ORIGINAL ARTICLE ÖZGÜN ARAŞTIRMA

Depressive Symptoms in Primary Caregivers of Children with Beta-thalassemia

Beta-talasemili Çocukların Birincil Bakım Verenlerinde Depresif Belirtiler

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Abstract

Introduction: Beta-thalassemia major is a chronic hematologic condition that requires lifelong medical care and imposes substantial psychosocial demands on families. Primary caregivers, particularly parents, face ongoing emotional, financial, and practical stressors that may place them at increased risk for depressive symptoms. Despite this burden, routine screening for caregiver mental health remains limited in many pediatric settings. This study aimed to assess depressive symptoms among primary caregivers of children with beta-thalassemia major using the Patient Health Questionnaire-2 (PHQ-2) and to explore potential associations with sociodemographic and clinical characteristics.

Materials and Methods: This cross-sectional descriptive study included 49 primary caregivers of children with beta-thalassemia major followed at a tertiary pediatric hematology center in Türkiye. Data were collected using a structured sociodemographic questionnaire and the PHQ-2. Relationships between depressive symptoms and caregiver- and child-related variables were examined.

Results: Sixteen percent of caregivers scored above the PHQ-2 cutoff, indicating increased risk for depression. PHQ-2 scores did not differ significantly according to the child's gender, transfusion frequency, medication use, or presence of medical complications. Similarly, no significant associations were found with parental age, education level, chronic illness, household income, household size, or immigration status. Although not statistically significant, higher depressive symptom scores were observed among caregivers with first-degree relatives affected by chronic illness and among those whose children did not receive formal social support services.

Conclusion: A meaningful proportion of caregivers of children with beta-thalassemia major exhibited elevated depressive symptoms, even in the absence of clear sociodemographic or clinical predictors. These findings highlight the importance of incorporating brief mental health screening tools into routine pediatric hematology follow-up and emphasize the need for multidisciplinary approaches that address both medical and psychosocial aspects of chronic childhood illness. Further studies with larger samples are warranted to better identify risk factors and to inform targeted support strategies for caregivers.

Keywords
Beta-thalassemia, caregiver, depressive signs

Anahtar kelimeler
Beta talasemi, bakım veren, depresyon bulguları

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Öz

Giriş: Beta-talasemi majör, yaşam boyu süren tedavi gereksinimi olan kronik bir hastalık olup yalnızca çocukları değil, bakım veren aile üyelerini de önemli ölçüde etkilemektedir. Süregelen hastane ziyaretleri, tedaviye bağlı yük ve geleceğe yönelik belirsizlikler, birincil bakım verenlerde ruhsal zorlanmaya yol açabilmektedir. Bu çalışmanın amacı, beta-talasemili çocukların birincil bakım verenlerinde depresif belirtilerin sıklığını Patient Health Questionnaire-2 (PHQ-2) ile değerlendirmek ve bu belirtilerin sosyodemografik ve klinik değişkenlerle ilişkisini incelemektir.

Gereç ve Yöntem: Bu kesitsel tanımlayıcı çalışmaya, üçüncü basamak bir çocuk hematoloji merkezinde izlenen beta-talasemi majör tanılı çocukların 49 birincil bakım vereni dahil edilmiştir. Veriler, sosyodemografik özellikleri içeren yapılandırılmış anket formu ve PHQ-2 ölçeği kullanılarak toplanmıştır. Depresif belirtiler ile bakım verene ve çocuğa ait değişkenler arasındaki ilişkiler değerlendirilmiştir.

