

Women's Autonomy with Kidney Disease on Peritoneal Dialysis at Home
Autonomia de mulheres com doença renal para a diálise peritoneal no domicílio
Autonomía de mujeres con enfermedad renal para diálisis peritoneal en casa

Luiza Pereira Vargas Rodrigues¹, ORCID 0000-0002-8737-0957
Juliana Graciela Vestena Zillmer², ORCID 0000-0002-6639-8918
Franciele Roberta Cordeiro³, ORCID 0000-0001-6194-5057
Tássia Racki Vasconcelos⁴, ORCID 0000-0001-6831-0038

¹ *Universidade Luterana do Brasil*

^{2 3 4} *Universidade Federal de Pelotas, Brasil*

Abstract: Introduction: Peritoneal dialysis is a complex treatment because it requires both a strict therapeutic regimen and a greater development of autonomy to manage it. Objective: To analyze the construction of the autonomy in women with chronic kidney disease to perform peritoneal dialysis at home. Material and Method: This is a qualitative study, theoretically supported by Paulo Freire's concept of autonomy. Fourteen women on peritoneal dialysis participated in the study. The data were produced in a nephrology service in the Southern Region of Brazil, from April 2013 to June 2014, through semi-structured and open interviews, organized in the Ethnograph v6 program and submitted to content analysis. Results: Four categories were identified that describe the construction of women's autonomy, which are: Emergence of the disease: search for care and diagnosis, need to perform peritoneal dialysis in the hospital; Care transition: support and assistance for returning home, and managing peritoneal dialysis at home. Conclusion: The construction of women's autonomy occurred during the illness process and continued when they returned home with self-management of dialysis. Still, it was evidenced that the recognition of the own body and constant evaluation of the dialysis had a key role in the empowerment of such women and help them to decide on the treatment.

Keywords: personal autonomy; renal insufficiency; dialysis; women's health; health personnel; qualitative research.

Resumo: Introdução: A doença renal crônica se caracteriza pela disfunção dos rins na eliminação de toxinas. Uma das alternativas de terapia é a diálise peritoneal, na qual o indivíduo encontra diversos desafios, visto que, além das mudanças no estilo de vida devido à doença, o tratamento exige certa adaptação e disciplina, tanto da pessoa, quanto da família. Objetivo: Analisar a construção da autonomia de mulheres com doença renal crônica para

realizar a diálise peritoneal no domicílio. Método: Estudo de abordagem qualitativa, sustentado teoricamente pelo conceito de autonomia proposto pelo educador brasileiro Paulo Freire. Os dados foram produzidos entre abril de 2013 e junho de 2014, por meio de entrevista semiestruturada e aberta, organizados no programa Ethnograph v6, tendo sido submetidos à análise de conteúdo proposta por Laurence Bardin. Resultados: Foram construídas quatro categorias que descreveram a construção da autonomia das mulheres, sendo elas: Surgimento da doença: busca por cuidados e diagnóstico; Necessidade de realizar a diálise peritoneal no hospital; Transição do cuidado: apoio e assistência para o retorno ao domicílio, e Gerenciando a diálise peritoneal no domicílio. Conclusão: A construção da autonomia das mulheres ocorreu no decorrer do processo de adoecimento e seguiu-se no retorno ao domicílio com o auto manejo da diálise. Ainda, evidenciou-se que o (re)conhecimento do próprio corpo e avaliação constante da diálise foram indispensáveis para empoderá-las e decidir sobre o tratamento.

Palavras-chave: autonomia pessoal; insuficiência renal crônica; diálise; saúde da mulher; pessoal de saúde; pesquisa qualitativa.

Resumen: Introducción: La enfermedad renal crónica se caracteriza por una disfunción renal en la eliminación de toxinas. Una de las alternativas terapéuticas es la diálisis peritoneal, en la que el individuo se enfrenta a varios retos, ya que, además de los cambios en el estilo de vida debido a la enfermedad, el tratamiento requiere cierta adaptación y disciplina, tanto de la persona como de la familia. Objetivo: Analizar la construcción de la autonomía de las mujeres con enfermedad renal crónica para realizar diálisis peritoneal en el domicilio. Método: Estudio cualitativo, teóricamente apoyado en el concepto de autonomía propuesto por el educador brasileño Paulo Freire. Los datos fueron producidos entre abril de 2013 y junio de 2014, mediante entrevistas semiestructuradas y abiertas, organizadas en el programa Ethnograph v6, habiendo sido sometidos al análisis de contenido propuesto por Laurence Bardin. Resultados: Se construyeron cuatro categorías que describieron la construcción de la autonomía de las mujeres, a saber: Aparición de la enfermedad: búsqueda de atención y diagnóstico; Necesidad de realizar diálisis peritoneal en el hospital; Transición de la atención: apoyo y asistencia para el regreso a casa y Manejo de la diálisis peritoneal en casa. Conclusión: La construcción de la autonomía de la mujer ocurrió en el transcurso del proceso de la enfermedad y siguió en el regreso a casa con el autocontrol de la diálisis. Aun así, se evidenció que el (re)conocimiento del propio cuerpo y la evaluación constante de la diálisis eran indispensables para empoderarlas y decidir el tratamiento.

