

Reflections on the meanings, experiences and perspectives of chronic kidney patients after kidney transplantation

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Keywords— *Kidney Transplantation. Quality of Life. Emotions. Renal Insufficiency, Chronic.*

Abstract— *Objective: to investigate the meaning, experiences and perspectives of people with chronic kidney failure undergoing kidney transplantation. Method: descriptive, exploratory research of a qualitative nature. An interview script was used as an instrument and a semi-structured interview was used as a collection technique. Ten people who underwent kidney transplantation, registered with the Association of Chronic Kidneys and Transplants of the State of Pará, Brazil, participated in the research. Research conducted from October to November 2018, and for the construction of data, the thematic content analysis technique proposed by Bardin was used. Result: the participants believe that the transplantation gave them an opportunity for a new life, recognizing that it allowed them to experience well-being, satisfaction and emotional growth, which, therefore, allowed them to resume the quality of life and conditions prior to illness. Conclusion: kidney transplantation has a meaning of blessing and represents the expectation of being able to resume their lives, and continue from where it was interrupted by kidney disease; it represents, from the perspective of these individuals, the hope of a better life and of being able to envision a healthier future, which may require the collaboration of family members and health professionals, and personal care peculiar to the transplant recipient's new life condition.*

I. INTRODUCTION

Kidneys are organs located in the posterior region of the abdomen, outside the retroperitoneal cavity. They perform several important functions for body homeostasis, such as excretion of metabolites and foreign chemicals; regulation of the balance of osmolarity, water and electrolytes in the body; regulation of systemic blood pressure; the acid-base balance; regulation in the production of red blood cells among other functions. To perform these functions, the organ has the nephron as a functional unit, where each kidney contains about 800,000 to 1 million nephrons, performing the function of blood filtration. The kidney does not have the capacity to regenerate its nephrons, therefore, any kidney damage, aging, and other comorbidities have the potential to reduce the number of nephrons, without the possibility of tissue recovery¹.

Chronic kidney failure is a disease that causes structural or functional damage to the kidneys. Slowly, insidiously and irreversibly, it causes a decline in the number and function of nephrons. Such pathology can be caused by other underlying etiological factors, such as: genetic abnormalities, systemic arterial hypertension, obesity, smoking, autoimmune diseases, glomerulonephritis and other diseases².

Due to the progressive loss of renal tissue, several organic and psychosocial changes begin to appear, and this directly interferes with the quality of life of people affected by chronic renal failure. Urine color, pain or burning when urinating, urination several times a day and night, hypertension, nausea and vomiting, loss of libido, tiredness and muscle atony are common symptoms of chronic renal failure. The uremic crisis, consequence and most serious clinical condition of renal failure, occurs because the blood ends up not being filtered properly, and thus, several metabolites remain in the bloodstream, triggering a cascade reaction at the systemic level³.

This disease is currently configured as a public health problem with a global impact. This statement is due to the fact that the morbidity and mortality rate is high, in addition to the negative impact on people's quality of life. Over the years, the number of patients who have been undergoing dialysis treatment, one of the therapeutic strategies in the management of chronic renal failure, has been gradually increasing, causing direct and indirect impacts on public coffers, patients and their families. It is estimated that, worldwide, diseases of the kidney and urinary tract are responsible for approximately 850 million deaths annually, and chronic renal failure increases around 8% each year. In Brazil, about 12 million people have

some degree of Kidney Failure and approximately 95 thousand chronic kidney patients depend on dialysis to survive^{4,5}.

There are three different types of treatment for chronic renal failure, which are: hemodialysis (HD), peritoneal dialysis (PD) and kidney transplantation (TxR). Hemodialysis consists of filtering the blood through a machine, which performs the kidney function. Peritoneal dialysis is the process where the kidney function is replaced by a filter that uses the force of gravity to do this work inside the patient's body through a cavity between the organs (peritoneal cavity). TxR is a surgical option, where there is removal of a kidney, in a living or deceased person (organ donor), and its implantation in the recipient. Kidney transplantation is the most complete treatment alternative, in this sense, it is essential to understand and clarify the alternatives for the patient, considering that he has the right to choose or refuse⁶.

