

# DOMAINS AFFECTED IN THE QUALITY OF LIFE OF RENAL PATIENT IN HEMODIALYTIC TREATMENT: SYSTEMATIC REVIEW

# DOMÍNIOS AFETADOS NA QUALIDADE DE VIDA DO PACIENTE RENAL CRÔNICO EM TRATAMENTO HEMODIALÍTICO: REVISÃO SISTEMÁTICA

## DIMENSIÓN AFECTADOS EN LA CALIDAD DE VIDA DEL PACIENTES RENAL CRÓNICO EN TRATAMIENTO HEMODIALÍTICO: REVISIÓN SISTEMÁTICA

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# ABSTRACT

**Objective:** To synthetise the knowledge generated by nationally and internationally published studies on the domains affected in the quality of life of patients with chronic kidney disease on hemodialysis. **Methodology:** A systematic review was carried out in the past 10 years in the LILACS, MEDLINE and CINAHL databases. **Results:** 9 articles were analysed, most of which were based in descriptive crossectional studies and presented evidence of the relations of the dimensions affected in the quality of life of individuals undergoing hemodialysis. The findings indicate low scores of quality of life, mainly in the physical domain, with the social one having the best score. The identification of the items that affect the quality of life of these people enables health care professionals to rethink the care currently offered in order to minimise the negative consequences inherent to the process. **Conclusion:** It was observed that the care provided to patients must encompass strategies to improve their health and quality of life.

Descriptors: Quality of Life; Chronic Kidney Disease; Adult; Renal Dialysis.

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### **RESUMO**

**Objetivo:** Sintetizar o conhecimento produzido acerca das publicações na literatura nacional e internacional sobre os domínios afetados na qualidade de vida dos pacientes renais crônicos em tratamento hemodialítico. **Métodos:** Foi realizada uma revisão sistemática nas bases de dados, LILACS, MEDLINE e CINAHL, nos últimos 10 anos. **Resultados:** Foram analisados 9 artigos, a maioria dos estudos eram descritivos e transversais, apresentaram evidências sobre as relações das dimensões afetadas na qualidade de vida dos indivíduos em tratamento hemodialítico. Os achados revelaram baixos escores de qualidade de vida, principalmente no domínio físico, sendo o aspecto social aquele de melhor escore. A identificação dos itens impactantes da qualidade de vida dessa população permite, aos profissionais de saúde, repensar a assistência atualmente oferecida, minimizando as consequências negativas decorrentes desse processo. **Conclusão:** Revela-se que o cuidado dispensado aos pacientes deve englobar estratégias para melhorar a saúde e qualidade de vida dos pacientes.

Descritores: Qualidade de Vida; Insuficiência Renal Crônica; Adulto; Diálise Renal

#### RESUMEN

**Objetivo:** Sintetizar el conocimiento producido sobre las publicaciones en la literatura nacional e internacional sobre los ámbitos afectados en la calidad de vida de los pacientes renais crónicos en tratamiento hemodialítico. **Métodos:** Se realizó una revisión sistemática en las bases de datos, LILACS, MEDLINE y CINAHL, en los últimos 10 años. **Resultados:** Se analizaron 9 artículos, la mayoría de los estudios eran descriptivos y transversales, presentaron evidencias sobre las relaciones de las dimensiones afectadas en la calidad de vida de los individuos en tratamiento hemodialítico. Los hallazgos revelaron bajos escores de calidad de vida, principalmente en el dominio físico, siendo el aspecto social el de mejor puntaje. La identificación de los elementos impactantes de la calidad de vida de esa población permite, a los profesionales de salud, repensar la asistencia actualmente ofrecida, minimizando las consecuencias negativas derivadas de ese proceso. **Conclusión:** Se revela que el cuidado dispensado a los pacientes debe englobar estrategias para mejorar la salud y calidad de vida de los pacientes.

