

## LIFE AFTER HEMODIALYSIS

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### ABSTRACT

**Objective:** to know the problems people face as a consequence of chronic kidney disease and their hemodialysis treatment.

**Method:** a qualitative, exploratory and descriptive study with 12 people who were undergoing hemodialysis in a reference hospital. Semi-structured interviews were carried out at the people's homes from September to December 2018. Data were analyzed according to directed content analysis, starting with identification of codes, which were later grouped into subcategories and categories.

**Results:** people experienced significant changes in their lives after starting hemodialysis, presenting problems derived from treatment that were faced in order to maintain their lifestyle or resigning themselves to living abandoning aspects that gave them pleasure. The importance of maintaining power of will to continue treatment was appreciated, added to the acceptance process that was different for each person. Finally, a familiarity with death was evidenced due to frequent exposure to it through the death of hemodialysis colleagues, causing preparation for it.

**Conclusions:** change in people's lives as a result of disease and treatment is a complex situation for which they must mobilize personal tools that entail great efforts, living an acceptance process that can take years. Attention by health professionals must achieve closeness, empathy, humanity in treatment to promote own resources that favor personal well-being.

**DESCRIPTORS:** Chronic kidney disease. Renal dialysis. Lifestyle. Chronic disease. Death.

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# VIDA DESPUÉS DE LA HEMODIÁLISIS

## RESUMEN

**Objetivo:** conocer los problemas presentados por las personas como consecuencia de la enfermedad renal crónica y su tratamiento de hemodiálisis.

**Método:** estudio cualitativo, exploratorio y descriptivo con 12 personas que realizaban su hemodiálisis en un hospital de referencia. Fueron realizadas entrevistas semi-estructuradas en el domicilio de las personas, durante los meses de septiembre a diciembre del 2018. Los datos fueron analizados de acuerdo a análisis de contenido dirigido, iniciando con la identificación de códigos, los cuales posteriormente fueron agrupados en subcategorías y categorías.

**Resultados:** las personas vivieron un cambio significativo en sus vidas al momento de comenzar la hemodiálisis, presentando problemas derivados del tratamiento que fueron enfrentados con la intención de mantener el estilo de vida o resignándose a vivir abandonando aspectos que le provocaban placer. Se apreció la importancia de mantener la fuerza de voluntad para seguir el tratamiento, sumado al proceso de aceptación que fue diferente para cada persona. Finalmente se evidenció una familiaridad con la muerte debido a la exposición frecuente a ella a través de la muerte de sus compañeros de hemodiálisis, provocando una preparación ante ella.

**Conclusión:** el cambio que se produce en la vida de las personas a consecuencia de la enfermedad y tratamiento es una situación compleja para lo cual deben movilizar herramientas personales que conllevan grandes esfuerzos, viviendo un proceso de aceptación que puede llevar años. La atención por el equipo de profesional de salud debe lograr cercanía, empatía, humanidad en el trato para fomentar los recursos propios que favorezcan el bienestar personal.

**DESCRIPTORES:** Insuficiencia renal crónica. Diálisis renal. Estilo de vida. Enfermedad crónica. Muerte.

## A VIDA APÓS A HEMODIÁLISE

### RESUMO

**Objetivo:** conhecer os problemas enfrentados pelas pessoas como consequência da doença renal crônica e seu tratamento hemodialítico.

**Método:** estudo qualitativo, exploratório e descritivo, com 12 pessoas submetidas a hemodiálise em um hospital de referência. As entrevistas semiestruturadas foram realizadas nas residências das pessoas durante os meses de setembro a dezembro de 2018. Os dados foram analisados de acordo com a análise de conteúdo dirigida, iniciando com a identificação dos códigos, que, posteriormente, foram agrupados em subcategorias e categorias.

**Resultados:** as pessoas vivenciaram uma mudança significativa em suas vidas no início da hemodiálise, apresentando problemas decorrentes do tratamento que são enfrentados com a intenção de manter seu estilo de vida ou resignando-se a viver, abandonando aspectos que lhes davam prazer. A importância de manter a força de vontade para continuar o tratamento foi destacada, adicionada ao processo de aceitação que foi diferente para cada pessoa. Por fim, evidenciou-se familiaridade com a morte devido à exposição frequente a ela pela morte de seus colegas em hemodiálise, preparando-a para tal evento.

**Conclusão:** a mudança que ocorre na vida das pessoas como resultado de doenças e tratamentos é uma situação complexa para a qual elas devem mobilizar ferramentas pessoais que envolvem grandes esforços, vivendo um processo de aceitação que pode levar anos. A atenção da equipe de saúde deve ter proximidade, empatia, humanidade no tratamento, para promover recursos próprios que favoreçam o bem-estar pessoal.

