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RESEARCH ARTICLE (ORIGINAL)

Health literacy of patients admitted to a surgical oncology unit

Literacia em saúde da pessoa internada em serviço de cirurgia oncológica

Alfabetización en salud de las personas ingresadas en un servicio de cirugía oncológica

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Abstract

Background: Health literacy (HL) is the ability of an individual to obtain and translate information in order to maintain and improve their health**.**

Objective: To characterize the level of HL of patients admitted to an oncology hospital and assess the reliability of the Portuguese version of the European Health Literacy Survey (HLS-EU-PT).

Methodology: Cross-sectional, quantitative, descriptive, and methodological study. Sample of 188 patients admitted to a surgical oncology unit between May and September 2020. Data were collected through a sociodemographic and health characterization form and a HL assessment tool.

Results: The HLS-EU-PT had a high level of internal consistency. All domains and information-processing levels correlated positively with each other. Participants had on average a problematic level of HL.

Conclusion: The results indicate the need for greater investment in HL training. Further studies are needed in this population and in other populations and healthcare settings to provide an effective response to health problems.

Keywords: health literacy; health knowledge, attitudes, and practices; attitude to health; chronic disease; oncology service, hospital

Resumo

Enquadramento: A literacia em saúde (LS) é a capacidade da pessoa obter e traduzir informações a fim de manter e melhorar a saúde.

Objetivo: Caracterizar o nível de LS da pessoa internada num hospital oncológico; avaliar a fiabilidade do instrumento *European Health Literacy Survey in Portuguese* (HLS-EU-PT).

Metodologia: Estudo transversal, quantitativo, descritivo e metodológico. Amostra de 188 pessoas internados num serviço de cirurgia oncológica entre maio e setembro de 2020, os dados foram colhidos através de formulário de caracterização sociodemográfica, de saúde e instrumento de avaliação da LS.

Resultados: O HLS-EU-PT apresentou elevado nível de consistência interna. Todos os domínios e níveis de processamento do instrumento se correlacionam positivamente entre si. Os participantes apresentam em média um nível problemático de LS.

Conclusão: Os resultados indiciam a necessidade de um maior investimento na capacitação da LS. São necessários mais estudos nesta e noutras populações e contextos de prestação de cuidados de saúde, de forma a direcionar a prática de cuidados na resposta eficaz aos problemas de saúde.

Palavras-chave: literacia em saúde; conhecimento, atitudes e práticas em saúde; atitude frente a saúde; doença crónica; serviço hospitalar de oncologia

Resumen

Marco contextual: La alfabetización en salud (AS) es la capacidad de una persona para obtener y traducir información con el fin de mantener y mejorar su salud.

Objetivo: Caracterizar el nivel de AS de las personas ingresadas en un hospital oncológico; evaluar la fiabilidad del instrumento *European Health Literacy Survey in Portuguese* (HLS-EU-PT).

Metodología: Estudio transversal, cuantitativo, descriptivo y metodológico. Muestra de 188 personas ingresadas en un servicio de cirugía oncológica entre mayo y septiembre de 2020, se recogieron datos mediante un formulario de caracterización sociodemográfica y de salud, y una herramienta de evaluación de AS.

Resultados: El HLS-EU-PT mostró un alto nivel de consistencia interna. Todos los dominios y niveles de procesamiento del instrumento correlacionaron positivamente entre sí. Por término medio, los participantes tienen un nivel problemático de AS.

Conclusión: Los resultados indican la necesidad de una mayor inversión en formación en AS. Son necesarios más estudios en esta y otras poblaciones, y en entornos sanitarios para orientar la práctica asistencial hacia una respuesta eficaz a los problemas de salud.

