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RESEARCH ARTICLE (ORIGINAL)

Health literacy in patients with chronic kidney disease undergoing regular hemodialysis

Literacia em saúde na pessoa com doença renal crónica em programa regular de Hemodiálise

Alfabetización sanitaria en personas con enfermedad renal crónica en programa regular de hemodiálisis

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Abstract

Background: Health literacy is a relatively recent approach but has gained considerable prominence in the field of public health. It constitutes a dynamic research area in which various researchers have contributed to understanding its importance

Objectives: Assessing the Health Literacy of Chronic Kidney Disease Patients.

Methodology: Quantitative, descriptive, cross-sectional study using the HLS-EU-PT. The sample consisted of 268 patients aged between 25 and 90 years in seven clinics in Portugal.

Results: We found that 74% of our sample had limited health literacy. It was also observed that educational qualifications ($p < 0.01$) and age ($p < 0.01$) were related to the literacy index. Furthermore, in the analysis of HLS-EU-PT, all indices showed a lower score with statistical significance when compared to the Portuguese population.

Conclusion: It became evident that it is essential to develop strategies that can improve health literacy rates for individuals with renal failure.

Keywords: health literacy; renal insufficiency, chronic; renal dialysis

Resumo

Enquadramento: O aumento da prevalência da doença renal crónica nos últimos anos levou ao seu reconhecimento como um problema de saúde pública, enquanto a literacia em saúde ganhou destaque no campo da saúde pública

Objetivo: Avaliar a literacia em saúde na pessoa com doença renal crónica em programa regular de hemodiálise.

Metodologia: Estudo de abordagem quantitativa, descritivo transversal usando a versão portuguesa do *European Health Literacy Survey* (HLS-EU-PT). A amostra incluiu 268 doentes com idades compreendidas entre os 25 e os 90 anos, em sete clínicas de Portugal continental.

Resultados: Observamos que 74% da nossa amostra apresentava literacia em saúde limitada. Além disso, verificou-se que as habilitações académicas ($p < 0,001$) e a idade ($p < 0,001$) estavam significativamente associadas aos níveis de literacia. Na análise do HLS-EU-PT aplicado à nossa amostra, todos os índices apresentaram *scores* inferiores e com relevância estatística quando comparados à restante população portuguesa.

Conclusão: Ficou evidente a necessidade de desenvolver estratégias eficazes para melhorar os níveis de literacia em saúde em pessoas com insuficiência renal.

Palavras-chave: letramento em saúde; insuficiência renal crónica; diálise renal

Resumen

Marco contextual: El aumento de la prevalencia de la enfermedad renal crónica en los últimos años ha hecho que se reconozca como un problema de salud pública, mientras que la alfabetización sanitaria ha ganado importancia en el ámbito de la salud pública.

Objetivo: Evaluar la alfabetización sanitaria en personas con enfermedad renal crónica en programa regular de hemodiálisis.

Metodología: Estudio cuantitativo, descriptivo, transversal, en el que se utilizó la versión portuguesa de la *European Health Literacy Survey* (HLS-EU-PT). La muestra incluyó a 268 pacientes de entre 25 y 90 años de siete clínicas de Portugal continental.

Resultados: El 74% de la muestra tenía escasos conocimientos sanitarios. Además, descubrimos que las cualificaciones académicas ($p < 0,001$) y la edad ($p < 0,001$) se asociaron significativamente con los niveles de alfabetización. Al analizar el HLS-EU-PT aplicado a nuestra muestra, todos los índices mostraron puntuaciones más bajas y significación estadística en comparación con el resto de la población portuguesa.

Conclusión: Se puso de manifiesto la necesidad de desarrollar estrategias eficaces para mejorar los niveles de alfabetización sanitaria en los pacientes con insuficiencia renal.

