Revista
ARACÊ
ISSN: 2358-2472

SOCIAL SUPPORT: PERCEPTION OF THE PERSON UNDERGOING HEMODIALYSIS TREATMENT

https://doi.org/10.56238/arev6n4-351

Submitted on: 11/20/2024 **Publication date:** 12/20/2024

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ABSTRACT

Chronic kidney disease manifests itself when the functional unit of the kidneys fails to perform adequate filtration of the blood and subsequent excretion of metabolites, which causes the accumulation of substances that are not necessary for the body. The treatment of renal failure represents a public health problem of great magnitude and relevance, especially when its complexity, risks, diversity of options and cost are recognized. Social support for people living with a chronic disease is an influential factor in the acceptance of the diagnosis and consequent adaptation to treatment, however, it is worth noting that this support is considered subjective and will depend on personal conceptions, as well as on

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pre-established relationships in their life. In view of the above, this study aims to understand the perception of people with chronic kidney disease undergoing hemodialysis about social support for adaptation to the disease and treatment. And as specific objectives: to know the social support network of the person undergoing hemodialysis treatment; and to identify potential sources of social support to be used by the person undergoing treatment. This is a qualitative study with an exploratory approach, carried out in a dialysis clinic in the interior of northeastern Bahia, which had 17 participants. Data collection was carried out from January 10 to 24, 2024, with a semi-structured interview script and the data were treated according to Bardin's content analysis. Categories: dependence and limitation in the lives of people on hemodialysis; the family as the main perceived social support; kidney transplantation as a support to live better. With this approach, it was possible to identify sources of social support that are still unexplored or little explored by this specific group, demonstrating the care approaches, the social aspects involved and how they can contribute to hemodialysis therapy. It is considered that the family represents the greatest source of social support for the people who responded to the survey. This study reiterates the importance of raising subsequent discussions in the academic environment, bringing evidence of the results obtained in order to favor transformations on the subject. The research was approved by the Research Ethics Committee under No. 6,448,518.

Keywords: Hemodialysis, Perception, Social Support.

INTRODUCTION

Chronic Kidney Disease (CKD), a clinical manifestation that imposes specialized and continuous care, which includes not only the sick person, includes the participation of family members and/or support network as essential social support linked to home care routines and follow-up in Renal Replacement Therapy (RRT) units, together with the health team responsible for the care of patients undergoing hemodialysis. That is, it means living with a range of negative aspects and functional dependence, in addition to necessary adaptations and the explicit threat of the possibility of dying.

According to Cockwell and Fisher (2020), the prevalence of CKD in the world is 9.1%, which corresponds to about 700 million people, resulting from various causes. There is a worldwide trend towards an increase in the number of patients on dialysis, as well as in prevalence rates. Neves et al. (2020) showed in their study that in 2018, about 133,464 people were on dialysis in Brazil, and add that the absolute number of patients and incidence and prevalence rates increased substantially in the period from 2009 to 2018, although there are considerable differences in the rates by state. During this period, there was a progressive increase in the number of patients prevalent in dialysis programs, corresponding to an average annual increase of 5,587 people in treatment.

According to the Brazilian Society of Nephrology (SBN), Chronic Kidney Disease (CKD) manifests itself when the functional unit of the kidneys, the renal glomeruli, fails to properly filter the blood and subsequent excretion of metabolites, which causes the accumulation of substances dispensable to the body. With kidney malfunction, the sick person begins to manifest characteristic signs and symptoms, including intense pain that turns on the warning sign to seek health services and after due investigation and confirmation of the diagnosis, care at RRT is immediately initiated (Brazilian Society of Nephrology, 2021).

RRT consists of performing the function of the kidneys when the organ can no longer perform these functions satisfactorily, being a complex therapy that requires the participation of the sick person, specialized professionals and the family. Given the complexity of treatments, people with chronic diseases face daily challenges, either due to the difficulty of access to health or due to factors involving adaptation, family support and welcoming society (Brasil, 2014). Along with the disease, doubts and questions may arise, often associated with little or no knowledge about the disease, difficulty in adaptation, exacerbation of symptoms due to the lack of intervention, among other possible inclement weather that reflect on the difficulty of adherence to treatment.

Adherence to treatment and change of habits is one of the main obstacles, being directly related to the type of treatment that the person will undergo, and consequently becomes a risk factor for the aggravation of CKD. Currently, there are three types of treatment available for kidney failure, peritoneal dialysis, which is less conventional, hemodialysis, corresponding to 92.6% of people undergoing treatment, and kidney transplantation, considered the most effective option, according to the Brazilian Dialysis Census (Nerbass, 2020). Generally, hemodialysis (HD) lasts an average of three to four hours and is performed three to four times a week. To start the treatment, it is necessary to insert a central venous catheter (CVC) and/or an Arteriovenous Fistula (AVF), allowing the vein used to be more caliber to provide adequate blood flow (Madeiro et al., 2010).

In this context, investigating the theme from the social perspective becomes relevant, as it evidences the perspective of the sick person in the face of the feeling of seeing themselves in society as an individual with a chronic disease who needs specialized support, access to health, study, work, religion and social experience.

In view of the above, the following questions arose that guided this study: How is the social support network presented in the perception of the person undergoing hemodialysis treatment? What sources of social support are not yet fully explored by people on hemodialysis?

