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ORIGINAL RESEARCH

A Multidimensional Digital Approach to Pain Assessment in Sickle Cell Disease: A Feasibility Study in Ghana

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Purpose: Pain is the most common symptom in sickle cell disease (SCD). Due to a lack of objective markers, pain assessment relies on patient report, which can be highly subjective and lead to miscommunications regarding care. While digital pain tools show promise for improving pain communication, digital literacy barriers and cultural differences may limit their use, particularly in low-resource settings. There is a lack of data on the effectiveness of digital pain tools in sub-Saharan Africa, the region with the highest burden of SCD. Painimation is a digital application that uses animations and graphical images to assess pain location, quality, and intensity. We evaluated its feasibility, acceptability, and utility in a Ghanaian SCD cohort.

Patients and Methods: This cross-sectional study was conducted at Korle-Bu Teaching Hospital in Ghana. Individuals age >10 years with SCD were recruited from the pediatric and adult SCD clinics. Participants were asked to use Painimation and complete a clinical history and an 11-item questionnaire addressing the feasibility, utility, and acceptability of the app.

Results: Of the 38 consented patients (66% female, median age: 16 years), 87% reported being comfortable using the touchscreen, and 74% said the app was easy to use. Most participants (68%) reported the app was not burdensome to complete during a pain episode. Participants reported that the body shading (92%), animation selection (92%), and intensity adjustment (87%) features were useful for communicating pain. The app took 102 seconds to complete on average. The most commonly selected pain animation was throbbing (50%), and the most frequently reported pain locations were the legs (35%), back (42%), arms (35%), and chest (35%).

Conclusion: Painimation was feasible, acceptable, and useful for pain reporting in this Ghanaian SCD cohort. Pain reports using Painimation mirrored known SCD pain profiles, with predominant throbbing pain and frequent leg and back involvement. Digital health tools may improve pain assessment and management in low-resource settings in sub-Saharan Africa.

Keywords: pain assessment, pain tools, eHealth

Introduction

Sickle cell disease (SCD) is a genetic blood disorder that affects millions worldwide with the highest burden of SCD being in sub-Saharan Africa.[1] In Ghana, the prevalence of SCD is notably high, with approximately 2% of newborns affected by the disease.[2,3] Mutated hemoglobin lead to deformed red blood cells that block vessels, resulting in vaso-occlusive episodes (VOEs) that can cause debilitating pain and organ damage.[4] Years of VOEs and accumulated tissue damage lead to chronic pain which becomes more prevalent throughout the lifetime of patients with SCD.[5,6] Research has shown that chronic pain in SCD can stem from multiple mechanisms, including inflammation, degenerative changes,

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opioid-induced hyperalgesia, and neuropathic pain. Unlike for acute pain, identifying the underlying causes of chronic pain in SCD is challenging, which contributes to the complexity of pain management particularly in long-term care.[7–9]

Accurate pain assessment and identifying the pain etiology are critical for clinician-patient communication, treatment planning, and patient satisfaction. Because there are no objective markers to identify pain in SCD, pain assessment relies heavily on patient report. However, effectively communicating pain can be challenging, as pain is a multidimensional experience that varies widely between individuals. Patients are asked to describe the intensity, type, and location of their pain using adjectives and numerical ratings, which may not fully reflect or resonate with the full scope of their pain experience. Further, in SCD, feelings of stigma and mistrust can strain patient-provider relationships leading to breakdowns in communication.[10]

Cultural differences in how pain is experienced, understood, and expressed, can create barriers between patients and healthcare providers, complicating effective pain assessment and management.[11,12] A multinational clinical trial spanning Ghana, Kenya, the US, Canada, and Brazil identified significant geographic variation in reported pain intensity among individuals with SCD.[13] Specifically, participants in the Americas reported a 43% higher mean pain intensity than those in Africa.[13] Such regional variations in pain reporting despite similar disease pathology emphasize the necessity of investigating how cultural norms, environmental factors, and healthcare access collectively influence how pain is experienced, communicated, and managed across diverse populations. Given Africa's high SCD burden, it is important to explore pain reporting in this region to meet the need for culturally appropriate and evidence-based pain assessment tools that help provide a deeper understanding of how pain is experienced and expressed in diverse SCD populations.

Traditional pain assessment tools such as the 0–10 visual analog scale (VAS) and numerical rating scale (NRS) may not effectively capture the full complexity of pain in patients with SCD as they largely focus on intensity rating, a unidimensional measure of pain.[14,15] Or similarly, numerical rating scales are used to assess the impact of pain on daily functioning, a complex relationship that is challenging to describe with numbers.[16] Other tools attempt to capture the quality of the pain experience and differentiate pain types. However, these scales rely on word descriptors and adjectives that face challenges with language and literacy, and lack cross-cultural relevance.[17] Visual pain reporting tools have been found to be feasible, acceptable, and to perform well against written measures.[18]

To address barriers in pain assessment, we developed a patient-centered measure that allows patients to convey the quality, location, and severity of their pain in a more comprehensive and intuitive way.[19,20] Delivered via electronic tablet, the Painimation app, allows the individual to describe and visualize their pain using intensity adjustable animations and a paintable body map. This multidimensional approach addresses common barriers to pain assessment, including limited literacy, the challenge of describing pain verbally, and potentially, cross-cultural differences in the experience of pain. Preliminary data from studies in adults with chronic pain and adult and pediatric sickle cell populations in the US have shown Painimation to be feasible and acceptable in these settings, and valid for use in SCD. These findings demonstrate its potential as an adaptable digital health tool to enhance pain communication.[20–22]

Successful clinical adoption of patient-reported outcome tools like Painimation depends on factors such as time burden, perceived benefit, ease of use across age groups and varying levels of health and digital literacy.[23] While electronic health (eHealth) tools have been increasingly studied in low- and middle-income countries,[24] digital literacy remains a concern. Urban tertiary care centers in West Africa, such as Korle-Bu Teaching Hospital (KBTH) in Ghana, the country's largest comprehensive sickle cell center, offer an ideal environment for piloting these tools given their existing infrastructure and patient volume. The study assesses the feasibility, acceptability, and perceived utility of the eHealth app Painimation for assessing pain in patients with SCD at KBTH. The study tests the appropriateness of Painimation for further study and eventual clinical use among patients with pain from SCD. It will inform its clinical implementation in healthcare systems with varying levels of technological infrastructure.

