Check for updates

The People-First Liver Charter

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Reducing the stigma and discrimination that people living with liver conditions experience requires rethinking how diagnoses, diseases, etiologies and circumstances are perceived – a shift that begins with the language used to name and describe them.

Liver disease, a leading contributor to disability-adjusted life years worldwide that disproportionately impacts people of working-age 1 , has emerged as a global health threat. In 2021, liver cirrhosis ranked as the 12th principal cause of death globally 2 . Liver health-related stigma has deterred people from seeking and receiving proper care and has contributed to their exclusion from treatment, including participation in clinical trials 3 , owing to personal circumstance or behavior 4 .

Stigma, both a consequence and a driver of health inequities, can present at various levels, from internalized beliefs and public perceptions to policy and legislation. Health and socioeconomic inequities exist across the liver disease spectrum, with a higher prevalence, more-severe illness and poorer outcomes often occurring among those who are the most resource constrained, which further fuels inequities and stigmatization. Regardless of where it manifests and subsists, stigma can have catastrophic consequences on health, from discrimination during engagement with care services

to treatment avoidance. As a result, conditions or situations that are manageable may deteriorate needlessly, particularly among those who are most marginalized⁴.

Thus, we believe it is time for the those of us in the liver health community, including people with lived experience, to examine our language choices as mindfully as our peers in other health communities have done, and as called for in the 2021 EASL–*Lancet* Liver Commission⁴.

Stigma and discrimination

There are countless instances of people living with liver conditions continuing to experience unacceptable levels of stigma and discrimination. For example, people living with alcohol-related liver disease often face structural stigma (for instance, policies that limit their opportunities for transplantion, employment and social service eligibility), public stigma (for example, discriminatory attitudes of others, including healthcare providers (HCPs) perceiving them as less deserving of medical treatment) and self-stigma (for instance, shame about their condition). These layers of stigma, largely driven by the perception that their condition is self-inflicted, collectively contribute to negative health outcomes, including avoidance of seeking necessary medical care⁴.

Stigma surrounding the hepatitis C virus (HCV) is pervasive across political, economic and social systems and is often driven by assumptions that link HCV infection to socially unacceptable behaviors, such as injection drug use. This stigma is further fueled by negative attitudes toward marginalized populations, among whom HCV infection rates may be higher than in the general population⁴, as well as fear

Language matters "What can you do?"

- Put people first, not their condition
- Avoid labelling or defining people by their condition
- Use neutral language
- Avoid overstating the severity of a condition
- Highlight abilities over limitations
- Emphasise people's capacity to manage their health and right to support
- Recognize people as contributors to society, not burdens
- Use comprehensible, consistent and precise language

Language for better care "What can people-first language achieve?"

- Reduction of stigma and discrimination
- · Avertion of blame and fear
- Empowerment of people
- Fostering of a supportive environment
- Increments in health service utilisation
- Enhancements in the quality of care
 Improvements in the care experience
- Boosts in treatment uptake and ongoing engagement
- Improvements in health outcomes

Further research "What else is needed?"

- Delivering proof of impact
- Assessing people's language needs and preferences across age and socioeconomic strata, genders, ethnicities and geographies
- Collaborating across health fields to promote consistent use of people-first language

Fig. 1| **People-first language: putting people at the forefront of liver care.** The development of this figure was inspired by those mentioned in the Acknowledgements section. Please consider this information when citing this work.

