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

Mahdie Shojaei Baghini1*, Kambiz Bahaadinbeigy2*

1Medical Informatics Research Center, Institute for Futures Studies in Health, Kerman University of Medical Sciences, Kerman, Iran
2Digital Health Team, Australian College of Rural and Remote Medicine, Brisbane, QLD, Australia

**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 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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**Keywords:** Health Literacy, Multiple Sclerosis, Systematic Review

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*Corresponding author:*
Mahdie Shojaei Baghini

Medical Informatics Research Center, Institute for Futures Studies in Health, Kerman University of Medical Sciences, Kerman, Iran
Email: mahdiehsh@gmail.com

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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 was 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 1 our inclusion criteria (Fig 1).

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

**Table 1: Search Strategy**

**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.

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

<table>
<thead>
<tr>
<th>Author [Ref]</th>
<th>Country</th>
<th>Sample Size</th>
<th>Study Type</th>
<th>Statistical software</th>
<th>HL Tool</th>
<th>Scores of Health Literacy</th>
<th>Adjustment Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Synnot [20]</td>
<td>Australia and Italy</td>
<td>51 MS patients</td>
<td>qualitative study</td>
<td>NVivo</td>
<td>Health literacy questionnaire (MSHLQ)</td>
<td>Intervention (67.10)/Control (44.66)</td>
<td>Gender/ Marital status/ Educational level/ Relapse frequency during last year/ Type of MS/ Type of drugs</td>
</tr>
<tr>
<td>Dehghani [21]</td>
<td>Iran</td>
<td>90 MS patients</td>
<td>quasi-experimental study</td>
<td>SPSS</td>
<td>Health Literacy Questionnaire (HLQ), subscale 1-5</td>
<td>below average health literacy score</td>
<td>Engel/ Diet rating/ Disease duration/ MS status</td>
</tr>
<tr>
<td>Claffin [22]</td>
<td>Australia</td>
<td>104 MS patients</td>
<td>cross-sectional study</td>
<td>STATA</td>
<td>Health Literacy Questionnaire (HLQ), subscale 6-9</td>
<td>Age/ gender/ education</td>
<td>Favourable</td>
</tr>
<tr>
<td>Sedghi [23]</td>
<td>Iran</td>
<td>384 MS patients</td>
<td>descriptive-analytic survey</td>
<td>SPSS</td>
<td>Health literacy for Iranian adults (HELIA)</td>
<td></td>
<td>Age/ gender/ education</td>
</tr>
<tr>
<td>Reen [24]</td>
<td>United Kingdom</td>
<td>24 MS patients</td>
<td>RCT</td>
<td>SPSS</td>
<td>Rapid Estimate of Adult Literacy in Medicine - Revised (REALM-R)</td>
<td>7.79 (0.59)</td>
<td>Age/ gender/ education/ Employment status/ Time since MS diagnosis/ HAI disability scale/ Current DMD</td>
</tr>
<tr>
<td>Williams [25]</td>
<td>United States</td>
<td>179 MS patients</td>
<td>single-site, prospective study</td>
<td>SPSS</td>
<td>Short Test of Functional Health Literacy in Adults (STOFHLA)</td>
<td>Adequate health literacy</td>
<td>Outcome/ medication adherence</td>
</tr>
<tr>
<td>Bessing [26]</td>
<td>Australia</td>
<td>1182 MS patients</td>
<td>Rasch analysis</td>
<td>RUMM</td>
<td>Health Literacy Questionnaire (HLQ)</td>
<td>Resilience</td>
<td></td>
</tr>
</tbody>
</table>
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.
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.

REFERENCES


FINANCIAL DISCLOSURE

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


