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Cognitive Testing of PAINReportIt® in Adult African Americans with Sickle Cell Disease

Aruna Jha, PhD¹, Marie L. Suarez, PhD¹, Carol E. Ferrans, PhD, RN, FAAN¹, Robert Molokie, MD^{2,3}, Young Ok Kim, DrPH, RN¹, and Diana J. Wilkie, PhD, RN, FAAN¹

¹University of Illinois at Chicago College of Nursing Department of Biobehavioral Health Science

²University of Illinois at Chicago College of Medicine Division of Hematology/Oncology

³Jesse Brown VA Medical Center

Abstract

PAINReportIt,[®] a computerized version of Melzack's (© 1970) McGill Pain Questionnaire, presents pain measurement items to responders in serial display screens accompanied by pop-up screens. In this study, we used cognitive interviews to examine further validity of **PAINReportIt**[®] with 25 African Americans with sickle cell disease. The specific aims were to determine if the questions in the **PAINReportIt**[®] program were relevant to and understood by African Americans with SCD and to describe the nature of the pain they experienced. Most study participants were enthusiastic and able to use the tool as intended, appreciated the comprehensiveness, detail, and multidimensionality of its pain data. For some screens, two to six participants' responses suggested some question understanding and interpretation issues, inability to retrieve the requested information, or technical issues. Their responses indicated that screens lacked sufficient specificity for the temporal nature of pain recurrent over a lifetime. The program captured both nociceptive and neuropathic aspects of sickle cell pain, and provided detailed information on the location, intensity, quality and pattern of pain experienced by participants. We recommend that future revisions to the **PAINReportIt**[®] program address the temporal issues of measuring recurrent pain, resolve technological issues related to pop-ups, and simplify difficult words to better match the typical health literacy levels of patients. These revisions could further enhance the technological aspects, usability, and cultural appropriateness of the tool for African Americans with SCD.

Keywords

computerized pain assessment; cognitive interviewing; sickle cell pain; McGill Pain Questionnaire

Introduction

Samples composed primarily of Caucasians with cancer¹ have successfully used **PAINReportIt**,[®] a validated computerized extension of Melzack's (© 1970) McGill Pain Questionnaire (MPQ).² However, it is unclear if this method of pain assessment is valid for African Americans with sickle cell disease (SCD). Computerized pain assessment programs are an efficient, cost-effective, and user-friendly adjunct to a clinician's pain assessment, which suggests that **PAINReportIt**[®] could be an effective way for patients with SCD to quantify and describe their pain. For the more than 72,000 Americans living with SCD

Correspondence to: Diana J. Wilkie, PhD, RN, FAAN, Professor and Harriet H. Werley Endowed Chair for Nursing Research, Department of Biobehavioral Health Science (MC 802), University of Illinois at Chicago, 845 S. Damen Ave., Room 660, Chicago, IL 60612-7350, 312.413.5469, 312.996.4979, diwilkie@uic.edu.

(mainly African Americans, with those of Mediterranean and Hispanic descent making up the majority of the others),³ the multidimensional and ever-changing nature of their pain is a constant challenge that compromises quality of life and, if untreated, could potentially hasten death. There are important differences in pain related to SCD compared to cancer pain, and many cultural differences between Caucasians and African Americans, that underscore the importance of validating **PAINReportIt**® in patients with SCD. The purpose of this study was to examine further the validity of **PAINReportIt**® using cognitive interviews with African American SCD patients as they completed each screen, to understand the meanings they attributed to the instructions and items.