Palabras clave: alfabetización en salud; insuficiencia renal crónica; diálisis renal

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Introduction

Chronic kidney disease (CKD) is characterized by a progressive and irreversible decline in kidney function due to structural and functional changes in the kidneys that are multi-causal and multifactorial. It is a long-term condition with an insidious onset and asymptomatic in its early stages. Due to the increase in its incidence and prevalence rates in recent years, CKD has been recognized as a public health problem (Medeiros et al., 2015). The number of people with CKD receiving hemodialysis treatment has increased significantly over the past 10 years. In Portugal, there were approximately 12,458 people receiving hemodialysis treatment in 2020, almost double the number in 2000, which was approximately 7,000 people (Galvão et al., 2021).

Health literacy (HL), although a phenomenon with ancient roots, has only recently gained greater prominence and importance in public health. It has become a dynamic field of research, where several researchers have explored and clarified its relevance (Pedro et al., 2016).

The main objective of this study is to assess HL in people CKD undergoing regular hemodialysis. It also aims to explore the association between sociodemographic variables (age, gender, residence, educational level) and HL.

Background

HL is a concept introduced in the 1970s related to students' education and competency in different domains. Over time, HL has become more specific and linked to each person's ability to care for and make informed decisions about their own health (Sørensen et al., 2012). One way of understanding HL is to consider the different dimensions that affect health at each stage of life, from childhood to old age. HL is a strategy to promote and protect health over time, taking into account the needs and resources of each individual and community (Galvão & Batista, 2022).

The definition of HL has been adjusted and expanded since the 10970s. Currently, HL is widely defined as the ability to make informed decisions in various contexts of everyday life, whether at home, in the community, at the workplace, or when using health services. It is seen as a strategy that increases people's control over their health, including their ability to seek out information and take responsibility for managing it (Kickbusch et al., 2006). The World Health Organization (WHO) defines HL as the set of "cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (WHO, 2021, p. 6).

HL is related to the knowledge, motivation, and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention, and health promotion in order to maintain or improve quality of life (QoL; Sørensen et al., 2015). HL involves many aspects of life, from physical and mental health to social and professional relationships. Therefore, HL depends on various factors that can positively or negatively affect quality of life, namely health services, education, the media, the family, work, the community, and public policies (Nunes, 2020).

Research suggests that HL can play an important role in maintaining or improving health status and may be a key element in health inequalities. Galvão and Batista (2022) argue that HL is conceptualized as a resource, an empowerment tool for the individual to perform all functions in a healthy way in the various contexts of daily life in society. Studies indicate that higher levels of HL are associated with better health status, reduced care costs, greater knowledge about health, and less frequent use of health services (Pedro, 2018). HL has been widely identified in several studies as a risk factor for multiple diseases. The risk of mortality in older and chronically ill patients is higher in those with low HL, which may be due to older people's lower ability to manage and administer medicines correctly, lower ability to interpret labels and health messages, and worse general health status (Lee, Arozullah et al., 2015). Arriaga et al. (2022) suggest that HL is higher among younger age groups, males, people with greater economic capacity, people with higher educational levels, and employees. These findings contribute to a broader understanding of the factors that influence HL and have important implications for the development of strategies to promote health literacy in different population groups.

Training is especially important in hemodialysis, where patient autonomy and responsibility are critical. For example, a lack of HL can lead to errors in medication administration or interpretation of warning signs, putting the patient at risk for complications (Lee, Arozullah et al., 2015). Institutional support and health policies also play a crucial role. Kim et al. (2019) highlight the importance of appropriate educational interventions and a supportive environments to improve HL and treatment adherence. Health policies that include health education strategies and ongoing support can help mitigate the barriers associated with low HL and contribute to better health outcomes. Therefore, when addressing HL in patients with CKD undergoing hemodialysis, it is essential to integrate into the theoretical framework the specificity of the impact of low HL on patient adherence and educational needs, as well as the importance of institutional support policies. This not only reinforces the relevance of the study, but also ensures that the interventions are tailored to the clinical realities and needs of patients undergoing hemodialysis, helping them to better manage their disease and, consequently, improve their quality of life.

