Experiences of pregnant women at risk of having babies with severe thalassemia in Phitsanulok province, Thailand

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ABSTRACT


The objective of this study was to explore the experiences of pregnant women at risk of having babies with severe thalassemia. It considered their knowledge of thalassemia, financial problems, psychological problems, health care services and other social problems. The study group comprised 10 pregnant women in Phitsanulok province who were screened and diagnosed at high risk of having severe thalassemic babies. In-depth interviews were conducted for data collection from May to August, 2009. Data analysis was performed by content analysis.

The study showed that pregnant women lacked knowledge about thalassemia. Most had gained their knowledge from newspapers, text books in school, from relatives or neighbours in the community with thalassemia. Little thalassemia knowledge was gained from health providers when they visited antenatal care clinics.

With regard to financial issues, pregnant women under the universal health care cover scheme did not pay for screening and diagnosis but had to pay for transportation when they went to health care service units. Pregnant women covered by the social security scheme had to pay in advance for all antenatal care.

Waiting to perform subsequent tests and waiting for test results had psychological consequences for the pregnant women and their spouses. Some health providers were found to have little knowledge of the screening process. Health providers spent little time counseling pregnant women about thalassemia at antenatal care clinics.

Late antenatal care was a frequent problem for women who were unaware that they were pregnant or who had unwanted pregnancies, especially teenagers. As a result of delayed antenatal care, pregnant women at high risk of having severely thalassemic babies were not screened.

This study emphasizes the need for continuous education and promotion to raise disease awareness so that pregnant women will come for early antenatal care. Continued education and especially guidelines for thalassemic screening should focus on health providers. Financing thalassemic screening activities under existing health benefit schemes should be reviewed. Further research should focus on unwanted pregnancies and early screening of teenagers.

Keywords Pregnancy Risk Severe thalassaemia
ประสบการณ์ของหญิงตั้งครรภ์ที่เสี่ยงต่อการบริหารเป็นโรคอัลซีเอียร์ ชนิดรุนแรง กรณีศึกษาจังหวัดพิษณุโลก

บทคัดย่อ

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การศึกษาพบว่า หญิงตั้งครรภ์ต่อสิ้นหรูถึงถึงได้กล่าวว่าการอัลซีเอียร์ชนิดรุนแรงเป็นเรื่องที่ต้องคำนึงถึง ความสามารถที่จะป้องกันและรักษาให้ได้รับการรักษาให้ดีที่สุดเท่าที่จะเป็นไปได้ แต่การรักษาให้ดีนั้น ต้องมีการจัดการที่เหมาะสม

ศิรินทร์ นิทานรัตน์ ฟารีนีร์ สิริสุก ศุภภาพ พรหมรุ่งโรจน์ 2554; 9(1): 28-38.
INTRODUCTION

Thalassemia is a genetic recessive haemoglobin (Hb) disease. It is a major public health problem in many countries, especially in northern Thailand and has become most important with a high incidence of carriers. About 40% of the Thai population are carriers and 1% of Thai population is affected by it. In 2007, Thailand was found to have 500,000 cases of thalassemia. Annually, 50,000 pregnancies are at risk of resulting in children with thalassemia.

Thalassemia patients with severe illness must receive life-long continuous treatment, specifically blood transfusions and iron chelator. The chronicity and complications of thalassemia affect the quality of life of victims and parents and cause physical, psychological and economic problems.

Thailand has had a programme for prevention and control of thalassemia since 1994. The programme consists of four strategies: education, carrier screening, genetic counselling and prenatal diagnosis. Three severe forms of thalassemia (Hb Bart’s hydrops faetalis, homozygous beta thalassemia and beta thalassemia/Hb E) have been focused on for prevention and control. The severity of symptoms leads to high health care expenditure. Screening of all pregnancies is a national strategy leading to proper prenatal diagnosis. Pregnant women and their spouses are screened at antenatal care clinics. If both are thalassemia carriers, they are counted as a couple at risk and their unborn babies should be properly and quickly investigated for prenatal diagnosis. If the babies are diagnosed with any kind of severe thalassemia, the pregnant women have the choice of terminating the pregnancy or continuing the pregnancy to delivery.