Background

Pain assessments are an integral aspect of pain management in SCD, a genetic disorder affecting 1 in 500 African Americans³ that is characterized by periodic, self-limiting episodes of excruciating musculoskeletal and visceral pain.⁴ Pain assessment in SCD is challenging because the disease predisposes to both chronic pain and acute episodic pain. Over the years, several different approaches to pain assessment in patients with SCD have been tried with varying success, including the Wisconsin Brief Pain Questionnaire,⁵ Visual Analog Scales,⁶ Numerical Rating Scales⁷ and pain diaries.⁸ Each of these measurement approaches is limited by its focus on one dimension of a complex multidimensional pain phenomenon. Fortunately, there are several tools to measure pain as a multidimensional phenomenon,⁹ with one of the most popular being the McGill Pain Questionnaire (MPQ).²

The MPQ² is a well-known, valid, and reliable tool that guides patients in providing the necessary information for clinicians to diagnose pain etiology and select appropriate analgesic therapies.¹⁰ Wilkie and colleagues have demonstrated that the paper version of the MPQ could be completed in 10 to 15 minutes by patients at home and showed in studies of more than 800 outpatients that cancer patients were grateful that the MPQ allowed them to describe their pain in concrete terms. Education level was not a barrier to using the MPQ in a sample of 137 outpatients.¹¹ The psychometric properties of the paper-and-pencil MPQ are well documented, including concurrent,¹² predictive (67 to 77%),¹³ and construct validity (3 factors);^{12, 14, 15} alternate forms (.72)¹⁶ and test-retest reliability (.70 to .90), and sensitivity.^{2, 17}

Although extensively used with cancer and other chronic pain conditions, the MPQ has been used infrequently to assess SCD pain. Anderson and Rehm¹⁸ used the MPQ to assess pain in sixty African American subjects equally distributed into three medically diagnosed chronic pain groups: arthritis, SCD, and low back pain. Although the authors did not report reliability scores for the measure, they did report that, based on the MPQ, the three groups were similar in their experience of pain.

Capitalizing on the multidimensional assessment benefits of the MPQ and technological advances, **PAINReportIt**® (Nursing Consult, LLC, Seattle, WA, 801-414-0627) as developed as an interactive electronic extension of the MPQ.¹⁹ The program uses the 1970 MPQ version, a four-page document that allows the patient to mark areas of pain on a body outline drawing, circle words to describe pain quality and pattern, write narrative text to indicate activities that increase or reduce the pain, and select pain severity indicators. When tested on 213 subjects experiencing cancer or other chronic types of pain, subjects completed the tool in 16 minutes on average, answered all questions, and scored it high on acceptability. Previous research by Wilkie and colleagues¹⁹ has established that **PAINReportIt**® is user-friendly and not limited by age or gender. But neither the paper-version MPQ nor **PAINReportIt**® have been sufficiently tested in African American populations or with patients who have SCD. Cognitive interviewing techniques are widely

used for assessing validity and cultural appropriateness of paper-and-pencil or computerized questionnaires.²⁰ Therefore, the specific aims of this study were to use cognitive interviewing to determine if the questions in the **PAINReportIt**[®] program are relevant to and understood by African Americans with SCD and to describe the nature of the pain experienced by African Americans with SCD.

Methods

Design

We used scripted interviews with concurrent verbal probing to explore the validity of **PAINReportIt**[®] as a pain assessment instrument for use with adult African Americans diagnosed with SCD. The study protocol was approved by the University of Illinois at Chicago IRB, and all participants provided written informed consent.

Setting

Trained research specialists conducted the interviews at the outpatient Sickle Cell Clinic (SCC) of the University of Illinois at Chicago (UIC) Medical Center. The UIC SCC is the largest treatment program for adults with SCD in the Midwest and the only one in the Chicago area.

Subjects

Inclusion criteria required that the patient: (a) had a diagnosis of SCD; (b) was scheduled for continuing care at the UIC SCC; (c) currently had a moderate to severe level of pain (≥ 3 on a 0–10 scale) related to the SCD; (d) spoke and read English; and (e) was 18 years or older. Patients were excluded if they were: (a) legally blind or (b) physically unable to complete study procedures.

