

What is the meaning of health literacy? A systematic review and qualitative synthesis

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ABSTRACT

The objective of this review was to clarify what health literacy represents. A systematic review with qualitative syntheses was performed (CRD42017065149). Studies concerning health literacy in all settings were included. Studies before 15 March 2017 were identified from PubMed, Medline, Embase, Web of Science, Scopus, PsycARTICLES and the Cochrane Library. The included literature either had defined the concept of health literacy or made a detailed explanation of health literacy. A total of 34 original studies met the inclusion criteria, including 13 involved in previous systematic reviews and 21 new studies. Health literacy was commonly conceptualised as a set of knowledge, a set of skills or a hierarchy of functions (functional-interactive-critical). The construct of health literacy covers three broad elements: (1) knowledge of health, healthcare and health systems; (2) processing and using information in various formats in relation to health and healthcare; and (3) ability to maintain health through self-management and working in partnerships with health providers. Health literacy is defined as the ability of an individual to obtain and translate knowledge and information in order to maintain and improve health in a way that is appropriate to the individual and system contexts. This definition highlights the diversity of needs from different individuals and the importance of interactions between individual consumers, healthcare providers and healthcare systems.

services.¹⁰ Inadequate health literacy is associated with difficulties in comprehension of health information, limited knowledge of diseases and lower medication adherence, which contribute to poor health, high risk of mortality, insufficient and ineffective use of healthcare, increased costs, and health disparities.^{4 6 11} The existing evidence seems to suggest health literacy as one of the most promising and cost-effective approaches to overcome the NCD challenges.^{12 13} Many countries have included health literacy as a key priority in their policies and practices, such as the USA, Canada, Australia, the European Union and China.¹⁴ The WHO recommends health literacy as an instrument for achieving several key targets listed in the Sustainable Development Goals.¹⁵

Despite the realisation of the importance of health literacy to human health and extensive studies into this area over the past few decades, there is still a lack of consensus on 'what the concept actually represents'.¹⁶ Such an essential research question has often been overlooked.¹³ The concept of health literacy seems to be very flexible, which allows anyone to identify nearly whatever one wants as health literacy. Over 250 different definitions exist in the academic literature.¹⁷ The unclear and inconsistent interpretations of health literacy are projected to limit the development of valid and reliable measurements, the accurate evaluation and comparisons of health literacy initiatives, and the synthesis of evidence to support strategies for improving health literacy.^{13 14 16–18} Furthermore, the confusion of the concept is likely to produce disjointed and even contradictory findings, jeopardising the development and implementation of trustworthy and effective health literacy-related interventions and policies.^{13 14 16}

This study aimed to clarify 'what health literacy represents' through a systematic

INTRODUCTION

Health literacy, as a term first proposed in the 1970s,¹ generally concerns whether an individual is competent with the complex demands of promoting and maintaining health in the modern society.² Over the past two decades, increasing attention has been attached to the concept due to its significant benefits to individual and public health and the sustainability of healthcare systems.^{3–8} It is considered particularly important when non-communicable diseases (NCDs) prevail and their corresponding costs are steadily rising,⁹ highlighting the need for people to take more responsibility in managing their own health with more effective use of health



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review and qualitative synthesis of existing studies across different contexts in relation to this complex concept.

METHODS

Search strategy and selection criteria

A systematic review following a registered protocol (no: CRD42017065149) was conducted, which followed the ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative research) guidelines. The search strategy was adapted based on a previous systematic review,⁵ using a combination of keywords such as 'health literacy', 'definition', 'concept' and so on. We searched PubMed, Medline, Embase, Web of Science, Scopus, PsycARTICLES and the Cochrane Library and restricted our search to articles published from 1 January 2010 to 15 March 2017 (date of last search) simply because the most recent systematic review analysed literature published before 2010 (details of the search protocol in online supplementary table S3).

Title, abstract and full texts of retrieved records were examined by two authors against the inclusion and exclusion criteria, independently. Discrepancies, if occurred, were resolved through consultations with the third author.

