HIV pregnant women received the recommended antenatal care, HIV treatment, and counselling, and PMTCT counselling:

   Postnatal visits I think it’s continuing to at least to grow. The comprehensive care for HIV-positive pregnant women is that we are caring for these women antenatally, focusing on antenatal care.

   A minimum of four antenatal care visits were recommended to ensure that pregnant women receive the interventions they need to prevent and manage complications. HIV pregnant women are encouraged by healthcare professionals to come more often for services in case of complications or if they need support counselling:

   We encourage them to come for four visits, the ones who are not HIV positive. But the HIV-positive ones you can tell them to come as often as they want, because there are times when they get issues and their visit date has not reached, the appointment date has not reached. Do you tell them to stay home? No, you tell them to come when they want to talk to you.”
According to hospital staff, women usually came later in their pregnancy for antenatal care and often did not come for the recommended four visits. In their view:

The four visits now is the problem, because our people opt to come to the clinic when it is late. When they are almost approaching delivery they come for the card. Their main reason is to come for the card … Which they think will allow them to deliver in our facility. The number which comes for ANC services you find another small group they don’t finish the four services.

While there have been improvements made to training of hospital staff, it was noted that there were still staff who were not fully trained. For example, the hospital was given the newest curriculum from the Ministry of Health regarding prevention of mother-to-child transmission (PMTCT) of HIV, but in the maternity unit and the antenatal care clinic not all staff received full training. One healthcare professional interviewed was a trainer and counsellor for PMTCT and supervisor for HIV/AIDS in outpatient services. This healthcare professional mentioned that all nurses in maternity and antenatal clinic were required to be PMTCT compliant, but only one-quarter of the nurses were trained. It was also noted that most of the training delivered was done through Continuing Medical Education (CME), where staff received two hours of training each week. The healthcare professional felt that CME was inadequate:

Though it is not enough, because two hours compared with a course of more than six days is a drop in the ocean. I wish we could get somebody for a year to concentrate on training our nurses. We would finish the whole group of midwives so that at every corner, if a mother comes at every corner of the hospital asking about PMTCT, they know.

There appeared to be a shortage of staff. It was mentioned that “the work load is usually high for the nurses, for the service providers, because of shortage of staff.” According to those interviewed, the provincial general hospital “manpower was at an estimated eighty percent,” and because of the shortage, hospital staff experienced “burn out.”

Other shortages at the hospital related to HIV testing equipment. According to one healthcare professional, shortage limited women’s access to care:
Because, one, once in a while you get a shortage of reagents, or breakdown of machines. So, you find that however much you want to start this client on ARVs, you are not able to because you are not able to access the CD4 count. Drugs are always there. Drugs we are doing quite well. The only problem is the testing kits.

Reportedly, efforts are being made to provide comprehensive healthcare to women living with HIV who may be pregnant or have young children. However, inadequate training, staff shortage and burn out, and inadequate medical equipment for testing is a challenge to the system. The healthcare professionals interviewed recognized that although there were some challenges, services were available, but the percentage of women accessing the ANC services in particular remained low.

6.4 Private Sector: For-Profit and Not-for-profit Organizations

The private sector, in Kenya, includes both for-profit and not-for-profit entities such as faith-based organizations (FBOs) and non-governmental organizations (NGO).

6.4.1 For-profit private practice physicians

In brief discussions with the primary investigator, two private practitioners who recruited pregnant and lactating women for the study stated that most of their patients were of higher social class. Many of the pregnant and lactating women living with HIV who attended their private practice were also of higher social class and wanted to maintain their privacy and to ensure that their HIV status was kept confidential (which was not often possible at the public health facilities). One physician asked that my Kenyan research assistant not be part of the interview because the participant “did not want another Kenyan in the room.” Both physicians said that pregnant women, including those living with HIV, accessing their services preferred to deliver in a private health facility with a skilled health professional in attendance. Patients paid a consulting fee (1000 – 1500 KSH) for each visit at the physician’s office and several thousand Kenya shillings to deliver at a private health facility. If the pregnant woman wanted her obstetrician in attendance at the delivery, there was an additional cost.
6.4.2 APHIAplus

APHIAplus, an NGO, is funded through USAID; the goal of its activities is to ensure access to quality health services and products by building the capacity of healthcare providers to deliver high quality health services. Specifically, APHIAplus helps people living with HIV and AIDS to gain access to counselling and treatment, and reduces child deaths through improved maternal and newborn child health services at health facilities. One official described APHIAplus’s role:

We have placed at the provincial hospital nurses to supplement the government staffing. We’ve also placed counsellors to provide the HIV testing component. We have supported the link between the outpatient, ANC, and also the CCC to be able to give a comprehensive package. We have the community component where the health community workers have been trained. In that training there is a component for PMTCT to ensure that there is demand creation from that end for service uptake where they are being established.

APHIAplus improves the lives of mothers, children, and their families in Kenya’s Rift Valley region. The project focuses on delivery of quality health services related to HIV and AIDS, family planning, reproductive health, malaria and tuberculosis. APHIAplus leads interventions to strengthen HIV counselling and testing, prevent mother-to-child transmission of HIV, increase family planning and reproductive health resources, and improve maternal and child health. The official mentioned that one of the NGO’s main focuses was on maternal health:

Well, in our project here we put a lot of emphasis in following and implementing the government policies in terms of healthcare … [W]e ensure that there is a capacity for all service providers to be able to provide comprehensive healthcare services and we mostly focus on women.

APHIAplus are in 937 facilities that offer PMTCT services in the Rift Valley. They also support USAID partners in the community that provide the linkage between the facility and the community. APHIAplus helps to improve and expand civil society activities to increase healthy behaviours. APHIAplus and partners develop messages to encourage mothers to have at least four antenatal care visits, to be tested for HIV, and to deliver at a health facility. According to the
official, APHIAplus hopes to influence healthy behaviour by creating awareness through messages:

Developed messages that are geared towards ensuring that mothers have more visits to the antenatal care for purposes of first and foremost ensuring there are in good health … Secondly, that their HIV status is established, and thirdly that they deliver by skilled service providers in the facilities.

APHIAplus is also involved in activities to improve and expand support for people and families affected by HIV and AIDS. The following are services supported by APHIAplus:

So, we also support them and give them so many skills and we also talk of food security. When we talk of food security we give those skills and ensure that this guardian or this parent still without the support from the program can still survive and get something to feed the children and we give so many skills like – skills concerning the farming, like organic farming in kitchen garden. Sometimes you might find a guardian saying “I’m able to do this, but the capital to begin that sukuma wiki kiosk we don’t have.” So, we’re able to give those skills on how to carry out that small business and then we have a big farm at PGH.

APHIAplus builds capacity, addresses service gaps at the health facilities, improves the well-being of the poor by providing life-skills training and ways of generating income to support themselves, and helps people gain access to HIV services.

6.4.3 PCEA comprehensive care clinic

The Presbyterian Church of East Africa (PCEA) opened a healthcare facility in 2008 in this urban setting in Kenya. At the time of the interview, it was serving 300 patients, of whom two-thirds were women. The services offered included HIV treatment and care, PMTCT, family planning, and antenatal and maternity services.

The facility could potentially provide services to 1,500 patients, but at the time of the interview served only 300 due to the shortage of staff. The comprehensive care clinic (CCC) was staffed with only one clinical officer and one pharmacist, and the ANC/maternity unit was staffed with four nurses. There were no medical doctors on staff. In cases of emergency or high-risk
pregnancies and caesarean sections, patients were referred to the provincial general hospital (PGH). A healthcare professional at the PCEA CCC mentioned that the shortage of staff impacted the number of patients for whom the facility could provide services:

Provider gaps, you could say, not enough time to handle all these clients … So, it’s basically a problem. Currently, we’ve been getting clients from PGH – we enroll them, yeah. But the problem is that with the workforce that we have … Potentially … Actually, we can reach even 1,500 clients … But we’ve been trying to limit the numbers because, actually, if you have a bigger number and you don’t have enough workforce, it’s going to be really difficult for even the clients. So, what I advice them [PGH] is that because of the numbers that we have, we cannot take more.

At this clinic, patients can be tested for HIV, hemoglobin levels, and pregnancy free of charge. The clinic does not have a CD4 machine and has to send the patients’ samples to the provincial hospital for this service. However, the results are often delayed if the hospital is having problems with the machine. The healthcare professional mentioned the challenge posed due to the lack of medical equipment, which reduces the chances of women receiving appropriate and timely HIV care:

We’ve been having problems with CD4 which is very important for – to check the immunity of that client. But we’ve been having problems with the CD4 machine, which we don’t have currently. And the one at PGH, usually we take blood from here and send it to PGH. They’ve got a problem with their reagents … so once it’s out, the clients can stay without even having the results. And it usually reduces the chances of capturing more women and starting them on HAART.

The PCEA clinic offered a number of services at no cost or reduced cost to patients, but due to staff shortage the clinic served a significantly reduced number of patients. Lack of medical equipment at the facility resulted in treatment delays.
6.5 Navigating the Landscape

The key institutional actors recognized the various dimensions of access to healthcare and the exogenous factors that hamper women’s access, even when healthcare service provision is available. These factors include the social practice of stigma and discrimination. Healthcare professionals believed that “it’s primarily the stigma and the poverty that prevents women from accessing care.” Reportedly, many women living in poverty in this urban setting in Kenya are not able to afford the associated fees for maternal and HIV healthcare services.

All five healthcare professionals interviewed at the provincial hospital mentioned that stigma was a factor influencing women’s access to healthcare, as was pointed out by one professional who said:

Still stigma and discrimination of HIV is a big challenge in our community. I have others who come as far from Nairobi and Kiambu, bringing their child all this way, so that it is their own secret.

One healthcare professional said that as a mentor in the province she visits other institutions to examine the number of patients seeking care at the facilities. Based on the high volume at the provincial hospital, she recommended that the services be decentralized so that people would access healthcare closer to home rather than travel to the provincial hospital. She mentioned, however, that people living with HIV said they would prefer to come to the provincial hospital because of fear of being stigmatized if seen at a facility closer to home. Patients told her “If I go to that facility near my home, my neighbours will see me.” The healthcare professional noted that it was decided to continue to allow these patients to access services at the centralized provincial hospital rather than risk losing them, “as we try to look for ways on how we can reduce that stigma.”

Reportedly, because stigma was a significant factor influencing access to healthcare, social support had become another important factor:

Stigma is still with us. So, this woman needs a lot of support. We have offered the clinical care. As she exits, where are we sending her? Does she have – is there a source of support in the community? Because if there is a source of support, you
find that this is a woman who will be able to come back even for hospital delivery.

The provincial hospital encouraged pregnant women with HIV to attend a peer support group organized in a private area of the hospital. The healthcare professionals interviewed often facilitated the peer group sessions and found that women who attended these sessions received social support which often motivated them to access treatment and care and live positively. One nurse spoke about a patient she had met:

Within about a month after testing positive, that lady has come up so well because she was so low, but when she attended the group she heard of how the others went through pregnancy with HIV … dealt with stigma in the community. She also came and she decided to live for her baby, she started to live for her family. And, in fact, she brought her husband for the test.

According to the APHIAplus official, that organization is engaged in activities to reduce stigma:

There is a whole component for stigma reduction as training. In all our care service health providers trainings we slot in the stigma component about it. And then we have the peer education in the communities. We have peer support groups within the communities that are addressing the stigma issues.

An official at the NACC Constituency AIDS office described the situation of many women in this constituency:

Because the same mother needs to feed well because of the pregnancy and the virus at the same time, the compromised body. So, you’ll find at times these mothers, they are not able to meet the minimum budget of a nutritional food for her and maybe even time for resting. She doesn’t have because she will go to look for money and all that and she is needed in the clinic. So, at times they opt to go look for money and not go back to the clinic. You’ll find like, during delivery at the same time the nearest hospital that could be there, they’ll still be charged when they go for delivery. So, you’ll find the mother opting to deliver at home.
The NACC constituency official noted that women do have knowledge of antenatal care, delivery with a skilled attendant, and prevention of mother-to-child-transmission, but financial constraints are a barrier to women’s access to healthcare:

Because even the Ministry of Health – Public Health and Sanitation, the NGOs we have, they are also creating awareness, our community has got access to a lot of information through the media, through the organized groups which are going to give information. But the element now … implementation level of the knowledge or the practice of the knowledge that you have gained now is dictated by your pocket. Mostly it’s poverty, because – you know, a mother who is of medium class earnings – is a middle class earner, will not miss to go to the clinic because she knows she still has a meal at the end of the day, but a mother who doesn’t even have a meal will not prioritize health issues.

The official from APHIAplus also mentioned that poverty is a challenge for many in accessing healthcare and that the NGO links patients to the health facility and requests that user fees be waived:

They face quite a lot of challenges in accessing services and quality services. One is that poverty level; affording transport from where they are to the service delivery point is a challenge. Secondly, is the levies for facilities.

The government policy that whoever cannot be able to pay should not be denied services. So, there is a committee in the institutions that actually provides that waiver and, when that is not forthcoming and we get to know, we are able to intervene and we do know that they cannot be able to afford and the facilities will actually provide those services.

Hospital healthcare professionals also mentioned that user fees were often prohibitive for many of the women seeking maternal healthcare and HIV treatment at the provincial hospital. It was suggested that the “majority” of the problem was women’s ability to pay for hospital fees:

Delivery is normally left to the client to decide, because there are those ones who cannot afford. Yes, the cost … they might decide not to come because of that cost.
And they can’t afford the taxis [transportation cost to the hospital], so it’s a big challenge. Delivery at the hospital is expensive… It is going for – is it $3,500. Caesarean section is even more expensive.

While CD4 – T-cell count test is free of cost at the hospital, other baseline tests such as viral load, and blood and liver function tests are costly. Reportedly baseline tests such as the “viral load” test cost several thousand Kenyan shillings, and “not all of them can afford that fee”:

They get a free CD4 count. They get a free HIV testing. Now, those who are positive they have to pay for the other parameters, the other baseline investigations like LFTs, hemoglobin levels and then, as an antenatal mother, the antenatal profile whereby we check the VDRL, we check the hemoglobin, we check the blood grouping. Those ones they pay a fee. Yeah, and the [registration] card is a challenge because not everybody can afford that amount. There are those who delay at home because they do not have that $100 – actually, $350 for the tests and a card is $100. There are those who stay home because they cannot afford that.

The healthcare professionals interviewed at the hospital all agreed that one of the main challenges to accessing healthcare was financial, and women with some form of employment were in a better position to access healthcare. “If you look around, you’ll see that those ones who are working are in a better position to access medical care, and especially those ones who are HIV positive.” It was also noted that women with a source of income were “better off than those ones who depend on the husbands.”

The PCEA healthcare professional indicated that while patients do not pay a consulting fee and most medical services are free, patients are responsible for a “file” fee of 110 KSH, and the fee to deliver at their maternity unit was 3,500 KSH. Also, laboratory tests such as liver function or viral load tests were not available at either the PCEA or PGH facilities. These tests were costly and could only be obtained at a private laboratory facility. Many of the clinic’s patients were low-income and reportedly the fees could be prohibitive. For example, the healthcare professional noted that the maternity unit was not doing well in terms of the volume of patients because of the high costs of delivering at their clinic:
The only thing that we are charging there is for file because it is difficult to buy them files. Here, we charge around 3,500 … We are a bit higher because of the upkeep of the maternity. Maternity is not doing that well.

The kidney tests … The liver function tests … Those are very important tests. And that’s why financial stability comes into place. There is no laboratory that can offer these services for free. So, we’re having a problem with that. Financially, these mothers are not stable enough.

According to these key institutional actors, a system is being built to supply quality healthcare to pregnant or lactating women living with HIV but there are concerns about low uptake. Is this a system failure or failure of individual women?

6.6 Homogenizing of Women by the Healthcare System

How essentializing is this healthcare landscape? Does it recognize the heterogeneity of women in this urban setting? Or does the healthcare system homogenize women? The evidence in this present study suggests that the healthcare system homogenizes women. In service provision, certain assumptions from the institutional point of view are made about the beneficiaries, the end users. Assumptions are made about how women living with HIV who may be pregnant or have young children should navigate the healthcare system; it is assumed that creating awareness will increase demand for healthcare, that improved knowledge will change health behaviour, and that women will access antenatal care and have facility-based deliveries if services are available. These assumptions homogenize women in this setting. However, as evident from the institutional responses discussed in this present study, awareness and mobilization does not ensure uptake or utilization.

As discussed in Chapter 2, the homogenizing of women stems partly from HIV policy and practice that tend to reinforce essentialisms about women and women’s health. Health policy assumes that women living with HIV share the same experiences, views, and priorities regardless of economic status or other differences (Hankivsky et al., 2010). The biomedical model of HIV prevention reinforces the view that women living with HIV are rational decision-makers who can adopt and adhere to the health advice provided by health professionals, or change their behaviour to reduce HIV transmission. Health behaviours are dissociated from social conditions or how
communities shape individuals’ lives, and individuals exist without culture and history (Kippax & Stephenson, 2012; Fee & Krieger, 1993).

The other reason the healthcare system homogenizes women stems from neoliberal polices and major reforms such as the reduction in government expenditure and the introduction of user fees, as discussed in chapter 4 (Karingi & Siriwardana, 2008). These reforms transferred the cost of health services to Kenyans and did not account for women’s economic status, such as the fact that thirty-eight percent of women in Kenya live in poverty (Barnes et al., 2010). The institutional perspective, from the present study, that user fees were prohibitive for some women and that there were shortage of trained health professionals and shortage of medical technology and supplies supported these previous findings.

Health policy and practice and the economic restructuring of the health system results in women and their health needs being homogenized; services are not tailored or tightly targeted to address the diversity of women and their healthcare needs. However, as the evidence in this present study indicates, key institutional actors are aware of women’s heterogeneity and the wider social and structural challenges faced by women in this urban setting.

The preliminary findings of this study were presented to the key institutional actors at a dissemination workshop. The following was an email response from one healthcare official who was in attendance:

On behalf of the whole team, the MCH/PMTCT lead by Matron [name], the CCC team led by Dr. [name], and the PASCO team led by Dr. [name], I take this opportunity to convey our gratitude for what you have helped us see today. You have touched our hearts on the activities and the findings that you have shared with us in that it is going to be our base for scaling up and improving our services. Allison you are a mirror that has given us a true reflection of what is there and what the real issues are. We thank you … God bless you from all team members.

I have systematically described the health services landscape and provided institutional perspectives on the system constraints and exogenous factors that hamper women’s access. But
the supply side is only one side of the healthcare context that the study is interested in addressing, which is why the women’s point of view is important. Subsequent chapters will provide the women’s lived experiences and their perspectives on access to healthcare in this setting.
Chapter 7
Accessing Healthcare 1: Women’s Agency
and Engaging with Patriarchy

7.1 Locating Women within the Health Services Landscape

This is the first of three results chapters looking at twenty-three women’s perspective of healthcare access in this urban setting. This chapter conveys the findings, the multiplicity, and the diversity of these women’s lives with regards to their access to healthcare, drawn from women’s narratives in this qualitative inquiry. The following are the descriptive characteristics of the twenty-three women who participated in the present study.

Women did not talk about high levels of government institutions involved in health service provision and did not speak to the accountability of these institutions. Instead they emphasize their experience of accessing healthcare at the local hospital, clinics, private physicians, NGOs and CBOs. The erasure of the top levels of the governmental hierarchy in these women’s narratives is possibly because they can only speak to the immediate, the local level, where they directly access services. However, as the informants in Chapter 6 indicate, there are many ways to navigate the healthcare system in this urban setting. The system is complex, uneven, changing, with gaps and deficits, and it is this system that women must navigate.

This chapter addresses the first research question: How do patriarchy and agency shape experiences of access to and utilization of healthcare for HIV-positive pregnant and lactating women in an urban setting in Kenya? The chapter presents the findings on how women navigate the healthcare system and how they demonstrate agency and engage with patriarchy. Having laid out the landscape this study addresses patriarchy which is posited to be the ideological foundation for gender inequity and the lack of autonomy and decision-making ability that limits women’s access to health resources in many low-income countries (Ahmed, Adams, Chowdhury, & Bhuiya, 2000; Nikiema, Haddad, & Potvin, 2008; Okojie, 1994; Ojanuga & Gilbert, 1992; Vlassoff, 1994; Zaidi, 1996). The role that social relations, including interpersonal relations, play in women’s access to healthcare will be discussed in the following chapters.
Table 7.1: In-depth Interview Participants (n = 23): Descriptive Characteristics

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<tr>
<th>Characteristic</th>
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<th>%</th>
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<td>25 – 30</td>
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<tr>
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<td>13</td>
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<td><strong>Child deaths</strong></td>
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<td>9</td>
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<td>0</td>
<td>14</td>
<td>61</td>
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<tr>
<td>1</td>
<td>7</td>
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<td>78</td>
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<td>Private Physician/Private Hospital</td>
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<td>22</td>
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<tr>
<td><strong>Site for delivery</strong></td>
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<td>52</td>
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<tr>
<td>Private Hospital</td>
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<td><strong>Relationship with current partner</strong></td>
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<tr>
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### Employment

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<tr>
<th>Category</th>
<th>Count</th>
<th>%</th>
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</thead>
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<td>Government – Civil Servant</td>
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<tr>
<td>Informal</td>
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<td>22</td>
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<tr>
<td>Informal/Survival Sex</td>
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<tr>
<td>Unemployed</td>
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### Income (Kenya shillings)

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<tr>
<td>5001 – 10000</td>
<td>8</td>
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<td>10001 – 15000</td>
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<td>17</td>
</tr>
<tr>
<td>15001 – 20000</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>&gt;20000</td>
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<td>4</td>
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### Housing

<table>
<thead>
<tr>
<th>Housing</th>
<th>Count</th>
<th>%</th>
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<tbody>
<tr>
<td>Government Housing</td>
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<td>4</td>
</tr>
<tr>
<td>Living with Kin</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Own</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Rent</td>
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</tr>
<tr>
<td>&lt;500 – 1000</td>
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<tr>
<td>1001 – 5000</td>
<td>8</td>
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<td>5001 – 10000</td>
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<td>4</td>
</tr>
<tr>
<td>10001 – 20000</td>
<td>1</td>
<td>4</td>
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* Percentage inaccuracies due to rounding error.

As Hammersley and Atkinson (2007) point out, “one of the major problems [of ethnographic writing] is that the social world does not present itself as a series of separate analytic themes … [W]e have to disentangle the multiple strands of social life in order to make analytic sense of them” (p. 193). While the authors relate this insight specifically to ethnographic writing, I believe it is also relevant to making analytic sense of autobiographical narratives or stories, which represent many sides of a set of intersecting social relations. For a clear, cogent analytic account, the women’s narratives and identified themes have been separated into three chapters to better expand, support, and describe the social factors that influence their access to healthcare.

### 7.1.1 Respondent’s stories: Entry into the analysis

Respondent’s stories provide a useful entry into the analysis. The stories shared below are not fictional or composite, but I have changed their names to anonymize the women’s identities. The stories are personalized and capture many key issues. During the interviews, I did not specifically probe for statements about agency, class, gender, social support, and stigma, but during initial analysis of the data these issues were identified as topics of central concern with
regard to the respondents’ access to healthcare. Follow-up interviews focused on these topics and were explored in greater detail with respondents.

I present women’s narratives where these issues were articulated. A few women’s stories were selected because of their comprehensiveness, their breadth and depth. I did not select specific stories because they were compelling, the most powerful, or because the women were the most vocal, or to exclude the most silent women. All the stories were compelling. But the stories selected were stories where turning points in women’s lives were demonstrated, stories that spoke to the research questions and offered nuances, and stories where the complementarity of the accounts conveyed the richness and heterogeneity of the women’s lived experience. Therefore, the stories selected were exemplars of the issues of interest to the study. There is overlap between stories. For example, issues of stigma emerged in the first two stories, but the focus will be on agency. Additionally, these selected stories compliment and ground the tables that present quotes from all respondents (see Tables 7.1, 8.1, 8.2, 8.3, and 9.2).

I let the women speak for themselves. I “cleaned” the data (removed fillers) to allow for ease of reading. This removal seemed justifiable since the purpose of the study was not to deconstruct the narratives for structure (as in a conversational analysis), but to provide an understanding of the women's experiences accessing healthcare. I labelled the abstractions/vignettes with a statement drawn directly from the particular narrative to highlight its core meaning. At the level of substantive content, I am not arguing that these abstractions are representative of responses from the rest of the sample. They are simply used as informative examples. On the other hand, the issues of agency, class and gender, stigma, sick role, and social support illustrated by these examples were common throughout the interviews.

Two participants were particularly emotional during their respective interviews and were referred to the counsellor retained for the study. Both had only recently been diagnosed HIV positive. One participant was particularly troubled because her husband tested negative, and his attitude towards her had changed. The counsellor spoke with the respondent at length, and she later visited the respondent and her spouse at their home to provide couples counselling.

This study included respondents who were (a) receiving antenatal care, and delivering/planning to deliver at the PGH, (b) not seeking or receiving services from a healthcare facility/had given birth or planned to give birth at home, and (c) seeking and receiving services from a private
healthcare professional/facility. Based on Acker’s (2006) definition, class represents the “differing and unequal situations in access to and control over the means of provisioning and survival” (p. 55). I created two categories of class status:

- Women of higher social class: higher family monthly income ($\geq 10,000$KES), higher level of education (college or university), and formal employment (permanent, full-time)
- Women of lower social class: lower family income ($\leq 9,999$KES), lower level of education (primary, high school), and informal employment (temporary, part-time) or unemployed

Based on Orchardson-Mazrui’s (2006) hierarchy of class structure, the “higher social class” group belongs to Kenya’s middle class. The “lower social class” includes women from the working class and those who are unemployed (Orchardson-Mazrui, 2006). These two categories were relevant because, while some respondents had non–facility-based deliveries, they all accessed some healthcare according to their differing and unequal situations, and means of provisioning and survival. This categorization based on income intersects with ethnicity. The study focuses on income level as a form of class structure, but recognizes income cross cut with all ethnicities in this urban setting.

Six stories were selected as exemplars: four were lower social class and two were higher social class. Hamisi, Gathoni, Njeri, and Kaweria were lower social class and lived in a low-income area in this urban setting. They were recruited by a community health worker and were interviewed in a private room attached to a church close to their homes. It was not possible to conduct the interview in their homes because they either lived in a shared compound where visits from foreigners would raise questions from neighbours, or lived with family members to whom they had not disclosed their HIV status. Wangari and Nyambura, who were from a higher social class, were interviewed in the office of a private physician in town. The physician on behalf of the primary investigator recruited them during a visit to the physician for maternal and HIV care and treatment.

7.1.2 Intimate partner relationships

The seventeen women of lower social class were married at the average age of nineteen, and the six women of higher social class married at the average age of twenty-four. Of the total twenty-three respondents, four engaged in short-term intimate relationships but were never married; two
of these four respondents previously engaged in prostitution, and one of these respondents said it was because she wanted to have “fun” and opted to not finish school even though her mother could afford the school fees. Three of the twenty-three respondents were widowed; two of these respondents were involved in other intimate relationships at the time of the interview. Five respondents left their husband because of domestic abuse or dereliction of his family responsibilities; four were involved in other relationships at the time of the interview.

7.1.3 Discordant partner relationships

Two respondents were abandoned by their partners when HIV tests revealed they were discordant. One other respondent sought counselling with her husband because “his attitude changed toward her” when their tests revealed they were discordant. One respondent’s husband accepted her status despite being discordant because she was “faithful and contracted the disease while caring for her sister who died of AIDS”; the respondent said her husband “turned to be so supportive through God’s mercy.” Another three respondents disclosed their HIV status at the early stages of their relationships, were accepted, and married their partners despite their discordant status. One respondent discovered her HIV status when she was pregnant with her second child. Her husband was negative, and he brought a second wife into their home. However, this respondent was the primary income earner, and eventually her husband sent the second wife away.

7.1.4 Employment and disclosure of HIV status

Four of the six respondents of higher social class had formal employment. Two were self-employed. The four married respondents of higher social class disclosed their HIV status and shared financial responsibility for household and children. Two of the six respondents of higher social class divorced their husband due to his abuse and refusal to seek HIV treatment. One remarried someone who was discordant, and the other married someone who was also HIV positive; each disclosed their status prior to remarriage. One respondent discovered her status first, started treatment, and encouraged her husband to get tested and seek treatment and care after he also tested positive. One respondent was getting counselling with her husband after the recent diagnosis of their discordant status.
Of the ten respondents of lower social class, who were in relationships, seven engaged in informal work or farming. Four of these seven respondents appeared to be primarily financially responsible for their own and their children’s needs. In the lower social class category, nine of the ten respondents in relationships disclosed their HIV status to their respective partners and actively sought HIV treatment and care. Six of the nine who had disclosed were in discordant relationships.

Narrative 7.1: Wangari’s Story

Wangari is a woman in her early thirties and is formally employed with a mid five-figure KES salary per month. She has a professional position, the details of which will not be recorded to protect confidentiality. She has post-secondary education with two health-related diplomas.

