

THE PERSON'S PERCEPTION ABOUT ITS CONDITION AS A CHRONIC RENAL PATIENT IN HEMODIALYSIS

A percepção da pessoa sobre sua condição enquanto doente renal crônico em hemodiálise

La percepción de la persona sobre su condición como paciente renal crónico em hemodiálisis

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ABSTRACT

Objective: to know the person's perception about his condition as a chronic renal patient on hemodialysis.

Method: a qualitative study of the exploratory type, conducted through interviews with a specialized philanthropic association, in the Itajaí Valley region, Santa Catarina state. Data analysis was based on the Thematic Analysis, which unfolded in three interdependent stages. **Results:** ten interviews were conducted, and from the analysis of the data emerged two thematic categories entitled 'Itinerary in health services' and 'The mixed feelings'. **Conclusion:** it was observed the importance of the formal health network for these subjects, being the majority with comorbidities such as systemic arterial hypertension and diabetes mellitus. In relation to experienced feelings, negation appeared in a recurrent way, along with other feelings of negative connotation, such as fear and anxiety, being fundamental the offer of support and acceptance by health professionals in the confrontation and treatment of the disease.

Descriptors: Renal Insufficiency Chronic; Renal Dialysis; Nursing Care; Perception; Chronic Disease.

RESUMO

Objetivo: conhecer a percepção da pessoa sobre sua condição enquanto doente renal crônico em hemodiálise. **Método:** estudo qualitativo do tipo exploratório, realizado por meio de entrevistas em uma associação filantrópica especializada, na região do Vale do Itajaí, estado de Santa Catarina. A análise de dados foi embasada na Análise Temática, que se desdobrou em três etapas interdependentes. **Resultados:** foram realizadas 10 entrevistas, sendo que da análise dos dados emergiram duas categorias temáticas intituladas 'Itinerário nos serviços de saúde' e 'O misto de sentimentos'. **Conclusão:** observou-se a importância da rede formal de saúde para estes sujeitos, sendo a maioria portador de comorbidades como hipertensão arterial sistêmica e diabetes mellitus. Em relação aos sentimentos vivenciados, a negação

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apareceu de modo recorrente, junto a outros sentimentos de conotação negativa, como medo e ansiedade, sendo fundamental a oferta de apoio e acolhimento por parte dos profissionais da saúde no enfrentamento e tratamento da doença.

Descritores: Insuficiência Renal Crônica; Diálise Renal; Cuidados de Enfermagem; Percepção; Doença Crônica.

RESUMÉN

Objetivo: conocer la percepción de la persona sobre su condición como enfermo renal crónico en hemodiálisis. **Método:** estudio cualitativo del tipo exploratorio, realizado por medio de entrevistas en una asociación filantrópica especializada, en la región del Valle del Itajaí, estado de Santa Catarina. El análisis de datos se basó en el análisis temático, que se desdobló en tres etapas interdependientes. **Resultados:** se realizaron 10 entrevistas, siendo que del análisis de los datos surgieron dos categorías temáticas tituladas 'Itinerario en los servicios de salud' y 'El mixto de sentimientos'. **Conclusión:** se observó la importancia de la red formal de salud para estos sujetos, siendo la mayoría portador de comorbilidades como hipertensión arterial sistémica y diabetes mellitus. En cuanto a los sentimientos vivenciados, la negación apareció de modo recurrente, junto a otros sentimientos de connotación negativa, como miedo y ansiedad, siendo fundamental la oferta de apoyo y acogida por parte de los profesionales de la salud en el enfrentamiento y tratamiento de la enfermedad.

Descritores: Insuficiencia Renal Crónica; Diálisis Renal; Atención de Enfermería; Percepción; Enfermedad Crónica.

INTRODUCTION

Chronic Kidney Disease (CKD) has been assumed as a public health problem, because combining aging and increased life expectancy of the population - which are traditional risk factors for their development - to other chronic diseases, the CKD presents itself as a major determinant of risk of cardiovascular events - which currently account for about 30% of all deaths worldwide.¹

Chronic Kidney Disease (CKD) represents advanced and irreversible loss of renal function. The function of the kidneys is to filter the blood, removing toxic waste produced in the body and water and various other substances. The kidneys produce hormones responsible for controlling blood pressure, bone metabolism and red blood cell production. Thus, "loss of renal function leads to a host of complications such as hypertension, anemia, water retention, urea, creatinine, potassium, and acids, among others."^{2:114}

Ordinance No. 1168 / GM on June 5, 2004, which establishes the National Policy on Care for Chronic Kidney Disease, defines structured care strategies in the pursuit of equitable and qualified care of patients with chronic kidney disease including prevention, promotion, treatment, rehabilitation, social control, and access to different modalities of renal replacement therapy: peritoneal dialysis, hemodialysis, and transplantation as a result of the articulation between the various levels of health care in the Unified Health System (SUS).³⁻⁴

