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DOS HOSPITAIS E DA FACULDADE DE CIÉNCIAS

# Patients' perception of quality of life and hemodialysis chronic kidney disease

Percepção dos pacientes sobre qualidade de vida e doença renal crônica hemodialítica

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#### **Abstract**

*Introduction:* The renal replacement therapy (RRT) hemodialysis (HD) causes abrupt changes in the daily lives of patients with chronic kidney disease (CKD). Changes and limitations in performing activities of daily living cause great impact on the emotions and quality of life (QoL) of patients with dialysis CKD. Objective: To identify the perception of QoL of patients with chronic kidney disease on hemodialysis. **Method:** This was a descriptive field study, cross-sectional, with a qualitative approach. The research was submitted to the Ethics and Research Committee (CEP) of the Institution, Certificate for Ethical Appreciation  $n^{\varrho}$  20689819.0.0000.5479. The data collection instrument included sociodemographic and clinical information of the patients, besides three questions on QL and CKD, based on the scientific literature. Discourse analysis occurred according to the collective subject discourse model. Results: Sample was composed of 54 patients; categories were created and four questions to assess QL during HD. The first question asked what the patient understands about QL, 29.6% of the patients answered to have health, the second question evaluated how they perceive their QL after the beginning of HD, 16.7% of the patients answered that they perceive to be better, 5.5% of the patients said that hemodialysis impacts their QL, despite this 18.5% answered that health is the most impacting, regarding the improvements in QL during treatment, 31.5% answered that the transplant would improve their QL. Conclusion: We conclude that having health and the hope for a definitive treatment, the kidney transplantation, are among the main perceptions of QL for patients with CKD in HD. There is a physical and psychological impairment of patients in renal replacement

**Keywords**: Chronic renal insufficiency, Hemodialysis, Renal replacement therapy, Quality of life

#### Resumo

Introdução: A terapia renal substitutiva (TRS) hemodiálise (HD) ocasiona mudanças abruptas no dia a dia dos pacientes com doença renal crônica (DRC). Alterações e limitações na realização de atividades de vida diária ocasionam grande impacto nas emoções e na qualidade de vida (QV) do paciente com DRC dialítica. **Objetivo**: Identificar a percepção da QV de pacientes com doença renal crônica em hemodiálise. **Método**: Tratou-se de um estudo de campo descritivo, de corte transversal, com abordagem qualitativa. A pesquisa foi submetida ao Comitê de Ética e Pesquisa da Instituição, Certificado para Apreciação Ética  $n^{\varrho}$  20689819.0.0000.5479. O instrumento da coleta de dados incluiu informações sociodemográficas e clínica dos pacientes, além de três perguntas sobre QV e DRC, fundamentadas na literatura cientifica. A análise dos discursos ocorreu segundo o modelo do discurso do sujeito coletivo. Resultados: Amostra foi composta por 54 pacientes, categorias foram criadas e quatro perguntas para avaliar a QV durante a HD. A primeira questão que perguntou o que o paciente entende sobre QV, 29,6% dos pacientes responderam que ter saúde, a segunda questão que avaliou como ele percebe sua QV após o início na HD, 16,7% dos pacientes responderam que percebem estar melhor, 5,5% dos pacientes afirmam que a hemodiálise impacta em sua QV, apesar disso 18,5% responderam que a saúde é o mais impactante, quanto à melhorias na QV durante o tratamento, 31,5% responderam que o transplante melhoraria sua QV. Conclusão: Concluímos que ter saúde e a esperança de um tratamento definitivo o transplante renal estão entre a principal percepção de QV para os pacientes com DRC em HD. Existe um comprometimento físico e psicológico dos pacientes em terapia renal substitutiva e que merecem um olhar diferente para acompanha-los diariamente, amenizando o impacto sobre suas vidas.

**Palavras chave:** Insuficiência renal crônica, Hemodiálise, Terapia de substituição renal, Qualidade de vida

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therapy and that deserve a different look to accompany them daily, mitigating the impact on their lives.