Palabras claves: autonomía personal; insuficiencia renal crónica; diálisis; salud de la mujer; personal de salud; investigación cualitativa.

Received: 10/11/2020

Accepted: 04/08/2021

How to cite:

Rodrigues LPV, Zillmer JGV, Cordeiro FR, Vasconcelos TR. Women's Autonomy with Kidney Disease on Peritoneal Dialysis at Home. *Enfermería: Cuidados Humanizados*. 2021;10(2):58-72. DOI: 10.22235/ech.v10i2.2337

Correspondence: Tássia Racki Vasconcelos. E-mail: tassiaracki@gmail.com

Introduction

Chronic kidney insufficiency is an important public health problem, with worldwide relevance due to its increasing incidence, prevalence and mortality ⁽¹⁾, in addition to the economic impact for both individuals and families who bear the costs of treatment ^(2,3) and for the health systems. Among the treatment modalities is outpatient and continuous peritoneal dialysis, which presents itself as a complex therapy by requiring a rigorous therapeutic regime. ⁽²⁾

Entering the peritoneal dialysis modality requires that the person, over time, develops more autonomy to self-manage the treatment and make decisions⁴. The concept of autonomy described by Paulo Freire ⁽⁵⁾ is adopted, understood as something that is culturally constructed and thus dependent on human relations. For Freire, the autonomous subject has conditions of emancipation, as it performs its actions in a pertinent way, manages to defend its points of view through argumentation, and has rationality and sensitivity in the defense of its personal and collective interests. ⁽⁵⁾ In this construction process, the dependence existing in each space gives rise to freedom and, thus, to the act of assuming responsibilities. ⁽⁵⁾

It is justified to study women since they are predominant patients in peritoneal dialysis. ⁽⁶⁾ In addition to that, when on dialysis, they present different complications from men and are more likely to be kidney transplant donors than recipients. ⁽⁷⁾ Gender differences also continue to exist around the world, including access to health care; in addition to the fact that pregnancy is a unique state for them and a phase of the life cycle in which acute and chronic kidney diseases can manifest and exert an impact on future generations, regarding kidney health. ⁽⁷⁾ However, women with kidney disease present more chances of not being able to be mothers. ⁽⁸⁾

The studies exploring the development of autonomy in women who experience a chronic disease are incipient. In the international literature, it was identified that the experiences ^(2, 9) and autonomy of individuals with chronic kidney disease ⁽¹⁰⁾ are in fact analyzed; however, not specifically with an emphasis on women. In Brazil, the scarcity of studies on kidney disease and dialysis is even greater. ⁽¹¹⁾ However, a larger number of studies on autonomy for the care of people in other chronic health conditions was found. ^(12- 15)

From this, there is a need to broaden the perspective on women's renal health, bearing in mind the need to be welcomed in a comprehensive manner, with qualified listening and promotion of autonomy. Given the above, the following research question was elaborated: How is the autonomy of women with kidney disease to perform home peritoneal dialysis developed? The objective was to analyze the development of autonomy in women with chronic kidney disease to perform home peritoneal dialysis.

Method

This is a study elaborated from a clipping in the database from a qualitative research study with an ethnographic design. Paulo Freire's concept of autonomy⁽⁵⁾ was used to analyze the development of autonomy in women to perform home peritoneal dialysis. The field work was developed between April 2013 and June 2014, in a nephrology service from southern Brazil. In the data collection period, there were 40 women on dialysis; among them, the study population consisted of 14 women aged between 22 and 63 years old, three being single, seven married, three divorced and one separated. Regarding schooling, 11 had complete elementary school, two had complete higher education, and one had complete high school. In addition, eight reported being white-skinned, three black-skinned, two German and one Pomeranian; with 11 living in urban areas and three in rural areas. Regarding their time on dialysis, it varied from one to nine years. The study included women who met the following inclusion criteria: being registered in continuous outpatient peritoneal dialysis for more than six months, living in urban and rural areas, and not having communication difficulties. The women excluded were those who did not live in the nephrology service coverage area.

