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Coping strategies used by chronic renal failure patients on hemodialysis

Estratégias de enfrentamento utilizadas por pacientes renais crônicos em tratamento hemodialítico

Estrategias utilizadas por los pacientes con insuficiencia renal crónica en hemodiálisis afrontamiento

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ABSTRACT

Objective: To learn the coping strategies used by chronic kidney patients undergoing hemodialysis, facing the difficulties inherent to the disease. **Methods:** A descriptive, qualitative study, conducted with 30 people living with chronic kidney issues in a hemodialysis unit in northeastern Brazil. Data were collected from January to March of 2013 through a semi-structured interview tool and analyzed according to content analysis, thematic modality. It was used as a reference the theory of coping. **Results:** The categories that emerged from the interviews were: family support; attachment to religion/belief; denial and avoidance; and resilience. **Conclusion:** The way to handle the difficulties inherent to the disease was revealed by coping strategies that were based on emotion as on the issue. Thus, efforts have been made to administer or change the initial problems, as well as attempts to replace or regulate the emotional impact of the disease.

Keywords: Nursing; Renal Dialysis; Adaptation psychological.

RESUMO

Objetivo: Conhecer as estratégias de enfrentamento utilizadas por pacientes renais crônicos submetidos ao tratamento hemodialítico, frente às dificuldades inerentes à doença. **Métodos:** Estudo descritivo, qualitativo, realizado com 30 pessoas que viviam com condições renais crônicas, em uma unidade de hemodiálise no Nordeste do Brasil. Os dados foram coletados de janeiro a março de 2013 por meio de um instrumento de entrevista semiestruturada e analisados segundo a análise de conteúdo, modalidade temática. Utilizou-se como referencial a teoria do Enfrentamento ou *coping*. **Resultados:** As categorias que emergiram dos discursos dos entrevistados foram: apoio familiar; apego à religião/crença; negação e esquiva; e resiliência. **Conclusão:** A forma para manejar as dificuldades inerentes à doença revelou-se por estratégias de enfrentamento tanto baseadas na emoção, como no problema. Assim, foram desenvolvidos esforços para administrar ou alterar os problemas iniciais, bem como tentativas de substituir ou regular o impacto emocional da doença.

Palavras-chave: Enfermagem; Diálise renal; Adaptação psicológica.

RESUMEN

Objetivo: Conocer las estrategias de afrontamiento utilizadas por los pacientes renales crónicos sometidos a hemodiálisis, frente a las dificultades inherentes a la enfermedad. **Métodos:** Estudio cualitativo descriptivo, realizado con 30 personas que viven con problemas renales crónicos en una unidad de hemodiálisis en el noreste de Brasil. Los datos fueron recolectados de enero a marzo de 2013 a través de una herramienta de entrevista semi-estructurada y analizados según el análisis de contenido, modalidad temática. Se utilizó como referencia la teoría de *coping*. **Resultados:** Las categorías que surgieron de las entrevistas fueron: apoyo a la familia; apego a la religión/creencias; negación y evasión; y la resistencia. **Conclusión:** La manera de manejar las dificultades inherentes a la enfermedad fue revelado por las estrategias que se basan en la emoción como en la cuestión de supervivencia. Por lo tanto, se han hecho esfuerzos para administrar o cambiar los problemas iniciales, así como los intentos de sustituir o regular el impacto emocional de la enfermedad.

Palabras clave: Enfermería; Diálisis renal; Adaptación psicológica.

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INTRODUCTION

It is estimated that in the world, diseases of the kidney and urinary tract account for about 850 million deaths annually, and the incidence of Chronic Renal Failure (CRF) is increasing by around 8% every year[1,2]. In Brazil about 12 million people have some degree of renal insufficiency (RI) and approximately 95,000 people with chronic renal disease depend on dialysis to survive. Epidemologic researches estimate that this dependence will grow 9% a year due to the lack of diagnosis in the early stages of the disease[2-4].

Chronic renal failure is related to the decrease in the filtration rate, coupled with the loss of regulatory, endocrine and excretory functions of the kidney. The types of treatment for chronic renal insufficiency are: peritoneal dialysis, hemodialysis and kidney transplantation[4].