Descriptores: Calidad de Vida; Insuficiencia Renal Crónica; Adulto; Diálisis Renal

### **INTRODUCTION**

Chronic Kidney Disease (CKD) is a metabolic syndrome caused by the gradual and often slow loss of kidney function.<sup>1</sup> Considering that the excretion of catabolites results mostly from glomerular filtration, CKD is characterized by the loss of glomerular filtration which may be clinically assessed by determining creatinine clearence in 24-hour urine.<sup>2,3</sup> Thus, the definition of CKD is based on alterations on the glomerular filtration rate or the existence of a parenchymal injury for a period longer than three months.<sup>2</sup>

Although data on the prevalence of kidney disease in Brazil are uncertain, there are cross-sectional and cohort studies which establish a 1.5% rate of selfreportation for the disease.<sup>4</sup> The same studies indicate prevalence of a hypercreatininemia in 3% of the population. Thus, according to these data, 3 to 6 million adults in a population sample would have the disease, with 0.05% undergoing dialysis, that is, 100 thousand patients.<sup>5</sup>

The overall prevalence rate of dialysis has grown each year, and in 2016, 39,714 patients started treatment. Of these, 48% are in the Southeast region of Brazil, 19% in the Northeast, 17% in the South, 10% in the Midwest and 5% in the North.<sup>6</sup>

Some factors may hinder or facilitate adherence to treatment by patients with chronic kidney disease, such as: family support; attachment to religion/belief; denial and avoidance; and resilience. These factors, in general, do not appear isolated, since some of them are difficulties inherent to the condition, while other are consequences of the former.<sup>5</sup>

In their process of coping with the disease and its impact in their daily lives, patients rely mostly on their religion/belief and family support. Many times they choose denial or avoidance when facing stressful situations, however, resilience has been shown to be an important resource for coping with the initial problems caused by CKD and as an adapting method to deal with changes in their daily lives caused by treatment.<sup>1</sup>

Treatment consists of hemodialysis for the entire life of patients or until they undergo a successful kidney transplantation<sup>6</sup>. Hemodialysis consists of the extracorporeal filtration of the patients' blood by an apparatus called dialyser which ´performs kidney functions.<sup>7</sup>

The main objective of hemodialysis is to minimise the symptoms caused by poor kidney function and provide the patient with better quality of life, while always monitoring the plasma levels of potassium, urea, sodium and chlorides.<sup>8</sup>

CKD treatment is quite rigorous and leads to drastic changes in lifestyle, imposing restrictions and limitations to several activities of daily living (ADL). Consequently, this situation generates several stressors to patients which may contribute to poor adherence to treatment, which in turn causes a significant increase of complications and has a negative impact on quality of life.<sup>9</sup>

Therefore, the quality of life of patients with CDK may be assessed using specific instruments such as the Kidney Disease Quality of Life Instrument (KDQOL), the Kidney Disease Quality of Life - Short Form (KDQOL-SF), Dialysis Quality of life (DIAQOL), and the choice of instrument is fundamental for the feasibility of the study since it has to be aligned with the research objectives and contain the necessary domains that need to be assessed in the study population.<sup>10</sup>

Given this context, the objective of the study was to synthetise the knowledge generated by nationally and internationally published studies on the domains affected in the quality of life of patients with chronic kidney disease on hemodialysis.

### METHODOLOGY

review of the The systematic literature is done with the objective of grouping and summarising research results related to a specific theme or question.<sup>11</sup> The review was organised as follows: the first step was the formulation of the review question; the second was the definition of the inclusion and exclusion criteria; the third was the selection of the articles to make up the sample; the fourth was the critical evaluation of the quality of the studies selected; the fifth was the interpretation of the results; and the sixth was the preparation of this article with the purpose of disseminating the findings.<sup>12</sup>

In order to frame the research question for the review, the strategy used was PICO (an acronym for population, intervention, comparison and outcome), which was changed into the descriptors/keywords used to search for scientific evidence. Thus, the guiding question for the study was: "What domains of quality of life were most affected in patients with chronic kidney disease undergoing hemodyalisis?"

