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A scoping review of educational methods to optimize parental self-efficacy and health literacy in improving the quality of life among children with thalassemia: Evidence from Asian studies

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ABSTRACT

Background: The success of parents in managing thalassemia in children is influenced by several important aspects, including self-efficacy and health literacy. Educational programs specifically designed for parents and children with thalassemia have been shown to improve the quality of life of children significantly. This scoping review aimed to identify and map family-centered educational interventions that enhanced parental self-efficacy and health literacy to improve the quality of life for children with thalassemia.

Methods: This research employs a scoping review method, following the preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews (PRISMA-ScR) guidelines. A literature search was conducted across four databases: EBSCO, PubMed, Scopus, and Taylor & Francis, as well as the search engine Google Scholar. Inclusion criteria included full-text articles in English, primary studies discussing educational interventions related to self-efficacy and health literacy, and studies with a quality score ≥70% based on the Joanna Briggs Institute (JBI) assessment. Exclusion criteria consisted of secondary research such as literature reviews and editorials, as well as studies with a JBI score below 70%. The study selection strategy used the PICO (population, intervention, comparison, and outcome) approach. Total of 17 articles were finally included in the analysis.

Results: A total of 17 articles were found and included in the study. There are two types of interventions, conventional and digital-based educations. The media used in conventional education include booklets, pamphlets, posters, and PowerPoint presentations, along with methods such as lectures, group discussions, and training sessions. In addition, digital-based education in this study was a smartphone app and mobile learning.

Conclusion: Conventional and digital-based educations have the potential to be effective methods in optimizing parental self-efficacy, health literacy, and knowledge, which can improve the quality of life for children with thalassemia.

Keywords: health literacy, intervention, parental self-efficacy, quality of life, thalassemia.
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INTRODUCTION

Thalassemia is a genetic disorder that disrupts the process of hemoglobin synthesis in red blood cells, leading to a deficiency of globin chains in hemoglobin.[1] Thalassemia is classified based on the hemoglobin chain affected and the number of globin chains synthesized.[2] The two main categories are α (alpha)-thalassemia and β (beta)-thalassemia. Alpha thalassemia primarily affects individuals of Southeast Asian, Chinese, and Filipino descent, with the severity ranging from mild forms to cases that may result in fetal or newborn death. Beta thalassemia, also known as Cooley's anemia, is more common among people of Italian, Greek, Middle Eastern, South Asian, and African descent.[3] Beta-thalassemia is the most common thalassemia and is divided into thalassemia minor, intermedia, and major. Thalassemia major is the type that causes severe anemia that can lead to heart failure and death in early childhood without transfusion support and iron chelation therapy.[2]

Children with thalassemia require long-term care such as regular blood transfusions and iron chelation therapy. However, frequent hospital visits, physical discomfort, and complications of iron overload often have an impact on psychosocial aspects, developmental delays, decreased physical function, and poor quality of life.[4-6] The side effects of treatment that change appearance can also cause stigma, isolation, and reduce self-esteem and social relationships.[7] In addition, they are susceptible to stress, anxiety, and depression due to lifelong illness.[8,9] The strict treatment regimen also adds to the challenge of maintaining quality of life (QoL). A study by Mikael and Al-Allawi (2018) showed that children with thalassemia reported significantly lower QoL scores in physical health compared to their healthy peers, with frequent transfusions and high serum ferritin levels being the main contributors to this decline.[5]

In addition, parents play a crucial role in managing thalassemia.[10,11] Their involvement is critical to ensuring adherence to the treatment regimen, as parents are often the primary caregivers responsible for coordinating the child's care.[10] Parents also play a role in providing emotional and psychological support to their children, helping them overcome social and emotional challenges, which contribute to an improved quality of life.[12,13]

The success of parents in managing disease in children with thalassemia is influenced by several important aspects, namely self-efficacy and health literacy.[13-15] High parental self-efficacy empowers parents to effectively manage their child's medical needs, such as ensuring timely blood transfusions and providing iron chelation therapy, which is critical to preventing complications such as organ damage.[10] Previous research has shown that parents who are more confident in their parenting abilities are better prepared to navigate the health care system, make informed decisions, and maintain medication adherence, all of which have a significant impact on their child's quality of life.[16] Conversely, low parental self-efficacy may lead to inadequate disease management, which may exacerbate physical and psychosocial challenges for the child.[16] A study shows that home care training interventions significantly increase self-efficacy scores, which have implications for parents' ability to cope with care challenges and improve overall child health.[14]

Another aspect that influences the success of disease management is adequate parental health literacy, which enables parents to understand the complexity of the disease, the treatment required, and how to prevent complications.[13,15] Previous studies have shown that parental knowledge and involvement significantly impact the quality of life of children with thalassemia, as knowledgeable parents are better equipped to manage the condition and cope with potential complications effectively.[4,16,17]

In addition, parents face significant psychosocial burdens, including stress, guilt, financial pressure, and social stigma.[10,12,13] In the study of Nabavian et al. (2018, 2021), mothers, in particular, reported high levels of mental and physical exhaustion due to childcare responsibilities.[18,19] Lack of knowledge about the disease further exacerbates this challenge.[16] Educational interventions designed to improve parental health literacy are effective in addressing this problem.[16,20] Parents who are equipped with adequate health literacy are better prepared to manage their children's complex medical needs, navigate the health care system, and make informed decisions.[16,20] Additionally, improved self-efficacy enables parents to adopt adaptive coping mechanisms and provide emotional stability for their children.[16,21,22]

