GENETIC COUNSELING FOR THALASSEMIA IN THAILAND : PROBLEMS AND SOLUTIONS

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Abstract. Thalassemia, a hereditary anemia, has been a major public health problem in Thailand and Southeast Asia for decades, yet the prevalence of thalassemia in Thailand is not decreasing due to lack of awareness of this disease in Thai population, which implied that genetic counseling was a failure. We determined the problems and obstacles in thalassemia counseling in Thailand and proposed the possible solutions in order to deliver genetic counseling and services to the communities more efficiently. A survey in thalassemia services was carried out in 12 hospitals; 9 in Bangkok, 3 in the North, Northeast, and South of Thailand respectively, by using questionnaire designed to assess the healthcare system, characteristics of target population, methods of genetic counseling, knowledge and attitudes of counselors, thalassemia support group, and researches in thalassemia, in a cross-sectional descriptive research design. The main problems in genetic counseling for thalassemia in Thailand are the followings; thalassemia problems not visible to the administrators, unorganized teamwork and services, lack of knowledge and inadequate numbers of counselors, lack of thalassemia support group, and inadequate researches in thalassemia prevention and control. The possible solutions are proposed. This study has pointed out the unseen problems and obstacles, along with the solutions in genetic counseling, given correctly, will help create awareness of thalassemia impact on health and socioeconomics in the Thai population. Thus, genetic counseling, with well-established guidelines, is a critical component for the success of prevention and control of thalassemia in Thailand.

INTRODUCTION

Thalassemia is the most common inherited single-gene disorder in the world, with the highest prevalence in Southeast Asia, where approximately 55 millions are carriers (Wong, 1984). The gene frequencies of alpha-thalassemia reach 30-40% in Northern Thailand and Lao PDR, of β-thalassemia vary between 1-9%, and HbE has a frequency of 50-60% at the junction of Thailand, Lao PDR, and Cambodia (Fucharoen and Winichagoon, 1992).These abnormal genes in different combinations lead to 3 major thalassemic diseases (Hb Bart's hydrops fetalis, homozygous β-thalassemia, and β-thalassemia /HbE disease), in such a high magnitude that they pose public health problems in Thailand. Approximately 40% of Thai people are heterozygous carriers of these genes.

The role of genetic counseling to increase public awareness of thalassemia problems is supposed to prevent the birth of thalassemia (Mouzouras *et al*, 1980) but it was not successful in Thailand. We assessed the efficiency of thalassemia services in hospitals from different regions of Thailand to determine the problems and obstacles in genetic counseling, in order to find better solutions for effective thalassemia prevention and control in Thailand.

MATERIALS AND METHODS

A survey in thalassemia services was carried out in 12 hospitals; 9 in Bangkok, the capital of Thailand, and 3 in the north, northeast, and south of Thailand respectively. We inter-

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viewed the administrators and the personnel involved in thalassemia services in each hospital by using pre-tested questionnaire designed to assess the administrative and healthcare system, characteristics and interests of target population, methods of genetic counseling, knowledge and attitudes of counselors, supports available for thalassemia patients and family members, and on-going researches in thalassemia, in a cross-sectional descriptive research design.

RESULTS

Of the 12 hospitals, 7 were supported for thalassemia services by hospital funds or government funds, but 5 hospitals were not supported (Table 1). Five out of 12 hospitals had well-organized program with team leaders, who were all physicians. There was no official evaluation of the thalassemia services in all, except 1 hospital, which had been evaluated annually for the past 2 years. The standard guidelines for thalassemia control in Thailand includes blood screening (hemoglobin-Hb, hematocrit-Hct, and mean corpuscular volume-MCV), diagnosis of disease and carrier (hemoglobin electrophoresis and DNA analysis if the result of hemoglobin electrophoresis is inconclusive), and prevention (prenatal diagnosis and genetic counseling). Not all of the hospitals could do all of these steps (Table 2). Blood screening could be done in all hospitals. Seven hospitals out of 12 had to refer the counselees or send blood samples to other hospitals for accurate diagnosis, and/or prenatal diagnosis due to lack of these services in their hospitals.

The target population were mostly pregnant women, others were thalassemia patients and their family members, and couples at risk (both were carriers). The average age were 18-40 years (Table 3). Languages, cultures, religions, and belief did not pose any problems in counseling, but poor education and poverty caused some difficulties in counseling in 4 out of 12 hospitals. The major concerns of target population were the treatment of thalassemia (8/12), and prenatal diagnosis (4/12).

