Redefining fatty liver disease: an international patient perspective

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Despite its increased recognition as a major health threat, fatty liver disease associated with metabolic dysfunction remains largely underdiagnosed and undertreated. An international consensus panel has called for the disease to be renamed from non-alcoholic fatty liver disease (NAFLD) to metabolic-associated fatty liver disease (MAFLD) and has suggested how the disease should be diagnosed. This Viewpoint explores the call from the perspective of patient advocacy groups. Patients are well aware of the negative consequences of the NAFLD acronym. This advocacy group enthusiastically endorses the call to reframe the disease, which we believe will ultimately have a positive effect on patient care and quality of life and, through this effect, will reduce the burden on health-care systems. For patients, policy makers, health planners, donors, and non-hepatologists, the new acronym MAFLD is clear, squarely placing the disease as a manifestation of metabolic dysfunction and improving understanding at a public health and patient level. The authors from representative patient groups are supportive of this change, particularly as the new acronym is meaningful to all citizens as well as governments and policy makers, and, above all, is devoid of any stigma.

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Introduction

Evidence is mounting that disease labels are a crucial starting point for perceptions of a disease and that they have a pivotal impact on a person's psychological responses, beliefs about disease, and their decisions on health-related behaviour, management adherence, and willingness to cooperate with health-care personnel and institutions.[1,2] A substantial body of research shows that patients construct organised perceptions and cognitive representations of their disease, and this process in turn guides behaviour aimed at managing the disease. To a substantial extent, these perceptions stem from the disease label.[3,4]

Patients who are well informed and have a good understanding of their condition work actively with their physicians to improve self-management and to enjoy a better quality of life.[5] This cooperation is especially important in the case of chronic diseases, for which the subjectively experienced burden and perception of disease is fundamental for the success of diagnostic and therapeutic endeavours.[6] Despite this evidence, the medical community does not typically pay sufficient attention to the effect of disease labels on patients and their families.

Similarly, religion and spirituality are crucial facets of patient-centred care and can affect patient wellbeing, including fostering better coping mechanisms and psychosocial adjustments across the disease continuum. Yet, religion and spiritual perspectives are largely ignored by medical practitioners.[7] There is growing evidence for a mismatch between what is medically possible and practised, and what is acceptable from a religious and spiritual perspective.

In recent years, it has become increasingly common for patients to seek information about their diseases, to actively participate in the process of health care, and to take responsibility for their health. Similarly, we have seen improvements in the role of the patient voice in disease management and health-care policies; however, gaps still exist in the consideration of patients' experiences. In this context, patient associations and patients who are willing to act as informed representatives have an influential role in supporting patients and caregivers, from the provision of better quality health information to involvement in research, drug development, and treatment guidelines. Patient associations also offer psychological, spiritual, and religious help, if needed. This assistance ensures better compliance from patients to treatments and enables better outcomes. Patient groups provide an overall patient perspective that is integrated with interactions of similar groups across countries and health-care systems. Implicitly, this process would be more informative than gathering information on the experiences of one or a few patients. Indeed, patient associations and advocacy groups are starting to formulate their own quality indicators for chronic health care and play a pivotal role in implementing models of care that incorporate patient empowerment strategies, such as involvement in research funding, scientific activities, clinical trials, and clinical guidelines or health policies.

Challenges for patients with NAFLD: a patient perspective

Despite the growing burden of fatty liver diseases, patients still report delays in receiving a diagnosis, indicating a general lack of disease awareness or the ability of health professionals to communicate information in ways that can be understood, or both.[8,9] Hence, understanding the patient perspective is an important step in identifying areas of unmet need and ways to improve patient care.

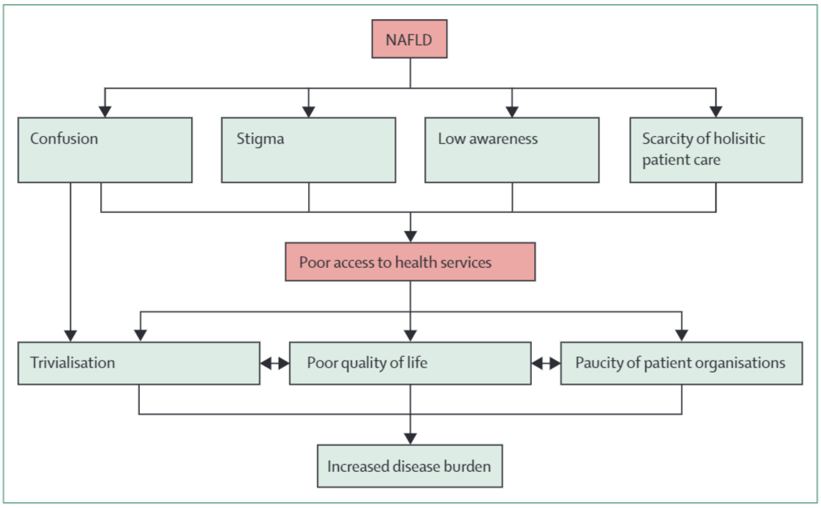

Figure 1: **Key negative implications of the name NAFLD from a patient perspective**
NAFLD=non-alcoholic fatty liver disease.