**DESCRITORES:** Insuficiência renal crônica. Diálise renal. Estilo de vida. Doença crônica. Morte.

## INTRODUCTION

In the current global epidemiological context, increased chronic diseases can be seen as the main cause of morbidity and mortality in the population; it is one of the main focuses of interest by health teams, due to the great impact on people's lives, having to endure a pathology for the rest of their lives. Chronic kidney disease (CKD) is one of them, having great repercussion in people who suffer from it, especially in those who are undergoing renal replacement treatment as is the case of hemodialysis (HD). HD produces a change in people's lives as it is of a daily nature, having to be carried out three times a week, in addition to maintaining strict care, such as changes in diet and fluid consumption, changes compared to adopting a new lifestyle, which is a major challenge to face.<sup>1-2</sup>

The worldwide prevalence of CKD is estimated at 11-13%, the majority at stage 3, while 4-13% is at stage 5. In the group of people at stage 3 to 5, Chile has a prevalence of 12.10%, surpassed by the United States and Canada, with a prevalence of 14.4%.<sup>3</sup> The impact of CKD is based on the fact that it has a relationship with morbidity and mortality of other pathologies such as hypertension or diabetes mellitus.<sup>4</sup> Moreover, it has increased alarmingly in recent years, 32% between 2005 and 2015.<sup>5</sup> This can be seen in the number of people under HD in Chile, which has increased more than 30 times in the past 25 years.<sup>6</sup> In Chile, in 2017, there were 249 HD units in the country, 46 hospitals and 203 centers, serving 21,223 people, almost two thousand more people than in 2016, in which the number of people treated in the country was 19,973.<sup>7</sup>

The World Health Organization expresses the importance that public policies can be effectively put into practice. Such policies can thus face this new need in the health of the population where nursing professionals play a fundamental role, having daily and direct contact with people.<sup>8</sup> Also, there is evidence that nursing care needs additional training, considering that special attention should be given to people for their well-being. As it is a routine service, periodic connection and disconnection with the HD machine, the end of the nursing service can fail to provide comprehensive care.<sup>9</sup>

For a person with CKD, undergoing HD can be an imposed reality, often without having an idea of what the treatment involves in their life. This is undoubtedly a crucial event for people involved in experiencing this treatment through an adaptation and learning process, having to face changes in different areas of their lives. It is here where people experience acceptance or not of this new reality, where people can strive to maintain the life they had before treatment or they can take refuge in the new life that HD implies, leaving jobs, leisure activities or social environment.<sup>10-11</sup>

Carrying out this study is essential to understand the life of people once they start HD treatment. By better understanding this fact, health teams can empathize with the process experienced, paying attention not only to the connection of people with HD machines, but also to cooperation with them to face this new reality, offering comprehensive and humane care; and it can help keep their health and relevant care.

This is an area that has been little studied in Chile, especially with regard to qualitative studies. These studies allow us to understand the phenomenon from the point of view of people, allowing us to describe the phenomenon in more detail and develop more solid knowledge.

Based on the above, the study aimed to find out the problems people face as a result of CKD and treatment for HD at a public HD service in Chile.

## METHOD

This qualitative-exploratory-descriptive study was carried out with people from a hospital in southern Chile. From September to December 2018, data were collected from people with CKD undergoing treatment at the HD unit. People over 18 years old, with more than six months in HD and lucid were included. People with very debilitating associated conditions, such as cancer or mental disorders and severe emotional stress associated with the disease and treatment were excluded. Assessment of these criteria was performed subjectively by the researcher and also with the professionals who worked at the HD service.

Concerning selection of participants, it was carried out by intentional sampling, with 12 people out of approximately 100 who were undergoing HD at a public hospital in southern Chile and who met the selection criteria selected. Furthermore, to conduct a sampling that included different personal characteristics, we seek to have people at different times in HD, age and equitable gender distribution.

For data collection, a first contact was made with people at the HD unit so that they could get to know the researcher, creating greater proximity and trust, in addition to identifying those who could be potential informants. Invitation was made to those who met the criteria previously described in the HD unit and reported what the study consisted of. Finally, those who in the first instance showed interest in participating were called by telephone, informing them of the investigation and detailing the schedule of the interview.

The interviews were conducted in people's homes through a semi-structured interview, using as an initial question "Tell me your experience with chronic kidney disease". Then, other questions arose according to the objectives of the study and to favor the history of the interviewees' experiences. All interviews were conducted by the first author of the article.

To start the interviews, a data registration form was used, together with the Informed Consent Form to participate and authorization to record the interview, the main element for obtaining people's statements. Everyone accepted this condition without problems. Likewise, they had the option of reviewing the transcript of their interviews, for which they declared that it was not necessary, which was repeated in all participants.

