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iACT – An Interactive mHealth Monitoring System to Enhance Psychotherapy for Adolescents with Sickle Cell Disease

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***Abstract*—Sickle cell disease (SCD) is the most common inherited disease, and SCD symptoms impact functioning and well-being. For example, adolescents with SCD have a higher tendency of psychological problems than the general population. Acceptance and Commitment Therapy (ACT), a cognitive-behavioral therapy, is an effective intervention to promote quality of life and functioning in adolescents with chronic illness. However, traditional visit-based therapy sessions are restrained by challenges, such as limited follow-up, insufficient data collection, low treatment adherence, and delayed intervention. In this paper, we present Instant Acceptance and Commitment Therapy (iACT), a system designed to enhance the quality of pediatric ACT. iACT utilizes text messaging technology, which is the most popular cell phone activity among adolescents, to conduct real-time psychotherapy interventions. The system is built on cloud computing technologies, which provides a convenient and cost-effective monitoring environment. To evaluate iACT, a trial with 60 adolescents with SCD is being conducted in conjunction with the Georgia Institute of Technology, Children's Healthcare of Atlanta, and Georgia State University.**

I. Introduction

Sickle cell disease (SCD) is an inherited chronic disease, affecting approximately 1 in every 600 African-American newborns in the U.S. [1]; there are approximately 72,000 people currently living with the disease. Annually, there are 75,000 hospitalizations with cost of $475 million in this population [1, 2]. In SCD, 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. Children and adolescents with SCD have increased frequency of psychological problems when compared with the general population [3, 4], which are closely associated with their physical and social disabilities [5, 6]. Currently, treatments consist of a multidisciplinary combination of psychological and medical treatments. However, the effectiveness of the most commonly used psychological "attention diversion" strategies is still doubtful and the results from clinical studies are inconclusive [7]. Medical treatments, which may be effective for acute crisis management, are often ineffective for chronic pain management [8].

Recently, acceptance-based psychotherapies have been proposed and proven as an alternative approach to cognitive pain management [9]. Acceptance and Commitment Therapy (ACT) focuses on increasing patients' daily functioning and quality of life by motivating and teaching them to engage in goal-consistent behaviors while being open to, and accepting of psychological struggles [10]. Although ACT has been found to be efficacious in various medical conditions (e.g., Type II diabetes [11] and chronic pain [12]), sustained benefits are unclear due to limited follow-up assessments. This challenge has been identified as a common barrier that interferes with treatment adherence in youth with SCD [13]. Prolonged time between clinic visits (e.g., every 3-6 months) results in limited data collection and potential delayed intervention. Reliance on the young patient's ability to recall and express symptoms often limits the care provider's capacity to adjust treatment.

Applications of computer-assisted technology provide potential solutions for traditional outpatient psychotherapies [14]. Internet-based interventions are the most common approaches; they offer practical advantages by adding asynchronous communication to remove time constraints. Internet-based programs have been used successfully in pain-related psychiatric treatment [15]. However, Internet-based treatments require patients to carry notebooks or smartphones connected to WiFi or mobile networks, and limits use in diseases associated with lower economic status. In addition, traditional Internet-based treatment programs usually lack a reminding function, or only remind via e-mail, which imposes a challenge on real-time responses.

These challenges raise the need for a more generic mobile health (mHealth) technology. For pediatric SCD, the technology should provide an efficient channel for adolescents to report, and for providers to monitor progress and apply interventions, with minimum spatial, time, or technology constraints. McClellan *et al.* indicated that using a handheld electronic mobile device is feasible for cognitive behavior coping skills in pediatric SCD population [16]. However, this study only focused on feasibility of the mobile devices for SCD psychotherapy and did not investigate whether interventions would improve outcomes. In addition, the study focused only on a single specific technology (i.e., smart- phone) that is applicable to a small portion of the disease population. In our previous study, we have

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demonstrated that Short Message Service (SMS) provides an effective monitoring technology for care providers and adolescents with sickle cell disease [17]. Nonetheless, we are not aware of any published study investigating mHealth technologies in pediatric psychotherapy for SCD. In this paper, we present a new system, called *Instant Acceptance and Commitment Therapy (iACT)*, combining web-based tool, cloud computing, and mobile Short Message Service (SMS) technologies. This interactive text messaging system aims to enhance ACT by 1) increasing the frequency of data collection without additional hospital revisits, 2) monitoring a multidisciplinary response to treatment, and 3) providing instant and personalized interventions.

