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Liter to Editor (Pages: 1321-1325)

Integrating Regionally Prevalent Hemoglobinopathies into Medical Education in Iran: From Theoretical Knowledge to Clinical Readiness

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Abstract

Thalassemia and sickle cell disease are important hemoglobinopathies that impose a substantial burden of care in Iran and the wider region. Despite the success of thalassemia prevention programs in Iran, affected individuals require timely diagnosis, longitudinal care, complication management, genetic counseling, and appropriate referral. Geographic variation in the prevalence of thalassemia and sickle cell disease—particularly in southern and southwestern Iran—underscores the need for medical education that is responsive to local health priorities.

Education on hemoglobinopathies should extend beyond theoretical genetics and the classification of anemias. Medical students and postgraduate trainees should develop competence in interpreting laboratory findings; differentiating thalassemia from iron deficiency; recognizing transfusion-related complications, iron overload, and sickle cell disease emergencies; providing initial genetic counseling; and arranging timely referral. Longitudinal, regionally responsive curricular integration—supported by case-based learning, team-based learning, clinical simulation, and structured patient encounters—may help bridge the gap between theoretical knowledge and clinical readiness.

Key Words: Clinical readiness, Hemoglobinopathies, Pediatrics, Medical education, Thalassemia.

*Please cite this article as: Hesabi A. Integrating Regionally Prevalent Hemoglobinopathies into Medical Education in Iran: From Theoretical Knowledge to Clinical Readiness. Med Edu Bull 2026; 7(1): 1321-25. DOI: **10.22034/meb.2026.604098.1149**

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Received date: Mar. 22, 2026; Accepted date: Jun.22, 2026

Dear Editor,

Hemoglobinopathies, including disorders of globin-chain synthesis such as thalassemia and structural hemoglobin disorders such as sickle cell disease (SCD), are among the most common monogenic disorders worldwide. They are not merely topics in genetics or basic hematology; rather, they are directly relevant to child health, family medicine, outpatient care, transfusion medicine, genetic counseling, mental health, and public health. Global estimates indicate that approximately 7% of pregnant women carry a clinically significant hemoglobin disorder and that more than 1% of couples are at risk of having a child with a major hemoglobinopathy (1). In low- and middle-income countries, limited access to screening, diagnosis, safe transfusion services, iron chelation, and comprehensive care may further amplify the burden and consequences of these disorders (1, 2).

Iran lies within the thalassemia belt, and beta-thalassemia remains one of the country's most important inherited disorders. The national premarital screening program, genetic counseling, and prenatal diagnosis have been recognized as important public-health strategies for reducing the number of births affected by severe thalassemia (3, 4). By identifying at-risk couples and providing access to counseling and prenatal diagnostic services, this program has made a substantial contribution to thalassemia prevention in Iran (3–5). Nevertheless, preventing new cases does not eliminate the continuing need for clinical care. Many individuals with transfusion-dependent thalassemia and other clinically significant thalassemia syndromes survive into adolescence and adulthood and require lifelong, multidisciplinary, and carefully monitored care (5, 6).

The burden of hemoglobinopathies is not evenly distributed across Iran. In a study of 17,581 couples in southwestern Iran, the prevalence of beta-thalassemia minor, alpha-thalassemia, and sickle cell disease or trait was reported as 5.6%, 6.65%, and 7.05%, respectively (7). Genetic studies in southwestern and southern Iran have also documented the presence and molecular diversity of SCD (8). Therefore, although thalassemia should remain a core component of hemoglobinopathy education throughout the country, SCD and compound conditions—particularly HbS/beta-thalassemia—should receive greater curricular emphasis in medical schools located in higher-prevalence regions.

This need aligns with the principle of social accountability in medical education. Medical schools should align their education, research, and service activities with the priority health needs of the populations they serve. A uniform and inflexible curriculum may not adequately address regional variation in disease burden or the clinical realities that future graduates will encounter. Universities in provinces with a higher prevalence of thalassemia or SCD can strengthen learner preparedness, without altering national core curricula, by incorporating locally relevant cases, structured clinical experiences in comprehensive thalassemia centers, and region-specific assessment scenarios.

The key concern is the potential gap between knowing and doing. Medical students may learn about hemoglobin structure, autosomal recessive inheritance, and the classification of thalassemia syndromes, yet still require practical decision-making skills when encountering a child with microcytic anemia, a transfusion-dependent patient with possible iron overload, or a child with SCD presenting with fever and severe pain. Reported challenges in Iranian clinical medical education—including imperfect alignment among curricula, hands-on learning opportunities, clinical settings, and workplace needs—underscore the importance of performance-oriented education (9, 10). However, dedicated needs-assessment and performance-evaluation studies are required to determine the precise level of knowledge and clinical readiness of Iranian students and graduates in hemoglobinopathy care.

At the undergraduate level, learners should be able to differentiate iron deficiency from thalassemia trait and other causes of microcytic anemia in children and adolescents. Interpretation of complete blood count indices, serum ferritin, peripheral blood-smear findings, and, where indicated, hemoglobin electrophoresis should be taught as an applied clinical skill rather than as isolated factual knowledge. Clinical guidance emphasizes that thalassemia should be considered in patients with hypochromic microcytic anemia, while iron deficiency should be appropriately evaluated or excluded (6). Graduates should also recognize when referral to pediatric hematology or other specialist services is required and be able to communicate initial information clearly, accurately, and nonjudgmentally to patients and families.

