



MOBILE APPLICATIONS FOR PAIN SELF-MANAGEMENT IN SICKLE CELL DISEASE: AN INTEGRATIVE REVIEW

APLICATIVOS MÓVEIS PARA AUTOGESTÃO DA DOR NA DOENÇA FALCIFORME:
UMA REVISÃO INTEGRATIVA

APLICACIONES MÓVILES PARA LA AUTOGESTIÓN DEL DOLOR EN LA ANEMIA FALCIFORME: UNA REVISIÓN INTEGRADORA

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ABSTRACT

Objective: to identify and describe the characteristics and functions of existing mobile apps for pain self-management in Sickle Cell Disease. **Method:** this is an integrative literature review, developed in May 2021, using MEDLINE via PubMed, CINAHL-Ebsco, Web of Science™, SCOPUS, LILACS, and Science Direct databases. **Results:** 1,488 articles were identified which, after being examined for titles, abstracts, and full texts, 1,474 were excluded, resulting in 14 eligible publications. The characteristics of the applications found were language, target audience and operating system. The functions of the applications are organized in three central aspects: those interested in supporting the user in pain assessment, monitoring and interventions; those intended to assess the user's general condition and promote health maintenance and control actions; and those that encourage engagement for the adoption of self-care practices. **Conclusion:** the use of apps can help nursing care for people with FD, considering the essential role of the nurse in activities that stimulate self-care. It is noteworthy that the nurse's conduct includes facilitating the understanding of clinical manifestations and applying feasible therapies in symptom management for pain control and relief.

Descriptors: Mobile Applications; Anemia, Sickle Cell; Chronic Pain; Nursing; Self Care.

RESUMO

Objetivo: identificar e descrever as características e funções dos aplicativos móveis existentes para autogestão da dor na Doença Falciforme. **Método:** trata-se de revisão integrativa da literatura, desenvolvida em maio de 2021, utilizando as bases de dados MEDLINE via PubMed, CINAHL-Ebsco, Web of Science™, SCOPUS, LILACS e Science Direct. **Resultados:** foram identificados 1.488 artigos que, após serem examinados títulos, resumos e textos na íntegra foram excluídos 1.474, resultando em 14 publicações elegíveis. As características dos aplicativos encontradas foram: idioma, público-alvo e sistema operacional aplicado. Já as funções dos aplicativos se organizam em três aspectos centrais: aquelas com interesse em apoiar o usuário na avaliação, monitoramento e intervenções diante da dor; as destinadas a avaliar a condição geral do usuário e a promover ações de manutenção e controle sobre a saúde; e as que estimulam o engajamento para adoção de práticas de

autocuidado. **Conclusão:** o uso dos aplicativos pode auxiliar os cuidados de enfermagem dirigidos às pessoas com DF, considerando o papel essencial da enfermeira(o) em atividades estimuladoras do autocuidado. Destaca-se que a conduta da (o) enfermeira(o) inclui facilitar a compreensão das manifestações clínicas e aplicar terapias viáveis no manejo dos sintomas para controle e alívio da dor.

Descritores: Aplicativos móveis; Anemia falciforme; Dor crônica; Enfermagem; Autocuidado.

RESUMEN

Objetivo: identificar y describir las características y funciones de las aplicaciones móviles existentes para la autogestión del dolor en la enfermedad de Falciforme. Método: se trata de una revisión integrativa de la literatura, desarrollada en mayo de 2021, utilizando las bases de datos MEDLINE a través de PubMed, CINAHL-Ebsco, Web of Science™, SCOPUS, LILACS y Science Direct. **Resultados:** Se identificaron 1.488 artículos de los que, tras examinar títulos, resúmenes y textos completos, se excluyeron 1.474, lo que dio lugar a 14 publicaciones elegibles. Las características de las aplicaciones encontradas fueron: idioma, público-objetivo y sistema operativo aplicado. Las funciones de las aplicaciones se organizan en tres aspectos centrales: las que tienen interés en ayudar al usuario en la evaluación, monitorización e intervenciones frente al dolor; las destinadas a evaluar la condición general del usuario y a promover acciones de mantenimiento y control sobre la salud; y las que estimulan el compromiso para la adopción de prácticas de autocuidado. **Conclusión:** el uso de apps puede ayudar a los cuidados de enfermería a personas con DF, considerando el papel esencial de la enfermera en actividades que estimulen el autocuidado. Cabe destacar que la conducta de la enfermera incluye facilitar la comprensión de las manifestaciones clínicas y aplicar terapias viables en el manejo de los síntomas para el control y alivio del dolor.

Descriptores: Aplicaciones Móviles; Anemia de Células Falciformes; Dolor Crónico; Enfermería; Autocuidado.

