Family experience in the kidney transplant process from a living donor

Vivência da família no processo de transplante de rim de doador vivo

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Abstract

Objective: To understand the family experience of kidney transplantation process of a living donor.
Methods: Qualitative study conducted with four families of patients undergoing kidney transplantation of living donor. The research instrument used was a semi-structured interview conducted at the homes of families and recorded audio. The interviews were transcribed verbatim and from the saturation of data, categories emerged.
Results: The following categories were observed: impact of chronic kidney disease and dialysis treatment in the family; family experience at different stages facing kidney transplant of a living donor; family interaction with the healthcare team; Resignifying the family system in the process of chronic kidney disease and kidney transplant; and support from social networking and spirituality as coping strategies.
Conclusion: Kidney transplantation from a living donor involves aspects of physical and emotional care of everyone involved in the process, considering the potential and experienced adaptations where spirituality is seen as a contributing factor.

Resumo

Objetivo: Compreender a vivência da família no processo de transplante de rim de doador vivo.
Métodos: Estudo qualitativo realizado com quatro famílias de pacientes submetidos a transplante de rim intervivos. O instrumento de pesquisa foi a entrevista semi-estruturada realizada nos domicílios das famílias e gravada em áudio. As entrevistas foram transcritas na íntegra e a partir da saturação dos dados as categorias emergiram.
Resultados: Observaram-se as seguintes categorias: impacto da doença renal crônica e do tratamento dialítico na família; experiência da família frente às diferentes fases do transplante de rim de doador vivo; interação da família com a equipe de saúde, ressignificando o sistema familiar no processo da doença renal crônica e transplante de rim; e apoio da rede social e da espiritualidade como estratégia de enfrentamento.
Conclusão: O transplante de rim de doador vivo envolve aspectos de cuidado físico e emocionais de todos os envolvidos durante o processo, considerando as potencialidades e adaptações vivenciadas onde a espiritualidade é um fator coadjuvante.

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Introduction

In chronic kidney disease in terminal stage, transplantation is the only treatment option, and in the process, both the patient and family can be deeply affected.[1]

The transplantation performed with a living donor offers advantages because as a therapeutic choice, it is a procedure that helps reduce the time in the waiting list, increasing patient survival, in addition to promoting quality of life and even family relationships.[2]

Even given the benefits provided, the process of transplantation with living donor is not simple. It is a time consuming process because it involves ethical issues, specific assessments of recipient and donor. These factors can affect the family system that suffers great impact, because the family faces dilemmas, both by the possibility of organ removal from a healthy relative, surgical risks, such as feeling responsible to ensure patient survival.[3,4]

A familiar movement of negotiation regarding the decision-making is commonly observed among those who are willing to participate in this process. Thus, it is important to understand the expectations of the people involved in donating and the acceptance of the organ by the recipient, being fundamental family mutual support to allow the transplant.[3]

The family as a complex system governed by rules of homeostasis and development, searches for points of balance between maintenance and growth of its members. From this viewpoint, the family subsystems are part of both the problems and solutions.[4] Facing uncertainty and difficulties in preparing for transplantation with living donors, are essential factors in the process and should be considered before surgery. However, the inclusion of family in this scenario is still an unexplored fact.[4,5]

Considering that the family system is configured as ideal field for research, we sought to explore subjectivity in the face of crises and conflicts, facing the kidney donation process and its consequences. Upon these reflections, the present study aimed at understanding the family experience in the kidney transplant process of a living donor.

Methods

The qualitative study was the method of choice, which allowed us to investigate, in depth, the experiences of families translated by meaning. Data collection occurred during the year 2013 under two scenarios: first stage in the Post-Transplant Unit linked to a hospital specialized in transplants in Sao Paulo. A total of 15 families were approached for the clarification and information by the researcher, who is an expert in family therapy, which were addressed during the monitoring of the kidney recipient at the first outpatient visit after surgery. Only four families met the inclusion criteria: having a family member who went through kidney transplantation with a living donor related by blood within six months of surgery; availability of all family members to participate in the interview, including recipient and donor.

The second stage of data collection was conducted in the homes of families through semi-structured interviews, audio recorded, with an average duration of ninety minutes The main question was: "How is it for you to experience the transplant having, at the same time, a kidney recipient and donor in the same family?"

For the analysis, the interviews were transcribed verbatim, outlined, analyzed and discussed. From the data saturation categories emerged, there was no need to return to the participating families, although there was a commitment to present the results of the research for the participating families.

The development of the study met national and international standards of ethics in research involving human subjects.

Results

Participating families were identified by ordinal numbers according to chart 1.

The statements analysis were organized into five categories emphasizing the experiences of families considering the dynamics, structure and the coping strategies in the transplant process of the living donor.