The data were produced through open and semi-structured interviews, carried out individually at times agreed upon with the participants and lasting from 60 to 180 minutes in their homes. The first interview to be carried out, an open interview, was guided by the following question: "Can you tell me when your kidney disease started?" In the subsequent semi-structured interviews, themes that emerged during the fieldwork were deepened.

The sample size and completion of data production were determined by the information saturation criterion, as the collected information was repeated. The Ethnography v6 program was used to organize the information. The data from the audio-recorded interviews were transcribed in full by two trained transcribers, and later submitted to content analysis.⁽¹⁶⁾ This method comprises three stages: pre-analysis, exploration of the material, and treatment of the results obtained and interpretation.⁽¹⁶⁾

In the first stage, pre-analysis, the first author proceeded with the organization of the material to systematize and thus facilitate conduction of the analysis itself. Then, a floating reading of the transcribed material was performed. Subsequently, there was an exhaustive reading of the entire content of the material and thus, relevant excerpts were highlighted, through the choice of words and codes that represented the central ideas. These codes were introduced into the interviews and made up the codebook in the Ethnography v6 Program.

In the second stage, exploration of the material, a total of 25 codes were listed, which were later grouped by similarity. Afterwards, each group of codes was named forming an expression that best represented them, turning them into subcategories. The third stage, treatment of the results obtained and data interpretation, corresponded to the synthesis and elaboration of the categories from the subcategories. Thus, four categories were elaborated: Disease onset: search for care and diagnosis; Need to perform peritoneal dialysis in the hospital. Care transition: support and assistance for the return home; and Managing home peritoneal dialysis. Subsequently, we proceeded with a brief description and illustration with excerpts from the statements, followed by a discussion of the description based on Paulo Freire's concept of autonomy, and an interpretation resuming this concept and studies on the subject matter.

Regarding the ethical aspects, the research was approved by the Research Ethics Committee of a public university, under opinion number 538,882. Resolution 466/12⁽¹⁷⁾ was

observed, and the participants signed the Free and Informed Consent Form. To ensure anonymity, pseudonyms chosen by the participating women were used, which were employed throughout the excerpts from the interviews chosen to present the results.

Results

Four categories were elaborated, namely: Disease onset: search for care and diagnosis; Need to perform peritoneal dialysis in the hospital; Care transition: support and assistance for the return home; and Managing home peritoneal dialysis. Such categories describe how the women developed their autonomy to perform home peritoneal dialysis.

Disease onset: search for care and diagnosis

Disease onset is one of the phases in the illness course, in which women reported the appearance of signs and symptoms of chronic kidney disease, such as: swelling, body aches, tiredness, weakness, changes in systemic blood pressure, shortness of breath, excessive sleep, poor appetite, poor sight and vomiting. These signs and symptoms indicted that there was something going on in their bodies, which was not 'normal'. From this recognition, they performed practices arising from experiences in the family group. An example was the use of medicinal plants, in the form of teas, such as stone breaker, *Phyllanthus niruri*, and lizard/horsetail collar, *Equisetum arvense* L., according to the reports below.

The stone breaker [medicinal plant] also, and that other one, lizard collar, which is full of knuckles. It grows a little high tree, as they call horsetail, I used to drink that tea, they say it's very good, it was very diuretic, I urinated more, but it doesn't help in my case, it wasn't just that. [Júlia]

Over time, the women did not show improvements in the signs and symptoms and, thus, they sought public health services, with the Basic Health Unit (BHU) that integrates Primary Health Care being the most accessed. When they found no improvement in their health status after the appointment in the BHU, they sought private assistance. The referral to the specialized nephrology service was made by medical professionals after clinical evaluation and exams. However, not all the women received information on what was happening.

When I took the exam at the Unit [Basic Health Unit], the doctor said I had nothing, but I continued with the same symptoms, so I went to a private doctor, took the exams I had done, she said that I was already with the kidney working very poorly, she referred me to a nephrologist, so I chose the doctor for the treatment. [...] after he saw that I had to undergo dialysis, then I entered the SUS, automatically, then I didn't need to pay anything else, that's how it was. [Lívia]

The women's experience with a previous illness of themselves or of family members led them to relate the signs and symptoms to other diseases due to the involvement of organs such as the heart and the lungs. The fact that they were urinating ruled out the presence of a nephrological disease and reinforced the belief that it could be a "bad disease", described as cancer. In a first meeting with the professional, the women tried to position themselves based on what they believed they had, based on their experiences.