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INTRODUCTION

Sickle cell disease (SCD) is the most common inherited condition worldwide, and is characterized as a set of hemoglobinopathies caused by a mutation in the genes of the beta-globin chain identified by the presence of hemoglobin S. This mutation triggers polymerization of hemoglobin S and causes changes in red blood cells, leading to a cascade of events such as ischemia, vaso-occlusive episodes, chronic inflammation, and hemolysis, causing multiple organ damage, as well as acute and chronic complications.¹

The SCD is a public health problem with high morbidity and mortality, and the alcoholic crises caused by it are responsible for a high cost to (SUS- in Portuguese) due to the large number of emergency department admissions and hospitalizations. Pain events in SCD can be unpredictable or last more than three months, affecting the behavioral, emotional, cognitive, academic, and social development of this population.²

Through the perception of the beginning of painful crises, the person with SCD performs at home care such as teas, massages, and protection against cold following the results obtained in previous crises. When these measures are not successful, they seek health professionals, who often fail to establish a plan of care before the painful crisis, making the moment tiresome and stressful for the patient.³

The ideal pain management, experienced by many people with chronic diseases such as SCD, involves the application of active self-management strategies daily. These strategies must be financially accessible and innovative, to help in the coping of pain from the construction of their self-management capacity.⁴ It is understood as a concept belonging to the subset of self-care focused on the management of the current or potential impact of the disease, besides being applied to health promotion activities and often related to chronic disease.⁵

In view of the impact that the pain resulting from the SCD causes in the life of the person who has it, and the urgency of continuous attention, the need to build efficient, effective, and easily accessible self-care tools is perceived, so that the patient can manage it, avoiding unnecessary itineraries that generate stress and, consequently, increase pain.⁶

Within this context, mobile applications appear as a great ally, because they help in the monitoring of people with acute or chronic pain and can support them in pain management through features and functions that provide coping strategies to control pain.⁶ Such features include layout, presence of an avatar, language, form of access, among others. The functions include daily pain logs, pain assessment, pharmacological and non-

pharmacological intervention options, record history, communication with health professionals, reminders for medication use, changes in dosage, early detection of adverse effects, among others. In this sense, this study aimed to identify and describe the characteristics and functions of existing mobile applications for pain self-management in Sickle Cell Disease.

OBJECTIVE

To identify and describe the features and functions of existing mobile applications for pain self-management in Sickle Cell Disease.

METHOD

This is an Integrative Literature Review structured in six research steps: elaboration of the guiding question; literature search or sampling; data collection; critical analysis of the included studies; discussion of the results; and presentation of the review.⁷ The final writing of this review met the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist.⁸

To establish the roadmap for this review, the research question was elaborated from the acronym PICO, where P (population) = people with sickle cell disease, I (Interest) = mobile apps (features and functions) and Co (context) = pain self-management (strategies that help people with SCD to identify, interpret, evaluate their pain and make decisions in order to prevent, minimize, and solve it), resulting in the following question: What are the features and functions of mobile apps for pain self-management in people with sickle cell disease?

The inclusion criteria were primary source studies available in full text, published between 2010 and 2021. The time frame was delimited during the pre-search stage, when it was identified that the first publications on mobile applications begin from 2010. It was unnecessary to establish the language cut-off. Review studies, experience reports, opinion pieces, and editorials were excluded.

To operationalize the search, we selected controlled and non-controlled descriptors available in the Health Sciences and Medical Subject Headings Descriptors (DeCS/MeSH), and List of Headings of the CINAHL Information Systems. The combination was performed using the Boolean operators AND and OR. Chart 1 presents the descriptors as well as the strategy and filters adopted in each database.

The proposed search strategy was developed in consensus by three reviewers, respecting the words defined with the help of the acronym PICo. The strategy was entered into the databases by each reviewer. Then, a round of adjustments took place, when each reviewer's suggestions were inserted, adapting them to the specificities of each database as shown in figure 1.

After the superficial search in general databases, the bibliographic survey was performed on May 3, 2021, by including search strategies in electronic databases: Medical Literature Analysis and Retrieval System online (MEDLINE via PubMed®), Cumulative Index to Nursing and Allied Health Literature (CINAHL-Ebsco), Web of Science™, SCOPUS, Latin American and Caribbean Literature on Health Sciences (LILACS) and Science Direct.

Table 1 - Search strategies used in each database and the respective results.

