



PATIENTS' PERCEPTION FOR KIDNEY TRANSPLANTATION ON HEMODIALYSIS OUT OF WAITING LIST

PERCEPÇÃO DE PACIENTES PARA TRANSPLANTE RENAL SOBRE A HEMODIÁLISE FORA DA LISTA DE ESPERA

LA PERCEPCIÓN DE LOS PACIENTES DE TRASPLANTE RENAL EN HEMODIÁLISIS FUERA DE LA LISTA DE ESPERA

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ABSTRACT

Objective: to describe the perception of patients referred for kidney transplants that are out of the waiting list, on the disease and the hemodialysis treatment. **Method:** exploratory and descriptive study with a qualitative approach, developed with 15 patients on hemodialysis of a renal clinic in Rio Grande do Sul, Brazil. Data production occurred from March to July 2012, through narrative interview of their experiences and submitted to thematic analysis technique. **Results:** the discovery of renal disease, changes and limitations resulting from hemodialysis and adaptation to the treatment constituted the categories of this study. **Conclusion:** the perception of patients on hemodialysis is guided by their experiences that depict a process of adaptation to this condition, causing them to remain in this therapy, even having indication for transplantation. Nurses should promote educational activities to patients about their disease and treatment possibilities, contributing to conscious and clarifies decisions. **Descriptors:** Nursing; Chronic Renal Failure; Renal Dialysis; Kidney Transplantation.

RESUMO

Objetivo: descrever a percepção de pacientes com indicação para transplante renal que estão fora da lista de espera sobre a doença e o tratamento de hemodiálise. **Método:** estudo exploratório e descritiva, com abordagem qualitativa, desenvolvido com 15 pacientes em hemodiálise de uma clínica renal, no Rio Grande do Sul, Brasil. A produção dos dados ocorreu de março a julho de 2012, por meio da entrevista narrativa de vivências e submetidos à Técnica de Análise temática. **Resultados:** a descoberta da doença renal; mudanças e limitações decorrentes da hemodiálise; e, adaptação ao tratamento constituíram as categorias do estudo. **Conclusão:** a percepção dos pacientes sobre a hemodiálise pauta-se em suas experiências e vivências, que retratam um processo de adaptação a essa condição, fazendo com que permaneçam nesta terapia, mesmo possuindo indicação para transplante. Cabe ao enfermeiro promover ações educativas aos pacientes sobre sua doença e possibilidades de tratamentos, contribuindo para decisões conscientes e esclarecidas. **Descritores:** Enfermagem; Insuficiência Renal Crônica; Diálise Renal; Transplante de Rim.

RESUMEN

Objetivo: describir la percepción de los pacientes referidos para trasplantes renal que están fuera de la lista de espera en la enfermedad y el tratamiento de hemodiálisis. **Método:** estudio exploratorio y descriptivo con un enfoque cualitativo, desarrollado con 15 pacientes en hemodiálisis de la clínica renal en Rio Grande do Sul, Brasil. Producción de datos sucedió entre marzo y julio de 2012, a través de entrevista narrativa de experiencias y sometido a la técnica de análisis temático. **Resultados:** el descubrimiento de la enfermedad renal, cambios y limitaciones resultantes de hemodíálises y la adaptación al tratamiento constituían categorías de estudio. **Conclusión:** la percepción de los pacientes en hemodiálisis es guiado en sus experiencias que retratan a un proceso de adaptación a esta condición, causando que se queden en esta terapia, ni siquiera tener indicación de trasplante. Las enfermeras deben promover las actividades educativas a los pacientes sobre sus posibilidades de enfermedad y tratamiento, lo que contribuye a las decisiones informadas y aclarado. **Descriptores:** Enfermería; La Insuficiencia Renal Crónica; La Diálisis Renal; El Trasplante Renal.

