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THE EXPERIENCE OF PATIENTS WHO NEED RENAL TRANSPLANTATION WHILE WAITING FOR A COMPATIBLE ORGAN¹

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ABSTRACT: The aim of this study was to understand the experience of patients with chronic renal failure, who were included in a list of subjects waiting for a kidney transplant. This is an exploratory, descriptive, and qualitative study, with phenomenology as theoretical basis. Twenty patients have undergone hemodialysis as a renal replacement therapy. These subjects were active while they waited for a kidney transplant. Analysis of material obtained in this study allowed us to understand the fear and insecurity of these patients in view of both dialysis treatment and the possibility that a compatible donor is not found. They have shown faith strength and courage while using self-care to stay well when transplanting arrived. They idealized a new life, a fresh start, away from the machine for hemodialysis. The present study has detected a need for monitoring, by an interdisciplinary team, of patients included in waiting lists in order to help them experiencing such wait.

DESCRIPTORS: Nursing. Transplantation. Renal insufficiency, chronic.

A VIVÊNCIA DE PACIENTES QUE NECESSITAM DE TRANSPLANTE RENAL NA ESPERA POR UM ÓRGÃO COMPATÍVEL

RESUMO: O estudo teve como objetivo compreender a vivência do paciente com insuficiência renal crônica em lista de espera por um transplante renal. Trata-se de uma pesquisa exploratória, descritiva, de natureza qualitativa, tendo como referencial teórico a fenomenologia. Os sujeitos do estudo foram vinte pacientes submetidos à hemodiálise como terapia renal substitutiva, que aguardavam em lista por um transplante e que estavam ativos na lista de espera. A análise do material obtido possibilitou compreender o medo e a insegurança dos pacientes diante do tratamento dialítico e da possibilidade de não encontrar um doador compatível. Revelando força e coragem, por meio do autocuidado em manter-se bem para a chegada do transplante. Idealizando uma nova vida, um recomeço longe da máquina de hemodiálise. O presente estudo revelou a necessidade de acompanhamento do paciente em lista de espera por equipe interdisciplinar, no sentido de auxiliá-lo a vivenciar essa espera.

DESCRIPTORES: Enfermagem. Transplante. Insuficiência renal crônica.

LA EXPERIENCIA DE LOS PACIENTES QUE NECESITAN TRASPLANTE RENAL EN ESPERA DE UN ÓRGANO COMPATIBLE

RESUMEN: El estudio tuvo como objetivo comprender la vivencia del paciente con insuficiencia renal crónica en lista de espera por un trasplante renal. Tratase de una pesquisa exploratoria, descriptiva de naturaleza cualitativa, que uso como referencial teórico la fenomenología. Los sujetos del estudio fueron veinte pacientes sometidos a hemodiálisis como terapia substitutiva, que esperaban en la lista por un trasplante renal y que estaban activos en la lista de espera. El análisis del material obtenido nos permitió entender el miedo y la inseguridad de los pacientes ante la diálisis y la posibilidad de encontrar un donante compatible. Revelando fuerza y coraje, a través de auto cuidado de mantener bien a la llegada del trasplante. La elaboración de una nueva vida, un nuevo comienzo alejado de la máquina de hemodiálisis. El presente estudio ha revelado la necesidad de acompañamiento del paciente en lista por el equipo interdisciplinario para ayudarle a vivenciar esa espera.

DESCRIPTORES: Enfermería. Trasplante. Insuficiencia renal crónica.

INTRODUCTION

In recent years, while the authors worked in outpatient transplant units, they had the opportunity to assist patients with chronic renal failure (CRF) on hemodialysis, with indication and possibility of undergoing transplantation. Direct contact with patients included in these waiting lists allowed us to observe and monitor the expectation and moments of anxiety and distress of waiting for a kidney transplant.

The path taken by these people to be included in the list and the waiting time with their names in the list reveal distinct feelings in both thought and action. During the pre-transplant preparation, which was accomplished through routine examinations and care by the interdisciplinary team, it was possible to follow the expectation that everything be solved as soon as possible, including that there was no contraindication to transplantation. However, we could realize the disappointment of these people as months and years passed, especially when they had been called to undergo transplantation, which was not performed for many reasons. In other situations, frustration occurred due to waiting, which was determined by incompatibility of the organ, and expectation of cure, which at times seemed would never happen.

