

# Chronic pain health literacy: A scoping review of existing instruments

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## ABSTRACT

**Atm:** Patient self-management is considered one of the preconditions for successful control of chronic conditions (including chronic pain), and health literacy is a relevant factor that can affect patient outcomes. The aim was to conduct a scoping review to synthesize studies within the healthcare context that have dealt with chronic pain in adults and measured literacy, and also to explore what literacy instruments were used.

**Methods:** After determining clear inclusion and exclusion criteria, 8 electronic databases were searched for relevant articles; additional articles were obtained through reference lists of the obtained articles. Of the 56 records that were screened, 14 were included for data abstraction.

**Results:** Most ( $n = 11$ ) obtained studies were quantitative and most were based on a definition of literacy that focused on individuals, i.e. either on their reading level or on their abilities to access, read, understand, appraise, and act on health information. Correspondingly, most ( $n = 10$ ) instruments measured individual-level characteristics; they did so mainly to examine the relationship between health literacy and various pain-related variables. Most studies were conducted in the USA and Germany.

**Conclustons:** Chronic pain health literacy is a topic with emerging research. However, most instruments are generic and are oriented mainly towards individuals. Thus, chronic pain-specific instruments should be developed, and the existing instruments should be expanded to include contextual factors as well. Research is urgently needed in non-Western countries, especially given the current and predicted future global trends concerning chronic pain.

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## Introduction

Chronic pain can be defined as pain that lasts longer than the usual course of an acute injury or disease, or the pain that recurs for months or years; typically, for more than 3–6 months [1, 2]. Chronic pain includes primary,

postsurgical, post-traumatic, neuropathic, orofacial, visceral, musculoskeletal, and cancer pain as well as headaches [1, 2]. Chronic pain constitutes a complex, long-term challenge worldwide due to its high prevalence, high economic costs and negative impact on the individual's quality of life [3–5]. In some parts of the world, chronic pain affects up to 20% of the adult population, including Europe [4,6], and

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because the world's population is ageing, its prevalence is expected to rise [5]. Moreover, according to the World Health Organization (WHO), the global burden of non-communicable diseases – mainly cardiovascular diseases, diabetes, cancers and chronic respiratory diseases – is rising fast [7]. Chronic pain is an important co-morbidity associated with all of these.

Nowadays, patient self-management is considered one of the preconditions for the successful control of chronic conditions (including chronic pain), as long as the patients are adequately supported by their healthcare professionals [8, 9]. Self-management often encompasses complex tasks, such as adherence to prescribed medical regimens, frequent healthcare visits, and lifestyle adjustments, which presents patients with a steep learning curve [10]. Mastering such tasks may be difficult, especially in cases of suboptimal health literacy (HL), which is associated with poorer health outcomes and higher health-related costs [9–12]. However, deficits in HL are an independent predictor of outcomes distinct from attained educational level and other measures of socioeconomic status [9, 13]. HL deficits are widespread; the European Health Literacy Survey revealed that almost 50% of the respondents had limited HL [14]. In the USA, a large-scale national assessment of adult HL levels administered to more than 19,000 Americans showed that only 12% of Americans had proficient HL skills [15].

However, the opinion on what constitutes HL varies. According to the European HL Consortium, HL “entails people’s knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course” [16, p. 4]. It is sometimes referred to as “comprehensive HL” [17]. While some experts view health knowledge (e.g. vocabulary and health knowledge) as a domain of HL, others view it only as a predisposing factor for HL [13]. Some experts differentiate between HL and other basic skills, such as reading, writing, listening, oral communication, and the ability to use math (numeracy), sometimes referred to as “primary literacy”, which are important skills in any health care setting [13,18]. Moreover, the traditional understanding of HL as an individual-level construct has recently been challenged, and a broader and more complex model that emphasizes contextual factors of the health care system has been embraced [10, 14, 19, 20].

