



Family management styles: A possibility of evaluation in pediatric liver transplant

Estilos de manejo familiar: uma possibilidade de avaliação no transplante hepático pediátrico

Estilos de manejo familiar: Una posibilidad de evaluación en el transplante hepático pediátrico

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ABSTRACT

Objective: To identify the styles of family management during the experience of liver transplantation of a child, according to the Family Management Style Framework. **Methods:** A descriptive study with a qualitative approach, conducted by means of a secondary analysis of nine semi-structured interviews previously collected with eight families who had a child who experienced a liver transplantation. **Results:** From the analysis, it was possible to identify five styles of management: adjusted family, family in adaptation, struggling family, family in conflict and family in waiting. **Conclusion:** The model proved useful in assessing families in the context of pediatric transplant and its use is encouraged in this and other scenarios of chronic disease.

Keywords: Family; Transplantation; Pediatric nursing

RESUMO

Objetivo: Identificar os estilos de manejo familiar durante a experiência do transplante hepático da criança, de acordo com o *Family Management Style Framework*. **Métodos:** Estudo descritivo, com abordagem qualitativa, realizado mediante uma análise secundária de nove entrevistas semiestruturadas, previamente coletadas com oito famílias que tiveram uma criança que atravessava a experiência de transplante hepático. **Resultados:** Pela análise, foi possível identificar cinco estilos de manejo: família ajustada, família em adaptação, família lutando, família em conflito e família em espera. **Conclusão:** O modelo mostrou-se útil na avaliação de famílias no contexto do transplante pediátrico e seu uso é encorajado neste e em outros cenários de doença crônica.

Descritores: Família; Transplante; Enfermagem pediátrica

RESUMEN

Objetivo: Identificar los estilos de manejo familiar durante la experiencia del transplante hepático del niño, de acuerdo con el *Family Management Style Framework*. **Métodos:** Estudio descriptivo, con abordaje cualitativo, realizado mediante un análisis secundario de nueve entrevistas semiestructuradas, previamente recolectadas con ocho familias que tuvieron un niño que atravesaba la experiencia del transplante hepático. **Resultados:** Por el análisis, fue posible identificar cinco estilos de manejo: familia ajustada, familia en adaptación, familia luchando, familia en conflicto y familia en espera. **Conclusión:** El modelo se mostró útil en la evaluación de familias en el contexto del transplante pediátrico y su uso es incentivado en éste y en otros escenarios de enfermedad crónica.

Descriptorios: Familia; Trasplante; Enfermería pediátrica

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INTRODUCTION

Families who have a child going through the experience of transplantation must adapt their functioning in accordance with the needs and demands of the family system. A study performed to understand the family dynamics during liver transplantation revealed that the child's transplantation experience is full of uncertainties and vulnerability, and the resources that the family uses to confront their situation in everyday life, creates a great influence on the way family members perceive the child, the disease and the treatment ⁽¹⁾.

In this regard, the authors have raised new questions, specifically on how families deal with management and adaptation facing transplantation. We found that some families adopt certain management behaviors that may change during the course of the disease, and others remain with the same characteristics and behaviors. As it has already been observed in studies in the context of chronic disease, such behaviors can influence how the family go through the experience and even the child's prognosis ⁽²⁻⁶⁾.

Recently, there is growing interest in learning the different styles of family management in various disease situations. The term "family management style" is used in literature to refer to a relatively consistent pattern of response of family unit to any disease condition, and the term "management" reinforces the focus on behavioral ingredient of family response, differing the other components of family dynamics, such as communication and decision making. ⁽⁷⁾ Family management can be defined as "the role of the family while actively responding to disease and different situations of health care" ⁽⁸⁾.

Studies dedicated to the definition of family response styles have been described as "taking a typological approach to the understanding of family life, rather than a variable approach" ⁽⁹⁾. The types of family behavior incorporate data from multiple aspects of family life and have the advantage of being able to conduct and preserve data, such as how family as a unit responds to the disease. Although this is not a dominant approach among family researchers, there has been a growing interest in typological studies, and the same authors cited above highlight that "for the professional to apply personalized interventions and with specific relevance to individual families, perhaps it is more important to identify patterns and profiles of disease management, rather than review each indicator management separately".

