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Effect of family-centered empowerment model on HOPE of adolescents with thalassemia major

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ABSTRACT

Thalassemia Major is a hereditary blood disorder and is a chronic disease that can cause various problems regarding future expectations for sufferers. Adolescents with thalassemia major experience various psychosocial problems which have an impact on decreasing hope, quality of life, interpersonal relationships, self-esteem which results in depression. The aim of this study was to identify the effect of the family centered empowerment model on the hope of adolescents with thalassemia major in Indonesia. This study uses a quasi-experimental design. The sample in this study were 240 adolescents with thalassemia major. Participants were given 4 sessions of family empowerment interventions for 4 weeks. Each session is carried out for 90 minutes. this study uses Children's Hope Scale (CHS) for data collection. Data analysis used independent t test and chi-square. The results of the study showed that the hope score increased significantly after the family-centered empowerment model in the intervention group (P=0.002). In addition, there was a significant difference between the intervention group and the control group in the mean of hope score among adolescents with thalassemia. The family centered empowerment model is an effective intervention to improve the hope for adolescents with thalassemia.
Keywords: Adolescent; family-centred empowerment; hope; thalassemia.

ABSTRAK

Talasemia Mayor adalah kelainan darah herediter dan merupakan penyakit kronis yang dapat menyebabkan berbagai masalah terkait harapan masa depan bagi penderitanya. Remaja dengan talasemia mayor mengalami berbagai masalah psikososial yang berdampak pada penurunan harapan, kualitas hidup, hubungan interpersonal, serta harga diri yang pada akhirnya dapat menyebabkan depresi. Penelitian ini bertujuan untuk mengidentifikasi pengaruh family-centered empowerment model terhadap harapan remaja dengan talasemia mayor di Indonesia. Penelitian ini menggunakan desain kuasi-eksperimental. Sampel dalam penelitian ini adalah 240 remaja dengan talasemia mayor. Partisipan diberikan 4 sesi intervensi pemberdayaan keluarga selama 4 minggu, dengan setiap sesi berlangsung selama 90 menit. Pengumpulan data dilakukan menggunakan Children's Hope Scale (CHS). Analisis data menggunakan uji t independen dan chi-square. Hasil penelitian menunjukkan bahwa skor kualitas hidup meningkat secara signifikan setelah penerapan family-centered empowerment model di kelompok intervensi (P=0.002). Selain itu, terdapat perbedaan yang signifikan antara kelompok intervensi dan kelompok kontrol dalam skor rata-rata skor harapan di antara remaja dengan talasemia. Family-centered empowerment model adalah intervensi yang efektif untuk meningkatkan kualitas hidup remaja dengan talasemia.
Kata kunci: Family-centred empowerment; harapan; remaja; talasemia

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INTRODUCTION

Beta-thalassemia has a notably high incidence across vast regions, from the Mediterranean basin and parts of Africa to the Pacific Islands, Middle East, Indian subcontinent, Melanesia, and Southeast Asia. Carrier frequencies for β-thalassemia in these regions range between 1% and 20%. In Southeast Asia, approximately 3-9% of the population are carriers, with Thailand reporting a carrier frequency of 3% - 9%, and Malaysia 1% - 4.5% (Angastiniotis & Lobitz, 2019; Shafie et al., 2020). In Indonesia, the prevalence is significantly high, with 6-10% of the population identified as carriers (Ministry of Health, 2019). The Association of Parents of Thalassemia Survivors (POPTI) reported an increase in cases from 4,896 in 2012 to 10,647 in 2020. West Java recorded the highest number of cases, accounting for 3,264 cases or 40% of total thalassemia major cases in Indonesia (Ministry of Health, 2020). Furthermore, medical records from Hasan Sadikin Hospital, Bandung, documented 3,280 thalassemia patients aged 11-16 years between January 2018 and February 2019 (Poengoet et al., 2017).