_I was just open to tell this man that this is what the doctor has told me and he refused to go know his status._

I have children from my first marriage, which did not work. I entered in a second one (marriage) which now I am having this baby… this baby is 7 weeks. I have known my status since early 2000s and separated six years ago from my first husband. I don’t know if my first husband is positive because he refused to go know his status but before we got married we knew our status and we were both negative. After knowing my status we started having issues and he started accusing me of being unfaithful. I was just open to tell this man that this is what the doctor has told me and he refused to go know his status. He started being violent, drinking and coming home late and coming home with women. I would caution him that this would bring us problems. So, there and then the marriage started wobbling, wobbling and it was over.

_I decided to just move out and start my own life._

I decided to just move out and start my own life. When I knew my status, I decided to do courses in counselling and psychology so that I can be able to understand myself better and know how to go about issues. It helped me deal with my status. My second husband is negative and because it was a new relationship it was easy to disclose. I told him I knew my status but he didn’t believe me because I have a big body (laughs). He is very supportive and he would want me to eat well, so he provides. He said that it is not HIV that kills people; it is many things that kill people. He works for [name of employer] and they usually train them on how to support people who are living positively, even the workers within the institution, so he had some knowledge. African men rarely tells us how much they earn but my husband gives me money every month and I am the one who decides what to do with the money.
So I decided to come to a private clinic.

I decided to come here (private clinic) because being in the public, working as a professional position, many people in the field of employment know you so with stigma all around, somebody would wonder you are a person in the medical field so how come I am [positive]. So I decided not to go to a public hospital, so I decided to come to a private clinic. My children are all negative and this baby I will get the test done. Before I got pregnant I went for a viral load [test] and the viral load was saying it is undetectable. So when I got pregnant the doctor told me to continue with the treatment. And then when the baby was born, the baby was also given Nevirapine, which she is still taking. The doctor said that because now the viral load is very low there is no need for C-section. I just deliver normally. I delivered in a private hospital. I have health insurance [NHIF] but there was a problem so I paid 6000 KES. Every month I went to Dr. [Name] for check-ups because knowing my status I would not want to take a risk of missing clinics (this doctor is a well-known private obstetrician/gynecologist in town). Even though I am supported getting that 1000 KES to come and see a consultant is not easy. Even the viral load test is very expensive 8000 KES so if the doctor told me to go for another test now I would have to search for that money. Right now I am at home on 90 working days maternity leave but I have not taken my annual leave so I have combined all of that.

My family is very supportive...

My family is very supportive because even my eldest brother is also HIV positive and he knew his status since late 1990s and he is doing well. You feel free because now when it is time to take your medication, you don’t have to go and hide somewhere. Now in this private clinic you would not get everything like counselling, even before starting medication. The doctor tries to counsel but it is overwhelming for him. It is so busy and there are a lot of patients…many people trust him, you know. I don’t belong to a support group because like I told you I am a public figure so I decided to be on my own. Even people in church would sideline you if you say you are positive. I depend on my family and my husband. Most people don’t get support, but I thank God because this man I met is just like god-sent because he supports me fully.

Narrative 7.2: Gathoni’s Story

Gathoni is a woman in her early thirties. She finished high school and immediately started a family. Gathoni was married twice, but both husbands, who were discordant, abandoned her when they were told of her HIV status.

When he (husband) was tested he was found negative and deserted us in hospital.

The child (second) started to suffer from TB and we took him to hospital to seek medication. The child was tested and the results were HIV positive. When I was tested I was also found HIV positive. When he [husband] was tested he was found negative and deserted us in hospital. I have since then been struggling with my children. He was supporting us with anything we required. When he never tested positive he reacted very
negatively towards me. I suffered and lost weight from 76kgs to 50kgs. This was in late 2000s. I was struggling. He had run away and so I called him and told him you left me in the hospital and the bill is out just help us even in with the bill although you have left us. He went to our home and gave my mother money, 3,000 KES. I told mum let us use it all you, the child and myself we were paying 900 KES each, let us use it all. If he had not given me I would have strained I would not have started [ARVs] that particular time. I would have been affected so much because my CD4 was low and that of the child was so low and also of my mother because we were tested and started adherence immediately. I moved back home with my mother and I was working in [name].

I am looking forward to have some casual job to support them because I cannot rely on my husband...

I met this second husband last year and now I have this baby... I don't have any income, he is the one who is earning but I myself am just at home. He is an [employer and position] and earns [amount] KES per month but he is more of a drunkard…There was a time I tried to look for a job when I was expecting but he came and asked the manager that he was the one who was employing people’s wives and he caused disharmony. He does not support my two children. Financially, it is difficult to pay school fees for them, like my oldest son is in secondary and my brother sometimes pays the school fees. So I am even contemplating separation after the baby stops suckling. I am looking forward to have some casual job to support them because I cannot rely on my husband …so this is not someone to rely on (husband).

I have not revealed my status

I never revealed my status to him because when I told the first one (first husband) he went away from me. I have never told him (current husband) up to now, but at their work place they are tested and he is still negative. I organize myself even if it means 10 KES as fare. Sometimes I wash people’s clothes and get some 100 KES but without his knowledge. My older sister stays around and my oldest son stays with her. So I usually take them (ARVs) when he (husband) has left to his work place. Ordinarily my son collects them (ARVs) and brings them to me. For me I would rather get one who is positive, you will enjoy living positively. You see I flout adherence but I live as if I was negative because of him. The only obstacle is my husband especially when he is off duty I am forced not to take drugs that week. He is the only obstacle and you can also not send anybody else.

My mother helped me to get the courage to accept my situation…she challenged me to soldier on...

My mother helped me to get the courage to accept my situation when I found out I was positive. When my child was hospitalized and tested the results were HIV/AIDS positive I then told my mother to be tested. She was also positive because my father had died three years earlier, it seems my mother knew what caused my father’s death. She challenged me to soldier on because she herself had done that for three years. I took it easy because even I myself started encouraging people who looked weak so that they could go for tests and take drugs. I did not waste any time after ascertaining my status, actually my health did not deteriorate because I started taking drugs straight away.
In a follow-up interview one year later.

The youngest child went and passed on he was 11 months old… at night he started having a breathing problem. Rushing him to medi (provincial hospital)...He died receiving the treatment. After I went there to CCC so he [husband] timed me and got me there…he waited until he heard that the name was mine. So he entered to be tested and he was found negative and he told me he lived knowing I wanted to kill him. He told me “so you wanted to kill me the way you killed the child... Our relationship between me and you is closed here.” I told him it is okay, let me go and take care of my children you don’t even normally help me. So we parted that way and I went back to my home. Mum has rented a big plot and so when we help her there is a lot of food and the problem is not food and now the child is sitting for exam the elder one, so she told me to sell beans to pay for him and clear school fees so that he is not chased now.

They have not segregated me...

For me like here in [location in which she lived] I got used to it and you see he (neighbour) is a drunkard and spread and spread (gossip) and when we meet I tell him yes I am good, AIDS has not finished me I am still there (laughter). The virus is not making me suffer and he is shocked that I have accepted it and you find he is not going on so much. My team (fellow conductors) asked me if I left [husband’s name] because of the story they heard? I tell them you go and be tested. They have not segregated me and because of that they are there and they don’t miss to call me when there is a job. Others I think for instance there is a neighbour and she was going to take the drugs. I told her so you belong to the church she said no I have come to take for another girl who she is very sick. I told her why didn’t you tell her early instead of waiting until she is very sick and these drugs it is like a common cold. Then I heard her name being called out it forced her not to take the medicine and go away and she went to stalls to wait for me to go away. She escaped that day and did not take the medicine.

7.2 Patriarchy and Pragmatism

The findings in this section pertain to how patriarchy shapes experiences of access to and utilization of healthcare in this urban setting in Kenya. The findings indicate that women do value and adhere to traditional roles, and that they make pragmatic and strategic decisions as they engage with patriarchy in order to live positively and meet their healthcare needs (Table 7.1).

7.2.1 Deploying traditional roles and values

Respondents generally appeared to value the traditional roles of being a wife and mother. While respondents did not specifically mention a need to occupy the traditional role of a wife, the majority (19) were involved in an intimate partner relationship. Respondents placed particular
value on having a partner to share the responsibility of providing for their children. But as one respondent mentioned, it was for the security of saying she was married:

No, income was not a problem because even when we were staying together he used not to help me so much. He used – most of the time he used to drink and forget even the house duties, even to pay the rent. I used to pay the rent myself. I used to buy the food in the house. So, he was just important for me maybe for security purposes. As in “I’m married.”

All respondents showed sensitivity to their children. Respondents were the primary caregivers of their children. All respondents mentioned the importance of caring for their children; they considered it their responsibility to ensure their children’s survival, upbringing, and education. Respondents mentioned that seeking HIV treatment and care was important to prolong their lives so that they could be there to take care of their children. Two participants of lower social class prioritized their child’s HIV healthcare services over their own when they could not afford services for both themselves and their child.

There was some evidence of adherence to cultural practices and tradition in terms of polygamy and payment of dowry. One respondent could not have children, and her husband’s family brought a second wife into her household. Another respondent also accepted a second wife when her husband and his family found out about her HIV status. One respondent left her husband because he had an extramarital affair and neglected his financial responsibility to the family. Their families encouraged the respondent to reconcile with her husband because he had paid her dowry.

7.2.2 Engaging with patriarchy

Higher-class women did not appear submissive in their relationships. They were financially independent and had decision-making power within those relationships. There was also little evidence that respondents of lower social class were submissive in their relationships; in fact, the opposite appeared to be true. For example, one respondent reported to the Chief’s Office that her husband had abandoned her and his child because of her HIV status. They were reconciled, and he resumed his financial obligations to the family. This respondent also said:
When he is drunk … he does not want [to use a condom] so we use to have misunderstandings and we come here in the APHIAplus drop-in centre (DIC) office (NGO). I say my part. So if he refuses to use condoms I will die early and leave my children. So he is told and he agrees.

This respondent insisted on counselling in order to get the financial assistance she needed from her husband and to minimize her risk of reinfection. Another respondent explained that when her husband refused to use condoms she left him, and when she returned he agreed to use condoms. She also solicited a family friend and her husband’s mother to counsel her husband, who was in denial about his status, to access HIV treatment and care. She said:

We use to use [condoms] but at times he use to refuse because he was still under denial. I was very scared … so when I turned positive … I left being stressed. I was the first to go for medicine … I went … my husband you know he does not use this medicine so going to tell him you are starting medicine … it is very stressing … I was able to disclose to my mother-in-law. She cried and cried and later she accepted. She supported me. Although this son does not want to tell her his situation and what he is going through … So I went and told her … he was talked to and he has gone on changing slowly by slowly. A little by little though he has not accepted to use the medicine the behaviour is changing. (IDI 06)

All six women in the higher social class group received or planned on getting antenatal care from a private physician. All six also delivered or planned to deliver their babies at a private facility. Four of the women in this group initiated HIV testing and treatment. Two of these women left their husband when he refused HIV testing and treatment; these two respondents later remarried. The third respondent’s husband agreed to be tested and began treatment. The fourth respondent initiated HIV testing after her husband died and she fell sick. Two respondents found out their HIV status when they became pregnant and were tested during an antenatal care visit. All six respondents were accessing HIV treatment and care. The women in this group did not appear to be economically dependent on their intimate partners to access maternal care or HIV treatment and care. Respondents in this group appeared to have decision-making ability to access healthcare.
The number of antenatal visits and place of delivery varied for women of lower social class. Most of the women of lower social status who were in relationships had disclosed their HIV status to their respective partners and actively sought HIV treatment and care. There was some evidence that women in this group were economically dependent on their intimate partner to access healthcare. All women in this group also appeared to have decision-making ability to access healthcare.

As indicated in their narratives, both Wangari and Gathoni made the decision to leave abusive husbands. Women of higher and lower social class employed various strategies to be able to access healthcare and live positively in this patriarchal society, including leaving their husbands and seeking counselling from various sources.

### 7.2.3 Being pragmatic

Not all women made the decision to leave their husbands when they were in abusive marriages or had been infected with HIV by their husbands. Another participant, Elinah (IDI-16, narrative not included) decided to return to her husband even though he was an alcoholic:

> The reason for parting was that he was drinking so much … so we were disagreeing all the time … so it was I who supported myself. Our parents put us back together … when I was being married they went there and they gave out the dowry.

The participant was counselled by her family and her in-laws to reconcile with her husband because he had paid the bride price (dowry is a tradition for many ethnic/linguistic groups in Kenya). This respondent acknowledged that a woman was better off alone if her husband was abusive and did not provide, but contradicted her decision to reconcile by saying that a woman should stay if the man did not go out (have sexual relations outside the home) and did not abuse his wife, which were acts her husband committed. More revealing was when she followed up with these words:

> Now when someone knows her status with her husband better he knows and you stay together so that you will not move out and
brings you another one and you don't bring to him so that you stay for many days…

There are those who persevere … so she perseveres there because they are helped. Because if she sees that she goes out it will be heavy to those children … you are not in a job so you see to help one another is good because maybe if today he brings tomorrow you go to work and bring and you will help those children.

This participant did not want to risk transmitting the disease to anyone else or risk reinfection so that she can live longer. She felt it would be better to stay with her husband who was also HIV positive and who knew her HIV status. She also decided to return for financial reasons; she was both HIV positive and diabetic, and could not work at the casual jobs she was able to get. She knew she could not afford the cost of healthcare and could not provide for her children due to her ill health, and staying with her husband would at least ensure some financial security. In addition, the detailed narratives provided in Table 7.2 convey respondents’ accounts.

7.3 Turning Points and Becoming Active Agents

The findings in this section pertain to the question of women’s agency in this setting. Women were proactive, strived to live positively, and took steps to become independent, learn about their illness, and help others. It is through these findings that women’s diversity and agency is revealed.

A person’s life may resolve around an epiphany or a turning point in that life (Denzin, 1989) or punctuated by critical, formative, or “incidents” (McAdams, 1988) that “define who we are, who we were, and who we are to become” (p. 133). According to De Souza (2010) these “points” to pinpoint where women expressed heightened emotion, where there was a sense of something having changed, and where an important moment or point in their illness journeys was revealed. At these “points” in their lives participants may have been expressing agency through articulations of “who they are, who they want to be, and how they see themselves relative to the larger socio-cultural context” (de Souza, 2010, p. 246).
Table 7.2: Traditional Values and Patriarchy

<table>
<thead>
<tr>
<th>Code</th>
<th>Respondents’ Responses (n = 23)</th>
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</thead>
<tbody>
<tr>
<td>Traditional values</td>
<td>I was not able to get children and his family brought him another girl who he married (IDI 04).</td>
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<td>I had even been brought for a second wife and we stay in one house with them (IDI 09).</td>
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<tr>
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<td>Our parents put us back together … when I was being married they went there and they gave out the dowry (IDI 16).</td>
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<tr>
<td>Patriarchy</td>
<td>After three month the man started being harsh telling me that I not getting kid. So every time I had periods he was beating me up (IDI 01).</td>
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<td></td>
<td>I was never in peace because of the abuse I used to get from the in-laws and from him. I left him … for now am totally in peace using the little I get from my business and am very free in making decision. He was also an obstacle to my accessing care since I used to fear he knew my status (IDI 02).</td>
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<td></td>
<td>I tried to look for a job but he [husband] came and asked the manager if he was the one who was employing people’s wives and he [husband] caused disharmony (IDI 03).</td>
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<td></td>
<td>We use to use [condoms] but at times he use to refuse because he was still under denial. I was very scared … so when I turned positive … I left being stressed. I was the first to go for medicine … I went and told my husband you know he does not use this medicine so going to tell him you are starting medicine … it is very stressing … he asks you what medicine are they for? I was forced to collect slowly by slowly … I was forced to lie that there is something required for the child (IDI 06).</td>
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<td></td>
<td>What caused that is that my father said he cannot educate the girl child. Because there is my sister who got pregnant so there he said even if he educates us there is nowhere we will go … but the males completed their education (IDI 07).</td>
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<tr>
<td>Sensitivity to others</td>
<td>Because of my health status and seeing how I have suffered bringing these children … No jobs … sleeping hungry … the children sleep hungry and I find it so bad and seeing I don’t have … what to give them? (IDI 01).</td>
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<td></td>
<td>I need to look for some money for the up keep for the children. So sometime I need to skip my clinic for my business. I encourage instead since I accepted myself I see I never have any fear of being discussed so I direct those that are positive and try to give them hope (IDI 02).</td>
</tr>
<tr>
<td></td>
<td>I am normally jovial so I encouraged others to be tested and start medication (IDI 03).</td>
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<td></td>
<td>You see like now in the morning I had sh. 50. And those fifty shillings I bought sugar and two mandazis that the children will eat and I have remained with some few coins and there is lunch. So if you think of leaving the children without food it is you who will have problems because they will not have strength and you will not have peace inside, the stress will be too much (IDI 04).</td>
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<td></td>
<td>Yes when I was not feeling well I go there very fast I do not wait for tomorrow no I do not delay because I look at the welfare of my children (IDI 05).</td>
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<td></td>
<td>On my part I am stressed because I have children, I can die easily so I decided not to compare myself … For now is to try to make sure I am reducing stress and am attending all the clinic dates (IDI 06).</td>
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</tbody>
</table>
For example now when they are going to open school. They do not have shoes, they do not have sweaters … So I will have to work and buy for one this month and the other one next year (IDI 07).

Let us say it has made it easy because let us say for my work I get money so if I want something I do have stress for money, if it is buying milk for the baby (IDI 08).

So I am the one supporting him & all the household needs (IDI 11).

I negotiate with the head teacher to wait for some time in case of school fees and things are worse I get some loan from credit facilities, e.g., microfinance or support groups (IDI 12).

We support each other since I got the job as community health worker it have been easy because I support on the clothing of all of us and he does the part if water bills, food, and schools fees (IDI 13).

In PMTC clinic I asked the doctor on whether the kid could be negative and he instructed me on it (IDI 14).

I went to see her I knew she had … it is a person who had this disease … so I told her even us … we are just like that … so persevere and take medicine as told by the doctor and you will live (IDI 16).

The money I had was just enough for the baby so after he was admitted I bought the file for the baby at the CCC. From there I lacked mine and because the baby was badly off I saw that I help him until he gets well and I get money. But I have never got the money because the money I get is for food only (IDI 17).

I have known myself I know I have kids I have to be cautious of everything I do about their life about my life taking my medication because I want to see them grow (IDI 18).

Agency is considered to be an expression of the “voice” of participants engaged in dialogue and represents the capacity they have to participate in their environments and shape the circumstances in which they live (Dutta, 2007; de Souza, 2010). Dutta (2007) refers to agency as the “capacity of cultural participants to participate in day-to-day actions in response to their contexts based on a deeper level of understanding of these contexts and the structures surrounding them” (p. 321). Mohanty (2003) considers that “[a]gency is figured in the small, day-to-day practices and struggles of Third World women” (p. 83).

7.3.1 Being proactive in the face of adversity

The majority of respondents from both higher and lower social class appeared to react in a proactive manner to the adversities in their lives. After initial reactions of anxiety, depression, and fear subsequent to learning of their HIV status, most (19 of 23) responded by seeking information, obtaining healthcare, and committing to living positively. They all appeared to be
agents of change in terms of their health. Of the remaining four respondents, one respondent was newly diagnosed and was still coming to terms with her condition and had not disclosed her status to the baby’s father or her family. The other three were heavily reliant on family members for financial assistance, and two had not disclosed their status. These four respondents appeared passive, reactive rather than proactive, and spoke of not having a choice or control over their life circumstances.

Four respondents of lower social class mentioned that they had joined a support group for women living with HIV and AIDS. Through this group, they were referred to organizations to be trained as community health workers for various NGOs. They saw this training as an opportunity to learn more about the disease, earn extra income, and help others understand and deal with their illness. Another three respondents mentioned that with family and peer group support, they had learned to accept their status and often encouraged others to get tested and seek treatment. Two of these respondents mentioned personally escorting others who were afraid of getting tested to the voluntary counselling and testing clinic (VCT). One respondent of higher social class decided to take courses to help her understand her illness and learn about healthcare. Through her place of employment, she counselled others on living positively with HIV and AIDS.

Commitment to improve their lives, taking initiative, and being agents of change was not as obvious for other respondents. Women of lower social class employed various strategies, including accessing healthcare from multiple sources such as CBOs, NGOs, and the public hospital. This strategy meant that if they could not afford services at the hospital, they might get assistance through one of the other organizations. They also employed other strategies, such as counselling or threatening to leave their marriage, to get their partners to seek treatment or use condoms to minimize risk of reinfection.

Women from both higher and lower social class made significant changes in their lives by leaving their husbands when it became apparent that their health was being placed at further risk because of continued spousal abuse, neglect, or the refusal to seek healthcare. Respondents showed sensitivity to others experiencing the same illness. Most respondents appeared to have a proactive attitude towards adversity in their lives.
7.3.2 Striving to enjoy positive living

Wangari expressed agency at a turning point in her life through her decision to leave her abusive and violent husband to start her own life. When she tested HIV positive, she was “open” about her status with her husband. Wangari asked him to get tested, but he refused to get tested and begin HIV treatment. Wangari’s actions were significant because of patriarchal dominance in Kenyan society.

Gathoni saw her husband as a hindrance to her access to healthcare and ability to live positively because she had not disclosed her HIV status to him. She said, “[F]or me I pretend to be negative so as to make him happy, so I do not enjoy living positively.” Even though her husband left after discovering her HIV status, Gathoni was “okay” with it because he was an alcoholic and did not provide for her and her children. In fact, in her first interview she was already considering leaving him. Gathoni believed that she was fully capable of providing for herself and her children. She was looking forward to getting a job so she could support her children when she realized she could not rely on her husband. It is this epiphany that highlights Gathoni’s agency.

Both Wangari and Gathoni revealed agency in their practical assessment of their situation, decision-making, and subsequent resolution to start their own lives without husbands who were either abusive and placed them at risk for HIV infection and reinfection or were obstacles to their access to healthcare.

7.3.3 Steps to becoming independent, understanding illness, and helping others

The narratives highlight the important role that family, education, and support groups play in respondents’ experiences of illness. There was a sense of powerlessness and lack of voice in respondents’ personal relationships, but they took steps to become independent, understand their illness, and help others. These decisions reflected turning points in their lives. Wangari mentioned that she decided to get a diploma in counselling from the Kenya Institute of Professional Counsellors so she could “understand” herself and learn “how to go about issues,” which helped her deal with her status. Gathoni joined a women’s group and received counselling at “meetings” on how to live positively. With family support and counselling from the group, she learned to accept her status and started encouraging others to get tested and begin treatment. The
women demonstrated agency by taking steps to become knowledgeable about their infection and seeking immediate treatment, and by advising others – Wangari in her position as counsellor and public health officer, and Githoni in the women’s group and with her co-workers.

7.3.4 Practices and struggles in response to the lived context

Women appeared to value the role of wife and mother, and adhered to certain cultural traditions. Evidently, women engaged with patriarchy but their partners did not limit respondents’ decision-making ability to access health resources. However, for some women of lower social class, there was evidence of economic dependence on intimate partners to access healthcare resources.

Women appeared to have a clearly defined role, often a separate life, and a separate important job within the home. Reportedly, women did not appear totally reliant on their male partners and appeared used to the expectation that they will fend for themselves and provide for many of their own needs and those of their children. Women seem be competent, independent, and managerial in their roles of mother, farmer, and employee.

Respondents’ demonstrated their agency through their practices and struggles in response to their contexts based on a deeper level of understanding of these contexts and the structures. As one respondent mentioned, she learned to be independent, and being “sick” does not mean that she needs to be dependent:

To help one to be independent is what they taught me … when one is sick … is desperate you consider yourself as dependent … they have helped me to be independent so that you see that being independent is better than being dependent … I depend on my farm … then I harvest maize or beans I sell them for money. (IDI 10)

Another respondent blamed for “bringing the disease” and causing her husband’s death, was disinherited by her in-laws. With help from a CBO and NGO, she was able to make significant changes in her life:

I had been defeated … really defeated. I have been a big prostitute … I slept with many people so on finding myself pregnant … it was difficult to tell whose it was.
It reached a time when I was not caring for the children and they are the ones I went to go and fend for … but later I was counselled and returned to form and I took the medicine and the disease stopped. Now I am a hairdresser … I don’t have a salon … but I do it in a mobile. (IDI 04)

Respondents demonstrated their agency in the context of HIV by their adherence to positive living, particularly through their preventive behaviours and appropriate healthcare seeking, as well as having an open and accepting attitude towards HIV, demonstrated through disclosure of their status to friends and family and participation in support groups.

Yes until I came to learn a HIV-positive person can work like any other person and gets what is hers… living positively so that I can live fully (IDI 10).

My life is good because when I had not known myself ... I wanted to die but since I started going there I no longer want to die … A woman I met there … looking at her she was healthy. She told me not to fear that I should go and take the drugs and I will be happy because you will live like others (IDI 16).

It is through these epiphanies, turning points, in their lives that women show that they have a clear understanding of the context in which they lived and that by being proactive, they are able to be independent, earn a living, and live positively (Table 7.2).

Women also demonstrated agency by how they dealt with the stigma of being HIV positive. For example, Wangari’s position as a public health officer was made complicated by her HIV status; she felt that people would question her capability as a counsellor if they knew of her status. She made a choice, made possible by her social class and family support, to seek private healthcare to minimize becoming stigmatized. As is the case for most women seeking healthcare at the public facility, Gathoni found it was difficult to maintain privacy and ensure confidentiality; the comprehensive care clinic (CCC), which provides HIV care, has an open waiting room where anyone seeking care can be easily identified as HIV positive by members of the public, including friends and neighbours. Gathoni was encouraged by her mother and support group to accept her status. She was defiant when confronted by stigmatization and made a decision to be open about her status and live positively. These women came to the conclusion that “HIV does not kill
people and that with medication it is like a common cold!” Table 7.3. lists the turning points and epiphanies from the twenty-three respondents.

### 7.4 Summary: Women’s Heterogeneity

The findings discussed above demonstrate women’s heterogeneity and indicate that they navigate the healthcare system in different ways. As discussed in Chapter 4 and Chapter 6, the healthcare system is complex and in flux, and homogenizes women. However, women’s diversity and their agency are reflected in how they access healthcare within this complex healthcare system and within the existing social constraints in this setting.

As unveiled through the interviews, many of the turning points in women’s lives came with counselling and social support from various sources. Having made these turning points through a greater understanding of their situation, they engaged with patriarchy and employed various strategies to deal with stigma, access healthcare, and strive for positive living.

The subsequent chapters will provide further details of social relation, interpersonal relationships that influence these women’s access to healthcare. The next chapter (Chapter 8) will discuss the micro level social relations that shape women’s access to healthcare.
Table 7.3: Turning Points and Epiphanies

<table>
<thead>
<tr>
<th>Code</th>
<th>Respondents’ Responses</th>
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<tbody>
<tr>
<td>Turning points/epiphanies</td>
<td>After the medication I had regained the strength. When I go there [hospital] and we share our experience with other women I feel relieved the stresses and more hope of living and especially when I see I am not alone. Also the free medicine that they give makes me seek their services because were it not for them I know I would have died long ago (IDI 01).</td>
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<td></td>
<td>I was just waiting for my death but the fear is no more after the counselling. I can now go freely without fear with my children during the clinics. Also the fare [transport cost] is no longer a problem since I have a job (IDI 02).</td>
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<tr>
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<td>I am still there … AIDS has not finished me … the virus is not making me suffer. So you see people viewing you just with AIDS but as I have learnt it is not a problem … it is like a common cold (IDI 03).</td>
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<td>I had been defeated … really defeated. I have been a big prostitute … I slept with many people so on finding myself pregnant … it was difficult to tell whose it was. I decided let me cling to this God … because he has removed me from alcoholism. Now I am a hairdresser … I don’t have a salon … but I do it in a mobile way (IDI 04).</td>
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<td>I smoked, drank alcohol and would walk with men … prostitution increased so at some point I got sick and was admitted in medical. So when I delivered the children made me live like a mother. Then I relaxed. I love my mother very much because she did not leave me … I took heed of my mother’s advice … I settled down and rented a house, now I usually see myself to be like any other person (IDI 05).</td>
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<td>I hated him very much and I even went home then later but I came back … at times you look at him and say if he had controlled himself we would not have been the way we are. I had a lot of anger but now I have accepted myself and I see it as any other state (IDI 06).</td>
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<td>I was desperate and I had seen that it is better I do prostitution so that I can die early, but I did not do that for long. It reached a point I saw that there is need and I decided to abstain. I have accepted myself and I am seeing those drugs are good because there is a time I had said that I will not use them, my health went down very much, my CD4 went down (IDI 08).</td>
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<td>First is that I have accepted and I do not want to go back to where I was. Secondly is that I have that business and I have a supporting husband (IDI 09).</td>
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<td>Yes until I came to learn a HIV-positive person can work like any other person and gets what is hers … living positively so that I can live fully (IDI 10).</td>
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<td>By the time I was pregnant it changed me a bit … I have accepted myself and started to survive (IDI 11).</td>
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<td>After the test I was so down and I had prepared for death via suicide, but when I told my husband he encouraged me and gave me hope for life (IDI 12).</td>
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I relate to sometime my sister was sick and I was the caregiver, she had wounds which her status then. This has contributed to my husband accepting me because he knows this. He is negative … the 1st year he had stress but he accepted. We support each other since I got the job as community health worker it have been easy (IDI 13).

