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Case Study

Family management for transplantation children patients with grandparents as caregivers: a case study

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ABSTRACT

Aim: To understand the family management experience of a child undergoing liver transplantation when grandparents are also caregivers, from the view of the *Family Management Style Framework*. **Method**: Case study. We used the referred model as a theoretical framework and thematic analysis as the analytical method. Data were collected through interviews and analysis of medical records. **Results**: The family defines the transplant as a threatening situation and highlights the conflicts between mother and grandparents, not knowing how to act. The consequences reflect the fear and uncertainty that pervade daily family life. **Discussion**: The evaluation allows a discussion about the influence and the role of grandparents when one of their grandchildren is affected by a serious illness. **Conclusion**: The use of theoretical models can help in the planning of specific interventions, though further studies are needed to understand the grandparents' experience when their grandchildren are sick.

Descriptors: Family; Pediatric Nursing; Liver Transplantation.

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INTRODUCTION

Today's society shows great interest in understanding family management in different situations of disease. Family management can be defined as "the role of the family while actively responding to disease and in different health care situations"(1).

The theoretical paradigm called *Family Management Style Framework* – FMSF(1) – was developed to assist health professionals analyze and evaluate family management styles in chronic diseases. The model has three main dimensions: definition of the situation, management behaviors and perceived consequences. The definition of the situation is how the family perceives the child and the disease. Management behaviors include the principles on which families base the development of a disease management routine. The perceived consequences are defined as the actual or expected results that shape behaviors and affect the situation(1).

FMSF has been applied, both in Brazil and internationally, in different situations of disease. The results reinforce the view that it can be successfully used in the evaluation of families of children with chronic diseases and it helps to plan personalized interventions(2-6).

In the context of pediatric transplants, a recent national article covered the family management experience via FMSF of a teenager who received a transplant. Research has found important data about the difficulty of family adaptation and the daily care demands required by a teenager facing a transplant, and has shown the impact of the disease on family routines and the importance of support(6).

The study converges with the literature about family experience in the context of pediatric transplants, reinforcing the uncertain and unstable character of family life and the urgent need for support at all times, not only during hospitalization and surgery(7-8).

However, we notice that the studies have evaluated the management in the context of the nuclear family, i.e. including only parents and children. It is known that, in Brazilian society, participation and inclusion of other family members in care, especially grandparents, is increasing and its influence on family management is significant(9).

This case study is carried out with the aim of understanding the family management of a child who underwent transplantation with grandparents as caregivers, according to the FMSF(1).

METHOD

This is a qualitative case study. A case study is "*[...] an empirical inquiry that investigates a contemporary phenomenon within its context*"(10).

This article is part of a research that aims to understand the family management experience in pediatric liver transplantation(11). For primary research, four case studies were conducted with families who had a child who received transplant care for at least one year, and who underwent the postoperative follow-up at the Pediatric Gastroenterology outpatient clinic of a teaching hospital in the city of Salvador (BA).

The case presented here is of Gustavo's family (not his real name). They were chosen by medical staff who reported frequent conflicts between the child's mother and grandfather. Gustavo, a five-year-old boy, is the only son of S. (mother, 24 years old) and Ad. (father, 26). He underwent a living donor liver transplantation (mother's) in December 2008. His parents' relationship broke-up shortly after his birth and no longer have any contact with each other. Gustavo lives with his mother and his grandparents; E. (grandmother, 57 years old), and A. (grandfather, 58), both retired, who also take care of him. S. used to work as a saleswoman, but left her job to devote her full time to motherhood. Her income is restricted to the pension she receives due to the child's disease. Despite having three older brothers, S. has no contact with any of them. With respect to her father, they no longer speak to one another due to a fight in the past, and her mother died five years ago.

The study included the mother and the paternal grandfather. It is noteworthy that both agreed to participate by signing the Instrument of Consent. The study was approved by the Research Ethics Committee (CEP protocol 754/2008). The data in this case were collected in October 2011.

