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Mobile App Deployment for Quality-of-Life Patient with Thalassemia: A narrative review

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Abstract: *Thalassemia is a hereditary hemolytic anemia disease inherited from parents. Occurs due to the inability of red blood cells to form hemoglobin. Thus causing thalassemia patients to undergo transfusion therapy for life. The mobile application contains detailed information about thalassemia that can be easily accessed by thalassemia patients and their families aiming to maintain the quality of life of patients with thalassemia. The purpose of the literature review is to determine the effectiveness of mobile applications applied to the quality of life of patients with thalassemia. The method used in this preparation is by electronic search of online databases, namely: Google Scholar Science Direct, PROQUEST. The criteria for writing are full text and publications in 2018-2022. Research search found 10 articles had been extracted. The results obtained are mobile applications for the quality of life of patients with thalassemia have a positive response and dynamically need to be developed.*

Keywords : *Thalassemia Patient, Mobile Application, Quality of Life*

INTRODUCTION

Thalassemia is a hereditary hemolytic genetic disorder that occurs as a result of a red blood cell disorder in which the α- or β-globin chains that form hemoglobin do not form partially or are absent altogether. Hemoglobin is the main component in red blood cells whose job is to distribute oxygen throughout the body's tissues and return carbon dioxide from the tissues to the lungs. Patients with thalassemia do not produce enough hemoglobin (Hb) A ($\alpha 2\beta 2$) because their cells are unable to produce human hemoglobin alpha or beta polypeptide chains. Alpha-thalassemia suppresses the production of alpha chains, and beta only suppresses the production of beta chains. Clinically, alpha and beta thalassemia can occur in major (homozygous), intermediate, and minor (heterozygous), genetic forms and can also interact with abnormal hemoglobin in the same individual (Wood, 1993). Thalassemia is a group of anemias that result from inherited defects in the production of hemoglobin. Thalassemia is one of the most common genetic disorders worldwide, occurring more frequently in the Mediterranean region (No et al., 2018).

Thalassemia is a genetic blood disorder in which the sufferer cannot make enough hemoglobin and causes severe anemia (Manasa, 2016). Classify Beta Thalassemia is of two types, depending on the severity of the symptoms: thalassemia major (known as Cooley's anemia) and thalassemia intermedia (Galanello, 2001). Severe beta thalassemia has a long treatment time, and the disease causes repeated cations (Pavani, 2021).

Blood transfusion therapy has an important role in extending the life expectancy of thalassemia patients and is carried out repeatedly. A thalassemia sufferer is very dependent on blood transfusions that are carried out for the rest of his life. Generally, thalassemia patients receive transfusions every two to four weeks. The purpose of transfusion in thalassemia patients is to maintain a stable level of hemoglobin in the blood in order to reduce the excessive reactivity of the bone marrow. Repeated therapy undertaken by thalassemia patients can cause boredom. Family or parental support can help thalassemia patients maintain their quality of life.

Thalassemia patients, families or caregivers need sufficient information, is current and in accordance with facts. Therefore, information becomes an easy thing to obtain both for patients with

thalassemia and their families or caregivers. Adequate information about the assessment of the disease. An efficient health system must have accessibility and availability, so that thalassemia patients can benefit from following up on their condition and providing the necessary information.

It is hoped that information containing knowledge will not only go one way, but the availability of a system that provides a platform for thalassemia patients, families or caregivers to interactively communicate in real-time with health workers providing services even though they are not in the same place. Technology in the times has become a new challenge that spurs service providers to continue to provide excellent service in order to achieve health goals for patients. It is hoped that thalassemia patients can consistently maintain their quality of life by utilizing their mobile applications. Supervision carried out through a mobile application can help thalassemia patients in monitoring during the treatment process, where a thalassemia patient must carry out treatment giving blood transfusions for the rest of his life. Monitoring the activities of thalassemia children through applications is useful for achieving optimal quality of life in their lives so that they can help them continue to develop their daily abilities.

