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Mobile and Web-Based Apps to Support Self-Care in Adolescents with Thalassemia: A Systematic Review

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ABSTRACT

Background: Thalassemia affects physical and emotional well-being, necessitating long-term treatment. Empirical information on mobile and web-based applications for adolescent self-management in thalassemia is limited.

Objectives: This research aims to evaluate the effectiveness and practicality of health applications for teenagers with thalassemia, focusing on those that encourage engagement beyond self-monitoring and its functionalities.

Methods: This review adhered to the guidelines set out by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. The databases used included Web of Science, EMBASE, PsycINFO, MEDLINE, EMBASE, and the Cumulative Index to Nursing and Allied Health Literature. This review focuses on peer-reviewed research on the use of mobile devices or web-based applications for self-care in adolescents diagnosed with thalassemia. The systematic review used Downs and Black's criteria for randomized and nonrandomized studies.

Results: Out of 137 entries, 76 were duplicates, and six articles met data extraction requirements out of 34 full-text articles. The review includes six articles from the USA, China, Iran, and Malaysia. Four studies used feasibility, one used quasi-experimental, and one used case-control design. Studies created a self-care app for Android and web-based users, MEMS®, a mobile app-based FCC model, "Selfie" with provider-led education modules iManage, and SMART, a continuous record of clinical symptoms and treatment strategies.

Conclusion: The study reveals insufficient evidence on the efficacy of mobile and web-based applications for teenagers with thalassemia, suggesting high costs and limited marketability.

Keywords: Mobile application, web-Based Apps, self-care, adolsecent, thalassemia, review.

Introduction

Thalassemia syndrome is an inherited disease caused by a gene defect in globin chain construction, reducing red blood cell oxygen transport capacity (Ghazisaeedi et

al., 2015; Mikael et al., 2018). There is a global prevalence of beta thalassemia, affecting around 240 million individuals (Boorimenaj et al., 2018). Thalassemia, a medical condition requiring long-term treatment, significantly impacts physical and emotional well-being (Cappellini, Porter, Viprakasit, & Taher, 2018). Adolescence is a developmental phase where adolescents undergo significant psychological changes to form self-identity and gain independence (Hassan & Azzab, 2016; Mohamadian et al., 2018). A survey in Indonesia found that a significant number of individuals with thalassemia exhibit various clinical symptoms, including facies cooley, hyperpigmentation, enlarged abdomen, and underweight (Puteri et al., 2019). Adolescents with thalassemia experience hormonal issues, delayed puberty, and fatigue due to disease-adverse consequences, therapy duration, and psychological concerns (Abusaad & Ali, 2019).

Self-care is a crucial aspect of preventing disorders, as it involves consistent actions within daily routines, regardless of the environment (Orem et al, 2011; Karkazloo et al, 2011). It is influenced by an individual's growth, development, health status, and environmental factors (Orem et al, 2011). Self-care behaviors are situated within temporal sequences and promote vitality and optimal functioning (Cohen et al, 2000). Research in nursing shows that self-care changes over time (Coyle et al, 2007). When individuals detect potential dangers to their well-being or physical condition, they tend to accept personal responsibility by engaging in self-care practices (Orem et al, 2011). Nursing treatments aimed at individuals with chronic illnesses are primarily focusing on promoting self-care, as noted by Jenerette et al. (2011).

Self-care education is beneficial for patients with chronic conditions as it increases their sense of control over their condition (Pouraboli et al. 2017). Lecture-based education is still widely used, but it is criticized for its location- and time-specific nature (Kheiri et al, 2016). The advent of smartphone app technology has liberated education from time and place, making it possible to study anywhere, anytime (Tufts et al, 2010). Electronic learning offers many advantages over traditional methods, including more adaptability, multimedia content, simultaneous student and teacher engagement, an appealing learning environment, and deeper learning (Abolghasemi et al, 2007).

Smartphones and tablets are extensively utilized by adolescents and young adults, with 95% of adolescents in the United States possessing or having the means to use a smartphone (Anderson et al, 2018). The proposition of using mobile and Web-based health technology to engage with young individuals with chronic illness during their vulnerable transition period is a logical and expected development (Dennison et al, 2013). Currently, there is a scarcity of empirical information about the utilisation of mobile and Web-based applications designed to facilitate self-management in thalassemia in adolsecent (Peng et al, 2016). A systematic analysis of literature published from 2003 to 2014 found that mobile applications have shown potential in helping teenagers with physical chronic or long-term diseases (Majeed-Ariss et al, 2015). However, there is a need for further research on the efficacy and practicality of health-related applications. The purpose of this research was to synthesise what is already known about the efficacy and practicality of health applications developed for thalassemia in teenagers, specifically those that encourage engagement beyond simple self-monitoring. Secondly, to outline the app's functionalities that might both directly and indirectly aid thalassemia-afflicted teenagers.

