

**THE REPRESENTATION OF PREVENTION OF MOTHER-TO-CHILD TRANSMISSION SERVICE SYSTEM IN SURAKARTA INDONESIA**

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Health Personnel; PMTCT.**DOI**<http://dx.doi.org/10.15294/kemas.v13i2.9567>**Abstract**

The data trend showing the increase in number of HIV/AIDS case through perinatal transmission in Indonesia, including Surakarta, is worrying. This qualitative study with exploratory method took place in Surakarta on February to May, 2015. The units of analysis in this study were recipient and provider of Prevention of Mother-To-Child Transmission (PMTCT) service. The informants were selected using purposive sampling. The data was collected using observation, in-depth interview, Focus Group Discussion and documentation, and was then analyzed using Parsons' system theory. PMTCT service system in Surakarta was ineffective because of HIV-positive women's limited knowledge and information on PMTCT, unequal relation between provider and recipient of PMTCT service, medical decision making pattern that is inherent to service provider, and inadequate financial resource and supervision process. For that reason, an action plan is required to accommodate the need of women and children in term of budget allocation, program implementation and civil society involvement in PMTCT to prevent and to cope with HIV/AIDS.

**Introduction**

The development of HIV/AIDS in Indonesia is increasingly worrying and tends to be HIV/AIDS-feminization-oriented, particularly related to risk factor of perinatal transmission (from HIV-positive mother to her baby) (Demartoto, 2015; Tasa, 2016; Nugroho, 2017). Data of Kementerian Kesehatan Republik Indonesia in 2011 revealed that the number of AIDS case with perinatal transmission risk factor is 742 cases. Until June 2011, 26,483 AIDS and 66,693 HIV cases were reported, in which 72.3% and 27.7% was male and female,

respectively. In 2014, the cumulative number of AIDS cases according to perinatal transmission risk factor was 1,506 cases (increased by 844 cases within 3 years) and the number of women with AIDS was 16,149 or 28.94%. In Surakarta on October 2005 to May 2015, there were 1,565 HIV/AIDS cases consisting of 532 HIV and 1,033 AIDS cases. By gender, 265 (49.9%) HIV cases in female and 267 (50,1%) in male, whereas 343 (32.6%) AIDS cases in female and 710 (67.4%) in male was reported. Meanwhile, by perinatal transmission risk factor, there were 75 cases (4.8%).

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The government had taken some measures through National Action Strategy and Plan (*Strategi dan Rencana Aksi Nasional*) of 2010-2014 of People Welfare Coordinator Minister and AIDS Control Activity Action Plan of Health Minister of Republic of Indonesia in an attempt to cope with it using Prevention of Mother-to-Child Transmission (PMTCT) program. Some reasons underlying it are: most (90.3%) HIV-positive women is in active reproduction age; more than 90% of HIV-positive children case is transmitted through transmission process from mother to child; HIV-positive children often developed impaired growth and development, sometimes for life; HIV-positive children more frequently develop infectious disease; and every child has the right to live a healthy and long life, and to develop his/her best self-potential.

PMTCT is a primary strategy that can include a wide spectrum of HIV/AIDS coping strategies (Gumbo, 2011; Torpey, 2011; Ruton, 2012; Ditekemena, 2015; Burton, 2015). PMTCT National Guidelines from Kementerian Kesehatan Republik Indonesia (2012) mentioned that PMTCT consists of 4 pillars: prevention of HIV transmission to reproductive-age women; prevention of unplanned pregnancy in HIV-positive women; prevention of HIV transmission from HIV-positive pregnant mother to her child; and provision of psychological, social and care support to HIV-positive mother, her children and relatives. There were at least 214 PMTCT services in Indonesia during 2014, distributed in Provincial, Regency or Municipal capitals, including in Central Java with 23 services. Surakarta Dr. Moewardi Hospital is one of the examples.

