Original Article

Work and health-related quality of life of patients on peritoneal dialysis*

Trabalho e qualidade de vida relacionada à saúde de pacientes em diálise peritoneal

Trabajo y Calidad de Vida Relacionada a la Salud de Pacientes en Diálisis Peritoneal

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ABSTRACT

Objective: To describe and compare Health Related Quality of Life (HRQoL) of patients on peritoneal dialysis (PD) who had and who did not have paid work. **Methods:** A cross-sectional and populational study with 82 patients from the two PD services in Ribeirão Preto (SP), Brazil. Data collection was conducted by interviews between December/2009 and March/2010. The questionnaires for the characterization of patients, the Mini Mental State Examination and the *Kidney Disease and Quality of Life-Short Form* were used. Analyses were performed using exploratory univariate and bivariate statistics, and the confirmatory bivariate among the independent variables and the dimensions of HRQoL. **Results:** Patients with paid work presented higher mean scores reflecting better HRQoL for the majority of the dimensions of the instrument used. **Conclusion:** Work is an important facet of life for these patients and merits the attention of health professionals in the search for strategies that promote and incentivize its maintenance and the reintegration of patients into the labor market.

Keywords: Work; Peritoneal dialysis; Quality of life

RESUMO

Objetivo: Descrever e comparar a Qualidade de Vida Relacionada à Saúde (QVRS) de pacientes em Diálise Peritoneal (DP) que tinham ou não trabalho remunerado. **Métodos:** Estudo seccional e populacional com 82 pacientes dos dois serviços de DP de Ribeirão Preto, (SP). A coleta de dados foi realizada por entrevistas entre dezembro/2009 e março/2010. Os questionário para caracterização dos pacientes, o Miniexame do Estado Mental e o *Kidney Disease and Quality of Life-Short Form* foram usados. Foram feitas as análises estatística exploratória uni e bivariada e a confirmatória bivariada entre variáveis independentes e as dimensões de QVRS. **Resultados:** os pacientes com trabalho remunerado apresentavam maiores escores médios refletindo melhor QVRS para a maioria das dimensões do instrumento utilizado. **Conclusão:** o trabalho é uma faceta importante da vida desses pacientes e merece a atenção dos profissionais da saúde na busca de estratégias que favoreçam e incentivem sua manutenção e reinserção no mercado de trabalho.

Descritores: Trabalho; Diálise peritoneal; Qualidade de vida

RESUMEN

Objetivo: Describir y comparar la Calidad de Vida Relacionada a la Salud (QVRS) de pacientes en Diálisis Peritoneal (DP) que tenían o no trabajo remunerado. **Métodos:** Estudio seccional y poblacional realizado con 82 pacientes de los dos servicios de DP de Ribeirão Preto, (SP). La recolección de datos se realizó por medio de entrevistas entre deciembre/2009 y marzo/2010. Fueron usados los cuestionarios para la caracterización de los pacientes, el Mini examen del Estado Mental y el *Kidney Disease and Quality of Life-Short Form*. Se realizaron los análisis estadísticos exploratorio uni y bivariado y la confirmatoria bivariada entre variables independientes y las dimensiones de QVRS. **Resultados:** los pacientes con trabajo remunerado presentaban mayores escores medios reflejando mejor QVRS para la mayoría de las dimensiones del instrumento utilizado. **Conclusión:** el trabajo es una faceta importante de la vida de esos pacientes y merece la atención de los profesionales de la salud en la búsqueda de estrategias que favorezcan e incentiven su manutención y reinserción en el mercado de trabajo.

Descriptores: Trabajo; Diálisis peritoneal; Calidad de vida

** Study conducted in the Nephrology Service of Ribeirão Preto (SENERP) and in the Dialysis Service of the Hospital das Clinicas, Faculty of Medicine of Ribeirão Preto, University of São Paulo, Ribeirão Preto (SP), Brazil.*

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INTRODUCTION

The meaning of work varies, based on its psychological and social attribution; it is derived from the process of attributing significance, and has been associated to the historical conditions of society. This activity can satisfy countless needs of the individual for obtaining prestige and financial support, permanence in activity, social interaction and interpersonal relationships, and to permit a feeling of usefulness to society and personal achievement [1].

Patients with chronic diseases depend on long-term treatments that impose limitations, and high-impact alterations that impact on their lives [2]. The performance of specific work tasks can be hindered or even made impossible by physical and cognitive limitations, pain and fatigue, a fact which makes the employment rate of people with chronic diseases, a little or considerably lower than those of healthy people [3].

