### Exploring Women's Experiences of Amniocentesis: A Qualitative Content Analysis

#### Abstract

**Background:** The decision and experience of high-risk pregnant women to undergo amniocentesis can depend on their setting, context, social structures, and significant others, including cultural values and beliefs. What is less understood is women's experience with decision-making, which may contribute to their anxiety during and after amniocentesis. This study aimed to explore the decision-making experiences of Thai pregnant women undergoing amniocentesis. **Materials and Methods:** A qualitative content analysis approach was employed to collect and analyze data. Purposive sampling and in-depth interviews were conducted between July and October 2021 with 15 Thai high-risk pregnant women after undergoing amniocentesis. Data analysis involved multiple readings of transcriptions to discern themes and understanding of the women's stories. **Results:** Four themes of decision-making experiences were identified: (1) "Shocked, worried, and questioned why the risk was high"; (2) "Does my baby have Down syndrome? I want to know"; (3) "Worried"; and (4) "Relief from anxiety." **Conclusions:** Women's experiences with amniocentesis involved uncertain positive and negative feelings through the journey of undergoing, waiting, and receiving the test results. The nurses and nurse-midwives played an important role in counseling Thai pregnant women about whether to undergo amniocentesis.

**Keywords:** *Amniocentesis, life experience, maternal serum screening test, nurse-midwives, qualitative research* 

#### Introduction

The Quadruple Test (QT) is a sensitive screening<sup>[1-3]</sup> test for pregnant women<sup>[4-7]</sup> to detect the risk of spina bifida, anencephaly, trisomy 21, and other fetal defects.<sup>[6,7]</sup> A positive QT usually leads to amniotic fluid testing or amniocentesis to confirm results. Although advanced maternal age has been a primary factor influencing a woman's decision for amniocentesis,[8-10] the results of the QT have become a significant factor in women's decision-making additional high-risk for testing in pregnancies.[11-13] Nevertheless, pregnant women are concerned about amniocentesis' accuracy, and convenience<sup>[14]</sup> safety, One study in Thailand reported high anxiety among women when undergoing amniocentesis due to their apprehension about the procedure and its possible results.<sup>[7]</sup> Reasons to accept amniocentesis have been investigated quantitatively in different countries and contexts.<sup>[9,12-19]</sup> Not only have advanced age and screening

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Less is known about women's emotional complexities in arriving at a decision to undergo amniocentesis. For nurses and midwives, having a clearer understanding of high-risk pregnant women's feelings or ambivalence may contribute to ways of lessening their anxiety during and after amniocentesis. Qualitative research can

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capture the expressive information from high-risk pregnant women as they reflect on their experiences and perceptions when deliberating a decision for amniocentesis. Thus, the research question was: What do high-risk pregnant women experience in their decision-making to have amniocentesis? The findings will enable nurses and midwives to understand, manage risk, provide support, and respect the decisions made by women and families.

#### **Materials and Methods**

A qualitative study was undertaken by describing how high-risk pregnant women experience a particular phenomenon – decision-making to undergo amniocentesis – and interpreting how they perceive the meaning of their lived experiences.<sup>[20,21]</sup> The qualitative content analysis approach was used to observe and engage<sup>[20]</sup> with Thai information-rich, high-risk, pregnant women who could share their experiences about considering amniocentesis.

In 2021, 1308 pregnant women in the antenatal care unit of a tertiary hospital in northeast Thailand had QT screening. Of those, 115 women underwent amniocentesis. Using purposive sampling, the unit's nurse-midwives identified eligible women who met the following inclusion criteria: (1) aged  $\geq$ 18 years, (2) diagnosed by an obstetrician to have a high-risk pregnancy, and (3) underwent amniocentesis at the gestational age between 16 and 20 weeks. Exclusion criteria were women who (1) were referred for amniocentesis/ diagnosed at another hospital, or (2) had complications after amniocentesis, such as severe abdominal pain, vaginal bleeding, rupture of membrane, or unusually severe abdominal or puncture pain. Fifteen Thai women volunteered to participate. None of the women approached to participate declined to be interviewed.

