

**Original Article** 

#### THE CHRONIC RENAL DISEASE COURSE: FROM EARLY SYMPTONS TO DISCOVERY

O ITINERÁRIO DA DOENÇA RENAL CRÔNICA: DO PRENÚNCIO À DESCOBERTA EL ITINERARIO DE LA ENFERMEDAD RENAL CRÓNICA: DEL PRELUDIO AL DESCUBRIMIENTO

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An exploratory and descriptive study with a qualitative approach aim at understanding the significance of the discovery of chronic kidney disease and the need for the hemodialysis machine. The research was made with twenty patients from two hemodialysis services of the city of RS. The data collection took place between September and December of 2007, throughout semi-structured interviews. The thematic analysis generated the following categories: history of chronic kidney disease, from the silence of the disease to the classical clinical symptoms; the discovery and its immediate effects; life after the discovery; acceptance of the dependence on a machine. We conclude that there is a need to adapt the daily life of patients with chronic kidney disease, because the hemodialysis causes physical and social changes, requiring support from health-team to manage the disease. The professional should not abdicate knowledge, safety and technical skill, as requirements to care.

**Descriptors:** Chronic Disease; Chronic Kidney Failure; Nursing Care; Health Education.

Estudo exploratório descritivo com abordagem qualitativa, com o objetivo de compreender o significado da descoberta da doença renal crônica e a necessidade da máquina de hemodiálise. Estudo realizado com vinte pacientes de dois serviços de hemodiálise de uma cidade do interior do RS. A coleta de dados ocorreu entre setembro e dezembro de 2007, mediante entrevista semi-estruturada. A análise temática originou as categorias: historiando a doença renal crônica; do silêncio da doença ao quadro clínico clássico; descoberta e seus efeitos imediatos; a vida depois da descoberta; aceitação da dependência de uma máquina. Conclui-se que há a necessidade de adaptação no cotidiano da vida do paciente renal crônico, pois a hemodiálise provoca alterações físicas e sociais, necessitando de apoio da equipe para o enfrentamento da doença. O profissional não deve abdicar do conhecimento, da segurança e da habilidade técnica, como condições indispensáveis ao cuidado.

**Descritores:** Doença Crônica; Falência Renal Crônica; Cuidados de Enfermagem; Educação em Saúde.

Estudio exploratorio, descriptivo, con enfoque cualitativo, cuyo objetivo fue comprender el significado del descubrimiento de la enfermedad renal crónica y la necesidad de la máquina de hemodiálisis. Estudio realizado con veinte pacientes de dos servicios de hemodiálisis de una ciudad del interior de RS, Brasil. La recolección de los datos ocurrió entre septiembre y diciembre de 2007, mediante entrevista semiestructurada. El análisis temático origino las categorías: historiando la enfermedad renal crónica; del silencio de la enfermedad al cuadro clínico clásico; descubrimiento y sus efectos inmediatos; la vida después del descubrimiento; aceptación de la dependencia de una máquina. Hay necesidad de adaptación en el cotidiano de la vida del paciente renal crónico, pues la hemodiálisis provoca alteraciones físicas y sociales, exigiendo apoyo del equipo para enfrentamiento de la enfermedad. El profesional no debe abdicar del conocimiento, seguridad y habilidades técnicas, como condiciones indispensables a la atención.

Descriptores: Enfermedad Crónica; Fallo Renal Crónico; Atención de Enfermería; Educación en Salud.

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#### **INTRODUCTION**

The line between health and disease is sometimes tenuous, and in silent diseases, symptomatic signals occur late. Chronic kidney disease (CKD) has stages of gradual evolution, and is usually diagnosed at an advanced stage due to a practically hidden clinical picture.

The silent character, slow progression, weaknesses in the prevention and comorbidities of nowadays unveil a worrying situation in public health worldwide, because the number of patients starting dialysis each year is alarming, not to mention that, in Brazil and in many countries there are underdiagnosed cases and deaths before being discussed the possibility of dialysis.

