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WAITING THE RENAL TRANSPLANTATION: FEELINGS AND EXPECTATIONS[1]

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ABSTRACT

Patients waiting for a kidney transplant face complex situations that go beyond the biological process. Thus, the objective was to learn the feelings and expectations of patients with chronic kidney disease in the renal transplant. This is a study with qualitative approach, with dialysis patients at a university hospital, a questionnaire for socioeconomic characterization and semi-structured interviews used. The sample met the criterion of saturation. Data analyzed from the content analysis in the subject embodiment. Analysis emerged two thematic units: feelings caused by waiting, highlighting impotence, anxiety, distress, instability, and lack of motivation; and changing expectations after transplantation, with better quality of life, the end of dependence on hemodialysis and return to work. The possibility of social reintegration, return to work, or a chance to not be at the mercy of symptoms associated with dialysis becomes the main source of transplant DRC carrier.

Keywords: Emotions. Perception. Kidney transplantation.

INTRODUCTION

Chronic diseases have received the attention of health professionals in the last decades the important role in the morbidity and mortality of the population. Among these diseases is Chronic Kidney Disease, multifactorial pathology progressive and irreversible(1). For replacement of kidney function, dialysis and kidney transplantation treatments provided, allowing greater survival of patients(2).

In Brazil, the latest census of the Brazilian Society of Nephrology showed that there was gradual increase in the number of patients undergoing dialysis. In 2000, that number was 42,695; in 2013 it was 100,397 and in July 2016, the estimated total number of dialysis patients was 122 825(3).

The dialysis treatment, despite maintaining life, can cause changes in the biological, psychological, economic, and social conditions(2). This is a permanent source of stress, which can lead to social isolation, loss of labor activity, impossibility of movement and pleasure, decreased physical activity, and the loss of autonomy and changes in body image(4).

Thus, the life changes caused by this type of treatment often trigger frustration, discouragement, anxiety, and impotence, intervening in how individuals view themselves and their relationship with the world(5). Fear is also a present sense, since there is the possibility of side effects of treatment, the need for surgery and the imminence of death(6).

Kidney transplantation, in turn, seen as the option that guarantees, besides the survival of chronic renal patients, improving their quality of life. Despite fears inherent in relation to the surgical procedure, the DRC patient sees transplantation as a return to the state before the disease, which provides sense of well-being and the possibility of becoming are again(5).

In fact, this treatment offers lessen restrictions and lower social costs, and gains in functional capacity, reducing pain and asthenia, better general condition, rescue expectations and plans, increased social integration and better chance to return to affective routine and family(6).

Kidney transplantation, however, is a surgical procedure that depends on the donation of a healthy kidney and in the case of a deceased donor, organized through a waiting list for compatible organ(7). This is a lengthy process, which involves waiting limitations and suffering, reaching more than 11 years(8).

Thus, it is essential to carry out research on the kidney transplant waiting. In the present study, we aimed to know the feelings and expectations of patients undergoing dialysis treatment in relation to kidney transplantation. The guiding question for the meeting was "what the

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[1] From the dissertation titled "Quality of life of patients with chronic renal disease, São Luís-MA", presented to the Graduate Program in Public Health in 2010.

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feelings and expectations of people with chronic kidney disease on hemodialysis for renal transplantation".

METHODOLOGY

This is a qualitative study in Nephrology Department of a university hospital that is a reference for kidney transplantation of Maranhão. Data collection took place from March 2008 to December 2010. At the time of the research, they found themselves enrolled in regular hemodialysis patients 137.

The study included men and those women with chronic kidney disease, aged between 18 and 60 years on hemodialysis for at least six months, since the beginning of the dialysis procedure marked by clinical instability, and possible emotional influences linked to recent interruption of its activities, and may pass on expressed feelings. The age range was chosen to correspond to the productive phase, may result in changes of life plans of individuals based on the disease. They were not included people with communication difficulties, identified at the time of interview.