Research question/ Hypotheses

What is the level of HL of patients with CKD undergoing regular hemodialysis?
H1 - Patients with CKD undergoing regular hemodialysis have worse HL than the general population.
H2 - Patients with CKD undergoing regular hemodialysis

with less years of schooling have worse HL than patients with more years of schooling.

H3 - Younger people with CKD undergoing regular hemodialysis have better HL than older people.

H4 - The level of HL of patients with CKD undergoing regular hemodialysis is the same in the north, center, and Lisbon and Tagus Valley regions.

H5 - Male patients with CKD undergoing regular hemodialysis have better HL than female patients.

Methodology

A quantitative, descriptive, cross-sectional study was conducted using the Portuguese version of the Health Literacy Survey European Questionnaire (HLS-EU-PT) to assess HL in patients with chronic CKD undergoing regular hemodialysis. Data were collected between March 1 and April 30, 2022, at seven hemodialysis clinics in the North, Center, and Lisbon and Tagus Valley regions of mainland Portugal, following approval by DaVita's Ethics Committee.

The study population consisted of patients with CKD undergoing regular hemodialysis at hemodialysis clinics in the North, Center, and Lisbon and Tagus Valley regions of Portugal.

The following inclusion criteria were applied: patients over 18 years of age; diagnosis of CKD (stage 5); willingness to participate in the study; ability to give written informed consent to participate in the study; intact cognitive functions as assessed by the health professional involved in the study; ability to read and write in Portuguese.

The sample included 268 patients. A non-probability convenience sampling technique was used, since only people undergoing hemodialysis in a clinic in the North, Center, and Lisbon and Tagus Valley regions were selected. Given that the allocation of people for treatment in the clinics is based exclusively on criteria previously defined by the health policy, without any direct intervention by the clinics, the sample is treated as a probability sample (Lohr, 2021). In addition to the HLS-EU-PT, the questionnaire included sociodemographic questions, namely regarding age, gender, educational level, and area of residence.

Data collection tool

The instrument used for data collection was the HLS-EU-PT, validated for the Portuguese population by Pedro et al. (2016). It consists of 47 questions grouped into three very important health domains: Healthcare (16 questions), Health promotion (16 questions), and Disease prevention (15 questions). In order to ensure their correct calculation and comparison, the four domains were standardized on a variable metric scale from 0 to 50, where 0 represents the least possible HL level and 50 represents the best possible HL. The following cut-off points were identified for the four levels: scores equal to or lower than 25 points = inadequate HL; scores between 25 and 33 points = problematic HL; scores between 33 and 42 points = sufficient HL; and scores between 42 and 50 points = excellent HL (Marques, 2015).

Data analysis was carried out using IBM SPSS Statistics, version 26.0. For descriptive statistics, absolute (n) and relative frequencies were used for categorical variables, while the median (Mdn) and percentiles (P25-P75) were used for the continuous variable (age), after observation of the histograms with a markedly skewed distribution. The psychometric properties of the HLS-EU-PT scale were assessed by calculating internal consistency, measured by Cronbach's alpha (α) and item-total correlation. Internal consistency was considered adequate if $\alpha = 0.70$ (Nunnally, 1994) and item-total correlation above 0.30 (Nunnally & Bernstein, 1978).

ANOVA was used (after checking the assumptions for its use) to compare the dimensions of the HLS-EU-PT scale with categorical variables with three or more groups. Differences between groups were assessed using Tukey's multiple comparison test. The association with the age variable was assessed using Spearman's correlation coefficient. The Chi-square test was used to assess whether the frequency distribution differed from a theoretical distribution in the literacy domains. The significance level for rejecting the null hypothesis was 5%.

For the analysis of HL, a total of 243 participants answered the Healthcare section, 233 the Disease prevention section, and 235 the Health promotion section. For the analysis of General literacy, 233 participants with complete data in the three sections were used, excluding cases with missing data.