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Here, we use our experiences as patient representatives involved in advocacy to provide our view on calls to replace the term non-alcoholic fatty liver disease (NAFLD).[10,11] We consider the potential implications of removing the "alcohol" label and redefining the disease to improve patient care for individuals with fatty liver disease. The following aspects were identified by participants as key themes, in terms of unmet needs from a patient perspective: stigmatisation, confusion, trivialisation, lack of choice of treatment and holistic patient management, inadequate consideration of religion and spirituality in patient care, and a paucity of patient organisations (figure 1). Renaming NAFLD to metabolic-associated fatty liver disease (MAFLD) helps in addressing many of these challenges.

Stigmatisation

Health condition-related stigma is a type of stigma attached to individuals living with a specific health condition or disease and can be subdivided into public stigma and self-stigma.[12] Stigmatisation can have a negative effect on self-esteem and lead to an impairment in quality of life, personal management of health, and the ability to cope with a disease. The fear of stigma is also a factor linked to adverse attitudes and behaviours, including self-denial of a diagnosis, treatment avoidance, decreased compliance, missed appointments, and early termination of treatment.[13–16] Hence, addressing stigma, understanding its underlying factors, and undertaking all possible measures to minimise it are crucial to delivering quality health care.[17]

The concept and the name NAFLD have been questioned by various stakeholders, particularly patients. An important reason for this dissatisfaction is the high degree of stigmatisation of all diseases and disorders that have the terms "alcohol" or "alcoholic" in their names.[13,18] This stigma is even more relevant in paediatric diseases,[19] for which alcohol consumption is typically not a concern; however, the name brings its associated stigma with it. In our experience, inclusion of the word "alcohol" reduces the likelihood of follow-up and adherence to medical care. We have heard heart-breaking stories from patients diagnosed with NAFLD, about the way their disease is perceived among family and friends, often leading to non-disclosure of their diagnosis. Thus, besides the burden of being sick, these patients also carry the burden of silence. Notably, in our experience, we have not seen the same stigma associated with NAFLD in the field of viral hepatitis. Studies consistently show that patients with NAFLD report worse health-related quality-of-life scores, physical and mental health, and fatigue than do patients with other chronic liver diseases, such as chronic hepatitis B and C.[20] This stigma represents one of the major challenges we face in raising awareness of NAFLD.

In addition, NAFLD is often referred to and perceived as a self-inflicted disease, implying that personal behavioural choices are the primary determinants of the chances of developing the condition. This convenient and simplistic framing places the responsibility on the individual, ignoring the influence of other non-personal and non-dietary factors (eg, age, sex, ethnicity, medications, genetic variation, comorbidities, ability to exercise, and broad socioeconomic and cultural factors) that contribute to the disease or the development of risk factors for NAFLD such as obesity.[21] The perception of personal blame leads to shame and stigmatisation, compounds the burden of disease on patients, and diminishes their motivation to seek help.

Confusion

Inaccurate lay views of a disease can lead to the adoption of unhelpful treatments and coping strategies or poor adherence to treatment. When the name NAFLD was originally coined, it was intended to clearly differentiate the causes of this disease from alcohol-induced fatty liver disease. However, the name NAFLD perpetuates false assumptions among patients that fatty liver disease represents a diagnosis of exclusion or a prime example of a self-inflicted disease.[22] Moreover, the name NAFLD focuses on a criterion—exclusion of alcohol—that is neither necessary nor sufficient to diagnose the disease. It is ill-advised to convey NAFLD as a disease with pathological changes that simulate alcohol-induced liver changes to individuals who have never consumed alcohol. This message initiates misunderstanding between clinician and patient, and results in confusion. Misunderstanding is a barrier to effective patient education and communication with the public and policy makers. The actual cause—metabolic dysfunction—is misinterpreted and the control strategy—metabolic health awareness—is ignored. It is time to recognise that the advances made since first coinage of the NAFLD disease label four decades ago make it imperative to assign a name that reflects the complex metabolic interactions characterising the disease and its complications, both within and outside the liver. Indeed, addressing this issue by developing more specific criteria for diagnosis should ultimately lead to more people being engaged in care than are at the moment.

