Scoping Review of the Literature on the Use of PMTCT in Sub-Saharan Africa

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² Participated in the development of the protocol, and review of the paper for inclusion and the manuscript multiple times.

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Abstract

**Background:** The prevention of mother-to-child transmission (PMTCT) program, which was initiated by WHO in 2000 (WHO, 2007), can virtually eliminate Human Immunodeficiency Virus (HIV) infection among children. However, despite the efforts and emphasis on the PMTCT program, mother-to-child transmission (MTCT) of HIV continues to be high, especially in sub-Saharan Africa (SSA). Our aim was to conduct a scoping review to examine the literature on use of the PMTCT program.

**Methods and Analysis:** A scoping review framework, proposed by Arksey and O’Malley (2005), was used to guide the study. A comprehensive literature search was performed in the following electronic databases: MEDLINE, EMBASE, Cochrane Library, CINAHL, Scopus, Web of Science Core Collection, Global Health, and Dissertations & Theses Global. The primary research articles published in peer-reviewed journals and grey literature addressing our research question was included. Two independent reviewers conducted title, abstract, and full text screening. Data analysis included a thematic content analysis.

**Summary:** Our findings will be useful to PMTCT implementers, policy makers, and researchers working in the HIV/PMTCT program. The findings will contribute to strengthening the PMTCT program in SSA by identifying knowledge gaps and providing direction for further research. The intention of this scoping review is to build and contribute to a body of literature on the use of the PMTCT Program.

**Keywords:** Access, experiences, PMTCT program, vertical transmission, women
Introduction

Communities worldwide are significantly affected by the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). United Nations Program on HIV and AIDS (UNAIDS) reported that approximately 37 million people worldwide were living with HIV, and 1.8 million people were newly infected with HIV in 2017 (UNAIDS, 2018). In addition, HIV and AIDS are one of the leading causes of mortality among women of reproductive age. Furthermore, an estimated 180,000 children under 15 years of age acquired HIV in 2017 and more than 90% of them are due to Mother-to-Child Transmission (MTCT). Moreover, 90% of MTCT occur in sub-Saharan Africa (SSA) (UNAIDS, 2015) and evidently four hundred children are infected every day just in Rwanda (UNAIDS, 2017).

Without preventive interventions in SSA countries, 20-45% of HIV positive mothers will transmit HIV to their children. Among that proportion, five to 10% occur during pregnancy, 10-20% during labor, and delivery, and five to 20% through breastfeeding (World Health Organization [WHO], 2019). The global health plan is to reduce MTCT of HIV by 90% and reduce the HIV related maternal mortality rate by 50% before 2020 (UNAIDS, 2015). To achieve this target, prevention, treatment, and care are needed and should be delivered to at least 80% of HIV positive pregnant women and their children. The Prevention of Mother-to-Child Transmission of HIV/AIDS (PMTCT) program is one of the approaches to reduce the risk of HIV transmission from a mother to her child. This strategy includes Anti-Retroviral Therapy (ARV) given to pregnant women and during labor and breastfeeding, ARV prophylaxes given to breastfed infant; access to HIV testing and counselling, safe delivery, and infant feeding information, counselling, as well as support for safer practices (Aregbesola, & Adeoye, 2018; WHO, 2019).

While the effort has been implemented to make the PMTCT strategies more effective through availing ARV, PMTCT guidelines, and services, as well as providing support to HIV positive women, the adherence to all the PMTCT strategies among HIV infected women remains low and continues to be a major health concern in SSA. Consequently, the MTCT of HIV rate is high (Nachega et al., 2012; Oladokun, Ige, & Osinusi, 2013). There is an urgent need to understand the reasons for low uptake of the PMTCT program in SSA, to prioritize strategies to improve the uptake in SSA.

Purpose

The purpose of this project was to conduct a scoping review to assess the experiences of mothers using the PMTCT program for preventing HIV transmission in SSA.

