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Factors associated with low health literacy in haemodialysis patients: an observational study

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ABSTRACT

Introduction: Haemodialysis requires adaptations in patients' lives due to imposed restrictions, directly impacting their quality of life. Health literacy is fundamental for understanding and applying information related to therapy, influencing adherence and clinical outcomes. The contribution of health literacy to dialysis patients in developing countries still requires further investigation.

Objectives: To determine the prevalence of low health literacy among haemodialysis patients and its associated factors.

Material and Method: We conducted a cross-sectional and prospective study conducted in a dialysis unit in southeastern Brazil between September 2023 and April 2024. Sociodemographic, clinical, and dialysis data were collected through interviews and review of health records. Health literacy was assessed using the HLS-EU-Q6 instrument, categorising participants as having problematic, inadequate, or sufficient literacy.

Results: Of the 218 patients on haemodialysis, 112 were included; 61.8% (n=68) were male, with a mean age of 50.11±23.47 years and a mean of 7.44±3.61 years of schooling. Low literacy was observed in 60.72% (n=68). Years of schooling were associated with literacy levels.

Conclusion: Low health literacy was found in more than half of the participants, associated with educational attainment and interdialytic weight gain. It is suggested that health information should be adapted to patients' literacy levels, using visual resources to facilitate understanding, promote self-care, and improve clinical outcomes. However, interventional studies are needed to evaluate the effectiveness of these strategies.

Keywords: health literacy; chronic kidney failure; renal dialysis; education; nursing.

RESUMO

Fatores associados ao baixo letramento em saúde em paciente hemodialíticos: estudo observacional

Introdução: A Hemodiálise exige adaptações na vida do paciente devido às restrições impostas, refletindo diretamente na sua qualidade de vida. O Letramento em Saúde é fundamental para compreender e aplicar informações relacionadas à terapia, influenciando a adesão e os resultados clínicos. Destaca-se que ainda precisa ser melhor investigado as contribuições do Letramento em Saúde nos pacientes dialíticos em países em desenvolvimento.

Objetivos: Determinar a prevalência do baixo letramento em Saúde em pacientes em hemodiálise e seus fatores associados.

Material e Método: Estudo transversal e prospectivo realizado em uma Unidade de diálise no Sudeste do

Brasil, entre setembro de 2023 e abril de 2024. Dados sociodemográficos, clínicos e dialíticos foram coletados por meio de entrevista e consulta ao prontuário. O letramento foi avaliado pelo instrumento HLS-EU-Q6, categorizando os participantes em letramento problemático, inadequado ou suficiente.

Resultados: Dos 218 pacientes em terapia, 112 foram incluídos, 61,8% (n=68) eram do sexo masculino, com idade média de 50,11±23,47 anos e escolaridade de 7,44±3,61 anos. O baixo letramento foi de 60,72% (n=68), com influência dos anos de escolaridade.

Conclusão: O baixo LS foi encontrado em mais da metade dos participantes, com associações ao nível de escolaridade e ganho de peso interdialítico. Sugere-se que as informações em saúde sejam adaptadas aos níveis de letramento dos pacientes, utilizando recursos visuais para facilitar a compreensão, promover o autocuidado e melhorar os desfechos clínicos. No entanto, são necessários estudos intervencionistas para avaliar a eficácia dessas estratégias.

Palavras-chave: letramento em saúde; insuficiência renal crônica; diálise renal; escolaridade; enfermagem.

RESUMEN

Factores asociados con el bajo nivel de alfabetización en salud en pacientes en hemodiálisis: un estudio observacional

Introducción: La hemodiálisis requiere adaptaciones en la vida del paciente debido a las restricciones impuestas, reflejándose directamente en su calidad de vida. La Alfabetización en Salud es fundamental para comprender y aplicar la información relacionada con la terapia, influyendo en la adherencia y en los resultados clínicos. Las contribuciones de la alfabetización a los pacientes en diálisis en los países en desarrollo aún necesitan ser mejor investigadas.