Trivialisation

Trivialisation is a minimising behaviour, in which a disease is perceived or conceptualised as being easier to acquire, live with, or treat. Trivialisation might also be considered as a form of stigma and has negative consequences.[23] Evidence suggests that trivialisation mainly arises through an inappropriate condition name or when disease perceptions or diagnoses are confusing to lay people.[24] One example is chronic fatigue syndrome, a disorder that has for decades been trivialised by an inappropriate name, which in turn negatively affects treatment.[25] Another example is the abuse of the term obsessive-compulsive disorder (OCD), to describe a personal preference (eg, being supposedly obsessive-compulsive about cleaning your home), which might devalue the experience of people living with OCD.[26] A further example, which is even more relevant to NAFLD, is the adverse effect of the prefix “non-” in the term non-communicable diseases (NCDs) on prioritising this category of diseases for prevention and control.[27–29] Although the expected global health and economic burden of NCDs is on course to exceed US$47 trillion and cause 30 times more deaths than HIV over the next two decades, these diseases receive 17 times less funding than HIV.[27–29] Experts believe this discrepancy is largely attributed to the negative effect of the prefix “non-” that conveys a perception of the disease as not important.[27–29] Furthermore, the term NCDs is not widely understood and, as a result, measures to prevent and control NCDs are harder to justify to tax payers and funding bodies. Various studies have shown that there is low awareness of NAFLD, even among individuals with high metabolic risk factors, and more than 95% of patients with suspected NAFLD are still unaware of having liver disease.[30–33] Furthermore, studies on the perceptions of NAFLD have shown that most participants (>75%) did not feel that they were at risk of having NAFLD. Similarly, patients might not perceive the disease as a health challenge, probably until it progresses to its advanced stages,[34] and this indifference unfortunately leads to a decrease in adherence to weight-loss interventions.[35] In addition, underestimation of risk might lead to affected patients remaining undiagnosed and presenting only in the later, advanced stages of the disease.[36] Other studies have shown that most patients with NAFLD are diagnosed incidentally at the time of diagnosis of cirrhosis.[9] Worryingly, many physicians are sceptical about the severity and clinical significance of NAFLD,[37] which is substantially underdiagnosed in real-world settings.[8] A study on general practitioners’ experiences in the UK showed that liver disease, particularly NAFLD, is not perceived as a priority in primary care.[38]

Patient management

The increase in deaths worldwide from liver disease is in stark contrast to the temporal trends in mortality from other major diseases such as heart disease. In fact, it has been suggested that, in the UK at least, liver disease will surpass ischaemic heart disease and many cancers as the main source of years of working life lost, whereas for ischaemic heart disease, the number of deaths has remained stable or decreased.[39] Despite these statistics, NAFLD has attracted much less attention than other chronic and complex metabolic diseases. Furthermore, there is low awareness among the public and the health-care community that obesity and diabetes can contribute to serious liver disease, compared with other conditions such as cardiovascular disease.[40] Low awareness, together with the stigma and socioeconomic disparities that are associated with liver disease, lead to health inequalities and consistent underfunding.[41]

Notably, the incorporation of screening for NAFLD in the management of patients with other metabolic diseases has been insufficient, probably because the current name does not imply any strong association with metabolic dysfunction. The disease is simply viewed as being related to alcoholic liver disease. Consequently, many individuals who are at high risk of cirrhosis and liver cancer are not being screened for these conditions, substantially diminishing the quality of patient care. Even patients who understand that they are at risk of life-threatening liver disease might avoid screening because the disease remains strongly stigmatised or dismissed.[13,18] Thus, there is a pressing need to better communicate the liver-related risks of obesity and type 2 diabetes to patients, general practitioners, and health-care professionals. These groups need to consider a holistic approach to disease management that includes all diseases associated with metabolic dysfunction, including diseases of the liver. Indeed, the name MAFLD places the condition, and its pathogenesis and progression, firmly in the same camp with other diseases, such as cardiovascular disease, chronic kidney disease, and type 2 diabetes, which have received considerable attention. This change should increase the consideration and diagnosis of fatty liver disease in patients with diabetes and other comorbidities. In addition, it would stimulate a multidisciplinary model of care for patients with MAFLD.

Is the name NAFLD suitable from a global perspective?

