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REPERCUSSIONS OF CHRONIC KIDNEY DISEASE ON THE LIFE OF A PERSON UNDERGOING DIALYSIS TREATMENT

Repercussões da doença renal crônica na vida da pessoa em tratamento dialítico

Repercusiones de la enfermedad renal crónica en la vida de una persona en tratamiento de diálisis

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RESUMO

Objetivo: analisar as implicações da Doença Renal Crônica na vida de uma pessoa em tratamento dialítico. **Método**: estudo qualitativo realizado por meio de entrevistas com pessoas com essa condição atendidas em um serviço de hemodiálise; os dados foram submetidos à análise de Bardin. **Resultados**: a perda crônica da função renal tem impactado diversos aspectos da vida de uma pessoa, além de alterações fisiológicas, incluindo sua autonomia e inserção nas atividades profissionais. Mudanças nas relações corporais e emocionais são relatadas com desconforto; a repercussão familiar reflete os ajustes necessários a esta nova condição. **Conclusão**: a vivência das perspectivas do processo de adoecimento crônico por insuficiência renal adquire contornos singulares pela história de vida, pelo apoio familiar e pela assistência a que a pessoa tem acesso. O conhecimento das necessidades de saúde pode subsidiar a produção do cuidado com vistas à ampliação do apoio às adaptações à doença.

DESCRITORES: Insuficiência renal crônica; Doença crônica; Diálise renal.

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ABSTRACT

Objective: to analyze the implications of Chronic Kidney Disease on the life of a person undergoing dialysis treatment. **Method**: qualitative study carried out through interviews with people with this condition treated at a hemodialysis service; the data were subjected to Bardin analysis. **Results**: chronic loss of kidney function has had an impact on several aspects of a person's life, in addition to physiological changes, including their autonomy and insertion in professional activities. Changes in body and emotional relationships are reported with discomfort; the family repercussion reflects the necessary adjustments to this new condition. **Conclusion**: the experience of the chronic illness process due to renal function failure acquires unique perspectives outlined by the life history, family support and assistance to which the person has access. Knowledge of health needs can support the production of care with a view to expanding support for adaptations to the disease.

DESCRIPTORS: Renal Insufficiency Chronic; Chronic disease; Renal dialysis.

RESUMEN

Objetivo: analizar las implicaciones de Enfermedad Renal Crónica en la vida de una persona en tratamiento de diálisis. **Método**: estudio cualitativo realizado através de entrevistas personas con esta condición atendidas en servicio de hemodiálisis; los datos fueron sometidos al análisis de Bardin. **Resultados**: la pérdida crónica de función renal ha impactado varios aspectos de la vida de persona, cambios fisiológicos, incluyendo su autonomía e inserción en actividades profesionales. Se reportan cambios en cuerpo y en las relaciones emocionales con malestar; la repercusión familiar refleja los ajustes necesarios a esta nueva condición. **Conclusión**: la vivencia del proceso de enfermedad crónica por insuficiencia de función renal adquiere perspectivas únicas delineadas por la historia de vida, el apoyo familiar y la asistencia a que tiene acceso. El conocimiento de las necesidades de salud puede apoyar la producción de atención con miras a ampliar el apoyo a las adaptaciones a enfermedad.

DESCRIPTORES: Insuficiencia renal crónica; Enfermedad crónica; Diálisis renal.

INTRODUCTION

Chronic illness produces broad and varied changes in the lives of people and their families, with repercussions in different aspects and dimensions. The lived experience is not limited to the duality of good or bad, adequate or inadequate; it is also related to a movement of search, resignification n and new approaches to re-existence in a new condition.[1]

In turn, Chronic Kidney Disease (CKD) consists of the final stage of a process of structural and functional lesions in the kidneys due to various etiologies that include some chronic diseases and interventions carried out in health care.[2] A recent study examined the viral nucleocapsid protein in the kidney of post-mortem patients and found that SARS-CoV-2 viral antigens accumulated in the renal epithelial tubules, suggesting that SARS-CoV-2 directly infects the human kidney, leading to renal dysfunction and contributing to viral spread in the body.[3]

It causes physiological changes that manifest as increased volume of fluid in the systemic circulation, albuminuria, hematuria, leukocyturia, hydroelectrolyte disorders and acidobasic. Other associated complications include: anemia, hypertension, and hypertriglyceridemia.[4]

