Original Article

Health literacy of home caregivers in a Brazilian capital

Letramento em saúde de cuidadores domiciliares de uma capital brasileira

Alfabetización en salud de cuidadores domiciliarios de una capital brasileña

Thales Antônio Martins Soares[1] https://orcid.org/0000-0001-5780-6476
Virginia Visconde Brasil[1] https://orcid.org/0000-0002-0279-9878
Katarinne Lima Moraes[2] https://orcid.org/0000-0001-6169-0461
Laidilce Teles Zatta Santos[3] https://orcid.org/0000-0003-0566-6883
Vanessa da Silva Carvalho Vila[3] https://orcid.org/0000-0002-1785-8682
Laerte Honorato Borges Júnior[4] https://orcid.org/0000-0001-9593-9405

How to cite:
Soares TA, Brasil VV, Moraes KL, Santos LT, Vila VS, Borges Júnior LH. Health literacy of home caregivers in a Brazilian capital. Acta Paul Enferm. 2021;34:eAPE002255.

DOI
http://dx.doi.org/10.37689/acta-ape/2021AO002255

Keywords
Health literacy; Caregivers; House calls

Descritores
Letramento em saúde; Cuidadores; Visita domiciliar

Descriptores
Alfabetización en salud; Cuidadores; Visita domiciliaria

Submitted
17 August, 2020

Accepted
7 December, 2020

Corresponding author
Thales Antônio Martins Soares
E-mail: enf.thalesams@gmail.com

Abstract

Objective: To analyze the health literacy conditions of caregivers of Brazilian Home Care Program users.

Methods: Cross-sectional study conducted with 90 caregivers of the Brazilian Home Care Program in a municipality in central Brazil. Data collection was performed at users' homes using a sociodemographic questionnaire and the Brazilian version of the Health Literacy Questionnaire (HLQ-Br). Descriptive statistics were used for sociodemographic variables, the mean scores of the HLQ scales and non-parametric tests for measures of association of health literacy.

Results: Most respondents were women (90.0%), with a partner (58.9%), lived in the same location as the user (75.6%), had a personal income of up to one minimum wage (72.2%), did not have the habit of reading (57.8%), studied nine years or more (53.3%), were informal caregivers (91.1%) and had parents who did not study (42.2%). Health literacy limitations were identified in the scales "Actively managing my health" and "Navigating the healthcare system". Health literacy conditions were negatively influenced by the infrequent reading habit; schooling of caregivers and their parents; the fact of being an informal caregiver; by the low income and less time as a caregiver. The strengths of caregivers were related to the access to those who understand and support the caregiver; understanding health information and knowing what to do, and understanding health professionals' requests.

Conclusion: It is necessary to incorporate the principles of health literacy in the routine of caregivers, professionals and managers for better health outcomes and decisions in the home care context.

Resumo

Objetivo: Analisar as condições de letramento em saúde dos cuidadores de usuários vinculados ao Serviço de Atenção Domiciliar de uma capital brasileira.

Métodos: Estudo transversal realizado com 90 cuidadores vinculados ao Serviço de Atenção Domiciliar, de município na região central do Brasil. Coleta realizada no domicílio dos usuários, usando questionário sociodemográfico e a versão brasileira do *Health Literacy Questionnaire* (HLQ-Br). Utilizada estatística descritiva para variáveis sociodemográficas, a média dos escores nas escalas do HLQ e testes não paramétricos para medidas de associação do letramento em saúde.

Resultados: A maioria dos entrevistados era mulher (90,0%), com companheiro (58,9%), vivia no mesmo local do usuário (75,6%), possuía renda pessoal até um salário mínimo (72,2%), não possuía o hábito de ler (57,8%), estudou nove anos ou mais (53,3%), era cuidador informal (91,1%) e tinha pais que não estudaram (42,2%). Limitações foram identificadas nas escalas "Cuidado ativo em saúde" e "Navegar no sistema de

---

[1] Universidade Federal de Goiás, Goiânia, GO, Brazil.
[2] Universidade Federal de Jataí, Jataí, GO, Brazil.
[3] Pontifícia Universidade Católica de Goiás, Goiânia, GO, Brazil.
[4] Universidade Federal de Uberlândia, Uberlândia, MG, Brazil.
Conflicts of interest: none to declare.

saúde". As condições de letramento em saúde foram influenciadas negativamente por não ter hábito de ler; escolaridade do cuidador e de seus pais; pelo fato de ser cuidador informal; pela renda e tempo cuidando dos pacientes. As potencialidades foram relacionadas ao acesso a quem entende e apoia o cuidador; à compreensão das informações sobre saúde e saber o que fazer, e a entenderem o que os profissionais de saúde lhes pedem.

