

TRAJECTORY OF LIFE OF KIDNEY TRANSPLANT RECIPIENTS: SEIZING THE CHANGES IN THE LIVES OF PATIENTS

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ABSTRACT

The present study aimed to apprehend the changes occurred in the life of kidney transplanted patients, from the diagnosis of chronic renal failure to the coexistence with the transplant. This is a study with qualitative approach, exploratory and descriptive, having the oral history as a technique. The network consists of the first nine kidney transplant patients from Rio Grande do Norte, assisted in an outpatient clinic of Nephrology of a university hospital in Natal- Rio Grande do Norte. Through the content analysis of Bardin were found three themes: Impact on social relations, impact on social status and behavior against disease and treatment. We conclude that major changes in the lives of kidney transplant patients appear as losses in social relationships, work, income and leisure, however, stigma and prejudice characterized as important factors for social exclusion, however, the acceptance of the pathological condition was strengthened, especially by family support and belief in the Divine.

Keywords: Renal insufficiency. Nursing. Kidney transplantation.

INTRODUCTION

Patients affected by chronic renal failure often coexist with the limitations imposed by the disease and suffering and the substitutive renal therapy, resulting in prejuízos biological, psychological and social factors ⁽¹⁾.

Among the available treatment modalities, renal transplantation constitutes the best treatment for chronic kidney disease, the method to be more physiological and less painful, making individuals free of the limits imposed by dialysis with subsequent generation of higher quality of life ^(2,3).

Acting as nurses in the care of kidney transplant, witness reports of improvement in quality of life affected by chronic kidney disease, provided the transplant, freeing patients from the daily suffering experienced in hemodialysis. The benefits of therapeutic liver transplantation are easily observed in the reports of those who undergo renal replacement modality.

In our experience welfare also witness reports of divergent situations, people who

failed to experience the benefits offered by renal transplantation for those patients suffering sense of freedom in hemodialysis, the independence of dialysis machines, lack of familiarity with the weekly health staff and other patients with hemodialysis, generated mental suffering to the point of arousing the desire to return to hemodialysis and renal allograft rejection.

It has raised the memory of a patient who made dialysis for many years, and encouraged by his family, received a kidney from her daughters, but could not live with the freedom that gave her the transplant, developing a framework of deep depression resulting in suicide.

Featuring another situation related to a patient, to be transplanted, began to feel lonely, though with more time to be near family and friends, he complained that he lacked the daily contact with patients of hemodialysis, and will no longer accept the immunosuppressive medication, claiming that the feeling of loneliness made him take the decision rejecting the transplanted kidney, in order to resume hemodialysis sessions after

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the process of kidney graft rejection, and so it happened.

This paradoxical situation in which escapes the reach of therapy, we emphasize the need for nurses to grasp the perceptions of patients regarding chronic renal failure and transplant, try different ways to experience the new reality, assigning multiple values to the disease and treatment interfering drastically in their way of life ⁽¹⁾.

The general consensus is improving the quality of life of patients undergoing renal transplantation, however, does not admit the possibility of contradictions concerning the therapeutic, health professionals exposes the mistake of believing that there is a downside of the treatment can cause its failure ⁽²⁾.

Satisfactory results of renal transplantation are related to objective questions such as assessments of graft function, and subjective, which are more difficult and sometimes impossible to be measured ⁽³⁾.

We believe that studies of the subjective context involved in organ transplantation, bring the nurses questions that tend to build new perspectives of care, which is not a static knowledge, but something dynamic, where the inquiry is indispensable. Technological innovations provide more organ transplantation, culminating in responsibility of reflections on life and death ⁽⁴⁾.

Thus, this study aims to grasp the changes in life after kidney transplant disease diagnosis and treatment, through the story of the life course of patients undergoing transplantation in a teaching hospital in the city of Natal, Rio Grande do Norte.

METHODOLOGY

This is a qualitative, exploratory and descriptive, with the technique of data collection and methodological reference oral history of life. Approved by the Research Ethics UFRN, under protocol n^o 199/2010.