As recommended by the case study, we used multiple points and data collection strategies. Such an approach is essential to ensure the necessary depth to the study, insertion in its contextand credibility of the results(10).

Three stages of data collection were performed:

First: after obtaining consent for inclusion in the study, we collected information for identification and a first open interview to understand the experience of the transplant and family life in its broadest context.

Second: interview using semi-structured questions based on FMSF(1) to understand the family management.

Third: case closing and clarifying questions.

The meetings were held individually, scheduled at the dates most convenient to participants, recorded and fully transcribed soon after its completion.

We also used the collection of documentary evidence as a strategy, by analyzing medical records. This procedure took place between the first and second stagesdescribed above to complement and deepen knowledge of the case, and provide information for better targeting of the interview and any necessary explanations.

The analysis of the elements was based on thematic analysis, in recognition of patterns within the data, in which the issues brought up are configured in categories(12). In this assessment there are different approaches: the deductive, based on predetermined model codes – called *templates*, and the data-driven inductive. In this study, the method chosen is a hybrid model that incorporates both deductive and inductive modes(12). Thus, the data is inductively analyzed first by generating codes and initial themes, and then the template (this research used the FMSF theoretical model) is applied in order to identify significant word units also in a deductive way.

RESULTS

a) Disease course

When Gustavo was one-year old the pediatrician detected hepatomegaly during a routine visit to the doctor in Salvador. He underwent tests, but as nothing was found the investigation was interrupted. At the age of four, his grandfather discovered spots around Gustavo's body and a swelling in his abdomen. He took him to the hospital and the medical staff decided to hospitalize him for investigation. After 15 days in hospital, doctors confirmed the diagnosis of Budd-Chiari syndrome and the need to undergo a liver transplantation.

After two weeks in hospital, Gustavo was discharged and sent to São Paulo to begin pre-operative monitoring. At this time, his mother was working and could not leave in time to go with the child. For this reason, the family decided that his grandmother would accompany him to Sao Paulo.

Twenty days after discharge, Gustavo and his grandmother went to São Paulo. His mother was released from work twenty days later and traveled to São Paulo to undergo examinations to verify the possibility of being the donor. The grandfather remained in Salvador during that period, maintaining frequent telephone contact to be informed about his grandson's health. Gustavo's father did not appear even once at the hospital.

For three months, Gustavo, his mother and grandmother remained in São Paulo taking the necessary steps to begin the donor transplantation and making the necessary preoperative preparations.

On 17 December 2008, the liver transplant was performed with Gustavo's mother as the donor. The grandmother alone accompanied Gustavo and his mother during their recovery in Sao Paulo.

In March 2009, Gustavo, his mother and grandmother returned to Bahia. Since then, he has had periodic monitoring in Salvador and São Paulo.

At the first visit to the clinic in Salvador, he was referred for specialist psychological and psychiatric attention. These appointments were all interrupted two months later at the mother's request, with no notification to grandparents. She refused to give explanations about the reasons that led her to make the decision for closure. From this moment, intense conflicts began to appear between her and Gustavo's grandparents about how to care for him.

In December 2009, Gustavo had chickenpox and endured a long and difficult recovery of about three months. For the mother, his illness was her fault and that brought feelings of ineffectiveness, making her think that she was unable to take care of her child properly.

S. left work in January 2010 to devote herself exclusively to Gustavo. The two moved to a house far from his grandparents and contact was restricted to weekends or following a request from the mother.

Gustavo is currently healthy and stable, and goes to school, but according to his grandfather missed his first year due to frequent consultations.

b) Family management experience

Situation definition

Gustavo has a central role in his mother's and grandparents' lives. As their only son and grandson, attention is naturally focused on him. Due to the disease, his care and the desire to protect him further, the family sees him as a frail child who requires much care and time investment. Therefore, they consider it impossible to have a normal life.

