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Work Activity Challenges among Hemodialysis Patients and Their Impact on Quality of Life

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Abstract

Most patients undergoing hemodialysis are of working age, and this poses a challenge in maintaining their jobs. A cross-sectional study was carried out in hemodialysis centers in the north of Santa Catarina, between December 2020 and February 2021. Patients aged between 18 and 55 years old on hemodialysis for more than 3 months were included. Aspects related to work, remaining at their job after starting hemodialysis, and quality of life were evaluated using the SF-36 instrument. Their working situation was evaluated in relation to quality of life through logistic regression. Of the 108 patients, the mean age was 43.34 ± 8.88 years old, with a median time on dialysis of 19 months. Of the participants, 78.9% were working six months before starting hemodialysis and 39.8% were working 6 months after. There was no difference in terms of sex, age, and marital status with regards to work before or after 6 months of starting hemodialysis. Working was associated with a better quality of life, even after adjusting for other variables (OR=5.30; 95% CI 1.43-19.61, p=0.013). It is concluded that there is a significant drop in employment after starting hemodialysis. The stimulus to keep working can favor a better quality of life in these patients.

Keywords: Hemodialysis. Chronic Renal Failure. Job. Quality of life.

INTRODUCTION

There is a growing incidence of people with chronic kidney disease (CKD) requiring hemodialysis all over the world, mainly in underdeveloped or developing countries[1,2]. Hemodialysis has been the most used dialysis modality among patients with kidney failure[3]. In addition to the factors related to CKD, the initiation of hemodialysis treatment represents a major challenge for maintaining work-related activities[4], which may lead to a lower quality of life for these patients[5]. Although Brazil is the third country with the highest number of patients on hemodialysis[6], little is known about the factors related to maintaining working life and its association with quality of life among patients undergoing chronic hemodialysis.

It is estimated that about 3 to 6 million Brazilians have chronic kidney disease (CKD)[7]. In 2020, 144,779 patients were on a chronic dialysis program in Brazil, 92.3% on hemodialysis[8]. This number represents an increase of 3.6% in the estimated prevalence between 2019 and 2020 of patients on dialysis in the country[8]. In addition, the most prevalent age group undergoing dialysis treatment in Brazil is between 45 and 64 years old[9], which represents an economically active population. However, studies have shown that patients on hemodialysis therapy have difficulties maintaining their job-related activities[9], both due to factors

Revista O Mundo da Saúde

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related to the disease itself, such as fatigue[10], anemia[11], dietary restrictions[12], and to factors related to hemodialysis therapy, such as fear of harming venous access[13], incompatibility of hemodialysis shifts with the work routine[14], patient's low self-esteem of meeting the employer's expectations[5], and the demands of the current job market[15]. Consequently, the loss of work capacity may be one of the factors for the development of a worse perception of quality of life among these patients[9].

Studies carried out in developed countries indicate that the prevalence of patients on hemodialysis who maintain their work activities is around 18.9% to 35%[16,17]. Even before the beginning of the chronic hemodialysis program, only 30 to 35% of the patients were performing some work-related activity, and after starting hemodialysis, one third of these patients had to leave work[18]. This represents a much lower employment rate compared to the general population that does not undergo age-adjusted dialysis in developed countries, approximately between 68 to 78%[19]. Living in urban areas[20] and the number of comorbidities[21] were associated with a lower employment rate after starting hemodialysis therapy in studies carried out in developed countries. In Brazil, it is estimated that 23.2 to 29.1% of patients on hemodialysis maintain their jobs[4,15]. However, such studies were limited to isolated hemodialysis units[4,15] and did not consider regions with greater employability potential, such as the northern region and Vale de Itajaí in Santa Catarina[22].

Considering the important role of work, not only as a factor of subsistence, but also as a means of self dignity[23] and its possible impact on quality of life[24], the need to increase knowledge about this topic in patients undergoing hemodialysis in other regions of Brazil is relevant to understanding its impact and opportunities for improving public policies. Thus, the objective of this study was to evaluate the prevalence of patient employment before and after the start of hemodialysis treatment, the factors related to maintaining employment, as well as its association with quality of life.

