Health literacy in e-oncology care: challenges and strategies

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Abstract:
Given the impact of health literacy (HL) on patients’ outcomes, limited health literacy (LHL) is a major barrier in cancer care globally. HL refers to the degree in which an individual is able to acquire, process and comprehend information in a way to be actively involved in their health decisions. Previous research found that almost half of the population in developed countries have difficulties in understanding health related information. With the gradual shift toward the shared decision making (SDM) process and digital transformation in oncology, the need for dealing with low HL issues is more crucial. Decision making in oncology is often accompanied by considerable consequences on patients’ lives, which requires patients to understand complex information and be able to compare treatment methods by considering their own values. How health information is perceived by patients is influenced by various factors including patients’ characteristics and the way information is presented to patients. Based on the findings, identifying patients with low HL and using simple data visualizations are the best practice to help patients and clinicians in dealing with LHL. Furthermore, preparing reliable sources of information in tools such as patient decision aids (PDA), as well as involving HL mediators in consultation sessions supports patients to make sense of complex information.

Keywords: Health literacy, oncology, patient decision aid, visualization, risk communication

1. Introduction:
Cancer is the second leading cause of death in the world, with a mortality rate of 10 million in 2020 (1). Given that patients’ understanding of their disease and its appropriate treatments is critical to the medical decision making process, HL plays an important role in improving patients’ awareness and empowering them (2). HL refers to the set of individual skills to
access, process, understand and use health information to stay healthy (3). HL skills are important during a healthy life span, but especially in disease-related decision making. These skills not only aid in preventing disease but also help a person make smart decisions in the event of disease and enable them to manage the disease and associated self-care (4).

Due to the importance of HL in prevention and disease management, LHL has the potential to cause serious problems. Factors associated with HL include the patient's characteristics (5), the communication between physician and patient (6) and the way information is presented (7). As a result, how health-related information is presented has a significant impact on individuals' perceptions of disease risk and, consequently, on how individuals make decisions about their health and related behaviors (4). For example, during the onset of disease, people experience higher levels of stress and receive a lot of new and complex information, which is challenging for patients with LHL. And yet care providers often assume that HL levels are higher than they really are (8). This is further exacerbated due to patients' reluctance to expose their inability to understand health information due to the stigma associated with LHL (8,9). Nowadays, a lot of attention is paid to patient participation in decisions related to their health, and patient centered care. SDM is the process in which caregivers and the patients work together to make the best decision, requires the exchange of information and discussion about treatment options and exploring patients' values (10). However, the inconsistency between the often complex nature of the presented information and the level of HL of the individual influences patient-physician communication negatively and may impact patients' outcomes (9). In addition, how risk is perceived by patients depends on how the information is presented to them (11). LHL is not limited to a certain population or region. In fact, LHL is a common issue around the world (12,13). For instance, almost half of the European population has LHL (14); similar findings have been reported in Australia (15), US and UK (9). Given the impact of socioeconomic status on HL (16), in developing countries HL is remarkably poor (17).

To get the most out of SDM, it is therefore important to consider factors that cause and influence HL and examine strategies to deal with LHL. The goal of this mini-review is to explore the consequences of LHL and propose strategies to effectively deal with patients with LHL during medical decision making in oncology.

2. The impact of poor HL skills
A person with good HL is able to identify and access reliable sources of information, as well as differentiate it from misinformation, perceive risk and analyze data about their own situation (19). Good HL is associated with patients' ability to manage their disease in general, their ability to effectively communicate with care providers and participate in the health decision-making process (20,21). Therefore, adequate HL will put the patient on the right care path and eventually, promote the quality of care (22).

In oncology in particular, poor HL could lead to many undesirable outcomes. For instance, wrongfully interpreting risks produced by a clinical decision support system (CDSS) could lead patients and their doctors to choose not the most suitable treatment decision due to misinterpretation of the results (23,24). In turn, wrong decisions could lead to decisional regret later on especially, when there are multiple options that involve trade-offs between harms and benefits (25). In addition, using health services requires some HL skills to compare the benefits and limitations. For example, the aim of screening is to diagnose cancer in the early stage but there is a possibility of harm due to overdiagnosis and false positive or negative results. An example of this is breast and prostate cancer screening, where 92% of women and 89% of men in nine European countries overestimate the benefits of mammography and PSA as markers for breast and prostate cancer respectively (26,27). On the contrary, overestimating
risks instead of benefits might lead to unnecessary fear, decreased mental health status (28) and may cause patients to choose the ‘safe’ (i.e. more invasive but not necessarily more effective) treatment option even though this may increase side effects and negatively influence daily life in a more pronounced way (29).

