PERCEPTIONS OF CHRONIC KIDNEY PATIENTS IN THE REFUSAL OF THE KIDNEY TRANSPLANTATION

PERCEPÇÕES DE PACIENTES RENAI CRÔNICOS NA RECUSA AO TRANSPLANTE RENAL PERCEPCIONES DE PACIENTES RENALES CRÓNICOS EN LA RECUSA AL TRANSPLANTE RENAL

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ABSTRACT

Objective: to learn the reasons that lead patients with chronic kidney disease to refuse kidney transplantation. **Method:** this is a qualitative, descriptive and exploratory study of 22 patients submitted to hemodialysis at a Center for the Treatment of Renal Diseases. A semi-structured interview was used, transcribed and submitted to Content Analysis in the Thematic Analysis modality. **Results:** it is noticed that after the content analysis for the organization of the data, the categories "Feeling guilty for wanting someone's death and concern for the life of the living donor" emerged; "Financial implications and delay in carrying out the transplant" and "Adaptation to hemodialysis treatment and uncertainties regarding transplantation". **Conclusion:** it was observed that several reasons influence the refusal for renal transplantation, such as financial and bureaucratic issues, fear of surgery and its prognosis influenced by the knowledge of negative experiences of transplanted patients, fear justified by adaptation to dialysis treatment and some comorbidities, as well as the guilt for wanting an organ. Health professionals play a key role in clarifying the transplant so that these patients make a conscious decision about the treatment. **Descriptors:** Waiting Lists; Kidney Transplantation; Fear; Uncertainty; Kidney Failure Chronic; Organ Transplantation.

RESUMO

Objetivo: conhecer os motivos que levam os pacientes com doença renal crônica a recusarem o transplante renal. **Método:** trata-se de estudo qualitativo, descritivo e exploratório realizado com 22 pacientes submetidos à hemodiálise em um Centro de Tratamento de Doenças Renais. Utilizou-se uma entrevista semiestruturada transcrita e submetida à Análise de Conteúdo na modalidade Análise Temática. **Resultados:** percebe-se que após a análise de conteúdo para a organização dos dados, emergiram as categorias "Sentimento de culpa por desejar a morte de alguém e preocupação com a vida do doador vivo"; "Implicações financeiras e demora na realização do transplante" e "Adaptação ao tratamento hemodialítico e as incertezas quanto ao transplante". **Conclusão:** constatou-se que vários motivos influenciam a recusa para o transplante renal, como questões financeiras e burocráticas, o medo da cirurgia e do seu prognóstico influenciado pelo conhecimento de experiências negativas de pacientes transplantados, o medo justificado pela adaptação ao tratamento dialítico e a algumas comorbidades, bem como a culpa por desejar um órgão. Os profissionais de saúde têm papel fundamental no esclarecimento sobre o transplante para que esses pacientes tomem uma decisão consciente acerca do tratamento. **Descritores:** Listas de Espera; Transplante de Rim; Medo; Incerteza; Falência Renal Crônica; Transplante de Órgãos.

RESUMEN

Objetivo: conocer los motivos que llevan a los pacientes con enfermedad renal crónica a rechazar el trasplante renal. **Método:** se trata de un estudio cualitativo, descriptivo y exploratorio realizado con 22 pacientes sometidos a la hemodiálisis en un Centro de Tratamiento de Enfermedades Renales. Se utilizó una entrevista semiestructurada transcrita y sometida al Análisis de Contenido en la modalidad Análisis Temático. **Resultados:** se percibe que después del análisis de contenido para la organización de los datos, emergieron las categorías "Sentimiento de culpa por desear la muerte de alguien y preocupación por la vida del donante vivo"; "Implicaciones financieras y demora en la realización del trasplante" y "Adaptación al tratamiento hemodialítico y las incertidumbres en cuanto al trasplante". **Conclusión:** se constató que varios motivos influencian la negativa para el trasplante renal, como cuestiones financieras y burocráticas, el miedo a la cirugía y su pronóstico influenciado por el conocimiento de experiencias negativas de pacientes transplantados, el miedo justificado por la adaptación al tratamiento dialítico y a algunas comorbidades, así como la culpa por desear un órgano. Los profesionales de la salud desempeñan un papel fundamental en la aclaración del trasplante para que estos pacientes tomen una decisión consciente sobre el tratamiento. **Descritores:** Listas de Espera; Trasplante de Riñón; Medo; Incertidumbre; Fallo Renal Crónico; Trasplante de Órganos.

