
OBSTETRICS

Knowledge and Attitude of Pregnant Women at Risk for Having a Fetus with Severe Thalassemia After Genetic Counseling at Srinagarind Hospital

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ABSTRACT

Objectives: The primary objective was to assess the knowledge and attitude of pregnant women at risk for having a fetus with severe thalassemia after receiving genetic counseling from Maternal and Fetal Medicine Staffs at Srinagarind Hospital and the secondary objective was to analyze the factors associated with decision of prenatal diagnosis and termination of pregnancy.

Materials and Methods: Descriptive study recruited 105 pregnant women who were at risk for having a fetus with severe thalassemia after genetic counseling during September 1, 2010 to January 31, 2011. The questionnaire consisted of four parts demographic characteristics, knowledge of thalassemia, attitude towards thalassemia and factors associated with decision of prenatal diagnosis and termination of pregnancy after genetic counseling. Data analysis was done by using descriptive statistics, chi-square test and odds ratio.

Results: More than half of the participants (57.1%) had adequate knowledge of thalassemia. The three significant contributing factors of thalassemia knowledge were education level (bachelor degree) (OR 33.4, 95% CI 3.6-310.3), family income (more than 20,000 Baht/month) (OR 6.4, 95% CI 1.5-27.1) and desire to have children (unplanned pregnancy) (OR 0.3, 95% CI 0.13-0.82), ($p < 0.05$). Most of participants (85.7%) had good attitudes towards thalassemia. Ninety five percents of participants decided to have prenatal diagnosis of thalassemia when indicated and 88.0% of those accepted to terminate pregnancy if the fetuses were affected.

Conclusion: Knowledge and attitude of thalassemia in pregnant women at risk were adequate and good. Factors associated with decision of prenatal diagnosis and termination of pregnancy probably were education level, family outcome and desire to have children.

Keywords: Knowledge, Attitude, Thalassemia, Pregnant women, Genetic counseling.

Introduction

Thalassemia is the most common single-gene disorder in the world, with the highest prevalence in

Southeast Asia, where approximately 55 million are carriers⁽¹⁾. The gene frequencies of alpha-thalassemia reach 30-40% in Northern Thailand and Laos PDR,

beta thalassemia vary between 1-9%, and Hb E has a frequency of 50-60% at the junction of Thailand, Laos PDR, and Cambodia⁽²⁾. These abnormal genes in different combinations lead to severe thalassemia including three major thalassemia diseases (Hb Bart's hydrops fetalis, homozygous beta thalassemia, and beta thalassemia/hemoglobin E disease), in such a high magnitude that they pose public health problems in Thailand⁽³⁾. Forty percents of Thai people are carriers. Role of genetic counseling in increasing public awareness of thalassemia problems is the important step in prevention of severe thalassemia^(4,5). Pitchayapan S et al⁽⁶⁾ revealed that knowledge about thalassemia in pregnant women at risk was limited and misunderstanding could lead to the wrong attitude and decision of pregnancy termination.

The primary objective was to assess knowledge and attitude of pregnant women who are at risk for having a fetus with severe thalassemia after genetic counseling from Maternal and Fetal Medicine Staffs at Srinagarind Hospital and the secondary objective was to analyze the factors associated with decision of prenatal diagnosis and termination of pregnancy.

Materials and Methods

Study design

This descriptive study was conducted at the Genetic Counseling Clinic of Srinagarind Hospital, Faculty of Medicine, Khon Kaen University. The protocol was approved by the Ethical Committee on August 16, 2010 (Ethical number was HE 531200). Written informed consents were received from all participants before study. Parental consent was also needed from those under eighteen years old.

Study population

The total of 105 pregnant women at risk for having a fetus with severe thalassemia after genetic counseling from Maternal and Fetal Medicine Staffs of Srinagarind Hospital were selected randomly (opportunity sampling technique). The sample size was calculated using descriptive study formula with $p=0.48$ (derived from previous study in the same hospital)⁽⁶⁾. Inclusion criteria

was pregnant women at risk for having a fetus with severe thalassemia (carrier pregnant women) who accepted to be a part of this study. Exclusion criteria were inability to understand Thai language and the questionnaire.

Study protocol and data collection

The questionnaire was developed from previous studies^(6,7) and consisted of four parts, namely demographic characteristics, knowledge of thalassemia (16 items), attitude towards thalassemia (14 items), and factors associated with decision of prenatal diagnosis and termination of pregnancy after genetic counseling (2 items). Part with knowledge of thalassemia was further divided into four categories such as definition, treatment, effect on children and prevention. Knowledge and attitude towards thalassemia were calculated into scores by dividing the sum of the correct answers by the total items in each part. These scores were used for further comparison. Validity was tested by three experts in Maternal and Fetal Medicine. Reliability was tested (Cronbach alpha equal 0.86). Data collection was carried out from September 1, 2010 to March 31, 2011. All participants were informed about the objectives of the study. After signing the consent forms, they were asked to complete the questionnaire by themselves and ensured both anonymity and confidentiality.

