



HIV testing of housewives with HIV in Lampung, Indonesia: A qualitative study[☆]



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Abstract

Objective: This study aimed to explore the experiences of housewives with HIV in Lampung, Indonesia, while undergoing HIV testing.

Method: It used a phenomenological approach and purposive sampling as the participant selection technique. In total, 16 housewives with HIV were interviewed at the Voluntary Counseling Test (VCT) Clinic in Lampung, Indonesia. Data were analyzed using Colaizzi's method.

Results: Our findings suggest that specific education on HIV and the importance of testing for it should be provided to housewives, who are often perceived as a group at low risk of contracting HIV.

Conclusions: This will ultimately contribute to their awareness regarding undergoing HIV testing on their own. In addition, enhanced counseling services must be offered by healthcare facilities in order to motivate housewives to undergo HIV testing, reduce HIV stigma, and empower their roles as mothers.

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Introduction

The incidence of HIV among housewives in Indonesia is sharply increasing. A report from the Ministry of Health of

the Republic of Indonesia shows that housewives are the primary AIDS sufferers, accounting for 12,302 cases in 2016.¹ As many as 65% of the 235 women infected with HIV are housewives, according to a study from Jakarta, Indonesia in 2018.² In 2016, Lampung had the highest new case growth rate of HIV up to 3.1% rather than other provinces in Sumatera Island, Indonesia and showed a 44.91% increase in HIV-infected housewives in 2016.³ An increased HIV incidence in housewives will certainly contribute to the incidence of morbidity and mortality in children due to HIV transmission from mother to child.⁴

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The increase of housewives with HIV is not in line with the increase in the amount of HIV testing program which had been conducted. In Lampung, the amount of HIV testing on housewives, as demonstrated by the Lampung General Hospital Annual Report in 2017, is only 387 out of 1160 (33.3%). It obviously will affect the disease spreading and the recommended treatment obtaining because there are still many infected housewives that have not been diagnosed.⁵⁻⁷ As well, there are fewer housewives undergoing HIV testing than female students or working women.⁸ Some study revealed that stigma against HIV and a lack of information about HIV and tests related to it cause women's low participation in HIV testing.^{9,10} The low degree of HIV testing in housewives causes a delay in HIV diagnosis and its treatment, leading to increased HIV transmission and related deaths.¹¹ Additionally, low levels of HIV testing create difficulty in providing HIV-related health services because many of those infected do not know they are infected and do not seek treatment and obviously HIV testing is the only way to know someone's HIV status.⁶

Today, the Indonesian government's HIV transmission prevention programs still focus more on key populations, such as commercial sex workers and those with deviant sexual behaviors, than on housewives, who are considered a low-risk group. HIV testing practices for housewives have not focused on the quality of services, such as counseling and meeting the needs of housewives regarding HIV testing.¹² The housewives only receive the usual counseling regarding HIV whereas only little important information obtained.

Increasing HIV testing rates among housewives is an essential part of HIV prevention; early diagnosis can lead to early treatment and thus benefit both the individual and the general population. In addition, the exploration of housewives' experiences with HIV testing can improve nurses' knowledge, empathy, and understanding regarding their needs. This exploration will provide appropriate information and facilitate improved services to increase housewives' participation in HIV testing and continued treatment.¹³

Method

This study used a qualitative phenomenological method, which is an approach useful in understanding and describing people's life experiences.¹⁴ It was conducted at the Voluntary Counseling Test (VCT) Clinic of the RSUD Dr. H. Abdul Moeloek, Lampung. A total of 16 participants were included. The inclusion criteria called for housewives with HIV who spoke Indonesian, communicated well, and agreed to participate in audio-recorded interviews.

The researcher was assisted by VCT officers and volunteers who worked for a non-governmental organization (NGO). Participants who came to the clinic and met the eligibility criteria were approached by the officers and volunteers first. The officers or volunteers then built a close relationship with the housewives by describing the study and inviting them to participate. When the women agreed to participate, the researcher then also established a close relationship with them by further describing the study and agreeing on where the study would take place. On several occasions, the researcher took part in events held by NGOs to build a closer relationship with participants.

Interviews were conducted after participants signed an informed consent sheet. Further, 14 of the 30 women who met the criteria refused to participate in the study because they needed permission from their husbands or did not wish to be interviewed.

