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# The impact of chronic kidney disease: experiences of patients and relatives from the extreme north of Brazil

Maria Virgínia Filgueiras de Assis Mello<sup>1</sup>  
Margareth Angelo<sup>2</sup>



Original article



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## The impact of chronic kidney disease: experiences of patients and relatives from the extreme North of Brazil

**Objective.** To identify the impact of chronic kidney disease on patients and their families. **Method.** This is a qualitative study conducted by the theoretical and methodological reference of Symbolic Interactionism and Narrative Research. The scenario of the study was the State of Amapá, in the extreme north of Brazil. Semi-structured interviews were conducted with 15 patients who experienced hemodialysis therapy and 16 family members. **Results.** The thematic analysis of the narratives resulted in the identification of two themes: life before the disease and life invaded by the disease. **Conclusion.** The diagnosis of chronic kidney disease and the need undergo hemodialysis emerged as a source of intense suffering, affecting the daily lives of the families as a whole and causing physical, psychological and social damages.

**Descriptors:** renal insufficiency, chronic; renal dialysis; qualitative research.

1 Nurse, Ph.D. Adjunct Professor, Federal University of Amapá-UNIFAP. Macapá-AP, Brazil.  
email: virginia@unifap.br

2 Nurse, Ph.D. Full Professor, Department of Mother Child Nursing and Psychiatric Nursing, School of Nursing, University of São Paulo - EEUSP. São Paulo-SP, Brazil.  
email: angelm@usp.br

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## Impacto de la enfermedad renal crónica: experiencias de pacientes y sus familiares del extremo Norte de Brasil

**Objetivo.** Identificar el impacto de la enfermedad renal crónica sobre el paciente y su familia. **Método.** Estudio cualitativo conducido por el referencial teórico metodológico del Interaccionismo Simbólico y de la Investigación Narrativa. El escenario del estudio fue el Estado de Amapá, localizado en el extremo Norte de Brasil. Se realizaron entrevistas semiestructuradas a 15 pacientes con experiencia en terapia de hemodiálisis y a 16 familiares. **Resultados.** El análisis temático de las narrativas identificó dos temas: la vida antes de la enfermedad y la vida invadida por la enfermedad. **Conclusión.** El diagnóstico de la enfermedad renal crónica y la necesidad de realizar hemodiálisis son experiencias generadoras de intenso sufrimiento, que afecta el cotidiano de la familia como un todo y que causa daños físicos, psicológicos y sociales.

**Descriptores:** insuficiencia renal crónica; diálisis renal; investigación cualitativa.

## O impacto da doença renal crônica: experiências de pacientes e familiares do extremo Norte do Brasil

**Objetivo.** Identificar o impacto da doença renal crônica sobre o paciente e sua família. **Método.** Estudo qualitativo, conduzido pelo referencial teórico metodológico do Interacionismo Simbólico e da Pesquisa Narrativa. Teve como cenário o Estado do Amapá, localizado no extremo Norte do Brasil. Entrevistas semiestruturadas foram conduzidas com 15 pacientes que vivenciam a experiência da terapia hemodialítica e 16 familiares destes. **Resultados.** A análise temática das narrativas resultou na identificação de dois temas: a vida antes da doença e a vida invadida pela doença. **Conclusão.** O diagnóstico da doença renal crônica e a necessidade de realizar hemodiálise se configuraram como uma experiência geradora de intenso sofrimento, que afeta o cotidiano da família como um todo e causa danos de ordem física, psicológica e social.

**Descritores:** insuficiência renal crônica; diálise renal; pesquisa qualitativa.

# Introduction

While reflecting on the global health context, a study<sup>(1)</sup> highlights chronic diseases as a challenge to the global health policy of the 21st century. Chronic diseases are likely to soon become a global epidemiological archetype and this has multiple repercussions on the quality of life and productivity of people. Within this perspective, the present study focus on chronic kidney disease (CKD), a disease that leads to progressive and irreversible loss of renal function and has multiple causes and varied prognostic factors. It is a long-term, insidious and asymptomatic disease in most of the of its evolution.<sup>(2)</sup>

It should be noted that until 1965, many CKD patients worldwide would progress to the final stages of the disease and die. The high mortality rate was associated with limitations in the treatment of renal disease and the extremely high costs of the usual treatment. Then, in 1972, a federal program to support dialysis and kidney transplantation, called *Medicare*, was launched in the United States. Since then, renal replacement therapy, dialysis and transplantation, as treatment options for patients who progressed to end-stage renal disease, proliferated in the public and private health network, and from that moment on, the treatment of CKD has received increasing attention from the scientific community, as demonstrated by population studies conducted in different countries.<sup>(2-4)</sup> Among the modalities of renal replacement therapy, hemodialysis has as a peculiarity the fact that it has to be permanent, including periodic dialysis sessions, restricted liquids intake, and use of medications. This treatment contributes to increase the patients' life length, but on the other hand has physical, psychological and social implications that impact their quality of life, as well as that of their families.

