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Kownaklai, Jaruwan, Graham, Moira and Hayter, Mark  (2022) Pregnancy decision making among Thai women living with HIV: a grounded theory study. *Midwifery*, 115. p. 103490. ISSN 0266-6138

DOI: <https://doi.org/10.1016/j.midw.2022.103490>

Publisher: Elsevier

Version: Accepted Version

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Additional Information: This is an Accepted Manuscript of an article which appeared in final form in *Midwifery*, published by Elsevier

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Pregnancy decision making among Thai women living with HIV: a grounded theory study

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Abstract

Objective: this qualitative research study aims to understand and generate a model of the pregnancy decision-making process in Thai women living with HIV.

Method: the constructivist grounded theory of Charmaz was chosen as the research approach and method to generate a pregnancy decision-making process which is shaped and constructed by personal and social processes.

Data collection: was undertaken in antenatal clinics (ANCs) at two provincial hospitals located in the Northeast of Thailand. In-depth semi-structured interviews were conducted with 15 HIV positive pregnant women. Data analysis involved open coding, making-memos and using the constant comparative method to develop a grounded theory substantive model of HIV pregnancy decision making.

Findings: the substantive model consists of 6 categories; 1) concealing HIV positive status from partner; 2) desire to have a child; 3) becoming pregnant; 4) keeping or terminating pregnancy; 5) accepting the decision; and 6) adapting to the decision. This research finds that the main concerns women living with HIV have in deciding to have a child are balancing fear, concealing HIV status and the information that they have in each decision making step. Based on the research findings, a unique process of decision making has been found amongst these women that relates to personal and Thai social beliefs.

Conclusions and implications for practice: the concept illustrates not only the process of decision making but also highlights the main stages, issues and concerns of women living with HIV wanting a child.

This study recommends that health care providers need to pay more attention to counselling women and couples living with HIV by giving sufficient contraceptive information to prevent unplanned and unwanted pregnancy, to support and guide the women who want and plan for pregnancy, in advance of this happening, and helping women to deal with HIV disclosure issues related to morality and the rights of couples. Moreover, respect and support must be accorded to HIV positive women about their right to have a child if they choose to do so.

Introduction

Thailand's current standard of care for HIV-infected pregnant mothers is considerably better than in the past, with the improved quality and efficacy of ART treatment with the mother to child transmission rate (MTCT) decreasing from 5 to 12% during the 1990s to 3.5% - 3.62% in 2010–2016. However, these rates were higher than the target set of <2% by the Thai Department of Health (2016). However, in 2016 the Thai Government, through the Ministry of Public Health, announced that the MTCT rate in Thailand had been reduced to less than 2% for the first time (Ministry of Public Health, 2016). In 2022, the Dept of Health in Thailand has set a new challenging target to achieve <1% by 2024 (Department of Health, 2020; 2022). Caring for pregnant women living with HIV requires interdisciplinary collaboration by both the health team and relevant professional team because HIV infection affects women and their families in every aspect of their lives. The core care team in Thailand consist of the obstetrician, paediatrician, nurses who work as midwives in ANC, labour and post-partum rooms (1 class of nursing license in Thailand including midwife), social worker and clinical psychologist. The Ministry of Health announced a policy to prevent mother to child transmission

in the form of guidelines for healthcare professionals across the country (Anamai, 2020; Department of Health, 2020; 2022). These guidelines consist of the following; First, providing pre-counselling and post-counselling about the HIV test, including couple counselling and keeping the result strictly confidential. Second, pregnant women who have a positive HIV result will be treated with potent ART following the guidelines of the Ministry of Health. Third, infants born to mothers infected with HIV will receive antiretroviral therapy and artificial formula milk for their babies who will also receive a blood test for HIV infection. Fourth, women, infants, and partners who are HIV-infected will receive antiretroviral treatment according to their state of infection or symptoms or their CD4 count, as well as monitoring of their health and continuous follow-up (Anamai, 2020).

The desire to have a child appears to be no different in women who are HIV positive or without the diagnosis. Numerous qualitative and quantitative studies report that while many women with HIV express the desire to have a child, some do not go on to have one (Cooper et al., 2007; Kanniappan et al., 2008; Carter et al., 2013). However, there is also a body of research revealing that many women living with HIV do intend to get pregnant (Sowell et al., 2002; Nobrega et al., 2007; Gogna et al., 2009; Loutfy et al., 2009; Marcellin et al., 2010; Firth et al., 2012; Loutfy et al., 2012; Huntington et al., 2013; Hernando et al., 2014). This is especially true of those women who, after receiving ARV medication, experience improved health and feel well (Rujkorakarn et al., 2010). This improvement may lead women to think about becoming pregnant (Chin-Hong et al., 2005; Bouhnik et al., 2007; Rujkorakarn et al., 2010).

Several qualitative and systematic review studies have shown the reasons women living with HIV go on to have a child include; women being aware that their viral load was very low, they trusted the anti-virus medication and medical science, they trusted their health care professional's information and advice on managing their health, they needed to be a mother (Thiangtham and Bennett, 2009), and that, after becoming pregnant, they could not have an abortion as it contradicted their religious beliefs. Some women were also responding to their partner or family's desire for them to have a child (Taha et al., 1995; Sheri et al., 2004; Nobrega et al., 2007; Chilongizi et al., 2008; Gruskin et al., 2008; Oosterhoff et al., 2008; Suryavanshi et al., 2008; Finocchiaro-Kassler et al., 2010). However, there is a dearth of literature about the decision-making process in HIV related pregnancy – particularly from a qualitative perspective and from a south east Asian setting with high HIV prevalence amongst women.

