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HIV and prevention of mother-to-child transmission awareness, perceptions, and attitudes of pregnant women in Malang: qualitative research

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Abstract

Introduction: Human immunodeficiency virus (HIV) continues to be the cause of mother and child deaths and morbidity. Prevention of mother-to-child transmission (PMTCT) therapies have been demonstrated to be useful in lowering the number of children infected throughout pregnancy, intra-partum, and during nursing period. This qualitative study investigates the knowledge and perspectives of pregnant women regarding HIV, experience of health workers in national PMTCT program, and barriers to PMTCT in Malang district.

Material and methods: 18 women and 10 key informants were interviewed in-depth at the local antenatal clinic and community health center in Malang district.

Results: There is still a lack of knowledge about HIV and PMTCT among women who are infected with the virus. When a test is conducted close to the moment of birth, there were several reports of non-consensual testing. Inadequate counseling can be caused by a lack of confidentiality, insufficient training of health workers, a lack of time, and perceptions of occupational dangers. Inadequate counseling can be caused by any of these factors. HIV stigma, discrimination, and worries of partnership breakup are some of the demand-side hurdles to PMTCT, which include a lack of HIV and PMTCT awareness.

Conclusions: Socio-cultural and practical issues, such as HIV testing without permission, are the major barriers to strengthening PMTCT services. Prenatal testing and counseling must be provided in a manner that is appropriate for local population. Additional research is needed to investigate people's traditional beliefs regarding HIV.

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Key words: HIV, PMTCT, knowledge, awareness, barriers.

Introduction

A major contributor to the high mortality and morbidity of pregnant women and newborns is human immunodeficiency virus (HIV). As of 2018, there were an estimated 1.5 million new HIV infections, of which 210,000 were the result of mother-to-child transmission of HIV, according to the World Health Organization (WHO). Some progress has been made with regard to pediatric infections [1]. Prevention of mother-to-child transmission (PMTCT) is

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critical in lowering this number [2]. There are several obstacles for PMTCT at every level of society, including individual, communal, national, and worldwide. In most cases, these barriers reduce the inability to successfully implement PMTCT [2].

Stigma, difficulty with partner disclosure, perception of required testing, confidentiality issues, inadequate counseling, obstacles with healthcare workers' attitudes, and medical supply issues all play a role in PMTCT's effectiveness at individual, societal, and institutional levels [3]. According to Indonesia's Ministry of Health, a 90 percent HIV testing rate is followed by an ARV treatment rate of 90 percent, successfully suppressing 90 percent of the virus in the population and preventing it from spreading to others [4]. In addition to a decline in HIV incidence, there has been a decrease in the prevalence of HIV and other health conditions. In 2020, pregnant women were subjected to prenatal screenings [5]. More than half a million pregnant women would not be tested for HIV, syphilis, and other mother-to-child communicable illnesses during the 2020 pandemic [6]. Interviews with 10 pregnant women in a small town revealed that all of them (100%) feared getting pregnant during the outbreak of COVID-19 [7].

Many public health agencies, including CDC, have made eliminating PMTCT HIV a top priority [8]. Comprehensive prenatal HIV treatment reduces the incidence of HIV PMTCT from 25% to less than 1%. Prenatal HIV testing is necessary to implement complete risk reduction strategies [9]. All pregnant women should be tested; however, not all pregnant women who have been infected during pregnancy and have since seroconverted will be discovered by early universal screening [10].

Only 4% of pregnant women who took part in a health study knew about vertical transmission, despite the fact that 94% of them attended a prenatal clinic at least once. HIV testing is administered to women before or after birth at community health centers since many of them have never had prenatal care or HIV test; PMTCT has been available in ANCs in Malang since 2020 [11]. A 2014 district health office study found that women's awareness of vertical transmission had grown by 76%. In Malang, there is a lack of qualitative study regarding HIV-positive pregnant women's views and barriers to administering PMTCT. Maternal HIV/AIDS and prevention of mother-to-child transmission (PMTCT) were the focus of a study conducted in Malang in 2021.

