



The Use of Smartphone Technology to Improve the Health of Sickle Cell Patients

Bridgette Stasher-Booker^{1*}, PhD, RHIA, CHTS-IM, MCCT, Danita Stapleton², Ed.D, LPC-S, CRC, NCC, Greshundria M. Raines³, OTD, MPA, OTR/L, CAPS

^{1*}Associate Professor and Program Chair, Department of Health Information Management, Alabama State University, 201D Buskey Building, PO Box 271, Montgomery, AL 36101-0271, United States.

²Associate Professor and Rehab Studies Chair/MRC Coordinator, Department of Rehabilitation Studies, Alabama State University, United States.

³Professor of Occupational Therapy, Department of Occupational Therapy, Alabama State University, United States.

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Corresponding Author: Bridgette Stasher-Booker PhD, RHIA, CHTS-IM, MCCT Associate Professor and Program Chair, Department of Health Information Management, Alabama State University, 201D Buskey Building, PO Box 271, Montgomery, AL 36101-0271, United States. E-mail: bbooker@alasu.edu

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Abstract

Sickle cell disease (SCD) is a serious health issue in society. The United State continues to register a large number of people affected by the disease. Due to the prevalence and severity of this hereditary condition, reliable and effective monitoring and prevention systems are needed. Smartphone technologies have the potential of improving health outcomes of people with SCD by promoting the empowerment and health literacy of people with SCD who live in underserved communities. The vast adoption of smartphones in the country provides an opportunity for the implementation of applications to support current healthcare systems. Mobile applications provide an opportunity to reform the healthcare sector by mitigating cost, yet maximizing accessibility, safety, and quality of care. The study aimed to provide insights into the use of smartphone technology and its impact on improving the health of SCD patients. A literature analysis methodology was adopted. The study found that smartphones provide enhanced means of sharing data and collaborating. The benefits of using smartphones in SCD management included pain tracking and monitoring, reinforcing treatment guidelines, and patient education.

Keywords: technology, smartphone technology, sickle cell disease, m-health

Introduction

Sickle cell disease (SCD) affects millions of people in the world, particularly those from middle and low-income countries [1]. Adam, Adam, and Mohamed [2] define SCD as a blood disorder leading to abnormal red blood cells in the body and mutation of the hemoglobin encoding gene is a major cause. SCD is a precarious condition because it is often poorly managed. According to Hockham et al. [3], SCD has the second-highest burden in India. The same results are replicated in other vulnerable regions like the Sub-Saharan African region. According to Adam, Adam, and Mohamed [2], 50% to 90% of the children born with SCD in Africa die at an early age. The extent of the problem is well captured from a global perspective. Wastnedge et al. [4] argue that SCD is a global problem and mainly affects children. According to the researchers, SCD accounted for approximately 305,000 births in 2010. A statistical examination of the prevalence of SCD shows that it remains to be a significant health issue in society. Although medical advances have contributed towards the reduction of the effects of the disease, more needs to be done. Thus, the implementation of technology in the management

of SCD provides a different perspective on addressing the problem. Hence, the purpose of this project is to discuss the role of smartphone technology in dealing with SCD.

Sickle Cell Disease in the U.S

Although the U.S. is not on the top list of the most vulnerable nations, it has reported a large number of SCD cases over the years. According to the CDC [1], about 100,000 Americans are affected by the disease. Also, SCD occurs in about 1 in every 365 African Americans births. The CDC [1] statistics go on to show that it occurs in 1 in every 16,300 Hispanic American births. Among African Americans, 1 in 13 babies born has a sickle cell trait (SCT). Over the years, phenomenal strategies have proved pivotal in improving the quality of life for people with SCD, including the use of a vaccine to protect against invasive pneumococcal disease. Due to immense improvements in medical care, the mortality rate of the disease has declined by almost 42% (from 1999 to 2002). On average, the CDC estimates that the mortality rate varies from state to state – 1.5 to 2.0 per 100 black newborns. Besides the healthcare complications, SCD is an economic burden to society. In 2005, the medical examination for children with the disease averaged \$11,702 (Medicaid covered) and \$14,772 (employer-sponsored insurance). Hospitalization cost due to SCD average in excess of \$400 million [1]. The socio-economic and healthcare issues linked to SCD trigger a call for action to deal with the rarely talked about the condition (SCD).

