

## **Non Disclosure Of HIV Positive Status Of Women To Their Partner : Implication For PMTCT**

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### **ABSTRACT**

**Background** : The prevalence of HIV virus from mother to baby or Mother to Child Transmission (MTCT) is the largest cause of infant and children infected with HIV / AIDS, which is 90%. This is the result of mother to infant transmission during pregnancy, childbirth and breastfeeding. Without intervention, there is a 20-45% chance that the baby will be born infected with HIV from a mother with HIV. Although many efforts have been carried out over the past few years, PMTCT coverage is still low in Indonesia

**Objective** : to explore non disclosure of HIV positive status of women and the implication for PMTCT program in Semarang City

**Method** : The method of this research is qualitative study with case study design by purposive sampling for choosing the subject. Interviews were carried out with 3 participants. These were transcribed verbatim and manually analysed using the thematic content analysis.

**Results** : The reasons of nondisclosure HIV status among respondent that was respondent felt that her partner might leave them after know about HIV positive status, the partner might be afraid of HIV from them, their husband might think that their unfaithful because their husband might think that HIV from person with sexual multipartner. The stigma related to HIV/AIDS and the behaviors associated with HIV risk have resulted in significant barriers to nondisclosure HIV status among respondent. All of the respondents didn't take ARV during pregnant, labour with pervaginam delivery, and they gave formula feeding.

**Conclusion** : Need designing the explicit rules in Central Java to the people who living with HIV/ AIDS who nondisclosure with their partner, health provider and deliberate to transmission her virus to the other. Counselling when VCT also explained about PMTCT focus on dealing with social factors, and behavioural beliefs that impact on disclosure of HIV status. Management should address health system factors that result in non-disclosure of HIV status.

**Keywords** : nondisclosure HIV status, PMTCT, partner

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## **INTRODUCTION**

Based on the WHO or UNAIDS in 2010 there were 33.4 million people with HIV/AIDS in the worldwide. A total of 15.7 million (47%) of them were women and 2.1 million children younger than 15 years. Globally, HIV is the leading cause of death of women reproductive age. During the year 2008 there were 1.4 million HIV-positive women with birth in a developing country and happened 430,000 HIV-infected infants. Majority of infections occur in poor and developing countries like Indonesia. The prevalence of HIV virus from mother to baby or Mother to Child Transmission (MTCT) is the largest cause of infant and children infected with HIV/AIDS, which is 90%. This is the result of mother to infant transmission during pregnancy, childbirth and breastfeeding. Without intervention, there is a 20-45% chance that the baby will be born infected with HIV from a mother with HIV. (Kemenkes, R.I. 2011, Depkes, R.I. 2008, Cock, De, et al. 2000, UNAIDS. 2010, WHO. 2010)

Currently, Indonesia has been an increase in the mothers with low risk of HIV infected sexual partner, and the babies born with HIV positive (Kemenkes, R.I. 2011 ). Estimated at around 400,000 people infected with HIV in 2010, and 1 million people living with HIV/AIDS in 2015 with 350,000 deaths. The risk of HIV transmission is not only limited to the sub-populations with high risky behaviour, but also to spread the partner or wife, and to his daughter. At the end of 2015 there will be a cumulative HIV transmission in more than 38,500 children born from HIV-infected mothers. WHO estimated 1,000 daily a new baby born with HIV and 2/3 of it is death. Most are in developing countries. Every hour around 32 infants died because of AIDS. Nearly 1,800 babies born per day has been infected with HIV. (KPA. 2007, Laksono, B. 2010) HIV transmission from mother to baby is from the transmission that generally obtained from an HIV-positive man.

HIV transmission from mother to infant can occur during pregnancy, childbirth and breastfeeding. HIV transmission from mother to baby is from an HIV-positive man who transmit HIV to a female partner through sexual, and transmit HIV to her baby. During the active reproductive age, women still have a risk to transmit HIV to the baby if they pregnant.

