

## PERSPECTIVES OF THE PERSON IN PERITONEAL DIALYSIS IN RELATION TO THE ILLNESS PROCESS\*

PERSPECTIVAS DA PESSOA EM DIÁLISE PERITONEAL EM RELAÇÃO AO PROCESSO DE ADOECIMENTO

PERSPECTIVAS DE LA PERSONA EN DIÁLISIS PERITONEAL EN RELACIÓN AL PROCESO DE ENFERMEDAD

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### ABSTRACT

**Objective:** To know the perspective of the person in Continuous Ambulatory Peritoneal Dialysis in relation to their illness. **Method:** Exploratory descriptive study of qualitative nature, performed with 20 people in Peritoneal Dialysis. Data was collected through semi-structured and open interviews performed between April 2013 and June 2014, in a nephrology service of a public hospital in Rio Grande do Sul, Brazil. The full transcripts were submitted to thematic content analysis. **Results:** The analysis of the perspectives of the person in dialysis allowed the construction of three categories, namely "Living with uncertainties", "Living in liminality" and "Planning the future". **Final thoughts:** It was possible to know the perspectives of the person in continuous ambulatory peritoneal dialysis and to conclude that the suffering permeates the illness process of those who experience the discovery of renal disease and the beginning of the dialytic treatment, as well as the fear and uncertainties associated with renal transplantation.

**Keywords:** Nursing; Chronic Renal Insufficiency; Continuous Ambulatory Peritoneal Dialysis; Perception.

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## RESUMO

**Objetivo:** conhecer as perspectivas da pessoa em diálise peritoneal ambulatorial contínua em relação ao seu adoecimento. **Método:** estudo descritivo exploratório de natureza qualitativa, realizado junto a 20 pessoas em diálise peritoneal. Os dados foram coletados por meio de entrevistas semi-estruturadas e abertas, realizadas entre abril de 2013 e junho de 2014, em um serviço de nefrologia de um hospital público, no Rio Grande do Sul, Brasil. As transcrições na íntegra foram submetidas à análise de conteúdo, modalidade temática. **Resultados:** as perspectivas da pessoa em diálise permitiram a construção de três categorias, sendo elas "Convivendo com incertezas", "Vivendo na liminaridade" e "Planejando o futuro". **Considerações finais:** Foi possível conhecer as perspectivas da pessoa em diálise peritoneal ambulatorial contínua e concluir que o sofrimento permeia o processo de adoecimento de quem vivencia a descoberta da doença renal e o início do tratamento dialítico, bem como o medo e as incertezas associadas ao transplante renal. **Descritores:** Enfermagem; Insuficiência Renal Crônica; Diálise Peritoneal Ambulatorial Contínua; Percepção.

## RESUMEN

**Objetivo:** conocer las perspectivas de la persona en Diálisis Peritoneal Ambulatorial Continua con relación a su proceso de enfermedad. **Método:** estudio descriptivo exploratorio de naturaleza cualitativa, realizado junto a 20 personas en Diálisis Peritoneal. Los datos fueron recogidos por medio de entrevistas semiestructuradas y abiertas, realizadas entre abril 2013 y junio 2014, en un servicio de nefrología de un hospital público, en el Sur de Brasil. Las transcripciones en la íntegra fueron sometidas al análisis de contenido, modalidad temática. **Resultados:** las perspectivas de la persona en diálisis permitieron la construcción de tres categorías, siendo ellas "Conviviendo con incertidumbres", "Viviendo al límite" y "Planeando el futuro". **Consideraciones finales:** Fue posible conocer las perspectivas de la persona en diálisis peritoneal ambulatorial continua y concluir que el sufrimiento permea todo el proceso de la enfermedad de quien vivencia la descubierta de la enfermedad renal y el inicio del tratamiento dialítico, así como el miedo e las incertidumbres asociadas al trasplante renal. **Descritores:** Enfermería; Insuficiencia Renal Crónica; Diálisis Peritoneal Ambulatoria Continua; Percepción.

