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THE PERSPECTIVES OF NURSES AND HIV-POSITIVE WOMEN ON A SELECTED MODEL OF PREGNANCY DECISION-MAKING PROCESSES IN NORTHEAST THAILAND

Jaruwan Kownaklai^{1*}, Mark Hayter²

1. Faculty of Nursing, Mahasakham University, Thailand.
2. Manchester Metropolitan University, UK

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*Corresponding Author

Jaruwan Kownaklai
jaruwan.o@msu.ac.th

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ABSTRACT

Many women living with HIV intend to become pregnant. This is especially true for women who have received ARV treatment for a certain period. The purpose of this study was to explore the perspectives of nurses and Thai pregnant women living with HIV on pregnancy decision-making processes. This is a descriptive and qualitative study. Small group discussions were conducted with five nurses working with HIV-positive women and in-depth interviews were conducted with five Thai HIV-positive pregnant women. A model of the pregnancy decision-making process was provided to participants for the discussion. The nurses' and women's perspectives on the model can be divided into two themes: 1) The perspective of the selected model and its five sub-themes, namely: 1.1) How the substantive model reflects the pregnancy decision-making process; 1.2) Complexity; 1.3) Usability; 1.4) Strength; 1.5) Weaknesses, in addition to the perspectives of women and nurses on the application of the model. The model reflects the real-life experiences and decision-making processes of Thai women with HIV, where each category shows the trail of the women's decision-making process. However, the model is complex and requires substantial explanation. From the participant's point of view, the model reflects the barriers to the practices and services provided.

Keywords: Decision-making; developing model; pregnancy with HIV; midwives



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INTRODUCTION

Several studies gathered internationally and in Thailand have shown that many women living with HIV express the need to have a child and intend to get pregnant (Cater et al., 2013; Firth et al., 2012; Hernando et al., 2014; Huntington et al., 2013; Kownaklai & Hayter, 2022; Loutfy et al., 2012; Liamputtong & Haritavorn, 2014a). This is especially true for women who, after receiving ARV medication for a period of time, experienced improved health and returned to feeling strong as they were before infected (Rujkorakarn & Kownaklai, 2010). This has led these women to think about having sexual intimacy and intercourse with partner and to have children (Carter & Kraft, 2013; Kownaklai & Hayter, 2022).

International studies have discovered several reasons why women living with HIV intend to have a child. These reasons

include them believing that their infection rate is very low, trusting anti-virus medication and medical advancement, as well as trusting their healthcare provider's information and guidance on managing their being healthy (Demissie et al., 2014; Gruskin, 2012; Rujumba et al., 2013; Thurling & Harris, 2012). Other reasons include the need to be a mother and that after becoming pregnant they could not have an abortion since it is against their religious beliefs. However, the most significant factor was shown to be the desire to have a child with a partner (Demissie et al., 2014; Hernando et al., 2014; Liamputtong & Haritavorn, 2014a). The research conducted in Thailand, it was explored that women living with HIV believe that having a child is like a blessing, they represent succession of family task, and the most significant factor was the partner's desire for a child (Kownaklai & Hayter, 2022; Liamputtong & Haritavorn, 2014a). Surprisingly, many women became pregnant by hiding their HIV status from a partner

because they feared that their partner would leave them (Kownaklai et al., 2022; Liangputtong & Haritavorn, 2014b; Ross et al., 2012).

In the Thai context, currently, Thailand's standard of care for pregnant women with HIV has considerably improved. The Ministry of Health announced a policy and guidelines to prevent mother-to-child transmission for healthcare professionals across the country. These guidelines consist of providing pre-counseling and post-counseling about the HIV test for women and couple, and keeping the results strictly confidential. Pregnant women who have positive HIV results will be treated with potent ART following the standard guidelines. Infants who born to mothers with HIV positive will receive ART and artificial formula milk and will also receive a blood test for HIV infection at the age of 6, 12 and 18 months after birth. Furthermore, women, infants, and partners who contracted with HIV will receive antiretroviral treatment according to their progression of CD4 count, viral load or symptoms, as well as monitoring of their health, taking combination of ART and continuous follow-ups (Anamai, 2020; Department of Health, 2020).

