


# Predictors of Health Literacy among Caregivers of Patients with Multiple Sclerosis: A Family-Centred Empowerment Approach

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## Abstract

With regards to the importance of multiple sclerosis (MS) and the sufferers' caregivers, and also by focusing on the importance of identifying factors influencing health literacy based on theoretical principles, it is necessary to detect the most effective factors involved in forming these direct or indirect effects. This study aimed to determine the relationship between health literacy and self-efficacy, and knowledge among caregivers of individuals with MS in Iran. One hundred and twenty caregivers of individuals with MS participated in this cross-sectional study. Data were collected through TOFHLA health literacy. Data were analysed using SPSS with independent *t*-tests, Pearson correlation and linear regression. More than 80 per cent of the participants had border and insufficient health literacy. Statistically, there was a significant relationship between health literacy level and self-efficacy, income source, economic situation and education.

The results showed that for every 1 score increase in knowledge, self-efficacy, self-esteem and health literacy increased by 2.17, 0.62 and 2.71, respectively. Considering that there is a significant relationship between health literacy, self-efficacy and the knowledge of caregivers of people with MS, which plays a role in caring for patients, effective strategies should be developed in order to promote health literacy and consequently, the individuals' self-efficacy.

**Keywords:** family empowerment, health care, health literacy, health promotion, multiple sclerosis, self-efficacy

*Accepted: June 2022*

## Introduction

Multiple sclerosis (MS) is a common promotable disabling disease of the central nervous system in young adults (Scolding *et al.*, 2015). The most important symptoms related to this disease are visual disturbance, walking problems, sense disturbance, centralisation disturbance, non-balancing and heart and vessel control disturbance, physical weakness, fatigue, minor disability and spasm (Neal *et al.*, 2017). MS cannot be absolutely cured; thus, the main purpose of MS treatment is to prevent progression of the disease (Lublin *et al.*, 2014). Since chronic diseases like MS affect all aspects of the individual, family and the society, medical treatment and monitoring of those suffering from the disease cannot just be enough (Dendrou *et al.*, 2015).

With regards to the widespread developments, high death rate, high expenses and immense problems encountered in medicine-curing, the use of some non-medicine methods that can reduce MS problems and promote MS sufferers' performance level, would be reasonable. With the obtained advancement in solving health problems, family caregivers are replaced with the care institutions (George and Gwyther, 1986). The family as a care source is considered as an interesting and concern-related subject for the health caregivers. The caregivers are a group of individuals who are depressed on account of high pressures and demands. Caring for a sufferer creates much tension for the caregiver and his/her family (Kobelt *et al.*, 2006). The caregivers are especially vulnerable to tension because the sufferer's biological and neuro-social demands exceed their needs (Ayar *et al.*, 2021). These people do not have enough knowledge and skill, and this reduces motivation in using the prevention methods; thus, a non-complete circle is created, which leads to appropriate non-prevention (Oldenkamp *et al.*, 2016).

Health literacy is related to the individual's capabilities to acquire, process and discern the information and health services needed to make

proper health decisions (Sany *et al.*, 2019). Health literacy includes being able to discern the direction of transcribed medicines, medical education brochures, satisfaction-letter sheet, utilising the medical sophisticated system, reading and listening to skills, analysing, decision-making and using these skills in health situations (Olyani and Peyman, 2021). Three decades after the creation of health literacy concept, many researches have been conducted in order to answer the question: how does health literacy affect the individual's health (Smith *et al.*, 2009)?

Among health education models, the caregivers are very important in family-centred empowerment model. This pattern emphasises on self-esteem and self-efficacy. Having self-esteem together with a sense of self-worth is like a capital and a vital value, and is one of the major factors in the flourishing of talent and creativity in individuals. In other words, cognitive processes, emotions, motivation, decision-making and choice are influenced by a sense of value (Bamm and Rosenbaum, 2008).

Self-esteem is a personal judgement about the value of a person who is present in the form of mental experience. It is transmitted through verbal and non-verbal behaviours. Since low self-esteem in chronic diseases has an adverse effect on interpersonal relationships, thoughts, feelings and performance of patients, it is important to consider it as a key point (Yasfard *et al.*, 2019).

Empowerment enhances the participation of community members and organises them to create environmental changes, so that they can develop their problem-solving strategies, and in such a society, one believes that he/she is able to make a change (Olyani *et al.*, 2021).