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INTRODUCTION

Chronic Kidney Disease (CKD) is a public health problem in Brazil and in the world evidenced by the increase in its incidence and prevalence over the years. CKD is characterized by the failure of functional nephrons, progressively and irreversibly, with a high morbidity and mortality rate. Its etiology is multifactorial, treatable, through various modalities, controllable, however, without cure.¹

To reduce the signs and symptoms, as well as to establish the control of the disease, forms of treatment that include: drug therapies, dietary therapies and Renal Replacement Therapies (RRT) have been developed. Peritoneal dialysis, hemodialysis and renal transplantation are the modalities of RRT available to the patients affected by the disease, allowing the maintenance of the individual's life, but they do not result in a cure.

Dialysis consists of a treatment for the removal of excess fluid and toxic substances from the body through high technology equipment, which accompanies several restrictions, consequently bringing considerable changes to patients' daily lives.²⁻³

Kidney transplantation is defined as a surgical procedure for the donation of kidneys from one individual (donor) to another (recipient) in order to replace or remedy kidney function lost by CKD.⁴ This treatment is pointed out as the best therapeutic modality due to the lower cost to the health system and offers a better quality of life when compared to other methods, thus enabling a more independent life outside the hemodialysis machine and offering to these patients, better autonomy.⁴⁻⁵

It is known that individuals submitted to transplantation have greater dietary and water freedom, feel healthier and have better social rehabilitation. However, the choice of therapy should be individualized by analyzing the clinical, psychic and socioeconomic situations of the individual.⁴⁻⁵

In 2017, 5,929 kidney transplants were carried out in Brazil: 1,136 with a live donor and 4,793 with a deceased donor. In Bahia, 137 transplants were carried out, 18 with a live donor and 119 with a deceased donor. In December of that same year, in Brazil, 21.059 patients were active on the waiting list and 838 were in Bahia.⁶

It is revealed that with the accomplishment of the transplant, the patient longs for a normal life within the possibilities, since a

rigorous self-care is fundamental for the success of the treatment. Even though it is a therapy recognized for its effectiveness, the surgical treatment in question can bring uncertainties about its effectiveness and duration due to the risks and complications that it can present.³⁻⁵

It is therefore important that health professionals begin to understand the patients' perceptions of CKD, taking into account their biopsychosocial context, about renal transplantation, aiming at an interaction in order to collaborate to better meet their needs. Individuals aiming at orientation based on the main doubts and difficulties that permeate the performance of the transplant.

OBJECTIVE

- To know the reasons why patients with chronic kidney disease refuse kidney transplantation.

METHOD

This is a qualitative, descriptive and exploratory study carried out with individuals undergoing hemodialysis at a Center for the Treatment of Kidney Diseases in the Piedmont Norte Territory of Itapicuru (BA), a private administrative institution, which provides services to the Unified Health System (UHS) in the care of patients with renal diseases offering the services of hemodialysis, peritoneal dialysis and outpatient Nephrology.

There is a multiprofessional team in the clinic, which includes 38 hemodialysis machines, and patients are treated in the three shifts, from Monday to Saturday.

They were listed as inclusion criteria for this study: renal replacement therapy for at least three months; have 18 years or more; have a medical indication for kidney transplantation; not being on the waiting list for kidney transplantation and presenting conditions to express themselves verbally. Patients who did not sign the FICT or refused to participate in the study were excluded from the study.

A total of 206 patients undergoing hemodialysis were treated at the clinic during the study period. Of these, 16 were enrolled on the waiting list for renal transplantation and 45 had no clinical indication to perform the transplant, resulting in 145 patients that met the inclusion criteria. It is reported that the researchers had the help of the professionals of the service to identify the patients that would be excluded by the criteria already mentioned.

Twenty-two subjects who were invited to participate in the study were randomly selected from the different shifts where patients underwent hemodialysis. In order to determine this number of interviewees, the information saturation criterion was used, when it was identified by the researcher that the statements began to present similarity or repetition in the responses.

The data was collected from August 14, 2017 to September 26, 2017 through a semistructured interview, a method of data collection that combines closed and open questions and the interviewee can discuss the proposed topic without answers or fixed conditions by the researcher.⁷

Patients were interviewed at each hemodialysis point individually, recording and subsequently transcribing in full the content in the text editor. Participants were made anonymous by replacing their names with the letter "P" followed by sequential numbers according to the interview order (P1, P2, P3 ...). The interviews were conducted on the following thematic axes: the knowledge and perspectives patients had about kidney transplantation.

Therefore, the data was submitted to the technique of Content Analysis, proposed by Bardin, which consists of pre-analysis, exploitation of the material, treatment of results obtained and interpretation, emphasizing the thematic analysis.⁷

The research project was approved by the Research Ethics Committee of the Bahiana School of Medicine and Public Health (FBDC) under the Certificate of Presentation for Ethics Appreciation (CPEA): 66646817.5.0000.5544 respecting the ethical principles that involve research with human beings. All the participants were informed about the objectives of the study and they signed the Free and Informed Consent Form.

