Prevention & control strategy of thalassemia in Bangladesh
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Introduction
Thalassemia is the most common inherited gene disorder in the world and varies in different population groups in the world¹. With global improvement in childhood diseases, due to prevention and treatment with targeted programs to prevent mortality from malnutrition, diarrhoea & acute respiratory infections, thalassemia will become a major issue in developing countries like Bangladesh in this millennium. World Health Organization (WHO) estimates that at least 6.5% of the world populations are carriers of different inherited disorders of Hemoglobin². It is predicted that when the world population finally stabilizes, at least 8.0% of the world population will be the carrier or trait of different types of Thalassemia syndromes & hemoglobinopathies².

The world population of carriers of beta thalassemia trait is reported to be more than 100 millions worldwide and about 100,000 children with thalassemia major are born each year². Abnormal hemoglobin, called hemoglobin-E, which is quite common in Bangladesh no definite data regarding carrier status of hereditary hemoglobin disorder exist. No screening programme had ever been taken in any population group. A conservative World Health Organization (WHO) report estimates that about 3.0% of populations are carriers of Beta Thalassemia and 4.0% are carriers of Hb-E in Bangladesh, which means that there are about 3.6 millions carriers of beta thalassemia and 4.8 millions carriers of Hb-E and affected birth per thousand of Beta thalassemia is 0.106 & 3.000 of Hb-E/Beta thalassemia and affected birth per thousand of Beta thalassemia is 0.106 & 0.300 of Hb-E/Beta thalassemia¹. It is presumed that approximately six thousands thalassemic children are born each year in Bangladesh¹.

The birth of a thalassemic child could place a considerable health and economic strain not only on the affected child and its family but also on the whole community and country. Since it is a severe and incurable disease, emphasis must shift from treatment of the affected child prevention of such births in future. All forms of thalassemia are transmitted only through hereditary. Identification of carriers of the thalassemia gene plays an important role in preventing this fatal but preventable disease.

All over the world efforts are being made to prevent the birth of thalassemic child and to improve the quality of life those who are being suffering. Thalassemia needs to be recognized, as an important health issue in this country and steps need to be taken to control the birth of thalassemic children. The following steps to be recommended and which are being followed in many countries:

1. Creating awareness
Creating awareness about thalassemia to the general population, government and medical communities by holding seminars, workshops and writing articles in the daily newspapers, broadcasting in television and radio is of prime importance. Thalassemia day is observed on the 8th May all over the world. On this day various activities has to be arranged and media should be utilized for dissemination of information and recent advances about thalassemia. The government must also take steps to create awareness among the rural populations by involving

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than health complexes and other different local organizations through different activities like seminars, symposium, publications etc. It is very much painful that other than Dhaka city, no facilities are exists for the diagnosis of thalassemia in any other parts of the country.

2. Population screening

Population screening of such a vast problem in such a huge population and hence it is reasonable to select a cohort for screening e.g. pregnant women. They are usually accessible to the health system and information on reproductive risk is of immediate relevance to them. Screening of close relatives of the couples of affected child also is aggressively pursued.

A cheap, easily reproducible & simple screening test "NESTROF {Naked Eye Single Tube Red Cell Osmotic Fragility} has been developed along with the morphology of red cells & red cell indices (MCV, MCH, RWD) for detection of beta-thalassemia trait & other hemoglobinopathies like Hemoglobin-E trait which is most common abnormal hemoglobin in Bangladesh and showed to be very effective in mass population screening. It is being done in India, Iran, Thailand and Iraq. In Iraq this screening method was applied in national survey to detect the carrier state all over the Iraq. We are doing this screening test for carrier detection in our countries. A practical approach would be to perform NESTROF on an accessible way to unmarried cohort of peoples like adolescents at school leaving or before starting college, or young adults starting a job or going to marry, must perform this screening HbA2 or Hb-E. By diagnosing and counseling thalassemia carriers, it becomes feasible and attractive alternative for prevention of thalassemic birth in our country.

3. Genetic counseling

Genetic counseling needs to be given to thalassemia carriers and parents who have a thalassemic child. It should be not-directive and the counselor's mail role is to provide people at risk with full information; give them time for consideration and support them in making decisions. Genetic counseling without prenatal diagnosis has not been very successful in Greece and Cyprus but in Iran where 10,000 people preparing for marriage were screened for the thalassemia trait using CBC (Complete Blood Count) and Hb-A2 level measurement showed that the average of high risk couple initially deciding not to marry was 90% and no new cases of thalassemia was detected in the children of the screened population and the conclusion was that where both members of the couple were trait positive for their preferred choice was not to marry than to marry. We have no experience in genetic counseling and work need to be done to assess the attitude and results of genetic counseling in our country.

4. Prenatal diagnosis

Prenatal diagnosis in being carried out in our neighboring countries like India, Pakistan, Thailand & also in countries like Indonesia, Malaysia & jordon. It is a well-established procedure in developed countries. There is need for religious and legal scrutiny of prenatal diagnosis and therapeutic abortion in our society.

With the introduction of first trimster diagnosis by chorionic DNA techniques, specifically PCR methods chorionic villi sampling (CVS) has become the simplest and most acceptable method for prenatal diagnosis and most suitable method for use in developing countries. As a result prenatal diagnosis, which was initially limited to North America, Europe, Australia has spread to many developing countries. Training for collection of chorinic villi samples and villous sampling and DNA analysis that represents a major advance in prevention of genetic disorders like thalassemia. With the simplification of DNA analysis needs to be given to our doctors & DNA centres need to be set up for giving facilities for diagnosis of thalassemia and its prevention. Thalassemia needs to recognized as an important health problem and plans need to...
set up to reduce the number of cases born by development of population screening programme, awareness creating by using mass media like radio, television, leaflets, booklets, poster, festoons & improving treatment strategy those who are being suffering from thalassemia within our limited resources.

References
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