IEEE EMBS Int Conf Biomed Health Inform. Author manuscript; available in PMC 2017 February 01.

Published in final edited form as:

IEEE EMBS Int Conf Biomed Health Inform. 2012 January ; 2012: 408–411. doi:10.1109/BHI.2012.6211602.

SickleREMOTE: A Two-Way Text Messaging System for Pediatric Sickle Cell Disease Patients

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Abstract

Sickle cell disease, the most common hemoglobinopathy in the world, affects patient lives from early childhood. Effective care of sickle cell disease requires frequent medical monitoring, such as tracking the frequency, severity, and duration of painful events. Conventional monitoring includes paper- or web-based reporting diaries. These systems require that patients carry forms, which are easily lost, or laptop computers, which are impractical to scale to large populations. Both are prone to sporadic use by older adolescents due to lack of reminders. In this paper, we design and prototype a Sickle cell disease REporting and MOnitoring TElemedicine system (SickleREMOTE), aiming to resolve limitations of conventional monitoring diaries. This monitoring system is configured as automated short message service text (SMS-text) messages that arrive at a mobile phone anywhere on a cellular network. The messages may be reminders to encourage treatment adherence or questionnaires to collect self-assessed clinical data relating to treatment adjustments. Patients respond to the messages using pre-determined templates and a cloud database parses and stores messages automatically. Providers use a web-based interface to view, analyze, and download collected data. SickleREMOTE is developed by Georgia Institute of

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Technology in conjunction with Children's Healthcare of Atlanta (CHOA). System effectiveness will be evaluated using a trial of 30 adolescents with sickle cell disease and measured by response rate, time to response, error rate, and correspondence with data collected by telephone calls.

Introduction

Sickle Cell Disease (SCD) is the most prevalent hereditary disease. It is characterized by chronic hemolytic anemia and vaso-occlusion, leading to irreversible organ damage as early as 9 months of age. Vaso-occlusive pain crisis (VOC) is the most common reason for hospitalization, comprised of acute painful episodes in multiple body sites, such as the abdomen and extremities. SCD patients who suffer a larger number of painful crises often require frequent hospital readmissions, and are at increased risk of early mortality [1].

Effective SCD management includes tracking treatment adherence in the context of the severity of a patient's pain crisis. Previous studies support that adherence to prescribed medications is directly linked to health outcome [2]. The standard instruments used for tracking this data are paper- based or web-based diaries. These are ineffective due to no reminding functions, incomplete data recording, and lack of context with clinical status when compared with electronic reporting [3]. According to the Pew Internet & American Life Project, about 75% of 12–17 year-olds now own cell phones [4]. It exceeds the percentage with computer access and becomes the favored communication hub for this population. Among cell phone activities, short message service text (SMS-text) messaging is the most prevalent, both in overall likelihood and in frequency [4]. SMS-text provides an unobtrusive means of communication. It can be scaled for a large number of users, is widespread and well-understood, and saves the cost of custom-built web interfaces or expensive mobile devices. Finally, SMS-text provides long-term usage robust to' system or user equipment upgrades. Studies have demonstrated that SMS-text can be an effective tool in clinical and health behavior interventions [5], clinical management [6], and health-related behavior modification [7], However, we are not aware of any published study investigating SMS-text in the SCD population. In this paper, we design and prototype the SickleREMOTE, a Sickle cell disease REporting and MOnitoring TElemedicine system, targeting SCD children and young adults who are comfortable using SMS-text technology. The two-way SMS- text system aims to resolve limitations of conventional monitoring diaries.

System Requirements

A. Use Cases

Use cases are represented using the Unified Modeling Language (UML). Two main roles are defined as Caregiver, including healthcare nurses, doctors, and case managers, and Patient who are children with all genotypes of SCD. Six use cases of these two roles are shown in Fig. 1.

1. Patient Profile Management: Caregivers manage (e.g., add and update) patient profiles like telephone numbers.

2. Reminder/Reporting Scheduling: Caregivers set up schedules for SickleREMOTE to automatically send patients SMS-texts as reminders.

3. Critical Threshold Setting: Caregivers set critical thresholds on specific health aspects like unusual high pain levels. When a critical threshold is reached, the system can notify associated caregivers for a just-in-time follow-up.