Statistical analysis

Descriptive statistics were used with demographic characteristics, obstetric and gynaecologic data, scores of knowledge, scores of attitude and factors associated with the decision of prenatal diagnosis and termination of pregnancy after genetic counseling. The chi-square test and odds ratio were used for comparison. The significant level was considered at $p<0.05$. The Stata version 10.0 (StataCorp, College Station, TX) was used to calculate all statistical analyses.

Results

Mean age of participants in this study was 27.4 years (ranging from 16 to 43 years). Most of them lived in Khon Kaen (73.3%). Thirty one percent of participants

completed their bachelor degree. Thirty five percent of them were employee while 2.8% were still students (Table1). Ninety nine percent of participants were Buddhists. Of all pregnancies, 44.8% were first pregnancies and 68.6% were planned. Eighty percents of participants had no information about thalassemia before, and in those who had it, the source were mostly doctors and healthcare providers (67.6%) (Table2).

After genetic counseling, the mean score of knowledge was 11.62 ± 0.3 (score +/- standard error). Score more than 12 was considered as having adequate knowledge about thalassemia. More than half of the participants (57.1%) had adequate knowledge about thalassemia. The unknown part of information consisted mainly of diagnosis (45.6%) and symptoms of thalassemia (27.6%). There was a strong association between score of knowledge and education level ($p < 0.05$) and also between score of knowledge and desire to have children ($p < 0.05$) (Table3).

Three significant contributing factors that were identified were education level (secondary school) (OR

10.2, 95%CI 1.2-85.7) especially bachelor degree (OR 33.4, 95%CI 3.6-310.3), family income (more than 20,000 Baht/month) (OR 6.4, 95%CI 1.5-27.1) and desire to have children (unplanned pregnancy) (OR 0.3, 95%CI 0.13-0.82) were found by using univariate analysis (Table 4).

The mean score of attitude was 24.43 ± 2.83 (score +/- standard error). Score more than 22 was considered as having good attitude towards thalassemia. About 85.7% of the participants had good attitude towards thalassemia (Table5). Most of the participants (68.9%) experienced a feeling of guilt when they learnt that the fetuses they carried a risk for severe thalassemia. Ninety five percents of participants accepted for prenatal diagnosis if they had fetal risk of severe thalassemia but the rest denied citing reasons such as "fear of abortion" and "financial problems." Eighty eight percents of accepted prenatal diagnosis pregnant women decided to terminate pregnancy if the fetuses were affected. but 12% denied due to fear of sin. All participants agreed with thalassemic campaigns.

Table 1. The relationship between knowledge and demographic characteristics of participants (N=105)

	Score of knowledge				Total 105 cases	
	Adequate (60 cases)		Inadequate (45 cases)		N	(%)
	N	(%)	N	(%)		
Age (yrs.)						
<20	2	3.3	7	15.6	9	8.6
20-34	49	81.7	31	68.8	80	76.2
≥35	9	15	7	15.6	16	15.2
Education level						
Primary school	1	1.6	9	20	10	9.5
Lower Secondary school	10	16.7	14	31.1	24	22.9
Upper secondary school	10	16.7	9	20	19	18.1
Vocational	13	21.7	6	13.3	19	18.1
Bachelor degree	26	43.3	7	15.6	33	31.4
Occupation						
Housewife	10	16.7	6	13.3	16	15.2
Employee	15	25	22	48.9	37	35.2
Merchant	7	11.7	3	6.7	10	9.5
Government/officer	15	25	4	8.9	19	18.7
Business person	2	3.3	0	0	2	1.9
Agriculturalist	9	15	9	20	18	17.2
Student	2	3.3	1	2.2	3	2.9
Family income (Baht/ month)						
<1,000	3	5	3	6.7	6	5.7
1,000-10,000	24	40	26	57.8	60	57.2
10,000-20,000	19	31.7	1	2.2	22	20.9
>20,000	14	23.3	3	6.7	17	16.2

Table 2. The relationship between knowledge score and source of thalassemia informations

	Knowledge score		Total
	Adequate (60 cases)	Inadequate (45 cases)	105 cases
	N (%)	N (%)	N (%)
Unknown	9(15)	12(26.7)	21(20)
Known			
Pamphlet	35(58.3)	21(46.7)	56(53.3)
Cutout	8(13.3)	3(6.7)	11(10.5)
Newspaper	11(18.3)	10(22.2)	21(20)
Television	23(38.3)	10(22.2)	33(31.4)
Internet	18(30)	4(8.9)	22(20.9)
Doctor/healthcare providers	44(73.3)	27(60)	71(67.6)

