PERCEPTION OF CHRONIC KIDNEY PATIENTS UNDERGOING HEMODIALYSIS, ABOUT KIDNEY TRANSPLANTATION

PERCEPCIÓN DE PACIENTES CRÓNICOS EN HEMODIÁLISE SOBRE TRASPLANTE RENAL

Gabyrelle de Lima Silva, Kelly Cristiane Rocha Lemos, Analúcia Oliveira Barbosa, Gabrielle Morgana Rodrigues dos Santos

ABSTRACT

Objective: to identify the perception of patients with chronic kidney disease undergoing hemodialysis about kidney transplantation. Method: this is a qualitative, descriptive, exploratory study, with 20 patients undergoing hemodialysis in a public hospital through semi-structured interviews, which were then transcribed and submitted to the Content Analysis technique in the Category Analysis mode. Results: the following categories emerged: << Perspectives on kidney transplantation >>; << Kidney transplantation: the chance for a new life >>; << Behind the kidney transplant: uncertainties and frustrations >> and << Communication as a care tool >>. Conclusion: it was found that the interviewees' perception of kidney transplantation was related to life change, guaranteeing a sense of freedom in relation to other therapies and increased life expectancy. It was presented, however, to some interviewees, as another treatment option, not being associated with a cure and, due to the cases of failure and long waiting time to perform it, it causes frustrations and uncertainties regarding this therapy. It was also identified the importance of health education, especially by Nursing, influencing the clarification and reduction of anxieties regarding transplantation.

Descriptors: Chronic Kidney Failure; Kidney Transplantation; Renal Dialysis; Health Education, Quality of Life; Nursing.

RESUMEN

Objetivo: identificar la percepción de pacientes con enfermedad renal crónica sometidos a hemodiálisis sobre trasplante renal. Método: se trata de un estudio cualitativo, descriptivo, exploratorio, con 20 pacientes sometidos a hemodiálisis en un hospital público por medio de entrevistas semiestructuradas, que, en seguida, fueron transcritas y sometidas a técnica de Análise de Contenido en la modalidad Análisis Categorial. Resultados: emergieron las siguientes categorías: << Perspectivas sobre el trasplante renal >>; << Transplante renal: una oportunidad de vida >>; << Por detrás del trasplante renal: incertidumbres y frustraciones >> y << La comunicación como instrumento de cuidado >>. Conclusión: se constató que la percepción de los entrevistados sobre el trasplante renal se relacionó a la percepción de la mutación de vida, garantizando la sensación de libertad en relación a otras terapias y aumento de la expectativa de vida. Se presentó a algunos entrevistados como una opción de tratamiento, no siendo asociado a la cura y, debido a los casos de insucceso y largo tiempo de espera para realizarlo, provoca frustraciones e incertidumbres a respecto de la terapia. Se identificó, además, la importancia de la educación en salud, sobretodo por la Enfermería, influenciando el esclarecimiento y reducción de las ansiedades con respecto al trasplante. Descriptores: Fallo Renal Crónico; Transplante de Rrión; Diálisis Renal; Educación en Salud; Calidad de Vida; Enfermería.

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INTRODUCTION

Chronic Kidney Disease (CKD) is defined as the failure of functional nephrons in a progressive and irreversible way. It is revealed that, due to the increase in incidence and prevalence, this disease has already become a public health problem worldwide and is related to a decrease in the individual's quality of life, increased spending on health care, in addition to a high mortality rate.1

Among the main risk factors for CKD, cardiovascular disease, diabetes, hypertension and obesity are added to the socioeconomic, racial and gender disparities that are considered determining factors.2

CKD is classified into stages whose management is specific to each of these. It is suggested, when the individual reaches the last stage, characterized by the glomerular filtration rate <15mL / min / 1.73m, to initiate Renal Replacement Therapy (RRT) to maintain some vital functions. As RRT, hemodialysis, peritoneal dialysis and kidney transplantation are used, and these partially replace kidney function, relieving symptoms of the disease and preserving the individual's life. Despite this, none of them is considered to be a curative measure.3-4