Conclusão: Necessário incorporar os princípios do letramento em saúde no cotidiano dos cuidadores, profissionais e gestores para melhores desfechos e decisões em saúde no contexto da assistência no domicílio.

Resumen

Objetivo: Analizar las condiciones de alfabetización en salud de los cuidadores de usuarios vinculados al Servicio de Atención Domiciliaria de una capital brasileña.

Métodos: Estudio transversal realizado con 90 cuidadores vinculados al Servicio de Atención Domiciliaria de un municipio en la región central de Brasil. La recopilación fue realizada en el domicilio de los usuarios, mediante un cuestionario sociodemográfico y la versión brasileña del *Health Literacy Questionnaire* (HLQ-Br). Se utilizó la estadística descriptiva para variables sociodemográficas, el promedio de puntuaciones de las escalas del HLQ y pruebas no paramétricas para medidas de asociación de la alfabetización en salud.

Resultados: La mayoría de los entrevistados era mujer (90,0 %), con compañero (58,9 %), vivía en el mismo lugar que el usuario (75,6 %), tenía un ingreso personal de hasta un salario mínimo (72,2 %), no tenía el hábito de leer (57,8 %), estudió nueve años o más (53,3 %), era cuidador informal (91,1 %) y sus padres no estudiaron (42,2 %). Se identificaron limitaciones en las escalas "Cuidado activo de la salud" y "Navegar en el sistema de salud". Las condiciones de alfabetización en salud fueron influenciadas de forma negativa por no tener el hábito de leer, por la escolaridad del cuidador y de sus padres, por el hecho de ser cuidador informal y por los ingresos y tiempo cuidando a los pacientes. Las posibilidades se relacionaron con el acceso a quien entiende y apoya al cuidador, con la comprensión de la información sobre salud y saber qué hacer y entender lo que los profesionales de la salud les piden.

Conclusión: Es necesario incorporar los principios de la alfabetización en salud en la cotidianidad de los cuidadores, profesionales y administradores para obtener mejores resultados y tomar mejores decisiones respecto a la salud en el contexto de la atención domiciliaria.

Introduction

Health literacy is defined by the World Health Organization as 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 maintaingood health".(1) Determining the health literacy conditions of individuals helps to improve the quality of information provided by services, community participation in self-management and decision-making, service planning and public health education.(2)

Limitations in this construct contribute to higher mortality and hospitalization rates, less use of preventive services, higher expenses, difficulty navigating the health system (locating, having access and deciding on the service and health professionals), ineffective communication with professionals and difficulties in understanding the guidelines provided by health services.(3,4)

The assessment of this construct in different care contexts is essential for a better health management by people and services.(5,6) This includes home care provided by caregivers. Caregivers are defined by the Ministry of Health as people who spend most of their time providing care, regardless of being family members or not.(7)

The literature has described limitations and weaknesses in the health literacy of home caregivers, which contributes to flaws in home care and generates worse health outcomes, such as difficulty in navigating health systems(8) and understanding the pathology of their patients;(9) negligence in care;(10) difficulty in understanding the guidance provided by professionals and not being able to identify the literacy limitations of those being cared for.(11)

The presence of home caregivers is essential for the functioning of health actions in the care modality that performs prevention, treatment, rehabilitation, palliation and health promotion actions at home, in the context of the Brazilian public health service.(12)

Thus, it is necessary to include the assessment of home caregivers' health literacy as a priority in public health policies with the aim to improve the health outcomes of caregivers themselves and of individuals they care for.(13)

In order to assess the individuals abilities to be successful in different health contexts, if they understand the guidance provided by professionals and apply such deliberations in their routine, and if they can navigate the system and manage their health by guaranteeing equitable access and use of services, the objective was to analyze the health literacy conditions of caregivers of the Brazilian Home Care Program users.

Methods

This is an analytical cross-sectional study. It was conducted in 2019 with 90 caregivers of the Brazilian Home Care Program that attends users of the Unified Health Service (Brazilian SUS) in a city in the central region of Brazil.

This service is decentralized and health care teams are distributed by regions in the city. The profile of users served by the multidisciplinary teams is of individuals with chronic pathologies, infectious diseases, oncological diseases, malnutrition and who need home oxygen therapy.

The study included all caregivers aged 18 or over, linked to the Brazilian Home Care Program for at least 30 days, time considered as a period of adaptation to the home care activities. Caregivers of patients who died, were discharged from the service, hospitalized and not located after three attempts of contact were excluded.

