Use of Handheld Wireless Technology for a Home-based Sickle Cell Pain Management Protocol

Catherine B. McClellan,1 PHD, Jeffrey C. Schatz,1 PHD, Eve Puffer,1 MA, Carmen E. Sanchez,1 BS, Melita T. Stancil,1 BS, and Carla W. Roberts,2 MD

1Department of Psychology and 2Department of Pediatrics, University of South Carolina

Purpose To evaluate use of a handheld electronic wireless device to implement a pain management protocol for participants with sickle cell disease (SCD). Methods Participants were 19 patients with SCD aged 9–20 who experienced vaso-occlusive pain. A single-session training on the use of cognitive–behavioral coping skills was followed by instruction on how to practice these skills and monitor daily pain experience using the device. Daily pain experience and practice of coping skills were collected for the 8-week intervention period using wireless technology. Results High rates of participation, daily diary completion and consumer satisfaction support the use of handheld wireless devices to implement this protocol. A comparison of the rates of self and device-recorded skills practice provides important information about the use of electronic monitoring for behavioral interventions. Conclusion Wireless data transfer technology has significant potential to become a practical method to improve symptom monitoring and communication between patients and providers.

Key words coping skills and adjustment; chronic and recurrent pain; e-health; pain; sickle cell disease.

Introduction Advances in telehealth and internet technology have allowed researchers and clinicians to develop innovative “e-health” applications that improve access to care and health outcomes for adult and pediatric populations (Harper, 2003; Spittaels, De Bourdeaudhuij, & Vandelanotte, 2007). When used to monitor health behaviors and symptoms, researchers have found distinct benefits of e-health applications. For example, researchers investigating self-reported illness symptoms have found electronic pain diaries, or e-diaries, to be superior to traditional paper and pencil methods in terms of compliance to daily diary completion and accuracy in the diary reporting for pain in pediatric sickle cell disease (Palermo, Valenzuela, & Stork, 2004). Using e-health approaches to measure medical regimen adherence has also led to improvements in data collection by allowing researchers to overcome many of the limitations inherent in self-reported adherence measurement, including reporting biases and missing data (Riekert & Rand, 2002). Advances in technology have allowed researchers to develop novel methods to deliver behavioral interventions using computer- and internet-based programs for a range of pediatric conditions including pain, obesity and elimination disorders (Hicks, von Baeyer, & McGrath, 2006; Liss, Glueckauf, & Ecklund-Johnson, 2002; Ritterhand et al., 2003; Williamson et al., 2006). These e-health interventions have the potential to overcome numerous barriers that limit the usefulness of traditional clinic-based interventions, including limited access to care due to rural location or travel difficulties and lack of trained intervention staff (Devineni & Blanchard, 2005; Jerome & Zaylor, 2000).

Internet-based behavioral interventions have most commonly employed participants’ personal computers or study-provided laptop computers for intervention delivery. These interventions have shown significant promise in that they are well received, feasible and effective (Hicks et al., 2006; Williamson et al., 2006). Despite these strengths, there are several limitations associated with delivering internet-based interventions on traditional computers. For instance, using a laptop computer to deliver an intervention incurs a significant cost which reduces the sustainability of the program (Harper, 2003). Further, these
computers are limited in their portability and can require extensive training, technology trouble-shooting, and costly Internet service contracts. As an alternative to these full-size computers, more recent technology has resulted in handheld computers that can be purchased at a fraction of the cost, are attractive and easy to use, and allow for wireless access to the Internet.

As wireless and handheld technology advances, Internet bandwidth improves, and associated costs decrease, many interventions could be primarily home-based and employ wireless technology (Darkins & Cary, 2000). Wireless technology offers several advantages over earlier methods that required data to be downloaded during home visits or via a modem (Palermo et al., 2004; Walker & Sorrells, 2002). By allowing for frequent and automatic data transfer, such technology reduces the likelihood of lost or incomplete data should a device break or be lost. Automatic data transfer also reduces the burden on participants and study staff when compared with devices that require manual data download. At the present time, the feasibility and usability of handheld wireless devices with pediatric populations are relatively understudied.