So, once diagnosed with CRF, the patient should be submitted as early as possible to treatment, either conservative or dialytic. The treatment is characterized as a difficult and painful experience, but it is essential for maintenance of the life of people with CRF. Therefore, patients with renal diseases must adapt to changes such as new eating habits, modified routine, and dependence on the family and loss of autonomy. And this entails changes in their physical and emotional integrity[5].

What can make a difference in the outcome of the individual adaptation is by learning how to cope with the situation. Thus, for this study, it was adopted as reference the theory of coping, which consists in behavioral and cognitive skills to be used to control internal and external demands, when evaluated by the subject as exceeding the resources available. According to the theory, coping would have as major functions the management or power of change of the stressor event - in this case, coping is focused on the problem; and the control, reduction or elimination of emotional responses to the stressor event, which would be focused on the emotion, as a palliative and when the subject tries to relieve stress, or feel better before an event that can't be removed. Coping strategies focused on the issue will be used if the consequences of a stressful situation are appreciated as reversible, i.e., if they can be removed and or altered; while emotion-focused coping is used more on cases where the stressor consequences are considered unchangeable. These two ways of coping are interrelated, because people when facing a stressor event, use both ways of coping, as a strategy that, in principle, is focused on the problem, but that can also have a focused role in emotion and therefore the emotion and coping occur in a dynamic and reciprocal relationship[6].

Studies on coping strategies in chronic renal failure patients on hemodialysis positively analyze the participation of the family and the care team, which are considered as supportive measures to help face the difficult situations. Besides that, we also have the faith, the religion and the resilience that can be used as measures to address and understand the stressors[7-11].

A study highlights the resilience that some renal patients have. Being resilient is being able to adapt or modify their reality unpredictably and act appropriately and quickly[12]. Initially proposed by physics as the ability of a material to return to its previous state after suffering deformation, resilience, for the psychological sciences, is seen as an explanation for why individuals, even through adverse situations, manage to survive and achieve well-being in their lives, while others in the same situations, are unable to do so[13,14] Studying resilience is very useful in the search the understanding of human phenomena, from the inter-relationship between early experiences, the environment, neurobiology and genetics[15].

To support and justify the development of the study we have sought scientific productions that date from the last five years to the present days on the subject in question and that belong to the computerized databases of the Virtual Health Library (VHL): Latin American and Caribbean Health Sciences Literature (Lilacs) and Medical Literature Analysis and Retrieval System Online (Medline); SCOPUS, CINAHL. There have been few studies that address the coping strategies of chronic renal patients on hemodialysis, with predominance of quantitative, descriptive studies, aimed at the clinical-individual model and systematic reviews with meta-analysis[7-11].

The studies mentioned above addressed: anxiety and psychosomatic symptoms in patients on hemodialysis; Religious/spiritual Coping and psychological adaptation strategy before the IRC; the influence of psychosocial factors in the quality of life of people with chronic kidney conditions; the association between socio-demographic characteristics and coping strategies; the association between psychological distress and quality of life in patients on hemodialysis[7-11].

Thus, the relevance of this study is focused on learning the psychological adaptation strategies in patients with CRF, in order to guide the structuring of humanistic care models that consider not only the biological side of the patients, but also their psychosocial being, targeting to perform comprehensive and multidisciplinary care in nephrology.

From the identified gap of knowledge on the subject, the question is: What are the coping strategies used by patients with chronic renal failure who are undergoing hemodialysis, in face of the difficulties related to the disease? Due to the guiding question of this research, it has aimed at learning about the coping strategies used by chronic renal patients undergoing hemodialysis, before the difficulties inherent to the disease.

