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ORIGINAL ARTICLE

"WE LIVE ON THE EDGE": MEANINGS OF HEMODIALYSIS FOR THE CHRONIC KIDNEY DISEASE PATIENT

"A GENTE VIVE NO LIMITE": SIGNIFICAÇÕES DA HEMODIÁLISE PARA O PORTADOR DE DOENÇA RENAL CRÔNICA

"VIVIMOS EN EL BORDE": SIGNIFICADOS DE LA HEMODIÁLISIS PARA EL PORTADOR DE LA ENFERMEDAD RENAL CRÓNICA

Lorena Olegário Freitas[1], Bruna Queiroz Viera[2], Renê Ferreira da Silva Junior[3], Silvania Paiva dos Santos[4], Henrique Andrade Barbosa[5], Mariza Alves Barbosa Teles[6]

ABSTRACT

Objective: recognizing the meaning of hemodialysis for patients with chronic renal failure. ***Method:*** a descriptive and exploratory study of a qualitative approach carried out at the Nephrology sector of a hospital in the North of Minas Gerais/MG, with 12 patients with chronic renal failure. The data were produced through individual interviews with a semi-structured schedule; then the data were transcribed in full and analyzed by reference of Symbolic Interaction. The research project was approved by the Research Ethics Committee, CAAE 18496013.3.0000.5141. ***Results:*** after data analysis three categories emerged: << Meaning of hemodialysis >>, << Experience gained with hemodialysis >> and << Interpersonal relationships>>. ***Conclusion:*** the meaning of hemodialysis for patients with chronic renal failure is dual, represents life and clash. ***Descriptors:*** Renal Dialysis; Change Events Life; Interpersonal Relations.

RESUMO

Objetivo*:** conhecer o significado da hemodiálise para pacientes com insuficiência renal crônica. ***Método*:** estudo descritivo e exploratório, de abordagem qualitativa, realizado no Setor de Nefrologia de um hospital, localizado no Norte de Minas Gerais/MG, com 12 pacientes com diagnóstico de insuficiência renal crônica. Os dados foram produzidos por meio de entrevistas individuais com um roteiro semiestruturado; em seguida, os dados foram transcritos na íntegra, e analisados pelo referencial do Interacionismo Simbólico. O projeto de pesquisa teve a aprovação do Comitê de Ética em Pesquisa, CAAE 18496013.3.0000.5141. ***Resultados*:** após a análise dos dados emergiram três categorias: << Significado da hemodiálise >>, << Experiências adquiridas com o tratamento hemodialítico >> e << As relações interpessoais >>. ***Conclusão*:** o significado da hemodiálise para o pacientes com insuficiência renal crônica é dual, representa vida e choque. ***Descritores: Diálise Renal; Acontecimentos que Mudam a Vida; Relações Interpessoais.

RESUMEN

Objetivo: conocer el significado de la hemodiálisis para pacientes con insuficiencia renal crónica. ***Método:*** un estudio descriptivo y exploratorio, de enfoque cualitativo, realizado en el Sector de Nefrología hubicadoen un hospital en el norte de Minas Gerais/MG, con 12 pacientes con insuficiencia renal crónica. Los datos fueron producidos a través de entrevistas individuales con una hoja de ruta semiestructurada; luego, los datos fueron transcritos textualmente y analizados por el referencial Interaccionismo Simbólico. El proyecto de investigación fue aprobado por el Comité de Ética en la Investigación, CAAE 18496013.3.0000.5141. ***Resultados:*** tras el análisis de los datos, surgieron tres categorías: <<Significado de la hemodiálisis >>, << La experiencia adquirida con la hemodiálisis >> y << Las relaciones interpersonales>>. ***Conclusión:*** el significado de la hemodiálisis para pacientes con insuficiencia renal crónica es dual, representa la vida y el embate. ***Descriptores:*** Diálisis Renal; Eventos que Cambian la Vida; Relaciones Interpersonales.

