Development of a health-related website for parents of children receiving hematopoietic stem cell transplant: HSCT-CHESS

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Abstract

Introduction—Parents of pediatric hematopoietic stem cell transplant (HSCT) play a pivotal role in the care of their child during and after transplant. In addition to the child's comforter, parents also serve as care coordinators and conduits of communication between various health care providers, family and community members. The stress on the parent and family is enormous during this process, which for many is compounded by geographic dislocation to accompany their child during the rigorous treatment and recovery process. For many parents, their own recovery spans months to years.

Methods—Parental activation, a process of becoming informed to participate in decisions, collaborate with health care providers, and manage care provided the conceptual framework to develop an eHealth approach for this population. HSCT-CHESS was developed, based on previous success with an existing eHealth system of integrated services, the Comprehensive Health Enhancement Support System (CHESS™). CHESS™ is designed to help individuals and families cope with a health crisis or medical concern. The iterative user-centered development process for HSCT-CHESS included parents of HSCT recipients, representatives from an HSCT Advocacy Group, and members of the clinical, research, development and design teams. This

rigorous process, including online focus groups and surveys, utilization of a parental user group, and an editorial and development process are described.

Conclusion—As the population of cancer survivors and caregivers increase and as the oncology workforce becomes more stretched; developing eHealth applications may be an approach to address many of caregivers unmet needs. The purpose in describing this process is to help others when considering such an endeavor. HSCT-CHESS is now being tested in a randomized controlled trial versus standard care to evaluate its impact on the quality of life of both the parent and child HSCT recipient.

Keywords

Internet; Patient education; Caregivers; Parents; Information services; Self-efficacy

Introduction

Hematopoietic stem cell transplantation (HSCT) is an intense treatment for some cancers and bone marrow failure disorders in adults and children. HSCT now represents the second most frequent major organ transplant in the US with an estimated 17,450 transplants performed in 2005; approximately 12.9% (2250) were performed in patients less than 20 years old in one of the 100 pediatric transplant centers in the US (CIBMTR data).[1] HSCT is generally offered at specialized facilities that are often far from the transplant recipient's home. Most recipients are accompanied by a family caregiver, the parent in the case of pediatric HSCT, who remain with the recipient for the weeks to months following transplant. HSCT recipients and their families are extremely vulnerable during the demanding HSCT process, an intensive clinical treatment made even more stressful by issues related to geographic dislocation, physical and social isolation, treatment duration and impact, and burden on the accompanying parent to coordinate their child's care [1,2].

During the HSCT process, the accompanying parent becomes an active participant in their child's care. This activation is akin to the patient activation in chronic illness management where the individual learns enough and develops the confidence to act on his/her own behalf [3,4]. Information technology has been shown to empower individuals in matters of health and self-management in chronic care [5–7]. Therefore, in conceiving this project, we hypothesized that a web-based education and support program for the accompanying parent could help ameliorate the impact of HSCT individually and collectively on the family.

This paper describes the process used to create a pediatric transplant-specific web-based education and support module (HSCT-CHESS) from a proven interactive health communications system, the Comprehensive Health Enhancement Support System (CHESS™, http://chess.chsra.wisc.edu/Chess/). CHESS is the umbrella name for a variety of eHealth programs developed at the University of Wisconsin [8]. It is an evolving, non-commercial system, initially designed to help people cope with breast and prostate cancer and other serious diseases such as HIV [9]. The development process described here can be applied to other eHealth programs, using interdisciplinary teams.

HSCT-CHESS development process

A number of steps were implemented to accomplish our goals (Fig. 1). When viewing a website, most end users note the appearance, navigation, and functionality without particular regard for the time, effort, skills, and team work necessary to produce such a site. [10]. When we embarked on this project, our first step was to identify key participants for development. Second, we conducted a needs assessment (focus groups and survey) of the intended users to identify needed content and services for this population. [11,12]. Third, we

kept the end user (parents) at the center of our design and functionality development [13]. We created content and services based on both the conceptual framework of parental activation and empowerment and the results of the needs assessments. And last, we conducted beta and pilot testing the HSCT-CHESS site with parental end users prior to commencing the randomized controlled trial. Each step of this process is described below.

