



www.bioinformation.net
Volume 22(9)



Research Article

Received September 1, 2026; Revised September 30, 2026; Accepted September 30, 2026, Published September 30, 2026

DOI: 10.6026/973206300225884

SJIF 2026 (Scientific Journal Impact Factor for 2026) = 8.478

2022 Impact Factor (2023 Clarivate Inc. release) is 1.9

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Citation: Hariharaputhiran *et al.* Bioinformation 22(9): 5884-5888 (2026)

Maternal illness linked cognition and psychological well-being in Chennai

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Abstract:

Thalassemia places a substantial caregiving burden on mothers, yet its psychological impact remains underexplored in India. Therefore, it is of interest to assess the illness cognition and psychological well-being among 60 mothers of children with thalassemia in Chennai. Most mothers had moderate illness cognition (73.33%) and low psychological well-being (68.33%). Illness cognition correlated positively with psychological well-being ($r=0.36$, $p=0.01$) and both were associated with maternal age, education and family type ($p\leq 0.05$). Thus, data shows that integrating illness-cognition assessment with psychosocial support into routine thalassemia care to improve maternal outcomes.

Keywords: Thalassemia, mothers, caregivers, cognition, psychological well-being, mental health, cross-sectional studies

Background:

Thalassemia is one of the world's most common monogenic disorders, articulated by impaired globin-chain synthesis, chronic hemolytic anemia and lifelong dependence on blood transfusion and iron-chelation therapy in its severe forms [1]. India shoulders a disproportionate share of this burden: an estimated carrier prevalence of 3–4% (rising to 17% in certain communities) translates to roughly 35–45 million carriers and approximately 10,000 children are born each year with transfusion-dependent thalassemia [2, 3]. The constant cycle of monthly transfusions, hospital visits, financial strain and uncertainty about the child's future creates a parallel and often invisible burden on the family, particularly mothers. Mothers of children with chronic illness are known to experience markedly higher rates of depressive and anxiety symptoms than the general population [4]. In thalassemia, more than half of mothers have been reported to suffer clinically significant depression, anxiety or stress and the magnitude of distress correlates with frequency of transfusion, treatment cost and concern about the child's future [5]. Caregiver burden is consistently inversely related to maternal psychological well-being and the constraints of long-term caregiving are reflected in poor health-related quality of life, disrupted family routines and social withdrawal [6, 7]. How a mother makes sense of her child's illness, termed parental illness cognition, is a key but often overlooked psychological mediator. Illness cognition captures three generic ways of dealing with a chronic disease: helplessness, acceptance and perceived benefits [8]. Helplessness emphasises the aversive meaning of the disease, whereas acceptance and perceived benefits represent adaptive cognitions that protect mental health [9]. Among parents of children with chronic illness, maladaptive cognitions are linked with higher distress and lower quality of life, while acceptance correlates with better adjustment [10]. In spite of this conceptual clarity, very few quantitative studies in South Asia have examined illness cognition in mothers of Thalassemia children and almost none have linked it directly to standardised measures of psychological well-being. Studies have reported the prevalence of depression in mothers of children

with thalassemia or blood malignancies to be above 50% [11] and data have showed higher psychiatric symptom scores among mothers caring for children compliant with chelation therapy [12]. In a study, caregiver burden has been shown to negatively predict psychological well-being, with self-acceptance and personal growth emerging as strong protective dimensions [13]. Structured interviews with adolescents on transfusion-dependent thalassemia have documented adverse psychosocial impact in 70–72% of education- and sports-related domains, signaling parallel strain on caregiving parents [14]. Therefore, it is of interest to evaluate the illness cognition and psychological well-being among mothers of children with thalassemia and to examine their demographic and clinical determinants in a South Indian tertiary-care setting.