RESULTS

Twenty-two participants, aged between 27 and 73 years (mean age 52.1 years), predominantly female, with fifteen participants. As to color, eleven were self-referred as brown; five, white and six, black. In relation to the marital situation, thirteen were married; two, separated / divorced; six, singles and one widow.

Seventeen patients considered themselves Catholics and five were evangelicals. Family income ranged from one to four minimum wages and the majority received social security benefits (CSB - Continuous Service Benefit). In terms of schooling, nine were

illiterate, nine had incomplete elementary education, three had completed high school and one had completed tertiary education.

The majority of respondents were affected by the underlying diseases: Diabetes Mellitus type 2 and chronic hypertension. With regard to renal replacement therapy, all participants underwent hemodialysis and the treatment duration ranged from one to thirteen years (mean of 6.3 years).

The discussion of this research was composed from the methodology used, emerging three categories that made the discussion of this research: 1 - Feeling guilty for wanting someone's death and concern for the life of the living donor; 2 - Financial implications and delay in carrying out the transplant and 3 - Fear of the possibility of a new treatment. The latter was divided into four thematic units: Adaptation to hemodialysis treatment and uncertainties regarding post-transplant results; Fear of the surgical procedure justified by the comorbidities associated with CKD; The fear generated by the negative experiences of transplant patients and the fear of receiving an organ from a deceased donor.

♦ Category 1 - Feeling guilty for wanting someone's death and concern for a living donor's life

It is noteworthy that the participants showed a fear of wanting a transplant, either living or living with a deceased donor. They expressed a sense of guilt for imagining the living donor undergoing an invasive procedure or at risk of becoming ill and even dying. My brothers are hypertensive and can not do it, my children are still young, I do not want to, no, I'm only 19, it can be hereditary, right? (refers to CKD)? (P02)

I feel like I've been wishing death to the other to be able to happen to me because it has to be from a corpse, right?? [...]. (P05)

[...], I do not feel comfortable with "you" gives me a kidney and I accept because, first, I'm going to leave the machine and you get a kidney, and if you get sick of the kidney tomorrow? There you go to the machine? How does my conscience stay? So, I would not want to do that ever with anyone, [...] I'm here of my own free will, I have nothing to complain about. (P15)

I have a son in his early 50's and he said he was giving and I said no, [...] Leave it to me because I'm already used to the treatment and the disease, too. Because I think so, if he gives, he will suffer too, right?? (P20)

♦ Category 2 - Financial Implications and Delay in Transplantation

It has been shown that some patients have tried or had an interest in enrolling in the list,

however, the financial and bureaucratic issue involved refusal or withdrawal for treatment.

If it were not for the difficulty of the exams, because they are many exams they pass and for us [...] it is all private. [...], because we already have the treatment here and still run after several exams, because it is very examination, so, I myself am not able to do [...] (P1)

The transplant is good, the problem is the financial conditions that is difficult, right? And the exams are only worth a year. When you finish doing it, if it is by the UHS, the former no longer pay. That's why I never got it. Because it's difficult, if it's UHS, it will not. And for you to pay is complicated. (P2)
[...], I've made a test run for Juazeiro and it's there to this day [...]. Spend too much. You have to go to Salvador, spend money from your pocket. I do not want. If they did all the exams, right? [voice of indignation]. (P21)

It was also noticed that the time of the waiting list recipients is uncertain and this discourages them, because without the certainty that they already have an organ available to receive, patients fear the expenses to enter the list by tying them to the delay in finding a compatible kidney.

I'm going to take the exams, I'll stand in line, nobody knows if it's a year, two, three or four or five, and I'm in that emotion and it can be even worse for me. (P11)

Because it is difficult for me, I found it easy only if I had a donor and, also, there is another problem, it is a test run. (P13)

Oh, it's hard. The donor is difficult [...]. (P21)

Category 3 - Fear about the possibility of a new treatment

♦ Thematic unit 1 - Adaptation to hemodialysis treatment and uncertainties regarding transplantation

Doubts are raised regarding the adaptation to hemodialysis in patients regarding transplantation, since they are already accustomed to the routine imposed by the disease.

I do not want it at all. Leave me alone because I'm already used to the treatment and the illness, too. [...], I'm afraid, I'm afraid, so ... they'll put something that does not work, then I'm afraid that's it. (P20)

I do not have the courage, fear of the operation, of taking the kidney, of throwing a kidney. The doctor even once asked me to give my name, the girls there (nurses) already asked to put my name, but I told them that I did not want to, because I'm afraid of everything. I know it's not a good thing for us to risk, right? (P14)

So the transplant, for me, is something like this, it's an adventure, it's good if you get lucky, I'll say, like, 50%. So let's say like that, you get off the machine and "let's do a transplant on him now" so you get off the machine, but it's not guaranteed. [...], I do no other treatment except dialysis, I do not want to. (P15)

♦ Thematic unit 2 - Fear of surgical procedure justified by comorbidities associated with CKD

It is apparent from the participants' statements that comorbidities associated with CKD are considered to be impeding the transplantation, since they assume that certain comorbidities interfere with the surgical treatment or prognosis.

