



REFLECTION

Renal donor's life path: memories, resilience and altruism*

Trajetória de vida de doadores renais: memórias, resiliência e altruísmo*

Ruta de vida de los donantes renales: recuerdos, resiliencia y altruismo

Fernando de Souza Silva¹ <https://orcid.org/0000-0003-4225-8889>

Clélia Albino Simpson

 <https://orcid.org/0000-0003-4960-8589>

Felismina Rosa Parreira Mendes

 <https://orcid.org/0000-0001-9518-2289>¹Federal University of Rio Grande do Norte, Rio Grande do Norte, Brazil. ²University of Évora-Portugal, Portugal.

ABSTRACT

OBJECTIVE: to analyze how narratives that mark the life trajectory of renal donors. **METHODOLOGY:** Exploratory, descriptive research and a qualitative approach. After the apprehension and analytical preparation of the audio recorded reports, using the oral life history technique, Bardin's content analysis was carried out, which consists of the stages: pre-analysis, exploration of the material or coding, treatment of results, inference and interpretation of the thematic axes that emerged. **RESULTS:** The sample of 12 kidney donors who underwent transplantation at Hospital Universitario Onofre Lopes-UFRN, answered the guiding questions: How was your life before kidney donation. How is your life after kidney donation. The narratives converged on the themes "experiences lived before kidney donation" and "experiences lived after kidney donation". Employees identified the disease as a tragic moment and kidney donation as a means of minimizing the suffering experienced by the family. **CONCLUSION:** Employees recognize more positive interferences from kidney donation, mainly the improvement in the quality of life of donors and the social recognition of the nobility of the kidney donation act.

KEYWORDS: Kidney transplantation. Living donors. Life change events.

RESUMO

OBJETIVO: analisar as narrativas que marcam a trajetória de vida dos doadores renais. **METODOLOGIA:** pesquisa exploratória, descritiva e de abordagem qualitativa. Após a apreensão e preparo analítico dos relatos gravados em áudio, por meio da técnica da história oral de vida, realizou-se a análise de conteúdo de Bardin que consiste das etapas: pré-análise, exploração do material ou codificação, tratamento dos resultados, inferência e interpretação dos eixos temáticos que emergiram. **RESULTADOS:** a amostra de 12 doadores renais que se submeteram ao transplante no Hospital Universitário Onofre Lopes-UFRN, respondeu às questões norteadoras: como era sua vida antes da doação renal? Como é sua vida após a doação renal? As narrativas convergiram para as temáticas "experiências vividas antes da doação renal" e "experiências vividas após a doação renal". Os colaboradores enredaram o acometimento da doença como um momento trágico e a doação renal como meio de minimizar o sofrimento vivido pela família. **CONCLUSÃO:** os colaboradores reconhecem mais interferências positivas da doação renal, principalmente a melhoria na qualidade de vida dos doadores e o reconhecimento social da nobreza do ato da doação renal.

PALAVRAS-CHAVE: Transplante de rim. Doadores vivos. Acontecimentos que mudam a vida.

RESUMEN

OBJETIVO: analizar las narrativas que marcan la trayectoria de vida de los donantes de riñón. **METODOLOGÍA:** Investigación exploratoria, descriptiva y del enfoque cualitativo. Después de la aprehensión y preparación analítica de los informes grabados en audio, utilizando la técnica de historia de vida oral, se realizó el análisis de contenido de Bardin, el cual consta de las etapas: preanálisis, exploración del material o codificación, tratamiento de resultados, inferencia e interpretación de los ejes temáticos surgidos. **RESULTADOS:** La muestra de 12 donantes de riñón sometidos a trasplante en el Hospital Universitario Onofre Lopes-UFRN, respondió a las preguntas orientadoras: Cómo era su vida antes de la donación de riñón. Cómo es tu vida después de la donación de riñón. Las narrativas convergieron en los temas "experiencias vividas antes de la donación de riñón" y "experiencias vividas después de la donación de riñón". Los empleados identificaron la enfermedad como un momento trágico y la donación de riñón como una forma de minimizar el sufrimiento vivido por la familia. **CONCLUSIÓN:** Los empleados reconocen las interferencias más positivas de la donación de riñón, principalmente la mejora en la calidad de vida de los donantes y el reconocimiento social de la nobleza del acto de donación de riñón.

PALABRAS CLAVE: Trasplante de riñón. Donantes vivos. Acontecimientos que cambiam la vida.

