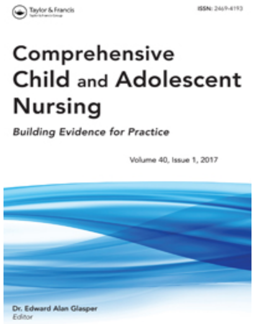

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The Family Management Styles Framework as A Tool for Tailoring Interventions for Pediatric Transplant Recipients and Their Families: A Case Study

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ABSTRACT

The aim of this research study was to explore family management in pediatric liver transplantation. This qualitative case study research project used a hybrid model of thematic analysis methodology and employed the Family Management Style Framework (FMSF) as the theoretical framework. Four families of transplanted children who were outpatients in a public hospital in Brazil were analyzed in depth through interviews and analysis of medical records in the parent study. In this article, the case of 1 of those families is presented. The results show that the family defines the condition as threatening, and has dichotomous feelings about the child's identity, sometimes seen as "special" and other times as "like any other child." The family's perceived consequences, one of the FMSF dimensions, bring uncertainty about the future as an important issue that deserves nursing attention. A deeper understanding of family management can promote informed discussions about the best interventions for this and other similarly affected families. The use of the FMSF in evaluating family management in pediatric transplantation and other chronic pediatric conditions can aid pediatric nurses and other nursing professionals in planning tailored interventions that maximize patient and family outcomes.

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Family nursing; pediatric nursing; family management; organ transplantation; child health

Introduction

Organ transplantation is no longer considered an experimental procedure. It is a surgical intervention to treat progressive dysfunction of vital organs resulting in an increase in improved patient survival and better quality of life (Dharnidharka, Lamb, Zheng, Schechtman, & Meier-Kriesche, 2015; Kaller et al., 2014). Among the organs that can be transplanted, the liver takes prominence in Brazilian records. During the first half of 2015, there were 835 liver transplants in the country, out of 3,770 transplants of solid organs (Brazilian Association of Organ Transplantation [ABTO], 2015).

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In 1963, Thomas E. Starzl performed the first liver transplant in a 3-year-old child with biliary atresia, which is the major indication for pediatric liver transplantation. Pediatric patients undergoing liver transplantation have survival rates that reach 90% (Dharnidharka et al., 2015).

Since transplantation requires adaptations and adjustments for the rest of life, the health team must consider the family as the unit of care, not just the patient. This is even more important when the affected person is a child. To better assist the family in this experience, nurses need a comprehensive understanding of how family members manage caring for the transplanted child. Without this, they limit their efforts to guide and support individuals through this experience. The purpose of this study is to explore how a family with a child who has undergone liver transplant manages the condition, based on the Family Management Style Framework (FMSF), and to recommend nursing interventions within this context.

The Impact of Pediatric Transplantation in the Family

In the past decade, more attention has been focused on studying the impact that the transplant has on pediatric patients and their families. Research regarding the psychosocial problems that affect transplanted children and their families has grown, as well as research regarding the measurement and assessment of quality of life of the children/adolescents, parents, siblings and donors (Kikuchi et al., 2015; Kosmach-Park, 2013; Taylor, Wray, & Gibson, 2010).

The family is most appropriately considered a system and can be defined as elements that coexist in mutual interaction, so that if one of the elements gets out of balance in the system, all others must be reorganized so the unit can again reach equilibrium. Wright and Leahey (2009) state that Illness is a family event. We know that the family typically unites to care for its members in times of crisis, however, the onset of disease sometimes damages the unity of families, resulting in a decrease in this ability. When the affected person is a child, the crisis tends to be bigger, given the family's life cycle stage. Families with children or adolescents usually do not expect serious chronic disease to enter the lives of their children (Carter & McGoldrick, 2001).

The changes in family functioning may have a negative impact on the prognosis of the child who has undergone a transplant. Experts suggest that the outcome of the procedure and prognosis are optimized when the family unit stays together in the midst of the experience (Kaller et al., 2014; Kikuchi et al., 2015; Kosmach-Park, 2013; Mendes-Castillo, Bousso, Ichikawa, & Silva, 2014). Furthermore, success of transplatation is no longer attributed to survival rate. Rather, success in now measured by the quality of life of the transplanted patient and family (Kikuchi et al., 2015). Research shows that mothers suffer a great impact on their life quality because of the child's illness, especially in their social relations (Kikuchi et al., 2015). In addition, the family suffers a big impact as well, causing a decrease in social relations and an increase in problems between spouses and relationships among siblings (Kikuchi et al., 2015).

