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The evaluation of the level of hope of elderly chronic kidney disease patients undergoing hemodialysis

AValiação do Nível de Esperança de Vida de Idosos Renais Crônicos em Hemodiálise

Evaluación del Nivel de Esperanza de Vida de Ancianos con Enfermedad Renal Crónica en Hemodiálisis

Fabiana de Souza Orlandi¹, Barbara Garbelotti Pepino², Sofia Cristina Iost Pavarini³, Damiana Aparecida dos Santos⁴, Marisa Silvana Zazzetta de Mendiando⁵

ABSTRACT

The objective of the present study was to evaluate the level of hope of elderly chronic kidney disease patients undergoing hemodialysis, using the Herth Hope Scale (HHS). This cross-sectional descriptive study was performed at a Renal Replacement Therapy Unit located in upstate São Paulo. The sample consisted of 50 elderly patients currently undergoing hemodialysis treatment. After obtaining the participants' consent to participate, individual interviews were performed with the elderly individuals, utilizing a characterization instrument and the Herth Hope Scale. All of the ethical premises were complied with (protocol 512/2009). Regarding the results, most participants were male (60%) and their mean age was 70.20 (± 6.1) years. The mean score on the Herth Hope Scale was 36.20 (± 2.90). In conclusion, compared with the Brazilian study regarding the validation of the Herth Hope Scale, the subjects' level of hope was lower, thus indicating a need to intervene regarding this feeling.

DESCRIPTORS

Aged
Renal insufficiency, chronic
Renal dialysis
Life expectancy

RESUMO

O presente estudo teve por objetivo avaliar o nível de esperança dos idosos renais crônicos em hemodiálise, por meio da Escala de Esperança de Herth (EEH). Trata-se de um estudo descritivo transversal, realizado em uma Unidade de Terapia Renal Substitutiva do interior do estado de São Paulo. A amostra foi composta por 50 idosos em tratamento hemodialítico. Após o consentimento em participar da pesquisa, realizou-se entrevistas individuais com os referidos idosos aplicando-se um instrumento de caracterização e a Escala de Esperança de Herth. Todos os preceitos éticos foram respeitados (protocolo 512/2009). Quanto aos resultados, houve predomínio do sexo masculino (60%) e idade média de 70,20 ($\pm 6,1$) anos. O escore médio obtido com a aplicação da Escala de Esperança de Herth foi de 36,20 ($\pm 2,90$). Conclui-se que em comparação com o estudo brasileiro de validação da Escala de Esperança de Herth, o nível de esperança dos sujeitos do presente estudo foi mais baixo, indicando a necessidade de intervenção sobre esse sentimento.

DESCRIPTORES

Idoso
Insuficiência renal crônica
Diálise renal
Expectativa de vida

RESUMEN

Se objetivó evaluar el nivel de esperanza de vida de ancianos con enfermedad renal crónica en hemodiálisis, mediante Escala de Esperanza de Herth (EEH). Estudio descriptivo, transversal, realizado en Unidad de Terapia Renal Sustitutiva del interior del estado de São Paulo. Muestra compuesta por 50 ancianos en tratamiento de hemodiálisis. Con consentimiento para participar en la investigación, se realizaron entrevistas individuales con los sujetos, aplicándose un instrumento de caracterización y la Escala de Esperanza de Herth. Fueron respetados todos los preceptos éticos (protocolo 512/2009). Los resultados mostraron predominio del sexo masculino (60%), edad promedio de 70,20 años ($\pm 6,1$). El puntaje promedio obtenido con EEH fue 36,20 ($\pm 2,90$). En comparación con el estudio brasileño de validación de la EEH, el nivel de esperanza de vida de los sujetos de este estudio fue más bajo, indicando la necesidad de intervención sobre tal sentimiento.

DESCRIPTORES

Anciano
Insuficiencia renal crónica
Diálisis renal
Esperanza de vida

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INTRODUCTION

End-Stage Renal Disease (ESRD) is a pathology that, in addition to having physical consequences, also causes psychological harm and changes in patients' daily lives. It is characterized as a social problem and interferes in the roles individuals play in society.

As a consequence of population aging, people become more vulnerable to pathological processes resulting from multiple factors and become more likely to present diseases such as cardiovascular, respiratory, neoplastic, cerebrovascular, osteoarticular, and endocrine diseases, which may or may not be associated with one another, characterizing co-morbidities⁽¹⁾. Co-morbidities include hypertension, diabetes mellitus, and heart failure, which predispose elderly individuals to ESRD.