Table 1 The People-First Liver Charter	
When speaking with and referring to a person, do the following:	
1. Put the person first, not their condition, and avoid labeling them by their condition. Avoid impl	lying that the condition defines the person.
Use this:	Rather than this:
Person living with Example: person living with overweight or obesity	person Example: overweight or obese person
Person diagnosed with Example: person diagnosed with hepatitis C	person Example: hepatitis C-positive person
Person who has Example: person who has cirrhosis	person Example: cirrhotic person or cirrhotic
Person with a(n) Example: person with a disability	person Example: disabled person
Person who uses or consumes Example: person who uses or consumes drugs	user or consumer, or addict, junkie, druggie, smoker, vaper, alcoholic or drunk Example: drug user or consumer
Person who injects Example: person who injects drugs	Injection or intravenous user Example: injection or intravenous drug user
Person exposed to Example: person exposed to hepatitis B	exposed person Example: hepatitis B-exposed person
2. Use neutral language, avoid overstating the severity of a condition and avert fear. Avoid negatiful the scope of a condition.	ive overtones, suggesting that the person is helpless and/or at
Use this:	Rather than this:
Person living with Example: person living with hepatitis C	Person infected, diseased or contaminated with (or carrying) Example: person infected, diseased or contaminated with (or carrying) hepatitis C
Person living with and Example: person living with hepatitis B and D	Person co-infected with and Example: person co-infected with hepatitis B and D
Person diagnosed with Example: person diagnosed with steatotic liver disease	Person suffering from Example: person suffering from steatotic liver disease
Person experiencing symptoms of Example: person experiencing symptoms of diabetes	Person afflicted with Example: person afflicted with diabetes
Person who has Example: person who has hepatitis E	victim Example: hepatitis E victim
Person who is living with transmittable Example: person who is living with transmittable hepatitis C	Person who is contagious with Example: person who is contagious with hepatitis C
Person living with or experiencing challenges related to use or consumption Example: person living with or experiencing challenges related to alcohol use or consumption	Person who abuses, misuses or is addicted to, or alcoholic, drunk, addict, junkie, druggie, smoker or vaper Example: person who abuses, misuses or is addicted to alcohol
Person who is in recovery from use or consumption Example: person who is in recovery from substance use or consumption	Recovering addict, abuser or misuser Example: recovering substance addict, abuser or misuser
Person who has stopped using or consuming Example: person who has stopped using or consuming drugs	person Example: sober, clean or drug-free person
Person experiencing Example: person experiencing housing insecurity or incarceration	person Example: homeless or incarcerated person
Person who is (not) taking as recommended Example: person who is (not) taking treatment as recommended	Person who is (not) compliant with (or adhering to) Example: person who is (not) compliant with (or adhering to) treatment
Person experiencing suboptimal outcomes Example: person experiencing suboptimal treatment outcomes	Person failing Example: person failing treatment
Share or discuss status Example: share or discuss hepatitis C status	Disclose status Example: disclose hepatitis C status
Alcohol-associated or alcohol-related Example: alcohol-associated or alcohol-related cirrhosis	Alcoholic Example: alcoholic cirrhosis
Person	Patient
Substance use or consumption challenge	Substance abuse, misuse, addiction, habit or dependence, or alcoholism

nature medicine

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BOX 1

Emphasizing the person

The People-First Liver Charter asks that, when speaking with and referring to a person, one does the following:

- Put the person first, not their condition, and avoid labelling them by their condition. For example, use 'person living with cirrhosis' rather than 'cirrhotic person' or 'cirrhotic'.
- 2. Use neutral language, avoid overstating the severity of a condition and avert fear. For example, use 'person living with hepatitis C' rather than 'person infected, diseased or contaminated with (or carrying) hepatitis C'.
- Highlight abilities over limitations. For example, use 'person managing diabetes with insulin' rather than 'insulin-dependent person'.
- 4. Emphasize the person's right and capacity to manage their health, bearing in mind that certain conditions may impact this

- capacity. For instance, use language that reflects collaborative care, including shared decision-making, with the person, rather than being imposing. For example, use frames such as 'person engages with the treatment plan' rather than 'person adheres to the treatment plan'.
- 5. Recognize the person as a contributing member of society, rather than as a burden, and avert blame. For instance, consider the responsibilities that communities have toward supporting the person, rather than their community-support needs. For example, use frames such as 'person will be provided with the resources necessary to engage with their treatment plan' rather than 'person requires extra support to follow their treatment plan'.
- 6. Use language that is comprehensible, consistent and precise to communicate with the person, considering the person-specific nature of language, and give them the opportunity to seek

of contracting a potentially chronic condition. Pejorative language used in relation to HCV can influence how people are described or 'marked' in medical records, which leaves behind a 'scarlet letter' that may follow them for years. This stigma can persist even after a person is cured, spilling over into subsequent health encounters and resulting in a lifelong burden⁵.

