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Combating Thalassemia in Bangladesh: A case for framing Anti-thalassemia Legislation and National Policy

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Abstract

Thalassemia is an inherited genetic blood disease that causes excessive destruction of red blood cells and leads to anemia. The special characteristics of this disease is that, only when both the parents are carriers of thalassemia, there is the chance of giving birth of a child inheriting 'thalassemia major'. If only one of the parents is a carrier of thalassemia, there is the chance of giving birth of child with 'thalassemia minor' which generally does not show major symptoms of thalassemia, the child would lead normal life, but be only the carrier of thalassemia. The symptoms of 'thalassemia major' is life threatening. Regular blood transfusions at every 2-4 weeks are the only treatment for such patients. The genetic cause of thalassemia was discovered in the 1970s. But the medical cure of this disease is yet to be discovered. Considering the nature of the disease inherited from parents, thalassemia can effectively be prevented by pre-marital or prenatal mandatory blood screening legislation identifying thalassemia carriers among couples. Many countries, such as, Cyprus, Sri Lanka, Saudi Arabia, United Arab Emirates, Iran, Lebanon, Bahrain, Qatar, have gained remarkable success adopting such anti-thalassemia legislation and national policy for it. Bangladesh has attained considerable success in many other areas like reduction of child mortality, birth rate control, child marriage prevention, vaccinations etc. But it paid little attention to thalassemia. Within near future this disease is likely to appear as great national tension for Bangladesh. This article examines the national policy to be adopted in such anti thalassemia legislations and addressing the related social contingencies.

Key words: *Anti-Thalassemia Legislations, Thalassemia Carrier Screening, Preventing Thalassemia, National Policy on Thalassemia*

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Introduction

Thalassemia is an incurable life threatening disease described in medico terminology as the inherited/genetic haemolytic disorder possessed by birth causing to anaemia or low haemoglobin production. The symptoms of this disease in the affected child usually reveals at or around the first anniversary of the birth. Any child born with this disease needs regular blood transfusion generally after two or three weeks for his or her survival. But the complicacy of the disease does not end on with such expensive routine blood transfusion only. As the blood cells damages in each span of blood transfusion, a great number of iron cast deposits as the byproduct in the body of thalassemic patient that damages different organs of the body like heart and endocrine glands leading to organ failure and other complications. To reduce this complicacy, the patient is to take expensive iron removing medications, but complete removal of iron cast is not possible. As a result, the patient despite his/her regular blood transfusions and medications, steps to death. Now a pertinent question may be raised that how far this disease is our national problem. There is no Government survey in our country as to how many people are affected with thalassemia, or how many people are carrier of it, or how many couples are at risk of giving birth of thalassemic child. Some researchers conducted at private initiatives which show that the number of affected people and the potential carriers of this disease in our country is no less alarming than those countries of the world which had already placed the 'national thalassemia prevention program' acknowledging this disease as their national problem or potential threat to national health. There are two types of thalassemia shown in Bangladesh: β-thalassemia and 'Hb E-thalassemia'. Persons born as β- trait have the defect in synthesis of β-globin chain, and the HbE- trait is the hemoglobin structural defect. Depending on the severity of the disease, thalassemia may again be divided in two types: thalassemia trait/carrier and thalassemia major. Persons born as thalassemia carrier do not normally show any major symptoms of thalassemia and can lead normal life. But persons born with thalassemia major, shows symptoms of this disease generally before their first birth day anniversary occurs. A report says that, the carrier status of thalassemia trait is about 10% in Bangladesh which is about 16 million of our population, and more than 7,000 thalassemic children are born each year (Waqar, 2016). Another report says that, β- thalassemia carrier is 17.94% and β- thalassemia major is 4.02%; Hb E Carrier 12.50% and 'Hb E disease' is 2.50% (Waqar, Banu, Sadiya, and Sarwardi, 2017, p. 19). HbE alone does not cause any significant clinical problems except that they are mildly anemic. But the 'β- thalassemia major' cause severe anemia requiring regular red blood cell transfusions.

