Assessment of Health Literacy in Hematologic Cancer Patients Undergoing Hematopoietic Stem Cell Transplantation

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Avaliação do Letramento em Saúde em Pacientes com Câncer Hematológico Submetidos ao Transplante de Células-Tronco Hematopoiéticas

Evaluación de la Alfabetización Sanitaria en Pacientes con Cáncer Hematológico Sometidos a Trasplante de Células Madre Hematopoyéticas

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ABSTRACT

Introduction: Patients with hematologic cancer candidates for hematopoietic stem cell transplantation (HSCT) require extensive self-care, with complex treatments and appropriate health behaviors that are considered a key factor. The importance of health literacy emerges because of these complexities. **Objective**: To describe the level of literacy and assess the interrelationships between health literacy, nutritional status, clinical and sociodemographic conditions in patients with hematologic cancer and candidates for HSCT in a tertiary university hospital in Fortaleza-CE. **Method**: Cross-sectional study conducted with 69 HSCT candidates, treated at a university hospital, who responded to the validated and translated version of the Newest Vital Sign (NVS-Br). Clinical and sociodemographic data were collected through the analysis of medical records. Nutritional status was assessed using body mass index (BMI), waist circumference (WC) and WC associated with hip circumference (WH). **Results:** Inadequate literacy was found in 78.3% of patients. Factors were associated with age (p=0.024), low income (p=0.005) and less years of education (p=0.047). **Conclusion:** The results indicated the necessity to improve the level of health literacy of patients for better treatment results, especially in older adults with low income and poor education level. **Key words:** health literacy; hematopoietic stem cell transplantation; hematology; leukemia; nutritional status.

RESUMO

Introdução: Pacientes com câncer hematológico, candidatos a transplante de células-tronco hematopoiéticas (TCTH), requerem um autocuidado extenso, com tratamentos complexos e comportamentos de saúde adequados que são considerados fator-chave. Frente a essas complexidades, surge a importância do letramento em saúde. Objetivo: Descrever o nível de letramento e avaliar as inter-relações existentes entre letramento em saúde, estado nutricional, condições sociodemográficas e clínicas nos pacientes com câncer hematológicos e candidatos a TCTH em um hospital universitário terciário de Fortaleza-CE. Método: Estudo de caráter transversal realizado com 69 pacientes candidatos a TCHT, atendidos nesse hospital, que responderam à versão validada e traduzida do Newest Vital Sign (NVS-Br). Os dados clínicos e sociodemográfico foram coletados por meio da análise dos prontuários. O estado nutricional foi avaliado pelo índice de massa corporal (IMC), circunferência da cintura (CC) e CC associada à relação cintura-quadril (RCQ). Resultados: O letramento inadequado foi encontrado em 78,3% dos pacientes. Os fatores foram associados à idade (p=0,024), à baixa renda (p=0,005) e a menos anos de estudo (p=0,047). Conclusão: O estudo aponta para a necessidade de se melhorar o grau de letramento em saúde dos pacientes para obter melhores resultados no tratamento, principalmente naqueles que apresentam idade mais avançada, baixa renda e menor escolaridade.

Palavras-chave: letramento em saúde; transplante de células-tronco hematopoéticas; hematologia; leucemia; estado nutricional.

RESUMEN

Introducción: Los pacientes con cáncer hematológico candidatos a trasplante de células madre hematopoyéticas (TCMH) requieren un autocuidado extenso, con tratamientos complejos y conductas de salud adecuadas que se consideran un factor clave. Frente a estas complejidades, surge la importancia de la alfabetización en salud. Objetivo: Describir el nivel de alfabetización y evaluar las interrelaciones entre alfabetización en salud, estado nutricional, datos clínicos y condiciones sociodemográficas en pacientes con cáncer hematológico candidatos a TCMH en un hospital universitario terciario de Fortaleza-CE. Método: Estudio transversal realizado con 69 candidatos a TCMH, atendidos en este hospital, que respondieron a la versión validada y traducida del Newest Vital Sign (NVS-Br). Los datos clínicos y datos sociodemográficos se recolectaron mediante el análisis de historias clínicas. El estado nutricional se evaluó mediante el indice de masa corporal (IMC), la circunferencia de la cintura (CC) y la CC asociada con la circunferencia de la cadera (CCR). Resultados: Se encontró alfabetización inadecuada en el 78,3% de los pacientes. Los factores se asociaron con la edad (p=0,024), bajos ingresos (p=0,005) y menos años de educación (p=0,047). Conclusión: Este estudio apunta a la necesidad de mejorar el nivel de alfabetización en salud de los pacientes con el fin de obtener mejores resultados de tratamiento, especialmente en aquellos que son mayores, tienen bajos ingresos y tienen menos educación.

