

# Prevention of HIV Transmission from Mother to Child: Challenges to the Successful Program Implementation and Practice in Indonesia

Journal of the International  
Association of Providers of AIDS Care  
Volume 20: 1-7  
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DOI: 10.1177/23259582211040701  
journals.sagepub.com/home/jia



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## Abstract

**Introduction:** The level of human immunodeficiency virus (HIV) transmission from mother to child in Indonesia ranks first worldwide. Newborn babies in Indonesia are at greater risk of experiencing the burden of HIV infection than babies born in other countries. **Objectives:** To explore the full extent of Prevention of Mother to Child Transmission (PMTCT) in South Sulawesi Province in 2020 and to discuss program and policy implications for PMTCT. **Methods:** This is a health system analysis study with a qualitative approach using focus group discussion, in-depth interviews, and observations in primary health centers and hospitals. **Results:** There is no local policy and guidelines for PMTCT programs and services; the coverage of HIV testing in pregnant women has not achieved 100% according to the target. There are limitations to human resources in public and private services to conduct the program. The assistance's activities to ensure antiretroviral (ARV) adherence are limited, and HIV-positive women faced stigma and discrimination, not only from the community but also from health workers. **Recommendations:** Some recommendations are to improve the HIV test coverage to 100% in pregnant women as well as the coverage and quality of ARV treatment.

## Keywords

HIV, women, prevention, ART, PMTCT

Date received: 25 January 2021; revised: 13 June 2021; accepted: 30 July 2021.

## Introduction

### Background

Despite major progress in the prevention and control, epidemic on the human immunodeficiency virus (HIV) continues to pose serious public health threats in all regions, including Southeast Asia. Indonesia has the fastest growing HIV epidemic, with a prevalence of 0.27% among adults (population above 15 years old) in 2019.<sup>1</sup> The Sustainable Development Goals aimed at ending the AIDS epidemic in 2030.<sup>2</sup> In reality, the UNAIDS report on the level of HIV transmission from mother to child showed that Indonesia ranks first worldwide.<sup>3</sup> In Indonesia, only 28% of pregnant women are HIV tested, and only 13% of HIV-positive pregnant women who receive ART in 2017.<sup>4</sup> The low coverage of pregnant women tested might associated with the limited number of health facilities that provide PMTCT services as only 1.7%.<sup>5</sup> According to the result of Systematic Literature Review, around the world, factors influencing PMTCT were socio demographics, distance to health

care facilities, number of ANC visits, knowledge and awareness, partner engagement, stigma and counseling.<sup>6</sup>

The minimum Prevention of Mother to Child Transmission (PMTCT) impact targets set by the World Health Organization for HIV are 50 new pediatric infections per 100,000 live births and a transmission rate of either below 5% in breastfeeding populations or below 2% in non-breastfeeding populations annually.<sup>7</sup>

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### What Do We Already Know about This Topic?

In Indonesia, PMTCT policy exists at the national level, however, in South Sulawesi, there are no local policies on PMTCT program management guidelines that are highly needed by program management officers and standard operational procedures for health providers in health services delivery, thus, it made the program implementation did not perform very well as shown by the low coverage of PMTCT.

### How Does Your Research Contribute to the Field?

This research contributes to national program by exploring root causes of the low coverage of PMTCT in South Sulawesi, particularly in Makassar City and Maros District and from our findings there are some recommendations as clearly stated in the manuscript.

### What Are Your Research's Implications toward Theory, Practice, or Policy?

This research found what are the root causes of PMTCT low coverage (theory), thus by solving those constraints and develop a policy as guidance; hopefully it could improve the program implementation (practice).

With the continuation of HIV transmission from mother to child, Indonesia has not been able to break the chain of transmission, which implies that the transmission continues into the next generation.<sup>8</sup> There is a need to explore the reasons for low PMTCT coverage in Indonesia. Thus, we conducted this study in South Sulawesi Province. The objectives of this study are to explore the full extent which includes policy at the local level focusing on PMTCT, PMTCT management mechanism, and services delivery mechanism of PMTCT in Makassar City and Maros District in South Sulawesi Province, Indonesia, and to discuss program and policy implications for PMTCT.