The sample of 25 SCD patients included 19 (76%) women and 6 (24%) men, all African American. Participants reported an average age of 39.3 (SD=16.6) years with the youngest being 20 and the oldest being 82 years. For the 22 participants who reported their education level and marital status, 12 (55%) had completed high school and 10 (45%) had some college or vocational school education; 18 (82%) were single and 4 (18%) were married or partnered. For the 20 participants who reported family income, 7 (35%) reported less than \$10,000 annual family income; 9 (45%) reported \$11,000 to \$20,000, and 4 (20%) reported greater than \$21,000. Participants were diagnosed with the following sickle hemoglobinopathies: 20 (80%) hemoglobin SS disease (SS); 2 sickle Beta-thalassemia + (Sβ-thal+); two hemoglobin SS with hereditary persistence of fetal hemoglobin (SS+F); and one hemoglobin SC disease (SC).

Procedure

Participants were referred to the study by registered nurses (RNs) or physicians at the SCC. At the time of patients' scheduled clinic visit, the clinic RN introduced them to a trained research specialist, who recruited eligible patients and obtained written informed consent. Then the research specialist scheduled the participant for the interview session at a regularly scheduled clinic appointment or time convenient to the participant. All participants used an Acer pen-tablet (C100; Taipei, Taiwan) with touch screen technology (Figure 1) to complete **PAINReportIt**[®] and demographic questions. As the patient touched the appropriate response on the screen, data were automatically stored in an Access[™] database file, including saving an image file for the body outline markings in one of the fields. Selected variables from the Access[™] file were exported into statistical programs for further analysis.

The interview team consisted of an interviewer and a recorder. As participants completed each screen, they were asked questions regarding what they thought about when they answered the questions and made their choices on the screen, while the recorder documented participants' responses and the recorder's own observations. Upon completion of the first five interviews, the project investigators reviewed the procedures for the think-aloud interviews with the research specialists conducting the interview to assure consistency in data collection. A graduate research assistant transcribed the notes, which the first author coded and analyzed for emergent themes with independent review by another author (MLS). Consensus between the two coders established agreement regarding the final interpretation of the findings.

Instruments

Think-aloud interview—Based on previous work by Ferrans et al.²¹ with African Americans and Hispanic Americans with low literacy, we used a 97-item interview guide to explore (1) the participants' understanding and interpretation of the items, (2) their ability to retrieve relevant information (information retrieval) as they completed the screens and pop-up messages, and (3) their subjective experience of the computer technology.

PAINReportIt®—The current version of **PAINReportIt®** includes 15 electronic screens or pop-ups to collect the same information as the paper-and-pencil version of the MPQ (1970 version),² 7 additional screens or pop-ups for the patient to document the analgesics currently used, and 11 additional screens or pop-ups (with two items measuring goals for pain levels and one item addressing each of the following nine concepts: amount of time that pain is greater than the tolerable level; patient satisfaction with pain level; expectations about the pain; effectiveness of previous pain treatments; pain medication treatment pattern; non-drug treatments used for pain; tendency to tell or not tell others about the pain; onset of pain; and belief about the cause of the pain). Finally, **PAINReportIt®** includes additional screens that allow the patient to respond to demographic questions and provide a brief health history. Patients respond to all queries by touching the screen or typing information on the keyboard. The paper-and-pencil MPQ and the **PAINReportIt®** demonstrated equivalence in a previous study.²²

Results

Qualitative results include a synthesis of participants' responses from the cognitive interviewing framework²¹ and reflect issues that some participants encountered in one or more of the following areas: (1) question and instruction understanding and interpretation (e.g., participants' answers to the **PAINReportIt®** item or to the cognitive interview questions indicated that they did not understand or correctly interpret the **PAINReportIt®** item); (2) information retrieval (e.g., participants' answers or further questions showed that the **PAINReportIt®** question was not directly applicable to their situation, was not specific enough for them to be able to answer accurately, or the patient could not retrieve the necessary information to answer the question because he/she did not know what information to retrieve); and (3) technological elements in the screen (e.g., issues directly related to the computer or technology). Additionally, we summarize participants' descriptions of their pain with quantitative analysis.

