Original Article

It was/wasn’t everything I had imagined: advantages and disadvantages after kidney transplantation

Foi/não foi tudo o que pensava: facilidades e dificuldades após o transplante renal

Fue/no fue lo que pensaba: facilidades y dificultades después del trasplante de riñón

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ABSTRACT

Objective: To know the advantages and difficulties that people with chronic kidney disease experience after renal transplantation.
Methodology: A qualitative and descriptive study with 20 kidney transplant patients in a city in Southern Brazil, from May to July of 2013. Semi-structured interviews were used, analyzed according to the critical incident technique.
Results: The main advantages were presented in the similarity to “normal” living: advantages resulting from the kidney transplant category, related to the patient’s discharge from dialysis, food and water restriction, among others. The difficulties were presented in the permanent chronic condition and the need for care category.
Final considerations: The advantages and disadvantages depend on each person’s experience. The health professionals need to understand and promote health actions that promote the uniqueness and context of renal transplant.
Keywords: Chronic renal insufficiency. Kidney transplant. Life changing events. Nursing.

RESUMO

Objetivo: Conhecer as facilidades e as dificuldades que as pessoas com doença renal crônica vivenciam após o transplante renal**.**
Metodologia: Estudo qualitativo e descritivo, realizado com 20 pessoas transplantadas renais em um município do Sul do Brasil, de maio a julho de 2013. Utilizaram-se entrevistas semiestruturadas, analisadas conforme a técnica dos incidentes críticos.
Resultados: As principais facilidades foram apresentadas na categoria “Aproximação do viver ‘normal’: facilidades decorrentes do transplante renal”, estando relacionadas à libertação da diálise, à restrição alimentar e hídrica, entre outras. As dificuldades foram apresentadas na categoria “Permanência da condição crônica e a necessidade de cuidados”.
Considerações finais: As facilidades e as dificuldades dependem da vivência de cada pessoa. Os profissionais da saúde necessitam entender e promover ações de saúde que favoreçam a singularidade e o contexto do transplantado renal.
Palavras-chave: Insuficiência renal crônica. Transplante de rim. Acontecimentos que mudam a vida. Enfermagem.

RESUMEN

Objetivo: Conocer las facilidades y dificultades que las personas con enfermedad renal crónica viven después del trasplante de riñón.
Metodología: estudio cualitativo-descriptivo realizado con 20 personas trasplantadas renales en el sur de Brasil, de mayo a julio de 2013. Se utilizaran entrevistas semiestructuradas, analizadas según la técnica de incidentes críticos.
Resultados: Las principales facilidades se presentaron en la categoría aproximación de la vida “normal”: facilidades consecuentes del trasplante de riñón, estando relacionadas a la liberación de la diálisis, a la restricción alimentaria e hídrica, entre otras. Las dificultades se presentaron en la categoría permanencia de la condición crónica y la necesidad de cuidado.
Consideraciones finales: Las facilidades y dificultades dependen de la vivencia de cada persona. Los profesionales de salud necesitan comprender y promover acciones de salud que favorezcan la singularidad y contexto del trasplantado renal.
Palabras clave: Insuficiencia renal crónica. Trasplante de riñón. Acontecimientos que cambian la vida. Enfermería.

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INTRODUCTION

The incidence and prevalence of chronic kidney disease (CKD) have increased in the world, and renal transplantation is a surgical procedure used as a treatment indicated for patients with end – stage renal disease(1), with 5,556 surgeries in 2015(2). This procedure involves transferring a deceased or living donor's kidney to a recipient's body, and is performed so that the transplanted organ can perform the functions that patient's kidneys can no longer maintain(3), such as electrolyte stability and endocrine excretion.

This form of treatment improves kidney disease patient's quality of life, and in many cases increase their life expectancy(4) when compared with other treatments such as hemodialysis and peritoneal dialysis. However, the quality of life is subjective and changes constantly in relation to treatment outcomes, as well as the expectations of the transplant patients(5).

Renal transplantation often means independence from the dialysis machine, but it does not represent a cure for CKD, because the receptors continue to have a chronic condition. Thus, they depend on immunosuppressive drugs and the constant ambulatory medical monitoring. Their lives will have some restrictions from there on, often leading to psychological distress(6).

Transplants can cause an emotional impact and be a traumatic event that disrupts the sense of continuity and personal integrity, provoking strong emotions that require the person to mobilize all of their biopsychosocial resources during the body's process of adapting to the new organ. Furthermore, the transplant can bring about changes in self-representation and identity, with possible psychopathological impacts(7).