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INTRODUCTION

Chronic renal failure has a progressive and irreversible loss of tubular, glomerular, and endocrine renal functions impairing its metabolic, hormonal, and homeostasis activities and generating hydro-electrolytic imbalance, neurological, cardiovascular, gastrointestinal, muscular, and osteoarticular complications⁽¹⁾.

There are different causes commonly related to kidney failure. The primary causes (glomerulonephritis, pyelonephritis, and obstructive syndromes), the systemic causes (diabetes mellitus, high blood pressure, and autoimmune diseases), those transmitted by heredity (polycystic kidneys, Alport's syndrome, and cystinosis), and the atypical congenital formations (renal agenesis, bilateral renal hypoplasia, and posterior urethral valve)⁽²⁾.

The patient and his family together with the medical team must choose the most appropriate therapeutic modality. However, they must also consider the clinical status and social factors of the person affected by chronic renal failure⁽³⁾. Some therapeutic modalities are conservative treatment and renal replacement therapies.

Renal replacement therapy consists of the institution of treatments that maintain renal function, partially such as the dialysis (hemodialysis and peritoneal dialysis), or entirely such as renal transplantation⁽⁴⁾.

Kidney transplantation is characterized by the replacement of a kidney incapable of maintaining hydro-electrolytic and endocrine excretory stability, by a healthy kidney which can be donated by a living person, with or without a family connection, or by an individual with brain death⁽⁵⁾. The procedure requires biological, ethical, and legal prerequisites that cannot be disregarded⁽⁶⁾.

Kidney transplantation has been considered the preferred choice as a painless procedure after the discomfort caused by the surgical procedure, quickly reintegrating the individual into social life, allowing greater adherence to working practices, improving the physical and mental condition and the need for less time to perform the treatment.

Transplantation with a living donor is considered a minimal risk procedure for those who donate. The United States of America registered perioperative mortality rates between 0.03% and 0.06% mainly due to pulmonary embolism, arrhythmias, and infarction. Other complications after uninephrectomy can be arterial hypertension, proteinuria, and chronic renal failure⁽⁴⁾.

Although kidney transplantation with a living donor is a very frequent therapeutic modality, the long-term consequences of uninephrectomy for the donor are not clear, needing to carry out other studies that may help to better understand the possible repercussions arising from the donation act in life^(6,7,8).

A better understanding of the life context of kidney donors is a primary tool for the optimization of nursing care, in which its humanistic mission seeks to understand the individual and his multifaceted condition^(9,10).

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We justify this study because chronic renal failure is a serious and growing public health problem, with a consequent increase in the number of interventional transplants in the world. However, we need further clarification of the repercussion of uninephrectomy in the life of living kidney donors after a long term^(6,7).

Thus, the objective was to analyze the narratives that mark the life trajectory of kidney donors to identify possible interferences of donation in the daily life of donors.

METHOD

This is qualitative, exploratory, and descriptive research, using data collection technique and methodological reference as the oral life history. The study was carried out at the Kidney Transplantation Unit of Hospital Universitário Onofre Lopes (HUOL) - UFRN as a reference in nephrological treatment in the state of Rio Grande do Norte.

We chose the participants according to the established inclusion criteria: a minimum of one year of kidney donation; having donated the kidney at the Hospital Universitário Onofre Lopes-UFRN; not presenting speech disorders that prevent the recording of narratives, such as aphonia and dysarthria.

According to the oral life history method, the research participants must be called collaborators since the researcher is committed to carrying out the study according to the scientific method, and the participant is committed to collaborating with the reports of the lived experiences and the defense of their ideologies and worldviews. Collaborators are not only proactive participants or objects of study but builders of individual knowledge, in the socially lived experiences⁽¹¹⁾.

In studies of oral life history, the networks of collaborators are people who, in addition to meeting the inclusion criteria, are indicated by other collaborators interviewed. In this sense, the size of the network is determined when there are no further indications⁽¹¹⁾. The network had 12 collaborators.

The first collaborator of the network is called zero points. According to the oral life history method, this collaborator must be an individual who knows the group of people who experienced the situation that is the subject of the study and, therefore, can indicate other collaborators⁽¹¹⁾. In this case, the zero points of this study were the living kidney donor with the longest donation time at Hospital Universitário Onofre Lopes.

The data collection technique used was the semi-structured interview, carried out individually, at the location chosen by the collaborator. To record the reports, we used an audio recorder and the researcher determined the speech time when he realized the impossibility of continuing with the recording, or by decision of the collaborator.