Our interest in developing this study arose in this context, and included different feelings and disappointments of these patients. We were seeking to broaden and deepen the understanding of problems arising from waiting for a kidney transplant. Thus, extending knowledge on CRF, replacement therapy, and renal transplantation was necessary to support this study.

In Brazil, the number of CRF patients has increased steadily and alarmingly every year. Prevalence of diseases such as arterial hypertension and diabetes have contributed to the growth of these indices.¹⁻³

In CRF, the patient needs renal substitutive treatments such as peritoneal dialysis, hemodialysis, or kidney transplantation. These treatments are recommended when the rate of kidney function is smaller than 10-12%.²⁻³ CRF is a disease that affects kidney function, causing physical, psychological, and social changes.³ Prevalence of dialysis patients has shown a progressive annual increase.¹

Treatment due to a replacement therapy requires great emotional and physical effort from the patient and his/her family. Most often, this treatment is marked by many hours per week in

sessions, in which the patient is attached to a machine. This trajectory is associated with physical discomfort, malaise, pain, or more severe complications.

Chronic kidney disease reduces the professional and physical ability of the patients. It brings social limitations, and can even alter their mental health in addition to being a disease with high morbidity and mortality.^{2,4} As the chronic disease cannot be cured, the cure desired by the patient can turn into a dangerous myth. In moments of despair, discouragement, and disbelief, the patients often conceive and generate many expectations about the possibility of transplantation.⁵⁻⁸

Transplantation is considered one of the best treatment options not only from the medical but also social and economic point of views. The opportunity and expectation that result from the possibility of transplanting can cause many different feelings in patients after they are included in a list to undergo such a procedure.

Kidney transplantation is the organ transplant modality more carried out in Brazil, with an average of 4,240 transplants made in the last three years (2009-2011). This number is significant when compared with that of other transplants performed in the country.⁷ Despite this large number of kidney transplants, waiting for a kidney by patients is very long, ranging from one to 11.1 years.^{6,8-10}

While patients wait, they need to continue treatment through dialysis or hemodialysis. This waiting is marked by an expectation of freedom and hope that at any moment they can be graced with a phone call stating that a compatible donor was identified.⁴⁻⁶ Thus, such people live for many years devising a new reality although they have limited health conditions and quality of life.

The indefinite period these people wait for news of a compatible donor is differently experienced by them, involving anxiety, distress, and fear. Particularly, they are afraid of the unknown because they have followed the death of colleagues in the hemodialysis unit in both the waiting list and after transplant. Their fear is minimized by their faith and hope of having a better life after the transplant is performed.⁴⁻⁸

In the waiting period, the chronic nature of the disease, their fear of dying, the change in their body image, and expectations arising from the transplant trigger stressing factors that can significantly influence the success of the ongoing treatment.

Therefore, the aim of this study was to understand the experience of patients with chronic renal failure included in the waiting list for a kidney transplant.

Surely, knowledge of this experience will help the interdisciplinary team to provide assistance geared to the real needs of those who spend years waiting for a compatible organ.

METHOD

This is an exploratory, descriptive and qualitative study, with a phenomenological approach. We have analyzed the experience of patients seeking to better understand our object of study in its historical context and/or according to their structure.¹¹

Patients undergoing hemodialysis, who were waiting for a kidney transplant for more than six months and were active in the waiting list, were the study subjects. Only patients with a waiting time for transplantation longer than six months were interviewed. This decision took into account that the waiting time of patients included in list can reach 11.1 years.^{4,6,10} Therefore, we understood that a waiting time shorter than six months would be too short for them to experience the reality of such a long period.

This study was conducted in a dialysis unit in the south of Brazil. After approval by the unit, the interviewees were chosen through a survey in medical records to identify patients who were active on a waiting list for a time longer than six months. A total of 21 patients was obtained, and 20 of them agreed to participate in the study after we presented its objectives.

Data collection occurred after the interviewees read and signed the term of Free and Informed Consent, in accordance with the law regulating research with human beings. The project was evaluated by the Committee for Ethics in Research in the University for Development of the High Valley of Itajaí (UNIDAVI; Protocol n. 923). Data collection occurred in the period Oct-Dec 2011. A semi-structured interview was conducted starting from a guiding question: "How is the experience for you of waiting for a compatible organ to undergo renal transplantation?"