Data were collected by one-on-one interviews between July and October 2021 by using a flexible schedule. Each participant was interviewed twice, first on the day of the procedure and then after receiving the procedure's result. The two doctorally prepared interviewers (PI and CA) had extensive knowledge in providing comprehensive perinatal care and were experienced in conducting qualitative research.

Each interview lasted approximately 45–60 minutes, was audio recorded, transcribed verbatim into Thai, and then translated into English by a research team member.<sup>[22]</sup> An English translator was used to audit the transcripts for accuracy. Three experts in obstetrics and nurse-midwifery developed the content and structure of the initial semi-structured interview guideline [Table 1]. Memos and field notes were recorded following each interview to document the interviewer's ideas and note significant non-verbal elements during the interview.

Five quality markers were applied to the qualitative process to ensure reflexivity and rigor of the research:

### Table 1: Semi-structured interview questions asked ofThai high-risk pregnant women

Questions\* to probe the women's feelings about amniocentesis

- 1. How was your prenatal care this visit? How is your baby's health?
- 2. Tell me about yourself. Why are you here for an amniocentesis?
- 3. What do you think will happen during the procedure? Or did everything go as you expected?
- 4. How did you feel [before, during, and after] the amniocentesis?
- 5. Tell me how did you decide to have amniocentesis? Who was involved and how did you feel?
- 6. If you could rate the pain during amniocentesis from 1 to 10, what score would you give it? (10 points hurt the most, 5 means hurt moderately, 0 means no pain)
- 7. Do you know the results of the test yet? Can you share it with me? How do you feel?
- 8. What steps do you fear or worry about the most? How do you feel? Why?

\*Developed by a hospital obstetrician, an antenatal care unit nurse-midwife, and a nurse-midwife lecturer

credibility, member checking, peer debriefing, originality, and cross-checking. The process ensured the quality of the transcriptions, language, and accuracy by checking reiteratively the interview data, refining, extending, and confirming themes, sharing insights with several participants, and seeking new insights and significance of the analysis.

The narratives of high-risk pregnant women of their experiences with amniocentesis were analyzed using the content analysis method. This process is an inductive method that involves interpreting and breaking the raw data into small pieces, codes, and emerging themes or subthemes.<sup>[23,24]</sup>

As all team members read and reread the transcripts, codes were applied to "micro" ideas that were later analyzed and grouped into clusters of ideas (subthemes) that were then interpreted and categorized into larger themes.<sup>[25-27]</sup> This method gives an in-depth understanding of the women's stories as they were told. As the stories unfolded, the nuances of what the women experienced, how they expressed themselves, and their feelings brought greater clarity to what their stories meant to them.<sup>[28,29]</sup> Data saturation was judged to have been reached when the interviewers recognized that the categories developed were strong, reflected to the research objective, were well supported by the data, and there were no further issues or concerns to investigate.

#### **Ethical considerations**

The Mahasarakham University Ethics Committee approved the study for research involving human

subjects (#129/118/2021). Eligible participants received a clear explanation of the study's purpose, method, study period, and possible risks. They were free to ask questions and were assured of confidentiality. If they became upset during the interview, they could stop the interview at any time or opt out of the study. Those who volunteered to participate signed an informed consent form. All interviews took place in a private room after the women's prenatal clinic visit.

#### Results

All participants were Buddhist and had a positive QT. Their ages ranged from 19 to 36 years with mean(SD) 26.40 (5.64). Eleven were married, and four were separated, divorced, or widowed. Seven completed a 12<sup>th</sup>-grade education, seven had finished the 9<sup>th</sup> grade, and one had earned a bachelor's degree. Ranges for gravidity, parity, abortions, and living children were 1–4, 0–2, 0–3, and 0–2, respectively [Table 2].

Four themes emerged from the interviews of Thai high-risk pregnant women about amniocentesis decision experience. Each theme had two or more subthemes. Table 3 displays the relationships of the four themes:

(1) "Shocked, worried, and questioned why the risk was high"; (2) Reasons to have amniocentesis: "Does my baby have Down syndrome? I want to know."; (3) "Worried" while waiting for the test results; and (4) "Relief of anxiety" after receiving the test results.