Talcott Parsons stated there should be at least two or more personnel and interaction between them in service system, purposefulness, structure, symbol and mutual expectation to which it refers (Torpey, 2011; Octaviany 2015). This system provides conceptual framework to interact between fellow human beings in a variety of situations, established by norms, trust, and values organized with role expectation. The Actor's role is highly determined by other's role by providing appropriate patterns. Therefore, social system could be measured as patterned

group of social roles that can run well like PMTCT service (Royce, 2015).

In its implementation, PMTCT in countries such as South Africa, Ethiopia, India, Senegal, Zambia, and Nigeria still found constraints and difficulties (Doherty, 2009; Balcha, 2011; Darak, 2012; Weiss, 201; Desclaux, 2013; Kim, 2013; Iwelunmor, 2014). Some problems were related to PMTCT access and service. The hospitals constituting PMTCT service referral had in fact yet to implemented good medical management to HIV-positive women despite their obligation to provide safe, high-quality, anti-discrimination and effective service by emphasizing more on patient benefit according to the Hospital's standard service (Mirkuzie, 2010; Gumbo, 2011; Rokhmah 2014). In many cases, a variety of medical measures not referring to guidelines, relatively difficult and expensive access, sterilization practice as if compelled, and discrimination by medical personnel were among the challenges in access and service quality of PMTCT (Nasution, 2012; Koye, 2013; Turan, 2013; Isni, 2016; Shaluhayah, 2017). This research is intended to study the effectiveness of PMTCT service system in Surakarta.

### **Method**

The qualitative research design with exploratory method was chosen to answer question, how and why concerning the PMTCT service phenomena for HIV-positive women in Surakarta, Indonesia. Data collection to build database was conducted from February-May 2015 using in-depth interview, recorded with tape recorder, using notebook, non-participatory observation, Focus Group Discussion (FGD) and documentation. The sampling technique used was purposive sampling. The informant in this study was individual and/or institution related to PMTCT service either as recipient or provider of PMTCT service with specified criteria.

The recipients of service were HIV-positive women who had or had not accessed PMTCT service, had ever been pregnant and given birth during 2012-2015 (Informants A, C, and E) along with their husband (informant B, D, and F). Service provider was referral hospital that had provided PMTCT service for more than 5 years, with high rate of client referral and whose

funding source was derived from state or other fund providers, i.e. Surakarta Dr. Moewardi Hospital, in this case, gynecologist (Informant K) and midwife in Obstetric Polyclinic of Dr. Moewardi Hospital (Informant L). Health Service is in charge of and responsible for PMTCT program represented by the chairman of Surakarta Health Service (Informant M) and Chairman of Disease Control and Environment Health Division of Surakarta Health Service (Informant N), then the organizer of AIDS Coping Commission Program of Surakarta City (Informant O), manager of Spek HAM NGO program (Informant P) and Chairman of Solo Plus Peer Support Group (Informant Q).

Data was analyzed using Parsons' general system theory. We conducted in-depth interview using an interactive model of analysis consisting of data reduction, data display and conclusion drawing (Miles, 2014). In this study, informants were reluctant to answer sensitive questions pertaining to HIV status and sexual relationship. In addition, funding and work program problems undertaken by an institution is sometimes not for the public's consumption. However, it is important to obtain the information because this study aimed to find out the service and response of provider and recipient of PMTCT services. To ensure the informants' confidentiality, the research was completed with informed consent document related to data obtained.

### **Result and Discussion**

HIV transmission to infant (baby) is 90% due to the transmission from HIV-positive pregnant mother and 10% due to blood transfusion. Mother-to-child HIV infection harms the child/baby's health. HIV infection resulted in social problems among mothers and increases mothers' death due to HIV. Meanwhile, it results in impaired growth, lifetime disease and social problem and it increases baby's death rate due to HIV and orphan among the babies. HIV transmission from mother to baby could be prevented by up to 50% through PMTCT intervention. PMTCT allows for first prevention to partner, family treatment and medication to prevent HIV transmission from mother to child. The Chairman of Surakarta Health Service stated:

“There are 4 interconnected pillars in PMTCT. Pillars 1-2: service recipient should be prevented from being infected with HIV, whereas pillars 3-5: health service provider should take medical measures such as treatment and medication in HIV-positive women and children” (Informant M).