In 2017, it was estimated that the total number of individuals on dialysis was 126,583, representing an increase of 28,997 in the last five years. It was also estimated, in the same year, that the number of individuals who started treatment in Brazil was 40,307 and this corresponds to an incidence rate of 194 individuals per million of the population (pmp). It was also revealed that the prevalence rate of individuals undergoing dialysis was 610 individuals pmp, showing the permanent trend of annual growth, when compared to the rate of the previous year (596 / pmp) and, in Pernambuco (PE), the prevalence rate was 633 individuals pmp.5

Among RRTs, kidney transplantation is considered the treatment of choice for patients with CKD as long as they are able to perform the surgery and have no contraindications to the use of immunosuppressants. In relation to dialysis therapies, this type of treatment offers a better quality of life for the individual, as it offers better socioeconomic rehabilitation with less social cost, in addition to freeing him / her from dependence on dialysis.4

According to statistical data on organ transplantation in Brazil, from January to September 2019, 6,722 solid organ transplants occurred, and among these, 4,617 were kidney transplants, which was the organ that obtained the highest record in relation to other transplanted organs. Furthermore, there was an increase in both kidney transplantation with deceased donor (3.3%), and with a living donor (4%). It was also evidenced that PE presented a drop of more than 10% in transplant rates in relation to the previous year, however, it is among the six states that most performed this type of transplant in 2019, being highlighted in the Northeast region, adding up to a total 299 kidney transplants between the months of January to September.6

Individuals undergoing kidney transplantation are required to take specific precautions to be successful in this treatment and to avoid complications after surgery, including graft rejection. It is necessary for the individual to be guided about this new way of life, without dialysis sessions, however, with the dependence on immunosuppressive medications, in addition to receiving adequate information about the possibility of rejection.4-7

It is noteworthy that, even with the clarification of the factors mentioned, it is still common the absence of important information from health professionals about the transplant, such as: the time on the waiting list; the possibility of loss of the new kidney and, also, the possible resumption of dialysis therapy. The lack of information contributes to the lack of understanding of individuals about this type of RRT, influencing self-care.8

Among health professionals, nurses are considered the most present during the treatment of individuals with CKD, regardless of RRT. The nurse becomes, by being present in all stages of the process experienced by these individuals, capable of knowing, evaluating, acting in the care, intervening and preparing educational actions and, with this, provides a better quality of life, satisfaction and safety at all stages of treatment. For this, constant training with these professionals must be carried out in a way that contributes to the improvement of nursing practice, identifying the individual's health needs so that he / she presents the minimum of complications and, with this, promotes the self-care, in addition to a sense of well-being.9

The option for an RRT can be considered a problem faced by the patient with CKD; in addition, the possibility of performing a transplant can generate conflicting and subjective conclusions due to the lack of clarification about this treatment modality, often due to the inefficient relationship of the individual with the health team that assists him, which does not allow him to verbalize your doubts and concerns about the surgical procedure, as well as its consequences.

It is considered that kidney transplantation appears as an alternative that contributes to improving the health and life conditions of individuals affected by a disease with no expectation of cure. However, those undergoing...
this treatment modality need to be oriented about the benefits, care after surgery, as well as the negative consequences such as rejection. Thus, the interaction between the individual and the health team that accompanies them becomes important in order to clarify the main changes and care, in addition to providing better therapeutic adherence.

It is questioned in light of the above: “What is the perception of the individual with chronic kidney disease undergoing hemodialysis about kidney transplantation?”

**OBJECTIVE**

- To identify the perception of patients with chronic kidney disease undergoing hemodialysis about kidney transplantation.

**METHOD**

This is a qualitative, descriptive, exploratory study with patients on hemodialysis in a state hospital, affiliated to the Unified Health System (UHS), in the city of Recife / PE, Brazil, a reference in the treatment of individuals with CKD.

Twenty individuals were selected to participate in the study, which took place during the months of September and October 2019.

It is clarified that, for participation in the research, individuals should meet the following inclusion criteria: being over 18; perform hemodialysis for at least six months; having an indication for kidney transplantation through medical evaluation reported in medical records and being available to participate in the study, agreeing with the recording of the interviews and accepting the disclosure of data in scientific circles.