METHODS

This is a descriptive study with a qualitative approach, developed in a reference unit of hemodialysis in northeastern of Brazil. The population of the research was composed by 230 registered patients, who were regularly monitored and who were undergoing hemodialysis in that the service. For the selection of the sample subjects, it was necessary to consider the following criteria: age equal to or above 18 years; confirmed medical diagnosis of CRF; and to be on hemodialysis for more than six months. Study patients who were in other treatment modalities, such as peritoneal dialysis, and presented in addition to the IRC, other diseases such as neoplasms, AIDS and Viral Hepatitis, which could change the profile of human responses in these patients were not allowed to participate in the study.

In this sense, considering the chosen criteria, the sample consisted of 30 chronic renal patients. Therefore, it is worth noting that for the composition of the research sample we have applied the assumptions of qualitative tradition, which do not confer relevance to the statistical representativeness of the sample. The goal is, however, to be directed to the generalization of the findings, but through the subjective accumulation at the object to unveil, corresponding to what is known as a theoretical sample[16].

In this context, the present study used the sampling process by theoretical saturation. Data collection was interrupted always when new elements to support the theory (or possibly under the circumstances) were not gathered from the field observation. Right after this stage, the speeches were fully transcribed and categorized by the codename and in order to maintain the anonymity of patients[16].

Data collection occurred from January to March 2013. To gather the empiric material it was used a semi-structured interview tool that was divided into two parts. The first, related to the characterization of the participants (age, sex, marital status, ethnicity, education, monthly income and treatment time) and the second containing issues related to the purpose of the study, such as the difficulties related to the disease and treatment as well as the strategies used to address them. Data were collected at the study site, in a private room with average duration of 25 minutes. The previous scheduling of the study subjects was carried out through the management department and according to the patients' availability. To record the reports a digital recorder was used to capture the discourse of patients[16].

Fieldwork was carried out by three researchers of this study. In order to standardize data collection, these previously participated in a training of 20 hours, taught by research coordinator, and where questions about the study object were answered: pathophysiology of renal failure, epidemiology, types of treatment , complications and Coping. Besides that we also applied the main methodological and theoretical frameworks, techniques, interview and theme analysis of qualitative research for qualitative data. It is noteworthy that all the questions from the collection instrument were discussed in detail with the researchers who collected the data.

Moreover, the ethical principles were highlighted to be addressed during the course of an interview, namely: presentation; justification of the reasons for the search; justification of the choice of respondents; the importance of ensuring anonymity, the confidentiality of responses, and that participants should feel free to stop and ask for clarification; read the Term of Informed Consent (IC) and authorize the recording of the interview, where they explained the reason to being part of it.

After data collection and transcription of the first three lines initiated, we opted to start the analysis and interpret the data. As collections and transcription occurred, the data were analyzed. So the report of field research was consolidated when it appeared that the analysis of the speeches allowed the understanding of the community under study[16].

For such, we have applied the content analysis technique, with thematic modality, which is defined as a set of communication analysis techniques to obtain, through systematic procedures and description of goals of message content, indicators (quantitative or not) that permit the inference of knowledge concerning the conditions of production/reception of these messages[17].

Accordingly, the organization of the content comprised the following steps: encoding the data; categorization of data; and interaction of the theme topics. The analysis began with the reading and rereading of the interview reports, where we sought to identify the focus of the coping strategies experienced by the individuals with chronic renal failure who were undergoing hemodialysis. Thus the Figure 1 exposes the methodological route[17].

Because it is an investigation involving human subjects, the research project was approved by the Ethics and Research Committee of the Federal University of Rio Grande do Norte - UFRN, by Opinion Nº 147,431 and Nº CAAE 03563712.9.0000.5295. Before starting data collection, the study participants were informed about the purpose of the research, we read the IC, so that finally the research could be initiated.

