

LETTER TO EDITOR

A Culturally Embedded and Family-Oriented Approach to Thalassemia Prevention through Multisectoral Community Nursing Collaboration

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DEAR EDITOR

Thalassemia is a hereditary blood disorder transmitted through mutated genes and is highly prevalent in Southeast Asia and Mediterranean regions, constituting a major public health challenge. Individuals with thalassemia major require lifelong treatment, such as regular blood transfusions and iron chelation therapy, which impose significant physical, emotional, and economic burdens. Because thalassemia is inherited within families, prevention must adopt a family-oriented approach that recognizes families as the primary unit for genetic risk identification, counseling, and reproductive decision-making. Community nurses play an essential role in educating families, facilitating premarital screening, and supporting informed reproductive choices. The most effective prevention strategy is to reduce the birth of new cases, particularly from marriages between two carriers, through premarital screening and genetic counseling. However, these efforts remain limited due to low public awareness, cultural barriers, and insufficient multisectoral coordination.¹

To address this gap, a Multisectoral Community Nursing Model (as presented in Figure 1) is needed, requiring collaboration among government institutions, academia, healthcare providers, and clinical experts. In this model, community nurses function as multisectoral coordinators who connect families with healthcare services and facilitate collaboration across religious, educational, and community systems. These collaborations are reinforced by social, religious, and educational systems that shape health behaviors and public perceptions.¹ Through this coordination, community nurses ensure that family-centered thalassemia prevention extends beyond clinical settings and becomes integrated into family and community life.²

At the individual and family level, religious leaders play a crucial role in promoting healthy marriage preparation as part of thalassemia prevention. Evidence from hemoglobinopathy-related premarital genetic counseling programs suggests that educational interventions for faith leaders improve genetic literacy and enhance their willingness to advocate for premarital counseling. Through sermons and religious gatherings, they can promote responsible marriage practices and genetic compatibility to prevent inherited disorders. Their moral authority fosters community acceptance and encourages behavioral change.³ Community nurses can collaborate with religious leaders by providing accurate health education and facilitating family counseling referrals, ensuring families receive culturally appropriate guidance before marriage.