Data analysis was based on assessing all interviews. After being transcribed, they were analyzed by directed content analysis,<sup>12</sup> according to changes that occur in people's lives due to CKD and HD.<sup>12</sup> Analysis included the following steps: 1) reading and rereading the interviews; 2) coding the interviews, having as reference words and phrases that express an idea of interest in the study; 3) reading all codes; 4) identification of topics present in the referred codes; 5) collection of similar codes by topic, taking into account the research objectives; 6) definition of categories, considering the content of the codes; 7) delimitation of the subcategories that characterized the categories. This process was interpretative, i.e., the categories were defined subjectively, considering what was most representative of the stories and which helped to better understand the experiences expressed by people.

All ethical aspects considered in this research were based on the seven principles for conducting scientific research: scientific value; validity; equitable selection of experimental subjects; favorable risk-benefit ratio; independent review at the project stage; informed consent; and respect for the subjects enrolled in the study.<sup>13</sup> This study was approved by the institutional ethics committee for research on human beings at the University of Magallanes and with the permission of the hospital to conduct the research. Along with this, during the investigation process, special care was taken to respect the will of the interviewees. Confidentiality was guaranteed, data management, schedule and the possibility to withdraw from the investigation without harm to their treatment. All of these aspects were discussed previously, during and at the end of the interview, which was finally reflected

in the signing of informed consent. There was no abandonment of participation, only one person was excluded because it was difficult to talk about his experience due to his cognitive limitations, which had not been previously detected.

## RESULTS

Twelve people participated in this study, of whom six were male and six female, whose ages ranged from 26 to 73 years old. Regarding marital status, seven were single, four were married and one was separated. In relation to family nucleus, six of them lived with more than two people, five with a relative and one participant lived alone. Occupation varied, two were workers, one was student, two were housewives and seven were pensioners. Finally, the most frequent health system was the National Health Fund with 11 participants and only one belonging to the Social Health Institute.

Analysis of all interviews reflects that people experienced a change in their lives since they were diagnosed with CKD as well as when they started HD. The lived experience was wide, but they could be classified into three categories that reflect what their realities were, according to Figure 1:



**Figure 1** – Classification of categories and subcategories

## Being under hemodialysis is another life

CKD and HD have caused drastic changes in people's lives; there were those who faced more effectively, trying to advance or more defeated, living a life under resignation. As the start of HD treatment was sudden, people had to create sudden changes in their lifestyles, sometimes without understanding the importance of these.

### **Changes in the daily life**

The changes are occurred in different aspects of life, such as loss of relationship with friends and family, work, roles within the family, travel possibilities, scheduling of time, and limitations in sports. Since the start of HD, people have been affected by their lifestyle or have to do daily activities because they feel limited due to complications from CKD or HD. Therefore, we will feel two moments when we are free to carry out activities according to convenience. Frequent are those who feel more resignation, abandoning business, leisure activities, social circle, among others.

On the other hand, there were those who wanted to continue with their lives so they made an effort to maintain the pace of life they had, with more fatigue than before, but maintaining the same activities that produced pleasure. Although they were a new weight in their lives, they did not want to live exclusively around their new condition, they wanted to continue enjoying life and continued to feel that they were free and autonomous. This is seen in the following words:

*I will never have a stable relationship and that is why I think I am self-sufficient, because usually you tell men that you have a disease and they are afraid, they cry (P1).*

*[...] I lost my job, I'm already selling my truck to get out of my expenses, I'm going to be idle as before, but now my lady left to work... she has 44 years of service (laughs)... she doesn't want to retire, because your pension is nothing (P2).*

*[...] hemodialysis days are lost days ... they are Monday, Wednesday and Friday, in addition it is three days, out of the five that is done, so it is horrible (P9).*

### **Physical changes that prevented living fully**

People stated that they noticed changes in their body since HD began, physical limitations in their daily life that caused them to abandon activities that they enjoyed due to not being able to do it properly, either for the time spent on HD or for the symptoms, such as tiredness and lack of appetite. This was one of the main problematic changes for people, having noticed different in their essence, they could not carry out their role in society as before, HD in addition to having taken four hours a day, three times a week, also took away the desire to be able to live, to carry out activities, to go on, to interact with others. People noticed that they were different, that they had greater limitations and that, although they wanted to overcome them, the body, physical exhaustion limited it, and those who continued to maintain the usual rhythm of life found it extremely difficult. Here are some ideas regarding:

*I had relationships with people who have no idea that I am on hemodialysis and sometimes I think "tell or not?" ... what do you denounce? The arm, so I have to hide. How do I hide it? I always wear long sleeves, things like that, I'm ashamed and sometimes it works, in general, but inside, I think "screw it", then I take it off. [...] ... my mental state was good, but now I noticed that I was disconnected and that makes me sad, because I feel that I have many things to do, but the body does not follow me, the mind thinks the body does not (P1).*

*[...] I can no longer play sports, I can no longer work on what I worked on, before working as a plumber, and I can no longer do it. If I make a little effort, I get tired a lot, my bones and muscles start to hurt, everything hurts when it takes a little effort (P6).*