Experiences of stigma among people living with hepatitis B have been increasingly documented, and these may harm entire families, with repercussions that include barriers to healthcare, education, employment and travel⁶. Liver condition-associated stigma can intersect with stigma related to identity, such as gender, ethnicity and socioeconomic status. This triggers a compounded stigma⁴ that suppresses the voices and needs of those living with disease, disregarding their complex identities as autonomous human beings and adding to the structural factors that shape their health outcomes.

As long as International Classification of Diseases coding language continues to include terms such as 'alcoholic liver disease', people living with liver conditions will remain trapped in a cycle of self-fulfilling prophecies where beliefs shape actions that undermine their health interests and the support that HCPs offer them. Tackling health-related stigma requires rethinking how diagnoses, diseases, etiologies and circumstances are viewed, beginning with the language used to name and describe them.

People-centered care

Person-centered care aims to prioritize the person, not merely their health condition, so that medical support is directed to them as a whole. This approach yields numerous benefits, from improved individual health management to reduced overall morbidity and mortality. Words matter in this context. The right words can empower people, and those close to them, while the wrong ones can demoralize them. Establishing an environment of person-centered care thus requires the use of language that instills respect and empathy, averting stigma, discrimination, fear and blame. People-first language that focuses on people, rather than medical labels, challenges the notion that a person

is defined by a diagnosis, disease, etiology or circumstance. Using the right words dignifies people and can support movement toward equality and neutrality within clinical interactions.

The people-first language movement is already viewed as a valuable approach to reducing stigma related to mental health, HIV, infectious diseases, substance use, cancer, overweight, obesity and diabetes. However, although the benefits of people-first language are theoretically apparent, the topic has not been thoroughly investigated. For instance, a systematic review of 33 studies on peoples' preferences for weight-related terminology identified only one study that addressed people-first language¹⁰. This study, focused on people preparing for bariatric surgery, found that most participants preferred terms such as 'person with obesity' rather than 'obese person'. Moreover, about half of the participants indicated that discussing weight stigma with their HCP would help them feel better about themselves and foster a sense of comfort and understanding; however, the potential impact of people-first language on health outcomes and patient-reported experiences was not investigated¹¹.

The lack of research on the implications of people-first language on care and health outcomes creates an opportunity to explore a number of as-yet unasked and unanswered questions (Fig. 1). Nonetheless, the ongoing need to develop better evidence should neither cast doubt on nor delay the advancement of a movement that aims to empower people to seek care in an environment free of stigma.

The People-First Liver Charter

In mid-2023, the liver health community took an important step toward reducing stigma in disease terminology by renaming fatty liver disease as steatotic liver disease (SLD), non-alcoholic fatty liver disease (NAFLD) as metabolic dysfunction-associated steatotic liver disease (MASLD) and non-alcoholic steatohepatitis (NASH) as metabolic dysfunction-associated steatohepatitis (MASH)¹². This nomenclature change represents a step toward person-centered care. Building on this work, experts recommended the creation of non-stigmatizing communication guidance for health professionals¹³ and called on international

Table 2 | Organizations and journals that endorse the People-First Liver Charter

Full name	Territory or country
Africa Advocacy Foundation	Europe
American Association of Clinical Endocrinology	USA
Annals of Hepatology	Mexico
Barcelona Institute for Global Health (ISGlobal)	Spain
BMC Biology	UK
BMC Global and Public Health	UK
BMC Medicine	UK
Biomedical Research Networking Center in Diabetes and Associated Metabolic Diseases	Spain
Brazilian Nursing Association Minas Gerais Section	Brazil
British Liver Trust	UK
Canadian Association for the Study of the Liver	Canada
Canadian Association of Hepatology Nurses	Canada
Chilean Association of Hepatology	Chile
City University of New York Graduate School of Public Health and Health Policy	USA
Colombian Association of Hepatology	Colombia
Communications Medicine	UK
Correlation-European Harm Reduction Network	Europe
Egyptian Foundation for Integrated Medicine in HepatoGastroenterology and Pulmonology	Egypt
European AIDS Treatment Group	Europe
European Liver Patients' Association	Europe
European Society of Paediatric Gastroenterology, Hepatology and Nutrition	Europe
Fatty Liver Alliance	Global
Fatty Liver Foundation	USA
Forum for the Study of the Liver	Bangladesh
Genome Biology	UK
Genome Medicine	UK
Global Liver Institute	Global
Harvard Medical School Program in Global Primary Healthcare	USA
International Liver Cancer Movement	Global
International Network on Health and Hepatitis in Substance Users	Global
Intersectoral Forum for Non-communicable Diseases in Brazil	Brazil
Irish Liver Foundation	Ireland
Italian Liver Foundation	Italy
Kalinga Gastroenterology Foundation	South Asia
Liver Patients International	Global
LiverWELL	Australia
Macedonian Society for Gastroenterohepatology	Republic of North Macedonia
MASH Cities	USA
National Liver Institute	Egypt
Nature	UK
Nature Communications	UK
	USA
Nature Cancer	00A