Stubblefield and Murray (1998) have described the phases of the experience of illness in the child who experiences a liver transplant. The phases include knowing about the need for transplantation, waiting for it, receiving it, and living with it. Two of the phases are associated with particular crisis, the knowledge of the need for transplantation and receiving a transplant, and are both marked by an imbalance in the family and intensity because of the adjustments that must be made during those periods. Two phases, waiting for a transplant and living with it, are marked by relative stability and constancy, though there are still risks and uncertainties in those stages. The family should be assisted throughout all stages, not just in times of crisis when they often receive the attention needed (Mendes & Bousso, 2009; Mendes-Castillo, Bousso, Silva, Melo, & Conceição, 2011; Mendes-Castillo et al., 2014; Taylor et al., 2010;).

The wait for a transplant has been well documented in the literature as a critical period during which nurses play an important role in assisting families (Chou, Chen, Chen, Chen, & Mu, 2009). There is an important gap in the literature, however, regarding the phase of living with the transplant using a family-centered perspective (Mendes-Castillo et al., 2011). Understanding this phase of the disease from the family standpoint is essential because it gives the nurse fuller knowledge of the family's experience, not only in times of hospitalization and surgery.

Theoretical Framework

Family Management Style Framework (FMSF)

Family management can be defined as “the family's role while actively responding to different situations of disease and health care” (Knafl & Deatrick, 1990). The term “family management style” refers to a relatively consistent response of the family unit to a condition of disease, and the term “management” reinforces the focus on the behavioral ingredient of the family response (Knafl & Deatrick, 2006; Knafl, Deatrick, Havill, 2012). Identifying patterns or typologies of family response to health care challenges is increasingly recognized as useful to the precise description of family processes and illness management strategies (Knafl & Deatrick, 2003). The FMSF is a model that provides a guide to researchers investigating these typologies.

The FMSF was constructed from an extensive literature review to identify the key aspects of how the family responds to a child's chronic illness (Knafl & Deatrick, 2003). The FMSF consists of three main dimensions: definition of the situation, management behaviors, and perceived consequences. Definition of the situation is how the family views the family member and the illness. Management behaviors include the principles on which management behaviors are based and the ability to develop a routine for managing the family member's illness. Perceived consequences are defined as actual or expected outcomes that shape management behaviors and affect the subsequent definition of the situation (Knafl & Deatrick, 2003). The FMSF has been used worldwide in the past decade to study chronic illness in children in a variety of settings (Bousso, Misko, Mendes-Castillo, & Rossato, 2012; Deatrick et al., 2006; Deatrick, Mullaney, & Mooney-Doyle, 2009; Gallo, Hadley, Angst, Knafl, & Smith, 2008; Ichikawa et al., 2014; Knafl, Knafl, Gallo & Angst, 2007; Mendes-Castillo, Bousso, Santos, & Damião, 2012; Mendes-Castillo et al., 2014; Nelson, Deatrick, Knafl, Alderfer & Ogle, 2006; Ogle 2006).

To date, very little work has been done in pediatric transplantation that explores the experience of family management through the lens of the FMSF, although some studies describe isolated dimensions of the FMSF using other theoretical and methodological approaches. We believe that understanding family management within the context of pediatric transplantation according to the definition of the situation, management behaviors and perceived consequences, using FMSF, will improve our understanding about each situation and enhance our ability to develop and implement effective nursing interventions with these families.

Methods

Design

This is a qualitative case study research design using a series of in depth and semi-structured interviews.

Participants

Four families that included a child who had received a liver transplant at least one year prior, regardless of the pathologies that led to the transplantation, were invited to participate in the parent study. This paper presents one of these cases. The fictitious name of the child is Paula.

Ethics

All study procedures were completed in accordance with the study protocol approved by the Institutional Review Board of the hospital.

Procedure

We used multiple strategies for data collection, and the process was conducted in three steps, as follows:

First Step

After obtaining consent for inclusion in the research, an open interview was conducted in the family home to gain some initial understanding of the experience of the transplant and family life in its broader context. In this step, the interviewer also gathered general demographic data and data to construct the genogram and ecomap.

Second Step

A semi-structured interview was conducted in the family home with questions based on the FMSF, in order fully explore the family's management.

Third Step

A phone interview was conducted to answer any questions, validate information, and close the case.

All meetings were held by the same researcher, the main author of this study, a pediatric nurse specialized in organ transplantation and in conducting qualitative interviews. The meetings were scheduled according to convenience for the family, conducted in Portuguese, audio recorded, and transcribed shortly after their completion. The third step, to validate and close the case, was done via telephone. We also collected data from the medical records of the child. We searched for clinical data to gain a better understanding of the child's illness experience. This occurred between the first and second steps, to complement and deepen the knowledge of cases and provide better direction for the interview and any necessary clarifications.