In an examination of a wireless electronic pain diary, Stinson and colleagues found that standard pain assessment tools, such as visual analog scales, required modification when used on the handheld device (Stinson et al., 2006). Other disadvantages of handheld wireless devices include the small screen size, connectivity issues, and limited software programs available for customizing programs designed to record symptoms and intervention use.

In spite of these limitations, e-health interventions may be particularly well adapted for cognitive–behavioral therapy (CBT) interventions for pain management. Such interventions include the use of relaxation, distraction, and cognitive reframing to reduce pain intensity and frequency, increase the use of active coping strategies, and limit the functional impairment resulting from pain. Researchers have found that these skills can be taught with minimal in-person clinician–patient interaction (Gil et al., 1997; McGrath et al., 1992). Despite its efficacy, CBT skills for pain management have not been adequately disseminated and adopted as the standard of care in treatment of youth with chronic and recurrent pain. Further, many CBT interventions require frequent practice to develop proficiency with coping skills; however, many children may lack incentives to practice these skills on a regular basis, thus preventing the skills from being learned and applied. Technology-based tools for behavioral interventions have also been shown to hold greater appeal to children than traditional pencil and paper approaches and result in greater involvement and learning of the information presented (Chan et al., 2007; Kumar, Wentzell, Mikkelsen, Pentland, & Laffel, 2004; Shegog et al., 2001).

Researchers have employed daily pain diaries and CBT interventions to understand and manage the pain experiences of pediatric patients with sickle cell disease (SCD), a genetic blood disorder characterized by unpredictable pain episodes resulting from vaso-occlusion. A home-based training intervention for SCD pain may be particularly useful given that the majority of SCD pain episodes are treated at home. Of the psychosocial interventions available for pain management, CBT interventions are superior to placebo and efficacious in managing chronic pain in adults and children with SCD (Compas, Haaga, Keefe, Leitenberg, & Williams, 1998; Gil et al., 1996, 1997). These previous studies of CBT interventions for pain in SCD have employed paper and pencil records of skills practice to evaluate the relationship between skills practice, skill use during pain, and treatment outcomes. However, the validity of these self-reported frequencies has not been established, and data on self-reported adherence rates for other health maintenance behaviors have indicated poor correlation between self-reported and actual behavior (Riekert & Rand, 2002). A more comprehensive measurement of participants’ rehearsal and use of the strategies may be helpful in understanding the optimal quantity of training and practice needed for intervention efficacy.

The goal of the current work is to evaluate the feasibility of using a handheld, wireless electronic device to guide skills practice and to monitor daily pain experience in a pediatric SCD population. Specifically, the current work entails a preliminary analysis of the usability, practicality, and technical viability of the device. Regarding outcomes of this work, we anticipate that: (a) the device will be attractive and well received. (b) Participants will demonstrate a 71% or higher daily pain diary completion rate on the days that the device was accessible to them. This rate was selected to demonstrate higher rates than those reported previously for long-term paper pain diary completion in pediatric SCD. Specifically, the rate of 71% falls above the 95% confidence interval of the rates reported by Dampier and colleagues (2002a). (c) This method will allow for an important comparison between rates of self-reported versus device-recorded skills practice.

**Methods**

**Participants**

Participants were 19 children and adolescents with SCD aged 8–20 years and their primary caregivers recruited from regional SCD specialty clinics in the Southeastern...
United States (see Table I for additional details of participant demographics). This sample represents the first 19 consecutive participants who enrolled in the ongoing randomized clinical trial between the dates of January 2007 and October 2008. To be eligible, participants had to: (a) demonstrate adherence with standard SCD treatment as evidenced by a minimum of one health maintenance hematological clinic visit per year and 50% attendance to scheduled specialist appointments over a 24-month period; (b) have had at least one major pain episode (those requiring an emergency department visit or hospitalization) or three other pain episodes in the previous 6 months that resulted in functional impairment; (c) not be receiving chronic transfusion therapy, and (d) not have significant cognitive limitations that would limit the validity of many of the self-report measures that are primary study outcomes. Patients receiving therapeutic doses of hydroxyurea were not automatically excluded as research has shown that even at therapeutic doses vaso-occlusive pain is not uncommon (Ballas et al., 2006; Koren et al., 1999). Sixty patients were assessed for eligibility over a 12-month timeframe. Thirty-six patients did not meet eligibility criteria. Of this sample, 77% (n = 28) patients were ineligible due to infrequent pain, 14% (n = 5) patients were ineligible due to non-adherence with SCD care, and the remaining 9% of the participants were ineligible for other reasons (one patient each due to developmental delays, chronic transfusion therapy, and due to a subtherapeutic dose of hydroxyurea). Of the 24 eligible patients, 19 choose to participate, indicating an 80% participation rate. There were no significant differences between participants and non-participants with regard to age \[ t(22) = 0.43, p = .67, \] gender \[ X^2(1, n = 24) = 1.36, p = .24, \] or SCD subtype \[ X^2(1, n = 24) = 1.26, p = .26 \]. Of those 19 participants, the majority (n = 10) were receiving therapeutic doses of hydroxyurea. Nine participants were allocated to the intervention and 10 were allocated to the waitlist control.

