

The role of health literacy in the healthcare decision-making process

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Abstract

Health literacy is defined as “the knowledge, motivation, and competence to access, understand, appraise and apply information to make decisions in terms of healthcare, disease prevention, and health promotion” according to Quaglio et al.⁵ Poor health literacy has direct consequences on the ability to acquire and evaluate information on health issues.⁵ Therefore, strategies should be pursued to improve health literacy, from large-scale policy actions to optimise schooling to interventions targeted at small communities or patient groups. Medical writers and science communicators can play a proactive role in improving health literacy by providing faultless and correct content and drafting clear and understandable documents.

Introduction

One of the Agenda 2030 goals for Sustainable Development of the United Nations is the “quality of education to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all”.¹ A variety of efforts are planned to guarantee literacy and numeracy worldwide, regardless of age or gender, by 2030. For example, the European Union has included health literacy in its Health Development and Improvement Program (EU Regulation 2021/522).²

The principles, strategies, and actions to attain this goal are based on the modern conception of literacy as “a continuum of proficiency levels in a given context”, in contrast to the simplistic dichotomy of “literate” versus “illiterate”. Its ultimate objective is for individuals to acquire

adequate and recognised competence in both literacy and numeracy, corresponding to that attained through primary education.³

Education is one of the pillars of self-consciousness and is an essential tool for making informed choices about one’s health, wellbeing, work, family, and community. Education depends greatly on literacy and numeracy. Literacy is therefore considered a human right; it is not only a tool of personal awareness and empowerment but also a means for social and human development. Indeed, improving literacy and numeracy can help improve the socio-economic status of communities and promote sustainable development at the local, regional, and national levels.³ In 2016, UNESCO stated, “Literacy is a fundamental human right and the foundation for lifelong learning. It is fully essential to social and human development in its ability to transform lives.”⁴

Definition of health literacy

Health literacy is literacy related to health and wellbeing. This concept, which originated in the United States and Canada in the 1970s, has spread around the world and is used to define competencies in a public and personal health context.⁵ More specifically, health literacy is defined as “the knowledge, motivation, and competence to access, understand, appraise and apply information to make decisions in terms of healthcare, disease prevention, and health promotion”.⁵

Therefore, health literacy provides a level of knowledge, personal skills, and confidence to change lifestyles and living conditions, allowing individuals to improve their and their community’s health.⁵

Nutbeam et al.⁶ describes three dimensions of health literacy:

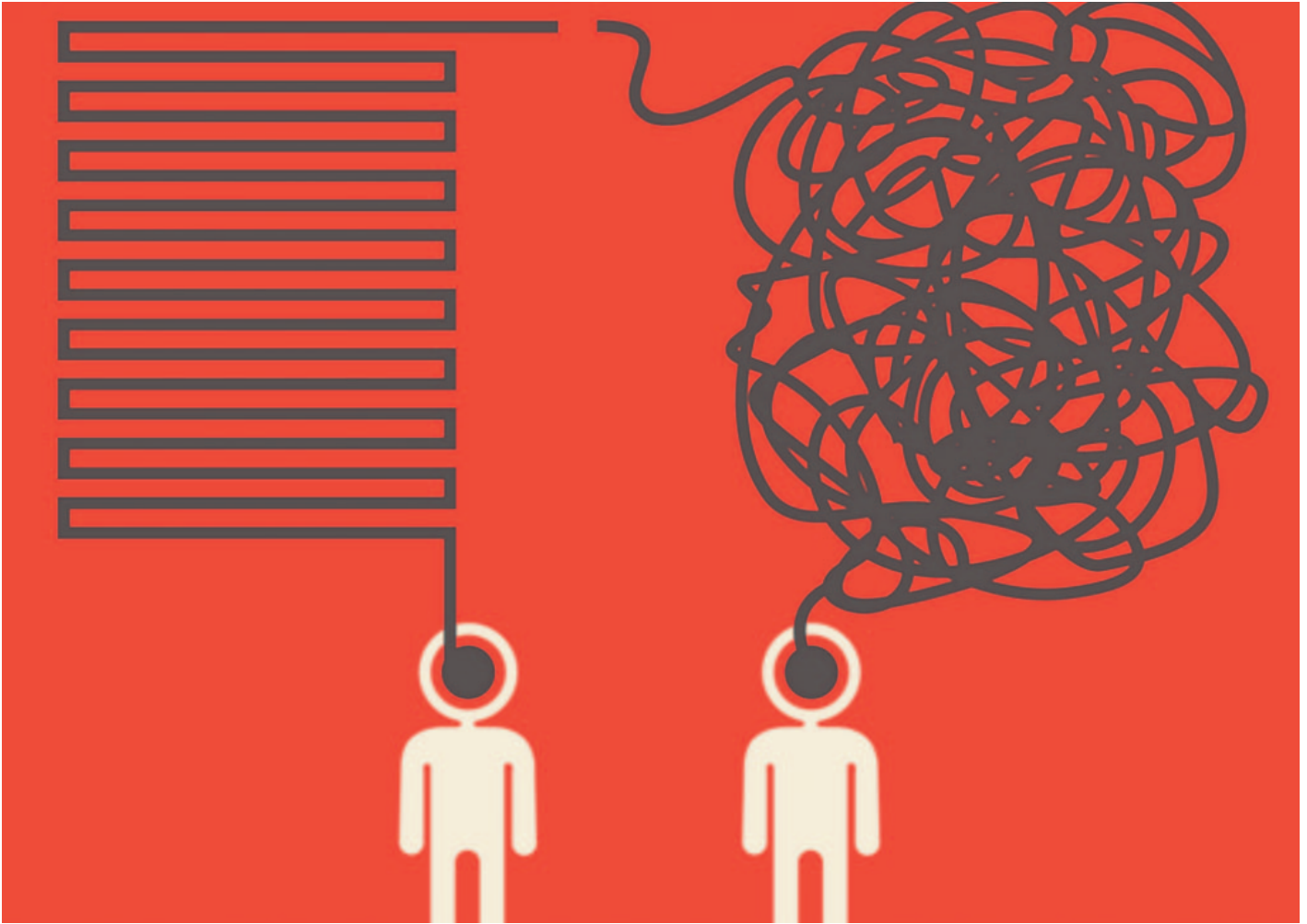
- Functional health literacy is “the ability to read health information.”⁶ This dimension sometimes includes numeracy (the ability to use mathematics in everyday life).
- Interactive health literacy refers to “more advanced cognitive and literacy skills, which, together with social skills, can be used to participate in everyday situations actively, extract information and derive meaning from different forms of communication, and apply this to changing circumstances”.⁶
- Critical health literacy refers to “more advanced cognitive skills which, together with social skills, can be applied to critically analyse information and use this to exert greater control over life events and situations”.⁶

Health literacy is defined as “the knowledge, motivation, and competence to access, understand, appraise and apply information to make decisions in terms of healthcare, disease prevention, and health promotion”.⁵

To increase health literacy, access to medical information and abilities to evaluate and critically to use it must be improved. Unfortunately, in a vicious circle, health literacy depends upon more general levels of literacy. Therefore, poor literacy can negatively affect health directly not only by limiting personal, social, and cultural development but also by hindering the development of health literacy.

Although health literacy is becoming increasingly important, few studies have systematically determined its level and the factors that determine and affect it.

A 2011 study in Europe by the European Health Literacy Project used the HLS-EU-Q, a multidimensional, comprehensive questionnaire that measures health literacy in the general population.⁷ The questionnaire uses a broad definition of health promotion as described by the World Health Organization in the Ottawa Charter.⁸ The survey found that more than 10% of all respondents and 1.8–26.9% by country had an inadequate level of health literacy. Furthermore, specific subgroups of the



population had the lowest health literacy, namely, people with poor health status, low socioeconomic status, lower school education, and older age. Financial deprivation was the strongest predictor of low health literacy, followed by social status, education, and age, whereas gender had a minor effect. Although the study included only a few European countries and had a limited sample size, the results should help understand the reasons for deficiencies and disparities in health literacy.⁷ The results also show that health literacy is a public health challenge in some European countries.⁴

Two case studies

Two case studies exemplify how poor health literacy can have direct consequences on the acquisition and evaluation of health-related information and how acquiring good health literacy can help individuals make good choices about their personal health.