Hemodialysis is a necessary palliative treatment, considering the slow and gradual progression of CKD with

the loss of nephron functionality, keeping others with their functions in adequate conditions until the impairment of renal functions is irreversible. "It is a silent condition, as the patient only begins to realize that he or she has some kidney change when the onset of uremic symptoms begins, that is, when the kidneys lose approximately 50% of their function."^{5:841}

People on dialysis treatment for chronic kidney disease are subject to various impacts on their lives, as well as on the lives of their families, since there are many psychosocial issues involved in adherence and maintenance of this treatment. The difficulties faced, therefore, by patients and their families can range from physical discomfort to the side effect of medication, as well as issues of alteration of eating habits, infections, rejection and decreased quality of life, which may lead these subjects to seek other alternatives to healing.⁶⁻⁷

The practices of coping with the disease adopted by each individual and their relatives are directly related to the socio-cultural context in which they are inserted. So, even though there are different perceptions about the search for care, it is possible to identify different systems used for this purpose, from the professional system - constituted by formal health services - to the forms of care associated with the social support networks of the subjects.⁸

Thus, this study aims to know the perception of the person about his condition as a chronic kidney patient on hemodialysis. This work is based on the need to know the person's perception of their condition, as well as the itineraries traveled through their experiences in illness and treatment, thus allowing the construction of a more qualified look and care for these individuals.

METHODOLOGY

This is a qualitative, exploratory study, conducted through interviews focusing on the person's perception of their condition as a chronic kidney patient on hemodialysis.

The study participants were people with chronic kidney disease undergoing hemodialysis treatment in a specialized philanthropic association. This association has been operating for about 40 years in the Itajaí Valley region, state of Santa Catarina, and its services are 90% provided by the Unified Health System.

Inclusion criteria were users treated by SUS in hemodialysis treatment, of both sexes and over 18 years old, lucid and residing in a specific municipality of the region attended by the clinic. It is noteworthy that patients were excluded in contact isolation, mental confusion, or who had any alteration of feelings that made them unwell, annoyed, irritated, and did not accept to participate in the research.

The interviews took place in the morning between July and September 2018, during the hemodialysis of these individuals. First, there was presentation of the researchers

and, after explanation of the purpose of the research, the invitation to participate in it. Always taking care to respect the moment and time of the participants, the interviews were recorded with their consent.

Data analysis was based on the Thematic Analysis, which was divided into three interdependent stages.⁹ In the pre-analysis stage, a broad reading of each interview was first performed, in order to select the material that best suited the purpose of the study. ; In the exploration phase of the material, each interview was carefully treated, where we tried to highlight and extract the most significant codes from each text, in order to raise the relevant categories to the work; In the data treatment and interpretation stage, there was an analysis of the speech of each interviewee. In order to preserve the identity of the participants, they were given codenames to be presented in the research results, namely, names of Brazilian birds.

Data collection began after the approval of the Research Ethics Committee under opinion No. 2,644,021. Subjects were granted, through the Informed Consent Form, the right to withdraw from the study at any time or to refuse to participate in the study from the beginning or in any of its stages, according to Resolution No. 466/2012, of the National Health Council.

RESULTS AND DISCUSSION

Ten interviews were conducted, with an average duration of 30 minutes each. Of the people interviewed, 08 were male and two female, with ages ranging from 24 to 70 years old. As for religion, only one of the participants reported not practicing any, while one called himself a theist, an evangelical and seven Catholics. The time of diagnosis of chronic kidney disease ranged from 01 to 24 years, while treatment time was from 1 year and 3 months to 24 years.

From the analysis of the speech content, it was noticeable the emergence of two thematic categories indispensable to the achievement of the objectives that made up this research. The categories emerged from the data were as follows: Itinerary in health services and; The mixed feelings.

Health Services Itinerary

While reporting their experiences with the discovery, treatment and coping of CKD, the search for formal health services, such as specialized clinics, hospitals, basic health units and first aid were the most expressed in the interviews. Although 9 out of 10 respondents reported having some religious belief and / or faith, support in these places and religious practices was not emphasized by the study participants. Thus, this first category discusses with greater emphasis the Itinerary for Health Services as reported by the subjects.