METHOD

The databases used in compiling this topic include: Google Scholar and Library UI. Search the database for this topic using relevant keywords, such as thalassemia patients, quality of life, apps, and mobile-health. The total number of articles obtained from the search engines mentioned was 6,791 (Science Direct, PROQUEST, Google Scholar), then an analysis was carried out using a prism diagram, so that the results of articles that match the inclusion criteria of the literature review related to the topic of discussion were obtained. The inclusion criteria consist of thalassemia patients, mobile applications or websites related to information used by thalassemia patients or their caregivers, use of internet-based applications or websites that are easily accessed by thalassemia patients and their caregivers, and the quality of life of thalassemia patients after using mobile applications in their daily lives.

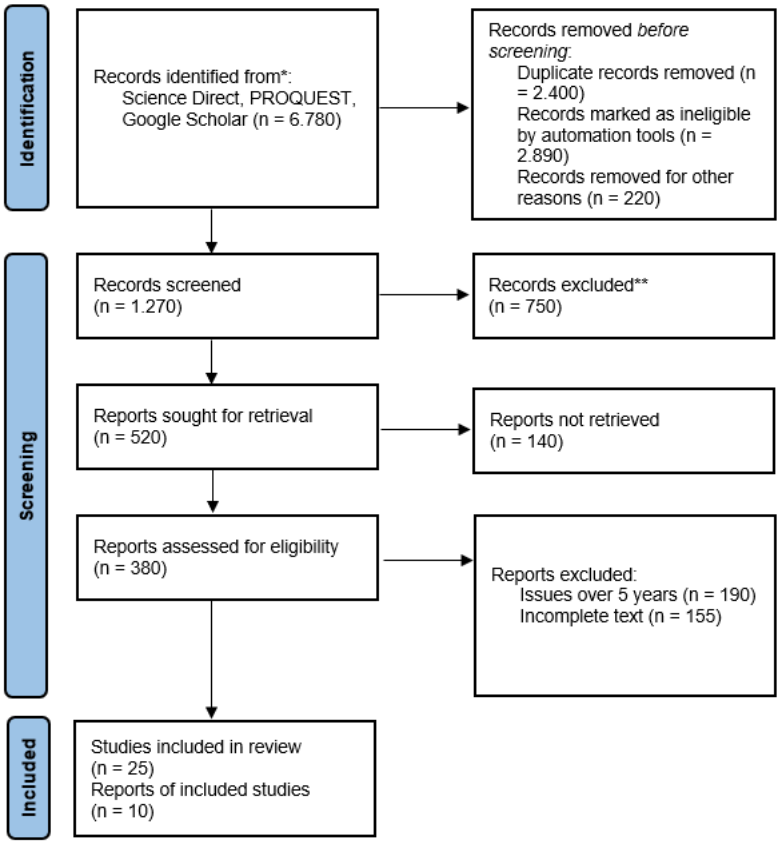

Figure 1. Flow Diagram

The inclusion criteria where thalassemia patients range from children to adults. A mobile application that contains information about thalassemia that can connect thalassemia patients or their caregivers with health workers or connect with the nearest health care facility for thalassemia patients. The application is also useful for storing daily activities and medical history of thalassemia patients. The quality of life of thalassemia patients can be seen after completing applications that are routinely carried out by thalassemia patients and their caregivers.

A literature search based on keywords was carried out, thus obtaining the topic, "Application of mobile applications for the quality of life of patients with thalassemia". The preparation of this literature review uses research articles or journals published for 5 years (2018-2022). The journal criteria are research articles in English with research subjects being thalassemia patients who use mobile applications for their quality of life. Next, the authors began to search for articles in the database and screened the appropriate titles and abstracts to determine which articles were relevant to the topics discussed.

The entire title of the article or journal which is declared in accordance with the author is then entered in the table as in the results discussed, the order of which is adjusted from the articles obtained by the author first and discards articles that do not match so they do not mix. The resulting output is that the mobile application developed can help improve the quality of life in thalassemia patients and optimize the ability of thalassemia patients to carry out daily activities. Furthermore, a website model can be developed that is integrated in the completeness of available health services.

RESULTS

The following are study characteristics and subjects which are displayed in tabular form. Articles that have been collected by the authors are then extracted to become a source that can be used in the topic of this literature review.

