

NOT BEING ABLE TO LIVE LIKE BEFORE: THE FAMILY DYNAMICS DURING THE EXPERIENCE OF PEDIATRIC LIVER TRANSPLANTATION

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This study aims to understand families' dynamics during the experience of pediatric liver transplantation, and to identify families' demands and resources. Symbolic interactionism was used as the theoretical framework and grounded theory as the methodological reference. Data were collected through semi-structured interviews with eight families at a public hospital in Sao Paulo, SP, Brazil. Two phenomena were identified: having life controlled by the transplantation represents the vulnerability of families experiencing uncertainty and fear during their children's disease experience; and struggling to reacquire autonomy refers to families' reaction when exposed to the first phenomenon, which consists of continuous adaptation to overcome suffering caused by the situation. The relationship of these two phenomena allowed for the identification of the central category: not being able to live like before. Based on this analysis, a theoretical model could be proposed to explain the experience.

DESCRIPTORS: liver transplantation; pediatric nursing; family

NO PUDIENDO VIVIR COMO ANTES: LA DINÁMICA FAMILIAR DURANTE LA EXPERIENCIA DE TRASPLANTE DE HÍGADO EN NIÑOS

Esta investigación tuvo como objetivos entender la dinámica familiar durante la experiencia del trasplante de hígado pediátrico e identificar las demandas y los recursos de la familia. El estudio utilizó como marco teórico el Interaccionismo Simbólico y como marco metodológico la Teoría Fundamentada en los Datos. Los datos fueron recolectados durante entrevistas semiestructuradas con 8 familias en un hospital escuela en el municipio de San Pablo. Fue posible identificar dos fenómenos que componen esta experiencia: teniendo la vida controlada por el trasplante, que representa la vulnerabilidad de la familia al vivir las incertidumbres y el miedo constante durante la experiencia de la enfermedad del niño; y, luchando para rescatar la autonomía, que consiste en el movimiento de reacción de la familia para enfrentar el primer fenómeno, adaptándose continuamente para enfrentar el estrés y el sufrimiento desencadenados por la situación. La articulación de esos fenómenos permitió identificar la categoría central, que fue - no pudiendo vivir como antes - a partir de la cual se propone un modelo teórico explicativo de la experiencia.

DESCRIPTORES: trasplante de hígado; enfermería pediátrica; familia

NÃO PODENDO VIVER COMO ANTES: A DINÂMICA FAMILIAR NA EXPERIÊNCIA DO TRASPLANTE HEPÁTICO DA CRIANÇA

Este trabalho teve como objetivos compreender a dinâmica familiar na experiência do transplante hepático pediátrico e identificar as demandas e recursos da família. Utilizou-se como referencial teórico o Interacionismo Simbólico e, como referencial metodológico, a Teoria Fundamentada nos Dados. Os dados foram coletados através de entrevistas semi-estruturadas com 8 famílias em um hospital escola do município de São Paulo. Foi possível identificar dois fenômenos que compõem essa experiência: tendo a vida controlada pelo transplante, representando a vulnerabilidade da família ao vivenciar as incertezas, e o medo constante no decorrer da experiência de doença da criança; e lutando para resgatar a autonomia, que consiste no movimento de reação da família diante do primeiro fenômeno, adaptando-se continuamente para enfrentar o estresse e sofrimento desencadeados pela situação. A articulação desses fenômenos permitiu identificar a categoria central não podendo viver como antes, a partir da qual propõe-se um modelo teórico explicativo da experiência.

DESCRIPTORES: transplante de fígado; enfermagem pediátrica; família

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INTRODUCTION

Organ transplantation is a surgical intervention accepted and recommended in the treatment of degenerative and progressive disorders, which allows for patients' increased survival and better quality of life. Continuous advancements have been achieved, especially in terms of improvements in surgical techniques and increasingly efficient immunosuppressor mechanisms⁽¹⁻²⁾.