## Methods

This is a health system analysis with focus to 3 aspects, including policy at the local level focusing on PMTCT, PMTCT management mechanism, and services delivery mechanism and took 5 months from preparation to final report (December 2019-April 2020). This study used a qualitative approach using focus group discussion (FGD), in-depth interviews, and observations in health offices, primary health centers, and public hospitals. As a sample we did not involve the private hospitals, but we confirm their role to the program managers and it is very limited.

The analysis used was content analysis with relational analysis based on policy, program management guidelines, program coverage, HIV prevalence in pregnant women, private

sector involvement, support mechanism as well as stigma and discrimination. The instrument used was a questionnaire adopted from the WHO that has been used previously in West Java, Riau and Bali in Indonesia entitled: Validation of EMTCT of HIV and/or Syphilis: Tools and checklists for in-country evaluation of 4 required components.<sup>9</sup>

The site of this study was in Indonesia, specifically in South Sulawesi, as 1 of 10 provinces with a high number of HIV cases in Indonesia from 34 provinces. The study sites consisted of Makassar City and Maros District. Makassar City is the capital of South Sulawesi (that has the highest HIV prevalence in South Sulawesi) and compared with Maros District as the nearest place to Makassar City.

Each site was represented by 1 local public hospital and 5 primary health centers (PHCs). Data were validated by triangulating data from several sources (pregnant or breastfeeding women, midwives, HIV program managers in PHCs, hospitals, and health offices). The method considered aspects of the adequacy of participants, as well as several methods (FGD, in-depth interviews, and field observations).

Each site was represented by 35 participants. The FGD consisted of 10 pregnant and breastfeeding women, 10 midwives working at PHCs or private services, 10 program managers from 5 PHCs consisting of mother and child health staff and HIV program managers in PHCs. Participants for in-depth interviews consisted of 3 HIV program managers in a local government hospital and 2 program managers in a health office consisting of 1 family health staff and disease control staff. The number of person involved in FGD and interviews was the result of discussion between researchers and research assistant in the field with City and District Health Offices. One FGD consist of 8-10 persons that we thought it was manageable for dynamics during the discussions and hopefully could represent each component from FGD group, as well as the midwives from PHC and private sectors.

## Ethics Approval and Informed Consent

Ethics approval for the study was not sought because written permission to access data and health facilities was granted by the Ministry of Health—Directorate of Community Health, reference letter number K6.01.03/1/1558/2019 dated 2 October 2019. Consent was obtained from key informants and staff at the facility, sub-district, and district levels using a written informed consent form.

## Results

This section will present result based on 3 aspects: PMTCT policy at the local level, PMTCT management mechanism, and services delivery mechanism that break down into 7 themes: policy, program management guidelines, program coverage, HIV prevalence in pregnant women, private sector involvement, support mechanism as well as stigma and discrimination.

## Policy

Although the PMTCT policy exists at the national level, apparently in South Sulawesi, there are no local policies on PMTCT program management guidelines that are highly needed by program management officers and standard operational procedures (SOPs) for health providers in health services delivery. They only have the Local Regulation (*Perda*) No. 4/2010 about the Prevention and Control of HIV and AIDS for the development of HIV programs in general and as a basis of annual program budgeting for HIV. For HIV treatment, at the national level, there is a Ministry of Health Regulation No. 87/2014, which should be implemented in all health facilities, including PHCs. The PHCs that implements HIV testing and treatment is the Comprehensive Sustainable Service/CSS (*Layanan Komprehensif Berkesinambungan/LKB*), unfortunately, in Makassar City, the number of LKB PHCs is still limited, whereas in Maros District, there is no PHC that can provide comprehensive services for PMTCT.