Objetivos: Determinar la prevalencia del bajo nivel de alfabetización en salud en pacientes en hemodiálisis y sus factores asociados.

Material y Método: Estudio transversal y prospectivo realizado en una unidad de diálisis del sudeste de Brasil entre septiembre de 2023 y abril de 2024. Se recogieron datos sociodemográficos, clínicos y de diálisis mediante entrevista y consulta de historias clínicas. La alfabetización se evaluó mediante el instrumento HLS-EU-Q6, categorizando a los participantes en alfabetización problemática, inadecuada o suficiente.

Resultados: De los 218 pacientes en hemodiálisis, se incluyeron 112, el 61,8% (n=68) eran varones, con una edad media de 50,11±23,47 años y una escolaridad de 7,44±3,61 años. La alfabetización baja fue del 60,72% (n=68). Los años de escolarización influyeron en los niveles de alfabetización.

Conclusión: El bajo nivel de alfabetización en salud se encontró en más de la mitad de los participantes, con asociaciones con el nivel educativo y el aumento de peso interdialítico. Se sugiere adaptar la información sanitaria a los niveles de alfabetización de los pacientes, utilizando recursos visuales para facilitar la comprensión, promover el autocuidado y mejorar los resultados clínicos. Sin embargo, se necesitan estudios de intervención para evaluar la eficacia de estas estrategias.

Palabras clave: alfabetización en salud; insuficiencia renal crónica; diálisis renal; escolaridad; enfermería.

INTRODUCTION

Hemodialysis (HD) is the most widely used renal replacement therapy for patients with chronic kidney disease (CKD), a modality that requires significant lifestyle adjustments due to imposed restrictions, which directly affect quality of life[1,2].

According to the Brazilian Nephrology Census, the estimated number of patients on dialysis in 2022 was 153,831.3 Among prevalent patients, 95.3% were on HD (4.6% of these on hemodiafiltration) and 4.7% on peritoneal dialysis (PD). Together, systemic arterial hypertension (33%) and diabetes mellitus (32%) accounted for two-thirds of the underlying diseases leading to kidney failure[3].

Patients with CKD on HD face daily decisions related to self-management of the disease. To minimize risks, the adoption of healthy lifestyle behaviors is recommended, including regular physical activity, dietary and fluid restrictions, and adherence to complex therapeutic regimens at all stages of the disease[3].

Given the importance and complexity of correctly adhering to therapeutic regimens, the relevance of health literacy (HL) among patients becomes evident, as it may contribute to understanding and using health information, thereby improving the effectiveness of renal replacement therapy (RRT) and overall quality of life[4]. In addition to being a determinant of self-care and therapeutic effectiveness, HL allows identification of patients who require greater instructional support[4].

HL is a multidimensional concept that encompasses cognitive, affective, social, and personal skills that determine an individual's motivation and ability to access, understand, and use health information[5]. It is not limited to the ability to read and comprehend exchanged information, but also includes the ability to actively manage one's own health, locate and evaluate information, and seek resources for better health maintenance[5].

HL may help patients understand and adhere to restrictive diets and complex medication regimens, as well as adhere rigorously to medical appointments and dialysis sessions for those in CKD stage 5D[6].

Research indicates that HL remains understudied in developing countries, including Latin America. A 2017 systematic review of studies conducted in developed countries found that 25% of participants had low HL.7 In contrast, a systematic review in Latin America and the Caribbean identified 84 studies conducted across 15 countries[8-11], reporting a prevalence of low HL of 86.49%[12].

There is a scarcity of high-quality studies examining how low HL negatively impacts health outcomes, highlighting the need for large-scale research and interventions to improve outcomes for patients with CKD and low HL[13]. Given these considerations, the contributions of HL among dialysis patients in developing countries require further investigation.

The objective of this study was to determine the prevalence of low HL among patients undergoing HD and its associated factors.

MATERIAL AND METHOD

Study Design, Setting, and Period

We conducted an observational, cross-sectional study in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines[14]. The study was carried out at the Dialysis Unit of the Hospital das Clínicas, School of Medicine of Botucatu, São Paulo State, Brazil, from September 2023 to April 2024.

