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A SickleInAfrica mHealth Tracker and Dashboard Application for Sickle Cell Disease Patients in Africa: User-centred design and preliminary study

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Abstract

Objective: This work presents a personalised SCD management tool for assessing patient (pain, medication adherence, overall quality of life) and research (quality, quantity, and precision of registry data) outcomes in Africa. The piloting phase addressed the following questions followed by adapting the design based on feedback accordingly: (1) What components from existing SCD management mHealth tools might be beneficial to add to our prototype design? (2) How do SickleInAfrica SCD patient representatives, healthcare providers, and researchers perceive the usability of the prototype and what requirements do they suggest? An iterative user/stakeholder-centred approach was used to develop an mHealth and dashboard app in accordance with the Centre for eHealth Research (CeHRes) Roadmap.

Results: A holistic mHealth and dashboard app were designed, of which during piloting, researchers, clinicians, and patients found it useful, particularly the activity section, and suggested that more information about the disease be added. Our findings suggest that, unlike existing SCD mHealth apps, this app has the potential to enhance clinical care in African through the collection of pertinent patient lifestyle data, improve the quality of registry data, and support ongoing research. Future work includes a formal implementation study to evaluate app adoption, adherence, and efficacy.

Keywords: Sickle cell disease; Mobile health; Health management; African settings

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Introduction

A. Sickle Cell Disease

The World Health Organisation (WHO) has identified Sickle Cell Disease (SCD) as a major health concern in Africa, where it currently has an 80% mortality rate in children under five (1,2,3). SCD is characterized by numerous health complications, which often pose a significant burden on poor health infrastructures like the ones found in Africa. Further challenges of literacy, stigmatisation and effective disease management exist in this region (4,5,6). Despite SCD being a major cause of death and hospitalisation, it is still largely ignored and unresearched in Africa, often leading to higher mortality rates, misdiagnoses, delayed treatments, and increased risks of stroke (4,7,8,9). Even though technologies such as mobile health apps have been beneficial for SCD patients overseas, there has been limited access and development of such apps for African cohorts (10,11,12). We therefore aimed to describe the user/stakeholder-centred approach used to design and develop an African-centred mHealth app, the SCD Chommie App, and dashboard platform.

Methods

Study Design

The development process was based on the *Centre for eHealth & Wellbeing Research (CeHRes) roadmap, however, particular to our study we only adopted four of its six concepts:* contextual inquiry (gathering information from target users and environment), value specification (refers to the realisation of possible healthcare improvements, and their fulfilment limitations and challenges), design (building prototypes that fit the values and user requirements), and an informal implementation of operationalization (defines the introduction, adoption, and employment of designed prototype in daily practice) (13,14,15).

Phase 1: Contextual Inquiry & Value Specification

The contextual inquiry was conducted in Phase 1; we identified the user requirements for both healthcare providers and SCD patients based on health management challenges among SCD patients in Africa. This data was obtained from available literature. A literature review was conducted to consolidate the data in this field. Simultaneously, value specification was also conducted to ensure that each provided solution created value and was implementable (13).

Phase 2: Design & Operationalization

The SCD Chommie App's medium-fidelity prototype was created using Ionic 4, a front-end framework that utilizes web technologies such as Angular and React for cross-platform app design. The initial design was made using Balsamiq Cloud version 5.3.1, which included sketches, wireframes, and mock-ups. The app prototype incorporated all the prioritised user requirements and was converted into Ionic/Angular source code. The low-fidelity prototype was built into an Android package and uploaded to Google Play Store for internal testing. Healthcare providers and relevant patients were invited to download and use the app prototype and provide feedback and suggestions informally, without a formal response questionnaire.

Results

Phase 1: Contextual Inquiry & Value Specification

We contextualised four high-level barriers to effective SCD management in African populations from the available literature (**Table 1**). We further define user requirements (descriptions of what is important to users) to minimise each barrier, and tool specifications (applicable functions to add to prototype design) to meet the user requirements. The identified user requirements were translated into the prototype design.

