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Digital Health Interventions to Empower People with Sickle Cell Disease: Toward Patient-Led Design

David-Zacharie Issom

Abstract

This chapter will provide a state of the art of digital health interventions for people with sickle cell disease. It will use WHO classification of digital health interventions to elaborate on existing intervention, the gaps, and how technology could be useful to support people with sickle cell disease. A description of the existing possibilities, the current trends, and the future opportunities will be provided. As well, methodologies to increase patient adherence to digital health interventions, the importance of participatory approaches, open innovation, and patient-led approaches to designing such interventions will be discussed. Importantly, a holistic/planetary health approach will be chosen to introduce the subject and ensure to keep a broad eye on the domain and to include sustainability challenges.

Keywords: digital health interventions, artificial intelligence, self-management, integrated care, patient empowerment, participatory design

1. Introduction

Sickle cell disease (SCD) is the world's most common monogenic pathology. SCD is a complex multisystem red blood cell disorder, which leads many patients to experience acute life-threatening dysfunctions and chronic complications. The hallmarks of the disease are vaso-occlusive pain crises (VOCs), avascular necrosis, hemolytic anemia, endothelial dysfunction, transient ischemic attacks, acute chest syndrome (ACS), bacterial infections, and chronic inflammation. These complications cause reduced Health-Related Quality of Life (HRQoL) and increased mortality [1].

To limit complications and reduce early mortality, integrated care, also known as comprehensive and coordinated care (CPC), is paramount. Indeed, CPC has demonstrated efficacy in improving health outcomes of people affected by multisystemic diseases such as diabetes [2]. In the case of SCD, CPC shall cover different forms of care provision, including acute care (e.g., treatment of VOCs), usual care, defined as routine evaluations and treatments (e.g., transcranial Doppler testing), chronic transfusion therapies, or disease-modifying treatments (e.g., hydroxyurea) [3].

The latter treatments remain underutilized and limited [4]. Access to curative options (e.g., hematopoietic stem-cell transplantations, gene therapy) remains restrained [5]. As well, specific comprehensive and preventative care (CPC) programs are inconsistently available for most people with SCD [6]. Consequently, many patients do not receive adequate treatment, as outlined by evidence-based guidelines, and may suffer from mistrust, stigmatization, or neglect [7].

As a result, patients must rely heavily on themselves and their community to manage symptoms, maintain control over the course of the disease, and preserve an acceptable level of Health-Related Quality of Life (HRQoL) [4, 8]. Because of its complexity, SCD self-management can be particularly challenging to master [9]. Indeed, self-management covers various aspects, ranging from self-care in hospitalization, post-hospitalization care, hospital-at-home care, preventive care, health maintenance, or self-care aspects such as self-monitoring, self-diagnosis, self-treatment [10, 11].

For instance, every day, patients should take prescribed drugs, follow a healthy diet, hydrate frequently, avoid strenuous exercise, check indicators of anemia, which could manifest by increased pallor, dark urine color, or jaundice. As well, patients should observe warning signs of complications, monitor and treat their chronic or acute pain with prescribed medication and other nondrug therapies (e.g., breathing exercise, physical therapy, phytotherapy), or pay attention to numerous and omnipresent potential precipitants of VOCs [9, 10].

Such triggers include certain food, stress, infections, acidosis, dehydration, fatigue, hypoxia, alcohol intoxication, daytime exertion, exercise, airline travel, altitude, pregnancy, nocturnal hypoxemia, or environmental factors including pollution, exposure to the elements, change of temperatures, wind, or humidity [12–15]. The quantity and complexity of these factors demands autonomy, resilience, high self-efficacy, and empowerment levels, as well as adequate psychosocial support [16, 17].

Due to their socioeconomic positions, most patients lack such skills and consequently adherence to recommended treatments, self-care recommendations, or attendance to routine clinic appointments (RCA) remains low [18]. However, some patients have proven to be exceptions. As long-term users of healthcare services, some acquired knowledge that made them efficient navigators of healthcare systems, while gaining singular expertise in self-management, succeeding to learn how they could improve their HRQoL [19, 20].

As Ballas et al. [20] pointed out, these strongly equipped patients succeeded to identify their own best self-care practices or became able to notice and react to warning signs from their body. Some would journal their symptoms, manage their pain successfully, follow adequate dietary habits, practice moderate physical activity, or attend RCA [21, 22].