The literature demonstrates that women with HIV face many challenges in their lives – and it remains unclear where the decision to become pregnant fits in with those challenges. Examination of the research reveals a gap in the knowledge base on this issue. There are studies that have looked at different aspects of pregnancy in HIV but none that set out to describe and conceptualise the whole social process of being HIV positive, deciding to become pregnant and then moving through the pregnancy process. This study aimed to fill the identified gap and set out to explore and attempt to understand this decision-making process. The research will enable health care providers and healthcare services to understand, manage risk and respect the reproductive decisions made by HIV positive women.

Research aim and question

The aims of the study were; 1) to enquire into why HIV positive pregnant women in Thailand decide to become pregnant and have a child, 2) to explore decision-making processes throughout these HIV positive women' pregnancies. The research questions were; what is the decision making process to become pregnant in Thai

women living with HIV? and what are the decisions Thai women living with HIV make throughout their pregnancy and how do they make them?

Method

Approach: Given the aim to enquire and conduct an in-depth exploration of the process of decision making amongst HIV positive pregnant women, a qualitative design was chosen for this study. The research questions in this study lend themselves to a qualitative rather than quantitative approach because these questions focus on complex issues and processes around pregnancy which Corbin and Strauss (2008) call the inner experiences of people; their feelings, beliefs, values, and perception in their social context. There are many approaches in qualitative research, the common qualitative approaches in social and health science are ethnography, phenomenology, case study, and grounded theory (Creswell, 2007; Parahoo, 2014). Generally, any of these approaches could explore the topic of this research study – but when applied to the particular research questions in this study Grounded theory seemed the best fit to address them.

Grounded theory itself is not a theory but describes, generates and develops the concept or theory grounded from the data to provide an explanatory model/theory about the subject under investigation (Parahoo, 2014). The constructivist approach of Charmaz (2006) was chosen for this study as this approach values the participant's voice and experiences, gathering rich data to learn how people make sense of their experiences and actions can be conducted by a variety of methods – as tools – rather than recipes or packages. Grounded theory includes these tools for instance; memos, coding categories, comparing data, theoretical sampling, saturation and sorting. These processes are argued to be the most appropriate way to construct an explanatory theory to explain the pregnancy decision making process and pregnancy journey of Thai HIV positive pregnant women – the central aim of this study.

Setting: This study took place in the antenatal care unit of a provincial hospital in Northeast Thailand which receives patients from 22 district hospitals. The population of this province is 1.3 million and has the fifth highest prevalence of HIV in Northeast Thailand. This hospital provides services for HIV negative and HIV positive pregnant women in the Department of gynaecology and obstetrics. There is also an AIDS care clinic connected to this Department which offers conveniently located and safe and private rooms for counselling which can also be used for research interviews.

Researcher's roles and experience

- J.K. the first author, as a PhD student and midwife, has been working with people living with HIV in the North-eastern region of Thailand for 10 years. Delivering women's reproductive health care, providing care for people living with HIV and their families in the community as well as in hospital. She has considerable experience in providing antenatal care (ANC) services, assisting birth as a midwife in the Labour room (LR) and providing care and support to mothers and babies in the Post-partum period (PP). J.K is also a researcher and has studied and published research papers related to HIV/AIDS in Thailand, including a study examining decision making in HIV positive women about amniocentesis tests. In this study, J.K led the data collection, analysis and theory development activities – working under the supervision of MG and MH.
- M.G. and M.H. as supervisors advised on the design and conduct of the study. They were involved in supervising data analysis. This meant that the three researchers (J.K., M.G., and

M.H.) cross-checked the quality of the transcriptions and language accuracy and also exploring the data for new insights. MG and MH provided critical advice in the development of the grounded theory and were also involved in writing and making critical revisions to manuscripts.

In constructivist grounded theory the researcher is considered a part of processes of data collection and analysis rather than being objectively removed from the data or phenomenon under study (Charmaz, 2006). Categories and models emerge and are constructed from the interpretation of both the participants and the researcher (Charmaz, 2006). In this study, although the elements of the 6 categories of pregnancy decision making were expressed by these women, the findings were interpreted, determined and shaped by the first author's clinical experience in the field of HIV maternity care in a Thai context. Although J.K.'s principal position in the field was as a researcher, her other background as a nurse and midwife working with people and women living with HIV enabled her to understand the women's experiences in a more contextual manner. JK's clinical experience also enabled her to be theoretically sensitive to pregnancy decision making from the participant's viewpoint.

Data collection

commenced with an initial purposive type sampling approach in order to select participants with the appropriate experiences to start the process of data collection and analysis off; finally, 15 women were recruited to in-depth interview in this study. The inclusion criteria to participate in the study were: 1) HIV positive pregnant women, aged above 18 years of age, and at any gestational age (GA) 2) women who knew their HIV positive status before the current pregnancy.

Purposive sampling was initially used to recruit participants for the study with nurse-midwives at the antenatal care unit identifying eligible women who met the inclusion criteria. After initial recruitment, the first in-depth interviews commenced. Theoretical sampling was used to recruit the next participants as new theoretical categories emerged. Theoretical sampling helps researchers choose key participants, which assists the researcher form the categories and theory (Creswell, 2009). A total of 15 Thai women were recruited and saturation was judged to have been reached. Each interview took approximately 60–90 min conducted in a private room. Interviews were guided by a flexible interview schedule and semi-structured question guideline (see Table 1), particularly in the early interviews, however, this was adapted as analysis and theoretical sampling guided the study (Charmaz, 2006). Field notes were also recorded following each interview to record ideas, serve as memos and note any significant non-verbal elements of the interview (J.K.).

Data analysis

As a grounded theory method, data collection and analysis occur concurrently. Data are gathered and analysed almost immediately. Starting with open codes the theory is built as more data are collected, guided by memos and theoretical sampling. Constant comparative method (CCM) is used to compare the similarities and differences between categories from case to case to reach theoretical saturation and a solid, complete conceptual model of the social process under investigation alongside all data analysis processes.