Bulgular: Bakım verenlerin %16'sının PHQ-2 eşik puanının üzerinde skor aldığı ve depresyon açısından risk altında olduğu saptanmıştır. PHQ-2 skorları; çocuğun cinsiyeti, transfüzyon sıklığı, medikal komplikasyon varlığı ve ilaç kullanımı gibi klinik değişkenlere göre anlamlı farklılık göstermemiştir. Benzer şekilde, ebeveyn yaşı, eğitim düzeyi, kronik hastalık öyküsü, hane geliri ve göçmenlik durumu ile depresif belirtiler arasında anlamlı bir ilişki bulunmamıştır. Bununla birlikte, birinci derece akrabasında kronik hastalık bulunan bakım verenlerde ve sosyal destek hizmetlerinden yararlanmayan çocukların bakım verenlerinde depresif belirti puanlarının daha yüksek olduğu gözlenmiştir; ancak bu fark istatistiksel olarak anlamlı değildir.

Sonuç: Beta-talasemili çocukların bakım verenlerinin kayda değer bir bölümünde depresif belirtiler bulunmasına karşın, bu durumun belirgin sosyodemografik ya da klinik yordayıcıları saptanamamıştır. Bulgular, pediatrik hematoloji izleminde bakım verenlerin ruh sağlığının kısa tarama araçlarıyla rutin olarak değerlendirilmesinin önemini vurgulamaktadır. Ayrıca, kronik hastalık yönetiminde yalnızca tıbbi değil, psikososyal boyutları da kapsayan bütüncül yaklaşımlara gereksinim olduğunu göstermektedir.

Introduction

β-thalassemia major (β-TM) is an autosomsbal recessive hemoglobinopathy characterized by impaired production of the beta-globin chain. This condition is particularly prevalent in the Mediterranean region and is typically diagnosed in early childhood, requiring lifelong medical management. Children diagnosed with β-TM depend on regular red blood cell transfusions and iron chelation therapy to sustain life (1). These medical requirements not only affect the physical health of the child but also significantly impact the family system and the psychological well-being of the primary caregivers. The presence of chronic illnesses during childhood represents a substantial source of stress, particularly for primary caregivers. Continuous hospital visits, financial burdens of treatment, uncertainties regarding the child's quality of life, and social isolation are among the factors that may negatively influence the mental health of parents (2). Depression is one of the most commonly reported psychological problems among this group. Studies have shown that parents of children with chronic illnesses exhibit higher levels of depressive symptoms compared to the general parent population (3).

Studies from different sociocultural contexts have reported inconsistent findings regarding depressive symptoms among families of children with β-TM. Research from Sri Lanka and Pakistan highlights an increased psychosocial burden among parents, with coping being influenced by caregiver burden and spiritual beliefs (4,5). In Türkiye, depression was reported in 13.15% of parents of children with β-TM (6). Overall, low socioeconomic status, limited education, insufficient social support, and gender have consistently been identified as key factors associated with parental depression (7). Depressive symptoms not only diminish the quality of life of parents but may also adversely affect the child's treatment adherence, developmental outcomes, and overall psychosocial functioning. Therefore, early identification and provision of psychological support services are as crucial as the medical follow-up of the child.

In Türkiye, studies focusing on depression screening among parents of children with chronic pediatric conditions such as β-TM remain limited. This study aims to assess the prevalence of depressive symptoms using the Patient Health Questionnaire-2 (PHQ-2) among parents of children with β-TM followed at Ankara Bilkent City Hospital, and to explore potential associations between depressive symptoms and parental sociodemographic characteristics. The findings of this study are expected to highlight the need for psychosocial support and contribute to the development of follow-up policies.

Materials and Methods

This cross-sectional descriptive study was conducted to evaluate the depression levels of mothers of children diagnosed with β-TM followed in the Pediatric Hematology Department of City Hospital. The study included mothers of 49 children with β-TM aged between 7 and 18 years.

Children whose mothers declined participation or could not be reached were excluded from the study. Data were collected using a sociodemographic information form and the Patient Health Questionnaire-2 (PHQ-2). The PHQ-2 is a brief screening tool that assesses depressive symptoms experienced in the past two weeks, with total scores ranging from 0 to 6 (8,9).