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#### Introduction

The Brazilian population is increasing in the number of growth of the elderly, but it does not mean that they are aging in a healthy way. According to data from the Brazilian Institute of Geography and Statistics (IBGE) (2016), life expectancy increased from 70 to 73.1 years in the last decade<sup>(1)</sup>. Some comorbidities such as systemic arterial hypertension (SAH) and Diabetes Mellitus (DM) are the main triggering factors of kidney disease. Moreover, non-treatment and essential care with diseases may favor the worsening of the disease<sup>(2)</sup>.

On renal diseases, we highlight two main ones: acute kidney injury (AKI) and chronic kidney disease (CKD)<sup>(3)</sup>. AKI is characterized by an abrupt loss of renal function causing accumulation of nitrogenous substances, such as urea and creatinine, and may or may not be accompanied by a reduction in diuresis volume. The causes of AKI may be of prerenal, renal and postrenal origin<sup>(3)</sup>. The pre-renal etiology indicates that the lesion was caused by decreased renal perfusion, especially when the mean blood pressure is below 80mmHG, in cases of hypovolemia due to hemorrhage or decreased cardiac output due to arrhythmias, or peripheral vasodilation in the case of anaphylactic shock, for example<sup>(3)</sup>.

The incidence of AKI of pre-renal cause varies from 40% to 60% of cases and if an early diagnosis is made it is possible to reverse it. Renal etiology is equivalent to 70% of AKI cases, and occurs by direct injury to the renal parenchyma, in 50% of cases due to ischemia and in 35% of cases due to nephrotoxicity, preferably aminoglycoside antibiotics<sup>(3)</sup>. The post-renal cause is the least common and results from urinary tract obstructions, such as bilateral obstruction of the ureters in the prostate tumor or retroperitoneal hemorrhage, bladder obstruction or even in urethral obstruction<sup>(4)</sup>.

The other renal condition that we can discuss is CKD, defined as a lesion present for a period of three months or more, caused by renal parenchyma injury without change in function, or progressive decrease in renal function; may or may not have a reduction in the glomerular filtration rate, which are evidenced by histopathological tests, such as blood, urinary alteration or markers of renal injury and imaging tests<sup>(4)</sup>.

CKD can also be characterized by a glomerular filtration rate < 60mL/min./1.73m², for a period greater than or equal to 3 months and with or without kidney injury<sup>(5)</sup>. There are populations that are more susceptible to the development of CKD, being: hypertensive, diabetic, obese, elderly, family history, cardiovascular diseases and patients using nephrotoxics. Many complications occur as a result of the disease, such as anemia, metabolic acidosis, alteration of mineral metabolism, malnutrition<sup>(6)</sup> and even Renal Failure (RF),

which is the most advanced stage of progressive loss of renal function, described by a glomerular filtration rate value <15mL/min<sup>(7)</sup>.

Renal function is important for basic acid control, performed through urinary acidification, i.e., hydrogen secretion and bicarbonate resorption; and hormonal functions of vitamin D secretion, regulation in the production of erythrocytes through erythropoietin, prostaglandin secretion and an renin-angiotensin-aldosterone system, the latter two mainly related to the maintenance of renal blood flow<sup>(8)</sup>.

The scientific literature describes that 90% of cases diagnosed with CKD in renal replacement therapy (RRT) come from developing countries. Treatment involves high cost of treatment, difficulty in accessing therapy and insufficiency of health promotion programs, in addition to the primary prevention of compromised risk factors, the low number of notifications of cases of patients with the disease<sup>(3-5)</sup>. From the moment the medical diagnosis of CKD is established, treatment alternatives are presented according to the defined stage, such as hemodialysis, peritoneal dialysis or kidney transplantation<sup>(3)</sup>.

Hemodialysis is defined as a mechanical and extracorporeal process that promotes blood filtration through a capillary, which is responsible for removing the products of degradation of metabolism and excess liquids. The procedure is usually performed in three sessions per week lasting four hours each, most often. Patients who undergo this treatment should take medications and follow diets, restricting the amount of fluid ingested<sup>(3-5)</sup>. In the context of quality of life (QoL) of the renal patient, the low treatment is due to low schooling, with regard to adequate treatment as well as access to health education, the difficulty in understanding the orientations that are performed by health professionals, and it is necessary that the health professional is well prepared to transmit effectively for better understanding of the patient(9-10). Assisting quality renal patients is essential for the health team as a means of adding quality to care results, in order to minimize social, economic, professional losses that are caused to frail patients undergoing hemodialysis<sup>(9-11)</sup>. Thus, the importance of this study is highlighted as a means of identifying the perceptions of the quality of life of hemodialysis patients, due to several physical limitations, which influence the emotional, physical and psychic state. The study aims to identify the perception of quality of life of patients with chronic kidney disease undergoing hemodialysis.