Despite renal transplants being a common Brazilian reality, since Brazil ranks second in number of kidney transplants(2), it is experienced by the person as a complex combination of positive and negative issues. These factors may be influenced by the patient's life cycle phase, education and socioeconomic levels.

Thus, this study becomes important for addressing the advantageous and disadvantageous encountered by kidney transplant patient's – and according to them – in their daily lives after they have performed the procedure. Despite the fact that freeing themselves from dialysis represents a "cure" for their disease and a "return" to normal activities still requires treatment and care for the rest of their lives.

Therefore, the main question of this study was "What are the advantages and disadvantages that people with CKD experience after kidney transplant?", where the objective was to get to know the advantages and disadvantages that people with CKD experience after renal transplantation.

METHODOLOGY

Qualitative and descriptive study, which used the Critical Incident Technique (CIT) as methodological framework, completing the following the steps: establishing the stud's overall objective; developing a plan for collecting information; data collection (critical incidents); grouping and categorization of critical incidents; positive and negative critical incidents frequency survey and data interpretation(8).

ICT involves all sufficiently complete observable human activity so that through it, one can make predictions about the person who performs the action. In order to be critical, an incident should occur in a situation where the action's purpose is clear its consequences are evident to the observer. In regards to behavior, it is a reaction or set of reactions that form a person's answer to a situation they experience(8-9).

Twenty transplanted patient's who fit into the following inclusion criteria took part in this study: age 18 or younger; agree to the recording of the interviews; accept the dissemination of data in scientific circles; have preserved mental faculties; do not present verbal communication difficulties; are linked to the nephrology service; have had their kidney transplant at least one year ago and have been subjected to any dialysis treatment previously. People who underwent kidney transplantation, but returned for some kind of dialysis treatment were excluded.

The study was conducted in a city in Southern Rio Grande do Sul, Brazil, in the period from May to July, 2013. After receiving the list of transplanted people, courtesy of three nephrology services, the first approach was made by telephone contact. During the call, the interviewer identified themself, the study was presented, its development purpose was explained, as were the objectives and how the collection would take place with a recorder.

After that, an invitation to participate highlighting its voluntary character and anonymity was presented. Once the person accepted, the interview dates, times and locations were agreed, according to the participant's availability, where some chose to give the interviews in their homes and others decided it would be given in a room provided by the nephrology service. The location was chosen respecting where the person would feel more comfortable to answer the questions.

Before the interview began, a Free and Informed Consent Form (FICF) was provided in writing. The document was read along with the interviewee in order to clarify doubts and the procedures used to develop the study, ensuring that participation would be voluntary, and the interviewees would be able to withdraw at any time. Then, the interviewee was asked to sign the FICF, in two counterparts, where one was given to the them and the other remained with the interviewer.

A semi-structured script with questions was used for the interviews. Questions were recorded where the total length of all answers added up to 607 minutes, and each individual response ranged from nine to 82 minutes and was held only between the interviewee and a single interviewer. At the end of the meeting, it was explained that the interviews could be divided into two other moments. This means that the first interview could have a follow-up to clarify doubts or ask questions that were missing from the first encounter, and that, during the second interview, it was guaranteed that the main results of the study would be addressed. Data collection ended after reaching a sufficient number of interviews, because there was similarity of the data.

Data were transcribed in full and read successively in order to analyze the content through thorough and continuous reading, recommended by the Critical Incident Technique, following the steps described, as follows: identification of the situation that occurred, of behaviors shown and the resulting consequences; category building, involving situations that are similar to each other, containing the name and definition in an utmost operational manner, of what it meant or represented, proceeding in the same way with the behavior and the consequences. Data were registered in a file (incidents and data on the interviewee)(8-9).

As for the ethical principles, the study's project was submitted to the Research Ethics Committee that issued its approval through opinion No. 192/2013. The principles drawn from Resolution 196/96 of the National Health Council of the Ministry of Health(10), in force at the time this study was approved, were respected. Each interviewee was identified by a code, namely, E for interviewee, followed by an Arabic number according to the sequence of interviews plus the interviewee's age (for example: E1, 43 anos).

RESULTS AND DISCUSSION

Two themes were developed after analyzing the data, which deal with the advantages disadvantages experienced by people with CKD after their renal transplantation, described below.

Similarity to "normal" living: advantages resulting from kidney transplant

This category presents the advantages that result from renal transplantation, freedom from dialysis, being able to perform social and domestic activities, the extinction of food and water restrictions, in addition not worrying about one's health. Only the main statements will be presented.

So the first of the advantages was the fact that the CKD carrier no longer needed dialysis, which was represented as freedom. This fact can be considered as a return to life before the onset of kidney disease.

> [...] *I think you have more freedom. I think that's the issue* (E5, 30 years old).