Thalassemia major presents as a chronic, inherited blood disorder that can severely affect both the physical appearance and mental health of patients (Cappellini et al., 2018). Clinical symptoms commonly observed among thalassemia patients in Indonesia include pallor, jaundice, growth retardation, hepatosplenomegaly, genu valgum, foot ulcers, and characteristic facial features such as Cooley's facies (Layarta et al., 2019). Srisukh et al., (2016) further noted a delayed onset of puberty in adolescents with thalassemia due to hormonal imbalances. Psychological challenges associated with the disease, such as exhaustion from prolonged treatments, anxiety about the future, and reduced self-confidence, exacerbate the burden of living with thalassemia (Abusaad & Ali, 2016). Adolescence, a critical developmental phase, introduces additional psychological stressors as individuals seek to establish their identity and gain autonomy (Hassan & Azzab, 2016; Mohamadian et al., 2018). Mental health issues, low self-esteem, and disengagement from extracurricular activities are prevalent challenges faced by adolescents with thalassemia (Tarım & Öz, 2022; Thirafi, 2017). Recent data indicate that nearly half of adolescents with thalassemia experience moderate levels of stress (48.2%), severe anxiety (54.5%), and depression (23.2%) (Khedr et al., 2021). Thus, psychological support is essential in reducing anxiety, fostering effective coping strategies, and enhancing treatment adherence (Tarım & Öz, 2022; Babaei et al., 2019).

Research consistently shows that depression and maladaptive coping strategies are associated with diminished hope (Perveen, 2019; Schiavon et al., 2017). Adolescents with thalassemia often demonstrate maladaptive coping mechanisms, such as giving up hope, which significantly impacts their psychological well-being (Othman et al., 2022; Ahmadian et al., 2022; Ali et al., 2018; Beighton & Wills, 2017). Conversely, high levels of hope have been linked to better psychological health and a reduction in depressive symptoms (Antonio et al., 2019). Adolescents with a strong sense of hope are more likely to engage in adaptive behaviors, such as adhering to treatment regimens and actively participating in their healthcare (Seyedoshohadaee et al., 2022). These findings underscore the critical role of hope in influencing health behaviors and psychosocial outcomes for thalassemia patients. Families play a central role in providing care and emotional support to individuals with chronic conditions (Kokorelias et al., 2019). While some families effectively cope with the demands of caring for a child with thalassemia, others face significant challenges due to a lack of information, inadequate social support, financial burdens, and emotional distress (Beighton & Wills, 2017; Mediani et al., 2017). In response to these challenges, healthcare models have shifted from child-centered care to family-centered approaches, recognizing the importance of engaging families in the care process (Yeh et al., 2016).

Family-centered care focuses not only on meeting the needs of the patient but also on addressing the needs of the family unit. This approach integrates the family into the recovery process, treating them as vital contributors to the patient's well-being (Kokorelias et al., 2019). According to Krajnc & Berčan (2020), family-centered care encompasses five core elements: communication, patient and family involvement, family support, organizational aspects, and nurse attitudes. The effective implementation of family-centered care relies on structured approaches aimed at optimizing satisfaction for all involved parties, acknowledging the interdependence between patients, families, and healthcare providers (Krajnc & Berčan, 2020). To enhance their involvement in the care process, families require comprehensive knowledge about the disease, treatment, and rehabilitation options (Harris, 2018).

The Family-Centered Empowerment Model has proven particularly effective in fostering hope among adolescents with Thalassemia Major. By actively involving families in the care process, this model leads to improved psychosocial outcomes (Mardhiyah et al., 2022). Adolescents with high levels of hope exhibit greater commitment to self-care, including adherence to iron chelation therapies, regular medical checkups, and consistent blood transfusions (Perveen, 2019). Research highlights the role of hope in promoting a proactive approach to disease management, reducing complications, and enhancing treatment adherence (Seyedoshohadaee et al., 2022). Numerous studies support the effectiveness of family-centered empowerment as a valuable intervention in addressing the psychological challenges and enhancing the hope of children and adolescents with chronic diseases. Therefore, this study aims to investigate the impact of the Family-Centered Empowerment Model on the hope of adolescents with beta-thalassemia major in West Java, Indonesia.

RESEARCH METHOD

Research design

A quasi-experimental design with a pre-test and post-test was employed in this study. Experimental research aims to determine the impact of specific interventions on outcomes under controlled conditions (Abramson et al., 2018). Quasi-experimental designs have evolved to include a control group; however, they do not offer complete control over external variables that may influence the experimental process.