End-stage chronic kidney disease (CKD) and its treatment involve changes in the family, psychological, occupational and social environments, as well as the need for dietary restrictions and time for completion of treatment [4].

The limitations are significant for the patient, but do not constitute the direct and absolute impediment for the realization of work activity [5]. The economic implications of end-stage CKD influence the entry into the labor market and can also be associated with reductions in hours worked, lower wages, early retirement, early departure from the labor market and the need for income transfer programs, thus provoking a negative impact on the earnings of these patients [6].

It is important that health professionals pay attention to these patients, and the needs experienced by them, not only with regard to financial aspects, but also to psychosocial factors, such as the presence of idleness, the feeling of uselessness and worthlessness, and a sense of being a weight / burden upon the family[5].

Peritoneal Dialysis (PD) has been identified as a modality of Renal Replacement Therapy (RRT) that favors the return and maintenance of patients with end-stage CKD in the labor market , as a function of the greater autonomy for self-care, and the flexibility to perform treatment at home with a return to the clinic only once a month. However, it can be observed that these patients still encounter difficulties with continuing the performance of their work activities[7].

The various implications of work in the lives of CKD patients on PD may reflect on their quality of life. In the health area, the term encountered in the literature which establishes more direct relationships with disease or health interventions is *Health Related Quality of Life* (HRQoL), defined as an optimal level of mental, physical, social and role function in life, covering relationships, health perception, aptitudes, level of life satisfaction and feelings of well-being, and also relates to future prospects and patient satisfaction with treatment, its outcomes and their own health status[8].

To measure HRQoL of PD patients, it can be observed in addition to the physical consequences visually perceived in clinical practice. The dialysis treatment, as well as the disease itself, can also result in accentuated consequences for the patient, family and friends, in relation to the human, social and economic aspects[9].

Given the above, the objective of this study was to describe and compare the HRQoL of PD patients treated in Ribeirão Preto (SP) who had paid work and those who did not.

METHODS

This was a study of a quantitative nature, sectional and populational, conducted with adults (18-59 years) and elderly (60 years and over)[10], with end-stage CKD receiving PD treatment , attending the two services that offered this treatment modality in Ribeirao Preto – (SP, Brazil).

In the study, patients who met the following criteria were included: 18 years or older; receiving treatment of Continuous Ambulatory Peritoneal Dialysis (CAPD) or Automated Peritoneal Dialysis (APD) for 3 months or longer, a period of psychological adaptation to the disease and stabilization of the indices of QOL [11]; had a satisfactory cognitive evaluation on the Mini Mental State Examination (MMSE) [12], in order to gain a better understanding of the HRQoL instrument; and were not hospitalized for acute complications or treatment of peritonitis.

Data collection was conducted by means of interviews with patients in the monthly consultation on the dialysis service, occurring between December 2009 and March 2010, during which time there were 114 patients on PD. Of these, 32 were excluded who did not meet the inclusion criteria, totaling 82 participants in the study.

The instruments used were: MMSE for cognitive assessment, an instrument of socioeconomic and demographic characteristics for end-stage CKD and PD, adapted and validated for the study[13] and for the assessment of HRQoL, the *Kidney Disease Quality of Life-Short Form* (KDQOL-SF™) was used)[14] in the translated version, adapted and made available for the Brazilian culture[15]. The KDQOL-SF™ is an instrument that includes, as a general assessment of the individual's overall health, the Medical Outcomes Study MOS 36-Item Short Form Health Survey (SF36), composed of eight domains: physical functioning (10 items), role-physical (4 items), role-emotional (3 items), social function(2 items), emotional well-being (5 items), pain (2 items), energy/

fadigue (4 items) and general health (5 items). In the SF36 supplement, there is a scale addressing individuals with end-stage CKD on dialysis which includes 43 items: Symptom/problem list (12 items), effects of kidney disease (8 items), burden of kidney disease (4 items), work status (2 items), cognitive function (3 items), quality of social interaction (3 items), sexual function (2 items) and sleep (4 items). It also includes two items of social support, two items on the support of the professional dialysis team, and a section on patient satisfaction. The scores of the KDQOL-SF™ items vary between 0 and 100; the lower values correspond to less favorable HRQoL, and higher scores reflect better HRQoL [14,15]. It is important to note that this instrument has as one of its dimensions the work status , showing that this is a dimension within the construct HRQoL.