When I had the kidney biopsy, they found that my kidney had lesions. It was then that my mother thought it was cancer, so did I. [...]. I called this a bad disease for Dr. Sheila, she said "what do you call a bad disease?" Yeah, I call cancer a bad disease. [Marta]

Some of the participants were unaware of kidney disease and of peritoneal dialysis. This lack of knowledge can influence the development of autonomy in the women who did not have information about what was happening to their bodies during the disease; others report that they were instructed by the health professionals, facilitating understanding about the disease and the symptoms it causes.

This works [peritoneal dialysis], then I was afraid that it's very painful, I thought that I didn't even know about this here [peritoneal dialysis], I knew about that other one that is in the vein, hemodialysis. I thought, my God in heaven, then he says that it's not something like that anymore, that it's not very painful, right. [Helena]

Need to perform peritoneal dialysis: choice and training in the hospital

In this category, the choice for dialysis is described, as well as the training to perform it at home. With confirmation of the diagnosis of end-stage renal disease, some women need to start this treatment modality immediately. Due to the late diagnosis, some had hemodialysis as their first option due to the seriousness of the clinical condition and, later, they were transferred to peritoneal. In view of the urgency, not all of them knew about dialysis, participated in the choice and/or decided on the treatment.

So I did the catheter through the neck first here [hemodialysis] and then from the neck he said that for me it was better to prepare myself to go home and put the catheter in my belly, which was the best thing for me. I didn't want to, but he said that I was supposed to agree that this [peritoneal dialysis] was better than what I came here to do on my neck. [...] And then it reached a point that I agreed, now let's do it at home to see how it goes. [...]. He [doctor] told me that next week they will already have the catheter implanted [...]. Ah, I was so afraid, but I didn't have a choice. [Joana]

However, some women reported that the choice of peritoneal dialysis as a treatment was made through dialog with professionals and that they presented advantages and benefits, because of the clinical condition, place of residence, and activities of daily living. In addition to that, some had the opportunity to talk to a nurse, a nursing technician; in addition to their peers, who performed peritoneal dialysis.

She was a nurse, a [Nursing] technician [...]. But she's the one who encouraged me a lot to start [peritoneal dialysis]. [Marli]

Tiredness due to the trip from home to the hemodialysis service and the fact that they were often away from their homes, gave the participants autonomy in the decision about changing the treatment. Dialog with other people who undergo peritoneal dialysis facilitated the participants' understanding of the treatment, making decision-making more autonomous.

[But then I felt so tired with this trip [from home to the nephrology service for hemodialysis] and one day at home and another day not, one day I took a risk, I spoke to the doctor, I said: doctor, could it be that I couldn't put the bag on? Could it be that the bag didn't work for me? It does, he said, everything works for you. [Marta]

It was more because, as I'm young, I wanted to work and study, it would favor me, doing this peritoneal, because every six hours I could do it, study and work, I do it at home, there's no hospital environment, which helps a lot. [Lívia]

After the decision for peritoneal dialysis, the learning process was initiated to perform it at home. For women, the first contact was difficult, as there were countless details and information to be acquired. It was a time when they got to know the materials, the phases of dialysis exchange, the process of infusion and removal of the dialyzer fluid, care with the peritoneal catheter, the complications and to recognize their own body and intervene, when necessary, as well as how they should seek the nephrology service. The development of autonomy in carrying out the therapy in the hospital had as a first step observing the procedure performed by nurses, gradually assuming it themselves. Over time, with the routine required by the therapy, they began to grow independent in conducting the dialysis procedure.

It took me a while to get used to dialysis, after some time I started to learn dialysis on my own, it took me two days to learn to do it alone, after seeing them doing it so much [Nursing team], that in two days I already knew how to do it for me at home. [Paula]

The training carried out by the nurses with the women and family members was fundamental in promoting autonomy for self-care and self-management. The diverse information provided gradually clarified doubts during the procedure and was necessary for treatment success, with the objective of empowering women in conducting the therapy.

As for the treatment, I accepted it very well, I already had my head prepared and knew that I was going to go through this [...]. They [children] did training here, on the second day one of them was ready and had already learned, the other took three classes, then the nurse released them. [Joana]

Some of the participants mentioned that sharing experiences with other people who have the same disease provided support in the decision and choice for the therapy, both by them and by other people who were joining the nephrology service. Such people were referred by the physician with the objective of providing an approach to the treatment mediated by someone who was already undergoing it, thus enabling them to show autonomy and empowerment over the treatment itself.