Material and methods

We used in-depth interviews and preliminary focus group discussions (FGD) to perform a qualitative study [12]. The research was carried out in Malang between February and August of 2021. At the time of this inquiry, the majority of PMTCT was delivered in accordance with the World Health Organization criteria. As PMTCT ANC expanded across Malang, the Puskesmas (government-mandated community health clinics located across Indonesia) also provided counseling and testing in the delivery room for women, who had never had a prenatal screening or been tested for HIV. In this scenario, midwives perform PMTCT work on the front lines. Women may be counseled and examined prior to or following childbirth, depending on the therapeutic setting. Medical, psychiatric, and follow-up treatments for women who test positive are provided by community non-governmental organizations [13]. Free of charge HIV testing and antiretroviral medication are available [14]. Because of their role in developing and maintaining a database of pregnant women undergoing HIV testing at community health centers, the lead researcher realized that pregnant women's attitudes and awareness about HIV and PMTCT as well as potential barriers to PMTCT in Malang needed to be examined.

Focus group discussion

Study participants were recruited in focus groups discussion (FGD). Participants were a midwife, a research assistant with social research expertise, a nurse, and two female parents. Women who participated in FGD and other related qualitative research studies were given a brief interview guide, based on the findings. An additional benefit of FGD was the identification of many key informants. Before moving on to chain and target sampling, we sought for further key figures.

In-deep interview

Over the course of the investigation, data were collected from 19 different sources. Five midwives, six nurses, and one social assistant as well as three cadres, two PMTCT program directors, and two HIV volunteers were among the health professionals working in PMTCT. Additional 27 women, ranging in age from 18 to 29, were recruited for the study (8 at the antenatal clinic and 19 post-partum at the community health center). Due to limited study resources and timelines, a smaller sample size was chosen. After birth (as opposed to prenatal), more women could be recruited within the study's time limit due to greater accessibility of this group. Women were invited to participate in the study after attending a group information session at the recruiting site. Each participant was asked a single question during the study. Key informants and women participating in the study were made aware of the research's goals (interview studies to enhance maternity and delivery care in Malang) as well as the background and connections of the interviewer. As a part of our pilot interview guide, we ask open-ended questions: "Can you tell us about your prenatal appointment and what happened?" and "Please describe your birth" (Attachment 1 is an example).

Conducting in-depth interviews provided an instant framework for establishing and laying out interview questions as well as context for focusing on long-term concerns. Patients were interviewed in private by two social science study assistants, who were proficient in Javanese. The lead

investigator conducted interviews with important informants. Length of the interviews, which spanned from 25 to 120 minutes, was captured on digital tape. It was then translated into Indonesian by a second research assistant, who double-checked the accuracy of translation. Participants (n = 28) had their socio-demographic and clinical characteristics combined, but not the key informants. Only women who willingly disclosed their HIV status during the interview had their status reported. Interviews with key informants were performed during their working hours.

Data analysis

Constant comparative content analysis (CCCA) was used to analyze the data [15]. During the course of the investigation, new themes emerged, which led to an expansion and modification of the initial coding network (data coded by two researchers). To arrive at a final list of themes and sub-themes, the analysis must be refined and completed. According to the COREQ criteria for reporting qualitative research, NVivo (QSR International) was used to manage and analyze interview data.

Ethics committee

In accordance with National Council of Health decision No. 279/VIII/2021, study ethics committee teaching institution accepted the research project. An informed consent form was completed by each participant.

Results

Women who participated came from a variety of backgrounds

Besides the Javanese and Madurese, there were a few other minorities. Participants ranged in age from 18 to 39 years, with an interquartile range of 21-28 years. Thirty-three percent of the participants (nine women) were unmarried, and majority of them had a college degree (85%). Eight of the nineteen women who were questioned after giving birth had attended the prenatal clinic at least once. Pre-interview HIV testing was performed among all women recruited (25/27, 93% of the total).