Table 1 : Characterization of health management challenges for SCD patients in Africa.

Barriers/Challenges	Reference	User requirement/need	Translation of user requirements in SCD Chommie App
Lack of adequate research on SCD	[16-22]	More research on SCD	Data collection functionality Registration functionality
Lack of education/training for healthcare providers and patients	[2,9,16,19,20,21,22,23, 24,25,26,27,28,29]	Information on SCD	SCDO Health belief model
Lack of SCD awareness and advocacy	[18,19-22,24-27,30]	Find SCD supportive initiatives	SickleInAfrica website
Lack of basic resources e.g. electricity	[18]	Tailored SCD platforms	Online/Offline functionality

Lack of adequate research on SCD

SCD is highly understudied among African populations, as such that its true magnitude is not adequately documented (21). For the purpose of addressing this challenge, specific user requirements were translated into the prototype design. The prototype was designed with a data collection function, both for registration and general purposes. The prototype allows users to register on the app for access to more advanced functions or use the general user version prototype. In the registration section, users are required to indicate if they have SCD. This information is then recorded and stored in a MySQL server database.

Lack of education/training for healthcare providers and patients

Information on SCD was provided on the prototype through the implementation of the layperson Sickle Cell Disease Ontology (SCDO), a comprehensive knowledge system for SCD-related

terms and concepts. Particularly for our design, we employed the patient-oriented terms defined as layperson terms (31).

Lack of SCD awareness and advocacy

The SickleInAfrica website - an African SCD research consortium - was adapted in the prototype design to inform SCD patients on current SCD advocacy in Africa (32,33).

Lack of basic resources (e.g. electricity)

There is a need for robust and engaging mHealth interventions that can operate in remote rural settings with limited resources. This is most prominent in African countries with a shortage of healthcare providers and exacerbated patient numbers where there are 2.3 healthcare providers for every 1000 patients compared to developed countries with 24.8 healthcare providers (18).
As a result, to offer functional autonomy in rural areas, we implemented an offline-functionality to our prototype. It is able to fully function with no network provision.

Phase 2: Design

The design process includes translating user requirements into a working prototype. To ensure that the design benefits the users, a unified set of components are added to the prototype, each of which address a different set of user requirements. Additionally, end users (e.g. healthcare providers, care givers, patients) are involved in this process to evaluate the proposed prototypes.

The prototype, which included an mHealth app and web portal dashboard, was designed using Balsamiq Cloud version 5.3.1 (Balsamiq, Sacramento, California, United States). Thereafter, an iterative process was adopted where we presented the prototype design repeatedly to stakeholders, healthcare providers and patients at formal and informal conference meetings. A

comprehensive prototype design was reached after numerous presentations and feedback alterations. This design was translated into a digital prototype of which the mHealth app was made publicly available on Google Play Store (appgoogle/dszH6).

mHealth Engagement: Interface Design and Development

The mHealth app is provided in two modes of connection: online and offline. The online mode stores data on a remote server accessible to app providers, while offline stores data locally on the users' device. The app collects the following groups of data: user, health, lifestyle and geographic data. The app also functions with an external wearable device to collect lifestyle data. Patients are also able to interact with a local notification system that allows them to schedule reminders with specific messaging at specific times. . Additionally, a clickable body image has been added to capture users' pain locations, a journal to capture hospital admissions, a dictionary section with layperson SCDO terms, promotional messaging to improve app uptake through a health belief model, information on SCD research on the SickleInAfrica website, and a dashboard to display recorded information (**Figure 1**).