However, as literature indicates, on the contrary of technological advancements, the emotional impact of transplantation-related experiences in children and their respectively families⁽³⁻⁴⁾ has been little studied. The transplantation experience entails important aspects that affect these families' quality of life. The quality of life of transplanted patients and their families, not patients' length of survival⁽⁵⁻⁶⁾ as it used to be, has been the factor considered in the assessment of transplantation success.

There is evidence that mothers of children submitted to renal or liver transplantation suffer a great impact in their quality of life due to the children's disease, especially in their social relations⁽⁷⁾. Sufficient evidence was found in literature supporting that the whole family suffers the impact of a child's transplantation experience, which leads to the conclusion that the disease is an event that affects the whole family⁽⁸⁾.

Alterations in the functioning of the family system can exert a negative impact on the prognosis of the transplanted child. The impact of pediatric transplantations on families should be considered by health care professionals because the result of the procedure and prognosis are optimized when the family unit is kept intact and united amid the experience⁽⁹⁻¹⁰⁾.

If pediatric nursing and transplantation clinicians are apt to identify these families' needs, as well as potential resources, working towards the approximation of the family, many difficulties can be resolved and both family and child can face the experience with less suffering. A Brazilian study that sought to understand the experience of nurses in the liver transplantation program at a public hospital revealed that nurses consider the family of a transplanted patient as part of the care. However, they consider that nursing care to these patients is harmed due to fragmentation, since it is improbable that the same nurse will follow preoperative and postoperative care⁽¹¹⁾. In this perspective, further studies are needed

which address family dynamics and seek to provide tools for professionals to promote families' better understanding of the experience amidst these conditions.

Thus, in this perspective – "How is the experience of the family that has a child submitted to liver transplantation?", the study was carried out and aimed to understand the family dynamics during the experience of pediatric liver transplantation, as well as to identify demands and resources of the family who experiences the pediatric liver transplantation.

METHOD

Theoretical and methodological frameworks

This is a qualitative study, since it aimed to understand a phenomenon through the subjects' own perspective. Symbolic Interactionism and Grounded theory were the theoretical and methodological frameworks, respectively.

Symbolic interactionism is a theory on human behavior, primarily based on the premise that human experience is mediated by interpretation. According to this perspective, as people interact mutually and with other social objects, they attribute meaning to them and react based on these meanings, which are dynamic and change as interactions occur⁽¹²⁾.

Grounded theory has been increasingly used in nursing research. It consists of a methodology that studies phenomena and aims to generate theory. The conceptual development follows the data collection process and systematic analysis of data. The result of this process is a theory that emerges from the relation of concepts that are gradually discovered⁽¹³⁾.

Methodological steps

Data were collected between December 2005 and October 2006 in a specialized outpatient clinic at a teaching hospital in São Paulo, SP, Brazil. Data collection was initiated only after the project had been approved by the institution's Research Ethics Committee.

Eight families experiencing their children's liver transplantation participated in the study. Two of them were awaiting the transplantation at the moment of interviews and six were in the post transplantation follow-up phase. Postoperative periods varied from six months to five years. Seven of the eight families

experienced transplantation with cadaveric donor and one transplantation with live donor, the child's father. The six first families, belonging to the first sample group, had children affected by chronic conditions that justified the transplantation. The two families composing the second sample group had children who had been affected by fulminant hepatitis and had to be submitted to transplantation immediately.

Participation in the study was voluntary. The study objectives were fully explained before each interview and doubts regarding the study nature were clarified. In case of interest to participate in the study, interviewees were asked to fill out the free and informed consent term. No family refused to participate in the study.

Data collection was initially carried out through structural family evaluation instruments, called genogram and ecomap^(8,14). After the elaboration of these instruments, a semi-structured interview was carried out, which yielded qualitative data regarding the family's experience. The guiding question for the first interviews was "how are you and your family experiencing your child's liver transplantation?" In subsequent interviews, as categories were being formed, new questions that could clarify participants' ideas were added. Interviews were recorded and fully transcribed afterwards to avoid losing significant data.