## INTRODUCTION

Chronic kidney disease is characterized as an impairment consisting of progressive and irreversible damage to renal functions<sup>(1)</sup> most often triggered by primary injury resulting from hypertension, diabetes, chronic glomerulonephritis and polycystic kidneys<sup>(2)</sup>. In the illness process, in addition to changes in the biological dimension, there are also emotional, social and economic impact on the lives of people who have this disease<sup>(3)</sup>.

Although the technological advances on Renal Replacement Therapies, such as continuous peritoneal dialysis, have made possible greater longevity to the people, on the other hand, there has been an increase in the functional disabilities<sup>(4)</sup>.

The psychological implications are expressed in the form of feelings such as fear, sadness, anxiety, anguish, rejection, suffering and stress triggered by the treatment<sup>(5)</sup>.

Thus, the beginning of dialysis therapy is marked as a period of living the unknown as, in the following, moment the person undergoing the dialysis therapy can perceive a possibility of life and rebirth. Thus, when well oriented and accompanied by competent health professionals, the person receives knowledge about the therapeutic need that places and empowers them to perform the treatment actively and not just as a mere spectator<sup>(6)</sup>.

The diagnosis of chronic kidney disease brings a new reality to the person, who needs to adapt to changes that impose dietary and social restrictions and

consequently loss of quality of life, since the practice of a continuous therapy leads the person to live on limited freedom<sup>(7)</sup>. Although Continuous Ambulatory Peritoneal Dialysis allows the person to perform the treatment at home, which provides greater independence and freedom when compared to hemodialysis, this form of treatment requires the client to develop autonomy for their self-care<sup>(8)</sup>.

Faced with this complex and multi-faceted process of illness and search for the treatment, the person experiences a series of uncertainties regarding the disease, treatment and even the future, which may affect their way of thinking, acting and feeling. In the meantime, it is necessary to know the perspectives of the person with chronic kidney disease undergoing dialysis so that nurses and other health professionals can address their anxieties, uncertainties and fears<sup>(7)</sup>.

In view of the above, the present study aimed to know the perspectives of the person in continuous outpatient peritoneal dialysis in relation to their illness process.

## METHODS

This is a descriptive, exploratory study of a qualitative nature and ethnographic design conducted between April 2013 and June 2014 in a nephrology department of a public hospital in Rio Grande do Sul, Brazil. Twenty people undergoing continuous ambulatory peritoneal dialysis participated in the study. Inclusion criteria were being male or female aged 18 years or older, having been enrolled in the continuous ambulatory peritoneal dialysis service for more than six months (so they could better demonstrate the experience); living in the urban or rural area, with different socioeconomic conditions and not presenting difficulties to communicate. The total number of people in this modality was defined by following the principle of theoretical saturation, which occurs when no new information is revealed<sup>(9)</sup>.

For the selection of the subjects, a nurse responsible for peritoneal dialysis provided a list that allowed identifying the participants, who were invited in a preliminary and individualized contact

that allowed explaining the objectives of the study, the process of data collection, as well as the techniques that would be used. After accepting, they signed the Informed Consent Form in two copies of equal content.

Data were collected through open interviews, participant observation and medical records analysis, seeking to know some clinical and socio-demographic information and on the place participants lived. Interviews and observation were performed at home and at the dialysis service.

The interviews lasted between 60 and 180 minutes and were audio recorded and transcribed in full, which allowed the analytical process to occur. For the analysis of those that correspond to the objective of the study, we considered only the data from the interviews in which the content analysis technique, in the thematic modality, was used<sup>(10)</sup>. The first stage, the pre-analysis, consisted in establishing an approximation with the collected material, determining the record unit and the delimitation of the context. The second occurred with the exploration of the material through codification, classification and choice of themes. The third stage was characterized by the interpretation of data meanings with the construction of three categories, namely Living with uncertainties; Living in liminality; and Planning the future.

