Experiences of Mothers Using the Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent Human Immunodeficiency Virus (HIV) Transmission in Rwanda.

by

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Abstract

The purpose of my study was to explore the experiences of mothers using the PMTCT Program to prevent HIV transmission in Rwanda. Critical ethnography was the research design for my study. The intersectionality framework guided this study. The population of my research study included HIV + women; healthcare providers working in the PMTCT program; policy makers; and PMTCT program leaders. Purposive sampling was used to recruit research participants. Observation, field notes, individual and focus group interviews, and document reviews were used to collect the data. Data analysis included reflexivity, thematic analysis, and the use of ATLAS.ti software to facilitate analysis and organize the data. Ethical approval was sought and received from the University of Alberta Ethics Committee (Pro00096520), and the permission to access and collect the data within Butare University Teaching Hospital (BUTH) was requested and received from the BUTH Ethics Committee (Ref: CHUB/DG/SA/02/0401/2020). Themes that emerged from the findings were: factors that influence and challenge the uptake of the PMTCT program; identities intersecting with the uptake of the PMTCT program; health system factors affecting the delivery of the PMTCT program; and experiences of HIV+ mothers during the prenatal, perinatal, and postnatal periods to prevent HIV transmission. The experiences of mothers using the PMTCT program to prevent MTCT of HIV in Rwanda are fashioned by a complex intersection of gender roles and norms, cultural ideology, power relationships, and a system of domination and oppression; as well as other potentially significant social determinants of health identified in the study findings.

Keywords: Intersectionality, HIV; health system, PMTCT; pregnant women; vertical transmission

Preface

This thesis is an original work by Joyce Kamanzi. This research has received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Experiences of Mothers Using the Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent HIV Transmission in Rwanda“, No. Pro00096520, February 12, 2020.

Dedication

Bless the Lord, O my soul and all that is within me

Oh Lord my God, you are very great: you are clothed with honor and majesty

I will bless the Lord at all times; his praise shall continually be in my mouth

Oh, magnify the Lord with me, and let us exalt his name together

I south the Lord and he heard me and delivered me from all my fears

I will make a joyful shout to the Lord, serve the Lord with gladness

I will come before his presence with singing,

I will enter into his gates with thanksgiving, and into his courts with praise

I will be thankful to him, and bless his name

For the Lord is good, his mercy is everlasting

And his truth endures to all generations

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I would like to share my gratitude to the University of Alberta Faculty of Nursing that provided me various avenues to enhance my learning experience during my doctoral studies, and strengthen my research potential towards a program of research surrounding the "health promotion of the marginalized population, especially women and children affected by HIV and MTCT of HIV".

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Acronyms List

AFASS	Acceptable, Feasible, Affordable, Sustainable, and Safe
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Anti-Retroviral Treatment
ARVs	Anti-Retroviral
AZT	Zidovudine
BUTH	Butare University Teaching Hospital
CD4	Cluster of Differentiation 4
CDC	Centers for Disease Control and Prevention
CHUB	Centre Hospitalier Universitaire de Butare
EBF	Exclusive Breast Feeding
ERF	Exclusive Replacement Feeding
HCPs	Health Care Providers
HIV	Human Immunodeficiency Virus
KFF	Henry J Kaiser Family Foundation
MTCT	Mother-to-child Transmission
NVP	Nevirapine
PCR	Polymerase Chain Reaction
Ph.D.	Doctor of Philosophy
PLWHIV	People Living with HIV
PMTCT	Prevention Mother-to-Child Transmission
PMTCTL	PMTCT Leaders

PMTCTPM	PMTCT Policy Makers
PMWNB	Positive Mother with Negative Babies
PMWPB	Positive Mother with Positive Babies
RWF	Rwandese Franc
SIV	Simian Immunodeficiency Virus
SSA	Sub-Saharan Africa
STIs	Sexual Transmitted Infections
TBAs	Traditional Birth Attendants
TRAC-Plus	Center for Treatment and Research on AIDS Malaria Tuberculosis and Other Epidemics
UN	United Nations
UNAIDS	United Nations Program on HIV/AIDS
VIP	Very Important Person
WHO	World Health Organization

Chapter One: Background

Communities across the globe are significantly affected by Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). In 2021, approximately 38 million people worldwide were living with HIV, and 1.8 million people were newly infected with HIV (United Nations Program on HIV/AIDS [UNAIDS], 2021; KFF [Henry J Kaiser Family Foundation], 2021). HIV/AIDS is one of the leading causes of mortality among women of reproductive age. Globally, an estimated 180, 000 children under 15 years old acquire HIV every day, and more than 90% of those infections are due to MTCT of HIV (UNAIDS, 2020). Furthermore, 90% of MTCT of HIV occur in sub-Saharan Africa (SSA) (UNAIDS, 2020a). In Rwanda, 5300 people of all ages were newly infected in 2019; of these, 2800 were women of reproductive ages, and 500 were children aged less than 15 years (UNAIDS, 2020a).

MTCT, or vertical transmission of HIV, happens when a mother transmits HIV to her baby during pregnancy, labor and delivery, or breastfeeding (through breastmilk). However, the risk of MTCT of HIV is 1% or less if the HIV + woman follows recommended PMTCT strategies such as: HIV testing as early as possible before or during pregnancy; preventing unwanted pregnancies; starting and continuing Anti-Retroviral (ARV) and HIV counseling during pregnancy, labor, and breastfeeding; giving ARV prophylaxis to her infant for four to six weeks after giving birth, and during the breastfeeding period; using safe childbirth practices; practicing appropriate infant feeding; and accessing physical, social, and psychological support (World Health Organization [WHO], 2019; Nachega et al., 2012). When HIV + women decide to breastfeed their infants, the ARV prophylaxis will be given to the infants during the breastfeeding period (WHO, 2019).

Without preventive interventions, 20 to 45% of HIV + mothers will transmit HIV to their children (WHO, 2019). Among that proportion, five to 10% of transmissions occur during pregnancy, 10 to 20% during labor and delivery, and five to 20% through breastfeeding (WHO, 2019). To achieve the global health plan target of ending the AIDS epidemic by 2030 (WHO, 2020), prevention, treatment, and care are needed, and should be delivered to at least 80% of HIV + pregnant women and their children.

The implementation of the PMTCT program is one of the most important interventions to prevent the spread of HIV from an HIV+ mother to her child (Kamanzi & Richter, 2019). The World Health Organization initiated this program in 2000 to provide guidance and assistance to national ministries of health in the selection and provision of antiretroviral treatment and prophylaxis for women and infants in the context of prevention of MTCT of HIV (WHO, 2007). The PMTCT program offers a range of services before conception and during the prenatal, perinatal, and postnatal periods (WHO, 2019). It focuses on women in their reproductive years (15 to 49 years), living with or at risk of HIV, to help them maintain their health, and prevent MTCTC of HIV through a range of services for preventing HIV infection, preventing unwanted pregnancies among women living with HIV, providing ART to maintain their health, and preventing MTCT during pregnancy, labor, and breastfeeding. The PMTCT program also supports safe childbirth and appropriate infant feeding practices (WHO, 2019). For infants exposed to HIV, the PMTCT program provides HIV testing after birth and during the breastfeeding period, as well as ARV prophylaxis and effective treatment. On its initial introduction to SSA, the PMTCT program was not integrated into other healthcare services. Later, research studies revealed the need to integrate it into maternal and newborn healthcare services specifically to reach women during pregnancy, labor, delivery, and postpartum (Mazia et al., 2009; Nkonki et al., 2007).

In Rwanda, the Ministry of Health introduced the PMTCT program in 2001 (Kayirangwa, Hanson, Munyakazi, & Kabeja, 2006). A single dose of Nevirapine (NVP) regimen was administered as antiretroviral prophylaxis for both infants and their mothers within 72 hours after birth (Center for Treatment and Research on AIDS Malaria Tuberculosis and Other Epidemics [TRAC-Plus] & Rwanda National AIDS Control Commission, 2010). In 2005, the Rawandan national PMTCT guidelines were revised to reflect 2004 WHO recommendations for more effective multidrug-ART regimen protocols that added Zidovudine (AZT) to the NVP treatment regimen (Tsague et al., 2010). Option B based on the WHO recommendations has been implemented since 2010. This regimen entails triple ART to pregnant women infected with HIV, taken for life from the HIV diagnosis and onwards irrespective of the Cluster of Differentiation 4 (CD4) count or clinical stage, and with the hypothesis that this option is more effective than the other existing options (Binagwaho et al., 2013; WHO, 2019). The babies born from HIV+ mothers receive Nevirapine once a day starting as soon as possible after birth, and continuing for six weeks (TRAC-Plus & Rwanda National AIDS Control Commission, 2010). HIV + women who decide to breastfeed are given ARV prophylaxis during the breastfeeding period (WHO, 2019). The risk of MTCT of HIV can be 1% or less if HIV + women follow the above mentioned PMTCT strategies, take ART daily as prescribed, and give ARV prophylaxis to her infant for four to six weeks after giving birth (Nachega et al., 2012; WHO, 2019).

While efforts have been implemented to increase the effectiveness of the PMTCT program, its coverage remains low in Rwanda, as well as the rest of SSA. Consequently, the HIV mother to child transition rate is high (Nachega et al., 2012). There is an urgent need to understand the reasons for the low uptake of the PMTCT program in Rwanda, and to prioritize strategies to improve the uptake. This study investigates the experiences of HIV+ women in Rwanda who participate in the PMTCT program, using a critical ethnographic design and an intersectionality framework, with the aim of uncovering recommendations for increasing the uptake of the PMTCT program.

Rationale for the Study

My passion for PMTCT of HIV work began when I started to work as a quality assurance manager in 2012 at Butare University Teaching Hospital (BUTH) in Rwanda. My office was in the Columbia building where the PMTCT program is delivered. I remember the morning of July 01st, 2012, my first day of work. After a short orientation given by my direct supervisor, I was alone, arranging my new office when I started to hear the voices of babies crying. I tried to concentrate on my work, but I was disturbed to the point that I decided to talk to the PMTCT program manager who had an office close to mine. He said that those babies have HIV, and they have to attend the PMTCT program every month for blood samples to test their viral load. It was so painful to hear that babies continued to be infected while the PMTCT program was initiated to protect and prevent HIV transmission.

I worked in the same office for seven years, and I could not stop thinking about those innocent and vulnerable babies. I questioned why babies continued to get infected, but I did not get any answers. I wondered what my contribution to those babies would be, and how babies born in Rwanda could stay HIV free in the future. I promised God that when an opportunity arose to upgrade my education, my research would focus on finding answers to why the PMTCT program is in place and yet babies continue to be infected by HIV.

During my Ph.D. application at the University of Alberta, I submitted my research proposal on the PMTCT program and was accepted as a doctoral student. As I progressed during my course work and read the literature on the PMTCT of HIV, I started to understand my research area. I realized that besides the cries of babies, there are cries of HIV + mothers who are willing to protect their babies and do not manage to do so due to multiple complex and interrelated factors. I decided to explore the experiences of HIV + mothers using the PMTCT program to develop a better understanding of the factors that affect the PMTCT program uptake.

What is Known about HIV (Human Immunodeficiency Virus)?

HIV is a virus that compromises the human immune system and weakens defense systems against infections and diseases, resulting in acquired immunodeficiency syndrome (AIDS), and ultimately in death (WHO, 2018). An HIV infected individual (HIV+) can transmit HIV to a non-infected individual through the exchange of bodily fluids, typically via sexual intercourse, during maternal-infant blood exchange in utero or at birth, or via breastfeeding (WHO, 2018). There is no cure for HIV infection; however, it can be prevented, and effective ART is available to control the virus, prevent transmission, and prevent HIV from advancing to end-stage disease (AIDS) so that people can enjoy healthy, long, and productive lives (WHO, 2018). Without treatment, HIV infected people will develop AIDS usually within 10 to 15 years, which will finally lead to death (WHO, 2018). The progression of HIV is categorized into three stages including (1) acute HIV infection; (2) clinical latency of HIV infection; or (3) AIDS (Centers for Disease Control and Prevention [CDC], 2019).

In stage one, which lasts from two to six weeks after HIV infection, people have a large virus load in their blood and are highly contagious (CDC, 2019). People with acute infection may experience flu-like symptoms, which is the body's natural response to infection, although they often do not feel symptomatic and are unaware that they are HIV+ (CDC, 2019). An antigen/antibody test or a nuclear acid test is needed to diagnose an acute infection (CDC, 2019).

Stage two is called asymptomatic or chronic HIV infection (CDC, 2019). During this stage, HIV is still active with low levels of reproductive rates due to the compromised immune system response (CDC, 2019). For people who are not taking ART, this stage can last a decade or longer, though some may progress at a faster rate (CDC, 2019). As HIV continues to replicate at low levels during this stage, infected people may continue to transmit HIV (CDC, 2019). To move from stage two to stage three, the viral load within the body increases and the CD4 count decreases. At this point, a person again becomes symptomatic (CDC, 2019; Miceli & Parnes, 1993).

Stage three is the most severe stage of HIV infection, in which the virus severely compromises the immune system, and the disease progresses to AIDS (CDC, 2019). People are diagnosed with AIDS if their CD4 cells count drops below 200 cells/mm, they have a high viral load and become very infectious, and they develop opportunistic illnesses such as pneumonia, different types of cancers, or fungal infections (CDC, 2019). In addition to flu-like symptoms, people with AIDS can experience fever, swollen lymph glands, sweats, chills, weakness, and weight loss (CDC, 2019). Without ART, people with AIDS survive approximately three years (CDC, 2019).

HIV can be transmitted at any stage of HIV; however, using ART and maintaining an undetectable viral road can dramatically reduce the risk of transmission. WHO recommends life long ART adherence for effective long-term viral suppression (WHO, 2019). The sooner ART is initiated after HIV infection, the better the immune recovery and protection, with improved prognosis for a near-normal life expectancy (Paterson et al., 2000).

Global Challenges and Progress in HIV and the PMTCT

The HIV epidemic has become one of the world's most serious public health challenges (KFF, 2019). HIV is similar to Simian Immunodeficiency Virus (SIV), a disease that is present only in chimpanzees and African monkeys (Locatelli & Peeters, 2012). The African monkeys and chimpanzees who carry SIV are often hunted for food and SIV disease may have been transmitted to humans through chimpanzees or monkey's blood infecting cuts or wounds on people during hunting (Sharp & Halin, 2011). The first case of HIV in humans was found in a person who died in Kinshasa, in the Democratic Republic of the Congo, in 1959 (Zhu et al., 1988). In 1981, the first case of AIDS was reported, and the first classes of ART drugs were developed a remarkably short time later, in 1987 (KFF, 2017; Mann, 1989).

Significant progress has been made since the 1980s to promote the prevention of HIV infection and improve the lives of people living with HIV/AIDS, as well as in the scientific advances in the development of ARV treatments. In 1996, UNAIDS was formed to serve as a coordinating body for the United Nations to alert the world, and mobilize worldwide efforts to combat AIDS (KFF, 2017). In 2000, the World Health Organization initiated the PMTCT program to prevent MTCT of HIV (WHO, 2007). In 2003, the United States President's Plan for Emergency AIDS Relief (PEPFAR) was authorized as a bilateral commitment program by the United States Government to support HIV prevention and treatment programs (US Department of State, 2017)..

Unfortunately, the PMTCT program is failing to sufficiently reduce the rate of MTCT of HIV, and HIV continues to result in morbidity and mortality of mothers and children on a large scale (KFF, 2017). The success of the PMTCTprogram relies on HIV+ pregnant women being tested for HIV, providing them with the test results, and initiating ART and adhering to it for life

(WHO, 2019). Mothers must also give the proper ARV prophylaxis regimens to their exposed babies, bring them for early HIV testing, and ensure prompt ART treatment if they are found to be infected (WHO, 2019). The requirements of the PMTCT program can be daunting for HIV+ women without the support of families, and communities, and societies.

African Culture, Women, and HIV

African culture. Culture is not innate, but is learned from family and surroundings; and is a complex whole that includes beliefs, art, knowledge, morals, laws, customs, and any other habits and capabilities acquired by man as a member of society (Mazrui, 1986; Ngubane, 2010). Culture is interrelated values that influence judgment, perception, behavior, and communication in a given society (Mazrui, 1986). Understanding African culture, beliefs, and tradition in relation to women is central to exploring the experiences of mothers using the PMTCT program.

Pre-colonial era. The majority of African traditional society was patriarchal in the pre-colonial era. Woman's roles were specific, and complemented male roles (Msila & Gumbo, 2016). African women played key roles in the transmission of moral values to their children, as well as in their education (Afasi, 2010). Women played a vital role in African communities which were mainly agricultural (Msila & Gumbo, 2016). Various rituals and ceremonies in Africa required the woman's role. African women, linked to the nature of mothering, were instrumental in nurturing and growing communities (Msila & Gumbo, 2016). They were inventors of agriculture and had an active role in sustaining the family, assuming a significant role in villages and communities, and being on the forefront of food security, biodiversity, and many other aspects of the household (Afasi, 2010). In traditional African societies, women possessed the power to bind society together (Afasi, 2010). Women enacted their feminine nature in bringing balance to the workplace, and to navigate cultural prejudices when trying to build networks and relationships (Msila & Gumbo, 2016).

Before Africa was under the domination of any foreign power, there was a dual gender political system in most African countries, which involved women in governance and administration by allowing substantial female representation (Afasi, 2010, Msila & Gumbo, 2016). The queen mother position is still seen in Egypt, Ghana among the Akan, Rwanda, Uganda, and Ethiopia, giving women visible and prominent political authority in running the nation (Msila & Gumbo, 2016). In some cases, the Queen mother was biologically related to the king and was older than him. She had her courts with staff and courtiers. The Queen mother had supreme authority, and political, spiritual, military, and economic power over all inhabitants of her queen-dom (Afasi, 2010). She was responsible for nominating the king's successor, and she was the one who made decisions and convinced a panel of advisors to agree with her choice (Msila & Gumbo, 2016; Akosua Aidoo, 1977). The Queen mother and her staff had an important role to ensure the well-being of the women and children of that nation (Afasi, 2010; Akosua-Aidoo, 1977). Some African societies are still marked by matriarchy where mothers exercise political influence, and hold the source and principle of power (for example in Ghana, they still have Queen mothers among the Akan tribes) (Steegstra, 2009).

Economic and socio-political effects of colonialism of African women. Colonization of Africa strengthened, and negatively influenced the patriarchal system by transforming women's complementary role into subordination. When African cultures met European cultures, women began to experience oppression from men because African people encountered cultures where men were more dominant and powerful in social structures (Msila & Gumbo, 2016). As a result, African women lost control and access to land with subsequent decrease of autonomy, economic dependence on men (Afasi, 2010).

Colonialism imported the European ideas of gender domestication; women became domesticated, and thus experienced gender inequality and dehumanization (Msila & Gumbo, 2016). In a country that was already patriarchal it could be suggested that colonialism exacerbated the issue.

Currently, African women generally do not participate in sexual decision making, nor are they allowed to expess their thoughts (Buvé, Bishikwabo-Nsarhaza, & Mutangadura, 2002). Consequently, women are often exposed to sexual relationships without the power to negotiate choices with their partners. This contributes to violence related sexual exploitation, multiple sexual partners, and polygamy, which expose and increase the risk of sexually transmitted infections (STIs), and HIV transmission (Hogg, 2010; Ramjee & Daniels, 2013).

Women in Africa. Notions of masculinity and femininity social-cultural norms, and have a great influence in the creation of unequal power relations between women and men in Africa. African societies determine their traditional practices and beliefs related to socio-cultural norms, which play a role in defining the position of women and girls in society. In most African cultural expectations, men assume the patriarchal attitude which considers wives, daughters, and partners as their possessions (UN, 2012). In certain African cultures, men are considered as the heads of families, the ones who control finances and resources, and make decisions while women are expected to obey and respect their husbands, fulfill family and community tasks, and accept polygamous relations (UN, 2012).

African culture, women, and HIV. The cultural and social reality in African societies is that gender roles are characterized by gender inequality, economic marginalization, male dominance, and female subordination (Coquery-Vidrovitch, 2013; Maleche & Day, 2011), rendering African women as the most vulnerable population to be infected with HIV. The cultural and social norms in Africa contribute to the spread of HIV infection and increase women's risk taking and vulnerability to HIV (Coquery-Vidrovitch, 2013; Ngubane, 2010) . In many parts of Africa, factors like social and economic inequalities between men and women, discrimination in terms of access to employment, credit, education, healthcare, land, and inheritance expose women to HIV infection (Ngubane, 2010).

Knowledge about the HIV/AIDS pandemic has been limited by excluding the study of practices like the structure of power in African communities as these structures play a vital role in the feminization of the HIV pandemic (Skjolingstad, 2005). African cultural and traditional acts expose women to HIV transmission: initiation ceremonies (girls and boys in their preparation for marriage learn theory and practice related to sexual intercourse); twin rituals (the biological parents must have sex in the event of sending away their daughter to get married, whether still married or separated and no matter their relation at the time) (Sengendo & Sekatawa 1999); property grabbing (a widow without a child is left with nothing because her property is taken by male relatives; widow inheritance (the deceased man's brother is given the widow, or widower is given wife's young sister) (Baylies, 2000); polygamy; and death rites or cleansing ritual (widow has sexual intercourse with another man at the end of burial ceremony of her late husband) (Haram, 1995; Ngubane, 2010). In countries such as Kenya, Tanzania, Botswana, Malawi, Rwanda, Uganda, Burundi, and Zambia it is believed that a widow becomes unclean after the burial ceremonies of her late husband (Maleche & Day, 2011). The cleansing rituals require unprotected sexual intercourse to purify the recipient through entering semen in the widow's body (Maleche & Day, 2011). It is the role of the community leaders to identify who is the right man with whom the widow is to have sex. Cultural practices such as this increase the exposure of women to HIV and other STIs.

Other examples are numerous. Traditional healers obligate women to have sex with them or with others in order to heal infertility. (Kondowe & Mulera, 1999). Practices such as wife sharing, and male and female circumcision (due to reuse and sharing of unsterilized materials) contribute to spread of the HIV infection (Mulama, 2003; Skjolingstad, 2005). Drying the vagina is another cultural belief in Zimbabwe, South Africa, and Zambia which is done with the purpose to please the sexual partner, increase the women's sexual drive, warm the vagina, and persuade the partner to be faithful (Kun, 1998; Ngubane, 2010). The dryness is a source of vaginal lacerations during intercourse, increasing the rate of infections and contributing to the spread of HIV/AIDS (Ngubane, 2010; Ramjee & Daniels, 2013). Furthermore, there is a belief in some African countries that sex with a virgin will cure AIDS, and this increases the number of rapes of female children and the risk of HIV transmission (Maleche & Day, 2011).

In some African countries, such as Kenya and Tanzania, men's infidelity is tolerated because of the practice of post-partum sexual abstinence (Bond & Dover, 1997). In this practice, a wife has to return to her parents at the time she is pregnant, leaving her husband to find other sexual partners because of fear that sexual intercourse may seriously affect the child (Rweyemamu, 1999). There is an increased risk of HIV to the couple due to the extramarital relationship. In Kenya, Tanzania, and Zambia, cultural traditions and values discourage and reject the use of condoms under the argument that it reduces sexual satisfaction and sensitivity, and prevents a healthy flow of semen which is believed to improve health for men (Akeroyd, 2004). African women believe that engaging in intravaginal practices without condoms promotes fertility, good health for the couple, cleanliness, and enhances male sexual arousal (Skjolingstad, 2005).

History of Women in Rwanda

In Rwanda, women have a vital role in the economy, which influences the well-being of their families and communities (Dimandja, 2004; Vansina, 2000). They are the major food producers, and the economic powerhouses of the nation due to the market system and trade they have developed (Chukwu, 2015; Kagame, 1954), giving them a certain amount of economic independence and influence.

Besides the culture-centered role, Rwandan women have eminent and unique roles as spouses, mothers, and educators in their Rwandan way (Msila & Gumbo, 2016; Kagame, 1954). In addition, they hold the indispensable functions of peacekeeper and life-giver, and exercise the power to protect life in dignity and pride more than anyone else in Rwandan society (Dimandja, 2004; Kagame, 1954). To claim equality with their husband in a time of conflict, Rwandan spouses do not protest democratically. Rather, they talk to their husbands with polite respect and do good acts in order to resolve conflicts. Evenings are the family time to discuss professional and family business, and other issues; and this helps to support the core family values (Dimandja, 2004; Msila & Gumbo, 2016).

Rwanda is a world leader for women in politics and in building women's capacity in civil society. Female representation in parliament occupies 54 out of 80 (67.5%) parliamentary seats (The News Times Rwanda, 2018). Though several women are in political office, it is insufficient to affect gender equality. There is little evidence that having gendered policies in place have had a significant impact on the lives of the majority of Rwandan women (Wallace, Haerpfer, &

Abbott, 2014). Rwanda has taken action to correct gender imbalance and equality through promoting equality in healthcare, educational advancement for young girls, and advancing gender equality, but improvements still need to be made in the implementation of gender equality laws. Socially and culturally, men still dominate women in Rawanda.

Rwandan culture permits men to be the head of the family, and all rules to be followed in the family are elaborated by him (Hogg, 2010). In the Rwandese tradition, women stay under their husband's shadow. They are expected to be discrete and reserved, agreeing with what husbands say rather than giving their opinions or challenging him about family life (Nteziryayo, 2009). From a young age, a girl is expected to stay next to her mother, and help her with domestic and agricultural work (Hogg, 2010). It is the responsibility of a mother to educate her daughter about agricultural and domestic work, the qualities of a good wife, sexuality, and what to do to please her husband (Hogg, 2010).

In Rwanda, sugar daddies exist where a man seeks out younger girls, with a wide age difference, to have sex, because they believe a virgin is clean of any sexual diseases and safe (Nteziryayo, 2009; Hogg, 2010). Also, extramarital sex is prevalent in Rwanda society, and it is accepted with dignity, respect, discretion.

Other traditional practices such as polygamy, widow cleansing, widow inheritance, and ritual sex practices in relation to children undermine the status of women, and are dangerous to women's health because those men involved do not test for HIV and do not use condoms (Coquery-Vidrovitch, 2013; Nteziryayo, 2009). Widow cleansing is a tradition in which a widow is expected to have sex with a male agnate of her deceased husband as a cleansing ritual after becaming widowed or having an abortion (Coquery-Vidrovitch, 2013; Nteziryayo, 2009). Widow inheritance is a social and cultural practice whereby no widow can inherent or own clan land; she is required to marry a male relative of her late husband who is often his brother (Nteziryayo, 2009; Hogg, 2010). Other sexual rituals in which the biological parents must have sexual intercourse even if they are separated or divorced cerebrate significant events in relation to children such as child birth, child death, and child marriage. Those kinds of practices are social norms that dictate female defferance to males, and expose families to all kinds of STDs, especially HIV and MTCT of HIV.

Culturally, girls are brought up to believe that males are superior in all spheres of life and should be masters of sexual relationships; and boys are taught that manhood is to have control in relationships (Maleche & Day, 2011; Ngubane, 2010; Ramjee & Daniels, 2013). Women's inferior status exposes them to powerlessness to protect themselves because of lack of economic status as they feel they cannot risk losing their partners as their source of financial support, and accept unprotected and abusive sex which exposes them to HIV (Hogg, 2010; Ramjee & Daniels, 2013).

Chapter Two: Literature Review

A literature review is defined as an objective summary and explanation of the current state of knowledge on a limited topic obtained from a critical analysis of the relevant available literature on a topic being studied (Cronin, Ryan, & Coughlan, 2008; Polit & Beck, 2006). The purpose of the literature review is to increase the likelihood of getting the best available research evidence on the topic, and to form a foundation on which to guide future research (Polit & Beck, 2006). Moreover, a review of literature serves to identify established knowledge about a phenomenon, and every aspect of such a review is considered important in providing a foundation on which to base new evidence (Boote & Beile, 2005; Polit & Beck, 2012). Through a critical review of the existing body of knowledge, researchers can identify gaps or inconsistencies in research evidence requiring further inquiry.

A comprehensive literature review was conducted on the experiences of mothers using the PMTCT program to prevent HIV transmission. In consultation with a librarian, multiple health databases were searched, including MEDLINE, EMBASE, Cochrane Library, CINAHL, Scopus, Web of Science Core Collection, and Global Health. In addition, I searched in grey literature. Grey literature was used to enhance the depth and breadth of the review, and to show that the review was as exhaustive and comprehensive as it could be (Benzie, Premji, Hayden, & Serrett, 2006). The grey literature search included information from Google, Google Scholar, and the reports related to PMTCT/MTCT. The search keywords included: access to antiretroviral therapy, barrier, breastfeeding, challenge, children, delivery, experiences, HIV, MTCT, pregnant women, PMTCT, prevention and control, testing, and vertical transmission.

Studies were selected if they referenced HIV infected pregnant and breastfeeding women and their children from birth to two years; had the PMTCT program as an outcome, or MTCT, or vertical transmission; or if they were primary studies using qualitative and mixed-method study design and were published in English between March 2008 and March 2018. Primary studies using quantitative designs were excluded because the review focused on the experiences of HIV+ women in using the PMTCT program. I excluded as well as those consisting of a published abstract, poster, review, thesis, or conference publication, books, book chapters, commentaries, and editorials. The steps of the PRISMA flow diagram (Figure 1) were followed during data selection (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). The initial search yielded 9367 articles. Of these, 5517 were excluded based on duplication, leaving a total of 3850 articles for further screening. After the title and abstract screening, 165 articles were considered relevant. Thirty-five were included after reading all 165 articles in full. The relevant information from included articles was mapped with the research questions, and entered into a data extraction form. After fulfilling the data extraction table, two papers were excluded, one was a duplicate and another was quantitative. Thirty-three papers were included.

Figure 1

PRISMA flow diagram

Research on the PMTCT Program

Research has been conducted to study the PMTCT program. I summarize the various characteristics of 33 qualitative and mixed methods studies related to the experiences of mothers using the PMTCT program in Table 1. Those characteristics include publication date, countries represented in studies, research design, and data collection methods and are also part of methods used to study the PMTCT program.

Table 1

Summary of Characteristics of the Included Articles

Items	**Characteristic**	**Number (n)**	**Percentage %**
Publication date	2009 to 2012	11	33
	2013 to 2021	22	67
Countries represented in studies	Malawi	12	36.4
	South Africa	8	24.2
	Tanzania	3	9.1
	Uganda	2	6.1
	Abidjan, Botswana, Cameroon, Cote d'Ivoire, Ghana, Guinee Bissau, Kenya, and Nigeria	1 each	24.2
Research design	Qualitative methodology	25	76
	Mixed methodology	8	24
Data collection methods	Interviews	19	58
	Questionnaires	5	15
	Focus group	3	9
	Survey	3	9
	Interviews and focus group	2	6
	Observation	1	3

Considering the complex associations between the individual practices, the physical environment, health, social, and structural factors, the findings from this segment of the literature review are reported using five themes that align with types of factors that influence MTCT of HIV (Onono et al., 2015). Many of the factors seem to be inter-related (Cornelius, Erekaha, Okundaye, Sam-Agudu, 2018; Laar & Govender, 2011). The five themes are represented in level factors: individual factors, interpersonal factors, community factors, health system factors, and social factors.

Individual factors. The individual-level factors are those related to the level of mothers' acceptance of HIV testing, receiving the results, and belief that their children are susceptible to contracting HIV through MTCT (Cornelius et al., 2018; Onono et al., 2015). An HIV + woman may decide to stop attending the PMTCT program due to factors such as lack of disclosure of HIV status; fear of stigma and discrimination; and lack of money for antenatal care (ANC) and transportation costs (Bwirire, Fitzgerald, & Zachariah, 2008; Hatcher, Stöckl, Christofides, & Woollett, 2016; Landefeld, Fomenou, Ateba, & Msellati, 2018; Lubega et al., 2013). Women feared testing positive for HIV, and many refused testing (Katirayi et al., 2016; Varga & Brookes, 2008a). Similarly, women found it difficult to have their infants tested because they feared getting a positive result, and involuntary disclosure (Katirayi et al., 2016; Varga & Brookes, 2008a).

Lack of awareness and knowledge related to HIV/AIDS and MTCT among HIV+ women contributes to increased HIV prevalence among children (Ferguson et al., 2012; Wettstein et al., 2012). Mothers who lack knowledge and awareness of MTCT readily refuse ANC attendance and treatment. Additionally, women experience difficulties with medication adherence which consequently results in drug resistance and medication side effects (Katirayi et al., 2016; Klaus et al., 2014; Fleek, 2014; Mepham, Zondi, Mbuyazi, Mkhwanazi, 2011; Ramoshaba & Sithole, 2017).

The findings from the research indicate that Exclusive Breast Feeding (EBF) is a good option for HIV+ women living in low resource countries, but mothers are often unclear about what EBF entails (Levy, Webb & Sellen, 2010). Counseling received from health care providers (HCPs) on infant feeding was often confusing, incomplete, or incorrect (Laher, Cescon, & Lazarus, 2012; Levy et al., 2010).

Interpersonal factors. Household inequities, such as women's limited decision-making power, have been shown to contribute to their lack of participation in the PMTCT program (Ferguson et al., 2012; Sewnunana & Modibab, 2015). Male partners play an important role in decision-making. For instance, some women refused counseling and treatment or did not collect their results because of partner disapproval; this may be linked with a lack of knowledge of HIV, AIDS and MTCT among the male partners of HIV+ women (Brittain, Giddy, Myer, Cooper, & Harries, 2015; Ramoshaba & Sithole, 2017). Women found it difficult to negotiate with their male partners regarding the use of condom, possibily resulting in increased risk of higher viral loads, and a negative impact on the women's adherence to the PMTCT program (Chinkonde, Erekaha, & Okundaye, 2009; Varga & Brookes, 2008b).

Financial vulnerability can result in non-disclosure of HIV status due to fear of social stigma, being abandoned, domestic violence, and losing social and/or financial support (Klaus et al., 2014; Landefeld et al., 2018). Women may have no one to trust, and prefer to keep their HIV status secret (Cornelius et al., 2018; Flax, Yourkavitch, Okello, & Kadzandira, 2017). This directly affects infant testing because of fear of involuntary disclosure (Flax et al., 2017; O'Gorman, Nyirenda, & Theobald, 2010; Nyondo-Mipando, Chimwaza, & Muula, 2018).

The fear of MTCT through breastfeeding contributes to women choosing replacement feeding, whether or not it meets Acceptable, Feasible, Affordable, Sustainable, and Safe (AFASS) criteria (Woldegiyorgis & Scherrer, 2012; Nyondo-Mipando et al., 2018). However, the implementation of the exclusive replacement feeding (ERF) has many challenges including economic challenges to maintain replacement feeding that meets AFASS criteria; and fear that babies will develop diseases related to replacement feeding, and lack of love (Madiba & Letsoalo, 2013; Traoré et al., 2009).

Additionally, persons around the mothers have been found to add challenges, such as pressure to breastfeed from husbands, mothers, mothers-in-law, friends, and neighbors (Levy et al., 2010; Madiba & Letsoalo 2013; Traoré et al., 2009). HIV+ women need their partner's physical, social, emotional, and economic support. They also require support for feeding choice and safety, as well as to address negative religious influences regarding ART uptake for PMTCT (e.g., use of holy water to cure HIV in Ethiopia); and to address issues related to stigma and discrimination (Levy et al., 2010; Klaus et al., 2014; Madiba & Letsoalo 2013). Lack of male involvement is related to insufficient family resources, refusal to be tested, polygamy, decision-making power, and lack of being supportive (Brittain et al., 2015; Flax et al., 2017; Fleek, 2014; Nyondo-Mipando et al., 2018).

Community factors. Lubega et al. (2013) and Varga and Brookes (2008b) reported that the relationship between sociocultural and community influences, and maternal-child practices in the face of MTCT risk has not been addressed. Sociocultural issues are known to affect HIV prevention efforts and pose significant obstacles to operationalizing the PMTCT program (Varga & Brookes, 2008a). These factors include stigma and discrimination, gender inequity, lack of support, abandonment and social isolation, divorce, and poor community acceptance of people living with HIV (Varga & Brookes, 2008b; Were et al., 2011). These factors also contribute to the lack of infant testing and loss of follow-up to the PMTCT program due to fear of involuntary HIV disclosure and negative community reactions (Cornelius et al., 2018; Elwell, 2016; Lubega et al., 2013; Madiba & Letsoalo 2013). In addition, there is a stigma related to not breastfeeding and a negative association with replacement feeding (bad motherhood, disliking her child, killing child, desiring adultery). Cultural norms (three years of breastfeeding) and traditional feeding practices were found to be challenging to the success of the PMTCT program (Madiba & Letsoalo, 2013; Traoré et al., 2009; Woldegiyorgis & Scherrer, 2012).

Health system factors. A range of health system factors influence the decision-making of HIV+ women about enrolment into ANC and the PMTCT program. Some of these issues are related to facilities and others to the attitudes of healthcare providers. Factors related to health care facilities include system-level obstacles, shortage of staff, lack of ART stock, and indirect labels due to isolated or public locations of the clinic. These have been shown to contribute to a loss of follow-up in the PMTCT program (Elwell, 2016; Miya & Mgutshini, 2016). In addition, long distances to health facilities combined with a lack of money for transport and health facility charges were found to limit the number of ANC visits. These factors increased the number of women opting for home deliveries, assisted by traditional birth attendants (TBA) (Laar & Govender, 2011; Onone et al., 2015).

The research also suggests that factors related to the competency, skill, and attitudes of health care workers impact on the delivery and efficacy of the PMTCT program. Women lacked trust in TBAs to maintain confidentiality of their health information, which contributed to non-disclosure of their HIV status, and newborns therefore not receiving NVP prophylactic medicine (Buesseler, Kone, & Robinson, 2014; Elwell, 2016). HIV+ women complained that pre and postnatal counseling was ineffective, inadequate, or even absent, and without adequate informed consent (Ramoshaba & Sithole, 2017; Vieira et al., 2017). Furthermore, they lacked counseling related to infant feeding, and messaging was unclear or conflicting because HCPs were inadequately trained to provide it (Buesseler et al., 2014; Laher et al., 2012). In addition, women complained about the attitudes of HCPs, such as poor interactions, bad treatment, discrimination and stigmatization, and breach of privacy and confidentiality that resulted in lack of trust.

Improving relationships between HCPs and patients, medical follow-up for women and infants, making treatment available, and providing formula substitutes were found to improve the delivery of the PMTCT program (Gourlay, Wringe, Birdthistle, & Mshana, 2014; Onono et al., 2015). Male involvement during couple HIV counseling and testing was effective for the success of the PMTCT program, however, the lack of clinical space was a barrier for males to be involved in the PMTCT program (Brittain et al., 2015; Miya & Mgutshini, 2016).

In the majority of studies reviewed, adherence to the PMTCT program was identified as the main component of the prevention of MTCT of HIV. The results from the literature review also showed that individual, social, and structural factors are determinants of the PMTCT program success (Cornelius et al., 2018; Flax et al., 2017; Varga & Brookes, 2008b). In general terms, both individual and interpersonal factors are interlinked with community factors, health systems factors, and larger societal factors to determine the efficacy of the PMTCT program in preventing MTCT of HIV.

Larger societal factors. Research has shown that societal factors such as stigma and discrimination, gender inequity, lack of support, abandonment and social isolation, divorce, and absence of male involvement contribute to the loss of follow-up for HIV+ women using the PMTCT program (Nyondo, Chimwaza, & Muula, 2014; Sewnunana & Modibab, 2015). To address the larger societal factors, there is a need to develop and provide healthcare system laws and national norms that address gender inequity, stigma, and discrimination issues; provide qualified and skilled HCPs; engage People Living with HIV (PLWHIV) peers, partners, and TBAs in the PMTCT program; and increase media messages to prevent MTCT of HIV (Buesseler et al., 2014; O'Gorman et al., 2010).

The vast majority of the studies reviewed reported that multiple levels of factors interacted in one or another way to influence adherence to and effectiveness of the PMTCT program. For example, individual factors can arise from subjective perceptions of other levels of factors, magnifying or reducing their effect. Poor support from husbands and families to HIV+ women is an example of an interpersonal factor that can mediate the decision-making of HIV+ women to stop PMTCT program adherence. Stigma and discrimination and fear of divorse are examples of societal factors that are sources contributing to HIV+ women's fear of disclosure and potentially increase the risk of MTCT of HIV. The relationship between the levels of factors can also work in the other direction. Beliefs held by HIV+ women in interpersonal factors (e.g., support from husband, and families) and health system factors (e.g., trust in the advice received from HCPs) can influence the individual factors such as ARV adherence and keeping a HIV baby.

Community factors (e.g., stigma) damage the individual's ability to adhere to the PMTCT program (Nyondo, Chimwaza, & Muula, 2014; Sewnunana & Modibab, 2015). Also, gender inequality can affect the success of the PMTCT program because, in African culture, the women are dependent on the husband and have to get their approval before taking any action (Cornelius et al., 2018; Elwell, 2016).

Several studies showed a conflict between individual factors, larger societal factors, and interpersonal factors (Bwirire et al., 2008; Kasenga et al., 2010; Kebaabetswe, 2007). In the context where breastfeeding is the norm and highly valued socially, following WHO guidelines to ERF often exposed HIV+ women to stigma and fear of involuntary disclosure of HIV status. This was less of a concern in the societies where breastfeeding is a choice, not dominant or expected (Ramoshaba & Sithole, 2017; Vieira et al., 2017).

Poverty and financial issues are significant in SSA, and expose HIV+ women to MTCT of HIV. Some countries like Botswana and South Africa give free infant formula to mothers living with HIV to ensure that babies are not exposed to HIV due to poverty (Kebaabetswe, 2007; Laher et al., 2012). Similarly, in Canada, HIV+ mothers receive substitute formula for their newborns to encourage them to follow all steps to prevent MTCT of HIV (WHO, 2013). However, formula provision creates a conflict for many mothers who fear that ERF will lead to involuntary disclosure of HIV status, especially in SSA.

Other studies reported that women decided to keep their HIV status private and not to disclose to anybody because of fear of negative repercussion from their partners including blame, emotional and financial abandonment, physical violence, and household conflicts that may result in divorce, stigma, and discrimination. While some studies reported negative consequences, Kenyan and Zambian mothers reported improved relationships with their partners after disclosure. Those who had disclosed appeared to have stronger relationships than those who had not disclosed. Ross, Stidham, and Drew (2012), and Fadnes et al. (2010) supported that women who disclosed to their husbands and family members perceived them as having a good understanding of HIV disease, and perceived greater support from them before the HIV diagnosis.

Isolation of the PMTCT clinic was another cause of loss of follow-up due to exposure of HIV+ women to involuntary disclosure, because if a clinic is in an isolated location, patients at the clinic will be known to have positive status. Women avoided the clinic to hide their HIV status (Varga & Brookes, 2008b; Chinkonde et al., 2009). This is consistent with reports from Botswana, Zambia, and South Africa where participation in PMTCT initiatives placed women at risk for involuntary disclosure through engagement in socially stigmatized practice such as breastfeeding avoidance (Wouters, van Loo, van Rensburg, & Meulemans, 2009, Rasmussen et al., 2013).

Another way in which cultural, societal and interpersonal factors overlap with individual factors is the area of decision making for the household. The results from the literature review showed that women in need of the PMTCT program often face the issue of stigma from partners and family members who may make a decision that prevents women from having access to it. In some contexts, the woman herself may not have the autonomy to make decisions about her health and her baby, depending instead on a male head of household or mother-in-law (O'Gorman et al., 2010). This decision making also applies to the financial resources of the household. The husband is considered the leader of the house and is the only person who owns the household resources and decides how resources should be used. For example, resources such as transport money may be available, but not given to the woman who needs the PMTCT services due to social norm related issues.

The literature review indicated that improvement of the PMTCT program outcomes requires increased knowledge and awareness not only on the part of HIV+ women, but also of husbands, mothers-in-law and families, communities, and society. The results from many studies stated that awareness and knowledge of HIV and the PMTCT program remains low in SSA (Katirayi et al., 2016; Mepham et al., 2011; Ramoshaba & Sithole, 2017). The most vulnerable groups among women are those who are poorly educated, from a rural background, and who are economically dependent on men (Burgoyne & Drmmond, 2008). Access to HIV knowledge and awareness in SSA is mainly through HIV counseling, health education, and sometimes through media. Mothers who lacked knowledge and awareness of MTCT ignored the PMTCT follow-up services and missed HIV treatment for both their health and that of their babies (Katirayi et al., 2016; Ramoshaba & Sithole, 2017)..

The role of healthcare providers was found to be vital in improving HIV+ women's use of effective and adequate counseling and medical follow-up. However, some HCPs explained they felt underprepared, and described the counseling process as difficult (Onono et al., 2015). Failure to understand the importance of knowledge resulted in healthcare providers doing HIV testing and prescribing medication to HIV+ women without informed consent and pre and post counseling. This may have contributed to fear of infection, HIV stigma and discrimination, and loss of follow-up, with a risk of MTCT of HIV (Gourlay et al., 2014). A study in Ethiopia revealed that similar factors may cause women and their spouses to develop perceptions of HIV testing as compulsory in ANC clinics, concomitantly limiting access to the PMTCT program (Mills & Rennie, 2006). A study conducted in West Africa indicated that if HIV testing is perceived as being an obligation, there may be an adverse effect on ANC attendance rates (Landefeld et al., 2018). HIV+ mothers thus need to be informed that they can opt out of HIV testing until they feel prepared to take the HIV test.

The findings from this review propose that prevention of MTCT of HIV can be improved through increasing the knowledge and awareness of HIV+ women, their husbands, and their families; availing of the resources and logistics required to increase access to the PMTCT program; and addressing the larger societal issues that impact on HIV+ women's decision-making related to preventive measures and use of the PMTCT program. In particular, the review identified that regular and continuous training to improve the skill of healthcare providers in providing counselling and education, and deter negative attitudes; the use of PLWHIV peers in the education of HIV+ mothers; and increases in quantity and quality of media messages would improve HIV knowledge and awareness, and increase access to services (Landefeld et al., 2018; Onono et al., 2015).

Other societal issues include the economic vulnerability of women in SSA, and the cultural and economic factors supporting it. The gap between poor and rich is widening and there are few options for women in SSA to obtain financial independence (Leclerc-Madlala, 2008). Their poverty and economic dependence on men make them vulnerable often with few options; they sell themselves for their own survival, or to feed their children (Duffy & Regan, 2012).

Strengths of the Studies on the PMTCT Program

The PMTCT program has been studied using different research designs, data collection and sampling methods, and multiple varieties of stakeholders. This strengthens and enables the synthesis of findings from different methodologies and perspectives to enhance validity. The papers using qualitative and mixed methods approaches were considered in the literature review with the intent of exploring the experiences of HIV+ women using the PMTCT program and gathering adequate information on barriers or challenges experienced by women using the PMTCT program. Qualitative approaches included ethnography (Levy et al., 2010; Woldegiyorgis & Scherrer, 2012) and narrative design (Varga & Brookes, 2008b). Most of the studies were qualitative without a specific design (Onono et al., 2015; O'Gorman et al., 2010; Sewnunana & Modibab, 2015; Vieira et al., 2017). Mixed-method studies included focused ethnography combined with principles of grounded theory (Buesseler et al., 2014), and combined interview and survey (Creek et al., 2009). Some studies were identified as qualitative, but the researchers added quantitative data to qualitative (Cornelius et al., 2018).

Most studies used multiple data collection methods, which presents a systematic and rigorous way to study the relationship between social and programmatic context, decision-making, and behavior. For instance, the studies used purposive sampling (Chinkonde et al., 2009; Elwell, 2016); convenience sampling (Nyondo et al., 2014; Brittain et al., 2015); convenience and purposive sampling (Madiba & Letsoalo, 2013; Nyondo-Mipando et al., 2018]; and criteria sampling (Buesseler et al., 2014). However, Four studies did not clarify the sampling method used during the data collection (Katirayi et al., 2016; Laher et al., 2012; Landefeld et al., 2018; Traoré et al., 2009). Sampling description helps the readers to make inferences about the study population and to determine the accuracy of the research which may directly reflect on the final results of the research (Polit & Beck, 2006).

All studies included self-reported data, which might serve as an effective program monitoring and evaluation tool. Some studies used a narrative, social constructionist approach to interviews, and intentionally focussed on techniques like validation, highlighting resistance, and locating identity within participants' stories (Gourlay et al., 2014; Hatcher et al., 2016). Therefore, the interpretations are different from that of a neutral observer as utilized within a more positivist research paradigm. Furthermore, studies used participants with different characteristics (e.g., a study that compared reports from mothers with HIV infected infants and those with HIV negative infants) (Ramoshaba & Sithole, 2017). This may reveal potential factors related to the PMTCT program failure at multiple levels. In addition, some studies used community surveillance datasets to facilitate the recruitment of HIV women who were not enrolled in PMTCT care, helping to improve the validity of findings and maximize confidentiality (Gourlay et al., 2014). Most studies received ethical approval to protect research participants and conducting research with the highest ethical standards (Brittain et al., 2015; Elwell, 2016; Katirayi et al., 2016; Landefeld et al., 2018; Nyondo et al., 2014; Nyondo-Mipando et al., 2018; Ramoshaba & Sithole, 2017).

Gaps in the Literature

The literature review reveals gaps in what is known. It gives the researcher insight into the significance of the issue, and directions to explore the experiences of mothers using the PMTCT program to prevent HIV transmission. Statistically, an estimated 18 million women live with HIV globally. 1.7 million were newly infected with HIV in 2016 and 56% of them live in SSA (UN [United Nations] Women, 2017). An estimate of 2000 women are newly infected with HIV every day (UNAIDS, 2017). Young women are 2.5 times more likely than young men to be newly infected with HIV (UNAIDS, 2019). It is now undeniable that SSA is the only region in the world where the rate of HIV in women is higher than in men (Duffy & Regan, 2012). The primary HIV transmission in SSA is through heterosexual intercourse and women are more vulnerable to HIV than men (Duffy & Regan, 2012). Clearly, the experiences of HIV + women using the PMTCT program are deserving of further study.

Social and cultural practices that are associated with the subordination of women to men in SSA contribute to the vulnerability of women to be infected by HIV and develop AIDS. Many countries in SSA accept the cultural practice of multiple concurrent sexual partnerships and these practices expose African people to HIV and AIDS. The research revealed that the reason SSA is the most impacted by HIV/AIDS is the subordination of women's social status, and the many negative traditions and cultural practices that sustain that subordination (Chersich, Rees, Scorgie, & Martin, 2009; Duffy & Regan, 2012). Mertens (2016) states that the issues related to social and cultural norms are difficult to solve due to many factors, such as the number of people and opinions involved; incomplete and contradictory knowledge; large economic burden; and the intersecting nature of socio-cultural problems with other problems. Due to this intersecting nature, resolving socio-cultural problems requires addressing power inequalities, poverty, and violations of human rights (Mertens, 2016). Duffy and Regan (2012) added that the vulnerability of women seems to be aggravated by poverty, social injustices, income inequality, and gender injustice.

The majority of men in SSA do not have to negotiate sex with their wives; they can insist on sex at any time and this is culturally accepted. Women are sometimes exposed to dry sex which increases their vulnerability to HIV transmission (Hooks, 2009). Women in SSA are educated from a young age that when they are married they must respect and answer to all needs of their husbands, and boys are socialized to expect the right to sexually exploit a woman's body (Hooks, 2009). In SSA, egalitarian societies have been replaced by power centered patriarchal approaches, resulting in domination and oppression that feminists seek to overcome (Ahmed, 2017). Other African cultural and traditional practices such as levirate (marriage by a man's brother to his widow), polygamy, or sororate (concurrent marriage with a wife's sister) and sexual cleansing contribute to women's vulnerability to HIV (Chersich et al., 2009; Duffy & Regan, 2012). In this review, I did not find any literature that addressed these cultural and traditional aspects, or their contribution to addressing the challenges related to PMTCT program delivery in SSA and Rwanda.

I found an interesting concept called Feminine Mystique which is defined as the false notion that a women's role in a society is to be a wife, mother, and housewife, nothing else (Friedan, 1963; Ahmed, 2017). The gender role prescribed for African women and femininity demands submissiveness and passivity in sexual relations, whereas the role prescribed for African men is to be knowledgeable, dominating, and sexually experienced (Chersich et al., 2009; Duffy & Regan, 2012). Roles assigned to African women are limiting, and expose them to powerlessness and vulnerability in legal and political spheres.

Though,theoretically, African women are seen to be equal in rights to men, in practice this has been denied in constitutional as well as traditional law which discriminate against women. Political and legal structures and institutions enforce this discrimination (Duffy & Regan, 2012). Violence against African women is the result of the intersection between women's vulnerabilities, gender roles, and gender inequalities where women are continuously objectified and subjected to rape and abuse. Lorde (1984) mentioned that as long as male domination exists, rape will exist. Only when women resist do men become conscious of their responsibility to fight sexism, and this can stop the culture of rape (Chersich et al., 2009; Duffy & Regan, 2012). There is a high possibility of HIV transfer and MTCT of HIV transmission if women are abused or raped (Duffy & Regan, 2012). Research findings revealed that condoms are used more in commercial sex or sex workers than in the home for African people (Duffy & Regan, 2012). The reality for women is that unless they are empowered to have some degree of control in a sexual relationship, the use of a condom will depend on the male, thus highlighting underlying gender inequality.

Women in SSA are also vulnerable to a lack of education. There are challenges of ensuring their access to, and completion of primary and post-primary education levels which contribute to women's subordination to men. Poor educational attainment generally entrenches gender inequalities and often leaves African women ill-informed on the issues related to HIV transmission and prevention. From the literature reviewed, I did not find any studies addressing gender inequality to prevent MTCT of HIV transmission and this may be a recommendation for further research.

Some religious beliefs that support male domination of women marginalize women in Africa especially in Rwanda. Women often accept this domination without questioning and, to be accepted by society, they become marginalized (Hooks, 2009). As well, some African religious beliefs have a negative influence regarding ART uptake for PMTCT of HIV. One study conducted in Ethiopia mentioned that HIV+ women were asked by the church leaders to stop ART and rather use holy water (Klaus et al., 2014). Future studies exploring the influence of religious beliefs on PMTCT of HIV would be valuable.

The other gaps identified in this review include limited literature on the experiences of mothers using the PMTCT program in Rwanda; lack of studies using a critical design; and a lack of intersectionality framework to assess the complexity of the interrelated factors affecting the uptake of the PMTCT program. Research that adopts a critical lens within an intersectionality framework may help to understand the intersecting factors related to the PMTCT of HIV and contribute to knowledge that addresses this multifactorial issue. Using critical ethnography to address holistic human experience and its relationship to power and truth would offer the opportunity to closely examine health challenges from the perspective of those who live it daily (Harrowing, Mill, Spiers, Kulig, Kulig, & Kipp, 2010). There is a need to explore power relations, and social and cultural norms in decision-making through addressing a variety of interconnected contextual factors that constrain how HIV+ mothers live and manage health-seeking behaviors (Woldegiyorgis & Scherrer, 2012).

The findings of this literature review recommend research in the arena of social change interventions to clarify links between those complex contextual factors and specific health outcomes; the flexibility to adapt those complex factors to community-specific contexts; and a holistic approach that recognizes the roles and interrelationships of individuals, groups, and broader social dynamics in determining behavior (Woldegiyorgis & Scherrer, 2012; O'Gorman et al., 2010).

In conclusion, a literature review is an essential and well-regarded approach to reviewing health research evidence. The main strength of a literature review is its ability to extract the essence of a diverse body of evidence and give meaning and significance to a topic (Benzie et al., 2006). The focus of this literature review was to synthesize knowledge on the experiences of HIV+ mothers using the PMTCT program. Five level factors (individuals, families, communities, health systems, and larger societal complexities) were used to represent factors that directly or indirectly relate to the complexities and challenges experienced by HIV+ mothers using the PMTCT program in SSA. The low rate of PMTCT enrollment and ART adherence among HIV+ women in SSA was associated with factors related to individuals, families, communities, health systems, and larger societal complexities.

The data suggest that the PMTCT program enrollment and ART adherence play a crucial role in MTCT of HIV. Addressing healthcare system barriers and promoting health education are important components in reducing the risk of MTCT of HIV in SSA. Based on the above-mentioned gaps, there is a need to develop interventions that respond to the complexity of factors that are associated with improving the PMTCTprogram enrollment and ART adherence as well as prevention of MTCT of HIV. While the counseling sessions in the PMTCT program are focused only on pregnant women, involving partners, families, and the community could strengthen this program. Engaging PLWHIV peers in the education of HIV+ mothers and their families and increasing media messages were also found to be useful.

Chapter Three: Methodology

Burns and Grove (2009) define research methodology as the logical and systematic application of all the steps, strategies and procedures for gathering and analyzing data from a research investigation. The purpose of this chapter is to describe the methodology that was used in this research project. This study explores the experiences of mothers using the PMTCT program for preventing HIV transmission in Rwanda using a critical ethnographic approach, and an intersectionality framework.

Significance of the Study

MTCT remains a public health crisis. More than 1.8 million children are living with HIV/AIDS globally, and more than 80% of them live in SSA (KFF, 2021). Over 90% of children are infected with HIV through MTCT. In 2020, an estimated 180, 000 children under 15 years old acquired HIV every day globally and more than 90% of them were due to MTCT of HIV (UNAIDS, 2020). Without appropriate care and treatment, more than 50% of newly infected children will die before their second birthday (UNAIDS, 2018). The risk level for breastfeeding without preventive intervention varies depending on the duration of breastfeeding. Six months of breastfeeding with no intervention increases the risk to 30%, and 18 to 24 months of breastfeeding raises it to 35% (WHO, 2007). In 2019, only 53% of 1.8 million children living with HIV were receiving ART. Among those without access to effective treatment, which represents 47% of 1.8 million children living with HIV, 110,000 died due to AIDS related illness (KFF, 2021). In 2020, 50% of 180,000 children diagnosed worldwide with HIV were infected during breastfeeding and 90% of them are living in SSA (KFF, 2021; UNAIDS, 2020). The target is to reduce the MTCT rate to 5% or less among breastfeeding women and 2% or less among non-breastfeeding women (WHO, 2020).

In Rawanda, HIV prevalence among women aged 15 to 49 years has been estimated at 3.8% (UNAIDS, 2020a). In 2019, 2800 children were newly infected with HIV in Rwanda (UNAIDS, 2020a). Regardless of the effort of the PTMCT program, the MTCT of HIV still exists in Rwanda. There are limited studies that explore the experiences of mothers using the PMTCT program to prevent HIV transmission in Rwanda. It is necessary to explore the experiences of users of PMTCT to describe the interventions needed to improve the program.

Research Question

The research question addressed in this study is: What are the experiences of mothers who use the PMTCT program to prevent HIV transmission in Rwanda?

Purpose and Objectives

The purpose of this research was to explore the experiences of mothers using the PMTCT Program to prevent HIV transmission in Rwanda. The objectives were: (1) to identify factors that influence and challenge the uptake of the PMTCT program within sub-Saharan Africa; (2) to explore the role of health services in supporting women in the PMTCT program; (3) to critically examine the experiences of mothers during the prenatal, perinatal, and postnatal period to prevent HIV transmission; and (4) to describe how the PMTCT program can be implemented effectively.

Research Approach

Researchers orient their research toward qualitative or quantitative inquiry. The choice depends on their objectives, and the goals they want to achieve. The nature of the research questions is also critical in the selection of a particular research approach. Investigators are guided by epistemology, ontology, ideology, and ethical tenets. This research study was guided by a qualitative approach. A qualitative approach is the best way to answer my research objectives as it aims to discover meaning, process, and context (Harrowing et al., 2010).

Methodological Design

Ethnography is a qualitative research design that has been traditionally used in anthropology and sociology (Brewer, 2000). It has become a more predominant feature in the study of health and other social problems (de Laine, 1997). Brewer (2000) defines ethnography as a study of people in a naturally occurring setting or field where the researcher spends time with research participants in their setting and participates directly in their activities. Ethnography is considered as a methodology that helps the researcher get a better understanding of the meaning of a phenomenon through getting closer to the participants (Cunningham, 1993; Fetterman, 1998; Hammersley & Atkinson, 1995).

Ethnography has a long history that started within anthropological inquiries, moved to the sociology discipline with a focus on urban problems, and is now commonly used in nursing and health disciplines to investigate phenomena related to health (Liamputtong, Haritavorn, & Kiatying-Angsulee, 2014). Researchers from different disciplines, including sociologists, nurses, educators, and others interested in the cultures and social interactions of groups have adopted ethnography (Minichiello, Sullivan, Greenwood, & Axford, 1999). It is a suitable design for examining and resolving sociocultural problems in health institutions by trying to find out what and why of behaviors or actions (Groenkjaer, 2002).

The main characteristics of ethnography include participants' interactions, research in a natural setting, inductive data interpretation, accurate reflection of the participants' perspectives and behaviors, recursive data collection, and analytic strategies framed within a socio-political context (Ben-Ari & Enosh, 2013; LeCompte, Schensul, Weeks, & Singer, 1999). Ethnography is a recommended design for researchers whose intent is to bring about change in their phenomena of interest. Ethnographers use direct learning through social and physical involvement by spending significant amounts of time in the field, doing observation, participating in activities within the community of interest, recording the collected data, getting a better understanding of meaning, and acknowledging the transformative quality that the researcher adopts to be culturally competent or not (De Chesnay, 2015).

Ethnographers use multiple sources of data collection to examine the behaviors of participants in a specific social situation, and understand meaning through the interpretation of such behavior (Schensul, Schensul, & LeCompte, 1999, Madison, 2012). Typical data collection strategies include: observation, formal and informal interviews, and examination of available documents (Roper & Shapira, 2000). The use of multiple methods of data collection, or triangulation, aims to secure understanding about the phenomenon in question that adds “rigor, breadth, complexity, richness, and depth to the inquiry” (Flick, 2002). Validity of the data is also ensured through cross-checking (Minichiello et al., 1999).

Ethnography may take several forms, depending on the research questions, its scope, and the researcher’s perspective. Ethnography forms include auto ethnography, traditional, focused, critical, participant action research, visual, ethnomethodology, ethno-science, evaluation research, and experiential description. My research study was guided by critical ethnography.

Critical Ethnography Methodology

Critical ethnography is a methodology that studies people in naturally occurring settings referred to as the field. A researcher using critical ethnography needs to do intensive field work that involves the participation of the researcher in the setting to capture the social meanings of ordinary activities (Madison, 2012, Groenkjaer, 2002). An integral part of critical ethnography involves the researcher in constantly monitoring, reflecting upon, and reporting their role as a research instrument. This reflexivity helps the researchers better understand the findings and avoid misinterpretation (Harvey, 2011, Bamberger, Rugh, & Marby, 2006).

Critical ethnography was chosen as the most appropriate research methodology for my study as it allowed for an in-depth exploration of HIV+ women's experiences of using the PMTCT program to prevent HIV transmission in SSA. The emphasis of critical qualitative research is on holistic human experience and its relationship to power and truth, and offers the opportunity to closely examine health challenges from the perspective of those who live them daily (Harrowing et al., 2010). It allows a researcher to not only study and understand society but also to critique and potentially bring about change in society through his/her work. Additionally, it is an appropriate methodology for health research considering the contemporary perspective of health as a sociopolitical phenomenon that is influenced by power issues and dominance (Cook, 2005). Finally, it has been effectively applied in communities, healthcare settings, and common working areas of nurses.

Critical ethnography in my study. Critical ethnography is based on different ideologies, including emancipation, liberation, and social change (Scotland, 2012; Weaver & Olson, 2005), as well as on relativist ontology and belief in multiple truths (Scotland, 2012; Weaver & Olson, 2005). Relativism in critical ethnography means that researchers believe that if there is an absolute truth, it is difficult to know. Epistemologically, the truth is both socially constructed and influenced by the power of relationship and reciprocity from within society. (McCabe & Holmes, 2014; Scotland, 2012; Weaver & Olson, 2005). Critical ethnographers argue that truth and reality are socially constructed and influenced by interpersonal relationships in society (Scotland, 2012). Truth is, therefore, co-constructed by research participants and researchers. Thus, in my research, knowledge was constructed in collaboration with HIV+ women using the PMTCT program, the researcher, healthcare workers, experts in HIV/PMTCT, and policy and decision-makers. Knowledge generation around a phenomenon of interest and within research studies is defined as an active and context-based process influenced by the histories, values, and practices of both research participants and researcher (Barton, 2001).

My intention in this research was to increase knowledge related to the delivery of the PMTCT program to prevent HIV transmission to the newborn. Critical ethnography is an appropriate exploratory and descriptive method that helped me identify factors that influence and challenge the uptake of the PMTCT program, and critically examine the experiences of mothers using the PMTCT program to prevent HIV transmission.