In addition to increasing the coverage of PMTCT interventions, women who disclose to their partners report more frequent condom use or abstinence (Nebie et al, 2001; Violari et al, 2004). After disclosure, partners often seek voluntary counseling and testing (Kilewo et al, 2001). If the partner tests negative, he can protect himself by using condoms during sex.

Although there are barriers to disclosure, disclosing one's HIV status can benefit people living with HIV infection in several ways, especially new mothers in need of support from their families. Disclosure to a partner or family member will help support planning for the child's future care. If the mother passes away or becomes ill, a partner or other family member can prepare to take care of the child. By disclosing their status, women often experience relief from no longer having to keep their HIV status a secret and they can be open to receiving support from family and friends (Bennetts et al, 1999; Violari et al, 2004). Finally, HIV-infected women often must disclose their HIV status to health and service providers to gain access to social, psychological, health, and other services that are increasingly available to people living with HIV infection.

Despite the many benefits of disclosure, HIV-infected women attending antenatal clinics often do not disclose their status (Medley et al, 2004). Stigma and social isolation related to HIV still exist in many communities (Skunodom et al, 2006) HIV-infected women are often discriminated against because some people associate HIV infection with behaviors known to cause infection (eg, commercial sex work and

injecting drug use), and from an unfounded fear of HIV transmission following casual exposure to HIV-infected persons. (Skunodom et al, 2006) They do not disclose their status so as to protect themselves and their children from harmful societal response. Moreover, fear of violence, abandonment or blame, along with concern about placing new burdens on loved ones, are additional barriers to disclosing one's HIV infection to family members and partners (Antelmen et al, 2001; Issiaka et al, 2001; Kilewo et al, 2001; Galliard et al, 2002; Kalyesubula et al, 2004; Kumar et al, 2004).

Although many efforts have been carried out over the past few years, PMTCT coverage is still low in Indonesia, 10% in 2004, then increased to 35% in 2007 and 45% in 2008, 6% in 2010. (Kemenkes, R.I. 2011, WHO, 2010)

One of the causes for the low participation of HIV positive women in PMTCT programmes is the nondisclosure of HIV test results to a sexual partner. (Medley A, Garcia, 2004). This study is aimed to explore non disclosure of HIV positive status of women and the implication for PMTCT program in Semarang City.

## **METHOD**

The method of this research is qualitative study with case study design. A case study design was used from April to September 2012. The study setting was in the Semarang City, the respondents included three HIV positive women with non disclosure status with their partner. Informed written consent was obtained after the study. All interviews were conducted in a private room with the case manager. The case study methodology satisfies the three tenets of the qualitative method: describing, understanding, and explaining. Case studies can be single or multiple case designs. Single case studies are used to confirm or challenge a theory, and they are also useful in gaining access to a phenomenon that was previously seen to be inaccessible.

However, in both approaches, case study is done in a way that incorporates the views of the individuals in the case under study, and therein lies the methodological dilemma.

A frequent criticism in terms of limitation is that case study methodology is dependent on a single case, which results in difficulties regarding the generalizability of findings (Yin, 1994). In response, generalization of results, using case study as a methodology is made to theory and not to populations. However, the value of using case study as a methodology is its quintessential characteristic, which strives towards a holistic understanding of cultural systems of action (Warne, 1999). Cultural systems of action refers to interrelated activities engaged by individuals in a social situation, and for this reason, the case study must be bounded (Stake, 1995). The unit of analysis is a critical factor in the case study. It is typically a system of action rather than an individual or group of individuals. Case studies tend to be selective, focusing on one or two issues that are fundamental to understanding the system being examined. In addition to the above, case studies can provide multiperspective analyses. The researcher must consider not just the voice and perspective of the actors, but also the relevant groups of actors and the interaction between them. This is salient point in terms of the case study methodology as case studies can give a voice to the powerless and the voiceless. In-depth interviews were used for data collection, allowing for further exploration of specific topic areas that had emerged from a review of the literature. All interviews were audiotaped and transcribed, and each transcript was subjected to a thematic content analysis.

