

## ORIGINAL ARTICLE

## PROFILE AND LEVEL OF HOPE IN PATIENTS UNDERGOING HEMODIALYSIS AND PERITONEAL DIALYSIS\*

Rayane Alves Moreira<sup>1</sup>, Moema da Silva Borges<sup>2</sup>

### ABSTRACT

**Objective:** To identify the clinical and psychosocial profile and measure the level of hope of patients undergoing hemodialysis and peritoneal dialysis.

**Method:** Exploratory, descriptive and quantitative study conducted in a renal unit in Distrito Federal with patients undergoing dialysis. Data was collected in September and October 2018 with the use of a characterization questionnaire and the application of the Herth Hope Index (HHI). Mann-Whitney test was used for comparison of the levels of hope.

**Results:** Overall, 122 patients participated in the study. The average hope score obtained was 39.79 ( $\pm 5.3$ ) and the highest value was 48. A comparative test showed no significant difference between the levels of hope.

**Conclusion:** Despite all the limitations imposed by treatment and illness, this population has a high level of hope. The present study contributed to the expansion of scholarly debate, which allowed the identification and establishment of the key elements of an effective planning of nursing care, especially in the context of the treatment of chronic kidney disease.

**DESCRIPTORS:** Hope; Chronic Kidney Disease; Nursing; Renal Dialysis.


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<sup>1</sup>Nurse. Master's degree in Nursing. Universidade de Brasília. Brasília, DF, Brazil. 

<sup>2</sup>Nurse. PhD, Nursing. Nursing Professor from Universidade de Brasília. Brasília, DF, Brazil. 

## PERFIL E NÍVEL DE ESPERANÇA ENTRE PACIENTES QUE REALIZAM HEMODIÁLISE E DIÁLISE PERITONEAL

### RESUMO

*Objetivo:* identificar o perfil clínico, psicossocial e mensurar o nível de esperança entre pacientes que realizam hemodiálise e diálise peritoneal.

*Método:* estudo exploratório, descritivo e quantitativo, realizado numa unidade de nefrologia do Distrito Federal com pacientes em tratamento dialítico. A coleta aconteceu entre setembro e outubro de 2018, com questionário de caracterização e aplicação da escala de esperança de Herth. Para comparar o nível de esperança, utilizou-se o teste de Mann-Whitney.

*Resultados:* participaram 122 pacientes. O escore médio de esperança obtido foi de 39,79 ( $\pm 5,3$ ) com maior nível em 48 e, no teste comparativo, não houve diferença significativa entre os níveis de esperança.

*Conclusão:* apesar de todas as limitações impostas pelo tratamento e doença, essa população possui bom nível de esperança. Este estudo contribuiu para a ampliação do debate acadêmico que permitiu identificar e construir pontos essenciais para um bom planejamento dos cuidados de enfermagem, em especial no âmbito do tratamento da doença renal crônica.

**DESCRITORES:** Esperança; Insuficiência Renal Crônica; Enfermagem; Diálise Renal.

## PERFIL Y NIVEL DE ESPERANZA ENTRE PACIENTES QUE HACEN HEMODIÁLISIS Y DIÁLISIS PERITONEAL

### RESUMEN

*Objetivo:* identificar el perfil clínico, psicossocial y mensurar el nivel de esperanza entre pacientes que hacen hemodiálisis y diálisis peritoneal.

*Método:* estudio exploratorio, descriptivo y cuantitativo, que se realizó en una unidad de nefrología del Distrito Federal con pacientes en tratamiento dialítico. Se obtuvieron los datos entre septiembre y octubre de 2018, con cuestionario de caracterización y aplicación de la escala de esperanza de Herth. Para comparar el nivel de esperanza, se utilizó el test de Mann-Whitney.

*Resultados:* participaron 122 pacientes. El escore medio de esperanza obtenido fue de 39,79 ( $\pm 5,3$ ) con mayor nivel en 48 y, en el test comparativo, no hubo diferencia significativa entre los niveles de esperanza.