METHODS

Study Design and Location

This is a descriptive and analytical, observational, cross-sectional study carried out in three hemodialysis centers in the northern region and Vale do Itajaí in the state of Santa Catarina - Brazil, from December 2020 to February 2021. The sample consisted of patients undergoing chronic hemodialysis from the following clinics: Joinville Nephrology (Joinville), Clínica Renal Vida (Blumenau), and Clínica Renal Vida (Itajaí). Joinville is the largest city in Santa Catarina, with an estimated population of approximately 605,000 inhabitants in 2021[25]. Blumenau and Itajai have an estimated population of 366,000 and 226,000 inhabitants, respectively, in 2021[26]. These three cities have an economic sector focused on the textile and electromechanical industries[26]. In 2021, these cities had an economic impact on the low unemployment rate in the State of Santa Catarina and was one of the lowest in the country (11.1%)[22].

Sampling, Inclusion and Exclusion Criteria

All patients with stage V CKD on hemodialysis treatment at one of the three clinics above and who met the inclusion criteria were invited to participate in the study. All patients aged between 18 and 55 years old, without cognitive impairment or previously recognized dementia, who were literate and who had been on hemodialysis for more than 6 months

REVISTA O MUNDO DA SAÚDE

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were included. Participants who were retired 6 months before the start of hemodialysis or with an incomplete questionnaire, making the analyses unfeasible, were excluded. All participants signed an informed consent form, and the research was approved by the Research Ethics Committee of the University of Joinville Region (number 4.374.916/CAAE 36757120.20000.5366).

Instruments used and variables collected

Sociodemographic variables (age, gender, skin color, marital status, education, and place of residence in relation to the dialysis center) were collected directly from the medical records of each patient. Likewise, comorbidities and variables associated with hemodialysis treatment (etiology of kidney disease, time on dialysis, type of access in the first chronic dialysis, and presence of diabetes and systemic arterial hypertension). A self-administered questionnaire created by the authors was used to assess employment-related factors before and after starting hemodialysis. Quality of life was assessed using the SF-36 quality-of-life questionnaire (SF-36)[27]. The SF-36 consists of 8 domains: functional capacity, limitation due to physical aspects, pain, general health status, vitality, social aspects, emotional aspects, and mental health. Each domain is scored from 0 to 100, where the highest score is associated with a better quality of life[27].

Statistical analysis

Categorical variables are presented by their frequency and percentage. Quantitative variables by their mean and standard deviation or median and interquartile range. Clinical characteristics and those related to work were evaluated in relation to three periods: 6 months before beginning chronic hemodialysis treatment, in the 6 months following the beginning of their treatment, and after 6 months. The chi-square test or Fischer's exact test were used to compare frequencies, and the Man Whitney test to compare means, after verification of non-normal distribution using the Kolmogorov-Smirnov test. The effect of maintaining work-related activities after starting hemodialysis treatment with the highest quality-of-life score was evaluated. For this purpose, the median of the SF-36 total score was defined as a binary outcome (lower quality of life, <40; higher quality of life, ≥40). The association between employment status and better quality of life was evaluated using the crude odds ratio and bivariately adjusted with other confounding variables using the Mantel Haenszel method. All covariates that modified the effect between the primary exposure (employment situation) and the outcome (greater quality of life) by more than 10% were considered as potential confounders and included in the multivariate model using logistic regression. The value of $p<0.05$ was considered as significant. Data were analyzed using STATA statistical software version 15.1.

RESULTS

Of the total number of patients undergoing hemodialysis at each hemodialysis center (50 from Joinville, 185 from Blumenau, and 239 from Itajai), 14 patients from Joinville, 45 from Blumenau, and 66 from Itajai met the inclusion criteria. From this initial sample of 125 participants, 17 (13.6%) were excluded because they were already retired. The final sample consisted of 108 participants: 9 (8%) from Joinville, 39 (36%) from Blumenau, and 60 (55%) from Itajai.

The main characteristics of the total and stratified sample, whether or not they were working six months prior to starting hemodialysis, are shown in Table 1. Of the 108 patients, 62 (57.4%) were men, mean age

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43.3± 9 years old, with a predominance of white skin color (n=76; 70.4%). With regards to education, 80 (74.1%) of the patients had 8 or more years of study and most of them had no private health plan (78.7%). Systemic arterial hypertension was identified in 46% of the sample. Of the total sample, 86 (79.6%) of the patients were working in the six months prior to starting dialysis. When stratified by employment or unemployment six months before the start of dialysis, there was no significant difference for age, gender, skin color, marital status, education, type of health plan, or comorbidities.

