

CHILDREN'S LIVER TRANSPLANT: BOOKLET AS CARE TECHNOLOGY

*TRANSPLANTE HEPÁTICO INFANTIL: CARTILHA COMO TECNOLOGIA DE
CUIDADO*

*TRASPLANTE DE HÍGADO INFANTIL: FOLLETO COMO TECNOLOGÍA DE
CUIDADO*

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ABSTRACT

The discovery of a chronic disease in childhood or adolescence and the need for a liver transplant can have important emotional consequences and change family dynamics. As it is a complex process, which goes far beyond surgery, there is a need to better understand the biological and psychological aspects involved. The objective of this article is to describe the process of constructing and developing a booklet on pediatric liver transplantation, aiming to assist the experience of parents/caregivers and providing a space for greater reflection and visibility regarding psychological aspects. The booklet was organized in the format of topics or guiding questions, with a total of 21 pages. It is noteworthy that the creation of care technology in the health sector can be an important ally in disseminating information and raising awareness among the population, but it does not replace the monitoring of the multidisciplinary team.

Keywords: *Liver Transplantation; Child Health; Psychology Medical.*

RESUMO

A descoberta de uma doença crônica na infância ou adolescência e a necessidade da realização de um transplante hepático podem trazer importantes consequências emocionais e modificação da dinâmica familiar. Como se trata de um processo complexo, que vai muito além da cirurgia, se identifica a necessidade de compreender melhor sobre os aspectos biológicos e psicológicos envolvidos. O objetivo deste artigo é descrever o processo de construção e desenvolvimento de uma cartilha sobre o transplante hepático infantil, visando auxiliar na vivência de pais/cuidadores e trazendo um espaço de maior reflexão e visibilidade quanto aos aspectos psicológicos. A cartilha foi organizada no formato de tópicos ou perguntas norteadoras, apresentando o total de 21 páginas. Ressalta-se que a criação de uma tecnologia de cuidado na área da saúde pode ser um importante aliado na divulgação de informações e conscientização da população, mas não substitui o acompanhamento da equipe multiprofissional.


Descritores: *Transplante de Fígado; Saúde da Criança; Psicologia Hospitalar.*

RESUMEN

El descubrimiento de una enfermedad crónica en la infancia o la adolescencia y la necesidad de un trasplante de hígado pueden tener importantes consecuencias emocionales y cambiar la dinámica familiar. Al tratarse de un proceso complejo, que va mucho más allá de la cirugía, es necesario comprender mejor los aspectos biológicos y psicológicos involucrados. El objetivo de este artículo es describir el proceso de construcción y desarrollo de un folleto sobre trasplante hepático pediátrico, con el objetivo de auxiliar la experiencia de padres/cuidadores y brindar un espacio para mayor reflexión y visibilidad sobre los aspectos psicológicos. El cuadernillo se organizó en formato de temas o preguntas orientadoras, con un total de 21 páginas. Es de destacar que la creación de tecnología de atención en el sector salud puede ser un aliado importante en la difusión de información y sensibilización de la población, pero no reemplaza el seguimiento del equipo multidisciplinario.

Descritores: *Trasplante de Hígado; Salud Infantil; Psicología Médica.*

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INTRODUCTION

The period of childhood and adolescence is generally seen as a period of great development and growth, with a positive connotation regarding the main milestones of these phases. However, some factors can interfere with the life cycle and bring important changes to family dynamics. One of these factors is the diagnosis of a chronic disease, which can be considered a very painful event with important emotional consequences for both the child or adolescent and their family¹.

Depending on the case, the disease can be considered life-threatening and a period of search for the most appropriate or effective treatment begins, which may include the use of medications, alternative therapies and/or surgical interventions. Surgical interventions can be defined as a complex procedure, even more so when there is a need for a transplant. In the case of liver transplantation, there is the prospect of an important evolution over the years, with this surgery establishing itself as the only effective option in the treatment of patients with advanced liver disease². Thus, the indication for transplantation occurs when there is a possibility of improvement in the quality of life of the child or adolescent, and there is no positive response to another type of treatment³.