## Program Management Guidelines

There are no standardized SOPs for PMTCT services at hospitals, PHCs, and midwives from private practices for pregnant women. The service procedures or flow of PMTCT are still different between PHCs. As we observed directly, some PHCs described the flow very clearly as acknowledged by the midwife, including the blood tested for HIV while other PHC did not.

Pregnant women come to the first antenatal care (ANC) visit at maternal and child health (MCH) unit will be tested for triple elimination, counseling at MCH, tests in the lab, then from the lab, the results are returned to MCH, if reactive then we refer them to the LKB room in our primary health centers. (Midwife from PHC in Makassar, YA)

## Program Coverage

The program coverage of HIV testing in pregnant women should be able to cover all pregnant women (100%) to prevent any HIV transmission from mother to child. However, currently the coverage has not reached 100% because The Health Offices in Makassar City and Maros District have not yet involved private hospitals and clinics. Those facilities refer pregnant women to undergo HIV testing to PHCs or local public hospitals with HIV testing facilities, but most of these pregnant women did not comply.

The target of K1 (first ANC visit) has not been achieved 100%, only 72% because there are around 8000 pregnant women come to midwives from private practices (*bidan praktik mandiri/BPM*). This is what we want to reach with local government funds: socialization program for midwives from private practices in PHC working area to bring it to the nearest health facilities. We are now inviting BPM and private hospitals and set network with them. The logistics are prepared to be sent to BPM. Therefore, the

midwife can test HIV for their patients. (Family Health/Nutrition Unit in Makassar, EH).

... There was only 79.8% achievement in HIV testing because there were pregnant women going to midwives from private practices (BPM) who were not given an HIV test. They need to be empowered. Our future strategy is socialization of PMTCT to BPM until they are ready to conduct HIV test for their patient and we give a triple elimination reagent. The first test (R1) is test for indication, if positive, the patient will be referred to the PHC, if the skills are good then they can use reagents 2-3 (HIV program manager for Health Office in Maros, VH)

## HIV Prevalence in Pregnant Women

HIV prevalence rate is a number of HIV positive pregnant women compared to all pregnant women. Since the coverage of pregnant women who tested for HIV in Makassar City and Maros District was still below 80%, therefore the HIV prevalence among pregnant women cannot be known exactly. Currently, HIV prevalence among pregnant women ranging from 0.03% (Maros) to 0.12% (Makassar). The proportion of HIV positive pregnant women who received ARV therapy was 96% in Makassar City and 100% in Maros District.

## Private Sector Involvement

All midwives in PHCs in Makassar City and Maros District have been able to do PMTCT, in contrast to the midwives from private practices who have not received training, so their patients must be referred to the PHCs. There is a challenge for the referral system in which patients did not come to PHC as referred. There are several reasons given by the patients who did not come to the PHCs, including long queues, long distances, expensive transportation costs, and no one assists their children in homes.

In Makassar, a patient with HIV from a non-LKB PHC will be referred to the LKB PHCs. In Maros, all PHCs have not been LKB; thus, patients will be referred to the local public hospital (Salewangang District Hospital), which has a risk of being non-compliant to take medication due to access and side effects.

There is no network with the private sector yet. Most patients referred to the PHC. With or without referral, patients will be served at the PHC. Primary health centers should also serve patients from BPM and are always monitored by the health office staff through WA. (HIV program manager at PHC in Makassar, NA)

## Support Mechanism

Positive pregnant women will only be accompanied by NGOs in Makassar if they are HIV positive, especially to monitor ARV adherence, while there is no such mechanism in Maros District.