**Procedures**

**Recruitment and Assignment to Study Conditions**

Institutional ethics approval was obtained prior to starting any participant recruitment. Potential participants were identified by their treating Hematologist. The Principal Investigator (PI; first author) and the Hematologist reviewed the patient’s medical chart to assess eligibility. Eligible families were approached by the researcher at their routine hematological health maintenance appointment. Parent informed consent and child assent was obtained from families who agreed to participate and an intake session scheduled for that day or the earliest possible convenient date. At the intake session, the parent and child met with the researchers and a research assistant separately to complete baseline measures for the intervention outcome research (not described in the current study), and then randomly assigned to one of the two study conditions using random assignment without replacement.

**CBT Coping Skills Training**

Participants in the intervention condition received the CBT coping skills training immediately following intake procedures. Participants in the waitlist control group received the skills training ~2 months after intake procedures. The PI followed standardized procedures, including a step-by-step guide for intake procedures and a script for the skills training, to ensure treatment integrity for this and all other study components. Participants were provided the opportunity to have their parent present. The majority (11 participants, 65%) elected to have their parent present during the skills training. Those who did not have their parent present were most commonly in the older range of ages, between 15 and 20 years. The training session involved participatory activities and demonstrations using materials to engage the youth in understanding the mechanisms of SCD pain, and how CBT methods help one to cope with pain. For example, deep breathing was introduced using a red ball and a pump, and blockages caused by the clumping of sickled cells was explained using small water balloons and a clear plastic tube. Youth were asked about their favorite sports star or entertainer in order to discuss how CBT skills could help these icons shift their focus away from their discomfort so that they could put forth

| Table I. Participant demographic information (n = 19) |
|---------------------------------|------------------|
| Participant age                 | Range            |
| Mean (SD)                       | 9–20 years       |
| Gender (no.)                    |                 |
| Female                          | 13 (68%)         |
| Male                            | 6 (32%)          |
| Racial background (n,%),        |                 |
| African-American                | 19 (100%)        |
| Reporting caregiver (n,%),      |                 |
| Mother                          | 17 (90%)         |
| Father                          | 1 (5%)           |
| Grandmother                     | 1 (5%)           |
| Distance from participant home to clinic (miles) |         |
| 0–24                            | 9 (47%)          |
| 25–50                           | 5 (26%)          |
| 50–74                           | 0 (0%)           |
| 75–100                          | 4 (21%)          |
| >100                            | 1 (6%)           |
their best performance. Each CBT technique was introduced using examples relevant to the participant along with the sound file that guided the participant through the skills practice, including progressive muscle relaxation, deep breathing, and guided imagery skills. The sound files for the skills guides were loaded on the device and could be played using the internal speakers or through headphones. The duration of the skill guides was ~1 min for the deep breathing skill and 4 min for the progressive muscle relaxation and guided imagery skill. The guided imagery script was generic to allow for the participant to change and modify their “favorite place” without having to change and reload the guide on the device. When introduced, each new skill was discussed along with a handout that included the same icons on the device accompanied by brief text to reinforce the information presented when introducing each skill. After reviewing how the specific skill could be used for improving pain management, participants navigated the device to practice the skill and to familiarize themselves with how to access the skill guides on the device. Details of how to practice the skill were reviewed and documented on a paper form included in the participants’ packet of take home materials.

