Journal of Science, Technology, and Humanities : 2014, Vol. 12, No. 1 pp. 65-73

PSYCHOSOCIAL ASPECT FROM THALASSEMIA SCREENING TEST OF ACTIVE-REPRODUCTIVE PEOPLE IN TUNGSUKHLA SUBDISTRICT, SI RACHA DISTRICT, CHON BURI PROVINCE, THAILAND.

Suwanna Junprasert[1*] and Anna Sumano[2]

[1] *Community Nursing Division, Faculty of Nursing, Burapha University, Chon Buri 20131, Thailand.*
[2] *Laem Chabang Hospital, Chon Buri 20230, Thailand.*

ABSTRACT

This study was aimed to study the psychosocial aspect of active-reproductive people who came for a thalassemia-screening test during 2012 at Laem Chabang Hospital, Si Racha District, Chon Buri Province, Thailand. The psychosocial factors were investigated and analyzed against selected factors. One hundred and forty seven active-reproductive people selected by simple random sampling were used as samples for the thalassemia-screening test, where the specialist pediatrician gave them a counseling when they came to follow-up the results. Self-directory questionnaires were used for data collection. The questionnaires consisted of two parts dealing with personal and psychosocial aspect data, which were developed by researchers. Data were analyzed by using descriptive statistics, exploratory factor analysis, and Mann-Whitney U test.

It was found that the thalassemia-screening test yielded 35.1% of trait and 1.7% of disease. The hereditary group with trait and disease gene in the positive-test samples felt moderately frightened with doubts and anxiety. The body appearance of the positive group of participants was moderately healthy, whereas the normal group of participants felt relief at moderate levels, but still had slight feelings of doubt, fear and anxiety, while the body appearance was strongly healthy.

The factor analysis found that 68.08 % were related to three factors of psychosocial aspects, i.e., factor 1, which consisted of 13 items that related to "bad feeling", factor 2, which consisted of seven items that related to "poor health", and factor 3, which consisted of three items that related to the body appearance "look blue". The comparisons regarding to the three factors of psychosocial aspect between the hereditary group and the normal group were statistically significant different at the level $p < 0.05$.

Keywords: Screening test, thalassemia, carrier, trait, and active-reproductive people.

*Corresponding author. E-mail address: suwanna@buu.ac.th

INTRODUCTION

Thalassemia are the most common forms of inherited autosomal recessive blood disorders that have a highly prevalent rate worldwide, especially in the west Pacific, northern European, and several countries in the eastern Asia, i.e., China, Vietnam, the Philippines, Malaysia, Cambodia, India, Afghanistan, Pakistan, Myanmar, and Thailand (Chetsreesupha, 2009; Langlois et al, 2008). It has been documented that approximately one percentage of the population live with thalassemia, that is about 630,000 persons in total for the whole country, and 30% - 40% of people carry autosomal recessive blood disorders gene, and thalassemia traits or carriers that can transfer their genetics to newborns. If spouses of marry couples, which are carriers of the same type of thalassemia gene are conceived, there is a chance of one in four that a child would be afflicted with the disease. The estimate risk rate of newborn with serious disease is 195.3 per 10,000 pregnancies (Lertruangpanya, 2008). It is a very suffering problem for not only the patient and family, but also contributed to high costs of care, social stigma, and very difficult to manage because there are seriously complicated characteristics to understand (Chetsreesupha, 2009).

The strategies for the management of thalassemia is focused mainly on prevention and control transferred. There are several important ways for controlling thalassemia, i.e., by informing people about the disease, give counseling for carriers, and do the prenatal screening test for new cases. The Thai national health policy and program has been set up for activities in prevention and control from 1997 to 2002, where it focuses to reduce the number of birth with serious type of disease, i.e., Hb Bart's hydrops fetalis, homozygous β-thalassemia, β-thalassemia/Hb E, and also emphasizes on the quality care for those with the disease. The Ministry of Public Health has established and supported health education in secondary school student projects, and a test for screening carrier of pregnancies in antenatal care clinic. If a pregnant woman is found to be a carrier, their couple will be tested for thalassemia (Junprasert et al., 2011; Voramongkol, 2001; Wanapirak et al., 2011).