[...] *I try to do everything, I didn't cut anything out of my life, I pretend that my life adapts to my current situation, but I keep doing the same, I think I do more things than before, but it's difficult. But if you can, I think it depends on you (P9).*

### **Hemodialysis allowed to return to life**

Despite the fact that for most people CKD and HD caused negative changes, some recognized that HD treatment helped them get back to some aspects of their lives. Due to the diffuse onset of CKD, many times, the initial treatments used failed to compensate for people's health, which led to a long period of physical and emotional discomfort, with its corresponding limitations. When entering and starting HD, people reported a noticeable change, since they were compensated, being able to return some activities and make their daily lives more effective:

[...] *I didn't go anywhere... I was locked at home all day, now I work all day since I get up, I don't stop, I'm better at hemodialysis, at least I move, I have no problem and now I go out to work... [...] I haven't been hospitalized for a long time, I used to live in the hospital. I underwent hemodialysis and I don't know what is urgent anymore, hemodialysis changed me a lot, because before I started hemodialysis, I was more hospitalized than my home... I think hemodialysis changes a person a lot (P12).*

### **They have to keep fighting**

People with CKD under HD treatment showed different views of their experience, most saw their condition as something difficult, as a burden to bear, who did it passively, resignedly, accepting. Others lived more positively and actively trying to continue with their activities despite the additional effort.

### **Hemodialysis dependence**

People stated that since they debuted in HD treatment, they feel that this has been a burden in their lives, an additional weight with which they must live daily changing routines, jobs and habits. This became an assumed responsibility, part of a routine, of her life, coming to normalize as a job to be completed. Attending a job is given voluntarily; however, for these people HD came suddenly as an obligation that was difficult for them to assume and in a dependent relationship with which they had to learn to live to maintain their state of health.

[...] *in fact, Mrs. X once told me that she considered me to be a very intelligent woman, because I make decisions and go ahead, I go through hemodialysis, but I keep going (P1).*

[...] *when you're connected, it doesn't depend on you anymore, it depends on someone else and it depends on the machine and that's my life (P2).*

[...] *I was very afraid, the fact that they say that machines are your kidneys, knowing that without it you will not live (P7).*

[...] *it's exactly how I work, it's an obligation that you have, so I don't worry, of course I live with it, but I don't spend all day thinking that I have to go there tomorrow (P10).*

## **Non-acceptance/acceptance of hemodialysis**

In most cases, the onset of CKD and/or HD started unclear and with little information available due to the severity and the need for a rapid therapeutic start, this caused people to adapt to their new health situation with many doubts and fears. As time passed, they became more knowledgeable and more experienced about the pathology, treatment, and their life in the face of these new changes, thus adjusting their adaptation. Based on this, there were two large groups of people, the first were accepting the idea of having a life-long health condition that needs permanent care and attention, accepting their HD treatment without major problems, as something that added to their life and what they had to take care of.

*... I saw some young children playing, 8 to 12 years old, and I saw that they were also dialyzed, so I thought that if they are dialyzed, they are younger and I have come a long way, why should I not hemodialysis? I already did my youth, my childhood, I did everything and then I started to support hemodialysis (P2).*

*... so, being four hours there, for me it's not serious, I don't feel that way, honestly. I am happy because I live, besides having to thank these people a lot (P3).*

The other group of people still struggled with the idea of being routinely connected and depending on a machine for the rest of their lives. They were in a permanent struggle to accept their condition, rejecting both the disease and the treatment, considering that their situation was something temporary, that had a cure and that would be healed or rejecting the associated care. For those people, CKD and HD was something to be overcome, as if a miracle could happen.

*[...] it was difficult for me, because I also didn't adapt, I don't like hemodialysis, I never accepted and I don't like it and I will never accept it, it's a temporary thing that I won't have the rest of my life (P4).*

## **Learning how to live with hemodialysis**

The onset of CKD was difficult, having to get used to the routine and dependence on HD, over time people adapted to their new condition, took HD as their own struggle, participating in their care and obtaining information from different means to carry it in the best way:

*[...] but, over time, he is getting used to the same nurses, the same hemodialysis companions, who try as hard as possible to row on the same side and need to take it. I will not go in a humorous tone, a disease cannot be taken with humor, but maybe with a little resignation, let's say (P7).*

## **Death surrounding life**

Since HD started, people with CKD had a very close relationship with death, witnessing it in their own treatment partners. This made them perceive death as something close, that could reach them without warning and for which they should be prepared. In addition, the death of her companions, which was initially a traumatizing process, was eventually taken with less sadness and surprise for being used to it.