The included literature either had an explicit objective to define the concept of health literacy or made an implicit contribution to people's understanding of health literacy: for example, studies that explored the constructs of health literacy. Studies with an interpretive nature using an existing conceptual framework without making further contributions to the conceptualisation of health literacy, without any theoretical presentation of the concept of health literacy and those that were not written in the English language were excluded.

Additional studies were identified at this stage through scrutinising references of the included literature. These included studies published before 2010 but had been omitted in the two previous systematic reviews.^{5 19}

Data analysis

A data collection chart (online supplementary table S4) was developed and guided the extraction of the bibliographic information and the results of the conceptualisation of health literacy in the included studies. The bibliographic information covered study objectives and methods, describing why and where the study was undertaken, who participated in the study, and how data were collected and analysed. The results of the conceptualisation of health literacy focused on the underlying constructs and meaning of health literacy.^{5 19} Two of the authors extracted data independently. The two sets of chart were crosschecked and eventually amalgamated through group discussions.

A data-driven thematic analysis was adopted using a semigrammatical coding approach.²⁰ According to Braun and Clarke,²¹ this involved four steps: data familiarisation, initial coding, themes searching, and themes reviewing and naming.

In the first step, included studies were repeatedly read, and all statements relevant to the research question were identified using the data collection chart, forming a data pool for qualitative syntheses. A total of 570 statements were recorded.

In the second step, each statement was divided into several parts using a semigrammatical coding approach, which included cores, actions, objects, aims and others (such as context). For example, Freedman *et al.*²² interpreted health literacy as 'the skills necessary to obtain, process, evaluate, and act upon information needed to make public health decisions that benefit the community'. This statement was coded as 'necessary skills' (cores), 'to obtain, process, evaluate and act upon' (actions), 'needed information' (objects), and 'to make public health decisions that benefit the community' (aims).

The third step extracted shared common themes. The clustering procedure was mainly based on the codes (n=74) labelled as 'cores', but also considered other codes (actions, objects, aims and others) embodied in each statement.

Finally, the extracted themes were reviewed against the initial coding and data pool and renamed if necessary. This was to ensure that the data pool was well represented and the relationships between codes and themes were not distorted.

Two reviewers conducted steps 1 and 2 independently, and their results were crosschecked and reconciled through negotiations. Steps 3 and 4 were conducted in groups. Consensus was achieved through constant negotiations and discussions within the research team.

RESULTS

Characteristics of included studies

A total of 6029 records were retrieved from the databases and 2368 duplications were removed. After screening of titles and abstracts, 589 studies were kept for full-text reviewing. The full-text reviews identified 569 studies that failed to meet our inclusion criteria: 394 due to a lack of conceptualisation; 139 due to their interpretive nature for existing conceptual frameworks; 3 due to a lack of interpretations of the concept; and 33 due to language barriers (non-English publications). We then added the 13 studies included in the two previous systematic reviews.^{5 19} One more study was identified from references screening. This resulted in a final sample size of 34 for our systematic review (figure 1).

About two-thirds of the included studies explored the concept of health literacy in general populations,^{3-5 19 20 22-37} while the others focused on children and adolescents,³⁸⁻⁴² elderly people,⁴³ patients with chronic diseases,⁴⁴⁻⁴⁷ gay men,⁴⁸ cancer caregivers,⁴⁹ and people with limited English proficiency.⁵⁰ Most studies adopted a broad and general concept of health literacy without restricting to a specific health topic. But eight studies placed the concept of health literacy under a particular context, such as public health,²² sexual health,⁴⁸ tobacco control,⁴¹ complementary medicine,³⁷ verbal exchange of

