SYSTEMATIC REVIEW

Intervention Programs to Improve Self-management and Quality of Life Among People with Thalassemia: A Systematic Review

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ABSTRACT

Introduction: People with thalassemia often require lifelong care, including regular blood transfusions and medication to manage iron levels, in order to prevent severe health complications. Additionally, these individuals face numerous physical and psychological challenges that can significantly impact their overall well-being. This systematic review aims to evaluate the effectiveness of various intervention approaches designed to strengthen self-management skills and quality of life (QoL) among individuals with thalassemia. **Methods:** This study was conducted in accordance with the recommendations outlined by PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines. Relevant research findings were sourced from online databases such as Science Direct, Scopus, SpringerLink, MEDLINE, and Web of Science. **Results:** A total of 12 articles that satisfied all the eligibility requirements were selected and studied in the present research. The interventions analyzed included various approaches such as self-care education, acceptance and commitment therapy, positive psychotherapy and family-centered empowerment programs. The results indicate that these interventions significantly enhance self-care behaviors and QoL in thalassemia patients. **Conclusion:** This review underscores the importance of patient-centered, comprehensive intervention strategies to manage thalassemia effectively. However, variations in study design, outcome measures, and follow-up periods highlight the need for standardized approaches and further research to confirm long-term benefits.
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INTRODUCTION

Thalassemia is a hereditary condition that prevents the body from producing sufficient hemoglobin, resulting in severe anemia and related complications (1). Patients with thalassemia often require lifelong management, including frequent blood transfusions and iron removal therapy, to prevent serious health issues (2). Despite advancements in clinical management, individuals with thalassemia continue to face challenges in maintaining a good quality of life (QoL) due to physical, psychological, and social burdens (3). In Malaysia, thalassemia poses an ongoing public health challenge due to its widespread occurrence within the population. The Malaysian Thalassemia Registry reports an estimated 4,541 individuals living with thalassemia, highlighting the ongoing burden of the disease (4). Recent research has highlighted the need to enhance the quality of life (QoL) for those affected by thalassemia, stressing the value of holistic care that integrates both medical interventions and psychological support (5).

Various intervention programs have been developed to address these challenges and enhance self-management and QoL among thalassemia patients. These include educational programs, psychological therapies, family-centered approaches, and technological interventions, each aiming to empower patients and improve their overall well-being (6–8). While numerous studies have evaluated the effectiveness of these interventions, there is still a need for a comprehensive review of the existing evidence to inform clinical practice and shape future research.

Research gap; existing studies related to interventions strategy to enhance quality of life and self-management

among people with thalassemia.

Despite numerous studies on intervention strategy designed to enhance quality of life and self-management among individuals with thalassemia, significant gaps remain that necessitate a comprehensive systematic review. Existing research has explored a variety of interventions, including educational programs, psychological therapies, and technological solutions, each demonstrating varying degrees of effectiveness. However, these studies often differ in their methodologies, outcome measures, and follow-up durations, making it challenging to draw consistent conclusions. Furthermore, much of the research has been geographically limited, which raises concerns about the generalizability of the findings to diverse populations. Moreover, numerous studies have short follow-up durations and small sample sizes, restricting insights into the long-term effects and broader relevance of these interventions (9). Given these limitations, a systematic review is essential to synthesize existing evidence, standardize intervention protocols, and provide clear guidance for future study and fieldwork, ultimately aiming to enhance the efficacy of interventions for thalassemia patients globally.

This systematic review is centered around a key research question - What are the standard intervention programs implemented to enhance self-management and quality of life in individuals with thalassemia?

The study seeks to fill existing gaps by systematically reviewing previous experimental studies to gain a deeper understanding of the efficacy of various intervention programs aimed at improving self-management and quality of life (QoL) in people with thalassemia. This systematic review focuses on intervention programs due to several reasons. Studies have shown that comprehensive intervention strategies, including educational, psychological, and technological approaches, can significantly enhance self-management and QoL among thalassemia (10). Numerous studies have examined the effects of these interventions on thalassemia patients in various regions, underscoring both the potential advantages and the challenges of these programs (11). This review aims to consolidate current knowledge on intervention programs for thalassemia patients and provide insights for future research and practice in managing this chronic condition effectively.