The following databases were used to search for articles: the Medical Literature Analysis and Retrieval System Online (Medline), the Latin American and Caribbean Health Sciences Literature (LILACS), and the Cumulative Index of Nursing and Allied Health Literature (CINAHL).

The descriptors used in Portuguese, English and Spanish were: quality of life, chronic kidney disease, and dialysis, included in both the Health Sciences Descriptors (DeCS) and the Medical Subject Headings (MeSH), in addition to related keywords.

The inclusion criteria used for this study were: primary researches with adult patients (over 18 years of age) undergoing hemodialysis, which used a quantitative approach, were available in the databases, had been published in Portuguese, English and Spanish, provided information to answer the research question, with no limitations regarding time frame for the search, and full articles. Were excluded from this study every article not available in its entirety, books, book chapters, technical reports, letters and editorials. As for any duplicated articles, the version kept was the most complete.<sup>13</sup>

Even though the objective was to carry out a systematic literature review, a choice was made to use the guide Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA).<sup>11</sup> This tool allows a broader observation of the synthesis of the different types of evidence through a rigorous process used to carry out this critical evaluation as well as to ensure the accuracy of the systematic review. Data were collected and selected through double-blind search and reading, with an additional third reviewer for the final selection. The critical evaluation of the studies used the Critical Appraisal Checklist for Analytical Cross Sectional Studies provided by The Joanna Briggs Institute (JBI).<sup>12</sup>

The results are presented in a descriptive manner in order to summarise

the evidence related to the dimensions affected in the quality of life of individuals undergoing hemodialysis.

### RESULTS

Initially, 1,934 articles were identified as being potentially relevant for the study. Of those, 194 met the inclusion criteria and were read in full (Figure 1) and evaluated according to the guiding question of the review. Afterwards, 9 articles were included in this studied because they presented evidence of the relationships between the areas affected and the quality of life of individuals undergoing hemodyalisis (Table 1). From the description of these articles, it was possible to identify the studies carried out in clinics and hospitals with hemodyalisis facilities for the patients.



Figure 1 – Diagram of the articles selected for the systematic review.

**Chart 1**: Distribution of the selected articles according to author, database, country, periodical, study design, tools used, results and summary of conclusion – 2008 a 2017.

AUTHORS	DATABASE/C OUNTRY/PUB	STUDY DESIGN	PERIODI CAL	OBJECTIVE	TOOLS	RESULTS	SUMMARY OF CONCLUSION
	LISHING DATE						
Guerra- Guerrero, V; Sanhueza- Alvarado, O; Cáceres-Espina, M.	LILACS Chile 2012	Correlation, exploratory, descriptive, cross- sectional study	Rev. Latino-Am. Enfermage m	To determine the quality of life of people undergoing chronic hemodialysis and its connection with sociodemographic, medical-clinical and laboratory variables.	KDQOL -SF	The results of QOL indicated lower scores in the physical, mental and psychosocial aspects. The scales for symptoms/problems (S) and effects of disease (E), on the contrary, had the high	The conclusion was that the sociodemographic profile along with medical, clinical and laboratory characteristics of patients undergoing dialysis contribute to the low level of QoL related to older age, low schooling, low income, duration of treatment, hospitalisation and absence of transplantation.
Kusumota, L.; Marques, S; Haas,VJ.; Rodrigues, RAP.;	LILACS Brazil 2008	Cross-sectional, population study	Acta Paulista de Enfermagem	To describe the population of adult and elderly patients undergoing hemodialysis living in Ribeirão Preto, in the state of São Paulo, and assess and describe the differences in their health-related quality of life.	KDQOL-SF	The patients reported physical complications related to chronic end-stage kidney disease and hemodialysis, of which the most relevant were: anemia, cramps, weakness, pain, hypotension during hemodialysis, and pruritus, among other	The conclusion was that the comparison of HRQoL of adults and the elderly is important to assess the impact of the disease and treatment on their living conditions and, therefore, to guide the care offered to them individually and collectivelly. KDQOL-SF was shown to be an efficient tool to assess the HRQoL of adults and elderly people undergoind hemodialysis.
Marinho, CLA.; Oliveira,JF.de.; Borges,JE.da.S.; Silva, RS.da.; Fernandes, FECV	CINAHL Brazil 2017	Descriptive, cross- sectional study	Revista Rene	To analyse the quality of life of people with chronic diseases.	KDQOL-SF	The most affected dimensions were those related to work status and physical functioning. The domains with the highest averages were: sexual function, cognitive function, social	The conclusion was that chronic kidney disease and hemodialysis treatment interfere with the quality of life of individuals, the greatest losses being observed in work status and physical function, and the best repercurssion observed in the pain,

