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Thai pregnant women knowledge and attitudes about maternal serum screening for Down's syndrome

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ABSTRACT

Objective To study the knowledge and the attitude about maternal serum screening for Down's syndrome in Thai pregnant women.

Study design Cross-sectional descriptive study.

Setting Department of Obstetrics and Gynecology, Faculty of Medicine, Chiang Mai University.

Subjects 242 pregnant women who were 18 years or older, with a singleton live fetus and gestational age of 10 through 21 weeks. All of them attended antenatal clinics between 1 January and 30 April 2007.

Methods An experimental maternal serum screening program offered to pregnant women, together with a series of questionnaires to be completed before and after the counseling.

Main outcome measure Women's knowledge and understanding of prenatal screening test; attitude towards screening offer; perceive freedom of choice and satisfaction with information given.

Results Ninety-seven percent of women accepted the offer of maternal serum screening. Most of women had previous knowledge of Down's syndrome, whereas there are limitations in knowledge of maternal serum screening and diagnostic tests. Almost (80%) of them considered the information given before screening was clear and sufficient for decision making. Fifty-three percent of women felt worried to some extent after being given the information. The majority of women showed a positive attitude towards the offer of maternal serum screening. Eighty-seven percent of women agree that information on Down's syndrome screening should be extended to all pregnant women.

Conclusion Maternal serum screening was well accepted after the counseling, although the pregnant women had limited understanding. Majority of women were satisfied with this offering. However effective and clear communication are needed.

Keywords: maternal serum screening, Down's syndrome, patient knowledge, patient attitudes

Introduction

Down's syndrome is the most common cause of mental retardation with an incidence of approximately 1 in 660 live births.[1] In Thailand the incidence of Down's syndrome is about 1,000 live births per year.[2] The risk of Down's syndrome birth

increasing by maternal age from 1:900 at 30 years to 1:100 at 40 years.[3]

Because of the known association between maternal age and Down's syndrome, invasive prenatal diagnosis by amniocentesis, cordocentesis and later by chrionic villus sampling, was initially offered only to women older than 35 years of age. This strategy detected only 30% of all Down's syndrome pregnancies, because the majority of such pregnancies are in younger women.[4] This limitation was because of the small but significant risk of miscarriage associated with these procedures, therefore, invasive prenatal test would not typically be offered to all pregnant women. Other methods of prenatal screening tests were developed for identify a subgroup of women who may be at the higher risk of carrying a fetus with a Down's syndrome. Maternal serum screening for Down's syndrome and individual risk associated with age are corrected using a factor related to serum marker concentrations. In 1988, Wald et al proposed a triple test, in the second trimester, a range of maternal serum alpha-fetoprotein (AFP), unconjugated estriol (uE3) and human chorionic gonadotropin (hCG). Triple test is based on a composite likelihood ratio determined by levels of all three analyses. The maternal age-related risk was multiplied by this ratio. At a 5% false positive rate, the Down's syndrome detection rate is 60% in women younger than 35 years.[5] By the 1990s, using Quadruple test, base on the measurement of AFP, uE3, βhCG and inhibin A together with maternal age, were achieving detection rates of about 80% for 5% false-positive rate.[6,7] The development of first trimester test based on free βhCG and pregnancy associated plasma protein A (PAPP-A) and maternal age, increase detection rates to 85% for 5% false positive rate. Screening performance was improved, if combine the nuchal translucency (NT) measurement and maternal serum markers.

Currently, some centers of Health-care units in Thailand, biochemical screening of metabolites in maternal blood was introduced to refine the risk of Down's syndrome and to target at risk pregnancies across all maternal age groups. The success of any screening program depends also on the knowledge, the willingness of women to participate and on their attitudes toward it. The purpose of this study is to study the knowledge and the attitude about maternal serum screening for Down's syndrome in Thai pregnant women.