Materials and Methods

The scoping review focused on evidence from published literature and from websites of relevant organizations such as HIV/AIDS, WHO, and UNAIDS. Compared to traditional systematic reviews, a scoping review approach is more feasible in finding evidence using broad objectives. The findings of this scoping review will lead to clear insights on how the PMTCT program is implemented and operated in response to prevent mother-to-child transmission of HIV, as well as insights on the challenges experienced by mothers in SSA.
Arksey and O’Malley’s (2005) framework was used to provide guidance for the scoping review. It supported the researchers to conduct a review in a transparent and rigorous way (Centre for Reviews and Dissemination (CRD), 2009) and provided an explicit approach, which increased the reliability of the findings. The scoping reviews consist of six stages: (1) identify the research question; (2) identify relevancy of the studies; (3) study selection; (4) chart the data; (5) collate, summarise, and report the results; and (6) consultation.

**Research Question**
The main research question was: What are the experiences of mothers using the PMTCT program to prevent HIV transmission in SSA? The research question was framed based on the SPIDER tool. The SPIDER tool assists researchers in conducting effective searches for qualitative research studies in the public and/or community health area (Cooke, Smith, & Booth, 2012). The application of the SPIDER tool is as follows: S: Studies that include women using the PMTCT; PI: Experience of mothers using the PMTCT to prevent HIV transmission; D: Data from qualitative studies and mixed methods; E: Examine critically the different experiences of mothers using the PMTCT to prevent HIV transmission; and R: Qualitative research and mixed methods.

**Search Strategy**
The researchers conducted the literature search using two main approaches. In the systematic search, we searched in numerous health databases including MEDLINE, EMBASE, Cochrane Library, CINAHL, Scopus, Web of Science Core Collection, and Global Health. We additionally searched in grey literature. The grey literature search included information from Google, Google Scholar, and reports related to the PMTCT/MTCT. The search keywords were constructed as follows: (MH "Disease Transmission, Vertical") or "vertical transmission" or "mother-to-child transmission" or PMTCT AND (MH "HIV Infections+/PC") OR ( TI (( hiv or aids or "acquired immun*")) and prevent*)) or (MH "Anti-HIV Agents+") OR (MH "Anti-Retroviral Agents+") or antiretroviral* AND Africa* Sub Saharan Africa. In the purposive search, we retrieved relevant reports and policy briefs from the HIV/AIDS, WHO, and UNAIDS websites.

**Inclusion and Exclusion Criteria**
Studies were selected if they referenced HIV infected pregnant and breastfeeding women and their children from birth to two years; had the PMTCT as an outcome or MTCT or vertical transmission; were published between April 2008 and April 2018; were primary studies using qualitative and mixed method study design; and were conducted sub-Saharan Africa. Studies not in English were excluded, as were those consisting of a published abstract, poster, review, thesis, or conference publication. Books, book chapters, commentaries, and editorials were also excluded.

**Tools and Tables Used for Screening**
The steps of the PRISMA flow diagram (Figure 1—see next page) were followed during our data selection (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). All duplicates were removed. Two independent reviewers performed a title and abstract screening of all articles retrieved from the databases based on the inclusion criteria. We proceeded with carrying out full
article screening using the inclusion and exclusion criteria. When disagreement between the two reviewers occurred, we came to a mutual agreement for in- or exclusion.

To manage our data, the results from the searching were exported to a web-based citation manager. We used a data extraction form for qualitative research adapted from United Kingdom (UK) National Institute for Health and Clinical Excellence (NICE) universal template (British Psychological Society & Gaskell, 2007) to record the key information of the selected primary studies. A pilot test was conducted by two independent reviewers on ten randomly selected studies using the data extraction tool to refine the tool, deal with discrepancies, and avoid misunderstandings or disagreements. Selected articles were read and assessed in full during discussions among the reviewers. Key information of the selected articles was extracted and entered into the data extraction form, which was designed in correspondence with the research questions.

Figure 1: Prisma Flow Diagram
Findings
The findings from the included articles were mapped with the research questions.