#### **Material and Method**

This was a descriptive field study with a quali-

tative approach. The research was carried out in the hemodialysis unit of a Teaching Hospital in the central area of the city of São Paulo. Inclusion criteria included patients over 18 years of age undergoing treatment in the unit, with preserved level of consciousness and cognitive. The research was submitted to the Ethics and Research Committee (CEP) of the Brotherhood of the Santa Casa de Misericórdia de São Paulo (ISCMSP) and Certificate for Ethical Appreciation (CAAE) n. 20689819.0.0000.5479 and opinion n. 4,185,273. The instrument used for data collection included sociodemographic and clinical information of patients, as well as three questions about quality and CKD, based on the scientific literature. The analysis of the discourses occurred according to the model of the discourse of the collective subject, which proposes that the discourses of the statements be reconstructed from pieces of individual discourses, similar to a puzzle, with the purpose of gathering in synthesis discourses the content and arguments that conform similar opinions, using as many discourses as necessary to express the social representation about a phenomenon. After reading the literal transcriptions of the collected data, the **key expressions** (KE) were selected, which are pieces or excerpts that reveal the essence of the content. From the KE, the main **central ideas** (CI) will be extracted, which are an expression that briefly describes the meaning of the discourse analyzed and of each homogeneous set of KE<sup>(12)</sup>.

#### **Results**

The sample consisted of 54 patients undergoing hemodialysis treatment at a teaching hospital in the central area of the city of São Paulo, from morning, afternoon and evening shifts.

For the analysis of the clinical profile, comorbidities and in relation to CKD, we present the Table 2.

When we asked about how their quality of life could be improved during hemodialysis, patients describe their needs, seven categories were created to better evaluate their meanings. Let's see below.

# Question 1. What do you know about quality of life? Category 1 - Synonym of Health

"Feeling good, being in good health" (P1)

"Not having health problems" (P4)

"Being healthy" (P2, P3, P7, P9, P18, P20, P22, P23, P31, P 37, P42, P44, P48, P51, P52, P54)

"Good health" (P13, P17)

"A stable life, without major health problems" (P21)

"Life without health problems" (P25)

"If it were healthy" (P24)

"Having a better life with health" (P47)

Tabela 1
Dados sociodemográficos dos pacientes hemodialíticos.
São Paulo, 2021.

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Variável	N	%	
Age (mean)	45,9 anos (DP)		
Gender			
Male	31	57,4	
Female	23	42,6	
Marital Status			
Married	26	48,1	
Single	19	35,2	
Separated/divorced	5	9,3	
Widow(er)	4	7,4	
Education			
High School	24	44,4	
Elementary	19	35,2	
Higher Education	08	14,9	
Illiterate	03	5,5	
Ocupation			
Retired	14	26,0	
Housekeeper	10	18,5	
Autonomous	8	14,9	
Others*	6	11,1	
General Services	5	9,2	
Seller	4	7,4	
Day worker	2	3,7	
Security services	2	3,7	
Teacher	2	3,7	
Doctor	1	1,8	
Religion			
Catholic	21	38,9	
Evangelicals/Christians	21	38,9	
There is not	10	18,5	
Others	2	3,7	
Total	54	100,0	

#### <u>Category 2 - Nutrition and differentiated hydration</u>

### Category 3 - General well-being

"Feeling good" (P10)

"Good spiritual, physical and emotional state" (P34)

"Well-being in all aspects of life" (P43)

"Physical and emotional well-being and good financial status" (P50)

# Category 4 - Having freedom

"Freedom" - (P11)

#### Category 5 - Does not know how to define

"I don't know" (P5, P6, P12)

# <u>Category 6 – Synonymous with being healthy, life improvements and happiness</u>

"A means of providing a better life" (P14)

"Being healthy and happy" (P29)

"Being healthy" (P30, P35, P36, P41, P45)

"Be happy" (P39)

<sup>&</sup>quot;Balanced diet and drinking lots of water" (P8)