Regardless of the various approaches to HL and its elements, it is relevant to nurses, as they need to communicate with their patients and educate them concerning their health conditions and related self-care and management. Specifically, nurses should be aware of their patients’ HL level to address their information needs effectively [21]. Furthermore, they should use evidence-based strategies that promote HL and ultimately empower patients to access, understand, appraise, and act on information that is needed for optimal health [22].

HL has been considered in studies focusing on patients with chronic conditions that require long-term management, such as asthma [23], HIV [24], hypertension [25, 26], diabetes [27], rheumatoid arthritis [28], and

chronic pain [29]. However, the question is what aspects of literacy such studies consider, what methods and instruments they use, and to what extent such instruments reflect the mentioned constructs of HL. As for literacy relevant for chronic pain management, i.e. chronic pain HL, answering such questions is especially important due to the mentioned high prevalence of chronic pain and its predicted future trends.

### **Review aims**

The aim was to conduct a scoping review to synthesize studies within the healthcare context that have dealt with chronic pain in adults and measured literacy, and to map the underlying definition of literacy, study designs, geographical location, and setting of the identified studies. The second aim was to explore what literacy instruments were used, what aspects of literacy such instruments reflected, and for what purpose they were used.

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## **Material and methods**

### **Methodology**

A scoping review methodology was used to address the mentioned review aims. Scoping reviews differ from systematic reviews; they are used to present a general overview of the evidence pertaining to a topic, explore new, emerging areas, and to clarify key concepts underpinning such areas and identify knowledge gaps [30]. Although a guideline (checklist) for reporting scoping reviews is not available, many authors follow Peters et al.’s [31] scoping review guidance, which has been endorsed by the Joanna Briggs Institute [30]. Specifically, to identify instruments that exist to measure chronic pain HL in adults, the following review question was defined: “What tools are currently available to measure chronic pain management literacy?” This question guided the search strategy.

### **Identifying relevant studies**

The researchers determined clear inclusion and exclusion criteria for deciding on the sources to be included in the review (Table 1). As for the types of articles, only primary research articles published in a peer-reviewed journal were considered (both quantitative and qualitative); however, research study protocols were not considered. The articles had to be published in English, up to May 31, 2018.

As for the type of participants, studies were considered if they focused on adults, i.e., one of the following three conditions was met: (1) it was mentioned in the study that the participants were “adults”, (2) the age of the study participants was  $\geq 18$  years, or (3) their average age was  $\geq 45$  years (if neither age criteria nor age range was reported). Furthermore, the participants had to be dealing with chronic pain issues. Specifically, studies were considered if they focused on any “chronic pain” or pain that lasted or recurred for  $\geq 3$  months. Studies that examined other issues faced by the study participants

**Table 1 – Inclusion and exclusion criteria**

Criterion	Inclusion	Exclusion
Period	Any time up to May 31, 2018	Any study after this date
Language of the publication	English	Non-English
Type of article	Original research (both quantitative and qualitative) article published in a peer-reviewed journal, with published results	Any article that was not original research and/or was not published in a peer-reviewed journal
Study population	Adults (≥18 years) with chronic pain or with pain lasting or recurring for ≥3 months	Age <18 years; no study participants facing chronic pain management issues
Study focus	The use or development of an instrument to measure literacy in the study participants; the study should provide a description of the literacy instrument	No description of a literacy instrument
Geographical area of interest	Any geographical area, including international as well as local studies	None
Setting	Any	None

in addition to chronic pain were considered as well, and so were studies that used – in addition to a subgroup of patients with chronic pain – a control group without chronic pain, or subgroups of patients dealing with other health issues than chronic pain.

In order to be included in the review, the study had to provide a description of an instrument that measures literacy in the mentioned study participants. Only partial description of the instrument was sufficient (e.g., an overall description of the instrument's categories or a description of the scoring). The article could also include a description of interventions using the instrument, the development of a new instrument, or an exploration of the relationship between literacy and pain management behaviour or other relevant phenomena of interest. Any geographical areas, including international and local studies, were considered, and so was any setting.