Completion of the Daily Pain and Activity Diary on the handheld wireless device was explained and the participant was shown how the diary was transmitted to the researcher via e-mail. Participants, parents and the PI worked together to select a time of day that allowed the participant to have enough time to practice the skills and complete the diary. The PI provided and reviewed handouts for parents and children with device instructions. Families were also provided with the PI’s contact information, a manual for the device, the device charger, and a postage pre-paid envelope to return the device to the researcher should any problems occur. In accordance with local school rules, participants were instructed to refrain from taking the device to school. The CBT training session and instructions on the handheld wireless device typically took ~2 hr total time.

Three days after the initial visit, families were contacted by telephone to address questions and ensure implementation of skills. Families received a weekly telephone contact at a pre-arranged time to address any new difficulties with the protocol. Pain diaries and other data were sent daily via wireless technology. If participants did not complete a pain diary for three consecutive days, they were contacted to check on barriers to adherence. Any reports of medical difficulties were relayed to clinical staff for follow-up. Adverse events were recorded and relayed to the IRB. Two months after the initial skills training session intervention participants completed the post-intervention measures and returned the device.

**Handheld Wireless Electronic Device**

Custom software was loaded on a Motorola Q Smartphone (Motorola Inc, Schaumburg, IL), which will be referred to as “the device” throughout this article. The device is a combination of a cellular telephone and personal digital assistant with wireless capabilities. For the purposes of the current work, the telephone capabilities were disabled, but other data-transfer services were available. The device costs approximately $200, is approximately 4 inches tall, 3 inches wide, and half inch thick and weighs 4 oz. For additional information on the device, please visit the manufacturer’s website (www.motorola.com). Each device was provided in a clear hard plastic case for protection.

The device and software were designed to make coping skills practice, daily pain reporting, functional limitations, and self-monitoring of skill practice attractive and straightforward. For example, icons for the coping skill audiofiles were symbols to represent the skill (e.g., a red balloon for deep breathing) and used consistently throughout the program when the skill was referred to on the device or on the paper handout used during the skills training session.

For the purpose of the current study, the device was loaded with two programs: a daily pain diary program and a program to deliver and monitor audio files to guide coping skills practice (additional details on the coping skills guide provided in the procedures section). Questions for the daily pain diary were presented in order to assess morning and evening pain, followed by questions about sleep quality, functional limitations, and use of the coping skills program. One question was presented on the screen at a time and a response was required before the next question was presented. Responses were selected by using the corresponding key on the keyboard. Once a response was selected, it remained highlighted on the screen. At the bottom of each screen, options for returning to the previous screen and going on to the following screen were provided so that participants could review their responses and make changes, if necessary.

The device was programmed to compile data into text files that were sent electronically via a wireless internet connection to a research e-mail account on a secure server created specifically for data receipt. Data were sent immediately after any participant completed a pain diary entry or a skills practice session. The data were sent in a format that was imported easily into excel files for data management and analysis, but used a unique study
identifier for the participant and no meaningful variable labels to those outside the research team. This system allowed researchers to ensure confidentiality while: (a) monitoring how often participants completed pain diaries and practiced their skills, (b) minimizing opportunities for data to be lost, and (c) troubleshooting problems with devices’ internet connections quickly and efficiently. Prior to study entry, each device was tested to ensure that the software, hardware, and wireless data transfer functioned properly.

Measures

Background Information Questionnaire
Caregivers completed a questionnaire to provide demographic information.

Daily Pain and Activity Diary (DPAD)
The DPAD represents a combination of the Daily Pain Diary (Gil, 1994) and the Daily Home Diary (Dinges et al., 1997). The DPAD has been used successfully in SCD intervention studies with children as young as 9 years of age (Powers, Mitchell, Graumlich, Byars, & Kalinyak, 2002). The diary assesses the severity of pain using a 10-point Likert scale with anchors and a report of the location of the pain. Participants also record sleep quality, participation in functional activities, and the self-reported use of medication and cognitive–behavioral coping skills that day. Diaries typically take 2–3 min to complete. Participants are provided incentives of $1 per day to complete daily pain diaries. Participants were specifically instructed that the incentive was provided for pain diary completion, and not for skills practice. On completion of the daily diary, the responses and details of coping skills practice are sent as a text file via wireless internet to a secure server and routed to the PI via e-mail.