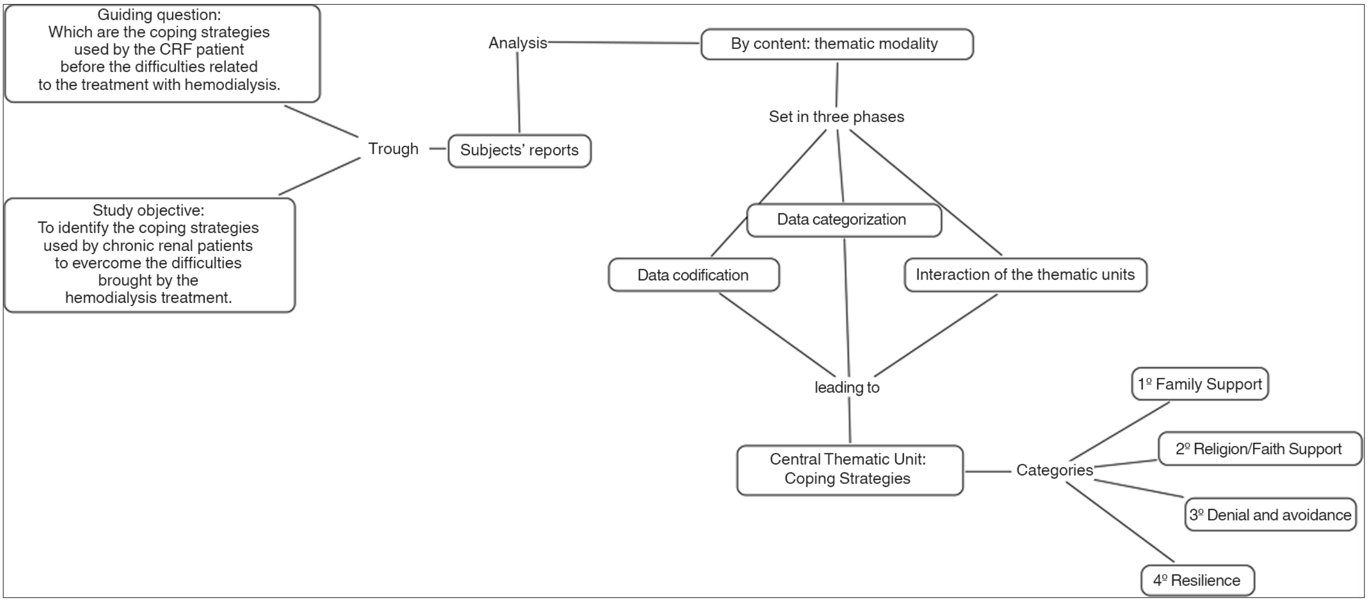
RESULTS AND DISCUSSION

The age of the participants ranged from 25 to 81 years, but was predominantly from 38-49 years. Most of the subjects were male (57.14%), and committed partner (56%). In regards to the ethnicity, 42.85% were black. As for their education, 35.71% had a high school degree, monthly income of a minimum wage (57.1%), and 60% of them were accompanied by family members in the hemodialysis sessions. The duration of treatment ranged from six months to 13 years, and 50% were in the interval of 4-8 years on hemodialysis treatment.

The analysis of the content of the interviews allowed the establishment of the Central Thematic Unit entitled "Coping Strategies" and from this the perceptions of participants emerged into four distinct categories: Category 1: family support; Category 2: religion/faith support; Category 3: Denial and avoidance; Category 4: Resilience.

The results showed that the interviewees used multiple strategies to face the difficulties fostered by the disease and that these are all interrelated. The approach of the coping as a theoretical framework unveiled that these strategies were based both on the emotions and the problems. In the first case, participants looked for in support in their religion/faith, sought the support of their family, and acted in denial and avoidance before stressful situations. However, in the second case, the resilience stood out as a means to face the early problems caused by chronic renal failure and as a form of psychological adaptation to the daily changes brought by the treatment.

Figure 1. Methodological route of content analysis - thematic modality, Natal / RN, Brazil, 2014.



Category 1: Family Support

Through the findings of this study, family support stood out as an important psychological tool in the process of adaptation to the stressful events brought by the hemodialysis therapy.

In the speech of some interviewees it was found that the family generated the psycho-emotional support necessary to overcome the moments of tension and discouragement, as follows:

> *[...] The disease brought many losses and disappointments in my life [...] it changed my life routine [...] it was my family who gave me support when I needed it and also offered me assistance (E5).*
>
> *[...] It was support of my family that helped me face hemodialysis [...] mostly my girls. Whenever I was down (discouraged), they helped me a lot (E1).*

The family, when around and close to the ill individual seeks to help their members at all times. It emerges as the primary means to assist CRF patients cope with the difficulties brought by the disease, minimizing the losses and frustrations imposed by the pathology in their life. Such fact favors coping with the disease and the treatment[18,19].

