## The Experiences of Pregnant Women in Having HIV Test at the Community Health Center in East Jakarta, Indonesia

#### Rita Ismail

School of Nursing, Health Politechnic Jakarta III, Jl. Arteri JORR, Pondok Melati, Bekasi, Jawa Barat, Indonesia

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Abstract:

Background: In 2013, East Jakarta was the area in Jakarta province with the highest HIV cases. However, it is not followed by the awareness for having an HIV testing, especially pregnant women. Objective: to describe the experience of pregnant women in having an HIV test at a community health center (CHC). Methods: Descriptive narrative was used in this study. In-depth interviews about the women' experiences in having HIV test were conducted with 10 pregnant women at the CHC. Interviews were conducted on 2017 and recorded using a digital voice recorder. Data were analyzed using content analysis method and validated with health care provider (HCP) and observation. Results: Three themes emerged: obedient to the health care providers' recommendations, HIV testing as part of a pregnant woman's health test, lack of knowledge about HIV testing. All women agreed to have an HIV test, however they still had limited knowledge about HIV test and the right to have an HIV test. Conclusion: Pregnant women have an HIV test based on HCP's recommendation. Providing more information about test HIV and private room at the CHC and having more health education in the community is needed to increase pregnant women's understanding about HIV test.

## 1 INTRODUCTION

Indonesia is one of the countries in Asia with the highest HIV new cases (National AIDS Commission Republic of Indonesia [NAC], 2010). In 2005, the number of HIV cases in Indonesia was 859 and increased to 30,935 by 2015 (Ministry of Health Republic of Indonesia [MoH], 2016). In 2015, Jakarta was the province with the highest HIV rate in the Indonesia, 4,695 cases, followed by East Java (4.155 cases) and West Java (3,741 cases) (MoH, 2016). Compared to other districts in Jakarta, East Jakarta had the highest number of new HIV cases (MoH, 2013). The number of new HIV cases in 2013 in East Jakarta was 240, while in other districs were less than 200, 199 cases in South Jakarta, 196 cases in Central Jakarta, 156 cases in West Jakarta, and 78 cases in North Jakarta (Badan Penelitian dan Pengembangan Kesehatan, 2013).

The number of women living with HIV in Indonesia also increases sharply, from 3,565 in 2008 to 12,279 in 2013 (MoH, 2014). Although the number of new HIV cases in women increases every year, awareness of women, especially mothers, to have HIV testing is still very low (MoH, 2014). The Ministry of Health reported, only 0.4 percent

(21,103) of 5,060,637 pregnant women performed HIV testing in 2011. Of those who had HIV test, 2.5 percent (534) were HIV positive (NAC, 2012).

A study in Jakarta showed that women were tested for HIV not during their ANC visits but because of the advice of doctors when their husband's HIV test was positive (Hardon et al, 2009, Ismail et al, 2018). A study in Bali showed that lack of knowledge about HIV in pregnant women, receiving information about the prevention methods of HIV transmission from mother to fetus with early detection of HIV was only delivered by health workers when offering HIV testing, resulting many pregnant women refuse to have HIV testing (Anggraini, 2014). This condition results delay of pregnant women knowing their HIV status, not geting adequate treatment, and increasing the risk of HIV transmission to the fetus. The number of AIDS cases through mother-to-child HIV transmission was 244 in 2010 and became 294 in 2015 (MoH, 2016).

Indonesian government has implemented any programs to increase the coverage of HIV testing in pregnant women. In 2013 the MoH launched a program to prevent HIV transmission from mother to child (PMTCT). Pregnant women who visit health facilities for ante natal care (ANC) will be offered an

HIV test. Health care providers (HCPs) are required to offer HIV testing to pregnant women, especially in the HIV epidemic area. HIV testing is carried together with other routine laboratory examinations (MoH, 2012). After applying this program, the number of women diagnosed with HIV increased from 12,279 in 2013 to 12,573 by 2015 (MoH, 2016). Based on these conditions, the purpose of this study was to describe the experiences of pregnant women in having an HIV test at a community health center (CHC) in East Jakarta.