Eighty percent of PMTCT service operations in Surakarta still use donor institution help, in this case, The Global Fund for AIDS, Tuberculosis and Malaria Round 8. The hospital providing PMTCT service, particularly Voluntary Counseling and Testing (VCT) clinic of Dr. Moewardi Hospital as coordinator of VCT program and clinic in Dr. Oen Hospital. PMTCT team consists of Gynecologist, Maternal Room Midwife, Infant Room Nurse and Midwife of Obstetric polyclinic. PMTCT team of Dr. Moewardi Hospital had actively socialized PMTCT to housewives, particularly those pregnant in 51 sub-districts of Surakarta in the People Care About AIDS program. Communication, information and education related to PMTCT include: all HIV-positive pregnant women should have themselves examined routinely to monitor their disease and pregnancy. Any disease found should be treated according to the health service guidelines. All HIV-positive pregnant women should give birth using sectio caesarian method, as a way of mitigating the risk of HIV transmission from mother to baby. HIV-positive pregnant women are recommended not to breastfeed her baby because HIV can be transmitted to her baby through lactation. Newborn babies from HIV-positive mother should be given antiretroviral medication immediately. In addition, material about the safest and best food choice for baby is presented, for example: the HIV-positive mother is mainly recommended not to breastfeed her baby but to replace it with formula milk.

National Guidelines of PMTCT specified by Kementerian Kesehatan Republik Indonesia in 2012 stated that all pregnant women coming to health service is obligated to obtain information on HIV transmission prevention during pregnancy and lactation. It is

associated with the service of HIV transmission prevention integrated into Maternal and Child Healthcare and Family Planning Service packages in individual levels of healthcare service. An effective way to prevent the transmission of HIV from mother to baby is to prevent unplanned pregnancy in reproductive-age HIV-positive women. As an attempt of preventing unplanned pregnancy among HIV-positive women, counseling service related to pregnancy planning, called Family Planning/Contraceptive, should be integrated into all of HIV treatment and medication service phases. In addition, HIV-positive pregnant women and their partners should be obliged to be informed through counseling about the risk of HIV transmission to baby during pregnancy, childbirth and lactation. HIV-positive pregnant women should also be given counseling regarding ARV use, options of delivery (childbirth) method and information about respective options, counseling regarding baby feeding and postpartum psychological support.

Our result showed that compared to National Guidelines of PMTCT, some discrepancies were found in the implementation of PMTCT in Surakarta. Basic information on HIV and PMTCT was still very limited for most HIV-positive women. In informants' perception, PMTCT program is only intended to HIV-positive pregnant women to protect their newborn from being infected with HIV. Knowledge related to pregnancy planning, particularly related to contraceptive, was still very inadequate. Information on how to access PMTCT service, according to most informants, was obtained through Non-government organization (NGO), Peer Support Group, mass media and internet. It is suggested by HIV-positive woman A and her husband B in FGD activity on April 2015 as follows:

"I knew about PMTCT from Spek HAM NGO rather than from Health Service." (Informant A)

"I knew about information on PMTCT by searching from internet by myself. I have ever gotten leaflet from AIDS Coping Commission in Surakarta City, and then accidentally visited there leisurely and asked for some in-

formation by myself." (Informant B).

Limited information on PMTCT program in HIV-positive women leads most informants to visit the service center when they were already pregnant. Such situation make the PMTCT service accepted by informants become incomprehensive, because they include only 3 pillars. K, the provider of PMTCT service in Dr. Moewardi Hospital said that:

"Generally, HIV-positive women came when they are already, they should have accessed PMTCT from pillars I, then II and so forth." (Informant K).

This is justified by HIV-positive woman C and her husband D.

"I indeed access PMTCT service at 5-month gestation." (Informant C).  
"The interval of pregnancy between my first to my second child is only 6 months, because my wife and I were uninformed concerning Family Planning service." (Informant D).

Most informants admit they have yet to receive service as mentioned in the guidelines. They do not understand the options of contraceptive, childbirth method, baby feeding and ARV prophylaxis administration to baby. E, the husband of HIV-positive woman E, suggested that:

"So far, in control period, my wife is only given vitamin, weighed, undertakes USG and is examined for her fetal condition" (Informant F).

