Refining Woman–Centered Care in Prenatal Screening and Diagnosis for Thalassemia: A Qualitative Descriptive Study among Northeastern Thai Women

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Abstract: When caring for pregnant women at risk for fetal thalassemia, genetic counseling is typically employed to ensure the quality of care and to fulfil individual needs. This qualitative descriptive study aimed to understand women's experiences and further refine their woman-centered care. Through a purposive sampling technique, 20 Thai women in a northeastern province participated in this study, having had undergone prenatal screening and diagnostic tests, and terminated the pregnancy or given birth. Most informants were interviewed in-depth two or three times. Data were analyzed using thematic analysis. Six caregiving themes emerged from their experiences: Theme 1, *Amending ambiguity* containing sub-themes of *Assessing ambiguity in thalassemia*, and *Making clear the unknown*; and Theme 2, *Respecting individual difference* which described the sub-themes of *Assessing and accepting different values*; *Mother's heartbreak versus a baby living normally, Safeguarding a baby from suffering versus giving life to a baby*, and *Facilitating shared decisions, without using directives and coercion*. Theme 3 was *Prioritizing an unborn baby's well-being* including the subthemes of *Nourishing an unborn baby*, and *Reassuring an unborn baby's safety*, while Theme 4 was *Caring beyond courteousness* that described the sub-themes of *Assistance to regain emotional balance; Enhancing mental strength,* and *Facilitating religious and spiritual coping*. Theme 5, *Care given extensively to family and community* involved *Intervening when 'My family hurt,'* and *'I hurt my family,'* and *Alleviating concerns over community attitude.* The last theme, *Reducing negative experiences with service delivery*, involved sub-themes of *Reducing a sense of prolonged waiting and being rushed*, and *Reducing a sense of limited expertise and technology*.

In conclusion, regarding a woman-centered approach for these women, nurses should respond to their unique psychosocial, cultural, ethical, religious, and spiritual needs, respect the woman's values, dignity, and decisions, as well as extend the care to the fetus, family, and community.

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Introduction

Thalassemia is a common inherited hemoglobin disorder worldwide, prevalent in North Africa and Asia. Each year nearly 57,000 babies with thalassemia

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major are born, mostly in low–or middle–income countries.[1] In Thailand, thalassemia disease and trait is about 1% (650,000 persons) and 30% to 40% of the population (20 to 26 million persons), respectively. Annually, over 39,400 couples are at risk, and over 4,200 new babies among 800,000 babies are born with severe thalassemia.[2] A national health care policy and program for thalassemia prevention and control have been in place in Thailand for over two decades. A blood screening test to identify the carrier of Alpha^0 (α^0) thalassemia, beta (β)–thalassemia, and Hemoglobin E (Hb E) is available to all couples for prevention of the severe forms. The presence of homozygous α^0 thalassemia, homozygous β – thalassemia, and β – thalassemia/HbE disease legally allows termination of the affected pregnancy. If the screening results indicate a couple at risk of severe thalassemia, prenatal diagnostic tests, including chorionic villi sampling, amniocentesis or cordocentesis, during 10–13 weeks, 15–20 weeks, or 18–22 weeks of gestation, respectively, are offered to obtain a definite fetal diagnosis of thalassemia diseases.[3] A low effectiveness of thalassemia detection and prevention in Thailand has been reported.[4,5,6] The quality of care based on the existing approach is problematic.

In prenatal screening and diagnostic testing, four basic components of genetic counseling can be applied, including risk assessment and genetic testing, disease education, psychosocial management, and reproductive decision making.[7] This counseling requires a collaborative team effort due to providers' constraints of time, inadequate staffing, and limited genetics expertise.[8] Midwives in Thailand are not formally trained as genetic specialists, but they necessarily work in conjunction with obstetricians and are thus mainly responsible for, but not limited to, the two basic components of education and psychosocial management. Midwives provide information about thalassemia and screening/diagnostic procedures, prepare couples for the tests, provide emotional support, and facilitate couples' decision–making. A decade ago, pregnant women in Thailand acquired inadequate thalassemia knowledge from antenatal care clinics.[9] The complexity of thalassemia in terms of types, severity levels, inheritance chance, and treatments, likely brings about misconceptions about the disease as evidenced by 40% of parents of a thalassemic child who demonstrated low knowledge scores.[10]

Thalassemia screening and diagnosis requires pre– and post–test counseling and informed consent. The most common barrier of the screening test for Thai pregnant women was the late first visit,[2] but other issues cannot be overlooked, such as routine information, lack of understanding of information from websites, and feeling unprepared.[11] Invasive prenatal diagnosis tests require genetic expertise to ensure women make a voluntary and genuinely informed decision. This highlights the importance the women receiving correct and accessible information and reassurance in prenatal diagnosis of fetal growth restriction,[12] despite the disinterest in pursuing tests such as amniocentesis.[13] A study of Thai pregnant women undergoing amniocentesis indicates that using either computer–assisted instruction or reading a leaflet improved their knowledge and this knowledge increased further after individual counseling.[14] Not only knowledge but moral values were found to be interrelated and essential for informed choice.[15] There are those against prenatal genetic testing due to contradictions with their religion and personal beliefs.[16] In the USA, southeast and east Asian women undergo prenatal genetic counseling and pregnancy termination because of socio–cultural aspects (societal shame, stigma, paternalism, resources, family pressure, and religious and spiritual beliefs).[17] However, healthcare providers' and women's perspectives regarding religion and spirituality can be different.[18]

Different preferences among the women who undergo the procedures are reported, such as between individual and group sessions for amniocentesis counseling.[14] Sometimes, the information given to pregnant women may cause emotional distress, especially among those who are vulnerable.[15] One study indicated that prenatal genetic counseling for undergoing testing brought them confidence, a sense of autonomy, and empowerment,[19] but the anticipation of undesired outcomes and emotional stress caused some women to decline prenatal diagnostic tests.[16] Diverse experiences in and expectations for autonomy in making decisions have been reported, such as the experiences of non-directive discussion about pre-test counseling versus routine treatment, or feeling pressured to accept it,[15] preference of independent roles,[20] and directives for making their decision.[17] One study reported preferred approaches as 39%, 56%, and 5% for autonomous decision-making, shared decisions with healthcare providers, and a provider driven approach, respectively.[21] A variety of reasons to terminate or continue the affected pregnancy include moral, personal, religious beliefs, values of the baby's life, wanting to avoid future regrets,[22] and socio-cultural norms of the child's disabilities.[23]