Palabras clave: alfabetización en salud; conocimientos, actitudes y prácticas sanitarias; actitud ante la salud; enfermedad crónica; servicio hospitalario de oncología

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Introduction

Health literacy (HL) is a rapidly developing field that has gained recognition in academia and policy-making circles in recent years. It is also a significant public health challenge throughout Europe (Sørensen et al., 2020). HL plays a crucial role in health promotion and facilitates access to information. Therefore, promoting HL is crucial in empowering individuals to enhance their autonomy and take responsibility for their health (Holden et al., 2021; Sørensen et al., 2012; Vandraas, et al. 2022), thereby improving their engagement with health systems (Smith, 2021). The promotion of individual and collective health, which is achieved through the practice of HL, is determined by the motivation and abilities of individuals, including the social and cognitive skills, to gain access to, understand, and use information (Minh, 2022). Thus, HL is the ability of an individual to take action to improve their health to protect themselves, their families, or their society. It is the responsibility of each individual to maintain their health and the health of the people around them (Sørensen et al., 2012).

Cancer is a global problem that affects a large proportion of the world's population, with far-reaching effects on individuals and their families. These effects can be physical, psychological, emotional, social, professional, and economic (Martin et al., 2022). HL has an impact on the behaviors of people with cancer and the use of health services (Holden et al., 2021; Samoil et al., 2021). Inadequate HL levels are often associated with unfavorable health outcomes (Samoil et al., 2021). According to Pedro et al. (2016), a low level of HL has been identified as a risk factor for various diseases, particularly cancer. Therefore, it is crucial to know the level of HL of the population and to implement strategies to increase it so that individuals can better understand and apply health information and, consequently, improve health outcomes. HL is essential for the management, control, and prevention of diseases, particularly chronic diseases that significantly impact daily life. A good level of HL is essential to monitor the patient's health status and make decisions about disease prevention (Pedro et al., 2016). In particular, it is a priority to conduct studies to evaluate HL in cancer because of its potential impact on disease outcomes and patients and their quality of life (Barros et al., 2022).

This study aimed to characterize the HL level of individuals admitted to the Head and Neck Surgery unit of an oncology hospital and to assess the reliability of the Portuguese version of the European Health Literacy Survey (HLS-EU-PT).

Background

HL is the ability of an individual to obtain, process, and understand information, identify the means needed to make appropriate health decisions, and use and interpret texts, documents, and numbers (Liu et al., 2020), leading to an increased ability to take responsibility for one's health (Smith, 2021). Samoil et al. (2021) conducted a study to identify the most commonly used health literacy (HL) tools in cancer HL research. Although there is a wide variety of HL tools, they concluded that they are inadequate or incomplete and that none of them holistically assesses HL.

Sørensen et al. (2012) defined HL as a multidimensional concept that integrates three domains: healthcare, disease prevention, and health promotion. The Healthcare domain refers to the ability to access information on health problems and to understand, interpret, and evaluate information from health professionals when making health decisions. The Disease prevention domain refers to the ability to access information on risk factors for health and to understand, interpret, and evaluate information when making decisions to protect one's own health. The Health promotion domain refers to the ability to identify health determinants in the social and physical environment, understand the influence of contextual variables on the health of the person or family member, and act on them to minimize their harmful effects. HL also considers four dimensions of information processing for decision-making: access, understand, appraise, and apply (Sørensen et al., 2012).

Liu et al. (2020) also refer to HL as the ability of an individual to obtain and translate knowledge and information to maintain and improve health in a way that is appropriate to the context. The definition and operationalization of HL is essential to designing effective interventions (Holden et al., 2021; Mor-Anavy et al., 2021; Segado-Fernández et al., 2023). To assess HL, Sørensen et al. (2015) created the European Health Literacy Survey (HLS-EU).

There is evidence that individuals with sufficient or excellent levels of HL are more likely to make decisions about their health, their family, and their community, contributing to reducing the social gradient in health and increasing health equity (Sørensen et al., 2012, Sørensen et al., 2015). Low or inadequate levels of HL are associated with higher mortality rates, worse health outcomes, higher use and costs of health services, and lower participation in prevention programs (Pedro et al., 2016).