The complex nature of SCD such as a high individual and population variability, or a rising number of people affected due to lack of systematic screening, poor awareness about the disease or migrations of populations [23], its scientific and social history, its high economic burden, and the diversity of the endogenous and exogenous factors combining to influence health outcomes (e.g., multifaceted health disparities, stigma, racism, underfunding) require researchers and policymakers to take care of SCD through various lenses [24].

For all these reasons, it appears particularly relevant and urgent to investigate cost-effective and easily scalable interventional strategies to prevent serious complications, avoid hospitalizations, and more generally, empower and improve the quality of life of people with SCD.

2. Strategies to empower people with SCD

Given SCD global burden, the complexity, and number of challenges to be overcome (e.g., neglect, continuous rise, stigma, underfunding) [25–29], it is important to prioritize effective interventions and shorten the timeframe for action. Fortunately, after the great advances in the 1970s (e.g., American civil rights organizations promised to vote for the future President Nixon if policies and funding were put in place to counter SCD), FDA approval of Hydroxyurea in 1995 [30], repeated calls to action during the last couple of years and recent advances in genomics [26–28, 31], SCD has been increasingly regarded as an interesting model to study and address from different angles in particular since 2017 [32–39]. This renewed interest opens hope that research advances could enable possibilities of generalization, reutilization, and transfer to other NCDs, while subsequently empowering more populations and enhancing life opportunities.

To move forward in a coordinated manner, and to effectively shape health and social policies aiming at empowering underserved populations, global health agents need a clear strategy, a unified agenda, and a strong commitment with the adequate resources. To proceed, the American National Academy of Sciences [40], the WHO, and various scholars have proposed priority targets for SCD [4, 26, 41–44].

These recommendations range from installing national surveillance programs, promoting better use of disease-modifying treatments, increasing the funding of disease-specific research, raising awareness, improving pain relief management, tackling systemic violence (e.g., stigma, racism), improving training for healthcare providers, increasing the numbers of specialists, promoting access to comprehensive and preventative care, empowering communities, creating therapeutic education programs, supporting self-care management, and encouraging the use of Information and Communication Technologies (ICTs) [4, 26, 41, 42].

3. Digitalization as a lever to reduce health inequalities

As research suggests (e.g., health impact pyramid), interventions that could empower as many individuals as possible should be prioritized [45, 46]. Today, as the International Telecommunication Union (ITU) illustrates [47], Information and Communications Technologies (ICTs), thanks to their increasingly important presence in people's daily lives (e.g., smartphones, smart sensors), could play major roles in driving rapid social transformation, empowering populations from their social determinisms, and accelerating the achievement of challenges of the centuries such as the Sustainable Development Goals (SDGs) [48].

Recent years have seen the rise of digital technologies in the healthcare sector (e.g., computerized drug prescription systems reducing risks of medical errors, remote surgery, early detection of seizures or heart failures) [49]. To achieve most vital SDGs such as *no poverty, no hunger, good health and well-being*, exploring the potential of digital health technologies seems particularly relevant to empower people with SCD and reduce the health inequality gap.

As the WHO acknowledged, thanks to their potential to be scaled up rapidly to reach large numbers of people, digital technologies hold the potential to accelerate a decline in health inequalities through disease-specific actions [50].

Notably, stressing the importance of ensuring that such tools provide an evidence-based improvement in health outcomes, the WHO emphasizes that *such interventions should (i) complement and (ii) enhance health system functions through the acceleration of the exchange of information, (iii) improve access to healthcare, (iv) be affordable, and (v) should not replace the fundamental components needed by health systems, such as the health workforce, financing, leadership and governance, or access to medicines* [50]. The following sections describe WHO's classification of digital health interventions (DHIs) and illustrate what specific DHI characteristics might support SCD-important challenges [51].

4. Digital health interventions

In the context of low availability of specialized healthcare service and thanks to potential wide reach and relatively low cost, digital health interventions (DHIs) could offer a potential route to help patients become experts in self-management [52–55].

As per WHO definition, digital health encompasses various concepts including eHealth (i.e., effective use of information and communication for health-related purposes), mHealth (i.e., provision of information and services through mobile technologies), or telemedicine (i.e., remote practice of medical interventions or examination) [56–58]. Additionally, digital health includes computing techniques (e.g., artificial intelligence, natural language processing, interoperability), which assist in extracting and making sense of a large volume of health-related data (e.g., genomic sequencing, medical imaging, health records, medical devices, wearables, pharmaceutical research, search engines, online patient communities, healthcare payor records) [59, 60]. Health interventions using digital technologies can be classified in four categories, based on the targeted primary user.