The general objective is to understand the perception of people with CKD undergoing HD about the social support for adaptation to the disease and treatment. And as specific objectives: to identify the social support network of the person undergoing hemodialysis treatment; and to identify potential sources of social support to be used by the person undergoing treatment.

METHODOLOGY

This is a qualitative study with an exploratory approach. Data collection was carried out in a HD Unit located in a city in the state of Bahia, in the northeastern region of Brazil. A total of 17 people of both sexes undergoing hemodialysis treatment were interviewed.

The sample was non-probabilistic and intentional, and was selected according to the perception developed by the researcher during the technical visits previously carried out at the unit. The participants were presented with the theme, objective, importance of participation and the possible contributions of the study.

The inclusion criteria were: people over 18 years of age, who had been performing HD for more than 06 months, the time considered for adaptation inherent to the treatment, and who expressed interest in the research during the visits. And as an exclusion criterion: people who, at the time of data collection, presented hemodynamic changes (malaise, hypotension, hypertension, etc.) that prevented them from participating in the interview.

Data collection was carried out from January 10 to 24, 2024 and a semi-structured interview script was used as a collection instrument. The semi-structured interviews were carried out using a previously prepared research instrument with a flexible approach and margin for the interviewee to expose their perception of social support in HD. The procedure was aided by a recorder so that it was possible to analyze the speeches later in detail.

After the invitation, the participant was explained the theme, with the objectives and importance of the research, and possible doubts were resolved. Next, the Informed Consent Form (ICF) was presented, which was signed by the participants.

Data treatment was carried out with Bardin's (2016) content analysis to estimate the participants' conceptions of perception. The main objective was to extract information for a theoretical basis focused on the perception of the person undergoing hemodialysis treatment. It should be noted that the research was submitted to the evaluation and approval of the Research Ethics Committee (CEP) of UEFS according to opinion No. 6,448,518.

RESULTS

This study had the participation of 17 people who had been on hemodialysis treatment for more than 06 months and who agreed to participate in the research. The mean age of the participants was 55 years and there was a predominance of males. Among the participants, the shortest treatment time was 6 months and the longest time was 12 years. Regarding preexisting diseases, SAH was considered the disease that most triggered CKD, considered the main risk factor. The study participants were collaborative throughout the interview process, which facilitated data collection.

Changes related to food are strongly present in the statements of the study participants, some report having difficulty adapting to diet therapy and its restrictions, while others demonstrate that the allowed foods are often insufficient and eventually cause "weakness". The speech fragments of P3, P10 and P11 address this aspect.

> [...] The diet that changed, I wanted it to go back to what it was before. [P3]
>
> There's nothing to do, you get thirsty, you can't drink water, you're hungry, you just stay there in the beans, you can't eat anything else, so in the meantime you exaggerate, but the effect doesn't come at the time, it comes later, if you repeat it within the month, two, three times [...] a mistake like that gives you a problem, you know. [P10]
>
> Food if you go with the malice of the nutritionist you die, you have to eat a little bit of everything, I've seen a lot of people die here because of that. [P11]

In some scenarios, there is disbelief in the possible harm that can arise when an adequate diet is not followed.

> [...] Sometimes I put my foot in the jackfruit and eat something, but it's normal, today I was in the mood to eat a sun-dried meat, I ate it with beans and rice, I know how I do it and that's it. [P4]
>
> [...] You have to adjust because if you eat only the things in their diet here you get weak, I eat everything myself, but then when you overdo it at home it gets complicated. [P10]

In some reported scenarios, confirmation of the diagnosis of CKD arrived in an announced and gradual manner, even with the possibility of reversal if immediate interventions were instituted. Despite insecurities, lifestyle changes, dietary restrictions, body weight control and drug therapy, the improvement becomes palpable in the face of the possibility of dependence on HD treatment, as demonstrated by P10 and P15.

> At first it was fast, I started to get swollen, I didn't drink water for days, 10 days, then the kidney started working again, then I could only take 200ml, it was just to take the medicines. Then 40%, 45% went back to work. But I still spent 15 years, but I had pneumonia and it overloaded. [P10]
>
> I had to be hospitalized and it was kind of complicated at first, I had to stay on absolute rest... I just stayed on the bed. My oldest (daughter) was the one who took care of my family, the youngest stayed with me on the bed, and I only started dialyzing 3 years and 9 months later, I was still controlling it with medication. [P15]

This scope of time between acceptance, adaptation and confirmation when there is a possibility of regression of the disease, in a way, reduces the rigidity in which the news is processed. While other participants brought the shock of receiving the diagnosis of the disease already at an advanced stage, with the need to dialyze, having to deal with all the imposed changes, with difficulties in adaptation, changes with the body and psychological load accompanied by the feeling of dependence.

> I didn't even know what that was. Then Cesár came saying, you go to the clinic to do a hemodialysis session. I thought I was going to do it and I was going home, oxe, then I stayed there, the penny only came to fall when I was two years old, then I got used to it, and when we enter here it is with one body and leaves with another because we lose weight. [P11].
> I didn't know anything, I didn't even know that there was high blood pressure, I worked with a formal contract, I traveled to stay away for a long time, that's what got in the way of me all. [P12]

The physical changes caused by the use of CVC or AVF are aggravating factors that impact the performance of daily activities such as working, not being able to apply force to the arm that has the fistula, the limitation of movement and the risk of catheter infection. These changes directly influence the work practices of people on dialysis treatment, bringing insecurities, a higher degree of dependence and feelings of uselessness, especially in the initial phase of discovering the disease and adapting the treatment, as can be seen in the following statements.