Respondents chosen intentionally, according to the characteristics of the qualitative sample, trying to include men and women of different ages, socioeconomic status, and education, to contemplate the possibilities of the study of the universe and the number of interviews was determined during collecting data through the saturation criterion(9).

For data collection, we used a semi-structured interview, conducted just after the dialysis procedure in order not to change the routine of patients. For the collection of demographic data was used a structured questionnaire and a semi-structured interview developed an interview script, with the following questions: what you know about your health condition, compared experiences the limitations, and expectations of changes with the transplant. The interviews recorded with the consent of the interviewer and later transcribed. In the process of transformation of speech into written text, allowing its analysis, we made some corrections, aiming to remove repetitions and language vices without changing the meaning(9).

To ensure participants anonymity and confidentiality of information at the time of transcription of the interviews, their names have replaced by the letter "M" for men and "W" for women, followed by cardinal number for the chronological order of the interviews. Each interview took an average duration of 40 minutes.

From the content analysis, we sought to describe experience, perceptions and responses to statements contained in the reports of responders(10), emphasizing uniqueness. The subject analysis followed the steps: ordering the data, and exhaustive reading floating material, the separation of meaning and identifying and grouping into thematic units.

This study is part of a larger research entitled "quality of life of patients with chronic kidney disease on Hemodialysis in São Luís", approved by the Research Ethics Committee second opinion Embodied No. 262/2008, in accordance with the standards for research in humans. This study is part of a larger research entitled "quality of life of patients with chronic kidney disease on Hemodialysis in São Luís", approved by the Research Ethics Committee second opinion Embodied No. 262/2008, in accordance with the standards for research in humans.

RESULTS AND DISCUSSION

Four women and three men, aged 20-59 years, who underwent dialysis at the Nephrology Service at the institution studied, interviewed. Of these, four patients resided in the interior, one in another state and the other in the municipality of São Luís. The majority had low level of education, two patients were not literate, one finished high school and one completed the nursing technical course, the others had the fundamental course incomplete.

As for occupation, three men were farmers, a student, and a sales promotion; a woman was nursing technique and a homemaker. Five patients were married and, of these, all had children. Only one patient continued with the labour activity previously carried out, that others abandoned the work after the start of dialysis. The minimum time of chronic kidney disease, among those interviewed, was one year and a maximum of five years, one of which was the death, during the period of research.

From the analysis of the interviews emerged two thematic units: feelings caused by waiting for kidney transplantation and expectations of change after transplantation. The first thematic unit represents the patients' feelings and reactions regarding chronic kidney disease, as well as waiting for renal transplantation while undergoing dialysis treatment. The second one addresses expectations about the arrival of the new organ while on the waiting list, in addition to the possibility of changes from the transplant.

Feelings caused by waiting for kidney transplant

The respondents of this study reported different feelings on the context of chronic kidney disease and waiting for kidney transplant. It turns out that this is a moment of sadness; especially not only for diagnosis, but also by changes in which the patient is required to pass so I can survive. In addition, respondents experienced the anguish on the unknown and the fear facing the possibility of suffering and death.

Study in the literature demonstrates that the discovery of the disease and the need for the hemodialysis treatment also raised reactions of grief and despair(11). The experience of receiving the diagnosis of chronic kidney disease appears, in many cases, as one of the most difficult moments for the patient, bringing with it the idea of the imminence of death, causing numerous psychic conflicts(6).

Once the dialysis, the patient needs to get used to the new routine, showing fear, stress by frequent requests to perform routine procedures, the fears in face of the possible side effects of treatment and to organic and physical repercussions caused by these, in addition to the charges part of the team of health professionals(12).