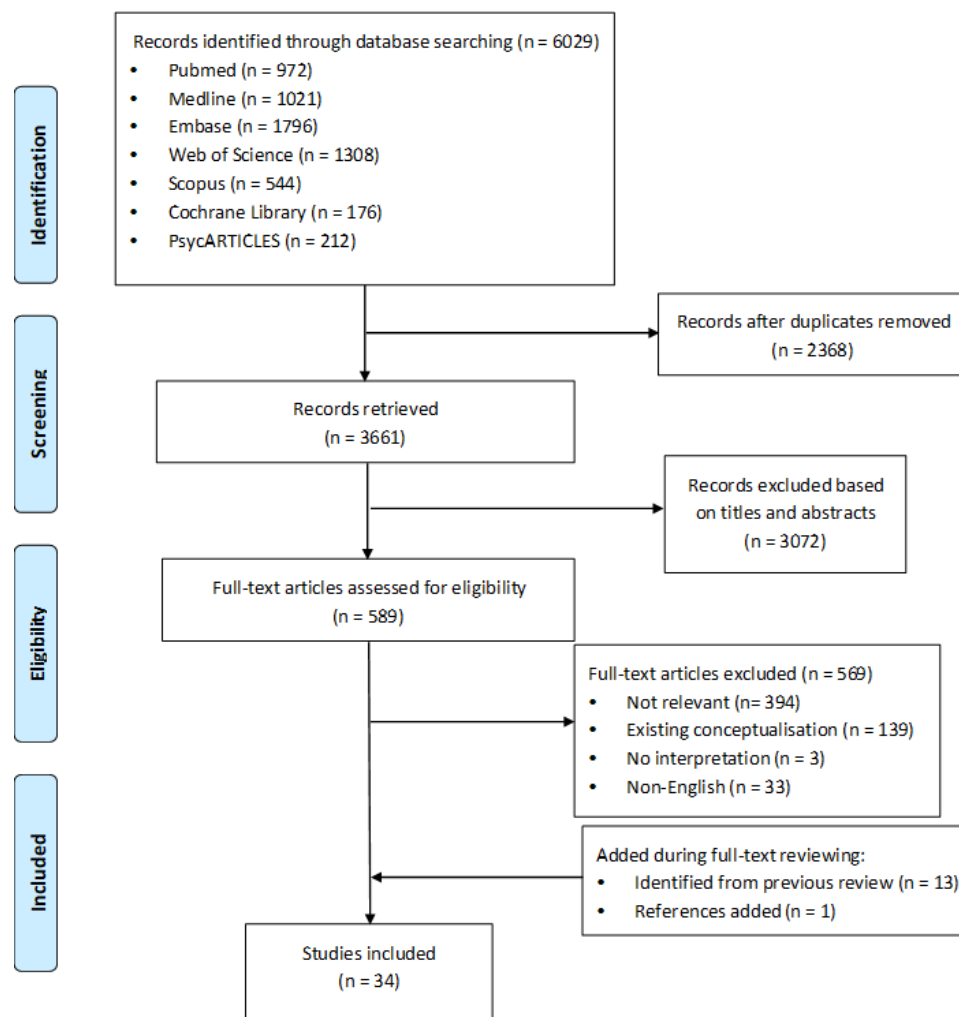


Figure 1 ENTREQ flow diagram of systematic review.

information,³⁵ functional health⁴⁷ and critical thinking^{34,36} (online supplementary table S1).

Of the 34 included studies, 19 involved original data^{4,5,19,20,23,24,26,28,32,35–37,39,41–44,48,49} and 15 were theoretical proposals.^{3,22,25,27,29–31,33,34,38,40,45–47,50} The former performed concept analyses,^{28,32,36,43} concept mapping,^{23,49} thematic analyses,^{5,19,24,35,41,42,48} grounded theory analyses,^{26,35,39} semigrammatical analyses²⁰ or framework analyses⁴⁴ on qualitative data collected from documents, interviews or focus groups. The latter were largely views from experts, with limited information about how the conceptualisation was done. Those theoretical studies were usually published before 2013 during the early stage of arguments about the concept of health literacy. Since then, the literature has been dominated by empirical studies (online supplementary table S1).

What is health literacy?

Health literacy was commonly conceptualised as a set of knowledge, a set of skills or a hierarchy of functions (functional-interactive-critical).

