

Private Midwives' Perceptions of Barriers and Enabling Factors to Voluntary Counseling and HIV Testing in Bali, Indonesia

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Abstract

In Indonesia, more than half of pregnant women seek antenatal care (ANC) at private midwifery clinics. Midwives play an important role in advocating for voluntary counseling and testing (VCT) uptake among pregnant women during ANC. This study examined midwives' perceptions of barriers and enabling factors about referring pregnant women for HIV testing. The study was conducted in Denpasar City and Badung District, two localities in Bali with high HIV prevalence. Two focus group discussions with 15 private midwives and five in-depth interviews were conducted. Data were transcribed verbatim, and thematic analysis methods were used to examine patterns emerging from the data. Results showed that private midwives face personal barriers in the form of stigma as well as institutional barriers such as VCT operational hours that limit how and when they refer women for VCT. Barriers are strengthened by the lack of support or reward from the health office. However, opportunities for integrated and comprehensive support systems within the health system and supportive social environment, which would make it easy and rewarding for midwives to refer women to VCT clinics, were seen as enabling factors. Increasing uptake of VCT is a necessity for eliminating mother-to-child HIV transmission.

Keywords: Antenatal care, midwives, prevention-of-mother-to-child transmission, private clinics

Introduction

Human Immunodeficiency Virus (HIV) is a major contributor to the global burden of disease and disability. The Joint United Nations Program on HIV/AIDS (UNAIDS) estimates that 35.5 million people are living with HIV globally,¹ of which 4.7 million are living in the Asia Pacific Region.² India, China, and Indonesia are the top three countries, with the highest HIV burden in the region. UNAIDS estimates that 610,000 people living are with HIV in Indonesia.² The five provinces reporting the highest rates of HIV cases are Jakarta (n = 28,790), East Java (n = 16,253), Papua (n = 14,087), West Java (n = 10,198), and Bali (n = 8059).³

Human Immunodeficiency Virus can be transmitted vertically, also known as 'mother-to-child HIV transmis-

sion' (MTCT) during pregnancy, childbirth, or breastfeeding. A systematic review and meta-analysis study showed that MTCT could occur during pregnancy and post-partum, with the pooled HIV incidence rate of 3.8/100 person-years (95% CI 3.0-4.6).⁴ The World Health Organization (WHO) has stated that without any prevention program and treatment, the risk of MTCT is 40%, where two-thirds of babies born are infected during delivery, and the remaining third are infected during breastfeeding. In Bali, results of the serosurvey by the provincial health office in 2009 and 2010 showed a two-fold increase in HIV prevalence during pregnancy, from 0.2%-0.5%.⁵ Of note, disparities between HIV reports are common, because different populations and methods use different measures. For example, a report from a lo-

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cally based non-government organization (NGO) in Bali, the Kerti Praja Foundation, reported a prevalence of 0.9%, double that reported by the serosurveillance of 321 pregnant women who underwent HIV testing.⁶

Human Immunodeficiency Virus testing during antenatal care (ANC) is the key to eliminate MTCT. Early detection of HIV in pregnant women and antiretroviral medicines can reduce the risk of vertical transmission to less than 5%.⁷ In Indonesia, more than half of pregnant women attend ANC in private midwifery practices. These private practices can easily be found in the community, making private midwives a crucial entry point for the prevention of mother to child transmission of HIV (PMTCT), as noted in previous studies.⁸ Hence, referrals from midwives for pregnant women to undergo HIV testing are crucial.

Despite published research on the implementation of the PMTCT in Indonesia, only a few studies have focused on the challenges faced by the midwives working in the private sector about referring pregnant women for HIV testing. This study aimed to explore the barriers and enabling factors faced by midwives working in private clinics, in referring women to voluntary counseling and testing (VCT) for PMTCT. This study is timely, as recent UNAIDS direction identified Indonesia as one among 23 high-prioritized countries for PMTCT, along with 21 Sub-saharan countries and India.⁹