Qualitative Analysis

Pain Location: Body Outline—This first screen required participants to draw all their pain locations, one at a time, on a body outline. All 25 participants were able to complete this screen, and the cognitive responses of all but one participant indicated that they chose the locations to mark based on where they usually experienced pain, where they had the

most pain, or where they were hurting at the time that they completed the tool. Nineteen participants indicated that they completed the screen easily and with no issues. The responses of six participants reflected the following issues:

- **Information Retrieval Issues**
 - Two participants' responses suggested that the temporal component of their pain influenced their responses to the instruction *"Show where you usually have pain or discomfort."* A woman wondered about the time frame that was referenced, saying she *"didn't know whether to draw everywhere I had pain or just on last 7 days."* An elderly man said that he thought about *"which pain to draw sickle cell crisis, back pain and aging pain."* As he reflected on whether he should *"Draw another pain area?"* he said that he, *"Didn't want to complain of aging pain"* and he would *"try to distinguish between the two"* because *"As I get older, I look at pain different."*
 - This screen also asked participants to choose one of three buttons to indicate the time frame for a particular location; *"Now," "Today,"* or *"During the past week."* After she finished marking her pain locations on the body outline, a female participant (who was in pain at the time of the interview, had been feeling the pain all that day, and also been in pain all of the previous week) reported being *"Confused as to which box to select for answer."* *"I was confused-do I hit NOW? Hit all 3 because I was not sure."*
- **Technological Issues**
 - Four participants indicated issues with the sensitivity of touch-screen technology and the program design that noted new pain sites when pressure was released from the screen. All four participants were confused by pop-up questions specific for one site occurring before they had marked all their sites. For example, a female participant *"Lifted the pen before she was finished,"* and reported that she *"Thought it rushed me. I wasn't even finished and it asked me."*

Pain Intensity—There are three screens for documenting the range of a patient's pain intensity on a scale of 0–10: "Pain Now," "Least pain" and "Worst pain." All participants completed the "Pain Now" screen without issues, but five participants encountered issues with the other two screens that suggested question understanding and interpretation issues. None of the participants reported technical issues for these three screens.

- **Question Understanding and Interpretation Issues**
 - **Least Pain Screen** - four participants had difficulty understanding the instruction, *"Now touch the number that describes your pain at its LEAST in the PAST 24 HOURS."* One participant responded *"I didn't know what it was trying to ask, I just put 2-you're not in crisis 24 hours."* A male participant stated: *"I just answered this question"* after completing the Pain Now screen. One participant indicated brief confusion with the instruction but corrected her response after discussing it with the interviewer, who noted *"Marked 8 – discussed what the question meant and changed score to 5."* Another participant responded that for her it was *"How I feel in the middle of the night – I have to get up and take pain meds"* which would suggest she was thinking about experiencing significant pain, and so was not interpreting the instructions as intended.

- **Worst Pain** - One participant asked about the “*Time frame, did they mean overall?*” when the question specified the worst pain in the last 24 hours.

Pain Goal—The pain goal screen asks about the participants’ goal for pain level. Like the other pain intensity screens, it is scaled from 0 to 10. Three participants recorded a “10” on the pain goal screen but gave different explanations for their choices during the interview. Their responses suggested question understanding and interpretation issues. For example, a female participant selected 10 as her pain goal because she wanted to show, “*How bad it [pain] can get.*” When asked, “*Are you sure,*” she said “*yes.*” Another female participant also chose “10” but said it was “*How I want to feel.*” A male participant selected “10” because he wanted to show “*how your head is feeling now – it’s hurting.*”

Pain Tolerable—The instruction on this screen is “*Please indicate how much time during the past 24 hours that your pain was [program inserts the person’s tolerable pain level from another screen] or less*” with options of 0–6 hours, 7–12 hours, 13–18 hours, and 18–24 hours. Three participants did not complete this screen.