Materials and Methods:

A descriptive, cross-sectional, hospital-based study was conducted in the Department of Paediatric Haematology at the Institute of Child Health and Hospital for Children, Chennai. Data were collected over a four-week period. Biological mothers of children aged 1–12 years with thalassemia diagnosed at least six months earlier; ability to understand Tamil or English; and willingness to provide informed consent were included in the study. Mothers of children with co-morbid chronic illnesses, critically ill children, or children with psychological/cognitive impairment were excluded. The sample size was calculated using a published proportion ($p=83.99\%$) of moderate-to-good psychological well-being among Indian Thalassemia caregivers [15], with 95% confidence and 10% relative precision; the resulting estimate of 52 was rounded up to 60 to allow for non-response. A non-probability convenience sampling technique was used. Socio-demographic Questionnaires of the mother and the child, clinical variables, Illness Cognition Questionnaire-Parent version (ICQ-P) and Carol Ryff's 18-item Psychological Well-being Scale were used to collect data [16]. After approval from the Institutional Ethics Committee (Madras Medical College, Chennai) and administrative permission from the institute's director, eligible mothers were approached

individually in the day-care waiting area. The aim, procedure, voluntary nature, anonymity and right to withdraw were explained in the participant's preferred language; written informed consent was obtained. Each face-to-face administration took 20–25 minutes in a quiet space. Data were entered in Microsoft Excel and analysed using IBM SPSS version 26. A two-tailed p-value of <0.05 was considered statistically significant.

Results:

The combined socio-demographic, clinical and outcome profile is presented in (Table 1). Most mothers (56.67%) were aged 26–35 years, 35.00% had completed secondary education and 73.33% were homemakers. Most belonged to nuclear families (60.00%) and 73.33% earned less than ₹20,000 per month. Among the children, 70.00% were male, 40.00% were aged 1–3 years, 96.66% had thalassemia major, 96.67% had received their first transfusion before 12 months of age and 98.33% were on monthly transfusions and regular iron chelation. A family history of thalassemia was reported by 56.67% of mothers. The mean ICQ-P score was 42.02±9.45, representing 58.36% of the

maximum possible score; the mean Ryff score was 60.10±9.45, representing 47.70% of maximum. As shown in (Figure 1), most mothers (73.33%) had moderate illness cognition with only 6.67% in the low category, but two-thirds (68.33%) reported low psychological well-being and none scored in the high range. A significant positive moderate correlation was found between parental illness cognition and psychological well-being ($r=0.36$, $p=0.01$), indicating that mothers with more adaptive illness cognition reported better psychological well-being. Statistically significant associations were observed between illness cognition and mother's age ($\chi^2=7.94$, $p=0.05$), educational qualification ($\chi^2=11.58$, $p=0.01$) and family type ($\chi^2=6.29$, $p=0.01$). The same variables were associated with psychological well-being-age ($\chi^2=6.40$, $p=0.05$), education ($\chi^2=14.01$, $p=0.01$) and family type ($\chi^2=4.15$, $p=0.05$). Figure 2 shows that younger, less educated and joint-family mothers consistently fared worse on both outcomes. None of the clinical variables (thalassemia type, age at first transfusion, transfusion frequency, chelation status, hospitalisation history) showed significant associations.

Table 1: Socio-demographic profile, clinical characteristics and outcome distribution of mothers of children with thalassemia (n=60).

Variable	Category	Frequency (n)	Percentage (%)
Age of mother (years)	18–25	6	10
	26–35	34	56.67
	36–45	20	33.33
Educational qualification	Informal education	8	13.33
	Primary	15	25
	Secondary	21	35
	Higher secondary	16	26.67
Occupation	Homemaker	44	73.33
	Daily wages	12	20
	Private/Self-employed	4	6.67
Type of family	Nuclear	36	60
	Joint	24	40
Monthly family income (₹)	<20,000	44	73.33
	20,001–40,000	15	25
	>40,000	1	1.67
Family history of thalassemia	Yes	34	56.67
	No	15	25
	Don't know	11	18.33
Child's age (years)	1–3	24	40
	4–6	14	23.33
	7–9	9	15
	10–12	13	21.67
Child's gender	Male	42	70
	Female	18	30
Type of thalassemia	Major	58	96.66
	Minor	1	1.67
	Intermedia	1	1.67
Transfusion frequency	Monthly	59	98.33
	Bi-weekly	1	1.67
Iron-chelation therapy	Yes, regularly	59	98.33
	Yes, occasionally	1	1.67
Parental illness cognition	Low	4	6.67
	Moderate	44	73.33
	High	12	20
Psychological well-being	Low	41	68.33
	Moderate	19	31.67
	High	0	0