Ontology assumptions of critical ethnography. Ontology refers to beliefs about the nature of reality (Tuli, 2010). In philosophical terms, it refers to the study of our existence and the fundamentals of reality or being. Beliefs about the nature of reality are for determining what can be known about it (Flaming, 2004). Ethnography is one of the qualitative research designs that assume meaning and reality are socially constructed. Ontologically, critical ethnographers assume that individuals make sense of their reality and that there are multiple truths (Scotland, 2012; Weaver & Olson, 2005). Critical ethnography reveals underlying issues that produce reality, which is not conclusive but is grounded in historical realism.

Historical realism embraces the view that reality is shaped by social, political, cultural, economic, ethnic, and gender values (Guba & Lincoln, 1994; Scotland, 2012). Critical ethnographers embrace an ontology based on the understanding that organizations are historically born in conditions of struggle and domination (Thomas, 1993). Critical ethnographers adopt a political purpose to change, believe there is something better out there, and aim to work toward it (Thomas, 1993).

Epistemology assumptions of critical ethnography. Epistemology examines the relationship between knowledge and researcher during discovery. It is the nature of knowledge and it addresses the questions of how we know what we know, what is the relationship between the knower and what is known, and what accounts as knowledge (Tuli, 2010). Knowledge in critical ethnography is both socially constructed and influenced by power relations from within society (Scotland, 2012). Critical ethnographers start to explore a phenomenon having their preconceived ideas whereas they seek to expose underlying meaning(s) with an aim for change (Thomas, 1993). In critical ethnography research, knowledge is both socially constructed and is created through a dynamic interaction between the participants and researchers, the emancipation of both, and the transformation of the lived reality (Gorden, Holland, & Lahelma, 2001). The research aims to discover what is distorted and, through the praxis, tries to transform reality. Critical ethnographers assume reality can be transformed through the critical review that may bring about an emancipatory function of knowledge and human activity beginning with consciousness-raising, which addresses matters of social justice reality (Scotland, 2012).

Axiology assumptions of critical ethnography. Axiology is defined as a study of intrinsic value and what is worthy (Hill, 2011). It is referred to as a moral positioning, or values that form the basis for the research activities (MacDonald, 2010). In the broadest sense, axiology can mean ethics, economics, religion, aesthetics, politics, and/or science (Encyclopædia Britannica, 2015). In critical ethnography, researchers acknowledge the ethical responsibility that addresses unfairness and injustice (Madison, 2012). Conducting critical ethnography to explore the experiences of mothers using the PMTCT program to prevent HIV transmission raised awareness that will lead to consciousness-raising about the PMTCT of HIV, promoting maternal and child health, and community health care.

Ideology assumptions of critical ethnography. Ideology is a system of beliefs retained by an individual, group, or society. Rejai (1991) defines ideology as an emotion-laden, myth-saturated, action-related system of values and beliefs about people and society, legitimacy, and authority that is acquired to large extent as a matter of faith and habit. Rejai (1991) considers that the values and myths of ideology are communicated through symbols in a simplified, economical, and efficient manner. Ideologies have a potential for mass mobilization, manipulation, and control; in that sense, they are mobilized belief systems (Rejai, 1991).

Critical ethnographers examine the dominant societal ideologies about a phenomenon and assert that ideological domination is strongest when oppressed groups see their situation as inevitable, natural, or necessary (Cohen, Manion, Morrison, & Wyse, 2000). Scotland (2012) highlights that the pre-existing meaning-making system which people are born into distorts their understanding of phenomena, and that they are unaware of this. Interpretive research studies often neglect external structural forces which influence behavior, but critical ethnography looks upon all of those factors. Participants might not be aware of the invisible ideology which guides their actions, and so their explanations of phenomena are incomplete. Consequently, the researcher must have both etic and emic positions to uncover reality (Scotland, 2012).

Critical ethnographers believe that exposing the existing system and liberation ideologies reflects emancipation. Critical ethnography critiques and exposes existing systems in a bid to serve the interests of disempowered or marginalized people. There is an assumption that the dominant or existing system is unjust or repressive and needs to be exposed to trigger the possibility for change (O’Leary, 2004). This research methodology attempts to expose the political nature of knowledge and unmask the dominant forces that shape our worldview or research participants' views. By critical examination of worldviews, power, and ideology, the critical ethnographer attempts to contextualize the current situation in a larger socio-historical framework that offers and encourages others to engage in critical reflection (O’Leary, 2004).

Critical ethnography is considered as ethnography in action. It strives for social change as the ideology of inquiry. It first changes the cognitive thinking of the investigator, offers a voice to marginalized or disempowered people, instigates interactions with others that raise social awareness, creates networks of those with common goals, and becomes a starting point for policy or/and legislative reform (O’Leary, 2004).

Critical ethnography derives from the multiple critiques of research approaches that recognize that society dominates people either overtly or covertly, and rather than identifying the imbalance, seek to create fundamental social change through power. This power is a force that can be derived from multiple angles, such as having to fit in with workplace politics, wear a specific uniform, conform to rules and regulations, or perform according to specific standards or expectations. The power of discourse encompasses the ways of thinking, seeing, and conversing about something that create a virtual arena where action can be enabled (Ross, Rogers, & Duff, 2016).

Positionality: emic and etic perspective. Critical ethnography is subjective, using the researcher as a key instrument (Roper & Shapira, 2000). It is not the aim of critical ethnography research to be neutral or value-free. Researchers need to acknowledge their power, privilege, and biases that surround their subjects (Madison, 2012). Any interaction between participant and researcher is influenced by the researcher's beliefs, biases, values, gender, age, sexual orientation, ethnicity, culture, nationality, language, class, privilege, education, professional, status, and life experiences (Ravitch & Riggan, 2012). Researchers using critical ethnography must likewise address how subjectivity informs and influences reality or is informed by researchers' engagement and representation of others.

The terms emic and etic help to understand how ethnography researchers position themselves within the research as an insider or an outsider. Emic and etic are two constructs that are well tied to the epistemological principles, and address issues on how knowledge is acquired and to what degree a particular topic can be known (Naaeke, Kurylo, Grabowski, Linton, & Radford, 2011). The researcher's insider (the emic) or the outsider (the etic) role is to acknowledge that the interpretations of participant interactions and observations are shaped by the researcher's norms, cultural values, and social locations (Creswell, 2009). Likewise, participants have their own values, norms, biases, and beliefs that influence their interaction with the researcher. In short, these factors shape the research questions and the participants' answers, and determine the interaction and relationship between the researcher and participants (Bhugra & De Silve, 2000).

As a primary researcher in this study, it is important to reflect on my background, my experiences, values, beliefs, and social locations to determine my perceptions and interpretations of my participants and their experiences. I consider myself an insider because I am a Rwandese with proficiency in the national language (Kinyarwanda), female, married and mother, and share the same culture, values, taboos and misconceptions, and perceptions that shape the community where the participants live. However, I also consider myself as an outsider as I am an educated woman studying at a North American university. I am not HIV+ and have not had an HIV+

infant. As mentioned by Spradley (1980), I want to understand the world from participants' point of view, their experiences in using the PMTCT program, the barriers they are facing, and how the PMTCT program can be implemented more effectively.

Being an insider (emic) to the research context has multiple benefits including better knowledge and understanding of the context and language which positively influence participants' interaction and connection. However, the researcher has to be vigilant and as objective as possible to not miss information. Participants might assume that the researcher knows the answers to the questions and the researcher may be biased in favor of the researcher's culture (Naaeke et al., 2011). The advantage of being an outsider (etic) is that it allows you to ask a variety of questions; however, it takes a while to gain the trust of participants.

Mutual respect between researcher and participants, patience, avoiding judgment, and continuous self-evaluation are the key elements that support the researcher to understand the phenomenon. (Naaeke et al., 2011). Vandenberg and Hall (2011) advise that there is a need for researchers to balance their distance from and involvement with participants. I stayed in contact with my supervisory committee during the fieldwork where I provided regular updates on the research process, discussing with them the issues arising in the field, sharing the emotional issues arising during data collection, and themes arising during the data analysis.

Theoretical Framework: Intersectionality

Intersectionality is a theoretical framework that has been used for at least the last three decades; it has been used in different research studies that aimed to improve population health. It has also been used for overcoming health issues in vulnerable populations (Bowleg, 2012; McCall, 2005; Viruell-Fuentes, Miranda, & Abdulrahim, 2012).

Historical background of intersectionality. The root of intersectionality is traced to black feminist scholarship. Kimberle Clenshaw, a lawyer and African American feminist scholar, first introduced the term intersectionality in the late 1980s (Caiola, Docherty, Relf, & Barroso, 2014). In her early scholarly work, she was inspired by both women and people of color (Guidroz & Berger, 2009). According to Crenshaw, intersectionality is not merely a multiplying of identity categories like race, and gender, rather it is a kind of analysis for how particular identities and conditions are located with power structures (Crenshaw, 1991; Guidroz & Berger, 2009; McCall, 2009). Furthermore, intersectionality is a way of understanding social location in relation to the way systems of social class, race, gender and other identities interact on multiple and often simultaneous levels, contributing to inequality (Hankivsky, 2012).

In 1990, an African American sociologist and feminist scholar, Patricia Hill Collins started publishing a large number of works on intersectionality including writings on feminist thought on knowledge, consciousness, and the politics of empowerment (Committee on Lesbian Gay, Bisexual, & Transgender. 2011). In her work, Collins critiqued feminist scholarship of that time and mentioned that social theories fail to acknowledge that social context produces theories that seem to be universal; but in reality, theories are positioned within their specific social context (Spelman, 1998). Intersectionality is defined as a theoretical framework used to analyze how social and cultural categories intertwine (Bowleg, 2012).

Intersectionality was developed to help people consider that discrimination happens based on a variety of factors and the interrelationships among them. Intersectionality provides the ability to see the various causes of discrimination, as well as the language needed to address them. Viruell-Fuentes and colleagues (2012) argued that different identities and social categories link one another and work together, consequently resulting in inequality. The main goal of intersectionality is to grasp the relationships between identities and cultural categories instead of looking at various sources of discrimination separately (Buell, Glancy, Kartzow, & Moxnes, 2010).

Intersectionality framework in building nursing knowledge. Intersectionality is well suited to the nursing discipline because an understanding of how social location identities affect individuals, families, and communities allows nursing practice to become more efficient in caring. It can help nursing researchers, scholars, or practitioners to make sense of the world and provide detail on intersecting factors that may contribute to ill-health, and on how to promote, prevent, and take care of people. I agree with Van Herk, Smith, and Andrew (2011), who purport that an intersectionality perspective is a means by which nurses can respond adequately to issues of privilege and oppression within their profession and practice in general. In addition, nurses work in different conditions that affect healthcare access, such as racism, oppression, and disadvantage, which are fundamental to inequalities in healthcare outcomes (Pauly, MacKinnon, & Varcoe, 2009). I believe that clients are well cared for if they are considered as a whole. Within this statement, intersectionality mirrors holistic care in nursing.

Intersectionality framework and HIV+ women. Intersectionality is a strong approach to investigating health disparities experienced by HIV+ women. It provides better understandings of the social determinants of health, social inequality, and power structures (Caiola et al., 2014) that impact their lives. The choice to use an intersectionality framework in this study is based on two considerations: the magnitude of the HIV disease burden and disparity in health outcomes in marginalized people across racial, gender and socioeconomic status (Caiola et al., 2014); and the promise of the intersectionality framework in focusing on knowledge development via minority, non-dominant, and marginalized groups.

Why the intersectionality framework guided my work. The PMTCT of HIV as described in the literature review is a complex phenomenon in which social identities are multiple and intersecting. There are reciprocal interactions between gender, race, dissimilarities in individuals' lives, and other categories such as social practices, religious beliefs, education level, institutional norms, cultural ideologies, legal and political aspects, poverty, and outcomes of these interactions in terms of power (Davis, 2008; Parmar, 2017). An intersectionality framework for this research provided resources for more comprehensive identification of inequalities, contributing factors, and directions for developing intervention strategies specific to the community studied (McCall, 2005; Rogers & Kelly, 2011). The intersecting factors that contribute to the complexity of the issues of the PMTCT of HIV were better understood through intercategorical approaches to intersectionality, that is, the pragmatic use of categorization to explore health impacts of multiple identities or social positionalities (Bowleg, 2012; McCall, 2005).

Furthermore, intersectionality aims to address issues like racism, patriarchy, class oppression and other systems of discrimination that create inequalities, and in return shape the relative positions of minorities. Likewise, it takes account of the historical background of people, and their living, social, and political contexts (Women's Rights & Economic Change, 2004). An intersectionality framework suggests and seeks to delve into how various biological, social, and cultural categories such as class, gender, sexual orientation, race, and other identities interact on multiple and often simultaneous levels, contributing to inequality, and allows for a focus on the experiences of subjects whose voices have been ignored (Bowleg, 2012; McCall, 2005; Nash, 2008).

Social identities such as race or ethnicity, socioeconomic status, religion, age, mental health, disability, gender, and geographic location are historically linked to exclusion or discrimination (Bowleg, 2012), and are known to have a great influence on health status (United States Department of Health & Human Services, 2011). Acknowledging the existence of multiple intersecting identities is an important and initial step in getting a better understanding of the complexities of health disparities for people from historically oppressed groups. The critical step is recognizing how systems of privilege and oppression that result in numerous social inequalities (e.g., sexism, racism, heterosexism, and classism) intersect at the macro-social structural level to maintain health disparities (Bowleg, 2012).

Intersectionality is a theoretical framework for understanding how multiple social identities such as race, gender, sexual orientation, socioeconomic status, and disability intersect at the micro-level of individual experiences to reflect on interlocking systems of privilege and oppression at the macro-social structural level (Crenshaw, 1991; Davis, 2008). In addition, intersectionality provides the disciplines related to health with a critical unifying interpretive and analytical framework for framing how scholars may conceptualize, investigate, analyze and address health disparities and social inequality.

It is reasonable to use an intersectionality perspective to study a phenomenon using critical ethnography methodology, as is the approach in my research. Harvey (2011) explains that critical ethnography is a particular approach to ethnography that attempts to link the detailed analysis of ethnography to wider social structures and systems of power relationships to get the truth that lies beneath the surface of oppressive structural relationships. Intersectionality marries critical ethnography ontology which focuses on not only the obvious, but on the truth that lies beneath of surface. We can observe increased MTCT of HIV as an obvious phenomenon, but the contributing factors may have a root in different identities. In addition, critical ethnography holds in its ontology that reality and meaning are socially constructed, and that truth is neither conclusive nor linear. Truths are multiple and shaped by history (historical realism) (Scotland, 2012). Within this context, critical ethnography marries relativism truth; what is truth to one individual or social group may not be true to another (Scotland, 2012; Weaver & Olson, 2005). The results from this study were a picture of truths experienced by mothers using the PMTCT program in Rwanda.

Intersectionality helped me in exploring the experiences of mothers using the PMTCT program to prevent HIV transmission in Rwanda. I found intersectionality to be an excellent tool to explore more on the roots of inequality, oppression, and discrimination. It offers a way to study complexity around a phenomenon and illuminates social forces shaping inequalities, which then may be useful to PMTCT implementers, policymakers, and researchers working in the PMTCT program to address the high rate of MTCT of HIV. Furthermore, it can contribute to building nursing knowledge and improving nursing practice, policy, and research related to PMTCT of HIV.

The Setting of Research Study

My research setting was in Rwanda, specifically the region serviced by the PMTCT program delivered at the Butare University Teaching Hospital (BUTH). Rwanda is a country in central and east Africa, bordered on the north by Uganda, on the east by Tanzania, on the south by Burundi, and on the west by Lake Kivu and the Democratic Republic of the Congo (formerly Zaïre). Its size is approximately 26,338 square kilometers, and it has an estimated population of 12 million (World Population Review, 2019). Rwanda's capital city is Kigali.

Figure 2
Rwanda Map with Districts: Source: https://maps-rwanda.com/rwanda-map-with-districts

BUTH is in Huye District, Southern Province, within the premises of the National University of Rwanda. It is one of the national referral hospitals and serves mainly the Southern and Western provinces'populations, estimated to be 3,777,230 peoples (CHUB [Centre Hospitalier Universitaire de Butare], 2019). These provinces are predominantly rural. There are eleven districts under BUTH's catchment area, including Huye, Nyamagabe, Gisagara, Nyamasheke, Rusizi, Nyaruguru, Nyanza, Ruhango, Muhanga, Karongi, and Ngororero.

The research study was carried out in the PMTCT program that is delivered at the Butare University Teaching Hospital (BUTH). The number of HIV+ women, and infants and children in the CHUB/PMTCT program was 153 by the end of July 2021 (CHUB, 2021). The PMTCT program at BUTH began in January 2006 as the center of excellence to pilot the model care of infected and exposed children on HIV.

In August 2019, I did a preliminary visit to my research study setting. This visit was very helpful in terms of getting information about the PMTCT program and the catchment area. I met with the PMTCT program manager at Butare University Teaching Hospital (BUTH) and he explained how the PMTCT is provided at BUTH.

Access to the research setting. After getting all required authorization including ethical approval from the University of Alberta and the Butare University Teaching Hospital ethics committee, I presented the above obtained ethical approval document to the hospital leaders and the PMTCT manager to get permission to access the research setting.

The Study Population and Sample

The population of the study. The population of my research study was composed of various categories of people who are closely related to the PMTCT program at BUTH, including HIV+ mothers who used or are using the PMTCT program and who have a child or children (either HIV+ or negative); healthcare providers working in the PMTCT program; the PMTCT leaders (such as PMTCT manager; in charge, nurse managers, and heads of departments for both internal medicine and paediatrics); HIV+ women attending the PMTCT program at internal medicine and children under 15 years attending the PMTCT program at the pediatric department; and policymakers (such as policy coordinator, PMTCT manager, and policy committee).

The Sample of the study. In this study, I conducted 29 individual interviews which included 15 HIV+ mothers with HIV negative babies and 14 HIV+ mothers with HIV+ babies. I conducted focus groups with two HCPs groups working at the PMTCT program at pediatric and internal medicine department, and one group with policy-makers. Sixteen people participated in these focus group. I also conducted six individual interviews with two HCPs who were not present at the time of the focus group, and four PMTCT leaders. Data were collected until I obtained a rich and in-depth understanding of the phenomenon under study (Kumar, 2011).

Recruitment of Research Participants

The process of recruitment of research participants is explained using the table to make it easier to understand with a quick view (Table 2).

Table 2:

Recruitment of Research Participants

Sampling Methods	Inclusion Criteria	Exclusion Criteria
Purposive sampling	HIV infected pregnant and breastfeeding women with an infant or children	Mentally disabled
	HIV+ mothers who used or are using the PMTCT program	Participants who experienced any kind of control and needed permission from their husband and/or partner, to be part of the study
	Healthcare providers working in the PMTCT program	
	Being part of PMTCT leaders (e.g., head of a department, nurse manager, in-charges and in charge for PMTCT)	
	Policymakers (e.g., policy coordinator, policy committee)	

To enhance the richness of data, I employed purposeful sampling and network strategies to recruit knowledgeable participants who met the inclusion criteria, had sound experience with the phenomenon of interest, could communicate their experiences, and were willing to participate in the study. I did my recruitment at the PMTCT program, and HCPs working in the program helped in the recruitment process by introducing me to participants and asking them to complete consent for release of contact information. I clearly explained to them that completing this form did not provide consent to participate in the study but only gave me permission to contact prospective participants to give them more information about the study and aske them to participate. Those who accepted to participate then signed a consent form.

Data Collection

I employed multiple sources of data collection to develop an understanding of the experiences of mothers using the PMTCT program to prevent HIV transmission in Rwanda. Given my theoretical lens and emancipatory agenda of critical ethnography, the use of multiple sources of information was preferable in order to give me the ability to become closer to participants and to capture what was happening in their daily lives and activities (Shi, 2012). Critical ethnnographers use multiple means to collect data, including interviews, focus groups, field notes, documents review, and observation (Batch & Windsor, 2015). In exploring the experiences of mothers using the PMTCT program to prevent HIV transmission in Rwanda, I used participant documents review, observation, field notes, and interviews (individual and focus group interviews).

I entered Rawanda prior to the outbreak of the coronavirus pandemic (COVID-19) which has created a dramatic situation throughout the world. To protect the Rwandan people, national guidelines and policies around COVID-19 prevention and response to this pandemic were implemented. The COVID-19 situation in Rwanda on April 20, 2021 was 22 new cases out of a total of 23,934 total cases, 22,408 recoveries, 1,322 active cases, and 326 deaths. Clients are still visiting clinics and meet with their physicians and other HCPs, but they have to respect the measures to prevent the spread of COVID-19 during their visit by practicing physical distancing, wearing a mask, washing their hands frequently, avoiding touching their faces, and self-isolating if they have COVID-19 symptoms.

The services at the PMTCT clinic have continued since the outbreak of the pandemic as it is considered an essential service. Throughout the time of data collection, strict measures were in place to protect both the staff and patients during interactions: wearing protective wear, face masks and facial screens; ensuring social distancing, and performing regular handwashing. The physical health of all health care providers was screened every time before participation in the clinic. These guidelines were similar to the guidelines required by the University of Alberta related to data collection during the pandemic.

As critical ethnography requires long-term engagement in the field as a participant-observer, I received consent to be a volunteer at the PMCTC clinic at BUTH. I continued to volunteer at BUTH and I engaged to some extent in the activities taking place, observing people in their daily activities, doing home visits with PMTCT healthcare providers, interacting with people socially outside of a controlled research place, and identifying and developing relationships with stakeholders. I strictly followed the same personal protective measures as the health care providers.

Document analysis. Document analysis is a method of data collection used by researchers to interpret documents, and give a voice and meaning around the area of study (Bowen, 2009). Document analysis was used in combination with observation, field notes, and interviews as means of triangulation, and as a source of research evidence. It helped me to seek convergence and corroboration through the use of different data sources and methods.

I conducted a document review related to information about HIV+ women using the PMTCT program at BUTH. I gathered information from PMTCT policies and guidelines, patient files, and some reports in relation to my research participants. Patients' files provided me background information, contact information, the results of HIV tests for all family members, as well as the historical insight of my research participants. The information contained in the patients' files and the PMTCT program reports helped me to suggest some interview questions that I asked, inform my data, and develop a better understanding of my research question and the situations to be observed as part of my research. From the monthly reports, I found the list of clients, how many missed their appointments, ARV adherence participant report, and the schedule of home visits. I went with HCPs on home visits to build trust with my research participants, and to observe them in their daily activities.

Observation and field notes. Observation is a common method of data collection in critical ethnography, and requires long-term engagement in the field as a participant observer. (Madison, 2012). I received consent to be a volunteer at the PMCTC clinic at BUTH on December 16, 2019 (See Appendix O). I used participant observation; that is, observing the scene and being a part of it (De Chesnay, 2015).

Participant observation goes hand in hand with taking field notes and documenting what was observed. Participant observation was done in the different events of the PMTCT program, and during home visits with PMTCT healthcare providers. Inspired by Mack, Woodsong, MacQueen, Guest, and Namey (2011), my roles and responsibilities as participant-observer were observing people in their daily activities, engaging to some extent in the activities taking place, interacting with people socially outside of a controlled research place, and identifying and developing relationships with stakeholders. I spent 12 months doing observations.

I also did document review, and wrote field notes from my observations. This gave me the ability to capture what was happening to participants in their daily lives and activities. Consequently, it contributed to an in-depth understanding of the phenomenon or social problem. I recorded actions and events observed and their context for the field notes to become meaningful to an outsider (see appendix G). Scratch notes were kept during the observation periods, which were then developed into detailed field notes as soon as possible after the period of observation (Batch & Windsor, 2015). Hence, data generation involved observing what the research participants said and did, their daily activities, and non-verbal interactions in the PMTCT program environment. This kind of observation implied that I paid attention to the voices of participants, and voiceless items or objects/behavior that give meaning to the reality in my community of interest. I used a narrative recording to present my observation (Kumar, 2011). Also, field notes were recorded directly following observation periods with attention to thick description.

I participated in home visits with HCP teams. The purpose of the HCPs' home visits was to discover the clients' situations and assess their health needs, provide both psychosocial and emotional support, provide preventive, promotive, curative, or rehabilitative services, improve followup of the PMTCT clients, help the clients retention in the PMTCT program, and improve ARV adherence. The HCPs left their cars far from the clients' homes and walked for five to 10 minutes to preserve confidentiality of the PMTCT clients. They used to rent cars and avoid hospital cars with hospital identifiers to keep their visit confidential. As well, they visited neighboring families and provided health education sessions for a few minutes to make the visit more general and avoid exposing the PMTCT program clients.

During the HCPs and HIV+ women interaction, HCPs tried to act in the best interests of the women and maintain relationships that were with all intent to only benefit the clients. Before the home visit, the HCPs discussed the cases in their staff meetings to gain the necessary knowledge needed for a good interaction. Most women felt comfortable disclosing their personal information and asking questions. A few were not open to the HCPs. Typically, these were new cases and their openness was dependent on their level of HIV acceptance and their disclosure status.

Individual interviews. Data were collected in the participants' language, Kinyarwanda, which was also my mother tongue. Individual interviews, which were one to two hours in length, were conducted with HIV+ mothers who have used or are using the PMTCT program and who have or not have an infected infant or children. I conducted the interviews myself. Interviews were conducted at an agreed-upon time and place, and were audio recorded. If participants had been uncomfortable about being recorded I planned to give them the option to decline the audiorecording. None of the participants were uncomfortable being recorded.

The interview process was guided by a semi-structured interview guide for both individual and group interviews. Semi-structured interviews allow an interviewer to follow up on an idea raised by research participants that needs clarification or further discussion (Olson, 2016). In addition, a semi-structured interview aims to begin a relationship with research participants, and create a conducive environment where research participants feel free to tell their story.After data collection, I transcribed all interviews in Kinyarwanda. Additionally, after each interview, I did a self-debriefing session to review the information gathered and possible challenges.

During volunteering and field work, I maintained trusting relationships with HIV+ women and engaged in dialogue with them. I also established trusting relationships with HCPs working in the PMTCT program, and key stakeholders. I shared the intent of the research, clarified my role as a critical ethnographer, and provided information about the potential implications of the research findings. I continuously evaluated my actions while undertaking field observations and interacting with research participants and stakeholders.

During formal and informal interactions with research participants, I ensured that my social class as an educated female, as well as my positionality as a nurse did not serve as a barrier. I avoided attending to any unrequested act such as helping, advising, teaching, or intervening. I tried to maintain field notes to demonstrate a non-judgemental attitude, and maintain trusting relationships with the participants. That is in line with building rapport with the research participants. Rapport is very important in critical ethnography as it allows easy flow of the interview as well as the conversation. Moreover, rapport enables researchers to become more aware of how their behaviors may impact or affect research participants negatively (Mack et al., 2011).

It is wise to determine where the interviews would take place, bearing in mind that a researcher in a qualitative research study has power over research participants (Olson, 2016). Power imbalance was considered, and I strived to overcome the potential power situation by creating a conducive space for information exchange, and additionally giving space for participants' concerns to be raised. The researcher is cognizant that simply being researched can create feelings of discrimination (Devereux & Hoddinott, 1993). During data collection for my study, the appropriate and/or the best place for conducting the interviews was discussed with key informants and stakeholders. I received an office in the building close to the PMTCT clinic where no one could hear my conversations with participants. The office was in a neutral and quiet setting, with little distraction and noise, and the phone was on silence to make the interview more comfortable, effective, and private. Participants were also asked where they would like to be interviewed and most of them were happy with the interview office. The length of each interview was between one to two hours.

Focus group interviews. I also conducted focus group interviews. All interviews were audio-recorded with the permission of participants. A focus group interview is a qualitative data collection method where a researcher interviews a group of participants face to face, to answer questions on a topic of interest. Within a focus group, the research participants interact with each other (Moser & Korstjens, 2018). Focus groups enabled me to observe interactions among group members (Olson, 2016).

In this study, focus group interviews were conducted with each of the following groups: (1) healthcare providers working in the PMTCT program (paediatric); (2) healthcare providers working in the PMTCT program (Internal Medicine); and (3) policymakers (policy coordinator, policy committee). This supported knowledge development related to the experiences of mothers using the PMTCT program for preventing HIV transmission in Rwanda, and how the PMTCT program can be implemented effectively. Similar to individual interviews, the focus group interviews lasted between one to two hours.

Data Collection Instruments/Tools

In critical ethnography, a researcher is a primary research instrument. Normally, data quality or the quality of the result is a product of a good interviewer (De Chesnay, 2015). As a novice qualitative researcher, my doctoral supervisor played a significant role in the data collection phase, as she provided me with guidance. I arranged for weekly meetings with her.

Besides human beings as data collection instruments, the data were collected using an interview guide (see appendices B, D, E, and F). The interview guide was in English but was translated in Kinyarwanda, the language of the research participants, prior to data collection. I did forward and backward translation where bilingual people (BJ, NT, KS, and AH), fluent in both Kinyarwanda and English, conducted the translation. Translation was both from Kinyarwanda to English (BJ and NT) and in the reverse direction (KS, and AH). I then compared the translations and handled the points of differences. To ensure confidentiality, all translators signed a confidentiality agreement consent.

Data Management

All interviews were transcribed verbatim by a professional transcriber (EH) after he signed consent for confidentiality (appendix K). I did the required data cleaning by going through each interview audio-recording and transcription. Data cleaning was required to check the accuracy of the interview transcription with the audio recording and fill any missed pieces of information. This helped validate that the interview data had been transcribed fully and allowed filling in any gaps in the data.

The electronic data were stored in an encrypted laptop to maintain confidentiality. I deleted the data from the recording devices once I had transferred the files to my laptop. The hard copies, field-notes, and other data collection materials (interview guide) were stored in a locked cupboard, and the key was accessible only to the researcher. I used a password protected shared Google drive to store the research data in a confidential and secure virtual research environment. The secured Google drive enabled me to secure the research data throughout the study, and provided a secure way of sharing files of audio interviews with my thesis supervisory committee. The access rights of the password protected shared folder was assigned to my thesis supervisors to facilitate continued mentorship from them during the data collection and analysis process. Immediately after data cleaning, I proceeded to data analysis.

Data Analysis

In this study, the data analysis included reflexivity, thematic analysis, and the use of ATLAS.ti software nine version to facilitate analysis, and organize data. There is no appropriate linear way to conduct qualitative data analysis, although there is universal agreement that qualitative data analysis is an ongoing and iterative process that normally starts in the initial stages of data collection and lasts throughout the study (Bradley, Curry, & Devers, 2007).

Reflexivity during observation was part of data analysis and a reason why I considered analysis during the early stage of data gathering. After data collection, the next step was reading transcripts for an overall understanding of the data collected. This highlights that data analysis involves frequent readings of the transcripts and field notes to increase familiarity (Manias & Street, 2000). The thematic analysis consisted of identifying, analyzing, and reporting themes or patterns within research data. By using thematic analysis, a researcher can describe and organize a data set in well presented detail (Braun & Clarke, 2006). Inspired by Moser and Korstjens (2018), after transcribing data from the field notes, interviews, and observations, I read transcripts, classified them into themes and added notes in the margins on the appropriate space in ATLAS.ti, and then assigned preliminary codes.

I described the social settings, events, and actors. Subsequently, I ordered themes, patterns, and regularities. In addition, I interpreted the experiences of mothers using the PMTCT program for preventing HIV transmission in Rwanda, and how the PMTCT program can be implemented effectively. Finally, I wrote the findings narratively by offering a detailed description of the experiences of research participants in using the PMTCT program.

The data were collected and analyzed in Kinyarwanda. Only a subset of data (three interviews: one with HIV+ mother with HIV+ baby, another with HIV+ mother with HIV negative baby, and another with HCPs) was translated into English so that my supervisory committee could have an idea of the data and help me to ensure rigor.

My supervisor and I extracted codes independently for comparison. I developed the coding framework that was crosschecked and agreed upon by my supervisor. She actively participated in the process of derivation of categories, sub-categories, themes, and sub-themes. This helped ensure that the analysis of the data reflected the experiences shared by the participants, and was able to answer the research questions. I then translated into English the quotes that I put in the text.

As documented by Maguire and Delahunt (2017), Nowell, Norris, White, and Moules (2017), Karlsen, Gabrielsen, Falch, and Stubberud (2017), and Clarke and Braun (2013), in my thematic analysis I followed these steps: become familiar with data, generate initial codes and sub-codes, search for themes, review themes, define themes, and write-up the findings. Becoming familiar with data is the step where the researcher starts immersing themselves in the data. It involves reading and re-reading the transcripts or data, listening to the recording audio, and remarking initial analytic observations (Clarke & Braun, 2013; Maguire & Delahunt, 2017). Nowell et al. (2017) call this step a repeated reading of the data phase.

Generating initial codes is the initial production of codes (Nowell et al., 2017). It is simply a process for coding data, generating labels to the vital features. Coding was conducted inductively, which means that it was data-driven rather than using pre-established codes (Clarke & Braun, 2013; Nowell et al., 2017). This step helped in reducing data because I tried to group data in specific codes, sub-codes, sub-themes, and themes (Clarke & Braun, 2013; Nowell et al., 2017). Coding helped me to systematically organize data to simplify and focus on specific features or characteristics of the raw data (Maguire & Delahunt, 2017; Nowell et al., 2017). I identified the important sections in the data and attached a label/code to each.

Searching for themes was the step where I developed meaningful and coherent patterns of findings or data based on research questions. In this step, I combined the codes to detect similarities in the data. Analogous to the coding step, themes were developed inductively. The themes were strongly linked with the data.

Reviewing themes is a step where I tested the workability of the themes. I checked if themes told a compelling and convincing story about the collected data. In this step, I also combined or split themes, and discarded others (Clarke & Braun, 2013; Maguire & Delahunt, 2017; Nowell et al., 2017). At this stage, I generated a new theme when a relevant issue that was not covered by existing themes was identified, and I managed to diminish the number of themes into a manageable set.

Defining themes is a step where a researcher writes a thorough analysis of each theme, identifies the importance of the themes, and constructs a succinct theme (Clarke & Braun, 2013; Nowell et al., 2017). I verified if theme names gave the readers a sense of what the theme was about. As the final stage or phase of refining themes, it was the time to check how subthemes related to the main theme, and how themes were related to each other (Maguire & Delahunt, 2017). At this stage, I solicited input from experts in thematic analysis to check if there was no aspect left behind as suggested by Nowell et al. (2017). I used my supervisor to verify the development of the themes.

Writing the findings is the step where a researcher documents the findings in a way he/she tells readers a persuasive and cohesive story about the data (Clarke & Braun, 2013). This is the final step where a researcher uses quotes to help a reader to understand specific points of interpretation (Nowell et al., 2017).

Trustworthiness

Several qualitative researchers have opted to use the term trustworthiness instead of rigor to distance themselves from a positivist paradigm. Irrespective of the terminology used, a research process that is sound and credible with consistent results is required. According to Lincoln and Guba (1985), trustworthiness is achieved when the research findings closely reflect the meaning described by the participants. Nowell et al., (2017) revealed that trustworthiness goes with obtaining valuable results and this requires an active approach, building strategies into the methodology design to ensure that methods and procedures used are appropriate. For this study, I followed the framework described by Lincoln and Guba (1985) as supported by Nowell et al. (2017) for ensuring rigor whereby trustworthiness is established through credibility, dependability, transferability, and confirmability.

Credibility. Credibility is equivalent to the internal validity concept in quantitative research. Credibility is the key component in qualitative research because it deals with the degree to which the findings are congruent with the reality of the research participants (Lincoln & Guba, 1985; Nowell et al., 2017). In this study, credibility was achieved through prolonged engagement, persistent observation, negative case analysis, triangulation, member checking, external audits, peer review or debriefing, thick and rich descriptions, and preventing researcher bias. During my data analysis that was done concurrently with data collection, I found some complexity of data that had viewpoints that differed from the main body of the evidence, that did not support or appeared to contradict patterns or explanations that were emerging from data analysis, confronting messages on HCPs attitudes, the duration of breastfeeding, and availability of the PMTCT policies. The complexity and varied formats of qualitative data often lack consistent structure; however, all are useful and imperative for conducting a comprehensive analysis which increases the credibility of my study. The complexity of data helped me gain good understanding from different perspectives of the phenomenon under investigation. It increased my level of knowledge about my research area, and strengthened the researcher's standpoint for various aspects.

Morse (2015) proposes that a prolonged engagement between researcher and participants helps to gain a better understanding of the area of study, and to build a trusting relationship. I spent one year in the research field. Furthermore, I did persistent observation during the time I spent on the field, which contributed to the enhancement of my research credibility. As well, I attempted to consider negative cases that occurred during data collection. The negative cases often provided the key to understanding the norm or the most commonly occurring cases, which is one of the core elements in critical ethnographic studies (Morse, 2015).

Additionally, triangulation, member checking, and external audits are commonly used to highlight the credibility of research inquiry (Nowell et al., 2017). Triangulation refers to using different methodologies to study the phenomenon of interest; or based on multiple researchers where a researcher uses more than one investigator to study the same phenomenon; or based on data where a researcher uses different resources to gather information on a phenomenon under investigation (Anney, 2014). I used multiple methods to ensure that all aspects of the phenomenon had been investigated, as well as to overcome methodological shortcomings since no one method can fully deliver on multiple truths (Morse, 2015; Guba, 1981). The multiple methods helped me to provide several different angles. In this study, I utilized data gathering triangulation by using observation, review of documents, individual interviews, and focus group interviews to collect data. I did not plan to use member checking; however, I documented systematically the methods used to collect the data thereby allowing external audits to be possible.

In most qualitative research studies, peer review or debriefing is considered a strategy for a researcher to distance from research ‘etic positionality’ instead of building the credibility of the study (Baumbusch, 2010). In this study related to the PMTCT of HIV, peer review or debriefing played both roles, both adding to credibility, and distancing from the research setting. I shared information related to the fieldwork and data gathering with my supervisory committee members.

Another element of credibility is having frequent debriefing sessions with a member of the supervisory committee. Debriefing sessions are respected since the supervisory committee provides an environment for strong discussions about what is going well and what needs to improve within the research process (Krefting, 1991). Similarly, because most researchers are intimately involved with their work, allowing an impartial researcher to review one's work with a fresh pair of eyes and a clear mind can keep the researcher honest while contributing to the rigor of the study (Krefting, 1991). I, therefore, did a debrief with my doctoral supervisor and the supervisory committee regularly to seek clarity and guidance.

Transferability. Transferability appraises whether research findings are transferable to other specific settings. The concept of transferability in qualitative research is similar to external validity or generalisability in quantitative research, which means extending the research results, conclusions, or other accounts that are based on the study of a particular population, times, setting, to another area than those directly studied (Morse, 2015). This concept was introduced by Lincoln and Guba in 1985 to evaluate the trustworthiness of findings. To ensure transferability in my study, I provided enough contextual information about participants' background information, where the research took place, and data generation to enable readers of this study to determine its transferability to similar sites. In my study, transferability was achieved through the thick description. When I took the field notes, I tried to contextualize my observations using all my senses, and wrote things that I saw, tasted, and heard. I also put myself in the research environment, recorded, and wrote all things that happened in the research field so that I had a thick description. This helps the readers of my research to get a better understanding of the context of the research so that they can situate themselves based on a similar situation described in the thick description.

Dependability. Dependability is another component of trustworthiness, which is similar to reliability (Shenton, 2004). Dependability questions whether the study can be repeated with the same results if it were conducted in the same context and with the same methods and participants (Guba, 1981). To ensure dependability in my research, I tried to be consistent with my research findings in the way I did observation and analyzed the data. I met dependability criteria by providing the operational aspect of data generation in detail from data collection, analysis, and interpretation. Also, to achieve dependability, I documented the research process in a traceable, logical, and clear way. Furthermore, trustworthiness was ensured via dependability by implementing an independent coding procedure by two researchers (Krefting, 1991). As part of ensuring dependability, I selected a subset of the coded data and had my supervisor ascertain the similarities, differences, and inconsistencies in the corresponding analyses. This allowed me to correct conflicting perspectives.

Confirmability. Confirmability refers to the ways the researchers demonstrate how findings, interpretations, and conclusions have been reached and delivered from the data (Newell et al., 2017). Confirmability is the final component of trustworthiness that refers to the quality of the research findings, and is achieved by way of reflexivity. "Reflexivity is the process of reflecting critically on self as the researcher and the human as an instrument" (Denzin & Lincoln, 2003, p. 183). Vandenberg and Hall (2011) advocate for every researcher to be reflexive to avoid reinforcement of power imbalance and oppressive behaviors. Considering the nature of qualitative research, which is subjectivity, the researcher should think about the two most important ways to gather information: observations and interviews.

Self-reflexivity refers to being aware of one's own assumptions, and the multiple social locations that one occupies, including class and gender (Creswell & Miller, 2000). Self-reflexivity enables critical ethnographers to undertake rigorous examination of their own selves, examine their relationship with participants, question if they hold any power over the participants, analyze the need to change their behaviour during the field work, gain know-how with their unconscious behaviour that affects the research process, and critically scrutinize their own motives and methods affecting any aspect of the research (Creswell & Miller, 2000; Anderson 1989; Horner, 2004). My regular interaction with the thesis supervisory team was another strategy that helped me to keep track of my self-reflexivity and positionality. I wrote my self-reflections and recorded them together with participants' interviews so that they could be included in my research. This helps the readers of a study to have more knowledge of who wrote the research in an attempt to limit subjectivity. Self-reflexivity is a necessary step in research to limit subjectivity in qualitative research.

Confirmability is also enhanced when truth claims, interpretations, and analyses are co-created with participants as was the case in this study. To apply reflexivity in my research study, I kept open reflection about my values and beliefs during the research process to prevent power imbalance in the research field between researcher and participants. Also, to be reflective, I took emic and etic positionalities. In the end, upholding the four components to establishing trustworthiness secured that knowledge development in this study is reliable and valid.

Ethical Considerations

Ethical approval was sought from the University of Alberta Research Ethics Board before the commencement of the fieldwork. Refer to Appendix M to view the ethics approval letter from the University of Alberta Ethics Board, Canada. The permission to access and collect the data within Butare University Teaching Hospital (BUTH) was requested and received from the BUTH Ethics Committee (Appendix N). The HCPs working at the PMTCT program helped me to identify HIV+ mothers, HCPs, policy makers, and PMTCT leaders who met the inclusion criteria, and invited them to participate in this study. At that stage, consent for release of contact information was utilized to recruit study participants. Refer to Appendix L to view the invitation (Consent for Release of Contact Information) for the research participants eligible to participate in the study.

On my first contact with study participants, I explained my role as a researcher. I informed HIV+ mothers, HCPs, policy makers, and PMTCT leaders about the purpose of the research, the research's expectation of participants, the risks and benefits of participating, the data collection methods that were employed, how long the data would be kept, and how it would be stored, and their right to withdraw from the study without any penalty. Refer to Appendix H, I, J to view the information letter and consent form for the study participants.

The participants were told that their participation was completely voluntary and that they would have the option to withdraw their data by contacting the researcher during the fieldwork of this study. The individual participants had the opportunity to withdraw their data for one month after the interview happened. In ethnography, analysis is iterative. I collected and analyzed the data concurrently, so one month was manageable on my behalf as a researcher for the participants to withdraw their data. They were informed during the consent process that they could do that by communicating their wishes to the researcher. The people participating in the focus group did not have the option to withdraw their data from the group discussion, but they could discontinue participating in the focus group. They were informed that withdrawal from the study would not affect their relationship with the PMTCT program. During this study, I did not receive any request from the participants to withdraw.

Considering the varied literacy levels (reading and writing levels of the participants), participants were given the option to give informed consent by either signature, thumbprint, or verbally. With the permission of the study participants, their verbal approvals to participate in this study were recorded after assigning a unique identification number. All of the information was provided in the national language of Rwanda (Kinyarwanda: see Appendix H1, I1, J1). Participants were allowed to ask questions or seek clarification before giving informed consent, or anytime during data collection. Participants were informed that only the principal investigator and the thesis committee members would have access to the data. Participants were additionally informed that they had a choice not to answer any questions if they did not want to. The participants were compensated for their time ($5=2000RWF [Rwandese Franc]) and any expenses incurred because of the research. No participants who were available at the time of research and met the inclusion criteria were refused from participating in the research.

Being a critical ethnographer, I was mindful of my positionality as an educated woman and nurse, hence I did not intervene or become involved in the provision of healthcare services to study participants. HIV+ women were my study population, they are vulnerable and have experienced pain of living with HIV+ with all related trauma in the recent past. Accessing them as study participants and asking to hear their insight came with great emotional and psychological risk. I ensured availability of psychologist services, and resources were readily available to participants during the interview. I decided that on encountering such a situation, I would pause the interview to allow the participant to settle down, and if required I would reschedule that interview at some other time. During the in-depth interviews, most participants cried during the interview but asked to continue to allow them to vent their feelings.

Participants were assured of their anonymity and confidentiality during the process of data collection, analysis, reporting, and dissemination. To assure anonymity and strict confidentiality of the participants, identification numbers were used instead of real names or pseudonyms to report the study findings. Consent forms were linked to identification numbers.

Conclusion

In this chapter, I have discussed ethnography, critical ethnography, and its related philosophical assumptions, and illustrated the rationale for the use of critical ethnography to study the PMTCT program. As well, I have described the theoretical framework of intersectionality, which informed and structured this research.My research aimed to explore the experiences of HIV+ women using the PMTCT program to prevent HIV transmission. The research study was guided by relativist ontology, which values multiple truths, constructivist epistemology, society change as the main ideology, and value-laden principle as its axiology. The ethical principles of respect, beneficence, and justice were considered in the research process. Data were generated using participant observation, document reviews, and both individual and focus group interviews. The data analysis was done thematically, and concurrently with data gathering, and ATLAS.ti software was used.

Chapter Four: Findings

This chapter presents the demographic characteristics of the participants and the findings derived from the analyzed data. Data were collected using participant observation, field notes, document reviews, and individual and focus group interviews. Demographic data were collected from HIV+ mothers and the healthcare providers. In view of the research question and aims, the findings are presented under four main themes: factors that influence and challenge the uptake of PMTCT; identities intersecting with the uptake of the PMTCT program; health system factors affecting the delivery of the PMTCT program; and experiences of HIV+ mothers during the prenatal, perinatal, and postnatal periods to prevent HIV transmission. Each theme has sub-themes, categories, and codes that present the experiences of mothers using the PMTCT program to prevent HIV transmission in Rwanda. To assure strict anonymity and confidentiality of the participants, the quotes of the participants were assigned numbers instead of pseudonyms or any other identifier. The codes used are as follows:

-PMWNB: Positive Mother with Negative Babies
-PMWPB: Positive Mother with Positive Babies
-HCP: Healthcare Provider
-PMTCTL: PMTCT Leaders
-PMTCTPM: PMTCT Policy Makers

Demographic Characteristics of the Participants: HIV+ Mothers

A sample of 29 HIV+ mothers who met the inclusion criteria were recruited and used in the study. I included HIV+ mothers who had used or were using the PMTCT program and who have had a child or children (either HIV positive or negative). The demographic characteristics are summarized in Tables 3 and 4, and Figure 3. Table 3 summarise the data on age of participants, level of education, marital status, women and husband employment status, and religion.

Table 3

Summary of the Demographic Characteristics of the 29 Participants

Characteristics	**Findings**	
Age of participants	**Number (n)**	**Percentage**
40-49 years	12	42
30-39 years	11	38
20-29 years	5	17
50years and more	1	3
Total	29	100
Maximum age: 50 years		
Minimum age= 24 years		
Level of Education		
No schooling	9	31
Primary school	10	35
Intermediate	4	14
Secondary school	3	10
College/university	3	10
Marital Status		
Married	19	66
Single mothers	7	24
Widow	2	7
Divorced/separated	1	3
Women Employment Status		
Housewife	21	73
Employed with government	1	3
Self-Employed/Owner of a Business	4	14
Employed by NGO	3	10
Husband Employment Status		
Other not married	12	42
Farmer/Agriculture	9	31
Employed with government	4	14

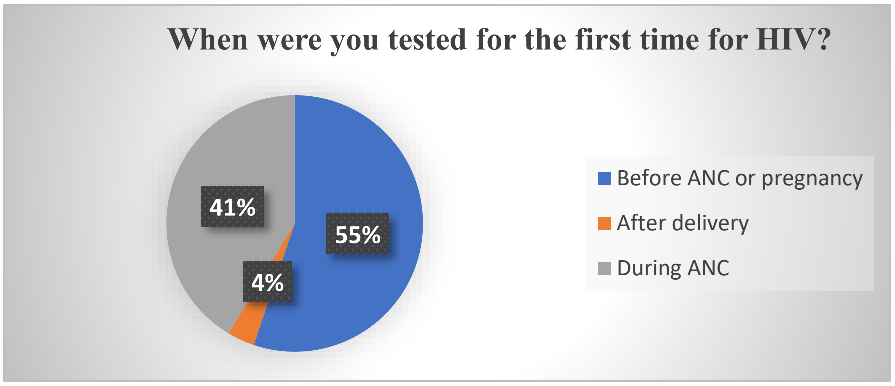
Self-Employed/Owner of a Business	3	10
Employed in the Private Sector	1	3
Religion		
Protestant	15	52
Roman Catholic	12	41
Seventh-day Adventist	2	7

The demographic profile of HIV+ participants with regard to their age, education, marital status, employment status for both women and husbands, religion, the first time for HIV testing, total number of children, number of children diagnosed with HIV, and number of children infected while they were enrolled in the PMTCT program is available as Appendix A. The participants' ages ranged from 24 to 50 years. The education level of the HIV+ mothers varied from illiterate to university education (Bachelor of Science). Their marital status ranged from married women (66%), followed by single mothers, those who were not in marital relationship (24%), widowed (7%) and divorced/separated (3%). Most HIV+ women who used or are using the PMTCT program were housewives (73%), and 42% were single mothers or widowed. Their religious backgrounds included Protestant, Roman Catholic, and Seventh-day Adventist.

The researcher asked the participants to answer the question on the time they were tested for HIV for the first time.

Figure 3

When were You Tested for the First Time for HIV?



As shown in the Figure 2, the majority of the HIV+ mothers (55%) were tested before ANC or pregnancy, 41% during ANC and 4% after delivery.

Table 4 summarizes the data on the number of children by participants, the number of children born after being diagnosed with HIV, the number of children infected through MTCT and the number of children infected while the participants were enrolled in the PMTCT program.

Table 4

Summary of the Demographic Characteristics of the 29 Participants cont

Characteristics	**Findings**
Number of children by HIV+ mothers (n)	
Number of mothers (n)	**Number of Children (n)**
1	1
10	2
5	3
5	4
4	5
4	6
Number of children since being diagnosed with HIV (n)	
Number of mothers (n)	**Number of Children (n)**
8	1
12	2
6	3
4	4
1	4
1	5
1	6
Number of children infected by MTCT of HIV (n)	
Yes	16 (55%)
If yes, how many children?	20 HIV+ children
No	13 HIV- children
Number of children infected while mothers were enrolled in the PMTCT program (n)	
Yes	13 (45%)
If yes, how many children?	14 HIV+ children
No	16 HIV- children

As shown in Table 4, the total number of children per participant ranged from one child to six children. Based on the findings from this study, the HIV+ mothers continued to have one to six pregnancies/babies after being diagnosed with HIV. Most of those pregnancies were unplanned, a factor that exposed children to MTCT of HIV as demonstrated by the collected data. Fifty five percent of HIV+ mothers interviewed caused MTCT of HIV to their babies. Of the 55% HIV + participants, 45% were followed in the PMTCT program and their babies were tested HIV+.

Demographic Characteristics of the Participants: Healthcare Providers

A sample of 14 healthcare providers working in the PMTCT program were recruited. Table 5 summarises the ages of these participants, employment status, length of work experiences at the PMTCT program, how they got to work in the PMTCT program, and the training received before or during their work at the PMTCT program.

Table 5

Summary of the Demographic Characteristics of the 14 Healthcare Providers

Characteristics	**Findings**	
Age of participants	Number (n)	Percentage %
20-29 years	1	7
30-39 years	5	36
40-49 years	7	50
50years and more	1	7
Total	14	100
Employment status		
Physician	3	21
Registered Nurses	6	44
Social Worker	2	14
Psychologist	3	21
Total	14	100
Length of work experience at the PMTCT program		
6 month - 1 years	1	7
1 – 5 years	4	29
5 – 10 years	5	36

10- 15 years	2	14
Above 15years	2	14
Total	14	100
Choice to work in the PMTCT program		
Yes	5	36
No	8	51
I do not know	1	7
Total	14	100
Entry into the PMTCT program		
Appointed	3	21
Applied and pass exam	7	50
Rotation	4	29
Total	14	100
Pre-employment training at the at the PMTCT program		
Yes	6	43
No	8	57
Total	14	100
In-services or refresher training at the PMTCT program		
Yes	11	79
No	3	21
Total	14	100
Every quarter	1	7
Every six months	1	7
Every year	6	43
Other (please specify)2 years	2	14
5 years	1	7
None	3	22
Total	14	100

The healthcare provider (HCPs) participants' ages ranged from 24 to 56 years. Out of 14 HCPs interviewed, six (44%) were nurses, three (21%) physicians, three (21%) psychologists, and two (14%) social workers. Their length of work experience in the PMTCT program varied from 6 months to above 15 years. Of 14 HCPs participants, five (36%) had five to 10 years of experience, four (29%) had one to five years of experience, two (14%) had 10 to 15 years of experience. Two other (14%) HCPs had work experience of above 15 years, and only one HCP (7%) had work experience between six months to one year.

Most of the HCPs interviewed (51%) did not choose to work in the PMTCT program. Seven HCPs (50%) were employed at the PMTCT program through passing a work-related exam, four (29%) through staff rotation, and three (21%) had been appointed by the hospital leaders. The majority (57%) did not get any training before starting their position at the PMTCT program. Only 43% received pre-employment training on PMTCT protocol and counselling; and 79% received in-service or refresher training on HIV rapid test, updated PMTCT protocol, and on follow-up of HIV+ mothers. The frequency of in-service/refresher training ranged from every year (43%), none (22%), two years (14%), every six months (7%), every quarter (7%), and every five years (7%).

Themes that Emerged from the Collected Data

Theme One: Factors that Influence and Challenge the Uptake of PMTCT

The first theme presents the findings surrounding the factors that influence and challenge the uptake of the PMTCT program at BUTH/Rwanda. This theme has been divided into sub-themes: social determinants of health that influence the uptake of the PMTCT program, HIV + status related factors, and cultural factors that influence the uptake of the PMTCT program.

Social determinants of health that influence the uptake of the PMTCT program. Social determinants of health are the range of social, economic, and environmental factors that determine the health status of individuals and populations. Of the history of participants, housing related factors, poverty, stress due to unemployment status, employment, and low education and literacy play a role in exposing babies to the risk of MTCT of HIV, and limiting the ability of HIV+ mothers to uptake the PMTCT program through seeking treatment, care, and support.

Housing issues as factors influencing on the PMTCT program uptake. Housing and accommodation issues were commonly reported by the HIV+ mothers as having a negative influence on PMTCT program uptake. One client explained: “Lacking a place to live, uhuuu, housing is an important issue I am facing, you can see it is a problem even to find a place to keep my drugs” (PMWNB4).

An HIV+ mother explained how housing issues exposed her to drop out of taking Anti-Retrovirals (ARVs) and said:

> I was taking the ARVs, yes, I use to take my pills regularly, but I stopped to take it, uhuuu! I stopped them after my aunty drove me out to her house! I did not have any place to live! You can see I use to keep my pills to my aunt’s house; I could not go back there… uhuuu I missed to take my pills doses (PMWPB10).

Lacking a comfortable place to live exposed participants to low ARV adherence with risk of MTCT of HIV. Some of the participants mentioned that they experienced accommodation issues where two or even more families lived in the same house. Lacking enough place to live exposes HIV+ women to miss their ARVs doses because of fear of involuntary disclosure. One participant said:

> In general life, I am a quiet lady who is living with my brother, we are two families of eight persons sharing a small house of two rooms. One family in the one room and another family in the other room. I used to miss my doses especially if there are people in the house…I would love to have my private room…I tried to hide it, but it is not easy. I do not want them to know that I have that disease (PMWPB6).

During our focus group interview, a healthcare provider reminded me what we observed during a home visit and stated:

> … eh you can see how hard it is to live with mother in-law in the same house! Remember during our home visit to X client! Three families with more than 12 people living in the same house, the small one. Most of our clients want to keep their HIV status secret. With the overpopulated house, they miss a private place to keep their medications, and some decided to stop their ARVs adherence just to avoid involuntary disclosure (HCP1).

An HIV+ mother explained how house crowding is a factor contributing to low ARVs adherence:

> Sometimes, it is hard to keep my HIV status secret with this overcrowding of people… I do not have a private space to keep my stuff! I decided to stop the ARVs… you can see they can discover my HIV status and I do not want them to know it…and I dropped out the ARVs (PMWNB9).

Poverty as a factor contributing to low uptake of the PMTCT program. Poverty exacerbated the risk of MTCT of HIV. HIV+ mothers stated that they experienced extreme poverty and they struggled to provide basic needs (food, school fees, clothing, etc) to their children and to themselves. Most participants often go to sleep without food and stopped taking the ARVs. One participant explained:

> Yes, I got the ARVs from the PMTCT program, after I did not return there, no, no! I stop to take the ARVs! You can see, the ARVs must be taken with food at all the times, and for me I used to sleep without food. Can you take the medication on an empty stomach? No (PMWPB8).

Participants reported that the side effects of ARVs were so severe if taken on an empty stomach that they had difficulty sleeping at night and often struggled to function normally during the day. One participant stated: “The painful thing is that we do not have any food to eat at home. When I take my ARVs hungry, I get severe headaches and burns in my stomach” (PMWPB4).

Another participant added:

> Most of times I do not have anything to eat! Without food, I can’t take the ARVs. I took them three times and then I stopped! Yes, the ARVs are a problem if you take them hungry because you get dizzy, they make you shake, and have hallucination (PMWPB8).

Some HIV+ mothers reported taking pills late because they did not have a clock, radio, or cell phone to help them keep track of time. Uncertainty of the daytime was a common reason cited for failing to take daily dosage on time. They reported that repeatedly asking “what time is it?” to their children, family members, or neighbour put added stress on those relationships, increasing the risk of involuntary disclosure of their positive status. One mother said: “…you know I don’t have a radio or a clock…if I ask a neighbour what time it is so I can take my drugs…the neighbour gets angry and goes around telling people that I keep bothering them” (PMWPB3). Poverty was experienced as a more serious challenge than being or becoming HIV+ as shared by a participant: “Even I am HIV+; this is not really a preoccupied problem in my mind; poverty and lack of something to feed my babies are my primary concern” (PMWPB9).

Unemployment status as constraint on ARV adherence and PMTCT services adherence. HIV+ mothers described feelings of stress related to unemployment as an important constraint on ARV adherence and PMTCT services adherence. Primary sources of stress included lack of financial resources to support their children. They reported sometimes forgetting to take pills due to emotional and stressful life events. One positive mother said: “Problem I encounter is that I am unemployed… so sometimes… something happens because of stress… because I have too much stress and I forget taking my pills" (PMWNB13). Poverty is linked with unemployment and was commonly reported by HIV+ mothers as having a negative influence on the uptake of PMTCT program. Unemployed HIV+ mothers reported insufficient financial resources and were facing difficulty to meet their appointment at the PMTCT program for treatment and care. An HIV+ mother stated:

> My life is a complicated life! Yes, it is complicated! In general, if I did not get a job, it means that I will not eat! And I do not have any fixed job, every morning I have to go house by house in my village to see if someone can offer me any kind of farming job. Every time that I feel healthy and have strength, I wake up in the morning and go to find something to do! Sometimes I do not get any job (PMWPB6).

Employment related factors that pose a challenge to uptake of the PMTCT program. Many HIV+ mothers expressed how stressful balancing their daily duties of being a wife and mother could be. This posed challenges in uptake of the PMTCT program and adherance to their ARVs. For instance, some HIV+ women were working but had to take time off work to make appointments for PMTCT services. Women reported that they sometimes had a hard time with their managers/supervisors, even though they provided a doctors' notes for their requested absenses from work. An HIV+ mother added:

> I am poor and have to feed my family… I have to find a job daily. If I did not get job, it means that my family and I will suffer with no food that day. I sometime miss my appointment because of my house situation and you know there is no afternoon and weekend appointments! Anytime I attend the PMTCT program, my family will not eat! Let me tell the truth, I missed my appointments because I had a job that day (PMWNB5).

Most employed HIV+ mothers reported that they did not disclose their HIV status to their employers and co-workers. Quite a few women talked about occasionally missing appointments or failing to refill ARVs due to a boss/supervisor at work refusing to give them time off. When they ask to attend a clinic appointment, direct supervisors demanded a reason for going, which resulted in fear of disclosing status, and/or being overheard requesting time to pick up ARVs. Some of the women also experienced threats of job termination by their supervisor/boss when they requested time off to attend a PMTCT clinic appointment. One mother reported:

> Like I've said… it is a problem at work. When I asked to come to the clinic from my boss, he told me to leave and never come back. I told him that the reason I asked is because I needed to pick up my pills… he refused and said if I leave, I leave for good. I stayed (PMWPB9).

An HCP added: "But another big problem here at the clinic… are the firms, their bosses don't want them to take a day off to come pick-up their pills every month, even if we give them a sick note" (HCP4).

Low education and literacy as factors that challenge the uptake of the PMTCT program. Although Rwanda introduced free primary education in 2003, the majority of women in my sample had not gone to elementary school. Many women failed to continue their education because they faced education costs like school materials and were unable to afford them. One HIV+ mother said: "I failed to continue with school… I was required to have books, uniforms, notebooks, pens….and that time I was staying with my aunt and she could not help me with that… So, I quitt" (PMWNB9).

Losing parents compounded difficulties with women completing their education. Children who had lost one or both of their parents often moved around within their extended families and sometimes faced neglect and abuse, or had to care for siblings. This situation inhibited their education. One mother stated:

> When I was about to finish primary school… Primary (level 5) … it is when my mother died, and she left me with a small baby of about seven months. My relatives refused to take care of the baby. As a result, I failed to continue school because I was taking care of the baby… I stayed with baby for a year and later she passed away… I never went back to school despite the baby dying… there was no one to support me with school materials and I was not getting any support from anywhere (PMWPB4).

Those with low literacy often had trouble understanding ARVs scheduled appointments. Some reported missing their PMTCT program appointments because they could not read and/or were reluctant to ask someone to check the date of their next appointment on the ARV health card due to fear of disclosure of their HIV status. A participant emphasized:

> Many times, I missed the date for my PMTCT appointment…Even now I do not know when I need to go back because I do not know how to read. I ask somebody else to check the date for me, but it is not easy to find someone to trust. Last time, uhuuu, the person I asked to check reacted badly and disclosed my HIV status in the village. I was concerned about my accidental disclosure of my HIV status to the members of my village (PMWPB8).

HCPs reported that women with certain characteristics such as having a high educational background, and older people were more likely to adhere to the PMTCT program and their ARVs, and said:

> You know because we got different people up there… some are doing good job in terms of good adherence of ARVs…and you will find they are taking the tablets, like teachers…you understand what I mean, old folks… but the young ones and the illiterates, you know, oh God…nurse, I fed up drinking tables; why I must drink this tablets every day; oh God…I fed up (HCP2).

HIV+ Status Related Factors

The most frequently mentioned factors that constrained HIV+ women from using the PMTCT program and exposing children to MTCT of HIV are those related to HIV+ status. The research participants pointed out that HIV+ status is connected to stigma and discrimination, violence, and disclosure related factors.

Stigma and discrimination as factors that constrain HIV+ women from using the PMTCT program. Participants recognized that HIV/AIDS stigma was still prevalent and HIV+ mothers faced discrimination due to their HIV status. For example, HIV+ mothers were afraid to be seen by family members and thus were not taking their drugs regularly. One of PMTCT leader supported this: "You can understand that the discrimination exists but is hidden inside of the family and is powerful; to make changes about it is not easy" (PMTCTL1).

An HIV+ mother shared her experience: "I was fired from rented house in the second day of my delivery. The house renter asks me why I give syrup for the newborn and I told them that it is HIV prophylaxis then she told me to leave the house immediately" (PMWPB6). Another participant added:

> I do not want to have visitors and even my in-law family… you know… when they are in my house, they use to ask me a lot of questions and I do not want to disclosure my HIV

> status! I missed some doses for my baby and myself because I was afraid of them how they may treat me after knowing my HIV status (PMWPB1).