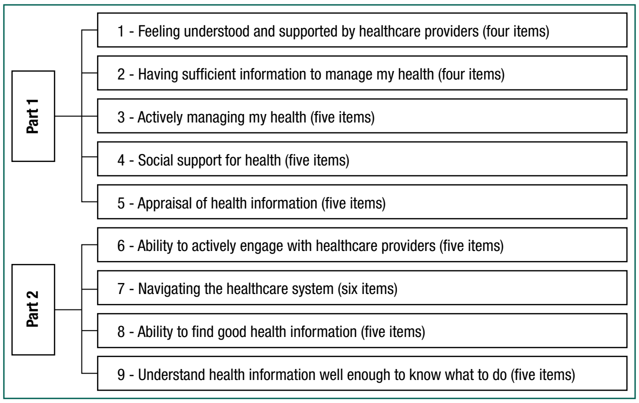
The request for authorization to use the Brazilian version of the Health Literacy Questionnaire (HLQ) was made to the Australian university (e-mail hl-info@swin.edu.au) and the authors of the Brazilian version. Participants were informed about the objectives of the study and signed an Informed Consent form.

Data collection took place at the home of users registered at the Brazilian Home Care Program during home visits performed by the multidisciplinary teams from March to June 2019.

The research team was trained for data collection. The Brazilian version of the Health Literacy Questionnaire (HLQ-Br) and a sociodemographic characterization questionnaire were used. Health literacy was the outcome variable.

The HLQ is a multidimensional instrument. It was translated to Brazilian Portuguese in 2018, validated with 794 adult users of the Brazilian SUS from three different regions of the country and called HLQ-Br. It achieved good psychometric properties in the validation process for Brazilian Portuguese.(14)

The instrument has 44 items distributed in nine scales divided into two parts,(15) as described in figure 1.



Source: Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health. 2013;13(658):1-17.(15)

Figure 1. Scales of the Health Literacy Questionnaire

Part 1 has four response options between "strongly disagree" and "strongly agree" (scores 1-4). Part 2 has five answer options between "cannot do or always difficult" and "always easy" (scores 1-5). This questionnaire does not provide an overall score, but scores with the individual mean value of the nine scales. The closest scores to the upper or lower limit indicate, respectively, the health literacy strengths and limitations of the caregiver in the care of his/her own health.(15)

The time taken to complete the HLQ varies depending on the interviewee's abilities when self-administered or orally administered.(15) In this study, the time required to apply the sociodemographic questionnaire was 3.29±1.00 minute (range 1-7), median of 3 minutes. The application of HQL-Br lasted an average of 12.67±4.38 minutes (6-29) and a median of 11 minutes.

For the participant's easier understanding of the Likert-type scale of the HLQ-Br items, the authors created a visual resource with association of different facial expressions and colors for responses of agreement/disagreement with statements, and of ease/difficulty in performing the actions (Figure 2).

The normality of data was analyzed by the Shapiro-Wilk test. The Mann Whitney test was used to compare scores with the two-level categori-

Figure 2. Visual aid to facilitate understanding of HLQ-Br responses

cal variables, while the Kruskal-Wallis test was used for variables with three or more levels.

The calculation of scores was performed by adding each item of the scales; this value was divided by the number of items in the scale and presented as the mean score.

The Cohen's d was presented to measure the effect size or difference in standard deviations between the mean scores of two groups, and considered small between 0.20 and 0.50; medium, between 0.50 and 0.80; and large, if greater than 0.80.(16) The p-value <0.05 was considered as statistical significance.

The study followed the ethical precepts in Brazil for research with human beings (CAAE 06178519.0.0000.5078).

Results

Most caregivers were female (90.0%); had a steady partner (58.89%); lived in the home of the person cared for (75.56); did not have a reading habit (57.78%); did not perform paid work (80.0%) and were informal caregivers (91.11%); had parents with nine or more years of schooling (43.33%). They attended mainly public schools (84.44%), for nine years or more (53.33%). The predominant personal income was up to one minimum wage (72.22%) and the family income was up to two minimum wages (52.22%). Caregivers were mainly children (34.44%), who had performed the role for between approximately six months and five years (45.56%).

Through descriptive analysis and analysis of the mean values of each item in scales of the HQL-Br questionnaire, limitations in health literacy were identified in terms of Actively managing my health and Sufficient information to manage my health (part 1); and Navigating the health system (part 2). The higher mean values representing the health literacy strengths were Social Support and Appraisal of health Information (part 1) and Ability to actively engage with healthcare providers, as described in table 1.