Those who were under evaluation for kidney transplantation or who had already undergone this treatment and who had cognitive deficits due to their low ability to understand and communicate were excluded, according to the parameters of the Mini Mental State Examination (MMSE). It should be added that, of the fifty-four patients registered at the hospital, twenty-eight met the inclusion criteria and, among these, two refused to participate, two died during the period that the collection was being performed and two underwent the transplantation process.

A semi-structured interview was used for data collection, following a script divided into two stages: the first with information related to the individual’s sociodemographic situation and the other with guiding questions focusing on topics related to kidney transplantation, these being recorded and later transcribed in full and analyzed. It is informed that they occurred in the chosen institution, in the hemodialysis service itself, in a private room and in the pre-dialysis period, due to the possible complications that could occur during hemodialysis, making data collection unviable after the procedure.

The interviews ended when, in the course of organizing the testimonies, data saturation occurred, that is, the existence of recurrence and complementarity of information, given that quantification, at first, differs from the logic of qualitative studies.

For the organization and analysis of the data, the Content Analysis technique was used, which is characterized by the set of communication analysis techniques, through systematic and objective procedures, to describe the content of the statements and obtain indicators that allow the inference of knowledge related to the conditions of production and reception of the same. It is divided into three fundamental steps: pre-analysis, material exploration and treatment of results through inference and interpretation.10

During the pre-analysis, an organization process was carried out through exhaustive reading of the interview transcripts. In the second stage, similar and significant data were added, classifying them for the constitution of the theme and, in the third stage, the treatment of the results obtained and the interpretation occurred, with further discussion of these findings.

Bioethical issues were respected, using them according to the National Health Council of the Ministry of Health, through resolution 466/2012. Research approval was obtained from the Research Ethics Committee with Human Beings of Agamenon Magalhães Hospital under the Certificate of Presentation for Ethical Appreciation (CAAE): 16560219.7.0000.5197. All participants were informed about the objectives of the study and they signed a Free and Informed Consent Term (FICT). The interviews were identified, for the purpose of maintaining the anonymity of the participants and the confidentiality of the information, by the letter “E” plus a numeric number that did not mean the order in which the interviews were conducted.

**RESULTS**

- **Characterization of interviewees**

In this study, 20 participants came together, aged between 18 and 74 years old, fifteen male and five female and, regarding marital status, nine were single, ten, married and one, divorced; as for family income, seventeen individuals received between one and two minimum wages per month and three received above two minimum wages; about schooling, six of them had incomplete elementary school, five had complete elementary school, two had incomplete high school, six had complete high school and one had incomplete
higher education, and the time of treatment in hemodialysis ranged from ten months to 20 years.

The discussion of this research was composed from the methodology used, emerging from four categories: Perspectives on kidney transplantation; Kidney transplantation: the chance for a new life; Behind kidney transplantation: uncertainties and frustrations and Communication as a care tool.

**Perspectives on kidney transplantation**

It was observed, through the reports, that the perception of individuals in relation to kidney transplantation is associated with the improvement of the clinical picture, the change in routines and the desire to no longer depend on hemodialysis.

What I know about kidney transplantation is that it is a totally different life from today that we do dialysis, you know, how can I say (pause), it is another life, it is better health, everything, you know, that we don't depend on the machine. (E07)

The transplant, it gives me more freedom, it gives me another option for a better life. (E13)

It was also emphasized that the interviewees understand kidney transplantation as a treatment, not associating it with the cure.

What I do know is that it is not a cure, right and that it is practically an exchange of the machine for medications. (E02)

[...] what I know that he (doctor) says is not a cure; you know, it is a solution to just come out of the machine, it is not a cure. (E14)

**Kidney transplantation: the chance for a new life**

The following are excerpts from the interviews that represent the positive expectations about kidney transplantation demonstrated through expressions such as improved quality of life, in addition to increased expectations.

I think it means an improvement, right, let's say a little improvement, right in my life expectancy. (E02)

Transplantation, when we choose to do it and do it, we think about a better quality of life. (E08)

It was also noticed that the question of freedom was widely addressed by the interviewees, appearing at various moments in the interviews, especially when they mention their dependence on hemodialysis. It is detailed that another example would be to be able to travel without worrying about having to return in a short time due to hemodialysis sessions or even having to look for where to dialysis during a trip.