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INTRODUCTION

Chronic kidney disease has high morbidity and mortality and is characterized by slow, progressive and irreversible loss of the renal function. The incidence and prevalence of End-stage Renal Disease (ESRD) has been increasing each year, in Brazil and in the world, constituting a public health problem.¹ According to the 2012 census, the most frequent diagnoses of primary renal disease were high blood pressure and diabetes.²

Early detection of chronic kidney disease allows the patient to perform conservative treatment before entering dialysis. This treatment is designed to slow the progression of kidney disease through nutritional therapy, blood pressure control, control of risk factors, monitoring of renal and nutritional function and preparation for the start of dialytic treatment.³ The weakness of knowledge of the population about prevention, and care provided by health professionals in relation to the clarification of the importance of preservation of renal function and the necessary care, contribute to the late discovery of disease.⁴

The modalities of treatments available for patients with ESRD are hemodialysis, peritoneal dialysis and renal transplantation¹. The 2012 census showed an estimated number of 97.586 patients on renal replacement therapy, among them, 91,6% were at hemodialysis treatment, and 31,2% of all dialysis patients were waiting for renal transplantation.²

Hemodialysis is a treatment that uses high-tech equipment and materials for performing the process of removing toxic substances and excess fluid from the body. This treatment lasts an average of four hours, three times a week, according to the clinical status of the patient¹. The dialysis treatment is also accompanied by several limitations and restrictions, causing significant changes in the daily lives of these patients. Physical, sexual, psychological, social and family limitations can affect negatively on these patients' quality of life.⁴

Kidney transplantation is considered the best form of treatment for most patients with chronic kidney disease, due to its lower cost, higher quality of life and increased surviving⁵. It is indicated when there is ESRD, being the patient at dialysis or even at the pre-dialysis phase, and may be performed with living or deceased donor.⁶

The possibility of kidney transplantation needs to be discussed with the patient and

this option deserves to be considered, taking into account their beliefs, fears and worries⁷. Some patients do not accept the condition of depending on dialysis and opt for the possibility of transplantation. As for others, they adapt to their living conditions provided by dialysis and do not show interest in renal transplantation, as they fear its possible risks and complications.⁸

The motivation for the development of this research comes from the experience with hemodialysis patients, in which it was empirically observed some expressions that oscillated between hope to perform the transplant and no longer need to undergo hemodialysis treatment and the fear of the unknown, possible complications and transplant failure. One can also see a considerable number of patients with clinical indication for transplant, but who were not included on the waiting list, or under investigation for transplantation, which raised concerns about this condition.

From these considerations, the study has the following guiding question: what is the perception of patients referred for kidney transplants that are out of the waiting list on the disease and the hemodialysis treatment? With this question, the objective was to describe the perception of patients referred for kidney transplants that are out of the waiting list on the disease and the treatment of hemodialysis.

METHOD

Exploratory and descriptive study with a qualitative approach, developed with 15 hemodialysis patients with indication for transplantation and out of the waiting list. The survey was conducted at a dialysis clinic located in Rio Grande do Sul, Brazil. The clinic is contracted to the Health Unic System/SUS, and provides dialysis treatment for patients with ESRD at regular hemodialysis, three times a week, in three daily shifts.

The subjects inclusion criteria were: being at hemodialysis for at least three months; being 18 years or older; not being on the waiting list for kidney transplantation; having clinical indication for renal transplantation and being able to answer the survey. Patients who had undergone renal transplantation or were under investigation for kidney transplantation from a living or deceased donor were excluded from the research.

To identify the subjects, the list of patients registered for renal transplantation at the clinic, the nurse and physician responsible for hemodialysis shift and the patients' records

were consulted in order to check those that met the criteria for inclusion/exclusion from the study. Having a list with the names of patients who suited the inclusion criteria, the participants were selected, randomly, according to the availability and interest of patients. The number of interviews followed the criteria of saturation of information, by repetition and uniformity of the responses.

Data collection occurred from March to July 2012, through narrative interview of experiences. This narrative includes the story of the experience of a person with the disease, containing several episodes that are placed in a sequence of events, building up experience as a process⁹. The interviews were conducted by two themes: the evolution of the disease and the experience with hemodialysis treatment.

The interviews were conducted in a private room of the hemodialysis clinic, before or after the hemodialysis session, and previously scheduled. The interviews were recorded and, later, transcribed into a text editor and identified by the letter "P" of the patient, followed by sequential Arabic numerals according to the order of application.