When opting for the treatment of chronic renal failure through kidney transplantation, patients have a tendency to believe that their lives will return to conditions prior to diagnosis. However, this therapeutic modality requires several restrictions (food, physical, and pharmacological - through immunosuppressants). When they become aware of these facts, various feelings such as guilt, remorse and hopelessness surface, mobilizing in the individual a feeling of loss of autonomy, quality of life, fragility and grief⁷.

In addition to the difficulties inherent to kidney transplantation, individuals are challenged to live with a range of negative factors, such as side effects and changes in drug dosages, psychosocial pressure to return to their autonomy and difficulties in professional (re)adaptation⁵.

In this context, conditions emerge that directly impact the quality of life, understood as the human notion about the degree of satisfaction in their family, love, socio-environmental and existential aesthetics. The set of these factors is what society considers as a standardization of comfort and well-being, which is impacted by a chronic disease such as kidney failure⁷.

Given the above, we aim to investigate the meaning, experiences and perspectives of people undergoing kidney transplantation, registered in the Association of Chronic Kidneys and Transplants of the State of Para, Brazil.

II. METHOD

Descriptive, exploratory study with a qualitative approach, carried out in an Association of Support for Chronic Kidney and Transplant People in the State of Para, Brazil, from October to November 2018.

Ten patients participated in this research, who were identified through alpha numeric codes, with the following name: "P1, P2..." where the "P" means participant and the number the order in which they were addressed in the interview.

An interview script was used as an instrument for data collection, and a semi-structured interview was used as a technique, in which the interviewees' statements were recorded for transcription, analysis and interpretation. The sampling was carried out for convenience, through the snowball process, where respondents and/or service professionals indicated individuals to participate in the research.

Sampling was closed by saturation around two thematic axes. Minayo (2017), describes that in this type of research, the researcher closes the group when after the information collected from a certain number of individuals, new interviews start to present a number of repetitions in its content⁸.

The inclusion criteria were: people undergoing kidney transplantation, of both genders, aged between 18 and 60 years old, with the ability to dialogue, registered with the State Association of Chronic Kidney Transplants. The following were excluded: people who were not submitted to the kidney transplantation procedure, those who were not in full mental faculties or had speech limitation.

The content of the interviews was transcribed in an original way, preserving the expressions used by the participants. However, to use them as a unit of analysis, spelling corrections were made, excluding language vices, exchange or absence of letters, but keeping the linguistic vices that present meaning in the context of speech.

From the collection of information, it was followed to the construction of data, from the methodological

framework of thematic content analysis proposed by Bardin (BARDIN, 2016)⁹. The corpus of the study made it possible to organize the content into empirical categories, grouped according to the theme extracted from the responses. The results allowed the construction of four empirical categories, namely: Understanding of life before transplantation; Knowledge and meanings about kidney transplantation; Transplant recipients' understanding of the changes that occurred after the procedure and the main difficulties encountered, and Changes and improvement in the quality of life after the transplant.

This research was submitted to the Research Ethics Committee (CEP) of the University of the State of Pará (UEPA), Brazil, with the Certificate of Presentation and Ethical Appreciation - CAAE: 98289218.8.0000.5170, with approved opinion, number 2.997.807. All participants signed an Informed Consent Form and a Voice Recording Authorization Form before participating in the study.

The research was carried out following the norms that regulate research involving human beings contained in resolution n. 510/16 National Health Council (CNS)/ National Research Ethics Commission (CONEP).

III. RESULTS

Among the ten participants, six were male and four female. Age ranged from 35 to 56 years, mean of 48.6, median of 49.2 years, with a standard deviation of 6.4. Half of them were single (50%), 30% have high school and higher education, respectively. The predominant religion is Catholicism with 70% and the transplant time ranged from 1 to 14 years.

Participants were characterized according to marital status, gender, age, education, religion and time since transplantation (Chart 1).

Chart 1 - Characteristics of study participants, according to marital status, gender, age, education, religion, transplant time, Belem, Para, Brazil, 2018.