> I think it's bad that I can't lift weight like I used to, I worked, dug a fountain, cut firewood from the outside to the outside and today I don't cut anymore, I can't even cut a lot of firewood, nowadays I can't do any of that and then I get angry. Fishing, playing cast net, today I can't do it anymore. [P6]
>
> Everything changes, the work, I used to deliver on a motorcycle, I can't do it anymore, sometimes I stayed in the fields because when you reach the age you don't want to. [...] Brazil is like that, it only gives more opportunity to the modern person. Everything you did before you can't, you have to wait [P7]
>
> I worked. After hemodialysis... I do nothing, just at home [...] [P8]
>
> The main thing that changes is work, and I really liked to travel, I used to travel a lot and now [...] you can't [P10]
>
> [...] It made things difficult because we are limited, a lot of things we can't do and before we could do everything, we could work, we could do everything. [P13]
>
> Change, change... I used to do my things at home and today I depend on my daughters, I take my shower alone, I do something on the stove, but the girls don't want me to go to the stove to do anything, they're afraid of me getting burned. Then it gets hard, it gets hard, I have to wait for the girls. [P17]

Of the 17 participants in the research, 08 reported that they stopped practicing leisure activities that they performed before discovering CKD, the reports of P8, P11 and P13 stand out, which show that in addition to the lack of time and physical limitations, the discomfort when returning from the sessions makes it impossible to perform these activities.

> He liked to play dominoes, but he doesn't even have time for anything. That's all there is, doing hemodialysis on Mondays, Wednesdays and Fridays, there's just that, there's not much to do, when you get home today, you get tired, you can't do any activity. [P8]
>
> [...] I used to play ball, I rode horses, today I don't do that anymore, because we have to go back and forth the next day. I used to travel, but you do hemodialysis today on Tuesday, and Wednesday you don't do it, Thursday you do it, then you do Saturday or you do two sessions on Thursday and Friday, to have Saturday, Sunday and Monday, but Tuesday you have to be here again [...] my mother lives next to the beach, but I can't go, because to spend two days, three days [...] I want to go is to spend the month. [P11]
>
> [...] About 04 years ago I worked, then the kidney stopped and I leaned against the INSS. I used to run cowboys, but now I can't, the arm can't make any force.... It made things difficult because we are limited, a lot of things we can't do and before we could do everything, we could work, we could do everything. [P13]

From another perspective, financial stress impacts not only the life of the person undergoing hemodialysis treatment, this obstacle also influences the emotional well-being of all family members, which can lead to internal conflicts, especially for the partner that may be struggling to balance the demands of treatment with responsibilities such as work, child care, concerns about their own health, such as P7's report that mentions that his partner is facing treatment for cancer and together they live with financial difficulties on a daily basis. This can hinder mutual support, since all members of the family nucleus will need emotional support.

> What helped me was the medicines so I wouldn't buy them, you know, but you don't think so, you buy them every month when one is running out, you have to buy another one, I've looked for it and there is never the same, it's difficult. I have a son who lives there in [...] and has an average there, he has already achieved it once. [P6]
>
> [...] It's because I never saw the medicines if the government gives them. When I took another one, the pharmacy gave it but this one who passes it on to me is the cardiologist and I can't take medicine for nothing because when I discovered the disease my heart swelled [...]I hope the government looks more at people who do hemodialysis, because health, education and as you say, safety is very important. [P7]
>
> To make life easier, only if you rolled a basic food basket. Is there a way? A meal, if there was a way to get a meal, a resource to get it, would be a good thing. The city hall said that it can only get help like this if it is more than 50 km, if it got these medicines for free for me it was already a lot. [P8]

According to the data collected in this survey, 89% consider the family to be the greatest source of social support, on the other hand, there were reports of family abandonment that resulted in anguish when faced with a lack of support, and further enhanced the challenges faced.

> I was 22 years old, ignorant, like a horse, when I started to lose weight, I started to get ugly and then I was injured, I was... kicking everyone, stressed, and then my wife held on for two more years, I think she endured it too much, because at first it was difficult, and then I started to feel uglier than her and be jealous of her more than she was of me, and all this accumulates and then she couldn't stand it and separated. [P12].

In another scenario, the adaptation of the family appears as a possibility to reorganize the roles and intensify the bonds of companionship, as pointed out by P14.

> My wife does everything for me even when she can't, goes to the doctor, goes to and fro, quit her job to be with me and then today it's me and her. [P14]

The participants of this research reported that they find in the family the main support to cope with the physical, emotional and psychological difficulties generated by chronic kidney disease and treatment. This statement is evident when P1, P3, P4, P6 and P9 bring the following considerations.