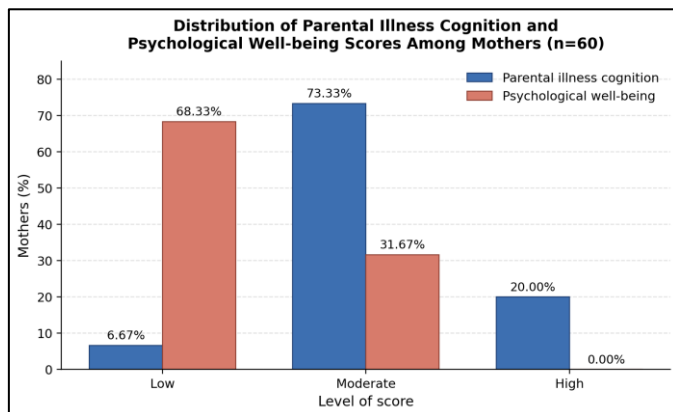


Figure 1: Distribution of parental illness cognition and psychological well-being score levels among mothers of children with thalassemia (n=60)

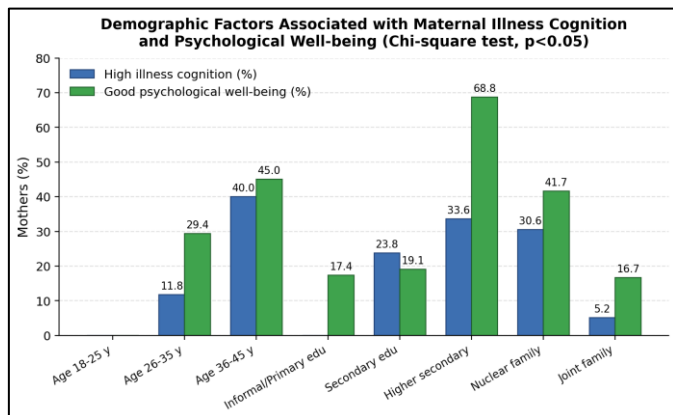


Figure 2: Demographic factors significantly associated with maternal illness cognition and psychological well-being (chi-square test, $p < 0.05$)

Discussion:

The two central findings of this study, predominantly moderate illness cognition (73.33%) yet predominantly low psychological well-being (68.33%) among mothers of children with thalassemia mirror a broader regional pattern. A multi-hospital study similarly found that although a sizable subset of caretakers reported anxiety or depressive symptoms, many drew on adaptive cognitions and religious coping such as acceptance and positive reframing to manage their burden [17]. Comparable data have shown that parents of children with thalassemia can show reasonable understanding of the illness while still suffering substantially impaired well-being in caregivers scored 30–40 points lower on Ryff's scale than reference samples, with self-acceptance and personal growth being the most consistent predictors of quality of life [18]. Our finding that no mother reached the high psychological well-being category dovetails with these reports and underscores the universality of caregiver distress in transfusion-dependent thalassemia. The significant positive correlation between illness cognition and psychological well-being ($r=0.36$, $p=0.01$) supports the hypothesis that

adaptive cognitive appraisals acceptance and perceived benefits rather than helplessness buffer maternal mental health. A previous study reported a positive relationship between family well-being and the quality of life of children with thalassemia [15], suggesting that interventions strengthening maternal cognition could indirectly benefit the child. Likewise documented psychiatric morbidity in the majority of caregivers of children with thalassemia and emphasized the under-utilization of mental-health services in this group [19]. The associations of age, education and family type with both outcomes warrant attention. Younger, less educated mothers, who are typically newer to the diagnosis, may lack the health literacy needed to translate clinical information into adaptive cognition. Counter-intuitively, joint-family residence was associated with poorer outcomes, possibly because of layered demands of multigenerational caregiving and intra-family stigma rather than the protective social support traditionally attributed to such structures. Limitations include the single-center design, modest sample size, brief data-collection window and reliance on self-report. Targeted, culturally adapted psychoeducational and peer-support interventions, integrated into transfusion visits, are likely to yield meaningful gains in maternal well-being and paediatric outcomes.

Conclusion:

Routine nurse-led screening with brief, validated instruments, combined with structured illness-cognition counselling and peer-support programmes, should be embedded in transfusion-day services. Strengthening maternal mental health is a clinically pragmatic strategy that supports better treatment adherence, family stability and the long-term outcomes of children living with thalassemia.

Declarations:

Ethical approval: Obtained from the Institutional Ethics Committee, Madras Medical College, and Chennai.

Funding: No external funding.

Conflicts of interest: The authors declare no conflicts of interest.

Acknowledgments: The authors thank the participating mothers and the staff of the Department of Pediatric Hematology, Institute of Child Health, and Chennai.

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