Methods

This study was conducted at antenatal clinic of Maharaj Nakorn Chiang Mai Hospital from January to April 2007. It was approved by the research Ethics Committee, Faculty of Medicine, Chiang Mai University, and the participants gave written informed consent. The inclusion criteria were the women of 18 years old or older, pregnancy with singleton live fetus and gestational age of 10 through 21 weeks at study entry and understanding of the Thai language. Women were excluded from the study if fetal abnormality was diagnosed or incomplete questionnaire answering.

Maternal serum screening was offered and explained to the participants by a standardized oral explanation given by the counselor. The information included characteristics and risks of Down's syndrome, characteristics and procedure of the screening test offered, the possible test results, the options available after a positive test, the characteristics and procedure of prenatal diagnosis testing. The participating pregnant women were requested to fill in two self completion questionnaires. The first questionnaire handed before the offer of the test was made. This questionnaire assessed demographic characteristics, background knowledge on Down's syndrome, risk factors, screening and diagnosis testing. The second questionnaire had to be filled after receiving information, but before the test (if accepted) was performed. There were two sections of the second questionnaire. The first section intended to assess knowledge after receiving information from counselor, comprised 15 questions same as first questionnaire. The second sections covered the attitude to the unsolicited offer of maternal serum

screening, the perceived degree of freedom in the decision whether or not to be screened and anxiety raised by offering. Other covered issues were: the reasons for opting in or out of screening. Following completion of the second questionnaire, maternal serum screening was performed on the acceptors.

Statistical Analysis

Descriptive statistics were used to describe the women's knowledge and report their preference for maternal serum screening test. The difference of the knowledge before and after the counseling was compared using Wilcoxon Signed-rank test. A significant level of 5 percent was used. All data were analyzed by using SPSS software version 15.0 (Chicago, USA).

Results

Two hundred and fifty initial questionnaires were handed out. All of these were returned. Eight were excluded because of the answering of the questionnaire was incomplete. The final study sample comprised 242 women whose age, parity and education are reported in Table 1. All the women also completed the second questionnaire. Thirty-nine women (16.1%) were 35 years or older. One hundred and six (43.8%) were nulliparous. One hundred and eighty six women (69%) had completed senior high school or more. Almost of the women (76%) had heard of Down's syndrome. Source of information mentioned by some women included medical or midwifery staff (133); friend (43); Media (115) such as television, magazine, internet; experience from previous pregnancy.[8]

Knowledge and understanding of information

Table 2 describes women's prior knowledge of Down's syndrome, risk factors, screening techniques and of the availability of invasive testing. Seventy-six percent of the women knew that Down's syndrome was chromosomal abnormality. Most of them were aware of the associated with physical and intellectual handicap. Women apparently understood the chance of having a baby with Down's syndrome was higher in the older mother. But 86% thought that risk extremely low if in the family with negative history for Down's syndrome. Only a minority of women were aware of the miscarriage risk of Down's syndrome pregnancy was higher than normal. The understanding of the concept of screening, before receive explaination by counselor, had limited. The knowledge of Down's syndrome and available tests after informed are significant increase (Table 3). Overall, the women had good knowledge of Down's syndrome, risk factors and miscarriage risk for diagnostic procedure. Nevertheless, only half of women understanding of the difference between a screening test and a diagnostic test. Question on the meaning of a positive screening result were answered correctly by 31.4 - 54.1% of women.

Acceptance of screening

237/242 (97.9%) women accepted the offer of maternal serum screening. The main reasons for accepting or declining screening are reported in Table 4. The primary reason cited by younger women was wanted to assess the risk (93.5%). The next important reason was receiving advice from medical or midwifery staff (80.9%). Some women (30.8%), wanted to be able to prepare themselves for carrying a child with Down's syndrome. Women aged 35 and older often accepted screening because receiving advice (92.1%). Only 8 women (21.1%) accepted screening in the hope of avoiding invasive testing if the new maternal serum screening based risk was reassured.

Decline of screening offer

5/242 (2.1%) declined maternal serum screening. More than half of them (60%) would not undergo invasive testing if their risk was increased. Other reason for declining was rejection of any interference with the pregnancy.