Results

This study included 268 patients with CKD, aged between 25 and 90 years (Mdn = 68.0, P25 = 59, P75 = 75). The duration of hemodialysis treatment ranged from less than 1 year to 38 years, with a median of 3.0 years (P25 = 2.0, P75 = 7.0). Participants were mainly from the Center region (n = 112, 41.8%), followed by the Lisbon and Tagus Valley region (n = 81, 30.2%) and the North region (n = 75, 28.0%). Most of them were men (n = 177, 66.0%). Most of the participants had a low educational level, with almost 50% of them falling into the ≤ 4th grade category (n = 130, 48.5%), followed by those who had completed 9th grade (n = 58, 21.7%). Only 28 (10.4%) had completed higher education and 51 (19.0%) had completed 12th grade. The majority of respondents were retired (n = 216, 80.6%), only 31 (11.5%) were employed, 16 (6.0%) were unemployed, and one was a student.

Internal consistency, as assessed by Cronbach's alpha, was greater than 0.90 (0.91-0.97) for all scales, meeting the Nunnally criterion ($\alpha > 0.70$). Item-total correlations were higher than 0.30 for all items. These results confirm the reliability of the HLS-EU-PT scale in this sample.

Figure 1 shows that the levels of HL were low. The combined prevalence of *inadequate* and *problematic* levels was over 65% in all domains of HL.

In the General literacy domain, 74% of respondents had *inadequate* or *problematic* levels (limited literacy); in the Disease prevention domain, 67% of respondents had

inadequate or *problematic* levels; in the Health promotion domain, 83% of respondents had *limited* literacy; and in the Healthcare domain, around 67% of respondents had *limited* literacy.