Care transition: support and assistance for the return home

This category identifies the women's transition regarding care and dialysis from the hospital to their homes. This transition was marked by the women enrolling in the peritoneal dialysis program, guidance on home preparation, reinforcement of the guidelines on dialysis, the necessary care with its handling, care with the catheter, food restrictions, use of medications, and routine of monthly medical and nursing consultations to assess health status and monitor the treatment.

At the end of the training for peritoneal dialysis, the women were ready for hospital discharge, at which time the guidelines regarding the materials needed for dialysis were also fundamental, such as gauze and alcohol and medications, their access to the health network, mainly in the health network, mainly in the BHU. Not all the participants knew that they had the right to receive materials free of charge, both dialysis bags and medications and materials for the exchanges.

The bag comes every month, then the nurse makes the order correctly, at each appointment she asks me what's missing. [Júlia]

Dialog between the women and the nurse can influence them in accepting the therapy, as the responsibility during the treatment would be theirs, assisting them in their independence. In addition to that, women's self-knowledge about their bodies facilitated the development of autonomy in making decisions about what is important during treatment, for example, diet.

At the beginning I didn't care at all, there's mother to do it, I would sit there and she would come and change. Then someone said I was there and the nurse came and said: "you have to accept your disease, you're the patient, not your mother, you have to take your dialysis and learn how to do it, because the day she may not be here or have a problem and not be able to do it and how are you going to do it"? "[...]. I said: "Bah, what is this woman talking about?" I told my mother: "What is the nurse talking about, how to deal with this disease, I'm going to be able to do it?" "Okay, I'm going to learn how to do it, she wants me to learn how to do it, I'm going to learn how to do it". [Paula]

In situations that require assistance, the participants were instructed to seek the nephrology service before any other, as it was the space to which they were linked. One of the situations frequently experienced was peritonitis. In the course of time and professional guidelines, in person or over the phone, the women began to recognize the signs and symptoms of this complication and decide which service to seek and the care they need to perform.

You can't [go to other health services] because in the other places they don't know what, what you take, what you have, you know, and here they already have all our medical records, in the folders. [Sueli]

They always said "Look, anything that changes the liquid you have to come to the hospital, because it's working, they explain but I don't know what it is, that day it was very dark, very brown [...] then he said "it was nothing at all, very good to have brought the bag here for us to look at it, as it has to be", he cheerfully said "This is how it has to be, anything that happens you have to come and tell us". [Luisa]

The waiting room was also considered as an enhancer for the development of autonomy, as it enabled sharing experiences among those waiting for the appointment there. The presence of posters on care with diet and dialysis also allowed the participants to access certain information. Likewise, access to the Internet was identified as a mediating resource in the development of autonomy.

Managing home peritoneal dialysis

The return home was marked by the responsibilities regarding the treatment, as well as by the adaptations both in the physical part and in the household routine. Gradually, the women began to feel satisfied for assuming responsibility for the treatment, reinforcing and developing their autonomy in the face of the new health condition. Performing home dialysis required women to make countless decisions, one of them being the physical adaptations in the space where they lived. At this moment, they reported having the support of family members, friends and neighbors.

I put a flower stand so I don't know if you understand, where you put the vases to fall down, then my husband put it there, I put the bag there and from there I can stay lying down, I can stay seated. [Luisa]

The women showed themselves to be responsible for their own bodies, taking control of the disease and treatment, considering that they would not like to depend on someone for their routines. Some of the participants reported other health problems that prevented them from having autonomy in performing peritoneal dialysis. Despite having limitations, the women show that they would like to have independence to perform the treatment, as they have the autonomy to perform the procedure even if not indicated by the health professional.

What I had to assume was my disease, that I had to take priority over my illness, assume that I had to do my dialysis alone. [...] But I do it alone, I sit there, I do what I have to do and I don't depend on anyone. [Paula]

The autonomy developed by the women made them report contentment with the therapy, as they felt comfortable in carrying out the treatment at their homes. The participants reported following a normal life, considering their condition. They were able to perform the same activities prior to treatment, but with limitations since, depending on the time they are away from their homes, they need to carry dialysis materials with them. The movement to adapt in relation to the times to go out of the house, as well as the women's independence in their routine, shows autonomy in the face of challenges.

I worked in the morning, released half a day and did the bag. In the afternoon I went back to work, at 6 pm I came home to do my bag, I went to college at night and at midnight I did a bag again, I studied and worked. I think it's normal, in college then, people don't even know that I do dialysis. [Lívia]

I'm pretty independent, I go to the city, do all my rounds, I pay my bills, I do my accounting, I see myself, I do dialysis alone, I do my vaccinations, alone, thank God I don't I depend on anyone to do it for me. [Júlia]

Discussion

The results of this study make it possible to broaden the understanding of how the development of women's autonomy for home peritoneal dialysis occurs in a nephrology service. The development of women's autonomy occurred through their experiences during the illness, interaction with professionals, their peers, and, later, with home dialysis.

