# FROM HEMODIALYSIS TO PERITONEAL DIALYSIS: PATIENTS' EXPERIENCES REGARIDNG THE CHANGE OF TREATMENT

# DA HEMODIÁLISE À DIÁLISE PERITONEAL: EXPERIÊNCIAS DE PACIENTES SOBRE A MUDANÇA DE TRATAMENTO

# DE LA HEMODIÁLISIS A LA DIÁLISIS PERITONEAL: EXPERIENCIAS DE PACIENTES EN EL CAMBIO DE TRATAMIENTO

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**How to cite this article:** Oliveira JF, Marinho CLA, Silva RS. From hemodialysis to peritoneal dialysis: patients' experiences regaridng the change of treatment. Rev baiana enferm. 2019;33:e33818.

Objective: to understand the perceptions of users with chronic renal insufficiency who underwent peritoneal dialysis and previously experienced hemodialysis about the change of treatment. Method: exploratory and descriptive study, with qualitative approach, performed with nine patients treated with peritoneal dialysis. Data were collected through a semi-structured interview, organized and analyzed according to the Thematic Content Analysis Technique. Results: the analysis of the meaning units originated three thematic categories: Overcoming the fear of changing the therapy through the positive perception of the treatment; Ambivalence of feelings: independence and autonomy versus imprisonment; and Relief of physical symptoms. Conclusion: the change in the treatment of users with chronic renal insufficiency who underwent peritoneal dialysis generated fear of the unknown, but the achievement of autonomy, despite the feeling of being trapped to a new routine, allied to the relief of physical symptoms, were recognized as positive experiences.

Descriptors: Nephrology Nursing. Renal Insufficiency, Chronic. Renal Dialysis.

Objetivo: conhecer as percepções dos usuários com insuficiência renal crônica que realizavam a diálise peritoneal e vivenciaram previamente a hemodiálise, acerca da mudança de tratamento. Método: estudo exploratório e descritivo, de abordagem qualitativa, realizado com nove pacientes em tratamento com diálise peritoneal. Os dados foram coletados por meio de entrevista semiestruturada, organizados e analisados conforme a Técnica de Análise de Conteúdo Temática. Resultados: da análise das unidades de significado emergiram três categorias temáticas: O medo da mudança de terapia superado pela percepção positiva do tratamento; Ambivalência de sentimentos: independência e autonomia versus aprisionamento; e Alívio dos sintomas físicos. Conclusão: a mudança de

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tratamento dos usuários com insuficiência renal crônica que realizavam a diálise peritoneal gerou medo do desconhecido, todavia a conquista da autonomia, apesar do sentimento de aprisionamento a uma nova rotina, aliada ao alívio de sintomas físicos, foram experiências reconhecidas como positivas.

Descritores: Enfermagem em Nefrologia. Insuficiência Renal Crônica. Diálise Renal.

Objetivo: comprender las percepciones de usuarios con insuficiencia renal crónica sometidos a diálisis peritoneal y la bemodiálisis experimentada anteriormente sobre el cambio de tratamiento. Método: estudio exploratorio y descriptivo, de enfoque cualitativo, realizado con nueve pacientes tratados con diálisis peritoneal. Los datos fueron recolectados a través de una entrevista semi-estructurada, organizada y analizada de acuerdo con la Técnica de Análisis de Contenido Temático. Resultados: del análisis de las unidades de significado, emergieron tres categorías temáticas: Temor al cambio de terapia superado por la percepción positiva del tratamiento; Ambivalencia de sentimientos: independencia y autonomía frente a la prisión; y Alivio de los síntomas físicos. Conclusión: el cambio en el tratamiento de usuarios con insuficiencia renal crónica sometidos a diálisis peritoneal genera el miedo a lo desconocido, sin embargo, la conquista de la autonomía, a pesar de la sensación de estar atrapado en una nueva rutina, aliada al alivio de síntomas físicos, fueron reconocidos como experiencias positivas.

Descriptores: Enfermería en Nefrología. Insuficiencia Renal Crónica. Diálisis Renal.

### Introduction

Chronic Kidney Disease (CKD) is a public health problem due to the increasing number of people affected. According to the Brazilian Society of Nephrology, which conducts the Chronic Dialysis Census, there was an increase of 40 thousand new patients in 2017, with an estimated total of 126,583 patients under dialysis treatment in Brazil that year<sup>(1)</sup>.