METHODOLOGY

Source

This systematic literature review adhered to the framework provided by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (12). The process of selecting relevant articles followed the PRISMA-recommended steps of identification, screening, determining eligibility, and final inclusion.

Research Question

This study's research question was developed using the PICO framework, a widely used approach in quantitative systematic reviews (13). This model emphasizes four essential elements: “Population or Problem, Intervention or Exposure, Comparison, and Outcome Measures” (14). In cases where the comparison aspect was irrelevant, studies were required to address three key components: individuals with thalassemia (Population or Problem), various intervention strategies (Intervention or Exposure), and enhancements in self-management and quality of life (Outcome Measures). These criteria informed the development of the central research question: What types of interventions have been implemented to improve self-management and quality of life in people with thalassemia?

Information Sources

The search for articles in online databases was conducted on July 4, 2024, using the keywords listed in Table I. The search encompassed multiple databases, such as ScienceDirect, Scopus, Web of Science, SpringerLink, and MEDLINE. Articles published from early 2016 to December 2023 were included in the review process.

Search Strategy

The search process involved the use of keywords such as “thalassemia,” “intervention,” “enhancing self-care management,” and “quality of life (QoL).” The search strategy focused on reviewing article titles, study settings, intervention types, and outcomes. Studies qualified for inclusion if they were released from 2016 onwards, written in English, involved experimental study designs (RCTs and quasi-experimental), and focused on individuals with thalassemia. Additionally, the references from the chosen articles were thoroughly examined to guarantee a comprehensive exploration of the subject.

Selection Process

A search for English-language articles published between early 2016 and 2023 yielded 250 results from the specified online databases, of which 50 were found to be duplicates. A single reviewer (A.F.Z.) screened the titles and abstracts of 124 articles, eliminating 140 that did not meet the eligibility requirements. Full-text reviews were conducted on 60 articles, leading to the exclusion of 48 due to insufficient detail or lack of relevance to the review's objectives. The study ultimately included 12 articles. Afterward, a second group of reviewers evaluated the quality of the chosen articles. The distribution of articles across databases was as follows: ScienceDirect (68 articles), Web of Science (74 articles), Scopus (44 articles), MEDLINE (26 articles), and SpringerLink (38 articles). The selection process was summarized using the PRISMA 2009 Flow Chart (12), as depicted in Fig. 1.

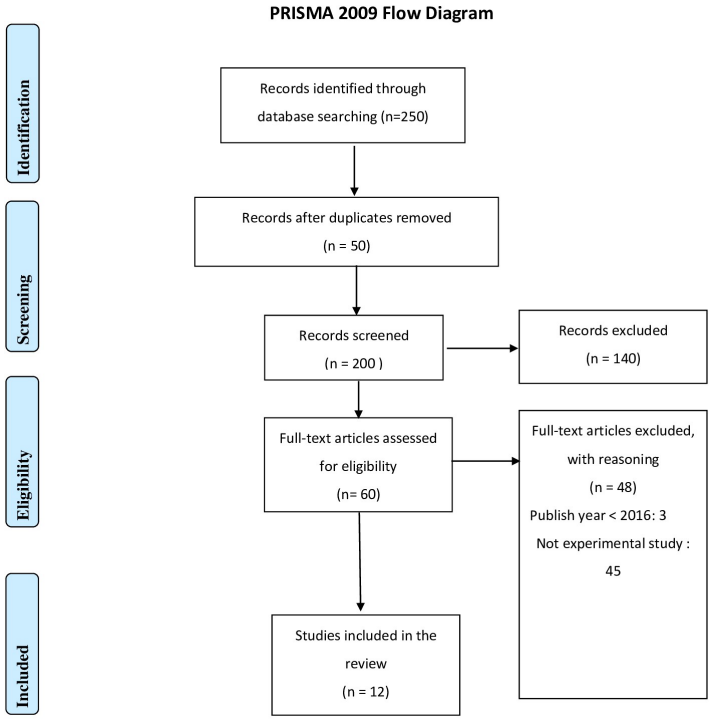

Fig. 1: PRISMA 2009 Flow Diagram. Flow chart to summarise the selection of potent articles for the review

Inclusion Criteria

Population:

- Studies involving patients diagnosed with thalassemia.
- Participants of all age groups, including children, adolescents, and adults.