### Search strategy

A three-step search strategy was used. An initial limited search of the PubMed database was performed to identify articles on this topic, and the words used in the title and abstract of the articles as well as the keywords informed the development of a comprehensive search strategy. Key search terms were identified, and truncation was used to enable broader searches using words with the same root and various endings. Two core Boolean search operators were used: OR and AND. In order to obtain only relevant results, the search using the above-mentioned key terms was limited to specific fields: either "Title/Abstract" (TI/AB) or "Abstract" (AB) (if "title/abstract" function was not available in a given database). An example of a final search string (in PubMed) was: (chronic pain[TI/AB]) AND (measur\*[TI/AB] OR tool[TI/AB] OR instrument[TI/AB] OR questionnaire[TI/AB]) AND (literacy[TI/AB]). Databases searched included PubMed, Cumulative Index of Nursing Allied Health Literature (CINAHL), MEDLINE Complete, ProQuest, SAGE Journals, Cochrane Library, Scopus, and Web of Science. Finally, reference lists of the obtained articles were scanned in order to identify any additional articles.

### Study selection

Using the developed search terms, 78 articles were identified through searches in the above-mentioned databases (Chart 1). After the deletion of duplicates, 51 articles remained. An additional 5 articles were identified through reference lists of the obtained articles. Next, screening of the articles was conducted, i.e., the title, abstract and keywords of the articles were scrutinized against the inclusion and exclusion criteria with the involvement of all members of the review team. This process led to the exclusion of 20 articles, which were considered irrelevant. The remaining articles were assessed in depth for eligibility; in order to do so, their full texts were obtained and read by two reviewers independently. Finally, the reviewers met to discuss their findings and whether or not the articles met the eligibility criteria; any disagreements between them were resolved through a discussion. Overall, 14 studies remained and were included for data abstraction.

### Methodological quality appraisal

A methodological quality appraisal was not conducted, which is consistent with guidance on scoping review conduct [30, 31].

### Data extraction and synthesis

Data were extracted from studies included in the scoping review by two independent reviewers; relevant units of text from the studies were charted into a Microsoft Excel table, using a framework established a priori as a guide. The data extracted included specific details about the study design, respondents, definition of literacy, study objectives, literacy instruments, geographical context, and setting, as determined by the specific aims of the scoping review. The synthesis of the extracted data included quantitative analysis (e.g., frequency analysis) of the phenomena of interest (e.g., the definition of literacy, type of study, geographical location, and setting) as well as qualitative analysis (i.e., content analysis). Any disagreements that arose between the reviewers were resolved through discussion, or with the third reviewer.

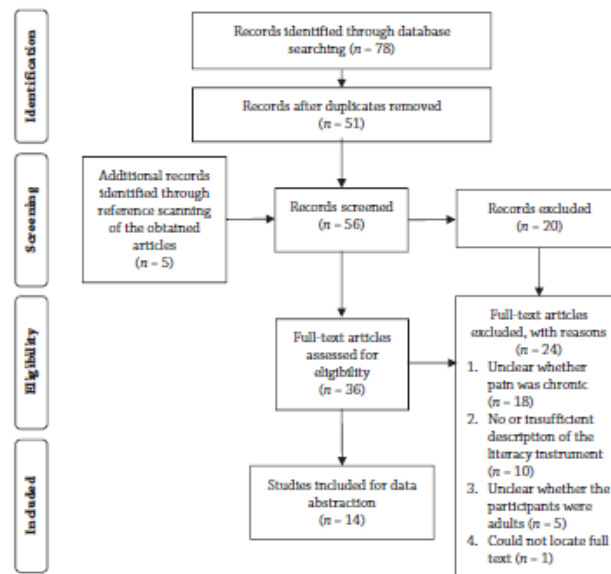


Chart 1 – Scoping review flow diagram [28]

## Results

### Frequency analysis

Of the 14 studies that were included for data abstraction (see Table 2), most ( $n = 11$ ) were quantitative and based on a definition of literacy that focused on individuals, i.e.,

either on their reading level ( $n = 3$ ) or on their abilities (competencies) to access, read, understand, appraise, and act on health information ( $n = 8$ ). Three studies viewed HL as an interaction between individual-level characteristics and contextual factors, e.g., comprehensibility of health education programmes [12, 19, 41]. Most studies were conducted in the USA ( $n = 5$ ) and Germany ( $n = 4$ ); outpatient clinics were the most frequent setting.