The appearance of signs and symptoms mobilized the women to carry out popular knowledge practices, from the family micro group, such as the use of medicinal plants, to recover their health, being the first instance of self-care and autonomy. Similar findings were pointed out by other studies, ^(18, 19) in which individuals start to observe and analyze their body and reflect on what may be happening, and, from then on, they decide what to do. ⁽¹⁹⁾ The women's perceptions about health or disease make them interact with different alternatives for the preservation or recovery of their health. Thus, the use of traditional medicine “is replicated as a custom that comes culturally from their ancestors, in which women continue with the task of promoting this knowledge in their homes”. ⁽¹⁸⁾ After resorting to popular knowledge practices, they searched for health services, with the BHUs being the most sought after. This search was also found in other studies, ^(18, 19) which pointed at the BHUs and the urgency and emergency services as gateways to the health system. ⁽¹⁹⁾

The referral of women to the health services, in the different care and complexity levels, is fundamental to offer assistance that is adequate to their needs and to promote resoluteness. The women sought their appointment in Primary Care and were later referred to the specialized nephrology service. However, for some, the BHU was not efficient because it did not identify the health problem and did not provide sufficient and clear information about what they had and, due to this, they sought private care, resulting in out-of-pocket expenses. A study ⁽¹³⁾ conducted with individuals with ostomy evidenced the importance of the health professionals in carrying out the correct referral for each person, considering their needs, thus aiming to promote the necessary health care support for everyone. Also in this study, the restriction of the health services in primary care is highlighted, leaving aside guidelines and specific care needed.

The lack of information about health status and treatment, at the different health levels and services, exerted a negative influence on the development of women's autonomy. Communication of the diagnosis followed by the decision to start dialysis will depend on how the space for dialog will be constructed by the medical professional and will impact on how women will react and self-manage the treatment autonomously. Women are faced with insufficient information to understand what is happening, as well as to participate and decide on dialysis considering their clinical condition, sociocultural and family context. Most of them did not actively participate in decision-making, some because of the clinical condition seriousness and others because they did not have clear information on what the treatment corresponded to.

According to the Brazilian Bill of Rights of Health Users, it is a “patient's right to be informed about the different treatment alternatives and their benefits, ensuring them free choice of the method, respecting the contraindications”. ⁽²⁰⁾ Several studies indicate that the patients remain less informed and less involved in making decisions about their health care than they would like to. ^(21, 11, 22-24)

Non-participation of the patients in the decision-making process regarding the therapy ^(23,24) is for obeying the medical decision ^(11, 23) and, in some cases, due to the late diagnosis and severity of the clinical condition, they start hemodialysis immediately, without knowing another option or understanding their health-disease process and the therapy that is being initiated. ^(11, 23) When decision-making is shared, it can improve patient satisfaction by helping to make better quality decisions; creating more accurate expectations of benefits and possible harms. ^(21, 22)

The development of autonomy in the face of peritoneal dialysis can be related to accepting the disease and the treatment. The absence and fragility of listening spaces that allow for dialog can result in non-acceptance and consequent abandonment of the treatment. In this case, the availability of the professionals to listen to the women's statements and to see their gestures and singularities is considered as the listening space. In this study, the dialysis service nurse is described as fundamental in the process of assisting them in understanding the illness and in dealing with limitations and restrictions in daily life, in addition to training them for peritoneal dialysis and, in the assessment, monitoring and intervention during the monthly Nursing consultations. This allowed them to become subjects of their own treatment, gradually exercising autonomy, restoring self-esteem, and promoting self-care.

Several studies indicate that health professionals assist in the development and promotion of autonomy, ^(13, 14, 25) as they can provide expansion of knowledge in order to promote the development of reflective ability for decision-making, recognizing and restoring and/or promoting autonomy. ⁽¹³⁾ In addition to that, as this is a chronic condition, there is an unavoidable association between self-care and autonomy. ⁽¹³⁾ Therefore, multidisciplinary work is important for joint planning and unique care. However, specific proximity between nurse and patient allows for the creation of strategies seeking autonomy in a differentiated manner. ⁽¹²⁾