Self-efficacy means one's judgement of his ability to carry out an action that can enable him/her to adopt health-promoting behaviours and to leave behaviours harmful to health (Vahedian *et al.*, 2013). Self-efficacy can be influenced by health literacy. Inadequate knowledge on a special health problem may affect people's self-efficacy and their abilities to cope better with the caring programme (Chen *et al.*, 2013). Bandura (2006) defined self-efficacy as a determining factor in behavioural change because it can affect the individual's choice in the various behavioural levels. Moreover, it helps the individual to make more attempts to perform an act completely and to promote resistance to the problems and blockages. Self-efficacy promotion can prepare the caregivers to face life challenges and, subsequently, reduce caring consequences (Masoudi *et al.*, 2011).

Therefore, with regards to the importance of MS and the sufferers' caregivers, and also by focusing on the importance of identifying factors influencing health literacy based on theoretical principles, it is necessary to detect the most effective factors involved in forming these direct or indirect effects, so that effective educational interventions can be designed and planned. The purpose of this study is to investigate the

predictive factors of health literacy among sufferer's caregivers based on family-centred empowerment model.

## **Methods**

### **Design**

In this correlation descriptive study, which was carried out in 2017, in Bojnord City, Iran, 120 caregivers of MS sufferers were included. In this study, all the caregivers of people with MS who met the criteria of entering the study were selected. To obtain samples for this research, those who were registered in MS association and one of the neuro-brain clinics located in the city (having the highest number of MS patients) were used after obtaining informed consent from them and their caregivers.

The inclusion criteria of this study for the caregivers are: living with the sufferer, capability of decision-making relating to the sufferer's treatment and medicine, and daily responsibility of caring for the sufferer. The exclusion criteria of this study are: disease background like neurotic disturbance, cognitive disturbances, addiction to drugs and other neurotic substances, and also, not willing to continue with the study.

### **Instruments**

To collect the necessary data, questionnaire on demographic information, Test of Functional Health Literacy in Adults (TOFHLA) health literacy, caregiver's self-efficacy, caregiver's knowledge and Rosenberg self-esteem questionnaire were used.

The TOFHLA questionnaire includes two parts: numerical perception and reading comprehension. The reading comprehension part evaluates the patient's ability to read and understand the text. These texts refer to the guidelines for preparing upper gastrointestinal imaging, the rights and responsibilities of patients in insurance and the standard forms of hospital consent. The individual score in this section is considered to be between 0 and 50. The numerical comprehension part evaluates the individual's ability to understand and act based on the physician's order, needing calculation. This part includes ten explanations or health recipes in the field of prescribed drugs, physician referral times, phases of using donations and an example of the medical outcome. The individual score in this part is between 0 and 50. This part contains seventeen questions. Among the total scores of these two parts, the total health literacy score, which is a number between 0 and 100, was obtained. The scores between 0 and 59 are considered as inadequate health literacy, 60 and 74 are considered as the border health literacy and 74 and 100 as sufficient health

literacy. [Tehrani Banihashemi et al. \(2007\)](#) confirmed the validity and reliability of this questionnaire for Iranian society.

The questionnaire on caregivers' self-efficacy contains sixteen questions which are grouped into three alternatives including completely, approximately and at all, with the points of 0, 1 and 2, respectively, and was calculated by Cronbach's Alpha of about 0.8. This questionnaire evaluates self-efficacy in the field of nutrition, medications, appropriate exercises and caregiver's relationships with patient and the ability to obtain information.

The self-efficacy questionnaire is driven from the study conducted by [Karimi Mouneghi et al.](#), and by using the test-retest method they confirmed the validity and reliability of this test for the Iranian society ([Karimi Mouneghi and Hares Abadi, 2009](#)). The questionnaire measures self-efficacy in the field of nutrition, medications, patient's appropriate sports, caregiver's relationships with the patient, and the ability to obtain information.

The questionnaire on caregiver's knowledge was obtained from [Vahedian-Azimi et al.'s \(2015\)](#) study which was designed for measuring the degree of the caregiver's knowledge on MS sufferers, and includes twelve questions grouped into two alternatives: true and false, ranking from 0 to 1. The Cronbach's alpha of this questionnaire was 0.72.