Table3. The relationship between education level, desire to have children and score of knowledge

	Knowledge score				Total		p-value
	Adequate (60 cases)		Inadequate (45 cases)		105 cases		
	N	(%)	N	(%)	N	(%)	
Education level							0.002*
Primary school	1	1.7	9	20	10	9.5	
Lower secondary school	10	16.7	14	31.1	24	22.8	
Upper secondary school	10	16.7	9	20	19	18.1	
Vocational	13	21.7	6	13.3	19	18.1	
Bachelor degree	26	43.3	7	15.6	33	31.4	
Desire to have children							0.008*
Planned pregnancy	48	80	24	53.3	72	68.6	
Unplanned pregnancy	12	20	21	46.7	33	31.4	

p-value<0.05 is statistic significance

Table 4. The contributing factors of demographic characteristics of participants (univariate analysis)

Contributing factors	OR	95%CI	p-value
Age (yrs.)			0.070
<20	1		
20-34	5.5	1.0-28.3	
≥35	4.5	0.7-28.7	
Education			0.0002*
Primary school	1		
Secondary school	10.2	1.2-85.7	
≥Bachelor	33.4	3.6-310.3	
Family income (Baht / month)			0.02*
<10,000	1		
10,000-20,000	1.9	0.7-4.6	
>20,000	6.4	1.5-27.1	
Desire to have children			0.017*
Planned pregnancy	1		
Unplanned pregnancy	0.3	0.1-0.82	

p-value<0.05 is statistic significance

Table 5. Attitude toward thalassemia of participants

	Total 105 cases	
	N	(%)
Good attitude (score more than 22)	90	85.7
Bad attitude (score less than 22)	15	14.3

Discussion

According to the policy announcement in 2005 for health promotion, prevention and control of thalassemia diseases, all participants can access basic health right followed by basic right of health insurance policy for better health, safety and well-being of infant and mother during childbearing⁽⁷⁾. Pitchayaphan S et al⁽⁶⁾ studied about attitude towards thalassemia among adult women who were ill or carriers and reported good level of attitude while knowledge of control and prevention were still needed. Karnchanatit D⁽⁸⁾ reported the similar opinion on control and prevention of thalassemia program among carrier pregnant women. The sample group agreed that it was difficult to

understand thalassemia and only a few talked about benefit of carrier screening.

This study found that just more than half of participants had adequate knowledge about thalassemia after genetic counseling. Education level and desire to have children appeared to have an effect in knowledge about thalassemia. People with higher level of education are more likely to undertake self-care than those with lower level. Junsri M⁽⁹⁾ found that education level has a significant relationship with knowledge and understanding of pregnant women towards using mother and child handbook.

A study conducted by Pitchayaphan S et al⁽⁶⁾ about the knowledge and attitude of women with

thalassemic disease or who were carriers and who visited the Obstetrics and Gynaecology Clinic found that only 40% had knowledge about thalassemia but they had good attitude towards the disease. The findings differ from this study as the latter showed more than half of participants had an adequate level of knowledge of thalassemia. Wiwatpattanakul K et al⁽¹⁰⁾, however, found that genetic counseling was effective in increasing the knowledge of thalassemia ($p < 0.05$) but not in changing attitude towards it. The findings regarding the knowledge about thalassemia is consistent with this study and also with the study conducted by Wongkham J et al⁽¹¹⁾.

Pregnant women with higher education level and family income had an ability to retain knowledge after genetic counseling better than those with lower education and those who had planned pregnancy showed adequate knowledge more than those who had unplanned pregnancy (Table 4). If couples have adequate knowledge before pregnancy, there is a better chance of thalassemia prevention and control.

More than 80.0% of participants in this study had good attitude toward thalassemia although more than half of them felt guilty. Sopajaree C et al⁽¹²⁾ who studied about the anxiety of parents having high risk of giving birth to a disabled child in primigravida, reported the similar results. They were these parents felt happy when they learnt about the pregnancy but were confused, shocked, in fear and experienced anxiety when they knew that this pregnancy bore certain risk. According to Jetsrisuparb A et al⁽¹³⁾ who studied about thalassemia in patients and their parents, only 49.6% of the mothers with a thalassemic child knew about this disease from before and most of them would accept termination of pregnancy if they knew that they were at risk for having a child with thalassemia. Although this suggests lesser knowledge as compared to the current study, the presence of some participants not agreeing to termination of pregnancy for fear of sin is consistent in both studies. This study could not statistically analyze factors associated with the decision of prenatal diagnosis and termination of pregnancy due to small sample sizes of denied prenatal diagnosis group (4.8%) but education level, family income and decided to have

children (planned pregnancy) probably were those factors. Thailand, as a developing country, should aim to prevent thalassemia disease by supporting expenses in carrier screening and prenatal diagnosis for high-risk couples, which ultimately leads to global cost-effectiveness⁽¹⁴⁾.