The employees were selected through the book of records of the renal transplant unit at the University Hospital Onofre Lopes (HUOL)-UFRN. The zero point of this study was the first kidney transplant patients from Rio Grande do Norte, which indicated two

other patients to be interviewed, they indicated seven others, making a total of ten participants, however, the network consisted of nine employees, because a waiver.

During the months of January and April 2011, we conducted interviews those were recorded individually in type apparatus Mp3 and guided by the following guiding questions: - Talk about your life before chronic renal failure: - Contact your living with chronic kidney disease: - Tell about your life after renal transplantation.

The interview location was chosen individually for each employee, which mostly opted for outpatient transplant HUOL - UFRN. At this time the employees signed the consent form and were informed about the assumptions required by Resolution 196 of 10/10/96, the National Health Council which provides for the scientific and ethical requirements of research involving humans .

Employees also signed the letter of agreement, instrument required in studies of oral history, in order to establish the legal and ethical relationship of the respondent, the interviewer and research ⁽⁵⁾. As a guarantee of anonymity names of birds used as aliases, in order to protect the identity of participants.

Later recordings of reports, perform transcription, textualization, the conference, and finally trans-creation of narratives, as the technical assumptions and methodology of oral history of life in perspective Meihy ^(5,6).

In the analysis of the narratives we use the assumptions of the analysis of Bardin, which is a set of analytical techniques of communication that uses systematic and objective procedures to identify indicators to infer knowledge concerning the conditions to produce and receive messages ⁽⁷⁾.

We conduct exploration narratives transforming the collected data into thematic content, by encoding the interviews, three emerging themes for discussion, they were confronted with scientific studies published on the subject in question, confirming and consolidating the analytical considerations of this research.

RESULTS AND DISCUSSION

Of the nine employees who were part of the network of this survey, the majority (seven) are male. The age group between 21 and 56 years, in which 80% of them get up to minimum wage, pension benefit from 10% to more than five salaries and 10% have no income. Six employees have completed grade school, two with incomplete high school and finished high school, showing the low education group. The religion is predominantly Roman Catholic, with seven respondents, for two evangelicals.

Socioeconomic data for this sample are worrying, given the relationship between education level and low financial income with indicators that contribute to poor quality of life, difficulties in maintaining adequate food and housing, and consequently lower survival^(2,3).

The ages presented in this study are favorable, between 21 and 56 years old, be evidenced by a greater loss in survival in individuals over sixty^(2,3). Guiding the discussion and analysis that follow, categorize, by aggregating and definition of common elements, the three topics below:

Impact on social relations

The transition from being healthy and being sick refers to the condition of interdependence of man and the environment in which they live. The disease causes a rupture of the old life (be-healthy) and present (be-sick), so that the future becomes uncertain given the possibility to leave-to-be (non-being). In this sense, the person is not seen simply as a body affected by a disease process, but as a social and psychological entity (one being in the world), subject to change variables of their relationship to the whole⁽⁵⁾.

Changes in social relations could be perceived on family ties and friendships broken by prejudice and stigma, or strengthened by the goal of better coping crises, through the collaborative union between loved, experiences observed in clippings of speeches of employees:

When I got sick, my family was very supportive, whenever approached, but friends have stayed out longer, but those who are true friends approached. (Azulão)

When I started dialysis, my wife began to leave me, called me useless, I did not pay, was a leading zero, called me undead, until the time comes to tell her to look for a live-dead and I had to leave, to separate myself from it. I ended up separating my children... (Araponga)

Today I live in the center, I live with my partner, we thank God helps me, is everything to me and I am very happy, I will be a daddy (laughs), thank God, is already two months pregnant is a blessing in my life. (Araponga)

Among the social relationship problems experienced by employees, prejudice and stigma were narrated often acts viciously attack those suffering from severe kidney disorders, persons under everyday situations inconceivable⁽⁸⁾, as reported below:

Sometimes I take the bus and people see the healing of the fistula and go away from me, sit in another chair farther, thinking that I have some contagious disease, it has happened to me on the bus! ..., I wonder: will staff believe that this will never get sick? have more serious problem?!, and when I wore mask!, the people looked at me amazed, like I had a bad disease that infects other people. (Galo de campina)

There are people who discriminate the transplanted, especially when wearing a mask, sometimes the person does not know, move away and sit somewhere else, I get it! ... (Sabiá)

Stigma and prejudice label kidney patients as people without prospects in life, condemned to live constantly with the impending death⁽⁷⁾, although this is a reality for patients and healthy. The coming day, the realization of future projects or science of the moment of death, are in uncertainties for all human beings.

