KIDNEY TRANSPLANT: PERCEPTIONS FROM PATIENTS AND HEALTHCARE PROFESSIONALS ABOUT KIDNEY TRANSPLANTS

TRANSPLENTE RENAL: PERCEPCIÓNES DE PACIENTES TRANSPLANTADOS E PROFESIONAIS DA SAÚDE

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ABSTRACT

Objective: Make an analysis from the viewpoints of patients and healthcare professionals about kidney transplants. Method: An exploratory study, describing in a qualitative approach, undertaken in a hospital located at the south region of the country. The sample involved sixteen kidney transplanted patients and fourteen healthcare professionals. The data was collected in October and November of 2013 from a semi-structured survey interview. It was made an analysis of content for his appreciation. Results: Three main categories were defined: << Consequent Changes from the Kidney Transplant >>; << Main difficulties observed after the Kidney Transplants >>; << Treatment Compliance >>. Conclusion: Both patients and healthcare professionals realize that Kidney's Transplant makes a meaningful change in patients' lives, causing difficulties specially concerning its treatments’ compliance. Which demonstrate a need of establishing a bond of confidence between patients and healthcare professionals as a way to improve the process of treatment’s compliance. Descriptors: Nursing; Renal Insufficiency; Kidney Transplant.

RESUMO


RESULTADO

Método: estudio exploratorio, descritivo, con una abordaje cualitativa, realizado en un hospital universitario en el Sur de Brasil. Los sujetos fueron 16 pacientes trasplantados y 14 profesionales de salud. La coleta de datos se realizó en los meses de octubre y noviembre de 2013 por medio de una entrevista semi-estructurada. Para apreciación de los datos, se utilizó la Análisis de contenido. Resultados: se definieron tres categorías temáticas: << Cambios consecuentes del trasplante renal >>; << Principales dificultades encontradas después del trasplante renal >>; << Adhesión al tratamiento >>. Conclusión: los pacientes y los profesionales de la salud perciben el trasplante renal como una modificación significativa para los pacientes trasplantados, habiendo dificultades principalmente en las relaciones de adhesión al tratamiento pos-trasplante. Esto viene a demostrar la necesidad de establecer un vínculo de confianza entre pacientes y profesionales, como forma de optimizar el proceso de adhesión al tratamiento. Descriptores: Enfermería; Insuficiencia Renal; Trasplante de Riñón.
INTRODUCTION

Chronic Kidney disease is considered a public health matter in the whole world. In Brazil, the increasing number of cases and the prevalence of failure from renal functions have grown progressively. Besides the prognosis is still difficult to be done and the costs of treatment for the disease are very expensive. Therefore, it is not a surprise to observe that a decrease from the renal function affects all other organs.1

Renal dysfunction is a clinic syndrome characterized by a decline from the renal function with the accumulation of metabolites and electrolytes, which can be classified as acute renal insufficiency or chronic renal insufficiency, according of the development of the disease.2

The available treatments for the terminal diseases are: continuous ambulatory peritoneal dialysis (CAPD), continuous cyclical peritoneal dialysis (CCPD), intermittent dialyses peritoneal dialysis (IDP), hemodialysis (HD), and Kidney transplant. These treatments partially substitute the renal functions bringing some relief to the symptoms of the disease and preserving the patient’s life but none of them are a complete cure.3

The renal transplant is the choice of treatment for patients with chronic renal insufficiency, provided that the patients are in fare condition to submit for surgery and immuno-inflammatory medication. This kind of substitute therapy brings a better life quality to the patient, when he is well oriented, which offers a better social and economical rehab with a low social cost.4

Therefore the transplant comes as a complementary contribution to improve health and life conditions of patients that still have no cure for their diseases.5

The patients are frequently exposed to the risks of kidney graft rejection. So it is important to be well informed to survive from the real possibilities of rejection and adapt in his new way of life, without hemodialysis but reliant of the daily routine of immune-inflammatory medication. Although the transplant brings a much better quality of life for the patient releasing him from the machine of hemodialysis, it compels him to adopt a different way of life forcing him to change hygiene, feeding, medication and cares habits.6

The relationship between the medical staff and the patient is an important issue that might be able to predict a better healing compliance. It is important to understand the aspects related to the perceptions of the chronic renal patients subordinated to the kidney transplant. They can be used as a material for strategies to be followed by the different members of the multi-professional staff, helping to develop programs to prevent and tackle the real needs of these patients.