## **The death of hemodialysis companions became routine**

People stated that they had witnessed the death of their companions since they began their care in HD, this would have been so routine that awareness of death was lower and lower, even having a routine as a unit when one of them died:

[...] *It is difficult, I try to take this as something common, I have a friend, one of my best friends who... she works at the hospital's ICU and sees much more than me, she is super cold. But over time, I think I got a little bit the same, so I think I already assumed that death comes, and death comes (P1).*

[...] *I'm sorry, because practically a person becomes part of the family ... I cried ... how do you want me to feel? The rest takes more years as they assumed, but not me, I feel sorry, sometimes, like, why? Because they let it go, because they let it die, because they don't do anything (P4).*

[...] *it is clear that someone is shocked, as I say, because when the person is close to you and then this person dies, you feel shocked a little, it is a few days, but then everything normalizes, life goes on normally (P10).*

### ***Their future death caused concern in their family***

Due to the presence of death in their HD colleagues, it was common for people to socialize this in front of their family and friends, generating the topic of their own death to be discussed with their close circle, as something that was imminent. For this reason, they even went so far as to state that they respected certain decisions after their death, as shown below:

[...] *I am much more concerned that family members will not suffer, because the person goes out and forgets the pain, is no longer suffering, so it is like a relief, the pain is what remains for the family [...] I discussed all this and it hurts... I have to tell you, because when I leave, you will be alone and there you will know what it is and I don't want you to be alone, I want to leave when you are already settled with yours ... I have the peace of mind that he stays with his house... and I have insurance... the only thing I can leave is education and try to face life alone (P1).*

[...] *so, he always had to learn to progress... I told him, one day, he knows that, one day we are going to die, I am not going to die of old age, living at 90, at 100, you never know, neither do you you know when you're going to die, not even my daughters (P8).*

### ***Uncertainty of the future***

People have difficulties to project themselves in different areas of their lives, mainly due to the vulnerability associated with the disease and the treatment and previous experiences. They were suddenly admitted to intensive care without being sure of having a positive prognosis or the variability of their state of health and, therefore, mood, where each day is different. This, added to the fact that some people are elderly and have a daily experience close to death through their peers, makes the projection in their lives uncertain, living day by day until the disease determines it:

[...] *I don't know if I can go this far, I can be separated for 5,6, 7 years, it seems that I am different from others (P3).*

[...] *I'm already old, I don't have much left, so whatever God wants will be good (P11).*

## DISCUSSION

CKD is a serious condition that, in its later stages, can have a short survival without adequate treatment or care.<sup>14</sup> The implication of CKD in people's lives generates a series of emotional, physical and social manifestations, causing changes in the way of life, together with the permanent fear of the complications of the disease and the possibility of change. Moreover, HD is a treatment that prolongs life; being under HD is perceived with a feeling of dependence that requires strict care with life so that people can always be prepared to overcome. They are similar to those found in other studies that show that the changes resulting from CKD have an important implication in people's lives.<sup>15-16</sup>

Detecting the diagnosis and starting HD treatment is part of a negative memory. It is mainly based on the surprise of the need to start treatment quickly, due to hospitalization and/or referral to HD. Not all people were able to generate an adaptation to deal with this new health condition. Since then, people perceive changes in their lives in different aspects, generating a mobilization of internal resources to respond to them. For the vast majority, these changes are perceived negatively, where they feel limited to maintaining the same lifestyle they previously had. This correlates with the study carried out in northeastern Brazil, with 39 people, with a qualitative approach. The results do not differ much, as people also have limitations in their daily lives, having to leave their jobs, with the feeling of not having more fun in their life, in addition to maintaining daily care.<sup>11</sup>

For these reasons, people can acquire emotional disorders derived from the process they are going through and which must be addressed by the treatment team in order to improve general well-being and prevent the development of other mental illnesses. Based on data from a study carried out in Córdoba, Argentina, emotional changes are manifested in 92.4% of study participants, an impact number that should not be ignored in therapeutic treatment.<sup>17</sup>

HD generates a dependency relationship manifested by people, qualifying treatment as "a job", with imposed responsibilities such as maintaining their care, feeling an obligation to comply with this new reality. This is also observed in the qualitative-descriptive study carried out at a nephrology service at a large hospital in southern Brazil. Their results show that there is a dependence on HD that is difficult to endure, since a situation imposed with an emotional impact on the person with CKD must be accepted. The interviewees expressed themselves in prison, feeling in a prison, among others. Furthermore, this study shows the annoyance of relying not only on HD, but on other people, when these people previously depended on it.<sup>18</sup>

Precisely for this reason, the acceptance of this new reality becomes confused, living a process that can drag on for years, with a series of emotional manifestations. This is also observed in a qualitative descriptive study carried out in northeastern Brazil, where people maintained the idea that HD was temporary due to the denial of being able to face the daily problems and to deal better, one step ahead. Acceptance is a complicated process, tending to look for other defense mechanisms, such as avoiding the problem. People who accepted their condition related to family support and health professionals.<sup>19</sup> Likewise, it has been shown that both personality and coping strategies are relevant in adapting to this new health condition, thus influencing the way of perceiving their own quality of life.<sup>20</sup>