Another HIV+ woman participant reported that stigma and discrimination exist and showed how she experienced it. She stated: “After they known that I am sick…they refuse to share with me food, clothes, washroom, and cannot sit with me…they think I can give them my disease…No one sit on a place where HIV person sits…this is how it is” (PMWPB1). Public stigma (perceived or real), and self-stigma were reported as reasons HIV+ mothers missed ARVs dosages, discontinued ARV treatment, and missed the PMTCT program visits. HCPs reported that self-stigma and perceived public-stigma were highly prevalent among HIV+ mothers, which in turn impacted the PMTCT service delivery. One HCP shared:

> The self-perceived stigma is so high that people are even ashamed of being seen anywhere near a hospital vehicle, and they don’t want the hospital cars to visit them at their homes. During the home visit, we use to find other cars without any hospital signs and pay them! And during our visit, we also visit other houses near the house of our clients, looking on nutrient status and providing health education. We do this to avoid exposing our clients to involuntary disclosure (HCP2).

During home visits most clients were found in their daily activities as farmer, in agriculture, in house activities. The clients were not informed about the time of the visit because the HCPs would like to find their clients in their real life. Most of them were surprised to see HCPs visiting them. The HCPs interacted with their clients, assessed how they were doing, asked the clients to bring their ARVs bottles to check if they were taken regularly, asked about the barriers they were facing for good ARVs adherence and PMTCT uptake, and provided health education and support accordingly. Two ladies were unhappy with the home visit; they had not disclosed their HIV status and found the home visit exposed them to the risk of involuntary disclosure. After the HCPs team reached their houses, the two ladies approached the HCPs and asked them to not mention anything on HIV. They discussed general issues and ended the visit.

Giving daily medicine to a child who is not sick exposed participants to involuntary disclosure, causing them to refrain from doing it. Some HIV+ women thought it was easier for them to keep their HIV status a secret if they were to take drugs themselves, rather than if they had to give medicine to their children. HIV+ children were treated unfairly and discriminated against in the villages, and this caused children uncomfortable feelings. One mother reported:

> So, when they see the child taking everyday medicine, they will point fingers at the children when he is very young… and they may discriminate against the children when they go from house to house… this will make the children feeling uncomfortable and they won't be free to play with other children (PMWNB12).

Disclosure factors as barriers to ARVs adherence that affect the implementation of the PMTCT program. Most of HIV+ mothers had godmothers (a treatment supporter) who were aware of their HIV status, but many had concerns about disclosing their HIV status to their families, communities, or social network for fear of being rejected. One PMTCT leader reported clients' complaints about gossip and stated: "Some reported having heard negative gossip about individual receiving ARVs, and worried that people would think less of them if they knew they were taking drugs and they would also become the source of gossip" (PMTCTL2).

HCPs reported that patients often would provide false contact details regarding their godmothers (treatment supporters). It was suspected that many positive mothers likely had not disclosed their HIV status to anyone. During our focus group interview, one HCP stated.

> …and you find that when we call the phone number, they gave us, the person on the phone either does not know the client or they are not aware that they have been registered as the patient's treatment supporter. Sometimes it is very difficult to reach them, especially those who refused to disclosure their HIV status… they run away and hide from us…they do not like home visits (HCP4).

On inquiring the reasons for refusing to disclose their HIV status, another participant responded: "I am afraid because I don't know what people would say if they knew I am taking pills. It is not easy to tell them… Sometimes you tell someone… they laugh at you and go tell their friends (PMWNB2).

Most women living with HIV hid their serostatus and treatment from their husbands and family members. HIV infection is sometimes considered a punishment for promiscuity and people living with HIV are thought of as dangerous or almost dead individuals in the society. This was one of the major barriers to ARVs adherence and effective implementation of the PMTCT program. One mother said:

> This is a secret disease… you should not go around spreading news that you are sick… because once people get to know that you are infected… they will treat you as dangerous and a dead person and will consider you as a punished person…people try to avoid you and would prefer to stay far from you (PMWPB1).

Fear of divorce was the most frequently cited reason for discontinuing ARVs and participating in the PMTCT services. Most HIV+ mothers took the drugs without the knowledge of their husbands and were afraid of disclosing their HIV status due to fear of divorce. An HIV+ mother said:

> Nine years living with HIV and taking drugs… I refused to disclose it to my husband; he may fire me out and I do not have anywhere to go… I have to keep quiet and keep it secret…I know my baby became positive because of that! I did not provide proper care to him… every time my husband was home, I discontinued the drug because I was afraid of my husband (PMWNB12).

Most HIV+ women in this study depended on their husbands for survival, making disclosure of their HIV status more difficult and riskier. Many were not sure of their next meal and had to walk around to find a job to earn money for food. One woman told me:

> They tell me that I should eat fruits and vegetables… but one has to buy all these things… they should give us some assistance on this. At the moment… a whole day may pass without a meal and one is not even able to afford an orange. I am still depending on him and I have to keep it a secret (PMWPB6).

Many HIV+ women felt the need to hide their HIV status and their medication due to fear of losing their partners and not having support to provide for their new-born child and other dependents. One woman stated:

> I had this disease about four years ago…sometimes I use a condom… Now that I am taking my medication around my partner, I am more careful and make sure to use a condom… my partner does not have an idea what my treatment is for… sometimes he

> sees me drinking it. They say I must not tell him because he may not like that, I have HIV. This baby was not planned, and I do not want to lie you. I will tell him after… may be at the clinic and disclosure the status after the birth of the baby (PMWPB4).

HIV+ mothers conveyed fear of having their HIV status revealed to family or community members. Women were concerned about accidental disclosure of their status to members of their social group and communities. Furthermore, women reported fear of being seen near PMTCT services during their visits and worried about being recognized at the PMTCT clinic when picking up drugs or attending appointments. Some even opted to travel a great distance to attend a PMTCT clinics to avoid being seen by people they know at the facility closer to their homes. One client said: "Even though refills are done at health center…, I like coming here to take my drugs, because nobody can see me. Even though I accepted my situation, I don't want other people to know it because you know people talk" (PMWNB6).

Many HIV+ women found disclosure very difficult, especially when women thought that their husbands would react negatively or interpret their HIV status as being unfaithful. A participating woman stated:

> No, I have not told anyone since I tested, not even my husband! The HCPs advised me to tell my husband, but every time I think about it… I find myself crying… I do not know how to start or how he will take it. He may think I have been cheating on him. No… not now! I feel telling my man I have HIV is too heavy to come out of my mouth, I do not even want to think about it. Not now. May be after giving birth we will go together and test so that HCPs can tell us when we are together (PMWNB13).

Violence related to HIV + status as factor related to low uptake of the PMTCT program. Most HIV+ women experienced violence after they disclosed their HIV status to their husbands. One mother explained the reason she refused to disclosure her status to her husband:

> The reason I refused to disclose to him is because I was afraid to him, to his violent reaction…you know the men… I refer to what he had earlier… the way he uses to treat me…you know if he finds out that I am sick… uhuu he would kill me! I am even afraid to attend the PMTCT clinic… you people talk… I may meet someone who know my husband… I do not want my husband to know it… I am afraid of him (PMWNB12).

Disclosure to family members may also have been a source of violence, as a woman stated:

> I do not share my HIV status with my in-law-families…I prefer to keep it secret because of fear of stigma and violence… you know them… they can accuse me of being harlots…they can also abuse me and told me that I infected their son…I just keep it as a secret to avoid fights (PMWNB8).

Some HIV+ mothers also reported experiencing conflict with their husbands after disclosing their positive HIV diagnosis. These encounters with intimate partners sometimes led to break ups, rejection, blame and/or verbal abuse, and consequently made it difficult for women experiencing such conflict to adhere to PMTCT service appointments and/or ARVs treatment. A woman in a discordant relationship explained:

> Another thing is the issue with my husband, after being tested and find that I was positive and my husband is not… uhuu… he is negative…he comes back and accuses me of sleeping around with all men…he asked me to many questions and accuse me of

> cheating… this is giving me problems because I find there is no support and sometimes, he tells me that he doesn't trust me and will never trust me because he doesn't understand where I got the HIV from because he doesn't have it (PMWNB12).

An HIV+ mother who was afraid of the possible violent reaction after disclosure, said:

> I am afraid to take pills in front of him…worrying that simply seeing the pills might trigger a violent reaction! I have to wait until he falls asleep to take my daily pills. It was a little bit tricky because I had to hide my pills. I am afraid… yes, I am afraid that one day my husband may sneak up on me… God helps me (PMWNB12).

In terms of women's experiences with violence events, most women experienced their husbands insulting them, making them feel bad about themselves, being slapped, and physically forced to have unwanted sex. One mother said: "Since that disease entered in my house… my husband mistreated me… beat me every day and threw whatever he founds on me! He makes me feel like I am nothing. He does whatever he wants to humiliate me" (PMWNB5). Another woman stated that she was verbally and emotionally abused by her husband:

> My husband was convinced that the PMTCT program could prevent HIV in their infant. He tried to give me instrumental support to attend program. But he uses to remind me that I will die, and this HIV will lead me to death… and my children will be alone (PMWNB8).

One participant tried to commit suicide by drinking poison several weeks prior to the interview. Her husband was extremely violent, hitting her in front of the neighbours, publicly shaming her, and withholding food. She described feeling bad and so stressed, and this caused her to forget to take her treatment for a period:

> Sometimes I forget to take my pills… it happened two months ago. I had pills... not take them… sometimes... just I forgot dates to go to clinic fetch my drugs. Stress is not good... I was always thinking… I was thinking about the time he threatened me! I just end up thinking about too many things. By the time, I remember it is too late, my day have passed (PMWNB5).

One mother mentioned the controlling behaviours her husband exhibited against her and said:

> My husband was suspicious when I responded to phone call, assuming I was planning with other men… and cheating on him. He asked me too many questions…sometimes he beats me! He refused me to use the phone…. Anytime I had a phone he threw it out and destroyed it (PMWNB5).

Another woman added: “I can’t accuse him to the local authority…he always makes me feel afraid to go there… this may lead to involuntary disclosure, you know… I don’t want people to know it…I have to accept whatever he is doing to me” (PMWNB7).

No participant was able to use the notion of motherhood to feel more confident around PMTCT program adherence. One client felt that stress related to the violent relationship was making her a worse mother. She illustrated by describing how her suicidal thoughts were linked to the thoughts of hurting her children:

> I am an orphan… I sometimes have suicidal thoughts because I do not have anyone. The only people I have are my kids. You know the worst part is with these suicidal thoughts I

> may always pronouncing… if I had to kill myself, I would not leave my kids behind, I would take them with…if there is a technique whereby, I would kill me and my kids, I would do it. So, it is just… it is not well. I am not even a good mother these days (PMWPB12).

It is however important to note that not all HIV+ mothers experienced physical violence after disclosing their HIV status. Some husbands were very supportive, as one participant shared:

> He was my instructor at secondary school, and he did not know my HIV status. He came to ask me for marriage, I was afraid to disclose to him my HIV status, but I decided to do it thinking he will reject me! He was HIV negative. After disclosure, I found different reactions! He was broadly supportive of me throughout taking medication, remind me of my treatment time, and we have now two kids that are HIV negative and my husband is still HIV negative (PMWNB6).

Cultural Factors Influence the Uptake of the PMTCT Program

During field observation and interviews, participants demonstrated some cultural factors that challenge the uptake of the PMTCT program. Those included MTCT of HIV and traditional practice, traditional beliefs, traditional birth attendant (TBA) practice and related risks, and religious beliefs.

MTCT of HIV and traditional practice as factors influencing the uptake of the PMTCT program. Traditional practice was discussed extensively in the interviews with HIV+ mothers and HCPs. Some women reported that their children experienced traditional diseases that were not healed with modern medicine. They added that they did not feel confident to share this with

HCPs because they felt they would not support them, and their babies would die because of traditional diseases. One woman stated:

> I did not mention to the HCPs…you know they refused the existence of traditional diseases… uhuuu those kinds of diseases killing babies quickly… the neighbours mothers help me to diagnose the diseases and orient me to the traditional healers, my baby was three months…the healer used the cutting instrument to treat Ibyinyo (the name of disease) (PMWPB7).

Another mother added "…there is a lot of ladies in the village that talk to you and confirm that disease to your baby… some said their babies died because of this disease! You start panicking and bringing your baby without thinking risks behind" (PMWNB5).

The way the traditional healers treat those diseases often exposed the babies to MTCT of HIV. For example, they use cutting and shared instruments with herbs that cause wounds in the mouth. After these practices, the traditional healers asked mothers to breastfeed their babies. One participant who experienced the traditional practice thought that her baby was exposed to HIV due to that practice and said:

> I should not do this… my baby became positive after I brought her to traditional healer, she was tested negative in her first exam… after they removed the stuff in her mouth, they asked me to breastfeed her, and she was bleeding… and you know my breastmilk has the virus… I think she got the disease at that time, yes, the HIV test of nine month she was positive (PMWPB5).

HCPs felt paternalistic at times and faced conflict with balancing their personal beliefs and the message that they were trained to deliver in advising the HIV+ mothers. This can be a source of confusion for the HIV+ mothers. Most of the time, the HCP team were unaware of the engagement of mothers with traditional practices. A paediatrician stated:

> Women want to pursue traditional practice with ARVs sometimes… and I am not sure that the women feel reluctant to tell me that… I do not feel like that they have to hide that; thing may adversely interact. I think we need to create an environment where they can discuss their traditional practices openly. Not their options are bad necessarily but to be realistic in how we discuss it because we do not know what they are traditionally doing. If we are aware then we can possibly advise (HCP2).

Although the use of traditional medicine was not frequently reported by the clients to the HCPs, some PMTCT program leaders reported clients who alternated between ARV and traditional medicine, while other clients stopped ARVs treatment entirely in favour of traditional medicine. During our focus group interview, one PMTCT program leader said:

> About traditional medicine, I know some cases who stopped the ARVs hoping the traditional medicine from M can heal the HIV. M was a guy who declared that he discovered the HIV cure. He used the herbs as traditional medicine. HIV+ persons stopped the ARVs and started to use the traditional medicine and started to develop opportunistic diseases (PMTCTL3).

Traditional beliefs as barriers to accessing the PMTCT services. Traditional beliefs related to conception, pregnancy and childbirth sometimes acted as barriers to accessing PMTCT services to prevent MTCT of HIV. The message shared by some participants was that pregnancy and delivery are women's issues. Most women are able to bear the pain during labor, but they do not trouble their family with their pain; they keep quiet and do not disturb their family until the water breaks. This exposes most HIV+ women to home delivery with MTCT of HIV risk. One client said:

> I want that no one in the family should face any trouble because of me…I kept quiet until the water breaks, then I tell them, this was very late by then… taking me to hospital was not possible… I was assisted by a TBA and had natural delivery (PMWPB4)

Birthing at home is a normal occurrence that does not require medical intervention, and is a contributing factor in low PMTCT program adherence, and MTCT of HIV. An HIV+ woman with a positive baby stated:

> I had delivered at home under assistance of TBA…there is no problem in delivery at home…when it comes to visit the hospital after delivery… uhuuu…it becomes a big issue…what should I tell my mother-in-law…I know I should go there for getting sirup of my baby but…I cannot tell…I just kept quiet until I went for vaccination… I was really afraid to infect my baby but…my in-law-family was there, and I can't tell (PMWPB11).

TBA practice and related risks as a barrier of the PMTCT uptake. HIV+ women experienced challenges especially during home deliveries when it was time to take the ARVs. TBAs, grandmothers, or other family members assisted with home delivery. The HIV+ pregnant women who delivered at home and who had received ARVs from the PMTCT program swallowed the pills privately, without disclosing it to their TBAs. Furthermore, HIV+ mothers had difficulties with taking their babies to the hospital to be given the ARV prophylactic. One woman explained how she hid her secret from her TBAs:

> During my delivery… I took my pills following the instructions that I got from ANC… the decision to take my pills during labor was made by me… nobody was aware that I took it… this means that my grandmother, my mother, and the two sisters never knew since I never told them about my HIV status… this was my secret. But I did not have the syrup for my baby… it took time until I went to vaccination (PMWNB14).

Many HIV+ women who birthed at home described the stress of not adhering to the prophylaxis treatment for the baby. A mother reported:

> I had a home delivery…because I knew it was going to be difficult for me to pay hospital bills after delivery… I delivered under the assistance of TBA, my grandmother, my mother, and two sisters… I felt bad that my new-born could not be protected. During my delivery, the TBA did not know that I was HIV+ and I took the pills without her knowledge (PMWNB7).

Some HIV+ mothers indicated that hospital delivery was a measure that could prevent MTCT of HIV, but for those who desired to keep their status confidential, the tendency was to avoid returning to facilities where they were diagnosed; preferring a home or assisted delivery in a private clinic where their status was unknown. One HIV+ mother reported:

> It is a shameful thing to be diagnosed with HIV. How should I say I got it? Even if my husband is responsible, people will conclude it is my fault. To avoid trouble, I don't give birth in the hospital where my status is known…may be in the private hospital so that

> relatives will not become suspicious when they give special medication (ARVs) to the mother and baby shortly after birth (PMWNB3).

HIV+ mothers often blamed themselves and felt bad about their situations. One stated:

> After delivery, I felt bad because my child could not be given the drug… but this was my fault… my husband died and the reason for his death could be the AIDS… also people around me are suspicious that I am HIV infected… so they are not happy with me! They even asked me why I stopped breastfeeding my baby… and I said that my child will die (PMWPB1).

The HIV+ women who lacked husband and family support had challenges to accessing hospital birth services despite their knowledge of safe birth in a hospital, which is illustrated in the following statement:

> I delivered at home because my husband didn't show any commitment to support me…at that time he every so often drunk and quarrelled with me… so if I had gone to the hospital… my parents would have experienced problems in trying to find for money to pay my hospital bills… I was assisted by TBA and my mother (PMWNB5)

Religious beliefs as challenges of non-adherence to the ARVs and PMTCT services. Some HCPs reported that some HIV+ mothers had beliefs that God would cure them through their religion, and this resulted in non-adherence to their ARVs and PMTCT services. During the interview with HIV+ mothers I asked them about religious beliefs about HIV, and one mother said:

> I am Christian in Pentecostal church… one day my pastor told me that God healed me…I said to me that there is no need for drugs…I spent four months without drugs because I believed what my pastor told me! I went back to see my doctors with skin rash and diarrhoea… I had high viral loads…I am still having that disease (PMWNB8).

Religion can affect health by influencing the system of meanings, and by offering feelings of strength to cope with stress and adversity of other intersecting influences. In addition religion often defined the participants' social practices both at home and within the community. One participant stated:

> I am a Christian woman… I can say that I used to pray, there is something which I cannot describe… once I pray… I feel much better… I find prayer as a way of coping with stressors and difficulties that I encountered during my sick life and every day challenges (PMWNB1)

Theme Two: Identities Intersecting with the Uptake of the PMTCT program

HIV intersects with long standing social forces shaping inequality. It is an epidemic of intersectional inequality that is fuelled by gender, class, and sexual inequalities. These inequalities severely shape the likelihood of exposure to the virus, and the realities of living with and responding to the HIV infection. This theme represents one sub-theme called social forces shaping inequality.

Social Forces Shaping Inequality

Participants showed that cultural ideology, gender related issues, power relationships, role of mothers-in-law, and judgmental challenges represented social forces shaping inequality and intersecting with uptake of the PMTCT program.

Cultural ideology as factors that increase risk of MTCT of HIV. I examined cultural ideology that put women at increased risk of MTCT of HIV. The cultural construction of women is linked with their sexuality which restricts what is permissible for them and makes it extremely difficult for women to navigate expectations, and negotiate lifestyles and safe sex that will protect them from HIV. The flow of power between males and females, bounded by culturally prescribed femininities and masculinities, contributed to the MTCT of HIV.

While I focus on women, HIV equally endangers men's lives through the cultural construction of manhood. Rwandan culture values sex and sexuality, and tends to emphasize and strengthen the dominance of men and boys, and subordination of women and girls. The advice from elders is that women must respect their husbands and not cause a fuss, and women's economic positions often leave women vulnerable to abuse. Cultural expectations to be good women and proper wives shape their relationships with men. The advice at puberty also emphasizes respect for elders and husbands. One mother in my study described: "… good women are those who selflessly care for their families, are quiet, do not make noise in the house, and are reasonable" (PMWNB8).

Another HIV+ women defined a good woman based on cultural ideology. She stated: "… being a good wife means ensuring their husband's sexual fulfillment" (PMWNB14). HIV+ mothers, however, said that they would never have initiated sex because they might be seen as prostitutes and too interested in it. One mother said: "I would like to entice my husband away from prostitutes… I may feel like have some knowledge about sex, but feel that… I cannot discuss my sexual needs with my husband for fear that he will accuse me extramarital affairs" (PMWNB12).

Being a good wife and getting married do not protect Rwandan women against HIV because extramarital affairs and polygamy are common even if law does not accept it. It is culturally permissible and even expected that men will have multiple sexual partners. Findings showed that most HIV+ women experienced relationships between either one husband with multiple wives or one wife with multiples husbands. The problem with polygamy is that it exposes multiple people to STIs and HIV transmission as well as MTCT of HIV. One mother stated:

> As we are talking here… he is already in bars drinking beer…and having other wives… you know the men are like that… they all need partners… men cannot endure without sex… but for us we can endure and abstain… you cannot know men because where they go… we don't go with them. I have never heard anything like that, but again I cannot praise him that he doesn't have girlfriends or wives (PMWNB12).

Another woman described the many impacts of their husband's girlfriends on their lives, marriages, and families:

> When the husband has girlfriends, he supports them so much and gives no support at all to his own house and wife… he doesn't leave food at home… children and wife suffer. You can see with other relationships; the result is contracting HIV and STIs (PMWPB3).

Some women in my study were in or had been in polygamous unions:

> At first, it was me alone… he later married another wife… I did feel bad…my heart pained… when he took a second wife, I did not want to stay with him. But, after the elders spoke to me saying that is how men behave, I changed and accepted (PMWPB7).

Another woman tells how her husband decided to get married a second time because she failed to produce a child:

> My husband started blaming me for the deaths of the children…saying that he can't just be wasting his energy for nothing… he married a second wife, but regrettably during delivery the second wife had a stillborn. So, I asked him who has a problem… because he left me for a second wife accusing me of having a problem… he said maybe women were not moving well (cheating him). The second wife fell pregnant again and miscarried…and that is the time I had my son, that was in 2004. So, he left the second wife and came back to me (PMWNB1).

Polygamy was believed by HCPs to negatively affect the PMTCT program adherence and expose to MTCT of HIV. Although not legally accepted, polygamy exists, and mothers mentioned that their husbands had multiple wives. During an interview with a PMTCT leader, she mentioned that:

> …we have a guy here with four wives… I was not sure if the disclosure happened, I make an appointment with all family and he came with all his wives. Three were tested positive and under ARVs. Only one was HIV negative. I asked her if she had an idea of her husband status and if she is not afraid to be positive one day. She replied to me that she knows that she is under risk to contract the disease, but she said she loves him, and he is taking care of her. She added if she becomes positive, she will take the ARVs like the other wives (PMTCTL1).

Additionally, wives in polygamous households are associated with large families and some wives reported fearing disclosure of their HIV status to their husbands because they could reveal their illness to co-spouses who would then judge and blame them for bringing the disease into their families. An HCP reported that many HIV+ mothers in polygamous and large families chose not to reveal their HIV status to anyone, which in turn made it difficult for them to adhere to the PMTCT program and take their medications consistently. A HCP said:

> I think living in a big family does play a role. Sometimes HIV+ mothers are afraid to tell their husbands… they worry that if they disclose it to them the husband will tell the other wives… everybody will blame her for being a source of HIV to the family. The mothers in polygamous situation are highly exposed to low PMTCT adherence with high risk of MTCT of HIV (HCP2).

Poverty exposed most HIV+ mothers to multiple partners and prostitution. Women did not want to practice prostitution, but because they had no other option for financial survival they sometimes engaged in it. A participant from the PMTCT programcvleaders group shared his thoughts: "Once they are met with sugar daddy who gave them everything they need (phone, accommodation, food) in exchange with sex, they are not hesitant to accept the risk of unplanned pregnancy and MTCT of HIV" (PMTCTL3). An HIV+ mother who experienced multiple partners due to poverty added:

> I was a single mother very poor; a lot of men approached me and wanted sex in exchange of money! I needed the money; you know it is not easy to refuse…I was in that life with multiple partners to feed my babies. This kind of life exposed me to unplanned pregnancies and one of my babies is HIV+ through MTCT (PMWPB6).

When conducting interviews with HIV+ women, I realized that many of them had multiple partners. Some were married and had boyfriends. Most HIV+ women in this study were involved in sexual relations with multiple men, either married or not. One stated:

> I am not sexually active, luckily. The last time I was sexually active…I was still together with my partner…who knows I am pregnant…a condom was used consistently, except that first time we met… and then I became pregnant…. This was not planned… I cannot say I regret it; I am an adult and responsible for my actions… my partner knows I am taking the pills and he is angry at me actually… he said it is going to take time because he is HIV negative and asked for some time to go and heal. Meanwhile I am with my boyfriend (PMWPB8).

Another participant stated: "I had a tough life…become prostitute, do sexual intercourse with different men with one requirement; yes they have to pay me! Yes, I did this to be able to feed my kids…, this was my life" (PMWNB1). Another lady decided to live with different men, some already married, because they agreed to support her financial needs:

> I was living with many boyfriends, I live with one boyfriend today, I will take another tomorrow, and continue like that! I got many kids from them! It is me who takes care of them and try to answer their needs without any support from them! I do not have another choice! At this time, I pray God for good health so I can keep taking my ARVs (PMWPB4).

Gender related issues as a factor increasing women's risk of HIV and MTCT of HIV. Gender based violence is a foremost determinant of women's risk of HIV and MTCT of HIV infection in SSA and in Rwanda. It includes sexual, physical, emotional, and economic abuse, and has evolved in part from the subordinate position of women in society. Violence against women increases women's risk of HIV and MTCT of HIV through limiting women's ability to negotiate safe sex, forced or coerced sexual intercourse, and through the association between childhood sexual abuse and high sexual risk-taking in adulthood. In this study, violence against women was recognized as a most important public health concern and a human right issue. One woman described it:

> Yes, indeed, my man beat up myself… he said I am talkative. But this is not the exact problem… it is because he has found girlfriends who he feels that they are more beautiful than me. So, whenever he came home, he just starts beating up his wife (PMWNB7).

Women felt vulnerable to violence when they tried to discuss household finances or address their husbands' infidelity or polygamy:

> …when I try to reason with him about lack of clothes or other things, he ends up beating me because he thinks I am troubling him…mostly men who behave like that were just born cruel…they lack some love. They take you as their slave… forgetting that they married you as a wife, this is a lack of love (PMWNB5).

One mother explained gender violence as resulting from power difference between men and women: "I don't feel good when such things happen, but what can I do? It happens because it is taken that women are powerless against men" (PMWNB5). The majority of participants were marginalized; their husbands had put them into a position of less power, and they were isolated within their family and society because of fear of discrimination. This marginalization had a great impact on making HIV+ women more vulnerable to MTCT of HIV and to low ARVs adherence. Some of them did not have the ability to peacefully voice their grievances; they spoke of staying silent with families and authorities about the violence in their relationships. One client said:

> It was easier to pretend that things were fine than disclose to my friends that I lived in a violent relationship…It is hard to tell people I've got a problem. Yes, I am not living a good life… with a husband that I'm worried, you know… we're always fighting… things like that, you just pretend, like now, I am pretending that I'm ok but I'm not ok. I did not have the ability to peaceful voice my grievance, I just accept like it is (PMWNB5).

Gender inequality accelerated the spread of MTCT of HIV and limited successful utilization of the PMTCT program. The dominance of men, women's economic dependency, poverty, limited knowledge about PMTCT, and low decision-making power of women highly affected utilization of the PMTCT program. During our interview with one PMTCT leaders, he mentioned:

> Traditionally, a wife has to respect her husband. This exposes a wife to accept whatever the husband said and want. A husband can have sex at any time he wants too and do not have to negotiate sexual intercourse. This exposes woman to sexual violence. He may also have multiple partners without wife to complain; she has to accept it as it is. You can see that it is not sure if those partners are tested for HIV and not sure if they have good ARV adherence. In addition, most of husbands refused to use the condoms. Those acts expose babies to MTCT of HIV **(**PMTCTL3).

In sub-Saharan Africa and Rwanda, women's social status depends on their ability to produce children. Moreover, and in relation to HIV and MTCT of HIV, when having children is a goal of marriage, advocating condom use will fail. Some husbands had negative attitudes on the use of condoms, and this influenced the women's responses to the PMTCT program. One said:

> My husband does not like condom… he hates it… he uses to say: 'I am a man of the house and I paid your dowry, I will not us the condom'… this make the male partner to be unfaithful and it can lead to divorce (PMWNB13).

Unsafe sex practices were common among HIV+ pregnant women. They thought that having unprotected sexual intercourse with a HIV+ partner was fine as long as they were on ARVs. Some women did not understand and were not aware that re-infection could occur; they thought that taking ARVs made it safe to engage in unprotected sex. Most women did not understand why their viral load was increasing while on treatment. One pregnant woman said:

> I am sexually active… the last time I had sex was two weeks ago… I use a condom every time and I do not want to make any mistake. I am now pregnant with this child, I do not know what happened, may be the condom broke! I was having problems with my boyfriend… we would always use a condom, but for this pregnancy, during the intercourse, it was taken off… I felt like he knew something and took it off… always coming up with excuse during sex… like how he has a rash. I used to have high viral load while on treatment. I missed to understand why (PMWPB9).

Power relationships as factors that limit women's accessibility to the PMTCT program. In some parts of Rwanda traditional beliefs are practiced where women are not guaranteed equal rights and equal status with men. This results in women needing consent from their husbands to be tested for HIV. One PMTCT leader said:

> HIV+ mothers faced difficulties related to unequal gender power relations. Understanding and adequately responding to gender related and cultural barriers is critical to maximize access and adherence to the PMTCT program to prevent MTCT of HIV and keep HIV+ mothers alive and healthy (PMTCTL3).

Unequal gender relations and women's socio-economic dependency were found to limit the HIV+ mothers' decision-making power regarding accessing the PMTCT program. Husbands sometimes refused to allow their HIV+ pregnant wives to visit ANC because they did not want to pay a fee for transport or services. One mother said: "I cannot do anything…because he is the owner of the pregnancy…and he is the one who can give me money to go to the hospital" (PMWNB3).

Some participants reported the power imbalance between HCPs and HIV+ women as a challenge to uptake the PMTCT program. HIV+ women articulated there was no possibility of declining the test: "I can't refuse… I must be tested to receive further pregnancy services… otherwise I won't be provided the service" (PMWNB5). A combination of poor provider communication and patient subservience led to one pregnant woman not receiving her HIV+ test result until after delivery, and being without ARV prophylaxis. She said: "The HCP didn't tell me if I was supposed to come back tomorrow or wait for HIV test results… when I finished, I just left… It is like that… we didn't understand each other" (PMWNB8).

Some participants said they had followed or accepted HCPs' advice because they were told to. This both enabled and challenged uptake of the PMTCT services:

> I told the HCP that I am ready to know my HIV status… because she is the one who made the diagnosis and found I have the disease…I will not deny the results. She will give the direction that I must follow (PMWPB6).

Another added:

> A nurse told me that I will die and leave my kids orphan without having anybody caring [for] them… I found taking ARV as a must…I did not have another option than using the program so that I can live and take care of my kids (PMWPB9).

Role of mothers-in-law in constraining the uptake of the PMTCT program. In Rwanda like in many African countries, the mother-in-law has traditionally had an important role in matters related to reproduction and childcare. In their position as elderly women and grandmothers, they generally see themselves as being responsible for decisions concerning health issues in the family. However, some mothers stated that the mother-in-law was an influential person with great power over her daughter-in-law and this had negative influence in the PMTCT program, one stated:

> She asked to do something against my will, and I have to listen to her… because she is who she is. She has a lot of control over me and my infant. It is hard to implement the PMTCT program while my status is still secret (PMWNB5).

When asking HIV+ mothers a question concerning who they would have as their primary confident to disclose their HIV status, they stated their husband as their first choice and secondly their own mothers, sister, or close aunt. None of them mentioned their mother-in-law. One participant said:

> I would not tell her because she would not understand me… she would think I brought it (HIV infection) to her son and would send me away. I usually keep my status secret… when she is in my house, I just stop the drugs (PMWNB7).

Another client mentioned:

> Just think if this disease would have happened to me first instead of my husband, what my husband and in-laws would have thought about me? They would have thrown me out of the house; my mother-in-law would be talking about my husband's second marriage… but now things are different as my husband was the first one to get this (PMWNB7).

Judgmental challenges interfering with the uptake the PMTCT program. HIV was found to be associated with perceptions of the women being engaged with infidelity and multiple partners. Many participants indicated that living with HIV was perceived as having been immoral, and felt ashamed because of the nature of the HIV disease. A participant stated: “I felt shameful in my own eyes…the problem with this disease is because of this sexual nature of HIV… none gives you trust and respect, they don’t give sympathy and don’t talk to you anymore” (PMWNB8).

Most of the HCPs and people held the view that HIV+ mothers should not get pregnant, as they believed that the babies would be born with HIV and the mothers would die sooner. It was considered irresponsible since they were less capable of fending for their children. On HCPs said:

> I feel like…it is irresponsible or may be ignorant of the HIV+ women to bring a child into this world…they know they are dying… what for…the children to such women will eventually die…they will ultimately be contaminated by their mothers…they will not have along life (HCP1).

Some HIV+ pregnant women internalized this stigmatizing belief; they reported going through depression periods upon learning of their HIV status and refusing to seek treatment because they believed there was no hope for them. One client said: “I considered myself a dead person…I believe that God does not like me…how come that is me…his faithful servant…I can suffer this much” (PMWPB8). In addition to feeling ashamed, some HIV+ mothers felt guilt due to the risk of their children acquiring HIV:

> My morale went lower until I got to zero. The positive results of my little baby killed me! I tried to commit suicide many times… one day, I wanted to take poisoned drugs for

> mouses…should not my firstborn daughter be there, I would kill myself already (PMWPB6).

Theme 3: Health System Factors Affecting the Delivery of the PMTCT Program

The care provided at the PMTCT program mostly served as an incentive for HIV+ pregnant women to access and use the PMTCT services, although not all women adhered to the program and mentioned health system related issues as barriers. A number of reasons have been combined in two subthemes: health system obstacles and accessibility related factors.

Health System Obstacles

Poor relationships between HCPs and HIV+ mothers affected the adherence of women to the PMTCT program. Under this section I discuss professional confidentiality, ethical practices, attitudes of HCPs, and VIP service.

Professional confidentiality challenges as factors affecting the delivery of the PMTCT program. Lack of privacy and confidentiality at the PMTCT program was reported as a major barrier to adherance by mothers and HCPs. Some patients complained that HCPs did not maintain confidentiality as they would sometimes gossip or discuss patients' HIV status with community members. The lack of confidentiality in handling the results of HIV tests was a barrier for HIV+ mothers to uptake HIV testing. One HIV+ mother noted:

> … in some cases, I may know the HCP administering the test and so… I decide not to go for the test for fear that they will disclose my results… I remember… I was tested positive in a clinic, and one of the staff from that clinic came to my office and told people… I was feeling ashamed for being positive… so you can see lack of confidentiality among HCPs and the idea that HCP could share results with other

> community members is a strong deterrent against testing. I felt very sad and finally stopped to go the PMTCT services (PMWPB3).

Many HIV+ mothers preferred one-to-one sessions rather than group sessions at the hospital as they had more privacy to discuss with the HCP any questions they might have had. An HIV+ mother stated:

> I do not really feel comfortable asking questions… yes, the HCPs are nice… I am nervous and they will keep telling me things I already know… sometimes I can't keep asking, so I just listen to what they have to say… then keep my business private (PMWNB13).

It was very important to provide HIV+ mothers with different options and ways that they could be proactive and interact with the HCPs comfortably. Another woman stated:

> The conversation was friendly… I like that she recognizes people, and this is the way HCPs should interact with patient… I feel comfortable to get and not nervous to ask the HCP questions… I want to ask but in privacy and not in front of everybody (PMWNB14).

The HIV+ mothers spoke of feeling uncomfortable and anxious being seen entering the location of the PMTCT program as there were no other services provided there, and they were afraid of involuntary disclosure. They additionally complained about a confidentiality issue with open clinic software where all hospital staff have access to patient information, and were afraid to access the free medical insurance offered to HIV+ people because of the possibility of involuntary disclosure. For some HIV+ mothers, the lack of privacy and risk of exposure was so unbearable that they stopped going to the PMTCT program entirely.

> Problems I encounter are problems at the hospital… because sometimes you get scared to go register for laboratory exams… when you get there sometimes… it is different with others… all services are free… you can see all staff receiving me, they know that I have that disease…everybody working there can see it in their machine (PMWPB3).

Another mother said:

> Another issue is that PMTCT services are in isolated place… all who are sitting there have the disease, which makes me uncomfortable… especially for me, nobody knows it… I have not disclosed my status to anybody… I don't want to be seen sitting in that house for HIV+ people (PMWNB1).

Concerns related to ethical practice. Ethical issues arise in everyday practice of HCPs, and can often be relatively simple to deal with. However, in relation to HIV disease, ethical issues may be exceedingly complex and difficult to resolve. It is then imperative that HCPs have skills, knowledge, and right attitudes in regards to ethical practice to be able to respond to the issues in an appropriate, ethically warranted, and just manner.

Ethical issues relating to HIV+ women's rights, privacy, and confidentiality have taken on a heightened emphasis throughout the HIV epidemic due to HIV related stigma. Moreover, the tangled web between HIV+ women's rights violations and the impact and spread of HIV on individuals and communities is now well understood. Some HIV+ mothers felt unhappy about the treatment and judgement from HCPs; they expressed that some HCPs failed to implement the ethics requirements of their profession and had some judgmental behaviors. One mother said: "The HCPs are very knowledgeable… but sometimes they were looking down on me because I am sick…they don't have to judge people yes… I felt that sometimes they were judgmental" (PMWPB9). Another HIV+ mother added:

> I thought one of the nurses was judging me… she kept asking questions that I could not answer and at that time I was still in a shock… I felt guilt even though I did not know how I got the disease… but at the end they treated me very well (PMWNB8).

Attitude of HCPs as a constraint to effective delivery of the PMTCT services. The HIV+ mothers reported being treated poorly by HCPs working at ARV and PMTCT clinics, describing that they would get yelled at or punished if they arrived at the clinic late or missed an appointment. Some women stated excuses for missed appointments were not accepted, and, when they did attend the clinic at a later time, HCPs would humiliate them and make them wait outside until everyone else had been helped. One mother stated:

> They don't understand, they yell… one time I missed the date for PMTCT visit and they made me sit outside for hours. I was so hungry, and I had no money to buy food… I thought of leaving but I couldn't because I knew I was going through the same thing if I left (PMWPB3).

Women also described being reprimanded when their medications were checked and they had the incorrect number of pills left. Consequently, they reported throwing away excess pills prior to them being counted to ensure that they would not be treated poorly. Some PMTCT clinics reported high adherence rates; however, HCPs indicated their suspicion that these numbers may have been grossly inaccurate. One HCP reported: "…but you find that sometimes HIV+ mothers would show a 100% adherence, but you look at them… they look so sick with high viral loads. Then you wonder what they do with the drugs… sometimes I think they throw them away" (HCP2).

Inadequate human resource capacity was also identified as a constraint to effective delivery of the PMTCT services. HCPs reported that some PMTCT units were inadequately staffed and overworked. Thus, as one HCP said: "…the problem is not just that of training, but we need more staff to increase our capacity to provide the effective PMTCT services (HCP4).

One woman who defaulted from the PMTCT program due to the behavior of HCPs stated:

> Sometimes HCPs do not interact well with us… they shout… so based on how they raised up their voices and you know… they … the respect they received in society… some mothers, like me, decide to stop the PMTCT program uptake rather than go to the hospital for a refill and get embarrassed at the facility (PMWPB3).

Negative experiences with HCPs were not uncommon. One participant reported: "Some HCPs are abusive… they used abusive words because of my HIV status… they are hostile… some don't give feedback after examining me and the baby in the womb… they always say: see you next time" (PMWPB13).

A good relationship with HCPs enhanced adherence to PMTCT program. This is expressed below:

> When I was told that I am HIV+… honestly, I felt like I will die tomorrow, so when I go for appointment and refill of drugs… I am already stressed up…If they can welcome and interact well with me… I can open up and get assisted well… in that case, I think nobody can then decide to default from the program and treatment due to the mistreatment of HCPs (PMWPB12).

VIP service as a way to improve the PMTCT uptake. Very Important Person (VIP) service at BUTH, organized for those who are famous, influential, important, and who need quick services, helped the clients by eliminating the need to ask for monthly permissions at work with risk of involuntary disclosure and subsequent exposure to stigma and discrimination at work. These services were, however, not affordable for everyone. One PMTCT leaders reported:

> The VIP services is provided in the weekend with all package of services such as consultation, counselling, laboratory, and ARVs provision. They are different kind of personality including intellectuals, public, and private employees, people from other provinces and districts. Most clients are from other districts/provinces who travel many hours to reach PMTCT program/BUTH. They refused to attend the near HIV clinic because they are very popular and known by the staff and people around (PMTCTL3).

Another woman added:

> I would love the VIP services; it is in the weekend and the service is quick… but it is expensive… this would be my answer to avoid problem with my manager and troubles at work… I don't think I could afford the VIP service but if I had money… I would have to pay and be willing to do so (PMWNB12).

Accessibility Related Factors

Under this sub-theme, geographical accessibility (distance related factors), limited access to a quality program, and availability of the PMTCT program are discussed.

Geographical accessibility as barrier to PMTCT program uptake. Accessibility involves economic and physical access. In terms of economic accessibility, Rwanda is a resource limited country. The economic status of the majority of Rwandan women is very low. Even with free ARVs and increased availability of PMTCT services in remote health centers, in this study, most HIV+ mothers seeking treatment had to travel long distances to avoid meeting people who know them. Transportation costs and travel distance were reported by the women and HCPs as contributing factors to non-adherence of the PMTCT program. Unemployed women with limited financial resources reported that bus fare was unaffordable. Many were forced to walk for more than three hours to and from the clinic. These financial and geographic challenges to healthcare access led to missed PMTCT appointments and poor adherence to ARVs with MTCT of HIV risk. One participant said:

> It is too far… like me I get them from…, I need to have enough for s bus fare. If I do not have money, I walk through the cane fields… by the time I get back my feet hurt… then I need to come back and work here at home (PMWNB11).

During a focus group interview, one HCP added: "Yes, lack of money for transport makes them skip PMTCT clinic visit… some live in areas where there is no public transport… they walk long distances through mountains to get to the clinic" (HCP3).

Some participants identified the reason of doing this long travel while the PMTCT service was available nearby at the health centers was that they did not want to be victims of gossip in the community. Patients reported fear of being scorned and gossiped about by community members if their HIV status was discovered:

> I also find that I am worried that if I tell people I live with about my situation… they will go around telling everybody in the community. That is another problem that even if I go get the drugs at the PMTCT clinic… when people see me… they will laugh at me that I am taking these pills. They gossip about people in the community… I prefer to travel and get tired instead… they will never see me there… I keep my status secret (PMWPB4).

Limited access to quality program as challenge of the PMTCT uptake. Certain HIV+ women travelled long distance looking for specialized, high quality PMTCT services. Limited access to quality healthcare services was one of the greatest barrier to the uptake of the PMTCT program. Most of participants resided closer to health center facilities with a PMTCT program but preferred to travel long distances to reach the PMTCT program at BUTH. One HIV+ women reported:

> There are other closer places… I could go to for the services, but I decide to travel and come here because of how kind the HCPs are… everyone here treats you like a human being. They make feel that I am normal person because they treat me just like they trait everybody else. And they speak to me privately… they don't shout about our status in front of other people like other hospitals and health centers do (PMWNB2).

Another HIV+ mother who had to travel a far distance to access quality service added:

> I don' t feel like there is enough service at my local health clinic. I have participated in education workshop here at PMTCT program/BUTH and find it useful. I learned about using condoms when having sex, eating healthy food, and not just sleep around. Though I feel comfortable asking questions here even if it far… I come here, spend a lot of money, and receive more education (PMWNB3).

Too many appointments made it difficult for women who were poor, those who had other children to care for, or those who were employed to attend all PMTCT appointments. The PMTCT program at BUTH does not have integrated care, which meant that HIV+ pregnant women had ANC on one day, HIV treatment on another, and associated laboratory exams on yet another day. One client asserted:

> …you know the PMTCT program, I have to come there to many times… with my child I have to take him at the PMTCT pediatric, then I have to come at HIV clinic for my appointment and you know about Cluster of Differentiation 4 (CD4) count exam, it is only on Wednesday… so sometimes I have to comeback to get the test done. Meeting those appointment seems to be challenging even though it was necessary. (PMWNB4).

Availability of PMTCT program as constraint of the uptake of the PMTCT services. Other factors that constrained the uptake of the PMTCT services included the availability of the program at district, provincial, referral, and private hospitals. Those HIV+ women who delivered their infants at hospitals had to access the PMTCT program at the health centers. The only hospital in Rwanda that has the PMTCT program is the BUTH. Most HIV+ women found it challenging to deliver at the hospital, then be referred back to the health centers to disclose their HIV status and to access to the ARV treatment. A head of department in an individual interview reported:

> I think the availability of the PMTCT program at all level of the health system should be addressed. Can you imagine delivering at the hospital and going back to the health center to disclosure the HIV status and ask for ARVs for both mother and baby? This may hinder our ability to intervene in those critical early hours of life of a new-born during which first line drugs should be administered. I think we have to understand those women…I don't blame the women if they fail to go to the health centers… they may lack of confidence and ability to prevent their children from getting MTCT of HIV (PMTCTL1).

Early identification of HIV infection combined with effective prevention counselling and follow up should help to reduce MTCT of HIV. However, contact tracing is missing in the PMTCT program at BUTH even though it is an important tool to identify HIV+ women in the acute stages of HIV infection. Contact tracing could thus help with effective linkage to care, and with initiation of ARV treatment when HIV+ women are ready; and has great potential to reduce MTCT of HIV. One PMTCT leader reported the challenge in terms of contact tracing and said:

> Most women are still able to avoid the system since we have no way to trace them…so they do not go to any facility when the time comes for delivery…health facilities should be able to share the information about HIV+ women so that our efforts to prevent MTCT

> of HIV can be more effective. It is not just enough to give ARVs and counselling… we need strategies to address current lapses with the health system (PMTCTL3).

Theme four: Experiences of HIV+ Mothers During the Prenatal, Perinatal, and Postnatal Period to Prevent HIV Transmission

Today it is possible for HIV+ women to prevent MTCT of HIV, as well as prevent transmitting it to their partners or husbands. All women need to be tested for HIV during their first prenatal care visit and if they become HIV+, they have to start ARVs as early as possible in pregnancy and continue this for their lifetime. Good follow up by HCPs working in the PMTCT program during prenatal, perinatal, and postnatal periods can lower the risk of MTCT of HIV and improve health for both mothers and children.

HIV+ women experienced many challenges during pregnancy, delivery, and in postpartum while attending the PMTCT program which consequently increase their MTCT of HIV risks. Under this theme, I present findings in relation to HIV testing, support factors experienced by HIV+ mothers, experiences of HIV+ mothers with the delivery of the PMTC program, experiences of HIV+ pregnant women during labor, delivery, and postpartum, and how the PMTCT program could be implemented more effectively.

Promoting HIV Testing for the Success of the PMTCT Program

One factor that facilitated HIV testing as mentioned by participants was the need to know one's HIV status. The majority of participants perceived HIV testing as necessary; however, shortage of HCPs in the obstetrics/gynecology department contributed to lack of HIV testing ability, which could increase risk of MTCT of HIV. Shortage of staff also resulted in sub-optimal counselling on the ARVs, and patients obtaining inadequate knowledge about their benefits. This may have translated into HIV+ mothers defaulting from ARVs. An HCP stated:

> HCPs too are contributing to default from ARVs… sometimes due to staff shortage…with many HIV+ mothers waiting to be initiated on ARVs…we sometimes initiate them with limited counselling just to clear the queue. It is obvious with inadequate information, the HIV+ mothers can easily default from ARVs (HCP2).

Knowledge of HIV status as a strategy that improves the delivery of the PMTCT program. The delivery of the PMTCT program must be accompanied by strategies that improve HIV and PMTCT of HIV knowledge. HIV+ women reported that knowing their HIV status was beneficial even when the test results were positive. One woman reported:

> I may not know that I have it till I test… it is good to do HIV test as it helps me to know my status. You know some people may be positive without knowing it…the virus has killed many people in my village…many people thought they were poisoned, but now, testing has helped a lot to discover and treat the virus (PMWNB8).

One mother stated: “It is good that everyone does HIV testing because without this test I would have died, and my babies would get HIV… knowledge of my HIV status enabled me to start pills early since I became positive” (PMWNB9). Another woman reported how important it was get tested even when the test is negative: “You may also be tested negative… this knowledge is very important… it enables that person to be careful…so as to avoid occasions and things that would lead someone to contract the HIV” (PMWNB8). One participant was of the opinion that testing is good especially when you are HIV+. She said:

> It is good to be tested… if someone is tested positive, it will enable them to start their pills in order to prolong life. If one is tested negative, it will help them to maintain their healthy status…also by knowing your HIV status, the spread of HIV and MTCT of HIV can be controlled and cannot be transmitted to others (PMWPB9).

Most of the participants mentioned that they gained knowledge from the PMTCT program and valued the advantage of participating. One reported:

> The program gives me information on how to protect myself and care for the child… it made me know my status… I was also relieved of all the stress of not knowing my status… the program increases the chance of my babies being HIV negative… I have had three kids followed in the program and they were tested HIV negative. Nothing could be more heartwarming as getting a result of HIV negative baby by a positive mother (PMWNB15).

The role of prenatal testing and associated fear and shame. A high number of pregnant women, who have not tested for HIV, delayed starting ARVs, and their babies missed their nevirapine doses. The participants stated that HIV testing was important not only for knowing HIV status but also, in the case of pregnant women, to prevent MTCT of HIV. Most HIV+ mothers said that HIV testing has become a part of the routine prenatal exam. One HIV+ mother stated:

> Routine HIV testing during ANC mattered not only for healthy babies but also to ensure that these babies were born without any challenges… for instance I knew that I was sick during ANC…after testing, I found out that I had the virus, got into care, and had a healthy baby… I recognized that even if I did test positive, I could still have healthy children if I followed through with the PMTCT rules (PMWNB12).

Some HIV+ women became fearful when attending the ANC too late, discontinued their ARVs, and did not take their child for an HIV test after having a blood sample drawn by an unfriendly HCP. One HIV+ women reported:

> I was afraid of going to the hospital because I missed to go there during my pregnancy… if I was not going to the hospital it will be difficult to go to the hospital to deliver… they will ask for my hospital card… it will show that I was not attended… they will scold me (PMWNB8).

Participants were of the opinion that the primary reason why people did not test for HIV was fear, particularly fear of the unknown, fear of HIV+ results, fear of collection of blood samples, or fear of needles in some cases. One HIV+ mother stated:

> People are afraid to test because they believe that they will die if they contract the disease… so they would rather not know their HIV status. For me, I was thinking that I will not be able to cope with positive results and will poison myself (PMWNB15).

There was a perception and fear that HIV+ mothers would soon die, resulting in a loss of hope. An HCP reported: “People are afraid to do a HIV test because they don’t want to die…rather than hearing that HIV+, they will prefer to die and not know their status” (HCP3). Yet, another HIV+ mother indicated that: “Fear comes to mind because people are preoccupied with thoughts on what will happen if they become HIV+…fear of knowledge of HIV status is enough reason for refusing to perform the HIV test” (PMWNB13). While another participant shared that some people’s fear was associated with their risky lifestyles:

> The fear of their lifestyle and their past risky behavior they engaged in… one may already be infected… this also influences the decision to not want to know their HIV status. You know a positive result may force some to kill themselves so they would rather not test (PMWNB1).

Other participants were afraid of the needle to obtain the blood. An HIV+ mother said: “People do not test out of fear of contracting HIV through infected needles” (PMWPB4).

Perceptions of shame were cited as a reason why people chose not to test for HIV. Some pregnant women did not want to test because of shame and the potential for perceived ridicule due to a seropositive status, as one stated: "People do not test for HIV… they want to avoid putting their families to shame if the result is positive… they would prefer to die rather than bring their family to disrepute" (PMWNB11).

To a number of women, couples therapy provided a convenient platform for couple testing. Another intimidating task expressed by HIV+ mothers in relation to HIV testing was disclosing the HIV+ status to a husband and bringing them to be tested. Most women lied to convince their husbands to be tested. One mother reported:

> When I first got tested… I was alone… my husband was not with me…and when I got home, I did not tell him about it. I was afraid of his reaction… so I told him that the doctor had said that we must go together to the next clinic appointment. When we came back together, we both got tested and were found to be both positive…we then made the choice of starting on medication together. See if I had told him upfront that I had been tested and I was positive…he would probably have blamed it on me… he would not have accepted to come to the hospital with me… I decided to tell him the doctor had said they would not treat me if he did not come with me to the hospital…I wanted him to know his status too… so we got tested together and were told what to do to prevent MTCT of HIV (PMWNB14).

Another woman shared her experience with couple testing. She was tested for a second time to motivate her husband to be tested. She stated:

> When I found out that I was HIV+… I asked my husband to accompany me to the next hospital appointment… we came and got tested again together…and he was found to be HIV negative… that was very hard… I did not know how to face him…the HCPs were very helpful and supportive… they gave us information on how to live as a discordant couple… our marriage has changed quite a bit since then… but my husband still loves his kids and works hard to provide for us (PMWNB12).

Another woman who experienced discordant results shared:

> When we got couple testing… my husband was tested HIV negative and I tested positive…this made it very difficult for me… we were helped by HCP team and we decided to live a positive live and not dwell on blame games since what happened could not be reversed (PMWNB1).

A woman whose husband refused HIV testing said: "My husband refused to do the HIV test… he usually says to me:' this is yours and not mine, you brought it into the marriage or relationship, and he refused to do the test" (PMWPB6).

Polymerase Chain Reaction test delay children's care. The results from this study showed that HIV+ mothers experienced delays in getting feedback on PCR test results for their babies. This in turn caused delays in linking to HIV care for their children. One mother reported: "At the age of six weeks, my baby was tested for HIV… and the results came late when the child was three months old" (PMWNB3).

Some HIV+ mothers expressed that they had a difficult anxious time waiting for their children's PCR test results. Concerning the long wait for test results, a client added: "Ah I can't clearly remember how long I waited… I came back at three months and the results were not ready… during the period I was waiting for the results… I was worriedly waiting… I was anxious" (PMWPB13).

HIV+ Results: A Challenging Life Event

Most participants reported that they were scared when told they were HIV+, the majority related that they felt the HCPs were joking when they gave them a positive result. One participant stated:

> I was so scared; I was so nervous. I honestly did not believe it was me… I felt like the end of the world, I couldn't understand what to do, I was shocked, and I was not expecting myself to have HIV. I thought I am healthy enough that I could not have that disease… I thought I was having a faithful husband in a such an extent that I won't have it. It took longer to accept that situation… it was not simple, but I accept myself that I am HIV+ (PMWPB9).

The majority of participants were diagnosed during ANC and stated that they were shocked with the life-changing experience related to the newly diagnosed HIV+ status. Some expressed a complex mix of psychosocial, emotional, relationship, and economic issues that arose directly from the HIV diagnosis. Pregnant women that tested HIV negative initially would routinely repeat HIV testing every three months throughout their pregnancy. One participant said:

> I got to know about my HIV status when I attended ANC; I was pregnant… They had to test me. I think I was five or six months… I found out about being HIV+ during that time. I thought I was going to die and leave my child" (PMWNB4).

Most participants said that receiving an HIV+ diagnosis was the beginning of a long road of challenging life events, and its impact was not limited to the immune system, but also affected psychological functioning, social network, culture, and religion for them as an individual. Most participants reported that it was not easy to cope with being a mother and having a virus at the same time. Their only option was to accept their HIV status. One mother reported: “It was hard … yes it was so hard…I was stressed but I have to manage to accept my status of HIV because I was carrying a baby (PMWNB7)”

Counselling-a key element of the PMTCT program. The majority of HIV+ mothers singled out counselling as the key element that played the greatest role in their decision to uptake the PMTCT program. An HIV+ result was devastating and unwelcomed news to those who found out about their status for the first time at the ANC clinic. Mothers explained how counselling was critical for them to come to terms with realities of HIV, accept themselves, and act in a balanced way to preserve their health and protect their unborn child. One mother reported:

> I did not know my status until I came to the ANC clinic… they requested me to get tested. I declined at first because the tests are done at reception without any counselling session, and I was not happy about that. The second ANC visit, the doctor insisted… he said that it was good to get tested and know my status. So, I went for test and it came out positive. I did not receive any counselling before HIV testing, but the post-test counselling has helped me so much… through counselling, I have become strong, accepted that I am sick, start the PMTCT uptake, and started on medication to save my child (PMWPB7).

Some HIV+ women reported not receiving any formal pre-test counselling or any explanation of the testing process. One participant stated: “…those kinds of formal counselling were rarely observed… sometimes some health education and group classes before HIV testing without individual counselling…they just tell me sit there so we can check your health" (PMWNB12). Another woman added:

> When I went to be tested… I remember the nurse did not tell me anything… Others are saying that when you go there for test the nurse will first give you counselling… she will ask you 'are you ready'? But I remember I did not get any counselling… she took my blood sample at reception and she didn't ask me anything (PMWPB2).

Some HIV+ mothers reported not attending to the recommendation they received during the counselling:

> I was pregnant for my fourth baby…after a few months, I decided to attend an ANC clinic by myself. At the ANC clinic I received a HIV testing and the HCP told me that I have that disease… but explained that there are medicines that I could take to save the baby from being infected with that disease. She also added that it would be important to deliver at the hospital. I received the pills from the HCPs to take during my pregnancy… I did not manage to take them because I feared my husband… I also feared suspicion of my relatives who might escort me to the delivery wardroom… I gave birth at home (PMWNB14).

Support Factors Experienced by HIV+ Mothers

Coping with emotional, physical, and social stressors were identified to be important facilitators of living positively and surviving with the virus. Support came in various forms: spousal support, family support, and HCPs support.

Spousal support as a way to cope with HIV disease. Receiving the news of HIV diagnosis changed the feelings some participants had towards their pregnancy and the unborn baby they were carrying. Most participants described that acceptance of their HIV status helped them cope and live with the reality. An HIV+ mother mentioned the support needed and said:

> "For me… at the time I was pregnant, spousal support was critical… it was the very important support that I need daily. After getting this disease, I was worried about health complications and fear of inevitably dying! You know this disease may cause some disruptions in relationships not only with my husband but also with friends and families or people at work." (PMWNB13)

An HCP added that HIV+ mothers need special care:

> Special care and support are needed to those HIV+ pregnant women… you can understand their situation, they are HIV+… living with a chronic disease which will end in death yet carry new life within them…yes, we know that effective ARVs help them living longer with the disease… however we cannot ignore the associated stressors… having support from husband, families, and HCPs are important aspect (HCP2)

HIV+ mothers expressed mixed reactions after receiving their HIV+ results. The reactions were feelings of shock, hopelessness, crying, and blaming themselves. There were also feelings of hope, as they were now able to take action to prevent MTCT of HIV. It was common for some women to blame their husbands' behavior for bringing HIV into the family. Some of them were not surprised at the HIV+ results:

> … I also thought of my husband… who I believe had slept with other women and must have infected me… you can never trust a man as is his tendency to move around with other women even though he is married… for men are children who do not listen (PMWNB4).

Spouses were often not seen as a source of support and trust. Few women had told their husbands about their plans to take the HIV test, and most of the husbands had refused testing. Some women had their families divided. Below is an illustration of how an HIV+ woman was abandoned by her husband and left with four children to feed after revealing her HIV status to him:

> When my husband knew that I was tested HIV+, he never wanted to stay with me and hardly came home after work… he took like three months or even more to visit me and regarded me as a prostitute… he never accepted that he could as well be HIV infected. As a result of this, he was unwilling to help and support me with my children… and the general support that I used to get from him was missed… you can just imagine… I have four kids… and I am unemployed, but I have to feed them (PMWNB4).

Family support making HIV disease manageable. Some participants indicated that they relied on family support to cope with the disease. One HIV+ woman stated: "I think mainly is the support I am getting from my family and my husband; they make things easy to me to see that only different between me and them is HIV disease and is manageable… I am able to manage it as I am coping with it" (PMWNB3).

Another participant elaborated on how supportive her family is:

> I disclosed my status to my sisters and mother… they were shocked but later were very supportive… they are always there for me. My sister used to call me, asking how I feel and advise me to have a good ARV adherence and follow medical advice so I will leave longer and healthy (PMWPB9).

HCPs encourage HIV+ mothers to find someone to disclose to although it was a process that may take some time. Some HCPs added that keeping the diagnosis of HIV as a secret left HIV+ mothers vulnerable to having to bear the burden alone. A participant shared:

> I felt I can be able to fight this virus after disclosure… disclosing to my family was something which I don't regret… I felt much lighter after disclosing because they accepted and supported me. I have learnt that my family is everything… they did not turn their back on me… I am very happy (PMWNB2)

HCPs empower HIV+ women to initiate ARVs and adhere to the PMTCT program. To some HIV+ women, adherence to the PMTCT program and initiating ARVs were difficult steps to take due to reservations about ARVs side effects and the lifetime commitment. The HCPs' support and counselling helped them to overcoming their fears and empowered them to initiate ARVs and adhere to the PMTCT program. One woman stated:

> I was reluctant to start on medication… I had heard that they have very serious side effects… but the HCPs team supported me and made me understand that I needed them for not only my own good but also for the sake of my child. I am so grateful to that HCPs because if it was not for them… I do not know where I would be today. My health has really improved since I started taking these medications. And my three years baby is negative… If I could advise any HIV+ women out there I would recommend that medications and tell them ARVs are very important… you may fail to shower but please never and ever forget to take your medication (PMWPB10).

Another woman reported:

> When I first came in the PMTCT service… I had very low CD4 count… the HCPs team encouraged me to take medication… but the fact that ARVs are a lifetime thing was

> difficult and dreadful to accept. It took a lot of appointment and counselling with HCPs to overcome my fears. Today these drugs have become part of me… and I see them as my food. I did suffer side effects on earlier days… but they have now subsided…I followed three babies in the program, and they were discharged with negative status (PMWNB14).

Experiences of HIV+ Mothers with the Delivery of the PMTCT Program

Despite some progress in the PMTCT delivery, newborns continue to become infected during prenatal period, and during labor or delivery. Effective functioning of the PMTCT program is the key to reducing the risk of MTCT of HIV. HIV+ women in this study experienced several barriers with the delivery of the PMTCT program. These barriers commonly relate to ARV adherence, motivation of adhering to ARVs, challenges for drug adherence, personal behaviour related factors, and infant feeding options.

ARV adherence barriers in the delivery of the PMTCT program. Early initiation of ARVs during pregnancy reduced the chance of MTCT of HIV. Some HIV+ mothers failed to comply with ARVs medication and other prophylaxis practices, as well as follow up to the PMTCT service visits that disrupted the PMTCT interventions to eliminate MTCT of HIV. One mother reported: “My baby became HIV+ at the first test… I sometime judge myself… I was not fine when I started the pills… I used to vomit… I realized my body was changing sometimes” (PMWPB12).

Some pregnant mothers attended the ANC, but they were not tested for HIV due to ignorance and HCP negligence, and they missed starting ARVs during pregnancy. One mother stated:

> Honestly, it was hectic… I did not know what to do…. I came just to deliver and when they tested me, they said I am sick…. I did not take it like seriously… I was discharged and go home… nobody told me about the pills… after six months, my baby started to get

> sick… he was tested HIV+… I don't think the HCPs helped me the way they did, I thought maybe they do their things for the sake of doing… but what I have notices is that they missed to explain to me about the PMTCT program… maybe I should have done something to save the life of my baby (PMWPB6).

Another stated:

> I delivered at the hospital… I had already known that I am sick, and I showed the card to the HCPs… they know I am sick… my baby did not receive ARV sirop… I was asking about it…nobody heard me… I decided to stop breastfeeding my baby… I was really afraid to infect her…she was crying and myself too… we got the sirop on the second day… I can say they are responsible for the HIV status of my daughter (PMWPB6).

One HIV+ mother reported that defaulting from ARVs also occurs after experiencing a positive health change. Some participants started the ARVs while they had opportunistic diseases, but after they became healthy they did not see any reason to continue ARVs. "Before I started my pills… I was often sick but when I started ARVs, immediately got well and was fit just like those who are without HIV… not taking the ARVs… and I thought I was cured… so I did not see any reason to continue taking ARVs" (PMWPB7).