It is believed that, as we elaborate our knowledge about the questions related to the caring of transplanted patients we improve the health services creating the possibility to re-think our practices and improve the quality of assistance for this public.

Facing this problem, a oriented study was organized for the following research question: Which are the perceptions of transplanted patients and healthcare professionals about the Kidney transplant? The aim of this study is to make an analysis of those perceptions about the renal transplant.

METHOD

Article originated from a paper thesis made in the conclusion of Graduation <<Kidney Transplant: perceptions of transplanted patients and perceptions of healthcare professionals>> presented in the Graduation Course of Nursing in the Federal University of Santa Maria. Santa Maria-RS, Brazil. 2014.

An exploratory study, describing in a qualitative approach5, undertaken in a hospital located at the south region of the country.7 The ones subordinated to the research were patients that received their transplant from donors that were alive or brain death donors and also healthcare professionals who work directly with those patients.

As a criteria of inclusion to transplanted patients it was considered: patients who received a transplant who had been subordinated to hemodialysis for a period of, at least, six months; patients who had received their transplant from a donor (alive or with brain death) for equal or over one year, older than 18 years old, who were assisted in the hospital and were psychologically able to answer the research.

In connection with the healthcare professionals it was traced the following criteria of inclusion: the healthcare professional would be working in the Kidney ambulatory or/and in the Nephrology Unit for a period of at least six months, not considering which kind of formation, nurse or doctor, the professional was. The number of participants obeyed to the criteria of saturation of data, which were a total of 16 transplanted patients and 14 healthcare professionals. Among them, we interviewed
three doctors, three graduated nurses, four technical nurses and four auxiliary nurses.

The data was collected in October and November of 2013 from a semi-structured survey interview. Every person was individually interviewed in an appropriate room reserved in the hospital where they were encouraged through opened questions to report their own perceptions about the treatment.

In the aim to register extensively the reports of the interviewed, the interviews were recorded by a digital recorder, which assured to give a reliable and rich report having an average duration of 12 minutes each. Afterwards, the interviews were registered and copied by a text editor program. The number of interviewed professionals was considered enough when the aim of the research was reached.

The prospects were identified by a code and received a numbered sequel. Therefore, the patients were identified by the letter (P) for patient, followed by the numeric order (P1, P2, P3...). The healthcare professionals were identified by their professional category letter and also followed by a sequential numeric order. (D1 - doctor 1; N2 - nurse 2; NT3 - technical nurse 3; AN4 - Auxiliary nurse 4).

The data was analyzed according to the content analysis9 reference proposed, which obeyed the following steps of organizing material and make a pre-analysis (fluctuating reading of findings); organizing categories analysis (based in readings and substantial scientific material); and interpretation analysis, with an interpretation from the authors and discussion with a pertinent literature.

This study firmly respected the ethical aspects of researching, according to the norms and regulatory statements of research involving human beings.10

Such implication relies on keeping anonymous the names of the people involved in the research and also implies explaining the aims of this research that were taken. The Committee of Ethics approved the research for Research (CAAE), code: 18933613.0.0000.5346.

RESULTS AND DISCUSSION

We interviewed 30 subjects, having 16 transplanted patients and 14 healthcare professionals. Among the patients there were nine women and seven men, with an age group range varying from 36 to 66 years old, and having received the transplant from a range of time of a year until 23 years from the surgery. The time range of hemodialysis treatment was between six and eleven years. Most of the transplanted organs were donated from death brain donors.

Among the healthcare professionals, there were 4 male and 10 female, 4 were specialized in nephrology. The age group range varies from 31 to 62 years old. Their working time in the hospital vary from three to 30 years old, and their specific time working at the nephrology unit was between two and thirty three years old.