Table 2 – Study characteristics – frequency analysis ( $N = 14$ )

Study characteristics		Count (%)
Type of study	Quantitative	Cross-sectional RCT
	Mixed	Cross-sectional / focus groups / cognitive interviews Cross-sectional / in-depth interviews
Literacy definition	As an individual-level construct	Reading level <sup>a</sup> The person's abilities (competencies) to access, read, understand, appraise, and act on health information (comprehensive HL) <sup>b</sup>
	As an interaction between individual-level and contextual factors	
Continent / Country	Europe	Germany
		Austria
		Switzerland, Italy
	North America	USA
	Australia	Australia
Asia	Japan	
Setting		Home/community
		Outpatient
		Inpatient
		Mixed

Legend: HL, health literacy; N, number of studies included for data abstraction; RCT, randomized controlled trial; <sup>a</sup> referred to as primary literacy [18, 32, 33] or as general literacy [34] rather than HL; <sup>b</sup> there were slight differences in the definition of HL contained in the individual studies.

**Table 3 – Study characteristics – content analysis**

Author (publication date)	Study design	Country	Setting	Literacy definition	Literacy instrument (no. of items)	N
Briggs et al. [37]	Mixed (cross-sectional; in-depth interviews)	Australia	Community	Comprehensive HL <sup>a</sup>	S-TOFHLA (40 items)	117 (CP 47.9%)
Briggs et al. [38]	Cross-sectional	Australia	Community	Comprehensive HL <sup>a</sup>	HELMS (29 items)	80 (CP 45%)
Camerina and Schulz [35]	Cross-sectional	Switzerland, Italy	Outpatient and inpatient departments	Comprehensive HL <sup>a</sup>	Lower Back Pain Knowledge Questionnaire (12 items)	273 <sup>f</sup>
Day and Thorn [32]	Cross-sectional	USA	Outpatient health clinics	Reading level <sup>b</sup>	WRAT-4	115 <sup>f</sup>
Devraj et al. [40]	Cross-sectional	USA	Outpatient family health centre	Comprehensive HL <sup>a</sup>	NVS (6 items)	139 <sup>f</sup>
Farin et al. [19]	Mixed (cross-sectional; focus groups; cognitive interviews)	Germany	Inpatient rehabilitation centres	An interaction between individual-level and contextual factors	COHEP questionnaire (30 items)	577 (CP 55.3%)
Farin et al. [12]	Cross-sectional	Germany	Inpatient rehabilitation centres	An interaction between individual-level and contextual factors	HELP questionnaire (18 items)	577 (CP 55.3%)
Farin et al. [41]	Mixed (cross-sectional; focus groups; cognitive interviews)	Germany	Inpatient rehabilitation centres	An interaction between individual-level and contextual factors	HELP questionnaire (18 items)	1,264 (CP 48.3%)
Gellert et al. [36]	Cross-sectional	Germany	Home	Comprehensive HL <sup>a</sup>	HLS-EUQ16 (16 items); health knowledge test on 6 chronic conditions <sup>e</sup> (CP subscale: 4 items)	4,144 (CP 8%)
Kimble et al. [34]	Cross-sectional	USA	Outpatient clinic	Comprehensive HL <sup>c</sup>	SORT-R <sup>d</sup>	27 <sup>f</sup>
Kogure et al. [39]	Cross-sectional	Japan	Outpatient clinic	Comprehensive HL <sup>a</sup>	NVS-J (6 items); CGI-HL (5 items) <sup>a</sup>	43 <sup>f</sup>
Koppen et al. [29]	Cross-sectional	Austria	Outpatient clinics	Comprehensive HL <sup>a</sup>	HL "screening questions" (3 items) <sup>a</sup>	121 <sup>f</sup>
Newman et al. [18]	Cross-sectional	USA	Community health centres; community outreach (flyers, snowballing, etc.)	Reading level <sup>b</sup>	WRAT-4	290 <sup>f</sup>
Thorn et al. [33]	RCT	USA	Outpatient health clinics	Reading level <sup>b</sup>	WRAT-4	83 <sup>f</sup>