The data were submitted to the thematic content analysis procedure. In this mode, the central concept is the theme that includes a bundle of relationships that can be graphically presented by means of a word, a phrase, or summary¹⁰. The systematic and thorough reading of the material was performed, which allowed the seizure of the expressed content and the identification of the repeated and/or semantically similar content of the different fragments. Subsequently, the categorization of the distinctive elements of each subject was realized, comprising the steps of pre-analysis, material exploration and treatment of the results and interpretation.

The ethical principles of Resolution 196/96 of the Health National Council of the Ministry of Health, which regulates researches involving human subjects, were followed for the accomplishment of this research¹¹. Therefore, the study participants were informed and signed Free Consent and Informed Form, which was provided in two ways. Still in compliance with the law, the research had the project approved by the Research Ethics Committee of the institution under No. of Presentation Certificate for Ethics Assessment: 01169012.40000.5346.

RESULTS

The participants were between 27 and 58 years old, nine women and six men, most of

them living at the city where research took place. Regarding marital status, eight were singles; four, married; two, separated; and one, divorced. With regard to religion, 13 identified themselves Catholic; one, evangelical; and one reported no religion. As for education, seven didn't finish elementary school three finished elementary school; two didn't finish high school, and three finished high school. Family income ranged from one to three minimum wages, and all received Social Security benefit. The hemodialysis treatment time ranged from two to 15 years.

From the methodological framework used, three themes emerged and made up the discussion corpus of this study: the discovery of kidney disease: impact and ignorance; changes and limitations resulting from hemodialysis; and adaptation to hemodialysis treatment.

♦ The discovery of kidney disease: impact and ignorance

Chronic kidney disease is silent. Uremic symptoms appear when renal function is already compromised, occurring, most of the time, the late diagnosis of the disease. Most respondents reported that the discovery of the disease and the onset of hemodialysis occurred abruptly, without prior knowledge of diagnosis and treatment.

Then I went to do a lot of tests, then he already presented himself, you're with both kidneys "conked". Then I entered into despair, we enter into despair. I had never been to a doctor, and said: What will I do now? Since I'm here I have to go putting up, then did all tests, already got cleared on time, there (hospital) did for me what they had to do. (P1)

At dawn that I got there in the university (hospital), with pain, much pain in the chest, then there they did an examination and it already accused the kidney problem. Then they already began the task of passing the catheter, it took no long. (P2)

And then I didn't know very well what it was. I've never heard of what hemodialysis was, you know, never. Then I started to do such hemodialysis. (P9)

Against the diagnosis of the disease and the need for a complex and unknown treatment, patients undergo a process of denial/acceptance which is expressed by different reactions and feelings.

We never accept it. No, there's always a bit of rejection [...]. We revolt. Then I revolted, like this: why haven't I treated myself? Why haven't I done this, haven't done that? I regret a thousand things [...]. (P5)

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[...] in the beginning it was hard. I was willing to (pause) even do something to myself. I was willing to kill myself. (P7)

It was really hard, it took me too much to accept. It was really hard. Sometimes, when the day of going (hemodialysis) arrived, I started to cry, sometimes didn't want to go, not at all. But then, people were telling me, you must come, because you're gonna get better, everything. Then I was, very slowly and was accepting everything. (P8)

After the impact against the diagnosis of chronic kidney disease and the need for renal replacement therapy, the respondents reported the limitations and changes related to disease and treatment.

♦ Changes and limitations resulting from hemodialysis

The hemodialysis treatment brings changes in the daily lives of patients. Food and liquid restriction, and regular use of drugs are needed for effective treatment and the patient's well-being, meaning that the disease dictates their lives. The need for care imposed by the treatment modifies the previous lifestyle, requiring patients to adapt to a new way of living.

You have to take care of it, but I take care of myself on the liquids, on food too. There are things that increase potassium, these things like this I can't eat. So I take care of myself on these things too. (P3)

My life is about undergoing hemodialysis and taking medicines. For blood pressure, I take every day [...]. I take care of myself. This addiction thing, those things, I don't have. I never ever put alcoholic drinks in the mouth. Before, I took a bit of beer at the weekends [...] then, after I got this problem, nevermore. (P10)

Other changes that interfere in the patients' lives are related to labor activities and social life. In addition to dependency of care and a machine to stay alive, there is need for compliance with days and times established by the treatment, which implications make impossible the continuity of work activities, compromise leisure activities, especially trips longer than two days or to locations that do not have a dialysis center. The life of these patients changes because of the treatment.

