



COPING WITH CHRONIC KIDNEY DISEASE: CHALLENGES EXPERIENCED BY HEMODIALYSIS USERS

¹Bruna Karlla da Silva Campos, ²Nathália Roberta de Menezes Barbosa Serafim, ³Silvana Cavalcanti dos Santos, ⁴Valdeilson Lima de Oliveira, ⁵Valquíria Farias Bezerra Barbosa, ⁶Juliane da Silva Pereira, ⁷Robervam de Moura Pedroza, ⁸Valdirene Pereira da Silva Carvalho, ⁹Luana Eugênia de Andrade Siqueira, ¹⁰Claudia Daniele Barros Leite Salgueiro, ¹¹Lucicláudio da Silva Barbosa, ¹²Ana Karine Laranjeira Sá, ¹³Nelson Miguel Galindo Neto, ¹⁴Jhenyff de Barros Remigio Limeira, ¹⁵Leonardo Silva da Costa and ¹⁶Ana Carla Silva Alexandre

¹BSN. Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

²BSN. Laboratory Technician, Federal Institute of Education, Science and Technology of Pernambuco

³MSc in Collective Health, Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

⁴BSN. Emergency nurse. Nursing Department, Arcoverde School of Health

⁵DSc in Human Sciences. Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

⁶BSN. Collaborative Researcher of Health Care and Promotion Research Group, Federal Institute of Education, Science and Technology of Pernambuco

⁷MSc in Collective Health, Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

⁸MSc in Economy and Management of Health, Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

⁹BSN. Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

¹⁰DSc in Gerontology. Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

¹¹MSc in Biology, Federal Institute of Education, Science and Technology of Pernambuco;

¹²MSc in Health Sciences. Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

¹³DSc in Health Sciences. Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

¹⁴Nursing undergraduate student. Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

¹⁵Nursing undergraduate student. Department of Nursing, Federal Institute of Education, Science and Technology of Pernambuco

¹⁶DSc in Health Sciences, Department of Nursing, Federal Institute of Education of Pernambuco, Science and Technology

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ABSTRACT

Background: Chronic Renal Failure presents high mobility and mortality, so hemodialysis patients change their routine and need more support for coping with the diagnosis. This study aimed to identify the main difficulties experienced by patients undergoing hemodialysis. **Method:** A cross-sectional study with a sample size of 30 users from a renal replacement therapy clinic through a survey by Likert scale. It was stored and analyzed by SPSS version 18.0. **Result:** It was observed that 56.67% were males, 33.33% age range was 18 - 30, about the current health status, 40% said that was reasonable. Regarding self-image associated with hemodialysis devices, 75% of users with dual lumen catheters report that the use of the device interferes with body image ($p = 0.03$) and 70.59% of people with positive feelings and hopeful, affirm that the disease had little effect on social relations ($p = 0.01$). Among the main difficulties found was the impossibility of working, thus they experienced financial loss (56.7%). **Conclusion:** Individuals who used this type of therapy suffer interference from physical, psychological and social factors. The study allowed to know this reality and to reflect on challenges in coping with the disease. It is hoped that future discussions will favor the social and clinical progress of users.

INTRODUCTION

Chronic renal failure (CRF) is classified as irreversible and often fatal loss of total capacity of renal function, thus it subjects the patient to dialysis or renal transplantation (Gracelli *et al.*, 2012). Chronic kidney disease (CKD) affects 5-10% of the world's population and affects people of all ages, races and social status. The incidence of the disease is one in five men and one in four women between 65 and 74 years of age. Chronic renal insufficiency (CRI) is the most advanced stage of renal disease and has as its main characteristic, the progressive and irreversible loss of the multiple functions of the kidney, which cause several changes in all systems of the organism. Such losses contribute to the failure of the body's ability to maintain metabolic and hydro electrolyte balance, which leads to retention of urea and other blood components (Coutinho, Costa, 2015). Once diagnosed with CRF, the user should start treatment as soon as possible, conservative or dialysis. This process is characterized as a difficult and painful experience, but essential for maintaining the life of the CKI sufferer. It is necessary to adapt the users to such changes resulting from dialysis treatment which includes new eating habits, water restriction, daily activities changes, family dependency and autonomy loss which, consequently, modify the user's physical and psychological integrity (Silva *et al.*, 2016). Brazil has the largest public transplant system in the world, and it includes support for surgical procedures, medication and essential follow-up to post-transplantation (Machado *et al.*, 2012).