Rev Enferm Atenção Saúde [Online]. Out/Dez 2018; 7(3):140-154

						function and pain.	social functioning, cognitive function and sexual function domains.
Cunha, MS.; Andrade, V.; Guedes, CAV.; Meneghetti, CHZ.; Aguiar, AP; Cardoso, AL	LILACS Brazil 2009	Descriptive, cross- sectional study	Fisioterapia e Pesquisa, São Paulo	To assess the functional capacity and quality of life of patients with chronic kidney disease (CKD) undergoing hemodialysis and verify possible correlations between these clinical variables and age, body mass index (BMI) and duration of hemodialysis.	SF 36	The functional capacity of patients with chronic kidney disease undergoing hemodialysis was below the predicted values for the distance walked in the six- minute walking test (SMWT) and for the strenght of the muscles of respiration (mainly those responsible for expiration). Patients reported feeling mild fatigue.	Pain and impaired vitality were pointed out as the aspects the interfere the most in the health-related quality of life of patients. Aspects like age, body mass index and duration of hemodialysis were not shown to be relevant in most domains.
Mortari, DM.; Menta, M.; Scapini, KB.; Rockembach, CWF.; Duarte, A; Leguisamo, CP	LILACS Brazil 2010	Descriptive, cross- sectional study	Scientia Medica (Porto Alegre)	To assess the quality of life of individuals with chronic end-stage kidney disease undergoing hemodialysis.	SF 36	The greatest impairment was observed in the physical and general health state aspects. The subjects schieved intermediate scores of quality of life in the vitality, pain and mental health domains. The social aspect domain was the one less impaired.	It was observed in the study that the sample of patients with end-stage chronic kidney disease undergoing hemodialysis, both men and women, experieced a decrease in the quality of life scores, especially in the general health and physical limitations domains.
Grasselli, CSM.; Chaves, E.C; Simão, TP.; Botelho, PB.; Silva, RR.	LILACS Brazil 2012	Descriptive, cross- sectional study	Revista Brasileira Clinica Medica São Paulo	To assess quality of life of patients undergoing hemodialysis.	KDQOL-SF	The lowest average scores were observed in the professional role and physical function, which encompass any possible problems the patient may have regarding work or any other usual activities due to physical health. By analysing the averages of the energy/fatigue, kidney disease overload in the lives of patients, general health and	In the study, it was observed that the QoL of patients was negativelly affected by the professional role, vitality (energy/fatigue), physical function, emotional function, general health and kidney disease overload on the lives of patients dimensions; which may be attributed to the difficulties and challenges caused by the kidney disease and its treatment. On the other hand, high scores were observed for the dimensions of patient satisfaction with the support received