> Even if we know that he will not be able to have a normal life, and so neither will we, we still expect he can be at least a little normal. (Grandfather)

For the family, Gustavo's disease is serious, unpredictable and of uncertain prognosis. The transplant is seen as the solution for the preservation of his life, and so they must be careful and maintain a strict monitoring, because any distraction may lead to the loss of Gustavo.

> With him like this we need to be very careful. You never know what will happen, it's a serious disease; it's a transplant! So we really need to watch it. (Mother)

Because they define the disease as a serious and threatening condition, Gustavo's family still find it difficult to adapt to his health care. They are not able to cope with the demands of the disease, and their management actions and planning revolve around the difficulties they face in looking after him.

> For us, being there every day, taking care of everything, it's very difficult; often it's too heavy. It requires much time, and there are many complicated things still to understand and to do... If you don't get really organized, you just can't take it. (Grandfather)

Within the family there is no one with the ability to lead them through this experience. According to the grandparents, the mother wants their support, but only at convenient moments, like taking the child to medical visits and paying for his school. They, in turn, are unhappy with the way their grandson has been treated, but do not make decisions they see as important, feeling divided by not knowing for sure what space and role they should take. They push the mother not only to decide but to decide in the way they want.

> To give you an idea, during the investigation of his disease, a genetic evaluation was requested to see his genetics, to understand and care for her if she were to have other children; we were doing everything right, in a good place and then, in the middle of the study she interrupted it. And... we had to stop the investigation because she is his mother. And... just to think about it... it is very difficult! She won't let us go on with that, she took all the paperwork, she got upset and ordered the investigation to stop. How can a grandfather understand this? It's too hard... I can't. (Grandfather)

In Gustavo's family the biggest challenges are the frequent family conflicts between mother and grandparents. This situation exists primarily because the grandparents, who were very present in the care and education of the child, strongly disagree with mother's values and beliefs, and this causes the discomfort. Disagreements are constant and brought up mainly by the grandparents who argue that the grandson should receive much more attention.

> His mother and us have very different views on how to raise a child. I do not agree with the way she does it, she doesn't give priority to him when she has to; to have a son is not only give birth to a kid, especially for him. (Grandfather)

With the strain from family conflicts the bonds between them weaken. The mother has no relationship with Gustavo's father. The father has little contact, and almost exclusively by phone. The tension between mother and grandparents is such that they currently maintain contact essentially because of Gustavo. The existing relationship and dialogue between them are based on the exchange of information about aspects of the disease.

> Today, it's a relationship... almost ... due to him only. We can't be closer, because for the sake of ... habits, maybe ... we can't anymore. If we keep talking to each other, it's because of him. We have very different opinions from his mother. But we have to close our eyes and deal with each other, because of him. Just imagine a baby, with liver cirrhosis, taking too long to be taken to the doctor... You get concerned about his health, you know? But basically we

> understand that our role is just being there to provide all the support, because she is his mother. But it hurts us. (Grandfather)

Management behaviors

S. had to learn to become the mother of a child with a serious condition, which required great changes from her. Her love for the child is evident. She expressed her feelings of love and zeal when defining him as precious, as her greatest and only love.

Threatened by the uncertainties resulting from the disease, she fears losing him; so protecting him is a priority. With time and the progress of the disease, she believes that, to assume her role as a mother, she has to give up her work.

> I live just for this. I live only for his transplant now and I think that's the way it has to be, actually I even quit my job just to be with him. I want and I need to be with him. (...) Everything I do is for him, in general. (Mother)

Isolated from her family and not knowing where to look for resources, the mother has in the grandparents an important source of support to provide care for her son, but that causes the existing conflicts.

For the grandparents, Gustavo and the care measures regarding his disease must be prioritized over other aspects of family life, and they organize their daily routine for this. However, they become upset since they believe the mother does not do the same.

