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DAILY LIFE OF PATIENTS WITH CHRONIC RENAL FAILURE RECEIVING HEMODIALYSIS TREATMENT

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This analytical descriptive study aimed at assessing the perception of people with chronic renal failure in relation to their daily and occupational activities. The sample was formed by 35 men and 35 women receiving hemodialysis treatment with ages between 17 and 60 years. The instrument used was the SAOF (Self Assessment of Occupational Functioning). The data were submitted to statistical analysis and the areas with greater choice of the alternative "need to improve" were habits (20%) and values (20.5%). In these areas, the proportion related with difficulties was more evident regarding organization of the daily life, the changes of routines and the expectations about the future. Therefore, occupational therapy, as it presents instrumental resources to reorganize daily life of these patients, can contribute for their care as well as with information for nursing.

DESCRIPTORS: renal insufficiency, chronic; renal dialysis; activities of daily living

EL DÍA A DÍA DE PERSONAS CON INSUFICIENCIA RENAL CRÓNICA EN TRATAMIENTO DE HEMODIÁLISIS

Este estudio analítico-descriptivo tiene como objetivo evaluar la percepción de las personas con insuficiencia renal crónica en relación con las actividades cotidianas y ocupacionales. El análisis fue compuesto por 35 hombres y 35 mujeres en tratamiento de hemodiálisis con edad entre 17 y 60 años. El cuestionario utilizado fue el SAOF (Self Assessment of Occupational Functioning). Los datos fueron sometidos a análisis estadístico y las opciones que fueron las más escogidas en la alternativa "necesidad de mejorar" fueron la de hábitos (20%) y valores (20,5%). En esas áreas la proporción relacionada a las dificultades fue más evidente en lo que se refiere a la organización de lo cotidiano, a cambios de rutinas y las expectativas sobre el futuro. Por lo tanto, la terapia ocupacional, por presentar recursos instrumentales para la reestructuración de lo cotidiano de esos pacientes, puede contribuir para asistirlos, así como entregar informaciones importantes para la enfermería.

DESCRIPTORES: insuficiencia renal crónica; diálisis renal; actividades cotidianas

O COTIDIANO DE PESSOAS COM INSUFICIÊNCIA RENAL CRÔNICA EM TRATAMENTO HEMODIALÍTICO

Este estudo analítico-descritivo objetivou avaliar a percepção das pessoas com insuficiência renal crônica em relação às atividades cotidianas e ocupacionais. A análise foi composta por 35 homens e 35 mulheres em tratamento hemodialítico com idade entre 17 e 60 anos. O questionário utilizado foi o SAOF (Self Assessment of Occupational Functioning). Os dados foram submetidos à análise estatística e as áreas com maior escolha da alternativa "necessidade de melhora" foram de hábitos (20%) e valores (20,5%). Nessas áreas, a proporção relacionada às dificuldades foi mais evidente no que se refere à organização do cotidiano, a mudanças de rotinas e às expectativas quanto ao futuro. Portanto, a terapia ocupacional, por apresentar recursos instrumentais para a reestruturação do cotidiano desses pacientes, pode contribuir para a assistência deles assim como informações para a enfermagem.

DESCRIPTORES: insuficiência renal crônica; diálise renal; atividades cotidianas

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INTRODUCTION

For a better understanding of the importance of kidneys, some of their functions are: excretion of metabolic waste products, production and excretion of hormones and enzymes, and hormone metabolism (insulin). Chronic Renal Failure (CRF) is considered a complex disease that leads to loss, usually slow and progressive, of the capacity of kidneys to excrete. This concept may be translated by the progressive reduction in glomerular filtration which is the main mechanism to excrete toxic metabolites produced by the body⁽¹⁾.

The main signs of renal loss are blood hypertension and anemia. There are also neurological signs (irritability and tremors), cardiovascular (pulmonary edema), endocrine (hyperglycemia and weight loss), and metabolic (weakness)⁽¹⁾. Other important information supplied by the Brazilian Society of Nephrology⁽²⁾ are the manifestations of renal disease that people can present such as pain at urination, low back pain, weakness, and nausea.

Susceptibility of people with CRF to infections due to blood transfusion is much greater in the presence of diseases such as B and C Hepatitis and AIDS⁽¹⁾. Most common diseases that may lead to CRF are: diabetes, blood hypertension and glomerulonephritis. Because of that, controlling pressure is extremely important to prevent hypertension, as well as controlling diabetes which is one of the main causes for kidney failure⁽²⁾.