Participants

The study was conducted at the Thalassemia Foundation, also known as the Association of Parents of Thalassemia Survivors (POPTI), located in Bandung, West Java, Indonesia. Bandung, the capital of West Java, is bordered by various surrounding areas, including Bandung Regency and West Bandung Regency to the north, West Bandung Regency and the city of Cimahi to the west, Bandung Regency to the east, and Bandung Regency to the south. According to the 2020 Population Census, Bandung has a population of 2.44 million people, with males comprising 50.37% (2.23 million) and females 49.63% (1.21 million) of the total population. POPTI's activities in the Bandung region involve data collection and coaching for thalassemia patients across Bandung City, Bandung Regency, West Bandung Regency, and Cimahi. Data from a local thalassemia center as of March 1, 2020, indicated that there were 374 thalassemia patients in Bandung City, 448 in Bandung Regency, 168 in West Bandung Regency, and 77 in Cimahi City, totaling 1,067 registered patients in the region. For this study, a sample of 240 adolescents with thalassemia was selected.

Procedure

To meet the goals of the empowerment program, researchers designed a structured intervention consisting of four learning sessions for both adolescents and their parents. The intervention was delivered online over the course of one month, incorporating a supportive education and consultation program. The sessions were held once a week for four weeks, with each session lasting 90 minutes. The first session, conducted in the first week, involved a 90-minute supportive education program for adolescents and parents, which covered four stages: understanding treatment, problem-solving, participation, and educational evaluation. In the second week, the second session focused on consultation regarding health issues. The third session, held in the third week, involved further health consultations or question-and-answer discussions. The final session in the fourth week continued with consultations and discussions addressing health challenges faced by adolescents with thalassemia. Following the completion of the four-session intervention, post-intervention assessments were conducted in the first and second months after the pre-test. Booklets containing relevant information were distributed to the adolescents and their parents two days before the commencement of the online education sessions.

First Session (In the first week of/ Psychoeducation Program)

In this stage, adolescents with thalassemia and their parents participated in a 90-minute psychoeducation session delivered online via Zoom. The first session was divided into four stages:

1. *Stage 1: Perceived Threat Perception* – This stage aimed to assess participants' perception of danger through a dialogue-based approach. The online education covered essential information about thalassemia, including its definition, signs and symptoms, classification, genetic patterns, complications, and prevention strategies.
2. *Stage 2: Problem-Solving to Strengthen Self-Efficacy* – This stage focused on enhancing participants' self-efficacy by providing detailed information about thalassemia therapy, the role of treatment in preventing complications, and sharing experiences of dealing with complications and treatments (such as medications and blood transfusions). The aim was to build confidence in self-care, covering aspects such as diet, exercise, and sleep, while also developing technical skills in stress management. Participants were taught to identify psychological and treatment-related problems and strategies for addressing them.
3. *Stage 3: Educational Participation Method* – This stage sought to increase self-esteem by encouraging adolescents to take ownership of their self-care and set future goals. Participants were urged to share what they had learned with their peers and family members. Small group discussions (4 to 6 participants per group) were conducted to practice self-efficacy skills and foster belief in hope. Participants demonstrated relaxation techniques for stress management, practiced self-talk, and expressed their hopes for their illness and the future. They also discussed health-related goals and problem-solving strategies with their group and the facilitator. Parents were included in a 30-minute session focused on the basics of thalassemia care, complications, diet, physical activity, treatment, and their role in supporting their adolescent children.
4. *Stage 4: Evaluation* – In the final stage, researchers assessed participants' understanding by asking questions related to each educational step. Participants were also encouraged to share their feelings and discuss any challenges they encountered after the intervention.

Second to Fourth Sessions: Group Consultation

The researchers, along with research assistants, organized group sessions using social media platforms such as WhatsApp. Participants were divided into six groups, each consisting of 20 individuals. These sessions provided an opportunity for participants to ask questions related to thalassemia, self-care, stress management, and to present their "dream board" in the form of a picture. The online group consultations lasted for 120 minutes. One month after the intervention (T1), the researchers collected data again using the CHS instruments to assess outcomes.

Fifth Session: Follow-up Intervention

In this session, the researcher assessed the participants' comprehension and application of self-care practices. Additionally, the researcher gathered CHS data during the second month following the intervention (T2) to evaluate the progress and impact of the intervention.

Data Collection

Data collection for this study took place over nine months, from March 2021 to November 2021. The Children's Hope Scale (CHS) Questionnaire was used to gather data, which was adapted from Snyder et al. (1997). This widely recognized instrument is commonly employed to assess children's motivational orientations toward their future (Hellman et al., 2018; Bean, 2020). The CHS is a self-report tool designed for children aged 8 to 16 and serves as a modified version of the adult Hope Scale. The scale uses a six-point Likert format, with responses ranging from 1 (never) to 6 (all of the time), allowing participants to indicate how often they engage in specific behaviors or thoughts. The Children's Hope Scale comprises six statements designed to assess different aspects of hope.