Data saturation

Bryant and Charmaz (2007) describe that researcher's know when they have reached saturation when they hear nothing new

Table 1
The interview schedule and questions.

| Activities | Time frame |
|--|------------|
| > Explain the purpose of the study, method and time frame | 5–10 min |
| > Informed consent | 5 min |
| > Interview (Example of questions) | 60–70 min |
| <ul style="list-style-type: none"> • Pregnant women <ul style="list-style-type: none"> - Tell me about your pregnancy - When did you know your HIV status? How? - Have you revealed your HIV status to anybody? Who? Why? How? - How did you decide to become pregnant with HIV-positive status? - Who was involved in your decision? - Who was the most significant person in your pregnancy decision? - How did they help you in your decision? - How have others in your family reacted to HIV status and pregnancy? - What are your information sources on HIV? - How did you deal with ... (struggles)... related to become pregnant with HIV-positive status? - How do you feel now? - How do you plan for your/baby's future? | |

from the data and they are also satisfied the categories are robust and well supported by the data. This study reached this point around 12 interviews – although additional ones were conducted to test this – after 15 interviews no new codes emerged. After interviewing 15 participants, the researcher was satisfied and ceased data collection as it was clear that the categories developed were strong and well supported by the data – and that the theoretical explanation of the process of pregnancy decision making that these women living with HIV had undergone was robust and complete.

Ethics

The study was approved by the University of Hull (#210/2016) and the Roi-et Hospital and branches (Thai language (#1/2016) Ethics Committee for research involving human subjects where the research was conducted. Participants were provided with a clear explanation of the purpose, method, study period and risks of the research – this was done verbally and also by the provision of an information sheet. Informed consent was obtained from the participants and a pseudonymous name was used to replace real names.

Addressing ethical and accuracy aspects in the interview transcribing process

After each interview was conducted and recorded, the transcripts were transcribed verbatim into Thai and then translated to English by the researcher (J.K.). An English translator was used to audit the transcripts for accuracy before sending to English Native Speakers (M.G. and M.H.). The following procedures were applied to the translation process – to ensure ethical practice and also to ensure the accuracy of translation, this was guided by the advice of Poland (2001):

The translator (bilingual Thai and English) had been briefed on the confidential nature of the tapes and asked to sign a confidentiality agreement. In addition:

Table 2
General demographic data.

| Pseudonymous name | G ¹ -P ² -A ³ -L ⁴ | Age | Marital status | Religion | Education | Planned/unplanned pregnancy | HIV caused | HIV disclosure | Partner's HIV status |
|-------------------|--|-----|----------------|----------|-----------|-----------------------------|-------------------------------|------------------------------------|----------------------|
| 1.Panida | G ₂ P ₁ A ₀ L ₁ | 22 | Couple | Buddhist | Grade 12 | Accidental/Unplanned | Sexual (from one of partners) | None | unknown |
| 2.Peungpen | G ₄ P ₃ A ₀ L ₃ | 25 | Couple | Buddhist | Grade 8 | Accidental/Unplanned | Sexual (from one of partners) | None | unknown |
| 3.Urainwan | G ₃ P ₁ A ₁ L ₁ | 21 | Couple | Buddhist | Grade 12 | Accidental/Unplanned | Sexual (from ex-partner) | Family and partner | Negative |
| 4.Kanchana | G ₁ | 19 | Couple | Buddhist | Grade 12 | Planned | Mother (MTCT) | Family and partner | Negative |
| 5.Aree | G ₂ P ₁ A ₀ L ₁ | 36 | Couple | Buddhist | Grade 12 | Accidental/Unplanned | Sexual (from ex-partner) | Partner at ANC | Negative |
| 6.Buraya | G ₁ | 19 | Couple | Buddhist | Grade 9 | Planned | Mother (MTCT) | Family and partner before pregnant | Negative |
| 7.Tukta | G ₂ P ₁ A ₀ L ₁ | 21 | Couple | Buddhist | Grade 9 | Accidental/Unplanned | Sexual (from ex-partner) | Partner at ANC | Negative |
| 8.Napat | G ₄ P ₀ A ₃ L ₀ | 33 | Separated | Buddhist | Grade 12 | Accidental/Unplanned | Sexual (from one of partners) | Mother and partner | unknown |
| 9.Malee | G ₃ P ₁ A ₁ L ₁ | 29 | Couple | Buddhist | Grade 12 | Accidental/Unplanned | Sexual (from current-partner) | Partner before pregnant | Positive |
| 10.Hom | G ₂ P ₁ A ₀ L ₁ | 33 | Separated | Buddhist | Grade 9 | Accidental/Unplanned | Sexual (from one of partners) | Partner after pregnant | unknown |
| 11.Navarat | G ₂ P ₁ A ₀ L ₁ | 30 | Widow | Buddhist | Grade 9 | Accidental/Unplanned | Sexual (from current partner) | Partner | Positive |
| 12.Muay | G ₂ P ₁ A ₀ L ₁ | 22 | Couple | Buddhist | Grade 12 | Accidental/Unplanned | Sexual (from ex-partner) | Partner at ANC | Negative |
| 13.Lew | G ₄ P ₀ A ₃ L ₀ | 23 | Divorced | Buddhist | Grade 9 | Planned | Sexual (from ex-partner) | Partner at ANC | Negative |
| 14.Aonicha | G ₃ P ₂ A ₀ L ₂ | 36 | Couple | Buddhist | Bachelor | Accidental/Unplanned | Sexual (from partner) | None | unknown |
| 15.Sai | G ₂ P ₁ A ₀ L ₁ | 24 | Couple | Buddhist | Grade 9 | Planned | Sexual (from current-partner) | Partner before pregnant | Positive |

¹ G:Gravidity = number of pregnancy.

² P:Para= number of baby birth.

³ A:Abortion= number of successful abortion.

⁴ L:Living child= number of living child.

- The translator was given the opportunity to debrief with the researcher to express any emotional concerns raised by the process and any technical terms
- The translator was instructed to discuss with the researcher if they were not clear on any word (s) or meaning (s).