If I were young, younger, and I did not have diabetes, it was just the kidney, I did, but I'm afraid beyond diabetes and kidney [...]. (P03)

I have diabetes, I think it's more complicated, right? It might not work [...]. (P06)

Once, I said that I wanted to, but then again, I said that I did not want to because my colleague said: that for the transplant I had to have two surgeries, one of the pancreas, that I had diabetes, and another one of the kidney, and then I got scared. Then, the next time he asked, I said, "I do not want to." [emphatic voice] (P12)

Those who cannot do it, do not do it, as I can not do. Because I'm diabetic and all, high blood pressure and everything. My diabetes is very high, I do not even get into it. (P22)

♦ Thematic unit 3 - The fear generated by the negative experiences of transplanted patients

Through the statements of the participants, the fear of complications, rejection of the graft, and even of death, is something that is thought by the individual in the decision-making to join the waiting list.

[...], but I have also seen colleagues in the room, who go do it again and come back in a coffin. (P03)

What I think is because there are many people who do and it works and there are others who do and do not come back anymore. Passes away. [...] I am afraid, I am afraid of dying. [...] one did, when it was a month, inflamed and died, is a friend of ours who was with us, there, did not work. It was a good month there, it got worse and died. (P07)

[...], because I'm afraid of the surgery and says that if you get any infection, you say you die, right? [...] we had a friend who did

it and it was his brother who donated it and then, when he finished doing it, he did not last for a month and then he died. (P09)

♦ Thematic unit 4 - Fear of receiving an organ from a deceased donor

Fear of receiving a kidney from a "stranger" by the participants presented. For some patients, there is a greater probability of rejection or death due to the fact of receiving an organ from someone who is not of the family.

[...], I do not know ... I find it difficult. If it's family people, I think it's easy, I think. I have a mother, I have a father and a brother, but they can not give. So, so, of the others, I think it's hard to work, I think so. Because I think so: "we who have" original (kidney) happened what happened, imagine of the other (kidney of another person) [...]. (P05)

[...], the corpse transplant, for example, I was in the clinic, there, soon they arrived and: "Look, you have to go to Recife now to do a transplant because you have a kidney there waiting for you"; you do not know if that kidney is a young person, you do not know it yourself, but "they" (doctors) know if it's a really good kidney. [...], and it does not work, it can give rejection, it can die in the hour, it understands? (P15)

DISCUSSION

Non-transmissible chronic diseases are blamed for stressful treatments that involve adaptations and changes in the lives of individuals. One of the CKD's treatment options is transplantation. It is understood that for the accomplishment of the transplant, a deceased donor is necessary and this generates a confusion in the patients for supposedly they are desiring the death of somebody and, perceiving this desire, the remorse and the guilt come out⁸.

The decision-making of these individuals directly influences the decision-making process of these individuals, since they imagine the possibility of a living donor becoming ill and / or dying, as well as entering the list, the fear of supposedly wishing someone's death to achieve a viable organ for treatment. Such feelings generate a strong influence on the continuity of these patients on hemodialysis.

There are some patients in the transplant between living people in a conflict with the possibility of being transplanted, because the kidney that would give them a healthy life again could not be desired without endangering the health/life of another person. Because of this, they fear the guilt they would carry if something happened to

the donor, because there is concern about the life of the donor who will only have a kidney that can be affected by the CKD or, also, the fear of complications happening in surgery leading to sequelae and/or death.⁸

In a recent survey of donors and kidney recipients, recipient reactions to the opportunity to receive a kidney were described. They were surprised and rejected because of the difficulty in understanding the gesture of the donation, with feelings of ambivalence arising, because, at the same time that they felt that they had no choice and should accept the graft, they also faced guilt for supposedly withdrawing an organ someone who can make this donor susceptible to kidney disease someday.⁹

It is inferred that the financial implications and the delay in carrying out the transplant also culminated in the refusal of treatment. To enter the single list system, patients undergo the clinical evaluation including several tests such as: sodium dosage; potassium dosage; glycemia; biochemical and hematological dosage. In addition to these, specific imaging tests are still required for enrollment in a waiting list for a kidney, which are usually delayed by the UHS, leading patients to pay for exams for agility when they join the list.¹⁰

It is noted that there is the possibility that some patients are still unaware that the expenses arising from the exams are paid by UHS, which is the main funder of transplants in Brazil, and yet there are many difficulties of access. Currently administered by the National Transplant System, Brazil has one of the largest public organ and tissue transplant programs in the world.¹¹