To analyze this category, it was important to study and understand the care provided by the Unified Health System for people with CKD. Care line can be thought of as an

illustration that expresses health production in a systemic way, through a care flow that aims to meet the health needs of an individual, family or community. It seeks to demonstrate the itinerary that the individual makes when accessing a health network.¹⁰

Ordinance No. 483 of April 1, 2014 specifies which components are part of the Health Care Network (RAS) of People with Chronic Diseases, namely: Primary Care and Specialized Care. In the context of Primary Care, it is the responsibility of performing the integral and continuous care of its population, being the main gateway for care planning.¹

Of the ten respondents, only three began the investigation of CKD through the Basic Health Unit:

I only went to a private clinic to do the lab tests, it was just the collection of exams, so I took the exams and took them to the same place where I had been consulted that was at the Health Post. At this Health Post she [doctor] looked at my examination and detected that I had Nephrotic Syndrome, then she immediately passed me to a Nephrologist. (Hummingbird)

I got a very high fever, 40 degrees, so the doctor over there sent me to the hospital. (Swallow)

First I went to the post, right? Then he said he was looking for this doctor ... he indicated me here because I had a kidney problem, so I came. (Eagle)

Primary Health Care (PHC) is the starting point for access to all other levels of health care, however, it is noticeable that in Brazil some people with CKD or at risk for the disease are not yet assisted by most appropriate form in primary care, 11 contributing to the hospital's continuing entry into the Unified Health System for a significant portion of the population:¹²

I only came to look for the Hospital, I went straight there, right? Taken by a neighbor, then went straight to the ICU. (Sabiá)

Portanto, se a Atenção Básica se caracteriza como porta de entrada preferencial aos usuários é fundamental que a mesma tenha um vínculo efetivo com as pessoas que apresentam pré-disposição a desenvolver alterações renais, como os portadores de hipertensão arterial e diabetes mellitus. O vínculo com a sua comunidade adstrita permite o diagnóstico precoce e o encaminhamento imediato aos demais serviços que compõe a Rede de Atenção à Saúde.

Em relação aos fatores desencadeantes para a DRC, a Hipertensão Arterial Sistêmica (HAS) e o Diabetes Mellitus (DM) assumem papéis de destaque:

I went to the emergency room, so I was there in observation, after two hours they called me, measured my blood pressure, went down to 18, so he [doctor] said: oh it's still high, you better look for a nephrologist and see what's happening to you. (Canary)

Around 2016 I had my retina shifted, then after a year I began having these problems ... kidney problems, diabetes, I already had diabetes, right? But did not it control much. (Sabiá)

Currently, systemic arterial hypertension is considered one of the main risk factors for chronic kidney disease, being directly responsible for the majority of patients with renal replacement therapy (RRT), especially when associated with diabetes mellitus.¹³ As pathologies are important predisposing factors for CKD, it is necessary to improve care actions in primary care for this population, with a preventive approach.¹²

Considering the data emerging from the research and the formal recommendations for health services in monitoring the person with CKD, it was noted that in reality exposed in this study there is still much to advance in terms of organization of the care line in the municipality where they occurred. the interviews.

It was evident that Primary Health Care is not configured, in this context, as a gateway for the subjects in the System or as an orderer of the Health Care Networks, given the diversity of places reported by participants as seeking care (private clinics, emergency care units, hospital first aid and basic units).

Thus, it is possible to reflect on the importance of strengthening this service, considering its relevance in the organization of the care line, but also in the prevention of many of the underlying pathologies that were mentioned by the research subjects, since this function - together with promotion of health - it is one of the great differentials of PHC in terms of humanization, longitudinality of care and resoluteness of the system.

It is important to point out that among the interviewees, there was no demand for informal support services. One of the factors that may explain this fact is the severity with which each respondent discovered the pathology, leading to the rapid search for formal health services.

The mixed feelings

Contemplating the life trajectory of each person interviewed, it is evident the many feelings that pervade those who are committed of a Chronic Kidney Disease. Emotions and sensations such as anxiety, fear, denial, regret and acceptance are part of the itinerary taken by these individuals. This fact is confirmed by the reports of the study participants:

It was a very disturbing time, I was very moved, we think we will die, when you go on dialysis you hear so much, so much I looked on the internet... (Sparrow)

There are different stages through which the reactions and feelings of the subjects at the moment of diagnosis of CKD pass. In general, this moment carries a content of rupture, suffering and loss. In the early stages one can observe reactions of fright, fear and anxiety, once the individual begins to glimpse how much will be the outcome of his illness; In the final stages, when hemodialysis becomes essential, not knowing what its difficulties will be in face of this therapy can generate a mixture of suffering and sadness.¹⁴

Even aware of their pathological condition and the need for hemodialysis, some people try to cling to a reality in which CKD is not present, seeking to see treatment as something temporary. Some individuals also try to turn their thoughts to other occupations, seeking to soften or even forget the need for complex treatment to replace renal functions.¹⁵

So I postponed about eight months. I thought I would get better but it got worse. (Bem-te-vi)

At first it seems like it wasn't that scary, of course I had a problem, but I knew that one day I was going to be able to do hemodialysis. I didn't worry so much, until when I received that there was no way. I had to start hemodialysis, so that was a shock.(Rufous Hornero)