At least, getting out of the machine, not doing dialysis anymore, you're not suffering from being punctured, you're not getting out of the machine feeling dizzy, feeling sick. [...] you will have freedom to do what you want, understand, you will be able to travel, be able to enjoy life properly. (E18)

[...] doing the transplant, the outlook on life is much better. [...] it is the possibility that I can leave, that I can travel to visit my family, who lives in São José da Coroa Grande, and can walk, you know, there is no commitment for you, three times a week, to have who is in a hemodialysis room. (E17)

**Behind kidney transplantation: uncertainties and frustrations**

During the interviews, it was noted that fear of the surgical procedure or even death, in addition to the possibility of graft rejection and having to resume hemodialysis, are pessimistic examples cited by the participants in this study, being the main causes of dropout or non-acceptance of the transplant.

[...] I'm afraid too, I'm afraid of going wrong in the surgery. (E11)

[...] before, it was the solution, but now, I'm afraid, after what has already happened to the patients who did. (E09)

[...] this is luckily there are some who do and do well, others do not do well. [...] here (he mentioned the name of a colleague) he underwent the transplant, then he underwent hemodialysis again; then, I don't want to be cut and days later, I will do hemodialysis again, I prefer to stay like this. (E16)

It was revealed, by the interviewees, that dealing with restrictions and uncertainty regarding the success and duration of the transplant, as well as the waiting time for a compatible donor to meet, intimidates some individuals and relates to the unfavorable aspects of the kidney transplant.

The doctor gave me all the information, he even did an interview with me to see, he told the situation about how the transplant was, that it can work, it may not work, you have to take the right medicine, you have to do a food regimen, sugar, salt, which I don't do today, I do the right medicine, you have to do a food regimen, sugar, salt, which I don't do today, I do the basics more or less. [...] it's good and, at the same time, it's bad and it's a lottery it can work and it may not work. (E12)

[...] I did all the exams, but, as it didn't arrive and it was five years too, now I don't want it anymore, I was five years old at the machines when it appeared, I was already in the routine of the machines, then, I didn't want to anymore. (E19)

**Communication as a care tool**

In this category, the importance of health education for respondents is presented and how it can be significant for clarification or even decision making in relation to the best treatment option, as shown in the following statements.

What I wanted was this: to have a person to indicate me better, you know, about this transplantation issue, information [...] I wanted to have a person to explain the general process properly. (E04)

The doctor (name of the doctor) passed on the information, telling me to do it, that I would be fine, that everything would be okay [...] it

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wouldn’t be 100%, but it would be 80% and then we have to do it, she said it’s better for people, right, than undergoing hemodialysis. (E14)

[…] the day I went there [referral hospital for transplant in PE], get it to do the exams, they explained to me all the procedures that are done after the transplant […] they said everything that is necessary, right, to do after the transplant, care, you understand? (E07)

The importance of communication and the provision of information about transplantation by professionals were highlighted, highlighting the notoriety of this care tool.

It is good information that you will get rid of the machine, you will have a better life and such, these things. (E03)

It was good, it was good for us to know that it is interesting, for us to know if it is good or not, it was good. (E05)

It is warned that, despite the favorable statements, testimonies showed that the health team did not clarify, as well as the abandonment of health education as a care strategy.

[…] at the beginning, we had lectures here (cites referral hospital for patients with CKD) and we always participated in these lectures, these lectures were explanatory pamphlets and explained about the transplant, about the functioning of the kidneys, about what is an infection urinary, about what is the chronic kidney or not right, so, we always had these lectures here; today, in 2019, it’s still, but there was this at the beginning, back there, this awareness. (E08)

[…] I who went to get the information, I asked him (doctor), he said: “No, (name of the interviewee), you can have a transplant if you want, if you want, of course, right and you can apply” I asked where was that I signed up for the transplant. (E18)

It was also highlighted that the interviewees emphasized the encouragement by nursing professionals to perform the transplant, as well as clarifying the procedure.