*Conclusión:* a pesar de todas las limitaciones impuestas por el tratamiento y enfermedad, esa población presenta buen nivel de esperanza. Este estudio contribuye para la ampliación del debate académico que posibilita identificar y construir apuntes esenciales para un buen planeamiento de los cuidados de enfermería, especialmente en el ámbito del tratamiento de la enfermedad renal crónica.

**DESCRIPTORES:** Esperanza; Insuficiencia Renal Crónica; Enfermería; Diálisis Renal.

## INTRODUCTION

Hope is a construct that facilitates adaptation to treatment<sup>(1)</sup>. It is a multidimensional, universal and dynamic concept described as a cognitive process in which individuals actively seek to achieve their goals, in an effort to change their status, attempting to create more favorable conditions in the future<sup>(2)</sup>.

Hope is not specifically related to a particular discipline because it is a multidimensional concept. Having multiple facets, hope is a transversal phenomenon, with various meanings, covering different areas of knowledge<sup>(3)</sup>. It is a subjective feeling, experienced in a totally subjective and unique way.

The life context of patients with chronic illness and their sociodemographic, clinical and psychosocial profile directly impact their levels of hope<sup>(4)</sup>. The concept of hope has gained increasing relevance and strength in the health care field. Nurses play a key role in health promotion, through hope, since these professionals are in a privileged position to encourage this feeling in the recipients of nursing care<sup>(4)</sup>.

Thus, spaces for reflection should be available to raise nursing professionals' awareness of the need to encourage hope in their patients<sup>(5)</sup>.

In the context of chronic kidney disease (CKD), hope is a relevant factor, as it is what leads the patient to undergo tireless invasive procedures, to change their lifestyle and to adhere, even debilitated, to a painful and delicate, difficult treatment<sup>(5)</sup>.

According to estimates of the "Brazilian Chronic Dialysis Survey" of 2016, there were approximately 122 thousand chronic renal patients in Brazil, and more than 39 thousand had started their dialysis treatments<sup>(6)</sup>. These patients face severe limitations, mostly physical and emotional, imposed by hemodialysis and/or peritoneal dialysis<sup>(7-8)</sup>. These limitations have negative effects on the vitality/energy levels of these individuals, make them unable to perform daily activities, impact their productivity and their lives, leading to functional disability<sup>(7,9)</sup>.

Chronic kidney disease is an unpleasant disease that is difficult to accept. Chronic renal patients on hemodialysis are very likely to live in distress, fear and with deep uncertainties about the future. Therefore, they may tend to abandon their habitual desires, as well as their dreams of a brighter future<sup>(10)</sup>.

The use of validated instruments, such as the Herth Hope Index, to measure the levels of hope is a crucial tool for the construction of evidence-based practice in the field of nursing<sup>(11)</sup> because recognizing the levels of hope of chronic patients contributes to better coping with diseases<sup>(5,12)</sup> and prepares the individuals to deal with their pain and the uncertainties of the future<sup>(12)</sup>.

The growing interest in the concept of hope reflects the commitment and concern of nursing professionals to reinforce this aspect with the patients<sup>(13)</sup>, in order to improve their ability to deal with situations of crisis and suffering.

In view of the alarming statistics of chronic renal patients on dialysis, further research on this topic is urgently needed. Given the various challenges faced by these patients (physical, social, professional and spiritual) and the importance of hope as a central feeling for adaptation to the referred disease, the present study aims to identify the clinical and psychosocial profile and measure the level of hope in patients undergoing hemodialysis and peritoneal dialysis.

## METHOD

Exploratory and descriptive study based on a quantitative approach conducted in the Renal Unit of a public hospital of Distrito Federal within the Unified Health System (SUS).

The sample consisted of patients with chronic kidney disease undergoing dialysis, and data was collected in September and October 2018. The following inclusion criteria were adopted: individuals aged 18 years old or over, diagnosed with CKD on dialysis, undergoing hemodialysis or peritoneal dialysis. Patients with cognitive problems were excluded.