All participants concerned about the problem of thalassemia and wanted the government to conduct a thalassemia campaign by using various media.

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ความรู้และทัศนคติของสตรีตั้งครรภ์ที่เสี่ยงต่อการมีทารกในครรภ์เป็นโรคธาลัสซีเมียชนิดรุนแรงหลังการให้คำปรึกษาทางพันธุศาสตร์ที่โรงพยาบาลศรีนครินทร์

สุรางรัตน์ เป็อยศรี, ปิยะมาศ ศักดิ์ศิริวุฒโฒ, ถวัลย์วงศ์ รัตนศิริ

วัตถุประสงค์: เพื่อศึกษาความรู้และทัศนคติของสตรีตั้งครรภ์ที่เสี่ยงต่อการมีทารกในครรภ์เป็นโรคธาลัสซีเมียชนิดรุนแรงหลังการให้คำปรึกษาทางพันธุศาสตร์โดยสูติแพทย์ผู้เชี่ยวชาญด้านเวชศาสตร์มารดาและทารกในครรภ์ที่โรงพยาบาลศรีนครินทร์ และปัจจัยที่มีผลต่อการตัดสินใจในการวินิจฉัยก่อนคลอดและการยุติการตั้งครรภ์

วัสดุและวิธีการ: เป็นการศึกษาเชิงพรรณนา โดยผู้เข้าร่วมการวิจัยจำนวน 105 ราย เป็นสตรีตั้งครรภ์ที่มีความเสี่ยงต่อการมีทารกในครรภ์เป็นโรคธาลัสซีเมียชนิดรุนแรงหลังการให้คำปรึกษาทางพันธุศาสตร์ระหว่างวันที่ 1 เดือนกันยายน พ.ศ. 2553 ถึงวันที่ 31 เดือนมกราคม พ.ศ. 2554 ซึ่งแบบสอบถามประกอบด้วย 4 ส่วนได้แก่ ข้อมูลประชากร ความรู้เกี่ยวกับโรคธาลัสซีเมีย ทัศนคติเกี่ยวกับโรคธาลัสซีเมีย และปัจจัยที่มีผลต่อการตัดสินใจในการวินิจฉัยก่อนคลอดและการยุติการตั้งครรภ์หลังการได้รับคำปรึกษาทางพันธุศาสตร์ การวิเคราะห์ข้อมูลทางสถิตินำเสนอด้วยร้อยละ ค่าเฉลี่ย chi-square test และ odds ratio

ผลการศึกษา: มากกว่าครึ่งหนึ่งของผู้เข้าร่วมการวิจัยมีความรู้ที่เพียงพอเกี่ยวกับโรคธาลัสซีเมีย (57.1 %) มีสามปัจจัยที่มีผลต่อความรู้เรื่องโรคธาลัสซีเมีย ได้แก่ ระดับการศึกษา (ระดับปริญญาตรี) (OR 33.4, 95%CI 3.6-310.3) รวมถึงรายได้ครอบครัว (มากกว่า 20,000 บาทต่อเดือน) (OR 6.4, 95%CI 1.5-27.1) และความต้องการมีบุตร (การตั้งครรภ์ที่ไม่ได้วางแผน) (OR 0.3 95%CI 0.1-0.82) ($p < 0.05$) ร้อยละ 85.7 มีทัศนคติที่ดีต่อโรคธาลัสซีเมีย ร้อยละ 95.2 ตัดสินใจตรวจวินิจฉัยก่อนคลอดหากมีข้อบ่งชี้ และร้อยละ 88.0 ของกลุ่มนี้ยินยอมยุติการตั้งครรภ์ ถ้าพบว่าทารกในครรภ์เป็นโรคธาลัสซีเมียชนิดรุนแรง

สรุป: ระดับความรู้และทัศนคติต่อโรคธาลัสซีเมียของสตรีตั้งครรภ์ที่มีความเสี่ยงอยู่ในระดับที่เพียงพอและดี ส่วนปัจจัยที่สัมพันธ์กับการตัดสินใจในการวินิจฉัยก่อนคลอดและการยุติการตั้งครรภ์คือระดับการศึกษา, รายได้ของครอบครัว และความต้องการมีบุตร