In the first 6 months after starting treatment, 35 patients (32.4%) were employed. When compared to the characteristics of patients who were or were not working in the first 6 months after starting hemodialysis treatment (Table 2), there was no statistical difference with the same variables analyzed above. The same goes for the place of residence in relation to the center of hemodialysis, the dialysis shift, the type of access at the beginning of hemodialysis, and the type of work performed previously. Among the patients who were employed in the first six months after starting hemodialysis, 9 (25.7%) needed to change jobs at the same workplace and 3 (8.6%) needed to change their workplace. Of those who were working, 17 (48.6%) needed to reduce the number of hours worked with a wage reduction.

Six months after starting hemodialysis treatment, 21 (19.4%) patients were working. Of these 21 patients who were working six months after the start of hemodialysis, 11 (52.4%) reported concern about losing their job due to hemodialysis, and 11 (52.4%) believed that there was good acceptance of their health condition by their standard. Still, 14 (66.7%) were motivated to continue working, and the main motivation for 19 (90.5%) was financial gain. Among those who continued working after six months, 13 (68.4%) worked more than 20 hours a week and 8 (44.4%) had a monthly family income greater than R$5,000.00.

Among the 87 (80.6%) patients who were not working six months after starting hemodialysis, 51 (58.6%) of the patients had a family income below R$3,000.00 (USD 577.00). Of those who were not working, 60 (69%) would like to go back to work. Among those who were not working after six months, 52 (60%) were receiving sick pay. Also, among those who were not working, 8 (9.2%) had looked for a job in the last six months. Among the 83 who had not looked for a job, 29 (42.6%) reported that the main reason was not feeling well enough to work.

As for quality-of-life and its association with work status six months after the start of hemodialysis, Table 3 shows the overall SF-36 score and domains of the total sample, stratified by employment status. The limitation due to physical aspects domain had the lowest score median and the mental health domain had the highest SF-36 score median. When stratified into those who were or were not working, individuals who were working had a higher score median in the domain of functional capacity compared to the group who were not working (median 70 vs. 50; p=0.004). Regarding the other domains, there was no significant difference between the groups, but there was a tendency towards a higher median of the SF-36 total score for those who were working compared to those who were not working (median 52 vs. 38; p= 0.064).

Patients on hemodialysis who were currently working had a rough chance of a better quality-of-life, 3.16 times greater, than those who were unemployed (OR=3.16; 95% CI 1.11-8.99, p=0.023). The effect of this association was modified when adjusted for the median time on hemodialysis, sex, education, and income (Table 4). In the multivariate analysis (Table 5), work remained associated with a better quality-of-life, even after adjusting for other confounders (OR=5.30, 95% CI 1.43-19.61; p=0.013).

REVISTA O MUNDO DA SAÚDE

DOI: 10.15343/0104-7809.202347e14092022I

Table 1 - Characteristics of patients working or not 6 months before starting hemodialysis. Joinville, Santa Catarina, Brazil (2023).

	Total Sample n=108		Unemployed n=22		Employed n=86		
	Total or Average	% or SD	Total or Average	% or SD	Total or Average	% or SD	P-value
Age, years	43.3	8.9	45,23	8.53	42.98	8.93	0.308
Gender							
Female	46	42.6	11	50	35	40.7	0.585
Male	62	57.4	11	50	51	59.3	
Race							
White	76	70.4	14	63.6	61	70.9	0.687
Not white	32	29.6	8	36.4	25	29.1	
Marital status							
Married	52	48.1	10	45.5	42	48.8	0.965
Not married	56	51.9	12	54.5	44	51.2	
Schooling (n=103)							
≤ 4 years	23	22.3	7	31.8	16	20	
8 to 11 years	9	8.7	3	13.6	6	7.5	0.270
>12 years	71	68.9	12	54.5	58	72.5	
Health plan							
UHS	85	78.7	20	90.9	65	75.6	0.202
Private	23	21.3	2	9.1	21	24.4	
Comorbidities							
SAH	50	45.9	11	50	38	44.2	0.803
DM	13	11.9	3	13.6	10	11.6	1.000

SD= standard deviation; UHS=unified health system (public service); SAH= systemic arterial hypertension; DM = diabetes *mellitus*

REVISTA O MUNDO DA SAÚDE

DOI: 10.15343/0104-7809.202347e14092022I

Table 2 - General characteristics of employed or unemployed patients in the first 6 months after starting hemodialysis (n=108). Joinville, Santa Catarina, Brazil (2023).