Figure 1
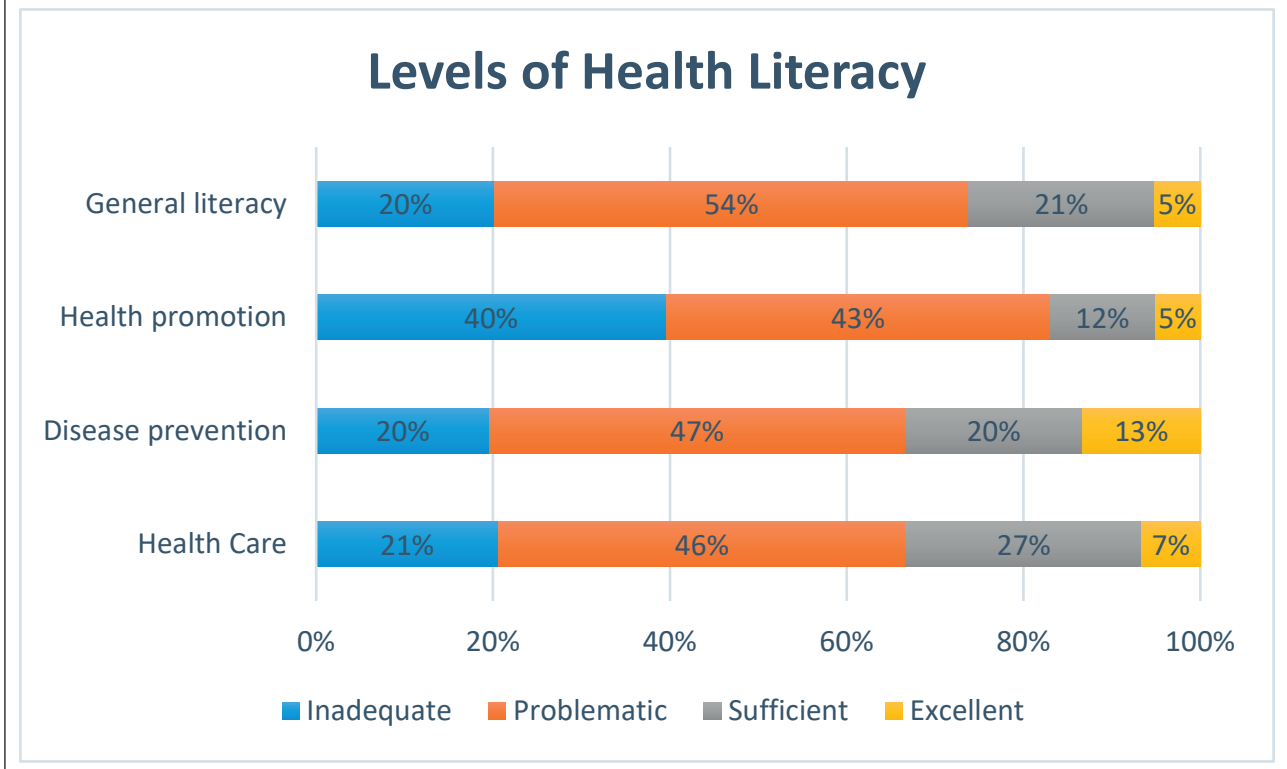
Levels of health literacy

Table 1 shows the results obtained in the study that validated the instrument for the Portuguese population, which serves as a reference for this study and this sample. For all domains, there is evidence ($p < 0.005$) that the proportions are different between the general population and the sample. Therefore, it can be concluded that people with CKD have a lower level of HL than the Portuguese population in general.

Table 1

Comparisons of the literacy domains of the Portuguese population/sample

Domain	Inadequate		Problematic		Sufficient		Excellent		X²	*p*
	PT	S	PT	S	PT	S	PT	S		
Healthcare	16.9%	20.6%	38.9%	46.1%	35.1%	26.7%	16.9%	9.1%	68.0	*p* < 0.001
Disease prevention	19.4%	19.6%	35.7%	47.0%	33,7%	20.1%	19,4%	11.1%	45.1	*p* < 0.001
Health promotion	22.4%	39.6%	37.8%	43.4%	30.3%	11.9%	22.4%	9.5%	310.0	*p* < 0.001
General literacy	17%	20.2%	44%	53.6%	30%	21.0%	8%	5.2%	15.0	*p* = 0.002

Note. PT = Portugal; S = Sample; χ² = Chi-square. **p** < 0.05 indicates statistical significance.

The comparison between HL domains and educational levels found that the lowest educational level (≤ 4th grade) was associated with lower scores in the domains of Healthcare (F = 6.92, *p* < 0.001), Health promotion (F = 7.42, *p* < 0.001), and General literacy (F = 8.01, *p* < 0.001). The comparison between those in the ≤ 4th grade group and those who had completed the 12th grade or higher education showed that HL levels were higher in secondary and higher education. The scores in the Disease prevention domain (F = 5.19, *p* = 0.002) were lower in the group with the lowest educational level (≤ 4th grade), but only when compared to those with higher education. These results are shown in Table 2.

Table 2

Association between the HLS-EU-PT and the educational level

Domain	≤ 4th grade[1]	9th grade[2]	12th grade[3]	Higher education[4]	ANOVA
Healthcare	29.12 (7.49)[3,4]	30.97 (6.50)	33.38 (7.86)[1]	34.71 (7.74)[1]	F = 6.92; $p < 0.001$
Disease prevention	29.93 (7.60)[4]	32.08 (7.36)	32.76 (7.98)	35.66 (7.60)[1]	F = 5.19; $p = 0.002$
Health promotion	26.52 (7.55)[3,4]	28.07 (7.32)[4]	30.71 (7.07)[1]	32.79 (9.02)[1,2]	F = 7.42; $p < 0.001$
General literacy	28.54 (6.61)[3,4]	30.33 (6.25)[4]	32.33 (6.77)[1]	34.36 (7.66)[1,2]	F = 8.01; $p < 0.001$

Note. Superscript values indicate statistically significant differences between groups, as assessed by Tukey's tests.