Method

This study was conducted in Denpasar City and Badung District, two localities contributing to the most HIV cases in Bali. It is a part of a larger PMTCT project, conducted between June and December 2010, aimed at advancing the role of private midwives in referring pregnant women for VCT.⁶ During that project, 70 midwives were trained in PMTCT strategies and directions, and referral systems. It was noted that the training participants had made 619 referrals to VCT clinics in both regions; yet, only 312 women, or half of those being referred, had ever visited a VCT clinic. The results of the project on VCT uptake have been published elsewhere.⁶

The current explorative qualitative study employed two focus group discussions (FGDs) with 15 midwives and five in-depth interviews to explore midwives' perceived barriers and enabling factors in their efforts to refer pregnant women for HIV testing in Bali. Participants were recruited and purposively selected from the 70 private midwives who had participated in the larger PMTCT projects.⁶ Midwives had working experience more than five years and had referred at least five women to VCT clinics. All 15 midwives were trained on PMTCT principles and how to refer patients for VCT. A topic guideline for FGDs was developed to explore the perceived barriers and enabling factors, which influenced

midwives in making referrals to VCT. Verbal informed consent was provided by the participants and was audio-recorded.

All FGDs and interviews were digitally audio-recorded and then transcribed verbatim. The FGDs and interviews were conducted in Indonesia with the length of each FGD and interviews for around one hour. Relevant quotes were then translated into English for this paper. Thematic data analysis was conducted using Braun and Clarke's steps to identify and examine themes in a way that was credible and transparent. The use of an inductive approach was supportive of the critical lens used in this study.¹⁰ The resultant themes were grounded in the FGDs and interview data. Subsequently, two workshops with the research team were conducted to discuss emerging and coherent themes and agree upon preliminary codes.¹¹ Preliminary codes were recommended by the main research questions on barriers and enabling factors on VCT referrals of pregnant women by private midwives. Triangulation was used to validate the themes and included variations in the data source and member checking. This study was approved by the Ethics Committee of Faculty of Medicine, Udayana University [1533/UN.14.2/Litbang].

Results

The study findings are presented according to the types of barriers and enabling factors surrounding VCT referrals by private midwifery practices. Table 1 lists the themes and subthemes to emerge from the discussants.

People living with HIV (PLWH) are socially stigmatized in Indonesia and condemned as sinful and immoral. Hence, it is generally taboo to talk about HIV. Three types of barriers emerged from the data are barriers faced by midwives, barriers within the referral system (institutional barriers), and barriers faced by pregnant women from the midwives' perspectives.

As noted in Table 1, there are two main barriers faced by midwives, namely feeling fearful for referring pregnant women to VCT because of the highly stigmatized nature of HIV, and lack of training, monitoring, and evaluation, and reward mechanism for midwives. Midwives' fears of being rejected by women and their families when offering HIV testing may put midwives in a very uncomfortable and awkward position. For example, a pregnant woman who lacks knowledge of HIV, may understand HIV as a death sentence and, without proper counseling and support, she may refuse HIV testing.

"One woman told me that it was better for her not to take the test, as she was anxious and scared of the unanticipated result...therefore, it was better for her to opt out." (IDI-3- Denpasar)