> [...] at home, in the family, is where we find support, when everyone is gone, the family is the one who stays and helps at all times, it is to cling to God and ask to endure everything and trust that everything will work out the way it is. [P1]
> The children help me a lot, the three grandchildren, aged 4, 6 and 2, children help. [P3]
> The children, they are everything, they bring me here, they look for me [...] family. No group, I don't have any of that, I don't want this blah blah blah. [P4]
> The family. Just this week, someone who lives in Santo Estêvão arrived and said: oh dad, I'm going to help you. He got there and washed a lot of things, passed water on the house. This other week who goes there is the fia, spend a few days there but I, I have seven men and a girl, Until yesterday there was more me, but he left, he left the girl at home and went home to take care. I have 19 grandchildren. [P6]
> The family that helped me and has helped me since the beginning. My wife is the one who solves everything, she is the one who gives me a lot of support. [P09]

It is important to pay attention to the emotional burden that also affects family members, who often face fatigue and exhausting hours. Therefore, it is important that everyone receives support, strengthening ties and creating a network of resilience in the face of challenges, reinforce P1, P7 and P12.

> At home, in the family, is where we find support. [P1]
> If it weren't for the family, I don't know what would become of me and the woman who also does treatment here. [P7]
> The family, Hail Mary, is fundamental! Fundamental... It's our family, to be together with you at that moment when you need it, our brothers, the main thing of all, my son, my wife put up with me for 02 years, but I think she put up with it too much, the mother of my son, I think she put up with it too much, because in the beginning it was difficult. [P12]

On the other hand, only one participant mentioned friends as perceived social support, but in a specific situation of need for blood transfusion. Therefore, friendship relationships emerge in the research as a source of social support that is little explored.

> I have friends who donated blood to me when I needed it. [P14]
> The friends have all disappeared, the family that is [...] [P05]

The multiprofessional team of the dialysis unit represents an important source of support for the participants, especially because of the bond created over time, it is noticeable the creation of a bond of trust inherent to professional care. Andrade *et al.,* (2021) consider that a care relationship based on trust is essential for the patient to feel safe and follow the recommendations suggested by the health team. Many reports arise with a demonstration of gratitude for receiving quality care, for having a close team by their side, who is not only there to continue the treatment, but who integrates throughout the context, demonstrating commitment and promoting general well-being.

> The nursing technicians here are all good people, who help us, treat us well, are a source of support for us, they give the support arm, help, teach, for me before it was all in the dark, today we already know everything, know. [P13]
>
> I consider the nursing team too important, I have nothing to say, they treat me very well. To answer questions I talk to them. [P8]
>
> Note 10. They give a lot of support. They are true, they get involved with patients, they care. [P9]
>
> It's also a support because they talk to us, give advice and talk a lot, you know, we often get stressed, you know, because it's not easy to be in a machine either, we get stressed, they talk, they give support, the girls talk, they know it's difficult, it's like a family for us, that we see every day, Many times we, as they say, even say ignorant things to them, we talk about it, but it's the stress here, and they understand, then we go and apologize, because they are family to us, because we are seeing them every day. [P11]

Religiosity is present in several discourses reported as a source of support to deal with the challenges of the disease and treatment. In this context, faith in God emerged as a perceived social support, as can be seen in the fragments of speech below.

> [...] God knows us, he knows what we need and I also don't like to go too deep because there are also many enigmas in these religions, many unanswered questions, it's faith, I talk to him sometimes, I say, oh sir... And everything is fine because everything we go through today is because we have to go through because when we are born our curriculum is already ready, from our birth, from our mother's belly. [P4]
> [...] Sometimes I go to the service, but I have to sleep early. [P7]
> Support only from Jesus himself. Church?! No. And if it wasn't for the machine, dialysis, we would have already left, move on. But first God. [P13]

The transplant is desired by almost everyone who responded to the survey, of the 17 participants, only 1 reported that she would not like to perform it due to her advanced age, she believes that younger people represent a priority to receive a healthy kidney, the following score arises.

> I have everything thanks to God. Sometimes there are younger people, with life ahead of them, I've already lived everything I had to live so I don't ask for a transplant. I have my God, I have my children, there is, right. I have my wonderful granddaughters, I have my grandchildren, I take care of my health. [P4]

While the other participants demonstrate the desire to undergo the transplant to live a life without dependence on hemodialysis, as shown in the following reports.

> Doing the transplant, right... to live a more stable life. we need to go out too, right, to go for a walk, but I depend on having someone to go out with me [...] [P02]
> I wanted my kidney, the transplant, but I'm in line there, waiting... 14 years of treatment I've seen everything, I've been through everything, I've seen many friends leaving, friends from a long time who have passed away, this room here has already changed and a lot of new people have come and have already left [...] you stay... [P12]
> The question you left for the end I'll answer you like this: to improve for me? The transplant! because if you transplant, you get out of the machine, you won't depend on it [P13]
> When I arrived, I was dying, suffering, what would help me? To leave here, not to need to do hemodialysis anymore. [P14]

Among the answers to the interviews, a consensus emerged about the feeling of gratitude for the existence of a treatment that makes it possible to continue living and the bond through the machine.

> The machine pulls a lot, then we get used to it too, you know? There are days here that it doesn't even seem like I'm doing hemodialysis, you get used to it... At first it is difficult. [P11]
> We can't complain, thank God that there is this treatment, right, worse is without him. Nothing is perfect. [P12]
> And if it wasn't for the machine, dialysis, we would have already left, so I can't mistreat her and say, it's worse! Because if it weren't for her I wouldn't be here, I say, from 100 it dropped to 50%. We can't judge, because if here we are alive because of them, because of the machine, right? [P13]

On the other hand, there is another aggravating factor demonstrated by the feeling of being trapped, of having one's life limited. The changes imposed by the treatment bring this feeling, the reports state that it was necessary to stop performing habits they performed, due to the continuity of HD.