Data Analysis

Data analysis was conducted using a modified intention-to-treat approach for both interventions, including participants who had completed at least one post-baseline assessment. The analysis provided a summary of the characteristics of adolescents, parents, and hope scores in both the control and intervention groups. To assess differences between the intervention and control groups, homogeneity tests were performed using an independent t-test and chi-square test to identify any variations between the two groups.

RESULTS OF STUDY

The respondents in this study comprised 240 adolescents diagnosed with thalassemia major, who were members of the Association of Parents of People with Thalassemia in Bandung, West Java, Indonesia.

Table 1 presents a demographic comparison between the intervention and control groups. In the intervention group, which comprised 120 adolescents with thalassemia, the mean age was 13.7 years (SD = 2.55), with 54% being male and 41.7% attending junior high school. The majority (61.7%) were diagnosed with thalassemia before the age of one. Pre-transfusion hemoglobin levels averaged 7.05 g/dL (SD = 1.15), with 93.3% undergoing ferritin checks every 3 to 6 months, and 43.3% receiving transfusions biweekly. The parents of adolescents in the intervention group had a mean age of 39.7 years (SD = 7.64); 58.3% had an education level below senior high school, and 87.5% were employed.

In the control group, the mean age was 14.0 years (SD = 2.39), with 55% male and 57.5% attending junior high school. Most adolescents (56.7%) were diagnosed with thalassemia before the age of one. The mean hemoglobin level was 6.92 g/dL (SD = 0.86), with 94.2% undergoing ferritin checks, and 48.3% receiving transfusions every two weeks. The parents in the control group had a mean age of 41.5 years (SD = 6.99); 62.6% had an education level above senior high school, and 87.5% were employed. Apart from parental age (p = 0.003), there were no statistically significant differences between the intervention and control groups in terms of baseline characteristics for either the adolescents or their families.

The adolescents in this study ranged from 10 to 18 years old. According to univariate analysis, the mean age in the intervention group was 13.7 ± 2.55 years, while in the control group, it was 14 ± 2.39 years (Table 1). These findings are consistent with previous studies. For instance, Aung et al. (2021) reported an average age of 14.4 ± 1.4 years for adolescents with thalassemia. Similarly, a study by Premawardhana et al. (2019) conducted at 23 thalassemia care centers in Sri Lanka, found that the mean age of patients with thalassemia major was 13.2 ± 7.6 years.

Regarding gender, the intervention group had a higher proportion of male participants (54.2%), whereas the control group had a larger proportion of female participants (55%) (Table 1). Overall, female participants accounted for 50.5% of the total sample across both groups, compared to 49.5% for males.

Table 1
Demographic Comparison Between Intervention and Control Group (N=240)

Variables	Intervention group n=120 (%)	Control group n=120 (%)	p-value
Age, Mean ± SD	13.7±2.55	14.0±2.39	0.286[a]
Gender			
Male	65 (54.2)	54 (45)	0.132
Female	55 (45.8)	66 (55)	
Current education			
Elementary school	21 (17.5)	21 (17.5)	0.104
Junior high school	50 (41.7)	69 (57.5)	
Senior high school	49 (40.8)	30 (25.0)	
Age at first diagnose			
Less than one year old	74 (61.7)	68 (56.7)	0.712
1-5 years old	32 (26.7)	35 (29.2)	
More than 5 years old	14 (11.7)	17 (14.2)	
Comorbidities			
Yes	4 (3.3)	7 (5.8)	0.354
No	116 (96.7)	117(94.2)	
Frequency of ferritin check			
Once in every 1 to 3 months	8 (6.7)	7 (5.9)	0.953
Once in every 3 to 6 months	112 (93.3)	113 (94.2)	
Frequency of transfusion			
Every one week	28 (23.3)	23 (19.2)	0.953
Every two weeks	52 (43.3)	58 (48.3)	
Every three weeks	35 (29.2)	30 (25.0)	
Every month	5 (4.17)	9 (7.50)	
Hb pre- transfusion (mg/dl), Mean ± SD	7.05±1.15	6.92±0.86	0.312[a]
Parent age, Mean ± SD	39.7±7.64	42.5±6.99	0.003[a]
Education level			
Below senior high school	70 (58.3)	45 (37.5)	0.507
Above senior high school	50 (41.7)	75 (62.7)	
Working status			
Employee	105 (87.5)	103 (85.8)	0.316
Unemployed	15 (12.5)	17 (14.2)	

Note: p-value resulted from chi square test; [a]: p-value resulted from independent t test.

