

## Review Article



# Health Literacy in Multiple Sclerosis patients: A Concept Analysis Using the Evolutionary Method

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Email: ali.dehghani2000@gmail.  
com.**Abstract****Introduction:** Health literacy is one of the effective factors in health promotion of chronic patients. However, little attention has been paid to it; no exact and clear definition of health literacy has ever been accessible in chronic diseases. This study was conducted with aim of defining and clarifying attributes, antecedents, and consequences of health literacy in multiple sclerosis (MS) patients.**Methods:** Rodgers' evolutionary method of concept analysis was used to clarify the concept of health literacy in MS patients. A literature review was conducted with key terms "multiple sclerosis", "health literacy", "information literacy", "functional health", "health education", "health promotion" and "health behavior". Eight hundred and sixty papers for the period 1980–2019 were found and finally 23 articles and texts were selected for the analysis. Data analysis was carried out using a thematic analysis.**Results:** Health literacy in MS patients is a multidimensional concept with forth attributes: health information evaluation, understand disease and its related issues, reading skills and capacity to use knowledge. Ability to read and comprehend, interacting with health personnel, and interacting with peers as an antecedents and improved self-care, health promotion, medication adherence, and decreased use of health care services to be the consequences of these attributes were found.**Conclusion:** The findings can add knowledge about the concept of health literacy in MS patients. Also, health care professionals can use a deeper understanding of the concept of health literacy in providing care plan for MS patients.**Introduction**

Multiple sclerosis (MS) is a chronic progressive and debilitating disease of the central nerve system which affects motor and sensory functions.<sup>1</sup> This disease is one of the most common chronic neurological diseases in young adults and creating changes in the person's life.<sup>2</sup> There are an estimated 1.1 million patients worldwide.<sup>3,4</sup> Patients with MS experience a variety of physical and psychological disorders.<sup>5,6</sup> Therefore, it is necessary that patients with MS have the adequate information about disease, prognosis, symptom management and treatment to improve quality of life and self-management. Health literacy is a global issue and according to World Health Organization (WHO) statement, plays a pivotal role in determining health inequalities.<sup>7</sup> This concept is known as a vital indicator in health care outcomes and costs and is important in patients with chronic illness such as patients with MS.<sup>8,9</sup>

In various studies, concept of health literacy in MS patients differently has been perceived that these matter needs further explanation and clarification.<sup>10,11</sup> From Videto and Dake point of view, health literacy has three

levels of functional, interactive and critical health literacy.<sup>12</sup> In the study of Tormey et al., health literacy conceptualized into different sectors including basic literacy, academic literacy, civil literacy and cultural literacy.<sup>13</sup> Health literacy helps patients to overcome many problems and symptoms and as a result can advocate patient in a right manner and quality of life.<sup>14,15</sup>

Although health literacy has been seen as an important factor in chronic diseases, little attention has been paid to it, and the number of research done in the field has been limited. However, with the expansion of health literacy research and policy measures, it becomes clear that there is no altogether accepted definition of the concept particularly in Iran.<sup>11</sup> A clear understanding of the concept is essential as health literacy has implications that are far-reaching and impact both the individual and society in patients with MS. Increasing and updating the knowledge framework and clarifying the concepts would be a factor of evidence-based operation and can provide a basis for evidence-based practice.<sup>16,17</sup> The concept of health literacy is affected by various factors including cultural, social etc. and have different definitions.<sup>18</sup> So, using the

concept analysis can lead to transparency, identity-giving, and providing meaning to health literacy in patients with MS.<sup>16,17</sup> This concept analysis using evolutionary method in this study tries to answer the following questions:

1. How are health literacy defined in patients with MS?
2. What are its attributes, antecedents, and the consequences?

### Materials and Methods

In this study, the concept of health literacy in patients with MS was analyzed using a Rodgers' evolutionary approach. In this approach, six preliminary activities are suggested for the study.<sup>19</sup>

Evolutionary concept analysis activities: (1) Identify the concept of interest and associated expressions (including surrogate terms). (2) Identify and select an appropriate realm (setting and sample) for data collection. (3) Collect data relevant to identify (A) The attributes of the concept; and (B) The contextual basis of the concept, including interdisciplinary, sociocultural, and temporal (Antecedent and consequences) variations. (4) Analyze data regarding the above characteristics of the concept. (5) Identify an exemplar of the concept if appropriate. (6) Identify implications, hypotheses, and implications for further development of the concept.<sup>19</sup>