The treatment of hemodialysis (HD) favors care improvements since it allows the early identification of high-risk individuals which raises well-being conditions and contributes to healthcare strategy and actions planning. Studies show that the increase in HD expenditures is due to the survival growth of population treatment and not to the therapeutic growth demand (Teixeira *et al.*, 2015). Even with all the investment in technological and therapeutic advances in dialysis that have contributed to a greater survival of patients with CRF, the factors that affect their living conditions are still sensitive. The users submitted to hemodialysis therapy present low coping patterns which include physical, psychological and social aspects, with an unsatisfactory clinical response, high difficulty of treatment adherence, increased hospitalizations, morbidity and mortality rates (Guedes *et al.*, 2012). The rising incidence of individuals with CKD in hemodialysis treatment is a known fact that has evoked many discussions. One of the greatest challenges is related to the welcoming, health assistance, and the vast majority of people's health condition cases with CRF that is impaired due to the symptoms severity, routine and social life changes, HD machine and specialized team dependency, and the acceptance of a rigorous therapeutic scheme for maintenance of its lifetime. Faced with this problem, this study aimed to identify the main challenges experienced by patients with CRI undergoing hemodialysis.

MATERIALS AND METHODS

This is a cross-sectional study with a quantitative approach, performed in a clinic for renal replacement therapy, agreed with the Unified Health System (SUS), located in Arcoverde, Pernambuco, Brazil, between the years 2016 and 2017. This clinic serves to 309 patients from 28 surrounding cities that travel on average three times a week for HD treatment, lasting

four hours daily. The sample size consisted of 30 individuals, randomly selected, who underwent hemodialysis treatment. Participants of the study were those with CRI who sign the voluntary informed consent form (VICF), over eighteen years of age and who had the physical and mental capacity to respond to the survey. Patients who presented some intercurrent at the time of data collection or those who were not present at the clinic during the study period were excluded. The questionnaire was validated through the pilot test survey with 10 users who were not part of the sample. Possible failures were minimized and data collection started. The current study has been approved by the ethical committee in charge (Research Ethics Committee of the Federal Institute of Sertão, under opinion 1,850,701. Afterward the application, it was applied socio-demographic variables, challenges referred after disease diagnosis and coping behaviors. The information was settled with the users during the HD session and pre-scheduled at the administrative department. The Likert scale was used for a better evaluation and understanding of the variables of the users' health conditions. This scale is based on a result and allows analyzing the affirmations and definitions that answers indicate according to the statements and its degrees of agreement or disagreement regarding the attitude that is validated. The psychometric scale is assigned to reflect the intensity of respondents' responses (Júnior, Costa, 2014). Data were stored and the analysis performed through descriptive statistics using the Statistical Package for Social Sciences (SPSS) for Windows, version 18.0. It was given a 95% confidence interval and the chi-square test was used to compare qualitative variables.