Literature reviews show that the key success factors of the thalassemia prevention programme have been people and community awareness of the thalassemia disease. Additionally, genetic counselling is also important in increasing a couple’s awareness of thalassemia problems. Nurses as counsellors should be able to provide counselling to pregnant women and their spouses about the genetic transmission of thalassemia. The process of identifying potential couples at risk and confirmatory prenatal diagnosis is based on decision making of pregnant women and their spouses. Moreover, early antenatal care in each pregnancy is important. If pregnant women come late for antenatal care and test positively for thalassemia, it is too late and termination becomes too risky.

Phitsanulok is a provincial capital in lower northern Thailand with a high Hb E prevalence compared with the other northern provinces. The high prevalence of Hb E, and beta thalassemia/Hb E, presents a major problem and 30 children with thalassemia are born annually in Phitsanulok. Additionally, empirical studies have shown that the thalassemia prevention programme in Phitsanulok has not been successful. Therefore, this study aimed to explore the experiences of pregnant women who were at risk of having thalassemic babies in order to explore the pregnancy feeling and problems about the thalassemia screening process and to understand and represent the pregnant women’s attitudes about thalassemia.
METHODOLOGY
This was a qualitative study. The inclusion criteria were that a pregnant woman had tested positively for severe thalassemia; had received antenatal care at the antenatal care clinic at the Buddhachinaraj Phitsanulok Hospital; had continued the pregnancy; and was willing to participate in the interview.

In-depth interviews were conducted for data collection using interview guidelines. The interview guidelines comprised open-ended questions based on a literature review. All interviews were recorded on audio-tape and transcribed. After signing a consent form, the pregnant women were individually interviewed in a comfortable setting chosen by the interviewer. Ethical approval was obtained from the research ethics committee of Naresuan University.

Content analysis was undertaken. All interview transcripts were reviewed along with the audio-tape to check accuracy. The transcribed interviews were repeatedly and carefully read following the code categories related to the aims of the study.

Table 1  Participant characteristics

<table>
<thead>
<tr>
<th>Case No.</th>
<th>Age (years)</th>
<th>Number of gravida</th>
<th>Age at first antenatal visit (weeks)</th>
<th>Occupation</th>
<th>Years of schooling</th>
<th>Health benefit coverage</th>
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<tr>
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<td>2</td>
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<td>1</td>
<td>21</td>
<td>Student</td>
<td>11</td>
<td>UC</td>
</tr>
</tbody>
</table>

Note: UC means the universal health care coverage scheme
RESULTS

The study group consisted of 10 pregnant women who were at risk of having thalassemic babies. Six were married and 4 were students. Their ages ranged from 15 to 35 years old, with a mean age of 24 years (see Table 1).

Five core themes were identified from the pregnant women interviewed after they had learnt that their babies were at risk of having thalassemia. The five themes were lack of knowledge about thalassemia, their psychological experiences, financial difficulties faced during pregnancy, the efficiency of health care services, and social problems.

Lack of knowledge about thalassemia

All participants reported that they had been given some information about thalassemia by the nurses when they first attended the antenatal care clinic. In addition, the pregnant women were advised to read more about thalassemia from a booklet. However, they still felt that they had insufficient knowledge about the causation of thalassemia, its genetic components, and complications.

Some pregnant women knew about thalassemia prior to attending the antenatal care clinic. They had known about thalassemia from textbooks and newspapers.

Some had seen thalassemia patients in their community or had had relatives or known women with thalassemia. Despite prior knowledge, they expressed an inadequate, and demonstrated a lack of knowledge about thalassemia and its complications, once they themselves faced it. One pregnant woman said -

“I used to read about thalassemia in the newspaper. And my sister is a known case of thalassemia, but she is very strong and can do everything. So I think thalassemia is not fearsome. This disease is less likely to occur with my child because both I and my husband are very strong and in good health.” (Case 4)

One pregnant woman expressed confusion related to her understanding and knowledge of this genetic disease. She said -

“I first knew about thalassemia from textbooks when I studied in secondary school. I think that thalassemia is not terrible. My mother is a known case of thalassemia. Her body is not yellow or pale. The doctor told her that she was only anaemic. She doesn’t need to meet the doctor or get a blood transfusion. She does everything so well. I think thalassemia shouldn’t have happened to my baby because I didn’t get thalassemia from my mother.” (Case 10)

“I need to know why thalassemia occurs to my baby. What is the cause of thalassemia? Why does my baby have severe thalassemia? I don’t really understand. But the nurse gave me a pink book - handbook for antenatal care, and told me to read about it in this book. She didn’t have time to explain to me; a lot of pregnant women were waiting for antenatal care.” (Case 8)
Most of the participants had no idea what thalassemia screening was. When the women were examined and listed positive, they were referred for genetic counselling and a screening process provided by nurses.