All the data collected from the group were divided in three categories and they address the changes in the patients' lives since their renal transplant and especially the difficulties found after the transplantation and the treatment compliance.

 Generated changes caused by the kidney transplant

The transplant is not a cure for the disease, but it is a kind of treatment that helps the patient to live with more autonomy and freedom. This therapy implies in some great changes, when it is compared to other renal treatments, and it is considered to be an important therapeutic resource. Despite the surgery doesn't cure, it gives a new perspective of life.11

The patients say that, before their transplant, their lives suffered from some difficulties related to eating restrictions, water restriction and eventually hospitalization caused by the treatment and some routine activities. Besides, the patient depends on the machine to survive and he often suffers from worries and anxieties related to his treatment and cares.

On a certain measure, the patient becomes dependent from the technology of hemodialysis and also dependent from specialized trained professionals who maintain this technology after being subordinated to its treatment. For the patient, the hemodialysis machine represents the maintenance of his physiological homeostasis, which also symbolizes his life support.12

The interviewed, patients and professionals related some limitations demanded by the hemodialysis treatment:

Hemodialysis patients are not able to do a thing, they are only alive. But if you are not doing the treatment you die, they can't discuss, there are no argument about it. You are alive but nothing more than that, you have no will. (P6)

[…]. things have to be planned. You are living through a constant threat, you have to care about what you eat, what you drink,

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the quantities of salt, potassium ... This is a load for a person’s life, not mentioning the thirst ... people without this kind of limitation hardly can imagine what it is. (M2)

It depends on the type of dialysis they make, they complain a lot about the punctures. In the hemodialysis they feel very much imprisoned at home by the machine by a bag, they feel jailed in a way and they feel depressed. (TE2)

In a hemodialysis program the patient is obliged to go through a painful treatment which demands long hours depending from the individual needs and from which program his needs, involving three or more days during the week. This treatment may cause significant limitations and the evolution of the disease and complications altogether may bring a relevant impact into the patient’s life and family.13

It is generally accepted that dialysis treatment needs to have many specific cares, which generates restrictions and feelings of anguish. In the opposite way, the kidney transplant is a form of treatment that creates great hopes to the patients desiring not to depend on the hemodialysis and also desiring to have a better quality of life. This way of treatment allows the patient almost to have a normal life, with greater freedom just being supported continually by the immuno-inflamatory medication.14

Most of the interviewed refers to the kidney transplant as a new opportunity of life giving their lives back. The renal transplant brings to the life of the patients with chronic renal insufficiency some changes mentioned by them such as the feeling of being restrained, the special cares for eating and water drinking, their will to have their social life back and their normal activities of working and routine affairs that were prevented from being done since they started their treatment, as it was recorded in their testimonies:

Oh, it made a big change in my life. Now I have more freedom to be with my family and I am able to do my things [...] to plant my little garden. Before that I could not do anything, I only stayed in my bed. (P14)

 [...] a grande e principal melhoria é a liberdade, a independência, o tempo livre para a pessoa poder continuar suas atividades produtivas, a qualidade de vida, eles se livram daquela rotina de hospital, de didilise e da hemodiálise. (E1) [...] It is quite different. It is a free life; I can eat whatever I want and I can drink a lot of water, I can go to a party. Before I could not eat some things I have to avoid because of potassium [...] now it is much better. (P12)

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[...] The greatest and main improvement is freedom, independence, free time to let people continue with their productive activities, it is a much better quality of life, they get rid of the routine of hospitals, hemodialysis and dialysis. (E1)

According to the interview of patients and healthcare workers there is an agreement of thoughts related to the benefits of kidney transplants. Most of interviewee describe a strong correlation improvement of life satisfaction received after the procedure of kidney transplant.

It is notable the sensibility from the professionals once they seem to have a clear vision from what it means to the patients and which are the implications from the process for the patients with the transplant made. This is extremely important since those professionals have to maintain a close relationship with the patients and also it conceals an important role in the procedure for orientation and help for establishment of autonomy and self-care.