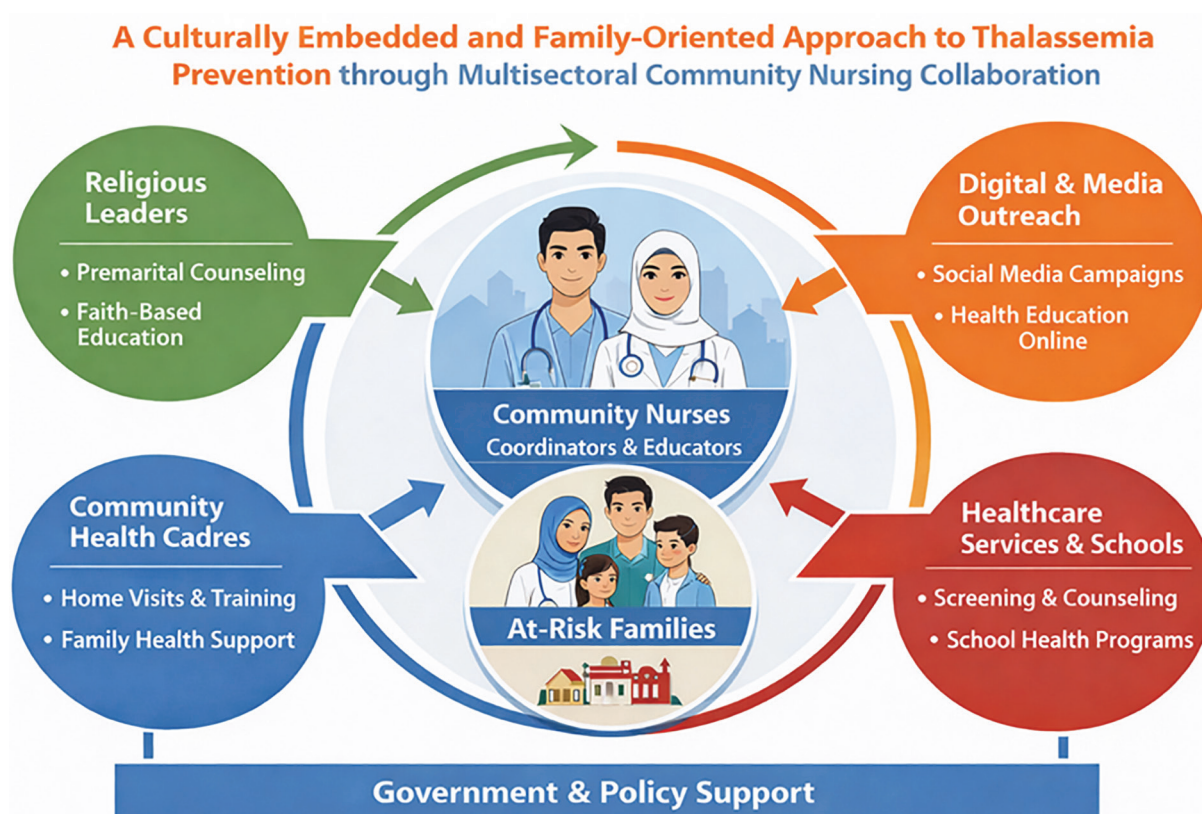


Figure 1: Multisectoral community nursing model for thalassemia prevention (authors' conceptual framework, visually generated with assistance from OpenAI GPT-4)

Concurrently, social media influencers and digital content creators have become key actors in thalassemia prevention campaigns. With broad reach and the ability to simplify complex health information, they raise awareness about premarital screening and discourage high-risk marriages. Evidence indicates that online initiatives improve genetic literacy and promote preventive behaviors.^{1,4} Community nurses can collaborate with digital platforms and influencers to disseminate accurate, family-oriented thalassemia education and encourage families to participate in screening programs.

Community engagement constitutes a critical component in embedding preventive strategies within sociocultural contexts. Community health cadres function as community-based health promoters who facilitate household-level dissemination of thalassemia prevention information. Their sustained interaction and contextual understanding enable culturally sensitive education and support early identification of individuals at-risk.¹ Community nurses can coordinate and support these cadres by providing training, supervising family-based education, and facilitating screening referrals for families at risk.

Peer-led interventions also demonstrate effectiveness, particularly those involving youth ambassadors. These strategies utilize shared identity to foster communication regarding reproductive health and premarital screening. Empirical findings indicate that peer-based education improves knowledge and preventive behaviors.⁵ Community nurses can facilitate and supervise peer-led programs, ensuring accurate information and strengthening connections between individuals, families, and healthcare services.

Healthcare facilities remain at the frontline of prevention. Public Health Centers conduct screenings and provide counseling, while hospitals support family planning and genetic referrals. Mandatory screening programs have proven effective although barriers persist, including limited awareness and cultural norms.¹ Community nurses can play a central role in coordinating family-based screening, educating families about inheritance patterns, and ensuring continuity of

prevention between healthcare facilities and communities.

Government involvement is pivotal in institutionalizing thalassemia prevention across religious and educational sectors, particularly through the Religious Affairs Office, which mandates premarital health checks, and the Department of Education, which integrates genetic health awareness into school-based programs, strengthening these policies to include targeted thalassemia screening, and counseling could reduce carrier marriages and promote early identification of at-risk individuals and families.⁶ Within this governmental framework, community nurses can play a critical role in operationalizing prevention efforts by providing family-centered education, facilitating access to premarital screening, collaborating with religious and educational institutions, and supporting families in understanding genetic risks and informed reproductive decision-making. This integrated government–nurse collaboration enhances genetic literacy, increases screening uptake, improves carrier detection, and ensures that prevention strategies are culturally appropriate, sustainable, and responsive to family and community needs.¹

Central to this comprehensive approach is the role of the community nurse, who serves as an educator, advocate, facilitator, and multisectoral coordinator. Through partnerships with families, religious leaders, educators, and community stakeholders, community nurses ensure that thalassemia prevention remains family-centered, culturally appropriate, and sustainable. Their role bridges healthcare systems and families, enabling prevention to become a shared responsibility and supporting the goal of reducing future thalassemia births.

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Authors' Contribution

H.S developed the conceptualization and wrote the draft of the manuscript, I.A.R performed document search and funding administration. Y.D.L.S developed the conceptualization and revised the manuscript. All authors have reviewed and approved the final draft and are responsible for the letter's content.

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Conflict of Interest

Non declared.

Declaration on the Use of AI

The authors used OpenAI, GPT-4 to assist with language refinement and visual generation of Figure 1 based on the authors' original conceptual framework. No AI tool was used for data generation, analysis, interpretation, or scientific decision-making. The authors take full responsibility for the integrity, accuracy, and originality of the manuscript.

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