The relationships between PHQ-2 scores and various factors, such as the child's gender, age group, parental education, presence of chronic illness, medication use, transfusion frequency, and household income level, were statistically analyzed. In addition to medical and sociodemographic data, the study assessed whether families had obtained the "Report for Children with Special Needs" (ÇÖZGER), which is a formal document issued in Türkiye to facilitate children's access to educational and social support services (10). Ethical approval was obtained from the Scientific and Ethical Evaluation Board for Medical Research (TABED; approval no.: 2-25-1051, date: 19.03.2025). Statistical analyses were performed using IBM SPSS Statistics for Windows, Version 20.0 (IBM Corp., Armonk, NY, USA). The normality of distribution for continuous variables was assessed using the Shapiro-Wilk test. For comparisons between two groups with normally distributed data, the independent samples Student's t-test was used, while one-way analysis of variance (One-Way ANOVA) was applied for comparisons involving more than two groups. For non-normally distributed data, non-parametric tests such as the Mann-Whitney U test and the Kruskal-Wallis test were employed. A p-value of <0.05 was considered statistically significant for all analyses.

Results

A total of 49 primary caregivers of children with β-TM were included in the study. The relationships between caregiver depressive symptoms (measured via PHQ-2) and various sociodemographic and clinical variables were examined.

Depressive symptom scores (PHQ-2) did not significantly differ according to the child's gender (female: M = 2.03, SD = 0.94; male: M = 2.30, SD = 0.98; p = 0.345). Similarly, medication use (yes: M = 2.16, SD = 0.91; no: M = 2.00, SD = 1.41; p = 0.729) and transfusion frequency (3 weeks: M = 2.16; 4 weeks: M = 2.08; p = 0.692) were not associated with statistically significant differences in PHQ-2 scores.

Although not statistically significant, caregivers of children with medical complications reported higher mean PHQ-2 scores (M = 2.27, SD = 1.03) compared to those without complications (M = 2.09, SD = 0.93; p = 0.553). Similarly, caregivers of children without a ÇÖZGER (Report for Children with Special Needs) had higher PHQ-2 scores than those with the report (2.27 vs. 2.04; p = 0.397). Receiving a social support payment through ÇÖZGER was also associated with slightly higher mean scores (2.29 vs. 2.09; p = 0.515), though this was not statistically significant.

No significant differences were observed in PHQ-2 scores in relation to mother's age (<35: M = 2.13; ≥35: M = 2.15; p = 0.909), mother's education level (<8 years: M = 1.94; ≥8 years: M = 2.26; p = 0.370), or mother's chronic illness (yes: M = 2.00; no: M = 2.17; p = 0.303).

For fathers, neither age (<35: M = 2.00; ≥35: M = 2.24; p = 0.338) nor education (<8 years: M = 2.33; ≥8 years: M = 2.03; p = 0.328) was significantly associated with PHQ-2 scores. Caregivers whose fathers were unemployed had higher PHQ-2 scores than those whose fathers were employed; however, this difference was not statistically significant (p = 0.102).

A trend toward higher depressive symptoms was also noted among caregivers with first-degree relatives with chronic illness (M = 2.47, SD = 0.87) compared to those without (M = 1.97, SD = 0.97), though the difference was not statistically significant (p = 0.074).

Household income (≤ minimum wage: M = 2.22; > minimum wage: M = 1.92; p = 0.371) and household size (≤4 persons: M = 2.07; ≥5 persons: M = 2.17; p = 0.745) were also not significantly associated with PHQ-2 scores.

Across all analyses, none of the sociodemographic or clinical variables demonstrated statistically significant associations with caregiver depressive symptoms ($p > 0.05$) (Table 1).

Discussion

In this study, 16% of parents of children with β-TM scored above the PHQ-2 cutoff, indicating increased risk for depression. No significant associations were found between parental PHQ-2 scores and children's sociodemographic or clinical characteristics. These findings suggest that parental psychological well-being in β-TM may not be directly determined by the child's clinical profile or socioeconomic factors.