> I think that, when we have a son, priorities must change. Especially in his case! But she has no priorities. You need to set priorities, you need to avoid doing something for you, because your child needs more. And that's not what happens. (Grandfather)

The grandparents changed their habits to give more attention to Gustavo because they see this as necessary. Defining the transplant surgery as the salvation of his life from a very serious condition, they aim to monitor his health as much as possible, even if this requires changes in their own lives.

> I'm always, always monitoring him. I don't take him to the park, because it was a surgery! You must be cautious at all times. He wouldn't be alive without it; will I put that at risk by letting him do what he wants? We always have to be in control. (Grandfather)

However, when speaking of the mother, the grandparents add examples to attest that she does not take the right decisions in caring for the child, and claim they want to provide more help and support as needed.

> He is late at school. We do everything we can to see if he can keep up, but he's late, he misses too many classes because of the medical visits... It's complicated. I wanted to move him to another school, I wanted a school closer to my house, because then maybe he wouldn't need to miss so many classes, but his mother doesn't want it, she wants me to pay the school that is near her house, and so I pay. But that's not what I want, I want to be closer to him so I can monitor him more, to see him better. (Grandfather)

Perceived consequences

One year after the transplant the family has a focus on the weaknesses and limitations the disease has imposed on Gustavo and everyone. His illness is seen as of primary importance; it requires a large investment of time and there is no balance between disease management and other activities.

Looking at the limitations resulting from the disease, family members believe that the transplant makes life very difficult, as it sometimes completely controls them. They cannot take control of the care measures, and became disoriented in relation to the organization of the demands of the disease and its balance in daily life. They think about it all the time, are controlled by the uncertainties arising from it and believe they cannot have a normal life.

> It's been ... It's ... a very busy life, quite an investment of time. It hasn't been easy at all. (...) We expect it to get better in future, although we know that he won't be able to have a normal life, and so neither will we ... Still, we expect that it can be at least normal somehow. (Grandfather)

The family is dysfunctional. Afraid about the health of Gustavo and unable to make decisions in an organized way, since there is no mutuality or clarity about how to act, no one has their own life. Everybody is controlled by the fear of loss, and by the lack of someone to take more responsibility for decisions; they cannot establish a direction and a routine to organize their lives and the demands of the disease.

The mother lives in the present fearing for the future, focusing on the uncertainty of the disease and knowing its possible outcomes; medical visits and monitoring are sources of concern. She fears something will happen to Gustavo and when it happens, she blames herself for what happened, as if it was her responsibility. She lives controlled by the fear of losing him.

> Some days ago, at home, he got chickenpox! I got so depressed... I mean, wow! I spent four days crying, like, how did I let this happen, you know? And ... he's the only thing I have. He's so precious... There are days I try to forget it, but there are days I keep looking at him as if it was the last day of his life. I live almost every day actually thinking as if it was the last day of his life. (Mother)

S. faced the challenges of a young woman who had to learn to become a single mother without the help of her family and, later, also to be a mother of a sick child who will need special care for his entire life. She has the support of their grandparents and often calls them to help her, while at same time she wishes to assume greater freedom and independence in providing care for her son.

They, in turn, face difficulties in finding the best way to provide support; they disagree with everything she does and do not believe she takes care of the child properly. Thus, mother and grandparents live a situation in which no one truly assumes responsibility for decisions about the child and for the organization of the care measures he requires.

As a result, the whole family lives a chaotic situation, where persistent conflicts increase the difficulty of its members to be organized in favor of balancing their lives and the demands of the disease. The family is controlled by fear, uncertainty and confusion resulting from their experience of the disease at this stage of its development.

DISCUSSION

It is clear that the arrival of a disease changes the balance of an entire family system(13). Nurses must understand how a family seeks to reorganize itself to handle the demands of the disease, so they can intervene in order to help it regain its balance. In this scenario, the use of a family management styles framework(2) provides in-depth understanding of the experience. In this brief case study we realized that the use of FMSF(1) enhances our understanding about the management experience when extended family members present themselves as caregivers.

