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Evaluation of Pairing Mobile Health with Simulation Technology to Assist Sickle Cell Caregivers

Original Research

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Abstract

Introduction: Sickle Cell disease (SCD) affects approximately 100,00 Americans and occurs in about one in every 365 black or African American births. SCD caregivers could utilize health technology such as mHealth to assist them with appointment reminders, medication management, education, and pain management as it relates to better managing this disease process.

Methods: A mixed-methods approach was utilized to explore the perceived influential factors that impact the caregivers' ability to care for the children with SCD and utilize mHealth and simulation. A 33-question survey was administered which included questions on: demographics, SCD, mHealth and simulation, General Self-Efficacy, Adult Hope, and four opened-ended questions.

Results: In total, 36 SCD caregivers completed the survey and three of them provided an additional interview. Sixty nine percent of the caregivers were mothers (n = 25) of the children with SCD and all the caregivers were African American. Self-Efficacy (p=.568) and Adult Hope scores (p=.762) were not a predictor for willingness to use mHealth or simulation.

Conclusions: SCD caregivers are using some forms of technology to help them however an all-inclusive (one-stop location) mHealth app along with simulation training would allow these caregivers to better manage their patient's/loved ones SCD.

Key Words: mHealth, digital health, children.

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Introduction

Sickle cell disease (SCD) refers to a group of hemoglobinopathies that include mutations in the gene encoding of the beta subunit of hemoglobin[1]. Its' pathophysiology involves a single amino acid substitution of valine for glutamic acid on the sixth position of the β-globin chain[2]. According to the Centers for Disease Control and Prevention (2021), SCD affects approximately 100,000 Americans, and occurs in about one in every 365 black or African American births. Patients with sickle cell anemia (SCA) experience a vaso-occlusive crisis at some point in their lives and presenting as early as 6 months of age[1]. In addition, other complications that include acute chest syndrome, hepatic or splenic sequestration crisis, acute stroke, aplastic crisis, acute intrahepatic cholestasis, infections, priapism in males, acute ocular complications such as hyphema and central artery occlusion, iron overload, avascular necrosis of joints, pulmonary artery hypertension, and renal complications including infarction. Prevention of complications and management of

SCD and SSA through primary and secondary prevention strategies is an integral component to improve patient outcomes, decrease morbidity and mortality, and improve quality of life. Preventive efforts should begin with the patient and caregiver in order to promote a healthy, self-determined life.

Sickle Cell Caregivers

Optimal control of SCD and related complications in children is improved when caregivers have appropriate knowledge of factors leading to complications and effective home-based preventative interventions[3]. In the medical and nursing management of pediatric and young adults (PYA) with SCD, caregivers are encouraged to learn as much as possible about the disease, including how to avoid triggers of pain crisis, encouragement to join support groups, and helping the PYA to manage and control their disease.

Previous research has shown that mobile health (mHealth) applications have been co-designed by adolescents to promote accessibility to disease knowledge and self-management skills as a component of transition services[4]. However, few web-based and mHealth applications have been co-designed by the family SCD caregiver. SCD caregivers need to be included in the design process for mHealth apps and other digital health tools as it relates to their caregiving status for children with Sickle Cell disease. Additionally, research on the feasibility, accessibility, and acceptability of digital health informatics and simulation mobile applications by the family SCD caregivers is sparse[4–6]. The primary purpose of this study was to explore the perceived influential factors that affect the family SCD caregivers' ability to care for children with SCD. The secondary purpose was to evaluate the feasibility, accessibility, and acceptability of a digital health informatics stimulation mHealth applications by the family SCD caregivers. By knowing and understanding the perceived influential factors of the family SCD caregivers' ability to care for children with SCD, tools such as web-based and digital health informatics stimulation mHealth applications could be developed that would alleviate geographical constraints, promote autonomy, and provide readily accessible educational tools and platforms[6]. Additionally, such tools could also be used to promote the engagement of the family SCD caregiver in the acquisition of disease knowledge, self-management strategies, and transition skills by the child with SCD necessary to navigate the adult healthcare system[4,6]. These tools could promote a family SCD caregiver and PYA with SCD centered culture in partnership with the HCP to facilitate the delivery of health informatics and interventions in the home[6]. Knowledge from this research could provide insight into the feasibility, accessibility, and acceptability of a web-based and digital health informatics stimulation mobile application culturally in the home by the family SCD caregivers in the care of children with SCD for the delivery of health informatics, disease knowledge, and symptoms management strategies.