In this study, a systematic literature review based on

Cochrane Community Search Strategy was conducted. These guidelines including (A) selection of review questions, (B) inclusion and exclusion criteria, (C) search strategy, (D) selection of study, (E) data extraction, (F) quality assessment, (G) data synthesis, and (H) plan for dissemination was implemented.<sup>20</sup> The databases of Science Direct, PubMed/Medline, ProQuest, Ovid, Scopus, Web of knowledge, CINAHL, EBSCO and Iranian databases like SID, Magiran, Irandoc, Iran Medex were searched. In this broad review, a combination of keywords "health literacy", "health promotion", "health behavior", "functional health", "information literacy" and "health education" and "multiple Sclerosis or MS" were searched.

In the primary search, 860 titles (paper, book..., in Persian and English languages) were obtained. The search was conducted to include articles from 1980 to 2019. After reviewing the abstracts and eliminating the inappropriate studies, 85 were read in their entirety. Finally after reviewing full text, 23 studies in English and Persian met the inclusion criteria and were analyzed. Forth review articles, 15 original research articles, one dissertation, and three books were analyzed in the study. Figure 1 shows the process of reviewing and selecting the literature in the search process. An example of search strategy in PubMed/Medline database was as follows: (1) (multiple sclerosis or MS).m titl. (2) health literacy/or health promotion/

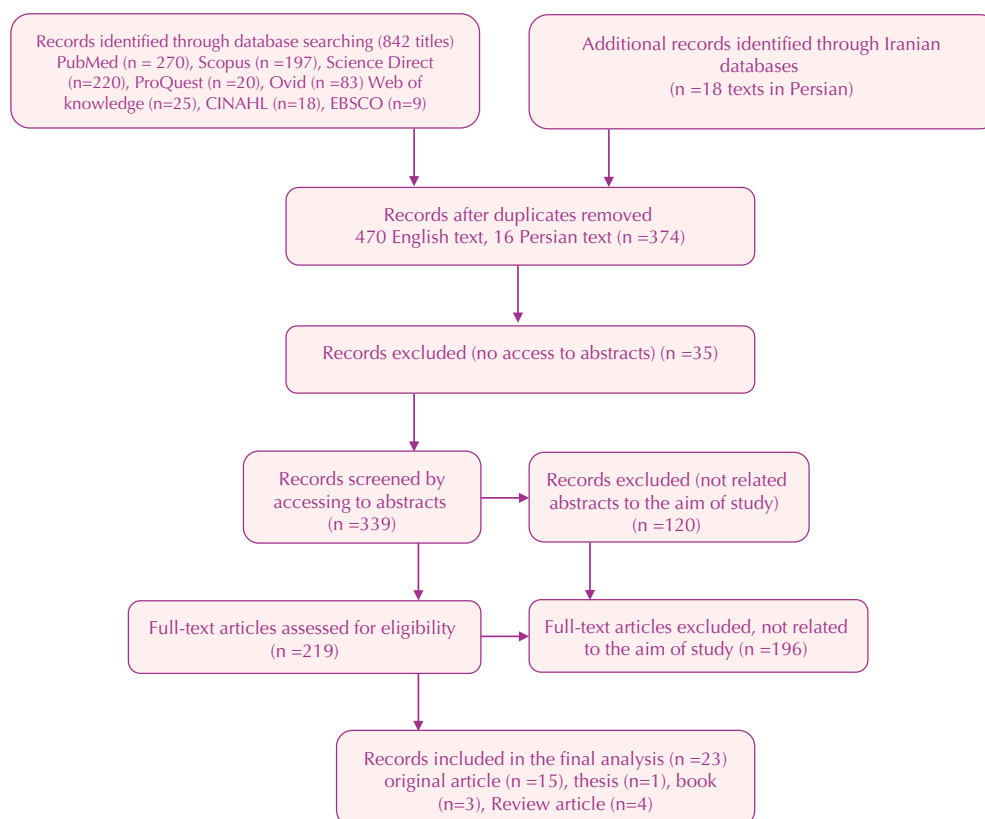


Figure 1. Flow chart of the literature reviewing and selecting

or health behavior/or functional health/or information literacy/or health education. (3) 1 and 2. (4) limit 3 to (English or Persian). (5) limit 4 to yr. = '1980-Current'