Transcripts were edited by a bilingual translator and English Native Speaker for accuracy.

Findings

The demographic data of the 15 participants in the study can be seen in [Table 2](#)

All 15 women were Buddhist. Most of them (11 out of 15) were married and living with their partner. Seven women had finished secondary school, with one woman holding a bachelors degree. The 2 youngest participants were 19 years old and pregnant for the first time. Seven of the 15 women were aged 20–25 years, and 6 women were older than 30 years. Seven of the 15 were pregnant for a second time, 3 women were pregnant with their third pregnancy and 3 of the women, were pregnant for a fourth time. Six of the 15 women had prior experience of having an abortion in previous pregnancies, with 2 of these women having had an abortion on more than one occasion. Thirteen of the 15 women contracted HIV from sexual intercourse and 2 women were infected by their mothers. Six of the 13 women who contracted HIV through sexual intercourse, reported this was from an ex-partner and were convinced they could identify them, 4 of the women knew that they had contracted it from a partners but could not identify them, and the remaining 3 women reported that they had contracted HIV

from their current partner. Four of the 15 women had revealed their HIV status to their partner before becoming pregnant, 9 of the women had revealed their status after becoming pregnant and 2 of the women were maintaining secrecy about their HIV status from their partners at the point of interview.

Core category

The product of this study is a grounded theory to explain the “Pregnancy decision making process in Thai women living with HIV”. It presents the decision-making process in a chronologic manner – and links this to key aspects of the decision-making process. The data in this study reveals the complexity of the decision-making process affecting these women. The model consists of the core category and its 6 categories (see [Fig. 1](#)). The core category of the process is the theoretical concept which is in the central aspect of the grounded theory and incorporates and connects the categories ([Charmaz, 2014](#)). In this study the core category is the main process by which the participants move through their pregnancy journey and is presented as “**balancing or weighing on concealing HIV status, fears and information**”. This process is evident the whole journey, for example, in early coding a key main concern and problem for the women was “*concealing HIV status and try to control it*” Whether women chose to conceal or reveal their HIV status involved them balancing their decision on “*feeling fears to the cons of HIV disclosure and insufficient information*” in the early stages of their relationship with their partner so most of them (11 women) decided to hide their HIV status first rather than disclose. In each step of the decision process “balancing on concealing HIV status, fears and information” was evident as the core essence of

Decision making process to become pregnant in Thai HIV positive pregnant women

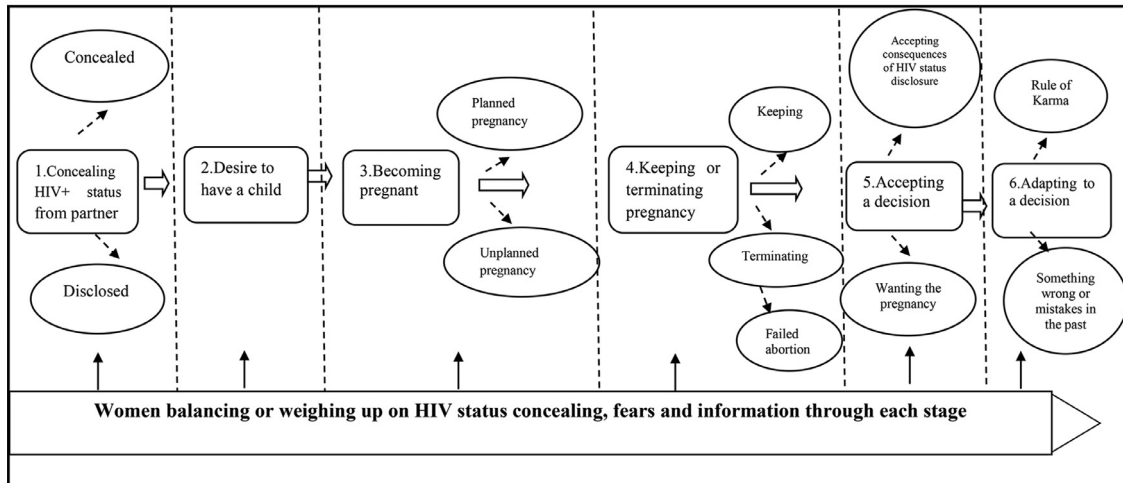


Fig. 1. A substantive model developing.

the way women navigated their pregnancy journey as describe follows:

Concealing HIV positive status from partner

Eleven women chose to conceal their HIV status from their partners from the beginning of their relationships, they tried to keep their HIV status secret for as long as possible until they could not conceal the information any longer. This element seems to be about retaining some control over their lives and also about control over their decisions relating to pregnancy. They had to balance these fears against the knowledge that they must ultimately disclose their status. Women responded to this situation differently and disclosed at different stages – however, this was always related to the desire not to lose control of their situation.

Fears

Fear was the most significant feeling within the women since starting to live with their partners, becoming pregnant and during their pregnancy. Before becoming pregnant 11 women decided to conceal their HIV positive status because of fears such as; they feared their partners would not accept their HIV status, they feared their partners would not want to have a child, they would not accept a baby and they feared being stigmatised and discriminated against by society and their partners. They were also afraid that with a baby becoming infected, their partners would discover their HIV and abandon them. They also had fears about the consequences of an abortion – socially, and in relation to their religious beliefs.

Information

In this study, information was a key aspect upon which women based their decisions. Information could have a positive effect – such as information from health professionals or other reliable sources of HIV information. This type of information reduced fears and supported women in continuing with and accepting their pregnancy. In contrast, negative or inaccurate information could increase fears and contribute negatively to the decision-making process. For example, receiving information such as concealing HIV status from a partner was the best choice, having an illegal abortion being a solution, and to continue with unsafe sex behaviour to conceal their HIV status. This appeared connected to some HIV women living with a partner not getting enough information on contraception, safer sex and pre-marriage counselling.