### Theme 1: Feelings before the amniocentesis; "Shocked, worried, why?"

The main concern for women in the initial decision for amniocentesis was realizing that they were a "high-risk person" who might have a baby with a birth defect or congenital abnormality, such as Down syndrome. All but one of the women questioned why their pregnancy was high risk as most were under 35 years old. They believed that only older pregnant women risked having babies with Down syndrome. The women expressed surprise, shock, and worry about the lingering question of why they or the baby were at high risk because they were younger.

Participant stated: "... at my second visit, the nurse reported that the results of my blood test for Down syndrome put me at high risk..... That night, I couldn't sleep at all, I thought a lot, I thought about it, I worried, I was afraid that my child could be." (W1, Age 25, Gravida 1)

Another participant expressed: "The nurse called to inform me that the blood test was high risk. I had to come to test the amniotic fluid to find out if the child was Down or not because [the test] would be more accurate...... I'm shocked.very shocked because [the news] was sudden [that] the child might be Down. So, I decided to come and check...." (W2, Age 23, Gravida 1).

All women were nervous and fearful while anticipating the amniocentesis. They were apprehensive about pain during the needle puncture, imagining that the needle would be very painful, and gave an anticipated pain score of 10 out of 10 points. Most women felt less pain than expected during the amniocentesis, scoring it between 3 and 5 points.

One participant indicated: "Before piercing, I thought it must hurt 10 times, but when [the needle] actually pierced me, it didn't hurt as I thought. But it felt clumpy...more [like] pregnant than hurt (i.e., tight and uncomfortable). Score 3 out of 10. It's good." (W3, Age 32, Gravida 1)

Table 2: Characteristics of participants						
Participant code name	Age	GPAL	Marital status	Religion	Education	Risky
W1	25	G <sub>1</sub> P <sub>0</sub>	Couple	Buddhist	Grade 12	QT increased
W2	23	$G_1P_0$	Couple	Buddhist	Grade 12	QT increased
W3	32	$G_1 P_0$	Couple	Buddhist	Grade 12	QT increased
W4	32	$G_2 P_1 A_0 L_1$	Couple	Buddhist	Grade 12	QT increased
W5	25	$G_2 P_0 A_1 L_0$	Couple	Buddhist	Grade 9	QT increased
W6	32	$G_2P_1A_0L_1$	Couple	Buddhist	Grade 9	QT increased
W7	36	$G_2 P_1 A_0 L_1$	Couple	Buddhist	Grade 9	QT increased
W8	19	$G_1P_0$	Separated	Buddhist	Grade 12	QT increased
W9	25	$G_{3}P_{1}A_{1}L_{1}$	Couple	Buddhist	Grade 12	QT increased
W10	23	$G_2P_1A_0L_1$	Separated	Buddhist	Grade 9	QT increased
W11	26	$G_2 P_1 A_0 L_1$	Widow	Buddhist	Grade 9	QT increased
W12	20	$G_2 P_1 A_0 L_1$	Couple	Buddhist	Grade 12	QT increased
W13	19	$G_4 P_0 A_3 L_0$	Divorced	Buddhist	Grade 9	QT increased
W14	35	$G_3P_2A_0L_2$	Couple	Buddhist	Bachelor	QT increased
W15	24	$G_2 P_1 A_0 L_1$	Couple	Buddhist	Grade 9	QT increased

G: Gravidity=number of pregnancies; P: Para-=Number of baby births; A: Abortion=Number of successful abortion; L: Living child=Number of living children

### Table 3: Relationship between the subtheme and main theme

theme						
Subtheme	Main theme					
Shocked	Feelings before the					
Worried	amniocentesis					
Questioned why the risk was high						
Does my baby have Down syndrome?	Reasons for the					
I want to know	decision					
Persons involved in amniocentesis decision						
Worried	Waiting for the test					
The most distressing period	results					
Relieved of anxiety	After receiving the					
	test results					