HIV+ mothers felt burdened by taking ARVs on daily basis and by the need to adhere to a medication regime. At times, HIV+ mothers deliberately missed a dose for a temporary rest, and then later decided to default from using ARVs. One participant reported: "Honestly… I was tired of taking pills every day… it was just too much… you know… I wanted to rest a bit" (PMWPB8). During our focus group, an HCP revealed: "Many HIV+ mothers are defaulting from ARVs because they are tired of taking ARVs daily… also with the fact they will take the ARVs for the rest of their life" (HCP3).

HIV+ women may have difficulty accepting the reality of an impending HIV+ life. Typically, acceptance of HIV status is viewed as being ready to move forward with the process of taking ARV medication and adhering to the PMTCT program. Adherence is usually measured by testing the viral load. This viral load test informs the healthcare worker whether the HIV+ women has reached the accepting phase ARVs, and is adhering to her medication. If the viral load is less than 20 copies/ml, there is no risk of HIV transmission and MTCT of HIV. HCPs should educate HIV+ mothers about the link between their viral load and the risk of MTCT and safety of ARVs in pregnancy.

Use of alternative medicines also influenced the HIV+ women to default from using the PMTCT program. Women referred to some traditional medicines, such as herbal remedies, that were not taken on a daily basis and were believed to work better. Herbal medicines could be initiated and discontinued at any point when they felt better. This was an attractive alternative treatment unlike ARVs that have to be taken daily for a lifetime. A participant stated: “Ah… I don’t see any reason for taking these drugs… you know ARVs are made from herbs, so it is good for me to take herbs… any time I feel like rather than these ARVs…taking these drugs daily give me a tough time” (PMWPB8).

Limited motivation to adhere to ARVs. Some women stopped taking ARVs even though they knew it was for their own health, and that it was important for them to survive for the sake of their children. However, many HIV+ women noted that they took the ARVs mainly to protect their children from MTCT of HIV. A HIV+ woman reported:

> It was the same when I was breastfeeding… but I was afraid to stop taking the drugs, as I did not want to transmit the disease to my baby. So, when I stopped breastfeeding… I

> was not sure that I can’t now have drug holidays… I could go for the three to four days without taking the pills (PMWPB7).

Some women added that the main reason that they chose to take one pill a day for life is to protect the health of the baby. A few of them felt that pills could be stopped after giving birth, which was the largest barrier for effective PMTCT program. One HIV+ mother responded:

> I feel like I have no option…I do this for the sake of my baby…I do not want to lie but I am very bad with tablets…I just care about the baby… I do not want to play with its life and mine… I am responsible for another life and it is better this way. I take the tablets just to survive and protect my baby, my number one priority (PMWPB3).

Another added:

> I would say it is a must… I would not say it is a choice because if I choose not to take it, that means I will die… Instead of tablets I wish there were something else. They told me that it is not healing but it can treat the virus to be manageable. I choose to take the tablets because with them I feel like I will live a very long time… I have given a choice in life and it is either up to me to use it or not (PMWNB9).

An HCP added:

> For HIV+ pregnant women, breastfeeding mothers, and the newly pregnant, it is a must that they take tablets or else they are going to get sick… They do not really have a choice; it is a must because if they do not take it then the risk of transmission is great to the baby, partners, and themselves as well. The quality of their life does not remain the same… they have to know that HIV is not the end of the world… there is much more they can achieve (HCP4).

However, there are still choices that have to be made by the HIV+ mothers for successful adoption of the PMTCT program. One physician mentioned:

> I do think the women have a choice, the first choice is to undergo an HIV voluntary test, the second to take the ARVs, and the third is to maintain PMTCT adherence… it is a problematic program… it is not an option but a prescription. This it is for life…there are some women that refuse it and the bulk who take it… As long as they got to know the importance of the program… you are not judging them… at the end of the day as we provide enough information… it is up to the HIV+ women whether or not they utilize certain PMTCT practices or not (HCP2).

Challenges for ARV adherence that influence the success of the PMTCT program. HCPs recognized that one of the biggest challenges was the opportunity for proper counselling that could influence HIV+ pregnant women to make informed choices about treatment for life. Most pregnant women came for ANC visits, and tested positive through routine exams. Many were tested and started the ARVs medication the same day. They had no time to work through acceptance of the diagnosis, as they had to start the ARV treatment immediately. They had difficulty in understanding the immediacy of ARVs initiation. Same day testing and initiation on ARVs were viewed as too rapid for HIV+ women to be able to process. One HCP stated:

> A pregnant woman comes into the hospital and may enter our ANC clinic thinking she is just fine and healthy. Then, HCP asks her to run HIV test after of course waiting approximately from 7am to mid-day. She is tired and exhausted and carries on to pre-test thoroughly. Her test results come out as HIV+ after cross checking, and she went for posttest counselling… keep in mid now she has not seen the doctor yet and she waits to hear that she is HIV+… she may be very upset, not know how to register what is going

> on… and hardly has any time at this moment to process before she is given pills and told that this will help herself and baby… whether or not she fully understand the benefits… who knows (HCP2).

The challenge that came up in the postpartum period related to drug adherence was how to combine one's routine activities with the child's drug adherence. HIV+ women explained how inconvenient it was for them to resume their daily routines after delivery if they had to adhere to exclusive breastfeeding and timely medication administration to the child. It was even more complicated when they did not disclose to their family members. One reported:

> You know… I cannot stay with the baby everyday… sometimes emergencies happen and may need to be away for long period… and it may be the time to take the medication and you are not around. What I think it is much better if I take the medicine myself… as I will know when and how to take them (PMWNB9).

HIV+ women were also concerned about the lifelong daily medication, as one explained: "The challenge is not only taking the same medication… but also taking it every day… you know I have to take it every day… it is somehow tired… sometimes I forget to take them at the right time." (PMWPB1)

Another participant reported:

> The HCPs use to tell me to take pills everyday… it is somehow to use them… instead I throw them away under the bed… this is not only me, but there are also so many HIV+ people doing that… taking pills every day is confusing people. Whenever they come to the PMTCT service… they will make sure they take pills and the next visit they do the same, but I know when HCPs give us the pills to take home… others do not take them (PMWPB12).

HIV+ mothers reported having to wait long hours for services at the PMTCT clinics. Women described being frustrated over the waiting times in the clinic. The wait was particularly difficult for employed individuals, risking wage loss and sometimes their employment. Both HCPs and women also mentioned long wait times as a major problem, especially for people rushing to go back to work and those living in remote areas. HCPs pointed to understaffing issues as being the source of the problem:

> Some women complain about the waiting at the ANC clinic… for instance I am working here alone following both PMTCT activities and family planning… and my first priority is the family planning… I am understood what they meant… you know we understaffed here so sometimes it takes a long time to help everybody… some pregnant women missed their HIV testing or they did not get their results on time (PMWNB5).

An HIV+ mothers added: “Even if you can wake up early and reach there… like at the firm you ask permission from the boss thinking that you will get helped early but no… Then you miss work, and they don’t give you a sick note… then it is a problem now” (PMWNB15).

Personal behaviours contribute to HIV+ women’s defaulting from using the PMTCT program. Most single mothers were without any support and reported that they sometimes forgot to take their ARVs due to being away from home, being too busy, being stressed, using alcohol, or having to attend family or community events. One participant stated: “I don’t work, it is just walk around looking for any job in the village…anytime I got job…I just do it…I may get busy, come late, and forget to take my pills on time” (PMWNB5). A few HIV+ mothers reported drinking alcohol as a way to cope with hunger and stress: “I drink…yes… I drink when I am going through a lot of stress. I can say it helps me somehow… it helps me to relax and just not think about my problems too much… it also makes me not feel hungry you know” (PMWNB12).

HCPs noted that HIV+ mothers' behavior significantly contributed to the rates of defaulting among mothers using the PMTCT program. An HCP stated: "Those HIV+ mothers who are addicted to smoking and alcohol… tend to forget to take their drugs and miss the clinic appointment" (HCP1).

HCPs echoed mothers' comments, though they believed that alcohol use was another reason HIV+ mothers forgot to take their drugs. During the individual interviews, I found that most HIV+ mothers were apprehensive about discussing their alcohol use. They spoke about alcohol use in very general terms, identifying the behavior as a barrier to adherence. However, during the focus group interviews with HCPs, excessive alcohol use emerged as the most frequently cited reason for both HIV+ mothers and their babies to miss their ARV doses. Likewise, HCPs also identified alcohol use as a barrier to PMCTC adherence, since HIV+ mothers who drank alcohol excessively were more likely to forget to take their daily doses, as well as the doses of their babies. Additionally, HCPs perceived that alcohol overuse resulted in missed PMTCT clinic appointments. "…alcohol use plays a role…yes, alcohol makes them forget the dates of PMTCT clinic appointments. I also think that it makes them forget taking their drugs on time at home" (HCP4).

Infant feeding options as a way to prevent MTCT risk. HIV+ mothers have two options to feed their children: they may choose either EBF or exclusive replacement feeding (ERF). However, both feeding options contain risks to child health and survival. HIV+ women tended to overestimate that breastfed babies contract HIV, and this resulted in their choosing ERF even when their financial situation was precarious. The findings showed that guiding HIV+ mothers on infant feeding was the weakest aspect of the PMTCT program. HIV+ mothers struggled to make feeding choices that matched with their socio-economic contexts and that were culturally accepted. Some mothers practiced mixed feeding though this practice is not advocated by the PMTCT guideline. One senior specialist following the HIV+ pregnant women reported:

> I felt that the counselling and the support on feeding options they had received was ineffective… it seems that HCPs imposed or guided them to breastfeed… HIV+ mothers should choose to not breastfeed if their infants will consistently receive safe and adequate replacement feeds (HCP2).

HIV+ mothers were frequently exposed to conflicting messages from the PMTCT program staff, family members, and traditional healers. Some HIV+ women experienced a dilemma where HCPs wanted them to EBF of ERF, and the community demanded that they breastfeed longer and mix feed. This feeding dilemma exposed their infants to MTCT of HIV through breastfeeding. One other mother said:

> The HCPs also talked to me about the advantage and disadvantages of infant formula feeding… they highlighted advantages of exclusive breastfeeding… I opted to breast feed the baby… exclusive breastfeeding was explained as breastfeeding the child on demand and not giving the child other fluids for six months. I opted to breastfeed.” (PMWNB6)

Another woman stated: “The HCPs said that other feeds should be avoided… the emphasis was on feeding the baby on breastmilk for six months without giving water or other feeds. They stated that the other feeds could cause injury to the child leading to MTCT of HIV” (PMWNB8).

The majority of HIV+ mothers chose the breastfeeding option. One mother reported she breastfed her baby for six months only:

> Yes, I breastfed my baby… at that time we used to breastfeed for six months only… I fed my baby but sometimes I was scared that my child may be infected… I still do not

> understand why he is not infected… you know the breastmilk came from me and I am HIV+. Before I was not sure about what they said… how come… being positive and get negative baby… yes baby was on syrup and myself I took pills (PMWNB11).

Furthermore, because breastfeeding seemed to be socially constructed as being an essential feature of motherhood, replacement feeding reflected negatively on the mother's commitment to motherhood and her children. Also, HIV + mothers' feared that if they chose not to breastfeed, that would be an indication of their HIV positive status.

> After delivery, I can't choose for not-breastfeeding…people will ask me why I am not breastfeeding? Then it is very difficult for me to answer them…they know that all who are not breastfed their babies have the disease… also my mother and sisters-in-law will be with me after delivery for a period of one to two months…then it becomes problematic…you can see… I can't give ARVs sirup to the baby…and I can't stop breastfeed my baby…they can judge me for not being a good mother. (PMWPB6)

The conflict between a breastfeeding culture and PMTCT guidelines was another concern raised by the participants. Various social and cultural factors about ERF influenced the experiences, attitudes, and behaviour of HIV+ women. There was pressure to breastfeed directed towards HIV+ women from in-law families arguing that ERF in early infancy violates the rules of good motherhood. One participant stated:

> The mother-in-law does not agree that I am not breastfeeding… it is against the culture… according to culture I am supposed to breastfeed the baby up to three year or even more… I did not disclose my status… she does not know my disease nor why my baby is not breastfed. She said she was born before that doctor and she know much better (PMWNB14).

Based on community infant feeding culture, prolonged breastfeeding makes infants healthier, stronger, and faster in development. In the African community, mothers who use replacement feedings are identified as bad mothers, irresponsible, dislike their child, desire adultery, desire to kill the child, and/or desire to maintain breast beauty. Some participants expected negative reactions from their family members if they followed the PMTCT program advice. Some of these reactions were influenced by cultural and traditional values. One HIV+ mother stated: "The grandmothers and the elders will want you to follow culture and will not understand why baby is not breastfed or why baby is not given porridge or water" (PMWNB2).

Rapid weaning was recommended in the previous PMTCT guidelines, and mothers were allowed to breastfeed up to only six months. The majority of participants applied the infant feeding with rapid weaning at six months. Though an effective method in reducing the risk of MTCT of HIV, the harsh realities of rapid weaning were distressful to both mothers and their babies. One participant mentioned:

> It has not been easy… it takes a lot of commitment with weaning at six months… it took a lot of courage to stop him from breastfeeding… a baby crying all night long and you have breasts filled with milk… but I cannot breastfeed… it is tormenting… it took so much strength and support from the HCPs to get through it. He was resilient to other foods… but after… about one month he got used to it (PMWNB15).

When weaning, HIV+ mothers worried about weight gain of their babies and their financial inability to offer adequate replacement foods. One client reported:

> Weaning was very hard… it is just too rough… I see my baby cry nonstop…she was too small, and she used to breast milk and all over sudden you take that away… then she rejected other foods…the food was not appropriate for her; I just give what I had because

> of poverty… it is really tough. One day I called the HCP in the middle of the night… luckily, she picked up… if she had not uhuu I think I would have given in that night. But she reminded me that I was doing this for the good of my daughter… so I stayed firm and she has adjusted… she is now five and she went out with negative results (PMWPB3).

Replacement feeding is rare in a breastfeeding culture, because many communities, particularly in Africa, believe that infants cannot survive without breastmilk. The feeding method is under the surveillance of their husbands and more experienced senior women including mothers, mother-in-laws, and grandmothers. Women are expected to internalize socio-culturally prescribed practices related to pregnancy, childbirth, and childcare with support from experienced senior persons. Most women have limited power in terms of making independent decisions about how to feed their infants, and their practices reflect what senior women in the family have instructed them to do.

In this study, the community attached negative meanings to replacement feeding practices and labeled mothers who used replacement feeding as irresponsible. The replacement feeding was accepted only when the mother revealed her HIV status or had a breast disease or was not allowed to breastfeed by doctors. In these cases, the community and family saw the mother as sacrificing her motherhood function for the welfare of her infant. Some HIV+ mothers tried to hide their HIV status and the weaning became more complicated when husbands were not aware of the HIV status of their wives. One HIV+ mother stated:

> My husband is not aware of my HIV status… we fought a lot over the breastfeeding issue… I made him trust that the baby did not want to breastfeed… I put some pepper on my nipples therefore the baby would reject them… it was very hard… I came to talk to

> the HCPs team often, they were very supportive and encouraged me. When the questions came up, I said the baby had voluntarily refused to breastfeed (PMWNB13)

Cultural preference for extended breastfeeding may eventually make rapid weaning unacceptable and inadvisable. Some HIV+ women stated that appropriate and effective counselling, education, and support from HCPs could contribute to good weaning management. A mother shared her experience on weaning and the support received from the HCP:

> …stopping breastfeeding at six months was very difficult… cries of baby pushed people to ask questions and I told them that my baby had voluntarily refused to breastfeed… but personally I was hurting inside…I wished I could have breastfed my child until she begins to walk. I tried to hide it to my in-law family… they would prefer my baby to breast up to three years. But the thought of keeping her safe and healthy kept me going. After talking with HCP about it… she encouraged me… yes, she even gave me pills to reduce my milk production (PMWPB7).

Experiences of HIV+ Pregnant Women During Labor, Delivery, and Post-Partum

This theme describes the experiences of HIV+ women during labor, delivery, and in post-partum, discharge, and continuity of care.

Experiences during the labor and delivery period that increase the MTCT of HIV risk.

Difficult interactions between HIV+ women and HCPs was another barrier that contributed to the increase of the MTCT of HIV. Several women reported being hesitant about coming to the hospital, especially for delivery, because of the poor treatment they had experienced in the past, or had heard about through HIV+ friends or family members. Difficult interactions may further discourage HIV+ women who already have multiple intersecting obstacles to uptake the PMTCT program. An HIV+ woman described what happened to her during labor and delivery:

> For example, when it comes for the time to deliver… they are so rude and very harsh, they shout at me instead of just telling us nicely what to do… they shout at me and tell me… sit there, it is not yet time, just sit. When I… myself know that my time has come for me to give birth (PMWPB6).

HIV+ pregnant women feared neglect by HCPs when they reported to the hospital in labor. One participant stated:

> I was not sure on how I would be treated by HCPs when they knew that they were conducting a delivery on a woman living with HIV… how could I address this? HCPs were not free to touch me during labour… I finally delivered my baby on the floor (PMWPB2).

Most HIV+ women reported disrespectful and demeaning behaviour by HCPs including insulting language, not being provided services, and being treated without dignity particularly during delivery. One woman stated:

> What is important is the HCP at the hospital… when someone is rude or harsh, it can hamper your service… some do not use good language which makes woman fearful… she may return home… so the behaviour and language of those HCPs are very important (PMWNB8).

HIV+ mothers experienced discrimination and stigmatizing attitudes by HCPs after they delivered. One mother reported:

> That HCP would tell me… I am suffering from AIDS and I will also give birth to positive baby… she said that I will suffer! She added that I am supposed to wash the delivery clothes myself… so that I may not infect the person who attended to me (PMWNB15).

Another woman reported:

> The HCP told me to raise my dress… she can't touch my body because she feels I am dirty… this is one way of stigmatizing someone irrespective of whether she is infected with HIV or not… in short, some HIV+ women are just really being harassed and some stopped using the PMTCT services (PMWPB5).

As BUTH is a referral hospital, most of the women who delivered there were transferred from district or provincial hospitals a distance way. Findings from this study showed that some women were tested and diagnosed as HIV+ during labor or delivery. Those women were discharged with HIV+ status results, but HCPs mentioned that there was no standardized way to follow them up and make sure they were continuously adhering to the PMTCT program at the health centers. An HCP stated:

> The HIV+ women were discharged with few ARV doses… they have to continue their care at the nearest PMTCT program. Women may decide to adhere the PMTCT program either at the PMTCT program at health center or at BUTH. But there is no way to connect with the PMTCT program especially in the health center (HCP2, P30).

This may expose infants to MTCT of HIV as most of the HIV+ women breastfeed. There was also inadequate monitoring and referral structures within the health system, as one senior specialist reported: "We don't have appropriate monitoring strategies to follow up after a HIV+ women were discharged. The fact that we continue seeing previously undiagnosed HIV+ women during labor indicated to me that something is not right" (HCP1).

Deficiency during the discharge process that affected the success of the PMTCT program. Discharge planning is the process of moving the HIV+ mother from one level of care to another; it helps to ensure continuity of care within the PMCTC program. The lack of understanding of the importance of discharge planning among the HCPs contributed to a low referral rate and impacted negatively on a number of steps in the PMTCT care continuum. A PMTCT leader reported:

> Discharge plan was found to be compromised or deficient… most HIV+ mothers especially those new cases are discharged without showing them the next step... they do not receive clear instructions for follow up. For those who come from far we don't know the nearest health centers… we just tell them to go there and disclose their HIV status to them so they can continuously support them… we are not sure if the mothers will have the courage to do so… and we do not have the way to follow up and the MTCT of HIV risk may be high. There is a need to enhance the transition between hospital delivery and PMTCT program in post-partum (PMTCTL3).

Continuity of care issues that affects the success of the PMTCT program. Trust in and familiarity with HCPs was positively related to continuity of care. HCPs described how HIV+ pregnant women were anxious about being referred to other HCPs after having established trust in their original provider. An HCP reported:

> If an HIV+ pregnant woman started being given the PMTCT service by you, it will be you only… she does not want another HCP to know her status. If you sent her to another staff or place, she saw as if she is going to start there afresh (HCP1).

Lack of continuity in care also occurred when the regular HCP was not on duty, which could lead the client to drop out, or miss PMTCT components. An HCP shared: "One patient can need only you to serve her… if she can't find you… you are not present… she does not trust the other HCP who is present, so she turned back" (PMWNB4). Another woman stated:

> I was tested that day… I didn't get the results and I went back home. I came the next month, but I did not find the nurse who tested me… I returned for the third time then I was given the results… my result was positive (PMWNB13).

The PMTCT program is only available in the health centres and BUTH. The district, provincial, referral, and private hospitals lack PMTCT programs although the majority of HIV+ pregnant women deliver at these levels. A PMTCT leader stated:

> We need more PMTCT program in our hospitals. We don't supply to every HIV+ pregnant women and that is maybe a reason of some MTCT of HIV. This somehow abuse the system. They are a lot of HIV+ pregnant women that come in those hospital for delivery and not have the PMTCT services… this is totally wrong; they fly in and out… it is causing a major problem, women have to go back to health center or BUTH, disclosure their status to get access to PMTCT program. Some of them will miss the courage, strength, and willing to go there and the MTCT of HIV is high (PMTCTL2).

Recommendations From Participants for Effective Implementation of the PMTCT Program

HIV+ women in this study faced multiple challenges and barriers in implementation of the PMTCT program as the requirement to keep their children HIV negative. This subtheme highlights the recommendations shared by the research participants to support the effective implementation of the PMTCT program. During the interviews, participants shared recommendations surrounding delivery of the PMTCT program, stigma and discrimination, health system factors, knowledge, delay starting ARVs, HCPs support, PMTCT policies and guidelines, HIV testing, delay in provision of HIV test results, retention of women in the program, male involvement, reporting issues, tracking patients, accessibility of the PMTCT care, and intersection of overlapping factors.

Improving the delivery of the PMTCT program. HIV+ women felt the need for more education to understand the need to take ARVs and learn more about the PMTCT program. Lack of knowledge of the PMTCT program acted as a barrier to ARVs adherence. One HIV+ woman said: “I think as HIV+ women, we need knowledge… this knowledge translation should occur from HCPs to HIV+ women…but it often impeded by unequal power dynamics that causing the patients to feel intimidated or nervous to be proactive or ask questions” (PMWNB5, P10). Some clients viewed HCPs as authority figures, as one woman stated:

> It was difficult to understand what HCP told me at times… because it was either unclear or too noisy to hear… sometimes it was hard to ask questions in front of their peers…I just waited until I could get a chance to do so in private. Changes on the HCPs behaviors and attitude would be useful to improve the use of the PMTCT program (PMWNB8).

Another woman added:

> I was obligated to obey what she (nurse) told me… I thought she was the one who knew it…I knew that I could not have kids… nurse said I shouldn’t have a baby because of my status…uhuu I spent five years without a child and marriage was about to end…it was the time I met one lady who testified having chirdren without HIV that I decided to try… I got one and he is HIV negative (PMWNB2).

Addressing stigma and discrimination in service provision. Stigmatizing attitudes and discriminating behavior from HCPs can limit the impact of the PMTCT interventions for the HIV+ women. One HCP reported:

> Some HCPs behavior of reluctance or refusal to assist HIV+ women during labor or delivery process limit the HIV+ women to uptake the PMTCT program. They have concerns of contracting HIV due to occupational exposure. This may be the results of lack of personal protective equipment or poor training (HCP3).

The current findings indicated that the continuation of stigma and discrimination against women leads to a less desirable PMTCT enrollment, care, and treatment for HIV+ women. A PMTCT leader stated: “Offering mandatory education that focusses on changing behavior and addressing attitudes and how to share sensitive information about women living with HIV to HCPs will be an importance step in subtle change among HCPs” (PMTCTL2). During a focus group with PMTCT leaders, another senior leader added: “To address these problems, it is essential to establish protocols and guidelines that regulate the conduct of HCPs caring for HIV+ women” (PMTCTPM1).

Addressing health system factors. Health system related factors hindered the effectiveness of the PMTCT program at BUTH. These included shortage of HCPs, poor quality of pre-/posttest counselling, and lack of monitoring and referral programs. One senior specialist reported: “Addressing those health system factors could improve the provision and the success of the PMTCT program” (HCP2).

Promoting knowledge given to the HIV+ women. Knowledge is power; the more educated, the more aware the HIV+ mothers were. Strong education and counselling can be a useful component in increasing ARVs adherence and PMTCT program uptake. Education and information were not consistent across the PMTCT program at health centers. This could be harmful if only parts of the educational messages get across to HIV+ women. Women in this study became overwhelmed with information they received from various sources, which included HCPs, media sources, local health centers, and family/friends. One PMTCT leader stated:

> I am finding a big gap… and it is quite scary what education is being told to our HIV+ women at times… they are falling off the grid and incorrect information which is an example of the issues with the PMTCT program education component. The first interaction that HIV+ woman has with information or the first person that speaks to HIV+ woman is what they will believe. It is somehow hard to come in and say something different to them. Incorrect information can act as a barrier (PMTCTL2).

Lack of knowledge of women's HIV status and/or availability of skilled traditional birth attendants represented a missed opportunity for initiating ARVs among HIV+ pregnant women and newborns. The findings showed that most women went through HIV testing but experienced low enrollment in the PMTCT program as they tried to hide their status from their families, TBA, and communities where stigma was pervasive. This contributed to a high number of HIV+ women not linked to PMTCT care and failure to prevent MTCT of HIV. One HCP stated:

> To improve the effectiveness of the PMTCT program, it is important to change HIV perceptions at both local and national levels… it will help to emphasize that with proper treatment, care, and access to ARVs, HIV+ women and their infants can lead healthy, productive, and long lives (HCP1).

Another HCP in a focus group reported: “Involving all stakeholders including HCPs, families, and communities can catalyze a change in how people treat and perceive the HIV+ women which can improve the PMTCT program’s effectiveness” (HCP4).

Addressing gaps in the uptake of ARVs. Another gap that was raised in interviews was that some pregnant women knew their HIV status but did not start ARVs. This was sometimes due to negligence of HCPs, or was a hand over report issue. A PMTCT leader reported:

> Making time for HIV+ patients are very crucial. HCPs are under pressure due to the high demand of clients at the PMTCT program. Time management is a challenge for HCPs…it has unfortunately caused them to deal with clients inappropriately. Some delayed to be initiated to the ARVs. The HIV+ women need to start ARVs as soon as possible to save the life of newborns against MTCT of HIV (PMTCTL4).

Improving the support services HIV+ women received from HCPs. The findings suggest the PMTCT program requires more consistency in the delivery of support services and counselling to patients. The role of HCP in communicating and educating the HIV+ women in the PMTCT program is changing. Until now, the PMTCT program placed onus on the HIV+ women for adherence, being sent home with ARVs the same day as their diagnosis. The majority of HIV+ women did not understand the actual benefits of ARVs, and some of them discontinued the treatment after delivery of the baby. HCPs could help to reduce waiting time and provide quality counselling, education, and support, as compared to the rushed services the HIV+ women in this study described experiencing. A PMTCT leader stated:

> The success of the PMTCT program will be determined by women’s ability to remain on lifelong ARVs; consequently, characterizing challenges and designing interventions to

> support HIV+ women will help ensure that the investment of resources in PMTCT program translates to long term improvements in maternal and child health (PMTCTL1).

Psychosocial support services are an essential component of the PMTCT program. One HCP in a focus group stated:

> HCPs must identify HIV+ women at higher risk for poor ARVs and PMTCT adherence in order to provide enhanced support, especially those who presented any signs of depression, food insecurity, substance abuse, lack of social support, and gender-based violence. The majority of HIV+ women prefer one-to-one counselling with the option to discuss in private any questions they may have with the HCPs (HCP3).

The findings further showed a lack of compassion and understanding by some HCPs. During the focus group interview with policymakers, one reported:

> The first contact of care for a HIV+ woman is with a frontline HCP at the PMTCT program. Some of the frontline HCPs reported they were more agitated and sometimes moody when dealing with HIV+ women and communicating messages to them about the PMTCT program and ARVs. The constant repetition and inability to get through to HIV+ pregnant women triggered a lack of understanding and compassion for HIV+ women (HCP4).

A senior HCP added:

> Often our HCPs missed to address issues that the HIV+ woman feels are as relevant to maintaining their care, and insufficient attention is issues like poverty and transport to and from the PMTCT program facility. Most of the times, the women's behaviour depend on their first interaction with an HCP. The importance of PMTCT care for mother's own health must be embraced by PMTCT program and HCPs (PMTCTL2).

Addressing gaps in the PMTCT program policies and guidelines. Participants commented that Rwanda in general has a national PMTCT guideline that closely reflects the guideline provided by the World Health Organization. To implement this guideline, each health institution has to develop their local guidelines and policies in a way that reflects how they want to implement it. During my document analysis, I observed that, at the clinical level, there were no local guidelines or policies. In addition, there was a gap in follow up with HIV+ women due to lack of standardized policies and guidelines at the PMTCT program/BUTH. One PMTCT leader reported: “To be successful, there is a need to overcome the issue of PMTCT policies, avail the PMTCT program at all levels of health system in Rwanda, and improving the follow up system of the PMTCT program” (PMTCTL2). During a focus group interview with policymakers, the lack of PMTCT policies was highlighted. One stated: “the lack of policies is a big concern… it exposes to unstandardized PMTCT techniques and conflicting messages on behalf of HIV+ women” (PMTCTPM1). One senior specialist added:

> A commitment of improving political leadership or to decrease societal stigma and discrimination may be what is needed. Beyond the blanket recommendations such as encouraging political leaders to support the PMTCT program, it must be necessary to target the areas of the PMTCT program implementation that will strengthen Rwanda efforts to improve the MTCT of HIV outcomes (PMTCTPM1).

Expanding the availability of the HIV testing services. A substantial challenge to reduce the MTCT of HIV is to get more mothers to test. Expanding the availability of PMTCT services access is a critical step to encourage all women to connect with health services during pregnancy, increase the uptake of HIV testing, start ARVs treatment as soon as possible, and ultimately reduce the number of children with MTCT of HIV. The importance of this cannot be disregarded. During a focus group interview, an HCP reported:

> Those women who tested for HIV before pregnancy gain individual health benefits through knowledge of their status and are more likely to participate in the PMTCT program. Regular access to pre- and post-natal care greatly increases HIV+ women's likelihood of participating in the PMTCT program (HCP3).

Avoiding the delay in provision of HIV test results. The findings reported challenges in how HIV test results are communicated to the women. Most participants said that the period between the HIV test and communication of the results was a stressful period that generated feelings of anxiety and depression. The delay between collection of blood sample and the availability of HIV test results was one barrier to starting the ARVs, and contributed to low uptake of the PMTCT program with risk of MTCT of HIV. Some women refused or delayed collecting their HIV results because of fear. One HCP mentioned that: "It is much less difficult to convince a woman to have an HIV test than to convince her to return to get her HIV test results and remain in the treatment process" (HCP1). Another added: "It is necessary to strengthen the follow up to ensure retention and proper implementation. Furthermore, HIV testing, and provision of HIV results need to be done on the same day to avoid the risk of collecting between the two with the risk of MTCT of HIV." (HCP2).

Improving the retention of HIV+ women in the program. The PMTCT program faces a retention problem as it is common for HIV+ women to start the PMTCT program and then drop out. An HCP reported: "HIV+ women can be lost at all stages of treatment… after being referred to the PMTCT service, registering at the service, being assessed for their need for lifelong ARVs, or after starting ARVs" (HCP4). The need to retain all women who test HIV+ in the PMTCT program is evident.

Findings showed reasons why HIV+ women drop out the PMTCT program that included gender and community dynamics, particularly stigma of being discovered as being HIV+. One PMTCT leader said:

> HIV+ mothers have been known to actively cover their status… which often means dropping out of the PMTCT program or not following PMTCT guidelines due to the fear of having their status discovered… Domestic violence and separation or divorce are similarly concerns if women are found by their husbands or partners to be HIV+. Addressing these factors can contribute to the success of the PMTCT program (PMTCTL2).

Including male partners in the PMTCT program. The lack of male involvement in the PMTCT program process is of particular concern. One PMTCT leader highlighted: "The inclusion of male partners in the PMTCT program has the potential benefit ARVs adherence, improve the PMTCT uptake and continuation, decrease the MTCT of HIV risk, and improve maternal and child health" (PMTCTL1).

Addressing reporting issue in the PMTCT program. One senior HCP mentioned the reporting issue as a barrier for follow up of HIV+ women: "It also harshly complicates the sharing of data within and between health organizations…Most private hospitals do HIV testing but there miss to report the results" (HCP1). Without accurate data, informed decisions cannot be made, and any investments that are made in the PMTCT program in Rwanda are going to be less equitable, less effective, and less sustainable than they could be. A senior specialist added:

> The system needs to be in place to gather essential data to support accountability and the capacity needs to be build up to use for PMTCT program planning, implementation, and course of collection. At the same time, the issue of duplicate and missed data must be addressed (PMTCTL2).

Efforts that combine the effective data collection methods together with specific plans for the use of data to improve the PMTCT program should be encouraged. A critical review of the data is important with a focus to promote sustainable initiatives. A PMTCT leader stated:

> For instance, introducing electronic medical records at the PMTCT programs may help to link the HIV+ women to the PMTCT services and would be a powerful of data collection, nevertheless it would be expensive and difficult to implement in inaccessible areas. In addition, the efforts to increase the number of women being tested should be encouraged. Besides, facilitating and encouraging the use of data will help to assure that the PMTCT interventions are adapted and designed based on strong evidence, leading to more effective PMTCT program (PMTCTL1).

Another senior HCP who wasfollowing HIV+ women added:

> I think the quality improvement projects and policies need to be based on the data collected and this needs to be done as soon as possible… I recommend the use of an interdisciplinary collaboration approach when develop PMTCT policies and follow up the HIV+ women. This can be executed through interdisciplinary department meetings and training… Before developing policies, I propose collect the perceptions of both HIV+ women and HCPs as this can help to address a lot of issues. (HCP3)

Addressing the issue of tracking HIV+ women patients. Normally, the ARV and PMTCT clinics provide a card with names and track-net number to every patient tested and taking ARVs.

Under this card there is also a place for both clinical and laboratory appointments. Women in this study who were tested during labor and delivery, received the HIV test results without a track-net number; they had to attend the PMTCT program to get the track-net number. There was no way to fast track those new HIV diagnosed cases as they did not have a track-net number and most of them had transferred from places that were far from BUTH. Staff shared that it was difficult to follow up if women were initiating treatment and accessing the PMTCT program after they were delivered of their babies, and discharged from the hospital.

One HCP proposed:

> I think to address the issue of tracking our patient it could be better to switch to a national electronic database instead of having HIV+ women working around with an institution track net card to their appointments. With this way, a unique identification (ID) number could be used to track the patient and have access to their medical history. The electronic database could also be useful to do follow up of HIV+ women in terms of ARVs adherence (HCP5)

Enhancing the HIV+ women's accessibility of the PMTCT care. Participants recommended that the Rwandan Ministry of Health needs to create and implement policies, guidelines, and regulations as direct political actions to build supportive environments for HIV+ women accessing PMTCT services. In this regard, participants proposed some strategies to enhance the HIV+ women's accessibility of PMTCT care. Participants believed that: "relevant and up to date information on both HIV and PMTCT of HIV should be accessible, available, and visible to women in ANC clinics and health settings using local language" (PMWPB2). Furthermore, "PMTCT services should ensure the protection and respect of HIV+ women's right to privacy, non-discrimination, confidentiality, and relevant health services" (HCP1).

Participants believed that HIV+ women should be able to make independent decisions regarding their health and treatment, without asking permission of their husbands or partners.

Addressing intersection of overlapping factors to improve the uptake of the PMTCT program. There is a need to address the intersection of overlapping factors to enable HIV+ women to improve PMTCT program uptake and ARVs adherence. During a focus group discussion with HCPs, one senior HCP stated:

> Early HIV diagnosis among pregnant women by undergoing antenatal HIV testing should be encouraged. This needs to be followed by early prevention and treatment to eliminate MTCT of HIV. Likewise, implementing these strategies will guarantee children who have been tested HIV+ get proper ARVs, and both HIV+ women and children get their right to live healthy (HCP4).

Moreover, there is a need to think of other important measures that might be implemented outside the health facility, targeting other barriers such as: lack of decision-making power on sexual and reproductive health, women's economic dependance, and masculine norms that encourage gender-based violence and male dominance.

Conclusion

To sum up, this chapter presents findings from the research study conducted in the PMTCT program/BUTH in Rwanda. The findings were delivered from the data gathered through multiple sources, including documents reviews, observation and field notes, and individual and focus group interviews with HIV+ women, HCPs working in the PMTCT program, policy makers, and the PMTCT program leaders. Four main themes were derived from the data: 1) factors that influence and challenge the uptake of the PMTCT program, 2) identities intersecting with the uptake of the PMTCT program, 3) health system factors affecting the delivery of the

PMTCT program, and 4) experiences of HIV+ mothers during the prenatal, perinatal, and postnatal period to prevent HIV transmission. The following chapter presents a discussion of the findings.

Chapter 5: Discussion of the Findings

This chapter presents the discussion surrounding the findings of this critical ethnographic study that focused on the experiences of HIV+ mothers with the PMTCT program in Rwanda. As described in the methodology chapter, an intersectionality framework provides a theoretical foundation to explore the experiences of mothers using the PMTCT Program to prevent MTCT of HIV in Rwanda. An intersectionality framework offers philosophical and conceptual grounds to examine the intersecting factors that contribute to the complexity of the issues of the PMTCT of HIV. In view of this theoretical foundation, this chapter presents a discussion of the findings and draws on insights from the literature. Furthermore, this chapter presents the strengths and limitations of this study undertaken on the PMTCT program, Rwanda.

Critical Ethnography Design

During the research process, the critical realist ontology provided the grounds to uncover challenging factors that directly and indirectly influence HIV+ women's uptake of the PMTCT program at BUTH in Rwanda. Ontology refers to beliefs about the nature of reality (Tuli, 2010). In philosophical terms, it refers to the study of our existence and the fundamentals of reality or being. Beliefs about the nature of reality are for determining what can be known about it (Flaming, 2004). Ethnography is one of the qualitative research designs that assumes meaning and reality are socially constructed. Ontologically, critical ethnographers assume that individuals make sense of their own reality and that there are multiple truths (Scotland, 2012; Weaver & Olson, 2005). Critical ethnography reveals underlying issues that produce reality, which are not conclusive, but are grounded in historical realism which embraces the view that reality is shaped by social, political, cultural, economic, ethnic, and gender values (Guba & Lincoln, 1994; Scotland, 2012). Critical ethnographers embrace an ontology based on the understanding that organizations are historically born in conditions of struggle and domination (Thomas, 1993). Critical ethnographers adopt a political purpose to change, they believe there is something better out there, and the aim must be to work toward it (Thomas, 1993).

A close exploration of the experiences of HIV+ mothers using the PMTCT program to prevent MTCT of HIV suggests that limited information was previously available about factors that expose HIV+ mothers to low uptake of the PMTCT program. Use of the ontological assumption of critical ethnography, as described in the methodology chapter, provided an opportunity to gain insight into a reality that is multifaceted, complex, and interrelated. The findings suggested a wide range of challenging factors that are shaped by social, political, cultural, economic, ethnic, and gender values, and that directly and indirectly affect the uptake of the PMTCT program (Scotland, 2012; Turan et al., 2019). While using the critical realist ontology (Archer et al., 2013), I discovered multiple truths about the challenging factors for HIV+ mothers to uptake the PMTCT program by gaining access to their experiences and triangulating those experiences with perspectives gathered from HCPs, PMTCT leaders and policy-makers interviews, field observation, and document analysis. None of the previous studies in this area used a critical lens to explore the reality behind a wide range of experiences of mothers using the PMTCT program to prevent HIV transmission in Rwanda. The critical nature of this inquiry contributes to the depth and breadth of knowledge related to the delivery of the PMTCT program to prevent MTCT of HIV.

Intersectionality Framework Recall

The PMTCT of HIV is a complex phenomenon in which social identities are multiple and intersecting. The intersectionality lens has the potential to effectively explore overlapping social identities and related systems of domination, oppression, and discrimination (Parmar, 2017).

Intersectionality helps to understand how multiple social identities such as gender, race, dissimilarities in individuals' lives, and other categories such as social practices, religious beliefs, education level, institutional norms, cultural ideologies, legal and political aspects, poverty, and power may impact individual experiences (Bowleg, 2012). Rogers & Kelly (2011) posit that the intersectionality framework provides resources for more comprehensive identification of inequalities, contributing factors, and directions for developing intervention strategies specific to the community studied. Intersectionality is useful not only to understand relations of oppression and power but to change or transform them (Carbado, Crenshaw, Mays, & Tomlinson, 2013).

HIV+ women experience intersecting factors that influence and challenge their uptake of the PMTCT program. Factors are often connected and interrelated, and their combined effects can intersect and be more complex than individual factors alone. An intersectional approach is useful in guiding the interpretation of findings on the experiences of HIV+ mothers using the PMTCT program (Veenstra, 2011). However significant gaps in our understanding of intersectional factors that challenge the uptake of the PMTCT program must be addressed to improve MTCT of HIV outcomes.

The discussion chapter was very challenging to write because most of the concepts are interconnected, and it was difficult to highlight what was most important. HIV+ women's adherence to the PMTCT program is a complex phenomenon which intersects with adversities arising from a diversity of cultural ideologies, power relationships, social inequalities and oppressing identities like gender, stigma and discrimination, as well as the social determinants of health. Understanding the intersectionality between health-related multilevel factors and other forms of social marginalization provided a richer and more comprehensive picture of the experiences of HIV+ women in relation of using the PMTCT program. Such experiences of oppression, discrimination, and marginalization are enacted and reinforced by social actors, systems, and institutions often having negative psychological, social, financial, behavioral, and medical effects on HIV+ women using the PMTCT program (Jackson-Best & Edwards, 2018; Seroalo, Du Plessis, Koen, & Koen, 2014; Sharac, McCrone, Clement, & Thornicroft, 2010). Further adding to this complexity, studies have discovered that low ARV adherence and low PMTCT uptake interact and intersect with other forms of oppression and social marginalization to create challenges and barriers for women to use the PMTCT program, thus negatively impacting the level of MTCT of HIV (Chambers et al, 2015; Jackson-Best & Edwards, 2018; Logie, James, Tharao, & Loutfy, 2011; Turan et al., 2019).

In this chapter, I use multilevel risk factors to identify and understand the dynamic interplay on HIV+ women's experiences in relation to the social determinants of health that challenge or influence the uptake of the PMTCT program in Rwanda. The findings revealed that uptake of the PMTCT program is a complex phenomenon that is strongly influenced by challenges or barriers operating at individual, household, family, community, and institutional levels. I also orient my discussion around the larger conceptual pieces in my findings: gender roles and norms, cultural ideology, power relationships, and systems of domination and oppression.

Social Determinants of Health that Influence the Uptake of the PMTCT Program

Women's health concerns extend across the life cycle, and are not limited to reproductive and gynecological problems. Women's health is related to the political, cultural, social, and physical conditions in which they live. Consequently, the factors and conditions that affect women's health include mental, social, physical, and spiritual dimensions (Abbott & Williams, 2015). To create programs and models that can improve health, the full range of the determinants must be considered. While quality of health services can affect women's health, employment, quality of housing, poverty, and access to education have a greater impact (Abbott & Williams, 2015; McGibbon & McPherson, 2013). Addressing the social determinants of health is crucial if we want to achieve health equity. The transition from eradicating health disparities to eradicating health inequities and creating health equity underlines the necessity of placing the issue of social justice, human rights, and the right to access healthcare in the forefront of any discussion of the health status of any population group (Bleich, Jarlenski, Bell, & LaVeist, 2012).

In this section, I use an intersectionality lens to demonstrate how the social determinants of health influence the health of HIV+ women and their decision to uptake the PMTCT program. Considering the experiential aspects of living daily with HIV, HIV+ women, as individuals, helped me to illuminate the heterogeneity of the complex interactions of the social determinants of health, as well as the individual responses of participants to their social location. Thus, I will substantiate the need for structural interventions to change the social context in which these HIV+ women make health decisions.

Individual factors that influence the uptake of the PMTCT program. Analysis of the multi-dimensional elements within HIV+ women's experiences is needed to explain and understand the complexity of the situation and their lives, as related to their vulnerability to HIV (Bowleg, 2012; Ponic et al., 2010). Women are individuals living at the intersection of multiple identities, all of which influence each other and together shape their constantly changing interactions and experiences (Reid & Frisby, 2008). Complex interactions in an HIV+ woman's life mean that factors that contributed to women's vulnerabilities to HIV infections differed for individual participants. Each of their stories and experiences represent different pathways and intersections that determine their vulnerability. Manifestation of intersectional women's vulnerability to HIV, among HIV+ women using the PMTCT program, operated at multifaced factors, such as socioeconomic advantage, transportation barriers, low health literacy, poverty and unemployment. When considering multiple dimensions of health, socioeconomic disadvantage, low opportunity, and limited options for transportation may increase disparities.

Areas of extreme poverty not only reflect disadvantage but may also result in poorer health outcomes for HIV+ women. My critical ethnographic approach allowed me to understand the complex associations between poverty, health literacy, and health outcomes that make explicit factors that challenge and influence the uptake of the PMTCT program. Socioeconomic factors account for almost half of the factors that challenge the PMTCT program and health outcomes (Abbott & Williams, 2015; McGibbon & McPherson, 2013). Under this section, I discuss health literacy, poverty and unemployment, challenges related to ARVs use, and transportation barriers and healthcare access.

Health literacy promotes women's engagement in the PMTCT program. In this study, health literacy was an important factor associated with HIV+ women's engagement in health promotion and prevention activities both for HIV+ women and their children (Shieh & Halstead, 2009, Nutbeam, 2000). Health literacy is a concept embraced in health education and a key outcome of health education activities. Health literacy within the context of health promotion needs to be promoted, and people working in the health promotion field should be held accountable to promote it (Nutbeam, 2000; Simon, Li, & Dong, 2014). Health education and information are integral to improving health literacy (Nutbeam, 2000; Simon et al., 2014).

Three levels of health literacy have been identified and defined: functional, interactive, and critical (Nutbeam, 2000; Simon et al., 2014). The functional level of health literacy refers to basic skills of reading and writing that are necessary for effective functioning in a health context. The interactive level of health literacy is more advanced social skills and cognitive literacy that permit active participation in health care activities. The critical level of health literacy is the ability to use information through critical analysis to participate in different actions that overcome structural challenges and barriers to health (Nutbeam, 2000; Simon et al., 2014).

Health literacy directly or indirectly impacts health outcomes, and there are significant associations between inadequate health literacy and poor health outcomes (Simon et al., 2014). For instance, a low level of health literacy is associated with a diminished likelihood of understanding diagnoses, treatment, drug label instructions, time for medications and clinical appointments (Davis, Federman, Bass, Jackson, Middlebrookds, & Wolf, 2009; Lee, Tsai, Tsai, & Kuo, 2010). HIV+ women with low health literacy tend to have decreased understanding of the necessities of HIV testing and the benefits of using the ANC and PMTCT services (Jovic-Vranes, Bjegovic-Mikanovic, & Marinkovic, 2009). Therefore, it is important to understand and promote health literacy levels to grow the knowledge of HIV+ women to prevent MTCT of HIV.

Interactive and critical health literacy suggest the expansion of health literacy to the health promotion domain through their link with the concept of empowerment, self-efficacy, and social action (Kanj & Mitic, 2009; Lee et al., 2010). A level of interactive health literacy enables HIV+ women to notice health problems, contact an HCP at the right time, and adhere to the treatment and follow up with the PMTCT program to limit the risk of the MTCT of HIV (Lupattelli, Picinardi, Einarson, & Nordeng, 2014; WHO, 2016).

The current study revealed that HIV+ women have differences in vulnerabilities with multiple intersections of aspects related to health and HIV literacy. A lack of HIV literacy may disempower HIV+ women not only their own health but also the health of their families (Shieh

& Halstead, 2009; Nutbeam, 2000; WHO, 2016). Some women with lower levels of education, as well as economic dependence on their husbands' income were likely to get tested for HIV only after their husbands had been tested and knew their HIV status. The current study suggests HIV+ women who are educated and have HIV knowledge, despite their physical, psychological, social, and financial dependency to their husbands, can protect their health and their infants without blame and condemnation. Most participants in this study had not completed primary school education and this intersects with their ability or inability to prevent the MTCT of HIV.

An inadequate understanding of health information contributes to less informed decisions for HIV+ women which can result in low ARV adherence and low uptake of the PMTCT program. Additionally, women's power is impacted by education level, wealth, and income level (Ismail, Ardini, Mohamad, & Bakar, 2018; Lumbantoruan et al., 2018). As a result of low education levels and low health literacy, most women in my study knew their HIV status only after their husbands had been diagnosed as HIV+, or the sickness or death of their husband and/or children. HIV+ women with low education levels, and who come from poor families are less likely to get adequate information, and may even experience delays in receiving the information from HCPs (Gourlay et al., 2013). Furthermore, lack of HIV literacy may result in misconceptions about HIV disease, and prevent HIV+ women's access to the PMTCT services. It may then contribute to women's vulnerability to HIV and may result in increasing mortality risk due to AIDS (Sangaramoorthy, Jamison, & Dyer, 2017).

The ability to access, understand, and manage health information as well as the ability to critically understand, and assess and challenge its credibility and applicability may be skills held by empowered HIV+ women, their families, and communities. However, most of the women in my study were not able to critically use health information. For health literacy to create change, there is a need to classify what is the basic and functional health literacy, skills and knowledge related to communicating or interacting with health information, and the skills needed to critique health information (Skykes, Wills, Rowlands, & Popple, 2013). This would help in applying health literacy to the health context, and providing critical action to address social, economic, cultural, and environmental determinants of health (Camerini, Schulz, & Nakamoto, 2012; de Leeuw, 2014).

Developing critical health literacy of HIV+ women and HCP's would promote and increase health knowledge, health information skills, and effective interaction at the PMTCT services between the HCP and HIV+ women using the program, as well as support informed decision-making and empowerment of both HIV+ women and HCPs at the PMTCT program (de Leeuw, 2014). Critical health literacy demonstrates its potential effect in promoting health literacy; creating more effective use of health services; reducing inequalities in health; supporting public health, health promotion, and disease prevention; and improving health outcomes (Skykes, Wills, Rowlands, & Popple, 2013; de Leeuw, 2014). However, there is no evidence of the implementation of critical health literacy in the PMTCT practice, or by PMTCT program leaders and policy makers, particularly around social, cultural, political, and empowerment actions implemented at individual, family, health system, and community levels.

Counselling sessions were regarded as the most successful element of the PMTCT program. HIV+ women credited their ability to get through difficult and distressful realities of HIV to the emotional and psychological support they obtained through counselling. Testing HIV+ is stressful, and to some is a life shattering experience. However, proper counselling enabled HIV+ mothers to accept the dignosis and make informed decisions to preserve their own health and protect their babies from MTCT of HIV. The value of counselling was not limited to

HIV testing only, but extended throughout the PMTCT continuum of care. HIV+ mothers reiterated that disclosing HIV status and testing of partners, initiating ARVs, and rapid weaning from breastfeeding at six months were among the steps that required emotional strength, and where supportive counselling was invaluable (Ahmed et al., 2013).

Among HIV+ women interviewed, knowing that their infants could have a chance to live without being infected with HIV was a great motivator for them to continue ARV adherence and follow up PMTCT care, especially in the postpartum period (Chadambuka et al., 2018). Another interesting finding was the existing gap between HIV+ women's knowledge on MTCT of HIV and PMTCT interventions, and the application of the knowledge. For instance, HIV+ pregnant women were told to practice safe sex to minimize MTCT of HIV risk, and the majority of HIV+ women mentioned that use of condoms was also necessary for a breastfeeding HIV+ mother. However, several of them conceded that they did not practice safe sex, either because they had not disclosed their HIV status to their husbands, or because they could not get their husbands to agree to use condoms. This indicates that knowledge acquisition does not necessarily result in its correct application. That is, because HIV+ women were knowledgeable about the importance of safe sex in preventing MTCT of HIV to their unborn babies of breastfeeding infants, this did not mean that they could negotiate the use of condoms with their partners. Likewise, HIV+ women could not force their partners' involvement in the PMTCT program, even though they agreed that male partnership was valuable.

Poverty and unemployment issues among HIV+ women. Poor women struggle with PMTCT adherence compared to HIV+ women with high incomes and who are well educated (Lumbantoruan et al., 2018). HIV+ women's vulnerability is depicted by the intersections of poverty, health literacy, and dependency on husband's income. Most importantly, these findings may help us to understand why the PMTCT program needs to address multiple barriers and challenges caused by different intersecting factors based on women's experiences in using the PMTCT program at BUTH.

Poverty contributes to differing health risks and ability to use health services due to lack of transportation (McGibbon & McPherson, 2013). Inconsistent and scarce employment opportunities within informal settlements limit choice for those seeking jobs, preventing engagment in regular, meaningful employment and escape from poverty (McGibbon & McPherson, 2013; Gathuthi, Muindi, Mwalali, Chiuri, & Kariuki, 2010). Poor women are more vulnerable to HIV and MTCT of HIV than wealthy women who have more options for accessing treatment and care. As well, economically independent women have more decision-making power to access HIV test and PMTCT services, compared to those who are economically dependent on their partner or husbands (Lumbantoruan et al., 2018). The majority of participants in this study were economically dependent on their husbands with limited incomes due to unemployment, and few resources for supporting their families. Still, HIV+ women with supportive husbands were more likely to be resilient, and to access the PMTCT program than those who had less support from their husbands (Badriah, Tahangnacca, Alkaff, Abe, & Hanifah, 2018; Hlartaithe et al., 2014; Lumbantoruan et al., 2018).

Poverty may intersect with other social determinants for health dimensions, such as health literacy, geographic accessibility, and marital status, to further limit employment opportunities, and place women at increased risk of financial dependance (Grineski, Hernández, & Ramos, 2010). This has negative health implications; however, if HIV+ women are well informed even if economically dependant on their husbands, they can protect their own health and that of their children. Most HIV+ women claimed that love for their partners was compared with valuing economic security (Jewkes & Morrell, 2012). Alternately, some HIV+ women used multiple partners and/or boyfriends to meet their material needs, and continued their marital relationships which exposed them to increased MTCT of HIV (Jewkes & Morrell, 2012).

The combination of financial hardship and food insecurity due to unemployment and poverty contributes to exposure to increased magnitude of acute and chronic stressors, subsequently leading to a wide range of challenges and barriers that negate the ability of HIV+ women to consistently engage with initiating and continuing the ARVs and adhering to the PMTCT program (Bezabhe et al, 2014; Brawner, 2015). The multiple intersections of unprivileged elements may contribute to the low adherence of HIV+ women to ARVs and low uptake of the PMTCT program (Baral, et al., 2013; Brawner, 2015; Ostrach & Singer, 2012). For instance, HIV+ women with food insecurity did not mind discontinuing ARVs though they were aware of the negative consequences of doing so; this is consistent with the findings of a study in northern of Ethiopia (Hadgu, Worku, Tetemke, & Berhe, 2013). Furthermore, 63% of HIV+ people on ARVs experienced food insecurity due to unemployment and poverty; and this impacted access and adherence to the HIV clinics (Tiyou, Belachew, Alemseged, & Biadgilign, 2012). Given food insecurity and the presumed ARVs side effects, isolated PMTCT services may not succeed in ensuring uptake to the PMTCT program (Bezabhe et al., 2014; Hadgu et al., 2013).

For HIV+ women, stable housing is connected with emotional and physical wellbeing, reduction of risky behaviors, and ARV adherence (Delavega & Lennon-Dearing, 2015). The findings from the current study complement the empirical evidence, pointing to the importance of housing as a social determinant of health. Additionally, single mothers, widowers, or divorcees, coming from poor families, and with unstable housing, often see having multiple partners as the only way to support themselves. This behavior contributed to women's vulnerability to HIV and MTCT of HIV. In summary, poverty, unemployment, health literacy, multiple partners, and housing related factors contribute to low uptake of the PMTCT program, and high risk of MTCT of HIV. These intersecting elements prevent HIV+ women from making informed choices to access ARV treatment, and to access the PMTCT program (Badriah et al., 2018; Sangaramoorthy, et al., 2017). In addition, low levels of health literacy, housing issues, and illiteracy imposed upon women and girls have effects in other aspects of their social lives, especially when negotiating key life decisions (Fulu & Miedema, 2015).

ARV use challenges. The findings from my study revealed factors that challenge the acceptance and initiation of the lifelong ARVs for newly diagnosed HIV+ women. Those include dealing with adhering to using lifelong medications, fear of developing medication resistance, dealing with secrecy in using ARV medication and HIV status, and accepting one's HIV status by taking ARVs.

The majority of HIV+ people default from ARVs because of fatigue (Shet et al., 2011; Schneider, Chersich, Temmerman, & Parry, 2016; Azia, Mukumbang, & Wyk, 2016), delaying initiating ARVs because of the life treatment duration required (Loeliger, Niccolai, Mtungwa, Moll, & Shenoi, 2016; Schneider et al., 2016). The possibility of having simple ARV regimens that are taken once a month or less in a year may be the answer to this specific barrier (Loeliger et al., 2016). As well, adoption of expert peers may assist with peer support and counselling for HIV+ women who are struggling with ARVs compliance (Kang'ethe & Nomngcoyiya, 2015). The PMTCT guideline in Rwanda suggest on having godmothers (treatment supporters) for the PMTCT clients and the treatment supporters are counselled alongside the HIV+ women on the program, this could be adopted in the PMTCT program for willing participants.

Most HIV+ women cited strengthened health as a benefit of using the PMTCT program that permitted them to take care of their families and perform all other tasks expected of them. Other participants perceived that ARVs made one look healthy and normal as opposed to having negative effects on physical appearance, and this for them was a sufficient reason to accept ARVs. In contrast, some participants discussed the challenge of HIV+ pregnant women initiating ARVs when they did not feel ill (Hodgson et al., 2014; Kim et al., 2016; Tenthani et al., 2013). The main reason for rejection of ARVs initiation was feeling healthy and having low CD4 cell counts after two months of counselling (Katz et al., 2011).

Overall, the main reason that HIV+ women defaulted from ARVs treatment and PMTCT program was poor relationship with HCPs (Kranzer et al., 2016; Wasti et al., 2012). The notion of patient centeredness which is a foundation for quality health services needs to be intensified in the PMTCT services (Scholl, Zill, Harter, & Dirmaier, 2014). Patient centeredness encourages active participant involvement, and considers them as experts in their care (De Man et al., 2016). Consequencial to staff inadequacy, this study revealed that HIV+ women received suboptimal counselling on their ARVs treatment and PMTCT program. Likewise, health services are faced with a shortage of human resources for handling the increased numbers of HIV+ clients resulting in insufficient counselling about the disease and the benefits of ARVs, thereby inadvertently affecting HIV+ women's retention in the PMTCT program (Wasti, Simkhada, & Teijlingen, 2009; Wasti et al., 2012; Shubber et al., 2016).

The findings from this study showed that women who may have known their HIV status previously, or predicted that they may be HIV+ may require fewer counselling sessions prior to ARV initiation, whilst those struggling to accept their new HIV status and who need to initiate ARVs may necessitate more sessions. Some women may need additional time to accept their

HIV status in order for them to be emotionally prepared to commit to lifelong ARVs (Kim et al., 2016; Hodgson et al., 2014). Providing additional counselling sessions before initiating ARVs, especially among those newly diagnosed as HIV+, may improve ARV adherence and the PMTCT program uptake. Furthermore, health facilities that strengthened and offered additional counselling decreased the loss of follow-up rate in the PMTCT program (Katz et al., 2011; Kim et al., 2016; Tenthani et al., 2013). Strengthening counselling messages to ensure that HIV+ women understand how lifelong ARVs benefit their health, as well as that of their partners and children is important (Kim et al., 2016).

The findings related forgetfulness to take ARVs secondary to misbehaviors, such as alcohol use, as attributing to low ARVs adherence (Jones et al., 2015; Scholl et al., 2014; Kranzer et al., 2013). Low ARVs adherence in the context of alcohol use is influenced by a desire to keep one's HIV status confidential, thus omitting taking ARVs although taking alcohol (Scholl et al., 2014). Moreover, the fear of side effects resulting from combined alcohol and toxicity of drugs resulted in defaulting (Scholl et al., 2014). Conversely, abstinence from drugs and alcohol use is associated with PMTCT uptake and ARVs adherence (Kessler, Nucifora, Li, Uhler, & Braithwaite, 2015). Some HCPs in this study expressed inadequate knowledge and training on the effects of combining alcohol and ARVs, and recommended more education which may, as well, be applicable to Rwanda. Schneider et al. (2016) shared that HCPs have been viewed to be non-judgmental on alcohol use while on ARVs and that counsellors could lead the alcohol related counselling.

Transportation barriers and healthcare access. The availability of health services to the community depends on priority setting decisions that can limit geographic accessibility. Historic forces involving colonization have contributed to wide change in health service coverage, with those living in previously marginalized areas having limited health service coverage (McCollum et al., 2019). Since gaining independance, many countries have sought to address coverage by increasing availability of primary health care services in underserved areas. Nevertheless, countries have been slow to address challenges and barriers to service use relating to women's autonomy, and access to information and knowledge about health and services (Gilson, Doherty, Loewenson, & Francis, 2007; O'Connell, Bedford, Thiede, & McIntyre, 2015).

In this research, an important observation was related to travel cost and time to reach the PMTCT program. Most of the HIV+ women interviewed indicated that it took them over two hours to reach the PMTCT program. In-depth individual interviews further revealed that some HIV+ women chose to seek care at the PMTCT program at BUTH because it was far from their workplaces or living premises, to minimize the chances of meeting a colleague, neighbor, family member, or friend that might recognize them. This suggests that HIV+ women spend money and time in order to hide their HIV status, rather than seeking ARVs near their homes. High transportation cost and long distance to the health facility are health access factors that negatively impact adherence and utilization of health services due to loss of follow up (Abbott & Williams, 2015; Shubber et al., 2016; Kang'ethe & Nomngcoyiya, 2015). The literature supports the conclusion that poorer people experience transportation barriers to access healthcare which leads to gaps in managing chronic diseases (Syed, Berber, & Sharp, 2013).

Women in this study engaged with and reinforced a culture of secrecy that surrounded the experiences of HIV+ women using the PMTCT program (Van Hollen, 2013). These women utilized a number of strategies to remain in the PMTCT program while keeping their HIV+ status a secret. Such strategies included traveling to a distant PMTCT clinic where they did not expect to meet relatives, friends, or members of the community; hiding their PMTCT cards and

ARVs; asking strangers to serve as godmothers; and providing false contact information and addresses to the HCPs. Such strategies enabled them to preserve their marriages, at the same time as they continued to participate in the PMTCT program to meet their maternal needs to protect their own health and well-being of their children. Furthermore, some HIV+ women travelled to distant PMTCT clinics to prevent the potential for stigma, discrimination, and marginalization that challenged their social identities and constrained their ARV adherence and access to PMTCT services.

The financial burden expressed in this study that related to transportation costs acted as a barrier in accessing the PMTCT clinics, and rendered as economically demanding the process of refilling ARVs prescriptions (Miller, Ketlhapile, Rybasack-Smith & Rosen, 2010; Shubber et al., 2016; Kang'ethe & Nomngcoyiya, 2015). Related to financial accessibility, this study reported that geographical accessibility led to low ARV adherence and PMTCT program uptake. This builds on what participants reported that HIV+ patients who reside in rural areas and who are far from the hospital, frequently default from ARVs and PMTCT clinics because of the long distance (Wasti et al., 2012; Shubber et al., 2016). However, not all HIV+ women served by BUTH are from the rural areas, which raises the possibility that the geographical accessibility observed in this study is strongly linked to financial accessibility since there are few referral, provincial, districts, and private hospitals available as compared to health centers facilities. BUTH/PMTCT services could orient HIV+ women to alternative free PMTCT programs at health centers closer to where they reside in the event of financial constraint.

Gender Roles and Gender Inequality

Research on masculinities conceptualizes gender as intersecting with other systems of inequality. Because all people claim multiple identities and occupy multiple social statuses, performances of masculinity are interrelated with performances of class, age, race, ethnicity, and other social identities (Collins, 2004; Connell, 1995). Scholars of intersectional masculinities hypothesize gender not only as a hierarchy in which men and masculinity are privileged over women and femininity, but also as a hierarchy within which various men are systematically privileged over others (Connell, 1995; Connell & Messerschmidt, 2005). According to Connell (1995) the term patriachal dividend was associated to the respect, authority, status, and marital benefits associated with masculinity, and are not distributed across social groups. Race, class, ethnicity, and sexuality shape not only the ways in which men enact masculinity, as well as the contexts within which these performances take place, but also the extent to which men are able to benefit from gender inequality. I was inspired by the masculinity lens to discuss the findings of my study and understand it's link to gender violence and gender inequalities (Connell, 1995).