						emotional function dimensions, in the dimension of effects of the kidney disease on daily life conditions, the average was 62.37%, while in the sleep, pain, physical function, emotional well-being and sexual function, the average was 76.03%.	from family and friends (time spent with them), sexual life, cognitive function, pain, sleep, social support, list of symptoms/problems, effects of kidney disease, stiumulation by the dialysis team, physical function, emotional well-being, social functioning and quality of social interactions, therefore, these were domensions which had a positive impact on the assessment of the quality of life of patients.
Kharame, ZT.; Zamanian, H; Foroozanfar, S; Afsahi, S.	MEDLINE Iran 2014	Descriptive, cross- sectional study	Global Journal of Health Science	To establish the connection between spiritual well-being and quality of life of patients undergoing hemodialysis.	SF 36	Higher and lower scores were observed for social functioning and function limitation due to physical health problems. The results of the multiple logistic regression model indicate that religious well-being is associated to better QoL in both the physical and mental domains.	The findings highlight the importance of spiritual well-being for the QoL of patients undergoing hemodialysis. Religious well-being was a sign of a better QoL in patients. The focus on strenghtening spirituality in the daily care of patients could improve different aspects of their QoL. Besides, spiritual support from family or charities can have a positive impact on quality of life of patients. Regarding the high correlation between religious well-being and spiritual well-being, it seems clear the religious basis of existential beliefs.
Silva, KAL; Cargnin, MCS; Ventura,J; Paula, SF; Groos, JV	LILACS Brazil 2017	Descriptive, cross- sectional study	Revista de Enfermagem REUOL on line	To assess, with the tool KDQOL-SF1.3, the quality of life of people with chronic kidney disease undergoing hemodialysis.	KDQOL-SF	The dimensions of the KDQOL-SF with the lowest scores were: emotional function, physical function, kidney disease overload and professional role. The highest scored were observed in the social functioning, pain, stimulation by the dialysis team and cognitive function	It was observed that the health-related quality of life of the patients is compromised in several aspects as assessed with the KDQOL-SF 1.3. The professional role had the worst score, followed by physical function, emotional function and kidney disease overload. On the other hand, the results of the stimulation by the dialysis team, cognitive function,

						domains.	social functioning and pain domains were satisfactory, which contributed to the HRQoL of the study population.
Stockschneider, FBM; Imhof, S; Silva, RMGS; Baggio, FB; Luz Filho, HA; Vieira, MA	LILACS Brazil 2017	Descriptive, cross- sectional study	Saúde e Ambiente (Revista Interdiscipli nar)	To assess the changes in the quality of life (QOL) of patients undergoing hemodialysis during a period of four years.	KDQOL-SF	In the 2013 assessment, higher scores were observed in the stimulation by the team and patient satisfaction aspects, while the lowest scores were in the physical function, general health and social functioning aspects. The total QoL score was similar in both assessment periods.	The study showed that the overall QoL of patients remained about the same from 2009 through 2013, but the elderly patients experienced a significant decrease in overall QoL during the study period which was influenced by physical and social aspects.

After observing the selected studies, some common characteristics stand out and may be used to establish actions to address the issue in question.

The search in the databases was done without any sort of filter and yet the nine studies selected were published in the past nine years. This indicates a recent concern with the quality of life of patients undergoing hemodialysis and hence the shortage of specialised literature. It is noteworthy that in two articles the populations studied were from other countries, specifically Chile and Iran.<sup>14,15</sup>

Another aspect that may compromise the quality of the evidence is the predominant method. In this search, seven of the articles found were based on crosssectional studies. Cross-sectional studies provide a description of a specific moment and are not the type of research indicated to establish any kind of association or relationship between the variables observed because they usually offer what is considered weak evidence.<sup>16</sup> It is also worth adding that no interventional study was found. All limited themselves to providing a situational diagnosis.

On the other hand, six studies used the research instrument KDQOL. This instrument was specifically designed to assess the quality of life of patients undergoing hemodialysis. Thus, this review indicates that KDQOL, besides having been translated and validated to different locations, is also a consensus amongst several researchers, which recommends its use for studies of this nature.

