EASL Patient Forum 2021: Health literacy to empower liver patients and address inequities

On 22 November 2021, the European Association for the Study of the Liver (EASL) held its annual Patient Forum on the topic: **health literacy to empower patients and address inequities**. During the webinar, it was emphasised that patient involvement is important at every stage. Improving health literacy in healthcare contributes to strengthening effectiveness and efficiency of the healthcare system. Including health literacy in public policy is essential for overcoming challenges and for ensuring sustainable benefit. A revised concept of digital health has appeared in recent years. The COVID-19 pandemic has made critical health literacy increasingly important and relevant. At this event, representatives of patient organisations and academia provided insights into their organisations' actions – both scheduled and underway – taking place regarding health literacy.

Opening remarks

Prof. Maria Buti, EU Policy Councillor at EASL, noted that Europe is facing a health literacy crisis as health systems are becoming more and more difficult to navigate, even for more educated people. She emphasised that policy actions are needed at all levels, and it is crucial to have patient views and needs guiding the change.

Marko Korenjak, President of the European Liver Patients Association, stated that from a patient association perspective, when patients have higher health literacy, this helps with any engagement with health community. He recalled that EASL has always integrated patients in its work.

Introduction to health literacy

The topic of health literacy was introduced by **Prof. Diane Levin-Zamir**, Director at the National Department of Health Education and Promotion of Clalit Health Services, Israel and Associate Professor at the University of Haifa, School of Public Health, Israel and Chair of the National Health Promotion Council, Israel Ministry of Health, and also founder and leader of the IUHPE Global Working Group on Health Literacy.

From the World Health Organization (WHO)'s Health Promotion Glossary: "Health literacy represents the personal competencies and organizational structures, resources and or commitment which enable people to access, understand, appraise and use information and services in ways in which promote and maintain good health."

Health literacy is about finding health information, which must be accessible and available; understanding it in terms of language, reading level, and images; appraising it for reliability through available references; and, finally, applying it. Other dimensions include interaction with healthcare and other professionals to express their need for information to make decisions, while remaining critical of the information supplied. Key concepts introduced include:

- <u>Personal health literacy</u> - the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

- Organisational health literacy is the degree to which organisations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
- The impact of limited health literacy is manifold because people with limited health literacy use fewer preventive services, need more emergency treatment, undergo more hospital admissions, have more problems understanding health-related information, and are less able to take their medications correctly. They have greater difficulty with self-management, experience worse treatment outcomes, and have higher risks of complications.

- Digital health literacy is a new concept, on the skills needed to use digital resources for health. It was an underestimated health issue that emerged during the COVID-19 pandemic and is important in the battle against the infodemic (the spread of incorrect information). Digital health literacy is critical to addressing infodemics.

The spread of misinformation may be as harmful as a disease itself, as it impedes public health responses. Including health literacy in public policy is essential for overcoming challenges and for ensuring a sustainable benefit. For instance, health literacy was a main pillar in the *Shangai Declaration on promoting health in the 2030 Agenda for Sustainable Development*. The WHO has developed a publication, *Health literacy: The solid facts*, with accompanying policy recommendations, as well as the *IUHPE Position Statement on Health Literacy,* and most recently, the forthcoming *Geneva Charter for Well-being*.

Health literacy and liver diseases

Dr Marcus Ranney, author of *At the Human Edge*, highlighted the impact of digitalisation and technology on human existence. There has been a massive increase of the role of digital therapeutics in healthcare; the use of mobile apps to deliver evidence-based interventions to supplement or, in some cases, even replace conventional treatment, forms a large part of this growth. The role of technology goes beyond patient care, by tracking outbreaks, enabling contact-tracing, and boosting awareness-raising. Despite this level of growth in health and wellbeing products and services and access to the internet, global health literacy rates remain low. In the United States, only 12% of the adult American population has proficient health literacy and in India, only 10%. Physiological data can now be collected via consumer health tech such as portables, wearables, and implantable devices. Digital technologies can provide a personalised approach, such as by monitoring our sleep and exercise and providing related advice. Digital health technologies can thus allow us to use data to our advantage and make better health decisions.

Panel contribution from EASL's Patient Synergies: What does your patient organisation do to increase health literacy?

George Kalamitsis, Liver Patient International (LPI), talked about his experience as patient. He was diagnosed with hepatitis C in 2000, when lack of knowledge and misinformation about the infection were prevalent, resulting in thousands of patients experiencing severe consequences of hepatitis C and thousands more dying. Most of these deaths could have been prevented. LPI wants to measure the gaps in health literacy and identify what patient needs. In Europe, because there is a wide variety of contexts, liver patients are experiencing different challenges. LPI would like therefore to create customised services to improve health literacy among specific patient groups. Furthermore, LPI is planning to organise a joint "after Covid-19" meeting to invite patient associations around Europe to exchange views on their experiences during the pandemic and from this exchange to derive the best-case examples, and in accordance with the findings, try to make changes.