The Rosenberg Self-Esteem Questionnaire also contains ten general phrases that answer the questions based on the scale of the two options of I agree and I disagree ([Greenberger et al., 2003](#)).

The reliability and validity of Self-Esteem Questionnaire have been measured by several studies. Among the results of the researches, [Greenberger, Drmitrieva, Farruggia and Chen](#) results showed the internal consistency of this scale to be 0.84; and [Pullmann and Allik \(2000\)](#) reported 0.91. In addition, [Mohammadi and Sajjadinejad](#) reported the coefficients of Cronbach's alpha and examined two semi-structured Rosenberg scale on the students of Shiraz University (0.69 and 0.68, respectively). Furthermore, the re-evaluation coefficients of the above scale were reported to be 0.77, 0.73 and 0.78 ([Mohammadi and Sajadinejad, 2006](#)).

## Analysis

Data analysis was performed using descriptive statistics (frequency, percentage, mean and standard deviation) and inferential statistics (independent *t*-test, Pearson correlation coefficient and one-way Analysis of variance) at a significance level of 0.05. To determine the effect of self-efficacy, self-esteem and knowledge, and some demographic variables on public health literacy, a general linear regression was used.

## Ethics approval and consent to participate

The present study was approved by the ethics committee of the Mashhad University of Medical Sciences (IR.MUMS.REC.1396.107). Written informed consents were obtained from all the study participants. Moreover, they were assured that all the information would be kept confidential and would not be revealed unless for research purposes and in an anonymous form. Participants were allowed to withdraw at any stage of the research. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee with the 1964 Helsinki declaration.

## Results

In this study, 120 active MS sufferers' family members participated; 71.7 per cent (86) were women and 49.2 per cent of the caregivers were employed (Table 1).

The participants' mean age was  $40.9 \pm 8.3$ . The mean of health literacy level was  $62.2 \pm 14.2$ ; thus, 14.2 per cent had enough health literacy, 47.5 per cent had average health literacy, and 38.3 per cent had inadequate health literacy. The mean score of self-efficacies was  $16.9 \pm 35$  and the mean score of knowledge for the active members of the family was  $12.8 \pm 2.1$ . The mean of self-esteem was  $8.26 \pm 1.35$  (Table 1).

All the variables follow a normal distribution except knowledge and self-esteem. The correlation test on the relationship between age and health literacy, and knowledge and self-efficacy did not show a significant relationship. The variance analysis test demonstrated a significant relationship between the health literacy level with the income source and education ( $P < 0.05$ ).

Independent *t*-test showed a significant relationship between marital status and health literacy. Also, there was a significant relationship among self-efficacy with gender, income source, economic status and education ( $P < 0.05$ ) (Table 1).

As shown in Table 2, health literacy had a positive and significant correlation with knowledge ( $r_s = 0.582$  and  $P < 0.0001$ ). Health literacy was positively correlated with self-esteem and self-efficacy but not significant.

Table 3 shows correlation between the dimensions of the family-centric empowerment model. Knowledge and self-esteem had the highest correlation ( $r_s = 0.991$  and  $P < 0.001$ ). There was a positive correlation between knowledge and self-efficacy, but it was not significant ( $r_s = 0.095$  and  $P = 0.302$ ).

After determining the relationship and correlation between the studied variables, to determine the impact of dimensions of the family-centred empowerment model on caregivers' prediction of literacy with MS,

Table 1. Demographic characteristics among caregivers of patients with MS and its relation with health literacy, self-efficacy, knowledge and self-esteem