Intervention:

- Studies that implemented any form of intervention aimed at improving self-management and/or quality of life (QoL) among individuals with thalassemia. This includes but is not limited to educational programs, psychological therapies, family-centered approaches, technological interventions, and supportive care programs.

Comparison:

- Studies that included a control group, either receiving standard care, placebo, or no intervention.

Outcomes:

- Studies reporting relevant outcomes such as improvements in self-care behaviors, QoL, psychological well-being (e.g., stress, anxiety, depression), self-efficacy, and other health-related outcomes.

Study Design:

- Randomized controlled trials (RCTs) and quasi-experimental studies.

Language:

- Studies published in English.

Time Frame:

- Studies published from early 2016 until end of 2023.

Exclusion Criteria

Population:

- Studies involving patients without a diagnosis of thalassemia.
- Studies focusing solely on patients with other chronic diseases without including thalassemia patients.

Intervention:

- Studies that do not include any specific intervention aimed at improving self-management or QoL.
- Pharmacological-only studies without any educational or psychological component.

Comparison:

- Studies lacking a control group or comparator.

Outcomes:

- Studies that do not report on relevant outcomes related to self-management or QoL.

Study Design:

- Case reports, case series, cross-sectional studies, qualitative studies, reviews, editorials, and commentaries.

Language:

- Studies published in languages other than English.

Time Frame:

- Articles published prior to a specified time frame or

those not considered within the relevant period of interest.

Quality Assessment and Data Extraction Process

The initial screening of titles, abstracts, and full texts from the retrieved articles was conducted by a single reviewer (A.F.Z.). To maintain thoroughness, two additional reviewers (S.K.A.S. and S.M.A.W) reviewed the articles to resolve any uncertainties about their eligibility. The articles were evaluated based on specific objectives, including interventions focused on enhancing self-management and quality of life (QoL) in individuals with thalassemia, the application of any theoretical frameworks, study design, program structure, setting, methodology, providers, follow-up and evaluation, outcome measures, and key findings. Due to the heterogeneity in study designs, interventions, and outcomes, a meta-analysis was not performed. No contact was made with the study authors to obtain further details.

To assess the quality and methodological rigor of the included studies, we applied the criteria outlined by the Non-Randomised Studies Methods Group (NRSMG) of The Cochrane Collaboration (15). This approach ensures a comprehensive evaluation of both randomised controlled trials (RCTs) and non-randomised controlled trials (NRCTs), addressing potential biases and the validity of the findings. The following criteria were used to assess each study: Study Design: Identification of the study as either an RCT or NRCT, Comparability at Baseline: Evaluation of whether the intervention and control groups were comparable at the start of the study, Intervention Description: Assessment of the adequacy of the description of the intervention provided, Outcome Measures: Verification that the outcome measures used were valid and reliable, Blinding: Determination of whether outcome assessment was blinded to reduce detection bias, Follow-Up Completeness: Examination of whether follow-up was complete and if incomplete outcome data were adequately addressed, Selective Outcome Reporting: Checking for the absence of selective outcome reporting, Other Biases: Identification of any other problems that could introduce bias into the study. The findings of this assessment are presented in Table I. providing a detailed overview of the methodological features of the 12 included studies. This evaluation helps to ensure the robustness and credibility of the findings reported in this systematic review.

The selected studies were additionally evaluated to determine the risk of bias using an approach adapted from the Cochrane Collaboration's tool for assessing bias risk (16) (Table II). This tool evaluates eight key aspects: random sequence generation (to address selection bias), allocation concealment (to address selection bias), blinding of participants and personnel (to minimize performance bias), blinding of outcome assessment for patient-reported outcomes (to reduce detection bias), blinding of outcome assessment for mortality (to reduce detection bias), incomplete outcome data for short-term outcomes (2–6 weeks) (addressing attrition bias), incomplete outcome data for long-term outcomes (over 6 weeks) (addressing attrition bias), and selective reporting (to address reporting bias).