Data were analyzed following all steps recommended by the Grounded theory⁽¹⁵⁾. These steps include codification, in which meanings for all units of information (codes) are established. Codes are then reviewed, aggregated and grouped in theoretical categories. The second level of analysis, the axial coding, involved a process of elaborating categories according to their proprieties and dimensions, as well as their relation with other categories, so that theoretical saturation was reached. The final analysis phase involved the construction of conceptual definitions for the categories. Thus, we sought to understand the central phenomenon – that is, which constitutes the link between categories. This phase is characterized by the challenge of integrating categories, aiming to "elaborate the history" and form a Grounded theory. In the elaboration of this history, categories have to provide an enlarged focus instead of individual experiences.

Based on the analysis of identified phenomena and how they interact in the experience of families with children submitted to liver transplantation, a theoretical model that explained the experience was

proposed. To validate the theoretical model, it was presented to two families who constitute the second sample group. Both families identified themselves with the experience and considered the model representative of what they had lived.

RESULTS

A detailed comparative data analysis allowed revealing meanings of the experience of families with children in a liver transplantation situation. This is an experience permeated by a set of diverse feelings, which are constantly interpolated, characterized by the process of continuous events along the disease experience.

During this process, two phenomena could be identified that compose the experience: **having life controlled by the transplantation and struggling to reacquire autonomy**. Both represent an interaction between challenges and learning, experienced by the family along the course of disease, and they are recurrent as the family is exposed to new events caused by the disease.

Based on the phenomena analysis and the way these phenomena interact, the main category was identified: *not being able to live like before*, which integrates both phenomena.

The dimensions of the experience are presented below and comply with the following format: phenomena are in bold font and the categories, which each phenomenon is composed of, are underlined. The main category is in italic. The first phenomenon, **having life controlled by the transplantation**, represents the family's vulnerability in experiencing uncertainties and constant fear because of the child's disease. Discovering the liver disease in the family and facing the need for a liver transplantation to assure the child's survival break down the family's life. Families watch their dreams and plans being ruined and have to face a completely unknown and scaring new and crude reality, being surrounded by the unknown. Along the process, families' energy is drained, especially as they perceive the child's loss of vitality. They lack abilities to deal with challenges imposed by the disease, whether in personal life or in family and extra-family relations, feel insecure and vulnerable. They do not know what to do and by learning how the disease develops, they understand crises children have due to the disease and care that will be necessary during their

whole life. It leads families to perceive that they are *not able to live like before*, and are surrounded by the unknown that invaded their daily lives.

All activities depend on children's increasing care demands. Living in a state of alert represents the family working to carefully preserve the child, so that (s)he is not exposed to any risk. Afraid that children will not be ready to receive the transplantation at the moment they are called, families cancel travel plans, move closer to the transplantation center and, by **having life controlled by the transplantation**, they act so as to assure that the child will be ready to receive the organ when (s)he is called.

The family reacts when it faces the first phenomenon. The transplantation or its need imposes changes on each of the family members and, consequently, on the family as a whole. Conventional behaviors some family members used to have before the disease need to be re-adapted, not only to new demands that originate due to the disease, but also to expectations of members in relation to each other. Because the family is *not able to live like before*, it searches for ways to adapt to the new condition, so that the transplantation does not exert any control over them.

The second phenomenon, *struggling to reacquire autonomy*, is the family's reaction to the first phenomenon. It consists of a continuous adaptation of the family system to cope with stress and suffering triggered by the disease. Even though families are aware they will not have the life they planned and desired back, they use resources and strategies to give meaning to adversities.

Changing the way of being in the family represents the reorganization and new forms of relating in the family environment through changes in family members' roles, sharing tasks among them, as well as adopting communication styles that respect the limits of its respective members and everyone's better adaptation to the disease context.

Reconsidering external relationships is the family **struggling to reacquire autonomy**, searching and receiving support out of the family context to be able to give meaning to adversities imposed by the experience. The family finds support through reinforced family bonds, and perceives it is not alone and can count on members of the extended family to meet practical demands imposed by the disease, such as taking care of the other children or taking turns in care for the sick child, in addition to emotional support.