Situations that restrict the patient bring to reality your dependence on procedure(13), which can identified also in the lines below:

> We depend on that machine, come here three times a week, and cannot stay long with the family ... that is kinda sad. I am afraid to play on the network, in the sand ... also has the whole ballgame that I liked to play and now I cannot. I cannot go out in the rain.... (H7, 20 yrs.).
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> I was isolated. Because at the very beginning we feel that thing, huh? We are thinking about everything we used before and now were sitting in... I change the chair there with my daughter, in the kitchen, thinking, thinking ... I thought they were going to separate the girl from me. I could not get out to the ballads, because I like to go to the ballad (M5, 43 years).

It's almost unanimous realization that hemodialysis-the machine-is the technology which depend on for a living, what often brings the idea of compulsory treatment, imprisonment and sense of fear in the face of this treatment(11.14). The dependence of specialized service enforces restrictions on daily life of patients concerning, for example, to work, to leisure and to travel, causing impacts on sociability, allocated by the chronicity with the permanent treatment of hemodialysis, potentially leading to social isolation(15).

Another sentiment expressed by participants was the loneliness that can related to distance of family members, due to the need to carry out the treatment away from your House, and the expulsion of people who before were part of your social circle.

> I had a good friend, a great friend even, my mother said, "my God in heaven, my daughter has a baby", but when I got sick were all, until the father of my son. He also turned away. So I got this boyfriend, and when I told the story he also turned away. Because everyone is equal right? I felt too. When I needed blood no one across the street was donate, anyone (M2, 29 years).

In this study, the patients also considered the withdrawal of the treatment as a real possibility.

> I started dialysis ... was very difficult; I wanted to give up because every time I was wrong every time. Every time I wanted to quit, I could not take it anymore. There was a time I came, put me on the stretcher to dialysis, I spent the whole time crying, that day I did not feel a thing was just nervous, since then I have not felt anything (M2, 29 years).

Sometimes, the patient finds himself compelled to give up in the face of so many difficulties, which is detrimental to the treatment, whose success depends largely on the participation and membership of the individual(12,16).

It found the perception of dependency and loss of autonomy because of the treatment, reverberating, especially, in the exercise of a labour activity.

Although chronic kidney disease and your treatment do not constitute direct impediment to work, the impact of the treatment WINS important dimension when associated with the impossibility of carrying out the daily labour activities(15), especially due to the difficulty of income maintenance, which exacerbates the suffering, especially of men, because it compromises the role of effective provider and House worker, as can be seen in the lines:

> These six months I stayed home was that I became sicker. I was not working understand? I was nagging me with nonsense, with my family, because I have always liked to work (H6, 38 years).
>
> My dad really wanted to have a son who could help him work. Then he went to the town, he works in the farm, he wanted to have a boy. I am sick ... I feel so much ... because I wanted to be helping him, but I cannot (H7, 20 years).

A financial difficulty generated by limitations to work due to routine of treatment also increases the sense of helplessness among those interviewed. During treatment, issues such as decreased mobility, physical strength, pace of work, and other ailments that eventually appear, can interfere with productivity. Therefore, it is quite common to stop the activities and the necessary adjustments for the continuity of the working life(17).

Another important issue related to body image of these patients. In this study, it was identified the hassle on the change in appearance that occurred because of the deployment of the catheter or fistula. Many reported that, mainly, at the beginning of the treatment, they felt embarrassed with these marks.

> At first hid because I was ashamed of others to stay looking at me. I even was embarrassed, I was embarrassed because

> of the ignorance of not knowing, and I say so. Not now, I expose my fistula, before I found this here very ugly (H6, 38 years).

The change in appearance is a potential stressor factor, common in the daily life of patient chronic kidney(16). This modification can also lead to feelings of difference, of inferiority compared to other healthy people, negatively affecting your self-esteem(12), as well as sadness and social isolation, which demonstrate the impacts of living with a chronicle disease(18).

Were evidenced even mixed feelings related to wait for a new organ, depicting both hope, as disappointment? The treatment means hope, since it is given the opportunity to stay alive and waiting for better days, in the event of the arrival of the new organ(12). Living with the limitations as well as the thinking about death is inevitable(13).