Methods

Study Design

This study was a cross-sectional study assessing the feasibility, acceptability, burden, and perceived utility of Painimation in a Ghanaian SCD cohort.

Participants

Participants aged 10 years and older were recruited from the adult and pediatric sickle cell clinics at Korle-Bu Teaching Hospital. Participants who consented to the study completed the study activities during their normal clinic waiting time or after their pain had subsided if they presented with acute vaso-occlusive pain events, as determined by both clinician and patient report.

Procedures

Participants first completed a brief demographic and medical history questionnaire. Participants 17 years old and younger were allowed to ask their parent/guardian for help with this portion. As part of the questionnaire, participants were asked to describe their maximum pain in the past 24 hours. Patients who reported 0 out of 10 pain in the past 24 hours were asked to use Painimation to describe their most recent vaso-occlusive pain episode (VOE) or pain crisis, and to complete subsequent questions related to acceptability and perceived utility, following methods of a previous Painimation study.[22] At the end, participants were asked a series of 11 questions to evaluate the feasibility, acceptability, and perceived utility of Painimation, as shown in Figure 1. Questions were developed with consideration to the concepts of value and burden in other validated measures tools.[25] We designed our questions to focus on specific aspects of the Painimation app (eg, shading a body image, choosing an abstract animation) and unique challenges of patients with SCD (such as the ability to complete the tasks during a VOE) Answer choice for Question 1 was a dichotomous Yes/No. Response options for Questions 2–10 utilized a 5-point Likert scale with options: 0: Strongly Disagree, 1: Disagree, 2: Neutral, 3: Agree, and 4: Strongly Agree.

	Question	Responses				
		No			Yes	
1	I use a touchscreen electronic device (eg. tablet, smartphone) on a daily basis.	☐			☐	
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
2	I feel comfortable using a touchscreen electronic device (eg. tablet, smartphone).	☐	☐	☐	☐	☐
3	The length of Painimation would be reasonable for me to complete while in pain from a sickle cell pain crisis.	☐	☐	☐	☐	☐
4	Painimation would be too long to complete during a sickle cell pain crisis.	☐	☐	☐	☐	☐
5	The length of Painimation would be appropriate in a routine clinic visit.	☐	☐	☐	☐	☐
6	Shading the body image to describe my pain was too difficult.	☐	☐	☐	☐	☐
7	I think being able to show a health provider the Painimation body image I shaded would improve my communication with them.	☐	☐	☐	☐	☐
8	I was able to find an abstract animation that represented my pain well.	☐	☐	☐	☐	☐
9	Choosing an abstract animation to describe my pain was too difficult.	☐	☐	☐	☐	☐
10	I think being able to show a health provider the abstract animation(s) I chose would improve my communication with them.	☐	☐	☐	☐	☐
11	I think changing the intensity of image helped me to communicate my pain.	☐	☐	☐	☐	☐

Figure 1 Questionnaire items assessing feasibility, acceptability, and perceived utility of Painimation.

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Feasibility, Acceptability, and Utility Measures

Feasibility was assessed through metrics including app completion rate, time to complete the Painimation app, comfort with the touchscreen, and technical errors encountered. Acceptability was evaluated using participant ratings of ease of use, enjoyment, and perceived burden of completing the app during both routine visits and acute pain episodes. Utility was measured by participants' ability to find an animation that matched their pain, and whether features such as body shading, animation selection, and intensity scaling were perceived to improve pain communication with healthcare providers.

Instruments

Visual Analog Scale

The visual analog scale allows participants to rate their pain on a continuous line, from 0 (no pain) to 10 (maximum pain).[14,26] Patients were asked to describe their highest pain intensity in the past 24 hours.

Painimation

Painimation is a digital pain assessment app that allows patients to describe areas affected by pain using a paintable body image, followed by describing their pain quality and pain intensity, using abstract animations, or "painimations", (Figure 2).[20] The app includes three sequential screens: first, participants report whether they currently have pain using the visual analog scale described above; second, if they report pain >0, they are asked to "shade where you have pain" on the front and back of a 2D body image, which is scored by mapping the shading to predefined anatomical regions (eg, lower leg, upper chest) and calculating the percentage of pixels selected within each region as well as the total percent body area affected; finally, participants can choose up to three out of eight possible animations to describe their pain. These animations can then be adjusted in size, speed, and intensity using an adjustable sliding scale to better reflect the patient's experience. The animations were developed using a human-centered design process that included input from patients, clinicians, researchers, and design students. Within the app, these abstract animations are intentionally presented without labels to allow participants to interpret them based on their personal pain experience. However, for clarity in reporting our findings, we have assigned descriptive labels to each animation based on their intended representation: "pounding", "shooting", "cramping", "throbbing", "tingling", "burning", "electrifying", and "stabbing". The psychometric properties and design of the application are described elsewhere.[19,27] Figure 1 of Jonassaint et al 2018 provides additional screenshots of the app display[20] The app was administered on a tablet with data uploaded to a REDCap database. Data was uploaded through portable hotspot devices connected to a cellular network. Clinic-based wireless internet connection was not available at the time of the study.