Overall, DHIs are increasingly used to provide effective, safe, and scalable interventions improving chronic patient's health outcomes [61]. However, prior studies found that patients who stand to benefit most from DHIs were least likely to download or use them [62, 63]. With discontinued or inconsistent use, it is less likely that the intended effectiveness of DHIs can be realized.

Studies have shown that DHIs responding effectively to patients' specific health problems while being easy to use had better long-term engagement [64, 65]. Interestingly, Stenft et al. [66] demonstrated that engagement in DHIs was higher among patients who were dissatisfied with healthcare service delivery (HSD). Additionally, Lee et al. [67] suggested that these patients particularly desired to get access to novel technologies and would request specific digital health services keeping them away from hospitals. As prior studies suggest [68–70], including patients' input from the start to the end of design, development and evaluation phases could help creating DHIs that are desired, used, and engaging in the long run.

The potential of digital health technologies for SCD is far from being fully exploited, and patients' experiential knowledge is largely untapped. Indeed, most DHIs focus on symptom monitoring or medication adherence [71]. However, given the multisystemic nature of SCD, its multiple vulnerability factors, its clinical variability, and severe comorbidities, it is paramount to encompass every components of self-management and to comprehensively support the day-to-day and long-term self-care needs of patients.

5. Categories of digital health interventions

5.1 Category 1: interventions for clients

The first category defines interventions for clients, i.e., individuals such as patients, citizens, or informal caregivers. The aim of such DHIs ranges from improving access to care for remote populations, disseminating targeted education to providers and patients through eHealth, and supporting patient empowerment with mHealth self-management apps targeting smoking cessation, medication dosage calculators, support for medication adherence, symptoms self-monitoring, or remote medical consultations, see **Figure 1**. For instance, Jacob et al.recently demonstrated how telemedicine could help deliver CPC to remote children with SCD in underserved areas [72].

Today, mHealth apps are flooding app stores, with more than 200 new apps each day, and a sharp rise during the COVID-19 outbreak [73–75]. Many of these apps can significantly improve health outcomes and support people with diverse medical conditions [54, 76].

In the case of SCD, some of the existing DHIs could be those that play a role in targeting individual behavioral factors, which are known to cause more than 35% of premature death and are responsible for a large proportion of disease burden [77]. For instance, DHIs could be greatly adapted to help reduce knowledge-based inequalities among individuals with SCD (e.g., support therapeutic education and self-management, disseminate disease-specific knowledge), or those that could improve awareness about the disease. Several authors have demonstrated tools to support
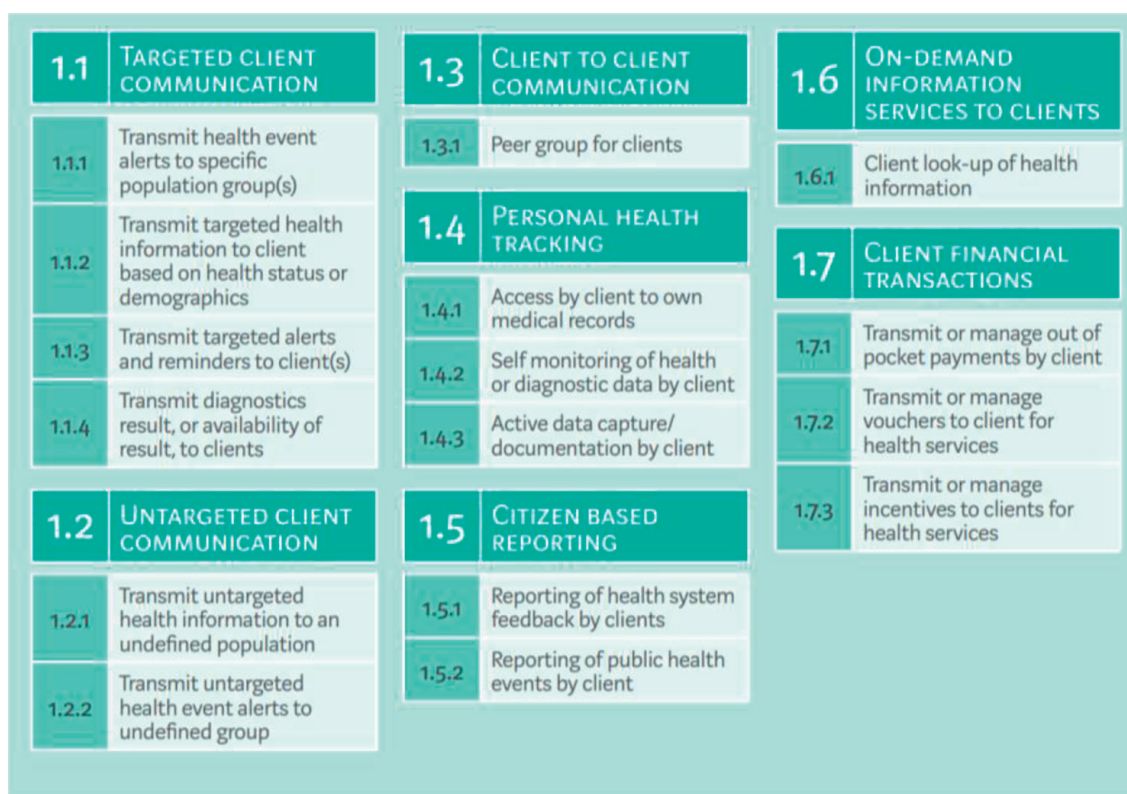