This condition implies the need for renal replacement therapy (RRT), which consists of artificially cleansing the blood to remove renal wastes. However, CKD affects not only organic systems, but also several dimensions of the life of the person, their family and other participants in their life. These effects are subjectivized from the perspective of those experiencing them and can be perceived as reasons to resign oneself to living in this new condition, but they can also be perceived as obstacles to the necessary adaptations to this condition.[5]

Once installed, CKD produces implications in different aspects and dimensions of life at any time from diagnosis to the initiation of RRT.[6] In this sense, adaptation to chronic illness consists of a process whose interpersonal variation is associated not only with the disease itself, but also with personal characteristics, the intensity of family and social support, and health services.[7]

Therefore, considering the specificities of the chronic illness process and the contexts of the life of the person with CKD (familiar, assistive, professional and affective), it is understood that the experience of the impact of CKD is subjectivized in care demands.

Although there are several studies on the subject, it is necessary to develop research that broadens the understanding of the changes imposed on the lives of these people in order to subsidize the production of health care. This study aimed to analyze the impact of chronic kidney disease on the lives of people on dialysis.

METHOD

This qualitative study was conducted in the municipality of Mossoró, State of Rio Grande do Norte, between August and October 2022. The participants were 36 people diagnosed with CKD, aged between 18 and 77 years.

People aged 18 years or older with a diagnosis of CKD and who had been on renal replacement therapy for at least one month were included. Individuals on dialysis for acute renal failure, those unable to provide their own history, and those diagnosed with hemodynamic or metabolic instability were excluded.

Data were collected through a semi-structured interview developed in the premises of the service where people had access to hemodialysis and later subjected to Bardin's content analysis. The study was approved by the Research Ethics Committee (CEP) of the State University of Rio Grande do Norte (UERN) with protocol no. 5.505.823 of 07/03/2022.

RESULTS AND DISCUSSION

The impact of CKD on people's lives was grouped into 4 final categories: impact of CKD on the person's life; physical changes related to CKD; changes in affective relationships; and impact on family life.

Impact of CKD on the person's life

The lifestyle of a person diagnosed with CKD is significantly affected in terms of eating habits. The difficulty in adapting to this change may be related to the denial of the disease itself. This can be explained by the fact that the individual goes through several stages of accepting this condition, that is often difficult to accept and understand, which affects adherence to treatment.[8] For a participant:

> *[...] Life stopped, it didn't just stop my kidneys, it stopped my life. I don't go out anywhere, I don't want to go anywhere, I live inside the house, it's from here to home, that's it. I come home and lie down, I spend the day lying down, I get up and sit on the sidewalk, I lie down... It's like that every day of my life, not before, before I was a happy, cheerful person, because I walked, I went everywhere, today it's over... (P18, 53 years old).*

The sudden changes in life have a direct impact on the way of coping, on the acceptance or not of the state of chronic illness. Thus, coping is characterized by the elaboration of cognitive and behavioral strategies used by individuals to control the internal and external demands inherent in the proposed treatment.[9] For P14:

> *Oh, it changed a lot... Before I went out alone, I went out to go to church, to solve one thing or another, and after the disease really got worse, I spent a long time without being able to go out alone, I only go out when I am taken... so this is very limiting, right? (P14, 55 years old).*

Chronicity, the care trajectory, the limitations and the changes imposed on the lives of people with CKD and those around them are aspects that have a direct impact on life according to the meaning attributed to them.[10] As the following report illustrates:

> *It has changed, it has changed because in social life I think I used to travel a lot with friends, I used to... work, for a restaurant, although I don't drink now it's more restricted because I have to take care of myself more (P7, 50 years old).*

One of the changes that most affected the lives of the respondents was the loss of freedom and autonomy they had previously enjoyed. The need to undergo hemodialysis at least three times a week, for 3 to 4 hours per session, makes it impossible or difficult to engage in other activities, leading to feelings of restriction, dependence and fragility, as reported below:

> *It's very sad ... because now I don't have the freedom to go anywhere, my children live far away, I want to go and I can't ... There must be a clinic there to do it, then it becomes very difficult, right... (P5, 68 years old).*