Compared to previous literature, the proportion of parents scoring above the PHQ-2 cutoff in this sample was lower. While research from Malaysia, Sri Lanka, and Pakistan has documented relatively high rates of depressive symptoms among caregivers of children with β-thalassemia major (β-TM), ranging from 29% to over 60%, a study from Türkiye reported prevalence rates comparable to our findings (4,6,11-15). These cross-national differences may reflect variations in sociocultural contexts and the presence of protective factors.

Table 1. Variables that may influence Patient Health Questionnaire-2 (PHQ) scores

Variables	n (%)	Mean PHQ score (SD)	Statistical test (F/t; p)
Gender			
Female	29 (59.2)	2.03 (0.94)	0.953; 0.345
Male	20 (40.8)	2.30 (0.98)	
Medication use			
Yes	44 (89.8)	2.16 (0.91)	0.349; 0.729
No	5 (10.2)	2.00 (1.41)	
Transfusion frequency			
3 weeks	37 (75.5)	2.16 (0.16)	0.574; 0.692
4 weeks	12 (24.5)	2.08 (0.26)	
Complication status			
Yes	15 (30.6)	2.27 (1.03)	0.597; 0.553
No	34 (69.4)	2.09 (0.93)	
Report for Children with Special Needs (ÇÖZGER)			
Yes	27 (55.2)	2.04 (1.13)	0.855; 0.397
No	22 (44.9)	2.27 (1.03)	
Immigrant status			
Turkish	18 (36.7)	2.00 (0.94)	244.0; 0.335
Immigrant	31 (63.3)	2.23 (0.98)	
Social support payment granted through the Child Special Needs Report (ÇÖZGER)			
Yes	14 (28.6)	2.29 (1.07)	0.657; 0.515
No	35 (71.4)	2.09 (0.92)	
Mother's age			
<35 years	16 (32.7)	2.13 (0.50)	0.114; 0.909
≥35 years	33 (67.3)	2.15 (1.12)	
Mother's education			
<8 years	18 (36.7)	1.94 (1.11)	0.896; 0.370
≥8 years	31 (63.3)	2.26 (0.85)	
Mother's chronic illness			
Yes	9 (18.4)	2.00 (0.00)	1.045; 0.303
No	40 (81.6)	2.17 (1.06)	
Father's age			
<35 years	5 (10.2)	2.00 (0.00)	1.110; 0.338
≥35 years	40 (81.6)	2.24 (0.66)	
Father deceased	4 (8.2)	1.79 (1.00)	
Father's education			
<8 years	18 (36.7)	2.33 (1.02)	0.978; 0.328
≥8 years	31 (63.3)	2.03 (0.91)	
Father's chronic illness			
Yes	11 (22.4)	2.55 (1.29)	1.260; 0.231
No	38 (77.6)	2.03 (0.82)	
Working status of father			
Working	38 (77.6)	1.97 (0.75)	1.775; 0.102
Not working	11 (22.4)	2.73 (1.35)	
Paternal consanguinity			
Yes	38 (77.6)	2.05 (0.87)	1.025; 0.324
No	11 (22.4)	2.45 (1.21)	
Chronic illness in 1st degree relatives			
Yes	17 (34.7)	2.47 (0.87)	1.842; 0.074
No	32 (65.3)	1.97 (0.97)	
Household income			
≤ Minimum wage	36 (73.5)	2.22 (0.93)	0.915; 0.371
> Minimum wage	13 (26.5)	1.92 (1.04)	
Household size			
≤ 4	14 (28.6)	2.07 (1.14)	0.125; 0.745
≥ 5	35 (71.4)	2.17 (0.89)	

Although no statistically significant difference was found in our study, PHQ-2 scores were observed to be higher among parents who reported a history of chronic illness in first-degree relatives. This finding suggests that the presence of similar health conditions among family members, may contribute to increased psychological burden for caregivers. Supporting this, a study conducted in Bangladesh by Islam et al. (11) investigated depression levels among parents of children diagnosed with β-TM and reported that a family history of mortality due to β-TM was associated with higher depression scores among caregivers. This similarity highlights that the disease burden in relatives may have not only medical but also psychosocial consequences, underscoring the need for comprehensive support for these families.