Methods

Search Strategy

To find papers that met the criteria, this review searched five different bibliographical databases thoroughly. The databases used included Web of Science, EMBASE, PsycINFO, MEDLINE, EMBASE, and the Cumulative Index to Nursing and Allied Health Literature. The all-encompassing search method was fine-tuned for use with additional databases after its inception in MEDLINE. The specified chronic conditions were included to ensure continuity of treatment and specialist-to-specialist transfer, while also including all relevant literature. This review only inlcuded english paper. This study updates two previous systematic reviews, evaluating 2013 publications (Majeed-Ariss et al., 2015; Fedele et al., 2017). Article searches closed in November 2023. Reference lists were manually searched for further research..

Inclusion and Exclusion Criteria

This review focuses on peer-reviewed research on the use of mobile devices or web-based applications for self-care in adolescents diagnosed with thalassemia. The research aims to examine behavioral, physiological, attitudinal, and knowledge changes in adolescents aged 10-19. Adolescents are defined by WHO as individuals aged 10-19.(WHO, 2018). Studies involving mental health, acute illness, pain, or lifestyle/health risk behaviors were excluded.

Study Selection

This review adhered to the guidelines set out by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009). The review followed the PRISMA guidelines, eliminating duplicate research. A reviewer screened titles and abstracts based on study question, inclusion, and exclusion criteria. Two reviewers examined abstracts for inclusion in full-text screening. There were no conflicts between reviewers, requiring a third party to address consensus questions. Scientific abstracts published in peer-reviewed publications were included, providing sufficient data to meet inclusion and exclusion criteria. The review followed the PRISMA flowchart for research selection.

Data Extraction

The recorded information included the following variables: author, years, study design, setting, sample, and measurement outcome. Furthermore, where feasible, additional specifics on the application used to administer an intervention were documented, including the app's name, platform, purpose, content, educational information provided about its usage, availability (such as whether an access code was necessary), as well as the accessibility of the app for parents and healthcare professionals.

Quality Assessment

The systematic review used Downs and Black's (1998) criteria for randomized and nonrandomized studies, which includes a 27-item checklist to assess power, bias, and confounding in the research's internal validity, study reporting, and external validity (. The updated checklist has a maximum score of 28 and is dependable. The highest possible score on one question was 2. The score range was adjusted based on the presence or absence of statistical power to detect a clinically significant impact. The criteria were classified into four groups: excellent (26-28), good (20-25), fair (15-19), and bad (≤14). The updated checklist has high internal consistency and reliability.

Results

Figure 1 presents a procedure for identifying and selecting manuscripts. Out of 137 entries, 76 were duplicates, and six articles met data extraction requirements out of 34 full-text articles, excluding zero items found manually in bibliographies.

Of six articles included in the review, three studies were conducted in the USA, one study in China, one study in Iran, and one study in Malaysia. Four studies were conducted a feasibility or usability and evaluation design (Hildenbrand et al., 2023; Leonard et al., 2017; Crosby et al., 2017; Jonassaint et al., 2015), one study used a quasi-experimental study (Kharaman-Nia et al., 2023) and one study used case-control design (Chen et al., 2022). All study settings were hospital-based (Table 1)

Kharaman-Nia et al (2023) developed a self-care app with Android and web-based versions. This content includes the importance of self-care, including diet, physical activity, stress management, iron chelation, blood transfusion, and regular visits to specialties, as well as improving psychological and social issues. The results of utilization of this mobile application found that the self-efficacy mean scores of the smartphone app group significantly increased post-test, while the lecture and control groups showed no statistically significant increase. While, Hildenbrand et al (2023) created MEMS®, an electronic adherence monitoring, ensuring sustained use and timely provision of bottles for data download. The barriers to MEMS® use included medication changes and transition to adult care; facilitators included tip sheets and reminders. Chen et al (2022) developed a mobile app-based FCC model which consists of a professional intervention team, community healthcare personnel, and basic health service professionals implementing an FCC intervention via a network mobile app. The senior nurse manages the WeChat group, providing online consultations, answering queries, and assessing children's quality of life (Table 2).