II. Measurements and Interventions

The main measurement of iACT is subject's consistency of meeting and living within self-selected values-based goals. We also consider four more assessments of function, including pain experience, school attendance, and two standard quality-of-life scales, that provide additional information about the causes and results of the consistency changes. These measurements and their scales are depicted in Figure 1 and described in detail in the following section.

1) Living Goal Success: Based on the pre-treatment assessments, the adolescent patients select one or multiple goals from eight categories (Figure 1). The self-assessment of success in meeting goals is recorded on a numerical rating scale from 0 (no success) to 10 (highest success). Upon receipt of self-reports, iACT classifies the response into three performance levels from low (0-3), medium (4-7), to high (8-10), and provides corresponding interventions via text messaging. For example, if an adolescent submits a success score of 1 (low), the system will send an encouragement message (e.g., "*Try to do something right now that can help you meet your goals.*"). If a success score of 9 (high) is sent, a reinforcement text will be sent (e.g., "*Excellent job at living in line with your values!*").

2) Pain Experience: Adolescents are prompted to report their physical pain once a day. Similar to goal success, pain is recorded using a 0 (no pain) to 10 (worst imaginable pain) numerical scale and categorized into three levels from low (0-3), medium (4-7), to severe (8-10) with corresponding interventions from the iACT. Additionally, care providers can assign pain thresholds for adolescents according to their pain tolerance and self-management skills. If a reported pain hits the threshold, iACT will trigger a notification message to the corresponding medical team for review and consideration of needed care adjustments.

3) School Attendance: Studies have shown that increases in the number and severity of pain episodes have adverse effect on adolescents' school attendance [18, 19]. School absenteeism may also be a causal factor for lower academic performance and poor social interaction. For adolescents using iACT, the system queries their daily school attendance during the weekdays. The options include: 0) No school/ holiday; 1) absent whole day; 2) attended morning only; 3) attended afternoon only; and 4) attended whole day. Similar to the pain ratings, providers can assign adolescents thresholds that indicate how long of an absence will trigger a notification to care providers, such as "*Alert Dr. Brown if Patient-A has reported school absences two days in a row.*"

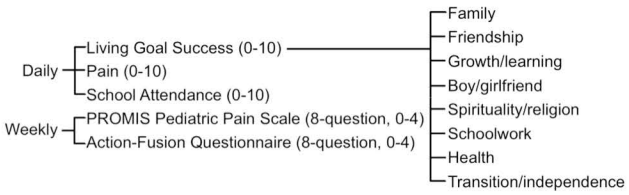

Figure 1. iACT measurements

4) PROMIS Pediatric Pain Interface Scale: The National Institute of Health (NIH) Patient Reported Outcomes Measurement Information System (PROMIS) has developed standardized self-reported measures covering a wide range of health domains. The PROMIS Pediatric Cooperative Group focuses on the development of pediatric self-report scales for ages 8 through 17 years. We include their 8-question Pain Interference Scale to assess SCD adolescents' quality of life and the dependence of pain interference [20]. Because the scale uses a 7-day recall period, adolescents will only be prompted once a week.

5) AFQ-Y8: The Action-Fusion Questionnaire (AFQ) is a scale representing a theoretically cohesive conceptualization of psychological inflexibility, which ties to ACT's theoretical model [21]. Studies support the AFQ's youth version (AFQ-Y) and the 8-item short form (AFQ-Y8) for measurements of core ACT processes [22].