Analysis

The analysis was based on thematic analysis, a form of pattern recognition within the data where the issues that emerge are configured into categories for analysis (Fereday & Muir-Cochrane, 2006). Researchers use different approaches to thematic analysis, including deductive models based on predetermined codes, proposed by Crabtree and Miller (1999), and inductive, data-driven models (Boyatzis, 1998). In this study, we chose a hybrid model of thematic analysis as described by Fereday and Muir-Cochrane (2006), which incorporates both deductive and inductive models. The hybrid model of thematic analysis has been used and recommended in nursing research (Fereday & Muir-Cochrane, 2006).

Findings

Family´s Description

Paula was 8 years old and she received the liver transplant from a living donor 4 years prior, through her maternal aunt's donation. Her parents got divorced a few months after her birth.

Paula's mother has been married to her current spouse for 6 years and had another son. She works at home and her current spouse is a musician. Paula lives in Salvador, Brazil with her mother, her stepfather and two of her brothers. Her aunt, who made the liver donation, is facing serious health problems and even though those issues are not related to the donation, Paula's mother feels responsible for her, since she donated her liver to Paula.

Family Management Experience

Definition of the Situation

In Paula's family, the liver transplantation experience didn't change the view they have of the child. They define her as a child who enjoys life just like any other child and they express their perceptions of her focusing on her abilities and the normalcy she achieved with the transplant. They don´t think she's any different from other children at the same age.

> She does everything that other children do. She is normal! I don't care for her as if she were…. special because of the transplant.

Post transplant, Paula's mother still views her condition as serious, knows that the seriousness will last as long as Paula survives, and thinks it takes a great deal of time to manage. Paula's mother believes that the disease will be forever in the family.

> In transplantation there is not such a thing as an end, I know I'll always be here. Her story is endless!

Her mother feels very confident in taking care of Paula, especially because she is quite sure about how to properly administer her medications. However, the mother's perception is threatened by the consequences that the disease progression can have on Paula's life, such as organ rejection. The family feels very insecure about how to effectively handle the situation when signs of organ rejection appear, which they view as a threat to the child's health and future.

> I feel confident about almost everything! But there are a few things that are far beyond my reach, then I worry. And when I worry, I don't feel confident at all. I worry about rejection!

Paula's biological father is not involved in taking care of her at all, and this makes the mother feel burdened and alone from the beginning of the illness course. She sought support in her current spouse and in other resources. At the time of the interviews, she reported finding support in her husband. In spite of these sources of support, the mother believes that the biological father's support is extremely important and that, since he is the father, he should be the one to share the burden with her. His absence increases her sense of burden and isolation.

> I wanted her father to be there with me at that moment [day of surgery], not my husband. It was her father who was supposed to be there… Because I was there all alone, and I've been alone forever. I could never find his support on anything…. So, I've been in this battle all by myself, without his support, without his family's support… All the support I have comes from my family alone.

Management Behaviors

After the transplant, the mother was able to organize her routine to balance family life and Paula's needs. According to her, it doesn't take a great deal of time to take care of her, and Paula is able to do things she wants and needs to do, despite her illness, and is treated as a normal child.

In Paula's family, the transplant brought the opportunity to reorganize family life as similar to that of other children her age, and this improved the quality of life for all family members. At one point, the mother had to stay most of the time at the hospital with her daughter; now she is back to her family and she feels happy that she can do things she used to do before the illness.

… [after transplant], now there are no complications, I don't live in the hospital all the time… My life has changed 100%! I have much more time now… Don't live in a rush anymore, don't stay in the hospital all day long, now I have time, I work, I do my own things […]

Perceived Consequences

While day to day life is much better, uncertainty still remains with the family when they think about the future. Paula's upcoming adolescence, though expected, worries the family. Even though she is seen as a normal child, when the mother thinks about adolescence she fears that Paula will want to act like other teenagers who don't have the disease.

> I don't want her to date soon because of her illness, I don't think she can. And I don't know if she is going to want to… That worries me.

The impossibility of predicting what to expect of the illness in a few years frightens the family, and organ rejection is the most feared event of the whole experience. Thinking about rejection means thinking about Paula's death, and her mother acknowledges that she doesn't have control over it at all.

