

# Employment status and coping strategies of renal patients on hemodialysis

## Summary

Chronic Kidney Disease is a disabling and high-cost chronic disease for patients who suffer from it and their families. When it manifests itself at a productive age and people are active at work, permanence in employment is at risk and the world of life of the patient's changes in the face of physical damage, constant absences from the workplace, derived from medical consultations, studies and relapses; as well as secondary effects of renal replacement therapy. Faced with this situation, kidney patients of productive age who receive hemodialysis face multiple stressors in their day-to-day life to remain active in the workplace and economically independent. For this reason, they often resort to mechanisms and alternatives to deal with the disease and preserve their employment, autonomy, self-esteem, as well as control over them and the disease.

The objective of this research is to describe, based on the experiences of a group of kidney patients of productive age who receive hemodialysis, the coping strategies they use to face the disease, recover their autonomy, self-esteem and control over them and the disease and continue to be active at work, either formally or on their own.

**Keywords:** work, hemodialysis, psychological adaptation, kidney disease

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## Introduction

Work, to which at least a third of the day is usually dedicated, configures the physical, emotional and economic well-being of people when they start, leave or abandon working life. Through this it is possible to achieve personal and work identity, autonomy, independence, opportunity for interaction; time structuring; mandatory; learning; status and prestige, socialization and control; power as well as comfort and enjoyment.<sup>1,2</sup>

When the continuity of employment of people of productive age is impeded by a progressive and permanent disease, such as chronic kidney disease, they usually implement various strategies to continue working and face the deterioration of physical and mental health caused by CKD and its treatment.

Studies carried out in various regions of the world have documented that only one in five people who have CKD and receive hemodialysis as treatment retain their job,<sup>3</sup> while more than 60% of people who were active in the labor market, at the beginning of a renal replacement therapy, they lost it.

Coping allows the individual to handle situations that can generate stress to deal with overwhelming situations through strategies to tolerate, minimize, accept or ignore events that are out of their reach and exceed their capacities, by giving new meaning to the stimulus through actions, thoughts or affections.<sup>4</sup>

Lazarus and Fockman define coping strategies as "those constantly changing cognitive and behavioral efforts that are developed to handle specific external or internal demands that are evaluated as exceeding or exceeding the individual's resources" Lazaruz & Folkman (1986) cited in Macias et al.<sup>5</sup>

The strategies used by people with a chronic condition such as CKD to face the disease and continue with their activities or work routines can be functional or dysfunctional.<sup>6</sup>

Coutinho<sup>7</sup> points out that the strategies that focus on the problem are more efficient than those that focus on the emotion, when a

patient has an effective management of his illness, he usually resorts to dysfunctional coping strategies that are characterized by the resignation of the illness, which instead of benefiting the sick, leads them to present high levels of depression.

Rupp et al.,<sup>8</sup> in their study, reported that kidney patients who were able to find ways to accept themselves and reconcile the state of their disease, presented a better evaluation of their abilities and, with this, combine work activities with RRT.

Therefore, the objective of this research is to describe, based on the experiences of a group of kidney patients of productive age who receive hemodialysis, the coping strategies they use to face the disease, recover their autonomy, self-esteem and control over them and illness to continue working, either formally or on their own.

## Material and methods

The research assumed a qualitative approach with a descriptive design, from the perspective of the social phenomenology of Edmund Schütz.<sup>9</sup> The participants were men and women over 18 years of age, beneficiaries of a social security clinic at the service of state workers, in Mexico City, active at the time of being diagnosed with CKD and receiving hemodialysis three times a week.

The selection of the participants was based on the attendance records and direct information provided by the physician responsible for the hemodialysis service. Semi-structured interviews were conducted with the participants from January to July 2018, after signing an informed consent and authorization from the clinic managers, within the hours assigned by the health institution to receive hemodialysis. The interviews were audio-recorded and fully transcribed. The names of the participants were changed to pseudonyms. A thematic analysis<sup>10</sup> was carried out based on the Colaizzi<sup>11</sup> method.

Based on the analysis of the information obtained from the interviews, four themes considered as strategies were identified: Neglecting the diagnosis, labor agreements, changes in working life and I have to work, in two aspects, based on the labor situation

of the participants at the time of the interview, those who maintain their employment and those who had a change in their employment situation, with the intention of evidencing the relevance of work in the experience of CKD in the lives of the participants. The validity of the information was carried out with the participants, by reading, reviewing and confirming that the transcribed information was what they had provided.