Some of the treatments adopted include the Hemodialysis (HD), the most widespread in Brazil, the Peritoneal Dialysis (PD), still little used, since only 7.9% of the patients underwent this treatment in 2016, and the renal transplantation<sup>(2)</sup>. The underutilization of PD is not just a Brazilian reality, since several studies in other countries indicate a rate of use below 10%<sup>(3-7)</sup>.

Asian authors<sup>(4)</sup> affirm that, some of the reasons for the low adherence include the predominant practice of starting dialysis patients by HD and the inertia of medical professionals, hospital managers and health systems in relation to implementing changes, once there is evidence that the PD can be initiated in a timely, safe and effective way in urgent cases, presenting good results.

The two modalities (HD and PD) of treatment differ in the way they affect the patients' lives. The first can be very stressful for the physical conditions, once the sessions cause, among other symptoms and complications, an intense fatigue, in addition to interfering in the life style and social and labor activities<sup>(8-9)</sup>. The second, the PD, allows for patients' greater autonomy and flexibility in time and space, allowing for the maintenance of their daily activities<sup>(10)</sup>.

While choosing the modality, the decision usually is often more influenced by the doctors' opinion and the availability of methods than by the patient's preferences, since the complete information about the types of dialysis and their implications in daily life is not always available<sup>(8)</sup>.

The choice of dialysis modality should be a decision shared between the health team, the patient and the family<sup>(8)</sup>. To this end, it is necessary to ensure that patients and families are informed about the dialysis methods available, in order to know their preferences and respect the patient's decision-making power to choose the method. The active participation of the patient in this process can contribute to greater adherence and satisfaction with the treatment.

Therefore, the following research question emerged: How do patients who had previously undergone hemodialysis and began peritoneal dialysis perceive this process of change?

In order to broaden the discussion, trying to answer the question and contribute to the field of knowledge about the effects of the change between the two modalities in their ways of life, the present study aims to understand the perceptions of the users with chronic renal insufficiency who undergo peritoneal dialysis and previously experienced hemodialysis about the change of treatment.

### Method

Exploratory and descriptive study, with qualitative approach, developed at a clinic specialized in renal replacement therapy, located in a town in Northern Piemonte do Itapicuru, countryside of Bahia, Brazil. It is a clinic of private administrative sphere, which provides service to the Unified Health System (UHS) and meets 203 hemodialysis patients and 10 patients under peritoneal dialysis.

The inclusion criteria were: patients registered in the peritoneal dialysis program and with treatment time of more than three months. The exclusion criteria were: age under 18 years, no previous hemodialysis and cognitive limitations.

The technique used for data collection was a semi-structured interview, consisting of questions in which the interviewees could expose their perceptions about the change of therapy. Among all ten patients under peritoneal dialysis, monitored at the service, nine met the inclusion criteria and only one did not meet for not having undergone hemodialysis previously.

Data collection occurred at the service, in August 2017, after the monthly appointment, once the peritoneal dialysis is performed at home. The interviews were audio-recorded with the participants' consent, after clarification and signing the Informed Consent Form (ICF), and lasted an average of 15 minutes. To ensure the secrecy and anonymity, the participants were identified with the letter "I", followed by the number of interview in chronological order (I1... I9).

The speeches were organized and analyzed using the Thematic Content Analysis Technique<sup>(11)</sup>, which consists of three stages: preanalysis, material exploration and treatment of results. In pre-analysis, the interviews were read in order to grasp the meanings of the participants' statements, giving rise to sense units; during the exploration of the material, there was the separation and grouping of the sense units, in order to generate the meaning units; and, finally, after the inferences and interpretation of ideas, the thematic categories emerged.

The study was examined and approved by the Research Ethics Committee (REC), receiving the Opinion n. 2.182.169, and met the formal requirements governing researches involving human beings.

#### Results

Among the nine participants of this study, seven were women and two, men. Regarding marital status, five were unmarried and four, married. All had an income of up to one minimum wage and had no labor activities. Seven were in the age group of 29-39 years and two were over 60 years old. In relation to schooling, concerning years of study, four had up to eight years of studies and five, more than eight years.

In relation to the treatment time, eight had between one and five years of peritoneal dialysis and only one had more than five years. Two participants reported need for help to perform dialysis at home; the other performed self-care; eight were undergoing Continuous Ambulatory Peritoneal Dialysis (CAPD) and only one, Automated Peritoneal Dialysis (APD).

The analysis of the meaning units originated three thematic categories: Overcoming the fear of changing the therapy through the positive perception of the treatment; Ambivalence of feelings: independence and autonomy versus imprisonment; and Relief of physical symptoms.