In transfusion-dependent thalassemia, learning objectives should extend beyond the mechanics of transfusion. Future physicians need a foundational understanding of transfusion safety; recognition and initial management of transfusion reactions; documentation of alloantibodies and previous reactions; surveillance for iron overload; and the need for referral and follow-up within multidisciplinary care teams. Iron overload can lead to serious cardiac, hepatic, and endocrine complications, making appropriate monitoring and treatment central to long-term care (6). The aim is not to replace hematologists or specialized centers; rather, it is to prepare frontline physicians to recognize problems early, initiate safe initial measures, and make timely referrals.

SCD also requires a clearer place in Iranian medical education. Children with SCD may present with vaso-occlusive pain, fever, acute anemia, splenic sequestration, acute chest syndrome, or neurological manifestations. These presentations can be life-threatening and require rapid recognition, safe initial assessment, and prompt referral when indicated (2, 11). Although the highest global burden of SCD is concentrated in sub-Saharan Africa, the disorder is also present in the Middle East, the Mediterranean region, India, and parts of southern Iran (2, 8). Thus, SCD should not be viewed as a remote or clinically irrelevant subject in Iranian medical curricula, particularly in southern and southwestern regions.

Educational evidence also supports concern about the gap between basic knowledge and readiness for clinical care in SCD. A recent study among medical students at two universities found that previous exposure to patients with SCD was associated with greater knowledge, confidence, and comfort in caring for affected individuals, whereas students reported limited preparedness in some clinical and treatment-related domains (12). Although these findings cannot be directly generalized to Iranian learners, they indicate that theoretical instruction alone may be insufficient to prepare students for complex clinical situations.

Competency-based medical education (CBME) offers a practical framework for addressing this gap. In CBME, curriculum design begins with observable and assessable outcomes, and education focuses on learners' ability to perform professional tasks rather than solely on the volume of content delivered (13). In hemoglobinopathy education, this approach could define competencies such as interpreting initial complete blood count and hemoglobin electrophoresis findings; assessing a child presenting with fever and pain in whom SCD is suspected; recognizing possible transfusion-related complications; and providing initial counseling to a couple identified as carriers of beta-thalassemia.

Horizontal and vertical integration of hemoglobinopathy content is therefore needed. During the preclinical phase, genetics, biochemistry, physiology, and pathology should be linked to authentic clinical cases. During clerkships and internships, students should practice interpreting complete blood counts, differentiating iron deficiency from thalassemia trait, selecting appropriate confirmatory tests, applying core transfusion principles, and undertaking early assessment of SCD emergencies. In postgraduate training programs in pediatrics, internal medicine, family medicine, obstetrics and gynecology, emergency medicine, and medical genetics, the expected level of competence should be tailored to each specialty's professional responsibilities.

Active learning methods can operationalize this integration. Case-based learning, team-based learning, clinical simulation, and structured patient encounters can connect foundational knowledge with clinical reasoning and communication. For example, a simulated scenario involving a child with SCD who presents with fever, chest pain, and reduced oxygen saturation could assess history taking, recognition of possible acute chest syndrome, selection of appropriate initial investigations, supportive management, family communication, and referral decisions. Team-based learning modules and scenario-based educational interventions in SCD have demonstrated the feasibility of integrating genetics, pathophysiology, disease complications, and clinical management within structured learning activities (14, 15).

Medical schools may consider the following practical actions:

- Develop locally relevant clinical cases, including a child with transfusion-dependent thalassemia, a couple carrying beta-thalassemia trait, an adolescent with clinical features of

iron overload, and a child with HbS/beta-thalassemia presenting with fever or vaso-occlusive pain.

- Use case-based learning and team-based learning to integrate genetics, pediatrics, family medicine, transfusion medicine, ethics, and genetic counseling.
- Incorporate Objective Structured Clinical Examination (OSCE) stations assessing complete blood count and hemoglobin electrophoresis interpretation, counseling of at-risk couples, and the initial assessment of a child with suspected SCD.
- Establish structured learning opportunities in thalassemia centers, pediatric hematology clinics, genetic counseling services, and transfusion medicine units.
- Use simulation-based education to practice clinical decision-making in children with SCD presenting with fever, severe pain, acute anemia, or possible acute chest syndrome.
- Complement knowledge-based examinations with performance-oriented assessments, including Objective Structured Clinical Examinations (OSCEs), Mini-Clinical Evaluation Exercises (mini-CEXs), direct observation, formative feedback, and case-based examinations.

The ethical dimension of hemoglobinopathy education is equally important. Genetic counseling is not merely the delivery of laboratory results; it is a process that helps individuals and families understand genetic risks, available options, and the implications of potential decisions. Physicians should be prepared to provide such information without judgment, coercion, or stigmatization while respecting cultural contexts, personal values, and informed family choices (3, 4). Communication and counseling skills should therefore be integral components of hemoglobinopathy education.

CONCLUSION

Integrating regionally prevalent hemoglobinopathies into medical education in Iran is not simply a curricular-content decision. It is a response to disease burden, geographic variation, long-term care needs, and the social accountability of medical schools. Iran's experience in thalassemia prevention demonstrates the value of screening and genetic counseling; however, safe and high-quality care for existing patients and timely identification of new cases require physicians who are competent not only in theoretical knowledge but also in laboratory interpretation, initial clinical decision-making, referral, longitudinal care, and professional communication.

A longitudinal, regionally responsive, interdisciplinary, and competency-based approach—supported by outpatient and comprehensive-care learning environments—may reduce the gap between knowledge and performance. Such curricular reform should be regarded as a priority, particularly for medical schools located in regions with a greater burden of thalassemia and sickle cell disease.

CONFLICT OF INTEREST: None.

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