<sup>&</sup>quot;Eat adequate food" (P26)

#### Table 2

# Clinical data related to clinical profile, comorbidities and DM. São Paulo, 2019.

,		
Variable	N	%
Personal comorbidities		
Yes	27	50,0
No	27	50,0
Comorbidity type*		
SAH	17	31,5
SAH and DM	5	9,2
DM	3	5,5
Others	2	3,8
Hemodialysis time (average – months)	66,2	
Complications in hemodialysis		
Yes	36	66,7
No	18	33,7
Type of Complications in Hemodialysis**		
Hypotension	12	22,2
Cramps	07	13,0
Weakness	04	7,4
Glycemic changes and Ca++	03	5,5
Nausea and vomiting	03	5,5
Arrhythmias and Cardiovascular		
Emergencies	03	5,5
Sweating and dizziness	02	3,8
Infection	01	1,9
Venous access problems	01	1,9
Total	54	100,0

<sup>\*</sup>some patients had more than one comorbidity (50%) \*\*some patients had hemodialysis complications (n=36).

# <u>Category 7 - Possess financial stability</u>

"Financial stability" (P16)

### Category 8 - Principles of human life

"It is the main thing for human beings" (P15)

#### Category 9 - Independence

"Being able to do and live in a way that the treatment does not interfere day by day" (P27)

"Being independent" (P28)

# Question 2 - How do you perceive your quality of life after starting hemodialysis?

#### Category 1 – Better with hemodialysis

"It improved a lot after hemodialysis" (P1)

"Yes, better" (P2, P6, P9, P11, P13, P17, P18, P20, P31)

"I feel stronger, willing" (P10)

"Best" (P12)

"Feeling like another man" (P15)

#### Category 2 - Changes in life habits

"I realized that after hemodialysis I had to reduce drinking water a lot" (P8)

#### Category 3 - Worsening quality of life

"More or less" (P3)

"Sadness" (P4)

"Daily attempts at survival" (P7)

"Worse in quality of life" (P21)

"Difficult" (P22)

"I would only have quality of life if I were not on hemodialysis" (P24)

"Treatment slave" (P26)

"Very bad" (P28)

"Low quality of life" (P29, P43)

"Complicated" (P30, P40, P46)

Change????? (P35)

"Bad" (P38)

"It has changed a lot" (P42)

"Difficult" (P49)

"I got sicker" (P51)

"Very sad" (P52)

"Pretty complicated" (P54)

### Category 4 - Limitation of quality of life

"Limitation in leaving" (P5)

"It interferes with activities of daily living" (P32, P33)

"Complicated, interferes with activities of daily living" (P44)

"The treatment interferes a little" (P45, P50)

# Category 5 - Unchanged quality of life

"Nothing has changed" (P16, P34, P37, P39, P41, P47, P48)

"Nothing" (P17, P19)

"It changed little" (P23, P25)

#### Category 6 - Time Limiter

"In the beginning it's bad and in the course only with time interference" (P27)

# Question 3. What do you think has the most impact on your QoL?

Category 1 - Unable to evaluate

No opinion (P5, P12, P14, P35)

Category 2 - Impact on health

Impact on health (P29, P41, P42, P43, P46, P47, P51, P52, P53, P54)

Pain, more pain (P7)

Lack of being physically and psychologically healthy (P10) Chronic diseases (P16)

Kidney problems (P20, P36)

Poor health (P30)

# **Category 3 - Financial impact**

Financial impact (P18, P25)

Health and Money (P22, P23, P26, P32, P44, P49)\_

<sup>&</sup>quot;Means to improve life" (P53)

<sup>&</sup>quot;Having financial independence and health" (P32)

<sup>&</sup>quot;Having friends, health and money" (P33)

<sup>&</sup>quot;A life without financial and health losses" (P46)

<sup>&</sup>quot;Having health and money" (P49)

<sup>&</sup>quot;Living" (P19)

<sup>&</sup>quot;The family is well and healthy" (P40)

<sup>&</sup>quot;Being able to travel, work, be healthy" (P38)

<sup>&</sup>quot;I can give you a better life" (P14)

<sup>&</sup>quot;Impaired" (P53)

<sup>&</sup>quot;It changed my day to day" (P36)