A client-centered approach for genetic counseling is recommended due to the diversity of women's needs and values[8] as this takes individuals' psychosocial and cultural issues and values into consideration rather than leading them into any particular direction, such as therapeutic abortion.[18] Women's authentic understanding about the genetic tests and pregnancy termination requires accurate and balanced information that can reflect the women's values and beliefs about social, cultural, religious, and moral aspects; their autonomy; avoiding negative stereotypes; and stigmatizing language for the affected baby's conditions.[24] Standard care is decentered where no one is at the center of care,[25] and mainly targets accomplishing the tasks, whereas, woman-centered care is humanized, prioritizing each woman's unique needs.[25] Woman-centered care also includes health needs of the woman's baby, family, and community; the woman's rights to informed decisions, control, dignity, and respect; and a woman's connection with her social support system.[12,26-27]

An exploration of ten midwives in the Netherlands showed that one perceived barrier of woman-centered care included incorrect interpretation of a woman's needs whereas the midwives' being familiar with the characteristics and the health needs of their population was helpful to provide such care.[27] Therefore, authentic and deep understanding of women's subjective experiences about prenatal screening and diagnostic testing for thalassemia is crucial in providing woman-centered care for this population. However, women's worldviews from northeastern Thai contexts are not specifically clarified regarding this matter. This qualitative descriptive study gave voice to these women to express their experiences and needs in a relaxing atmosphere. The findings provide evidence and understanding to refine existing clinical practice to optimize the quality of care for these women.

Research Question and Study Aim

The research question of this study was "*What are the lived experiences of northeastern Thai women in prenatal screening and diagnostic tests for thalassemia?*" The study aimed to gain a deep understanding of these women, applicable to refining woman-centered care for those undergoing prenatal and diagnostic tests for thalassemia.

Methods

Study Design: A qualitative descriptive study was used. This is a naturalistic inquiry,[28] aiming to elicit and capture testimonies of the special experiences of individuals and those of relevance to practitioners and policymakers.[29] Individuals construct reality based on their worldviews and experiences, which cannot be understood through objectivity but inter-subjectivity.[29] A person is a being for whom things have value and significance, which cannot be eliminated but brought into their reality construction.[30] In this study, the women who had undergone prenatal screening and diagnostic tests were invited to share their subjective experiences, which were further interpreted to refine woman-centered care appropriate to their values and contexts. In keeping with the direction of qualitative descriptive research, this inquiry is less interpretive, presenting the findings in everyday language instead of conceptual, philosophical, and abstractive terms to be applicable among practitioners.[29,31]

Informants and Setting: The setting for data collection was Khon Kaen Province, where thalassemia carriers and the disease are prevalent and this is the center of the Northeastern region for thalassemia treatment. Twenty informants were recruited from seven hospitals located within 30 to 85 kilometers from downtown Khon Kaen. A purposive sampling technique was used to select informants who were 20–45 years old Thais, previously underwent prenatal diagnosis for severe thalassemia, and had already given birth or terminated a pregnancy within the last year. The potential informants were given an invitation letter and an information document for the research volunteers. After they expressed their interest, the researcher verbally explained in detail and answered their questions.

Ethical Considerations: Ethics approval was obtained from the Ethics Review Board of the Faculty of Nursing, Chiang Mai University (Approval number Exp–092–2017). All informants were informed about the study process, risks and benefits, their contributions, and the right to refuse and/or withdraw from the study. Written signed consent was obtained and no one withdrew from the study. Confidentiality and privacy were assured throughout the study. A few informants had emotional distress at a mild level and obtained mental support by the researcher at the end of the interview. Each informant received 100 Thai baht (US$3.17) for their contribution.

Data Collection: Data were collected and analyzed between November 2017–October 2018 until saturation was obtained. In–depth interviews were conducted in 2–3 sessions for 19 informants (only once for one informant) and these were 30–90 minutes in duration. Most were interviewed at their home where privacy and a relaxing atmosphere were secured. Initially, broad and open–ended questions were posed: *"How did you feel and /or think when you knew that your baby was at risk to severe thalassemia?," "In what ways did you deal with your feelings and thoughts?"* and *"What kinds of help did you need or obtain?"* Probes, such as *"Please tell me more about that."* and *"What made you do this in such ways?,"* were used to obtain a deeper and broader understanding of each informant's experiences, and were tailored to emerging data. The interviews were audio–recorded with the informants' permission and redundant. Rapport was developed through attentive and non–judgmental listening. All audio–recording and transcripts were destroyed after the completion of the study.

Data Analysis: Data collection and analysis were conducted simultaneously. The qualitative data were analyzed with thematic analysis proposed by Braun and Clarke,[32] consisting of six steps: 1) reading and re–reading the data while noting initial ideas; 2) coding the data line by line; 3) extracting themes and sub–themes from candidate themes, and all were coded again; 4) reviewing themes and validating that each related to the coded extracts and the full data set; 5) generating names and defining each theme; and 6) selecting vivid examples, involving relationship to the research question, and finally literature was compared to explain the findings.

Trustworthiness: Trustworthiness was attained through credibility, dependability, confirmability, and transferability.[33] For credibility, member checking was verified by having three informants review the tentative findings; peer debriefing was performed by having the advisory committee and three specialists validate all research processes and tentative findings. Auditing all research processes and documents also ensured dependability and confirmability. Regarding confirmability, a reflexive journal for the researcher's self–awareness was recorded before and immediately after the interviews to reduce bias. Transferability was reached through a thick description of the findings.

Findings

All 20 informants, aged 20-36 years, were Thai, Buddhist, and married. Seven informants had obtained a bachelor degree while 13 had lower educational levels. Nineteen informants underwent amniocentesis, one by cordocentesis. Ten fetuses were found to have severe thalassemia and nine of them were terminated. The informants' characteristics are summarized in **Table 1**. The informants' experiences were interpreted and conceptualized in terms of caring for these women based on a woman-centered approach. Six caregiving themes along with 13 subthemes are summarized in **Table 2**.