Interdisciplinary team

A variety of team members is needed to develop a credible and user-centered website, including designers, programmers, writers, clinicians, researchers, and representative users (parents of children who had received a HSCT and representatives from a HSCT advocacy group) [10]. Each team member brings a unique perspective and expertise to the project along with a specialized language related to their field. Effective communication, including translating this specialized language so all team members could understand, is a critically important feature for a team [14]. We designated an active project manager (DKM), who acted as a "translator" between teams, interacting with each of the groups to keep the project moving forward in a timely manner.

Understanding the iterative nature of the development process is an important concept, especially early in the process before the 'product' starts taking shape [15]. In our project, this aspect was especially challenging, given that the team members were located across three organizations and geographic locations. It was also challenging because the clinicians had no previous website development experience, while the website experts had no content knowledge about the transplant experience. To enhance day-to-day communication within the team, we used face-to-face meetings, regular audio, video, and web-assisted conference calls on a regular basis.

Needs assessment

It was important to understand the unmet needs of the end user. Insight was gained by conducting needs assessments of both parents and health care providers [16–20]. Wanting a geographically representative sample for the needs assessment, we partnered with a HSCT advocacy group, Blood & Marrow Transplant Information Network (BMT Infonet; www.bmtinfonet.org), to advertise both the focus groups and survey through listservs and print newsletters. We conducted five virtual focus groups with purposive samples of parental caregivers (n=14) and health care providers (n=9) from 20 different states, which is described elsewhere. [11]. Briefly, focus group participants were asked open ended questions to identify key issues facing families during the first year following HSCT including: describe the HSCT experience and identify the biggest issues you and your family faced before, during, and after the transplant; and describe what major change they would recommend to make the HSCT easier. Based on these focus group results, an online survey was developed and advertised through the BMT Infonet that included a topical outline of key medical and non-medical issues [12]. Parental caregivers (n=161) completed an online survey identifying issues that needed to be addressed in the planned website. For example, while the most cited sources of information were the HSCT team (87.7%), books and other print materials (83.1%), and the Internet (81.5%), more than half also reported that it was a problem finding resources and services. Over half identified managing the emotional and social impact of the transplant on their child, post-transplant and follow-up care, practical strategies for caregiving, maintaining the family and taking care of themselves during this first year as important topics to address.

We then developed a parents' user group from some of the interested survey and focus group participants. We established a virtual mechanism where they could advise us after being shown different aspects of the developing website. Most of this was done by email

after sending images, documents, or weblinks to review. The end result of this phase of the development process was a topic structure or outline of what needed to be included in the website (Fig. 2).

Content development

We then began to obtain and develop content and resources addressing areas within the topic structure based on the needs assessment and the experience of the CHESS, Tufts, and BMT InfoNet investigators (Fig. 3). While the basic infrastructure for all HSCT-CHESS services was present in the existing CHESS system, new HSCT content and resources were either imported from the BMT Infonet, National Institutes of Health, or were created by the clinical team.(SKP, SJR).

An editorial guideline and review process was developed to ensure quality, currency, reading level (6–8th grade level), and consistency across writers and developers and to facilitate communication within the team, as proposed by Garneski and co-workers. [21] Reviews occurred by health care providers and some members of the parents' user group both before and after posting online. After copyediting to conform to the site's editorial guidelines, a final step in the content development process was the addition of production coding to tag content for programming. This tagging principally included time point (before, during, and after the transplant) and topic.

Design and functionality

In a parallel and often overlapping iterative process, the look and feel and functionality (how it worked and interacted within the site) of the website was developed. The HSCT-CHESS team was well versed in the design and functionality of health-related websites. Evidence-based usability standards (http://www.usability.gov/) were used in making decisions about the design and function of the site. We also followed Health on the Net Foundation's Code Principles (http://www.hon.ch/HONcode/Webmasters/Conduct.html). The HSCT-CHESS website was designed to be user friendly and functional in a variety of settings (in the hospital, outpatient area, hospital housing, and home) to be viewed on a range of screen sizes (it was set to a minimum of XX x XX screen resolution for that purpose) (see Fig. 4). The Parents' User Group was included in the review of various aspects of the website when making some of the decisions. For example, parents wanted to be able to access information about poor outcomes and end-of-life issues but only wanted to see it if they were looking for it. As a result, we created a topic area within 'Transplant Basics' called 'If the transplant doesn't work' based on their feedback. In addition, parents talked of the long periods of time when boredom sets in for the child and parent so the 'kids corner' and 'parents corner' were developed to provide access to games and other features for relaxation and entertainment. Personal stories of other families were added, collaborating with National Public Radio's StoryCorp (http://www.storycorps.org/record-your-story) to record the interview session. Content was then made available in the Personal Stories section as well as embedded within relevant content.