Figure 1.
Digital health interventions for clients—WHO [51].

mental health among people with SCD. Some systems utilize text-based technology to conduct psychological interventions [78], while others propose effective ways to conduct cognitive behavioral therapy remotely using mobile apps [79].

As **Figure 2** illustrates [8], self-care elements of disease management are particularly important when designing mHealth apps targeting patients. Indeed, because good self-care practices lead to positive health outcomes, DHIs, thanks to their relatively low cost and wide reach, could be a potential route to support people with SCD's numerous self-care management tasks, for instance, by improving their health literacy or increasing their self-efficacy levels [80–82].

Findings from multiple studies have identified an increasing number of digital health interventions aiming to support people with SCD [39, 71, 83]. However, the potential of digital health technologies for people with SCD is far from being fully exploited but has started to accelerate in the recent years. Indeed, most DHIs focus on symptom monitoring or medication adherence, but promising studies described how self-management mHealth apps could enhance patient engagement in disease management [71, 84, 85]. Although not comprehensive, this study provides useful evidence on the needs and wants of adults with SCD.

However, similar to other chronic diseases, the frequency of downloads and long-term adoption remains in its infancy [84]. In an attempt to tackle such an important issue, Philips et al. [86] and Issom et al. [87] proposed to put more efforts in the direction of patient-centered and patient-led approaches when designing digital health interventions, so we can better understand factors encouraging adoption [88]. Authors suggested methodologies such as the Behavior Change Wheel to understand human and societal factors important to take into account to reach higher rates of appreciation and increased motivation in using DHIs by patients [89].
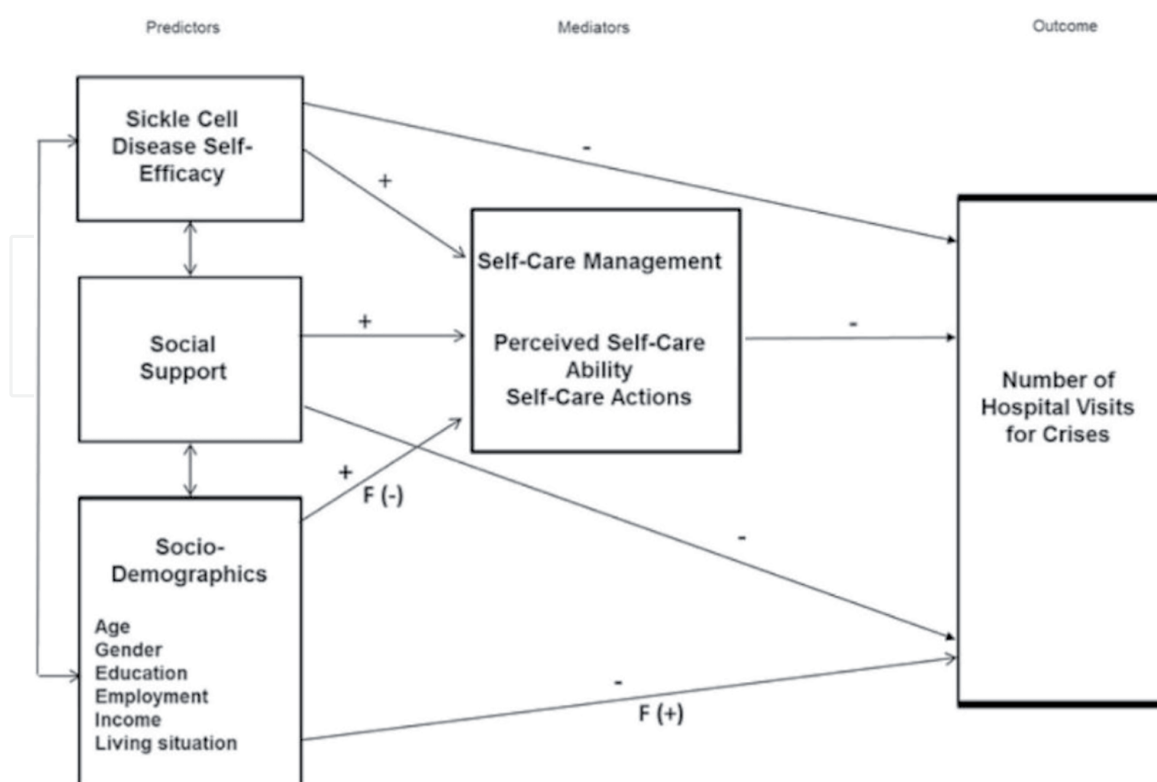

