BMT-App: development and validation of a mobile application for families of children/adolescents with cancer

TMO-App: construção e validação de aplicativo para famílias de crianças/adolescentes com câncer

TMO-APP: elaboración y validación de aplicación para familias de niños/adolescentes con cáncer

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Abstract

Objective: To develop and validate an informative technology for families of children/adolescents with cancer undergoing hematopoietic stem cell transplantation.

Methods: A methodological study grounded on the Patient-and Family-Centered Care Model and User-Centered Design, conducted in four stages: assessment of information needs; theoretical construction and development of the mobile application; content and semantic validation by a committee of experts and target population; usability evaluation by computer experts. The participants of the study were professionals and families of children with cancer. For content and semantic validation, an inter-rater agreement percentage of 80% and a Content Validity Index of 0.8 were established. For usability evaluation, Nielsen's heuristics were used. The data were analyzed using descriptive statistics.

Results: After the information about the family's needs was obtained from the published literature and field study, the application was developed and validated by experts. Agreement of 87%, and a content validity index of 0.87, were achieved with the expert group; 98% and 0.98, respectively, with the target population. With regard to usability, the level of simple severity was reached. The BMT-App mobile application contains 268 screens and 95 illustrations, addressing the family's information needs before, during, and after transplantation.

Conclusion: The methods used for development and validation were satisfactory to achieve the intended objectives. The application constructed is reliable, easy to use, useful, complete, and adequate. The study advances the proposition of a new informative strategy to promote empowerment of the family confronting chronic disease.

Resumo

Objetivo: Construir e validar uma tecnologia informativa para famílias de crianças/adolescentes com câncer submetidos ao transplante de células-tronco hematopoiéticas.

Métodos: Estudo metodológico fundamentado no Modelo do Cuidado Centrado no Paciente e Família e *User-Centered Design*, realizado em quatro etapas: avaliação das necessidades de informações; construção teórica e desenvolvimento do aplicativo; validação de conteúdo e semântica pelo comitê de juízes e população-alvo; avaliação da usabilidade por *experts* em informática. Os participantes do estudo foram profissionais e famílias de crianças com câncer. Para a validação de conteúdo e semântica, estabeleceu-se percentual de concordância entre juízes de 80% e Índice de Validade de Conteúdo de 0,8. Para a avaliação da usabilidade foram utilizadas as heurísticas de Nielsen. Os dados foram analisados por meio de estatística descritiva.

Resultados: Após identificação das necessidades de informações da família, na literatura e no estudo de campo, e construção do aplicativo, este foi validado por especialistas, obtendo percentual de concordância de

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Conflicts of interest: nothing to declare.

87% e índice de validade de conteúdo de 0,87; e pela população-alvo, de 98% e 0,98, respectivamente. Quanto a usabilidade, atingiu o grau de severidade simples. O aplicativo móvel TMO-App apresenta 268 telas e 95 ilustrações, contemplando as necessidades de informações da família antes, durante e após o transplante.

Conclusão: Os métodos utilizados para o desenvolvimento e validação mostraram-se satisfatórios para atingir os objetivos propostos. O aplicativo construído é confiável, de fácil uso, útil, completo e adequado. O estudo avança na proposição de nova estratégia informativa para promover o empoderamento da família em situação de doença crônica.

Resumen

Objetivo: Elaborar y validar una tecnología informativa para familias de niños/adolescentes con cáncer sometidos al trasplante de células madre hematopoyéticas.

Métodos: Estudio metodológico fundamentado en el Modelo del Cuidado Centrado en el Paciente y la Familia y *User-Centered Design*, realizado en cuatro etapas: evaluación de las necesidades de información, construcción teórica y desarrollo de la aplicación, validación semántica y del contenido por el comité de jueces y el público destinatario, evaluación de usabilidad por especialistas en informática. Los participantes del estudio fueron profesionales y familias de niños con cáncer. Para la validación semántica y de contenido, se estableció un porcentaje de concordancia entre los jueces del 80 % y un Índice de Validez de Contenido de 0,8. Para la evaluación de usabilidad se utilizaron las heurísticas de Nielsen. Los datos fueron analizados mediante estadística descriptiva.

Resultados: Después de identificar las necesidades de información de la familia, en la literatura y en el estudio de campo, y de elaborar la aplicación, esta fue validada por especialistas y obtuvo un porcentaje de concordancia del 87 % y un Índice de Validez de Contenido de 0,87. A su vez, los resultados del público destinatario fueron 98 % y 0,98, respectivamente. Respecto a la usabilidad, alcanzó un nivel de severidad simple. La aplicación móvil TMO-App presenta 268 pantallas y 95 ilustraciones que contemplan las necesidades de información de la familia antes, durante y después del trasplante.

