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3 Health Literacy for Multilingual and Multicultural Populations

Sharon Moonsamy and Sandra Levey

Key information for local and national policy and lawmakers

Health literacy is described by the World Health Organization (2021) as the achievement of a level of knowledge, personal skills, and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. The WHO argues that improving health literacy allows populations to play an active role in improving their own health and meets the needs of the most disadvantaged and marginalized societies to reduce inequities in health and beyond. The purpose of this chapter is to inform political leaders, healthcare practitioners, professional organizations, and institutions about the need to foster greater health literacy among those in lower socioeconomic groups and in medically unserved populations.

Health literacy should be high on the agenda in all countries to promote health and improve access to health services. A review of intervention programmes showed that they were often designed to support individuals with lower or absent health literacy, to improve health literacy capacity and to improve organizational, government, policy, and system practices to support this goal. Health literacy allows clients to process and understand basic health information (Health Resources & Services Administration, 2019). Additionally, health literacy allows individuals to access, process, and fill out medical forms (Health Resources & Services Administration, 2019). Limited health literacy occurs when individuals lack basic literacy skills (Center for Disease Control and Prevention, 2019).

Incidence and prevalence of health literacy

The incidence and prevalence of health literacy has shown that, unsurprisingly, developed nations have a higher rate of literacy. However, many countries have lower rates of literacy: Gambia, Iraq, Liberia, and Côte d'Ivoire (47%–51% of the population); Sierra Leone, Afghanistan, Benin, and Burkina Faso (41%–43% of the population); Central

African Republic, Mali, South Sudan, and Guinea (30%–37% of the population); and Chad and Niger (19%–22% of the population) (United Nations, 2021).

An early study of literacy in Europe found that one in five 15-year-olds and one in five 16- to 65-year-olds had poor reading skills and it was estimated that around 13 million children under 15 years of age and around 55 million adults between 15 and 65 years of age have literacy difficulties (European Literacy Policy Network Association, 2015). Current figures show that 22% of students are underperforming regarding literacy on average across the EU, while there are even lower levels of literacy (40%) in some European countries. The lowest levels of literacy are found in the lowest quarter of populations when ranked by economic, social, and cultural backgrounds (Brozo & Sulkunen, 2020).

Within the U.S., there are 43.0 million people who possess low literacy skills (National Center for Education Statistics, 2019). Those with low literacy abilities are White U.S. born adults, representing one-third of the low-skilled population, and Hispanic adults born outside of the U.S., representing a quarter of low-skilled adults. Populations with language barriers and cultural diversity must be considered as culturally diverse populations and recognized as among the most vulnerable groups (Andrulis & Brach, 2007). It is an important objective to consider cultural and language differences of multilingual populations. Thus, health services should be designed to provide effective, accessible, understandable, and respectful care of all populations including those with low literacy (Centers for Disease Control and Prevention, 2020).

Impact of the absence of health literacy

Illiteracy has an impact on educational attainment, employment, and the general quality of an individual's life. Literacy improves the productivity of workers, allowing them to use a higher level of technology, and reduces the burden of unemployment and poverty on government budgets. Research shows that functionally illiterate people have a considerably lower income than those who are literate (Van Vugt, 2016). Health literacy not only improves the health of the population but also contributes to improved education and prosperity. Health literacy can predict an individual's health status, with those with higher literacy benefiting from better health and wellbeing (World Health Organization, 2013).

Key information for health professionals, social workers, community leaders, and education practitioners

It is important to consider those with limited proficiency in the languages spoken by those who are determining their literacy skills. Limited or absent language skills in a new language will have an impact on their ability to understand public health campaign brochures or signs or other written health information.

How to identify the absence of health literacy

To begin a discussion, it has been found that WH questions (*who, what*, *when*, *where*, *why*, and *how*) rather than yes/no questions are effective, as yes/no questions require

a one-syllable or short phrase response (Davis, 1995). In this way, one can see if the person understands questions and is able to respond appropriately and with a clear narrative. Engaging in conversation with WH questions is less threatening than testing the person by asking them to read or write, as they may find that intimidating if literacy abilities are low or absent. If written materials are necessary, it is important to have these available in the most common languages spoken in the region/locality and to appreciate that there may be language barriers. In this case, there is a need for a person who can act as an interpreter. Finally, it is important that practitioners are aware of a client's culture, given that cultural differences may influence how an individual responds, cooperates and communicates with healthcare practitioners.