These fears have caused a deceptive practice, where-

Table 1. Theme, Subthemes, and Examples by Relevant Quotes from the Participants

Theme	Subtheme	Informants Statement/Keywords
Barrier faced by midwives	Stigma attached to HIV	[...] Informant’s to visit the VCT clinic and I never let them know, that the referral is Fear to offer testing for HIV testing. I cannot let them know. Because, I sometimes afraid. Therefore, I only said that this is for blood test especially for pregnant women. It is free from the government. (FGD Badung)
	Disguising or not revealing purpose of the blood testing for fear of causing offense	I give them a blur or grey information, I am afraid they become offended. Pregnant women are afraid to undergo the test because they fear the unanticipated results. They said, they are afraid to face the result. It is better we don’t know. (FGD Denpasar)
Institutional barriers	Limited VCT opening hours do not cater for working, pregnant women	[...] there is a problem with opening hours which clash with the working hours of the mothers. Since the majority of the mothers are working, the opening hours do not match with their time. When women have time to undergo HIV testing, the HIV testing staff were not available. (FGD Badung)
	One-roof ANC and VCT service or mobile VCT services	Since the VCT clinic is not a one roof service within ANC service. It would have been easier to encourage patients to do HIV test... if it is possible, the VCT test be available ANC clinic. This may increase the number of pregnant women tested for HIV. If the test is in different venue, there will be a chance of lost opportunity, the patients do not come to the test, patients may decide to refuse the test and run away to different practice. (FGD Denpasar)
Enabling factors	Free HIV test for pregnant women	This service is free for pregnant women from health office, if there is a free blood test, there will be a lot of people coming. My patient asked me if I heard a free blood test. So, she directly asked, and I give her a referral letter. (FGD Badung)
	Support needs from the health office, NGOs and the Provincial Health Office	
	Reward and punishment system as well supervision and monitoring and evaluation system	There is no comprehensive support or reward mechanism to motivate midwives to refer their clients to VCT. Supports needed might include supervision, monitoring, evaluation, and reward mechanism. (FGD Badung)
	Training and ongoing support for midwives	I learn about HIV and how to refer the patients to the VCT clinics from my training. I found it is easier for me to explain about the test to the pregnant woman. (IDI-2-Badung)

by, a midwife might choose not to inform her patients about the real purpose of the blood test for which she is being referred. Fears from both parties, the midwife and the woman, are counterproductive to the recent effort to halt the high MTCT in Indonesia. One midwife in the FGD Badung believed that pervasive fears in the community around HIV would make women afraid to take the blood test,

“When I gave an ‘honest’ reason for the blood test referral, my patients tended to reject the test with reasons. Midwives from Badung concurred with the fears and tensions experienced by midwives on referring women to VCT: giving the right information to the women for VCT referral is important, but at the same time, women might feel denigrated, upset, stigmatized, and finally, choose not to do it (HIV testing).” (IDI-3, Midwives Badung)

Midwives, with their training, acknowledge the importance of providing the right information to their clients. However, at the same time, they faced constant tension between doing the right thing and protecting their clients from shame and fear. In the example above,

the midwife denied the woman’s right to information, ensuring that she made an informed decision. Such a practice may lead to women lacking trust in their midwives.

Arguably, private midwives may also be afraid of losing their patients. Good relationships, even when they have instances of deception, could provide a means by which midwives survive in their private practice. Directly asking a woman to undergo VCT can be frightening for both the midwife and the pregnant woman. Hence, deception and lies might be the safest way to manage and negotiate the potential tension that may hamper the midwife’s relationship with her clients. Participants suggested that deception is a normalized practice, wherein women are not given a full account of the purpose of the referral blood test. Rather, the client will be told that the test is a regular test in ANC. In both FGDs, midwives concurred that deceptive practice is often unavoidable not to offend clients:

“... I give them a bit of a vague or blurred information. I am afraid they become offended.” (IDI, Denpasar)

Other midwives added,
"I never let them know that the referral is for HIV testing. I cannot let them know because I am afraid." (FGD Badung)

Midwives in this study also discussed institutional barriers that prevent them from referring pregnant women for VCT, including poor communication between VCT and ANC services. A particular institutional barrier mentioned by participants was linked to poor referral communication and follow-ups from the VCT clinic to midwives' practices. Participants expected to receive a return-referral letter from the VCT clinics. Participants wanted to have communication from the VCT clinics regarding the results that would inform their practice and treatment for the women.

A return referral is needed to update the medical condition of the client. None of the participants had ever received a return-referral letter from the VCT clinics. One of the participants noted that in current practice, there was no transparent communication system in place between the VCT and ANC clinics. Hence, private midwives were likely to be kept in the dark, 'not knowing' the test results of their clients.