> Some habits change and I'll tell you, the person is more stuck, they can't travel to another state. There are places that still don't have treatment. Because of the delay

> that sometimes we arrive to be able to do it, to have to travel, there should be support, more clinics everywhere. [P9]
> […] I really liked to travel, I traveled a lot and now... If there was this possibility of getting a card for us and where to go to do hemodialysis, it would be very good, right, because here you are stuck. [P10]
> I used to travel, but you do hemodialysis today on Tuesday, and Wednesday you don't, Thursday you do, then you do Saturday or you do two sessions Thursday and Friday, to have Saturday, Sunday and Monday, but Tuesday you have to be here again. So it is.. We get stuck, my mother lives next to the beach, but I can't go, because to spend two days, three days, I want to go is to spend a month. [P11]

Some scores make clear a lack of prior knowledge about the risk factors for the onset of CKD. The fragments of the dialogues show this and reinforce that prevention measures need to be used at all times in low-complexity services, mainly.

> If I knew that there was this risk of stopping my kidney, I would take the medicine. [P5]
>
> I didn't know anything, I didn't even know that high blood pressure existed, I worked with a formal contract, traveling to be away for a long time, that's what got in the way of me all. [P12]

DISCUSSION

Of the main aspects that permeate the research in the perception of the people interviewed about the social support received and the impacts on health and disease, the predominance is the questions related to adherence to treatment associated with the adaptation of the imposed changes, food and its restrictive mishaps, especially in the first months, the abandonment of leisure habits and the harsh reality of being in the HD clinic 3 times a week for more than 4 hours, difficulties in locomotion and use of venous catheters, among others.

Changes in routine can cause stress and discomfort, these changes are directly linked to the expression of dependence of people who are undergoing HD treatment and who live daily with the disease and its challenges. For Silva et al. (2016), social support is a factor that facilitates coping with the disease and patient recovery, therefore, the inclusion of the evaluation of social support is essential to improve the direction of health professionals in care planning. With this implementation directed to the perception of the support received, it will be possible to detect individuals who will possibly present greater difficulties to adapt to the changes imposed by the treatment and, consequently, it will be possible to carry out the necessary interventions.

Zambeli et al. (2021) point out that one of the great challenges for hemodialysis patients is to follow the oral diet, especially due to changes in eating habits and the behavioral pattern of each one. In this context, the fragments mentioned in the research make it evident how challenging this dietary therapy process is and how adapting to new habits, when it comes to dietary restrictions, requires great resilience and overcoming power. They are often culturally consumed foods that are considered hypercaloric and should be avoided or are prohibited, in some cases they are diets that must be strictly followed, which makes this process even more difficult.

Without the support of the people closest to them, this factor becomes even more complex. The person affected by CKD needs adequate and specific nutritional therapy, therefore, food preparation should be with sodium, potassium, phosphorus control, with fluid reduction, among other restrictions, in addition, it is essential to provide nutritional guidance with the inclusion of family members, since they are often responsible for this function (Castro, 2019).

It is important to highlight that the intake of fluids recommended for patients undergoing hemodialysis should be limited to up to 5% of dry weight between sessions, excessive fluid consumption can increase the risk of complications during hemodialysis, such as hypotension and cramps, in addition to contributing to the increase in cardiac mass, resulting in left ventricular hypertrophy (Castro, 2019). In addition, uncontrolled fluid intake can cause serious complications outside the dialysis environment and favor new problems in addition to hemodialysis treatment.

Despite receiving guidance, some reports mention resistance when following the oral diet and, therefore, disbelieve the damage that can be affected by maintaining deliberate caloric intake, however, food and water restrictions are fundamental for the success of the treatment and for the well-being of the individual with CKD. In addition, without the correct direction of people who are part of the closest family nucleus or who is responsible for preparing food, this diet can become ineffective and cause harm to people undergoing treatment.

In this way, understanding the individual, their difficulties, limitations and the social support received in general will imply the recognition of the specific needs that are involved in this process in order to act in the implementations aimed at each reality experienced.

For Viegas et al. (2017), although hemodialysis treatment is necessary for those who depend on it and indispensable to prolong life, it is also tiring, time-consuming, exhausting, unpleasant and full of restrictions.

Teixeira and Borges (2023) point out in their study that after the start of dialysis, there is a worsening of the physical function of individuals with end-stage CKD, in which RRT becomes essential. As the disease progresses, physical performance worsens, as does quality of life. The authors also emphasize the need to improve fundamental nutritional behaviors in kidney disease that drive the development of habits that positively impact quality of life.

Rocha et al. (2021) argue that the educational interventions carried out by nurses in the care of chronic kidney patients can favor the understanding of the disease and adherence to treatment, this promotes improvements in the quality of care provided with accesses and thus also reduces patient morbidity and mortality. The authors add that the implementation of health education regarding the correct manipulation of the catheter and AVF is directly linked to the lower incidence of access losses, infections and other complications with the devices, therefore, care with vascular accesses needs to be encouraged from the beginning of hemodialysis therapy and maintained throughout the treatment so that effective results can be guaranteed.

In addition to physical changes and food adaptation, changes related to leisure and the abandonment of recreational habits are also highlighted, which is considered an important support for mental health and emotional well-being, in addition to representing a balance between work and personal life.