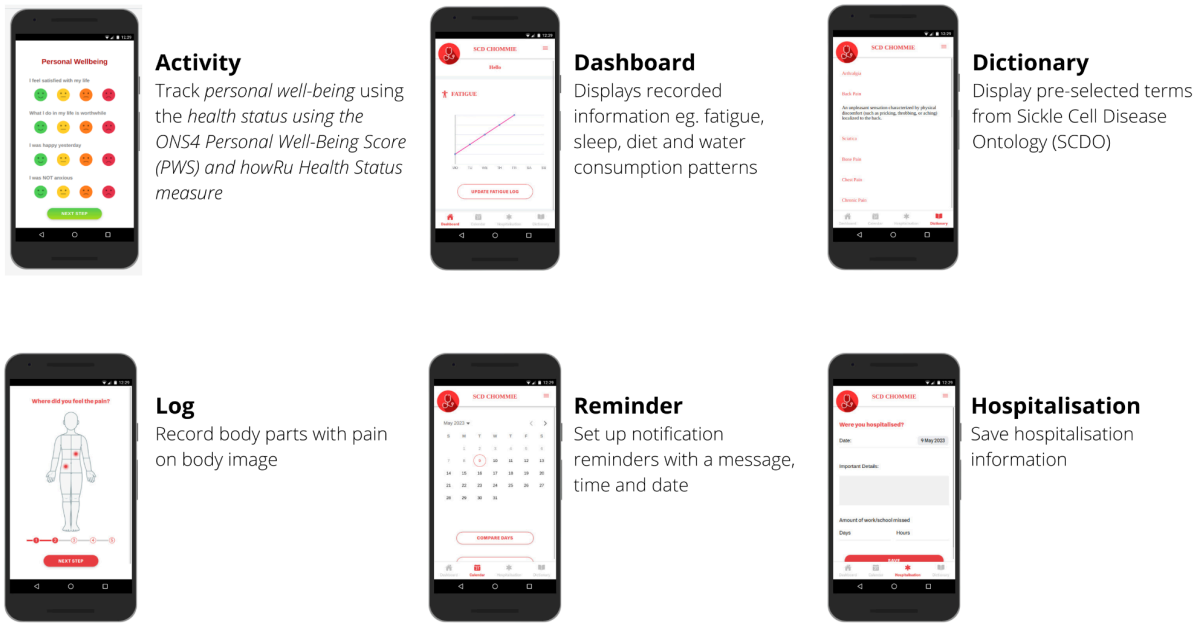

Figure 1: Digital prototype interface design (the native version).

Overview of Data Collection Process

REST API

A REST API is an intermediate service that enables third-party access to web applications hosted on remote cloud services, such as servers. For instance, customer-facing applications like ours make use of an intermediate API system to display updated information by retrieving data from online relational databases. In particular, we employed a server-hosted MySQL database to store consolidated user data, which is delivered to the end-user app through an API system (34).

Our API endpoint collects the following information through the app:

• User statistics: We collected general user information on the signup request, which included username, password, first name, last name, date of birth and a disease they have (if applicable). The username and password was used to log into the app.

• Health statistics: Every time users logged into the app we presented five main health questions capturing their fatigue, pain level, pain location, remedial intake, dietary and water patterns. Furthermore, users are able to record their hospital admissions as well as their health and personal-wellbeing.

• Lifestyle statistics: Users can track their lifestyle journey through a wearable device and view it on the app.The wearable device currently captures steps, distance and calories consumed with the ability to add more activities. This allows for automatic health monitoring even when the app is closed.

• Geographic statistics: The app automatically collects users' geographic information when online, including their country code, city name, launch time, cloudiness, visibility, atmospheric pressure, humidity, wind speed and direction, current weather parameters, temperature in Celsius, and carbon dioxide pressure in milligrams per cubic metre.

Ethics and Consent

To consider the ethical implications of our app design, we sought approval from the relevant university ethics committee. Our app considered the following implications:

• Informed consent. Our app required users to read and understand the data collection process on app initialisation. Users could then choose to use the online or offline mode of the app. We included the following information on the Terms and Conditions page: data collection process, the type of data collected from users, as well as the research purposes of the collected data.

• Research consent. To ensure that collected information could be of use in future research work, we registered our database system with the university ethics committee.

