

The role of health literacy in multiple sclerosis: A systematic review

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ABSTRACT

Introduction: Health literacy is an essential indicator of health care habits and consequences. Health literacy and having the right information is effective in better managing symptoms and problems and improving the overall quality of life. This systematic review aimed to analyze previous studies and collect information on multiple sclerosis patients' health literacy.

Material and Methods:

The PRISMA guidelines were used to define the systematic review methods. PubMed, Cochrane, Web of Science, Scopus, ScienceDirect Journal, ProQuest, Wiley Online Library, SID, and Magiran databases were searched on 14 January 2022, without restrictions in publication time. We also searched Google Scholar and Research Proposal Information System. Two independent reviewers reviewed the papers' eligibility and extract data into a spreadsheet using a structured form.

Results: Of the 165 articles retrieved, 14 were eventually included in the study. All of the studies' audiences and targets were MS patients and their families or caregivers. Four studies examined the level of health literacy of individuals. Other objectives included determining variables affecting the relationship between patients' health literacy and behaviors, comparing the effects of lecture-based teaching and peer group experience on improving patients' health literacy, and determining psychometric characteristics of the MS patient's health literacy questionnaire. Studies assessing people's health literacy revealed that most people have an adequate or acceptable health literacy level.

Conclusion: Improving the level of health literacy is one of the fundamental ways to improve the physical and mental health of MS patients to increase compliance and self-care and medication adherence. Accordingly, policymakers need to work on designing effective programs to develop health literacy and overcome the challenges associated with it.

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INTRODUCTION

Multiple sclerosis (MS) is a central nervous system inflammatory self-immune illness that is becoming increasingly common worldwide [1, 2]. In 2016, 2.2 million persons worldwide were diagnosed with MS, according to the most recent estimates [3]. In Iran, recent research has revealed a considerable increase in the prevalence of MS [4, 5]. MS impacts patients' identity, psychosocial traits, emotional balance, self-satisfaction, and sense of competence and efficacy, just like other chronic diseases. It also impacts social interactions, needing more health literacy and

information to manage symptoms and difficulties better and improve the overall quality of life [6, 7]. To manage their symptoms and issues and improve their quality of life, MS patients require health literacy. Health literacy is an essential indicator of healthcare habits and results [7-9]. Effective self-management is linked to better health outcomes. Furthermore, evidence suggests that self-efficacy and health literacy are linked to practical actions and eventual healthcare utilization [10]. Health literacy is defined by the US Department of Health and Human Services Health Resources and Services Administration (HRSA) as "the degree to which individuals can

receive, process, and understand fundamental health information needed to make acceptable health decisions" [11]. In truth, health literacy refers to a set of abilities that people must have to work effectively in healthcare environments [12]. Finding health information, analyzing data, creating communication, and understanding and implementing physician directions are all examples of these talents [13]. Health literacy is critical for ensuring that health systems and outcomes are used efficiently [14]. It is one of the three pillars of attaining sustainable development in health promotion, according to the Shanghai Declaration [15]. Increasing people's health literacy is critical to making health services more cost-effective and enhancing public health [14]. Health literacy has recently been identified as a predictor of people's health state [16].

The importance of health literacy has been highlighted due to patients' enhanced capabilities and a large amount of available health information and misinformation [17]. As a result, health literacy must be assessed in managing MS patients. Physicians can organize the educational process for patients by assessing their health literacy during the initial appointment. Education must be tailored to their health literacy levels to promote patient engagement in medical decision-making, better knowledge and adaptation, and improved health outcomes [18].

Despite the increased interest and studies in the field of health literacy of MS patients, we could not find a study covering all the relevant studies on this issue. As a result, this systematic review aimed to analyze previous studies and collect information for future studies on MS patients' health literacy. To this end, the three questions mentioned below were put forward and evaluated:

1. Who is the audience of studies on health literacy in MS patients?
2. What is the aim of studies on health literacy in MS patients?
3. What is the result of conducting studies on health literacy in MS patients?

MATERIAL AND METHODS

Selection of Studies

The PRISMA guidelines were used to define the systematic review methods [19]. Table 1 summarizes the entire search process. In order to access studies related to health literacy in MS, a search were conducted using A search of the PubMed, Cochrane, Web of Science, Scopus, ScienceDirect Journal, ProQuest, and Wiley Online Library databases was done to find papers on health literacy in MS. Scientific Information Database (SID), and Magiran, were also

searched (from 11 to 14 January, 2022). In order to complete searches, we also searched Google Scholar and Research Proposal Information System (<https://rpis.research.ac.ir/>).