Population and Sample

All adult patients enrolled in the chronic HD program were considered eligible, according to the following criteria:

Inclusion criteria: Individuals aged ≥18 years; enrolled in a chronic HD program for at least 3 months; receiving dialysis treatment 3 times per week.

Exclusion criteria: Individuals with CKD not enrolled in the local chronic HD program (transplant recipients, hospitalized dialysis patients); illiterate individuals and/or those with cognitive impairment according to the Mini-Mental State Examination (MMSE).

Variables

Variables were collected through participant interviews and electronic medical record review (sociodemographic, clinical, and dialysis-related data). During the interview, participants completed three questionnaires (MMSE, HLS-EU-Q6, and lifestyle habits), administered once during an HD session.

Mini-Mental State Examination (MMSE)

The MMSE was first administered to assess global cognitive function, including temporal and spatial orientation, registration, attention and calculation, recall, language, executive function, visuospatial skills, and abstraction. The total score ranges from 0 to 30 points, corresponding to the following categories: cognitive decline: <2 4 points; mild decline: 23–21 points; moderate decline: 20–11 points; severe decline: <10 points[15]. If the participant remained eligible, the remaining questionnaires were administered.

HLS-EU-Q6

HL was assessed using the HLS-EU-Q6 (Health Literacy Survey Questionnaire). Derived from the multidimensional HLS-EU-Q47 developed by the European Research Consortium[16], the instrument aims to evaluate the ability to understand, assess, and perform tasks related to health. The Brazilian Portuguese translation and validation demonstrated a unidimensional structure, adequate factorial indices, and high reliability[16]. The questionnaire includes 6 Likert-scale questions assessing the patient's ability to locate, understand, and apply health information. The final score is calculated as the mean of all items answered and classified into 3 HL levels: inadequate (≤2); problematic (>2 and ≤3); and sufficient (>3)[16].

Ad hoc Questionnaire

An ad hoc questionnaire was developed for this study to identify self-care practices related to diet and medication therapy. It consisted of 5 questions: ***1)*** *Do you come to hemodialysis alone?* (Yes / I come with a family member or caregiver); ***2)*** *Do you attend your medical appointments alone?* (Yes / I come with a family member or caregiver); ***3)*** *At home, do you take your medications by yourself?* (Yes / I receive help for this); ***4)*** *Do you prepare your own meals?* (Yes / Someone else prepares them); ***5)*** *At home, do you consume processed foods (boxed juices, soft drinks, cookies, instant noodles)?* (Yes / No).

Electronic Health Record Data

With participant consent, sociodemographic data were collected, including age (years), sex (female or male), nationality (Brazilian or other), place of birth (city of origin), educational level (years of schooling), and occupation. Occupations were categorized according to occupational risk type: physical risk: machine operator, security guard, butcher, locksmith; chemical risk: farm worker, rural producer; biological risk: waste collector; ergonomic risk: real estate agent, saleswoman, driver, general services assistant, shopkeeper, homemaker, domestic worker, waiter, salesperson, caretaker, administrative assistant, business owner, seamstress, student; mechanical risk: auto mechanic.

Clinical Variables

Clinical variables included underlying diseases, time on RRT, creatinine, and urea. Dialysis-related data included dry weight, therapy duration, and type of vascular access. Ultrafiltration rate, initial and final weight, and mean arterial pressure (MAP) at the start and end of the last 12 sessions were collected. For analysis of systemic blood pressure, pre- and post-dialysis systolic and diastolic pressures from all HD sessions were reviewed. Interdialytic weight gain (IDWG) was defined as the postdialysis weight of one session and the predialysis weight of the following session.

Data Analysis

For data analysis, participants were categorized into 2 groups (sufficient HL and problematic/inadequate HL). Descriptive

statistics were performed using means, standard deviations, minimum and maximum values, and medians for quantitative variables, and frequencies and percentages for categorical variables. Mean IDWG was calculated as: predialysis weight (current session)−postdialysis weight (previous session)÷number of sessions. Relative IDWG was calculated as: mean IDWG÷dry weight×100.