Because now we are stuck to the machine, we say we're not, but we are! Those days you have to come, it's no use. So I wanted to have a more normal life, I mean, away of the machine. (P3)

It wasn't easy, for I worked (long pause). Som y life was Always working, you know? And, suddenly, everything stops. For me, it wasn't easy. (P10)

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You have to get up early, three times a week, it isn't easy. You can't do anything, you can't go out, travel. I just travel to here (he lives at other city). I can't know other places; I can't go to other place. If I go, I have to take the filter, you know? You have to get a place to undergo hemodialysis. (P13)

The changes in the life of a patient undergoing hemodialysis are successive and can mean anxiety and worries, when facing the complications related to the disease and its treatment, as well as the imminent fear of death.

It gets me anxious because of the sex, the sex "conked". It's not like in the past, so this thing, the man is like (pause) new man already [...] this is what screws up the most, this part, otherwise the rest [...]. (P1)

It concerns me for I see like this, my mates leaving, showing up things like in myself [...] I'm with my bones misshapen. (P5)

Sometimes the person gets to think like this: bah!

Às vezes a pessoa se pega a pensar assim: bah! Geez. Will I live until next year? Will I die next year? Will I live more? Why do I have to die before the others? It's complicated. (P6)

♦ Adaptation to hemodialysis treatment

The perception that patients at hemodialysis have on a practically normal life is related to the ability to perform most daily activities, even in the face of changes and limitations the treatment requires.

No, it doesn't change me at all, normal, I take a normal life (emphatic voice), any other person like this, of course, not like other people who eat all they want to, drink all they want to, not like this! So, [...] it has its limits, so it enters in my limits that I have to do. (P1)

[...] I keep a good life, in the case with the machine. I think, in my point, I keep a better life like this. It's right it was better before, I could do everything I wanted to and a bit more. There are some limitations, but you can live well. (P2)

I live a normal life. I arrive at home, eat, if I want to go out, I go. I go fishing, go to the river. I take a normal life. I don't have that fear, that worry of going out: ah! I can catch no rain, or I can catch no sun! There isn't that worry. (P12)

The patients claim their health conditions improved, substantially, after beginning the hemodialysis treatment. Therefore, they told their difficulties at the pre-dialytic phase and conceptualized the hemodialysis as responsible for their lives's continuity.

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Now I know that it's very good, because, if I hadn't begun at that time, I wouldn't be here. Now I see what I've been through, I couldn't put a spoon of food in my mouth, nothing, nothing [...] and ow I feel very well now. (P8)

I think that for me, it's being good. Very good, if I hadn't this treatment, maybe, I wouldn't even be here anymore [...]. (P11)

The safe and satisfaction with hemodialysis, towards the uncertainty of success of the transplantation may contribute to keep them at the therapy they're experiencing.

I'm not afraid of rejection, of not succeeding. And, as I feel fine like this, it's like that saying: "do not mess with what is quiet" (smile). If I'm feeling fine like this! I do everything, everybody says: look, you look like a normal person [...]. (P5)

I think like this, I feel very well in the way I am undergoing hemodialysis. (P9)

[...] in the beginning, I even thought about transplantation, but nowadays, I don't know, I got used to it, I don't know. I feel fine, in the case, with the vitamins, everything we take over there [...] I take an almost normal life. (P14)

With this, one sees that the participants remain at hemodialysis, conditioning and adapting themselves, even against the changes and limitations imposed by this therapy.

DISCUSSION

Chronic kidney disease is a complex disease that requires different approaches in its treatment. In most patients of this study, the discovery of chronic kidney disease and initiation of dialysis was sudden, unexpected and unknown, which leads to the results shown in a study in which most cases of kidney disease was diagnosed in a late stage, already requiring dialysis.⁴

This study confirms that early diagnosis and immediate referral to specialists are essential steps that enable pre-dialysis education and the implementation of measures to mitigate the progression to more advanced stages and reduce morbidity and mortality.³ Furthermore, it is necessary to develop educational activities in health, in order to assist the patient at the understanding and acceptance of the disease and its treatment, besides the necessary care for maintaining their life.