A well-succeeded kidney transplant is attested by a significant improvement of the quality of the patient. Despite of the probability from a common variety of complications after this procedure rehabilitation is much higher than any of those other therapeutic dialysis procedures.15

Difficulties found after the renal transplant surgery

The patient needs to adapt to a new routine facing a new reality and dealing with other cares that are essential to the success of the treatment. Even providing a better quality of life to the kidney transplanted patient it results in some adversities to the new adaptation treatment process.

The first three months after the surgery are considered the most critical ones, due to the risks of surgery, early complications, infections and cardiac disorders events. This moment of the surgery the patient faces a higher risk of death. After this period of time, the risks are reduced also showing an improvement of life expectancy in comparison to the patients who did not receive the transplants.16

For the adequate following of the treatment the main recommendations and cares to the patient are: proper use of the medication necessary, attending to the regular clinical booked consultations, follow the diet prescriptions as well as monitor the vital signs, regularly practice body exercises, prevent from obesity, avoiding smoking and drinking alcohol aside from hygiene special cares and infections controls.17
The patient must follow these recommendations to keep the kidney graft and have a longer life, turning these cares procedures into a daily routine. But there are some patients that feel some uneasiness to adapt especially in the beginning of the treatment. The most relevant testimonies indicating difficulties were: access to the medication, feeding control, side effects from medication and the worries to maintain the kidney graft:

For me, the hardest was the issue of eating. Other could drink beer and I couldn’t, they could eat something with fat and I couldn’t. I tried to get into the swimming pool to forget and I got an allergy through the whole body. (P14)

After the transplant surgery despite there were many infectious events they were much weaker than before, and I am almost reaching 20 years old from the surgery, we know there is a cyclic period of infection events and if I have one more […] well, if I am healthful I will go cross it. (P15)

The patients subordinated to the surgery have to comply with a strict medication scheme, which side effects may bring some psychological and physical changes. For this reason, it is important to give orientation after the surgery transplant about the need of taking medication to the survival of the kidney graft. One of the identified problems by the healthcare professionals and refrained in their testimonies is the difficulty to make patients follow their medication treatment:

The continuous use of medication is a major difficulty after the transplant because the patient gets tired of using it and they are tempted of stopping it. The use the medication and then comes a time they do not want to take it anymore, the hardest problem is to continue to use the medication. (E2)

More often doctor’s appointments, transportation, slightly recent side effects from medication, even physical deformities caused by the corticoid having an aesthetic impact such as acne, rush, loss of hair, obesity. Today we use less corticoid but still it is a problem. (M3)

Among the difficulties highlighted by the interviewed, the access to medication after surgery was also something quite mentioned in the report. Patients become dependent from high costs medication, once to have access of free drugs they periodically need to renew their prescription from the public service which is hard to be attended.

It is important to highlight that, in Brazil, a person having a chronic renal insufficiency has free access to the treatment and also free access to his remedies. Yet it is sometimes hard to have access and be attended by this public service that can affect the sustaining of the treatment. Because of it, some patients who did not get their drugs in the public service end up looking for medication in the private sector with the intention to keep their treatment and not taking the risk of loosing their kidney graft:

I think the biggest difficulty is about their drugs, even the coordination warehouse department for receiving the medication, because they apply for it but then it does not come in the right time required. (TE2)

After surgery, the staff continues acting to give medication, if there is no medication in the warehouse they usually get them in the nephrology unit, and then nobody gets affected from not having it. If the unit is empty they make a request for the warehouse, nobody is left without it. (TE4)

In light of this context, the awareness of the multi-professional staff about this process and the main difficulties lived by the patients; it contributes in a significant way for making an effort to emphasize the guidance as well as to establish joint actions, which can minimize such problems.

For such, it is essential to establish a strong link between the staff and places to hear suggestions, because this creates opportunities in a dialogical relation that can result in a greater compliance for the treatment.