Spearman's correlation coefficient was used to assess the association between HL and age, since the age variable was skewed, as described above.

The results indicate a negative correlation between age and the different domains of HL. As age increases, there is a slight reduction in HL levels in the Healthcare, Disease prevention, Health promotion, and General literacy domains. Although weak, these correlations are statistically significant, suggesting that age has a moderate but consistent influence on the different domains of HL, as can be seen in Table 3.

Table 3

Association between the HLS-EU-PT Scale and Age

Domain	Age
Healthcare	$r_s = -0.186$**
Disease prevention	$r_s = -0.187$**
Health promotion	$r_s = -0.168$**
General literacy	$r_s = -0.196$**

*$p < 0.05$; **$p < 0.01$; correlation calculated using Spearman's correlation coefficient, after checking for skewness in the distribution of the age variable.

To assess the association between HL domains and the area of residence, the ANOVA test was used to analyse the variance of the means of the different groups. No statistically significant differences were found between the means in the following domains: Healthcare ($p = 0.067$), Disease Prevention ($p = 0.462$), Health Promotion ($p = 0.620$), and General Literacy ($p = 0.284$). These results are shown in Table 4.

Table 4

Association between the HLS-EU-PT Scale and the Area of Residence

Domain	North	Center	LTV	ANOVA
Healthcare	30.88 (6.26)	29.88 (9.14)	32.46 (6.15)	F = 2.73; $p = 0.067$
Disease prevention	31.64 (7.07)	30.97 (8.51)	32.39 (7.54)	F = 0.78; $p = 0.462$
Health promotion	27.71 (7.38)	28.31 (8.23)	28.94 (7.75)	F = 0.48; $p = 0.620$
General literacy	30.06 (5.93)	29.73 (7.84)	31.30 (6.46)	F = 1.27; $p = 0.284$

Note. LTV = Lisbon and Tagus Valley.

The analysis by gender showed that 75.6% of male participants and 70.2% of female participants had limited HL, as can be seen in Table 5.

Table 5

General Health Literacy and Gender

Domain		Male		Female		Total
General literacy	Inadequate	33	21.7%	14	17.2%	47
	Problematic	82	53.9%	43	53.0%	125
	Sufficient	27	17.7%	22	27.1%	49
	Excellent	10	6.5%	2	2.5%	12
	Total	152	100%	81	100%	233

The *t*-test was used to assess the association between HL levels and gender, revealing no statistically significant correlations ($p > 0.005$) to conclude that HL levels were associated with gender. Table 6 shows the *t*-test results.

Table 6

Association between the HLS-EU-PT Scale and gender

Domain	Male	Female	*t*-test
Healthcare	30.67 (8.05)	31.45 (6.74)	$t = -0.79$, $p = 0.430$
Disease prevention	31.29 (8.18)	32.17 (7.11)	$t = -0.87$, $p = 0.386$
Health promotion	28.34 (7.94)	28.32 (7.68)	$t = 0.02$, $p = 0.982$
General literacy	30.10 (7.25)	30.68 (6.33)	$t = -0.65$, $p = 0.516$

Note. t = *t*-test value; *p* = significance value.

Discussion

This study found that 73.8% of participants had *limited* (*inadequate* or *problematic*) General literacy, a figure higher than that reported in the literature, which ranged from 59.5% (Costa et al., 2016) to 61% (Pedro et al., 2016). In the Health promotion domain, around 83% of participants also had *limited* HL, a figure higher than that reported for the Portuguese population (60.3%; Pedro et al., 2016). In the Disease prevention domain, 67% of participants had *limited* HL, again higher than the 55.1% found in the validation of the instrument for the Portuguese population (Pedro et al., 2016). Consistent with this data, 67% of participants had *limited* literacy in the Healthcare domain, higher than the 61% reported by Pedro et al. (2016).

