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Original Article

Occupational repercussions in people with end-stage chronic kidney disease who attend hemodialysis: an occupational justice framework[1]

Repercusiones ocupacionales en personas con enfermedad renal crónica terminal que asisten a hemodiálisis: un marco de justicia ocupacional

Repercussões ocupacionais em pessoas com doença renal crônica terminal que fazem hemodiálise: um marco na justiça ocupacional

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Abstract

Objective: To know the occupational repercussions caused by hemodialysis treatment in people suffering from Terminal Chronic Kidney Disease and how public policies in Chile, specifically, Explicit Health Guarantees address the needs of this population. **Method:** Environmental observation guidelines, field notes, and semi-structured interviews with users and professionals who work in the Hemodialysis Unit of the Hospital Base de Valdivia, Chile were used. In addition, a documentary analysis was carried out that included clinical guidelines and technical standards of the Hemodialysis Unit. **Results:** The data were organized into 5 topics: Hospital Base Valdivia hemodialysis unit, Process of change and adaptation, Routines and habits, Roles and Sufficiency of public policies. Breaks in occupational histories, difficulties in the adaptation process and the need for a comprehensive approach that is not considered by public policies are evidenced. **Conclusion:** The need for a multidisciplinary treatment is proposed that considers

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[1] The ethical principles for research in human beings of the Declaration of Helsinki were considered. In accordance with current Chilean legislation, this research was evaluated and approved by the Research Ethics Committee of the Valdivia Health Service, as stated in Ord 168 of June 5, 2019. Informed Consent was obtained from the participants.

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an accompaniment in the process of occupational adaptation, especially in the early stages after diagnosis in order to prevent the impact on the quality of life of this population, as well as the need to develop more studies on the subject.

Keywords: Hemodialysis Units, Hospital, Occupational Therapy, Renal Insufficiency, Chronic, Health Policy/Chile.

Resumen

Objetivo: Conocer las repercusiones ocupacionales que provoca el tratamiento de hemodiálisis en personas que padecen Enfermedad Renal Crónica Terminal (ERC) y de qué manera las políticas públicas en Chile, específicamente, Garantías Explícitas de Salud (GES) abordan las necesidades de esta población. **Método:** Se utilizaron pautas de observación ambiental, notas de campo, entrevistas semiestructuradas a usuarios, usuarias y profesionales que se desempeñan en la Unidad de Hemodiálisis del Hospital Base de Valdivia, Chile. Además, se realizó un análisis documental que incluyó guías clínicas y normas técnicas de la Unidad de Hemodiálisis. **Resultados:** Los datos se organizaron en 5 tópicos: Unidad de hemodiálisis Hospital Base Valdivia, Proceso de cambio y adaptación, Rutinas y hábitos, Roles y Suficiencia de políticas públicas. Se evidencian quiebres en las historias ocupacionales, dificultades en el proceso de adaptación y la necesidad de un abordaje integral que no es considerado por las políticas públicas. **Conclusion:** Se propone la necesidad de un tratamiento multidisciplinario que considere un acompañamiento en el proceso de adaptación ocupacional, en especial en etapas tempranas después del diagnóstico, a fin de prevenir el impacto en la calidad de vida de esta población, así como la necesidad de desarrollar más estudios acerca del tema.

Palabras-clave: Unidades de Hemodiálisis en Hospital, Terapia Ocupacional, Insuficiencia Renal Crónica, Salud Pública/Chile.

Resumo

Objetivo: Conhecer as repercussões ocupacionais do tratamento hemodialítico em pessoas com Doença Renal Crônica Terminal e como as políticas públicas no Chile, especificamente as Garantias Explícitas de Saúde atendem às necessidades dessa população. **Método:** Foram utilizadas diretrizes de observação ambiental, notas de campo, entrevistas semiestruturadas com usuários, usuários e profissionais que atuam na Unidade de Hemodiálise do Hospital Base de Valdívia, Chile. Além disso, foi realizada uma análise documental que incluiu diretrizes clínicas e normas técnicas da Unidade de Hemodiálise. **Resultados:** Os dados foram organizados em 5 tópicos: Unidade de hemodiálise da Base Hospitalar Valdívia, Processo de mudança e adaptação, Rotinas e hábitos, Papéis e Suficiência das políticas públicas. São evidenciadas quebras nas histórias ocupacionais, dificuldades no processo de adaptação e a necessidade de uma abordagem abrangente que não é contemplada pelas políticas públicas. **Conclusão:** Propõe-se a necessidade de um tratamento multiprofissional que considere um acompanhamento no processo de adaptação ocupacional, principalmente nas fases iniciais após o diagnóstico, a fim de prevenir o impacto na qualidade de vida desta população, bem como a necessidade de desenvolver mais estudos sobre o assunto.