So prostitution was a bit fair … yaah you could earn from it … I worked for five years then I decided to call it quits. I got tested that is when I got the information … then after enrolling in community health work. I am a community health worker (IDI 14).

My husband got sick and was tested … So that’s how I decided: “Now maybe it’s high time I know my status” … after I knew my status then I absorbed the shock … as part of counselling for HIV, you’re not supposed to apportion blame. You’re supposed to deal with the situation as it is. I have been able to access care. I think that was a major step (IDI 15).

My life is good because when I had not known myself … I wanted to die but since I started going there I no longer want to die … A woman I met there … looking at her she was healthy. She told me not to fear that I should go and take the drugs and I will be happy because you will live like others (IDI 16).

When you are sick you have hope for dying you do not have hope for living. Let us say I started getting hope when I met with [xxx] and she told me she has even been admitted the way she was sick … and I saw mine was better because I have never been admitted in hospital and I got courage. The sister [nurse] for TB the first time I came we understood each other from the first day she gave me counselling … So she really encouraged me (IDI 17).

He used to take beer and so his signs showed first thus I decided to go for test … we separated. I was strong being led by the mind that it is my life and not a death sentence so I don’t care what people say (IDI 18).

We all look so healthy and I think this is what gives us the encouragement every day. That’s the thing, yes. Because we are fine, we’re not sick. Those days people used to grow so thin and frail and all that, so (IDI 19).

He’s negative. Initially he used to be loving …but of late he has changed a bit (IDI 21).

I was tested. I cried, I cried … I was feeling fit and I thought those people who are reactive they die immediately. No, I just felt I’m strong, I can work … I thought I can’t be. It can’t be me … The counsellor who was at PGH, CCC … he counselled me … I started creating my courage (IDI 22).

After knowing my status and he didn’t want to know his status, we started having issues within the family. He started accusing me of being unfaithful. He started being violent, drinking and coming home late. So, I decided to just move out and start my own life (IDI 23).
| Reactions to adversity – growth/Proactive attitude | What made me not to fear I went to my home and disclosed and our people secluded me … I said if my one people can seclude me can other people love me? So I said I will love myself … Also the support group in the family care also motivates me in getting the services when we meet and share our experiences (IDI 01).

My husband and in-laws was abusing me … they suspected my status … so I left … I disclosed to my mother and sister … they helped me with a job … I would stand up and support myself because I knew how to work. I started going to a support group … For now am totally in peace using the little I get from my business and am very free in making decision (IDI 02).

I told him it is ok let me go and take care of my children you don’t even normally help me … so I went back to my home so now I am at home … now we are at home farming (IDI 03).

It reached a time when I was not caring for the children and they are the ones I went to go and fend for … but later I was counselled and returned to form and I took the medicine and the disease stopped. I went for God and told God from that day save me … and show me good ways (IDI 04).

I had taken him to the chief in order to separate legally depending on my status … but when he said he had come to take care of his child I welcomed him and now we are together (IDI 05).

When I conceived I went there first clinic and join mothers club and from there I knew those women it was good because they opened me up slowly by slowly until now I am able when I find someone else who is down and I can talk to her and help her be uplifted (IDI 06).

We used to sell fish but after my husband died I had no capital … now I wash clothes … That of clothes it does help me … so much because I will not sleep hungry even if I get sh. 200 I will buy flour sugar and charcoal (IDI 07).

I was very heartbroken and I even said I will commit suicide, I became hopeless and I saw that I do not have a life but after 1 week I went back there and then my aunt told me to go to Nairobi we have a talk with her. She also gave me confidence and the counsellors are good, they told me that there is medication and if I accept and agree to take the medicine I will live like other people (IDI 08).

When I didn’t know my status I was stressed up … I got sick every other time and all the money was channeled to hospital … so after knowing my status I joined people … we shared similar status went for many trainings (IDI 09).

To help one to be independent is what they taught me … when one is sick is desperate you consider yourself as dependent … they have helped me to be independent so that you see that being independent is better than being dependent … I depend on my farm … then I harvest maize or beans I sell them for money (IDI 10).

For now I am independent. I have a business on you way to Langa Langa where I sell second hand clothes (IDI 12).

I got the job as community health worker … But since I had joined a support group in this program they came asking who would want to take up the responsibility as health worker and I volunteered (IDI 13). |
I am a community health worker with the municipality ... I am doing it voluntarily from down deep my heart nobody pays me. I am attending another training on financial illiteracy (IDI 14).

My husband and I share the financial responsibilities ... I handle household food ... I pay for my own medical expenses ... I also have NHIF through my employer (IDI 15).

Because this is not something that is a death sentence ... it is not meant that it is a must ... it happened so the way I accepted it ... I accepted myself so if he sees me and he doesn’t accept me as I have accepted myself the problem is not me as far as I have accepted myself (IDI 18).

I’m self-employed ... I’m a widow. You know, we turn to doctors when we feel so low and all that. In fact he’s really given me a lot of encouragement. So, every time I talk to him I feel – wow ... So, there’s life. (IDI 19).

It’s like now that I stay in Nairobi, it’s like I manage my own money. We only paid the doctor’s fees, then the ones were for NHIF. My husband is negative ... Initially he used to be loving, but of late he has changed a bit ... I need counselling ... together with my husband (IDI 21).

Right now things have changed. You see, now I can take care of the kids all alone. They can eat. Barack is going to school. I can pay the rent. Now, I can say things are changing ... I decided to go for the community health work (IDI 22).

When I knew my status, I decided to do psychology, so that I can be able to understand myself better and know how to go about issues (IDI 23).

| Reactions to adversity – problems/Reactive attitude | We are discordant ... It was when he abandoned me and the pregnancy so I started going down ... When he is not coming I usually tell my sisters ... I have not disclosed to them ... my sisters they just support me [financially] because of this child. If I had money I would not even be thinking about him ... those are things that would have become past tense (IDI 11).

When he went I did not live here ... I took the children we went back to our rural home and we lived there. There now my mum had a farm and we were depending on her. Our parents decided to bring us back together ... You know now when I was being married they went and they went there and there is how they gave out the dowry (IDI 16).

I did not have a choice (home delivery) because ... I did not have money and the person you depended on if she [her mother] refuses so I did not have a choice (IDI 17). |
Chapter 8
Accessing Healthcare 2: Lived Experiences, Interpersonal Relations, and Possibilities

8.1 Social Relations: Interpersonal Relations

This chapter will address the question: How do other social relations shape these women’s ability and willingness to access healthcare? As the findings in the previous chapter demonstrate, respondents were active agents pursuing various strategies to access healthcare and live positively. However, it was evident that certain interpersonal relations played a crucial role in these women’s ability and willingness to access healthcare in this urban setting.

As discussed in Chapter 3, the definition of social relations was extended to include interpersonal relations. Negative or non-supportive and positive or supportive social interactions are functions of interpersonal relations. The following narratives are used to exemplify the interpersonal relations identified in the data analysis.

Narrative 8.1: Hamisi’s Story

Hamisi is a woman in her early forties. When she was first interviewed in August 2011, Hamisi was stressed, very thin, and looked unhealthy. Hamisi explained that she was unable to complete high school because of her family’s financial constraints. She married at a very young age to minimize the financial burden on her family. She was married for many years before her husband died of AIDS. During her interview, Hamisi pleaded for counselling\(^\text{10}\). As required for ethics approval by KEMRI, a counsellor was retained for this project. After the interview, Hamisi received counselling from the project’s counsellor. A follow-up interview was conducted in October 2012.

\(^{10}\) Hamisi lacked the financial resources to support herself and her children. She was pregnant again and wanted to have an abortion. Because abortions are illegal in Kenya Hamisi wanted to get a “backroom” abortion which she knew was risky but she felt she did not have a choice because her financial constraints.
They alleged that I had killed their brother...

I started my schooling in [late seventies]. I continued with my education until form two. I found a man whom I have children with now because my father was not in a position to take me up to form four. I stayed with him for … until it reached a time I couldn’t bear children anymore and he was brought another lady by the family members whom he later married and I suppose that lady was the one having this problem (HIV positive). We were staying in the same house, the other lady and I were cooperating in that she could take the duty of sleeping with our husband this week and the following week I could step in. We were sharing in a bad way … we were doing things traditionally. I contracted the disease in that way.

Later God helped me and I started bearing children. I got the first child but it died, the second born also died while still young … they died early. I got another child in the year late 1990s but also died. I have two others in early 2000s. When my husband died in [year] I started hearing them say it is as a result of AIDS. But I thought that this was just TB. My husband’s family scolded me that I should take my hot blood to town and engage in prostitution. They alleged that now that I had killed their brother that I should go and engage fully in prostitution until I was satisfied. For the children there is a shamba there and when they saw that my husband had died they came with force to take things in the house like beds, cupboards. So they took a lot of things from me and abused me that I was a prostitute.

So things like that give me fear.

My neighbours are the people who have a lot of stories. They want to know who that coming to your house is and spread stories like we hear her husband died of AIDS. You know they will not lack something to say. What does she got to do in the hospital and she is not sick, why she goes to hospital every now and then. But if you go once it is okay but every month they wonder why you go to hospital and you are not sick. So things like that give me fear.

Now when I have recovered they say eeh I don’t know it is medicine or what nowadays she is very big you may not know it is her…what does she eat? This is where they are confused…is it the same woman who was sick?

So church members came and held a fundraising and cleared the bill.

In the early 2000s I found out that I was HIV positive but I had denial but then I went ahead to test my two children and the results indicated that one was HIV/AIDS positive. The first-born proved negative but the second one the blood sample was not good. I was told to go back and I did not. After my husband’s death I went to look for a room worth Ksh. 300 and that is where I stay. I sometime look for casual work like washing of clothes or even planting but jobs that do not require me to use more energy because I will be hospitalized. In late 2000s the virus weakened me and I never knew where to start from, if I went to the hospital, I didn’t have a husband to stand by my side or even meet all my hospital bills. When I had been hospitalized at PGH (provincial hospital) the bill had risen to 4000 KS and some hundreds which was too much by then so church members came and held a fundraising and cleared the bill. I am in a similar situation now as we are speaking…that is I am pregnant again and I even don’t know where I got it. I am confused because I have other
children and I don’t know how they will eat, go to school and how my health needs will be met. I would abort the fetus because I don’t know who the father is (engaged in prostitution).

**Follow-up interview one year later: October 2012**

*I was seeing the cost of going to the hospital*

I gave birth to this child and giving birth I was seeing the cost of going to the hospital. I was seeing I could not afford. I prayed to God to help me give birth in the house and God helped me. I gave birth very successfully to the child in the house. This child had a problem he stayed for two months and almost six days and then he died. I did not test him but I gave birth to him in the house and I stayed and only took him to the clinic in Langa. I was told I have to take the child at the clinic at Medical (provincial hospital). I thought who would return to medical to start queuing and get abuses so let him grow up a little but he died before I took him there.

*I was not caring for the children…*

The people of the church helped me and also another support came from these people (the research team counsellor), they told me not to do so, not to abort. I was stressed up and it reached a time when I was not caring for the children and they are the ones I went to go and fend for. I was suffering so I returned I started taking drugs (ARVs) after their counselling. I went to Medical and they opened a file. I was tested and CD4 was down, it came down, so low. I had CD4 of 80 and so I even could not walk, I was not healthy, I had no strength, my eyes sank, you see my skin it was like that of a grandmother. The older one (her son) while I was sick and down there I don’t have food so he usually went and searched for scrap metals, and plastics and sold them so that he buys flour. Then a woman (good Samaritan) came, I told her the girl is going to class seven and she asked does she have any problem? I said no she is performing well but we have a problem of food. She took my daughter to stay with her and she will send her to school. My third child was taken away and I don’t count him. His father took him.

*The child’s health was becoming worse…*

I only stay with my second child, he is positive. The boy was full of rashes in the whole body. I asked the people of (name of an NGO) to come and help the child with food because the child’s health was becoming worse and the person to attend to him was sick (referring to herself and her inability to care for him). People at PGH, their work is good especially the children’s doctor. I was surprised I felt in my heart I was so happy, you see the CD4 it has gone up (her son’s). So now I did go through that challenge but the child passed through it but the people of (name of an NGO) helped him because I went and told them that the child is treated at Medical and he has the papers and I have been sent to test the blood but I do not have the money for the test, KES 950 for one and 350 another and 350 another but CD4 was free. Then going to Medical there is someone who gave me a waiver for one of the test so I went to (name of an NGO) and they helped me in the other tests that were remaining. I saw it was easy, no more stress and the child went and started being given medicine. I was not tested. No I came and I was given medicine and being given medicine within two weeks I had the weight of 38 kilograms, when I came back for
Then I decided let me cling to this God

People told me that I should take care of the children I had and not get pregnant again. Then I decided let me cling to this God because he has removed me from alcoholism. So I decided to go for Him, let me go church and tell people I did fall, I have been a big prostitute. I have done disgusting things until I reached somewhere I got a child and I did not know who the father was. God will just help me. Now I am a hairdresser. I don’t have a salon but I do it in a mobile way. I am called and I am told come to certain place at certain time to plait. In a day if I wake up well and I get customers who stay in Section 58. I may get KES 500 or KES 400 or when it goes so low it is KES 200.

Narrative 8.2: Kaweria’s Story

Kaweria is a woman in her mid-twenties, married with a very young child. Her husband tested HIV positive and though she tested negative at that time, she would test positive six months later.

That is when couples test, during the pregnancy of the wife ... I attended four times for those antenatal clinics.

Before I got married I was a house girl. I got married … and in [year] my husband tested positive. After him being tested positive I didn’t stay long, after six months, because they say you test after 3 months and I was testing negative. I was also found positive after six months. When I was pregnant that is when his status was known that is when couples test during the pregnancy of the wife and I had not tested positive even when I gave birth. After a period of time that is when I was also tested positive. It forced me to stop breastfeeding the child. I attended four times for those antenatal clinics. I was trained on how to take good care of the baby and how to stay with him. With this pregnancy I went to the hospital and I was advised. We were also told about maintaining good hygiene. You are advised that you ensure that you deliver in hospital but you are told that breastfeeding is a mother’s decision on how you can breastfeed or not and when to do it but with me I opted for breastfeeding for six months.

They will just tell you to go for the test because they can’t treat you without knowing what they are treating, so you will be forced to go and struggle to raise the money.

Yes, sometimes when you are sick and you are sent to the lab you have to cater for that. If it is malaria or typhoid you will pay for it but if it is TB it is free. Some you will go and you will be charged. Yes, even if you don’t have and you are sick you will be forced to borrow because you can’t stay with sickness in the house. My husband will make sure that by all means I get fare because it is a must I get those services because it is compulsory so he gives me fare which makes it easy. I also usually see it that those services are so important so I can’t miss. When you are sent to the lab or you are told to go somewhere and you will be requested to pay and you don’t sometimes have the money you can come and tell them (lab tech) that you don’t have the money but not many will accept that because they will
just tell you to go for the test because they can’t treat you without knowing what they are treating, so you will be forced to go and struggle to raise the money. It is so expensive I stayed for very long before testing because I was seeing the money I had was very little. It took me time to do a collection, little by little, until it was enough and I was supposed to start treatment immediately because I was low.

I was counselled mostly with a woman who was visiting my place regularly. You know I was so much stressed...

I was counselled mostly with a woman who was visiting my place regularly. You know I was so much stressed, in fact I even decided to go home for three months before coming back again and giving birth to my child, but the teachings and counselling helped me a lot. They came back to talk to me regularly. I had piled a lot of anger. I started calming down slowly. We were in [name of place], in fact I give birth in [name of place] General Hospital where I was treated very well and the entire treatment process was very okay and I had normal delivery. They were coming from a given support group although they were affiliated to the hospital and in fact a certain woman who was their leader was the one who was coming and was also going to see those ones who were down and stressed.

For now they receive me warmly, but when they know and they see you they may segregate you and they can make sure the cup you are using they don’t use it again.

What is hard is saying your status because the only one who knows is the one you stay with knows. Saying your status has been very hard, for instance my mother-in-law does not know about it. In fact there is a time I stayed with her and she didn’t know, she did not even see the drugs. I haven’t even told my mother because I do not have that courage. I also feel that I can tell them and they take it negatively. For now they receive me warmly, but when they know and they see you they may segregate you and they can make sure the cup you are using they don’t use it again. I had fear at that time again to say such a thing in the rural area where victims of the disease are far apart again people could associate it to sin. So I prefer keeping quiet. I haven’t trusted my neighbours. They may appear so good but after sometime when you disagree they can reveal the secret in public so I haven’t tried telling them.

You are the one who will decide.

But for the condoms the both of us made the decision. You know this men are drunkards mine is a drunkard…when he comes drunk you will tell him but you will fight and pull one another and the neighbours will come to know, so at times it was fights or like forcing one eeh ... we use to use (condoms) but at times he use to refuse because he was still under denial … but when mine turned he became serious and saw that it was true and I also became serious and I called the doctor … and brought him to the house to talk to him. Because as for me I was very scared that I would turn positive so when it turned positive I saw that when I go down and also he is down no one would help the other so I tried to help him and also myself. So that doctor would talk to him and I would also listen. So I stopped being stressed. I went there myself, you know here in [hospital] they give a lot of attention to sick people … they educate you … when you are stressed they will teach you and you can even stay for three months without even thinking about it. Happiness is always there because it will depend on you. On my part I am stressed because I have children, I can die easily so I decided not to compare myself with him and that instead everyone has to take
care of himself or herself individually. For now is to try to make sure I am reducing stress and am attending all the clinic dates and if I have all the problems I go there. It also makes you responsible because I may not want to die and yet I have not raised my children to be adults. I must maintain myself so that I can add some years to my life.

**In a follow-up interview in October 2012:**

*Encouraged me to go and do CS because my CD4 also was low... The bill was high because when I came out...*

The madam we were with who had called me last time encouraged me to go and do CS. They (hospital) charged, they charged by then when you are found with complication you are taken fast to theatre I went I was operated on Monday. I went there on Thursday, I was operated on Monday and I came out Thursday so you see that is a whole week. The bill was high because when I came out it was Kshs. 13,820. Yes my husband had Kshs. 5,000, because he knew giving birth normally and it was normally 3,500. When he told mum that the bill had gone up its mum who gave the other amount.

*I was able to disclose to my mother-in-law...she supported me.*

Also last year in December I was able to disclose to my mother-in-law. She cried and cried and later she accepted. She supported me. I saw because she is so close to her son, she usually is so close to her children. Although this son does not want to tell her his situation and what he is going through and it reached a time where I was not happy he is drinking sometimes, he comes sometimes he does not. So I went and told her, so that she knows how to talk to him because you know we as women talk but they don’t hear. I went and he was talked to and he has gone on changing slowly by slowly. A little by little though he has not accepted to use the medicine the behaviour is changing.

*There is my immunity and I see it affecting me a little but my way of life I am not affected, it is normal.*

Before I was like that I had that mentality. I had a lot of anger but now I have accepted myself and I don’t see anything hard, I have accepted myself. I see it as any other state. I don’t fear that I will die tomorrow because that was my mentality. I am seeing it okay now. There is my immunity and I see it affecting me a little but my way of life I am not affected, it is normal. No I am seeing it okay now there is in my immune I see it affecting me a little but my way of life I am not... it is normal. Because I shower and wear well and go to the road I can still catch somebody’s eye. Let me say first it is the PGH (hospital) because when I conceived I went there first clinic and they made me join mothers club (a support group at the hospital for HIV-positive women) and from there I knew those women was good because they opened me up slowly by slowly until now I am able when I find someone else who is down and I can talk to her and help her be uplifted.
8.2 Non-Supportive or Negative Social Interactions

In this urban setting, there were threats to women’s efforts to keep their HIV status confidential, particularly for lower social class women. Reportedly, labelling and stereotyping of women living with HIV led to negative social interactions such as stigmatization and discrimination. As a result, these women employed various resistance strategies and managed disclosure to minimize these negative interactions, which threatened their ability to access healthcare.

Women living with HIV feared being blamed for “bringing the disease,” and some lacked a supportive network or had inadequate material support and were unable to relinquish their social obligations.

8.1.1 Threats to non-disclosure and confidentiality

In the area that participants like Gathoni (narrative from Chapter 7), Hamisi, and Kaweria live, houses are typically close together, usually shared compounds. Residents have frequent contact with neighbours, who closely monitor their daily activities. As Hamisi mentioned, her neighbours would be aware if she made regular visits to the hospital:

What does she got to do in the hospital and she is not sick, why she goes to hospital every now and then. But if you go once it is okay but every month they wonder why you go to hospital and you are not sick. So things like that give me fear.

Visits to the public hospital’s comprehensive care clinic can have serious consequences because of the lack of privacy afforded to patients who seek to access HIV treatment and care. A friend who saw Gathoni at the clinic revealed Gathoni’s HIV status to her husband:

After I went there to CCC because I was taking medicine there and his (referring to her husband) girlfriend she was here and she was telling him that we meet with her mum always there so he timed me and got me there. Coming and getting me there I told him I had come for my mum’s medicine and when I took the medicine he waited until he heard that the name was mine. So he entered to be tested and he was found negative and he told me he lived knowing
I wanted to kill him. He told me “so you wanted to kill me the way you killed the child but God has saved me. Our relationship between me and you is closed here.”

Gathoni recognized a neighbour and fellow church member at the clinic and suggested to the woman that she should have come earlier for treatment and not delay until she was very ill:

For instance there is a neighbour and she was going to take the drugs. I told her so you belong to the church she said no I have come to take [medicine] for another girl who she is very sick. I told her why didn’t you tell her early instead of waiting until she is very sick and these drugs it is like a common cold. Then I heard her name being called out it forced her not to take the medicine and go away and she went to stalls to wait for me to go away. She escaped that day and did not take the medicine.

Based on their lower class status, Gathoni, Njeri, Hamisi, and Kaweria could only afford to access care at facilities that were not able to ensure privacy and confidentiality. Neither could these women afford housing that would protect their privacy. In the social environment where these participants lived, they could not strategically manage potentially stigmatizing information about themselves, nor could they control what others knew about them by selective disclosure or concealment.

Wangari and Nyambura, women of higher social class (narratives in Chapter 7 and Chapter 9), did not share the same challenges with respect to their living environment and the facility where they accessed healthcare. They were able to maintain their privacy and confidentiality, and thereby minimize the risk of being stigmatized.

Nyambura and Wangari were concerned about being stigmatized in the workplace. They were both civil servants working in the health sector and appeared concerned about loss of status and discrimination. But based on their class status, they were able to mediate the stigma process by accessing healthcare from private physicians at private health facilities. Their permanent full-time employment meant that their daily absence from home and visits to town did not raise suspicions about their HIV status from their neighbours as it did for the lower class women.
8.1.2 Being labelled

Respondents mentioned that they would be labelled or stereotyped if their HIV status was discovered (Table 8.1). This labelling could result in loss of status and discrimination. One respondent was “chased” from her home by her in-laws when her husband died; she was accused of being a prostitute and killing her husband. The discrimination against this respondent led to the loss of her status and to her disinheriance. Another respondent lost her job as a maid because her employer suspected her status and was afraid that the respondent would “infect her child.” Neighbours of one respondent who sold food told her customers that she had the disease and was putting infected blood in the food. Because of successful negative labelling and stereotyping, these respondents reportedly suffered from a loss in status and discrimination, and, as a consequence, their access to and control over the means of provisioning and survival were reduced. The negative impact on these respondents’ financial stability, which we see from Hamisi’s narrative, influenced their ability to access adequate healthcare.

Hamisi married at a very young age; because her babies did not survive infancy, her husband, with encouragement from his family, took a second wife. It was only after the second wife came into their home that Hamisi and her husband started showing symptoms of being HIV positive. Her in-laws blamed Hamisi for killing her husband. They accused her of being a prostitute and “bringing the disease.” When Hamisi was chased away, she and her children lost their home and were disinherited. Hamisi’s HIV status was perceived as her responsibility, and it was assumed that she contracted the disease through voluntary and immoral behaviour. This view evoked social disapproval, anger, and moralism on the part of her in-laws and led to Hamisi’s stigmatization. Hamisi was linked to undesirable characteristics and labelled “a prostitute”. She was discriminated against and suffered loss of status. This discrimination worked to disadvantage her and her children, and led to social inequalities in their life circumstances. Hamisi’s downward placement in status due to stigma and discrimination meant a loss of social ties and inheritance, which led to her inability to access adequate healthcare on a regular, consistent basis. Hamisi had to rely on free services provided by an NGO and charity from church members to access healthcare.

Another participant, Kaweria, mentioned that she did not have the courage to even disclose her status to her mother because “she may take it negatively.” Kaweria believed her family would
“segregate” her due to their fear of being infected by casual contact and because they associated the disease with “sin.” In this case, stigma is associated with the perception of danger and fear of AIDS as a contagion as well as being linked with undesirable characteristics.

Participants also mentioned distrust of their neighbours because of their fear of being stigmatized. Hamisi was concerned that her neighbours would tell others that her husband had died of AIDS, and she was afraid that if she went to the hospital regularly, they would become aware of her status. Kaweria also expressed distrust of her neighbours, fearing they would reveal her status to others, which could lead to stigmatization and discrimination.

8.2.3 Selective disclosure and resistance strategies

The women in this study demonstrated complex responses to stigma, and challenged the stigma accorded to women living with HIV and AIDS. A few women rethink stigmatizing interactions and avoid contexts where they expect to encounter difficulty. As seen with the women of lower social class, women living with HIV and AIDS cannot avoid their neighbours who live in close proximity.

When some of the study respondents received critical comments about their HIV and AIDS status or expected to be stigmatized, they attempted to re-evaluate the incidents and deflect self-blame. Her in-laws accused Hamisi of being a prostitute and killing her husband. But in her interview she mentioned a number of times that the second wife, whom her in-laws brought into the household, was the person responsible for bringing the disease. Kaweria believed that she would be stigmatized because the disease is associated with “sin,” but she knew that it was her husband who transmitted the disease to her. She admitted she sometimes thought that “if he could have controlled himself” and not had extramarital sex, they would not be in trouble.

Respondents mentioned that selective disclosure was to minimize gossip about their HIV status, avoid being stigmatized, and escape the resulting “shame.” All respondents in this study managed disclosure of their HIV status. Women of higher social class did not join support groups. Two respondents did not disclose to their boyfriends or other family members. Of the other four respondents who disclosed to their husbands, two also disclosed to family members, one of whom also shared her status with others she met in the waiting room at the public hospital. Women of lower social status also limited disclosure of their HIV status to their
partners and close family members. Nine respondents belonged to peer support groups and disclosed to group members.

For women of both higher and lower social class, selective disclosure was a way to avoid being stigmatized. Selective disclosure meant that respondents had to maintain their health with medication, making it difficult for anyone to know their status because “they looked like everyone else.” Respondents were therefore motivated to access healthcare in order to minimize the risk of their disease becoming visible, which in turn lowered the risk of being stigmatized. Two respondents of lower social class, however, mentioned not wanting to disclose because they feared being stigmatized; as a result, they were afraid to even access healthcare.

Resistance strategies to manage stigma by higher social class respondents included accessing healthcare only through private physicians and facilities. This tactic ensured confidentiality and protected their privacy. Their resistance strategies included accessing healthcare so that they “look like others” or appear “normal.” Lower social class respondents were not assured this level of confidentiality and privacy. However, these respondents also accessed healthcare so that they could “look like others” or appear “normal.” Other strategies included being open about their status and confronting individuals who gossiped about them.

These women strategically avoided stigma by accessing healthcare so that they could look “normal.” Kaweria mentioned that she had accepted herself and did not fear she would die tomorrow, based on her previous understanding of the disease:

I am seeing it okay now. There is my immunity and I see it affecting me a little but in my way of life I am not affected, it is normal. Because I shower and wear well and go to the road I can still catch somebody’s eye.

Hamisi also mentioned the need to access healthcare so people would not be able to tell she was living with HIV:

I don’t know it is medicine or what nowadays she is very big you may not know it is her … what does she eat? This is where they are confused … is it the same woman who was sick?
Another participant, Elinah, made a similar claim:

> You know now that one when you do not want people to find out how you are … that will kill you and you will leave problems for your children. So to deal with the stigma you go and take the drugs so that you live like the others. (Elinah, narrative not included)

Some women living with HIV and AIDS choose not to access healthcare to avoid the stigma of being seen at the hospital’s comprehensive care clinic (CCC), where only people living with HIV and AIDS receive care. They sometimes leave CCC without receiving healthcare to evade being seen by someone familiar, or they may not access healthcare at all.

