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Hope and Quality of Life among Adolescent with Thalassemia: A Cross-sectional Study in Indonesia

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Abstract

BACKGROUND: Adolescents with thalassemia major had a worse quality of life (QOL) than healthy adolescents. Hope is considered as a protective factor to enhance QOL. The relationship between hope and quality of life in adolescents has been evaluated in various chronic diseases, across multiple countries, cultures, and settings. However, studies on exploring the relationship between hope and QOL among adolescents with thalassemia are limited, especially in Indonesia.

AIM: This study aimed to determine the relationship between hope and QOL among adolescents with thalassemia in Indonesia.

METHODS: A cross-sectional study was carried out from April to June 2021. The respondents in this study were 120 adolescents who met the criteria (1) they were teenagers (10–19 years old) who received regular blood transfusions, (2) they could write and read, and (3) adolescents who are not mentally retarded. Instruments include demographic data sheets, Child Hope Scale (CHS), and TranQOL. Data were analysis using the Pearson correlational test and multiple regression hierarchical analysis.

RESULTS: This study found that 65 (54.17%) were boys and 55 (45.83%) were girls. About 64.17% had transfusion period for once in 2–4 weeks, and 4.17% with comorbidity, and 77.5% having hemoglobin 7 mg/dl. The mean QOL score among adolescents with thalassemia was 47.82 (SD = 15.38). Hope and TranQOL scores were positively and strongly associated ($r = 0.463$, $p < 0.01$). After adjusting for demographic and clinical factors, this finding revealed that hope was significantly and positively associated with QOL in step two. Hope had a significant impact on thalassemic adolescents' QOL ($R2 = 0.371$, $R2$ change = 0.239)

CONCLUSION: Hope is a factor that is related and greatly influences the quality of life of thalassemia survivors so that the development of programs and policies that design the expectations of thalassemia survivors and their families will improve the quality of life of patients with thalassemia.

Introduction

Thalassemia is a significant public health issue that affects not only patients and their families, but also the country's economy [1]. Approximately 80% of thalassemia occurs in low- or middle-income countries, including South and Southeast Asia [2], [3]. According to the World Health Organization (WHO) (2018), around 1.5% of the global population is heterozygous for or a carrier of thalassemia, and at least 12% of children born with thalassemia require blood transfusions [2]. Between 50,000 and 100,000 children die each year from thalassemia major, and at least 3000 die each year from uncontrolled iron overload in their teens or early 20s [3]. In Indonesia, thalassemia prevalence increased from 4896 in 2012 to 9028 in 2018, and an estimated 2500 babies are born each year with thalassemia [4]. The growing number of thalassemia patients increased the cost of supportive treatment, such as blood transfusions and lifetime iron chelation, as well as the cost of treatment for complications [5]. Thalassemia has a wide impact on both children and families.

Thalassemia has a negative impact on the life and health of adolescents due to the severity of the disease, the need for long-term treatment and care, and the psychological consequences (Phaktoop and Sananreangsak, 2015). Although treatment can extend life expectancy, adolescents with thalassemia continue to face a variety of complications, including disruptions in academic and social activities and a parent's inability to care for their children [6], [7], [8]. Adolescents who are thalassemic may suffer from short stature, skeletal abnormalities, and inadequate sexual development, all of which can have a negative effect on their self-image and self-confidence [9]. The adolescent with thalassemia, both men and women, fails to experience pubescent changes, with less than 20% menarche causing sexual immaturity [10]. Adolescents with thalassemia have a variety of social challenges, including school dropout, family strife, and limited

social interactions [11]. The physical and psychosocial problems of thalassemia adolescents pose a risk to their quality of life.