Regarding CRF treatment, normally, it occurs in the most developed stages of the disease, in a period where loss of renal function is almost total, requiring either dialysis or transplant⁽¹⁾. Treatments available in terminal renal diseases are: Continuous Ambulatory Peritoneal Dialysis (CAPD), Automated Peritoneal Dialysis (APD), Intermittent Peritoneal Dialysis (IPD), Hemodialysis (HD), and renal transplant. We must remember that all treatments are to relieve patients' symptoms patients, not to heal⁽³⁾.

Regarding dialysis, hemodialysis is a procedure that depends on a dialyzer (capillary filter) to filter the blood. In the procedure, patients' blood is withdrawn from one vein, through an arteriovenous fistula or a catheter and taken directly by tubes to a filter connected to a machine. This filter can extract blood, waste and excess of water and salts. After filtering, clean blood is then returned to patients⁽⁴⁾.

Regarding statistical dates, Census of 2005 of the Brazilian society of Nephrology with the support of 83% of the existent dialysis units, reports that there are 54,311 patients undergoing dialysis, 48,362 patients in HD, 3,638 in CAPD, 2,073 in APD, and 238 in IPD. Annual incidence in patients undergoing HD is around 100 cases per million inhabitants; however, regarding annual cost, transplant has a lower cost when compared to dialysis and hemodialysis⁽⁵⁾.

CRF is a disease with high morbidity and mortality. There is progressive increase in the incidence and prevalence of patients with end stage renal disease in Brazil, thus, renal disease is a major public health problem. Prevalence rates of end stage renal disease treated in Brazil are 4 times lower than those of the United States (USA) and Japan, and half of the rates of Italy, France, and Germany⁽⁶⁾.

Regarding risk factor, the most important ones are diabetes and advanced age. According to statistical data from 1999, in Brazil, 52% of dialysis patients were male and, as for age group, 26% were over 60, with an estimate of increase in this age in the last years; 2.2% were less than 18 and only 297 of these patients had age equal to or below 10 years old⁽⁶⁾. In the last years, the Ministry of Health in Brazil has invested in hemodialysis machines, in supplying medication and performing transplants⁽⁷⁾.

Because of all the above mentioned regarding definition, signs, symptoms, and treatment of the disease, we understand that patients with CRF suffer several physical, social, and emotional limitations, including difficulties in occupational performance, water restrictions, special diets, medical appointments, and hemodialysis sections, making people fragile and affecting their every day lives. With this regards, talking about the emotional aspect of renal patients is, above all, talking about a path of losses that goes beyond losing renal function. From the moment of diagnoses to the possible performance of transplant (the only real expectation of "cure"), the path of chronic renal failure patients is filled with several other issues that put their problem and the family dynamics into evidence⁽⁸⁾.

Because of that, it is necessary to assess the every day life of people with CRF, by that we mean the every day activities, such as getting up at the right time, going to work, going to school, making breakfast, lunch, practicing sport. That is, activities that are performed mechanically and automated⁽⁹⁾. Among the several discussions and issues regarding the routine, we have considered as the daily life, the place of human development, showed through some

aspects such as work, language, thinking, and feeling, actions and reflections of men⁽¹⁰⁾.

The difficulties faced by these people are countless, and they influence their routine and the way they relate, either because of the dependency on the machine, or the visits to the doctor, thus, hindering the performance of their occupational activities, that, in turn, disrupts their every day lives⁽¹¹⁾.

Based on what was reported on the routine, we understand that people with CRF may have difficulties in their every day chores. On the other hand, occupational therapy has the goal of restructuring the routine of people as one of its main objectives, as well as to favor their occupational performance and to promote strategies that favor their connection with the social environment. To develop this work, it is important to report on areas of occupational development. Occupational therapy is the art and science of helping people to perform daily activities that are important to them despite the inabilities or deficiencies. "Occupation" in occupational therapy does not refer only to professions or professional training, it refers to activities that take people's time and give meaning to their lives⁽¹²⁾.