The interviews were recorded and fully transcribed, but the content was analyzed only after each interviewee read and signed as the author. Identity of patients was preserved, thus ensuring

their anonymity. Each name was represented by the number of the corresponding interview, eg, E1, E2, up to E20.

Data were analyzed using a proposal for content analysis.¹² This method allowed us to consider the different meanings expressed in the speech of each interviewee. The first step included a description of the interviews, in which the original verbal expressions were kept. In addition, the observations and comments were organized and the interview records were assembled. In the second step, data of the empirical material thus obtained were organized and classified into topics. This material was read repeatedly until meaning units could be formed. In the third step, we sought to complete this set by combining the empirical and theoretical, abstract and concrete, and particular and general aspects, seeking to distribute the information into categories according to relevance criteria.

RESULTS

A total of 12 men and eight women participated in the study. Regarding education, these people had incomplete five or complete three elementary school, incomplete four or complete four high school, and incomplete three or complete three higher education.

Arterial hypertension six, pyelonephritis five, urethral stenosis four, and diabetes four were the pathologies that led the patients to develop CRF. In one patient, the cause of CRF could not be identified. All interviewees underwent dialysis three times a week. The mean value for the time of each interviewee on the waiting list was 30 months including extreme values such as 9 months and 7 years.

Content analysis of the material so obtained allowed us to identify 4 categories of eight subcategories. Categories: waiting as determined by a compatible organ (subcategories: indefinite time and compatible donor); confrontation of feelings (subcategories: distress and anxiety; pain and fear; optimism; and hope and faith); search for balance (subcategories: self-care and family support); and perspectives before transplantation (subcategories: rebirth and dignity).

Waiting as determined by a compatible organ

This category, comprising the subcategories indefinite time and compatible donor, indicates

the time of patients on the waiting list. This time, which often seems to have no end, is marked by a wait during months to years for the call to undergo transplant. Wait for the donor includes the difficulty to identify a deceased donor whose characteristics are compatible with those of the person who is on the waiting list.

Indefinition in time anticipates the uncertainty of tomorrow and brings the fear that something will happen (even death) before undergoing transplantation. In addition, it characterizes the experience of another day connected to the machine and the unpleasant consequences of a hemodialysis session. This corresponds to days, months, and years waiting for a call to undergo a transplant, as indicated by the following reports: *at the beginning, it seemed that everything would work out. Each day I expected them to call me, but now I doubt whether I'll really undergo transplantation. Days pass, time runs, and I'm still on the list* (E3); *at the beginning it was only joy, but now it seems it won't happen anymore. I count the hours and days that pass. Each time my phone rings, I hope it's their call telling me to undergo transplant. Sometimes I even think they have forgotten me* (E2).

The patient waiting for a compatible donor leaves the feeling that the donor is unreal. At the same time, waiting reflects the strong desire to receive the organ. At times, this interest, this will to undergo this transplant is blended with the desire that someone dies so that the compatible organ will appear. It can be perceived in the following narratives: *sometimes it seems that the donor will never come. I didn't think it would take so long. I thought I would undergo transplantation soon* (E5); *I hope this organ with such faith that it seems I'm all the time praying and wishing someone to die* (E8).

Confrontation of feelings

This category is represented by the sub-categories of distress and anxiety, pain and fear, optimism, and hope and faith. It reveals ambiguity of the feelings and emotions involved in this experience. Feelings clearly indicate how difficult it is for the patient to bear the emotional burden of a chronic disease associated with the uncertainty of a procedure that does not have a definite hour to happen.

The speeches show moments of enthusiasm with regard to undergoing transplantation. At other times, uncertainty of waiting is expressed as fatigue, discouragement, distress, and anxiety.

Distress and anxiety translate the uncertainties of tomorrow, of what is to come, whether a new hemodialysis session or being called to undergo transplantation. Such feelings appear in the following speeches: *I hope every day. This is distressing. They can call me at any time to undergo transplantation. I hope all the time but they do not call me, and then hemodialysis comes again* (E10); *ah! I'm always turned on. When phone rings, I get scared. I think maybe it's now. This makes me seem that I'm always plugged in* (E1).