Inclusion criteria: (1) papers and texts published both in English and Persian language were included; (2) an access to the full text of studies with different designs (qualitative, quantitative, mixed method) was implemented; (3) studies of systematic and integrative review, and peer review of articles were carried out; (4) definition, attributes, antecedent, and consequence of the concept should be mentioned in the texts. Exclusion criteria included book reviews and studies with other languages except English and Persian. Also, for assess the quality of articles; STROBE checklist<sup>21</sup> for quantitative studies and COREQ checklist<sup>22</sup> for qualitative studies was used. The quality of book and thesis also was reviewed on the basis of publication by valid international publications such as ProQuest, Springer, Wiley etc.

For data analysis of studies in this phase from conventional content analysis according to stages proposed by Graneheim and Lundman was used.<sup>23</sup> The studies full texts were read for several times to obtain a general understanding. In the first, the initial codes were extracted. Then, similar codes were classified as sub-categories. Finally, the sub-category formed categories together. This analysis was reviewed by researcher with experience of this model of concept analysis and familiar with Rodgers' evolutionary approach.<sup>19,24</sup>

## Results

The result of this study led to the identification of the definition, attributes, antecedents, and consequences of the health literacy in patients with MS. According to results, the concept of health literacy in patients with MS is defined as a dynamic and multidimensional concept that its main attributes extracted including health information evaluation, understand disease and its related issues, reading skills and capacity to use knowledge. Ability to read and comprehend, interacting with health personnel, and interacting with peers as antecedents of health literacy and improved self-care, health promotion, medication adherence, and decreased use of health care services to be the consequences of these attributes were found. Also, a summary of reviewed studies<sup>7,10-15,18,25-39</sup> is presented in Table 1. In this study, 283 initial codes, 32 sub-categories, and 11 categories including attributes (4), antecedents (3), and consequences (4) of the health literacy in patients with MS were obtained (Table 2).

The attributes of health literacy in patients with MS are described in Table 2.

Health information evaluation is known as the most important attribute of health literacy. Some studies reported health literacy is known as health information evaluation. Sørensen et al., mentioned health literacy as the capacity to obtain, interpret and understand basic health information and services and the competence to use

such information to enhance health.<sup>10</sup> As well as Bröder et al., reported health literacy as the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course.<sup>25</sup>

From other attributes of health literacy in patients with MS that found in literature it was the person knows his illness and knows his limitations, such as diet, treatment, and etc. Australian Bureau of Statistics reported health literacy as the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy.<sup>26</sup> As well as, American studies linked literacy to health, showing an association between low literacy and decreased medication adherence, knowledge of disease and self-care management skills.<sup>27</sup>

From other attributes of health literacy in patients with MS that repeatedly found in literature was reading skills. Though there is a range of definitions of functional literacy, most focus on the ability to read basic text and write a simple statement on everyday life. Reading skills include a complex array of meta-cognitive behaviors, such as focusing attention, using contextual analysis to understand new terms, using text structure to assist in comprehension, word recognition, and organizing and integrating new information.<sup>28</sup> Dreger and Tremback mentioned that literacy is "the ability to read and write".<sup>31</sup> Kooshyar et al., reported that health literacy can be defined as the ability to read, understand and act on health advice.<sup>28</sup> Zarcadoolas and Kondilis defined health literacy as the constellation of skills, including the ability to perform basic reading and numeral tasks required to function in the healthcare environment.<sup>33</sup>

One of the most important attributes of health literacy in patients with MS that is people can use the knowledge they have acquired. Bonaccorsi and Modesti reported that health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions".<sup>34</sup> So that individuals who have a low level of health literacy often receive health information in a manner that they cannot use. Some researchers contend that health literacy goes beyond the ability to read and write and understand health information and instructions. He expanded that health literacy enables people to make informed choices, to influence events, to better manage, and to handle greater control over their lives.<sup>12</sup> The US Institute of Medicine report defines health literacy as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.<sup>33</sup>

The next iterative process of the evolutionary conceptual analysis cycle is an examination of the antecedents and consequences of the concept.<sup>19</sup> Antecedents describe as events or incidents that must precede the occurrence of