Four studies highlighted knowledge as the core in the concept of health literacy. Schulz and Nakamoto²⁵ identified health literacy as a set of basic literacy, declarative

knowledge, procedural knowledge and judgement skills. Declarative knowledge represents people's understanding of factual information about health, while procedural knowledge represents people's understanding of rules that guide people's reasoned choices and actions. In combination, they enable people to acquire and use information in various contexts and govern the competence of different tasks.²⁵ Similarly, Paakkari and Paakkari³⁸ defined health literacy as a set of theoretical knowledge, practical knowledge and critical thinking, corresponding to declarative knowledge, procedural knowledge and judgement skills proposed by Schulz and Nakamoto.²⁵ In addition, Paakkari and Paakkari³⁸ argued that self-awareness and citizenship also form a part of health literacy because they represent one's ability to assess oneself in an informed way and to take responsibility to improve health beyond a personal perspective. Rowlands *et al*²⁴ found that health literacy is reflected in people's ability to acquire, understand and evaluate knowledge for health. Shreffler-Grant *et al*⁸⁷ specified the knowledge regarding the dosage, effect, safety and availability of medicines as health literacy associated with complementary medicines (online supplementary table S1).

Arguably, the Institute of Medicine (IoM) presented one of the most influential models of health literacy. The IoM model contains four underlying constructs: cultural and conceptual knowledge, print health literacy (writing and reading skills), oral health literacy (listening and speaking), and numeracy.⁴ It has a strong focus on the required skills for people to obtain, process and apply information for the purpose of medical care. This model has attracted support from many researchers. For example, Baker³⁰ refined the contents of health-related print literacy and oral literacy in general populations. Harrington and Valerio³⁵ refined details of verbal exchange of health information, similar to the concept of oral health literacy. Yip⁵⁰ argued that speaking, reading, writing, listening and numeracy are particularly important for people with limited English proficiency. Squiers *et al*¹⁹ added negotiation skills into oral health literacy and re-labelled it as communication skills. Navigation skills were also proposed by Squiers *et al*¹⁹ as an important element in the eHealth context. Sørensen *et al* summarised the literature and presented skills to access, understand, appraise and apply information and knowledge as four core skills of health literacy, which can cover all related works that people need to carry on when dealing with health information to improve and maintain health.⁵ Mancuso²⁸ and Oldfield and Dreher⁴³ emphasised the importance of comprehension skills. Speros³² further added successful functioning in the patient role as a core construct of health literacy (online supplementary table S1).

Several studies viewed health literacy as a hierarchy of functions, which require different levels of social and cognitive skills. Nutbeam³ first proposed the three-level model: functional health literacy, interactive health literacy and critical health literacy. This model was further clarified and expanded by several researchers.^{34 36 40–42 45 47} In Nutbeam's prototypical model, functional health literacy refers to 'basic skills in reading and writing to enable individuals to function effectively in everyday situations'; interactive health literacy covers 'more advanced skills to extract information and derive meaning from different forms of communication, and to apply new information to change circumstances'; critical health literacy requires 'the highest-level of skills to critically analyse and use information to exert greater control over life events and situations'.³ Schillinger⁴⁷ interpreted functional health literacy as literacy and numeracy. Chinn³⁴ considered critical health literacy as the function of understanding social determinants of health and engaging in collective actions. Sykes *et al* believed that critical health literacy covers advanced personal skills, health knowledge, information skills, effective interactions between service providers and users, informed decision making, and empowerment including political actions.³⁶ Manganello⁴⁰ added media literacy, the ability to critically assess media messages, as a separate construct into health literacy for adolescents to highlight the importance of media use in the specific population. Liao *et al*⁴² examined the meaning of the Nutbeam model in children:

functional health literacy—understanding basic health concepts, comprehending the relationship between health behaviours and health outcomes, and performing basic health behaviours; interactive health literacy—maintaining good relationships with peers, appropriately expressing oneself and responding to others, and sufficiently understanding a variety of information from the environment; critical health literacy—assessing, analysing and predicting the influence of health information of all types and responding appropriately (online supplementary table S1).