Women's reaction to screening offer

In general women showed a positive attitude towards the offer of maternal serum screening for

Down's syndrome. The information given was perceived as clear and sufficient by most women (80%) and it was new to almost (88%) of them (Table 5). Fifty-six percent of the women had felt no need for screening before the program offering; 53% felt worried after receiving information on Down's syndrome and screening. Although 21% of the women accepting screening considered the very decision to accept or refuse were difficult, 52% disagreed with the statement "I wished that someone else could decide for me". However almost (91%) of women choosing maternal serum screening felt comfortable with given opportunity of screening (Table 6). Younger women who accept screening were also more often inclined to invasive testing if risk for Down's syndrome was increased (78%) and frequently thought they would terminate the pregnancy in case of Down's syndrome (74%). In this study, only 2.1% of all women decline screening, all of them felt more or less forced to participate in maternal serum screening. The majority of women (92%) agreed with the statement that "all women should be informed on Down's syndrome screening and be able to decide for themselves". Almost (87%) of them prefer maternal serum screening should be offered to all pregnant women.

Table 1. Characteristics of the women (n=242)

Category	Number	% of women
Maternal age		
-Mean $\pm$ SD = 29.64 +/-5.359years		
-Age < 30 years	119	49.2
-Age 30-34 years	84	34.7
-Age ≥ 35 years	39	16.1
Primigravida	106	43.8
Previous miscarriage	63	26.0
Previous delivery	106	43.8
Education		
-No qualification	2	0.8
-Elementary education	21	8.7
-Junior high school	51	21.1
-Senior high school	52	21.5
-Undergraduate	23	9.5
-Graduate	76	31.4
-Postgraduate	17	7.0

Table 2. Women's knowledge of Down's syndrome, risk factors and prenatal testing before and after counseling.

Questions	Correct answer (%)	
	Before	After
Down's syndrome is a chromosome abnormality[a]	76.0	97.5
Major cause of child with Down's syndrome is chromosome 21 abnormality[a]	52.9	96.3
Children with Down's syndrome have normal feature	69.8	87.2
Children with Down's syndrome have multiple malformations[a]	74.4	94.6
All children born with Down's syndrome have mental impairment[a]	74.8	97.9
Children with Down's syndrome can not learn in school placement	61.6	78.1
The risk of miscarriage of a Down's syndrome pregnancy was higher than normal[a]	20.7	28.5
The chance of having a baby with Down's syndrome is higher in the older mother[a]	75.2	93.0
If family history for Down's syndrome negative, risk extremely low	14.0	57.4
A previous baby with Down's syndrome increases the risk of Down's syndrome[a]	46.3	93.0
It is possible to have a risk assessment for Down's syndrome by maternal serum screening[a]	59.9	93.0
Maternal serum screened positive result means that the baby is definitely suffering from Down's syndrome	8.3	31.4
A maternal serum screened can detect all babies has Down's syndrome	16.1	54.1
Amniocentesis or Chorionic Villus Sampling can tell for sure if baby has Down's syndrome[a]	57.4	97.5
Amniocentesis or Chrorionic Villus Sampling have the risk for fetal loss[a]	43.8	98.3

[a] Correct statement

Table 3. score at pre-counseling and post-counseling. (n=242)

Questions	Pre-counseling (point)	Post-counseling (point)	P-value
Domain: Characteristics of Down's syndrome (Questions 1-7)	4.30	5.80	<0.05*
Domain: Risk factors of Down's syndrome (Questions 8-10)	1.36	2.04	<0.05*
Domain: Maternal serum screening (Questions 11-13)	0.84	1.78	<0.05*
Domain: Diagnostic test (Questions 14-15)	1.01	1.95	<0.05*

* $P < 0.05$: statistically significant

Table 4. Most important reasons for accepting maternal serum screening.