Women of higher social class, like Wangari and Nyambura, also practice strategic avoidance of stigma by accessing healthcare so that they do not show symptoms of AIDS:

> No, I think it has become like any other disease. I think gone are the days when it used to be treated like, you know. Nowadays I think everybody walking on the streets, how would you know? We all look so healthy and I think this is what gives us the encouragement every day. That’s the thing, yes. Because we are fine, we’re not sick. Those days people used to grow so thin and frail and all that, so … (Ingumba, narrative not included)

Accessing healthcare from private physicians at private facilities is also a stigma-avoidance strategy practiced by women of this social class.

Gathoni (narrative in Chapter 7), a woman of lower social class, demonstrated direct action against stigma, which involved talking back to challenge discriminatory behaviour. She directly confronted a neighbour who was gossiping about her HIV status:

> [Y]ou see he [neighbour] is a drunkard and spread and spread [gossip] and when we meet I tell him yes I am good, AIDS has not finished me I am still there [laughter]. The virus is not making me suffer and he is shocked that I have accepted it and you find he is not going on so much.
Hamisi eventually stood up to her in-laws and told them that they were the ones responsible for bringing the second wife, who had transmitted the disease. By talking back, these women challenged stigma and discrimination, and reallocated fault to the accuser. While resistant thinking and avoidance strategy do not attack stigma and discrimination directly, they were tactically necessary. Some avoidance strategies also create further health risks for those women who may opt not to access healthcare to avoid being stigmatized. For example, some women in the study avoided or delayed accessing healthcare due to the fear of being stigmatized.

Table 8.1: Stigma and Discrimination

<table>
<thead>
<tr>
<th>Code</th>
<th>Higher Social Class (n = 6)</th>
<th>Lower Social Class (n = 17)</th>
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</thead>
<tbody>
<tr>
<td>Labelling and stereotype</td>
<td>When they see somebody coming my way they tell them that I am HIV positive ... that my husband is a carrier (IDI 05).</td>
<td>They abused me saying I should go back to town with my prostitution (IDI 04).</td>
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<tr>
<td></td>
<td>I went to be employed somewhere ... I asked that woman for permission to go and take the medicine at Medical ... I told her I had a sick child ... I went but when I came back she fired me ... she feared ... she saw as if I could infect her child with the disease ... from then I have struggled with casual jobs of laundering (IDI 01)</td>
<td>Those I stay with are worse in that they spread rumors ... she told customers that I take tomatoes and mix with my blood that I am HIV positive. She kept spreading rumors about me ... I hardly got a customer ... when I came to know that she was the one spreading the rumors/we engaged in physical fight (IDI 05).</td>
</tr>
<tr>
<td>Status loss/ discrimination</td>
<td>My husband’s family scolded me that I should take my hot blood to town and engage in prostitution. They alleged that now that I had killed their brother ... they saw that my husband had died they came with force to take things in the house like beds, cupboards. So they took a lot of things from me ... But the children have the right over everything of their dad (IDI 04).</td>
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</table>
| Selective disclosure | So, there are people who would actually discriminate against you. So, it’s not easy to go public (IDI 15).

I have disclosed only to my God and my doctor (IDI 19).

I have disclosed to my husband and family only … because even in the church when you say you are positive people start sidelining you. I am not in a support group because of what I had told you, being a public figure I just decided to be on my own (IDI 23).

My mum and sister know … Others they will look down upon you … others would see that earlier on you were living as a prostitute … so there is no reason of telling them Neighbours you will be ashamed when they know … when one knows they tell another one and they will avoid you and even if it is the children they will avoid (IDI 02).

December I was able to disclose to my mother-in-law … She cried and cried and later she accepted … and spoke to him [husband] … he is slowly changing … stop drinking … and taking his medicine. When you discuss about HIV with others they talk so bad about it and so I also talk with them but I have never disclosed it to them and so I think people still have bad attitude towards HIV (IDI 06).

My mother took me well and when she came home she told me not to worry that I am still her child. She even told my sisters, brothers and my father so now I do not see that they take me badly they just love me. It is good to keep privacy because when I come here a lot of people do not know me it is not good to expose myself to everybody because if you do that you will get a lot of stigma and people who are negative do not accept other people it is a must that they will talk and stay away from you. Like neighbours I do not want them to know (IDI 08).

I disclosed to my mum since I never wanted to lose the second child the way I had lost the first one … this second one I saw that I should tell my mother so that she could support me. If the neighbours know about you they will start gossiping … but if you have got out of the stigma stage … you will leave them to talk but you will move on … you will eat well and there will be no changes in your body … when there are changes you go to hospital (IDI 10).

Because to be understood is hard … there is my sister we are close with her but my sister has her sister in-law who is sick and she was visiting her … the way I saw her treating her I said if should I tell her it would be worse … |
| Resist dominant perspective | I come here [private physician] because there are issues of stigma and confidentiality at the facility level [public hospital] (IDI 15).  

I come to the PGH [public hospital] because I meet others like me and we get counselling. There no one who will see me that when I come and when I go he will start beating me on the road. I stood with my principles and I was strong being led by the mind that it is my life and not a death sentence so I don’t care what people say. They will say anything but I have to live (IDI 18).  

That stigma. So, I decided not to go to a public hospital. So, I decided to come to a private hospital (IDI 23). | I went to my home and disclosed and our people secluded me ... and when they did so I said if my own people can seclude me can other people love me? So I said I will love myself and I will be disclosing to all people who would like to know and are very close to me. I can stand in a church and talk about my status ... there is nobody who does not know (IDI 01).  

One of them [neighbour] spread and spread [gossip] and when we meet I tell him yes I am good ... AIDS has not finished me I am still there ... the virus is not making me suffer and he is shocked ... and you find he is not going on so much. A women I met at the CCC I told her there is medication and that I have pushed on for 7 years ... I knew it is fear when you are starting ... she was starting when she is used or we meet two or three times it will give her encouragement and she views it as something normal (IDI 03).  

They [public hospital] helped me because I use to hide while going there but it reached appoint I would find someone I know like a neighbour, friend. Sometimes I use to go back home. But now I do not have that problem (IDI 05).  

People will know because you know there [public hospital] it is segregated and you will know who enters. I come here because ... here [NGO] is none [segregation] ... the way the person who is having malaria is treated is the same way that we are treated (IDI 07).  

She also gave me confidence and the counsellors are good, they told me that there is medication and if I accept and agree to take the medicine I will live like
You know now that one when you do not want people to find out how you are that will kill you and you will leave problems for your children. So to deal with the stigma you go and take the drugs so that you live like the others. So another woman told me she was like that she had 33 CD4 count. Looking at her she was healthy. She told me not to fear that I should go and take the drugs and I will be happy because you will live like others (IDI 16).

8.2.4 Bringing the disease

Women of both higher and lower social class mentioned being blamed for “bringing the disease” (Table 8.2). Hamisi was accused of being a prostitute and bringing the disease. Kaweria was afraid of disclosing to her family because they would associate the disease with “sin.” As the narratives in this study suggest, HIV and AIDS is often seen as a disease of immorality, and consequently the individual is often blamed for “bringing the disease” and accused of being unfaithful and promiscuous. Being blamed for “bringing” the disease had implications for women’s ability to access healthcare.

Some women were afraid to admit they had been tested before their partners or were afraid to be seen receiving HIV treatment by intimate partners, other family members, and neighbours. This worry often meant that they were afraid to be tested, access care, or to disclose their status, which meant that they would hide the fact that they were accessing care or hide their medication. Respondents also delayed or did not adhere to treatment:

During the clinic days, I had to give other commitment so that they may not get to know I was going to CCC. (IDI 02)

The ARVs, they have a box container and then a bottle. I carried the bottle with me and I left the outside box inside another paper bag. I used to put it on the bed and it had my inner pants. He took the box and put it on the table. “Where did this box come from?” He said if I go through all the belongings I won’t find those drugs in your belongings?” I said: “No, go through them.” I was very confident
because … I removed the bottle and hid it somewhere else. Now, I knew he wouldn’t find anything. (IDI 22)

I have never failed but I normally skip the dates. You are supposed to go for the drugs when three days are remaining but sometimes I can’t. I put the drugs in my sister’s house … My sister who lives next to me we take the drugs at 9 with my son. In the evening the boy comes and take and gives me then I take them when my husband has left for work. (IDI 03)

All three of these women were afraid of being blamed for bringing the disease. All three were confronted by their male partners, accused of bringing the disease, and when their home situation became difficult they made the decision to leave the relationship.

One participant believed she contracted the disease when she provided care for her sister who died of HIV/AIDS:

I disclosed to my husband and he was supportive so we have been staying together in peace. I relate to sometime my sister was sick and I was the caregiver, she had wounds … This has contributed to my husband accepting me because he knows this. (Chanya, narrative not included)

Chanya was not blamed for “bringing the disease” or for being unfaithful. Her husband accepted her, and she freely disclosed to her mother. Under these circumstances, Chanya was “not at fault” and was given emotional support, and space and time to get treatment and care.

8.2.5 Social obligations

Respondents of both higher and lower social class continued to perform their social duties and obligations such as employment and domestic duties, including caring work (Table 8.2). As a result, most respondents were willing to access HIV treatment and care so that they could continue to perform these duties and responsibilities. The following is an example of one respondent’s obligations, typical of most lower social class women:
I wake up and wash clothes and prepare the child to go to school. The shamba [farm] you know it goes with seasons you can dig and it can stay for long without weeds when there is sunshine but now it gets a lot of weeds so you say I will go this week. (IDI 06)

Respondents were not usually exempt from their responsibilities, and they therefore were often adamant about ensuring their access to healthcare in order to be able to meet their social duties and obligations. They sought treatment and care to ensure they could live longer, healthier lives and would be able to provide and care for their children.

I have known myself I know I have kids I have to be cautious of everything I do about their life about my life taking my medication because I want to see them grow. (IDI 06)

Hamisi became seriously ill because she did not adhere to her treatment and had to relinquish her responsibilities in terms of providing for her children. The father of one of her children took his child away to live with him. A woman who knew of Hamisi’s poor health took Hamisi’s daughter to live with her. Hamisi’s 10-year-old son, who was also living with HIV, was left to scavenge for scrap metal and plastics to sell in order to purchase food. Hamisi explained to the hospital and NGO that she lacked the financial resources for HIV treatment for herself and her child and needed assistance. She realized that:

I was not caring for the children and they are the ones I went to go and fend for … I was counselled and returned to form and I took the medicine and the disease stopped …

Women of the lower social class in this study were not usually exempt from social duties and obligations. Despite the physical demands on their bodies, these women continued to work at mainly manual labour jobs to support their families. They continued to perform domestic duties in spite of their illness. Women of higher social status like Wangari and Nyambura, while continuing to maintain their formal employment, could afford to take occasional sick days and employ someone for domestic duties.
Women living with HIV in this setting were only likely to relinquish social duties and responsibilities when they were too sick to carry out those responsibilities and only if they had the supportive network or material support to be able to do so.

Table 8.2: Social Obligations and Blame

<table>
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<tr>
<th>Code</th>
<th>Higher Social Class (n = 6)</th>
<th>Lower Social Class (n = 17)</th>
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<tbody>
<tr>
<td>Social obligations</td>
<td>Household chores … mostly it’s me … and sometimes the young girl that we stay with. I will get help when this baby is born (IDI 15).</td>
<td>So you see the children will sleep hungry it forces you to seek in all ways may be the casual jobs (IDI 01).</td>
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<td>In 2008 because she normally became sick it was on and off to the hospital like that so I decided let me test her so coming here upon being tested she was found positive. I employed somebody to help look after her when she was 2 years old.</td>
<td>I need to look for some money for the up keep for the children. So sometime I need to skip my clinic for my business (IDI 02).</td>
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<td>In Nairobi I live with my brother and the house girl. Sometimes I work day and night (IDI 21).</td>
<td>Mum has rented a big plot … and so when we help her there is a lot of food … I sell beans to pay for him and clear school fees (IDI 03).</td>
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<td></td>
<td>I work at [government] … Now, when I have the baby I’m at home [maternity leave] … 90 working days, but I hadn’t taken my annual leave, so I’ve combined all of that (IDI 23).</td>
<td>I have not depended on the man too much because when my children lack shoes it is me they tell … so I am seeing if I do not work hard it is me and my children. At times it gives me stress but not lots of it because I love my job very much because that is where I get my income (IDI 05).</td>
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<td>I wake up and wash clothes and and prepare the child to go to school. The shamba (farm) you know it goes with seasons you can dig and it can stay for long without weeds when there is sunshine but now it gets a lot of weeds so you say I will go this week (IDI 06).</td>
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<td></td>
<td></td>
<td>Let us say for my work I get money so if I want something I do have stress for money, if it is buying milk for the baby (IDI 08).</td>
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<td></td>
<td></td>
<td>I get farm produce and I come and sell to people. I stay with the small one since the other child goes to school (IDI 10).</td>
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<tr>
<td></td>
<td></td>
<td>I cannot be able to work … the baby is sick … a problem with the eye and cannot sit up … I take him to medical for therapy every Tuesday (IDI 11).</td>
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</table>
| Blame                                                                 | We the women are very secretive but let just say it. I went for the 1st pregnant clinic and I got tested which turned positive but I didn’t have word to tell the husband (IDI 02).  
He told me he lived knowing it I wanted to kill him … he came and found me there and he said I killed the child (IDI 03).  
We parted with the in-laws when they brought trouble they said … they did not want to see me that I had bad blood and so I should do prostitution … they said I killed their brother (IDI 04).  
I couldn’t disclose to the husband because I didn’t know how he could react … I wanted to look as if I’ve never tested even a single day. Now, we went for the test. I was just panicking because I thought: “If at all he will turn negative, we’ll separate from that point.” My God, too unfortunate, we were both positive (IDI 22). |
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<tr>
<td>After knowing my status and he didn’t want to know his status, we started having issues within the family. He started accusing me of being unfaithful (IDI 23).</td>
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</table>
officer to speak to her husband, who remained in denial and refused treatment. She stated that the counselling helped her deal with her stress and allowed her to begin treatment and care:

The doctor would talk to him and I would also listen. I stopped being stressed. I went there myself, you know here in [hospital] they give a lot of attention to sick people for example if you go the clinic first of all they educate you first and even when you are stressed they will teach you and you can even stay for three months without even thinking about it.

When Kaweria disclosed her status, her mother-in-law accepted her and did not blame her for bringing the disease. Her mother-in-law also paid Kaweria’s hospital fees when she went to deliver her baby.

Kaweria’s membership in a support group provided her with the opportunity for regularized social interaction and gave her the concomitant feedback that allowed her to adopt appropriate health-seeking behaviours. Her integration into a social network led to an increase in Kaweria’s self-esteem, which was evident from her comment that others still found her attractive, especially if she dressed up. Kaweria’s social network also helped her gain control over her relationship with her husband. In turn, her newfound self-esteem and control over her relationship influenced her susceptibility to her illness through changes in health-promoting behaviours such as continuing to seek HIV counselling, treatment, and care. Kaweria’s health and well-being was enhanced by the support she received from her social network. In other words, support from her social network directly benefited Kaweria’s health and well-being by encouraging health-promoting behaviours such as accessing healthcare.

The support Kaweria received also had a “buffering” effect on her by protecting her from the pathogenic effects of stress. From her narrative, it was clear that she suffered from a tremendous amount of stress:

In the past we were fine but since we tested positive, first I came to hate him you even understand that I decided to go back to our home, then later we were advised is when I decided to go back in marriage again. Although sometimes we may be well but you can
think if he could have controlled himself we could not be in trouble but it is just sometimes since I make sure that I try to avoid something that can cause me stress again.

Kaweria was also stressed because she was afraid of dying and leaving her children without a parent to care for them, and she was afraid of being stigmatized as a woman living with HIV. With counselling and HIV treatment, Kaweria began to accept herself and came to see her illness “as any other state”:

Let me say first it is the PGH [hospital] because when I conceived I went there first clinic and they made me join mothers club and from there I knew those women was good because they opened me up slowly by slowly until now I am able when I find someone else who is down and I can talk to her and help her be uplifted.

The support she received helped her to access healthcare and provided her with information which changed her “mentality” that HIV was going to kill her. As Kaweria’s perceptions changed, the situation did not seem as stressful, and she became less reactive to her HIV status. This change facilitated her healthful behaviours and even led to her providing support to others.

In the Mothers’ Club, Kaweria was able to share her personal experiences with others who had similar problems; there was no criticism, only sympathy, reassurance, and encouragement. By sharing her problems with other women living with HIV, Kaweria’s perception of the threat value of HIV decreased. Gathoni’s (narrative from Chapter 7) mother, who was also living with HIV, helped Gathoni to find the courage to accept her situation, which in turn encouraged Gathoni to “start taking drugs straight away.” Gathoni began providing information to her co-workers about HIV and encouraging them to be tested. This “consensus information” facilitates help seeking.

Kaweria, Gathoni, Njeri, and Hamisi received instrumental or material support from their support networks. Kaweria’s mother-in-law paid for her hospital fees and provided her with land to farm to supplement her income. Gathoni’s mother provided her with a home and rented land so they could farm for their livelihood. Hamisi received financial support from her church and a non-governmental organization to pay for health services, and a Good Samaritan took one of
Hamisi’s children to live with her when Hamisi’s health deteriorated. This type of support has both direct and buffering effect, and is particularly relevant to low-income individuals. Material support facilitates access to healthcare, either directly by paying for health services or indirectly by taking care of children or providing a means to earn an income, which in turn enables the individual to access healthcare.

Nyambura and Ingumba, both women of higher social class, did not seek support from their social networks. Due to her employment at the hospital, Nyambura had been trained as a peer educator, and in this role she counselled others about their HIV status. This training and education helped her accept her own HIV status. Nyambura also attributed her acceptance to her ability to access healthcare. She said, “I have been able to access care. I think that was a major step.” What information or counselling Ingumba received came solely from her private physician, who ran a very busy practice. Wangari, who accessed care from the same private physician, mentioned that it was not always possible to get counselling support from the physician:

Because, you know, now this is a private clinic and you wouldn’t get everything like counselling, even counselling before starting medication. The doctor does it himself and you feel it is very overwhelming for him.

Nyambura and Ingumba did not disclose to close family members. Nyambura’s husband knew her status, whereas Ingumba did not disclose to her boyfriend, the father of the child she was pregnant with at the time of the interview. Ingumba had also not disclosed to her teenage children whom she had with her now-deceased husband. Both women were university educated and knew that they were not necessarily going to die from HIV. Ingumba mentioned that it was like any other disease: with appropriate treatment and care, one could not tell that she was living with HIV just by looking at her. Informational support appears to have been sufficient to motivate these participants to access treatment.

Respondents of higher social class did not generally share their concerns with others who had similar problems. Only one respondent mentioned that she shared with other women in the waiting room at the public hospital; this waiting area is for all patients seeking HIV treatment and care, and therefore anyone seen there is easily identified as someone living with HIV and
AIDS. Women of higher social class did not appear to rely on “consensus information,” the sharing of their illness with others also living with HIV and AIDS, to decrease the perceived severity and threat value of their illness. Rather, this group of women relied on informational support provided by their private physicians to “know how to deal with issues” (Table 8.3). Two respondents of higher social class (n = 6) received motivational support from family members. Informational support and motivational support facilitated this group’s access to healthcare and motived them to adhere to their medication.

Respondents of lower social class shared their concerns with others who were also living with HIV and AIDS, and often did this through peer support groups (Table 8.3). Because these women shared their concerns with others who also suffered from the same illness, their perception of the severity and threat value of their illness decreased.

It was through their social networks that women in the lower social class group usually received informational, material, and motivational support (Table 8.3). Their peer support groups provided information, advice, and guidance on how to live positively and on the importance of accessing and adhering to treatment and care. Family members often provided material support to women in the lower social class group. Family helped with childcare and provided food and financial resources to these respondents.

Women in the lower social class group benefited from consensus information, informational support, material support, and motivational support from their social networks. Social support helped reduce the perceived severity of their illness and facilitated this group’s access to healthcare. With counselling, most participants in this study learned not to attribute blame for being infected with HIV and how to deal with their illness. Social support played a key role in the women’s acceptance of their illness and their willingness to access healthcare.
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<tr>
<th>Code</th>
<th>Higher Social Class (n = 6)</th>
<th>Lower Social Class (n = 17)</th>
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<tbody>
<tr>
<td>Consensus</td>
<td>Whenever we come for clinics here, we usually discuss a lot life experiences with other women and we learn a lot from the women. I learnt about various safe methods of delivery, which no one could have told me. In private hospital you never meet as a group of WLHIV and share our life experiences (IDI 18).</td>
<td>I got counselling in PGH when I got tested ... when I go there and we share our experience with other women (IDI 01). The colleagues who are living with HIV give me a lot of hope and strength (IDI 02). When I feel low emotionally I normally visit CCC and I meet women telling stories and I enjoy and I say it is not me alone that I have a problem and I feel my heart is calmed (IDI 03). I conceived I went there first clinic and they made me join mothers club and from there I knew those women it was good because they opened me up slowly by slowly (IDI 06). We have grouped ourselves since we know each other (IDI 08).</td>
</tr>
<tr>
<td>Informational support</td>
<td>I’m part of the workplace committee for HIV (IDI 15). As well herein PGH you taught ... guide accordingly. For instance in giving birth they teach you on various delivery methods ... breastfeeding and in nutrition (IDI 18). I think counselling has helped me. Counselling has really helped me... And, as I was learning, we were also taken through therapy. We would go for like more than ten sessions (IDI 23).</td>
<td>For the second one I was informed properly on what to do so I breast fed for 6 months and then ceased (IDI 01). I know my status and I was counselled on how to live healthy. I am the one who make the decision on the usage of protection (IDI 02). Yes they give us counselling concerning family issues. Sometimes they bring people from the bank who teach us how to get money (IDI 03). At CCC we were getting training on how to give birth, on food, breastfeeding and how to go about with your pregnancy ... there were generally very good teachings (IDI 05). PGH doctors are very many and what also makes me like PGH is before they treating people they educate you and that teaching inspires me (IDI 06). PGH I used to go for my ARVs there. Also we were taught how to use family planning methods ... my husband and I got counselled there ... how to eat well and to protect ourselves and to accept our status and live positively (IDI 08).</td>
</tr>
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</table>
In the support group ... we were taught how to bring up the child ... to prevent the child from getting infected, even how to disclose ... they are ones who helped me to disclose to my mother (IDI 10).

I went to CCC for three weeks counselling one on how to fight stigma, second on disclosure. Also on nutrition on how to get my immunity boost via vitamins, and not take alcohol. Finally it was on how to take the medication and how to live with other people (IDI 13).

<table>
<thead>
<tr>
<th>Material support</th>
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<tr>
<td>KAG support me financially when I don’t have enough money to get to hospital (IDI 01).</td>
</tr>
<tr>
<td>My mother gave me the capital and I started selling women stuff like browses and the like ... In addition, my brother usually support in paying the fees for me child in nursery school here in the KAG program (IDI 02).</td>
</tr>
<tr>
<td>Yes mum has rented a big plot and so when we help her there is a lot of food (IDI 03).</td>
</tr>
<tr>
<td>I have been sent to test the blood and the money of testing the child’s blood I don’t have so they ... I went PGH and they and told me I will help you in this one then I went to Family Care and they helped me in the others that were remaining I saw it was easy ... no more stress and the child went and started being given medicine (IDI 04).</td>
</tr>
<tr>
<td>My mother gave me fifty shillings and told me that we could disagree if she notices that I did not go to medical. I tell my mother that my child does not have school shoes so that she can help me (IDI 05).</td>
</tr>
<tr>
<td>The bill was high because when I came out it was Kshs. 13,820. Yes my husband had Kshs. 5,000 ... When he told mum that the bill had gone up its mum who gave the other amount (IDI 06).</td>
</tr>
<tr>
<td>There is money we raise and therefore you can get a loan from the group if you want to open a business and pay later in installments. When your person dies, or is bed ridden in the house, the support group</td>
</tr>
</tbody>
</table>
| Motivational support | My sister too helped me very much since we were with her when I was being tested (IDI 18).  
You know, we turn to doctors when we feel so low and all that … In fact he’s really given me a lot of encouragement (IDI 19).  
Support from the family … They are supportive. Because even my eldest brother is also HIV positive and he knew his status back in 1998 and he’s doing well. | I am the last-born of the family and I went my sister, told them my status and what was on with my life. My mother and my elder brother encourage me and give me hope. So they keep on visiting me and they are very supportive in term of emotional support (IDI 02)  
When my child was hospitalized and tested the results were positive … I then told my mother to be tested she was also positive because my father had died three years earlier … it seems my mother knew what caused my father’s death … she challenged me to soldier on because she herself had done that for three years (IDI 03).  
They were coming from a given support group although they we affiliated to the hospital and in fact a certain woman who was their leader was the one who was coming and was also going to see those ones who were down and stressed (IDI 06).  
I was given counselling and told that I should go there to talk to them. They saw that I was broken and I really cried so they gave me counselling to encourage me (IDI 08).  
They give us a lot of support … the teachings we get there really help us to get out of rejecting yourself and to not despise yourself (IDI 10).  
The support groups adds more hope and strength … In our sharing we get more experiences in life and it makes me stronger (IDI 11). |
8.4 Summary: Interpersonal Relations: Motivating or Hampering Access

As the findings indicate, social relations, specifically interpersonal relations, shape individual experience and influence access to healthcare. Positive social interactions were instrumental in motivating women’s access to healthcare. Negative social interactions worked to both hamper and motivate women to access healthcare. Reportedly, fear of being stigmatized or being blamed for bringing the disease can deter or delay access or adherence to healthcare. However, when there were visible signs of the disease, women accessed healthcare to avoid being stigmatized. Social obligations worked to motivate women to access healthcare. Women’s social class played a role in how these women met their obligations. It appeared that strategies to resist stigma and discrimination also varied depending on women’s social class. The following chapter provides the findings on how the intersection of gender and class structure access to healthcare.
Chapter 9
Accessing Healthcare 3: Salience of Gender and Class

9.1 Social Relations: Intersections between Class and Gender

This chapter will address the question: How does the intersection of gender and class structure access to and utilization of healthcare? As we have seen in the previous chapters, there were healthcare services available in this urban setting. Women were active agents; they engaged with patriarchy, and employed various strategies to minimize stigma and access healthcare. They also relied on various positive social interactions to be able to access healthcare. It was evident the strategies these women employed differed based on their social class. The evidence presented in this chapter indicates women have differential access based on their social class and that gender was also a significant factor in their access to healthcare.

9.1.1 Income-based access to antenatal care

9.1.1.1 Higher social class

Women of higher social class (n = 6) generally sought healthcare from private physicians (Table 9.1). All higher social class respondents in this study had monthly antenatal visits during their pregnancy; the fee for each visit was 1,000 Kenyan shillings (KES) ($9.80 USD). These women were planning to deliver by caesarean section at a private facility. Two participants went into labour and had normal deliveries. Their hospital costs were paid by NHIF (Kenya’s national health insurance), which the respondents contributed to through their employers. These respondents also sought HIV care and treatment from their private physician.

Four of these respondents mentioned that by adhering to their medication they could live like others, that no one could tell they were “sick.”

9.1.1.2 Lower social class

Women of lower social class (n = 17) generally sought antenatal care later in their pregnancy, usually after they were three to four months pregnant, and averaged only four antenatal visits
(Table 9.1). Two respondents said that they accessed antenatal care services more frequently because of problems with their pregnancy. Respondents had to pay a one-time fee of 200 KES to open a hospital file and were responsible for any lab costs. Hospital costs can and often do exceed the delivery fee (2,500 KES) that respondents expect to pay for the cost of the hospital bed and other miscellaneous costs; in one case, the fee amounted to 4,800 KES for a normal delivery, while in another case, the cost was 13,000 KES for an emergency caesarean section. In both these cases, the respondents could not afford to pay the fees and sought help from others.

Of the five respondents who delivered at home, one chose to remain at home because of the distance to the hospital, but the other four respondents stated their decision was due to lack of funds for the hospital fees. Two respondents mentioned that they could not afford the hospital fees and that a church-based organization (CBO) had paid the fees. It is common for the hospital not to release a patient if the hospital fees have not been paid. The eleven respondents who delivered at the public hospital relied primarily on economic transfers from intimate partners and sometimes also received help from other family members.

In terms of HIV care and treatment, two respondents mentioned that they could not afford the hospital fees and that they had applied and were granted a waiver by the hospital staff. Another two respondents said that they were single, did not have family support, had engaged in prostitution until they became very ill, and could not afford to pay for the hospital file or the lab fees for themselves. What little money respondents had was used to pay for healthcare services for their children who were also HIV positive. One of these two respondents eventually received assistance from an NGO. Seven respondents depended primarily on economic transfers through marriage for healthcare expenses, including transportation costs. Four respondents received material support from family to assist with healthcare costs.

