

DIALOGIC RELATIONSHIP WITH PATIENTS REGARDING KIDNEY TRANSPLANTATION: NURSING EDUCATIONAL CARE *

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ABSTRACT: Objective: to describe the knowledge of chronic kidney patients about kidney transplantation, and discuss the contributions of this knowledge to nursing educational care. **Method:** this is a convergent-care study with 11 chronic kidney disease patients who were eligible for transplantation, at a university hospital in the city of Rio de Janeiro. Individual interviews were conducted between March 2016 and February 2017, and their content submitted to thematic content analysis. **Results:** the results bring the reflection that chronically ill people need integrated actions with the participation of several areas of health knowledge. It is imperative that patients share the experience of those who live with chronic illnesses with health professionals through a critical-reflexive dialogue. **Conclusion:** the dialogue allowed the reflection on the construction and reconstruction of knowledge and practices about kidney transplantation, and revealed co-responsibility among professionals, patients and their families in the process of recovery from the surgical procedure, and graft maintenance.

DESCRIPTORS: Nursing; Health education; Chronic renal insufficiency; Nursing care.

RELAÇÃO DIALÓGICA COM O CLIENTE SOBRE TRANSPLANTE RENAL: CUIDADO EDUCATIVO DE ENFERMAGEM

RESUMO: Objetivo: descrever os saberes de clientes renais crônicos sobre o transplante renal e discutir as contribuições desses saberes nos cuidados educativos de Enfermagem. **Método:** pesquisa convergente-assistencial, com 11 portadores de doença renal crônica aptos ao transplante, em hospital universitário da cidade do Rio de Janeiro. Realizaram-se entrevistas individuais entre março de 2016 a fevereiro de 2017. A análise foi de conteúdo temático. **Resultados:** os resultados trazem à reflexão que as pessoas em condições crônicas necessitam de ações integradas com a participação de várias áreas do saber em saúde. Torna-se indispensável que o cliente compartilhe a experiência de quem vive a cronicidade com os profissionais da saúde por meio do diálogo crítico-reflexivo. **Conclusão:** o diálogo possibilitou a reflexão sobre a construção e reconstrução de saberes e práticas sobre o transplante renal e revelou corresponsabilidade entre profissionais, clientes e seus familiares no processo recuperação do procedimento cirúrgico e manutenção do enxerto.

DESCRIPTORES: Enfermagem; Educação em saúde; Insuficiência renal crônica; Cuidados de enfermagem.

RELACIÓN DIALÓGICA CON EL PACIENTE SOBRE TRASPLANTE RENAL: CUIDADO EDUCATIVO DE ENFERMERÍA

RESUMEN: Objetivo: describir los saberes de pacientes renales crónicos sobre trasplante renal y discutir las contribuciones de tales saberes en cuidados educativos de Enfermería. **Método:** Investigación convergente-asistencial, sobre 11 pacientes con insuficiencia renal crónica aptos para trasplante, en hospital universitario de Rio de Janeiro. Se realizaron entrevistas entre marzo de 2016 y febrero de 2017. Fue aplicado análisis de contenido temático. **Resultados:** Expresan la reflexión de que las personas con condiciones crónicas necesitan acciones integradas, con participación de varias áreas del saber en salud. Resulta indispensable que el paciente comparta la experiencia de quien vive la cronicidad con los profesionales de salud mediante el diálogo crítico-reflexivo. **Conclusión:** El diálogo permitió reflexionar sobre la construcción y reconstrucción de saberes y prácticas sobre trasplante renal, y reveló corresponsabilidad entre profesionales, pacientes y sus familiares en el proceso de recuperación del procedimiento quirúrgico y de preservación del injerto.

DESCRIPTORES: Enfermería; Educación en Salud; Insuficiencia Renal Crónica; Atención de Enfermería.

*Article extracted from the master's dissertation entitled: Knowledge and Practices Shared with Renal Patients to be Transplanted: Health Education for Self-care. Nursing School Anna Nery-UFRJ, 2017.