There are gaps to be solved by patients, such as underfunding of resources, which is a structural challenge of the UHS, since guaranteeing and expanding access to these services depends on the availability of financial resources and this has repercussions on the difficulty of access to the HUS services by these patients.¹²

The State Incentive Policy for the donation of organs and tissues and promotion of transplants in the State of Bahia was instituted in 2015, by means of Portaria n. 1169, dated October 20, 2015, which allowed for a financial transfer for the State in order to reduce the difficulties involved in carrying out the transplants. It is observed that in addition to reducing waiting time for an organ, the patient's access to pre and post-transplant exams are among the main objectives of this ordinance, which, through structuring strategies, aims to increase the

number of donations, abstractions and transplants of organs and tissues in the State of Bahia.¹³

However, although there are protocols to guarantee access to more complex care, such as access to pre-transplantation exams and consultations, there is still a deficiency in care resources directed at the municipalities, with a higher concentration of these resources at the state level.¹⁴

Consequently, it is difficult for renal patients to enter the waiting list, mainly because it is a population where the majority are low-income, living in cities in the interior, away from the transplantation centers and, therefore, the displacements for the accomplishment of the examinations are configured as one of the obstacles for the accomplishment of the exams and / or consultations. In this circumstance, it ends up harming the patient even more, since the integrality of care becomes compromised.¹⁵

In a recent study, it was shown that, although transplants performed in Brazil are mostly performed by the public system, patients who have access to private care can be evaluated in a shorter time and, consequently, transplanted. On the other hand, individuals accompanied exclusively by UHS find it difficult to carry out the evaluation and all the examinations in a timely manner.¹⁶

It is understood that, while waiting on the waiting list, these patients undergo several situations. On the one hand, they envision the possibility of a new life, but over the years they experience feelings of frustration, hopelessness and disappointment due to the delay in receiving the organ.¹⁷ The delay is faced as a reality imposed due to the large number of enrollees compared to the small amount of organs captured.¹⁸

It is necessary that the health team, in particular, the nurse, due to the attributions of care inherent in their profession, establish a relationship of trust providing clarifications regarding the surgical treatment involving all its aspects, from the benefits, to the existing risks. In addition, they should report on the rights to free access at all stages of the transplant, as well as try to address patients' fears, concerns and anxieties regarding the possible delay in the waiting list so that a conscious choice is possible is safe.

It is seen, in addition to other reasons that lead to the refusal, the transplant also as something new and permeated by uncertainties. In this way, it is stated that insecurities and fears can arise when faced

with the possibility of performing a surgical procedure and / or putting something in the body that is not "his." The adaptation to the hemodialysis treatment allows the patient a physical and psychic stability with safety and real chances of staying alive. From this point of view, given the opportunity to perform the transplant, feelings that they experienced at the beginning of treatment reappear, such as fear and uncertainties of success.³

It is recalled that, faced with the discovery of the CKD, the patient undergoes complex physical and psychological modifications, which interferes directly in their lifestyle. Patients with renal disease gradually adapt to dialysis and find hope in the continuity of life, which suggests that transplantation may not be a safe option.¹⁹

It has been demonstrated in some studies with renal patients that they adapt and acquire safety in the dialysis treatment justifying their questions and choices in performing the transplant.³⁻¹⁷ Other studies have shown that patients see hemodialysis as something safe, which brings life, while transplantation is related to doubts and uncertainties.⁸⁻²⁰

In a recent study, reports of transplant patients on the significant changes after transplantation, such as regaining autonomy, without the numerous restrictions caused by hemodialysis, and the possibility of performing activities that were previously not possible, have been reported. with life approaching a normality bringing the feeling of satisfaction and freedom.²¹

In another study of post-transplant patients, they reported that they felt younger, with a sense of hope and self-confidence to overcome the difficulties posed by post-treatment. In addition, the benefits of mental and physical health were mentioned referring to the improvement in the mood and greater energy in the day to day. However, other patients also mentioned the difficulties and complications that the transplant can also bring expressing feelings of disappointment due to the long recovery time of the treatment and the life changes and continuous care necessary for the maintenance of the graft.²²

Although kidney transplantation is considered the most adequate treatment when compared to other modalities for CKD and many patients are able to progress successfully to surgical treatment, it still presents some risks to the health of the recipient, since it is a procedure complex, ranging from infectious and immunological

complications to rejection of the organism itself or even to relapse of the disease.²³

In this modality, essential care is required, such as the continuous use of immunosuppressants for the rest of the life, due to the possibility of complications/rejections that will interfere in the quality of life of the transplant.²³

It is important to emphasize, however, that, even without the need for hemodialysis, transplanted patients still live with a chronic disease and they need follow-up and continuous medication to avoid such complications.²⁴⁻²⁵

It was also found in this study with participants who refused treatment because they assumed that certain comorbidities prevented the transplant from being performed or that they would interfere with the prognosis of the procedure, however, as in any other surgery, contraindications are imposed by health conditions of the patient.²⁶

It is warned that Diabetes Mellitus and Systemic Arterial Hypertension are the main pathologies that lead to CKD accounting for 50% of cases of renal disease.²⁷ As a result, these underlying diseases are often referred to in social media or the dialysis service itself, which leads these patients to believe that they are contraindications to transplantation.