Ethical approval for the study was gained through a university research ethics committee governing the work of one of the authors. This research use purposive sampling for choosing the subject. The three participants for each of the case studies were recruited via manager case with inclusion criteria : nondisclosure with her

partner, knew about PMTCT, didn't follow PMTCT programme. Written information and the opportunity to clarify any questions they had about the project were provided. Written consent was obtained from each participant. Participants were assured that they could opt out at any point during the study and that their contributions would remain anonymous and confidential. The study protocol was reviewed and approved by the Research Ethical Committee at Diponegoro University. For this article, the analysis focused on the data regarding nondisclosure of HIV positif. These were transcribed verbatim and manually analysed using the thematic content analysis.

## **RESULTS AND DISCUSSION**

All the respondent got HIV for their husband or partner. Two of them married again after their husband passed away because of HIV infection. This respondent didn't open status with a new husband. The reasons of nondisclosure HIV status among respondent that was respondent felt that her partner might leave them after know about HIV positive status. One respondent said that the partner might be afraid of HIV from them. Two respondent reported that their husband might think that their unfaithful because their husband might think that HIV from person with sexual multipartner. Their partner might think that they a bad person. All respondent said that they felt the results were their secret. The stigma related to HIV/AIDS and the behaviors associated with HIV risk have resulted in significant barriers to nondisclosure HIV status among respondent. Among three respondent, one of them was sexual worker that nondisclosure with their sexual partner. The main reason from her decision was because when in the past she always used condom 100% with all of her sexual partner, but she never used condom with her boyfriend. After 5 years they got the relationship, her boyfriend said that he was HIV positive man. Respondent was dissappointed because she got

HIV from her boyfriend that she trusted. After that she did not always used condom to her sexual partner but the decision of condom used depend on her partner.

Regardless of HIV status, disclosure is of importance in PMTCT programmes as it allows an individual to get spousal or family support for preventive actions they may decide to undertake. Among negative women disclosure may motivate the sexual partner to seek testing and among positive women it enables couples to make informed reproductive health choices (Medley, A, 2004, Mucheto, 2011). Failure to disclose by positive women make the partner could be infected and therefore transmission can still occur to the unborn child. In this study, respondent with nondisclosure HIV status with their partner made their didn't follow PMTCT programme. All respondent knew about PMTCT programme.

In this study, all of respondents knew that mother to child transmission of HIV virus can occur during pregnancy, delivery and breast milk feeding. One respondent had take ARV but when she married with a new husband, she stopped to take the ARV. Two respondent did not take ARV, they afraid from side effect of ARV, although one respondent knew that she got HIV in 2006, and the other in 2009. When they peggant in 2008 and 2011, they still didn't take ARV because if it. This nondisclosure status may prevent women from providing a blood sample for CD4 cell enumeration in an HIV/AIDS care and treatment setting. Being known by their partner if they HIV infected and fear of stigma made their decision wether didn't take ARV.

All of the respondents did not planned their pregnancies according to the procedure of HIV positive pregnancy in aspects of both social and medical aspects. No mothers before pregnancy had examined and reaching levels minimum of CD4 500/mm<sup>3</sup> as a condition of HIV positive women who allowed to pregnant. Two of respondents in early marriage did not use a condom during sexual intercourse. Illustrative

quotes include:

*"I am nondisclosure with my husband, he was single status when marry me and we never used condom in aim to be pregnant..."*

A, 36 th

*"In my second pregnancy when I am HIV, I didn't planned.. I knew that I am pregnant in 16 weeks..."*

B, 32 th

Vaginal delivery experienced by the three respondents. One respondent in the PMTCT Unit Hospital. Two respondents undergoing vaginal delivery with midwife. One respondent labor in the PMTCT Unit hospital. The process without any problems and complications.