This surgical procedure can be defined as the replacement of an organ from a sick person with another healthy one from a donor. Liver donation is made possible coming from a deceased individual (brain dead) or a living donor, in which a fraction of the organ will be removed for donation. The two basic principles of this procedure are: the need for a donor and the fact that the transplant does not begin or end with surgery². These principles announce the complexity of transplantation, which encompasses the process of evaluation, diagnosis, continuous care, pre- and post-surgical period, with the continuity of treatment, including going to appointments, use of medications, and changes in lifestyle habits.

The multidisciplinary team plays a very important role in this context. However, some factors can influence the communication and understanding of patients and family members. One of the possible strategies to assist this system is the creation of educational materials that enables guidance to the target audience in a facilitated form, favoring the understanding of their health-disease process in a more didactic and dynamic way, constituting, therefore, an important care technology. Thus, the objective of this article is to describe the process of construction and development of a booklet on childhood liver transplantation.

METHODS

This article is part of the "Technological Innovation" axis, proposing to describe the creation of a booklet on Childhood Liver Transplantation aimed at parents or caregivers. In the process of developing a booklet, some principles must be considered, such as the use of clear and objective language; light and attractive look; adequacy to the target audience and reliability of the information. It should follow these elaboration steps: definition of the theme and subsequent definition of the topics; bibliographic research; elaboration of the script and development of the booklet itself⁴. It is a pertinent proposal because it is a complex topic and presents a reduced quantity of materials available to the general population and with a language directed to the lay public.

The research and construction process of the booklet took place between August 2022 and April 2023. In preliminary research, it was noticed the existence of a small number of booklets on the subject, and topics regarding psychological aspects were often absent. No material of this type was found directed to parents and relatives. After this initial research, a literature search was carried out (SciELO and Google Scholar databases - descriptors: Childhood Liver Transplantation; Pediatric Liver Transplantation; Child Liver Transplantation and Psychology) by the theme of child liver transplantation, considering general materials (physical and medical aspects), but mainly focusing on psychological aspects and their repercussions for family dynamics. Thus, the booklet was structured based on guiding questions or topics, with the objective of facilitating the reader's understanding and making the reading more fluid, totaling 21 pages (with front and back cover).

It is a material designed for parents or caregivers aiming to deal with the most pertinent topics according to the authors' experience in Hospital Psychology, especially the interventions carried out by one of them as a resident psychologist at a hospital that is an important reference in the area of Child Liver Transplantation (Outpatient Clinic, ICU and Pediatric Hospitalization) in agreement with data in the literature.

RESULTADOS

For the construction of the booklet "Child Liver Transplantation: what is important for parents and caregivers to know?" were identified the possible demands from parents and family members related to the child/adolescent in the process of liver transplantation. At first, it is explained about the organ (liver) that will be transplanted, about the surgery and about the follow-up stages. Subsequently, the main psychological aspects that may be involved are presented, considering possible fears, fantasies and doubts.

After the cover, there is a brief presentation for a better acclimatization on the part of the reader, followed by a total of 10 questions and 2 topics, with the last topic formulated with the objective of stimulating writing (personal record) on the part of the booklet bearer, encouraging the record regarding follow-up, possible doubts and externalization of their feelings. Below are selected pages of the booklet for viewing regarding the aesthetic part and some of the contents worked in the material, considering that physical/biological aspects, practical aspects (such as new family routine and organization) and greater emphasis on psychological aspects and also on the role of the Psychology professional are addressed.

For the creation of the art part of the booklet, the "Corel" program was used, through the service of a professional designer. Pastel colors were used, aiming to create a more harmonious art, which would convey a sense of tranquility to the reader. Illustrations related to the theme were also used, bringing a more playful tone to the material.

Figure 1: Cover and selected pages of the Educational Booklet.



Source: Produced by the authors.

DISCUSSION

When thinking about the Liver Transplant process, it is necessary to consider the diversity of factors that are involved and that it is not only about the surgery itself, but about all the preparation and constant care to maintain the patient's quality of life. Among these factors are those considered physical/biological, social and psychological factors. In this scenario, there is an important indication for multidisciplinary follow-up in the context of chronic disease, which deserves greater emphasis when it comes to performing a transplant⁵. As highlighted in the literature, successful survival requires permanent follow-up of this child or adolescent in the post-transplant period².