[1]Nurse, United Colleges of Norte de Minas, Montes Claros (MG), (MG), Brazil. Email: lorensfreitas16@yahoo.com.br; [2]Student, Graduate Course of Medicine, United Colleges of Norte de Minas / Funorte. Montes Claros (MG), Brazil. Email: brunaqvieira@yahoo.com.br; [3]Student, Nursing Graduate Program, United Colleges of Norte de Minas / Funorte. Scientific Initiation Program – Scholarship Holder. Montes Claros (MG), Brazil. Email: renejunior_deny@hotmail.com; [4]Nurse, Master in Health Sciences, State University of Montes Claros. Montes Claros (MG), Brazil. Email: silvaniapaivasantos@yahoo.com.br; ; [6]Nurse, Master of Health Sciences, United Colleges of Norte de Minas / Funorte. Montes Claros (MG), Brazil. Email: henriqueabarbosa@ig.com.br; [6]Nurse, Master of Health Sciences, United Colleges of Norte de Minas / Funorte, State University of Montes Claros/Unimontes. Montes Claros (MG), Brazil. Email: aziramteles@gmail.com

INTRODUCTION

Chronic Kidney Disease (CKD) is a disease that brings physical consequences to the individual and psychological impacts that affect his daily life, and also characterized as a social problem, as it interferes with the role of the individual play in society.[1]Patients with renal insufficiency chronic hemodialysis who performs live with the fact that they have an incurable disease, which requires a painful, long-term treatment and that usually causes limitations and changes that generate large impact on their life and on the lives of their families.[2]There are a lot of patients requiring hemodialysis throughout life due to progressive loss of renal function, with involvement of cellular metabolism and life of all organs.[3]

The patient suffers the initial impact at the time realize the changes caused by the malfunction or failure of the kidneys. He experiences various emotions, from perceptions of disease; conditions that actually have a kidney disease can lead you, whether to join forces in an attempt to maintain balance and well-being, are stressful experiences.[4]

When becoming dependent on hemodialysis (HD), patients experiencing sudden changes in their daily lives and the way will face the situation is particular, but of great importance to nursing care that treats the individual as a whole.[4] This same individual will be submitted to situations and circumstances that may weaken it. Its limitations are: emotional, physical, social and occupational, since it will have to attend medical appointments and HD sections, shall be subjected to food and water restrictions.[5]For patients with end-stage renal failure, hemodialysis machine is maintaining a physiological balance, and for that matter, the maintenance of its life. Each person experiences this initial experience differently because each one brings its history, its culture, its own way of behaving faced with a chronic health condition and need for achievement of a treatment.[7]

This study is justified by the seriousness of the IRC and the importance of the renal system takes in the body. Therefore, any change is responsible for significant impacts on an individual's life. The view of the patient as a whole, not just the disease itself, is of great importance to improving the quality of life of people undergoing hemodialysis. It becomes easier to see it in all its aspects by recognizing the meaning that the disease and the treatment take in their life, so know the feelings and perceptions of hemodialysis patients is needed to try to help them to overcoming the barriers imposed by IRC.

Given the above, this study sought to learn the meaning of hemodialysis for patients with chronic renal failure through the following research problem: "What is the meaning of hemodialysis for patients with chronic renal failure?" In the search for such a meaning, it was necessary to characterizing the profile of patients with chronic renal failure, identifying what changes occurred in the life of the patient after starting hemodialysis, and recognizing how the interaction with family, friends and health professionals is, that are part of IRC wearer's life.

METHOD

This is a descriptive study of a qualitative approach, in order to interpret the meaning and intentionality that are inseparable from the actions, relationships and experiences acquired by men. As discussed, we used the symbolic interactionism for theoretical reasons and for data analysis, the set of techniques used helps to understand the implicit meanings in messages. The analysis recommends the following steps, namely. Pre-analysis: transcription of the interviews in full, detailed reading and in depth, in order to grasp how the family lives that experience; Systematization of data: there are some further reading in order to exploit the material through the break-up processes and reunification. Following the data, which have been initially separated by topics, receive a reinterpretation, a process of reflection and analysis of the results produced their interpretation. The methodological framework is the qualitative analysis based on assumptions organization, coding, categorization and inference Bardin.[8]

The research was conducted between the months of September and October of 2013, in the sector of Nephrology Dilson Godinho boards Hospital, which performs hemodialysis in patients with chronic renal failure. The choice of this institution was given by fit to the study proposal, allowing contact with individuals. The legal representatives of the institution signed the Agreement Institutional Agreement to authorize the collection of data. The study included 12 patients undergoing hemodialysis, who met the inclusion criteria. The data was collected by applying a semi-structured form to allow respondents freely discourse about the subject. The interviews took place in an appropriate environment in the institution, with the participation of the interviewer with

duration ranging from 10 to 30 minutes. There was used as a guiding question of the study: "What is the meaning of hemodialysis for patients with chronic kidney disease?"