Religion and spirituality can contribute to a patient’s sense of hope, optimism, trust, and purpose. In turn, research has suggested that many patients would like these aspects to be incorporated into routine health care.[42,43] Unfortunately, clinical practice has largely neglected this facet of patient-centred care.[44,45] Religion and spirituality can also affect the clinical encounter, depending on how providers potentially frame or present treatment options.[43,46] For example, the refusal of Jehovah’s

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For a more **in-depth understanding of patient experience** see https://elpa.eu/living-with-stigma-of-alcohol-dependance/ and https://www.fattyliverfoundation.org/tags/stigma

Witnesses to accept blood products is well recognised. It has also been shown that baseline positive religious coping mechanisms (eg, spiritual support, seeking support from church members) are predictive of improved physical and mental health among older patients 2 years after hospitalisation.[43]

In this context, many parts of the world, including the Middle East, north Africa, large parts of Asia, and the Maldives (ie, regions with the highest prevalence of fatty liver disease) have both a religious prohibition on alcohol consumption and social discouragement of drinking. Unfortunately, intended or otherwise, strong stigma associated with the current term NAFLD remains and reference to alcohol is an additional stressor, reducing the likelihood that people will engage in health-seeking behaviour and support. Thus, from a global perspective, NAFLD is considered by many an unsuitable term.

The power of renaming

Confusion and trivialisation

Changing a disease label can have a pivotal effect on disease perceptions, causal beliefs, and management strategies.[47,48] Changing the name might be especially useful in contexts for which the lay perception of a disease does not align with the current understanding of the condition. Studies have shown that perceptions of consequences of severe illness were major determinants of lifestyle modification among patients with NAFLD.[49] Another study showed that a major barrier in the adoption and maintenance of the Mediterranean diet, a diet with beneficial effects on fatty liver disease, might be attributed in part to NAFLD conceptualisation and the viewing of long-term outcomes as inevitable.[50] Therefore, changing the name might be fundamental to helping patients properly understand their disease, including projected risks and complications at an early stage, so that they believe in the importance and effectiveness of changing their lifestyle to alter the course of the disease. In addition, the long and insidious natural history of NAFLD, before the occurrence of complication events, adds to the reduced awareness of the risks. Consequently, the condition becomes less of a priority in disease management than other diseases with earlier complication events. The move to the MAFLD nomenclature brings fatty liver disease into the fold with other metabolic diseases, which makes patients and physicians alike more cognisant than previously of the myriad other interconnected conditions, and also makes the disease easier to identify and relate with.

In similar contexts, previous studies in other diseases have shown the positive effects of changing disease names on perceptions and health outcomes. For example, studies have shown that the term gout was considered by patients and lay people as representing something more embarrassing, less serious, and less chronic than the disease itself; renaming to urate crystal arthritis led to improvements in disease perception, understanding, and beliefs about management.[47,51] Similarly, a targeted text-message programme that changed patients' perceptions of their illness and medications led to improved medication adherence in young adults with asthma.[52] As another example, a brief in-hospital intervention for illness perception after myocardial infarction led to fewer reports of angina symptoms after discharge and an earlier return to work than the control group who received the usual care from rehabilitation nurses.[53] Thus, the change to MAFLD could decrease confusion and trivialisation and increase disease awareness. Clearly, studies will need to be done to examine the effects of renaming to MAFLD on patient perceptions and outcomes.

Stigmatisation

The power of renaming diseases extends to effects on stigma, and lessons can be garnered from other diseases. For example, the European Liver Patients' Association (ELPA) and the International PBC Foundation participated in the name-changing process of primary biliary cholangitis. Renaming the disease from primary biliary cirrhosis resulted in lowering the stigmatisation and discrimination of patients who were previously considered cirrhotic and who, as a consequence, did not have the same access to health-care services and health-care insurance.[54,55] In several Asian countries, schizophrenia has been renamed from split-mind disorder (a direct translation of the word schizophrenia) to attunement disorder. This change has been accompanied by improvements in attitudes toward patients and knowledge about the disease.[56,57] Mental health practitioners have suggested that the negative meaning of the name schizophrenia was one of the main reasons for not informing patients and guardians about the diagnosis.[58] In turn, the name change led to substantially increased disease notification rates.[59] In our experience, individuals living with fatty liver disease have been hoping for years that the word "alcoholic" would be dropped from the name. Noting their alcohol consumption as but one of multiple risk factors for liver disease would reduce stigmatisation and its attendant consequences. The change of nomenclature from NAFLD has been suggested as a priority at key events organised by ELPA and other patient organisations, as the connection between the term and patient stigmatisation was clear.[60–62] In sum, renaming a disease is seen as a means and an opportunity to reduce stigmatising negative beliefs and prejudice, which will translate to improved liver health.