The results show that living with CKD and the exhaustive treatment routine directly implies the practice of leisure habits, associated with socioeconomic factors. On the other hand, the literature points out that leisure can be an element of help and helps to overcome feeling sick through hope in the future and renewal of the meaning of one's existence (Cunha *et al*., 2022).

For Cunha et al. (2022), there is a growing consensus that leisure has the potential to facilitate symptom management, improved well-being, and adapt to life in the face of living with chronic pathologies. The authors add that when leisure habits are impaired, whether by external restrictions, changes in routine or other reasons, this can negatively affect psychological health in several ways and agree that the lack of time for leisure activities or the inability to participate in activities that previously brought pleasure, can increase stress and anxiety levels.

Participation in physical and leisure activities is seen as a strong stimulus for the patient to adapt to the treatment and continue life through HD, and the practice of these can also contribute to the person improving the perception of themselves and the situation they are experiencing (Panzetti *et al*., 2020).

In the context of changes in daily habits, the effects evidenced after the session show great discomfort on the part of some participants, in addition to dealing with the pain of punctures for those who use AVF access, it is also necessary to consider the unpredictability of complications and possible unwanted reactions. At the end of each session, it is essential to prepare for the next session and some participants reported a continuous concern about returning in good physical condition, which considerably limits the time allocated to the practice of leisure habits, for example.

From this perspective, there are also changes in lifestyle, such as leisure options and family life, in some testimonies there are reports in which they mention that they stopped performing leisure habits that give them pleasure because they do not have time to do it or even due to financial limitations.

The cost of hemodialysis treatment can be significant, even when the cost comes from the SUS, since there are expenses with medications, transportation to the sessions and possible indirect costs, such as loss of income due to the inability to work to maintain household expenses. This financial aspect can put a strain on the family, leading to additional conflict and concerns beyond treatment.

The lack of financial support is very present in the participants' speeches and experiences, only 03 of them reported that they have adequate financial conditions that cover their needs and do not harm the treatment and their general well-being. While the others stated that despite receiving the Continuous Cash Benefit (BPC) from the government, they still need help from other people to be able to maintain an adequate diet, carry out complementary exams when necessary and buy the medicines that are mandatory for treatment, even those that are made available by the SUS, as there were reports of difficulties in accessing these medicines.

For Pereira (2011), there is a tendency to equate basic human needs with merely biological survival, without considering the idea that basic needs are a relative social phenomenon, subject to variations. It is essential and urgent to formulate social care policies for the population, in which they consider the essential basic needs, taking into account the demonstrations of well-being, habits that promote personal satisfaction and access to health services in an easier way, encompassing both the biological and social dimensions.

Government social support is a right guaranteed by the federal constitution, especially when referring to people with chronic diseases such as CKD, the principle of equity prevails in the meantime, when the focus needs to be on those who need it most, on the vulnerabilities and potential problems inherent to each reality. Chronic conditions require continuous and comprehensive treatments, encompassing not only the disease, but the entire health context, which is biopsychosocial and spiritual.

This social protection network is a crucial step to generate positive impacts on the lives of people who struggle daily with treatment and families who care for and need care so that social awareness of the needs of the HD population is created, without having to reach extreme, unfavorable, undignified conditions that are so full of adversity. Above all, we need to intervene at the root of the problem.

Regarding aspects related to work while living with HD, difficulties were evidenced, which reflect limitations imposed by the treatment. These are people who often face physical or psychological limitations and as a result may have difficulties entering or remaining active in the job market. The fast pace and productivity demand of capitalism are not always compatible with the health needs and recovery rates of these people.

In the social dimension, Garcia and Moreira (2020) mention that it is through work that the relationship between man, society, and nature is established, which guarantees the transition from a merely biological being to a social being. In this social interaction, the attributions are established as an individual who is part of a society and actively participates in it, in the family environment it is the basis of sustenance, in bonds of friendship he participates in moments of group leisure, his work arises from his contributions and they are considered of great use, therefore, in a general context, they permeate all dimensions and make him a socially active figure.

Most of the interviewees receive a monthly amount referring to the BPC, provided for in the Organic Law of Social Assistance (Loas), this is a guarantee of one minimum wage per month to the elderly aged 65 or over or to the disabled person of any age (Brasil, 1993). However, in view of the expenses necessary for the maintenance of the family, which was previously provided by the resource of work and now also depends on the aid in the face of the impossibility of working, this amount is also directed to cover expenses related to health and dialysis treatment.

In line with what was reported by the participants, it is also provided in the Organic Law that the benefit will only be granted to people with disabilities when the inability to perform work activities is evidenced and proven through medical expertise, this rule includes people with CKD undergoing hemodialysis (Brasil, 1993). When the proof goes through medical refusal and/or documentary difficulties, this waiting time for the release of the benefit increases a lot, which exposes the sick person to distressing scenarios due to lack of income. In the face of these challenges, it is crucial that HD patients and their families seek financial and emotional support whenever needed, whether in the community, support groups, through other family members, or government assistance programs.

For Mendes (2012), the family represents a predominant link in this process of kidney disease and demonstrates the most effective source of support with regard to positive responses to the acceptance of the disease and treatment efficacy. The patient who is undergoing hemodialysis treatment clings to the nearest sources of support, because along with the diagnosis, fears and insecurity arise that lead to a greater need for social support. In addition, according to the interview reports, they consider the hemodialysis treatment to be extremely physically and emotionally exhausting, especially after the end of the sessions.