This question emerged additional clarifications were needed for the further development and recognition of life experiences, namely: the main changes that occurred in the patient's daily life, the patient's relationship with family, friends and health professionals, and that the memory of patient in relation to the time that he learned that would be submitted to hemodialysis. The interviews were recorded and transcribed soon after they occur, in order to allow a better analysis of the speeches.

There were held interviews until they reached theoretical saturation, until it was found that more interviews would add no new information relevant to the study when it was found the repetition of speeches by different individuals, the non-occurrence of new data and the perception of the proposed meanings of the objectives of the study.

All individuals participating in the study signed the Informed Consent and Informed Permission for analysis and publication of data. To ensure confidentiality, individuals are represented by the letter E (respondents) and the Arabic numeral determines an assigned code by the researchers. For evaluation of the interviews, the steps of content analysis were followed. Initially, it proceeded to the pre-analysis stage, comprising successive readings of the transcripts to identifying similarities and differences between the lines for categorization. Exploration of the material was carried out with the issue of securities for emerging categories; and subsequently the treatment of the results, which allows confronting the findings to the scientific literature.[11] Thus, there were formed three conceptual categories and eleven subcategories based on the principles of Symbolic Interaction (Figure 1).

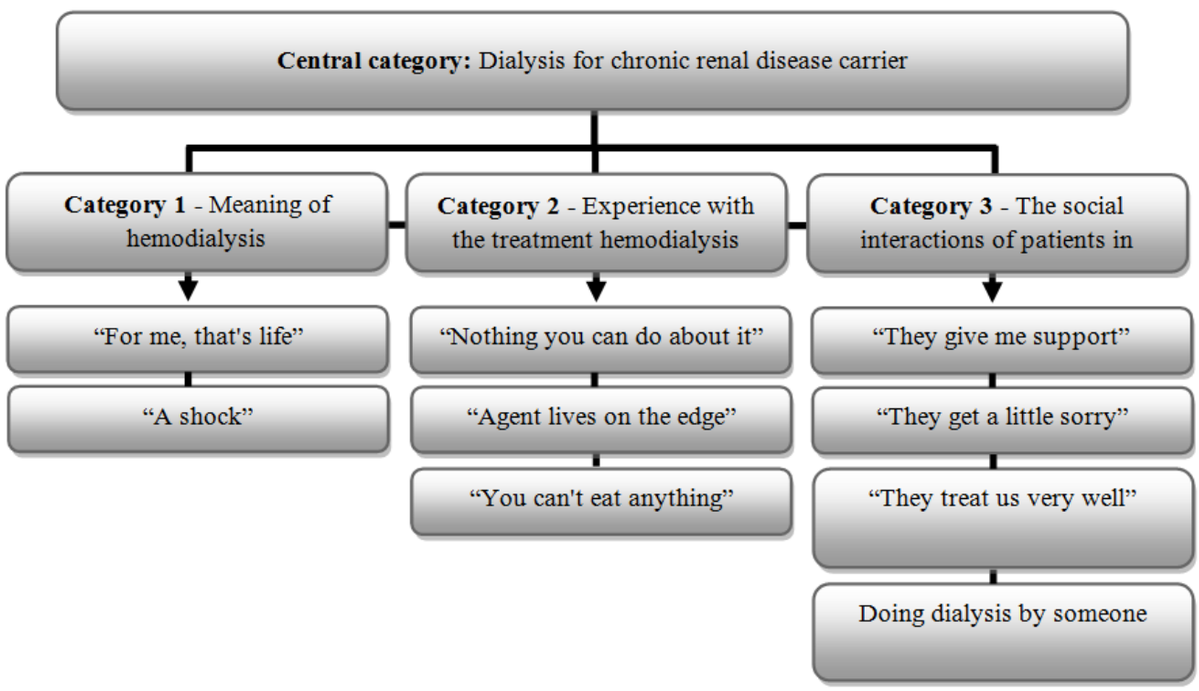

Figure1. Conceptual categories and subcategories of the meaning of hemodialysis to the patient with Chronic kidney disease.

