Functional Health Literacy and Associated Factors in Cancer Patients at a University Hospital

Letramento Funcional em Saúde e Fatores Associados em Pacientes com Câncer de um Hospital Universitário
Alfabetización Funcional en Salud y Factores Asociados en Pacientes con Cáncer de un Hospital Universitario

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ABSTRACT

Introduction: Functional health literacy (FHL) is an individual's ability to comprehend health information, influencing the engagement in preventive practices, early disease detection, management of chronic illnesses, and access to healthcare services. **Objective:** To identify FHL levels and associated variables in patients undergoing intravenous antineoplastic outpatient treatment. **Method:** Between July 2020 and March 2021, 116 patients undergoing intravenous antineoplastic therapy responded to a sociodemographic and health questionnaire, along with an FHL assessment tool. The dependent variable in this study was the level of LFS (Life Satisfaction) of the interviewees, while the independent variables were their sociodemographic, health, and professional-patient relationship characteristics. **Results:** Around 54% presented inadequate or borderline FHL. The analysis revealed higher odds of limited FHL among older patients (OR 1.05), those receiving chemotherapy for the first time (OR 4.57), and individuals with education up to elementary school (OR 23.42). **Conclusion:** The study highlights priority groups that require specialized attention and detailed guidance to improve care, especially patients at the beginning of cancer treatment.
Key words: Health Literacy/statistics & numerical data; Health Education; Social Factors; Neoplasms/nursing.

RESUMO

Introdução: O letramento funcional em saúde (LFS) é a capacidade de um indivíduo compreender informações de saúde, influenciando o envolvimento em práticas preventivas, detecção precoce e gestão de doenças crônicas, além do acesso aos serviços de saúde. **Objetivo:** Identificar os níveis de LFS e as variáveis associadas nos pacientes em tratamento ambulatorial antineoplásico endovenoso. **Método:** Entre julho de 2020 e março de 2021, 116 pacientes em terapia antineoplásica endovenosa responderam a um questionário sociodemográfico de saúde e a um instrumento de avaliação de LFS. A variável dependente deste estudo foi o nível de LFS dos entrevistados, enquanto as variáveis independentes foram suas características sociodemográficas, de saúde e relação profissional-paciente. **Resultados:** Cerca de 54% apresentaram LFS inadequado ou limítrofe. A análise revelou que a chance de ter LFS limitado era maior em pacientes mais velhos (OR 1,05), naqueles recebendo quimioterapia pela primeira vez (OR 4,57) e entre pessoas com educação até o ensino fundamental (OR 23,42). **Conclusão:** O estudo destaca grupos prioritários que requerem atenção especializada e orientações detalhadas para aprimorar o cuidado, especialmente pacientes em início de tratamento contra o câncer.
Palavras-chave: Letramento em saúde/estatística & dados numéricos; Educação em Saúde; Fatores Sociais; Neoplasias/enfermagem.

RESUMEN

Introducción: La alfabetización funcional en salud (AFS) es la capacidad de un individuo para comprender información de salud, lo que influye en su participación en las prácticas preventivas, la detección temprana y el manejo de enfermedades crónicas, así como en el acceso a servicios de salud. **Objetivo:** Identificar los niveles de AFS y variables asociadas en pacientes sometidos a tratamiento ambulatorio antineoplásico intravenoso. **Método:** Entre julio de 2020 y marzo de 2021, 116 pacientes en terapia antineoplásica intravenosa respondieron a un cuestionario sociodemográfico y de salud, y a un instrumento de evaluación de AFS. **Resultados:** Alrededor del 54% mostró un AFS inadecuado o límite. El análisis reveló que la probabilidad de tener un AFS limitado era mayor en pacientes de mayor edad (OR 1,05), en aquellos recibiendo quimioterapia por primera vez (OR 4,57) y entre personas con educación hasta la escuela primaria (OR 23,42). **Conclusión:** El estudio destaca grupos prioritarios que requieren atención especializada y orientación detallada para mejorar el cuidado, especialmente en pacientes que inician tratamiento contra el cáncer.
Palabras clave: Alfabetización en Salud/estadística & datos numéricos, Educación en Salud; Factores Sociales; Neoplasias/enfermería.

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INTRODUCTION

The term health literacy appeared for the first time in the 1970s[1], it concerns the knowledge and competencies of persons to access, understand, evaluate and apply health information in decision-taking, disease prevention and health promotion to keep and maintain the quality-of-life"[2]. Functional health literacy (FHL) is also used in the literature interchangeably with health literacy[3], and functionality in this case is the ability of the individual to use reading, writing and calculation whenever necessary to perform a certain activity or acquire new information necessary to its development and personal context[4].