The study considered the fundamental principles for the ethical conduct of research with human beings identified in the Belmont Report<sup>12</sup> and the guidelines of the General Health Law on research with human beings.<sup>13</sup> The study was approved by the ethics committee of the health institution, where the participants were contacted with number 430.2018.

**Table 1** Study participants according to their employment situation

Name	Age	Labor Old	Work activity	Before diagnosis	During the Study
<i>They keep the job</i>					
Woman-1	32	7 years	Secretary	Active	Active
Woman-2	33	3 years	Lawyer	Active	Active
Woman-3	55	23 years	Administrator	Active	Active
Woman-4	44	24 years	Lawyer	Active	Active
Man-1	40	15 years	Editor	Asset	Asset
<i>Leave Employment</i>					
Woman-5	55	30 years	Nurse	Active	Pensioner
Man-2	64	40 years	Businessman	Asset	Unemployed
Man-3	40	7 years	Employee	Asset	Unemployed
Man-4	64	22 years	Head of Area	Asset	Pensioner
Man-5	30	2 years	Supervisor	Asset	Unemployed

**Source:** Own elaboration based on the information obtained from the interviews, 2018.

**Topic 1: Neglecting the diagnosis**

Ignorance of the disease, minimizing its severity and not giving importance to the symptoms were some of the aspects that contributed to exacerbating the presence of the disease and had an impact on the job performance of the interviewees. Five of the study participants neglected the diagnosis to keep their job, given the anguish and fear of losing it; all of them assumed that the signs and symptoms that they manifested such as: fatigue, headache, excessive sleepiness, tiredness, among others, were a consequence of the workload, demands and stress that arose from the execution of their activity and others. They considered they had received an erroneous diagnosis.

*“No! I’m not going to believe them, because they are general doctors, [it’s] not a specialist.” It was time, time passed, a month, two months passed, I had nausea, vomiting, headache, sleepiness, the smell of urea. Mmm I said: No, well, maybe it’s the disease he’s talking about, right? and if” (Man-3).*

The imminent progress of the disease led to an increase in discomfort and a deterioration in his physical condition; aspects that affected job performance and in some of them, his permanence in employment. Three of them decided to leave their job or retire early, while two more participants tried to remain in the same with the support of their colleagues and coworkers in the execution of their activities; until the severity of the symptoms made it impossible for them to carry out the activities assigned to them.

The same way attendance at consultations, studies and occasionally days of hospitalization are some of the clinical and medical care requirements of the CKD, which are scheduled during working hours and which the participants have to resolve, a situation that places

**Results**

Ten random informants participated, five women and five men with an average age of 40 years and a higher level of education. On average, they had been receiving hemodialysis as RRT for five years and had worked seniority from 2 to 40 years. All the participants, before or during the study, worked in the service sector, characterized by more mental than physical demands and with constant interaction of people. At the time of the study, five participants maintained their jobs, two had been pensioners due to disability and three more had resigned from it (Table 1).

them in a permanent state of uncertainty when seeing how they attend their medical consultations without threatening their permanence in employment.

Receiving an irreversible chronic diagnosis when there is a life plan projected on the economic and social benefits provided by employment for an indefinite period, plunged all the participants into a state of depression, stress and uncertainty towards the future, given the possible loss of social and economic benefits such as: a stable salary, economic days, vacations and access to health services.

*“I already had a clear diagnosis, I already knew it was a nephropathy, but... it was stress, it was stress, what do I do? Stop working? This, what am I going to do with the money? (Woman-3)*

The five participants who at the time of the interviews maintained their employment, refer to excessive physical effort and personal willingness to attend the workplace after receiving the hemodialysis session, and continue with work activities. Side effects caused by renal replacement therapy and fear of suffering a mishap during your journey from the workplace to the hemodialysis clinic or vice versa, or; a possible relapse during the execution of the tasks, were put in the background by the participants when they understood the disease and considered the advantages of staying active and productive.