- **Question Understanding and Interpretation Issues**
 - A woman stated: “*This question does not pertain to pain. Pain does not stay at 1, pain steadily increases.*”
 - A man said “*None of these apply. It’s been more than 24 hours.*”
 - One woman stated her reason for not completing the screen as: “*The choices available do not apply. No choice with hours of 0 or less.*”

Pain Expectation—Three participants indicated that they could not relate the pain that they were experiencing now to the available options “*worse than expected,*” “*not as bad as expected,*” or “*better than expected*”.

- **Information Retrieval Issues**
 - Two participants could not select an option because their pain pattern did not change and there was no option on the screen that reflected that condition. When asked to reflect aloud on their thinking, the first participant responded, “*How far back- yesterday or two months-same as expected-it is how pain feels;*” and the second participant stated “*Not a time frame- it is always the same.*” The third participant was unable to answer the question because he did not know the time period to which this question referred.

Satisfied with Pain Level—This screen asks participants “*Are you satisfied with your pain level?*”, with the options of an answer being “*yes,*” “*no,*” and “*not sure.*” There were information retrieval issues for three participants. They questioned the time frame of the question, asking “*Whether it meant overall or just now,*” “*Do they mean now? Now- yes, crisis – no,*” and “*What was the time frame?*”

Pain Quality Descriptors—In a series of five screens, each with different pain quality descriptors, participants were asked to choose all the words that described their pain. Information retrieval issues with these screens were expressed by those participants who did not understand the meanings of specific words (Table 1).

Matching Pain Location Sites with Pain Quality Descriptors—On this screen, participants were asked to match their pain descriptor words to each of the pain locations

they marked on the body outline. Six participants reported issues with this section: four participants reported question understanding and interpretation issues, one reported information retrieval issues related to the temporal nature of the pain, and one reported difficulties with the technology.

- **Question Understanding and Interpretation Issues**

- Two participants needed a lot of help with these instructions. *“I don’t know what they are asking.”* Another participant successfully matched a pain word to her knee but had a question about the meaning of the option labeled *“Word describes all pain areas.”* Re-reading the directions was sufficient to help the fourth participant complete the page on her own, and she commented, *“First I didn’t understand – after – I think I read it too fast.”*

- **Information Retrieval Issues**

- A female participant was unable to think past a recent pain crisis *“None of these words were associated with last week,”* despite having selected the words on previous screens.

- **Technological Issues**

- A female participant was experiencing pain and stiffness in her hand, and she acknowledged difficulty in manipulating the pen, saying, *“I couldn’t put an X in box.”* The interviewer noted that the participant had not drawn three separate areas but connected them all (an issue on the body outline screen), and she only had one box to check.

Relieves Pain—The screen consists allows participants to type into a text box what they do to relieve their pain. The only issues related to this screen were technological. Two participants had issues related to locating the on-screen keyboard and needed to be reminded how to access it. For example, one participant asked, *“Do I write on this?”*

Notice Pain—This screen has the instruction, *“When did you first notice your pain?”* with a blank window that allows participants to type their answers. Five participants appeared to have issues with this screen.

- **Information Retrieval Issues**

- Five participants reported issues in responding to this question because there was no time frame or context suggested for describing when they first noticed their pain. One woman asked, *“What do you mean when I first notice my pain? It usually comes when I lay down, as far as my pain goes-chest pain-predominant pain.”* Another woman stated, *“I don’t understand this. I remember having pain at five. I had it since I was two, but remember having pain at five.”* Another participant stated, *“Didn’t understand the question - first noticed pain I am having right now?”* A man asked *“Which pain? Now, or during a crisis?”* A woman asked *“My whole life or just past crisis?”*

Final Comments—Of the 21 participants who came to this screen before needing to stop the interview, 18 (86%) offered final comments about the program, and three did not. In general, the comments were positive regarding the ease, relevance and applicability of the program and are summarized in Table 2.