In the search to maintain itself strong, the family seeks support in its beliefs, church and faith. In the search for bonds, the family also attempts to have a good relation with the healthcare team, to know each member of the transplantation team and choose their favorite professionals to share confidences regarding the liver transplantation experience. Reconsidering external relationships means the family searches for bonds with families of other transplanted children, who are experiencing the same situation, to help them to develop strength and persistence. Approximation to these families gives them a sense of identity, of being understood. They feel they are not lonely and can exchange experiences with each other with mutual growth and encouragement.

When the family experiences its child's transplantation, it goes through moments when everything is fine, it feels supported by available resources and confident in the treatment success and conditions to manage the child's disease. However, there are moments when it acknowledges its limitations and perception that life has permanently changed – *not being able to live like before*. This observation brings them deep sorrow because family members recall how life was before or how it could be, and consider the current situation. **Struggling to reacquire autonomy**, the family seeks to proceed keeping hope in the future. This category represents families' attempt to keep their mind focused on the good things that can happen in the child's and family's future. Even though the family is aware that the transplantation does not mean the child's cure, it manages to keep focused on positive results like improvement of quality of life and the child's satisfactory adaptation, resuming education activities, gaining weight, making friends and being able to maintain family life.

Families manage to proceed with their lives **struggling to reacquire autonomy**, keeping themselves strong and persistent, even with the perception that they will *not be able to live like before*.

Acknowledging achievements acquired through care, acquiring knowledge that permits some control over the disease, and keeping hope the child will be cured, are strategies supported by diverse sources that push families to adopt a compatible life style. This category represents families' ability to transform dreams and life styles previously adopted and keep connected with their current reality and possibilities.

Acknowledging changes in the child's and family's life and having the goal of staying ahead,

despite everything else, and incorporating behaviors towards an equilibrium within their conditions help to incorporate the transplantation into the family's routine. Based on this behavior, families start to deal with life, aware that disease complications, due to the transplantation waiting period or post-transplantation, can emerge at any moment and that they cannot vacillate, but they cannot allow these thoughts to overcome them either. Thus, they live a day at time, developing patience as if they were about to take a walk of which they do not know how many steps it will be.

Adopting a compatible life style is the result of **struggling to acquire autonomy** and brings a new meaning to *not being able to live like before*. *Not being able to live like before* can assume different meanings in the family's experience, depending on the intensity and duration of obstacles it faces. If the family is vulnerable in the face of adverse conditions presented, *not being able to live like before* is the family **having life controlled by the transplantation**. When the family interacts with elements from experience, and searches for ways to adapt to its condition, changing the way of being in the family, reconsidering external relationships and keeping hope in the future, the meaning is **struggling to reacquire autonomy**. These meanings emerge from families' experiences as they interact with elements present in the pediatric liver transplantation.

Thus, the described theoretical model, represented by Figure 1, presents the central category *not being able to live like before*, capable of integrating all components related to the experience of families with a child submitted to liver transplantation.