[…] the technician and the nurse also said that we had the possibility of having a transplant, right, it will depend on us, if we want too, right. (E05)

[…] if you have any questions about the transplant, about kidneys, any questions really, the nurses and the heads of the unit, they give you the basic information. (E08)

[…] the head nurse, her name was (she mentions) her name and told me everything, she did an interview with me too, then she told me everything, she gave me a paper too for me to read. (E19)

DISCUSSION

Kidney transplantation is considered the best therapeutic modality for the individual with CKD, whether from a clinical, social or economic point of view. This treatment appears as an alternative for these individuals who do not expect to cure their disease, as it contributes to improving their health and life conditions, in addition to providing a sense of independence, well-being and better quality of life.14

In relation to the sociodemographic aspects presented in this study, there is a worrying situation in relation to the level of education and low financial income of the participants, represented by a greater number of individuals with income between one and two minimum wages per month and having elementary education, most, even, incomplete. It was shown, in a study, that these indicators could contribute to low quality of life and, consequently, lower survival in CKD.11

In the results of another research carried out also in Recife - PE, the correlation between sociodemographic factors and level of knowledge was presented and, in this analysis, it was concluded that, even with the result of 52.5% of the study population showing a restricted and insufficient level of knowledge about the knowledge about CKD, in the comparative analysis between the knowledge groups (full, medium, restricted and without knowledge), there was no significant difference between these and the sociodemographic characteristics. In the same survey, participants were asked about their knowledge of CKD treatments and only 27.5% answered correctly what kidney transplantation would be.12

It reflects on the other results found pointing to a research carried out in the southern region of Brazil, which also related the transplant to freedom in view of the possibility of not depending on the hemodialysis machine and to a better and less restricted life condition when compared to those who perform other RRT.13 It was identified, in another research, published recently, how limited the individuals who undergo hemodialysis felt in relation to the activities that, before starting the treatment, gave him pleasure such as work and leisure.14

It has been demonstrated, by some individuals, that the hope of changes, mainly in the quality of life, favors the choice of kidney transplantation as the best alternative in view of the limitations caused by hemodialysis.15 It was emphasized, in research reports, that the interviewees’ lives, before the transplant, were characterized by difficulties arising from dietary and water restrictions, in addition to possible hospitalizations due to the treatment prior to the transplant. It was also mentioned the fact that the hemodialysis machine is dependent on survival, associated with constant anxiety and concern with the care of hemodialysis treatment.4

It is pointed out, in another research, that opting for a transplant is a distressing decision,
surrounded by uncertainties, fear and doubts about the effectiveness of this therapeutic option, causing different feelings to the individual affected by CKD.\textsuperscript{16}

It is noteworthy that death after transplantation or the return of a transplanted colleague for hemodialysis, in addition to fear and other negative feelings, impacts individuals who are waiting for a transplant, as it relates this treatment to a situation that poses a risk to life, causing fear and doubts and, consequently, interfering in the decision to enter the waiting list for transplantation.\textsuperscript{15}

Another study was carried out in Minas Gerais, which revealed that the interviewees were apprehensive about the waiting time for not knowing when they would be called to perform the transplant; these still reported that, even fulfilling all the requirements, such as updated exams, name on the waiting list or even summons, the transplant could not occur, causing a feeling of frustration and disappointment in the face of this situation.\textsuperscript{17}

It was found, in a research carried out in a reference hospital for kidney transplantation in Sobral - CE, that the study population would like to be better informed about their disease, but mainly about the transplant. Thus, there are implicit failures in relation to effective communication and, consequently, in the health system. It was also observed that the same situations understood as facilities for some could be considered obstacles for others, emphasizing the subjectivity and the way of understanding of each one.\textsuperscript{15}

It is noticed that the failure in communication is a reality not only in Brazil. In an international study, it was shown that all of its participants shared negative feelings, as well as a lack of information about their kidney disease and treatment options, including transplantation, and wishing for more knowledge about these options. It is perceived that these negative experiences and the lack of knowledge possibly contributed to the participants expressing a series of concerns about the performance of kidney transplantation, such as load of immunosuppressive drugs, fear of surgery, fear of organ rejection and old age.\textsuperscript{18}