One important intervention to implement is a targeted educational program that provides practical skills training and emotional support, which has been shown to increase parental self-efficacy and reduce stress levels.[14,23] In addition, genetic counseling programs help parents understand the hereditary nature of thalassemia and make informed decisions about family planning.[10,24] Educational programs specifically designed for parents and children with thalassemia have been shown to significantly improve children's quality of life.[4,5,20] This education encompasses medical, nutritional, mental health, and psychosocial support aspects, enabling parents to become active partners in managing their child's illness.[11]

Based on these problems, existing interventions only focus on medical aspects and management of physical symptoms, such as blood transfusion and chelation therapy, but often ignore the psychosocial and educational needs of parents who play an important role in caring for children with thalassemia.[7] This scoping review aimed to fill this gap by identifying family-centered education methods that can improve health literacy and parental self-efficacy in supporting the quality of life of children with thalassemia more comprehensively. This gap highlights the need to explore strategies that empower parents with knowledge and confidence through more comprehensive educational interventions, such as home-care training, the use of digital applications, and community-based educational programs, to effectively support the improvement of their children's quality of life.

This scoping review was important to conduct to identify the types of family-centered education methods that optimize parental self-efficacy and health literacy, thereby improving the quality of life for children with thalassemia.

METHODS

Study design

This literature review employed a scoping review design, which was a flexible methodological approach suitable for exploring rapidly evolving research topics.[25] The scoping review method encompasses a broader conceptual scope, enabling the synthesis of diverse relevant research findings. The key stages in a scoping review framework include defining the research question, identifying relevant studies, selecting appropriate research, summarizing the data, and compiling a comprehensive report of the findings.[25] In this review, the preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews (PRISMA-ScR) was utilized to identify interventions aimed at improving the quality of life of children with thalassemia by strengthening parental self-efficacy and health literacy. The scoping review approach was chosen because it facilitates a thorough summary of interventions, offering a holistic view of strategies to enhance the well-being of children with thalassemia through parental empowerment and knowledge development.[25] Additionally, this design incorporates a systematic process for data collection and analysis, ensuring the reliability and credibility of the findings.[25]

Eligibility criteria

The selection of articles for this review was carried out using the PRISMA-ScR guidelines.[26] Research questions and eligibility criteria for research articles use the population, intervention, comparison, and outcome (PICO) approach; P: children with thalassemia and their parents/caregivers; I: interventions to optimize parental self-efficacy and health literacy; C: no comparison; O: parental self-efficacy and health literacy, knowledge, quality of life.

Secondary research, such as literature reviews and editorials, was not included in this review. Inclusion criteria were (1) full text in English; (2) focuses on parental self-efficacy and health literacy, and quality of life of children with thalassemia (3) the type of research analyzed is primary studies (original articles) which discuss educational interventions to optimize parental self-efficacy and health literacy to improve quality of life children with thalassemia, and (4) this review does not limit the year of publication. The authors did not restrict the year of publication to ensure a comprehensive review. To maintain relevance and comparability, only studies with a quality score of at least 70% (as assessed by the Joanna Briggs Institute; JBI) were included. The analysis focused solely on the interventions provided, including educational methods and their outcomes. Older studies were interpreted in their historical context, while more recent studies were highlighted for their relevance to current practice.

Search strategy

The systematic identification of articles was conducted across four primary databases: EBSCO, PubMed, Scopus, and Taylor & Francis, CINAHL: Medline Ultimate, and Google Scholar. The keywords used were "Children OR Pediatric OR Childhood AND Adolescent OR Teenagers OR Youth AND Thalassemia AND Quality of Life OR HRQOL OR Health Related Quality of Life AND Parent OR Parental AND Self-efficacy AND Health Literacy OR Knowledge AND Intervention". Synonyms were employed to retrieve all potentially relevant articles for each term validated by Medical Subject Headings (MeSH).

Study selection and quality appraisal

Researchers selected studies that met the eligibility criteria using Mendeley to remove duplicates. Initial screening of titles, abstracts, and full texts was conducted independently by two reviewers (YS and FPA) based on the inclusion and exclusion criteria. For quality appraisal, the JBI critical appraisal tools were utilized, with nine items applied to quasi-experimental studies and thirteen items to randomized controlled trials (RCTs), by the official JBI guidelines.[27] Each item was scored as yes, no, unclear, or not applicable. Studies with a score below 70% were excluded from the analysis. Two reviewers (ZH and G) independently assessed the methodological quality of the study. Any discrepancies in scoring were discussed and resolved through consensus. If consensus could not be reached, a third reviewer (FPA) was consulted to make the final decision.

A 70% JBI score was used as a cut-off to determine study inclusion based on methodological quality. Although the JBI does not mandate a specific threshold, using a threshold of ≥70% is a common and pragmatic approach in reviews to ensure the inclusion of studies with an acceptable risk of bias.[28] This cut-off reflects a balance between methodological rigor and inclusivity, and is widely recognized in the literature as a benchmark for acceptable quality. While JBI advises caution in excluding studies solely based on appraisal scores, applying a threshold like 70% is justified when aiming to enhance the reliability of findings or conduct sensitivity analyses.[28,29]

Data extraction and analysis

In this review, data extraction from the analyzed studies was conducted using a table that provides a detailed description of all results related to the discussed topic. The information presented in the extraction table pertains to the study design (country, design, sample size, and mean age), interventions, comparison, and results. All included studies were original research with a quasi-experimental design. The data analysis process began by identifying and presenting the data obtained in tabular form based on the reviewed articles. After obtaining the data, the researcher analyzed and explained each finding about interventions aimed at optimizing parental self-efficacy and health literacy to enhance the quality of life for children with thalassemia. Finally, the researcher rechecked the included studies to ensure and minimize errors.