Palavras-chave: Unidades de Hemodiálise em Hospital, Terapia Ocupacional, Insuficiência Renal Crônica, Política de Saúde/Chile.

Introduction

According to the National Health Survey 2009 – 2013 (Chile, 2010) in Chile, Chronic Kidney Disease (CKD) has a prevalence of 2.7% of the general population, with an increase of 12.7 people with this condition per million inhabitants since 1980 (Chile, 2010; Zúñiga et al., 2011). This increase in prevalence is also observed in other countries in the region, such as Brazil (Sociedade Brasileira de Nefrologia, 2017), with similar levels of per capita income.

The aging of the population is a global phenomenon that in Chile has occurred in a shorter period than in other countries in the region (Díaz-Franulic, 2017). This process is accompanied by an increase in the prevalence of chronic diseases, in which we can find CKD that is associated with other diseases such as hypertension and diabetes mellitus (Aguilar et al., 2010). Thus, the process of population aging that has occurred intensively in Chile, allows us to foresee a rapid increase in the prevalence of this type of health problem.

If we consider that CKD implies an alteration of all the dimensions of occupational performance (Madalosso & Mariotti, 2013; Goto, 2017; Orduña et al., 2018), we can see the need for an approach to this condition from Occupational Therapy. However, when reviewing the literature, we find very little evidence in the Chilean context. In this way, this investigation seeks to investigate how people suffering from terminal CKD who attend hemodialysis in a city in southern Chile, see their occupational life affected and how the consequences on occupational performance are addressed by the guidelines issued by the authorities in health to address CKD.

The research is part of the theoretical and philosophical bases of Occupational Therapy in which occupation is a dynamic process typical of our condition as human beings, through which we maintain the organization of our body and mind (Wilcock, 2006). From these premises, the purpose of the discipline is to encourage people to have occupations according to their motivations, which allow them to fulfill the roles according to their cultural tradition learned through the socialization process (Kielhofner, 2011), under the premise that, the lack or the imbalance between activities of daily life, play or fun and productivity, can impact on health and well-being.

Research that has addressed CKD from a bio-psycho-social perspective, accounts for the burden on quality of life (Barros-Higgins et al., 2015; Goto, 2017; González-Tamajón et al., 2020), as well as alterations at the emotional level, such as anxiety and depression (Rojas-Villegas et al., 2017; Goto, 2017), especially in people who are in the terminal stage of this disease, TCKD, which, in turn, is associated with organic symptoms, and the limitations imposed both by the disease and by the hemodialysis treatment, especially a large amount of time and physical and emotional energy that these requirements, which has repercussions on social isolation (Perales -Montilla et al., 2016).

Taking critical Occupational Therapy (Salvador, 2015) as its support, this research seeks to advocate for the possibility of impacting social reality to improve the living conditions of individuals and groups. From an emancipatory, ethical, and socially responsible attitude, Critical Occupational Therapy seeks to contribute to social transformations, from the philosophical principles of the discipline (Laliberte-Rudman et al., 2019). We rescue, in particular, the framework of Occupational Justice (Durocher et al., 2019) which assumes that, when some people and groups see their participation in occupations that are satisfactory to them limited, there is an unfair situation that, rather than refer to individual aspects, it must be understood as a collective phenomenon (Parra-Esquivel, 2015) that is maintained by the social, economic and political contexts in which these people and groups are immersed (Malfitano et al., 2016). From this perspective, a call is made to adopt an active socio-political role as researchers, directing our work to the study and analysis of the specific conditions that power relations adopt in the specific contexts in which situations arise that, from an occupational perspective, are unfair (Carrasco, 2018), avoiding falling into generalizations.

Within the multiple aspects to consider for the analysis of situations of occupational injustice, in this research we focus on the regulatory frameworks in public health, considering that their analysis is a key to being able to later adopt a position as social and political actors (Arango-Soler et al., 2018). We will focus on the legal framework in which the treatment of people with TCKD who are part of this study is given, as well as the repercussions of the framework on the opportunities that these people have to participate in meaningful occupations and on their states of health from an occupational perspective. For this reason, a brief description of the Chilean health system in general and of the EHG (Explicit Health Guarantees) policy in the case of TCKD is provided below.