Ten respondents mentioned issues of morbidity such as weight loss, body pains, dermatological problems, and generally not feeling well.
**Table 9.1: Healthcare Access**

<table>
<thead>
<tr>
<th>Access to Healthcare</th>
<th>Higher Social Class (n = 6)</th>
<th>Lower Social Class (n = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to private h/c</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Access to public h/c, NGO, CBO</td>
<td>1 (negative case)</td>
<td>17</td>
</tr>
</tbody>
</table>

Two respondents of lower social class suffered significant financial decline when their husbands died. One was accused of killing her husband by his family, was disinherited, and forced out of her home. She was a housewife with no employment prospects and had to resort to prostitution to support herself and her children. The other respondent helped her husband in his business, but she could not sustain it after he died. She got occasional work washing clothes and relied on economic transfers from both her own and her deceased husband’s family. Both stated they had been stable financially when their husbands were alive. Of the respondents who left their husbands because of abuse or neglect, those of lower social class also suffered a decline in financial status.

Most respondents in this study bore primary responsibility for caring for their children. Women of higher social class with formal employment were able to take maternity leave. Five of the respondents mentioned that they would have “househelp,” a maid, to assist with the household and caring work. Lower social class women did not have maternity leave and resumed work shortly after delivery. They could not afford to employ a maid and relied on family, neighbours, and friends to help with child care when they went to work or to the hospital for healthcare.

**Narrative 9.1: Nyambura’s Story**

Nyambura is a woman in her mid-thirties. She is married, has a preteen child, and is currently pregnant with her second child. Nyambura, her husband, and her child are all HIV positive. To protect her identity, the place of her employment and her position will not be revealed. I will say that she is a government employee. The recruiting physician advised me that Nyambura did not want any Kenyans present during the interview. Therefore, my research assistant was not allowed to conduct the interview. Nyambura’s English language skills were excellent, so I, as the principal investigator (PI), was able to conduct the interview.
I take home around [high 5-figures] KES and him maybe around [low 5-figures]. We split responsibilities.

I’m a university graduate, my first degree. I did [university program] and I’m [mid-thirties] now. I’m married and I have one other child [preteen] years old. My husband is a [professional position]. I work in the [employer]. I take home around [amount] KES and him maybe around [amount]. We split responsibilities. Like, he would take care of things like rent, maybe. The recurrent budget like rent, electricity, water supply, then I take care of household food. Mostly I take care of the household chores and my child. When this baby is born I will get a househelp (maid).

It’s not going to be expensive because my health card covers that.

For this baby I will do a C-section at a private nursing home and I’m going to do replacement feeding. It’s not going to be expensive because my health card covers that. It’s contributory and then you get subsidized, but now nursing home is one of the facilities that have signed the comprehensive cover with NHIF for maternity. So, whether it’s a normal delivery or a CS, the card covers everything. The only difference would be if I had my own doctor, like they have a resident doctor, but if I came with my own gynecologist then I would need to pay him separately. I will ask him to be there. My first child I had a normal delivery. It was at PGH, the private wing annex, but then I didn’t know my status at that time. I was not sensitized enough for PMTCT. I started my antenatal at 15 weeks and I’ve been seeing a gynecologist, actually the one who’s next door. So, I got a referral from Dr. [Name] and then I went. So, I’ve been visiting him monthly; so I’ve done most of the tests. And I’d also worked in the [employer, department] for around one and a half years, so I had an idea about protection and how to get pregnant safely. Yeah. So, I just went and saw them just to consult and then I kept my calendar, a close check on my calendar to see my fertile days. So, I only had one exposure.

There are issues of stigma and confidentiality...

Okay, and then the work situation, I’m part of the workplace committee for HIV in the workplace and there are issues of stigma and confidentiality ... So, not everyone has accepted. So, there are people who would actually like discriminate against you. So, it’s not easy to like go public. Yeah, in the [employer] or to disclose to people because of that breach of confidentiality. So, the time that I have worked in [employer] I have noticed that the people who- when they know your status they always tell the next person. Even though I got tested at the facility, at the VCT and then now for services for treatment, I decided to come to the private sector. The ARVs are from the GOK (Government of Kenya) and I don’t pay for them. I pay a consulting fee.

Narrative 9.2: Njeri’s Story

Njeri is a woman in her late twenties with three children; her first child is also living with HIV. She left her husband when he and his family became abusive. Njeri engaged in survival sex for some time to support herself and her children. When she disclosed to her family, they helped her start a business and provided emotional and financial support.
I was denied so they could not support me and you could see they had changed...

Now you know I went … you know we mothers normally have secrets. I went to the clinic concerning my first baby and I was told about my situation then I was completely at a loss on how I could tell him. After one year I took the child to hospital and it was confirmed it was positive (HIV positive). I still did not disclose … Then I decided I should leave his place because it was my feeling that the more we stayed together the more were unfair to each other so I went home. Our separation was caused by disagreement, because I was at his place and the parents and he also got involved. That is what made us to separate. After separating I went back to my home.

I never wanted anybody to know due to the stigma factor.

There was a difficulty at first because I had not informed anybody. I could not give the child drugs because when they saw me administering drugs to the child … they asked me why but I challenged them that his ears had a discharge and I usually visit the clinic on monthly basis … then I saw they are becoming more curious … I never wanted anybody to know due to the stigma factor. When he [husband] left money to cater for food I could take some and rush to hospital without anybody’s knowledge … sometimes I could be late to collect drugs for my child … adherence was difficult to attend … this affected me. I readily left and now I have the freedom and even for my child I can collect drugs on time. He [husband] said he couldn’t support when I am staying alone unless I go back to him. I can’t go back to him because if I compare my living standards now as a single mother it is better than when we were together. When together he could do things out of marriage [extramarital affair] and when I come to know about them I could not ask because it could result into chaos in the house. Now I can move around with my blouses as I sell and in the evening I just relax or have a walk because I have freedom. I am also enjoying my meals because there is no one to scold me and remind me of the past. I have freedom and I am also fine. Now I am literally the husband of the family.

At that time I was desperate and was hopeless I did not know what to do so as to get food.

I have never thought … perhaps as a woman I try to engage in some mischief [survival sex] … you know as a woman you can get your way somehow … you know as a woman you cannot lack a person to play around with so that you can get some daily bread. I would never wish to experience it again but because you have no otherwise you can move around because selling blouses to get 50 shillings which cannot sustain you and the family. At that time I was desperate and was hopeless I did not know what to do so as to get food. No one knew because I left the children and came back in the morning. I went on like that until my mum saw I was hopeless and my sister put up a job for me and since then my job is okay.

I am not from a well off family…my mother asked me what she could do for me.

I went home … that is when I stayed with my mother. I did not hide anything from her … you know you cannot hide anything from your mother. We talked and she gave me courage to continue living … she asked me what she could do for me. I told her that if she gave me a job life will continue well. I sell blouses … I can tell you when I sell that is where lunch, supper comes from, rent … That is why I say you know if you sell you know I have eaten or every day you know I will not fail to get a hundred shillings … fifty shillings. When I sell every day I normally reserve two hundred shillings so that I can replace stock. In a day
I normally go around two hours and then at lunchtime … when I come I wash the baby … let us say I normally take four hours a day. I am not from a well off family although my mum does some farming at times. She supports me with vegetables and potatoes and the like. In our family we are five girls but the ones before me are four so I am the youngest. I sat them down and disclosed to them … so they normally come to give some support.

*My mum and sister helped me.*

I accepted myself … I prayed that God helps me to take care of my children. My mum and our first-born helped me. My sister … she normally helps with school matters … so at such times when I need her … she asks whether it is school fees, rent, food that I need help … so she usually helps. I usually show them [her children] that I am everything … if they request anything I must struggle to avail it to them. I usually show them that what a man can do a woman can do better.

*I was hopeless but as I started going to a support group I met many and we talked and now I felt I was not sick…*

When you go there other women encourage you … when you come home you see your situation as better. At CCC you will never miss somebody to talk to … like the caregivers … so they make your burden light. Before I never wanted to get in because I had denied myself. I would hang around and if I happen to see somebody I know I would not go in. I would tell the watchman to go and get drugs for me … because there is somebody around there who knew me and I did not want him or her to see me. I saw death approaching me according to the way people saw it. I took heart and when I visited the CCC … I saw I was not alone. I became patient, soldiered on with life … Earlier on it was hard to have self-esteem. I had seen as if I had reached the end. I had nowhere to head to, I was hopeless but as I started going to a support group … now I felt I was not sick … I encouraged myself I said I would make it. In this community in which I live I am actually the one who helps them … they know themselves but they live in fear because of stigma. I tell them why can’t you take medicine because look at me I am this good … So it is big support I give them so that even if it is a man I will take him [to the hospital] so that he can access counselling.

9.2 The Significance of Gender

As seen in Chapter 7, women valued and adhered to the role of being a mother. They were the primary caregiver in the household and were often responsible for domestic work as well as held employment outside of the home. The following section provides further details concerning the significance of gender in these women’s access to healthcare.

9.2.1 Providing for their children

From their narratives, the women in this study appeared to have primary responsibility for, the bearing and caring for their children (Table 9.2), and provision for their household. Nyambura
admitted that she takes care of the household and is the primary caregiver for her child. When she gives birth to her second child, she will employ a “househelp” to assist with childcare and household chores. During her marriage, Njeri was unemployed and depended on her husband for financial support. After she left her abusive husband, Njeri mentioned that her mother and eldest sister helped her to start a business so that she would be able to provide food and school fees for her children. Before disclosing to her family and starting a business, Njeri engaged in survival sex to support herself and her three children.

Most respondents continued to have primary responsibility for domestic work while also engaged in paid employment. These women’s domestic responsibility varied based on their class status. Those with high incomes like Nyambura could afford to employ a “househelp” to assist with household chores; househelp is the local word used to describe a live-in maid who is responsible for most household chores and some childcare. Stay-at-home wives often do this work, and it becomes part of unpaid domestic duties. Single mothers like Njeri, with low incomes, have the fewest resources for this work.

All women included in the study were concerned about the well-being of their children and made efforts to access healthcare to ensure that they would be able to look after their children. Several women made specific mention of this concern:

Yes when I just feel unwell I rush there because I can’t wait until it is worse. I do not wait for the next day … I normally look at my children and ask myself in case anything happens hey … what their fate will be? (Jebet, narrative abstract not included)

It also makes you responsible because I may not want to die and yet I have not raised my children to be adults. Therefore I must try anyhow to maintain myself so that I can add some years to my life. (Kaweria, narrative abstract included in Chapter 8)


9.3 Class Matters

Social class intersects with gender and other social relations to influence women’s access to healthcare, as seen previously in Chapters 7 and 8. The following section provides findings of social class and how it shapes women’s access to healthcare in this urban setting.

9.3.1 Access to and control of resources

Nyambura’s formal employment suggests that she was in a position to adequately support herself and her children. She was not entirely dependent on relations of distribution through her marriage for essential economic transfers to have access to and control over the means of provisioning and survival.

Njeri’s situation differed because during her marriages she was a full-time housewife and relied primarily on personal distribution. Njeri’s HIV status made her situation extremely difficult when her husband and his family began abusing her after he discovered her status. Because she had not disclosed her status, she had to use household money secretly in order to access healthcare. When her marriage ended, she was able, with the help of kin relations, to work and regain access to and control over the means of provisioning and survival.

Nyambura’s and Njeri’s narratives provide evidence that their access to and control over the means of provisioning and survival were different and unequal along the configurations of class practices of reproduction and relations of distribution. Their class divisions, based on education and relations of distribution from intimate partners and family members, were both powerful influences in shaping access.

These women’s narratives indicate that they were from different social classes. Nyambura had a higher level of education and had formal full-time employment as a government employee. Njeri had a lower level of education and was unemployed during her marriage. After she left her husband, Njeri engaged in survival sex and later in informal employment to support herself and her children. Both Nyambura and Njeri benefited from essential economic transfers, relations of distribution, through marriage. Nyambura’s formal employment meant that she had the power, control, and access to the means of provisioning. Njeri’s situation in class processes was risky and financially disastrous because she was completely reliant on relations of distribution within
marriage, and had little power and control or access to the means of provisioning. With the dissolution of her marriage, her income fell rapidly. Njeri turned first to survival sex and then to family and kin networks for some financial and emotional support when her economic survival was threatened.

Njeri’s narrative reflects those of the women who belonged to her social class (Table 9.2). These women mentioned that their families could not afford to send them to school. They married early or left home to find work to ease the household burden. They often lacked the power, control, and access to means of provisioning, and found themselves in risky and disastrous situations. They were usually reliant on relations of distribution from informal work, marriage, or family for an income.

Not all women were able to rely on relations of distribution from an intimate partner or family members. When Hamisi’s (narrative in Chapter 8) husband died of AIDS, his family accused her of “killing” him and “chased” her from her home. Her own family did not have the financial means to assist her. Hamisi engaged in prostitution to earn an income to support herself and her children. Hamisi’s class status, which was tied to her husband’s, was reduced to the lowest social class or the most oppressed and impoverished members of Kenyan society. Hamisi now lived in very poor housing in a slum, in abject poverty, and was unemployed. Women of this lower social class group have limited access to healthcare as their dependence on relations of distribution from family, FBOs, or NGOs for financial support to access healthcare makes their situations precarious.

The program coordinator from the National Legal Aid and Awareness Program (NALEAP), an advocate by profession, emphasized that most women who come to them for legal help are women of lower social class. Reportedly, women living with HIV will seek legal services primarily to ensure her children inherit their father’s property:

Women who come in, they say: “Because my husband died and I’m HIV positive, they’ve chased me out of the land.” She is more interested in fighting for that land, that succession … Their succession … they have kids. Usually what’s happening is they’re being chased away. Even the kids are chased away. So, we will go to court for succession.
The coordinator mentioned that even when women living with HIV are informed of their rights, some women opted not to pursue legal action in order to keep their HIV status confidential:

But then, because of our culture, they look at culture so much that they forget what provision of law is there. Even if you tell them of their rights, they only want to look at the children. They don’t want to go public. They feel it will mean going public about their status. Now, in that case, she will not even want to bring any child because of being stigmatized because of her HIV.

Legal services that involve children are free, but adults have to pay legal fees. Pro bono services are provided, but, according to the coordinator, these free services are not always available due to lack of government funding:

We don’t have enough. The government is supposed to pay a token to pro bono services just for their transport. But they – it hasn’t – they haven’t released that money yet for quite a while.

Without pro bono services, women have to pay a fee for legal services. Many women of lower social class cannot afford to pay the fees and therefore have no recourse. Also, lower social class women living with HIV allow customary law to take precedence; they do not fight for any matrimonial property if they are chased away by a spouse or by their in-laws, possibly because they do not have the funds to proceed with legal action or because of the fear of being stigmatized.

Lower social class women living with HIV who were financially dependent on relations of distribution were often in a very precarious position; their spouse could abandon them, or they could be “chased” away by in-laws if their husband died, which ultimately impacted their ability to access healthcare.

9.3.2 Financial resources and ‘choice’ of healthcare facility

Nyambura and Wangari accessed healthcare that included HIV care from a physician who operated a private clinic, went to a well-known obstetrician/gynecologist in private practice for regular monthly check-ups, and delivered their babies at a private facility. As government employees, they had medical insurance that covered many of their healthcare costs, including the
delivery of their babies and their stays at the private facility. These women also had paid maternity leave for three months after the birth of their babies. Wangari admitted that it was a challenge to pay for healthcare fees not covered by the national health insurance fund (NHIF), such as consulting fees for private physicians and lab tests such as viral load. She had to “search for the money,” but still managed to come up with the funds to afford the cost of private healthcare and expensive lab tests.

Women interviewed in the study who belonged to a higher social class accessed private healthcare. Awiti was an exception. Awiti delivered her baby at a private facility by Caesarian section and opted to formula feed her baby, but went to the public hospital to access other healthcare needs:

I love here because here I get a lot of things … there are other advice you are given. When you go to private doctors you will get a doctor in there and the time that he will give you is limited because he has other patients he wants to see but once you are here we are all of us you understand you have the problem … she has it … is not only you so you confide on one another.

My husband goes to private doctors … for privacy. If we compare mine and his he does not get services that I get here. Okay if we compare the same thing he does not get somebody he can be so close to him to talk to like for instance I can give you an example last year when I was pregnant by coming here I met two women … the three of us were all pregnant … So this meeting here you get a lot of ideas you talk about … coming here you see you get ideas you get whoever has gone before you and tells you the way it was…

Her testimony was similar to Wangari’s:

Now in this private clinic you would not get everything like counselling, even before starting medication. The doctor tries to
counsel but it is overwhelming for him. It is so busy and there are a lot of patients … many people trust him, you know.

Women of lower social class who were interviewed for this study, like Njeri, accessed healthcare from public hospitals, clinics, church-based organizations (CBOs), or non-governmental organizations (NGOs). Sometimes these women accessed care from more than one of these locations. They navigated the system of public healthcare, NGOS, and CBOs to maximize access to healthcare that would otherwise not be available to them due to financial constraints. Hamisi (narrative included in Chapter 8) mentioned that she could not afford the laboratory tests for herself, but was able to get the tests done for her 10-year-old son, who was also HIV positive, through an NGO:

…the people of [name of NGO] helped him because I went and told them that the child is treated at Medical and he has the papers and I have been sent to test the blood but I do not have the money for the test, KES 950 for one and 350 another and 350 another but CD4 was free. Then going to Medical there is someone who gave me a waiver for one of the test so I went to [NGO] and they helped me in the other tests that were remaining. I saw it was easy, no more stress and the child went and started being given medicine. I was not tested.

This NGO provides comprehensive and integrated sexual and reproductive health information and services to all Kenyans, with a special focus on youth and the marginalized and socially excluded, through its clinics, community-based programming, and capacity building.

Nyanjera (narrative not included) sought services at another NGO:

They help one to be independent is what they taught me … when one is sick is desperate you consider yourself as dependent. They have helped me to be independent so that you see that being independent is better than being dependent … From the skills I got here I was able to go and get the farm. Right now we cooperate as a mother’s group and pool for funds, merry go round, it helps a
woman like that ... Like right now we were buying each other charcoal burners…we give out money and we buy charcoal burners. There is sometime my child was given [school] uniform if need arises they give it to us.

This NGO provides services that include the strengthening of food and economic security for households caring for orphans and vulnerable children, addresses gender issues in health services, and scales up and expands community and facility health service delivery.

A number of the respondents of lower social class gave birth at home, sometimes by themselves, with the help of family or friends, or with a traditional birth attendant. This choice was usually because of the hospital fees:

At the same time, the bills are very high. Like now – right now when, you’re an adult, you go and get admitted at the PGH, per day you’ll pay for the bed for 400 shillings. You’ve not counted for the medicines, the IVs, for the what not, the gloves, you’ve not counted all those. When you stay for a week, you are asked for around 8,000, 9,000 shillings. Where will you get the money from? … Many people – they refuse to go to the hospital. And the midwives who normally help women, they are very cheap … you can pay even 500 shillings and you are assisted … you go to the house of that midwife. You save for clothes for the baby, for food, for shopping that you’ll use that time when you’ve given birth. You save for the rent. You can’t make all those. How can one save and yet she’s earning 100 bob (ksh). 100 bob is not even enough for the meals. As for me, I get a pregnancy I can’t go to the hospital. No, that’s a lot of money. (Wangai, narrative not included)

Women in this social class sometimes borrow money from family, friends, and neighbours. At times, church members or “well wishers” would raise the funds to help pay hospital fees.
Table 9.2: The Intersection of Gender and Class

<table>
<thead>
<tr>
<th>Codes</th>
<th>Higher Social Class*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 6)</td>
</tr>
<tr>
<td>Distribution through wages/salaries</td>
<td></td>
</tr>
<tr>
<td>I work at [formal employment]. I take home around $19,000 KES (IDI 15)</td>
<td></td>
</tr>
<tr>
<td>Self-employed ... Before expenses maybe around forty (IDI 19).</td>
<td></td>
</tr>
<tr>
<td>I am a [formal employment]. I take home 9000 KES (IDI 20).</td>
<td></td>
</tr>
<tr>
<td>I am a [formal employment]. I take home around 15,000 (IDI 21).</td>
<td></td>
</tr>
<tr>
<td>I work for [formal employment]...I am a [xxx officer]. Personally, I'm paid around 15,000 KES (IDI 23).</td>
<td></td>
</tr>
<tr>
<td>I started selling women stuff ... So per day I may save may be 200 shilling (IDI 02).</td>
<td></td>
</tr>
<tr>
<td>I farm with mum and on Sundays I am called out to do the conductor's job ... Many times they give me Ksh. 500 (IDI 03).</td>
<td></td>
</tr>
<tr>
<td>Yes now I am hairdresser even to date ... I plait someone with 300 (IDI 04).</td>
<td></td>
</tr>
<tr>
<td>When God helps me to make sells of three hundred shillings (IDI 05).</td>
<td></td>
</tr>
<tr>
<td>I get a casual job ... washing clothes ... I get 200 shillings...(IDI 07).</td>
<td></td>
</tr>
<tr>
<td>Let us say my husband normally tries but even me since I do not have anywhere paining I go and look for small jobs like washing and plaiting ... Some times I get 100 or 150 and at times I do not get so that I could help (IDI 08).</td>
<td></td>
</tr>
<tr>
<td>I depend on my farm ... then I harvest maize or beans I sell them for money (IDI 10).</td>
<td></td>
</tr>
<tr>
<td>I sell second hand clothes ... After my calculations I save about 1000/- weekly (IDI 12).</td>
<td></td>
</tr>
<tr>
<td>I usually save 300 shillings per day although it depends with how the market is (IDI 14).</td>
<td></td>
</tr>
<tr>
<td>Let’s say when I have gotten a job they normally pay 150 and you buy something that will be enough when I lack I go and tell mum and she helps us (IDI 17).</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Distribution through marriage/intimate partner</th>
<th>Lower Social Class*</th>
</tr>
</thead>
<tbody>
<tr>
<td>We split responsibilities. Like, he would take care of things like rent, maybe. The recurrent budget like rent, electricity, water supply (IDI 15).</td>
<td></td>
</tr>
<tr>
<td>I don’t have money he usually gives me something when he gets (IDI 06).</td>
<td></td>
</tr>
<tr>
<td>He just normally leaves for me money that will be enough like sh.200 daily (IDI 08).</td>
<td></td>
</tr>
<tr>
<td>Household financial needs are met by the husband (IDI 18).</td>
<td>He gives me a big share since I am the one who takes care of the children (IDI 10).</td>
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<tr>
<td>---</td>
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<tr>
<td>Basically, we don’t sit and decide. But what he does is he just gives me money every month (IDI 23).</td>
<td>In a week he gets 4000 which enough is enough for our food &amp; other family needs (IDI 13)</td>
</tr>
<tr>
<td>He does what he gets … sometimes digging … It is just sh.150 … It is not enough but we just squeeze our needs (IDI 16).</td>
<td></td>
</tr>
<tr>
<td>Distribution through kin</td>
<td>She [mum] gave me the capital and I started my business … In addition, my brother usually support in paying the fees for my child in nursery school (IDI 02).</td>
</tr>
<tr>
<td>The hospital bill had gone up … its mum who gave the other amount (IDI 06).</td>
<td></td>
</tr>
<tr>
<td>My sisters they just support [financially] me because of this child (IDI 11).</td>
<td></td>
</tr>
<tr>
<td>I stayed without paying because even the money that I had was not enough but my people were able to help me (IDI 16).</td>
<td></td>
</tr>
<tr>
<td>Caring work</td>
<td>I mainly look after the children. I will get help when this baby is born (IDI 15).</td>
</tr>
<tr>
<td>I have known myself I know I have kids I have to be cautious of everything I do about their life about my life taking my medication because I want to see them grow. I employed somebody to help look after her [child] when she was 2 years old (IDI 18).</td>
<td></td>
</tr>
<tr>
<td>In Nairobi I live with my brother and the house girl. Sometimes I work day and night (IDI 21).</td>
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<tr>
<td>Because of my health status and seeing how I have suffered bringing these children … No jobs … sleeping hungry … the children sleep hungry and I find it so bad and seeing I don’t have … what to give them? (IDI 01).</td>
<td></td>
</tr>
<tr>
<td>I need to look for some money for the up keep for the children. So sometime I need to skip my clinic for my business. (IDI 02).</td>
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<tr>
<td>I sell beans to pay for him and clear school fees (IDI 03).</td>
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<tr>
<td>You see like now in the morning I had sh. 50. And those fifty shillings I bought sugar and two mandazis that the children will eat and I have remained with some few coins and there is lunch (IDI 04).</td>
<td></td>
</tr>
<tr>
<td>Yes when I was not feeling well I go there very fast I do not wait for tomorrow no I do not delay because</td>
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</table>
I look at the welfare of my children (IDI 05).

On my part I am stressed because I have children, I can die easily so I decided not to compare myself... For now is to try to make sure I am reducing stress and am attending all the clinic dates (IDI 06).

For example now when they are going to open school. They do not have shoes, they do not have sweaters ... So I will have to work and buy for one this month and the other one next year (IDI 07).

Let us say it has made it easy because let us say for my work I get money so if I want something I do have stress for money, if it is buying milk for the baby (IDI 08).

So I am the one supporting him and all the household needs (IDI 11).

I negotiate with the head teacher to wait for some time in case of school fees and things are worse I get some loan from credit facilities e.g., microfinance or support groups (IDI 12).

I support on the clothing of all of us and he does the part if water bills, food, and schools fees (IDI 13).

In PMTC clinic I asked the doctor on whether the kid could be negative and he instructed me on it (IDI 14).

The money I had was just enough for the baby so after he was admitted I bought the file for the baby at the CCC. From there I lacked mine and because the baby was badly off I saw that I help him until he gets well and I get money. But I have never got the money because the money I get is for food only (IDI 17).
9.4 Summary: Intersection of Social Class, Gender, and Other Social Relations

All women in the study were concerned with being healthy so that they could take care of their children, which often acted as a motivator for them to access healthcare. Reportedly, women of higher social class were able to employ domestic help whereas women of lower social class did not have the financial means to do so. This meant that women of lower social class sometimes had to prioritize their children’s needs over their own healthcare needs which had implications for their own health and their access to healthcare.

Women’s social class resulted in differential access to healthcare. Women of higher social class accessed private healthcare, monthly antenatal care, and delivered at a private hospital. Women of lower social class accessed healthcare from the public hospital but sometimes found the user fees prohibitive and would also access care from an NGO or CBO. Often women of lower social class accessed four or less antenatal care clinics, and some would opt for a home delivery rather than a facility-based delivery because of the hospital delivery fees.

As the findings in this and previous chapters indicate, women in this urban setting are not homogeneous. While their heterogeneity was reflected in the broad social class they occupy, it was clear that even within these broad categories there was further diversity based on whether they were married or single; had spousal or other kin support; were employed, had formal or informal work, or were unemployed. Women’s social class intersected with other social relations, gender, stigma and discrimination, social obligations, and social support to determine their access to healthcare.
Chapter 10
Discussion: Diverse Forms of Women’s Agency within the Social Structure

10.1 The Findings: Convergences and Differences

Key institutional actors (Chapter 6) describe Kenya’s healthcare system as one which aims to ensure that access to basic services is and continues to be given priority, with an emphasis on increasing awareness, creating demand, and reaching pregnant or lactating women living with HIV. These institutional actors do acknowledge system constraints and exogenous factors that hamper women’s access and result in low uptake of services.

Women’s narratives (Chapters 7 to 9) indicate that they are active agents, being pragmatic, devising strategies, and engaging with patriarchy to access healthcare and live positively. Interpersonal social relations can serve to either hamper or motivate women to access healthcare. Gender roles can motivate women to access healthcare or to prioritize the needs of others rather than their own. Class can be a major constraint or can greatly improve women’s ability to access healthcare services.

As mentioned previously, women did not speak to the high levels of governmental institutions involved in health service provision; this erasure of the top levels of the governmental hierarchy was possibly related to the fact that they could only speak to the level at which they directly accessed the services. This is where the women’s perspective diverges from the institutional perspective. The institutional perspective provided an overview of the system constraints, deficits, and gaps in health service supply and delivery. The institutions try to ensure the supply and availability of services and to create awareness and demand for these services. However, despite availability of services and women’s increased awareness, uptake of these services remains low – another divergence. The perspectives converge on the exogenous factors that hamper women’s access to healthcare thereby reducing uptake.
The findings suggest that patriarchy alone as an analytical tool does not adequately account for the material conditions of women’s lives and does not provide the sole basis for theorizing the noted variations – women’s heterogeneity – in this urban Kenyan setting. This converges with the claims made by Acker (1989) and Pollert (1996). The study highlights the intersecting factors and findings noted: social support, class, gender, stigma, and agency, which converge with postcolonial feminist perspectives on the factors that converge to structure diverse women experiences, their suffering and health.

This chapter examines the findings and determines how these findings fit in with the greater literature and what additional conclusions can be drawn. It will discuss how the providers’ data compare with women’s lived experience.

10.2 Institutional Perspective on the Supply and Availability of Healthcare Services

As discussed in Chapter 4, neocolonialism and neoliberal policies have shaped the current healthcare landscape. Conditions imposed by the Bretton Woods institutions on countries such as Kenya resulted in tighter restrictions on government spending on social programs, including health programs. Restrictions resulted in reduced government expenditure on health and infrastructure, which affected access to quality healthcare (Lister & Labonté, 2009). The institutional perspectives on the system constraints that follow align with the literature.