A study conducted in European countries showed that 47% of the population has limited FHL[5]. In the United States, 53% of the Americans have an intermediate level of FHL, enabling them to navigate most health-related numerical information and texts, although difficulties in comprehending complex documents and issues[6].

Individuals with low FHL levels face hurdles while utilizing health services, such as difficulties of understanding the instructions on drugs use[7], low adherence to drug therapy[8], low utilization of health services, worst quality-of-life, high costs of treatments[9], difficulty to recall medical instructions[10], higher risks of hospitalization and increased mortality risk[11].

The importance of knowing the level of FHL is evident among carriers of chronic non-communicable diseases (NCD[6], because these patients receive a large volume of information[12] and need continuous medical and pharmacological care[13].

There are few national studies addressing the FHL levels of cancer patients[13,14]. However, the National Cancer Institute (INCA) estimates an annual occurrence of 704 thousand new cancer cases in the triennium 2023-2025[15], therefore, it is important to stimulate an adequate FHL for patients with cancer to ensure access to the health system[2].

The objective of this study is to assess the FHL levels of oncology outpatient clinic patients at a university hospital and analyze the associations with sociodemographic and health factors, as well as the patient-health professional relationship.

METHOD

Cross-sectional study conducted with patients of an oncology university hospital of the State of Rio de Janeiro from July 2020 to March 2021.

Inclusion criteria comprised patients older than 18 years of age, both sexes, who received intravenous antineoplastic therapy. Individuals diagnosed with neurologic impairments, assisted by caretakers and self-claimed illiterate were excluded.

The sample was calculated from a population of 173 eligible participants and estimates that 60% would present limited FHL with confidence level of 95% and accuracy of 5%, resulting in 118 patients. The participants were selected randomly from an oncology outpatient who met the eligibility criteria from July 2020 to March 2021. Two patients were excluded due to incomplete data and the final sample consisted in 116 patients.

Data were collected through a sociodemographic and health questionnaire in addition to an instrument to evaluate the FHL. Sociodemographic and health information included age, municipality of residence, sex, skin color, marital status, education, income, family, date of the diagnosis, number of hospitalizations in the last year, basal disease and other comorbidities. In addition, questions about the health service were asked: whether a professional has provided information and guidance about the treatment, if the patient asked about its health, treatment or had any doubt and if the patient believed the information and guidance received were satisfactory and felt safe with the treatment.

The participants' FHL was checked with the instrument Short Test of Functional Health Literacy in Adults (S-TOFHLA)[16], validated and applied in Brazil[17], consisting in a stage of understanding what was read and numeracy.

The first stage comprehends 36 items with medical instructions to evaluate the understanding of health information. For numeracy, four cards are utilized to evaluate the calculation skills of the hours when the medication should be taken, recognition of the normality of the glycemic index compared with reference values and date of the next visit, and calculation of the hour of the medication administered during fasting.

For each correct response of numeracy, a weight 7 is attributed (total 28 points for this section) and for each item of understanding reading is attributed weight 2 (total 72 points). The test lasts 12 minutes to be applied and literacy level is classified as inadequate (0-53 points); marginal (54-66 points) and adequate (67-100 points)[16].

The forms were tested in a pilot-study with six patients (5% of the total sample)| and the mean time of application of the data collection instrument was 20 minutes. Further details about these instruments can be found in the dissertation which is the source of this article[18].

The dependent variable was the level of FHL of the interviewees while the independent variables were the health and sociodemographic characteristics and relation professional-patient.

The quantitative variables analyzed were age and score of FHL and qualitative, sex, skin color, education, family income, marital status, municipality of residence, occupation, basal disease, comorbidities, whether in the first chemotherapy, if received guidance from any health professional, who provided guidance, if usually asked the professional, if understood the guidance and levels of FHL. In the final analyzes, inadequate and marginal levels were grouped as limited FHL.

Later, an exploratory and descriptive analysis of the data utilizing absolute (n) and relative (%) frequencies for qualitative variables and median with its respective interquartile range for quantitative variables was conducted.

Pearson's chi-square or Fisher exact test were utilized to evaluate the relation between the qualitative variables and the outcome to identify associations and the Mann-Whitney (Wilcoxon rank-sum test) for the variable age. The variables with $p < 0.20$ were considered in the next stage of the analysis.

Crude and adjusted logistic regression analyses were performed to calculate the odds ratio (OR) (crude and adjusted) and 95% confidence intervals (CI 95%). Statistical significance was determined when confidence intervals did not overlap ($p < 0.05$).