Adolescents with thalassemia major had a worse quality of life (QOL) than healthy adolescents [12]. In Indonesia, it was reported that the quality of life of children with thalassemia was lower than that of their healthy siblings [13]. A systematic review emphasized the low quality of life (QOL) of pediatric and adolescent patients with thalassemia major [14]. Haghpanah *et al*. [15] noted that the QOL of intermediate thalassemia patients is comparable to that of patients with thalassemia major. In line, a study conducted in Iran found that all QOL dimensions were poor in adolescents with thalassemia [16]. The low quality of life (QOL) may be related to the high burden of disease and treatment management, including the occurrence of complications. Adolescents with thalassemia could have a better quality of life if blood transfusions, iron chelation therapy, adequate management of complications and good supportive care were more readily available [17]. Support for adolescents with thalassemia is an essential part because they experience various challenges that may have an impact on their psychology.

Adolescents with chronic illnesses face ups and downs in their feelings of hope and despair, causing disruption in their life, anxiety about the future, and increased reliance on caregivers [18]. Several researches on the subject of hope in children and adolescents with thalassemia have been conducted. According to a study conducted in Iran, 59% of thalassemic patients experienced low despondency, 51% experienced moderate loneliness, and 55% experienced moderate self-esteem [19]. Another study in Pakistan found that male children had higher hopes than female children, and that there was a negative association between physical and emotional health problems and children's hope [18]. Adolescents with thalassemia have experienced maladaptive coping, which includes emotions of pessimism and powerlessness [20], [21]. Thalassemia patients with high hopes take proactive measures to avoid side effects by having to adhere to iron chelation therapy, trying to maintain the physician's recommended regularity of control, and receiving regular blood transfusions [18], [22].

Hope is a fundamental multidimensional psychological concept that refers to an individual's belief in the possibility of achieving desired outcomes based on rational, potential goals [23]. Shane *et al*. [24] define hopes as human strengths that are defined by an individual's capacity to set specific goals, develop specific strategies to accomplish those goals (pathways), and maintain motivation to employ existing strategies. Among the characteristics of hope are a realistic assessment of one's circumstances, the capacity to consider alternatives, and the capacity to set goals [22]. Hope is a powerful motivator for initiating or continuing actions toward a goal, and it can be fostered or sustained through individual support networks and interpersonal relationships [25]. Individuals are encouraged to have optimistic expectations for the present and future [26].

The relationship between hope and quality of life in adolescents has been evaluated in various chronic diseases, across multiple countries, cultures, and settings. A systematic review of five included studies found a positive correlation between hope and quality of life; hope was found to have both direct and indirect effects on QOL in adolescents with chronic diseases [27]. Hope is considered as a protective role for improving the quality of life in adolescents with cancer [28]. Enhancing hope to adolescents who are suffering from a chronic health condition would improve their overall quality of life in all domains, including physical, mental, social, and educational functions [29]. Hope reflects quality of life in a variety of chronic diseases including thalassemia, but studies are limited linking these aspects. This study aimed to determine the relationship between hope and QOL among adolescents with thalassemia in Indonesia.

Methods

Study design and setting

A cross-sectional study was conducted in four different outpatient thalassemia clinics in Bandung city, West Java, Indonesia between June and October 2021.

Sample

The number of patients who visited those clinics was variate, ranging from 20 to 50 patients in adolescents. Out of 150 patients, 120 patients participated in the study. Patients were included if they met the following criteria: (1) They were an adolescent (10–19 years old) who received regular blood transfusions as recommended by physician, (2) they could write, read, and participate in the study, and (3) patients who met the following criteria were excluded from the study: They had a history of mental health or cognitive dysfunction. The sample size was determined using G-Power Software Version 3.1.6 with the assumption that = 0.05, effect size = 0.15 [30] and power level = 0.95. The participants who were eligible were chosen using a convenience sampling approach. Of the 150 adolescents with thalassemia who met the inclusion criteria with a response rate of 80%.

Ethical consideration

The research has been approved according to ethical standards by the ethics committee of an

affiliated university with ethical clearance number 035/KEPK/STIKEP/PPNI/JABAR/VIII/2021. Patients who agreed to take part in this cross-sectional study were provided with survey questions and a consent form to read and sign. Everyone who takes part is guaranteed confidentiality and that they have the right to refuse or withdraw completely at any time without incurring any consequences.

Instruments

The demographic datasheet included age, gender, educational level, ethnicity, family monthly income, and co-morbidity.

