



Chapter 2: Humanising health literacy

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Imagine a healthcare system that complements evidence-based medicine with self-care and traditional knowledge about health. A healthcare system that acknowledges and respects traditional knowledge and elevates it to the level of evidence-based medicine.



Problem statement

Lack of self-care and poor health literacy can result in people taking less responsibility for their own health and not engaging effectively with their healthcare systems.

- ▶ Health literacy refers to a person's ability to understand and use information to make decisions about their health
- ▶ Self-care is the process of taking care of oneself with behaviours that promote good health and encompasses good choices, exercise, sleep and proactive management of illness.

Paakkari and Okan (2020) give the following guidance in their article: "...health literacy should be seen in relation to social responsibility and solidarity and is needed from both people in need of information and services and the individuals who provide them and assure their accessibility for the general population".



Discussion Summary

Self-care has been an integral part of health and social services around the world for millennia. In its Guideline on Self-Care Interventions for Health and Well-being (2021), the WHO acknowledges the growing importance and urgency of self-care interventions in healthcare systems under duress.

Around the world, there has been a significant change in the general public's behaviour as a result of the COVID-19 pandemic. Many people have become more empowered in their self-care but the pandemic has also highlighted how poor health literacy can act as a barrier to self-care and as well as being an underestimated public health problem. For example, Leese, Backman, Ma et al. (2021) describes the importance of physical and mental self-care in rheumatoid arthritis patients with special focus on the impact of telemedicine. Another study conducted in several South-American countries confirmed that the prevalence of self-care practices increased after the first pandemic lockdown (Bermejo-Martins, Luis, Sarrionandia et al. 2021).

A consequence of the COVID-19 pandemic is the 'COVID Infodemic'. In a joint statement, WHO, UN, UNICEF et al. (2020) describe the infodemic as "an overabundance of information, both online and offline. The consequences of the infodemic are clearly visible: confusion, misinformation leading to decreased trust in science and the spread of wrong or misleading information about vaccines and ignoring health information because it is too overwhelming to understand (Hotez 2021). Conflicting attitudes have surfaced that ironically and simultaneously reject the authority of the state in health-related matters while relying on the state for healthcare services more than ever.



Self-care will not improve unless people have a better understanding of biology and medical language. Improvement in health literacy needs to be driven by people who are using health services instead of people who deliver them, a recommendation that is referenced in this chapter's calls to action.

Health literacy is still too weak

In their analysis of knowledge maps of health literacy research, Qi, Hua, Xu et al. (2021) found that health literacy needed improvement, even in academic circles, and that cooperation and the exchange of information between stakeholders is far from ideal. In a German study comparing the health literacy of the population before and after the COVID-19 pandemic, Schaeffer, Berens, Gille et al. (2021) found that 58.8% of the population still have very low health literacy levels, despite a 3-percentage point improvement observed as an effect of the pandemic.

The democratisation of science

There is often a wide and harmful gap between the scientific community and the general public. The effects of this are increasingly visible in the growing anti-science sentiments and movements during the COVID-19 pandemic, undermining the related vaccine research and rollout efforts (Hotez, 2021). There are several explanations for the erosion of respect for science, which stem mainly from psychology and political science (e.g. Burrage 2015; Saltelli 2018; Hotez 2021).

It is not sufficient to blame biases and lack of education when trying to understand why science is losing its reputation. When sharing medical information, further thought and care needs to be considered to ensure it's clear, succinct and simplified. Even if science is not always straightforward or cannot posit ultimate truths, some key messages can and should be conveyed in a manner that makes them justified and unambiguous.

Patient organisations can play an essential role here. Already, many patient organisations are involved in the development of lay language summaries in a wide variety of situations including the development of research protocols and the writing of patient information and package leaflets, as well as a host of other educational materials. However, information should continue to be delivered to people in creative formats that engage them, such as audiobooks, podcasts, visuals (videos and drawings), theatre, etc. In order to communicate information effectively there needs to be a thorough understanding of different patient populations. In October 2021, the European Commission published a Good Lay Summary (LS) Practice that outlines the most important principles for why and how summaries should be developed. The guidance states: "The contributions from patients should be regarded as valuable input into LS planning, review and dissemination, ensuring the suitability of the LS for patients, trial participants and the general public. Patients can contribute by providing perspectives and terminology that may be different to those of researchers and healthcare providers.

Social media plays an important role in communicating understandable science and today, a considerable amount of patient data with transformative power comes out of social media. For example, if one person tweets about a weird side effect or symptom, someone else from the other side of the world might respond with a similar experience... then another, then another and so on. After two weeks, they set up a group for themselves to continue the discussion, and that's how a community can be born on social media. It has allowed the creation of large, international, even global disease communities that have developed through sharing information.

The real-life patient experiences that are built via these online communities can pull together what was previously sporadic information into a large body of meaningful evidence.



The role of education and its intersection with health

Transformational change is not just the responsibility of healthcare systems, it also includes

- ▶ Investment in health literacy
- ▶ Understanding the role of education - including academia
- ▶ Recognising the contribution of the biopharmaceutical industry in creating open and transparent dialogue
- ▶ Caring for a sustainable approach including our environment to minimise air pollution and support broader environmental goals.