RESULTS

Study selection

The study selection process began with the identification of articles from various databases, including EBSCO, PubMed, Scopus, Taylor & Francis, CINAHL: Medline Ultimate, and Google Scholar, totaling 22,217 articles. After the deduplication process, 1,400 articles were removed because they were duplicates, leaving 8,117 articles for further screening. In the initial screening stage, articles were evaluated based on their title and abstracts.

From this process in Figure 1. 8,090 articles were eliminated because they did not meet the established criteria, leaving only 27 articles to advance to the next stage. The remaining articles were then assessed based on the completeness of the information and their suitability for inclusion, considering the population, intervention, and language criteria. At this stage, 10 articles were excluded due to inconsistent results (8 articles) and samples that were too heterogeneous (2 articles), resulting in 17 articles remaining. Furthermore, the 17 articles that passed the selection stage were assessed for their eligibility using the JBI critical appraisal tools. After the assessment process, all of these articles were deemed to meet the standards and were finally included in the manuscript analysis.

Quality appraisal results

According to the critical appraisal results in Table 1, the critical appraisal using the JBI instrument, the studies analysed in this scoping review generally showed good to very good methodological quality, with scores ranging from 77% to 100%. The majority of studies employed relevant quasi-experimental designs to investigate the effectiveness of the intervention.

In the quasi-experimental study, question item 3 ("*Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?*") received the most unclear answers. This means that the study did not provide sufficient information about the standard treatment or treatment received by participants in the intervention and control groups. In addition, item question item 4 ("*Was there a control group?*") also received the most "*No*" answers, indicating that not all quasi-experimental studies have a clear control group. Some studies employed a pre-post test design without a control group, which could compromise the study's quality.

In RCT studies, the JBI items that most often received a "*No*" answer were question items 4 ("*Were participants blind to treatment assignment?*") and 5 ("*Were those delivering treatment blind to treatment assignment?*"). A "*No*" answer to these two items indicated that blinding was not performed or was not reported in the study.

Overall, the studies analyzed in this review were of good quality (>70%), indicating that the methodologies used were valid and reliable to evaluate the intervention studies. This indicates that most studies had strong designs, transparent reporting, and minimal risk of bias, ensuring that the results obtained can be trusted and used as a basis for clinical or policy decision-making.

