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EDITORIAL

Health literacy development: co-design for health and equity outcomes

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The concept of health literacy has become increasingly popular. But what actually is it, and how is it relevant to health and equity?

Our team began investigating these questions nearly two decades ago. The first measures of health literacy in the 1990s focused on functional literacy and numeracy in health contexts, the measurement of which no longer fully captures modern multidimensional health literacy concepts. Importantly, measurement of only health-related literacy may lead to discrimination and stigmatisation and may even increase health inequities because broader health literacy factors are not considered. While literacy is required (e.g., to read medication labels and health promotion materials), there are other skills and resources that individuals and families need to access, understand, appraise, remember, and use health information and services.

To advance health literacy measurement to equitably support health-related decisions and behaviours, our research team explored what people actually need. We asked community members this question: *Thinking about your experiences in trying to look after your health (or the health of your family), what abilities does a person need to have in order to get and use all of the information they need?* When combined with input from healthcare providers and policy makers, health literacy was found to be more than just literacy. Through extensive consultation and testing, a nine-dimension health literacy construct was confirmed (**Table 1**) and now comprises the Health Literacy Questionnaire (HLQ), which has demonstrated strong psychometric properties[1]. The nine HLQ scales are scored separately (i.e., no single overall score) to reveal profiles of health literacy strengths (scales with higher scores) and challenges (lower scores), with each scale score being relative to the other eight scale scores in the profile.

After presenting these nine dimensions to experienced primary healthcare physicians, we received strong confirmation that these dimensions reflect struggles many of their patients may have daily. Further input from across sectors confirmed that the HLQ dimensions are meaningful and useful to clinicians, giving us impetus to push this field forward.

Health literacy is woven through the community fabric

Our research demonstrates that health literacy is embedded in the relationships, values, and knowledge in families, communities, organisations, and nations[2]. It is found in people's daily practices, routines, cultures, community connections, workplaces, and environments. To understand how to develop health literacy, we need to understand people's strengths and challenges in their contexts. We need to learn about the "community fabric"[3] to find what works, for whom, under what circumstances, and why. Such learning means engaging – authentically engaging – with community, especially with those who are likely to be left behind from receiving the care they need. These are usually the people for whom the social determinants of health make circumstances difficult for patients to get and receive care, and for clinicians to deliver equitable care.

Our work in primary care and community health aims to improve outcomes for community members and to improve how healthcare providers can do their daily work. Our conceptualisation of health literacy seeks to provide researchers and health organisations with key information about community needs and what health services can do to improve health outcomes. To achieve this, we use health literacy data to uncover mechanisms that lead to health inequities, and to generate actions that reduce the burden on clinicians and on community members so they can seek and receive the care they need.

Table 1. Health Literacy Questionnaire (HLQ) scale descriptions

HLQ scale	Low scale score	High scale score
1. Feeling understood and supported by healthcare providers	Unable to engage with doctors and other healthcare providers. Doesn't have a regular healthcare provider and/or has difficulty trusting healthcare providers as a source of information and/or advice	Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health
2. Having sufficient information to manage my health	Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns	Feels confident that they have all the information that they need to live with and manage their condition and to make decisions
3. Actively managing my health	Doesn't see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them	Recognises the importance and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health. They make health a priority
4. Social support for health	Completely alone and unsupported for health	A person's social system provides them with all the support they want or need for health
5. Appraisal of health information	No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information	Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others
6. Ability to actively engage with healthcare providers	Are passive in their approach to healthcare, inactive i.e., they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they do not understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns. Does not have a sense of agency in interactions with providers	Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional healthcare providers when necessary. They keep going until they get what they want. Empowered
7. Navigating the healthcare system	Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Does not look beyond obvious resources and has a limited understanding of what is available and what they are entitled to	Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level
8. Ability to find good health information	Cannot access health information when required. Is dependent on others to offer information	Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date
9. Understanding health information well enough to know what to do	Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms	Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required