Palabras clave: alfabetización en salud; trasplante de células madre hematopoyéticas; hematología; leucemia; estado nutricional.

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INTRODUCTION

Ageing has become a global issue because of the significant reduction of mortality and fertility in the XX century. The rapid demographic transition occurred in Brazil impacted the health status of the population and organization of the world health systems as ageing increases the risk of chronic diseases¹.

Neoplastic diseases stand out within this context, particularly hematologic cancers because this pathology may quite often lead to hematopoietic stem-cells transplantation (HSCT). Due to this protocol, extensive selfcare is pivotal with complex procedures and adequate health-related behavior with food restrictions, for instance, and ability of the patient to understand and correctly utilize health² information.

This ability is known as health literacy (HL) and it is necessary that the patient is functionally enabled to utilize and interpret texts, documents and numbers to reach satisfactory levels³.

For the World Health Organization (WHO)⁴, HL represents the 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.

In practice, individuals with adequate HL are more knowledgeable, skilled and confident to take action to improve personal and community health. To strengthen HL means empowerment of personal and community resilience to deal with inequities and improve health and well-being. Poor knowledge of HL is associated with risk behavior, low selfcare and increase of hospitalizations and costs⁵.

Several studies show that poor HL may cause concerns for the patient to understand the risks and benefits associated with available treatment options and diminishing its role in healthcare shared decision making; in addition, is associated with more admissions, low adherence to the treatment or its well-being. Only individuals able to find, understand, evaluate and implement the information they need are empowered to have a positive voice in their own health⁶⁻⁹.

HL is essential for favorable clinical outcomes and to reduce health inequities. The utilization of validated tests allows to classify the degree of HL, determine the most adequate intervention and avoid the embarrassment of the patient to report its own limitations of reading and numeracy skills¹⁰.

Among the available instruments there is the New Vital Signs (NVS) proposed by Weiss et al.¹¹ and its Portuguese version (NVS-BR) validated by Rodrigues et al.¹² for the Brazilian population to classify the literacy

degree in adequate or inadequate; it encompasses literacy and numeracy skills.

Scarce are the studies evaluating the degree of HL in patients with cancer, one of them addresses prostate cancer in 1,581 patients where poor health literacy has negative impact from pre-cancer diagnosis through early survivorship stages when decision about treatments and management of complex information have to be dealt with. Poor HL limits the patient understanding about complex information of treatments and prognosis, becoming an obstacle for the participation of the patient in the medical process. The results revealed association between low functional HL and low education level, advanced age and other comorbidities¹³.

A multicenter literacy study conducted in San Diego, California with 1,344 recently diagnosed women with breast cancer detected the necessity of health literacy with targeted information to their unmet needs mainly for those less educated and younger¹⁴.

The objective of the present study was to describe the literacy degree and evaluate the existing interactions among HL, nutritional status, sociodemographic and clinic conditions of the patients with hematologic cancers and eligible for HSCT in a tertiary teaching hospital in Fortaleza, Ceará, Brazil due to the scarcity of the studies for this population.

METHOD

Cross-sectional, quantitative study carried out at "Hospital Universitário Walter Cantídio (HUWC)" that offers HSCT to the patient with or without malignant hematological diseases referred by the National Health System (SUS). The sample consisted of all the patients with hematologic cancer eligible for transplantation who attended the nutrition service from January to October 2018.

The inclusion criteria were: patient with hematologic cancer eligible for transplantation; consulted at the HUWC; males and females older than 18 years. Patients with some physical impairment hindering the nutritional evaluation and unable to complete the questionnaire and pregnant women were excluded.

Skilled professionals collected the data supervised by the study team through the application of the instruments of data collection and analysis of the charts. The participants were approached at the hospital or hematology nutrition outpatient at the admission in the date they were scheduled to attend study visits, not being necessary to go to the hospital.

For socioeconomic, demographic and clinical data a questionnaire was applied with the variables age, sex, years

of education (<9 years: incomplete elementary school; \geq 9 years: complete elementary school); per capita income in minimum wages, marital status, occupation and classification of the pathology.