RESULTS

Kidney disease (KD) has been marked by reaching a huge portion of the adult population. Table 1 presents the sociodemographic profile of the users in HD treatment, including gender, age, race, marital status, education level, income and occupation of the patients, moreover, mainly means of transportation to the clinic and treatment device. The higher prevalence of CKD patients was male, 56.67% (n = 17), age ranged from 18 to 75 years, mean age of 41 years and standard deviation (16, 18). Regarding the educational level, 43.3% (n = 13) attended only elementary school; in relation to race, 30% (n = 9) are white, and about marital status, 53.3% (n = 16) are married. Respecting to the occupation, 66.7% (n = 20) reported that they are retired, in sickness benefit or disability pension, and concerning to family incomes, 83.3% (n = 25) of the patient respondents is between 1 and 2 minimum wages. Regarding the means of transportation that ridden the patients to the clinic, 76.7% (n = 23) of the interviewees reported using vehicles offered by the government as the main transportation. It is observed that 26.7% (n = 8) are on HD at least for three to five years, 73.3% (n = 22) of the users use arteriovenous fistulas as the main hemodialysis access. The health perception and perspectives of coping with the disease after the diagnosis of renal disease (RD) is an important factor for the quality of life outcomes. Table 2 presents the users' analysis regarding their state of health and the interferences caused by the treatment in their lives. When asked about their current state of health and after CRI diagnosis, 40% (n = 12) stated that they had a reasonable health condition; in relation to the control of the disease, 53.3% (n = 16) reported being good and very good. Regarding the interference provided by the treatment, 50% (n = 15) stated that there is a lot of interference to perform general activities,

Table 1. NephrologyClinicUsers' sociodemographic profile, 2017, Arcoverde- Pernambuco, Brazil

CHARACTERISTICS	N	%
Gender		
Male	17	56,67
Female	13	43,33
Age range		
18-30	10	33,3
31-45	9	30
46-60	6	20
61-75	5	16,6
Race		
White	9	30
African descendent	5	16,7
Brown	16	53,3
Marital status		
Single	9	30
Divorced	5	16,7
Married	16	53,3
Educational level		
Primary	13	43,3
Secondary	11	36,7
College	4	13,3
Unlettered	2	
Occupation		
Student	4	13,3
Retired	20	66,7
Rural worker	4	13,3
Homeworker	1	3,3
Family and domestic activities by itself	1	3,3
Family Income (minimum wage)		
1-2	25	83,3
3-4	1	3,3
5 or more	3	10
Lower than 1	1	3,3
Developed environments		
Urban	16	53,33
Rural	14	46,67
Time of treatment (years)		
Lower than 1	7	23,3
1-2	9	30
3-5	8	26,7
6-10	2	6,7
Higher than 10	4	13,3
Hemodialysis access		
Central venous catheter	8	26,7
Arteriovenous fistulas (AVF)	22	73,3

Table 2. Analysis of the users' health status after CKD diagnosis, interference of diagnosis in the CKD patients' lives and daily activities. 2017, Arcoverde-Pernambuco, Brazil

LIKERT SCALES VARIABLES- N (%)	Very poor	Poor	Fair	Good	Excellent
How do you evaluate your health status?	5 (16,1)	19 (61,3)	5 (16,1)	0(0)	1 (3,2)
Actual health status	8 (26,7)	12 (40,0)	7(23,3)	2 (6,7)	1 (3,3)
Health status after diagnosis	9 (30,0)	12 (40,0)	8 (26,7)	0(0)	1 (3,3)
Coping with disease	6 (20,0)	8 (26,7)	8 (26,7)	8 (26,6)	0(0)

Table 3. Measurement of different interferences that appear after CKD diagnosis.2017, Arcoverde- Pernambuco, Brazil

LIKERT SCALES VARIABLES- N (%)	Low	Average	High	None
Interference in general activities	5 (16,7)	8 (26,7)	15 (50,0)	2 (6,7)
Interference in acquaintanceship	7 (23,3)	5 (16,7)	10 (33,3)	8 (26,7)
Interference in auto image	7 (23,3)	6 (20,0)	7 (23,3)	10 (33,3)

among them, leisure time, physical exercises, self-care and domestic activities. Relating to social relationships, the table 3 presents that 50% (15) of the sample referred strong interference in the labor activities, and 33,3% (n=10) of the users affirmed that chronic conditions had negative interferences in the acquaintanceship. Regarding self-imagining, 39.96% (n= 12) of the patients affirmed their feelings faced by the treatment.