Nevertheless, the etiological factors that lead to the development of CRF result from congenital diseases such as hypoplasia or renal dysplasia, and diseases that cause changes in renal structure of an individual. Because it is an illness whose cause can be hereditary, patients possibly have experienced at some point in their life living with relatives who developed DR and were in treatment[18-20].

This previous experience proved to be very effective as for the assistance provided to chronic renal patients during their psychological adaptation. The exchange of information and feelings softened the impact for those who have been recommended to undergo hemodialysis, as expressed in the following reports:

> *[...] I had a nephew who died doing the treatment with hemodialysis and he went through the same difficulties and troubles I have faced [...] my family supported me a lot [...] It was them who I counted on to get better [...] They helped me a lot [...] They explained to me all about the disease and the treatment (E6).*
>
> *[...] I had an aunt who was on hemodialysis[...] she explained how the treatment on the machine was and all about the medications. (E8).*

What is observed is that when close people can understand and explain the changes that will be imposed to the individual through the diagnosis and treatment, with a more personal language, coping becomes better managed[21].

In contrast, the research has shown that the lack of information and ignorance about hemodialysis act as stressors. The approach to these patients should therefore enable the transmission and understanding of the information with clear and accessible language, compatible with the context of each person[22].

So the family support should be considered by the health and nursing team as a decisive part in assisting chronic renal people. As the patient fights the disease, the family has the opportunity to avoid stressors, softening the impact that dialysis generates, allowing a positive assessment by the patient about their quality of life[22].

Category 2: Religion and Faith Support

The participants said they faced the disease, adverse situations and the difficulties inherent to the treatment more favorably with faith in God and the support of their religion. Some statements uttered by the participants reinforce this belief.

> *[...] It was my faith in God and my religion, my faith gave me optimism and helped me overcome this disease and the problems and difficulties of the treatment [...] if it were not so, I have no idea what I would have done (E2).*
>
> *[...] I sought God and practiced my religion with a positive thinking to overcome these stressful times, and to be able to go through it; to have the strength to continue fighting this disease [...] if it weren't for faith in God I would have given up the hemodialysis (E14).*

In most of the interviews it was found that the participants kept their beliefs as a way to find relief. Regardless of the religion they practice, it's the faith in a higher being which makes them able to handle the treatment and all the burdens cause by the disease[23].

According to a particular study, individuals who have any religion or belief demonstrate fewer difficulties in coping with renal disease than individuals who claim not to have any type of religion[24].

The faith in God, optimism and positive thinking that arise from the coping related to the religion are strong influences on the development of adaptive responses to the difficult situations brought by the disease. When the patient makes use of religious coping, such as praying and joining groups or meetings in the churches, the diagnosis of a chronic disease can be understood as part of a larger plan, rather than a simple random event. Such fact helps shape the sense of meaning in the lives of patients and the adaptation to the new situation faced[23,24]. This spectrum was quite emphasized in the speeches below:

> *[...] As I always attended church and lived in prayer groups, I believe that there is a divine purpose for everything, everything is God's will (E11).*
>
> *[...] When I found out I had to undergo hemodialysis, I prayed to God, and joined prayer groups. Well, then I could control my despair, it made me hang in there, because I know God will heal me and free me from that machine (E4).*

It is noteworthy that the search for religious practices may lead to the denial of the problem by assigning the solution of that problem to a divine being. Each person has a subjective way of dealing with the disease, with the treatment and the impact caused in the lives of those part of their social network. And, it is involved in this context that faith is unquestionably an important coping mechanism. The faith a higher power allows a dose conformity to the new situation, playing thus an important role in various spheres of the individual with chronic renal disease[25].