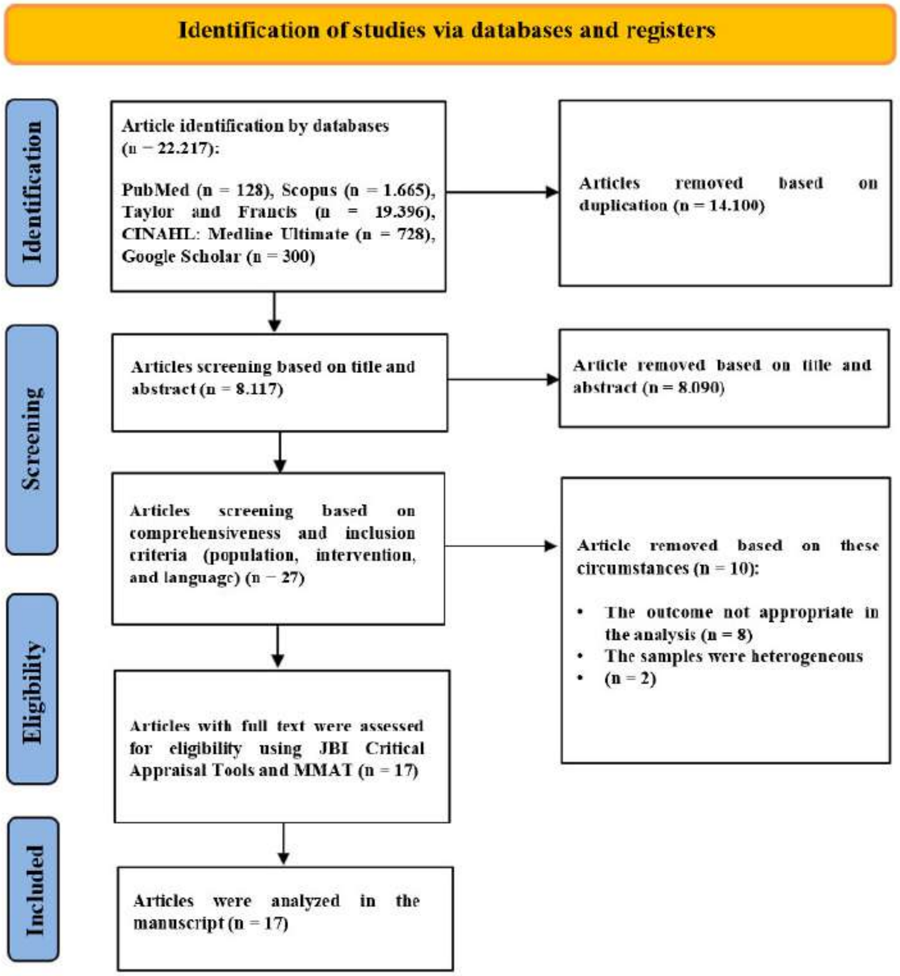

Figure 1. Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram

Table 1. Critical appraisal results of 17 included studies

Author, year	Study design	Critical appraisal (JBI)
Kharaman-nia et al., 2023[42]	Quasi experimental	88.9%
Hemmatipour et al., 2024[43]	Quasi experimental	100%
Dehnoalian et al., 2017[30]	Semi- experimental	85.7%
Atshan & Aziz, 2022[38]	Quasi experimental	88.9%
Mohammed et al., 2022[17]	Quasi experimental	85.7%
Lotfi et al., 2023[37]	Quasi experimental	100%
Elaasar et al., 2023[39]	Quasi experimental	85.7%
Atshan et al., 2022[31]	Quasi experimental	88.9%
Samra et al., 2015[35]	Quasi experimental	85.7%
Kia et al., 2018[32]	Quasi experimental	88.9%
Biabani et al., 2020[41]	RCT	100%
Sadeghloo et al., 2022[23]	Quasi experimental	100%
Sadek et al., 2020[36]	Quasi experimental	100%
Bazpour et al., 2019[33]	RCT	77%
Qadir & Hussein, 2013[34]	Quasi experimental	88.9%
Dashtban et al., 2021[40]	Quasi experimental	100%
Setiawan et al., 2025[24]	RCT	77%

JBI, Joanna Briggs Institute; RCT, randomized control trial

Study characteristics

In this review, Table 2 presents most of the studies analysed (n = 17) were conducted in several countries, including Iran (n = 9), Iraq (n = 3), Egypt (n = 4), and Indonesia (n = 1). The participants involved in this review study were 1,591 participants, including children, adolescents, parents, and beta-thalassemia carrier couples. The review results obtained participants with the least number of 20 respondents, namely in the study of Dehnoalian et al., 2017[30], and the most were 272 respondents in the study of Setiawan et al., 2025.[24] In addition, as many as 720 children and adolescents with thalassemia were the main subjects of interventions that focused on improving quality of life. The children involved ranged in age from 6 to 18 years. Meanwhile, as many as 679 parents or caregivers and 224 beta-thalassemia carrier couples were also an important part of the intervention, considering their important role in supporting children with thalassemia.

Types of educational interventions

The analysis in Table 3, seventeen different educational intervention methods were identified that were implemented in hospitals, clinics, homes, and through digital platforms. The most frequently used

Table 2. Characteristics of the 17 included studies

Author, year	Country	Study Design			Intervention		Comparison	Results
		Design	Sample size	Mean Age	Intervention	Media/method		
Kharaman-nia et al., 2023[42]	Iran	Quasi experiment	99 atients with thalassemia (<16 years), 33 smartphone app, 33 lecture, 33 control.	App = 24.52 ± 6.76 Lecture = 25.82 ± 5.39 Control = 24.12 ± 5.85	Self-care education via smartphone app or lectures	Smartphone app & lectures	Routine tutorials	Significant self-efficacy improvement in smartphone app group ($p = 0.001$), Smartphone vs lecture ($p = 0.003$)
Hemmatipour et al., 2024[43]	Iran	Quasi experiment	172 parents of children aged 6- 12 years with thalassemia, 86 intervention, 86 control.	Intervention = 8.22 ± 5.24 Control = 9.57 ± 5.58	Family-centered empowerment model via mobile learning	Video, images, and audiofiles	Standard care	Significant increase in children's QoL (p<0.001), parental awareness ($p < 0.001$), parental self-efficacy ($p = 0.002$)
Dehnoalian et al., 2017[30]	Iran	Semi-experiment	20 thalassemia patients age 15 to 30 years	23.06 ± 10.87 years	Educational counseling	Direct and phone	No comparison	Improved QoL in all dimensions post-intervention ($p < 0.05$)
Atshan & Aziz, 2022[38]	Iraq	Quasi experiment	70 parents of children with beta -thalassemia, 35 Intervention, 35 control	Intervention = 39.83 ± 10.11 Control = 37.60 ± 9.11	Educational program about Home Health Care Management to Children with Beta Thalassemia-Major	No information	No comparison	Significant improvement in parental knowledge post-intervention (p<0,001)
Mohammed et al., 2022[17]	Egypt	Quasi experiment	70 mothers and their children with beta-thalassemia	Mothers = 27.3 ± 4.18 Children = 7.54 ± 3.12	Health coaching intervention for mothers	Group discussion, discussion, role-playing, brain storming, demonstration, power points presentations, lectures, booklet, video tutorials, booklet	No comparison	Significant improvement in maternal practices and child QoL ($p < 0.001$)
Lotfi et al., 2023[37]	Iran	Quasi experiment	62 parents of children with thalassemia, 31 Intervention, 31 control	Intervention = 36.25 ± 11.55 Control = 34.09 ± 10.57	Teach-back care program	Teach-back	Routine training	Significant increase in parental knowledge, attitude, and performance ($p \leq 0.001$).
Elaasar et al., 2023[39]	Egypt	Quasi experiment	125 children with thalassemia	12-18 years (55.2%)	Educational program based on the Precede-Proceed model	Booklet, pamphlets, videos and posters	No intervention	Significant increase in children's quality of life post-intervention ($p < 0.05$).
Atshan et al., 2022[31]	Iraq	Quasi experiment	38 arents (38 mothers, 32 fathers), 35 Intervention, 35 control	No information	Education on chelation therapy and nutrition	No information	No intervention	High significance in parental knowledge improvement ($p = 0.001$)