... We need a technique to maintain privacy of the patient. So far, it has not been forced to take ARVs at the Salewangang District Hospital because the pharmacy is integrated with general pharmacy so other patient will recognize the HIV patient. It is important to consider the separation of the place for taking ARV with other drugs. There is no assistance from NGOs here, therefore, dropping out of ARVs in Maros is still a big problem because there is no assistance. (HIV Program Manager of the Health Office in Maros, VH)

### Stigma and Discrimination

Stigma and discrimination against HIV women are still high. They experienced stigma and discrimination from health workers (midwives and dentists), and this was also admitted by the midwives from PHCs and private practices. The midwives rejected HIV patients or even if they did not refuse, they felt worried about serving them. Apart from health workers, HIV women were also discriminated by the community around their homes; hence they closed their status. In Maros there are social factors such as the low involvement of men in accessing ANC in health facilities.

At first my neighbor knew that I was HIV positive, most of them distance from me and avoided to sit in chairs I was sit before. Finally after 2-3 years with close approaches and information dissemination, they get can accept it and get closed to me again. (Ay, women with HIV from Makassar City)

Other FGD participants also revealed that they afraid of get HIV from people living with HIV through some modes of transmission:

I do not want to get close to people living with HIV because I am afraid of getting transmitted with HIV, so I did not have meal with them and did not touch their hands. (Id, pregnant women from Makassar City)

### Discussion

Indonesia is a rapidly growing middle-income country with 262 million inhabitants presenting unique challenges for health systems and universal health coverage.<sup>10</sup> From 1960 to 2001, the centralized health system of Indonesia created a huge medical care infrastructure. The centralized one size fits all approaches did not address the complexity and diversity in many aspects. Decentralization of governance to 514 districts, further increased health system heterogeneity and degraded equity gaps. Hence, there are many limitations in municipalities and districts in solving their own problems, as we could see in the 2 study locations. Compared to other ASEAN countries that also decentralized their HIV services, Indonesia shown a very low coverage of HIV testing among pregnant women with only 28%. For example, in 2015, Malaysia achieved 95%, Thailand 95%, Myanmar 83%.<sup>11</sup>

In this study, which was conducted in Makassar City and Maros District, several progresses have been found in the prevention of HIV transmission from mother to child (PMTCT). One of the progress is, if compared to Maros District, Makassar City ready to implement PMTCT in terms of PHC that has the capacity to conduct one stop service of HIV testing and treatment. However, it appears that the current program achievement still has many challenges that need to be addressed immediately. Fortunately, there is hope to implement the PMTCT program to have high coverage and quality to achieve zero new infection in newborns.

In general, national and local policies on HIV and AIDS prevention and control have existed. Regarding PMTCT, only a national policy is available, Ministry of Health Regulation No.52/2017<sup>12</sup> that mandated all health facilities to implement elimination of HIV, syphilis, and hepatitis B transmission from mother to child. Since there is no local policy on PMTCT program management guidelines and SOPs, there is a need to release it and to increase the number of PHCs that implement HIV testing and treatment in Makassar City and Maros District.

The coverage of HIV testing in pregnant women at the ANC visit has not reached 100%, one of the reason was due to the absence of involvement from private hospitals, midwives, and clinics. It is estimated that if the infrastructure and capacity of PMTCT's programs and services like this continues, it will not cover 100% of pregnant women in Makassar City and Maros District. In other countries, factors influencing PMTCT were socio demographics, distance to health care facilities, number of ANC visits, knowledge and awareness, partner engagement and stigma.<sup>6</sup>

Regarding stigma, a study among private midwives conducted in Bali, Indonesia found difficulty to refer women to get HIV tested in other health facilities due to stigma, so it is recommended to enable midwives to screen their client for HIV onsite.<sup>13</sup> In Kenya, there are 5 approaches to improve programmatic coverage of PMTCT, consisting of better planning and management of resources, reaching all target populations through outreach services, supportive supervision for service providers, and linking communities with service delivery and monitoring for action.<sup>14</sup>

The proportion of HIV-positive individuals among pregnant women cannot be known exactly since the data collected were within a limited scope and not all pregnant women attended the antenatal care. In Maros District, there were social factors such as low involvement of men for their wives to access ANC in health facilities. In Kenya and Tanzania, this problem also existed for some reasons. Pregnant women did not come to antenatal care because their husbands prohibited their wives from attending ANC, religious leaders prohibited followers from seeking medical services, the perception that the service was too costly and conflicted with economic activities.<sup>14,15</sup>