Reasons for accepting	Total n (%)	Maternal age	
		<35 n (%)	≥35 n (%)
- Receiving advice from medical or midwifery staff	196(82.7%)	161(80.9%)	35(92.1%)
- Wanting risk assessment	217(91.6%)	186(93.5%)	31(81.6%)
- Trying to avoid invasive testing with reassuring serum screening	60(25.3%)	52(26.1%)	8(21.1%)
- Worried and not having the option of invasive testing	68(28.7%)	57(28.6%)	11(28.9%)
- Wanting to prepare for Down's syndrome child	73(30.8%)	61(30.7%)	12(31.6%)
- Other reasons	4(1.7%)	2(1%)	2(5.3%)

Table 5. Reaction of women to screening offer and acceptance of maternal serum screening, comparison in difference age groups. (Total n=242)

	Age < 35 years old (n=203)			Age ≥ 35 years old (n=39)			
	Agree (%)	Neutral (%)	Disagree (%)	Agree (%)	Neutral (%)	Disagree (%)	Total agree (%)
Information on MSS clear	81.3	14.3	4.4	74.4	15.4	10.3	80.2
Information on DS and MSS new	88.2	7.9	3.9	87.2	10.3	2.6	88.0
Prior to offer MSS no need for screening	60.6	21.2	18.2	35.9	17.9	46.2	56.6
Worried by information on DS and MSS	52.7	26.6	20.7	53.8	15.4	30.8	52.9
Comfortable with possibility of MSS	91.6	6.9	1.5	89.7	7.7	2.6	91.3
Don't mind being informed on DS and MSS	23.6	12.8	63.5	28.2	7.7	64.1	24.4
Difficult to decide on MSS	20.2	26.1	53.7	25.6	5.1	69.2	21.1
Wish someone else could decide for me	33.5	17.7	48.8	20.5	10.3	69.2	31.4
Will have invasive testing if risk is increase	75.9	22.7	1.5	89.7	2.6	7.7	78.1
Would probably terminate if DS is diagnosis	74.4	21.2	4.4	79.5	5.1	15.4	75.2
Feel more or less forced to participate in MSS	84.7	14.3	1.0	84.6	0	15.4	84.7
Content made regarding MSS	95.6	4.4	0	84.6	2.6	12.8	93.8
Unsolicited offer of MSS is unacceptable	60.6	18.2	21.2	79.5	10.3	10.3	63.6
All women should be informed and decide for themselves	93.1	4.4	2.5	89.7	5.1	5.1	92.6
MSS should be offered to all pregnant women	86.7	10.8	2.5	89.7	5.1	5.1	87.2

MSS = maternal serum screening

DS = Down's syndrome

Table 6. Reaction of women to screening offer and acceptance of maternal serum screening, comparison in difference attitudes (Total n=242)

	Accept screening (n=237)			Decline screening (n=5)			Total agree (%)
	Agree (%)	Neutral (%)	Disagree (%)	Agree (%)	Neutral (%)	Disagree (%)	
Information on MSS clear	80.2	14.3	5.5	80.0	20.0	0	80.2
Information on DS and MSS new	88.6	7.6	3.8	60.0	40.0	0	88.0
Prior to offer MSS no need for screening	57.0	19.8	23.2	40.0	60.0	0	56.6
Worried by information on DS and MSS	53.2	24.5	22.4	40.0	40.0	20.0	52.9
Comfortable with possibility of MSS	92.4	5.9	1.7	40.0	60.0	0	91.3
Don't mind being informed on DS and MSS	24.9	11.4	63.7	0	40.0	60.0	24.4
Difficult to decide on MSS	21.1	21.5	57.4	20.0	80.0	0	21.1
Wish someone else could decide for me	31.6	16.0	52.3	20.0	40.0	40.0	31.4
Will have invasive testing if risk is increase	78.1	19.4	2.5	80.0	20.0	0	78.1
Would probably terminate if DS is diagnosis	75.5	18.1	6.3	60.0	40.0	0	75.2
Feel more or less forced to participate in MSS	84.4	12.2	3.4	100	0	0	84.7
Content made regarding MSS	94.1	3.8	2.1	80.0	20.0	0	93.8
Unsolicited offer of MSS is unacceptable	65.0	16.0	19.0	0	60.0	40.0	63.6
All women should be informed and decide for themselves	92.8	4.2	3.0	80.0	20.0	0	92.6
MSS should be offered to all pregnant women	87.8	9.7	2.5	60.0	20.0	20.0	87.2