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Received: 07/05/2017

Finalized: 29/12/2017

● INTRODUCTION

Chronic kidney disease (CKD) is a structural or functional kidney lesion that persists for more than three months, and is classified according to the estimated glomerular filtration rate (GFR). It is a long-term condition, initially insidious and asymptomatic⁽¹⁾.

Several factors are associated with its etiology and progression to renal function decline, for example, prevention and treatment of diabetes, hypertension, dyslipidemia, obesity, cardiovascular disease, and smoking. The control and treatment of these conditions should be in accordance with the regulations and guidelines of the Ministry of Health⁽²⁾.

There is a close relationship between the stage of CKD and prognostic outcomes. In order to provide comprehensive care, the treatment includes clinical measures to delay the worsening of renal function, reduce symptoms, and prevent complications when in stages one to three - pre-dialysis, four and five - non-dialytic stages, and renal replacement therapy in stage five, dialytic. It begins with the diagnosis of CKD, remains in the long term, and the earlier conservative treatment begins, the greater the chances of preserving kidney function for a longer period⁽³⁾.

Despite the non-surgical treatment, CKD can progress to advanced stages, and then the patient is prepared for dialysis or transplantation. It should be emphasized that these patients have the right to choose whether or not to undergo transplantation and, thus, avoid dependence on the hemodialysis machine or peritoneal dialysis⁽⁴⁾.

Kidney transplantation is a surgery that involves ablation of the organ of a deceased or living donor (related or not), and its implantation into the recipient. It is indicated for people with stage-five CKD. However, preemptive transplantation may be considered, that is, transplantation is performed before the patient started kidney replacement therapy⁽⁵⁾.

As a modality of choice, kidney transplantation contributes to greater survival and better quality of life, because it allows individuals to resume their way of life, usually modified by the aspects involved with the dialysis treatment⁽⁵⁾.

Although kidney transplantation is a form of treatment available, and is increasingly used in Latin American countries, the expansion was not as rapid as it should be to compensate for the increase in the prevalence of patients on the waiting list. Data from the Latin American Registry of Dialysis and Renal Transplantation show that, in 2010, 10,397 kidney transplants were performed, of which 58% involved deceased donors, and the highest percentages were found in Uruguay (96.8%), Cuba (94.9%), Colombia (92%), and Argentina (78.7%)⁽⁶⁾. In Brazil, from 2007 on, there was a considerable increase in transplants with deceased donors. Since then, there has been a continuous reduction in the number of living-donor kidney transplants⁽⁷⁾.

In 2012, although Brazil ranked second in absolute kidney transplant numbers among 30 countries, with a total of 5,385 transplants, lagging behind the United States only, with 15,549 transplants, this number fell short of the need for 11,445 transplants. Between 2011 and 2013, there were 24,134 notifications of potential donors in Brazil, of which only 28.9% became effective donors⁽⁷⁾.

Data are significant, because they reflect the reality related to the growth of the number of patients with chronic renal failure, which is considered a social and worldwide problem, since it compromises the patient's daily life, as well as that of their relatives, thus requiring the involvement of all health professionals in CKD education and prevention measures.

Traditionally, health education has been an instrument of dissemination, affirmation of dominant knowledge, and accountability of individuals for reducing health risks and placing blame for damages. Criticism toward the dominant policy, which is characterized by reductionist conceptions of health and illness of the biomedical model, has led many professionals to work with health education alternatives, such as those referenced in popular education, like that by Paulo Freire, whose theoretical conception values the knowledge of the other, thus understanding that knowledge is a process of collective construction⁽⁸⁾.

Nursing educational care for patients with CKD, based on dialogue, reflection and criticism, allows the awareness⁽⁹⁾ of everything that involves the process of kidney transplantation. The construct "health education" applies here as constructive, not instructive, of care. Therefore, it is important to access the knowledge of chronic kidney patients, about kidney transplantation, so that health education work that adheres to the patients' needs and that is congruent with their socio-cultural reality can be developed.

Thus, the purpose of this study is to describe the knowledge of chronic renal patients about kidney transplantation, and discuss the contributions of this knowledge in nursing educational care.