Waiting for kidney transplant generates intense anxiety, because there is still uncertainty as to the possibility of the procedure and the absence of weather forecast for this occurs. The delay on the waiting list, and sometimes the constant disappointment of not being able to receive an available organ, ultimately accentuate the anxiety of patients who are.

> It is almost a dispute when it gets to receive a kidney. Six people sent to come and then I was the one that did not work (M4, 50 years).

The existence of a potential donor in the family, for your time, not always been received with satisfaction only because some respondents spoke of the concern about the health of the donor, demonstrating fear that will develop later, and kidney disease fear, in these cases, even bigger graft loss. The possibility of the family develop chronic kidney disease due to the donation of a kidney causes feeling of guilt in the receiver(7).

In my family, the most is hypertensive. The only one who does not have a very high pressure is my sister, but has problem of gastritis, of bone. There has to be 100% good. My family has even past death, diabetes; my mother died of high blood pressure, so you rather get scared even to donate and then need both kidneys (H6, 38 years).

Other factors may influence the decision of withdrawal of the donation, the donor or the recipient, such as uncertainty about the surgery and recovery, surgical pain, permanence of scarring and damage to the quality of life (due to fear of existence of risk to health)(12). In this study, was also verified the presence of such seizure.

It observed among patients, the possibility of coexistence between the inevitability of thinking about death and adaptive resilience.

> And I learned to look at the other side of life and the view that death is present and you don't have to be afraid of her not (H6, 38 years).

The mental aspect influences the quality of life over time, what is the psychological adaptation that occurs in patients with chronic diseases in General. How each person lives and relates to the disease is particularly unique, and is related to the historical and social Constitution of your subjectivity(17), being diverse the ways in which patients seek to adapt to your new condition, which provides better living with the current state of health.

> Dialysis is a means of our survival, as the transplant. One has to be careful of your way. "I don't need it anymore, I need it" and we are going to live. Then the person just has to take care of yourself. Watch out, lives a lot and is happy (H6, 38 years).

The renal patient above quoted depicts positive acceptance of the disease. When chronic kidney disease carrier accepts your condition, you can take advantage of opportunities that arise around, showing skills to choose or create appropriate contexts to their needs and values, eliminating barriers and doing personal adaptations, or the environment, according to need. The feeling of acceptance raises self-esteem, confidence, and security in yourself and in others.

> At the beginning, it was difficult because I was crying for anything. Not now, not anymore. Now it has changed much. From time to time, I still cry, but its difficult now. [...] We feel safer. In the old days we used to look at something, I thought it was unhealthy. Was worried about what I ate. We see that is different. (M5, 43 years)

It observed among patients of this research the manifestation of certain degree of conformity in relation to the wait, since, according to these, nothing could done to shorten that time. These findings have described in the literature(7).

> I hope God will make my day. I have called three times, but was not compatible with me. I hope that God give me sure that is my ... We get nervous, my heart feels like it is going to draw. [...] I hope the answer to both joy and nervous, but I hope if God wants it all works out. (M5, 43 years)

Such conformity contributes to increase the feeling of helplessness imposed on the individual, to which it remains only to wait for the arrival of the organ, while it is subjected to the only means of survival, dialysis.

Expectations for change after the transplant

The transplant represents the possibility of resumption of regular and reintegration activities in social life, such as the rescue of professional occupation and return to studies, without the elements and limitations imposed by hemodialysis. Such aspect was observed among patients interviewed, being represented by their desires and dreams.

> I think to make the transplant and start the course again because my dream is to become a nurse. [...]. I think yes to doing, someday ... Sometimes we find it hard because I am going to do 30 years ago. However, hope springs eternal. (M2, 29 years)

The hope that they can carry out the kidney transplant is associated with the way this procedure can change the daily life of the patients, providing rescue projects, greater social integration, greater workforce normal rapprochement, as well as the will and greater certainty of living and no longer need dialysis(16).

Hope serves as support to persist, despite the feeling of physical exhaustion caused by dialysis(19); there is also the expectation of eliminating sufferings from the new body reception, as noted in the following speech below.