In general, it is considered that the screening program in pregnant women may be too late for prevention and control genetic disease, because the infant may be already received the gene from the parents. It had been shown that under conditions of positive outcomes of the screening test and advanced investigation, there was fetal genetic illness in uterus, in which the parents must choose to continue the pregnancy period with suffering from the hereditary illness of newborn, or make a decision for the therapeutic abortion option with ethical conflict (Massarik and Kaback, 1981). As a result, some organizations' policies are trying to do early screening test in order to look for carrier before starting the pregnancy, such as the Laem Chabang Hospital's screening carrier project for adolescences in school that carried out in 2011, and the project for the reproductive people in the community in 2012, at Tungsukhla Sub-district, Si Racha District, Chon Buri Province, Thailand. The main objective of blood test was for screening of carriers before starting the pregnancy, with an aid of genetic counseling and an appropriate family planning. On the other hand, there is a possibility for the stigmatization of the psychosocial factors that affect those people with inherited gene.

It has been shown that several psychosocial factors (Aydin et al., 1997; Jain et al., 2013; Khurana et al., 2009) can affect thalassemia patients, resulting in having a lot of physical lesion, psychological burden on the patients and their families, social problems, and stigmatization. It brings along feelings of being different and inferior with consequent loss of self-esteem and increased dependence. The signs and symptoms of thalassemia are exhibited as specific facial characteristics, yellow-back skin color because of iron-anemia overload, deformity short stature and delayed puberty.

There is little information regarding the screening test in order to look for people with thalassemia or carriers, resulting in not having enough information to make a decision for the project of blood test to screen for carriers in students or in adolescents.

Mitchell et al. (citing in McCabe and McCabe, 2004) had addressed a long-standing screening program for Tay-Sachs disease and beta-thalassemia among high school students in Montreal, Canada. That program offered carrier testing and used the information in their reproductive decision-making. Some countries have policies related to newborn screening in order to find a model for all of genetic screening. However, since carrier–status will not be useful to them until they reach reproductive age, the American Academy of Pediatrics (AAP) Committee on Bioethics have argued against carrier testing in individuals under 18 years of age, unless pregnant or planning a pregnancy. This argument is also stressed the importance of genetic counseling before and after the test (McCabe and McCabe, 2004).

Therefore, the purpose of this study was aimed to determine several factors, i.e., the feeling, self-appearance, changes in daily living life style, and opinions regarding the screening test for carriers in the active-reproductive people who were the target groups of screening of Laem Chabang Hospital's Project. An analysis of all synthesized factors of elements would be done to compare the psychosocial aspect of each factor between normal and hereditary groups for the validity test. Results derived from the study would be valuable in the planning of prevention and control of Thalassemia not only for active-reproductive people in this area but also for others.

METHODOLOGY

Participants

One hundred and seventy four participants were selected by simple random sampling technique from 270 active-reproductive people who came to follow-up results of a test for screening of thalassemia or carriers and received a counseling from the specialist pediatrician in Tungsukhla Subdistrict, Si Racha District, Chon Buri Province, Thailand in financial year 2012. Eligible participants were approached and informed about purposes, procedures, benefits of the study, and protection of human subjects. They were agreed to participate in this research project.

The sample size was calculated using Yamane's formula (1960) by assuming 10% level of missing data questionnaires at a confidence level of 95%, and tolerated a difference of 0.05. That estimated numbers were more than three times of variables that used for factor analysis (Knapp and Brown, 1995 cited in Munro, 2001, p. 310). The subjects were simple random sampling using their names that registered to receive the screening result.

Instrument. The self–administered questionnaire used for the data collection was consisted of two parts, i.e., personal data and psychosocial aspect data. The psychosocial aspect data were developed by researchers which were derived from an interviewing of the feelings of 10 students in previous year during the special screening project of the hospital. It included the feeling after knowing of screening result, where there were five levels of rating scale (0-4); self-health or self-appearance were also five levels of rating scale (0-4); nine levels between -4 through +4 of daily living life style that would change; and open end questionnaire related to opinions about benefits of screening test. Three experts validated the content of instrument, where one of them was pediatrician and two were advanced practice nurses. Because this study was conducted for the first time while little theoretical or empirical based knowledge were used to develop the questionnaire, the participants were not the same target group as previously used participants that used in interviewing. We used salient points of feeling from specific subjects, which was appropriate to develop questionnaire (Ajzen and Fishbien, 1980), so the researchers did not try out and test reliability of questionnaire before collecting the data. However, we tested reliability in each factor on exploratory factor analysis process.