In addition to these measures, iACT also features daily-based health tips. These tips are important information that encourages adolescents with SCD to learn about how to manage their health during the transition to adulthood. A health tip is randomly selected from a pool of 60 messages in 10 categories. For example, a health tip in the "*Travel*" category is "*Before you travel, make sure your Sickle Cell is controlled. If you are in any pain, check with your doctor before you head off on your trip.*"

III. Use Cases and Development

The architecture of iACT is developed using open-source cloud computing services operated by Google, Inc. A Google App Engine (GAE) service acts as a central platform. It incorporates with other Google services, including Google Voice, Docs, and Calendar, for different purposes. The GAE service also has a web-based interface allowing care providers to perform patient management. These cloud services allow us to run the system in a cost-effective way (approximately $4/week). The following section describes key use cases, corresponding cloud services, and data storage units of the iACT system (Figure 2).

1) Report Scheduling: iACT incorporates with Google Calendar allowing providers to create and personalize reporting schedules. The Google Calendar service can have multiple calendars, and each one can link to one or more adolescents. A calendar can have one-time events or series of events that repeat daily or weekly. Upon occurrence of an event, iACT will prompt the corresponding measurement to all adolescents following the calendar.

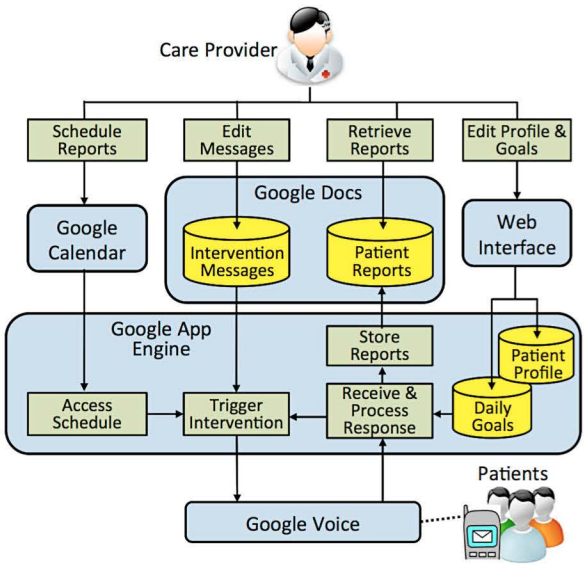

Figure 2. Use cases, the responsible cloud services, and the corresponding data storage units.

2) Message Editing: The *Message Pool* of iACT contains the queries, reminders, health tips, and ACT response texts. The message pool is hosted online on Google Docs service, which care providers can readily access by secure log in to edit responses.

3) Profile Management: Care providers use iACT's *Web Interface* to manage (i.e., create, modify, and remove) adolescents' profiles, which include their IDs, telephone numbers, and thresholds for pain and school absence. All of the profile information is stored in the *Patient Profile* storage unit in the GAE service. Additionally, care providers assign adolescents' living goals via the Web Interface, and the goal settings are stored in the *Daily Goals* storage unit.

4) Data Processing and Storage: The Google Voice service enables functions of sending and receiving text messages via a unique phone number. Upon receipt of a response, the voice service relays the message to the GAE service. If the response is invalid (e.g., reported pain intensity of 15 or unrecognizable free text), iACT will trigger another text message with instructions for correct reporting and ask the adolescent to respond again; otherwise, iACT will automatically store the response, send a corresponding intervention followed by the next question. An example iACT conversation is provided in Section IV.

5) Data Retrieval: In addition to the Message Pool, the Google Docs service also stores adolescents' chronological reports (i.e., pain experience, school attendance, living goals, and scale outcomes). Care providers can log in to review adolescents' report histories and download the data to Microsoft Excel, or other popular database formats. Google Docs service also stores important information regarding text message conversation, including 1) messages sent to adolescents, 2) messages received from them, and 3) reporting statistics (e.g., on-time reporting rate, reporting correctness, and average response time). This information provides the care providers with more data regarding adolescents' interaction with the iACT system.