A research of national and international literature between the years 2010 and 2015 revealed a plethora of studies reporting the experience of CKD in a fragmented way and from the perspective of sick individuals.<sup>(5-9)</sup> However, few studies have investigated this experience the perspective of the patient's family. In view of this, this article aimed to identify the impact of CKD on patients and their families. Considering that CKD and hemodialysis therapy are not widely known in the popular media, this contributes to a better understanding of the challenges and adversities that patients and their families face as a result of CKD. This study also aims to encourage nurses in the interest to intervene in the suffering of families, through the establishment of a relationship of trust that favors acceptance, adaptation to lifestyle changes and treatment adherence.

## Methods

In view of the object of this study, a qualitative approach was chosen because it is appropriate to explore subjective aspects and meanings that people attribute to their experiences.<sup>(10)</sup> Symbolic Interactionism was adopted as theoretical reference and represented the “lens” to guide this study.<sup>(11)</sup> Narrative research was adopted as methodological reference and made it possible to understand the experience “in a process of collaboration between researcher and researched subject.”<sup>(12)</sup> The context of the study was the State of Amapá, one of the 27 federative units in Brazil. It is the penultimate state in the country in terms of population size, with approximately 766 679 inhabitants distributed in 16 municipalities.<sup>(13)</sup> Amapá has the Tumucumaque Mountains National Park, one of the largest in the world, with almost 3.9 million hectares, and of great relevance because it presents a high number of endemic species and different ethnic groups in its surroundings: indigenous peoples, riverside dwellers and chestnut farmers. Its capital city, Macapá, the only Brazilian capital cut by the Equator Line, is located along the Amazon River and has no road or railroad connection with other Brazilian capitals, and thus the access is only possible by river or air.

A previous contact between the researcher and the participants of the study in the Nephrology Unit of Macapá was established during a period of ten days. The systematically planned insertion in the hemodialysis environment allowed a more careful look at the context, the approximation with the patients and the identification of patients who met the selection criteria. The selection of participants was intentional and they had to meet the following criteria: to undergo hemodialysis for at least six months, to live in the Capital or in a neighboring municipality, to be over 18 years of age and to be physically and psychologically able to respond to the interview. Participating relatives were indicated by the patients themselves, taking into account those who were involved in their care and routines regarding the disease and hemodialysis treatment since the initial phase. The selection criteria for the

relatives were: to be over 18 years of age, to live in the same house as the patient and to be available to respond to the interview.

The invitation to participate in the study was made personally by one of the researchers to 19 patients. Among them, one had no interest in participating in the study and there were successive mismatches in three cases that made the interviews impossible. Thus, the population consisted of 15 patients and 16 family members who had their participation formalized by signing the Informed Consent Term. The meeting with the participants occurred simultaneously with patients and relatives and began with the elaboration of a family genogram including three generations, which enabled the collection of data about relationships over time and health, occupation, religion, ethnicity, and migration.<sup>(14,15)</sup> A family form, an instrument developed by the researchers to list sociodemographic and clinical data of the participants, was then filled out. Finally, the semi-structured interview was the strategy adopted to access the narrative of the participants. The interviews were audio recorded for an average of 40 minutes, and were held between October 2014 and January 2015 at the participants' home, at previously scheduled dates and times. There was a need to resume the interviews with two families to better deepen the phenomenon studied.

Data were submitted to thematic analysis of the narratives by the researchers without using any professional software and contemplated six phases: verbatim transcription and strenuous re-readings, generation of initial codes, elaboration and refinement of themes, final definition of themes and production of the report.<sup>(16)</sup> In order to guarantee the confidentiality of the participants' identity, the identification “P” was used for the patients' narratives and “F” for the family members' narratives, followed by the number of the order in which the interviews took place. This study respected the ethical aspects of Resolution 466/12 and was approved by the Ethics and Research Committee of the Federal University of Amapá (Opinion N. 810.907).

# Results

This study was represented by 15 patients and 16 relatives: nine wives, three mothers, three daughters and one ex-husband, aged between 23 and 83 years. The hemodialysis time ranged from 1 to 16 years. Based on the participants' narratives, two thematic units were created and revealed the impact brought about by CKD and the need for hemodialysis on the lives of patients and their families.

## Life before the disease

Before the disease, life was filled by the typical chores of an active, independent and responsible person, a family provider. Independence, freedom, and physical disposition were elements that were part of the life before the disease; as for health problems, they did not exist or did not have priority in their daily lives.