Pain and fear result from concerns about risk associated with transplantation, afraid that a donor does not appear, and concern about complications from hemodialysis sessions. Pain and fear reflect the reality of the transplant because it is a procedure that can completely change the life of such persons. On the other hand, they had known colleagues who have undergone the procedure and had serious complications. *We have some fear, isn't it? Will it succeed? Will I succeed expecting it? I knew some colleagues who died during hemodialysis while they waited for a transplant* (E13); *I'm afraid time won't be enough, and I can die before* (E19); *Sometimes I'm afraid and I think about giving up, but I know hemodialysis is even worse* (E5).

Optimism contrasts with anxiety, distress, pain, and fear, revealing strength and persistence to live each day. Moreover, optimism motivates them to continue on the waiting list and go ahead, looking for something they believe is the best for their lives. [...] *I never think back [...] I always think everything will work, and tomorrow will be another day* (E10); *I raise my head, and I go ahead. So I survive each day. Sometimes I feel like giving up, but this goes by and I go ahead* (E12).

Hope supports the paradigm of strength, cherishing and remedying the uncertainties of the few moments of weakness shown in this trajectory. *I have much hope that everything will work out. Transplantation is everything for me, so I have much hope that I'll soon get out of this condition* (E14); *I always think and I hope that everything will work out, that they will call me soon to undergo transplantation* (E18).

Patients' faith that everything will work reveals their religious and spiritual basis, which is held every new day, strengthening their hope and optimism, as seen in the following reports: *I have great faith, for nothing is impossible with God, and this faith keeps me standing up* (E13); *I have faith, great faith, and that's what matters; this makes me continue on the waiting list* (E19).

Search for balance

This category includes the subcategories self-care and family support. It points to the need for the patients to keep themselves well until they are called to undergo transplantation. At the same time, it indicates the importance of shifting the focus from the list, by engaging in other activities not related to the disease. While the patients seek their own balance, they develop all possible strategies and means to survive this process.

Self-care was found to be a key strategy in the search for their balance, demystifying the assumed inability of chronic renal patients. He points out that the patients take care of themselves so that they are well when the organ arrives, as can be seen in the following testimonies: *I try to take care of me as much as possible, I do exercises when I can, I try to keep my body weight, eating correctly, doing what they tell us to do (E4); I try to do everything just right, taking my meds, and following their guidance; I do my own things, I take care of my food and salt. I organize myself for everything I need (E6); ah, I try to move on, I do my work at home, I knit and crochet (E1).*

The subcategory family support points to the importance of the families, highlighting the meaning of such basis for the patients to face their wait for a compatible organ. Such support is illustrated by the following statements: *families have a very important role in the treatment of patients with renal disease. They offer strength and more safety and hope to the patients (E1); my family helps me, they give me a lot of strength participating in all with me; My wife is fantastic, she helps me a lot giving me much support; She has adapted everything at home, including a very good menu for all of us (E3).*

Along the way, the family comprises ties such as the blood family, brothers in the hemodialysis, and family of the health team. Participants say so: *You know, what gives strength in all this is knowing that we are not alone; Other people are in the same situation and we support each other, giving strength to one another; We call each other brothers in the hemodialysis (E13); each speech, each aid, all of them give strength for us to continue on the list; You know, this team helps a lot; they are very partners; They do everything possible to distract us during hemodialysis, and they tell us not to give up that transplantation will arrive soon (E19); I try to do other activities, going out with my friends and children (E10).*

Perspectives before transplantation

This category includes subcategories rebirth and dignity. These subcategories, include what

patients know, imagine, and expect regarding transplantation. They show the imaginary related to transplant, what is idealized as being the best for their lives, according to the speech of the participants: *I'm still a young guy and I have all chances to undergo a transplant, improve my health, and return to the labor market (E10); I know that the transplant will change my life so that I can get out from the machine and return to live (E14); I think that transplantation will allow me to travel without worrying about having to undergo hemodialysis (E12).*

Subcategory rebirth indicates that transplantation is as a possibility for [the patient] to revive when the new kidney comes, as if this were a new beginning, a new chance, a new life, a better life without connection to the machine, as seen in the following reports: *I just think that after transplant I will live the rest of my life enjoying my children, my home, my husband, and all I imagine as good in the world; this is like a miracle (E16); now, I see the transplantation day as a new anniversary date, as I will be able to resume all things I left behind, such as college, work, and girlfriend; this will be a new life without the machine attached to me (E20).*

