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A Protocol to Assess Feasibility, Acceptability, and Usability of Mobile Technology for Symptom Management in Pediatric Transplant Patients

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Abstract

Background: Pediatric blood and marrow transplant patients (PBMT) experience significant symptom distress, and the use of mobile health technologies may enhance symptom management by providing *patient generated health data* to foster personalized health strategies.

Objectives: To present a study protocol to explore feasibility, acceptability and, usability of integrating mobile health technologies to collect and monitor symptom data for PBMT patients.

Methods: An exploratory mixed method design is employed for 20 PBMT patients to monitor symptoms using real-time data from two mobile health (mHealth) devices: 1) a self-developed mHealth application (app); and 2) a wearable tracking device. Patient-Reported Outcome Measurement Information System surveys (PROMIS) for fatigue, pain, and sleep disturbance are obtained monthly. Interviews are conducted to obtain further feasibility and usability data.

Results: The study began in October 2017, data collection should be completed in 2018. Feasibility and usability results to monitor and record symptom-related data daily via mobile devices will be reported. PROMIS surveys and interviews will further explore patients' symptoms and experiences with the mobile devices.

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The authors have no conflicts of interest to report.

Ethical Conduct of Research: The medical center Institutional Review Board approved the study protocol (Pro00068979). All authors complied with our institution's ethical standards.

Discussion: This study will be among the first to explore the feasibility, acceptability, and usability of integrating multiple mHealth technologies to obtain patient generated symptom data for the PBMT population. Results will enhance our understanding of how these data present, interact, and cluster together throughout the post-transplant period for these children and lead to symptom management strategies. Results will focus on a high-risk population that potentially stands to benefit from the use of mobile technologies.

Keywords

Symptom Science; Pediatric Blood and Marrow Transplant; Mobile Health; Symptom Management

Pediatric blood and marrow transplant (PBMT) is a procedure increasingly used to treat life-threatening oncologic, hematologic, immunologic, and metabolic diseases (Clarke, Eiser, & Skinner, 2008; Copelan, 2006; D'Souza & Fretham, 2017). More than 1,500 children undergo the procedure each year in the United States (D'Souza & Fretham, 2017). Recent estimates report that more than 34,000 children under the age of 18 have received a PBMT and this number is expected to exceed 47,000 by 2025 (Majhail et al., 2013). While the procedure offers real hope for a cure, post-transplant patients experience significant symptom distress (Rodgers, Krance, Street, & Hockenberry, 2014). Symptoms result from the underlying disease, an intense preparatory regimen for the transplant, and side effects of the procedure (Copelan, 2006; West et al., 2014). Children report the worst part of treatment is the distressing symptoms they experience (Rodgers et al., 2014), and managing these symptoms is a major challenge (Somers et al., 2018; Vasquenza et al., 2015). The prevalence of PBMT as a treatment option and severity of PBMT symptoms necessitates exploration of ways to improve symptom management for these patients. Mobile health technologies, successfully integrated into disease management for patients with asthma (Cook, Modena, & Simon, 2016), cancer (Baggott et al., 2012), and diabetes (Arsand et al., 2012), offer promise for PBMT patients as well.

Mobile health (mHealth) technologies are reshaping healthcare delivery (Shaw et al., 2014; White, Thomas, Ezeanochie, & Bull, 2016). Patient generated health data from the devices provide patients and their caregivers a means of reporting symptoms and monitoring progress. Patient-generated health data may enhance healthcare providers' understanding of symptom clusters, interactions, and trajectories, and allow them to develop tailored interventions to better manage symptoms (Collins, 2012; Hacker et al., 2006; van der Veer, Aresi, & Gair, 2017). Researchers have begun to use mobile technology as a tool to facilitate chronic disease monitoring and management with this population. A study by Rodgers et al., successfully employed a mobile app, EAT! to facilitate self-management of eating-related issues commonly experienced by PBMT patients (Rodgers et al., 2014). Thus, integrating mHealth technologies into other aspects of PBMT care may foster symptom management strategies and improve outcomes.

Today's children and adolescents are known as the "iGeneration" or "iGens," a group born in the 1990s, who grew up with technology at their fingertips (Rosen, 2011). iGens are typically highly engaged with mobile devices such as their smart phones (Rosen, 2011) even

when they are sick and/or hospitalized (Jonassaint, Shah, Jonassaint, & De Castro, 2015; Leonard, Anderson, Jonassaint, Jonassaint, & Shah, 2017; Rodgers et al., 2014). Thus, incorporating mobile technology into symptom assessment and management may improve acute phase symptom burden and outcomes for this population (von Niederhausern et al., 2017). Engaging iGens by using familiar technology tools, such as smart phone applications (apps), may lead to more accurate symptom reporting and data collection, improved communication with clinicians, and personalized symptom management interventions. Wearable technologies, such as trackers, are an unobtrusive way to collect objective physiologic data. These devices provide the ability to capture heart rate (HR), step count, minutes of physical activity, and hours of sleep more reliably than self-report. However, limited research exists in mHealth technology use in PBMT symptom assessment, monitoring, and management.