Nowadays, governments and health professionals are increasingly aware that the reduction of health inequalities and the improvement in health outcomes is potentially due to an increase in the HL level of the population (Smith, 2021). People with an adequate HL level have greater knowledge of the disease, which enables them to manage and be responsible for their own health, since the ability to seek information, take responsibility, and make informed health decisions increases their control over their health (Liu et al., 2020) and enhances their ability to self-manage the health/disease process (Smith et al., 2021). There is a direct association between the level of HL and the ability to effectively manage one's own health. Only continuous improvement at all levels of HL will make it possible to adopt healthy lifestyles and improve the health of communities. Therefore, promoting the level of literacy is a crucial objective with repercussions in various areas and significant benefits in

terms of public health. In Portugal, the promotion of HL has also been seen as a way to improve health care, since it increases autonomy and responsibility for one's own health through the adoption of healthy lifestyles, reduces barriers to adherence to health programs, reduces social inequality, and optimizes resources (Pedro et al., 2016). Health professionals play a key role through health education interventions and by providing accessible and comprehensible health information to patients and users of health services (Holden et al. 2021; Mor-Anavy et al., 2021; Segado-Fernández et al., 2023). Studies show that there should be specific interventions for people with chronic illnesses to adequately control their disease and prevent complications (Holden et al, 2021).

Cancer is a significant health concern in Portugal, being the second leading cause of death. Oncological diseases are feared by the population due to their negative and profound impact, affecting not only individuals but also their families and society as a whole. People diagnosed with cancer face many challenges and require a comprehensive understanding of their diagnosis and proposed treatment to make decisions about their care (Holden et al., 2021). Despite the implementation of cancer prevention programs and increased survival rates for people with cancer, low levels of literacy on cancer care can hinder the ability of an individual to manage risks and negatively impact both behaviors and outcomes. Cancer-related literacy poses unique challenges for Europe compared to other types of HL, particularly due to complex decisions about screening, treatment, and side effect management (Sørensen et al., 2020).

The chronic nature of oncological diseases, which are characterized by their slow progression and long duration, justifies a HL intervention with patients and their families, which includes raising their awareness to better understand disease progression and managing its symptoms in a timely manner. Low HL is known to contribute to the fear associated with cancer and, consequently, lower screening adherence rates in an area where early diagnosis is crucial (Boogar et al., 2018). Minh et al. (2022) state that it is essential to identify the level of HL of people with cancer, particularly in the early stages of the disease. Thus, educating the population about the determining factors, severity, and forms of prevention of oncological diseases will promote the adoption of healthy behaviors and the adherence to screening (Boogar et al., 2018).

Although the importance of the health information provided by nurses throughout the continuum of care is recognized, regardless of the healthcare setting, there has been little attention paid to the concept of HL in the literature and in nursing education (Smith, 2021).

Research question

What is the level of health literacy of patients admitted to the Head and Neck Surgery unit of an oncology hospital? What is the reliability of the Portuguese version of the European Health Literacy Survey?