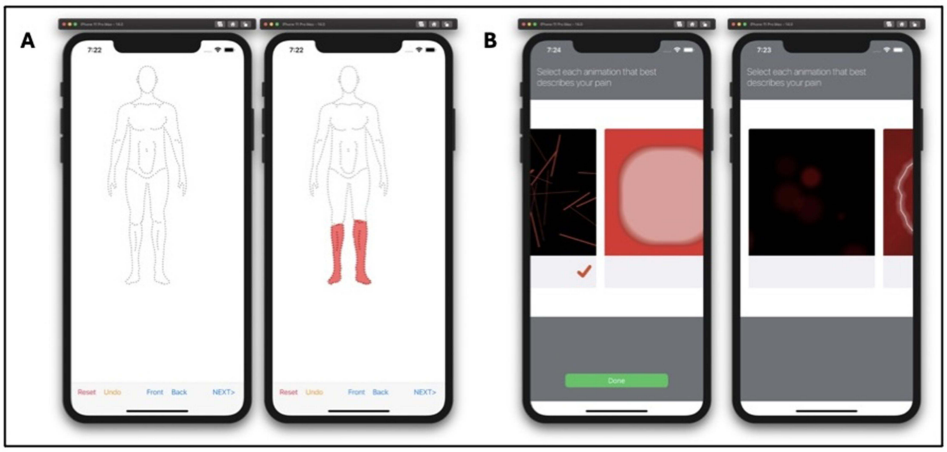

Figure 2 Screenshots from the Painimation app of the paintable body image, animation selection, and animation intensity adjustment. (**A**) Body shading feature used by participants to indicate pain location. (**B**) Adjustable visual animations depicting pain quality and intensity. The animations are not labeled on the app. Participants can choose up to 3 animations.

Ethics Statement

The study was approved by the institutional review boards at the Korle Bu Teaching Hospital (KBTH) in Accra, Ghana, and the University of Pittsburgh, in Pittsburgh, USA. The study was conducted in accordance with the Declaration of Helsinki. Informed consent was obtained for all participants. Parental or guardian consent and participant assent were obtained for all participants under 18 years of age. Data was collected by the first author and three research assistants based in Korle Bu Teaching Hospital with experience and training in ethical research. Three of the four data collectors had no direct patient care role in the clinic. One research assistant was also a clinic nurse but had no direct patient care role with study participants on the day of recruitment. Participants were made aware that participating in the study had no bearing on their ability to receive clinical care.

Statistical Analysis

The primary endpoints of this study were to assess the feasibility, acceptability, and utility, of using Painimation as a pain assessment tool for patients with SCD both during routine care and acute pain episodes. Based on the literature, the recommended sample sizes for feasibility studies are at least 12 participants per group.[28] With a target sample size of 35, we estimated that we could assess an 80% acceptability rate with a 95% confidence interval of ±13%. Descriptive statistics were used to summarize the results, including frequencies, mean, median, standard deviation, and range of responses. Agreement is defined as the combined responses "agree" and "strongly agree", while disagreement includes "disagree" and "strongly disagree". Finally, an exploratory post-hoc analysis was performed to examine whether educational status (senior high school [SHS] and above versus below SHS) influenced survey responses, using Fisher's exact test. Data was captured into a REDCap database and analyzed with SPSS software version 29.0.2.0.

Results

Participant Demographic and Pain Characteristics

Demographic data separated by adult and pediatric respondents are presented in Table 1. A total of 38 patients (66% female, n=25) with a median age of 16 years (range 10–49 years) were included in the study. Adults aged 18 years and older accounted for 37% (n=14) of the participants, while adolescents aged 10–17 comprised 63% (n=24). For education level, 45% (n=17) of participants (subgroup age range 15–42) had senior high school (SHS) or greater while 55% of

Table 1 Patient Demographics by Age Group

	Adult (N=14)	Pediatric (N=24)	Overall (N=38)
Age			
Median [Min, Max]	26.5 [18, 49]	12.0 [10, 17]	16.0 [10, 49]
Gender			
Female	9 (64%)	16 (67%)	25 (66%)
Male	5 (36%)	8 (33%)	13 (34%)
Education Level			
Elementary/primary	3 (21%)	10 (42%)	13 (34%)
Junior High	0 (0%)	8 (33%)	8 (21%)
Senior High	7 (50%)	6 (25%)	13 (34%)
Post-Secondary or higher	4 (29%)	0 (0%)	4 (11%)
Genotype			
HbSS	11 (79%)	22 (92%)	33 (87%)
HbSC	1 (7%)	2 (8%)	3 (8%)
HbS/ß+	1 (7%)	0 (0%)	1 (3%)
HbS/$ß^0$	1 (7%)	0 (0%)	1 (3%)
Clinical Setting			
Day Hospital	6 (43%)	0 (0%)	6 (16%)
Clinic	8 (57%)	24 (100%)	32 (84%)

Abbreviation: N, number of participants.

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participants had less than a SHS education (subgroup age range 10–49). The majority of responses (84%, n=32) were from participants presenting to the outpatient clinic, with the remaining 16% (n=6) were from patients presenting to the day hospital. Most participants (89%, n=34) reported having had at least one VOE in the past 12 months. Genotypes of participants included HbSS (87%), HbSC (8%), HbS/ß+ (3%, n=1), and HbS/$ß^0$ (3%, n=1).