Mobile Health and Simulation

The permeation of smartphone and electronic tablet utilization has enabled consumers to access more readily available healthcare information through mHealth apps[7,8]. These mHealth apps predominately target the direct consumer (i.e., patient) however there are opportunities to engage caregivers through mHealth apps. Previous research indicates that SCD caregivers would like the opportunity to utilize health technology such as mHealth to assist them with appointment reminders, medication management, education, and pain management[9,10]. Developing mHealth apps targeted for caregivers allows for a variety of targeted outcomes such as: improving the wellbeing of the individual with SC, preparing children for transition to adolescent SC care, improving the knowledge of the caregiver, reducing the stress upon the caregiver, and allowing for adaptive/tailored information based on the caregiver's perceived health literacy level[11,12].

Research demonstrates that modalities that increase the caregiver's level of knowledge to improve adherence to best practices, positively affect SCD management and decrease associated complications[3]. Limitations to these programs include that they are face-to-face for an extended period of time and are mainly verbal educational sessions[13]. Simulation and virtual reality training has been utilized in other disease/conditions processes for caregivers such as: children with tracheostomies and seizure management[14]. The research on these studies indicates improved caregiver confidence, improved post-simulation performance and improved post-simulation self-efficacy scores[14].

Simulation has been demonstrated to enhance caregiver knowledge and skills to manage the disease process[15]. Simulation exercises help with both caregiver confidence and critical thinking. Utilizing active learning, simulation can range from beginner to advanced care concepts, and caregivers may also use the simulation exercises to better prepare for emergency situations.

Scientific Methods

The purpose of this study was to evaluate the potential of utilizing mHealth and simulation for caregivers of children and adolescents who have SCD. The researchers hope by further understanding the needs and barriers to mHealth and simulation utilization by SCD caregivers that it can lead to the pairing of the two technologies to improve the health management SCD caregivers provide and to improve the overall health of the caregiver as well (i.e. stress, coping, self-management).

This mixed-methods approach was utilized explore the perceived influential factors that impact the caregivers' ability to care for the PYA with SCD and utilize mHealth and simulation. A 33-question survey was administered which included demographic questions, Sickle Cell questions, mHealth and simulation questions, validated General Self-Efficacy[16] and Adult Hope Scale[17] questions and four opened-ended questions. The General Self-Efficacy Scale consisted of ten questions using a 4-point Likert scale ranging from not at all true to exactly true. Participants answered questions about their overall self-efficacy such as: "I can always manage to solve difficult problems if I try hard enough" and "I can solve most problems if I invest the necessary effort". The Adult Hope Scale consisted of eight questions utilizing a 7-point Likert scale ranging from definitely false to mostly true. Participants answered questions about their overall hope such as: "I can think of many ways to get out of a jam" and "I can think of many ways to get the things in life that are important to me."

Participants

After Institutional Review Board (IRB) approval was obtained, this study was conducted at a comprehensive sickle cell center (CSCC) and Sickle Cell Disease Association of America, community based-organization (SCDAA-CBO). The CSCC is the primary care site for both adult and pediatric individuals with SCD who reside in the coastal and southern regions of Alabama and the panhandle of Mississippi and Florida. As such, the CSCC provides consultation services for the diagnosis, management, and treatment of approximately 175 children and 235 adults with SCD. The SCDA-CBO provides sickle cell trait counseling for individuals with sickle cell trait and psychosocial support services for individuals with SCD in partnership with the CSCC.

All individuals of legal age that act as caregivers for PYAs age 1 - 18 years with SCD (n = 175) were targeted, screened, and recruited as potential study participants. In total, thirty-six (n = 36) SCD caregivers were successfully recruited and consented to participate in this study. Thirty-six SCD caregivers completed the survey and three of the consented caregivers provided interviews. The mean age of the study population was 39.8 (SD = 10.13) with a gender differential of 78% (n = 28) female and 22% (n = 8) male. In addition, 93% of the SCD caregivers stated they owned a smartphone and 96% of the SCD caregivers stated they had access to Wi-Fi daily.