Table 1. Mean scores of the scales and items of the Health Literacy Questionnaire-Brazilian version that presented the greatest health literacy limitations and strengths of 90 caregivers of the Brazilian Home Care Program

Scales and questions of the HLQ-Br	Mean (SD)
Part 1 (Scores 1-4)	
1 - Feeling understood and supported by health providers	2.69(0.55)
Q22 - I can rely on at least one healthcare provider	2.81(0.58)
Q17 - I have the healthcare providers I need to help me work out what I need to do	2.53(0.66)
2 - Having sufficient information to manage my health	2.50(0.47)
Q01 - I feel I have good information about health	2.63(0.63)
Q10 - I have enough information to help me deal with my health problems	2.42(0.75)
3 - Actively managing my health	2.46(0.49)
Q18 - I set my own goals about health and fitness	2.76(0.66)
Q06 - I spend quite a lot of time actively managing my health	2.01(0.77)
4 - Social support for health	2.72(0.53)
Q03 - I can get access to several people who understand and support me	2.96(0.70)
Q15 - I have at least one person who can come to medical appointments with me	2.44(0.84)
5 - Appraisal of health information	2.72(0.49)
Q04 - I compare health information from different sources	2.77(0.70)
Q12 - I always compare health information from different sources and decide what is best for me	2.67(0.67)
Part 2 (Scores 1-5)	
6 - Ability to actively engage with healthcare providers	3.50(0.80)
Q20 - Ask healthcare providers questions to get the health information you need	3.86(1.07)
Q02 - Make sure that healthcare providers understand your problems properly	3.22(1.22)
7 - Navigating the healthcare system	2.84(0.89)
Q11 - Decide which healthcare provider you need to see	3.31(1.35)
Q01 - Find the right health care	2.40(1.21)
8 - Ability to find good health information	3.14(0.88)
Q14 - Get health information in words you understand	3.28(1.29)
Q18 - Get health information by yourself	2.98(1.32)
9 - Understand health information well enough to know what to do	3.39(0.81)
Q21 - Understand what healthcare providers are asking you to do	3.88(1.17)
Q17 - Read and understand all the information on medication labels	2.92(1.33)

Q - Question; SD - Standard Deviation

Tables 2 and 3 show the HLQ score patterns according to sociodemographic status. These descriptions considered, in particular, the significant differences observed in mean values and respective scales of the HLQ-Br and of the medium and large effect size. The analysis of the association and effect

Table 2. Differences evidenced in the analysis of the association between the mean scores of scales 1 to 5 of the Health Literacy Questionnaire - Brazilian version with the sociodemographic variables of 90 caregivers of the Brazilian Home Care Program

Variables (n)		Scale 1		Scale 2		Scale 5	
		Mean (S.E.)	d[1]	Mean (S.E.)	d[1]	Mean (S.E.)	d[1]
Type of caregiver	Formal (8)	3.00 (0.09)	-	2.69 (0.1)	-	3.13 (0.12)	-
	Informal (82)	2.66 (0.06)	0.62	2.48 (0.05)	0.44	2.68 (0.05)	0.93
p-value[2]		0.055		0.154		0.008	
Reading habit	No (52)	2.59 (0.08)	-	2.42 (0.07)	-	2.61 (0.07)	-
	Yes (38)	2.83 (0.07)	0.45	2.61 (0.07)	0.41	2.87 (0.08)	0.56
p-value[2]		0.030		0.077		0.004	
Caregiver's schooling	≤ 9 years (42)	2.59 (0.09)	-	2.43 (0.07)	-	2.48 (0.07)	-
	> 9 years (48)	2.78 (0.08)	0.34	2.57 (0.07)	0.30	2.93 (0.06)	1.02
p-value[2]		0.051		0.247		<0.001	
Personal income (MW)	≤ 1(65)	2.63 (0.07)	-	2.46 (0.05)	-	2.64 (0.06)	-
	> 1 (25)	2.83 (0.09)	0.36	2.62 (0.1)	0.35	2.94 (0.08)	0.63
p-value[2]		0.102		0.193		0.006	
Family income (MW)	≤ 2 (47)	2.56 (0.08)	-	2.39 (0.06)	-	2.63 (0.07)	-
	> 2 (43)	2.83 (0.08)	0.51	2.62 (0.07)	0.50	2.82 (0.07)	0.39
p-value[2]		0.022		0.037		0.114	
Parents' schooling (year)	None (33)	2.67 (0.09)	-	2.47 (0.07)	-	2.58 (0.07)	-
	≤ 9 years (13)	2.46 (0.14)	0.39	2.37 (0.11)	0.25	2.43 (0.14)	0.33
	> 9 years (39)	2.78 (0.09)	0.20	2.58 (0.08)	0.22	2.95 (0.07)	0.85
p-value[3]		0.098		0.344		<0.001	
Time as caregiver	< 6 months (18)	2.47 (0.14)	-	2.35 (0.1)	-	2.62 (0.12)	-
	6 months < 5 years (41)	2.84 (0.08)	0.70	2.62 (0.07)	0.60	2.86 (0.08)	0.48
	> 5 years (31)	2.62 (0.1)	0.26	2.44 (0.08)	0.21	2.59 (0.08)	0.06
p-value[3]		0.056		0.073		0.031	
Type of school	Public (76)	2.65 (0.06)	-	2.52 (0.05)	-	2.73 (0.05)	-
	Private (5)	3.15 (0.13)	0.92	2.55 (0.17)	0.08	2.84 (0.23)	0.27
	Both (5)	3.05 (0.05)	0.74	2.75 (0.3)	0.51	3.2 (0.33)	1.09
	None (4)	2.31 (0.4)	0.61	1.88 (0.22)	1.46	1.8 (0.29)	2.23
p-value[3]		0.029		0.056		0.007	