Measurement to inform intervention development

The value of measurement with the HLQ is the nine-scale health literacy profiles for needs assessment. In clinical research and epidemiology, health literacy measurement frequently generates single overall scores and population averages. These are of little use for clinical practice and community care where clinicians are treating individual patients who have their own personal strengths and challenges for managing their health. To treat each person as an average is anathema to good clinical practice. Moving beyond averages, we use cluster analysis to reveal different score patterns for different groups of people within a population[4]. Groups of people with multiple health literacy challenges may not benefit from, or even engage in, usual care or one-size-fits-all health promotion initiatives, which puts them at risk of being left behind. Even well-intentioned community care and health promotion will reach only some people (i.e., people who are mostly well, with resources, and who are able or are supported to manage their health) while excluding those most in need (i.e., people with multiple health conditions, without resources or support). We need different interventions to suit the situations of different groups of people.

How do we know what will best suit different groups of people?

We ask them! And co-design with them! Community members have personal knowledge and expertise in accessing and using health information and services, so let's build on what they know – on their strengths – and what they can share with others. Some community members, despite having little education and few resources, can have exceptionally positive behaviours and are efficient users of health services. Some individuals can be illiterate and have difficulty appraising health information or knowing what to do for their health, yet they have social support or a trusted clinician to explain information and treatments. Every day, clinicians recognise and overcome the health literacy challenges of their patients. Co-design enables the tacit expertise of community members and clinicians to inform and improve the quality of, and reduce inequities in, the delivery of health services. However, co-design does require a different way of thinking about health service reform.

Co-designing systematically for health and equity outcomes

Co-design is a way of designing with people, not for people[5]. Power must be given away by those who usually hold it. Shared power means relationships are prioritised. Those who usually do not hold power must learn that their voice is of value and will be heard. It can be challenging to incorporate the perspectives of many stakeholders, so respect and patience are needed.

A requirement for building co-designed initiatives is to be comfortable with uncertainty. Co-design elevates the lived experiences of community members and clinicians to see what can be learned about how services can be improved, which means the outcomes of a co-design initiative are uncertain at the beginning. At the start, the interventions to be implemented are unknown because they are built from stakeholder experiences – including community members and clinicians – rather than built from what is known in the literature or from a known intervention that has been implemented elsewhere. Using a strengths-based approach (see also assets-based model)[6], co-design helps to reduce research waste and the implementation of inequitable one-size-fits-all health interventions.

A breakthrough in co-design research is the Optimising Health Literacy and Access (Ophelia) process, a systematic participatory co-design methodology endorsed by the World Health Organization (WHO)[7,8] and widely used in Europe. Ophelia provides a three-phase, step-by-step co-design process that allows for flexibility in methods, depending on contextual factors. A health literacy needs assessment is conducted with the HLQ or eHealth Literacy Questionnaire (eHLQ)[9] to inform the development of interventions that are appropriate, meaningful and useful to communities and health services. The European Union Joint Action on Cardiovascular Diseases (CVD) and Diabetes (JACARDI) Work Package 6 (WP6) on Health Literacy[10] is applying the Ophelia process. There are four Spanish WP6 projects:

- Promotion of health literacy about CVD and diabetes through a massive open online course (MOOC) (Cantabria)
- Health literacy of adolescents (Basque Country)
- Health literacy of people who have suffered ischaemic stroke (Aragon)
- Health literacy on nutrition and physical activity in health-promoting schools (Aragon)

The strengths-based co-design approach of the Ophelia process applies the science of intervention development to transform needs assessment data into practical and tangible initiatives to generate health and equity outcomes for diverse community members. Ophelia projects co-design community-developed interventions that improve the health literacy responsiveness of services to meet the needs of the communities they serve. The well-recorded insights of all stakeholders, including from primary healthcare providers, is fundamental to the success of Ophelia projects to build and implement needed and wanted innovations.

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