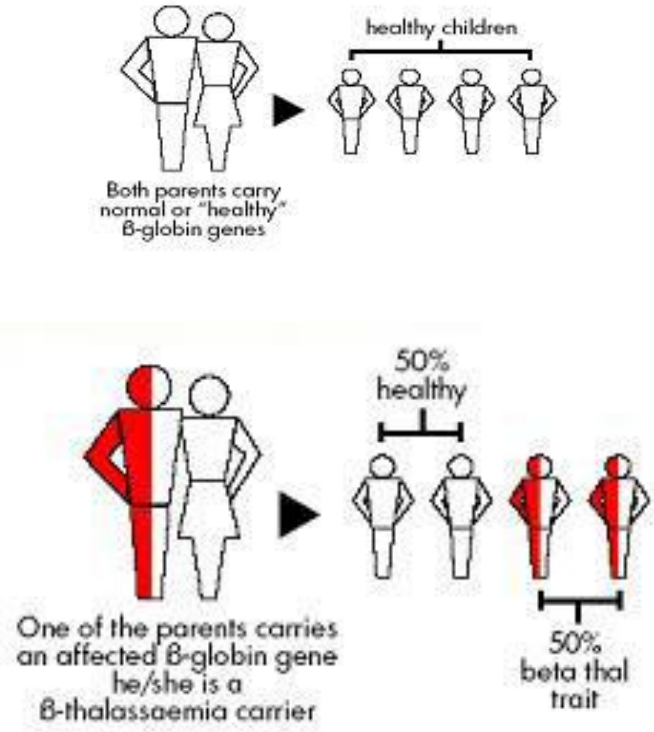
Since thalassemia is an incurable disease, the regular blood transfusion along with costly medication is the only treatment of it; we must emphasis on the preventive measures for it. A national policy on the mandatory pre-marital or at least pre-natal thalassemia screening can prevent this disease. This article describes— how the legislation can do in combatting such congenital disease, why such legislation should be considered the first priority before any medico treatment, the instance of other countries that have already adopted such legislation, what matters are to be dealt with in it, contingencies associated in implementing those and suggestion to launce effective anti-thalassemia legislative program. Before any discussion on anti-thalassemia national policy framing, it is pertinent to have a look on the cause of this disease.

Looking into the cause of this disease

Thalassemia is an inherited disease. The genes received from one's parents before birth determine whether a person will have thalassemia (Information Center for Sickle Cell and Thalassemic Disorders, 1998). The possibility of birth of child with genetic defect is created if both of them are carrier.

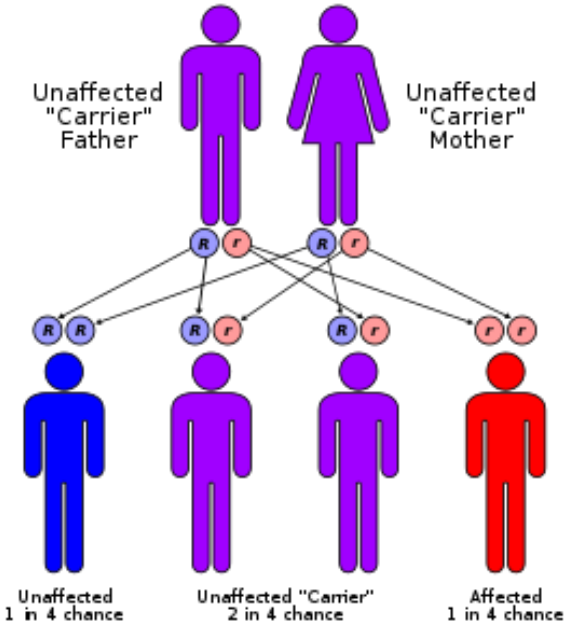
So the success of prevention of this disease depends on the prevention of the birth of thalassemic child. The birth of thalasssemic child can be prevented in following ways. To better understand this, the following chart taken from internet can be examined:

Image- 1: Thalassemia follow chart



The above chart explains two cases of the passing of thalassemia disease from parents to their children. The first case shows that, if one of the parents be the thalassemia carrier, in each pregnancy there is the 50% chance of having the normal healthy child, and 50% chance of having the thalassemia trait child (the carrier). Second case shows that, if both parents have thalassemia trait (i.e. thalassemia carrier), for each pregnancy, there is 25% chance that the child will born with thalassemia disease, 50% chance that the child will born with thalassemia trait (i.e. carrier); and 25% chance that the child will have normal hemoglobin (i.e. healthy).