[1]Cohen's d; [2]Mann Whitney; [3]Kruskal-Wallis; Bold: significant values and large effect sizes; MW: minimum wage; SE: Standard Error.

Table 3. Differences evidenced in the analysis of the association between the mean scores of scales 6 to 9 of the Health Literacy Questionnaire - Brazilian version with the sociodemographic variables of 90 caregivers of the Brazilian Home Care Program

Variables (n)		Scale 6		Scale 7		Scale 8		Scale 9	
		Mean (S.E.)	d[1]	Mean (S.E.)	d[1]	Mean (S.E.)	d[1]	Mean (S.E.)	d[1]
Type of caregiver	Formal (8)	3.58 (0.23)	-	2.81 (0.29)	-	3.75 (0.26)	-	3.38 (0.17)	-
	Informal (82)	3.5 (0.09)	0.10	2.84 (0.10)	0.03	3.08 (0.10)	0.78	3.39 (0.09)	0.02
p-value[2]		0.870		0.809		0.035		0.966	
Reading habit	No (52)	3.35 (0.12)	-	2.65 (0.12)	-	2.86 (0.11)	-	3.14 (0.11)	-
	Yes (38)	3.72 (0.11)	0.48	3.1 (0.14)	0.53	3.52 (0.14)	0.80	3.72 (0.12)	0.76
p-value[2]		0.056		0.014		0.001		<0.001	
Lives with patients and family income> one wage	No (23)	3.31 (0.14)	-	2.49 (0.13)	-	3.03 (0.17)	-	3.16 (0.15)	-
	Yes (67)	3.57 (0.1)	0.32	2.96 (0.11)	0.54	3.17 (0.11)	0.15	3.47 (0.1)	0.38
p-value[2]		0.135		0.023		0.597		0.147	
Caregiver's schooling	≤ 9 years (42)	3.45 (0.14)	-	2.57 (0.13)	-	2.73 (0.12)	-	2.93 (0.11)	-
	> 9 years (48)	3.55 (0.1)	0.12	3.07 (0.13)	0.59	3.49 (0.12)	0.96	3.78 (0.1)	1.23
p-value[2]		0.877		0.004		<0.001		<0.001	
Family income (MW)	≤ 2 (47)	3.46 (0.12)	-	2.69 (0.11)	-	2.94 (0.13)	-	3.25 (0.12)	-
	> 2 (43)	3.56 (0.12)	0.13	3 (0.15)	0.35	3.35 (0.12)	0.47	3.53 (0.12)	0.35
p-value[2]		0.509		0.081		0.020		0.135	
Parents' schooling (year)	No education (38)	3.52 (0.15)	-	2.75 (0.15)	-	2.82 (0.14)	-	3.11 (0.13)	-
	≤ 9 years (13)	3.08 (0.17)	0.53	2.27 (0.12)	0.59	2.72 (0.09)	0.13	3 (0.14)	0.14
	> 9 years (39)	3.63 (0.11)	0.14	3.12 (0.14)	0.42	3.58 (0.13)	0.89	3.79 (0.12)	0.89
p-value[3]		0.064		0.003		<0.001		<0.001	
Type of school	Public (76)	3.47 (0.09)	-	2.77 (0.10)	-	3.12 (0.09)	-	3.37 (0.09)	-
	Private (5)	3.72 (0.4)	0.31	3.47 (0.47)	0.81	3.56 (0.43)	0.53	4.04 (0.39)	0.85
	Both (5)	3.84 (0.38)	0.46	3.67 (0.37)	1.06	4.04 (0.23)	1.14	3.8 (0.34)	0.55
	Did not attend (4)	3.4 (0.42)	0.09	2.34 (0.43)	0.51	1.75 (0.36)	1.68	2.3 (0.10)	1.41
p-value[3]		0.610		0.077		0.003		0.010	

[1]Cohen's d; [2] Mann Whitney; [3] Kruskal-Wallis; Bold: significant values and large effect sizes; MW: minimum wage; SE: Standard Error

size between the mean scores of scales 1 to 5 (Part 1) of the HLQ-Br are described in table 2, and between the mean scores of scales 6 to 9 (Part 2) are described in table 3.