Device-Recorded Logs of Skill Practice
Electronic tallies of the frequency of accessing the coping skills module on the handheld device were sent with the daily diary text file as an unobtrusive measure of skill practice.

Logs of Participant Contacts
Records of all contacts made by the researchers with the participants were logged, including the purpose of the contact (e.g., device malfunction), the type of information exchanged, and the time required to clarify/resolve the issue triggering the contact. Review of contact logs allowed the researcher to examine device malfunctions rates and reasons, and evaluate the timeframes required for the resolution of these concerns.

Consumer Satisfaction Form (CSF)
The CSF was comprised of five questions designed to assess parent and child satisfaction with the pain protocol. Questions included level of difficulty in using the protocol, perceptions of efficacy of the pain management strategies, satisfaction with the protocol, and whether the parent or child would recommend the protocol to others. Participants rated each question using a visual analog scale (VAS) to record each their responses, a preferred method in pediatric research (McGrath, 1990; Varni, Walco, & Wilcox, 1990). The form also invited participants to provide comments about participation in an open-ended question format. This measure was completed immediately after the post-intervention measures.

Results

Several variables were used to evaluate participants’ overall perception of the protocol, including the rate of eligible participants electing to participate and post-intervention satisfaction rates. Initial protocol attractiveness was evaluated by examining recruitment and retention rates. The majority (80%, n = 19) of eligible participants elected to participate, indicating a high level of protocol attractiveness. Reasons for non-participation included not having enough time to participate (three families) and satisfaction with current pain management techniques (two families). All of the participants allocated to the intervention received the intervention and completed the follow-up measures. Two of the participants in the waitlist group did not return for the intervention and were non-responsive to the attempts at contact; therefore, reasons for discontinuing their participation are unknown and the total sample decreased from 19 to 17 participants. All of the eight waitlist participants who received the intervention completed the follow-up measures.

Participant and parent ratings of consumer satisfaction completed at the post-intervention period indicated high levels of satisfaction with the protocol. Consumer satisfaction data were available for 16 of the 17 participants. Questions evaluating the difficulty of coping skills practice and diary completion had anchors of “very easy” and “very difficult” at each endpoint, such that lower scores on the VAS indicated greater ease of use (0 = very easy; 100 = very difficult). Both parents and youth rated the coping skills (parent: M = 11.31, SD = 14.31; child: M = 9.94, SD = 21.20), and diaries as easy to use (parent: M = 20.00, SD = 22.56; child: M = 17.56, SD = 27.46).

Consumer satisfaction ratings indicated the coping skills intervention was well received. For these questions
anchors of “not at all” and “very much” were used at each endpoint such that higher scores on the VAS indicated greater satisfaction with the protocol (0 = not at all; 100 = very much). Both parents and children rated that the protocol was helpful for pain management (parent: $M = 79.19$, $SD = 21.73$; child: $M = 81.44$, $SD = 21.58$). The protocol was rated as well-liked (parent: $M = 92.75$, $SD = 14.97$; child: $M = 89.38$, $SD = 16.68$) and raters indicated that they were highly likely to recommend the program to others seeking to develop their pain management skills (parent: $M = 95.31$, $SD = 7.90$; child: $M = 93.75$, $SD = 11.64$). Paired-samples t-tests demonstrated no significant differences between parent and child ratings for any of the consumer satisfaction ratings.

**Technical Viability of the Device**

Devices were available and fully functional to the participants on 87% of the study days. Device malfunction occurred at one or more points in participation for eight of the participants. These difficulties were resolved within 2–10 days. This resolution period included the number of days of malfunction prior to detection and the days that it took to address the malfunction or get a replacement device to the participant. Replacement devices were provided using the method most convenient to the family, either via express mail if the participants lived a distance from the clinic ($n = 2$), at the clinic ($n = 4$) or at the participant’s home ($n = 2$).