The National Kidney Foundation<sup>(1)</sup> proposed a schema of definition and classification of the CKD which is divided into 5 stages: first the Glomerular Filtration Rate (GFR) is  $\geq$  90 ml/min/1.73m<sup>2</sup> already in the presence of renal failure but it may not have interfered with the GFR; in stage 2 GFR is from 60 to 89, in stage 3 GFR is from 30 to 59, in stage 4 it is from 15 to 29 and in the last stage, GFR is < 15 and it indicates renal failure.

In the early stages of CKD, the clinical and laboratory manifestations are minimal or absent. As it progresses, the metabolic consequences of the uremic state begins to manifest themselves, because substances not excreted in urine are retained in the circulation, affecting the various systems and creating laboratory abnormalities<sup>(2)</sup>.

With the discovery of a chronic illness, one imposes the need to change eating habits and daily activities by the continuous use of drugs, dependence and living with other people, sexual and physical limitations and also the dialysis routine. One adds to this the concerns and uncertainty about future problems that may worsen with time<sup>(3)</sup>.

Thus, renal patients who carry the mishaps of chronicity may feel hopeless, they become vulnerable to the instabilities of the disease, they have obligations and self-denials; they demand self-care, depend on professional care; they rebel or engage in their treatment.

Considering the need to understand these human beings who are dependent on a dialysis machine and the repercussions of the diagnosis in their everyday lives one focused as the research question: what are the meanings of the diagnosis of kidney disease and the effects of dependence on a machine in the patient's life?

In order to elucidate this question, the study aimed to understand the significance of the discovery of chronic kidney disease in terminal stage and the need of the dialysis machine.

#### **METHOD**

This is a descriptive exploratory study with a qualitative approach developed with twenty adult patients of both genders diagnosed with CKD who underwent hemodialysis provided by the Unified Health System (SUS) in two nephrology services in the city of Passo Fundo, RS. We invited patients who were undergoing hemodialysis in the morning.

The choice of participants was made by drawing names from a list of all patients who underwent sessions three times a week in the morning shift. We excluded patients with significant hearing loss and those who did not reside in the city of Passo Fundo. Patients who agreed to participate signed a consent form.

Data collection was conducted through semistructured interviews, conducted in the homes of patients after prior appointment contact from September to December 2007. In the interview one inquired what the patients felt before discovering that their kidneys had lost their function and what this discovery meant, which revealed the dependence of a machine for the maintenance of life. About these aspects one asked two questions: "What did you use to feel before the discovery of the disease?" And "How was it for you to discover the renal failure and the dependence on a machine?".

After reading the answers given by the subjects, the data were organized, classified and analyzed qualitatively. Each participant received the sequential number of the interview conducted (i1, i2, i3) to preserve their anonymity and the confidentiality of the data. To interpret them the technique used was the thematic analysis, grouping them into thematic units that originated categories of significance, which were analyzed in the light of the literature. Thus, the study covered the different phases proposed: Pre-analysis, material exploration, processing and interpretation of results<sup>(4)</sup>.

The patients randomly chosen from the hemodialysis program were invited to participate in the study. Out of these, thirty-six agreed to participate. One realized the data saturation, moment when the answers given by the subjects started to be repeated frequently. So the researchers decided to finish collecting data when the twentieth patient was interviewed.

The project was approved by the Research Ethics Committee of the Universidade de Passo Fundo (Registration No. 323/2006).

### **RESULTS AND DISCUSSION**

The participants of the study were mostly male (n=12) and their minimum age was 19 and maximum 72 years old, and the duration of dialysis ranged from two to 27 years. As the cause of renal failure, hypertension was the most prevalent, followed by diabetes mellitus, polycystic kidney disease and systemic lupus erythematosus.

The categories presented bring up their history lived until the illness, the dependence on the machine, the path drawn between the clinically silent or impaired past and the official diagnosis. One will describe the categories, studying the history of chronic kidney disease; from the silence of the disease to the classical clinical picture; the discovery and its immediate effects, life after the discovery; acceptance of the dependence on a machine.