Image-2: Thalassemia follow chart



Finding effective prevention program: The role of anti-thalassemia legislation and national policy

Considering the genetic cause of thalassemia inherited from parents, the effective prevention program can be designed on prevention of the birth of any new case. The central of this prevention program is the mandatory 'pre-marital screening and genetic counseling (PMSGC)' aimed at screening of at risk couples and counseling in the detected cases about the reproductive choices to prevent birth of child possessed with thalassemia or other genetic mutilations. Saffi and Howard states that the PMSGC program reduces β-thalassaemia births through: (i) prevention of at-risk marriages by discouragement during counseling and, where legal, (ii) termination of affected fetuses through prenatal diagnosis (PND) and therapeutic abortion (Safi and Howard, 2015). Referring to research of Alswaidi and O'Brian, they state that "screening could reduce the β-thalassaemia burden by reducing at-risk marriages and preventing up to 95% of affected births (Safi and Howard, 2015).

Besides the PMSGC, the screening should also be made to the extended family members of diagnosed patients because of the genetic homogeneity and carrier status may be detected among the consanguine members of thalassemia patient (Ahmed, Saleem, Modell, & Petrou, 2002, p. 1163). Similarly, consanguineous marriages have a higher risk of producing affected offspring than general populations due to high gene pool (Kumar, Arya, & Agarwal, 2015, p. 4). In a study of extended family screening in Pakistan found 62.2% β-thalassemia carrier in the immediate family members of the diagnosed thalassemia patient as opposed to 5% — 8% from general population (Ansari et al., 2012, pp. 1315-16). Thus the 'national policy and supporting anti-thalassemia legislation' should provide both for PMSGC program as well as carrier screening of extended family members in diagnosed thalassemia patients.

Some countries, such as, Iran, Cyprus, Tunisia, United Arab Emirates, Saudi Arabia, Italy, Bahrain, Jordan have adopted mandatory pre-marital screening enforced by law; whereas some other countries like India, Indonesia, Maldives, Thailand, Singapore, Spain, Egypt adopted the voluntary screening program in accordance with WHO mandate.

Voluntary screening programs are conducted at high schools, as well as before pregnancy and antenatal. During education sessions, information is provided to the high school students, and the students are given time to provide consent for the testing. This makes the students aware of their carrier status generally before they have settled with a partner with whom they plan to have children (Cousens, Gaff, Metcalfe, & Delatycki, 2010, p. 1081). Antenatal screening is another voluntary option conducted in many countries, e.g., in India and UK. The pregnant women may provide informed consent at their first antenatal visit, and in detected affected foetal case may choose abortion.

The screening is done on the basis of MCV and MCH reference value in blood test by an automated haematological analyzer. The test MCV value above 80 fl and MCH above 27pg are considered non-carriers and a green card would be given. The test can be repeated to ensure the accuracy of result. Recovery of MCV and MCH in repeated test also would be given a green card. Others with persistent MCV values below 80fl and MCH values below 27pg would be referred to HPLC test (high performance liquid chromatography test) to confirm thalassemia status, and if found positive they are given a card to undergo prescriptions by the certified genetic counselors. The HPLC test is the standard test for identification of thalassemia.