BASIS	P AND I AND Co	RESULTS
PUBMED	("anemia, sickle cell"[MeSH Terms] OR "anemia, sickle cell"[MeSH Terms] OR "anemia, sickle cell"[MeSH Terms]) AND 2010/01/01:2021/12/31[Date - Publication] AND ("mobile applications"[MeSH Terms] OR "mobile applications"[MeSH Terms] AND ("pain management"[MeSH Terms] OR "pain management"[MeSH Terms] OR "pain perception"[MeSH Terms] OR "pain perception"[MeSH Terms] OR "pain measurement"[MeSH Terms] OR "pain measurement"[MeSH Terms] OR "self-management of pain"[Title/Abstract] OR "self-management"[Title/Abstract])	13
CINAHL	MH (MH "Anemia, Sickle Cell+") OR TI "sickle cell disease" OR AB "sickle cell disease" AND MH (MH "Mobile Applications") AND MH (MH "Pain Management") OR TI (pain or self-care or "self-management of pain") OR AB (pain or self-care or "self-management of pain")	4
Web of Science™	TS=(("Anemia, Sickle Cell+" OR "sickle cell disease" OR "sickle cell disease" AND "Mobile Applications" AND "Pain Management" OR "pain or self-care" OR "self-management of pain" OR "pain or self-care" OR "self-management of pain")) Refinado por anos de publicação (2010 a 2021) e filtros da base (Nursing, Health care science services, psychology clinical, psychology multidisciplinar e computer science information systems)	356
Scopus	"Anemia, Sickle Cell " OR "sickle cell disease" OR	32

	"sickle cell disease" AND "Mobile Applications" AND "Pain Management" OR "pain or self-care" OR "self-management of pain" OR "pain or self-care" OR "self-management of pain" AND (LIMIT-TO (DOCTYPE, "ar"))	
Lilacs	"Anemia, Sickle Cell+" OR "sickle cell disease" OR "sickle cell disease" AND "Mobile Applications" AND "Pain Management" OR "pain or self-care" OR "self-management of pain" OR "pain or self-care" OR "self-management of pain"	02
Science direct	"Anemia, Sickle Cell+" OR "sickle cell disease" OR "sickle cell disease" AND "Mobile Applications" AND "Pain Management" OR "pain or self-care" OR "self-management of pain" OR "pain or self-care" OR "self-management of pain" Filters: Study area Medicine and Dentistry; Nursing and Health Professions; Psychology	1081

Source: Own elaboration, 2021.

Following the search, the collection of publications was exported by the first reviewer, who used the software Endnote Web (<https://access.clarivate.com/login?app=endnote>) to manage them, identifying, organizing, and excluding duplicate texts in the explored databases. Next, the selected publications were imported into the Rayyan software (<http://rayyan.qcri.org>), which was used by the two reviewers (first and second authors) to systematize data extraction by reading titles, abstracts, and full texts to be included and excluded from the material referring to the corpus of analysis. This step was performed individually and blindfolded until the two reviewers had analyzed all the publications. To resolve conflicts in situations of disagreement between the first reviewers, a third reviewer (fifth author) was consulted to proceed with the evaluation and decide on inclusion.

Once the eligible studies were included, their reference list was read independently and blindly by the first and fifth authors, and new studies that addressed the population, interest, and context were identified. These were accessed and their titles and abstracts were read, followed by reading in full by the same authors. Thus, the publications that matched the inclusion criteria were added to the articles included in the previous phase.

The included studies were organized in a Windows 10 folder for the data extraction phase, which was performed by filling out a data collection tool prepared by the first, third, and fifth authors, which included the following data Author and year of publication; Objective; Name of the application; and Pain Self-Management Strategies.

The deductive data analysis was organized in four dimensions of features and functions of mobile apps for pain self-management in SCD: App features that included: language