Conclusión: Los métodos utilizados para el desarrollo y validación demostraron ser satisfactorios para alcanzar los objetivos propuestos. La aplicación elaborada es confiable, de fácil uso, útil, completa y adecuada. El estudio avanza en la propuesta de una nueva estrategia informativa para promover el empoderamiento de familias en situación de enfermedad crónica.

Introduction

Technological advances, and evolution in pediatric oncology clinical research, have significantly improved the prognosis of children and adolescents with cancer.[1] Among the available advances, hematopoietic stem cell transplantation (HSCT), or bone marrow transplantation (BMT), is the most prominent as a highly complex therapeutic modality. It is associated with increased morbidity and mortality, although it enables the treatment of diseases that were previously invariably fatal.[2]

Even though HSCT is considered a life-prolonging treatment option, it is also extremely stressful for the family because of the long waiting and hospitalization periods, isolation from family members, and the omnipresent threat of imminent death.[3,4]

In view of all the changes imposed by this new situation, and several coping strategies described in the literature, the legally recognized informative process[5] is fundamental for families to understand what is happening to the health of their members. It allows them to perceive themselves as active subjects in the health/disease process, interacting with the team, having their doubts, anguish, and feelings addressed throughout treatment.[3,4]

Studies involving the use of software applications to mediate the delivery of information to patients have shown positive results, such as improvement in: self-efficacy and self-care; communication about the disease among professionals, patients, and families; and, support for coping with the imposed situation.[6-9] These findings confirm the current trends for the use of health technologies as strategies to provide care to individuals with chronic disease, including childhood and adolescent cancer.[6,10-14]

Knowing the benefits that this type of intervention can provide, the development of an application for families of children/adolescents with cancer undergoing HSCT, addressing issues about the treatment and management of the situation, is an important tool for information access. No studies of technological tools that translate information about HSCT to the family were found in the national and international scientific literature, which made it essential to innovate in this direction.

Thus, the objective of this study was to construct and validate an informative technology for families of children/adolescents undergoing hematopoietic stem cell transplantation.

Methods

This was a methodological study. The theoretical framework of Patient and Family-Centered Care (PFCC) [15] and the methodological framework of User-Centered Design (UCD)[16] grounded the study, which was conducted in four steps: 1. Assessment of information needs of the target population available in literature and field research; 2. Design and theoretical development of the mobile application 3. Content and semantic validation by the expert committee and target population; and; 4. Usability testing performed by informatics experts.

In the first steps, two studies were conducted: an integrative literature review and a field study, with identical objectives, in order to complement each other. For the review, the guiding question was: "What are the information needs during treatment of the family of a child/adolescent with cancer?" The expanded guiding questions enabled us to retrieve studies regarding the treatment of child/adolescent cancer and analyze the findings with a focus on the family's experience of HSCT. The databases consulted were PUBMED, MEDLINE, SCIELO and LILACS, using the descriptors in English and Portuguese: information; family member or caregiver; and neoplasms. Inclusion criteria: studies in national and international journals (Portuguese, English, and Spanish), with available abstracts, during the period of 2011-2017. Exclusion criteria: studies that focused on cancer treatment in adults, and on genetic/molecular aspects. The presentation and discussion of the results was descriptive.

The location for data collection was a reference hospital for treatment of childhood cancer, in São Paulo. The target population was families of children/adolescents with cancer, who had lived the experience of having a child undergoing HSCT for at least 30 days, recruited by convenience. Exclusion criteria: families with communication problems, or with children/adolescents suffering from an unfavorable outcome or critical situation after HSCT. The definition "family is who they say they are" was adopted. [17] Data collection was performed using a focus group technique,[18] and families were asked to describe their experience in managing a child un-dergoing HSCT, exploring their information needs. The discussions were recorded via digital media and transcribed. Qualitative Content Analysis guided the data analytic process.[19]

In the second step, a bibliographic study was conducted to support the theoretical construction of the application (texts and illustrations), based on the analysis of the previous step, following the guidelines proposed by Moreira et al.,[20] regarding development of informative materials. Articles published in indexed journals between 2011 and 2017, textbooks, teaching materials, manuals, and websites of hospital institutions were used. A team composed of a web designer, programmer, illustrator, and the study researchers was organized for this step. After the bibliographic research, texts and illustrations were submitted for editing and layout, using the Wireframe interface design strategy. The selected images were sent to the illustrator for the creation process. The finalized screens were sent to the programmer, who defined the data modeling, infrastructure, types of requests, and information traffic for the development of the prototype, resulting in version I of the application.