For the youngest, the changes suffered in their social life led to a feeling of loss of freedom, not only because of the routine established by the hemodialysis sessions, but also because of the perception of an incompatibility with the form of socialization with other people of the same age. Dissatisfaction with the perception of these changes can be seen in the following statements:

> *I used to go out a lot, go out and talk to people. I talk about it, but it's not the same as what I did before, because I liked... I'm not going to lie, I liked to drink, I liked to go out, enjoy, party, but nowadays I don't do that anymore, that was the change (P4, 23 years old).*
>
> *I I started going out after about 8 months that I was doing hemodialysis, that's when I started walking again. So, friends, leaving home... I was depressed, I don't know, I almost got a depression because of it, but thank God I didn't (P20, 28 years old).*
>
> *So, I moved away from some people because I have to go out less now, right? I don't like to go out and I don't feel good on dialysis days. I drink a lot less, right, I did not drink for 2 years and I started drinking again recently, because anyway, right, I can drink distilled. (P36, 24 years old).*

Due to the new routine established by the dialysis treatment and the health condition itself after the diagnosis of CKD, some difficulties are perceived regarding the employment in a formal job. Thus, in many situations, people are forced to quit their jobs and seek the rights guaranteed to them by social security, as mentioned below:

> *Yes, I worked... today I am retired due to disability for 10 years, because of the problem (P13, 31 years old).*
>
> *[...] Today I don't work anymore, I don't lift weights, I only go from here in the hospital to home and school (P12, 18 years old).*
>
> *I suffered because I stopped my activities and started to pay only, and when what we earn is already little and we have to share it with the worker, with the service [...]. I am no longer willing to work [...] (P14, 55 years old).*
>
> *I used to work, now I can't work anymore. [...] Today I live from my retirement; I have managed to retire. [...] (P19, 40 years old).*
>
> *Well, I can't get a job, it's more difficult because I have to be absent 2 to 3 times a week, so being employed is a delicate thing. So I have to go more towards self-employment [...] (P36, 24 years old).*

In addition, there is the cost of medication that regulates the production of some hormones previously produced by the kidney, which are responsible for regulating blood pressure, producing red blood cells and strengthening bones.[11] Therefore, as reported below, giving up work and increased expenditure on medication are the main factors that affect financial life:

> *The illness is like this, I buy, as it's called... the AAS and the pressure pill, because now I take it, I didn't take it before (P12, 18 years old).*
>
> *It has changed that I earned more, right?! [...] You have to be well controlled, because if you don't have precision... I buy medicines... (P19, 40 years old).*
>
> *We suffer, right? Because there is the heart medication that I take, there are several medications, there is the routine, you know, on a daily basis, we have small children... (P24, 36 years old).*
>
> *I didn't, because I don't work, I was studying. Only with the new anticoagulant, Apixaban. And also with food, it changed a lot (P34, 22 years old).*

The impact also extends to the need to perform the necessary tests to be in pre-transplantation condition; most of the time, these tests are performed outside the patient's city of residence. Since the SUS finances about 95% of the transplants performed, patients with health insurance or better financial conditions are able to keep these tests up to date and remain active on the waiting list longer, thus increasing their chances of receiving a transplant.[12] The lack of support from SUS also has an impact on the quality of the transplants performed.[12]

In these cases, the lack of support from public institutions means that the costs are borne by the individual and his or her family, as the following statements show:

> *It has changed because you spend a lot of money, right? You spend on consultations, you spend on tests, you spend on medicine [...] (P29, 59 years old).*
>
> *Yes, because you are not prepared anyway, right? You come from a poor family, right? You don't have a fixed income, right? (P32, 32 years old).*
>
> *Today I have more expenses with medicines, before I didn't spend on them, I didn't do tests, I didn't take care of my health in relation to it, it wasn't very present in my daily life, and now there is this. In addition to traveling for consultations, for example, before the transplant. So, it has had a financial impact, yes (P36, 24 years old).*

As for the diet of people with CKD, it is recommended that it be high in protein and low in phosphorus and potassium, so they have to avoid certain foods. Regarding fluid intake in general, if the person still urinates, it is limited to 500 ml per day added to their urine volume in 24 hours. If you do not urinate, your daily fluid intake is limited to about 500 ml.[13]

As a result, people with CKD must make changes to their diet and fluid intake, which presents many challenges, as evidenced by the following declarations:

> *I have a strict, rigid diet that I drink little water, I drink little liquid.... I drink two sips a day (P1, 77 years old).*
>
> *Now I say it like this, it's not everything, I analyze more or less, those foods that offend me I won't eat, right. Let's say shrimp, I won't eat shrimp, crab, I won't eat it. [...] I drink little water, all my life I have drunk little water (P2, 77 years old).*

I've changed some eating habits, yes, but it's... There are still a lot of things that I have to give up, but I haven't been able to, you know... I feel it because it's my culture, you know, I come from the culture, it's like, from the outback, and we have this business, we have to eat "mocotó", these things, you know?! (P3, 27 years old).