Table 1 Informant characteristics (n=20)

Informant Characteristics	Frequency	Percent
Age (years) (Range=20-36, Mean = 27.35, and SD =5.14)		
20-34	17	85.0
35-36	3	15.0
Level of education		
Senior high school or high vocational certificate	13	65.0
Bachelor degree	7	35.0
Occupation		
Employee/Merchant	14	70.0
Government officer	4	20.0
Housewife	2	10.0
Family income (Mean = 24,250; 1 USD=33 baht)		
Less than 15,000 baht	3	15.0
15,000 - 30,000 baht	14	70.0
Exceeding 30,000 baht	3	15.0
Result of prenatal diagnosis		
Normal	1	5.0
A carrier	9	45.0
Severe thalassemia (HbBart's hydrops fetalis=4, Beta thalassemia/Hb E disease=6)	10	50.0
Decisions following diagnosis results		
Continuity of pregnancy (Normal & a carrier=10, Beta thalassemia/Hb E disease=1)	11	55.0
Termination of pregnancy	9	45.0

Table 2 Themes and subthemes of refining woman-centered care in prenatal screening and diagnosis for thalassemia

Themes	Subthemes
1. Amending ambiguity	1.1 Assessing ambiguity in thalassemia 1.2 Making clear the unknown
2. Respecting individual difference	2.1 Assessing and accepting different values 2.2 Facilitating shared decisions, without using directives and coercion
3. Prioritizing an unborn baby's well-being	3.1 Nourishing an unborn baby 3.2 Reassuring an unborn baby's safety
4. Caring beyond courteousness	4.1 Assisting to regain emotional balance 4.2 Enhancing mental strength 4.3 Facilitating religious and spiritual coping
5. Caring given extensively to family and community	5.1 Intervening when '*My family hurt*,' and *'I hurt my family.'* 5.2 Alleviating concerns over community attitude
6. Reducing negative experiences with service delivery	6.1 Reducing a sense of prolonged waiting and being rushed 6.2 Reducing a sense of limited expertise and technology

Theme 1: Amending ambiguity

Information about thalassemia was complicated and detailed (ID4) and was confusing and sometimes misunderstood by some informants, leading them to develop ambiguity and further difficulties in making decisions.

Subtheme 1.1: Assessing ambiguity in thalassemia Several harms of thalassemia on the informants' offspring were perceived to be a vulnerability, low quality of life, being tortured, being different from other children, having difficulties in living, having a strange physical appearance, a child's sense of inferiority, and disability bringing financial burdens. Informants also viewed the disease as a chronic sickness, needing lifelong treatment of blood transfusions, eventually a shorter life and fatalism. However, ambiguity in the information about harms and curability was experienced when the informants' understanding was contradicted by healthcare providers' explanations. For example, it was thought to be less harmful, being alleviated by food or taking good care (ID8), or by drinking reddish soft drink (ID5).

> *If we take good care of food, the child can live a normal life. My cousin's child had thalassemia. Now the child is cured. It might not be cured completely. The child still needs a blood transfusion every two months.* (ID8, having an 8-month-old child with beta-thalassemia/Hb E disease.)

Thalassemia was believed to be prevalent in northeastern Thailand because the disease was related to race (ID3) and inherited by both a father and a mother (ID9). The chance was higher if only one parent had the disease (ID8). However, some informants did not fully understand the chance of inheritance. For example, a perceived lower chance was related to no anomalies, a strong and healthy baby, and good fetal movement shown in ultrasound screen, but a bad dream increased the perceived chance (ID9). The equal chance of one out of four for every pregnancy was misunderstood as being a chance of one out of four for all pregnancies; the informant had already had one normal child, and the next child would have higher chance thought one informant (ID1). If a husband was strong and used no alcohol or smoking, he was believed to have a lower chance of being a carrier, whereas the B blood group might contribute to thalassemia diseases (ID3).

Ambiguity in understanding testing accuracy was observed in one informant who was informed of a couple at risk of Hb Bart's hydropsfetalis (ID20), leading the couple to recheck the screening test twice from another two hospitals. All results were the same in the prenatal diagnostic tests, and the pregnancy was terminated. Disbelief about the abnormal diagnostic test result was strongly experienced and likely functioned as a defense mechanism (such as with ID2, ID4, ID5). Based on the informants' experiences, assessment of ambiguity in information about harm/curability, inheritance chance, and testing accuracy was needed, and caregivers helped them to deal with the unknown or ambiguous.

Subtheme 1.2: Making clear the unknown Unclear understanding and the unknown information about thalassemia and testing led the informants to search for more information (ID3) from the Internet (ID5), talk with experienced acquaintances (ID4, ID10) or visit different doctors (ID5, ID20). However, some of the information obtained, such as from non-professional websites, was superficial and sometimes inaccurate (ID4) and brought about 'a lot of stress' (ID5). The informants requested more information from healthcare providers tailored to their individual needs and presented in multiple ways to account for individual differences. More importantly, detailed, adequate, clear, and understandable information was needed not only by the women but also their families (ID4).

> *As for amniocentesis of thalassemia, we should have been provided with more detailed information, for example, its consequences or effects on the baby. In reality, I was given a piece of brief information. So far, I have not been informed about what type of thalassemia*

> *I have. They may be recorded in the pink book, but it's written in English. I tried to read it, but I don't understand at all.* (ID6)

Additional suggested practices based on the informants' experiences were the following: more audiovisual aids; self-learning materials with readable language and containing specific topics for particular individuals' concerns; lists of professional websites for laypeople; consulting and questions/answers services; communication through the LINE application and with experienced peers. Along with ambiguity, emotional distress was experienced and was managed mostly by religious and spiritual coping and by wishing the baby has no thalassemia.

Theme 2: Respecting individual difference

The informants held different values on a baby's conditions and life, further influencing their decisions. Their values must be assessed and accepted. Whatever values they had, facilitating shared decisions, without using directives and coercion, was crucial.