Anatomical and physiological alterations in the kidneys, resulting from the kidney aging process, are an aggravating factor for renal disease in elderly individuals, increasing vulnerability to renal dysfunction over the years⁽²⁾. With the progress of ESRD and eminent risk of death due to the accumulation of impurities in the body, dialysis treatment is required, which is either performed through hemodialysis or peritoneal dialysis. Even though these interventions do not replace all the functions of a normal kidney, they allow continuing with life and correcting severe biochemical disorders. A long process of adaptation to this new condition is then established and the individual needs to find ways to deal with his/her renal problem and with all the changes and limitations that follow⁽³⁾.

Hemodialysis treatment often generates frustration and limitations, since it imposes many restrictions, such as maintaining a specific diet associated with fluid restrictions and changed body appearance due to the presence of a catheter for vascular access or an Arteriovenous Fistula (AVF)⁽³⁾. The patient undergoing hemodialysis has to live daily with an incurable disease, comply with painful treatment that is of a long duration, which causes, together with the progressing disease and its complications, even greater limitations and high-impact changes⁽⁴⁾.

Every chronic disease impacts one's personal and professional life, requires complex therapeutic regimes and significant changes in daily living activities. Hence, patients are expected to experience feelings of helplessness⁽⁵⁾.

A study addressing the meaning assigned by chronic renal patients to hemodialysis verified that each respondent attributed different meanings to this modality of dialysis treatment. Various feelings in response to the irreversibility of renal disease and mandatory treatment were observed⁽⁶⁾. The author also reports that patients showed faith in a superior being and hoped for kidney transplantation.

Keeping hope in the face of a chronic disease is an endless process, though also a valuable resource in the coping process⁽⁵⁾. Hope has a beneficial effect on individuals' health because it enables people to deal with crises, to maintain quality of life, to remain resolute in achieving healthy objectives, promoting health⁽⁷⁾.

Assessment of hope enables the implementation of interventions to encourage patients and family members to keep hope when facing chronic diseases⁽⁸⁾. Researchers⁽⁹⁾ validated the *Herth Hope Index* (HHI), an American self-reporting scale that assesses individuals' level of hope⁽¹⁰⁾.

Studies measuring individuals' level of hope in the face of a disease reflect the commitment and confidence of professionals wanting to intervene and encourage a greater level of hope in patients, avoiding factors that reduce it⁽¹⁰⁾.

Therefore, the hope of individuals for regaining health leads patients to travel long distances in the search for a difficult treatment, to accept endless invasive procedures, to change lifestyles, and continue, even if weakened, undergoing treatment⁽¹¹⁾. It is worth noting that no studies assessing the level of hope of chronic renal patients were found either in the Brazilian or international contexts.

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This study's objective was to characterize elderly patients with chronic kidney disease undergoing hemodialysis according to socio-demographic and clinical aspects, and evaluate their level of hope through the HHI.

METHOD

This descriptive and cross-sectional study was conducted in the Nephrology Service in São Carlos, SP, Brazil. This is a Replacement Renal Therapy Unit in the interior of São Paulo caring for patients from the Brazilian Unified Health System (SUS), from health insurance companies, and private clients.

The sample was composed of 50 elderly individuals who met the following inclusion criteria: being 60 years old or older; having an ESRD diagnosis; attending the outpatient hemodialysis program; showing the cognitive ability to answer the instrument; and consenting to the study and signing a free and informed consent form. The following data were collected to characterize the sample: age, gender, ethnicity, current work situation, primary renal disease and clinical complications, duration of the hemodialysis treatment, type of vascular access, and whether the patient is included on the kidney transplant waiting list.

In addition to an instrument to characterize the individuals, we also used the Brazilian version⁽⁹⁾ of the *Herth Hope Index* (HHI), an American self-reporting scale⁽¹⁰⁾ that quantifies the level of hope. This scale has 12 statements classified according to a four-point Likert scale ranging from: 1 - *strongly disagree* to 4 - *strongly agree*. Two items, statements 3 and 6, present inverted scores. The possible

total score is 12 to 48 points; the higher the score, the greater the level of hope. It is a short scale (takes 10 minutes to be completed) and easily understandable.

The instruments were preferably applied prior to a hemodialysis session or, when that was not possible, as an interview during the first two hours of treatment, from January to April 2010.

The Statistical Package for the Social Sciences (SPSS) for Windows version 15.0 was used for data analysis. Cronbach's alpha was used to test the scale's reliability. Location (average, median, minimum and maximum) and dispersion (standard deviation) measures were computed for the descriptive analysis of data.