Table 1 Summary of characteristics of the included articles

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Publication date</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2008 to 2012</td>
<td>11</td>
<td>33 %</td>
</tr>
<tr>
<td>2013 to 2018</td>
<td>22</td>
<td>67 %</td>
</tr>
<tr>
<td>Countries represented in studies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malawi</td>
<td>13</td>
<td>33 %</td>
</tr>
<tr>
<td>South Africa</td>
<td>9</td>
<td>27 %</td>
</tr>
<tr>
<td>Tanzania</td>
<td>3</td>
<td>9 %</td>
</tr>
<tr>
<td>Uganda</td>
<td>2</td>
<td>6 %</td>
</tr>
<tr>
<td>Botswana, Cameroon, Cote d’Ivoire, Ghana, Guinea Bissau, Kenya, and Nigeria</td>
<td>1 each</td>
<td>25 %</td>
</tr>
<tr>
<td>Sampling methods</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purposive sampling</td>
<td>20</td>
<td>61 %</td>
</tr>
<tr>
<td>Not mentioned</td>
<td>10</td>
<td>30 %</td>
</tr>
<tr>
<td>Convenient sampling</td>
<td>2</td>
<td>6 %</td>
</tr>
<tr>
<td>Criteria sampling</td>
<td>1</td>
<td>3 %</td>
</tr>
<tr>
<td>Data collection methods</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple method: In-depth interviews, key informant interviews, focus group discussions</td>
<td>11</td>
<td>33.3 %</td>
</tr>
<tr>
<td>In-depth and semi-structured interviews</td>
<td>10</td>
<td>30.2 %</td>
</tr>
<tr>
<td>In-depth and focus group interviews</td>
<td>7</td>
<td>21.2 %</td>
</tr>
<tr>
<td>Focus group discussions</td>
<td>4</td>
<td>12 %</td>
</tr>
<tr>
<td>Key informant interviews</td>
<td>1</td>
<td>3.3 %</td>
</tr>
</tbody>
</table>

Of the forty-six existing sub-Saharan African countries, only 13 (28 percent) of these countries are represented in the studies included in this scoping review. The majority of the included articles, 27 (75 percent), were conducted in four SSA countries. A knowledge gap exists in SSA related to this area of interest. A number of data collection methods were used, and some studies combined two or three data collection methods. Consider the complex associations between the individual practices, the physical environment, and health, social and structural factors, our findings were reported at five levels: individual, family, institutional, community, and social factors (See the Table 2).

Individual Factors
The individual level factors are those related to the level of mothers’ acceptance of HIV testing, receiving the results, and believing that their children are susceptible to contracting HIV through MTCT (Cornelius, Erekaha, Okundaye, Sam-Agudu, 2018; Onono et al., 2015). An HIV positive woman may decide to stop attendance to the PMTCT program due to different factors such as lack of disclosure of HIV status; fear of stigma and discrimination, lack of money for antenatal care and transportation cost (Bwirire, Fitzgerald, & Zachariah, 2008; Hatcher, Stöckl, Christofides, & Woollett, 2016; Landefeld, Fomenou, Ateba, & Msellati, 2018; Lubega et al., 2013). The lack of awareness and knowledge related to HIV, AIDS and MTCT among HIV positive women contribute to increased HIV prevalence among children (Ferguson et al., 2012; Wettstein et al., 2012). Mothers who lack knowledge and awareness of MTCT easily refuse antenatal care attendance and treatment.
Additionally, women experience difficulty 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).

Our review found that exclusive breastfeeding is a good option for HIV positive women living in low resource countries, but mothers were often unclear what exclusive breastfeeding entails (Levy, Webb, & Sellen, 2010). The counseling received from healthcare providers on infant feeding were confusing, incomplete, or incorrect (Laher, Cescon, & Lazarus, 2012; Levy et al. 2010). Women were fearful to be tested positive for HIV and many refused testing (Katirayi et al., 2016). Similarly, women found it difficult to have the infants tested because they feared getting a positive result and additionally feared involuntary disclosure (Katirayi et al., 2016; Varga, & Brookes, 2008a).

When healthcare providers are supportive, they fulfill a key role in assisting women in adhering to the PMTCT program. However, HIV positive women often complained about the negative attitudes of healthcare providers, including carelessness, staff neglect, harassment, disrespect, disparities, late receipt/provision of test results, and insufficient counseling (Klaus et al., 2014; Gourlay, Wringle, Birdthistle, & Mshana, 2014; Onono et al., 2015). Moreover, HIV positive women were complaining about lack of accuracy of health information and insufficient counseling, which were related to high workload, inexperienced staff, low salaries, poor training related to HIV/AIDS, and lack of resources (Fleek, 2014; Vieira et al., 2017). The individual factors can be addressed by focusing on education of HIV positive women regarding understanding the benefit of ARVs, with the result of increased self-efficacy to participate (Onono et al., 2015). In addition, addressing the relationship between healthcare providers and patients may contribute to discourse regarding individual factors (Klaus et al., 2014).