In the third step, content and semantic validations were performed by theme experts and the target population, using the Delphi technique.[21] The sample of experts was composed according to information obtained from the Lattes Platform, to identify subjects that met at least two criteria: specialist, masters, doctoral, or lecturer degrees; at least three years of professional experience in the area; knowledge about PFCC; experience in HSCT; experience constructing/validating instruments; experience in the care of children/adolescents with cancer. The experts evaluated the information, considering: readers' perspective; content clarity; convenience and ease of understanding the items; concepts presented with clear and objective vocabulary. Regarding the illustrations, the adequacy of the visual composition, its attractiveness and organization, and quantity were assessed. After sending the material, via e-mail, the evaluator was asked to answer, - keep, change, or delete -, for each screen of the application. Data analysis was based on the

Concordance Index - CI (≥80%) and the Content Validity Index - CVI (≥0.8)[22] between the experts. The screens that obtained the established indexes were maintained; those that did not were revised and resubmitted for new validation, until a final consensus was reached. The results were presented descriptively. After this phase, version II of the application was released.

The semantic validation by the target population was performed in a focus group session.[18] Maintaining the same inclusion and exclusion criteria of the first step field study, different families were recruited. The families were shown the screens and the researchers asked about the following aspects: general appearance; relevance of the items; language clarity; understanding of the terms used; representativeness of the illustrations; and agreement between images and texts. For each screen projected, families responded: keep, change, or delete. Screens that scored CI≥80% and CVI≥0.8 were validated, following the same validation dynamics by the experts. Descriptive analysis of the results was performed. This step resulted in version III of the application.

For the usability test, in the fourth step, Nielsen's ten heuristics were used.[23] The criteria of the sample of experts were to have: a degree with specialization, master's or doctoral degree; experience as a Web designer for more than five years; and knowledge in evaluation using heuristics.

The experts received the documents by e-mail with the link to the application, via TestFlight. For each heuristic, the severity of the problem was rated from 0 to 4, where 0 = unimportant; 1 = cosmetic; 2 = simple; 3 = severe; and 4= catastrophic. A score of 3 or 4 required corrections, and between 0 and 2, the evaluation could be terminated. The data were presented descriptively. After this step, the final version of the application was developed. The assessment of applicability by the target population will be conducted in a later study.

All ethical aspects were respected with approval by the Research Ethics Committee[24] (Opinion 1.253.127) (CAAE: 47408015.0.0000.5505). This study was registered in the National Library - Ministry of Culture under number 788752.

Results

Step 1 - Assessment of information needs of the target population

In the integrative review, 16 articles were identified. From the content analysis, six categories related to the information needs of families were defined: General aspects of cancer and therapy; Side and late effects; Care plan; Coping strategies; Lifestyle changes before, during and after HSCT; and, Palliative care.

Information was needed about the disease, treatment (HSCT), expected outcomes, potential complications, side effects of the initial treatment, and late effects. Information about daily care during treatment in the hospital and home environments, both psychological and physical, was considered fundamental to participation in care. In the home environment, information needed included general care at home for the child/adolescent, and what emergency services were available. Families want to learn how to deal with: the psychological impact of treatment; their own emotions; stressful situations; the uncertainty imposed by treatment; imposed restrictions; how to talk about the illness/treatment; and the changing roles and responsibilities of each family member. In the post-treatment, the needs are about lifestyle changes, resumption of social life, long-term care, possibility of relapses, and information related to palliative care and death.

Five families participated in the field study, represented by 13 relatives (four mothers, two fathers, one brother, one wife, and five patients). Among the types of transplants performed, two were autologous, two allogeneic related, and one allogeneic unrelated, with post-transplant time ranging from six months to 15 years. The patients' ages ranged from three to 18 years. After the analysis, the families' needs were grouped into three categories: Information from reliable sources; Knowledge about HSCT; and Reception by the team.

The discourse reveals that the family wants information from safe sources that they can trust, and that brings knowledge, primarily from the medical

team and the nurse. Other sources of information mentioned are the Internet and parents of children/adolescents who have already experienced transplantation. The knowledge required regarding HSCT refers to the concept and phases; the prognosis; complications; rights; support network; how to care for the child/adolescent in the hospital and at home; how to talk about the treatment with the nuclear and extended family; how to deal with conflicts in the family environment; the late complications of treatment; the warning signs after HSCT; and strategies for dealing with the child/adolescent after discharge. However, they want to be welcomed so that they feel safe to care for the child/adolescent, suggesting that the information should comprise not only the risks, but also the benefits of the treatment.

