



## THE IMPACT OF CARING FOR A CHILD WITH THALASSEMIA ON MATERNAL HEALTH: A MIXED-METHODS STUDY

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### ABSTRACT

**Background:** Thalassemia is a lifelong inherited blood disorder requiring continuous medical care. Although therapeutic advances have improved survival, caregiving responsibilities create substantial demands on families, especially mothers who commonly serve as primary caregivers. **Objective:** To evaluate the psychological, emotional, and physical impact of caring for a child with thalassemia on maternal well-being and to assess the role of support systems. **Methods:** A mixed-methods study involving 20 mothers of children with thalassemia attending a tertiary care center was conducted. Data were collected using structured questionnaires and semi-structured interviews assessing anxiety, burnout, sleep disturbances, fatigue, social isolation, and perceived support. Quantitative data were summarized descriptively, and qualitative responses were thematically analyzed. **Results:** Chronic anxiety was reported by 65% of participants, caregiver burnout by 58%, and sleep disturbances by 61%. Social isolation affected 52% of mothers, while depressive symptoms were reported by 40%. Frequent hospital visits were identified as a major stressor by 72% of participants. Support from family and healthcare professionals played an important protective role. **Conclusion:** Mothers caring for children with thalassemia experience substantial psychological and physical strain. Integrating caregiver-centered counseling and structured support programs into thalassemia care may improve both caregiver and patient outcomes.

**KEYWORDS:** Thalassemia, caregiver burden, maternal health, psychological stress, chronic illness, family-centered care.

### INTRODUCTION

Thalassemia is one of the most common inherited hemoglobin disorders worldwide, particularly prevalent in South Asia, the Mediterranean region, and the Middle East.<sup>[1]</sup> Advances in transfusion therapy and iron chelation have markedly improved survival; however, management requires lifelong treatment and regular hospital visits.<sup>[2]</sup>

In many households, mothers assume primary caregiving responsibilities. Continuous medical dependence, fear of complications, financial strain, and uncertainty regarding long-term outcomes can negatively influence maternal emotional and physical health.<sup>[3]</sup> Caregiver burden in chronic pediatric illnesses has increasingly been recognized, yet caregiver well-being often remains under-addressed in routine clinical care.<sup>[4]</sup>

This study explores the multidimensional impact of caregiving for children with thalassemia on maternal

health and highlights the need for supportive interventions.

### AIM AND OBJECTIVES

#### Aim

To assess the psychological and physical impact of caring for a child with thalassemia on maternal health.

#### Objectives

- Identify psychological challenges such as anxiety and burnout.
- Assess caregiving-related physical health complaints.
- Evaluate the role of family and healthcare support systems.
- Highlight the need for caregiver-centered support interventions.

## METHODOLOGY

A mixed-methods study design was used. Twenty mothers of children diagnosed with thalassemia were enrolled during routine clinic visits at a tertiary care center. Participants represented diverse socioeconomic backgrounds.

### Data collection methods included

Semi-structured interviews exploring caregiving experiences.

Structured questionnaires assessing anxiety, fatigue, sleep disturbances, burnout, social isolation, and perceived support.

Quantitative data were analyzed descriptively, while interview responses underwent thematic interpretation.

## RESULTS

### Psychological and Emotional Impact

A substantial proportion of mothers reported persistent emotional distress. Anxiety related to disease progression and treatment complications was common. Emotional exhaustion and worry regarding repeated hospital visits and uncertainty about the child's future were frequently expressed. Social isolation due to caregiving demands was also commonly reported.

### Physical Health Impact

Sleep disturbances and persistent fatigue were widely reported. Several mothers described stress-related symptoms such as headaches and gastrointestinal discomfort. Limited opportunity for self-care and reduced physical activity further contributed to exhaustion.

### Role of Support Systems

Support from spouses and extended family members reduced caregiving stress. Mothers reporting empathetic engagement by healthcare professionals and connections with other caregivers demonstrated better coping abilities. However, structured community or NGO support was limited.

## DISCUSSION

The study findings highlight considerable caregiving burden among mothers of children with thalassemia. Similar psychological distress and reduced quality of life among caregivers have been reported internationally.<sup>[5-7]</sup>

Factors contributing to caregiver stress include financial pressures, chronic medical dependence, repeated hospital visits, and uncertainty regarding outcomes. Supportive family environments and empathetic healthcare interactions help mitigate emotional strain. Evidence suggests caregiver education programs, counseling services, and peer support networks improve caregiver resilience.<sup>[8-10]</sup>

## CONCLUSION

Maternal caregivers of children with thalassemia experience significant psychological and physical challenges that often remain unrecognized in routine clinical practice. Incorporating caregiver screening, counseling, and structured support services into thalassemia care programs is essential. A comprehensive family-centered care approach can improve quality of life for both patients and caregivers.

### Recommendations

- Routine psychological screening for caregivers.
- Establishment of caregiver support groups.
- Access to counseling and mental health services.
- Inclusion of caregiver education programs in treatment protocols.
- Strengthening community and NGO-based support systems.

### Ethical Considerations

Participation was voluntary, and confidentiality of participant information was maintained. Informed consent was obtained prior to data collection.

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### Conflict of Interest

The authors declare no conflict of interest.

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