Work had a central place in people's daily lives and was consistent with their possibilities, their geographical context and the demands of their families. Working used to confer a sense of freedom and power, especially when involved activities developed in the countryside: *I used to work in the countryside, we lived in the countryside, and my profession was to work as a cowboy, in the farm ... riding a fighting bull, a horse* (P1). As small landowners or employees of rural properties, generally outside the capital, they worked in a system of family labor, performing all kinds of activities related to planting, caring and management of animals, extraction of wood and everything else that was necessary for the maintenance and preservation of the family business. As it is typical of field work, the activities usually involved heavy work; they took long journeys, almost from the dawn to the sun set, and required a lot of physical vigor and disposition: *then he was employed on a farm. I went there, but it was 5 km from the roadside. And it was heavy, it was in the field, he would carry weighty stuff ... we would go to the field, and do everything!* (F1). *He worked in the*

*countryside, used to cut wood with a chainsaw* (P6). Besides the work in the field, the work activities included occupations in the industrial sector; despite such full day of activities, there were no difficulties, and physical vigor was evident: *I used to work hard, I would get up at four o'clock in the morning to work and arrive at ten at night every day, from Sunday to Sunday, I had no difficulties with myself. When it was time to leave at 5:00 PM, the boss in charge used to ask who wanted to work overtime, and I always stayed, I would only leave at 9:00 p.m., and I would only get home at 10:00 p.m., because my house was far away. I had much energy; I could not stand having nothing to do* (P9). Therefore, a working and untiring life and without limits was the way how patients and their families used to feel before the illness.

## Life invaded by the disease

It is in this context of life that the initial symptoms of CKD emerge. When these were manifested, they were usually attributed to some fatigue resulting from the intense work they performed, or went unnoticed, or considered as a minor and irrelevant issue, at least at that time. They could not stop their lives to care for something seemingly unimportant.

To the extent, they faced every day life, the symptoms of the disease arose, but they were interpreted by the patients as something that could not kill them, thus, not a reason for concern. Despite their feelings that something was different in their physical condition and vitality, they would not mention this, and would or postpone the doctor's appointment. The idea that something could be wrong with their health would go against their self-image, and therefore they did not complain or bother to investigate signs of changes in their health: *I began to feel some pains in my hip and my wife would urge me to go to Macapá, for me to see a doctor. But I'd say, 'No, that's nothing, this is not for me', because I was of that type, brave in my job, you know. For me, nothing could make me wave here and there* (P1). *He did not say anything; he did not complain about*



anything, he never complained about anything. The exams he did began to show many problems. The doctor was warning him, but he did not care ... (F8). But a few days ago, I was feeling a bit tired, you know, but I did not take it seriously ... I thought it was because of work, something I had done, I would wash the clothes and feel very tired. Then I would say, 'No, this is nothing'. I imagined it was nothing. Then I could actually even feel something, but I did not take it into account, I let it pass, I did not take any tests... (P13). In this way, the context of an active, independent life brimming with physical disposition began to be threatened. Some symptoms, previously unnoticed or neglected, progressed, got exacerbated and gained amplitude, interfering in or even making it impossible to carry out daily work and daily activities without any impediment: *I began to enter a process of swelling, my whole body swelled, I started to have orientation problem, I started to lose consciousness (P3); I had trouble getting around to certain places, because I could not even walk, because my kidneys were in pain. I could only walk if there was a car, it was not even because of the sight, because the lack of vision also disturbs, but it was because of the kidneys, when I walked, they would hurt, and I would feel tired (P4).*

Therefore, due to the silent nature of CKD in its early stages, along with the lack of preventive health behaviors, the disease progresses over time unnoticed. As health problems start to exert a greater impact on the patients' daily lives, they could not be ignored any longer. The situation becomes unsustainable, requiring attention and care. The search for health care for the purpose of maintaining or restoring health becomes, therefore, a priority: *my wife took me to the hospital, I spent four days in the hospital. In those four days I was debilitated, you know? So they requested my transfer to Macapá (P11).* The series of health problems that affected the patients culminated in the definitive diagnosis of CKD: *he did that exam that detected that he had only 15% of the functioning of the kidneys and there was also an ultrasound that detected*