Discussion

To our knowledge this is the first study to assess knowledge and attitude to maternal serum screening for Down's syndrome of Thai pregnant women. In this study the authors present the views and reactions of low risk pregnant women to the unsolicited offer of maternal serum screening for Down's syndrome, in a context where maternal age-based screening is the standard. A concern during screening program development was that women needed to fully understand the nature of Down's syndrome, the characteristics and implication of the test so that they could make appropriate, informed choices about having the test.

The authors were surprised that most of the participants (76%) knew that Down's syndrome was a chromosomal abnormality and aware of the associated with physical and intellectual handicap. It might be contaminated through the process of recruitment. There are limitations in knowledge of maternal serum screening and diagnostic test. S. Mulvey et al.[8], has previously shown that Australian women, overall of them had very limited prior knowledge of Down's syndrome and the potential screening and diagnostic tests that are available. As anticipated, after all women were given

information by counselor, the women had better knowledge of Down's syndrome, risk factors and miscarriage risk for diagnostic procedure. Nevertheless the women still appeared to have little knowledge of screening and diagnostic tests, which is similar to reports by others.[8,9]

The majority of women showed positive attitudes towards the offer of maternal serum screening and were in favor of its standard offer. As report by Roelofsen et al.[10], many women were in favor of the possibility of serum screening and would apply for this test in future pregnancy. Uptake of screening in the present study was very high (97%). However, high uptake rate must be interpreted with caution because it is known that multiple factors influence the way women feel about and response to the offer of prenatal screening. Social and personal factors interact in a complex way[11], weighing differently for each woman and influencing uptake. The reasons cited by younger women were the wanting to assess risk (93.5%) and receiving advice from medical or midwifery staff (80.9%). High uptake of prenatal blood tests suggests that women were vulnerable to the compliant behavior and need more information. Many women may choose screening if doing so was perceived to be normal.[12] In this study uptake of screening in younger women was 80.9% and 78.4% of these women indicated they will have invasive testing if screening is positive. The maternal serum screening test is often seen as a means of reassurance or as the obvious thing to do since it is offered. In this study women aged 35 and older often accepted screening because receiving advice (92.1%). Only 21% of these women accepted screening in hoping to avoid invasive procedure. This means that it may be not possible to drop out elderly indication for chromosome study.

In the present study uptake of screening was 97% and 74% of them agree with the statement "I would probably terminate the pregnancy if Down's syndrome is found". Thirty percent of women accepting screening stated they would like to prepare themselves for a baby with Down's syndrome, but in other study, when faced with the diagnosis, most women choose to terminate the pregnancy.[13]

In the present study counseling before testing appear adequate. The information given was perceived as clear and insufficient by most women (80%). However, of those accepting; 2.5% declined to invasive testing if risk of Down's syndrome was increase and 19% of them not to be certain. Although 21% of them considered the decision to accept or refuse is difficulty. A lack of understanding of the consequence of screening was reported previously in relation to maternal AFP testing[14] or Down screen.[15] Nonetheless, the decision to undergo prenatal screening should made by women only after they have received adequate counseling and information.[16] Health professionals will present prenatal screening test in ways that will lead to informed decision making by patients. Informing women about Down's syndrome and screening in general did cause some worries. In our study 53% of the women felt worried after receiving information on Down's syndrome and screening. However, the opportunities to make individual decisions still have benefit outweighed by the worrying effect of the information received.