	Employed (n=35)		Unemployed (n=73)		
	Total or Average	% or SD	Total or Average	% or SD	P-value
Age years	43,0	8.5	43.58	9.13	0.644
Gender					
Female	12	34.3	33	45.2	0.385
Male	23	65.7	40	54.8	
Race					
White	25	71.4	50	68.5	0.931
Not white	10	28.6	23	31.5	
Marital status					
Married	16	45.7	35	47.9	0.991
Not married	19	54.3	38	52.1	
Schooling (n=102)					
≤ 4 years	6	18.8	17	24.3	0.269
8 to 11 years	1	3.1	8	11.4	
>12 years	25	78.1	45	64.3	
Lives in the same city that makes HD	24	68.6	50	68.5	1.000
Health plan					
UHS	25	71.4	60	82.2	0.304
Private	10	28.6	13	17.8	
Dialysis shift					
Morning	10	28.6	28	38.4	
Afternoon	13	37.1	24	32.9	0.605
Night	12	34.3	21	28.8	
Initial HD vascular access type					
AVF	12	34.3	37	50.7	0.163
Catheter	23	65.7	36	49.3	
Presence of comorbidities, yes					
SAH	15	42.9	35	47.9	0.772

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REVISTA O MUNDO DA SAÚDE

DOI: 10.15343/0104-7809.202347e14092022I

...continuation table 2

	Employed (n=35)		Unemployed (n=73)		
	Total or Average	% or SD	Total or Average	% or SD	P-value
DM	3	8.6	10	13.7	0.652
Type of work* (n=84)					
Non-manual specialized work	8	25	15	28.8	
Non-skilled non-manual work	12	37.5	14	26.9	0.790
specialized manual work	8	25	15	28.8	
Non-skilled manual work	4	12.5	8	15.4	

HD=hemodialysis; UHS=unified health system (public service); SAH= systemic arterial hypertension; DM= diabetes mellitus; AVF= arteriovenous fistula; *Specialized work: higher education or technical course; manual: any activity that requires some physical effort.

Table 3 - Total score and by domains of the quality-of-life instrument (SF-36) in the total sample and stratified by the current employment status of patients on hemodialysis (n=96). Joinville, Santa Catarina, Brazil (2023).

	Total Sample n=96		Stopped Working n=73		Works n=19		
Domains	**Score med.**	**VRQ**	**Score med.**	**VRQ**	**Score med.**	**VRQ**	**P Value**
Functional capacity	50	30/75	50	27.5/65	70	45/85	0.004
Limitation	0	0/25	0	0/25	50	25/100	0.143
Pain	31.5	12/51	31	12/51	51	44/62	0.445
General state	40	25/61.5	37	23.5/55	52	25/67	0.495
Vitality	45	25/60	40	25/55	50	25/65	0.255
Social aspects	50	25/75	50	25/75	62.5	37.5/87.5	0.073
Emotional Aspects	33	0/91.7	33	0/67	33	0/100	0.378
Mental health	52	44/76	52	42/76	60	44/80	0.611
Total Score	40	31.2/56.7	38	29.5/52.5	52	34/65	0.064

VRQ=interquartile range (25th and 75th percentile).

REVISTA O MUNDO DA SAÚDE

DOI: 10.15343/0104-7809.202347e14092022I

Table 4 - Association between work situation and higher median (≥ 40) of the total quality-of-life score (SF-36), Mantel Haenszel method (n=91). Joinville, Santa Catarina, Brazil (2023).