Table 2
Score Difference of Hope Among Adolescents with Thalassemia Major Before and After Intervention in Both Groups (N=240)

Variables	Pre-test Mean ± SD	Post-test 2 Mean ± SD	Mean differences	t	p-value
Intervention group	18.43±14.53	20.60±4.24	2.04	1.89	0.002
Control group	18.39±4.54	18.89±3.22	0.50	0.45	0.111

Note: p-value obtained from paired t test

Table 2 presents the variation in hope scores between the two groups of adolescents with thalassemia. In the intervention group, the hope score increased significantly by 2.04 times from the baseline (T0) to one month after the follow-up (T2), with a t-value of 1.89 and a p-value of 0.002. In contrast, the control group showed no significant improvement in hope scores between the baseline (T0) and the one-month follow-up (T2), as indicated by a p-value of 0.111.

Figure 1 illustrates the difference in hope scores between the intervention and control groups over time. In the intervention group, the overall hope score increased from the pre-test (T0) to the follow-up measurement (T2), with a modest yet significant sustained effect observed over this period (difference-in-difference estimate (DDE): 2.2 percentage points). In contrast, the control group showed no significant improvement in hope scores over time. These findings support the researcher's second hypothesis, which predicted a difference in hope scores between the intervention and control groups over time.

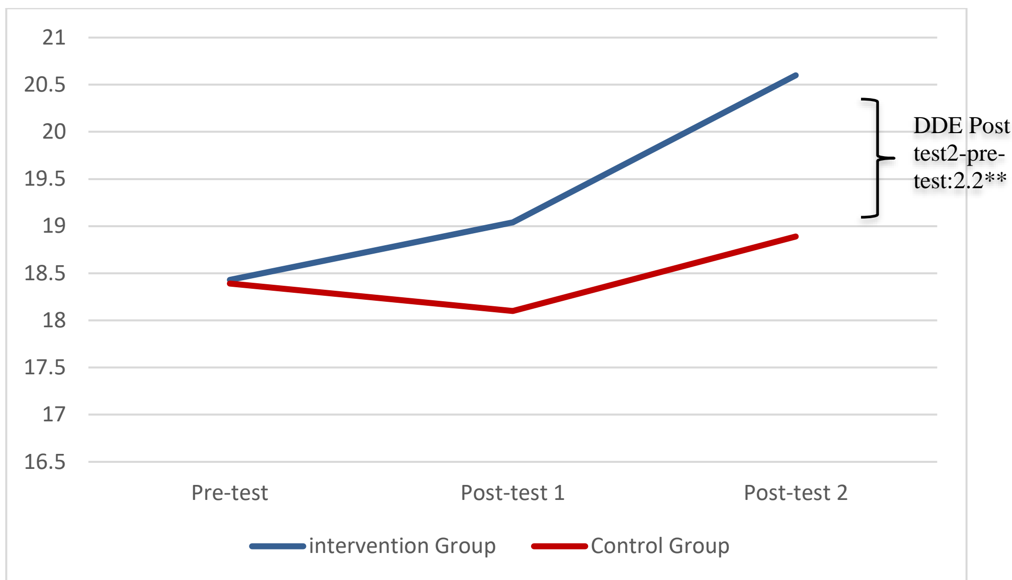

Figure 1. Change in Hope Between Intervention and Control Groups Overtime
Note: DDE: difference-in-difference estimate; *: $p < 0.05$, **:$p < 0.01$, ***:$p < 0.001$; #,##: Significant change from pre-test to post-test 2: #: $p < 0.05$, ##: $p < 0.05$.

Table 3
Estimated Difference-in-Differences (DID) For Intention-to-Treat (ITT) in Hope

Variables	T1 DID coefficient (95% CI)	T2 DID coefficient (95% CI)
Hope	2.08* (1.34 to 4.15)	4.31* (1.08 to 6.49)

Note: p<0.05*, p<0.01**.