Chart 1. Presentation of the families participating in the study

Family	Family composition	Family composition at the time of the interview	Hometown	Disease history	Donor
F1	Origin Family: father, mother and four brothers. Parents were separate. Father remarried with three children from the current relationship Current family: mother, two sisters, a nephew. Recipient was separate from partner, with no children	Recipient, donor, mother and father. Family lived in a rented house in the city of São Paulo (SP)	Campo Grande (RJ)	Chronic kidney disease began in 2008, hypertension in treating was the main cause. The immediate dialysis treatment was performed in the State of Minas Gerais	Sister
F2	Origin Family: father, mother and 12 brothers and sisters Current family of the recipient: wife and teenage daughter Current donor's family: wife and a child of school age	Donor and wife, Recipient and wife living in a house as Courtesy of the city of Itapecirica da Serra city (SP)	Recipient residing in Aracaju (SE) Donor. resident in Goiás (GO)	Loss of renal function in 2010, asymptomatic hypertension without treatment. Immediate dialysis treatment in the hometown	Brother
F3	Origin Family: father, mother and ten brothers Current Family: wife, two sons and a grandson Current donor family: husband and two sons	Donor, recipient, companion brother, cousin Recipient in temporary home of the donor during the transplant process	Metropolitan area of João Pessoa (PA) Donor resident in São Paulo (SP)	Loss of renal function was a result of hypertension without medical supervision. At diagnosis of chronic kidney disease, wife was diagnosed with renal failure (atrophy)	Sister
F4	Origin Family/current: father, mother and a sister younger than 21 years	Residents in Guarulhos (SP)	Metropolitan region of São Paulo	Sudden kidney failure without triggering diseases.	Mother

Impact of chronic kidney disease and dialysis treatment in the family

The treatment of chronic kidney disease imposed, on the participants, needs to trigger resources to deal with partial loss of autonomy and mood alterations. The sick person, temporarily dependent, needs care in basic activities and becomes a priority for the family, consequently, the routine of everyone undergone significant changes, primarily to promote the treatment in clinics and/or domicile. Family perception of changes in quality of life, physical, emotional, social and cultural aspects became evident.

Another important aspect reported was communication. The reports showed that while the dialogue was a facilitator in the process of coping, their fragmentation did not allow the clarification of doubts regarding treatment. These facts allowed the ideas to stay just in their thought, generating feelings of fear, insecurity, startle compassion and resignation about what failed to be understood.

Family experience at different stages facing kidney transplant of a living donor

The preparation for the transplant was a generator of much tension and ambivalence of feelings. Resulted in the choice of the donor, and in the growth process for all involved. A spontaneous decision to participate as a donor, given the absence of other treatment options, was an important step towards realizing the transplant and awaited with much anxiety. Once the surgery was done, the transplant brought relief and feelings of gratitude. However, the fear or the concern of facing an unknown situation amounted to the possibility of failure and return to the times of suffering.

Once the transplant was performed, the re-adaptations were perceived by most families as a time of change, including the care of the kidney graft, allowing all people involved conditions to make plans in the short, medium and long term. Some families revealed that ultimately could take more care of themselves, return to work, considering that before the procedure, the main concern was taking care of the patient, including neglecting the care of their own health.

Family interaction with the healthcare team

Families commented that during the process of transplantation, the recipient had established greater bond with the healthcare team.

However, some families felt they were placed in the background by the team, especially in decisions regarding treatment and procedure. It was highlighted that the nursing staff was instrumental in the process, being recognized and valued in the practice of care, attention and encouragement, facts they understood as important in responding to crises. Feeling welcomed, comforted, generating feelings of security, satisfaction and gratitude to the staff.

For the donor, the information about the procedures helped in the decision, but after the procedure, they left the scene of care.

Resignifying the family system in the process of chronic kidney disease and kidney transplant

The disease and transplantation were also seen as an opportunity to revisit familiar paradigms. It was noted that the approach of those who, for various reasons, had remained distant allowed the recognition, appreciation and effort of family members involved in transplants, changing the meaning of "being a family". This has gained prominence, being mentioned as the basis for facing the moments of crisis experienced throughout the process.

Demonstrations of affection and solidarity were perceived as more evident when compared to fear of loss and death of the patient. In this respect, kidney loss for both the recipient and the donor was re-signified as a gain for the entire family unit, noting that given the suffering, there was more mobilization to improve communication and coexistence, reducing conflict.

How each family developed the care is related to the presence of the transmission of family values and beliefs. The protection and appreciation of life on the changes caused by the disease was highlighted as family learning.

Although families highlight strengths related to its components, the resentment of those who chose not to participate actively in the treatment process, including transplantation, was also present, creating estrangement, resentment and hurt feelings among some families. The refusal or option of the family not to donate the organ was justified and understood by other family members as a lack of courage.

Support from social networking and spirituality as coping strategies

The support and help from social network were cited as essential to families on the physical, emotional and social aspects. There was emphasis on the solidarity of friends and church members at different stages of the process, including financial aid for maintenance, ensuring living conditions for when they are away from their homes, since many families had to leave work to care for and monitor the transplant process away from their homes.

