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Family support in the kidney transplantation process

Apoio familiar no processo de transplante renal

Apoyo familiar en el proceso de trasplante renal

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This study aims at clarifying doubts about the process of kidney transplantation and verifying what is the perception of the health team with respect to the importance of the support of the family to the patient who underwent a kidney transplant. This is an observational descriptive study, conducted with 51 patients who underwent kidney transplants and were being monitored in a health service in the west of Santa Catarina, Brazil from June 2015 to June 2016. Data collected showed that the contact with the patients is important to clarify the doubts that involve transplantation. The participation of the team is paramount for the identification of family support as something essential for the process.

Descriptors: Kidney transplantation; Family relations; Patient care team.

Este estudo tem como objetivo esclarecer dúvidas sobre o processo de transplante renal e verificar qual a percepção da equipe no que diz respeito à importância do apoio familiar ao paciente transplantado renal. Trata-se de um estudo descritivo observacional, realizado com 51 pacientes que passaram por transplante renal e estiveram em acompanhamento em um serviço no Oeste Catarinense no período de junho de 2015 a junho de 2016. Os dados coletados mostram que é importante o contato com os pacientes para esclarecer as dúvidas que envolvam o transplante. Com isso a participação da equipe se faz essencial para identificar que o apoio familiar é fundamental para facilitar esse processo.

Descritores: Transplante de rim; Relações familiares; Equipe de assistência ao paciente.

Este estudio tiene como objetivo aclarar dudas sobre el proceso de trasplante renal y verificar cuál es la percepción del equipo en lo que respecta a la importancia del apoyo familiar al paciente trasplantado renal. Se trata de un estudio descriptivo observacional, realizado con 51 pacientes pos-trasplante renal en acompañamiento en un servicio en el Oeste de Santa Catarina, Brasil en el período de junio de 2015 a junio de 2016. Los datos colectados muestran que es importante el contacto con los pacientes para aclarar las dudas que envuelvan el trasplante. Con esto, la participación del equipo se torna esencial para identificar que el apoyo familiar es fundamental para facilitar este proceso.

Descriptores: Trasplante de riñón; Relaciones familiares; Grupo de atención al paciente.

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INTRODUCTION

The chronic kidney disease (CKD) is understood as the progressive and irreversible loss of kidney functions, characterized by the deterioration of the biochemical and physiological functions of the kidney. Its evolution is classified based on the level of renal function, and the rate of glomerular filtration rate (GFR), factors that indicate the loss of the functions of the kidneys. The CKD is classified in stages. From the second stage on, the glomerular filtration is <90ml/min/1,73m^2, indicating that the kidney started function less optimally; stage five would indicate that glomerular filtration is <15ml/min/1,73m^2, meaning the patient is suffering from terminal kidney failure, need for dialysis or End-stage Kidney Disease (EKD)[1-3].

According to the Ministry of Health of Brazil,[4] CKD affects nearly 10% of the population of the world. It is estimated to affect one in every five men and one in every four women aged between 65 and 74.[5] In the end-stage of the CKD, the changes in the eating and life habits are no longer enough by themselves, demanding dialysis and, if possible, a kidney transplant[1].

The transplant consists in a surgical procedure aimed at replacing the non-working organ by another one which actively functions. After the first transplant, the individual is susceptible to a trajectory of many positive and negative situations, expectations, sensations, uncertainties and even frustrations[5].

The process is complicated, minute, and requires constant support and clarification. In this process, the support of the family is seen as a contributive factor, as are the support and the link to the health team. Caretakers directly involved with the patient during the transplantation process need to have the chance to update their knowledge, counting on the support of the health services[6].

Making effective knowledge exchange among those involved in the transplant process is paramount, as is the strengthening of a link between caretakers and users. To do so, a space for dialogue and interaction needs to be provided. Therefore, this study aims at clarifying doubts about the process of kidney transplantation and verifying what is the perception of the health team with respect to the importance of the support of the family to the patient who underwent a kidney transplantation.

METHOD

This is an observational descriptive study, conducted with patients who underwent kidney transplantations and were being monitored in a health service for CKD in the west of Santa Catarina. This study was originated from actions conducted through the extension project: "Patients after kidney transplantations: an interface of care", which is in accordance to Resolution Nº 466, from December 12, 2012. It was approved by public notice 804/UFFS/2014. The research was developed by undergraduates, one professor, acting as an advisor, and one co-advisor, all from the graduation course in Nursing of the Federal University of Fronteira Sul (UFFS), from June 2015 to June 2016.