In keeping with the Resolution 466/2012 of the National Health Council, which addresses Research Involving Human Beings, the principles of prior authorization request were followed by the general administration and clinical directors of hospital and dialysis clinics, where the study was conducted; agreements by the Informed Consent guarantee anonymity and the right to withdraw at any stage thereof to research participants; and submission of the study project to the Research Ethics Committee of Soebras with the consolidated report approval No. 332.356/2013 CAAE No 18496013.3.0000.5141.[10]

RESULTS AND DISCUSSION

♦Characterization of the participants

There were interviewed 12 people among which were five men and seven women, aged between 24 and 68 years old, and four were 24-34 years old; five 41-54 and three over the age of 60 years old. The merits: all individuals residing in the North of Minas Gerais and residents of the village. Regarding the time of completion of the first hemodialysis session, five participants had up to one year; three

with time of two to three years; time two with eight; one with 13 and one with about 18 years. This factor was predominant in interpreting the meaning of hemodialysis in the life of each of them, because the longer duration of hemodialysis, more adapted and resigned is the individual.[5]

Symbolic Interactionism is a theory that makes possible the understanding of how individuals interpret the objects and other people with whom lives and how such a process of interpretation defines individual behavior in specific situations. Thus, it is considered that the Symbolic Interaction is an adequate theory to analyzing processes of socialization and rehabilitation and also for the study of second thoughts, behaviors, expectations and social requirements.[12]Hemodialysis means an unforeseen event for the patient, besides imposing a dependent relationship of a specialized professional staff, a rigorous treatment plan and a machine. The trial of this new life takes place in disparate ways and enables the customer to assign meanings to the disease and treatment.[13]In this study, based on the theory of symbolic interactionism, categories were identified and sub-categories that emphasize the significance of the facts, social interactions and experience gained by participants.

● Category 1 - Meaning of hemodialysis:

♦Subcategory 1 A - "For me, that's life"

Immersed in a chronic health condition, the individual dependent on hemodialysis experience, at the time it is reported the situation of dependency on dialysis, a series of feelings and sensations derived from preconceived concepts concerning the context in which it is, and the ability to withstand stressful circumstances and the meaning attributed to such stressors. These aspects require that coping mechanisms are used in the process.[4]

> **E4***: A means of prolonging life for a few years, because there is no other way we live*.
>
> **E9:** *You have to take, for me is life, if not for her (hemodialysis) we don't live*.

The chronic renal patient constitutes a relationship of dependence to hemodialysis, to a specialized group and to the obligation to receiving and taking a strict regimen for the preservation of their lives.[2]

> **E1:***I didn't want to live; I thought I wasn't going to pass [...] Despair*.
>
> **E10***: Is my source of survival, without it I wouldn't be alive for many years, I and many others.*
>
> **E4:** *It was a shock because everyone's life changes completely.*

There is the perception that will change much, including, labor capacity and when it is the support of the family, concern occupies a prominent place.

> **E6:** *A horror [...] I cried a lot, I didn't want to live I thought how could I keep my two sons? How was I supposed to work? What I was going to work.*
>
> **E7:** *In fact I didn't know what the treatment was [...] hemodialysis, [...] when I was putting the catheter [...] hemodialysis [...] and saw the machines [...] gave me sadness!*

The reality experienced by them is dual, because many patients understand that hemodialysis, although many bring some positive changes, it is still the only way to ensure survival.

> **E8:** *It is very sad! The people just come because there's no way, today I can say we are already a few years longer I could live*.

When receiving the diagnosis, the feelings were expressed by patients in different ways; however, the attitude was rejected, at first. During treatment understood that hemodialysis, although not offering the possibility of healing and providing uncertainty regarding the future, it also provides an improvement in quality of life.[13]

♦Subcategory 1 B: "A clash"

The IRC and the hemodialysis treatment, trigger a succession of situations for chronic renal patients, compromising the appearance not only physical and psychological, with repercussions personal, family and social. In addition, chronic kidney disease experience a sudden change in their life, live with limitations and with a think about death.[14]

> **E9:** I cried a lot, I thought I was going to die soon, difficult!
>
> **E11:** I didn't even know what to think, nor enough time [...] The other day I put a catheter and I'm here today, I cried when I got home [...] I wanted to die!.