Table I: List of study design

Author(s)	Study Design	Was the study a non-randomised controlled trial (NRCT)?	Was the study a randomised controlled trial (RCT)?	Were the groups comparable at baseline?	Was the intervention adequately described?	Were the outcome measures valid and reliable?	Was the outcome assessment blinded?	Was follow-up complete?	Were incomplete outcome data adequately addressed?	Was the study free of selective outcome reporting?	Was the study free of other problems that could put it at a high risk of bias?
Masinaienejad et al. (17)	RCT	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Madmoli et al. (18)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Jabbarifard et al. (22)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Zeykani & Nikmanesh (23)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Gharaati et al. (19)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Rafii et al. (9)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Salehipour et al. (20)	RCT	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Jamalpoor et al. (25)	RCT	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Borimnejad et al. (21)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Hemmatipour et al. (8)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Sadek et al. (24)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y
Mediani et al. (26)	Quasi-experimental	Y	N	Y	Y	Y	Y	Y	Y	Y	Y

Y, yes; N, no

Table II: Risk of bias summary (Cochrane Statistical Methods Group and the Cochrane Bias Methods Group)

	Random Sequence Generation (Selection Bias)	Allocation Concealment (Selection Bias)	Blinding of Participants and Personnel (Performance Bias)	Blinding of Outcome Assessment (Detection Bias) - Patient-Reported Outcomes	Blinding of Outcome Assessment (Detection Bias) - Mortality	Incomplete Outcome Data (Attrition Bias) - Short-Term Outcomes (2-6 weeks)	Incomplete Outcome Data (Attrition Bias) - Long-Term Outcomes (>6 weeks)	Selective Reporting (Reporting Bias)
Masinaienejad et al. (17)	Low Risk	Low Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Madmoli et al. (18)	Low Risk	Unclear Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Jabbarifard et al. (22)	Low Risk	Unclear Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Zeykani & Nikmanesh (23)	Low Risk	Unclear Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Gharaati et al. (19)	Low Risk	Unclear Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Rafii et al. (9)	Low Risk	Unclear Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Salehipour et al. (20)	Low Risk	Unclear Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Jamalpoor et al. (25)	Low Risk	Low Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Borimnejad et al. (21)	Low Risk	Low Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Hemmatipour et al. (8)	Low Risk	Low Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Sadek et al. (24)	Low Risk	Low Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk
Mediani et al. (26)	Low Risk	Low Risk	High Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk

The articles were evaluated using the checklist from the Consolidated Standards of Reporting Trials (CONSORT) statement, which serves as a reporting guideline for assessing non-pharmacologic treatments (17) (Table III). The CONSORT framework encompassed 22 criteria, addressing (i) title and abstract, (ii) introduction, (iii) methods, (iv) results, and (v) discussion. Several studies were missing details on randomization, allocation concealment, blinding, ancillary analyses, and reporting of adverse events.

RESULTS

From the 250 articles retrieved across various databases, 50 were found to be duplicates, and 140 were removed based on their title, objective, target population, and lack of focus on interventions aimed at improving self-management and quality of life (QoL). Out of the remaining 60 articles assessed for eligibility, 48 full-text articles were excluded, leaving 12 that fulfilled all the inclusion criteria. These 12 eligible articles, all of which conducted experimental studies, were thoroughly reviewed and analyzed to identify relevant outcome measures related to interventions for enhancing self-management and QoL among individuals with thalassemia. Table III provides a summary of reviewed article. The interventions assessed ranged from self-care education based on Orem's model, acceptance and commitment therapy, positive psychotherapy, and family-centered empowerment programs to supportive educational programs. Notably, self-care education and family-centered empowerment programs were consistently effective in enhancing self-care behaviors and self-efficacy among patients (8,18–22). For instance, Masinaienejad et al. (18) reported significant improvements in self-care behaviors in mental health, physical activities, and therapeutic measures following a self-care education intervention ($p < 0.05$). Similarly, Gharaati et al. (20) demonstrated that a family-centered empowerment program significantly increased self-efficacy in adolescents with thalassemia ($p < 0.05$).

Psychological approaches, including acceptance and commitment therapy (ACT) and positive psychotherapy, also showed promising results. Jabbarifard et al. (23) found that ACT significantly reduced perceived stress and increased resilience and QoL in thalassemia patients ($p < 0.01$). Positive psychotherapy, evaluated by Zeykani and Nikmanesh (24), effectively enhanced perceived competence and QoL among children with thalassemia ($p < 0.05$). Additionally, the educational program was effective in significantly enhancing the self-efficacy of adolescents with thalassemia major. The results suggest the need for continuous health education programs to further support these patients in managing their condition and improving their quality of life (25).