Among currently available models, the theoretical model called Family Management Style Framework – FMSF ^(8,10) was developed to assist healthcare professionals in the analysis and assessment of family

management styles in the context of chronic diseases. The development of this model made it possible to perform a further study which identified five distinct family management styles in the context of childhood chronic disease ⁽¹¹⁾.

In Brazil, the Center for Interdisciplinary Research on Loss and Grief, at School of Nursing of University of Sao Paulo has been developing studies on family management in the context of pediatric oncology and palliative care ^(12,13). As there are no studies related to family management styles on transplant experience, we performed this research in order to identify the family management styles during liver transplantation experiences of the child, according to the Family Management Style Framework ⁽¹⁰⁾.

METHODS

This is a descriptive study with a qualitative approach, conducted through a secondary analysis of nine semi-structured interviews, collected from eight families of children who went through the experience of liver transplantation. Of these, two children were waiting for transplant at the time of the interviews, and six were already in post-transplant follow up, with periods ranging from six months to five years after transplantation. In all eight families, the mother was the person being interviewed. In one family, the father was also present at the time of the invitation and agreed to participate. In this case, the interviews of the mother and father were done separately.

The primary objective of these interviews was to understand the functioning of the family during pediatric transplant experience, and the question which guided the interviews was "how has it been for you and your family, this journey of having your child going through the experience of liver transplantation?". The interview data were collected in a teaching-hospital in the city of Sao Paulo and it is worth noting that the research project of the original study was approved by the Research Ethics Committee of the School of Nursing, University of Sao Paulo under the process No. 754/2008 and the participants agreed to participate by signing the Consent Form.

For the present study, a secondary analysis of the material was done through FMSF. In interviews already collected, data were reached on the three dimensions of this model, which are presented and defined below:

Definition of the situation: represents the subjective sense which family members attribute to important elements of their situation;

Management behavior: efforts addressed to disease care and adaptation of family life to the demands related to the disease;

Perceived consequences: parents evaluation regarding the impact that the disease and care due to disease engage on family functioning and on expectations about the future of the child and family.

The transcribed data were analyzed through a qualitative and descriptive manner, and the results were organized according to the family management styles found and the characterization of each of the dimensions shown.

Data in Table 1 show the characteristics of families, associated with the management styles defined, which will be presented later. Most children had already been transplanted at the time of the interview, and only two families had a child who was still waiting transplantation, and their management style differed from the others found in these data and from those proposed by FMSF^(10,11).

Table 1 – Characteristics of participating families

Family	Age of the child	Diagnostic	Transplant time	Management Style
1	8	AEBD	4 years	Struggling
2	13	AEBD	4 years	Thriving
3	5	AEBD	Waiting	Waiting
4	7	AEBD	5 years	Thriving
5	4	AEBD	Waiting	Waiting
6	5	Alagille syndrome	6 months	Enduring
7	5	Hepatitis	1 year and 4 months	Accommodating
8	8	Hepatitis	1 year and 6 months	Thriving

AEBD – Atresia of Extrahepatic Bile Ducts.

RESULTS

For data analysis, the authors identified five management styles: thriving family, accommodating family, Enduring family, struggling family and waiting family.

Thriving Family

The first family management style has as the main tone their perception experience of **Adjustment**.

In this style, the families see the child as normal and perceive the disease as a fatality that happened, but that life must go on.

They perceive themselves confident in their roles in disease management, they believe to know how to manage the disease treatment and feel safe for caring the child at home.

Regarding the relationship between the parents, they feel they receive support from each other and share a philosophy of care that seeks to accommodate the disease in everyday life, in an effort to normalize family life.

“Now everything is normal, we did not have to do much changes at home because he is doing well, there are many people who say it is not normal after the transplant, but for me everything is normal! Of course in the beginning it was difficult because it was insane! He had everything so fast, and suddenly he had the transplant, and had to take care and come straight to the hospital, and we did not know much of anything by that time, so it was difficult ... but it is over, and now we’re fine and everything is going to be normal, thank God!”