"We send the pregnant women, but no one is accompanying them. If we follow the patients up, there is no information from the VCT clinic whether the patients are coming to the VCT. We are curious whether the patients come to the VCT clinic, just like that. We usually made a letter of referral to the VCT clinic; we did not go with our client. We usually do a follow-up check with the VCT clinic whether our client came to have a test. They only said 'yes...ok' that's all. They did not give us any feedback or other information or even tried to confirm if our client had come or not...so, it leaves us with a big question mark." (FGD Badung)

Participants felt that such inadequate communication systems within health services were demotivating and unprofessional. Participants believed that VCT should be offered in all ANC clinics, including private midwife practices:

"Since the VCT clinic is not a one-roof service within ANC service, it would have been easier to encourage patients to do an HIV test. If it is possible, for the VCT test should be available at ANC clinic. This may increase the number of pregnant women who tested for HIV. If the test is in a different venue, there will be a chance of a lost opportunity, the patients do not come to the test, patients may decide to refuse the test and run away to a different practice." (FGD Denpasar)

A mobile VCT test is a way to bring the HIV test closer to the community. Midwives in the study suggested

increasing the number of mobile VCT centers for pregnant women to avoid a missed opportunity.

"If possible, it would be good to have a mobile VCT facility, bring the facility to the antenatal clinic or my private practice, certainly it will increase the coverage. When antenatal clinics are far from VCT clinics, it is very likely that you will miss a golden opportunity for a referral." (FGD Badung)

Main themes emerged regarding enabling factors related to a reward system, and acknowledgment of the midwives' work. Participants expressed feeling disheartened at the lack of support from the district public health office (PHO). Private midwife practices continue to need local PHO support to implement the referral system. The lack of acknowledgment of their work and role in PMTCT services, as well as lack of ongoing supervision, monitoring, and evaluation, left midwives feeling isolated and outdated regarding changes in services.

"Further, challenges to referring women for care are due to no committed support system and reward for midwives' efforts within existing provincial, city, or district public health authorities: There is no comprehensive support or reward mechanism to easily or motivate midwives to refer their clients to VCT. Supports needed might include supervision, monitoring, evaluation, and reward mechanism." (FGD Badung)

Most participants agreed that another enabling factor for referring pregnant women to undergo VCT was that VCT was free of charge. This made it easier for midwives to offer VCT to pregnant women.

"This service is free for pregnant women from the health office. If there are free blood tests, there will be a lot of people coming. My patient asked me if I heard that there is a free blood test. So, she directly asked, and I give them a referral letter." (FGD Badung)

One of the participants stated that since the testing was free, many pregnant women were keen to ask their husbands to undergo VCT also.

"When my patients know that the blood test was free... they then even asked their husbands to have the test as well." (FGD Denpasar)

"Because they came along with husbands, then they said, 'We want to do a blood test, mam', and her husband also joined the test. She asked me, 'May my husband join me to do the blood test?', then I said, 'Oh yes, absolutely, your husband can do the test. This is a free blood test.'" (FGD Badung)

Another factor enabling midwives' decision to refer pregnant women for VCT was the re-referral or return referral from the clinic. Most of the midwives required

the results of VCT to provide further services and treatment to pregnant women as needed.

“In my view, if there is feedback of information, a follow-up system available, as well as cooperation with the NGOs, we will get more motivated.” (FGD Badung).

All participants agreed that the benefits of the PMTCT training they received during the project were an enabling factor in referring the pregnant women for VCT. The training had improved their knowledge of HIV and AIDS, and VCT or PMTCT services available and referral systems. The counseling skills learned from the training had helped increase their confidence by informing pregnant women about HIV prevention, benefits of VCT, HIV treatment, and services available. Participants also mentioned that some of their clients had previously heard about VCT services, and this knowledge made it easier for them to make a referral.

“I learn about HIV and how to refer the patients to the VCT clinics from my training. I found it is easier for me to explain about the test to the pregnant women.” (IDI-2-Badung)

This quote acknowledges the importance of knowledge and communication with pregnant women on the vertical transmission of HIV, services available, and HIV treatment.