The HSCT-CHESS website was developed for a Microsoft server platform and the application is hosted using Microsoft's server offering — IIS for web hosting and SQL Server 2005 as the database server. Microsoft VB.NET and C# were used to program the delivery of the dynamic content and services. Document management tools were developed and used to create and index content. The content of each of our information services documents are organized by keywords and topics making it easy for users to find information by searching in a variety of ways. The application program is accessed using a code name and password on a secure website; all data submitted by users is encrypted.

HSCT-CHESS staff manages user accounts remotely and have access to administrative web page to manage user data and view reports online. The CHESS User Profile manager program allows the administration of user accounts — to add new users, and edit existing user logins. Website use data is collected and made available for analysis each month using the following methods. Every page accessed by a user is logged by the web server, but a server plug-in we developed allows us to attach user login information to each and every resource accessed and logged by the web server so we can tell the person who accessed each resource. This way, we can sort the use data for each user or create reports and analysis by resources and services offered by the website. Questions like the number of users who accessed a given service, how frequently services or pages are accessed can be merged with the demographics of users to answer relevant research questions or to identify areas that more content may be needed. We also gather more data on resources accessed such as IP numbers, date and time of access. This will help us identify the more helpful resources and analyze them by user and time since transplant.

Beta testing

The parental user group and others were invited to use the site over a 10 day period and then complete on online survey. We received feedback from 16 reviewers: 44% were parents of children who were HSCT recipients, 50% were a variety of health care providers (i.e doctors, nurses), and 19% 'other' volunteers. The survey assessed a number of usability features such as ease of navigation and ability to read and understand presented information, identifying the best and worst features, what was missing from the site and what one thing, if fixed, would make it a better site. Responses identified many of the different features such as the resources, personal stories, and planning tools and the ability to connect with others as being the best features of the site. Modifications were made over the next month based on the constructive feedback we received such as a slight modification of the site's color palette to make it brighter, organizing the tips section better or improving the search functionality. The majority thought the site was easy to understand (94% agree/completely agree) and navigate (93% agree/completely agree). Overall, 88% thought the website would be very useful for families facing transplant.

From the beginning to the end of the beta testing, we expected this process to take approximately 12 months but in reality it took approximately 18 months to launch. Some of the added time was due to an under appreciation of the time needed for the teams to communicate and work with each other across disciplines and settings. Other under appreciated aspects including the interdependent tasks in moving forward (e.g. needing the content to code before it could be entered into the server to work within the website) and the need to develop new content (the site has approximately 1000 pages).

Pilot testing

It was expected that many parents would be using this site from a hospital room, outpatient setting, or in an extended stay facility associated with the transplant center. Therefore, using a laptop and access to WiFi connectivity was the expected method of access. To test the ability to access the HSCT-CHESS program, we then conducted a pilot study at one of the clinical sites with the first three parents enrolled and from the research staff implementing the study. This provided feedback from the field and picked up other minor tweaks (a back button did not work, typos found, some change in language when discussing clinical problems) and the need to shift from WiFi to a mobile broadband card to ensure internet connectivity.

Site maintenance

Websites need to be reviewed and updated on a regular basis based on user feedback, technology advances (e.g. bandwidth, hardware), and changes in clinical care (transplant advances). This is also informed by user's experiences including most frequently used pages, reports of problems, areas brought up in discussion boards, etc. Part of any website development plan should include scheduled updating. We implemented a monthly review process to address users' needs and a quarterly review process to check on the functionality and accuracy of all weblinks and contact information within the site.