The interviews took place between January and May 2015, in which the collaborators answered the following guiding questions. - How was your life before kidney donation? - How is your life after kidney donation? Subsequently, to the recordings of the reports, we carried out transcription,

textualization, conference, and transcription of the narratives, meeting the technical and methodological assumptions of the oral life history, in the perspective of Meihy⁽¹¹⁾.

We used the assumptions of the content analysis of Bardin in the analysis of the narratives. This analysis deals with a set of analytical techniques of communication, in which systematic and objective procedures are used to identify the indicators and allow inferring the knowledge related to the conditions of production and receive messages⁽¹²⁾.

We explored the narratives transforming the data collected into thematic content through the coding of the interviews, emerging two thematic axes for the discussion. They were compared with published scientific studies on the subject, corroborating and substantiating the analytical considerations of this research.

The research was approved by the UFRN Research Ethics Committee, under protocol No. 859,922 and CAEE 34804214.1.0000.5292

The collaborators signed the Informed Consent Form and were instructed on the premises required by Resolution 466, 12/12/2012 of the National Health Council, which provides for the ethical and scientific requirements of research involving human beings.

The collaborators also signed the letter of consent. It is an instrument required in oral history studies, establishing the ethical and legal link between the interviewee, the interviewer, and the research.

We identified the collaborators by alphanumeric records to protect anonymity.

RESULTS

The network had 12 living kidney donors, seven of whom are male and five females, aged between 22 and 54 years old at the date of the transplant. Most donors are recipients' brothers and married marital status and Catholic religion were more prevalent.

Each collaborator chose the interview place individually. Most of them opted for their residence. The average interview time was 50 minutes.

The narratives converged on similar situations that usually followed a sequence of facts. The reports begin with the diagnosis of chronic renal failure as a tragic moment for the family, followed by the dialysis treatment that saves a life but promotes a series of limitations, and afterward, the transplantation instituted as a way of reducing the patient's suffering and ending with the report of the consequences of the donation for the collaborators.

There was a rearrangement of family dynamics, followed by the decision and effectuation of renal donation. We grouped the speeches according to the guiding questions, arranged according to the experiences lived before and after the transplant, establishing the two thematic axes for the discussion.

METHOD

Theoretical-reflective study, carried out between October and November 2020, based on the authors' experience, and using bibliographic review, focused

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Regarding organizational culture, the study was based on the Chiavenato framework⁽²⁾, whose expertise influences the definition and application of modern and innovative administrative concepts in successful organizations.

As to specialist nurses and nurse managers, the authors were guided by the Regulation of the Specialist Nurse Competency⁽⁸⁾ and the Regulation of the Nurse Manager Competency⁽⁹⁾, recommended by the Portuguese Order of Nurses, where respectively, the scientific, technical and human competences are established to provide specialized nursing care in all contexts of health care and the competencies that guarantee the quality of nurses' professional practice. Their specific knowledge was crucial in coping with this disease, through the assessment of each situation and the conception of specialized nursing care. On the other hand, their specialized skills allowed the management of care and the development of professional learning within each team.⁽⁸⁾

As for the aspects related to the COVID-19 pandemic, we chose to list only those that allow us to reflect on the repercussions of the organizational culture on the performance of specialist nurses and nurse managers and not an in-depth approach to the disease caused by the new coronavirus, neither the state of the pandemic, since it is not the defined objective.

DISCUSSION

Experiences lived before kidney donation

The diagnosis of chronic renal failure appears in the narratives as a destabilizing factor in family dynamics. According to the collaborators, the impact caused by the onset of the disease promoted concern, hopelessness, and anguish among them.

"It was very difficult. I cried a lot, I went to the bathroom, washed my face, and went back to my son who realized that I had cried. He was already very nervous when he said: "I know it is a problem". I tried to calm him down and asked him if it was necessary if he would make a fistula. He said: "I do it, even without knowing what will happen in my life doing hemodialysis", even so, he accepted it. Until then, I didn't know what kidney failure and hemodialysis were". (Collaborator 2)

"I took my sister to live with me and got the family together to see what we could do to help. My older brother gave me an idea

that at the time I thought it would not work, he said that the transplant could get her out of hemodialysis and my sister would have a normal life". (Collaborator 4)

When receiving the news of the diagnosis of a serious disease, such as chronic renal failure, patients are usually affected by a state of temporary shock, which ends with a phase of denial of the disease and therapy. The way the news was given and how the disease took place is related to the duration and transition time between the inaugural phases of shock and denial of the pathological condition and the need for treatment^(13, 14).