Traditionally, patient organisations have played a key role in promoting health literacy. Many of them, especially umbrella organisations like the European Patients' Forum, Rare Cancers Australia, EURORDIS, RARE-X, IAPO, EUPATI, and community-led programmes and platforms like IEEPO have an excellent track record in providing educational resources, training programmes and comprehensive libraries for health-related education - both general and disease specific.

Designing and developing health literacy materials can also be achieved together with other communities. Cultural and religious groups, schools and universities, organisations of migrant populations can all play an important part. Kramish Campbell, Alicock Hudson, Resnicow et al. (2021) describe the significance of church organisations in health education and participatory research. A study from India acknowledges the role of public schools specialising in health education and urges for the development of their network (Jain, Joshi, Bhardwai and Suthar 2019).

These efforts and projects deserve support and should not be seen as competitive but rather complementary to the offerings of educational systems. In order to ensure that patient groups can continue this important work the following resources need to be secured: unlimited and safe access to state of the art scientific information, broad and reliable disease information, educational resources, advocacy, including tools for advocacy capability development, and advocacy resources. This is why there is a call for the admission of patient experts and representatives into medical scientific conferences and symposia, and various open access initiatives in scientific publishing.

Aligning patients (especially expert patients and organisations) with the circulation of scientific information will not only make sure that they can disseminate credible and reliable information, it will also contribute to the democratisation of science and in turn, increase equity and inclusion. It will facilitate a better bidirectional flow of information: not only will patients better understand what is happening in health-related research, they can also contribute more by collecting, organising and analysing real-world patient data and making it relevant for the wider scientific community.

The anti-vaccination movements that emerged in the wake of the COVID-19 pandemic provide an excellent example in which one can observe the impact of health illiteracy. It is strongly believed that a general lack of understanding of what a vaccine is, and what effect it has on the body's immune system, has fuelled the anti-vaccination movement.

If health literacy was taught in schools from an early age, all citizens could grow up with a better understanding of how their bodies work and the role of science (medicine and otherwise) in maintaining and restoring their health. Consequently, improving health literacy is an overarching need encompassing health and educational policy, ethics, and active policy making on the part of governments.

Attitudinal change is needed in governments and healthcare systems, and other stakeholders as well. New approaches should be centred around the cooperation of equals for common objectives,



such as access to health and realising that money spent on prevention and healthcare is an investment in the future rather than a sunk cost.

The pharma and biopharma industry also plays a role. A culture of openness to build active trust in research and development, with all key stakeholders working together in partnership based on shared values in order to achieve this.



Case Study: Song and dance in disease prevention in Sub Saharan Africa

Project background and objective

With almost two-thirds of all people living with human immunodeficiency virus (HIV) there, the region of Sub-Saharan Africa has seen a ravaging impact of the pandemic. In addition to the very high number of people, especially women living with HIV, the number of annual new infections is also the highest globally.

The usual prevention, disease awareness and health messaging developed for the Global North does not always work well in settings in Sub-Saharan Africa where the population affected by HIV is different from the Global North, literacy levels are not always on par, and cultural traditions are different from those in countries where scientific research and political advocacy around HIV/AIDS are devised.

There are some important health related messages that people living with HIV can benefit from regardless of the setting they live in, and which can make it easier for them to pursue self-care and prevention.

Due to the similarities between the HIV and the COVID-19 pandemic, several approaches developed for HIV prevention and health literacy in Sub-Saharan Africa can also be implemented in COVID-19.

Activity outputs and outcomes

HIV related songs and dance have become an important vehicle to distribute key health messages to populations that are hard to reach by printed materials or social media (Browning 2006).

Based on the numerous projects in the dissemination of prevention, treatment and health related information through the use of arts (including but not limited to song and dance), a substantial body of evidence has emerged, which can be adapted also to settings different from Sub-Saharan Africa.

Non-traditional, arts-based methods used in HIV/AIDS are increasingly used in COVID-19 related education and information work (Thompson, Nutor, Johnson 2021).

Further information: <https://bit.ly/2ZP7M8I>



Calls to action

1. Stakeholders should develop joint strategies that address the current challenges in achieving health literacy by incorporating the specific needs of patient populations so that they are involved in the design, and delivery of solutions. Example challenges include, elderly patients may be socially isolated as a result of the pandemic, digital illiteracy and the 'digital divide' affects how people access health information and therefore manage their own health.
2. Governments should invest strategically in health literacy education and to mandate health literacy as a fundamental life skill to be taught in schools.
3. Patient organisations need to be resourced and supported by all stakeholders to enable them to play their own part in advancing high quality research and healthcare that is relevant, user friendly and able to make best use of scarce resources in order to maximise health gain.
4. Develop a lay-person's guide or global glossary of the concepts and phenomena in the healthcare system that affect everyone. Such a glossary can then be adapted to the local needs and circumstances. The participation of patient experts and patient organisation representatives in scientific and high-level policy and health technology conferences needs to become standard practice. This requires the clarification of underlying legal constraints and regulations in some regions of the world.