● METHODOLOGY

This is a qualitative study, with a convergent-care approach, because it allowed the involvement and inclusion of the participants in the research process in coordination with care. The main characteristic of the convergent-care research is the coordination of research with care practice. It can be applied as a strategy for the practice of health education, especially during the collection of information⁽¹⁰⁾.

As data were obtained, nursing care was shared through health education during the dialogue established in the interview. Stemming from a dialogical relationship, the themes were problematized with the patient, and this enabled a critical reflection of the reality.

The study was conducted at the nephrology clinic of a university hospital, in the city of Rio de Janeiro, from March 2016 to February 2017.

The patients selected were those with CKD in stages four and five, over 18 years of age, of both sexes, on surgical or non-surgical treatment, who were eligible for transplantation as renal replacement therapy through living and/or deceased donors, with enough level of awareness and guidance to answer the research questions and sign the informed consent form. The exclusion criteria were: patients who did not opt for kidney transplantation; those with psychiatric problems, and special patients (with a mental disability).

Semi-structured individual interviews, a socio-cultural identification form, and discussion scripts were used for data collection. The letter P was used to identify the statements, followed by the chronological sequence of the interviews, in order to endure anonymity.

In the analysis of the discursive material, the thematic content analysis was applied, with the categorization phase being through thematic analysis. In this technique, the categories are not determined a priori, because they emerge from the speeches of the individuals⁽¹¹⁾.

Ethical aspects were met, and the study was approved by the Research Ethics Committee of the proposing and co-sponsoring institution, under report no. CEP 1.329.470.

● RESULTS

A total of 17 patients were considered eligible to participate in the survey. However, six refused to participate. Therefore, the survey had the participation of 11 patients, with seven (63.6%) being female. Regarding the age group, one (9.0%) was less than 40 years old; three (27.3%) in the range of 40 to 50 years; four (36.4%) were between the ages of 50 and 60 years, and three (27.3%), aged between 60 and 65 years.

The dialogue between the researcher and the participants began with questions related to the discovery of the disease and the choice of replacement therapy. It was observed that five participants did not have the opportunity or the option to choose the replacement therapy, with hemodialysis being an immediate treatment, that is, of urgency. This was the case because the discovery occurred in an advanced course of the disease, according to the following statements:

It was in 1991. [...] I had eclampsia, then they found that I had lupus, that was stopping my kidneys. They said that my kidneys had stopped. (P1)

Three years ago, [...] I made some tests and, when I underwent the blood tests, the physician told me that my kidneys were stopping. (P2)

Well, now, after two years, in November. [...] I had been admitted for five days, I had a lot of shortness of breath. Then, on the same day that I arrived at the hospital, they soon inserted a catheter. A catheter! To make hemodialysis! (P10)

Choice for kidney transplantation

The choice was naively made because the patients were unaware of or did not consider the future implications of this new life situation. They emphasized the fact that they did not want to go to hemodialysis, and reported fear of the needles, the machine, the suffering caused by this therapy:

[...] it is because I saw that there was a possibility of having a new life through transplantation. (P2)

Because I decided, because the physician had always told me that my rate was 17% (glomerular filtration rate). And that I had to do it as soon as possible because, otherwise, I would have to go to the machine, then I was afraid! (P6)

Well, it is because of the better life condition I'll have. Well, I was taking many medicines, and I saw that the situation wasn't improving. Then, I chose for the transplantation because of improvement, I don't know, to have better health, isn't it? (P9)

Expectations and perspectives of changes after transplantation

The statements show the expectations and perspectives of change from experiences to be lived after transplantation.

I think it will improve a lot, right? One thing I'm sure will change: I will not need to make hemodialysis anymore! I'll resume getting out more! ... Got it? Traveling, that is what I like to do! What I was not doing now, I'll be able to do. (P1)

Yes, I hope I get normal, right? I mean, I already have a normal life! I hope that it gets even better, right? (P2)

[...] quality of life will change, won't it? Because it will reduce the amount of medication I take now. That's it, the use must be reduced and, then, I'll have better quality of life. (P9)

Like an athlete, a super-hero! (Laugh...). The iron man! (Laugh). (P4)

It was observed that there is a lack of information regarding transplantation, because P3 believes that after transplantation he will not need to come to the hospital as frequently as before, P4 compares himself to a superhero.