As it is a nutrition and HL-related study, the Brazilian version of the instrument NVS-Br designed both for the diagnostic of HL and nutritional literacy was applied. The instrument evaluates the literacy and numeracy where the interviewees were asked to find and utilize information from a nutritional information label and calculate. The participants received 1 point for each question responded correctly and were classified in one of the three categories: high likelihood of limited HL (0-1 scores); likelihood of limited HL (2-3 scores) and adequate HL (>4 scores)11, aware that inadequate HL negatively interferes in the best understanding of health treatment and comprehension. It was hypothesized that inadequate HL was associated with overweight, aged, less educated patients with low income. Then the HL was divided in two categories: adequate and inadequate (grouping high likelihood of limited HL with likelihood of limited HL) as other studies had done before^{1,15,16}.

The nutritional status was verified with the following variables: weight, height, waist circumference (WC) and waist-hip ratio (WHR) according to the standard of the International Society for the Advancement of Kinanthropometry (ISAK)¹⁷. To check the weight and height, the mechanic scale with coupled stadiometer of the brand Filizola[®], dully calibrated was utilized. An inelastic metric tape was used for the circumferences.

Based in the weight (Kg) and height (m) the Body Mass Index (BMI) was calculated [Weight (Kg) /Height² (m²)] to classify the nutritional status of adults and older adults respectively according to WHO⁴ and Lipschitz¹⁸.

The measure of the WC (cm) or in association with WHR allows to evaluate the patient in relation to abdominal obesity and risk of development of chronic diseases according to WHO⁴ and the Latin American Obesity Consensus¹⁹.

Descriptive analysis of the study variables was conducted for statistical analysis of the data. The numerical variables were presented as mean (or median) and measures of dispersion and the categorical, by simple and percent frequencies. The Kolmogorov-Smirnov was utilized to evaluate the normality of the variables. The discrete variables were analyzed through the chi-square test (χ^2) or Fisher's exact test and submitted to risk analysis by multinomial logistic regression expressed in odds ratio (OR). The level of significance was 5% and the data were analyzed with the Statistical Package for the Social Sciences (SPSS), version 19.0.

The study complied with Directive 466/12²⁰ of the National Health Council for clinical trials with

human beings and approved by the Institutional Review Board of HUWC, report number 2.613.745 (CAAE: 81079217.6.0000.5045). The participants who accepted to join the study signed the Informed Consent Form (ICF).

RESULTS

From January to October 2018, 69 patients eligible for HSCT were evaluated. The sample was predominantly of adults (91.3%, n=63) and males (50.7%, n=35), with mean age of 40 \pm 14 years. Of this total, the most prevalent diagnosis was acute leukemia (myeloid or lymphoid) (50.7%, n=35), followed by lymphoma (Hodgkin and non-Hodgkin) (39.1%, n=27) and multiple myeloma (10.1%, n=7). Table 1 shows the characterization of the population.

Based in the nutritional status, the mean BMI was $25.9 \text{ kg/m}^2 (\pm 5.0 \text{ kg/m}^2)$, mean WC was $90.7 \text{ cm} (\pm 12.1 \text{ cm})$ and mean WHR of $0.9 \text{ cm} (\pm 0;1 \text{ cm})$. Most of them had BMI of overweight/obesity (53.6%, n=37) and augmented risk for the development of chronic diseases by WC (56.5%, n=39) and WHR (75.4%, n=52). In addition, the majority (78.3%, n=54) had inadequate nutritional literacy.

There was significant association between age above 50 years (p=0.024), low education (p=0.005) and low family income (p=0.047) with inadequate nutritional literacy (Table 2).

Patients older than 50 years had more odds of inadequate NVS (OR=8.235; CI=1.006-67.426). Low-education (OR=12.069; CI=1.481-98.369) individuals or low family income (OR=7.091; CI=1.234-40.752) had also more odds of inadequate nutritional literacy (Table 2).

DISCUSSION

The prevalence of inadequate HL in candidates to HSCT was quite high. For being the first study of identification of the level of literacy for this population, no studies exist for comparison. However, a recent study² described the meaning of the experiences the patients eligible for HSCT lived with the treatment along the time and showed that there are obstacles for its understanding, in addition to the importance of an adequate HL. The main obstacle was the medical vocabulary because although the information has been provided, quite often the patients do not understand².