**Interpersonal Factors.**

Household inequities contribute in that women have little decision-making power to participate in the PMTCT program (Ferguson et al., 2012; Sewununa & Modibab, 2015). Male partners play an important role in decision-making. For instances, some women refused HIV counseling and treatment or did not collect their results because of partner disapproval; this may be linked with lack of knowledge of HIV, AIDS, and MTCT among the male partners of HIV positive women (Brittain, Giddy, Myer, Cooper, & Harries, 2015; Ramoshaba, & Sithole, 2017). Women found it difficult to negotiate with their male partners regarding the use of protection. It may thus increase the risk of higher viral loads and 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 (Cornelius et al. 2018; Hatcher et al., 2016; Klaus et al., 2014; Landefeld et al., 2018). A number of women 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 at al., 2017; O’Gorman, Nyirenda, & Theobald, 2010; Nyondo-Mipando, Chimwaza, & Muula, 2018).

The fear of MTCT through breastfeeding has contributed to women choosing replacement feeding, whether or not it meets AFASS criteria (Woldegiyorgis, & Scherrer, 2012; Nyondo-
Mipando et al., 2018). The implementation of replacement feeding has many challenges, including economic challenges to maintain replacement feeding that meets AFASS criteria; 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 challenge, 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 positive 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 ARV uptake for the PMTCT (e.g. use of holy water to cure HIV in Ethiopia); and to address issues related to stigma and discrimination (Klaus et al., 2014; Levy et al., 2010; Madiba, & Letsoalo 2013; Woldegiyorgis, & Scherrer, 2012). The 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) mentioned that the relationship between sociocultural, 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 to pose significant obstacles to operationalize the PMTCT program (Varga & Brookes, 2008a). These factors include stigma and discrimination, gender inequity, lack of support, abandonment and social isolation, divorce, and poor acceptance of people living with HIV in a community (Lubega et al., 2013; Varga & Brookes, 2008b; Were et al., 2011). These factors contribute to 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 with not breastfeeding and a negative association with replacement feeding (bad motherhood, dislike her child, killing child, desire adultery). Cultural norms (three years of breastfeeding) and traditional feeding practice were found to be challenging to the PMTCT’s success (Madiba & Letsoalo, 2013; Traoré et al., 2009; Woldegiyorgis, & Scherrer, 2012).

Health System Factors.
There is a range of factors that include the decision-making of HIV positive women about enrolment into antenatal care and the PMTCT program. Some of these issues are related to facilities and others to the attitudes of healthcare providers. The facility factors include system level obstacles, shortage of staff, lack of ARV stock, and indirect labels due to isolated or public locations of the clinic. It contributed to a loss of follow up in the PMTCT program (Buesseler, Kone, & Robinson, 2014; Cornelius et al., 2018; Elwell, 2016; Miya, & Mgutshini, 2016; Laar, & Govender, 2014; Miya, & Mgutshini, 2016; Onono et al., 2015). In addition, a long distance to health facilities combined with a lack of money for transport and for health facility charges was found to limit the number of antenatal care visits. It increased the number of women opting for home deliveries, where they are assisted by traditional birth attendants (Laar, & Govender, 2014; Onone et al., 2015).

Some of the included studies mentioned that women lack trust in traditional birth attendants in terms of keeping secrets, which contributes to them not disclosing their HIV status, and the newborns therefore not receiving prophylactic medicine (Nevirapine) (Buesseler et al., 2014;
HIV positive women complained that pre and postnatal counseling was ineffective, inadequate, or even absent, and without adequate informed consent (Katirayi et al., 2016; Ramoshaba, & Sithole, 2017; Vieira et al., 2017). In addition, they lack counseling related to infant feeding, and the messages were unclear or conflicting because healthcare providers were not prepared to provide infant feeding counseling due to inadequate training (Buesseler et al., 2014; Laar, & Govender, 2014; Laher et al., 2012).