The following tools were used for data collection: administration of a questionnaire based on the objectives of the study to identify the profile of the participants, and the Herth Hope Index (HHI). The instruments were applied during hemodialysis sessions, which last in average 2 to 4 hours. Patients undergoing peritoneal dialysis were approached before or after the follow-up visit.

The Herth Hope Index is a quick and easy to apply self-report scale. The HHI was developed and validated in the United States in 1992 and was culturally adapted and validated to the Portuguese language in 2007<sup>(14)</sup>.

The HHI aims to quantify the patient's hope in life and is composed of 12 yes/no questions, and items rated on a 4-point Likert scale, ranging from "I completely agree" to "I completely disagree", where 1 means "I completely disagree" and 4 means "I completely agree". Two items, 3 and 6, have inverted scores. The total score ranges from 12 to 48, and the higher the score, the higher the level of hope<sup>(5:250)</sup>.

The data collected using this scale were entered into a spreadsheet in Excel and then to the R Project for statistical computing, version 3.4., which is a free software environment for statistical computing and graphics. In descriptive analysis of data, measures of central tendency and other measures of position (mean, median, minimum and maximum) and dispersion (standard deviation) were calculated.

Mann-Whitney test was used to compare HHI values among the patients undergoing hemodialysis and peritoneal dialysis. This is a non-parametric test that checks whether two different samples belong to the same population<sup>(15)</sup>. P-values less than 0.05 were considered statistically significant.

The present study was approved by the Research Ethics Committee of *Faculdade de Ciências da Saúde of Universidade de Brasília* and *Faculdade de Ciências da Saúde do Distrito Federal*, under protocol no 2.849.218.

## RESULTS

The sample consisted of 122 chronic renal patients undergoing dialysis at the dialysis clinic of a public hospital in Distrito Federal, and the total number of patients assisted at the clinic was 143, of which 21 were excluded.

As for gender, 71 participants (58.2%) were males. The age group ranged between 18 and 85 years (mean age 56.8 years), with most individuals in the 48-70 age group, i.e. an adult population. As for marital status, 66 (54.1%) participants were married and/or in a stable relationship; 24 (19.67%) were single; 17 (13.93%) were widowed, and 15 (12.3%) divorced.

Regarding children, 105 (86%) participants had children and 64 (52.36%) lived with them. As for ethnicity, most participants were white: 46 (37.7%), followed by brown 44

(36%).

Since most participants had been diagnosed with diabetes mellitus (DM) and systemic arterial hypertension (SAH): (DM 52 (31.3%) and SAH 39 (23.4%), these were the main causes of CKD. Regarding the type of treatment, 71 (58.2%) patients were undergoing hemodialysis and 51 (41.8%) were undergoing peritoneal dialysis.

As for the registration on a renal transplantation waiting list, only nine (7.5%) patients were registered. A p-value of 0.306 was obtained in a comparative analysis between the variables patients on the transplantation waiting list and patients not on the transplantation waiting list using Mann-Whitney test. The result obtained shows that there was no significant difference between the hope levels of these two groups.

Of the patients undergoing peritoneal dialysis, the Tenckhoff catheter was used in 51 (100%). As for the patients undergoing hemodialysis, central venous catheter was used in 58 (47.15%) and arteriovenous fistula (AVF) was the hemodialysis access used in 14 (11.3%).

Regarding work, most participants, 86 (70.48%) were retired or received social security benefits from the Brazilian government's National Social Security System (INSS); 11 (9.02%) did not have a paid work and/or did not receive any social benefits from the government, and 25 (20.49%) had a paid work.