Apart from the abovementioned models, some researchers attempted to conceptualise health literacy from other perspectives. Drawn on experts' views, Soellner *et al*²³ proposed addition of self-perception, proactive approach to health, self-regulation and self-control into the concept of health literacy. By contrast, Jordan *et al*²⁶ examined the views of patients and proposed three dimensions of health literacy: identifying a health issue (knowing when and where to find health information), engaging in information exchange (verbal communication skills, assertiveness and literacy skills) and acting on health information (capacity to process and retain information, and application skills). Buchbinder *et al*²⁰ combined the views from both patients and health professionals and summarised health literacy as knowledge, attitude, attribute, relationship, skills, actions and context in relation to 16 aspects such as diseases, health systems, information and others. Several studies emphasised some special elements critical to a particular population: for example, consistency, delivery and contents of information for sexual health of gay men⁴⁸; self-management skills and active involvement in consultations for patients with chronic diseases⁴⁴; relationships and support systems for cancer caregivers⁴⁹; patient-provider relationship and preventive care (indicating a proactive approach to health); and the rights and responsibilities (capturing principles of self-efficacy and empowerment to manage one's health environment) for adolescents.³⁹ Freedman *et al* focused on public health literacy and proposed civic orientation, indicating skills and resources needed to address health concerns by civic engagement, as one of the aspects of health literacy.²² Zarcadoolas *et al*³¹ added science literacy (competence with science and technology) and cultural literacy (ability to notice and use various beliefs, customs and values) as common features required for interpreting and acting on health information (online supplementary table S1).

Elements of health literacy

The thematic analysis extracted three key themes that are well representative of the various models adopted in the included studies: (1) knowledge of health, healthcare and health systems; (2) processing and using information in various formats in relation to health and healthcare; and (3) ability to maintain health through self-management and working in partnerships with health providers (online supplementary table S2).

Knowledge of health, health care and health systems

The theme of knowledge refers to the understanding of factual information about health and can be further divided into four aspects, namely knowledge of medicine, knowledge of health, knowledge of health systems and knowledge of science.^{4 20 22 23 25 31 34 36–39 42–44 49} Knowledge of medicine refers to the understanding of information under the medical context, such as medications, treatments and illness states, while knowledge of health is focused on understanding information in regard to health under everyday situations, for example, healthy behaviours, healthy lifestyle, health terms and public health. Knowledge of healthcare systems refers to the understanding of information about the basic structure and available services of a health system, which helps people use the system in a more effective and efficient way. Finally, knowledge of science refers to the understanding of fundamental scientific concepts and scientific arguments (online supplementary table S2).

Processing and using information in various formats in relation to health and healthcare

This theme concerns whether people are able to process and use information in relation to health and healthcare effectively. It can be further divided into four subthemes: ability to process and use information to guide health actions, self-efficacy in processing and using health information, provision of health information (active engagement in dissemination of consistent information in a language that is appropriate to consumers), and access to resources and support for processing information.

Ability to process and use information to guide health actions

This subtheme refers to the multidimensional skill set that is necessary for dealing with and applying information in health actions. It has been widely accepted as an essential component of health literacy in the existing literature. The skill set contains general skills of literacy and numeracy, such as reading, writing, numeracy, listening and speaking, as well as special skills for obtaining, understanding, appraising, communicating, synthesising and applying health-related information. A health-literate consumer knows when and where to seek, find and retrieve printed information and whom to talk to for information advice; is able to comprehend the meaning of obtained information; and can assess the credibility and scientific context of the information and its relevance to oneself. The skill set also enables the consumer to share obtained information with others and express her/his own preferences effectively. The ability to compare, contrast, weigh up and integrate relevant information is required for the purpose of applying the information in making decisions at the individual level and/or at the societal level (online supplementary table S2).

Self-efficacy in processing and using health information

Self-efficacy is a psychological concept which refers to one's belief in one's ability to succeed and subsequent

efforts put in executing the tasks.^{20 23 26 28 36 38 39 49} Two components emerged from the subtheme 'self-efficacy in health actions': self-confidence and accountability. Self-confidence indicates the following psychological features: articulating oneself bravely, questioning healthcare providers and ensuring full comprehension of health information by asking for further clarifications. Accountability refers to one's attitudes towards her/his own health and willingness to take responsibilities in managing her/his health. Self-efficacy determines how a person perceives health and applies health information in health actions (online supplementary table S2).