4. Scheduled Reporting: Patients report via SMS-text following the schedules set by associated caregivers.

5. Unscheduled (Urgent) Reporting: If no critical threshold is reached, caregivers do not receive any SMS-text message directly from patients. However, an emergency may still occur even if no threshold is reached. Thus caregivers may not be immediately aware of such emergency occurrences. In this use case, a patient can make an unscheduled report, and the system can send a rapid SMS-text notification to the associated caregivers for follow-ups.

6. Reported Data Management: Caregivers retrieve, manage, and analyze, high volume reported data from one of more associated patients.

B. Measures and Reminders

1. Brief Pain Inventory Short Form: We adopt Brief Pain Inventory short form (BPI-SF) in the SickleREMOTE format for daily-based pain assessment. BPI-SF is a validated, widely used, self-administrated questionnaire developed to score pain intensity and its interference with daily functions [8]. It has been used in cancer studies [9] and other chronic conditions, such as osteoarthritis [8]. BPI-SF assesses sensory pain intensity on a numerical rating scale (NRS) with 0–10 where 0 = no pain and 10 = worst imaginable pain. On the SickleREMOTE, modified BPI-SF evaluates the impact of reactive pain on daily functions, including general activity, mood, walking ability, normal work, relations, sleep, and enjoyment of life.

2. *PROMIS Pediatric Pain Interface Scale:* The National Institute of Health (NIH) Patient Reported Outcomes Measurement Information System (PROMIS) initiative is developing self-reported measures which cover a wide variety of health domains, including physical function, pain, fatigue, emotional health, and social health. The PROMIS Pediatric Cooperative Group focuses on the development of pediatric self-report scales for ages 8 through 17 years. Unlike the daily-based BPI-SF, all items of PROMIS pediatric scales use a 7-day recall period. Thus, in addition to BPI-SF, we include the PROMIS Pediatric Pain Interference short form in the SickleREMOTE for a weekly- based pain assessment [10, 11].

3. *PROMIS Pediatric Physical Function Scales:* A physical impairment is defined as any disability which substantially limits the physical function, such as mobility and upper extremity. Chronic anemia in SCD can severely limit an individual's exercise tolerance and capacity for physical exertion. From a pediatric point of view, SCD children suffering physical impairment may be

experiencing more difficulties with academic performance at the start of formal schooling [12]. In order to deliver standardized assessment on limitations of physical function, the SickleREMOTE allows children to report outcomes of two questionnaires by the PROMIS Pediatric Cooperative Group, regarding mobility and upper extremity [11].

4. *Pulse Oximetry:* Children with SCD usually have mild hypoxemia, an abnormal deficiency of saturated oxygen in arterial blood ($Sa0_2$). The monitoring of arterial hypoxemia is important in the management of SCD patients who are suspected of suffering acute chest syndrome. Pulse oximetry is the most rapid, noninvasive method allowing the assessment of the oxygenation of a patient's arterial hemoglobin. Modem pulse oximeters are portable, battery- operated, and can be monitored. They are available for home blood-oxygen monitoring. A child can measure the current oxygen saturation using a portable oximeter, and report the value via a SMS-text.

5. *Preventive and Medication Reminders:* Early diagnosis and prevention of complications is critical in SCD treatment. For children with SCD, nonadherence to prescribed medical regimens may result in serious complications, particularly as they reach adolescence [13]. The SickleREMOTE allows caregivers to set up automatic reminding schedules. We prompt children to acknowledge compliance after taking one or more of following recommendations or medications [14]:

    1. Interventional therapies to reduce the frequency of pain crises and acute chest syndrome (e.g., hydroxyurea and inhaled steroids)

    2. Daily preventative measures to reduce pain crises (e.g., rest, hydration)

    3. Adjuvant therapies like antibiotics to prevent infections and folic acid to prevent severe anemia

System Development and Results

A. Short Message Service (SMS) Gateway

The SickleREMOTE is a two-way communication system (Fig. 2). A SMS gateway can send an automated SMS-text from the system without requiring a mobile phone. Instead of sending responses directly to caregivers, patient responses go to the gateway, and the gateway forwards the responses to the back-end server. We implement our SMS gateway using the commercial service, TextMarks. TextMarks uses group keywords that allow the SickleREMOTE to interact with subscribers (i.e., SCD patients) in a group. Following predefined schedules, the system can trigger the TextMarks service to send SMS-text to a specific patient, or broadcast to all patients in the same group.