It is evident, in Brazil, that some authors, in their studies, affirmed the need for good communication between the health team and the individual with CKD, so that they understand about the risk of rejection and, consequently, the need for use continuation of immunosuppressive medications, in addition to the mandatory lifestyle changes that these individuals must have after transplantation; they also emphasized the responsibility of health professionals, especially those involved in the transplantation process, in offering mechanisms related to education and guidance regarding this new way of life.\textsuperscript{4,19}

It was identified, in a recently published study, that research participants saw transplantation as a life-changing possibility, however, they did not demonstrate knowledge about the necessary care for graft maintenance, as they also had fragmented knowledge about the possibility of developing complications that could lead to transplant failure, and with that, the authors concluded that health education influences the construction of a line of care, reducing the chances of complications of this procedure.\textsuperscript{20}

It should be noted that, among health professionals, nurses stand out for their proximity to the patient during the treatment and their importance regarding the role of informing and clarifying. It was shown, in reports, that this professional has a fundamental role in keeping these individuals informed about the possibility of complications and exposure to risks in the treatment of hemodialysis over the years and reducing the viability of kidney transplantation over time. Therefore, the importance of the educational practice of nursing professionals in their work process is reinforced.\textsuperscript{13}

Remember that the nurse, with regard to kidney transplantation, has an important role in the health team, as it participates from organ harvesting to post-surgical follow-up. As a result, this professional must be highly specialized and trained in order to act efficiently in the various phases of this process.\textsuperscript{21}

Recently, in an article, the importance of training these professionals was reinforced when it presented data that showed the fear and fear of kidney transplant participants in relation to the lack of knowledge of nursing professionals about specific care for these individuals, such as the correct management of immunosuppressants.\textsuperscript{22}

It is also noteworthy that the nurse, due to the duties inherent to her profession, must establish a relationship of trust during the entire transplantation process, clarifying all stages of the surgical process, as well as the benefits or even possible risks. In addition, this professional can participate in the process, informing about the rights to free access in all stages of the transplant, as well as trying to alleviate the concerns, fear and anxiety of individuals regarding the time on the waiting list and, thus, contributing to the decision making of the best therapy in a conscious and safe way.\textsuperscript{1}

\textbf{CONCLUSION}

It is concluded that the interviewees' perception about kidney transplantation is related to the prospect of a new life, which provides, above all, the feeling of freedom that is limited by other treatments.

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It was also observed that kidney transplantation is understood as a new treatment that requires care, continuous use of medications and with the possibility of complications that may lead the individual to restart dialysis or even death. These individuals provoke fear and uncertainty in these individuals, influencing the acceptance of this treatment.

In view of the lack of information from the interviewees, there was a need to discuss changes in health practices aimed at this population. Thus, the importance of carrying out health education activities is emphasized as a way of raising awareness among this population, not only for the acceptance or refusal of the transplant, but also to alleviate the anxieties, fears, anxieties, incentive for self-care and continuity of renal therapy, in order to preserve the transplanted organ and improve the quality of life of these individuals.

It should be noted that nurses have a fundamental role in health education, providing clarifications, support and encouragement, as shown by the interviewees. It should be remembered, however, that this professional is in a current context marked by work overload and that this care strategy can be shared with other professionals from the multidisciplinary team.

As a limitation of this study, it is assumed that there is a lack of publications that relate the level of knowledge of individuals with CKD on kidney transplantation and their sociodemographic data, in addition to the lack of international studies.

It is expected that this study will provoke reflections on the topic discussed, so that these discussions contribute to the clarification of individuals affected by CKD and that they can choose the best treatment. Furthermore, it is suggested that new research be carried out with the aim of confronting, expanding or complementing knowledge about the subject in question.

**CONTRIBUTION**

It is informed that all authors contributed equally in the design of the research project, collection, analysis and discussion of data, as well as in the writing and critical review of the content with intellectual contribution and in the approval of the final version of the study.

**CONFLICT OF INTERESTS**

Nothing to declare.

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Corresponding author
Gabryelle de Lima Silva
Email: gabryelle_lima@hotmail.com

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