PMTCT and HIV/AIDS education among women

Participants' knowledge of HIV was found to be lacking, despite the fact that they had been tested for the virus throughout their current pregnancies, according to interviews. This showed that most women were aware that HIV may be transmitted through sexual contact, but it also indicated that many women were unaware of alternative ways of HIV spreading. Despite the fact that some people were aware of various communication methods, their replies were frequently insufficient or inaccurate. Sharing plates, dining utensils, and even clothes were all linked to HIV transmission:

"I've heard that intercourse, sharp items, and clothing may all transmit the virus. As long as the person you are borrowing from is a positive person, you can acquire his sweaty clothing."

Twenty-seven pregnancies were studied, and only two of them reported vertical transmission at the time of interviewing. The majority of women, according to the midwives, had no idea what PMTCT was or how to prevent it.

"I suppose this is because ladies have never seen it (manifest HIV), as they say here, sight to believe. In contrast to malaria, HIV is a disease that progresses much more slowly. For a long time after a person is diagnosed as HIV positive, no symptoms are apparent."

Male healthcare workers said women who believed in the presence of HIV do so, because they have seen or heard about someone suffering from HIV/ AIDS, have learnt about the virus and its' implications during pre-test counseling, or have overheard members of their communities discussing it. There were a lot of women who knew that there was no cure, but there were even fewer who knew about disease-modifying medications.

Women's attitudes and perceptions towards HIV/AIDS

Many women described HIV and people living with HIV/AIDS (PLWHA) as 'awful' or 'dangerous' in interviews, according to the findings. Instead of expressing their own opinions about PLWHA, women typically remarked on what the general public thought of organization in the media and other public forums. Adultery, immorality, and even criminal conduct and prostitution were shown to be linked to HIV-positives in this research.

"Having HIV is associated with being a bad person, according to one expecting mother I spoke with at the hospital. They [PLWHA] engage in heinous behavior, such as sleeping around... You'll be accused of being disloyal by many people if you're always optimistic... They're seen as criminals or prostitutes because they have the illness."

Pre-pregnancy HIV diagnoses were made in two of the women questioned. Their ex-partners and/or family members discriminated against and/or abandoned them.

Counseling and testing for HIV and PMTCT

A finger prick sample was taken from the majority of women at the time of birth or during prenatal care, although many were unaware of its' significance. Unwanted testing (and treatment) was reported by several women after or immediately after childbirth. The following is what a maternity patient had to say:

"I had my finger pricked at the hospital, but no one there explained why… They made no comment. To hold up my finger was all they said. At the prenatal clinic, I was also re-

quired to undergo a slew of tests. Despite the fact that I completed them all, I am unsure if an HIV test was performed."

Counseling, testing, and treatment can be difficult. Key informants voiced reservations regarding prenatal HIV counseling and testing. The lack of a place to reveal test findings was a significant barrier to privacy for midwives.

According to national guidelines at the time of the interviews, pre- and post-test counseling were not provided to patients. This suggests that there is a major health system gap that prevents patients from getting essential information.

Arguments in favor of and against HIV testing

A wide range of reasons were given as to why women decided to undergo the procedure. As a method to understand more about their health, some people sought HIV testing as a way to get counseling and testing. Few respondents were aware of vertical transmission, although those who viewed child safety as a key purpose for testing were more likely to be aware of that. Some women's loyalty and general 'good person' character were emphasized via tests. The most common reason given for not taking HIV test was fear of stigma. However, stigma and prejudice were not the only obstacles that stood in the way of proper testing.

"For now, we'll have to wait till no one is present so that we can do this [disclose a test result]. To avoid being overheard, I have to speak in a low voice (midwife)."