I don't follow the diet here for food, I eat everything. [...] No, water, water I can't miss, water for me no. For me it's only 1 liter a day, but I drink more (P4, 23 years old).

> *you feel very thirsty, without being able to drink water, when you drink, you come here heavy... anyway, this is very difficult. [...] No, I don't eat like I used to, so I don't get too thirsty, but when I realize I'm already drinking too much... (P14, 55 years old).*

It can therefore be observed that, when it comes to adhering to the dietary plan and water intake, some people resort to personal strategies to alleviate their needs and control their desires, which in a way favors the treatment. Restricting water intake is shown to be one of the greatest adaptive barriers:

> *I still haven't gotten used to the water, there are days when I get thirsty... so I don't drink too much water because you can't drink it, you know, then I put a candy in my mouth, a Brazil nut, something like that, you know, to get rid of the thirst (P1, 77 years old).*
>
> *Little water, only with medicine. Juice, if you have to choose between a glass of juice, you will reduce it already in the water of the medication (P19, 57 years old).*
>
> *[...] When I drink a juice, I don't drink water, I just drink the juice, and I reduce the food when I'm dry, I reduce the food and go and drink this little water, but I only drink water in terms of what I see I can drink (P22, 54 years old).*

physical changes related to CKD

Some physical changes were mentioned, especially body weight and skin characteristics. Although scarring from the arteriovenous fistula is a factor to consider for many, others do not identify it as a significant change:

> *At the beginning of dialysis, I think after about 5 or 6 months of dialysis, I started to feel that my skin was very dry, it was very dry... (P7, 50 years old).*
>
> *Yes, the change was that I lost a lot of weight, right? I lost 14 kg. [...] I take heparin here, sometimes a spot appears on my body, a red spot (P8, 59 years old).*
>
> *It has changed because when I came here I was a little bit fatter, I weighed what, about 90 kg, today I have managed to establish my weight at 78,500, so it has changed a lot (P13, 31 years old).*
>
> *Only when I leave here, I feel very dry, dry skin. Because I come here very heavy (P15, 30 years old).*
>
> *My skin is all stained, I have allergies, I have this thing here on my legs, I don't know what it is, this black thing that I didn't have on my body, I didn't have that... (P18, 53 years old).*
>
> *After you start hemodialysis, it is... The change, the person realizes that everything was swollen. I weighed 90 kg, today I weigh 73,5kg. The skin has changed, because of the skin that was swollen, it becomes scaly like this, the person's skin changes (P20, 28 years old).*
>
> *I notice that it became dry, sometimes I say 'I know I'm 54 years old but it's wrinkled', it's wrinkled, it's like passion fruit, when it's young it's one thing (P22, 54 years old).*
>
> *[...] I weighed 78 kilos, I weigh 71, with time you get smaller, your eating habits get smaller, and I already think I'm older than I am because my body is not the same as it was (P29, 59 years old).*
>
> *I have become more anemic, right? There are times when my anemia is more severe, and then my skin becomes more yellow, paler. [...] I lost weight. I have lost more than 10 kg since I started the treatment, but I also suffer from the yo-yo effect. So sometimes I gain weight, 1 kg, 2 kg, then I lose it again... (P36, 24 years old).*

The lack of physical fitness after dialysis is also seen as a physical change, especially among older people; there are also reports of hair loss, skin discoloration and decreased libido:

> *So, I just think I'm weak, the day I do dialysis I spend the afternoon weak, sometimes nauseous, the next day I'm back to normal (P14,* 55 years old).
>
> *I feel very sedentary, a lot of time off, lack of exercise... today I get tired more easily (P15, 30 years old).*
>
> *The body has changed, it has changed a lot, because every little thing we do makes us tired, we feel tired, we can't drink much water... (P19, 40 years old).*
>
> *My hair is falling out more, my libido is very low... it went down after I started the treatment (P36, 24 years old).*