Table 2 (continued) | Organizations and journals that endorse the People-First Liver Charter

Full name	Territory or country
Nature Medicine	USA
Nature Mental Health	USA
Nature Metabolism	USA
Nature Reviews Endocrinology	UK
Nature Reviews Gastroenterology & Hepatology	UK
Nature Reviews Oncology	UK
Nepalese Association for the Studies of the Liver	Nepal
New Zealand Society of Gastroenterology	New Zealand
Nobody Left Outside	Belgium
npj Gut & Liver	UK
Obesity Medicine Association	USA
Observatory of Chronic Conditions and Food	Brazil
Platform for International Cooperation on Undocumented Migrants	Belgium
Portuguese Association for the Protection of Diabetics	Portugal
Qazaq Association for the Study of the Liver	Kazakhstan
Rare Liver Diseases Alliance of Moldova	Republic of Moldova
School of Nursing of the Federal University of Minas Gerais	Brazil
Shanghai Xinhua Hospital	China
Slovak Society of General Practice	Slovakia
Society on Liver Disease in Africa	Africa
South Asian Association for Study of the Liver	South Asia
South East Asia Regional Alliance	Nepal
Specialised Rehabilitation Center III, City Hall of Volta Redonda	Brazil
Steatotic Liver Disease Study Foundation in Middle East and North Africa	Middle East and North Africa
Swedish Society of Gastroenterology	Sweden
Sweet Life Association	Brazil
The Global Think-tank on Steatotic Liver Disease	Spain
The Hepatitis C Trust	UK
Tri-state Obesity Society	USA
UNITE Parliamentarians Network for Global Health	Portugal
Working Group for Innovation in Healthcare	Poland
World Hepatitis Alliance	Global
Yellow Warriors Society Philippines	Philippines

societies to advocate for a global update of International Classification of Diseases terminology by the World Health Organization, to better align with the new nomenclature¹⁴.

Moreover, in late 2023, the liver health community moved to end stigmatizing language in liver disease related to alcohol use by recommending that the term 'alcoholic liver disease' be replaced with 'alcohol-related or alcohol-associated liver disease', among other recommendations¹⁵. If leveraged effectively, the momentum generated by these initiatives could propel the people-first language movement within the liver health community, marking a pivotal moment for action.

This People-First Liver Charter (Table 1 and Supplementary Material (Spanish translation)) represents the next step in advancing the

people-first language movement in the context of person-centered care for all. Inspired by existing people-first movements and at the request of the Global Think-tank on Steatotic Liver Disease, all co-authors here set out to build upon this body of work, tailoring it to be inclusive and representative of liver health and people living with liver conditions.

Our call (Box 1) for people-first language use might seem self-evident and straightforward, but its implementation requires commitment, as it challenges long-held biases in how liver health and people living with liver conditions are perceived and discussed. Rather than sacrificing progress for perfection, the focus should be on making steady improvements. This begins with adopting a universal approach to tackle stigma, recognizing that people can be targeted on the basis of their identity, attributes,

practices and health status⁴. The goal is to place people living with liver conditions at the center of their care teams, recognizing them as experts in their own lived experiences and essential partners in managing their health. Previous approaches have proven unsustainable; only by focusing on the entire individual can an environment be built that promotes improved overall health and well-being. Table 2 lists the organizations that have formally endorsed the People-First Liver Charter thus far, and we expect that more will do so.

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Additional information

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