Meanwhile, in FGD, F stated that:

"I feel pity to my child because he had to take bitter and coarse medicine while he is still a baby. I sometimes feel nauseated seeing him taking medicines. Hopefully, the medicine he consumes is efficacious (Informant F).

In our study, the relationship between service provider and recipient is defined as between those involved in service provider (hospital executing PMTCT, physicians, midwife, and nurse) and those in service

receiver (HIV-positive women, partner, and family). Our result showed that there was an unequal relation, suggested by both recipient and provider of PMTCT service in Surakarta. A situation where women with HIV as the service recipients that do not have opportunity or ability of making their own decision was often encountered. They have no choice because be it in the beginning of pregnancy, during and post-parturition, they received very limited even less understandable explanation from service provider. An HIV-positive woman giving birth with sectio caesarian told her experience that:

“It is just like in Dr. Moewardi Hospital, to get PMTCT service, those using Jaminan Kesehatan Masyarakat (Public Health Insurance) should bring a package of documents with them. But the physician did not tell us to do so, and when I was in Operation Theater he asked it and required us to provide money.” (Informant E).

“The physician does not allow me to give birth normally and even to breastfeed my baby, because it can transmit HIV.” (Informant E).

Our study showed that the information given to service recipient can be prohibition or mastery without accurate explanation. Informants stated that they obtain information by searching for it themselves rather than from service provider.

“I have been reprimanded by physician, “why can you be pregnant”! At that time my gestation was 4 months, thereafter the physician advocated me to attend PMTCT program”(Informant E).

Meanwhile, according to K (provider of PMTCT service):

“We consider case by case, when the patients have not consumed ARV yet and have unplanned pregnancy, the risk of transmission from mother to child is high. We also consider their condition, when it endangers mother and her child, we may consider other alternative after discussing it

with other physician. So the procedure is very strict” (Informant K).

E stated that:

“The clearer information concerns the program of giving birth normally, ‘how the procedure is’ is very important, and health service should be facilitated” (Informant E).

A variety of medical action not referring to the guidelines, presumably compelled sterilization case, and discriminative treatment by paramedic, were experience by most informants. Healthcare officer as service provider is felt less sensitive to women’s reproductive health right. Sterilization is performed when informants come to the hospital to give birth. Some informants undergoing sterilization are only informed when they have been on operation table. The signing of informed consent is made by husband during sectio caesarian operation. In certain context, it indeed can be justified, because medical measure taken by service provider is for the patient’s interest and corresponding to standard service of Hospital. Informants A and E stated that:

“When I went to the gynecology polyclinic, at that time we were devised to perform sectio caesarian, but in practice I give birth normally, because when we made room reservation, the management of hospital delayed it continuously with the excuse that it was not time for me to give birth according to the physician.” (Informant A).

“At that time, the physician did not ask me, and my husband signed the consent. I have entered the operation room. It was only when I would undergo operation, my husband was willing to sign the informed consent to perform sterilization” (Informant E).

It is justified by E, husband of E, as follows:

“I did not get couple counseling, I just know that the physician informed me that after giving birth,

my wife's uterus will be sterilized. I thought that when it has been sterilized, it will be able to recover to previous condition" (informant E).

Considering the data and information above, medical decision making pattern is more inherent to healthcare service officer as service provider. Most HIV-positive women as the recipient of service follow direction and decision made by healthcare service officer as service provider (Isni, 2016). It is in line with what was suggested by HIV-positive women, C, as follows:

"The physician did not allow me to breastfeed my baby because it can transmit HIVC" (Informant C).

Considering the result of interview, L, the provider of PMTCT service in Dr. Moewardi Hospital stated that:

"Although the choice is submitted to patient, but we always advocate the best one. For example, breastfeeding, it is very risky, so it is better to avoid it" (informant L).

"I asked for giving birth normally, but the physician said that sectio caesarian should be performed because it is risky to transmit HIV, finally sectio caesarian is performed" (Informant C).