The compliance of the treatment

The compliance of treatment involves an extension of aspects that will directly affect the obtaining therapeutic results. One of the routine actions and cares they definitely should follow is the immuno-inflammatory therapy besides many other procedures that influence directly or indirectly on the success of the kidney graft. The development of the therapy, in the later years has guaranteed a greater safety for the patient enhancing the benefits of the transplant.16

The comprehension of the interviewed showed that the non-compliance for the necessary cares after surgery, as well as to forget to take the medication and the lack of attention to care with health may bring complications and compromise the functioning of the kidney graft.

I walk six kilometers a day, I take care of my food and salt, I avoid certain things, I seek to sleep well, no intent of being mad, I do not drink alcohol, even the medication is influenced by all of it. (P13)

My attention is mostly about taking medication on the right time and the right dosage of it, attempting to suspend on the right days written in the prescription. Any

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problem brings me directly to the unit of nephrology! (P3)

Most of time the compliance is good, because we have been working hard on it: The importance of following the treatment and risk of rejection. So, the compliance has been good. (M1)

The transplant is a treatment that requests the following of cares, which are indispensable for the patient to benefit from the transplant. Its misuse or non-use is one of the factors that increase the numbers of death and reduces life quality, raising health costs and causing an excess of utilization for the public healthcare service, and it might be causing death and failures in the kidney transplant treatment. 13

Concerning to the compliance through medical therapy in general, the rate of compliance is satisfactory for the patients who report to have greater difficulty to follow the eating restrictions. Some patients mentioned that committed some mistakes and are not completely following some recommendations which were highlighted in their testimonies:

I am quite lazy, but I say this, but I drink a great deal of water and I walk and get fit. Sometimes I miscarry what I eat, but it is not a great thing. (P.5)

If the person is lazy already with his other things or other treatments, she will not comply, or she will do it for some time, but at the moment she feels fine, she will stop thinking she won’t need that anymore. (E2)

The youngsters think it is not going to be a problem. You explain but, actually, we see they do not get their treatment in a proper way, they don’t worry about if they are going to be without medication, they don’t worry to anticipate asking for it, to come and take it, to look forward for it, but even though there are some who do it. (TE1)

One of the identified problems was the difficulty for some patients to follow the treatment in a regular and systematic basis. This debate of ideas makes it possible to have a more effective action, for the staff, since both of sides, patients and workers, have a perspective from the main difficulties found in the treatment.

For the patients, their non-compliance have an impact of the increasing rates of deaths and decreasing quality of life, and might cause a rejection in the graft. That resembles the need of the constant actions of the healthcare staff; enhancing the importance of the compliance and making strategies that will search for better results to improve the patients cares after surgery.

We highlight that the non-compliance of the diet program prescript can lead to a metabolic unbalance, and more frequently, obesity joined by diabeto-genesis associated to immuno-inflammatory disorder, occurring diabetes, increasing the risks of death. The implementation in the programs of transplants of educational actions to the patients and their families with an effective intervention from the hospital dietician staff may contribute to minimize this problem. 18

The recent after surgery patients have shown a better compliance to the treatment, the reason as a possible explanation for this, is the fact that in an initial period of after surgery the patients are more thoughtful in relation to the therapy, since they may remember clearly their hemodialysis sessions, as well as willing to show some gratitude in respect to the transplant procedures. Another fact that contributes to a higher rate of compliance is that, in the beginning, the hospital’s consultations are the occasion where the need of the attention to commit with the therapy is emphasized. 19

The commitment to the treatment is a complex process that not only involves a professional effort but mainly a compromise from the patient, which is the greatest factor for effectiveness of the transplant. Besides, it is directly connected to attitudes taken by the healthcare professionals. The healthcare workers need to identify the main barriers that keep patients from following the treatment and give instructions for their patients with strategies to overcome them, in the aim to raise their compliance rates.

The nurse professional, in special, for having a closer relationship and for being a reference to the patient must be well informed with scientific knowledge and use it in a educational manner. This way, the nurse may better guide the patients from their restrictions and tasks in the treatment, stimulating changes in their behavior and preventing them from having possible complications, as education is a great strategy to be broadly applied.

For the healthcare staff it is important to be aware of the singularity and particularity of each patient, to know which aspects these patients submitted to the kidney transplant give more value to may constitute a start point to the elaboration of educational measures, and a development of preventive programs, adequate interventions and a following for the needs of these patients.