Against the discovery of the disease and the inevitable need for dialysis treatment, patients undergo a process of rejection/acceptance. During this process they may have different reactions, as well as

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moments of physical and psychic suffering.⁴ This process of non-acceptance was found in the reports of the respondents, by refusing to undergo the treatment and even intentions to take their own life.

The denial of the human being is described as a temporary defense stage before the recognition of the gravity and irreversibility of illness or death, and soon replaced by a partial acceptance.¹² In this study, the denial is demonstrated against the unexpected illness and fear of the unknown, expressed by feelings of guilt, anger, fear and despair. This result leads to the pointed ones in other studies, that also point out that these feelings may change with time and initiate the phase of adaptation and coexistence in this treatment.^{4,13}

Hemodialysis brings profound changes in the life of the patient. As in other studies, the patients of this investigation expressed the need for changes in eating habits and hydration, the continued use of medications, dependence on a machine and commitment of leisure and work habits.^{4,14}

The diet control and regular use of drugs are habits already acquired and known by respondents who changed their daily lives. The food and water restrictions are essential for the success of the treatment and the individual well-being, but can be a source of frustration for changing everyday habits and imposing multiple deprivations.¹⁵

Regarding the dependence on a machine, in the context of changes in the lives of patients, it is worth mentioning that, despite the hemodialysis machine provides the maintenance of life, its dependence also limits freedom.¹³ Because of these limits, they discontinue their professional, social and leisure activities, which was found in the statements of the respondents. A similar result was found in a study about the perceptions and changes in the quality of life of patients undergoing hemodialysis, mentioning the importance of work in their lives, both by the need for survival, as for carrying out activities that provide pleasure and satisfaction.⁴

With hemodialysis, the difficulty of traveling, meeting other places is committed as expressed by respondents. The possibility of traveling involves previous planning of the patient and staff, checking availability of vacancy in the desired location in order to ensure the continuity of their treatment without interruptions that may compromise their health.

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The evolution of the disease and the treatment time cause distressing situations to the respondents, towards the complications that come. Chronic kidney disease can cause various clinical complications: bone, cardiovascular, neurological, hematologic, skin and others. These complications usually require other treatments, compromising the health and quality of life of a chronic renal patient.¹

The experience of patients with chronic kidney disease becomes complex and the patient is weakened during the disease, finding it hard to cope with the risk of harm and the fear of death that permeate their daily lives.¹⁴ This study ratifies this weakness, given the health concerns and the fear of death, as the statements of the respondents. Moreover, the finite seems more factual for patients who depend on a machine for living.

The subjects of this study recognize the limitations and complications that the disease and treatment impose and, yet, at times, consider their life as normal, within the standards established by their culture. While living with this paradox, a process of acceptance and adaptation to the treatment is designed to keep them closer to normal life. A study dealing with hemodialysis patients vulnerability affirms that the time variable in hemodialysis is a factor that can affect the quality of life of patients and promote the acceptance of limitations and adaptation to their new life situation.¹³

Some features are found by patients to cope with all these changes caused by the disease. A study found that religion helps and comforts patients, strengthening them and promoting general well-being in the acceptance of this inevitable condition of illness.¹⁶ Another coping possibility is the expectation and hope of performing a kidney transplant, seen as a possibility that could change their lives and transform their suffering in better days.¹⁷⁻⁹

At the same time the kidney transplantation is considered the best therapeutic method for the treatment of patients with chronic renal failure with no contraindications, its realization is no guarantee of success. Thus, fear and distrust of the (un)successful kidney transplant cause insecurity in patients, being considered, by their imagination, as something nebulous and intangible.¹⁷

The perception of the participants of this study on hemodialysis is seen as something necessary and vital to ensure their survival, even with the many changes and limitations

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that this treatment imposes on their lives, opting to remain in therapy, in which they feel adapted. In addition, they have been at hemodialysis for a long time, have indication for kidney transplantation, but they are not on a waiting list, which can be related to their perceptions and experiences related to hemodialysis and kidney transplantation. A study about the perception of hemodialysis patients on their disease showed significant improvement over a period of treatment, leading to a more optimistic view of their disease by understanding it better and considering dialysis an effective treatment for their problem.²⁰

CONCLUSION

The discovery of kidney disease and the unforeseen need for dialysis, as a result of lack of an early diagnosis and appropriate preparation for the treatment, were possibly what caused intense suffering for the surveyed. The results of this study confirm that guidance and prevention of chronic kidney disease still constitute a challenge to nursing and the current public health.