# *Category 1 - Overcoming the fear of changing the therapy through the positive perception of the treatment*

In this category, the interviewees expressed the fear related to change of therapy, when there arose the need to perform peritoneal dialysis, and no longer hemodialysis, leading them to believe it was a more painful and complicated modality. This feeling was caused by their lack of knowledge about the new therapy, as well as by the adaptation regarding the routine of hemodialysis:

I couldn't accept in the beginning, because I was afraid, I didn't know what it was. I didn't understand anything, couldn't understand it well. So I didn't want to undergo this treatment. But some people who were undergoing it guided me. (11).

Peritoneal dialysis is completely different. If I knew about it, I would've done long before, because I didn't accept. The doctor told me to do it a long time ago, but I didn't accept. I was like "Ob, gosb! carrying this catheter in me..." Undergo the surgery, I thought it was something from another world. (13).

After you start the treatment, you see it is no rocket science [...] after I managed to change to peritoneal dialysis, I saw it is completely different. (18).

*Category 2 - Ambivalence of feelings: independence and autonomy versus imprisonment* 

After questioned about the transformations occurred in the routine after changing the therapeutic modality, the participants reported greater freedom to perform their daily activities and other activities related to leisure, as well as convenience, speed and autonomy to perform the procedures of dialysis.

With this treatment, I can still travel and take it, depending on my destination, which does not happen with bemodialysis. In bemodialysis, I had to come every day, couldn't miss it, it was worse. (13).

It is fast, in 20 minutes I do it, without any difficulty, it is manual [...] 15 minutes for the fluid enter, and 10 minutes to drain, it is easy, I do it by my own, I don't need anybody, I have no problems with it. (I4).

With this now, I do everything I want to, I do my things at home, which I couldn't do before [...] I clean the house, I take care of my daughter, which I couldn't do before, the others had to do it for me [...] and today, thanks to God, I have no difficulty doing nothing. (17).

However, the same participants also reported a feeling of imprisonment related to the routine treatment with peritoneal dialysis. Despite more free hours in the day, without the regular need to be at the clinic, this therapy requires a rigor both in relation to the care of hygiene as a routine with well-established timetables to change solutions, more than once a day. It's a treatment you do every four bours. Sometimes, you want to go out, the place is great, the environment is good and stuff, but you have to come back home to be able to do the treatment[...] after those four bours you have to go to do dialysis[...] (13).

I feel more imprisoned. I don't have time to almost everything anymore. I must always do the treatment at the right times, I cannot fail[...] if you have an appointment, you can't go, you have to do the treatment first, chasing the life, instead of going to the appointments [...] it's quite complicated. (14).

## Category 3 – Relief of physical symptoms

Concerning physical health, based on the meaning units, in addition to the symptoms caused by the disease, patients may suffer also with those resulting from the treatment. In this regard, participants experienced a positive change after the peritoneal dialysis, once there was relief or disappearance of symptoms frequent when performing hemodialysis:

With this treatment, I feel much better. At the beginning of the disease, when I was undergoing hemodialysis, I used to feel pain and had to stop what I was doing. I felt a lot of pain and fatigue, but not today. Today I don't feel pain, I do the dialysis quietly, don't feel anything. Today, thanks to God, I'm fine, thanks to dialysis. (12).

The bemodialysis, "Hail Mary", I don't even want to think! This is much better for me [laughs]. The bemodialysis was the greatest sadness in my life, because I got sick, so [...] I got really sick, couldn't right well, I was so thin, I got so cold in the room. (11).

In the peritoneal dialysis, you don't feel anything, you feel nothing, nothing at all. I don't feel anything [...] in hemodialysis, you spend four hours on a machine that gives you headache, nausea, low pressure, high pressure. Then, the anxiety of staying there also affects you. You get impatient, waiting for those four hours there, only laying down and with a cramp, these things, excess weight that makes you get a cramp [...] (16).

## Discussion

The fear of change reported by the participants results from the uncertainties and fears about the future, related to the time spent, dietary restrictions, schemes of administration of medications and complications, such as peritonitis, which was also observed in another study<sup>(12)</sup>. Furthermore, another study<sup>(6)</sup> with a similar population shows that, many times, patients end up receiving wrong and distorted information on bad outcomes in peritoneal dialysis, once

few nephrologists tend to recommend the PD to individuals with worse prognosis, due to the cardiac function and absence of venous access.