The current Political Constitution of the Republic of Chile of 1980, in article 19, number 9, makes explicit that the role of the State is to be the guarantor of access and coordinator of health actions (Chile, 2005), which implies a role other than a guarantor of the right to health.

Given the multiple problems of equity in access to health, starting in 2002 a new way of prioritizing problems began to be developed, definING baskets of minimum benefits that had to be guaranteed by the State (Bastías & Valdivia, 2007). In this process, as described in other post-dictatorship reforms in Latin America, economists played a leading role. In the Chilean case, there was the particularity that many of these technicians had basic training in medicine. Also, there was an important contingent of expert health economists linked to the so-called "Agreement of Parties for Democracy", a conglomerate that governed in the years that followed Pinochet's civic-military dictatorship. Thus, the economic logic allowed for maintaining a common language and continuity with the technical teams of the dictatorship (Fuentes, 2012).

With the reform of the health system, the State of Chile assumed the responsibility of guaranteeing previously defined benefit packages to certain groups selected according to diagnosis, age, and gender. With this, it maintained other non-guaranteed health benefits, as well as groups excluded from such guarantees. The logic for establishing priorities was based on epidemiological criteria and years of productive life lost due to disease.

In 2004, Law 19,996 established a Health Guarantee Regime (Chile, 2004), which considers access, opportunity, quality, and financial protection, for a series of health conditions, in which we find TCKD (Urriola et al., 2016). Hemodialysis is the treatment of EHG for TCKD, to which medications and tests are added. This procedure consists of extracting toxins that the kidney is no longer capable of eliminating and requires a frequency of three sessions a week, each of which lasts between three to four hours.

This research aims to find out how people with TCKD who attend hemodialysis at Hospital Base de Valdivia (HBV) in Chile see their occupational life affected and how such affectations are addressed by the EHG. Thus, we investigated the occupational history of users suffering from TCKD to identify areas affected either by the disease or by the treatment and the impact of the intervention actions established by the EHG on the affected areas.

Method

Starting from a qualitative paradigm (Driessnack et al., 2007), this investigation used an ethnographic design (Silva-Ríos & Burgos-Dávila, 2011) that sought to know the environmental conditions and the sociopolitical framework in which the hemodialysis treatment is carried out in HBV. Also, elements of the narrative design (Kielhofner et al., 1989) were incorporated to know the changes that those who attend this treatment have experienced in their occupations and their health situation.

To obtain data, we considered the ethical principles for research on human beings of the Declaration of Helsinki (World Medical Association, 2008). Also, following current Chilean legislation (Chile, 2006), this research was evaluated and approved by the Research Ethics Committee of the Valdivia Health Service.

The information production techniques were:

1. Participant observation in the HBV hemodialysis unit: Based on a previously prepared observation guideline, we collected information on the physical environment: number and size of rooms, ambulation spaces, daily use instruments, arrangement of objects, lighting, and temperature. Information on the social environment was also collected: number of professionals in the unit, interpersonal relationships between users, and interaction with professionals. Fields notes were made on aspects not considered in the guideline. The observations were made in July 2019;
2. Review of documents issued by the Ministries of Health-related to TCKD: The protocol established by the EHG for TCKD and technical standards for Hemodialysis Units was reviewed;
3. Semi-structured interviews with two professionals who work in the HBV hemodialysis unit: Personal data and information regarding the perception of the treatment provided and its effects on the users' occupations were collected. The inclusion criteria were: having a leadership position with three or more years and volunteering. The interviews were recorded and later transcribed. Table 1 identifies the participants according to profession, position, time they have been in the position and the date of the interview is specified.

Table 1. Identification of participating professionals and interview date.

Profession	Position	Identification	Permanence in the position	Date of the interview
Nephrologist Doctor	HBV Dialysis Unit Director	MN	3 years	07/31/2019
Nurse	Head Nurse Dialysis Unit HBV	EJ	12 years	08/02/2019

4. Semi-structured interviews with four users of the HBV hemodialysis unit: Personal, clinical, and socio-family data were collected. We also applied the script of the Occupational Performance Historical Interview II - OPHI-II (Kielhofner et al., 1989), which reconstructs the occupational history and the breaks that could have caused specific situations, including the appearance of a disease. The inclusion criteria were: attending hemodialysis in HBV for 4 or more years, voluntariness, feasibility, age range corresponding to adulthood, and being a beneficiary of the National Health Fund (FONASA). The interviews were recorded and later transcribed. In Table 2, a characterization of the interviewees is made according to gender, age, income bracket and the date and duration of the interviews are described.