The person who undergoes hemodialysis treatment sometimes presents a set of physical and psychological signs and symptoms, resulting in suffering and hopelessness. The suffered daily life and the dark future are part of the life context of many chronic kidney patients, who start to share their experiences with their family members⁽¹¹⁾.

The chronic renal patient becomes dependent on technological resources to survive, subjecting him to live with the fear of death, with the frustrations due to the loss of decision-making power, and the revolt for not recognizing the disease and the new ways of conducting his own life^(15,16).

The new complex context of life modifies and transforms the way patients and their families see the world around them, interfering in family dynamics, especially when hospital admissions, the time spent on hemodialysis sessions, and the expectation for kidney transplantation become recurrent^(3,17).

The collaborators narrated the family adjustment and the mobilization of some family members in a union of efforts to help the chronic renal patient in the adaptive process of hemodialysis and in the decision to transplant.

"When she saw the nephrologist, on the same day she was hospitalized on Monday to do some tests, and on Wednesday, she put a catheter and started undergoing hemodialysis. This catheter business is very heavy! Then she did the fistula which was blessed because she used it for about two years without any problems". (Collaborator 3)

Renal replacement therapies are palliative and work by relieving the symptoms of the disease and preserving the lives of those affected. Therefore, due to the suffering experienced by the complications of chronic renal failure, the patient is led to adapt to dialysis⁽¹⁸⁾.

The phase of acceptance of the chronic disease and its therapies results from the incorporation of

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the pathological condition and therapy in the patient's daily life, starting to live with the limitations of his health status. However, there are usually recurrences of clinical instabilities, states of anxiety and depression, and discontinuation of treatment.

Although reporting the patients' adaptation to dialysis, the collaborators described the constant suffering experienced by relatives affected by chronic renal failure undergoing hemodialysis. In the meantime, they sought in kidney transplantation the possibility of minimizing the suffering of complications from hemodialysis and the disease.

"Every time he came home from hemodialysis, he was very bad. I didn't know what else to do to make him look good. There was a time when he was ill on hemodialysis, who almost died, I just lived stressed and worried about what could happen to my son undergoing hemodialysis". (Collaborator 8)

The decision to donate is complexly involved in the family dynamics, in which the expectation of deciding for the donation can be considered a natural condition by the role that the individual plays in the family. Above all, the renal donation is an act of brotherly love, typically parental⁽⁵⁾.

We can also identify and name the reasons by categories: the desire to help, increased self-esteem, identification with the patient, self-benefit by improving the health condition of the recipient, logic, external pressure, and feeling of moral duty⁽³⁾.

"The decision to donate the kidney came from the love I feel for my father". (Collaborator 6)

"My brother and I have always been very connected because we are almost the same age, with little difference. And we were always very close to each other, we were always very friendly and I always protected him from everything". (Collaborator 12)

Decision-making for kidney donation is commonly built without much deliberation or knowledge about the transplant, present in the initial moments of recruitment and exams, as an impulsive desire of the possible donors. However, the desire to donate is consolidated with the progress of the process⁽⁵⁾.

The narratives of the collaborators showed the ambivalences of the act of donating the kidney, reporting the insecurity and anxiety related to the fear of not being able to maintain a normal life after the transplantation, the lack of information, the fear

of death, and pain or surgical complications. However, the most cited motivation in the statements was the desire to minimize the suffering of patients on hemodialysis.

“When my son was hospitalized because of complications from dialysis, I decided to donate the kidney to him and get him out of this suffering. I asked God a lot to get him out of this suffering and to make the transplant work”. (Collaborator 7)

Chronic illness is an opportunity to reframe the lives of the individuals involved. Thus, decisions regarding treatments are the result of dialectical processes and reinforce affective bonds. Therefore, kidney donation in life should be an act of altruism and empathy⁽¹³⁾.

Experiences lived after kidney donation

The rejection of the renal graft in the transplanted patient and the loss of the renal function of the collaborator are possible therapeutic outcomes. However, the collaborator sees these probabilities with serenity, considering the health care measures and the prevention of diseases, and faith in God to hinder such outcomes.

“I think it was too worth it to donate my kidney to my brother. I am not afraid of losing my kidney. I do the exams and everything is always fine, and my brother is out of dialysis”. (Collaborator 1)

The collaborators were resigned to the cases of therapeutic failure of kidney transplantation to the recipients and reaffirmed their non-regret for trying to help the chronic kidney relative and related the events to God's purposes.