Phase 2: Operationalization

Operationalisation involves the use of the intervention in production. This includes facilitating the introduction, adoption and long-term use of the intervention by the relevant caregiver and patient groups (14). To accomplish this, we conducted an informal pilot study of the mHealth SickleInAfrica Health Tracker app with a small group of SCD clinician and patient groups, where we aimed to introduce and evaluate the app design.

Patient perceptions on app prototype

An informal evaluation of the mHealth prototype was conducted with a small group of SCD patients, who were required to provide feedback on the design of the app, as well as

suggestions to further improve the app. Patients found the app useful and appreciated the ability to monitor their sleep, diet and water consumption. Furthermore, patients requested the inclusion of information on SCD advocacy initiatives and local emergency services.

Healthcare provider perceptions on app prototype

After healthcare providers evaluated the first prototype, they provided feedback and suggested several improvements. These included changing the smiley-face pain scale to a line and colour-centred pain scale, adding a function to capture user hospitalisation and measure its severity, incorporating a pain severity scale for the body image section, allowing users to comment on any other pain management methods they used, adding more options to the questionnaire section, and finally, creating two separate app versions: one for the general public and another for patients recruited at clinics.

Limitations

Our development process consisted of several limitations. We limited the number of evaluation iterations to one in our study, even though the CeHReS roadmap requests multiple iterations (14). Furthermore, our contextual inquiry only considered data from available literature and no field discussions, observations or interviews were conducted with the intended stakeholders (e.g. users, healthcare providers etc.). We also conducted an informal pilot study on our preliminary design, as a result this might not provide adequate data on user and healthcare provider perceptions on the intervention.

Discussion

The SCD Chommie App presents a multifaceted mHealth and dashboard app specific for African SCD patients. Currently, a new version of the app is currently being designed to incorporate feedback from patients and healthcare providers. Once released, the app along with

its web-based dashboard, will be formally evaluated in a structured randomised pilot study, of which the results will be published in a future paper.

In comparison to other SCD-related apps, our app promises to enhance both patients' quality of life and clinician registries. The app maintains both a web- and a mobile-based system, which both possess particular disadvantages and advantages. Even though both types of apps have been reported to be effective, more research is required to fully comprehend their regional value, particularly in Africa. As most of these apps have proven value in developed settings where specific health challenges exist that are far different from those in African settings. This not only points to the need of promoting mHealth research in Africa but also expands on the need for designing African-centred healthcare apps, that collectively look to solve and break barriers affecting healthcare in Africa.

Conclusions

This work presents the development process of the SCD Chommie App using the CeHRes roadmap. If our app is proved effective, this paper will serve as a guide for the development of more African-centred apps.

Abbreviations

SSA: sub-Saharan African

SCD: Sickle Cell Disease

mHealth: mobile health

app: application

apps: applications

Declarations

Ethics approval and consent to participate:

Not Applicable

Consent for publication:

Not Applicable

Availability of data and materials:

All data generated or analysed during this study are included in this published article [and its supplementary information files].

Competing interests:

None declared

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Authors' contributions:

Conception and design: MWM, GKM, VN, AW. Administrative support: VN. Provision of study materials: AW, KM, JM, VN. Collection and assembly of data: MWM, KM. Data analysis and interpretation: MWM, VN, GKM, JM. Manuscript writing: All authors. Final approval of manuscript: All authors.

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References

1. Machín GS, Svarch E, Menéndez VA, Hernández PC & Sosa PO. Morbidity and mortality of sickle cell anemia: thirty-six years of observational study. Revista Cubana de Hematologia, Inmunologia y Hemoterapia. 2015; 31 (3): 265-276.

2. Mulumba LL & Wilson L. Sickle cell disease amongst children in Africa: An integrative literature review and global recommendations. International Journal of Africa Nursing Sciences. 2015; 3: 56-64.