Theoretical Framework

The Theory of Unpleasant Symptoms (TUS) was selected as the guiding framework for this study. Developed by Lenz, Pugh, Milligan, Gift, and Suppe in 1997, the theory's purpose is to enhance understanding of the symptom experience and provide information to develop strategies to improve symptom management (Lee, Vincent, & Finnegan, 2017; Lenz, Pugh, Milligan, Gift, & Suppe, 1997). The theory has three main concepts, the symptoms the patient experiences, the factors that influence symptoms, and the consequences of the symptoms (Lenz et al., 1997). Symptoms are multidimensional and although they vary, they share certain characteristics such as intensity, timing, distress, and quality (Lee et al., 2017; Lenz et al., 1997). The TUS allows for exploration of individual symptoms and clustered symptoms which can co-occur and interact, and importantly, when this happens, can intensify the results (Lenz et al., 1997). Using this lens, we will examine symptoms, patterns, clusters and interactions to enhance understanding of the PBMT symptom experience.

Objective

This paper reports a protocol for a study currently enrolling participants. The study aims to explore the feasibility, acceptability, and usability of a mobile app and wearable tracking device to collect and monitor PBMT patient-generated health data. We hypothesize that combining subjective symptom data and objective physiologic data for these patients will provide a better understanding of their symptoms and lead to precision symptom management strategies, improved clinician-patient communication, and better quality of life.

Methods

Study Design

The longitudinal mixed-methods study began in October 2017 at a major medical facility in the southeastern United States. The study is midway through the recruitment process for 20 patients, ages 7–18, receiving their first transplant.

Participants receive a wearable tracker (Apple watch) that records physiologic data and an iPhone with a proprietary mobile app that requires the patient or a caregiver to enter daily

responses to queries about symptoms. Because some patients may be too ill to wear the tracker or record in the app daily, Patient-Reported Outcome Measurement Information System (PROMIS) measures for pain, fatigue, and sleep disturbances are given at days 30, 60, and 90. PROMIS measures are self-report surveys administered via an iPad. Semi-structured interviews are also conducted at days 30 and 90 to obtain feedback on participants' experiences with the wearable tracker and app. Figure 1 outlines the study timeline.

Setting and Sample Size: This single-site study seeks to enroll 20 patients, ages 7–18 years, and is currently ongoing at a major medical center in the southeastern United States that specializes in PBMTs. Our sample size ($N=20$) is an adequate number to evaluate study feasibility. Twenty participants will allow us to test out the study procedures, test the usability of the wearable and app, discover unexpected design problems and estimate dropout rates and reasons.

Participants are recruited from the PBMT clinic prior to transplant. A clinic nurse practitioner screens for potential participants then introduces the study to the patient and caregiver. If the patient and caregiver express interest, a nurse researcher meets with them to present the study, discuss objectives and risks, and answer questions. Informed consent is obtained from the caregiver and assent is obtained from the patient. Participants are enrolled prior to their transplants and can remain in the study up to 120 days, including inpatient and outpatient days.

The medical center Institutional Review Board approved the study protocol (Pro00068979). Data is secured on a server that meets Health Insurance Portability and Accountability Act requirements. Patient data is transmitted without identifying information and entered into the system with a study-provided password.

Procedure

Quantitative data collection.—Data is collected at baseline, daily, and monthly. Demographic data from the electronic health record (EHR) and a Health-Related Quality of Life (HRQoL) survey are collected at baseline and discharge. For the daily app data collection the investigative team used a pediatric blood and marrow transplant app, the Technology Recordings for better Understanding Pediatric Blood and Marrow Transplant (TRU-PBMT) app, designed by Vaughn and colleagues (Vaughn, Jonassaint, Summers-Goeckerman, Shaw, & Shah, 2018). This app was designed with questions and scales to elicit and measure PBMT patients' symptomatology. The app was developed in Apple HealthKit with patient, caregiver, and healthcare provider input. It features child-friendly language and graphics (Figure 2a).