Discussion

The purpose in describing this process is to help others when considering such an endeavor. It is important to identify and include the right team members, allow sufficient development and testing time and to adequately budget personnel and resources for this phase of development. As many others have discovered, developing a website is a complex, time consuming, and expensive endeavor [10]. It is unlike traditional print publication processes in that it is a more dynamic and iterative process especially when considering the end user [13]. In addition, technology changes at a rapid pace. A number of changes that have occurred during the development and initiation of this study including the use of smaller computers (net-books), incorporation of webcams and video and voice internet services (skype) to name a few. This allows a new level of connectivity within and between transplant families. As the population of cancer survivors and caregivers increase and as the oncology workforce becomes more stretched, developing eHealth applications may be an approach to address many of caregivers unmet needs. We are now currently evaluating both the impact and the potential mechanism of effect of HSCT-CHESS eHealth intervention in a randomized controlled trial in 200 families at six pediatric transplant centers in the US. We look forward to sharing the results of the randomized controlled trial on the impact this website has on outcomes.

Acknowledgments

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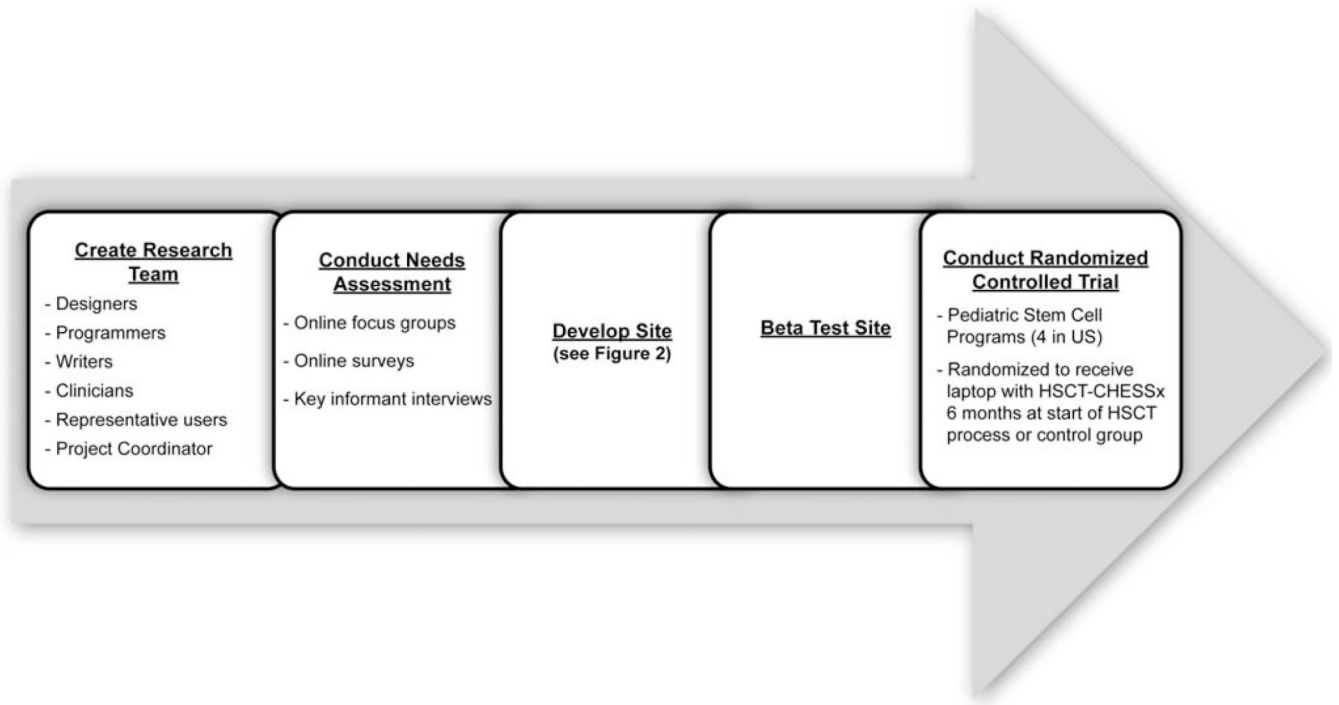
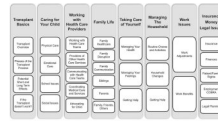**FIGURE 1.**
Development process overview.
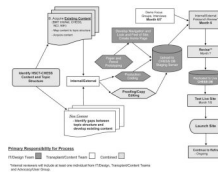
FIGURE 2.
HSCT-CHESS topic structure.

FIGURE 3.
Development & editorial process flowchart.

FIGURE 4.
Screen shots of HSCT-CHESS homepage and other. Note: The+sign indicates a second level of content when clicked on.