Holistic patient management

One of the challenges for fatty liver disease from a patient perspective is understanding who will be treating you—eg, whether it will be a hepatologist, diabetologist, obesity expert, or nutritionist.[63] Although it has been acknowledged that metabolic diseases require interdisciplinary care, the current NAFLD label is an obstacle in achieving this goal. Renaming would help to inform health professionals, policy makers, and society in general of the tight interconnections between MAFLD, metabolic syndrome, and type 2 diabetes.[64]

The proposal for redefining and renaming fatty liver disease also attempts to provide simple diagnostic criteria, addressing concerns that previous definitions were only based on exclusions. For instance, people who have viral hepatitis can now be diagnosed with concomitant MAFLD; previously, they had been excluded from a NAFLD diagnosis. From our patient group perspective, the most universally embraced aspect of this name change is the definitive statement about what constitutes MAFLD as a standalone entity.

Patient advocacy organisations

One estimate suggests that 844 million people have chronic liver disease, exceeding other major health problems, such as pulmonary disease (650 million), cardiovascular disease (540 million), and diabetes (422 million).[41] Despite these numbers, the paucity of patient organisations for liver diseases compared with organisations for other related diseases is a challenge. Renaming and reframing the disease with the label "metabolic" can help establish collaboration with other metabolic disease patient groups (eg, obesity, diabetes, renal and cardiovascular disease), through actions such as shared media campaigns, policies, and funding advocacy, ultimately for the benefit of patients.

Breaking the cycle of underfunded liver disease research

To raise funds to combat fatty liver disease, we need to translate the available evidence of disease burden into clear and simple, rather than technical, messages. These messages need to be conveyed to lay people in the context of community demands for better health, and political advocacy needs to be connected to this messaging. The term NAFLD represents a real barrier towards achieving this goal. Reframing to MAFLD would focus attention, stimulate shared funding with other metabolic diseases, and aid in implementing effective system-wide interventions.

Concerns and challenges of renaming

A number of questions remain. For instance, should the new name reflect associated metabolic disorders? The answer to this question is a resounding yes. The name MAFLD and the term "metabolic" give an indication of the link to other comorbid factors such as obesity, diabetes, dyslipidaemia, cardiovascular morbidity, and hypertension. Hence, this uniform terminology will facilitate consistency in patient orientation and understanding.

The more serious form of NAFLD, non-alcoholic steatohepatitis, should also be considered as part of this discussion. Many of the same arguments against the use on the term "non-alcoholic" apply to this condition, and metabolic-associated steatohepatitis would recognise the transition from the early stage disease to the more severe forms. Alternatively, it might be better to have one umbrella term (MAFLD) that could be easily explained to patients without confusing them with various terms. Medically, the progression can be classified with different severity stages.

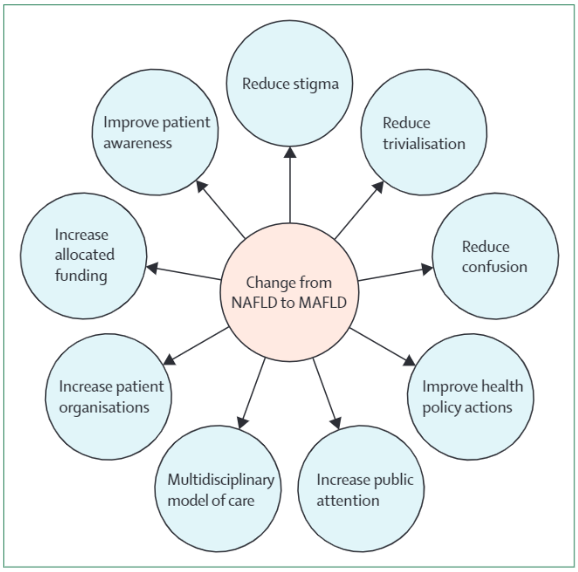

Figure 2: **Implications for redefining fatty liver disease from a patient perspective**
MAFLD=metabolic-associated fatty liver disease. NAFLD=non-alcoholic fatty liver disease.

There have also been concerns that renaming the disease from NAFLD to MAFLD will result in confusion. We appreciate these concerns; however, improved medical care for individuals most in need or left behind will bring comfort and respect rather than let them down and perpetuate the cycle of stigmatisation and confusion. Renaming will also allow a patient-centred holistic approach to care that addresses a disease caused by metabolic dysfunction.

Although the update of nomenclature and disease definition represents a positive first step towards better management of the disease, challenges and unmet needs still remain, such as finding effective pharmacological therapies for the disease and better non-invasive diagnostic methods, and developing more efficient strategies for screening for MAFLD and its complications, among high-risk populations, than are being used currently. These challenges will require further research from experts.