Quantitative Analysis of PAINReportIt® Data

The participants' pain scores indicated they had an average of 3.4 ± 2 pain sites and moderate to severe pain (now = 4 ± 2.7 , least = $2.9 \pm .2.6$, worst = 4.9 ± 3.4); 52% (n=13) were not satisfied with their pain, and 60% (n=15) did not tell others about their pain. Participants selected an average of 4.8 words indicative of neuropathic pain (e.g., aching, shooting, stabbing, spreading, hot, penetrating, cold, itchy) and 6 words indicative of nociceptive pain (e.g., throbbing, sharp, hurting, pounding, tender, cramping, sore). Amazingly, only 2 (8%) of the participants selected no neuropathic descriptors. Their pain pattern was continuous (n=14, 56%), steady (n=8, 32%), constant (n=5, 20%), rhythmic (n=4, 16%), periodic (n=6, 24%), intermittent (n=4, 16%), brief (n=7, 28%), momentary (n=2, 8%), or transient (n=2, 8%).

The participants reported using a variety of analgesics. Acetaminophen (n=14, 56%), ibuprofen (n=12, 48%), acetaminophen with codeine (n=12, 48%), hydrocodone (n=9, 36%), and morphine injection (n=8, 32%) were the five most frequently used analgesics. An adjuvant drug for neuropathic pain was being used by only 20% (n=5) of the participants, despite the possibility that 23 (92%) may have been experiencing neuropathic pain.

DISCUSSION

The most significant finding from this study is the evidence that the **PAINReportIt®** program is a valid method for assessing pain related to sickle cell disease (SCD) in African American patients. Most participants in the study were enthusiastic about the computerized pain assessment tool and appreciated the comprehensiveness, detail, and multidimensionality of its pain data. Similar to research done predominantly with Caucasian cancer patients and the general public,¹⁹ the **PAINReportIt®** program captured both nociceptive and neuropathic aspects of sickle cell pain, and provided detailed information on the location, intensity, quality and pattern of pain experienced by participants. A second important finding is that the temporal nature of SCD pain may not be adequately depicted by response options offered in the **PAINReportIt®** program. Additionally, we found that instructions for some questions may require revision to better help all individuals to understand what is being asked and how to answer.

We found that response options on some screens of **PAINReportIt®** did not accurately reflect the heterogeneity of study participants' temporal experiences with pain. SCD pain recurs throughout life, often starting in infancy and continuing throughout childhood, adulthood, and the elder years.²³ SCD pain is also characterized by marked variations in the character and severity of pain symptoms among individuals.²⁴ In previous research with sickle cell patients, participants have reported localized or generalized pain; recurrent, unpredictable episodes of acute pain; or episodes of intense pain with long periods of chronic aching pain in between.²⁵ In another study, with a large, random sample, 39% of patients experienced no pain, while 6.2% had 3 to 10 pain episodes per year that required hospitalizations.⁴ The longer duration, sporadic nature of acute episodes, and other variations in pain pattern introduce a temporal aspect to sickle cell pain that makes it quite different from other chronic pain conditions such as cancer pain. Participants in our study indicated that they were limited in their responses because the answer choices did not adequately reflect the temporal range of their experiences.

In addition to lifelong pain, study findings also highlighted the importance of reflecting temporal variations during a specific pain episode. Participants wanted to know if their answer should reference that day, during specific activities, or the first incident that they recalled in life. We believe that **PAINReportIt®** instructions about when pain began, an

indicator of pain duration, need to be revised to specify the time frame or context of the current pain episode or lifetime.