> When I think about rejection, I think I can lose my daughter! And it happens every time she has diarrhea, because we learned from other moms that it is the first sign of rejection. So when she has it, I go crazy. But that's it, whenever she has any little diarrhea, I think about rejection. My only fear about all that, from everything in the transplant is rejection.

Discussion

The use of the FMSF, besides making possible the organized understanding of the family management in the context of chronic disease, promotes the consideration of specific interventions for families, focused on their particular needs.

Paula's family makes an effort to believe that they can have a normal life. When speaking about her child, the mother highlights her skills, positive characteristics and her belief that Paula can have a high quality of life, performing activities consistent with her age and stage of development. Even recognizing the limitations of health and fearing the future, the identity of the child is focused on her capacity to be like her peers. When a family defines the identity of the child as based on his/her abilities and skills, instead of his/her health problem, family members may adopt behaviors that help the child and the entire family unit to manage the condition with less suffering and difficulty (Knafl, Breitmayer, Gallo, & Zoeller, 1996; Mendes-Castillo et al., 2012). Conversely, researchers have found that when the family tends to define the child or adolescent with a focus on his/her weaknesses and deprivation, the family has a lower quality of family life and the child may even have a shorter survival time (Kikuchi et al, 2015; Simons, McCormick, Mee & Blount, 2009).

The data in this study shows that the beliefs of Paula´s family regarding her illness have changed over time. At first, they were scared and afraid because they believed the disease was serious and frightening, but over time, family members have acquired knowledge that challenged their prior beliefs and gave rise to new values and definitions. For Rolland and Walsh (2006), the unfolding of the disease over time creates opportunities for families to interact with different elements in the experience so they can seek helpful alternatives and strategies to face and live with the disease. The concept of the helpfulness of time is also echoed by Woodson and colleagues (2015) who found that time in the context of chronic illness is an ally for families and helps them acquire important skills and abilities that can result in more safety or control in managing the family member's condition.

Our study confirms that time may give health professionals the opportunity to encourage the family to reevaluate and reformulate their belief system about the disease and their ability to manage it overall. However, such opportunities typically happen casually and unplanned, as Wright and

Leahey (2009) observe. Instead of relying on these unplanned occasions, nurses can recognize these potential moments of healing and intentionally promote meetings of families with other families in similar situations. Such meetings can be planned with a multidisciplinary team to provide participating families with a broad set of strategies and resources to help them meet their need for information. Currently, there are social networking sites that specifically target families who have one of their members affected by some disease, including in the context of organ transplantation (Bers et al., 2010; Zelikovsky & Dobson, 2010). In these websites, patients and families communicate and share experiences with people from many countries and find the sites to be an important resource. The use of these tools is encouraged, but we should acknowledge that some families lack the resources to access these websites. So while the opportunities for virtual meetings continue to grow, the team can strive to provide a physical space for families to interact directly to share and acquire knowledge.

The family in this case fears the moment of transition from pediatric care to adult care. This fear is very understandable and warranted because the transition to adult care of children who have undergone solid organ transplant has been associated with high risk of organ rejection and graft loss (Annunziato et al., 2014). The transition from childhood to adulthood is a significant factor of concern in contexts where the child has a chronic condition that requires ongoing treatment. Experts in the care of children with chronic illnesses have come to consider transition to be a period of time instead of one discrete point of time. It is a continuous process of transition from care that is fully supported by parents to more independence from parental oversight (Akchurin, 2015).

Self-management of chronic illness requires acquisition of self-care skills such as seeking knowledge, adhering to recommendations, practicing healthy behaviors, and life-long self-surveillance. Parents, such as the mother in our case study, often feel fearful about the capacity of the child, when entering adolescence, to adhere to treatment with the same rigor and zeal with which they watch over him/her (Betz, Nehring, & Lobo, 2015; Giarelli, Bernhardt, Mack, & Pyeritz, 2008; Simons et al., 2009). This transition is a concern for all parents, but the concern is heightened for parents of children with chronic conditions. The issue of transition to adult care is a prominent theme that is woven throughout the classic textbook about the primary care of the child with a chronic condition (Allen, Vessey, & Schapiro, 2009), and it is reinforced by a recent systematic review by Betz and colleagues (2015) who looked globally at issues for parents of children with special health care needs during the period of transition to adult care. Two common themes for parents were their reluctance to relinquish their primary caretaker roles as well as concern about the lack of an interdisciplinary team approach, which they depended on from the pediatric care providers, in the adult health care world.