Women's lives are constructed by multiple and intersecting systems of oppression. This insight that women's oppression and marginalization are not a singular process but are better understood as constituted by converging, multiple, or interlinked systems originates in antiracist feminist critiques. In the winter 2021, I was part of a gender and health reading group, and became inspired by the readings of Collins (2020) and Connell (2012) on feminist theory. This absolutely informed my thinking about my research data and is reflected in my analysis. An epistemological approach that views HIV disease through a masculinity lens of PMTCT of HIV would allow for the development of recommendations that could potentially lessen MTCT of HIV among HIV+ women.

When discussing the factors that challenge or influence the uptake of the PMTCT program, it is necessary to recognize gender as a key factor. Gender is a socially constructed concept that consists of a range of traits, personality, values, and attitudes that a society attributes to men and women on a differential basis. Gender influences access to economic and political resources (Tannenbaum, Greaves, & Graham, 2016; Libby, McGinnes, & Regensteiner, 2020). Although both men and women's health are affected by economic and social factors, the interactions of gender with the other social determinants of health creates different experiences of health and illness for men and women. While women are disadvantaged comparative to men on many aspects of equity related factors that affect women's health, some women are double or triple disadvantaged (Pease, 2012). The interconnected and compounding aspects that impact the health of women are sexual orientation, gender, class, age, interconnected with health status influencing social support networks, risk of violence, access to employment, access to education, and other resources. Additionally, it is necessary to recognize that factors such as unemployment, poverty, isolation, and stress may influence individual women differently and may interact to produce different effects.

Gender shapes health vulnerabilities, exposures, and behaviors, and influences health systems responses. It also intersects with other social determinants of health such as social and economic status, ability, and ethnicity. There is a link between health risks and gender inequality where gender inequality is transformed into health risk through a variety of factors, such as differential exposures and vulnerabilities to disease; disability and injuries; discriminatory practices; values, norms, and beliefs; and biases in health systems and research. While both men and women experience inequality, pervasive and sustained structured gender inequalities severely and frequently impact the health of women. Gender norms which determine idealized forms of masculinity, also have a substantial impact on women's health (Kallay, 2017; Szymanski & Lewis, 2016).

The nature of HIV as a sexual transmitted disease evokes ideas about sexuality, morality, fidelity, and relations between husbands and wives, concepts that are most important to how the marriage is practiced and understood within the Rwandan society. These social norms restrict ways of thinking about women's sexual behavior. Community and social understandings of HIV and MTCT of HIV are tied to women's sexual behavior and their intersection with gender roles and inequalities, as well as power relationships shaping women's sexual behavior and their decision to uptake the PMTCT program. Generally, gender intersects with power inequality to structure women's health seeking and social relations which then influence the low ARV adherence and the PMTCT uptake (Fasawe et al., 2013; Van der Straten et al., 2014). Gender disparities in employment and education, along with power inequality between men and women, and fear of violence, stigma, and discrimination are interrelated in increasing HIV vulnerability, and limit HIV+ women's ARV adherence and access to PMTCT services (Remme et al., 2014; Wang et al., 2018). Structural inequality and gender inequality are critical issues affecting HIV+ women's ARV adherence and uptake of the PMTCT program.

In the Rwanda social context, men are the providers of the family and women are the carers, and are primaryily responsible for all activities associated with home and family. Thus, gender roles and norms strongly affect male involvement in the PMTCT program. Some stakeholders demonstrated that husband support is highly relevant to HIV+ women's adherence to therapy in the PMTCT program. For instance, women revealed that one of the main barriers to women initiating ARVs and adhering to the PMTCT program was their husbands (Hampanda et al., 2020; Muwanguzi et al., 2019). HIV+ women with male support in the PMTCT program are 3.5 times more likely to have good ARV adherence than those without support (Zacharius et al., 2019; Katirayi et al., 2017).

Gender based violence was frequently discussed by participants. Most HIV+ women in this study discontinued formal education early, and lived in informal settlements with poverty and alcohol misuse. The literature confirms that these factors contribute to a risk of gender-based violence (Sinclair et al., 2013; World Health Organization and London School of Hygiene and Tropical Medicine, 2010). Participants in the study highlighted the high levels of gender-based violence within the community. Gender-based violence is generally shaped by strongly gendered expectations, values, norms, and practices, as is evident from other studies (Schaefer et al., 2017). Proposed solutions to address gender-based violence often center around treating the symptoms rather than addressing the underlying causes such as inequitable relations (Sinclair et al., 2013; Muindi, Egondi, Kimani-Murage, Rocklov, & Ng, 2014). In this theme, I discuss stigma and discrimination, and disclosure factors that constrained HIV+ women from using the PMTCT program.

Stigma and discrimination constrain HIV+ women from using the PMTCT program. The interviews with HIV+ women in this study demonstrated the effects of stigma and gender imbalance on the PMTCT program. Stigma refers to perceptions or attitudes of shame, blame, disgrace, or dishonour associated with disease (De Cock, Mbori-Ngacha, & Marum, 2002). HIV/AIDS related stigma originates from a powerful combination of fear and shame. Most of the interviewed HIV+ women and HCPs felt that people living with HIV experienced some level of stigma. The current findings show some decrease in stigma and discrimination against people living with HIV, and the increased role of friends, family members, and the community in encouraging HIV+ women to use the PMTCT program and to access HIV care. Nonetheless, stigma and discrimination still exist, and demoralize the acceptance of the PMTCT program and adherence to ARVs. The study found that community and family support provided to needy

HIV+ women was short-lived and inadequate; consequently, many HIV+ women doubted the value of their lives, and either failed or stopped adhering to ARVs and using the PMTCT program.

Most participants revealed that HIV stigma and discrimination were due to misconceptions about HIV transmission and prevention, and the conduct associated with acquiring the HIV (Lifson et al., 2013; Asgary, Antony, Grigoryan, & Aronson, 2014). It was obvious that the general knowledge and acceptance of the ARVs in the community needed strengthening (Cluvera et al., 2015). Providing community leaders with HIV knowledge, and sensitizing them on the impact of HIV stigma and discrimination, as well as introducing follow-up activities, can result in a decrease of stigma and discrimination (Nyblade et al., 2008). Furthermore, community sensitization through mass media communication has been associated with positive and significant trends in acceptance of people living with HIV (Fakolade, Adebayo, Anyanti, & Ankomah, 2010).

Every woman in this study had different intersections that made her vulnerable to HIV and to MTCT of HIV. Factors like financial dependency on husband’s economy, poverty, and housing issues appeared to intersect with HIV-related stigma and discrimination to disempower or empower HIV+ women to claim their rights to use and access the PMTCT services. The current study provided different experiences of HIV+ women, as an impact of HIV-related stigma. If his wife is diagnosed with HIV, the husband will not voluntarily undergo HIV testing, despite knowing his wife’s HIV status. Another example is that a husband may refuse an HIV test for both himself and his wife. Women with multiple intersections of unprivileged elements, thus, may be a factor to a cumulative effect on women’s vulnerability to decreased access to the PMTCT program and ARV adherence.

HIV+ women with multiple intersecting stigmas contributed to an aggregated effect on HIV+ women's vulnerability to the uptake of the PMTCT program. Some participants stated that stigma and discrimination are like death penalties. HIV+ women described the social stigma imposed on them as mentally and physically denigrating, socially distancing, and victimising (Risal & Gunawan, 2018). This caused the internalised HIV stigma that became a barrier for HIV testing, ARV adherence, and use of the PMTCT program. Some participants experienced self-stigma that was translated into personal loss, grief, and shame.

This study discovered a range of factors that restricted HIV+ women's uptake of the PMTCT program, the most frequently mentioned factors being stigma and discrimination. Understanding stigma necessitates consideration of the intersectional influences of the broader cultural, social, and economic factors that structure stigma beyond the level of individuals (Ganle, Otupiri, Parker, & Fitpatrick, 2015). Most of the participants recognized HIV stigma as still prevalent within families and communities, and HIV+ women were discriminated against due to their HIV status (Iroezi et al., 2013; Ndonga, Muniu, Matu, Ng'ang'a, & Karama, 2014; Ngarina et al., 2014). Being known by the family and community as living with HIV and the fear of stigma can impact a woman's decision on whether or not to access PMTCT care for herself and her infant. Moreover, stigma and shame associated with HIV also intersect with other factors related to disempowerment of HIV+ women to adhere to PMTCT services, such as poverty and lack of health literacy (Davies & Najmah, 2020a; Najmah, Kumalasari, Davies, & Andajani, 2020).

The stigma related to HIV is internalized by families, communities, and HCPs (Sangaramoorthy et al., 2017; Stangl et al., 2019). In this research, it would appear that there was no discrimination against HIV+ women at the health setting, though some practices in the

PMTCT program that were intended to be beneficial to HIV+ women were perceived by the women as exposing them to discrimination. As an example, HIV+ women were provided with free health insurance, and all services were accessed without charge. This non-payment status identified them in the health care system as having HIV, and since the software used was accessible to everyone working in the hospital, there was a perception of nonvoluntary disclosure. These actions were interpreted by HIV+ women as unfairness or discrimination in health setting (Sangaramoorthy et al., 2017; Stangl et al., 2019).

Some HIV+ women argued that HCPs contributed to stigmatization in the health setting through moral judgement, and labelling them as prostitutes and bad mothers. Labelling of HIV+ women was often made as a joke or normalized behaviour, but it resulted in institutionalized discrimination toward HIV+ mothers (Davies & Najmah, 2020a). It contributed to women losing their status as good mothers and wives who sought the PMTCT to prevent MTCT of HIV, and to their feeling shameful in a public sphere (Najmah et al., 2020; Davies & Najmah, 2020a). HIV+ people were viewed as walking corpses, or as receiving punishment from God (Kaler, Alibhai, Kipp, Rubaale, Konde-Lule, 2012; Muoghalu & Jegede, 2013; Olaore & Olaore, 2014).

Disclosure of HIV status as a barrier to implementing the PMTCT program. HIV+ women in low-income countries have experienced barriers to disclosure due to fear of abandonment, accusations of infidelity, discrimination, and violence (Medley, Garcia-Moreno, McGill, & Maman, 2004). The fear of disclosing one's HIV status was reported by HIV+ women in this study. The data revealed some women's choices on seeking and adhering to PMTCT services were affected by difficulties in disclosing their HIV status related to gender imbalances in their relationships with their partners. In most cases women did not disclose their HIV status to their partners. HIV+ women had a range of behaviors from reluctance to disclosure, to desperate fear and shame to disclose. Most of the HIV+ women in my study deferred disclosure until their husbands would agree to go with them for HIV testing and counselling. These findings illustrate the challenges with which HIV+ women are threatened, but also represent a danger to primary HIV prevention in cases of discordant relationships (Sinclair et al., 2013; World Health Organization and London School of Hygiene and Tropical Medicine, 2010). Likewise, non-disclosure can prevent HIV+ women from adhering to PMTCT program, thus increasing the risk of MTCT of HIV.

Gender norms in Rwanda and other parts of sub-Saharan Africa contribute to HIV+ women's choice to maintain their marriage bond by non-disclosure of their HIV status to their husbands or vice versa (Hampanda, 2020; Liamputtong et al., 2014). Non-disclosure of HIV status happens within couples, and contributes to low ARVs adherence and MTCT of HIV risk due to poor understanding of the ARVs benefits and lack of sufficient health information resulting in delay in the initiation of ARVs (McGuire et al., 2010; Wasti et al., 2012). Early disclosure of HIV status, partners' support, safe sex and consensual sexual practices, and honesty in marriage are keys to women's and families' HIV survival. Nevertheless, not all HIV+ women disclose their HIV status to their partners or vice versa after being tested for HIV, prior to or during their marriage (Badriah et al., 2018; Musumari et al., 2014).

HIV+ women fulfil their social roles by keeping secrets from their husbands, and by masking their husbands' affairs outside the marriage to conserve the integrity of the family, which may reflect a passive acceptance of social norms of infidelity. More likely, it is women's way of safeguarding the stability of marriage and the welfare of their children by ensuring continued economic support through maintaining the family structure (Jewkes & Morrell, 2012).

Fear of women's infidelity resulted in some husbands refusing to allow their wives to attend the PMTCT program (McCollum et al., 2019; Heise, 2011). While gender norms demand women to accept husbands' infidelity, husbands are supposed to be intolerant of wives' infidelity which may lead men to ask for divorce when their wives have been unfaithful (Jewkes & Morrell, 2012; McCollum et al., 2019; Sinclair et al., 2013). Sometimes the family-in-law is informed about the HIV status of their son in the health setting, but they choose not to disclose it to the wife (McCollum et al., 2019; Sinclair et al., 2013).

Non-disclosure due to stigma was reported to result in maladaptive coping such as denial of HIV+ results, stopping ARVs, skipping doses, or refusal to uptake the PMTCT program (Lifson et al., 2013; Asgary et al., 2014). The most mentioned factor that promotes program uptake was willingness to disclose HIV status (Lifson et al., 2013). While fear of stigma prevents women from disclosing their HIV status, positive disclosure experiences can help HIV+ women to receive support from partners, family, and community members, assisting them to overcome challenges and barriers to uptake the PMTCT program and to adhere to the ARVs.

Some HIV+ women who had overcome the fear of disclosure described positive reactions from their husbands. Some husbands went for HIV testing and received ARV treatment as a result of the wife's disclosure, as well as provided support and encourangement to their wives in ARVs adherence and PMTCT program uptake (Hoffman et al., 2017; McCollum et al., 2019). The majority of HIV+ women in my study confirmed fear of negative outcomes for themselves and their children as a barrier to disclosure. There is a need for HCPs to identify those women and develop suitable support mechanisms to addres their fear and negative outcomes when they occur.

Partner notification for HIV is regarded as a legal and ethical issue that highlights the importance of respecting patients' autonomy and confidentiality. Participants who provided false contact and address information to the HCPs were mostly newly diagnosed mothers, and typically described a lack of adequate counselling and poor acceptance of their diagnosis. HCPs who lacked skill in counselling were constrained in their negotiating power to encourage HIV+ women to voluntarily inform their husbands/partners about their HIV status. HIV+ women, provided both ethical and legal justification for defending their keeping their HIV status secret, claiming that they should not be obliged to disclose their HIV status for the benefit of others. Ethically, human beings merit treatment with dignity and respect as ends in themselves and a counsellor's duty to their client supersedes every other duty (Petrini & Gainotti, 2008).

The intersection of legal, ethical, and moral dilemmas between respecting individual HIV+ women' s rights and the collective rights of HIV+ women's sexual partners confronted by HCPs were underlined in this study. Although confidentiality is crucial in the HCP-patient relationship, there are exceptions where this can be subverted for instance where some HCPs disclosed the HIV status of their clients without their consent. Nevertheless, this should be balanced to make sure that the interests of both HIV+ women and their sexual partners are fulfilled.

UNAIDS/WHO policy protects and promotes public health, and also ensures that dignity and human rights of HIV+ women are not violated (WHO, 2007). In low-income countries, where the majority of the HIV epidemic exists, patient referral has been discovered to be the most preferred method in partner notification strategies (Alam, Chamot, Vermund, Streatfield, & Kristensen, 2010). However, it does not address the issue whereby HIV+ women deliberately hide their HIV status from their partners thereby placing them at HIV risk, despite counsellors' efforts to promote voluntary disclosure.

Using the intersectionality lens, my study adds to the understanding of how fear of abandonment among HIV+ women is linked to the profound fear of losing support for women and their children. HIV+ women's economic dependency on men, and women's roles as caring mothers for children intersect as barriers for disclosure to partners. Most HIV+ women depend on their husbands for their care and that of their children as the majority of households are headed by men who have control and power over distribution of resources, and who can choose to withdraw such resources as a form of punishment.

Furthermore, my findings showed that women in polygamous relationships who tested HIV+ feared that their husbands would leave them, and shift their relationship to co-wives resulting in loss of support for the women and their children. In this regard, individual's social identities deeply influence their experience of gender, and social stratifications such as gender norms and social economic status can lead to greater advantage or disadvantage (McCollum et al., 2018). The insinuation here is that HCPs should consider changing social positions in supporting and preparing women for disclosure. For instance, HIV+ women in polygamous relationships who are dependent on their partners may necessitate more support and counseling for disclosure.

HIV+ women who access the PMTCT program and counselling services generally have a positive attitude towards ARVs, but there is a knowledge gap in the community which may deter use of the PMTCT program and may make it more challenging for HIV+ women to disclose to their husbands. Enhancing community engagement and health education to addres HIV stigma and mobilization for support activities is important for improving ARV adherence and uptake of the PMTCT program. Additionally, support activities by families and community members were reported to improve self-worth that promotes positive coping such as using the PMTCT program and adhering to ARV prescriptions (Yakob & Ncama, 2016). In addition, incorporating community sensitization into HIV prevention strategies was effective in creating a demand of ANC and PMTCT services among HIV+ pregnant and post-natal women, and increased women's awareness of HIV transmission and MTCT of HIV risk (Orne-Gliemann, 2006; Muchedzi, Chadambuka, Musarandega, Machekano, Katirayi, & Woelk, 2016).

Patriarchal Power as Social Force Shaping Inequality

Patriarchy is a socially and ideologically constructed system where men are considered as superior to women. This power is linked to the practice and belief of patriarchy which subjugates women at social, cultural, economic, and political levels (VeneKlasen, Miller, Budlender, & Clark, 2002). Patriarchy imposes character stereotypes on both femininity and masculinity which strengthen the inequity of power relations between women and men (Ponic, Reid, & Frisby, 2010). It affects many aspects of life, from political leadership, religious institutions, health systems, economic systems, and property ownership, right down to the family where men are considered to be the head of the household. In patriarchal societies, men are major decision-makers for their families, hence decisions around where, when, and even if a woman should have access to healthcare services often fall on men (Greene, Mehta, Pulerwitz, Wulf, Bankole, & Singh, 2006; Kwambai et al., 2013; Langen, 2005).

Throughout the history of humanity, patriachy has presented and shaped societies, becoming a mode of life that is perceived as eternal, ahistorical, and endorsed by God. In her book, *Beyond Power: On Women, Men, and Morals* (1085:16), Marilyn French stated that, historically, women's marginalization and oppression amounted to a form of slavery. She argues that slavery in a patriarchal state occurs when women do not have the rights to their own bodies, marriage, sexuality, reproduction, education, divorce, when they are excluded from practicing a profession or trade, and when their freedom of movement is restricted (Wood, 2019). Because the roots of patriarchy run so deep in the fabric of society, it is very difficulty to change. It is deeply rooted in the principles of male dominance, control, identification, and centeredness. According to Johnson (2014), with her metaphor of a tree, the root of the tree represents the core of patriarchy, and demonstrates a deep-rooted male control that is very complex and hard to disentangle or remove. For instance, due to the patriarchal nature of Rwandan society, men govern behaviors regarding allocation of money, women's workload, family planning, transport, and time that women can use to access healthcare services (Ganle, 2014; Ganle et al., 2015). In the context of maternal health, high decision-making power of men is associated with low utilization of ANC and delivery care services, as well as low uptake of the PMTCT program (Mrisho et al., 2007). It has also been noted that husband's approval is an important determinant of use and access of maternal and child healthcare services (Craymah, Oppong, & Tuoyire, 2017).

Various social vulnerabilities arise at different stages of life through intersection with other social forces. At the community level, societal and cultural norms such as patriarchy, stigma, and discrimination continue to disempower women and girls, contributing to low economic empowerment and low education (McCollum et al., 2019). In Rwanda, the link between violence and patriarchy in research reveals that men are not the only perpetrators of violence against HIV+ women. Coercive force, control, and power are used by several perpetrators and instigators of violence, before and after HIV diagnosis. Some studies argue that power of elders intersects with patriarchal power in the subjugation of Rwandan women, especially women living with HIV, who are subjected to mundane and violent acts of discrimination (Messerschmidt, 2012; Jewkes, 2015). These HIV+ women frequently suffer silently and endure harmful consequences of physical injuries, psychological and emotional traumatic experiences, and economic deprivation.

In Rwanda, it is important to question how, in a patriarchal society, families adhere strictly to practices and gendered norms that negatively affect women. The participants in this research explained how religious, social, and cultural factors all interact and contribute to men and elders in regard to the utilization of dominance, power, and control over women and girls. I recognize that there are three primary overlapping forces or powers that expose women to experience violence before and after HIV testing: the interlocking factors of patriarchy, elders, and violence structures. In addition, I recognize that structural violence stemming from unequal gender opportunities, lack of freedoms, access to education and economic power affects them disproportionately. Under this theme, I discuss power relationships, women's rights and emancipation, and the system of domination and oppression as social forces shaping inequality.

Power relationships as social force shaping inequality. HIV+ women in this study described the husband as the king of the household, and primary decision maker. Women are positioned as inferior to men; they are there to listen and implement what the men say. This gender power dynamic is common in rural marriages where most HIV+ women hold little economic power when compared to that of their husbands. Decision making dominance is useful in exploring the factors exposing HIV+ women to low uptake of the PMTCT program where power inequalities intersect with women's sexual relations, decisions for HIV testing and ARV adherence, and decisions for HIV disclosure to their spouse. This social structure helps explain why many HIV+ women who are poor and live in rural and peri-urban settings fear HIV disclosure, and perceive few options for material and social security outside the marital relationship.

Negotiating use of condoms for safe sex as a way to prevent HIV and MTCT of HIV is widely discussed in the literature (Jewkes & Morrell, 2012). This inability to negotiate safe sex parallels with women's fear of disclosing their HIV status to their partners, reflecting the deficiency of the decision-making power with which to sustain control over the marriage relationship. Some studies revealed the need for a couple to discuss the possibility of outside partners to maintain a good relationship (Jewkes & Morrell 2012, Gugsa et al., 2017). The women's relationship power is decreased in terms of her capability to communicate needs because of the potential for conflict, abuse, and separation/divorce. Some studies noted the gendered consequences of divorce, emphasizing economic consequences as fundamental to women's fear of HIV status disclosure. Several studies noted that divorce for many women has social and economic consequences which are more salient, as most HIV+ women rely upon their husbands for economic security (Gugsa et al., 2017; Onono et al., 2015). Another study conducted in Malawi cited the need for material support for care for both mothers and children as the number one reason HIV+ women may discontinue with the ARV adherence and PMTCT program uptake (Conroy, 2013).

In this study, there are observable power imbalances such as access and control of resources, economic power, and power to make informed decisions because of traditions giving power to men as patriarchs in the family. The power imbalance affects HIV+ women who are dependent on men, making it difficult to leave relationships, including those that are abusive. These findings are consistent with research that assesses how practices of inequality and gendered norms interact with structural violence (lack of power, exclusion, and poverty) to render HIV+ women vulnerable to a range of abuses, including husband violence (Heise, 2011; Fulu & Miedema, 2015). They show how multiple factors may interrelate as causative and determinant elements to gender violence. Thus gender inequality may result in neglecting protection of women against male violence (Kallay, 2017). Many incidents of domestic violence may not be reported due to fear of involuntary disclosure, and of unjust response from the local authority.

I found that despite available laws and policy recommendations for inclusion of marginalized people within decision-making processes, social power relations influenced decisions and outcomes. This is because the exercise of power is complex and more subtle than being physically present when decisions are consulted upon or made, and has been described elsewhere (McCollum et al., 2019). Invisible power remains in place that fails to engage marginalized people to make informed decisions or choices and limits access to information (McCollum et al., 2019; VeneKlasen et al., 2002). I acknowledge how other forces and power, such as the rule of elders over the younger generation, contribute to the use of power to subordinate and control women and girls in Rwanda. For instance, some participants in this study left school before finishing primary education because of poverty, early marriage, or becoming responsible for siblings after death of one or both parents. This had a negative impact on their capacity to secure the prerequisite skills, knowledge, and training to understand preventive measures of HIV and MTCT of HIV. Also, their lack of knowledge and skills inhibited their capability to find employment and to earn their own independent income, therefore stimulating a cycle of dependency on men and elders. This is in keeping with previous studies which acknowledge the influence of social hierarchies, political and economic division on citizens' participation within decisions, which function within existing hierarchies and patterns of power and privilege (Abimbola et al., 2016; McCoy, Hall, & Ridge, 2012).

Women are economically dependent upon their husbands with a consequence that they may lose a husband after HIV status disclosure, while husbands remarry with relative ease. The literature reveals that the sexual freedom granted to men, and the sanctioning of women's sexuality bolster the power differentials which constrain women's agency in marriage, limiting women's negotiating power to stay in the marriage when asked to leave, to ask for fidelity when the husband has strayed, and to secure economic and social support to prevent MTCT of HIV within the PMTCT program (Abimbola et al., 2016; McCollum et al., 2019).

The research evidences that women's dependency on husbands and other family members for care and support makes them vulnerable to experiences of everyday naturalized and normalized violence. Moreover, the literature on violence and HIV intersections claims that the perpetrators of violence often belong to extended family households and polygamous relationships where intergenerational families live together. It reveals that HIV stigma and abuse work at multiple levels. The adoption of multilevel socio-culturally responsive approaches to promote resistance to everyday normalized violence on the part of HIV+ women can promote transformative processes via dialogue and engagement in preventive practices.

Women's rights and emancipation. In the Rwanda social context there is a deeply embedded gender ideology of the ideal standard of good womanhood. Maintaining this standard through traditional practices, forced sexual intercourse, and lack of negotiating sexual intercourse constitutes a violation of rights, although many describe it as traditional practices and norms. These forms of violence are exacerbated by a positive HIV diagnosis. My research participants presented stories of pain, and emotional, physical, and psychological abuses. HIV+ women also felt shamed, isolated, and devalued in many respects, but their narratives also revealed that HIV+ women actively resist the stigma and abuse that exclude them, seeking solidarity with other people living with HIV. The considerable role played by women living with HIV as peer supports cannot be overemphasized.

In a powerful patriarchal culture, the PMTCT services need to support women's right to information, and informed decision making. HIV+ women need to educate themselves and their husbands, and include their husbands in making the family's decision to access services, including family planing, HIV testing, and access to ANC through PMTCT services.

There is a need to protect women's rights through engaging governments and partners in gender equality interventions by ensuring that women gain equal rights with men, with equal access to economic resources (WHO, 2017). The need to address the intersection of gender violence and HIV commences within the family and moves to the community and society; therefore, the family is a strategic point of entry for addressing troubles linked with violence of various forms (Heise, 2011).

System of domination and oppression. The system of domination limits women's development and advancement. Despite differences in domination levels, the strong principles remain the same; men are in control of all, but the nature of this control may vary. Therefore, it is necessary to understand the system of domination which keeps women dominated and subordinate in order to work for women's empowerment and development in a systematic way (Akinola, 2018; Bhasin, 2006). This system of domination derives its forces from culture, tradition, custom, even religion which says that man was born to lead and woman to follow (Akinola, 2018). The system of domination is so powerful that men are able to secure the apparent consent of the women they oppress. They can do this through institutions such as the church, academy, and family which support, justify, and reinforce women's subordination to men (Bhasin, 2006). The system of domination is a system of social structure in which men oppress, dominate, and exploit women. This system mitigates against women's emancipation, and lays on a foundation for their oppression and marginalization (Akinola, 2018).

Male dominance over women and children in the family and over women in society in general does not imply that women are either totally powerless, or totally deprived of resources, rights, and influence (Akinola, 2018). HIV+ women understand the hierarchical power relationship and dominance of men and elders, yet they are shrewd and adopt strategies that are less adversarial and confrontational. For instance women may delay starting ARV medication waiting the approval from their husbands or miss to provide the ARV prophilaxis to her new born baby because of control of the family-in-law. My findings show that cultural influence in patriarchal and elder norms is extremely entrenched in rural and resource constrained communities (MICS, 2012). The results from this study illuminate the interlocking powers of both male and female elders as perpetrators and instigators of a range of abuses to HIV+ women (Njororai, Bates, & Njororai, 2010).

The current research is insightful in revealing that HIV+ women living in low socio-economic conditions are more vulnerable to poverty and exposure to oppression and gender-based violence. Research findings show how HIV brings social disruption and changes to the family, which had previously sustained the stonework of African life (VanTyler & Shields, 2013). These findings connect with my own work, as most of the HIV+ women in the present research experienced fracturing of family and social support networks, being rejected, ostracised, and divorced by partners, and/or thrown out of their homes by their own mothers, sisters, or in-law family because of HIV.

Fear of being abandoned, separated, or divorced has been problematised, as basic needs such as housing and food remain a challenge for many of the participants in this study. Based upon the common narratives of HIV+ women, they struggled to surmount poverty and their dehumanised life; they were isolated and feared because of HIV. Most HIV+ women were blamed for getting HIV, and some experienced divorce, abandonment, and other challenges as they were pushed to become homeless. The complex intersection of HIV illness, structural violence, and poverty is obviously visible from their accounts.

The majority of HIV+ women who use the PMTCT program live insecure lives and are poor; those who occupy low waged jobs, have little education and work experience, and experience gender inequality are forced to depend on men and elders. This dependency exposes many HIV+ women to sexual coercion and unprotected sex with the attendant risks of HIV and STDs. It is evident from participant's accounts that, upon being tested HIV+, the majority of marginalized and poor women experience divorce, abandonment, and fractured family relationships. HIV+ women experience lack of support and compassion from their partners and trusted family members, and their ostracization and isolation render them dependent on HCPs support for their ARV adherence and PMTCT care services. Most HIV+ women tried to keep their status secret from their husbands and families. However, women who could not hide their HIV status risked experiencing a range of psychological, economic, sexual harassment and physical abuses due to devalued status as women living with HIV.

Health Services in Supporting Women in PMTCT Program

HIV is a challenging disease and women living with HIV require significant medical care to survive, and prevent MTCT of HIV to their infants. Support is a central source of strength for HIV+ women that can enable them to uptake the PMTCT program. Positive psychosocial factors offer spiritual and emotional support for HIV+ women, as well as financial support for accessing the PMTCT program. A supportive environment within the health facilities is urgently needed for HIV+ women to use the PMTCT program. Under this theme, I discuss partner support and social support.

Spouse/partner influence the PMTCT uptake. A previous study has shown that male support strengthens HIV+ women's ARV adherence and PMTCT uptake to prevent MTCT of HIV (Bolu et al., 2007). Encouraging partners to accompany wives to the ANC is reported by HCPs to be an ongoing challenge for many PMTCT programs. As mentioned previously, few women were likely to test for HIV after their husbands were diagnosed for HIV. However, some pregnant women who attended ANC reported that they became aware of their HIV status while their partner's status was not known, leaving them vulnerable to blame as being the source of HIV in the family. In my study, HCPs reported low male involvement in the PMTCT program, which HIV+ women believed was due to the husband's lack of knowledge. Moreover, men in Rwanda perceive ANC and PMTCT of HIV as a women's activity. Women, because of their health seeking behavior, particularly around pregnancy, tend to obtain HIV education and awareness at a health facility while men who view illness as a women's issue, remain uneducated about HIV and PMTCT of HIV. This may cause problems when men neglect or fail to understand their wives and support their participation in PMTCT care.

Community sensitization does not appear to improve male partners' involvement at ANC and uptake of HIV testing (USAID, 2019). Nevertheless, sensitization of the community by HCPs, and engaging male partners' involvement was associated with an increase in women accepting counselling, HIV testing, and ARV adherence (Torpey et al., 2010). Furthermore, sensitization and engagement of husbands in supporting women resulted in a significant increase of ARV adherence and PMTCT program uptake (Farquhar et al., 2004).

Some studies revealed that in couples with a close relationship HIV+ women were enabled to receive support needed for ARV adherence during their pregnancy (Kuonza, Tshuma, Shambira, & Tshimanga, 2010; Peltzer, Sikwane, & Majaja, 2011). As the husbands tend to have the final decision in most matters within the relationship, HIV+ women have to consult their husbands to enroll in the PMTCT program, initiate the ARVs, and get their support in adherence. Additionally, men also control financial resources that HIIV+ women need for transportation to reach the health facilities; this may expose HIV+ women to low lifelong ARV adherence.

The findings of my study underline that HIV+ women who are supported by their husbands, are more likely to be resilient to uptake the PMTCT services (Badriah et al., 2018; Hlartaithe et al., 2014; Lumbantoruan et al., 2018). Lack of spousal support was frequently mentioned as a factor related to MTCT of HIV and low uptake to PMTCT program. Continuous spousal support was reported to improve the PMTCT program utilization and showed the contribution of partners in counselling, reminding HIV+ women to take their drugs, and facilitating them to PMTCT uptake (Chadambuka et al., 2018; Onono et al., 2015). This emphasizes the great impact that husbands have on the decisions of HIV+ women to use the PMTCT services.

Social support promotes the success of the PMTCT program. HIV disease has shifted from being an acute and fatal disease to being a chronic illness. Concurrently, the importance of social support for HIV+ women has become increasingly understood as a critical factor in their living longer and healthier lives (Mignone et al., 2014). A higher level of social support has been associated with high rates of HIV survival among people living with HIV, and being part of various social networks has, as well, been associated with longevity for people living with chronic disease (Cohen & Janicki-Deverts, 2009). Furthermore, there is an intersection between social support and motherhood where HIV+ mothers viewed their children as an important source of social support that facilitated positive health-seeking behaviour and the PMTCT program uptake (Szymanski & Lewis, 2016).

Lack of HCPs and family support, and acceptance by family and community, as well as poor quality of services, were found to be primary factors that explained the shortcomings of the PMTCT program, as they deterred the HIV+ mothers' choice to utilize and/or adhere to the PMTCT program (Sasaki et al., 2021). It is, hence, logical to presume that a reverse of these deficiencies would improve the execution of the PMTCT program. That means support and acceptance by family, HCPs, community, and society, and high-quality services would be positively associated with adherence and utilization of the PMTCT program. Physical, social, emotional, and financial support enhances ARV adherence and uptake of the PMTCT program (Bijker et al., 2017). The support could be from HCPs, family, society, and/or community members (Kang'ethe & Nomngcoyiya, 2015; Chen et al., 2013). HIV+ mothers who received support reported to have accepted their diagnosis, and to being motivated and encouraged which promote the ARVs adherence and uptake of the PMTCT program (Sahay, Reddy & Dhayarkar, 2011; Kalichman et al., 2016; Wang et al., 2016).

Cultural Ideology

The effort to limit the number of MTCT of HIV have been global and can be attributed to rapid HIV testing during pregnancy, ARV adherence, uptake of the PMTCT program, and the counseling on infant feeding (Gugsa et al., 2017; Fakolade et al., 2010; Schaefer et al., 2017). The elements from social and cultural characteristics, including religious beliefs, interfereing with the experiences, decisions, and behaviors of HIV+ women during the infant feeding choice (Sianturi, Perwitasari, Islam, & Taxis, 2019). It is not sufficient to provide ARVs and counselling to HIV+ mother but beliefs, attitudes, and practices of families and community members that will interact with and negatively affect the uptake and efficacy of the PMTCT program and ARV adherence, also need to be addressed. The following discussion focuses on three sub-themes: traditional practices, religious beliefs, and infant feeding.

Traditional practices. Traditional healing appears as an influential community-based resource that impacts utilization of the PMTCT program. Traditional medicine has a wide reach and high acceptability compared to modern medicine (Yakob & Ncama, 2016). HIV+ women's claims to have been cured of HIV after using herbal medicine and attending prayers were associated with ARV discontinuation and non-adherence, in this study. Similar findings have been reported in other African countries (Bezabhe et al., 2014; Katz et al., 2013; Yakob & Ncama, 2016). The findings of this study suggest the importance of avoiding the traditional medicine to use of the PMTCT program and adherance to ARVs.

Religious beliefs. Religious identity for HIV+ women cannot be separated out as a private sphere of activities (Reimer-Kirkham, 2014). For the participants in this study, religion incorporated a core part of HIV+ women's lives that informed, integrateed, and influenced both their private and public spheres. As a complex set of social practices, religion often served as a reference point from which these women made decisions, and influenced their choices and actions.

Spirituality, a less institutionalized and more individualized expression of beliefs and values, often happens concurrently with religious practices, however, both spiritual and religious practices depend on the social environment that can either enhance or hinder its practice. HIV+ women's lived realities in terms of beliefs can bring to light how to enhance possibilities for health. Alternately, religious identities can also position HIV+ women in marginalized spaces that become pathways for health and social inequality (Reimer-Kirkham & Sharma, 2011). At the individual level, religion can change health by providing feelings of strength to cope with HIV stress, influencing the system of meanings, and providing adversity to other intersecting influences. Furthermore, as an integral aspect, religion often defines many aspects of social practices of HIV+ women both at home and within the community.

Infant feeding. The experiences of HIV+ mothers using the PMTCT program concerning infant feeding were based on the social symbolism of breastfeeding, and the support of HCPS. The findings indicate that mothers consider breastfeeding an essential aspect of motherhood; and if they cannot breastfeed their infants, feelings of guilt, sadness, and insecurity are generated. In addition, exclusive replacement feeding (ERF) is rare in a breastfeeding culture especially in African communities where the belief exists that infants cannot survive without breastmilk (Woldegiyorgis & Scherrer, 2012). The PMTCT guidelines recommend that HIV+ women EBF unless ERF meets the criteria of acceptability, feasibility, affordability, sustainability, and safety (AFASS) (Zacharius et al., 2019). However, fear of MTCT of HIV through breastfeeding has forced HIV+ women to choose ERF whether or not they meet or not AFASS criteria (Woldegiyorgis & Scherrer, 2012). Even though EBF is easier and more practical, it has a five to 15% risk of MTCT of HIV and, in the context of low middle income countries, ERF exposes infants to malnutrition risks, infections, diseases, and related deaths (Woldegiyorgis & Scherrer, 2012).

EBF contributes to stigma reduction, especially highlighting that continued breastfeeding is a benefit of PMTCT program. However, HIV-related stigma tends to put breastfeeding women at risk of non-adherence to ARVs (Bii, Otieno-Nyunya, Siika, & Rotich, 2008). Previous PMTCT guidelines recommended HIV+ women to limit the time for breastfeeding to six months. Many participants stopped breastfeeding at six months which raised concerns and suspicion among family and community members when women stopped breastfeeding earlier than the general population, where breastfeeding frequently continues through two to three years. Currently, the PMTCT guidelines recommend breastfeeding duration to be similar to the general population and infants only receive nevirapine for six weeks after birth, as the infant would be protected by maternal ARVs (World Health Organization, 2020). While HIV+ women who participated in the study appreciated the PMTCT program, it was apparent that the general knowledge and acceptance of ARVs and the PMTCT program in the community needs strengthening.

Health System Factors and Organization of the PMTCT Program

This theme discusses factors in relation to the healthcare service delivery in the PMTCT program, and the extent to which they support the uptake of the PMTCT program and ARV adherence. Participants frequently mentioned health system related issues that challenged their PMTCT of HIV journey including the interaction between HCPs and HIV+ women, quality of the PMTCT program, continuity of care, health system obstacles, and retention.

Interaction between HCPs and HIV+ women. Interactions with HCPs was a very important aspect of PMTCT care for HIV+ women in this study. Good interactions, a welcoming reception, and attention to their concerns resulted in contentment with the PMTCT program. These characteristics demonstrate the importance open communication, respect, and responsiveness of the health system to HIV+ women, and were their legitimate expectations (Yakob & Ncama, 2016). Responsiveness has been described as a determinant of patient satisfaction with healthcare and is associated with uptake of the PMTCT program (Tateke, Woldie, & Ololo, 2012; Asefa, Kassa, & Dessalegn, 2014). Disappointment with PMTCT services, with frequent staff rotation and new HCPs occurred when HIV+ women were disrespected and unheard, or their comments were not attended to.

HIV+ women's experiences during pregnancy, labor and delivery, coupled with HIV-related risks and negative consequences, influenced their decisions about enrolling in the PMTCT program in the post-partum period. For instance, during pregnancy, labor, and delivery, women may also be handling a new HIV+ diagnosis, troubling about disclosing their HIV status to husbands or family members, anticipating, or experiencing violence or abandonment; or worrying about MTCT of HIV (Hoffman et al., 2017; Knettel et al., 2018; Psaros, Remmert, Bangsberg, Safren, Smit, 2015). Successful implementation of the PMTCT program during labor and delivery depends on both the women and their HCPs being capable of discussing freely and in depth the needs of women living with HIV (WHO, 2013). To understand what leads and motivates post-partum PMTCT engagement, there is a need to attend to the impact of labor and delivery, and the ways in which HIV+ women's experiences intersect and interact with issues related to living with HIV during pregnancy and receiving ANC and PMTCT care.

Many HCPs in this study maintained that some women acquired the HIV infection from their husbands. Further, many were devoted to their work, using multiple strategies in which to assist HIV+ women, going so far as to help women disclose their HIV status to their husbands. However, sometimes poor attitudes and negative behaviors of HCPs, who were perceived to be in positions of power, lead to interactions that resulted in further marginalization of HIV+ women. This mistreatment, while not ingrained in stigmatizing attitudes about HIV, eventually contributes to stigma production, thereby reproducing inequality. Furthermore, this mistreatment illustrates the double bind when HCPs expect HIV+ women to comply with ARVs and PMTCT program appointments, yet punish them for not being compliant when seeking PMTCT care at the PMTCT program. Negative interaction with HCPs caused HIV+ women to feel scared to attend the PMTCT clinic (Flax et al., 2017; Gugsa et al., 2017). Efforts to promote HIV+

women's adherence to ARVs and uptake of the PMTCT program are rooted in professional behaviors and attitudes, and the HCPs' dedication to serve the health of HIV+ women and their infants.

Quality of the PMTCT program. The PMTCT program faced a shortage of staff, compromising the quality of and satisfaction with the program. Shortage of staff and high turnover impacted satisfaction with services and constrained service provision (Johns et al., 2014; Asfaw et al., 2014). Health facilities need to make sure that they adhere to service standards in order to preserve the quality of care. The inavailability and inaccessibility of PMTCT services at the district, provincial, referral, and private hospitals challenged HIV+ women's uptake of the program, especially for those who were unable to afford VIP services.

Quality of care remains low in most health care facilities not only in Rwanda but also in other parts of Africa, due to the lack of adequate staff, supplies, and training (Miller, Abalos, Chamillard, Ciapponi, Colaci, 2016). This is compounded in this study by evidence of wide spread HIV stigma in healthcare facilities which reduces the uptake of the PMTCT program. This finding is consistent with that of another study in Ethiopia (Feyissa, Abebe, Girma, & Woldie, 2012). Consequently, avoiding stigma in health facilities and improving health system responsiveness through training of HCPs is required to enhance patient satisfaction with the program and use of the PMTCT program to ensure the prevention of MTCT of HIV.

Prevention of unplanned pregnancies among HIV+ women. Concurrent use of hormonal contraceptives and ARVs can lead to drug interactions, predominantly due to effects of liver metabolism (Edelman, Cherala, & Stanczyk, 2010). Such interactions could compromise contraceptive efficacy with increased risk of unintended pregnancies. Contraceptive use and HIV+ women was not the focus of my research, although women discussed contraceptives and unplanned pregnancies as factors that exposed their children to MTCT of HIV. Most of the participants reported experiencing unplanned pregnancies while they were using a contraceptive. In addition, my findings reported that condom use among married couples was low. Preventing unplanned pregnancies in HIV+ women is recognized as one of MTCT of HIV preventive strategies (Feyissa et al., 2012). Unintended pregnancies were observed with combined ARVs and some contraceptive methods. HIV+ women need to make effective reproductive choices through useful counseling and appropriate contraception provision to ensure planned pregnancies, protect their fertility intentions, and promote safe childbearing.

The success of the PMTCT program requires continual engagement with ARV adherence and PMTCT care throughout the pre-, peri-, and post-natal period. HIV+ women's experiences are often overlooked in the role they play in facilitating PMTCT long-term adherence and retention. The experiences of HIV+ women during labor and delivery have been largely seen as a key juncture in the PMTCT program that could shape women's commitment to PMTCT care during the postpartum period and beyond (Kendall et al, 2014; Hoffman et al., 2017; Turan & Nyblade, 2013). Studies have shown that poor delivery experiences may create barriers to sustained PMTCT care engagement by changing HIV+ women's perceptions of PMTCT care, and their trust in HCPs or the health care system (Geldsetzer et al., 2016). Furthermore, traumatic experiences during labor and delivery may contribute to continuing psychosocial distress and avoidance of future PMTCT care (Miller et al., 2016; Bohren et al., 2015)

Health system obstacles. HIV+ women experiences coupled with HIV-related risks and negative consequences to influence their decisions about enrolling in the PMTCT program. Some experienced high levels of mistreatment during labor and delivery, including verbal abuse, physical abuse, neglect, stigma, and discrimination (Bohren et al., 2015). While the possibility of experiencing negative attitudes of HCPs during the labor and delivery is not unique to HIV+ women, these events may have major ramifications when perceived in the context of PMTCT care. Furthermore, considering the other challenges associated with labor and delivery in resource-limited countries, such as financial cost associated with delivery, access to transportation, lack of basic and emergency obstetric services, and occurrence of abuse and neglect, living with HIV has the potential to additionally complicate the labor and delivery experience (Miller et al., 2016).

The majority of HIV+ women expressed dissatisfaction with the waiting times at the PMTCT clinic, yet the majority attended their PMTCT program appointments regularly. In fact, after discussing the long queues encountered at each PMTCT visit, HIV+ mothers were quick to add that at the end of the day what mattered to them was the kindness of the HCPs, and that their health information was kept private and confidential. As one HIV+ woman put it: "So long as the HCPs will keep our conversations and my health information private and will take his time and listen to me when my turn comes, I do not mind waiting" (PMWPB3. P632). Once again, this finding is a deviation from the conventional wisdom that argues that long waiting times at PMTCT clinics are disincentives to HIV+ women for following up and meeting their appointments (Jones et al., 2015; Azia et al., 2016).

This study also revealed long waiting times together with not getting friendly service as factors that contributed to not continuing the PMTCT program utilization. Other studies where HIV+ women underlined HCPs who were not happy to handle deliveries for HIV+ women due to fear of accidental infection have indicated similar findings (Flax et al., 2017; Gugsa et al., 2017; Onono et al., 2015; Vieira et al., 2017).

The majority of HIV+ women using the PMTCT program expressed concern that attendance at the PMTCT program meant their private information would be revealed due to the isolated placement of the PMTCT program building. As well, the literature confirms that women's HIV status is likely to be exposed due to lack of integration of the PMTCT program with other clinical services (Onono et al., 2015; Vieira et al., 2017).

Retention of the clients in the PMTCT program. The findings from my study on retention in PMTCT care highlighted the intersecting factors of social support, concerns about privacy and stigma, partner disclosure, and readiness for long term treatment as important barriers to sustained PMTCT care engagement. Likewise, the growing body of literature provides important information about PMTCT care engagement and identified socio-cultural, emotional, economic, and structural factors associated with low uptake of the PMTCT program (Hoffman et al., 2017; Knettel et al., 2018; Psaros et al., 2015).

Conclusion

The experiences of mothers using the PMTCT program to prevent MTCT of HIV in Rwanda are shaped by a complex intersection of gender roles and norms, cultural ideology, power relationships, and systems of domination and oppression; as well as other potentially significant social determinants of health identified in the study findings. The findings from this study recommend that further investigations should test and evaluate how social forces work to shape health behaviors and produce health outcomes for Rwandan HIV+ women using the PMTCT program. This can help to develop effective PMTCT interventions to enhance the overall health and wellbeing of both HIV+ women and their children, as well as their family members.

To date, the recognition by the scientific community of the role of social determinants of health in producing health inequalities has failed to translate into significant progress towards interventions that improve disparate health outcomes among the population. As healthcare scientists, we need to expand our understanding of inequalies in health, and the way in which we investigate them. An intersectional framework offers a complexity of inquiry matching the complexity around the social forces shaping those inequalities.

Chapter 6: Recommendations, Knowledge Translation, and Conclusion

This research study has explored the experiences of mothers using the PMTCT program to prevent MTCT of HIV in Rwanda. Their experienced knowledge, supports, barriers and challenges, and benefits as regards to the PMTCT program have been carefully considered. These experiences to a large extend have the potential to positively or negatively affect the implementation of the PMTCT program in the Rwandan community. This chapter presents recommendations for education, practice settings, and future research, as well as for strategic policies that protect, promote, and support the prevention of MTCT of HIV in Rwanda. Additionally, this chapter presents the plan for knowledge dissemination and the closing statement.

Recommendations

Recommendations are proposed for practice, education, future research, and policies for better support the HIV+ women using the PMTCT program, and to limit the level of MTCT of HIV. For the PMTCT program to be successful, policy makers and leaders need to consider the following recommendations.

Recommendations for Practice Settings

The theoretical perspectives of this study (ontological assumption of critical realism, and intersectionality framework) provided philosophical foundations to explore the experiences of mothers using the PMTCT Program to prevent MTCT of HIV in Rwanda. The findings of this critical ethnography are fashioned by a complex intersection of gender roles and norms, cultural ideology, power relationships, and systems of domination and oppression, as well as other potentially significant social determinants of health identified in the study findings. In view of the theoretical perspectives, the aim of suggested recommendations is to identify factors that influence and challenge the uptake of PMTCT within BUTH, and describe how the PMTCT program can be implemented more effectively. The recommendations for practice settings are as follows:

Consistent messages. There is a need to address knowledge gaps of HIV+ women in understanding the benefits of life long adherence to the ARVs, breastfeeding their babies while on ARVs, and the fact that reinfection can occur when having unprotected sex with a partner who is also HIV+. The pressure to take ARVs immediately with limited or no support around decision making can impact adherence to ARVs, and the retention rate of the PMTCT program. A recommendation is for interdisciplinary HCPs collaboration to address patient knowledge gaps, and identify step-by-step procedures on how to address these issues. To have collaborative sessions that are feasible, there is a need to strengthen and update the existing HCPs training sessions. There is also a dire need for consistency in the PMTCT messages to HIV+ women; some of them are extracting only portions of messages, and that can become detrimental to their own health and health of their babies.

Maintaining open communication. Open communication and discussion around PMTCT sensitive topics can be beneficial in understanding the HIV+ women's perspective. Often HCPs, especially physicians, transfer HIV+ women to counsellors because they feel there is no consistent programming on their side. Some HIV+ women receive mixed messages, and it is difficult to build trust with HCPs due to inconsistency with PMTCT service delivery. Maintaining open communication and working on compassion and patience will make HCPs more aware that their attitudes and behaviours towards HIV+ women can impact the quality care the women receive.

Quality improvement and evaluation program for the PMTCT services. There is a need for ongoing formal processes by which objective measures and standards are periodically used to monitor and evaluate the quality of the PMTCT program services provided. Quality improvement evaluation of the PMTCT program, comprising its structures, processes, and outcomes, should be done annually to ascertain the gaps in the program, as well as its overall efficiency and effectiveness. This process would assist to define and facilitate a systematic approach to identify gaps, resolve identified problems, pursue opportunities, and improve the PMTCT services. It would likewise help to modify and promote evidence-based policies and guidelines that would meet the needs of HIV+ women who are enrolled in the program.

The findings from these data could inform the development of the PMTCT program to improve the quality of the PMTCT care and facilitate a successful transition from pre and perinatal to postpartum care. The PMTCT program can learn from and contribute to the movement of respectful maternal and child health care which recognizes that events of labor and delivery may have important implications for women's long-term health.

PMTCT program and ARV clinics involvement in the OPDs to reduce involuntary disclosure and stigma based on the isolated PMTCT and ARV clinics, are important. The training of HCPs need to include knowledge about HIV to be able to take care of all patients including HIV+ people.

The global community and Ministry of Health must expand their efforts beyond elimination of MTCT of HIV and include a focus on capacity building for health care services that respect women, protect and promote their dignity, and enhance their trust in the health care system. With this lens, all intersecting factors with the health care system, including labor and delivery, should be examined for its potential to facilitate long-term ARV adherence and

PMTCT program retention. Integration efforts to ensure access to respectful fundamental maternal care and human rights, and to simultaneously support the implementation of the PMTCT program have the potential to limit MTCT of HIV, and reshape the health and wellbeing of million of women, not only in Rwanda but also in SSA.

Recommendation for Ministry of Health

Full integration of the PMTCT program into all levels of the health system in Rwanda. The PMTCT program needs to be integrated into all levels of the health system (referral, provincial, district, and private hospitals) as part of the horizontal delivery package. This would permit decentralized management responsibility, authority, and accountability which would give opportunity to these levels of health care to be responsible for the budget control of the PMTCT services in the concerned levels. Integration into these levels will ensure continuity of care, effective resources utilization, sustained regular supply of ARVs and adjuvant medications, as well as an effective referral system within and between different levels of care.

There is a need to promote effective condom use in married couples, and integrate family planning services within the PMTCT program in Rwanda. HCPs messaging in regard to family planning, options for use of long-term contraceptive methods, and condoms continues to be crucial for all HCPs, especially those working in PMTCT program and HIV clinics, to consider as part of routine clinical care. In additional, integrating mental health services within the PMTCT program would assist HIV+ women in navigating through the journey of acceptance of their results.

Social and cultural considerations. It is very clear that some cultural practices and beliefs, as well as traditional values, especially in African settings, act as barriers to uptake and implement the PMTCT program. It is important to consider community and social factors for the accessibility and effectiveness of the PMTCT program related interventions.

The PMTCT program would be more sustainable and effective if there was an integration of culturally appropriate interventions and carefully developed innovative health education that addresses the concerns of negative beliefs and cultural practices, but encourages and facilitates the positive traditional values. This would help to address the unjust effects of male domination, gender inequality, infidelity, and polygamous marriages on HIV+ women, and promote informed decision making by all pregnant women, especially those who are HIV+. These interventions would additionally empower HIV+ women to negotiate sex and safe sex, including condom use, as well as increase their ability to gain access to the PMTCT program, and maternal and child health or reproductive health services.

The findings of this study suggest the importance of traditional medicine to uptake of the PMTCT program and adherence to ARVs. Therefore, training traditional healers and integrating them into the healthcare system are important steps toward promoting ARVs adherence, and uptake of the PMTCT program. Moreover, during ARV initiation and follow-up sessions in the PMTCT program, HCPs need to counsel HIV+ women to adhere to ARV prescriptions and ask for advice before using traditional healing services.

Recommendations for Education

To overcome the barriers and challenges of PMTCT program adherence, educational settings must add course content on promoting the prevention of HIV and MTCT of HIV at the baccalaureate, graduate, and post-graduate levels of interdisciplinary learning for health sciences students. This would build the capacity of students who are associated with diverse health fields.

During student practices, the university health centers need to develop and share resources related to HIV and MTCT of HIV for all students during their hospital orientation..

Primary prevention of HIV should include education that challenges cultural practices and beliefs, as well as traditional values, and patriarchal ideology in the community to promote women and child health. This education needs to start at high schools and in all health sciences educational programs to foster future multidisciplinary and interdisciplinary professionals to understand the needs of maternal and child health, identify the importance of making a difference through collaborative work, and take part in designing innovative interventions (surrounding health, housing, economic upliftment, and well-being) for the HIV+ women groups. Furthermore, there is a need to introduce intersectionality assumptions into nursing education around stigma and discrimination, stimulate attitude changes among nursing students, and promote the autonomy, and economic development of women in Rwanda.

Proper counselling guidelines addressing the ethical and legal challenges in HIV should be made available to all HCPs and counsellors, and within the PMTCT and HIV treatment centers to facilitate the counselling process. In the meantime, approaches like contact tracing and counsellor-mediated patient referral for HIV+ women who lack the communication skills to disclose their HIV status to their partners should be considered. Furthermore, couple counselling where couples are encouraged to mutually disclose their HIV status, and continuous counselling for inflexible HIV+ women, particularly on shared responsibility in relationships, should be thoroughly explored where appropriate.

HIV and MTCT of HIV counselling needs to be adjusted depending on women’s needs. Additional counselling sessions are needed for those newly diagnosed as HIV+ before initiating ARVs. Strengthening counselling messages is needed to ensure that HIV+ women understand the benefits of lifelong ARVs to both mother and child health. Furthermore, HCPs need to facilitate the adoption and the counselling of godmothers together with the PMTCT clients as highlighted in the PMTCT guideline.

Specific recommendations are added to address nursing education on how to prepare nurses that are appointed to the PMTCT program to deliver support and services that are required by the government in relation to HIV.

Community Education. There is a need for educating the general public about HIV/AIDS. Rwandan people need to know more about the modes of HIV transmission, signs and symptoms, and prevention of the spread of the HIV disease. Primary prevention of HIV infection is important since there no cure for the disease to date. The most effective way to prevent the MTCT of HIV is to ensure that women do not become infected in the first place.

To strengthen the PMTCT program in Rwanda, community sensitization needs to receive more resources and higher priority to reduce HIV stigma and discrimination in the community, and thus make HIV disclosure more possible for women. In addition, the creation of a social marketing program targeting the whole population is needed to raise awareness, and improve health literacy on factors that challenge HIV transmission, and convince the community to change negative behaviours in order to promote women and child health.

By seeking to increase the overall health literacy not only of HIV+ women but of the whole community, there is a hope for improvement in attitudes, increased knowledge, and change to more positive beliefs and behaviours that relate to better health outcomes for HIV+ women. Adherence to ARVs and uptake of the PMTCT program is a complex and multifactorial issue; of which health literacy is only one component. An increased level of health literacy in the community can facilitate the development of HIV+ women's adherence strategies, family and community support, and improved relationships between HCPs and patients. HCPs should ensure that health information allows HIV+ women to be more active participants in their own health and health care. In the light of women's vital role in caring for all members of their families and making health related decisions, there is a need to promote health literacy through educating women and educating the nation.

HIV/AIDS education in the community would decrease misconceptions about the HIV disease and stigmatization of people infected with it. Community education can be accomplished by mobilizing and/or sensitizing the community with the use of carefully developed community-based materials such as community posters, as well as the use of media (radio and television) and the print media. Furthermore, multisectoral approaches would be necessary, with involvement of government trained facilitators and counsellors on HIV education and training, churches, and Non-Governmental Organizations (NGO).

From the above discussion, it is clear that HIV+ women are victims of oppression, violence, male domination, and subordination which influence and challenge the uptake of the PMTCT program. Women in Rwanda are guaranteed gender equality by the constitution of Rwanda and the general law. However, patriarchal interpretation of the law continues the domination of patriarchal attitudes. The main causes of women's subordination are the negative impacts of culture, tradition, religion, and patriarchal attitudes in the socio-economic and legal spheres. Despite some recent reforms purporting to improve women's status, there is no real change in the patriarchal structures which interlink with religion, culture, and traditional forces. The time has come to make a radical change in the dominant ideology of patriarchy which is found in all areas of social relations. It is not enough to change family value systems. What is needed is a transformation of property distribution, the balance of power between men and women, rights over children, and the establishment of equal rights between men and women in all aspects of life.

I believe that true democracies and egalitarian societies can be formed only if we practice equality, democracy, and mutual respect within the family. Real peace in the family and society would not only improve the adherence of the PMTCT program and reduce the MTCT of HIV, but also would promote women and child health. There is a need for education that challenges patriarchal beliefs in the Rwandan community, and promotes equity in gender relations, as well as informed decision making across diverse families, religions, and cultural groups.

Ongoing training of the HCPs. HCPs need to have adequate knowledge and skills to overcome barriers and challenges in dealing with HIV+ women using the PMTCT services. The right training approach is required as it is the foundation of respect, protection, promotion, and fulfilment of HIV+ women's rights to health, to be treated with respect and dignity, to access the best health care services, to confidential treatment, and to an informed decision.

Successful implementation of the PMTCT program depends on the availability of the quality services rendered by health care professionals that are involved in the PMTCT program. As innovative changes in policies, guidelines, and protocols, as well as restructuring of the program are expected from time to time, there is a need for a program of ongoing quality professional development for HCPs involved in the program. This would promote the effective implementation of the PMTCT program and capacity building.

PMTCT of HIV campaign in the community. The general public lack of awareness of the PMTCT program reinforces stigmatization and discrimination of HIV+ women on the PMTCT program. The Rwandan community needs to be educated about the program. The PMTCT of HIV materials needs to be developed to enhance household, family, community, and social awareness of barriers and challenges of PMTCT program uptake. These materials could include community posters, and community PMTCT workbooks, based on research that incorporates responses that would break challenges, barriers, and resistance, and at the same time facilitate and motivate the implementation of the PMTCT program. Furthermore, these materials should be able to promote community behaviour change that would improve the PMTCT program uptake. Electronic, as well as print media, would be very useful in disseminating this information. A multisectoral approach would be needed.

Recommendations on Strategic Policies that Protect, Promote, and Support the Prevention of MTCT of HIV in Rwanda

Policy development and implementation. To address factors that challenge the uptake of the PMTCT program at BUTH, it is necessary to establish policies, protocols, and guidelines that regulate the conduct of HCPs caring for HIV+ women. Moreover, it is important to develop monitoring and referral structures to promote the follow-up of PMTCT program clients. This would need investment in cost effective administration and information sharing at local, hospital, and national levels, while considering the necessity to promote patients' rights to privacy and confidentiality.

Within the sphere of public policy and gender norms, the Rwandan Ministry of Health needs to create and implement policies, guidelines, and regulations as direct political actions to build supportive environments for HIV+ women accessing PMTCT services. There is a need to provide financial support to poorer HIV+ women using the PMTCT program who experience transportation barriers to access healthcare. In addition, psychosocial and emotional support needs to be strengthened to help HIV+ women work through the early stages toward acceptance of their HIV diagnosis so that they can feel free to use the nearest PMTCT programs.

Women support needs in PMTCT program. The involvement of men as well as other family members in the PMTCT program is essential. This would expand community support and participation. Husband support is needed to allow HIV+ women to disclose safely their HIV status results to partners, and enable couples to provide support to each other. Men and close relatives' involvement in the PMTCT program would, as well, help to diminish stigma and discrimination, and negative attitudes against HIV+ mothers. Furthermore, the PMTCT program should link with support groups for people living with HIV/AIDS, and facilitate access to food support and community resources, as well as psychosocial and physical support for the baby, mother, and family.

Couples counselling as entry point to the PMTCT program would go a long way to eliminating nearly all of the barriers to a successful PMTCT program. Such couples counselling must have an integrated model which would include routine enquiry about violence to support safe disclosure of HIV+ status to the sexual partners. For the PMTCT program to be successful, the gendered physical and social vulnerabilities of women, as well as the inherent social restrictions that affect voluntary counselling and testing, antenatal care, hospital delivery, and the choice of infant feeding practices must be addressed.

To improve the effectiveness of the PMTCT program at BUTH, it is essential to change the social and community perceptions of HIV that encourage stigma and discrimination against people living with HIV at family and community levels. It would help to highlight that, with proper ARV adherence and PMTCT uptake, HIV+ women and their children can lead productive, healthy, and long lives. Interventions to mitigate the impact of HIV and limit the risk of MTCT of HIV should involve all stakeholders including HCPs, PMTCT leaders, policymakers, HIV+ mothers, families, and communities. It is critical, as well, to identify and build methods to enhance the positive contribution of grandmothers and in-law families as agents of positive change on overall household health. Understanding their role is a starting point to removing the cultural and social barriers that lead to negative stereotyping in Rwanda society. It would also be important to have female support groups to help stop the patriarchy system.

Recommendation for Future Research

The findings from this study recommend further investigations to test and evaluate how social forces work to shape health behaviors and produce health outcomes for Rwandan HIV+ women using the PMTCT program. This can help to develop effective PMTCT interventions to enhance the overall health and wellbeing of both HIV+ women and their children, as well as their family members.

To date, the recognition of the role of the social determinants of health in producing health inequalities by the community scientific has failed to translate into significant progress towards interventions that improve disparate health outcomes among populations. As healthcare scientists, we need to extend our understanding of inequality in health and the ways in which we investigate them. An intersectionality framework offers a complexity of inquiry matching the complexity around social forces shaping those inequalities.

Limitations of the Study

The number of 29 HIV+ women participants was relatively small for the findings to be generalized to the wider population of Rwandan HIV+women. To allow triangulation of data, I also recruited HCPs working in the PMTCT program, PMTCT leaders, and policy makers. All participants in this study were working at, or using the BUTH/PMTCT program. Therefore, these findings are transferable to other settings with people of the same characteristics as those who participated in this study. Further research in different PMTCT programs and provinces in Rwanda is required to extend these research findings.

I did not conduct interviews with HIV+ women who were in the community and were not using the PMTCT program. Such information could have strengthened the findings of this study and allowed me to present a more nuanced view of HIV+ women perspectives about MTCT and access to the PMTCT services. Future studies should combine both HIV+ women using and not using the PMTCT program with direct observations of the routine ANC consultation.

The findings show that the overall social, cultural, and traditional issues highlighted in this study, as well as the organizational and services delivery mechanisms through which the PMTCT program is organized and delivered, constitute significant challenges to the uptake of the PMTCT program. Understanding how unique contextual factors limit HIV+ women's access to or utilization of the PMTCT program is critically important. Addressing these contextual factors necessitates engaging communities to understand the importance of the PMTCT program developing sustainable and innovative strategies for removing challenges and barriers to its access and use.