In Thailand, there is no law to enforce an HIV-positive man or woman to disclose their HIV status to their partner(s) before marriage or having a child. This is unless it is related to medication/treatment or other reasons and after permission is granted from the person living with HIV. Thai pregnant women are recommended to the hospital and ANC to confirm their pregnancy and receive antenatal care. At the ANC, women will undergo an HIV screening. Once their HIV status is confirmed by staff members, they would be advised to have their partners take an HIV test. These clinic visits and advice are signals for these women to tell their partners about their HIV status— either themselves or with the support of nurses in the clinic. However, this advice is provided as a recommendation— there is no obligation for them to do so.

The authors of this study generated a pregnancy decision model in 2018 to understand how Thai women make their pregnancy decisions concerning their HIV-positive status (Kownaklai et al., 2018). This substantive model consists of six categories of factors; category 1) concealing HIV status from the partner; category 2) desire to have a child; category 3) becoming pregnant; category 4) keeping or terminating a pregnancy; category 5) accepting a decision, and category 6) adapting to a decision. The original study is found that the main concerns of women living with HIV in deciding to have a child are balancing fear as well as concealing their HIV status and the information that they have in each decision-making step. Based on the research findings, a unique process of decision-making that is related to personal and Thai social beliefs was determined.

Recommendation from this study, suggests that healthcare professional should pay greater attention to counseling women living with HIV and their partners by giving sufficient contraceptive information to prevent unplanned or unwanted pregnancies, to support and guide the women who want and plan for pregnancy in advance of this happening, and to help women deal with HIV disclosure issues related to morality and the rights of the couples. Moreover, respect and support must be provided to women living with HIV regarding their right to have a child if they choose to do so. As a result, the view of stakeholders such as nurses, midwives, and other health care professionals on this model and how it can assist them is an important topic to research.

METHOD

Study design

This qualitative study was developed from the first author's Ph. D. program which generated a substantive model on "the pregnancy decision-making processes in Thai pregnant women living with HIV". This study's main purpose was to extend this work by seeking to validate and develop the model using the perspectives of ante-natal professionals.

Research aim and question

The study aimed to explore the perspective of nurses on the model of pregnancy decision-making processes in Thai pregnant women living with HIV. The research question was how do nurses and women critique a decision-making processes model of Thai pregnant women living with HIV?

Design

Descriptive qualitative research was used to observe and engage with information-rich Thai pregnant women who are living with HIV and their nurses. They were asked to share their experiences and views about the decision-making processes among HIV-positive pregnant women and how to service them (Creswell, 2007; 2009). This type of descriptive qualitative research captured information from 10 participants as they reflected on their experiences and perceptions of a phenomenon within a Thai context.

Setting and participants

The study occurred in the antenatal care and counseling unit of a tertiary hospital in northeast Thailand from August to December 2021. The inclusion criteria to participate in the study were pregnant women who were (1) aged ≥ 18 years and considered to contract HIV before becoming pregnant, and (2) received ANC and counseling services at the study hospital at all gestational ages, (3) as well as nurse-midwives who provided service care for HIV-positive pregnant women in ANC and counseling services at the study hospital.

Purposive sampling was used to recruit participants for the study from nurse-midwives and HIV-positive women at antenatal care who met the inclusion criteria. A total of 10 participants, 5 HIV-positive pregnant women and 5 of their nurses, were recruited and was judged to reach data saturation.

Data collection

1. A total of 10 key informants were included in this study (five nurses and five HIV-positive pregnant women). The informants were interviewed, whereby data from the nurses were gathered from two small group discussions, and face-to-face in-depth interviews were conducted with the HIV-positive pregnant women.