Author, year	Country	Study Design			Intervention		Comparison	Results
		Design	Sample size	Mean Age	Intervention	Media/method		
Samra et al., 2015[35]	Egypt	Quasi experiment	173 children with thalassemia	8-12 years (68.2%)	Educational program on chelation therapy	Lectures, demonstrations and group discussions	No intervention	Improved child quality of life ($p < 0.05$)
Kia et al., 2018[32]	Iran	Quasi experiment	224 beta-thalassemia carrier couples, 112 Intervention, 112 control	31.16 ± 6.89 years	Educational intervention based on health belief model	lectures, group discussions and pamphlets	No intervention	Significant improvement in health belief constructs and behavior ($p < 0.001$)
Biabani et al., 2020[41]	Iran	RCT	70 mothers of children with thalassemia, 35 Intervention, 35 control	Intervention = 28.17 ± 6.42 Control = 29.37 ± 5.40	Group education on adaptive behaviors	Group discussions, pamphlet, booklet, telephone	Training session at the end of the study	Adaptive behaviors (p <0.001), reduced caregiver burden (p<0.001)
Sadeghloo et al., 2022[23]	Iran	Quasi experiment	52 parents of adolescents with thalassemia, 26 Intervention, 26 control	Intervention = 48.07±52.5 Control = 46.87±6.99	Positive thinking training	Training and discussion	Routine hospital training, pamphlets	Significant QoL improvement in parents ($p < 0.001$)
Sadek et al., 2020[36]	Egypt	Quasi experiment	80 adolescents (40 intervention & 40 control groups)	Intervention =13.65 ± 1.58 Control = 14.40 ± 1.93	Educational program on thalassemia major	Interview, discussion, brochures	Routine care only	Self-efficacy improved significantly (p=0.00)
Bazpour et al., 2019[33]	Iran	RCT	64 adolescents 16-20 years, 32 Intervention, 32 control	Intervention = 18.3 ± 1.37 Control = 17.84 ± 1.34	PRECEDE-PROCEED lifestyle program	Lecture and group discussion, instructional package: lifestyle modification	No intervention	Improved lifestyle scores across dimensions (p < 0.05)
Qadir & Hussein, 2013[34]	Iraq	Quasi Experiment	100 mothers of thalassemic children, 50 Intervention, 50 control	Intervention = 37.34 Control = 37.96	Health program on Desferal therapy	Lectures, group discussion, film and practical observed applications	No intervention	Improved maternal knowledge and practices ($p < 0.05$)
Dashtban et al., 2021[40]	Iran	Quasi Experiment	90 children 12-17 years, 30 Empowerment, 30 Participatory, 30 control	Empowerment = 14.33 ± 2.04 Participatory = 13.83 ± 1.91 Control = 13.80 ± 1.98	Family-centered and participatory care models	Power Point presentation, lecture, discussion	Routine care	Improvements in physical (p =0.002), social (p < 0.001), educational dimensions (p = 0.001)

Author, year	Country	Study Design			Intervention		Comparison	Results
		Design	Sample size	Mean Age	Intervention	Media/method		
Setiawan et al., 2025[24]	Indonesia	RCT	80 patients 13-18 years, 40 Intervention, 40 control. 192 caregivers >18 years, 96 Intervention, 96 control	Patients: Intervention = 15.25 ± 1.58 Control = 15.00 ±1.36 Caregiver: Intervention = 38.73 ± 6.57 Control = 42.72 ± 6.38	Mobile app-based genetic counseling	Mobile app-based: Cyber Gen	Standard care	Significant improvements in QoL, satisfaction, reduced depression, and anxiety ($p < 0.05$).

QoL, quality of life; RCT, randomized controlled trial.

methods were lectures, group discussions, and booklets, often combined with visual media such as videos or pamphlets. Most interventions were delivered in more than three sessions. Based on the analysis, educational methods were classified into two main categories: conventional education and digital-based education, which reflect a balance between traditional and technological approaches to knowledge dissemination.

Conventional education

In this review, the conventional education intervention method category aims to optimize the quality of life of children with thalassemia through health management education, chelation therapy, psychological support, and healthy lifestyle training.[17,30,31] The methods used are quite diverse, including direct/telephone counseling, group discussions, role-playing, demonstrations, and supporting media such as booklets, video tutorials, and films.[17,32,33] Interventions range in length from 2 to 10 sessions, with some programs including follow-up, such as follow-up calls after the main session. Longer-duration programs tend to be more in-depth, involving positive thinking training and health coaching for parents with active and reflective learning techniques.[17,23] In contrast, short-duration programs focus more on specific aspects, such as an introduction to Desferal therapy or a brief education on iron chelation therapy.[34,35]

The first educational intervention was an educational counseling program that included materials on symptoms, complications, and treatment of thalassemia, along with active discussions and the provision of booklets as supporting materials, as well as telephone consultations to answer participants' questions. The results showed a significant increase in quality of life scores, especially in physical and mental health aspects. A study conducted by Sadek et al. (2020) on educational programs for thalassemia major, using interview, discussion, and brochure methods, assessed the impact of these programs on the self-efficacy of adolescents with thalassemia major.[36]