Moreover, Leonard et al (2017) created the “Selfie” Application which comprises three components: provider-led education modules, patient recording of daily medication administration videos, and provider feedback via video messages via the ITP app. This mobile application uses iOS operating system. At 90 days, adherence rates remained consistent at 80% and disease knowledge retention was high at 96%. At 6 months, a clinically relevant decrease in serum ferritin was observed. Crosby et al (2017) developed iManage using the Android operating system, a smartphone app that tracks pain, fatigue, and mood symptoms, allows self-management goals, a visual calendar linking symptoms to goals, and features peer support. The prototype app (iManage) was rated as highly feasible and beneficial. The last is Jonassaint et al (2015) developed SMART with iOS operating system, patients maintained a continuous record of clinical symptoms, pain intensity, location, perceived severity, and treatment strategies using SMART for at least 28 days. The study found a strong correlation between pain measurements on paper VAS and SMART on iPhone and iPad, with daily compliance at 75.0%, with high compliance in week 1 and low compliance in week 4 (Table 2).

Quality Assessment

Included all papers ranged in quality. Two studies were considered "good," three were considered "fair," and one was considered "poor." The included studies had a mean score of 14.2 (range 14–17). Due to the lack of comprehensive participant population descriptions, all of the studies were deemed to have "poor" external validity. Two studies—Kharaman-Nia et al. (2023) and Chen et al. (2022)—reported insufficient power to identify any impact of clinical significance.

Discussion

This systematic study aimed to assess the efficacy and usefulness of mobile or Web-based health treatments specifically designed for adolescents with thalassemia. Although there has been a significant increase in the number of health applications in the last 5 years (Peng et al., 2016), our systematic analysis only found 6 new studies. This might be attributed to the expenses and limited target audience of these very intricate applications. Despite the importance of these outcomes, only a small number of researchers achieved statistical significance in any of their selected outcome measures. Possible explanations for this discovery include insufficient statistical power, insufficient length of use, and inadequate involvement of teenage users.

Two studies explicitly mentioned the use of a fixed design, which did not provide customization to meet the individual requirements of adolescents (Kharaman-Nia et al., 2023; Chen et al., 2022). Moreover, the indicated substantial results were specifically connected to adherence. The latter might be attributed to either the inherent usefulness of the application or the insufficient length of the research to impact the result measurement. Apps are advocated for their potential to enhance the provision of self-management assistance in adolescent care (Husted et al., 2018). However, the majority of research found in the first searches mostly examined mobile or Web-based health treatments designed for adult self-management, rather than for teenagers. The results obtained from research conducted on adults are likely to have limited applicability to teenagers. Adolescents have matured in an era dominated by technology, wholeheartedly adopting it as a means of social interaction. They have become proficient in using electronic media and are discerning in their use of social networking sites (Spies Shapiro et al., 2014). Apps designed for adults often prioritize providing clear instructions rather than include aspects that may captivate younger individuals (Veazie et al., 2018; Badawy et al., 2017).

The study's secondary objective was to delineate characteristics of the applications that might directly or indirectly assist teenagers with thalassemia. We were unable to derive any definitive inferences pertaining to this objective. Education was a prominent aspect in four applications (Crosby et al., 2017; Leonard et al., 2017; Chen et al., 2022; Kharaman-Nia et al., 2023), while two applications specifically concentrate on monitoring and providing reminders for adherence (Hildenbrand et al., 2023; Jonassaint et al., 2015). Providing education to the patient is a crucial factor in fostering the acquisition of self-management abilities. The continuous availability of illness-specific educational topics on an electronic device enables patients to effortlessly get trustworthy knowledge. However, education alone is inadequate for improving medication adherence and the acquisition of self-management skills. Incorporating other elements, such as reminders, goal setting, incentives, and social media contact with peers, may boost overall results (Virella Pérez et al., 2023).

This review was limited by the small number and heterogeneity of the studies, which prevented us from doing a meta-analysis. The absence of evidence about app development methodologies that included feedback from adolescents is a significant constraint in terms of both practicality and usefulness. An advantageous aspect of this evaluation is its ability to provide a current and comprehensive assessment of applications in the context of healthcare for adolescents with chronic illnesses. The limited amount of research we found enabled us to provide a more comprehensive description of applications, which might be beneficial for anyone contemplating app creation.