Table 2. Identification of participating users, income bracket according to insurance institution, date, and duration of the interview.

Characterization of participants and data production.	User 1 (U1)	User 2 (U2)	User 3 (U3)	User 4 (U4)
Gender	Female	Female	Male	Female
Age	34 years old	56 years old	48 years old	27 years old
Income bracket according to FONASA[2]	No income	Income equal to or less than U$ 445 per month	Income equal to or less than U$ 445 per month	No income
Interview date	08/01/2019	07/31/2019	08/02/2019	08/01/2019
Duration of interviews	45 minutes	52 minutes	60 minutes	62 minutes

The data was analyzed using elements of grounded theory, especially the conception of the analysis as a continuous, dynamic, and flexible process (Charmaz, 2013) that is integrated with the collection and coding of the data to provide an analytical interpretation of the world of participants.

First, we carried out an open coding of the content of the documents, the field notes, and the interviews with professionals. Then, the emerging codes were applied to the analysis of the interviews and related to the analytical matrix proposed by the OPHI II instrument. In this way, we sought to identify the relationships between interventions with EHG and their implementation, with the repercussions on the occupational narratives of people with TCKD. Finally, we selected the relevant topics for the research objectives.

Results

The treatment proposed by the EHG plan, as well as its implementation in the HBV, showed repercussions on the occupational narratives of people with TCKD, which, for

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[2] In Chile there is no universal health contribution fund: people can choose to allocate their mandatory health contributions to private insurers. In this way, the State Contribution Fund (FONASA- *Fondo de Cotización Estatal*) concentrates around 80% of the lower income groups. For purposes of establishing the percentage of bonus and copayment of benefits, FONASA classifies its policyholders into four brackets according to income level.

better understanding, were organized into 5 topics: Hospital Base Valdivia Hemodialysis Unit, Process of change and adaptation, routines and habits, roles and sufficiency of public policies. The topics are outlined below.

HBV hemodialysis unit

The team is made up of 32 people: 11 nurses, 12 nursing technicians, 1 kinesiologist, 2 kinesiology interns, 1 nutrition intern, 3 doctors, 2 secretaries, and 3 assistants. At the time of the investigation, 47 users attended the unit, both from Valdivia and neighboring cities.

There are 4 hemodialysis rooms with 6 machines each. In each room, there are stretchers and armchairs which are distributed depending on the type of user and their characteristics. There are 2 bathrooms for officials and 2 bathrooms for users and family members. The hemodialysis rooms work in 3 daily shifts, each one lasting between 3 to 4 hours. The shifts start at 8:00 a.m., 12:00 p.m., and 4:00 p.m., respectively, and in each session, users have their blood pressure taken and then connected to the blood filtration machine. In each room, there is a nurse and a fixed nursing technician, while the kinesiologist, his interns, and the nutrition intern go through the rooms in each shift. The doctors carry out rounds and punctual supervision when necessary.

We observed little interaction between users, although they state that there are good relationships between them. The relationship between users and professionals is recognized as positive and nurturing. The participants consider the unit as a "second family" and as fundamental support:

> *If I've been to other centers, there are some that have television, for example and other benefits, but I still wouldn't change, it's my second home* (U1).

> [...] *the assistants, with all of them, we have very nice bonds. Suddenly they annoy me, I annoy them, and that's how we get along, we have a very good relationship and I feel super comfortable. They sent me to another unit, there they were very good to me and everything, but I got sick, because it was like my family had been taken from me, and I felt sad, I felt bad...* (U2).

> *I consider the hospital to be a support network in my life, I am grateful. In the hospital, they have allowed me to choose the hours in which I dialyze* (U3).

Regarding the physical environment, decree number 45 of the dialysis benefits of the Ministry of Health of Chile in its article 15 establishes that "The establishment must have floors and smooth, washable, non-absorbent or non-adsorbent surfaces, lighting and ventilation following current regulations and an air conditioning system that allows regulating the ambient temperature. It must also present a "reception area and waiting room, free circulation routes that allow access for people with disabilities, wheelchairs, and stretchers", and hemodialysis rooms that allow free movement of personnel and equipment, with a space at least 50cm. between each module, with access to each patient from three sides (Chile, 2017).