Additionally, women complained about the attitudes of healthcare providers, such as poor interactions, bad treatment, discrimination and stigmatization, and breach of privacy and confidentiality that result in lack of trust. Improving relationships between healthcare providers and patients, medical follow-up for women and infants, making treatment available, and providing formula substitutes was found to improve the delivering 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).

**Larger societal factors.**

Some factors included at this level contributed to loss of follow up for HIV positive women using the PMTCT. Those include sexual inequity, stigma and discrimination, gender inequity, lack of support, abandonment and social isolation, divorce, and absence of male involvement (Lubega et al., 2013; Nyondo, Chimwaza, & Muula, 2014; Nyondo-Mipando et al., 2018; Sewnunana, & Modibab, 2015). To address the larger societal factors, there is a need to develop/provide healthcare system laws and national norms that address gender inequity, stigma, and discrimination issues; to provide qualified and skilled healthcare providers, engaging people living with HIV, partners, and traditional birth attendants in the PMTCT program; and to increase media messages (Buesseler et al., 2014; Cornelius et al., 2018, Klaus et al., 2014; O'Gorman et al., 2010).

### Table 2 Factors Associated with the Experience of Mothers Using the PMTCT Program in SSA

<table>
<thead>
<tr>
<th>Factors identified</th>
<th>Literature references</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loss of follow up:</strong> Lack of disclosure of HIV status; stigma and discrimination, lack of money for antenatal care and transportation cost (Cameroon)</td>
<td>Bwirire et al. (2008); Hatcher et al. (2016); Landefeld et al. (2018); Lubega et al. (2013); O'Gorman et al. (2010)</td>
</tr>
<tr>
<td><strong>Lack of knowledge:</strong> Refusal of antenatal care attendance; ARV treatment (due to lack of understanding the efficacy of treatment: refusal of treatment, drug resistance, and medication side effects)</td>
<td>Fleek. (2014); Katirayi et al. (2016); Klaus et al. (2014); Laher et al. (2012); Mepham et al. (2011); Ramoshaba et al. (2017)</td>
</tr>
<tr>
<td><strong>Infant feeding:</strong> Exclusive breastfeeding: Unclear understanding of exclusive breastfeeding, counselling on infant feeding confusing, incomplete, or incorrect information from healthcare providers</td>
<td>Laher et al. (2012); Levy et al. (2010)</td>
</tr>
<tr>
<td><strong>Fear occurs at different levels-Individual-interpersonal-community:</strong> Fear to be HIV positive, infant testing (positive result for child, fear of involuntary disclosure), negative community reactions, fear to disclosure HIV status, fear of social stigma; fear</td>
<td>Katirayi et al. (2016); Varga et al. (2008a); Bwirire et al. (2008); Chinkonde et al. (2009); Cornelius</td>
</tr>
</tbody>
</table>
### Interpersonal factors associated with the experiences of Mothers using the PMTCT Program in SSA

<table>
<thead>
<tr>
<th>Factor</th>
<th>Literature references</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loss of follow up:</strong> Difficulty engaging men in protective behaviour (condom use).</td>
<td>Chinkonde et al. (2009); Varga et al. (2008b)</td>
</tr>
<tr>
<td><strong>Knowledge:</strong> ART treatment adherence difficulty (dependence on husband agreement).</td>
<td>Brittain et al. (2015); Chinkonde et al. (2009); Ramoshaba et al. (2017)</td>
</tr>
<tr>
<td><strong>Infant feeding occurs at different levels-Interpersonal-Community-Health system:</strong> Replacement feeding (economic challenges to maintain feeding that met Acceptable, Feasible, Affordable, Sustainable, and Safe (AFASS) criteria, significant others (pressure to breastfeed from husbands, mothers, mother-in-laws, friends &amp; neighbours), infant feeding and partner’s support, social and culture (stigma of not breastfeeding; negative meaning of replacement feeding [bad motherhood, dislike her child, kill child, desire adultery]); culture of exclusive breastfeeding (stigma associated with cultural norms [3 years of breastfeeding]; traditional feeding practice); mothers using replacement feeding (lack of proper infant feeding counselling), exclusive breastfeeding (unclear medical scientific information), healthcare providers not providing infant feeding counselling (due to inadequate training).</td>
<td>Levy et al. (2010); Madiba et al. (2013); Traoré et al. (2009), Varga et al. (2008a); Woldegiyorgis, &amp; Scherr (2012); Buesseler et al. (2014); Laar, &amp; Govender. (2014); Laher et al. (2012); Woldegiyorgis, &amp; Scherr, 2012</td>
</tr>
<tr>
<td><strong>Support:</strong> Limited financial support, (affordability of transport), religious (negative influences), male involvement (support for feeding choice an safety; disclosure to sexual partner; physical, social, emotional, &amp; economic- support; couple counselling and testing; increase uptake of ARVs for the PMTCT; reduced risk of MTCT), barriers of male involvement (insufficient family resources [poverty]; men refuse to be</td>
<td>Brittain et al. (2015); Bwirire et al. (2008); Flax et al. (2017); Fleek. (2014); Hatcher et al. (2016); Klaus et al. (2014); Landefeld et al. (2018); Mepham et al. (2011); Nyondo-Mipando et al. (2018)</td>
</tr>
</tbody>
</table>
Factors identified