Return to the operation room after kidney transplantation

Of the 11 study participants, one female patient had undergone a transplantation before, and would still have another one. During the dialogue, when speaking about her experience with the transplant, she reported that, when returning from the surgical center, she had a deep access catheter:

I know, I have already had one! The one on the neck? The physician told me when I was receiving the peritoneal catheter! (P3)

Another participant, despite not having the experience of an earlier transplant, was able to associate it with his/her father's heart surgery, who returned from the operating room with a drain. The dialogue below highlights this association:

I remember the drain, when my father underwent a heart surgery, they put a drain down here! (At this point, he/she shows the site of the drain with the index finger) (P7)

The other participants demonstrated a lack of knowledge regarding the return from the operating room and the equipment attached, such as catheters and probes. They showed concern about the length of hospital stay, and equipment permanence, as highlighted below:

And how long do we stay like this? (P2)

How many days? (P2)

Another emerging concern, not always considered when it comes to replacement therapy, is body aesthetics, as evidenced in the speeches by P3. This concern was highlighted when the researcher used the illustration feature to explain how the incision is made in kidney transplantation surgery.

Oh, the incision isn't on the back! It is from on the front! [...] fortunately! Because I won't be without a belly button! [Laugh] (P3)

At that time, it was appropriate to explain that the umbilical scar would remain and thus a visible relief through facial expression was demonstrated by P3.

Knowledge about the graft and post-transplantation complications

During the dialogue, it was evidenced that some participants idealized that the graft has the duration of a lifetime, and that the transplant is the cure for CKD. The participants' speeches, regarding the location of the kidney to be transplanted and the graft life, were expressive:

They didn't say anything about this! What? Life time? All life, isn't it? But ... (P7)

My God! I didn't know that! [Seems sad, worried, thoughtful] (P9)

These are considered kidney patients, but renal transplanted patients are likely to have clinical complications. Kidney transplantation is not a guarantee of successful graft function because there is a possibility of graft dysfunction due to episodes of rejection, bacterial and viral infections, and problems resulting from the use of nephrotoxic and other drugs.

The participant who would undergo transplantation for the second time related rejection as one of the complications when addressed about post-transplant complications:

Well, today I would know, because of the strong pain! And also when my urine is increasingly reduced! If I am accustomed to go about five times a day and I start going three, two, then I know that something is happening! (P1)

Fever too! (P1)

Other complications mentioned were inflammation, pain, swelling, infection, fever, malaise, and graft loss. Many of these complications were presented in the form of questioning during the dialogue, and the researcher and participants had a discussion on these questions:

Inflammation, pain, swelling. (P2)

Yes, in this case, this infection, what precedes it? What are the symptoms of the infection? For example: urinary tract infection? Which symptoms do I have? Pain? Fever? [...] then, can this infection turn out to be a rejection? Or is it already a rejection? (P9)

● DISCUSSION

The line separating health and disease is sometimes fine and, in silent illnesses, symptoms emerge late. CKD has become a growing public health problem and the number of end-stage patients whose treatment is kidney transplantation increases annually. However, the inequality between demand and supply of kidneys is the cause of transplant delay. In Brazil, on average, 30% of those waiting in line receive the organ each year⁽¹²⁾.

Chronic kidney disease has stages of gradual evolution, with a diagnosis usually at an advanced stage, due to an almost hidden clinical picture. It is associated with high mortality, morbidity and costs, because transplants are part of the Unified Health System (SUS, as per its acronym in Portuguese) resources. In addition, it negatively impacts quality of life, because its silent nature, the slow progression, the weaknesses in prevention, and the comorbidities of the present day reveal a worrisome situation in the world's public health⁽¹²⁾.

Patients participating in this study have confirmed these assertions. Since the diagnosis of CKD, they have already begun hemodialysis, a therapy that imprisons them to the machine and the use of a large number of medications that bring physical discomfort, due to the successive punctures, and decreases quality of life. They perceive the dialytic treatment, that is, hemodialysis, as prison, pain and suffering.