Data are collected daily from the TRU-PBMT app and the **wearable** tracker. Patients or caregivers record and track symptoms such as pain, fatigue, and sleep quality in the app. Patients rate their symptoms numerically on a visual analog scale and record the timing, intensity, and duration along with any pharmacologic or non-pharmacologic interventions.

Wearable tracker data (heart rate, step count, minutes of physical activity) are continuously collected when a patient wears the device, then are manually uploaded by the research nurse who visits the patients daily to assist with technical or logistical issues (such as charging or software updates). Patients are asked to wear the tracker except when bathing or charging (Figure 2b).

Every month four pediatric Patient-Reported Outcomes Measurement Information System (PROMIS) surveys (Pain Behavior, Fatigue, Sleep Disturbance, and Sleep Impairment) are collected. One parent proxy PROMIS survey (Fatigue) is available to caregivers if participants are too ill to self-report. These valid and reliable surveys facilitate a systematic approach and were chosen to complement the daily data collection and assessment (Varni et al., 2014). The surveys provide symptom data if the patient does not wear the watch or record data in the TRU-PBMT app. At study completion, patients complete a satisfaction and usability survey and HRQoL survey (Table 1).

Qualitative data collection.—Interviews are conducted at 30 days (and 60 and 90 days if PBMT patient remains in the study). These interviews consist of five semi-structured questions designed to explore the patient and caregivers' experiences with the mobile devices. Questions ask about the participant's ability to use the devices, ease of use and satisfaction with the devices and overall experience using the devices (Table 2).

Data Analysis

Quantitative data analysis.—When the study is complete, quantitative data will be analyzed using SAS 9.4 (Cary, NC) statistical software. Descriptive statistics for participant characteristics: age, gender, ethnicity, primary disease, type and date of transplant, and date of engraftment will be summarized and described.

Wearable tracker.—Frequencies, means, and standard errors will be assessed (step count, HR, hours of sleep, daily number of hours the tracker is worn) and will provide a quantitative description of feasibility and usability. The tracker data will be plotted to visualize significant trends during transplant, engraftment, complications, and hospital discharge.

Mobile App.—Symptom data from the app will be assessed using frequencies, means, and standard errors to provide a quantitative description of the app's feasibility and acceptability. Individual symptoms will be analyzed for frequency, intensity, and duration at multiple time points. Frequency of daily app recording will be analyzed in relation to the post-transplant timeline to determine why data may be missing (for example, when patients feel sicker, such as during engraftment, they are less likely to record in app). These data also will be plotted with the objective data to demonstrate trends, and these visualizations will be shared with participants during interviews.

PROMIS survey data is collected monthly. The analysis will include descriptive statistics for symptom scores. At study completion, feasibility, acceptability, and usability survey data will be analyzed to describe participants' and caregivers' experiences using the mobile devices.

Qualitative data analysis.—The semi-structured interviews at days 30 and 90 will enrich the quantitative data and allow us to gain further understanding of participants' and caregivers' experiences with the mobile devices. Interviews are audio-recorded. Questions ask about the participant's ability to use the wearable tracker, app, facilitators, barriers, satisfaction, and how the device and apps affect communication with the healthcare team. The interviews are transcribed and systematically coded by the research team to identify themes and trends. Initial codes were based on the mHealth and symptom literature. Emergent codes will be generated based on participants' comments. Atlas.ti® software will support data analysis. Themes will reflect symptom management behaviors and challenges, as well as acceptability and usability of devices.

Results

Participant recruitment and enrollment into the study began in October 2017. Analysis of study results is expected in late 2018 following study completion.

Discussion

This manuscript describes the protocol for a mixed-methods study to examine the feasibility, acceptability, and usability of mobile technologies to enhance symptom monitoring in PBMT patients. This study will be among the first to explore the use of multiple mobile technologies to obtain patient-generated symptom data for PBMT patients. Subjective symptom data collected daily from the TRU-PBMT app combined with objective data collected continuously from the wearable tracker will allow visualization of PBMT symptom clusters and trajectories, and thus illustrate a more complete picture of the symptom experience. Although PBMT symptoms and symptom clusters may not be completely prevented or eliminated, data from mobile technologies can be leveraged to help patients, caregivers, and clinicians monitor symptoms and develop personalized health strategies. These, in turn, may improve outcomes and reduce the patient/caregiver burden. This study will focus on a high-risk population that stands to benefit substantially from the use of mobile technologies. Knowledge gained from this study will enhance our understanding of the use of mHealth technologies to facilitate physiologic and symptom data collection. Additionally, it will improve our understanding of how these symptoms present, interact, and cluster throughout the post-transplant period for these children.