Case study 1:

The spread of fake news in Italy about COVID-19 during the pandemic

An Italian study on misinformation about COVID-19 in Italy by Moscadelli et al.⁹ examined the spread of fake news related to eight topics: plot, origin, vitamin C, vitamin D, garlic, 5G, laboratory, and HIV. The study found that fake news accounted for 77.8% of all articles reviewed, indicating that fake news about COVID-19 was more likely to be viewed and shared than real news.⁹

These results illustrate a critical point: health literacy directly influences the sharing of news and information by allowing individuals to filter large amounts of information and discern what is fake. Key factors influencing this include:

- i. cognitive biases (confirmation bias, “cherry-picking”),
- ii. the willingness to fact check,
- iii. digital literacy, and
- iv. the extent of health literacy.

Thus, improved health literacy may lead to better understanding of scientific information and the ability to distinguish between real and fake news.⁹

Case study 2:

The influence of health literacy on patients’ decision-making when enrolling in an oncology clinical trial

The second case study highlights the direct impact of health literacy on health-related decision-making. The study focussed on patients with breast cancer, who are normally involved in many shared decisions during their therapeutic journey. These patients have many choices to make because they often have to decide between numerous treatment options and clinical trials; these decisions may be even more challenging when they have limited health literacy.

In the study, women with breast cancer were invited to enrol in a clinical trial. In accordance with Good Clinical Practice, each woman received an informed consent form to help her

weigh the risks and benefits associated with the treatment and decide whether to be enrolled. The study then analysed the relationship between health literacy and enrolment. Patients who were more confident in their decision to enrol perceived a lack of risks associated with the experimental treatment option. Also, those who recalled recurrence as a risk of enrolling in the trial had an average health literacy score higher than the overall cohort.

Of note, participants who understood the risk of recurrence and its weight in the decision-making process also had a better understanding of informed consent.¹⁰ The finding that understanding of informed consent seemed to be related to the level of health literacy suggests that improving health literacy can help improve patients' awareness when making decisions about enrolling in a clinical trial.

What interventions can improve health literacy?

Strategies to improve health literacy range from large-scale policy actions to optimise schooling to interventions targeted at small communities or patient groups. A systematic review analysed the interventions for improving health literacy in Europe between 1995 and 2018. Although firm conclusions about the effectiveness of interventions could not be drawn because of the low quality of the studies included, the type of intervention (group, individual, community-based) appeared to have little importance. The study suggested that to improve health literacy and thereby improve motivation, empowerment, and self-confidence, interventions should be tailored to the needs of participants, with information and critical skills presented in an appropriate format with correct and engaging language.¹¹ Improving comprehension, acknowledgment, and application of health literacy can support policy action intended to address major public health challenges.⁹

Why should medical writers be interested in health literacy?

Medical writers should not be indifferent to health literacy as they are responsible for writing

clear and understandable documents for the target audience. To create documents for patients, such as an informed consent forms or layperson summaries, that they can use and understand, the writer must consider the reader's health literacy. Good Lay Person Summary Practice¹² suggests keeping in mind the level of health literacy when writing a layperson summary and keeping the language as simple as possible so that it will be accessible to people with primary education or low health literacy skills. A conversational style can help. The challenge for medical writers, who usually work on scientific or regulatory documents, is to convey complicated messages related to clinical trial results to people with varying levels of health literacy.¹²