> *My life has returned to how it was before. Before I got sick* [...]. *Just being free and not needing to rely on ... "Oh, it's that time again, in a while I have to go to dialysis," you know what I mean? To me, that is a huge amount of freedom* (E8, 50 years old).

Positive feelings were shown towards kidney transplantation, especially with not having to go through dialysis anymore. This positive reference linked to the procedure was also found in a survey, namely: transplantation promotes satisfaction with the patient's new living experiences, especially due to their independence from dialysis and is considered the greatest benefit of the adopted therapy(11).

The freedom gained by transplanted people who were hemodialysis bound is owed to the lack of restrictions that result from the session schedules. In this context, the participants also stated that being independent from the dialysis treatment gave them the opportunity to carry out social / leisure activities, favoring their quality of life.

> *It improved, because I don't need to go there* [nephrology service]. *My children used to stay there with me, my husband is much calmer now. I can go out as much as I want, all I have to do now is take my medicine* (E8, 50 years old).

> *First in quality of life, transplantation has given me that. Just the fact of not relying on that machine, it makes my life totally different.* [...] *When you don't depend on the machine, you're not worried about hemodialysis, the day you need to have your hemodialysis, forgetting it. That's definitely the tranquility it brought for me. Being able to go out, to travel, because when you need to have hemodialysis, your life is restricted to that machine. You can't go out,* [...] *you don't go to the beach because your arms are ugly,*

> *people will run away from the water if you're in it. You don't travel because you have your hemodialysis schedule, so it's complicated.* [...] *I've never been that kind of guy that goes on great trips, specially because the situation never allowed me to, but then you think: I"m going to spend three days at my brother's house in Porto Alegre, except I couldn't go. So, all I could really do was spend a day, so that's complicated.* [...] *My son had three years of treatment in Minas* [Minas Gerais], *and I would spend 20 days there, every six months, so that I could go* (E11, 54 years old).

> [...] *I live more with the family now than I did before. I would virtually not step inside my home for three days a week.* [...] *There was a time I caught a bacterium in my capillary, and I was admitted to the hospital for almost 15 days. So right there it increased.* [...] *For me, what changed with the transplant was that I didn't have that obligation of staying away from home for three days a week anymore, and I can do practically everything I did before, but with more time* [...] (E14, 41 years old).

For the study participants, renal transplantation represented the ability to perform several activities previously made impossible by hemodialysis. Thus, transplantation impacted daily life positively, due to the improvement in quality of life, dialysis machine independence, travel, proximity to family, among others.

A study that aimed to know the impact of renal transplantation in the quality of life of people with CKD pointed out that the transplant had a positive impact on all areas related to quality of life, especially with regard to general perception(12).

Aside from being able to spend more time with family, there was also the opportunity to perform tasks that they were used to performing previously, including domestic tasks.

> *Just not having to be on the machines, locked in for three days of the week on the machine, five hours a day, it's a great thing. So I guess my life went back to normal. I went back to doing most of the things I used to do* [...] *I like to always be doing one thing and another. When people asked, "Oh, can you put a door up over there?" "Oh, can you do this or that?", I went there and did it* (E15, 39 years old).

> *There was no fuss after the transplant. It's a life where I don't need to, let's say, go to hemodialysis like before, it was three times a week.* [...] *I can go about the rest of the day without any worry* [...]. *I can even clean my kitchen, make food, because I make my own food. I make bread, food, I even wash some clothes too.* [...] *I don't feel anything. So to say that I feel pain or something, I don't feel anything and to me it's a quiet life, it couldn't be better in view of what life was like before* (E12, 45 years old).

One can notice that performing housework was a facilitator that interviewees highlighted and the performance of such activities is often considered as normal. They also refer to the fact that their families cannot perform such tasks, either for professional or health reasons, as shown in the following statements.

> *I do all the house work, I drive, do everything.* [...] *I work, I take the hoe* [...] *and go up on the roof, I clean it, nail something, nail another without any problem. I sweap, I do all of the housework, because my wife workd, so I stay at home and do everything. I lead a normal life; I don't feel anything. Nothing at all* (E1, 66 years old).

> *I wash, cook, tidy the house, sweep it. Everything is normal, just like a housewife would do. All of the housework. I go to the market, the pharmacy, the Bank, I do everything. There's mom as well, but she's sick too, and my husband works.* [...] (E2, 53 years old).

Being able to perform tasks, such as domestic tasks, reinforces the idea of being an active person and able to be "useful" in environment one inhabits. This fact is based on the cultural construction of society, where people need to be in constant activity in order to be recognized.