Feasibility and Acceptability

Of the 41 patients approached, 93% (n=38) agreed to participate in the study. Two individuals declined to participate due to time constraints and one individual was not interested in participating. All 38 consented participants completed both the Painimation assessment and study questionnaires. The median time to complete Painimation was 101.6 seconds (Q1=81.9, Q3=134.6). Regarding digital literacy, 66% (n=23/35) of respondents to this question reported using a touchscreen electronic device daily, and 87% (n=33) agreed or strongly agreed to feeling comfortable with a touchscreen device (Figure 3). Seven of the 38 respondents (18%) experienced technical errors when using Painimation. The application closed when trying to move past the body image screen for six participants, and for one participant, one of the eight animations showed as blank. All seven errors were corrected upon reopening the application. The majority of the 38 participants agreed or strongly agreed that Painimation was easy to use (74%, n=28) and enjoyable to use (79%, n=30).

Most participants reported that completing Painimation was not too burdensome (68%, n = 26/38) or too long to complete 61% (n = 23/38) during a pain crisis (Figure 4). An even higher proportion (83%, n = 30/36) felt that the length would be reasonable for routine clinic visits. Most participants did not feel that it was too difficult to choose an abstract animation (81%, n=30/37) or express their pain location by shading the Painimation body image (79%, n=30/38).

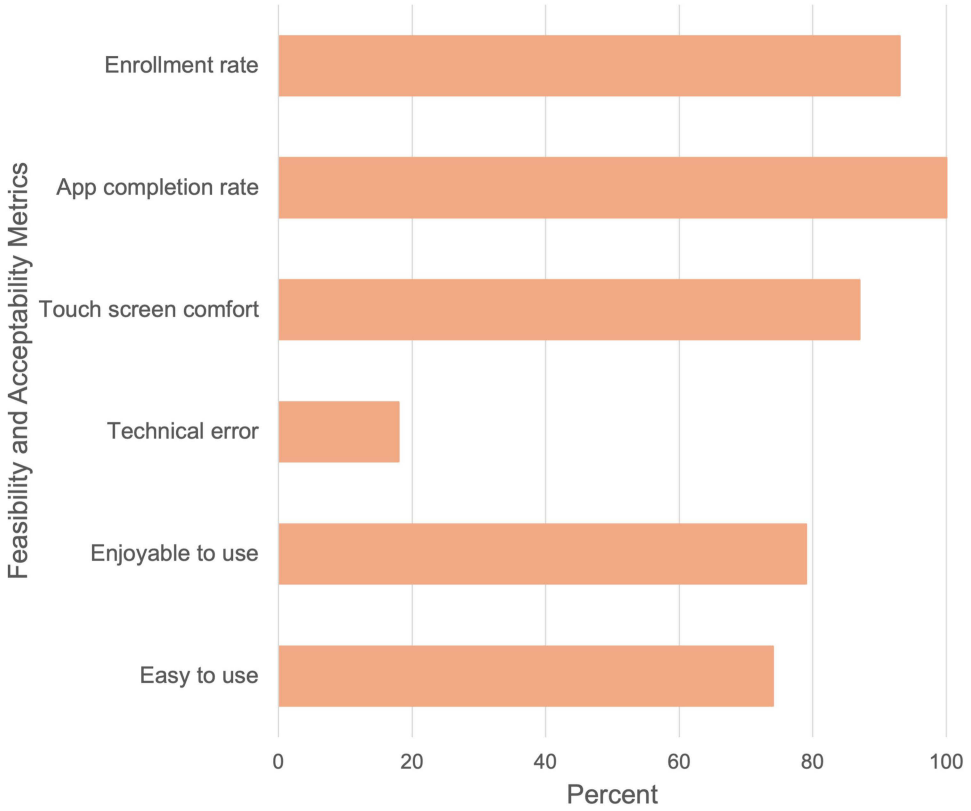

Figure 3 Feasibility and acceptability outcomes (n=36–38).

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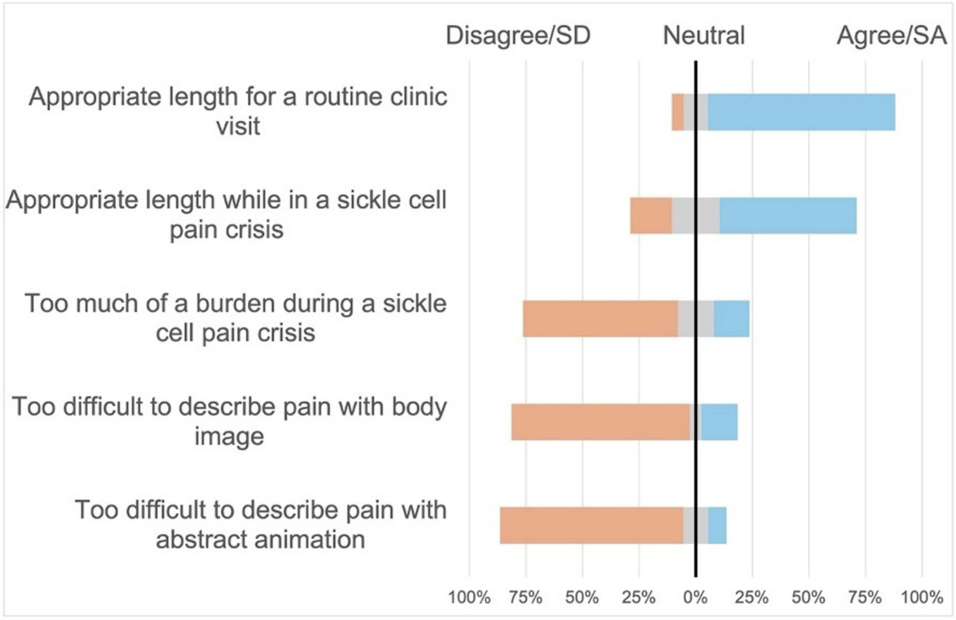

Figure 4 Perceived burden and appropriateness of Painimation.
Abbreviations: SA, strongly agree; SD, strongly disagree.