The Children's Hope Scale (CHS) is a questionnaire developed by Snyder *et al*. [31] to assess children's feelings of hope. This scale, which employs a self-report measure for children aged 8 to 16, is a downward extension of the Hope Scale for adults and is used to assess children's hope. The scale consists of six items, three of which assess "thinking pathways" (items 2, 4, and 6) and three of which assess "agency" (items 1, 3, and 5). In addition, six verbal response options range from "None of the Time" = 1 to "All of the Time" = 6. In the original version, Cronbach alphas for CHS scores ranged from 0.70 to a high of 0.86 [30]. In the current study, the Cronbach Alpha was 0.705.

TranQOL is a disease-specific measure of thalassemia major quality of life for children and adults developed by Klaassen [32]. Child self-report was employed in this tool. The questionnaire contained a total of 29 items (children). The questions are classified into four categories: physical health, emotional well-being, family functions, and school and career functions. The higher the TranQOL score, the higher the quality of life. In the current study, the Cronbach Alpha was 0.813, indicating satisfactory reliability.

Data analysis

The ANOVA/t test used this study to describe the mean QOL values for various categorical demographic and clinical variables. The correlation between QOL and hope was determined using Pearson correlation analysis. Hierarchical analyzes of multiple regression were carried out to study the effects of factors influencing QOL. Age and potential factors (which were correlated with QOL in univariate analysis) were inputted in step 1 of hierarchical regression analysis. In step 2, hope has been added. The regression models included indicators such as R^2, R^2 change, p-value, and standardization regression coefficient (β). The statistical analyses were carried out using SPSS for Windows (version 22.0), with a two-tailed p-value of 0.05 deemed statistically significant.

Results

The results of this study explain the demographics and clinical characteristics of patients, the correlation between hope and quality of life and explain the relationship between independent variables (demographic and clinical characteristic) and hope on quality of life.

Descriptive statistics

Table 1 summarizes the demographic and clinical characteristics of the patients, as well as the TranQOL scores for various categories of variables. Of the 120 patients, 65 (54.17%) were boy, and 55 (45.83%) were girl. The age of the patients ranged from 10 to 19 years and 35.83% of the participants were elementary student. In terms of clinical variables, 64.17% had transfusion period for once in 2 to 4 weeks, and 4.17% with comorbidity, and 77.5% having hemoglobin 7 to 8 mg/dl. The TranQOL scores of all variables differed considerably between the individual variables' categories, including age (t = 3.621, p = 0.025), transfusion period (t = 4.167, p = 0.011), and hemoglobin (t = 3.008, p = 0.021); however, the differences in the other variables were not statistically significant.

Table 1: Demographic and clinical characteristics and the score of QOL among adolescents with thalassemia (n = 120)

	n (%)	TranQOL			
		Mean	SD	F/t	p-value
Age					
10–15	76 (63.33)	41.86	13.77	3.621	0.025
16–19	44 (36.67)	49.18	15.55		
Gender					
Boy	65 (54.17)	43.07	13.17	1.534	0.349
Girl	55 (45.83)	47.69	14.82		
Education level					
Elementary school	38 (35.83)	43.51	12.05	1.321	0.187
Junior high school	25 (20.83)	46.32	11.13		
Senior high school	32 (26.67)	44.64	10.43		
Transfusion period					
Once in 1–2 weeks	77 (64.17)	47.44	9.07	4.167	0.011
Once in 3–4 weeks	43 (35.83)	35.29	11.43		
Comorbidity					
Yes	5 (4.17)	44.76	11.01	1.829	0.242
No	115 (95.8)	46.93	12.99		
Hemoglobin (mg/dl)					
5–6	27 (22.5)	37.08	13.77	3.008	0.021
7–8	93 (77.5)	46.71	15.55		

Correlation between hope and QOL

Table 2 presents the results of correlation analysis of continuous variables. The mean QOL score among adolescents with thalassemia was 47.82 (SD = 15.38). Hope and TranQOL scores were positively and strongly associated (r = 0.463, p < 0.01).