The analysis of the information needs of families, from sources, integrative review, and field research, showed similar elements, representing the perspective of what the family considers relevant to contain in informational material about HSCT. In the field research, families expanded this perspective to the need for information that respects their time required to understand what is being experienced.

Step 2 - Design and theoretical construction of the application

After the identification of the families' information needs, obtained from the literature review and the field research, construction of the theoretical content was based on a bibliographic study, aimed at answering these needs. The organization of the mobile application content was structured in five categories: Definitions; Pre-BMT; BMT; Post-BMT; and Warning Signs (Chart 1).

The data was forwarded to the Webdesigner and the software programmer, and 38 wireframes were developed to visualize the interface and organize the icons and navigation sites. A visual identity was established, with the definition of character traits and color palette, developing a group of characters (Figure 1), represented throughout the entire trajectory of HSCT, without impacting the conception of the different cultural and ethnic groups.

Chart 1. Distribution of categories and content structure of the application

Category	Content
1. Definitions	Concepts related to HSCT: bone marrow; blood cells; bone marrow transplantation (BMT); types of transplantation; sources of stem cells HSCT indications Multidisciplinary Team
2. Pre-BMT	Guidelines for decision making on whether or not to undergo HSCT Mobilization and stem cell collection Management of complications resulting from the conditioning phase (chemotherapy and/or radiotherapy) First outpatient visit Pre-admission laboratory and imaging tests (patient and donor) Multiprofessional assessment before HSCT Hospital admission process Care in the inpatient environment Hospitalization HSCT phases Preparing the child/adolescent for HSCT Daily care routines Donor
3. BMT	Stem Cell Infusion Stem Cell engraftment waiting period
4. Post-BMT	Stem Cell engraftment Main complications after stem cell engraftment Follow-up after HSCT Caregiving when the patient and family return home
5. Warning Signs	Main signs and symptoms that the child/adolescent and the family should watch for after hospital discharge
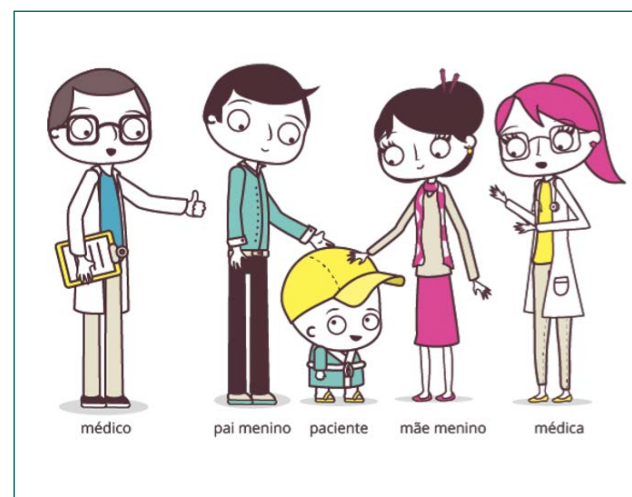
Figure 1. BMT-App characters (Male physician; Father of the child; Patient; Mother of the child; Female physician)

In this process, the mobile application's representative image was developed and its name, BMT-App, was defined, totaling 266 screens and 93 illustrations. When starting the application, after the terms of use screen, the application's presentation interface appears. The categories were distributed in tabs, represented by a bottom menu, and the subcategories were represented by icons (Figure 2).

The application was developed for the IOS operating system on Ipad® tablet devices.

Figure 2. BMT-App presentation screen, categories and subcategories

Step 3 - Content and semantic validation by the expert committee and target population

Four healthcare professionals (one physician, one nurse assistant, two nursing professors) and one educator, aged between 27 and 54 years, participated in the expert validation. The mean time of education was 16.4 years, with a mean of 14.4 years of professional practice; three held doctoral degrees, one had a master's degree, and one had a degree with specialization.

In the first round, of the 266 screens analyzed, 73 obtained 100% agreement (CVI=1.0); 110 had 80% agreement (CVI=0.8); 57 had 60% agreement (CVI=0.6); 19 had 40% agreement (CVI=0.4); and 7 had 20% agreement (CVI=0.2), totaling 183 (68.8%) screens with agreement above 80% (CVI≥0.8) and 83 (31.2%) below 80% (CVI<0.8). Among the 83 screens with scores below those established, in 46 (55.4%) the non-agreement was due to typing/spelling errors, which were corrected. Only 37 (44.6%) were re-sent for a second round of analysis and of these, there was a CI of 100% in 5 screens (CVI=1.0) and 80% (CVI=0.8) in 32 screens. The overall CVI of the application was 0.87 and the CI was 87%. There were no changes in the number of screens and illustrations.