Differences in HLQ mean scores were identified considering subgroups in terms of the type of caregiver, reading habits, schooling of the caregiver and parents, personal and family income, time as a caregiver.

The health literacy limitations identified for "Feeling understood and supported by health providers" (Part 1) were evidenced in informal caregivers with family income of less than two minimum wages, who had no reading habit, with less than nine years of schooling and who had never attended any kind of school.

In terms of "Having sufficient information to manage my health" (Part 1), the limitations were among caregivers with a family income of less than two minimum wages and who did not study. As for "Appraisal of health information" (Part 1), lower scores were observed among informal caregivers; who did not have the habit of reading; schooling of caregiver and parents of less than or equal to nine years; personal income of less than or equal to a minimum wage, who took care of their patients for more than five years and had never attended any type of school.

Regarding the "Ability to actively engage with healthcare providers" (Part 2), limitations were observed in caregivers who did not have a reading habit. In relation to "Navigating the healthcare system" (Part 2), the lower mean values were associated with caregivers and their parents who had less than or equal to nine years of schooling and who did not have the habit of reading.

As for "Ability to find good health information" (Part 2), the lower mean values were related to being an informal caregiver, not having a reading habit, family income of less than or equal to two minimum wages, schooling of caregiver and parents inferior or equal to nine years and not having attended school. Literacy in terms of "Understand health information well enough to know what to do" (Part 2) was limited to those who do not have the habit of reading, schooling of caregiver and parents under nine years and caregivers who did not attend any type of school.

Discussion

To the authors' knowledge, this is the first study conducted in the world that analyzed the health literacy conditions of home caregivers using a multidimensional assessment instrument. By using the HLQ-Br, it was possible to map the health literacy needs of individuals or groups of individuals,(17) and this proved to be a highly reliable instrument with adequate psychometric properties, just as it occurred in other countries where it was validated.(18,19)

By recognizing the essential role of informal caregivers in health and in the care outcome of their patients, the present study showed that their performance was weak in the responses to all scales of the questionnaire applied. Limited health literacy affects the proper care provision and the health outcomes of beneficiaries.(11)

The practice of self-care among caregivers is also a major problem. Caregivers often become intensely involved in the care, and consequently, forget about their own health needs, which has a negative impact on their physical, psychological and financial status.(20)

The lack of guidance and social support exposes caregivers to a great burden of stress and overload that can affect their health, wellbeing and quality of life.(20) Confirming literature data about caregivers, the little time they spend on care of their own health indicates that study participants may be suffering physical and emotional burden given the high demand for time to care for others.(21,22)

On the other hand, the social support referred to, as well as the ability to understand health information and understand health professionals' requests were positive factors in this group of caregivers. Interaction with healthcare providers can promote understanding. According to a study, the ability to find, understand and use health information is an important skill for caregivers,(23) as they also need to seek, access and understand health information on behalf of the patients they care for.(24)

This positive result differs from the study that mentions the lack of communication with health professionals as a result of the caregiver's difficulty in understanding the medical language and feeling overwhelmed with the amount and type of information provided.(25)

The following were reported: communication problems between caregivers and professionals related to the lack of privacy with health professionals during conversations and the lack of attention to caregivers' wellbeing;(26) lack of accurate information from professionals;(25) and insecurity resulting from the poor communication regarding the care provided.(27) Thus, communication is clearly a psychosocial barrier to care and behavioral changes are necessary to navigate the health system, identify and achieve health goals.

Healthcare professionals must facilitate the process of communication, management and decision-making in the health of populations. According to the literature, although caregivers have cited health professionals as their preferred source of information,(28) other authors have shown the challenges faced by caregivers in accessing health information in health settings. Caregivers feel the need to express their concerns without the presence of the patient and do not receive the due importance from professionals during consultations,(29) in addition to the lack of recognition of the care role.(30)

The variable schooling of caregivers and their parents can be understood as a potential limitation or strength in health management and health literacy outcomes. The higher education level of interviewed caregivers had a positive influence on score performance, as in other studies(13,31), reaffirming that it can improve people's ability to respond to their health problems.(32)