As we found in a systematic review on PMTCT around the world, there are some factors that influence the low coverage of PMTCT, including partner support,<sup>6</sup> a study in the eastern part of Indonesia, Papua, shows that the majority of women had disclosed their HIV status to their partner and requested they

get tested for HIV.<sup>16</sup> Sero-discordant and HIV positive partners were reported to be more supportive than partners who refused to get tested. The latter could be mentally or physically abusive, and prevented women from adhering to treatment. The presence of domestic violence before and/or after HIV status disclosure became a main reason for PMTCT non-adherence reported by women. A study in Central Java, Indonesia showed that reasons of nondisclosure HIV status among respondent to their husband were afraid of her partner might leave them after know about HIV positive status and might think that they were unfaithful.<sup>17</sup> A study in Cambodia found a higher proportion of mothers who said the necessity of the permission by partners before HIV testing.<sup>18</sup>

Therefore, the importance of partner involvement in HIV testing should be stressed, although basic knowledge of HIV transmission is the best predictor for HIV testing. Promoting HIV knowledge to young women and men through communication strategies and health education by healthcare providers involving partners seems to lead HIV testing to be more acceptable and involve more male partners in the services. Regarding health education, there was one quasi experimental study conducted in West Java Indonesia involving 770 pregnant women in 2 districts with 4 stages consisted of exploration, installation, initial implementation, and full implementation. Activities given included the provision of health education, an offering of HIV testing, and the implementation of HIV tests for pregnant women in the community. The study showed that the implementation model effectively improved access to PMTCT services and was able to overcome the barriers to access PMTCT services.<sup>19</sup>

Therefore, the importance of partner involvement in HIV testing should be stressed, although basic knowledge of HIV transmission is the best predictor for HIV testing.

Findings from South Sulawesi also suggest a need to develop empowerment of midwives from private practices to be involved in the PMTCT program. So far, they can only refer patients to PHC; however, some of the patients did not show up due to long queues, long distances, and no one assists their children in homes, similar to a study in Tanzania.<sup>15</sup>

This study also revealed that assistance mechanisms for compliance with HIV testing and medication are still limited. For HIV testing, the PHC staff did not assist or accompany them; they will only be accompanied by NGOs if they are HIV positive, especially to monitor ARV adherence. According to a study in Tanzania, HIV-positive pregnant or breastfeeding women did not go to health centers for PMTCT or did not comply with medication for several reasons.<sup>15</sup> Among others, it includes pregnancy-related illnesses and ARV side effects, stopping medication to explore traditional healers' treatment, home birth, stigma and discrimination in health settings, weak health infrastructure, long distances to access medication, misunderstanding, and misconceptions of ARV treatment and drug instructions.

In Makassar City, there was a case of a pregnant woman who did not adhere to the treatment because of side effects, while compliant with ARV therapy (ART) significantly

prevented mother-to-child HIV transmission. A study in Rwanda showed that maternal ARV, infant prophylaxis, and maternal age older than 25 years were significantly protective to HIV.<sup>20</sup> ART for all HIV-positive women during pregnancy, and breastfeeding was associated with a low MTCT rate of 1.58%. Lack of disclosure showed an almost 7 increase in HIV transmission from mother to child. However, lack of disclosure and stigma may impact both treatment adherence and safe infant feeding. Stigma and disclosure to family and friends of HIV status have consistently been seen to impact PMTCT care and treatment adherence in the literature.<sup>21-24</sup> A study in Ghana showed that the knowledge of HIV-positive women on ART and PMTCT are important factors in adherence to ART.<sup>25</sup>

A systematic review in Sub Saharan African found that the successful PMTCT program could be achieved by increasing adherence of counseling of pregnant and breastfeeding mothers of PMTCT programs through all stages: prenatal, delivery, and post-partum, which will significantly improve health outcomes including reduction of premature deaths.<sup>26</sup> WHO strategies for ANC and PMTCT include prevention of HIV infection among women at reproductive age, prevention of unintended pregnancy among HIV-infected women, provision of specific intervention for PMTCT, provision of CST for HIV-infected women and their families.<sup>27</sup> Other innovative methods include the improvement of PMTCT therapies, use of m-health, and e-health as proxy adherence methods, promoting adherence techniques through direct observed therapy, especially in settings where the infected mother is unable to support herself.

