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BMT Roadmap: A User-Centered Design Health Information Technology Tool to Promote Patient-Centered Care in Pediatric Hematopoietic Cell Transplantation

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A B S T R A C T

Health information technology (HIT) has great potential for increasing patient engagement. Pediatric hematopoietic cell transplantation (HCT) is a setting ripe for using HIT but in which little research exists. "BMT Roadmap" is a web-based application that integrates patient-specific information and includes several domains: laboratory results, medications, clinical trial details, photos of the healthcare team, trajectory of transplant process, and discharge checklist. BMT Roadmap was provided to 10 caregivers of patients undergoing first-time HCT. Research assistants performed weekly qualitative interviews throughout the patient's hospitalization and at discharge and day 100 to assess the impact of BMT Roadmap. Rigorous thematic analysis revealed 5 recurrent themes: emotional impact of the HCT process itself; critical importance of communication among patients, caregivers, and healthcare providers; ways in which BMT Roadmap was helpful during inpatient setting; suggestions for improving BMT Roadmap; and other strategies for organization and management of complex healthcare needs that could be incorporated into BMT Roadmap. Caregivers found the tool useful and easy to use, leading them to want even greater access to information. BMT Roadmap was feasible, with no disruption to inpatient care. Although this initial study is limited by the small sample size and single-institution experience, these initial findings are encouraging and support further investigation.
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INTRODUCTION

One of the basic principles for designing a patient-centered healthcare system is allowing for the continuous, unfettered, bidirectional flow of clinical information and knowledge between patient and provider [1]. However, few healthcare organizations have the infrastructure to support individuals with chronic medical conditions in this patient-centered fashion. Pediatric hematopoietic cell transplant (HCT) is a medically complex and high-stakes procedure. A dedicated, 24/7, caregiver is necessary and expected in bone marrow transplantation. Often, a caregiver is tasked with monitoring treatment side effects, managing symptom burden, making treatment decisions, administering medications, and performing medical tasks (eg, central line care and dressing changes). As such, the HCT trajectory may be long and unpredictable [2], which creates a complex and multifaceted caregiving process. Caregivers become overwhelmed and juggle multiple roles, such as "interpreter" of medical information, "organizer" of medical appointments and juggling the needs of other family members, and "clinician" to assess and identify health changes in the patient [3].

We have previously shown that caregivers of pediatric HCT patients desire more information and support throughout their healthcare trajectory [4], and technology could support

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this unmet informational need (phase 1) [5]. A paper prototype of a health information technology (HIT) tool, called "BMT Roadmap," was developed to meet these needs. We then took the important step in gaining end-user feedback of our paper-based prototype, getting feedback from patients and caregivers in the design of our HIT using both low-fidelity and high-fidelity prototypes (phase 2) [6].

These studies eventually led to the development of BMT Roadmap, a HIT tool delivered on a consumer-friendly tablet computer (Apple iPad, Cupertino, CA) that integrates patient-specific health information [7]. BMT Roadmap includes the following domains: (1) real-time laboratory results that families can view even before the clinical team; (2) medications, with plain language summaries of common toxicities, indications for use, and instructions for administration; (3) clinical trials in which the patient was enrolled accompanied by a 1-page plain language study summary; (4) healthcare provider directory with "yearbook-style" photos; (5) visual depiction of the trajectory of HCT or "Phases of Care" as patients progress through the inpatient hospitalization; and (6) interactive discharge checklist that incorporates educational videos to prepare families for discharge (eg, central-line care). Herein, we report the implementation of phase 3 of our research, a qualitative study based on semistructured interviews conducted in caregivers who used BMT Roadmap throughout the patients' hospitalization. Unlike phases 1 and 2 where we evaluated HIT prototypes, we now report on a study of BMT Roadmap conducted in real-time among caregivers of patients undergoing HCT.

METHODS

This study was approved by the University of Michigan Institutional Review Board (IRB number HUM00100126) and registered under ClinicalTrials.gov (NCT02409121). This work is the final part of a 3-phase project, as described previously [6] (Supplementary Data S1. BMT Roadmap Project: Phases 1, 2, and 3). In phase 1 an experimental paper-based prototype of BMT Roadmap was developed [4,5,8,9]. In phase 2 design session were conducted with patients and caregivers using multiple prototypes [6,7]. In phase 3 (the present study) we examined the implementation of BMT Roadmap in the inpatient setting, performing semistructured qualitative interviews of caregivers of pediatric HCT patients and healthcare professionals to assess for recurring themes regarding the use of HIT during the HCT process.

