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CORRESPONDENCE

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Thalassemia prevention: Religious and cultural barriers to premarital screening in Bangladesh

1 | INTRODUCTION

Thalassemia, an inherited condition of hemoglobin, has become a global public health concern due to rapid globalization.[1] It is noted that 23% of the world's population lives in South Asia, a region plagued by hemoglobinopathies.[2] Each year, about 500,000 infants are born with significant hemoglobin abnormalities, with over 90% of these births taking place in developing nations.[1] The number of thalassaemic children in the majority of developing countries is anticipated to increase in the next years as a result of improved management of infectious illnesses and malnutrition.[3] The population of Bangladesh is approximately 165 million, and the country is developing. A staggering 70% of the population lives in remote areas with insufficient resources and little resources for the detection and treatment of hemoglobin problems.[4] Bangladesh belongs in the thalassemia zone, yet there is a paucity of accurate data on the prevalence of thalassemia-related sickness in the country. According to conservative estimates, between 6% and 12% of the population has one or more hemoglobinopathies, primarily beta-thalassemia, and hemoglobin E; the proportion can reach as high as 40%.[5]

2 | MANAGEMENT OF THALASSEMIA

Thalassemia requires complex and high-priced management. Allogeneic bone marrow transplantation is the only known way to treat this disease. This is also a very economical option. As already mentioned, a thalassemia major patient costs more than the typical Bangladeshi family's monthly household income. According to a study done in Israel, the expense of preventing thalassemia is at least four times cheaper than the expense of treating it. Therefore, prevention is probably the best strategy to maintain a sustainable healthcare system and makes it easier on the families of people with thalassemia.[6] The two most crucial preventive strategies for thalassemia are mandatory premarital screening and genetic counseling which is a primary preventive strategy whereas prenatal screening is a secondary preventive program.

3 | MAJOR OBSTACLES

A primary preventive approach is built around counseling and heterozygous carrier detection to deter marriage between carriers. Premarital testing for thalassemia and other hereditary illnesses that can be avoided is becoming increasingly commonplace across the world.[7] But when it comes to premarital screening, several obstacles must be taken into consideration, such as sociocultural and religious issues. Religious beliefs limit the effectiveness of screening programs. Some people embrace the possibility of having a sick child because they believe that God determines their fate. It was found that a minority of the participants declined the premarital screening program because they felt that by doing so, they would be going against God's will. About a quarter of these patients decided to continue with the marriage.[8] Bangladesh is a Muslim-majority nation and has a strong consanguineous marriage tradition because it is seen as a method to retain wealth, improve partner compatibility, lower the rate of divorce, and maintain links within a tribe.[9] Rahman et al. reported that Bangladeshis have a similar negative attitude about screening because of their religious beliefs.[10] Consanguinity, a deeply rooted phenomenon in some countries, is another issue with premarital screening. In some cultures, notably those of first cousins, marriages between members of the same tribe or extended family are encouraged. It takes time to increase public awareness of the negative effects of consanguineous marriages on health. The prevalence of consanguineous marriage in Bangladesh was 14% in 2015–2016.[11] Premarital screening is influenced by a wide range of sociocultural factors, including the inability to find a compatible match elsewhere, social disgrace anxiety, and the failure of the medical personnel to give couples with adequate information. People in Bangladesh ignored healthcare professionals' recommendations for premarital screening due to financial constraints and a lack of knowledge about thalassemia.[11]

4 | PREMARITAL AND GENETIC SCREENING

When socioreligious problems are taken into account, premarital and genetic screening is feasibly the potential method of preventing beta-thalassemia. However, target-based approaches will be more

successful in lowering the incidence of thalassemia disorder in a developing country like Bangladesh, where resource constraints are the main issue. In these circumstances, selective screening among thalassemia-affected households might be a workable strategy in Bangladesh. In Bangladesh, the majority of thalassemic spouses are found prospectively after the diagnosis of one or more ill children in their family. This could be used as a stand-in for the actual indicator while testing the entire family and developing a successful carrier identification strategy in Bangladesh. This could increase knowledge of thalassemia genetic vulnerability if the affected and extended families received the proper public health dissemination messaging. Only 15% of the adult population in the Mediterranean island of Sardinia was subjected to this screening method, yet it allowed for the detection of 90% of couples who are at risk.[12] In a study done among college students in Bangladesh, 88% of them reported a positive perception of premarital screening.[5] In another study which was done in Bangladesh, 68.2% exposed a positive attitude towards premarital testing.[13] Therefore, more health education programs should be conducted in view of sociocultural factors among college students because of their positive attitude towards premarital screening.

5 | CONCLUSION

The prevalence of high-risk thalassemia has not changed much despite a mandatory national premarital screening program. But there is a much greater need for health education about thalassemia prevention and awareness, as well as for public lectures and seminars to help people with thalassemia and their families learn more about the disease and address the religious and sociocultural barriers which can be avoided to prevent the illness. People will realize how crucial the disorder is to their daily lives. So, it will be helpful to educate the public with the help of the community. Implementing a complete prevention plan that includes premarital counseling, genetic testing, prenatal profiling, and society-wide awareness programs particularly focusing on the religious and sociocultural barriers may actually reduce the number of cases. In countries with limited resources, like Bangladesh, this will significantly aid in thalassemia prevention. An initiative to launch a thalassemia screening program at the national level should be launched by the Bangladeshi Ministry of Health. More focused campaigns on premarital screening should be implemented all around the nation to raise awareness of thalassemia.

AUTHOR CONTRIBUTIONS

Harshini Suresh: Data curation; formal analysis; methodology; validation; visualization; writing—original draft. **Safayet Jamil**: Data curation; formal analysis; investigation; methodology; project administration; resources; software; validation; visualization; writing—original draft. **Bijaya Kumar Padhi**: Investigation; methodology; resources; software; validation; visualization; writing—original draft. **Md Jamal Hossain**: Conceptualization; data curation; formal analysis; supervision; validation; visualization; writing—review and editing.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Not applicable.

TRANSPARENCY STATEMENT

All of the authors of the manuscript attest that the information reported in this manuscript is honest, accurate, and transparent; that no important aspects of the study have been left out; and that any deviations from the initial design of the study have been addressed.

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