# <u>Category 4 - Impact on time, life habits, routine and autonomy</u>

The distance from treatment (I live in the countryside) (P1)

"Having to stay 4 hours?????? (P3)

"Not being able to travel, limitations to eat (P6)

"Wake up early to come for dialysis (P15)

"Freedom due to treatment (P21)

"Freedom" (P50)

"Limits work" (P34)

"Displacement for dialysis treatment" (P31)

"The impossibility of doing things, for consecutive days" (P27)

"The lack of health and travel" (P38)

"Impact on the family" (P37)

### <u>Category 5 – Impact of hemodialysis treatment</u>

"The treatment of hemodialysis" (P4)

"Do hemodialysis, because it does not completely replace the kidney" (P8)

"Do dialysis" (P9, P13, P17, P19, P24, P33, P40)

"Going for dialysis 3 times a week" (P11)

"Being committed to dialysis" (P28)

#### <u>Category 6 - Physical limitation</u>

"I use AVF, it prevents me from using the AVF member more" (P45)

"Being sick" (P48)

"Being sad" (P39)

# Question 4. What do you think would improve your quality of life during treatment?

# <u>Category 1 – Mobility and displacement for treatment</u>

"Having the treatment close to my house" P1

"Do it at home" P48

P40

"A medication so you don't have to come to the hospital" P39 "Transplantation, not going to the hospital 3 times a week"

"Do not go to the hospital or times a week" P43

"Coming less often for dialysis treatment" P44

"Not having to come for hemodialysis 3 times a week" P45

### Category 2 - Hope for a definitive treatment

"Kidney transplant" P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P12, P13, P14, P15, P16, P17, P51

"Nothing, I would like a transplant" P41

"A means of renal improvement" P35

"The end of treatment" P 37

"Continue treatment" P36

"Some medicine" P38

"No more pain" P47

"Have less time on hemodialysis" P49

#### Category 3 – Autonomy of daily life

"Being able to drink more liquid" P18

"Being able to travel and eat whatever you want" P19

"Feeding right" P20

"Having more flexibility to reconcile other sectors of my life" P22

"To be able to travel" P31

"Improve food" P32

"Not working" P26

"Something that doesn't need to be stuck in the machine" P50

# Category 4 - Feeling of self-indulgence and conformation

"Nothing" P23, P25, P27, P28, P29, P30

"Nothing, everything is fine" P24

"Anything" P33

"Don't know" P34, P42

"To be fine like this without the need to modify" P47

# <u>Category 5 – Improvement of the therapeutic environment</u>

"Less gossip in the HD environment and more tranquility during dialysis there are many complications, sometimes you get out of the treatment well, and other times you are very weak" P21

### <u>Category 6 – Effects of hemodialysis</u>

"If HD didn't hurt me in the days after the HD session" P46

### Category 7 - No evaluation

"They did not answer" - P52, P53, P54

#### **Discussion**

In an analysis of sociodemographic data, in this study it was possible to verify that most patients are male 54.7%. These data are in accordance with the literature, which indicates that in Brazil most dialysis patients are male<sup>(13-17)</sup>.

The predominant age group is 45.9 years, mostly retired 26.0%. Most of the subjects are married 48.1%. It was also verified that 35.2 studied until elementary school and 5.5% are illiterate.

With regard to marital status, most of the users surveyed are married. The fact that they are married indicate that, in general, they have support to assist in the fight against kidney disease. Thus, family contribution minimizes the effects generated by dialysis therapy and its adverse events<sup>(17)</sup>.

Patients with low schooling tend to have difficulties in understanding the guidelines, which may interfere with treatment adhering. Studies show the higher the schooling, the better the quality of life. This is because they have better emotional and intellectual adaptation to deal with treatment difficulties<sup>(18)</sup>.

Dialysis treatment allows improvement of signs and symptoms resulting from the initiation of treatment, providing beneficial effects on the health of chronic kidney patients. However, it interferes in quality of life, such as changes in physical function, difficulties with displacement until treatment and loss of autonomy<sup>(17)</sup>.