As the practitioners and health context confirm, a relatively large proportion of health services are provided by the private sector (for-profit and not-for-profit entities), and in terms of number of facilities and personnel, the private sector is larger than the public sector and growing (Barnes et al., 2010; Luoma et al., 2010). The data indicated that not-for-profit organizations in the private sector such as NGOs and CBOs/FBOs worked in collaboration with the public health sector to provide appropriate and adequate healthcare services in this urban setting. The private not-for-profit sector helps build capacity and addresses gaps in healthcare service in the public sector. Danida (2011) confirms that, along with capacity building, the NGOs advocate for better access and equity.
The data from key institutional actors suggest that the private for-profit health sector largely caters to the higher social class, many of whom are covered by the national health insurance fund (NHIF). The majority of those covered by the NHIF are formal sector employees and their dependents (MOMS & MOPHS, 2010). Patients paid a consulting fee (1000 – 1500 KSH) for each visit at the physician’s office, and pregnant women paid several thousand Kenyan shillings to deliver at a private health facility. For patients employed by the formal sector, much of the hospital fees are covered by the NHIF.

Based on the providers’ data, the government organizations involved in healthcare and the public health sector pursued various strategies to ensure that healthcare services would be available to pregnant and lactating women living with HIV in this urban setting. The public health sector ensured that health services were available, prioritizing services for the poor. For women living with HIV who were pregnant or had small children, the public health sector focused on health promotion and prevention; through messaging, the public health sector created awareness to increase demand for antenatal care, HIV testing, treatment and care, and PMTCT. It also provided training for healthcare professionals who were working with pregnant and lactating women living with HIV in order to provide the appropriate services. These data correspond with the mandate outlined by the Ministry of Medical Services and the Ministry of Public Health and Sanitation (MOMS & MOPHS, 2010).

The healthcare professionals interviewed in the study recognized that there were staff shortages, staff burnout, inadequate training for healthcare providers due to lack of funding, and insufficient medical supplies to provide efficient and timely service at the general hospital (level 5 facility: see Chapter 4). Lower levels of the health delivery system were not adequately staffed, and existing staff often lacked the training required to provide services. Danida (2011) confirmed that public services catering to the poor are inadequate, particularly at the lower levels. The MOMS and MOPHS (2010) acknowledged that some of the challenges facing the health sector included insufficient skilled human resources and inadequate budgetary allocation.

Key institutional actors acknowledged that, while there were challenges, as noted above, a health delivery system was in place to supply quality healthcare to pregnant or lactating women living with HIV in this urban setting. However, low uptake was a concern, because it was clear that
awareness and mobilization does not ensure uptake and full utilization. The key institutional actors recognized the exogenous factors that hamper women’s access, even when healthcare service provision is available. These factors include the social practice of stigma and discrimination. Healthcare professionals believed that “it’s primarily the stigma and the poverty that prevents women from accessing care.” The other factor, reportedly, is that many women living in poverty in this urban setting in Kenya were not able to afford the associated fees for maternal and HIV healthcare services.

Kenya’s health sector financing is predominantly financed by private sector sources, including household out-of-pocket spending and bilateral, multilateral, or philanthropic donors. According to the Kenya national health account 2012/2013 report (Ministry of Health, 2015), the total health spending in 2012/13 accounted for 6.8 percent of Kenya’s gross domestic product (GDP) and 6.1 percent of the total government expenditures. The data obtained from the key institutional actors converge with the literature that low government expenditure compromises the quality of care in the public sector, evident in the shortage of medical supplies and inadequate human resources (Luoma et al., 2010).

The institutional perspectives offered in this study aligns with the literature that high out-of-pocket expenditures limit access to care, especially by poor Kenyans. An estimated 16 percent of sick Kenyans did not seek care due to financial barriers, and 38 percent disposed of their assets or borrowed to pay for medical bills (Luoma et al., 2010). Studies exploring the utilization of maternal health services by women in an urban setting in Kenya confirm that low socioeconomic status is a major barrier. Because of financial constraints, availability of services did not translate into increased utilization of maternal health services (Fotso, Ezeh, & Oronge, 2008; Ochako, Fotso, Ikamari, & Khasakhala, 2011). The institutional perspective also converges with the literature, which found that stigma was an overwhelming factor influencing decision-making regarding HIV care access (Otieno et al., 2010). As will be discussed in greater detail in the following sections, these two findings from the institutional perspective regarding stigma and discrimination and poverty also closely align with the women’s perspective.

The institutional perspective provided an overview of the landscape of Kenya’s healthcare system and the challenges that exist within this healthcare structure, and gave some insight into
the social relations, both micro and macro-level factors, that hamper women’s access to healthcare in this urban setting. These perspectives convey the context in which these women live and access healthcare. The following is a discussion of these women’s lived experiences and how they navigate the healthcare system. Are they victims of patriarchy or active agents who engage with patriarchy and employ various strategies to access healthcare? What are the social relations that hamper or promote respondents’ access to healthcare in this setting?

10.3 Revealing Kenyan Women’s Agency

As mentioned in Chapters 2 and 3, much of the research literature indicates that patriarchy, the ideological foundation for gender inequity, limits women’s access to health resources in many low-income countries (Ahmed, Adams, Chowdhury, & Bhuiya, 2000; Nikiema, Haddad, & Potvin, 2008; Okojie, 1994; Ojanuga & Gilbert, 1992; Vlassoff, 1994; Zaidi, 1996). However, the concept of patriarchy alone is inadequate as an analytic tool because it denies women’s agency and erases the complexities such as class that characterize their lives (Mohanty, 2003). While Kenya is considered to be a patriarchal society (Mwangi, 2006) where women are usually disadvantaged in terms of material and status rewards, the findings of this present study indicate that women do have decision-making power to access healthcare.

The women’s narratives in this study provide a glimpse into the complex range of emotions and rational decision-making that they were engaged in. These narratives allow us to see how women make sense of their circumstances, account for their social roles, and transform their conditions. The patriarchal and traditional values and roles respondents adhered to and the sensitivity to others that they displayed accounted for the social roles and the gender power relations in their lives.

In this study, the institutional mechanisms of patriarchy, such as limited educational opportunities, lack of access to formal employment, and customary laws, serve to limit women’s economic autonomy relative to men’s. For example, according to the new constitution, women can own and inherit land, matrimonial property is protected during and after termination of marriage, and customary law inconsistent with the constitution is void (Amukowa, 2013; Kramon & Posner, 2011). However, as some women’s stories have shown, women often lacked formal education and access to formal employment, and they did not appear able to secure
inherited and matrimonial property. The stories also showed that social relations with a material base enabled men to dominate women. Women who were financially dependent on their partner were often reticent to disclose their HIV status because they feared being abandoned. This finding is consistent with another research study done in Kenya (Dworkin et al., 2013), which found secure property rights could decrease women’s HIV vulnerability. If their property rights were secured, women would have a secure place to live, a site for economic activity, and a means of livelihood, thereby “reducing the exchange of sex for goods, food, money, or shelter, and reducing economic dependencies with male partners” (Dworkin et al., 2013, p. 710).

According to Dworkin et al. (2013) some Kenyan women do not have any collateral for loans because property is usually registered in the man’s name only as the head of the household. Securing women’s property rights and preventing disinheritance and asset stripping would allow women to use their property as collateral for credit to support income-generating activities and increase their ability to secure their livelihood (Dworkin et al., 2013).

While study respondents all adhered to traditional values and gender roles, the higher social class women in this study appeared to make independent decisions to access healthcare. They had the education, employment, and financial resources to leave abusive husbands and to access voluntary HIV testing and counselling, HIV treatment and care, and maternal care. The findings of this study echoes Mwangi’s (2006) claim: patriarchal structures do exist in Kenya, but women of higher social class have significant decision-making power with regard to healthcare. Mwangi (2006, p. 109), in a discussion on household decision-making processes in Kenya, reports that, although patriarchy has a profound influence on decision-making, economic and educational factors also affect decision-making patterns. When women were in control of resources, as were the women of higher social status in this study, they were better able to look after themselves and their families, and to ensure the material and educational advancement of their families (Orchardson-Mazrui, 2006).

Most of the respondent women of lower social class who were involved in intimate partner relationships had disclosed their HIV status to their partners; therefore non-disclosure was not a factor in their access to healthcare. Those like Gathoni, who did not disclose to their partners, utilized various strategies to access healthcare. All women of lower social class accessed some
maternal and HIV healthcare. One of the main factors that limited women’s ability to access healthcare was their financial resources.

Respondents expressed agency through articulations of their capacity to participate in their environments and shape the circumstances in which they lived. It was through an examination of the turning points and epiphanies in their lives that their agency was revealed. Important moments in their illness journeys were revealed in the women’s stories. These moments often prompted a turning point in their lives, resulting in a commitment to improve their life circumstances. Their reactions to adversity resulted in introspection and growth, and a proactive approach in their efforts to live positively and access healthcare.

Resisting patriarchal and cultural oppression was crucial to these women’s empowerment. Women in this study demonstrated agency by engaging with patriarchy, the relative power of males over females learned through gender socialization, so that they could live positively. They did so by finding employment to support themselves and their children and to minimize dependency on their spouse. They also engaged with patriarchy in their efforts get their spouse to use condoms and seek treatment so that they can reduce reinfection.

The women further demonstrated agency by seeking education and knowledge of the disease and then articulating their own understandings of their illness, recognizing the critical role that their family and support group played in their lives. They took steps to become independent, access healthcare, and live positively, and they helped others in similar situations by providing information and counselling.

Consistent with previous findings (de Souza, 2010), the women in this study were not “Third World” passive victims, nor were they “tradition-bound” and ignorant. Patriarchal attitudes and HIV- and AIDS-related stigma do serve to silence these women’s voices, but by examining the turning points and epiphanies in these women’s lives, we see that they were able to demonstrate their decision-making power, their agency, in their day-to-day practices and struggles. Their lives challenge the constructed passivity of the “Third World woman” by illuminating the complex negotiation between cultural traditions and material resources, and by the agency they demonstrate.
These stories most likely reflect hundreds of thousands of women’s stories. They show that Kenyan women, though often beset by multiple factors limiting their available and expressed choices, are effectively finding ways to reduce the impact of tradition and patriarchy. Though they are often victimized, Kenyan women are not passive, as shown by the demonstration of the complex social relations they have to negotiate.

The following describes the micro–macro level social relations that influence these women’s ability and willingness to access healthcare.

10.4 Social Relations

Social relations are multifaceted and include a “diverse set of interpersonal relationships and exchanges that people engage in both within and between families, friendships and group affiliation” (Fuhrer & Stansfeld, 2002, p. 812). According to Fuhrer and Stansfeld (2002), interpersonal relationships influence health by enhancing a person’s ability to cope with stressful events, thereby improving well-being. Non-supportive interpersonal relationships increase the potential of stressful events and thus exacerbate ill health (Rook, 2015).

At the micro level, social relations are shown to influence women’s access to healthcare in this study. Non-positive social interactions, such as various manifestations of HIV- and AIDS-related stigma and discrimination ultimately impacted women’s access to healthcare in this urban setting. Positive social interactions often encouraged and motivated women to access healthcare.

Link and Phelan (2001) define stigma as the co-occurrence of a number of interrelated converging components: labelling of human differences, negative stereotyping, separation of labelled persons (“us” versus “them”), status loss, and discrimination. They argue that because human differences are socially selected for salience, stigma should not be seen as an attribute (something located in the discriminated person) but rather as a “label” affixed by others. This label usually links a person to a set of undesirable characteristics that form a stereotype. Labels connote a separation of “us” from “them.” For example, incumbents are thought to “be” the thing they are labelled. People are stigmatized when they experience status loss and discrimination because they have been labelled, set apart, and linked to undesirable characteristics (Link & Phelan, 2001). Status loss is seen as the consequence of successful negative labelling and
stereotyping, where the person connected to the undesirable characteristics suffers a downward placement in a status hierarchy. Discrimination is understood to be practices that work to disadvantage persons who have been labelled and stereotyped, and which lead to social inequalities in life circumstances (Link & Phelan, 2001). Stigmatization processes impact life chances such as employment, earnings, social ties, housing, health, or life itself (Link & Phelan, 2001; Goffman, 1963).

10.4.1 The expectation of stigma, combined with actual experiences of prejudice and discrimination

Narratives from participants showed the manifestations of HIV- and AIDS-related stigma. Consistent with previous literature (Herek, 1999), HIV- and AIDS-related stigma in this study was expressed through social ostracism, personal rejection, and discrimination. Some women in this study were blamed for “bringing the disease.” Often women were abandoned or chased away, lost their homes, and were disinherited. A woman’s HIV status was perceived as her responsibility, and it was assumed that she had contracted the disease through voluntary and immoral behaviour. This view evoked social disapproval, anger, and moralism on the part of spouse, in-laws, and neighbours, which led to stigmatization. Women were linked to undesirable characteristics and were often labelled as prostitutes. Women who were discriminated against suffered loss of status. Discrimination worked to disadvantage women and their children, and led to social inequalities in their life circumstances. These findings align with previous literature (Link & Phelan, 2001). Women’s downward placement in status due to stigma and discrimination meant a loss of social ties and inheritance, and usually a loss of income, which led to their inability to access adequate healthcare on a regular, consistent basis.

Some women mentioned that they did not have the courage to even disclose their status because it might be taken negatively. They worried that they would be “segregated” because of people’s fear of being infected by casual contact and because people associated the disease with “sin.” This finding is consistent with previous studies (Link & Phelan, 2001; Herek, 1999), where stigma was found to be associated with the perception of danger and fear of AIDS as a contagion, and was also linked with undesirable characteristics. Women expressed concern that
frequent visits to the hospital would raise their neighbours’ suspicions and bring about disclosure of their HIV status.

Consistent with previous literature (Herek, 1999, p. 1110), this study found that the widespread expectation of stigma, combined with actual experiences of prejudice and discrimination, has a considerable impact on people living with HIV and AIDS. Expectation of stigma affected many of the choices women in this study made concerning being tested and seeking assistance for their physical, psychological, and social needs. These findings align with other research (Carr & Gramling, 2004; Malcolm et al., 1998), which found that HIV- and AIDS-related stigmatization and discrimination represent a major barrier for people wanting access to treatment and care. Stigma was overwhelmingly mentioned as a barrier to access in a study examining access to care in mothers referred to HIV treatment programs in Nairobi, Kenya (Otieno et al., 2010).

Riessman (2000, p. 118) emphasized that a woman’s physical and social environment influences exposure to stigma, which in turn reflects class position. This conclusion was borne out by the women in this study. Women of lower social class could only afford to access care at facilities that were unable to ensure privacy and confidentiality. These women also could not afford housing that would protect their privacy. In the environment where these participants lived, they could not strategically manage potentially stigmatizing information about themselves, nor could they control what others knew about them by selective disclosure or concealment. Women of higher social class did not share the same challenges with respect to their living environment and the facility where they accessed healthcare. They were able to maintain their privacy and confidentiality, and thereby minimize the risk of being stigmatized. Based on their class status, they were able to mediate the stigma process by accessing healthcare from private physicians at private health facilities. Their permanent full-time employment meant that their daily absence from home and visits to town did not raise suspicions about their HIV status from their neighbours as it did for the lower class women.

Social class carries with it privilege that affects the experience of stigma, resistance strategies, and resolution (Riessman, 2000). The women in this study demonstrated complex responses to stigma, and challenged the stigma accorded to women living with HIV and AIDS. Women rethink stigmatizing interactions and avoid contexts where they expect to encounter difficulty.
As seen with the women of lower social class who participated in the study, women living with HIV and AIDS cannot avoid their neighbours who live in close proximity. When some of the study respondents received critical comments about their HIV and AIDS status or expected to be stigmatized, they attempted to re-evaluate the incidents and deflect self-blame. One participant mentioned a number of times that the second wife, whom her in-laws brought into the household, was the person responsible. Another knew that it was her husband who transmitted the disease to her. She admitted she sometimes thought that if he could have controlled himself and not had extramarital sex, they would not be in trouble.

Women strategically avoided stigma by accessing healthcare so that they could look “normal” and so that other people would not be able to tell they were living with HIV. Some women chose not to access healthcare to avoid the stigma of being seen at the hospital’s comprehensive care clinic (CCC), which had an open-air waiting room, where patients were visible to the public. They sometimes left the CCC without receiving healthcare to evade being seen by someone familiar, or they did not access healthcare at all.

Women of higher social class also practiced strategic avoidance of stigma by accessing healthcare so that they did not show symptoms of AIDS. Accessing healthcare from private physicians at private facilities is also a stigma-avoidance strategy practiced by women of this social class. A study by Arrivillaga et al. (2012) supports these findings. The study showed that higher income women sought private care, a strategy to minimize threats to the confidentiality of their diagnosis. For these women, “economic cost was less important than maintaining the secret of their diagnosis” (p. 932). This group of women held strong convictions with respect to HIV-related stigma and discrimination, and as a result, they employed multiple strategies to keep their diagnosis secret, including maintaining their physical appearance (p. 932). The study confirms that “[p]resenting a socially acceptable image was the main motivations for adherence” (p. 932).

By talking back and challenging discriminatory behaviour, women of lower social class took direct action against stigma and reallocated fault to the accuser. According to Riessman (2000, p. 126), “women who are stigmatized at one point in their lives can transform their situation later with new ideas and values that allow them to define their current selves and lives as equal to or more valuable than their previous ones.” Riessman (2000, p. 124) also notes that resistant
thinking and avoidance strategy is sometimes tactically necessary even if it does not attack stigma and discrimination directly. As the present study found, some women opted not to access healthcare to avoid being stigmatized. While this might be tactically necessary, this avoidance strategy could create further health risks for those women. The findings of this present study align with the findings of an earlier study which showed that fear of HIV and AIDS testing and disclosure on the part of women in Kisumu was one of the factors that discouraged facility-based delivery in that city (Turan et al., 2008).

Erving Goffman (1963) asserts that there are different types of stigma, such as physical deformities and blemishes of individual character. According to Goffman (1963, p. 5), those who do not depart negatively from particular expectations are deemed “normals.” Normals believe the person with stigma is not quite human, and based on this assumption they discriminate against the stigmatized individual and reduce that individual’s life chances. According to some researchers (Link & Phelan, 2001; Parker & Aggleton, 2003; Riessman, 2000), Goffman’s definition of stigma is seen as a significantly discrediting attribute.

Parker and Aggleton (2003) suggest that the concepts of “stigma” and “discrimination” need to be examined for their adequacy and usefulness. Parker and Aggleton also suggest that while Goffman’s formulations of stigma have been useful and important, a more comprehensive understanding of stigmatization, at least as it functions in the context of HIV and AIDS, is required (Parker & Aggleton, 2003). This re-evaluation is needed primarily because the emphasis on Goffman’s work has encouraged highly individualized analyses in which the stigma is seen as something in the person rather than as a designation others affix to that person (Link & Phelan, 2001; Parker & Aggleton, 2003). Another reason for re-evaluation is that stigma is often depicted as a “static attitude rather than a constantly changing (and often resisted) social process” (Parker & Aggleton, 2003, p. 14). This outlook has limited the ways in which stigmatization and discrimination have been approached in relation to HIV and AIDS (Parker & Aggleton, 2003).

Riessman (2000) asserts that two other problematic assumptions underlie Goffman’s theory of stigma. Goffman’s theory presumes a “self-determining, autonomous individual with choices and a mass society that allows for privacy,” and that individuals “manage” potentially stigmatizing information about their condition by “selective disclosure or concealment” (p. 113). Riessman
argues that this theory is a product of Western thought, and that it may be problematic in a non-Western context (Rießman, 2000). As the women’s narratives have described, selective disclosure and concealment of their HIV status did not ensure them privacy and confidentiality because of the neighbourhood in which they lived. It appeared that they were stigmatized, not because of individual character but rather because of their HIV status. Parker and Aggleton (2003) note that bonds and allegiances to family, village, neighbourhood, and community in the global south indicate that stigma and discrimination are social and cultural phenomena linked to the actions of whole groups of people, and are not simply the consequences of individual behaviour.

Gussow and Tracy (as cited in Riessman, 2000, p. 113) suggest the second problematic assumption inherent in Goffman’s theory is the presupposition that stigmatized individuals have no “possibility to destigmatize themselves” – that they “react” rather than “resist or reject” the critical appraisals of others. As this study has shown, women do reject the critical appraisals of others; women are active agents employing various strategies to resist stigma and access healthcare. This finding aligns with Riessman’s work (2000), which emphasizes women’s agency in situations where they face discrimination and abuse, and where individuals “disavow dominant perspectives” (p. 114). This scholar also argues that social structure, specifically the stigmatized person’s social class, age, and gender, need to be considered (Reissman, 2000). For instance, “women in different class contexts can mobilize different resistance strategies, because social class carries with it privilege that affects the experience of stigma, strategies, and resolution” (p. 114).

10.4.2 The female, sero-positive sick role in Kenya

This study found that women’s social network sometimes failed to provide support or withdrew support. Women living with HIV experienced the loss or disruption of their social network ties when their HIV status was discovered, or even suspected. It appears that, particularly for women of lower social class, life circumstances, chronic stressors, and loss or disruption of social network ties create unmet needs because these women with a stigmatizing disease such as HIV are not able to relinquish social duties and obligations, or employment and domestic duties.
In very simple terms, Talcott Parsons (1951) claims “illness is a state of disturbance in the normal functioning of the total human individual, including both the state of the organism as a biological system and of the individual’s personal and social adjustments” (p. 431). Parsons confirms that sick individuals assume the burdens of suffering, the risk of death, and the complex problems of emotional adjustment. They experience disruption in their social relationships, undergo emotional shock, and often deny their illness. According to Parsons, “being sick” constitutes a social role, namely the “sick role.” The sick role exempts an individual from normal social responsibilities: the individual is helpless and needs assistance, is not responsible for his or her condition, and is “not at fault” (Parsons, 1951, p. 436–447). Another aspect of the “sick role,” as described by Talcott Parsons (1951), indicates that sick individuals should seek medical help and cooperate with their doctors. In keeping with this aspect of the sick role, most of the women in this study sought treatment and care. Therefore, the sick role should provide individuals with the space and time to deal with their vulnerable physical and emotional state, which comes with being sick. Sick individuals will be exempted or excluded from normal role responsibilities, will seek out and cooperate with medical help, will be exempted from blame for their condition, and finally, will wish to get better.

There are a number of weaknesses in Parsons’ depiction of the sick role, such as the fact that many diseases are chronic but those with chronic illnesses are not necessarily exempt from social obligations like employment (Bissell, Traulsen & Haugbolle, 2002). It was found that women of both lower and higher social class, in this study, considered HIV to be simply a chronic condition. Some felt that it was like having a common cold, and they could live like everyone else as long as they were on treatment. Most women in this study did not adopt the sick role, and did not relinquish their social obligations and duties, but sought a more independent position in learning to live with their illness. This finding is supported by previous research (Ezekiel et al., 2009), which found that the health and well-being of people living with HIV and AIDS have been improved with ART. Where treatment and care is available, the disease is no longer considered a death sentence but rather a chronic condition (Ezekiel et al., 2009).

Another weakness of Parsons’ depiction of the sick role is that some illnesses are viewed as the responsibility of the sick person and carry stigmas (Bissell, Traulsen, & Haugbolle, 2002). In this study it was found that women, such as Wangari, Gathoni and Hamisi, both higher and lower
social class, were blamed for “bringing the disease.” As the narratives in this study suggest, HIV and AIDS is often seen as a disease of immorality, and consequently the individual is often blamed for “bringing the disease” and accused of being unfaithful and promiscuous. This view converges with the findings of another study that found Kenyan husbands often refused to be tested, and instead, in the most extreme instances, accused their wives of adultery (Pell et al., 2013). Being blamed for “bringing” the disease had implications for women’s ability to access healthcare, particularly in this present setting where there was widespread antenatal HIV testing. Pregnant women were often the first family member to be tested and were blamed for bringing the virus into the family and often suffered from adverse consequences of status disclosure. These findings of the present study converge with previous studies (Pell et al., 2013; Bond, Chase, &Aggleton, 2002), which found that women were blamed for bringing the disease and were often abandoned. Consistent with other research (Pell et al., 2013, p. 7), women in my study also reported delaying accessing antenatal care to postpone discovering their HIV status.

On the other hand, women’s narratives suggested that they made sure to take their “drugs” so they could be seen as “normal” and avoid being stigmatized because of their HIV status. They also sought treatment and care to ensure they would live longer, healthier lives and are able to provide and care for their children. Prior to accessing treatment and care, women in the study spoke of losing significant amounts of weight, skin looking “like a grandmother’s” or becoming “spoiled.” Accessing treatment was not only to improve the women’s health but also to avert peoples’ suspicions about their health. This finding aligns with previous research (Ezekiel, Talle, Juma, and Klepp, 2009), which showed that once patients were on ART, it became difficult to judge their HIV status based on their physical appearance.

Parsons’ also did not consider that the sick role might be historically and culturally variable (Bissell, Traulsen & Haugbolle, 2002). For example, women of the lower social class in this study were usually not exempt from social duties and obligations. Despite the physical demands on their bodies, these women continued to work at mainly manual labour jobs to support their families. They continued to perform domestic duties in spite of their illness. Women of higher social status, while continuing to maintain their formal employment, could afford to take occasional sick days and employ someone for domestic duties. These findings are consistent with the evidence cited by another study, which examined adherence to HIV and AIDS treatment
Arrivillaga et al. (2012) found that women of mid- to high socioeconomic position were aware of the “benefits of staying healthy with favorable adherence.” Because of this awareness, these women did not delay or refuse treatment, so they could continue to “meet economic and social obligations” (p. 931).

The temporal span of illness influences whether an individual can relinquish social duties and obligations as described by Parsons (Bissell et al., 2002; Segall, 1976). The women living with HIV in this study considered their illness to be chronic, took a more independent position in learning to live with their illness, and were not exempted from domestic duties in spite of illness; their social class determined their access to the sick role.

The concept of the sick role was specific to the patient-professional relationship and has been criticized for not accounting for the conflict and radical change in societies (Bissell et al., 2002). According to Bisell et al. (2002) the concept, a functionalist systems approach to understanding social relations, does not fully encapsulate women’s experiences, the contradictions and ambiguities of living with HIV. However, the sick role concept does have relevance to people living with HIV, in that it recognizes the emotional vulnerability of women living with HIV, which has implications for rational judgment and action in accessing healthcare (Bissell et al., 2002).

10.4.3 Social support

According to Fuhrer and Stansfeld (2002), interpersonal relationships influence health by enhancing a person’s ability to cope with stressful events, thereby improving well-being. Social relationships may affect health through physiological effects by encouraging or discouraging certain health-related behaviours (Sarason, Sarason, & Pierce, 1990). Families have the potential to be either particularly helpful or harmful for people with HIV and AIDS (Schmitz & Chrystal, 2000).

Women of lower social class received counselling from support groups. Some women solicited assistance from family, support groups, and clinical workers to counsel their husbands as well. It appeared that counselling helped the women cope with stress and encouraged them to begin treatment and care. Membership in a support group provided women with the opportunity for
regularized social interaction and gave them the concomitant feedback that allowed them to adopt appropriate health-seeking behaviours. Women’s integration into a social network led to an increase in their self-esteem. Improved self-esteem and control over relationships influenced women’s susceptibility to their illness through changes in health-promoting behaviours such as continuing to seek HIV counselling, treatment, and care. Women’s health and well-being was enhanced by the support they received from their social network. In other words, support from social networks directly benefited women’s health and well-being by encouraging health-promoting behaviours such as accessing healthcare.

The support women received also had a “buffering” effect on them by protecting them from the pathogenic effects of stress. Social support facilitated women’s access to healthcare and provided them with information, which changed their “mentality” that HIV was a death sentence. As women’s perceptions changed, the situation did not seem as stressful, and they became less reactive to their HIV status. This change facilitated healthful behaviours and even led them to provide support to others.

In support groups, women shared personal experiences with others who had similar problems; there was no criticism, only sympathy, reassurance, and encouragement. By sharing their problems with other women living with HIV, perception of the threat value of HIV decreased. This “consensus information” facilitates help seeking. Many women of lower social class received instrumental or material support from their support networks. This type of support has both direct and buffering effect, and is particularly relevant to low-income women. Material support facilitates access to healthcare, either directly by paying for health services or indirectly by taking care of children or providing a means to earn an income, which in turn enables the individual to access healthcare.

Women of higher social class did not seek support from their social networks. Often they did not disclose to close family members. Informational support appears to have been sufficient to motivate these participants to access treatment. Women of higher social class did not appear to rely on “consensus information,” the sharing of their illness with others also living with HIV and AIDS, to decrease the perceived severity and threat value of their illness. Rather, this group of women relied on informational support provided by their private physicians.
It was through their social networks that women in the lower social class group usually received informational, material, and motivational support. Their peer support groups provided information, advice, and guidance on how to live positively and on the importance of accessing and adhering to treatment and care. Family members often provided material support to women in the lower social class group. Family helped with childcare and provided food and financial resources to these respondents.

