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Original Research Paper

The Association of Hospitalization with Parenting Stress and Quality of Life in Parents of Children with Thalassemia

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Abstract

Background: Children with thalassemia require repeated hospital attendance for transfusion and related care, which may contribute to parental stress and quality-of-life burden. **Objectives:** This study aimed to assess the association of hospitalization-related attendance with parenting stress and parental quality of life. **Methods:** This cross-sectional study included 35 parents of children with thalassemia at the NTB Provincial General Hospital. Parenting stress and quality of life were assessed using the PSI-SF and WHOQOL-BREF. Hospital attendance duration, frequency, and interval were analyzed using Spearman, chi-square, and Fisher's exact tests as appropriate. **Results:** Low parenting stress was reported by 68.6% of parents and very good quality of life by 88.6%. No statistically significant association was detected between hospital attendance duration, frequency, or interval and parenting stress (p=0.606, 0.884, and 0.121) or quality of life (p=0.951, 0.359, and 0.726). Splenomegaly was associated with parenting stress (p=0.020), and parental age was associated with quality of life (p=0.009). **Conclusion:** In this small cross-sectional sample, hospitalization-related attendance parameters were not significantly associated with parenting stress or parental quality of life; the findings should be interpreted cautiously because of limited statistical power.

Keywords: Hospitalization; Parenting stress; Quality of life; Thalassemia

Introduction

Thalassemia is an inherited hemoglobin disorder caused by abnormalities of alpha or beta globin synthesis, resulting in ineffective erythropoiesis and chronic anemia[1]. Thalassemia is commonly classified clinically as non transfusion dependent thalassemia (NTDT) or transfusion dependent thalassemia (TDT). Patients with TDT require regular blood transfusions[2,3]. Transfusions are commonly administered every two to four weeks, depending on clinical condition and hemoglobin targets[4].

Indonesia lies within the global thalassemia belt. National reports have documented a substantial burden of thalassemia, and patients with TDT require repeated transfusion services[4]. In West Nusa Tenggara (NTB), local screening data from Lombok have also identified individuals suspected of beta thalassemia trait[5]. Consequently, families of children with thalassemia may have repeated contact with hospital services for transfusion and disease monitoring.

Hospitalization traditionally refers to an inpatient stay, whereas routine transfusions for children with thalassemia may also be

delivered through One Day Care (ODC) or other short hospital attendance episodes. In this manuscript, the variable originally recorded as "hospitalization" is therefore interpreted operationally as transfusion related hospital attendance, which may include day care visits and longer inpatient episodes. Planned attendance is commonly related to transfusion, while unplanned inpatient care may occur because of complications. Hospital based treatment and repeated attendance can affect children and their families[6].

The well being of children with chronic illness and that of their parents are closely connected. Caring for a child with thalassemia requires continuing physical, emotional, and financial involvement. Previous studies have described substantial family and caregiver burden in thalassemia[1], and clinical management requires repeated contact with health services[2,3]. Research on this topic in NTB remains limited. Therefore, this study aimed to determine the association of hospitalization related attendance with parenting stress and parental quality of life among parents of children with thalassemia. The study also examined child, parent, and environmental characteristics as potential covariates.

The findings are expected to provide local evidence regarding parental stress and quality of life in families caring for children with thalassemia and to support future studies with larger samples and more comprehensive adjusted analyses.

Materials and Methods

Research Design

This study employed an analytical observational approach with a cross sectional design and was conducted at the NTB Provincial General Hospital from September to December 2024. The study examined the relationship between transfusion-related hospital attendance, parenting stress, and parental quality of life among parents of children with thalassemia. Parent, child, and environmental characteristics were considered potential covariates or confounding factors; however, they were not treated as confirmed confounders because no multivariable analysis was performed.

Sample

The study included 35 parents of children with thalassemia who were recruited using non-probability purposive sampling. The inclusion criteria were respondents who provided informed consent and were able to participate in the study; parents of children with thalassemia who had undergone at least one blood transfusion at the NTB Provincial General Hospital during the preceding three months; and parents of children aged 0–18 years. Respondents were excluded if they had severe physical or psychological conditions that could interfere with participation or were currently receiving medication for a mental health disorder diagnosed by a psychiatrist or psychologist.

Given a sample size of 35, a two-sided alpha level of 0.05, and 80% statistical power, a sensitivity calculation indicated that an absolute correlation of approximately 0.46 or greater could be detected. Therefore, smaller associations may not have been identified in this study.

Data Collection Techniques

Primary data consisted of parenting stress and parental quality of life. Parenting stress was assessed using the 36 item Parenting Stress Index Short Form (PSI-SF). Based on the scoring system applied in the study dataset, parenting stress was categorized as low (<60), moderate (60–83), and high (≥84). The term "low" was used consistently throughout the manuscript. An Indonesian version of the PSI-

SF has previously been used among Indonesian parent populations and demonstrated an internal consistency coefficient of α=0.82[7]. However, the available study documentation did not specify the exact language or version of the instrument administered to the present sample, and internal consistency was not reported for the current respondents.