Recommendation

Adopting the name MAFLD is important for a range of stakeholders, especially patients, and is timely and needed to overcome the adverse effects of the current name, while simultaneously meeting the pressing needs of both patients and their families (figure 2). A similar adoption of the term metabolic-associated steatohepatitis should be included to maintain consistency with the disease process; alternatively, this classification could simply be abandoned. The right name will enhance recognition of fatty liver diseases as a public health issue, help with branding, public relations, and educational outreach, and will assist in expanding research support.

Contributors

Following discussions, an initial concept sheet was developed by GS, RS, and MK, and then circulated to the potential panel of contributors. The remaining authors provided their thoughts and inputs on this concept sheet. Subsequently, a manuscript was drafted by GS and RS, circulated to the panel, and feedback incorporated over several rounds of revision. GS and RS contributed to the conceptualisation and drafting of the manuscript and approved the final version. MK, WE, TC, PV-M, SH, BR, CM, SS, AC, MM, FB, NWYL, VM, SO, EB, NP, AEH, TR, EP, BB, MA, CKD, LM, YK, J-FD, and ME contributed to the conceptualisation and critical review of the manuscript and approved the final version.

Declaration of interests

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References

1 Nickel B, Barratt A, Copp T, Moynihan R, McCaffery K. Words do matter: a systematic review on how different terminology for the same condition influences management preferences. *BMJ Open* 2017; **7:** e014129.

2 Nickel B, Moynihan R, Barratt A, Brito JP, McCaffery K. Renaming low risk conditions labelled as cancer. *BMJ* 2018; **362:** k3322.

3 Hagger MS, Koch S, Chatzisarantis NLD, Orbell S. The common sense model of self-regulation: meta-analysis and test of a process model. *Psychol Bull* 2017; **143:** 1117–54.

4 Petrie KJ, Weinman J. Patients' perceptions of their illness: the dynamo of volition in health care. *Curr Dir Psychol Sci* 2012; **21:** 60–65.

5 Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: a review. *Iran Red Crescent Med J* 2014; **16:** e12454.

6 Seidlein A-H, Salloch S. Illness and disease: an empirical-ethical viewpoint. *BMC Med Ethics* 2019; **20:** 5.

7 Vincensi BB. Interconnections: spirituality, spiritual care, and patient-centered care. *Asia Pac J Oncol Nurs* 2019; **6:** 104–10.

8 Alexander M, Loomis AK, Fairburn-Beech J, et al. Real-world data reveal a diagnostic gap in non-alcoholic fatty liver disease. *BMC Med* 2018; **16:** 130.

9 Bertot LC, Jeffrey GP, Wallace M, et al. Nonalcoholic fatty liver disease-related cirrhosis is commonly unrecognized and associated with hepatocellular carcinoma. *Hepatol Commun* 2017; **1:** 53–60.

10 Eslam M, Sanyal AJ, George J, et al. MAFLD: a consensus-driven proposed nomenclature for metabolic associated fatty liver disease. *Gastroenterology* 2020; **158:** 1999–2014.

11 Eslam M, Newsome PN, Anstee QM, et al. A new definition for metabolic associated fatty liver disease: an international expert consensus statement. *J Hepatol* 2020; **73:** 202–09.

12 Stangl AL, Earnshaw VA, Logie CH, et al. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Med* 2019; **17:** 31.

13 Vaughn-Sandler V, Sherman C, Aronsohn A, Volk ML. Consequences of perceived stigma among patients with cirrhosis. *Dig Dis Sci* 2014; **59:** 681–86.

14 Vega WA, Rodriguez MA, Ang A. Addressing stigma of depression in Latino primary care patients. *Gen Hosp Psychiatry* 2010; **32:** 182–91.

15 Sirey JA, Bruce ML, Alexopoulos GS, et al. Perceived stigma as a predictor of treatment discontinuation in young and older outpatients with depression. *Am J Psychiatry* 2001; **158:** 479–81.

16 Sirey JA, Bruce ML, Alexopoulos GS, Perlick DA, Friedman SJ, Meyers BS. Stigma as a barrier to recovery: perceived stigma and patient-rated severity of illness as predictors of antidepressant drug adherence. *Psychiatr Serv* 2001; **52:** 1615–20.

17 Fagerström C, Frisman GH. Living with liver cirrhosis: a vulnerable life. *Gastroenterol Nurs* 2017; **40:** 38–46.

18 Schomerus G, Lucht M, Holzinger A, Matschinger H, Carta MG, Angermeyer MC. The stigma of alcohol dependence compared with other mental disorders: a review of population studies. *Alcohol Alcohol* 2011; **46:** 105–12.

19 Sogolow ED, Lasker JN, Sharim RR, Weinrieb RM, Sass DA. Stigma and liver disease. *Illn Crisis Loss* 2010; **18:** 229–55.