In this perspective, kidney transplantation afterlife seems to have advantages, because it influences the person's ability to develop everyday tasks, reduces pain, improves general health, vitality and social context, which favors the transplanted person's daily life and welfare(13).

Being able to participate in leisure activities was also mentioned. Thus, the act of traveling and going out to dance were the most highlighted elements. One interviewee stated that such experiences would be just like those of a normal person.

> [...] *travelling because the only thing I need is my medication* (E8, 50 years old).

> *Everything is easy for me. I do gymnastics, I go dancing, I do everything. My life is normal, the same life that you would have if, you know, if you do something or not, but it is the life of a normal person. Nothing stops you. You don't feel a pain. I at least, I don't feel pain from anything, at all* [...] (E9, 55 years old).

Leisure activities such as travel, participating in festive meetings, going to the gym, being important in people's lives. As highlighted by the participants of this study, those were tasks that the transplant allowed patient's to resume.

The kidney transplant was an opportunity to change for the best, to rebuild their life, bringing them closer to their daily lives prior to the disease, be it for those who have already been through the procedure or are waiting to have it done. In this sense, a greater chance for freedom stems from the procedure, although there are precautions(14).

Food and water intake also resulted in advantages for people after kidney transplantation, by improving their way of life. Furthermore, the fact that they were able to ingest liquids without limitations was a great facilitator.

> *Everything I couldn't eat before, here's a comparison, I could only have half an orange, not a whole orange. I couldn't eat watermelon. These fruits have a lot of liquid, you know? Nothing. Bergamot? Nothing. Now I can eat. There's no restriction. Just food itself, it's improved a lot* (E2, 53 years old).

> [...] *after the transplant, after that initial period that follows until the kidney starts working, the more liquid you drink, the better, the more the kidney works because it performs the equivalent function of two kidneys. He has to perform the function of the two as one now. So that's just in the beginning, until the kidney starts working, then you can have normal liquids.* [...] *You can take as much as I did, because I urinate normally. It's not like before when I didn't urinate and I had to control my liquid intake so that I wasn't full of liquids during dialysis. Now, there's no limite, I can just take as much as I can, as much as I want* (E3, 40 years old).

As far as the foods presented, the liberty to consume those who possess a high liquid content is seen as a freedom conquered due to the kidney transplant, since the dialysis treatment impost constant restrictions on the patient's diet and water intake, in order to avoid weight gain. Furthermore, the achievement of ingesting liquid, in this case meaning unrestricted amounts of water, may be one of the major advantages of the renal transplantation.

After the transplant, as already mentioned, the person regains their autonomy, rescues the decision-making power to come and go, eat, drink fluids according to what suits them, which promotes a sense of satisfaction(6).

Not being worried anymore, specially in relation to their health was also pointed out, and lead people to not depend on other to accomplish what they needed. In the testimony presented, having a working kidney mitigates the problems transplanted persons might have.

> *What did I consider easy?* [...] *The way I live now, I guess. It became much easier. So, not having that concern, I had several concerns. The exams going wrong, coming back with alterations and sometimes you didn't know why. And with kidney transplantation it,* [...] *the kidney started functioning normally. There was no longer a problem. Well, a number of problems. So it was much easier to live, actually.* [...] *I just have to say it was much better. Everything, everything was better. Things I depended on others to do* [...] *I now do myself, I go myself* (E15, 39 years old).

In this speech, it is possible to observe the advantages experienced by people after kidney transplants and how they reflect in their quality of life. The situations that led to freedom from dialysis treatment, and food and water consumption restrictions, returning to leisure activities and developing domestic tasks better without having any health concerns, can contribute to knowing the benefits of kidney transplantation.

Kidney transplantation rebuilds important dimensions in life, allowing greater freedom and performance in daily activities(15). Probably for this reason, a study held in the Nephrology unit of Pernambuco comparing quality of life among transplanted people and those who underwent hemodialysis scored highest in the perspective of participants who performed the graft(16).

Therefore, to have the transplant can mean leaving darkness be recovering one's "vision", allowing the beauty in things to be observed and the return of independence. This fact was described by a participant in a research conducted at a university hospital in southern Brazil, to compare transplantations with blindness(14).

Permanence of chronic condition and the need for care after surgery: disadvantages experienced by kidney transplant recipients

While kidney transplantation is considered one of the best therapeutic options for CKD, there are difficulties experienced by transplanted patient's to be presented in this category. One of them was the routine care they need to maintain, and that can affect social life.

> [...] *I can't go to the beach. I can go but I have to stay in the shade, at most take a quick dip in the ocean and immediately go back to the shade. So why should I go anyway? I just don't go* (E8, 50 years old).