Similarly, PHQ-2 scores were relatively higher among parents of children with β-TM living in households with income at or below the minimum wage, although this difference was not statistically significant. This finding suggests that β-TM, which is already more prevalent in low-income populations, may impose not only a medical but also an economic burden, thereby negatively affecting the mental well-being of families (16). Similarly, a study conducted in

Bangladesh demonstrated that parental depression scores were associated not only with household income levels but also with monthly treatment-related expenses (11). In our study, we did not specifically investigate treatment-related expenses, as all medical costs are covered by the government. However, factors such as frequent hospital visits may still impact the economic stability of families and adversely affect the mental health of caregivers.

Another notable finding of our study may be related to the presence of social support mechanisms. Parents who had obtained the ÇÖZGER (Report for Children with Special Needs) showed lower PHQ-2 scores, suggesting that the financial and social support provided by the state may contribute to greater psychological resilience. In Türkiye, the ÇÖZGER report allows families to access various social services and economic benefits based on the child's special needs. This finding indicates that social support systems contribute not only to financial stability but also to the mental well-being of caregivers. Therefore, expanding and tailoring social support programs based on individual needs may serve as an important strategy for promoting caregiver mental health.

With regard to clinical factors, no statistically significant association was observed between transfusion frequency and parental depression levels, although parents of children with medical complications showed relatively higher PHQ-2 scores. In contrast, previous studies have reported significant associations between transfusion-related factors and caregiver depression, suggesting that more intensive treatment and medical complications may increase psychological burden (4,11). The absence of a significant relationship in our study may be explained by the limited sample size and the higher mean age of the children, which may have given parents more time to adapt psychologically to chronic illness and the demands of long-term treatment.

Finally, no significant association was observed between immigrant status and parental PHQ-2 scores. Although migration has frequently been associated with increased psychological vulnerability among caregivers of children with chronic illnesses (16), this finding may reflect the influence of contextual protective factors such as access to healthcare services, social support networks, and adaptive coping mechanisms within our study population (17). This underscores the importance of considering sociocultural context when interpreting psychosocial risk among families of children with β-thalassemia major.

Study Limitations

One of the strengths of this study is that it was conducted in a major thalassemia center in Türkiye, providing access to a representative clinical population. Another strength is the use of a screening tool with established validity and reliability. However, the study has several limitations. Its cross-sectional design does not allow for causal inferences between variables. In addition, the relatively small sample size and the absence of a comparative control group limit the contextual interpretation of the observed depression levels.

Conclusion

In conclusion, although depressive symptoms were found to be higher among certain risk groups of caregivers of children diagnosed with β-TM, no statistically significant associations were identified in our study. These findings highlight the importance of integrating mental health assessments into routine follow-up protocols and indicate the need for further research with larger sample sizes to better understand the psychosocial needs of this population.

During the preparation of this work, the author(s) utilized ChatGPT (OpenAI) to assist with language editing. The tool was used to refine sentence structure, ensure coherence, and check grammar throughout the article. The validity and appropriateness of all AI-generated outputs were carefully reviewed, edited, and approved by the author(s). After thoroughly evaluating and modifying the content as needed, full responsibility for the publication's content is taken by the author(s). This incorporation of AI tool usage primarily impacted the language editing and phrasing aspects of the manuscript.

Ethics

Ethics Committee Approval: Ethical approval was obtained from the Scientific and Ethical Evaluation Board for Medical Research (TABED; approval no.: 2-25-1051, date: 19.03.2025).

Footnotes

Conflict of Interest: No conflict of interest was declared by the authors.

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