Methodology

A cross-sectional, quantitative, descriptive, and methodological study was carried out with 188 participants admitted to the Head and Neck Surgery unit of an oncology hospital in Portugal by consecutive sampling. Data were collected from May to September 2020. All patients admitted (population-based sample) to this unit who gave their informed consent to participate were included in this study. Due to limitations in understanding the questions, even after explanation, 23 patients were excluded. Data were collected through a self-administered paper form. The form consisted of questions on sociodemographic characteristics, health status, and HL using the HLS-EU-PT, which was adapted and validated for the Portuguese population (Pedro et al., 2016) with good psychometric characteristics (Cronbach's alpha between 0.90 and 0.96). Authorization was sought from the authors who translated and validated the scale into Portuguese for use in this study. The HL assessment tool consists of 47 questions rated on a four-point scale (from *very easy* to *very difficult*). It has three domains: healthcare (16 questions), health promotion (16 questions), and disease prevention (15 questions) and four levels of information processing: accessing, understanding, appraising, and applying information essential for decision-making. The indicators were standardized on a single metric scale ranging from 0 to a maximum value of 50, where 0 represents the minimum HL level and 50 its maximum. As a result, HL levels can be *inadequate* (0-25), *problematic* (> 25-33), *sufficient* (> 33-42), or *excellent* (> 42-50). This study complied with the ethical principles and was approved by the Ethics Committee of the oncology hospital where it was carried out (Opinion no. TI 07/2020). Data were processed using IBM SPSS Statistics 24.0 software. Descriptive statistics tests were used, namely frequencies (absolute and relative), mean (measure of central tendency), and standard deviation (measure of dispersion). The normality of the distribution of the HL variable was studied using the Kolmogorov-Smirnov test ($p < 0.01$). In the inferential analysis, Spearman's correlation coefficient was used for association tests. A p-value less than 0.05 was considered the critical value of significance for test results.

Results

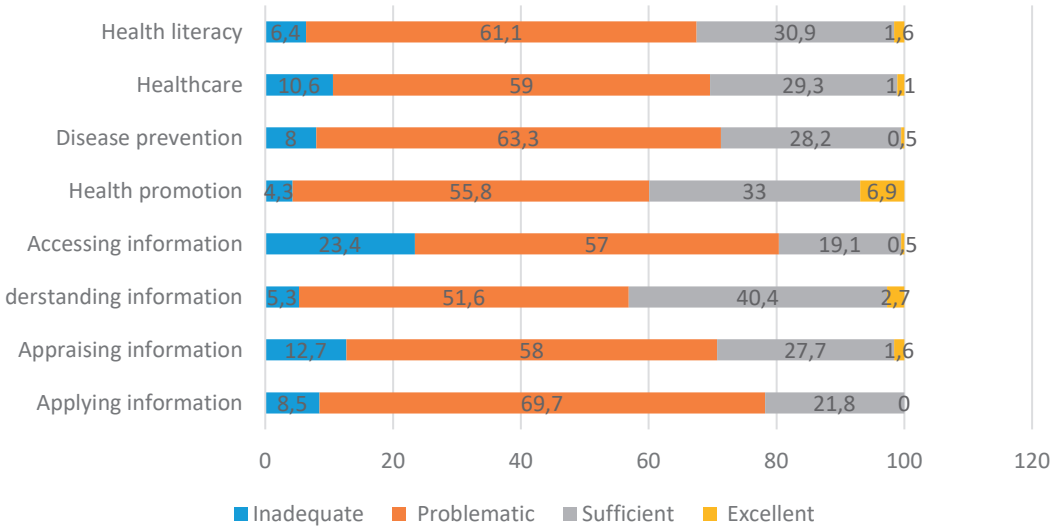
Of the 188 participants, 52.7% were women (n = 99), with a mean age of 61.28 ± 16.06 years. The majority of participants (46.3%; n = 87) were over 65, followed by those aged between 52 and 64 (28.7%; n = 54), and those aged between 31 and 50 (21.3%; n = 40). The group aged 18 to 30 was the least represented (3.7%; n = 7). The majority of participants were married/in a de facto union (64.9%; n = 122), followed by those who were single (12.8%; n = 24), widowed (12.2%; n = 23), and divorced/separated (10.1%; n = 19). Regarding the education level, 45.7% (n = 86) of the participants had completed elementary school, 33.5% (n = 63) had completed secondary school, and 14.9% (n = 28) reported having a university degree. Seven participants

reported being unable to read or write (3.7%), while four participants reported incomplete schooling despite being able to read and write.