The interviews were conducted in a private counseling room at the VCT Clinic or in the participants' homes and lasted 45–75 min. Interview locations were determined by an agreement between the researcher and the participants to guarantee their privacy. Interviews were held according to interview guidelines, and each participant was paid \$3.40 after being interviewed as compensation for their time.

The researcher analyzed the data using Colaizzi's method. New themes were not found beyond the 15th data analysis. The researcher interviewed the 16th participant to ensure data saturation. All data obtained were transcribed and stored in a file that could only be accessed by the researcher. The data collection process was carried out after approval was obtained from the Universitas Indonesia Faculty of Nursing Ethics Committee.

Results

Participant characteristics

Of the 16 participants included in this study, 7 (44%) were aged 31–40 years and 10 (63%) had a secondary level of education. Additionally, 10 participants (63%) were married, and 6 (37%) were widowed. Based on the data, 10 participants (63%) had husbands who had died due to HIV, 3 participants (19%) were former commercial sex workers, 2 participants (13%) had sex outside of their marriages, and 1 participant (6%) had been infected from tattoo needles.

Based on the data analysis, three themes were identified regarding HIV testing among housewives with HIV.

1. "Unintentional" HIV testing

This first theme revealed that most participants (13 of 16) underwent HIV testing unintentionally. They did not realize that they had been infected by HIV or tested for it, saying that the tests were taken by healthcare providers while they were hospitalized due to illness, due to the illnesses of their husbands, or for pregnancy examinations. They were asked for a blood sample without being told what sort of tests were being done.

"At that time, my husband was sick. So we went to the health center. The doctor (name) told him to check the blood. But when I arrived there, I was told to do a blood check too. I had no idea that it was for HIV." (p. 4)

This theme includes the following subthemes:

1. A lack of HIV knowledge. This was the main factor contributing the housewives did the test unintentionally. Most of them stated that they didn't know anything about HIV; a lack of information on HIV caused participants never to undergo HIV before.

"Because I was healthy at that time, and I didn't know anything about HIV before. There wasn't any information about that. All my life, I'd say, I only work in my kitchen. Well, I really didn't know what HIV was or anything about its transmission or characteristics. Let's say that we would never think to check for it if we didn't know about it and never thought about it." (p. 12)

2. The perception that they were not at risk for HIV infection. Most housewives believed that they were not at risk of being infected with HIV because they thought they were clean, had good husbands, and had good relationships.

"Yes, I thought HIV was only for 'bad' people. A disgusting disease. Because I didn't do anything bad so that it couldn't be that way. Then, I thought I had a good husband who never had free sex outside our marriage." (p. 4)

As well as perceiving themselves as not at risk for HIV infection, most participants stated that they wanted to be a good wife to their husbands by fully believing in them. They had strong beliefs in their husbands' faithfulness. They believed that having full trust in their husbands would prevent them from being infected with HIV.

"Especially when I got married, I followed my husband. I, in my whole life, only took care of my husband, my children, and my house. I also fully believed in my husband. I thought positively. My husband has acted so well in front of me. He's not all that different, even though I've found condoms in his bag. So why do you think I want to test? I did think that, my husband and I have never done bad things like that." (p. 14)

3. A lack of counseling prior to the HIV test. All participants in this study expressed that they received little or no explanation about the test before it was taken.

"I thought it was just a usual test, like that. Just like typhus or malaria. The point is, I thought it was a basic blood test just like when my child got sick. I thought so. I didn't realize that I had been checked (HIV)." (p. 10)

2. Experiences of HIV stigma and discrimination upon discovering their HIV statuses

Most participants (14 of 16) received negative responses from their families after being diagnosed with HIV.

"After I was diagnosed with HIV, my parents didn't let me drink or eat together with them. They didn't permit me to kiss my son. They just wanted me to be the only one who got sick and didn't want me to spread it to others. My parents thought this way because HIV is a deadly virus. It was really bad." (p. 4)

Some participants also experienced poor treatment from healthcare workers both before and after the results of positive HIV tests.

"When (the staff) knew that was positive, they just gave the results without any comment. They did not say

anything. Yes, it was different from how they treated me the first time I came to check it. Before the test, they were friendly. Now, after learning the result, they have changed. Maybe they know the results were positive." (p. 3)

The participants also experienced stigma to their children and husbands after revealing their HIV statuses.