Limitations

We remark on three limitations in our study. First, we provide an Apple Watch and iPhone to participants, some, who have neither of these devices. These may be novel devices for this age group, thus there is potential to influence engagement in the study. Secondly, we are conducting this study at a single institution with a limited sample size, which may limit generalizability of the findings. Finally, we measure feasibility based on device use, such as number of hours the watch is worn each day, however, the limited battery life of the wearable combined with the patient's level of health may not fully represent the patient's engagement.

Conclusion

This study is unique in regards to exploring the feasibility, acceptability, and usability of incorporating multiple mobile technologies into PBMT patient care. Further understanding of symptoms will foster personalized health strategies and lead to improved outcomes and quality of life. This study seeks to expand the growing body of mHealth research used to enhance symptom management. Knowledge generated from this study may potentially offer a framework to guide other study designs in the incorporation of mobile technologies to facilitate patient care, improve symptom management, and improve patient outcomes.

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Clinical Trial Registration: Trial Number: [NCT02895841](https://clinicaltrials.gov/ct2/show/NCT02895841) the trial was registered September 12, 2016, the first patient enrolled for this sub-study was October 25, 2017. Link: <https://clinicaltrials.gov/ct2/show/NCT02895841>

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Figure 1. Study Schema

Figure 1 illustrates the study schema. The figure represents baseline survey data, mobile device daily data, Patient-Reported Outcomes Measurement Information Systems (PROMIS) survey monthly data, and interview data collection timelines for pediatric blood and marrow transplant (PBMT) patients. The arrows illustrate the sequence of data collection. The study is in progress, with results expected to be reported in late 2018.

Figure 2a. TRU-PBMT app

Figure 2b. Wearable tracker

Figures 2a and 2b. Mobile devices

Figure 2a depicts screenshots of the Technology Recordings to better Understand Pediatric Blood and Marrow Transplant (TRU-PBMT) app used for the study. App selections including the Symptom Tracker are listed on the first screen while the next screen illustrates the symptom intensity scale and symptom status. The third screen shows General Health the user can select to chart on. Figure 2b shows the Apple Watch used in the study.

Table 1**Study Measures**

Study Variable	Instrument/Measure	Description	Time	Time Points
Demographics & patient characteristics	EHR	Date of birth, gender, race, ethnicity, diagnosis, type of transplant, transplant date, engraftment	N/A	Baseline & Discharge
Heart rate, physical activity, hours of sleep	Apple Watch	Tracks HR, step count, minutes of physical activity	N/A	Continuous
Symptom record (pain, fatigue, sleep disturbance)	TRU-PBMT App	App has visual analog & Likert scale for rating symptom intensity, duration & timing	2–5 min	Daily
Pain	Survey	PROMIS Pediatric Pain Behavior SF v1.0 Pain	2–5 min	Monthly
Fatigue	Survey	PROMIS Ped Fatigue SFv2.1 Fatigue 8 item survey for patient or caregiver	2–5 min	Monthly
Sleep quantity and quality	Survey	PROMIS 8-item survey for sleep impairment PROMIS 6-item survey for sleep disturbance	2–5 min	Monthly
Pediatric QoL	Survey	Neuro-QoL Ped SF v.2.1	2–5 min	Baseline & Discharge
Feasibility, usability, & satisfaction	Feasibility Survey	A 24-item survey was developed for parents and children to assess technical feasibility, usability and satisfaction	10 min	Discharge

Table 2**Interview Questions**

Question 1: <i>Technical capability</i>	Please tell me about your experiences with the devices (iPhone, wearable)? How often were there problems? Describe the problems Did it work reliably?
Question 2: <i>Ease of Use</i>	How easy or difficult was it for you to use the devices: Using the app to track pain, fatigue and sleep disturbance and/or interventions: Using the wearable device: Uploading pain ratings and interventions to the app
Question 3: <i>Satisfaction/Acceptability of the App</i>	Tell me about how satisfied you were with using the app. Was it practical for you to use the app to track your daily pain, fatigue, and sleep disturbance while in the hospital? Did you remember to use the app to track your symptoms? Did someone need to remind you? Did you feel frustration using the app? Did you enjoy/not enjoy using the app?
Question 4: <i>Satisfaction/Acceptability of wearable device</i>	Tell me about your experience with the wearable tracking device: was it comfortable, uncomfortable to wear, easy/bothersome to use. Did you use the features, (i.e. step count) to encourage yourself to (walk) during the study?
Question 5: Overall experience	Question 5: Tell me your perspectives on whether or not being part of this study impacted your symptom management. Did you use the wearable/app to communicate your symptoms with your providers? Did you track your symptom trends throughout the study?