Participant	Gender	Age	Marital status	Education	Religion	Transplant time
P1	Female	35	Divorced	Elementary school incomplete	Catholic	7 years
P2	Male	49	Married	Elementary school incomplete	Catholic	7 years and 6 months
P3	Female	49	Single	Complete high school	Catholic	7 years and 10 months
P4	Female	50	Married	Elementary school	Catholic	14 years
P5	Male	56	Single	Incomplete high school	Catholic	1 year and 8 months
P6	Male	52	Single	University education	Catholic	5 years and 3 months
P7	Male	56	Married	University education	Spiritist	2 years and 6 months
P8	Female	41	Single	Complete high school	Catholic	6 years and 4 months

P9	Male	47	Single	Complete high school	Evangelical	3 years and 4 months
P10	Male	51	Married	University education	Evangelical	11 months and 20 days

Source: Prepared by the authors, field research, Belém, Pará, Brazil, 2018.

The results indicate aspects related to experiences, senses and meanings attributed to important and significant changes that occurred in the lives of people undergoing kidney transplantation, thus defining the following categories resulting from the research.

Understanding life before transplantation

This first category describes the meanings attributed by the participants to the experiences before the transplant, highlighting issues related to CRF and the treatment of renal replacement therapy, especially hemodialysis, considering that this is a process that causes discomfort and impacts on various aspects of life of people. Thus, the speeches allowed to understand that this therapy seems to be understood as a form of "imprisonment" that leaves marks in people's lives even after undergoing kidney transplantation, considering that the interviewees mention hemodialysis treatment as a difficult and arduous, as can be seen in the following reports:

"[...] The life of hemodialysis patients is not easy" (P3).

"[...] I say that I was hostage to a machine" (P3).

"[...] Now I have freedom. I want to do something, I go there and do it" (P5).

"[...] You need to undergo hemodialysis all the time, you have the problem of not drinking water, the problem of traveling! I couldn't travel. I had no life. I was a prisoner of that machine" (P2).

"[...] Difficult, very difficult" (P10).

Knowledge and meanings about kidney transplantation

This category analyzes people's knowledge about kidney transplantation, the meanings attributed to this therapy and how it intertwines and impacts in different ways on the continuity of life. The speeches allowed the understanding that the interviewees had no knowledge about the disease before the diagnosis, as observed in the following reports:

"[...] Nothing, I didn't know anything! Today I know a lot more, and I will be more careful" (P1).

"[...] No, I never knew (pause) anything. I found out when I got sick. I had a lot of hope in having the transplant, it was a lot of suffering to wait for the kidney, a lot of anguish" (P2).

"[...] I was ignorant in this part. I had never heard of a kidney problem, or hemodialysis, or anything. What I do know is that it was extremely distressing to wait for the transplant" (P8).

"[...] Before, I knew almost nothing, I confess" (P9).

"[...] I even attended some lectures. I asked my clinic doctor a lot, but I was always very limited in this matter" (P10).

In this study, participants highlighted kidney transplantation as significant, especially for those on hemodialysis. The expectations of a transplant are related to the hope of a new life, of improving their biopsychosocial and spiritual condition.

It is highlighted that transplantation has a meaning of hope and faith, providing the person with the opportunity to gather conditions to free themselves from the dependence of hemodialysis, resume their autonomy of life and continue their daily routines. And among the highlighted aspects that most contribute to such reframing, the time and feelings they experienced during the hemodialysis process and the changes that occurred after the transplant stand out.

Discourses were identified that allow us to understand the meaning attributed to the kidney transplantation procedure, and how it is related to the improvement in the quality of life after the procedure. People related the idea of kidney transplantation as something that set them free, as evidenced in the statements:

"[...] I was reborn. Today I know a lot more, and I will be more careful" (P1).

"[...] For me, an improvement in life. I started to know about things I didn't know, even taking certain precautions in my diet, in my way of acting" (P2).

"[...] 100% improved. I feel reborn... Because that machine over there (pause), that over there is not life! Of course we live because we have to. I feel reborn, another life." (P4).

"[...] Improved. No need is going to the hospital, stuff! It's not in a machine. Regarding health, it has changed, I am no longer a hostage to that machine" (P8).

"[...] It's like I said... the fact of being able to do those things that were prevented from doing again, right, reborn. Renewed faith" (P10).