Regarding lighting, ventilation, and air conditioning system, from the reports of users and professionals, we can conclude that these do not fully meet their expectations. For users, the place has poor ventilation, lighting, and air conditioning

> *I would put more light on it and make it look outside, but nothing more* (U2).
>
> *I would like the room to have more ventilation, it is very hot* (U1).

The medical director of the Unit corroborates this by pointing out that: "[...] *we are in a unit that was never intended to be a dialysis unit, the comforts are not met neither for users nor for the professionals, it is gloomy* [...]".

Regarding the circulation routes, these are not expeditious nor do they comply with the norm, which has repercussions in the fact that there is a high density of personnel circulating through the Unit. As a consequence, there are strong restrictions on the entry of other people outside the Unit. An element that draws attention is that companions are not allowed to enter, so if someone accompanies a male and/or female user, they must wait in the common waiting room spaces. Exceptionally, a companion enters to carry errands or objects, always supervised by professionals, however, most users attend without a companion.

Inside the hemodialysis rooms, there are objects intended for the entertainment of those who attend, such as a television and a radio, which are usually turned on, especially televisions, at a low volume. In addition, in the waiting room, there is a shelf with books that are available for users and companions; however, we did not observe that they use them.

Despite this, the users say they are familiar with the spaces and conditions of the unit and that even when they are not ideal, they constitute a space where they feel comfortable.

Process of change and adaptation

In the users' accounts, the moment in which the TCKD diagnosis is known implies a break, that is, a milestone that marks a before and after and that requires an adaptation process that generates multiple transformations, and complex situations both for them and for their surroundings.

> *It was still hard for me to structure it, but it was also hard for me to accept it, I was stuck in a hole when I found out I had to attend dialysis, it was a break in my life since I had to leave my children alone, they were very young, and I had to rely a lot on the people around me* (U1).

Both because of the lack of knowledge of the repercussions on the health status of the disease, and because they have to depend on a treatment that involves allocating time and energy permanently, the people interviewed report having gone through difficult times after being told hemodialysis treatment as described in other investigations (Madalosso & Mariotti, 2013; Fernández-Díaz et al., 2019).

In addition, after starting treatment, users report having experienced limitations in maintaining activities that they previously performed, mainly due to associated physical problems. This implies that in addition to the discomforts typical of TCKD and the time they must allocate to hemodialysis, there were consequences in the perception of their abilities and, therefore, in their emotional states.

> [...] *the topic of dialysis is something strong, I felt more tired, I couldn't even take care of my children, it's a tremendous change and before dialysis, I didn't feel tired, I had more energy* (U1).
>
> *I felt bodily bad and I felt like a useless woman, I cried, because I said that I was not going to be the same as before and complained* (U2).

The same user reports feeling her effectiveness in performing household activities diminished than before diagnosis and treatment:

> *My routine used to be my house, I liked it to be blown out and at whatever time it was* [...]. *I used to get up earlier, before I did everything earlier, at noon I had my lunch ready, my toilet cleaned, my clothes hung up, everything, and that has changed* (U2).

Other users also report feeling that they have lost skills and abilities associated with a lower tolerance for effort.

> *I feel that due to the disease and all that it entails, I have lost the manual and work skills because I get more tired. I believe in myself a lot, but even if the disease wears me out more or the dialysis, subtracts more than it adds to me* (U3).
>
> *When I go out, I feel great, but then I start to have tachycardia, I'm more tired, and sleepy, with anemia up to the top, I sleep all the time* (U4).

These reports contrast with the Head Nurse, who rules out that the disease must necessarily lead to loss of capacities and states that, with adequate care, there should be no problems. What the professional pointed out also contrasts with the literature, even more so in the case of users who have been on hemodialysis for long periods (Blanco Nagore et al., 2014).

On the other hand, the interviewees also report positive changes in affective relationships in the family environment, either because they begin to value more the support of their close ones or because they modify the way they relate to them.

> [...] *the fact of getting together more, doing everything in my house, that changed, what if before we were a little more dispersed, now we unite more because of the dialysis issue, for me it has been positive* (U1).
>
> [...] *they all joined in more, they were always worried, but now they think* <damn my mom is sick...> [...] *I notice it in the way they approach me, to be kind with me, I also tell them to leave me alone if I'm not going to die, they went to the other extreme in terms of affection* (U2).

Routines and habits

All the users interviewed have attended hemodialysis three times a week on the first shift for more than four years and report that this meant drastically restructuring their routines, configuring two different patterns; one for the days that they attend hemodialysis and another for the days that they do not.