One of the respondent was pregnant again with a new husband in which he did not disclose their HIV positive status. Respondents had vaginal delivery in fourth prgenancy with the midwives in the Rose Hospital (pseudonym name). Two days after delivery, the baby of respondents died with the unknown cause. Possible respondents baby died because of HIV / AIDS which may be obtained from the HIV respondents during pregnant, or delivery. Respondents did not said the HIV positive status at the hospital. In the fifth labor, the respondent had done vaginal delivery but without any complications. Respondents had a normal delivery again at one hospital in the city of Semarang, Rose Hospital (pseudonym name). The delivery process was helped by a midwife. Respondents did not disclose their HIV status remains positive on health workers, especially midwives who helped in delivery process. Illustrative quotes include:

*.. ya she helped my delivery but she didn't knew my HIV positive status...*

A, 36 years old

*.. women who helped my delivery process was midwife, I didn't told that I am HIV positive.. there was no complication in the delivery..*

C, 32 years old

An elective caesarean section (CS) reduced substantially vertical transmissions among untreated or non-highly active ART (HAART) treated pregnant women (Lancet, The International Perinatal HIV Group, 1999 ). In 2001, new Spanish guidelines on the management of HIV-infected pregnant women were issued (Iribarren JA, 2007). These guidelines no longer recommend an elective caesarean section for all HIV-infected women, with offer of vaginal delivery deemed to be acceptable if women were treated with HAART and had a viral load before labor of below 1000 copies/mL. In 2000, the American College of Obstetricians and Gynecologists (ACOG, 2000) issued a Committee opinion recommending that women with viral loads greater than 1000 copies/mL should be counseled regarding the potential benefit of scheduled caesarean section.

Vaginal delivery in HIV-infected women requires careful management, particularly regarding potential MTCT risk factors. Risk of intrapartum transmission may be increased with fetal scalp blood pH monitoring, and this procedure should be avoided (Coll O, Fiore S, Florida M, et al, 2002). The possibility of an increased MTCT risk associated with the use of episiotomy and/or forceps/vacuum extraction cannot be excluded on the basis of current data (European Collaborative Study, 2005 ; Mandelbrot L, Mayaux MJ, Bongain A, et al, 1996). Furthermore, MTCT risk is increased with prolonged duration of rupture of membranes, with an approximate 2% increased risk with every increase of 1 hour in the duration of ruptured membranes (The International Perinatal HIV Group, 2001). Finally prostaglandin to achieve cervical ripening when pregnancy



termination is indicated should be avoided due to their association with long delivery. All these conditions limit labor management in such a way that a high percentage of women in labor will usually undergo a caesarean section. Concerns regarding the potential for increased risk of postpartum complications following caesarean section deliveries have been raised since elective caesarean section was first suggested as an intervention for preventing MTCT (The International Perinatal HIV Group, 2001, Bulterys M, Chao A, Dushimimana A, Saah AJ, 1996, Read JS, Tuomala R, Kpamegan E, et al. 2001, Marcollet A, Gofûnet F, Firtion G, et al. 2002, Read JS, Newell ML. 2005, Stutchûeld P. 2005, Taylor LK, Roberts CL, Olive EC, Henderson-Smart DJ. 2005).

Nondisclosure status of HIV positive to the birth attendant, made the risk of HIV transmission, if they didn't used standard of universal precaution. The partus instrument if didn't sterilization made high risk to another women who had vaginal delivery in these midwife or birth attendant who had attended the delivery process of HIV positive women.

There was no complications or problems that occurred during childbirth for all respondents. All respondents use formula feeding during lactation. No respondents gave the breastfeed even if they did not follow the PMTCT programme. All respondents stated that breastfeeding was the one way to prevent HIV transmission from mother to child. Two of respondents giving milk substitute from birth until the age of 2-3 years. Without fostered counseling including information about the risks and benefits of breastfeeding, HIV-positive women may have made suboptimal infant feeding decisions (e.g., mixed feeding, underfeeding) based only on the knowledge that HIV can be transmitted by breastfeeding. (Muluye, 2012). Despite of disclosure of HIV status greatly influenced infant feeding options of HIV positive mothers

when the partner was aware of the HIV status of the mother and involved in the decision (Bulterys M, Chao A, 1996).