3. Makani J, Williams TN & Marsh K. Sickle cell disease in Africa: burden and research priorities. Annals of Tropical Medicine & Parasitology. 2007; 101(1): 1-12.

4. Rees DC. Managing the burden of sickle-cell disease in Africa. The Lancet Hematology. 2014; 1(1): e11-e12.

5. Poku BA, Caress A & Kirk S. "Body as a Machine": How Adolescents With Sickle Cell Disease Construct Their Fatigue Experiences. Qualitative Health Research. 2020; 30(9): 1431-1444.

6. Isa H, Okocha E, Adegoke SA, Nnebe-Agumadi U, Kuliya-Gwarzo A, Sopekan A, Ofakunrin AO, Ugwu N, Hassan A, Ohiaeri C, Madu A, Diaku-Akinwumi I, Ekwem L, Dogara LG, Okoh D, Jasini J, Girei A, Ekwere T, Okolo A, Kangiwa U, Lawson J, Chianumba R, Brown B, Akinola N, Nwegbu M & Nnodu O. Strategies to improve healthcare services for patients with sickle cell disease in Nigeria: The perspectives of stakeholders. Frontiers in Genetics. 2023; 14.

7. Paintsil V, Ally M, Isa H, Anie KA, Mgaya J, Nkanyemka M, Nembaware V, Oppong-Mensah YG, Ndobho F, Chirande L, Makubi A, Nnodu O, Wonkam A, Makani J, Ohene-Frempong K. Development of multi-level standards of care recommendations for sickle cell disease: Experience from SickleInAfrica. Frontiers in Genetics. 2023; 13: 1052179.

8. McGann PT, Hernandez AG, Ware RE. Sickle cell anemia in sub-Saharan Africa: advancing the clinical paradigm through partnerships and research. Blood. 2017; 129(2): 155-161.

9. Ansong D, Akoto AO, Ocloo D & Ohene-Frempong K. Sickle Cell Disease: Management Options and Challenges in Developing Countries. Mediterranean Journal of Hematology and Infectious Diseases. 2013; 5(1): e2013062.

10. Jonassaint C, Shah N, Jonassaint J & De Castro L. Usability and Feasibility of an mHealth Intervention for Monitoring and Managing Pain Symptoms in Sickle Cell Disease: The Sickle Cell Disease Mobile Application to Record Symptoms via Technology (SMART). Hemoglobin. 2015; 1–7.

11. Hankins JS & Shah N. Tackling adherence in sickle cell disease with mHealth. The Lancet Haematology. 2020; 7(10): E713-E714.

12. Kumar R & Das A. The Potential of mHealth as a Game Changer for the Management of Sickle Cell Disease in India. JMIR mHealth and uHealth. 2021; 9(4): e25496.

13. Rothgangel A, Braun S, Smeets R & Beurskens A. Design and Development of a Telerehabilitation Platform for Patients With Phantom Limb Pain: A User-Centered Approach. JMIR Rehabilitation and Assistive Technologies. 2017; 4(1): e2.

14. van Gemert-Pijnen JEWC, Nijland N, van Limburg M, Ossebaard HC, Kelders SM, Eysenbach G & ER. A Holistic Framework to Improve the Uptake and Impact of eHealth Technologies. Journal of Medical Internet Research. 2011; 13(4): e111.

15. Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, Hinder S, Fahy N, Procter R & Shaw S. Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies. Journal of Medical Internet Research. 2017; 19(11): e367.

16. Makani J, Ofori-Acquah SF, Nnodu O, Wonkam A & Ohene-Frempong K. Sickle Cell Disease: New Opportunities and Challenges in Africa. The Scientific World Journal. 2013; 193252.

17. Ansong D, Akoto AO, Ocloo D & Ohene-Frempong K. Sickle Cell Disease: Management Options and Challenges in Developing Countries. Mediterranean Journal of Hematology and Infectious Diseases. 2013; 5(1): e2013062.