**Table 1.** Summary of concept analysis for health literacy in multiple sclerosis patients

Authors/Years	Attributes	Antecedents	Consequences
Sorensen et al., 2012 <sup>10</sup>	Health literacy as the capacity to obtain, interpret and understand basic health information and services.	-	-
Bröder et al., 2018 <sup>25</sup>	Health literacy is the ability to access, understand and evaluate information to health promote.	-	-
Speros, 2005 <sup>26</sup>	-	The ability to read and written	Improve of self-reported health status, lower health care costs, increased health knowledge, shorter hospitalizations
Mancuso, 2008 <sup>18</sup>	-	Interacting with others especially patients with MS	Decrease of health-care costs, more knowledge about diseases and treatments, more self-care skills, more ability to care, less treatment errors.
Chakkalakal et al., 2017 <sup>27</sup>	-	Use of effective information resources	-
Kooshyar et al., 2014 <sup>28</sup>	-	-	Better health-related quality of life
Nandyala et al., 2018 <sup>29</sup>	Writing and reading skills	-	-
Ta Park et al., 2018 <sup>30</sup>	-	-	Use less health-care services, the fewer risk for hospitalization, and a lower utilization of expensive services
Dreger and Tremback, 2002 <sup>31</sup>	The skills of read and write	-	-
Vellar et al., 2018 <sup>32</sup>	The skills to read, understand and act on health advice	-	-
Zarcadoolas and Kondilis et al., 2018 <sup>33</sup>	The ability to perform basic reading and numeral tasks required to function in the healthcare environment	-	-
Bonaccorsi and Modesti, 2017 <sup>34</sup>	The capacity to obtain, process, and understand basic health information needed to make appropriate health decisions	-	-
Videto and Dake, 2019 <sup>12</sup>	The ability to read and write and understand health information	-	-
Stormacq et al., 2019 <sup>35</sup>	The capacity to obtain, process and understand basic health information	-	-
Lindgren et al., 2018 <sup>36</sup>	-	Interaction with peers	-
Sansom-Daly et al., 2016 <sup>37</sup>	-	-	Health promotion
Toronto, 2016 <sup>38</sup>	-	-	Improve of care ability
Tavousi et al., 2014 <sup>11</sup>	The ability to use knowledge	-	-
Waverijn et al., 2016 <sup>15</sup>	Awareness about disease	-	-
Davey et al., 2015 <sup>14</sup>	-	-	Improve of health status
Sanders, 2019 <sup>39</sup>	Understanding of disease conditions	-	-
Tormey et al., 2016 <sup>13</sup>	-	Interacting with peers	-
Soto Mas and Jacobson et al., 2019 <sup>7</sup>	assessment of gathered information	-	-

**Table 2.** Attributes, antecedents, and consequences of health literacy in multiple sclerosis patients

Attributes	Antecedent	Consequences
Health information evaluation	Ability to read and comprehend	Improve of self-care
Understand disease and its related issues	Interacting with health personnel	Health promotion) Physical, Psychological, Social and Spiritual)
Reading skills	Interacting with peers	Medication adherence
Capacity to use knowledge	-	Decreased use of health care services

the concept. The antecedents of health literacy in patients with MS that are reported in sciences literature include the ability to read and comprehend, interacting with health personnel, and interacting with peers (patients with MS).

Ability to read and comprehend plays an important role in improved health literacy in patients with MS. The results of Speros study showed that the ability to read and

ability to comprehend written words are from effective antecedents in increase health literacy.<sup>26</sup> Studies show that the requirements for health literacy education are the ability of individuals to read and understand the subject.<sup>18, 26</sup>

Interacting with health personnel plays an important role in improved health literacy in patients with MS.

Patients with MS can increase their health literacy by accessing information from health personnel such as doctors, nurses, etc. From the perspective of Mancuso, interaction and interactive competence is considered as a one of the most important antecedents in health literacy.<sup>18</sup> Interactive competence is the collaboration of one with others for individual improvement and enhancement through self-management. The individual is involved in the self-management of problems in partnership with healthcare professionals.<sup>26</sup> Chakkalakal et al., showed that the use of effective information resources and interacting with MS patients in relation to the nature and problems of the disease in increased health literacy related the disease is effective.<sup>27</sup>