Of the three respondents, one of them getting HIV prevention drugs for children. Two of the respondent did not get cotrimoxazole prophylaxis, the reason one of them based on the results of consultation with HIV/AIDS doctor team that said the drug was not given to the consideration of the social aspects. The reason was based on respondents who nondisclosure HIV status to her husband. Cotrimoxazole use in HIV infected children can result in decreased morbidity and mortality.

The condition of the children among the three respondents was healthy. The respondents fear the child's HIV status, so that the respondents did not examined their child's HIV status. One respondent examined the child's HIV status with negative result. Possibility in this case because of the respondents use formula feeding during lactation. Illustrative quotes include:

*.. I didn't examined my child, because I am afraid if the results was HIV positive ..*

A, 36 th

The results of this study was same with the findings of the Ditrane Plus study in Cote d'Ivoire which consistent with a previous clinical trial of randomly allocated infant feeding practices in Kenya (Becquet R, Bequet L, Ekouevi DK, Viho I, Sakarovitch C, et al, 2007), with the preliminary results of a cohort study in Uganda and with a large African pooled analysis (Mbori-Ngacha D, Nduati R, John G, Reilly M, Richardson B, et al. 2001 ; Magoni M, Bassani L, Okong P, Kituuka P, Germinario EP, et al. 2005 ; Newell ML, Coovadia H, Cortina-Borja M, Rollins N, Gaillard P, et al. 2004).

However, these findings differ from operational research suggesting that formula feeding was associated with higher mortality, morbidity, and stigma in field settings (Bahl R, Frost C, Kirkwood BR, Edmond K, Martines

J, et al. 2005 ; Doherty T, Chopra M, Nkonki L, Jackson D, Greiner T, 2006). More recently, a clinical trial conducted in Botswana allocated at random 6 mo of breast-feeding plus prophylactic infant zidovudine, or formula feeding plus 1 mo of zidovudine (Thior I, Lockman S, Smeaton LM, Shapiro RL, Wester C, et al., 2006). In that trial, the probability of infant death by month 7 was significantly higher in the formula-fed group than in the breast-fed group (9.3% versus 4.9%;  $p < 0.003$ ), but this difference diminished beyond month 7, such that the time-to-mortality distributions through 18 mo of age were not significantly different (10.7% versus 8.5%;  $p = 0.21$ ).

Women play important productive and reproductive roles in society (Green C, 1994) : the biopsychosocial model of health care in which societal values and culture are considered can offer solutions for a more appropriate PMTCT service, as pregnant women are part of a family and a community, and babies are born into that family and community (Borrell-Carrió F, Suchman A, Epstein R, 2004 ). Behavioural intention that disclosure may cause divorce, physical abuse by spouse and fear of the rejection were risk factors for nondisclosure of HIV status. The uptake and adherence to PMTCT programmes is difficult for women whose partners are unaware of their HIV status. Women lack power to make independent decisions with regard to the safety of their own and their children's health. It is, therefore, difficult for HIV positive women to seek social and medical support from care and support programs for themselves and their infants without disclosing their HIV status to their partners. (Medley A, Garcia, 2004 )

## CONCLUSION

One of the reason why PMTCT coverage low in Indonesia was because nondisclosure of HIV positive status of women. In this study, although all of the respondent didn't followed the PMTCT programme, but all of them gave infant

feeding, they didn't gave breastfeeding. The impact of these, one of the child had negative HIV status.

Socialization of PERDA HIV No. 5 of 2009 in Central Java HIV to the community and people living with HIV in relation to health care providers are obligated to protect people living with HIV from stigma and discrimination. Need to enforcement it rules in Central Java and the explicit rules to the people who living with HIV/AIDS who nondisclosure with their partner, health provider and deliberate to transmission her virus to the other.

Counselling when VCT also explained about PMTCT focus on dealing with social factors, and behavioural beliefs that impact on disclosure of HIV status. Management should address health system factors that result in non-disclosure of HIV status.

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