In occupational therapy these areas are called occupational performance, and they can be divided into activities of daily living, professional, and leisure and play activities. For a better understanding, the areas of Occupational Performance are described below according to the Terminology of AOTA⁽¹³⁾:

- Activities of Daily Living (ADL): *it refers to dressing, cleaning mouth, showering, toilet hygiene, care for one's own body, feeding, medical routine, keeping health, socialization, functional mobility, and community mobility;*
- Professional activities: *home management (maintaining clothes, cleaning, preparing food, shopping, managing money, maintaining the household, safety procedures), taking care of others, educational activities, vocational activities (vocational exploration, acquiring a job, planning retirement, voluntary participation);*
- Leisure and Play activities: *leisure exploration and fun, playing games, leisure and entertainment.*

OBJECTIVES

The objective of the present study was to assess the perception of people with CRF on their routine, regarding their occupational functioning in two

public health service: UTR (Hemodialysis and Renal Transplant Unit) of the Hospital das Clínicas in Ribeirão Preto - HCRP and at SENERP (Nephrology Service of Ribeirão Preto).

MATERIALS AND METHODS

The project was seen and approved by the Ethical Research Committee of the HCRP and of the School of Medicine of Ribeirão Preto-USP, following, therefore, the ethical guideline on research with human beings. Subjects were asked to give their written consent and we explained that participation would be voluntary and that subjects could give up.

This is a cross-sectional analytical-descriptive quantitative study.

The sample was formed by 70 patients undergoing hemodialysis at UTR and at SENERP. At SENERP, patients were interviewed to complete the sample (n=70), we did not try to compare services and our purpose was not for samples to be proportional and representative of services.

Regarding inclusion criteria, in both services, patients with CRF undergoing hemodialysis, with ages ranging from 15 to 60 years old and that could answer the questionnaires took part in the study. Exclusion criteria were: not being the age defined, not being able to understand questionnaires, and presence of a more severe disease other than CRF.

A previous study was conducted with 10 individuals from the same gender with ages ranging from 15 to 70, 5 from each service, and we have applied three questionnaires for each, one was sociodemographic, one was the WHO Quality of Life (WHOQOL-bref) and one was SAOF - Self Assessment of Occupational Functioning. Questionnaires were individually and self -applied. In this study, we noticed that some participants had problems understanding some questions, because of that, we have excluded these questionnaires from the definitive sample and decided that the application would be done by the researcher and the age was limited at 60 years old.

Initially, information of all patients from UTR-hemodialysis that met the inclusion criteria was gathered, there were 16 patients that, together with the 54 from SENERP, totaled 70 patients, with ages ranging from 17 to 60 years old. Interviews from SENERP were performed through a draw, considering patients that were scheduled for that day and time

and that also met the inclusion criteria. Research was conducted from June 14th to September 27th, 2005.

SAOF is the instrument whose theoretical bases is the model of human occupation and it was developed in 1990, in the Department of Occupational Therapy of the University of Illinois⁽¹⁴⁾, Chicago, with recent validation, in 2000 in Brazil. This model supplies a way to think on the occupational behavior of people and their occupational dysfunction. Their concepts involve encouraging people to take up an occupation, with standards of occupational behavior routine, with the nature of the work performed and with the influence of the environment on the occupation⁽¹⁵⁾.

This instrument may be used by people between 14 and 85 and presents as the main purpose identifying the perception of patients regarding their occupational functioning, including understanding their strengths, suitability area, and limitations. SAOF presents an application form encompassing 23 questions, covering seven content areas: personal causation, values, interests, roles, habits, skills, and environment. To that end, a scale with three classification grades is used: strength, adequate, needs improvement that quantifies the perception of patients on areas of occupational functioning. Performance of patients is assessed as: very good (strength), good (adequate) and presence of difficulties (needs improvement)⁽¹⁶⁾.

DATA ANALYSIS

For each value of the scale self assessment was written down and in each area the percentage of their answers classified as Strengths, Adequate or presents difficulties. For the set of patients mean of percentages was calculated, together with the respective deviations to find differences and similarities.

RESULTS AND DISCUSSION

Table 1 presents the percentage results of mean and standard deviation obtained by the application of instruments. We have observed that in all areas "Strengths" was the most commonly selected option. The area called Environment presented mean 74.3% and it was the greatest area. The smallest mean, 46.2%, referred to area 5 (Habits), still considering the alternative Strengths. Areas where difficulty was chosen were area 2 (20.5%) and 5 (20%). Regarding area 5 (habits), there is similarity with studies developed in 2000⁽¹⁶⁾, because it was one of the areas with greater score percentage in the option "needs improvement".