Subtheme 2.1: Assessing and accepting different values. There were two core values found to be different and contributing to the informants' different decisions on pregnancy options. The first value was 'Mother's heartbreak versus a baby living normally.' When considering the affected child's conditions, the informants felt suffering, varying according to their perception about thalassemia's harm to their baby. Their suffering could be so intense as to be described as heartbreaking.

> *How can I endure seeing the child in pain while undergoing procedures? Whether can I endure seeing the child crying? It is heartbreaking for moms.* (ID3)

On the contrary, the aforementioned informant having an 8-month-old baby diagnosed with beta-thalassemia/Hb E disease (ID8), perceived that her baby could live a normal life, although blood transfusions might be required. Her mother, her cousin, and her cousin's children also had thalassemia. She underwent amniocentesis with the fear of diseases other than thalassemia. That is, she previously observed that her neighbor refused the test and the child was found to be sick with some other disease.

The second value was 'Safeguarding a baby from suffering versus giving life to a baby.' The anticipation of a baby's suffering from thalassemia brought about maternal heartbreak and the decision to terminate the pregnancy for the baby's sake although they felt this sinful. As Buddhists, their beliefs in *Karma* and reincarnation helped them to feel relieved.

> *It was critical that I had to terminate my pregnancy, as both mother and baby might suffer. In fact, abortion is also suffering, but when the fetus does not sense the pain. It is even worst to let them grow up with suffering and pain. In fact, I had no choice at all.* (ID9, fetal β thalassemia/Hb E disease, pregnancy termination)

On the contrary, one informant insisted on keeping her baby although there was a risk of lethal thalassemia, and the child was found to be a carrier (ID6). The aforementioned informant (ID8), who viewed the disease as being harmless and curable, kept her baby additionally due to her beliefs in *Karma*, and the value termed 'give a life to a baby.'

> *I think nothing but giving birth to him, which is my happiness... I told the personnel that my mom remarked that a baby may want to be born with me and that everybody has Karma to be compensated, so I would let my baby be born.* (ID8)

In respecting informants' different values on a baby's life, the women's perception of the harms attributed to thalassemia, and their cultural, religious, and spiritual beliefs about pregnancy termination, were assessed with an open mind and without judgment. A sense of maternal heartbreak needed psychological management, whereas the perception of fewer harms needed further investigation for under-estimation of the harms. They needed to be ensured that their values were accommodated based on their obtaining accurate, adequate, and nondirective information of thalassemia's possible outcomes. Their past experiences and context needed to be accommodated to understand their points of view. Caregivers needed to be aware of the differences in values among the women and between the women and healthcare providers, to accept different values, and to acknowledge the influence of values on decisions.

Subtheme 2.2: Facilitating shared decisions, without using directives and coercion. Before their final decision, all informants discussed pregnancy options with their families. The one who kept her baby with β thalassemia/Hb E disease felt dissatisfied with being directed and coerced by healthcare providers to change her mind.

> *I don't understand why they so directed and discouraged me... When a pregnant woman decides not to terminate her baby, the medical team should not keep telling or convincing her to terminate. The medical team should allow her to live her regular life or tell her how to live with the affected child.* (ID8)

The informants needed healthcare providers to facilitate their decision-making process in a nondirective manner and without coercion, and by having them and their families share the decisions. Additionally, the informants' experiences throughout the process also implied how to facilitate their decision-making as summarized in **Table 3.**

Table 3. Summary of activities in facilitating shared decisions, without using directives and coercion, based on the informants' experiences

The informants' experiences in making decisions about pregnancy	Facilitating shared decisions, without using of directives and coercion
Pregnancy termination as a dead-end (ID10) and no choice (ID9, ID10), and chosen for the baby's sake (ID9, ID10). A need for time and shared decisions with family *I didn't prepare myself for bad news. When informed the result, I burst into cry. The doctor asked some questions, but I couldn't answer anything. So she allowed me to go back home so that I could consult with my family.* (ID12) A need for non-directive and non-coercive decisions and neutral information *They showed me the pictures. 'Your child will be like these. Can you accept? The child will...' I asked them if my child would be as bad as this child. I don't think it would be like that.* (ID8)	- Discuss the options after regaining consciousness - Discuss all possible options and the risks/benefits of each option - Discuss cultural, ethical, religious, and spiritual values/beliefs on a baby's life and pregnancy options - Be aware of and accept different attitudes and choices among the women, which could be contradicted with healthcare providers - Facilitate sharing decisions with family - Provide accurate and neutral information - Encourage to reason the chosen option in the positive manners - Accept their hesitation and inform the time frame - Reassure their final decision

Theme 3: Prioritizing an unborn baby's well-being

The invasive prenatal diagnosis testing was sometimes viewed by healthcare providers as a routine procedure, whereas the informants viewed it and their condition of being a couple more seriously at risk, sensing a threat to their baby's life. The priority they gave to their baby's well-being led them to take very good care of their baby. When prenatal diagnostic tests were undertaken, they attempted to protect their baby from the complications.

Subtheme 3.1: Nourishing an unborn baby. Whether the baby had or did not have severe thalassemia, and whether the baby would be kept or aborted, the informants behaved in several ways to nourish their baby, hoping that the baby would be strong and healthy and tolerated with potential complications. The informants nourished the baby with food, rest, no vigorous activities, supplemental vitamins and minerals, and complied with medical advice.

> *I nourished my baby, eating well and taking vitamins from the hospital every day. According to the Internet, it is recommended to nourish myself and baby so that he will be born healthy. In addition, according to the doctors, I should stop working and take sufficient sleep.* (ID5)

Subtheme 3.2: Reassuring an unborn baby's safety. Amniocentesis and cordocentesis were performed in 14 and 1 informants, respectively. They were scared of the possibilities of miscarriage, amniotic fluid leakage, infection, and injuries, which might make them hesitate to undergo those procedures (ID6). Miscarriage was the outcome most often worried about and prevented. Interestingly, fetal injuries by needle puncture were anticipated by many informants, especially in case of having no previous experience of amniocentesis, lack of knowledge about the procedures, and seeing the needle.