“I do not really understand that there are several kinds of thalassemia. The doctor told me that I should get a prenatal diagnosis. I don’t understand about the method for investigating my baby, but I allowed it. I wanted to check my baby; I needed to know whether my baby would have severe thalassemia. If my baby had severe thalassemia, I should go for termination of pregnancy. Does that mean I don’t love my baby; no... I love my baby by thinking about the future problems that will come after my baby is born.” (Case 4)

Psychological Problems

Nearly all the respondents reported that they had experienced psychological distress and denial as the most common feeling caused by the initial news that their babies would suffer severe thalassemia. One said -

“I and my husband felt sorrow and distress. I felt like a phantom. I could neither eat nor sleep. I thought why this had to happen with my child. It was impossible for this to happen to my child.” (Case 10)

Furthermore, some of the respondents explained about their feelings while waiting for result of couple at risk identification.

“Even though I and my husband have free care from the universal coverage scheme, we still have to pay for transportation. The hardest part is the cost of the transportation in getting to hospital. We spent around 500 baht for transportation.” (Case 6)

Financial Problems

The government of Thailand offers a universal health care coverage scheme for all Thai people. The benefit package for pregnancy has been designed to fit within the overall prevention and promotion care package. Pregnant women with this universal coverage usually receive thalassemia screening with other blood tests when they have their first antenatal care visit. They pay nothing for all the blood tests. However, financial problems were related to the respondents’ living and transportation costs of visiting the hospital for screening and prenatal diagnosis. Transportation was the main cause of financial burden for these women. Most of the cases were referrals from a community hospital to stay in the province for proper investigation and treatment. As one mother commented about the cost of transportation-
One pregnant woman was a full time employee and covered by the social security scheme. She expressed her feelings about the cash advanced for antenatal investigations thus -

“I have a social security scheme card. Whenever I come to hospital for antenatal care, I have to pay money for blood tests including thalassemia screening. The social security scheme only pays a sum of 12,000 baht after I have delivered. At the first time for antenatal care, I paid 1,100 baht for blood tests. Today the nurse told me that I must pay a total of 2,000 baht for diagnosing my baby. I am an employee. My income is low. It is very hard for me.” (Case 9)

One pregnant woman mentioned the complexity of the referral system, and that her spouse was not covered when he attended the referral hospital-

“Last time, the doctor at the community hospital referred me for screening my baby at a provincial hospital. He wrote a referral letter only for me. When I came to the provincial hospital, my blood tests were free of charge but not for my husband because he did not have a referral letter. The nurse told my husband that if he had had a referral letter, he would not have had to pay for the blood tests. There were too many rules at the hospital that I did not know about.” (Case 7)

The Efficiency of Health Care Services

All participants used two types of government health care service for carrier screening and identifying severe thalassemia: the provincial hospital and the community hospital. Some participants had their first antenatal care visit at a primary care unit.

The respondents in this study expressed their feelings about the health care service at the primary care units, particularly their lack of knowledge about the screening process. One woman complained about lack of knowledge of the screening process in the following terms -

“I have to meet the doctor at the community hospital for carrier screening; the nurse at the primary care unit didn’t explain clearly. She said that I could go to the hospital alone. If your blood test result is positive, your husband has to go for screening later. So I went to the hospital alone. The doctor asked me why my husband did not come. He did not give me a blood test but made an appointment for me and my husband to go for blood tests the following week. If she had explained clearly, I and my husband would have come together. It was a waste of time.” (Case 4)

Most participants complained about the services at the provincial hospital, particularly health education. Their spoke about the time for health education as follows -
“The nurse said now we have to check blood to investigate disease in pregnancy. She tells me about complications of diseases such as thalassemia, HIV and many diseases.....I don’t remember. She takes only 10 minutes to explain these diseases. I don’t understand all of it. I think it would be better if she took more time to explain.” (Case 2)

Social Problems

Social problems are an important aspect of late antenatal care, especially with teenage pregnancies. The study group selected by purposive sampling included four who were students and came late for antenatal care. Their ages ranged from 15 to 19 years. It is important to know the cause of late antenatal care in teenage pregnancies. As one said-

“I and my boy friend were studying in high school. My father and mother didn’t notice I was pregnant. Now I am around 7 months pregnant and my mother only knew from my increased abdomen. Then, she took me to antenatal care at this hospital.” (Case 3)

Parents are an important part of the support system in cases of teenage pregnancy. They play an important role in providing mental support and taking care of pregnant teenagers.