This statement shows that the transplanted person ends up not partaking in certain activities, because he/she needs to follow some restrictions, such as going to the beach and abiding to some restrictins, in this case, having to stay in the shade. In this experience, freedom is gained, but at the same time the restrictions also hinder that freedom.

People imagine that with the kidney transplant life will return to "normal". However, this thinking changes, since they need continuous maintenance of a therapeutic measure, such as dietary and physical constraints, in addition to drug dependency. Thus, there is conflict once again with the pathology and its barriers(14).

Another situation was related to certain cares in order to preserve the transplanted organ.

> *Now that it's cold, it's harder, because we have to bundle up more.* [...] *You can't walk barefoot* [...]. *You have to bundle up more [*...] (E2, 53 years old).

> [...] *you can't come into contact with people who have the flu, a sore throat, any sick people, you just can't have contact with them* (E10, 46 years old).

> *I was about to go to Porto Alegre with my son, but since he's there his daughter in the hospital, I avoid going because of colds, infections, because I don't know how far I can* [...]. *The doctor just told me to avoid contact with any kind of disease, including a cold, so I just go by him* (E13, 53 years old).

Such care shows the need for those transplanted to protect themselves from the cold and contact with people. Especially those with an infectious disease, restricting the development of activities even further.

This fact was pointed out in an integrative review that listed the immunosuppressants and invasive interventions for infectious complications, where the most common infections in transplanted people were urinary tract infections, systemic infections and surgical wound infections. Thus, the review authors emphasize that the nurse needs to promote safe practices and minimize the person's exposure to complications(17).

It is believed that the study participants' conception regarding infecction prevention is related to information passed on by health professionals. As in the above study, in which one of the concerns of renal transplant should be "to remain free" of infectious processes due to the risk of losing the graft.

The interviewees also mentioned a difficulty in developing or even continuing a task due to their physical state, that at times was debilitated.

> *You can use strength a little, you just can't do anything too strenuous, like in my case, I was a farmer* [...]. *Because nowadays, most of the process is based on toxic treatments, those things they use in the field, you know, herbicides. So I can't* [...] *work on those things anymore, the heavy tools and stuff. You can't ride your bike either. If I* [...] *fall and hurt myself, my kidney may stop. So I just can't. You can ride in a car, but you have to be careful. Let's just say you can't be in a car accident. Motorcycling is not recommended, you can have an accident and get hit* [...] *right where the kidney is placed.* [...] *The kidney can move internally or something, so it's not recommended* [...] (E12, 45 years old).

> *I was a clerk in a butcher shop. I miss this part too, but I just take the lesser of evils.* [...] *how can I say this in other words, it's better to lose the saddle than the horse.* [...] *I would take the large cuts of meat, put them on my shoulder and carry it out, cut it, and now I can't because I have a fistula and the surgery* (E14, 41years old).

The restrictions imposed or the simple fact of performing tasks with the utmost caution are justified by the care that one should have in order to preserve the transplanted organ. Another fact that may limit life after kidney transplantation, is the need for a constant use of immunosuppressive drugs, according to an established schedule and also having to live with the side effects.

> [...] *it's not it's a bad thing, but the post-transplant medication we take is very strong* (E3, 40 years old).

> *So the meds that I'm always forgetting are supposed to be taken at nine o'clock in the morning and nine o'clock at night. They are few, but I end up forgetting, but I always make up for it by taking them on the same day, but I'm usually late* (E8, 50 years old).

> [...] *There was a time that I also had pain in my legs because of the medication. Not everyone gets these pains because of the medication. I couldn't walk* [...] (E19, 52 years old).

In these statements, the interviewees highlighted the fact that they forgot the schedules for taking their immunossupressants, in addition to the adverse effects, such as the presence of localized pain in the lower limbs. These are some of tje factors that end up hindering people's lives after transplantation, and may compromise adherence to treatment.

In a study that aimed to identify the main factors that influence the quality of life of 42 people with a kidney transplant in a hospital in Montes Claros – Minas Gerais, it was evident that their health was still a cause for stress after the transplant, due to complications that may happen and the need for adjustments, including therapeutical, and to living with the adverse effects of the medication(13).

In contrast, in a survey held with 21 people who had a transplanted kidney in a Hospital located in the Federal District, there was adaptation after the operation, from the continuous use of drugs, dietary control and outpatient follow-ups, and most did not have any difficulty(11). It is believed that, although the study's participants have reported some post-renal transplant adversities, the benefits prevail, and so some people mention that there are no further difficulties to the procedure, as shown by these authors.

Thus, people who are transplanted emphasize that they prefer the use of the necessary medication after the kidney transplant, as opposed to returning to their hemodialysis routine, an experience that does not bring positive memories(15).