Comparisons of means for quantitative variables according to HL level were performed using the Student t test for normally distributed data and a gamma distribution adjustment for skewed data. For bivariate analyses, associations between HL groups and categorical variables were assessed using the chi-square test.

A significance level of 5% (p<0.05) was adopted for all tests. For multivariate correlation, logistic regression using the Wald test was performed, with HL as the outcome. Results were presented as odds ratios with corresponding 95% confidence intervals; intervals not including 1 were considered statistically significant. All analyses were performed using SAS for Windows, version 9.4.

Ethical Procedures

In accordance with Resolution 510/2016, the study was approved by the Institutional Research Ethics Committee (CAAE 73273823.0.0000.5411/Approval No. 6.589.572), and all participants provided written informed consent.

RESULTS

Of the 218 patients enrolled in the HD program, 5.9% (n=13) were illiterate and 15.5% (n=34) presented cognitive impairment, thus being excluded. Additionally, 27.9% (n=61) did not provide consent. A total of 112 participants were included in the study. Among them, 61.8% (n=68) were male, with a mean age of 50.11±23.47 years and mean schooling of 7.44±3.61 years. The prevalence of low HL was 60.72% (n=68). The most prevalent comorbidities were systemic arterial hypertension (40%) and diabetes mellitus (29.1%). Participant data are shown in **table 1.**

When evaluating results according to HL level (**table 2**), statistically significant differences were found for educational level, occupation, and vascular access. Regarding education, having 6 to 8 years of schooling was more frequent in the inadequate/problematic HL group (n=34; 50%; p=0.0013). Conversely, having 9 to 13 years of schooling predominated in the sufficient HL group (n=23; 52.3%; p=0.0002).

For occupation, there was a significant difference between HL groups (p=0.0112), with ergonomic-risk occupations being significantly more common in the sufficient HL group (68.2%; p=0.0143).

Vascular access was associated with HL (p=0.0307), with central venous catheters (CVC) more prevalent in both HL groups vs arteriovenous fistula (AVF). Inadequate/problematic HL was predominant among men (61.8%; n=42), with a mean age of 51.82±23.21 years.

Table 1. Sociodemographic, clinical, and dialysis characteristics of participants.

Variables	N = 112	%
Male sex	68	61.8
Age (years)*	50.11 ± 23.47	–
Education (years)*	7.44 ± 3.61	–
Occupation: Occupational Risk	–	–
Ergonomic	59	52.67
Physical	29	25.89
Mechanical	12	10.71
Biological	1	0.89
Chemical	7	6.25
Health literacy	–	–
Inadequate/Problematic	68	60.72
Sufficient	44	39.28
Underlying disease	–	–
Systemic arterial hypertension	44	39.28
Diabetes mellitus	32	28.57
Glomerulopathies	10	8.92
Others	39	34.82
Dialysis data	–	–
Mean IDWG (%)*	2.85 ± 1.34	–
Time on dialysis therapy (months)*	44.8 ± 73.76	–
Treatment duration (hours)*	3.98 ± 0.36	–
Entry MAP*	94.3 ± 6.16	–
Exit MAP*	87.7 ± 5.15	–
Vascular access	–	–
Arteriovenous fistula	39	34.82
Central venous catheter	73	65.17

*Mean ± standard deviation; **MAP:** Mean arterial pressure; **IDWG:** Interdialytic weight gain.

In the multivariate analysis, no significant association was found between vascular access (CVC vs AVF) and HL (OR, 2.247; 95% CI, 0.897–5.626; p=0.084). However, educational level remained significant, especially for Group G2 (9–13 years of schooling) (OR, 7.661; 95% CI, 2.676–21.935; p=0.0014). For Group G1 (6–8 years), lower educational level was associated with a higher risk of low HL (OR, 2.862; 95% CI, 1.054–7.777; p=0.006) **(table 3)**.