As a consequence of the above, people with CKD in HD maintain the will to continue fighting, in order to continue with their lives in the same, or similar, way they used to. They strive in a daily struggle to respond to the activities they enjoy, such as work, study, sport, among others, despite the fact that the presence of associated symptoms affect their ability to carry out daily activities.<sup>21-22</sup> On the other hand, there were interviewees who stated that HD caused compensation for their health, resuming activities that gave them pleasure, as they presented no complications and reduced hospitalization, almost permanent before HD. It can be seen in research that nursing professionals and the family can enhance the tools that will make people move forward, since, although the start is somewhat

traumatic, CKD can be considered as an aspect to generate a change, generate new skills and life opportunities.<sup>19,23</sup> Likewise, the timely action of health professionals before starting HD treatment has been shown to improve coping, providing real information about the prognosis and implications for the disease and treatment.<sup>24</sup>

Finally, the process in the face of death becomes routine, given the frequency with which they face it among their own HD colleagues, which causes sensitivity to decrease and practicality to guide their family towards their own death. This is seen in a Canadian study on end of life of people with CKD in stages 4 and 5. In this study, people reported the importance to be able to discuss their prognosis with the treating doctor and future care with their family, wanting to involve them in their life-ending decisions.<sup>25</sup>

In another study, which aimed to identify the role of HD treatment in the daily lives of people with CKD, also emphasized that death is something that is present in the lives of people under HD. The study highlighted that this situation has as a consequence mood disorders, anxiety, hurt and challenges. This shows that it is a complex situation and requires constant evaluation and mobilization of professionals to help people better deal with their health-illness situation.<sup>10</sup>

Nursing care for people under HD should take into account the aspects presented, with empathy to be able to provide immediate benefits according to the needs of people. Not only for the improvement of knowledge or technology in HD, but also for the meaning of guaranteeing quality in each nursing action for the person and also for family members, seeking the balance between therapy and humanity.<sup>26-27</sup>

The limitations of this study are based on the fact that the interviews were carried out by a nurse, whose first contact was in the HD service, and they did not have a longer contact that would enable a relationship of greater trust.

## CONCLUSION

This study reflects the lives of those who are diagnosed with CKD and must follow treatment for HD; shows the daily reality of those who suffer from a chronic and serious disease, with extremely restrictive care. These people must follow a standard of living associated with their state of health, often imposed, without the option of changing it. They yearn for previous times of freedom, where their actions were validated of their own free will, without awareness of the repercussions that can cause complications in their illness. It will depend on their internal resources to maintain the lifestyle they had before and face their own death with a certain kindness. Faced with this reality, the imminent work of health professionals is promoted comprehensively for people, especially with chronic pathology. Their care generates support and permanent attention that enhances using personal tools, not abandoning people who remain their whole lives holding their lives in front of their environment and themselves.

The implications of the results of this study lie in delivering guidelines to health professionals, especially nursing professionals who live with HD CKD on a daily basis. It is necessary to know what it is like to live with HD, beyond the daily care in the unit, connecting and disconnecting, evaluating routine exams, weighing and evaluating complications, will guide the human process of empathizing with vulnerable people who want to continue living.

This study points to the need for more research, in the sense of deepening the understanding of why people face their condition in different ways. There are elements to be better investigated, such as understanding what personal characteristics and/or sociocultural aspects can change the way people assess their condition.

## REFERENCES

1. Organización Mundial de Salud. La salud de los adultos en peligro: el ritmo de las mejoras disminuye y las diferencias se acentúan. Capítulo 1: Salud mundial: retos actuales [Internet] Ginebra(CH): OMS. 2003 [cited 2019 Feb 03]. Available from: <https://www.who.int/whr/2003/chapter1/es/index3.html>
2. Albañil Frías T, Ramírez Moreno M, Crespo Montero R. Análisis de la calidad de vida en pacientes en hemodiálisis ambulatoria y su relación con el nivel de dependencia. *Enferm Nefrol* [Internet] 2014 [cited 2019 Aug 16];17(3):167-74. Available from: [http://scielo.isciii.es/scielo.php?script=sci\\_arttext&pid=S2254-28842014000300002&lng=es](http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S2254-28842014000300002&lng=es).
3. Hill N, Fatoba S, Oke J, Hirst J, O'Callaghan C, Lasserson D; et al. Global Prevalence of Chronic Kidney Disease - A Systematic Review and Meta-Analysis. *PloS One* [Internet] 2016 [cited 2019 Aug 4];11(7):e0158765. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4934905/>
4. Wang H, Naghavi M, Allen C, Barber R, Bhutta Z, Carter A; et. al. GBD 2015 Mortality and Causes of Death Collaborators. Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* [Internet] 2016 [cited 2019 Aug 7];388(10053):1459-544. Available from: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)31012-1/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)31012-1/fulltext)
5. Mehta R, Cerdá J, Burdmann E; Tonelli M, Garcia-Garcia G, Vivekanand J; al. International Society of Nephrology's oby25 initiative for acute kidney injury (zero preventable deaths by 2025): a human rights case for nephrology. *Lancet* [Internet] 2015 [cited 2019 Aug 7];385(9987):2616-43. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/25777661>
6. Luyckx V, Tonelli M, Stanifer J. The global burden of kidney disease and the sustainable development goals. *Bulletin of the World Health Organization. WHO* [Internet] 2018 [cited 2019 Aug 7];96:414-22. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5996218/>