We found 165 reviews using the search method. There were 14 studies left after deleting duplicates and excluding reviews that did not meet our inclusion criteria (Fig 1).

Table 1: Search Strategy

Item #	Data Base (No.)	Search Strategy
1	PubMed (25 results)	("multiple sclerosis"[Title/Abstract]) AND ("Health literacy"[Title/Abstract])
2	Scopus (41 results)	(TITLE-ABS-KEY ("Health literacy") AND TITLE-ABS-KEY ("multiple sclerosis"))
3	Web of Science (28 results)	TOPIC: ("multiple sclerosis") AND TOPIC: ("Health literacy")
4	ScienceDirect (3 results)	Title, abstract, keywords: "multiple sclerosis" AND "Health literacy"
5	Cochrane Library (4 results)	Trials matching "multiple sclerosis" in Title Abstract Keyword AND "Health literacy" in Title Abstract Keyword - in Cochrane Reviews, Cochrane Protocols, Trials, Clinical Answers, Editorials, Special Collections
6	Wiley online library (2 results)	""multiple sclerosis"" in Abstract and ""Health literacy"" in Abstract
7	Magiran (4 results)	"Multiple sclerosis" AND "Health literacy"
8	SID (0 result)	"Multiple sclerosis" AND "Health literacy"
9	https://rpis.research.ac.ir/ (0 result)	"Multiple sclerosis" AND "Health literacy"
10	Google Scholar (60 results)	"Multiple sclerosis" AND "Health literacy"

Data Extraction

Two authors reviewed each citation's titles and abstracts. All full texts were then reviewed, and those that met inclusion criteria for the systematic review were identified. When there was uncertainty about eligibility, a third reviewer was consulted for decision making on inclusion. Name of the authors, year of publication, the country of study, sample size, target population, type of study, statistical software, objective of the study, health literacy tool, scores of health literacy, adjustment factors, and main consequence, were retrieved from publications that met the inclusion criteria.

Selection Criteria

Inclusion criteria were as follows: (1) It was to be published in peer-reviewed journals, book chapters, dissertations, and conference proceedings. (2) It was investigated the role of health literacy in MS.

Exclusion criteria were as follows: (1) non-English and non-Persian publications; (2) the publication was a non-peer-reviewed journal article, pre-publication drafts letter, comment, editorial, case report, or case study.

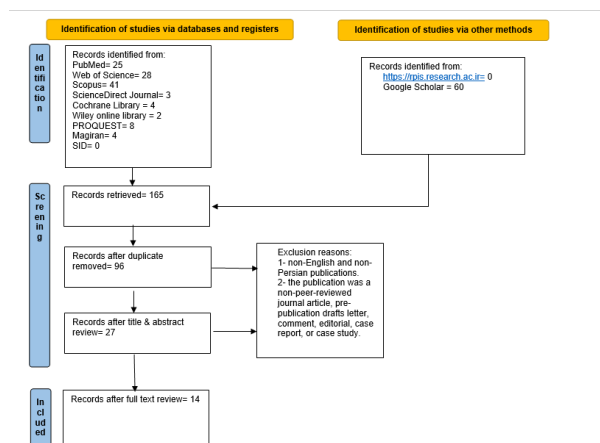


Fig 1: Preferred Reporting Items for Systematic reviews (PRISMA) flow diagram detailing the process of study selection.

Ethics

Formal approval from the ethics review board was not required, as we did not use any personal or patient data, and this study did not include the initial data collection.

Data Synthesis

Table 1 and the findings section include the results of the eligible research. Meta-analysis was not performed due to the wide range of study types and objectives.

RESULTS

Literature Search

Fig 1 summarizes the results of the literature search. In total, 165 articles were found during the initial search; 96 were deleted when duplicates were removed, and 27 were reviewed for full-text inclusion. In the end, 14 studies were examined. It should be mentioned that these studies followed the protocol and all of its terms and were screened.

Study Characteristics

The systematic review comprised 14 studies in total, with research characteristics summarized in Table 2.