Hemodialysis patients with indication for transplantation, and out of the waiting list, realize that the disease and hemodialysis cause changes that interfere in lifestyle, limiting their daily activities and, thus, compromising their quality of life. However, despite the recognition of the limitations and privations imposed by the disease and its treatment, patients adapt and consider having a normal life within their possibilities, which does not prevent them from suffering with such changes.

The perception of patients on hemodialysis comes from their experiences. The long living with the disease and hemodialysis makes them, in a way, safe and adapted to this mode, which makes them realize hemodialysis as essential, both to improve their health, as to ensure their survival. Thus, considering the obtained "gains", hemodialysis is in an option that seems guaranteed and safe.

The possibility for kidney transplantation and the proper explanations about this treatment option, however, should be provided to patients with indication for transplantation, since this therapy can provide a better quality of life and survival of patients. Fear of the unknown and the uncertainty of success of a kidney transplant may pervade the thinking of these patients and influence the decision of not joining, temporarily or permanently, a waiting list, which must be respected and understood by staff attending these patients.

Therefore, educational activities promoted by nurses are considered essential to encourage patients at hemodialysis to know more about the disease, treatments and possibilities. The sensitive listening can be an important tool in order to provide a better understanding of the individual needs. Thus, nurses can help patients answering their questions and minimizing their fears, in order to contribute to conscious and informed decision-making, as well as finding ways to live within their possibilities.

The limitations of the study were the theme specificity and lack of studies with this population, making it necessary to carry out some approaches to research results conducted with hemodialysis patients regardless their status in relation to kidney transplantation.

Such limitations recommend the need to consider the results in its uniqueness, but also underscore the need for further studies with patients at this condition in order to complement and compare the results. One also suggests conducting studies about the perception that these patients have on kidney transplantation and the reasons they don't join a transplant list. Thus, one can provide, to the professionals, greater understanding and clarification on the subject and contribute to the development of effective care practices.

REFERENCE

1. Riella MC. Princípios de Nefrologia e distúrbios hidroeletrólitos. 5ª ed. Rio de Janeiro: Guanabara Koogan; 2010.
2. Sesso RCC, Lopes AA, Thomé FS, Lugon JR, Watanabe Y, Santos DR. Relatório do censo brasileiro de diálise crônica 2012. J bras nefrol. [Internet]. 2014 [cited 2015 Feb 20]; 36(1):48-53. Available from: http://www.jbn.org.br/detalhe_artigo.asp?id=1617
3. Bastos MG, Kirsztajn GM. Doença renal crônica: importância do diagnóstico precoce, encaminhamento imediato e abordagem interdisciplinar estruturada para melhora do desfecho em pacientes ainda não submetidos à diálise. J bras nefrol. [Internet]. 2011 Jan-Mar [cited 2015 Feb 10];33(1):93-108. Available from: <http://www.scielo.br/pdf/jbn/v33n1/v33n1a13.pdf>
4. Silva AS, Silveira RS, Fernandes GFM, Lunardi VL, Backes VMS. Percepções e mudanças na qualidade de vida de pacientes submetidos à hemodiálise. Rev bras enferm. [Internet]. 2011 Sept-Oct [cited 2015 Jan 15];64(5):839-44. Available from: <http://www.scielo.br/pdf/reben/v64n5/a06v64n5.pdf>
5. Cantekin I, Ferah H, Keles M, Gulcan E. Investigation of features of patients in renal transplantation waiting list: Who wants much more of what for renal transplantation? Pak J Med Sci. 2013 July-Aug [cited 2015 Mar 10];29(4):962-5. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3817754/>
6. Noronha IL, Ferraz AS, Silva Filho AP, Saitovich D, Carvalho DBM, Paula FJ, et al. Transplante renal: indicações contra-indicações. Projeto Diretrizes - Associação Médica Brasileira e Conselho Federal de Medicina [Internet]. 2006 [cited 2015 Jan 30]; [aprox.6 telas]. Available from: http://www.sbn.org.br/pdf/diretrizes/TX1-Indicacoes_e_contra-indicacoes.pdf
7. Ghahramani N, Wang C, Sanati-Mehrziy A, Tandon A. Perception About Transplant of Rural and Urban Patients With Chronic Kidney Disease; A Qualitative Study. Nephrourol Mon. 2014 Mar [cited 2015 Mar 15]; 6(2):e15726. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3997949/>
8. Camargo VP, Quintana AM, Weissheimer TKS, Junges N, Martins BMC. Transplante renal: um caminho para a vida ou um passo para a morte? Revista contexto & saúde [Internet]. 2011 Jan-June [cited 2015 Feb 25];10(20):515-24. Available from: <https://www.revistas.unijui.edu.br/index.php/contextoesaude/article/view/1572>
9. Silva DGV, Trentini M. Narrativas como técnica de pesquisa em enfermagem. Rev latinoam enferm. [Internet]. 2002 May-June [cited 2015 Jan 24];10(3):423-32. Available from: <http://www.scielo.br/pdf/rlae/v10n3/13352.pdf>
10. 10-Minayo MCS. O Desafio do conhecimento: pesquisa qualitativa em saúde. 12ª ed. São Paulo: Hucitec; 2010.
11. Ministério da Saúde (BR), Conselho Nacional de Saúde, Comissão Nacional de Ética em Pesquisa. Resolução Nº 196 de 10 de outubro de 1996: diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. Brasília (DF): MS; 1996.
12. Ross EK. Sobre a Morte-Morrer. 9ª ed. São Paulo: Martins Fontes; 2006.
13. Salati MI, Hossne WS, Pessini L. Vulnerabilidade referida pelos pacientes renais crônicos-considerações bioéticas. Bioethikos (Online) [Internet]. 2011 Oct-Dec [cited 2015 Jan 10]; 5(4):434-42. Available