Factors associated with QOL

Table 3 shows that all of the independent variables associated with thalassemic adolescents'

Table 2: Empirical Data Correlation Matrix of CHS (n = 120)

	Overall QOL score r	Physical health r	Emotional health r	Family functions r	School and career functions r
Overall hope score	0.463**	0.336*	0.542**	0.489**	0.358*
Agency	0.394*	0.369*	0.499**	0.503**	0.403**
Pathway	0.472*	0.401**	0.540**	0.441**	0.314*

r = correlation between raw survey scale score values using the Pearson correlation coefficient. *p < 0.05; **p < 0.001.

QOL in univariate analysis (p = 0.05) were inserted into the hierarchical multiple regression models. Each independent variable contributed significantly to the variance in QOL. In step 1, demographic and clinical characteristics, such as age, transfusion period, and hemoglobin, explained 13.2% of the variance in QOL. After adjusting for demographic and clinical factors, this finding revealed that hope was significantly and positively associated with QOL in step two. Hope had a significant impact on thalassemic adolescents' QOL (R^2 = 0.371, R^2 change = 0.239).

Discussion

This study of adolescents with thalassemia was carried out in the Indonesian province of West Java, and it was the first to investigate the relationship between hope and quality of life (QOL) in Indonesia. Our findings indicated that adolescents with thalassemia had a lower mean quality of life than adolescents with thalassemia in Indonesia. Furthermore, the previous research has revealed that adolescents with thalassemia major have a poorer quality of life than those with healthy or intermediate thalassemia [12], [13], [33]. Despite advances in diagnosis and treatment technologies, and the ease with which quality care can be obtained in Indonesia, our findings revealed that adolescents with thalassemia still have a low quality of life. As a result, it is critical to identify the critical influencing factors and targeted solutions that can help them improve their quality of life.

Some demographic and clinical characteristics, such as age, hemoglobin, and transfusion frequency, were found to be associated to QOL. The quality of life of a child decreases with age; younger children (under 7 years) have a better quality of life than older children (between 7 and 18 years) [12]. Our findings indicated that adolescents with thalassemia who had a higher hemoglobin level and a lower frequency of transfusion had a higher QOL score, which corroborated previous research [12], [34], [35], [36]. Adolescents who receive one transfusion per month have a higher quality of life when compared to children who receive transfusions three to four times per month. More frequent hospital admissions have an adverse effect on people's lives of young kids in terms of the physical liability, mentally impaired, and academic disruption.

Our findings revealed that adolescents with thalassemia have a low hope score, which is consistent with earlier research [18], [19]. This was in contrast to a research in Greece that found that thalassemia teenagers have high aspirations 21). There is a knowledge gap regarding the development of hope in adolescents. Knowing how hope changes as adolescence proceeds (early, middle, and late) can help researchers evaluate whether a maturational effect occurs. Future research should focus on adolescents in a more defined developmental stage: early, middle, or late adolescence, or divide by stage. Theoretical and empirical researches on hope have explored the connection between hopeful thought process and physical health. To determine whether hope can motivate adolescents with thalassemia to maintain their efforts toward improving their health and completing their treatment regimens, more research should be conducted on this topic. Hope was found to be positively connected with QOL in individuals with adolescents. Patients with a high level of hope were more likely to have a great quality of life, according to a prior study [18], [19], [21].

Hope has been identified as a protective factor in the development of resilience and quality of life in disease adolescents and young adults [28]. Furthermore, a higher level of hope has been linked to greater hopefulness, and people who are hopeful try to engage in healthy behaviors despite of their symptom severity, which contributes to the recovery of chronic diseases [37]. People who have a high level of hope are better equipped to bear suffering. Snyder [38] states that hopeful

Table 3: Hierarchical multiple regression analysis results of QOL in adolescent with thalassemia (n = 120)