As it is not possible to intervene immediately in people's education, the reorientation of effective public strategies towards the optimization of health outcomes should involve a combined effort to improve communication between professionals, the health system and its users(33) and provide health information, so caregivers are prepared in advance to take over direct functions of care for others in health.(34)

The lower personal and family income of the interviewed caregivers contributed to limitations in health literacy. Other studies also corroborate these results, confirming that low income leads to greater difficulties in receiving health information and accessing services.(35)

No studies analyzing the reading variable associated with health literacy were found. The reading habit was assessed to check that they understood health information and, from that, could make assertive decisions, remembering that the health literacy concept is not restricted to basic functional skills, such as reading. It is important to be able to read, but also understand the information for a better involvement in the care with health.(36)

Conclusion

Caregivers' income, education and reading habits influenced most scales of the HLQ-Br. The results indicate that the health literacy conditions investigated were limited by the schooling of caregivers and their parents, the low income, the infrequent reading habit, the fact of being an informal caregiver and less time as a caregiver. However, health literacy conditions were favored by caregivers' access to people who understand and support them, and by the fact of understanding health professionals' requests, understanding health information and knowing what to do. As a public policy, the proposal that care is better at home should guarantee access and continuity of care, as it is the responsibility of services, even if they occur at home. Health literacy is a product of the ability of individuals, but also of the investment of public health services in ways of learning and teaching in health for a better provision of services and the consequent outcome. By right, health needs require qualified listening, understanding, access to the solution of the identified problems and bonds of reference and trust with members of the health team. Thus, users will participate in the process of taking care of themselves and the other. It is necessary to go beyond the ability to read and understand texts by understanding health literacy as the ability to act.

Acknowledgements

We thank the Coordination for the Improvement of Higher Education Personnel (Portuguese acronym CAPES; Master's scholarship granted for Thales Antônio Martins Soares) for the financial support.

Collaborations

Soares TAM, Brasil VV, Moraes KL, Santos LTZ, Vila VSC and Borges-Júnior LH collaborated with the project design, analysis and interpretation of data, writing of the article, relevant critical review of the intellectual content and final approval of the version to be published.

