Perspective Article

Thalassemia in Iraq: Time to Reform Policy

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Abstract

Thalassemia is one of the most common hemoglobinopathies worldwide, particularly within the Middle Eastern demographics. Despite the existence of a nationwide screening program in Iraq and a decline in disease incidence, its optimal effectiveness remains uncertain, as β-thalassemia prevalence continues to rise. This paper seeks to evaluate the weaknesses of the thalassemia screening program in Iraq. It also suggests actionable strategies for policy change to further reduce disease incidence. Additionally, the discussed concepts can be applicable to other regions facing a similar burden. Factors like widespread consanguineous marriage, inadequate public knowledge, and restricted access to prenatal diagnostic services impose further burden on prevention efforts. To attain national elimination of β-thalassemia in Iraq, the Ministry of Health, in collaboration with medical organizations, must promptly address these barriers by revising policies and substantially investing in essential services.
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Introduction

Thalassemia is a prevalent genetic haemoglobin disorder, occurring at a rate of 4.4 per 10,000 live births worldwide. [1] The World Health Organization (WHO) identifies β-thalassemia as one of the most prevalent monogenic disorders, particularly in the Middle East, where high carrier rates are attributed to genetic bottlenecks and a high incidence of consanguineous marriages. The prevalence of intrafamilial marriage in Iraq is substantial, with national consanguinity rates reported between 24% and 71%.[2] This marriage pattern in Iraq contributes to its classification as a high-risk region, with β-thalassemia trait carrier frequencies ranging from 3.7% to 6.5%. This prevalence poses a potential increased risk of the said genetic disorder in offspring, thereby imposing a potential burden on the government and health system.[3] According to the Iraqi Federal Board of Supreme Audit in 2016, the monthly cost of managing each patient ranges from $ 1,428 to $ 3,785. Extrapolating these estimates to the 11,165 registered patients in 2015 across 16 of the 19 thalassemia centres in Iraq, the annual national expenditure is projected to range from approximately $191 million to over $507 million.[4] Nevertheless, lack of recent national epidemiological data on prevalence, incidence, and registered patients limits our ability to accurately evaluate the current epidemiological and economic burden of β-thalassemia in Iraq.

In addition to this substantial economic burden of β-thalassemia, the disorder is associated with several complications, including transfusion-related iron overload, blood-borne viral infections such as hepatitis C virus (HCV) and hepatitis B virus (HBV), endothelial dysfunction, and thrombotic events, all of which contribute to patients' morbidity and mortality.[5] This paper aims to investigate the shortcomings and barriers in screening that continue to hinder the complete elimination of β-thalassemia in Iraq. It further seeks to propose actionable measures for stakeholders and policymakers to facilitate the reduction and elimination of β-thalassemia, including targeted public health education initiatives and policy reforms. Additionally, the concepts, experiences and recommendations presented in this paper may be applicable to other regions experiencing similar disease burden, including parts of South Asia and Africa.

Role of screening programs

Premarital screening serves as an essential preventive strategy for genetic blood disorders, including hemoglobinopathies. This approach is fundamental for couples intending to marry, safeguarding both individuals and society while fostering healthier family outcomes.[6] Thalassemia screening is widely implemented in many countries and is often included in government-mandated premarital health evaluations aimed at reducing the incidence of thalassemia.[7] Since the 1970s, various countries with high rates of consanguinity and hemoglobinopathies, such as Cyprus, Greece, the United Kingdom, Italy, and the broader Middle East, have established screening programs that have effectively decreased the rates of affected births.[8]

The Cyprus thalassemia prevention program, initiated in the 1970s, is recognized as a successful and effective intervention in the region. Their program was founded on four key components: public education, population screening, genetic counselling, and antenatal diagnosis. In 1983, Cyprus implemented mandatory screening for all couples as part of premarital screening. Since then, the incidence rate among newborns has dropped from approximately 30 cases per year to nearly zero by 2000. [9,10]