Discussion

Midwives play an important role in preventing the vertical transmission of HIV from mother to children by participating in HIV referral systems. Previous studies support the important role of health providers in referring women to VCT services.¹³⁻¹⁵

This study highlights the challenges faced by Indonesian midwives in private practice when referring pregnant women for VCT in Bali Province. Barriers faced by midwives in referring pregnant women to VCT services were primarily influenced by negative stigmatization of HIV in society, lack of training, and ongoing monitoring system and recognition of midwives' significant contribution to PMTCT services in Indonesia. Of concern, are the tensions that midwives have to face when referring women for a highly-stigmatized HIV test, which may lead to lies and deception in practice. A study conducted with private midwives in Semarang, West Java, concurred that midwives in Indonesia are the product of the culture, which condemns people living with HIV/AIDS. Therefore, without relevant training on HIV transmission, the rights of the patients with HIV, and strong institutional support, normalizing a practice that is discriminatory against women living with HIV, is unavoidable. Denying patients the rights to receive accurate information and consented services are examples of abuse and disrespectful practices that needed

addressing.¹⁶⁻¹⁷

The findings in this study strongly suggested the desire that private midwives had to work closely with the Provincial and District Health Office to increase the uptake of PMTCT services, especially HIV testing in pregnant women. A similar finding was found in Sorong, West Papua.¹⁸ Participants appreciated the opportunities for training, ongoing supervision, monitoring and evaluation, and improved communication between VCT clinics and their practices. Studies elsewhere, like those in Sub-Saharan Africa with a high HIV epidemic, have noted the impact of regular PMTCT training on reducing midwives' negative perception against PLHIV.¹⁹

Offering free HIV testing for pregnant women in selected VCT clinics has been stated as one aspect that makes it easier for midwives to offer the testing. This was supported by a study in Semarang, which noted that the cost of VCT was a critical factor in uptake.²⁰ Findings suggest that making VCT services closer to the community of private midwives' practices will ensure adequate uptake of the VCT program. Previous studies conducted in South Jakarta²¹ and Papua¹⁸ echoed a similar suggestion for integrated PMTCT/VCT and ANC services.

Recently, there has been a change in the direction of HIV testing for pregnant women. The Regulation of Minister of Health has set HIV testing as the minimum standards of services for pregnant women; every health facility should offer the test to pregnant women.¹² However, to date, HIV testing is not available in any of the private midwives' clinics. Midwives, therefore, need to refer pregnant women to primary health care to undergo VCT. As there has been a growing interest in introducing HIV self-testing at ANC clinics, the introduction of HIV self-testing at private midwife clinics is worth considering.

This study²²⁻²³ had identified the need for continuous training for midwives, as well as improving access to VCT clinics. In other studies, support from the district health office has been identified as one of the critical successes of the PMTCT services. Routine HIV education, counseling, and training could improve midwives' skills for encouraging pregnant women to undergo VCT.¹⁸ Offering free, no-charge HIV testing for pregnant women in selected VCT clinics has been stated as one factor that enabled midwives to offer the testing. Another study, in Semarang, indicated that external factors, such as the cost of VCT had been barriers to undergoing VCT.²⁰ Most pregnant women have stated that since VCT is offered without payment, they were not willing to do the test. Only a small percentage of mothers know the purpose of undergoing VCT.²⁰ The cost of the test as consideration for pregnant mother has been the focus for study in Semarang because some mothers are the only

breadwinner in their family. Another study in South Jakarta and Papua suggested that the integration of PMTCT services and ANC services into community health services improved uptake of the PMTCT program.²¹ In the context of ANC at private midwife clinics, the integration of PMTCT and ANC might take the form of midwives conducting HIV testing at their clinics.

Conclusion

This study has revealed that the barriers and enabling factors for midwives referring pregnant women to VCT are multifaceted and interconnected. Social stigma against PLHIV, including HIV positive pregnant women, has been ingrained in society, and normalized within the health system, resulting in a practice that is potentially abusive and disrespectful. Findings highlight the needs for current PMTCT program to address different levels of barriers at institutional, community, and private midwives' practices. Targeted efforts need to focus on strengthening factors that enable midwives to make effective VCT referrals; which may include one roof services, improvement in the availability of mobile VCT clinics, clinic opening hours which suit working women, as well as ongoing training, supervision, monitoring and evaluation of VCT services for pregnant women. Subsequently, private midwives in Indonesia, are a key component in PMTCT. Their roles need to be strengthened and their contribution to PMTCT programs acknowledged.

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