Understanding of transplanted individuals about the changes that occurred after the procedure and the main difficulties

In this category, discourses were identified that allow us to infer that transplantation enabled significant changes in people's daily lives, as well as the main difficulties experienced by the participants. Data emerged that associate well-being and emotional growth after transplantation, and consequently significant and positive changes in quality of life. A highlight was given to changes related to food, travel, leisure, return to family life, and independence from the hemodialysis machine, as can be seen in the speeches:

"[...] It improved in relation to food and water intake, liquids in general" (P1), (P5).

"[...] The first change was that I was able to return to my house. to live again with my family (pause), because I used to live here, and the husband had to stay in my city! Many good things, I'll tell you, the first thing I know is this (pause) to be able to go home again" (P4).

"[...] Big life changes. Now I can do what I did before. Whenever I can, I still go with my friends to "ball" (P7).

"[...] Change of life. Look for a job. (P6).

"[...] I left the hemodialysis machine" (P8).

Changes and improvement in quality of life after transplantation

Results show that participants attribute a new meaning to this new life that begins with kidney transplantation. Lifestyle changes, mainly related to hemodialysis treatment, emerged as something that profoundly affects the daily lives of these individuals in family, professional and social relationships, which end up modifying habits and lifestyle.

The return to daily routines was highlighted, as they no longer needed the hemodialysis machine. From the findings, it is inferred that the quality of life was restored and resignified, with a return to their autonomy, which allowed them to perform activities that were previously impeded due to the limitations imposed by the disease. The speeches revealed show that people attribute a new meaning to life, referred to here as "new life", as they report:

"[...] I started to know about things I didn't know, even taking certain precautions in my diet, in my way of acting! New life" (P2).

"[...] Yes, it's almost normal. Can I drink water! I take medication, but now it's all reduced. I took 3, I took 2, I took 1" (P6).

"[...] Improved. There's no need to go to the hospital and stuff, it's not on a machine. Regarding health has changed, I'm no longer hostage to that machine, new life!" (P8).

"[...] It didn't get better, it was excellent". I started to eat better, the quality of life improved, I go out more, I can go on a trip, I feel reborn" (P3).

IV. DISCUSSION

Understanding life before transplantation

Feelings of uncertainty, sadness and frustration were reflected in the speeches, allowing us to understand the difficulties faced by the patients in this study, regarding the limitations and clinical manifestations underlying the chronic disease and its hemodialysis treatment, and these findings are in line with other studies^{10,11}. The statements highlight feelings of "imprisonment" or "dependence on the machine" during the hemodialysis treatment sessions, and reports of hope and freedom were associated with TxR.

A world full of rules and treatment routines surrounding the patient was something that emerged as a great nuisance and that has a profound impact on the quality of life of people with chronic kidney disease. Hemodialysis sessions take place in a period of three to four hours, on average three times a week, and this has a significant impact on the daily routines of the participants in this study¹².

In this perspective, corroborating the findings, Santos and collaborators (2016) report that kidney transplantation is a treatment that considerably improves the quality of life of people with chronic renal failure. The freedom gained after the transplant is comforting to them, as they feel free to do things they could not do before. However, it is noteworthy that in this context, the person and the family are presented with various cares that a person should have when receiving a new kidney, as the transplant does not exclude the chronic character of kidney disease¹³.

Knowledge and meanings about kidney transplantation

Regarding knowledge, it was found that prior to transplantation, participants had low levels of knowledge about the subject. From these findings, it is inferred that the topic was little discussed during the course of treatment of those surveyed, supporting the development of taboos, myths and mistaken beliefs. For Santos and collaborators (2018), every treatment performed through transplantation causes several hesitations, ambiguities and uncertainties in patients. In view of such complexity, education and awareness policies about kidney

transplantation are needed, aimed at professionals, students in the health areas and the general population⁷.

Regarding the meanings attributed by the participants, the findings allow interpreting the awareness of transplantation as a new beginning, a new chance to live. Feelings and expectations of hope emerge around the transplant, and these feelings that permeate the experiences of patients are supported by the desire to have a new life, a significant change in the quality of life and the desire to start over.