Eberhard Schatz, **Correlation European Harm Reduction Network (C-EHRN,** hereafter "the Network"), explained the activities of the Network, which works both directly with people who use drugs and with other organisations also engaged with this population. Empowering this target group has been a priority for many years. This particular group faces considerable risks, threats, stigmatisation, social inclusion, and criminalisation. These organisations strive to prevent communicable diseases, such as HIV, hepatitis C, and tuberculosis, across certain regions.

For three years, the Network conducted a **civil society monitoring of drug policies in 33 countries across Europe**, on concrete interventions with a particular focus on hepatitis C-related activities including initiatives of drug users themselves. This project witnessed the developments, improvements and the gaps rising throughout the years, regarding actions on drug policies.

Furthermore, the Network analysed numerous best practices from European countries around drug policies, selected 20 best practices (from 100 organisations) and presented them. The Network provides many trainings, seminars, and workshops for European audience and has organised a hepatitis community summit inviting community members to share their experiences. Mr Schatz emphasised the need to enhance the literacy of policymakers, hepatologists, and doctors, enabling them to work better with different groups to overcome barriers and stigma.

Livia Alimena, **Global Liver Institute (GLI),** spoke on the challenge of digital health literacy, especially for some elderly patients and their families. The GLI is exploring what can be done by doctors to avoid medical jargon or strictly medical language, given that most patients have a lower level of education. One possibility is to break down information into distinct pieces to make it more readable. The GLI additionally provides patients with printed information in plain language and using infographics. Furthermore, on the International Non-Alcoholic SteatoHepatitis (NASH) Day, GLI organises webinars with the scientific community and patients. The most impactful action undertaken is patient guides. Several such guides published on NASH and diabetes management have been translated into many languages and have been disseminated across the world, including to villages in African countries. Ms Alimena also mentioned that the GLI has a university for patients, which holds meetings twice a year, conveningpatients and patient representatives, at which new treatments and the latest technologies that support digital health literacy are presented.

Eleni Antoniou, Thalassaemia International Federation (TIF), outlined key facts on the condition of thalassaemia. The majority of thalassaemia patients live in low- and middle-income countries. Less than 20% of patients living with the disease globally receive appropriate and timely blood transfusions and iron chelation therapy. In most of these countries, patients have low health literacy. For TIF, health literacy means health education, better quality of care, and thus a better quality of life. TIF works on the development and continuous upgrading of an educational programme including organising events and publications and promoting academic courses.

The organisation aims to contribute to creating educated and knowledgeable patient advocates to be partners to healthcare professionals and decision-making bodies at national, regional, and international levels. Accordingly, TIF has invested in making its resources accessible, both in terms of form (online, offline) and language.

Health literacy to address stigma, overcome sociocultural barriers, and reduce inequities for cancer patients: the case of viral hepatitis C

Charles Gore, Medicines Patient Pool, spoke about his initial experience with hepatitis C in the UK. Specific groups are mostly affected by the viral infection in the UK, such as people who use drugs and people who used drugs in the past, including homeless people and immigrant populations. Thus, socio-economic issues such as stigma, socio-economic inequities, including low literacy levels and languages barriers, are considerable challenges.

Mr Gore explained that he was first diagnosed with hepatitis C in 1995. Because he did not receive adequate information then, he could not take the actions he needed for his health. He stated that the common assumption that patients receive enough information is incorrect. Later, he was diagnosed with cirrhosis. Mr Gore mentioned that one's level of literacy is not constant, especially when affected by fear. Thus, it is very important to take into account the emotional state of people one is talking to. This is similarly and particularly true for cancer. Although the Internet provides a significant amount of information, it is difficult to distinguish factually right and trustworthy from wrong. When diagnosed, Mr Gore wanted to talk to other people in a similar situation. Noting this lack of suitable information, he then wrote the most comprehensive website possible on hepatitis C, pitched in accessible language. Since treatment at the time offered very little benefit, he explored the evidence behind these drugs. He also set up a peer-to-peer network, accessing people with backgrounds as drug users or as hepatitis C patients, and travelled by mobile van to visit prisons and drug and alcohol and treatment centres. There, he trained people to become peer educators.

Peer-to-peer communication is a critical part of health education, which incorporates talking to people without making assumptions about what they need. Further complexity lies in accommodating the issues of stigma facing people who have moved away from drug use yet are still sensitive about the past. Past mistakes have shown that campaigns should avoid blaming and stigmatising the individual. Given that drug use can be stigmatised in prison, many people in prison are reluctant to admit to their hepatitis C status. It is thus very important to have a peer-to-peer system in the prisons, so that prisoners can talk to other prisoners who have hepatitis C. As conclusion, Mr Gore stated that health literacy is vital, not just for managing one's health, but also for to navigating both health systems and the sometimes poor communication from scientists.