

analysed internet search patterns over time using Google Trends for MAFLD compared to NAFLD, which showed that there was a continuous increase in public interest in MAFLD that in some regions (e.g., Chile, Mexico and Spain) reached comparable levels to the term NAFLD, despite differences in the time scale of availability of both terms.

MAFLD has been translated into the clinic in multiple regions around the world and numerous clinical recommendations have been published.¹⁰ Studies have shown the positive implications of the transition to MAFLD in increasing disease awareness among patients, healthcare providers and for increasing attention to MAFLD at conferences across countries and health systems.¹ A completely new name other than MAFLD merely undermines the momentum and stalls progress.

In conclusion, there is no question on the necessity to redefine fatty liver disease. All the other terms that have been proposed fall far short as descriptors and fail to define the disease. Therefore, scrutiny of these other suggestions requires a reality check. Overlooking the growing evidence and support for MAFLD is like an ostrich with its head in the sand. Not acknowledging the data does not change the fact that the data exists. Whether we like it or not, MAFLD is heavily embedded in the literature and there is no turning back. In our view, moving the discussion away from the debate on MAFLD-NAFLD is unrealistic and has no potential to move the field forward. Instead, we believe that building on the momentum generated by the transition to MAFLD is the way forward.

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Authors' contributions

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MAFLD 2022: An ELPA/ALPA/EASO-ECPO joint statement on disease stigma

To the Editor:

Metabolic (dysfunction) associated fatty liver disease (MAFLD) is a highly prevalent and complex condition¹ and can lead to

serious complications such as liver failure and liver cancer. MAFLD also increases the risk of non-liver complications such as cardiovascular disease, diabetes and chronic kidney disease.²

In hepatology, our language has not always been right and this is why we are looking to change the narrative. From the perspective of patient advocacy, the non-alcoholic fatty liver

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disease (NAFLD) acronym was extremely problematic.³ Among many other deficiencies, stigmatisation, confusion, trivialisation, and unsuitability for all patients and patient groups across the globe has been a fundamental concern. Because of this, patient buy-in and therefore advocacy has suffered and progress in the field was naturally stymied. This is reflected in a serious lack of awareness, with a recent study reporting that nearly 96% of adults with NAFLD in the United States were unaware they had liver disease and presented late with complications.⁴ Naturally, this has led to difficulties in communicating the NAFLD message to patients, policy makers and other patient organisations.³

Increasing awareness of NAFLD requires simple, effective messaging and non-stigmatising terminology that communicates the risks and consequences of the disease to the public, policy makers, primary care providers and specialists working in related fields such as in diabetes and obesity.⁵ Towards attaining this goal, the European Liver Patients' Association (ELPA), African Liver Patient Association (ALPA) and The European Association for the Study of Obesity-The European Coalition for People Living with Obesity (EASO-ECPO) among 30 other patients associations expressed their early endorsement of the transformational change from NAFLD to MAFLD. The new term we believe ensures that all patients, like all people, receive high-quality, just, and equitable patient-centred healthcare.³ Over the last 2 years we have consistently advocated for the change, conducted a series of activities including our recent participation in the fatty liver day. We have been glad and reassured that the emerging strong evidence supporting the MAFLD name is helping increase awareness among patients and healthcare providers across different sectors and healthcare systems across the world. This ultimately is the Holy Grail for all patient advocacy groups – a patient centred approach to care, irrespective of their circumstance and location.⁶

At the centre of the ongoing discussion on the redefinition of fatty liver disease, stigma is a key conversation point. We realise there is some confusion around stigma that has resulted in misleading statements. We would therefore like to firmly clarify our stand. It is beyond any semblance of doubt that using “alcohol” in the name to describe fatty liver associated with metabolic dysfunction brings with it a heavy burden of stigma. We however have been surprised that misconceptions have surfaced around the term “fatty liver” as stigmatising. Further, other terms that fall far below the accepted minimum standards from a patient perspective have been proposed. People who identify as “fat” should be understood as authoritative sources of knowledge, not passive recipients of the outcome of discussions by others. Thus, two key liver patient advocacy organisations (ELPA and ALPA) consulted and liaised with EASO-ECPO to inform the hepatology community with a more nuanced and comprehensive view. To assist the debate, we first bring clarity on what is stigma and then the ramifications for the ongoing discussion.