Data collection: The Ethics Committee for Human Research of Burapha University approved the research project and instrument before conducting the study (39/2555). The subjects had been informed of the purposes, procedures and benefits of the research. Information sheets and consent forms regarding to the research were sent to the participants,

where parents or participants with age lower than 18 years old were also sent in parallel. The participants were allowed to complete the self-directory questionnaires freely on voluntary basis with confidentiality and freedom to withdraw from this research at any time without penalty or effect of accessibility to the health service. The process of answering the questionnaires was done after receiving their screening test result in the meeting room of Thai-oil Group Community Health and Learning Center. All of them had received a counseling by a specialist pediatrician both before and after knowing the screening result. The participants completed the questionnaires in approximately 10 minutes and returned the questionnaires to the assigned box for collection.

Data analysis. An analysis of all data was carried out by using the computer statistics program, where descriptive statistics and exploratory factor analysis (EFA) were used. Each factor between normal and hereditary groups was compared by Mann-Whitney U test, while the known group validity technique was utilized in the processes. The nonparametric statistics were designed to compare the group analysis because of normal distribution of data did not expect to assume.

RESULTS

The selected participants were consisted of 174 active-reproductive people, where 69.5 % of them were female in which 79.3 % were still single, and 79.7 % of them were married but were still not showing any sign of pregnancy up to the study date. It was found that one third, or 35.1 %, of the participants were hereditary carriers, and 1.7% of them were disease inheritance.

It was found that the level of feeling of the participants' motion was at the moderate level regarding to frightening, distrust, anxiety, and unconcerned feeling, where the values of mean for frightening, distrust, anxiety, and unconcerned feeling were 1.80, 1.73, 1.67, and 1.63, respectively; while the values of SD for frightening, distrust, anxiety, and unconcerned feeling were 1.10, 1.20, 1.14, and 1.41, respectively; and the possible scores were between 0 to 4. Meanwhile the normal control group showed unconcerned feeling at the moderate level, in which the values of mean and SD were 2.22 and 1.61, respectively, whereas the levels of expression of frightening, distrust, scare, and anxiety were at the low level, where the values of mean for levels of expression of frightening, distrust, scare, and anxiety were 0.64, 0.58, 0.56, and 0.52, respectively; and the values of SD for levels of expression of frightening, distrust, scare, and anxiety were 0.91, 1.02, 0.96, and 0.80, respectively; and the possible scores were between 0 to 4.

It was shown that the self-appearance of the hereditary carriers were at moderate healthy level where the values of mean and SD were 2.44 and 1.15, respectively, with the possible scores between 0 to 4, whereas the self-appearance of the normal control group looked a little more healthy, with the values of mean and SD as 2.77 and 1.32, respectively.

An analysis of psychosocial factors was carried out with twenty-five psychosocial items were used in the exploratory factor analysis. The value of sampling adequacy tests done by Kaiser-Meyer - Olkin measurement was 0.941, and the result of Bartlett's test of Sphericity was significant at the level $p < 0.001$, which was indicated that the factor analysis model was appropriate to be used in this study. The factors were analyzed by the principal components analysis (PC) with varimax rotation technique.

There were four appropriate factors loading, i.e., bad feeling, poor health, look blue, and signs of well being, where the eigen values were more than one, and the total percentage of factors that explained the variance of psychosocial aspects were 72.87%, as shown in Table 1.

Table 1. Eigen value, percentage of variance explanation and cumulative variance percentage of psychosocial factors

Factor	Eigen value	Variance explained (%)	Cumulative variance explained (%)
Factor 1	13.361	53.44	53.44
Factor 2	2.329	9.32	62.76
Factor 3	1.329	5.32	68.08
Factor 4	1.198	4.79	72.87

Factor 1 that dealing with "bad feeling" consisted of 13 items, i.e., frightening, anxiety, sad, scare, suffering, grief, stress, confuse, pressure, irksomeness, distrust, dismalness, and unbelief. The values of factor loading were between 0.656 and 0.868, while the value of Alpha Cronbach's coefficient for this factor was at very high level, with the value of α as 0.964. These results could be used to explain the variance of 53.44%, as shown in Table 2.