The literature highlights the importance of family ties in the emotional and psychological support of the patient, highlighting its contribution to the maintenance of mental health, adherence to treatment, and the way renal patients deal with the experience of becoming ill (Borges *et al*., 2023).

Abandonment of family ties after diagnosis of CKD and hemodialysis treatment can be a significant emotional challenge and result from a variety of factors, such as prolonged stress that can lead to family conflicts and relationship wear and tear resulting in abandonment. Borges et al. (2023) raise the discussion about the family's adaptation as a source of closer support, considering their roles before SRT and after its emergence, this requires time to adapt since the family also goes through a transition process to this new stage that arises.

During the interviews, the perception of social support often emerges as the personification of someone to share the burden of the process of living with a chronic disease, with being present sharing the daily assignments and the routine of attending the hemodialysis unit for the sessions.

The family, therefore, is pointed out as the main source of support. Thus, when health professionals involve family members in care and integrate them in the treatment process, a greater understanding of the family can be favored as a fundamental factor to encourage it to be a source of support. This aspect corroborates Ferreira et al. (2022) when they mention that family support is decisive in the process of reframing and overcoming the difficulties imposed by the disease.

The evaluation of family dynamics is extremely important in the health context, especially inherent to the adaptation process, since it helps in the definition of steps such as planning, implementation, and evaluation of health actions, enabling the multiprofessional team to define interventions that are more appropriate to the reality of each family unit, taking into account its context, dynamics, levels of functioning, and satisfaction (Sousa; Flowers; Erdmann, 2010).

The need to adapt to new family roles, such as caregiver or caregiver, can cause tensions and imbalances in family relationships, some family members may find it difficult to cope with the emotions associated with the treatment of a close family member and the changes when adapting to the new routine (Sousa; Flowers; Erdmann, 2010). As a result, after the discovery of the disease, the abandonment of family ties may be even more frequent, given that the person undergoing HD treatment feels more isolated and lonely due to the overload and exhaustion, which can indirectly have a negative impact on their mental and emotional health.

The treatment, being demanding and continuous, consequently generates psychological, financial and social exhaustion, making emotional support necessary. Providing a welcoming and understanding environment will consequently reduce the impact caused by the disease, in this sense, the involvement of the family in medical and nutritional monitoring, in the organization of routine and daily care will promote a higher quality of life.

The lack of emotional support from the family can lead to a decline in physical health as well, making treatment even more difficult. It is important for people on hemodialysis and their families to recognize the importance of mutual support and seek help when needed. This could include participation in support groups, family counseling, or individual therapy to help cope with the emotional challenges inherent in treatment.

Only one participant mentioned friends as perceived social support, but in a specific situation of need for blood transfusion. Superficial friendships, characterized by limited social interactions and lack of deep emotional connection, contribute unsatisfactorily to well-being, linked to this, the quality of social relationships, and not quantity, is more strongly associated with emotional and psychological well-being (Demi; Davidson, 2013).

The bond established with the team makes the anguish experienced during the process more easily verbalized, people in treatment who need to be on HD normally 3 times a week, find support in this team that is always present providing care before, during and after the sessions, who know the specific characteristics, fears, restrictions and parameters of each patient and becomes a fundamental member of this therapeutic process.

The multiprofessional team works directly with patient care and from the perspective of interaction and creation of bonds, nursing acts in closer contact and, consequently, establishes important social support relationships from the point of view of the interviewees. Pennafort and Queiroz (2011) highlight the importance of nursing professionals being trained to work in this sector, given its relevance in the process of maintaining treatment.

Nursing also plays an essential role in health education in the various environments in which it operates, whether through practical guidance or individual and community training, with a humanized approach, especially when bonds are created that favor communication and stimulate autonomy, especially with regard to people who live with chronic diseases.

In the hemodialysis center, this discourse was present in many moments, where the participants bring positive reports of the importance of the nursing team not only in care

Religiosity is present in several panoramas, especially in the face of health issues, many people find comfort and hope in the faith they cultivate, it becomes, therefore, an important offer of emotional, psychological or even physical support. Individuals turn to this support when they are faced with uncertainty or suffering caused by chronic illness, whether through prayers, rituals, or participation in communities, as a result, religions help them deal with pain, fear, and uncertainty about the future.

Koenig (2012) reinforces that being linked to any religion can positively influence the quality of life of people living with chronic diseases, reducing their levels of anxiety, depression and suffering, adding that prayer practices, meditations and religious rituals have been associated with a decrease in symptoms of pain and stress, in addition to promoting emotional and physical well-being.

They corroborate Leimig et al. (2018) when they bring that spirituality and religiosity emerge as a strengthening measure to deal with the difficulties of daily life and point out that hope also has its role as an effective strategy to cope with the condition imposed by chronic kidney disease, as it is the state that is related to the perspective of a better future and argue that health professionals should address these issues at the time of assistance to people with CKD.

Most participants report participating in some religion and consider it important in their process of living with the disease. Ottaviani (2014) points out that when these factors are encouraged, the ability to overcome difficulties is also greater, in addition to developing a greater capacity to adapt to a new reality, as it acts as a driving force, added to faith in the presence of a supreme being, who supports the individual and directs him to accept the disease and deal with the possibility of death.