"After I knew I was positive, the hardest thing was figuring out how I was supposed to act around my child. I didn't want to touch him (child), I was afraid he would get infected. I just looked at him. I was afraid that I would infect him. He wanted to be near to me, but I could not let him. I was afraid that he would be like me. Afraid of him being infected by me, that's it." (p. 10)

"Yes, I felt different because of this disease (HIV). Sometimes I felt ashamed in front of my husband. My husband was negative (HIV). I was afraid even just to sleep near my husband. I was afraid that he would be infected." (p. 11)

This stigma and discrimination experienced by the participants occurred due to the lack of post-HIV test counseling given by healthcare staff to the housewives and their families. Most participants and their families did not know anything about what they should or should not do about their diagnoses. They sought information on HIV by themselves, which can sometimes lead to misperceptions about the virus.

"In the end, I was looking for information about the treatment myself. The explanation given by (the clinic) was so basic ... we were not satisfied. The explanation we received was also very theoretical. We needed support, positive energy to lift us up, but we did not get it here. We got a lot of counseling from the other institution. The doctor's explanation was theoretical. No emotional support was provided." (p. 15)

3. Disempowerment of motherhood roles upon learning HIV status

When the participants learned their HIV statuses, they found that some motherhood roles could not be fulfilled due to the risk of viral transmission.

"I couldn't breastfeed my baby anymore. I felt like I was useless. I failed at becoming a mother. You couldn't take care of your child, you couldn't breastfeed him either. Ahhh, it was really bad (crying)." (p. 10)

Indeed, 8 of 16 participants sent their children to their parents' homes when they were diagnosed with HIV. Participants stated that they lived in anxiety about their children's conditions, knowing it was possible to transmit the virus.

"My husband asked me to send away my child to my mom's home because of my disease (HIV). My husband told me that it was dangerous for our child to live with us because I was no longer healthy and couldn't take care of her. I was so sad, but I couldn't do anything. I thought this was for her future." (p. 8).

Discussion

It was found that most participants (10 of 16) had been infected with HIV by their husbands. Several previous studies revealed similar results, where the incidence of HIV in housewives resulted from unprotected sexual relations with their HIV-positive husbands.^{2,15,16} The low degree of condom use by housewives results from ignorance of their husbands' HIV statuses and a lack of knowledge about HIV and its transmission, leaving them unable to evaluate their risk of HIV infection and their partners' risky sexual behavior.^{17,18}

Knowledge is a determining factor in the use of health-care services.¹⁹ A lack of knowledge regarding HIV signs, symptoms, and tests causes housewives never undergo the test on their own. Many housewives are late in taking the test because they do not recognize that they have been infected with HIV.¹⁰ Often, HIV testing is only undertaken when they are already sick or have developed AIDS.²⁰ The lack of knowledge also contributes to the housewives' perceptions that they will not be infected by HIV due to their good attitudes and relationship. These misperceptions among housewives regarding HIV transmission obviously diminish their awareness of their risk of infection.^{10,21} Besides, housewives are considered a low-risk group because HIV is usually associated with prostitution.²² There is an assumption that HIV will only infect husbands exhibiting risky behaviors like having multiple sex partner or using the drug without transmitting it to their wives.^{16,23}

This study reveals that the housewives in Lampung dedicate their whole lives to their families and this makes them feel save by becoming a good mother and wife. Due to their main duties, which are taking care of their husbands and children, make them seldom to access healthcare information. Other qualitative studies which are done by Musheke et al.²⁴ and Ismail et al.²⁵ also reveal that self-perceptions as good wives and mothers among housewives often make them believe that they are not at risk of contracting HIV and subsequently mean that they have low levels of awareness about its testing processes. Hutchinson et al.²⁶ stated that HIV testing is very important for housewives, even if they feel they are not at risk and there are reasons for not putting too much trust in partners. Haffejee et al.²⁷ also stated that marriage does not guarantee that people are not at risk of HIV infection.