<table>
<thead>
<tr>
<th>Community factors associated with the experiences of Mothers Using the PMTCT Program in SSA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support</strong>: religious (negative influences [holy water], socio-cultural factors (stigma, discrimination, gender inequity, lack of support [abandonment, social isolation, divorce], poor acceptance of people living with HIV in the family and community (prostitute); male involvement (involvement of partner, family, and community in addressing social and culture stigma)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factors identified</th>
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<tbody>
<tr>
<td><strong>Health system factors associated with the experiences of Mothers Using the PMTCT Program in SSA</strong></td>
</tr>
<tr>
<td><strong>Loss of follow up</strong>: Isolated or public or physical location of the ARV clinic, violate confidentiality, ineffective, inadequate, or absent pre and post counselling</td>
</tr>
<tr>
<td><strong>Knowledge</strong>: HIV testing (ineffective, inadequate, or absent pre and post counselling; no or inadequate informed consent, gaps in HIV and MTCT knowledge among women)</td>
</tr>
<tr>
<td><strong>Facilities</strong>: Inaccessibility (home delivery [traditional birth attendants respectful and dignity]; no trust in traditional birth attendants to keep secret, unable to give baby Nevirapine), limited number of ANC, shortage of staff, system level obstacles, long waiting time, ARV treatment [lack of continuity of care due to shortage of stock])</td>
</tr>
<tr>
<td><strong>Attitudes of healthcare providers</strong>: Trust (privacy and confidentiality breach; lack of continuity of care [shortages of stock], discrimination and stigmatizing, poor interactions between healthcare providers and patients, poor treatment and conflicting messages from health care providers), inaccuracy of health information, carelessness, staff neglect, harassment and complacency particularly to health facility delivery, negative attitude [disrespect, disparities due to workload, less experience, low salaries, poor training, lack of resources], inadequate training and logistics, unable to provide sufficient counselling</td>
</tr>
<tr>
<td><strong>Support</strong>: Male involvement (couple HIV counselling and testing), barrier of male involvement (lack of clinical space).</td>
</tr>
<tr>
<td><strong>Delivering the PMTCT programming</strong>: healthcare providers (improve relationship with the patients, medical follow-up for women and infants, treatment available, and formula substitute)</td>
</tr>
<tr>
<td><strong>Larger societal factors associated with the experiences of Mothers Using the PMTCT Program in SSA</strong></td>
</tr>
<tr>
<td><strong>Loss of follow up</strong>: Sexual inequity, stigma, discrimination, and gender inequity, lack of support, abandonment and social</td>
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</tbody>
</table>
isolation, divorce, and male involvement (Reduced risk of MTCT).

Delivering the PMTCT programming: Reduced risk of mother-to-child HIV transmission, health care system (medical follow-up for women and infant, treatment available, formula substitute, qualified and skilled health workers, engaging people living with HIV peers, partners, traditional birth attendants and increase media message

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nyondo-Mipando et al. (2018); Sewununana &amp; Modibab (2015)</td>
<td></td>
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<tr>
<td>Buesseler et al. (2014); Cornelius et al. (2018); Klaus et al. (2014); O’Gorman et al. (2010); Ramoshaba et al. (2017)</td>
<td></td>
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</tbody>
</table>