Legend: CGI-HL, global impression scale of participants' comprehensive HL levels; COHEP, comprehensibility of health education programs; CP, chronic pain; HELMS, The Health Literacy Measurement Scale; HELP, health education literacy of patients with chronic musculoskeletal diseases; HL, health literacy; HLS-EUQ16, The European Health Literacy Survey; N, sample size; No., number; NVS, The Newest Vital Sign; RCT, randomized controlled trial; SORT-R, The revised Sloan Oral Reading Test; S-TOFHLA, The short form Test of Functional Health Literacy in Adults; WRAT-4, The Wide Range Achievement Test-4.

<sup>a</sup> there were slight differences in the definition of comprehensive HL contained in the individual studies.  
<sup>b</sup> referred to as primary literacy (not HL).  
<sup>c</sup> divided into two categories: the ability to read and comprehend health education material (medical literacy); the skills to successfully negotiate the health care system (functional health literacy).  
<sup>d</sup> the instrument measures patients' basic ability to read common vocabulary words, which the authors referred to as general literacy. <sup>e</sup> the instrument does not have any specific name.  
<sup>f</sup> 100% with CP.

## Content analysis

Content analysis of the obtained studies identified 12 different instruments that met the inclusion criteria for the review; the amount of available detail concerning individual items, the method of administration, and scoring varied (Table 3). The instruments were analysed from the viewpoint of their focus and their purpose.

### Focus of literacy instruments

Ten instruments measured individual-level characteristics: either reading level, condition-specific knowledge, or comprehensive HL. The Wide Range Achievement Test-4 (WRAT-4) tested the participants' reading level, i.e. their basic ability to read common vocabulary words [18, 32, 33], and so did the revised Slosson Oral Reading Test (SORT-R) [34]. Two instruments tested condition-specific knowledge: The lower back pain (LBP) Knowledge Questionnaire [35] and a health knowledge test on six chronic conditions (including chronic pain) [36]. The following instruments were used to assess selected or all aspects of comprehensive HL: The short form Test of Functional Health Literacy in Adults (S-TOFHLA) [37], the Health Literacy Measurement Scale [38], the 16-item European Health Literacy Survey (HLS-EUQ16) [36], the global impression scale of participants' comprehensive HL levels [39], HL "screening questions" [29], and the Newest Vital Sign (NVS) in its original, English version [40] and a new, Japanese version [39]. Two newly developed instruments were used to assess an interaction between the person's abilities and the contextual factors of the health care system: The health education literacy of patients with chronic musculoskeletal diseases (HELP) questionnaire [12, 41] and the comprehensibility of health education programmes (COHEP) questionnaire [19].

### Purpose of use of literacy instruments

Most studies used instruments in order to examine the relationship between HL and various pain-related variables, such as pain intensity [29, 32, 38], pain perception [29] the impact of pain [32, 38], pain awareness [40], pain-related knowledge [36, 40], and beliefs and experiences in seeking, understanding and utilizing CP information [37]. Two studies used instruments to explore the relationship between HL and variables potentially relevant not only in the context of chronic pain, i.e. patient empowerment [35] and patient communication competence [41]. One study aimed to translate an existing instrument (NVS) into Japanese and validate it [39]. Several studies used literacy instruments solely to screen patients and to ensure they met the determined inclusion criteria. Specifically, this was the case in studies involving low socioeconomic groups [18, 33, 34], in which a certain minimum literacy level was necessary in order to ensure participants' understanding of the required procedures. Finally, two newly developed questionnaires (the HELP and COHEP questionnaires) were used in order to examine the interaction between individual-level characteristics and contextual factors [12, 19, 41].