Category 3: Denial and avoidance

In the words of the participants, it was noticeable that in spite of their awareness about their pathological status and the need for hemodialysis, some clung to a reality in which the disease was no longer present, and that the treatment was just a temporary thing, as it is explicit below:

> *[...] my son, I know I have to come to do this treatment, but I have faced it all as if it were the treatment of any disease. [...] I avoided thinking about this disease (E1).*
>
> *[...] every time I come here, I say it just needs this one more time on this machine, that this will be the last time. Deep down I know it's not true, but if I keep thinking otherwise I'll have to come here for the rest of my life, I would go mad* (E2).

Putting away some thoughts to other activities, in order to mitigate or even forget the need and requirement of a treatment to replace kidney function was also demonstrated in this study, as the lines:

> *[...] I tried to do so to overcome the difficulties of everyday life: when the hemodialysis was finished, I disconnected myself, I forgot that it existed [...] It didn't use to keep thinking about it.[...] I was thinking about my work (E25).*
>
> *[...] I really forgot I had this disease and didn't care about it, but I was not careless with the treatment, I always took the drugs and never missed the hemodialysis sessions (E15).*

By finding out the existence of an incurable disease, the person goes through a series of feelings that cause conflicts. The most obvious feelings in general are denial, anger, bargaining, depression, isolation and the acceptance. The important thing is understand that each person goes through these changes individually, with intervals and own sequences[25,26].

Accepting their own condition becomes an event that is, to put it mildly, difficult, because in these situations one may be induced to seek defense mechanisms, such as the avoidance and denial. Due to the fact the chronic renal disease, along with the treatment of hemodialysis, brings significant restrictions on maintaining the quality of life of these patients, the denial of the disease and need for treatment becomes a coping option found[27].

The denial or avoidance, as an escape from reality, or attempt to adapt to their new condition, causes the individual to stop seeking help for their emotional and physical health, decreasing their support network. This factor becomes relevant because strategies involving denial are described as more associated with low levels of suffering and quality of life[28].

The acceptance of difficulties of the disease are dependent on external and internal conditions of the individuals. The external arise from the participation and support of the family health professionals, and that can influence the process of acceptance of the disease. So it is up to the health professionals to be attentive to contribute positively in this acceptance[13].

Category 4: Resilience

The reports of the participants showed that, for more debilitating that hemodialysis treatment might be, some mentioned that they managed to overcome the stressful situations and took advantage of them, achieving better levels of quality of life:

> *[...] I'm the only one who knows what I went through, knowing that you are a renal patient at the beginning was complicated, difficult, but we have to overcome everything in life [...] all this brought a great impact to my life [...] Many things also go better [...] nowadays live better [...] even my family, friends and the nursing staff said that I became very different [...] I had their help to overcome difficulties caused by the disease and this treatment (E4).*

In this last speech, it was observed that the family, the interviewee's friends and the nursing staff were part of building their resilience because resilience arises not only due to an innate characteristic of an individual, but by the interaction of one and the complexity of their social context.

As noted in the speech above, hemodialysis generates impact and significant changes in the way of life of chronic renal patients, and usually it's very difficult for them to cope with this stage of their life. As nurses are close to all these changes, it is their duty to help the CRF patients in the resilience process, acting as an educator and facilitator in the hemodialysis therapy process[12].

In this sense, the role of nurses is emphasized as the main agent of the patient's resilience during the process in hemodialysis, once they offer ways of understanding about the disease, so that the chronic renal patient may develop self-responsibility, changes in their lifestyle and produce hope and perseverance to promote their adaptation to hemodialysis[12].

This process will only be effective and extremely important if the nurse attach to their routine periodic assessment of the level of adaptation of chronic renal patients on hemodialysis, offering them information about the treatment, such as new modalities, advantages and disadvantages of therapy. They need to act as educators and facilitators in the resilience process of chronic renal patients on hemodialysis treatment. As a result, the application of the concepts of resilience by the nurses will create a new opportunity to see and carry out the care of chronic renal failure patients on hemodialysis[12].