Intervention with other educational methods, specifically the teach-back program for parents of children with thalassemia, was implemented, where health information was delivered simply, and parents were asked to repeat the information to ensure their understanding. This intervention was proven to significantly increase the knowledge, attitude, and practice scores of parents.[37]

An intervention with a demonstration method was conducted by Qadir and Hussein (2013) in the education of Desferal administration, which was delivered through two sessions comprising lectures, group discussions, and film screenings. The results showed improved maternal knowledge and practices ($p < 0.05$), which contributed to a reduction in complications and an improvement in the quality of life for children.[34] In addition, the health coaching method by Mohammed et al. (2022) for mothers of children with beta-thalassemia also involves demonstration and observation. The study's results showed a significant increase in the knowledge and practice of mothers caring for children with thalassemia, as well as an improvement in the quality of life for children, particularly in terms of physical and emotional well-being.[17]

Other interventions include education on chelation therapy and nutrition for parents of children with thalassemia major, which includes lectures, interactive discussions, and the distribution of printed materials related to managing chelation therapy at home. The study's results showed a high level of significance in parental knowledge improvement ($p = 0.001$) regarding chelation therapy and proper nutrition, as well as an overall improvement in child health.[31] Similar interventions were also found in the study by Atshan & Aziz (2022), where educational programs about blood transfusion, chelation therapy, and healthy diets with similar methods also increased parental knowledge.[38] In addition, specific educational programs about chelation therapy, which combined lectures, demonstrations, and group discussions, increased children's understanding of chelation therapy and reduced symptoms of complications due to iron overload.[35]

In addition to standard educational interventions, there are also educational

Table 3. Summary interventions for optimizing quality of life children with thalassemia

Author, year	Intervention	Media/method	Session
	Conventional education		
Dehnoalian et al., 2017[30]	Educational counseling	Direct and phone	5 sessions + 2 follow-up calls
Mohammed et al., 2022[17]	Health coaching intervention for mothers	Group discussion, discussion, role-playing, brainstorming, demonstration, power points presentations, lectures, booklet, video tutorials, booklet	8 sessions
Elaasar et al., 2023[39]	Educational program based on the Precede-Proceed model	Booklet, pamphlets, videos and posters	4 sessions
Atshan & Aziz, 2022[38]	Educational program about home health care management to children with beta thalassemia-major	No information	No information
Lotfi et al., 2023[37]	Teach-back care program	Teach-back	3 – 6 sessions
Atshan et al., 2022[31]	Education on chelation therapy and nutrition	No information	No information
Samra et al., 2015[35]	Educational program on chelation therapy	Lectures, demonstrations and group discussions	5 sessions
Kia et al., 2018[32]	Educational intervention based on health belief model	lectures, group discussions and pamphlets	4 sessions
Biabani et al., 2020[41]	Group education on adaptive behaviors	Group discussions, pamphlet, booklet, telephone	4 sessions
Sadeghloo et al., 2022[23]	Positive thinking training	Training and discussion	10 sessions
Sadek et al., 2020[36]	Educational program on thalassemia major	Interview, discussion, brochures	3 sessions
Bazpour et al., 2019[33]	PRECEDE-PROCEED lifestyle program	Lecture and group discussion, instructional package: lifestyle modification	6 sessions
Qadir & Hussein, 2013[34]	Health program on Desferal therapy	Lectures, group discussion, film and practical observed applications	2 sessions
Dashtban et al., 2021[40]	Family-centered and participatory care models	Power Point presentation, lecture, discussion	4 sessions
	Digital-based education		
Kharaman-nia et al., 2023[42]	Self-care education via smartphone app or lectures	Smartphone app & Lectures	8 sessions
Hemmatipour et al., 2024[43]	Family-centered empowerment model via mobile learning	Video, images, and audio files	5 sessions
Setiawan et al., 2025[24]	Mobile app-based genetic counselling	Mobile app-based: cyber gen	3 sessions

approaches with a health promotion focus, such as those based on the Health Belief Model (HBM) in couples carrying thalassemia traits, aimed at increasing risk perception and promoting preventive behavior related to prenatal diagnosis.[32] Next, a six-session educational program utilizing the PRECEDE-PROCEED model approach was designed to educate thalassemic adolescents about healthy lifestyles, addressing nutrition, physical activity, stress management, interpersonal relationships, and self-development. The results showed significant improvements in healthy living behaviors, including adherence to therapy and an enhanced quality of life.[33] A method with a similar approach was employed by Elaasar et al. (2023), who designed an education program based on the PRECEDE-PROCEED model to enhance the quality of life for children with thalassemia.[39]

Interventions using other models were carried out by the Family-centered and participatory care model approach by Dashtban et al. (2021), which compared the family empowerment model and participatory care in terms of the quality of life of thalassemia children. The intervention consisted of structured educational sessions lasting 2 weeks. As a result, both models improved the physical, social, educational, and quality of life dimensions of children.[40] In addition, intervention with group education on adaptive behaviors focused on improving adaptive behavior and reducing caregiver burden in mothers with thalassemia children showed Improvements in physical, social, and educational dimensions. This shows that group education can strengthen mental resilience and family adaptability.[41]

Education with training methods is found in another study conducted by Sadeghloo et al. (2022), namely positive thinking training for parents of thalassemia adolescents consisting of 10 sessions and including techniques for changing negative thought patterns, stress management, and relaxation exercises has also been shown to improve mental resilience, emotional health, quality of life of parents and overall family well-being.[23]

Digital-based educational

The next category in this review is digital-based educational interventions. The methods used vary, including smartphone applications, video, image, and audio-based learning, as well as genetic counseling through digital platforms. The duration of the intervention also varies, ranging from 3 to 8 sessions, depending on the complexity of the material being addressed. Programs with longer sessions, such as those developed by Kharaman-nia et al. (2023)[42], allow for deeper exploration of the material, while shorter sessions, such as the Cyber Gen application-based genetic counseling by Setiawan et al. (2025)[24], are more focused on specific education.

