



Policy Brief: Is Follow-up Care the Missing Link in Thalassemia Quality-of-Life Policies?

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Abstract

Context: Despite improved survival, many patients with thalassemia major continue to experience a poor quality of life that is not adequately addressed by routine treatment alone. This represents an important gap in thalassemia care.

Objectives: To underscore the need to integrate a structured follow-up care model into chronic thalassemia services as a practical policy response to improve patients' quality of life.

Evidence Acquisition: Evidence was obtained from a clinical intervention conducted among patients with thalassemia major in southeastern Iran. The follow-up care model integrated patient education, psychosocial support, and family involvement into existing healthcare settings.

Results: Implementation of the structured follow-up care model significantly improved quality-of-life outcomes among patients with thalassemia major and was feasible in existing care settings.

Conclusions: Structured follow-up care should be incorporated into thalassemia management policies and routine chronic care services. Health authorities and service managers should support its implementation through workforce training, integration into routine monitoring systems, and the strengthening of patient-centered care.

Keywords: Thalassemia Major, Follow-up Care Model, Quality of Life, Chronic Disease Management, Health Policy

1. Background

Thalassemia major is a lifelong genetic condition that imposes a substantial burden on patients, families, and health systems (1). In Iran, where more than 30,000 people live with thalassemia and provinces such as Sistan and Baluchistan report the highest prevalence, the condition has shifted from a fatal childhood disease to a chronic disorder requiring lifelong care (1). Although advances in transfusion therapy and iron chelation have improved survival, many patients continue to experience poor quality of life that routine treatment alone does not adequately address. Thus, thalassemia care remains both a clinical priority and a major health policy challenge.

Evidence from national and international studies indicates that patients with thalassemia major commonly experience physical limitations, psychological distress, social isolation, and reduced participation in education and employment (2). These challenges are often associated with frequent hospital visits, treatment burden, psychosocial stress, and limited supportive and follow-up services (3, 4). Poor quality of life affects patients, families, and health system performance by contributing to lower treatment adherence, a higher risk of complications, and increased long-term service use. Consequently, gains in survival are insufficient unless accompanied by strategies to improve daily functioning and long-term well-being.

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2. Objectives

This policy brief provides an actionable, evidence-based response to this gap. Drawing on findings from a clinical intervention conducted in a routine care setting in southeastern Iran, it identifies structured follow-up care as a feasible policy option to improve the quality of life of patients with thalassemia major. Given the growing number of patients and the ongoing limitations of treatment-centered care alone, timely action is needed to integrate follow-up care into chronic disease management frameworks. This integration has the potential to improve patient outcomes, strengthen continuity of care, and increase the value of existing investments in thalassemia services.

3. Methods

This policy brief was developed using evidence from a clinical trial conducted in 2020 at Hazrat Ali Asghar (AS) Hospital in Zahedan, Iran, which assessed the effect of a structured follow-up care model on quality of life in patients with thalassemia major. Sixty patients were recruited using convenience sampling and randomly allocated to the intervention and control groups. The intervention comprised patient education, psychological support, and family involvement, whereas the control group received routine care. Quality of life was measured using the brief version of the World Health Organization Quality of Life questionnaire (WHOQOL-BREF) at baseline and at 1 and 3 months after the intervention. The policy options presented in this brief were identified based on the intervention components, observed outcomes, and their feasibility within existing service settings. The study received ethics approval from Zahedan University of Medical Sciences (IR.ZAUMS.REC.1399.169) and was registered in the Iranian Registry of Clinical Trials (IRCT20200926048842N1).

4. Results

Implementation of the structured follow-up care model significantly improved quality-of-life outcomes among patients with thalassemia major and was feasible in existing care settings.

5. Discussion

5.1. Key Policy Options and Messages

Continuous care models have also improved quality of life in patients with heart failure (5).

- Integrate structured follow-up care into routine thalassemia services to address persistent quality-of-life gaps that treatment-focused care alone does not resolve.
- Adopt a nurse-led follow-up model based on structured education, psychosocial support, and regular patient contact to strengthen continuity of chronic care.
- Implement the model within existing thalassemia centers and public hospitals, as it is noninvasive and can be delivered with minimal additional cost or infrastructure.
- Include patient and family education as a core component of care, as family involvement supports adherence, self-management, and long-term effectiveness.
- Plan gradual scale-up through existing chronic disease programs, with attention to staff training, service coordination, and routine monitoring.
- Anticipate system-level benefits, including improved patient-centered outcomes, fewer avoidable complications, and more efficient use of chronic care services.

5.2. Description of the Policy Options

The following policy options were identified to address persistent quality-of-life gaps in thalassemia major care. Together, they provide a practical framework for integrating structured follow-up care into routine services. Each option is described in terms of its purpose, advantages, limitations, feasibility, and the key actors responsible for implementation (Table 1).

Overall, these policy options are complementary rather than competing. Integrating structured follow-up care into routine thalassemia services, supported by nurse-led delivery, patient and family education, implementation through existing facilities, and gradual scale-up with monitoring, offers a feasible, evidence-informed strategy to improve quality of life while strengthening chronic care performance.