IV. iACT Conversation

Comparing to our previous SickleREMOTE system [17], one of the new advantages of the iACT system is its interactive conversation with users at least once a day. By following the prompts, adolescents can read the incoming messages and reply with their answers. All of the messages from the system are automatically generated. Thus, care providers do not need to manually text. A conversation starts with a prompt of daily sensory pain. If the number is valid (i.e., 0-10), the adolescent will receive an acknowledgement based on the pain level (i.e., low, medium, and severe), followed by the next school attendance question. The adolescent responds to the school attendance, and then continues by responding to queries about success in meeting goals in the order of prompt, response until the ending message. If required, the conversation may also include the weekly PROMIS Pain Scale and AFQ-Y8. If not answered, iACT also has a reminding function for users to resume the incomplete conversation (e.g., the 7:30PM message in Figure 3). If the user does not reply after the 2nd reminder, the system terminates the conversation and a missing data point is recorded. Depending on the adolescent's reaction time, the entire conversation can be completed as quickly as 10 minutes. Figure 3 shows an example of a conversation with two living consistency goals and two weekly scales.

iACT: Rate today's worst pain (0-10). *7:00PM*

Me: 2 *7:02PM*

iACT: Good job managing your pain. Continue to find distractions to help with your pain – listen to music, talk to friends, and read. *7:02PM*

iACT: School attendance today? (0:No School/holiday; 1: Absent whole day; 2:Attended morning only; 3: Attended afternoon only; 4: Attended whole day) *7:02PM*

Me: 4 *7:03PM*

iACT: Small investments lead to a big payoff. *7:03PM*

iACT: Rate success in meeting today's friendship goals (0-10) *7:03PM*

iACT: (Reminder) Rate success in meeting today's friendship goals (0-10) *7:30PM*

Me: 9 *7:32PM*

iACT: Great work! *7:32PM*

iACT: Rate success in meeting today's transition/independence goals (0-10). *7:32PM*

Me: 8 *7:33PM*

iACT: Glad to hear it. *7:33PM*

iACT: Please reply the 8 PROMIS Pain Scale answers in 1 message, for example "13421032". *7:33PM*

Me: 02310021 *7:35PM*

iACT: Thank you. Please reply the 8 AFQ Scale answers in 1 message, for example "13421032".*7:35PM*

Me: 01420341 *7:37PM*

iACT: Thank you for today's reporting. *7:37M*

Figure 3. iACT conservation between the system (**iACT**) and an adolescent (**Me**) who has two daily living consistency goals (i.e., Friendship and Transition/Independence). This conversation also includes the weekly 8-question PROMIS and AFQ-Y8 questionnaires in the end.

V. System Evaluation Trial

Our system evaluation trial has been approved by the Institutional Review Boards (IRBs) from the Georgia Institute of Technology, Children's Healthcare of Atlanta (CHOA), and Georgia State University. The system will be evaluated by 60 adolescents with SCD (ages 12-18 years old) recruited by medical staff from CHOA's sickle cell disease clinics (CHOA-SCD clinic). We will randomize participants into control (n=30) and treatment (n=30) groups. The control group will follow standard ACT to improve functioning, while the treatment group will also be enhanced by the iACT system. This type of design allows for 2 (groups) x 5 (months) repeated-measures analyses of variance (ANOVAs) to determine if care providers' and adolescents' ratings of pain interference, functioning, psychological flexibility, valued living, sickle cell self-care, and transition readiness significantly change both between and within groups and over the 5 time points.

In order to address the security and privacy issues presented in cloud computing systems, we do not store any personally identifiable information on the cloud database. Each patient is identified by a randomly-assigned study ID. Access to all Google services is controlled by a unique Google account and a high-strength password. The password is shared only with authorized personnel on the IRB protocol and changed every three months at a minimum. Data from the cloud database will be backed up weekly using secure internet protocol, encrypted, and then archived in the password-protected server.

VI. Conclusion

Children and adolescents with sickle cell disease have a higher frequency of psychological problems when compared with the general population. The effectiveness of traditional psychotherapies is constrained by challenges including sparse data collection and delayed interventions. This project demonstrates a self-reporting system that realizes daily psychotherapy data collection and delivers real-time interventions. Adolescents can report measurements via interactive conversations using mobile text messaging technology, which is the favorite cell phone activity of this population. The system was developed using low-cost cloud computing services to perform a variety of tasks, including report scheduling, data storage, and text messaging. The iACT system allows care providers to effectively and easily manage, monitor, and communicate with adolescents outside of the hospital environment.

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