The research conducted by Jamalpoor et al. (26) revealed that creative activities such as storytelling and painting led to a notable improvement in the self-concept of children with thalassemia ($p < 0.05$), demonstrating the effectiveness of non-invasive and affordable therapies in enhancing psychological well-being among pediatric patients. Conversely, Rafii et al. (9) reported that a short-term orientation program did not significantly improve the quality of life in people with thalassemia; therefore, the implementation of sustained and multi-faceted strategies may yield more significant improvements.

On the other hand, Mediani et al. (27) demonstrated that psychoeducation intervention significantly improved both self-efficacy and coping skills among adolescent thalassemia survivors. Post-intervention, participants demonstrated enhanced abilities to manage the psychosocial challenges of their condition. Overall, the review underscores the importance of comprehensive,

Table III: Literature summary for the intervention programs among people with thalassemia

Author(s)	Design	Title	Objective	Education Programme Method	Follow Up	Outcome Measure	Primary Outcome	Secondary Outcome	Conclusion
Masinaienejad et al. (17)	RCT	The Impact of Self-care Education Based on Orem's Model on Self-care Behaviors of Patients with β-Thalassemia Major	Investigate the effects of self-care education on self-care behaviors of patients with major β-thalassemia based on Orem's model.	Individual and group training for 5 sessions of 30 to 45 minutes.	1 month	Self-care scale	Improved self-care behaviors in mental health, physical activities, and therapeutic measures ($p < 0.05$).	No improvement in nutrition	Self-care interventions based on Orem's model can improve self-care behaviors in patients with major β-thalassemia.
Jabbarifard et al. (22)	Quasi-experimental	The effectiveness of acceptance and commitment therapy on perceived stress, resilience, and quality of life in thalassemia major patients	Determine the effect of acceptance and commitment therapy on perceived stress, resilience, and quality of life in thalassemia major patients.	Eight-week sessions of acceptance and commitment-based therapy.	3 months	Perceived Stress Questionnaire, Conner and Davison Resilience Scale, WHO Quality of Life (SF-26)	Significant reduction in perceived stress, increase in resilience, and improvement in quality of life ($p < 0.01$).	None	Acceptance and commitment therapy can reduce stress, increase resilience, and improve QoL in thalassemia major patients.
Zeykani & Nikmanesh (23)	Quasi-experimental	The Effect of Positive Psychotherapy on Perceived Competence and Quality of Life Among Children with Thalassemia	Investigate the effect of positive psychotherapy on perceived competence and quality of life among children with thalassemia.	Eight sessions of positive psychotherapy.	1 month	Harter Perceived Competence Scale for Children, KIDSCREEN-Quality of Life Measure	Significant improvement in perceived competence and quality of life ($p < 0.005$).	None	Positive psychotherapy can enhance competence and QoL in children with thalassemia.
Gharaati et al. (19)	Quasi-experimental	Effect of a Mobile-Phone Mediated Based Education on Self-Care Behaviors of Patients with Thalassemia Major	Explore the effects of mobile phone-mediated education on self-care behaviors of patients with thalassemia major.	Mobile-phone mediated education program.	2 months	Knowledge, attitude, and self-care behaviors questionnaire	Significant increase in knowledge, attitude, and self-care behaviors in intervention group	None	Mobile-phone mediated education is effective in improving self-care behaviors in patients with thalassemia major.
Madmoli et al. (18)	Quasi-experimental	The Effect of Orem Self-care Model on Health-related Quality of Life of Patients with Thalassemia Major	Determine the effect of Orem's self-care model on quality of life in patients with β-thalassemia major.	Educational package, self-care based on need assessment and Orem's model, taught in a 60-minute session.	Not specified	SF-36 questionnaire	Significant improvement in quality of life in the intervention group ($p < 0.005$).	None	Orem's self-care model can be used as a simple, low-cost non-pharmacological treatment to increase QoL in thalassemia major patients.
Rafii et al. (9)	Quasi-experimental	The Effects of an Orientation Program on Quality of Life of Patients with Thalassemia	Examine the effects of a nurse-implemented orientation program on quality of life in patients with thalassemia.	Orientation program over 1.5 months	1 month	Thalassemia Quality of Life Questionnaire (TQOLQ), SF-36	No significant improvement in quality of life.	None	A short-term orientation program was not effective in enhancing quality of life. Longer-term strategies may yield better results.
Jamalpoor et al. (25)	RCT	Effect of Narration and Painting Methods on the Self-concept of Children with Thalassemia Major	Compare the effect of narration and painting methods on the self-concept of children with thalassemia major.	Six sessions of narration and six sessions of painting.	3 months	Piers-Harris Self-Concept Scale	Improvement in self-concept in the painting group ($p = 0.033$).	No significant improvement in the narration group	Narration and painting therapies are effective, non-invasive, and affordable methods to improve self-concept in children with thalassemia major.