One of the digital-based educational interventions was carried out by Kharaman-nia et al. (2023), who developed an education program focused on self-care for thalassemia patients through a smartphone application consisting of 8 sessions. The use of the application enables participants to access educational materials flexibly, resulting in improvements in self-efficacy, knowledge, self-care skills, and children's quality of life in the smartphone app group.[42]

Meanwhile, Hemmatipour et al. (2023) employed a family empowerment model through mobile learning, utilizing an approach that integrates video, images, and audio as the primary media for education during five sessions on medication management, psychosocial support, and coping with emotional challenges in children with thalassemia. The evaluation results showed a significant increase in children's QoL ($p<0.001$), parental awareness ($p<0.001$), and parental self-efficacy ($p = 0.002$).[43]

In addition, another digital-based education is in the form of application-based genetic counseling called Cyber Gen, developed by Setiawan et al. (2025), which is designed to support couples at risk of thalassemia in understanding the genetic aspects of this disease. This application provides structured information on thalassemia inheritance, prenatal diagnosis options, and long-term health implications. The results showed significant improvements in QoL, satisfaction, reduced depression, and anxiety ($p<0.05$).[24]

Among the digital-based interventions reviewed, some studies used standardized and validated instruments to assess outcomes such as parental self-efficacy and quality of life, for example, studies by Kharaman-nia et al., 2023; Hemmatipour et al., 2024; Setiawan et al., 2025.[24,42,43] However, not all studies explicitly stated the names or validation status of the instruments used. Therefore, some variability exists in the tools applied, which may affect comparability between studies.

DISCUSSION

This review examines various health education methods to enhance parental self-efficacy and health literacy, ultimately improving the quality of life for children with thalassemia. The results of this review suggest that numerous educational interventions can enhance parental self-efficacy and health literacy, particularly among parents and children with thalassemia. This review identified 17 educational interventions, which were subsequently categorized into two methods: conventional education and digital-based education.

Conventional education is an educational method that has been widely applied. However, along with the advancement of technology, digital-based education has begun to develop rapidly as an educational method for children, parents, or caregivers.[42] There are differences between these two types of educational methods. The main differences lie in accessibility and depth of interaction. Conventional education is stronger in building emotional support and practical skills through direct interaction by relying on group discussion methods, demonstrations, and physical media such as booklets or pamphlets.[17,39] This educational method enables intense interpersonal interaction, facilitating a deep understanding through hands-on practice and real-time feedback.[37,38] Meanwhile, digital-based education offers easy access through mobile applications, video, and audiovisual media, allowing participants to access materials at any time and support continuous learning without being tied to time or place.[24,42] Both intervention methods have proven effective in optimizing parental self-efficacy and health literacy.

Parental self-efficacy and health literacy play a crucial role in enhancing the quality of life for children with thalassemia. This optimization is done by empowering families through mobile learning[43], and home health education programs.[38] Both studies significantly increased parents' self-efficacy in managing their child's care. This increase in self-efficacy was found to be positively correlated with an improvement in children's quality of life, suggesting that when parents feel more capable and confident, they can provide more effective support for their children's physical and emotional needs.[17,23,24,30,35,39,43]

Increasing parental knowledge through health education programs also plays a crucial role in enhancing children's quality of life. A previous study reported that health coaching interventions for mothers significantly improved care practices and the quality of life for children with thalassemia.[17] Similar findings were also reported by Qadir & Hussein (2013), where an education program and demonstration of Desferal therapy improved mothers' knowledge and practices in child health care management.[34] In addition, digital-based education, including the use of smartphone applications and mobile app-based genetic counseling, has been shown to significantly increase parental self-efficacy, knowledge, children's quality of life, satisfaction, and reduce depression and anxiety.[24,42] Another study conducted in Oman reported that a parent education intervention program using a smartphone application significantly improved knowledge, self-efficacy, and health-related quality of life in children with chronic diseases.[16]

Comprehensive health education interventions, combined with a family-centered empowerment model, consistently show a strong impact on children's quality of life by strengthening parental self-efficacy and health literacy.[21,40,43] This approach not only enriches parents' knowledge but also builds their confidence in caring for children holistically.[40,43] In addition, education with home care training programs can increase the self-efficacy of parents and children, so that it can reduce the duration of hospitalization and improve disease management outcomes.[14,23,38]

Structured and ongoing education has been proven to optimize parental self-efficacy and health literacy, which play a crucial role in enhancing the quality of life for children with thalassemia.[43] When parents feel more confident and have a strong understanding of their child's condition, they are better able to make informed decisions, manage routine therapies, and respond proactively to symptoms or complications.[24,43] This increase in health literacy also strengthens the family's ability to be an active partner in the care process, which ultimately improves the child's physical, emotional, and social aspects as a whole.[24,43]