After receiving a new SMS-text from a patient, TextMarks forwards the content to the cloud server based on the keyword. Then the cloud server can parse the message, and store the results into the database.

B. Cloud Computing Server

Development of traditional databases introduces several challenges, such as the hardware cost and the potential of loss of data. Cloud Computing refers to computing resources in which end users access the computing infrastructure remotely over the Internet (the "cloud"). We built our cloud infrastructure on the Google App Engine (GAE), the cloud computing business platform operated by Google, Inc. Data is stored in Google's Big Table technology with database query and transaction capabilities. The cloud-based database is free for low-utilization systems, but can automatically scale the database for a fee if the system is in high demand. This solution can manage outpatient tracking of a large, geographically-diverse population. Most importantly, the GAE introduces Sandbox technology that isolates the database and protects sensitive personal health data from being violated. As shown in Fig. 2, information stored in the SickleREMOTE's cloud database includes user (i.e., caregiver and patient) profile, reporting and reminding schedules, reported data, and critical thresholds of measures. It controls the SMS gateway (i.e., the TextMarks) to send scheduled reminding messages to patients and parse responded content from the gateway. For emergency occurrence, it can perform role- and rule-based logic interpretations of collected data, and set up appropriate alerts and notifications to caregivers.

C. Web-based Management Tool

Using the Google Web Toolkit (GWT) development framework, we provide a web-based management tool that can accesses the cloud server. Caregivers can manage (i.e., create, modify, and remove) patient profiles like telephone numbers and set up patient reporting schedules. The tool contains powerful query and transaction capabilities, helping caregivers efficiently retrieve and manage high volume reported data. For example, the Report Scheduling Interface allows a caregiver set reporting schedule with critical thresholds on specific health aspects, like pain levels, which allow the system to alert the caregiver for just-in-time follow-ups (Fig. 3). Afterwards, the caregiver can retrieve a patient's reporting history, such as reported pains with intensities and locations in past two weeks (Fig. 4).

D. SMS-text Formatting

Current SMS-embedded healthcare systems do not impose format restrictions on user reports. Manually processing unformatted messages requires effort from medical staff, and may result in human interpretation error. We develop a computer readable format to provide wide coverage of reporting styles. The format templates and reporting instructions are embedded in the messages sent to the patient. The patient forwards the incoming message to the TextMarks phone number (41411) by replacing data placeholders (e.g., X in template) with a response according to instructions in the question. The patient has no need to remember any template.

They only need to recognize the data placeholders. Messages sent to patients are formatted as *groupKeyword {template with X}@question/instruction* Patient responses are expected to have a similar format, but everything after the @ symbol is ignored by the system parser, which is shown as *groupKeyword {template with data}@ignored. groupKeyword* allows the TextMarks gateway forward the message to our database. As for pain location (LOC in template), we provide eight symbols to cover most common pain sites in SCD [15], including HEAD, CHEST, BELLY, BACK, ULEX (upper left extremity), UREX (upper right extremity), LLEX (lower left extremity), and LREX (lower right extremity).

Conclusions

Management of patients with chronic medical conditions, such as SCD, is a well-recognized public health problem. Conventional paper- or web-based monitoring systems introduce error and data lapses that may result in inaccurate clinical trial results, dissatisfaction with health care, preventable complications, or hospital readmissions. We present SickleREMOTE using SMS-text technology to build a two-way communication channel in pediatric SCD healthcare. It automatically sends messages to encourage treatment adherence or remind patients to complete self-assessments via standard pain and physical function questionnaires. Patients use pre-defined templates to respond to messages so the cloud system can parse messages automatically and store the data directly in a cloud database. In addition to reported data, the cloud database stores user profiles, reporting schedules, and critical thresholds that can be retrieved and managed by a web-based tool. In future, we will use and evaluate the SickleREMOTE at Children's Healthcare of Atlanta (CHOA) and other participating institutions in the Aflac Cancer Center & Blood Disorders Service. After being approved by the institutional review board (IRB) of CHOA, Emory University, and Georgia Institute of Technology, a pilot and feasibility study will use the Technology Acceptance Model (TAM) to measure perceived ease of use, perceived usefulness, attitude, and behavior intention of adopting the SickleREMOTE by children and youth with SCD [16].