> *The days that I don't come for dialysis I do housework, sometimes I have to go out to buy or pay the bills and when I come here I get up early, I help my daughters get ready to go to school, I take care of things at home, I leave everything ready and then I come here* (U1).

On the other hand, the symptoms associated with TCKD and the effects of hemodialysis have also implied a greater concern for their health and, therefore, changes in the patterns of leisure activities and free time.

> *I have been invited, but I am afraid that I will get cold and hurt myself, I am a coward, in that sense, I am a coward* [...] *after the illness before I was not afraid* (U2).

The incorporation of the treatment into the routines implies a difficulty to make schedules and transfers more flexible and, therefore, developing social activities and productivity in most cases. Thus, the interviewees see the possibility of traveling to other cities restricted, because they do not have the option of carrying out the treatment in other centers.

> *When they get together to go out, they go to the fields, I don't do those things anymore, I only stay with my husband and my son at home* (U4).
>
> *I used to go out, every year I traveled to Valparaíso to see my family, but not anymore* (U2).

Another aspect with an impact on changing routines is the change in eating habits that people with TCKD must make when starting the hemodialysis process since they must adopt a diet with a severe restriction of protein, phosphorus, sodium, potassium, and even liquids (Albor-Suárez et al., 2016).

> *Before dialysis, I was a fan of eating raw, because they are rich and in the table of things, I can eat it is at the bottom, you cannot eat raw meat* (U3).

These changes do not occur immediately with the diagnosis: in the reports, the participants report that the most drastic changes occurred after facing life-threatening situations, which has meant a deterioration in their well-being.

> *Yes, it was hard for me to get used to it, because I ate grapes, shellfish, bananas, and all those things that we can't eat, and it was hard for me to leave them, that's why I came to the ICU so many times, but now, if they invite me, no I eat certain things because I got used to it* (U2).

These dietary restrictions also lead users to withdraw from participating in social activities, as has been described in the literature (Madalosso & Mariotti, 2013). The importance of modifying the diet is reinforced by the professionals of the Hemodialysis Unit as something central to avoiding complications. We also observed the multiple posters with information on recommended and restricted food groups and ways to restructure the diet to avoid complications associated with the clinical picture.

A novel aspect that was not found in other studies reviewed is that the interviewees consider the dialysis period as a time for themselves and to rest.

> *I always sleep, this is my break time, it's a time for me, I listen to music* (U1).
>
> *For me, the time I spend here is positive, because I rest, I do nothing, I am relaxed* (U2).

However, this is problematized by the medical director of the Unit who considers that given the number of time users spend there, it would be beneficial to provide them with alternative activities.

> *For example, it would be good if they could have occupational therapy, work individually and also in groups because they spend a lot of time here and since the comforts of the unit are not the best, it is difficult for the process to be friendly* (MD).

Roles

Associated with the breakdown produced by the TCKD diagnosis, the users, in most cases, report changes in the roles in which they participated during their lives, especially the productive role. Several of them reported having had to leave jobs that gave them satisfaction.

> *I want to exercise, but because of the time I spend on dialysis and my daughters, it is complicated* (U1).
>
> *When I started dialyzing, I quit my job, if I didn't go on dialysis I would die, so I couldn't work. I liked working, I liked cooking, I was happy working* (U2).

There are also limitations in the exercise of parental and partner roles:

> *The illness limits my role as a father. There are times that we go downtown, and for those things, we have to play with her and she asks me to take her in the arm and I can't do it because of the arm, I get tired* (U3).

The same user also said:

> *Hemodialysis has limited my intimate life, I no longer have an active sexual life, I have problems with erections, and I also get home exhausted. Before the disease, it happened to me once, but now it is constant. My wife understands me; however, I feel ineffective. This has been one of the worst areas to overcome* (U3).

Professionals identify the need for users to try to make their lives as normal as possible, maintaining their roles to improve their quality of life, which is consistent with what is proposed in the literature (Madalosso & Mariotti, 2013). However, the guaranteed benefits for TCKD do not consider the therapeutic approach to achieve this purpose. Thus, the Head Nurse of the Unit, when asked about the sufficiency of the EHG says:

> [...] *in the places that are needed, either there are no charges or there are no supplies. The weight of the situation has not been taken, nor has the importance both in healthy people and in people who are sick. OT can help prevent. Therefore, I believe that these policies are proposed insufficiently* (HN).

Sufficiency of public policies

The EHG for the case of TCKD considers access to continuous hemodialysis treatment and medications and tests. These benefits must be carried out within a period stipulated by law, which is counted from the date the medical indication is given. In the case of hemodialysis, this term is seven days.