Furthermore, it is known that one needs to pay attention to diet. Although there are statements that after the kidney transplant there was improvement in the food issue compared to when they underwent dialysis, people need to maintain restrictions, and intrersperse eating with the schedule of their immunosuppressive drugs, following a ritual, which can be considered a disadvantage after transplantation.

> *You only have top cut back on salt. You almost can't have any. Your food must have almost no salt. The less the better* (E2, 53 years old).
>
> [...] *that's the hard part, but you have to do it* [...], *you take the medication at eight in the morning, and then at nine you can eat. At nine you have to take another medication, and then you can't eat until ten o'clock in the morning. At ten o'clock you take three pills. Three pills, and then you can eat normally Then, at eight o'clock at night you start all over again* (E2, 53 years old).

Corroborating with what was mentioned by the participants in regard to the constant medication routine, in a study held with kidney recipients, they stated that the medication was part of their daily routine just like other commitments. They also said that from the time of the surgery to when they lived with the transplant, the use of medication with its due dosages consists in a practice that echoes naturally(15).

Also related to the use of immunosuppressive drugs, another problematic factor that can bring harm to people with kidney transplantation is attributed to the risk of their absence in the distribution established by the public health system. Failure to deliver or errors in prescribing the type of drug or its dosage may interfere in the treatment.

> *I came in to receive my medications once a month* [...] *and they didn't have it. And I said: What do you mean you don't have it? There's no way you can't have it. I have a kidney that took me a long time to get, that is my life and you're telling me there is no medication. No, sir, I am not leaving without medication.* [...] *So, they didn't have it and I went to the State Department of Health* [...]. *So I got there and* [...] *a young man said: "Oh no, you know, there are so many people." "Just a minute mister, one day you'll know what it's like, the day you have someone from your family in your situation, God willing you will never need it. Now, I am not leaving without my medication." And a lady in front of me, she had left the State Pharmacy without the medication and I got there and they had the medication.* [...] *So the medication had arrived, but it cam with a bad invoice so they didn't deliver it. So some people went for one or two days without medication. That, I think is absurd, it is a disrespect with human beings. That's life, they can mess up a person's life.* [...] *Now, there is a lack of willingness to help. People forget that one day it can happen to them. You know, no one is free from that sort of thing* (E7, 58 years old).
>
> [...] *they still don't have the medication* [product name]. *I´ve been without it since yesterday.* [...] *I don't know why? They said it was because the doctos increased the dosage and never gave me the prescription* [...] *and then the medication was missing here and I am freaked out with the medication, because this one is against organ rejection too* [...]. *Now I don't know what's going to happen, my brother said he was able to get it, that they were going to get two dosepacks in Arroio Grande, another city. In the end, I'm going to have to cut back on the dose because I couldn't find the medication at SUS yet. I'll have to take two a day only, when I should actually be taking two in the morning and one at night. Now I'm going to have to take one morning and one in the evening* [...]. *What if something happens to me? God forbid!* (E19, 52 years old).

The statements express the concern of people losing kidney function for not taking their medications, caused by the government not making them available or failures in prescriptions. These factors can compromise the immune system and affect the transplanted organ which, as compatible as it is, is still a foreign body to a person's organism and may be rejected. Thus, respondents showed strategies used to get the drugs, often having to seek the Health Departments or go to in other municipalities.

Problems that result from renal transplantation were also described in a survey with 21 transplanted people conducted in Mexico, who did not have access to private or public insurance, or even resources to finance renal therapy. These participants reported that what they were living after transplantation was different than health professionals had promised, such as reducing costs, returning to a normal life and achieving an improved quality of life, due the impossibility to continue treatment, in particular, as a result of economic difficulties. Thus, the fear of rejecting the organ due to the absence of immunosuppressive drugs afflicted the people involved in the study(18).

Moreover, a respondent once again stated there was a possibility of becoming ill because of a depressed immune system and that he had to travel to the city where he received the transplant in order to receive clinical care. This situation leads to a reflection on why health care can not be held in the city in which the person resides.

> *So, there's that detail, the person who is transplanted has a weak immune system. So if they get wet in the rain, they can catch a cold. If that happens, fever symptoms begin and you need to seek medical attention. But that and everything medical is only available in Porto Alegre. Unfortunately, everythinh is still only available in Porto Alegre.* [...] *Here* [city of residence] *a center is needed,* [...] *at least for basic care. If the person has a problem, afine, then the center can send that patient back to the hospital of origin, because then there have the person's entire record since the transplant. I think it would be interesting, but we currently have to go Porto Alegre to have an appointment. You lose the whole day* (E11, 54 years old).

