Facilitating Pediatric Patient-Provider Communications Using Wireless Technology in Children and Adolescents With Sickle Cell Disease

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Conflicts of interest: None to report.

Funding was received from the National Institutes of Health, National Heart Blood & Lung Institute American Recovery & Reinvestment Act grant #1RC1 HL100301-01. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Heart, Lung, And Blood Institute or the National Institutes of Health.

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0891-5245/$36.00

http://dx.doi.org/10.1016/j.pedhc.2012.02.004

ABSTRACT

Introduction: Use of wireless devices has the potential to transform delivery of primary care services for persons with sickle cell disease (SCD). The study examined text message communications between patients and an advanced practice registered nurse (APRN) and the different primary care activities that emerged with use of wireless technology.

Methods: Patients ($N = 37$; mean age 13.9 ± 1.8 years; 45.9% male and 54.1% female) engaged in intermittent text conversations with the APRN as part of the Wireless Pain Intervention Program. Content analyses were used to analyze the content of text message exchanges between patients and the APRN.

Results: The primary care needs that emerged were related to pain and symptom management and sickle cell crisis prevention. Two primary care categories (collaborating and coaching), four primary care subcategories (screening, referring, informing, and supporting), and 16 primary care activities were evident in text conversations.

Discussion: The use of wireless technology may facilitate screening, prompt management of pain and symptoms, prevention or reduction of SCD-related complications, more efficient referral for treatments, timely patient education, and psychosocial support in children and adolescents with SCD. J Pediatr Health Care. (2013) *27*, 284-292.

KEY WORDS

Sickle cell disease, pain, symptoms, wireless technology, smartphone, text message communication

Effective communication between providers and patients is needed to improve health outcomes and delivery of care (Chaudhry et al., 2006; Institute of Medicine [IOM], 2001). Children and adolescents with sickle cell disease (SCD) require ongoing medical care and often depend on their parents or caregivers to mediate the required communications with care providers. They may not be comfortable with or be able to ask the right questions or provide relevant information to care providers. They tend to answer only what they are asked and may not be given very much information during health care visits (Ngo-Metzger, Hayes, Chen, Cygan, & Garfield, 2010). Although patient-centered approaches and interactive communications have the potential to improve the quality of care delivery (Chaudhry et al., 2006; IOM, 2001), these approaches have not yet been well implemented in the continuum of care for children and adolescents with SCD.

Recent advances in wireless technology may facilitate patient-centered approaches and establish interactive communications that previously were not possible (Puccio et al., 2006). The use of mobile phones, smartphones, and other wireless devices (e.g., personal digital assistants, iPADs, and netbooks) is increasingly more common among children and adolescents, which may empower them to communicate directly with care providers. This enhanced communication would then encourage them to be more involved in decisions regarding their own care instead of heavily relying on their parents or caregivers as they transition into young adulthood (Gentles, Lokker, & McKibbon, 2010).

Lenhart, Madden, and Hitlin (2005) found that an overwhelming majority of the 1100 adolescents in their survey (84%) reported owning at least one personal media device, such as a desktop or laptop computer, a cell phone, or a personal digital assistant, and almost one third (31%) used them to access health information. About half (45%) reported having a cell phone, and one third (33%) used it to send text messages. Children and adolescents are technology savvy and use instant messaging and text messaging for conversations with other technology-savvy peers, as well as to communicate with parents (Lenhart et al., 2005).

Marciel and colleagues (2010) designed a Web-enabled cell phone intervention that provided information about management of symptoms and social support to improve treatment adherence among adolescents with cystic fibrosis. The intervention included visual, tactile, auditory, and interactive modes of communication and focused on peer-to-peer support using a Web application. Web site moderators provided suggestions about communications and referrals provided to relevant mental health professionals. Thus a combination of phone and Web-based tools provided the adolescents with individualized information about management of cystic fibrosis symptoms (Marciel, Saiman, Quittell, Dawkins, & Quittner, 2010).

Health care and information services may be delivered and enhanced directly through the use of wireless technology. Gentles and colleagues (2010) recently reviewed studies that implemented interventions featuring different modes of wireless technology (e.g., Internet, telephone, e-mail, and a short message service). They found that wireless technology was used to facilitate different functions (e.g., support, medication management, education, and monitoring).

The use of wireless technology may be an effective strategy for meeting one of the recommendations of the IOM that advocates for patient-centered care and increased access to care in a more timely manner (IOM, 2001). The IOM report recommends that care should be provided whenever patients need it and that providers should be available at all times (24 hours a day, every day). It also recommends that care should be made more accessible by offering it over the Internet, by telephone, and by other means in addition to face-to-face visits (IOM, 2001).

As part of our Wireless Pain Intervention Program that examined pain and symptoms in children and adolescents with SCD, we used smartphones as a medium for facilitating communications between an advanced practice registered nurse (APRN) and children and adolescents with SCD. The purpose of this study was to examine how patients with SCD communicated with a health care provider (an APRN) while using smartphones and to examine the different health care provider activities that resulted from the interactions using content analyses of their text message communications.

METHODS

Design

Children and adolescents with SCD were invited to enroll in the Wireless Pain Intervention Program and were asked to complete pain and symptom measures using a smartphone to access a Web-based e-Diary twice daily (Jacob et al., 2012). An APRN with expertise in SCD remotely monitored the e-Diary entries, responded to alert messages based on preprogrammed parameters, and responded to text messages sent by patients (Duran, Jacob, Stinson, Lewis, & Zeltzer, 2010). The results presented in this portion of the study represent the content analyses of the text message exchanges between patients and the APRN between April 2010 and December 2010.

Sample and Setting

The Sickle Cell Disease Foundation of California (SCDFC), a community-based organization in Southern California, distributed study information flyers and invited patients from their programs to be part of the study. This organization serves approximately 5000 people with SCD across several regions of Southern California (Ontario, Corona, San Diego, and Los