In general terms, the benefits of EHG can be delivered by public or private providers. However, in the case of beneficiaries of the lower-income sections of FONASA, the treatment must be carried out in the public health network devices. For these groups, the treatment is free since it is considered full coverage, taking as a reference a monthly cost of $765,540 (Chilean pesos), that is, the equivalent of approximately US$1,040 (US dollars) (Chile, 2017).

In addition to the guarantees of access (benefits), opportunity (maximum waiting times), and financial protection (co-payment), the EHG considers that the care must be given by a provider accredited by the Superintendence of Health, that is, they consider guarantees of quality. In the case of hemodialysis, in 2009 this body prepared the Manual of the General Standard of Accreditation for Dialysis Centers (Superintendencia de Salud, 2009), which provides guidelines on the basic aspects that both public and private dialysis centers must consider. throughout the country to be able to deliver care with EHG. Despite this, according to the Chilean Society of Nephrology (Sociedad Chilena de Nefrología, 2014), they have not been implemented, nor have mechanisms been created to make compliance with these standards mandatory, so many centers that provide hemodialysis care under the EHG regimen do so without complying with that the same policy has established as minimum standards.

The lack of control is identified by the head doctor of the Unit as the problem of the policy

> *Policies are not bad, if you read them on paper, they cover everything and work well. The problem is that the execution fails, nobody controls that it is being fulfilled* (HD).

In this way, for the professional, the policy is well formulated since everything necessary for the treatment of TCKD would be covered. The problem would lie in the lack of enforcement of compliance with the rules. Even though the EHG benefits do not include care associated with addressing the emotional, physical, or occupational repercussions that this pathology entails, it occurs in other health systems, for example in Brazil, where the TCKD approach considers the start of Occupational Therapy care once the diagnosis is delivered, which includes actions such as accompaniment to guide self-care techniques, restructuring of routines and articulation of networks for continuity of care (Pereira et al., 2020). Neither are psychology, kinesiology, or nutritionist services considered in the access guarantees.

In the particular case of the Unit where we carried out the study, nutritionist and kinesiologist attention are given, which is possible due to the nature of the HBV's teaching assistance center; Through agreements with the Universidad Austral de Chile, users have access to professional assistance provided by clinical tutors within the framework of their teaching functions with their intern students.

The EHG does not consider the possibility of an integrated network of providers. Each financing entity, in this case, FONASA, defines the providers where the services must be provided, which is also to whom the financing entity makes the payment, prior agreement, in which the users can't carry out their treatment in other cities. The EHG also does not consider other therapeutic alternatives to hemodialysis. An integrated network of providers and other treatment alternatives could have a lesser impact on quality of life and occupational performance.

Also, there are no monitoring mechanisms or budgets to monitor compliance with the EHG, as stated by the Unit's head physician.

Discussion

Based on the users' reports, there are repercussions on their occupational histories derived not only from the TCKD but also from the treatment proposed by the EHG plan and its implementation in the HBV space. The perception of physical deterioration is verified, which affects the performance of significant activities and roles, all of which are consistent with the literature reviewed (Aguilar et al., 2010; Madalosso & Mariotti, 2013; Blanco-Nagore et al., 2014; Barros-Higgins et al., 2015). We also see the appearance of emotions, such as frustration, anguish, and loss of autonomy, especially in the first periods of hemodialysis treatment such as those described in the literature (Coutinho & Costa, 2015; Fernández-Díaz et al., 2019). In the case of HBV, we also see another edge of the emotional repercussions. Users develop a strong affective bond with the Hemodialysis Unit, which is related to support and good treatment at a time of vital breakdown.

After the diagnosis, we see that there is a process of change and occupational adaptation: routines and roles are modified depending on the time and energy that the treatment demands, mainly in terms of productivity and family. Several of them left paid jobs that gave them satisfaction, at the same time that their families adopted a protective attitude towards them. On the other hand, social life is limited mainly due to the loss of mobility that procedures and dietary restrictions imply. All this allows us to propose that TCKD and its treatment limit participation in occupations according to motivations and roles learned through the socialization process (Kielhofner, 2011).

These adaptation processes occurred abruptly due to the need to make the treatment compatible with the main life roles, without support to generate healthy adaptation strategies and balanced routines. This may be related to the fact that, after several years of treatment, users have incorporated hemodialysis time into their routines as self-care, mainly rest, given the multiple demands that prevent them from having this type of activity at other times.