As also seen in this speech, the constant health reviews sounded like a disadvantage, due to being held in another city, specifically where the kidney transplant was performed. Thus, one interviewee pointed out the route traveled on the day of consultation.

> *The difficult one for me is going to Porto Alegre in the morning* [...] *that you have to get up at three, two in the morning to get dressed, take a shower. I have a car, I drive, I leave it there in the Department's* [Department of Health] *courtyard, take the bus, come back, pick it up. But those who don't have a car need to go by bus or call a taxi or something, so that makes it more difficult.* [...] *It is only bad because you don't sleep, it's exhausting. Of course, you leave at three in the morning to catch a bus, you go to Porto Alegre, I sleep for the whole trip and I'm already there when I wake up* [appointment location]. *And you have to spend the whole day there, because you get blood drawn in the morning. When you arrive, you collect blood and you only see the doctor at two, three, sometimes four or five o'clock* [in the afternoon], *depends on what time you were scheduled for* [afternoon hours]. *So you have to stay in Porto Alegre all day basically doing nothing* (E9, 55 years old).

The comings and goings of the study participants to reference services in the state capital cause discomforts, because of the distance, lost time [nothing to do] and the grueling routine. Corroborating with this data, another study showed that transplanted people needed to move away from the place of origin to go to follow-up appointments in other municipalities, since they needed skilled professionals(15).

In addition to the distance between cities where interviewees live and carry out health reviews, they still live with a lack of information, mainly linked to the treatment performed. This deficiency constitutes a problematic factor experienced by people who wish to preserve the established therapy and the necessary care it comes with.

> [...]. *It's really difficult here. We lack a lot of things. The city here is difficult.* [...] *We need a lot of information here* [...] *on transplanted people, a lot of information.* [...] *No, there's nothing here.* [...] *our problem, the lack of information* [...] (E4, 55 years old).

It is observed that the participant would like to be better informed, particularly about the transplant. Thus, they are implicit possible flaws in the health system, in which effective communication, according to the needs of people, is not always the case.

In this situation, the authors mention that health professionals believe that there is a need to improve the communication system and education directed to patients and caregivers in order to improve the management of symptoms, for example, which would be beneficial to those involved in this process(19). Therefore, the person who obtains more information about their condition and treatment, will present a better quality of life(20).

Difficulties in this category sound as a warning to be known by people with kidney transplants, as well as by health professionals who care for them. Note that, despite living with the obstacles caused by kidney disease, and therefore by the transplant, they face situations that need attention, as well as those that cause concern and stress.

Despite the difficulties faced by those who experience kidney transplantation, such as having the chronic condition, the need for continuous medication and frequent monitoring, this remains the best alternative therapy for the disease, since it allows improvement in quality of life, independence from dialysis and the possibility to return to a social and professional life(13).

FINAL CONSIDERATIONS

By knowing the advantages that people with CKD experience after kidney transplantation, the following were highlighted: dismissal from dialysis and lack of food and water restrictions, being able to do everyday activities previously performed such as social and domestic tasks, and not being concerned with health issues, which may reflect positively on their quality of life. In contrast, the idealization of the disease's cure was deconstructed, from the moment people realized the limitations and difficulties that would be a part of their daily lives.

Thus, these obstacles were related mainly to the fact that they still had a chronic disease, requiring continuous medication and frequent monitoring, the side effects of drugs and the fear of not having them, to the routine care need in order to preserve the transplanted organ and cares needed to diet and the use restrictions related to salt, and performing some heavier tasks, the lack of information regarding the transplant and treatment, causing worry and stress. These factors caused a certain ambiguity in the answers, because on the one hand the patient has his or her freedom, and on the other, the restrictions that need to be followed in order to preserve the transplanted organ.

It is noticed that the same situations understood as advantages for some people can be considered disadvantages for others, which highlights the subjectivity and the way each person experiences the situation. Therefore, it is believed that the health professionals, especially nurses, need to understand and promote health actions that favor the uniqueness and context of the person with a kidney transplant.

The fact that this is a qualitative research, was considered a limitation, since it can not be generalized and works with the person's subjective aspects. This way, the need to for more qualitative studies that focus on this these is reinforced, with the intention of deepening the knowledge presented.