Variable	Number	Per cent	Health literacy		Self-efficacy		Knowledge		Self-esteem	
			M±SD	Test result	M±SD	Test result	M (IQR)	Test result	M (IQR)	Test result
Sex										
Female	86	71.7	64.2 ± 12.3	P = 0.762	16.91 ± 3.7	P = 0.828	13(3)	P = 0.002*	9(1)	P = 0.122
Male	34	28.3	65.2 ± 18.05	t = -0.305	17.08 ± 4.16	t = -0.218	13(3.25)	Z = -2.253	8(2)	Z = -1.547
Age categories, years										
20-30	13	10.8	62.6 ± 25.9	P = 0.956	18 ± 4.47	P = 0.576	13(3.5)	P = 0.14	8(2)	P = 0.161
31-40	45	37.5	64.4 ± 11.04	F = 0.107	16.4 ± 3.45	F = 0.664	12(2)	X <sup>2</sup> = 3.93	8(1)	X <sup>2</sup> = 3.653
41-50	48	40.0	65.1 ± 12.99		17.04 ± 4.21		13(3)		9(1)	
51-60	14	11.7	64.4 ± 13.1		17.4 ± 2.92		12(4)		9(2.5)	
Employment status										
Housewife	47	39.2	63.4 ± 12.59	P = 0.805	15.9 ± 3.69	P = 0.020*	13(3)	P = 0.776	8(1)	P = 0.419
Employed	59	49.2	65.2 ± 15.91	F = 0.217	17.9 ± 3.91	F = 4.049	13(3)	X <sup>2</sup> = 0.533	8(2)	X <sup>2</sup> = 1.738
Others (retired, break down, pensioner)	14	11.7	64.8 ± 11.05		16.9 ± 2.91		14(2.5)		9(1.25)	
Marital status										
Married	107	89.2	65.4 ± 12.49	P = 0.044*	16.91 ± 3.88	P = 0.677	12(2.5)	P = 0.04*	8(2)	P = 0.969
Single	13	10.8	57.07 ± 22.91	t = -2.037	17.38 ± 3.37	t = -0.416	13(2)	Z = -1.96	8(1)	X <sup>2</sup> = 0.39
Source of income										
My own rights	47	38.1	64.7 ± 16.56	P = 0.04*	18.4 ± 4.22	P = 0.007*	13(3)	P = 0.036*	9(1)	P = 0.327
Family	63	53.4	62.6 ± 11.46	F = 3.091	16.2 ± 2.84	F = 5.243	13(2)	X <sup>2</sup> = 6.651	8(1)	X <sup>2</sup> = 2.235
Others (Pensioner, etc.)	10	8.5	64.4 ± 14.19		16.1 ± 5.42		14.5(3.25)		7.5(4)	
The economic situation										
Good	14	11.7	64.7 ± 23.42	P = 0.911	20.07 ± 5.07	P = 0.003*	13(2.5)	P = 0.677	8(2)	P = 0.722
Medium	68	56.7	64.02 ± 12.93	F = 0.094	16.8 ± 3.44	F = 6.115	13(3)	X <sup>2</sup> = 0.779	8(9)	X <sup>2</sup> = 0.635
Poor	38	31.7	65.26 ± 11.94		16.1 ± 3.47		13(3)		9(1.25)	
Education										
Elementary and cycle	41	34.2	64.9 ± 13.35	P = 0.1	16.6 ± 2.98	P = 0.008*	13(2.5)	P = 0.62	9(1)	P = 0.492
Diploma and Associate Degree	64	53.5	62.6 ± 12.83	F = 2.334	16.5 ± 3.92	F = 5.24	13(2.75)	X <sup>2</sup> = 0.956	8(2)	X <sup>2</sup> = 1.419
BS and Masters	15	12.5	71.2 ± 19.34		19.8 ± 4.92		14(4)		9(1)	
Relationship										
Parents	14	11.6	67.4 ± 16.9	P = 0.301	18.4 ± 3.99	P = 0.444	12(5.5)	P = 0.171	9(2.25)	P = 0.093
Siblings	8	6.7	61.2 ± 27.23	F = 1.233	17.5 ± 3.92	F = 0.9	13(1)	X <sup>2</sup> = 5.01	9(1)	X <sup>2</sup> = 6.42
Spouse	95	79.2	64.7 ± 11.6		16.6 ± 3.82		13(2)		8(1.5)	
Child	3	2.5	64.5 ± 14.09		17.3 ± 2.81		10		8	

**Table 2.** Correlation between the constructs of the family-centred empowerment and health literacy

Variables	Correlation coefficient	P-value
Self-efficacy	$r = 0.085^*$	0.354
Self-esteem	$r_s = 0.137^*$	0.134
Knowledge	$r_s = 0.582^*$	<0.001

\* $r$ : Pearson.**Table 3.** Correlation between the constructs of the family-centred empowerment model

Variables	Self-efficacy $r_s^*$ (P)	Self-esteem $r_s^*$ (P)	Knowledge $r_s^*$ (P)
Self-efficacy	1	–	–
Self-esteem	–0.131 (0.153)	1	–
Knowledge	0.095 (0.302)	0.991 (<0.001)	1