Patients often report a feeling of helplessness in the face of illness and life in general, showing anger and often blame for being in this situation.¹⁶ In order to overcome the process of initial denial of the disease, it is necessary for them to acquire understand their meaning, and understand the reflexes generated in their daily lives, relationships and life-giving meaning, as the physical and emotional changes to which they are exposed represent obstacles to the continuity of treatment.¹⁷

A week into it, I freaked out, I didn't want to do [hemodialysis] anymore, I wanted to go out, it was bothering me, so the psychologist came and talked to me. (Sparrow)

I can't stand it, when I have to come here it gives me a 'state of nerves', I don't know ... I don't know if it's my mind, I don't like to stay here ... there are days when I come here, that I feel like running away. I can't explain why, it's a war, right?! (Eagle)

I don't want this thing for myself, I prefer to die, I won't do hemodialysis anymore, it's not normal. (Canary)

By discovering a chronic disease with subsequent need for dialysis treatment, individuals may initially view this process as painful, which leads to physical and mental suffering for patients. The sudden change that occurs in their routine, the limitations that now accompany their experience, the idea of hemodialysis as a continuous reality and the possibility of death negatively influence their quality of life.⁵

The presence of negative feelings may be related to the fact that these people are often still of an economically active age, making them feel disgusted, distressed or even anxious. It is also necessary to think about the economic responsibility that many of these individuals have in their families, because internal conflicts can be generated through the uncertainties of treatment and disease.¹⁸

In this context, paying attention to the psychological dimension, the individual has difficulties in accepting his new physical state. There is a grief that is experienced by the loss of the body considered healthy, which now gives way to a body with weaknesses. From the discovery of CKD, the discourse of people who go through the process acquires varied meanings, through the reflection that arises about the finitude of human beings. The body carries physical marks of the hemodialysis process, which leads the individual to think about his existence and also about the possibility of death. Reports of feelings such as anguish, insecurity, restlessness, panic, depression, feelings of imprisonment with the hemodialysis machine and fear are frequent in these people and come from the modifications generated by treatment.¹⁹

I have witnessed people who do not accept and start taking drugs to dope, end up dying, many end up not wanting to do more hemodialysis and give up. I've seen people here, dying in front of me, it's not easy, right? (Sabia)

I couldn't believe ... I looked over there, all people older than me, I was like 'I'm dead, I'm dead...' I'll just do that there for a while and in a little while I will erase myself. (Quiriquiri)

The psycho-emotional suffering that the disease brings generates internal conflicts permeated by feelings that induce psychological changes in the individual, and may trigger other symptoms, such as aggression, insomnia, irritability, among other mood changes. The meanings of feelings are different for each one during treatment. How each person deals with the disease depends directly on their psychological modulation and life course. Thus, the person with chronic kidney disease needs a social, family and multiprofessional support network that assists in the ups and downs that make up the hemodialysis treatment, supporting this individual in the many stages of the therapeutic process.

In fact, hemodialysis contributes positively to the increase in survival of these people, however it imposes on the patient a feeling of anguish, as it interferes with the individual's daily life with the different physical and emotional losses suffered by him.¹⁹ Support in this phase is crucial because the patient needs someone available to whom he can report not only the feeling of sadness but all the impactful feelings that will arise as a result of the treatment.

Thus, we realize the importance of the health professional who assists these subjects to seek to know what are the feelings that permeate the life course of these individuals, seeking to welcome each human being, considering their particularities and differences and respecting it in their integrally, knowing that each person has a different perception of the situation experienced.

When the professional understands the mixed feelings that are present in their lives, they have the opportunity to offer them the necessary support to build the bond between the professional and his client. The formation of this bond can often be crucial for the continuity of treatment.

FINAL CONSIDERATIONS

Through the interviewees' statements, it was evident that everyone, feeling the symptoms, first sought formal health services. Here, the importance of the formal health network is clear to these people. Of the interviewees, most reported having discovered CKD through clinical examinations, and were thereafter followed exclusively by the renal specialty clinic, performing the same hemodialysis treatment. Although Primary Care is responsible for the care management of these people, this fact was not verified in any of the therapeutic itineraries of these individuals.

Another fact observed was that most interviewees have some comorbidity associated with CKD, the most prevalent being Diabetes Mellitus and Systemic Arterial Hypertension; Thus, the active participation of Primary Health Care in the prevention of these diseases becomes extremely important, promoting a significant reduction in the rates of CKD.

Regarding the feelings experienced by people facing CKD, the denial appeared recurrently, showing that, when they find themselves as patients with CKD, many do not understand the magnitude of the problem, and it is essential that the multiprofessional health team embraces these people, offering the necessary support for a better understanding of the care process.

Thus, even with the adversities faced by people with CKD, the professional can make this stressful and stressful time in their lives a less painful and more easily acceptable moment, generating positive impacts on their lives and treatment itinerary.

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