Comments by several participants in this study indicated issues related to the technological aspects of **PAINReportIt**[®], with many expressing surprise at the sudden appearance of pop-ups. Compeau, Higgins and Huff²⁶ found strong associations between an individual's affective and behavioral reactions to technology and computer self-efficacy and outcome expectations. Based on previous research by Wilkie et al.,¹⁹ four practice screens were included in this version of **PAINReportIt**[®], to give participants an opportunity to get to know the program, but we did not ask participants their opinions about the effectiveness of the practice screens in preparing them to respond to **PAINReportIt**[®] items. In particular, findings indicate that some participants needed help with the instructions and others asked for more time to finish tasks related to the body-outline screen. The body-outline screens are key elements of the comprehensive measurement of pain in the **PAINReportIt**[®] program, and we assume that improving participants' ability to complete these screens would improve the quality of pain data collected and reduce measurement error. We recommend adding pop-ups to the practice screens to increase participants' ability and comfort in responding to them as they report the location of their pain. This revision is especially important if **PAINReportIt**[®] is to be used as a self-administered assessment tool in sickle cell clinics serving minority populations.

In this study, words like *lancinating* and *lacerating* presented comprehension difficulties for many participants, and there were some participants who did not know several pain descriptor words. Since pain descriptor words define a specific characteristic of pain, an important implication of not knowing the word is that respondents are not able to describe their pain even if it meets the definition embodied in that word. Other researchers have simplified the words *lancinating* and *lacerating*. Respondents interpret questions according to habits developed over a lifetime of everyday conversations,²⁷ and the use of academic terminology makes it difficult for participants to provide relevant information. Survey design specialists recommend that ambiguous words and medical terminology should be avoided.²⁸ Our finding is consistent with previous research that found that 39% of 390 participants were unable to understand health information presented at a 9th-grade reading level and an additional 31% did so with assistance.²⁹ Our findings support simplifying words like *lancinating* and *lacerating* to enhance the usability of the **PAINReportIt**[®] program by patients with SCD.

Health literacy has been defined as a constellation of skills, including the ability to perform basic reading and numerical skills required to function in the health care environment.³⁰ Some participants who were confused by instructions on screens that used a pain scale may have been challenged by issues related to health literacy. For example, some participants selected a high number on the 0-to-10 pain intensity scales to indicate their pain goal. Participants in this study were not probed further when they misunderstood instructions, and so we do not know the underlying cause for their apparent wrong answers. Previous research has found that African American and Hispanic patients who had marginal or inadequate functional health literacy were more likely to have difficulty reading, understanding, and interpreting most written health texts and instructions.³¹ Our findings related to question understanding and interpretation suggest the need to further consider the issues related to functional health literacy in the **PAINReportIt**[®] program.

The MPQ has been extensively used to measure pain in patients with cancer or other chronic pain conditions,^{2, 19, 32–39} but a computerized version of the MPQ has never been tested with more than a few African Americans and none with SCD. Use of pain assessment instruments is important because they can help SCD patients get a better standard of care.⁴⁰

To our knowledge, there are only two studies that have documented the use of MPQ with African American patients with SCD.^{18, 41} As a computerized version of the MPQ, **PAINReportIt**[®] was effective in capturing the pain experience of African American patients in our study. The cost of **PAINReportIt**[®] \$500 per computer license with discounts available for multiple licenses, is similar to many software programs and less expensive than many others. Clinicians, agencies, and community organizations could easily afford such a cost and can obtain the software from Nursing Consult, LLC by calling 801-414-0627. A significant finding was that almost all these participants reported descriptors consistent with neuropathic pain, but a very small percentage were using adjuvant drugs for pain treatment. Furthermore, the large majority of participants were dissatisfied with the pain that they were experiencing, but most preferred not to tell others about it. These findings suggest that it was easier for study participants to report their pain experience via the **PAINReportIt**[®] program than it was to discuss it in person with a doctor or family member. This finding has important clinical implications, given research evidence that some emergency doctors and hematologists are likely to manifest negative attitudes and beliefs about helping SCD patients manage their pain.⁴² Our study findings show that the data gathered by **PAINReportIt**[®] are sufficient to generate a comprehensive diagnostic report that could help doctors plan and monitor effective pain treatment for African American SCD patients.