The study was approved by the Ethics Research Committee at the Federal University of São Carlos (Protocol No. 512/2009).

RESULTS

A study⁽⁹⁾ conducted in Brazil validated the Herth Hope Index for the Brazilian Portuguese language and culture. The internal consistency found in this study's sample was 0.86; thus it was considered reliable.

The sample was composed of 50 elderly patients with chronic renal disease undergoing hemodialysis treatment residing in São Carlos, SP, Brazil. A significant portion of

the individuals (42%) was aged from 67 to 73 years old; male (60%) and white (74%) individuals predominated; and 90% reported being retired.

Duration of the hemodialysis treatment ranged from one to 132 months, with an average of 26 months. Most regimens of treatment, however, had lasted between one and 12 months (50%), more than 26 months (32%), followed by 13 to 26 months (18%).

With regard to the route of vascular access, 43 (86%) elderly individuals presented AVF. Twenty-seven (54%) individuals manifested the interest to have a kidney transplant, while 31 (62%) were enrolled in the kidney transplant waiting list.

The following was observed in relation to the level of hope of the studied elderly individuals assessed through the HHI: the average total score was 36.20 (\pm 2.90) and median was 36.00 (Table 1). The total possible score for the scale was from 12 to 48; the higher the score, the greater the individual's level of hope. The total score obtained in this study ranged from 31 to 46. Table 1 shows that among the 12 items in the scale, Item 2 presented the lowest score (average of 2.46), indicating that 54% of the studied sample disagreed from the statement *I have short and/or long range goals*. On the other hand, the item with the highest average score was Item 5 (average of 3.52), that is, 98% of the respondents agreed (34%) or strongly agreed (64%) with the statement *I have a faith that gives me comfort*.

Table 1 – Descriptive statistics per item and total score obtained on the Herth Hope Index – São Carlos, SP, Brazil – 2010

Questions	Average (SD)	Median	Variation observed	Expected variation
1. I have a positive outlook toward life.	2.98 (\pm 0.65)	3.00	1-4	1-4
2. I have short- and/or long-range goals.	2.46 (\pm 0.64)	2.00	1-4	1-4
3. I feel all alone.	2.90 (\pm 0.73)	3.00	1-4	1-4
4. I can see possibilities in the midst of difficulties.	3.00 (\pm 0.42)	3.00	2-4	1-4
5. I have a faith that gives me comfort.	3.62 (\pm 0.53)	4.00	2-4	1-4
6. I feel scared about my future.	3.08 (\pm 0.54)	3.00	2-4	1-4
7. I can recall happy/joyful times.	3.18 (\pm 0.69)	3.00	2-4	1-4
8. I feel deep inner strength.	2.78 (\pm 0.74)	3.00	2-4	1-4
9. I am able to give and receive caring/love.	3.06 (\pm 0.51)	3.00	2-4	1-4
10. I have a sense of direction.	2.86 (\pm 0.61)	3.00	1-4	1-4
11. I believe that each day has potential.	3.12 (\pm 0.39)	3.00	2-4	1-4
12. I feel my life has value and worth.	3.16 (\pm 0.55)	3.00	2-4	1-4
Total	36.20 (\pm2.90)	36.00	31-46	12-48

DISCUSSION

Most individuals in the studied population were men, which is in agreement with the results of other studies addressing patients with ESRD undergoing dialysis⁽¹²⁻¹⁴⁾, suggesting that men may be more susceptible to this pathology. With regard to the age of the participants, this study's results are similar to those found by another Brazilian study⁽¹⁴⁾, which indicates increased life expectancy among elderly individuals undergoing hemodialysis. In terms of ethnicity, most individuals were white, which is also ob-

served in other studies⁽¹²⁻¹⁴⁾ conducted with both young and elderly chronic renal patients.

The predominant access route was Arteriovenous Fistula (AVF), also in agreement with other Brazilian studies⁽¹²⁻¹⁴⁾, which indicates that AVF is safer than the double-lumen catheter. In relation to kidney transplantation, the great demand for it may be explained by the meaning attributed to the procedure by a large part of patients who believe it will cure their renal disease⁽¹⁵⁾. Nonetheless, the number of patients included on the kidney transplant waiting list is larger than the number of those who in fact

intend to have the procedure. Such a fact may indicate a lack of information or misinformation on the part of the elderly patients.

No Brazilian or international studies were found in the search for papers addressing the level of hope among individuals with renal disease. Nonetheless, studies using the Herth Hope Index (HHI) were found. One study using the HHI was conducted in the Brazilian context and assessed cancer and diabetes patients and their companions (family members or caregivers) and reported a level of hope higher than that found in this study (36.20 ± 2.90). The average scores were above 40 points and showed no significant difference among the groups⁽¹¹⁾.