The Institutional Review Board (IRB) approved the study, report number er 3898539 (CAAE: 25835819.5.0000.5243) in compliance with ethics guidelines for studies with human beings of Directive 466/20212[19] of the National Health Council and initiated only after the participant agreed to participate and signed the Informed Consent Form (ICF).

RESULTS

Of the 116 participants who submitted to the FHL tests, 85 (73.3%) were females predominantly younger than 59 years of age, non-White (62.1%), without spouse (53,4%) and living in Niterói (54.3%). 56 interviewees (50%) completed high-school, 43.1% were employed and 44% reported family income between one and three minimum wages.

Breast cancer (31.9%) was the most prevalent among basal diseases, followed by hematologic disease (25.9%), with hypertension (44.8%), diabetes and metastatic disease (both 14.7%) as the main comorbidities. In addition, 17 patients claimed they were submitted to the first infusion during the interview (Table 1).

When asked about the guidance received about diseases and treatments, 100 respondents affirmed having received explanations from a professional of the service (86.2%). The team doctor was the most mentioned (72.4%) followed by nurses and licensed nurse practitioners (25.9%) and nutritionists (25.9%). 68.1% of the interviewees affirmed they usually clarified their doubts with a professional and 59.5% claimed they understood the information received while 39.7% affirmed they understood "sometimes" (Table 2).

Regarding the FHL levels (Table 3), 53 (45.7%) patients had adequate FHL and 63, limited – 36.2% were inadequate and 18.1%, marginal. The median score of numeracy was 14 points (two questions responded correctly). Five respondents failed to score in the stage and 17 hit only one of the questions. The median was 46 points for understanding what they read and only six interviewees reached 100 points, the upper score of the instrument.

In the bivariate analysis (Table 4), the worst levels of FHL were related to older age, low education and worst relation with professionals of the health service (did not receive guidance or did not ask the professionals).

After logistic regression, the final model (Table 5) revealed that age, education and first chemotherapy were significantly associated with levels of limited FHL (inadequate and marginal). The odds of having limited FHL increased 5% at each additional year of life. For patients in chemotherapy for the first time, the odds of limited FHL was 4.57-fold higher than those who have already been treated. And among individuals who have completed elementary school, the odds of limited literacy were 23.42-fold higher than those who completed university.

DISCUSSION

It was possible to conclude that more than half of the patients submitted to intravenous antineoplastic therapy presented marginal or inadequate FHL and the main factors associated were advanced age, low education and in first-time oncologic treatment.

The instrument S-TOFHLA was utilized to evaluate the patient's literacy level because although there are instruments to measure the FHL of patients with cancer as Dumenci et al.[20], no version validated to Portuguese was found. In addition, these instruments are too specific for cancer and the present study believes it is important that the patient has autonomy to manage not only its oncologic treatment but other health situations they might potentially face. Although the Recognizing and Addressing Limited Pharmaceutical literacy (RALPH)[21] instrument attempts to evaluate "pharmaceutical literacy", it is not validated to Brazil.

Patients with low FHL have difficulties to read, understand and interpret most of the health materials and guidelines, possibly resulting in errors in taking

Table 1. Sociodemographic and health profile of patients submitted to intravenous antineoplastic treatment at an oncologic outpatient of a university hospital (n = 116)

Characteristics	n	%
Sex		
Female	85	73.3
Male	31	26.7
Age		
Up to 59 years	69	59.5
60 or more	47	40.5
Race		
White	44	37.9
Non white	72	62.1
Education		
Elementary 1	19	16.4
Elementary 2	22	19.0
High-school	58	50.0
College (incomplete or complete)	17	14.6
Marital status		
With spouse	54	46.6
Without spouse	62	53.4
Residence (municipality)		
Niterói	63	54.3
São Gonçalo	40	34.5
Others	13	11.2
Family income*		
Up to one minimum wage	49	42.2
From one to three minimum wages	51	44.0
More than three minimum wages	12	10.3
Unknow/did not report	4	3.5
Occupation		
Retired	46	39.7
Unemployed/Does not work	14	12.1
Housewife	6	5.2
Employee	51	43.1
Basal disease (cancer)		
Breast	37	31.9
Hematologic	30	25.9
Gastrointestinal	19	16.4
Lung	13	11.2
Genitourinary	6	5.2
Gynecologic	4	3.4
Hepatobiliary	3	2.6
Others	4	3.4
Comorbidities		
No comorbidities	45	38.8
With comorbidities	71	61.6
Hypertension	52	44.8
Diabetes	17	14.7
Metastasis	17	14.7
Anxiety/depression	10	8.6
Respiratory diseases	2	1.7
Other diseases	24	20.7
First chemotherapy		
Yes	17	14.7
No	99	85.3

(*) Minimum wage July 2020, beginning of data collection: R$ 1,039.00.