> *It was the first time I was given an amniocentesis test. I felt shocked when I saw a doctor carrying a needle. I didn't know what would be like. I was concerned that the needle might hurt my baby.* (ID7)

A long needle and the nature of needle fear (ID5), fetal movement (ID4), the lengthy procedure (ID3), and a novice doctor (ID3), intensified the informants' fear of injuries. However, watching the needle in an ultrasound screen was sometimes preferred to having assurance about the baby's safety (ID3). Some informants felt relieved after talking with other women who had similar experiences.

To reassure the informants about fetal safety, the procedures and measures for preventing complications were described in detail. Individual concerns with the contributing factors, such as attitudes and past experiences, were assessed and reduced in different ways tailored to individuals. Arranging a discussion with the women who had similar experiences was also needed. Encouragement and confidence were enhanced realistically.

Theme 4: Caring beyond courteousness

Modestly, the informants requested healthcare providers only to treat them with gentle and kind manners (ID1, ID3, ID8, ID12). They suffered and attempted to manage their suffering by themselves and their resources. However, their painful and traumatized feelings were remembered with crying as they described their experiences in interviews. This implied that they needed substantial assistance beyond courteousness, including psychosocial and spiritual care.

Subtheme 4.1 Assistance to regain emotional balance. Immediately after receiving an abnormal result, several devastating feelings developed: shock, numbness, confusion, disbelief, ambiguity, inability to think and talk, unpreparedness, and feeling overwhelmed.

> *The period for knowing the blood result, It was shocking to a level similar to the first few unacceptable. Then come to gather consciousness. It was quite shocking, not talking, nothing.* (ID2)

The informants needed assistance to regain their emotional balance, which could be provided by the following ways: stay with, be silent, avoid discussing, attentive listening, non-judgmental listening for some irrational hopes, allow to cry, and provide accurate and concise information as requested.

Subtheme 4.2: Enhancing mental strength. Several painful feelings, including sadness, loss of hope (no opportunities to embrace nor raise the child, ID2), disappointment, guilt and self-blaming (for passing the disease to the child, ID4), and as though killing one's child (ID12), made the informants feel powerless and unable to go on with their normal lives. Initially, during the weakness, they stayed away from the stressful conditions and did other things to distract themselves, such as: isolating, avoiding mention about, ignoring additional and relevant information, and keeping busy (such as by working, entertainment activities, visiting friends). Another way of strengthening their minds was adjusting their thoughts in the following ways: prohibiting negative thinking (*trying not to think about it*, ID6); no overthinking (ID2); positive thinking (ID2); productive acting, such as eat supplementary diets (ID2); downward comparing (*I'm much better than them*, ID9); and placing hope (*the baby might be OK*, ID10). Fear of testing procedures could be reduced by discussing with other informants who had similar experiences (ID1, ID3, ID13).

In enhancing the informants' emotional strength, their negative feelings were assessed by the caregivers, who facilitated coping strategies using the following behaviors: preparing private rooms for mourning; informing that it is OK to feel sad, hopeless, guilty, disappointed, and to cry; encouraging expression, listening to, and accepting their feelings; setting limits of avoiding strategies in terms of time and some non-productive methods, such as accepting to delay an appointment instead of discontinuing antenatal care (ID8); and importantly, not neglecting their religious and spiritual coping methods.

Subtheme 4.3: Facilitating religious and spiritual coping. Beliefs and rituals regarding religion and spirituality were strong coping resources throughout the screening and diagnosis process. Accepting the truth and living in the real world rather than having unrealistic wishes was hurtful, but those behaviors helped the informants to think logically (ID10) and to deal with the matters in the realistic manners (ID2). Religion and spirituality influenced how the informants expressed their values about a baby's life and pregnancy termination. The law of *Karma*, that is, things happen according to *Karma*, is a strong belief among Buddhists and was the essential source of mental coping, as one informant said:

> *'Believing in Karma helped me accept the truth and could tolerate the suffering.'* (ID4)

Although terminating their pregnancy was believed to be killing their baby and sinful, their beliefs in *Karma* lessened their feelings of sinfulness, guilt, and self-blame.

> *Let go by Karma. If I have bad deeds, I won't have a baby.* (ID 2)

> *If the baby can go through it, it means that the baby has good deeds. If we have good deeds together, we, mother and child, will live together.* (ID4)

The belief in *Karma* also helped one informant (ID8) accept the baby's suffering from thalassemia and chose to give birth to the affected baby.

> *One thing I thought to let the baby be born or not is up to the baby's good deeds and bad deeds. To have the disease or not is the way the baby compensated to the baby's bad deeds.* (ID8)

In addition to *Karma*, reincarnation (ID11) was another Buddhist belief that could reduce a sense of guilt from interrupting the baby's birth. It was believed that the baby's reincarnation with a new normal and healthy life was better than the baby's birth and suffering from thalassemia.

Buddhist rituals, such as making merit (ID6); listening to a sermon (ID2); and praying (ID5), were also performed to reduce suffering. Rituals regarding supernatural powers, such as worshipping holy things (such as Ganesh) (ID5); visiting a fortune teller (ID5); walking under an elephant's belly (ID7), and taking a holy water shower (ID11) were performed while believing that their baby did not have thalassemia. Only one informant did not get good luck, but she insisted to do it in the future. She thought,

> *The baby still had bad deeds, but the baby escaped from the death angels to be born. Now the baby had to go back to pay back for the baby's bad deeds. It might be parents' bad deeds and sent to the baby.* (ID11)

In conclusion, accepting the truth, *Karma*, reincarnation, Buddhist rituals, beliefs and rituals regarding supernatural powers were regarded as religious and spiritual coping, needing to be assessed, accepted, and facilitated suited to individuals.

Theme 5: Care extensively given to family and community

Suffering was not experienced only by the informants but their family were also stressed and needed to be taken care of. The informants were also concerned with their neighbors' attitudes about pregnancy termination.