> Will change ... will change little, but, anyway, it changes. I know that with the transplant I will not be here all day. I want to do something at home... and no longer do because I have to come here. If I do not come, my foot starts to swell and then start to get heavy, I start to get bad, and there is no way. (M4, 50)

The proximity of the transplant intensifies and renews hope that this will serve as a foundation and support for other feelings, which, as already mentioned, are constantly restricting the patient's daily life, such as fear of the unpredictable, anxiety and fear of failure.

Note also that sometimes the patient associates the transplant to a form of relief as the dialysis treatment that imposes a stressful journey and frequent episodes of hypotension risk.

> Sometimes I think I am going to transplant or to pass only ten months, eight months ... at least I rest a little (H1, 46).
>
> It is also not a cure [...]. You have to take medicine forever, but it is something you do not come over to the machine. It is what we need right now. Because it is very difficult (M2, 29).

Therefore, even if the graft is not successful or did not occur with the full return of the activities of the past, the patient would be able to have some time of freedom of the machine(13), which is "trapped".

Although the patient has the consciousness of later dependence on immunosuppressive drugs, transplantation seen as a better alternative to dialysis, since the main gain is in the freedom of the machine(12).

The issue of security of kidney transplantation in the face of possible hardships during and after the process of transplantation was not mentioned among respondents, probably due to this waiting is so loaded with good and positive expectations. However, it can inferred from the speeches the fear and uncertainty to this procedure, since there is no guarantee of success of the graft function and its loss would mean the disappointment resulting mainly from the need to return to dialysis.

The patient is facing a dichotomy between the desires to perform or not the transplant, because once covered the advantages of the arrival of the new body, there is also the need for risk visualization and possible side effects of necessary medications after the procedure providing a further source of insecurity for the patient with chronic kidney disease(6).

This concern exacerbated by contact with other patients who have received or who donated a kidney and later developed various health problems or who returned to hemodialysis(5). As noted among respondents, this concern leads them to hope for the best and prepare for the worst, without, however, be no security for the future.

> I imagine do and not do but I ask God "if it works, keep everything right; if it fails to be all the time, better not to have that! “ Because then that girl did and still in direct hemodialysis. So do not give (M3, 56).

It was also reflected in the interviewees' understanding not conceive of kidney transplantation as a means of healing. While providing a significant improvement in quality of life, this procedure concomitantly become subordinate to patient medical care, with their restrictions and testing routines(19), which requires adherence to a new treatment modality.

These expectations related to the performance of the health team, as the transmission of data to DRC patients.

> They explain well for us. Now I understand and have known that even though I was transplanted, it is not the cure. It is only other means of treatment. Therefore, I already know every little thing, the care that I have to have even transplanted (M5, 43).

From the moment of diagnosis, the multidisciplinary team has an important role to facilitate the adaptation of patients to change processes. Consequently, the role of health professionals is to encourage patients to accept the limitations of the disease and its treatment, and enable them to undertake self-care responsibly(20).

Gains expected to achieve also drive the patient to adapt to a peculiar way, seeking alternatives to regain their quality of life and, therefore, wait for the transplant alive(13). In this study, this issue highlighted.

> If the case appears [transplant] I am willing to do; if it is consistent in the list, you should do. [...] The way I to live there, feeling good, doing well, working is good; I do well; thank God I do not exaggerate in the water did not get all the time wanting to take water. [...] It would all also not to take rejection (H6, 38).

In this case, the patient is also preparing to be active in transplant success, pledging to adhere to treatment even in the dialysis stage and waiting for the new body with patience rather than anguish(7).

Severity disease of the majority of respondents and the handler hampered the interviews, especially regarding the choice of an adequate and nearby location to hemodialysis rooms, creating the need for adjustments and identify a more suitable location in the time availability of respondents, thus avoiding damage to this research. Despite the period in which data collection performed, the results not affected by time. Thus, revisits to the database did not bring harm to this work given the relevance of the topic presented.