In the international context we found studies addressing individuals with chronic diseases such as cancer⁽¹⁶⁾, amyotrophic lateral sclerosis⁽¹⁷⁾, chronic obstructive pulmonary disease⁽¹⁸⁾, cerebrovascular accident⁽¹⁹⁾, cardiac and circulatory diseases⁽²⁰⁾, Parkinson's disease⁽²¹⁾, and cystic fibrosis⁽²²⁾, though various studies addressed cancer patients.

The level of hope observed among the individuals (36.20 ± 2.90) assessed in this study was below those observed in most of the aforementioned studies addressing individuals with chronic diseases^(17-19,21-22), with the exception of the study conducted with cancer patients⁽¹⁶⁾ and the one conducted with patients with cardiac diseases; the level of hope observed in these last two studies was lower. It is worth noting that these studies include, in addition to the patients with chronic diseases, their family members and the population in general.

A study conducted in the United States investigating the level of hope, optimism, and self-care among people with Chronic Obstructive Pulmonary Disease (COPD) reported that the studied patients obtained an average score of $39.47 (\pm 5.61)$ on the HHI⁽¹⁸⁾. In the study addressing both patients who experienced a cerebral vascular accident and their family members, the following average scores were obtained on the HHI: $37.70 (\pm 4.46)$ and $39.90 (\pm 4.73)$, respectively⁽¹⁹⁾.

The study addressing hope and lifestyle in the health promotion of individuals with Parkinson's disease verified that an average score of $38.00 (\pm 5.42)$ was obtained on HHI⁽²¹⁾. A study conducted in Canada with 13 individuals with a diagnosis of amyotrophic lateral sclerosis applied the HHI at the end of a semi-structured interview and reported an average score of 40 points⁽¹⁷⁾.

A study comparing expressions of hope by patients with cystic fibrosis ($36.10/\pm 4.1$) and the general population ($37.20/\pm 4.1$) in Norway verified that the individuals with cystic fibrosis presented a lower level of hope⁽²²⁾.

An investigation addressing pain, uncertainty, and hope among lung cancer patients in Taiwan verified that the individuals experiencing pain presented a lower level

of hope than those not experiencing pain. The average scores obtained on the HHI were $30.81 (\pm 5.95)$ and $36.91 (\pm 5.18)$, respectively⁽¹⁶⁾.

A study conducted with women who received cardiac transplantation investigated hope, mood, and quality of life and reported that these women obtained an average score of $35.84 (\pm 5.08)$ ⁽²⁰⁾ on the HHI.

In this study, the HHI Item number 2 ("I have short and/or long-range goals") obtained the lowest score (2.46), that is, most (54%) elderly individuals disagreed with this statement. The search for other studies reporting the average per item score obtained on the HHI resulted in a study that investigated the level of hope of patients with cystic fibrosis, which showed that the item with the lowest average score (2.25) was Item number 5 (*I have a faith that gives me comfort*)⁽²²⁾. Such a result differed from that found in this study in which the chronic renal elderly patients undergoing hemodialysis obtained the highest average score (3.62) on this item. The highest score obtained in another study⁽²²⁾ was on Item 7 (*I can recall happy/joyful times*) with an average of 3.61⁽²²⁾. It is worth noting that this study's respondents obtained an average score of 3.18 for this item. Therefore, most of the elderly individuals addressed in this study agreed with the item stating they can recall happy and joyful times, though strong agreement was not observed.

Given the preceding discussion, it is important to address the issue of spirituality and religiosity, since the HHI item in which most of the studied individuals presented a higher level of agreement is the one stating that faith gives then comfort. Spirituality and religiosity play an important role in the lives of patients undergoing dialysis and should be taken into account by professionals caring for these patients.

CONCLUSION

In general, the comparison with studies addressing patients with other chronic pathologies revealed that the level of hope among this study's participants was low, showing the need to implement interventions designed to improve their level of hope.

Analysis concerning the scores obtained on the HHI showed the importance of religiosity, indicating that the studied elderly individuals have the willpower to cope with the burdens resulting from the renal disease due to their faith, which gives them great support. However, their classification of the item concerning short- and long-term plans also shows that these individuals are afraid they will not be able to carry out future plans.

Together, these results show the need to implement interventions that encourage a greater level of hope among elderly patients undergoing replacement renal therapy, and to avoid factors that reduce hope.

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