Most participants rated their economic situation as average (82.0%; *n* = 154), while 9% rated it as either bad (*n* = 17) or good (*n* = 17). The majority of participants rated their health condition as neither good nor bad (44.1%; *n* = 83), 35.6% (*n* = 67) rated it as good or very good, and 16% (*n* = 30) rated it as bad. Finally, with a similar percentage (2.1%), some participants rated their health condition as very bad (*n* = 4) or very good (*n* = 4). The majority of participants reported having a chronic disease (54.3%; *n* = 102). Hypertension (36.3%; *n* = 37) and diabetes (19.6%; *n* = 20) were the most common diseases. Only 3.9% (*n* = 4) mentioned cancer as their chronic disease. The participants' HL level was 31.41 (± 4.48; Table 1), which represented a problematic HL level. Figure 1 shows that the majority of the participants (61.1%) had a problematic HL level, while approximately one third of had a sufficient HL level. Health promotion had the highest HL level, while disease prevention had the lowest. With regard to the levels of information processing, information understanding had the highest HL level, while accessing information had the lowest HL level, with 23.4% of the participants having an inadequate HL level.

Figure 1

Distribution of participants according to HL levels, domains and information-processing levels



Cronbach's alpha was calculated to assess the reliability of the instrument. The HLS-EU-PT Cronbach's alpha was 0.968, reflecting its high reliability. Cronbach's alpha values were higher than 0.97 for all domains and information-processing levels of the HLS-EU-PT, indicating high internal reliability (Table 1).

Table 1

HL level and internal reliability of the HLS-EU-PT, its domains and information-processing levels

		Mean	Standard deviation	Cronbach's alpha
Health literacy		31.41	4.48	0.968
Domains	Healthcare	30.78	4.96	0.972
	Disease prevention	30.72	4.60	0.973
	Health promotion	32.79	5.01	0.974
Information-processing levels	Accessing information	29.15	5.12	0.975
	Understanding information	33.18	4.84	0.972
	Appraising information	30.77	4.89	0.972
	Applying information	30.07	4.36	0.976

This study aimed to correlate the domains with the information-processing levels and the total score of the HLS-EU-PT using Spearman's correlation test. Table 2 shows positive significant correlations between the domains and information-processing levels ($p < .01$) and with the total score of the HL assessment tool, which demonstrated the contribution of each of them to HL.

Table 2

Correlation of the total score of the HL assessment tool, its domains and information-processing levels (Spearman's correlation)

	Health literacy	Domains			Information-processing levels			
		Healthcare	Disease prevention	Health promotion	Accessing information	Understanding information	Appraising information	Applying information
Health literacy	1.000							
Healthcare	0.933*	1.000						
Disease prevention	0.897*		1.000					
Health promotion	0.907*	0.764*	0.713*	1.000				
Accessing information	0.807*	0.824*	0.829*	0.774*	1.000			
Understanding information	0.924*	0.911*	0.820*	0.796*	0.763*	1.000		
Appraising information	0.932*	0.845*	0.874*	0.840*	0.749*	0.823*	1.000	
Applying information	0.859*	0.782*	0.720*	0.859*	0.629*	0.775*	0.776*	1.000

*$p < .01$

Discussion

The internal consistency of the HL assessment tool was analyzed. The levels of internal consistency obtained were higher than those reported by the authors of the Portuguese version (Pedro et al., 2016). The domains and information-processing levels are positively correlated to each other and to the HLS-EU-PT, which reveals the contribution of each domain and information-processing level to the total HL assessment.