Evidence of success in carrier screening program

Cousins et al. (2010, p. 1081) referring to several researches provides the country instance about success in the reduction of new cases of thalassemia affected patient stating as follows:

> *The voluntary carrier-screening programme, which began in Sardinia, Italy, in 1975 reduced the incidence of* β*-thalassaemia from 1:250 to 1:4000 in 1995. All of the carrier couples originally identified as carriers in a high school screening programme in Montreal, Canada, chose prenatal diagnosis, and all affected foetuses were terminated. Therefore, because of this carrier screening programme, no one screened has given birth to an affected child, which has caused a 95% decrease in the incidence of* β*-thalassaemia in that region. Similar results were seen in Marseille, France, where 86% of partners of carriers identified many years earlier in a high school screening programme were carrier tested, and all carrier couples requested prenatal diagnosis and all of the affected pregnancies identified were terminated. A premarital screening programme began in Cyprus in 1973 and the number of affected births decreased from 51 in 1974 to 8 in 1979. The incidence continued to decrease after the screening programme further developed into a mandatory screening programme in the early 1980s, with only five affected births occurring between 1991 and 2001 and no affected births occurring between 2002 and 2007. …*

Such a reduction result also was referred to for the countries Taiwan, China. In UK the all parents in detected cases choose to terminate their pregnancy if the foetus is affected by β-thalassemia. The antenatal screening program conducted at Central Middlesex Hospital in UK between 1986 and 1995 resulted in the prevention of 80% of *β*-thalassaemia-affected births (Cousens et al., 2010, p. 1081).

Instances of some national legislations and policy fighting thalassemia: Their approaches

In **Saudi Arabia** a program known as Premarital Screening and Genetic Counseling (PMSGC) was introduced by law in December 2003 and implemented in February 2004 (Ibrahim et al., 2013, p. 42). The program was implemented under a national project of the Saudi Ministry of Health. The mandatory nature of the program was preceded by national debates at the scientific, social, and religious levels and was followed by widespread media advertising (Memish & Saeedi, 2011, p. 4). The program infrastructure consisted of 150 health care reception clinics, 70 laboratories, and 78 genetic counseling clinics covering the country through 13

administrative regions. The PMSGC program began as a screening program for hemoglobinopathies, particularly sickle cell anemia and thalassemias. Since January 2008, to this program added "the viral pathogen screening" to test participants for HIV, hepatitis B virus (HBV) and hepatitis C virus (HCV). The tests have been made prerequisite for issuing a marriage certificate. Couples with marriage proposals need to report to the nearest health care clinic to apply for premarital certificates. A safe marriage is declared when both or at least one of the couple are healthy. At-risk marriage is declared when both couples are carriers. A compatibility certificate is issued to couples with safe marriage test results while at-risk couples are asked to attend personal genetic counseling meetings before issuing incompatibility certificates. During these meetings the counselors explain to the marriage partners about the potential hazards of their proposed marriages and the voluntary nature of their compliance (Memish & Saeedi, 2011, p. 4). Although the pre-marital screening program is mandatory but the compliance to the recommendation of genetic counselor is voluntary.

Memish & Saeedi (2011, p. 4) describes the results of 'six year study of the implementation of the program' that, between 2004 and 2009, a total of 8925 incompatibility certificates were issued because both couples were carriers or patient (or one of the couples was patient and the other was a carrier) of sickle-cell disease and/or β-thalassemia. The annual frequency of incompatibility certificates was 5.7 per 1000 examined persons and 8.9 per 100 positive results. The frequency of at-risk couples (incompatible certificates) decreased by about 60% between 2004 and 2009. This represented a 43.1% reduction of issuing incompatibility certificates per 100 positive results. Out of the 8925, who had been issued incompatibility certificates between 2004 and 2009, the staff of PMSGC program was able to follow up the decision of 5370 (60.2%) at-risk couples. Out of the 5370 at-risk couples followed, 1425 (26.5%) cancelled their marriage proposals. The frequency of voluntary cancellation of marriage proposals among followed at-risk couples showed more than a 5-fold increase between 2004 and 2009.

Sri Lankan Ministry of Health adopted a National Policy of 'Safe Marriage'. A "safe marriage" is defined as a union where (at least) one partner is not a carrier (Mudiyanse, 2015, p. 792). It is a voluntary process of pre-marital carrier detection promoted by public education, monitoring and counseling at risk marriage proposals. This program is based upon that, if at least "one of the partners in a couple is not a thalassemia carrier, chance of their offspring having 'thalassemia major' becomes zero. Therefore, at

least one of the partners should be screened and confirmed to be a non-carrier before a couple and the family pursue on a relationship leading to marriage" (Mudiyanse, 2015, p. 792).