Subcategory dignity indicates the patient's impotence regarding replacement therapy, (physical and emotional) marks, and suffering. Above all, it reveals an idealization of the opportunity for them to direct again their own lives. This subcategory indicates the patients' desire to decide what to do at the time they wish, without depending on the machine rules; this desire is registered in the following speeches: *you know, people undergoing hemodialysis can't do anything, go out, eat, or even put a low-cut clothing in the summer because everyone keeps staring at the fistula. I think I can change my life after transplantation (E9); I think I will be able to do things that seem simple but are of great value, such as being able to go again to the beach in the summer without this yellow color, my belly like this, and my arm, oh my goodness!, at the beach my arm seems to be from another world (E13).*

DISCUSSION

This study has revealed the detailed experience of patients who are waiting for a compatible organ to undergo transplantation. Thus, they represent those who fight for a better quality life. This experience revealed the meaning of faith and hope in achieving the transplant as expressed in lucid moments, but merged with unrealistic and remote ideas on a light at the end of the tunnel. People who are fragile and vulnerable to treatment

can be seen from the perspective of waiting given the uncertainty of tomorrow.^{6,8,13-15}

The speeches enabled us to know both the perception of these subjects on their own trajectory and the process of chronic kidney disease given the possibility of undergoing transplantation. The experience of this reality is marked by feelings of pain and fear given both hemodialysis and the probability of not undergoing transplantation. The human being only understands the experience to be lived based on the essence of what is presented to him.¹⁴⁻¹⁵

The essence of this trajectory is the lack of information on the transplant process, including on the dialysis they undergo for years.⁵⁻⁷ Although major advances have occurred in the health area, it is still possible to find patients included in treatment programs, which cause significant changes in their lives and in the life of their families. However, there is no formal information and guidance on either how each step of the treatment will develop or the prerogatives derived from this therapy. In the treatment for CRF by either replacement therapy or transplantation, independence from either medications or the health team does not exist.^{5-6,15}

Disinformation of patients included on waiting list showed to be a major cause of anxiety and disappointment during their wait. When they are included on the list, the first months are marked by the possibility of healing and, above all, by release from dialysis. Over months and years however, this waiting is transformed into disappointment, frustration, and misunderstanding about not undergoing transplantation. Despite great advances and efforts to increase the number of transplants and decrease the time of patients on list, the number of donors is insufficient to meet the demand of those who are waiting for an organ.⁹

Waiting by patients for a transplant is a long and lengthy way, and the results from such waiting not always correspond to what they have dreamed and idealized. While these patients wait for a transplant, many times they envision a better life.⁴⁻⁷ The time for each patient on list is variable, and their wait is rewarded by the arrival of a compatible organ. For some patients, such wait may be short whereas for others it may take years or can even not happen.^{6-7,10}

In many cases, patients are included on list but are not informed about the average time they have to wait for a transplant or even about the prerogatives associated with the possibility of a compatible organ to be identified. The experience

of each individual in the process of his/her disease can interfere with the way he sees the pathology in his/her life context.¹³⁻¹⁴

Health and disease are clinical and sociological phenomena that are culturally experienced by people. They are faced in an experimental and distinct manner according to the meaning that each human being assigns to the course of his/her disease. The course of the disease of chronic renal patients is marked by limitations, physical and psychological pain, and clinical malaise during and after dialysis sessions. Significant changes occur in the quality of their lives, especially in the social, physical, sexual, and professional dimensions. Patients report a feeling that they are chained to the dialysis machine.^{14,16-18}

The patients' reports allowed us to realize the meaning of limitation and the perception of a world marked by rules, schedules, and concerns given the uncertainty and doubt in enduring such waiting. Many times, dialysis causes pain, revolt, and sadness.^{14,16-18}

Thus, while the patients wait for an organ, they feel as if they were waiting for the death of someone to give them life. When they realize that such desire occurs, their sense of guilt and remorse comes because desiring someone's death is inconceivable to them, including when they consider the advantage they will have. Yet, transplant is perceived as a better life, even if they cannot recover the time spent during hemodialysis. Expectations from such waiting reflect their meaning of faith and hope, while they are also in doubt.^{6,15,19}

Faith and hope contribute to exchange thoughts plagued with days of penury for assertive feelings and ideas associated with a way that deserves life after transplantation. Such feelings and ideas are strengthened by thinking and certainty of better living far from hemodialysis.