20 Dan AA, Kallman JB, Wheeler A, et al. Health-related quality of life in patients with non-alcoholic fatty liver disease. *Aliment Pharmacol Ther* 2007; **26:** 815–20.

21 Eslam M, Valenti L, Romeo S. Genetics and epigenetics of NAFLD and NASH: clinical impact. *J Hepatol* 2018; **68:** 268–79.

22 Eslam M, Sanyal AJ, George J. Toward more accurate nomenclature for fatty liver diseases. *Gastroenterology* 2019; **157:** 590–93.

23 Kushner I, Greco PJ, Saha PK, Gaitonde S. The trivialization of diagnosis. *J Hosp Med* 2010; **5:** 116–19.

24 Robinson P, Turk D, Jilka S, Cella M. Measuring attitudes towards mental health using social media: investigating stigma and trivialisation. *Soc Psychiatry Psychiatr Epidemiol* 2019; **54:** 51–58.

25 Jason LA, Eisele H, Taylor RR. Assessing attitudes toward new names for chronic fatigue syndrome. *Eval Health Prof* 2001; **24:** 424–35.

26 Pavelko R, Myrick JG. Tweeting and trivializing: how the trivialization of obsessive–compulsive disorder via social media impacts user perceptions, emotions, and behaviors. *Imagin Cogn Pers* 2016; **36:** 41–63.

27 Kozelka EE, Jenkins JH. Renaming non-communicable diseases. *Lancet Glob Health* 2017; **5:** e655.

28 Zou G, Decoster K, McPake B, Witter S. Renaming non-communicable diseases. *Lancet Glob Health* 2017; **5:** e656.

29 Lincoln P. Renaming non-communicable diseases. *Lancet Glob Health* 2017; **5:** e654.

30 Cleveland ER, Ning H, Vos MB, et al. Low awareness of nonalcoholic fatty liver disease in a population-based cohort sample: the CARDIA study. *J Gen Intern Med* 2019; **34:** 2772–78.

31 Singh A, Dhaliwal AS, Singh S, et al. Awareness of nonalcoholic fatty liver disease is increasing but remains very low in a representative US cohort. *Dig Dis Sci* 2020; **65:** 978–86.

32 Zhang W, Chao S, Chen S, et al. Awareness and knowledge of nonalcoholic fatty liver disease among office employees in Beijing, China. *Dig Dis Sci* 2019; **64:** 708–17.

33 Wieland AC, Mettler P, McDermott MT, Crane LA, Cicutto LC, Bambha KM. Low awareness of nonalcoholic fatty liver disease among patients at high metabolic risk. *J Clin Gastroenterol* 2015; **49:** e6–10.

34 Mlynarsky L, Schlesinger D, Lotan R, et al. Non-alcoholic fatty liver disease is not associated with a lower health perception. *World J Gastroenterol* 2016; **22:** 4362–72.

35 Stewart KE, Levenson JL. Psychological and psychiatric aspects of treatment of obesity and nonalcoholic fatty liver disease. *Clin Liver Dis* 2012; **16:** 615–29.

36 Goh GB, Kwan C, Lim SY, et al. Perceptions of non-alcoholic fatty liver disease—an Asian community-based study. *Gastroenterol Rep (Oxf)* 2016; **4:** 131–35.

37 Wattacheril J, Chalasani N. Nonalcoholic fatty liver disease (NAFLD): is it really a serious condition? *Hepatology* 2012; **56:** 1580–84.

38 Standing HC, Jarvis H, Orr J, et al. GPs' experiences and perceptions of early detection of liver disease: a qualitative study in primary care. *Br J Gen Pract* 2018; **68:** e743–49.

39 Williams R, Alexander G, Armstrong I, et al. Disease burden and costs from excess alcohol consumption, obesity, and viral hepatitis: fourth report of *The Lancet* Standing Commission on Liver Disease in the UK. *Lancet* 2018; **391:** 1097–107.

40 Lazarus JV, Ekstedt M, Marchesini G, et al. A cross-sectional study of the public health response to non-alcoholic fatty liver disease in Europe. *J Hepatol* 2020; **72:** 14–24.

41 Marcellin P, Kutala BK. Liver diseases: a major, neglected global public health problem requiring urgent actions and large-scale screening. *Liver Int* 2018; **38** (suppl 1): 2–6.

42 Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol* 2010; **28:** 445–52.

43 Swihart DL, Martin RL. Cultural religious competence in clinical practice. In: StatPearls. Treasure Island, FL: StatPearls Publishing, 2020.