Understanding Sickle Cell Disease

SCD occurs due to the inherited gene: sickle β -globin gene variant (β^S). In order to have SCD an individual must have two copies of the recessive allele (one from each parent). In cases where only one gene is passed on, the child will only become a carrier. However, if two of these genes are passed on to the off spring, the child develops SCD. People with sickle cell traits (SCT) have healthy functioning red blood cells and typically lead normal lives. According to Hockham et al. [3], SCD denotes a group of inherited disorders that affect the red blood cells (hemoglobin). The pathophysiology of the disease stems from the polymerization of the sickle hemoglobin variant (HbS). The polymerization triggers erythrocyte alterations. Instead of the red blood cells retaining their standard shape and structure, they become rigid and sticky in people with SCD [5]. Persons with the disease have to battle such complications as stroke, organ failure, blindness, gallstones, hypertension, acute chest syndrome,

pregnancy complications, and priapism. According to Lubeck et al. [5], the life expectancy of people with SCD is shorter as compared to the general population, and this is linked to the high mortality in adulthood. Owing to the nature of the disease, the best long-term prevention strategy is effective disease management and increased medical support. Thus, the role of technology becomes crucial in the monitoring and control of SCD, especially at a time when its impact is projected to grow.

Barriers to Treatment of Sickle Cell Disease

Brennan-Cook, Bonnabeau, Aponte, Augustin, and Tanabe [6] discuss some of the common barriers in the treatment of SCD. According to the researchers, the primary barriers include the clinician-patient knowledge gap, perception of addiction and chronic pain, frequent visits of healthcare facilities by patients, stigma, and bias in treatment. Almost similar findings were reported by a study completed by Masese, Bulgin, Douglas, Shah, and Tanabe [7]. According to the researchers, other barriers included poor communication among providers, a high volume of patients in institutions of care, and lack of SCD care protocols. Cecilio, Pereira, Pinto, and Torres [8] found that the barriers to SCD care involved individual behaviors and emotions along with environmental factor such as stigma, bias, and knowledge of care factors. Lack of proper information sharing between clinicians and patients adversely impairs the management of SCD. Also, patients' perceptions of pain management impair the treatment of the disease.

In most cases, clinicians fail to properly acknowledge the pain of their patients due to inadequate monitoring systems. At the same time, frequent and unsuccessful visits to hospitals for repeated issues adversely affect the attitudes of patients towards available treatment options. People with SCD are subjected to the stigma of the disease in the community. Hence, many of these people do not seek medical attention as required. In some cases, clinicians exhibit racial bias in their service delivery, meaning that those from minority or poor backgrounds fail to get the best care. The cost of medical care in the United States is another high-ranking barrier to SCD management. Low-income earners are often unable to effectively receive desired medical attention or interventions. Those in rural areas are adversely affected due to the scarcity of resources and the high costs involved in moving to larger, urban areas.

Possible Solutions

Common barriers to the treatment of SCD can be resolved through the implementation of technology. As the country advocates towards universal health coverage, the focus on cost efficiency and access to low-income earners can be facilitated through smartphone technology. Today, the U.S. has a high percentage of smartphone consumers, with over 200 million users [9]. With such a high number of smartphone users, the U.S. can effectively implement the use of technology in the healthcare system. Through smartphone technology, the country can lower the number of visits to healthcare institutions, enhance clinician-patient interaction, facilitate collection of information on SCD, lower stigmatization and bias, and reduce the cost of care. According to Watkins, Goudge, Gómez-Olivé, and Griffiths [10], mobile phone use in healthcare provides solutions to enhance access to healthcare information and service delivery. The benefit of using technology is more profound in middle and low-income regions in the country, as the majority of the people in these areas are limited by cost factors. Mobile health (M-health) solutions ensure that SCD treatments are tailored to meet the needs and preferences of the patients involved. Also, the technology enables clinicians to track and monitor their patients to ensure that they comply with treatment requirements. Besides, smartphone technologies facilitate the sensitization of a large number of patients in real time. Education is a major dynamic in the empowerment of the masses.