So, the domains most affected were assessed, which were 8 in the KDQOL-SF scale and assessed physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), social function (SF), role-emotional (RE) and mental health (MH).<sup>1,4,6,14,17,18</sup>

The SF-36 questionnaire, *Medical Outcomes Study* 36-*Item Short-Form Health Survey*, was used in 3 studies. It is a generic instrument which assesses quality of life, made up of 36 questions with the following dimensions: physical functioning, role-physical, bodily pain, general health, vitality, social function and role-emotional.<sup>19-21</sup>

Assessment of quality of life may offer important data regarding the psychological and social domains which affect patients with CKD. However, even with the improvement and search for quality in the healthcare system, the increased life expectancy and survival rate of patients, the technological advances in treatment and scientific evidence, it was observed a decline in the quality of life of patients with CKD and negative consequences of hemodialysis to the daily lives of patients. In general, the domains most affected in quality of life are the physical and psychological ones.<sup>22</sup>

Global studies indicate decreased physical functioning in patients with endstage kidney disease, as well as an exarcebated decrease in the SF-36 physical scale of patients undergoing hemodialysis (HD) and peritoneal dialysis (PD).<sup>23</sup>

All articles in this study showed the quality of life of patients undergoing hemodialysis is compromised and the aspects most affected are the physical and cognitive ones. However, in patients with CKD with symptoms of fatigue and loss of energy in addition to a restricted social life, the domains related physical to bodily pain and functioning, social function were the ones with the lowest scores as assessed with the KDWOL-SF.<sup>18-</sup> 20

Authors Kalender, Ozdemir, Dervisoglu, and Ozdemir<sup>24</sup> report that the negative consequences to the quality of life of patients undergoing continuous outpatient peritoneal dialysis may be explained by factors related to treatment, such as the need of "daily" dialysis and the existence of any associated medical complications like peritonitis. However, in the study carried out by Ikonomou *et al*<sup>25</sup>, it was observed a difference regarding the physical functioning, vitality and bodily pain amongst the groups of patients, which indicates an association between age and dialysis, with physical scores being inversely proportional to physical domain scores.

Even though patients with CKD need renal replacement therapy, changes in and healthcare are common. lifestyle Thus, it was observed in the studies a prevalence of depression, anxiety, perceived social support, fatigue and signs of stress affecting the levels of quality of life of patients.<sup>18,20</sup> Although the objective of this study was not to assess the quality life of family members and/or of caregivers of patients, a study selected that assessed the quality of life of patients with CKD and their caregivers obtained similar data showed variables with lower scores for the caregivers as well.<sup>26</sup>

It is evident, through these studies, that patients get emotionally unstable after being informed they have a chronic disease that will require dialysis and that they will need to attend dialysis centres and will be subject to water and food restrictions as well as changes in their working hours and social lives. Patients often have to deal with losses that go beyond kidney function and family support is essential.<sup>27</sup>

Some articles indicate that the longer the treatment, the lower the scores related to daily activities, and that patients over 60 years of age have more trouble to perform physical and leisure activities.<sup>28</sup> These studies also indicate that females are less capable of performing physical activities and basic activities of daily living (ADLs), as they experience lower sleep quality and worse sexual functioning.<sup>29</sup>

### CONCLUSION

Despite the rise in the number of publications regarding the impact of CKD on the quality of life of adults with the disease, the theme is not object of many studies yet. However, it was possible to

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verify that the dimensions most impacted, in those patients, were the physical domain and functional capacity, which explains the low levels of vitality and the problems related to mental health.

The identification of aspects that impact the quality of life of these people allows healthcare professionals to reimagine the assistance currently offered in order to help patients thus minimising negative consequences of the process.

It is believed that the care offered to patients must take into consideration socioeconomic and cultural aspects that allow for better quality of life.

It is expected that this knowledge will help patients to better adapt to the changes they are living and create their own internal tools for coping with the limitations imposed by the chronic condition.

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RECEIVED: 14/06/2018 APPROVED: 17/09/2018 PUBLISHED: 12/18