Chronic renal hemodialysis patients often feel inferior, sad and ashamed for possessing arteriovenous fistula (AVF), because it is easily viewed and possess unique appearance provokes the perception of bodily difference, culminating in prejudice and social stigma, causing detachment from society to people who use the FAV⁽⁹⁾.

Impact on social condition

We noticed in our experience with the welfare CKD patients, they have trouble keeping their jobs when they are forced to

spend hours performing hemodialysis or due care inherent therapeutic liver transplantation, many lose their primary source of income, resulting in the difficulties remain financially yourself and your family, as we noted in the accounts of employees.

I spent a lot ... choke, if not for the assistance of my father and my mother, with these things power and everything, I do not know how it had been, with two young daughters, unable to work. (Galo de campina)

After the transplant worked another season, but not to get increasingly damaging my new kidney, I had to stop. (Azulão)

Holders of chronic kidney disease are entitled to receive disability retirement and health insurance, guaranteed by the Federal Constitution, through the Social Security and the National Institute of Social Security, conditioning the patient to be enrolled in government agencies as insured as an individual⁽¹⁰⁾.

The developers believe that the benefit received is critical to their survival and their dependents, but report that the amount paid is not enough to pay the expenses proposed by benefit receipt has been secured, but irregularly, and have decreased two to one minimum wage.

Already cut the benefit twice!, I had to go back to the INSS continue to receive, at the time I was receiving two salaries, today only get one to keep house with four people, is just too much!. (Galo de campina)

The Brazilian Constitution aims to rescue the citizenship of people affected by chronic kidney disease through welfare and social benefits, and distribute high-cost drugs, ensuring access to high complexity as exam preparation for renal transplantation^(10,11).

The employees of this research demonstrated how the network of assistance to public health is flawed report that lack basic supplies that must be purchased with part of the benefits they receive, making it impractical to maintain the treatment and own subsistence, materials high cost inaccessible, unavailability of exams for periods less distant, compounded by the need for a large amount of laboratory

testing for development and maintenance of renal transplantation.

Brazil is in the paradoxical condition of constitutional rights and guarantees a fragile citizenship, the promulgation of the 1988 constitution was not enough to exterminate the serious institutional and regulatory violations that plague the country, it is through the gap between the letters that make the laws and functioning of institutions charged with safeguarding and protecting people⁽¹²⁾.

The contributors to this study left transpire financial difficulties that patients face chronic renal disease since installation to maintenance of replacement therapy, in the case of transplantation this problem is more apparent, since the material resources for the good outcome therapy is costly and often unavailable.

[...] A lot of people doing a transplant and cannot afford to maintain, does that have to do the same, do not have a family or adequate food, and so lives in hospital for any food to eat, can get an infection [...]. (Sabia)

Clearly the relationship between low income and poor conduct and outcome of liver transplantation therapy, the impact of poverty on the lives of patients with renal disease, through the crippling potential social inequities reflected in lower survival and limited access of disadvantaged population groups to services health is a cruel reality and unacceptable⁽²⁻¹²⁾.

The feelings of inadequacy and worthlessness are commonly observed in patients with renal disease, it is strongly linked to reduced family income, caused by job loss, and even for the transplant, this is a present reality. Financial difficulties caused by job loss relate to the physical limitations imposed by the disease and by the renal replacement therapy⁽²⁻¹²⁾.

