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Editorial

Burden of Thalassemia; Time to Act

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Thalassemia is an inherited autosomal recessive disorder which affect millions in the world and result in thousands of death each year.[1] It poses dual burden i.e. psychological and financial, on the families, societies and countries especially in Asian countries where consanguineous marriages are more common. About 5% of the world's population is the carrier of hemoglobin pathologies resulting in 300,000 newborns with thalassemia syndrome annually.[2] Thalassemia is broadly characterized as thalassemia minor (trait) i.e. asymptomatic and affected can survive without any treatment, thalassemia major i.e. severe and affected children needs regular blood transfusions and thalassemia intermedia i.e. milder as compared to beta thalassemia and affected need intermittent blood transfusions. The regular transfusion in thalassemia major cases result in iron overload and need iron chelating therapy. Both transfusion and iron chelating therapy is a huge burden on health care system especially in developing countries.[3,4]

In Pakistan, 5.4% people are carrier of thalassemia i.e. about 9.8 million of the total population [5] Every year 5000 children are diagnosed with thalassemia [6] which is becoming a major health challenge in the country. Thalassemia is a burden for Pakistan which is unfortunately increasing day by day. It was reported that monthly average treatment cost of a thalassemia patient in Pakistan was about Rs. 8,000 to 10,000 PKR (77-96 USD).[7] A recent study which was conducted all over the Pakistan and is being published in this edition (page XXX) also showed that the treatment cost of a thalassemia patient was about Rs. 9626 PKR (93 USD) in both public and private sector. This shows that the annual treatment cost in Pakistan is about Rs. 120,000 PKR (1,116 USD).

Due to poor blood screening, thalassemia patients are at high risk of getting viral infections like HBV, HCV and HIV as they need regular blood transfusion throughout their lives. A study conducted at five different thalassemia centers at Islamabad, Rawalpindi and Karachi reported that the prevalence of 21.7% HCV, 3% HBV and 0.5% in thalassemia patient.[8] These co-infections are either untreatable or difficult to treat increasing burden on healthcare system as well as on the families. In addition to the medical cost, the parents and families of the affected also face different psychological issues. It was reported that in Pakistan, 29% parents of thalassemia children had moderate to severe depression while 16% had excessive sleep problems.[9]

The only way to decrease the burden of disease is prevention. Different strategies like mass education, population screening especially screening of the couples before marriages, prenatal diagnosis and genetic counseling have been employed. In Pakistan, about 70-80% marriages are consanguineous which is a major risk of genetic diseases especially thalassemia. The mass education and awareness about the risk factor associated with cousin marriages may help in reducing the burden. Although population screening is a useful approach but this might not be a feasible option in our setting. It was reported that screening of < 20 years i.e. 50 million population might cost millions of dollars.[10] However, the premarital screening and genetic counseling of the couples are more feasible and result oriented. It was reported that in Iran, premarital screening and genetic counseling helped in averting 70% of annual births of affected infants.[11,12] Prenatal screening might have some social and legal issues in Pakistan. However, index families may be asked for prenatal screening and advised accordingly. There is need to sensitize the general public, physicians and especially the religious scholar about this issue and to start the dialogue.

After 18th amendments, the health has been devolved and is now the Provincial subject. Keeping in view the gravity of the issue, provinces have to take initiative to reduce thalassemia burden in the country. At the moment, the government of Punjab has initiated thalassemia prevention program which is providing premarital screening to the couples and families of affected along with genetic counseling.[13] But this is still at the premature stages and is available in major cities of the Province. There is need to create awareness in the public about its utility and availability to achieve the objectives. Although, the government of Sindh has

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promulgated and made the premarital screening compulsory but this is not happening at the ground. There is a need to take concrete steps in Sindh to address this issue. Similarly the governments of Khyber Pakhtunkhwa (KPK) and Baluchistan also need to take initiatives to cope this issue. Besides this, the Federal government has to introduce the program at the Federal level as well as in the regions (Azad Jammu Kashmir, Gilgit Baltistan and Federally Administered Tribal Areas), so that the burden of thalassemia can be reduced in the country.

Conflict of interest: Dr. Arif Nadeem Saqib is the Managing Editor of the journal.

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