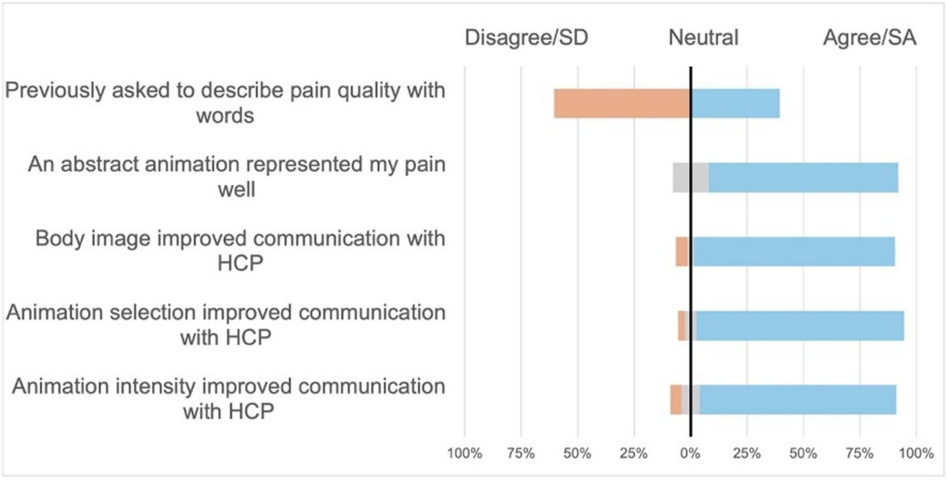

Figure 5 Utility of Painimation for pain communication (N=38).
Abbreviations: HCP, health care provider; SA, strongly agree; SD, strongly disagree.

Utility

The majority of the participants (n=32, 84%, Figure 5) agreed or strongly agreed that they were able to find an abstract animation that accurately represented their pain. Most respondents (92%, n=34/37) agreed or strongly agreed that showing a health provider the body image they shaded would improve their communication with each other. Most patients (92%, n=35) agreed or strongly agreed that showing their chosen abstract animation(s) and changing the intensity of the image (87%, n=33) would improve their pain communication with a health provider.

As an exploratory analysis, responses were stratified by education level, Figure 6. All participants with SHS education level or higher (n=17/17) felt comfortable with a touchscreen device, compared to 76% (n=16/21) of participants with lower than SHS education. The largest difference was seen in daily exposure to touchscreen devices (80% vs 55%, p=0.163) and comfort with use (100% vs 76%, p=0.053). However, less educated participants did not answer differently

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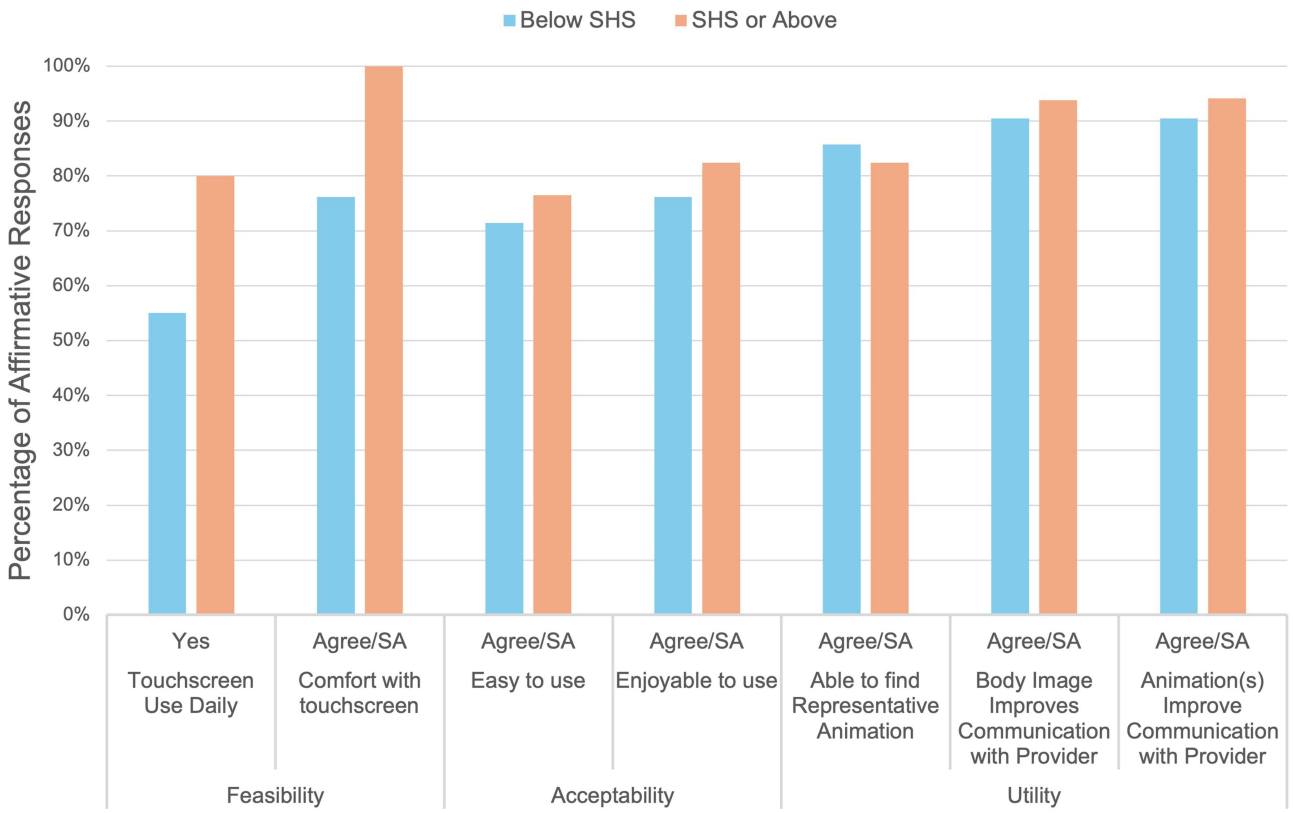