On the other hand, due to the fear and insecurity that the patients feel for not knowing the possible prognosis of the surgery, that the comorbidities are factors of contraindication and can be a way of justifying the refusal to carry out the treatment.

Diabetes Mellitus is defined as a contraindication when decompensated or associated with other conditions such as cardiovascular problems.²⁶ Systemic arterial hypertension, when uncontrolled, also presents risks for graft loss, since decompensated SAH causes tubular necrosis and other functional and/or structural complications of target organs.²⁸

It is also added that, regardless of the comorbidities that the patient has, prior to performing the surgery, the patient undergoes an evaluation to analyze if he has clinical conditions to perform a surgery and, if any alteration is identified that puts him at risk, the transplant will not happen and the next one on the list will benefit.

In the analysis of the list of patients contraindicated for transplantation, it was verified by the medical professionals of the dialysis service, at the time of data collection, that the patients interviewed did not appear

in the same, thus confirming the indication for the procedure.

Uncertainties, doubts and fears are generated through misinformation, which directly influences the participants' point of view about renal transplantation, thus contributing to the non-entry of these into the waiting list.

It is also seen that the surgical procedure presents some risks, complications and the possibility of death in the postoperative period. The main complications are of infectious and immunological origin. It is evidenced that in the first year after transplantation, many patients undergoing this treatment develop some infectious complication, which is an important challenge for the success of the procedure collaborating with the increase of morbimortality among these patients. The knowledge of these factors generates fear and insecurity contributing to the refusal to surgical treatment.²⁹

It translates to failure of the transplanted kidney as a difficult experience, which implies a return to hemodialysis, and changes in the lives of these patients are generated, since they believed that transplantation would allow a better quality of life away from the machine. The loss of the kidney causes those individuals to relive the experience of intense suffering from the initial phase of treatment feeling powerless and without choice, since they need to retake dialysis to avoid death.³⁰

It is then uncertainty to know negative experiences after transplantation, provoking a negative impact on the decision of these patients, which corroborates a study carried out in a dialysis clinic in Rio Grande do Sul where they affirm that the knowledge of these experiences causes the refusal of treatment.³

In addition to the aforementioned reasons, the return of a patient to hemodialysis can also have a negative impact, which points to the need for these patients to be aware of the durability of the transplant, the type of donor and the conditions organ.³ It is shown that performing the surgical treatment leads to expectations causing feelings of uncertainty, anxiety and fear, usually resulting from poor or misleading information about treatment.¹⁹

The lack of knowledge of the patients about the subject was captured, as well as the need for a follow-up by the team in order to offer guidance to these individuals. Clarifying guidance on therapeutic modality is essential for a better understanding of the risks and benefits that the procedure offers. In

addition, it is necessary to establish a moment of listening so that these individuals share their fears and afflictions in order to heal their doubts and questions about the subject.

CONCLUSION

It is concluded that, although transplantation is considered the best option among the treatments for CKD, there are still a large number of patients who refuse to enter the waiting line for a kidney. Several factors seem to influence this decision, such as fear of the unknown and the uncertainties that this treatment can bring, fear of transplant failure, adaptation to dialysis treatment, fear of receiving a deceased donor organ without being sure of good functionality the blame for receiving the kidney from another person, the negative experiences of other patients, the bureaucratic process and financial issues.

Thus, it is possible to know the perspectives of patients with CKD on renal transplantation, a better understanding of the individual needs of these patients, offering health professionals, especially nurses who are closest to patients, for a more intimate care directed to a holistic care in the health services that assist these clients, as well as the clarification of the doubts and erroneous information on the subject.

It is hoped that this study will lead to reflections and discussions about the treatment in question, since a better clarification is needed on all types of treatment available for chronic kidney disease, especially transplantation, so that, in a conscious and safe way, patients can choose their treatment.

This study was limited by the lack of researches with the subject studied. Therefore, further research involving these patients is encouraged in order to guide the health team's actions in the stages that cover renal transplantation, as well as to base the construction of knowledge, thus broadening the discussion about CKD and its respective treatments.