Performing kidney transplantation can result in fewer daily limitations, such as getting rid of dependence on hemodialysis sessions, in addition to providing more freedom of movement, improved diet, more time to practice leisure habits, among others. Faced with the possibility of a more independent life, with autonomy, without hemodialysis being inherent to the continuity of life, transplantation becomes the incessant search of people who face the challenges related to RRT on a weekly basis (Santos *et al.*, 2021).

Added to the desire to get rid of the limitations of hemodialysis, many patients face a natural fear of post-surgical complications. Santos et al. (2021) ratify that the support of the family and the health team, in addition to adequate psychological support, are essential for CKD patients to be able to deal with the expectation and challenges of the possibility of receiving kidney transplantation.

This statement starts with ambiguous content, since it demonstrates the exhaustion and difficulties faced daily, it also exposes the gratitude for the existence of an effective treatment to maintain life. In addition, many find in the hemodialysis center a very strong identification with people who also undergo the treatment, which can strengthen the social bond and avoid feelings of loneliness, since these aspects are often neglected in the lives of patients.

On the other hand, there is another aggravating factor demonstrated by the feeling of being trapped, of having one's life limited. At the same time that an arduous reality full of restrictions is evident, it becomes, despite everything, necessary.

Undergoing hemodialysis and feeling trapped is a common experience reported among patients with chronic kidney disease. The treatment, which involves regular sessions to filter the blood, can be exhausting both physically and emotionally. The sessions last from 3 to 4 hours and need to be performed three times a week, which implies a large part of the time focused on the HD routine and can generate a feeling of imprisonment. On an emotional level, hemodialysis can generate frustration and discouragement, because dialysis does not cure the disease, it only keeps the person alive.

HD treatment, although vital for the survival of patients, often leads to feelings that impact emotional well-being, such as the fact of not being able to make long trips, or the discomfort that prevents them from leaving after sessions. Some reports raise these aspects and arise from the desire for strategies to be implemented, such as the integration of the care network with the possibility of performing HD in other clinics more easily by presenting a specific document such as a "dialysis card", for example. Therefore, psychological and emotional support is essential to discuss these aspects and establish measures to mitigate such negative feelings.

Among the factors that triggered CKD, 76% of the participants bring SAH as a previous disease, to a lesser extent another 35% point to DM, this aspect suggests that the stimulus and search for primary health care should be continuously reinforced in educational spaces, in communities and in the major transmission channels. The two underlying diseases mentioned above have great potential to prevent complications such as CKD when properly treated. PHC has support to intervene in patients with SAH and DM so that complications are avoided, but there is still a deficiency in the effective dialogues of the integration network between the population and the basic health units.

Interventions to prevent the emergence of pathologies or worsening of the condition should be implemented early, especially in relation to health education measures, since this is the tool that will imply the effectiveness of preventive actions through the awareness of the population at risk (Correa and Silveira, 2019).

CONCLUSION

With the deepening of the theme studied, it was possible to understand the existing sources of social support that permeate the health process and aspects of CKD, in addition to contributing to the identification of facilitating and hindering factors that hinder this process of living with the disease and treatment in HD. Changing habits carries the weight and difficulties of adaptation, when it is already difficult to deal with the treatment, eventually one also needs to deal with complications, malaise and abandonment of old habits, which culminate in an exhausting emotional load. Food is no longer the same and having a favorite food may no longer be possible, also contributing to emotional aggravations.

The cost of the SUS allows the continuity of treatment and maintenance of life, however, it is not always possible to cover other aspects that allow for comprehensive quality of life, demonstrated through financial difficulties and lack of social security support in some cases. In this sense, the study points to the need for implementations aimed at improving the repercussions sustained by CKD, as it is a chronic and irreversible disease, which depends on permanent treatment.

With this approach, it was possible to identify sources of social support that are still unexplored or little explored by this specific group, such as participation in support groups, psychotherapy as a regular habit, friendship relationships, the practice of physical activities, this demonstrates that there are still weaknesses in the process of implementing care and stimuli aimed at its continuity, recognizing the social aspects involved and how they can adapt to different realities and contribute to hemodialysis therapy.

Integrating the family in care represented a strong determinant of how the disease impacts the lives of different people, in different realities. Each story told represents unique ways of how the disease is seen and how it impacts quality of life, thus making evident the need to understand from an adapted perspective, with expanded support for both patients and family members.

It is considered that the family represents the greatest source of social support for the people who participated in the research, both with regard to food, hair control and water intake, as well as in the financial part, in the help for follow-up in sessions and consultations, in emotional issues, in support to deal with the complications of the disease, in adherence to treatment and other imposed changes.

The psychological burden must be validated in front of each individuality, being faced with a chronic disease undergoing such a complex treatment can be understood with degrees of acceptance equivalent to different realities and it is necessary to adapt the look so that new perspectives of support are developed. Having professional support in the discovery stage is an indicator of better results in adherence and consequently in the response to treatment.

In addition, the research reiterates the importance of raising subsequent discussions in the academic environment, through the results obtained it promotes transformations on the subject, can guide the construction of new research with the production of scientific evidence and contributes to the understanding of how the sources of social support can be diversified and favor a positive response to hemodialysis treatment.

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