Comparing the HL scores found in this study with those of the Portuguese population, there is statistically significant evidence that HL scores in people with CKD are lower than in the Portuguese population in all domains: General literacy ($p = 0.002$), Health promotion ($p < 0.001$), Disease prevention ($p < 0.001$), and Healthcare ($p < 0.001$). These results suggest that CKD has a significant impact on HL, as shown by other studies that associate low HL with worse prognosis in people with CKD. Devraj et al. (2015) found a strong correlation between limited literacy and worse kidney function, reinforcing that people with CKD have greater difficulty understanding and adhering to complex treatments. Taylor et al. (2016) also found that limited literacy is associated with poorer health outcomes and lower levels of knowledge about dialysis and transplantation.

The results of this study also highlight that as the educational level increases, the mean scores in the HL domains also increase. Statistically, respondents with lower educational levels had significantly lower scores in the dimensions of Healthcare (F = 6.92; $p < 0.001$), Health promotion (F = 7.42; $p < 0.001$), and General literacy (F = 8.01; $p < 0.001$) compared to those with secondary and higher education. In addition, the scores in the Disease prevention domain (F = 5.19; $p = 0.002$) were lower in the group with lower educational levels (≤ 4th grade), but only when compared to higher education. These results are consistent with studies showing a direct relationship between the educational level and HL rates (Arriaga et al., 2022; Pedro, 2018). However, they contradict the study by Marques (2015), which found no association between HL and educational level in Portugal.

With regard to age, all HL domains showed a significant negative correlation with age, although the correlations were weak ($r_s < 0.3$). These findings are consistent with those of Sørensen (2015), who reported a significant association between age and HL in the European context. Cunha et al. (2014) and Arriaga et al. (2022) also found that young adults have higher HL scores, while older individuals tend to have greater difficulties. A similar result was observed by Fraser and Roderick (2019) for people with chronic diseases, particularly when managing complex health information.

In the analysis of the gender variable, no statistically significant correlations were found to conclude that the level of HL is associated with gender ($p > 0.05$). The-

se results contrast with those of Sørensen (2015), who found small differences between men and women, with men showing slightly lower values. Lee, Lee et al. (2015) reported that women tended to have higher HL, often attributed to higher educational levels, while Cunha et al. (2014) and Arriaga et al. (2022) found that men had higher HL scores in some contexts.

The analysis of the association between HL domains and the area of residence showed that the Lisbon and Tagus Valley region had higher mean HL scores than other regions. However, the results were not statistically significant to conclude that the area of residence influences HL levels: Healthcare (p = 0.067), Disease prevention (p = 0.462), Health promotion (p = 0.620), and General literacy (p = 0.284). This finding is consistent with the study by Levy and Janke (2016), who found that although urban areas have better access to health information, regional differences do not always reach statistical significance.

Conclusion

A comprehensive analysis of HL domains in people with CKD reveals worrying levels of limited HL, with rates higher than those observed in the relevant literature. The significantly high prevalence of limited literacy in the General literacy, Health promotion, Disease prevention, and Healthcare domains indicates an urgent need for educational interventions aimed at this specific population. The results also show a positive correlation between educational levels and HL domains, reinforcing the importance of education as a determining factor. Although weak, the statistically significant association between age and HL suggests that communication and health education strategies should be adapted to different age groups. The analysis of the gender variable revealed no statistically significant differences in HL levels, contradicting some previous research. However, regional variations, particularly with higher HL levels in the Lisbon and Tagus Valley region, highlight the need to take into account contextual factors when addressing HL.

Finally, this study highlights the importance of educational strategies tailored to people with CKD with lower educational levels and older age groups. It underlines the importance of regular HL assessments to inform public health policies and improve the effectiveness of interventions for vulnerable populations, such as people with CKD undergoing hemodialysis.

Although the results of this study provided important insights into the HL levels of people with CKD undergoing hemodialysis, the discussion could have been more robust. The lack of comparative studies in this population hindered a more in-depth and relevant analysis and limited the ability to make comparisons consistent with the existing literature.

Author contributions

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