The study respected the formal requirements contained in the national and international standards regulating research involving human beings and received approval from the research ethics committee of the Signatory Institution under Approval Certificate 11965413.5.0000.0121. Participants were identified by the letter "E" followed by an ordinal number referring to the order in which the interviews were analyzed.

## RESULTS

When fieldwork began, there were 60 people enrolled in peritoneal dialysis, of whom 49 were in continuous ambulatory peritoneal dialysis. Of the total, 20 met the inclusion criteria. Among the participants, 14 were women and six were

men, aged 22 to 63 years. In relation to the geographical area, five lived in the rural area and 15 in the urban area. Only one participant had paid work, but in the informal sector. The others received a pension in the amount of a national minimum wage, which was equivalent to R\$ 724.00 in the period of data collection, because they had terminal chronic kidney disease. Of the total number of participants, only five reported their perspectives through interviews, of whom two were men and three were women, who had completed elementary education and had been in continuous ambulatory peritoneal dialysis for more than one year and three months.

### Living with uncertainties

This category includes the participants' discourses on daily living with personal uncertainties regarding the adaptation, evolution and treatment of the disease. Adaptation to chronic kidney disease can lead to uncertainties because it is an unknown process, which requires different care with food and reduced fluid intake.

In addition to these factors, the uncertainty regarding the treatment to which they will be submitted and the uncertainty regarding the evolution of the disease can trigger feelings of frustration and impotence due to the inability to self-care, dependence on other people and also unexpected events in relation to the evolution of the disease and of the treatment. These factors contribute to the development of questions regarding the future, about the continuity or non-continuity of treatment.

*Then they started to tell me, "Look, you cannot drink chimarrão [traditional yerba mate from Brazil], you cannot drink water, you cannot eat vegetables," and I was addicted to chimarrão! I say, what will become of me? (E 4).*

*I keep wondering "what will happen to my life now?". So young and with this little problem. Dying is not a problem, but keep disturbing others, suffering, this is difficult (E 1).*

*I was joking or not when I said to the nurse, "some people last twenty years, I may not last five, so I think I'm not doing the transplantation anymore." Life is something we do not know the next day. We joke about it, but we do not know. I'm lucky, I've escaped*

*death once, so I wonder if I'm going to do the transplantation or not, if I'm okay (E 2).*

The reports describe ambivalent and insecure feelings of people on continuous ambulatory peritoneal dialysis regarding the proposed therapy, which involves body care for their own survival. Such feelings are probably triggered by the lack of communication between professionals and users of the health service, in addition to the provision of insufficient information. However, it is worth mentioning that several factors are involved in understanding this process, which has a strong relationship with socioeconomic and cultural conditions. These uncertainties contribute to increase anxiety and negatively affect the adaptation to the new condition in which the person has to live, with changes that go beyond the daily routine, which impose the need to reorganize life.

### Living in liminality

This category addresses the discovery of the diagnosis. When discovering chronic kidney disease, the person usually experiences the feeling of being in a fine line, like they were living and dying every day. Fear of the unknown, infections and accidental catheter trapping may be a consequence of the lack of preparation for the care for which they become responsible. In addition, these people feel fear of sleeping in a position above the catheter and compromising their health condition.

However, even with this fear, at first, the person seeks care practices that have led them to adapt to the changes that go beyond the care of their body, care with the environment where they are and with whom they are. Participants report the day-to-day care imposed by the changes of the body with dialysis, the risks in the contact with the environment and with the people, as seen in to the following report:

*"We'll have to change your treatment for continuous ambulatory peritoneal dialysis" and I was afraid to do continuous ambulatory peritoneal dialysis, I thought, "I'll have to put a catheter in my belly, it's very dangerous". They talked about infection, I was very scared. Oh! God forbid if that hooks on anything. I was afraid to sleep, because I used to sleep on my*



*tummy, so sleeping on top of this here is very complicated; I had to learn to sleep on my side (E 1).*