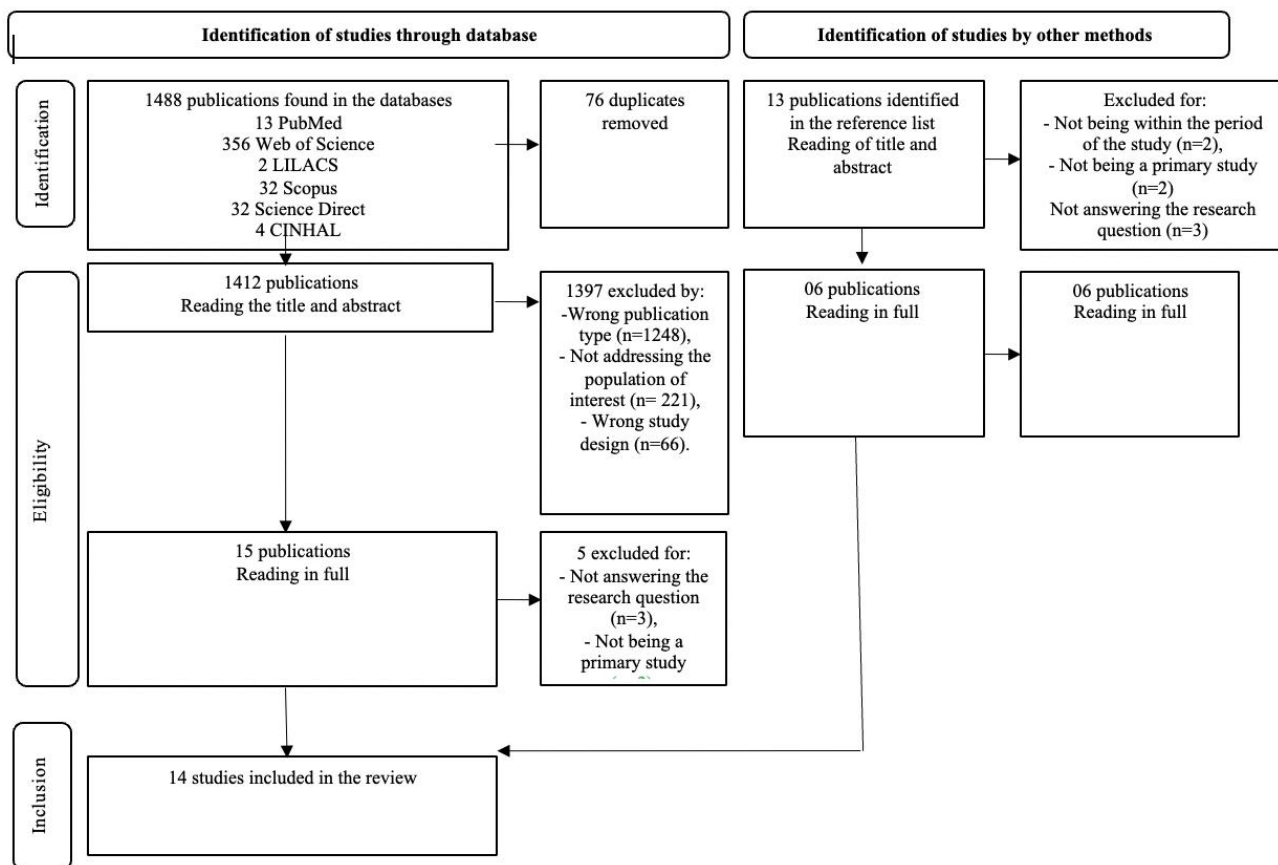
used; target audience and operating system; pain assessment functions that included pain diary, pain aura, pain interference in daily life and pain tracking chart; health monitoring functions that consisted of tracking physiological states, tracking of Complications of SCD and contact with the Health Unit; and finally, motivation functions for self-care that included treatment support, educational support and interactions between the user and the App.

Once the dimensions were defined, the authors, based on the Thematic Analysis thought by Braun and Clarke,⁹ followed six phases of thematic analysis, in order to identify the main themes and relate them: 1. Familiarization with the data through reading and re-reading them; 2. Generating initial codes: Coding the interesting features of the data in a systematic way, resulting in nine codes; 3. Grouping the codes into potential themes, generating four themes; 4. Creating a 'visual map' identifying the relationship among the themes; 5. Defining clear names for each theme; 6. Producing the final analysis report. The synthesis of the results was carried out in consensus by the first, third and fifth authors and developed according to the visual map of the literature, resulting in the figure 2 presented in the following section.

RESULTS

A total of 1488 productions were found, then the duplicates were excluded, and the eligibility step was fulfilled according to the inclusion and exclusion criteria, totaling 14 articles included in this review. Figure 1 shows the selection, eligibility, and inclusion process according to the recommendations of the PRISMA 2020 flowchart.

Figure 2 - Flowchart of the selection process of the studies included in the review.



Source: Own elaboration according to PRISMA (2020) recommendation, 2022.

The synthesis of the articles in this review is shown in Figure 3.

Table 2 - Authors, year, objective, application name, and pain self-management strategies of the articles included in the integrative systematic review.

Author/Year	Objective	Application Name	Pain Self-Management Strategies
Jacob E, Duran J, Stinson J, Lewis MA, Zeltzer L./ 2013 ¹⁰	Examine (a) symptoms, (b) pain characteristics (intensity, location, quality), (c) pain medications and non-pharmacological pain strategies used, (d) thoughts and feelings, and (e) health care visits	e-Diary base-ado na web	Daily pain monitoring by an Advanced Practice Registered Nurse (APRN) who provided ongoing training, psychosocial support, educational interventions, and referrals to specialist providers when needed.
Jonassaint CR, Shah N, Jonassaint J, De Castro L/ 2015 ¹¹	Helping patients and their providers to monitor and control clinical symptoms related to sickle cell disease and pain in particular	SMART	Suggestion of actions based on pain intensity; Pharmacological and non-pharmacological interventions, such as