Regarding religion, 59 participants (48.3%) were Catholic, 40 (32.7%) were Evangelical and 17 (13.9%) did not have any religious affiliation. As for the origin of the patients, most were from Distrito Federal: 24 (19.6%); 18 (14.7%) from Bahia, and 16 (13.1%) from Piauí. A smaller percentage of patients were from Minas Gerais, Goiás, Ceará, Maranhão and Pernambuco.

As for the length of time undergoing treatment, 72 (60%) patients were undergoing treatment for 1 to 12 months; 16 (13%) were undergoing treatment for 13 to 24 months, and 16 (13%) for 61 months or more, i.e. an average of 25.7 months.

The levels of hope of the participants in this study, assessed by the HHI, reached a total mean score of 39.79 ( $\pm$  5.3) and a median of 41. The variation of the total score obtained in this study was 24-48 (Table 1). A p-value of 0.407 was obtained in the comparative study between the variables patients on hemodialysis and patients on peritoneal dialysis using the Mann-Whitney test. Therefore, there was no significant difference between the levels of hope of the groups. The peritoneal dialysis group obtained an average score of 40.31 in the HHI, while patients undergoing hemodialysis obtained a score of 39.30.

Table 1 – Descriptive statistics of the scores of the Herth Hope Index for items and total. Brasília, DF, Brazil, 2018 (continues)

Questions	Mean (SD)	Median	Variation obtained	Specific variation
1. I have an optimistic vision of life.	3.42 (0.9)	4	1-4	1-4
2. I have short and long-term plans.	2.65 (1.1)	3	1-4	1-4
3. I feel very lonely.	2.96 (1.2)	3	1-4	1-4
4. I see possibilities in the midst of difficulties.	3.27 (0.8)	3	1-4	1-4
5. My faith brings me comfort.	3.79 (0.5)	4	1-4	1-4
6. I am afraid of my future.	3.12 (0.9)	3	1-4	1-4
7. I remember happy and pleasant times.	3.56 (0.9)	4	1-4	1-4
8. I feel very strong.	3.15 (1)	3	1-4	1-4

9. I feel capable of giving and receiving affection/love.	3.62 (0.7)	4	1-4	1-4
10. I know where I want to go.	2.88 (1.1)	3	1-4	1-4
11. I value every day.	3.74 (0.5)	4	2-4	1-4
12. I feel that my life has value and meaning.	3.63 (0.7)	4	1-4	1-4
Total:	39.79 ( $\pm$ 5.3)	41	24-48	12-48

## DISCUSSION

The profile of the participants of this study corroborates other studies with patients with chronic kidney disease undergoing dialysis aged 19-89 years<sup>(1,5,7,16-18)</sup>. There was a predominance of male individuals. According to the "Brazilian Chronic Dialysis Survey" of 2016, the majority of patients undergoing hemodialysis in Brazil were males<sup>(6)</sup>. This may suggest that males are more likely to develop this type of pathology<sup>(16)</sup>.

Regarding the sociodemographic profile of the patients of this study, there was a predominance of adults and retired individuals. The psychosocial profile showed that for most of the participants, their relatives and religiosity constituted a possible support network for maintaining hope. This finding is similar to those from other studies that obtained the highest HHI score (44.06), when aspects related to the profile of patients, such as age, retirement, religion and support network were compared. It should be noted that patients who counted on a support network during their treatment obtained a higher level of hope and resilience compared to those who did not count on such support<sup>(1)</sup>.

Regarding marital status, most participants were married or in a stable relationship, corroborating other studies and showing that most patients on dialysis are, in fact, married or in a stable relationship<sup>(5,17-19)</sup>.

Most participants had children who lived with them. These data suggest that these patients most likely have a social bond that helps them cope with the disease. It should be stressed that social/emotional support is extremely important for these individuals, as it favors an attitude of acceptance of the disease and medical treatment<sup>(20)</sup>.

Regarding ethnicity, most patients were white. Some studies on the topic reported a prevalence of white ethnicity among patients on dialysis<sup>(5,16-17,20)</sup>. However, it is known that black individuals are more predisposed to hypertension and renal failure. Therefore, the results of these studies do not contain conclusive evidence, because due to the huge racial miscegenation in Brazil, white individuals may have inherited an increased susceptibility to some diseases that usually affect non-white individuals<sup>(21)</sup>.