Looking at the results and considering the family management styles proposed by this international study, Gustavo's family is "*floundering*"(3).

In this style, chaos and confusion are the dominant features. The definition of the situation is negative in all aspects. The child is seen as weak and unable to live like other children of the same age. The disease is a tragic episode.

In families such as this there is no defined style of management we can see this in Gustavo's family. It is not organized to take care of him. The lack of a clearly defined management plan influences the behaviors adopted to deal with the situation(8,14).

Motherhood in adolescence is a critical period of change involving a series of individual, group and family transformations. To study, work or have any leisure activities, young mothers need help to take care of their babies(15). In addition to all of these challenges, Gustavo's mother also had to learn to become the mother of a child with a serious illness who will require care for the rest of his life. Without the father's help, or her parents', she found in her paternal grandparents the support she needed. However, the different perspectives on how to raise and take care of Gustavo generate much tension and many conflicts.

The grandparents silence their suffering because they believe that their role in the family should be just supportive, even if they would prefer to participate more and do not agree with the way Gustavo is being educated by his mother and with the decisions she makes regarding his health care. A study describing the experience of grandparents when mothers are young has found similar results, indicating confusion and conflict in the roles of grandparents, and the even parents, about who will effectively assume a paternal role and responsibility for the child(15).

However, these studies focus on the mothers' perspective about the participation of grandparents, not the grandparents themselves. There was no analysis found in the national literature that investigates the grandparents' experience in the context of a serious illness. However, international studies show a double suffering,(16-17) and also report a feeling of helplessness because, due to the fact they cannot be responsible for the child, they cannot have the final word in decisions(17).

We observe that grandparents usually have not been considered as a part of the family who suffers in the context of a serious illness. In international studies, grandparents' testimonies exist that say "the true suffering is what our children (the parents) are going through. Who are we? Only the grandparents." Such statements are a powerful way to illustrate the loneliness of this experience, though grandparents are often very close to the family in these situations(16-18).

Since the transplant requires life-time adaptations and adjustments, the health care team should see the whole family as a health care unit, not just the patient(19-20). To better assist them in this experience, it is important that professionals understand how the family responds in their daily lives to the care demands of a child who underwent transplantation. And with this, the team obtains subsidies to target specific interventions to the reality and needs of each family(8,19). This case study presents a contribution to demonstrate that family answers are often directly linked to, and inseparable from, the influence that other family members, previously considered outside the action-axis by professionals as not being part of the "main family core", have in disease management.

CONCLUSION

The case presented here deals with the family management experience of a sick child when grandparents are also caregivers. Based on the definitions the family makes about the child, his illness, its own ability to deal with the care demands and support it receives, it shapes its behavior to incorporate the transplant reality to the family dynamics.

In Gustavo's family we find that the conflicting intergenerational relationships complicates the management of the disease, preventing the family as a whole to feel confident and secure in care. At this stage of the family life cycle, the opportunities for support or conflicts between generations are plentiful, as education and health care practices to the children are manifested. Health professionals should be aware of such relationships and seek strategies to deal with any conflicts and help the family pursue together the best way to manage the care measures for a sick child.

In this case, it was evident that the suffering of grandparents facing their grandson's disease is intense and must be taken into account by professionals. Further studies are needed to understand the experience of grandparents of a sick child in our society and culture, since the participation of grandparents in the provision of care is increasingly present in Brazilian families.

In this context, the identification of components and dimensions proposed by FMSF is useful in professional practice. The use of theoretical models in family management assessment, when members of the extended family are caregivers, can help health care professionals in the planning of specific interventions to each family, and should be encouraged.

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Authors' participation

Ana Márcia Chiaradia Mendes-Castillo – article writing, chief-researcher.

Regina Szylit Bousso- article councilor.

Luciana Rodrigues Silva – aid in introduction writing, bibliographic references and results discussion.

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