			hydration, encouraging the use of the spirometer, rest, among others.
Espinoza J, Shah P, Veluswamy S, Zeltzer L, Khoo MCK, Coates TD, et al./ 2020 ¹²	Collect data on pain episodes, including pre-pain symptoms or contributing factors such as stress and aura.	R-Helper	Evaluation of the frequency and intensity of pain in patients with SCD, and identification of a possible association between pain episodes, mental stress, and the presence of aura.
Anderson LM, Leonard S, Jonassaint J, Lunyera J, Bonner M, Shah N./2018 ¹³	To examine the feasibility, acceptability, and preliminary impact of a provider-developed mHealth intervention (Intensive Training Program [ITP]) in pediatric patients with Sickle Cell Disease for whom Hydroxyurea was prescribed.	ITP	Basic knowledge of the disease and psychosocial measures
Ezenwa MO, Yao Y, Nguyen MNT, Mandernach MW, Hunter CT, Yoon SL, et al./ 2019 ¹⁴	To evaluate the feasibility and examine the mechanism of a self-managed relaxation intervention in outpatients with Sickle Cell Disease.	Relaxing video	12min video with relaxation techniques. Based on the Multidimensional Theory of Pain (Ahles, Blanchard and Ruckdeschel, 1983)
Pereira, AS/ 2019. ¹⁵	Provide educational support for youth to enhance self-care practices in sickle cell disease.	Globin	Educational and motivational support. Encouragement of self-care through reminders.
Johnson A, Yang F, Gollarahalli S, Banerjee T, Abrams D, Jonassaint J, et al./ 2019 ¹⁶	Show the feasibility of using objective physiological measurements obtained from a wearable device during an acute pain crisis to predict patient-reported pain scores using machine learning techniques.	TRU-Pain integrated into wearable device (Microsoft Band 2)	Possibility of developing a pain prediction model.
Alberts NM, Badawy SM, Hodges J, Estepp JH, Nwosu C, Khan H, et al./2020 ¹⁷	Designing an mHealth intervention for individuals with sickle cell disease to improve hydroxyurea adherence	InCharge Health	Daily recording of pain level; Contact with your clinic, access to educational information for pain management and talking to other people with pain experience.
Palermo TM, Zempsky WT, Dampier CD, Laloo C,	To improve pain self-management and functionality in young people (aged 12-18 years) with Sickness by	iCanCope	Cognitive behavioral therapy (CBT)-based coping skills, deep

Hundert AS, Murphy LK, et al./ 2018 ¹⁸	developing and testing a customized web-based and smartphone application.		breathing, relaxation, and cognitive skills.
Crosby LE, Ware RE, Goldstein A, Walton A, Joffe NE, Vogel C, et al./ 2017 ¹⁹	To describe Internet access and use in adolescents and youth with SCD; to identify barriers to self-use in this population; to collaborate with adolescents and youth to design a mobile application that would minimize the barriers; and to evaluate the feasibility and acceptability of the application.	iManage	Individualized tasks, motivation by contact with health professionals and other people with sickle cell disease.
Curtis K, Lebedev A, Aguirre E, Lobitz S./ 2019 ²⁰	Developing a theory- and evidence-based medication adherence app to support children and adolescents with SCD.	MyMate & Me	Reminders, self-monitoring, feedback on your behavior, peer support, and problem solving.
Schatz J, Schlenz AM, McClellan CB, Puffer ES, Hardy S, Pfeiffer M, et al./ 2018 ²¹	To describe the primary outcomes of a pediatric SCD pain management intervention for pediatric SCD that involved a single session of CBT skills training CBT skills training session followed by home practice using smartphones.	Digital Pain and Activity Diary (DPAD)	Practice application / use of skills to access audio files for deep breathing, progressive muscle relaxation, and guided imagery.
Bakshi N, Stinson JN, Ross D, Lukombo I, Mittal N, Joshi SV et al./ 2018 ²²	To develop and evaluate the psychometric properties of a web-based multidimensional electronic pain diary for adolescent and young adult patients with SCD.	Multidimensional Pain Journal	Characterization of the relationship of pain and activities of daily living, school, sleep, and interactions with others. This instrument has the potential to be used as an endpoint in pain clinical trials. Increase in provider knowledge and understanding of the disease process, leading to better appreciation of the pain experience in people living with SCD.
Gary K. et al. 2015 ²³	Reduce pain-related readmission rates within 30 days and improve quality of care for patients with sickle cell disease (SCD)	mHealth Mobile Application	Alert provider to initiate outpatient intervention when patient indicates worse pain.

Source: Own elaboration, 2021.

About 78.6% of the selected articles were published in the United States, and only 7.1% of them were published in Germany, 7.1% in Canada and 7.1% in Brazil, which clearly shows the incipient development of technologies aimed at the SDC in the Brazilian context.