*“At first it was difficult for me, I would go out and arrive at work very tired, there are times when I would arrive and want to go to bed and then, well, it was difficult [...] but later, as I began to understand the disease a little, I began to understand it and well, I treated also to strive to be strong. And then going back to work for me was wonderful.” (Woman-2)*

While for the participants who had a change in their work situation, the increase in symptoms and side effects caused by hemodialysis made it impossible to continue their work activity, to which is added the lack of support from immediate bosses and/or superiors. To be able to reconcile the work schedule or activities with the schedules assigned by the health agency, which resulted in at least half of the participants resigning from work or retiring early.

As evidenced in the following narrative, health services tend to provide care during morning hours, like most workplaces where the working day is during the day, making it impossible for many of the patients who work and attend to receive an TSR, have continuity in the sessions or stick to your treatment. It is the worker who has to adjust their schedules, request permission on a recurring basis or have their day discounted, in order to attend their hemodialysis sessions or medical consultations.

*“You adjust to the hospital, you don’t go to the hospital according to the hours they give you, and if that affects your working hours, well, you have to check what you’re going [to] do, So I arrived and told them: “Look, they hemodialyze me Monday, Wednesday, and Friday, in the morning shift,” “So, where are we going to put you? And now what are we going to do?” One of the questions or proposals was “And that there is a great need for you to take your dialysis or hemodialysis? Can’t you ask for it just once a week? Or why don’t you ask for it? for Saturday?” (Woman-4).*

### Topic 2: Labor agreements

This topic evidences the coping strategies carried out by the workplace, both by the participants who retained their jobs, prior agreement with the managers or superiors of the workplace, which are circumscribed in tacit agreements to be able to reconcile assistance to both the TSR to comply with work activities. For the participants who maintained their employment, communication with superiors and/or with the company union was essential to reach various agreements that would allow continuity in the work. One of these agreements was to agree flexible hours; strategy that made it easier to balance working hours with the time required in the hemodialysis session, although this required having mealtimes or extending the day to complete the day; Change of area or work activities to places or positions with fewer physical requirements or stressors. Make use of social benefits, such as economic days and days of rest and/or vacations to negotiate temporary permits and recurring disabilities.

In the public sector dependencies, to which the interviewees belong, the mobility of managers or superior managers to other areas or dependencies is frequent; Faced with this change in management, the participants who are still active have to renegotiate with the new boss or superior the continuity of the agreements agreed with the previous boss. The possible refusal to continue with what has been established or to reach a new agreement, causes in the respondents a high load of stress and fear, given the possibility of losing their job.

*“In my job, the bosses change every three years, in 2013 there was another boss and I had no problems with him, the day was occupied like this, but when she arrives, she later, later despite the fact that my [previous] boss I expose my case, that teacher if she starts treating me that way [demand more in her position]. (Woman-1)*

### Topic 3: Changes in work lifestyle

In order to give continuity to the work activity, it was necessary for the participants to modify their work habits to stabilize their state of health and to be able to continue being active. Following the diet rigorously and taking the medications at the appropriate time

allowed them to remain stable in their health and to continue in their workplace. At the beginning of the disease, continuing with a diet was difficult to implement given the excessive workload and demands of the activity that made it difficult to eat healthy foods and have time to take medications at certain times.

Another of the strategies that stand out is care in personal appearance and clothing. Four of the participants narrate having changed their way of dressing to attend their workplace with garments that allow them to cover the neck or forearm to hide the fistula or catheter. The “normal” physical appearance that kidney patients show, when they are stable and continue their treatment, causes the lack of credibility of the disease on the part of some employers or co-workers, who tend to question the absences recurring from the participants in their workplace, judging these excessive and unnecessary. This situation alienates the participants from their co-workers, both inside and outside the workplace.

*“I didn’t like being seen with the patch, I told the lady to put it lower down please, what I least wanted was a pity, shirt or scarf, because the big problem is that, “there’s poor thing”. No, I behave normal, many people do not know that I am sick”. (Man-1)*

The lack of solidarity and support from the bosses to frequently attend consultations and clinical studies required for the treatment of CKD, decapitalized the economy of the interviewees, having to resort to private health services to attend to the sequelae of the ERC outside of working hours or on rest days. To compensate for out-of-pocket expenses, some of the interviewees changed their place of residence to a place close to the clinic, they usually look for offers or support to obtain medicines or go to the hemodialysis service alone, to reduce the cost of tickets and foods.