Social and demographic determinants are one of the dimensions to understand HL²¹. In general, individuals with low HL have low education level, income and are older²².

 Table 1. Clinicodemographic characteristics of patients eligible to HSCT in a tertiary university hospital. Fortaleza, Ceará, Brazil, 2018 (n=69))

Variables	n	%
Sex		
Male	35	50.7
Female	34	49.3
Age (years)		
<50	48	69.6
≥50	21	30.4
Marital status		
With spouse	36	52.2
Without spouse	33	47.8
Origin		
Rural	36	52.2
Urban	33	47.8
Education		
<9 years	26	37.7
≥9 years	43	62.3
Family income		
≤ 1 minimum wage	28	40.6
2-3 minimum wages	24	34.8
≥ 3 minimum wages	17	24.6
Diagnosis		
Leukemia	35	50.7
Lymphoma	27	39.1
Multiple myeloma	7	10.1
NVS		
Inadequate	54	78.3
Adequate	15	21.7
BMI (kg/m²)		
Malnourished	5	7.2
Eutrophy	27	39.1
Overweight/obesity	37	53.6
wc		
Reduced risk	30	43.5
Augmented risk	39	56.5
WHR		
Reduced risk	17	24.6
Augmented risk	52	75.4

Captions: NVS = Newest Vital Sign; BMI = Body Mass Index; WC = Waist circumference; WHR = Waist-hip ratio.

Patients submitted to HSCT present mortality rates by cardiovascular disease (CD) higher than healthy individuals and HSCT survivors are at higher risk of developing premature CD and metabolic syndrome²³. Apparently, it is relevant to monitor the nutritional status through several obesity measures, as WC and WHR quoted in the literature as good markers of abdominal obesity, easy to measure and strongly associated with CD²⁴.

Mostly, the sample investigated consisted of young adults in concurrence with the projection of eligible to HSCT as older adults may present comorbidities which may contraindicate transplantation²⁵. The Brazilian Society of Bone Marrow Transplantation (SBTMO) affirms that age do not hamper HSCT because comorbidities and performance status are more important in determining the mortality risk of transplantation than age²⁶.

In the current study, older than 50 years was associated with worse nutritional literacy. Santos and Portella²¹ showed that low HL can determine self-care because it implies in skills to understand and self-management related decision-making, in addition to higher prevalence of inadequate HL with ageing possibly explained by alterations that occur as age advances²¹.

It was found no significant difference between HL degree and sex contrary to a study conducted in Ceará with 506 patients of basic attention at SUS which revealed association between low HL and women. In addition, the sample consisted of more than 80% of women because of the health services investigated where their presence was more prevalent²⁷, reinforcing the findings of the National Health Research²⁸, conducted by "*Instituto Brasileiro de Geografia e Estatística (IBGE)*", in partnership with the Ministry of Health which has also concluded that a higher number of women (78%) seek for health services.

In addition, HL was associated with low income in the population investigated, however, no Brazilian studies analyzing this scenario were found for comparison. The international literature affirms that lower HL is more prevalent in low-income population²². The economic implications of the own disease are relevant, in some circumstances they are associated with obstacles to work, reduction of workload, retirement and premature exit of the working market, inclusion in diseases-supporting programs causing adjustments in family dynamics and scarce financial condition for self-maintenance²⁹.

The level of school attendance was another determinant investigated in this study because individuals with until nine years of education were the lowest proportion of the population and lower yet in comparison with individuals with inadequate HL. In despite of this, low education was associated with low literacy (p<0.005). The data obtained by the Indicator of Functional Literacy (Inaf)³⁰ show that, regardless of education being the major factor justifying literacy not always the education degree ensures the expected literacy skill.

 Table 2. Association of nutritional literacy and clinicodemographic characteristics of patients eligible to HSCT in a tertiary university hospital.