The reflective and analytical image of thoughts about a better life brings the possibility of change in the patients' life. The act of thinking, while clarifies the meanings virtually involved in different modes of appearance in the intentional conscience, explores the richness of meanings and attitudes in the universe.²⁰

The option of leaving dialysis to undergo transplant has an uncertain result from the viewpoint of therapeutic efficacy. Although this decision is not easy, the patients believe that transplant, including their dependence on drugs and monitoring by the health team for the rest of their lives, is the best option.^{6,8,21-22}

The significance of this certainty is apparent in their desires of rebirth, social inclusion, and live again. Uncertainty about what awaits them is clear, and simply thinking about transplant brings doubts. Such insecurity leads the patients to develop strategies to expect, withstand time pass, and neglect their concern for having both a chronic disease and doubts about the therapeutic option that awaits them. Thus, their need to engage in other activities to balance body and mind becomes evident. Routine, domestic, and manual activities help patients endure the wait, besides keeping them busy.¹⁴ Doing something different either for themselves or to pass time is important to divert negative thoughts and the emotional response to the phone ring.

During such experience, deprivation of both organic function and enjoyment of life requires a great emotional and physical effort from the patients. Transplantation is seen as an opportunity to improve both health and quality of life. It is conceived as a way of healing and returning to the called normal life.^{5-6,15}

Freedom of patients from the dialysis machine means that they can then develop activities as simple as going to the beach, walking with their families, leaving home, or simply satisfying their desire for eating what they want (e.g., a banana), which seems very simple for those who are healthy. An action that brings a great joy to patients after transplantation is that they can drink water again. Resuming such routine means that they can again develop activities until then restricted. Such routine gives them back the sense of satisfaction and control, send them back to self-control, puts them in a position to choose, gives them back the sense of autonomy.

As dialysis patients are sure that transplantation is the best choice for them, they occupy part of their days with dreams to be pursued after transplantation. Thus they fill their time based on evidence from the empirical and natural plan.²⁰ Evidence from the experience under replacement therapy allows them to believe that transplantation is still the best option of living in this world of impositions by hemodialysis.

However, some studies show that frustration with replacement therapy can also arise after transplantation, especially when patients either do not receive effective monitoring by the health team or do not show a good adherence to treatment. Transplantation is a safe and effective alternative when both the treatment is followed properly and the organ works well.²¹⁻²²

On the other hand the quality of life envisioned and idealized through transplantation not always happens. In many situations, some patients report that significant improvement has not occurred in their lives after transplantation. Immunosuppressive therapy brings a number of complications and side effects over the years. A large portion of people who wish to undergo transplantation ignore this fact. After transplantation, pain, vitality, social aspects, and mental health are among the factors most harmful to the quality of life.²¹⁻²²

Thus, the essential role of the interdisciplinary team is to guide and help patients decide for the safest and most effective treatment according to the reality of each. Equip these people with information about the treatment they are receiving, pre-transplantation evaluation, operation of the waiting list, and prerogatives associated with the possibility of finding a compatible donor seems to be ideal

Teach patients the care that arises from treatment they undergo so that they can understand the care and restrictions resulting from transplantation is a function of the interdisciplinary team. Before patients are included on the list, they must be instructed that there are dietary and physical restrictions and dependence on medications after transplantation. Orientation is essential to help patients deal with transplant and empower them about their own limitations, thus minimizing the probability of a new grieving process with regard to the cure imagined and idealized by them after this procedure.^{6,15,21-22}

Education of patients and their relatives about the actions of health promotion is a function almost essential of nurses because they spend much time together with these patients during hemodialysis sessions. Furthermore, they are those professionals who seek to develop activities directed to home care, change in eating habits, physical activity appropriate to each individual, strict administration of medications, and attention to any signs of infection, rejection, or any clinical manifestations that may arise after transplantation.²¹⁻²²

It is imperative that communication used by all professionals be adequate, simple, clear, and free from technical terms in order to transmit to these patients all required information about their treatment. Nurses should enjoy the time spent together with patients during hemodialysis sessions to strengthen ties and thus solve their doubts about the procedure they will undergo.