The interaction enabled between the woman and the health professional of the nephrology service was fundamental for the development of autonomy. For Paulo Freire, autonomy is a cultural construction, which depends on the relation of man with the others, and of these with knowledge. ⁽⁵⁾ Faced with such a construction process, the act of teaching is essential. For Paulo Freire "teaching is not transferring knowledge but creating possibilities for its production or construction". ⁽⁵⁾

A number of studies signal lack of information as an important aspect that favors uncertainties and obstacles for autonomy. ^(2, 26) Therefore, the importance of guidelines that allow the person to develop a critical and reflective perspective towards their disease is highlighted. ⁽²⁶⁾ When considering autonomy as something to be developed, the guidelines must be designed for everyone, considering that each subject is unique, and it is not up to the health professional to deduce the meaning that the situation has for each person, thus emphasizing the importance of dialog between professional and patient. ⁽¹⁵⁾

In health, the educational practice involves bringing new knowledge about the disease, care related to it and to the treatment. Under the emancipatory perspective, in which Paulo Freire's thought is inserted, the teaching process takes place through the subject's involvement with the object of knowledge, and teaching/learning occurs through dialog. Thus, educating someone is not synonymous with knowledge transfer, but means providing possibilities for its production or (re)construction. From this movement, the individual becomes an autonomous subject, that is, the driver of their own existence. ⁽⁵⁾

For the participants of this study, the Nursing consultation in the nephrology service is an essential element in the nurse's performance. These professionals are perceived as significant collaborators in the development of women's autonomy, as they promote active listening and dialog, and provide information about the transformations that occurred after the disease.

In this sense, the Nursing consultation is a powerful space for the development of actions to promote the autonomy of women with kidney disease. A study with similar results, which addressed the Nursing consultation with women, pointed out that this space is of fundamental importance for the expression of feelings, helping them to overcome limits that interfere in women's lives, opening paths for their empowerment. ⁽²⁷⁾

The self-knowledge acquired by the women over time and experience with the treatment allowed them to choose which decisions would be best for them. Obtaining information and developing reflection and awareness of the current condition allowed the women to expand their knowledge, skills, attitudes and self-knowledge, making them responsible for themselves, in order to solve their problems and needs. For Freire ⁽²⁸⁾ the more human beings reflect critically on their existence, on their environment, the more they will be led to a critical awareness and attitude towards a change.

Conclusions

The study made it possible to analyze the trajectory of women who face chronic kidney disease and, thus, how they develop autonomy for self-care with home peritoneal dialysis. Women's autonomy is based on the independence constructed in each stage of the illness, from the onset of the disease, the need to perform dialysis in the hospital and the transition from this space to the home, to management itself. Autonomy is constituted through information, dialog, support from the family and health professionals, which also help in accepting the health condition and in self-knowledge; thus, they gradually resume activities of daily living and make personal decisions. Such factors are essential to turn them into active participants regarding the choices referring to their health care.

As implications for Nursing practice, the visibility of aspects that can be worked on by nurses during care in nephrology services for the development of autonomy is identified. As an example, there is the Nursing consultation, the use of the waiting room and the Internet through social media, for sharing quality information, which can help the patients to adopt practices and make decisions safely.

As for research, the importance of studies that consider the perspective of people with chronic health conditions and their families is evident, to promote autonomy in the process of falling ill, living and caring. The study limitation was the use of a clipping from a database already collected, where the first author did not participate in the fieldwork collection stage.

Bibliographic References

1. Sanyaolu A, Okorie C, Annan R, et al. Epidemiology and management of chronic renal failure: a global public health problem. *Biostatistics Epidemiol Int J*. 2018;1(1):11-16.
2. Díaz-Medina BA, Guerreiro DVDS. Las experiencias de incertidumbre de jóvenes mexicanos en tratamiento de diálisis peritoneal. *Enfermería Nefrológica*. 2020; 23(2):160-167.