The majority ($n = 6$) of the malfunctions were detected by the PI during routine telephone check-ins or when a period of 3 days without electronic communication had been recorded. The remaining malfunctions ($n = 5$) were detected following participant-initiated contact to the PI. These concerns ranged from minor problems, such as the screen “freezing” that were addressed with basic troubleshooting techniques over the telephone for six of the cases of device malfunction; to concerns that required a device exchange for five of the cases of device malfunction. Of the devices that required an exchange, the majority appeared to be working without problem, likely indicating a transient problem in the device functioning or participant factors including limited technology troubleshooting knowledge or adherence concerns. For three of the cases, the complicated nature of the malfunction required that the device be returned to the manufacturer. The rates of device malfunction did not occur at a greater frequency in participants who lived in the more rural areas. One participant had sequential difficulties with multiple devices that resulted in the device freezing and requiring a manual reset totaling 30 days of device malfunction. Ultimately it was concluded that this particular participant was downloading large programs that overwhelmed the device capabilities causing the device to crash.

**Diary Reporting**

On average, diaries were completed on 76% of the days that the devices were available to the participants ($SD = 18\%$, range: 45–100\%). To date, there has been no incomplete data when the diary has been accessed (100\% of items completed). Periods of >3 days of missing diaries for reasons other than device malfunction occurred at some point over the course of the study for all but one of the participants. Reasons for missing diary entries fall into three major categories: forgetting (71\%), major illness or hospitalization (17\%), and device being inaccessible due to loss or theft (12\%). Thirteen of the participants reported that they forgot to complete their diaries at some point over the 2-month period with an average of 7 days of forgetting per participant (range: 3–19 days). Two of these participants had major life changes, including a move and a death in the family that resulted in diary non-completion. Major illness and hospitalization were cited by four participants as the cause of their non-reporting, resulting in an average of 7 days of non-reporting (range: 3–14 days). Finally, over the course of the study-to-date, one device was reported stolen and two devices were temporarily lost, but located several days to several weeks later. Lost or stolen devices accounted for an average of 7 days of non-reporting (range: 5–10 days).

Rank order correlations were used to examine association between age, gender and practice rates. Age correlated $r = -0.18$ with self-reported practice rate and $r = -0.34$ with the device-recorded rate. Gender correlated $r = -0.26$ with self-reported practice rate and $r = -0.39$ with the device-recorded rate, indicating a trend for higher practice rates for males. The mean age for males and females was highly similar ($t = 0.90$, $p = .40$).

**Guided Skills Practice**

Self-report of skills practice indicated an average practice of 1.7 times per days with a range of 0.3–2.7 times per day on days that the device was accessible to the participants. Of the three skills, Deep Breathing was reported to be the most frequently practiced skill (Table II). Self-reported rates of Deep Breathing were significantly higher than self-reported rates of Guided Imagery, $t(16) = 2.74$, $p = .01$. Self-reported rates of Progressive Muscle Relaxation were not significantly different than rates of Deep Breathing, $t(16) = 1.65$, $p = .12$ or Guided Imagery, $t(16) = 0.66$, $p = .52$. Device-recorded measurement of skills practice indicated that participants accessed the skills at a rate of 0.8 times per day, with a range of 0.1–2.5 times per day. Similar to self-report of skills practice,
participants accessed the Deep Breathing significantly more frequently than Guided Imagery, \( t(16) = 3.82, p = .00 \), and Progressive Muscle Relaxation \( t(16) = 4.20, p = .00 \). Device-recorded rates of Progressive Muscle Relaxation and Guided Imagery were not statistically different, \( t(16) = .44, p = .66 \).

The pattern of use of the device for skill practice changed during the intervention with fewer total practice sessions over time. The device-recorded practice rate showed a trend toward decreasing from the first half of the intervention period to the second half, from 1.1 to 0.6 sessions/day; \( t(16) = 1.66, p = .11 \). However, this pattern appeared to be due to adopting a preferred coping skill rather than decreasing the frequency of practicing at least one skill in a day. During the first half of the intervention period youths accessed the practice modules approximately one out of every 2–3 days and tended to access multiple skills on those days. In the second half of the intervention period participants accessed the skills practice modules approximately one out of every 2 days and tended to access only one skill.