REFERENCES

1. Branco JMA, Lisboa MTL. Peritoneal dialysis treatment: self-care practice in the family context. *Rev enferm UERJ*. 2015 May/June; 23(3):344-9. Doi: <http://dx.doi.org/10.12957/reuerj.2015.5132>
2. Frazão CMFQ, Ramos VP, Lira ALBC. Quality of life of patients undergoing hemodialysis. *Rev Enferm UERJ* [Internet]. 2011 Oct/Dec [cited 2017 Sept 12]; 19(4):577-82. Available from:

<http://www.facenf.uerj.br/v19n4/v19n4a12.pdf>

3. Pauletto MR, Beuter M, Thome EGR, Girardon-perlini NMO, Camponogara S, Timm AMB. Patients' perception for kidney transplantation on hemodialysis out of waiting list. *J Nurs UFPE on line* [Internet]. 2016 [cited 2017 Sept 20]; 10(4):1194-201. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/11103/12567>
4. Associação Brasileira de Transplantes de Órgãos. Manual de Transplante Renal. [Internet]. Barueri: ABTO;2015 [cited 2017 Sept 22] Available from: http://www.abto.org.br/abtov03/Upload/file/Profissional_Manual/manual_transplante_rim.pdf
5. Brito DCS, Paula AM, Grincenkov FRS, Lucchetti G, Sanders-Pinheiro H. Analysis of the changes and difficulties arising from kidney transplantation: a qualitative study. *Rev Latino-Am Enfermagem*. 2015 May/June;23(3):419-26. Doi: [10.1590/0104-1169.0106.2571](https://doi.org/10.1590/0104-1169.0106.2571)
6. Associação Brasileira de Transplante de Órgãos. Dimensionamento dos transplantes no Brasil e em cada estado. Registro Brasileiro de Transplante [Internet]. 2017 [cited 2017 Sept 02]; 23(4):1-104. Available from: <http://www.abto.org.br/abtov03/Upload/file/RBT/2017/rbt-imprensa-leitura-compressed.pdf>
7. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 13rd ed. São Paulo: Hucitec; 2013.
8. Quintana AM, Weissheimer TKS, Hermann C. Meaning attributions to renal transplantation. *Psico* [Internet]. 2011 Jan/Mar [cited 2017 Set 25];42(1):23-30. Available from: <http://revistaseletronicas.pucrs.br/ojs/index.php/revistapsico/article/view/6057/6295>
9. Ummel D, Achille M. Transplant trajectory and relational experience within living kidney dyads. *QualitHealth Res*. 2015 Feb;26(2):194-203.Doi: <https://doi.org/10.1177/1049732315570128>
10. Ministério da Saúde (BR), Gabinete do Ministro. Portaria nº 2.600, de 21 de outubro de 2009. Aprova o Regulamento Técnico do Sistema Nacional de Transplantes [Internet]. Brasília: Ministério da Saúde; 2009 [cited 2017 Sept 02]. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2009/prt2600_21_10_2009.html
11. Silva SB, Caulliraux HM, Araújo CAS, Rocha E. Cost comparison of kidney transplant versus dialysis in Brazil. *Cad Saúde Pública*.