	Gross OR	CI 95%	P Value	Homogeneity Test
Working (yes vs. no)	3.16	1.11-8.99	0.023	
	Adjusted OR			
Sex	3.45	1.20-9.92	0.014	0.072
Lives in the same city HD	3.33	1.15-9.66	0.019	0.855
HD shift	3.30	1.17-9.26	0.016	0.448
Initial HD vascular access type	3.00	1.06-8.50	0.030	0.100
Schooling (>6 vs. <6 years)	3.51	1.03-11.94	0.032	0.237
Income (>3,000 vs. ≤3,000)	3.54	1.16-10.84	0.018	0.137
Diabetes	3.22	1.13-9.19	0.021	0.610
Systemic Arterial Hypertension	3.01	1.04-8.68	0.032	0.775
Median Age (< 46 vs. ≥46)	3.17	1.10-9.10	0.023	0.140
Median time on HD (<18 vs. ≥18meses)	2.74	0.99-7.58	0.024	0.089

OR= *odds ratio*; HD= hemodialysis; vs=versus.

Table 5 – Multivariate analysis between the association of work situation and quality-of-life score (SF-36) above the median (n=91) by Logistic Regression.

	OR	CI 95%	P Value
Currently works (yes vs no)	5.30	1.43-19.61	0.013
Sex (male vs. female)	0.51	0.19-1.34	0.171
Education (>6 vs <6 years)	2.14	0.67-6.81	0.198
Income (>3k vs <3k)	0.50	0.19-1.34	0.170
Median time in HD (<18 vs >18m)	0.76	0.30-1.91	0.555

OR=*odds ratio*; HD=hemodialysis.

REVISTA O MUNDO DA SAÚDE

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DISCUSSION

The present study found that, although most patients were working in the six months before starting hemodialysis (79.6%), only one third continued working within the first six months after starting treatment (32.4%), and there was a significant reduction six months after starting hemodialysis (19.4%). Furthermore, the highest score in the functional capacity domain of the SF-36 instrument was associated with those patients who were working six months after starting hemodialysis therapy. Employment retention in hemodialysis patients increased the chance of a better quality-of-life by more than five times after adjusting for potential confounders.

It is important to note that the prevalence of maintaining employment in hemodialysis patients is low in both national[1,2] and international studies[3-7]. Many patients already begin to stop working when they start dialysis therapy, and this number of work abandonment increases over the time that patients remain on dialysis[4,8]. A study conducted at a US dialysis center involving patients aged between 18 and 54 years old compared employment trends (6 years before initiation of dialysis and at initiation of dialysis) in two periods (1996-2001 and 2008-2013)[4]. The authors found a decline in being employed from 24% in the first period to 23% in the second period, as well as a decline in the prevalence of people employed 6 months before the start of dialysis between the two periods (from 38% to 37%)[4]. This lower employment rate was even higher among individuals with greater social vulnerability[4].

The low prevalence of maintaining work activities after starting hemodialysis therapy has been pointed out in other studies in the North American population with a job abandonment rate between 71%[7] to 81%[6]. In Brazil, although there are still few studies on this topic, the proportion of patients who need to stop working after starting dialysis treatment has been similar to that of developed countries[1,2,9]. A study carried out in a hemodialysis clinic in the city of Curitiba, Parana, found a high rate of 77% of job abandonment after starting hemodialysis[1]. Considering that the Brazilian studies that evaluated the prevalence of patients still working are restricted to a sample of only one clinic and in medium-large cities[1,2], the situation of low employment may be even greater in regions with fewer job offers in the country.

Despite non-significant findings in the studied sample, individuals who were working in the six months prior to starting hemodialysis had a higher education and a greater prevalence of a private health plan. The low educational level has been identified as an independent risk factor for abandoning work in these patients[5,10]. As for the private health plan, it is believed that its presence can characterize patients with a higher income or, patients from better structured companies that provide health plans to their employees[11]. Such companies can allocate such patients to other functions contributing to the maintaining their employment. However, the sample size of our study may have significantly limited the verification of such findings.

As for the hemodialysis shifts, no clear association was found with continuing to work after starting treatment in the studied sample. The hemodialysis shift has not been identified as a limiting factor for maintaining work among these patients, but rather the time spent during hemodialysis treatment has been[6]. In our study, it was not possible to evaluate such an association between the number of hours on hemodialysis per week

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and maintaining employment; however, almost all the patients evaluated underwent three hemodialysis sessions per week, lasting three to four hours each.

When evaluating the patients who were or were not employed in the first 6 months after beginning HD, no significant differences were found in the variables analyzed. However, it was noticed that among the people who were working there was a higher frequency of men compared to those who were not working. Patients who had a higher level of education stayed at work longer than those who were no longer working. In the sample studied, patients who were working did less manual work than those who were not working. Although the sample size may have significantly limited such differences in our study, greater socioeconomic vulnerability has been associated with a lower prevalence of formal employment relationships in hemodialysis patients[4], thus, caution is needed in ruling out that such factors as not being associated for future studies with larger samples.