Figure 2.
Role of self-care in sickle cell disease—Matthie et al. [8].

As well, authors suggested the use of systems using lower energetical resources and easy to learn (e.g., chatbots) to foster adherence and reduce costs. Still, more research is needed and important patient-important needs (e.g., reduce the incidence of pains, self-care support, improve self-efficacy, increase disease-specific knowledge, support transition to adulthood) are yet to be tackled effectively [90, 91], but existing research studies are encouraging, showing potential in increasing important these important outcomes [92–94]. Johnson et al. [95] demonstrated the feasibility of an innovative way to mitigate pain crises by using wearable devices signals to monitor pain and attempt at predicting symptoms using machine learning approaches. Similarly, Ajayi et al. showed how such systems could be used to collect a wide range of biophysical measurements [96]. Yet, today, most apps for people with SCD reported in the scientific literature focus on medication adherence or the monitoring of symptoms [71, 84]. Hankins and Shah analyzed the matter and the importance of adherence and proposed a framework to tackle medication adherence using mobile apps [97].

5.2 Category 2: interventions for healthcare providers

Research is scarce regarding DHIs for healthcare providers specialized in SCD [98]. Nevertheless, such digital health interventions could be helpful in supporting the scarcity of healthcare professionals specialized in SCD care. As **Figure 3** illustrates, the WHO promotes the development of tools such as micro-learning apps for healthcare provider training, decision support systems, or infrastructure for remote consultations. Such DHIs hold the potential to increase the pool of specialized healthcare providers, improve patient-provider communication, or coordinate care. Researchers have investigated tools to improve medical decision-making, for instance, by providing guidance on pain management and curative treatment [98, 99] or by supporting diagnostic of sickle cell disease using digital PCR or mobile microscopy [100, 101].

5.3 Category 3: interventions for health systems or resource managers

In the case of SCD, DHIs for health systems managers (**Figure 4**) could be very useful to support the collection of populational epidemiological data (i.e., civil registration, mortality and morbidity data, geographical prevalence) and public health policies to provide patients with targeted support. As well, such DHIs could be helpful in monitoring the quality of SCD care. Today, advances in specific DHIs to help manage disease-specific logistics (e.g., blood products, oxygen tanks, epidemiological data) or to provide targeted information to clinicians susceptible to encounter people with SCD (e.g., clinical guidelines, emergency protocols, screening equipment) are lacking.

5.4 Category 4: interventions for data services

Data management is a crucial but challenging aspect of DHIs. As **Figure 5** illustrates, DHIs for data services could benefit global health by (1) allowing patients to own their health data; (2) developing robust governance processes that ensure respect of values and principles in the use of data and risk minimization; (3) creating systems that allow for automated collection and aggregation of data; (4) implementing data interoperability standards; (5) allowing anonymized data sharing in real time; and,

Figure 3.
Digital health interventions for healthcare providers—WHO [51].

(6) formatting and representing data so that they can be easily used by patients, healthcare providers, entrepreneurs, or policymakers [102].

In the case of SCD, DHIs could be crucial to foster the establishment of national data collection of burden of SCD. DHIs focusing on information management could involve supporting national disease surveillance programs, collecting of mortality and morbidity incidences, synthesizing PROMS, analyzing forecasting (e.g., health outcomes, prevalence), and mapping of socioeconomic assistance to the SCD population or promote the creation of health data cooperatives (e.g., databases owned, partly financed, and controlled by the people who use it) [103–105].