	Quality of life									
	Overall QOL score		Physical health		Emotional health		Family functions		School and career functions	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
Age	0.128 (0.054)*	0.170 (0.023)*	−0.114 (0.888)*	0.120 (0.832)*	0.130 (1.034)*	0.133 (0.065)*	0.166 (0.0 45)*	0.111 (0.089)	0.130 (0.0 11)*	0.178 (0.026)
Transfusion period	−0.107 (2.011)*	−0.041 (1.324)	−0.150 (2.286)*	−0.187 (1.461)*	0.186 (1.333)*	−0.178 (2.415)*	−0.132 (2.374)	−0.108 (1.053)	−0.110 (1.570)	−0.148 (1.011)*
Hemoglobin	0.128 (0.060)*	0.100 (0.019)*	0.296 (0.067)*	0.165 (0.011)*	0.182 (0.013)*	0.041 (0.013)	0.108 (0.011)	−0.080 (0.010)	0.108 (0.059)	0.200 (0.074)
R^2	0.132		0.108		0.159		0.101		0.191	
Hope		0.234 (0.065)**		0.365 (0.110)**		0.363 (0.138)**		0.367 (0.105)**		0.367 (0.105)**
R^2		0.371		0.288		0.349		0.287		0.232
R^2 change		0.239		0.180		0.190		0.186		0.041

*p < 0.05; **p < 0.001.

people have different goals, including maintaining good health, in various life sectors. The diagnosis of thalassemia may be interpreted as a "goal impediment" that encourages individuals with high hopes to forge alternative paths to the original goal (e.g., adherence and participation in treatment) and expand their initiatives in treatment collaboration, thereby diminishing the focus placed on the disease and its treatment-related restrictions [38].

These findings, which suggest a link between expectations of a positive outcome and anxiety, may have a psychological explanation. As might be expected, adolescents with thalassemia who have higher levels of hope have higher quality of life as they are more confident in both their everyday lives and their ability to cope with disease. Thus, fostering hope is a critical strategy for improving the quality of life of adolescents with thalassemia in Indonesia. However, there are limitations which must be taken into account. Due to the cross-sectional nature of this study, the direction of causality between the study's variables could not be differentiated. Second, this study did not look at specific age developments or other clinical parameters such as iron chelation or disease prognosis, which could have a big impact on how patients deal with this issue. This method would enable a more thorough evaluation of the effects of development stage on adolescents' hope. Future studies should explore the moderating/mediating effect of a patient's stage of development on the correlation between hope and QOL. Finally, given the sole focus on the adolescents' self-reports, caution is required owing to single-method subconscious biases, reinforcing the need for additional research based on multi-method analysis approach with a group of key respondents (e.g., parents, teachers, and/or clinicians). Finally, the sample was collected from the West Java Province; we could indeed eliminate the possibility that outcomes may have been affected by the quality of organizational support provided or other contextual variables, and these must, therefore, be considered carefully. The current research highlighted the importance of implementing evidence-based practice that enhance cognitive-motivational strengths, such as hope, with the goal of assisting adolescents in coping more adequately with their illness and any associated adverse experiences. The hope intervention proposed by Snyder [38] based on problem-solving, narratives, and motivational interviewing [38] may be effective in developing evidence-based therapies to aid adolescents dealing with thalassemia [39]. These findings suggest that future research should focus on the effect of hope on the quality of life of adolescents with thalassemia and their families. Further research to map the importance of hope for QOL in the face of adverse conditions could examine how hope is linked to certain types of coping and thalassemia-related behavior. In view of the lack of research on this subject, qualitative studies may be particularly informative by examining perceptions of hope and its promoting factors in thalassemic adolescents. The study of the developmental course of hope from childhood to adolescence and through the treatments is also possible another way forward for research. Further studies would benefit from the inclusion of a comparison group in research into specific perceptions and the impact of hope in thalassemia in adolescents in relation to control groups (e.g., healthy teens or adolescents with other chronic diseases).

Conclusion

The current study demonstrates that hope plays a unique role in adolescents with thalassemia, improving adolescents' quality of life. As a result, it is critical to develop information and empirically proven interventions that help juveniles and caregivers make the most of their cognitive-motivational strengths.

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