In the meantime, the possibility of transplantation is presented as a reality since when people are notified about the need and possibilities for treatment, and consequently the inclusion of this in the transplant “queue” (Single National Registry in Brazil); and this possibility is understood as the only resource and way to return to the conditions of life before the disease, a real possibility of cure and return to a so-called “normal” life⁵.

Understanding of transplanted individuals about the changes that occurred after the procedure and the main difficulties

The speeches allowed us to infer that the transplant enabled the reestablishment of the biopsychosocial and spiritual state, enabling the performance of activities of daily living, which were previously impeded by the disease and treatment routine.

Based on the findings, we consider that transplantation provided a new existential meaning to patients. We emphasize the search for new ways and means of living in the face of conditions after transplantation, taking into account that the patient still experiences the constant risk of organ rejection, requiring the daily use of immunosuppressive drugs, and adaptation to a new Lifestyle.

Silva (2015) states that the expectation that comes from performing the transplant procedure is related to the feeling of freedom that comes from not depending on hemodialysis machines and the obligation of weekly sessions of this treatment¹⁴. In the reports, it was noticeable that the feeling of hope was renewed after the transplant and that there were significant and beneficial changes, which allowed the expression of feelings of joy, reestablishment of dreams and perception of freedom.

Changes in physical fitness and health were another point reported. On this subject, Navarrete and Slomka (2014) corroborate the evidence of new horizons and hope after kidney transplantation, linked to the desire to have a new life and significant change in quality of life¹⁵.

This statement was confirmed by Brito and collaborators (2015), stating that the meaning of

transplantation involves an expectation of increased quality of life and hope for a better life, especially the belief in the freedom and independence of the hemodialysis machine⁵.

Changes and improvement in quality of life after transplantation

We can see that despite the different meanings attributed by patients to kidney transplantation, the experience after transplantation enabled a feeling of expectation for a better life. It should be noted that the expectation attributed to kidney transplantation encompasses the sociocultural dimensions existing in the life of each individual submitted to it.

Although kidney transplantation improves the patient's life in several aspects, it is necessary to understand that this procedure does not exclude the chronic nature of the disease, since the person will still have certain limitations and dependencies on care, medications, professional monitoring and institutions of health. It is understood that the person needs to reinvent themselves in the way they will live, looking for other ways to deal with their limitations and at the same time being more autonomous than they were before the transplant. Therefore, it is essential to monitor health professionals, especially nurses, to assist in this path of seeking to improve quality of life⁵.

Kidney transplantation allows the patient to ingest a less rigorous diet, compared to before the transplant, and thus can ingest water normally. Water is a vital element for human beings. One of the factors that increase the quality of life is the possibility of this person being able to ingest this fluid without worry, since during dialysis treatment, they remained with restrictions on the amount of fluid ingested in a certain period¹⁶.

In this study, we showed that after kidney transplantation, people had a significant improvement in their quality of life in its broadest dimension. Discourses emerged with reports of returning to activities of daily living which were impossible before the transplant. Participants consider that their autonomies were almost completely restored, which also contributed to an improvement in their quality of life.

Corroborating these findings, Brito and collaborators (2018) describe that kidney transplantation, in addition to allowing the rehabilitation of the patient to a normal lifestyle, also allows for significant savings for the health system. It is worth mentioning that, although transplantation has been considered the most cost-effective treatment, one must consider the setback in organ harvesting and the need for a well-structured and

equipped transplant center, in addition to a clearly defined and competent multidisciplinary team⁵.

Thus, the disease process caused by pathologies, in this case, kidney, gives the possibility for individuals to reflect on their lives and values, since they were between life and death, and now, they are receiving new opportunities conquered after the transplant. Transplant recipients, in most cases, believe that they have been given a new encounter with life, a moment in which the values previously learned are rethought; understand and recognize the real meaning of being alive, assuming a personal commitment to valuing life⁷.

Regardless of the various positive and negative characteristics that transplantation produces in patients with chronic renal failure, it is evident that the performance of this procedure enables a new meaning in their lives, which were marked by the realization of dialysis sessions for a long period. Quality of life is directly related to hope and spirituality, the greater the tranquility and happiness of a person, the greater the chance of having a high quality of life, which we believe that in the context of life of people with chronic kidney disease is a very affected dimension due to the strenuous treatment routine and the limitations imposed by the disease^{5,17}.