Table 2. Characteristics of the relations of patients who underwent intravenous antineoplastic treatment with health professionals of the oncology outpatient of a university hospital (n = 116)

Information	n	%
A professional provides information	100	86.2
Yes	16	13.8
No		
Which professional?		
Physician	84	72.4
Nurse	30	25.9
Nutritionist	30	25.9
Pharmacist	9	7.8
Licensed nurse practitioner	4	3.5
Others	5	4.3
Patient asks the health professional	79	68.1
Yes	15	12.9
No	22	19.0
Sometimes		
Understands the guidance received	69	59.5
Yes	1	0.9
No	46	39.7
Sometimes		

Table 3. Characterization of the level of functional literacy of patients who underwent antineoplastic treatment at an oncologic outpatient of a university hospital (n = 116)

Sections	Score
Numeracy	
1st quartile	14
Median	14
3rd quartile	21
Understanding reading	
1st quartile	32
Median	46
3rd quartile	68
Functional health literacy	n (%)
Inadequate	42 (36.2)
Marginal	21 (18.1)
Adequate	53 (45.7)

medications, inappropriate understand of diets and treatment regimens, among other problems[3].

Low FHL found in the present study is consistent with other studies conducted in Brazil with patients with chronic diseases who utilized the same instrument. Passamai[3] noticed that 68.2% of a sample of users of the National Health System (SUS) in Fortaleza, Ceará, presented low FHL. Chehuen Neto et al.[13] identified that 64.5% of the patients with low FHL, including oncologic in a study conducted at a secondary attention

Table 4. Sociodemographic and health factors and relation patient-health professional per level of health literacy of patients assisted at an oncology outpatient of the university hospital. Niterói/RJ, 2020-2021 (n= 116)

Characteristics	Adequate	Limited	Total	p
Sex				0.95
Female	39 (45.9)	46 (54.1)	85 (73.3)	
Male	14 (45.2)	17 (58.8)	31 (26.7)	
Median age (IQR)ᵃ	55.0 (45.0-62.0)	60.0 (53.5-63.0)	58.5 (51.0-63.0)	0.01
Race				0.27
White	23 (52.3)	21(47.7)	44 (37.9)	
Non white	30 (41.7)	42 (58.3)	72 (62.1)	
Education				< 0.01
Elementary 1	0 (0.0)	19 (100.0)	19 (16.4)	
Elementary 2	5 (22.7)	17 (77.3)	22 (19.0)	
High-school	35 (60.3)	23 (39.7)	58 (50.0)	
College (incomplete or complete)	13 (76.5)	4 (23.5)	17 (14.7)	
Marital status				0.90
With spouse	25 (46.3)	29 (53.7)	54 (46.6)	
Without spouse	28 (45.2)	34 (54.8)	62 (53.4)	
Family income*				0.10
Up to one minimum wage	18 (36.7)	31 (63.7)	49 (43.8)	
From one to three minimum wages	27 (52.9)	24 (47.1)	51 (45.5)	
More than three minimum wages	8 (66.7)	4 (33.3)	12 (10.7)	
First chemotherapy				0.05
Yes	4 (23.5)	13 (76.5)	17 (14.7)	
No	49 (49.5)	50 (51.5)	99 (85.3)	
Professional guidance				0.04
Yes	50 (50.0)	50 (50.0)	100 (86.2)	
No	3 (18.8)	13 (81.2)	16 (13.8)	
Patient asks the professional				0.02
Yes	42 (53.2)	37 (46.8)	79 (68.1)	
No	11 (29.7)	26 (70.3)	38 (32.5)	
Understands guidance received				0.06
Yes	37 (53.6)	32 (46.4)	69 (59.5)	
No	16 (34.0)	31 (66.0)	47 (40.5)	

(a) IQR = Interquartile Range; (b) four individuals did not know the family income.

reference center in Juiz de Fora, Minas Gerais. Most of the hypertensive older patients presented inadequate FHL (59.7%).

Although family income and relation with the service as associated variables have been shown significant association with the level of FHL, it was not kept in the multiple regression. Age and education appeared as predictors of low levels of FHL similar to other studies[3,12,13,22,23].