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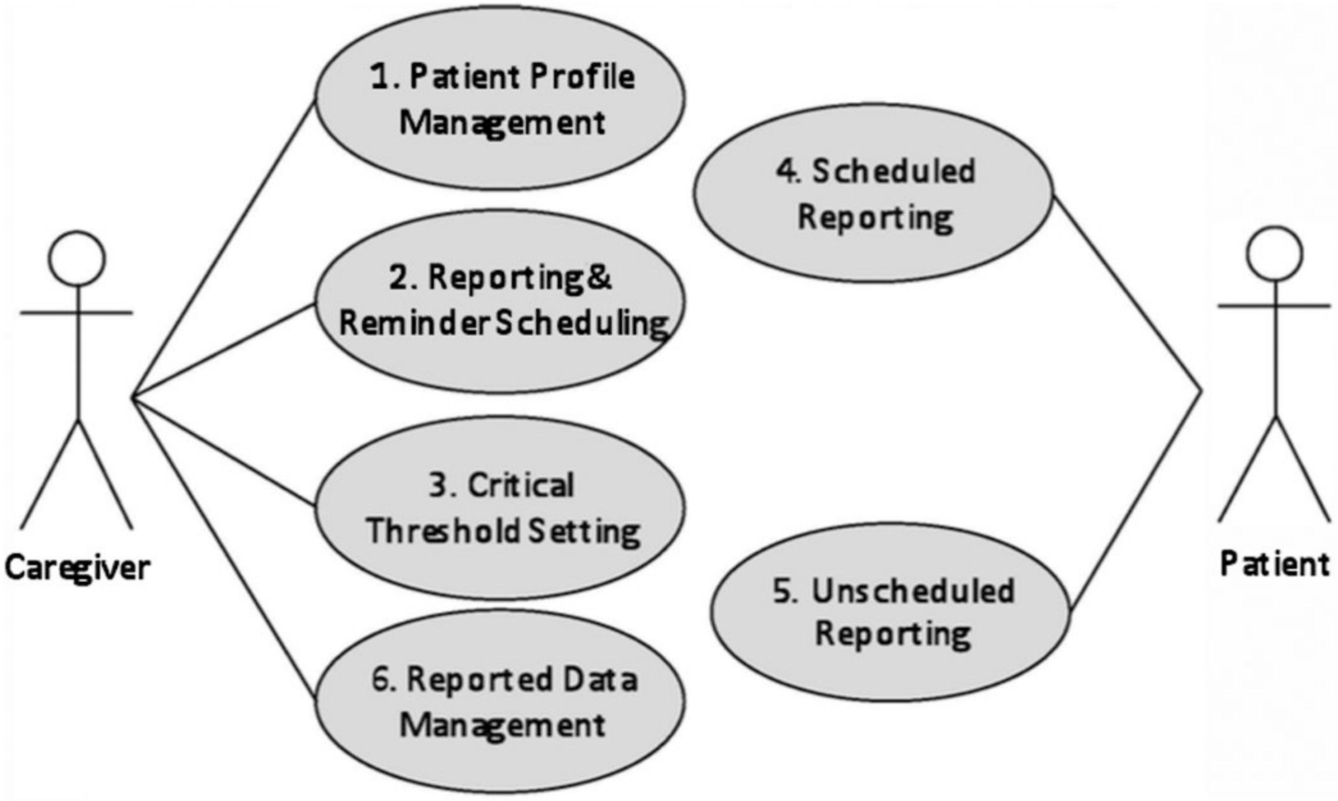

Fig. 1.

Roles and use cases in SickleREMOTE.