When asked about women who refused testing, key informants said they did so out of concern for their own safety, even if it meant missing treatment and preventing vertical transmission. They also mentioned the fear of being deserted (by their partner or family), if received positive test results. ANCs and SMNHs did not have the resources to provide partners with counseling and testing. Before agreeing to get tested, several women stated that they would consult their husbands. The decision to be tested was not necessarily made by women, according to one healthcare professional.

Customary and cultural attitudes about HIV/AIDS

Key informants and women discussed HIV/AIDS in terms of traditional beliefs and rites, which played a vital role in describing illness.

"My partner has been unwell for a long time, said a pregnant woman who tested positive for HIV. It is tarbessadu [traditional belief] according to them [family and community members]."

There were two distinct types of births in ancient India: Tarbessadu (a footling breech delivery) and bajudesa (pregnancy or sexual intercourse prior to customary marriage). Until a traditional healer conducted a ceremony, both were connected with sickness. Tarbessadu and bajudesa disease exhibited many of the same symptoms as AIDS in women, such as weight loss, hair loss, bone/ joint pain, and diarrhea, among others. Healthcare providers also noted difficulties in supporting nursing mothers, who were seropositive while receiving antiretroviral therapy:

"Until they have had a ritual [with the traditional health practitioner], they refuse to breastfeed. As an alternative, parents opt to give their children unclean water-based formula (healthcare professional)."

Because of their fear that nursing might damage their child, patients who fell sick or were diagnosed with an illness often refused to nurse their babies.

Discussion

As a result, even though women had been tested for HIV during pregnancy or immediately after delivery, they lacked basic knowledge of HIV and particularly on PMTCT. HIV testing without proper informed consent and counseling, a lack of women's knowledge of HIV and MTCT, perceived stigma at home and in community, and HIV-related cultural views were some of the issues identified in the study [16].

This study confirms findings from qualitative research and district health office surveys conducted in Malang, which showed significant gaps in HIV awareness. Antiretroviral treatment adherence in Malang patients has been shown to be affected by low health literacy, defined as difficulty acquiring and digesting health-related information [17]. District health office survey was conducted as follow-up three years later and revealed significant gains in most knowledge indicators [18]. For example, Malang's recent district health office survey found that vertical transmission awareness had increased significantly, possibly due to a significant expansion of awareness activities, counseling and testing services in Malang at the time of current study. Even though most of the women in our study had been tested for HIV prior to participating in our study, only two of our participants specifically discussed vertical transmission of the virus.

Pre- and post-test counseling are required by national policy, but the results of this study show that it was ineffective, insufficient, or even non-existent. Several participants in the study remembered taking a test, but they were unsure of what it was for. Health literacy can play a role, but it is more likely that poor counseling, which prevents patients from receiving and digesting critical health information, is the reason for that. For healthcare workers, who were responsible for providing follow-up care and explaining the consequences of a positive test result, this lack of appropriate counseling made it extremely difficult. Stigma surrounding HIV testing may have led to uninformed consent and/ or inadequate pre- and post-test counseling. Some midwives admitted that they were unprepared for the counseling process and described it as difficult. It was also known that needle stick injuries could occur when assisting HIV-positive women, so the midwives took extra precautions. Additionally, the stigma and prejudice associated with HIV may have played a role in the lack of counseling [19]. The adequacy and effectiveness of pre- and post-test counseling may have been harmed as well apparent lack of room for providing and discussing personal

information. Routine (opt-out) HIV testing at the time of delivery was implemented in Malang in 2021 in response to the fact that many pregnant women had no antenatal HIV counseling or testing. Opt-out testing has been shown to benefit women in the antenatal context by providing an opportunity for education and counseling [20]. Appropriate counseling and testing at the time of delivery, on the other hand, appeared to be difficult, as healthcare providers were tasked with presenting extensive information in a short period of time to patients with minimal awareness of HIV and vertical transmission. Unless and until working conditions for patients and healthcare workers are improved, opt-out peripartum HIV counseling and testing should be discontinued or restricted to selected cases, and efforts to prevent vertical transmission should instead be directed towards improving antenatal counseling and testing. Without informed consent, testing is unethical and contributes to HIV stigma. While the absence of anonymity in public healthcare institutions may appear to be an issue, it may also have the ability to increase unfavorable views regarding delivery and treatment in healthcare facilities [21]. At the end of 2021, regular opt-out testing during delivery was ceased in Malang due to a lack of money [22].