There are several reasons for being cautious about the findings from our study. Our first concern is related to the length of the cognitive interview process, which may have introduced a fatigue-related bias in the responses. A few participants did not complete all interview questions because the amount of time required to do so was greater than they could commit to the study. Also, the level of some patients' pain may have biased their responses to the cognitive probes.

The cognitive interviewing approach supports the validity of **PAINReportIt**[®] as a pain measurement tool for African Americans with SCD. Most participants were able to use the tool as intended. Study findings also suggest the need for caution in interpreting the data from several screens because of possible health literacy-related bias in the responses for a few people. Finally, study findings prompted our recommendations that future revisions to the **PAINReportIt**[®] program address the temporal issues of measuring recurrent pain, resolve technological issues related to pop-ups on the body-outline screens, and simplify difficult words to better match the typical health literacy levels of patients. These steps could further enhance the technological aspects, usability, and cultural appropriateness of **PAINReportIt**[®] for African American patients with SCD.

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Figure 1.
PAINReportIt® displayed on an Acer pen-tablet computer.
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Table 1

Words Not Recognized by Participants on the Pain Descriptor Screens (N = 25).

Pain Descriptor Word Screen Screen	Number of Participants	Pain Descriptor Word not Recognized by Participants
Sensory Groups 1–5	10	Lancinating
	8	Lacerating
	1	Sharp
	1	Stabbing
	1	Pinching
	1	Flickering
	1	Gnawing
	1	Quivering
	1	Pricking
Sensory Groups 6–10	4	Rasping
	3	Grueling
	1	Taut
	2	Splitting
	2	Searing
	2	Tingling
	2	Wrenching
Affective Groups 11–15	2	Blinding
	1	Wretched
	1	Torturing
Miscellaneous Groups 17–20	1	Nagging
	1	Radiating
	1	Nauseating
	1	Agonizing,
	1	Penetrating
	1	Piercing
Pain Pattern	1	Transient
	5	Intermittent,
	1	Momentary
	3	Rhythmic
	2	Continuous
	2	Steady
	2	Constant

Table 2

Final Comments about PAINReportIt® Comment Type, Frequency, and Exemplars (n = 18).

Comment Type	Frequency (n)	Exemplar Comments
Enthusiastic	8	<ol style="list-style-type: none"> 1 It's great –give it a 10. Everyone with pain should try this. Help you think about your pain. Help you decide what to do about it. Instructions are very easy. I'm not computer literate, but this was easy. 2 I liked it-it got you to talk about pain because they usually don't ask; it helps. 3 It made me think about myself more; directions were easy to understand. 4 I think it's a great program. Computer use was very easy. 5 Instructions were very easy. I am not computer literate, but this was easy. 6 I think it is cool that you want to know about pain and pain management. How do you feel about having pain. How it affects you emotionally; no other pain outside of crisis pain.
Hopeful	6	<ol style="list-style-type: none"> 1 Maybe this program would help doctors. 2 A better way to deal with pain. 3 I am glad about the medication section –so I can report to the doc. 4 Good that you are doing it. 5 I hope my answers helped our goals. 6 I like it. Once you get used to the program it's easier.
Problems and negative comments	3	<ol style="list-style-type: none"> 1 Directions were really easy... just think, it would help understand what to do, completely didn't know if time frames were specific or overall; was confused use of keyboard. 2 Too many questions. 3 Some questions didn't refer to me and were too long.
Suggestions for improvement	3	<ol style="list-style-type: none"> 1 Add questions about where you see yourself and SC status in future. 2 What to do in a pain crisis. 3 Ask future questions in reference to SC, how has pain affected you over the years.