Another aspect found in the sample studied is that the vast majority of patients who were not working earned up to three minimum wages and, although there was an important desire to return to work, salary was not the main reason. Furthermore, only a little more than half of the patients who were not working were entitled to sick leave with pay in the studied population. Patients who worked autonomously and did not contribute to Social Security beyond the established grace period are not entitled to such sick leave benefits in Brazil. This finding suggests that most of these patients were supported by family and friends to meet their needs. Another aspect found in the present study was that most patients who are not working do not feel well enough to go back to work. Possibly many patients with CKD already stop working even before starting HD due to the limitations imposed by the diseases and their associated comorbidities, as well as episodes of exacerbation during medical follow-up, which ends up culminating in multiple exams, consultations, and hospitalizations that impact the lifestyle[12]. After starting the dialysis treatment there are many limitations in the physical, mental, and social activities of these patients[13].

In the present study, of the patients who continued to work throughout the treatment, half were concerned about losing work due to HD; although, most patients had a perception of good acceptance of their health condition by their employer. This good acceptance by the employer has also been pointed out in another study carried out in Brazil[9]. On the other hand, both for patients working and for those who were not working, the self-perception of the disease as a limiting factor for work was pointed out by most participants. This perception can be manifested in changing the type of work or workload. A study involving working-age hemodialysis patients found that 75% of the patients who continued to work required changes in type and/or workload[9]. Although the employment status of patients with CKD varies throughout their illness[14], most of the evaluated patients were motivated to continue working, with financial gain and enjoying what they did being the most prevalent reasons among those evaluated. Continuing to work has been pointed out as a means of maintaining a certain degree of "normality" in life for some hemodialysis patients[15].

Thus, to continue working has been associated with a better quality of life among HD patients[13]. Adapting to the changes imposed by hemodialysis is a complex process, with many implications and varied repercussions[16]. Work is part of each person's self-identification; therefore, it becomes one of the most precious values for human beings and, due to the treatment condition, pa-

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tients often need to stop working, which interferes with their quality of life[17]. Generally speaking, the quality of life of HD patients has been lower than that of the general population[13,14,16]. When stratified according to their current work situation, the present study identified that individuals who worked had a greater association with a higher score in the Functional Capacity Domain and a tendency towards a higher overall score on the quality-of-life instrument, in relation to the group that was not working. This domain has a strong association with the patient's physical condition and mobility[7]. This association with a higher quality-of-life score was maintained in the studied sample, even after adjusting for other confounders. Studies indicate that patients who are able to maintain their work activities have a better quality of life. In Brazil, few studies have evaluated the association between work in hemodialysis patients and quality-of-life[2,17].

Our study has some limitations that must be considered. First, due to the cross-sectional design of the study, it is not possible to rule out the risk of reverse causality in some variables studied in relation to the patient's current employment situation imposed by the disease. As an example, the change in the type of work activity and lower education could already be a reflection of the limitations imposed by CKD before the onset of HD. Furthermore, other confounding variables could not be considered in the final multivariate model due to the sample size. Another important aspect is that this research was conducted during the time of restrictive measures imposed by the pandemic, and some responses may have been influenced by this situation.

On the other hand, the present study deepens new issues related to work in a working-age sample undergoing dialysis treatment in cities with a high employability rate in the country. Therefore, regions with a lower development index, and where manual labor is the main area of activity for such patients, may have more worrying results in this population on dialysis. Moreover, the present study sought not only to assess the current work situation of the patient on hemodialysis, but also to consider the period before and shortly after the start of treatment. Thus, it is believed that the present study may raise new questions about the challenge of maintaining employment in the different periods of dialysis treatment to be deepened in future research.

CONCLUSION

The present study found a significant decrease in the employment activity of individuals on hemodialysis within the first months after starting HD, gradually declining over the course of treatment. In these patients, maintaining their jobs seems to be associated with a better perception of quality of life in terms of physical aspects. New studies should be conducted in order to evaluate the possibility of interventions that may favor employment retention, mainly related to the physical capacity of patients on hemodialysis.

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Revista O Mundo da Saúde

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