7. Flores J, Alvo M, Borja H; Morales J, Vega J, Zúñiga C; et al. Enfermedad renal crónica: Clasificación, identificación, manejo y complicaciones. *Rev Méd Chile* [Internet]. 2019 [cited 2019 Aug 1];137(1):137-77. Available from: [https://scielo.conicyt.cl/scielo.php?script=sci\\_arttext&pid=S0034-98872009000100026](https://scielo.conicyt.cl/scielo.php?script=sci_arttext&pid=S0034-98872009000100026)
8. Poblete H. Cuenta de hemodiálisis crónica (HDC) en Chile (al 31 de agosto de 2017) [Internet] 2017 [cited 2017 May 7]. Available from: <https://www.nefro.cl/v2/biblio/registro/23.pdf>
9. Angel Z, Castano G, Cortes D. Cuidados de enfermería en el paciente con enfermedad renal crónica en hemodiálisis: una revisión sistemática. *Enferm Nefrol* [Internet]. 2016 [cited 2018 May 24];19(3):202-13. Available from: [http://scielo.isciii.es/scielo.php?pid=S2254-28842016000300003&script=sci\\_abstract&tlng=pt](http://scielo.isciii.es/scielo.php?pid=S2254-28842016000300003&script=sci_abstract&tlng=pt)
10. Rudnicki T. Doença renal crônica: vivência do paciente em tratamento de hemodiálise. *Contextos Clínic* [Internet]. 2014 [cited 2019 Feb 3];7(1):105-16. Available from: [http://pepsic.bvsalud.org/scielo.php?script=sci\\_arttext&pid=S1983-34822014000100011](http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1983-34822014000100011)
11. Araújo J, Neto V, Anjos E, Silva B, Rodrigues I, Costa C. Cotidiano de pacientes renais crônicos submetidos à hemodialise: expectativas, modificações e relações sociais Chronic renal patients everyday on hemodialysis: expectations, modifications and social relations. *Rev Pesqui Cuid Fundam.* [Internet]. 2016 [cited 2019 Feb 3];8(4):4996-5001. Available from: <http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/4404>
12. Hsieh H, Shannon S. Three approaches to qualitative content analysis. *Qual Health Res.* [Internet] 2005 [cited 2019 Feb 3];15(9):1277-88. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/16204405>
13. Emanuel E, Wendler D, Grady C. What Makes Clinical Research Ethical? *JAMA* [Internet] 2000 [cited 2019 Feb 1];283(20):2701-11. Available from: <https://www.dartmouth.edu/~cphs/docs/jama-article.pdf>
14. Romão J. Doença Renal Crônica: Definição, Epidemiologia e Classificação. *Braz J Bras Nefrol* [Internet] 2004 [cited 2018 May 16];26(3):1-3. Available from: <http://bjn.org.br/details/1183/en-US/doenca-renal-cronica--definicao--epidemiologia-e-classificacao>
15. Mercado-Martinez F, Guerreiro D, Silva S, Vestana J, Rozza S, Böel J. Vivendo com insuficiência renal: obstáculos na terapia da hemodiálise na perspectiva das pessoas doentes e suas famílias. *Physis* [Internet] 2015 [cited 2019 Feb 21];25(1):59-74. Available from: <http://www.scielo.br/pdf/physis/v25n1/0103-7331-physis-25-01-00059.pdf>
16. Dutra G, Costa A, Rusa S, Alves A, Moralez R, Ramos V, et al. Factors associated with the quality of life of patients undergoing hemodialysis. *Texto Contexto Enferm* [Internet] 2017 [cited 2019 Feb 20];26(2):e05600015. Available from: [http://www.scielo.br/scielo.php?pid=S0104-07072017000200338&script=sci\\_abstract](http://www.scielo.br/scielo.php?pid=S0104-07072017000200338&script=sci_abstract)
17. Ruiz MA. Estudio del estado emocional de los pacientes en hemodiálisis. *Enferm Nefrol* [Internet] 2017 [cited 2019 Mar 28];20(1):48-56. Available from [http://scielo.isciii.es/scielo.php?script=sci\\_arttext&pid=S2254-28842017000100007](http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S2254-28842017000100007)
18. Pozza B, Athaydes V, Correa M, Schwartz D. Doença renal crônica: relação dos pacientes com a hemodiálise. *ABCS Health Sci* [Internet]. 2017 [cited 2019 Feb 3];42(1):8-14. Available from: <https://www.portalnepas.org.br/abcshs/article/view/943>
19. Silva R, Souza V, Oliveira G, Silva C, Rocha C, Holanda J. Coping strategies used by chronic renal failure patients on hemodialysis. *Esc Anna Nery* [Internet]. Mar. 2016 [cited 2019 Feb 3];20(1):147-154. Available from: [http://www.scielo.br/scielo.php?pid=S1414-81452016000100147&script=sci\\_arttext&tlng=en](http://www.scielo.br/scielo.php?pid=S1414-81452016000100147&script=sci_arttext&tlng=en)