*“What they didn’t explain to themselves, in my work, that’s where the problem began, right? Because it’s the ignorance of... well, of people, of kidney failure, they usually told me: “Oh! How exaggerated”, “Is it a headache?”, “Well, take an Aspirin” oh! “So what or do you go to the doctor?” So I had to explain to them that I did go to the doctor, but he is being treated for a rare disease, but they said: “I see you well”, “I see that you walk”, “I don’t see you as bad”. Because normally they have the idea that a... a kidney patient must have symptoms like... or look like cancer, like a cancer patient, right?, that they can’t walk, that they are very skinny, that they have haggard eyes, but well... no! We see ourselves as all people, normal unlike the symptoms.” (Woman-4)*

In the case of the participants whose employment situation changed, the lack of financial resources to cover the costs generated by private health services led them to wait for a medical appointment at the medical service of which they were beneficiaries; same that are usually postponed for several months or, postponing their assistance to the health service, until it was absolutely necessary, while they could work. This decision led, in at least two of the participants, to their emergency admission to the hospital and, consequently, their premature departure from the workplace as they had to resign because they could not join their activities immediately.

*“Then they [Public Health Institute] told me “decide it, see how, while they find space in some institution, it will be expensive but it is the only alternative there is [how to resolve them] and I began to see that... And so it was How did I go to the individual, embarking with more than \$100,000 pesos, but hey, here I am”. (Man-3)*

Leaving a formal workplace entails the loss of benefits and continuity of social security; To preserve the latter, the support of

the family (children or parents) was essential for the interviewees who had to leave their jobs. The family that had access to public health services, chose to insure them again as dependents and with this, be able to reduce the high costs involved in hemodialysis and medications.

*“At the beginning I was the worker, when I had my normal job and that, later since my job was to coordinate, I worked for a while normally, every six months I had to renew myself and I lost ISSSTE for a certain time, a month or so ,[...] they spoke to me and told me “it is not convenient for you to waste so much time at ISSSTE, while they give you a contract again”, “can’t someone give you one?” what they chose, since my mother is from the base and has been in the government for many years, she assured me, now it will be for life.”* (Man-2)

For the men and women in whom their work situation changed, leaving work for some of the participants was good, it makes them feel calmer since they are not exposed to long work hours and stressors typical of the work routine work, in addition to being able to allocate time for their personal or family activities, which they could not do due to excessive workload or extended work hours.

*“...the change [when I stop working] that I feel, I say away from [the disease is], well, I have to come here to do the hemodialysis, because it was a very good quality of life, I am with my family, I enjoy it, I do things that I couldn’t do before.”*(Man-3)

While for others, staying at home for the longest time makes them feel overwhelmed by the family, given the lack of privacy and independence.

*“...if you have this [disease] in the house, it is death; no!, you have to be active and forget about this, you have to get used to the idea that you’re fine, because if you don’t fall”.* (Man-1)

For some of the interviewees, they modified the social and work life with friends and co-workers. The outings they shared at mealtimes or outside their workplaces ended, not wanting to be questioned about the disease on a recurring basis or cause “pity” according to their words. The strategy to deal with this situation consisted of isolating himself from co-workers and focusing on the execution of his work tasks.

Those participants who positively face the disease do not conceive that this is a limitation or impediment to transforming their activities and daily routines as they used to do before being diagnosed. To do this, they usually lead their daily lives as they used to, especially their social life, they ignore the social stigma that other people may have about CKD.

*A lot of people are locked up... they get locked up with this problem, a lot of people don’t want to see reality, what it is, what happens, aha! No, and I do, I like to be together, I like to read and then they talk to me on the phone and tell me tomorrow there will be a meeting, come on, yes, how do I say if I attend, or that I have hemodialysis and I tell them “you know I can’t go because I have to go in...” I call this a treatment, I call it a treatment, they tell me “because you don’t want to go” no, well I get my treatment.”*

Regarding the participants who retired from their employment, they point out the impossibility of doing activities with greater physical effort; It is a consequence of excessive fatigue, as well as little flexibility and understanding of their bosses or managers to be absent from work hours and attend consultations or carry out studies. When she left her job, her routine changed, as she had more time to

organize her daily activities, including her attendance at hemodialysis, and spending more time with her family. Some of the participants highlight doing personal or family activities that they could not do before, due to the hours they dedicate to work, as well as feeling calmer, since they are not under the pressure and stressors of their job.