Chronic renal patients experience severe transformations and allied limitations to their own condition itself, trigger the unpleasant living with cogitations about death that are complicating that help hinder acceptance.

> **E8:** *Total desperation, I didn't want to accept, for me it was better to die than go through this!*

The treatment is reported as prison and nightmare, the patient feels bad physically and psychologically.

> **E3***: I feel trapped! It's hard to find people that it is good.*
>
> **E12:** *Each day I wake up and look at my arm I think I'm living a nightmare [...] Hemodialysis is a nightmare that happens with me three times a week.*

With the advance of the time of treatment, the HD becomes a standard procedure in the

life of the patient and bearable for patients, however, the involvement of emotional and social aspects is notorious. Patients who held recently live with the discomfort, irritation and intolerance.[5] In addition to this non-adherence to treatment can lead to complications, which may be resolved when it understand the etiology of non-compliance, with such relevant understanding for quality planning.[6]

● Category 2 - Experiences gained with hemodialysis treatment:

Functional capacity can be subjectively classified as poor in patients with CKD compared to other citizens, because there are factors that cause low physical condition, such as anemia, heart disease, hypertension, uremic neuropathy, fatigue, depression and pain in the lower limbs, and all such as present in these customers.[5]

♦Subcategory 2 A: "There is nothing to do"

Although the treatment interfere with the client's quality of life, some consider an improvement in your life, while others reported that treatment only brought losses. The limitations by the lesions caused by the disease indicate that the client needs to modify its activities and routines. Need available time to perform the treatment three times a week. Some stop working, others are transferred from their homes and move in the larger centers to facilitate treatment. For the IRC carrier customer, social activities and other occupations for the living are dispensed, as it prioritizes the satisfaction of other basic needs for survival.[15]

> **E1:** *I get up very early to come here [...] can't do anything.*
>
> **E8***: I had to move from one city to another.*

The performance of daily activities and work ends up being reduced, because with the advance of dialysis, regular activities and work experience a decrease in time as a result of impaired physical health:

> **E4:** *Changed you have to leave home at that time, be as many hours in this treatment, we live on the edge!*
>
> **E7:** *Have to comply this time [...] you can't do almost anything, arrest me too, I can't travel, gotta ask for vacancy.*
>
> **E9:** *I can't go anywhere can't go anywhere, you can't eat anything, you can't drink, and everything changes.*
>
> **E10***: My time was very low, and a stampede to take care of everything.*

Many changes happen in their lives and their families to recognizing the need for dialysis, because there is a commitment to attendance at dialysis centers, water and food shortages as well as changes in working hours and social life. Thus, the patient begins to live with the losses that go far beyond the renal function, generating emotional instability.[16]

♦Subcategory 2 B: "We live on the edge"

While offering advantages over catheters, the fistula has the disadvantage of carrying out the punches with extremely caliber needles in each hemodialysis session. For patients, the catheters are very uncomfortable and because of its location limits the natural movements and are not just these reasons that bother both hemodialysis-dependent patients, after the end of HD, it is necessary to cover the catheter with a bandage in order to protect the patient from infection.[17]

> **E4:** *Equal that arm that has this thing (fistula), I can't use it for almost anything [...] get so many hours in this treatment, we live on the edge.![...].*

After the HD session, patients have higher incidences of prostration, incapacitating them for activities that require physical effort.[16]

> **E2***: [...] people looked at with disgust, I was with that thing on my neck (catheter), and my friends are gone all.*
>
> **E4:** *Changed you have to leave home at that time, be as many hours in this treatment, we live on the edge, you can't eat salt or fruit, little water.*
>
> **E6***: People's life changes completely [...] the nerve of some people, the day we do not cheer for nothing.*
>
> **E10***: Everyone thinks that this treatment is very painful when we say that no pain, except when it sticks to my skin, no one believes.*

The need one nursing prepared to promote psychological comfort for these patients, since the nurse is the professional that relates more closely to the care that is given in the hemodialysis sessions, which makes it able to demonstrate greater trust and intimacy, that way they possess.[19]