6. Structural barriers to the effectiveness of digital health interventions

Setting up effective, sustained, and globally scalable digital health interventions that can contribute to the reduction of disparities is challenging. DHI projects often

Figure 4.
Digital health interventions for health system managers—WHO [51].

Figure 5.
Digital health interventions for data services—WHO [51].

struggle to scale up sufficiently and are often unsustainable for targeted communities once donor funding ceases [106]. As a result, some projects succeed in transforming the lives of those who have been able to access the technologies, while also disadvantaging those without access to them [107]. Consequently, the number of successfully

implemented digital interventions that move beyond the pilot or feasibility stage remains limited. Equally, if and when they pass these initial stages [108], scholars have identified that few users use the technologies for a prolonged period of time, despite offering high potential to improve health outcomes and empowering patients [109–112]. As a result, those who would most benefit from such apps often underuse them [63, 112–124]. The main reasons for low adoption include:

1. lack of personalization;

2. lack of perceived added value;

3. deficient or inadequate infrastructures (e.g., access to Internet connectivity);

4. lack of equipment, low literacy (e.g., digital, health);

5. technology gap issues;

6. maladaptation to local context;

7. hidden costs;

8. unwanted data sharing;

9. insufficiently useful features;

10. inability to sustain required attention for longer periods of time;

11. financial unsustainability;

12. poor usability (e.g., suboptimal design, manual data entry) [113, 125–128].

These observations may partially be explained using such top-down approaches to design interventions and decision-making. Similarly, in more user-centered design paradigms [120], end users are generally included as partners, from the beginning of the project, during the design process, or when the development of the intervention is complete, in order to test usability or safety, but not as decision-makers. With these processes, i.e., when end users are not contributing to decision-making, it is likely that their important interests are not put as central, prioritized, nor fully acknowledged. Subsequently, this results in technologies that may be disempowering, alienating, or irrelevant to the end users, therefore increasing the risk they will abandon them.

7. People with neglected diseases: from technology enthusiasts to patient innovators

Individuals with orphan diseases and affected by diabetes have been leaders in fostering these approaches using crowdsourcing (i.e., individuals of varying knowledge and skills voluntarily undertaking a task for mutual benefit) or crowdsensing techniques (i.e. using smartphones to sense, collect, and analyze data) to accelerate knowledge discovery and promote patient empowerment [129, 130].

The most famous patient-led innovations are PatientsLikeMe (i.e., the first online community for people with Amyotrophic lateral sclerosis), the #WeAreNotWaiting and #OpenAPS movements (i.e., do-it-yourself methods for creating an artificial pancreas system) [131], the Nightscout project (i.e., a parent-developed solution for remote blood glucose monitoring), or the Crohnology project (e.g., an online platform for patient-to-patient information sharing).

These projects have rapidly reached high number of users, some of them have been acquired by companies in order to ensure financial sustainability or scale-up [132]. These early success stories highlight the importance of user-driven initiatives in research and development and show high potential for patient empowerment [133].

8. Disparate evidence

In June 2019, the WHO and the Organization for Economic Co-operation and Development (OECD) from the European Commission (CE) supported PLR approaches, concluding that digital health interventions should be designed to meet the needs of people and health systems and suit local contexts [134]. Aligned with these conclusions, bottom-up models such as PLR or the free innovation paradigm are becoming increasingly popular [135, 136], exemplifying how researchers in academia, industry, and patient communities can create patient-centric solutions and reduce the disease burden together. Only a few PLR initiatives are mentioned in the scientific literature about SCD, suggesting that most DHIs have been driven by healthcare professionals of software implementers [39, 71]. With their potential of being implemented and scaled up rapidly globally when adequately implemented [137–139], DHIs targeting people with SCD may hold the capacity to address various health inequalities faced by historically disadvantaged populations.

9. Conclusions

Digital health interventions to empower with sickle cell disease remain relatively scarce if we look at their number compared with diseases with higher prevalence, but current research shows a strong potential for improving health outcomes. The important aspects to work on are the human factors allowing a strong adhesion in its interventions and to seek to better understand how to use artificial intelligence to lead to the prediction of symptoms and then to prevent them.

Conflict of interest

The author declare no conflict of interest.

Notes/thanks/other declarations

Place any other declarations, such as "Notes," "Thanks," etc., before the References section. Assign the appropriate heading. Do NOT put your short biography in this section. It will be removed.

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