- 2016;32(6):1-7. Doi: <http://dx.doi.org/10.1590/0102-311x00013515>.
12. Viacava F, Oliveira RAD, Carvalho CC, Laguardia J, Bellido JG. SUS: supply, access to and use of health services over the last 30 years. *Ciênc Saúde Coletiva*. 2018; 23(6):1751-62. Doi: <http://dx.doi.org/10.1590/1413-81232018236.06022018>
13. Bahia (Estado), Secretaria de Estado da Saúde. Portaria n° 1169 de 20 de outubro de 2015. Institui a Política Estadual de Incentivo à doação de órgãos e tecidos, e de fomento à realização de transplantes no Estado da Bahia [Internet] Salvador: Secretaria do Estado da Saúde; 2015 [cited 2017 Set 23]. Available from: <https://www.escavador.com/diarios/181648/DOEBA/executivo/2015-10-22?page=21>
14. Albuquerque MSV, Lyra TM, Farias SF, Mendes MFM, Martelli PJJ. Accessibility to health services: an analysis of the Primary Care in the state of Pernambuco. *Saúde Debate*. 2014; 38(Spe):182-94. Doi: <http://dx.doi.org/10.5935/0103-1104.2014S014>.
15. Machado EL, Cherchiglia ML, Acúrcio FA. Profile and clinical outcome of patients in waiting list for kidney transplantation, Belo Horizonte (MG, Brazil), 2000-2005. *Ciênc Saúde Coletiva*. 2011 Mar; 16(3):1981-92. Doi: <http://dx.doi.org/10.1590/S1413-81232011000300032>.
16. Sidney Filho LA, Gentilli RML, Sogame LCM. O público e o privado em um procedimento de saúde de alta complexidade. *Salus J Health Sci*. 2016 Sept; 2(2):89-92. Doi: <https://dx.doi.org/10.5935/2447-7826.20160020>
17. Souza AM, Filipini CB, Rosado SR, Dázio EMR, Fava SMCL, Lima RS. Kidney transplantation: experience of men in hemodialysis entered on the waiting list. *Rev RENE*. 2015 Jan/Feb; 16(1):11-20. Doi: <http://dx.doi.org/10.15253/rev%20rene.v16i1.2658>
18. Cajado MCV, Franco ALS. Organ and tissue donation for transplantation: subjective impasses before the family decision. *Rev baiana saúde pública*. 2017 Sept; 40(2):480-99. Doi: <https://doi.org/10.22278/2318-2660.2016.v40.n2.a2164>
19. Cruz MZF, Salimena AMO, Souza IEO, Melo MCSC. Discovery of chronic kidney disease and everyday of hemodialysis. *Ciênc Cuid Saúde*. 2016 Jan/Mar; 15(1):36-43. Doi: <http://dx.doi.org/10.4025/cienccuidsaude.v15i1.25399>
20. Camargo VP, Quintana AM, Weissheimer TKS, Junges N, Martins BMC. Transplante renal: um caminho para a vida ou um passo para a morte?. *Rev Contexto Saúde*. 2011; 10(20):515-24. Doi: <https://doi.org/10.21527/2176-7114.2011.20.515-524>
21. Prates DS, Camponogara S, Arboit ÉL, Tolfo F, Beuter M. Kidney transplant: perceptions from patients and healthcare professionals about kidney transplants. *J Nurs UFPE on line* [Internet]. 2016 [cited 2017 Sept 25];10(4):1264-72. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/11112/12584>
22. Pinter J, Hanson CS, Chapman JR, Wong G, Craig JC, Schell JO, et al. Perspectives of Older Kidney Transplant Recipients on Kidney Transplantation. *Clin J Am Soc Nephrol*. 2017 Mar; 12(3):443-53. Doi: [10.2215/CJN.05890616](https://doi.org/10.2215/CJN.05890616)
23. Santos WN, Rocha FCV, Ribeiro IAP, Coqueiro JM. Atuação do enfermeiro nas complicações decorrentes do transplante renal: uma revisão de literatura. *Uningá Review*. [Internet]. 2016 [cited 2017 Sept 26];25(1):136-42. Available from: <http://revista.uninga.br/index.php/uningareviews/article/view/1751>
24. Ribeiro DF, Mendonça RCHR, Baptista MASF, Cesarino CB, Rodrigues CC, Landim WP. Demographic and clinical factors associated with health-related quality of life of kidney-transplanted patients. *J Nurs UFPE on line* [Internet]. 2016 [cited 2017 Sept 26]; 10(1): 57-64. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/10921/12203>
25. Santos BP, Lise F, Feijó AM, Garcia RP, Schwartz E. Care carried out by people with renal transplants for organ maintenance. *J Nurs UFPE on line*. [Internet]. 2017 Aug [cited 2017 Sept 26]; 11(8):3108-21. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/110216/22126>
26. Sociedade Brasileira de Nefrologia, Sociedade Brasileira de Urologia. Transplante Renal: indicações e contra-indicações [Internet]. São Paulo: SBN/SBU; 2006 [cited 2017 Sept 27]. Available from: https://sbn.org.br/app/uploads/TX1-Indicacoes_e_contra-indicacoes.pdf
27. Barros ME, Santos AHC, Araújo LHF, Carvalho ES, Guerrer BL, Menezes JL, et al. Indicadores antropométricos e avaliação da pressão arterial da verificação de risco de doenças renais da população geral. *Realização* [Internet]. 2015 [cited 2018 July 08];2(3): 26-30. Available from:

<http://ojs.ufgd.edu.br/index.php/realizacao/article/view/5543/2869>

28. Santos MC, Ribeiro RCHM, Berolin DC, Cesarino CB, Fernandes CHI, Mazer LE. Sociodemographic and clinical factors of patients who have lost kidney grafting. *Arq Ciênc Saúde*. 2017 Oct/Dec; 24(4):3-7. Doi: <https://doi.org/10.17696/2318-3691.24.4.2017.680>

29. Muniz NCC, Santos FK, Silva FVC, Tavares JMAB, Rafael RMR, Vieira IFO. Prevalence of urinary tract infection in the first month after kidney transplant at a university hospital. *J Enferm UERJ*. 2017; 25(e26479):1-6. Doi: <http://dx.doi.org/10.12957/reuerj.2017.26479>

30. Bomfim RE, Schwartz E, Garcia RP, Lima JF, Santos BP, Silva MS. Experiences of people that had the kidney graft rejected and returned to hemodialysis. *Saúde (Santa Maria)*. 2016; 42(1):93-102. Doi: <http://dx.doi.org/10.5902/2236583420445>

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