Cohen and Syme define social support as the resources provided by other persons, such as potentially useful information or financial help (Cohen & Syme, 1985a). There are two different ways to measure social support: structural and functional. Structural measures describe the existence of and interconnections between social ties, such as marital status or the number of relationships. Functional measures assess whether interpersonal relationships serve particular functions such as affection, feelings of belonging, or material aid (Cohen & Syme, 1985a). Structural measures are generally considered objective, while functional measures are subjective. In this study, I am more interested in an individual’s perceptions or subjective experiences of the availability or adequacy of resources provided by other persons.

According to Cohen and Syme (1985b), it has not been established why social support is associated with health, because the correlational nature of existing data makes causal interpretation difficult. Their stance is to focus on the process by which support is linked to well-being rather than merely determining whether a link exists. These scholars suggest that to gain a better understanding, we should look at how social support relates to various behavioural, emotional, and physiological mediators of health. The authors offer specific hypotheses that provide possible explanations for the direct and buffering models (Cohen and Syme, 1985b).

According to the “direct effect” hypothesis, health and well-being is enhanced by social support irrespective of stress levels (Cohen & Syme, 1985a). Direct benefits may occur due to the perception that others will provide aid in the event of stressful occurrences or as a result of integrated membership in a social network. This perception could lead to an increase in self-esteem, stability, and control over the environment, which in turn may influence susceptibility to physical illness through changes in health-promoting behaviours. Membership in social networks may also provide the opportunity for regularized social interaction and the concomitant feedback
that allows adoption of appropriate roles and behaviours (Cohen & Syme, 1985a). This converges with the findings of this present study that women integrated in a support network, family and support groups, felt less stressed, had better self-esteem, and accessed healthcare and wanted to live positively and be role models for others in similar situations.

In “Supportive Functions of Interpersonal Relationships,” Thomas A. Wills (1985) maintains that resources provided by interpersonal relationships play an important role in determining people’s adaptive functioning and health outcomes. The theoretical basis for this phenomenon rests on the functions that these relationships provide and on the psychological processes through which these functions have their effects (Wills, 1985).

Self-esteem issues arise when people experience doubts about their ability or social attractiveness, for example. Interpersonal resources, such as having someone with whom to discuss personal problems, provide esteem or emotional support. An important element of this supportive function or resource is the experience of feeling accepted and valued by another person (Wills, 1985). Supportive interactions include offering sympathy and reassurance, sharing personal experiences, and avoiding criticism. Wills suggests that sharing problems with others, especially others who have similar problems, may decrease the perceived severity and threat value of the problem. He refers to this as “consensus information,” and claims that it has been shown to facilitate help seeking (Wills, 1985). The present study findings converge with the literature. Some women who shared their status with members of support groups felt that they were not alone and that their illness was not a death sentence.

Another hypothesis, the “buffering” hypothesis, argues that social support exerts beneficial effects in the presence of stress by protecting an individual from the pathogenic effects of such stress (Cohen & Syme, 1985a). Support during difficult situations may reduce the perception that a situation is stressful, may help the individual become less reactive to perceived stress, and may facilitate healthful behaviours such as exercising, attending to personal hygiene, ensuring proper nutrition, and getting sufficient rest (Cohen & Syme, 1985a). Women in the present study mentioned that the social support received helped them to deal with the stress of their illness, to learn to accept their illness, and to begin accessing healthcare and live positively.
Wills (1985) suggests that when problems cannot be resolved easily and quickly people often seek information and guidance. Social network members may provide informational support by giving information, advice, and guidance. Wills notes that the literature on help seeking indicates that social networks are an important source of referral information for medical and psychological treatment. When environmental stresses exceed the person’s available knowledge and problem-solving ability, additional information and guidance become necessary. At these stressful times, network members may provide assistance, and this informational support operates as a buffering process (Wills, 1985). Women in the present study sought information on their illness, which helped them to understand the importance of accessing, adhering to medical care and living positively.

Instrumental or material support includes a wide range of activities, such as giving assistance with household chores, taking care of children, lending or donating money, and providing transportation. According to Wills (1985), this type of support is particularly relevant to low-income individuals, and has a buffering effect as well as being a main effect process. Several women in the present study relied on social networks, particularly, family members for financial support to access healthcare and to take care of household and the needs of their children.

When psychosocial stressors are chronic, motivational support may be an important function. When stressors are chronic, they are usually not easily resolved, have significant implications for the future, and require persistence and endurance before they can be finally overcome. When a problem is chronic, people often think that they will be unable to overcome ongoing difficulties and that things will not get better. Social networks play an important role by providing motivational support. Motivational support also has a buffering effect (Wills, 1985).

Consistent with previous research (Pakenham and Rinaldis, 2001; Leserman, Perkins, & Evans, 1992) this study found that positive interactions and social support was strongly linked to social adjustment to HIV and buffered some of the difficulties associated with the threat of the illness and helped individuals maintain a positive and empowering approach to the disease, including a willingness to access healthcare.
10.4.4 Gender and class

Macro-level social relations such as gender and class coordinate people’s activities (Smith, 1999). Analysis of gender and class processes revealed practices of oppression and power, which had a significant impact on women’s access to healthcare.

Gender appeared to affect women’s access to healthcare in this study. Gender was central to both childbearing responsibilities and relationship status. Accessing maternity care was primarily the women’s responsibility, but some participants mentioned a certain dependency on male figures for the necessary resources to do so. Single or widowed mothers of lower social class often had inadequate resources to access health facilities.

Results suggest that women’s overall autonomy influenced their access to maternal and HIV healthcare. Lower income women or housewives lacked economic autonomy, often creating a dependency on men for the resources needed to access healthcare. Such findings are consistent with two other Kenyan studies which demonstrated that this gender dynamic or relationship status influenced the participants’ access to maternity care (Fotso et al., 2009; Byford-Richardson et al., 2013).

High cultural value was placed on maternity and the social representation of the role of women in children’s survival, upbringing, and education. These cultural and social values attached to female gender created conditions that favour access to healthcare by pregnant women living with HIV. These findings were consistent with another study conducted in Bukina Faso (Bila & Egrot, 2009).

The findings of the present study have shown that women of higher social class in this study tended to hire domestic help to assist them with household chores. Lower social class women without a “housegirl” to help them with housework frequently started their daily chores at dawn and worked continually throughout the day. Lower social class women appear to put in considerably longer hours doing household and caring work than do most higher social class women. For lower social class women, in particular, the imbalance in gender division of labour can be seen as a major structural constraint to women’s empowerment and their ability to access healthcare. These results are consistent with Suda’s (1996) findings that “the time devoted to
housework, food production, and childcare determine the time available to seek healthcare or engage in paid work outside the domestic domain.”

Participants’ access to and control over the means of provisioning and survival, and their access to healthcare were different and unequal based on class configurations. For women who were reliant on relations of distribution within marriage, their situation was often risky and financially disastrous; they had little power and control or access to resources and means of provisioning. Women who were head of households also had limited access to resources and means of provisioning. Suda (1996, p. 89) notes, “Kenyan women live and work under different environments in a gender and class-structured society in which the entire equation is a factor in the distribution of resources.” The study findings converge with previous research (Clark, 1984) that found Kenyan women who head households generally lack formal education, and have limited access to employment, social services, and production resources. Clark (1984, p. 348) notes that to improve their situation women depended on social support networks and multiple sources of income. Clark (1984) states that social support networks, which included kin and neighbours, provided cash, goods, and services to help these women meet their needs. Women who headed households often relied on mother-daughter cooperation, and residential proximity of sisters (Clark, 1984, p. 348). Women who headed households, particularly in urban areas, diversified their source of income by relying on income transfers from adult kin and or becoming self-employed in the informal sector. Self-employment for this group of women often entailed selling sexual favours, selling food, and doing laundry (Clark, 1984, p. 350).

The findings of this study also converge with another Kenyan study which found that household wealth is an important factor in the utilization of maternal health facilities, with the least poor being more likely to deliver at a health facility. Clients’ financial capability was found to be a major barrier to the utilization of health services (Fotso & Mukiira, 2012).

A World Bank working paper, “Private Health Sector Assessment in Kenya,” authored by Barnes, O’Hanlon, Feeley, McKeon, Gitonga, & Decker (2010), found that the location of delivery varies by wealth. Public sector deliveries increased with wealth; the richest also had the most private facility–based deliveries. With regard to antenatal care, the majority of the richest
women accessed care at private hospitals and clinics, while the poorest went to public or mission hospitals and many still delivered at home (Barnes et al., 2010).

The results underscore the central importance of economic resources in shaping women’s access to healthcare in this urban setting. Education and employment and income opportunities offer these women economic stability and improve their ability to access healthcare.

10.5 Summary: Social Relations, Social Structure, and Agency

Most women were proactive in the face of great adversity in their efforts to access healthcare and live positively. At turning points in their lives, women devised successful strategies, mobilized support networks, and resisted stigma and discrimination so as to be able to access and adhere to HIV health services. It is through their efforts and turning points in their lives that these women demonstrated their agency, their autonomy, and their decision-making ability to independently access healthcare.

From an institutional perspective, while there are health system constraints, gaps, and deficits, a health delivery system is in place to supply healthcare to pregnant or lactating women living with HIV in this urban setting. However, institutional response indicates that creating awareness and the mobilization of resources did not ensure uptake, utilization of healthcare services.

Social class shaped women’s ability to assume the sick role, how they resisted stigma, the type of social support networks they utilized, their strategies to access healthcare, where and how frequently they accessed healthcare. Gender also influenced women’s access to healthcare. Many women in this study had primary responsibility, including financial responsibility, for their children. Women often prioritized their children’s needs over their own healthcare needs. Conversely, the high cultural value placed on maternity and the social representation of the role of women in children’s survival, upbringing, and education created conditions that favoured women’s access to healthcare.

Stigma worked to prevent some respondents, particularly women from lower social class, from accessing healthcare. But, conversely, it often motivated them to seek healthcare so they could improve their health and “look like other people,” thereby avoiding the stigma. Women of higher
social class were able to successfully minimize the risk of being stigmatized by employing a number of resistance strategies, including accessing healthcare from private physicians and facilities.

Women living with HIV and AIDS suffered stigma and discrimination and were abandoned by intimate partners or faced obstructions in their rights over inheritance after the death of their husbands. Gender equality is an issue addressed in Kenyan statutory law, but traditional customary viewpoint has yet to catch up with statutory laws. While Kenyan women may be aware of their rights, they are prevented from exercising them due to social and economic factors. There is a need for legal assistance programs that eliminate barriers to the legal system. For example, the National Legal Aid and Awareness Program (NALEAP) is overburdened and costly for lower social class women seeking their rights to child support or inheritance. Protecting women’s rights and access to their inheritance can provide economic stability to women living with HIV and AIDS and enhance their ability to access healthcare.

Women’s HIV status, whether they were from higher or lower social class, prevented them from assuming the sick role, which usually served to limit their social obligations. As these respondents were not accorded the benefit of assuming the sick role, they were often willing to access healthcare to ensure that they could continue to perform their social obligations. Fear of “bringing the disease” and of being blamed also discouraged women from assuming the sick role and affected their willingness to access healthcare.

Social support was instrumental in all these respondents’ willingness and ability to access healthcare. Women of higher social class relied primarily on informational support. This support provided them with the information and guidance required to access healthcare. Women of lower social class relied on consensus information, informational support, material support, and motivational support from their social networks. Social support helped them deal with their perception of the severity of their illness and assisted them with financial, household, and caring responsibilities. Social support also played an important role by providing motivational support, which made respondents believe that things would get better. Social support facilitated their help seeking, including their access to healthcare. It is important to understand the social support networks, particularly those successfully employed by lower social class women, so that any
programs and policies developed can be complementary and “take into account specific local needs” (Clark, 1984, p. 354).

The data suggest that social relations, such as stigma, sick role, and social support, influenced respondents’ ability and willingness to access healthcare. Other social relations, macro-level social factors such as class and gender, also influenced women’s access to healthcare. Social structures shape women’s agency in this urban setting.
Chapter 11
A Contextual View in an African Setting

11.1 Women as Diverse Actors on the Healthcare Landscape

Crucial to understanding these Kenyan women’s experiences in this urban setting is an awareness of the array of oppressive structures, besides patriarchy, against which they struggled. This study has given an analytic description of patriarchy, social relations, and agency that women engage in. Postcolonial feminist theory provided a way to articulate what I heard and saw during fieldwork. Taken together the stories of the women interviewed indicate that they are actors pursuing creative and effective strategies to seek health care and manage their lives.

Women in this study were situated differently within social structures and, as such, their responses to patriarchy and other forms of oppression were as varied as their experiences. Some women suffered more from patriarchal oppression than others, and faced other forms of oppression such as class and stigma. This finding confirms that patriarchy alone did not impede their access to healthcare.

It appeared that for some women in this study, the conjugal relationship was not the central one, and they were often not psychologically or economically dependent on their intimate partners as Western feminism suggests. These women were active in both production and reproduction, which were interwoven into their lives. Their goals were to establish their own economic and social position, and to protect themselves against material and status vulnerability from divorce, widowhood, or singlehood. The women in this study employed different strategies to meet their healthcare needs in the context of the diverse circumstances of their lives.

While women in this study appeared duty-bound, traditional, and self-sacrificing, they were not submissive. These women were not a homogenous sociological group characterized by common dependencies or powerlessness. They resisted oppression by seeking to understand their disease and illness, living positively, and becoming role models.
Respondents were active agents who pursued various strategies to access healthcare. The intersection of gender and class served as an oppressive social structure that limited lower social class respondents’ access to maternal healthcare and to HIV treatment and care. Stigma, the sick role, and social support were other social factors that influenced respondents’ ability and willingness to access HIV treatment and care.

A postcolonial feminist perspective provided valuable insights into women’s agency and the social structures that influenced their freedom and social possibility to access healthcare. The study respondents were actors pursuing creative and effective strategies which challenged gender and class structures that intersected to produce advantages and disadvantages.

The narratives of the women in this study revealed a rich contextual framework of tradition and oppressive social structures. In many instances, the women had a shared historical landscape; they came from a shared culture and adhered to traditional values. However, they were not powerless. They found ways to work within these shared structures. They had agency and aspirations, but lived within socially oppressive, historical structures.

The women did not want to avoid dealing with HIV and AIDS, and they did not want to unburden themselves by neglecting their responsibilities. Instead, women in the study wanted to live positively, be good mothers, and serve as role models. They continued to work, performed their duties, and pursued their responsibilities, such as caring for their children, household, and intimate partner. The women were self-sacrificing; their concern for self was redirected towards their responsibilities for raising their children. Often this sense of responsibility motivated them to access healthcare, which was evident from their mention of wanting to live longer so that they could look after their children and provide them with a future.

11.2 Implications for Kenyan Health Policy and Practice

This study has identified factors that limit access to healthcare, and supports the claim that improving the health of mothers is not making the progress it should in Kenya because of issues such as poverty and HIV and AIDS. The restrictions lower social class respondents’ experienced in terms of maternal healthcare and HIV treatment and care have implications for both maternal and child health. There is increased risk of maternal and infant mortality for lower social class
women who deliver at home and cannot access healthcare because of their financial constraints. There is also increased risk of mother-to-child transmission of HIV and AIDS. Ways to reduce differential access to healthcare based on class are needed. The knowledge this study produced can be useful for addressing the inequities in access to healthcare within Kenya and for reducing maternal mortality. Results from this current study also have implications for health policy and practice in Kenya.

As the institutional actors’ data suggest the focus of healthcare interventions for pregnant women living with HIV is on increasing demand for access to antenatal care and delivery at a health facility. This focus is primarily to eliminate mother to child transmission of HIV and ensure an HIV free generation. As a result other areas of women’s health such as postnatal care is neglected. It is recommended that in addition to antenatal care postnatal care should also be prioritized. A more woman centred approach to reproductive and HIV treatment and care and access to healthcare is required.

Other specific recommendations include the provision of sustainable social support services that include material support to improve women’s access to healthcare. Waiving hospital fees for delivery and introducing paid maternity leave for lower social class women may have implications for their access to health services. Waiving or eliminating user fees may influence the social possibility and individual ability to access health services such as delivery at a health facility. Also as this current study has shown, despite the physical demands on their bodies, low income women continued to work at mainly manual labour jobs to support their families. Paid maternity leave for low income women living with HIV will allow them to temporarily relinquish their work obligations. This could provide these women with the opportunity to assume the sick role to deal with their emotional vulnerability which has implications for rational judgment and action in accessing healthcare. Private counseling space is also recommended to minimize stigma, ensure privacy and confidentiality. The experiences of lower social class women suggest private counselling space and innovations are appropriate immediate approaches to help women adhere to HIV treatment. These recommendations may be aspirational due to the economic constraints in this low-income setting.
Alternatively, addressing gender inequities can be enforced and is more likely to have an impact. Therefore, it is recommended that gender inequities specifically marriage, inheritance, and land-ownership rights be addressed to ensure women’s access to resources. Also recommended is the need for greater engagement with inter-sectoral stakeholders on the need for girls and women’s education and economic opportunity and jobs. Improved women’s rights, education, economic, and employment opportunities will ensure greater access to healthcare.

Kenya’s health policy focuses primarily on ensuring the availability of services and on recommending that pregnant women living with HIV access these services. Attempts to achieve equity, equality, and universal access to antenatal care and facility-based deliveries, policy and practice have, in fact, homogenized women. The challenge is the operationalization of HIV and sexual and reproductive health policies to address the inequities in access to healthcare. As noted previously (page 22) the global challenge is how to implement policy and health system support practices within local contexts in populations that are fundamentally heterogeneous.

Policies need to include strategies to ensure confidentiality of women’s HIV status while helping them achieve timely adoption and adherence to HIV treatment, until they are ready to make disclosures. Policies need to address the intersection of gender and class, oppressive social structures that restrict some respondents’ access to healthcare. Policies should also address social factors such as stigma, which may prevent respondents’ access to HIV treatment and care. Policy makers should consider the added stress and fear that women living with HIV and AIDS, especially lower income women, experience because they are not afforded the benefit of assuming the sick role, which would allow them to limit their social obligations to deal with their illness.

There is a need for policy and practice to consider women’s agency and the role of micro and macro social relations in shaping their access to healthcare. New policies to help empower women in some of these relations could go a long way towards improving their ability to access healthcare and to increase health service demand, because much drive and effort to improve women’s lives and access to healthcare is already present.
11.3 Limitations of the Study

One of the limitations of this study is that I did not consider ethnicity issues (there are 42 ethnic/linguistic groups in Kenya), and may have attributed differences in the ability to access healthcare to issues like class or stigma when they could have been influenced by ethnicity.

The experiences of these respondents cannot be generalized to other women living with HIV and AIDS in Kenya or elsewhere. Rather, their stories are offered as “exemplars to illuminate the agency that even seemingly powerless women exhibit through various strategies of resistance against both HIV- and AIDS-related stigma and patriarchy” (de Souza, 2010, p. 251). Although much of the findings of this study are not new, they empirically inform and extend the literature in relation to gender-based struggles and the social relations that women living with HIV, who were pregnant or had young children, contend with in their day-to-day practices and efforts to access healthcare. Although the narratives of these twenty-three women were consistent in identifying patterns related to access to healthcare efforts, these narratives cannot be taken to represent the experiences of all Kenyan women living with HIV.

11.4 Contribution to Scholarly Research

Using women’s narratives of lived experience, mapping the health sector and interviewing with mutlistakeholders such as health professional to contextualize, capture and theorize access to healthcare by pregnant and lactating women living with HIV and AIDS in Kenya was important to provide the basis for planning and implementing equitable care at local and national levels.

Much of the research that examines women’s health through a postcolonial feminist lens focuses on immigrant women’s health in a Western setting (Anderson et al., 2011). This present study expands the use of postcolonial feminism to examine Kenyan women’s experiences, their stories, to provide a more nuanced and contextual view of their healthcare access in an African setting. The contextual understanding this study provide illuminates the “complexity of the intersectionalities of respondents’ poverty and suffering, and their inability to access appropriate healthcare (Anderson et al., 2009, p. 289).

This study listened to voices that have been silenced and homogenized, and therefore contributes to the research on maternal health in countries with high maternal mortality. The study confirms
that patriarchy alone does not adequately describe the obstacles facing African women in their efforts to access healthcare. Postcolonial feminism and the range of qualitative methods used sheds light on the diversity of respondents’ lives and discounts the universalizing tendencies and it disrupts the essentializing ideologies about African women in this empirical case, Kenyan women. A postcolonial feminist perspective has proven to be an effective tool that enabled this study to unmask the circumstances and conditions that affected women’s access to healthcare. This perspective was inclusive of the voices that interrupted the taken for granted structures, such as gender, class, and stigma, inscribed on these women through relations of power.

As previously mentioned this study may be the first to employ a theoretical perspective that considers the intersection of a number of social factors and its impact on women’s access to healthcare in Kenya. The contextual knowledge generated in this present study may prove useful to health professionals providing care to pregnant or lactating women living with HIV. The various strategies to access healthcare may also prove useful to women in different geographic spaces who are living in similar contexts to those of the women who participated in this study.

11.5 Implications for Research

Based on the data and the findings presented in this study there are implications for future research. The following are studies that need to be done to address the issues highlighted and move the field forward:

1. Comparative studies in other LMIC and in the diaspora can empirically inform and extend the literature. Canadian immigration criteria focus on recruiting economic class immigrants which suggest that many Kenyan immigrants may belong to the professional or business class. Exploration of gender-based struggles and the social relations that immigrant Kenyan women living with HIV, who are pregnant or have young children, contend with in their day-to-day practices and efforts to access healthcare in a Canadian setting can provide significant insight into issues of agency and powerless as well as insight into strategies of resistance against both HIV- and AIDS-related stigma and patriarchy and how access might differ for these women who may belong to a professional or business class in a high income country with universal access to health services.
2. Health providers counsel women living with HIV seeking antenatal care and HIV treatment to bring their male partners to their healthcare visits and to receive HIV testing and counseling together. This is to facilitate disclosure and to prevent HIV transmission within discordant couples, and to provide social support. In this current study while limited there was some partner involvement in women’s healthcare visits. Male involvement in positive women’s healthcare access and utilization need to be explored.

3. Kenya’s constitution address gender inequities with regards to improving marriage, inheritance, and land-ownership rights for women. However, as this current study has shown many women do not have access to a high level of education or permanent employment opportunities and their marital or inheritance rights are not respected. Addressing the issues of gender inequity by improving marriage, inheritance, and land-ownership rights can be enforced and is likely to have an impact. Engaging with women living with HIV and other key community stakeholders to conduct community based participatory research is crucial to finding pathways to achieve gender equity and improve women’s access to healthcare and other resources.

Research findings from these suggested studies would further contribute to improving the social possibility and the individual ability to access healthcare by women living with HIV.
References


Navarro, V. (2007). Neoliberalism as a class ideology: Or, the political causes of the growth of inequalities. In V. Navarro (Ed.), Neoliberalism, globalization and inequalities:


Appendix A: Focus Group Guide

**Project Title:** How do HIV-infected pregnant and lactating women describe their experiences in accessing comprehensive healthcare in an urban setting in Kenya?

**Project Dates:** March 1, 2011 – June 30, 2010

**Method:** Focus group discussion

**Topic:** Access to healthcare

**Target Audience:** Women receiving antenatal/perinatal services at the Provincial Government Hospital (PGH)

**Investigator(s):** Allison Gayapersad, PhD candidate, University of Toronto

**Instrument Title:** Focus Group Guide

**Total Participant time required:** 1.5 – 2 hours

The overall objective of the proposed study is to assess and identify supports and barriers to access to comprehensive healthcare by HIV-infected pregnant and lactating women in an urban setting in Kenya.

---

I. Introduction (10 m)

I would like to welcome and thank you for your participation in this study. I am XXX and as an interpreter I will be conducting the focus group on behalf of the principal investigator of this study Allison Gayapersad – a PhD student from the University of Toronto, Canada.

This study is about HIV-infected pregnant and lactating women’s access to comprehensive healthcare. The purpose of this study is to describe the economic and social structures that influence your access to comprehensive healthcare. This study will require your participation for 1.5 – 2 hours. You have been asked to participate because you are an HIV-infected pregnant or lactating woman receiving antenatal/perinatal services from the Rift Valley Provincial Government Hospital.

We are conducting the focus group to gain knowledge about your experience accessing comprehensive healthcare here at PGH. I will provide a brief summary of the study protocol shortly and then I will ask you a number of questions. The focus group should take 2 – 3 hours of your time. We value your opinions – you are the experts and we are here to learn from you.

With your permission we will record your responses. It would be greatly appreciated if everyone could contribute to the discussion, speaking one at a time. If we are running out of time I might interrupt you to move to another question to ensure that all topics can be covered.

All information obtained from this focus group will remain confidential. The information discussed is going to be analyzed as a whole and your names will not be used in any analysis of the discussion.
**Discussion Guidelines:**

We would like the discussion to be informal, so there’s no need to wait for us to call on you to respond. In fact, we encourage you to respond directly to the comments other people make. If you don’t understand a question, please let us know. We are here to ask questions, listen and make sure everyone has a chance to share.

If we seem to be stuck on a topic, we may interrupt you and if you aren’t saying much, we may call on you directly. If we do this, please don’t feel bad about it; it’s just our way of making sure we obtain everyone’s perspective and everyone’s opinion is included.

We do ask that we all keep each other’s identities, participation and remarks private. We hope you’ll feel free to speak openly and honestly.

As discussed, we will be tape recording the discussion, because we don’t want to miss any of your comments. No one outside of this room will have access to these tapes. Your personal information and data collected will be stored for 5 years after the completion of the study. After this time your data will be destroyed.

Let’s begin. Let’s find out some more about each other by going around the room one at a time. Tell us your first name and a bit about yourself. I’ll start.

II. Focus group questions (90 – 120 minutes)

This group is convened to assess and identify supports and barriers to comprehensive healthcare by HIV-infected pregnant and lactating women in an urban setting in Kenya. This will help us understand the challenges women face accessing healthcare and provide insights on strategies to improve services.

Let’s get started!

1. Please describe your experiences of accessing healthcare at the PGH.
2. Please describe what you consider comprehensive healthcare?
3. What do women need in terms of healthcare?
   - Resources needed
   - Do you have these resources?
4. What do you perceive are the barriers/supports to accessing healthcare at PGH?
5. What do you perceive are the barriers/supports to accessing healthcare by women in the community?

Closing (10 m)

Thank you for your participation. This has been an excellent discussion and the information you have provided is extremely helpful.
Appendix B: Interview Guide – Healthcare Worker

**Project Title:** How do HIV-infected pregnant and lactating women describe their experiences in accessing comprehensive healthcare in an urban setting in Kenya?

**Project Dates:** March 1, 2011 – June 30, 2010

**Method:** Interview

**Topic:** Access to healthcare

**Target Audience:** Healthcare professionals working with HIV-infected pregnant and lactating women receiving antenatal/perinatal services at the Provincial Government Hospital (PGH)

**Investigator(s):** Allison Gayapersad, PhD candidate, University of Toronto

**Instrument Title:** Interview

**Total Participant time required:** 1.5 – 2 hours

The overall objective of the proposed study is to assess and identify supports and barriers to access to comprehensive healthcare by HIV-infected pregnant and lactating women in an urban setting in Kenya.

---

I. Introduction (10 m)

I would like to thank you for your participation in this study. I am Allison Gayapersad – a PhD student from the University of Toronto, Canada.

This study is about HIV-infected pregnant and lactating women’s access to comprehensive healthcare. The purpose of the study is to describe the economic and social structures that influence HIV-infected pregnant and lactating women’s access to comprehensive healthcare. I have asked you to participate because you work primarily with HIV-infected pregnant or lactating woman receiving antenatal/perinatal services from the Rift Valley Provincial Government Hospital.

I will ask you a number of questions and the interview should take 1.5 – 2 hours of your time. If you need a question clarified please feel free to ask and I will be happy to do so.

You are the expert and I am here to learn from you. Your input will be extremely valuable.

All information obtained from this interview will remain confidential. The information discussed is going to be analyzed as a whole and your name will not be used in any analysis of the discussion. Your personal information and data collected will be stored for 5 years after the completion of the study. After this time your data will be destroyed.

With your permission I will record your responses.

Do you have any questions before we get started?
II. Interview questions (90 – 120 minutes)

Let's get started!

1. What are the policies and supports at the PGH for the provision of antenatal/perinatal services to HIV-infected pregnant and lactating women?
2. Please describe what you consider comprehensive healthcare?
3. What do women need in terms of healthcare?
   • Resources needed
   • Does PGH have these resources?
4. What do you perceive are the barriers/supports to HIV-infected pregnant and lactating women accessing healthcare at PGH?
5. What do you perceive are the barriers/supports to accessing healthcare by women in the community?