Decision making pattern occurring between HIV-positive women and her spouse is interesting to be studied further. Informant stated that decision for being pregnant, giving birth and taking care of and raising child is made by herself as a mother. In the informant's opinion, having offspring and taking care of and raising child is a mother's responsibility, in which the informant considers her husband's role is limited to economic aspect (breadwinner).

"I am, as a husband, confused of thinking of cost, buying milk, baby's need. My wife just stays at home and takes care of our child. We are often involved in dispute because of being stressed with the duty of taking care of the

child while working" (Informant B).

"I don't know because perhaps she views that husband's duty is to earn money for delivery cost, and the wife's is to take care of child" (Informant D).

Both service provider and recipient do not feel that their spouse's involvement is important in PMTCT program.

"I never obtain information on sexual health, because when you go to the clinic, you will get medicine, get weighed, and sick, that is all. You never asked about how your relationship is with your spouse, how your sexual relationship is, is it still safe" (Informant E).

"I never receive couple counseling" (Informant E).

From the aspect of funding, the recipient of PMTCT service in Surakarta has been able to access this program free of charge, despite some people spending private fund. An HIV-positive pregnant woman, E, suggested as follows:

"At that time, I was asked to prepare 20 million rupiah for surgery. We did not have that much money. But in other hospital, by uncovering my HIV status, I can pay 5-6 million rupiah only. Finally, at that time, I gave birth in private hospital by uncovering my status" (Informant E).

Our study found that most informants accessing PMTCT service free of charge generally obtain it through *Jaminan Persalinan* (Giving Birth Insurance), *Jaminan Kesehatan Daerah* (Local Health Insurance) programs and reimbursement mechanism through the Global Fund for AIDS, Tuberculosis and Malaria Round 8 Program.

"When the patient has *Jaminan Persalinan* (Giving Birth Insurance), *Jaminan Kesehatan Daerah* (Local Health Insurance), we will offer it for intervention. When the patient does not have it, she has to pay privately, and if she is really poor, we

will contact GF, to get surgery and nutrition fund aid” (Informant K).

This study still found poor monitoring and evaluation mechanism related to the implementation of PMTCT program in Surakarta, in which Health Service as the one responsible for the program stated not having any monitoring mechanism and program evaluation. There are some constraints in the attempt of improving PMTCT service in the future, including poor coordination between policy holder and related partners, such as NGO and Peer Support Group. It means there should be an attempt to harmonize and improve coordination in improving the quality of PMTCT service. P, the manager of Spek HAM NGO program, stated that Health Service, as the leading sector, should perform capacity building, synchronization, harmonization and coordination with stakeholders related to PMTCT service. So far, Health Service, Local AIDS Coping Commission, NGO, Peer Support and CSR rarely sit together to discuss this problem. It is also expected by Q, the Chairman of Solo Plus Peer Support Group.

Surakarta Health Service as the one responsible for the PMTCT program at municipal city stated that monitoring and evaluation attempt does not specifically focus on PMTCT program. Monitoring and evaluation attempt is performed generally in relation to HIV/AIDS prevention and coping program. AIDS Coping Commission of Surakarta City had Prevention and Treatment Work Group including PMTCT program and activity in the attempt of optimizing the function of coordination and improving the quality of service. So, the members of Prevention and Treatment Work Group come from Health Service only without the representative of civil society, particularly the representative of Solo Plus Peer Support Group as service recipient. It is suggested by O, the organizer of Surakarta City’s AIDS Coping Commission Program, as follows.

“PMTCT is a program and activity of Prevention and Treatment Work Group. So, as far as I remember, despite Program and Activity of Surakar-

ta City’s Coping Commission, NGO does not belong to it” (Informant O).

Therefore, we concluded that the implementation of PMTCT program in Surakarta was ineffective because this program was carried out partially, rather than comprehensively, when referring to four pillars of PMTCT. It is admitted by informant N, the Head of Environment Disease and Health Division of Surakarta Health Service.

“I can say that the implementation of PMTCT has not been optimal yet, because it has not been consistent with the standard specified by Health Ministry of Republic of Indonesia with its pillars. I think it has not worked yet” (Informant N).