The two major causes of chronic kidney disease (CKD), according to the 2016 census of the Brazilian Society of Nephrology (SBN), are still diabetes and hypertension. In this study, for most participants, diabetes and hypertension were the main causes of CKD, which also corroborates other studies<sup>(6,18,20,22)</sup>.

Regarding the type of treatment selected, most individuals were undergoing hemodialysis. This is consistent with information provided in the 2016 SBN census, according to which 92.1% of CKD patients in Brazil undergo hemodialysis and 7.9%, peritoneal dialysis, with automated peritoneal dialysis (APD) prevailing<sup>(6)</sup>.

Tenckhoff catheter was used in all patients undergoing peritoneal dialysis, as this is the access route recommended for this type of dialysis<sup>(23)</sup>. As for the patients undergoing hemodialysis, arteriovenous fistula (AVF) was used in only a few of them. In contrast, some

studies indicate that AVF is the most commonly access used<sup>(16,24)</sup>. On the other hand, the percentage of patients undergoing hemodialysis using central venous catheter has increased over the past few years<sup>(6)</sup>. The present study found that the average duration of the treatment is 26 months, corroborating the findings of another study<sup>(16)</sup>.

Patients on peritoneal dialysis may have higher levels of hope than patients on hemodialysis, because they undergo home dialysis, which gives them more autonomy, assuring better care. A study on the domain of self-care indicates that PD patients suffer less impact on activities of daily living and have more free time, with very few changes in their routine<sup>(25)</sup>.

Only a small percentage of patients were registered on the kidney transplantation waiting list. This result corroborates the findings of a study with 60 patients where only 12 were registered on the transplantation waiting list<sup>(1)</sup>. In the present study, the patients registered on the kidney transplantation waiting list (mostly young and of working age) had lower levels of hope than those who weren't, which suggests that patients who are not registered on the transplantation waiting list feel safe and adapted to hemodialysis.

It should be noted that kidney transplants depend on many things, such as the use of various medications, and carry a risk of significant complications, including death, in the case of rejection of the donated kidney by the recipient's body<sup>(1,26)</sup>. These aspects may prevent adherence to the transplantation list, and should be addressed in more detail in further studies.

Regarding the employment status of the participants, most 86 (70.48%) were retired or received social security benefits from the Brazilian government's National Social Security System (INSS). This is consistent with findings from other studies on the subject<sup>(1,5,16,18)</sup>. Therefore, it is important to emphasize that work is essential to the independence and freedom of the individuals, and is part of the identification of everyone. Due to the nature of the disease and the treatment, patients often need to stop working, and this has a negative impact on their quality of life<sup>(20)</sup>.

As for religion, there was a predominance of Catholics. Some studies corroborate this finding, as most of the population undergoing dialysis consisted of Catholics<sup>(1,5,17,19-20)</sup>. In the 2010 population census (IBGE), the total number of Brazilians who had religious affiliation was 190,755,799, and of these, 123,280,172 were Catholic, corroborating the studies cited. As for the origin of the patients, most were from Distrito Federal, since the clinic where the study was conducted is located there.

Of the five studies that administered the HHI to chronic renal patients on dialysis found in a literature review, four had lower scores than those obtained in this study (39.79)<sup>(1,5,16,18,24)</sup>. Only one study, carried out in Florianópolis, Santa Catarina, in two different dialysis clinics, obtained a score of 44.6<sup>(1)</sup>, which was, therefore, the largest score of all studies conducted that used the same<sup>(1,5,16,18,24)</sup>.