♦Subcategory 2 C: "You can't eat anything"

The various relevant restrictions on hemodialysis motivate frustrations and limitations, among which, the maintenance of a specific diet associated with water restrictions. Most patients cannot adequately restrict the treatment, and this becomes more intense in summer, it becomes difficult to ingest the amount stipulated.[13]

> **E2***: You can't drink water, drink and just a little bit.*
>
> **E5:** *My food was weak and little, I was used to eat fruit, now I don't eat anything else [...] and now what's left is little.*
>
> **E8***: [...]Food [...] you have to know what food I can eat.*

The removal of social relations, disruption in their lives, are due to various physical transformations and changes in their lifestyle causing the discomfort of restructuring and adapting to this new reality.[15]

● Category 3 –Interpersonal relationships

The restrictions imposed by the reduction treatment arise from society, and sometimes the patient fails to attend social events, family parties, sporting events, and others. Many questions permeate their life due to the unpredictability of the clinical uncertainty of the realization of a transplant and tolerate be dialyzed for long. The individual feels useless, as it starts to depend on the family, the health team and hemodialysis. The picture is getting worse by feelings of concern with the fear of not being able to have children, fear of being abandoned by her husband and fear for death.[2]

♦Subcategory 3 A –The family: "They give support".

The DRC involves many issues that mark the life of the individual; from diagnosis are common psychological manifestations that cause changes in social interaction and psychological imbalances in the patient and his family. [13]Interpersonal relationships are important points in quality of life, as the achievement of a harmonious life depends to obtain understanding and respect for limitations. Thus, the harmony in the family and with friends' coexistence, the possibility to know better, to exchange information, are critical to the quality of life of chronic renal patients.[18]

> ***E4****: They give me support, strength; since you have to do you have to do, have a sister who calls me every single day, to see if I'm right.*
>
> ***E7****: They support me enough [...] I think they see that is the way it's helping me survive.*

Suffering starts from diagnosis and crawls during treatment with psychobiological changes that bring interference with an individual's interactions in their social circle and functional capacity, the patient's family, likewise, is transformed.[18] During this period, the emotional support provided by family members is an important element for the acceptance of the diagnosis by the patient. And it provides subsidies to continue treatment.

> ***E8****: It is empowering, because who gives strength is the family [...] if the family say something there that we fall more.*
>
> ***E9****: My children support me too; my husband comes every day with me.*

The family is an important psychological support in this study, because they help in accepting the disease and treatment, as well as collaborating with the accession to it. Stimulation of family participation in the treatment process, assisting and supporting the individual with chronic disease are proven fundamental to occurring better adherence to therapy[5].

♦Subcategory 3 B-Friends: "They get a little sorry"

The presence and support of both family and friends directly influence the patient's treatment, making him feel safe and active. Some respondents reported receiving support from friends, however, due to the treatment, the living changed.

> **E5:** *Everyone we speak you so young, already entering a life like that, it has no cure [...] this leads to death.*

Dressings made in double-lumen catheter are commonly large and apparent when set in the subclavian or jugular; its constant presence still causes a psychological discomfort by the change in their appearance.[17]

> **E2:** *I felt like they got a little distant, people looked with disgust, I was with that thing on your neck (catheter), and my friends are gone all.*
>
> **E6***: How are you living? Until that day it will stay that way?*

By reports, the friends realize that people on hemodialysis do not have much life expectancy and express feeling of pity, which is not viewed positively by the patient.

> **E3:** They look at me with pity; I like to look at me as a winner.
>
> **E7:** *Like when I speak [...] causes an impact, maybe they get a little sorry.*
>
> **E10:** *I don't like to comment on [...] I don't like people feel sorry for me.*

Contrary to the majority, there was a declaration of conformity with compassion denoting self-pity:

> **E8:** *Everyone feels sad, it really is very sad!*

♦Subcategory 3 C-Health professionals: "They treat us very well"

The condition in which they live asks for effective professional intervention with these individuals, especially by health professionals committed to the reality of side effects and poor adherence.[5]

The professional is very important to reduce the suffering of chronic renal patients, it is the nurse, encourage him to settle in a positive way to the new way of life and become involved in resolving limitations caused by chronic renal failure and treatment as he is the professional element that most often interact with the patient.[13]