The validation with the target population was conducted in two focus group sessions, each lasting two hours. Five mothers from five families participated, aged over 40 years, most of them Catholic, with high school and college education, and an average of 2.6 children. Even though only mothers participated, they were asked to think about the experience of the family as a whole.

Among the types of transplantation, there were two autologous, two allogeneic related, and one allogeneic unrelated, with post-transplantation time ranging from six months to two years.

In the first session, 138 screens were assessed, 98.6% (136) showed agreement above 80% (CVI>0.8); and only 1.4% (2) were below the established CVI (discrepancies in content and illustrations). In the second session, 128 screens were evaluated and the two screens from the first round were reassessed with new illustrations. All screens obtained CIs above 80% (CVI>0.8). In the general analysis, families found the language easy and understandable; information clear and objective, with logical sequence; illustrations expressive and sufficient; attractive colors, fonts and graphics; and, adequate layout and design. The overall CVI of the application was 0.98, with 268 screens and 95 illustrations.

Step 4 - Usability testing by computer science experts

Three professionals who are experts in building interactive technologies participated, with a mean of 24 years of professional practice, two females and one male, two doctorally prepared and one with a

degree with specialization. The mean age was 52.6 years. The evaluation was off-line, via TestFlight application. The mean time of use was one hour and a half, with the identification of 11 problems in the heuristics: none catastrophic; three severe; six simple; and two cosmetic. In a single round, the severe problems were related to the application's software development (a single operating system) and also to a single type of mobile device, and the suggestions for future research were accepted. Some suggestions classified as simple and cosmetic were incorporated to increase the level of quality: removal of commercial names, and a "BACK" button from the Alert Signs category. This resulted in the final version of the application.

Discussion

The methodological study that was proposed, combined with the theoretical framework used, enabled the construction of reliable, precise, and usable material. The alignment of the PFCC and UCD was essential, as they share the idea of including the users, valuing their perceptions, feelings, and actions. Listening to the voice of the family, from conception through planning and validation, were essential for making the final product meet their information needs.[14-16]

The BMT-App is a strategy to promote a dialogical space with the family, in line with what the literature refers to as relational technology, in which the bond and welcoming of the care settings are valued. This is based on a worldview, in which the family and the child are subjects with rights, in a symmetrical relationship with the multiprofessional team.[25] With information, families feel more secure in caring for their children, enabling them to make better choices and share their perceptions and knowledge.[26] Consequently, the development of this application provides a tool to be used in the interactive process with the family.

The overall CVI of the application and the CI among participants were considered excellent, reaching all pre-established indexes, according to national and international literature. In the usability test using Nielsen's heuristics, the suggestions contributed to the improvement of the final version of the application.

International studies that developed well designed and easy to understand informative materials, for children/adolescents with cancer, showed that the participation of users allowed for the effective exchange of information and a team/child/adolescent/family relationship; it also improved their knowledge.[27,28] However, these technologies are still little used in practice with families, suggesting a gap to be explored.

Considering the limited existing knowledge in the nursing literature on the construction of interactive technologies for families of children/adolescents with cancer, this study advances that knowledge by presenting an interactive technology as a new way to promote empowerment of the family of children/adolescents.

The limitations of this study are related to the operational system in which the application was developed - IOS; and the mobile device chosen to provide the information - a tablet, which is a barrier to access for those who do not have them. New studies, using different systems and devices, are being developed by the researchers to expand access to future users.

Conclusion

The technology developed is valid, as it met the proposed objectives, demonstrating that it is easy to use, useful, innovative, complete, and provides important information. The process of construction and validation of the BMT-App had the family as a protagonist, considered experts in their experience of the disease, contributing to making it worthwhile from their perspective. This study shows that the BMT-App can be used by the family of children/adolescents with cancer undergoing HSCT, and also by the multidisciplinary team, in all phases of therapy. Therefore, it is an informative strategy that benefits families in obtaining their right to information, facilitating their coping process in a strengthened manner.

Collaborations

Duarte AM & Mandetta MA contributed to the study design, data analysis and interpretation, relevant critical review of the intellectual content, and final approval of the version to be published.

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