2. A substantive model "Pregnancy decision-making process in Thai women living with HIV" (see Figure 1) was selected. The model consisted of six categories: 1) concealing their HIV-positive status from their husband; 2) their desire to have a child; 3) becoming pregnant; 4) keeping or terminating a pregnancy; 5) accepting a decision, and 6) adapting to a decision. These categories were delivered to the participants for them to share their opinion on them.

3. A flexible interview schedule was implemented. Each interview was recorded and transcribed and took approximately 45–60 minutes. The content and structure of the initial semi-structured interview guideline were developed by three experts in obstetrics and nurse-midwifery (a hospital obstetrician, an antenatal care unit nurse-midwife, and a nurse-midwife lecturer). Field notes were also written following each interview to document the researcher's ideas

(JK). These served as memos and noted significant body language and activities of the interviews.

Trustworthiness in qualitative research

The authors have advocated two elements, triangulation and member checking (Lincoln and Guba (1985:300) to strengthen trustworthiness in this qualitative study.

Triangulation

By using different sources (women, nurses, and midwives) and methods (small group discussion, in-depth interview, and observation in the setting), the investigator (JK) rechecked the contextual validation of the collected data (Lincoln & Guba, 1985; Guba & Lincoln, 1989).

Member checking

As a quality marker, one of the researchers (JK) returned to the field to meet with three participants and shared this research's findings - they confirmed the findings and provided suggestions. MH also provided critical advice in the development of the grounded theory and was involved in the writing and critical revisions of the manuscripts.

Researcher's roles and experience

JK, the first author, has been working with people and women of reproductive age living with HIV in the Northeastern region of Thailand for 10 years. JK has considerable experience in providing services in antenatal care (ANC), labor room (LR), and the postpartum period (PP). Additionally, JK is a researcher who has studied and published research papers related to pregnancy decision-making with HIV/AIDS in Thailand. Therefore, in this study, JK led the data collection, analysis, and manuscript development.

MH, the co-author, is a professor of nursing and sexual health. MH was involved in the conception and design of the study, cross-checked the data analysis, and was involved in the writing and critical revisions of the manuscript.

Data saturation

Bryant and Charmaz (2007) described that researchers would know when they have reached saturation when they hear nothing new from the data and when the categories are robust and well supported by the data. After interviewing 10 participants, the researchers were satisfied with the information collected and ceased data collection as it was clear that the categories developed were strong and well supported by the data.

Data Analysis

Thematic analysis (Braun and Clark, 2006; Vaismoradi et al., 2013) was used to analyze the collected data. The analysis was divided into six steps; 1) familiarization; reading and re-reading the transcripts, 2) coding; coding interesting data concerning the research question, 3) searching for themes; collating and gathering codes into themes, 4) reviewing themes; combining, refining, separating, or discarding entire codes, 5) defining and naming themes; defining and refining each theme and, 6) writing up the report; finally, reporting of analysis into 2 themes and 5 sub-themes.

Ethical consideration

The study was approved by the Mahasarakham University Ethics Committee for research involving human subjects (#074-377/2021). Informed consent was obtained from the participants.

RESULTS

The socio-demographic characteristics of the participants are shown in Table 1

Table 1. Participants' socio demographic characteristics n = 10

Characteristic	Number	
	Nurse-midwives	Women
Age (year)		
< 20	-	1
20-30	-	3
31-40	4	1
41-50	1	-
51-60	-	-
Religion		
Buddhist	5	5
Marital status		
Single	1	-
Married	4	5
Divorced	-	-
Widowed	-	-
Single mother	-	-
Education level		
Primary	-	-
Secondary	-	5
Vocational college	-	-
Bachelor	4	-
Master	1	-
Occupation (year)		
1-5	-	3
6-10	-	2
11-15	2	-
16-20	1	-
21-25	1	-
26-30	1	-
Duration of being HIV-positive (year)		
1-5	-	4
6-10	-	1
11-15	-	-

After five HIV-positive women and five nurses and midwives were interviewed, the selected model was divided into two themes: 1) Perspective on the selected model, which contains five sub-themes, 1.1) A substantive model that reflects the pregnancy decision-making process; 1.2) Complexity; 1.3) Usefulness; 1.4) Strength; 1.5) Weakness; and 2) What is the matter? The perspective of women and nurses regarding the model's practice and services (see Table 2).