Table III: Continue

Borimnejad et al. (21)	Quasi-experimental	The Effect of Family-Centered Empowerment Program on Self-Efficacy of Adolescents with Thalassemia Major	Determine the effect of family-centered empowerment program on self-efficacy of adolescents with thalassemia major.	Family-centered empowerment program over six weeks	6 weeks	General Self-Efficacy Scale, Sickle Cell Self-Efficacy Scale	Significant increase in self-efficacy ($p < 0.01$).	None	Family-centered empowerment program significantly enhances self-efficacy in adolescents with thalassemia major.
Salehipour et al. (20)	RCT	Impact of Continuous Care Model on the Quality of Life of Patients with Thalassemia Major	Determine the impact of Continuous Care Model on the quality of life of patients with thalassemia major.	Six training sessions three times a week.	3 months	WHO Quality of Life-BREF, Self-Control Checklist	Significant improvement in quality of life in the intervention group ($p < 0.05$).	None	Continuous Care Model improved the quality of life in patients with thalassemia major.
Sadek et al. (24)	Quasi-experimental	Effect of an Educational Program on Self-Efficacy of Adolescents with Thalassemia Major	Assess the effect of an educational program on self-efficacy of adolescents with thalassemia major.	Three sessions covering thalassemia major, complications, and treatment with brochures.	6 weeks	Self-efficacy scale	Significant improvement in self-efficacy ($p = 0.00$).	None	The educational program significantly enhanced the self-efficacy of adolescents with thalassemia major.
Hemmatipour et al. (8)	Quasi-experimental	Effect of Family-Centered Empowerment Model Using Mobile Learning on Quality of Life in Children with Thalassemia	Assess the impact of family-centered empowerment model using mobile learning on quality of life in children aged 6-12 years diagnosed with thalassemia.	Five sessions of mobile learning focused on self-efficacy and awareness of thalassemia.	6 weeks	Pediatric Quality of Life Inventory (Ped-SQL), parental awareness and self-efficacy questionnaires	Significant increase in quality of life of children and parental self-efficacy ($p < 0.001$).	None	Family-centered empowerment model using mobile learning significantly improved QoL and increased parental awareness.
Mediani et al. (26)	Quasi-experimental	Effect of Psychoeducation Intervention on Self-efficacy and Coping of Adolescent Thalassemic Survivors in Indonesia	Examine the effect of psycho-education on self-efficacy and coping of adolescents with thalassemia.	Psycho-education intervention in two sessions using lecture, booklet, and discussions.	18-23 days	Chronic Disease Self-Efficacy Scales (CDSES), Ways of Coping (WOC) Scale	Significant increase in self-efficacy and coping scores after psychoeducation ($p < 0.001$).	None	Psycho-education intervention improved self-efficacy and coping among adolescent thalassemia survivors.

patient-centered intervention strategies that integrate educational, psychological, and technological approaches to effectively manage thalassemia and improve patients' quality of life.