## Studying the history of the chronic kidney disease

For some patients the cause of CKD was announced early in their life, since they reported that their childhood or youth were marked by poor health, suffering from malformations or affected early by comorbidities. This was mentioned by the participants as follows: ...I've had hypertension since I was 15 years old... (i1). Since I was little I was sick, I was born with my feet upwards and saggy belly. I would always go to the hospital because of my problems ... I used to use a probe since that time to urinate (i7).

The absence of symptoms in patients who are in the early stages of CKD requires that professionals always maintain an appropriate level of suspicion, especially in patients with clinical or sociodemographic risk factors for developing kidney injury. As previously mentioned, functional changes, particularly in GFR, are an important component in the diagnosis and classification of CKD<sup>(5)</sup>.

Most of the patients were aware of the causes that led to the CKD and its association with the need for dialysis. They point morbidities prevalent today, as well as other base diseases: ...My blood pressure was 290/240. They hospitalized me urgently (i3). Lupus can give kidney, joint and lung disease (i14). ...the gout took over 20 years to be discovered.... (i19).

Hypertension is the leading cause of CKD, with 35.1% of cases, followed by diabetes mellitus in 28.4% of the cases<sup>(6)</sup>. Hypertension and diabetes bearers need effective clinical control of these comorbidities, health education is essential for their acceptance of the treatment and control of disease<sup>(7)</sup>.

Less prevalent etiologies, but not uncommon in our environment, can make the renal function fail. Among these it is the gout, which is a genetic metabolic disorder, characterized by deposits of uric acid, preferably in the joints. When accompanied by severe renal insufficiency, it can be seen along with other underlying conditions such as urolithiasis, hypertension and urinary tract infection. Gouty nephropathy is a manifestation that depends on the degree and duration of the hyperuricemia and usually occurs due to nephrolithiasis<sup>(8)</sup>. Systemic lupus erythematosus often causes renal manifestations, in which there is glomerular injury by deposition or formation *in situ* of immune complexes, because anti-DNA antibodies are formed by the hyperactivity of B-lymphocytes<sup>(9)</sup>.

Due to the relevance of hypertension and diabetes as the main cause of CKD, the renal protection is guided on the commitment of health professionals, when they establish individualized goals; on the patients' own commitment, striving for the instituted treatment; and on the family's, co-participating in achieving those, in order to jointly minimize or delay the progression of the disease<sup>(10)</sup>.

# From the silence of the disease to the classical clinical picture

With a usually insidious character, CKD leads to a late diagnosis when there is the exacerbation of the classic signs of uremia, pointing to the possibility of dialysis in a medium or short term. The statements that follow reveal the glare of the disease, showing the invisibility of their symptoms: *I knew about it when there was only 38% of my kidney function left...* (i1). *I had never been to the doctor for anything. As I had a lot of headaches, I started getting swollen and stopped urinating, then I went to the health unit. Then, there they sent me to a nephrologist, who found out that I had to do hemodialysis ... I felt nothing, nothing at all.* (i2).

The morbid process develops slowly and imperceptibly hiding the renal failure, the patients do

not realize the pre-existence of the process. Thus, the confirmation of CKD (Chronic Kidney Disease) comes late, preventing the conservative treatment and requiring immediate renal therapy.

Renal protective measures are given to patients who still have residual renal function, with the aim of delaying the onset of dialysis through a supporting multidisciplinary health team and the adoption of a self-care proposal, but patients complain about the difficulty to attend the consultations and follow the guidelines of the diet<sup>(11)</sup>. A single statement reveals the experience of conservative treatment: ...I was going to donate blood and I had high blood pressure, before it I felt like a heat wave in the face. I went to the doctor and discovered the kidney problem, starting the treatment with diet and medication, seven years later I started hemodialysis (115).