#### Theme 2: Reasons for the decision: "Does my baby have Down syndrome? I want to know?"

After the women had been notified of the QT results and whether they were at high risk, the nurse-midwives at the antenatal care unit would make an appointment to discuss the need for an amniocentesis. The nurse-midwives provided information that amniocentesis is more accurate than the QT and that it can diagnose more precisely if the baby might have Down syndrome. The women wanted to know the probability of having a baby with Down syndrome to decide whether to continue the pregnancy or to plan its termination. "I want to know, will my child have Down syndrome or not? Is it dangerous? So, I can decide what to do about it." (W4, Age 32, Gravida 2)

Identified in theme 2 were also the "persons involved in amniocentesis decision." The most influential people for the women before they made the decision to undergo amniocentesis were the nurse-midwives at the antenatal care unit, followed by the obstetrician.

Participant mentioned that the midwife was a significant person for amniocentesis decision "The person who made me decide to have the amniotic fluid [tested] is the midwife, she explains things well for me to understand and gives good advice that my child is at risk, but still can't tell for sure. She said if I want a definite result, I will have to [test] the amniotic fluid to see for sure.... I believe her because she knows better than me." (W5, Age 25, Gravida 2, Para 0, Abort 1, Living 0)

Another participant agreed that "The one who called first was a nurse at the [antenatal clinic]. The nurse called and told me that there is a high risk that my child may have Down syndrome and to please come and pick up the blood result at the hospital. She explained how I need to know more by making an appointment to check the amniotic fluid to be clear. At the day of the amniocentesis, a doctor (obstetrician) explained it well to me again." (W6, Age 32, Gravida 2)

In addition to the nursing and medical staff significant in influencing the women's decision-making, the family members, the partner, and the women's parents were involved. "When I found out the blood test results that showed a high risk of having Down syndrome, I told my partner and talked about what to do next. My partner said that I should do an amniocentesis as the nurse and doctor recommended me and to know the exact results. So, I wanted to know and decided to do that." (W4, Age 32, Gravida 2)

A participant who decided based on their parent said: "*My* parent would help me taking care of my child weather he or she having Down syndrome or not, they both were the most important to me and I believed them." (W9, Age 25, Gravida 3)

These included others who had experience with amniocentesis during their pregnancy. A participant stated that her neighbor who had experience with amniocentesis shared her experience: "The neighbor next door had a QT test. My mother said this person had an amniocentesis too, but her son was not retarded. Let me try to talk to her. I went to talk to her and asked what the doctor did to her. She told me it was like injecting drugs in the tummy. It hurts like an injection. The doctor will puncture fresh [without anesthetic] but not hurt too much....she said....So, I was afraid that it would hurt if getting a puncture fresh. I asked her whether the doctor gives a patient an anesthetic before the puncture? (laughs)" (W1, Age 25, Gravida 1)

Although the women listened to others' opinions, the final step in making the decision was their own. Their rationale was that they were the ones who were pregnant and would determine whether to get an amniocentesis and receive the results. The women argued, "If the amniotic fluid test shows that the child has Down syndrome, the woman and child will be the most affected." This meant that it was they who would make the difficult decision of whether to continue the pregnancy or have an abortion based on the test results.

# Theme 3: "Worried" while waiting for the test results

The waiting period for the amniocentesis results was the most worrying and distressing period for the women due to their feelings of uncertainty, unpredictability, and lack of personal control. Some women were worried about bad results and the possible consequences, such as if the baby had Down syndrome, would their husbands leave them, or what if the baby/child dies? What would the future be like? These feelings persisted until the test results were known. Family members would encourage the women, "Don't worry." The women's coping/adaptation during this period was to try not to think about it too much. Women agreed, "There will be a solution whether the child has Down or not; they would have a way out somehow."