Performance before the disease and treatment

The first reaction of patients when they receive a diagnosis of a serious disease such as chronic renal failure, shock is temporary, with gradual recovery time dependent on how the news was reported. The outcome of this phase

will be the negation of the pathological condition ⁽⁴⁾.

Employees reported that the impact of the news was minimized due to installation and worsening of the disease has occurred gradually, which facilitated the acceptance of the pathological condition and therapy.

Denial is used by almost all patients receiving the news of the diagnosis of a serious illness, a statement abruptly or prematurely by people who do not know them well or are unknown ⁽⁴⁾. This phase can happen in the later stages of the disease or after observation.

It was discovered that I had kidney problem here in the Hospital, who discovered Dr. X was, at the time agent does not know what goes on in the mind of the person, which is the kidney problem, do not want to accept, but there comes a time you have to do hemodialysis, and then have to accept ... (embargoed voice). (Azulão)

Most employees started treatment of chronic kidney disease by hemodialysis, requiring variable time to accept to undergo therapy, and heard frequent reports of those found in the transplant refuge of the suffering imposed by dialysis.

Today would transplant again, my life is better at the time of transplantation than during hemodialysis. Today my life is normal agent makes the diet, leads a quiet life, I am a very happy, thank God. (Azulão)

The acceptance of the disease can occur at various times of people's lives as a result of the merger of the pathological condition and its treatment in everyday life. Patients after experiencing times of hardship, rejection, guilt and struggles, start to live harmoniously with their health ⁽⁴⁻¹³⁾.

The pain was present at various times of life trajectories reported by employees, either because of the process of evolution itself pathological, by hemodialysis or temporarily as a result of kidney transplantation, the same way the physical suffering, mental and social appeared with frequency in the interviewees' statements.

Among the more physical symptoms reported by patients is pain, causing major damages in the quality of life of individuals.

For a better intervention pain, practitioners should not stick solely to conduct drug, but should develop painful sensations as the result of a multidimensional context, built by physical, biological, social, psychological and spiritual ^(8,14).

My feet were living very swollen and I felt a lot of pain, so took medication, had difficulty doing physical effort, no matter how small!. (Canário)

The renal replacement therapies provide the maintenance of life through therapeutic embasadas in hard technologies and soft-hard, this is a relationship of dependence of patients with machinery, equipment, drugs, invasive procedures and grafted organs that transform the human condition the living world ⁽¹⁵⁾.

Even if the transplant has substantially improved the quality of life of employees do not realize the reports distortions regarding their therapeutic possibilities, a fact that surprises us, because the expectation of healing of chronic kidney disease through transplantation is a perspective commonly found in conversations informal patients.

Did you know that the average kidney was last ten years, I did not think that the transplant was healing, but it was a way out of the machine, because nothing is forever, especially you receive the kidney from another person!, The people of now stop! Imagine anyone else?! (Sabiá)

The speeches of the employees returned the dehumanization of health care, with criticism of professional conduct.

I think health professionals should pay more attention to what patients need, because there are people who take care of patients, but cannot afford to care, I also think that has a lot of nurse who is more stressed than the own patient (smiles) says something there he did not like, she replies abused and leaves, and leaves the patient talking to himself. (Canário-belga)

The National Humanization Policy (PNH) SUS proposes a change in the working relationship through the greater degree of contact and communication between people and groups involved in health care, ending the isolation and the imposition of power of this relationship ⁽¹⁵⁾.

It is argued that the inclusion of humanization in daily work, is not something insurmountable or complicated to implement, it is necessary to reflect on humanization and health care, with a view to strengthening humanism in acts caregivers considered an ethical duty moral and professional, which should be incorporated into daily behaviors⁽¹⁵⁾.

The intimate relationship between spirituality and religiosity proved important for the patient with chronic renal failure, especially with regard to the interaction with the health care team that assists and facing the difficulties imposed by the disease⁽¹³⁾.

All employees of this study call themselves Christians, observing this relationship between God and deliverance from death and improvement in quality of life, thus bringing therapeutic success, happiness and Divine protection.