In relation to the ethical aspects, we obtained consent of the two services in question, following the approval of the research project by the Ethics in Research Committee of HCFMRP-USP, in accordance with process n º 7272/2009, and patients who agreed to participate in the study signed the Terms of Free and Informed Consent .

The HRQoL instrument data were pre-analyzed in a program provided by the KDQOL-SF™ Working Group (www.gim.med.ucla.edu/kdqol/). Thereafter, the remaining analyses were generated by the Statistical Package for the Social Sciences (SPSS), version 11.5. Analyses of univariate frequency, contingency tables, measures of location (mean) and variability (standard deviation) were conducted, and the mean scores of HRQoL and the variable of having a job were compared.

For the sociodemographic and economic characteristics, we used variables of gender, age, skin color, schooling, marital status, with whom the patient lived, and sources of income. Comparisons were made between the mean scores of the KDQOL-SF™ for variables of having and not having work, CAPD and APD and self-reported clinical variables, such as weakness, visual impairment, diabetes and hypertension. We also used the Pearson correlation to test the dimensions of the KDQOL-SF™ and the following variables: time the patient has had CAPD or APD, number of comorbidities, and number of complications.

RESULTS

It is noteworthy that 50 (61.0%) patients were female, ages ranged from 21 to 85 years with a mean of 61 years: 36 (43.9%) patients were adults and 46 (56.1%) were elderly . Regarding education, it was observed that 27 (32.9%) had one to four years of study and only six (7.3%) were illiterate. The majority, 59 (72.0%) of the patients had a partner (a) and 50 (61.0%) lived with family (Table 1). More than half of patients, 49 (59.7%) lived in Ribeirão Preto or in municipalities within a 25 km distance.

Table 1. Description of sociodemographic and economic variables of the 44 patients on CAPD and 38 patients on APD. Ribeirão Preto, 2010

	CAPD		APD		Total	
	n	%	n	%	n	%
Age group						
Adult	17	47.2	19	52.8	36	43.9
Elderly	27	58.7	19	41.3	46	56.1
Schooling						
Illiterate	4	66.7	2	33.3	6	7.3
Able to read / write	2	100.0	-	-	2	2.4
1 to 4 years of study	18	66.7	9	33.3	27	32.9
5 to 8 years of study	8	57.1	6	42.9	14	17.1
9 to 11 years of study	11	50.0	11	50.0	22	26.8
12 or more years of study	1	9.1	10	90.9	11	13.4
Marital status						
Never married	2	40.0	3	60.0	5	6.1
Lives with a partner	31	52.5	28	47.5	59	72.0
Separated or divorced	5	62.5	3	37.5	8	9.8
Widowed	6	60.0	4	40.0	10	12.2
Sources of income						
Retirement						
Does not have	11	35.5	20	64.5	31	37.8
Has	33	64.7	18	35.3	51	62.2
Pension						
Does not have	44	55.0	36	45.0	80	97.6
Has	-	-	2	100.0	2	2.4
Work						
Does not have	40	57.1	30	42.9	70	85.4
Has	4	33.3	8	66.7	12	14.6
Other sources of income*						
Does not have	32	57.1	24	42.9	56	68.3
Has	12	46.2	14	53.8	26	31.7
Total	44	53.7	38	46.3	82	100.0

* Family financial and rent help

Only 12 (14.6%) patients had a job, the majority (51, 62.2%), remained in retirement, and retirees (17, 33.3%) were adults. Also in relation to income, 26 (31.7%) had other income, such as aid for elderly or income of the spouse, and two (2.4%) received their deceased spouse's pension.

In relation to the type of work done, we encountered a farmer, merchant, computer technician, dressmaker, driver, manicurist, accountant, nursing assistant, and a secretary.

Of the total patients interviewed, 44 (53.7%) underwent CAPD and 38 (46.3%) had DPA. The principal etiological causes of end-stage CKD in these patients, according to medical records, were: hypertension (30, 36.6%), diabetes (30, 36.6%), other causes (10, 12.2%), cause not specified (7, 8.5%), polycystic kidney (7, 8.5%) and glomerulonephritis (5, 6.1%).

The PD patients cited more frequently the comorbidities: arterial hypertension (74, 90.2%), anemia (45, 54.9%), *Diabetes mellitus* (33, 40.2%), other diseases (33, 40.2%), visual deficit (27, 32.9%), and cataracts (22, 26.8%). The mean number of comorbidities for each patient was 3.5.