In addition, 6 categories and the relationships within them emerged and are presented using paradigm extracts from the interview data.

Category 1: “Concealing HIV positive status from partner”

Concealing or disclosing her HIV positive status was a clear finding from the data. Most of the women (11 out of 15) did not tell their partners about their HIV before becoming pregnant. Four women had revealed this to their partners before getting pregnant. In Thai society, HIV stigma and discrimination remains significant. Participants had a strong perception that the community, family, health care providers even their partners would criticise and reject them if they revealed their HIV status;

“Quiet for a while... I was afraid that others might doubt me because I had to go to the hospital very often and receive ARV drugs even after giving birth. Many would have questioned why I had to take medicine, why I had to go to the hospital, and what I was.I'm afraid that the people will suspect me because my health has always been strong. They may question why I see a doctor so often. I have realized that, in the district hospital, there are many people who recognize me. So I must go to the provincial one to get drugs. (Pani)

“I just told a close family member, I've not told anybody in my village because they would discriminate against me. In my community people would not talk to me if they knew my HIV status, they would not have meals with me and would not want to be associated with an AIDS patient, as far as I know they would be like this” (Tuk)

“It is untreatable and a social stigma disease...., in our society, people have been stigmatising and discriminating so far” (Muay)

“I have known 2 women who knew they were HIV positive and got pregnant, they were suicidal, they could not cope and accept this news and they feared the social stigma and being undesirable. One of them I could help, she said to me that she had no one to talk with, then I encouraged, gave some information and took her to meet the doctor, she accepted herself and the baby, and kept going on her pregnancy later. Unfortunately, another woman, she killed herself, I'm so sorry to hear that..” (Sai)

Women explained that they would suffer blame and possibly abandonment from their partners if they disclosed;

"Before I became pregnant, I never told my partner about my HIV result.....I thought that if he knew earlier he would not have a child with me, he would ask and blame me, at worst he will run away from me to look for a better woman... I intended to tell him but didn't know how to start, which word?..." (Tuk)

"Yes, It shows that I need rely on him including for money. I don't want anything (from this bad news) to hurt him and as well don't want him to leave me later. If he leaves me, I'll be in trouble.Yes, I'm afraid that my family is not going to survive because I have to look after 2 children" (Pani)

"Why would I not tell my partner? It was hard to say...very difficult to let him know, I'm afraid that he would not accept me, he would be angry. I decided to tell him about getting pregnant first because that was good news for him, I left my HIV positive (status) to tell later" (Muay)

There was also a fear of an uncertain future with their partners because of their HIV status amongst some women. They feared that one day, if they told partners or family members, they would be rejected and abandoned;

"Yes, I have reminded myself because he isn't infectious. I'm afraid that he'll find another woman not HIV positive in the future. However, he told me that he would never leave me and our baby....but I don't know nothing is guaranteed and I'm infected, he isn't..." (Tuk).

Category 2 "Desire to have a child"

Living with their partners, like other couples of reproductive age, these women intended to have a child one day, not with standing their HIV positive status. The desire to have a child was affected by 3 factors: 1) *significant persons wanting to have a child*, significant people who influenced the decision making process were partners, women themselves and other family members 2) *the reasons to have a child*, women wanted at least one child with their current partners, they loved children and wanted to be mothers, they trusted in ARV and that it could improve their health and reduce the mother- to-child transmission rate. The doctors and nurses informed the women that ARV can protect mothers and babies against HIV (generally) and some women had a previous child without HIV and 3) *seeking information*, the most important information influencing the desire to have a child was information from doctors and nurses at ANC about the benefit of taking ARV consistently, seeing other children who born to HIV positive mothers who were HIV negative, and some participants had experiences of having a previous baby without HIV. Some women sought HIV information on TV, the internet and from friends.

"Yes, A doctor has let me know that if I take the drugs early and regularly, the baby won't be infected" (Kan).

"I got information from doctors, nurses, internet and some of family member such as my step mother she is a nurse" (Urai)

"I have intended to have a child and to be a mother, I searched through the internet by Google searching, I had looked for "Can HIV women become pregnant?, How about one having a child". The result was that they can be a pregnant but must take medicine to protect the transmission to a child" (Bura)

"The doctor said that I would live longer if I took constantly medicines, ARV is my hope..." (Aon)

Category 3 "Becoming pregnant"

Being pregnant in this study was divided into 2 types of pregnancy; planned and unplanned pregnancies *Planned pregnancy*: where women had disclosed their HIV to their partners before becoming pregnant. The main reasons for becoming pregnant were wanting a child and ceasing contraception in order to become pregnant. In addition, women prepared themselves by seeking information from health care providers (Doctors and nurses), the internet, friends and family members, the couple were able to talk about having a child and the risks that they would face in the future, and stopping contraception. *Unplanned or accidental pregnancy* was where women became pregnant earlier than expected. The participants all intended to have a child in the future, but not particularly at this time. The main reason for getting pregnant accidentally was missing contraceptive pills. For the group of women who avoided HIV positive disclosure to their partners, none of them were ready to get pregnant at that particular time because they understood that they would have to go to the hospital for routine HIV screening, and their partners might then discover their HIV positive status, respectively.