Figure 6 Participant responses stratified by education level.
Abbreviations: SA, strongly agree; SHS, senior high school.

regarding perceived ease of use or enjoyability of the digital application, ability to find a representative animation, usefulness of the shaded body image, or usefulness of the animations for pain communication. Figure 7 shows the same responses stratified by age group. Differences in touch screen usage and comfort appeared to vary more by education level than by age.

Pain Characteristics

Pain characteristics of the 38 respondents are presented in Table 2. A majority of participants (n= 34, 89%) reported at least one sickle cell crisis within the past year. Among adults, 93% reported a non-zero pain level in the past 24 hours, compared to 54% of pediatric participants. The median VAS intensity score among all participants was 3.55 (IQR: 0, 6.125). Among those with a non-zero pain score the median was 5.1 (IQR: 3.5, 7.1). Patients had the ability to choose a maximum of three descriptive animations. Patients chose to describe their pain with one animation (30.7%), two animations (53.8%), and three animations (15.4%). The most frequently chosen animations were animations corresponding to throbbing (50%), stabbing (35%), and burning (27%). Of those who reported pain in the past 24 hours (n=26, 68%), the majority of pain was located in the back (42%), lower limb (35%), chest (35%), arm (35%), hand (23%), and head (23%). Some participants also reported pain in the abdomen (19%) and foot (19%). The pain locations that had the biggest difference in responses by age group were back (adult 62% vs. pediatric 23%) and head (adult 8% vs. pediatric 38%).

Discussion

The present study assesses the feasibility, acceptability, and perceived utility of Painimation, a multidimensional pain assessment app, among patients diagnosed with SCD at the comprehensive pediatric and adult sickle cell centers in Korle-Bu Ghana. Overall, findings support Painimation as a culturally appropriate app, particularly in settings where literacy or language barriers may limit traditional assessment methods. Participants accepted and found utility in the

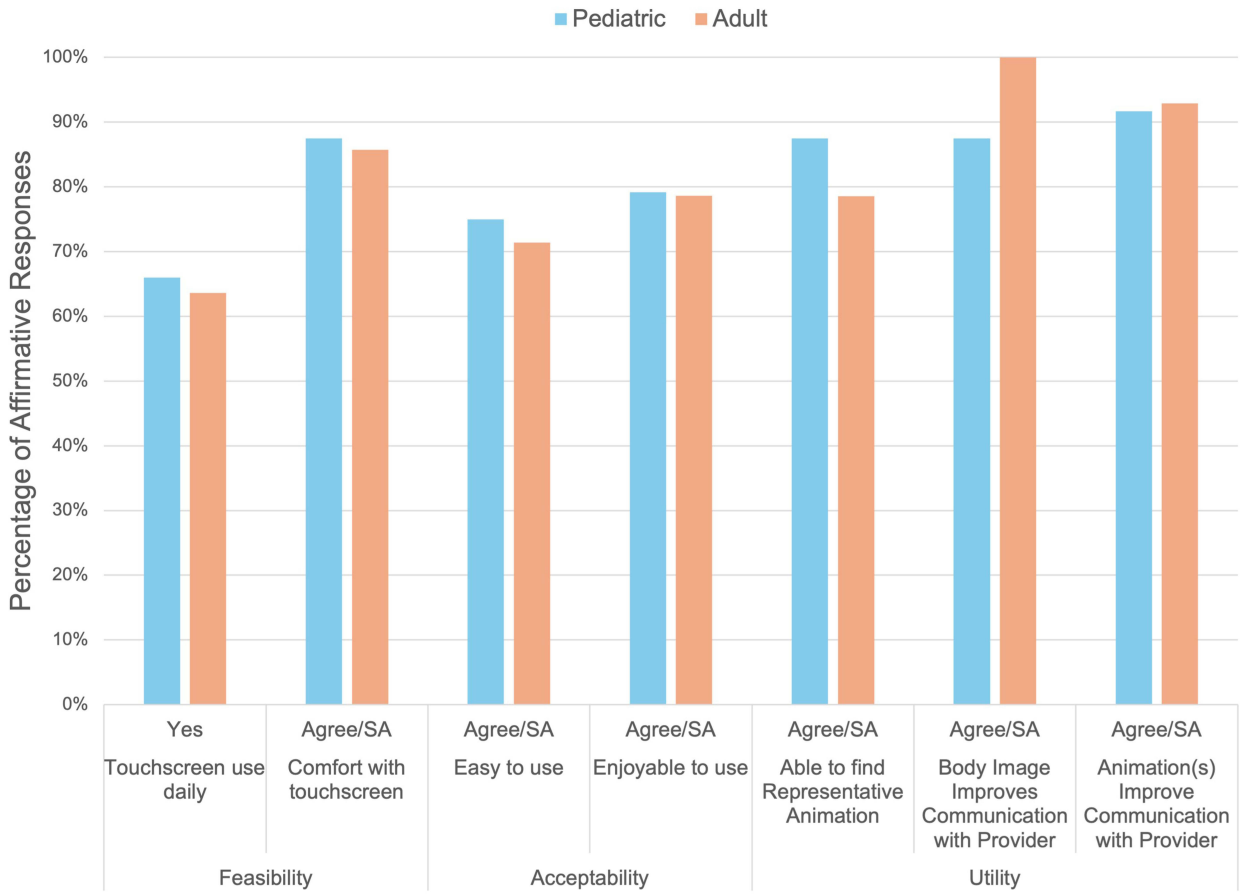

Figure 7 Participant responses stratified by age.
Abbreviation: SA, strongly agree.