Theme 1. Perspective on the selected model

Figure 1 was provided to nurses, midwives, and pregnant women to discuss.

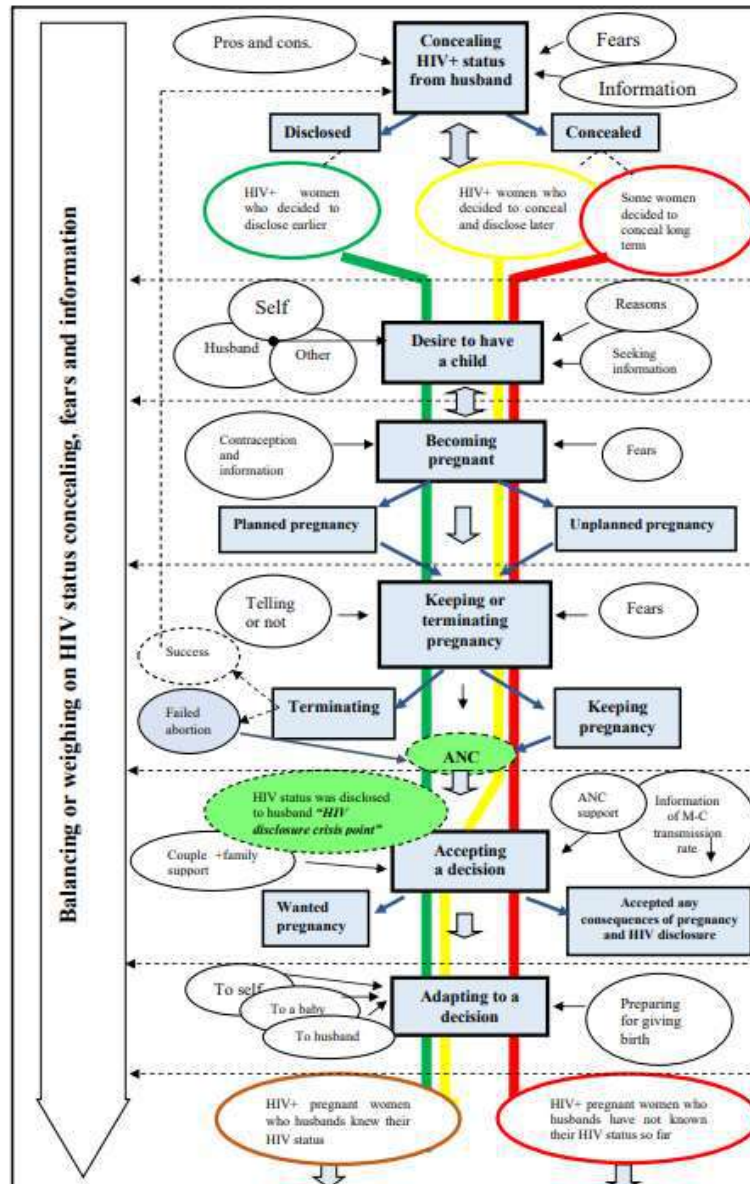


Figure 1: A substantive model developed by Kownaklai 2018

A summary of the perspectives of nurse-midwives and women based on the substantive model regarding the pregnancy decision-making process is shown in Table 2 below.