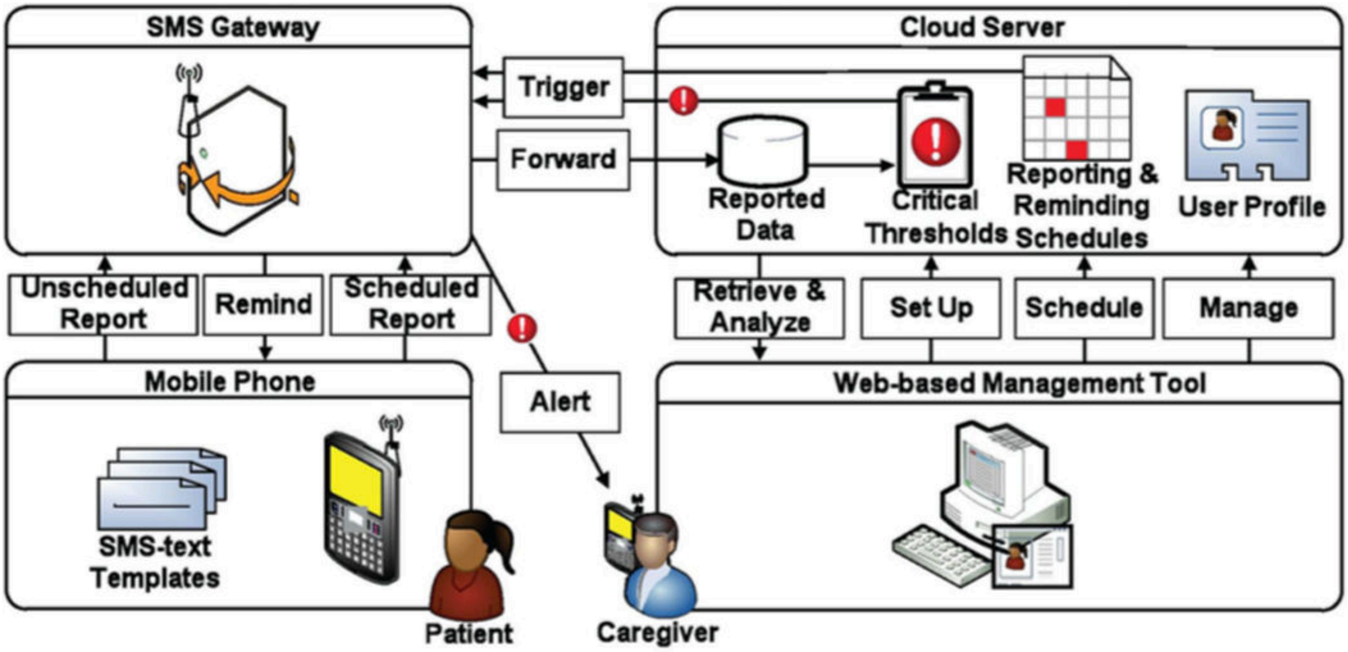

Fig. 2.
System overview of SickleREMOTE.