Table 2: Summary of the Studies Included in the Systematic Review

Author [Ref]	Country	Sample Size	Study Type	Statistical software	HL Tool	Scores of Health Literacy	Adjustment Factors
Synnot [20]	Australia and Italy	51 MS patients	qualitative study	NVivo	-	-	-
Dehghani [21]	Iran	90 MS patients	quasi-experimental study	SPSS	MS health literacy questionnaire (MSHLQ)	Intervention (67.10)/ Control (44.66)	Gender/ Marital status/ Educational level/ Relapse frequency during last year/ Type of MS/ Type of drugs
Clafin [22]	Australia	PwMS (N=772) Caregiver (N=494) Specialist HCP (N=66) Generalist HCP (N=282) Service provider (N=53) Researcher (N=32)	cross-sectional study	STATA	Health Literacy Questionnaire (HLQ), subscale 1-5 Health Literacy Questionnaire (HLQ), subscale 6-9	below average health literacy score	sex/ age/ Relationship status/ education level/ Vitamin D supplementation/ Smoking status/ English at spoken at home/ Diet rating/ Disease duration/ MS status
Sedghi [23]	Iran	384 MS patients	descriptive-analytic survey	SPSS	Health literacy for Iranian adults (HELIA)	favourable	Age/ gender/ education
Reen [24]	United Kingdom	24 MS patients	RCT	SPSS	Rapid Estimate of Adult Literacy in Medicine - Revised (REALM-R)	7.79 (0.59)	Age/ gender/ education/ Employment status/ Time since MS diagnosis/ HAI disability scale / Current DMD
Williams [25]	United States	179 MS patients	single-site, prospective study	SPSS	Short Test of Functional Health Literacy in Adults (STOFHLA)	Adequate health literacy	Outcome/ medication adherence
Bessing [26]	Australia	1182 MS patients	Rasch analysis	RUMM	Health Literacy Questionnaire (HLQ)	Resilience	

Author [Ref]	Country	Sample Size	Study Type	Statistical software	HL Tool	Scores of Health Literacy	Adjustment Factors
Cabrera [27]	Spain	57 MS patients	descriptive observational study	Excel	eHealth Literacy Scale-(eHEALS)	3.3±1.1 (acceptable level)	Sociodemographic data, technological profile (TP), knowledge and use of digital health tools (KD), assessment of the level of digital health literacy (AD) (using the eHealth Literacy Scale-eHEALS) and preferred patient-HP way of communication (PC).
Dehghani [8]	Iran	23 articles and texts	Rodgers' evolutionary method of concept analysis	-	-	-	-
Dehghani [28]	Iran	Phase 1- 22 papers & 9 MS patients Phase 3- 12 MS patients & 15 experts & 210 MS patients & 20 experts	exploratory sequential mixed method	MAXQDA SPSS	-	-	Age/ Duration of MS/ Gender/ Education status/ / recurrence during last year/ Number of readmission during the past year/ Type of MS
Jafari [29]	Iran	70 family caregivers	quasi-experimental study	SPSS	Test of Functional Health literacy in Adults (TOFHLA)	Before intervention: 57.2 (Experimental group) 57.82 (Control group) After intervention: 62.22 (Experimental group) 58.11 (Control group) 3 months after intervention: 62.45 (Experimental group) 58.4 (Control group)	Gender/ Age / Employment status / Marital status / Source of income / economic situation / Education / Relative / Self-efficacy
Marrie [30]	United States	8934 MS patients	cross-sectional study	SAS	eHealth Literacy Scale (eHEALS)/ Medical Term Recognition Test (METER)/ Newest Vital Sign (NVS)	adequate literacy	Gender/ Age/ Race/ Education/ Annual household income/ Insurance status/ Patient Determined Disease Steps/ Cognition
Pooryaghob [31]	Iran	100 MS patients	cross-sectional study	SPSS	Rapid Estimate of Adult Literacy in Medicine - Revised (REALM-R) & Newest Vital Sign (NVS)	Insufficient (NVS)/ Optimal (REALM-R)	Gender/ Age/ Marital status/ Education/ occupation/ Duration of the disease/ MBI/ Physical activity level/ Addiction
Jafari [32]	Iran	76 caregivers & 76 women with MS	descriptive correlational study	SPSS	Test of Functional Health Literacy in Adults (TOFHLA)	64.26	Gender/ Age / Employment status / Marital status / Source of income / economic situation / Education / Relative / behavior

The findings were reviewed into three main categories: the study audience, the purpose of the study, and the main Consequence of the study.

All the articles were published after 2014, and the majority in 2021 (5 papers). In terms of geographical distribution, most studies (7 papers) were conducted in Iran, followed by Australia and the United States (2 papers each), and Spain and England (1 paper each).