When stratifying participants by interdialytic weight gain (IDWG)—G1 (IDWG<2%), G2 (IDWG 2–4%), and G3 (IDWG>4%)—and comparing them according to HL level, a significant association was found (p=0.0474). In 79.4% (n=23) of participants with inadequate/problematic HL, IDWG was <2% **(table 4).**

Table 2. Comparison between HL groups regarding dialysis and sociodemographic variables.

Variables	Adequate HL N(%)	Inadequate/ Problematic HL N(%)	*p*-valor
Number of sessions evaluated*	10.39 ± 1.83	10.22 ± 2.18	0.6767
Participants*	44 (39.2)	68 (60.7)	-
Age*	47.5±4.17	51.82±23.21	0.5129
Male sex	28 (63.6)	42 (61.8)	0.8416
Occupation	-	-	0.0112
Ergonomic risk	30 (68.2)	29 (42.6)	-
Physical risk	11 (25.0)	18 (26.5)	-
Others	3 (4.6)	21 (30.9)	-
Education level	-	-	0.0002
1 to 5 years	13 (29.5)	22 (32.4)	0.9168
6 to 8 years	8 (18.2)	34 (50.0)	0.0013
9 to 13 years	23 (52.3)	12 (17.6)	0.0002
Dialysis data	–	–	–
Mean IDWG (%)*	3.39 ± 2.72	3.07 ± 2.59	0.529
Time on dialysis (months)*	44.8 ± 73.76	33 ± 41.14	0.1259
UF (mL)*	19.02 ± 13.35	17.32 ± 12.07	0.5815
Creatinine*	8.1 ± 4.63	8.61 ± 4.15	0.5422
Pre-urea*	109 ± 61.71	97.24 ± 48.56	0.266
Dry weight*	73.93 ± 24.14	74.33 ± 19.58	0.9237
Urea Reduction Rate*	0.67 ± 0.16	0.70 ± 0.12	0.3098
Vascular access	–	–	**0.0307**
CVC	34 (77.3)	39 (57.4)	–
AVF	10 (22.7)	29 (42.6)	–
Lifestyle habits	–	–	–
Do you prepare your own meals? (Yes)	21 (47.7)	27 (39.7)	0.4022
Do you come alone to hemodialysis? (Yes)	24 (54.5)	39 (57.4)	0.7699
Do you go alone to medical appointments? (Yes)	20 (45.5)	28 (41.2)	0.6550
At home, do you take your medications alone? (Yes)	24 (54.5)	39 (57.4)	0.4390
At home, do you consume processed foods? (Yes)	30 (68.2)	42 (61.8)	0.4888

HL: Health literacy; **N(%);** Mean ± standard deviation; **IDWG:** Interdialytic Weight Gain; **UF:** Ultrafiltration; **AVF:** Arteriovenous Fistula; **CVC:** Central Venous Catheter

Table 3. Multivariate logistic regression analysis.

Variable	Coefficient (OR)	95%CI	p-value
Vascular access:			
CVC vs AVF	2.247	0.897- 5.626	0.084
Education G1 (6–8 years)	2.862	1.054-7.777	0.006
Education G2 (9–13 years)	7.661	2.676-21.935	0.0014

CVC: central venous catheter; **AVF:** arteriovenous fistula; **OR:** odds ratio; **CI:** confidence interval; **Education G1 =** 6–8 years of schooling; **Education G2 =** 9–13 years of schooling.

Table 4. Interdialytic weight gain and health literacy.

Variable	G1	%	G2	%	G3	%	p-value
Sufficient HL	6	20.6	27	48.2	11	40.7	0.0474
Inadequate/ Problematic HL	23	79.4	29	51.8	16	59.3	–
Total	**29**	–	**56**	–	**27**	–	**112**

HL: Health literacy; **IDWG:** Interdialytic weight gain; **G1:** IDWG<2%; **G2:** IDWG 2–4%; **G3:** IDWG>4%.

DISCUSSION

Low HL was predominant, affecting more than half (60.7%) of participants. Significant associations were observed when comparing participants across HL levels: the fewer years of schooling, the greater the likelihood of inadequate/ problematic HL. Among dialysis-related variables, an IDWG <2% was significantly associated with inadequate/ problematic HL. No additional associations with HL were identified.