The results of the linear regressions with level fixed effects, presented in Table 3, show the estimated difference-in-differences (DID) for the intent-to-treat (ITT) analysis. The family-centered empowerment model led to improved outcomes in both measured variables compared to the control group at T1. Specifically, the hope score showed a modest increase of 2.08 (95% CI: 1.34 to 4.15). By T2, even better outcomes were observed, with the hope score increasing by 4.31 (95% CI: 1.08 to 6.49) compared to the control group. These findings support the researcher's hypothesis, which predicted a significant difference in hope scores between the control and intervention groups at post-test and follow-up.

The difference in hope scores is further illustrated by the average score at post-test 2 (T2) (Figure 1, Table 2). The study demonstrated a statistically significant increase in the mean hope score among adolescents with thalassemia from before the intervention (T0) to after the intervention (T2), as indicated by the higher post-intervention score compared to the baseline (Table 2). This suggests that the family-centered empowerment model effectively enhances hope over time in thalassemia adolescents. As shown in Table 3, a significant difference was found between the intervention and control groups in the mean hope score among adolescents with thalassemia ($P < 0.05$).

DISCUSSION

This study demonstrates that gender distribution between male and female participants was nearly equal. The findings are consistent with previous studies, which reported that thalassemia is more prevalent among females than males (Irdawati et al., 2021; Putranto et al., 2021; Anisawati, 2017; Aung et al., 2021; Mansoor et al., 2018). However, the difference in the number of male and female participants in this study was not significant. This aligns with Murtilita's (2018) research, which found an equal gender distribution (50%) among respondents. Thalassemia is an autosomal disease, a genetic condition found on autosomal chromosomes (chromosomes 11 and 16), which affects both males and females equally (Rujito, 2021).

Regarding educational level, both the intervention and control groups were primarily composed of participants with junior high school education—41.7% in the intervention group and 57.5% in the control group (Table 4.1). These results align with the findings of Susyanti & Prayustira (2018) which indicated that the majority of thalassemia patients had completed junior high school (42.3%).

In terms of the age of diagnosis, the univariate analysis showed that the majority of respondents were diagnosed with thalassemia before the age of one, with 61.7% in the intervention group and 56.7% in the control group (Table 4.1). This

is consistent with research by Barua et al. (2020) and Mansoor et al. (2018), which found that most thalassemia patients are diagnosed before age one. Thalassemia symptoms often appear around seven months of age (Cappellini et al., 2018; Rujito, 2021), and patients typically require blood transfusions from their first year of life (Bollig et al., 2017; Angastiniotis & Lobitz, 2019). In this study, 96.7% of the intervention group and 94.2% of the control group did not have comorbid diseases (Table 4.1). These results differ from Supriyanti & Mariana (2019) study, which found that 72.1% of children with thalassemia had comorbidities like hepatomegaly, cardiomegaly, and hypersplenomegaly.

In terms of serum ferritin level monitoring, both groups in this study regularly checked their levels every 3-6 months, with 93.3% in the intervention group and 94.2% in the control group (Table 4.1). Monitoring serum ferritin is crucial to assess iron accumulation in the blood due to repeated transfusions (Daud, 2020). The negative impact of excess iron is that it can cause damage to various organs such as the lungs (Sani et al., 2016). Elevated ferritin levels (>2,500 µg/l) pose risks of complications such as heart problems (Mansoor et al., 2018), while levels below 1,000 µg/l are recommended for children receiving regular transfusions (Iron Health Alliance, US).

The study also found that blood transfusions were most frequently administered every two weeks, with 43.3% of respondents in the intervention group and 48.3% in the control group receiving transfusions at this interval (Table 4.1). This is consistent with Mansoor et al. (2018), who reported that most respondents in their study received transfusions every two weeks (55.7%). The pre-transfusion hemoglobin (Hb) levels were 7.05 ± 1.15 mg/dL in the intervention group and 6.92 ± 0.86 mg/dL in the control group (Table 4.1). According tos Cappellini et al. (2018), transfusions are recommended before Hb levels drop below 8 mg/dL, aiming to raise post-transfusion Hb levels to between 10 and 14 mg/dL (Rujito, 2021).