Technology in Healthcare

In recent years, the implementation of technology in healthcare has gained momentum. Many researchers have explored how technology

will remodel healthcare in society. According to Vatandoost and Litkouhi [11], technology will change the traditional healthcare space. The researchers outline such technologies as artificial intelligence, the internet, and development in 3D-printing and robotics as the technologies that will shape the future service delivery of hospitals. Largely, the changes in healthcare are due to transformations in technology. Today, patients can get better improved and reliable diagnosis due to improved technology as compared to the past decade. According to the Mayo Clinic (2020), sickle cell can be diagnosed in unborn babies by sampling amniotic fluid as well as a routine newborn screening. Automation of medical processes has improved efficiency and reliability in healthcare facilities. Meetoo, Rylance, and Abuhaimid [12] argue that mobile health systems are vital in addressing rising cases of chronic illnesses and increasing patient-centered treatment. According to the researchers, powerful mobile computers provide a superior approach to monitoring, tracking, and transmitting health-related information in real time. Thus, technology has the potential of redefining acute illnesses in society and moving the management of such diseases away from hospitals to long term care at home.

Various benefits are associated with the use of technology in healthcare management. According to Alotaibi and Federico [13], patient safety is a sub-set of healthcare and a factor that is significantly improved through the implementation of technology. According to the authors, the use of technology significantly lowers the occurrence of medical reporting errors and aids in improving patient safety. The use of clinical decision support systems provides a real time approach to monitoring and tracking patient treatment. Also, with the use of such tools as alerts and reminders, clinicians can respond in real time to assist patients and deal with emergencies. The significance of technology is also appreciated by Wamble, Ciarametaro, and Dubois [14]. According to these researchers, using technology has enhanced the quality of care and life in the most vulnerable communities in the country. Therefore, technology adds value to healthcare and explains why it is vital to implement smartphone technologies in SCD management.

Smartphone Technology

The popularity of smartphones is inevitable as there are over 2 billion users in the world [15]. Smartphones are a class of portable mobile phones with multi-purpose computing power. They are mainly differentiated by their hardware capabilities and enhanced operating systems. These features enable smartphones to provide more extensive software, internet, and multimedia functionalities. In addition to the core functions of phones, smartphones support voice calls, text messaging, and the use of standard applications available on the internet. Like standalone computers, smartphones support an array of systems that enhance user experiences. Smartphone users can browse the internet, track the activities of their businesses, listen to music, watch videos, and use such applications as teleconferencing and telemedicine and e-learning systems. Hence, smartphones provide an integrated, reliable, and user-friendly approach to enhancing the lives of users. On this premise, there is a justification for the use of smartphone technology in augmenting healthcare delivery, particularly when it comes to SCD.

Today, the number of global smartphone users has surpassed three billion and is expected to grow significantly in the future [16]. According to O'Dea [16], in the last five years, approximately 1.4 billion smartphones were sold. Also, the researcher depicts that the penetration rate of smartphones is expected to grow significantly in the future as they become more affordable and relevant in society. According to O'Dea [9], the number of smartphone users in the U.S. in 2020 is estimated to reach 275.66 million. The high penetration rate of smartphones in the U.S. is hastened by the increased connectivity and availability of technology to support smartphones. At the same time, the country has a high population of middle and high-income earners, making it possible for most to own smartphones. The high penetration of these portable devices increases the ability of the country

to leverage the technology associated with smartphones to enhance service delivery in the healthcare industry.

Role of Smartphone Technology in Healthcare

Internet use is becoming a universal behavior. The internet offers immense benefits to the users, especially when it comes to information search. According to Rajurkar and Shirsagar (2017), the use of mobile phones to access the internet is a routine behavior for many consumers. By using smartphones, consumers can access educational materials on various subjects, including health. In their study, Dehnen-Schmutz, Foster, Owen, and Persello [17] argue that laypeople can use smartphones to enhance scientific studies. From a healthcare perspective, patients can facilitate the collection and analysis of data related to their illness. In so doing, they facilitate the development of medical solutions to common societal health problems. JafarzadehKenarsari and Pourghane [18] argue that smartphones are associated with an 'easy life.' Routine use of smartphones can conveniently enhance data collection, the reporting of health symptoms, and the access and sharing of other relevant health information.

Smartphones facilitate communication between users. Singh and Samah [19] explore the impact of smartphones in society. According to the researchers, most of the benefits linked to smartphones are associated with the communication they provide. Through smartphones, present generations can socialize virtually. Social chatting applications have made it easier for people to interact with friends and family. One of the implications of virtual social interaction is the sharing of health and wellness information.