Protocol

The process for informed consent included at least one parent or caregivers of the PYA age 1-19 years. The informed consent process involved full written and verbal disclosure to each potential study participant with a detailed description of the research purpose, procedures, risks, potential benefits, and selection process. The process of informed consent was conducted by two trained research assistants to address the potential for undue coercion. The criteria for inclusion consisted of family SCD caregivers defined as mother, father, maternal or fraternal grandparent, auntie, uncle, or legal guardian of the PYA with SCD age 1-19 years who had the ability to read and complete a self-report survey independently or surrogate assistance and could speak English. Data collection occurred between June 1 and December 31, 2019 at the end of a routine pediatric outpatient sickle cell clinic visit and annual Christmas party held at the SCDA-CBO using a valid semi-structured interview tool with demographics and open-ended questions.

Statistical Analysis

A descriptive analysis of the survey results was conducted on the 36 participants who completed the survey. In addition, a theme analysis was conducted on the four open-ended questions that focused on their needs as caregivers in relation to mHealth and simulation. A two-tailed independent samples t-test was conducted to examine whether the mean of the General Self-Efficacy (GSE) score was significantly different between the yes and no categories of the participants' willingness to use mHealth and simulation to better handle sickle cell patients need. Also, a Welch's t-test was conducted to examine whether the mean of the General Self-Efficacy (GSE) score was significantly different between individuals who have been caregivers of patients with SCD for ≤ five years and ≥ five years. The differentiation between ≤ five years and ≥ five years as a caregiver was utilized to classify "new SCD" caregivers vs. more experienced SCD caregivers. The initial data collection on years as a SCD caregiver was captured in the following categories however there were not enough responses per category for analysis: 1 – 2 years, 3 -5 years, 6 -8 years, 9 – 10 years,

more than 10 years and rather not state. In addition, two two-tailed independent samples t-tests were conducted to examine whether the mean of the Adult Hope Scale (AH) score was significantly different between the yes and no categories of the participants' willingness to use mHealth and simulation to better handle sickle cell patients need and whether the mean of the Adult Hope Scale (AH) score was significantly different between individuals who have been caregivers of patients with SCD for ≤ five years and ≥ five years.

Results

In total, 36 SCD caregivers completed the survey and three of them provided an additional interview. Most caregivers were mothers (n = 25) of the children with SCD and all the caregivers were African American. Thirteen (36%) of the caregivers had an annual income of less than $20,000 and 61% (n = 22) of the caregivers stated they were employed (Table 1).

Table 1. Participant Demographic Data

Category	Classification	Participant Results (n=36)
Gender	Female	28
	Male	8
Age	20 - 29	5
	30 - 39	11
	40 - 49	9
	50 - 59	5
	Rather Not State	6
Ethnicity	African American	36
Relation to SCD patient	Aunt	2
	Grandparent	4
	Father	5
	Mother	25
Timeframe as a SCD Caregiver	1 - 2 Years	7
	3 - 5 Years	8
	6 - 8 Years	6
	9 - 10 Years	1
	More than 10 Years	10
	Rather Not State	4
Are you Currently Employed	Yes	22
	No	12
	Rather Not State	2
Education	High School Graduate	18
	Some College	10
	Associate's Degree	1
	Bachelor's Degree	3
	Master's Degree	0
	Doctoral Degree	0
	Rather Not State	3
Annual Household Income	Under $20,000	13
	$20,000 - $29,000	7
	$30,000 - $39,000	2
	$40,000 - $49,000	1
	$50,000 - $59,000	1

	≥ $60,000	1
	Rather Not State	11
Living in the Household	1 Person	2
	2 People	10
	3 People	13
	4 People	7
	≥ 5 People	4
Own a Smartphone	Yes	25
	No	2

Additional survey questions show that the participants are actively engaged in using their digital devices to help manage their patients/loved ones manage Sickle Cell (See Table 2).