The impact of the absence of health literacy

The impact of weak health literacy competencies has been shown to result in less healthy choices, riskier behaviour, poorer health, less self-management, and more hospitalization (World Health Organization, 2013, p.1). These problems significantly drain human and financial resources in the health system.

The importance of identification for literacy absence

The absence of literacy affects the ability of individuals to access health care, understand health information, navigate healthcare systems, and make decisions regarding health care for themselves and their families. This has a significant effect on an individual's wellbeing. It is important to identify individuals who lack literacy as these individuals are more likely to have problems locating and seeking health services, filling out forms, and understanding directions for the use of medicine (Health Resources & Services Administration, 2019).

What to do when the absence of health literacy has been identified

When a client has been identified as having literacy difficulties, it is important to discuss this difficulty together with the individual and determine if the client would like support. It is essential to treat individuals with understanding and respect, explaining that support is important for accessing health services for them and their families, as well as for seeking education and employment. A method to improve the understanding of health information is *teach-back*, in which the client is asked to explain to the health professional what they have understood from the explanations they have been given (Jager & Wynia, 2012).

To support those who lack health literacy

To help and support individuals with literacy difficulties, a practitioner may work with an individual to address literacy abilities using general reading and writing resources,

along with using health documents and questionnaires. If a practitioner is not able to provide support, they should help the individual by identifying other ways, for example finding a person in the local community who may be able to offer help in finding a reading centre.

Information for professionals working with individuals with literacy difficulties

Assessment of approaches for absent health literacy

Assessment approaches begin with the identification of those who lack literacy abilities, in order to provide support for their health services. Literacy assessments may be informal or formal. As mentioned earlier, informal approaches may consist of avoiding yes/no questions, as WH questions provide greater information. If assessment is based on written materials, it is important to present materials in the individual's preferred language. Materials could be translated through Google Translate (2020). Material placed in this site can be translated into almost 100 languages but remember that these translations may not be entirely correct. If medical assessment is presented to non-literate individuals, conversations can be supported by using pictures, charts, or videos. It is also important to limit the length of utterances and avoid complex language vocabulary. If medical terminology is necessary, alternative terms should be used to improve understanding. Medical thesauruses offer these terms (Cornett, 2017). These lexicons offer plain language and can assist health communication.

Formal assessment methods have been developed for medical practitioners (Cornett, 2017). These tests include the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993); a short form of the REALM assessment (Arozullah et al., 2007); the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA-50) (Lee, Bender, Ruiz, & Cho, 2006); the Test of Functional Health Literacy in Adults (TOPHLA) (Nurss, Parker, Williams, & Baker, 2001); and a short form of this test (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Reading comprehension worksheets and tests that are printable and accessible online are offered by ReadTheory (2020). This website offers free reading worksheets for young children (kindergarten through grade 12), second language learners, adults, and special education reading worksheets for those requiring greater support.

Evidence-based intervention approaches have been developed to address health literacy. One study examined the effectiveness of literacy intervention approaches for socioeconomically disadvantaged populations (Stormacq, Wosinski, & Van den Broucke, 2016). These authors reported two approaches to health literacy: clinical health literacy and public health literacy. The clinical literacy approach is based on educating individuals to select healthcare providers, complete consent forms, understand medicine labels for taking medications, and to provide and understand information when interacting with health practitioners. The public health literacy approach is based on the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions

that benefit the community (Freedman et al., 2009). Public health literacy programmes have the goal of providing information on existing disease burdens, health outcomes, disparities, and threats to health, often based on an alliance of political, technical, and managerial leaders to implement programmes that protect and improve the health care of the public.

Other intervention programmes have addressed those with specific disorders. Individuals with human immunodeficiency viruses (HIV) and limited literacy skills were provided with intervention for the use of antiretroviral therapy (ART) (Perazzo, Reyes, & Webel, 2017). ART has provided viral suppression and longer life spans for those with HIV, and optimal treatment outcomes have been attributed even to those with limited health literacy. This intervention programme provided individuals with visual information that consisted of colour-coded schedules, minimal text, and dosage information (Kalichman et al., 2013). A second approach consisted of a brief verbal presentation, a patient education flipchart (a large pad of paper that is used for presentations that allows pages to be turned over to reveal the next page), the distribution of a pill box to support adherence, and a follow-up session. Additional sessions that focused on adherence challenges were conducted after initial sessions (Kalichman, Cherry, & Cain, 2005). Findings in this study showed that the participants, including those with lower health literacy, developed increased knowledge and self-efficacy for adhering to medical advice. These results show that interventions tailored for people with lower health literacy can have a significant influence on health-related actions and results for the patient.