Conclusion

To summarize, this research has determined that there is a scarcity of evidence about the usefulness and efficacy of mobile and Web-based applications that assist teenagers with thalassemia in managing their own treatment. This is a crucial period when autonomous support tailored for adolescents is necessary. This may indicate the limited marketability of these applications and the substantial expenses associated with building apps that may rival the vast array of options already accessible to young people. Subsequent research endeavors may explore the concept of collaborative creation with teenagers, obtaining monetary aid from non-professional organizations that provide care for illnesses, and implementing user-friendly but discreet methods for submitting feedback inside the application

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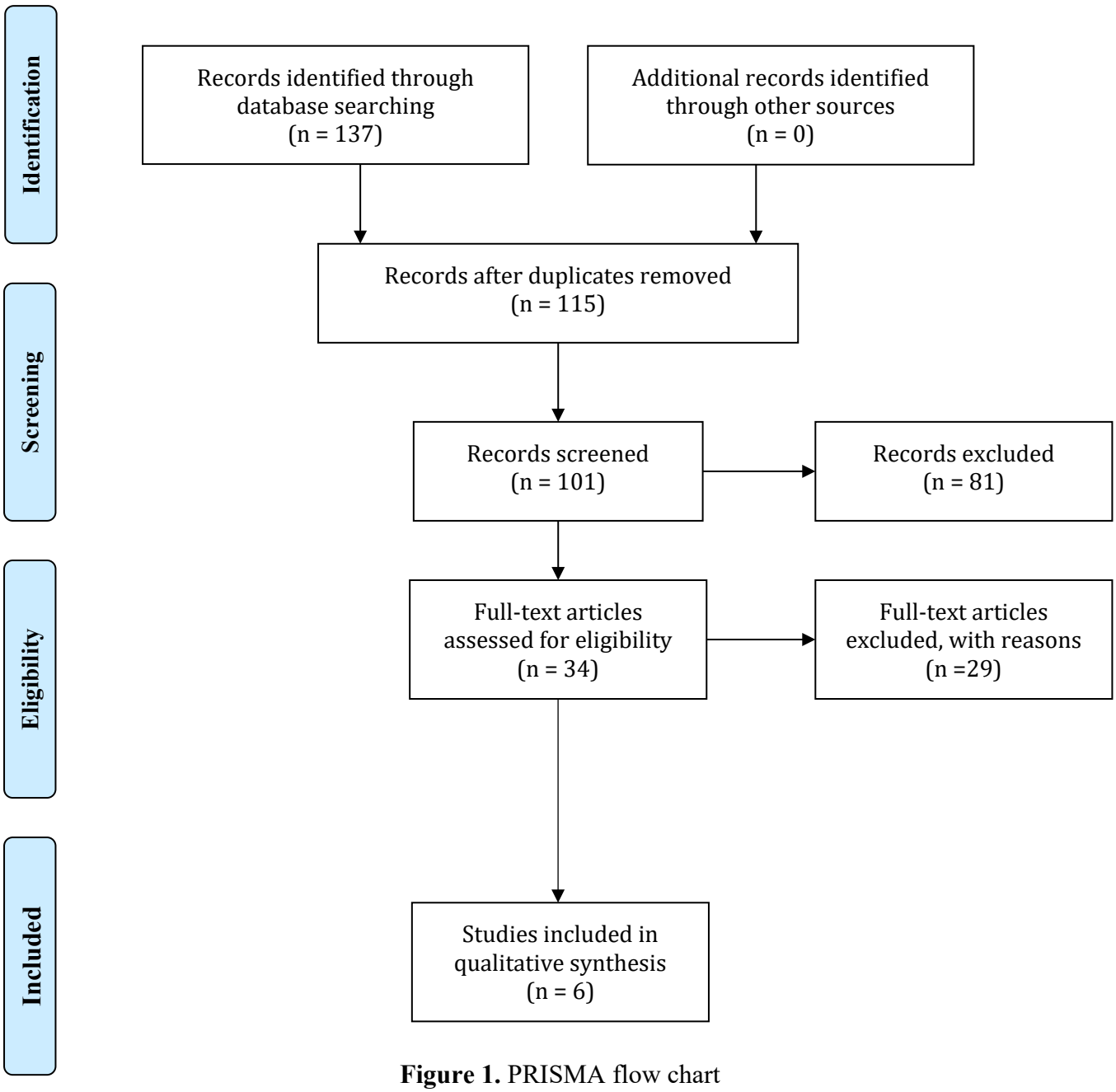