Table 2. Component of Factor 1 "bad feeling".

Code	Items	Factor loading
F1	Frightening	0.862
F2	Anxiety	0.868
F3	Sad	0.864
F4	Scare	0.844
F5	Suffer	0.852
F6	Dolorous	0.808
F7	Stress	0.769
F8	Confuse	0.710
F9	Pressure	0.733
F10	Irksomeness	0.668
F11	Distrust	0.733
F12	Dismalness	0.756
F15	Unbelief	0.656
	α = 0.964	

Factor 2 that dealing with "poor health" consisted of seven items, i.e., weakness, abnormal, unluckiness, sickness, evil, unlike other, and bad. The values of factor loading that regarding to poor health were between 0.553 and 0.817, while the value of Alpha Cronbach's coefficient for this factor was at a high level, with the value of α as 0.898. These results could be used to explain the variance of 9.32%, as shown in Table 3.

Table 3. Component of Factor 2 "poor health".

Code	Items	Factor loading
S1	Weakness	0.817
S2	Abnormal	0.745
S3	Unlucky one	0.800
S5	Sickness	0.706
S7	Evil	0.723
S8	Unlike other	0.568
S9	Bad	0.553
	α = 0.964	

Factor 3 that dealing with the body appearance of "look blue" consisted of three items, i.e., crying, hopeless, and valueless. The values of factor loading that regarding to the body appearance of look blue were between 0.597 and 0.661, while the value of the Alpha Cronbach's coefficient for this factor was at a high level, with the value of α as 0.845. These results could be used to explain the variance of 5.32%, as shown in Table 4.

Table 4. Component of Factor 3 "look blue".

Code	Items	Factor loading
F13	Crying	0.629
F14	Hopeless	0.661
S4	Valueless	0.597
	(α = 0.845)	

Factor 4 that dealing with signs of "well-being" was consisted of two items, i.e., strong, and unconcerned feeling. The values of factor loading that regarding to the signs of well-being were between 0.789 and 0.821, while the value of the Alpha Cronbach's coefficient for this factor was at a low level, with the value of α as 0.508. These results could be used to explain the variance of 4.79%. Therefore, the Factor 4 was not used to explain the carriers' psychological factor, while only three factors (or about 68.08%) could be used to explain those psychosocial aspects.

The differences in psychosocial factors between the normal control group and the hereditary group used only three factors to test the validity by using Mann-Whitney U test. All factors were found significantly difference between two groups at the level of $p < 0.05$, as shown in Table 5.

Table 5. The comparisons psychosocial factors between normal control group and hereditary group by Mann-Whitney U test.

Groups	n	Mean	SD.	Mean rank	U	p (2-tailed)
Factor 1						
Normal control group	108	0.41	0.67	67.21	1373.00	<0.001
Hereditary group	66	1.27	0.90	120.70		
Factor 2						
Normal control group	108	0.44	0.61	77.59	2494.00	0.001
Hereditary group	66	0.86	0.80	103.71		
Factor 3						
Normal control group	108	0.08	0.20	75.33	2250.00	<0.001
Hereditary group	66	0.20	0.22	107.41		

To see the effect of results of screening test for carriers against the change in the way of living in daily life, it was observed that after knowing the screening result, both groups, the normal control group and the hereditary carriers group, preferred to change the way of living in daily life in the positive direction, with the values of mean of the control group and the hereditary carriers group as 1.55 and 1.14, respectively, whereas the values of SD for the control group and the hereditary carriers group were 1.87 and 1.83, respectively, with the possible scores were between -4 to +4. These results were not significantly difference between both groups where the value of u was 3208.50 at the level p = 0.228.

In regarding to opinions of participants on the benefit of the test that used to screen for the hereditary carriers, it was shown that both groups, the normal control group and the hereditary carriers group, were absolutely agreed that the results of screening for carriers had advantages at a high level, with the values of mean for the normal control group as 2.86 and 3.20, respectively, while the values of SD for the normal control group and the hereditary carriers group were 1.55 and 1.46, respectively, with the possible scores were between -4 to +4. However, it was not significantly difference between both groups, where the value of u was 2931.00, and p = 0.084, which the tendency of the value was higher in hereditary carriers group (Table 6).

