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## Pain buddy: A novel use of m-health in the management of children's cancer pain



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### ABSTRACT

**Background:** Over 12,000 children are diagnosed with cancer every year in the United States. In addition to symptoms associated with their disease, children undergoing chemotherapy frequently experience significant pain, which is unfortunately often undertreated. The field of m-Health offers an innovative avenue for pain assessment and intervention in the home setting. The current study describes the development and initial evaluation of a tablet-based program, Pain Buddy, aimed to enhance pain management and foster improved quality of life in children ages 8–18 years undergoing cancer treatment.

**Methods:** An animated avatar-based tablet application was developed using state-of-the-art software. Key aspects of Pain Buddy include daily pain and symptom diaries completed by children, remote monitoring of symptoms by uploading patient's data through internet to a cloud server, cognitive and behavioral skills training, interactive three-dimensional avatars that guide children through the program, and an incentive system to motivate engagement. Twelve children between the ages of 8 and 18 participated in a pilot study of Pain Buddy.

**Results:** Children were highly satisfied with the program. Pain and appetite disturbances were most frequently endorsed. Symptom trigger alerts to outside providers were largely related to clinically significant pain. Children infrequently used analgesics, and reported using some non-pharmacological pain management strategies.

**Conclusion:** Pain Buddy appears to be a promising tool to improve pain and symptom management in children undergoing cancer treatment. Results from the current study will inform future improvements to Pain Buddy, in preparation for a randomized controlled trial to assess the efficacy of this innovative treatment.

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## 1. Introduction

Over 12,000 children are diagnosed with cancer every year in the United States [1], and existing research indicates that the majority of these children experience troubling symptoms that include pain, fatigue, and nausea [2]. Unfortunately, children with cancer not only suffer from distressing symptoms related to the disease process, but also suffer from symptoms related to the treatment for the disease. Indeed, given the aggressive protocols

children being treated with chemotherapy go through, they often experience painful conditions such as mucositis and peripheral neuropathy [3]. Uncontrolled pain not only has significant negative psychosocial effects, but also modulates the physiological pain response, resulting in sensitization and potentially deleterious effects on physiological and immune function [4]. Unrelieved symptoms related to either cancer or chemotherapy also lead to poorer quality of life, including increased distress [2]. Unfortunately, evidence suggests that cancer pain and symptoms are undertreated in most children [3,5–9], and there are few controlled studies in this area.

Although parents and children who suffer from cancer report that pain is a significant concern, pain assessment throughout cancer treatment is not performed systematically [3,10–12] and

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without accurate data, physicians are unable to intervene appropriately. Additional barriers to treatment of pain in children with cancer include misunderstanding of use of analgesia in children (i.e., fears of addiction) and lack of understanding of pain expression in children [10,12,13]. This is particularly relevant to management of symptoms in the home setting by parents, who have been shown to significantly under treat children's pain [3,14]. Unfortunately, there is an extreme dearth of research into children's cancer symptom management, particularly with regard to effective pain interventions. Moreover psychosocial interventions, particularly skills-based training, are effective for cancer pain and symptoms for adults and children [15,16], yet are not easily accessible by patients.

Recently there has been a national push toward involving information technology in health care, such as electronic medical records, personal health records, and real-time decision-support systems [17–19]. The growth in pervasive computing and wearable technology has led to the field of m-Health, defined as “mobile computing, medical sensor, and communications technologies for health-care” [20,21]. Accordingly, there is a growing literature of the impact of m-Health technologies, particularly involving the management of pain. Indeed, there is empirical evidence that the use of computer-based decision-support positively impacts management of chronic pain in adults [22] and can lead to significant improvements in overall clinical care [22–25]. Real-time pain assessment and decision-support guiding treatment implemented via mobile technology (e.g., smartphones, tablets) provides two innovative, key pathways to the translation of pain management guidelines to practice for cancer patients. First, the ability to communicate with children and families electronically (e.g., web-based assessment and intervention, text messaging, email notifications) is a simple, efficient system and over half of teens in the U.S. have mobile phones and over a third report using text messaging [26] and these numbers are increasing. Electronic communication is beginning to be used as a modality to engage teens in their healthcare [27–30], and such programs are very well-received [28]. Second, electronic means of assessment have been shown to greatly increase adherence to monitoring health information data [31].