Category 4 "Keeping or terminating the pregnancy"

Whether their pregnancy was planned or unplanned, weighed up the issues related to keeping or terminating their pregnancy. The reasons for keeping the pregnancy were linked to the fear of committing a religious sin (rule of Karma in Buddhism), fearing the complications of an illegal abortion, their advanced gestational age (GA), wanting a child, feeling love for the baby in the womb, a desire for motherhood, and acceptance of the woman's HIV status and baby by the partner;

"I never thought of abortion because I wanted a baby, I wanted to be a mother. I was excited and worried to have the first pregnancy but happy more than worried. I'm really happy especially when the baby is moving in my womb" (Bura)

"...I didn't do the abortion because I needed and loved the baby, motherhood is very important, I would do anything in order to protect against HIV infection for my baby such I would take medicines everyday even though sometime I could not tolerate the side effects, I would not abandon my child even if he was infected, whatever happened, I would love my child any way.... (Sai)

"I have never thought about doing abortion in this pregnancy because I have had 3 abortions, no more abortion, it's time to have at least one child for me " (Lew)

"I have never had an abortion, I'm afraid of complications like bleeding and shock. If an abortion failed and I was sick, I would be in trouble." (Aon)

The reasons the women gave for considering abortion were around not being ready to become pregnant at that time, the need to conceal her HIV positive status from her partner, fear of the negative consequences for her relationship with her partner, and concern that the child will be infected (6 out of the 15 women had a prior experience of abortion in previous pregnancies, 3 of 6 women attempted an abortion in this pregnancy but not success).

- Aree knew when she was 3 months pregnant. The reasons for having an abortion were fear of disclosure and infecting a baby.

"When I knew of my pregnancy, I was afraid, I was afraid that my cousins would know. I didn't want them to know and I didn't want my baby born with infection...I tried to drive the baby out. My pregnancy was nearly 3 months. I started taking a blood-driving medicine, which could be found in the general

pharmacy. After taking it, I had a uterus ache, but nothing happened. Then I decided to have an abortion in an illegal clinic. An officer at the clinic inserted a medicine into my vagina, half an hour later, there was blood flowing out except a baby, and I spent B12,000 (300 GBP) for an officer. A day later, I went to my home waiting to see if something dropped out from my womb but nothing. I phoned the illegal clinic to ask why the baby hadn't come out. They let me do an abortion three times, but it failed again and again. So I stopped doing an abortion because I had no more money. I thought that an abortion for me might fail, so I let it be." (Aree)

- Tuk knew when she was 2 months pregnant. The reasons for her wanting an abortion were that she was not ready, she was fearful for her marital relationship, and she was worried about the child.

"Not only a thought but also I tried, I bought a blood-driving medicine (herbal liquor, a trade mark is given here.....) from a grocery to drink. An acquaintance told me that a blood-driving medicine could drive off the blood and a very little baby. Some local people, they knew that I wanted an abortion, but I didn't tell them that I was infected. They kept asking me why I wanted to do an abortion. I told them that I was not ready and I wanted to do an abortion. So they suggested I buy a blood-driving medicine to take" (Tuk).

Category 5 "Accepting the decision"

The women described going through many milestones including receiving their initial HIV positive results, concealing their status from their partners, getting pregnant, both planned and unplanned, then deciding whether to keep or terminate their pregnancies. Once they had decided to keep their pregnancies, all women accepted their situations. There were 2 consequences to accepting the decision to continue with the pregnancy; wanting the pregnancy and accepting any repercussions resulting from the pregnancy and their HIV status disclosure.

A wanted pregnancy was described by women in terms of feeling they had the autonomy to decide to keep their baby, this was accompanied by their awareness of being HIV positive, while having a strong desire to be a mother; whatever the consequences. This study found that women all eventually came to accept their pregnancy, stop thinking about abortion, want to continue their pregnancies and have their baby, and eventually, feel happier.

Part of the latter stages of decision making involved women accepting the consequences of the decisions that they had taken. In terms of their pregnancy, women accept the outcomes; including whether a baby will be infected or not. MTCT is low, nothing is guaranteed until confirmation of the baby's blood result at 12-18 months of age and until this confirmation, mothers continue to worry. Women also accept the consequences of their HIV disclosure such as a period of instability within their relationship with their partners or being stigmatised by people who know their HIV status including their partners, families, neighbours and health care providers. The women are also reconciled to any economic impacts of revealing the pregnancy:

Yes, I'm worried about 2 things, firstly, the most worrisome thing for me is that I'm afraid my baby will be infected. Secondly, my relationship with my partner in the future because he isn't infected, I'm afraid that he'll find another woman without HIV positive disease. However, if my baby is infected, I will love and take care of my children always. If he leaves me, I will be strong and try to keep my life going on" (Tuk)

"There are two types of HIV mother, one is that the mother who does not accept the baby in the womb, they may think about

doing an abortion of the unborn baby or abandoning the baby after birth in order to have a new life, some women would kill themselves to eliminate any problems. Another type is women who can accept the baby, these women love their baby more someone they love more than she loves herself" (Sai)

Category 6 "Adapting to their decision"

Women use their beliefs as important strategies for managing fears and adapting, explaining and justifying their decisions in relation to their pregnancy. Their religious faith was an important element of this - called the "**Rule of Karma**". These women believed that their infection was caused by Karma and mistakes made by them in the past. So, the strategy women living with HIV used was the acceptance of "Karma". They had to accept and compensate for Karma. To manage Karma women are required to do good deeds for bad Karma to be 'blown away'.

Likewise, they believed that their HIV infection is also caused by such karma as some women had unsafe-sexual intercourse in the past and therefore believed that they were being affected by "**something wrong or mistakes in the past**":

"It's my Karma, I have accepted it and paid for it by myself, I didn't blame anybody including my ex-partner who had transmitted HIV to me, just blamed myself what a silly me...." (Aree)

"....I blame myself for the bad things and bad behaviours which I have done in the past.....It is my Karma to accept" (Na)

"It's my Karma which turned from my parent, my father was a playboy, he hurt many women then those women or their parents could have condemned him for his scandalous behaviours. So, this Karma can involve me. However, Karma isn't the main matter for me, it was something wrong which I had done in the past by foolishness, during my teenage time I spent my time in a wasted way and committed pranks" (Lew).

To summarise, the central process of *balancing* - the manner in which women weighed the consequences of each decision they took as part of the pregnancy process was the core - central - category in the grounded theory of pregnancy decision making in this study. This process played a significant role of each category as shown in [Diagram A](#) below.

