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Health literacy: Construction of an educational video about the postoperative period of pediatric cardiac surgery

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ABSTRACT

OBJECTIVE: To describe the process of building health educational technology aimed at mothers of babies recovering after pediatric cardiac surgery. METHOD: This methodological study consists of phases: (1) Integrative review of the technology to be developed; (2) Situational diagnosis to obtain content with greater maternal demand; (3) Preparation of the video after validation of the content by judges with expertise. RESULTS: After an integrative review and situational diagnosis, the type of technology and content to be addressed was defined, followed by validation with subsequent creation of the video. Following functional health literacy that involves the target audience, we opted for video in storytelling format, with accessible and playful language, with the mother's recognition of the narrated story. CONCLUSION: The developed video aimed to reach women of different levels of education, functioning as an instrument of maternal support at the moment after cardiac surgery, being able to alleviate anguish and concerns through information and encouragement of the mother during hospitalization.

Keywords: Congenital heart disease, Health technology, Heart surgery.

INTRODUCTION

Congenital heart diseases are cardiac malformations that can occur in the embryonic period and are associated with genetic factors and/or chromosomal alterations. The symptoms are related to the repercussion that the alterations promote, and are classified as acyanogenic (when there is no mixture between the oxygenated and non-oxygenated fractions in the systemic circulation) and cyanogenic when there is a mixture of the fractions1.

In many cases, there is a need for hospitalization to perform surgical, palliative or corrective procedures, with a high demand for hospitalization time, requiring follow-up by a family member. Normally, the mother remains hospitalized with her child while waiting for the necessary procedures and surgery to be performed.

As the main caregiver in the process of hospitalization of the child with heart disease, the mother begins to experience the exhausting hospital routine, which can cause anxiety, fear and anguish in the face

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of the performance of some interventions that the baby's condition requires, and it is common to have a lot of difficulty in understanding the demands of the treatment plus fear of the child's death2.

It is important that family members receive information to better understand, care for and stimulate the child, whether in simple practices such as proper positioning in bed, administration of medications, care in the face of hypoxia crises and how to act in situations that require immediate action3. It is believed that a well-oriented individual can safely take care of the patient needs, in addition to promoting a reduction in anxiety and anguish in the hospitalization process.

Recent studies have revealed that parents place great value on being well-informed, having knowledge about their children's condition, recognizing that the language with which this information is provided to them is often difficult, thus becoming a stressor factor in hospitalization, associated with moments of fear and tension, making it difficult to experience hospitalization.

Thus, to ensure that the information is really absorbed, it is important to evaluate the Functional Health Literacy of the target audience that is intended to be reached, in order to evaluate the real condition of understanding about the information that needs to be passed on, about the disease, the diagnosis and the treatment itself.

In a research on functional health literacy addressing mothers and caregivers of babies with Congenital Heart Disease, revealing a low literacy of reading comprehension by the S-TOFLA (Short Test of Functional Health Literacy in Adults) and readingability, by the Simpl Measure of Goobbeledygook (SMOG), corresponding to the fifth school grade, also highlighting discourses of difficulty and little understanding about the disease and about the care of the baby in the hospitalization and after discharge, linked to the fear of not being able to exercise their role as mothers5.

Based on the previously mentioned study about the low functional health literacy of mothers and family members of babies with congenital heart disease, we thought about the development of a technology whose format would allow easier access and good understanding so that there would be a real understanding of the content that was intended to be transmitted.

OBJECTIVE

Describe how the construction of educational technology in health took place, an educational video in storytelling format, addressing specific and relevant content to mothers of babies with congenital heart disease about what to expect and how to act after their child's heart surgery.

METHODOLOGY

This is a descriptive study about the process of building educational technology in health aimed at mothers who remain in a hospital unit, addressing the specificities of the postoperative period of cardiac

surgery. It is part of a larger study carried out during a doctorate in Clinical Health Care and Nursing at UECE, completed in 2023.

The research was conducted in the cardiopediatric unit of a tertiary health institution, a reference in the north and northeast of the world in the care of congenital heart disease and pediatric heart transplantation, located in the city of Fortaleza, Ceará, Brazil.

To define the type of technology to be built for the intended public, an integrative review was initially carried out on which health educational technologies would have the greatest impact and efficacy with mothers hospitalized for surgery.

In addition to the review with the definition of the possible types of technology, the situational diagnosis was initiated to establish the content that would be part of the technology aimed at mothers who remained in the cardiopediatric unit to monitor their children in the treatment of congenital heart disease. The intention was to find the real maternal needs in the face of this condition and that it could be met with the technology to be developed.