Table 1. Study Characteristics in this review

No	Authors	Method	Location
1.	Alturaiki et al., (2022)	Cross Sectional	Saudi Arabia
2.	Chen et al., (2022)	Retrospective study	China
3.	Setiawan et al., (2021)	System development	Indonesia
4.	Gharaati et al., (2019	quasi exsperiment	Iran
5.	Farhady et al., (2020)	Cross Sectional	Iran
6.	Akram & Ahmed Khan, (2022)	Cross sectional	Pakistan
7.	Hatem et al., (2022)	System development	Australia
8.	Paramore et al., (2021)	observational study	USA
9.	Ward & Taha, (2017)	Delphi method	Canada
10.	Banjar et al., (2021)	Web-based expert system	Saudi Arabia

This literature review including ten articles from several countries. Two Articles are from Saudi Arabia and Iran, and other countries such as China, Indonesia, Pakistan, USA, Canada only one article. Furthermore, each article has its own purpose. The research purpose for each article in this review could be seen at Table 2. Ten research articles at Table 2. Shows the research purpose of research using Application for Thalassemia Patients.

Table 2. The purpose of study for each article in this review

No	Authors	Aim
1.	Alturaiki et al., (2022)	Developing chatbots to help manage thalassemia patients.
2.	Chen et al., (2022)	Investigate the clinical impact of a Family-Centered Care (FCC) model based on a mobile app.
3.	Setiawan et al., (2021)	Designing, producing and testing the validity of the products produced
4.	Gharaati et al., (2019	Know the scores of knowledge, attitudes, and self-care behaviors
5.	Farhady et al., (2020)	Knowing the factors that influence experts in using Mhealth technology
6.	Akram & Ahmed Khan, (2022)	Assessing thalassemia patient satisfaction and the use of telemedicine as a service for thalassemia cases
7.	Hatem et al., (2022)	Find applications that can be developed specifically for people with rare diseases
8.	Paramore et al., (2021)	Evaluation of disease management received from thalassemia patients and caregivers, symptoms, and quality of life.
9.	Ward & Taha, (2017)	Develop and assess the feasibility of educational tools to improve the health of thalassemia patients.
10.	Banjar et al., (2021)	Implementation of a web-based expert system in the management of thalassemia patients for treatment and care support.

This review uses ten articles that underlie the topic of discussion. The ten articles were taken from the screening results of 35 international journals. These articles discuss thalassemia disease suffered by a patient, family support in caregiving, and the role of health services. This is a mobile application that contains information that is easily accessible to thalassemia patients and their families/caregivers with the aim that thalassemia patients can maintain their quality of life.

International characteristics, among others, come from Australia, Canada, China, Iran, Indonesia, London, Pakistan, and Saudi Arabia. This type of quantitative research uses cross-sectional and pre-experimental designs with the same research subjects and has an attachment relationship according to the topics discussed in this literature review.

Table 3. Research outcome article in Thalasemia App review

No	Authors	Research Outcomes
1.	Alturaiki et al., (2022)	The implemented prototype demonstrates that the chatbot can dynamically and flexibly provide the necessary assessment information to follow up and monitor thalassemia patients. The resulting output is the provision of information needs in chatbots. Chatbots have the potential to play a bigger role in the medical field of the future.
2.	Chen et al., (2022)	QLSCA scores, ESCA scores, and medication adherence scale scores in the control group showed significant differences. The scores of both groups increased over time, there was an interaction effect between grouping and time. The FAD score of the intervention group was significantly lower than that of the control group. FAD scores in both groups decreased over time. There is the effect of interaction between groups and time.The resulting output is a mobile application-based FCC that has an effect that can improve the quality of life in children with severe beta thalassemia.

Table 3 (continue from previous page). Research outcome article in Thalassemia App review