Two participants report feeling overwhelmed by the hours they spend at home, the lack of privacy and independence that their family does not give them, wanting to do everything for themselves and accompany them most of the day.

*“...I worked in homeland security [...] so it was very, very stressful. So if I said, no “I no longer want to be subjected to that stress” I prefer to retire and be with my family and in some way enjoy my pension, be more relaxed. So the change that I feel I say away from, well I have to come here to do the hemodialysis, because it was a very good quality of life, I am with my family, I enjoy it, I do things that I couldn’t do before.”* (Man-4)

#### Topic 4: I have to work.

This theme refers to the strategies that are implemented to give continuity to work, both within a workplace and outside the workplace. Among the reasons that participants highlight for continuing with their formal employment, is to meet the years required to be able to receive a full pension. At least three of the participants report that they have an average of three years left to start their retirement procedures. Given this situation, they look for strategies to be able to meet the established years because by retiring before completing the necessary years of service they would lose a significant percentage of the same.

CKD and hemodialysis therapy are exhausting processes by themselves. The participants who are active at work make an extra effort to report to work after receiving their therapy despite their diminished physical condition and the side effects caused by hemodialysis, in order to meet the years they still have to contribute to retire.

Another of the reasons indicated by the participants for continuing to work is that the type of formal employment they carry out gives them access to social benefits, among others health insurance; the latter essential to give continuity to their TSR and for which work is maintained so as not to pay the high cost of CKD in private health institutions.

Undoubtedly, the fixed economic remuneration that the active participants receive as salary is another of the reasons that stands out for keeping the job, Since CKD is an expensive disease, so-called out-of-pocket expenses (study fees, diet changes, transfers, medicines) reduce their economic situation and in some cases, loans are used to cover the costs of the disease and daily expenses which, if not paid, leads them into debt.

Given this panorama, the strategies the participants adopted to reduce the wear and tear generated by constant transfers and the costs of CKD were: change their place of residence to a home close to the hemodialysis clinic; go alone to the TSR; manage and reduce family expenses to the essentials, as well as include the family in the diet of the participant.

*“Being aware of the economic perception is essential to be able to be well, calm or impatient, so I say, well, in that aspect I hit myself a lot, because, for example, right now they are giving me a pension of two a thousand and a piece, imagine, with all the expenses that are always... at home, at the salary that I was receiving, which, without any presumption, was \$59,000 pesos. [...] the point is that one never waits to get sick so that one stops working.”*

Finally, another element that the interviewees point out in order to continue with their work activities is that continuing to be active at work allows them to still feel useful and not think about the consequences of their illness, in addition to being able to obtain or generate their benefits own economic resources so as not to depend totally on the family.

*“I was also hospitalized all the time and well, at home, well, lying down and then, I didn't have much strength and I plucked up my courage and said, no, well, I'm going to go to work, I'm going to go to work, talk with my boss and discuss my situation [...] and I told him that I was going through a very difficult time, that I had a terrible depression, and I asked him to give me the opportunity to return, to feel useful, to at least de-stress or thinking now about my work, being busy and not just being at home... thinking negative things and bad things.”*

With regard to the participants who suffered a change in employment situation, some of them reported that being at home all the time, not having economic independence, dealing with the symptoms of the disease and the secondary repercussions of the treatment, made them feeling unhelpful or depressed, which is why they decided to go back to work and become self-employed to cover their personal expenses and the out-of-pocket expenses generated by the CKD.

*“No, I try to be independent, yes, because I know that people get tired and then I try to do things independently, even if they cost me work, but I do them, rest and start again...”*

## Discussion

One of the areas that chronic kidney disease affects when it manifests itself in individuals of productive age, is the workplace, a space in which a productive activity is usually carried out and at least a third of the day is dedicated to it. Work, as an activity, allows not only the satisfaction of human needs, but also contributes to the physical and mental well-being of people. Seen in a broader way, in addition to obtaining not only the means to live, with the realization of it man can show his capabilities, feel useful and participate in the construction of new achievements.<sup>14</sup>

The evolution of symptoms such as fatigue, headache, decreased mobility, among other manifestations, reduce individual performance and, if not treated on time, lead to loss of work due to the increase in symptoms and access to RRT. Cuesta, Gaibor<sup>15</sup> mention that the diagnosis of this disease can be difficult for people who suffer from it to accept, because their lifestyle will change and they will be subjected to invasive processes for life, producing psychological, emotional and social changes.