Accommodating family

In this management style, the family demonstrates an effort to incorporate the transplant care to family routines, meaning that this is also the normalization and adjustment as main themes, but perceives their situation in a more negative way than the previous style.

Families in this style see the child, as someone with special needs, but with conditions to live a relatively normal life. They perceive the disease as a very sad incident in family life, but they have to struggle, so that life can continue.

Similarly to the previous style, they perceive themselves confident about their roles in disease management, they believe to know how to manage the disease treatment and feel safe for home caring the child.

The family relationship is stable, parents feel they receive support from each other and seek to accommodate the disease in everyday life, although such efforts are often alternated with periods of sadness, wondering how would the child be and family life if that fatality had not happened.

“Our family in general became more united ... we were already united, but now it’s much more because we know that we even need to be a little more careful with her, and even for the small kid, he says he has to take care of his sister, you don’t do this and that, it becomes hilarious even sometimes we have to take care of her because she is very messy, she is very naughty, so, now that she’s with the drain it is difficult because she doesn’t stay quiet, and we get worried.”

Enduring Family

This style is characterized by difficulties. The family holds a pessimistic view of their situation regardless of the time elapsed since transplantation and spends a tremendous effort in trying to keep caring for the transplant under control.

They believe that the child is in a serious condition, and that will always be with a lower quality of life compared with children of his/her age.

In relation to the care of the transplant, its members feel overloaded and sees the transplant as something very difficult to be accommodated to other family routines, usually requiring about one or two members the larger and heavier responsibilities.

Parents tend to adopt an overprotective posture with the child, not allowing him/her to develop activities that are compatible with his/her age for fear of something happening. Often there are discussions among parents about how to deal with the child and how to manage the disease care.

"You know, he's five years old, but he behaves like a newborn! Him .. all me! For bathing, food ... he was always bad to eat, if I let him eat by himself or with someone, he does not eat! Lunch, I give in his mouth, breakfast ... I'm always like this, he tries to eat alone, but I do not let ... (Laughs) I have a friend who says I do not let M grow because he wants to learn to do, right? But I don't let him (...)"

Struggling Family

Conflict between parents about the best way to manage the care of the child's disease was the main theme for the family with this style. There is no cohesion between parents, and they are constantly disagreeing about the behavior management regarding the disease.

In this style, families perceives the child as having a very serious condition, and the disease as a very serious problem, life and quality of life threatening of the child. They often feel overwhelmed and consider child care as something very heavy. Adopt an overprotective attitude to the child and support the belief that life will never be normal again.

"Today she goes to kindergarten again, but I'm worried, what if she gets hurt? And what if she eats something that she can't? Everybody says that I have to treat her like she was a normal child. Normal I do not think she is normal ... if she was normal, I would be normal too! But I'm not, I cannot go back to work and I cannot have a normal life, I cannot accept that it is normal, because she needs me caring, giving medicine, watching out and so on."

"And my family does not even care, for them the transplant is normal, but not normal as something usual, but a normal thing, even silly ... it seems like it was only a surgery ..."

Waiting family

Some peculiar characteristics of families who are still waiting for the child's transplant made us think of a different management style, which does not fit in any of the models proposed by FMSF. The family in waiting have as their main theme the feeling that life is suspended, paused, and that nothing can be done until the child receives the transplant.

Families in this style see the child as someone who needs special care and who have severely compromised the quality of life because of liver disease. They claim that liver disease puts life on hold until the arrival of the transplant.

They feel overwhelmed with the care caused by degenerative liver disease that the child requires, and

also with the demands of preoperative tests transplantation, preparation and apprehension by the uncertainty of how the child will still have to wait until the transplant performance.

Waiting families transplantation lack of knowledge about the disease and transplantation, as well as available sources of support.

The mutuality between parents may be present or not; regardless, they adopt an overprotective philosophy of care, especially because they do not know what to expect on the clinical condition of the child. Because they do not know what to expect, waiting families show reactive management behaviors rather than an active approach which can be found in other styles.

"It is an apprehension, every day that goes by and he's home, it is good for us, but well, he's at home today, tomorrow he might be dead and we have to rush ..."

"Me, I stay with him here and my husband stay there, because he works and he cannot come ... and also because I do not have the courage to leave him alone ... I need to be aware of everything and I know that If I stay far I won't be calm, without knowing ... then, I prefer to stop everything and stay here."