On the other hand, the professionals interviewed consider that this time could be used by offering opportunities for activities of interest. However, from an occupational perspective, we propose that, rather than offering alternative activities in the hemodialysis space, it would be necessary to support the diagnosis in the process of change to support the restructuring of routines, incorporating self-care spaces and free-time activities at home and/or other participation contexts and promote greater occupational balance (Wilcock, 2006). Considering that changes in habits and routines occurred, in several cases, after life-threatening situations, support from the moment of diagnosis could prevent these situations by providing tools that make it possible to reconcile significant activities with changes in habits and routine and reduce dependency and/or protection of relatives and hemodialysis unit.

The processes of occupational change and adaptation denoted by the narratives of the interviewees contrast with a professional, who indicates that it is possible to maintain normal life patterns despite TCKD if hemodialysis treatment is performed and the indications are medical. The sufficiency of hemodialysis treatment and medical indications to maintain life patterns also contradicts the need expressed by the same professionals to have other types of interventions, especially psychological, occupational and nutritional to support the adaptation process, reduce the perception of impairment and enhance autonomy. We consider it relevant to pay attention to this dissonance since it can be related to the predominance of a biomedical perspective focused on pathology that tends not to visualize associated psychosocial aspects, at least in the first instance.

Although the EHGs ensure access to biomedical services, they do not consider an approach to the occupational repercussions of the treatment, in which people with TCKD who access it see their participation limited. These limitations are not only related to the individual health condition of the interviewees, but also to a social and political context where a cost/effectiveness logic predominates, which tends to leave aside aspects such as the promotion of healthy lifestyles. (Merino, 2016). Therefore, the evaluation of therapeutic alternatives that the State can guarantee does not consider the impact on participation. For example, other procedures such as peritoneal dialysis, which may have less impact on routines and promote better performance, are not guaranteed (Pinto et al., 2020). There is also no possibility that people can perform hemodialysis in other cities or that they can count on therapeutic support in the process of change and occupational adaptation to reduce the repercussions from both the disease and the treatment. For all of the above, we propose that the EHG and its implementation in the HBV maintain a situation of occupational injustice (Durocher et al., 2019; Malfitano et al., 2016).

The results of this research cannot be extrapolated to other groups due to the type of design and sample size.

Finally, for future research, we propose to incorporate gender approaches, social determinants in health, and studies in the early stages, which would allow further refinement of the needs of this population.

Conclusions

The limitations that people with TCKD who attend the HBV have to get involved in activities that are meaningful and that are related to internalized roles are not explained only by their health condition. For an understanding of the process of change and adaptation that is evidenced in the narratives of the users from the diagnosis of TCKD, we also need to consider the impact of the treatment. On the other hand, the treatment that people receive is part of certain health policies, so it is important to pay attention to these and get involved in the political and social reality if we want to impact the living conditions of these people (Salvador, 2015). However, the treatment acquires specific characteristics that result from the actions carried out by health teams in a specific context, so it is also necessary to pay attention to the micro-field where these actions occur, avoiding generalizations (Carrasco, 2018). In the case of this investigation, the actions carried out for the treatment of TCKD in the HBV are part of a policy that guarantees access to a basic basket of benefits to all people who present the same health condition based on a cost/effectiveness logic. This is somewhat problematic from the perspective of Occupational Justice since by providing everyone with the same basic basket of benefits that is limited to biomedical aspects, a justice of difference is difficult (Whiteford et al., 2018), that is, to provide the necessary support, according to the conditions of each person, to equalize the opportunities to participate in occupations.

The homogenization of the EHG policy contrasts with the respectful and welcoming treatment provided by the professionals of the HBV Hemodialysis Unit to the users that in addition, to compensating for the operating conditions that are below the standards for the operation of these types of devices. Although this could be considered something positive, it means that the level of user satisfaction falls entirely on the efforts made by the members of the professional team, while the authorities disregard their role. These professionals maintain a critical attitude towards politics, which can be an important agent of change. However, we believe that this could be reinforced by an Occupational Justice perspective.

Finally, we propose that an Occupational Justice perspective requires being able to integrate a view focused on the individual and their occupational participation with another that analyzes the social, economic, and political conditions in which this participation occurs, integrating, at the same time, the particularities of the specific contexts in which daily life takes place. In this way, research can be produced in pursuit of the right of individuals to access sufficient benefits for a timely rehabilitation process, which makes them active agents in their process.

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