Kidney patients who show personal skills and abilities of self-confidence, decision, power, ingenuity, as well as adaptability and perseverance despite adversity, manage to accept themselves and life<sup>16</sup> as well as patients who feel they had disease control, achieve a positive appreciation of it and face it favorably,<sup>17</sup> they can reduce anxiety and depression, which leads them to have a better mental state, make possible a better adherence to treatment and therefore, a better quality of life.

Since most of the participants are heads of household, the economic remuneration received for their work performance becomes a priority, so the mechanisms to which they resorted to to continue in their job are intended to preserve their economic perceptions, thus reciprocity is established with the continuity of the TSR, since to receive it in a health institution, they must have a formal employment history.

Staying active at work is not only a financial necessity for kidney patients of productive age, it also gives them the opportunity to feel independent and productive for society. Cruz et al.,<sup>18</sup> point out that it is through work activity that people remain as social actors, interfering and modifying life through action and practice, while for Garrosa-Hernández et al.,<sup>19</sup> continuing to be active at work, It is a strategy used by patients to keep their “heads busy” and cope with the disease, avoiding depression and bad thoughts. In addition to the fact that “it is in the work context [where] relationships are built in which beliefs, values, interests and perceptions are shared that are related to psychological, emotional, social factors and quality of work life”.<sup>20</sup> (p.2)

You having a paid job was a financial necessity for being the breadwinner of the family; while for other participants, it gives them the opportunity to feel “useful” for society and independent. Having a job or activity gives the interviewees the chance to enjoy social contact, have good colleagues, while for others it gives them the chance to support their family.<sup>21</sup>

Continuing active at work does not exempt kidney patients from the presence of certain stressors derived from the activity such as: having to carry out activities that require strength or lifting heavy loads, long hours and/or work overload, in some cases, the impossibility of traveling and deal with the stress and uncertainty of a relapse in their health. Faced with this panorama, the strategies they resorted to were changing their activity, adjusting the work schedule, extending the work day, as well as giving up vacations or economic days.

The rigidity in the hemodialysis schedule and the loss of energy are aspects that contribute to unemployment or the reduction of work hours, which causes low self-esteem in the chronically ill due to the lack of understanding and support in the workplace.<sup>22</sup> Various studies have highlighted the importance that work acquires in emotional well-being and some others highlight the intrinsic meaning of work in the daily environment given that hemodialysis affects permanence in employment.<sup>23</sup>

The family and social isolation that the participants initially implemented were strategies to deal with their financial and health situation. Toasa et al.,<sup>24</sup> report that social isolation is a strategy that allows coping with stressful situations and avoiding questioning.

In summary, work is a fundamental part of the lives of people who have a chronic disease such as kidney failure, continuing work, both inside or outside a workplace, allowed the participants to improve and physical and mental stability, mood change, they felt useful and productive, as well as being self-sufficient and independent and being able to contribute to the expenses derived from CKD and its treatment. However, in order to keep their source of employment, the participants have to get hold of strategies that allow them to deal with the disease inside and outside the workplace.

## Conclusion

The strategies implemented by the study participants to deal with CKD and give continuity to the work activity, allow us to account for the importance and psychosocial benefit that work as an activity provides workers.

When it is possible to give continuity to the work activity, not only economic benefits are obtained, the work allows increasing the esteem and confidence of kidney patients, achieving physical and mental stability, as well as disease control, by having to remain stable to be able to continue working. Therefore, it is necessary to generate actions and legislate on the subject not only in the health system, but also in

the workplace to prolong the permanence and/or return to work of kidney patients, who can do so, through actions preventive to support kidney patients from the first symptoms of the disease and prevent them from reaching invasive procedures, such as hemodialysis; and, in turn, be able to reduce the rates of days lost from work.

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## Conflicts of interest

The author declares no conflict of interest.

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