20. D'Onofrio G, Simeoni M, Rizza P, Caroleo M, Capria M, Mazzitello G, et. al. Quality of life, clinical outcome, personality and coping in chronic hemodialysis patients, *Ren Fail* [Internet]. 2017 [cited 2019 Aug 28];39(1):45-53. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/27778533>
21. Jacobson J, Ju A, Baumgart A, Unruh M, O'Donoghue D, Obrador G, et. al. Patient Perspectives on the Meaning and Impact of Fatigue in Hemodialysis: A Systematic Review and Thematic Analysis of Qualitative Studies. *Am J Kidney Dis* [Internet]. 2019 [cited 2019 Aug 23];74(2):179-92. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/30955947>
22. Raj R, Ahuja K, Frandsen M, Jose M. Symptoms and their recognition in adult haemodialysis patients: Interactions with quality of life. *Nephrology* [Internet]. 2017 [cited 2019 Aug 23];22(3):228-33. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/nep.12754>
23. Herbias L, Soto R, Figueroa H, Avilés L. Significado de calidad de vida en pacientes con terapia de hemodiálisis: un estudio fenomenológico. *Enferm Nefrol* [Internet]. 2016 [cited 2019 Feb 3];19(1):37-44. Available from: [http://scielo.isciii.es/pdf/enefro/v19n1/05\\_original4.pdf](http://scielo.isciii.es/pdf/enefro/v19n1/05_original4.pdf)
24. Balogun S, May N, Briley M, Bosch A, Duer I, Owens J, et. al. A Qualitative Pilot Study of the Perceptions in Older Adults with End-Stage Kidney Disease on Hemodialysis. *Can Geriatr J* [Internet] 2019 [cited 2019 Aug 23];22(2):55-63. Available from: <https://cgjonline.ca/index.php/cgj/article/view/342/449>
25. Davison S. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *CJASN* [Internet] Feb. 2010 [cited 2019 Feb 3];5(2):195-204. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2827591/>
26. Rosales J, Díaz J, Molina B, Chávez O. Ética en los cuidados de enfermería a pacientes en tratamiento con hemodiálisis. *Medisur* [Internet]. 2016 [cited 2019 Mar 28];14(5):512-5. Available from [http://scielo.sld.cu/scielo.php?script=sci\\_arttext&pid=S1727-897X2016000500006](http://scielo.sld.cu/scielo.php?script=sci_arttext&pid=S1727-897X2016000500006)
27. Bossola M, Picca A, Calvani R, Marzetti E. Treating symptoms to improve the quality of life in patients on chronic hemodialysis. *Int Urol Nephrol* [Internet] 2019 [cited 2019 Aug 23];51(5):885-87. Available from: <https://link.springer.com/article/10.1007/s11255-019-02121-5#citeas>

## NOTES

### ORIGIN OF THE ARTICLE

Article extracted from the thesis - *Comprensión del autocuidado en personas adultas con Enfermedad Renal Crónica sometidas a Hemodiálisis*, presented to the Graduate Master's Program in Nursing, *Universidade Federal de Santa Catarina*, in 2019.

### CONTRIBUTION OF AUTHORITY

Study design: Andrade MBS, Silva DMGV.

Data collection: Andrade MBS.

Analysis and interpretation of data: Andrade MBS, Silva DMGV.

Discussion of results: Andrade MBS, Silva DMGV.

Writing and/or critical revision of content: Andrade MBS, Silva DMGV, Lopes SGR.

Review and final approval of the final version: Andrade MBS, Silva DMGV, Lopes SGR.

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### APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved by the Ethics Committee in Research with Human Beings the *Universidad de Magallanes, Punta Arenas, Chile*. Certificate 044/CEC/2018 of August 21, 2018.

### CONFLICT OF INTEREST

There is no conflict of interest.

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