No	Authors	Research Outcomes
3	Setiawan et al., (2021)	All menus and submenus on the system can be accessed and function properly after testing. Therefore, the Cyber Gen application can be used to carry out genetic counseling for people with thalassemia, both for services in hospitals and other health facilities.
4	Gharaati et al., (2019	The mean scores of knowledge, attitudes and self-care behaviors were not significantly different between the intervention and control groups before the intervention. After the intervention, there was a statistically significant increase in scores in the intervention group but no statistically significant increase in the control group. The resulting output is mobile technology for transferring educational content that contains knowledge, attitudes, and behavior in self-care of thalassemia major patients.
5	Farhady et al., (2020)	Based on the results of all theory models, the coefficient of variation appears to be more positive and test is lower than 5%. These results indicate that all factors introduced in the proposed model are significantly effective in adopting use of Mobile-Health (Mhealth) technology. The resulting outputs are in the design of applied studies and obtaining new information can be done by taking into account several suggestions, including factors of technology acceptance, ability to cope with medical services, and study challenges.
6	Akram & Ahmed Khan, (2022)	Thalassemia patients who received telemedicine health services during the study period were 347 patients. consisting of 182 male patients (52.4%) and 165 female patients (47.6%), with an age range of 1 – 15 years. A total of 289 (83.3%) telemedicine service seekers were in rural areas and 58 (16.7%) lived in urban areas. There were 97 families (28%) belonging to the poor category, 192 (55.35) lower middle class families, 55 (15.9%) upper middle class families and 3 (0.9%) rich families. The majority of the study sample (97.4%) were significantly satisfied with telemedicine services (p value 0.001). The resulting output is that health services through telemedicine have increased coverage and provided facilities for thalassemia children. Communities show high satisfaction and positive attitudes towards the provision of health services
7	Hatem et al., (2022)	This study found 29 relevant applications (out of 2271) in treating rare disease groups. Among the most frequently treated were cystic fibrosis (n=6), hemophilia (n=5), and thalassemia (n=5). The most common features are web-based information and a symptom tracker.The resulting output is an evaluation of mobile applications on the Apple App Store and Google Playstore that answer the needs of a person's rare disease diagnosis by focusing on providing factual and visual information
8	Paramore et al., (2021)	A total of 85 people participated in the study. The average BFI and TranQol scores were 5.0 (0-10 scale; 10 = worst symptom) and 51 (0-100 scale; 100 = best quality of life). The frequency of transfusion therapy averaged every 3.2 weeks, the time needed to manage TDT was 592 minutes on transfusion days and 91 minutes on non-transfusion days (11 hours per week). The mean BFI and BPI-SF "severe fatigue" and "most severe pain" scores were higher. The research output is that different levels of burden on the population occur because there are differences in the system of care in certain countries.
9	Ward & Taha, (2017)	This study resulted in a comprehensive list of features that are important for thalassemia patients. This application was downloaded 147 times globally between March 2015 to January 2016. Reports from respondents showed an increase in medication adherence. Personal adherence support features to achieve therapeutic goals. The outcomes generated in the study findings can be generalized for the development of mobile health applications, especially in centers with access to patients with chronic health conditions.
10	Banjar et al., (2021)	Technology through a web-based expert system provides detailed information to patients, such as medical records, reports, diagnoses, medicines, and appointments made to improve the management of thalassemia patients so that nothing is missed. The result is that β thalassemia patients can access their medical history using QR codes, making communications and information available on demand by doctors and other healthcare providers.

DISCUSSION

Literature review using 10 articles that discuss the quality of life of thalassemia patients by using chatbots can be useful in providing information needed by thalassemia patients as well as thalassemia patients who require follow-up and monitoring efforts so that action can be taken immediately (Alturaiki et al., 2022). Other research mentions that there is a Cyber Gen application which is useful in providing counseling to thalassemia patients by testing all menus and submenus in a system that can be accessed properly (Setiawan et al., 2021). The test was carried out on nurses, thalassemia patients and families or caregivers when using the application. The result of using the application is a comprehensive genetic counseling intervention process. Applications can be useful to know the exact condition of the patient. As the results of the study reported the condition of transfusions carried out by thalassemia patients through the management of Transfusion-dependent β-Thalassemia (TDT) on BFI (Brief Fatigue Inventory) and TranQol (Transfusion-dependent Quality of Life Questionnaire) scores and BPI-SF (Brief Pain Inventory Short Form) obtained a higher average score on BFI and BPI-SF. This is influenced by the time of disease management, fatigue and pain after transfusion causes a decrease in the quality of life of thalassemia patients according to the results of reports of thalassemia patients and caregivers (Paramore et al., 2021).

In addition, the results of other studies indicated that the average scores of knowledge, attitudes, and self-care behaviors experienced a significant increase between the intervention group and the control group in finding positive effects of mobile media education on thalassemia patients. (Gharaati et al., 2019). Recommendations for an effective way to transfer information about self-care of thalassemia patients is through the use of cell phones, especially those who have limited access to be able to maintain their quality of life. An effective way of the Delphi method in introducing educational tools and empowering thalassemia patient groups in the long term requires maturation. Use of health-based mobile applications (E-health) contributes positively to patient knowledge regarding disease-related information and outcomes. This feature indicates the existence of personal medication adherence of thalassemia patients which can support the achievement of therapeutic goals (Ward & Taha, 2017).