Fear related to failure of the proposed treatment, such as the transplant, its implications, complications and the consequent return of the disease were also present, as this meant having to return to renal replacement therapy. In this sense, having information on the consequences of choosing to perform the renal transplant impose the need for care for the maintenance of the graft. Such information is shared by those who have already experienced such treatment and did not succeed, which justifies the fear shown in to submit to such modality of renal replacement therapy, because the uncertainties do not end with the accomplishment of the transplantation, making it necessary the continuity of the care for the maintenance of the life. This can be seen in the following report:

*There is need of a great care. After the surgery it's not like that, you do the surgery and you are free of the disease; you have to be very careful. The care continues, the treatment continues; you cannot fail the treatment. If you does not return, there is colleague who was doing it together with me, we had been admitted together [they were hospitalized at the same time]. She had had a transplantation and stayed for five years after the transplantation, everything was fine and now she had an infection, she went back to dialysis, her kidney stopped again, I'm afraid to do it and have to go through it. Some people got very sick (E 2).*

Another aspect that causes anxiety among people who experience continuous ambulatory peritoneal dialysis refers to family abandonment. This can be identified in the speech of a participant who was abandoned by the husband after the diagnosis of chronic kidney disease and the beginning of renal replacement therapy, since there was the possibility of the former companion to profit from her death.

*[...] He wanted to retire with my death. My greatest fear, these days I told my mother, was that, after everything, after I almost die in the ICU, he would like to take me to the grave with his relatives [...] and retire the day that I die (E 3).*

In summary, the experience of chronic kidney disease can manifest conflicting and ambiguous feelings of feeling alive and having to deal continuously with the feeling of death. In addition, another aggravating factor is having to live with social segregation when experiencing the abandonment of the family in a time of physical and emotional frailty.

### **Planning the future**

For the study participants, planning the future is mentioned according to the stage of life they are in and the clinical condition experienced. For younger people, there is the desire to complete college and build a family. Regarding the cure of the disease, they mention that it can occur in two ways, the kidney regain its function or through renal transplantation. Both forms are sustained in faith by means of a miracle, and time is one of the factors to be considered in this process of illness. Still, living the present is common for all, as can be seen in the following reports:

*Sometimes I asked him [the physician] for the transplantation ... what changed for me to ask is that I want to live more now. If I can study, I want to do everything I can, everything I can do, travelling, studying. I told my boyfriend that if I can I even want to have a child (E 6).*

*Working, graduating, finishing college, working in the area...I think that's it, being a good professional (E 5).*

Transplantation is a passage, a rebirth. And with it a new life begins, a new path with plans to take back what was lost in the past life, however, the participants of this study avoid making long-term plans, since there is a possibility of not surviving to materialize them. In this way, they live the moment intensely, leaving a legacy for their family that they were happy while they lived. Plans for the future have peculiar characteristics to the stage of the person's life. The younger ones plan the future with personal and social perspectives, such as studying, working, forming a family and traveling.

For older people, it is not possible to plan the future in a process in which time has a different meaning. They live the present moment appreciating it, the

people and the activities that give them pleasure, as can be seen in the following reports:

*I'm living the present moment, I do not think much in the future, I'm doing everything I like, so I'm not in a hurry to get anything. I try to eat what I like, talk to whom I like and I'm not thinking much ahead (E 1).*

*I'm just waiting for a miracle from God, for Jesus to give me a new kidney, this is what I'm waiting for. So I'm young, I know God has a great work in my life. And I believe in my spiritual life with God, I believe that he can give me something new, a new kidney. I wish it were now, right away, to get well, get married one day, have children (E 5).*

Spirituality appears to people in continuous ambulatory peritoneal dialysis as a source of support for coping with their condition, thus contributing to the maintenance of the treatment. In this sense, spirituality can minimize suffering and improve the adaptation to care with chronic kidney disease.