44 Treloar LL. Integration of spirituality into health care practice by nurse practitioners. *J Am Acad Nurse Pract* 2000; **12:** 280–85.

45 Zollfrank AA, Trevino KM, Cadge W, et al. Teaching health care providers to provide spiritual care: a pilot study. *J Palliat Med* 2015; **18:** 408–14.

46 Stern RM, Rasinski KA, Curlin FA. Jewish physicians' beliefs and practices regarding religion/spirituality in the clinical encounter. *J Relig Health* 2011; **50:** 806–17.

47 Petrie KJ, MacKrill K, Derksen C, Dalbeth N. An illness by any other name: the effect of renaming gout on illness and treatment perceptions. *Health Psychol* 2018; **37:** 37–41.

48 Fouad Y, Waked I, Bollipo S, Gomaa A, Ajlouni Y, Attia D. What's in a name? Renaming 'NAFLD' to 'MAFLD'. *Liver Int* 2020; **40:** 1254–61.

49 Zelber-Sagi S, Bord S, Dror-Lavi G, et al. Role of illness perception and self-efficacy in lifestyle modification among non-alcoholic fatty liver disease patients. *World J Gastroenterol* 2017; **23:** 1881–90.

50 Haigh L, Bremner S, Houghton D, et al. Barriers and facilitators to Mediterranean diet adoption by patients with nonalcoholic fatty liver disease in Northern Europe. *Clin Gastroenterol Hepatol* 2019; **17:** 1364–71.

51 Dalbeth N, Douglas M, MacKrill K, Te Karu L, Kleinstäuber M, Petrie KJ. The impact of the illness label 'gout' on illness and treatment perceptions in Māori (Indigenous New Zealanders). *BMC Rheumatol* 2020; **4:** 23.

52 Petrie KJ, Perry K, Broadbent E, Weinman J. A text message programme designed to modify patients' illness and treatment beliefs improves self-reported adherence to asthma preventer medication. *Br J Health Psychol* 2012; **17:** 74–84.

53 Petrie KJ, Cameron LD, Ellis CJ, Buick D, Weinman J. Changing illness perceptions after myocardial infarction: an early intervention randomized controlled trial. *Psychosom Med* 2002; **64:** 580–86.

54 Moore L. Primary biliary cirrhosis has a new name (cholangitis). May, 2019. https://www.interceptpracticetopolicy.com/us/sites/p2pus.com/files/2019-05/NameChange-Final.pdf (accessed July 9, 2020).

55 Gastroenterology & Endoscopy News. Addressing the challenges of primary biliary cholangitis: a patient-centered approach. Nov 15, 2017. https://www.gastroendonews.com/Monographs-Whitepapers/Article/11-17/Addressing-the-Challenges-of-Primary-Biliary-Cholangitis-A-Patient-Centered-Approach/45231 (accessed July 3, 2020).

56 Yamaguchi S, Mizuno M, Ojio Y, et al. Associations between renaming schizophrenia and stigma-related outcomes: a systematic review. *Psychiatry Clin Neurosci* 2017; **71:** 347–62.

57 Maruta T, Matsumoto C. Renaming schizophrenia. *Epidemiol Psychiatr Sci* 2019; **28:** 262–64.

58 Park J, Chung Y. Renaming the term 'Schizophrenia' in Korea. *Korean J Schizophr Res* 2008; **11:** 107–17.

59 Franz L, Carter T, Leiner AS, Bergner E, Thompson NJ, Compton MT. Stigma and treatment delay in first-episode psychosis: a grounded theory study. *Early Interv Psychiatry* 2010; **4:** 47–56.

60 European Liver Patients' Association. Preventing NAFLD-NASH epidemic in EU—patients' perspective. Jan 10, 2019. https://elpa.eu/preventing-nafld-nash-epidemic-in-eu-patients-perspective/ (accessed July 5, 2020).

61 European Liver Patients' Association. ELPA announces Pre-Summit on NAFLD. https://elpa.eu/elpa-announces-elpa-pre-summit-on-nafld/ (accessed July 5, 2020).

62 European Liver Patients' Association . Annual Report 2017. https://elpa.eu/wp-content/uploads/2019/06/Annual-Report-2017.pdf (accessed July 7, 2020).

63 Korenjak M. Paris NASH Meeting 2019—patient perspectives on NASH and NAFLD. July 11–12, 2019. https://paris-nash.org/data-2019/NASH-2019-KORENJAK-M.pdf (accessed July 7, 2020).

64 Eslam M, George J. Genetic contributions to NAFLD: leveraging shared genetics to uncover systems biology. *Nat Rev Gastroenterol Hepatol* 2020; **17:** 40–52.