Spirituality was another highlight where the care from the recipient and the decision to be a donor come to mean a mission set by God.

The expectation of positive outcomes in transplantation has also been deposited in faith and belief in God that helped them coping with difficult times, even when there was no explicit religious practice.

Discussion

A limitation of the study is related to the geographical displacement of families involved in kidney transplantation with living donor to a specialized center, a fact that prevented observation "in loco" of the inter-family dynamics. Another limitation concerns the investigation of the social and family role played by interfaces donor-recipient dyad because of the need of other family members to communicate their experiences in the transplant process, highlighting the need for further studies.

The results showed that the experience of having a family affected by chronic kidney disease and experiencing the living donor transplant have particular meanings for family unity, supported by perceptions that each family constructs are based on their experiences in disease processes.[6,7] This corroborates the idea that any attempt to objectify and/or interpret the patient's complaints may generate tensions, crises or conflicts, which consequently affects the family context.

The diagnosis brings family instability and certainty of successive loss of independence, self control and limitations, generating fears and feelings similar to those in mourning. Feelings of anxiety, sadness and anger are permeated by the sense of shock compounded by the fear of death. These factors are indicators of the importance of valuing the family as the unit of care throughout the process.[8]

The dialysis treatment directly affected families requiring re-adaptations to family routines. Highlights the need for new coping resources and resizing roles, redefining the boundaries between family members on the changes in its structure and functionality. It was evident that the support of the

nuclear and extended family was crucial to dealing with the problems arising from the illness, fight for survival and to continue the treatment.[9]

Intra-family and healthcare team communication at diagnosis communication reinforced preconceived ideas about chronic kidney disease. Thus, the inefficiency of communication legitimizes feelings of exclusion among families in the resolutions of treatment and transplantation modalities.[10]

In some cases, the patient was responsible for the decisions. Considering the importance of the family system in the process, even if the relatives have different needs and interests through information, it is pertinent to consider the inclusion of the family system as a coadjutant in decisions and proposals carefully. In this respect, information strategies can contribute in the decision making process.

In the search for a donor, mobilization of the family was inevitable. So, there is the occurrence of an implicit family game, on one hand the recipient fails to explain his or her needs and desire, waiting for spontaneous offer, while other family members await someone who could offer themselves. In this sense, we observed that the donation is not always a spontaneous and on the verge of death act, saving the life of a person happens to be a compromise.

By intuition and/or lack of choice, the donor elevated his/her status in the family, gaining admiration and recognition. While the donor recognize the importance of the gesture and realize the implications of the loss of the organ in life, these feelings are not always seen by staff as a barrier to donation.

The emotional burden on the donor as a "hero" is significant because the expectation with respect to donation makes explicit the possibility of their not desistance. The refusal or difficulty in finding a family donor may be related to factors such as coping and stress management; pattern of ego defense; fear of hospitalization; concern about risks in the medium and long term vision involving cultural aspects of the family about organ donation.[6,7,11]

Family's expectations are generating feelings and sensations, and the waiting time for the procedure, can destabilize the system, reflected in family dynamics.[11] Even if the movement looks natural family gathering on the threshold between life and death, in living donor kidney transplantation process may favor the negotiation, reconciliation and closeness between distant relatives can thus be a facilitating factor for care.

Families understand that the settings for surgery are accompanied by uncertainty regarding the results. Likewise experiencing hospitalization of relatives for transplant can trigger dubious feelings in which the fear of failure, loss and death are constant.

At the end of the transplant, the donor loses visibility, leaving the concern scenario, care setting and family team. Thus, it is important to consider a proposal for comprehensive and humane care that includes family system and recipient.

With the performance of the transplant, recipients need to take responsibility for self-care with the graft and the concept of autonomy and other family members gain freedom to take care of their own physical and emotional needs neglected by the long time involved in treatment. These facts may be related to how each family builds their beliefs, their values on post-transplant care.[11]

In the whole process of living donor transplantation, the dyad of life and death was present in families, leading to reflection on the appreciation of life and the search for alternatives to reorganize family life, corroborating studies that highlighted the importance of faith and spirituality in moments of crisis and illness.[12]

The data showed that families have gone through the transition period before the need to adapt to new situations and changes. Thus, the understanding of transplantation demand continuity in treatment and family background sets as primary care source, reinforcing the need for their inclusion in treatment strategies aimed at physical and emotional health of its members.

Conclusion

Understanding the family experiences in the kidney transplantation process of a living donor reflects the need to rethink the care delivered not only to the recipient but also to the donor and family, whether in physical or emotional aspects. This study high-

lights the potential of families in search for support and resources in the community, ability to adapt to crises and re-encounters with spirituality.

Collaborations

Cross MGS contributed to the project design, execution of the research and manuscript writing. Daspett C; Roza BA and Ohara CVS collaborated with relevant critical review of intellectual content. Horta ALM contributed to the project design and execution of the study, drafting the manuscript and approval of the final version to be published.

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