In women's communities, seropositivity was often seen unfavorably as a sign of immorality, prostitution, and even criminal behavior. There is a strong link between these unfavorable views and discriminatory attitudes [23]. Changing community beliefs, attitudes, and understanding are all essential to reduce stigma and minimizing its' detrimental impacts. Patients and healthcare personnel might be negatively affected by HIV stigma [24]. As a result of the fear of repercussions, such as discrimination or partnership collapse, HIV stigma may have a negative impact on testing uptake, healthcare seeking behavior, and test results disclosure [25].

HIV-related bad health can be explained by traditional beliefs that are likely to thrive in Malang because of the prevalence of unfavorable attitudes about PLWHA in the city. In circumstances, when Western medicine is distrusted and fails to address social dimension of illness, traditional medicine may be chosen or used in conjunction with standard antiretroviral therapy. People with HIV/AIDS (PLWHA) may benefit from traditional beliefs that relieve them of personal responsibility for their condition, in favor of higher powers [11]. Beliefs, such as tarbessadu, which are prevalent in Malang, have been shown to hinder test- and treatment-seeking behavior and treatment compliance [26]. Women's cultural views around breastfeeding must be taken into consideration when discussing PMTCT policies, particularly the decision to breastfeed while taking antiretroviral therapy (ART) [27]. One of Malang's most recent studies, a district health office research, found that traditional views regarding HIV in the area are prevalent, and that informal healthcare is heavily relied upon [28].

This inquiry is subject to a wide range of constraints. Due to budget and schedule restraints, it is probable that some important subjects were overlooked throughout the interview process. Data collection was restricted to an urban area, and not all of Malang's ethnic groups were represented. Therefore, these constraints limit the study's generalizability. Secondly, we were unable to conduct a study among pregnant women's spouses because of a lack of participants. Socio-economic and cultural factors usually limit the ability of partners to participate in similar circumstances [29]. Additional studies are essential in Malang to better understand the attitudes and tactics for enhancing HIV testing of women's partners in the context of PMTCT. In 2020, only 15 percent of women's partners attended ANC with them, while only 5 percent of partners underwent HIV testing thereafter. There have been significant changes in PMTCT policy, including the deployment of option B since this evaluation was conducted in 2020 and 2021. In spite of this, the government is still struggling to reach PMTCT screening and treatment goals [30]. HIV counseling and testing during postpartum period at SMNH were halted in April 2020 due to a lack of funds. While HIV testing has been a problem in Malang since 2021 (manuscript in progress), the availability of HIV testing at prenatal clinics in Malang and other places has been insufficient since then (manuscript in preparation). Gray literature publications claim that PMTCT barriers in Malang require continuing qualitative investigation [31]. However, this is the first time a qualitative assessment of barriers to PMTCT in Malang was carried out in a systematic manner.

Conclusions

Significant socio-cultural and operational challenges, including HIV testing in the lack of informed consent, must be addressed in the age of increasing PMTCT services and the adoption of more complete PMTCT regimens (option B). It is vital to build local capacity for efficient counseling and testing in the prenatal setting, as sufficient counseling around the time of birth is difficult to obtain. PMTCT must be offered in combination with activities that improve general HIV and PMTCT awareness, eliminate stigma and prejudice, and integrate local customs and cultural beliefs. Additional study is needed to investigate their function as well as the relevance and practicality of partner's counseling in improving PMTCT uptake and adherence in Malang.

Conflict of interest

The author declares no conflict of interest.

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