> **E4***: [...] they charge us when we don't come [...]*

E5: *[...] they treat us very well, when we're disheartened they arrive and they give that encouragement [...] Let us not be discouraged, be scared.*

The patient recognizes his needs and constraints and evaluates how he is served in the services according to the satisfaction of his needs.[4]

E6: *I never lived with good people so, treat us super well [...] It's like my mother, my family really, despite the fact that the treatment is not easy.*

E7: *I think they see it as a way to help, to participate in the treatment.*

E8: *They try to give maximum support to us [...] everyone knows that it's painful to.*

The opinion of the respondents about the conduct of professionals was divided, as some see as solicitous professionals, while others feel themselves as a hindrance to the professional as we read in the E9 statement.

E9: *They are not to blame, so here to take care of us.*

And others do not like professionals performances, under observation, it is understood that particular circumstances of one's life gives them a special way to experience every experience of his life. Perhaps this is due to the different ways of perceiving the professional performance.

E2: *They look at us like a normal person who needs a follow up [...] There are times that deal with us until normal too.*

E12: *The professionals think it's good for us! I wanted to see one of their own here, should make something faster to take less time from us [...] every time I come here I feel like I'm losing my life.*

Professionals need to establish an ongoing dialogue with these patients, exceeding the usual technical formalism to provide information cold, difficult to understand, at the wrong time, and where virtually only the professional has reason .[13]Given the specificity of chronic renal client and the complexity treatment is not sufficient that the professionals worry only with the use of sophisticated technological resources or the conformation of dialysis services. Are indispensable to the rescue and customer value as a person that has its unique way of thinking, acting and feeling.[2]

It should be noted that the patient faces many issues involved with the new routine and adaptation to circumstances imposed by the dialysis treatment routine, so it is argued that the development of health education activities is an important aspect in their management and adaptation.[20]Thus, it should be noted that the changes in guided care methods for health education practices show up still embryonic and have little visibility nationwide.[21]

♦**Subcategory 3 D** – "Doing dialysis by someone"

When family members are present giving constant support in CRF patients pain is shared, and becomes less intense, so the disease is somewhat of the family too. Best fit to the disease and the uncertainty of their future, patients who have an intimate relationship with someone they can call upon in times of stress and discouragement.[5]

E2: *I come by my mother [...] When I do not come she is sad.*

E4: *When you have someone who depends on you, you do for love to that person.*

E6: *I ask God every minute so I can stay here and raise my kids!*

The family emerges as the primary means to help them cope with difficulties, as they are the family members who are near and seeking help at all times, causing them to fight, be optimistic and not feel alone.[15]

E7: *I only come because of my kids, if I wasn't even here, these needles nobody deserves.*

The statements reveal the family as a fundamental pillar in supporting the coping of difficult situations in the course of illness and treatment.

FINAL REMARKS

In this study, we sought for a more comprehensive perspective reaching the subjectivity of the patient under hemodialysis, bringing together the individual, his desires and his family, brought up to see how they adapt and respond to symptoms and disabilities and, as it could not be that strategies used to cope with the process so that it can perform its functions in society.

Symbolic Interactionism helped confirmation that the human being is not just a physical body, nor consciousness only or exclusively emotion, consider these aspects alone is relegated to the background the whole and the integrity to be a constant point of professionals dealing with health, as factors that are not entirely linked to the disease may be involved in its equilibrium state.

It is essential investing in constant educational activity with chronic renal patients, so these find ways to live with its limitations, so they do not conflict their lifestyle, albeit limited by disease and hemodialysis.

It is essential to identifying their needs; helping them feeling responsible and able to take care of themselves, enabling patients to take care and control of their treatment regimen. All individual relations web changes

after diagnosis, therefore it is important that the professional is sensitizes to capture the needs and difficulties of assisted clientele and make available all its knowledge on the reality experienced that combining the application of technical and specific knowledge. It was noticed also that the interdependence between knowledge and sensitivity to ensure that the care provided is based on the systemic view of the individual.

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Corresponding Address

Renê Ferreira da Silva Junior
Rua 2, nº 400
Bairro Planalto
CEP 39404537 – Montes Claros (MG), Brazil