LHL can also lead to a poorer quality of life (QOL). For instance, people with LHL are more likely to adopt an unhealthy lifestyle such as smoking or lack of exercise which will increase risk of developing chronic diseases (30) and subsequently reduce their QOL (31). Patients with lower HL are also less likely to use preventive health services, resulting in later diagnosis of cancer. This delay in diagnosis and treatment increases the risk of hospitalization (32), reduces the odds of survival and increases the cost of care (31). Due to this cascade of accumulating negative impacts patients with LHL are 1.5 to 3 times more likely to encounter undesirable health events such as higher risk of hospitalization (5). Additionally, certain characteristics make people more susceptible to LHL and influence risk perception. These risk factors include older age, lower educational level, lower socioeconomic status, immigration, having chronic diseases, and physical or mental disabilities (5,8,33).

New technologies such as artificial intelligence (AI) offered many opportunities in healthcare (34). AI methods have the potential to transform medical decision making by learning from vast amounts of data, updating state-of-the-art medical information, increasing the speed of diagnosis and reducing medical errors. In addition, AI is able to predict outcomes related to disease and treatment outcomes (35). Despite its potential, risks presented by AI may be difficult to interpret, especially for people with LHL. Even highly educated physicians trained in dealing with risky decisions have trouble assessing risks (36). In some cases the information presented is too vague or skewed to highlight the benefits, possibly resulting in misunderstanding by its users. For example, deep learning is a powerful form of AI which may outperform physicians in certain situations, but the logic of the method is unclear and may lead to misinformed decision making (37).

3. Practical solutions to deal with LHL/ insights for intervention

Due to the severe and cascading effects that LHL can have, strategies are warranted that allow better participation of LHL patients in medical decision making. Here we describe four strategies that could be applied in clinical practice immediately. The first and most important strategy is to identify patients with LHL in order to adapt communication and presentation of health information. The second, third and fourth strategy involve support measures to aid communication and visualization.

Strategy 1: Identifying patients with LHL to tailor SDM accordingly

Since physicians tend to overestimate a patient’s HL level, strategies are needed to objectively assess this before they convey health information and risks. A large body of literature concerning this issue and several questionnaires are available for this purpose. The S-TOFHLA (“Short version of Test Of Functional Health Literacy in Adults”) is a questionnaire that assesses the HL level of people specifically in healthcare settings. It consists of two sections for reading and numeracy skills, is available in multiple languages, and can be completed in less than 12 minutes (38). Alternatives for the S-TOFHLA specific to the field of oncology are the Cancer Health Literacy Test (CHLT-30) and CHLT-6 questionnaires which are externally validated and have been found reliable (22). Despite availability of HL screening instruments, there are many concerns such as lack of time for clinicians and risk of stigma for patients (39). Patients are reluctant to test for HL because of the risk of labelling as illiterate and shame around it. The disadvantages of testing HL may
outweigh the benefits as it may keep patients from seeking healthcare services (39). To prevent the risk of demotivating LHL patients, providing a shame free environment is essential. Cornet et al. (40) proposed an indirect framework for assessing HL by observing patients’ behavior and asking questions about their understanding from a piece of text. Inability to give a complete overview of their own medical history and feeling nervous with complex information are some examples of common observed behaviours in individuals with LHL. Recently, in the Netherlands first interactive digital tools have been developed to identify and practice communication to people with LHL (41). Given the fact that no consensus has been reached on the best method to assess HL and given the disadvantages of HL questionnaires, we propose a less formal and multidesign approach. This multidesign approach could consist of a combined e-learning and training to medical professionals to quickly identify patients with LHL. In addition, we propose to identify patients with LHL by using a short version of the HL screening tools and frame it as a way to personalize information. Ideally, the outcome of the test would result in a digital signal to the electronic patient dossier that a patient has a LHL. Identifying HL level is the first step to communicate risk information in a personalized way.

**Strategy 2: Including health literacy mediators to guide LHL patients**

A literacy mediator is a person who uses their literacy skills to help others in different areas. In the past, this mainly related to reading and writing as only a limited number of people had the ability to read and write. These literacy mediators assisted illiterate people in understanding and communication via written text (42,43). Mediators can also specifically help individuals, especially the vulnerable, with LHL in the (medical) decision making process. These mediators who are willing to use their HL skills to support others are called health literacy mediators (HL mediators). Edwards et al. (44) explored the potential of a personal social network as the function of a health mediator ranges from information seeking, self management to SDM depending on the situation. They also examined the possibility of HL support in training classes which provide the opportunity to discuss with other participants too. A successful example of HL mediators contribution showed in the study by Kosa et al. (45) where the high participation rate indicated the effectiveness of HL mediators in encouraging different groups including LHL people in using preventive service. Therefore, hiring a literacy mediator, especially in areas with a high prevalence of LHL, such as low income regions, is an essential step. In a shame free atmosphere patients with LHL are supported by mediators to talk about what they are struggling to understand.