The transplanted patients were previously invited to participate in conversation groups, which were formed between the waiting period for the results of exams and follow-up consultations with the nurse or physician.

The development of activities took place in two moments: the first stage included the conversation groups, that were integrative and used starting questions that would preserve the privacy of the participants, while assessing important information for the research, such as: time passed since the transplant; whether there was a hemodialysis treatment; patients' age; continued use medication; what disease led to the CKD. The questions also allowed the researchers to learn a little more about the patients' lives, their limitations, confrontations and changes in their lifestyle after the transplant.

Between the first stage and the second conversation group, a suggestion box for the patients to insert their doubts about the transplantation was left in the health service, with slips of paper requiring them to state the time since their transplant, the city from which they came, and write down their question. Later, the second stage was conducted. It aimed to clarify the questions deposited in the suggestion box, addressing the same patients from the first stage. The answers were based on consultations to research materials.

A questionnaire with two questions was given to the members of the health team who worked in the service, in touch with patients who had underwent transplantations. The questions were made to clarify the importance of family members in the process of transplantations and in the post-transplant period, as well as the main changes the professionals noticed in the receptor. The respondents were identified by color: R (red) for the first question and B (blue) for the second. The number corresponds to the order in which the professional answered the question.

A descriptive statistical analysis was conducted on the answers of the team, which were then organized, grouped and categorized. They were named as R (red) for answers of the first question and B (blue) for answers of the second one. They were also numbered according to the order in which the response was given.

RESULTS

The suggestion box as a source of information

The suggestion box was placed to find what were the doubts of the patients who underwent this reference CKD health service. It stayed in a visible and easy to access place, so that any patient could leave their doubts regarding the kidney transplantation process. Four patients participated.

The suggestion box stood in this environment for two months, its existence was announced in the first meeting and in the visits of the graduation students to the service, with three questions. After the suggestion box was returned, a second meeting was carried out with the same patients who participated in the first stage. In this group conversation, the doubts and respective possibilities of discussion were presented. The questions that arose from the patients who had been transplanted were:

1. "How many transplants took place in Chapecó-SC?"
2. "What are the main symptoms in cases of rejection? What foods contribute to the increase in creatinine?"
3. "Why is the donation anonymous? And why is it not possible to know the family of the donor so we can thank them?"

The answers to these questions will be presented below.

The perspective of the team regarding the importance of family support

The health team of the unit is made up of 27 members, nine of which (who are in touch with the transplanted patients) accepted answering a questionnaire, divided according to Table 1:

Table 1. Field of expertise of the professionals who work in the CKD service in the west of Santa Catarina. SC, 2016.

Field of expertise	Quantity
Nursing	2
Nursing technician	2
Nutrition	1
Psychology	1
Medicine	1
Administration technician	1
Social Assistant	1

The following categories were built: "Family Support", with the sub-categories "Participation" and "Safety"; and "Behavioral Changes", with the sub-categories "Quality of Life" and "Change".

It could be noted that the professionals believe that family support is of the essence, and significantly contributes to the process:

- "Very important, it provides emotional comfort to the patient, helps in the adherence to the assistance and to the use of medication (2v)".

- "Family is very important during this process, the patient feels safer [...] The patient has to deal with a lot of information and new habits (6v)".

It is worth highlighting the statements of a member of the team according to which the family, when present, can soften emotional discomfort. The participant also reported that the transplant demands a lot of attention, especially with the medications that the person who underwent it must take:

- "[...] A present family is capable of softening the emotional suffering caused by the disease process. The transplant improves the quality of life, but it is still a treatment that demands much more attention, especially as it relates to the medication (7v)."

Having a team in the health services that is willing to conduct the necessary care and give the information to the patients and family members is significant for the treatment, as described by a member of the team. Immediately after the transplant, the patients suffer with the changes, but in time, they get used to the new routine:

- "At first I notice that right after discharge they feel the "impact" due to the general care and especially the medications, but as days go by they start to understand better and the "good" part starts, enjoying the transplant and the "new" life" (3a).

Insecurity, anxiety and behavioral changes are very impactful for the team, but after a certain time, the quality of life improves, eating habits change and the feeling of satisfaction emerges, since they start being able to develop daily activities they could not in the past:

- "At first the patients seem more insecure, anxious and filled with doubts, but later the quality of life improves a lot, they feel freer, their eating habits change, the mood, they get happier" (5a).

- "The behavioral changes and the self-esteem that is influenced by the improvement in the uremic framework and the chance of staying free from Hemodialysis" (6a).