I spent more than one year in the field. The research questions were developed prior to the field work. Although the research objectives were achieved, I believe that the impact of the findings, and dissemination of the actions will continue even beyond my doctoral research. For instance, future research may look into the impact of the research findings in the long term.

Information bias. Based on the stigma and discrimination associated with HIV, it is possible that HIV+ women participants consciously hid information from me, and screened their narratives to express mainly good things about themselves. Such challenges are not new to qualitative studies. No participants were forced to share information, and participation was voluntary. Some participants were not comfortable sharing their experiences with the researcher. Furthermore, HCPs may have withdrawn information to protect the credibility of their health organization. However, efforts were undertaken to minimize information bias and increase the credibility of the findings. For example, the use of multiple sources of information, and triangulation with other groups in this study, as well as guidance gathered from the research supervisory committee were very beneficial.

Implications for Nursing

Intersectionality has implications for exploring the interaction of oppression and privilege within therapeutic nurse-client encounters, the practice environment, and within the nursing professional itself. The application of an intersectionality framework to nursing practice invites all nurses to reflect on their authoritative status, particularly when they deliver care to HIV+ women who may face different forms of marginalization or disempowerment. Most importantly, an intersectionality framework requires nurses to not only be aware of but also to identify and facilitate different processes that improve women's health, and integrate women's perspectives in the delivery of the PMTCT care. Nursing practice provided in this manner cultivates a space where HIV+ women's unique health, cultural, and obstetric concerns may be respected, recognized, and supported. Without careful attention to their authority within the health care context and their position of privilege, nurses, despite good intentions, might run the risk of delivering care that is disconnected from the needs of this specific group of women, or perpetuating processes such as stigmatization and discrimination that influence both access to the PMTCT care and health outcomes.

Intersectionality framework offers HCPs a more insightful picture of the experiences of HIV+ women and a better understanding of the cultural, social, political, and economic aspects of their lives in the context of MTCT of HIV. It may additionally provide alternate explanations to so-called resistance in care practices such as absences from medical appointments, or non-compliance with medical advice. Within the practice arena, an intersectional tool could be utilized in assessing factors that need to be addressed regarding a person's health by focussing on individual, family, community, social, and system forces that may limit or impact them in attaining their health goals.

Intersectionality framework, with it roots in social justice, can be a useful tool for nursing to advance its social mandate. Social justice is committed to decreasing the excess burden of ill health among groups most affected by social and health inequalities. HIV+ women constitute a group within society that have high health needs which are complicated by a range of challenges and barriers to access PMTCT care and services. Nurses delivering care to this specific group of women could use an intersectionality framework to address health disparities and access issues. To engage with an intersectionality framework, nurses would need to first understand that the women' s experiences of illnesses and health are embedded in the material conditions and the social location of their lives. They would, as well, need to examine how these conditions affect HIV+ women' s ability to adhere to nursing recommendations or a particular therapeutic regimen, attend to her healthcare needs, and participate in care. Such insights may result in expanded opportunities for negotiated choices in the delivery of healthcare and increased agency for women with the resultant advancement in health outcomes.

Intersectionality framework encourages nursing researchers to go beyond the individual informed perspective, and observe phenomena from the worldview of others, not simply from their sole perspective. It is pertinent in its capability to explore the way in which social identities shape women’s lives, and various levels of influences (individual, family, community, social, and system) interconnect to impact the experiences of HIV+ women regarding health and illness.

Because intersectionality framework has the potential to deconstruct categories and examine the systems and processes that construct a variety of identities, it becomes an important tool to assess the ways society is organized, and the structural conditions that contribute to vulnerability, health disparities, and illness for certain groups within a population. Intersectionality is also beneficial in detecting the effects of institutional practices on HIV+ women’s lives. With its emphasis on the institutional structures and processes that shape identities and interlocking oppression, it has the prospective to target areas of change needed to address health and social inequalities, and point to potential solutions of individual, family, community, social, and system levels.

As a method of nursing knowledge development, the intersectionality framework has the potential to provide new knowledge that can guide actions towards eradicating health disparities not only in race and ethnicity but also across sexual orientation, gender, social class, and socioeconomic status. Knowledge changes over time and reflects the political, social, and professional climate in which development of knowledge occurs. Intersectionality framework, with its time-dependent and contextual nature, is relevant in a world with constant changes, and where the effects of globalization are an everyday reality. With its attention to power dynamics and its roots in critical theory, intersectionality framework offers the possibility to create noteworthy contributions toward emancipatory learning. With the epistemic privilege, knowledge earned from lived experience may be the greatest way to gain understanding into several influences that shape the lives of HIV+ women. Intersectional ways of thinking provide an avenue for HIV+ women to understand their own experiences, and a window for HCPs, nurses, and health care organizations to gain access to this information that can contribute to new healthcare model development.

Knowledge Translation

Being a critical ethnographer who undertook this study with an emancipatory agenda, I will ensure translation of findings from this study in the practice setting. As the PMTCT program at BUTH is the collaborator and primary knowledge user of my study, I presented the preliminary findings of this study to the key stakeholders. I am also planning to do the final presentation at the end of this study and submit a written report sharing participants' voices about recommendations to support the effective implementation of the PMTCT program at BUTH. Moreover, I plan to present the results to HIV+ women at PMTCT program/BUTH to increase their awareness. and give briefing notes of my study findings to the BUTH's leaders. Furthermore, I will give a copy of my thesis to the University of Alberta.

To disseminate the findings to the scientific community, and promote further research in this area, I have published two articles from this thesis on an analysis drawn from the literature, and gaps in knowledge in the *International Journal of Nursing Student Scholarship*. I have presented this study at the 2021 *Thinking Qualitatively Virtual Conference*, *Canadian Association of Schools of Nursing (CASN) 2021 Virtual Nursing Education Con*ference, *Consortium of Universities for Global Health's 12th Annual Conference (CUGH 20*21), *CANAC's 27th Annual Conference*, and *Tradition, and Innovation: Informing Today's HIV Care, 2nd International Nursing and Midwifery Leadership Conference,* Accra, Ghana.

I have presented this study to gender and health teams composed of multidisciplinary and interdisciplinary professionals. As next steps, I intend to publish papers pertinent to intersectionality framework and its contribution to nursing knowledge, critical methodology, findings, recommendations, and policy briefs in the journals that hold readership of multidisciplinary and interdisciplinary scholars. I will furthermore disseminate the findings of my study by presenting at nursing and non-nursing conferences within and outside Rwanda.

Being a member of the Canadian Association of Nurses in HIV/AIDS Care (CANAC), and the Women and Children's Health Research Institute (WCHRI), I will disseminate knowledge to these organizations through short talks, presentations, workshops, and training sessions. I plan also to attend annual African, Caribbean and Black Canada HIV/AIDS Awareness Day and disseminate knowledge through short presentation.

The below epigraph reflects the words of my research participants, showing their wishes towards surrounding people. I would like to conclude this chapter with this closing statement. I wrote it in both Kinyarwanda and English.

Ijambo ry'umusozo

Mumarira yabo menshi, bakoze ku ndoto zanjye
Mumajwi yabo mato ateye imbabazi, banteye kubababarira
Mumajwi yuzuye imvamutima, baratabaza
Baratabaza kuko badashaka gupfa
Barabaza bagira bati, ese koko tugiye gupfa?
Bakisubiza bagira bati, ntidushaka gupfa.
Ababibarutse nabo bararira
Imitima yabo imenaguwe n'amarira yibibondo byabo bishaka kubaho
Kwihishira biranze, amarira atemba nk'amazi ashokera kumabere yabo
Baraboronzwa n'intimba yo kutabasha kurinda abo bibarutse.
Baratabaza nimureke tubumve, baratakira abahisi n'abagenzi

Baraborozwa no gusaba uburengezi

Baraborozwa no gusaba ubufasha

Nimureke tubumve kandi tubatege amatwi

Nimureke tubegere kandi tubahe ubufasha.

Umwanditsi: Joyce Kamanzi Joyce Kamanzi

Closing statement

Though their voices may shatter my dreams

Their voices are so small and sweet

Their soul cried out of them

They ask if they are going to die

They said, aim I going to die?

I do not want to die

Their moms are crying too, their heart would hurt if they cried for life

Those who stood near saw their tears falling upon their breast

Yet now they cry aloud into you

Let us hear their voices calling and shouting from field to field telling one another,

calling on the neighbours, to drive the conversation, to find the answer, to provide support

Let us listen to them; help them talk, help them be aware, and support them.

Author: Joyce Kamanzi

Joyce Kamanzi

When I started my PhD journey, one of the speakers in my PhD class reminded all of us: "remember, your research needs to benefit to your community". I am confident that I can answer "yes, my research has been and will continue to be beneficial to my community". I continue to keep in touch with my research participants and I am well aware that aspirations and voices of the HIV+ women and HCPs continue to travel visually and verbally to influence changes in the PMTCT program in BUTH.

From my research journey, I came to a deep understanding that being a Rwandan woman is full of complex challenges. The lives of HIV+ women are even more complicated, when their dreams to have healthy children are clouded by social judgement, cultural ideology, gender norms, and power imbalance, as well as stigma and confusion in navigating the Rwanda health system. Often, HIV+ women discover their HIV status at a very late stage. Due to fear of stigma and discrimination, HIV+ women may choose to hide or deny their status and not adhere to PMTCT services.

It is very important to protect babies against MTCT of HIV. But it has not been easy for Rwandan HIV+ women to access and adhere to the PMTCT program. Can we all, each of us, become the agent of change? Can we, as partners/spouses, neighbours, families, HCPs, policy makers, PMTCT leaders, religious leaders, community leaders, and politicians protect our siblings, mothers, cousins, and nieces from HIV? Do we care to save Rwandan babies and other babies worldwide every day from MTCT of HIV?

References

Abbott, L.S., & Williams, C.L. (2015). Influences of social determinants of health on African Americans living with HIV in the rural southeast: A qualitative metasynthesis. *Journal of the Association of Nurses in AIDS Care, 26*(4), 340-356. doi:10.1016/j.jana.2015.03.004

Abimbola, S., Molemodile, S. K., Okonkwo, O. A., Negin, J., Jan, S., & Martiniuk, A. L. (2016). The government cannot do it all alone: Realist analysis of the minutes of community health committee meetings in Nigeria. *Health Policy Plan, 31*(3), 332-345. doi:10.1093/heapol/czv066

Afasi, O.T. (2010). Power and womanhood in Africa: An introductory evaluation. Journal of Pan African Studies, 3(6), 229-238. Retrieved from https://www.researchgate.net/profile/Oseni-Taiwo-Afisi/publication/242770024_Power_and_Womanhood_in_Africa_An_Introductory_Evaluation/links/559306f508ae16f493ee4db6/Power-and-Womanhood-in-Africa-An-Introductory-Evaluation.pdf

Ahmed, S. (2017). *Living a feminist life.* Durham: Duke University Press.

Ahmed, S., Villalba-Diebold, P., Aliyu, G, Constantine, N., Ememabelem, M., Vertefeuille, J… Charurat, M. (2013). HIV counseling and testing and access-to-care needs of populations most-at-risk for HIV in Nigeria. *AIDS Care, 25*(1), 85–94. doi:10.1080/09540121.2012.686597

Aizir, J. G., Fowler, M. M., & Coovadia, H. (2013). Operational issues and barriers to implementation of prevention of Mother-to-Child Transmission of HIV (PMTCT) interventions in sub- Saharan Africa. *Current HIV Research, 11*(2), 144-159. doi:10.2174/1570162X11311020007

Akeroyd, A. (2004). Coercion, constraints, and cultural entrapments: A further look at gendered and occupational factors pertinent to the transmission of HIV in Africa. In Kalipeni, E., Craddock, S., Oppong, J. R. & Ghosh, J. (eds.). *HIV&AIDS in Africa: Beyond epidemiology.* Malden, USA: Blackwell

Akinola, A. O. (2018). Women, Culture and Africa's Land Reform Agenda. Frontiers in Psychology, 9(2234), 1-8. doi:10.3389/fpsyg.2018.02234

Akosua Aidoo, A. (1977). Asante Queen Mothers in Government and Politics in the Nineteenth Century. *Journal of the Historical Society of Nigeria 9*(1977), 1-13. Retrieved from https://www.jstor.org/stable/41857049?seq=1

Alam, N., Chamot, E., Vermund, S. H., Streatfield, K., & Kristensen, S. (2010). Partner notification for sexually transmitted infections in developing countries: A systematic review. *BMC Public Health, 10*(19), 1-11. doi: 10.1186/1471-2458-10-19.

Anney, N. V. (2014). Ensuring the quality of the findings of qualitative research: Looking at trustworthiness criteria. *Journal of Emerging Trends in Educational Research and Policy Studies, 5*(2), 272-281. Retrieved from https://pdfs.semanticscholar.org/1419/f7b54e6b7f1215717a5056e0709f8946745b.pdf

Archer, M., Bhaskar, R., Collier, A., Lawson, T., & Norrie, A. (2013). *Critical realism: Essential readings*. Lonon: Routledge.

Asefa, A., Kassa, A., & Dessalegn, M. (2014). Patient satisfaction with outpatient health services in Hawassa University Teaching Hospital, Southern Ethiopia. *Journal of Public Health and Epidemiology, 6*(2), 101-110. doi:10.5897/JPHE2013

Asgary, R., Antony, S., Grigoryan, Z., & Aronson, J. (2014). Community perception, misconception, and discord regarding prevention and treatment of infection with human immunodeficiency virus in Addis Ababa, Ethiopia. *The American Journal of Tropical Medicine and Hygiene, 90*(1), 153-159. doi:10.4269/ajtmh.13-0215

Azia, I. N., Mukumbang, F. C., & Wyk, V. B. (2016). Barriers to adherence to antiretroviral treatment in a regional hospital in Vredenburg, Western Cape, South Africa. *South African Journal of HIV Medicine, 17*(1), 1-8. doi:10.4102/sajhivmed.v17i1.476.

Badriah, F., Tahangnacca, M., Alkaff, R., Abe, T., & Hanifah, L. (2018). Implementation of Prevention of Mother to Child Transmission of HIV program in South Jakarta. *Kesmas: National Public Health Journal, 12*(4), 159-164. doi:10.21109/kesmas.v12i4.1707

Bamberger, M., Rugh, J., & Mabry, R. (2006). *Real world evaluation: Working under budget, time, data, and political constraints*. United State of America: Sage.

Baral, S., Logie, C. H., Grosso, A., Wirtz, A. L., & Beyrer, C. (2013). Modified social ecological model: A tool to guide the assessment of the risks and risk contexts of HIV epidemics. *BMC public health, 13*(482), 1-8. doi:10.1186/1471-2458-13-482

Barton, C. A. (2001). Science education in urban settings: Seeking new ways of praxis through critical ethnography. *Journal of Research in Science Teaching, 38*(8), 899-917. doi:10.1002/tea.1038

Batch, M., & Windsor, C. (2015). Nursing casualization and communication: A critical ethnography. *Journal of Advanced Nursing, 71*(4), 870-880. doi:10.1111/jan.12557

Baumbusch, J. (2010). Conducting critical ethnography in long-term residential care: Experiences of a novice researcher in the field. *Journal of Advanced Nursing, 67*(1), 184-192. doi:10.1111/j.1365-2648.2010.05413.x

Baylies, C. (2000). Perspectives on Gender and AIDS in Africa. In Baylies, C. & Bujra, J. (eds.). *AIDS, sexuality and gender in Africa: Collective strategies and struggles in Tanzania and Zambia.* London: Routledge.

Ben-Ari, A., & Enosh, G. (2013). Power relations and reciprocity: Dialectics of knowledge construction. *Qualitative Health Research, 23*, 422-429. doi:10.1177/1049732312470030

Benzie, K. M., Premji, S., Hayden., K. A., & Serrett., K. (2006). State of the evidence reviews: Advantages and challenges of including grey literature. *Worldviews on Evidence-based Nursing, 3*(2), 55-61. doi:10.1186/1471-2288-8-21

Bezabhe, W. M., Chalmers, L., Bereznicki, L. R., Peterson, G. M., Bimirew, M. A., & Kassie, D. M. (2014). Barriers and facilitators of adherence to antiretroviral drug therapy and retention in care among adult HIV-positive patients: A qualitative study from Ethiopia. *PLoS One, 9*(5), 1-10. doi:10.1371/journal.pone.0097353

Bhugra, D., & De Silva, P. (2000). Discussion paper: Couple therapy across cultures. *Sexual and Relationship Therapy, 15*(2), 183-192. doi:10.1080/14681990050010763

Bii, S. C., Otieno-Nyunya, B., Siika, A., & Rotich, J. K. (2008). Infant feeding practices among HIV infected women receiving prevention of mother to child transmission services at

Kitale District Hospital, Kenya. *East African Medical Journal, 85*(4), 156-161. doi:10.4314/eamj.v85i4.9639

Bijker, R., Jiamsakul, A., Kityo, C., Kiertiburanakul, S., Siwale, M., Phanuphak, P… Hamers, R. L. (2017). Adherence to antiretroviral therapy for HIV in sub-Saharan Africa and Asia: A comparative analysis of two regional cohorts. *Journal of the International AIDS Society, 20*(1), 1-10. doi:10.7448/IAS.20.1.21218

Binagwaho, A., Pegurri, E., Peter, C., Drobac, P, C., Mugwaneza, P., Stulac, S. N… Tsague, L. (2013). Prevention of mother-to-child transmission of HIV: Cost-effectiveness of Antiretroviral regimens and feeding options in Rwanda. *PLoS ONE, 8*(2), 1-12. doi:10.1371/journal.pone.0054180

Bleich, S. N,. Jarlenski, M. P., Bell, C. N., & LaVeist, T. A. (2012). Health inequalities: Trends, progress, and policy. *Annual Review of Public Health, 33*, 7-40. doi:10.1146/annurev-publhealth-031811-124658

Bohren, M. A., Vogel, J. P., Hunter, E. C., Lutsiv, O., Makh, S. K., Souza, J. P… Gülmezoglu, A. M. (2015). The mistreatment of women during childbirth in health facilities globally: A mixed-methods systematic review. *PLoS Med*icine, *12*(6), 1-32. doi:10.1371/journal.pmed.1001847

Bolu, O. O., Allread, V., Creek, T., Stringer, E., Forna, F., Bulterys, M… Shaffer, N. (2007). Approaches for scaling up human immunodeficiency virus testing and counseling in prevention of mother-to-child human immunodeficiency virus transmission settings in resource-limited countries. *American Journal of Obstetrics & Gynecology, 197*(3 Suppl):S83–S89. doi:10.1016/j.ajog.2007.03.006

Bond, V., & Dover, P. (1997). Men, women and the trouble with condoms: Problems associated with condom use by migrant workers in rural Zambia. *Health Transition Review, 7*(1997), 377-391

Boote, D. N., & Beile, P. (2005). Scholars before researchers: On the centrality of the dissertation literature review in research preparation. *Educational Researcher, 34*(6), 3–15. doi:10.3102/0013189X034006003

Bowen, G. A. (2009). Document analysis as a qualitative research method. Qualitative Research Journal, 9(2), 27-40. doi:10.3316/QRJ0902027

Bowleg, L. (2012). The problem with the phrase women and minorities: Intersectionality - an important theoretical framework for public health. *American Journal of Public Health, 102*, 1267-1273. doi:10.2105/AJPH.2012.300750

Bradley, H. E., Curry, A. L., & Devers, J. K. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Research and Educational Trust, 42*(4), 1758-1772. doi:10.1111/j.1475-6773.2006.00684.x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa

Brawner, B. M. (2014). A multilevel understanding of HIV/AIDS disease burden among African American women. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 43*(5), 633-643. doi:10.1111/1552-6909.12481

Brewer, D. J. (2000). *Ethnography*. Buckingham, Philadelphia: Open University Press.

Brittain, K., Giddy, J., Myer, L., Cooper, D., & Harries, J. (2015). Pregnant women's experiences of male partner involvement in the context of prevention of mother-to-child transmission in Khayelitsha, South Africa. *AIDS Care, 27*(8), 1020-1024. doi:10.1080/09540121.2015.1018862

Buell, D. K., Glancy, J., Kartzow, M. B., & Moxnes, H. (2010). Cultural complexity and intersectionality in the study of the Jesus movement. *Biblical Interpretation, 18*(4-5),1-2 doi:10.1163/156851510X517564

Buesseler, H. M., Kone, A., & Robinson, J. (2014). Breastfeeding: The hidden barrier in Cote d'Ivoire's quest to eliminate mother-to-child transmission of HIV. *Journal of the International AIDS Society, 17*(1), 18853-18860. doi:10.7448/IAS.17.1.18853

Burgoyne, A. D., & Drummond, P. D. (2008). Knowledge of HIV and AIDS in women in sub-Saharan Africa. *African Journal of Reproductive Health, 12*(2), 14-31. Retrieved from https://www.ajol.info/index.php/ajrh/article/view/7962/30531

Burns, N., & Grove, S. K. (2009). *The practice of nursing research: Appraisal, synthesis, and generation of evidence* (6th ed.). St. Louis, Mo.: Saunders/Elsevier.

Buvé, A., Bishikwabo-Nsarhaza, K., & Mutangadura, G. (2002). The spread and effect of HIV-1 infection in sub-Saharan Africa. *Lancet, 359*(9322), 2011–2017. doi:10.1016/S0140-6736(02)08823-2

Bwirire, L. D., Fitzgerald, M., & Zachariah, R. (2008). Reasons for loss to follow-up among mothers registered in a prevention-of-mother-to-child transmission program in rural Malawi. *Transactions of the Royal Society of Tropical Medicine & Hygiene, 102*(12), 1195-1200. doi:10.1016/j.trstmh.2008.04.002

Caiola, C., Docherty, S., Relf, M., & Barroso, J. (2014). Using an intersectional approach to study the impact of social determinants of health for African American mothers living with HIV. *Advances in Nursing Science, 37*(4), 287-298. doi:10.1097/ANS.0000000000000046

Camerini, L., Schulz, P., Nakamoto, K. (2012). Differential effects of health knowledge and health empowerment over patients' self management and health outcomes: A cross sectional evaluation. Patient Education and Counselling, 89(2), 337-344. doi:10.1016/j.pec.2012.08.005

Carbado, W. D., Crenshaw, W. K., Mays, M. V., &Tomlinson, B. (2013). Intersectionality: Mapping the movements of a theory. *Du Bois Review, 10*(2), 303-312. doi:10.1017/S1742058X13000349

Centers for Disease Control and Prevention [CDC]. (2019). *About HIV/AIDS*. Retrieved from https://www.cdc.gov/hiv/basics/whatishiv.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Factagainstaids%2Fbasics%2Fwhatishiv.html

Chadambuka, A., Katirayi, L., Muchedzi, A., Tumbare, E., Musarandega, R., Mahomva, A. I… Woelk, G. (2018). Acceptability of lifelong treatment among HIV-positive pregnant and breastfeeding women (Option B+) in selected health facilities in Zimbabwe: A qualitative study. *BMC public health*, *18*(570, 1-8. doi:10.1186/s12889-017-4611-2.pdf

Chambers, L. A., Rueda, S., Baker, D. N., Wilson, M. G., Deutsch, R., Raeifar, E… The Stigma Review Team. (2015). Stigma, HIV and health: A qualitative synthesis. *BMC Public Health, 15*(848), 1-17. doi:10.1186/s12889-015-2197-0

Chen, W. T., Wantland, D., Reid, P., Corless, I. B., Eller, L. S, Iipinge, S…Webel, A. R. (2013). Engagement with health care providers affects self- efficacy, self-esteem, medication adherence and quality of life in people living with HIV. *Journal of AIDS and Clinical Research, 4*(11), 1-6. doi:10.4172/2155-6113.1000256

Chersich, M. F., Rees, H. V., Scorgie, F., & Martin, G. (2009). Enhancing global control of alcohol to reduce unsafe sex and HIV in sub-Saharan Africa. *Globalization and Health, 5*(16), 1-6. doi:10.1186/1744-8603-5-16

Chinkonde, J. L., Erekaha, S. C., & Okundaye, J. N. (2009). The prevention of mother-to-child HIV transmission programme in Lilongwe, Malawi: Why do so many women drop out? *Reproductive Health Matters, 17*(33), 143-151. doi:10.1016/S0968-8080(09)33440-0

CHUB. (2021). *ART service monthly reports.* Department of planning and statistics/HIV/AIDS, STIs and OBBI Division: Author.

Chukwu, J. C. (2015). Role of women in the growth of the traditional Igbi economy. An *International Peer-reviewed Journal, 10*(2015), 1-10. doi:10.1.1.865.3061&rep=rep1&type=pdf

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist, 26*(2), 120-123. Retrieved from http://thepsychologist.bps.org.uk/volume-26/edition-2/methods-teaching-thematic-analysis

Cluvera, L. D., Hodes, R. J., Toskaa, E., Kidia, K. K., Orkina, F. M., Sherr, L., & Meinck, F. (2015). HIV is like a tsotsi. ARVs are your guns: Associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa. *AIDS, 29*(1), S57-S65. doi:10.1097/QAD.0000000000000695

Cohen, L., Manion, L., Morrison, K., & Wyse, D. (2000). *A guide to teaching practice* (5th ed.). Library cataloguing in publication data: British Library.

Cohen, S., & Janicki-Deverts, D. (2009). Can we improve our physical health by altering our social networks? *Perspectives on Psychological Science, 4*(4), 375-378. doi:10.1111/j.1745-6924.2009.01141.x

Collins, P. C., & Bilge, S. (2020). *Intersectionality,* (2nd ed.). United Kingdom, Medford: Polity Press.

Committee on Lesbian Gay, Bisexual, & Transgender. (2011). *The health of lesbian, gay, bisexual and transgender people: Building a foundation for better understanding.* Washington, DC: National Academies Press.

Connell, R. (2012). Gender, health and theory: Conceptualizing the issue, in local and world perspective. *Social Science & Medicine, 74*(2012), 1675-1683. doi:10.1016/j.socscimed.2011.06.006

Connell, R. W. (1995). *Masculinities.* Cambridge: Polity Press.

Connell, R. W., & Messerschmidt, J. (2005). Hegemonic masculinity: Rethinking the concept. *Gender & Society, 19*, 829–859. doi:10.1177/0891243205278639

Conroy, A. A. (2013). Gender, power, and intimate partner violence: A study on couples from rural Malawi. *Journal of Interpersonal Violence, 29*(5), 866-888. doi:10.1177/0886260513505907

Cook, K. E. (2005). Using critical ethnography to explore issues in health promotion. *Qualitative Health Research, 15*(1), 129-138. doi:10.1177/1049732304267751

Coquery-Vidrovitch, C. (2013). *Les Africaines: Histoire des femmes d' Afrique sub-saharienne du XIXe au XXe siècle.* Paris: Rue au Maire

Cornelius, L. J., Erekaha, S. C., Okundaye, J. N., Sam-Agudu, N. A. (2018). A Socio-ecological examination of treatment access, uptake and adherence issues encountered by HIV-Positive women in rural North-Central Nigeria. *Journal of Evidence-Informed Social Work, 15*(1), 38-51. doi:10.1080/23761407.2017.1397580

Craymah, J. P., Oppong, R. K., Tuoyire, D. A. (2017). Male involvement in maternal health care at Anomabo, central region, Ghana. *International Journal of Reproductive Medicine, 2929013,* 1-8. doi:10.1155/2017/2929013

Creek, T., Ntumy, R., Mazhani, L., Moore, J., Smith, M., Han, G… Kilmarx, P. H. (2009). Factors associated with low early uptake of a national program to prevent mother to child transmission of HIV (PMTCT): Results of a survey of mothers and providers, Botswana, 2003. *AIDS & Behavior, 13*(2), 356-364. doi:10.1007/s10461-007-9322-8

Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review, 43*(6), 1241–1299. Retrieved from http://www.jstor.org/stable/1229039

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Cronin, P., Ryan, F., & Coughlan, M. (2008). Undertaking a literature review: A step-by-step approach. *British Journal of Nursing, 17*(1), 38-43. Retrieved from https://www.researchgate.net/publication/5454130_Undertaking_a_literature_review_A_step-by-step_approach/download

Cunningham, J. (1993). *Action research and organizational development*. Westport, CT: Praeger.

Cypress, C. B. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimension of Critical Care Nursing, 36*(4), 253-263. doi:10.1097/DCC.0000000000000253

Davies, S. G., & Najmah. (2020a). Im/moral healthcare: HIV and universal health coverage in Indonesia *Sexual and Reproductive Health Matters, 28*(2), 1-18. doi:10.1080/26410397.2020.1785377

Davis, K. (2008). Intersectionality as buzzword: A sociology of science perspective on what makes a feminist theory successful. *Feminist Theory, 9*(1), 67-85. doi:10.1177/1464700108086364

De Chesnay, M. (2015). *Nursing research using ethnography: Qualitative designs and methods in nursing.* United States of America, NY: Springer.

De Cock, K. M., Mbori-Ngacha, D., & Marum, E. (2002). Shadow on the Continent: Public health and HIV/AIDS in Africa in the 21st Century. *The Lancet, 360*(9326), 67-72. doi:10.1016/S0140-6736(02)09337-6

de Laine, M. (1997). *Ethnography: Theory and applications in health research*. Sydney: MacLennan & Petty.

de Leeuw, E. (2012). The Political Ecosystems of health literacies. *Health Promotion International, 27*(1), 1-4. doi:10.1093/heapro/das001

De Man, J., Mayega, R. W., Sarkar, N., Waweru, E., Leys, M., Olmen, J. V… Criel, B. (2016). Patient-centered care and people-centered health systems in Sub-Saharan Africa: Why so little of something so badly needed? *International Journal of Person Centered Medicine, 6*(3):162-173. doi:10.5750/ijpcm.v6i3.591

Delavega, E., & Lennon-Dearing, R. (2015). Differences in housing, health and well-being among HIV-positive women living in poverty. *Social Work in Public Health, 30*(3), 294-311. doi:10.1080/19371918.2014.1001934

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2003). *Strategies of qualitative inquiry* (2nd ed.). Thousand Oaks, CA: Sage.

Devereux, S., & Hoddinott, J. (1993). *Fieldwork in developing countries*. Colorado: Lynne Rienner.

Dimandja, A. L. (2004). The Role and Place of Women in Sub-Saharan African Societies. Retrieved from http://globalag.igc.org/elderrights/world/2004/subsaharan.htm

Duffy, V., & Regan, C. (2012). *Understanding the vulnerability of women.* Retrieved from https://developmenteducation.ie/feature/this-is-what-has-happened/understanding-the-vulnerability-of-women/

Edelman, A. B., Cherala, G., & Stanczyk, F. Z. (2010). Metabolism and pharmacokinetics of contraceptive steroids in obese women: A review. *Contraception, 82*(4), 314-323. doi:10.1016/j.contraception.2010.04.016

Elwell, K. (2016). Facilitators and barriers to treatment adherence within PMTCT programs in Malawi. *AIDS Care, 28*(8), 971-975. doi:10.1080/09540121.2016.1153586

Encyclopædia Britannica. (2015). *Axiology.* Retrieved from www.britannica.com/topic/axiology

Fadnes, L. T., Engebretsen, I. M. S., Moland, K. M., Nankunda, J., Tumwine, J. K., & Tylleskär, T. (2010). Infant feeding counseling in Uganda in a changing environment with focus on the general population and HIV+ mothers: A mixed method approach. *BMC Health Services Research, 10*(260), 1-9. doi:10.1186/1472-6963-10-260

Fakolade R, Adebayo SB, Anyanti J, Ankomah A. (2010). The impact of exposure to mass media campaigns and social support on levels and trends of HIVrelated stigma and discrimination in Nigeria: tools for enhancing effective HIV prevention programmes. Journal of Biosocial Science, 42(3), 395-407. doi:10.1017/ S0021932009990538.

Farquhar, C., Kiarie, J. N., , Richardson, B. A., Kabura, M. N., John, F. N., Nduati… John-Stewart, G. C. (2004). Antenatal couple counseling increases uptake of interventions to prevent HIV-1 transmission. *Journal of Acquired Immune Deficiency Syndromes, 15*(37), 1620-1626. doi:10.1097/00126334-200412150-00016.

Fasawe, O, Avila, C., Shaffer, N., Schouten, E., Chimbwandira, F., Hoos, D… De Lay, P. (2013). Cost-effectiveness analysis of option B+ for HIV prevention and treatment of mothers and children in Malawi. *PLoS One, 8*(3), 1-10. doi:10.1371/journal.pone.0057778

Ferguson, L., Grant, A. D., Watson-Jones, D., Kahawita, T., Ong'ech, J. O., & Ross, D. A. (2012). Linking women who test HIV-positive in pregnancy-related services to long-term HIV care and treatment services: A systematic review. *Tropical Medicine and International Health, 17*(5), 564-580. doi:10.1111/j.1365-3156.2012.02958.x

Fetterman, D. (1998). *Ethnography step by step* (2nd ed.). Thousand Oaks, CA: Sage.

Feyissa, G. T., Abebe, L., Girma, E., & Woldie, M. (2012). Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. *BMC Public Health, 12*(522), 1-12. doi:10.1186/1471-2458-12-522.pdf

Fisher, S. (2019). Rethinking conceptual representations of masculinity in international development gender equality training. *NORMA, 14*(1), 50-65, doi:10.1080/18902138.2018.1519240

Flaming, D. (2004). Nursing theories as nursing ontologies. *Nursing Philosophy, 5*(3), 224-229. doi:10.1111/j.1466-769X.2004.00191.x

Flax, L. V., Hamela, G., Mofolo, I., Hosseinipour, C. M., Hoffman, F. I… Maman S. (2017). Factors influencing postnatal Option B+ participation and breastfeeding duration among HIVpositive women in Lilongwe District, Malawi: A qualitative study. *PloS one, 12*(4), 1-13. doi:10.1371/journal.pone.0175590

Flax, V. L., Yourkavitch, J., Okello, E. S., & Kadzandira, J. (2017). If my husband leaves me, I will go home and suffer, so better cling to him and hide this thing: The influence of gender on option B+ prevention of mother-to-child transmission participation in Malawi and Uganda. *PLoS ONE, 12*(6), 1-18. doi:10.1371/journal.pone.0178298

Fleek, K. A. (2014). *Perspectives of HIV+ women on the prevention of mother to child transmission of HIV in Addis Ababa, Ethiopia.* The United States of America: University of South Florida.

Flick, U. (2002). *An Introduction to qualitative research* (2nd ed.). London: Sage.

Forbat, L., & Henderson, J. (2003). Stuck in the middle with you: The ethics and process of qualitative research with two people in an intimate relationship. *Qualitative Health Research, 13*(10), 1453–62. doi:10.1177/1049732303255836

French, M., (1985). *Beyond power: On women, men and morals.* United States of Americam, New York: Ballantine Books.

Friedan, B. (1963). *The Feminine Mystique* (1st ed.). New York: Norton

Fulu, E., & Miedema, S. (2015). Violence against women: Globalizing the integrated ecological model. *Violence Against Women, 21*(12), 1431-1455. doi:10.1177/1077801215596244

Ganle, J. K. (2014). Addressing socio-cultural barriers to maternal healthcare in Ghana: Perspectives of women and healthcare providers. *Journal of Women's Health, Issues, and Care, 3*(6), 1-11. doi:10.4172/2325-9795.1000171

Ganle, J. K., Otupiri, E., Parker, M., & Fitpatrick, R. (2015). Socio-cultural barriers to accessibility and utilization of maternal and newborn healthcare services in Ghana after user-fee abolition. *International Journal of Maternal and Child Health, 3*(1), 1–14. doi:10.12966/ijmch.02.01.2015

Gathuthi, C., Muindi, M., Mwalali, T., Chiuri, M., & Kariuki, J. (2010). Korogocho socio - economic survey report final: Nairobi. Retrieved from https://silo.tips/download/korogocho-socioeconomic-report-final#report

Geldsetzer, P., Yapa, H. M. N., Vaikath, M., Ogbuoji, O., Fox, M. P., Essajee, S. M… Bärnighausen, T. (2016). A systematic review of interventions to improve postpartum retention of women in PMTCT and ART care. *Journal of the International AIDS Society, 19*(1), 1-17. doi:10.7448/IAS.19.1.20679

Gilson, L., Doherty, J., Loewenson, R., & Francis, V. (2007). Challenging inequity through Heath Systems - final report: Knowledge network on health systems. Retrieved from http://file.qums.ac.ir/repository/sdh/hskn_final_2007_en.pdf

Gorden, T., Holland, J., & Lahelma., E. (2001). Ethnographic research in educational settings. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland and L. Lofland (Eds), *Handbook of ethnography*. London: Sage.

Gourlay, A., Wringe, A., Birdthistle, I., & Mshana, G. (2014). It is like that; we didn't understand each other: Exploring the influence of patient-provider interactions on prevention of mother-to-child transmission of HIV service use in rural Tanzania. *PLoS ONE, 9*(9),1-12. doi:10.1371/journal.pone.0106325

Greene ME, Mehta M, Pulerwitz J, Wulf D, Bankole A, Singh S. (2006). Involving men in reproductive health: Contributions to development, background paper to the report on public choices, private decisions-sexual and reproductive health and the Millennium Development Goals. New York: UN Millennium Project, Washington, D.C. Retrieved from https://menandboys.ids.ac.uk/files/involving-men-reproductive-health-contributions-development

Grineski, S. E., Hernández, A. A., & Ramos, V. (2013). Raising children in a violent context: An intersectionality approach to understanding parents' experiences in Ciudad Juárez. Women's Studies International Forum, 40(10–22), 1-28. doi:10.1016/j.wsif.2013.04.001

Groenkjaer, M. (2002). Critical ethnographic methodology in nursing research: Issues and solutions. *Contemporary Nurse, 14*(1), 49-55. doi:10.5172/conu.14.1.49

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks, CA: Sage.

Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology, 29*(2), 75-91. Retrieved from https://www.jstor.org/stable/30219811

Gugsa, S., Potter, K., Tweya, H., Phiri, S., Sande, O., Sikwese, P… O'Malley, G. (2017). Exploring factors associated with ART adherence and retention in care under Option B+ strategy in Malawi: A qualitative study. PloS one, 12(6), 1-18. doi:10.1371/journal.pone.0179838

Guidroz, K., & Berger, M. T. A. (2009). Conversation with founding scholars of intersectionality: Kimberle Crenshaw, Nira Yuval-Davis, and Michelle Fine. In: Berger, M. T., Guidroz, K. (Eds.). *The intersectional approach: Transforming the academy through race, class & gender.* Chapel Hill, NC: The University of North Carolina Press.

Hadgu, T. H., Worku, W., Tetemke, D., & Berhe, H. (2013). Undernutrition among HIV positive women in Humera hospital, Tigray, Ethiopia, 2013: Antiretroviral therapy alone is not enough, cross sectional study. *BMC Public Health, 13*(943), 1-10. doi:10.1186/1471-2458-13-943.pdf

Hammersley, M., & Atkinson, P. (1995). *Ethnography: Principles in practice.* United States of America, NY: Routledge.

Hampanda, K., Abuogi, L., Musoke, P., Onono, M., Helova, A., Bukusi, E… Turan, J. (2020). Development of a novel scale to measure male partner involvement in the prevention of mother-to-child transmission of HIV in Kenya. *AIDS Behavior, 24*(1), 291–303. doi:10.1007/s10461-019-02546-0

Hankivsky, O. (2012). Women's health, men's health, and gender and health: Implications of intersectionality. *Social Science and Medicine, 74*(11), 1712–1720. doi:10.1016/j.socscimed.2011.11.029

Haram, L. (1995). Negotiating sexuality in times of economic want: The young and modern meru women. In Klepp, K. I., Biswalo, P. M. & Talle, A. (eds.). *Young people at risk: Fighting AIDS in Northern Tanzania.* Oslo: Scandinavian University.

Harrowing, J. N., Mill, J., Spiers, J., Kulig, J., & Kipp, W. (2010). Critical ethnography, cultural safety, and international nursing research. *International Journal of Qualitative Methods, 9*(3), 240-251. doi:10.1177/160940691000900301

Harvey, L. (2011). *Critical social research.* London: Unwin Hyman.

Hatcher, A. M., Stöckl, H., Christofides, N., & Woollett, N. (2016). Mechanisms linking intimate partner violence and prevention of mother-to-child transmission of HIV: A qualitative study in South Africa. *Social Science & Medicine, 168,* 130-139. doi:10.1016/j.socscimed.2016.09.013

Heise, L. (2011). What works to prevent partner violence? An evidence overview. London: Centre for Gender Violence and Health, London School of Hygiene and Tropical Medicine

Retrieved from Http: // Strive.ac.uk/system/file/attachment/What 20% to prevent %20partner%20 violence pdf.

Hill, C. (2011). *Enabling rural women's economic empowerment: Institutions, opportunities, and participation* (EGM/RW/2011/BP.1). Accra, GH: UN Women.

Hill, P. C. (1990). *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment.* Boston: Unwin Hyman.

Hlartaithe, M., O, Grede, N., de Pee, S., & Bloem, M. (2014). Economic and social factors are some of the most common barriers preventing women from accessing maternal and newborn child health (MNCH) and prevention of mother-to-child transmission (PMTCT) services: A literature review. *AIDS and Behavior, 18*(5), 516-530. doi:10.1007/s10461-014-0756-5

Hodgson, I., Plummer, M. L., Konopka, S. N., Colvin, C. J., Jonas, E., Albertini, J… Fogg, K. P. (2014). A systematic review of individual and contextual factors affecting ART initiation, adherence, and retention for HIV-infected pregnant and postpartum women. *PLoS One, 9*(11), 1-15. doi:10.1371/journal.pone.0111421.

Hoffman RM, Phiri K, Parent J, Grotts J, Elashoff D, Kawale P… Schooley, A. (2017). Factors associated with retention in Option B+ in Malawi: A case control study. *Journal of the International AIDS Society, 20*(1), 1-8. doi:10.7448/IAS.20.01.21464

Hogg, N. (2010). Women's participation in the Rwandan genocide: Mothers or monsters? *Review, 92*(877), 1-34. doi:10.1017/S1816383110000019

Hooks, B. (2009). Choosing the margin as a space for radical openness. In T. Prentki & S. Preston (Eds.). *The Applied Theatre Reader*. London: Routlegde.

Iroezi, N., Mindry, D., Kawale, P., Chikowi, G., Jansen, P., & Hoffman, R. (2013). A qualitative analysis of the barriers and facilitators to receiving care in a prevention of mother-to-child program in Nkhoma, Malawi. *African Journal of Reproductive Health, 17*(400), 118–129. doi:10.10520/EJC146920

Ismail, A.F., Ardini, Y.D., Mohamad, N. & Bakar, H.A. (2018). Association between parental oral health literacy and children's oral health status. *Revista Latinoamericana de Hipertension, 13*(3), 305-309. doi:1702/170263335022/170263335022.pdf

Jackson-Best, F., & Edwards, N. (2018). Stigma and intersectionality: A systematic review of systematic reviews across HIV/AIDS, mental illness, and physical disability. *BMC Public Health, 18*(919), 1-19. doi:10.1186/s12889-018-5861-3

Jewkes, R. K. (2015). From work with men and bo om work with men and boys to changes of social norms and r o changes of social norms and reduction of eduction of inequities in gender relations: A conceptual shift in prevention of violence against women and girls. *The Lancet, 385* (9977), 1580-1589.

Jewkes, R., & Robert, M. (2012). Sexuality and the limits of agency among South African teenage women: Theorising femininities and their connections to HIV risk practices. *Social Science & Medicine, 74*(11), 1729-1737. doi:10.1016/j.socscimed.2011.05.020

Johns, B., Asfaw, E., Wong, W., Bekele, A., Minior, T., Kebede, A… Palen, J. (2014). Assessing the costs and effects of antiretroviral therapy task shifting from physicians to other health professionals in ethiopia. *Journal of Acquired Immune Deficiency Syndromes, 65*(4):e140–147. doi:10.1097/QAI.0000000000000064

Johnson, A.G. (2014). *The gender knot: Unraveling our patriarchal legacy, (Revised and updated ed.).* Temple University, Philadelphia, PA.

Jones, D., Cook, R., Cecchini, D., Sued, O., Bofill, L., Weiss, S… Spence, A. (2015). Examining adherence among challenging patients in public and private HIV care in Argentina. *AIDS and Behavior, 19*(9), 1619-1629. doi:10.1007/s10461-015-1037-7

Jovic-Vranes, A., Bjegovic-Mikanovic, V., & Marinkovic, J. (2009). Functional health literacy among primary health-care patients: Data from the Belgrade pilot study. *Journal of Public Health, 31*(4), 490-495. doi:10.1093/pubmed/fdp049

Kagame, A. (1954). *Social and family organizations in the old Rwanda (Les organisations socio-familiales de l'ancien Rwanda).* Bergium: Brussels.

Kaler, A., Alibhai, A., Kipp, W., Rubaale, T., & Konde-Lule, J. (2012). Walking corpses and kindly Neighbours: Retrospective accounts of AIDS stigma in western Uganda. *World Journal of AIDS, 2*(3), 174-182. doi:10.4236/wja.2012. 23023.

Kalichman, S. C., Kalichman, M. O., Cherry, C., Eaton, L. A., Cruess, D., & Schinazi, R. (2016). Randomized factorial trial of phone-delivered support counseling and daily text message reminders for HIV treatment adherence. *Journal of Acquired Immune Deficiency Syndrome, 73*(1), 47–54. doi:10.1097/QAI.0000000000001020

Kallay, A. A. C. N. (2017). *Gambian women, violence, and its intersection with HIV/AIDS: Agency through feminist participatory research*. University of Sussex, School of Law, Politics and Sociology (Gender Studies). http://sro.sussex.ac.uk/id/eprint/72710/1/Campbell%20Nee%20Kallay%2C%20Agnes%20Adama.pdf

Kamanzi, J., & Richter, S. (2019). Protocol for a scoping review of the literature about use of the PMTCT (prevention of mother to child transmission) program. *International Journal of Nursing Student Scholarship, 6*(36), 1-10. Retrieved from https://journalhosting.ucalgary.ca/index.php/ijnss/article/view/68204

Kang'ethe, S. M., & Nomngcoyiya, T. (2015). Exploring underpinnings weighing down the phenomenon of adherence to Anti-Retroviral Drugs (ARVs) among the People Living With HIV/AIDS (PLWHA) in South Africa and Botswana: A literature review. *Journal of Human Ecology, 50*(3), 237-243. doi:10.1080/09709274.2015.11906879

Kanj, M., & Mitic, W. (2009). *Health literacy and health promotion: Defnitions, concepts and examples in the eastern mediterranean region. Individual empowerment conference working document.* World Health Organization, Geneva. Retrieved from https://www.who.int/healthpromotion/conferences/7gchp/Track1_Inner.pdf

Karlsen, M. W., Gabrielsen, A. K., Falch, A. L., & Stubberud, D.G. (2017). Intensive care nursing students' perceptions of simulation for learning confirming communication skills: A descriptive qualitative study. *Intensive and Critical Care Nursing, 42*, 97-104. doi:10.1016/j.iccn.2017.04.005

Kasenga, F., Hurtig, A. K., & Emmelin, M. (2010). HIV-positive women's experiences of a PMTCT programme in rural Malawi. *Midwifery, 26*(1), 27-37. doi:10.1016/j.midw.2008.04.007

Katirayi, L., Chadambuka, A., Muchedzi, A., Ahimbisibwe, A., Musarandega, R., Woelk, G… Moland, K. M. (2017). Echoes of old HIV paradigms: Reassessing the problem of engaging men in HIV testing and treatment through women's perspectives. *Reproductive Health, 14*(124), 1-13. doi:10.1186/s12978-017-0387-1

Katirayi, L., Namadingo, H., Phiri, M., Bobrow, E.A., Ahimbisibwe, A., Berhan, A.Y… Tylleskär, T. (2016). HIV-positive pregnant and postpartum women's perspectives about Option B+ in Malawi: A qualitative study. *Journal of the International AIDS Society, 19*(1), 209-219. doi:10.7448/IAS.19.1.20919

Katz, I. T., Essien, T., Marinda, E. T., Gray, G. E., Bangsberg, D. R… De Bruyn, G. (2011). Antiretroviral refusal among newly diagnosed HIV-infected adults in Soweto, South Africa. *AIDS, 25*(17), 2177-2181. doi:10.1097/QAD. 0b013e32834b6464.

Kayirangwa, E., Hanson, J., Munyakazi, L., & Kabeja, A. (2006). Current trends in Rwanda's HIV/AIDS epidemic. *Sexually Transmitted Infections, 82*(I), i27-i31. doi:10.1136/sti.2006.019588

Kebaabetswe, P. M. (2007). Barriers to participation in the prevention of mother-to-child HIV transmission program in Gaborone, Botswana: A qualitative approach. *AIDS Care, 19*(3), 355-360. doi:10.1080/09540120600942407

Kendall, T., Danel, I., Cooper, D., Dilmitis, S., Kaida, A., Kourtis, A. P… Wegner, M. N. (2014). Eliminating preventable HIV-related maternal mortality in sub-Saharan Africa: What do we need to know? *Journal of Acquired Immune Deficiency Syndromes, 67*(Suppl 4), S250-258. doi:10.1097/QAI.0000000000000377

Kessler, J., Nucifora, K., Li, L., Uhler, L., & Braithwaite, S. (2015). Impact and cost effectiveness of hypothetical strategies to enhance retention-in-care within HIV treatment programs in East Africa. *Value in Health the Journal of the International Society for Pharmacoeconomics and Outcomes Research, 18*(8), 946-955. doi:10.1016/j.jval.2015.09.294

KFF [Henry J Kaiser Family Foundation]. (2019). *The global HIV/AIDS epidemic: Key facts*. Retrieved from https://www.kff.org/global-health-policy/fact-sheet/the-global-hivaids-epidemic/

KFF. (2017). *Assessing global HIV targets in PEPFAR countries: A dashboard.* Retrieved from https://www.kff.org/hivaids/

KFF. (2021). *The global HIV/AIDS epidemic: Key facts*. Retrieved from https://www.kff.org/global-health-policy/fact-sheet/the-global-hivaids-epidemic/

Kim, M. H., Zhou, A., Mazenga, A., Ahmed, S., Markham, C., Zomba, G… Abrams, E. J. (2016). Why did I stop? Barriers and facilitators to uptake and adherence to ART in option B+ HIV Care in Lilongwe, Malawi. *PLoS One, 11*(2), 1-16. doi:10.1371/journal.pone.0149527.

Klaus, K., Baldwin, J., Izurieta, R., Naik, E., Seme, A., Jaime-Corvin, J… Enquselassie, F. (2014). *Perspectives of HIV+ women on the prevention of mother to child transmission of HIV in Addis Ababa, Ethiopia.* The United States of America: University of South Florida.

Knettel BA, Cichowitz C, Ngocho JS, Knippler ET, Chumba LN, Mmbaga BT… Watt, M. H. (2018). Retention in HIV care during pregnancy and the postpartum period in the Option B+ Era. *Journal of Acquired Immune Deficiency Syndromes, 77*(5), 427-438. doi:10.1097/QAI.0000000000001616

Kondowe, E. B. Z & Mulera, D. (1999). *A cultural approach to HIV/AIDS prevention and care: Malawi's experience-country report.* UNESCO/UNAIDS Research Project, Studies and Reports, Special Series, Issue no. 5, Cultural Policies for Development Unit, UNESCO. Retrieved from http://unesdoc.unesco.org/images/0012/001 222/122214e.pdf#xml=http://unesdoc.unesco.org/u lis/cgi-bin/ulis.pl?database= gEd.&set=3D0DD625_3_98&hits_rec=32&hits_lng=eng 220304

Kranzer, K., Lewis, J. J., Ford, N., Zeinecker, J., Orrell, C., Lawn, S. D… Wood, R. (2010). Treatment interruption in a primary care antiretroviral therapy programme in South Africa: Cohort analysis of trends and risk factors. *Journal of Acquired Immune Deficiency Syndromes, 55*(3), e17-e23. doi:10.1097/QAI.0b013e3181f275fd.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy, 45*(3), 214-222. Retrieved from https://ajot.aota.org/article.aspx?articleid=1876643

Kumar, R. (2011). *Research methodology: A step by step guide for beginners* (3rd ed.). Great Britain: Sage.

Kun, K.E. (1998). Vaginal drying agents and HIV transmission. *International Family Planning Perspectives, 24*(2), 93-94. Retrieved from https://www.guttmacher.org/journals/ipsrh/1998/06/vaginal-drying-agents-and-hiv-transmission

Kuonza, L., Tshuma, C. D., Shambira, G., & Tshimanga, M. (2010). Non-adherence to the single dose nevirapine regimen for the prevention of mother-to-child transmission of HIV in Bindura town, Zimbabwe: A cross-sectional analytic study. *BMC Public Health, 10*(218), 1-9. doi:10.1186/1471-2458-10-218

Kwambai, K. T., Dellicour, S., Desai, M., Ameh, A. C., Person, B., Achieng, F… Kuile, F. O. T. (2013). Perspectives of men on antenatal and delivery care service utilisation in rural western Kenya: A qualitative study. *BMC Pregnancy Childbirth, 13*(134), 1-10. doi:10.1186/1471-2393-13-134

Laar, S. A., & Govender, V. (2011). Factors influencing the choices of infant feeding of HIV+ mothers in Southern Ghana: The role of counsellors, mothers, families and socio-economic status. *Journal of AIDS and HIV Research, 3*(7),129–137. Retrieved from http:// academicjournals.org/JAHR

Laher, F., Cescon, A., & Lazarus, A. (2012). Conversations with mothers: Exploring reasons for prevention of mother-to-child transmission (PMTCT) failures in the era of programmatic scale-up in Soweto, South Africa. *AIDS & Behavior, 16*(1), 91-98. doi:10.1007/s10461-010-9875-9

Landefeld, C. C., Fomenou, L. A., Ateba, F., & Msellati, P. (2018). Prevention of mother-to-child transmission of HIV in Yaounde: Barrier to Care. *AIDS Care, 30*(1), 116-120. doi:10.1080/09540121.2017.1390540

Langen, T. T. (2005). Gender power imbalance on women's capacity to negotiate self-protection against HIV/AIDS in Botswana and South Africa. *African Health Sciences, 5*(3), 188-197. doi:10.5555/afhs

Leclerc-Madlala, S. (2008). *Intergenerational/age-disparate sex: An issue brief IN addressing the vulnerability of young women & girls to stop the HIV epidemic in Southern Africa.* Geneva; UNAIDS.

LeCompte, M., Schensul, J., Weeks, M., & Singer, M. (1999). *Researcher roles & research partnerships.* United Kingdom: AltaMira Press.

Lee, S. Y. D., Tsai, T. L., Tsai, Y. W., & Kuo, K. N. (2010). Health literacy, health status, and healthcare utilization of Taiwanese adults: Results from a national survey. *BMC Public Health, 10*(614), 1-8. doi:10.1186/1471-2458-10-614

Levy, J. M., Webb, A. L., & Sellen, D. W. (2010). On our own, we can't manage: Experiences with infant feeding recommendations among Malawian mothers living with HIV. *International Breastfeeding Journal, 5*(15). doi:10.1186/1746-4358-5-15

Liamputtong, P., Haritavorn, N., & Kiatying-Angsulee, N. (2014). Local Discourse on Antiretrovirals and the Lived Experience of Women Living With HIV/AIDS in Thailand. *Qualitative Health Research, 1*(11), 1-12. doi:10.1177/1049732314550005

Libby, A. M., McGinnes, H. G., Regensteiner, J. G. (2020). Educating the scientific workforce on sex and gender considerations in research: A national scan of the literature and building interdisciplinary research careers in women's health programs. *Journal of Women's health, 29*(6), 876-885. doi:10.1089/jwh.2019.8067

Lifson, A. R., Demissie, W., Tadesse, A., Ketema K, May R, Yakob B… Shenie, T. (2013). Barriers to retention in care as perceived by persons living with HIV in rural Ethiopia: focus group results and recommended strategies. *Journal of the International Association of Providers AIDS Care, 12*(1), 32-38. doi:10.1177/1545109712456428

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage.

Locatelli, S., & Peeters, M. (2012). Cross-species transmission of simian retroviruses: How and why they could lead to the emergence of new diseases in the human population. *AIDS, 26*(6), 659-673. doi:10.1097/QAD.0b013e328350fb68

Loeliger, K. B., Niccolai, L. M., Mtungwa, L. N., Moll, A., & Shenoi, S. V. (2016). Antiretroviral therapy initiation and adherence in rural South Africa: Community health workers' perspectives on barriers and facilitators. *AIDS Care, 28*(8), 982–93. doi:10.1080/09540121.2016.1164292.

Loeliger, K. B., Niccolai, L. M., Mtungwa, L. N., Moll, A., & Shenoi, S. V. (2016). I have to push him with a wheelbarrow to the clinic: Community health workers' roles, needs, and strategies to improve HIV care in rural South Africa. *AIDS Patient Care and STDs, 30*(80), 385-394. doi:10.1089/apc.2016.0096.

Logie, C. H., James, L., Tharao, W., & Loutfy, M. R. (2011). HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLoS Medicine, 8*(11), 1-12. doi:10.1371/journal.pmed.1001124

Lorde, A. (1984). Age, race, class, and sex: Women redefining difference. *In* s*ister outsider: Essays and speeches*. Trumansburg, NY: Crossing Press.

Lubega, M., Musenze, I. A., Joshua, G., Dhafa, G., Badaza, R… & Reynolds, S. J. (2013). Sex inequality, high transport costs, and exposed clinic location: Reasons for loss to follow-up of clients under prevention of mother-to-child HIV transmission in eastern Uganda - a qualitative study. *Patient preference & adherence, 7,* 447-454. doi:10.2147/PPA.S19327

Lumbantoruan, C., Kermode, M., Giyai, A., Ang, A., & Kelaher, M. (2018). Understanding women's uptake and adherence in option B+ for prevention of mother-to-child HIV transmission in Papua, Indonesia: A qualitative study. *PloS One, 13*(6), 1-17. doi:10.1371/journal

Lupattelli, A., Picinardi, M., Einarson, A., & Nordeng, H. (2014). Health literacy and its association with perception of teratogenic risks and health behavior during pregnancy. Patient education and counseling, 96(2), 171-178. doi:10.1016/j.pec.2014.04.014

MacDonald, D. (2010). *A guide to moral decision making.* Retrieved from www.ethicsweb.ca/guide/

Mack, N., Woodsong, C., MacQueen, M. K., Guest, G., & Namey, E. (2011). *Qualitative research methods: A data collector's field guide.* United States of America: Family Health International.

Madiba, S., & Letsoalo, R. (2013). HIV disclosure to partners and family among women enrolled in prevention of mother to child transmission of HIV program: Implications for infant feeding in poor resourced communities in South Africa. *Global Journal of Health Science, 5*(4), 1-13. doi:10.5539/gjhs.v5n4p1

Madison, D. S. (2012). *Critical ethnography: Method, ethics, and performance* (2nd ed.). Los Angeles, CA: Sage.

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *The all Ireland Journal of Teaching and Learning in Higher Education, 8*(3), 3351-33514. Retrieved from http://ojs.aishe.org/index.php/aishe-j/article/view/335/553

Maleche, A., & Day, E. (2011). *Traditional cultural practices and HIV: Reconciling culture and human rights.* Working Paper for the Third Meeting of the Technical Advisory Group of the Global Commission on HIV and the Law, 7–9 July 2011. http://kelinkenya.org/wpcontent/uploads/2010/10/traditional-cultural-practiceshiv-reconciling-culture-and-human-rights.pdf.

Manias, E., & Street, A. (2000). The handover: Uncovering the hidden practices of nurses. *Intensive and Critical Care Nursing,16*(6), 373-383. doi:10.1054/iccn.2000.1523

Mann, J. M. (1989). AIDS: A worldwide pandemic. *In* Gottlieb, M.S. et al (Eds). *Current Topics in AIDS Volume 2*. Geneva: John Wiley & Sons

Mazia, G., Narayanan, I., Warren, C, Mahdi, M., Chibuye, P., Walligo, A…Hainsworth, P. (2009). Integrating quality postnatal care into PMTCT in Swaziland. *Global Public Health*, *4*(3), 253–270. doi:10.1080/17441690902769669

Mazrui, A. A. (1986). *The Africans: A triple heritage*. Boston: Little, Brown.

McCabe, J. & Holmes, D. (2014). Nursing, sexual health and youth with disabilities: A critical ethnography. *Journal of Advanced Nursing, 70*(1), 77-86. doi:10.1111/jan.12167

McCall, L. (2005). The complexity of intersectionality. *Signs: Journal of Women in Culture and Society, 30*(3), 1771-1800. doi:10.1086/426800

McCall, L. (2009). Introduction. In: Berger, M. T., & Guidroz, K., (Eds.). *The intersectional approach: Transforming the academy through race, class & gender.* Chapel Hill, NC: The University of North Carolina Press.

McCollum, R., Taegtmeyer, M., Otiso2, L., Tolhurst, R., Mireku, M., Martineau, T… Theobald, S. (2019). Applying an intersectionality lens to examine health for vulnerable individuals following devolution in Kenya. *International Journal for Equity in Health, 18*(24), 1-15. doi:10.1186/s12939-019-0917-2

McCoy, D. C., Hall, J. A., & Ridge, M. (2012). A systematic review of the literature for evidence on health facility committees in low- and middle-income countries. *Health Policy Plan. 27*(6), 449-66. doi:10.1093/heapol/czr077

McGibbon, E., & McPherson, C. (2013). *Applying Intersectionality & Complexity Theory to Address the Social Determinants of Women's Health*: Nova Scotia, Canada. Retrieved from https://tspace.library.utoronto.ca/bitstream/1807/27217/1/10.1_mcgibbon_mcpherson.pdf

McGuire, M., Munyenyembe, T., Szumilin, E., Heinzelmann, A., Le Paih, M., Bouithy, N... Pujades-Rodríguez, M. (2010). Vital status of pre-ART and ART patients defaulting from care in rural Malawi. *Tropical Medicine & International Health, 15*(s1), 55–62. doi:10.1111/j.1365-3156.2010.02504.x

Medley, A., Garcia-Moreno, C., McGill, S., & Maman, S. (2004). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: Implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organisation*, *82*(4), 299-307. doi:10.1016/j.socscimed.2009.05.045.

Mepham, S., Zondi, Z., Mbuyazi, A., & Mkhwanazi, N. (2011). Challenges in PMTCT antiretroviral adherence in northern KwaZulu-Natal, South Africa. *AIDS Care, 23*(6), 741-747. doi:10.1080/09540121.2010.516341

Mertens, D. M. (2016). Assumptions at the philosophical and programmatic levels in evaluation. *Evaluation and Program Planning, 59*, 102-108. doi:10.1016/j.evalprogplan.2016.05.010

Messerschmidt, J. W. (2012). Engendering gendered knowledge: Assessing the academic appropriation of hegemonic masculinity. *Men and Masculinities, 15*(1), 56-76. doi:10.1177/1097184X11428384

Miceli, M., & Parnes, J. R. (1993). Role of CD4 and CD8 in T Cell activation and differentiation. *Advances in Immunology, 53*, 59-122. doi:10.1016/S0065-2776(08)60498-8

MICS (Multiple Indicator Cluster Survey) 2010- 2012). (2012). *Situation of women and children in the Gambia. Survey undertaken in 2010 with Final Report produced in 2012 by The Gambia Bureau of Statistics and United Nations Children Fund (UNICEF): The Gambia.* Retrieved from https://www.unicef.org/statistics/index_24302.html

Mignone, J., Migliardi, P., Harvey, C., Davis, J., Madariaga-Vignudo, L., & Pindera, C. (2014). HIV as chronic illness: Caregiving and social networks in a vulnerable population. *Journal of Nurses in AIDS Care, 26*(3), 235-345. doi:10.1016/j.jana.2014.09.002

Miller, C. M., Ketlhapile, M., Rybasack-Smith, H., & Rosen, S. (2010). Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa. *Tropical Medicine & International Health, 15*(s1), 48–54. doi:10.1111/j.13653156.2010.02514

Miller, S., Abalos, E., Chamillard, M., Ciapponi, A., & Colaci, D. (2016). Beyond too little, too late and too much, too soon: A pathway towards evidence-based, respectful maternity care worldwide. *The Lancet*, *388*(10056), 2176–2192. doi:10.1016/S0140-6736(16)31472

Mills, E., & Rennie, S. (2006). HIV testing and individual rights. *Science, 314*(5798), 417-419. doi:10.1126/science.314.5798.417b

Minichiello, V., Sullivan, G., Greenwood, K., & Axford, R. (1999). *Handbook for research methods in health Sciences*. Sydney: Addison Wesley.