Low HL among patients with kidney disease has been reported in other recent studies with similar prevalence. A study including 336 participants across five dialysis centers in Turkey found that 62.5% had inadequate or limited HL. In Portugal, an evaluation of HL levels among 268 HD patients across seven clinics showed a prevalence of low HL of 74%[17,18].

Additionally, we observed that 17.6% (n=12) of participants with low HL had more than eight years of schooling. Furthermore, 5.9% (n=13) of otherwise eligible patients were excluded due to illiteracy. Low educational attainment is frequently associated with low HL, as it plays a central role in this context.

Lower educational level and the need for assistance with reading and writing have been shown to be statistically significant predictors of HL scores in other studies[17,18]. Individuals with limited education face challenges in understanding health information and, consequently, in effectively managing their chronic disease[19]. As a result, they often have limited knowledge about health-related issues, making tailored interventions essential to adequately support this group[20].

The association between low HL and low educational level underscores the need to reconsider how health professionals deliver health education to patients. It is necessary to develop interventions specifically directed at this

population, as individuals with low HL have greater difficulty understanding health materials—whether printed or digital—and communicating with health professionals[20]. In a 2023 randomized clinical trial with 112 HD patients in China, multimodal health education was vs standard counseling. Three months after the intervention, significant differences were observed between the control and intervention groups in quality of life, HL, and self-care behaviors[21].

Nurses, due to their daily contact with patients, play a central role in health education, contributing to better treatment adherence and, consequently, improved quality of life[22]. A 2025 systematic review examined interventions used by nurses to promote HL in chronic non-communicable diseases[23]. Among the 25 included studies, 15 addressed CKD or its risk factors, such as diabetes and cardiovascular disease, including hypertension. Nurses were found to use simple language, avoid medical jargon, and simplify complex concepts to make information more accessible[23]. For patients with low HL, visual resources such as images or videos were used to enhance understanding, and patients were encouraged to ask questions to clarify doubts and participate actively in their care[23].

Participants with low HL had an IDWG <2%, when stratified by dry weight, a variable that was associated with HL. The literature shows that managing IDWG is a necessary component of self-care. In 2020, AlAwwa et al. found an independent correlation between low IDWG and atrial fibrillation in a cohort of 231 HD patients in Jordan[24]. Additionally, a study[25] including dialysis patients who were hypertensive due to hypervolemia found lower IDWG, similar to our findings, which also showed higher blood pressure levels in the low-HL group. A cross-sectional study conducted in four hospitals in China with 433 HD patients demonstrated that better HL levels were associated with better management of fluid restrictions and IDWG. Other factors may also influence IDWG management, such as family support and adherence to instructions from health professionals[26].

Lastly, no other clinical or sociodemographic associations with low HL were identified. This included vascular access type, although CVC use was more common than AVF among participants. A 2024 Brazilian study involving 167 patients receiving conservative treatment also found no significant association between HL levels and clinical or dialysis-related variables[27]. This absence of association suggests that clinical factors alone do not directly influence patients' HL skills. Socioeconomic conditions and access to technology appear to be more relevant, highlighting the need for educational interventions that account for patients' social and digital contexts[27]. In this sense, understanding how HL levels shape these choices and their impact on clinical outcomes is essential.

This study has some limitations. Data collection in the HD unit may have influenced responses and contributed to the number of participants who declined to participate, as HD machines and chairs are positioned close to one another, potentially causing discomfort when answering questionnaires. It is recommended that future studies avoid conducting data collection during dialysis sessions.

Based on the findings, we conclude that low HL was present in more than half of participants, influenced by educational level and associated with low IDWG. It is suggested that health information be tailored to patients' HL levels. Additionally, the use of visual resources to facilitate understanding may improve health education, support active participation in self-care, and consequently enhance clinical outcomes. However, interventional studies are needed for further evaluation.

Conflicts of interest

Non declared.

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