Provision of health information (active engagement in dissemination of consistent information in a language that is appropriate to consumers)

Consumer communication and participation is important in all levels of health actions.^{20 30 39 48 49} Baker argued that the complexity of health information can become a serious barrier for people to engage in healthcare.³⁰ There is a consensus that consumers need to participate in the generation and dissemination of health information in order to ensure the simplicity, consistency and accuracy of the presentation and dissemination of health information. The approach to provision of information may help or hinder people's understanding, processing and use of information.

Access to resources and support for processing and using information

Resources and support are essential not only for realising one's own ability in processing and using knowledge and information in health actions, but also for complementing one's shortcomings in processing and using information. Statements in relation to this subtheme were first treated as a component of health literacy by Freedman *et al.*²² The contents of this subtheme were further clarified by several other researchers,^{20 24 36 49} covering four aspects: access to health information and information infrastructure (eg, library and online services), information support from healthcare providers, information support from social networks (family, friends, colleagues and community organisations), and external resources (eg, financial resources and time committed to processing and use of information) (online supplementary table S2).

Ability to maintain health through self-management and working in partnerships with health providers

This theme refers to one's ability of using her/his knowledge and information skill set to effectively manage health and illness conditions.^{20 23 28 38 42} This often involves both self-management and working in partnerships with health providers, requiring abilities of self-regulation, goal achieving and interpersonal skills. Self-regulation encompasses self-perception (awareness of one's own situation and preferences), self-reflection (critical analysis of oneself) and self-control (ability to control oneself). Self-regulation is critical to enable one

to obtain individual-tailored information and apply the information in a way that is appropriate to oneself. The ability of goal achieving refers to a series of skills, based on which people can set meaningful health goals, adjust strategies and eventually attain the goals. Interpersonal skills are associated with one's ability to understand, respect, listen and respond to others, and to build and maintain a harmonious relationship with them (online supplementary table S2).

DISCUSSION

In this study, we synthesised the results of 34 studies and found that health literacy has been commonly viewed as a set of knowledge, a set of skills or a hierarchy of functions (functional-interactive-critical). Three themes emerged from the 34 studies in regard to the concept of health literacy: (1) knowledge of health, healthcare and health systems; (2) processing and using information in various formats in relation to health and healthcare; and (3) ability to maintain health through self-management and working in partnerships with health providers.

Health literacy started as a concept associated with the individual ability in obtaining information and knowledge to support health actions. Not surprisingly, all of the included studies examined the concept of health literacy from the 'information and knowledge' perspective. The ability of an individual to process and use information to guide health actions has been a major concern of those studies.

Health literacy has been commonly interpreted as an ability to use general literacy skills (reading, writing, numeracy, listening and speaking) in obtaining, understanding, appraising, synthesising, communicating and applying health-related information. The previous systematic review identified 'accessing, understanding, appraising, communicating and applying' health information as the five core components of health literacy.⁵ But it ignores the fundamental role of general literacy skills,⁴ which can actually shape the needs and the way of one obtaining and using health-related information. For example, a person with a high level of knowledge and writing skills may not necessarily be able to convey information effectively in verbal conversations. The literature also suggests that 'information synthesising' is missing in the previous systematic review.^{5 19} 'Information synthesising' is particularly important in the information era, where people are inundated with enormous amount of information. Under such circumstances, people should be able to compare, weigh up and integrate various information to make an informed decision.

Knowledge can be considered as a result of information translation, or a precursor that determines how information is processed and used.^{25 38} Schulz and Nakamoto²⁵ and Paakkari and Paakkari³⁸ categorised knowledge into declarative/theoretical knowledge and procedural/practical knowledge. In this study, the latter one is grouped into the theme 'processing and use of information', while

the declarative/theoretical knowledge covers knowledge of medicine, knowledge of health, knowledge of health-care systems and knowledge of science.