*that his both kidneys were already withering, compromised, and it was already time for him to start doing hemodialysis, immediately, before lost everything (F8) ... I spent five days in coma, when I woke up I had already a catheter in my leg. I had a hemodialysis machine in the ICU and dialysis there. After two days, they took me to the infirmary and gave me the information that I would have to continue doing hemodialysis (P6).* The shocking reality of initiating dialysis shows how such a treatment has the potential to shake people. Regarding the behavioral aspect of how patients and their families were affected by this situation, there was a variety of distressing feelings: *it was a very difficult situation for us, the whole family was impacted. My mother-in-law was so shaken by her son's illness that, in fact, it looked as if she had aged about ten years when she heard the news. She was in a very painful state to this day. Because sometimes you think you're strong, but you're not. (F2). The whole family was very sad, because nobody expected this, that he would end up like this, depending on a machine (F15). For me, it was a shock ... Because I did not accept it. I saw the suffering of the person there, so I did not want to accept it, I did not even want to let them do the fistula (P6).*

Concomitantly, the way of perceiving or interpreting the diagnosis of CKD was even more desperate, due to the previous coexistence with the family member who now experienced hemodialysis because of the renal disease. Putting oneself in the other's place would trigger emotional reactions, what is strongly suggested by the knowledge of the condition previously experienced by others. For this reason, the perception of the dialysis treatment experienced by other person inevitably burst into the concept of pain, invasive procedures and the finitude of life: *everyone fell into despair ... because we already had an uncle of her who had died for a kidney problem, so we were already aware of the routine. She especially because she lived with the uncle who was a chronic renal patient, she worked in his house. So we already had an idea of what was involved*



(F13). *I was desperate, because it's one thing to see someone doing hemodialysis, and another is seeing oneself one day in that same situation. The only think I thought was that I was going to die, because my uncle had died from this... and my youngest son was only one year old. So I cried a lot. My God! Why me? So many bad people in the world, why did this happen to me?* (P13). In that direction, the emotional and social impact of CKD on patients and their families is unquestionable, challenging them to deal to a lesser or greater extent with many stressful and adverse circumstances.

## Discussion

To identify the impact of CKD on the lives of patients and their families, it was necessary to understand how their lives were and the perception they had of themselves. **Life before the disease** portrayed the peculiarities of the lives of patients and their families before CKD, revealing that life and family roles had their own habitual dynamics, based on a healthy family functioning, in which work represented the central focus of their motivations. In several areas of knowledge, studies have shown that, throughout the civilization process, work holds an important place in society, as it is one of the main scenarios in human life, intervening in its insertion in society, demarcating spaces of social mobility and representing a constitutive factor of the identity and sense of accomplishment of people.<sup>(17,18)</sup> Furthermore, employment during productive ages is an important factor that influences the quality of life.

Nevertheless, there is a complex and multifaceted relationship between work and health;<sup>(19)</sup> when work activities are carried out under strenuous or inadequate conditions, this may result in damage to health and reduced ability to work. Considering that disease prevention is guided by actions to detect, control and mitigate risk factors,<sup>(20)</sup> in this study, the sense and meaning attributed to work, which was to provide for family demands, led the manifestations of the disease to be neglected, as well as the search for preventive medical care.

The advent of the CKD, as explained in the theme **the life invaded by the disease**, integrated the first signs of an illness that was progressively expressing signs and that culminated in the diagnosis of irreversible deterioration of renal function. In view of this reality, the need for hemodialysis was an imposition that could not be changed, at the same time that it represented the only alternative for prolonging the patients' lives. At this stage of the experience, reactions to diagnosis and treatment emerged quite expressively, revealing intense suffering, as a source of stress and repercussions that affected the emotional, personal, family and socioeconomic life, and that required the incorporation of new habits and the adaptation of family in roles. Despite scientific and technological advance in recent decades, the psychosocial burden generated by CKD to patients and their families is significant. They face the situation of having to live with a serious and persistent condition, with cumulative effects and multiple factors of stress,<sup>(21)</sup> that make the adaptation to a chronic disease a complex process.<sup>(23)</sup>

It should be noted that the symptoms and complications associated with chronic health conditions are often unpredictable and trigger changes of physical nature, as well as in the daily life of patients. Individuals need to find ways to deal with CKD and with all the changes and limitations caused by the disease.<sup>(23-25)</sup> Thus, the interaction established through listening and welcoming from the part of the health team represents an important factor to assist the coping of the and the family and the acceptance of the treatment, promoting more security and emotional stability for chronic renal patients and their families.

## Conclusion

This study identified that the diagnosis of CKD and the need to undergo hemodialysis were seen as an experience that generated intense suffering, affecting the daily life of the families as a whole and causing physical, psychological and social damages. In this context it is notable that when CKD affects a family member, the family unit

requires attention for the proper functioning and readjustment of all. For this reason, identifying the impact of CKD on the life of patients and their families brings into discussion other dimensions of care not only related to the pathophysiology and its control, but also to help the family deal with the disease, accept the limitations, adhere to treatment, adapt and carry on life in a positive way. It should be emphasized that in this study the data are based on patients' and family members' reports in a specific context, and there is therefore a need to expand the research to other geographical contexts.

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