Age can be strongly related to limited health literacy, mainly in studies evaluating FHL through understanding of reading and mathematics skills as in the case of S-TOFHLA. This occurs because it is common to notice a decline of fluid cognitive ability with age as verbal fluence, work memory and reasoning which are essential to perform daily activities and management of the individual's well-being[24].

In addition to cognitive loss triggered by ageing, cancer patients live the "chemotherapy-induced cognitive compromise", which eventually influences the understanding and processing of information. The chemobrain, as is also known, is a complex phenomenon influenced by several factors as class of chemotherapy or other treatment, duration, anxiety and depression related to cancer diagnosis, creating memory gaps, difficulty to learn, concentrate and multitasking affecting personal and professional life[25].

The strong association between education and level of FHL suggests that although they are different measures, encourage formal education has a great impact on FHL

Table 5. Sociodemographic and health factors and relation patient-health professional associated with inadequate or marginal health literacy of outpatient oncologic patients of a university hospital. Niterói/RJ, 2020-2021 (n = 116)

Characteristics	Crude OR (CI 95%)	Adjusted OR (CI 95%)
Median age	1.05 (1.02-1.09)	1.05 (1.01-1.10)
Education		
Elementary school	23.40 (5.96-114.99)	23.42 (5.38-129.23)
High-school	2.14 (0.66-8.32)	1.99 (0.55-8.64)
College (incomplete or complete)	-	-
Family income*		
Up to one minimum wage	2.83 (0.63-14.99)	
From one to three minimum wages	1.71 (0.39-9.05)	
More than three minimum wages	-	
First chemotherapy		
Yes	3.18 (1.04-11.92)	4.57 (1.17-22.00)
No	-	-
Professional guidance		
Yes	-	
No	4.33 (1.30-19.74)	
Patient asks the professional		
Yes	-	
No	2.68 (1.19-6.36)	
Understands guidance received		
Yes	-	
No	2.24 (1.05-4.90)	

Captions: OR = odds ratio; CI = confidence interval.
(a) Minimum wage July 2020, beginning of data collection: R$ 1.039,00.

level[12]. Despite the number of illiterates has declined significantly in Brazil, the literacy rate still needs to improve. According to the Indicator of Functional Literacy (INAF), only 49% of the individuals who completed high school reached the highest level in the literacy scale, showing that attending school does not warrant enough skills to read and write regularly[26].

The association between being submitted to the first chemotherapy and low FHL remains, regardless of the education level of the participant. Recently diagnosed cancer patients receive a large amount of technical information about the disease and options of complex treatments[27], of difficult understanding even for individuals with good health literacy[2].

A multicenter cohort study in Germany with patients with breast cancer revealed that low health literacy was associated with higher levels of fear of cancer progression[28]. In addition, patients with low level of FHL tend to avoid seeing a doctor, are more fatalist about cancer, are less familiar and unaware of common cancer screening tests and less propense to seek health information in other sources than the doctors[29].

Another important aspect was the low score of numeracy of the instrument, which can compromise the calculation of the doses, schedule of drugs administration and understanding risks and benefits of clinical information found in the routine of cancer patients. Difficulties with this dimension of FHL tend to be more prevalent in low education individuals[13].

The relation of the patient with the health service is essential for a well-succeeded cancer treatment. A multidisciplinary team available is a good strategy to improve the care to the patient. Each professional contributes with its skills and specific knowledge to educate the patient about the disease, objectives of the treatment, how it works, possible adverse effects and symptoms management. The oncologist is the first professional with whom the patient and caretakers first contact after receiving the diagnosis of cancer. If a bond is created since the beginning, the patients' anxiety can diminish before the first chemotherapy infusion and open the team a pathway to positively impact the process of education of the patient[30].

The study results should be understood within certain limitations as for, instance, only one site was selected to conduct the study, requiring caution to generalize the conclusions, however, the hospital is a reference for patients living in the metropolitan region II of Rio de

Janeiro, receiving patients from other municipalities, an important population to be investigated. In addition, the cross-sectional design does not allow causal relations among the variables analyzed. Furthermore, poor health conditions and inability to complete clinical trials can systematically restrain individuals with low FHL to participate in health literacy studies.

CONCLUSION

More than half of the patients interviewed presented inadequate FHL, associated with old age, low education, first oncologic treatment. This result allows health professionals to identify which priority groups need specialized care and detailed guidance to improve the assistance to patients with cancer.

CONTRIBUTIONS

All the authors contributed to the study design, acquisition, analysis and interpretation of the data, wording and critical review. They approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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