Miya, M., & Mgutshini, T. (2016). Female perspectives of male partners' inclusion in the prevention of mother-to-child HIV transmission programme in KwaZulu-Natal. *Curationis, 39*(1), e1-e7. doi:10.4102/v39i1.1691

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Public Library of Science Medicine, 6*(7), 1-6. doi:10.1371/journal.pmed1000097

Morse, J., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*(2), 75-91. doi:10.1177/160940690200100202

Morse, M. J. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research, 25*(9), 1212-1222. doi:10.1177/1049732315588501

Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *European Journal of General Practice, 24*(1), 9-18, doi:10.1080/13814788.2017.1375091

Mrisho, M., Schellenberg, J. A., Mushi, A. K., Obrist, B., Mshinda, H., Tanner, M… Schellenberg, D. (2007). Factors affecting home delivery in rural Tanzania. *Tropical Medicine and International Health, 12*(7), 862-872. doi:10.1111/j.1365-3156.2007.01855.x

Msila, V., & Gumbo, M. T. (2016). *Africanising the Curriculum: Indigenous Perspectives and Theories.* Stellenbosch: Sun Press.

Muchedzi, A., Chadambuka, A., Musarandega, R., Machekano, R., Katirayi, L., & Woelk, G. (2014). Stepping up the pace on demand generation and retention of prevention of mother-to-child transmission (PMTCT) services: A randomized control trial to evaluate the effect of a community based peer facilitator intervention in a rural setting in Zimbabwe. Retrieved from http://www.pedaids.org/page/-/uploads/conferences/IAS%202014/ZimAuxilia_IAS2014.pdf.

Muindi, K., Egondi, T., Kimani-Murage, E., Rocklov, J., & Ng, N. (2014). We are used to this: A qualitative assessment of the perceptions of and attitudes towards air pollution amongst slum residents in Nairobi. *BMC Public Health, 14*(226), 1-10. doi:10.1186/1471-2458-14-226

Mulama, J. (2003). *Cultural stereotypes remain major hurdles in AIDS battle*. Inter Press Service news Agency. Retrieved from http://www.aegis.com/news/ips/2003/IP030934.html 050204

Muoghalu, C. O., & Jegede, S. A. (2013). Perception of HIV/AIDS among the Igbo of Anambra state, Nigeria. *Journal of Social Aspects of HIV/AIDS*, *10*(1), 42-54. doi:10.1080/17290376.

Musumari, P. M., Wouters, E., Kayembe, P. K., Nzita, K. M., Mbikayi, S. M., Suguimoto, S. P… Kihara, M. (2014). Food insecurity is associated with increased risk of non-adherence to antiretroviral therapy among HIV infected adults in the Democratic Republic of Congo: A cross-sectional study. *PLoS ONE, 9*(1), 1-10. doi:10.1371/journal.pone.0085327

Muwanguzi, P. A., Nassuna, L. K., Voss, J. G., Kigozi, J., Muganzi, A., Ngabirano, T. D… Nakanjako, D. (2019). Towards a denition of male partner involvement in the prevention of mother-to-child transmission of HIV in Uganda: A pragmatic grounded theory approach. *BMC Health Services Research, 19*(1), 1-11. doi:10.1186/s12913-019-4401-x.pdf

Naaeke, A., Kurylo, A., Grabowski, M., Linton, D., & Radford, M. L. (2011). Insider and outsider perspective in ethnographic research. *Proceedings of the New York State Communication Association, 2010*(68), 152-160. Retrieved from https://docs.rwu.edu/cgi/viewcontent.cgi?article=1017&context=nyscaproceedings

Nachega, J. B., Uthman, O. A., Anderson, J., Peltzer, K., Wampold, S., Cotton, M. F… Mofenson, L. M. (2012). Adherence to antiretroviral therapy during and after pregnancy in low income, middle-income, and high-income countries: A systematic review and meta-analysis. *AIDS, 26*(16), 39-52. doi:10.1097/QAD.0b013e328359590f

Najmah, S. I. P., Kumalasari, T. N., Davies, S. G., & Andajani, S. (2020). Factor influencing HIV knowledge among women of childbearing age in South Sumatra, Indonesia. *Malaysian Journal of Public Health Medicine, 20* (1), 150-159. doi:10.37268/mjphm/vol.20/no.1/art.552

Nash, J. C. (2008). Re-thinking intersectionality. *Feminist Review, 89*, 1-15. Retrieved from https://philpapers.org/rec/NASRI

Ndonga, E., Muniu, E., Matu, M., Ng'ang'a, Z., & Karama, M. (2014). Barriers to uptake and effective integration of PMTCT into SRH services in selected health facilities in Nairobi Kenya. *Pediatric and Neonatal Care, 1*(4), 1-5. doi:10.15406/jpnc.2014.01.00020

Ngarina, M., Tarimo, E. A., Naburi, H., Kilewo, C., Mwanyika-Sando, M., Chalamilla, G… Ekstrom, A. M. (2014). Women's Preferences Regarding Infant or Maternal Antiretroviral Prophylaxis for Prevention of Mother-To- Child Transmission of HIV during Breastfeeding and Their Views on Option B+ in Dar es Salaam, Tanzania. *PloS one, 9*(1), 1-11. doi:10.1371/journal.pone.0085310

Ngubane, J. (2010). *Gender roles in the African culture: implications for the spread of HIV/AIDS.* Dissertation/ Stellenbosch University. Retrieved from https://core.ac.uk/download/pdf/37323864.pdf

Njororai, F., Bates, D. & Njororai, W. (2010). Review of literature on HIV/AIDS voluntary counselling and testing in sub-Saharan Africa: Towards a social transformation model.

International Journal of Health Promotion and Education, 48(3), 68-78. doi:10.1080/14635240.2010.10708185

Nkonki, L. L., Doherty, T. M., Hill, Z., Chopra, M., Schaay, N., & Kendall, C. (2007). Missed opportunities for participation in prevention of mother to child transmission programmes: Simplicity of nevirapine does not necessarily lead to optimal uptake, a qualitative study. *AIDS Research and Therapy, 4(*27), 1-5. doi:10.1186/1742-6405-4-27

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods, 16*, 1-13. doi:10.1177/1609406917733847

Nteziryayo, J. P. (2009). *Social cultural factors in HIV/AIDS transmission among women in Rwanda.* Thesis/Kigali Health Institute. Retrieved from https://www.memoireonline.com/07/10/3773/m_Social-cultural-factors-in-HIVAIDS-transmission-among-women-in-Rwanda-1.html

Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies in the 21st century. *Health Promotion International, 15*(3), 1-11. doi:10.1093/heapro/15.3.259

Nyblade, L., Hong, K. T., Van Anh, N., Ogden, J., Jain, A., Stangl, A… Ashburn, K. (2008). *Communities confront HIV stigma in Viet Nam: participatory interventions reduce HIV-related stigma in two provinces.* Washington, D.C. and Hanoi: International Center for Research on Women (ICRW), Institute for Social Development Studies; 2008. Retrieved from https://www.hivpolicy.org/bib/HPP001595.htm

Nyondo, A. L., Chimwaza, A, F., & Muula, A, S. (2014). Exploring the relevance of male involvement in the prevention of mother to child transmission of HIV services in Blantyre, Malawi. *BMC International Health & Human Rights, 14*(30), 1-12. doi:10.1186/s12914-014-0030-y

Nyondo-Mipando, A. L., Chimwaza, A. F., & Muula, A. S. (2018). He does not have to wait under a tree: Perceptions of men, women and health care workers on male partner involvement in prevention of mother to child transmission of human immunodeficiency virus services in Malawi. *BMC Health Services Research, 18*(1), 187-195. doi:10.1186/s12913-018-2999-8

O'Connell, T. S., Bedford, K. J. A., Thiede, M., $ McIntyre, D. (2015). Synthesizing qualitative and quantitative evidence on non-financial access barriers: Implications for assessment at the district level. International Journal For Equity In Health, 14(54), 1-13. doi:10.1186/s12939-015-0181-z

O'Leary, Z. (2004). *The essential guide to doing research.* London, United Kingdom: Sage.

O'Gorman, D. A., Nyirenda, L. J., & Theobald, S. J. (2010). Prevention of mother-to-child transmission of HIV infection: Views and perceptions about swallowing nevirapine in rural Lilongwe, Malawi. *BMC Public Health, 10*(354), 1-8. doi:10.1186/1471-2458-10-354

Olaore, I. B., & Olaore, A. Y. (2014). Is HIV/AIDS a consequence or divine judgment? Implications for faith-based social services: A Nigerian faith-based university's study. *Journal of Social Aspects of HIV/AIDS*, *11*(1), 20-25. doi:10.1080/17290376.2014.910134.

Olson, K. (2016). *Essentials for qualitative interviewing*. New York, NY: Routledge.

Onono, M., Kwena, Z., Turan, J., Bukusi, E., Cohen, C. R., & Gray, G. E. (2015). You know you are sick, why do you carry a pregnancy again? Applying the socio-ecological model to understand barriers to PMTCT service utilization in Western Kenya. *Journal of AIDS & Clinical Research, 6*(6), 11-21. doi:10.4172/2155-6113.1000467

Orne-Gliemann, J., Mukotekwa, T., Perez, F., Miller, A., Sakarovitch, C., Glenshaw, M… Dabis, F. (2006). Improved knowledge and practices among endusers of mother-to-child transmission of HIV prevention services in rural Zimbabwe. *Tropical Medicine & International Health, 11*(3), 341–349. doi:10.1111/j.1365-3156.2006.01563.x.

Ostrach, B., & Singer, M. (2012). At special risk: Biopolitical vulnerability and HIV/STI syndemics among women. *Health Sociology Review, 21*(3), 258-271. doi:10.5172/hesr.2012.21.3.258

Parmar, A. (2017). Intersectionality, British criminology and race: Are we there yet? *Theoretical Criminology, 21*(1), 35-45. doi:10.1177/1362480616677496

Parmar, A. (2017). Intersectionality, British criminology and race: Are we there yet? *Theoretical Criminology, 21*(1) 35–45. doi:10.1177/1362480616677496

Paterson, D. L., Swindells, S., Mohr, J., Brester, M., Vergis, E. N., Squier, C…Singh, N. (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Annals of Internal Medicine, 133*(1), 21-30. doi:10.7326/0003-4819-133-1-200007040-00025

Pauly, B. M., MacKinnon, K., & Varcoe, C. (2009). Revisiting who gets care: Health equity as an arena for nursing action. *Advances in Nursing Science, 32*(2), 118-127. doi:10.1097/ANS.0b013e3181a3afaf

Pease, B. (2012). The politics of gendered emotions: Disrupting men's emotional investment in privilege. *Australian Journal of Social Issues, 47*(1), 125-145. doi:10.1002/j.1839-4655.2012.tb00238.x

Peltzer, K., Sikwane, E., & Majaja, M. (2011). Factors associated with short-course antiretroviral prophylaxis (dual therapy) adherence for PMTCT in Nkangala district, South Africa. *Nurturing the Child, 100*(9), 1253-1257. doi:10.1111/j.1651-2227.2011.02253.x

Petrini, C., & Gainotti, S. (2008). A personalist approach to public-health ethics. *Bull World Health Organ, 86*, 624–629. doi: 10.2471/BLT.08.051193.

Polit, D. F. & Beck, C. T. (2012). *Nursing Research: Generating and assessing evidence for nursing practice* (9th ed). Philadelphia: Lippincott Williams & Wilkins,

Polit, D., & Beck, C. (2006). *Essential of Nursing Research: Methods, appraisal and utilization* (6th ed). Philadelphia: Lippincott Williams and Wilkins.

Ponic, P., Reid, C., & Frisby, W. (2010). Cultivating the power of partnerships in feminist participatory action research in women's health. *Nursing inquiry, 17*(4), 324-335. doi:10.1111/j.1440-1800.2010.00506.x

Psaros, C., Remmert, J. E., Bangsberg, D. R., Safren, S. A., & Smit, J. A. (2015). Adherence to HIV care after pregnancy among women in sub-Saharan Africa: Falling off the cliff of the treatment cascade. *Current HIV/AIDS Reports, 12*(1), 1-5. doi:10.1007/s11904-014-0252-6

Ramjee, G., & Daniels, B. (2013). Women and HIV in sub-Saharan Africa. *AIDS Research and Therapy, 10*(30), 1-9. doi:10.1186/1742-6405-10-30

Ramoshaba, R., & Sithole, S. R. (2017). Knowledge and awareness of MTCT and PMTCT post-natal follow-up services among HIV infected mothers in the Mankweng Region, South Africa. *The Open AIDS Journal, 11,* 36-44. doi:10.2174/1874613601711010036

Rasmussen, D. N., da Silva, T. D., Rodkjaer, L., Oliveira, I., Medina, C., Barfod, T…Wejse, C. (2013). Barriers and facilitators to antiretroviral therapy adherence among patients with HIV in Bissau, Guinea-Bissau: A qualitative study. *African Journal AIDS Research, 12,* 1–8. doi:10.2989/16085906.2013.815405

Ravitch, S. M., & Riggan, M. (2012). *Reason and rigor: How conceptual frameworks guide research.* Thousand Oaks, CA: Sage.

Reeves, S., Albert, M., Kuper, A., & Hodges, B. D. (2008). Qualitative research: Why use theories in qualitative research? *British Medical Journal, 337*(7670), 631-634. doi:10.1136/bmj.a949

Reid, C., & Frisby, W. (2008). Continuing the journey: Articulating dimensions of Feminist Participatory Action Research (FPAR). In P. Reason & H. Bradbury (Eds.), *Sage handbook of action research: Participative inquiry and practice*. London, UK: SAGE.

Reimer-Kirkham, S. & Sharma, S. (2011). *Adding religion to gender, race and class: Seeking new insights on Intersectionality in health care contexts, in Health Inequities in Canada: Intersection Frameworks and Practices*. Vancouver, BC: UBC Press.

Reimer-Kirkham, S. (2014). Nursing research on religion and spirituality through a social justice lens. *Advances in Nursing Science, 37*(3), 249-257. doi:10.1097/ANS.0000000000000036

Rejai, M. (1991). *Political ideologies: A comparative approach*. Armonk, NY: M. E. Sharpe.

Remme, M., Siapka, M., Vassall, A., Heise, L., Jacobi, J., Ahumada, C… Watts, C. (2014). The cost and cost-effectiveness of gender-responsive interventions for HIV: A systematic review. *Journal of the International AIDS Society, 17*(19228), 1-25. doi:10.7448/IAS.17.1.19228

Retrieved from https://pdf.usaid.gov/pdf_docs/PA00WH8R.pdf

Risal, A., & Gunawan, J. (2018). Men, masculinities, and HIV/AIDS in Indonesia. *Belitung Nursing Journal, 4*(1), 24-25. doi:10.33546/bnj.403

Rogers, J., & Kelly, U. A. (2011). Feminist intersectionality: Bringing social justice to health disparities research. *Nursing Ethics, 18*(3), 397-407. doi:10.1177/0969733011398094

Rogers, J., & Kelly, U. A. (2011). Feminist intersectionality: Bringing social justice to health disparities research. *Nursing Ethics, 18*(3) 397–407. doi:10.1177/0969733011398094

Roper, J. & Shapira, J. (2000). *Ethnography in nursing research*. London: Sage.

Ross, C., Rogers, C., & Duff, D. (2016). Critical ethnography: An under used research methodology in neuroscience nursing. *Canadian Journal of Neuroscience Nursing, 38*(1), 4-7. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/27468600

Ross, R., Stidham, A. W., & Drew, B. L. (2012). HIV disclosure by perinatal women in Thailand. *Archives of Psychiatric Nursing, 26*(3), 232-239. doi.org/10.1016/j.apnu.2011.09.005

Rweyemamu, C. (1999). Sexual behaviour in Tanzania. In Foreman, M. (ed.). *AIDS and men: Taking risk or taking responsibility?* London: Panos.

Sahay, S., Reddy, K. S., & Dhayarkar, S. (2011). Optimizing adherence to antiretroviral therapy. *Indian Journal of Medical Research, 134*(6), 835-849. doi:10.4103/0971-5916.92629

Sangaramoorthy, T., Jamison, A. M., & Dyer, T. V. (2017). HIV stigma, retention in care, and adherence among older Black Women living with HIV. *Journal of the Association of Nurses in AIDS Care* , *28*(4), 518-531. doi:10.1016/j.jana.2017.03.003

Sasaki, Y., Kakimoto, K., Dube, C., Sikazwe, I., Moyo, C., Syakantu, G… Kai, I. (2021). Adherence to antiretroviral therapy (ART) during the early months of treatment in rural Zambia: Influence of demographic characteristics and social surroundings of patients. *Annals of Clinical Microbiology and Antimicrobials, 11*(34), 1-11. doi:10.1186/1476-0711-11-34

Schaefer, R., Gregson, S., Eaton, J.W., Mugurungi, O., Rhead, R., Takaruza, A… Nyamukapa, C. (2017). Age-disparate relationship and HIV incidence in adolescence girls and young women: Evidence from Zimbabwe. *AIDS, 31*(10), 1461-1470. doi:10.1097/QAD.0000000000001506.

Schensul, S., Schensul, J., & LeCompte, M. (1999). *Essential ethnographic methods: Observations, interviews and questionnaires*. Walnut Creek, Calif: AltaMira Press.

Schneider, M., Chersich, M., Temmerman, M., & Parry, C. D. (2016). Addressing the intersection between alcohol consumption and antiretroviral treatment: Neds assessment and design of interventions for primary health care workers, the Western Cape, South Africa. *Globalization and Health, 12*(65), 1-12. doi:10.1186/s12992-016-0201-9

Scholl, I., Zill, J. M., Harter, M., & Dirmaier, J. (2014). An integrative model of patient centeredness: A systematic review and concept anaylsis. *PLosONE, 9*(9), 1-9. doi:10.1371/journal.pone.0107828

Scotland, J. (2012). Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *English Language Teaching, 5*(9), 9-16. doi:10.5539/elt.v5n9p9

Sengendo, J., & Sekatawa, E. K. (1999*). A Cultural Approach to HIV/AIDS Prevention and Care: Uganda's Experience*. Studies and reports, Special series, issue no. 1, Cultural Policies for Development Unit, UNESCO. Retrieved from http://unesdoc.unesco.org/images/0012/ 0012 06/120611e.pdf#xml=http://unesdoc. unesco .org/u lis/cgi-bin/ulis.pl?database=ged&set =3D0D D856_2_109&hits_ rec= 44 &hits_ lng=eng 220304

Seroalo, K. B., Du Plessis, E., Koen, M. P., & Koen, V. (2014). A critical synthesis of interventions to reduce stigma attached to mental illness. *Health SA Gesondheid, 19*(1), 1-10. doi:10.4102/hsag.v19i1.800

Sewnunana, A., & Modibab, L. M. (2015). Influence of the home environment on the prevention of mother to child transmission of human immunodeficiency virus/acquired immune-deficiency syndrome in South Africa. *SAHARA Journal of Social Aspects of HIV/AIDS Research Alliance, 12,* 59-65. doi:10.1080/17290376.2015.1123645

Sharac, J., McCrone, P., Clement, S., & Thornicroft, G. 2010). The economic impact of mental health stigma and discrimination: A systematic review. *Epidemiologia e Psichiatria Sociale, 19*(3), 223-232. doi:10.1017/s1121189x00001159

Sharp, P. M., & Hahn, B. H. (2011). Origins of HIV and the AIDS pandemic. *Cold Spring Harbour Perspectives in Medicine, 1*(1), 1-23. doi:10.1101/cshperspect.a006841

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*(2), 63–75. Retrieved from http://eds.a.ebscohost.com.login.ezproxy.library.ualberta.ca/eds/pdfviewer/pdfviewer?sid=c4cb18ce-3409-4b32-95f8-c8dd787d915a@sessionmgr4003&vid=2&hid=4108

Shet, A., De Costa, A., Heylen, E., Shastri, S., Chandy, S., & Ekstrand M. (2011). High rates of adherence and treatment success in a public and public-private HIV clinic in India: Potential benefits of standardized national care delivery systems. *BMC health services research, 11*(277), 1-9. doi:10.1186/1472-6963-11-277

Shi, Z. (2012). Opportunities and constraints with ethnography in examining the home literacy experiences of English language learners. *Alberta Journal of Educational Research, 58*(2), 232-245. Retrieved from http://www.ajer.ca/

Shieh, C., & Halstead, J. A. (2009). Understanding the impact of health literacy on women's health. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 38*(5), 601-612. doi:10.1111/j.1552-6909.2009.01059.x

Shubber, Z., Mills, E. J., Nachega, J. B., Vreeman, R., Freitas, M., Bock, P… Ford, N. (2016). Patient- Reported Barriers to Adherence to Antiretroviral Therapy: A Systematic Review and Meta-Analysis. *PLoS Med, 13*(11), 1-14. doi:10.1371/journal.pmed.1002183

Sianturi, E. I., Perwitasari, D. A., Islam, M. A., & Taxis, K. (2019). The association between ethnicity, stigma, beliefs about medicines and adherence in people living with HIV in a rural area in Indonesia. *BMC Public Health, 19*(55), 1-8. doi:10.1186/s12889-019-6392-2

Simon, M. A., Li, Y., & Dong, X. (2014). Levels of health literacy in a community-dwelling population of Chinese older adults. *The journals of gerontology Series A, Biological sciences and medical sciences, 69*(Suppl 2), S54-S60. doi:10.1093/gerona/glu179

Sinclair, J., Sinclair, L., Otieno, E., Mulinge, M., Kapphahn, C., Golden, N. H. (2013). A self-defence program reduces the incidence of sexual assault in Kenyan adolescent girls. *Journal of Adolescent Health, 53*(3), 374-380. doi:10.1016/j.jadohealth.2013.04.008

Skjolingstad, G. (2005). *Taking culture into account in the fight against HIV/AIDS: A literature review of gender and sexuality in south east Africa*. Theses: University of Oslo. Retrieved from https://pdfs.semanticscholar.org/a0f2/2cb28948d8d1323b47e4e33e3c2e23bd6909.pdf

Skykes, S., Wills, J., Rowlands, G., & Popple, K. (2013). Understanding critical health literacy: A concept analysis. *BMC Public Health, 13*(150), 1-10. doi:10.1186/1471-2458-13-150.pdf

Spelman, E. V. (1998). Gender and race: The ampersand problem in feminist thought. In: Ruth, S. (Ed.). *Issues in feminism: An introduction to women's studies* (4th ed.). Mountain View, CA: Mayfield.

Spradley, J. P. (1980). *Participant observation*. New York: Holt Rinchart & Winston.

Stangl, A. L., Earnshaw, V. A., Logie, C. H., Brakel, W. V., Simbayi, L. C., Barré, I… Dovidio,J. F. (2019). The Health stigma and discrimination framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine, 17*(31), 1-13. doi:10.1186/s12916-019-1271-3

Steegstra, M. (2009). Krobo queen mothers: Gender, power, and contemporary female traditional authority in Ghana. *Africa Today, 55*(3), 105-123. Retrieved from https://www.jstor.org/stable/27666987

Syed, S. T., Berber, B. S., & Sharp, L. K. (2013). Traveling toward disease: Transportation barriers to health care access. *Journal of Community Health, 38*, 976-993. doi: 10.1080/713612410.

Szymanski, D. M., & Lewis, J. A. (2016). Gendered racism, coping, identity centrality, and African American college women's psychological distress. *Psychology of Women Quarterly, 40*(2), 229-243. doi:10.1177/0361684315616113

Tannenbaum, C., Greaves, L., & Graham, L. D. (2016). Why sex and gender matter in implementation research. *BMC Medical Research Methodology, 16*(145), 1-9. doi:10.1186/s12874-016-0247-7

Tateke, T., Woldie, M., & Ololo, S. (2012). Determinants of patient satisfaction with outpatient health services at public and private hospitals in Addis Ababa, Ethiopia. *African Journal of Primary Health Care & Family Medicine, 4*(1), 1-11. doi:10.4102/phcfm.v4i1.384

Tenthani L, Haas AD, Tweya H, Jahn A, van Oosterhout JJ, Chimbwandira, F…Keiser, O. (2013). *Retention of HIV+ pregnant and breastfeeding women on universal antiretroviral therapy (option B+) in Malawi*. Retrieved from http://regist2.virology-education.com/2013/5hivped/docs/17_Tenthani.pdf

The News Times Rwanda. (2018). *Rwandan women in leadership*. Retrieved from https://www.konbini.com/ng/lifestyle/women-now-make-68-parliament-rwanda/

Thomas, J. (1993). *Doing critical ethnography.* Newbury Park, CA: Sage.

Torpey, K., Mwenda, L., Thomson, C., Wamuwi, E., & van Damme, W. (2010). Case study From project aid to sustainable HIV services: A case study from Zambia. *Journal of the International AIDS Society, 13*(19), 1-8. doi:10.1186/1758-2652-13-19

TRAC-Plus (Center for Treatment and Research on AIDS Malaria *Tuberculosis and Other Epidemics) & Rwanda National AIDS Control Commission.* (2010). HIV/AIDS and STIs unit annual report July 2009 - June 2010. Retrieved from http://www.rbc.gov.rw/library/sites/default/files/hiv_aids_and_stis_annual_report_2009_2010.pdf

Traoré, A. T., Querre, M., Brou, H., Leroy, V., Desclaux, A., & Desgrées-du-Loûe, A. (2009). Couples, PMTCT programs and infant feeding decision-making in Ivory Coast. (Special Issue: Women, mothers and HIV care in resource-poor settings). *Social science & medicine, 69*(6), 830-837. doi:10.1016/j.socscimed.2009.06.001

Tsague, L., Tsiouris, F. O., Carter, R. J., Mugisha, V., Tene. G., Nyankesha, E…Abrams, E. J. (2010) Comparing two service delivery models for the prevention of mother-to-child transmission (PMTCT) of HIV during transition from single-dose nevirapine to multi-drug antiretroviral regimens. *BMC Public Health, 10*(753), 1-9. doi:10.1186/1471-2458-10-753

Tuli, F. (2010). The basis of distinction between qualitative and quantitative research in Social Science: Reflection on ontological, epistemological and methodological perspectives. *Ethiopian Journal of Education and Sciences, 6*(1), 1-12. doi:10.4314/ejesc.v6i1.65384

Turan, J. M., & Nyblade, L. (2013). HIV-related stigma as a barrier to achievement of global PMTCT and maternal health goals: A review of the evidence. *AIDS and Behavior, 17*(7), 2528-2539. doi:10.1007/s10461-013-0446-8

Turan, J. M., Elafros, M. A., Logie, C. H., Banik, S., Turan, B., Crockett, K. B... Murrey, S. M. (2019). Challenges and opportunities in examining and addressing intersectional stigma and health. *BMC Medicine, 17*(7), 1-15. doi:10.1186/s12916-018-1246-9

UN Women. (2017). *Facts and figures: HIV and AIDS*. Retrieved from http://www.unwomen.org/en/what-we-do/hiv-and-aids/facts-and-figures

UN. (2012). *Women out loud: How women living with HIV will help the world ends AIDS, in United Nations Joint Programme on HIV/AIDS.* Geneva, Switzerland: Joint United Nations Program on HIV/AIDS (UNAIDS).

UNAIDS. (2017). *Country report overview: The HIV epidemic in Rwanda is generalized*. Retrieved from http://www.unaids.org/sites/default/files/country/documents/RWA_2017_countryreport.pdf

UNAIDS. (2018). *Facts sheet: Latest global and regional statistics on the status of the AIDS epidemic.* World AIDS Day. Retrieved from https://www.unaids.org/en/resources/fact-sheet

UNAIDS. (2019). *Global HIV & AIDS statistics: 2019 fact sheet*. Retrieved from https://www.unaids.org/en/resources/fact-sheet

UNAIDS. (2020). *Start Free Stay Free AIDS Free - 2020 report.* Retrieved from https://www.unaids.org/en/resources/documents/2020/start-free-stay-free-aids-free-2020-progress-report

UNAIDS. (2020a). *UNAIDS data 2020*. Retrieved from https://www.unaids.org/sites/default/files/media_asset/2020_aids-data-book_en.pdf

UNAIDS. (2021). *Global HIV & AIDS statistics: 2020 fact sheet.* Retrieved from https://www.unaids.org/en/resources/factsheet#:~:text=GLOBAL%20HIV%20STATISTICS&text=38.0%20million%20%5B31.6%20million%E2%80%9344.5,AIDS%2Drelated%20illnesses%20in%202019.

United States Department of Health & Human Services. (2011). *Affordable care act to improve data collection, reduce health disparities*. Retrieved from http://www.hhs.gov/news/press/2011pres/06/20110629a.

US Department of State. (2017). *Office of the U.S. global AIDS coordinator and health diplomacy.* Retrieved from https://2009-2017.state.gov/s/gac/

USAID. (2019). *Male Partner Engagement in Antenatal Care and Zika-related Health Care.* Retrieved from https://pdf.usaid.gov/pdf_docs/PA00WH8R.pdf

Van der Straten, A., Musara, P., Etima, J., Woeber, K., Montgomery, E., Hartmann, M… Mensch, B. (2014). Disclosure of Pharmacokinetic (PK) drug results promotes open discourse on non-adherence among women in VOICE. *AIDS Research and Human Retroviruses, 30*(S1), A42-A43. doi:10.1089/aid.2014.5071.abstract.

Van Herk, K. A., Smith, D., & Andrew, C. (2011). Examining our privileges and oppressions: Incorporating an intersectionality paradigm into nursing. *Nursing Inquiry, 18*(1), 29-39. doi:10.1111/j.1440-1800.2011.00539.x

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

Vandenberg, H. R., & Hall, W. A. (2011). Critical ethnography: Extending attention to bias and reinforcement of dominant power relations. *Nurse Researcher, 18*(3), 25-30. doi:10.7748/nr2011.04.18.3.25.c8460

Vansina, J. (2000). Historical Tales (Ibiteekerezo) and the History of Rwanda. *History in Africa 27*(2000), 375-414. doi:10.2307/3172121

VanTyler, S., & Sheilds, L. (2013). Stories of African HIV+ women living in poverty. *Health Care for Women International, 36*(8), 1-15. doi: 10.1080/07399332.2013.862797

Varga, C., & Brookes, H. (2008a). Preventing mother-to-child HIV transmission among South African adolescents. *Journal of Adolescent Research, 23*(2), 172-205. doi:10.1177/0743558407310771

Varga, C., & Brookes, H. (2008b). Factors influencing teen mothers' enrollment and participation in prevention of mother-to-child HIV transmission services in Limpopo Province, South Africa. *Qualitative Health Research, 18*(6), 786-802. doi.org/10.1177/1049732308318449

Veenstra, G. (2011). Race, gender, class, and sexual orientation: Intersecting axes of inequality and self-rated health in Canada. *International Journal for Equity in Health, 10*(3), 1-11. doi:10.1186/1475-9276-10-3

VeneKlasen, L., Miller, V., Budlender, D., & Clark, C. (2002). Power and empowerment. *PLA Notes, 43*, 39-41. Retrieved from https://pubs.iied.org/sites/default/files/pdfs/migrate/G01985.pdf

Vieira, N., Rasmussen, D. N., Inês Oliveira, I., Gomes, A., Aaby, P., Wejse, C…Unger, H. W. (2017). Awareness, attitudes and perceptions regarding HIV and PMTCT amongst pregnant women in Guinea-Bissau- a qualitative study. *BMC Women's Health, 17(*1), 71. doi:10.1186/s12905-017-0427-6

Vieira, N., Rasmussen, N. D., Oliveira, I., Gomes, A., Aaby, P., Wejse, C… Unger, H. W. Awareness, attitudes and perceptions regarding HIV and PMTCT amongst pregnant women in Guinea-Bissau: A qualitative study. *BMC women's health*, *17*(71), 1-11. doi:10.1186/s12905-017-0427-6

Viruell-Fuentes, A. E., Miranda, Y. P., & Abdulrahim, S. (2012). More than culture: Structural racism, intersectionality theory, and immigrant health. *Social Science and Medicine, 75*, 2099-2106. doi:10.1016/j.socscimed.2011.12.037

Wallace, C., Haerpfer, C., Abbott.,P. (2014). Women in Rwandan politics and society. *International Journal of Sociology, 38*(4), 111-125. doi:10.2753/IJS0020-7659380406.

Wang, K., Chen, W. T., Zhang, L., Bao, M., Zhao, H., & Lu, H. (2016). Facilitators of and barriers to HIV self-management: Perspectives of HIV-positive women in China. *Applied Nursing Research, 32*, 91-7. doi:10.1016/j.apnr.2016.06.004

Wang, X., Guo, G., Liang, X., Zhou, L., Zheng, J., Li, S… Lu, L. (2018). Health utility of pregnant women living with HIV/AIDS-Prevention of Mother-to-Child Transmission of HIV (PMTCT) programs in Yunnan province: A cross-sectional study. *Value in Health Regional Issues, 15*(2018), 27-33. doi:10.1016/j.vhri.2017.05.004

Wasti, S. P., Simkhada, P., & Teijlingen, E. R. (2009). Antiretroviral treatment programmes in Nepal: Problems and barriers. *Kathmandu University Medical Journal, 7*(27), 306-314. doi:10.3126/KUMJ.V713.2743

Wasti, S. P., Teijlingen, E. V., Simkhada, P., Randall, J., Baxter, S., Kirkpatrick P… & Gc, V. S. (2012). Factors influencing adherence to antiretroviral treatment in Asian developing countries: A systematic review. *Tropical Medicine & International Health, 17*(1): 71–81. doi:10.1111/j.1365-3156.2011.02888.x

Weaver, K., & Olson, K. J. (2005). Understanding paradigms used in nursing research. *Journal of Advanced Nursing, 53*(4), 459-69. doi:10.1111/j.1365-2648.2006.03740.x

Were, E., Curran, K., Delany-Moretlwe, S., Nakku-Joloba, E., Mugo, N. R., Kiarie, J… Partners in prevention HSVHIV transmission study team. (2011). A prospective study of frequency and correlates of intimate partner violence among African heterosexual HIV serodiscordant couples. *AIDS, 25*(16), 1-19. doi:10.1097/QAD.0b013e32834b005d

Wettstein, C., Mugglin, C., Egger, M., Blaser, N., Vizcaya, L. S., Estill J…Keiser, O. (2012). Missed opportunities to prevent mother-to-child-transmission: systematic review and meta-analysis. *AIDS, 26*(18), 2361–73. doi:10.1097/QAD.0b013e328359ab0c

WHO. (2007). *Prevention of Mother-To-Child Transmission (PMTCT): Briefing note, department of HIV/AIDS.* Retrieved from https://www.who.int/hiv/pub/toolkits/PMTCT%20HIV%20Dept%20brief%20Oct%2007.pdf

WHO. (2013). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: Recommendations for a public health approach June 2013.* Retrieved from: http://apps.who.int/iris/bitstream/handle/10665/44345/?sequence=1

WHO. (2016). *Health literacy: The mandate for health literacy*. Retrieved from https://www.who.int/healthpromotion/conferences/9gchp/health-literacy/en/

WHO. (2017). *HIV/AIDS: Mother-to-child transmission of HIV.* Retrieved from https://www.who.int/hiv/topics/mtct/en/

WHO. (2018). *HIV/AIDS: Key facts.* Retrieved from https://www.who.int/news-room/fact-sheets/detail/hiv-aids

WHO. (2019). *HIV/AIDS: Mother to child transmission of HIV.* Retrieved from https://www.who.int/hiv/topics/mtct/about/en/

WHO. (2020). *HIV/AIDS: Key facts*. Retrieved from https://www.who.int/news-room/fact-sheets/detail/hiv-aids

Woldegiyorgis, B. A., & Scherrer, J. L. (2012). Replacement feeding experiences of HIV-positive mothers in Ethiopia. *Journal of Community Practice, 20*(1), 69-88. doi:10.1080/10705422.2012.648123

Women's Rights & Economic Change. (2004). Intersectionality: A tool for gender and economic justice. *Women's Rights and Economic Change,* (9), 1-9. Retrieved from https://www.awid.org/publications/intersectionality-tool-gender-and-economic-justice

Wood, H. J. (2019). Gender inequality: The problem of harmful, patriarchal, traditional and cultural gender practices in the church. *HTS Teologiese Studies/Theological Studies 75*(1), 1-8. doi:10.4102/hts.v75i1.5177

World Health Organization and London School of Hygiene and Tropical Medicine. (2010). Preventing intimate partner and sexual violence against women: Taking action and generating evidence. *Injury Prevention, 16*(5), 1-102. doi:10.1136/ip.2010.029629

World Population Review. (2019). *Rwanda population 2019.* Retrieved from http://worldpopulationreview.com/countries/rwandapopulation/#targetText=In%202019%2%20the%20population%20is,Rwanda%2076th%20in%20the%20world.

Wouters, E., van-Loon, F., van-Rensburg, D., & Meulemans, H. (2009). Community support and disclosure of HIV serostatus to family members by public-sector antiretroviral treatment patients in the Free State Province of South Africa. *AIDS Patient Care STDs, 23*(5), 357–64. doi:10.1089/apc.2008.0201.

Yakob, B., & Ncama, B. P. (2016). A socio-ecological perspective of access to and acceptability of HIV/AIDS treatment and care services: A qualitative case study research. *BMC Public Health, 16*(155), 1-15. doi:10.1186/s12889-016-2830-6

Zacharius, K. M., Basinda, N., Marwa, K., Mtui, E. H,, Kalolo, A., & Kapesa, A. (2019). Low adherence to Option B + antiretroviral therapy among pregnant women and lactating mothers in eastern Tanzania. *PLoS One, 14*(2), 1-12. doi:10.1371/journal.pone.0212587

Zhu, T., Korber, B. T., Nahmias, A. J., Hooper, E., Sharp, P. M., & Ho, D. D. (1998). An African HIV-1 sequence from 1959 and implications for the origin of the epidemic. *Nature, 5*(391), 594-597. Retrieved from http://docencia.med.uchile.cl/evolucion/practicos/tphivpdfs/hiv-1sequencefrom1959.pdf

Appendix A: Demographic Questions English Version

1. Age ☐☐ years

2. Level of Education

No schooling	
Primary school	
Intermediate	
Secondary school	
College/university	

3. Marital Status

Not married	
Married	
Single mom	
Divorced/separated	
Widow	

4. Women Employment Status

Housewife	
Employed with government	
Employed in the Private Sector	
Employed by a NGO	
Self-Employed/Owner of a Business	
Other (please specify)	

5. Husband Employment Status

Farmer/Agriculture	
Employed with government	
Employed in the Private Sector	
Employed by a NGO	
Self-Employed/Owner of a Business	
Other (please specify)	

6. What is your religion?

Protestant	
Roman Catholic	
Adventist	
Muslim	
Traditional religion	
No religion	
Other (please specify)	

7. When were you tested for the first time for HIV?

Before ANC or pregnancy	
During ANC	

8. How many children do you have? ☐☐

9. How many children have you had since being diagnosed with HIV? ☐☐

10. Is any of your children affected by your HIV status?

Yes	
If yes, how many children?	
No	

11. Is there any children infected while you were enrolled in the PMTCT program?

Yes	
If yes, how many children?	
No	
I do not know	

Appendix A1: Demographic Questions Kinyarwanda Version

Igice cya A1: Ibibazo k’umwirondoro

1. Imyaka ☐☐

2. Urwego rw’amashuri

Ntiyize	
Amashuri abanza	
Amashuri y’imyuga	
Amashuri y’isumbuye	
Kaminuza	

3. Irangamimerere

Sindashyingirwa	
Ndubatse	
Umubyeyi wibana	
Natandukanye n’uwo twashakanye	
Ndi umupfakazi	

4. Imiterere y’akazi k’umugore

Nkora imirimo yo mu rugo	
Nkorera Leta	
Nkorera ikigo cyigenga	
Nkorera umuryango udaharanira inyungu	
Ndikorera ku giti cyanjye	
Nkora ibindi (bivuge)	

5. Imiterere y’akazi k’umugabo

Umuhinzi-mworozi	
Akorera Leta	
Akorere ikigo cyigenga	
Akorera umuryango udaharanira inyungu	
Arikorera ku giti cye	
Akora ibindi (bivuge)	

6. Idini ryawe ni irihe?

Umuporoso	
Umugatolika	
Umudivantisiti w’umunsi wa 7	
Umuyisilamu	
Umunyedini gakondo	
Ntaho nsengera nahamwe	
Ahandi (havuge)	

7. Ni ryari wisuzumushije bwa mbere virusi itera Sida?

Mbere y'uko nsama	
Mu gihe najyaga kwipimisha inda ntwite	

8. Ufite abana bangahe? ☐☐

9. Umaze kumenya ko wanduye agakoko gatera SIDA wabyaye abana bangahe? ☐☐

10. Hari umwe mu bana wabyaye waba ufite ikibazo cya HIV?

Yego	
Niba ari yego, ni bangahe?	
Oya	

11. Haba hari umwana wanduye waramaze kwinjira muri gahunda ya PMTCT?

Yego	
Niba ari yego, ni bangahe?	
Oya	
Simbizi	

Appendix B: Interview Guide HIV+ Mothers English Version

1. Tell me about your life as being a mother.

2. Can you tell me about your health?

3. What do you know about HIV/AIDS?

Probes: Tell me about people's attitudes towards HIV+ mothers (yourself, family, healthcare providers, community, society); in your community when people think they might have HIV what do they do?

Tell me about traditional believes about HIV? About traditional Birth Attendants, about religious believes about HIV; what factors either at the community or the individual level impact on your accessibility to HIV/AIDS information? (Probe factor in terms of cultural, economic and political)

4. Did you disclose your HIV status to someone? Please explain.

Probes: Will disclosure of your HIV status lead to more help or to cope (in family, community, social, PMTCT)?

How will disclosure of your HIV status affect your situation (violence, stigma, discrimination)?

Do you know the HIV status of your partner(s)?

Do you want you HIV status to stay a secret; why or why not? Explain

What has life been like since being diagnosed with HIV?

How is your life like at the moment?

What makes life easier, what makes life harder?

How do you feel about the future?

Tell me about your relation and/or involvement role with your family and community.

5. Can you tell me about your experiences in the PMTCT program? How is the PMTCT program constructed? How did you plan your pregnancy?

Probes: Your experiences during prenatal, perinatal, postnatal; tell me about your experiences of antenatal clinic services?

Tell me your experiences when your labour started.

Tell me what happened in the first few days after your baby was born?

Tell me about your infant feeding practices.

Is there anything that would make it easier for you in future?

Is there anything else you would like to tell me about your experiences/ thoughts about your pregnancy/delivery, any difficulties you had, or about the services you received?

Given your experiences what do you think might make PMTCT of HIV difficult?

Why do you think some women might miss the PMTCT program appointment?

What do you think will make the PMTCT program more effective?

Is there anything you would like to tell me the PMTCT managers or doctors about the program?

6. What would be the most important reason to accept/reject the PMTCT program?

Are there practical or physical barriers in the clinic or in the family or community that make it difficult to attend PMTCT program?

Are there some cultural taboos or gender power relations or religious believes that make it difficult to attend PMTCT program?

Probes: Challenges, barriers: setting (distance, cost), Supports (physical, social, emotional, psychology) from husband, families, community, healthcare providers, and society.

From your experience so far with the PMTCT programme what do you think should be done to improve it?

7. What is your experience with prevention of MTCT of HIV?

Probes: Statistics show that we still have babies who are infected by their mothers, what do you think may be the causes?

8. How can you prevent your baby to be exposed to HIV? Explain.

Probes: Did you attend prenatal, perinatal, and postnatal services with a purpose to prevent MTCT of HIV. Why and why not?

Did you feel at risk of transmitting HIV to your infant? If yes, what can you do to minimise that risk? What support is in the PMTCT program to minimise that risk?

10. Tell me about the barriers which inhibit you to prevent your baby to be exposed to HIV?

How did your environment (husband, families, community, healthcare providers, and society) influence or challenge your PMTCT of HIV?

If you have questions, do you feel you get enough help from a healthcare provider (e.g. traditional medicine use, mixing food)?

11. Barriers you experienced in PMTCT of HIV

Probes: Economy (employment, income, expenses, support, and poverty), culture, gender, power behind it and dependence, education, individual, family, community, health system, and social context factors.

How did the HIV testing and results of your baby affect your life (feeling, negative, positive, challenges)?

12. How does your husband, peers, parents, family, health system, community, society react toward you after MTCT of HIV? Why do you think they act in that way? Describe how you are supported and how you can be best supported.

Probes: Spouse/partner, parents, in low family, other families, community, health system, society, government, PMTCT program.

13. What do you think needs to be done differently in the PMTCT program (family, society, community,) to encourage MTCT of HIV or promote.

Probes: What do you think needs to be done differently in the way we provide the PMTCT services to make it easier and more comfortable for HIV+ women.

Interview Guide will be the same for HIV+ Mothers with or without HIV infant or child, but there is extract different probes for the mothers with HIV negative babies.

What will you tell other HIV+ mothers about MTCT of HIV?

What do you think helps you keep your baby HIV negative?

What support did you get from your environment (husband, family, community, healthcare system, society)?

Tell me about your experiences in using the PMTCT program.

How do you plan your next pregnancy?

From your experience so far with the PMTCT programme what do you think should be done to improve it?

Appendix B1: Interview Guide HIV+ Mothers Kinyarwanda Version

Igice cya B1: Inyoborabiganiro- Ababyeyi barwaye HIV bari muri program bafite abana banduye

1. Nganiriza k’ubuzima bwawe nk’umubyeyi w’umugore. Ubaye uho ute?

2. Ushobora kunsangiza uko ubuzima bwawe bihagaze?

3. Ni iki uzi ku gakoko ka HIV no k’uburwayi bwa SIDA?

Cukumbura umenye: Abantu bafata bate abyeyi babana n’ubwandu bwa Sida (wowe ubwawe, umuryango, abavuzi, abaturanyi, rubanda); abo mubana umunsi kuwundi iyo batekereje ko bashobora kugira agakoko gatera SIDA bakora iki?

Mbwira imyumvire gakondo kubyerekeranye n’ubwandu bwa Sida? Imyumvire ku byerekeye ababyaza ba gakondo bo bayifata bate, Abanyamadini bo bafata SIDA bate? imyemerere y’abantu itandukanye kubyerekeye ubwandu bwa Sida; ni izihe mpamvu haba aho utuye cyangwa se abantu ku giti cyabo zikubuza kubona amakuru cg ubumenyi ukeneye k’ubwandu bwa Sida? (Baza ucukumbure impamvu ureba izishingiye k’umuco, ubukungu na politiki).

4. Hari umuntu wigeze umenera ibanga ryuko wanduye? Nsobanurira.

Cukumbura umenye: Utekereza ko guhishura ko wanduye agakoko gatera Sida byagufasha kubona ubufasha ukeneye cyangwa se kubasha kwiyakira (mu muryango, aho utuye, mu mibereho rusange, muri servisi zifasha ababyeyi banduye Sida kutanduza abana babyara?)

Ni gute guhisura ko wanduye agakoko gatera Sida byagira ingaruka mu mibereho yawe (ihohoterwa, guhabwa akato, guhezwa, kwimwa amahirwe)? Waba uzi uko umugabo wawe cyangwa abo mukorana imibonano mpuzabitsina bahagaze?

Ushaka ko kuba waranduye agakoko gatera SIDA biguma ari ibanga; Niba ari byo kubera iki? Niba udashaka ko biguma ari ibanga nabyo kubera iki? Nsobanurira neza.

Imibereho yawe yahindutse gute nyuma yo kumenyeshwa ko wanduye agakoko gatera Sida?

Byakugendekeye gute ukimara kubwirwa ko wanduye agakoko gatera Sida?

Kuva icyo gihe ni iki cyakoroheye/kigufasha mu buzima? Ni iki cyagukomereye/kikubihiriza ubuzima?

Ni iki utekereza ku ejo hawe hazaza? Wumva imbere hawe hazaba hameze gute kuri wowe?

Ubanye ute n'ubo mu rugo/muryango wawe n'abaturanyi? Wumva uruhare rwawe muri iyo mibanire ari uruhe?

5. Ushobora kumbwira ubuhamya bwawe mu kwitabira gahunda yo kwa muganga ifasha ababyeyi kutanduza abana ubwandu bwa Sida bavuka? Ese iyi gahunda iteye gute/yubatse ite?

Ubusanzwe ni gute wateganyije kubyara uri muri program?

Cukumbura umenye: Reka noneho twibande k'ubuhamya bwawe mbere, mu gihe na nyuma yo kubyara; mbwira uko byakugendekeye mu gihe witabiraga gahunda zo kwisuzumisha mu gihe wari utwite?

Dutekerereze uko byakugendekeye igihe utangiye kujya ku bise.

Dutekerereze uko byagenze nyuma yo kubyara?

Wambwira uburyo wonkeje mo umwana wawe

Ese hari ikindi kintu wumva wifuza (kugira cg kumenya) cyazagufasha mu gihe kiri imbere?

Hari ikindi kintu wumva wifuzaga ku mbwira kubyerekeye uburyo watwise/wabyaye, ingorane wahuye nazo cyangwa se serivisi wahawe?

Ugendeye ku byakubayeho ni iki ubona gituma gahunda yo kwa muganga yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida bavuka igorana?

Ni iki ubona gishobora gutera ababyeyi bamwe kutitabira gahunda yo kwa muganga yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida bavuka?

Ni iki ubona cyatuma gahunda yo kwa muganga yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida ikora neza birushijeho?

Wumva hari ikintu wabwira abayobozi/ abagana bashinzwe gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida?

6. Ni iyihe mpamvu nyamkuru ishobora gutuma uhitamo kwitabira gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida? / Naho se impamvu nyamukuru yatuma ureka cg utitabira gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida ni iyihe?

Haba hari imbogamizi mu mikorere cyangwa indi mipaka ifatika mu mavuriro cyangwa mu muryango cyangwa mu baturanyi zatuma kwitabira gahunda ya PMTCT bigorana?

Ese hari imbogamizi zigaragara yaba ahatangirwa serivisi zo kurinda ababyeyi kwanduza abana ubwandu bwa Sida, mu muryango cyangwa aho utuye zituma bigorana kwitabira gahunda zo kurinda ababyeyi kwanduza abana ubwandu bwa Sida bavuka?

Ese hari kirazira zishingiye ku muco cyangwa ibijyanye ni imibonano mpuzabitsina cyangwa imyemerere ijyanye ni idini bituma bigorana kwitabira gahunda zo kwa muganga zo kurinda ababyeyi kwanduza abana ubwandu bwa Sida?

Cukumbura umenye: Imbogamizi: aho umuntu atuye (intera/urugendo, ikiguzi) ubufasha (ibintu bifatika, gushyigikirwa mu muryango, guhumurizwa, kwitabwaho) inkunga iva k' umugabo, imiryango, aho batuye, abakozi bo kwa muganga, abaturanyi, no muri sosiyeti/abaturage.

ugendekeye k'ubuhamya bwawe mukwitabira gahunza zo kurinda ababyeyi kwanduza abana ubwandu bwa Sida bavuka, ni iki ubona cyakorwa ku gira ngo irusheho gukora neza?

7. Mu gihe umaze ukorana na gahunda ya kurinda ababyeyi kwanduza abana ubwandu bwa Sida, wumva ari iki cyakosorwa kugira ngo irusheho gukora neza?

Cukumbura umenye: Imibare yerekana ko hakiri abana bavukan ubwandu bwa Sida banduje n'ababyeyi babo, ubona ari iki cyaba kibitera?

8. Ni ubuhe bumenyi ufite ku kwirinda ubwandu bw'agakoko gatera SIDA umubyeyi ashobora kwanduza umwana we?

Cukumbura umenye: Wigize witabira sirivisi zo kwa muganga zitangirwa muri gahunda yo kurinda ababyeyi kwanduza abana bavuka ubwandu bwa agakoko gatera Sida, mbere yo gusama, mu gihe wari utwite na nyuma yo kubyara? Niba aribyo kubera iki? Niba ataribyo ni iki cyabiteye?

Wigeze ugira impungenge ko wakwanduza umwana ubwandu bwa agakoko ka Sida? Niba ari yego ni iki wakora kugira ngo ibyo byirindwe? Ni ubuhe bufasha butangirwa muri gahunda zo kwa muganga zo kurinda umubyeyi kwanduza umwana ubwandu bwa Sida?

10. Wambwira inzitizi uhura nazo zakubuza kurinda kwandura agakoko gatera SIDA? Ni gute abo ubana nabo (Umugabo wawe, imiryango, abaturanyi, abavuzi na rubanda muri rusange) bagira uruhare cyangwa baba imbogamizi muri gahunda yawe ya PMTCT y'agakoko gatera SIDA?

Ese iyo ugize ibibazo, wumva ubona ubufasha buhagije buturuka ku bavuzi (urugero: imikoreshereze y'imiti ya gakondo, indyo yuzuye)?

11. Imbogamizi wahuye nazo muri gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa agakoko gatera Sida.

Cukumbura umenye: Ubukungu (kugira akazi ukora, kwinjiza no gukoresha amafranga, inkunga, n'ubukene), umuco, igitsina, ubushobozi bushingira ku gitsina no gukenera abandi, uburezi, umuntu ku giti cye, umuryango, aho atuye, inzego z'ubuzima, n'izindi mpamvu zishingiye ku aho umuntu aherereye.

Ni gute ibisubizo by'isuzuma ryubwandu bwa agakoko gatera Sida by'umwana wawe byakugizeho ingaruka (ibyiyumviro bibi cg se byiza, ingorane byateye)?

12. Ni gute umugabo wawe, inshuti, ababyeyi, umuryango, ubuvuzi, abo mubana, na rubanda babyitwaye bamaze kumenya ko wanduje umwana wawe agakoko gatera SIDA? Ni iki ubona cyabateye kwitwara uko babigaragaje? Dusangize uburyo ufashwa n'uko wifuza gufashwa neza?

Cukumbura umenye: Umugabo wawe/ uwo mukorana imibonano mpuzabitsina, ababyeyi, umuryango washatsemo, indi miryango, aho utuye, inzego z'ubuzima, umuryango mugari, leta, gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida.

13. Ni iki ubona gikwiye kunozwa muri gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida (umuryango, umuryango mugari, aho atuye) mu gushishikariza no guteza imbere gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida?

Cukumbura umenye: Ni iki ubona gikwiye guhinduka/kunozwa mu buryo bwa gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida itangwamo ku girango bibashe korohera ababyeyi babana n'ubwandu bwa Sida bayigana?

Inyoborabiganiro- Ababyeyi barwaye HIV bari muri program bafite abana bidafite ubwandu.

Ni iki wumva uzabwira abandi babyeyi babana n'ubwandu bwa Sida kubyerekeye uburyo umubyeyi yanduza umwana ubwandu bwa Sida?

Ni iki utekereza cyatumye urinda umwana wawe kwandura ubwandu bwa Sida?

Ni ubuhe bufasha wahawe n'aho utuye (k'umugabo wawe, m'umuryango, aho utuye, inzego z'ubuzima, n'umuryango mugari)?

Dusangize ubuhamya bwawe mu kwitabira gahunda yo kwa muganga irinda ababyeyi kwanduza abana ubwandu bwa Sida.

Urateganya gukora ute niwongera gutwita?

Ugendeye k'uburyo ukoresha serivisi zitangirwa muri gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida, ni iki ubona gikwiye kunozwa kugira ngo itangwe neza?

Appendix C: Demographic Questions-Healthcare Providers English Version

1. Age ☐☐ years

2. Employment status

Physician	
Nurse	
Social Worker	
Psychologist	
Other Name:	

3. What is the length of your work experience at the PMTCT program?

6 month - 1 years	
1 – 5 years	
5 – 10 years	
10- 15 years	
Above 15years	

4. Did you choose to work in the PMTCT program?

Yes	
No	
I do not know	

5. How did you get the appointment at the PMTCT program?

Appointed	
Applied and pass exam (Written and/or Interview)	
Rotation	
Upgrading	
Other (please specify)	

6. Did you get training before starting your position at the PMTCT program?

Yes	
No	

If 'yes', please indicate which type of training.

7. Do you get in-services or refresher training related to the PMTCT?

Yes	
No	

If 'yes' Please tell which courses or refresher courses did you receive?

8. If yes, how often do you get in-service/refresher training?

Every quarter	
Every six months	
Every year	
Other (please specify)	

Appendix C1: Demographic Questions-Healthcare Providers Kinyarwanda Version

Igice cya C1: Ibibazo k'umwirondoro-Abakozi bo munzego z'ubuzima

1. Imyaka ☐☐

2. Ubwoko bw'akazi

Umuganga	
Umuforomo/Umuforomokazi	
umusosiyali	
Umujyanama wize ubuzima bwo mu mutwe	
Undi mwuga Izina:	

3. Umaze igihe kingana iki ukora muri gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida?

Hagati y'amezi 6-umwaka 1	
Hagati y'umwaka 1 – 5	
Hagati y'imyaka 5 – 10	
Hagati y'imyaka 10- 15	
Hejuru y'imyaka 15	

4. Ese niwowe wahisemo gukora muri gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida?

Yego	
Oya	
Simbizi	

5. Ni gute wahawe inshingano zo gukora muri gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida?

Narabihawe	
Narasabye nkora ikizami (cyanditse/ikiganiro)	
Narahimuriwe	
Banzamuye mu ntera	
Ibindi(bivuge)	

6. Wigeze uhabwa amahugurwa mbere yo gutangira gukorera muri iyi gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida?

Yego	
Oya	

Niba ari yego, sobanura ubwoko bw'amahugurwa wahawe?

7. Ese ujya uhabwa amahugurwa uri mu kazi cyangwa ayo gusubiramo ayo wahawe mbere?

Yego	
Oya	

Niba ari yego, ni mahugurwa bwoko ki wabonye?

8. Niba ari yego, ni inshuro zingahe uhabwa amahugurwa uri mu kazi cyangwa gusubiramo ayo wahawe mbere?

Buri gihembwe	
Buri mezi 6	
Buri mwaka	
Ibindi (sobanura)	

Appendix D: Interview Guide-Healthcare Providers English Version

1. Can you tell me about your profession and your role in the PMTCT program?

2. Tell me more information about the PMTCT services.

Probes: Do you have specific training on the PMTCT program?

Guide me through the process a woman uses to access the PMTCT services at this facility from the time she comes to the antenatal clinic for the first time to the time she gives birth and then continues HIV care after birth.

Probes: -Counselling -HIV Diagnosis -Laboratory tests: CD4, Viral load, CBC, UECs, LFTs -ARTs -Monthly Visits: Adherence, side effects, disclosure, social and psychological support -Labor and Delivery -Breastfeeding and family planning -Postpartum care and transfer to CTC

3. What specific facility level factors do you think work well to support the implementation of the PMTCT?

Probes: Personnel, Medication and test kit availability/supply issues, Integration of PMTCT into routine care

4. What facility level factors slow down successful implementation?

Probes: Personnel -Clinic set-up -Stigma -Training and Support -Documentation issues -Availability of medication and lab tests.

Do you have any suggestions on what can be done to improve the implementation of Option B+ in your facility and in Tanzania as a whole?

5. Tell about the MTCT of HIV in University Teaching Hospital of Butare PMTCT program.

Probes: Prevalence, contributing factors, economy (employment, income, expenses, support, poverty), culture, gender, power behind it and dependence, education, family, community, health system, and social context factors.

6. How do Healthcare providers relate to HIV+ mother and infant?

Probes: What is the reaction of the husband, families, parents, peers, community, healthcare providers, and society towards an HIV+ mother and her infant?

7. How does the husband, families, healthcare providers, community, and society contribute to the welfare of a HIV+ women and her infant (physical, emotion, spiritual, and psychology support)?

8. How is the relationship between HIV+ women and healthcare providers in terms of PMTCT of HIV (e.g. delivery period, counselling, testing, follow up during prenatal, perinatal, delivery, postnatal period).

9. What initiatives do you take to make sure you are providing your patient with the best possible care (stigma, respect, individual privacy…)?

What do you do if your patient prefers alternative medicine practices (i.e. traditional medicine) instead of ARTs?

10. Do you think the way PMTCT programmes are organized or implemented affect the success of these programmes? Please explain.

11. What are some of the factors either at individual or community levels that affect PMTCT programmes among the HIV+ women?

12. What do you think needs to be done differently in the PMTCT program (family, society, community,) to encourage or promote the PMTCT of HIV; what do you think needs to be done differently in the way we provide the PMTCT services to make it easier and more comfortable for HIV+ women.

Appendix D1: Interview Guide-Healthcare Providers Kinyarwanda Version

Igice cya D1: Inyoborabiganiro-Abakozi bo kwa muganga

1. Ushobora ku nganiriza ku kazi ukora n'inshingano zawe muri gahunda yo kurinda ababyeyi kwanduza aban ubwandu bwa Sida?

2.Nsobanurira neza ibikorwa muri gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida.

Cukumbura umenye: Hari amahugurwa yihariye wabonye kubyerekeye gufasha ababyeyi babana n'ubwandu bwa Sida kutanduza abana bavuka?

Ntekerereza urugendo umubyeyi unyuramo muguhabwa serivisi muri gahunda yo kumurinda kwanduza umwana kuva aje bwa mbere kwisuzumisha inda kugeza abyaye na nyuma amaze kubyara.

Cukumbura umenye: -Ubujyanama- Kumenya ko umuntu afite ubwandu bw'agakoko gatera SIDA-Ibizamini byo uri laboratwari: Umubare w'abasirikare barinda umubiri, Uko ubwandu bungana mu maraso, insoro z'amaraso, Imikorere y'umwijima.

- Imiti igabanya ubukana-Ubwitabire bwa buri kwezi: Gukurikiza amabwiriza- Konsa no kuboneza urubyaro- kwitabwaho nyuma yo kubyara no kohereza abarwayi ku rwego rwisumbuye ho

3. Ni ibihe bintu by'umwihariko ukeka ko byafasha urwego uru n'uru gushyira mu bikorwa gahunda yaPMTCT muburyo budashimishije?

Cukumbura umenye: Abakozi- Uko ivuriro ryubatse- kwiheza- amahugurwa n'inkunga-ibijyanye n'inyandiko-kuboneka kw'imiti n'ibikoreshwa muri laboratwari.

4. N'ibiki ku rwego rw'ivuriro bituma iyi gahunda itagenda neza?

Cukumbura umenye: Abakozi, uko ahatangirwa serivisi za PMTCT hateye-akato-amahugurwa n'ubufasha-ibibazo mu kubika amakuru-iboneka ry'imiti n'ibyifashishwa mu gukora ibizamini bya laboratwari.

Hari ikifuzo ufite k'uburyo ishyirwa mu bikorwa bya Gahunda yo kurinda abana kwandure virusi ya HIV yakorwa neza mu ivuriro ryawe no mu Rwanda muri rusange?

5. Nsobanurira uko ikibazo cy'ubwandu bwa Sida hagati y'umubyeyi-umwana gihagaze muri gahunda yo kurinda ababyeyi kwanduza abana ya CHUB.

Cukumbura umenye: Uko ubwandu buhagaze, impamvu zibitera, ubukungu (kugira akazi, ayo winjiza, ayo ukoresha, impano, ubukene), umuco, igitsina, ubushobozi bushingiye ku gitsina no kugendera ku bandi, uburezi, umuryango, aho umuntu atuye, inzego z'ubuzima, n'izindi mpamvu zikomoka umuryango mugari umuntu abarizwamo.

6. ubona abakozi bo kwa muganga bafata bate umubyeyi wanduye virusi itera Sida n'umwana we?

Cukumbura ubaze: Ni iyihe myitwarire y'umugabo, umuryango, ababyeyi, urungano, abaturanyi, abakozi bo kwa muganga, n'umuryango mugari muri rusange imbere y'umubyeyi ubana n'ubwandu bwa Sida n'umwana?

7.Ni gute umugabo, umuryango, abakozi bo kwa muganga, aho umubyeyi atuye n'umuryango mugari bagira uruhare mu mibereho myiza y'ababyeyi babana n'ubwandu bwa Sida n'abana babo (ubufasha bufatika, guhumurizwa, gukomezwa no kwitabwaho, imitekerereze, inkunga ya amasengesho)?

8.Ubona gute imibanire hagati y'ababyeyi babana n'ubwandu bwa Sida n'abakozi bo kwa muganga (urugero: mu gihe cyo kubyara, ubujyanama, kwisuzumisha, gukurikiranwa igihe cyo gutwita, igihe cyo kubyara na nyuma yo kubyara).

9. Ni ibiki mukora byihariye kugira ngomwumve ko muhaye umubyeyi ubuvuzi bwiza (akato, icyubahiro, kugira ibanga, ibanga ry'umuntu…)?

Ni iki mukora iyo umurwayi ahisemo ubuvuzi butandukanye n'ubusanzwe (urugero: ubuvuzi bwa gakondo) aho gufata imiti igabanya ubukana bwa Sida?