Discussion

HIV positive mothers encounter several barriers to the PMTCT program in SSA that are at individual, interpersonal, community, national and international levels (Aizir, Fowler, & Coovadia, 2013; Kasenga, Hurtig, & Emmelin, 2010; Kinuthia et al., 2011). These barriers are commonly related to the implementation, uptake of, and adherence to the PMTCT program (Nestler, 2011; Sprague, Chersich, Black, 2011; WHO, 2019). The results from our scoping review showed that individual, social, and structural factors are determinants of the PMTCT success. Lack of knowledge, attitude of healthcare providers, stigma, difficulties with partner disclosure, fear, lack of family, social, and community support, problems related to cost and distance to reach the health facilities, challenges with healthcare providers attitudes, lack of medical supplies, and ineffective, inadequate, or even absent pre and post counseling (Hardon et al., 2012; Hatcher et al., 2016) are some of the factors. In addition, many women presenting for delivery had not done any antenatal care and/or HIV testing. In response, some countries offer food, transport fees, and substitute formula to increase the likelihood of HIV positive mothers attending the program (Landefeld et al., 2018; Wettstein et al., 2012).

Women experienced three important barriers in using the health services: negative attitudes, knowledge and awareness, and excessive distance in reaching the health facility. Women complained about poor communication and the way they are treated with disrespect, carelessness, neglect, harassment, and disparities (Bwirire et al., 2008). This is consistent with previous studies done across four African countries that came out with a statement saying that poor quality of services offered at health facilities kept many pregnant women from attending antenatal care clinics, consequently missing a chance to benefit from the PMTCT program (Ekouevi et al., 2012).

Mothers who lack knowledge and awareness of MTCT ignored the PMTCT follow up services and missed HIV treatment for both their own health and that of their babies. The role of healthcare providers was found to be vital in improving HIV positive women using effective and adequate counseling and medical follow up. The results from many included studies stated that awareness and knowledge of HIV and PMTCT remained low in SSA. A number of participants from the studies mentioned that they remembered having had a test but were unclear about its purpose (Klaus et al., 2014; Vieira et al., 2017). Although, this may partially be related to lack of effective counseling or low health literacy, it denied patients the chance to access and process crucial health information (Rasmussen et al., 2013; Turan, Miller, Bukusi, Sande, & Cohen, 2008; Gourlay, Iorpenda, & Wringe, 2013). Additionally, some healthcare providers explained they felt underprepared and described the counseling process as difficult. Failure to understand the importance of knowledge resulted in a number of healthcare providers formerly doing HIV testing and prescribing medication to HIV positive women without informed consent and without pre and
post counseling. Consequently, inadequate pre and post-test counseling may result in fear of infection, HIV stigma and discrimination, and loss of follow up, with risk of MTCT of HIV. A study in Ethiopia revealed those factors may cause women and their spouses to develop perceptions of HIV testing as compulsory in antenatal care clinics, which limits 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, this may adversely affect antenatal care attendance rates (Landefeld et al., 2018). HIV positive mothers thus need to be informed that they can opt out of HIV testing until they feel prepared to take the HIV test.

According to several studies (Fleek, 2014; Laar & Govender, 2011; Matji et al., 2009), factors such as distance to reach the health facilities, cost of transport, and availability of means of transport came out clearly as barriers to the PMTCT uptakes. Low PMTCT uptake was also associated with lack of confidentiality in public healthcare institutions, which increased negative attitudes towards health facilities and increased maternal and infant mortality (Onono et al., 2015). The delivery of PMTCT must be accompanied by strategies that improve general HIV and PMTCT knowledge, address issues of stigma and discrimination, and consider local customary and cultural beliefs (Mulugeta, 2008; Vieira et al., 2017).

The experience of mothers using the PMTCT program during the prenatal, perinatal, and postnatal period was depicted in different ideas including loss of follow up, knowledge, infant feeding, fear, health facility, attitude of healthcare providers, support, and delivering the PMTCT programming. Loss of follow up was related to many factors, including lack of disclosure of HIV status; fear of stigma and discrimination (Vieira et al., 2017; Varga & Brookes, 2008b); lack of involvement of the partners, families, and communities (Nyondo et al., 2014; Vieira et al., 2017); lack of physical, social, emotional, and financial support; fear of negative partner repercussions including blame, emotional, and financial abandonment; physical violence; and household conflicts that may result in divorce, stigma, and discrimination (Sewnunana & Modibaba, 2015; Vieira et al., 2017). Lack of disclosure has been documented as a problem in SSA (Ferguson et al., 2012). 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, & Drew (2011) and Fadnes et al. (2010) supported that women who disclose to their husbands and family members perceive them as having a good understanding of HIV disease and perceive greater support from than prior to the HIV diagnosis.