Subtheme 5.1: Intervening when 'My family hurt,' and 'I hurt my family.' The informants regretted when observing their family's pain, as one informant expressed, '*My mom kept crying*' (ID9). Some thought that they were the cause of their family's sadness by transmitting the disease to their baby (ID4) or destroying their family's expectation for the child (ID4). One informant expressed with worry that her eldest son (5 years old) felt very sad about losing his expectant sibling (ID9). She explained the reasons to her son and that his younger brother was in heaven. When the decision had to be made, some informants discussed with their family, and sometimes nuanced conflicts happened (ID19).

During the critical period, their family likely kept quiet and avoided talking about sad issues. Their husbands likely comforted and took good care of the informants. To stop hurting her family, one informant preferred '*crying in my heart* (ID2),' hiding her sorrow. Displaying their strength instead of their weakness was the way to be an anchor for their family. From the informants' experiences, it was essential to lessen their regret and guilt for their family, to provide mental caring for the family, and to enhance family support and shared decision-making.

Subtheme 5.2: Alleviating concerns over community attitude. An informant who chose to keep her baby, diagnosed with beta-thalassemia /Hb E disease (ID8), narrated about her relatives, neighbors, and community members.

> *I see many thalassemia persons. They're OK. She (her cousin) didn't get the baby out as suggested, and the baby looks normal.* (ID8)

In her community, there were many persons affected by thalassemia, some of whom needed a blood transfusion, but were believed by neighbors to be normal. Some neighbors and her family refused pregnancy termination. These community norms were internalized, influencing her values and decisions. If community attitudes and norms were disadvantaged, helping the informants to consider this in a more productive light was needed. In the case of contradictory attitudes, discussion on autonomy and assertiveness, and how to deal with other pressure were essential.

Theme 6: Reducing negative experiences with service delivery

Most of the informants' complaints and requests about service delivery were waiting too long and being rushed, and limitations in expertise and technology.

> *Waiting for the result is a long wait because I'm afraid that it'll not be resolved in time.* (ID9)

> *If I could change something, I would have consulted with the expert from the beginning, so that I had time to get it over, and that I had an opportunity to inform my family.* (ID4)

Subtheme 6.1: Reducing a sense of prolonged waiting and being rushed. The informants felt that the time to obtain their diagnostic testing results was long (ID 6), since they needed plenty of time to consider their pregnancy options, and it might not be in time (ID 4). They had to consult their family (ID 2). To have a clear understanding and confidence before making tough decisions, some informants searched for more information and opinions from lay and professional persons and the Internet. They needed time to become mentally prepared for undergoing the procedures (such as ID8). Since they had a sense of waiting too long, the time left for them to make the next necessary decisions were perceived to be too short, and they were rushed in making their decisions and undergoing the procedures. Some emotional distress also contributed to their negative feelings.

Subtheme 6.2: Reducing a sense of limited expertise and technology. Ambiguity was likely experienced for complex issues like thalassemia, bringing about suspiciousness about the expertise of health professionals, and the technology available for diagnostic testing. Some informants wanted special services provided by specialists and advanced technology, despite any extra payment, to ensure their understanding, the diagnosis results, and the optimal options for treatments (ID4, ID9, ID10).

To reduce their negative experiences with service delivery, caregivers needed to explain about the standard timeframe for undergoing the procedures and obtaining the results. Adequacy of the expertise of healthcare providers and quality technology provided to the informants were also discussed. Asking about the informants' readiness and their need for more time or better services, and being flexible if possible, was also undertaken. Lists of alternative services were provided. Importantly, acknowledging their difficulties and concerns, and expressing empathy, were helpful although all their requests could not be accommodated.

Discussion and Recommendations for Clinical Practice

A woman-centered approach highlights the fulfillment of individual women's unique needs and humanized care.[25] Caring by respecting individual difference in values about a baby's life and pregnancy options emerging from the informants' experiences confirmed that the women's values were diverse and needed to be considered. Humanized care that included all aspects of a woman's life as a human being and her loved ones instead of focusing only on performing the procedures was revealed as a concern about the women's needs in this study. The care being cold, not very personal, with no individual touch, and doing the job and just getting onto the next patient, dissatisfied some women undergoing prenatal diagnosis.[12] Also the routinization of care manifested as the minimal discussion about testing, leaving no choice, and receiving persuading or coercive advice.[34]

A woman-centered approach encompasses four key elements: 1) an individual woman's health needs and those of her baby, family, and community, 2) a holistic approach encompassing each woman's social, emotional, physical, spiritual, and cultural needs in her circumstances, 3) every women's right to attain informed decisions, control, dignity, and respect, and 4) a woman's connection with her social support system.[26] The caregiving themes in this study reflected all of these four elements, that is, Theme 3 and 5 for the first, Theme 4 for the second, Theme 1 and 2 for the third, and Theme 5 and 6 for the last element.

Ambiguity in thalassemia facts is common since the disease manifests in several types, varying in symptoms, severity, survival, and treatment. Over- and under-estimation of thalassemia harms can develop by mixing up among different thalassemia types. In thalassemia education, therefore, the core content is suggested to be each type of thalassemia. Apart from routine health education it is strongly recommended to provide more specific information tailored to individuals' ambiguous concerns. Since time constraint is a perceived barrier to woman-centered care,[13] self-learning materials containing various specific topics need to be produced and distributed to individuals as needed. The services for consulting, allowing for questions and answers, using face-to-face and LINE apps and other social media, and lists of reliable websites, can be valuable tools for self-searching. As an autosomal recessive dominant disease, the risk assessment of the inheritance chance is complicated and needs health numeracy. Low health numeracy is fairly common but found high in as many as 37% of pregnant women surveyed in the USA,[13] which might contribute to ambiguity. Also, the emphasis on meaning,[35] and descriptive phases of genetic risks are suggested, and convenience factors[15] cannot be overlooked.