The accuracy of the information needed by thalassemia patients is dynamic and fact-based, so that patient management can be carried out optimally. The application as a forum for information based on facts and visuals, provides resources for conducting consultation interactions and monitoring tools that can be used independently by patients of good quality. The involvement of users and health service providers, both doctors and nurses regarding application design, can be a separate evaluation from mobile-based application developers (Hatem et al., 2022). The content on the mobile application has relevance that can use input from hematologists in the use of mobile health technology in reducing complications in thalassemia patients who require blood transfusions. Plans made to determine priorities in the implementation of systems and usage models like this are recommended for doctors (Farhady et al., 2020).

New innovations emerged for types of services during the Covid-19 pandemic, namely with alternative modes through telemedicine. This also includes health services for thalassemia patients in receiving health services. Thalassemia patients can save costs and travel time in cases of thalassemia patients who require visits and follow-up at the hospital for life showing high satisfaction and a positive attitude towards health facilities that provide telemedicine services (Akram & Ahmed Khan, 2022). Lifelong web-based care support using an expert system designed for patients to benefit. Contains detailed information related to patients starting from diagnoses, medical records, reports, medicines and direct appointments that aim to prevent thalassemia patients from undergoing therapy. This has been proven to improve the management of thalassemia patients (Banjar et al., 2021). The application used can also be applied to families or caregivers of thalassemia patients using the mobile application-based Family Central Care (FCC) implementation model which can significantly improve family functions in helping thalassemia patients improve quality of life, self-care ability, medication adherence and application value high clinical (Chen et al., 2022). Family or caregivers play an important role in meeting the needs of thalassemia patients who also need to obtain detailed and dynamic information regarding

thalassemia disease suffered by their family members. Physical and psychological support is needed by thalassemia patients in living their lives.

Other studies also state that analysis of Hb in the fetus using capillary electrophoresis can help be an effective alternative for the characterization of fetal DNA with alpha-thalassemia syndrome (Singha et al., 2022). Besides that, the development and clinical application in testing for thalassemia disease has begun, as with the results of the study that there are detailed findings to describe the success of an application test that has been carried out. (Mai et al., 2021). A study conducted on thalassemia patients used BFI and TranQol scores to determine the quality of life of thalassemia patients after routine transfusions and seen from the control of mobile applications, obtained high results which were influenced by disease management time, fatigue, pain, and impaired quality of life. (Paramore et al., 2021).

Other studies have shown that there are tools used in the peripheral setting for screening thalassemia patients that are associated with quite specific and sensitive applications. (Jahan et al., 2021). The application of a website-based expert system for the management of thalassemia patients in order to provide treatment recommendations and support for lifelong care of thalassemia patients can help patients in real life as an effort to improve the management of thalassemia patients (Banjar et al., 2021). Mobile applications in self-management include health information on thalassemia patients developed by participating in the Delphi method to reach consensus (Ward & Taha, 2016). There is an application that is useful in containing information on various disease disorders that are useful in controlling and monitoring, one of which is thalassemia patients and several other genetic diseases (Luthra et al., 2021). Methods that can be combined with other methods such as NGS or digital PCR for complete non-invasive prenatal diagnosis of thalassemia patients are associated with applications that aim to determine the sustainability of thalassemia patient care (Byrou et al., 2018).

CONCLUSION

Based on the articles obtained regarding the application of mobile applications to the quality of life of patients with thalassemia has a positive effect. Various types of mobile applications either through chatbots, Cyber Gen, telemedicine, E-health, or the web that contain detailed information can be accessed easily by thalassemia patients, their families or caregivers. The involvement of health workers is also needed in the development evaluation. Families or caregivers of thalassemia patients play an active role in supporting blood transfusion therapy which is carried out for the life of thalassemia patients.

Researchers see various positive effects that can be developed in Indonesia related to mobile applications specifically used by thalassemia patients as a form of supporting thalassemia patients in achieving the best quality of life through optimal services provided by health facilities. In the future collection of articles can be done more broadly and in detail. The limitation in preparing a literature review is the short time

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