Parental quality of life was measured using the 26 item World Health Organization Quality of Life BREF (WHOQOL-BREF). A revised official Bahasa Indonesia version of the WHOQOL-BREF has demonstrated moderate to good test retest reliability across its four domains in the Indonesian population[8]. In this study, the available dataset contained a transformed overall score ranging from 0 to 100, which was descriptively categorized as very poor (0–20), poor (21–40), moderate (41–60), good (61–80), and very good (81–100). Domain-specific WHOQOL BREF scores were not analyzed separately. These categories represent the operational classification used in the study and should not be interpreted as clinical diagnostic cutoffs.

Secondary data were obtained from medical records. The exposure variable, labeled "hospitalization" in the original dataset, was operationalized as transfusion related hospital attendance. Duration was defined as the number of hours spent at the hospital per attendance episode, frequency as the number of attendance episodes per month, and interval as the number of weeks between consecutive attendance episodes. In accordance with the eligibility criteria, these attendance variables were assessed for the preceding three months.

Data Analysis Techniques

Data were analyzed using univariate and bivariate statistical methods. Univariate analysis was used to summarize respondent characteristics and study variables using appropriate descriptive statistics. Bivariate analysis was performed using Spearman correlation for ordinal or non normally distributed continuous variables and chi square or Fisher's exact tests for categorical variables according to the expected cell counts.

The archived statistical output contained p values but did not include correlation coefficients, complete contingency tables, or individual-level raw data. Consequently, effect estimates and 95% confidence intervals could not be reconstructed from the available study documentation. Multivariable analysis was not performed because of the small sample size and sparse categorical cells. Therefore, the possibility of residual confounding should be considered when interpreting the findings.

Ethical Consideration

Written informed consent was obtained from all respondents before questionnaire completion. Medical record information was accessed only for variables required for the study, and study findings were reported without personal identifiers. Confidentiality was maintained throughout data collection, data handling, analysis, and reporting.

The available study documentation did not contain the name of the ethics committee, ethical approval number and date, or specific documentation concerning authorization to access medical records. Therefore, these ethical approval details could not be independently verified from the available study file. Before publication, the authors should provide the official ethics committee information and approval documentation if these were obtained during the original research.

Result

A total of 35 respondents participated in this study. Respondent, child, and environmental characteristics are presented in Tables 1-4, while associations between hospitalization-related attendance, other characteristics,

parenting stress, and parental quality of life are presented in Tables 5-6.

Table 1. Child, Respondent and Environment Characteristics

Characteristics	n (%)
Child Characteristics	
Age group	5 (14.3%)
<5 years	12 (34.3%)
5-9 years	18 (51.4%)
10-18 years	
Gender	20 (57.1%)
Boy	15 (42.9%)
Girl	
Last blood transfusion duration	3 (8.6%)
≤3 hour	32 (91.4%)
>3 hour	
Last blood transfusion amount	19 (54.3%)
1 pack darah	16 (45.7%)
>1 pack darah	
Complication	22 (62.9%)
Splenomegaly	13 (37.1%)
No splenomegaly	
Respondent Characteristics	
Gender	
Man	4 (11.4%)
Woman	31 (88.6%)
Age group	
<20	0
20-30	8 (22.9%)
31-40	18 (51.3%)
41-50	8 (22.9%)
>50	1 (2.9%)
Education level	
Low	11 (31.4%)
Moderate	18 (51.4%)
High	6 (17.2%)
Occupation	
Housewife	25 (71.4%)
Labourer	3 (8.6%)
Entrepreneur	3 (8.6%)
Civil servant	2 (5.7%)
Others	2 (5.7%)
History of hypertension	
Yes	1 (2.9%)
None	34 (97.1%)
Marital status	
Marriage	34 (97.1%)
Divorce	1 (2.9%)
Deceased couple	0
Social relations	
Live together and have a good relationship	31 (88.6%)
Live together and don't have a good relationship	4 (11.4%)
Don't live together and have a good relationship	0
Don't live together and don't have a good relationship	0
Environment Characteristics	
Organization of Thalassemia	
Joining	31 (88.6%)
Not joining	4 (11.4%)
Distance from home (km)	
<5 km	10 (28.6%)
5-10 km	8 (22.9%)
>10 km	17 (48.5%)

The majority of patients were aged 10–18 years, most of whom were male. The duration of the last blood transfusion for most paediatric patients was more than three hours. The majority of paediatric patients underwent blood transfusions with one pack of blood. Most paediatric patients experienced splenomegaly.