Stigma is defined as an “attribute that is deeply discrediting”, reducing the person who possesses it “from a whole and usual person to a tainted, discounted one”. Stigma falls into three categories or sources, namely those with “visible abominations of the body”, those with “blemishes of individual character”, and those with “tribal stigma” which affects all members of the group and are passed from generation to generation.⁷ The

struggle to avoid stigma is also incomplete without serious attention to how other parts of the world think.

It is evident that patients with NAFLD suffer stigma because of having “alcohol” or “alcoholic” in the name (type 2 stigma). This is even more relevant in parts of the world that have both a religious and cultural prohibition on alcohol consumption, and similarly so for paediatric patients where alcohol is unlikely to be relevant, but still brings stigma.^{8,9} People living with two diseases can be misdiagnosed based on the current definition linked to NAFLD. Having “alcohol” in the name is also not justified in terms of explaining the nature of the disease as in “alcohol-related liver disease”. Therefore, NAFLD brings with it stigma and confusion with no added value for conveying any message about the disease.

In contrast, a conceptually and factually flawed premise that the word “fatty” is stigmatising has recently been argued. This is probably most likely attributable to a lack of understanding of what stigma is. First, while a fat body might be considered physically deviant because of its visibility (type 1 stigma), this is not the case for fatty liver which is not visible. A proportion of patients with fatty liver are lean. Second, even for people living with obesity, studies have shown that 80% of participants preferred the term “fat” which results in less stigma.^{10,11} In addition, in some cultures being fat is regarded as a sign of good health. For fat activists such as members of “the Fat Acceptance movement”, they publicly embrace the term as an affirming way to “reinstate it as a positive, self-identifying and political term,” much in the way that LGBTQ+ folks have reappropriated “queer.”

The word “metabolic dysfunction” is a new beginning that changes the existing collective narrative, but also overcomes the stigma that arises from the belief that the disease is self-inflicted. MAFLD makes no claims about the quality of individual lifestyles, nutritional choices, exercise behaviours, or personal qualities or failings. MAFLD by design, avoids the perception of personal blame by acknowledging the influence of numerous structural, environmental and biological and genetic factors that result in metabolic dysregulation.

It should come as no surprise that one of the recommended strategies to avoid stigma is using Person-first language with terms such as “related to” or “associated to” when referring to a disease. Person-first language describes a person as ‘living with diabetes’ rather than as a ‘diabetic’ or as ‘living with obesity or overweight’, rather than as ‘obese’ or ‘living with disability’ rather than as “disabled”. Just like alcohol which we now refer to as “alcohol-related liver disease”, “metabolic (dysfunction) associated fatty liver disease” reduces stigma.

Finally, it is important to distinguish between “benign, justified” and “toxic, unjustified” labelling. The former is merely descriptive, but the latter can lead to oppression and the potential for stigmatization is high. In contrast to “alcohol” which can never be justified as a term to describe fatty liver associated with metabolic dysregulation, the use of “fatty liver” is justified and pivotal for clarity of conversations with patients. Maintaining the balance between being devoid of stigma and confusion, while preventing trivialisation and retaining motivation is, we acknowledge, not an easy task. In our view, “MAFLD” is a term that meets all the criteria and strikes the delicate but right balance. In line with this, the recent EASL Lancet commission posited that it is important to reduce structural stigma resulting

from aberrant liver disease nomenclature and suggested MAFLD as a potential appropriate term.¹²

Based on the above arguments, using terms such as nutrition-associated fatty liver disease reinforces the flawed but commonly held belief that a person's fatty liver disease is purely within their control and is self-inflicted ("just by fixing my nutrition, the disease will go away"). This misconception leads to negative stereotypes of people with fatty liver disease, portraying them as lazy, gluttonous and lacking in willpower or intelligence – a perfect mixture that leads to further stigma and discrimination. This nomenclature is also not supported by evidence as MAFLD is regulated by numerous mechanisms, well beyond voluntary food intake.

There are concerns about the medicalisation of language relating to fatty liver disease. The term steatosis is confusing and will require further explanation using "fatty liver". In translation to many other languages this will come down to fatty liver.

In conclusion, we believe that MAFLD is the way to go and a welcome move forward. Whose responsibility is it to drive these changes? We argue that everyone involved in healthcare has a responsibility and this right is not restricted to a particular group or society. We will continue to be cognisant of our overarching patient-driven mandate and will earnestly support any transition plan for this to become a reality in clinical care.

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Authors' contributions

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