Consequences of health literacy include improved self-care, health promotion) physical, psychological, social and spiritual), medication adherence and decreased use of health care services. The results of study by Speros showed that consequences of health literacy include improved self-reported health status, lower health care costs, increased health knowledge, shorter hospitalizations.<sup>26</sup> The results of Mancuso study reported that individuals with inadequate health literacy have increased health-care costs, less knowledge of their diseases and treatments, fewer self-care skills, less ability to care for their conditions, more treatment errors.<sup>18</sup> The results of Kooshyar et al., showed that individuals with higher health literacy have better health-related quality of life.<sup>28</sup>

Many studies have emphasized that in other chronic disease contexts, health literacy and numeracy have been associated with medication adherence and medication management. The results of Nandyala et al., showed that low health literacy is a risk factor for incorrect identification of medications.<sup>29</sup> The results of Nandyala et al., and Kooshyar et al., showed that there is a direct and significant relationship between health literacy and medication adherence in diabetic patients.<sup>28, 29</sup> Patient's adherence to medication regimen is critical to achieving improved health outcomes, quality of life, and cost-effective health care.<sup>32</sup> A WHO review of adherence behaviors noted that, "increasing adherence may have a greater effect on health than improvements in specific medical therapy".<sup>39</sup>

Many studies have emphasized to adequate health literacy led to reduce the use of health care services and reduces patient health costs. The results of Speros and Kooshyar et al., showed that sufficient health literacy in about of illness and its related problems can prevent of harmful consequences and led to reduce the use of health care services and extra costs.<sup>26,28</sup>

## Discussion

While until recently the interest in health literacy was mainly concentrated in the United States and Canada, it has become more internationalized over the past decade. Research on health literacy has taken place in

e.g., Australia, Korea, Japan, the UK, the Netherlands, and Switzerland.<sup>10</sup> But in Iran, this concept has been less understood and fewer studies have been done in this regard. On the other hand, dimensions and areas of health literacy concept in patients with MS not defined.

This concept analysis reveals a unique set of attributes, antecedents, and consequences associated with health literacy in patients with MS. Health literacy should become a variable assessed by healthcare personnel at the initiation of any patients with MS encounter, as is mental status, and past medical history, so that recommendations and the plan of care can be adapted accordingly.

The aim of the analysis was to investigate health literacy in patients with MS with emphasize on identification of attributes, antecedent and consequences of concept. This analysis showed that health literacy in patients with MS is a multi – dimension and dynamic concept. Tavousi et al., reported that health literacy is a dynamic and complex concept that different definitions and dimensions are given.<sup>11</sup> This result indicates that health literacy in patients with MS is varies over time and it depends to various factors such as individual, interpersonal, reading and comprehending skills, etc.

The result of this study led to discovery of attributes for health literacy in patients with MS. This attribute can use for care interventions in patients with MS. Some of attributes identified in this analysis matched in some studies. The Institute of Medicine definition examines health literacy as a set of person abilities in the four domains of cultural and conceptual knowledge, speaking and listening skills, writing and reading skills and numeracy. This domains of health literacy as a set of capacities also implies that health literacy is somewhat knowledge based, and may be developed through educational intervention.<sup>35</sup> Numeracy skills is the ability to understand and use numbers in daily life and, when inadequate, is associated with weak health outcomes.<sup>40</sup> Similarly, Sørensen et al., found that health literacy is the capacity to obtain, interpret and understand basic health information and services and the competence to use such information to enhance health.<sup>10</sup> Also, In the Speros study, the extracted attributes for the concept of health literacy were Numeracy and reading skills.<sup>26</sup> In MS patients, low health literacy and numeracy skills have each been associated with weaker disease knowledge, self-care behaviors, and symptoms control. In the regards of other chronic disease, health literacy and writing and reading skills have been associated with medication adherence and medication management.<sup>36</sup> In another study, health literacy and writing and reading skills were significantly related to the capacity to manage medications.<sup>29</sup> These findings showed that in assessing the health literacy of individuals and patients, they should evaluate the gathered information and then use it.

Other findings in this study were the discovery antecedents and consequences of health literacy in patients with MS that have an important role in education, caring



interventions, drug adherence, and etc. By assessing the presence of the antecedents of health literacy, healthcare personnel can enhance their ability to identify those patients at risk of misunderstanding and non-adherence.