Table 2. The perspectives of nurse-midwives and women based on the substantive model regarding the pregnancy decision-making process

Sub-themes	Women's perspective	Nurses' perspective
A substantive model that reflects the pregnancy decision-making process	<ul style="list-style-type: none"> – They agreed on how the model reflects the experiences and decision-making processes of women. – There are options in each category that shows the footprint of each woman's decision; each category has two options. For example, concealing the infection from the partner has both disclosing and concealing options. – These options allow each woman to describe the path they took in reality. 	<ul style="list-style-type: none"> – It is interesting at first, but it is quite difficult to follow because of its complexity. However, after the researcher explained the model, the nurses felt that the model was accurate and reasonable. – It is good to have three colors to divide the paths of the three groups of women.
Complexity	There were too many details and it was difficult to follow. The women would swipe to only look for	Complex and requires somebody to explain some points.

Sub-themes	Women's perspective	Nurses' perspective
	their own decision rather than look at the whole diagram.	
Usefulness	<ul style="list-style-type: none"> - Useful and can be used in practice. - Reflects the real life of the sample. 	It makes nurses understand the perspectives and experiences of women more. The model helped identify how many issues were missed. The nurses agreed that the model is useful and can be used in practice with HIV-positive mothers and children.
Strength	<ul style="list-style-type: none"> - Matches the women's real experiences, as they agreed with the model shown. 	Reflects the real-life experiences of the participants in detail.
Weakness	Difficult to follow.	Due to its complexity, it required further explanation.

Theme 2. What is the matter? The perspective of nurses and women regarding the models' practice and services

The perspective of women regarding the model's practice and services

All pregnant women stated that some healthcare providers showed some form of discrimination against HIV-infected people. Despite being impressed with the care and services of the staff of this hospital, the women wanted the nurses to add the following services:

1. To take the time to explain the treatment, medicine, and prevention of infection methods from mother to child.
2. Have nurses in the antenatal care room provide a private room for pregnancy examination. This is because, at the present ANC, the services and explanations for HIV-positive and HIV-negative pregnant women are conducted in the same room. Therefore, sometimes unrelated people may hear conversations about women's infections during the service because the examination beds are quite close together. Thus, the women suggest that the hospital should have 2-3 private rooms for counseling.
3. During the postpartum period service, women would like to have a service to deliver formula milk to their homes instead of coming to the hospital to collect it. Currently, Thailand still has a policy for infants born to HIV-infected mothers to drink formula milk instead of breastmilk. Therefore, these women must come to the hospital every 3 months to collect the formula milk for their infants. According to the respondents, going to the hospital often wastes time and travel expenses for the women and family members.

The perspective of nurse-midwives regarding the model's practice and services

Nurse-midwives at ANC

From the nurses' perspective, women receiving antenatal care services, when receiving HIV-positive results from lab 1 and lab 2, tended to hide their circumstances and HIV status, especially from their partners. According to the nurses, "Most of the time, women will tell their partners themselves." Nurses are responsible for pointing out the pros and cons of informing their partners and M-C (mother-to-child) transmission. This is because Thailand's policy has given women the right to choose whether they wish to disclose this information to their sexual partners or not.

The barriers to action

Nurses or midwives in the ANC indicated that some hospital policies breach women's confidentiality. For example, this is seen in the labeling of HIV-positive in the mother's handbook (Pink book) as well as sending the patient's relatives to collect their outpatient home medicines.

As part of Thailand's routine care and policy, the nurse or doctor would write the word "UP" (stands for Universal Precaution) at the top of the mother's handbook when they receive service at the hospital. This allows for the unintentional exposure of the women's HIV status to close relatives who are health care providers (all care providers in Thailand know what UP stands for).

"A woman once asked a nurse not to write the word UP (universal precaution) in the pink mother handbook for fear that others would find out, especially officials or relatives who know this abbreviation", according to the policy of the hospital they still can't do, they must write it to communicate with other staff to take care or caution" (small group discussion, nurse group 1).