Genetic counseling in thalassemia was preferably given individually in non-directive method. Some hospitals used guided counseling (giving information with suggestive decision). Directive counseling was given in 1 hospital (Table 4). Most counselors had no background in genetic counseling and had no qualified training before pursuing this job. The most popular media used in counseling

Table 1
Support of thalassemia program and services.

Support	No. of hospitals (N=12)
Support available	7
Support not available	5
No finding	3
Problems not visible to the administrator	2

Table 2
Process in thalassemia prevention and control.

Process	No. of hospitals (N=12)
Blood screening (Hb, Hct, MCV)	12
Hemoglobin electrophoresis	10
DNA analysis	6

Table 3
Target populations in the surveyed hospitals.

Target population[a]	No. of hospital (N=12)
Thalassemia patients and family members	9
Couples at risk (carriers)	7
Pregnant women	10

[a]There are more than 1 category of target populations in each hospital.

Table 4
Methods of genetic counseling.

Method	No. of hospitals (N=12)
Individual counseling	9
Group counseling	3
Non-directive counseling	7
Guided counseling	4
Directive counseling	1

Table 5
Media in genetic counseling.

Media	No. of hospitals[a] (N=12)
Pamphlet	12
Booklet	4
Simulating dolls	3
Diagram drawing	3
Poster	2
Video	2
Dice	1

[a]More than 1 kind of media were used in each hospital

Table 6
Awareness of thalassemia problem in target populations.

Percentage of awareness created[a]	No. of hospitals (N=12)
50	1
10-20	6
0	2
Not sure	3

[a]Percentage of awareness of thalassemia problem in target populations was assessed by participation in the screening program, regular follow-up, and counselor's assumption.

for thalassemia was pamphlet. More than 1 media were used in each hospital (Table 5). The awareness of thalassemia problems in the target population was assessed by participation in the screening program, regular follow-up, and counselor's assumption (Table 6). There was no official support group for thalassemia in all surveyed hospitals. Most researches about thalassemia were molecular analysis for mutations.

DISCUSSION

Twelve hospitals with thalassemia services from different regions of Thailand were chosen for this study because of their differences in administrative and healthcare system, infrastructure, target population, and method of counseling in order to assess the comprehensive view of problems and finding the possible solutions in prevention and control of thalassemia in Thailand (Table 7).

The majority of hospital administrators did not support the thalassemia services because they were not aware that thalassemia patients required tremendous budget for treatment, which partly was from the government since most Thai people are poor and do not have health insurance. Their lives are dominated by the high cost of treatment, often amounting to 20-30% of the income of many families, which are about the same figure as other developing countries (Sangani *et al*, 1990). The services were run by interested pediatric hematologists or obstetrician separately with no organized teamwork or co-operation between departments. The lack of complete cycle (diagnosis, treatment, prevention) in the same hospital contributed to ineffective control of thalassemic births.

Poor education and poverty among the majority of Thai population was another contributing factor in unsuccessful counseling. Since there is no Thai word for "thalassemia", it is very difficult to make them understand what is foreign to them. Besides, lack of knowledge and inadequate number of genetic counselors complicated the process of genetic counseling in creating awareness of thalassemia in counselees.

Most genetic counselors were pediatric hematologists and obstetricians. Others were

Table 7
Problems and solutions for thalassemia prevention and control in Thailand.

Problems	Solutions
1. Hospital administrators were not concerned of thalassemia problem.	1. National plan to provide knowledge of thalassemia to hospital administrators in order to recognize the problem.
2. No organized teamwork and co-operation between the unit involved.	2. Establish a responsible team leader and program evaluation.
3. No complete cycle of services in each hospital (diagnosis, treatment, and prevention).	3. Establish a referral center in each region which povides a complete cycle of services.
4. Poor education and poverty.	4. Use easy-to-understand media and language for communication and financial support from government in high risk population.
5. Incorrect method in genetic counseling and lack of knowledge in counselor.	5. Train genetic counselors with well-established guidelines for the whole country.
6. Inadequate personnel for thalassemia services.	6. Enable primary care providers to provide a basic counseling.
7. Inadequate knowledge of thalassemia in Thai people.	7. Education on thalassemia into high school and college curriculum.
8. No support group for thalassemia in each hospital.	8. Establish thalassemia support group.
9. Lack of clinical research in thalassemia prevention and control.	9. Furnish specific funds for clinical research in thalassemia prevention and control.

nurses and social workers. Neither of them had a genetic background in thalassemia counseling. They used AIDS counseling as a model for thalassemia counseling, which both of these diseases were totally different. They focused only on psychological aspect about suffering and emotional support without genetic information about thalassemia.