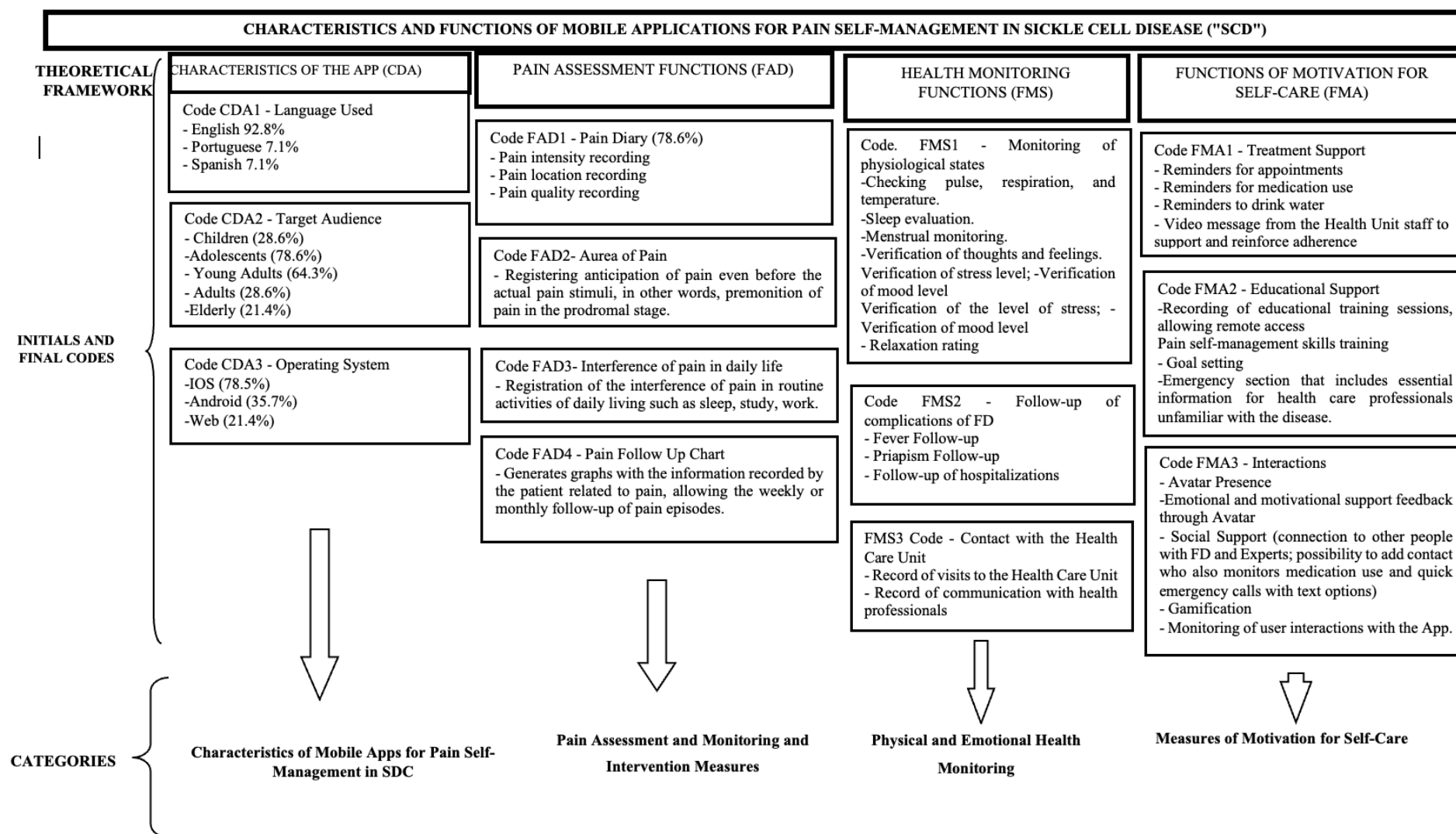
The results of this review show common characteristics in most of the applications, such as, for example, the fact that 78.6% of them are directed to the adolescent population and 64.3% to young adults, of which only 21.4% extend to the elderly population, as well as 92.8% of them have English as the predominant language, 7.1% have Spanish with English as an option, and 7.1% have Portuguese as an option. As for the operating systems: 35.7% were available only for iOS; 35.7% for iOS and Android; 7.1% iOS, Android and WEB; and 21.4%, based only on the WEB.

Among the studies analyzed, 42.8% dealt with the development stages of technologies, 21.4% were exclusively dedicated to evaluating the acceptability and usability by users, and 35.7% presented results of interventions and clinical studies with the use of mobile applications.

Regarding the characteristics of the applications found, with respect to the age range of the target audience, we found that the existing applications contemplate the groups of children,^{10,13,21,23} adolescents^{10,11,23,13,15,17-22} and young adults^{11,12,14-17,19,21,2} focusing mainly on the interest in transitional care.¹⁸ On the other hand, this type of technology directed to middle-aged and older adults was not identified. The emphasis on younger age groups may be explained by the limited life expectancy within the population with SCD, and therefore resulted in generating less demand from older people.

The synthesis of the results of this review is present in a visual map of the literature (figure 4), organized into four categories that describe the characteristics and functions of mobile applications for pain self-management in Sickle Cell Disease (SCD) evidenced in this study, namely: Characteristics of mobile apps for pain self-management in SCD; Pain assessment and monitoring; Physical and emotional health monitoring; and Motivation measures for pain self-management.

Figure 2- Visual literature map of features and functions of mobile apps for pain self-management in sickle cell disease (SCD).



Source: Own elaboration, 2022.

DISCUSSION

The development of care technologies requires mastery of existing resources. Therefore, the main contribution of this study is to synthesize the characteristics and functions of available applications to support the proposal of new applications that may meet the health needs of people with sickle cell disease.