Moreover, allowing relatives to collect the patient's medicines also allows for some women's HIV status to be exposed.

"Most of the time, the secret is broken when the baby admitted into the ward is a sick newborn, because all children born to HIV-infected mothers are required to receive the AZT syrup. A relative is required to collect the medication from the pharmacist and medicine rooms. At this point, the relatives will see what medicine the child has received and know it's AZT" (small group discussion, nurse group 1).

Another difficult and complex barrier is the unstoppable concealing cycle. All nurses at ANC confirmed that when these women conceal their HIV status from their partners, it would cause a new problem in a new cycle when their partners discover the truth.

"When women's HIV status is in the red (exposed) and their partner finds out their HIV status. Some men will leave the HIV-positive women. So, to survive, some women often have new partners and want to have another child. This will start a new cycle..." (small group discussion, nurse group 1).

"We won't stop women to have a new partner, but we can protect the transmission from mother to child. Most nurse-midwives and obstetrics will recommend a permanent vasectomy for the women's partner because in the next pregnancy, they may not be so lucky again..." (small group discussion, nurse group 1).

Nurses at the counseling clinic

The barriers to action

In this study, most nurses highlighted the importance of having a "premarital clinic" for premarital counseling. It is very important for providing advice on preventing the sexual

transmission of infectious diseases to the sexual partner and fetus. Sadly, women would get infected by their sexual partners who are unaware of their HIV status or those working in a sex trade occupation are at risk of getting infected. These barriers are supported by statements from the small group discussion, nurse group 2, as follows:

Nurses gave the opinion that premarital blood examination in Thailand is difficult to access, is a passive service, is not free, and lacks promotion to new couples. Therefore, to overcome such barriers, these services should be provided for free for voluntary couples for premarital counseling and examination.

"The barrier to service is the pre-marriage blood test... It is often costly and there is less publicity around it, so people pay less attention to it. These blood tests should be available for free to do before marriage or before having children"

"...it is difficult to access premarital services, such as a pre-marital blood test. These types of services are given by the obstetrics clinic. Then, when the clients want to take an STD blood test and treatment, they will have to go to another medical department service since there is no STD clinic at the hospital. There are no doctors and nurses who will come to work separately here due to the heavy workload in other areas. So, there it is very not convenient for clients to wait for every service and visit many clinics just to take a premarital blood exam..."

"The system is too passive, there is a lack of proactive service. The prevention of AIDS problems must be more proactive. Because when the problem comes, it is difficult and complicated to solve."

"In my opinion, another barrier is the law. Our current law does not favor discordant couple counseling because this law allows one side to conceal their HIV-positive result from his or her partner. Yes, I agree that he or she should not be forced to disclose this sensitive information to others. But we should consider both points of view, his or her partner should have the right to know such information and should have the right to protect themselves too. If there is a law or act to disclose the necessary information to the partner, it will be easier for our staff to work with and have a good preparation step to deal with it" (nurse A at the counseling clinic).

"I want women to open up to their partners ... they don't need to tell everyone around the world but should tell their partner"... to protect themselves and their partner from the transmission and get the treatment together if they stick together, if it doesn't stick together, it's fine. You know? HIV and disclosure consulting is very difficult and requires a lot of energy from counselors because each person's life is different, it is very complex for our patients..." (nurse B at the counseling clinic).

DISCUSSION

This study on Thai women living with HIV highlights the way that they still desire to have a child – which is also seen elsewhere in the previous literature (Hernando et al., 2014; Huntington et al., 2013; Moseholm et al., 2022). However, the severity of stigmatization in Thai society is still widespread at the family and community level, including among health service staff, as stated in other contexts and studies (Cuca et al., 2012; Kavanaugh et al., 2013; Kownaklai, 2022; Nattabi et al., 2012). In contrast, some studies indicated that some women have positive attitudes to healthcare providers and

services regarding their HIV status. For example, Hanh et al. (2009) described the role of healthcare professional in supporting HIV-positive pregnant women and found that most women believed they were being supported and encouraged by healthcare providers. Similarly, Hardon et al. (2012) found that most pregnant women living with HIV (85%) in Africa felt that health providers and counselors respected their desire for confidentiality by protecting their HIV results. Moreover, Moseholm et al. (2022) indicated that HIV-positive women's interactions with healthcare providers and community influence their experiences in both positive and negative ways.