The booklet presents a general summary of the main aspects involved in the transplantation process, including medical issues that require an initial understanding by family members. This focuses on psychological issues (which are often in the background due to ignorance or prejudice on the part of the general population), thinking about the relevance of early interventions and psychological follow-up aimed at children or adolescents and their families, with the aim of reducing psychological suffering⁵. There is some controversy about the reduction of psychological suffering, as it can be considered something that should not be seen as the central objective of the psychologist, emphasizing that patients and family members have different types of needs and that there is suffering inherent to the process of hospitalization and surgery. However, there is no doubt about the power of psychological care, providing a space for listening, welcoming and, mainly, talking to these patients and their families.

The booklet has the main objective of being a tool so that the family member can take a more active and conscious role in this process. This is not an easy task, because in addition to being informative material, it is intended to bring a welcoming tone to the reader, encouraging them to identify their feelings and get closer to other people who are going through a similar situation, so that they do not feel alone or inadequate in their experience. However, despite being a valuable support material, the booklet does not replace the follow-up of the multidisciplinary team, especially the Psychologist.

Having support material, which can elucidate the anxieties and indicate that many of your fears are expected reactions within this process, can be valuable and favors the reduction of stigmas related to Mental Health. Even more so considering that a careful look at parents/caregivers is fundamental for them to have better psychic conditions to support their children, because with the care of parents we are also taking care of their children⁶.

As discussed in the literature, it is notorious that the transplantation process is a very distressing event for family members, which includes a rupture of the family structure, imposing the need for a reorganization, which includes: feelings, roles played and the life of each person involved as a whole. The importance of the role of the Psychologist is reiterated, who can help to give names to the feelings that arise as a great whirlwind, in addition to providing support and assistance in the elaboration of the conflicts present in each phase of the process⁶.

The booklet is considered a light-hard technology, according to Merhy⁷'s discussions, because it contains specific knowledge from a field of knowledge - liver transplantation - but its use occurs through contact and exchange with the user through listening, bonding and welcoming. This type of material makes use of a graphic expression to organize and convey information and can be developed on the most different themes. As pointed out in the literature, informative materials are configured as sources of education and are adapted to the language of the target audience, with the objective of being easily understood, bringing clarity and objectivity. In general, the aim is to encourage dialogue between the parties involved, facilitate the acquisition of knowledge and, as a result of the work performed, provide greater comfort and quality of life for the patient⁸.

The creation of materials or even programs dealing with the theme of transplantation makes even more sense when we think about public policies and the need for greater awareness and knowledge on the part of the general population. This is an issue that deserves greater attention and is also mentioned in the literature, in order to increase the number of public education policies, both for society and for multiprofessional teams, including the different social actors that are part of the scenario of donation, procurement and transplantation of organs and tissues⁹.

CONCLUSION

The transplant process goes far beyond the performance of the surgery itself, including all the preparation and constant investment in the patient's well-being, both by the team and the caregivers, especially in the case of a pediatric transplant. Considering its complexity and with the objective of bringing a closer approach to the theme, the

creation of the booklet was structured beyond medical information. It is necessary to have an initial understanding of the psychological aspects that permeate this process, which can often be neglected to the detriment of other points. Thus, the production of the booklet aimed to bring a perspective of care, welcoming, and identification and validation of feelings.

The creation of booklets or similar materials can be an important ally in the dissemination of information and awareness of the general population, bringing very relevant themes that may be little known when we consider the advances in medicine and the increasing number of complex procedures performed by the Unified Health System (SUS). Thus, it is reinforced that the creation of technologies that can help users understand their health-disease processes are fundamental for collective health, since it favors the democratization of knowledge, fosters user participation and horizontalizes the relationships between health actors (patient, family and team).

Considering that this article is an explanation of the process of constructing the booklet, it is understood that there is a need for future research on the validation of the material, as well as on the users' perception of the technology. In addition, the need for more materials and research on the subject is indicated.

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