Some patients reported they neglected their health because, aware or not of their problem, they minimized comorbidities, not meeting the guidelines or even denying the warning that the situation was serious and that it could worsen: *I did not take high blood pressure seriously. I knew I had hypertension, but I used to run, drink, and I took medication only when I remembered. It is for being careless that I'm in this situation. I could be working (i5).* 

Due to terminal CKD, the clinical picture is revealed more clearly with the symptoms denouncing uremia. In this case, the patients remembered the most expressive discomforts of uremia that would reveal conclusive diagnosis of the disease, such as digestive disturbances and fatigue, remembered for generating discomfort and physical suffering: *I could not climb to the first floor, my legs and hump would hurt, I used to vomit. Then I set a consultation...* (i8). *I spent a week as if I had the flu, a discomfort in the entire body. There was no way to eat, I felt like I had an iron in my stomach, felt bitterness, fear, I could not sleep, I vomited a lot (i13).* 

The most common gastrointestinal manifestations are nausea, abdominal pain, vomiting, and dysphagia<sup>(12)</sup>. Some complain about a metallic taste and have ammonia breath odor that can be caused by zinc deficiency and metabolic disorders<sup>(13)</sup>.

Cardiovascular and lung symptoms, with their consequences, especially on fluid overload, dyspnea and edema, were remarkable: ....My feet were always swollen, I urinated less and less, until there was no more urine, I had high blood pressure... (i7). ...I had a heart problem and started to swell... (i12).

The secondary hypertension occurs in the later stages of the disease usually associated with excessive circulating volume, and could be controlled by reducing sodium intake, use of diuretics and by dialysis. In a minority, hypertension does not yield to those measures, responding to antihypertensive drugs. It is the main risk factor for developing coronary artery disease, heart failure and excess of salt and water in the body<sup>(14)</sup>.

Neurological manifestations which lead to the worsening of CKD, uremic coma, and the need for intensive care were identified like this: ...I used to get dizzy, did not see well and had malaise and dizziness. I thought it was a problem in the blood pressure.... one day I fainted. The doctor said I had a problem in the head because the kidneys had stopped working (i6).

The neurological status of the uremic syndrome includes fatigue, muscle weakness, insomnia, asterixis, peripheral neuropathy, irritability, tremor, twitching, spasms and progressive deterioration, lethargy, stupor and coma. Patients are worried and apathetic, with changes in concentration, memory, behavior and mood.

Due to the subtle nature of the disease, it is important to educate users to pay attention to organic misfits, and seek the health service; and for those who provide care, they should pay attention to adjacent chronic diseases.

## Discovery and its immediate effects

Remarkable symptoms or any serious episode forced patients to look for the hospital, usually in emergency or intensive care situation. Then the routine of an irreversible disease starts, but which has viable and durable treatment. The speeches below illustrate the discovery of the disease and its relation to sudden pains, emergency consultations, hospitalization: *I fell, I* 

was taken to the hospital and they saw that it was a kidney problem (i4). ...I had lost too much weight... I was taken to the emergency room, they called a doctor (i8). ...The urea was high. Then they made a fistula and I started hemodialysis (i19).

As one may notice, diagnostic confirmation arrived late, not allowing time for the renal protective measures, besides the fact that the patient is physically and psychologically debilitated. In this sense, the National Kidney Foundation<sup>(1)</sup> reiterates that in the fifth stage of CKD, there is the urgency to choose a form of renal therapy. Due to the risk of uremic coma, the patient only notices the dependence on the dialysis machine when he regains consciousness.

The difficulty of acceptance was a remarkable occurrence. When faced with a conclusive diagnosis of CKD, there was a great personal suffering which generated distress for most patients: *They said I was going on the same path of the deceased mother* (i7). ... *I did not want to accept it, I was terrified ... I asked why, will I die?* (i8). *It's a fright ... lack of dissemination of hemodialysis...* (i11).

Being informed about an irreversible diagnosis and about the need of a treatment which requires a machine brings about negative feelings in patients. Moreover, at this time comes the discovery that their lives need to be restructured, and that there is also the need to change their habits and lifestyle, such as the use of a diet with several caloric restrictions and water intake, medication use. Another impact factor to the routine is the inclusion of three hemodialysis sessions per week.

Bodily changes related to the disease or to the access for hemodialysis also affected the physical and emotional health of patients: At first I was very ill... They started cutting my arms, my hands. I was very vain... (i17). ...the fistula works well, but it starts to thicken (i13).