Closing (10 m)

Thank you for your participation. The information you have provided is extremely helpful.
Appendix C: Narrative Interview Guide

Project Title: How do HIV-infected pregnant and lactating women describe their experiences in accessing comprehensive healthcare in an urban setting in Kenya?

Project Dates: March 1, 2011 – June 30, 2010

Method: In-depth interview

Topic: Access to healthcare

Target Audience: HIV-infected pregnant or lactating woman (1) receiving antenatal/perinatal services from the Rift Valley Provincial Government Hospital, (2) who have given birth or plan to give birth at home, and (3) who seek and receive services from a private healthcare professional/facility.

Investigator(s): Allison Gayapersad, PhD candidate

Instrument Title: Interview

Total Participant time required: 3 – 4 hours

The overall objective of the proposed study is to assess and identify supports and barriers to EBF to 6 months in Kenya.

I. Introduction (10 m)

I would like to welcome and thank you for your participation in this study. I am XXX and as an interpreter I will be conducting this interview on behalf of the principal investigator of this study Allison Gayapersad – a PhD student from the University of Toronto, Canada.

This study is about HIV-infected pregnant and lactating women’s access to comprehensive healthcare. The purpose of the study is to describe the economic and social structures that influence your access to comprehensive healthcare. You have been asked to participate because you are an HIV-infected pregnant or lactating woman (1) receiving antenatal/perinatal services from the Rift Valley Provincial Government Hospital, (2) who have given birth or plan to give birth at home, and (3) who seek and receive services from a private healthcare professional/facility.

I will provide a brief summary of the study protocol shortly and then I will ask you a number of questions. The interview should take 2 – 3 hours of your time. We value your opinions – you are the expert and we are here to learn from you.

All information obtained from this interview will remain confidential. The information discussed is going to be analyzed as a whole and your name will not be used in any analysis of the discussion.

With your permission I will record your responses.

Do you have any questions before we get started?
II. Interview questions (120 – 180 mins)

Let’s get started!

1. Do you have a child less than 6 months of age?
2. Are you currently pregnant?
3. What is your age?
4. How many years of schooling have you had?
5. What level of education did you complete?
6. Do you contribute to the household income?
7. How much do you contribute?
8. What do you do to contribute money to the household?
9. What is the total household income?
10. Which Estate do you reside in?
11. Is this your first pregnancy or first baby?
12. Describe your current childcare arrangements.
13. Do you share in the decision-making of the use of contraceptives in your relationship?
14. Did you and your partner plan this pregnancy together?
15. Do you feel that you share in the decision-making of family planning in your relationship?
16. Describe what you perceive is comprehensive healthcare for a HIV-infected pregnant or lactating woman (probe if she is getting proper nutrition/balanced diet, help with household responsibility, HIV counselling, IYCF counselling).
17. Describe your experience accessing comprehensive healthcare as an HIV-infected pregnant or lactating women (probe as to who decides when/how she accesses healthcare services).
18. Describe your experience accessing comprehensive healthcare for your baby (if applicable).
19. Have you had your baby tested for HIV at the recommended 6 weeks after birth (if applicable)?
20. What do you perceive are the supports and barriers to comprehensive healthcare at PGH (if applicable)?
21. What do you perceive are the supports and barriers to comprehensive healthcare in community?
22. Who is the primary caregiver in your household?
23. Do you get emotional support from your partner?
24. Do you get help with household responsibilities/managing household?
25. How has this impacted your health?

Closing (10 m)

Thank you for your participation. The information you have provided is extremely helpful.
How do HIV-infected pregnant and lactating women describe their experiences in accessing comprehensive healthcare in an urban setting in Kenya?

Gender is seen as a significant indicator of inequality and disadvantage in relation to healthcare in most developing country context. According to the World Health Organization (WHO) women in developing countries are 300 times more likely to die than those in the industrialized world. Most maternal deaths occur in developing nations.

The goal of this study is to contribute to the development of effective strategies to reduce maternal and infant morbidity and mortality related to access to comprehensive healthcare. The specific objectives of the proposed study are:

1. To document Kenya’s health programs, services, and policies pertaining to access to healthcare by HIV-infected women.
2. To assess and identify the supports and barriers to accessing comprehensive healthcare by HIV-infected pregnant and lactating women at the Rift Valley Provincial General Hospital.
3. To describe HIV-infected pregnant and lactating women’s experience accessing comprehensive healthcare.

The benefits of this research are important in the long term. Aggregate results of the study will be communicated at regularly scheduled community meetings and feedback sessions. Findings have the potential to benefit HIV-infected women’s access to comprehensive healthcare by providing locally specific information that will inform interventions to provide improved access to healthcare. When the study is complete, as a part of local dissemination process, I will provide the hospital administration with a summary of the final report of study findings.

Your confidentiality will be protected. Only I, my supervisors and project employees (research assistants) will have access to data. Research files will be kept in a securely locked room and password-protected in a computer. I intend to write one or more reports on the research. I will not include any information that might identify participants in any report that I will make public.

Your participation is completely voluntary and you may withdraw at any time. You do not have to answer all the researchers’ questions and can refuse to answer any questions. Withdrawal from the study will not have any consequences.

If you have questions or concerns about the study, you contact me by: Telephone: 0714922184 or you may contact Prof. Elizabeth Kamau-Mbuthia, Egerton University, Department of Human Nutrition, P.O. box 536, Egerton; Email address: ekambu@yahoo.com; Telephone number: 0722395634. For any questions pertaining to your rights as a research participant, you may contact: The Secretary, KEMRI Ethics Review Committee, P. O. Box 54840-00200, Nairobi; Telephone numbers: 020-2722541, 0722205901, 0733400003; Email address: ERC@kemri.org.
Dear Focus Group Participant:

My name is _______________ and my colleague’s name is _______________. We work with Egerton University and the University of Toronto in Canada and we are asking you to join a research project.

We will now tell you about this project and ask your permission to include you. You should ask us any questions you have. You can ask us now or at any time. Your agreement to participate would be greatly appreciated.

I have designed this project and it is being conducted solely for educational purposes. The study has been funded by the Canadian Institutes of Health Research (CIHR). The purpose of the study is to understand your experiences accessing comprehensive healthcare in this urban setting.

Not everybody is eligible for this project. Let us tell you what is required to begin to participate:

1. You are pregnant or have a child less than 6 months in age.
2. You are enrolled for antenatal/perinatal services or participating in the mothers’ support group at the PGH, Nakuru.
3. Of consenting age (17 years in Kenya).

To know if you are eligible, please tell us if any of these statements are not true:

I understand the eligibility requirements and confirm that I am eligible because I have answered yes to each question on this page ______________

[If any answer is no → Thank you for your willingness to talk with us today. We wish you and your family very good health]

Thank you for confirming that you do meet the requirements to participate in the research project. Now we will explain what will happen if you decide to participate. This study will require your participation for 1.5 – 2 hours of your time.

For the Focus group discussion I will ask you:

- What is comprehensive healthcare?
- Your experience accessing comprehensive healthcare at PGH
- What supports and prevents access to comprehensive healthcare at PGH

Instead of your name and address, we will use a code in all our records so no one will be able to identify you. The information from all the people in the study will be kept together but without names in a locked file and on a computer with a secure password. Only I, my supervisors and project employees (research assistants) will have access to data.

Please be aware due to the nature of this group discussion your HIV status will be disclosed to other group participants. All information during our focus group discussions will be kept confidential. All of our team will be trained on the importance of privacy and they must protect your privacy as part of their job. This study poses a low risk of harm to you (and your baby). Although we do not intend this, some questions we may ask may make you uncomfortable or upset. If this happens you can refuse to
answer any question or withdraw from the FGD. If for any reason your participation in this study results in emotional distress you will be referred to the team counsellor (TBA).

Any participation in this project is completely voluntary. You may refuse to participate now or leave the study at any time later. You do not have to answer any of the questions asked of you during the interviews. You may skip any question that you do not want to answer.

If you decide to not participate in the study, or you decide to withdraw from the study, it will not result in any penalty or loss of benefits to which you are otherwise entitled. We will keep without your name any data already collected and include it in our report as if you had remained in the study. Should you remain in the study your personal information and data collected will be stored for 5 years after the completion of the study. After this time your data will be destroyed.

No one will be paid in the study but you will be reimbursed for transportation cost and you will be provided with milk and a snack during the FGD. When the study is complete I will provide you with a summary of my results by conducting information sessions at an appropriate community centre location. You may or may not benefit from this.

You have a right to receive all the information on this form and to ask any questions about the research project. You have a right to take a signed copy of this form if you wish.

By signing this consent form you are agreeing to participate in the study and acknowledging that I have explained the nature of the study to you and that I have addressed your questions and concerns regarding the study.

If you have questions or concerns about the study, you contact me by: Telephone: 0714922184 or you may contact Prof. Elizabeth Kamau-Mbuthia, Egerton University, Department of Human Nutrition, P.O. box 536, Egerton; Email address: ekambu@yahoo.com; Telephone number: 0722395634. For any questions pertaining to your rights as a research participant, you may contact: The Secretary, KEMRI Ethics Review Committee, P. O. Box 54840-00200, Nairobi; Telephone numbers: 020-2722541, 0722205901, 0733400003; Email address: ERC@kemri.org.

Participant’s Signature __________________________ Date __________________________
I have been told about this research study. I understand why the research is being done. I know that I might experience some benefits, but I might not. I might also experience some risks, and discomforts, but I might not. I want to be in this research as a subject. I know that I am free to change my mind and quit this research at any time. If I do decide to quit, I will not be punished. I will not lose any of my benefits.

Research assistant’s signature
(on behalf of participant unable to read or sign consent form)
Dear Interview (Phase II – narrative) Participant:

My name is _______________ and my colleague’s name is _______________. We work with Egerton University and the University of Toronto in Canada and we are asking you to join a research project. We will now tell you about this project and ask your permission to include you. You should ask us any questions you have. You can ask us now or at any time. Your agreement to participate would be greatly appreciated.

I have designed this project and it is being conducted solely for educational purposes. The study has been funded by the Canadian Institutes of Health Research (CIHR). The purpose of the study is to understand your experiences accessing comprehensive healthcare in this urban setting.

Not everybody is eligible for this project. Let us tell you what is required to begin to participate:

1. Pregnant or have a child less than 6 months in age.
2. Enrolled for antenatal/perinatal services at PGH, given birth or plan to give birth at home or, seek and receive antenatal/perinatal services at a private healthcare professional/facility.
3. Of consenting age (17 years in Kenya).

To know if you are eligible, please tell us if any of these statements are not true:

I understand the eligibility requirements and confirm that I am eligible because I have answered yes to each question on this page ______________

[If any answer is no → Thank you for your willingness to talk with us today. We wish you and your family very good health]

Thank you for confirming that you do meet the requirements to participate in the research project.

Now we will explain what will happen if you decide to participate. This study will require your participation for 3 to 4 hours of your time. This interview will ask you to describe in detail your experience accessing comprehensive healthcare in this urban setting.

Instead of your name and address, we will use a code in all our records so no one will be able to identify you. The information from all the people in the study will be kept together but without names in a locked file and on a computer with a secure password. Only I, my supervisors and project employees (research assistants) will have access to data.

All information during our interview will be kept confidential. All of our team will be trained on the importance of privacy and they must protect your privacy as part of their job. This study poses a low risk of harm to you (and your baby). Although we do not intend this, some questions we may ask may make you uncomfortable or upset. If this happens you can refuse to answer any question or withdraw from the study. If for any reason your participation in this study results in emotional distress you will be referred to the team counsellor (TBA).
Any participation in this project is completely voluntary. You may refuse to participate now or leave the study at any time later. You do not have to answer any of the questions asked of you during the interviews. You may skip any question that you do not want to answer.

If you decide to not participate in the study, or you decide to withdraw from the study, it will not result in any penalty or loss of benefits to which you are otherwise entitled. We will keep without your name any data already collected and include it in our report as if you had remained in the study. Should you remain in the study your personal information and data collected will be stored for 5 years after the completion of the study. After this time your data will be destroyed.

No one will be paid in the study but you will be reimbursed for transportation cost and you will be provided with milk and a snack during our interview. When the study is complete I will provide you with a summary of my results by conducting information sessions at an appropriate community centre location. You may or may not benefit from this.

You have a right to receive all the information on this form and to ask any questions about the research project. You have a right to take a signed copy of this form if you wish.

By signing this consent form you are agreeing to participate in the study and acknowledging that I have explained the nature of the study to you and that I have addressed your questions and concerns regarding the study.

If you have questions or concerns about the study, you contact me by: Telephone: 0714922184 or you may contact Prof. Elizabeth Kamau-Mbuthia, Egerton University, Department of Human Nutrition, P.O. box 536, Egerton; Email address: ekambu@yahoo.com; Telephone number: 0722395634. For any questions pertaining to your rights as a research participant, you may contact: The Secretary, KEMRI Ethics Review Committee, P. O. Box 54840-00200, Nairobi; Telephone numbers: 020-2722541, 0722205901, 0733400003; Email address: ERC@kemri.org.

___________________________
Participant’s Signature 
Date

I have been told about this research study. I understand why the research is being done. I know that I might experience some benefits, but I might not. I might also experience some risks, and discomforts, but I might not. I want to be in this research as a subject. I know that I am free to change my mind and quit this research at any time. If I do decide to quit, I will not be punished. I will not lose any of my benefits.

_________________________
Research assistant’s signature
(on behalf of participant unable to read or sign consent form)
Ni vipi wamama waja wazito na wanaonyeshwa wajia wazito na病毒 vya ukimwi wanasema kuhusu mambo wanayokumbana nayo katika hali ya kutafuta huduma ya afya ya wajoathiriwa na ukimwi mjini Nakuru, Kenya?

Jinsia inaonekana kama kiashiria kikuu cha kutokona na usawa kulingana na huduma za afya katika hali ya nchi maskini. Kulingana na World Health Organization (WHO) wanawake katika nchi maskini wana uwezekano zaidi mara mia tatu kufa kuliko wale ambao wakabinao. Vifo vingi vya akina mama vinatokea kwa nchi maskini. Nia kuu ya huu utafiti ni kuchangia kutengenezwa njia tabithi za kupunguza magonjwa na vifo vya akina mama na watoto vinavyohusika na kupata huduma ya afya. Sababu halisi za huu utafiti unaopendekeza ni:

1. Kunakili miradi ya afya, huduma na sheria za Kenya zinazoambatana na kupata hudumu ya afya kwa wamama wajia wazito na virusi vya ukimwi.
2. Kupima na kutambulisha usaidizi na vizungumkuti kwa kufikia huduma za afya kwa wamama waja wazito na wanaonyeshwa virusi vya ukimwi katika Rift Valley General Hospital.

Usiri wako utalindwa. Mimi pekee, wakubwa na wafanyi kazi wa huu utafiti ndio wanaweza kufikia majibu. Files za huu utafiti zitaweka kwa chumba ambacho kinafungwa na kwa computer iliyo na password. Sitaweka ujumbe wowote ambao utaweza kutambulisha mhusika yoyote wa huu utafiti kwa ripoti yoyote ambayo nitaitangaza.

Kuhusika kwako ni wa hiari ka bisa na unaweza toa muda wowote. Si lazima hujibu maswali yote na unaweza kukataa kujibu swali lolote. Kutoka kwa utafiti hautakuwa na kuadhibiwa.

Kama una maswali kuhusu huu utafiti, wasiliana nami kwa nambari ya simu: 0714922184 ama unaweza wasiliana na Prof. Elizabeth Kamau-Mbuthia, Egerton University, Department of Human Nutrition, P.O. box 536, Egerton; Email address: ekambu@yahoo.com; Nambari ya Simu: 0722395634. Kwa maswali yoyote kuhusu haki zako kama mhusika wa utafiti unaweza wasiliana na: The Secretary, KEMRI Ethics Review Committee, P. O. Box 54840-00200, Nairobi; Telephone numbers: 020-2722541, 0722205901, 0733400003; Email address: ERC@kemri.org
Mpendwa mshiriki wa kikundi cha mawasiliano:

Jina langu ni ______________ na mwenzangu ni ______________. Tunafanya kazi na chuo kikuu cha Egerton na chuo kikuu cha Toronto, Canada na tunakuuliza ujiunge na utafiti.

Sasa tutakueleza kuhusu huu utafiti na kukuuliza ruhusa ya kukuingiza. Tuulize maswali ulionayo. Unaweza kukuuliza saa hii au wakati wowote. Tunashukuru kukuuliza kwako kuhusika.

Nimeunda huu utafiti na unaendeshwa kwasababu ya masomo pekee. Utafiti huu umegaramiwa na Canadian Institutes of Health Research (CIHR). Sababu ya huu utafiti ni kuweza kuelewa mnayokumbana nayo katika kufikia huduma maalum za afya mjini Nakuru.

Si watu wote wanahitimu kuingia huu utafiti. Tutakueleza wanayohitajika kuanza kusajiliwa:

1. Una mimba au mtoto chini ya miezi 6 ya umri.
2. Umeandikishwa kwa huduma za wanawake mnyorogopa au unashiriki kwa kikundi cha wamama cha PGH, Nakuru.

Kujua kama unahitimu, tafadhali tuambie kama mojawapo ya hizi hoja si ukweli:

Naelewa mahitaji ya kusajiliwa na kuhakikisha kwamba nimejibu ndio kwa kila swali katika kusajiliwa ______________

Kama kuna jibu lolote “la”-[Asante kwa hiari yako ya kuongea nasi leo. Tunakutakia wewe na familia yako afya njema]

Asante kwa kuhakikisha unahitimu kusajiliwa kusajiliwa kwa utafiti. Sasa tutakuelleza kitakachofanyika ukiamua kushiriki. Utafiti huu utahitaji ushirikisho wako kwa masaa 1.5-2.

Kwa Kikundi cha majadiliano nitakuuliza:
- Ni nini huduma maalum ya afya ya waliaothiriwa na ukimwi.
- Nieleze makumbano yako kufikia huduma maalum ya afya ya waliaothiriwa na ukimwi katika PGH.
- Ni nini yasaidia na kutosaidia kufikia huduma maalum ya afya ya walioathiriwa na ukimwi katika PGH.

Badala ya jina lako na anuani, tutatumia alama katika rekodi zetu zote ili usiweze kujulikana. Ujumbe wa watu wote wa huu utafiti utawekwa pamoja lakini bila file inayofungiwa na kwa computer iliyo na password. Ni mimi pekee, wakubwa zangu na wafanyi kazi wa utafiti ambao wanaweza kufikia kufikia majibu.

Tafadhali makinika kuwa kwa sababu ya aina ya majadiliano haya ya kikundi, itabidi hali kako ya Virusi vya HIV ijulikane na wahusika wengine wa kikundi chako. Mazungumzo yote wakati wa majadiliano ya kikundi yatawekwa siri. Timu yetu yote itapata mafunzo kuhusu umuhimu wa usiri na ni lazima walinde usiri wako kama utaalamu wa kazi yao. Utafiti huu unakuwa tafadhali kikundisho. Ingawa hatukusudii haya, labda baadhi ya maswali tutakayokuuliza yatakuwa ya aibu kiasi au yakukasirishie. Hili likitendeka waweza kujibu lolote au kufikia majibu swali lolote au kujiondoa kwenye kikundi cha majadiliano. Ikiwa kwa sababu yoyote uhusika wako kwenye utafiti huu utasababisha mfadhaiko wa moyo au hisia, utaelkezwa kwa mshauri wa kikundi (TBA).


Ukiamua kutoshiriki kwenye utafiti au uamue kujiondoo, hautaadhibiwa wala kupoteza fidia yoyote unashostahili kupata. Tutahifadhi bila jina lako ujumbe au habari yoyote itakayokusanywa na kuuuhsisha kwenye ripoti yetu kana kwamba ulibaki kwenye utafiti. Ikiwa utabaki kwenye utafiti, habari zako binafsi au za siri na ujumbe tutakaokusanywa tutahifadhiwa kwa mtafuta miongo (5) baada ya utafiti kukamiliwa. Baada ya muda huu, ujumbe na habari zote zitaharibiwa.

Hakuna atakayelpwa kwenye utafiti huu lakini utafidiwa gharama ya usafiri na sahihi ukipenda. Utafiti utakapokamiliza, nitakupa mukhtasari wa matokeo kwa kuendeshwa vikao vya kukusanya ujumbe mahali panapofaa kwenye eneo hili. Waweza kufaidika na hili au la.

Una haki ya kupokea ujumbe na habari zozote kwenye fomu hii na kuuliza maswali kuhusu mradi huu wa utafiti. Unahaki ya kuchukua nakala ya fomu hii liyotishe sahihi ukipenda.
Kwa kutia sahihi kwenye fomu hii ya idhini, unakubali kushiriki kwenye utafiti na kukubali kuwa nimekuelezea aina ya utafiti na eti kwamba nimeyashugulikia maswali yako yote na hoja za utatanishi zinazohusiana na utafiti huu.

Ukiwa na swali au utatanishi kuhusu utafiti huu, waweza kuwasiliana nami kwa: Nambari ya simu 0714922184 au waweza kuwasiliana na Prof. Elizabeth Kamau – Mbuthia, Chuo Kikuu cha Egerton, Kitengo cha Lishe cha Bin adamu, S.L.P. 536, Egerton; Barua pepe: ekambu@yahoo.com; Nambari ya simu 0722395634.

Kwa maswali yoyote yanayohusiana na haki zako kama mhusika wa utafiti, waweza wasiliana na: Katibu, KEMRI Ethics Review Committee, P. O. Box 54840-00200, Nairobi; Nambari ya Simu: 020-2722541, 0722205901, 0733400003; Barua pepe: ERC@kemri.org.

______________________                                    ______________________
Sahihi ya mhusika.                                          Tarche


_________________________
Sahihi ya mtafiti msaidizi.

(kwa niaba ya mshiriki ikiwa hawezi kusoma au kutia sahihi kwenye fomu ya idhini)
Hujambo mhojiwa (AWAMU YA PILI - Ukariri). Mshiriki

Jina langu ni ________________ naye mwenzangu wa kazi ni __________________ tunafanya kazi na chuo kikuu cha Egerton pamoja na Chuo kikuu cha Toronto kule Kanada nasi twakuomba ujiunge na mradi wetu wa utafiti.

Sasa tutakueleza kuuhusu mradi huu na kuomba idhini yako ili kukujumisha kwenye mradi huu.


Nimeuunda mradi huu nao unaendeshwa kwa lengo na kusudi la elimu tu. Uchunguzi umefadhiliwa na halimashauri ya utafiti wa afya ya Kanada (The Canadian Institutes of Health Research [CIHR]). Kusudi kuu la utafiti huu ni kuelewa unavyofikia na kunufaika na huduma maalum za afya kwa wale waliafundisho na Virusi vya HIV (Comprehensive Healthcare) hapa Nakuru.

Sio kila mtu anahitimu kujumuishwa kwenye mradi huu. Acha tukueleze ni nini kinachohitajika ili kuanza kushiriki:

1. Uwe mja mzito au na mtoto aliye na umri wa chini ya miezi 6.
2. Umeandikishwa kwenye huduma za kabla na wakati wa kujifungu hapa PGH, umeshajifungu au unapanga kujifungu ukiwa nyumbani au kuomba usaidizi wa huduma za kabla/wakati wa kujifungu kutoka kwenye mhudumu/kliniki ya kibinafsi.
3. Mwenye umri wa kuamua (Miaka 17 huku Kenya).

Ili kujua ikiwa unahitimu, tafadhali tueleze ikiwa majowapo wa habari hizi ni sahihi:
Naelewa mahitaji na matawala yao kuhitimu na ninadhibitisha kwamba ninahitimu kwa sababu nimejibudie ndio kwa kilwa wakati wakati wakati wakati wakati wa kujifungua kwamba yote yao unahitimu.

[Kiwani jawabu lolote ni La, Asante kwa kuturuhusu kuzungumza nasi leo. Twakutakia wewe na familia yako afya bora zaidi]
Asante kwa kudhibitisha kwamba unayatosheleza matala yote ili kushiriki kwenye mradi huu wa utafiti. Sasa tutakueleza kitakachofanyika ukubali kushiriki. Uchunguzi huu utajitaji uhiriki wako kwa masaa 3 – 4 ya wakati wako. Kwenye haya mahojiano, tutakuomba uyeleze kwa ukamilifu hali yako ya
jinsi unavyopata huduma maalum za afya kwa walioathiriwa na Virusi vya HIV (Comprehensive Healthcare) kwenye Wilaya ya Nakuru.

Badala ya jina lako na anwani, tutatumia kidokezo kwa nakala setu ili mtu yeyote asiweze kutumia kidokezo kwa nakala zetu ili mtu yeyote asiweze kukutambua.

Habari kutoka kwa wote waliomwambia utafiti huu zina ni jina lako na anwani, tutumia kidokezo kwa nakala zetu ili mtu yeyote asiweze kukutambua.

Habari kutoka kwa wote waliomwambia utafiti huu zina ni jina lako na anwani, tutumia kidokezo kwa nakala zetu ili mtu yeyote asiweze kukutambua.

Habari zote zitakalotokana na majojiano haya zitawekwa kwa siri. Timu yetu yote itapata mafunzo kuhusu umuhimu wa kujisahau kwa usiri wao ili msimamizi wangu na wafanyi kazi (watafiti wasaidizi) ndio watakaweka kufikia habari hizi.

Habari zote zitakalotokana na majojiano haya zitawekwa kwa siri. Timu yetu yote itapata mafunzo kuhusu umuhimu wa kujisahau kwa usiri wao ili msimamizi wangu na wafanyi kazi (watafiti wasaidizi) ndio watakaweka kufikia habari hizi.

Habari zote zitakalotokana na majojiano haya zitawekwa kwa siri. Timu yetu yote itapata mafunzo kuhusu umuhimu wa kujisahau kwa usiri wao ili msimamizi wangu na wafanyi kazi (watafiti wasaidizi) ndio watakaweka kufikia habari hizi.

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Ushiriki wowote kwenye mradi huu ni wa hiari kabisa. Waweza kukataa kushiriki sasa au ujiondoe kwenye utafiti wakati wowote ule baadaye. Sio lazima ujumbe swali lolote utakaloulizwa wakati wa majojiano. Waweza kuruka swali lolote usilotaka kujibu.

Ushiriki wowote kwenye mradi huu ni wa hiari kabisa. Waweza kukataa kushiriki sasa au ujiondoe kwenye utafiti wakati wowote ule baadaye. Sio lazima ujumbe swali lolote utakaloulizwa wakati wa majojiano. Waweza kuruka swali lolote usilotaka kujibu.

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Kwa kutia sahihi kwenye fomu hii ya idhini, unakubali kushiriki kwenye utafiti na kukubali kuwa nimekuelezea aina ya utafiti na eti kwamba nimeyashugulikia maswali yako yote na hoja za utatanishi zinazohusiana na utafiti huu.

Ukiwa na swali au uatataniishi kuhusu utafiti huu, waweza kuwasiliana nami kwa: Nambari y simu 0714922184 au waweza kuwasiliana na Prof. Elizabeth Kamau – Mbuthia, Chuo Kikuu cha Egerton, Kitengo cha Lishe cha Bin adamu, S.L.P. 536, Egerton; Barua pepe: ekambu@yahoo.com; Nambari ya simu 0722395634.

Kwa maswali yoyote yanayohusiana na haki zako kama mhusika wa utafiti, waweza wasiliana na:
Katibu, KEMRI Ethics Review Committee, P. O. Box 54840-00200, Nairobi; Nambari ya Simu: 020-2722541, 0722205901, 0733400003; Bariua pepe: ERC@kemri.org.

______________________                                    ______________________
Sahihi ya mhusika.                                        Tarehe


_________________________
Sahihi ya mtafiti msaidizi.

(kwa niaba ya mshiriki ikiwa hawezi kusoma au kutia sahihi kwenye fomu ya idhini)
Appendix E: Research Assistant Contract Agreement

Dalla Lana School of Public Health

155 College Street • Toronto, Ontario • M5T 3M7 • Canada • Tel: 416-978-8559 • Fax: 416-978-1883

UNIVERSITY OF TORONTO

Allison Gayapersad, PhD Candidate
Dalla Lana School of Public Health
University of Toronto

[Name]
Egerton University
P.O. Box 536 Egerton, Kenya

Re: Research Assistant Contract Agreement

Dear XXX,

Based on your academic qualifications and your familiarity with the study population I am pleased to offer you the position of research assistant for the study titled “How do HIV–infected pregnant and lactating women describe their experiences in accessing comprehensive healthcare in Nakuru, Kenya?” that I am conducting as primary investigator.

For each day of training you will be compensated 600KES and 100KES for transport. For each day of note taking for focus groups or interviews you will be compensated 500KES. For each tape recording translated and transcribed you will be compensated 500KES. You will be compensated 200KES for transport for each day.

Confidentiality of all participants, particularly their HIV status, must be maintained. You are required to keep each participant’s identity, participation and remarks confidential.

You are required to be punctual, participate as a research team member, sharing knowledge, showing initiative and learning potential.

By signing this agreement you are accepting the terms and conditions as outlined above.

Sincerely,

_________________________
Allison Gayapersad
_______________________
Research Assistant