To date, m-Health programs have been developed with a specific focus on pain assessment [32]. Both children and adults show high adherence rates to completion of electronic pain diaries for a variety of illnesses that involve pain, including cancer [33,34]. There is some evidence that use of pain diaries to track chronic pain leads to improved patient adherence to treatment recommendations and additional data provided to health care providers to use for treatment decision-making [35]. Moreover, asking patients to recall their pain experience over the period of time leading up to their present medical visit (i.e., retrospective pain reporting) has been shown to be subject to bias and is inferior to real time measurement of pain using ecological momentary assessment approaches (i.e., electronic pain diaries) [36]. Despite the growth of m-Health programs focused on pain assessment; to date, little focus has been on capitalizing on pervasive computing technology to deliver interventions for pain management.

Because of changes in the U.S. healthcare system, there has been a shift in the management of care of cancer patients from the hospital to the home [37]. This shift has resulted in improved satisfaction among patients and families; however, it has come with an added burden of pain management by parents and caregivers in home setting, who often have little education regarding pain and pain management [38]. Pain management in children in the hospital setting has greatly improved in the past several decades [39], though in the home setting, there is growing evidence that children's pain is poorly managed [3]. Thus, the under management of children's pain in the home setting provides an avenue for

targeted research that incorporates electronic means of assessment and intervention that allows children to stay in the home setting to maximize satisfaction and quality of life. Moreover, there is a dire need to focus on children undergoing cancer treatment, as this vulnerable population has been neglected in the literature on behavioral management of pain and stress.

## 2. Development of an electronic pain management program: Pain Buddy

It is clear that management of children's cancer pain at home is in need of attention. The growing use of mobile technology, particularly among youth in the U.S., provides a promising means of merging engaging modalities for intervention with efforts to improve quality of life of children undergoing cancer treatment. Accordingly, the current focus of our program of research is development of an innovative m-Health application that provides remote monitoring of pain and symptoms and delivery of cognitive and behavioral skills training to children undergoing treatment for cancer. The conceptual framework of this newly developed program (Pain Buddy) [40,41] is grounded in social learning theory [42], which suggests that beliefs about self-efficacy, or beliefs about one's capabilities, play a role in coping responses. Early research highlighted the role of self-efficacy in health behavior change and suggested that manipulations of perceived self-efficacy impacted health-related changes in behavior [43]. In particular, opportunities for skill rehearsal may increase self-efficacy [44], and there is evidence that providing feedback during web-based learning modules leads to increases in perceived self-efficacy [45]. Accordingly, Pain Buddy is based upon the premise that providing children with real time feedback and opportunities for rehearsal of pain management strategies will increase empowerment and self-efficacy of pain management, thereby leading to improved quality of life and reduced suffering during cancer treatment. Pain Buddy is an Android-based program that has been developed to be used on a seven-inch tablet by children ages 8–18 years undergoing cancer treatment.

Development of Pain Buddy follows a three-phase model [46]: Program development, formative evaluation, and outcome evaluation. In this manuscript, we describe the first two phases of the project. Specifically, we discuss the development of Pain Buddy, including the various components of the program, and then present feasibility and preliminary outcome data from a pilot study of the intervention.

## 3. Materials and methods

This project was approved by the Institutional Review Board at Children's Hospital of Orange County (CHOC Children's).

### 3.1. Phase I – development of Pain Buddy

#### 3.1.1. Stakeholders

The components of Pain Buddy were developed with a multidisciplinary task force that includes psychologists, oncologists, anesthesiologists, nurses, engineers, and computer scientists, all who possess expertise in pediatric cancer, pediatric pain management, health information technology, and web-based intervention development and delivery. Children receiving cancer treatment were also included throughout the development process to provide input and feedback into the various components of the program. Utilizing a collaborative approach with patient stakeholders ensures appropriate input throughout development to generate a program that meets the needs of both patients and healthcare providers.

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