3. Zillmer JGV, Silva DMGVD. Gastos do próprio bolso das pessoas em diálise peritoneal: estudo qualitativo. *Revista de Atenção à Saúde*. 2019;17(61):83-92.
4. Zillmer JGV, Silva DGVD, Mercado-Martinez FJ. Sobre o meu corpo mando eu! O manejo do tratamento na vida das pessoas em diálise peritoneal. *Investigação Qualitativa em Saúde*. 2015;1:303-309.
5. Freire P. *Pedagogia da Autonomia: Saberes necessários à Prática Educativa*. São Paulo: Paz e Terra;2002.
6. Nobre DC, Soares ER, Zillmer JGV, et al. Qualidade de vida de pessoas em diálise peritoneal. *Revista de Enfermagem UFPE [Internet]*. 2017;11(7):4111-4117.
7. Piccoli GB, et al. Women and Kidney Disease: Reflections on World Kidney Day 2018. *Journal of Hypertension*. 2018;36(3):705–708.
8. Ramírez MP, et al. Explorando la sexualidad en mujeres en diálisis: una aproximación cualitativa. *Revista de Nefrología, Diálisis y Trasplante*. 2018;38(1):35-42.
9. Coronado-Vázquez V, et al. Equidad y autonomía del paciente en las estrategias de atención a personas con enfermedades crónicas en los servicios de salud de España. *Gaceta Sanitaria*. 2019;33(6):554–562.
10. Alba Martín, R. Insuficiencia renal crónica: cuando se pierde la autonomía. *Cultura de los Cuidados*. 2015;19(42):22-25.
11. Araujo ES, Pereira LL, Anjos MFD. Autonomia do paciente com doença renal crônica em tratamento hemodialítico: a aceitação como fator decisório. *Acta Paulista de Enfermagem*. 2009;22(1):509–514.
12. Bedin LF, et al. Estratégias de promoção da autoestima, autonomia e autocuidado das pessoas com feridas crônicas. *Revista Gaúcha de Enfermagem*. 2014;35(3):61–67.
13. Poletto D, Silva, DMGVD. Viver com estoma intestinal: a construção da autonomia para o cuidado. *Revista Latino-Americana de Enfermagem*. 2013;21(2):531–538.
14. Almeida ASD, Furegato ARF. Papéis e perfil dos profissionais que atuam nos serviços de saúde mental. *Revista de Enfermagem e Atenção à Saúde*. 2015;4(1):79-88.
15. Baade RTW, Bueno, E. Coconstrução da autonomia do cuidado da pessoa com diabetes. *Interface - Comunicação, Saúde, Educação*. 2016;20(59):941–951.
16. Bardin, L. *Análise de Conteúdo*. São Paulo: Edições 70;2016.

17. Brasil. Ministério da Saúde. Conselho Nacional de Saúde. Resolução nº 466 de 12 de dezembro de 2012: diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. Brasília;2012.
18. Posada-Zapata et al. ¿Qué hacer cuando estoy enferma? La búsqueda de alternativas para el bienestar en mujeres desplazadas, Medellín 2013-2014. *Revista Facultad Nacional de Salud Pública*. 2016;34(2):167-174.
19. Viegas, ADC, et al. Adulto jovem em hemodiálise: da descoberta da doença aos impasses do diagnóstico e do tratamento. *Revista Enfermagem UFPE [Internet]*. 2017;11(6):2339-2348.
20. Ministério da Saúde. Carta dos direitos dos usuários da saúde. 3. ed. Brasília;2011.
21. Lee A, Gudex C, Povlsen JV, Bonnevie B, Nielsen CP. Patients' views regarding choice of dialysis modality. *Nephrology Dialysis Transplantation*. 2008;23(12):3953-3959.
22. Keeney S, Mckenna H. An exploration of the choices of patients with chronic kidney disease. *Patient Preference and Adherence*. 2014;8:1465-1474.
23. Pereira E, et al. Choice of dialysis modality-clinical and psychosocial variables related to treatment. *Jornal Brasileiro de Nefrologia*. 2016;38(2):215-224.
24. Duarte L, Hartmann SP. A autonomia do paciente com doença renal crônica: percepções do paciente e da equipe de saúde. *Rev. Sociedade Brasileira de Psicologia Hospitalar*. 2018;21(1):92-111.
25. Silva ALS, Nascimento ERD, Coelho EDAC. Nurses practices to promote dignity, participation and empowerment of women in natural childbirth. *Escola Anna Nery - Revista de Enfermagem*. 2015;19(3):424-431.
26. Branco JMA, Lisboa MTL. Tratamento com diálise peritoneal: a prática do autocuidado no contexto familiar. *Revista Enfermagem UERJ*. 2015;23(3):344-349.
27. Durand MK, Heidemann ITSB. Promoção da autonomia da mulher na consulta de enfermagem em saúde da família. *Revista da Escola de Enfermagem da USP*. 2013;47(2):288-295.
28. Freire P. *Pedagogia do Oprimido*. 29a. Ed. São Paulo: Paz e Terra;2000.

Contribution of the authors: a) Study conception and design, b) Data acquisition, c) Data analysis and interpretation, d) Writing of the manuscript, e) Critical review of the manuscript.

L. P. V. R. has contributed in a, c, d; J. G. V. Z. in a, b, c, d, e; F. R. C. in d, e; T. R. V. in c, d.

Managing scientific editor: Dra. Natalie Figueredo