### 2 METHODS

This is a qualitative study with descriptive narrative method. The population of this study were pregnant women who visited the CHC in East Jakarta for ANC and got HIV test. The inclusion criteria included having an HIV test at the CHC during their current pregnancy; being able to speak Indonesian well; willing to be fully involved in the research; and signed the consent form as participants. The exclusion criteria are participant not able to complete the interview.

Data were collected from September to November 2017. In-depth interviews were conducted participants using interview guidelines. Interview questions included how they have an HIV test, their reason to have an HIV test, the result of their HIV test. Interviews were recorded using digital voice recorders. Interviews were conducted for 30-60 minutes in one of the rooms at the CHC. Before the interview, the researcher explained the purpose of the study, provided an opportunity for participants to ask questions related to the study. Once the participant agreed to get involved in the study, participants were asked to sign the informed consent sheet. During the interviews, the researcher made field notes as supporting data. The researcher also validated the data related to the answers of the participants at the end of the interviews to avoid misinterpretation and validated to the HCPs and observation.

Interviews were transcribed verbatim and analyzed using content analysis method with the process: 1. Open coding: reading the interview texts carefully and repeatedly, writing notes, labels, and headings the data); 2. Category creation: creating groups based on headings. Each category consisted of similar data. Each category was divided into subcategories; 3. Abstractions: Data were put together into general categories and used words that consisted of the content obtained. Ethical clearance

of this study were obtained from Ethical Committee Health Polytechnic Jakarta III.

### 3 RESULTS

## 3.1 Characteristic of Participants

Of 15 prospective participants who were asked to get involved in the study, only 10 who agreed. Three prospective participants refused to participate because of time constraints or they had to redeem drugs at the pharmacy. Two participants who were contacted by telephone did not respond. One HCP who worked at the ANC unit was interviewed to validate the data. The researcher also did observation on the process of HIV test on pregnant women at the CHC.

The age of participants ranged from ages 20 - 36 years in which more than half of participants are over 30 years old. Half of the participants completed high school, while others were junior high school. Only one participant had a bachelor degree. Almost all participants were housewives. One participant worked as a private employee while other two participants worked as traders.

Half of the participants had their first pregnancy, while others were their third, fourth and fifth pregnancy. All participants' HIV test results were negative. The average age of the participant's husband was 31 years with a range of 19-40 years. Half of the participating husbands completed high school, while the rest finished junior high school and undergraduate degrees. Almost all participating husbands had a job, except for one person (because of illness). Most of participants' husband worked at private companies, while others worked as entrepreneurs or couriers.

#### 3.2 Themes

There are three themes found in this study, namely:

## 3.2.1 Obedient to the Health Care Providers' Recommendations

All participants stated that they had HIV test because of the request from HCPs, midwives at the CHC and midwives who referred them to the CHC for having blood test. Some participants stated that HCPs informed them that pregnant women were required to take an HIV test. Only one participant came to the CHC to have a blood test. Another participants had an HIV test because of a referral

from the midwife. Other participants visited the CHC to check the condition of their pregnancy.

"The main thing is that when we have ANC we are immediately asked to... to have blood draw and a urine test." (H1, 28 years old)

"Actually, I had ANC at a midwifery clinic. The midwifery recommended me have HIV test and it can be done in the CHC. That's why I come to this CHC." (H1, 24 years)

The reasons of the participants agreed to be tested for HIV was because it was recommended by HCPs and useful to know the condition of their pregnancy.

"Yes, we just follow [the HCP's recommendation] so that it will be easy for us when we have ANC... If you know it, we refuse to have it [HIV test], we will get confused by ourselves if there is something happens on us...We will have trouble by ourselves." (H2, 28 years).

"We were just told [to have HIV test]. It's said that it [HIV] is a mandatory test. Every pregnant woman must get tested [for HIV]. It was for unpredicted diseases. Thus we must get tested. "(H7, 35 years).