“I was very worried after I knew that I was pregnant. At first, I did not know that I was pregnant. I went to the clinic for testing, then I knew that I was around 4-5 months pregnant. I was afraid of my father and mother. I didn’t know what to say to them. I tried to tell them 2 months later. They looked so sad but they didn’t blame me and took me to a hospital for antenatal care.” (Case 5)

DISCUSSION

The present study has explored the experiences of pregnant women at risk of having children with severe thalassemia, although the findings cannot be generalized because they come from a qualitative study. The main aim of the study was to elicit a series of individual accounts regarding the impact of the thalassemia screening process and their experiences from thalassemia screening. In this study, most of the participants lived in Phitsanulok province which had a high prevalence of Hb E. This study utilized a purposive sample of 10 pregnant women diagnosed at risk of having children with severe thalassemia. Generalizability to the overall health benefit coverage of pregnant women is limited. None of the participants participated in the Civil Servant Medical Benefit Scheme.

One of the most important aspects of thalassemia regarding the pregnant women was lack of knowledge about the occurrence, condition of thalassemia disease, and genetic issues. Although some women knew about thalassemia before because as they had had a relative who had had thalassemia, it seems that they were not aware of the terrible nature of the disease. On the other hand, Phitsanulok has a high prevalence of Hb E carriers in whom the symptoms
of disease are not severe.\textsuperscript{6} This may explain why pregnant women whose relatives were thalassemia carriers did not know about the disease. When the respondents visited antenatal nurses for the first time, they received some education. It seems that they have inadequate and unclear information about thalassemia. After they screened positive for thalassemia and completed the tests, the pregnant women still needed a better understanding of the disease, its conditions, and how it can be prevented. If these needs are not clear, it causes great stress. Therefore, the decision making of pregnant women to perform tests and termination of pregnancy depend on health education from health professionals.

These findings can help all health care providers better understand how they should provide thalassemia information. Providing information for pregnant women should be used a long time, especially providing about the content of thalassaemia disease and the next step of screening process.

In this study, some pregnant women received thalassemia information from text books and newspapers. However, they did not understand about the disease. The information did not bring awareness. So policy makers should consider this issue and should create thalassemia awareness for Thai people. Useful communication methods for public awareness should include radio and television.\textsuperscript{4,8,9,11}

On the other hand, this study shows that thalassemia screening programmes cause psychological problems. Because it takes a long time to obtain test results, pregnant women and their spouses worry about the prognosis for their babies. Most pregnant women plan termination of pregnancy when their babies were severely thalassaemia because of their concern for the future of their babies. If thalassaemia babies was born, many problem become such as thalassaemia babies will receive blood transfusions. These pregnancies were terminated in spite of their Buddhist background. They would not face of the future problems.

Some participants reported the reflected which their constraints about out of pocket although their have the 30-baht health card. And some pregnant women explained reflected from benefit package under Social Security scheme when their have received thalassaemia screening process at hospital. These kinds of experiences revealed that the health care benefit package in Thailand did not operate the same standard to all people. The universal coverage scheme in from of 30-baht health card also assistance for Thai people access to care the same as the Social Security scheme also preserve for employee access to care. However, the benefit package for thalassaemia screening under the protection of two schemes is not like.

The important finding reported that the causes of late antenatal care in pregnant women is there are teenage pregnancy or their have adolescent pregnancy. The rate of teenage pregnancy in Thailand is relatively high. Around 25\% of women admitted in hospital for abortion complications are students.\textsuperscript{12}
RECOMMENDATIONS

This paper has argued that the study group participants did not know about the burden and implications of severe thalassemia although they had received health education from health care providers. Health education about the genetic transmission of thalassemia should use methods or materials effectively and conveniently to give information. Information about thalassemia should be distributed nationwide in order to help control the disease. As well, health care providers must recognize the emotions of pregnant women at risk of having thalassemic babies and initiate appropriate counselling. With regard to prevention programmes, health providers should be receiving repeat thalassemia knowledge always. Therefore, policy makers should be rethinking the benefit package for thalassemia screening so that all pregnant women in Thailand can access the thalassemia screening process. And the government should be act to prevent unplanned pregnancies in students.

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