### Discussion

The current work investigates the feasibility of using a handheld wireless device used to capture daily pain experience and deliver CBT skills for pain management. Preliminary findings provide support for the use of this novel method, with high rates of consumer satisfaction and automated procedures that facilitated the reduction of missing and lost data. This work also provides novel information on frequency of CBT skills practice and allows for comparisons between self-reported and device-recorded skills access.

Rates of diary completion over an 8-week period were comparable to those found by researchers using e-diaries for a 1-week period, suggesting that this method may provide a feasible method for tracking health behaviors and symptoms in pediatric SCD for more than brief periods (Palermo et al., 2004). Research using traditional paper and pencil diaries to assess daily pain over a longer period of time has demonstrated significant variability with daily completion rates ranging between 55% and 96% (Dampier et al., 2002a; Gil et al., 2001; Powers et al., 2002). Direct statistical comparisons between the present research and previous studies would be questionable because the goals and methods differed significantly. Nonetheless, in the context of a home-based intervention project, we achieved a relatively high rate given minimal research efforts.

The current methodology appears to hold greater appeal than traditional methods, resulting in a more representative sample of participants. For example, research using traditional paper and pencil diaries to investigate daily pain experience in pediatric SCD enrolled ~25% of the eligible participants (Dampier et al., 2002a). Researchers conducting a cognitive–behavioral pain management intervention designed to facilitate access to care through home-based delivery of coping skills training indicated a participation rate of 57% of the eligible participants (Schwartz, Radcliffe, & Barakat, 2007). In the current work 80% of eligible patients choose to participate. This increased rate of engagement when using e-health interventions is also demonstrated in the rates of skills practice, with the current rate of self-reported skills practice of 1.7 times per day comparing favorably that reported by researchers using audiotape delivery of skills practice (1.3 times per day) with pediatric patients with SCD (Gil et al., 2001). It is important to note that we are in the preliminary stages of a larger study, and these promising rates of participation and adherence need to be maintained over a longer recruiting period with more families to make any definitive statements about the incremental benefit of this approach. Additionally, further investigation of the long-term use of this and other e-health interventions is merited. For example, researchers of an internet-based

### Table II. Diary completion and skill practice rates over the 8-week period of home-based coping skills support (n = 17)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of 8-week trial</td>
<td>Number of days ± SD</td>
</tr>
<tr>
<td>Range</td>
<td>30–56</td>
</tr>
<tr>
<td>Mean number of days ± SD</td>
<td>54 ± 11</td>
</tr>
<tr>
<td>Number of days with device</td>
<td>Number of daily diaries completed</td>
</tr>
<tr>
<td>Range</td>
<td>22–56</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>47 ± 11</td>
</tr>
<tr>
<td>Number of daily diaries completed</td>
<td>Range</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>12–56</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>35 ± 13</td>
</tr>
<tr>
<td>Self-reported frequency of skills practice</td>
<td>Device-recorded rates of guided coping</td>
</tr>
<tr>
<td>(% of days with skills practice on days device was accessible)</td>
<td>skills practice (% of total days on days device was accessible)</td>
</tr>
<tr>
<td>Deep breathing</td>
<td>60% (15–91%)</td>
</tr>
<tr>
<td>Progressive muscle relaxation</td>
<td>56% (7–83%)</td>
</tr>
<tr>
<td>Guided imagery</td>
<td>55% (0–91%)</td>
</tr>
<tr>
<td>Device-recorded rates of guided coping skills practice</td>
<td>Deep breathing</td>
</tr>
<tr>
<td>(% of total days on days device was accessible)</td>
<td>35% (2–100%)</td>
</tr>
<tr>
<td>Guided imagery</td>
<td>24% (0–82%)</td>
</tr>
<tr>
<td>Guided imagery</td>
<td>22% (0–82%)</td>
</tr>
</tbody>
</table>
pediatric weight-loss program found that the use of their program and associated improvements in weight loss declined over a 2-year period, suggesting that supplemental forums for behavioral change may be necessary to maintain treatment gains over time (Williamson et al., 2006).