## Discussion

Overall, most obtained studies were cross-sectional. While such studies can be conducted relatively fast and are inexpensive, it is difficult to derive causal relationships from studies based on such a design [42]. However, because HL is a complex phenomenon, it is not very amenable to randomized controlled trials (RCTs) [16]. In fact, only one study was an RCT; it examined the feasibility, tolerability, acceptability, and efficacy of group cognitive behaviour therapy compared to a group education intervention in low-socioeconomic groups [33]. However, the effect of these interventions was studied from viewpoints other than HL, and the WRAT-4 was used solely to determine whether the approached patients met the study inclusion criteria.

The fact that no studies were purely qualitative could have been caused by the search strategy used for the review. Despite this, a qualitative approach was included in three studies that used a mixed study design. Two of them aimed to develop and test a patient questionnaire; the involvement of focus groups and cognitive interviews in the qualitative part enabled the integration of the views of patients and providers in generating questionnaire items for the quantitative part of the study [19, 41]. The third study included in-depth interviews with patients in order to explore their chronic pain-related beliefs and their experiences in seeking, understanding, and utilizing information on chronic pain [37], i.e. to explore areas arising from constituents of HL that are congruent with the above-mentioned definition of comprehensive HL. This approach is especially valuable since it focuses on HL while also considering chronic pain issues. Apart from this, only two of the identified literacy instruments focused on pain; both were knowledge questionnaires. In all other cases, "generic" literacy instruments were used, i.e. instruments not intended solely for patients with chronic pain. Thus, further research could focus on the development of chronic pain-specific instruments.

As mentioned, most chronic pain HL research has been conducted in only selected high-income Western countries. One study aimed to translate an existing instrument – the NVS – into another language. The NVS is comprised of 6 questions about an ice cream nutrition label. It assesses HL numeracy skills and the ability of participants to make reasonable health-related decisions [39]. However, researchers need to think carefully about whether a specific instrument is suitable for translation into another language. For example, the NVS is based on a nutrition label and its use, which again is a well-researched area only in high-income Western countries [43]. Thus, it might not be a suitable instrument for other countries. Similarly, the 4-item chronic pain subscale of the health knowledge test on six chronic conditions includes an item concerning the reimbursement of acupuncture treatment by public health insurance [36], which is clearly an item specific to Germany, i.e. the country where the instrument originated.

Finally, the purpose of use of the literacy instruments varied, and so did the HL aspects that were measured.

This variety could easily lead to confusion. Thus, as the WHO pointed out, researchers need to be clear about what is measured and why [16]. The two newly developed questionnaires that include contextual factors in addition to individual-level factors could be considered at least a partial answer to the WHO's recommendation that the existing literacy instruments should be expanded to include literacy-friendliness of materials, organizations, and the environment [16]. Nurses could contribute to addressing the mentioned challenges and improving the HL of their patients as well as the general public [44]. They could do so by adopting such strategies as screening patients for low HL through key questions in the patient's history, simplifying patient teaching materials, and constantly validating that patients and their families understand the conveyed message while also creating a shame-free environment [22].

## Conclusions

The scoping review revealed that chronic-pain HL is a topic with emerging research. However, most instruments that have been used so far are generic and are oriented mainly towards individuals. Thus, chronic pain-specific instruments should be developed, and the existing instruments should be expanded to include contextual factors as well. All obtained studies have taken place in high-income Western countries. Thus, research in other countries is urgently needed, especially given the current and predicted future global trends concerning non-communicable diseases and chronic pain. Nurses need to be involved to mitigate negative patient outcomes arising from suboptimal HL.

## Conflict of interests

The authors have no conflict of interests to disclose.

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