REFERENCES

1. Hamilton D. Kidney transplantation: a history. In: Morris SPJ, Knechtle S, organizers. Kidney transplantation. 6th ed. Philadelphia: Elsevier; 2014. p. 1-8.
2. Associação Brasileira de Transplantes de Órgãos (BR). Dimensionamento dos transplantes no Brasil e em cada estado 2008-2015. RBT Registro Brasileiro de Transplantes. 2015 [cited 2016 aug. 13];XXI(4). Available at: http://www.abto.org.br/abtov03/Upload/file/RBT/2015/anual-n-associado.pdf.
3. Manual de transplante renal. Castro MCR, revisora. São Paulo: Associação Brasileira de Transplante de Órgãos; 2010 [cited 2015 may 22]. Available at: http://arquivos.sbn.org.br/leigos/pdf/manual_renal.pdf.
4. Gill P. Stressors and coping mechanisms in live related renal transplantation. J Clin Nurs 2012;21(11-12):1622-31.
5. Denhaerynck K, Dobbels F, Steiger J, De Geest S. Quality of life after kidney transplantation. In: Veroux M, Veroux P. Kidney transplantation: challenging the future Sharjah, United Arab Emirates: Bentham Publisher; 2012. p. 71-84.
6. Fontoura FAP. A compreensão de vida de pacientes submetidos ao transplante renal: significados, vivências e qualidade de vida [dissertação]. Campo Grande (RJ): Universidade Católica Dom Bosco, Programa de Mestrado em Psicologia; 2012.
7. De Pasquale C, Veroux M, Indelicato L, Sinagra N, Giaquinta A, Fornaro M, et al. Psychopathological aspects of kidney transplantation: efficacy of a multidisciplinary team. World J Transplant. 2014;4(4):267-75.
8. Flanagan J. La technique de l'incident critique. Rev Psychol Appl.1954;4(2):165-85.
9. Estrela MT, Estrela A. A técnica dos incidentes críticos no ensino. 2. ed. Lisboa: Estampa; 1994.
10. Ministério da Saúde (BR), Conselho Nacional de Saúde. Resolução nº 196, de 10 de outubro de 1996. Diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Diário Oficial [da] República Federativa do Brasil. 1996 out. 16;134(201 Seção 1):21082-5.
11. Sousa AMD, Dutra LMA. Qualidade de vida dos pacientes submetidos a transplante renal no Hospital Regional da Asa Norte. Comun Cienc Saude. 2013;24(1):9-20.
12. Mendonça AEO, Torres GV, Salvetti MG, Alchieri JC, Costa IKF. Mudanças na qualidade de vida após transplante renal e fatores relacionados. Acta Paul Enferm. 2014;27(3):287-92.
13. Carvalho MTVF, Batista APL, Almeida PP, Machado DM, Amaral EO. Qualidade de vida dos pacientes transplantados renais do Hospital do Rim. Motricidade. 2012;8(S2):49-57.
14. Quintana AM, Weissheimer TKS, Hermann C. Atribuições de significados ao transplante renal. Psico (Porto Alegre). 2011 [cited 2015 aug. 06];42(1):23-30. Available at: http://revistaseletronicas.pucrs.br/ojs/index.php/revistapsico/article/view/6057/6295.
15. Arruda GO, Renovato RD. Uso de medicamentos em transplantados renais: práticas de medicação e representações. Rev Gaúch Enferm. 2012;33(4):157-64. Available at: http://www.scielo.br/pdf/rgenf/v33n4/20.pdf.
16. Teixeira CG, Duarte MCMB, Prado CM, Albuquerque EC, Andrade LB. Repercussão da doença renal crônica na qualidade de vida, função pulmonar e capacidade funcional. J Pediatr. 2014;90(6):580-6.
17. Lucena AF, Echer IC, Assis MCS, Ferreira SAL, Teixeira CC, Steinmetz QL. Complicações infecciosas no transplante renal e suas implicações às intervenções de enfermagem: revisão integrativa. Rev Enferm UFPE On Line. 2013 [cited 2015 aug 06]; 7(esp):953-9. Available at: http://www.lume.ufrgs.br/bitstream/handle/10183/85366/000875872.pdf?sequence=1&locale=pt_BR.

18. Mercado-Martínez FJ, Hernández-Ibarra E, Ascencio-Mera CD, Díaz-Medina BA, Padilla-Altamira C, Kierans C. Viviendo con trasplante renal, sin protección social en salud: ¿qué dicen los enfermos sobre las dificultades económicas que enfrentan y sus efectos? Cad Saude Publica. 2014;30(10):2092-100.
19. Feldman R, Berman N, Reid MC, Roberts J, Shengelia R, Christianer K, et al. Improving symptom management in hemodialysis patients: identifying barriers and future directions. J Palliat Med. 2013;16(12):1528-33.
20. Guedes KD, Guedes HM. Qualidade de vida do paciente portador de insuficiência renal crônica. Rev Cienc Saude. 2012;5(1):48-53.

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