Factors such as ability to read and comprehend, interacting with health personnel and peers are important antecedents in improving the patients with MS health literacy. Health literacy in turn influences health behavior and the use of healthcare services, and thereby will impact on health outcomes and on the health costs in society. For example, at an individual level, ineffective communication and low of participation in public due to low health literacy will result in medication errors, risks to patient safety and use more from healthcare services. At a population level, health literate persons are able to participate in the ongoing public and private.<sup>10</sup> Interactive antecedents is the collaboration of one with others for individual improvement and enhancement through self-management. The patients are involved in the self-management of problems in partnership with healthcare professionals. Self - management includes actions taken by the patients to improve health. Also, self-management implies more advanced cognitive and literacy skills.<sup>38</sup> In the Mancuso study, one of the extracted antecedents for the concept of health literacy were interactive competence.<sup>18</sup>

Other findings from this study were the extraction of health literacy outcomes in patients with MS. Improve of self-care and health, medication adherence and decreased use of health care services are important outcomes of health literacy in patients with MS. Health literacy is the outcome of education and communication rather than a factor that may influence the outcome. People who have better developed health literacy will thus have skills and capabilities that enable them to engage in a range of health enhancing actions including personal behaviors and social actions such as preventive activities, follow up treatment or participating in screening programs.<sup>41</sup> Sanders and Lindgren et al., mentioned patients with inadequate health literacy have increased health-care costs, less knowledge of their diseases and treatments, fewer self-management skills, less ability to care for chronic conditions, poor compliance, more medical or medication treatment errors, a lack of the skills needed to successfully negotiate the health-care system, and less access to health-care services.<sup>36,39</sup> Also, Toronto reported patients with low health literacy use more health-care services, have a greater risk for hospitalization, and have a higher utilization of expensive services, such as emergency care and inpatient admissions.<sup>38</sup> The consequences of the study Sansom Daly et al., included Health behavior, Health costs and Health service use.<sup>37</sup> All of these findings showed that raising the health literacy of patients can have many positive effects in the individual and national levels.

Duo to the complex and broad nature of health literacy, it has different definitions in sciences literature. The philosophical foundation of Rodgers' evolutionary

method places emphasis on concept analysis as a basis for further inquiry and concept development rather than as an end point.<sup>24</sup> On the basis of our findings, the following definition is suggested for health literacy in patients with MS: health literacy in patients with MS is a dynamic and multidimensional concept with the dimensions of health information evaluation, understand disease and its related issues, reading skills and capacity to use knowledge. This concept has emerged in the context of ability to read and comprehend, interacting with health personnel, and interacting with peers so that health literacy leads to health outcomes including improved self-care, health promotion) physical, psychological, social and spiritual), medication adherence, and decreased use of health care services in the patient.

These findings not only add to the body of knowledge, but also serve as presentation of protocols for caring intervention in these patients and research in this context. Therefore, awareness of these attributes, antecedents, and consequences of health literacy helps promote the significance, use, and better application of this concept in caring planning in the chronic diseases such as patients with MS.

Although this study helped to clarify and identify the concept of health literacy in patients with MS, it had some limitations as well. Access to full text of all articles with database data was not possible. The use of texts in Persian and English was another limitation of present study.

## Conclusion

The findings of this study explored attributes, antecedents, and consequences of health literacy in patients with MS and described health literacy as a complex, multidimensional, and dynamic concept. These findings not only add to the body of knowledge, but also serve as an important motivation for further theory development and research in this context. Therefore, awareness of these attributes, antecedents, and consequences of health literacy can promote significance, using, and application of this concept in chronic diseases such as MS.

## Research Highlights

### What is the current knowledge?

Health literacy is a major concept in disease management and helps patients to overcome many problems and symptoms and as a result can advocate patient in a right manner and quality of life.

### What is new here?

So far, the concept of health literacy in MS patients has not been analyzed. Health literacy can have different definitions and meanings for patients with different diseases. The present study showed health literacy in MS patients is the complex, multi-dimensional, and dynamic concept with attributes of health information evaluation, understand disease and its related issues, reading skills and capacity to use knowledge.

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### Ethical Issues

This study approved by the ethics committee of Jahrom University of Medical Science in Iran with Ethics approval number IR.JUMS.REC.1395.177.

### Conflict of Interest

None declared.

### Author's Contributions

AD designed the review protocol. AD developed the search strategy and drafted the protocol. AD was searches and conduct data selection and extraction. AD involved in data analysis and interpretation of results. AD has read and approved the final manuscript.

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