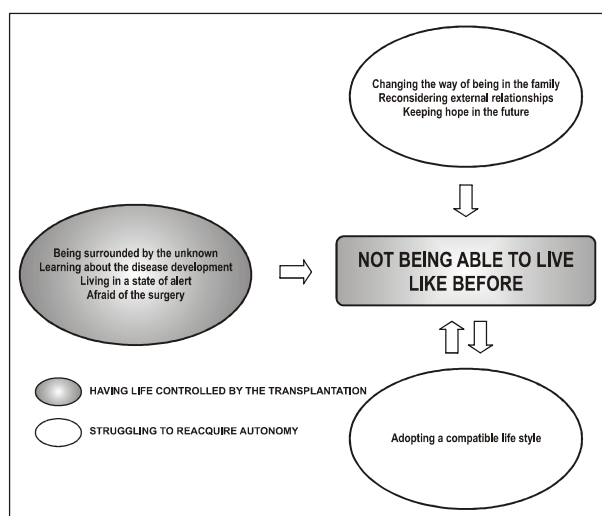


Figure 1 – Theoretical Model *not being able to live like before*

REFLECTING UPON THE PROCESS

In this study, families described their experiences related to the suffering triggered by fear and uncertainty, always present in the course of terminal liver disease and afterwards with the liver transplantation. The lives of families are completely altered. When they realize they are *not able to live like before*, they seek to experience the liver transplantation through strategies that make them feel strengthened amidst adversities imposed by the child's disease. Phenomena and categories that emerged from the central category, *not being able to live like before*, make them consider these results in the family resilience dimension.

The resilience model is a resource to work with families who are suffering. Resilience is defined as the capacity to be reborn from adversities, stronger and more resourceful⁽¹⁶⁾. A recent review study on the resilience concept describes the clinical utility of the model Family-disease System, and of a resilience approach to help families to overcome challenges imposed by children's and adolescents' diseases, hospitalization and death⁽¹⁷⁾.

In this model, family's resources are relevant for a positive adaptation to adversities in life, like in the case of severe diseases. When one thinks about coping and adaptation to a disease, the dynamic unfolding process of the disease under study and its treatments and processes over time need to be taken into account.

The transplantation phases have been described as follows: knowing about the need for transplantation, waiting for it, being submitted to it and living with it. Thus, in adapting the resilience model to the experience of children submitted to liver transplantation, we have: two phases of crises represented by knowing the need for transplantation and receiving it. Both are marked by a more intense unbalance in the family due to more intense adaptation needs in these periods; two chronic phases, which are: waiting for the transplantation and living with it, marked by relative constancy and stability though still exposed to risks and uncertainties⁽¹⁷⁻¹⁸⁾.

The study data indicate families' spontaneous movement towards family resilience as from the first phase of crisis, when they learn about the need for transplantation. However, the family can and should

have some help in this process in all phases and not only in moments of crisis, like when they learn about the need for transplantation, as well as when the patient receives it.

The transplantation-awaiting period is evidenced as a critical phase, determined by uncertainties in relation to the procedure and prognosis. The acknowledgment of the dilemma the family is facing in this period, questioning all aspects that permeate the surgical issue, can generate opportunities of dialog and interventions that can relieve the stress experienced by the family, thus reducing the stress of emotional and cognitive demands imposed by **having life controlled by the transplantation**.

The phase when the family experiences the transplantation is when it devises better conditions of living, adopting a compatible life style, adapting the transplantation to the family's routine and incorporating behaviors that permit balance within the family's new reality. However, diminished social support in this phase can harm the family, which still needs support to maintain its resilience, which has also been previously observed⁽¹⁹⁾. Acknowledging this phase during the course of the disease as a period that still imposes demands on families allows nurses to focus on the promotion of resources and to acknowledge families' strength, so as to help them to live **struggling to reacquire autonomy**.

Data show evidence of certain conditions that are essential to the family to experience the process with less suffering. Environments that favor the development of resilience are those that provide

social support. Interaction between the team and other families, who are waiting for the transplantation or who were already submitted to the procedure, is extremely important during the experience process.

Professionals who work with transplanted children can, from results presented here, understand the process families experience. Based on knowledge on this process and its challenges, as well as families' demands, resources and strength, professionals have support to identify in their practice the needs families experience during the process of having a child submitted to liver transplantation. Thus, they are able to search for strategies that can meet families' demands along the whole experience and not only during moments of hospitalization and surgery.

CONCLUSIONS

It is believed that the analysis of reports and reflections presented made it possible to experience and understand families' dynamics during their children's liver transplantation, as well as to identify demands and strategies families use in relation to this experience.

In the face of the results and reflections presented here, studies that appoint and test potential nursing interventions with these families are needed, so as to improve even more the care delivered to these families and promote progress in advanced nursing practice.

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