[...] And it was only God in my life, I surrendered, I fell into the arms of God, and that He sustained me, because they had the big world out there, had died long ago, and I'm here today telling this history. (Araponga)

Thank God I'm happy that way, and nothing is missing for me to be totally happy, despite living this problem, I have nothing to complain about!, I can only thank God. (Sabiá)

The public health policies have directed their efforts to the preventive chronic disease, believing that the company co-participatory and health professionals, especially nurses, can dramatically reduce the number of people affected by kidney failure⁽¹²⁾.

FINAL CONSIDERATIONS

The main changes in the lives of kidney transplant appear as losses in social relationships, work, income and leisure, however, stigma and prejudice characterized as important factors for social exclusion experienced by employees in this study.

Among the difficulties reported by employees is the precariousness of services provided by the Brazilian public health

system, in this perspective, we believe in the need for greater efforts to implement government with a view to provide the support essential to achieving and maintaining kidney transplant. Thus, understand that treatment becomes more costly to the state and suffered for patients when they are not offered satisfactory subsidies as medicines and basic tests.

Through the story of the life course of patients undergoing kidney transplantation in a teaching hospital in the city of Natal, Rio Grande do Norte, it was realized that the loss of renal function and transplantation, rebounded dramatically in the lives of employees, however, the acceptance the pathological condition and treatment was mainly for family support and belief in the divine.

An understanding of the experiences and counted by employees of this study allowed us to understand better the context of the struggle for life of transplanted patients, bringing benefits to the restructuring of nursing actions meet the demands of its clientele.

An understanding of the changes in the life of kidney transplant after diagnosis and treatment of disease, causes reflections on the individualization of care, on the understanding that people can interact in different ways to be affected by chronic renal failure or when undergoing transplant.

The nursing care given to patients suffering from chronic renal failure should envision the individual and his multidimensional context, seeking to assist them in adjusting the harmony of his psychological condition, biological, physical, social and spiritual, affected by the impositions of the disease and treatment in lives of these people.

The reflections about the interference imposed by chronic kidney disease and transplantation in people's lives, causing the construction of other studies on the accounts of employees who call for changes in the management and care of public health in Brazil.

TRAJETÓRIA DE VIDA DE TRANSPLANTADOS RENAI: APREENDENDO AS MUDANÇAS OCORRIDAS NA VIDA DOS PACIENTES

RESUMO

Este estudo objetivou apreender as mudanças ocorridas na vida dos pacientes transplantados renais, desde o diagnóstico da Insuficiência renal crônica à convivência com o transplante. Trata-se de um estudo de abordagem qualitativa, exploratório-descritivo, tendo a história oral como técnica. A rede compõe-se dos nove primeiros pacientes transplantados renais do Rio Grande do Norte, atendidos no ambulatório da Nefrologia de um hospital escola de Natal-RN. Por meio da análise de conteúdo de Bardin, foram encontrados três eixos temáticos: Impacto nas relações sociais, Impacto na condição social e Comportamento frente a doença e tratamento. Concluímos que as principais mudanças ocorridas na vida dos transplantados renais apresentam-se como prejuízos no relacionamento social, trabalho, renda e lazer, contudo, o estigma e preconceito caracterizaram-se como importantes fatores pela exclusão social, entretanto, a aceitação da condição patológica se fortaleceu, principalmente pelo apoio familiar e na crença divina.

Palavras-chave: Insuficiência renal. Enfermagem. Transplante renal.