Regionally, the Iranian thalassemia prevention program, established in 1995, represents an outstanding experience in the region, reducing the birth rate of thalassemic patients by 90%.[11] The thalassemia screening program is a new endeavour in Iraq, initiated as a part of premarital screening in the Kurdistan Region of Iraq in 2008, and the Iraqi Ministry of

Health launched a nationwide screening program in 2012. In this screening programme, all couples intending to marry undergo some screening investigations, including a complete blood count (CBC), and suspected cases identified based on CBC results are subsequently further evaluated using iron studies and haemoglobin electrophoresis. Despite the existence of a nationwide screening program and a decline in disease incidence, the optimal effectiveness of this program remains uncertain, as several studies have reported an increasing prevalence of β-thalassemia. [5,12]

Barriers to excellence

Although the implementation of the thalassemia screening program in Iraq has led to a reduction in the incidence of new cases, several cultural, social, and infrastructural barriers continue to hinder the achievement of the programme's intended outcomes. [13] Limited public awareness regarding thalassemia, its inheritance patterns, and inadequate knowledge about the potential consequences for the newborn, family, society, and healthcare system contribute to the poor acceptance and trust in premarital screening results. As a consequence, many at high-risk couples proceed with marriage despite the risks. Social and cultural norms further complicate the decision of at-risk couples to cancel their engagement solely based on screening program results. Moreover, the limited availability of specialised haematology clinics, molecular testing and the high cost of preimplantation genetic diagnosis and prenatal diagnostic services place an additional burden on prevention efforts.[14] These challenges are not only unique to Iraq but reflect a broader global health concern, particularly in low- and middle-income countries (LMICs). A review paper from Bangladesh, a country located in South Asia, reported comparable obstacles, including social stigma, financial difficulties, and limited access to prenatal diagnostic services.[15]

Steps to optimization

To attain national elimination of thalassemia in Iraq, the Ministry of Health must implement many reforms in policies and guidelines. Firstly, the establishment of a national centralised digital health database will facilitate continuous surveillance monitoring, identify high-risk locations, and support the development of customised public health initiatives. Secondly, public health activities must not be undervalued, and medical organizations should implement culturally suitable public campaigns, emphasizing the role of consanguineous marriage on the inheritance of genetic disorders to offspring. Thirdly, school-based health educational programs significantly contribute to preventive efforts, since research indicates that such activities enhance adolescents' health literacy, resulting in higher preventive actions.[16] Fourthly, investment in infrastructure for improving genetic counselling and prenatal diagnostic services should be directed towards accessible and public programs that reach all impacted populations.

Beyond the benefits of these reforms on β-thalassemia prevention, they align with the broader aims and objectives of the health system. Moreover, public and religious leaders should play a supportive role in enhancing population understanding of the potential health and social consequences of this hereditary disorder on offspring, families, society, and government. Additionally, the stigma associated with the termination of engagement between unmarried couples due to potential health risks in offspring should be mitigated.

Conclusions

Though a premarital thalassemia screening program exists, aimed at identifying thalassemia carriers among couples and preventing its inheritance, the prevalence of thalassemia continues to increase in Iraq. Although promising results have been observed in reducing incidence, the complete elimination of thalassemia remains an unmet goal. Factors like widespread consanguineous marriage, cultural, social, and infrastructural obstacles impede the attainment of complete elimination.

The Ministry of Health, in collaboration with medical organizations, must urgently tackle these barriers by reforming policies and significantly investing in required services.

Conflict of interest declaration

The authors have no conflict of interest to declare.

Author's contribution

Conceptualization: HAA, AAM, and NRH
Writing-Original draft: HAA
Writing-Review and Editing: AAM, and NRH
All of the authors have approved the final version to be submitted and take full responsibility for all aspects of the paper.

Generative AI statement

During the preparation of this manuscript, the authors used ChatGPT in order to improve the grammar and linguistic format of the paper. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

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