The majority of respondents were mothers aged 31-40 years old who worked as housewives. The majority of respondents had a secondary education level, having graduated from high school or equivalent. The majority of respondents did not have a history of hypertension. The majority of respondents were married parents who stated that they lived with their spouse and had a good relationship with their partner. The majority of parents are members of the Thalassemia organisation and live more than 10 km from the NTB Regional General Hospital.

Table 2. History of Hospitalization of pediatric patients with Thalassemia

Hospitalization	Mean ± SD	Min - Maks
Duration (hour)	10.4 ± 17.1	4 - 72
Frequency (x/month)	1.5 ± 0.7	1 - 4
Interval (week)	3.1 ± 1.7	1 - 12

Hospital attendance history was summarized by duration, frequency, and interval. Duration ranged from 4 to 72 hours, with a mean of 10.4 hours. Attendance frequency ranged from 1 to 4 times per month, with a mean of 1.5 times per month. The interval between attendances ranged from 1 to 12 weeks, with a mean of 3.1 weeks. Because the minimum duration was only four hours and ODC was used for transfusion care, these

values should be interpreted as hospital attendance duration rather than conventional inpatient length of stay.

Table 3. Level of Parental Stress

Parental stress	Category n (%)		
	Low	**Moderate**	**High**
Overall parenting stress	Skor <60 24 (68.6)	Skor 60-83 11 (31.4)	Score >=84 0

Most parents had low parenting stress (68.6%).

Table 4. Level Quality of life Parents

Quality of life	Score	n (%)
Very good	81-100	31 (88.6)
Good	61-80	4 (11.4)
Moderate	41-60	0
Poor	21-40	0
Very poor	0-20	0

Most respondents had very good quality of life (88.6%).

Table 5. The Relationship of Hospitalization, Child Characteristics, and Environment Characteristics with Parental Stress and Quality of Life in Parents of Children with Thalassemia

Variable	P Value	
	Parental stress	**QoL Parents**
Hospitalization		
Duration	0.606	0.951
Frequency	0.884	0.359
Interval	0.121	0.726
Child Characteristics		
Age group	0.24	0.61
Gender	0.72	1.0
Last Duration of transfusion	1.0	1.0
Last blood transfusion amount	1.0	0.31
Complication	0.02*	1.0
Environment Characteristics		
Distance from home (km)	0.76	0.41
Organization of Thalassemia	0.28	1.0

The Shapiro Wilk test indicated non normal distribution ($p<0.001$); Spearman analysis was therefore used for the continuous/ordinal hospitalization related variables. In this sample, no statistically significant association was detected between hospital attendance duration, frequency, or interval and parenting stress ($p=0.606$, $p=0.884$, and $p=0.121$, respectively) or parental quality of life ($p=0.951$, $p=0.359$, and $p=0.726$, respectively).

For child characteristics, no statistically significant association was detected between child age group, gender, last transfusion duration, or last transfusion amount and parenting stress or parental quality of life in this sample. These non significant findings should not be interpreted as proof of no relationship because the sample was small.

Fisher's exact test showed a statistically significant association between child complication status (splenomegaly) and parenting stress ($p=0.020$), while no statistically significant association was detected between complication status and parental quality of life ($p=1.000$).

No statistically significant association was detected between distance from home and parenting stress ($p=0.760$) or quality of life ($p=0.410$), or between membership in the thalassemia organization and parenting stress ($p=0.280$) or quality of life ($p=1.000$). The available archived output contained p-values only; effect estimates and 95% confidence intervals could not be reconstructed without the original raw data.

Among respondent characteristics, parental age group was not significantly associated with parenting stress ($p=0.570$) but was significantly associated with parental quality of life ($p=0.009$). No statistically significant association was detected between education level or occupation and either outcome in this sample.

Table 6. The Relationship of Respondent Characteristics with Parental Stress and Quality of Life in Parents

Respondents Characteristic	P value	
	Parental Stress	Quality of Life
Gender	0.57	0.39
Age group	0.57	0.009*
Education Level	0.42	0.12
Occupation	0.72	0.45
History of hypertension	0.31	1.0
Marital status	1.0	1.0
Social relations	1.0	1.0

Fisher's exact tests did not detect statistically significant associations between parental gender, history of hypertension, marital status, or social relationships and parenting stress or parental quality of life in this sample. Because multiple bivariate comparisons were performed in only 35 respondents and no multivariable adjustment was conducted, these estimates are imprecise and potentially affected by residual confounding.

Discussion

The largest respondent age group was 31-40 years (51.4%), and mothers represented 88.6% of respondents. Similar caregiver studies in thalassemia have also reported that mothers form the majority of primary caregivers[9,10,11]. This pattern is consistent with the substantial day-to-day caregiving role often carried by mothers. Most respondents in this study were not employed outside the home, which may have increased the time available to accompany children to transfusion related hospital visits. The demographic profile should nevertheless be interpreted descriptively because the purposive sample was small.