\* $r_s$ : Pearson.**Table 4.** Linear regression of family-centred empowerment model structures on health literacy

Dependent variable	Independent variable	Standard beta	Significant	$R^2$
Health literacy	Self-efficacy	0.178	0.009	0.256
	Self-esteem	0.216	0.031	
	Knowledge	0.447	<0.001	

the linear regression model was used simultaneously. Table 4 shows the results of this test. According to the findings, dimensions of family-centred empowerment model in 25.6 per cent of health literacy variance among caregivers of patients with MS are justified by the above variables; in this regard, all dimensions had a significant effect ( $P < 0.05$ ).

In order to study the effect of demographic variables on health literacy among demographic variables, those whose relationship or correlation with the total literacy rate was less than 0.15 ( $P < 0.15$ ) entered the general linear model. According to the results shown in Table 5, the variables totally predicted 34.3 per cent of variance in health literacy, and among them, self-esteem, knowledge, source of income and education had a significant effect on literacy ( $P < 0.05$ ).

The results of this test showed that for every 1 score increase in knowledge, self-efficacy, self-esteem and health literacy increased by 2.17, 0.62 and 2.71, respectively. Furthermore, the score of health literacy in married individuals was 5.90 higher than that of single individuals.



**Table 5.** Linear regression for effect of constructs of the family-centred empowerment on health literacy

Dependent variable	Independent variable	Beta	SE	t	Sig.	
Health literacy	Knowledge	2.176	4.567	4.567	<0.001*	
	Self-efficacy	0.62	1.914	1.914	0.058	
	Self-esteem	2.719	3.134	3.134	0.002*	
	Marital status	Married	5.901	1.588	3.715	0.115
		Single	0 <sup>a</sup>	—	—	—
	Source of income	My own rights	-11.524	4.612	-2.498	0.014*
		Family	-11.563	4.344	-2.662	0.009*
		Others (Pensioner, etc.)	0 <sup>a</sup>	—	—	—
	Education	Elementary and cycle	-6.798	3.832	-1.744	0.79
		Diploma and Associate Degree	-8.43	3.653	-2.308	0.023*
		BS and Masters	0 <sup>a</sup>	—	—	—

"a" is considered as a reference and significance shown with \*.

Discussion and conclusion

The purpose of this study is to investigate predictors of health literacy among caregivers of patients with MS based on family-centred empowerment model. The results of this research showed that >80 per cent of the participants did not have enough health literacy. However, due to the need for the ability to care skills and transfer information to patients, health literacy in this group is doubly important. According to a study conducted by [Tehrani Banihashemi et al. \(2007\)](#) in five cities of Iran, health literacy is generally low. Also, a study conducted on adults of Toiserkan using questionnaire on Iranian health literacy demonstrated that access to information was average, perceiving the information was weak, assessment was average and finally, using the information was average ([Afshari et al., 2014](#)).

The results of this study did not show a significant relationship between age and health literacy, and this is not in line with the study of [Eslami et al. \(2022\)](#) and [Reisi et al. \(2012\)](#). In this case, the researcher attributed this to the samples' difference. There was a significant relationship between education and health literacy. Based on [Tehrani Banihashemi et al.'s \(2007\)](#) study, educational level had the strongest relationship with health literacy level.

There was a significant difference between the mean literacy scores and marital status, and literacy in married individuals was higher than that in single individuals. [Tehrani et al. \(2007\)](#) found a relationship between marriage and literacy.

This can be due to the fact that married caregivers feel more responsive to their husbands than the singles and have more dealing with such forms; thus, they are quicker to read these forms. Moreover, there was a statistically significant difference between the mean literacy rate and

source of income; thus, literacy in people whose source of income is their own salary was higher as compared to other people.

In this study, there was no significant relationship between health literacy and gender, which is in line with the study of Mosher's *et al.* (2012). In this research, there was a significant relationship between self-efficacy and education which agrees with the studies of Rafiezadeh Gharrehtapeh *et al.* (2015) and Khezeerloo's and Feizi (2012). With increase in the educational level of the people, the level of their beliefs on self-efficacy is increased. In this study, there was a significant relationship between job and self-efficacy, which agrees with the study of Fekrizadeh *et al.* (2014).