A 92.8% percentage was found in relation to the predominance of the English language in the analyzed apps; thus, it is deduced from this finding that countries that do not have English as their native language are not reached by this technology. Sickle cell disease is the most prevalent genetic condition in the world, but, although the distribution is universal, access to knowledge and to the conditions for the development of care technologies in the various continents is unequal.

For the operationalization of the pain self-management programs, tablets, laptops, mobile devices (cell phones),^{14,17} iPhone, iPod Touch or iPad were used.⁹ Given these characteristics that we found in the App of the studies evaluated, we observed that the access to them is limited for the Brazilian population, since the people who have the SCD generally have a low income, which prevents them from mastering the English language and having access to cell phones with the iOS operating system.

As for the assessment and monitoring of pain and intervention measures, in the item pain assessment we identified functions for the assessment of pain intensity through visual analog scale,^{10-12,14,16,18,19} the self-report of pain through electronic diary¹⁸ and the identification of images.¹⁵ A comparison between the data obtained in the App TRU-Pain was performed with the data provided by health professionals during the crises in the care units.¹⁶

Mobile apps allow patients and providers to monitor and manage clinical symptoms related to SCD, among them, pain in a more effective and reliable way, since the record is made in real time and stored, and comparisons can be made, evidencing improvement, or worsening of symptoms.¹¹

The visual analog scale has been made available in the form of a sliding bar,^{10-12,14,16,18} and the "sliding control" option has also been used to document stress^{12,14} and so-no.^{10,18} In addition, the visual scale seeks to describe the type of pain as well as its location by means of an indication on a human body figure in the frontal and dorsal positions^{11,23} or by means of a written list of locations.¹¹

For pain records, the Apps offered users the option of doing it "at the moment", referring to the pain, the "aura", that is, the prodromal signs that precede the pain and "mental stress" that accompany the recorded moments,^{10,12,14} and the option of reporting the occurrence of pain and stress and their intensities, and also the use of medications throughout the day, identifying this option as "my day".^{11,12} Other apps have included tracking of "fatigue and mood",^{16,19,22} as well as "thoughts and feelings" in the diary.¹⁰

One study used a wearable device associated with the TRU-Pain mobile application. This device measured some physiological measurements such as skin temperature, heart rate, steps, and some cardiac measurements to correlate changes in these measurements at times of pain.¹⁶

As has been well put by Baskshi²², real-time pain recording makes it possible to capture the experience of pain in its multiple dimensions and the impact on their lives. Retrospective pain recordings are subject to recall bias, distorting pain experiences and affecting accurate reports, which makes clear the relevance of real-time pain diaries through mobile applications whose advantages are added to the fact that they offer the possibility of being used in their natural environment, providing more reliable results.

As for pain monitoring, only five of the apps had the functions of generating a report¹⁵ and allowing patient monitoring in real time^{10,11,14, 16,17,19,22,23} or later. To achieve this monitoring, the e-Diary app allows calls, text messages, text messages, and video calls.¹⁰ It is worth mentioning, among the apps, the SMART app in which, after the user indicates worse pain scores, an immediate message is created, suggesting an intervention appropriate to the pain intensity of the moment, such as occurring in relation to: "use Fentanyl patch, take Ibuprofen, rest a few minutes, drink water or other fluids, take deep breaths, use distraction, seek medical help."¹¹

Also, in relation to intervention measures, the InCharge Health application was found that allows the patient to contact his clinic when a pain crisis occurs, being able to access educational information on pain treatment and to talk with other patients about their experiences with pain.¹⁷ In the ITP application, patients received an education module on the disease and on Hydroxyurea, including its mechanisms of action and impact of its adherence, being able to have remote access at any time.¹³

Education is considered one of the major pillars for pain control intervention measures. Regarding health monitoring, we observed that the apps sought to monitor complications of SCD by monitoring fever, fatigue, priapism, menstruation, and hospitalizations. Only the Globin app mentions the monitoring of these complications, without, however, clarifying how exactly it is done. This same app reports emotional and motivational support feedbacks through Avatar.¹⁵

And, for the monitoring of physiological states, other functions found were sleep assessment; checking thoughts/feelings; measuring daily stress level; menstrual monitoring; relaxation rating scale; measuring respiration, pulse, and finger skin temperature; and rating general health stage and mood through a scale.

Considering that mood can exacerbate pain symptoms, a mood tracker has been inserted in some applications, where the patient has the option to indicate through "cell phone tilt", "scale" or "slider" how his mood is at that moment.^{16,18-20}

The SMART application was also found in one of the studies, which evaluated the quality of life and the impact of the disease on the family through questionnaires with varied quantities of items.¹¹ In addition to these, evaluations were made through the Multi-dimensional Fatigue Scale, Inventory of Behavioral Evaluation of Executive Function, Parents' Experience with Childhood Illnesses, Pediatric Inventory for Parents, and Sickle Cell Self-Efficacy Scale.^{13,18}

On the measures of motivation for self-care, there is the availability of resources for treatment support, evidenced through features such as appointment reminders, and medication and water intake through automated messages and personalized alerts. Some of these have reward systems to confirm that medication has been taken and appointments have been kept, such as receiving video messages from clinic staff to support and reinforce adherence.