FINAL CONSIDERATIONS

Chronic renal patients are daily subject to the obstacles inherent to the disease as the deprivation of liberty imposed by dialysis, causing your routine depends on the hours of hemodialysis. The patient is also compelled to change their eating habits, their activities, even sacrificing work, studies, and family. Obviously, with so many restrictions, the individual taken by feelings of helplessness, anxiety, distress, instability, and lack of motivation.

These feelings are the fears related to the transplant, seen as the greatest opportunity to return to "normal" life. At the same time in what seen, as the hope of freedom, is also a cause of anxiety since the wait is long, and may take years. In addition, there is the possibility of failure of the transplant, which would culminate with the return to dialysis, or even the "blame" for having deprived a loved one of an organ that the donor may be required later.

Nevertheless, there is an expectation that the transplant means the end of the dependence of the machine and the return to "before life". The possibility of social reintegration of achieving dreams, return to work or even the mere chance of not being at the mercy of the various symptoms associated with dialysis, transplantation make the main source of hope of chronic kidney disease carrier.

Support offered by the service, the health team, and the family is essential to help the patient the best deal with their condition, helping them to be active in their own care by developing effective means of adaptation and coping during therapy and waiting for the graft.

Accept yourself, adapt, and hope to get support instrumentalize confronting chronic kidney disease and make the wait for possible kidney transplant.

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À ESPERA DO TRANSPLANTE RENAL: SENTIMENTOS E EXPECTATIVAS

RESUMO

Pacientes à espera de um transplante renal enfrentam situações complexas que ultrapassam o processo biológico. Assim, objetivou-se conhecer sentimentos e expectativas de pacientes com Doença Renal Crônica em relação ao transplante renal. Trata-se de um estudo de abordagem qualitativa, com pacientes em diálise, em um Hospital Universitário. Foram utilizados um questionário para caracterização socioeconômica e um roteiro de entrevista semiestruturada. A amostra atendeu ao critério de saturação. Os dados foram analisados a partir da análise de conteúdo na modalidade temática. Da análise, emergiram duas unidades temáticas: sentimentos provocados pela espera, destacando-se impotência, ansiedade, angústia, instabilidade e desmotivação; e expectativas de mudança após o transplante, com melhor qualidade de vida, fim da dependência da hemodiálise e retorno ao trabalho. A possibilidade de reintegração social, retorno ao trabalho ou a chance de não estar à mercê dos sintomas associados à diálise tornam o transplante principal fonte de esperança do portador de DRC.

Palavras-chave: Emoções. Percepção. Transplante de rim.

LA ESPERA DEL TRASPLANTE RENAL: SENTIMIENTOS Y EXPECTATIVAS

RESUMEN

Pacientes que esperan por un trasplante renal enfrentan situaciones complejas que van más allá del proceso biológico. Por tanto, el objetivo fue conocer sentimientos y expectativas de pacientes con Enfermedad Renal Crónica respecto al trasplante renal. Se trata de un estudio de abordaje cualitativo con pacientes en diálisis en un Hospital Universitario. Fue utilizado un cuestionario para la caracterización socioeconómica y un guión de entrevista semiestructurada. La muestra atendió al criterio de saturación. Los datos fueron analizados a partir del análisis de contenido en la modalidad temática. Del análisis surgieron dos unidades temáticas: sentimientos provocados por la espera, destacándose impotencia, ansiedad, angustia, inestabilidad y desmotivación; y expectativas de cambio tras el trasplante, con mejor calidad de vida, fin de la dependencia de la hemodiálisis y regreso al trabajo. La posibilidad de reinserción social, regreso al trabajo o la oportunidad de no estar a merced de los síntomas asociados a la diálisis hacen del trasplante principal fuente de esperanza del portador de Enfermedad Renal Crónica.

Palabras clave: Emociones. Percepción. Trasplante de riñón.

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