Self-reported physical complications related to the end-stage CKD and treatment with DP with greatest frequency were: hypertensive peaks (49, 59.7%), weakness (41, 50%), cramping (40, 48.8%), weight gain (40, 48.8%), intestinal constipation (34, 41.5%) and pruritus (33, 40.2%). The mean number of complications for each patient was 3.7.

In regard to the comparison of mean scores of the dimensions of the KDQOL-SF™ attributed by patients who had and those without work, we encountered statistical significance for: physical functioning, pain, general health, role-emotional , energy/fadigue, burden of kidney disease, work status, cognitive function, sleep, and overall health. Those patients who worked assigned higher scores, reflecting better HRQoL to the dimensions cited, as represented in Table 2.

Table 2. Mean values and standard deviations of the dimensions of the KDQOL-SF™ in peritoneal dialysis patients with and without work (n = 82, unless otherwise indicated), and t-test comparison between the two groups. Ribeirão Preto, 2010

	Work		p-value
	Does not work	Does work	
	μ (dp)	μ (dp)	
Generic dimensions			
Physical functioning	49.6 (32.6)	87.5 (17.9)	<0.001*
Role-physical	34.6 (46.9)	50.0 (47.7)	0.299
Pain	80.1 (25.5)	97.5 (8.7)	<0.001*
General health	59.3 (23.7)	78.3 (15.0)	0.009*
Emotional well-being	61.7 (21.7)	75.7 (15.6)	0.037*
Role-emotional	68.1 (45.5)	83.3 (38.9)	0.279
Social function	67.0 (24.1)	80.2 (17.2)	0.073
Energy/fadigue	53.7 (20.7)	73.7 (12.0)	<0.001*
Specific Dimensions			
Symptom/problem list	81.8 (12.8)	88.7 (8.4)	0.077
Effects of kidney disease	70.9 (19.0)	79.4 (18.2)	0.156
Burden of kidney disease	43.5 (30.8)	62.0 (24.2)	0.050*
Work status	22.1 (27.8)	91.7 (28.9)	<0.001*
Cognitive function	81.5 (19.1)	93.3 (13.3)	0.016*
Quality of social interaction	69.3 (20.8)	77.8 (14.6)	0.100
Sexual function **	67.5 (26.8)	72.7 (26.7)	0.575
Sleep	62.7 (22.8)	79.4 (10.5)	<0.001*
Social Support	87.4 (22.4)	80.5 (35.4)	0.378
Dialysis staff encouragement	95.5 (14.6)	96.9 (10.8)	0.763
Overall health	65.6 (17.5)	77.5 (14.2)	0.028*
Patient satisfaction	80.2 (13.7)	76.4 (15.0)	0.377

* With statistical significance at p <0.05, with the assumption that the study group constituted a random sample from a population with similar characteristics.

** n = 46 patients

Regarding the dimension of HRQoL, work status, the overall mean score found of 32.3 and standard deviation of 37.2, this was the dimension that obtained the lowest mean score among all others in the instrument used.

There was no statistical significance in the dimension, work status , between adults and the elderly (p = 0.607); between males and females (p = 0.837); and between patients on CAPD and on DPA (p = 0.188).

As for the clinical factors that interfered with the work status dimension, there was statistical significance for visual impairment (p = 0.023) and diabetes (p = 0.012). We also observed the moderate inverse correlation of the variable, number of comorbidities, and the dimension, work status , (- 0.335) which confirms the negative impact of comorbidities in this dimension of the HRQoL for PD patients.

DISCUSSION

The largest number of female patients in the study population was also found in a study conducted in the Southern Region of the country [16] in a multicenter study conducted in Brazil with PD patients [17] and in a recent study conducted in Spain [18]. According to data presented by IBGE referring to August 2010, approximately 45.4% of women entered the labor market, a percentage lower than that observed in the male distribution (54.6%.) This evidence indicates that, despite the increase in the number of women working, they still represent a smaller portion of workers in the labor market [19] and they present an impaired HRQoL similar to men in the dimension, work status .

In addition to the emphasis on the greater number of patients being elderly, it was also observed that a significant portion of adults in less than a decade, will become elderly, A study conducted in Brazil, which evaluated 48% of PD patients in the country, showed a higher age distribution of patients aged 60-69 years[17].

The working life of patients with CKD has the focus of attention of dialysis teams and social researchers, however there are few studies on the subject, Although the DP has the advantage of greater independence of the schedule for return to work, because it is performed at home, only 12 of the patients in this study possessed this link, which has also been observed in other studies [20,21].