The discovery of the CKD, by itself, in addition to the dependency on a treatment to continue living, is a critical period for any individual, as well as the adaptation phase to therapy, in which the patient is physically and psychologically weakened. The dialysis treatment requires from patients not only the adoption of a new life style, but also the resignification of all the dimensions of their existence<sup>(13-14)</sup>.

The HD is the initial therapy, in most cases, due to late diagnosis and management of urgency situations, in which the patient starts dialysis immediately as a matter of survival and not as an option. In this context, there is the acceptance of the treatment, even without the proper clarification, facing the urgency situation, and the patient generally does not have the proper participation in the decisionmaking process or receive information about other types of therapy<sup>(15)</sup>.

The choice of treatment, theoretically, belongs to the patient along with the health team, but this has not happened in practice, and should occur not only at the beginning of therapy, but also when there is need for change of modality. A study<sup>(16)</sup> about the decision regarding the selection of therapy, conducted in the city of Pelotas (RS), showed that the decision on the selection of Renal Replacement Therapy (RRT) was the medical professional in 54.2% of cases and 83.5% for those patients who would undergo PD and HD.

The fear generated by insufficient information, the total unawareness about the modality or the difficulty to understand each therapeutic modality can be singled out as the main cause of initial refusals to PD, since not always the patients receive all the information about the types of dialysis, as well as on the possibility of renal transplantation<sup>(8)</sup>. Generally, the change in the type of treatment happens due to the need derived from clinical changes in the course of the treatment, when the patient does not have more conditions to perform hemodialysis, due to failure of the modality or problems in the fistula/vascular graft. In this way, the patient is notified about the need for change, but does not receive sufficient guidance on the PD, which leads them to feel fear, due to unawareness about the new modality, and also frustration, due to previous failure<sup>(17)</sup>. This fact was also observed in the meaning units present in this study.

Nevertheless, many times, during the appointment, the patient can feel shaken and with a limited ability of understanding. In this way, important details of the treatment may not be processed, despite the provision of a high-quality explanation<sup>(5)</sup>.

When facing the PD, the patient sees a whole new and unknown universe, in which they feel alone, as if they were the only one to pass through the situation. The search for information in various sources becomes a coping strategy. The most common among them is hearing other people who have already undergone the method, which not only allows for learning more about the new but also helps develop greater security<sup>(18)</sup>.

Hemodialysis is more widely used and, therefore, patients commonly have prejudice against another modality. Nonetheless, when informed about the PD and better understanding the details of the therapy, they leave the condition of hostages of fear and become aware about the method and more optimistic. Thus, the information sets free and promotes autonomy, decreases anguish, enables acceptance and makes believe that it is possible to continue living with another type of dialysis<sup>(18)</sup>.

The exchange of modality can be traumatic as it generates more changes in everyday life, since the individual needs to go through a new process of adaptation. This process involves not only new habits, behaviors and a new daily routine, but also modifications at home, so that it becomes compatible with the needs of the method<sup>(17)</sup>. After the initial moment of crisis and with the advance of the adaptation process, they begin to accept the PD, considering it a better method when compared to hemodialysis<sup>(18)</sup>.

It is worth mentioning that both therapies have advantages and disadvantages, and health professionals need to have teaching and communication skills to transmit understandable and quality information, use appropriate educational materials and demystify misinformation, so that the patient can understand the treatment and promote their self-care<sup>(13-14,18-19)</sup>.

In relation to changes in daily activities, different studies<sup>(12-13,20)</sup> compare PD and HD regarding the patient's autonomy and use indicators such as Quality of life (QOL) and levels of depression and anxiety to understand the level of autonomy. The results suggest that both modalities affect the QOL. However, in HD patients, the quality of life is seen with larger losses due to increased restrictions in the daily routine. This was also observed in the results of this study. Those who undergo the PD can present better QOL, by benefitting from greater autonomy and social integration, fewer dietary restrictions, greater freedom to travel and deal with financial matters<sup>(5,8,20)</sup>.

Concerning depression and anxiety, they are more frequent in HD patients due to the restricted independence, since these individuals need to be connected to the machine several hours a week and go to the dialysis service every two or three days, passing through various stressful situations<sup>(8,13,20)</sup>.

The PD stands out among the RRT currently available, since it is a home-based modality, providing for users flexibility of schedules, allowing for managing and planning their daily activities<sup>(17)</sup>. Therefore, PD patients have greater autonomy, because they are less dependent on the dialysis unit and health professionals. Once this modality is carried out at the patient's home, it allows for higher activity at work, greater social interaction and maintenance of the usual routine<sup>(8,21)</sup>. These advantages are even more evident when the PD is automated, performed only in the night period, by enabling greater free time during the diurnal period<sup>(14)</sup>.