Transition to self-management is more than planning the transfer of services from pediatric to adult care, and involves gradual changes in knowledge, attitudes, and behavior by parents, peers, and health care providers. Transition to self-management is part of an evolving model of participation in life-long surveillance (Annunziato et al., 2014; Giarelli et al., 2008).

For children with chronic conditions, the pressing issue of transition to adulthood includes several developmental aspects in the physical, cognitive, social,t = –b and vocational realms (Sawin, Cox, & Metzger, 2010). Specific to children who undergo liver transplant such as Paula, physical activity should be encouraged but may need to be altered to accommodate any physical limitations. Cognition develops in children over time, and children who have had a liver transplant must be encouraged to exert increasing independence in their health decisions, as much as their individual condition allows, but without compromising health. Social skills evolve rapidly throughout adolescence and relationships with peers take on increasing importance. Relationships with parents and family are important throughout the lifespan but may be overshadowed by peer relationships especially during adolescence; this shift may be especially challenging for parents of children with chronic conditions such as liver transplantation. The health of all adolescents is threatened due to the developmental inclination to experiment with drugs and alcohol. For adolescents with chronic conditions such as liver transplantation, this risk is accentuated because of potential dangerous interactions between drugs and alcohol and prescribed medications. In all of these developmental realms, the family will be challenged to adjust its function and interactions accordingly. The nurse and interdisciplinary health team can help assist the adolescent and family with these adjustments with the goal of optimum health and quality of life. Of prime importance is the parents' deep understanding of the developmental changes that the adolescent undergoes, which will help parents grant the adolescent as much independence as is possible.

In the opinion of Kralik, Visentin and Van Loon (2006), time is an essential element in transition, so the monitoring of these families during the early, intermediate, and final stages of this transition is critical for nurses who seek to better understand the challenges the family faces and intervene for best outcomes. In Paula's case, while she has not yet reached adolescence but whose mother already fears this moment, nurses have a unique opportunity to monitor the whole process of transition from early childhood and offer necessary support along the way.

The issue of transition has been largely discussed in pediatric transplantation. In 2015, a well-known journal specialized in pediatric transplantation published a special edition exclusively addressing this matter, with several papers well-highlighting the need for further research regarding the needs and challenges of successful transition for young adults. (Akchurin 2015; Lerret et al., 2015;

Marchak, Reed-Knight, Amaral, Mee, & Blount, 2015; Weitz, Heeringa, Neuhaus, Fehr, & Laube, 2015). A group of providers in Switzerland developed a structured step-by-step transition program for renal transplant patients that showed significant results with improved biological markers of success (Weitz et al., 2015). A United States team of providers developed a tool to assess the readiness of affected children to transition to adult care and found promising results through assessing parents, health care team members, and the affected adolescent (Marchak et al., 2015). In the review by Annunziato and colleagues (2014), the benefits of a "point person" during the transition process was identified as a helpful practice strategy that could lead to better outcomes. The nurse would be an ideal candidate for this position since he or she would have a long standing relationship with the family as well as deep knowledge of child and adolescent development, two requisite characteristics. We would hope that similar future research will ultimately result in an easier transition for parents and better outcomes for the affected child.

In our study, the prospective future of the transplanted child is full of fear and uncertainty. The family questions the child's maturity about caring for herself in the future, fears about her death and worries that they do not know how long Paula will survive. Thinking about the future is to think about what cannot be controlled, and it understandably frightens the family. Chesla (2005) points out that sustaining hope in the face of a chronic illness is probably not achievable as a permanent or stable state. For individuals and families with chronic illness, the future poses great risk because it brings threats and uncertainties. Therefore, hope can be better understood and offered to families as an opening to strive for changing their mental focus and accepting the possibilities that life offers at present.

In this context, then, hope comes from living one day at a time instead of thinking about the uncertainties of the future. Families that focus on positive results achieved in the course of the disease and thereby set milestones for progress in the course of the disease can rekindle the hope that if they get there, they can face the next day.

Conclusions

The aim of the study was to present and discuss relevant aspects of family management in a family of a transplanted child according to the FMSF. We are aware that the social-cultural context strongly influences how families define and manage illness and their own lives. This study was carried out in Brazil, a country with diverse beliefs and strong cultural influences. We therefore encourage conducting similar studies in different contexts and countries to address such limitations.

The biggest challenge for these families seems to be maintaining hope and remaining motivated for new possibilities in the present, because the future is so uncertain. Considering the dimensions and components of the FMSF enabled a clear understanding of family management in this context, and opened paths and options for effective nursing intervention. The use of theoretical models in the evaluation of families in different contexts is encouraged because it promotes the understanding and development of appropriate interventions for each family.

Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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