The team perceived that the patients go through a period of transition with the CKD in the process of transplantation and post-transplantation. Their relatives also go through a transition process, due to the need to adapt to new situations that demand changes in routine and organization.

DISCUSSION

Answering the questions of transplanted patients

In Chapecó-SC, up to January 18, 2016, there was a total of 249 transplants, 63 of which from living donors and 186 from deceased ones - data made available by the west Renal Clinic.

Considering the second question, the importance of the use of immunosuppressants for the remainder of the patients' life was addressed. That is what will help "confounding" their immunologic system, so it will not reject the transplanted organ. In the first days after the transplant, the doses are bigger, and they are reduced as time passes[7].

Rejection can be classified in three forms. It can be a hyperacute rejection, that takes place within the first 24 hours of transplantation or even during surgery itself. This type happens when the receptor presents antibodies that are targeted against the transplanted kidney even before the transplant, leading to a fast and irreversible loss of the organ. An acute rejection is the one that takes place from the 3rd day after transplant or later, commonly in the three first months. This is the most common type of early rejection, and the only one for which there is an effective form of treatment[7].

The chronic rejection takes place during the evolution of the transplant, leading to a slow and progressive loss of the transplanted kidney. The presence of proteins in the urine is a red flag, when it is followed by an increase in the creatinine in the blood. It is more likely to happen in transplantations conducted with organs from dead bodies, from unrelated living donors, and when the patient presents episodes of acute rejection[7].

In order to answer the second question, the types of rejection were presented to them according to the manual of Kidney Transplantation by Castro[7], in addition to the potential symptoms that are important to identify a probable rejection (Table 2).

Table 2. Possible symptoms of kidney transplant rejection according to the guidelines of the Brazilian Association of Organ Transplantation (ABTO).

Phlogistic signs in the site of the surgery
- Temperature > 37,5 ºC
- Diminution in urination
- Weight gain in a short period of time
- Edema in eyelids, hands and feet.
- Dysuria
- Blood in the urine
- Increased blood pressure with minimum BP over 100mmHg
- Cough or dyspnea
- Loss of the feeling of well-being

The importance of the information regarding eating habits was reiterated, as it is important to avoid the increase in the levels of creatinine. Even after transplantation there are restrictions to food ingestion, but these are less rigorous than those recommended for patients under hemodialysis. The diet is unique to the patient, defined according to the medications being used and the results of the exams, through medical monitoring.[7]

Regarding the third question from the participants, the dispositions of Law n. 9.4348, from February 4, 1997, Chapter II, Art. III, were highlighted, as they address the need for the process of organ donning to be anonymous (whether the organ, in this case a kidney, is from a living donor or not).

The removal of tissues, organs or parts of a human body destined to transplant or treatment must take place after brain death of after the donor has been verified and registered by two doctors who are not part of the teams of removal and transplant, with the use of the clinical and technological criteria defined by a resolution of the Federal Council of Medicine[8] according to Law n. 9.434[8].

When the donor is alive, the law states, in its chapter III Art. 9[8], that the person, if legally responsible, can offer, free of charge, their tissues, organs and other parts of their own living body for therapeutic ends or transplants for a spouse or for relatives up to four degrees removed. The donation will only be allowed when the organ being donated is not a single organ, is a part of an organ, a tissue, or another part of the body whose removal will not put the donor's organism at any risk to its integrity nor will it compromise the organism's vital aptitudes or mental health.

The act of donating is seen by the patients as something noble, since the donor will be undergoing a surgery, experiencing corporal changes, pain, etc[9]. The transplant favors the quality of life of the receptor as well as their family/friendship relations. However, factors that involve organ donation and reception are surrounded by bureaucratic aspects, oftentimes leading to emotional changes, especially if the results are different from the objectives[10].

In this sense, not only the Law gives support to the living and dead donors, as it also gives support to the donating families in cases of brain death, keeping the anonymity of the donor, as per decree n. 2.268[11], from June 30, 1997, in its chapter II, Art. 8, item 4, according to which health establishments and specialized teams will, in the authorization form, state that they are committed to undergo inspections and accept control from public powers, allowing the free and easy access of its agents to facilities, equipment and medical records, being necessary, when it comes to these records, the presentation of acceptable credentials, since these documents are confidential, according to the dispositions of the Federal Council of Medicine. Therefore, a person who received the organ from a donor who was already deceased will not be able to know who was the donor or the donor's family.

This study is directly related to the efficient care to the patient who undergoes the process of kidney transplantations involving the family and the health team. One of its limits is the lack of studies with patients after kidney transplantations, developing activities to make easier the communication between patient, family and team, as well as seeking to understand the real needs and the sharing of experiences.