Among these users, 33.3% felt shamed/ embarrassed, 3.33% felt isolated and 3.33% felt ugly. Regarding coping in daily life, 56.7% (n = 17) of users reported that absence from work and financial situation are the main difficulties experienced after renal replacement therapy (RRT), besides of 20% of effective and 23.3% social life losses. Table 4 presents the association between coping with disease variables presented by the users.

Table 4. Association between coping with disease variables that arise after diagnosis.2017, Arcoverde-Pernambuco, Brazil

Feelings- N(%)	Positives	Negatives	p (Value)
Social relationship			
Do Not interfere	12 (70,59)	3 (23,08)	0,01
Do Interfere	5 (29,41)	10 (76,92)	
Physical activity			
Do not interfere	9 (52,94)	2 (15,38)	0,03
Do Interfere	8 (47,06)	11 (84,62)	

Regarding the feelings experienced and handle with social relations, 70.59%. (n = 12) of people who think positively and have hopeful feelings, report that the disease does not interfere in social relations (p = 0.01). Regarding physical activity, 84.62% (n = 11) of patients who have negative and unmotivated thoughts about the disease, report that the chronic situation interferes too much in the physical exercise practice (p = 0.03). Among the users residing in the rural area, 71.43% (n = 10) reported an enormous interference of the distance between their homes and the renal clinic where they were treating the CKD in relation to coping with the disease against 31.25% from those who live in the urban area (p = 0.02).

DISCUSSION

CRI is a major public health problem and it has hemodialysis as the main therapeutic intervention. For this cause the individual who faces HD as a possibility for treatment, it experiences new experiences that generate countless feelings that negatively impact their lives, such as low self-esteem, poor adequacy of treatment and dissatisfactions which can cause interference in the clinical picture (Santos *et al.*, 2017). The confrontation of people with CRI suffers interference of physical, psychological and social changes, not only in the patient's life but also in the daily life of their relatives. All subjects become fragile, depend on increased family and specialized care. They begin to experience personal procedures and behaviors that alter the way of life, therefore, the feelings and the perceptions about the existence itself. The person with CRI undergoing hemodialysis coexists with the fact that they have an incurable disease that forces them to undergo painful and uncomfortable therapy that has limitations and impacts on life as a whole (Ribeiro *et al.*, 2013). These individuals go through a process of gradual adaptation after the diagnosis that often they are faced with obstacles that come to diminish the self-perception of improvement or appear depressive symptoms that follow from that phase of the adaptation. During the first year, from the beginning of treatment, the difficulties of adjusting itself to treatment have a greater degree of relevance (Nascimento, 2013).

Understanding health may vary between different individuals or in the same individual over time, as well as in the advancement of their disease. Usually, people relate the condition of global well-being to their health and end up often comparing the expectations with the lived experiences. Whereas it is a highly individual concept, there are several visions and interpretations, and it is difficult to associate with all the important aspects of each person's life (Cullis *et al.*, 2012). Studies conducted in dialysis clinics in Brazil, especially in the city of São José do Rio Preto, State of São Paulo, indicate that 63.55% of the users are males and the mean age is 58 years. Regarding marital status, 58.88% were married or had a stable union (Oller *et al.*, 2012). In Maragheh,