"The reason is so my baby and for our health ..." (H1, 28 years)

All participants stated that it was their first time testing for HIV test. None of the participants had HIV test in their previous pregnancy. There was one participant who planned to take an HIV test before becoming pregnant but she did not do it until got pregnant.

HCPs stated that they had to offer and persuade the pregnant women for having an HIV test on their first visit at the CHC. It is one of the government program to increase HIV test among pregnant women.

## 3.2.2 HIV Test as Part of a Pregnant Women's Health Test

All participants stated that there were several tests they had other than HIV testing during their first ANC at the CHC. These tests included blood drawn and urine tests for Hepatitis B, hemoglobin, platelets, glucose, leukocytes, blood types and rhesus, urinalysis (albumin and glucose). All these tests were free of charge because they were covered by the Indonesian national health care insurance.

Before having the tests, participants were given a brief explanation by HCPs at the MCH regarding the name and purpose of the test tests. They were also interviewed about high risk behaviors. Once they had received information about the test, they were referred to the STI clinic and laboratory for blood draw and urine collection

"I was asked to...I was interviewed and asked to have blood draw and urine test for HIV." (H1, 28 years old)

Participants had blood draw and urine test in the laboratory. The results of the tests were received at the same day or the next day if the participants did not have to wait for the results. The test results were read and explained by HCPs or they were contacted by HCPs by phone to inform their test results.

"At first, they did blood draw and urine test...and the process could take a whole day. The next morning, if I am not mistaken, we can get the test results." (H7, 35 years)

"Morning, at that time it was 10 o'clock? 9 o'clock? I had the test. At 3 o'clock the results were finished. I met the midwife, she explained to me that the thrombocyte and haemoglobin level were normal. Everything is normal. And she explained the HIV test result. The syphilis test was negative. For Hepatitis B, it needed a week to get the result. I was informed by phone about the HB test result. "(H5, 30 years)

The HCPs stated that pregnant women had to have several tests on their first visit including HIV, hepatitis B, and syphilis. The women were also checked for complete blood count and urine test.

# 3.2.3 Lack of Knowledge about HIV Testing in Pregnant Women

The main reason of participants did not have HIV test before becoming pregnant or initiated for having HIV test once they were pregnant was because they were not aware of HIV test for pregnant women. Some participants stated that they knew the importance of HIV testing for pregnant women when they had ANC at the CHC.

"I don't know about it [HIV test for pregnant women]" (H1, 24 years)

"People don't have time to do it [HIV test], we know about it when we are here [CHC] right here." (H3, 21 years old)]

Some participants were able to explain about HIV transmission, including sexual intercourse and needles; groups who needed to have HIV test were those who practiced high-risk behaviours such as prostitutes or injection needle users. Several participants stated that HIV can be transmitted through coughing.

"Usually it is transmitted through a syringe ... it is contagious ... Syringe, having sex other than

their partners [were the HIV transmission mode]." (H4, 35 years)

"Yes, it [HIV] is contagious ... it can be transmitted through coughing" (H1, 21 years)

Some participants stated that before having HIV test, HCPs only gave a brief explanation to the participants. The test is to determine the condition of maternal and infant health and identify treatment if the laboratory results were not normal. When explaining laboratory test results, the HCPs only stated that the results of the test were normal without any follow-up information.

"Yesterday, I was only told that it was for HIV test, as well HB test, that's what the HCP explained." (H1, 24 years)

"It was explained. I was just told that all the test results were normal." (H1. 21 years old)

Before the women have an HIV test, the HCPs explained the tests that the women would have. It included the name of the test, the purpose of the test, the place to have the test. It took about 10-15 for each patient to complete the assessment form and explanation for the HCPs. In the room, there were some table were each HCPs explain about the test and the examination rooms were only separated by a screen. Thus, other patients in the room were able to listen the explanation and discussion between patients and HCPs. The women would get the test result on the next day and the HCP would explain more detail if the test result not good.