This study also shows that stigma still occurs on housewives after revealing their HIV statuses. They are stigmatized and discriminated by their families after knowing their condition. A qualitative study done by Ismail et al.²⁵ in Jakarta, Indonesia, expressed that the families often viewed the housewives with HIV as guilty and dirty; this is because they were believed to have brought the disease into the family though they were infected by their husbands and they bear the shameful burdens of their husbands. HIV-related stigma and discrimination felt by the housewives in this study also come from health workers. They received different services given by health workers after knowing their HIV statuses. Waluyo et al.²⁸ stated that fear of being infected by HIV leads to the emergence of discriminative behaviors among nurses who were caring someone with HIV due to

the lack of knowledge about HIV and its transmission among them. Besides, revealing their HIV status makes housewives view themselves negatively, fear to be shunned, and worry about transmitting the virus to their children and partners. As a result, the fear of being seen as bad wives and mothers by the family and environment and the fear of being shunned and transmitting the virus often lead housewives hide their HIV statuses.²⁹⁻³¹

Some problems, such as depression, familial and communal stigma and discrimination, and diminished familial care roles, often develop after an HIV-positive status is revealed; this is due to the lack of knowledge and support provided to those living with HIV.³⁰ A lack of adequate counseling services from healthcare workers will lead to greater stigma experienced by housewives.³² The lack of appropriate counseling and HIV-related stigma to housewives will ultimately cause the disempowerment of motherhood roles. Though motherhood roles are natural for most women, they become complicated for housewives living with HIV. Such housewives have to deal with the psychological, social, and cultural issues associated with HIV as well as with their roles as a mother.¹⁷ Some roles, such as pregnancy, giving birth, breastfeeding, and caring for children, are considered to be methods of HIV transmission from mother to child. The fear of transmitting the disease to their families makes it difficult for housewives to fulfill these roles and causes them to perceive themselves as "contaminated," unfit, and irresponsible mothers.³³ On the other hand, by fulfilling motherhood roles will offer housewives the strength to deal with their difficulties and lead meaningful lives, although they have to live with a serious illness.¹⁷

The themes founded in this study indicate the unpreparedness of housewives receiving the test and the results of HIV testing. This unpreparedness results from the lack of HIV counseling services provided by healthcare professionals. Healthcare centers should offer housewives a complete and appropriate explanation about HIV and the test before the test is undertaken. Receiving adequate counseling prior to taking the test is a patient right and listed in government regulations, which stipulate that HIV tests require informed consent, counseling, and confidentiality. Counseling plays a role in the provision of appropriate information on HIV testing both before and after it is done.³⁴

High-quality HIV testing services must be supported by substantial pre- and post-test counseling. A lack of counseling services greatly influences someone's readiness to undergo the test, accept the results, and continue with their lives.^{35,36} Healthcare professionals should act as counselors for the housewives, thoroughly discussing the test and the disease with them so that they may give consent and consciously take the test after knowing the impact of delayed treatment that can happen on their children and families. Adequate counseling contributes to the readiness of someone in receiving the result of the test and may prevent misperceptions regarding HIV status.³⁷ Of course, the pair between unpreparedness and a lack of counseling can lead to greater stigma; consequently, HIV-related stigma contributes to housewives' low interest in HIV testing, the

refusals to undergo it and their involvement in treatment programs.^{8,38}

Conclusion

Various themes provide an overview of the experiences of housewives with HIV when they undergo HIV testing. The exploration of their experiences can increase nurses' knowledge, empathy, and understanding regarding the needs of housewives undergoing HIV testing. Nurses are expected to provide appropriate educations to housewives, families, communities, and other health providers on HIV so as to increase awareness of HIV testing and reduce its stigma. This study also reveals that insufficient HIV test counseling from healthcare professionals may lead to misperceptions, stigma, and the disempowerment of housewives upon learning their HIV statuses. There is a need for a revitalized program or re-socialization from the government, nurses, and healthcare institutions for healthcare professionals about HIV, its test, and the importance of HIV counseling. Enhanced HIV counseling will contribute to housewives' awareness about HIV and its testing processes and also may improve the quality of health services. This study only examines housewives as participants; its results are based on the perspectives of these housewives. The involvement of other participants, such as healthcare workers, family members, and the government, is needed so that a broader picture of HIV testing for housewives can be obtained. This study does not present any conflicts of interest.

Conflict of interests

The authors declare no conflict of interest.

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