V. CONCLUSION

The methodological resource applied allowed the understanding of the meaning, experiences and perspectives of people with chronic renal failure undergoing kidney transplantation, thus responding to the objective proposed in this study. In the meantime, we found that kidney transplantation aims to promote quality of life and enable greater autonomy, despite the need for care in the follow-up of treatment after transplantation, given the chronic nature of kidney disease that does not end with realization of this therapeutic modality.

The view of transplant recipients indicated that expectations in relation to kidney transplantation were achieved after the procedure was performed, giving rise to the feeling of rebirth and change in life. It was observed that the understanding of chronic renal failure and kidney transplantation were deficient, and that only after the start of treatment, this understanding was made possible.

This study provided understanding that kidney transplantation has a meaning of blessing for the person with chronic renal failure, and represents the expectation of being able to return to a healthy life and continue from where it was interrupted; it represents the hope of a better life and of being able to see a healthier future again, which

requires the collaboration of family members and health professionals, and personal care peculiar to the new condition of life, thus characterizing the network of care and support for the person transplanted.

We evidence that the independence of hemodialysis treatment, the fact of being able to better plan life, making it calm and normal, the feeling of well-being, the adoption of health care and the inexistence of some restrictions in the activities to be performed, counterbalanced with factors related to changes in dreams, changes in interpersonal relationships, obligation to use immunosuppressive medication, non-performance, the realization that the durability of the transplanted organ is not eternal, in addition to the constant search for knowledge of rights and way people should act.

We found in the testimonies that, although there were changes in the person's life, the transplantation process did not represent significant changes that would lead to suffering or despair. On the contrary, it represented a new way of life, which was permeated by a better quality of life.

Regarding what the transplantation process provided in people's lives, we highlight, based on the speeches, the independence of hemodialysis treatment, the existence of a quiet and normal life and the feeling of well-being. The transplant promoted changes that led to a new reality. Although important changes have taken place in the person's life, kidney transplantation did not represent significant changes that would lead to suffering.

The illness experience of kidney transplant recipients integrates meanings about the disease to the meanings constructed throughout their narrated life trajectories, based on the meanings of the phase in which they experienced hemodialysis, the way the transplant was performed and, now, as transplanted.

We highlight the importance of a network of health services that offer care to people in this condition, as they need continuous monitoring. The contribution of this study, in the voice of kidney transplant recipients, reveals their health needs, from the moment the need for the procedure is identified, until the moment they start living in the transplanted condition, in addition to highlighting that the nursing and a multidisciplinary team play a key role in the construction of positive meanings in the lives of kidney transplant recipients.

With the results of this study, we understand that it is necessary to train new professionals in this area, so that there is greater attention to patients who will undergo such procedures, and thus, proper awareness of this topic is given. Further studies are also needed, addressing the health professionals who provide care for these people, in

order to better understand the process of sensitization between professionals and patients.

In this sense, it is expected that this study will contribute to the construction of knowledge related to the person's life after kidney transplantation. And so, health professionals, especially nurses, have theoretical support to assist in this experience, which is permeated by positive and negative consequences.

It should be noted that, like all scientific studies, this research has some limitations that can be minimized in future work. One of them is the small number of participants, from a specific region of Brazil, making it difficult to generalize the results obtained, which, however, enabled us to reach the proposed objective. Another limitation, despite all the precautions, concerns the possible information biases on the part of the interviewees, such as lack of attention or understanding, rush to respond, self-censorship and fear of being identified through the statements, considering the fact of being few participants in this scenario in the State.

However, these limitations in no way devalued the results obtained and the conclusions we reached. The work records the meaning, experiences and perspectives of people undergoing kidney transplantation, and its results can serve to raise discussions and future comparisons, as this type of study should try to cover a greater number of institutions, states and people who experience chronic renal failure undergoing kidney transplantation in Brazil and worldwide. It is concluded that this study corroborates to reveal the vision and meaning of the experiences of kidney transplanted people on the importance and impacts of transplantation in their lives.

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