Participants were recruited by HCT nurse coordinators and physicians during the pretransplant workup stage in the ambulatory care setting before admission to the Pediatric HCT Unit (Supplementary Data S2. BMT Roadmap Brochure). The a priori sample size to assess feasibility of implementing the tool and conducting user assessments was a target of 10 caregivers. Eligibility included adult caregiver (age ≥ 18 years) of any pediatric patient (age ≤ 25 years) undergoing first-time autologous or allogeneic HCT, ability to speak and read in English, willing and able to provide informed consent, and willing to comply with study procedures and reporting requirements. Once enrolled, the research coordinator provided a tutorial on using the BMT Roadmap. Participants were allowed to use the device freely throughout the child's hospital stay.

Qualitative Assessment

In-depth, semistructured qualitative interviews were conducted in 10 caregivers by 4 trained research assistants at baseline, weekly during admission, at discharge, and at day 100 post-HCT. The goal of these interviews was to unearth commonly held views and perspectives on the use of a patient-centered HIT tool and to identify opportunities for improvement. Open-ended, semistructured interviews were also conducted in 12 healthcare providers to assess their perspectives on BMT Roadmap and its intended use or on any perceived workflow changes related to the tool. Healthcare provider interviews included physicians (5 HCT physicians), 3 staff nurses, 2 nurse specialists/educators, 1 advanced practice nurse, and 1 social worker. Adapted from Piette et al. [10], a priori domains to elicit caregivers' and healthcare perceptions were assessed in open-ended questions (Supplementary Data S3. Qualitative Assessment Domains; Supplementary Data S4. Semi-Structured Interview Guide in Caregivers; and Supplementary Data S5. Semi-Structured Interview Guide in Healthcare Providers).

Data Analysis

The interviews were audio-recorded with permission, de-identified, and professionally transcribed. The transcriptions were reviewed with a minimum of 3 study team members and analyzed using a deductive and inductive approach using best practices for qualitative research [11]. Participants were probed to allow the study team to better understand how BMT Roadmap was received and delivered in an actual complex care setting [12]. Qualitative thematic analysis of the data was performed through iterative cycles of coding and data collection [13]. Codebook structures were refined to reflect emerging themes until consensus of a final codebook scheme was achieved (Supplementary Data S6. Codebook) [14].

RESULTS

Participant Characteristics and Use of BMT Roadmap

Ten caregivers of pediatric patients undergoing first-time autologous or allogeneic HCT were enrolled in this study. As shown in Table 1, the median age of the caregiver population was 35 years (range, 25 to 54). Most caregivers were white (90%) and women (80%). Transplants were 50% autologous and 50% allogeneic. The diagnoses were heterogeneous and included acute lymphoblastic leukemia (n = 2), acute myelogenous leukemia (n = 1), myelodysplastic syndrome (n = 1), severe congenital neutropenia (n = 1), choroid plexus carcinoma (n = 1), Ewing's sarcoma (n = 1), and neuroblastoma (n = 3). The median hospital length of stay was 29.5 days (range, 20 to 117). BMT Roadmap was used frequently. Minutes used and days used were strongly intercorrelated (r = .90, $P = .001$) and correlated with inpatient days (r = .70, $P = .05$, and r = .81, $P = .01$, respectively). The most time spent was in the laboratory module, followed by healthcare provider directory, medication, and phases of care modules.

Qualitative Findings

Qualitative analyses revealed a wide range of user responses. We focused on 5 important themes that emerged during the qualitative assessment of caregivers throughout their children's hospitalization: (1) emotions associated with the HCT process itself; (2) communication between patients, caregivers, and healthcare providers; (3) BMT Roadmap use in the inpatient setting; (4) suggestions for improving BMT Roadmap; and (5) organization and management of patient healthcare.

Emotions

In baseline interviews before using BMT Roadmap, a wide range of emotions were expressed by caregivers undergoing the HCT process. By the time patients were admitted for HCT, most (80%) had received intensive chemotherapy for their underlying malignancy, and many caregivers reported being emotionally drained. Although caregivers understood the risks and complications associated with HCT, undergoing the process itself was overwhelming: "Yes. He's maxed out. We all are maxed out. . .It's getting rough."

Caregivers also described how their "new norm" had become caring for the patient and coming back and forth to the hospital for various clinic appointments, while also balancing other household commitments and tasks: "It's our normal life now, so if we ever do go back to that normal that everybody thinks is normal, it's going to be a bit awkward for us because we've always been back and forth to doctors' appointments and hospitals."

Communication

Caregivers described the importance of communication among patients, caregivers, and healthcare providers. Many

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