HIV-positive women in this study also faced stigma and discrimination from health workers and the community. The midwives rejected HIV patients or even if they did not refuse, they felt worried about serving them. This also happened in Ethiopia and Vietnam.<sup>28,29</sup> Stigma and discrimination in healthcare settings; deter many members of key populations from learning their HIV status or accessing life-saving prevention and treatment.<sup>4</sup> A study among health workers found that the low quality of PMTCT services was determined for several reasons.<sup>29</sup> For instance, their own fear of HIV infection, lack of operational guidelines, lack of knowledge on HIV and counseling skills, high workload, and lack of staff. Health workers are key medical care providers.

Persons with HIV are often grouped with drug users and prostitutes as marginalized, discriminated-against, and criminalized elements in society as well as by health workers. This also happened in Western Kenya.<sup>30</sup> Some health workers who did not serve HIV patients also fear getting close to health workers with HIV patients. This is partly because of incomplete knowledge and understanding about HIV and how they transmit.

Prevention of mother-to-child HIV transmission is part of the global effort to end the AIDS epidemic by 2030, where the 90-90-90 target should be achieved. By 2030, 90% of all people living with HIV will know their HIV status; 90% of all people with HIV will receive sustained ARV therapy, and 90% of all people receiving ARV therapy will have viral suppression. The study in South Sulawesi showed that there is a hope to

eliminate HIV transmission from mother to child with strong commitment from all stakeholders, especially from the local government.

## Recommendations

There are some recommendations to improve the PMTCT program and services to achieve the goal. First, improve the HIV test coverage to 100% for pregnant women. To achieve this, all health workers from ANC services in the private sector (clinics, hospitals, and midwives) must be empowered through training and logistical support. PMTCT officers at the LKB PHCs should be given refreshing training to strengthen their knowledge and skills. Second, the coverage, quality and prompt ARV treatment should be improved. It is proposed to add the LKB PHCs in Makassar City and establish LKB PHCs in Maros District. Any functional improvement at PHCs must be preceded by an assessment.

## Authors' Note

Made a substantial contribution to the concept or design of the work: KNS; Analysis or interpretation of data: KNS, LH, R; Drafted the article: LH; Revised the article critically for important intellectual content: KNS, LH, R, LW; Approved the version to be published: KNS. Ethics approval for the study was not sought because written permission to access data and health facilities was granted by the Ministry of Health—Directorate of Community Health, reference letter number K6.01.03/1/1558/2019 dated 2 October 2019. Consent was obtained from key informants and staff at the facility, sub-district, and district levels using a written informed consent form.

## Acknowledgments

We would like to express our sincere gratitude to all partners contributed to this study, especially to the leader and staff from Yayasan Pelita Ilmu, The Joint United Nations Programme on HIV/AIDS (UNAIDS) that supported the funding for this research and all resource persons and informants that were the main source of this study.

## Declaration of Conflicting Interests

The author(s) disclosed receipt of the following financial support for research, authorship, and/or publication of this article: This manuscript was made by assignment and funding from the Directorate of Research and Development of the Universitas Indonesia based on the Rector's Decree Number: 1016/SK/R/UI/2021.

## Funding

The author(s) disclosed receipt of the following financial support for research, authorship, and/or publication of this article: This manuscript was made by assignment and funding from the Directorate of Research and Development of the Universitas Indonesia based on the Rector's Decree Number: 1016/SK/R/UI/2021.

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