Parental education showed differences between the groups, with 58.3% of the intervention group having education below high school, while 62.7% of parents in the control group had higher education (Table 4.1). In both groups, however, parents with at least a high school education made up a majority (52%). This finding aligns with Mat et al. (2020) and Utami & Siska (2018), who reported that most parents of thalassemia children had junior high school education. Parental education is believed to influence support for their children, impacting quality of life and hope scores (Marnis et al., 2018). Most parents in both groups were employed, with 87.5% in the intervention group and 85.8% in the control group (Table 4.1). This is in line with Anisawati (2017) study, which reported that 80% of parents of children with thalassemia were working. Parental employment can affect caregiving, family time, and financial resources for healthcare (Anisawati, 2017).

Previous studies have primarily focused on the effect of family-centered empowerment on self-efficacy rather than hope. Borimnejad et al. (2018) found that self-efficacy among thalassemia adolescents significantly improved in the intervention group ($p < 0.01$), while it decreased in the control group ($p = 0.02$). Similarly, Teymouri et al (2017) reported improved self-efficacy in primary school students after a family-centered empowerment model intervention. This approach has also been shown to enhance self-esteem in asthmatic children, further supporting the effectiveness of family-centered empowerment (Teymouri et al., 2017).

Self-efficacy plays a crucial role in shaping the level of hope among adolescents with chronic illnesses (Bahryni et al, 2016). It is essential for fostering positive thinking in these individuals, as it empowers them to set goals, adhere to treatment plans, and remain motivated, even in challenging situations (Bahryni et al, 2016). The family-centered empowerment model aims to enhance the self-confidence of both patients and caregivers by providing education about the disease and its limitations, equipping them with skills to manage stressful situations, and ultimately improving their self-efficacy (El-Melegy et al., 2016).

The relationship between self-efficacy and hope is particularly significant for children and adolescents with chronic conditions, as self-efficacy supports their ability to maintain optimism, set goals, and stay committed to treatment despite the difficulties they may face (Bahryni et al, 2016). Psychoeducation through the family-centered empowerment model is a key intervention to support and enhance the psychological well-being of adolescents and their families in the context of chronic illness.

Research by Shahdadi et al (2018), involving 30 hemodialysis patients at Imam Khomeini Hospital in Zabol, Iran, demonstrated a significant reduction in anxiety and depression following the implementation of the family-centered empowerment model ($p=0.001$), with no significant changes observed in the control group. This model is designed to emphasize the family's role in various dimensions, including motivation, psychological factors (knowledge, attitudes, perceived threats), performance (self-efficacy), and self-confidence (self-esteem) (Boshagh et al., 2022). The model is structured around four key stages: perceived threat, problem-solving, educational involvement, and evaluation (Davarpanah et al., 2016; Borimnejad et al., 2018; Deyhoul et al., 2019).

Based on these studies, the family-centered empowerment model has been shown to enhance psychological well-being by improving self-efficacy, boosting self-esteem, and reducing anxiety in patients with chronic conditions. Furthermore, this model has been found to increase levels of hope. The primary objective of the model is to support the family system—comprising children and adolescent patients and their caregivers—in promoting overall health and well-being (Farahani et al., 2018).

CONCLUSION

This study revealed that adolescents with thalassemia exhibited a moderate level of hope overall. Specifically, the domain of "pathways" showed a moderate score, while "agency" scored lower. Among the variables examined, significant differences in hope scores were found across age, transfusion period, and pre-transfusion hemoglobin levels. These factors significantly contributed to the variance in hope scores. A significant difference was observed in the mean hope scores before and after the intervention between the intervention and control groups. Furthermore, the overall hope score in the intervention group increased from pre-test to follow-up measurements. There was a moderate and sustained significant improvement in hope between the baseline and follow-up periods, whereas no significant improvement over time was seen in the control group.

Nurses, in their role as educators, can implement family-centered empowerment model interventions as part of pediatric nursing practices to enhance the hope of adolescents with thalassemia. Future research may consider employing different methodologies, such as randomized controlled trials or qualitative studies, to further evaluate the effectiveness of the family-centered empowerment model on hope among thalassemia adolescents, their parents, or on other psychological outcomes.

ETHICAL CONSIDERATIONS

The researcher submitted the final proposal and proposal letter of recommendation for ethical clearance to Sekolah Tinggi Ilmu Keperawatan PPNI Jawa Barat with ethical number 035/KEPK/STIKEP/PPNI/JABAR/VIII/2021.

DECLARATION

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Conflict of Interest Statement

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