For this diagnosis, conversation circles were held with mothers who were in the hospital unit, in an inpatient condition, in the period from February to June 2021, in reserved rooms, maintaining all the care that the Covid-19 pandemic required. At the end of these meetings, the speeches were transcribed, organized and analyzed by the IRAMUTEQ software (Software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires), so that the content obtained could be organized in a script format to be validated by expert judges with expertise in congenital heart disease before applying it to the target audience.

The entire project was conducted in accordance with national and international ethics guidelines and approved by the Research Ethics Committee of a health institution, CAAE: 4 3229321.0.0000.5039, opinion number 4.550.044, following the standards required for research involving human beings.

DEVELOPMENT

The integrative review on the definition of which active methodologies would have the greatest reach for health education at the hospital level, revealed as a result that light-hard technologies, with technical resources such as lectures, conversation circles, educational videos, among others, would be the most appropriate for educational actions in the field of health, supported whenever possible by playful resources that are easy to understand and appropriate to the intended audience.

In the situational diagnosis, 5 conversation circles were held with mothers who were in the hospital unit to monitor the treatment of their child with congenital heart disease, a total of 15 participants in all, in the period from February to June 2021, in appropriate rooms, maintaining all the care that the Covid-19 pandemic required.

In these moments, the mothers were invited to talk about the experience of congenital heart disease in the face of hospitalization and the expectations with the surgery, encouraging spontaneous verbalization, enabling the exchange of experiences and the creation of bonds among the participants.

Mothers with different levels of education were found, one of them illiterate, which served as an incentive to think about a technology that could have a greater reach, such as an educational video, in a playful, non-infantilized format, which would allow easy understanding of the knowledge and orientations that were intended to be transmitted.

In view of the data observed in health literacy studies, a video in storytelling format was considered, coming from marketing, but already widely used in health education, popularly known as "talking hands", a playful and creative resource that associates real images while narrating a story in which the target audience recognizes itself and finds there information that they would like and need to receive.

The content to be part of the video was obtained after analyzing the mothers' speeches in the conversation circles by IRAMUTEQ. The analysis revealed numerous doubts and complaints of little understanding and lack of information about what would come after the son's heart surgery.

In view of the mother's demands, the production of an educational video in storytelling format was started, addressing the main information about the postoperative period of cardiac surgery, with the objective of minimizing such doubts, in addition to anxiety and stress in such a delicate phase that requires the presence and participation of mothers.

The video developed allows access on cell phones, tablets and computers, and can be used in various health spaces. The story told in storytelling enables interaction and easy understanding, using drawings and images that are superimposed on the screen when presenting the desired content, involving the subject who watches, by direct recognition or similar experiences6.

The content of the video based on the mothers' statements was validated by judges with expertise in the field of cardiopediatrics. This whole process was developed in several stages in the doctoral thesis "Effectiveness of educational technology in health on breastfeeding of babies with congenital heart disease: study in the light of the concepts of Imogene King's goal achievement theory.

The cognitive effects of *storytelling* in our neurology influence learning and remembering information that has implications for individuals, through a story visualized in the video, preparing them to make decisions and actions based on what is seen, in addition to understanding and remembering messages. Thus justifying the choice of video format for the intended technology7.

The integrative review pointed to active methodologies with yeast technologies as more effective, with materials that could be accessed in a more practical and realistic way, opting for the construction of a video in storytelling format, bringing a story to be told along with the information that was intended to be transmitted to the mothers, in a playful and easy-to-understand way.

The discourses of the mothers participating in the conversation circles, analyzed by the IRAMUTEQ software, presented classical lexical statistics and basic lexicography with an effective quantitative of active and supplementary forms and a total number of occurrences of 12,280 and 979 lexical units. The textual corpus, in turn, resulted in 100 Elementary Context Units (ECU), producing 5 classes later organized into two larger subcorpus.

In this study, subcorpus 2 will be presented, called "Experiences of the mother-baby dyad arising from illness and hospitalization", revealed maternal concerns with reports of difficulties in understanding and lack of information about situations experienced with hospitalization, about the postoperative period and recovery in the ICU, how to act in the intensive care environment, how to feed the baby after surgery, if she would be able to breastfeed, bathe, as well as doubts about discharge and the desire to feel prepared to take care of her baby after surgery.