Although studies demonstrate the improved quality of life when completing the PD sessions, the participants of the present study realized ambivalent feelings in relation to the PD routine. While expressing greater autonomy in the current modality to perform activities of daily living in comparison to the HD, since they do not need to attend the clinic three days a week for four hours/day, without considering the travel time to the unit, the participants showed dissatisfaction, because they feel imprisoned, due to the obligation to carry out the procedures at preestablished times and more than once a day.

The PD also implies some restrictions in the routine, despite being a home-based treatment, which allows for greater autonomy when compared to the HD. In this way, the patient needs to adapt their habits and activities in order to perform dialysis safely, at the correct times<sup>(18)</sup>.

The concern with the daily ritual of execution of the PD is more intense for those patients who use the CAPD, because the procedures are manually performed, on average, four times a day, every four hours. In this situation, the individual is subject to strict compliance with the treatment at times that may coincide with social, leisure or work activities, feeling obliged to renounce<sup>(22)</sup>.

The APD uses a machine called cycler which performs the infusions and drainage of the dialysis fluid during eight to twelve hours at night, during the sleep period<sup>(22)</sup>. The APD is a method of PD that offers an even greater freedom, because the diurnal period is totally free for the development of other activities. Therefore, it can offer great benefits to these patients who feel constrained to treatment.

Thus, regardless of the modality of treatment developed, the patient's dedication and commitment are necessary in favor of their self-care in living with a chronic disease, recognizing that, as any therapy, is has positive and negative points.

In the latter category, which addressed the physical symptoms, the person with CKD has impaired organic functions due to uremia, which affects their general well-being and QOL<sup>(14,23)</sup>. In addition to the symptoms caused by renal dysfunction, there are the effects of the therapeutic modalities used. The HD is a more exhausting treatment, with more aggressive techniques. Therefore, the patients often present

pruritus, nausea and cramps, besides intense fatigue, requiring time to recover after each session<sup>(8,19,24)</sup>.

In the present study, the meaning units indicate a positive change in the control of physical symptoms in those patients who migrated to the treatment with peritoneal dialysis, once there was the relief or the disappearance of symptoms frequent in the hemodialysis. Another study<sup>(16)</sup> points out that HD patients reported more pain than those in PD, justified by the positioning in the supine position during the whole session, in addition to the multiple venipuncture every HD session.

Of the dialysis modalities, the PD is less harmful in terms of physical health, when reducing the occurrence of these symptoms and showing better clinical results and preservation of residual renal function<sup>(7,25)</sup>. Although patients are subjected to the risk of developing complications, such as peritonitis, the symptomatic control is generally greater due to greater comfort and less hemodynamic instability provided by the method<sup>(19,23)</sup>. In this way, based on the reports, the relief of physical symptoms is a positive point and contributes to both patients' satisfaction as adherence to treatment.

As study limitations, one can cite the small number of patients and no possibility of another group of patients who could have experienced the opposite condition, i.e., having performed the DP previously and changed to HD, which can be a proposal for new studies.

## Conclusion

The analysis of the meaning units allowed for identifying the main perceptions about the change of modality to PD in those patients with previous HD experience. The fear of change due to the unawareness about the PD, the achievement of greater autonomy, the feeling of being trapped to the dialysis routine and relief of physical symptoms were the experiences most evidenced by the interviewees.

This study does not seek to exalt a method to the detriment of another, since both are extremely important and have their advantages. It only emphasizes that the change from HD to PD was very beneficial to these patients.

The study of experiences and perceptions of chronic renal patients with different modalities of dialysis provides an important contribution to the work of health professionals, especially nurses, while seeking a more integral health care, and can subsidize reflections on the importance of greater clarification regarding the therapeutic modalities and respect for the patient's autonomy in the decision-making process.

## **Collaborations:**

1 – conception, design, analysis and interpretation of data: Jeany Freire de Oliveira and Christielle Lidianne Alencar Marinho;

2 – writing of the article and relevant critical review of the intellectual content: Jeany Freire de Oliveira and Rudval Souza da Silva;

3 – final approval of the version to be published: Rudval Souza da Silva.

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- Received: October 9, 2019
- Approved: Novermber 8, 2019
- Published: February 17, 2020
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