On the other hand, medical writers have an opportunity to improve health literacy by communicating science responsibly. Many peer-reviewed journals now require a plain language summary of scientific studies and clinical trials, which may favour direct access to scientific information. Also, patients' associations, cultural associations, and even hospitals and company websites need to produce verified content. A challenge for medical writers in this context is writing text that is rigorous but appealing. When writing for people with varying health literacy levels, we suggest that medical writers remember Italo Calvino, an Italian literate who, throughout his career, focused on maintaining the reader's attention by using clear, incisive, and memorable visual images along with precise language.¹³

Conclusion

Health literacy is a valuable tool that empowers individuals and communities to improve their health status and achieve sustainable development. Training and educating healthcare professionals, teachers, social workers, and community volunteers about the importance of health literacy and effective health communication is vital. Adequate expertise can be obtained by reviewing materials and processes used by stakeholders and by receiving training in

verbal and written communication. Medical writers can play a proactive role by conveying truthful and flawless health information that can be understood by the targeted reader. This means adapting the language and the scientific content to the audience.

Disclosures and conflicts of interest

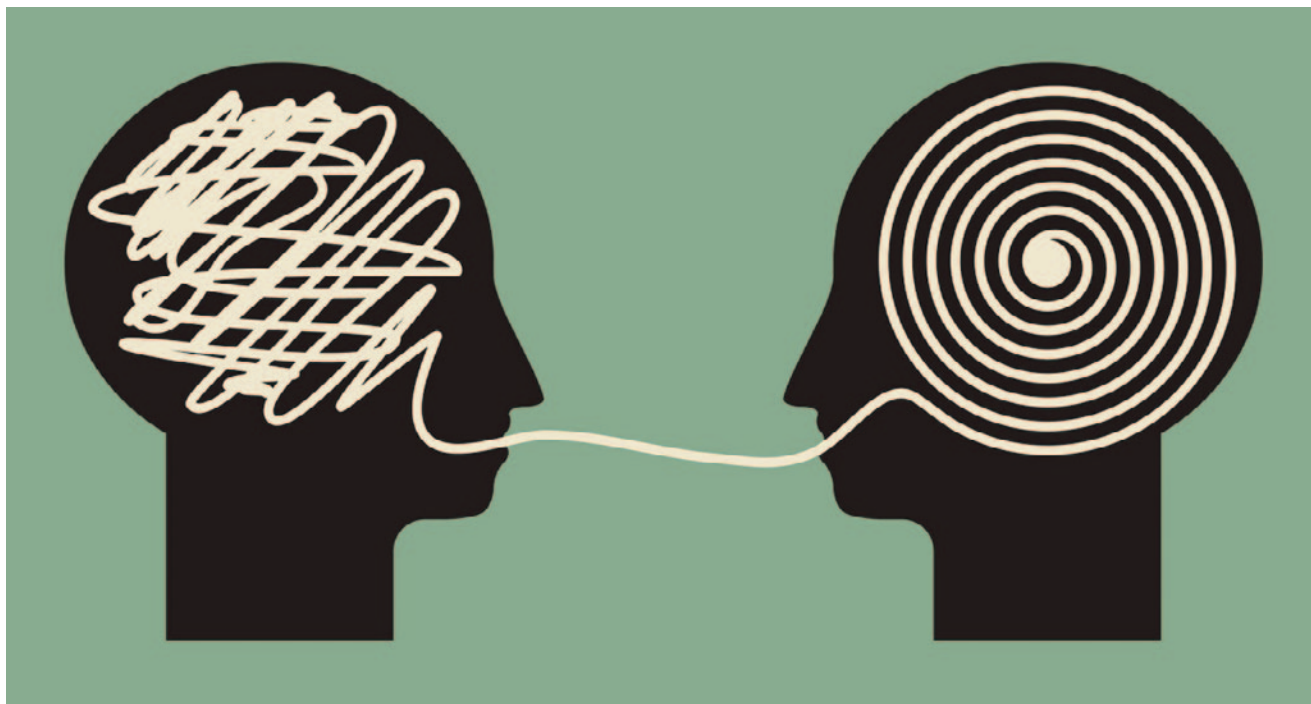
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Disclaimers

The opinions expressed in this article are the authors' own and not necessarily shared by their employers, clients, or EMWA.

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