a city located in Iran, it was found that 58.49% of the users were males, the mean age was 54 years and 86.8% were married (Matlabi, Ahmadzadeh, 2017). These data corroborate with the present study, portraying a high social significance, since the population most affected by chronic renal failure is part of the economically active group, implying social expenditures, evidenced by early retirement benefits, outpatient, hospital and medication expenses (Teixeira *et al.*, 2015). It can be confirmed that most of the users have a low educational level and a low income, resulting in an ineffective knowledge about the pathology, their respective treatments, and minimal financial conditions. On the other hand, another study affirms that high schooling provides a better understanding of the disease and the adoption of healthy lifestyle practices (Hajian-Tilaki *et al.*, 2017). The majority of users of the HD service residing in the urban area that coincides with another study at the Beheshti Hospital in Babol, northern Iran (Hajian-Tilaki *et al.*, 2017). The time devoted to treatment is extensive, which implies physical, psychological and financial exhaustion caused by the displacement of their cities of origin to the treatment center, in addition to the hours of hemodialysis therapy, ranging from 3 to 4 days a week for a period of 3-5 hours daily (Santos *et al.*, 2017). All these factors influence a decay of the user's life condition, since most of the time cause changes in daily activities, taking into account changes in diet, spending less time with the family and feelings of anxiety and dissatisfaction (Cullis *et al.*, 2012; Cavalcanti *et al.*, 2013).

The patients with chronic kidney disease in HD are not totally unable to perform activities related to their daily life, corroborating with studies that indicate that individuals undergoing hemodialysis have the possibility to perform some daily activities, once even facing all difficulties, they could join planning and carry out activities and relevant projects to life with their professionals and families (Silva *et al.*, 2016).

Regarding the coping impact, there is a statistically significant association among users who reported having negative thoughts about using the double lumen catheter. These refer that the device implies in simple daily activities and mainly in the self-image, beyond the cares and limitations that the catheter requires. In contrast, a study carried out in the Southern Region of Brazil points out the two types of access (AVF and double-lumen catheter) as generators of negative repercussions in the users' life (Santos *et al.*, 2017). AVF did not negatively affect most of the interviewees. It is considered the main viability resource of renal substitutive therapy generating a great concern to keep it in proper functioning. A minority reported embarrassment against laity curiosity. In agreement with a study carried out in Minas Gerais, interviewees presented conflicting opinions between perceptions of AVF as a safe and effective strategy, and as a discomfort that creates embarrassment among society (Ribeiro *et al.*, 2013). The main difficulty referred to handle, since the discovery of the diagnosis, is the tangent labor / financial situation since the HD process is a highly exhausting therapy, which consumes time and disposition, which generates feelings of frustration due to the difficulty of employed permanence (Cavalcanti *et al.*, 2013). Individuals believe that the health perception and meaning remained reasonable both after diagnosis of CRF and at the beginning of hemodialysis treatment. Other studies result in a parallel between worse and better than comparea current health status with a year ago health situation (Moreira *et al.*, 2009). Each individual has a different perception about the meaning of health, well-being,

positive and negative feelings that directly have an influence to confront the disease, agreeing with a research carried out in Piauí that shows that such feelings participate positively or negatively in the condition of life (Santos *et al.*, 2015). The user's circumstances may influence self-evaluation and self-perception, causing changes in the biological, psychological and social spheres that govern the breadth of the health meaning (Moreira *et al.*, 2016). It is essential to expand the knowledge focused on coping since it is an extensive theme, which directly reflects the modification of the morbidity and mortality profile. Thus, it is necessary to perform interdisciplinary interventions in renal replacement therapy, ensuring the physical and mental well-being of the users (Caveião *et al.*, 2014; Santos *et al.*, 2017).

Conclusion

The study allowed knowing the reality of the people affected by the CRI and its manner to handle that chronic disease in relation to the coexistence with the pathology and adaptation to its new health context. It is noticed that the users were men, with economically active age, that present positive and motivating feelings on the confrontation of the disease. As difficulties, they pointed out that the aspects related to low income and the workforces that are the major obstacles that they experience, besides the device that reflects negatively in the self- image and social life. The understanding of that health condition and the main modifications that occur in the daily lives favors a construction of reflections to consolidate this study. This research is expected to have professional and academic significance to stimulate reflective and empathic discussions about the relationship that the individual with CKD has with treatment and routine changes to promote holistic and humanized care in order to better health conditions and a better response to the disease.

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