A study with 50 elderly people who underwent hemodialysis in the inland of São Paulo, in the city of São Carlos, found a HHI score of 36.20<sup>(16)</sup>, while in another study, also conducted in the city of São Carlos-SP, with 127 patients aged over 18 years, the HHI score was 38.06<sup>(5)</sup>, which may suggest a certain vulnerability in the level of hope among the elderly population.

A comparison of studies with adult patients showed that clinical profile and physical vulnerability could influence the level of hope. A study carried out in Itajuba-MG, with 60 patients over 18 years, in a hemodialysis program, had a HHI score of 37.06<sup>(24)</sup>, while a study with 139 patients carried out in Recife-PE obtained a HHI score of 35<sup>(18)</sup>. The lowest HHI score, when compared to the other studies analyzed, was of patients who had low quality of life in the physical domain, although they had higher percentages in the domains of religiosity/spirituality and in social relationships<sup>(18)</sup>.

In the present study, item number 2 (I have short and long-term plans) of the Herth

Hope Index was the one with the lowest score (2.65), that is, most participants disagreed with that statement. This finding corroborates other studies with patients on hemodialysis<sup>(5,16)</sup>. In another study, this item obtained the highest HHI score, and the item with the lowest score (2.86) was item 6 (I am afraid of my future)<sup>(1)</sup>, which differs from another study where the highest score (3.82) was obtained for this item<sup>(5)</sup>. Two other items scored lower: item 3 (I feel very lonely) (2.96) and item 10 (I know where I want to go) (2.88), which is consistent with another study<sup>(1)</sup>. The item that obtained the highest score in this study was item 5 (My faith brings me comfort). It also obtained the highest score in another study<sup>(16)</sup>.

In short, it can be suggested that some patients have difficulty making plans, since they are afraid of the future. Lack of plans is worrying, as it may indicate the lack of meaning in life. The resources provided by religious faith can help minimize this situation. It is known that religious involvement is related to higher indicators of mental health and well-being<sup>(27)</sup>.

In this context, the approach to faith and religiosity is relevant. In this study, the HHI item that obtained the highest score was related to the faith that comforts the patients. It was found that faith and religiosity play an important role in the lives of patients on dialysis, since more than 85% of the study participants declared having a religion affiliation.

A study with chronic patients in a long-term care unit found a predominance of patients with low levels of hope, and the sociodemographic profile revealed patients with advanced age, low educational level and low family income. The clinical profile of the patients showed physical and emotional damage and their psychosocial profile revealed individuals with poor quality of life suffering from insomnia, characteristics that led them to hopelessness<sup>(4)</sup>.

Regarding the comparison of the variables patients undergoing hemodialysis and peritoneal dialysis, there was no significant difference in the levels of hope between the groups. Therefore, it appears that both groups have satisfactory levels of hope.

No correlational study was found in the national and international scientific literature, which could be used for discussing the level of hope in the variables patients on hemodialysis (HD) and peritoneal dialysis (PD). Thus, other comments on the specific correlation of this analysis were not possible, and we decided to focus on studies on the quality of life of each group.

One limitation of this study is the fact that it was conducted in only one setting, a public hospital located in Distrito Federal, and therefore its findings cannot be generalized to other patients with CKD.

## CONCLUSION

The results showed that, despite all the limitations imposed by the treatment and by the disease itself, the population investigated has a satisfactory level of hope, especially regarding family support and religiosity support for the maintenance of hope. Moreover, the patients had adequate sociodemographic, clinical and psychosocial profiles.

In view of the aforementioned, it can be seen that most participants had an optimistic profile, which may lead to favorable clinical outcomes and adaptation to disease's treatment.

It is suggested that the nursing team implement interventions focused on strategies that promote and maintain hope, favoring a comprehensive health care planning, to achieve a better quality of life.

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Corresponding author:

Rayane Alves Moreira

Universidade de Brasília

Campus Universitário Darcy Ribeiro - 70910-900 - Brasília, DF, Brasil

E-mail: enfermeiraray@gmail.com

Role of Authors:

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Drafting the work or revising it critically for important intellectual content - MSB

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