Smartphone Technology in the Management of Sickle Cell Disease

Smartphone technology has the potential to enhance the treatment of patients with SCD. Using technology, policymakers and clinicians can decrease health disparities for underprivileged patients living with SCD. According to Manring [20], in 2016, approximately 165,000 health applications were downloaded more than a billion times. The high traffic is linked to the increased awareness of the benefits of technology in enhancing healthcare service delivery. As compared to the traditional healthcare system, a digitized approach allows more continuous measurements of symptoms away from the hospital. The use of modern features such as microphones and cameras embedded in smartphones enable frequent interaction between clinicians and patients. Hence, these technologies limit the need for frequent visits to hospitals for consultations. They also play a vital role in the reduction of the cost of care, professional bias, and community stigmatization.

The adoption of technology in healthcare will bring about reforms for patients dealing with chronic illnesses. Despite the potential and popularity of these technologies, the majority of the applications lack evidence-based research, or the available evidence is inconsistent [20,10]. Nevertheless, from a patient perspective, mobile technology offers phenomenal opportunities to transform the management of SCD. Evidence shows that m-health enhances medical service delivery and advances healthcare systems [10, 21, 22]. The benefits of m-health are primarily linked to patient and clinician interactions, information sharing, diagnosis, symptom measurement, cost reduction, compliance, efficacy, and providing real time services. These benefits may vary from one patient to another based on their location, needs, income, culture, or condition. The overall objective is to address the specific needs of the patients – for this study, patients with SCD.

Analysis of Patterns and Trends: Pain Management

Alapan et al. [14] argue that early diagnosis of SCD remains a challenge due to the high cost and lack of skilled personnel. The researchers note that if the disease is to be controlled, there is a need to devise systems to diagnose and monitor the disease early

enough –especially in children. Thus, the use of technologies for SCD screening and monitoring is advised. Vaso-occlusive pain is one of the primary complications of SCD and ranks high as the common cause for most hospital visits [23]. Therefore, it is integral to address pain management as a segment in the comprehensive care plan; pain is not universal and varies from one patient to another. Successful pain management interventions should focus holistically on social and multicultural factors. These interventions can be best supported though the thoughtful integration of technology such as smartphones. At the same time, clinicians need recognize and have an awareness of their personal interactions and biases toward patients with SCD.

Researchers argue that while emergency departments (EDs) are crucial in the provision of patient care, their overutilization and over reliance should be avoided [24]. The consequences of being over-dependent on EDs include poor coordination of care and inadequate provision of preventive care. The assertions on the utilization of EDs by Maeng [24] show that smartphone technologies offer a superior and sustainable way of pain analysis and treatment in patients with SCD. Watkins et al. [10] found that more than half of their participants used technology to manage their chronic illnesses. According to the researchers, patients set reminders, alarms, and solicit support from friends and relatives to take medications. The use of m-health applications helps patients maintain diaries on pain and report this valuable information to their health providers. The information facilitates the development of tailored and responsive care plans and interventions.

Patient Education and Empowerment

Morilla et al. [21] depict that technology has transformed the way healthcare organizations operate. According to the researchers, increased cases of chronic illnesses, a larger aging population, and funding limitations have led to the adoption of technology in healthcare institutions. The purpose of technology in medical care is to improve the quality of services offered and to enhance equity in the industry. The collection, analysis, and dissemination of health data collected using smartphone applications expedite accurate and responsive decision making. From a patient perspective, sharing information via smartphones improves skills and knowledge in disease management. Evidence suggests that people with chronic illnesses who demonstrate self-management capabilities have better health and quality of life [25]. VanDusen [26] asserts that communication is fundamental in a healthcare setting and can aid nurses in the delivery of efficient and safe outcomes. Through technology, nurses can simultaneously communicate in real time with patients and care team members. Nurses can also use technological tools to educate and inform patients on their medical conditions.

M-health solutions have superior diagnostic abilities as compared to traditional models of care [22]. Hence, when dealing with SCD, patients are adequately informed of their conditions and the best way to prevent adverse symptoms. Most importantly, connections with friends, relatives, and other patients with similar conditions facilitate the healing process as people get to share experiences. The collaboration between the patients and their families or friends is what makes smartphone technologies integral empowerment tools.

Vearrier, Rosenberger, and Weber [27] explain that accuracy and efficiency of communications have improved due to smartphone use. Healthcare providers can communicate with patients using short text messages or notifications. The use of videos facilitates the interaction between patients and clinicians. Palermo et al. [28] found that smartphone iCan Cope applications addressed a vital service gap by delivering pain self-management therapy and providing access to engaging health services for youths. The use of technology also supports a patient-centered treatment model that will enable a successful transition from pediatric to adulthood healthcare for youths with SCD.