**Strategy 3: Adopting risk visualization aids**

The way risks, in particular those presented by AI, are presented to patients is crucial, especially for those with LHL. This risk presentation is two-fold: (i) the way a message is framed, either orally or in written text; and (ii) the way the risk is presented visually. First, the way a message is framed is an important component of conveying information. Message framing could emphasize benefits or losses based on how the message is written or spoken. Gain framing emphasizes the benefits of a decision or choice, for example by emphasizing cancer survival as a result of a treatment decision. On the other hand, loss framing emphasizes the harms of a decision, for example a patient’s risk of dying as a result of a decision instead of its opposite, survival. Which form of message framing is most beneficial depends on the situation. When gain framing is used to describe objectively risky treatments, people are more likely to choose that risky treatment than when it’s described with
loss framing (46,47). In contrast, loss framing resulted in patients choosing less invasive treatments (48).

A second component of risk presentation is the visual representation of that risk, ideally with visual aids. In general, visual aids will convey information better than conventional numerical formats (33), but there are many options to choose from. The most commonly used visual aids are icon arrays (Figure 1A) and bar charts (Figure 1B).

![Figure 1. Icon array (A) to bar chart (B)]

Icon arrays are a type of visual aid in which a shape is repeated a number of times, generally 100 times, when risks are displayed. A subset of those shapes will be presented differently to indicate a proportion. For example, a risk of 15% would be represented as 15 blue boxes in a field of 100 grey boxes (Figure 1A). This type of visual aid lends itself well to presenting percentages in a larger population.

It is important to note that the way the shapes are presented may influence the users’ understanding. Zikmund-Fisher et al. (49) found that anthropomorphic icons, i.e. icons that resemble human or human-like form (Figure 2A), were preferred by most patients and Wangeamsermsuk et al. (50) found that anthropomorphic icons were the preferred format in populations with varying HL levels, but that risk perception in LHL patients was better with shapes that referred to (close to) real-life objects (Figure 2B).
Bar charts on the other hand are represented as bars of various lengths, where the length of the bar indicates the height of the risk (Figure 1B). This type of visual aid lends itself well to comparing different options, each with associated risks that need to be compared (51). The selection of a type of visual representation of risks depends on the use-case and the intended audience’s overall level and variety of HL and demographic characteristics. For example, the elderly (>65 years old) will likely have more difficulty understanding pie charts than those below 65 years of age (52). It will generally also help to use textual information as additional info next to an icon array.

To sum up, due to the high impact of visualization on risk perception, especially patients with low HL, it is important to use well-designed formats such as icon arrays supported by plain language, to convey health information. Additionally, using gain and loss framing at the same time is a practical solution to avoid misinterpretation in this group of patients.

Strategy 4: Using patient information resources
While a wide range of information in different sources and platforms are available for patients, reliability is key for patients to make informed decisions. Medical information sources can take many forms. For example, as a pamphlet prepared by the healthcare institute or the doctor, as an online video developed by a patient advocacy group, or a medical mobile health (mHealth) app on their smartphone, tablet or computer. The goal is to assure that patients fully understand their own risk and empower them for informed decision making. mHealth in particular has become more prominent and is promoting HL skills as well as reducing cost (53,54).

A particular subgroup of information sources relevant to medical decision making is the field of PDAs. These aids are specifically designed to help patients with a particular disease understand relevant information to their disease and possible treatment, and provides them with tools for value clarification (55). These can be provided in a variety of forms as well, including paper and electronic versions (56,57), and have been shown to reduce decisional conflict (58). However, PDAs generally contain large amounts of information, which can be overwhelming for individuals with LHL. In addition, PDAs are not targeted at a population with LHL, but at patients with a general HL. It is therefore important that researchers take special care of making the information presented in a PDA understandable for LHL patients. As a short-term strategy we propose to provide patients with specific links to reliable sources. To assure the information on this site is reliable, we recommend having a central location with reliable health related information and a quality mark on that website. MedlinePlus for different diseases and kanker.nl specifically for cancer (in Dutch) are examples of reliable information resources.

Improvement of HL in future healthcare
The strategies described above provide an overview of the steps healthcare institutes and physicians are able to take immediately to alleviate problems related to LHL of their patients in medical decision making. Other strategies to improve HL of a population in the long term have not been described here, but are nonetheless crucial to medical decision making. Long term strategies include awareness and easy accessibility to terminology lists per health area and health related educational symposia for laymen, educational approaches such as training HL skills in schools for youth, as well as establishing educational materials for other age
groups. Raising awareness about the importance of HL in public through for example the media will aid HL in the long term as well. In addition, involving LHL patients in the design and implementation phases of PDA should be a requirement in development of any PDA.

6. Conclusion
Despite the emphasis on the importance of HL in the well-being of an individual, LHL is a major issue around the world. LHL may impact all aspects of individuals’ life, especially in chronic diseases such as cancer due to the need for identifying symptoms, early diagnosis, and being aware of the probability of side effects, recurrence or survival rate is more essential. We reviewed the current knowledge and have recommended a series of strategies that will help patients, physicians and healthcare organisations better deal with LHL. Future studies are required to assess the utility of provided strategies, as well as explore factors that influence HL skills in the AI era.

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