18. Eze E, Gleasure R & Heavin C. Worlds apart: a socio-material exploration of mHealth in rural areas of developing countries. Information Technology & People. 2022; 35(8): 99-141.

19. Dipty J, Lothe A & Colah R. Sickle Cell Disease: Current Challenges. Journal of Hematology & Thromboembolic Diseases. 2015; 3: 6.

20. Ryan N, Dike L, Ojo T, Vieira D, Nnodu O, Gyamfi J & Peprah E. Implementation of the therapeutic use of hydroxyurea for sickle cell disease management in resource- constrained settings: a systematic review of adoption, cost and acceptability. BMJ Open. 2020; 10: 038685.

21. Mubyazi GM & Njunwa KJ. Is sickle cell disease sufficiently prioritized in policy and socio-economic research on diseases in Tanzania? Lessons for the past 50 years. Tanzania Journal of Health Research. 2011; 13(1).

22. Adams-Graves P & Bronte-Jordan L. Recent treatment guidelines for managing adult patients with sickle cell disease:challenges in access to care, social issues, and adherence. Expert Review of Hematology. 2016; 9(6): 541–552.

23. Oron AP, Chao DL, Ezeanolue EE, Ezenwa LN, Piel FB, Ojogun OT, Uyoga S, Williams TN & Nnodu O. Caring for Africa's sickle cell children: will we rise to the challenge? BMC Medicine. 2020; 18: 92.

24. Alapan Y, Fraiwan A, Kucukal E, Hasan MN, Ung R, Kim M, Odame I, Little JA, Gurkan UA. Emerging point-of-care technologies for sickle cell disease screening and monitoring. Expert Review of Medical Devices. 2016.

25. Akingbola TS, Akinyemi OO, Amodu OO & Tayo BO. Sickle cell disease management in Nigeria: Understanding the challenges from the physicians' perspectives. African Journal of Medicine and Medical Sciences. 2018; 47: 195-203.

26. Dennis-Antwi JA, Dyson S & Ohene-Frempong K. Healthcare provision for sickle cell disease in Ghana: challenges for the African context. 2008; 5: 241–54.

27. Roberts I & Montalembert M. Sickle cell disease as a paradigm of immigration hematology: new challenges for hematologists in Europe. Haematologica. 2007; 92(7).

28. Meier ER & Rampersad A. Pediatric sickle cell disease: past successes and future challenges. Pediatric Research. 2017; 81(1): 249-258.

29. Brundisini F, Giacomini M, DeJean D, Vanstone M, Winsor R & Smith A. Chronic Disease Patients' Experiences With Accessing Health Care in Rural and Remote Areas. Ontario Health Technology Assessment Series. 2013; 13(15): 1–33.

30. Isaac O & Dipty J. Sickle cell disease: Progress made & challenges ahead. Indian Journal of Medical Research. 2020; 151(6): 505-508.

31. Sickle Cell Disease Ontology Working Group. The Sickle Cell Disease Ontology: enabling universal sickle cell-based knowledge representation. Database. 2019.

32. Darbari DS & Brandow AM. Pain-measurement tools in sickle cell disease: where are we now? Hematology, ASH Education Program. 2017; 2017(1): 534–541.

33. Munung NS, Nembaware V, Vries J, Bikini D, Tluway F, Treadwell M, Sangeda RS, Mazandu G, Jonas M, Paintsil V, Nnodu OE, Balandya E, Makani J, Wonkam A. Establishing a Multi-Country Sickle Cell Disease Registry in Africa: Ethical Considerations. Frontiers in Genetics. 2019; 10(943).

34. Rodriquez C, Baez M, Daniel F, Casati F, Trabucco JC, Canali L, Percannella G. REST APIs: A Large-Scale Analysis of Compliance with Principles and Best Practices. Proceedings of the International Conference on Web Engineering. 2016.

Figures

Figure 1: Digital prototype interface design (the native version).

Tables

Table 1 : Characterization of health management challenges for SCD patients in Africa.