The time that the CKD patient uses for coping with the disease and the potential problems that the treatment causes, is a complicating factor in job performance, a common activity in daily life for the majority of the population [22]. The physical involvement and physiological changes resulting from CKD problems may also result in difficulty in complying with the work-

ing hours required or the performance of activities required at work [22].

The work status appeared so impaired in this population that the expected difference between the means of adult and elderly patients, in the function of the limitations imposed by the aging process, did not appear in a significant form. The work activity is an aspect that must be addressed by health professionals, since this disease manifests itself in different age groups, especially in the productive phase of life, thus affecting the daily life of these patients and their families [5].

It is noteworthy that a major part of the subjects in this study were retired and, of these, 17 (20.7%) were adults, which confirms the considerations of the aforementioned study. The large number of people in the economically productive phase with end-stage CKD is shown in the Brazilian population on dialysis treatment, according to the findings of the annual census conducted by the Brazilian Society of Nephrology, because 62.1% of dialysis patients were between 20 and 59 years of age [23], which certainly contributes to the early exit of individuals from the labor market.

In those patients with end-stage CKD who compared their work activity before and after the onset of the disease, it was revealed that the majority experienced changes, as a result of the limitations that the disease and its treatment imposed on them. They referred to the necessity for some type of adaptation, as well as collaboration with family and/or employers [5].

It is noteworthy that the impediments to work activity encountered by end-stage CKD patients were: debilitated physical and emotional condition, living with the disease, concern about the loss of benefits related to income, the requirements of dialysis treatments, and the choice of treatment modality that can affect, significantly, the capacity and desire of the individual to work [7]. With regard to the estimates of PD patients, 51.3% had a chance of being employed, while of the patients on hemodialysis, only 32.2% had such chances [7].

Although impaired, this dimension presented higher mean scores for patients who underwent APD. The best conditions for work were experienced by patients in this modality, which corroborates the findings of a prospective, multicenter, randomized study that, when comparing APD and CAPD treatments, found that patients on APD had more time for work, family and social activities [24], because the treatment occurs during the night, whereas the CAPD occurs throughout the day.

A moderate inverse correlation of the dimension, work status, with the number of comorbidities was found, a result confirmed in the bivariate analysis between the dimension, work status, and *Diabetes mellitus*. These results can be inferred by the increased restrictions imposed by the disease, for example the visual impairment that, by itself, constitutes an impediment to daily activities and work, and that presented statistical significance in this study.

The comorbidities were associated with lower scores for physical functioning, work status, social functioning, emotional well-being, and cognitive function, and the disease most common among patients in this study was diabetes [25]; we also found a large number of patients in this study with arterial hypertension and anemia.

Participation in the labor market may improve QOL, and may contribute both to reducing the social aspects of the incapacity to work and the economic losses involved in an unnecessary and involuntary cessation of work, the inherent aspects to the individual of the financial losses, the social isolation and the reduction in self-esteem that occur when having to leave work [6].

Despite the existing limitations, it is necessary to invest in finding solutions to the work status of patients on dialysis treatment. Work constitutes a basic human need and when affected, it is a risk factor for mental health of human beings, therefore, health professionals must try to minimize these difficulties, seeking strategies that promote and encourage the reintegration of these patients into the labor market when there are conditions and motivations for this [5].

In this perspective, there are necessities, and the support of these professionals, the adaptations and collaboration on the part of the family and, especially, of society, so these patients can be inserted into the labor market, favoring the opportunity to be an active individual in the society in which they live [5].

CONCLUSIONS

Adults and elderly on PD with paid work, receiving treatment in Ribeirão Preto – (SP), showed much higher mean scores in ten of the 19 dimensions assessed in this study. Work proved to be an important facet of life for these patients and deserves more attention from professionals working in the Nephrology Service, in order to find strategies to promote and encourage the maintenance and reinsertion of these individuals into the labor market whenever possible.

The professionals who provide care to patients on PD may act by means of interventions of psychosocial support for the patients and their families, including emotional support and information. It is also possible to promote encounters between patients, in which there is exchange of experiences about work-related activi-

ties, obtaining information that assists them to better understand their illness and treatment, about their rights, as well as to find better ways to relate to their employer and with coworkers. It is believed that with the development of the proposed interventions, the health team promotes physical, mental and social well-being, and, consequently, improved HRQoL of PD patients.

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