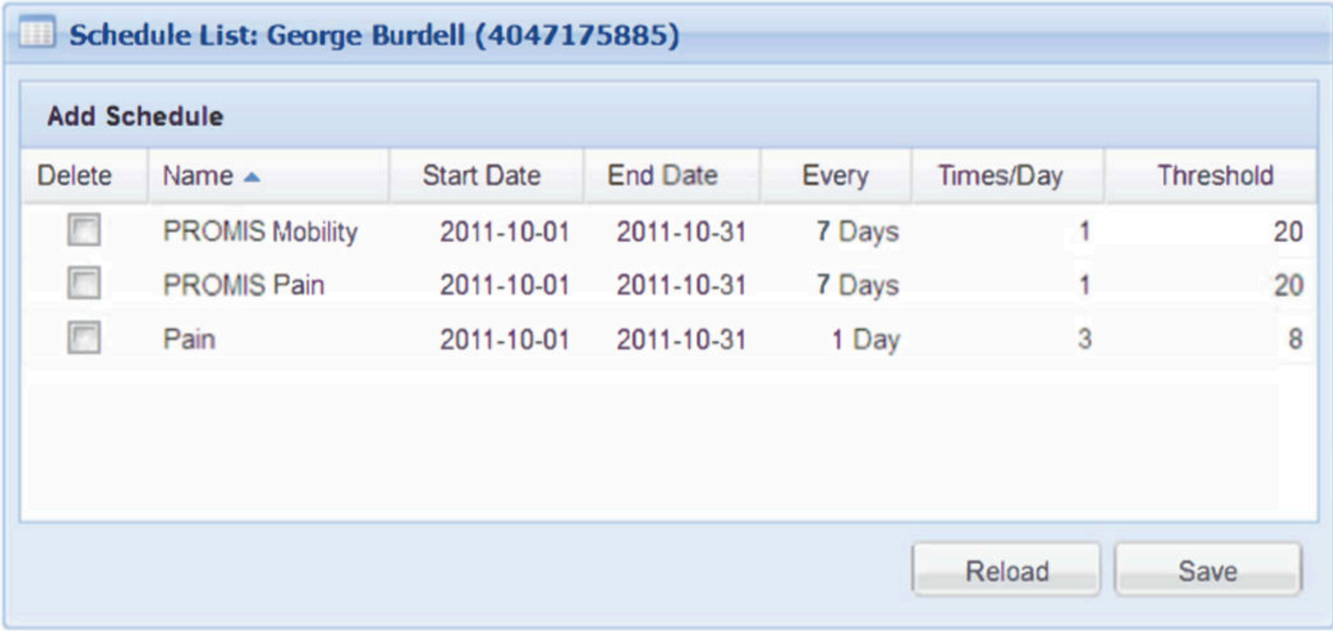

Fig. 3.

Report Scheduling Interface. Each schedule consists of name, start date, end date, reporting interval (from everyday to every 7 days), number of timea on the reporting day (from once to three times), and threshold.

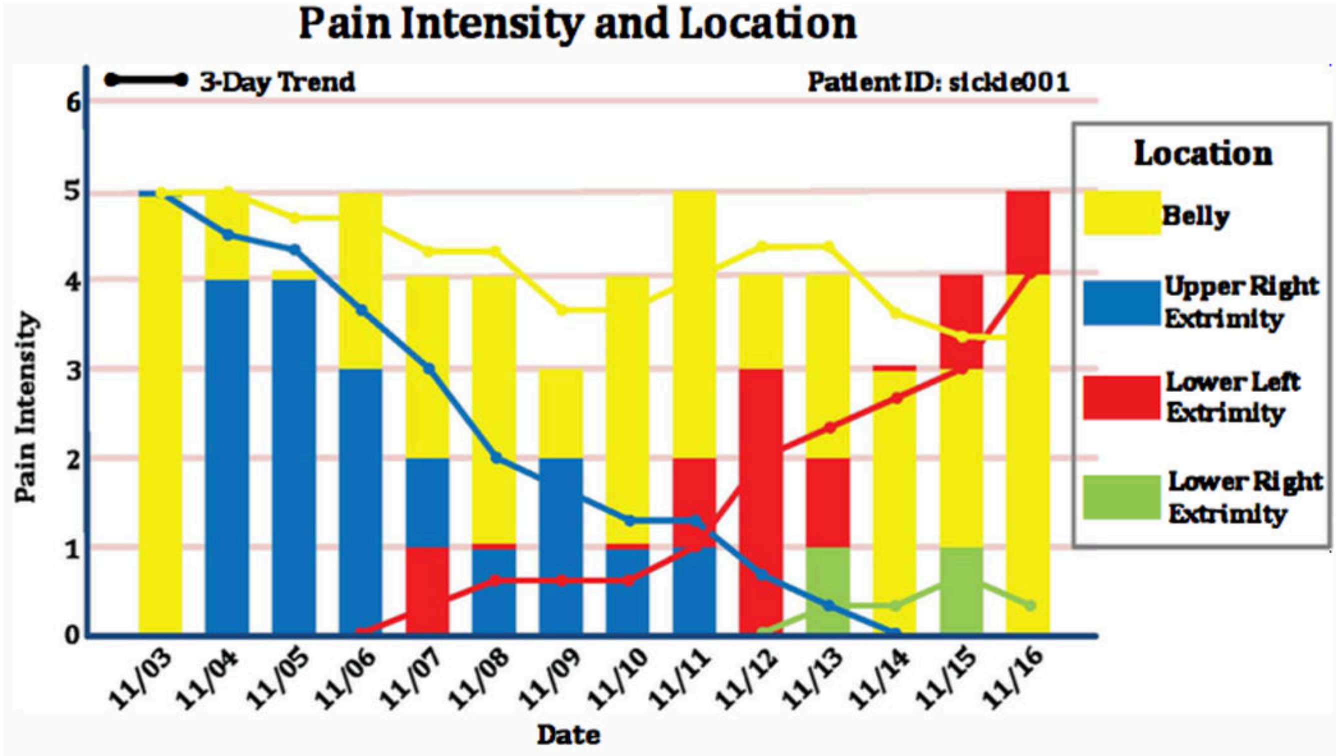

Fig. 4.

A visualization of a patient's pain intensity and location in a two-week period.