Treatment Compliance

A common problem associated with the management of chronic illnesses is a failure to comply with recommended guidelines – medications, hospital visits, and healthy behaviors. While in some cases, failure to comply is intentional, other times it is instinctive. Alberts et al. [29] explored the barriers to hydroxyurea adherence and found that forgetfulness, thoughts, and emotions played a role in the use of the treatment option. The facilitation of compliance with treatment requires the use of technology. Alberts et al. [29] recommend the use of a health application as an intervention to optimize medication adherence.

Watkins et al. [10] found that smartphone applications with such features as reminders, alerts, and alarms played a crucial role in

enhancing the quality of care in patients with SCD. In a study involving children exposed to a mobile application, it was found that the use of a mobile application provided an effective intervention for some of the children with SCD. The application increased engagement and reduced attrition [30]. Overall, there is a consensus that smartphone technologies offer reliable and practical approaches to tracking the behavior of patients and ensuring adherence to treatment guidelines.

Given the significance of smartphone applications in SCD management in young adults and adolescents, a new mobile application with unique features is recommended. The application considers the behavior and practices of the target patients, as illustrated in table 1 below.

Feature	Justification/Outcome
Rating Pain (Location, Intensity, Duration)	Track and monitor the pain of the patients and increase treatment options to enhance the quality of life and health outcomes.
Entertainment (Music, Videos, Images)	Provide alternative treatment options – nonpharmacological interventions
Data Sharing	Record and transfer data in real time to enhance decision making
Track and Monitor Triggers	Get early notifications for the emergence of serious issues that need urgent interventions
Social Links	Connect with friends, family, and other stakeholders
Resources	Provide educational materials on health
Groups	Link patients to other patients to share experiences
Goals/Objectives	Provide a medium for patients to set goals or objectives to accomplish desired treatment outcomes
Provide/Ask for Solutions	Provide a practical approach to share and engage with clinicians

Table 1: Recommended smartphone application features

The features depicted in Table 1 above are unique to the needs of adolescents and youths. A review of existing studies on the subject showed that there were no existent SCD applications with these comprehensive features. Thus, the implementation of an app with such features provides a customized way of involving adolescents and youths in the management of SCD.

Future Implications

The use of technology is inevitable in the healthcare industry. Thus, in the future, more operations in healthcare settings will be digitized. Technological tools provide an enhanced approach to dealing with chronic illnesses. In patients with SCD, smartphone technologies facilitate the customization of medical care interventions. Also, they offer real time communication between patients and clinicians. Although the value of smartphone technologies in dealing with SCD is appreciated, there are few studies on its efficacy and relevance in youths and adolescents. At the same time, investigations on the best

implementation models remain scarce. Researchers need to explore the best strategies for implementing SCD smartphone applications in diverse, multicultural contexts with priority given to age, income, ethnicity, culture, and location.

Conclusion

Patient-centered treatment models are gaining more popularity in society. Also, the use of evidence-based practices is replacing traditional healthcare interventions. Thus, the role of smartphone technologies in the management of chronic illnesses is immensely pursued as a better alternative in providing relevant, affordable, and customized care to patients. The management of SCD requires constant monitoring and information sharing in real time. These are benefits associated with the use of smartphone technologies. Through such applications, it is possible to track and monitor pain, empower patients, and enhance adherence to treatment options. Generally, smartphone technologies are integral in the improvement of health

outcomes of people with SCD as patients become actively involved in their treatment.

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Appendix

Author/Year/Condition	Intervention Purpose	Intervention Description
Palermo et al. (2018); Sickle cell disease	Pain self-management	<ul style="list-style-type: none"> • Patients use the ICanCope application. • Record and track their pain due to SCD • Set reminders and alerts to get medications.
Creary et al. (2019); Sickle cell disease	Hydroxyurea adherence	<ul style="list-style-type: none"> • Medication reminders through smartphone technology • Track medication patterns by setting reminders and alerts
Alberts et al. (2020); Sickle cell disease	Hydroxyurea adherence	<ul style="list-style-type: none"> • Patients use the InCharge health app to track their medication patterns. • Set reminders to get alerts on when to take medications

Appendix 1: Literature review