In this context, the health professional and family can contribute by encouraging the resilience, not only emphasizing the biological aspects of the disease and seeking to highlight the potential that the patient has, but also trying to help the patients to realize themselves as responsible for their treatment and able to manage and to control their impulses, develop empathy, be optimistic, analyze the causes, seek self-efficacy, maintain and create new bonds, and have always the meaning of their life as their basis.

> *[...] My philosophy of life is- if I get stuck on bad things, I will only attract bad things [...] so I adhered to the treatment [...] I had emotional and financial losses [...] a few friends moved away, but good things happened too [...] I started to have more responsibility in life, eat healthier things [...] I stopped drinking, smoking and doing drugs [...] I started to think better about what I was doing with my life [...] It was not all bad, [...] I feel better [...] ever since it happened I started to use my free time to be with my family (E12).*

It was noted in the reports that resilience was configured as an ability to give a new meaning to life, due to several changes of emotional, social, economic and family natures. In addition, it was also noted a change in the lifestyle and adherence to the treatment, through the accepting to their new chronic health condition, motivated by positive thoughts, which thereby led to the improving of their quality of life and interpersonal relationships.

This conception of resilience as a coping strategy, presented in the lines above, revealed that well-being and quality of life not always represent contradictory and incompatible states in the life of people living with chronic renal conditions. Thus, the initial impact of the disease can either be of extreme adversity, but may also be experienced and even redefined as a potential source for change and new opportunities in life.

In this sense, resilience contributed to the knowledge of the factors that allowed the patient develop healthy emotional conditions to overcome adversity, such as the limitations of chronic illness, and therefore were able to adapt without further damage[15]. Thus, emotion is characterized if as a feeling of complex and multifaceted dimension that arises from the subjective intrinsic relationships among various feelings, and that can provide the individual with discernment of the causes of reality and viability towards mechanisms for coping with the diversities in life[29].

The reports also indicated that resilience can explain the mobilization of psychosocial resources for dealing with disruptions, changes and situations of tension related to the disease. It was observed that in this new environment, brought by the transformation of the initial crisis into life-changing opportunities, the development of resilience can be the differential element between coping with the adverse situation which will lead to psychological growth. Thus, resilience involved the internal redefinition of the situation live, and possibility of personal growth as it seems to be associated with self-awareness, i.e., an understanding of the person-disease-subjectivity-overcoming.

In this context, the resilient individual demonstrates an optimistic attitude towards life, maintaining a dynamic balance during and after the conflicts of the treatment against the disease, allowing themselves to overcome the pressures of their world, developing self-confidence and a sense of self-protection that do not ignore the openness to new events, to changes and to the underlying reality[12].

Finally, the discourse of resilience has become visible in this study, where the interaction with the machine appears to no longer pose as a stressful event, but now as an acceptable factor necessary for the survival of those reliant on it[14].

CONCLUSION

This study evidenced that, despite the difficulties and limitations imposed by chronic renal failure, its treatment and the uncertainty present in the everyday life, patients develop strategies that enable them face and get along better with the disease.

The coping focused on the emotion was characterized by the religion/faith support, the search for family support, the denial and avoidance. The coping focused on the problem was represented by resilience as a way to give a new meaning to their experiences, to seek adherence to the treatment and the care for their body in an attempt to minimize the problems.

The reaction towards the disease and the strategies used by individuals, then, seem to be important factors that must be considered for the promotion of health and quality of life of these patients. The knowledge on coping measures will allow the health care team provide adequate support in order to prevent attitudes of pessimism and discouragement in regards to living with the disease.

In this sense, the findings indicate that the nursing care for people living with chronic renal conditions may not be limited to traditional treatments, but it needs to cover the experiences of life as a whole, because health is closely related to daily events.

It is constituted as a study limitation the fact that coping strategies are personal and subjective phenomena, but without scientific improprieties. Thus, It's necessary the development of new studies that may investigate and contribute to the use of coping strategies in the construction of care protocols and nursing care plans for people living with chronic renal disease. Moreover, it is also required the development of new researches that attempt to understand the perspective of health professionals about the importance of coping in the assistance provided to other patients with chronic diseases, which will favor the clinical application of this phenomenon.

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