To achieve the intended goal from the program, the government provides free thalassemia screening tests. In the test result those who have MCV above 80 fl and MCH above 27 pg are considered minimal chance of being thalassemia carrier, and given green card implying that the card holders can marriage with anybody.

Those who are having MCV less than 80 fl or MCH less than 27 pg are given iron 6 mg/kg/day for a period of 3 months by a qualified medical officer. Then further test is taken at the end of the iron therapy, and if the MCV and MCH have recovered they are given green cards and counselled accordingly.

Those who persist to have MCV less than 80 fl and MCH less than 27 pg are referred to HPLC (High performance liquid chromatography) test to ensure thalassemia trait, and once the thalassemia trait is confirmed they are given a red card indicating that they should select a partner with a green card.

The reason for adoption of voluntary screening policy in Sri Lanka, explained by Mudiyanse , Senanayake, & Rathnayake (2015, p. 2), was due to the cultural condition of difficulty to convince a couple to give up an agreed marriage proposal due to stigma and social and cultural belief.

Since the success of such voluntary screening program is highly dependent on the peoples' awareness rising programs, in Sri Lanka, thalassemia screening was integrated with school education curriculum, public education and counseling, free of cost testing, counseling, print and electronic media, and monitoring of marriage registrars. However, achieving the rapid reduction in a thalassemia-prevailed society through such a non-mandatory screening program is least hopeful. A research by Mudiyanse , Senanayake, and Rathnayake (2015, p.3) shows that, although screening is offered free of charge in Sri Lanka, only 17% of the population underwent carrier screening. They comments that, "making screening compulsory is a strategy that may need serious consideration if screening rates remain low even after these services are in place". It is further commented that, "compulsory screening and counseling seems a reasonable policy" in a society with high prevalence of thalassemia to gain reduction of the birth of new thalassemic child (Mudiyanse , Senanayake, & Rathnayake, 2015, p. 3 (Conclusion)).

Cyprus had one of the highest carrier rates in the world, with an estimated carrier rate of one in seven (Cowan, cited in Cousens et al., 2010, p. 1079). Since 1973 Cyprus introduced a premarital screening program.

The program accompanied with public education, population screening, genetic counseling, and antenatal diagnosis. Thereafter since 1980 the orthodox church required 'pre-marital certificate' in order to obtain a license to get married by the prescribed authority. The result of this program showed significant decrease in the birth of thalassemic child. The number of affected births decreased from 51 in 1974 to 8 in 1979. Such a decreased rate continued and with the introduction of mandatory screening program in the early 1980s, only five affected births occurred between 1991 and 2001 and no affected births between 2002 and 2007 (Bozkurt G, cited in Cousens et al., 2010, p. 1081). Thus it established instance as model success for other countries of the world.

The confidentiality of the laboratory results on pre-marital screening was in no way compromised, since the "pre-marital certificate" only contained the statement whether the certificate bearer was examined and properly advised for thalassemia. The actual diagnosis was given to individuals in the form of an identity-type card for their private use (Ioannou, 2013, p. 61). Thus the national policy of premarital certificate of Cyprus aimed at bringing the prospective couple to mandatory pre-cautionary measure only, and left the ultimate decision to the marriage partners after they received the counseling by the genetic counselors (Ioannou, 2013, p. 61). To ensure the authenticity or quality of the certificate, only the certificate from the Cyprus Thalassemia center was accepted by the church authorities.

Conclusion and Recommendation

In combatting diseases caused form genetic mutilation, like thalassemia, the prevention program should get the first priority even over the medico-treatment. The developing of medico treatment and the prevention have their distinct roles in combatting such diseases. Medico treatment or clinical management has the role to "ameliorate the consequences of the genetic defect on the overall quality of life of the patients and their families" (Ioannou, 2013). The prevention programs (such as, pre-marital diagnosis, genetic counseling and awareness rising programs etc.) have their role in preventing new birth of child with genetic mutation like thalassemia. The effective prevention program relieves the family from difficulty, tension and sufferings of upbringing such affected child. The failure to have effective national prevention program will result in excessive burdens for regular blood transfusions, spreading of blood transfusion related diseases (as excessive burdens on blood reservation will lead to relaxation on selecting risk free blood donors), economic pressures, hospitals engagement, family sufferings, social stigma or isolation and many more.