Most respondents were married and reported living with their spouse in a good relationship. Supportive family relationships can help distribute caregiving responsibilities and may reduce perceived burden[12]. In this sample, however, marital status and social relationship categories were not statistically significantly associated with parenting stress or parental quality of life. The absence of statistical significance in this sample should not be interpreted as evidence that family support is unimportant.

Low parenting stress was reported by 68.6% of respondents. Other caregiver studies have shown heterogeneous levels of stress and caregiver burden among families of children with thalassemia[10,13]. Repeated treatment attendance can create physical, emotional, and time burdens for caregivers, but the local One Day Care (ODC) model may shorten many transfusion visits. ODC services are intended to provide selected treatments in less than 24 hours and may reduce disruption to family routines[14]. A study of families accompanying patients for ODC chemotherapy likewise reported no statistically significant association between ODC-related care and caregiver stress[15].

Most respondents reported very good quality of life. Previous research has described reduced caregiver quality of life in families affected by thalassemia and has linked repeated care demands with family well being[9,11]. A local study at the NTB Regional General Hospital also provides relevant context regarding quality of life among patients with thalassemia[16]. In the present sample, hospital attendance duration, frequency, and interval were not statistically significantly associated with parental quality of life. This difference may reflect adaptation to repeated transfusion care, the short duration of many ODC visits, or limited statistical power. Similar caution is warranted when comparing these findings with studies in other chronic diseases and care settings[17,18].

No statistically significant association was detected between child age or gender and parenting stress or parental quality of life in this sample. Previous studies have reported mixed

findings regarding the influence of child characteristics on caregiver outcomes[9,10,11]. Parents may adapt over time to the child's condition and treatment routine[19]. Therefore, the present non significant results should be viewed as sample specific estimates rather than evidence that child characteristics cannot influence caregiver stress or quality of life[20,21].

Child complication status, particularly splenomegaly, was significantly associated with parenting stress (p=0.020). Splenomegaly is a recognized clinical feature and complication in thalassemia, related to chronic hemolysis, ineffective erythropoiesis, and increased splenic activity[22,23]. Visible or clinically important changes in a child's condition can reasonably heighten parental concern, consistent with prior caregiver research[11]. By contrast, the duration and amount of the most recent transfusion were not statistically significantly associated with parenting stress or parental quality of life in this sample.

Parental age group was not significantly associated with parenting stress (p=0.570) but was significantly associated with parental quality of life (p=0.009). This pattern suggests that age-related differences may be more apparent in perceived well being than in parenting stress within this sample. Prior studies suggest that caregiver age and developmental stage may shape coping, self acceptance, and well being[9,11]. Parental gender and educational level were not statistically significantly associated with either outcome in this sample, although previous studies have reported differing findings[11,21,24].

Employment status, history of hypertension, marital status, and social relationships were not statistically significantly associated with parenting stress or parental quality of life in this sample. These findings should be interpreted cautiously because sparse categories reduce statistical power. Studies on caregiver health and stress have reported differing patterns, including findings related to hypertension and stress[25,26], while other research has emphasized the potential roles of caregiver health, employment, and social support in caregiver burden and well being[19,27,28]. Thus, a non significant p-value here does not establish the absence of a clinically meaningful association.

Caregiver burden is multidimensional and may vary with caregiver characteristics, psychological factors, and the care needs of the child[29,30,31,32]. Coping strategies and social support may influence how parents adapt to chronic caregiving demands[33]. Participation in the thalassemia organization was not statistically significantly associated with parenting stress or parental quality of life in this sample; nevertheless, evidence from other chronic disease support settings indicates that duration of illness and peer support context can be relevant to quality of life[34]. Interpretation of the present study should also consider its small sample, purposive sampling, multiple bivariate comparisons, lack of multivariable adjustment, absence of archived effect estimates and confidence intervals, and potential residual confounding. These limitations reduce precision and restrict causal inference from the cross sectional findings.

Conclusion

Based on this cross-sectional analysis, no statistically significant association was detected in this sample between the duration, frequency, or interval of transfusion-related hospital attendance and parenting stress or parental quality of life. Child complication status (splenomegaly) was significantly associated with parenting stress, while parental age was significantly associated with parental quality of life. Other tested child, parent, and environmental characteristics did not show statistically significant associations in this

sample. Because the study included only 35 respondents, used multiple bivariate tests, and did not perform multivariable adjustment, the findings should be interpreted cautiously and should not be taken as evidence of absence of clinically meaningful associations. Larger studies with effect estimates, 95% confidence intervals, and adjusted analyses are recommended.

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