Table 6. Mean, standard deviation, the level of offer to change their living in daily life and the benefit of screening carrier test opinion between normal group and hereditary group.

Groups	n	Mean	SD.	Mean rank	U	p (2-tailed)
Their living in daily life						
Normal	108	1.55	1.87	90.79	3208.50	0.228
Hereditary	66	1.14	1.83	82.11		
Benefit of screening carrier test						
Normal	105	2.86	1.55	80.91	2931.00	0.084
Hereditary	65	3.20	1.46	92.91		

Various important opinions given by the participants in the questionnaire were also summarized. Some respondents in the hereditary carriers group felt very happy to know about their genetics, so they became aware of the disease and were willing to prevent the disease that could be transfered to their child and/or paid more concern to their health (5+19 opinions). The intention to motivate their boys or their girlfriends to seek for the screening test before marriage (6 opinions). Some respondents were afraid of their husbands or child would be carrier (4 opinions). After received a counseling with the pediatrician, they felt relieve about the thalassemia (3 opinions). It had advantages on family planning (2 opinions), etc. However, the normal group felt happy to know that they did not inherit the gene (34 opinions). They could plan to become the good quality families (8 opinions). It was agreed that the test that screened for carriers had some advantages for the prevention of thalassemia for their child in the future (7 opinions), etc.

DISCUSSION

The psychological aspects of the screening test for thalassemia can play as the psychological factors that affect on the thinking of the hereditary carriers group at a moderate level. Those psychological factors can cause several effects, i.e., frightening, distrust,

anxiety, and unconcerned feeling, in the recipients of the screening test. The factor-analysis showed that there were three major psychosocial aspects, i.e., bad feeling, poor health, and the body appearance of look blue, that were significant validity and high reliability level. Since patients with thalassemia can transfer genetics to their children, but there are no pathological symptoms in carrier, therefore, the respondents do not know about their genetics of genes related to thalassemia before doing the screening test, which resulted in various feelings or emotional stresses. However, it is not serious like those persons who have a positive test as carriers. The hereditary carriers group showed emotional outburst, whereas young adults (about 10-15 years old) were not concerned about the thalassemia and its future effect. Some of the hereditary carriers were overactive, aggressive, and had temper tantrums when they knew the results of the screening test, while adolescents were more concerned about future, anxiety, depression, nervousness, and afraid of death (Jain et al. 2013). Similar results (Khurana et al., 2009; Nash, 1999, citing in Chetsreesupha, 2009) reported that thalassemia patients were dependent, low self-esteem, bad self-image, that affect their future occupation, marriage, and then turn to have a lot of psychosocial problems.

Results of the screening test that run for pre-pregnancy may lead to psychological distress, however, the project for screening test can help to identify more than 36% of carriers. Thus, the benefit of doing screening test is valid in terms of to prevent the genetic disorders in the family. This benefit has been documented in the clinical practice guidelines by the Genetics Committee of the Society of Obstetricians and Gynecologists of Canada (SOGC), and the Prenatal Diagnosis Committee of the Canadian College of Medical Geneticists (CCMG) in such a way that they offer the screening thalassemia carriers test to a woman, who or her partner is at high risk of being carriers. The strategy could identify 25% risk couples of having a pregnancy with a significant genetic disorders. It has been suggested that it should be screened during pre-conception or as early as possible in the pregnancy (Langlois et al., 2008).

Both normal control and hereditary groups felt there were advantages on screening test because they could plan for their families' children. The Ministry of Public Health is considered to combine the policy to provide screening heritage in active-reproductive or premarital in community, not only for pregnant groups in antenatal clinic. In addition, to run a campaign on screening test for thalassemia carrier every year for new young-adult, or when the teenagers graduate from high school or secondary school on voluntary basis.

The positive results of screening test will also induce fear or frighten because of inheritable disease that cannot be cured. However, the participants felt better or relieve after receiving a counseling with specialists. Thus, the counseling with specialist should be provided for participants before providing the screening test, obtaining the result, and after knowing the result with knowledge in regarding to the genetic disease. The result of research had shown that the hereditary groups had better psychological feeling after receiving a counseling by pediatrician.