References

1. World Health Organization (WHO); Division of Health Promotion, Education and Communications, Health Education and Health Promotion Unit. Health promotion glossary. Geneva: WHO; 1988.
2. Batterham RW, Hawkins M, Collins PA, Buchbinder R, Osborne RH. Health literacy: applying current concepts to improve health services and reduce health inequalities. Public Health. 2016;132(1):3–12.
3. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. 2011;155(2):97–107.
4. Cajita MI, Cajita TR, Han HR. Health literacy and heart failure: a systematic review. J Cardiovasc Nurs. 2016;31(2):121–30.
5. Institute of Medicine (IOM). Health literacy: improving health, health systems, and health policy around the world: workshop summary. Washington: National Academy of Sciences; 2013.
6. Jessup RL, Osborne RH, Beauchamp A, Bourne A, Buchbinder R. Health literacy of recently hospitalised patients: a cross-sectional survey using the Health Literacy Questionnaire (HLQ). BMC Health Serv Res. 2017 Jan 19;17(1):52.
7. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde, Departamento de Atenção Básica. Melhor em Casa. A segurança do hospital no conforto do seu lar. Brasília (DF): Ministério da Saúde; 2012.
8. Fields B, Rodakowski J, James AE, Beach S. Caregiver health literacy predicting healthcare communication and system navigation difficulty. Fam Syst Health. 2018;36(4):482–92.
9. Creary S, Adan I, Stanek J, O'Brien SH, Chisolm DJ, Jeffries T, et al. Sickle cell trait knowledge and health literacy in caregivers who receive in-person sickle cell trait education. Mol Genet Genomic Med. 2017;5(6):692–9.
10. Metin S, Demirci H, Metin AT. Effect of health literacy of caregivers on survival rates of patients under palliative care. Scand J Caring Sci. 2019;33(3):669–76.
11. Yuen EYN, Knight T, Ricciardelli LA, Burney S. Health literacy of caregivers of adult care recipients: A systematic scoping review. Health Soc Care Community. 2018;26(2):e191-e206.
12. Brasil. Ministério da Saúde. Atenção Domiciliar. Portaria Nº 825, de 25 de Abril de 2016. Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS) e atualiza as equipes habilitadas. Brasília(DF): Ministério da Saúde; 2016.
13. Bonaccorsi G, Pieralli F, Innocenti M, Milani C, Del Riccio M, Donzellini M, et al. Health literacy among non-familial caregivers of older adults: a study conducted in Tuscany (Italy). Int J Environ Res Public Health. 2019;16(19):1–12.
14. Moraes KL, Brasil VV, Mialhe FL, Sampaio HA, Sousa AL, Canhestro MR. Validation of the Health Literacy Questionnaire (HLQ) to Brazilian Portuguese (prelo). Acta Paul Enferm. 2020;34(1).
15. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health. 2013;13(658):658.
16. Cohen J. Statistical power analysis for the behavioral sciences. 2nd ed. Hillsdale (New Jersey): Lawrence Erlbaum Associates; 1998. 680p.
17. Beauchamp A, Batterham RW, Dodson S, Astbury B, Elsworth GR, McPhee C, et al. Systematic development and implementation of interventions to optimise health literacy and access (Ophelia). BMC Public Health. 2017;17(1):230.
18. Nolte S, Osborne RH, Dwinger S, Elsworth GR, Conrad ML, Rose M, et al. German translation, cultural adaptation, and validation of the Health Literacy Questionnaire (HLQ). PLoS One. 2017;12(2):e0172340.
19. Kolarcik P, Cepova E, Madarasova Geckova A, Elsworth GR, Batterham RW, Osborne RH. Structural properties and psychometric improvements of the Health Literacy Questionnaire in a Slovak population. Int J Public Health. 2017;62(5):591–604.
20. Jesus IT, Orlandi AA, Zazzett MS. Sobrecarga, perfil e cuidado: cuidadores de idosos em vulnerabilidade social. Rev Bras Geriatr Gerontol. 2018;21(2):199–209.
21. Wittenberg E, Goldsmith J, Ferrell B, Ragan SL. Promoting improved family caregiver health literacy: evaluation of caregiver communication resources. Psychooncology. 2017;26(7):935–42.
22. Cruz MÉ, Silva DV, Carmo JR, Araújo GD, Camisasca LR, Pereira FA, et al. Burden of caregivers of patients under home care. Rev Enferm UFPE On line. 2020;14: e244235
23. Costa TF, Costa KN, Martins KP, Fernandes MG, Brito SS. Sobrecarga de cuidadores familiares de idosos com acidente vascular encefálico. Esc Anna Nery. 2015;19(2):350–5.
24. Smith PD, Martin B, Chewning B, Hafez S, Leege E, Renken J, et al. Improving health care communication for caregivers: A pilot study. Gerontol Geriatr Educ. 2018;39(4):433–44.
25. Robinson J, Gott M, Ingleton C. Patient and family experiences of palliative care in hospital: what do we know? An integrative review. Palliat Med. 2014;28(1):18–33.
26. Lund L, Ross L, Petersen MA, Groenvold M. The interaction between informal cancer caregivers and health care professionals: a survey of caregivers' experiences of problems and unmet needs. Support Care Cancer. 2015;23(6):1719–33.
27. Caswell G, Pollock K, Harwood R, Porock D. Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study. BMC Palliat Care. 2015;14(35):35.
28. Tunin R, Uziely B, Woloski-Wruble AC. First degree relatives of women with breast cancer: who's providing information and support and who'd they prefer. Psychooncology. 2010;19(4):423–30.

29. Swetenham K, Tieman J, Butow P, Currow D. Communication differences when patients and caregivers are seen separately or together. Int J Palliat Nurs. 2015;21(11):557–63.

30. Williams AL, Bakitas M. Cancer family caregivers: a new direction for interventions. J Palliat Med. 2012;15(7):775–83.

31. de Almeida KM, Toye C, Silveira LV, Slatyer S, Hill K, Jacinto AF. Assessment of functional health literacy in Brazilian carers of older people. Dement Neuropsychol. 2019;13(2):180–6.

32. Dodson S, Osicka T, Huang L, McMahon LP, Roberts MA. Multifaceted assessment of health literacy in people receiving dialysis: associations with psychological stress and quality of life. J Health Commun. 2016;21 Supl 2:91–8.

33. Passamai MP, Sampaio HA, Dias AM, Cabral LA. Letramento funcional em saúde: reflexões e conceitos sobre seu impacto na interação entre usuários, profissionais e sistema de saúde. Interface Comun Saude Educ. 2012;16(41):301–14.

34. Jiang Y, Sereika SM, Lingler JH, Tamres LK, Erlen JA. Health literacy and its correlates in informal caregivers of adults with memory loss. Geriatr Nurs. 2018;39(3):285–91.

35. Campos AA, Neves FS, Saldanha RF, Duque KC, Guerra MR, Leite IC, et al. Fatores associados ao letramento funcional em saúde de mulheres atendidas pela Estratégia de Saúde da Família. Cad Saude Colet. 2020;28(1):66–76.

36. Jindal P, MacDermid JC. Assessing reading levels of health information: uses and limitations of flesch formula. Educ Health (Abingdon). 2017;30(1):84–8.