Figure 1. PRISMA flow chart

Table 1. Characteristics of included studies

Author, Year Country	Study design	setting	Frequency	Sample	Outcome measure
Kharaman-Nia et al., 2023 Iran	quasi-experimental study	The patient was informed of their medical treatment referral date, which was recorded by a nurse in the app management panel.	two days for 8 weeks.	99 patients with thalassemia, age (16 years old and above)	The self-care questionnaire. Self-Efficacy of Patients.
Hildenbrand et al 2023 USA	Feasibility study	-	The study encompassed baseline assessments on day 1, post-treatment assessments on day 42, and follow-up assessments on day 126.	the ages of 13 and 21 years n=11	A survey assessing barriers to and facilitators of MEMS®
Chen et al., 2022 China	Case-control design	hospital	very week, a senior nurse in charge is designated as the WeChat group manager.	ages 6 to 14 There were a total of 148 cases, comprising 78 males and 70 females.	• quality of life scale for children and adolescents • The self-care ability assessment scale (ESCA • medication compliance scale
Leonard et al., 2017 USA	Feasibility study	participants' regularly scheduled transfusion appointment interval.	Participants completed a 90-day intensive training program, logging	11 children (4 males) ranging in age from 8 to 21 years (median = 11 y; mean = 12.4 y; SD:	• Disease Knowledge • Treatment Adherence

			compliance through an app, and continued attending regular transfusion appointments for 6 months after provider monitoring ended.	3.8) and a caregiver	
Crosby et al., 2017 Malaysia	Development and Evaluation	Hospital setting	-	An interview was conducted at Sultanah Aminah Hospital in Johor Bahru, Malaysia, to assess the application requirements in the context of Malaysian medical practices.	disease self-efficacy Anxiety Pain intensity
Jonassaint et al., 2015	Usability and Feasibility	Hospital setting	At least 28 days.	Patients 12 years of age and older with a confirmed history of sickle cell disease	Pain intensity

Table 2. Application feature and finding

Author, Year Country	Apps name	App content	Platform	Findings

Kharaman-Nia et al., 2023	self-care app	This text discusses the importance of self-care, including diet, physical activity, stress management, iron chelation, blood transfusion, and regular visits to specialties, as well as improving psychological and social issues.	Android and web-based version	The study found that the self-efficacy mean scores of the smartphone app group significantly increased post-test, while the lecture and control groups showed no statistically significant increase.
Hildenbrand et al	MEMS®	Electronic adherence monitoring via MEMS®, ensuring sustained use and timely provision of bottles for data download.	-	Barriers to MEMS® use included medication changes and transition to adult care; facilitators included tip sheets and reminders.
Chen et al., 2022	mobile app-based FCC model	A professional intervention team, community healthcare personnel, and basic health service professionals are implementing a FCC intervention via a network mobile app. The senior nurse manages the WeChat group, providing online consultations, answering queries, and assessing children's quality of life.	Phone-based	The intervention group demonstrated significantly higher QLSCA, ESCA, and medication compliance scores compared to the control group, indicating a significant difference in performance.
Leonard et al., 2017	“Selfie” Application	The ITP comprises three components: provider-led education modules, patient recording of daily medication administration videos, and provider feedback via video messages via the ITP app.	iOS operating system	At 90 days, adherence rates remained consistent at 80% and disease knowledge retention was high at 96%. At 6 months, clinically relevant decrease in serum ferritin was observed.
Crosby et al., 2017	iManage	iManage is a smartphone app that tracks pain, fatigue, and mood symptoms, allows self-management goals, a visual calendar linking symptoms to goals, and features peer support.	Android operating system	The prototype app (iManage) was rated as highly feasible and beneficial.

Jonassaint et al., 2015	SMART	Patients maintained a continuous record of clinical symptoms, pain intensity, location, perceived severity, and treatment strategies using SMART for at least 28 days.	iOS operating system	The study found a strong correlation between pain measurements on paper VAS and SMART on iPhone and iPad, with daily compliance at 75.0%, with high compliance in week 1 and low compliance in week 4.