According to the opinions of the participants in this study, the selected model is quite complicated to follow. This contrasts with the view of Charmaz who proposes that a constructivist grounded model must be not too difficult to follow and understand (Charmaz, 2006). However, a grounded theory should also be comprehensive. Therefore, the current model – with its explanation – should be made to be an accurate depiction of the decision-making process of HIV-positive Thai pregnant women.

In this study, the point of view of nurses and women was that they understood why HIV-positive women may not want to share their HIV status with anyone because of their fear of stigma and its consequences. Based on the model, women should not be forced to disclose their HIV status but should be motivated to share the information by themselves with nursing support.

Nowadays, with the rapid development of HIV/AIDS treatments, especially ART, the lives and health of people who are living with HIV/AIDS have been significantly improved. However, stigma and discrimination related to living with AIDS have not decreased as much as would have been expected. HIV/AIDS-related stigma and discrimination exist among people living with HIV themselves, in families, communities, countries, and worldwide. The WHO cites that fear of stigma and discrimination are the main reasons why people are reluctant to get tested, conceal their HIV status, and take antiretroviral drugs (AIDS Education & Research Trust, 2014; Ibrahim et al., 2019; Kownaklai et al., 2022). To reduce the level of stigma and discrimination in local and international societies, people need to understand and respect other humans and their sexual rights. This must also be supported by governments and international organizations, healthcare providers, communities, and family.

The needs and choices of reproductive women who living with HIV have been changed in recent decades. Deciding to become pregnant for those women is an unavoidable situation that healthcare providers must better concern respond to by providing appropriate choices and services, managing risk among couples and infants, and respecting these women's decision to become pregnant. The challenge in taking care of reproductive-age women who are living with HIV, despite the current efficiency of treatment, is in managing more complex problems related to personal and social context such as women who live with HIV becoming pregnant, their rights and choices, and addressing the associated stigma and discrimination.

Many studies also suggest that the social-cultural context within which women living with HIV of reproductive age live and how that affects pregnancy decisions should be better understood and treated by health professionals who hope to improve their quality of life and reproductive choices (Firth et

al., 2012; Kownaklai et al., 2022; Liamputtong & Haritavorn, 2014b; Moseholm et al., 2022; Nattabi et.al., 2012).

CONCLUSION AND RECOMMENDATION

The nurses' and women's views on the model were positive. The respondents agreed that the model reflects the real-life aspects of HIV-positive women's pregnancy decisions. It also reflected the problems of the service system for HIV-infected women of reproductive age. Although they are aware of the process, women and healthcare providers still face challenges and obstacles in providing and serving women, partners, and families in the Thai context. These obstacles and problems are from the operational level to the policy level, which is complex and difficult to solve, but everyone involved in this study is hopeful that this research will improve the current conditions. Based on this study's findings, we recommend the following actions for practice, policymakers, and further research:

For practice: integrate multidisciplinary marital counseling with STD clinics as a one-stop service for better proactive service for couples, women, and families in Thailand.

For policy: well-timed law in Thailand should be considered to favor discordant couple counseling and allow one side who contracted HIV to declare their HIV status to his or her sex partner.

For further research: The model should be tested by a quantitative method with other health care professionals such as doctors. Social and well-being service members should also be included to explore their views.

This study was written based on the perspective of pregnant women and counseling nurses and midwives at the ANC. This may limit its generalizability to other settings such as the labor room, postpartum period, and other cultures and contexts.

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CONFLICT OF INTEREST

None

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