## 4 DISCUSSION

The results of this study indicate that all participants were tested for HIV during their pregnancy because of recommendations of HCPs. HIV test is one of the laboratory examination procedures for pregnant women when they first time to check their pregnancy at the CHC. The HIV test is carried out with other blood and urine tests including hemoglobin, platelets, Hepatitis B, blood type, blood resus, albumin and glucose. Lack of knowledge about HIV testing in pregnant women results them to have their first HIV test at the CHC. To encourage pregnant women to take an HIV test, HIV test for pregnant women has been launched by the Ministry of Health since 2005. This is mainly done in areas with high HIV cases. HCPs are required to offer HIV tests to pregnant women when they some for ANC at the health facilities (MoH, 2011). Including HIV test with other tests on pregnant women has positive and negative impacts. Offering and including HIV test in a series of laboratory tests on

pregnant women can increase the number of pregnant women taking HIV test. However, this condition can lead the HIV testing counseling process to be less effective because of limited time and information as HCP have to explain different kind of tests. In addition, when HCPs offer HIV test for pregnant women it can give an impression that HIV test is an obligation for the pregnant women not an option.

Information about HIV test emphasizes the importance of identifying the mother's HIV status to prevent transmission to the fetus. This causes pregnant women agree to have HIV test because it is a standard procedure that must be done. Furthermore, HIV test is offered by health professionals who will carry out ANC during their pregnancy visit. The rejection from the pregnant women to have HIV test can lead problems in the future. Therefore, the pregnant women prefer to have HIV test. During the ANC, the atmosphere of the room was crowded and the room was not soundproof. These can cause pregnant women to be embarrassed to ask further about HIV test. The results of this study were similar in Canada. Pregnant women who have HIV test when having a pregnancy check-up at a health facility had difficulties in understanding the information provided HCPs about HIV testing and ignorance of the right of the women to refuse to have HIV test (Bulman et al., 2013).

Our study showed that all participants had never taken an HIV test before. This is due to a lack of information about HIV testing in pregnant women. Some participants thought that those who need to take an HIV test are individuals who practice highrisk behaviors, including prostitutes and injection needle users. Even though participants have received information about HIV testing and transmission before have HIV test, some participants have not been able to explain correctly about HIV test. A study in Guinea-Bissau, Africa, showed similar results. The level of knowledge of pregnant women regarding HIV test remained low despite getting counseled before having HIV test. This can be caused by ineffectiveness of the counseling process as well as privacy, limited time and the authority of health workers (Vieira et al., 2017).

Similar conditions also happened in Tbilisi (Georgia) and Ghana. Lack of knowledge about the importance of HIV testing, limited voluntary counseling and testing (VCT), low aspects of confidentiality, poor communication between patients and HCPs, HCPs not informing pregnant women about HIV testing were the reasons for

pregnant women not having an HIV test. The women also believed that that they would not get HIV because they never practice high risk behaviors (Butsashvili et al, 2014; Kwapong et al, 2014).

All participants in this study had negative HIV test results. As a result, they did not to seek more information about HIV. In addition, when the HIV test results were negative, participants were not given additional information about the importance of future HIV testing. More information about HIV testing in pregnant women and HIV transmission provided by HCPs needs to be improved when counseling for HIV test. In addition, it is important to provide a private room that can guarantee the privacy of pregnant women during counseling. This will allow them to ask further questions about HIV test without feeling uncomfortable and afraid that other people will listen to their questions.

## 5 CONCLUSIONS

Pregnant women have HIV test at the CHC on their first visit for ANC but they do not have any option other than having HIV test based on the HCPs recommendation. Providing more information about test HIV and private room are needed to allow pregnant women received adequate information about test HIV and being able to ask more about the test without feeling embarrassed and understand their right to decide for having an HIV test. Furthermore, health education in the community about HIV test among pregnant women should be conducted as pregnant women have had a better understanding about HIV test before they have it at the CHC.

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