The patient with chronic kidney disease presents self-image concerns, mentioning the bodily changes that are associated with the catheter use, feeling of worthlessness and fear of being interpreted as the

carrier of a contagious disease, which trigger feelings of distress, with consequent isolation<sup>(3)</sup>.

Therefore it is essential that nurses use empathic communication<sup>(14)</sup>, because in addition to pathophysiological changes, patients have their self-image changed by the creation of an arteriovenous fistula or by the insertion of a catheter. In practice, from what is observed with patients, the fistula becomes an object of rejection, which many prefer to hide, because they feel uncomfortable with stares or questions from curious people.

During the early days of dialysis, the accumulation and complexity of information interfere with the patients' understanding. The irreversibility can become frightening, and this fear may be accentuated when the information is not passed or understood. The speeches transcribed expose the fear: *I used to go to hemodialysis to spy, to know, but I could not look at or get inside. I had no strength, I was very afraid of needles* (i1). *I started thinking about my mother who died ...* (i7).

The fear triggered by hemodialysis is expressed because of the machine and the equipment, routine procedures, side effects of the treatment and inquiries of the healthcare team. Fear also emerges from the uncertainty of tomorrow and the possibility of death. Thus, many patients feel hopeless towards life and threatened by finitude<sup>(15)</sup>.

The patient needs to count on the health team's welcoming at all times and especially in the first sessions of hemodialysis. This multi professional support will strengthen the patient to find actions and strategies to deal with the disease and assimilate the dependence on the hemodialysis machine.

#### Life after the discovery

Dialysis is not something new anymore and there is a certain "grieving" to patients, due to successive losses or renunciation resulting from the disease. Negative feelings appear more due to the inability to

work, financial losses and the physical consequences regarding the sexual libido, translated in these sentences: *My wife started working and I retired* (i12). *I do not like being at home doing nothing...* (i19). *Our intimate life decreased. My wife at first thought I had another woman, but now she understands. It decreases very much our intimate relations* (i12).

The inability to maintain employment relationships arising from absenteeism or from physical limitations resulting from the disease causes the individuals' decreased self-esteem. Consequently, the responsibility of keeping the family is transferred to another person. Possible alternatives would be the informal ties and self-employment<sup>(16)</sup>, since they could minimize the pain and resentment due to the suspension of the activities they used to have.

The decreased sexual activity is multifactorial, involving psychological, neurological, biochemical, pharmacological and endocrine factors<sup>(17)</sup>. It is important that the patients understand this result and look for dialogue with their partners, trying to search for alternatives and a better understanding of the problem, by abolishing the use of remedies, teas or formulas to improve their sexual performance, as they will not provide the desired effect and will bring them serious consequences.

The mandatory hemodialysis sessions generate a sense of entrapment with the treatment, by not allowing trips or longer tours and the restricted intake of water or liquids in general exacerbates this misfortune: ...I thought: my life will change...I was not going to be able to drink water and even mate, that I was not going to be able to walk and travel (i7.) I used to drink a lot of juice, about two liters per day, now I have to take half a glass of water and that's all (i19).

Educational proposals for water control<sup>(18)</sup> are important because most patients have difficulty in following the fluid restriction that takes away from them a source of pleasure and satisfaction. So they count on nutritional counseling and on a multidisciplinary team in order to make them aware of the importance of euvolemia.

Nutritional restrictions and controlled liquid intake represent the hardest part of the treatment, requiring changes in the patients' habits. Thus the use of a diet is important for controlling proteinuria, glucose, hyperlipidemia, obesity and other cardiovascular complications<sup>(11)</sup>.

## Acceptance of dependence on a machine

As time goes by with dialysis, there is a more friendly relationship with the mandatory sessions. The enhanced technical apparatus and the pharmacological progress keep people for a long time in treatment, showing that the technoscientific evolution mitigates the impacts caused by the disease, and it also facilitates the treatment. The statements below confirm this adaptation: ...we conform with the idea that there is a machine to extend our lives (i11). Now I think I'm not sick, I only have a problem (i17).

Research with chronic renal failure patients<sup>(19)</sup> reveals that after the nebulous episodes of the beginning of the illness, occurs the understanding of the condition of a chronic disease; some patients feel thankful for being alive and they assimilated more calmly the dependency on the machine.