"My family is there ... Missing us, we miss each other, but now we cannot go back, we have to stay here, so, they know and we stay here, then once we do the transplant, we can go back ..."

DISCUSSION

The experience of liver transplantation in the child triggers profound changes in the family. Becoming aware of the break of the expected plans and dreams for the child with the devastating and sudden arrival of the disease requiring family important adjustments in how they organize to deal with the situation, while it faces mourning for the loss of a healthy being. Furthermore, they have to learn to become family of a sick child who requires special care.

It is clear that the arrival of a disease in the family alters the balance of the entire family system. The nurse must know the way the family seeks to reorganize themselves to handle the demands of the disease, so that he/she may intervene in order to help them to recover balance.

In this scenario, using the model of Family Management Styles Framework - FMSF⁽¹⁰⁾ - adopted to guide the data analysis in this study provides a deeper understanding of the experience lived in the management by these families.

Considering the proposed family management styles from the FMSF⁽¹⁰⁾ and looking at the cases studied, we find features and patterns of family response to the demands of child transplant consistent with four of the five styles presented. The style "Floundering family" in which chaos and confusion are the dominant features in

the family, was not found in this study. We imagine that the secondary analysis of data by limiting the number of interviews preventing the selection of new families for analysis, may have been the cause of this limitation.

However, a new management style seems to be present in the transplant experience: a waiting family, characterized by a sense of pause in family life, it requires a deeper understanding of their characteristics and already shows that waiting families for transplantation have great need for information and social support. Families going through the situation of waiting for a transplant and, on that account, they do not see them able to continue life, it has already been identified in other studies, reinforcing the need for attention and interventions addressed specifically to the child preoperative^(14,15).

Our study supports that the management family style undergoes changes over time; but rather frightened and fearful by the belief that the disease is serious and frightening, family members with time acquire knowledge that challenge their prior beliefs and give rise to new values and definitions.

We found that families who had a child transplanted for a long period of time seemed to have a more tailored management than those who recently learned to manage transplantation in everyday life.

This idea is shared by renowned international authors, when they say that the experience of disease undergoes transformations over time⁽¹⁶⁾. For these authors, the development of the disease over time causes the family to have opportunities to interact with different elements of the experience, creating space, so that it has the ability to seek alternatives and strategies to cope and live with the disease. However, it is important to highlight the fact it cannot be seen as a progression, and that the style may change according to different contexts and situations that the family faces.

Through conversations with families experiencing the same situation, the contact with the team and the experience for different moments of the the disease trajectory, we believe that time can give professionals the opportunity to challenge the family to reevaluate their beliefs system about disease, as well as their abilities to manage care.

The use of FMSF⁽¹⁰⁾, besides enabling understanding on the experience of family management in chronic disease contexts, it also allows to think in specific interventions to families, focusing on their real needs.

CONCLUSION

Although each family is unique, we found in our clinical practice and research with families, they tend to manage the disease according to certain standards of behavior and management, and the knowledge of these patterns may help develop a greater understanding of the needs of families, addressing us to more appropriate interventions.

With this preliminary work, it was possible to identify how family members define and manage the experience of transplantation, as well as which consequences they perceive within the context of family life.

We believe the FMSF may serve as a useful strategy for assessing families of children who have already received or are waiting for a transplant, for the multidisciplinary team to plan interventions that are directed to the main demands of families, in a systematic and particular way to each family. Within this context, we encourage the use of theoretical models in clinical practice, for a deeper assessment and based on the real needs of families.

There is a great need to develop interventions with families, especially from the perspective of family management styles, and also verify deeply the extent of using FMSF Model as instrument to assess these families. In this regard, we also believe that studies focusing on the use of evaluation models with families in practice are necessary, checking the possibility of addressing paths for interventions. The same authors of the FMSF have developed a tool to measure family management, the Family Management Measure, which has been implemented with positive results in the North American context. The translation and cross-cultural validation of the instrument to Brazilian culture and in different contexts of chronic diseases are already being performed and thus we believe it may further equip nurses and health teams that work under a child and family centered perspective.

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