'Making clear the unknown' involved the informants' ability for appropriate decision-making to lessen the uncertainty, and to provide informational support to their family. Generally, an accurate understanding of the condition that had been diagnosed is one important component of decision-making after a prenatal diagnosis.[24] Clear, sufficient, and relevant information also functions in reducing emotional distress from unclear understanding and uncertainty.[26] In searching for information, the study informants looked for details about thalassemia and prenatal diagnosis in all steps. This included the issues of causality, diagnosis, prognosis, potential outcomes, options, and limitations of treatment.[12,36-37] Personal searching on the Internet and reading books, visiting different doctors, performing various diagnostic tests and sonography by specialists were attempted because of the mistrust of diagnosis; and seeking peer experiences were also reported.[15] Acquaintances were personal resources for venting feelings and practical support.[15,37] Non-directive and balanced information was crucial for voluntary decision-making but healthcare providers tended to accept pregnancy termination for fetal abnormality.[24] The women needed to be informed with honesty, clarity, in layperson's terms and a sensitive way.[18] Personalized information, presented in multiple ways while remaining simple and unbiased, is suggested.[36] In addition to technical and factual information, personal information,[38] including individual values and beliefs regarding moral and religious dimensions, is also found to be crucial in genetic counseling.[24]

'Respecting individual difference' referred to the differences among the women, and between them and healthcare providers. Pregnancy termination was not always the option for thalassemia, as only 59.9% of 309 women would choose pregnancy termination if the fetus was diagnosed with beta-thalassemia major, and 26.5% were unable to decide.[39] Parents have reported more positive attitudes toward raising a child with a disability and more moral views about pregnancy termination than did providers.[40] Spirituality had a broader definition than religiosity, often focusing on the search for meaning or purpose in life; spiritual beliefs and practices assisted a person in looking outside of the self for dealing with a crisis; and could be expressed with some words as Allah, God's wills/hands, hope, miracle, believe/belief, faith/destiny, trust, and prayer/praying.[18] Spiritual beliefs and rituals, as well as values and religious beliefs, were fundamental for emotional coping and decision-making across cultural groups, such as hope and precious life/pregnancy in women in the United Kingdom;[41] and praying, acceptance of destiny as God's wills and reliance on faith in Muslim women[36] whereas in Thai women, hope and a miracle[40-42] and some supernatural rituals in the present study were reported. Re-interpreted and hopeful and positive reassurance sometimes goes beyond rational logic.[20] Hoping for a positive outcome from Internet searching sometimes provided 'false hope.'[41] Accepting and living on reality, enabling the informants to confront with the matters in a mindful, realistic and reasonable manner, was rooted in Buddhist's teaching about the law of *Karma* and the Four Noble Truths about suffering,[34] and is also found in other cultures as aforementioned.

It is recommended to consider the women's moral values on 'how life should be lived.'[15] Sin, the law of *Karma*, incarnation, acceptance of the truth, such as suffering is normal for human beings, are Buddhists' beliefs and were found to be employed in decision-making and emotional coping in this study. Beliefs in supernatural powers were also found, even among informants with a health sciences background (ID4, ID10) regardless of socioeconomic and educational status. However, these issues are rarely discussed in antenatal clinics, especially when it involves pregnancy termination, as one study showed that discussion on pregnancy termination (50% for nurses and 58% for doctors) was less favored among non-geneticist nurses and doctors than that on prenatal diagnosis (96%).[43]

'Prioritizing an unborn baby's well-being' through nourishing and reassuring the baby's safety no matter whether the baby would be terminated or not, was humanized caring rather than focusing only on step-by-step procedures, and mercy caring with the informants' concerned. They attempted to make their baby strong enough to tolerate complications from diagnostic tests, to acquire and maintain hope about their baby's safety, and to reduce their guilty feelings. Another reason could be a sense of parental responsibility as maternal instincts, love and bonding with their baby urged them to do everything in their power to protect and nurture their unborn baby with growth restrictions.[41]

'Assisting to regain emotional balance' was crucial following a prenatal screening and diagnosis of severe thalassemia with the feeling of shock, which was also reported in previous studies.[9] The women lost their concentration and energy to intervene with stressful issues. Giving more explanation and asking for decisions immediately were unhelpful and also put more pressure on the women, leading them to feel being rushed. The women needed some time and encouragement to regain their consciousness of the situation. It should be noted that sometimes they were given false hope, such as before diagnosis for fetal growth restriction.[41]

Various stressful feelings also developed such as sadness,[9] and grief.[24] Similar to being the carriers of Duchene muscular dystrophy,[42] guilt and self-blaming occurred as the perceived cause of the child's disease and killing their baby in case of terminating the pregnancy. Feelings of anger, envy, unfairness, and hate toward people unaffected with a fetal anomaly can develop,[37] but they were not found in this study. Only anger at healthcare providers was expressed by one informant who declined pregnancy termination (ID8), indicating the importance of respecting individual values, using non-direction and non-coercion while facilitating decision-making.

The women in this study employed both emotion- and problem-focused coping strategies. They tried to solve their ambiguity by searching for more information from various sources, even experts and advanced technology and discussing pregnancy options. Staying away from stressful events was similar to previous studies.[36,37] However, social engagement in some activities and talking with the women who had similar experiences, were still needed.[41,44] Keeping busy, or maintaining everyday plans and routine, and participating in everyday social activities,[44] and venting feelings with peers,[36] were helpful for the informants in killing the lengthy waiting time and forgetting their suffering. This was comparable with the coping method of catharsis, the release of emotions, distraction, and relaxation in recreational activities.

Family hurt and a sense of hurting the family were found in this study reflecting Thai culture which highlights strong relationships among family members, sharing both suffering and happiness. Although Thai couples live alone in a nuclear family, they still include all family generations to be their network, having close physical and social contacts. Having a baby is a happy event shared by family members. When the family lose their expectant baby, a woman as a mother giving life to the baby sadly feels that she disappoints her family's hope. A woman's responsibility to family well-being and reproductive health is likely internalized by Thai women. This womanhood attitude might have contributed to the informants' high concern about their family, therefore, it was found that the informants attempted to be emotionally strong to provide mental support to their family. Some informants concealed their suffering and expressed only their strength. The women's family also need to be the target group of caring, however, in clinical practice, family members are likely included as a woman's supporters. As a minimum, it is recommended to put efforts on reducing the women's concerns over their family stress and facilitate them to care for their family's well-being.