One participant expressed: "After knowing the blood results that the risk was high, I went to have amniocentesis. While waiting, I was worried, afraid that the child would be disabled because I'm old, I'm also afraid that my husband will leave me and my child because he is younger than me...." (W7, Age 36, G2P1)

Other participants stated: "I was shocked and surprised that I was at such a high risk of having a child with Down syndrome. While waiting for the results, I was very afraid. I'm afraid my child will be Down syndrome, thinking about many things." (W4, Age 32, G2P1)

"...scared and shocked to have to undergo amniocentesis because I never thought before that there would be anything wrong with us." (W1, Age 25, G1)

## Theme 4: "Relieve anxiety" after receiving the test results

Feelings of anxiety and worry became "relieved," "relaxed," and free from anxiety when the women learned the results. All 15 of the women who were interviewed received "normal" amniocentesis results, indicating there were no genetic or chromosomal problems detected. It made women feel great, like "*raising a mountain out of their chest.*"

Participants said:

"When I found out the results of the amniocentesis that the baby was normal, I felt relieved, it was like a mountain had been lifted off my chest." (W7, Age 36, G2P1)

"Today I received the results that my child does not have Down syndrome. I am very relieved and happy. From now on, I will focus on taking good care of my baby..." (W6, Age 32, G2P1)

#### Discussion

This study explored Thai high-risk pregnant women's experiences about undergoing amniocentesis. The women dealt with psychological factors, such as shock, fear, and worry, that stimulated their curiosity to inquire about the accuracy of amniocentesis and weigh the information against possible complications. Although they faced uncertainty, apprehension, and fear, the women decided to have amniocentesis. Other studies have reported that women choose to undergo prenatal testing or amniocentesis as part of their decision rights despite possible procedural complications and detrimental effects on the pregnancy.[8,9,11,14,16,30-34] Pregnant women need to know the well-being of the fetus and exercise the right to consult with the healthcare team.<sup>[10,35]</sup> Women with insufficient knowledge can be confused about invasive, screening, and ultrasound tests.[36] Recommendations to undergo genetic testing are associated with stress, but an informed choice has less decisional conflict and poses less anxiety for pregnant women.[17]

We found that the women relied heavily on the nurses' and nurse-midwives' advice, recommendations, and

encouragement as part of their decision-making. When informed of the initial QT results, the women appreciated their information and involvement. In contrast to Thailand, obstetricians in other countries primarily communicate and interact with high-risk pregnant women about amniocentesis rather than the nurses and nurse-midwives.<sup>[7,12,13,35]</sup> Our finding that other significant persons participate in the pregnant women's decision is similar to studies that have reported that husbands/ partners, families, and society are involved in their experiences.<sup>[10,12,13,37]</sup>

The stories the women told can help nurses and nurse-midwives better understand the concerns that Thai high-risk pregnant women have with their experiences in making the decision for amniocentesis. They reveal how women can manage, prepare, and adapt their physical and emotional readiness to deal with the test results. Decision-making by the women was not linear but was related to several factors previously reported about the procedure,<sup>[12,20]</sup> its safety, timing, patient satisfaction, risk, cost,<sup>[14,15,17-20,30,38-40]</sup> and the information and counseling given by the healthcare providers.<sup>[7,10,13,35,37,41]</sup>

There were some limitations in this study. Because the interviews were conducted at a provincial hospital in northeastern Thailand, generalizability to other settings, cultures, and contexts might be limited. Fortunately, all the women we interviewed had favorable outcomes from the amniocentesis, which skewed the study's findings. Reflections on decision-making might have been different if the test's results had not met the women's expectations.

#### Conclusion

When Thai pregnant women realize they are at high risk of having a baby with a birth defect or congenital abnormality, they have strong psychological reactions. Their concerns, however, lead them to ask appropriate questions and seek information from nurses and nurse-midwives that affect whether to undergo amniocentesis. After the decision to have the procedure, Thai women are apprehensive about the test results. If the results are as hoped, they feel relieved. The decision allows Thai pregnant women and their families to be involved and plan an appropriate course of action to enhance the mothers' and families' quality of life. Nurses and nurse-midwives play an important role in counseling Thai pregnant women in their decision on whether to undergo an amniocentesis.

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#### **Conflicts of interest**

Nothing to declare.

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