Discussion

This study has explored the journey of decision-making stages in pregnant Thai women who living with HIV. The core themes of this grounded theory come from the main concerns of the participants about their situation and how they navigated the pregnancy decision making journey; how they thought about the factors involved and the? decision making stages of that journey ([Charmaz, 2006](#)). Throughout the journey the concept of 'balancing' was identified as the process by which these women made their decisions. Each stage of the journey through pregnancy presented women with the need to balance and weigh the factors related to each step. Irrespective of what the decision was, the stages were constant for all women as was the process of 'balancing'. This study found that *fear*, to *disclose or not disclose HIV* and *information* were important factors in the decision to have a child, become pregnant, keep the pregnancy, accept the decision made, and adapt to the decision.

The desire to have a child amongst women who are living with HIV is seen within the global literature; HIV positive women desire a child despite their HIV infection ([Cooper et al., 2007](#); [Nóbrega et al., 2007](#); [Gogna et al., 2009](#); [Marcellin et al., 2010](#); [Firth et al., 2012](#); [Loutfy et al., 2009, 2012](#); [Huntington et al., 2013](#); [Hernando et al., 2014](#)). This desire is often in opposition

Diagram A

The relationship between balancing and 6 categories.

| Fears | Concealing HIV status related to 6 categories | Information |
|---|---|--|
| -fear husband know -fear husband will not accept her HIV status -fear stigma from social and husband -fear husband not desire a child if know her HIV status -fear husband not accept herself and a baby -fear husband know her HIV status because of getting pregnant -fear baby would be infected | Concealing HIV + status from husband | -disease stigma and discrimination |
| | Desire to have a child | -Mother to child transmission -ARV information -contraception -unsafe sex -lack of knowledge and information |
| | Becoming pregnant | -abortion information -Mother to child transmission -ARV information -information from ANC |
| -fear sins if doing abortion -fear husband know HIV status -fear baby would be infected -fear relationship with husband will be broken -fear husband will abandon -fear issues related income and money -fear the future -less fears but fear baby will be infected | Keeping or terminating pregnancy | |
| | Accepting a decision "Concealing out of control" | -counselling from ANC -Mother to child transmission -ARV information -pregnancy care from ANC |
| -adapt to fears | Adapting to a decision | -Mother to child transmission -ARV information -delivery information -baby care information |

to strong social disapproval of women with HIV having a child (Cooper et al., 2007; Ross et al., 2007; Kanniappan et al., 2008; Sanders, 2008; Barnes and Murphy, 2009; Demissie et al., 2014; MacCarthy et al., 2012; Liamputtong and Haritavorn, 2014). Despite this, many women in this study and those in prior studies still wanted children. Although the desire to have a child in women living with HIV is often counter to social opinion, as Barnes and Murphy (2009) found, many women choose to weather these social opinions and become pregnant. This present study also found that although women desired to have a child and become pregnant they were reluctant to tell their partners, family members including health care providers in HIV clinics. This was because they were afraid of negative reaction to this.

Deciding to have a child in women is related to the aspiration of motherhood (Miller, 2009; Vescovi et al., 2014; Fletcher et al. 2016; Leyva-Moral et al. 2017). In this study the women demonstrated their desire to become mothers and were influenced by their partners ambition to become fathers. In a Thai context, motherhood, male partners, and the family hold an important status and women are expected to have children when they marry. Consequently, there is social pressure on women to bear children that compounds their desire to have a child (Ross et al., 2007; Youngwanichsetha et al., 2010; Liamputtong and Haritavorn, 2014). Women living with HIV in a Thai context have to balance this tension against the stigma associated with HIV infection. The way they chose to do this was by becoming pregnant but concealing their HIV status.

In Thailand, disclosure of HIV status or any other sexually transmitted disease (STD) results to a partner is not obligatory, including when planning to conceive a pregnancy (Office of the Attorney General, 2019). This policy, permitting concealment, protects the positive person's rights, but it infringes those of the partner to protect themselves from STD's and complications, and importantly, also those of the unborn child. This study has shown that Thai women's decisions to disclose their HIV status to their partners was involved at all stages of the women's pregnancy decision making journey. The reasons for non-disclosure were similar to those found in prior studies; most women living with HIV had not disclosed their status to their sexual partners for fear of abandonment, violence and accusations of bringing HIV infection into the family (Brickley et al., 2009; Sander, 2009; Hardon et al., 2012;

Rujumba et al., 2012; Carter et al., 2013; Hernando et al., 2014). Most women deferred disclosure and requested health workers' support for this (Rujumba et al., 2012; Tyer-Viola, 2007; Kelly et al., 2013; Moodley et al. (2014). Those who disclosed their positive status generally experienced positive responses from partners (Rujumba et al., 2012; Visser et al. (2008). In this study the women were highly dependant on their partner's income, and they feared abandonment and a consequent struggle if they revealed their HIV status to their partners.

Women feared social stigma and discrimination. They had to weigh up and balance the consequences of revealing or concealing their pregnancy and HIV status throughout their pregnancy decision journey. Stigma is a significant part of living with HIV and has been reported widely (Cooper et al., 2007; Kanniappan et al., 2008; MacCarthy et al., 2012; Nattabi et al., 2012; Demissie et al., 2014;) however, the need for support and health care for HIV related pregnancies is also relevant and linked to women's and their babies health (Kanniappan et al., 2008; Hanh et al., 2009; Hardon et al., 2012; Ross et al., 2012; Thurling and Candice, 2012). This study shows how women must weigh up and balance these issues and expands and contributes to other work that shows the difficult decisions women living with HIV have to make – especially around pregnancy (Myer et al., 2005; Ross et al., 2007; Visser et al., 2008; Hanh et al., 2009; Ross et al., 2009; Darak et al., 2012; Ross et al., 2013; Liamputtong and Haritavorn, 2014).