In addition, educational interventions from the results of this review each have advantages and disadvantages. In the conventional education method, the advantages include direct interaction that allows for in-depth clarification of the material and stronger psychosocial support.[23,30] Practical demonstrations also help participants master specific skills.[17,34] However, the drawback of conventional education lies in the limited accessibility, because participants must be physically present and spend a lot of resources, requiring significant time, personnel, and logistical planning.[7]

The digital-based education method offers flexibility of time, repeated access to materials, and the ability to reach more participants simultaneously.[24,43] Digital applications and media also enrich the learning experience with audiovisual combinations that facilitate understanding.[20,21] Hassani et al. (2024), digital interventions play an important role if carefully integrated into the care plan.[20] For example, educational programs delivered through messaging applications such as WhatsApp and Telegram can strengthen knowledge while providing ongoing support.[20] However, the main drawback of digital-based education is the lack of personal interaction and the potential gap in technology access for groups with limited digital literacy or internet access.[7,43] However, this method still has a significant influence on optimizing parental self-efficacy and knowledge to improve the quality of life of children.

To provide a clearer comparison between conventional and digital education methods, it is also important to consider the influence each method has on the results achieved, not only in terms of access and interaction. Based on the results of several studies in this observation, digital-based education methods often show a statistically stronger influence. For example, a study by Kharaman-nia et al. (2023) showed that the increase in self-efficacy in the group using the smartphone application was much higher than in the group following the lecture method.[42] Likewise, in the study of Setiawan et al. (2025), the use of digital applications not only increased the knowledge and confidence of parents but also reduced levels of stress, depression, and anxiety, which are rarely found completely in conventional methods.[24] Although conventional methods still have advantages in direct interaction and training practices, the findings in this observation show that the digital approach tends to have a broader and stronger impact, especially if designed with interactive and audio-visual media. Thus, the digital approach has great potential in improving the knowledge, skills, and quality of life of families caring for children with thalassemia.

Among the 17 interventions reviewed, three studies showed the most significant outcomes. Setiawan et al. (2025) demonstrated that a mobile app-based genetic counseling (Cyber Gen) significantly improved quality of life, satisfaction, and reduced depression and anxiety.[24] Study by Hemmatipour et al. (2024), using a family-centered empowerment model via mobile learning, reported significant improvements in children's QoL, parental awareness, and self-efficacy.[43] In addition, Kharaman-nia et al. (2023) found that a smartphone app was more effective than lectures in improving self-efficacy.[42] These findings support the growing evidence that digital-based education, especially when combined with family empowerment approaches, offers impactful and scalable strategies to support parents and improve outcomes for children with thalassemia. Such interventions may be considered best practices for future program development.

In addition, optimizing parental self-efficacy and health literacy requires a balanced approach that utilizes both conventional and digital-based educational methods. Combining digital tools with conventional education such as face-to-face and online resources can maximize the benefits of both approaches. Additionally, family-centered care models delivered through interactive sessions remain the foundation of educational interventions for this population; however, integrating digital tools can enhance accessibility and scalability while strengthening learning outcomes.[20,43] Thus, the integration of these methods not only increases the effectiveness of education but also contributes to optimizing the role of parents in supporting their children's health and development.

This study has several strengths, including a comprehensive analysis of various intervention methods, both conventional and digital-based education, which provides a holistic overview of the educational approach for thalassemia patients and their families. Combining the results from different educational models allows the identification of key elements that contribute to improving children's quality of life and parental self-efficacy. However, several limitations exist, including variations in study design, intervention duration, and cultural context, which may influence the results. In addition, most of the studies analyzed were short-term, so the long-term impact of education still needs to be further explored through longitudinal studies and RCTs. Additionally, some articles in this review did not use a control group, making it difficult to determine whether the intervention truly caused the results obtained. This can increase the risk of bias and affect the accuracy of the findings.

CONCLUSION

The results of this review indicate that both conventional and digital-based educational methods are effective in improving parental self-efficacy, health literacy, and knowledge, which are factors that significantly contribute to improving the quality of life of children with thalassemia and strengthening long-term family support. Among these, educational interventions that incorporate family empowerment strategies appear to have the greatest impact. Therefore, strengthening these aspects through a structured and continuous educational approach is an effective strategy to improve outcomes for children and their families. Based on these findings, health care providers are encouraged to adopt and integrate educational interventions, especially those that combine conventional and digital-based methods into routine care. Policy makers should support this by providing resources, infrastructure, and training to implement hybrid educational models that are accessible, culturally appropriate, and scalable. Furthermore, future research is recommended to develop and evaluate hybrid intervention models that not only improve self-efficacy, health literacy, and quality of life but also improve the overall well-being of children and their caregivers.

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ETHICAL CONSIDERATION

This review was conducted using data taken only from published, open-access articles. Because it did not involve direct contact with human participants or access to data that could be identified at the individual level, institutional review board (IRB) approval was not required. This approach is consistent with ethical standards for secondary data analysis and literature-based research, as applied in similar previously published reviews.

CONFLICT OF INTEREST

All authors declare that there is no conflict of interest for this research.

AUTHOR CONTRIBUTIONS

All authors contributed to this study. The literature search was conducted independently by two authors (Y.S. and F.P.A.) through an initial search of pre-determined databases. The search results were then compared and combined to eliminate duplication and ensure consistency. The article selection process was based on title and abstract review, followed by full-text review by the same authors. Furthermore, two other authors (Z.H. and G.) verified the selected articles, provided clarification on any doubtful findings, and made the final decision on which articles to analyze.

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