visual approach, which allowed them to describe their pain without relying solely on numerical or verbal descriptions. This animation and graphical approach may provide an advantage in populations where literacy levels and linguistic barriers can complicate effective pain assessment.

Feasibility and Acceptability

Traditional unidimensional pain assessment tools such as the 0–10 NRS, VAS, or the Faces Pain Scale, are easy to administer and quick to translate. However, these measures may not fully reflect the complexity of pain presentation in SCD. Multidimensional tools such as the McGill Pain Questionnaire are more comprehensive but users report challenges

Table 2 Pain Characteristics and Participant Responses to Painimation by Age Group

	Adult (N=14)	**Pediatric (N=24)**	**Overall (N=38)**
Pain crises in past 12 months			
≥1	13 (93%)	21 (88%)	34 (89%)
None	1 (7%)	3 (13%)	4 (11%)
Self-reported SCD pain, highest level in past 24 hours (0–10 scale)			
Nonzero (>0)	13 (93%)	13 (54%)	26 (68%)
Zero (0)	1 (7%)	11 (46%)	12 (32%)

(*Continued*)

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Table 2 (Continued).

	Adult (N=13)	Pediatric (N=13)	Overall (N=26)
VAS intensity score (0–10)*			
Median [Q1, Q3]	6.2 [5.0, 7.3]	4.9 [1.5, 5.6]	5.1 [3.5, 7.1]
Number of animations chosen*			
One	4 (31%)	4 (31%)	8 (30.7%)
Two	6 (46%)	8 (62%)	14 (53.8)
Three	3 (23%)	1 (8%)	4 (15.4%)
Pain Location*			
Upper limb	4 (31%)	5 (38%)	9 (35%)
Lower limb	6 (46%)	3 (23%)	9 (35%)
Back	8 (62%)	3 (23%)	11 (42%)
Chest	5 (38%)	4 (31%)	9 (35%)
Head	1 (8%)	5 (38%)	6 (23%)
Abdomen	2 (15%)	3 (23%)	5 (19%)
Hand	3 (23%)	3 (23%)	6 (23%)
Foot	3 (23%)	2 (15%)	5 (19%)
Painimation animation*			
Pounding	2 (15%)	1 (8%)	3 (12%)
Shooting	1 (8%)	4 (31%)	5 (19%)
Cramping	3 (23%)	2 (15%)	5 (19%)
Throbbing	6 (46%)	7 (54%)	13 (50%)
Tingling	0 (0%)	1 (8%)	1 (4%)
Burning	5 (38%)	2 (15%)	7 (27%)
Electrifying	4 (31%)	1 (8%)	5 (19%)
Stabbing	4 (31%)	5 (38%)	9 (35%)

Notes: *Number and percentage of participants with a non-zero pain score (n=26) who chose to describe their pain with the respective animation. Participants had a choice of a maximum of three animations.
Abbreviations: N, number of participants; VAS, visual analog scale (0–10).

such as difficulty understanding the word descriptors due to unfamiliar vocabulary and language barriers.[18] Terms such as "gnawing" or "splitting", for example, may be unfamiliar or confusing to some patients. Prior researchers have highlighted that low literacy can limit the effectiveness of text-based tools.[23] Digital approaches have shown promise in addressing these limitations. In a chronic pain study, participants rated a computer-based pain assessment tool as the most preferred and easiest to use.[18] Participants liked being able to visually show their pain location as well as use visual descriptors of pain, which are both features of the Painimation application. In contrast to our study, 96% of the participants in that study had the technological modality of the study application at home (computers).[18] Our participants had relatively low rates (66%) of access to touchscreen devices, consistent with existing data in Ghana[29] that describes ownership of a laptop, desktop, or tablet at just under 20% in the Greater Accra Region (the most urban region of the country and where our study was held). That study of 30,916 individuals over 5 also listed mobile phone ownership in the region as 73.7%; among mobile phones owned by urban dwellers, only 58.4% of those are smartphones. Despite the relatively low touchscreen usage among our participants, nearly all participants felt comfortable using the app, and most found it easy to use. These results demonstrate feasibility even among users with limited prior digital exposure. Furthermore, in our exploratory analysis, although participants with lower education levels had lower exposure to and less comfort with the technical modality, this did not seem to impair their experience with Painimation. Notably, participants with lower education levels reported comparable ease of use and perceived benefit, reinforcing the inclusivity of the app's design across diverse populations. Our study supports previous research suggesting that when tools are appropriately designed and culturally acceptable, digital health technologies can be successfully implemented in diverse clinical environments, including tertiary care centers in sub-Saharan Africa.[30]