The perspective of general system theory focuses on the organization in broad definition, a set of components or elements existing in reciprocal relation (Royce, 2015). Considering the result of our study, there was incompatibility between the implementation of PMTCT program in Surakarta and National Guidelines of PMTCT issued by the Kementerian Kesehatan Republik Indonesia in 2012. Knowledge and information around PMTCT program should be obtained and understood by HIV-positive women and it becomes crucial. It is because, consciously or unconsciously, the ability of accessing information on PMTCT highly determines their perception on the program. In system theory perspective, information is very important because a continuous adaptation process between individuals and their environment will produce cognitive map, the subjective representation of material and social environments. Therefore, it is very reasonable that the HIV-positive women and her spouse/husband’s access to PMTCT program was still very limited in Surakarta, because the knowledge and information they obtain were also limited.

There is an unequal relationship between provider and recipient of PMTCT service and medical decision making pattern are inherent to service provider rather than to service recipient. The relationship between provider and recipient of service seems to be vague.

One of the parties, the service provider, tends to be more dominant. It occurred because the informants (HIV-positive women) cognitive map on HIV and PMTCT was very limited. Thus, it is not surprising that they eventually seem to be “submissive” to receive any treatment and medical decision completely from the service provider. Relation and medical decision making pattern that is dominated by service provider were due to the presence of shared symbolic meanings. In system theory’s view, individual construct their action corresponding to a symbolic meaning they gave to those objects in their environment. In this context, the informants, as the recipient of service, sometimes defines the explanation suggested by service provider as prohibition, in which anger is a form of power they have. Understanding that service provider has power compels the recipient of service to act passively and even to submissively receive any medical decision made for them. This medical social reality also occurs in India and South Africa (Darak, 2012; Burton, 2015).

Financial resource and supervision process also resulted in less effective PMTCT program in Surakarta. In this case, the importance of supervision or control is in the mechanism of establishing organizational balance. The implementation of supervision or control function can be clearly seen in the concept of cybernetics, emphasizing on supervision or control aspect of a system using feedback from the system environment itself. Feedback is a result and input all at once and it results from an interconnected and interdependent system. Supervision process reflected on monitoring and evaluation process had run less optimally. It is evident from unspecific monitoring and evaluation process in PMTCT program (Desclaux, 2013). Monitoring and evaluation have been performed in macro manner only over various attempts of coping with HIV/AIDS in Surakarta, in which PMTCT itself is a part of such attempt. In other words, the less optimal monitoring and evaluation process in PMTCT program indicated that the implementation of such program is less effective as well. Despite less optimal supervision process, a negative feedback remains valuable. It is because negative feedback can stimulate

improvement.

Apart from the interpretation that PMTCT service’s quality was still far below expectation, the recipients of service (HIV-positive women, spouse/husband and family) have shared expectation, to enable this service to protect the baby from the risk of HIV transmission. They, as the recipients of service, are highly dependent on the quality of PMTCT service. PMTCT service will be very useful when it can provide information comprehensively, involve husband/spouse, and sensitive to the need of women.

### **Conclusion**

PMTCT service system in Surakarta had run ineffectively due to incompatibility of the implementation of PMTCT service to the National Guidelines for PMTCT specified by Kementerian Kesehatan Republik Indonesia. Limited information given to HIV-positive women and their husband had put them on weak bargaining power in negotiating their need and decision related to access and treatment with healthcare service officer. It eventually leads to medical decision making dominated by service provider. So far, PMTCT program only emphasizes on women as the single beneficiary of this service. The involvement of their partner is the least prioritized aspect in PMTCT program. For that reason, the government, in this case AIDS Coping Commission, should develop an action plan that accommodates the need of women and children through PMTCT program in an attempt to prevent and cope with HIV/AIDS including budget allocation, program implementation and civil society involvement in any aspects. The action plan should confirm the active role of husband-wife couple in PMTCT program and require the presence of supervision attempt in the form of routine monitoring and evaluation in any area including imposing firm sanction to those omitting it.

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