The several expectations, prospects for changes, and experiences during hemodialysis have led patients to believe that kidney transplantation is an option that offers immediate advantages to hemodialysis. Kidney transplantation can provide better quality of life. With the exception of daily medication and routine consultations, transplant recipients have the opportunity to direct their interests and activities⁽¹³⁾.

The knowledge of the study participants, related to the choice of kidney transplantation, were shown as a possibility of change, but the necessary care for the maintenance of this transplant was not considered; in addition, they had fragmented knowledge about possible complications. Such gaps in knowledge are worrisome, because they may lead to the impairment of the transplanted organ.

When freedom, autonomy, and hope are considered, some practices need to be rethought and rebuilt, because the individual will not move away from the hospital, will not have the strength of the idealized hero, and will not stop taking medications. This way, the dialogue demystifies beliefs and values, leading to reflection and, thus, favors care after transplantation.

The doubts and uncertainties of a patient who will undergo a kidney transplantation reaffirm the absence of care and/or treatment in the post-transplant period, making coping difficult when these situations emerge in the post-transplant period⁽¹⁴⁾.

The transplantation process implies realities to be constructed and reconstructed through dialogue, the awakening of critical sense, and the sharing of knowledge about it and its implications. Even with a successful transplantation, after discharge and with a functioning graft, patients live with a chronic disease. After receiving the renal graft, they are always at risk for rejection.

Although transplant advances reduce the incidence of acute rejection to less than 15%, and increase graft survival from one year to more than 90%, the long-term graft survival rate remains unchanged, or to approximately 50% ten years after transplantation⁽¹⁵⁻¹⁶⁾.

Patients should receive adequate guidelines to live with the concrete possibility of rejection, and with the new way of life that they will have to assume. They have to know that, without the hemodialysis sessions, there is a dependence on the daily and correct use of immunosuppressive medications, a factor that influences the operating life of the transplanted kidney⁽¹⁷⁾.

The transplanted kidney may also be affected by some diseases that may alter its function, such as urinary tract infections, urinary tract obstructions, and acute or chronic rejections. Due to the presence of complications, rejection or insufficiency of the graft, kidney transplantation may mean an abrupt interruption of the transplanted patient's expectations, representing the need to return to dialysis, and living with the nuances of this situation, or even death⁽¹⁴⁾.

In daily care, nurses are challenged to provide quality care to patients and their families, and are confronted with the need to define their role in the transplant care process and its importance. It should be emphasized that people in chronic conditions need integrated actions with the participation of several areas of health knowledge. The approach of the multiprofessional team enhances the care of CKD and its comorbidities⁽¹⁸⁾. Thus, effective communication is indispensable between professionals and patients, who have the experience of living with a chronic condition, generating interdisciplinarity in care according to ethical concepts.

This way, a process of trust is established with the patients and both nursing and health professionals, through affection, tolerance, flexibility, fidelity, constant improvement, respect, reliability, good manners, and technical competence.

Health orientation converges with the pedagogy of autonomy in which patients share knowledge and practices in a democratic way. Professionals should take care of patients by providing the freedom necessary for them to access these practices and knowledge.

The study presented, as limitations, the changes occurred in the agenda of pre-transplant medical appointments, and the absence of an outpatient clinic for nursing appointments, as recommended by the Ministry of Health, due to lack of human resources.

● FINAL CONSIDERATIONS

There are several priorities for the success of kidney transplantation, and also many weaknesses imposed by the chronic condition, treatment, and surgery. The fragmented and naive knowledge presented by the participants reveals co-responsibility of professionals, patients and their families in the process of recovery from the surgical procedure and maintenance of the graft.

As a member of the health team, nurses play a relevant role in what regards the treatment modality and guidelines resulting from this choice. In this context, the role of nurses transcends the act of orienting to promote people's awareness, that is, their perception of themselves, about the situation they live, and the consequences of their choices for health, making them autonomous subjects in the relation of care.

Nursing care considers health education, the dialogic relationship, and reflection. In this process, the use of convergent-care research for nursing practice should be emphasized.

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