The use of technology described in this report also permits an unobtrusive measure of how frequently skills are being accessed and the correspondence between device-recorded and self-report rates of skills practice. Our work suggests participants typically may over-report skills practice with self-report, although we have noted individuals who also appear to under-report via self-report. Although it is tempting to conclude the device-recorded measure is more accurate than self-report, further research is needed to verify this assumption. Comparing our rate of skills practice via the unobtrusive measure to what is found by other researchers is complicated because of the lack of research comparing self-reported rates of behavioral intervention practice to electronic measurement of practice. Additionally, unlike applications that allow for the measurement of distinct behaviors, such as blood glucose monitoring systems and MDI logs for asthma inhaling techniques, our device-recorded measurement technique captures the frequency with which the skills were accessed on the device only and does not indicate whether the skills were practiced without the device or merely accessed but not actually practiced. The current discrepancy in reporting of skills practice could be attributed to social desirability effects or a misunderstanding about what constituted skills practice. Specifically, despite efforts by the PI to reinforce that skills practice should be done with the device, it is possible that participants were practicing and using the coping skills without accessing them on the device.

Although the use of technology in the current work presented several distinct advantages in terms of traditional challenges to home-based monitoring and intervention work, there is a new set of challenges for effective use of these new methods. In particular, the rates of technical problems over the 8-week period were not trivial. Given the longer time frame of our study, our rates of device malfunction were consistent with those found by other researchers employing handheld devices to record daily pain report (Palermo et al., 2004; Walker & Sorrell, 2002). Fortunately, the automatic wireless download system allowed us to identify and resolve malfunctions difficulties early, resulting in more complete data than if we had used other data transfer systems. Additionally, while it is not necessarily reflected in the quantitative data, our ability to resolve device malfunction difficulties over the telephone improved over the course of the study as our familiarity with the devices improved. However, the current rates of device malfunction remain higher than desirable for routine use of the devices in applied practice. The need to replace devices (the most common solution offered by the device provider during our study to address malfunction) creates missing data and additional time and energy on the part of the researchers than might be anticipated without experience with the devices.

Additional work is needed to refine the current protocol and evaluate the efficacy of this methodology on improving pain related outcome variables. It will be important to consider what variables influence use of skills and practice in order to understand who to target this program to for maximal effectiveness. Other research that also employed primarily relaxation-based CBT skills practice (Gil et al., 2001) found that age and gender predicted self-reported skills practice, with younger age and female gender predicting increased frequency of skills practice. Although based on a small sample, the current results suggest possible differences between those found by Gil and our electronic delivery method. Specifically, in the current work we found no age-related effects and a trend towards greater diary completion for males. Gender differences in e-diary engagement were also noted by other researcher, who found that males demonstrated greater compliance to e-diaries than did females (Palmero et al., 2004). Consideration of other factors, including the relative impact of family support for the intervention, participant adherence to their general medical care, and pain history, is also needed to develop and refine an intervention that can be used with the broadest possible spectrum of patients.

E-health approaches represent an exciting and potentially cost-effective method to improve measurement of health outcomes, engagement with behavioral interventions, and communication between patient and healthcare staff. These methods address limitations associated with traditional techniques such as paper diaries, including missing or incomplete data, allowing for greater confidence in conclusions drawn from the data, and greater opportunity to troubleshoot problems that occur for participants in treatment adherence. The specific wireless technology with automatic data transfer that we are testing may have particular usefulness in situations where care would be improved with increased frequency of feedback between the patient and health care providers. For example, programs designed for pediatric diabetes may also benefit from more regular feedback to health care providers so that shifts in blood glucose and difficulties with
self-management can be detected automatically and addressed promptly by both patients and health care providers. If implemented properly, such techniques could improve patient-provider communication; however, such methods may also place greater responsibility on the health care provider for direct follow-up communication with the patient or family. Interventions using handheld devices have potential to be implemented with a significant savings relative to laptop-based interventions, despite the cost of unintended technical support. Research has demonstrated that e-health interventions can result in improved knowledge, monitoring and health behavior change; however, additional research is needed to evaluate the associated healthcare savings. Future technological changes in the delivery of health care often may create broader changes to traditional roles and patient-provider relationships that must also be addressed in the training of health care providers.

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