Moreover, isolation of the PMTCT clinic was a cause of loss of follow up due to exposure of HIV positive 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 the 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).

Lack of clinical space to provide and discuss confidential health information has been a barrier of male involvement (Flax et al., 2017; Elwell, 2016). In addition, religious beliefs have been reported as a barrier to the PMTCT program in some countries in SSA. A number of women in Ethiopia have a belief in drinking holy water for healing, instead of taking ARV medication (Fleed,
Exclusive breast feeding is a good option recommended by WHO guidelines, especially to HIV positive women living in low resource countries. However, this exposes their children to 5 percent to 15 percent of MTCT. There are also social and cultural factors affecting the women’s ability to succeed exclusive breastfeeding, such as family pressure to introduce liquids and solids, stigma associated with a breast-feeding culture and cultural norms, and traditional feeding practices (Klaus et al., 2014, Woldegiyorgis, & Scherrer, 2012). A South African study supported these findings, where it was found that women who achieve exclusive breastfeeding successfully were those who had the ability to resist pressure from family members to introduce other fluids, and who had a supportive environment (Laar, & Govender, 2011; Moland et al., 2010). Choosing ERF is an ideal option because there is no chance of MTCT of HIV. The role of healthcare providers as facilitators is requested to help HIV positive women to be informed of their options and decision. However, the findings from our review showed that the women were lacking infant feeding information including counseling and they were exposed to unclear medical scientific information (Levy et al., 2010; Vieira et al., 2017). Lacking adequate information exposes HIV positive women to wrong decisions, which may negatively affect the health of both mothers and children. A Ghanaian study stated that women felt confused and unsure about the best infant feeding options because of conflicting messages provided by healthcare providers during counseling sessions (Laar, & Govender, 2014). Similarly, Matji et al. (2010) found that women who changed to exclusive breastfeeding were forced to breastfeed in the hospital. In contrast, good infant feeding counseling and support provided by healthcare providers could improve adherence to adequate infant feeding practices.

The findings from this review proposed that the issue of knowledge and awareness of HIV positive women needs to be addressed using qualified and skilled healthcare providers, as well as through the provision of regular and continuous training, and the availing of resources and logistics. In addition, engaging people living with HIV peers in the education of HIV positive mothers and increases of media messages were found to be useful. Furthermore, negative attitudes of healthcare providers need to be addressed.

**Conclusion**

In conclusion, the scoping review is an essential and well-regarded approach to reviewing health research evidence. The main strength of a scoping review is its ability to extract the essence of a diverse body of evidence and give meaning and significance to a topic (Benzie, Premji, Hayden, & Serrett, 2006). The focus of this scoping review was to answer the research question on what are the experiences of mothers using the PMTCT program to prevent HIV transmission in SSA? We used five level to organize the factors that directly or indirectly related to the complexities and challenges experienced by HIV positive mothers using the PMTCT program in SSA. The low rate of the PMTCT enrollment and ARV adherence among HIV positive women in SSA was associated with factors related to individuals, families, communities, health systems, and larger societal factors. The data suggest that the PMTCT enrollment and ARV adherence play a crucial role in MTCT of HIV. Addressing healthcare system barriers and promoting health education is an
important component in reducing the risk of MTCT of HIV in SSA. The gaps identified in this review include limited literature on the experience of mothers using the PMTCT program in SSA, lack of studies using a critical design, and a lack of an intersecting framework to assess the complexity of the interrelated factors affecting the uptake of the PMTCT. There is a need to develop interventions that respond to the complexities of factors that are associated with improving the PMTCT enrollment and HIV 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 community could strengthen this program. This review summarizes and describes the literature supporting my study. Research that adopts critical lenses within an intersectionality framework may help to understand the intersecting factors related to PMTCT of HIV in Rwanda and contribute to knowledge to address this multifactorial issue.

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