Genetic counseling was given individually in most of the hospitals, but using very little time (approximately 5 minutes) per case due to tremendous patients compare to the number of the counselors. The method of counseling was non-directive in the majority of hospitals. Guided and directive counseling were used in the hospitals that had overwhelming counselees because the decision could be made in a shorter time and the counselors could be able to finish all the waiting counselees in time. This method could make the thalassemia service faster but not more effective in the long run. Since the counselee did not fully participate in making the decision, they were still not aware of the thalassemia problem. The consequence was keeping the thalassemic fetuses after prenatal diagnosis result or loss follow-up.

This study proposed the possible solutions as the followings. The Ministry of Public Health should establish the national policy to provide the knowledge about thalassemia to hospital administrators and promote a thalassemia campaign by a media information. Public figures can be very helpful with this program (Zorcolo *et al*, 1986). It will be essential to make the thalassemia problem more visible

to governments and international health agencies that are involved in health care in the developing countries over the next decade (Weatherall, 1998). There should be an organized team work, a responsible team leader and a regular evaluation for thalassemia program (Loader *et al,* 1991) each year. A thalassemia referral center which can perform diagnosis, treatment, and prevention should be established in each region of the country in order to provide the effective services.

The fact that many of Thai people in the rural area, who have high gene frequencies of thalassemia (Pravatmuang *et al,* 1995) are illiterate, there should be Thai words for thalassemia and easy-to-understand media in genetic counseling. Their poverty was another factor for a consideration. How could they bother with thalassemia problem when they have no food to eat and no money to buy essential things. Thailand, as a developing country, should aim at prevention of thalassemia disease by supporting the expense in carrier screening and prenatal diagnosis for high-risk couples, which is global cost-effectiveness (Scriver *et al,* 1984).

Genetic counseling, which is the most important issue in thalassemia prevention and control (Cao *et al,* 1996), has drawn attention to solve the involved problems and obstacles. Due to overwhelming counselees, genetic counseling should be given in groups for the same type of thalassemia and for pregnant women at antenatal clinic. This could save time and the important issue could be explained more thoroughly. Using a media, such as videotape instruction and information can greatly reduce professional time required for genetic counseling and facilitate the incorporation of genetic screening into primary health care (Fisher *et al,* 1981).

Genetic counseling should be non-directive, but direct to the counselee's concern and the counselor should spend appropriate time for the counseling session in order to be able to create awareness in the target population. The object is to make them aware of the consequences of thalassemia disease on health and socioeconomics so that they would ask for screening and prevention, and change their reproductive plans when a possible risk is found. This, in turn, will decrease the prevalence of thalassemia disease in the future.

The genetic counselors should be trained by qualified genetic personnel and a standard guideline should be established for the whole country. Health personnel trained in medical genetics are insufficient to meet the demand for genetic services. Methods must be found to enable primary care providers to offer genetic counseling since the knowledge after counseling was similar for the primary and tertiary care provider groups for thalassemia (Rowley *et al,* 1995).

Education on thalassemia should be introduced into high school and college curriculum (Coa *et al,* 1989) than started at the elementary level because Thai people concern about mating and marriage at this age. Thus, this is the right time to give the information about carrier screening and pre-marital counseling for thalassemia.

Thalassemia support group should be officially established in the regional hospital for psychological and emotional support, besides the basic knowledge and information about thalassemia. This will help unloading the services with inadequate health personnel.

There should be more funds to support the clinical research about counseling, prevention, and control of thalassemia, in addition to molecular research. Genetic counseling is the most important method to convey thalassemia information to the population. Thus, the successful thalassemia program needs an effective genetic counseling.

The success in reducing the prevalence of thalassemia majors in Sardinia, Italy and elsewhere shows that information about carrier screening and prenatal diagnosis program given by effective genetic counseling can have a major impact in communities in which thalassemias are common (Cao *et al,* 1994; Modell and Kuliev, 1993). Our study demonstrates the problems and solutions of ge-

netic counseling in Thailand, which are more complex (Modell and Ward, 1980) than Northern America (Mitchell *et al*, 1996) and other European countries (Anonymous, 1989). We hope that the results and suggestions from this study can be applied to other developing countries in Asia which thalassemias are public health concerns. This is a pilot study for further work in genetic counselor training, national thalassemia policy revision, and thalassemia program evaluation in order to reduce the thalassemic births in Thailand in the near future.

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