Table 2. Survey Questions on the Utilization of Digital Technology for Sickle Cell Management

Questions	**Answer Types**	**Response Rates**
Q. 17 Do you own a smartphone?	Yes/No	Yes 25 No 2
Q. 18 Do you own an electronic tablet or computer?	Yes/No	Yes 19 No 10
Q. 19 Do you have access to Wi-Fi daily?	Yes/No	Yes 29 No 1
Q. 20 Do you use your smartphone to obtain medical information about Sickle Cell?	Yes/No	Yes 20 No 9
Q. 21 Do you use your smartphone to download apps about Sickle Cell?	Yes/No	Yes 13 No 17
Q. 23 Do you use your smartphone as a reminder for the patient's medical appointments?	Yes/No	Yes 25 No 4
Q. 28 Would it be helpful for you to receive text messages/alerts to help keep the patient on track with eating, staying hydrated, or any other health habits?	Yes/No	Yes 30 No 1
Q. 29 How many notifications would you like to receive per day about Sickle Cell disease management?	Free text number	Mean notifications per day = 2.16 (SD=1.23)

The result of the two-tailed independent samples t-test was not significant based on an alpha value of .05, $t(22) = -0.58$, $p = .568$, indicating the null hypothesis cannot be rejected. This finding suggests the mean of GSE score was not significantly different between the No and Yes responses of Willingness to use simulation and mHealth. The results are presented in Table 3.

Table 3. Two-Tailed Independent Samples t-Test for GSE Score by Willingness to use Simulation and mHealth

	No		Yes				
Variable	*M*	*SD*	*M*	*SD*	*t*	*p*	*d*
GSE Score	50.50	10.91	53.25	8.25	-0.58	.568	0.28

Note. N = 24. Degrees of Freedom for the *t*-statistic = 22. *D* represents Cohen's *d*.

Welch's t-test was used instead of Student's t-test, which is more reliable when the two samples have unequal variances and unequal sample sizes[18]. The result of the two-tailed independent samples t-test was not significant based on an alpha value of .05, t(17.97) = 1.37, p = .187, indicating the null hypothesis cannot be rejected. This finding suggests the mean of GSE score was not significantly different between the length of caregiver experience (≤ five years and ≥ five years). The results are presented in Table 4.

Table 4. Two-Tailed Independent Samples t-Test for GSE Score by Length of Caregiver Experience

	≤ Five Years		≥ Five Years				
Variable	M	SD	M	SD	t	p	d
GSE Score	55.25	2.38	51.56	10.21	1.37	.187	0.50

Note. N = 24. Degrees of Freedom for the t-statistic = 17.97. d represents Cohen's d.

The result of the two-tailed independent samples t-test was not significant based on an alpha value of .05, t(23) = 0.31, p = .762, indicating the null hypothesis cannot be rejected. This finding suggests the mean of the AH score was not significantly different between the No and Yes responses of the Willingness to use simulation and mHealth. The results are presented in Table 5.

Table 5. Two-Tailed Independent Samples t-Test for AH Score by Willingness to use Simulation and mHealth

	No		Yes				
Variable	M	SD	M	SD	t	p	d
AS Score	34.00	3.16	33.43	3.46	0.31	.762	0.17

Note. N = 25. Degrees of Freedom for the t-statistic = 23. D represents Cohen's d.

The result of the two-tailed independent samples t-test was not significant based on an alpha value of .05, t(23) = 1.00, p = .327, indicating the null hypothesis cannot be rejected. This finding suggests the mean of AH Score was not significantly different between the length of caregiver experience (≤ five years and ≥ five years). The results are presented in Table 6.

Table 6. Two-Tailed Independent Samples t-Test for AH Score by Length of Caregiver Experience

	≤ Five Years		≥ Five Years				
Variable	M	SD	M	SD	t	p	d
AH Score	34.50	3.55	33.06	3.27	1.00	.327	0.42

Note. N = 25. Degrees of Freedom for the t-statistic = 23. D represents Cohen's d.

In addition, the participants were asked four open-ended questions in an attempt to better understand the management of SCD and how it can be improved by the utilization of mHealth. Below are the four open-ended questions that were asked to the participants in the survey.