TRAYECTORIA DE VIDA DE TRASPLANTADOS RENALES: APREHENDIENDO LOS CAMBIOS OCURRIDOS EN LA VIDA DE LOS PACIENTES**RESUMEN**

Este estudio tuvo el objetivo de aprehender los cambios ocurridos en la vida de los pacientes trasplantados renales, desde el diagnóstico de la insuficiencia renal crónica a la convivencia con el trasplante. Se trata de un estudio de abordaje cualitativo, exploratorio y descriptivo, teniendo la historia oral como técnica. La red se compone de los nueve primeros pacientes trasplantados renales de Rio Grande do Norte, asistidos en ambulatorio de Nefrología de un hospital escuela de Natal-RN. A través del análisis de contenido de Bardin, fueron encontrados tres ejes temáticos: Impacto en las relaciones sociales; Impacto en la condición social; y Comportamiento frente a la enfermedad y al tratamiento. Concluimos que los principales cambios ocurridos en la vida de los trasplantados renales se presentan como pérdidas en las relaciones sociales, trabajo, renta y ocio, sin embargo, el estigma y el prejuicio se caracterizan como importantes factores para la exclusión social, pero, la aceptación de la condición patológica se fortaleció, principalmente por el apoyo familiar y por la creencia divina.

Palabras clave: Insuficiencia renal. Enfermería. Trasplante de riñón.

REFERENCES

1. Pereira LP, Guedes MVC. Hemodiálise: A percepção do portador renal crônico. *Cogitare Enferm.* 2009 out-dez; 14(4):689-95.
2. Almeida AM, Szuster DAC, Gomes IC, Andrade EIG, Acurcio FAA, Cherchiglia ML. Fatores associados à qualidade de vida de pacientes em terapia renal substitutiva no Brasil. *Ciência saúde colet.* 2013; 18(7):1903-1910.
3. Cordeiro JABL, Brasil VV, Silva AMTC, Oliveira LMAC, Zatta LT, Silva ACCM. Qualidade de vida e tratamento hemodialítico: avaliação do portador de insuficiência renal crônica. *Rev Eletr Enf.* [on-line]. 2009; 11(4):785-93. Available from: <http://www.fen.ufg.br/revista/v11/n4/v11n4a03.htm>
4. Klüber-Ross E. Sobre a morte e o morrer. São Paulo: Martins Fontes; 2000.
5. Meihy JCSB, Holanda F. História oral: Como fazer, como pensar. São Paulo: Contexto, 2011.
6. Barreto RADN, Mesquita IM, Santos LD. História oral: metodologia constitutiva de narrativas históricas. *Revista NUPEM.* 2013 jan-jun; 5(8).
7. Faller JW, Barreto MS, Ganassin GS, Marcon SS. Sobrecarga e mudanças no cotidiano de cuidadores familiares de paciente com doença crônica. *Cienc Cuid Saude.* 2012 jan-mar; 11(1):181-189.
8. Castro EK, Gross CQ. Percepção sobre a doença renal crônica de pacientes em hemodiálise: revisão sistemática. *Salud & Sociedad.* 2013 fev-abr; 4(1):070-089.
9. Cabral LC, Trindade FR, Branco FMFC, Balduino LS, Silva MLR, Lago EC. A percepção dos pacientes hemodialíticos frente à fístula arterio-venosa. *R. Interd.* 2013 abr-jun; 6(2):15-25.
10. Ministério da Previdência Social (BR), Presidência da República. Lei Orgânica da Seguridade Social. Lei Federal nº 8.212 de 24 de julho de 1991. Brasília(DF): Ministério da Previdência Social; 1991.
11. Almeida ND. A saúde no Brasil, impasses e desafios enfrentados pelo Sistema Único de Saúde – SUS. *Rev Psicol Saude.* 2013; 5(1).
12. Coutinho NPS, Tavares MCH. Atenção ao paciente renal crônico, em hemodiálise, sob a ótica do usuário. *Cad saúde colet.* 2011; 19(2):232-9.
13. Barreto MS, Augusto MA, Sezeremeta DC, Basílio G, Marcon SS. Conhecimento em saúde e dificuldades vivenciadas no cuidar. *Cienc Cuid Saude.* 2011; 10(4):722-730.
14. Lucchetti G, Almeida LGC, Granero AL. Espiritualidade no paciente em diálise: o nefrologista deve abordar?. *J bras nefrol.* 2010; 32(1):128-132.
15. Martínez BB, Silva FM, Veiga VT, Custódio RP, Silva JV. Desigualdade social em pacientes renais crônicos. *Rev Bras Clin Med.* 2011 maio-jun; 9(3): 195-9.

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