Knowledge score in male caregivers was higher than that in women. According to the researcher, this difference is due to the fact that the males have more than diploma degree as compared to the females. In addition, there was a significant difference between the mean score of knowledge and marital status; thus, the mean scores of this dimension were higher in the married individuals. Education in married individuals was higher than in the single ones; and this higher literacy rate resulted in the promotion of knowledge in the married individuals in comparison with the singles.

There was a significant difference between the mean score of self-efficacy and employment status; thus, self-efficacy rate in the employed individuals was higher than in the others. Heidari *et al.* (2016) also concluded that self-efficacy has a positive and significant relationship with employment status. The employment status has an effective impact on the individual's view on self-efficacy because unemployment negatively affects the mental status of individuals and perception of their abilities. Individuals, due to having inappropriate job, use the blaming method, which leads to lower self-efficacy.

In addition, the results also showed that there was a significant difference between the mean self-efficacy score and the source of income, thus, caregivers with a good economic situation had higher self-efficacy than others. Based on the results of Bastani *et al.* (2015) on caregivers of those ageing with Alzheimer, public self-efficacy had a significant relationship with the economic situation. Furthermore, families with low income often have limited resources and problems in controlling and/or changing stressful factors associated with their environment. Wadsworth and Compas (2002) reported that economic stress not only affects family relationships but also restricts compliance with tension and leads to psychological problems among family members.

It seems that with reduction in household income levels, caregivers have less access to supportive resources, medical and counselling services, and have less power to pay for the treatment costs. Perhaps, these factors have made caregivers with poor economic conditions to tolerate

more stress when caring for their patients and take care of their patients undesirably, and as a result, they feel less self-efficacy.

In addition, there was a significant relationship between the mean of self-efficacy score and education; thus, people with educational level higher than bachelor's degree had more self-efficacy than the others. The results of Rafiezadeh *et al.* (2015) and Khezerloo and Feizi (2012) also suggest a statistically significant relationship between self-efficacy and education. It seems that higher self-efficacy in educated people is probably due to the fact that these people have access to more information sources. Their greater knowledge leads to their better caring for patients, and as a result, having higher self-efficacy.

In this study, there was a significant and positive correlation between health literacy and self-efficacy which is in agreement with the result of Hojati and Abbasi (2013). In contrast to the results obtained in this research and other studies, the result of Chen *et al.* (2013) showed that there was no significant relationship between heart patients' health literacy level and their self-efficacy in following self-efficacy behaviours. In this study, there was a significant relationship among knowledge, gender and education. Also, there was a correlation between knowledge and health literacy. According to Khadem-Rezaeian *et al.* (2016), there was a significant relationship between knowledge level and responding to questions on particular fields. Furthermore, based on Mahmoudi and Taheri's (2015) study, there was a positive and significant relationship between health literacy and informational literacy.

In this study, there was a significant and positive correlation between self-efficacy and knowledge. According to Silver and Wellman (2002), if the caregiver knows the care giving principles better, he/she will be far from social isolation, addiction and other dangers. Therefore, his/her self-esteem is provided. Thus, high self-esteem increases the sense of one's self-efficacy and it motivates one to give better care.

One of the limitations of this study was the self-reporting of collected information and the limited number of patients and caregivers, which suggests that more studies be performed at higher levels to achieve more results.

## Conclusion

Finally, considering that there is a significant relationship between health literacy, self-efficacy and the knowledge of caregivers of people with MS, which plays a role in caring for patients, it is suggested that in educational interventions for caregivers of chronic diseases patients to improve self-efficacy and patient care skills, attention should be paid to the level of health literacy of these individuals and these subjects. Information and education should be provided in an understandable and simple manner.

## Acknowledgements

This article is based on the master's thesis of health education and promotion of health, approved by Mashhad University of Medical Sciences. In this way, we express our gratitude to the distinguished professors and all the people who provided the opportunity to do this research with their cooperation.

## Authors' contributions

M.V.-S. was involved in design and implementation of the project; H.T. in scientific monitoring of the project; H.E. contributed to analysis of data; Y.J. in involvement in implementation of project; M.S. participated in writing article.

## Funding

No financial support was received for this study.

*Conflict of interest:* The authors declared no competing interests.

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