from: <http://www.saocamilo-sp.br/pdf/bioethikos/89/A10.pdf>

14. Lima MA, Sousa GR, Sousa AM, Felipe GF, Oliveira ASS, Formiga LMF. Educação em saúde para pacientes em hemodiálise. J Nurs UFPE on line [Internet]. 2014 June [cited 2015 Jan 25];8(6):1510-5. Available from: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/4300/pdf_5214

15. Santos I, Rocha RPF, Berardinelli LMM. Necessidades de orientação de enfermagem para o autocuidado de clientes em terapia de hemodiálise. Rev bras enferm [Internet]. 2011 Mar-Apr [cited 2015 Feb 12];64(2):335-42. Available from: <http://www.scielo.br/pdf/reben/v64n2/a18v64n2.pdf>

16. Silva EA, Melo Júnior IM, Nepomuceno FCL, Lucena KDT, Deininger LSC. Atitude religiosa: uma espera e cura para os doentes renais crônicos no serviço de diálise. Rev enferm UFPE on line [Internet]. 2014 Aug [cited 2015 Mar 02];8(8):2576-83. Available from: <http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/6063>

17. Xavier BLS, Santos I. Sentimentos e expectativas de clientes com doença renal crônica aguardando transplante renal. Rev pesqui cuid fundam online [Internet]. 2012 Oct-Dec [cited 2015 Feb 24];4(4):2832-40. Available from: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1959/pdf_623

18. Knihs NS, Sartori DL, Zink V, Roza BA, Schirmer J. A vivência de pacientes que necessitam de transplante renal na espera por um órgão compatível. Texto & contexto enferm [Internet]. 2013 Oct-Dec [cited 2015 Jan 26];22(4):1160-8. Available from: <http://www.scielo.br/pdf/tce/v22n4/35.pdf>

19. Lopes SGR, Silva DMGV. Narrativas de mulheres em hemodiálise: à espera do transplante renal. Texto & contexto enferm [Internet]. 2014 July-Sept [cited 2015 Jan 26];23(3):680-7. Available from: http://www.scielo.br/pdf/tce/v23n3/pt_0104-0707-tce-23-03-00680.pdf

20. Tasmoc A, Hogas S, Covic A. A longitudinal study on illness perceptions in hemodialysis patients: changes over time. Arch Med Sci. 2013 Oct [cited 2015 Mar 10];9(5): 831-6. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3832830/>

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