According to the result of this study, it shows that the genetic disease in community is important, not only enhancing the knowledge in recipients but also contributing the perceptions to their families and future couples.

It is recommended that the study process should run as a cross-sectional study after knowing the results of the screening test. The study should be done for a longitudinal study in order to follow the changes in psychosocial aspects and other aspects in addition to the comparison with other groups to find out appropriate targets for the national policy of the prevention and control plan.

ACKNOWLEDGEMENTS

The researchers gratefully acknowledged the director and staff of Health and Learning Center, Thai-Oil Network for financial support and for providing facilities for data collection. Special thanks

to Dr. Wilasluck Thanongsuksakul, a pediatrician from Laem Chabang Hospital for her advise and giving counseling to all respondents. Thanks were also extended to all participants.

REFERENCES

Ajzen, I. and Fishbein, M. 1980. *Understanding Attitude and Predicting Human Behavior*. Englewood, New Jersey.

Aydin, B., Yaprak, I., Akarsu, D., Okten, N., and Ulgen, M. 1997. Psychosocial aspects and psychiatric disorders in children with thalassemia major. *Acta Paediatrica Japonica* 39(3): 354-7.

Bessell, A. G. 2001. Children surviving cancer: Psychosocial adjustment, quality of life, and school experiences. *Exceptional Children* 67(3): 345-59.

Chetsreesupha, A. 2009. *Holistic Thalassemia.* Khon Kaen University. Khon Kaen 40000, Thailand [in Thai].

Fuchaleon, S. and Fuchaleon, S. 2010. Thalassemia can prevent. Available at URL: http://www.biotec.or.th/ biotechnolog.il.asp?id =5488 [in Thai].

Jain, M., Bagul, A. S., and Porwal, A. 2013. Psychosocial problems in thalassemic adolescents and young adults. *Chronicles of Young Scientists* 4(1): 21-23.

Junprasert, S., Phunthawe, P., Krungkraipetch, N., Toruksa, W., and Luecha, T. 2011. Thalassemia control and prevention process from school to community. *Journal of Faculty of Nursing, Burapha University 19*(Supplement 2): 13 - 28 [in Thai].

Khurana, A., Katyal, S., and Marwaha, R.K. 2009. Psychosocial burden in thalassemia. *Indian Journal of Pediatrics* 73(10): 31-34.

Langlois, S., Ford, J.C., and Chitayat, D. 2008. Carrier screening for thalassemia and hemoglobinopathies in Canada. *Journal of Obstetric and Gynecologic of Canada* 30(10): 950–959.

Lertruangpanya, P. 2008. Prevention and control of thalassemia of Mong pregnant women in Phan district, Chiangrai. *Buddhachinaraj Medical Journal 25*(Supplement 2): 391-405 [in Thai].

McCabe, L.L. and McCabe, E.R.B. 2004. Genetic Screening: Carriers and Affected Individuals. Available at URL: http://media.eurekalert.org/.../2004/3McCabe-GeneticScreening-Paper.doc.

Massarik, F. and Kaback, M.M. 1981. Genetic Disease Control: A Social Psychological Approach. Sage Library of Social Research, London, UK.

Nash, K.B. 1999. A psychosocial perspective, growing up with thalassemia, a chronic disorder. *Annals of the New York Academy of Sciences* 612: 442-450.

Thalassemia Foundation of Thailand. 2005. Clinical practice guidelines for diagnosis and management of thalassemia syndromes 2006. Available at URL: http://www.thalassemia.or.th/thal/cpg [in Thai].

Voramongkol, N. 2001. Prevention and control thalassemia. Proceedings of the 7th meeting of National Thalassemia, held in Bangkok, Thailand, 27-29 June 2001. *In:* Department of Health, editor, Thammasat University, Bangkok. Thailand [in Thai].

Wanapirak, C., Piyamongkol, W., Sirichotiyakul, S., Tayapiwatana, C. Kasinrek, W., and Tongsong, T. 2011. Accuracy of immunochromatographic strip test in diagnosis of alpha-thalassemia-1 carrier. *Journal of Medical Association Thailand* 94(7): 761-765.