Changes in affective relationships

Given the context in which they are placed, the physical changes, the state of chronic illness that requires strict treatment, and the need to adopt new life habits, people with CKD experience changes in affective relationships. The most emblematic is the difficulty of finding a partner who accepts their disease and the difficulty of maintaining the relationship after the diagnosis. There are several reports on this:

> *I was a bit lost, right, because I thought the world was going to end, so I started dating, being with one and other... (P3, 27 years old).*
>
> *Everything changed because when I got sick, the woman left me. That changed my life completely (P8, 59 years old).*
>
> *My husband left me when he found out. It was from the beginning of the disease, when I started to swell, he started to treat me very badly. Then I went to Tarcisio, I checked in, then he made up a trip... what a trip it was, then he called... He didn't show up anymore, he said it didn't work anymore. It ended on the phone, you know? (P27, 55 years old).*
>
> *I was married, now I'm separated. Lots of problems, the disease too, a bit (P31, 36 years old).*

> *At that time, I was together, but now I'm not, because the person I was with left me in this situation, because it's not easy, you know... it's not easy for those who are doing it, especially those who are standing around providing care. (P32, 32 years old).*
>
> *Yes, it's much harder to introduce yourself to a new person. There's always this thing, in the beginning it's something to give satisfaction of where I am and I don't want to say I'm in the clinic, I don't want to introduce all that part, one more thing... 'I have this, I've been on dialysis for a while, I spend so much time doing this', so it was more difficult, it was (P36, 24 years old).*

Impact on family life

Chronic illness is usually accompanied by feelings of grief and pain, and can also lead to various changes in the daily lives of individuals and families.[14] Given the changes in the daily lives of people with CKD, relationships and family dynamics have changed, implying a reorganization of responsibilities and functions. At the same time, there is a sense of distance between family members and a sense of closeness through the care provided by family members, as illustrated by the following statements:

> *I couldn't help my daughters the way I used to, because they go to work and when they arrive, they have to do everything, and I had this taste, this pleasure that when 'they arrive' I do everything... (P1, 77 years old).*
>
> *In family life, more care, care was doubled, let's say... [...] For me it was more attention, it was tripled, let's say, you know! (P6, 42 years old).*
>
> *I have a very good support network, you know? Both my son, my husband, my brothers, my mother, they accept it, there was no conflict about it or anything, on the contrary, they support me in everything. (P7, 50 years old).*
>
> *Then when I got sick, he stopped working to take care of me and stay with the boy, because my boy was still little when I got sick (P9, 30 years old).*
>
> *[...] there was so much change and it was for the better, for the better because sometimes the attention that I didn't have because my life was very busy, everyone goes to work, another one goes, comes, no one even saw each other and now there is more contact (P21, 57 years old).*
>
> *So, it changed my life because we can't go out anymore, we can't, one day we don't have to be here, then it changes, life changes a lot. [...] it changes our life completely, it's a different life (P23, 36 years old).*
>
> *I got closer to my family, who I was a little estranged from. Then this thing, everyone is supporting me anyway, they want to know how I am... I also got closer to my mom, the relationship with my dad changed, so there was also an overprotection, exaggerated, there still is. I went from being such a person, more independent, to being very dependent in the eyes of my parents (P36, 24 years old).*

Although the family is also affected by this process, it is usually the family that is responsible for alleviating the person's experience by providing emotional support; family support is seen as comforting and hopeful.[15]

Chronic illness brings about relevant and permanent changes in the family's daily life, which can lead to structural, affective and economic changes. The need to change lifestyles, combined with cultural factors, in favor of new habits that are considered healthy and beneficial for chronic illness, creates conflicts in some situations, even when the reason for the changes is proven to be adaptation to a new condition.[15]

CONCLUSION

The process of chronic illness due to renal failure has had an impact on the person's life, physical changes, affective relationships and family life. The experience of this process acquires unique perspectives outlined by the life history, the family and the care support to which the person has access.

Awareness of these implications is fundamental to organizing health care that takes into account the care needs of these people, according to their passage through the different assistance levels. From the perspective that it is not only about organic and functional changes, but also about implications in the way of living and relating to other people.

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