Furthermore, one study was jointly conducted in Australia and Italy. All of the studies' audiences and targets were MS patients and their families or caregivers.

Most of the papers were quantitative studies. However, two were qualitative, and one had a mixed-method approach. In eight papers, SPSS was used for data analysis. Other software used in the studies

included SAS, STATA, NVIVO, MAXQDA, RUMM, and Excel.

In total, 12080 MS patients, 640 family members or caregivers, and 436 healthcare providers (specialists, general physicians, and experts) had participated in the studies. Moreover, 45 papers were analyzed, and 32 researchers were included in the studies.

Health literacy measurement tools were used in 11 studies; these tools included (REALM-R), (HLQ), (TOFHLA), (eHEALS), (NVS), (MSHLQ), (HELIA), and Test (METER).

Some studies used more than one tool to measure health literacy better. Most of the studies (4 papers) aimed to assess people's health literacy levels. Other objectives included determining variables affecting the relationship between patients' health literacy and behaviors, comparing the effects of lecture-based teaching and peer group experience on improving patients' health literacy, and determining psychometric characteristics of the MS patient health literacy questionnaire. Studies assessing people's health literacy revealed that most people have an adequate or acceptable health literacy level. Moreover, in MS patients, health literacy is a multidimensional concept with four features, including evaluating health information, understanding the disease and issues related to it, reading skills, and the capacity to use knowledge. Comparing the effect of peer group and lecture-based education indicated that peer group experience was more efficient in improving health literacy. Using it as an educational and supportive approach can benefit MS patients. Educational interventions merely aiming to increase knowledge might be ineffective in improving health-related outcomes. Interventions based on family-oriented empowerment can improve caregivers' health literacy and self-efficacy, help them provide specialized and effective care, and improve the quality of care.

DISCUSSION

This systematic review was conducted to identify MS patients' health literacy studies. Health literacy affects health behaviors and services, affecting health outcomes and expenses [16, 33]. MS affects patients' and their families' quality of life, economic status, and social interactions [23]. Ideal health literacy in MS patients can positively impact their physical and mental health and improve their sense of life satisfaction and quality of life [23]. Studies that assess people's health literacy show that most MS patients have a sufficient or acceptable level of health literacy.

By definition, health literacy is a dynamic, complex, and multidimensional concept [21], and is defined as people's knowledge, motivation, and capacity to access, understand, evaluate, and use health information to make judgments and decisions on

health issues in their daily lives [34]. Therefore, MS patients need different health literacy during their illness [8]. Based on this, health literacy affects factors such as health literacy, self-efficacy, resilience, quality of life (QoL), and MS symptom severity. Accordingly, to teach them responsibility, health promotion methods, independent decision-making, and self-care, they need to learn problem-solving techniques and skills and have information to improve their quality of life [23]. Educational interventions aimed solely at increasing knowledge may be ineffective in improving health-related outcomes. Interventions based on family-centered empowerment can improve caregivers' health literacy and self-efficacy, help them provide specialized and effective care, and improve the quality of care. Of course, research and education are necessary for teaching and learning, therefore, with attention and emphasis on previous studies, educational provisions should be prepared in accordance with the improvement of the health literacy level of society regarding MS. Consequently, healthcare staff needs to evaluate health literacy and check MS patients' medical records and mental status to plan their medical recommendations and programs [8].

Limitations and Strengths

One of the significant limitations of this study is that it only included papers written in English and Persian, excluding relevant studies done in other languages. In addition, the researchers could not do a meta-analysis of the studies because of the variety in populations, objectives, and study findings.

A comprehensive search strategy involving multiple databases and gray literature searches was one of the systematic review's strengths.

CONCLUSION

Easy access to neurologists, improving health literacy in public and increasing family physicians' awareness of MS symptoms can reduce the delay in MS diagnosis. Sufficient health literacy can lead to the improvement of MS patients' physical and mental health. Moreover, it can affect self-care and adherence to medication and reduce healthcare service use, thereby decreasing health expenses, creating a feeling of life satisfaction, and improving quality of life. Therefore, due to the importance of having an ideal level of health literacy, policymakers need to devise efficient plans to develop health and overcome literacy-related challenges.

AUTHOR'S CONTRIBUTION

All authors contributed to the literature review, design, data collection and analysis, drafting the manuscript, read and approved the final manuscript.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest regarding the publication of this study.

FINANCIAL DISCLOSURE

No financial interests related to the material of this manuscript have been declared.

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