The results have made it clear that the box for the suggestions of the kidney transplant patient, used as a source of information, was relevant, since in addition to showing how important the conversation groups were, it led to the raising of some questions regarding the process, which results in the construction of a base for their experiences not to be painful processes, but rewarding ones.

Similarly, the questionnaire applied to the theme also brought important information, pointing out how important is the participation of the family in this process, a participation that starts when the kidney disease is discovered and lasts until the period after the transplant, according to the health team involved in this cycle.

It is common for patients with some diagnosed chronic disease to feel afraid or discouraged when thinking about the future[3], they may even feel depressed. These feelings are normal and are part of the process of accepting the disease and the treatment. Knowing the disease, accepting it, and learning to deal with it will only do them well and make their treatment easier[7].

In fact, the diagnostic brings about family instability and certainty that there will be consecutive losses of independence, self-control and limitations, leading to fear and feelings similar to that of grief. Feelings of anxiety, sadness and irritation are permeated by the feeling of shock, made more intense by the fear of death. These factors are signs of the importance of valuing the family as a unit of care throughout the process[6].

After the transplant is conducted, the receptor needs to take responsibility for their self-care and the recovery of their own autonomy, as their relatives once again become free to care for their own physical and emotional needs, neglected during the long time the treatment lasts. These factors may be related to the way in which each family builds their beliefs, their values regarding post-transplant care[12].

The transplant, the constant changes, the lack of acceptance in the beginning, might be a big impasse for the patient to be able to do the adequate treatment, but with the support of the family, treatment becomes easier. The magnitude of the problem of the chronic kidney patients and the importance attributed to this type of transplant are very meaningful to these patients, to their families, and also to society[6].

The routine of medications, exams, follow-ups, exhausts the patient, who needs support[10]. As the CKD progresses, losses in autonomy and mood changes are common. The family is not always present and supportive during this process, which is not the case described by the team.

The way in which each family conducts their care is also related by the transmission of family values and beliefs, the protection and valorization of life when confronted with the changes brought about by the disease[12].

After transplantation, some caution is necessary: the patients must be aware of the enormous risks of losing the transplant and of the possible complications, that can result from the insufficient, inadequate or non-supervised use of the immunosuppressants, even years after the transplant. Because of these risks, exams and consultations are performed throughout the patients' entire lives[7].

The transplant requires continued treatment, and the family context is the primary source of care, once again showing the need for the inclusion of the family in the strategies of treatment for the physical and emotional health of all its members[12].

Para a família o diagnóstico traz instabilidade familiar e certeza das perdas sucessivas de independência, autocontrole e limitações, gerando medos e sensações semelhantes aos do luto. Sentimentos de ansiedade, tristeza e irritação são permeados pela sensação de choque agravada pelo medo da morte. Estes fatores são indicadores da importância de valorizar a família como unidade de cuidado em todo processo[13].

Desta forma, o entendimento do transplante demanda continuidade no tratamento e o contexto familiar configura-se como fonte primaria no cuidado, reforçando a necessidade de sua inclusão nas estratégias de tratamento, visando a saúde física e emocional de seus integrantes[10].

A study[10] has shown that the approximation of those who, for many reasons, were distant, allows for the recognition, valorization and effort of family members directly involved in the transplants, changing the meaning of what "being a family" is.

After the transplant, despite the recommendations and medical demands, the patient can lead a normal life. Every month that passes, their restrictions diminish and they need less care, making it possible for them to have full and healthy social experiences[7] As time passes by, they can go back to activities previously made impossible by the aggravation of the disease, recovering their quality of life, being well with themselves, with their lives, having healthy habits, caring for their body and mind and living well with their relatives, friends, and finding balance[7].

CONCLUSION

The family being the main support for the patient with CKD is positive. That is because the patient goes through a difficult period that requires patience both from the family and the health team. Some patients, as they receive the news, do not want to believe and end up not adhering to the treatment.

Data show that despite the knowledge of the patients on the subject, they still have doubts, and these doubts can be clarified when actions such as conversation groups are promoted to discuss the subject, as well as through the involvement of the team, so it is more present in the process and prioritizes family participation.

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CONTRIBUTIONS

Greici Daiani Berlezi and **Camila Zanesco** took part in data collection, literature review, writing and in the final review. **Maiara Vanusa Guedes Ribeiro** took part in data collection, design, analysis and data interpretation, as well as in the final review. **Alesandra de Paula** contributed in data collection. **Débora Tavares de Resende e Silva** was the advisor for the project and conducted the final critical review of the article.

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