The narratives highlighted the success stories of kidney transplantation for the recipient, who resumes social, family, and work-life, and for the collaborators, who continue without biopsychosocial complications.

Multiple factors influence the therapeutic possibilities of kidney transplantation. Therefore, donors and recipients must be prepared to live with favorable or unfavorable outcomes since their behavior in the success or failure of the treatment is preponderant for adaptation to new demands of life⁽⁵⁾.

Regardless of the therapeutic result, kidney transplantation can cause emotional distress in donors and recipients, determining an impact on their quality of life⁽²⁾. The consequences can be positive or negative and are related to the form and time of rehabilitation of the surgery, the functioning of the graft in the transplant, and the maintenance of the donor's renal function, in addition to the way

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We observed that the presence of chronic renal failure and dialysis treatment modify the family dynamics. However, kidney transplantation proved to be responsible for the restoration of functioning and the meaning of loved ones.

“My relationship with my sister improved after the transplant, we liked each other before the surgery, but now it has improved, even more, we already had a good relationship before the transplant, but then it improved. We became more brothers”. (Collaborator 11)

The donor and his recipient establish a strong affective bond, marked and reinforced by the identification of helplessness, as they are subject to the risks of living with a single kidney. This bond is strengthened based on an important emotional quality, egalitarian love, propagated by the donor and recognized by people who identify with the sublime and transcendent act of giving life to others^(9,10).

Generally, renal donors show an improvement in their quality of life after donation. Interestingly, this fact maintains a relationship with the success of the transplant to the recipient^(1,6). In the statements, negative feelings of transplantation were not expressed in the life of the donors, even when the therapeutic outcome was unfavorable for the collaborator and the recipient.

The collaborators reported that kidney donation improved or did not interfere with the quality of their lives and they did not report feelings of regret for having donated the kidney, even in cases of transplant failure.

“I think people shouldn't be afraid to donate the kidney. It is not what happened to me that it will happen to other people. People cannot look at the cases that went wrong, but at the ones that went right”. (Collaborator 9)

The collaborators reported situations in which they were treated as special and courageous people, given the nobleness of the act of kidney donation. However, the collaborators reinforced the naturalness of becoming donors, out of love for their family members, and the certainty of reciprocity.

“It's funny the people who know that I donated the kidney to my boy, they say

I'm a special person because of that, I did it and would do it again. Nothing has changed in my life, on the contrary, I think that today I am a better person after I donated the kidney, I don't feel anything".
(Collaborator 10)

The feeling of improvement in the donors' quality of life after transplantation is related to compensatory and adaptive resources used individually and socially, in which the feeling of fulfilled moral duty, social recognition, and the maintenance of life provide a feeling of happiness and satisfaction^(11,16).

The collaborators were satisfied after the transplantation for being recognized for their noble act (kidney donation), which is not related to excessive material or capitalist prosperity but due to the presence of external factors and willingness to do good.

"Other people speak well of what I did, say that I did something very beautiful, that I am a blessed guy (laughs), but I agree, I am very blessed by God".
(Collaborator 5)

The society and the family of the transplant recipients start to redefine values and beliefs and recognize different attributes of generosity and altruism in the living kidney donor⁽¹³⁾.

CONCLUSION

Renal donation interferes in the collaborators' lives. However, the interference is essentially positive even in cases of transplant failure in which the collaborator loses part of his renal function and the renal graft does not work in the transplant recipient.

The benefits promoted by kidney donation are improvements in the donor's quality of life, related to physical well-being, to the states of happiness and satisfaction felt, and to the social recognition of the nobility of the act of donation, in which the circle of social interaction starts to see the collaborator as a special person, giving him an inestimable capacity to love his neighbor and fulfill his moral duties.

We believe that the findings of this study provide nurses with subsidies that will assist them in the integration of care and in minimizing and resolving conflicts, optimizing nursing care to the renal donor and his families.

The reflections contributed to the construction of the intervening conceptions and perspectives of kidney donation, especially in the relationship of the chronic kidney patient and his family members with closer parental ties and, in an attempt to understand the issue of altruism in which the donor will daily

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exercise five fundamental principles: love, joy, smile, hug, and forgiveness.

The lack of follow-up of donors, the absence of records, and the outdated data in medical records were difficulties presented during the performance of this study. Also, the refusal of donors to participate in the research harmed the formation of the network.

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Corresponding author:

Fernando de Souza Silva

Email: fernandosouzajpa@gmail.com



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