5.3. Implementation Considerations

Successful implementation of the follow-up care model will depend on gradual integration into existing thalassemia services, supported by clear managerial oversight and clearly defined staff responsibilities.

Key enabling factors include the low-cost, noninvasive nature of the intervention, its reliance on existing service platforms, and the central role of nurses in chronic care

Table 1. Description of the Policy Options and Their Advantages and Disadvantages

Policy option	Description/rationale	Main advantages	Main disadvantages/risks	Feasibility/cost considerations	Key implementers
1. Integrate structured follow-up care into routine thalassemia services	This option incorporates follow-up care into standard thalassemia management to address needs that routine treatment alone does not fully meet, particularly in relation to quality of life, continuity of care, and long-term support.	Addresses physical, psychosocial, and social dimensions of care; strengthens continuity; improves patient-centered outcomes; aligns with chronic care principles.	Requires organizational commitment, role clarification, and coordination across providers; may face resistance if added to already busy services.	Relatively feasible because it builds on existing services; does not require major infrastructure; modest additional costs are mainly related to coordination, staff time, and supervision.	Ministry of Health, hospital administrators, thalassemia centers, clinical managers.
2. Use a nurse-led follow-up model	In this option, nurses play the central role in delivering structured education, psychosocial support, follow-up contacts, and care coordination. This reflects evidence that nurse-led models are practical for chronic disease management.	Makes efficient use of the existing workforce; strengthens continuity and accessibility of care; supports early identification of patient problems; enhances patient trust and engagement.	Success depends on adequate staffing, training, and clear role definitions; workload pressures may reduce consistency of delivery.	High feasibility in public hospitals and specialty clinics where nurses are already involved in chronic care; costs are mainly related to training, protected staff time, and ongoing supervision.	Nursing managers, hospital leadership, thalassemia clinic teams, professional training units.
3. Institutionalize patient and family education as a core component of care	This option formalizes structured education and family engagement within routine service delivery. It recognizes that long-term management of thalassemia depends on treatment, adherence, self-management, and informed family support.	Improves adherence and self-care; strengthens family support; may reduce treatment fatigue and prevent avoidable complications; promotes sustainability of care outside the clinical setting.	Effectiveness may vary according to family capacity, literacy, and willingness to engage; educational materials and sessions must be culturally appropriate.	Feasible with limited additional cost if integrated into routine clinic visits and follow-up processes; requires development of simple educational materials and staff guidance.	Care teams, nurses, patient educators, families, hospital education units.
4. Implement the model through existing hospitals and thalassemia centers	This option delivers follow-up care through current public hospitals and thalassemia centers rather than creating a new parallel program. The rationale is to improve care quality while minimizing disruption and cost.	Supports rapid implementation; avoids major structural expansion; increases acceptability within the health system; promotes efficient use of existing resources.	Existing facilities may differ in staffing, organization, and readiness; uneven implementation across settings is possible.	Good feasibility because the intervention is noninvasive and service-based; resource needs are limited, but local adaptation may be needed depending on clinic capacity.	Public hospitals, thalassemia centers, provincial health authorities, service managers.
5. Scale up gradually through chronic disease programs with monitoring systems	This option expands follow-up care in phases and links scale-up to staff training, service coordination, and routine monitoring. It allows the health system to test, refine, and institutionalize the model over time.	Supports manageable expansion; enables learning during implementation; improves accountability; generates data for policy refinement and future investment decisions.	Requires reliable indicators, data systems, and sustained managerial attention; weak monitoring may reduce impact and policy credibility.	Moderate feasibility if integrated into existing chronic disease monitoring structures; additional costs relate to indicator development, data collection, and review mechanisms rather than expensive infrastructure.	Health policymakers, program managers, monitoring units, hospital managers, clinic supervisors.

delivery. Likely barriers include limited staff time, uneven training capacity, and variation in patient and family engagement. Implementation should therefore be accompanied by simple monitoring indicators, including staff training coverage, delivery of follow-up contacts, patient and family participation, and changes in quality-of-life outcomes. Pilot implementation in selected thalassemia centers may support local adaptation before broader expansion. Additional evidence on long-term sustainability, cost-effectiveness, and applicability to other chronic disease settings would further inform future policy development.

5.4. Conclusions and Next Steps

Thalassemia major care must now move beyond survival-focused treatment alone. The evidence presented in this policy brief indicates that structured follow-up care is a feasible and practical approach to improving patients' quality of life within existing health service settings. Integrating this model into routine thalassemia care could

strengthen continuity, patient support, and the overall responsiveness of chronic disease services. The next step is to translate this evidence into implementation. Health authorities and service managers should begin phased adoption within routine thalassemia programs, supported by staff training, patient and family education, and simple monitoring systems. Early implementation in selected centers can inform broader scale-up and help ensure that improvements in survival are matched by meaningful improvements in daily life and well-being.

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Footnotes

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Data Availability: The dataset presented in the study is available on request from the corresponding author during submission or after publication.

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IR.ZAUMS.REC.1399.169) and was registered with the clinical trial (identifier: IRCT20200926048842N1).

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