FINAL CONSIDERATIONS

During this study, the authors were able to enter the world of patients who experience waiting on list for a kidney transplant. Such contact allowed them to know the reality experienced by such patients during their wait for an indeterminate time, which is permeated by distress, fear, and expectation, but, above all, also by faith and great courage necessary for them to face the barriers that arise in this trajectory.

We were able to understand that transplantation is included in all activities of these patients. Their speeches reveal tiredness due to the long time they remain on the waiting list, making it necessary for them to find ways to deal with this process. The families showed to be support and reference in giving assistance to the interviewees in aspects related to dialysis and their decision to remain on the waiting list.

Patients with CRF see in the transplant their hope of liberation from the limitations imposed by dialysis. At the same time, their speeches reveal distress, as they do not know when they will be called to undergo transplantation, and the simple phone ring causes anxiety.

The reports of these patients emphasize the importance of the role of nurses in this trajectory. Nurses, as members of the interdisciplinary team in transplant units, have a key role in education and guidance of these patients so that the entire process involving transplant succeeds.

Some limitations were present during the study. In this process, lack of interest of the health team in relation to the study was a major barrier, especially in identifying these patients.

REFERENCES

1. Sesso RC, Lopes AA, Thomé FS, Santos JRLDR. Relatório do censo brasileiro de diálise. *J Bras Nefrol* [online]. 2011 [acesso 2013 Mar 18]; 33(4):442-47. Disponível em: <http://www.scielo.br/pdf/jbn/v33n4/09.pdf>
2. Reis CK dos, Guirardello EdeB, Campos CJG. O indivíduo renal crônico como demanda de atenção. *Rev Bras Enferm* [online]. 2008 [acesso 2013 Mar 18]; 61(3):336-41. Disponível em: <http://www.scielo.br/pdf/reben/v61n3/a10v61n3.pdf>
3. Sociedade Brasileira de Nefrologia [online]. 2011 [acesso 2011 Jun. 20]. Disponível em: <http://www.sbn.org.br/>
4. Oliveira NTH de. As expectativas do paciente renal crônico diante da espera pelo transplante [dissertação na internet]. Ribeirão Preto (SP): Universidade Federal de São Paulo, Escola de Enfermagem de Ribeirão Preto; 2007 [acesso 2012 Jun 20]. Disponível em: <http://www.teses.usp.br/teses/disponiveis/22/22131/tde-13032008-160458/pt-br.php>
5. Fontoura FAP. A compreensão de vida de pacientes submetidos ao transplante renal: significados, vivências e qualidade de vida [Tese na internet]. Campo Grande (MS): Universidade Católica Dom Bosco, Programa de Mestrado em Psicologia; 2012 [acesso 2013 Mar 18]. Disponível em: <http://site.ucdb.br/public/md-dissertacoes/8221-a-compreensao-de-vida-de-pacientes-submetidos-ao-transplante-renal-significados-vivencias-e-qualidade-de-vida.pdf>
6. Xavier BLS, dos Santos I. Sentimentos e expectativas de clientes com doença renal crônica aguardando transplante renal. *Rev Pesq Cuid Fundam* [online]. 2012 [acesso 2013 Mar 20]; 4(4):2832-40. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1959/pdf_623
7. Flores RV, Thomé EG da R. Percepções do paciente em lista de espera para o transplante renal. *Rev Bras Enferm*. [online]. 2004 [acesso 2012 Fev 12]; 57(6):687-90. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672004000600011
8. Pauletto, MR. Percepção de Pacientes em hemodiálise fora de lista de espera sobre o transplante renal [Tese na internet]. Santa Maria (RS): Universidade Federal de Santa Maria, Programa de Pós-Graduação em Enfermagem; 2013 [acesso 2013 Mar 18]. Disponível em: http://www.ufsm.br/ppgenf/Dissertacao_Macilene%20Regina%20Pauletto.pdf
9. Registro Brasileiro de Transplantes [página na Internet]. Ano XVII- n. 4. 2011. [acesso 2012 Fev 15]. Disponível em: <http://www.abto.org.br/abtov02/portugues/populacao/rbt>
10. Alexandre M. Estudo sobre as filas para transplante no Sistema Único de Saúde. *Cad Saúde Pública* [online]. 2006 [acesso 2012 Fev 15]; 22(10):2229-39. Disponível em: <http://www.scielo.br/pdf/csp/v22n10/22.pdf>
11. Polit DF, Hungler BP, Beck CT. Avaliação da mensuração e da qualidade dos dados. In: *Fundamentos da pesquisa em enfermagem: métodos, avaliação e utilização*. Porto Alegre (RS): Artmed; 2004
12. Bardin, L. *Análise de conteúdo*. Lisboa (PT): Edições; 2002.
13. Maldaner CR, Beuter M, Brondani CM, Budó M de LD, Pauletto MR. Fatores que influenciam a adesão ao tratamento na doença crônica: o doente em terapia hemodialítica. *Rev Gaúcha Enferm* [online]. 2008 [acesso 2013 Mar 25]; 29(4):647-65. Disponível em: <http://seer.ufrgs.br/RevistaGauchaEnfermagem/article/view/7638>

