Feb 07, 2022

SickleSupport Project Brief

An app designed to support sickle cell patients in managing their disease.

1 Overview

Sickle cell disease (SCD) is a disorder of hemoglobin production which results in "sickling" of red blood cells and subsequent acute (e.g. pain crises, stroke, blood clots) and chronic (e.g. kidney failure, bone damage, blindness) complications. A mobile application was designed and developed to assist in the monitoring and management of SCD, with the following aims:

1. Enable patients to become proactive in the management of their disease by providing:
    a. simple tools that can help track pain episodes and other SCD-related complications outside of clinical environments, and
    b. learning platforms that educate the patient about SCD, as well as the various financial and social resources available to them
2. Improve quality of clinical care for SCD patients by:
    a. building exportable sickle cell crisis reports for physicians to review during clinical visits, and
    b. creating an information summary card to alert emergency department staff about the urgency of certain complications, as well as other useful information (e.g. physician contacts).

2 Problem Scope

2.1 Clinical Care

SCD patients tend to visit clinicians once every 2-4 months. When asked about pain episodes that occurred at home, patients may misremember the frequency or severity, as well as other potentially important characteristics. This results in missing information, which leads to suboptimal treatment. We hope to ameliorate this issue through the provision of electronic pain records, which are to be documented by patients and sent to physicians prior to (or during) visits.

Additionally, studies showed that SCD patients consistently endure longer wait times to see physicians in the emergency department (ED); findings suggest that this is related to both their race (SCD patients are predominantly black) and their status as SCD patients (many healthcare professionals in the ED are unaware about the urgency of SCD-related complications) [1]. We hope to ameliorate this issue through an info summary card that contains SCD-related information (to educate ED staff) and physician contacts (to add credibility and additional consults, should they be necessary).

2.2 Financial Strain

SCD is most common in families with African ancestry. Furthermore, studies have showed that SCD predominately affects families with low socioeconomic status (SES) [2]. Like many other chronic, life-long conditions, the diagnosis of SCD means a significant economic burden for most individuals and their families. Studies found that a lifetime cost of care averages at $460,151 per patient with SCD [3]. We hope to provide links to financial resources that can help alleviate some of this burden.

3 PROJECT TEAM

This project is a collaborative effort between various multidisciplinary groups. Contributors to this project are listed in the table below.

Table 1: Project Team

Project Roles	Name	Position/Affiliation	Contact
Project Coordinator	Ke Xin (Katie) Chen	*Co-Chair* Kitchener-Waterloo Society for Innovations in Medicine (KWSIM)	*katie@kwsim.ca*
Advisors	Ziad Solh, MD, MSc, FRCPC, DRCPSC	*Hematologist & Transfusion Medicine Specialist* London Health Sciences Centre	*Ziad.Solh@lhsc.on.ca*
	Eric To, MD	*PGY-4* London Hematology Clinic	*eric.to@medportal.ca*
Collaborators	Lanre Tunji-Ajayi, M.S.M.	*President/Chief Executive Officer* Sickle Cell Awareness Group of Ontario (SCAGO)	*sicklecellawarenessontario@gmail.com*
F2021 Developers	Dhvani Patel	*Software Engineering Student* University of Waterloo	dhvanipatel35729@gmail.com
	Mann Patel		patelmann1999@gmail.com
	Bruce Wang		brucetreewang@gmail.com
	Sam Sandhu		sandhusarih777@gmail.com

4 PROJECT TIMELINE

F2021 developers are no longer working on this project; currently seeking new developers. The release of version 1.0 on Google Play Store is prioritized as the next major milestone. Tasks remaining for first release are detailed as follows:

- Screen responsiveness
- “Resources” page
- Cross-platform testing
- Administrative tasks related to release (technical writing, logo design, packaging, etc.)

4.1 MILESTONES

This project was initiated in October 2021. Major progressions are dated below.

Table 2: Project Milestones to Date

YYYY-MM-DD	**Description**
2021-10-20	Initial meeting
2021-11-17	1st iteration feedback on app design
TBD	App release version 1.0

5 REFERENCES

[1] H. Carlton, R. Naik and M. C. Beach, "Do Sickle Cell Patients Wait Longer to See Physicians in the Emergency Department?," *Blood,* vol. 118, no. 21, p. 2070, 2011.

[2] A. Cristina da Silva de Jesus, T. Konstantyner, I. K. V. Lôbo and J. A. P. Braga, "SOCIOECONOMIC AND NUTRITIONAL CHARACTERISTICS OF CHILDREN AND ADOLESCENTS WITH SICKLE CELL ANEMIA: A SYSTEMATIC REVIEW," *Revista paulista de pediatria : Sociedade de Pediatria de Sao Paulo,* p. 491–499, Oct-Dec 2018.

[3] T. L. Kauf, T. D. Coates, H. Liu, N. Mody-Patel and A. G. Hartzema, "The cost of health care for children and adults with sickle cell disease," *American Journal of Hematology,* vol. 84, no. 6, pp. 323-327, 2009.