Table 7. Open-ended Survey Questions

Questions	Answer Options
Q. 30 Out of the following three Sickle Cell disease-management components, which is the hardest to accomplish and maintain:	-taking an active role in managing the patient's care -keeping record of the patient's vaccination and immunization status -medication treatment adherence -All of the above -Other : _____
Q. 31 What suggestions do you have regarding a mobile health (mhealth) app specifically for sickle cell caregivers?	Free text
Q. 32 What would you like the mobile health (mHealth) app to do to help you care for the sickle cell patient?	Free text
Q. 33 Tell me about a recent experience you've had caring for an individual with sickle cell disease.	Free text

In total, 21 participants answered question 30 in the above table with the responses ranging from: all of the above (8), keep record of the patient's vaccination and immunization status (7), medication treatment adherence (2), taking an active role in the managing the patient's care (2), and seeing her in pain which was in other (1). Eleven participants answered question 31 with the themed results being: simplicity/ease of use (4), medication management (2), learning more about Sickle Cell (2), manage record/lab results (1), support group (1), and make medical appointments (1). Eighteen participants answered question 32 with the themed results showing: track medications/reminders (8), SCD information/updates (5), managing daily life (3), Sickle Cell pain and crisis (1), and home remedies (1). Finally, eighteen participants answered question 33 with the theme results being: Sickle Cell crisis (6), hospital visit (4), pain (2), everyday living (3), platelets dropping (2), taking daily medications.

Discussion

The study population consisted of 36 caregivers all of which reported their ethnicity as African American. One of the common concerns with the implementation of digital health tools such as mHealth is the availability of smart phones and access to Wi-Fi within the study population. The survey results indicated that 93% of the study population owned a smart phone, and 96% answered yes to having access to Wi-Fi. Sixty-nine percent of the participants stated that they are using their smartphones to obtain medical information about SCD however only 43% of the participants stated that they have downloaded apps on their devices about SCD. Participants who answered "yes" to using their smartphone to obtain medical information were asked a follow-up question (How do you use your smartphone to obtain medical information), and 5 participants responded, four stating they used a Google search, and one stating a Sickle Cell app. This information suggests that the participants are using the smartphone as a "traditional computer" and not as a portable digital device with mHealth capabilities that can be leveraged for real-time information, support and decision-making assistance. This is further evidenced by the fact that 97% of the participants indicated they would find it helpful to receive text messages/alerts to help keep their patients/loved ones on track with eating, staying hydrated, or any other health habits. In addition, 86% percent of the participants stated that they use their smartphone as a reminder for patient medical appointments.

Two-tailed independent samples t-tests were conducted to determine whether there was statistical evidence that there was a significant variation between the means associated with general self-efficacy scale score, adult hope scale score and willingness to use simulation and mHealth. In addition, two additional two-tailed independent samples t-test were conducted to determine whether there was statistical evidence that there was a significant variation between the means associated with general self-efficacy scale score, adult hope scale score and length of caregiver experience. The analysis showed that willingness to use simulation and mHealth was not influenced by general self-efficacy or adult hope and that the length of caregiver experience was not influenced by the participants self-efficacy and adult hope scores.

Further evaluation showed that individuals who have been a SCD Caregiver for ≤ five years had a GSE mean of 55.25 (SD=2.38) whereas those who have been a SCD Caregiver for greater than 5 years had a GSE mean of 51.56

(SD=10.21). This is an interesting finding as the literature supports those caregivers who experience failure in the health system have trust issues moving forward[19]. Experiencing these negative outcomes could be a reason why SCD caregivers with greater than five years' experience in this capacity have a lower self-efficacy score than newer SCD caregivers. This is a unique finding as one would typically see a higher SE score when an individual continuously does the same type of activity or experiences the same type of event.

Conclusions

SCD caregivers want to utilize mHealth and simulation to help facilitate the overall management of the disease process. In particular, the participants of this study want to leverage mHealth technology for tracking medication usage and setting up reminder messages. Including SCD caregivers in a co-design process would allow for the creation of tailored components related to SCD management from a caregiver perspective. In addition, the participants stated they would like the mHealth app to deliver SCD information and help them manage their daily life. There is a heavy emotional burden that these caregivers face on a day-to-day basis as they have to visualize the pain and sacrifices their loved one is experiencing (all of the caregivers in this study were relatives of individual they were caring for which is consistent nationally). Finally, the participants stressed that the mHealth app should be simple to navigate and easy to use. These comments are commonly suggested by caregivers when discussing what they would like a mHealth app to do to help them manage the patient or loved one's chronic disease. It is clear that SCD caregivers are using some form of technology to help them however an all-inclusive (one-stop location) mHealth along with simulation training would allow these caregivers to better manage their patient's/loved ones SCD.

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