 Fortaleza, Ceará, Brazil, 2018 (n=69)

Characteristics	NVS (n%)			Multinomial logistic regression		
				Odds	CI	
	Inadequate n=54 (78.3)	Adequate n=15 (21.7)	Р	ratio** (Cl 95%)	Low	High
Age (years)	1		7			
18-50	34 (63.0)	14 (93.3)	0.024 †	8,235	1,006	67,426
≥50	20 (37.0)	1 (6.7)				
Sex						
Female	27 (50.0)	8 (53.3)	0.010*			
Male	27 (50.0)	7 (46.7)	0.819*			
Marital status						
With spouse	30 (55.6)	6 (40.0)	0.00.4*			
Without spouse	24 (44.4)	9 (60.0)	0.384*			
Origin						
Rural	29 (53.7)	7 (46.7)	0 / 0.0*			
Urban	25 (46.3)	8 (53.3)	0.629*			
Education						
<9 years	25 (46.3)	1 (6.7)	0.005+			
≥9 years	29 (53.7)	14 (93.3)	0.005 ⁺	12,069 [*]	1,481	98,369
Family income						
≤1 minimum-wage	26 (48.1)	2 (13.3)				
2-3 minimum-wages	17 (31.5)	7 (46.7)	0.047 [†]	7,091*	1,234	40,752
≥3 minimum-wages	11 (20.4)	6 (40.0)				
Diagnosis						
Leukemia	28 (51.9)	7 (46.7)				
Lymphoma	19 (35.2)	8 (53.3)	0.224†			
Multiple myeloma	7 (13.0)	0 (0.0)				
BMI (kg/m²)						
Malnourished	3 (5.6)	2 (13.3)				
Eutrophy	23 (42.6)	4 (26.7)	0.389†			
Overweight/obesity	28 (51.9)	9 (60.0)				
WC (cm)						
Reduced risk	24 (44.4)	6 (40.0)	0.759*			
Augmented risk	30 (55.6)	9 (60.0)				
WHR (cm)						
Reduced risk	12 (22.2)	5 (33.3)	0.377*			
Augmented risk	42 (77.8)	10 (66.7)				

Captions: NVS = Newest Vital Signs; BMI = Body Mass Index; WC = Waist circumference; WHR = Waist-to-hip ratio; CI95% = Confidence Interval of 95%.

(†) Fisher's exact test.

(*) Chi-square test.

(**) Odds ratio.

For Inaf³⁰, the Brazilian population is divided in two categories: functional illiteracy and functional literacy. Full and rudimentary illiterates were grouped as functional illiterates accounting for 4% and 24% of the population, respectively and as functional literates, rudimentary, basic and full with 42%, 23% and 8%, respectively³⁰.

Individuals classified as rudimentary literacy are able to read mid-size texts, carry out inferences and solve math problems with some level of planning and control. As basic literacy, reading, writing skills and solutions of problems consistent with finding multiple information, complex math problems and synthesize ideas from texts and comprehend effects of meaning. The full literacy level implies in domain of skills to usually understand and interpret texts unrestrictedly and solve problems involving multiple stages, operations and information³⁰.

As already mentioned, the NVS utilized was recently validated to measure the HL of the Brazilian population¹². The paucity of Brazilian studies utilizing this instrument hampers comparisons of findings. Typically, the status of health systems differs among countries which quite often makes the comparison of studies difficult.

Corroborating the findings of the present study, an American study about health primary attention has also adopted the instrument NVS and identified that 51.9% of 808 individuals evaluated from 18 to 91 years of age had low HL, but men had the worse literacy¹⁵. Another study¹⁶ conducted in Turkey with 456 patients from 17 to 71 years of age applied the NVS and also revealed a proportion of 71.9% of inadequateness. In addition, the lower levels of health functional literacy were found in women with low education degree, older and poor economic conditions¹⁶. However, the discrepancy among the literacy studies according to sex is possibly due to social and cultural differences where the researches were carried out.

It is possible to affirm that target-studies for health functional literacy in diverse settings to know better the different populations are necessary and where the effect of potentializing actions of autonomy and health selfmanagement are able to be evaluated⁵.

The sample size was one of the study limitations, which hampers more accurate inferences and duration of the interview because in the same day, the patient is consulted by a multiprofessional team leaving few time to collect consistent data and checking of anthropometric measures.

The present study contributes to understand and disclose the level the patients with hematologic cancer have about their health and treatment because transplantation requires much selfcare. So far, there is no HL-targeted investigation in Brazil for patients with hematologic cancers submitted to HSCT evaluating the impact on health self-management and its developments. Its relevance for health outcomes is quite clear.

CONCLUSION

The population investigated has high prevalence of inadequate literacy. Based in the associations found, it is necessary to study what the patients know about their health and treatment, mainly those older than 50 years, less education and low income. Healthcare teams should be aware of the existing interrelation between care and the patients' skills in comprehending and using health information correctly.

CONTRIBUTIONS

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

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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