In analysis of the results, it was observed that most patients had a worsening in quality of life with dialysis

treatment. A compromised dimension was physical function, one can identify in the following statements:
- "Daily attempts of survival" (P7); - "Worsening of quality of life" (P21); - "I would only have quality of life if I was not on hemodialysis" (P24) "I became sicker" (P51). The physical function of chronic renal patients can be affected by the difficulty of performing relatively simple daily activities, such as walking, leaning and making efforts, generating a feeling of discouragement and lack of energy.

Another dimension affected was category 1-Mobility and displacement for treatment. "Having treatment near my home" P1; -"Come less often for dialysis treatment" P44. - "Do not need to come for hemodialysis 3 times a week" P45. - "Do it at home" P48. Most patients need to move to a dialysis clinic, often in unfavorable conditions, consuming more time for treatment, in addition to the hours in the dialysis machine. The obstacles faced by users, such as fatigue and stress caused by hemodialysis treatment and difficulties in transportation, may hinder treatment adhering<sup>(17)</sup>.

Another category affected was category 9 – Independence. Identified by the statements: - "Being able to do and live so that the treatment does not interfere day by day" (P27); - "Being able to travel, work, have health" (P38) The autonomy of patients is often compromised by physical limitations and relationship of dependence with the hemodialysis machine, because it is an indefinite treatment period and with a frequency of 3 days a week, lasting 4 hours a day. The partial or total limitation on maintaining paid activities causes the individual to lose autonomy and sometimes a feeling of uselessness.

A study, published in 2012, conducted a quantitative and analytical approach to evaluate the quality of life in hemodialysis users. The survey was conducted with 77 users. The results showed that hemodialysis allows improvement of signs and symptoms resulting from the beginning of treatment, providing beneficial effects on the health of chronic renal patients. But that it interferes in quality of life, with loss of autonomy, restriction to work, alteration of physical and emotional function<sup>(17)</sup>.

Another study with 184 patients, with the objective of evaluating the quality of life of patients with different hemodialysis times. The results show a reduction in quality of life, presented in the dimensions analyzed by the SF-36 questionnaire, where the lowest values obtained from the score were related to physical aspects and vitality, and performance in daily activities and work was evaluated. It was also evidenced that the time of dialysis treatment can interfere with quality of life. Patients with a higher level of education may have better emotional adaptability for a better quality

of life. It was also shown that patients with normal hemoglobin concentrations had a better vitality index<sup>(18)</sup>.

A study developed revealed that the dimensions of professional role, vitality, physical and emotional function, general health and renal disease overload were negatively affected, impairing quality of life, however, high scores were found that contributed positively to the quality of life of chronic renal patients, such as the relationship of support received from friends and family, and stimulation of the dialysis team<sup>(19)</sup>.

The results of another study point to chronic renal patients as exposed to several changes in their lifestyle, including changes in emotional, physical and sexual functions, compromising quality of life<sup>(20)</sup>. It is contact that the dimensions that presented the lowest scores were professional role and work, physical function and emotional function. The restriction to work can occur to the fact of physical limitations and relationship of dependence with the hemodialysis machine, because it is an indefinite treatment period and with a frequency of 3 days a week, lasting 4 hours a day. The partial or total limitation on maintaining paid activities causes the individual loss of autonomy and sometimes feelings of uselessness<sup>(17, 19)</sup>.

Physical function was the second dimension with low score, chronic renal patients reported difficulty in performing relatively simple daily activities, such as walking, leaning and making efforts, generating a feeling of discouragement and lack of energy (18, 19). The dimension with the highest mean score was the satisfaction of patients in relation to the care received from the dialysis team. The encouragement offered by the health team allows the patient to feel welcomed, the bond formed between professional and patient contributes to a better treatment adhesion<sup>(17, 19, 21)</sup>.

Thus, the results point to similarities among other studies. However, the limitation of the study is highlighted due to the number of participants being small, however, it already highlights the need for further investigations since the problem is real and requires interventions, mainly because many patients maintain treatment for long years.

### Conclusion

The study concludes that the perception of patients in relation to quality of life is directed to an adaptation to the new conditions imposed by the treatment, to face changes in daily life and thus a new lifestyle. The way each individual deals with kidney disease and its consequences is quite personal, and there is no ideal way to cope with therapy. Hemodialysis negatively affects QoL because it is related to physical, emotional factors, occupation, displacement and complications of therapy.

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**Conflict of interests:** The authors declare no conflict of interest

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