Perceived Burden

The average time to complete Painimation was less than 2 minutes, making it longer to complete than a simpler 0–10 scale but significantly shorter than most multidimensional scales such as the Brief Pain Inventory, which takes 5 minutes for the short-form and 10 minutes for the long form,[31] or the McGill Pain Questionnaire, which takes on average 5–20 minutes to complete depending on whether the short or long form is used.[17] While no one in this study was actively in severe pain at the time of administration, all participants were asked to reflect on the potential burden of this app while having an acute VOE. Only a small minority (16%) felt that using the Painimation app might be too burdensome in VOE. Overall, participants' perceptions of the app's length and usability were positive, though acute pain episodes may present additional usability challenges. All self-report measures have inherent challenges when patients are experiencing acute pain or a vaso-occlusive episode, and capturing reliable data during these periods is difficult regardless of the assessment method. However, Painimation may offer an advantage over simpler measures: the interactive, visually engaging nature of selecting animations could provide a brief distraction and may feel less burdensome than translating a complex sensory experience into numbers or words. Indeed, verbal description of pain is often considered the easiest approach, yet articulating the qualities of pain through words alone is notoriously difficult—a challenge that animated visualizations are specifically designed to address.

Despite the potential perceived burden of completing a digital pain assessment during an episode, all aspects of the Painimation app received high usefulness scores. Future iterations could strive to minimize burden by eliminating the body image and intensity selection, instead allowing patients to simply select one animation that describes their pain and indicate whether it is "worse than usual"—an approach that may be sufficient for guiding treatment. Moreover, clinical history-taking at the beginning of a visit for VOE takes time, and if Painimation were integrated into the workflow in a non-duplicative way, it would likely be seen as less burdensome. A qualitative study could ascertain characteristics besides time that may be perceived as burdensome.

Utility and Communication Enhancement

At the time of this study, pain assessment was standard practice at the Korle Bu sickle cell clinics, with most patients assessed using a 0–10 intensity scale. Interestingly, most of the participants in this study (61%) reported no prior experience being asked to describe their pain quality, a tenet in the well-established P(Q)RST (standing for Provoking/Palliative, Quality, Region/Radiation, Severity, Timing) clinical pain assessment method.[32] This is especially important, as differentiating the quality of pain such as identifying features consistent with neuropathic pain (eg, burning, tingling sensation) can help inform clinical decisions and guide management strategies Despite the novelty of reporting pain quality, the large majority (84%) were able to find a representation of their pain using animations and perceived usefulness in the clinical application of this (92%). Moreover, participants' success finding an abstract animation to represent their pain supports the face validity of Painimation as a pain assessment tool.

These findings are consistent with a feasibility study conducted at a US adult chronic pain clinic where a majority of participants found Painimation to be enjoyable (84.6%) and potentially useful (80.2%) in communicating their pain to healthcare providers,[20] supporting its cross-cultural applicability.

Findings also align with a validation study of Painimation among 359 US adults with chronic SCD pain.[21] O'Brien et al found that "shooting" and "electrifying" painimations were significantly associated with daily pain intensity, interference, and severity, while "throbbing"—endorsed by over 40%—showed no association with severity, potentially indicating lower-level chronic pain[21] Throbbing was similarly the most frequently selected animation in our Ghanaian cohort (50%), consistent with research characterizing SCD pain as predominantly throbbing.[33] Common pain locations were also observed across studies: lower back, knee/shin, and hip were most affected in both the PiSCES project (308 US adults with daily diaries)[34] and Wilkie et al (145 US outpatients reporting 36 sites on average)[33]—patterns mirrored in this West African cohort. While clinical expression may differ between African and US populations due to healthcare infrastructure, therapy access, and survival bias, pain crisis remains the most reported symptom across settings,[35] underscoring the need for accurate assessment.

An important caveat is that our sample included pediatric and adult participants not actively experiencing chronic pain, whereas O'Brien et al studied exclusively adults with established chronic pain[21] Future studies should examine whether animation selections differ by age group and pain chronicity.

Limitations

This study has several limitations. Participants were recruited from a single tertiary care center, which may limit the generalizability of findings to individuals receiving care in primary or rural health settings. Additionally, the small sample size limited our ability to perform robust subgroup analyses, particularly by educational level. However, the sample size is sufficient to demonstrate the feasibility objectives of the study. A further limitation of this study is the reliance on self-reported data. While self-reporting is appropriate for capturing pain experiences, it is less reliable for objective clinical characteristics such as SCD phenotype. To address this, we supplemented participants' self-reported genotypes with medical record data for those who selected "other" or "unknown" when asked to report their genotype. Another limitation is that seven technical errors occurred while completing the study, which may have been due, in part, to poor internet connectivity. These errors were fixed upon reopening the application, but future studies would benefit from continued testing and updates to the application to enhance the feasibility of its use in a low-resource setting where there are challenges with internet connectivity. This approach would limit data loss.

Conclusion

This study suggests that the Painimation digital pain assessment app is feasible, acceptable, and useful, while providing low burden and time cost to our target population in Ghana, sub-Saharan Africa. Pain reports using Painimation mirrored known SCD pain profiles, with predominant throbbing pain and frequent leg and back involvement. These results contribute to the growing literature on digital health application use in low-resource settings and support the potential of tools like Painimation to improve care for underrepresented populations with high disease burden. Future research should involve a larger, multisite cohort to validate Painimation, compared to other validated pain tools, and explore its implementation in diverse clinical settings.

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Disclosure

Jonassaint: Expressive Painimation: Current Employment, Current equity holder in private company; Agios and Novo Nordisk: Consultancy, Honoraria. In addition, Jonassaint has a patent Painimation pending to Expressive Painimation Co. Obasohan, Asare, Segbefia, Owusu-Ansah, Mamauag, Dei-Adomakoh, Hillery, and Oluwole report no conflicts of interest in this work.

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