Approaches to improve health literacy suggest that the education sector is a critical domain in achieving this goal (Vamos, Okan, Sentell, & Rootman, 2020). Education centres are able to address literacy for all school-aged children, given that many schools contain children from varied socio-economic and cultural backgrounds. However, of the 7.1 million refugee children of school age across the globe, 3.7 million do not attend schools (United Nations Refugee Agency, 2019). While the education approach is positive for native populations in developing countries, it may not be available for migrant, refugee, or asylum-seeking children.

A review of various literacy health interventions found that specific approaches supported better comprehension for low-literacy populations (Berkman et al., 2011). These approaches consisted of presenting essential information without distracting information, videos with verbal narratives, pictorial representations, and slide show presentations. Approaches have also been developed to help health practitioners develop competence to support their clients' health literacy (Johnson, Jacobson, Gazmararian, & Blake, 2010). A plan to address the communication skills of health practitioners focused on the need for clarity and accuracy of health information, cultural and linguistic targeting of health information and services, a public health infrastructure that facilitates and supports healthy behaviours, and community, educational, and workplace infrastructures for access to health information (U.S. Department of Health and Human Services, 2010). This health literacy ecological approach addressed the need to create interventions, better prepare healthcare practitioners, educate the public, and remove obstacles for clients to access healthcare (McCormack, Thomas, Lewis, & Rudd, 2017).

Discussion

The goal of health literacy is for clients to obtain, process, and understand basic health information and health services to make appropriate personal health decisions. It is the combined responsibility of health providers and educators to ensure effective communication and interaction to achieve positive health outcomes. Given that those with low or absent literacy ability will have difficulty with reading or understanding medical information, it is essential that health practitioners become aware of this problem and consider health literacy training. In this way, both health practitioners and clients will benefit. Key recommendations consist of adapting the Four Habits Model (FHM) of Kaiser Permanente (Grice et al., 2013) which include: establishing rapport and building trust rapidly; facilitating the effective exchange of information; demonstrating care and concern; and sharing decision-making regarding treatment. This has been found to increase the likelihood of adherence and positive health outcomes and is recommended for those with both poor and good health literacy!

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4 Autism Spectrum Disorders (ASD) and Health Care Services for Underserved Populations

Kakia Petinou and Maria Christopoulou

Key information for local and national policy and lawmakers

This chapter presents key information related to Autistic Spectrum Disorders (ASD) for the attention of National Policy Members, stakeholders, lawmakers, and healthcare professionals. We set out to encourage the fostering and advocacy for greater health literacy pertinent to ASD. In our opinion, it is of particular importance to advance the knowledge on issues related to prevalence, early symptomatology, diagnostic characteristic etiology, aberrant behaviours, daily living challenges, disorders of verbal and nonverbal communication, schooling adaptation, social pragmatic deficits, and difficulties related to emotional affect. An increased awareness on these topics is paramount as awareness, particularly on early detection of symptoms, can lead to timely assessment and diagnosis. Early detection of ASD signs and early diagnosis through an interdisciplinary management programme contributes to positive therapy outcomes (Koegel & Koegel, 1995; Petinou & Minaidou, 2017; Rapin et al., 2009; Richard, 1997).

A recent publication by the Centers for Disease Control and Prevention (CDC) in its biennial upate in 2020, reports significant progress for early ASD screening resulting from rigorous research investigations and systematic ASD awareness campaigns over the past ten years. Such efforts capitalize on the available data and allow the fostering of ASD awareness. Robust advocacy for ASD has been undertaken by the NGO organizations. Of interest is the fact that increased screenings have contributed to the lowering of the age of diagnosis, especially in minority populations and in individuals with diverse cultural and linguistic backgrounds. A recent report by the World Health Organization (WHO, 2019) underscores the importance of implementing integrated services in accordance with the person's individual needs and preferences.

People with ASD do not differ from the rest of the population when it comes to health problems. Nevertheless, their special needs and co-occurring conditions necessitate awareness from politicians supported by committees who can address the societal needs and the level of support to increase the quality of life, access to services, family support and availability to resources of best service provision according to the Declaration of Human Rights (DHR) (United Nations, 1948).