Table 1 – Means and standard deviation of individual responses obtained by the application of SAOF questionnaire, according to each reference area

Areas	Mean			Standard Deviation		
	Strengths	Adequate	Needs Improvement	Strengths	Adequate	Needs Improvement
1. Personal casualty	60.5	24.3	15.2	35.6	30.5	25.8
2. Values	56.7	22.8	20.5	34.2	26.9	27.4
3. Interests	60	32.4	7.7	38.3	36.3	20.6
4. Roles	62.8	29.00	8.1	31.4	31.0	17.4
5. Habits	46.2	33.8	20	36.0	35.2	26.8
6. Skills	57.7	27.1	15.1	28.7	25.3	18.0
7. Environment	74.3	20	5.7	44.0	40.3	23.4

For a better understanding, each topic of the instrument was individually assessed: 1- Area of Personal Causation: the alternative "strengths" was one of the most commonly chosen (60.5%), therefore, most interviewees believe in their skills and capacities; 2- Area of Values: the alternative "needs improvement" accounted for 20.5% of the choices, and despite the small percentage, it was the one patients presented difficulties regarding having objectives and expectations for the future; 3- Area of

interest: there was no difficulties, with 60% in the option "strengths". Thus, even with limitations, these people try to be interested in doing something; 4- Roles: most people could perform their roles, either as workers, students or family member, regardless of the difficulties; 5- Area of habits: these people find it hard to organize their time, schedules, and to accept the changes in their routine. In this area, the option "needs improvement" accounted for 20% of the choices; 6- Area of skills: most people try to have a

social life, express themselves, solve problems, and perform every-day tasks within their abilities; 7- Area of Environment: it was the one with greatest percentage of "Strengths" (74.3%), showing that most people want to be in places they feel good.

The difficulty pointed out in the value area enabled these people to get in touch with more subjective issues and with their current reality, such as, for example, having objectives for the future and perform activities that are meaningful. This may be related with losses that occur with these people, there are social and financial losses, and they also lose physical capacity and leisure activities, that can lead to self-pity and overreactions. In these cases, it is necessary to help patients control the situation⁽⁴⁾.

It is observed in a summarized way that Habits and Values are the two areas with greater percentage of "needs improvement". We see here the opportunity and the need for the contribution of Occupational Therapy to restructure the routine of patients: support a new organization of time, change in routine, personal relations and, thus, reinforce the control on both the social loss and loss in physical capacity.

Naturally, it is expected that activities with body involvement and those recreational are the daily activities that are most involved⁽³⁾, and in this context, the outcomes of the present study point out to that health professionals need to use individualized actions to help individuals adjust to and live with inabilities.

Regarding SAOF questionnaire, some participants had difficulties understanding some questions. Overall, most participants understood it, however, some of them required explanation from the researcher and adjustment of some questions, such as in area 4, question number 10 which asks if the person is involved with his/her role (either as a student or worker), it was necessary to explain the meaning of role. There was also difficulty in the presence of more than one variable in the same item, such as for example, in the item 21 (taking care of personal hygiene, cook and laundry), which made

people think in all these variables, without understanding they were only examples. This fact was also reported in 2000⁽¹⁶⁾.

In 2004⁽¹⁷⁾, it was suggested that it would be easier if the statements were presented as questions and the options of answers were replaced by: a lot, sort of, and difficulty. Relating this comment to what was applied on the research, this replacement would also be considerable since, many times, and the researcher had to make this change for a better understanding.

CONCLUSIONS

The use of SAOF questionnaire showed that in the areas of values and habits, aspects regarding the organization of time, flexibility, routine changes, objectives, and expectations for the future, they were not structured in relation to the occupational functioning of these people. However, we must remember that the percentage was not very high regarding the difficulties and that the overall result was satisfactory. Therefore, we understand that in the present study, people that undergo hemodialysis are not totally incapable of performing their daily tasks.

From this, we can notice that even in face of difficulties, with a routine changed by hemodialysis hours, food restrictions, and in many case, loss of work/study, individuals with CRF can, if necessary, and with the help of professionals, develop a routine of tasks, build projects, and do something meaningful for themselves, that is, they can rebuild their daily lives.

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