In addition, there are features for educational support such as recording educational training sessions, allowing: remote access to modules; pain self-management skills training;

goal setting; and an emergency section that includes crucial information for health care professionals unfamiliar with the disease.

One of the applications found (ITP) combined face-to-face education sessions and daily remote medication adherence monitoring to educate patients about the effects of their medications. It also recorded educational training modules that could be accessed remotely.¹³

In the ICanCope application, young people and their caregivers are encouraged by the application to access the iCanCope website, which contains interactive education about sickle cell disease and self-management strategies. The site is organized in six main modules and two additional optional modules, and uses a rich multimedia format (animations, videos, audio clips) to provide content.¹⁸

In addition, there are functions to promote interactions based on Avatar customization; emotional and motivational support feedbacks through the Avatar; rewards; social support (ability to connect with other people with sickle cell disease and specialists; add contacts that also monitor medication use and quick emergency calls with text options); gamification and monitoring of user interactions with the app.

A way to promote interaction found by the applications was the use of the Avatar, which accompanies the user throughout his interaction with the application, and is customizable, which helps identify who is using the resource. In addition, the user can see the avatars of other users in the MyMate & Me app and compare their scores, which in a way is a stimulus to fulfill the proposed self-care goals.²⁰

The concern with developing user motivation for self-care was evidenced in the study by Ezenwa et al., which included relaxation measures for pain control through instructional videos on breathing and meditation¹⁴ and included strategies to avoid forgetting and increase adherence to the use of medications, especially hydroxyurea, such as the use of reminders and reward systems.^{17,20}

Another form of interaction found was the "social community" which is a structured forum where participants can interact with other young people living with the pain of SCD. Each week, the ICanCope app presents a new question for discussion, and participants can post answers and "favorite" the posts of other app users.¹⁸

One of the apps found proposed to develop a mobile platform to facilitate interactions between health professionals and patients with SCD after hospital discharge with two components: a mobile application ("app") for patients; and a web-based monitoring platform for providers.

The reward system was found and has been pointed out as a preference for adolescents, who judge that this confers greater attractiveness to apps with health education purposes, while for adults these resources are more attractive the more, they allow them to perceive that their health is under control, improving and bringing well-being.¹⁷

One form of reward identified in the "My Mate and Me" app was through a daily questionnaire, where the user earns points when he answers the questions correctly and receives points when he confirms the use of the medications. These points will be used to customize the Avatar with new clothes and accessories, among others.²⁰ In another app, rewards and gamification are used as incentive methods.²³

Regarding communication, a study that heard people with SCD raised some expectations of this population for the use of apps: accessing additional information about hydroxyurea; connecting with other patients, friends, and family; and communicating with their medical team.¹⁷

Among the limitations of the study is the impossibility of accessing the gray literature, besides the fact that the research design did not involve searching the app store, which could provide other characteristics and functions of newly developed apps that have not yet been published in the investigated databases. Therefore, future studies with different methodological designs are recommended.

CONCLUSION

This review study showed that the functions of the applications found in the literature are organized into three central aspects: those interested in supporting the user in the assessment, monitoring and interventions for pain; those intended to assess the general condition of the user and promote actions for health maintenance and control; and those that encourage engagement for the adoption of self-care practices.

It is perceived that mobile applications have a positive impact on health care, since they subsidize conditions for the continuous evaluation of health parameters, helping in the monitoring of patients with acute or chronic pain, supporting and assisting them in pain self-management through resources such as reminders for medication use, treatment recommendations, health education, direct communication with health professionals, among others, which facilitate and promote self-care.

The use of mobile applications can help nursing care for people with SCD, since the nurse plays an essential role in health education activities for self-care. It is noteworthy that the nurse's conduct includes qualifying and sensitizing these subjects to understand the clinical manifestations of SCD and its proper treatment as well as applying viable therapies in symptom management for pain control and relief. Apps are a possibility of continuity of care actions, supporting people 24 hours a day.

It is recommended that apps be developed to provide learning resources for pain monitoring and management in sickle cell disease that meet the needs of the Brazilian population.

CONTRIBUTIONS

Conceição, MPMC; Gomes, AS; Carvalho, ESS participated in the conception of the research project, data collection, analysis and discussion as well as in the final writing and content review, and approval of the final version of the article.

Borges, CL and Vale, PRLF participated in the collection, analysis and discussion of data as well as in the final writing and content review, and approval of the final version of the article.

CONFLICT OF INTERESTS

"Nothing to declare."

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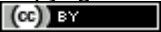
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