10.Utekereza ko uburyo gahunda yo kurinda ababyeyi kwanduza abana yubatse cyangwa itangwa bigira ingaruka k'ugutuma igera ku intego zayo? Sobanura.

11.Ni izihe mpamvu haba ku rwego rw'umuntu ku giti cye cyangwa aho umuntu atuye zibangamira gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida?

12. Ni iki ubona gikwiriye kunozwa muri gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida (m'umuryango, umuryango mugari, aho ababyeyi batuye) mu kuzamura ireme/mu gushishikariza cyangwa guteza imbere gahunda za PMTC; Ni iki ubona gikwiye kunozwa mu buryo gahunda za PMTCT zikorwa hagamijwe korohereza ababyeyi babana n'ubwandu bwa Sida.

Appendix E: Interview Guide-PMTCT Leaders English Version

1. Tell me about MTCT of HIV in University Teaching Hospital of Butare PMTCT program.

Probes: Prevalence, contributing factors, economy (employment, income, expenses, support, poverty), culture, gender, power behind it and dependence, education, family, community, health system, and social context factors.

2. Tell me about the social norms and cultural practices related to the PMTCT of HIV?

Probes: About people's attitudes towards HIV+ mothers (yourself, family, healthcare providers, community, society); in your community when people think they might have HIV what do they do? Tell me about tradition believes about HIV? About traditional Birth Attendants, about religious believes about HIV; what factors either at community or individual level impact the accessibility to PMTCT program? (Factor in terms of cultural, gender, polygamy, social, families, individual, economic and political)

3. What support systems are in place in this PMTCT program for HIV+ women?

Probes: prenatal, perinatal, postnatal period to prevent HIV transmission.

4. How do people relate to HIV+ mother and infant?

Probes: What is the reaction of the husband, families, parents, peers, community, health system, and society towards an HIV+ mother and her infant?

5. What do you think the PMTCT leaders, husband, families, community, health system, and society can do to help preventing MTCT of HIV?

6. What do you think needs to be done differently in the PMTCT program (family, society, community) to encourage MTCT of HIV or promote; what do you think needs to be done differently in the way we provide the PMTCT services to make it easier and more comfortable for HIV+ women.

Appendix E1: Interview Guide-PMTCT Leaders English Version

Icyiciro cya E1: Inyoborabiganiro-Abayobozi bwa PMTCT

1. Nsobanurira uko ikibazo cy'ubwandu bwa Sida hagati y'umubyeyi-umwana gihagaze muri gahunda yo kurinda ababyeyi kwanduza abana ya PMTCT y'ibitaro bya Kaminuza bya Butare.

Cukumbura umenye: Uko ubwandu buhagaze, impamvu zibitera, ubukungu (kugira akazi, kugira aho umuntu avana amafaranga, gukoresha amafaranga, ubufasha, ubukene), umuco, igitsina, ubushobozi bushingiye ku gitsina no kugendera ku bandi, uburezi, umuryango, aho umuntu atuye, inzego z'ubuzima, n'izindi mpamvu zikomoka umuryango mugari umuntu abarizwamo

2. Mbwira kubyerekeye imyitwarire rusange y'abantu n'imigirire ishingiye k'umuco ifitanye isano na gahunda yo kurinda umubyeyi kwanduza abana ubwandu bwa Sida bavuka?

Cukumbura umenye: Imyitwarire y'abantu imbere y'ababyeyi babana n'ubwandu bwa Sida (wowe ku giti cyawe, umuryango, abakozi bo kwa muganga, aho abantu batuye, umuryango mugari); Ese aho utuye iyo abantu wumva bavuga ko bakora iki baramutse bamenye ko banduye agakoko gatera Sida? Wambwira uko abantu bafata agakoko gatera SIDA muri gakondo yabo:traditional? Naho ababyaza gakondo? Abavuzi ba gihanga, Abanyamadini?Ni iki utekereza ku rwego rw'abaturanyi cyangwa umuntu ku giti cye kibangamira abantu mu kugera kuri gahunda ya PMTCT? (Ibijyanye n'umuco, igitsina, ubuharike, imibereho, imiryango, umuntu ku giti cye, ubukungu cyangwa politiki).

3.Ni ubuhe bufasha buhari muri iyi gahunda yo kurinda ababyeyi kwanduza abana ubwandu bwa Sida zigenewe ababyeyi banduye agakoko gatera Sida?

Cukumbura ubaze: mbere yo gusama, igihe cyo kubyara na nyuma yo kubyara m'ukwirinda kwandura agakoko gatera Sida.

4. Ni gute abantu bitwara imbere y'umubyeyi ubana n'ubwandu bwa Sida n'umwana we?

Cukumbura ubaze: N'iyihe myitwarire y'umugabo, ababyeyi, abandi babyeyi, aho umuntu atuye, inzego z'ubuzima, n'umuryango mugari imbere y'umubyeyi ubana n'ubwandu bwa Sida n'umwana?

5. Utekereza ko abayobozi ba gahunda ya PMTCT, umugabo, imiryango, abaturanyi, ubuvuzi na rubanda bakora iki mu kurinda umubyeyi kwanduza umwana ubwandu bw'agakoko gatera SIDA?

6. Ni iki utekereza ko cyakorwa ku bundi buryo muri gahunda ya PMTCT (umuryango, rubanda, abaturanyi)mu kuzamura ireme rya gahunda ya MTCT y'agakoko gatera SIDA? Ni iki utekereza ko cyakorwa mu bundi buryo mu mikorere ya gahunda ya PMTCT mu korohereza abagore bafite agakoko gatera SIDA no gutuma bumva baguwe neza kurusha ho?

Appendix F: Interview Guide-Policy Makers English Version

1. Tell me about the PMTCT of HIV policies and guidelines.

Probes: Before pregnancy, during prenatal, perinatal, delivery, and postnatal period to prevent MTCT of HIV

2. What support systems are offered by policy makers to support the PMTCT of HIV?

Is the current PMTCT policy supportive of the practices needed? Explain

3. What do you think needs to be done differently in the PMTCT program to encourage MTCT of HIV or promote; what do you think needs to be done differently in the way we provide the PMTCT services to make it easier and more comfortable for HIV+ women.

Appendix F1: Interview Guide-Policy Makers Kinyarwanda Version

Igice cya F1: Inyobora-biganiro: Abashinzwe gushyiraho amategeko n’amabwiriza

1. Tuganirize ku amategeko n’amabwiriza muri gahunda ya PMTCT.

Cukumbura ubaze: Mbere yo gusama, mu gihe cyo gutwita, mu gihe cyo kubyara, na nyuma yo kubyara kubyerekeye ibikorwa byo gukumira ko umubyeyi yanduza umwana ubwandu bwa Sida igihe cyo kubyara.

2. Ni ubuhe bufasha bwihariye butangwa n’abashinzwe gushyiraho amategeko n’amabwiriza mu gushyigikira gahunda yo gurinda umubbyeyi kwanduza umwana ubwandu bwa Sida avuka? Mubona amategeko n’amabwiriza bigenga gahunda yo kurinda umubyeyi kwanduza umwana batanga umurongo bishyigikira ibikorwa bikenewe? Sobanura.

3. Ni iki mubona ko gikenewe kunozwa muri gahunda ya PMTCT kugira ngo bizamure cyangwa biteze imbere gahunda yo kurinda umubyeyi kwanduza umwana ubwandu bwa Sida; Ni iki ubona gikwiye kunozwa mu buryo serivisi za PMTCT zitangwa kugira ngo byorohere ababyeyi babana n’ubwandu bwa Sida?

Appendix G: Ethnographic Observation Tool English Version

Instructions for observation: Use a separate observation tool form for each observation session.

Physical space: (e.g., include location for action, places where people act, where events are held)

People involved: (e.g. includes anything that might indicate membership in groups or in sub-populations of interest to the study, such as roles, social status, socioeconomic class, religion, or ethnicity)

Activities:

Actions/Behaviors: (e.g., includes nonverbal behavior/nuances and outcomes/results of actions. How people use their bodies and voices to communicate different emotions; what individuals' behaviors indicate about their feelings toward one another.)

Objects: (e.g. information/resources and include function/uses for the object)

Events: (e.g. Regular or irregular/formal and informal, sequencing of event or interruption)

Time: (e.g. season, month, day, time of the day 'morning, afternoon, or evening')

Goals people are trying to accomplish: (and rationale)

Adapted from: Spradley, J. (1980). *Participants' observation*. NY: Holt Reinheart & Winston

Appendix G: Ethnographic Observation Tool Kinyarwanda Version

Igice cya G: Inyobora kwitegereza hagamijwe gusesengura imico n'imyitwarire y'abantu

Amabwiriza ngenderwaho mu kwitegereza: Koresha inyobora kwitegereza yihariye buri gihe witegereza ibikorwa n'imyitwarire y'abantu.

Aho igikorwa kibera:(urugero: garagaza ahantu byabereye**,** ahantu abantu bahurira, aho ibikorwa byabereye)

Abantu babigizemo uruhare:(urugero: erekana niba umuntu ari umunyamuryango mu ma tsinda runaka cyangwa niba ari mu itsinda rikorwaho ubushakashatsi, urugero inshingano, umwanya muri sosiyeti, icyiciro cy'ubukungu, idini cyangwa ubwoko)

Ibikorwa:

Ibikorwa/imyitwarire: (Urugero: erekana imyitwarire igaragarira mu bimenyetso n'ingaruka z'ibikorwa. Ni gute abantu bakoresha imibiri n'amajwi yabo mu kugaragaza amarangamutima atandukanye; n'iyihe myitwarire y'abantu igaragaza ibyumviro byabo iyo barikumwe n'abandi.

Ibikoresho: (urugero: amaakuru/ibyifashishwa n'akamaro k'ibyo bikoresho.

Amahuriro: (urugero: amahuriro/ibikorwa bisanzwe n'ibidasanzwe, uko bikurikirana cyangwa bisubikwa/bikererwa).

Igihe: (urugero: igihe cy'ihinga, ukwezi, umunsi, igihe cy'umunsi "igitondo, nyuma ya saa sita cg umugoroba")

Intego abantu bagamije kugeraho: (n'impamvu)

Byakuwe mu gitabo cya: Spradley, J. (1980). *Participants' observation*. NY: Holt Reinheart & Winston

Appendix H: Information Letter and Consent Form for the Individual Interview Mothers

English Version

Study Title: Experiences of Mothers Using the Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent HIV Transmission in Rwanda.

Research Investigator:
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Background

Worldwide, HIV is an illness that causes many illness with women during the years that they are having babies. Mothers who have HIV can transfer it to their babies during pregnancy, delivery, and breastfeeding. The worldwide plan is to stop mother-to-child transfer of HIV through care given to you and your children. The prevention of mother-to-child transmission (PMTCT) program started in 2000 and can stop HIV among children. An effort has been put into the PMTCT program to make it better, but we still have many babies that become HIV+, especially in Rwanda. There is a need to understand the reasons why the PMTCT program in Rwanda is not working for mothers. The study will be conducted at the University Teaching Hospital of Butare, especially in the PMTCT program.

You are being asked to be in this study because you understand the experiences of mothers using the PMTCT Program to stop HIV transfer. What we learned from you, will help us to plan how the PMTCT program can be better to decrease the transfer of HIV to your children. Furthermore, the lessons learned will be used in support of my education.

Purpose

The reason for this this study is to learn about your experiences of being a mother using the PMTCT Program. I believe that the lessons learned will help in understanding the difficulties of using the PMTCT program and help us to make the program easier to use.

Study Procedures

I am asking you to have a conversation that will be between one to two hours. The conversation will be recorded.

Benefits

This study will not help you immediately, but the hope is that the program will improve and help other mothers and their babies. The findings will impact on planning future PMTCT programs. You will receive 2000 RWF (Rwandan Francs) for participation.

Risk

There will be no harm to you. There may be dangers to being in this study that are not known. If we learn anything during the conversation that may upset your, you can stop the conversation at any time without telling me the reason.

Voluntary Participation

The participants will be told that participating in this research will be free and voluntary and will have the right to withdraw from the study at any time without any negative consequences. The individual participants will have the opportunity to withdraw their data till one-month period after the interview happens. They will be informed during the consent process that they can do that by communicating their wishes to the researcher. The participants may feel uncomfortable to be recorded and they have the right to decline the recording. In that case, the researcher will have to do handwriting. The people participating in the focus group will not have the option to withdraw the data, but they can discontinue to participate in the focus group but it will be difficulty to withdraw the data out of the group discussion.

Confidentiality & Anonymity

The learnings will be used in my education. I will talk to other students and professors about what I have learned. We will not know who has said what. All your information will be locked on my machine and only me teachers we see it when they ask. No other women will know what you have told me. All the information will be kept for five years in secure place at the University of Alberta. After five years, the information will be destroyed.

At the completion, a copy of a report of the learnings will be available at the PMTCT program, at BUTH, and at the University of Alberta. We may use the learnings from this education in future work, but will ask permission from the consent committees.

Further Information

- If you have any other questions regarding this education, please do not hesitate to contact the researcher at +250785325142 or her professor +17804927953.
- The study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your reasons to take part, you can call +17804922615. This office is open for any questions.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have more questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

____ ________________

Participant's Name (printed) and Signature Date

Appendix H1: Information Letter and Consent Form for the Individual Interview Mothers

Kinyarwanda Version

Igice cya H: Ibaruwa sobanura-mpamvu y'ubushakashatsi n'inyandiko y'ubwumvikane igenewe umubyeyi witabiriye ubushakashatsi

Inyito w'ubushakashatsi: Ubuhamya n' imibereho by'ababyeyi bakoresha serivisi zo muri gahunda yo kurinda umubyeyi kwanduza umwana agakoko ka Sida(PMTCT) mu kwirinda ikwirakwira ry'ubwandu bw'agakoko gatera Sida mu Rwanda.

Umushakashatsi:	**Umuyobozi w'ubushakashatsi:**
Joyce Kamanzi Ishami ryigisha abaforomo Kaminuza y'Alberta 11405 87 Avenue Edmonton, AB, T6J 1A4 kamanzi@ualberta.ca +250785325142	Dr. Solina Richter Ishami ryigisha abaforomo University of Alberta 11405 87 Avenue Edmonton, AB, T6J 1A4 solina.richter@ualberta.ca +1 7804927953

Imvo n'imvano

Ku isi yose, ubwandu bwa Sida n'indwara itera izindi ndwara nyinshi ziyishamikiyeho ku babyeyi mu myaka baba bayara mo abana. Ababyeyi babana n'ubwandu bwa Sida bashobora kuyanduza abana babo mu gihe batwite, mu gihe cyo kubyara ndetse no mugihe cyo konsa. Gahunda iriho ku isi yose, ni uguhagarika ubwandu bwa Sida hagati y'umubyeyi n'umwana binyuze mu bufasha/buvuzi mu habwa mwebwe n'abana banyu. Gahunda yo kurinda umubyeyi kwanduza umwana agakoko gatera Sida(PMTCT) yatangiye muri 2000 maze ishobora gukumira ko abana benshi bandura agakoko gatera Sida. Imbaraga nyinshi zashyizwe muri gahunda ya PMTCT ku gira ngo ishobore gukora neza ariko n'ubu haracyari abana benshi bandura agakoko gatera Sida, by'umwihariko mu Rwanda.Hakenewe gusobanukirwa impamvu gahunda ya kurinda ababyeyi kwanduza abana agakoko gatera Sida (PMTCT) idafasha ababyeyi neza uko biba byitezwe. Ubu bushakashatsi buzakorerwa mu bitaro bya Kaminuza bya Butare, by'umwihariko muri gahunda ya PMTCT.

Turagusaba kugira uruhare muri ubu bushakashatsi kubera ko usobanukiwe neza serivisi zihabwa ababyeyi muri gahunda ya PMTCT igamije gukumira ubwandu bw'agakoko gatera Sida.Amakuru n'ubuhamya uzadusangiza bizafasha mugutuma hanozwa imikorere ya gahunda ya PMTCT bityo bigabanye ibyago byo kwanduza abana agakoko gatera Sida. Ikindi, ni uko ibyo nzamenyera muri ubu bushakashatsi bizamfasha mu masomo yanjye mu ishuri.

Ikigamijwe

Impamvu z'ubu bushakashatsi ni ugusobanukirwa ubuhamya n'imibereho by'ababyeyi bitabira serivisi za gahunda yo kurinda ababyeyi kwanduza abana agakoko gatera Sida(PMTCT). Nizeye ko amasomo azava muri ubu bushakashatsi azafasha mu gusobanukirwa ingorane ababyeyi bitabira gahunda ya PMTCT bahura nazo bityo bikazashingirwa mu kunoza uko gahunda yanogera ababyeyi bayigana.

Uko ubushakashatsi bukorwa

Nagusaba ga ko tugirana ikiganiro kiri bumare hagati y'isaha imwe n'amasaha abiri. Kandi amajwi y'ikiganiro ndaba nyafata n'icyuma cyabigenewe.

Inyungu

Nta nyungu zako kanya uribubone zivuye muri ubu bushakashatsi. Cyakoze hari ikizere ko gahunda ya PMTCT izanozwa igakora neza bityo bikazafasha abandi babyeyi n'abana babo bazayigana mu gihe kizaza. Ibizava mu bushakashatsi bizashingirwa ho mu gukora igenamigambi rya PMTCT.Urahabwa amafaranga y'u Rwanda 2,000 nk'agahimbaza mushyi ko wagize uruhare muri ubu bushakashatsi.

Ingorane

Nta nkurikizi zihari zo kugira uruhare muri ubu bushakashatsi. Nyamara hashobora kuvuka impamvu zitatekerejweho hagati mu kiganiro. Mu gihe bibaye ngombwa hagati mu kiganiro ko hari ikintu kibi cyakubayeho wibutse kikagukomeretsa, ufite uburenganzira bwo kurekeraho kuvuga ako kanya utiriwe unsobanurira impamvu.

Ubushake mukugira uruhare m'ubushakashatsi

Nta mpamvu n'imwe iguhatira kugira uruhare muri ubu bushakashatsi. Ni ubushake ubwawe kugira uruhare kandi ushobora kubikora cyangwa kubireka. Si ngombwa ko unsubiza kandi ntugomba no kwisobanura impamvu ubikoze. Ni ubwo wakwemera kugira uruhare, ushobora guhagarika gukomeza gusubiza ubushakashatsi igihe icyo aricyo cyose. Mu gihe kandi usubitse gukomeza kugira uruhare mu bushakashatsi, ibyo uraba wavuze byose bizahita biteshwa agaciro igihe ubyifuje. Ushobora gusaba ko amaakuru watanze yose ateshwa agaciro kugeza muri Gicurasi 2020.

Ukugira ibanga no kutagaragaza irangamimerere y'ugira uruhare mu bushakashatsi

Ibizava muri ubu bushakashatsi bizifashishwa mu masomo yanjye ku ishuri. Nzasangiza abanyeshiru bagenzi banjye n'abarimu ibyo nzaba namenyeye muri ubu bushakashatsi. Uwatanze amakuru ntazigera amenyekana. Amakuru uzatanga nzayabika muri mashini yanjye kandi uretse njye na mwarimu wanjye nawe igihe abisabye, nta wundi uzayabona. Nta bandi babyeyi bazigera bamenya ibyo twaganiriye. Amakuru yose uzatanga azabikwa neza ahantu hatekanye mu gihe cy'imyaka 5 muri kaminuza ya Alberta.Nyuma y'imyaka itanu ayo makuru azateshwa agaciro. Igihe ubushakashatsi buzaba burangiye, kopi ya raporo y'ibyavuyemo izashyikirizwa gahunda ya PMTCT mu kigo cy'ubuvuzi no kwigisha ku rwego rwa Kaminuza cya Butare ndetse no muri kaminuza ya Alberta. Dushobora kwifashisha kandi ibizava muri ubu bushakashatsi mu masomo yanjye y'igihe kizaza ariko icyo gihe nzabisabira uruhushya mu nzego zibishinzwe.

Andi makuru

- Mu gihe hari ibindi bibazo birebana n'ubu bushakashatsi,wahamagara umushakashatsi kuri izi nimero za telefoni: +250785325142 cyangwa se mwarimu we kuri +17804927953.
- Ubu bushakashatsi bwagenzuwe kandi busuzumwa n'inama ishinzwe imyitwarire m'ubushakashatsi muri kaminuza ya Alberta.Uramutse ufite ibibazo ku mpamvu yo kugira uruhare mu bushakashatsi wahamagara kuri iyi nimero ya telefoni: +17804922615.Iyi serivisi ihora yiteguye kwakira ibibabazo ibyo aribyo byose.

Indahiro y'ubwumvikane

Nasomye ibyanditse byose kuri uru rupapuro kandi nasobanuriwe neza ibyerekeye ubu bushakashatsi byose. Nahawe n'umwanya wo kubaza ibibazo ku byo ntarinsobanukiwe kandi nanyuzwe n'ibisubizo nahawe. Nemeye rero k'ubushake bwanjye kugira uruhare muri ubu bushakashatsi nk'uko nasobanuriwe hejuru kandi nasezeranijwe ko ndibuhabwe na kopi y'uru rupapuro rw'ubwumvikane mu kugira uruhare mu bushakashatsi maze kubusinyaho.

____ ________________

Izina ry'uwitabiriye ubushakashatsi (printed) n'umukono Itariki

Appendix I: Information Letter and Consent Form for the Focus Groups (healthcare providers, PMTCT leaders, and policymakers) English Version

Study Title: Experiences of Mothers Using Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent HIV Transmission in Rwanda.

Research Investigator:
Joyce Kamanzi
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11405 87 Avenue
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kamanzi@ualberta.ca
+250785325142

Supervisor:
Dr. Solina Richter
Faculty of Nursing
University of Alberta
11405 87 Avenue
Edmonton, AB, T6J 1A4
solina.richter@ualberta.ca
+1 780 492 7953

Background

Over 90% of children are infected with HIV through MTCT. In 2017, 11 000 children were newly infected of HIV in Rwanda (UNAIDS, 2017). In 2018, 156 HIV+ children attend PMTCT program at CHUB (CHUB, 2018). The study will be conducted in University Teaching Hospital of Butare/especially in PMTCT program. You are being asked to be in this study because you have valuable view that may contributes to better understanding the experiences of mothers using the PMTCT Program to prevent HIV transmission in Rwanda. The results from this study will help to develop strategies on how PMTCT program can be implemented more effectively with a result to reduce MTCT of HIV and promote maternal and child wellbeing. Furthermore, results of this study will be used in support of my doctoral thesis.

Purpose

The purpose of this study is to explore the experiences of mothers using the PMTCT Program to prevent HIV transmission in Rwanda. I believe that the results will help better identify the factors that influence and challenge the uptake of the PMTCT, exploring the role of health services in supporting women in PMTCT program; critically examining the experiences of mothers during the pre-, peri-, and postnatal period to prevent HIV transmission; describing how PMTCT program can be implemented effectively.

Study Procedures

You are invited to be participate in a focus group discussion. The interview will last one to two hours. The interview will be audio recorded. In addition to the interview, the researcher will collect data using observation.

Benefits

You will not have immediate benefit from being in this study. I hope that the information we get from doing this study will help us better understand the experiences of mothers using the PMTCT Program to prevent HIV transmission in Rwanda. The findings will impact on policy formulation for addressing the issue of MTCT of HIV in Rwanda. By being part of this research study, a research team will appreciate your time and there will be reimbursement of your transport by $5 (2000 Rwandan Francs).

Risk

There will be no harm to you. If we learn anything during the conversation that may upset your, you can stop participating at any time without telling me the reason.

Voluntary Participation

Your participation in this research is free and voluntary and you have the right to withdraw from the study at any time without any negative consequences. The people participating in the focus group will not have the option to withdraw the data, but they can discontinue to participate in the focus group, but it will be difficulty to withdraw the data out of the group discussion. The participants may feel uncomfortable to be recorded and they have the right to decline the recording. In that case, the researcher will have to do handwriting.

Confidentiality & Anonymity

The findings from this study will be used in a thesis report and in research articles as well as presentations. No individual identifying information will be used in any of the information that I will use. The data will be kept confidential, only research team members will access the data. Anonymity cannot be guaranteed in group context as you will participate in a focus group discussion; however, beside people who will participate with you in the same group on the time of data collection, no other person will know what you have shared.

At the completion of this study, the data will be kept for five years in secure drive at the University of Alberta and in a locked cabinet where the key will be accessible only by researcher and research supervisor. After five years, the data will be destroyed in a way that ensures privacy and confidentiality. At the completion, a copy of a report of the research findings will be available at the PMTCT program, at University Teaching Hospital of Butare, and at the University of Alberta. We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board.

Further Information

- If you have any further questions regarding this study, please do not hesitate to contact researcher, Ms J. Kamanzi at +1 780 266 9538 or research supervisor, Dr. Solina Richter at +1780 492 7953.
- The study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call +1 780 492-2615. This office is independent of the researchers."

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

Participant’s Name (printed) and Signature	Date
Witness Name (printed) and Signature	Date

Appendix I1: Information Letter and Consent Form for the Focus Groups (healthcare providers, PMTCT leaders, and policymakers) Kinyarwanda Version

Igice cya I1: Ibaruwa Isobanura Impamvu y'Ubushakashatsi n'Inyandiko y'Ubwumvikane Igenewe Umubumbe W'Abakozi Witabiriye Ubushakashatsi

Inyito w'ubushakashatsi: Ubuhamya Bwatanzwe n'abakozi bakora muri serivisi zo muri gahunda yo kurinda umubyeyi kwanduza umwana agakoko ka Sida (PMTCT) mu kwirinda ikwirakwira ry'ubwandu bw'agakoko gatera Sida mu Rwanda.

Umushakashatsi:	**Umuyobozi w'ubushakashatsi:**
Joyce Kamanzi Ishami ryigisha abaforomo Kaminuza y'Alberta 11405 87 Avenue Edmonton, AB, T6J 1A4 kamanzi@ualberta.ca +250785325142	Dr. Solina Richter Ishami ryigisha abaforomo University of Alberta 11405 87 Avenue Edmonton, AB, T6J 1A4 solina.richter@ualberta.ca +1 7804927953

<u>*Imvo n'imvano*</u>

Ku isi yose, ubwandu bwa Sida n'indwara itera izindi ndwara nyinshi ziyishamikiyeho ku babyeyi mu myaka baba bayara mo abana. Ababyeyi babana n'ubwandu bwa Sida bashobora kuyanduza abana babo mu gihe batwite, mu gihe cyo kubyara ndetse no mugihe cyo konsa. Gahunda iriho ku isi yose, ni uguhagarika ubwandu bwa Sida hagati y'umubyeyi n'umwana binyuze mu bufasha/buvuzi mu habwa mwebwe n'abana banyu. Gahunda yo kurinda umubyeyi kwanduza umwana agakoko gatera Sida(PMTCT) yatangiye muri 2000 maze ishobora gukumira ko abana benshi bandura agakoko gatera Sida. Imbaraga nyinshi zashyizwe muri gahunda ya PMTCT ku gira ngo ishobore gukora neza ariko n'ubu haracyari abana benshi bandura agakoko gatera Sida, by'umwihariko mu Rwanda.Hakenewe gusobanukirwa impamvu gahunda ya kurinda ababyeyi kwanduza abana agakoko gatera Sida (PMTCT) idafasha ababyeyi neza uko biba byitezwe. Ubu bushakashatsi buzakorerwa mu bitaro bya Kaminuza bya Butare, by'umwihariko muri gahunda ya PMTCT.

Turagusaba kugira uruhare muri ubu bushakashatsi kubera ko usobanukiwe neza serivisi zihabwa ababyeyi muri gahunda ya PMTCT igamije gukumira ubwandu bw'agakoko gatera Sida.Amakuru n'ubuhamya uzadusangiza bizafasha mugutuma hanozwa imikorere ya gahunda ya PMTCT bityo bigabanye ibyago byo kwanduza abana agakoko gatera Sida. Ikindi, ni uko ibyo nzamenyera muri ubu bushakashatsi bizamfasha mu masomo yanjye mu ishuri.

Ikigamijwe

Impamvu z'ubu bushakashatsi ni ugusobanukirwa ubuhamya n'imibereho by'ababyeyi bitabira serivisi za gahunda yo kurinda ababyeyi kwanduza abana agakoko gatera Sida(PMTCT). Nizeye ko amasomo azava muri ubu bushakashatsi azafasha mu gusobanukirwa ingorane ababyeyi bitabira gahunda ya PMTCT bahura nazo bityo bikazashingirwa mu kunoza uko gahunda yanogera ababyeyi bayigana.

Uko ubushakashatsi bukorwa

Nagusaba ga ko tugirana ikiganiro kiri bumare hagati y'isaha imwe n'amasaha abiri. Kandi amajwi y'ikiganiro ndaba nyafata n'icyuma cyabigenewe.

Inyungu

Nta nyungu zako kanya uribubone zivuye muri ubu bushakashatsi. Cyakoze hari ikizere ko gahunda ya PMTCT izanozwa igakora neza bityo bikazafasha abandi babyeyi n'abana babo bazayigana mu gihe kizaza. Ibizava mu bushakashatsi bizashingirwa ho mu gukora igenamigambi rya PMTCT.Urahabwa amafaranga y'u Rwanda 2,000 nk'agahimbaza mushyi ko wagize uruhare muri ubu bushakashatsi.

Ingorane

Nta nkurikizi zihari zo kugira uruhare muri ubu bushakashatsi. Nyamara hashobora kuvuka impamvu zitatekerejweho hagati mu kiganiro. Mu gihe bibaye ngombwa hagati mu kiganiro ko hari ikintu kibi cyakubayeho wibutse kikagukomeretsa, ufite uburenganzira bwo kurekeraho kuvuga ako kanya utiriwe unsobanurira impamvu.

Ubushake mukugira uruhare m'ubushakashatsi

Nta mpamvu n'imwe iguhatira kugira uruhare muri ubu bushakashatsi. Ni ubushake ubwawe kugira uruhare kandi ushobora kubikora cyangwa kubireka. Si ngombwa ko unsubiza kandi ntugomba no kwisobanura impamvu ubikoze. Ni ubwo wakwemera kugira uruhare, ushobora guhagarika gukomeza gusubiza ubushakashatsi igihe icyo aricyo cyose. Mu gihe kandi usubitse gukomeza kugira uruhare mu bushakashatsi, ibyo uraba wavuze byose bizahita biteshwa agaciro igihe ubyifuje. Ushobora gusaba ko amaakuru watanze yose ateshwa agaciro kugeza muri Gicurasi 2020.

Ukugira ibanga no kutagaragaza irangamimerere y'ugira uruhare mu bushakashatsi

Ibizava muri ubu bushakashatsi bizifashishwa mu masomo yanjye ku ishuri. Nzasangiza abanyeshiru bagenzi banjye n'abarimu ibyo nzaba namenyeye muri ubu bushakashatsi. Uwatanze amakuru ntazigera amenyekana. Amakuru uzatanga nzayabika muri mashini yanjye kandi uretse njye na mwarimu wanjye nawe igihe abisabye, nta wundi uzayabona. Nta bandi babyeyi bazigera bamenya ibyo twaganiriye. Amakuru yose uzatanga azabikwa neza ahantu hatekanye mu gihe cy'imyaka 5 muri kaminuza ya Alberta.Nyuma y'imyaka itanu ayo makuru azateshwa agaciro. Igihe ubushakashatsi buzaba burangiye, kopi ya raporo y'ibyavuyemo izashyikirizwa gahunda ya PMTCT mu kigo cy'ubuvuzi no kwigisha ku rwego rwa Kaminuza cya Butare ndetse no muri kaminuza ya Alberta. Dushobora kwifashisha kandi ibizava muri ubu bushakashatsi mu masomo yanjye y'igihe kizaza ariko icyo gihe nzabisabira uruhushya mu nzego zibishinzwe.

Andi makuru

- Mu gihe hari ibindi bibazo birebana n'ubu bushakashatsi,wahamagara umushakashatsi kuri izi nimero za telefoni: +250785325142 cyangwa se mwarimu we kuri +17804927953.
- Ubu bushakashatsi bwagenzuwe kandi busuzumwa n'inama ishinzwe imyitwarire m'ubushakashatsi muri kaminuza ya Alberta.Uramutse ufite ibibazo ku mpamvu yo kugira uruhare mu bushakashatsi wahamagara kuri iyi nimero ya telefoni: +17804922615.Iyi serivisi ihora yiteguye kwakira ibibabazo ibyo aribyo byose.

Indahiro y'ubwumvikane

Nasomye ibyanditse byose kuri uru rupapuro kandi nasobanuriwe neza ibyerekeye ubu bushakashatsi byose. Nahawe n'umwanya wo kubaza ibibazo ku byo ntarinsobanukiwe kandi nanyuzwe n'ibisubizo nahawe. Nemeye rero k'ubushake bwanjye kugira uruhare muri ubu bushakashatsi nk'uko nasobanuriwe hejuru kandi nasezeranijwe ko ndibuhabwe na kopi y'uru rupapuro rw'ubwumvikane mu kugira uruhare mu bushakashatsi maze kubusinyaho.

____ _______________

Izina ry'uwitabiriye ubushakashatsi (printed) n'umukono Itariki

Appendix J: Information Letter and Consent Form for the Individual Interview Apart of HIV+ Mothers in Case of Insufficient Numbers to conduct a Focus Group (Policy makers and PMTCT leaders and healthcare providers) English Version

Study Title: Experiences of Mothers Using Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent HIV Transmission in Rwanda.

Research Investigator:	**Supervisor:**
Joyce Kamanzi	Dr. Solina Richter
Faculty of Nursing	Faculty of Nursing
University of Alberta	University of Alberta
11405 87 Avenue	11405 87 Avenue
Edmonton, AB, T6J 1A4	Edmonton, AB, T6J 1A4
kamanzi@ualberta.ca	solina.richter@ualberta.ca
+250785325142	+1 780 4927953

Background

Over 90% of children are infected with HIV through MTCT. In 2017, 11 000 children were newly infected of HIV in Rwanda (UNAIDS, 2017). In 2018, 156 HIV+ children attend PMTCT program at CHUB (CHUB, 2018). The study will be conducted in University Teaching Hospital of Butare/especially in the PMTCT program. You are being asked to be in this study because you have valuable view that may contributes to better understanding the experiences of mothers using the PMTCT Program to prevent HIV transmission in Rwanda. The results from this study will help to develop strategies on how the PMTCT program can be implemented more effectively with a result to reduce MTCT of HIV and promote maternal and child wellbeing. Furthermore, results of this study will be used in support of my doctoral thesis.

Purpose

The purpose of this study is to explore the experiences of mothers using the PMTCT Program to prevent HIV transmission in Rwanda. I believe that the results will help in better identifying the factors that influence and challenge the uptake of the PMTCT, exploring the role of health services in supporting women in the PMTCT program; critically examining the experiences of mothers during the prenatal, perinatal, and postnatal period to prevent HIV transmission; describing how the PMTCT program can be implemented effectively.

Study Procedures

I am asking you to have a conversation that will be between one to two hours. The conversation will be recorded.

Benefits

This study will not help you immediately, but the hope is that the program will improve and help other mothers and their babies. The findings will impact on planning future PMTCT programs. You will receive 2000 RWF (Rwandan Francs) for participation.

Risk

There will be no harm to you. If we learn anything during the conversation that may upset you, you can stop the conversation at any time without telling me the reason.

Voluntary Participation

Your participation in this research is free and voluntary and you have the right to withdraw from the study at any time without any negative consequences. You will have the opportunity to withdraw the information shared until one-month period after the interview occurred. You can tell me anytime that you want to stop participating. The participants may feel uncomfortable to be recorded and they have the right to decline the recording. In that case, the researcher will have to do handwriting.

Confidentiality & Anonymity

The learnings will be used in my education. I will talk to other students and professors about what I have learned. We will not know who has said what. All your information will be locked on my machine and only my teachers we see it when they ask. No other women will know what you have told me. All the information will be kept for five years in a secret place at the University of Alberta. After five years, the information will be destroyed.

At the completion, a copy of a report of the learnings will be available at the PMTCT program, at University Teaching Hospital of Butare, and at the University of Alberta. We may use the learnings from this education in future work but will ask permission from the consent committees.

Further Information

- If you have any further questions regarding this study, please do not hesitate to contact researcher at +250785325142 or research supervisor at +1780 492 7953.
- The study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call +1 780 492-2615. This office is independent of the researchers."

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

____	_______________
Participant’s Name (printed) and Signature	Date
____	_______________
Witness Name (printed) and Signature	Date

Appendix J1: Information Letter and Consent Form for the Individual Interview Apart of HIV + Mothers in Case of Insufficient Numbers to conduct a Focus Group (Policy makers and PMTCT leaders and healthcare providers) Kinyarwanda Version

Igice cya J1: Ibaruwa Isobanura Impamvu y'Ubushakashatsi n'Inyandiko y'Ubwumvikane Igenewe Umubyeyi Witabiriye Ubushakashatsi

Inyito w'ubushakashatsi: Ubuhamya n' imibereho by'ababyeyi bakoresha serivisi zo muri gahunda yo kurinda umubyeyi kwanduza umwana agakoko ka Sida(PMTCT) mu kwirinda ikwirakwira ry'ubwandu bw'agakoko gatera Sida mu Rwanda.

Umushakashatsi:

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Ishami ryigisha abaforomo
Kaminuza y'Alberta
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kamanzi@ualberta.ca
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Umuyobozi w'ubushakashatsi:

Dr. Solina Richter
Ishami ryigisha abaforomo
University of Alberta
11405 87 Avenue
Edmonton, AB, T6J 1A4
solina.richter@ualberta.ca
+1 7804927953

<u>*Imvo n'imvano*</u>

Ku isi yose, ubwandu bwa Sida n'indwara itera izindi ndwara nyinshi ziyishamikiyeho ku babyeyi mu myaka baba bayara mo abana. Ababyeyi babana n'ubwandu bwa Sida bashobora kuyanduza abana babo mu gihe batwite, mu gihe cyo kubyara ndetse no mugihe cyo konsa. Gahunda iriho ku isi yose, ni uguhagarika ubwandu bwa Sida hagati y'umubyeyi n'umwana binyuze mu bufasha/buvuzi mu habwa mwebwe n'abana banyu. Gahunda yo kurinda umubyeyi kwanduza umwana agakoko gatera Sida(PMTCT) yatangiye muri 2000 maze ishobora gukumira ko abana benshi bandura agakoko gatera Sida. Imbaraga nyinshi zashyizwe muri gahunda ya PMTCT ku gira ngo ishobore gukora neza ariko n'ubu haracyari abana benshi bandura agakoko gatera Sida, by'umwihariko mu Rwanda.Hakenewe gusobanukirwa impamvu gahunda ya kurinda ababyeyi kwanduza abana agakoko gatera Sida (PMTCT) idafasha ababyeyi neza uko biba byitezwe. Ubu bushakashatsi buzakorerwa mu bitaro bya Kaminuza bya Butare, by'umwihariko muri gahunda ya PMTCT.

Turagusaba kugira uruhare muri ubu bushakashatsi kubera ko usobanukiwe neza serivisi zihabwa ababyeyi muri gahunda ya PMTCT igamije gukumira ubwandu bw'agakoko gatera Sida.Amakuru n'ubuhamya uzadusangiza bizafasha mugutuma hanozwa imikorere ya gahunda ya PMTCT bityo bigabanye ibyago byo kwanduza abana agakoko gatera Sida. Ikindi, ni uko ibyo nzamenyera muri ubu bushakashatsi bizamfasha mu masomo yanjye mu ishuri.

Ikigamijwe

Impamvu z'ubu bushakashatsi ni ugusobanukirwa ubuhamya n'imibereho by'ababyeyi bitabira serivisi za gahunda yo kurinda ababyeyi kwanduza abana agakoko gatera Sida(PMTCT). Nizeye ko amasomo azava muri ubu bushakashatsi azafasha mu gusobanukirwa ingorane ababyeyi bitabira gahunda ya PMTCT bahura nazo bityo bikazashingirwa mu kunoza uko gahunda yanogera ababyeyi bayigana.

Uko ubushakashatsi bukorwa

Nagusaba ga ko tugirana ikiganiro kiri bumare hagati y'isaha imwe n'amasaha abiri. Kandi amajwi y'ikiganiro ndaba nyafata n'icyuma cyabigenewe.

Inyungu

Nta nyungu zako kanya uribubone zivuye muri ubu bushakashatsi. Cyakoze hari ikizere ko gahunda ya PMTCT izanozwa igakora neza bityo bikazafasha abandi babyeyi n'abana babo bazayigana mu gihe kizaza. Ibizava mu bushakashatsi bizashingirwa ho mu gukora igenamigambi rya PMTCT.Urahabwa amafaranga y'u Rwanda 2,000 nk'agahimbaza mushyi ko wagize uruhare muri ubu bushakashatsi.

Ingorane

Nta nkurikizi zihari zo kugira uruhare muri ubu bushakashatsi. Nyamara hashobora kuvuka impamvu zitatekerejweho hagati mu kiganiro. Mu gihe bibaye ngombwa hagati mu kiganiro ko hari ikintu kibi cyakubayeho wibutse kikagukomeretsa, ufite uburenganzira bwo kurekeraho kuvuga ako kanya utiriwe unsobanurira impamvu.

Ubushake mukugira uruhare m'ubushakashatsi

Nta mpamvu n'imwe iguhatira kugira uruhare muri ubu bushakashatsi. Ni ubushake ubwawe kugira uruhare kandi ushobora kubikora cyangwa kubireka. Si ngombwa ko unsubiza kandi ntugomba no kwisobanura impamvu ubikoze. Ni ubwo wakwemera kugira uruhare, ushobora guhagarika gukomeza gusubiza ubushakashatsi igihe icyo aricyo cyose. Mu gihe kandi usubitse gukomeza kugira uruhare mu bushakashatsi, ibyo uraba wavuze byose bizahita biteshwa agaciro igihe ubyifuje. Ushobora gusaba ko amaakuru watanze yose ateshwa agaciro kugeza muri Gicurasi 2020.

Ukugira ibanga no kutagaragaza irangamimerere y'ugira uruhare mu bushakashatsi

Ibizava muri ubu bushakashatsi bizifashishwa mu masomo yanjye ku ishuri. Nzasangiza abanyeshiru bagenzi banjye n'abarimu ibyo nzaba namenyeye muri ubu bushakashatsi. Uwatanze amakuru ntazigera amenyekana. Amakuru uzatanga nzayabika muri mashini yanjye kandi uretse njye na mwarimu wanjye nawe igihe abisabye, nta wundi uzayabona. Nta bandi babyeyi bazigera bamenya ibyo twaganiriye. Amakuru yose uzatanga azabikwa neza ahantu hatekanye mu gihe cy'imyaka 5 muri kaminuza ya Alberta.Nyuma y'imyaka itanu ayo makuru azateshwa agaciro. Igihe ubushakashatsi buzaba burangiye, kopi ya raporo y'ibyavuyemo izashyikirizwa gahunda ya PMTCT mu kigo cy'ubuvuzi no kwigisha ku rwego rwa Kaminuza cya Butare ndetse no muri kaminuza ya Alberta. Dushobora kwifashisha kandi ibizava muri ubu bushakashatsi mu masomo yanjye y'igihe kizaza ariko icyo gihe nzabisabira uruhushya mu nzego zibishinzwe.

Andi makuru

- Mu gihe hari ibindi bibazo birebana n'ubu bushakashatsi,wahamagara umushakashatsi kuri izi nimero za telefoni: +250785325142 cyangwa se mwarimu we kuri +17804927953.
- Ubu bushakashatsi bwagenzuwe kandi busuzumwa n'inama ishinzwe imyitwarire m'ubushakashatsi muri kaminuza ya Alberta.Uramutse ufite ibibazo ku mpamvu yo kugira uruhare mu bushakashatsi wahamagara kuri iyi nimero ya telefoni: +17804922615.Iyi serivisi ihora yiteguye kwakira ibibabazo ibyo aribyo byose.

Indahiro y'ubwumvikane

Nasomye ibyanditse byose kuri uru rupapuro kandi nasobanuriwe neza ibyerekeye ubu bushakashatsi byose. Nahawe n'umwanya wo kubaza ibibazo ku byo ntarinsobanukiwe kandi nanyuzwe n'ibisubizo nahawe. Nemeye rero k'ubushake bwanjye kugira uruhare muri ubu bushakashatsi nk'uko nasobanuriwe hejuru kandi nasezeranijwe ko ndibuhabwe na kopi y'uru rupapuro rw'ubwumvikane mu kugira uruhare mu bushakashatsi maze kubusinyaho.

____ _______________

Izina ry'uwitabiriye ubushakashatsi (printed) n'umukono Itariki

Appendix K: Confidentiality Agreement English Version

Project title: Experiences of Mothers Using Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent HIV Transmission in Rwanda.

I, ____________________________, the________________________________ (specific job description, e.g., interpreter/translator) have been hired to

I agree to -

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the *Researcher(s)*.
2. Keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession.
3. Return all research information in any form or format (e.g., disks, tapes, transcripts) to the *Researcher(s)* when I have completed the research tasks.
4. After consulting with the *Researcher(s),* erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher(s)* (e.g., information stored on computer hard drive).
5. Other (specify).

____________________________	____________________________	______________________
(Print Name)	(Signature)	(Date)

Researcher(s)

(Print Name) (Signature) (Date)

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by Research Ethics Board *(specify which board)* at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at +1 780 492-2615.

Appendix K1: Confidentiality Agreement Kinyarwanda Version

Igice cya K1: Amasezerano yo kugira ibanga

Inyito y'ubushakashatsi: Ubuhamya n' imibereho by'ababyeyi bakoresha serivisi zo muri gahunda yo kurinda umubyeyi kwanduza umwana agakoko ka Sida(PMTCT) mu kwirinda ikwirakwira ry'ubwandu bw'agakoko gatera Sida mu Rwanda.

Njyewe,______________________________ , umu __________________________________

(sobanura icyo akora, urugero., umusemuzi) nahawe akazi ko…….

Nsezeranye gukora ibi bikurikira-

6. Kubika amakuru yose y'ubushakashatsi nahawe mu ibanga rikomeye, singire undi nyaganiriza cyangwa nyasangiza mu buryo ubwo aribwo bwose (urugero: disiki, utwuma dufata amajwi, inyandiko) n'undi muntu uwo ariwe wese utari Nyirubushakashatsi.
7. Kubika neza amakuru yose y'ubushakashatsi mu buryo bushoboka (urugero: disiki, utwuma dufata amajwi, inyandiko) butekanye igihe cyose nkiyafite.
8. Kumurika Nyirubushakashatsi amakuru yose y'ubushakashatsi nabitse mu buryo bunyuranye (urugero: disiki, utwuma dufata amajwi, inyandiko) igihe nasoje ibikorwa by 'ubushakashatsi nahawe gukora.
9. Nyuma yo kugisha inama Nyirubushakashatsi no kumumurikira amakuru yose y'ubushakashatsi nabitse mu buryo butandukanye, kuyasiba burundu no muri mudasobwa yanjye aho nayabitse hose.
10. Ibindi (bivuge).

______________________________ ______________________________ ______________________

(amazina) (Umukono) (Itariki)

Nyirubushakashatsi(s)

_____________________________ ____________________________ _____________________

(Amazina) (Umukono) (Itariki)

Gahunda y'ibikorwa by'ubu bushakashatsi yarasuzumwe n'iba yubahirije ambwiriza agenga imyifatire iboneye mu bushakashatsi kandi yemezwa n'akanama kabishinzwe muri kaminuza ya Alberta.Ku bind ibibazo byerekeye uburenganzira bw'uwemeye kugira uruhare mu bushakashatsi n'imyitwarire iboneye m'ubushakashatsi, wabaza mu biro bishinzwe imyitwarire iboneye mu bushakashatsi kuri nimero ya telefoni: +1 780 492-2615.

Appendix L: Consent for Release of Contact Information English Version

Study Title: Exploring the Experiences of Mothers Using Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent HIV Transmission in Rwanda.

Investigators: Joyce KAMANZI **Contact information +250785325142**

Supervisor: Dr. Solina Richter **Contact Information +17804927953**

This form is for you to provide consent for a member of the study team to contact you to tell you more about the research study and see if you might be interested in taking part.

Study Summary:

An estimated 180, 000 children under 15 years old acquire HIV every day in 2017 and more than 90% of them are due to MTCT of HIV (UNAIDS, 2018). In Rwanda, HIV prevalence among pregnant women was 3.8% and 400 children were infected every day in 2017 (UNAIDS, 2017). The PMTCT program is one of the most important interventions to prevent the spread of HIV through MTCT (Kamanzi & Richter, 2019). While efforts have been implemented to increase the effectivity of the PMTCT program, there is high number of MTCT of HIV not only in SSA but in Rwanda. There is an urgent need to understand the reasons for low uptake of the PMTCT program in Rwanda, in order to prioritize strategies to improve the uptake. The reasons for this this study is to learn about your experiences of being a mother using the PMTCT Program.

Completing this form does not provide consent to participate in the study. You do not need to provide your contact information at all.

CONSENT:

By signing this consent, I give permission to Joyce Kamanzi to contact me in order to give me more information about this study and to be asked to participate in the study.

Participant's Name: ___________________________________

Phone number: ____________________________________

Participant’s Signature: _________________ Date: __________________

Person obtaining consent:

Name: ______________________ Signature: ____________Date: __________________

Appendix L1: Consent for Release of Contact Information Kinyarwanda Version

Igice cya L1: Kwemera Gutanga Amakuru K' Ubushakashatsi

Inyito y'ubushakashatsi: Ubuhamya n' imibereho by'ababyeyi bakoresha serivisi zo muri gahunda yo kurinda umubyeyi kwanduza umwana agakoko ka Sida(PMTCT) mu kwirinda ikwirakwira ry'ubwandu bw'agakoko gatera Sida mu Rwanda.

Umushakashatsi: Joyce KAMANZI **Nimero ya telefoni: +250785325142**

Umuyobozi w'ubushakashatsi: Dr. Solina Richter **Nimero ya telefoni: +17804927953**

Uru rwandiko ni urwawe kugira ngo utange uburenganzira ku muntu wese uri muri ubu bushakashatsi kugira ngo abe yaguhamagara akubwire byinshi kuri ubu bushakashatsi cyangwa se niba ushobora nawe kumva wabugiramo uruhare.

Incamake y'ubushakashatsi:

Ikigereranyo cy'abana bagera 180, 000 bari munsi y'imyaka 15 banduraga agakoko gatera Sida buri munsi mu mwaka wa 2007 kandi hejuru ya 90% muri bo bayanduzwaga n'ababyeyi babo. Mu Rwanda, ubwiganze bw'agakoko gatera Sida mu babyeyi batwite bwari 3.8% kandi abana 400 banduzwaga n'ababyeyi babo buri munsi mu 2007. Gahunda yo kurinda ababyeyi kwanduza abana agakoko gatera Sida n'imwe mu ngamba zo kurinda ikwirakwira ry'agakoko gatera Sida binyuze m'ubwandu hagati y'umubyeyi n'umwana (Kamanzi & Richter, 2019). N'ubwo imbaraga nyinshi zashyizwe mu kongera ubushobozi bwa gahunda yo kurinda ababyeyi kwanduza abana agakoko gatera Sida(PMTCT) haracyari umubare munini w'ubwandu hagati y'umubyeyi n'umwana w'agakoko gatera Sida atari gusa muri Afurika yo munsi y'ubutayu bwa Sahara ahubwo no mu Rwanda. Bityo rero, hakaba hakenewe mu buryo bwihutirwa gusobanukirwa impamvu y'ubwitabire buke serivisi za gahunda yo kurind ababyeyi kwanduza abana agakoko gatera Sida mu Rwanda kugira ngo hashyirwe imbaraga mu ngamba zo kongera ubwitabire.

Kuzuza uru rwandiko ntibivuga ko wemeye kugira uruhare muri ubu bushakashatsi. Sinangombwa rwose ko utanga amakuru yawe yose akwerekeyeho.

Indahiro y'ubwumvikane:

Ugusinya kuri urupapuro rw'amasezerano y'ubwumvikane mukugira uruhare mu bushakashatsi, mpaye uburenganzira Joyce Kamanzi kumpamagara kugira ngo ambwire andi makuru yerekeye ubu bushakashatsi no kunsaba kugira uruhare mu bushakashatsi.

Amazina y'ugira uruhare mu bushakashatsi: ___________________________________

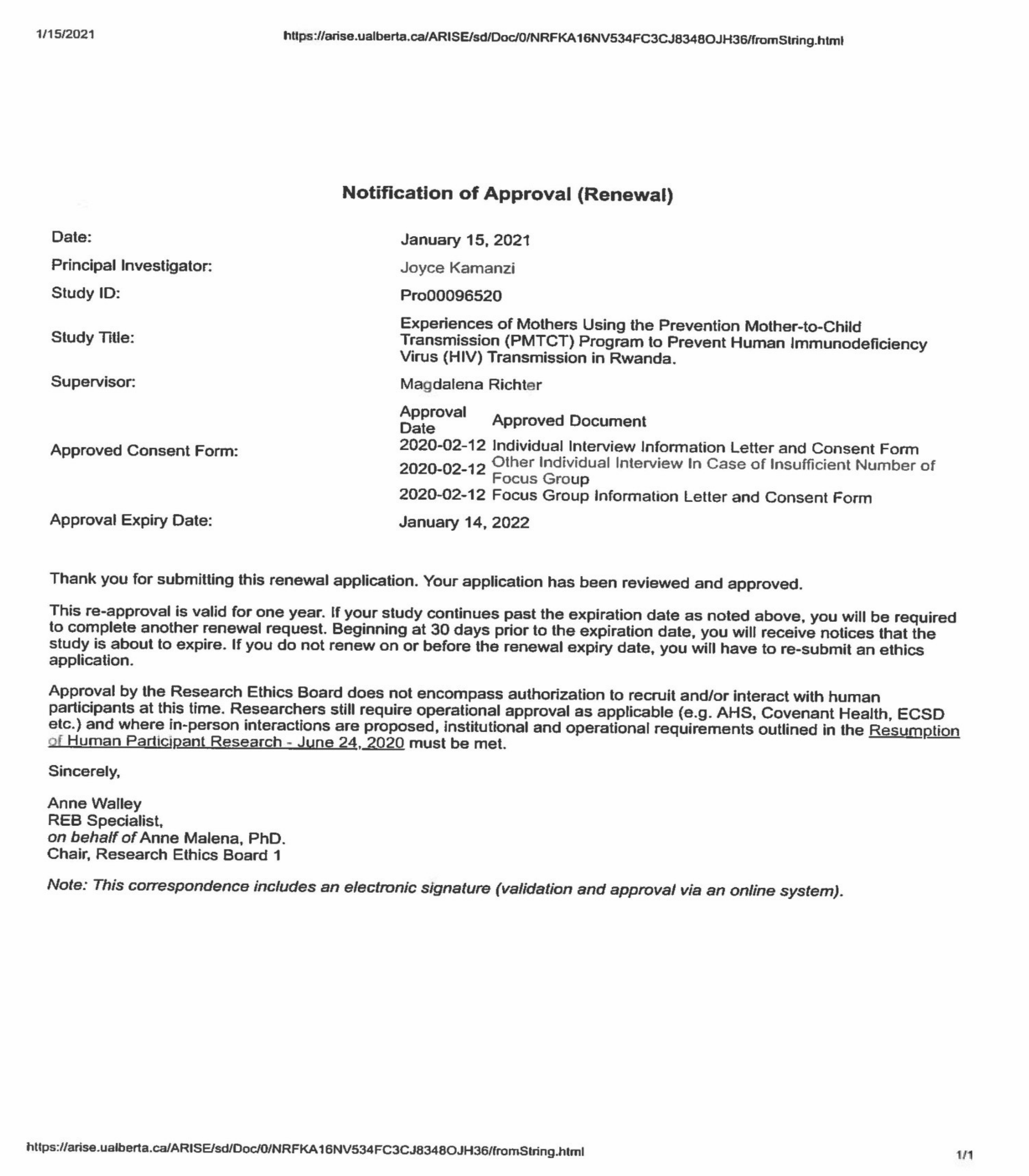
Nimero za Telefoni: ________________________________

Umukono w'ugira uruhare mu bushakashatsi: ________________ Itariki:_________________

Uwakiriye amasezerano y'ubwumvikane:

Izina: _____________________ Umukono: ___________Itariki: _________________

Appendix M: Ethics Approval Letter From University of Alberta



1/15/2021 https://arise.ualberta.ca/ARISE/sd/Doc/0/NRFKA16NV534FC3CJ8348OJH36/fromString.html

Notification of Approval (Renewal)

Date: January 15, 2021

Principal Investigator: Joyce Kamanzi

Study ID: Pro00096520

Study Title: Experiences of Mothers Using the Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent Human Immunodeficiency Virus (HIV) Transmission in Rwanda.

Supervisor: Magdalena Richter

Approved Consent Form:

Approval Date	Approved Document
2020-02-12	Individual Interview Information Letter and Consent Form
2020-02-12	Other Individual Interview In Case of Insufficient Number of Focus Group
2020-02-12	Focus Group Information Letter and Consent Form

Approval Expiry Date: January 14, 2022

Thank you for submitting this renewal application. Your application has been reviewed and approved.

This re-approval is valid for one year. If your study continues past the expiration date as noted above, you will be required to complete another renewal request. Beginning at 30 days prior to the expiration date, you will receive notices that the study is about to expire. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to recruit and/or interact with human participants at this time. Researchers still require operational approval as applicable (e.g. AHS, Covenant Health, ECSD etc.) and where in-person interactions are proposed, institutional and operational requirements outlined in the Resumption of Human Participant Research - June 24, 2020 must be met.

Sincerely,

Anne Walley
REB Specialist,
on behalf of Anne Malena, PhD.
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

https://arise.ualberta.ca/ARISE/sd/Doc/0/NRFKA16NV534FC3CJ8348OJH36/fromString.html 1/1

Notification of Approval

Date:	February 12, 2020
Study ID:	Pro00096520
Principal Investigator:	Joyce Kamanzi
Study Supervisor:	Magdalena Richter
Study Title:	Experiences of Mothers Using the Prevention Mother-to-Child Transmission (PMTCT) Program to Prevent Human Immunodeficiency Virus (HIV) Transmission in Rwanda.
Approval Expiry Date:	February 11, 2021

Approved Consent Form:

Approval Date	Approved Document
2/12/2020	Individual Interview Information Letter and Consent Form
2/12/2020	Focus Group Information Letter and Consent Form
2/12/2020	Other Individual Interview In Case of Insufficient Number of Focus Group

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Anne Malena, PhD
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix N: Ethics Approval Letter From BUTH

CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL

IKIGO CY' UBUVUZI CYA KAMINUZA

CENTRE HOSPITALIER UNIVERSITAIRE
DE BUTARE (CHUB)
OFFICE OF DIRECTOR GENERAL

Huye, ..02/03/2020..

Nº Ref: CHUB/DG/SA/02/...0402.../2020

Joyce Kamanzi
PhD Candidate
Faculty of Nursing
University of Alberta/Canada
Phone: +250785325142, +1780266538
Email: kamanzi@ualberta.ca

Dear Kamanzi,

Re: Your request for Data collection

Reference made to your letter requesting for permission to collect data within University Teaching Hospital of Butare for your research study entitled ***"Experiences of Mothers using the Prevention Mother-to-Child Transmission (PMTCT) program to prevent Human Immunodeficiency Virus (HIV transmission in Rwanda)";*** and based to the approval: **No: RC/UTHB/001/2020** from our Research - Ethics committee we are pleased to inform you that your request was accepted. Please note that your final document will be submitted in our Research Office.

Sincerely,

Dr. Augustin SENDEGEYA
Director General of CHUB

Cc:

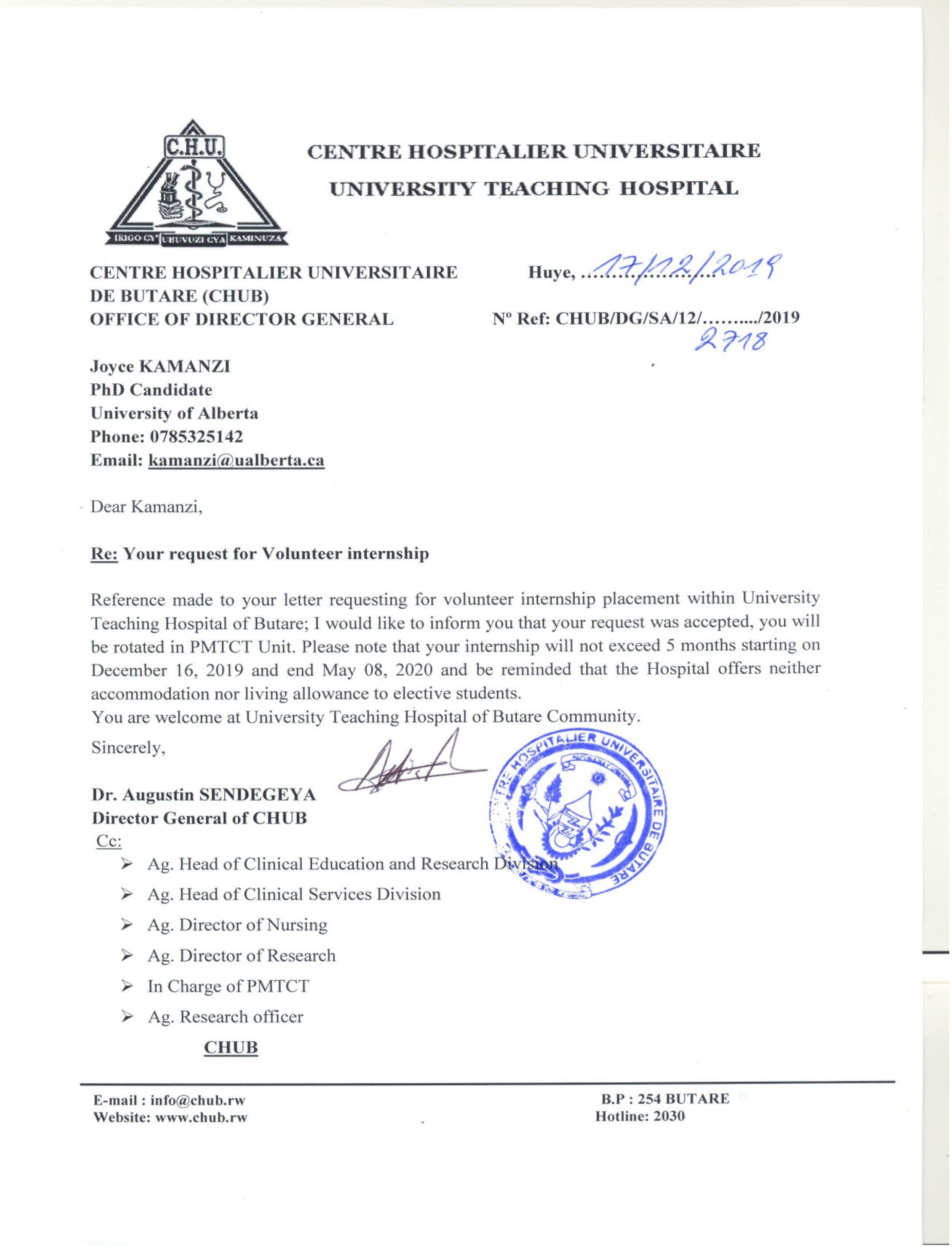
- Ag. Head of Clinical Education and Research Division
- Ag. Director of Research
- Chairperson of Research-Ethics Committee
- Ag. Research officer

CHUB

E-mail : info@chub.rw
Website: www.chub.rw

B.P : 254 BUTARE
Hotline: 2030

Appendix O: Request for Volunteering



CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL

CENTRE HOSPITALIER UNIVERSITAIRE
DE BUTARE (CHUB)
OFFICE OF DIRECTOR GENERAL

Huye, 17/12/2019

Nº Ref: CHUB/DG/SA/12/2718/2019

Joyce KAMANZI
PhD Candidate
University of Alberta
Phone: 0785325142
Email: kamanzi@ualberta.ca

Dear Kamanzi,

Re: Your request for Volunteer internship

Reference made to your letter requesting for volunteer internship placement within University Teaching Hospital of Butare; I would like to inform you that your request was accepted, you will be rotated in PMTCT Unit. Please note that your internship will not exceed 5 months starting on December 16, 2019 and end May 08, 2020 and be reminded that the Hospital offers neither accommodation nor living allowance to elective students.

You are welcome at University Teaching Hospital of Butare Community.

Sincerely,

Dr. Augustin SENDEGEYA
Director General of CHUB

Cc:

- Ag. Head of Clinical Education and Research Division
- Ag. Head of Clinical Services Division
- Ag. Director of Nursing
- Ag. Director of Research
- In Charge of PMTCT
- Ag. Research officer

CHUB

E-mail : info@chub.rw **B.P : 254 BUTARE**
Website: www.chub.rw **Hotline: 2030**