The successful prevention program depends on the taking of planned national policy implemented with central coordination, budgetary support,

ethical control and practices. According to Angastiniotis and Eleftheriou (2016, p. 2), a comprehensive prevention program should consist of the following:

1. Public education and awareness: the public must be aware of the disease and why it is asked to cooperate in a prevention programme.
2. Screening the population to identify carriers.
3. Providing carriers and at risk couples with responsible genetic counseling.
4. The provision of services for prenatal diagnosis or pre-implantation diagnosis.

The anti-thalassemia legislation has been proved as an important tool of "national thalassemia prevention Program". Such legislation provides for 'premarital screening and genetic counseling' aimed at preventing new cases of birth of child inheriting genetic mutilation related diseases, like thalassemia. The genetic counseling to diagnosed at-risk couples ensures that they understand the reproductive risks and exercise choices available to them. In the identified thalassemia trait/carrier cases of both the partners, they can chose options from several alternatives— e.g., refrain from establishing marital bondage, or adopt a child using donor egg or sperm, conceive through in-vitro fertilization (IVF) using pre-implantation genetic diagnosis, or perform prenatal diagnosis after conception and terminate the pregnancy within 12 to 16 weeks if the foetus is affected with thalassemia major.

The effectiveness of such legislation and national policy depends on the supporting infrastructure and services which shall include the following:

- Establishment of certified 'laboratories' for population screening and 'genetic counseling' departments.
- Establishment of 'certification authorities', defining their responsibilities to ensure quality control in 'screening of genetic defects';
- Establishment of genetic counseling departments at community level financed by the government and making services of genetic counselors at the door of common people.
- Establishment of training centers for lab technicians producing certified professionals in diagnosis of 'genetic mutilation' as well as for personnel engaged in thalassemia prevention program.

- Making availability the preventive choices to the at risk couples in pregnancy (e.g. pre-natal and pre-implantation genetic diagnosis, linked with legal therapeutic abortion).
- Define the role in the anti-thalassemia program of *Kazis*, church or marriage solemnizers in solemnizing or registering the marriage (e.g. require PMSGC certificate issued by competent authority under national legislation), and provide the penalty for their irresponsibility or negligence in complying the law.
- Take awareness rising program about the cause and prevention of such diseases which should include planned education at appropriate level of school going children (to increase their genetic literacy and incentive to perform genetic screening at their early life, and plan for selecting the marriage partners conscious about their respective thalassemia trait); serving leaflets; provide role of print an electronic media; government sponsored advertisements; etc. A research by Alswaidi, and O'Brien finds that, "carriers with prior knowledge of their status were more likely to cancel marriage with another carrier than those without prior knowledge (11.8 vs. 28.8% cancellation rates, respectively)" (as cited in Saffi and Howard, 2015, p. 199)

Further thing to be noted that, 'the PMSGC program", though is mandated by law, would attain little success unless associated with other supportive actions such as, antenatal diagnosis or permitted therapeutic abortion. Saffi and Howard explain that, 'without legal therapeutic abortion', the success of the program remains dependent upon 'separating carrier couples'. But 'given the low marriage cancellation rates and that abortion remains illegal' in some societies because of some social and religious constraints, the reduction of the birth of thalassemic child is unlikely to happen (Saffi and Howard, 2015, p. 201). They present examples of Bahrain, Jordan and Saudi Arabia, stating that data on the reduction of β-thalassaemia births was unavailable for the absence of supportive actions like pre-natal diagnosis (PND) and therapeutic abortion (caused on social unacceptability, lack of knowledge, access and costs etc). Whereas, the success of "PMSGC program" in Iran, Turkey and Iraqi Kurdistan were attributed to the availability of PND and therapeutic abortion (Saffi and Howard, 2015, p. 201). His research finds the success rate of these countries achieving reductions in β-thalassemia births of approximately 80, 90 and 65 per cent respectively (Saffi and Howard, 2015, p. 197).

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