In view of these maternal demands, the script was designed to assist and guide the child's care after cardiac surgery. Thus, the content was written and organized in 4 sections: (1) My baby in the ICU; (2) Breastfeeding in Congenital Heart Disease; (3) Oral feeding by utensil; and (4) The moment is to wait, with a total of 27 relevant items directed to mothers in a postoperative situation in a cardiopediatric ICU.

Section 1 entitled "My baby in the ICU" sought to provide information about the reality in which the mother would find her baby after cardiac surgery, the hard technologies to which he would be connected, such as electrodes, mechanical ventilation, feeding tube, accesses and devices needed after surgery, and how to help at this moment, emphasizing the approach to the team that will accompany them during the ICU period.

In the second section, the approach was directed to the return of oral feeding, widely reported with maternal distress in the ICU context, and to the possibility of breastfeeding in congenital heart disease. Here, information was inserted about the conditions necessary for breastfeeding the baby, steps that will need to be taken for BF to be effective in a safe and functional way, postures that are more suitable for breastfeeding in order to preserve the surgical wound and the situation of the technological apparatus linked to the baby, reinforcing the support of the speech therapist as well as the entire team. still in an ICU environment, whenever there are clinical conditions for this effectuation.

In the third section, "Oral feeding by utensil", we address situations in which breastfeeding cannot be effective or that does not occur exclusively due to the clinical and/or nutritional condition of the baby due to heart disease. At this moment, the work performed by the speech therapist to stimulate the baby's oral functions is presented, as well as the indications of ideal utensils for each baby, whether it is a bottle, cup or other utensil that best suits the baby's condition so that feeding occurs safely, without risk of choking, bronchoaspiration and functional to the point of resembling what is expected for the age group.

A functional diet that does not cause inadequacies in the oral motor system is important so that there can also be adequate development in important functions related to the child's speech and language.

In the fourth stage, we chose to bring the baby who is still in the ICU still unstable, without conditions for stimulation, in which the mother is faced with the fear of losing her child and the feeling of wanting to help in some way. For this situation, ways of being present were inserted, such as singing, talking, touching the baby, bringing the team as a partner so that in safe conditions this mother can be brought to a possible and humanized care of her baby, within the rigid structure that is often presented in an ICU.

For the elaboration of this video script, King's theory was used as a guide, focusing on the interaction between individuals who participate and share in decisions, in this case mothers and professionals. The role of the health professional is to guide the decision-making process, guiding, interacting, influencing and being influenced by the perceptions of patients and caregivers in the development of care, always being attentive to facilitate everyone's understanding8.

With the script defined, content validation was carried out by the E-Delphi method, with professionals with expertise in the area of cardiopediatrics, obtaining the consensus of the judges in the second round, being, therefore, considered as adequate and functional, for the production of the educational video aimed at the target audience of the study. The script was validated with 30 items, after a suggestion accepted from three guidelines made by the judges.

After validation, the script was sent to a professional with experience in videos in the stoytelling format, asking him to use real figures, or very close to reality, in order to enable the recognition of the mothers for the hospital experience when accompanying the child in the hospital. The intention was also to facilitate the understanding of the necessary guidelines for the dynamics of the baby's care after pediatric cardiac surgery while still in a hospital environment, so that well-informed women could have more peace of mind in conducting the baby's recovery, allowing improvement in mother-baby interaction.

At the end of the video, words of encouragement and encouragement were inserted for greater maternal participation, considering that more aware of the entire process of the child's treatment could act with more tranquility and security when caring for their baby. The video was called "Beyond the heart", because it is complementary information about heart disease and that follows the baby after surgery.

FINAL THOUGHTS

The in-depth analysis of the mothers' statements proved to be a differential for the construction of the technology, in view of having enabled the knowledge of the real maternal needs and thus, based on them, the elaboration of easy-to-understand material, according to the functional literacy appropriate to the

mothers still at the hospital level, about the repercussions arising from the surgery and treatment, helping to reduce anxious states and improve maternal care during hospitalization and after discharge.

The choice of the storytelling format for the video, based on the functional health literacy of mothers of babies with congenital heart disease, sought to facilitate the construction of an easy-to-understand material about the necessary postoperative care of the baby after cardiac surgery.

The video developed was proposed in order to reach women of different levels of education, functioning as an instrument of maternal support, and can also alleviate anguish and concerns through more information, encouraging mothering in the ICU, with a more active and cooperative mother at the time of her child's recovery after heart surgery.

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