The concept of health literacy has been evolving over the past decade. It started with a doubt about the usefulness of 'information and knowledge', simply because a highly knowledgeable person may not be able to materialise the benefits of acquired information/knowledge.^{20 23 26 49} As a result, some researchers recommended the addition of self-efficacy as a component of health literacy. Self-efficacy reflects the confidence and willingness of one in using information/knowledge for health actions. Some researchers proposed further expansion of the concept of health literacy, pushing it beyond the confinement to individual abilities.^{20 30 48 49} Health knowledge is usually produced by health professionals, while consumers are seen as passive recipients of knowledge. The language and clauses used by health professionals are often difficult, if not impossible, for consumers to understand.⁴⁸ This has resulted in a great deal of frustration in the interaction between health providers and consumers, prompting calls for increasing engagement of consumers in the synthesis and dissemination of knowledge information.

The conceptual expansion of health literacy came as a result of empirical enquiries into the meaningfulness of health literacy. Several studies explored the meaning of health literacy from the perspectives of different populations. Unlike the theoretical analyses at an early stage, these studies present empirical evidence for advocating a change in the concept of health literacy.^{12 18} The ability to maintain health using acquired information and knowledge is the utmost goal of the development of health literacy. This requires one to understand her/his own ability and situation and work in partnerships with others for achieving the best possible outcomes. Evidence from the UK shows that most patients, caregivers and health workers consider health literacy as a 'whole system outcome' rather than an attribute of individuals.⁵¹ Edwards *et al.*⁵² argued that one can acquire knowledge from others without necessarily going through the entire information processing process. When a person is looked after by a group of people from the family, the workplace, the health facility and the community, group health literacy appears to be even more important than individual health literacy. Access to resources and support can serve as a proxy indicator of 'group health literacy'.

This study makes a significant contribution to the conceptualisation of health literacy. Pleasant¹³ points out that none of the existing definitions of health literacy were generated through a robust and rigorous scientific approach. The widely used original definition of health literacy, based on the individual ability to process and use information for health gains, has failed to find its evidence support from an increasing body of recent empirical studies. We propose a renewed definition of health literacy, incorporating all relevant themes identified from the existing studies. Health literacy is "the

ability of an individual to obtain and translate knowledge and information in order to maintain and improve health in a way that is appropriate to the individual and system contexts'. This definition highlights the diversity of needs from different individuals and the importance of interactions between individual consumers, healthcare providers and healthcare systems for maintaining health. The whole-system view can help people better understand the role of health literacy and what needs to be done for improving health literacy. Such a whole-system view has been advocated by more and more researchers and practices.^{53 54}

Limitations

There are several limitations to this study. First, the included literature was limited to those published in English. Second, the quality of the publications was not assessed as there was, in general, a lack of detailed descriptions of methods in the publications, which included some highly cited and influential publications.^{3 4 22 29–31 33 47} A small number of the included studies did endeavour to provide information to ensure quality, including clear recruitment strategies of participants,^{26 36 39 41 42 44 49} detailed data collection process,⁴¹ justification of why a specific method/design was adopted,^{24 36 41 44} and critical examination of the researcher's own role in their studies.^{41 55} Along with more studies concerning 'health literacy' with detailed descriptions of methods published, further synthesis of qualitative studies adopting quality assessment would be soon achievable. Third, the proposed definition of health literacy via systematic review in the current study is only the first step; further studies adopting a Delphi process and/or consensus development conference are warranted to generate a refined and consensus for the definition and conceptualisation of health literacy.

CONCLUSIONS

Health literacy has been commonly conceptualised as a set of knowledge, a set of skills or a hierarchy of functions (functional-interactive-critical). We propose to define health literacy as the 'ability of an individual to obtain and translate knowledge and information in order to maintain and improve health in a way that is appropriate to the individual and system contexts'. Such a definition can cover the essence of the three broad themes identified from the literature review: (1) knowledge of health, healthcare and health systems; (2) processing and using information in various formats in relation to health and healthcare; and (3) ability to maintain health through self-management and working in partnerships with health providers.

Contributors CXL conceived of the scope of the review with XZ and CJL. Literature screening and review, data extraction and verification, and qualitative synthesis were conducted by CXL, DW and XZ. CXL drafted the first iteration of the manuscript. All authors made substantial contributions to the critical review, editing and revision of the manuscript. All authors approved the final version of the manuscript.

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