The compliance to the treatment is the main factor, in an individual level, which guarantees an adequate answer to the
treatment. Therefore, to reward the compliance for the treatment must be a constant practice among the health professionals. The recommendation is that the healthcare professional make open questions to identify factors related to the compliance, and elaborate counseling without judgments, creating bonds of trust with the patients.

It is important to observe that healthcare professionals who dedicate themselves taking more time in each attending consultation have better results of valorization and compliance from their treated patients.20

Another important aspect mentioned by the staff is a need in certain cases of a psychology professional to a constant assistance for a patient evaluation, especially before surgery, but also on the first days after the transplant surgery, because the patients usually show a need for psychological assistance.

The realization of a transplant usually generates moments of great expectations for the patient, arousing feelings of uncertainty plus followed by fear and anxiety caused many times by the little amount of information the patient have about this therapeutic procedure. The psychological aspects from the patient are remarkably involved in this matter and may cause emotional instability due to lack of knowledge from the population in general and this may be originating anguish.21

The compliance is directly equivalent to the relation established by the healthcare professionals and their patients. Therefore it is important that these workers concentrate in build a dialogue with their patients making use of a clear language, individualizing treatment and caring to every single one in particular, having in mind a great respect from their cognitive capacities, their cultural beliefs and their economic status.22

Confronted with this, there is no ideal program to be followed, what is important is to create strategies that can be adopted having in mind the facts and circumstances, the individual characteristics from the patients and also the characteristics from the healthcare professional.

**CONCLUSION**

The renal transplant is considered one of the best kinds of treatments to the patients with chronic renal insufficiency. Both treatments hemodialysis or kidney transplant generates deep transformations in the daily life of the patients, as well as to their self-image, self-valorization and into his meaning of life.

The perceptions from the interviewed about the renal transplant highlighted testimonies from those changes after the surgery transplant that related as they experienced again a life very close to an ordinary life, without so many restrictions and limits that are requested in a hemodialysis treatment. They indicated the recovery of their health and freedom as the most relevant points. The possibility to perform activities that were restricted before and were not possible to be done anymore brings for them a great sensation of satisfaction and autonomy, even considering the cares they will need related to the body, dietary and the immunoinflammatory medication, we realize that their conditions of health and life improve considerably after the kidney transplant.

For the effective success of the transplant it is essential that the staff actively participates since the pre-operation period as well as after the surgery and eventually in hospital stays. It becomes necessary to orient and stimulate the patients to adapt in a positive manner in their new style of life.

The staff must stimulate changes of attitude for the patient to him to take control of his treatment and his life in face of the kidney transplant. We realize that the ethical, coherent, tolerant, friendly and welcoming behavior from the healthcare staff brings a guidance that is fundamental to the establishment of a connection of confidence for the treatment which facilitates the cooperation from the patient and a greater compliance to the treatment.

It is notable the importance of the staff working together, considering that the health service is a complex structure in different stages of attention, even so because every assistance given to the patient requires an specific qualification from each member of the staff for attending the needs of the service user.

We hope that this study may benefits concerning the discussions and thoughts about the kidney transplant. Knowing the perceptions of patients and the perceptions of the staff may serve as a tool for a better understanding of the individual needs of the patients and, it may be resourceful for the healthcare professionals to act in a more directed and possible re-organization and re-orientation for some care services they hold to assist their patients.

Furthermore to comprehend the perceptions of patients and from the staff
gives a certain degree of specificity with whom the work is done and may also assist to coordinate the staff in a more efficient manner, administering the nursing actions, discussing demands from the staff and from patients and implementing more efficacy into an identified problem.

The limits of this study refer to the specificity and complexity of the theme, and the scarce quantity of researching with this population highlighting the need of new scientific researches with patients in these conditions to supplement and guide the approaching manners of the healthcare service in the kidney transplant process.

We suggest that new studies sprout and amplify the debate about the perceptions of the renal transplanted patient and his interaction with the healthcare staff contributing therefore to build a growing foundation of knowledge for health and nursing.

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