DISCUSSION

The findings from this systematic review highlight the significant impact of various intervention programs on improving self-management and quality of life (QoL) among individuals with thalassemia. Educational interventions, such as self-care education based on Orem's model, have shown to enhance patients' ability to manage their condition effectively. For instance, Masinaienejad et al. (18) reported that structured self-management training significantly enhanced self-care behaviors related to emotional well-being, exercise routines, and medical management. ($p < 0.05$). This underscores the importance of providing knowledge to patients, enabling them to play a proactive role in maintaining their health. Educational programs are vital as they equip patients with the knowledge and skills needed to understand their condition, follow treatment plans, and make informed decisions about their healthcare (28). Similarly, family-centered empowerment programs have proven effective in boosting self-efficacy among adolescents with thalassemia, as demonstrated by Gharaati et al. (20), who found a significant increase in self-efficacy ($p < 0.05$). This improvement can be attributed to the integration of close relations in the care pathway, which provides a supportive environment and enhances the patient's confidence in managing their condition. Family involvement is known to improve health outcomes by providing emotional support, encouraging adherence to treatment, and facilitating communication between patients and healthcare providers (29).

Psychological interventions are also essential in improving mental well-being of individuals with thalassemia. Acceptance and commitment therapy (ACT) and positive psychotherapy have been particularly

effective in reducing psychological distress and improving QoL. Jabbarifard et al. (23) found that ACT significantly reduced perceived stress and increased resilience and QoL ($p < 0.01$). Reducing psychological stress is essential for improving QoL, as prolonged stress can adversely affect mental and physical health, resulting in worse health outcomes (30). Additionally, positive psychotherapy, as studied by Zeykani and Nikmanesh (24), significantly improved perceived competence and QoL among children with thalassemia ($p < 0.05$). These interventions address the psychological burden associated with thalassemia, suggesting that integrating mental health support into standard care can lead to better overall outcomes for patients. Positive psychotherapy focuses on enhancing positive emotions, strengths, and meaning in life, which are crucial for psychological well-being and resilience (31).

Narration and painting therapies have also proven successful in improving self-identity among young patients with thalassemia. Jamalpoor et al. (26) found that these creative interventions significantly boosted self-perception scores in the group participating in painting therapy ($p=0.033$). Creative therapies provide a non-invasive and enjoyable way for children to express their feelings and experiences, which can lead to improved psychological well-being and self-esteem (32). Lastly, supportive educational programs and psychoeducation have been found to significantly enhance self-management and QoL. Mediani et al. (27) reported that these programs resulted in a significant increase in self-efficacy and coping among adolescent thalassemia survivors. Supportive educational programs provide ongoing education and resources, helping patients to continuously improve their self-care skills and adapt to changes in their condition (33).

Limitation of the Study

Despite the promising findings, this review has several limitations. First, the heterogeneity in study designs, interventions, and outcome assessments among the included articles makes it difficult to draw firm conclusions and compare results directly. Future research should aim to standardize intervention protocols and outcome measures to facilitate comparison and replication. Second, many studies had relatively short follow-up periods, ranging from one to six months, which may not capture the long-term sustainability of the intervention effects. Long-term studies are essential to assess the lasting effects of these interventions on self-management and QoL. Additionally, the most of the research were carried out in specific geographic regions, particularly in Iran, which May reduce the external validity of the results to broader populations and healthcare environments. More research is needed in diverse cultural and socioeconomic contexts to validate the interventions globally.

Another limitation is the potential for possibility and detection bias, especially in studies where blinding was not feasible. The lack of blinding could influence the behavior of participants and the assessment of outcomes, potentially overestimating the effectiveness of the interventions. To mitigate this, future studies should incorporate objective outcome measures and blinded data analysis whenever possible. Lastly, the sample sizes in several studies were fairly limited, potentially reducing the statistical power to identify significant differences. Larger, well-powered studies are required to validate the effectiveness of these interventions.

CONCLUSION

This systematic review demonstrates that various intervention programs, including educational, psychological, and technological approaches, significantly improve self-management behaviors and quality of life among individuals with thalassemia. Self-care education and family-centered empowerment programs were particularly effective in enhancing self-care behaviors and self-efficacy, while psychological interventions like ACT and positive psychotherapy lessened emotional distress and improved overall well-being. Technological interventions, such as mobile phone-mediated education and supportive educational programs, also showed promise in enhancing patient engagement and adherence to self-management practices. Despite these positive findings, further research is needed to address limitations such as standardization of protocols, longer follow-up periods, and larger, more diverse study populations. Future studies should incorporate objective outcome measures and blinded data analysis to reduce biases, ultimately developing more effective, evidence-based interventions to support thalassemia patients in managing their condition and improving their quality of life.

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