This study aimed to characterize the HL level of patients admitted to the Head and Neck Surgery unit of an oncology hospital, and it was concluded that the average level of HL is problematic. The HL level in this sample is identical to that reported by Pedro et al. (2016) on the HL levels of the Portuguese population. On the other hand, the literacy levels were lower than those found in a study carried out by Sørensen et al. (2015), where 47% of the sample from 12 countries in the European Union had limited (inadequate or problematic) HL levels. Higher HL levels were also obtained in a study (Arriaga et al., 2022) carried out to describe the process of adaptation of the short version of the Health Literacy Survey (HLS_{19}-Q12) to Portugal. In a sample of 1,247 participants (without reference to oncological diseases or others), the authors concluded that it was difficult for people to process information related to disease prevention, with a 21.3% of inadequate levels, compared to 14.4% for healthcare and 6.9% for health promotion. Health promotion is the dimension with the highest levels of HL (71.6%), followed by healthcare (54.6%) and disease prevention (54.1%). When comparing the results of this study with studies conducted on cancer patients, Minh et al. (2022) found that individuals who were recently admitted, particularly older individuals, experienced difficulties comprehending various treatment options (54%) and evaluating the credibility of health information on the internet (43%) in a sample of patients with cancer in Vietnam. In a study with cancer survivors, Coughlin et al. (2022) also found that low HL levels (16%) make it difficult to self-manage the disease. In a study with 262 women with breast cancer, Gunn et al. (2020) obtained the following HL levels: 38% had adequate HL, 33% had marginal HL, and 29% had inadequate HL. Women with inadequate or marginal HL had higher median scores for cancer needs and lower scores for attitudinal self-efficacy than those with adequate HL. In a study carried out with 1,355 breast cancer survivors eight years after diagnosis, Vandraas et al. (2022) found low HL levels (39% participants had an intermediate level and 19.3% reported a marginal or inadequate level of HL), despite the high socioeconomic status of the sample. According to this author, there are well-documented problems with the limited literacy levels in older adults, with consequent poor health outcomes and poor ability to prevent diseases. Information on cancer prevention can be made more readily available, as well

as more accessible and usable. It is essential to increase the accessibility of important health information and the potential for healthy action. In a recent systematic review (Holden et al., 2021) to identify records related to HL in patients with cancer, the authors concluded that lower HL levels were associated with greater difficulties in understanding and processing cancer-related information, poorer quality of life, and poorer experience of care. According to Sørensen et al. (2020), improved cancer literacy combined with health literate organizations and systems can potentially improve the quality of care and health outcomes among patients with cancer. According to Barros et al. (2022), cancer literacy throughout cancer treatment enables the identification and implementation of adequate socio-educational strategies with highly positive impacts on health outcomes.

Despite the condition of the cancer patient, self-perceived health was neither good nor bad, with a tendency towards good or very good, which is aligned with a study carried out by Su et al. (2021).

The limitations of this study were the small sample size, the data collection period (COVID-19 pandemic), and its restriction to a specific oncology unit, which limits its generalizability to other healthcare settings. Future studies should expand the sample size and the contexts for assessing HL using the HLS-EU-PT and the Cancer Health Literacy Test, which is specific to cancer (Barros et al., 2022).

Conclusion

This study presents a framework for HL in general and for the HL of patients with cancer in particular, with regard to accessing, understanding, and appraising information and applying it to health-promoting lifestyles. HL is a crucial health strategy that helps to reduce the impact of the social gradient on health and is an important factor in promoting global health equity.

This study achieved its objectives by demonstrating the reliability of the HLS-EU-PT in terms of internal consistency. All domains and information-processing levels correlated with each other and with the total scale. The majority of participants exhibited problematic HL levels, highlighting the need for strategic investment in health policies and training for health professionals to promote HL among patients with cancer. Therefore, healthcare professionals, especially nurses, should receive more training to provide care that promotes information understanding, increases HL, and encourages patients to become more involved in their healthcare through effective communication strategies.

This study identified the HL levels of patients admitted to the Head and Neck Surgery unit of an oncology hospital in Portugal. Further studies should be carried out to expand the sample and meet the requirements of representativeness. It is also important to conduct research in other regions and care settings, using more specific measurement instruments for patients with cancer.

The identification of the overall HL level may justify the creation of more suitable intervention plans, minimizing or filling the gaps in this area.

Author contributions

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