Within this perspective, over time patients generally assimilate their weaknesses and the changes in their daily routine. Monitoring by professionals strengthens their mental balance and can provide a better quality of life, within the limitations of each hemodialysis patient. This support will facilitate psychological adaptation, which occurs in chronic patients in general, by using strategies to cope with the disease and they end up valuing their daily life even with limitations<sup>(20)</sup>.

When seeking meanings of hemodialysis with renal patients<sup>(21)</sup>, it was evident that the compliance with this treatment and the self-responsibility for their care will provide a better life quality. These aspects are related to the active participation in their care,

understanding their situation and seeking to mitigate the consequences of being a carrier of a chronic disease. Of course they cannot deny that their illness is irreversible, being dependent on a machine, a device which maintains their lives.

The acceptance of the disease is seen as a key factor for the adherence to the treatment; so it is important that nurses are motivated and that they constantly stimulate the patients and provide them with alternatives which promote positive coping of the disease. Then, creating links with the patients and their families favors the treatment, and decreases the demonstration of negative feelings, such as, anger, aggression, sadness and despair. This bond may promote acceptance, the hope to keep fighting with all their strength and maybe have a better future, within their limitations<sup>(15)</sup>.

This study allowed us to analyze the anxieties of the people, which go beyond a machine, the volume loss during sessions or following the schedules stipulated in hemodialysis. Hence the professionals need to expand their attention, their listening and their look in the care relation. Care goes beyond the boundary of technological sophistication, the instrumental apparatus which, although important and indispensable in hemodialysis, are insufficient to meet the needs of a person with CKD.

### **FINAL CONSIDERATIONS**

Chronic kidney disease (CKD) and hemodialysis treatment interferes in people's lives by preventing or limiting the conduction of their daily activities. Regardless of the beginning of the loss of the kidney function, and the need to travel for the filtration of blood three times a week, the discovery of the event or the confirmation of the last CKD stage, can impact patients' lives.

The objective of this study was achieved, because it enabled a group of CKD patients to understand the meanings of the impact that the discovery of this disease brings and also of the dependence on hemodialysis, so the events that preceded this diagnosis become more evident. After the discovery the impact of the physical and emotional weaknesses in the daily lives of these people was remarkable.

CKD destabilizes its bearer, for having it permanently and undesirably in their daily living. Clinical instabilities and complications related to dialysis of greater or lesser severity, can follow the course of therapy, often leading patients to feel insecure, threatened and, knowing about its irreversibility. Given the irreversibility of renal failure, all motivations are focused for a future transplant.

Within this perspective, chronic kidney disease patients require ongoing support to adapt to the situations that arise from their health problem and limited quality of life. In this context, the bond with the team and continued support is a social ethical commitment of each professional. Moreover, there is the need for ongoing education process for self-care in order to prepare them to develop skills to deal with this new life condition.

The dependence on the machine associated with the treatment with many medicines and the diet interfere in the daily activities and life quality of chronic kidney disease patients. Associated with this, the changes related to self-image and the performance of social functions related to dependence on a machine, may trigger the need for monitoring by a team of qualified professionals throughout these people's lives.

Trying to change the focus of the patients' attention can be a great ally in acceptance, but it will also enable them to find coping strategies in relation to biological, emotional and aesthetic aspects.

Trying to stimulate the patients, even in adversity, to help them find new ways is the challenge for everybody involved in the care of these people undergoing hemodialysis. Maybe seeking new motivations and meanings in life can be a challenge for patients and a useful strategy used by professionals.

Within this perspective, it is necessary to think of actions and strategies that can give support for chronic kidney disease patients, making them have motivation, hope and self-empowerment in coping with their chronic condition.

Finally, the study results enabled discussions among the people involved, that humanized care goes beyond the technical and instrumental performance. The professionals who work in the hemodialysis environment should not abdicate knowledge, safety and technical skill, as indispensable conditions to care, but also demonstrate an ethical attitude, being aware of the multidimensional character of these human beings' lives.

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