14. Salati MI, Hossne WS, Pessini L. Vulnerabilidade referida pelos pacientes renais crônicos-considerações bioéticas. *Rev Bio Ethikos* [online]. 2008 [acesso 2012 Fev 15]; 29(4):647-65. Disponível em: <http://www.saocamilo-sp.br/pdf/bioethikos/89/A10.pdf>
15. Quintana AM, Santos TK dos, Hermann WC. Atribuições de significados ao transplante renal. *Psico* [online]. 2011 [acesso 012 Fev 15]; 42(1): 23-30. Disponível em: <http://revistaseletronicas.pucrs.br/ojs/index.php/revistapsico/article/view/6057/6295>
16. Coutinho NPS, Vasconcelos CM, Lopes MHL, Wadle WCA, Tavares MCH. Qualidade de vida de pacientes renais crônicos em hemodiálise. *Rev Pesq Saúde* [online]. 2011 [acesso 2013 Mar 18]; 11(1):13-7. Disponível em: <http://www.periodicoseletronicos.ufma.br/index.php/revistahuufma/article/view/328/243>
17. Correia RF, Silva Filho CR da. A qualidade de vida dos pacientes renais crônicos em hemodiálise na região de Marília, São Paulo. *J Bras Nefrol* [online]. 2011 [acesso 2013 Mar 18]; 33(2):129-35. Disponível em: <http://www.scielo.br/pdf/jbn/v33n2/a03v33n2.pdf>
18. Freire ARI, Braga VAB. Sentimentos e expectativas de pacientes candidatos ao transplante de fígado. *Rev Eletr Enferm* [online] 2011 [acesso 2012 Fev 15]; 13(3):413-21. Disponível em: <http://www.revistas.ufg.br/index.php/fen/article/view/12234>
19. Aguiar MIF, Farias DL, Pinheiro ML, Chaves ES, Rolim ILTPR, Almeida PC. Qualidade de vida de pacientes submetidos ao transplante cardíaco: aplicação da escala Whoqol-Bref. *Arq Bras Cardiol* [online]. 2011 [acesso 2013 Mar 24]; 96(1):60-7. Disponível em: http://www.scielo.br/scielo.php?pid=S0066-782X2011000100011&script=sci_arttext
20. Tourinho CDC. A consciência e o mundo: o projeto da Fenomenologia Transcendental de Edmund Husserl. *Rev Abordagem Gestática* [online]. 2009 [acesso 2013 Mar 18]; 15(2):93-8. Disponível em: <http://pepsic.bvsalud.org/pdf/rag/v15n2/v15n2a03.pdf>
21. Ravanguani LMB, Domingues NAM, Miyazaki MCO. Qualidade de vida e estratégias de enfrentamento em pacientes submetido a transplante renal. *Estud Psicol* [online]. 2007 [acesso 2013 Mar 18]; 12(2):177-84. Disponível em: <http://www.scielo.br/pdf/epsic/v12n2/a10v12n2.pdf>
22. Amaral RC. Qualidade de vida do paciente transplantado renal submetido à ampliação vesical. [Tese na internet]. São Paulo (SP): Universidade de São Paulo, Faculdade de Medicina; 2009 [acesso 2013 mar 18]. Disponível em: <http://www.teses.usp.br/teses/disponiveis/5/5148/tde-15042009-160825/pt-br.php>