## DISCUSSION

Upon receiving the diagnosis of chronic kidney disease and the need for peritoneal dialysis, one perceives oneself in a totally unknown universe<sup>(11)</sup>, in which routine changes and the daily living with the disease and its complications bring to the fore uncertainties in the process of adaptation of the person living with peritoneal dialysis<sup>(7)</sup>. These uncertainties are related to the knowledge and strategies used by this person and his/her family in the learning and acceptance of reality, thus necessitating significant reasons for the continuity of the care on which they depend to survive<sup>(6)</sup>.

Thus, living with the disease, despite the therapeutic possibilities, is a process of liminality for the person who experiences the repercussions of the disease and the treatment, which imply feelings that can be compared to living in limited freedom, in view of the restrictions and the limits imposed by therapeutics<sup>(7)</sup>, while others are waiting for a future without dialysis<sup>(12)</sup>.

In this sense, renal transplantation may be a modality of renal replacement

therapy that gives the person greater freedom<sup>(13-14)</sup>. However, there is the dichotomy of whether or not to do the transplantation, since it is not always considered by the people as the best option to continue living because it is associated with death<sup>(8)</sup>. Also, people who wait for kidney transplantation reveal the experience of feelings such as insecurity, fear, uncertainty, sadness, lack of autonomy, worry, dependence, lack of clarity about the procedure and the future, lack of perspective, difficulty to coping, inner conflict, hopelessness, nonconformity and anxiety<sup>(15-16)</sup>.

Therefore, some people are reluctant to perform the transplantation, while others choose to do it for believing that life will return to normal after the procedure. However, it is well known that the recipient of a transplanted kidney continues to face the maintenance of the treatment, and it is necessary to maintain physical and food restrictions and drug dependence. In this way, they confront themselves again with the disease and its limitations, generating a new process of mourning for that body they thought they would recover with the transplantation<sup>(14)</sup>.

In addition to these aspects, the perspective of the person facing renal replacement therapy can be affected by the social support network, initially formed by the family that plays a fundamental role in meeting the person's needs. In this way, the family can be the main source of support for the person with chronic kidney disease, or be responsible for the social exclusion of the affected family member. From this perspective, families, when instructed to promote care, can reduce their suffering and improve the quality of care<sup>(17)</sup>. This causes health professionals, especially nursing professionals, to focus on the inclusion of the families of this patient throughout the therapeutic process and in the decision making, so that the family becomes an ally of both the patient who experiences periods of exacerbation and remission of signs and symptoms of the disease and treatment, as well as of the health team that needs clear and reliable information to direct care practice<sup>(18)</sup>.

It is crucial that people with chronic kidney disease and their families receive full assistance, since when they receive

the diagnosis, they come to live with uncertainties and changes in their lives<sup>(19-20)</sup>, and the empowerment provided by knowledge can be a way of reducing the episodes of difficulties and fear that are related to doubts and uncertainties. Another form of confrontation is linked to religious beliefs, that is, ways of expressing spirituality<sup>(11)</sup>.

Thus, it is incumbent upon professionals to act interdisciplinarily, and nursing can facilitate the coping with the disease and develop a comprehensive care plan with the inclusion of measures to prevent or mitigate the fears and uncertainties experienced by people when receiving the diagnosis of chronic kidney disease and the need to undergo peritoneal dialysis, which may include spirituality, in order to minimize suffering and improve coping with chronic kidney disease.

## FINAL CONSIDERATIONS

In exploring the perspectives of people in continuous ambulatory peritoneal dialysis, we identified the presence of negative feelings permeates the illness process of those who experience the discovery of the disease and the beginning of the dialysis treatment, and the fear and uncertainties associated with renal transplantation, possibly related to the lack of information and perception of the experience of their peers who opted for renal transplantation and were not successful with the graft, returning to renal replacement therapy.

The limitation of this study is related to the small number of interviewees, which prevents the generalization of the data and allows the local reality of a group of people with chronic kidney disease to be analyzed and understood. Therefore, there is the need for further and broader studies to unveil the experiences of people with renal disease in peritoneal dialysis under other aspects, and also to analyze their family context as interfering in the process of illness and treatment.

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