In-time diagnosis procedures, also reported previously,[13] as well as the availability of specialists and advanced technology, were suggested by the informants. In-time diagnosis procedures helped the informants obtain more time for their decisions but limited time interfered with their understanding about the anomaly, legal permission for therapeutic abortion, and to make their decisions.[36] Advanced technology is essential for accurate diagnosis and effective fetal therapy. Trust and a clear understanding from specialists were found to be needed to ensure the rightness of their decision-making.[41]

In conclusion, in caring for women undergoing prenatal screening and diagnostic tests for thalassemia, a woman-centered approach needs to be incorporated into genetic counseling to fulfill individual women's unique needs and to attain humanized and quality care. Such caring encompasses amending ambiguity, respecting individual difference, prioritizing an unborn baby's well-being, caring beyond courteousness, caring extensively for the family and community, and reducing negative experiences with service delivery.

Study Limitations and Recommendations

The informants in this study were Northeastern Thai Buddhist women. Women in other regions of Thailand with different backgrounds may have different perspectives and experiences. The retrospective accounts of informant experiences were subject to memory and perceptions. The experiences recounted during the study might have been influenced by the process after pregnancy termination. How the experiences were remembered was psychologically revealing. The findings need to be extended by understanding experiences at each step of thalassemia screening and diagnosis. Moreover, similar studies should be conducted by nurses and other health professionals among women from other cultural backgrounds (e.g. Muslim women) to broaden the applicability of any chosen woman-centered caring. The perspectives of healthcare providers on each caring theme should also be explored to refine the existing finding and to enhance feasibility. A practice guideline or model of genetic counseling with the incorporation of woman-centered care for these women should be developed and evaluated. Nurse educators have an important role in assisting midwives and nurses to understand the importance of woman-centred care and to provide opportunities and resources for them to learn important factors about genetic counselling in such important conditions such as thalassemia.

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การปรับแต่งการดูแลโดยยึดสตรีเป็นศูนย์กลางในการคัดกรองและการวินิจฉัยในระยะตั้งครรภ์สำหรับโรคธาลัสซีเมีย: การวิจัยแบบพรรณนาเชิงคุณภาพในสตรีไทยในภาคตะวันออกเฉียงเหนือ

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บทคัดย่อ: ในการดูแลสตรีที่มีภาวะเสี่ยงต่อธาลัสซีเมียของทารกในครรภ์ เป็นการให้คำปรึกษาทางพันธุกรรมเป็นพื้นฐาน เพื่อให้แน่ใจในคุณภาพการดูแลโดยการตอบสนองความต้องการ เฉพาะเจาะจงของสตรีแบบปัจเจกบุคคล ต้องนำการดูแลโดยยึดสตรีเป็นศูนย์กลางเข้าไปบูรณาการด้วย การวิจัยแบบพรรณนาเชิงคุณภาพนี้มีวัตถุประสงค์เพื่อเข้าใจประสบการณ์ของสตรีกลุ่มนี้ซึ่งนำไปสู่การปรับแต่งการดูแลโดยยึดสตรีเป็นศูนย์กลาง จากการเลือกแบบเจาะจงมีสตรีไทยในจังหวัดหนึ่งของภาคตะวันออกเฉียงเหนือที่ผ่านการคัดกรอง การวินิจฉัยในระยะตั้งครรภ์ และได้ยุติการตั้งครรภ์หรือคลอดบุตรแล้วจำนวน 20 คน เข้าร่วมในการวิจัย ส่วนใหญ่ได้รับการสัมภาษณ์เชิงลึกคนละ 2-3 ครั้ง วิเคราะห์ข้อมูลด้วยการจัดหมวดหมู่จากประสบการณ์ของผู้ให้ข้อมูลพบว่าการดูแลประกอบด้วย 6 ประเด็น ประเด็นที่ 1) แก้ไขความรู้สึกคลุมเครือ: 1.1) ประเมินความคลุมเครือเกี่ยวกับโรคทาลัสซีเมีย และ 1.2) สร้างความกระจ่างในสิ่งที่ไม่รู้ ประเด็นที่ 2) เคารพความแตกต่างระหว่างบุคคล: 2.1) ประเมินและยอมรับความแตกต่างในคุณค่า: หัวใจสลายของแม่กับการมีชีวิตปกติสุขของทารก การปกป้องทารกจากความทุกข์ทรมานกับการให้ชีวิตแก่ทารก และ 2.2) ส่งเสริมการตัดสินใจแบบการมีส่วนร่วม โดยปราศจากการชี้นำและบีบบังคับ ประเด็นที่ 3) ให้ความสำคัญกับความผาสุกของทารกในครรภ์: 3.1) บำรุงทารกในครรภ์ และ 3.2) สร้างความมั่นใจในความปลอดภัยของทารกในครรภ์ ประเด็นที่ 4) ดูแลนอกเหนือเกินกว่าความสุภาพอ่อนน้อมและเมตตา: 4.1) ช่วยเหลือให้มีสติกลับคืนมา 4.2) เพิ่มพูนความเข้มแข็งทางจิตใจ และ 4.3) ส่งเสริมการเผชิญด้วยวิธีทางศาสนาและจิตวิญญาณ ประเด็นที่ 5) ดูแลครอบคลุมถึงครอบครัวและชุมชน: 5.1) จัดการเมื่อ ‘ครอบครัวรู้สึกปวดร้าว’ และ ‘ฉันทำให้ครอบครัวปวดร้าว’ และ 5.2) ลดความรู้สึกกังวลใจในทัศนคติของชุมชน ประเด็นสุดท้าย 6) ลดประสบการณ์เชิงลบกับการให้บริการ: 6.1) ลดความรู้สึกว่ารอนานและถูกเร่งรัด และ 6.2) ลดความรู้สึกว่ามีข้อจำกัดเรื่องความเชี่ยวชาญและเทคโนโลยี

โดยสรุป ในการดูแลโดยยึดสตรีเป็นศูนย์กลางสำหรับสตรีกลุ่มนี้ พยาบาลควรตอบสนองความต้องการทางจิตสังคม วัฒนธรรม จริยธรรม ศาสนา และจิตวิญญาณอย่างเฉพาะเจาะจง เคารพค่านิยมศักดิ์ศรี และการตัดสินใจ ตลอดจนขยายขอบเขตการดูแลไปถึงทารกในครรภ์ ครอบครัว และชุมชน

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