Women with HIV were faced with concerns that if they discussed issues such as becoming pregnant with their health care providers in the HIV services they faced potential negative reactions (Sanders, 2008; Barnes and Murphy, 2009; Gogna et al., 2009; MacCarthy et al., 2012). However, after becoming pregnant women in this study accessed the ANC clinic service. At this point the health care providers, especially nurses and midwives, played a significant role in helping the women to cope with their pregnancy. Women also received more information on mother to child transmission and the positive effects of taking ARV. This new support and information '**tipped the balance**' for the women regarding their feelings and decisions about their pregnancy. A negative experience was attributed to lack of communication, lack of knowledge and experience – this grounded theory helps explain how and where in the pregnancy decision process this information and support has an effect.

Conclusions and implications for practice

This study offers a whole decision-making process model which can be used to understand the pathway and steps women living with HIV make around pregnancy. The concept illustrates not only the process of decision making but also highlights the main stages, issues and concerns of women living with HIV wanting a child. It makes several contributions to the knowledge base around HIV and pregnancy and can serve as a starting point for conceptually understanding the pathways and issues facing women living with HIV considering or progressing through a pregnancy. This model constructed by pregnant women living with HIV and the researcher is based on the Thai context in which it was conducted, this may be similar or different from other regions in Thailand or other settings, cultures and contexts. The findings will be useful for the research community but also, it is hoped, also for health care providers working with women with HIV and, through them, hopefully informs and improve the care they deliver in similar context.

These are some examples of questions that clinical staff could ask in meetings with pregnant women living with HIV. These questions are based on the study results and are suggestions for clinical nurses, midwives and doctors.

- Tell me about your pregnancy?
- How did you feel when you knew you were pregnant?
- When did you know your HIV status? How?
- Have you revealed your HIV status to anybody? Who? Why? How?
- How did you decide to become pregnant with HIV-positive status?
- What happened when your partner discovered you were HIV positive? Could you tell me about his reaction with this news?
- Who was the most significant person in your pregnancy decision?
- How did they help you in your decision?
- How have others in your family reacted to HIV status and pregnancy?
- What are your information sources on HIV?
- How did you feel at that moment/ How did you feel more?
- How do you feel now?
- How do you plan for your/baby's future?

Strengths and limitations of the study

Strengths and rigour

This study presents, through Grounded Theory, a unique model that explains in detail the HIV related pregnancy decision making process. This is the first conceptual model of this kind and can be applied and refined by researchers in other settings to expand an understanding of how HIV positive pregnant women make decisions and how HIV positive pregnant women manage their HIV information. Again, this can be used by researchers and health care providers in their work, in extending the knowledge base about HIV positive pregnancy in South-East Asia. For the grounded theory's rigour, we adopted:

- The constant comparative method for creditability and originality. When a strong combination of creditability and originality is settled then the resonance will be increased, because creditability and originality increase resonance (Charmaz, 2006).
- Multiple sources of data (women and nurses) to establish creditability.
- Member checking: one of the researchers (J.K.) returned to the field to meet with three participants and share the emerging conceptual model with them. These participants confirmed it

accuracy and provided suggestions that guided further interviews. Also, during member checking, three of the 15 participants and two midwives rechecked the data from the interviews to refine, extend, and confirm categories.

- Peer debriefing (2 academic supervisors; M.H. and M.G.): as part of ensuring the rigour of the research process and outcomes of the study, peer debriefing by two researchers was undertaken by rechecking the data and transcriptions. for creditability and dependability. This process saw the three researchers (J.K., M.H. and M.G.) cross-checking the quality of the transcriptions and language accuracy by looking for new insights and significance of the analysis.
- Categories were derived from the significant coding of the concerns of women, and were coded line by line and focused coding of transcriptions for originality.
- Use of a bilingual translator to double check of bilingual transcriptions for originality (from Thai to English language).

Limitations

- 1) Although pregnant women of different gestational ages were interviewed to reflect on issues, situations and decisions relating to their past, present and plans for the future it is possible that some experiences would be recast by both time and environment.
- 2) The model constructed by pregnant women living with HIV and the researcher is based on the Thai context in which it was conducted. This may limit its generalisability to other settings, cultures and contexts.

Recommendation for practice

- 1) Some of the women became pregnant by mistake/accident/unintended or unplanned because of lack of knowledge. Therefore, safer sex and contraceptive education to people who are living with HIV should address the issues around pregnancy and its prevention more fully.
- 2) Health care providers should help women who are living with HIV to reveal their HIV status to their partner at an appropriate and agreed time – if this is their wish.. This advice should respect and balance the women living with HIV confidentiality and the rights of the partners to protect themselves from HIV.
- 3) Integrative services such as pre-marriage counselling, safer sex, antenatal and postnatal counselling related to maternal, child and partner's health should be provided by a multidisciplinary team to women living with HIV and their partners.
- 4) The pregnancy decisions by women living with HIV should be respected by health care providers. More training should be provided to prevent instances of judgmental care/remarks by health professionals.

Recommendation for further research

- 1) The model of Thai women living with HIV in this study could extend to cover similar groups or contexts and should be tested by qualitative, quantitative or mixed method studies.
- 2) Further research with the male partners of women living with HIV or female partners of men with HIV would add to the pregnancy decision making research field.
- 3) The model in this study focused on women living with HIV who knew their HIV positive status before deciding to become pregnant. Further research with women who do not know their status will add a further dimension to HIV pregnancy related research.

Funding

This review is a part of a Ph.D. programme at the University of Hull. Financial support for the study is provided by the Faculty of Nursing, Mahasarakham University, Thailand.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Ethical approval

The ethical approval of this paper has been approved by Faculty of Health and Social Care Research Ethics Committee (ref. no. 210, 7 March 2016) and Roi et Hospital no. 1/2559 (2016-2017).

Acknowledgements

All participants, University of Hull and Faculty of Nursing Mahasarakham University

The authors would like to thank all the women who are giving and sharing their invaluable experiences.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ejps.2020.105216.

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