In conclusion, in a country like Thailand, where screening is not part of routine prenatal care, women seem had limited knowledge of maternal serum screening and diagnostic tests for Down's syndrome. However the understanding can be improved with pre-test counseling and show a positive attitude towards it. Although women are generally in favor of the routine offer of screening, it remains a challenge for health professionals how to present maternal serum screening tests in ways that will lead to correctly informed decision making by patients. This will have important implications for the organization and structuring of our national service policy.

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ความรู้และทัศนคติของสตรีตั้งครรภ์ไทยต่อการตรวจคัดกรองการตั้งครรภ์ทารกกลุ่มอาการดาวน์ด้วยวิธีการตรวจสารชีวเคมีในซีรั่มมารดา

มนัสวี มะโนปัญญา, ชเนนทร์ วนาภิรักษ์

วัตถุประสงค์ *: เพื่อศึกษาระดับความรู้และทัศนคติเกี่ยวกับกลุ่มอาการดาวน์และการตรวจคัดกรองการตั้งครรภ์ทารกกลุ่มอาการดาวน์ด้วยวิธีการตรวจสารชีวเคมีในซีรั่มมารดาของสตรีตั้งครรภ์ไทย*

วิธีการศึกษา *: ให้ผู้เข้าร่วมวิจัยตอบแบบสอบถามก่อนและหลังจากรับฟังการให้คำปรึกษาแนะนำเรื่องการตรวจคัดกรองการตั้งครรภ์กลุ่มอาการดาวน์ด้วยวิธีการตรวจสารชีวเคมีในซีรั่มมารดา*

ผลการวิจัย *: ร้อยละ 97 ของผู้เข้าร่วมวิจัยตัดสินใจเข้ารับการตรวจคัดกรองการตั้งครรภ์ทารกกลุ่มอาการดาวน์ด้วยวิธีการตรวจสารชีวเคมีในซีรั่มมารดา, ผู้เข้าร่วมวิจัยส่วนใหญ่มีความรู้เกี่ยวกับกลุ่มอาการดาวน์ แต่ขาดความรู้เรื่องการตรวจคัดกรองด้วยวิธีการตรวจสารชีวเคมีในซีรั่มมารดาและการตรวจวินิจฉัยการตั้งครรภ์ทารกกลุ่มอาการดาวน์, ร้อยละ 80 ของผู้เข้าร่วมวิจัยมีความเห็นว่าข้อมูลที่ได้รับจากการให้คำปรึกษาแนะนำชัดเจนและเพียงพอสำหรับการตัดสินใจ, ร้อยละ 53 ของผู้เข้าร่วมวิจัยรู้สึกวิตกกังวลภายหลังจากได้รับข้อมูลเพิ่มเติม, ผู้เข้าร่วมวิจัยส่วนมากมีทัศนคติที่ดีต่อการตรวจคัดกรองการตั้งครรภ์ทารกกลุ่มอาการดาวน์ด้วยวิธีการตรวจสารชีวเคมีในซีรั่มมารดา และร้อยละ 87 ของผู้เข้าร่วมวิจัยมีความเห็นว่าสตรีตั้งครรภ์ทุกคนควรได้รับการให้คำปรึกษาแนะนำเรื่องการตรวจคัดกรองการตั้งครรภ์ทารกกลุ่มอาการดาวน์ด้วยวิธีการตรวจสารชีวเคมีในซีรั่มมารดา*

สรุป *: การตรวจคัดกรองการตั้งครรภ์ทารกกลุ่มอาการดาวน์ด้วยวิธีการตรวจสารชีวเคมีในซีรั่มมารดา เป็นที่ยอมรับภายหลังการให้คำปรึกษาแนะนำ แต่สตรีตั้งครรภ์ส่วนใหญ่ยังขาดความรู้และความเข้าใจเกี่ยวกับการตรวจคัดกรอง อย่างไรก็ตามการให้คำปรึกษาแนะนำที่มีประสิทธิภาพจะนำไปสู่การตัดสินใจเข้ารับการตรวจด้วยตัวผู้ป่วยเอง*