

NAFLD vs MAFLD: South Asian NAFLD Patients don't Favor Name Change

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ABSTRACT

Aim: There have been vociferous attempts to change the name of Nonalcoholic Fatty Liver Disease (NAFLD) to Metabolic Associated Fatty Liver Disease (MAFLD). Of the many arguments put forth in support of this, an important one is the presumed demand by patient groups insisting on the change. However, this claim does not have credible evidence to support it. Therefore, we decided to conduct a survey among South Asian NAFLD patients to understand their perspectives with regard to the change in nomenclature.

Materials and methods: The study was conducted at multiple centers across South Asia from January 2021 to June 2021. Patients were surveyed using an 8-question survey questionnaire and responses were categorized by multiple-choice format.

Results: Of 218 patients surveyed, 80.3% of the patients were not aware of the entity "NAFLD" before they were first diagnosed. Although 74.3% of patients admitted to being questioned about alcohol intake at the time of the first diagnosis, 75.9% of female patients were not questioned regarding this. After being labelled NAFLD, 92.1% of patients were never questioned again about alcohol intake. While 86.3% of patients found the term "NAFLD" consoling, 83% did not feel that "Non" in NAFLD trivialized their problem. In addition, only 6.9% of patients were scared of developing cardiovascular disease.

Conclusion: The term "NAFLD" stigmatizes patients of the taboo associated with alcohol use. It was found to be consoling to most patients and they did not feel it trivialized their problem. A change of name without considering patients' perspectives and peculiarities specific to different populations will have enormous ramifications for both patients and physicians.

Clinical significance: Our survey clearly shows that patients are happy with the term "NAFLD" and it effectively destigmatizes them from the taboo of alcohol. This would lead to higher compliance with management and greater patient participation in future studies and trials.

Keywords: NASH, Nomenclature, patients' sentiments, South Asia, Steatohepatitis.

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INTRODUCTION

There have been vigorous attempts by a panel of experts to change the name of Nonalcoholic Fatty Liver Disease to MAFLD.¹⁻³ Consensus statements have been published supporting this name change.² Multiple arguments have been advanced and reasons cited in favor of a change in nomenclature of NAFLD.³ One of the major arguments the proponents of MAFLD have put forth is the supposed demand by patient groups including the European Liver Patients' Association (ELPA) to change the name of the entity.¹ The proponents argue that while the term "Non" (a part of Nonalcoholic) in NAFLD trivializes the problem, the word "alcoholic" demeans the patient. A recently published "international patient perspective" endorsed the proposed name change and stated that this would have a positive effect on patient care.⁴ However, this "patient perspective" does not cite any study or data on patients' preferences or apprehensions. A careful perusal of this article clearly shows that the opinions put forth don't represent patients' feelings or sentiments. Before effecting a name change, multiple aspects including implications of the name change need to be thoroughly discussed with patients which clearly has not been done. Disease phenotypes and pathophysiological aspects of NAFLD vary across populations.⁵⁻⁷ In addition, perceptions of patients regarding the disease also vary depending upon sociocultural factors.^{8,9} It is often assumed by healthcare professionals that their perceptions of patients' health are immaculate and in sync with those of the patient. However, this is not always true and often leads to the dictatorial imposition of an idea upon patients.⁹

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The prevalence of NAFLD in Asia is 27.4% which is higher than the global prevalence.^{7,10} The burden of NAFLD in South Asia is increasing by leaps and bounds due to a number of factors. Since South Asia is home to almost 20% of the world's population, this region harbors a huge number of NAFLD patients.¹¹ Additionally, South Asian patients have a unique sociocultural milieu that is vastly

different from their Western counterparts.^{12,13} Specific cultural beliefs and perceptions unique to South Asia play an important role in determining perceptions and attitudes towards a disease. Therefore, it is imperative that perceptions of the disease and the implications of the name change among different population groups need to be studied in detail and understood before proceeding with the name change. We decided to conduct a survey among South Asian NAFLD patients to evaluate their awareness of the disease and their perceptions of various aspects of the name change.

MATERIALS AND METHODS

Study Design and Population

This was an observational cross-sectional study conducted at multiple centers across South Asia (India, Pakistan, Bangladesh, Nepal, and Sri Lanka) from January 2021 to June 2021. Subjects aged 18 years and older who were diagnosed cases of NAFLD were included in the study. Subjects with known chronic liver disease such as viral hepatitis B and C, alcohol-related liver disease, Wilson disease, and liver diseases due to autoimmune etiology were excluded from the study. The study was approved by the institutional ethics boards at each one of the respective centers.

Data Collection

An 8-question survey questionnaire was developed and responses were categorized by multiple-choice format. The questionnaire was in bilingual format (English and a region-specific language). All consecutive subjects who agreed to participate in this study were interviewed using this questionnaire. Survey responses were collated and analyzed.

Statistical Analysis

Descriptive statistics were computed for all variables. Continuous variables were expressed as means and standard deviations, while categorical variables were expressed as frequencies and percentages. SPSS version 25 (Chicago, Illinois, USA) statistical software package was used for statistical analysis.

RESULTS

A total number of 218 patients were surveyed in this study. Details of age and sex were available for 198 patients. The mean age of the patients was 41.17 ± 10.46 years. 66.1% of the patients were males.

Of 218 patients, 175 (80.3%) had not been aware of the entity NAFLD before they were diagnosed (Fig. 1). 162 (74.3%) patients admitted to being questioned about significant alcohol intake when they were first diagnosed, while 56 (25.7%) patients denied being asked so (Fig. 2). Among female patients, 41 (75.9%) said that they had never been asked about the history of alcohol intake at first diagnosis (Fig. 3), 201 (92.1%) patients said that after being diagnosed as NAFLD, they were never questioned again regarding alcohol intake during subsequent visits (Figs 1 and 2) while 189 (86.3%) patients did not find the label "NAFLD" disrespectful (Fig. 4) and 181 (83%) patients did not think that the term "Non" in NAFLD trivialized their problem and they were not bothered by it (Fig. 4). Further, 153 (70.2%) patients thought NAFLD was not a bad disease if managed properly while 63 (28.9%) patients considered it to be a dangerous disease. While 156 (71.6%) patients were concerned that they had the disease, only 53 (24.3%) patients admitted to being scared of it (Fig. 5), 118 (54.1%) patients were concerned or scared because they thought it could cause liver cirrhosis while 72 (33%) patients thought it could lead to liver cancer (Fig. 6). Only 15 (6.9%) patients thought that they were prone to developing heart disease and only 4 (1.8%) patients thought they were prone to developing other cancers (Fig. 6).

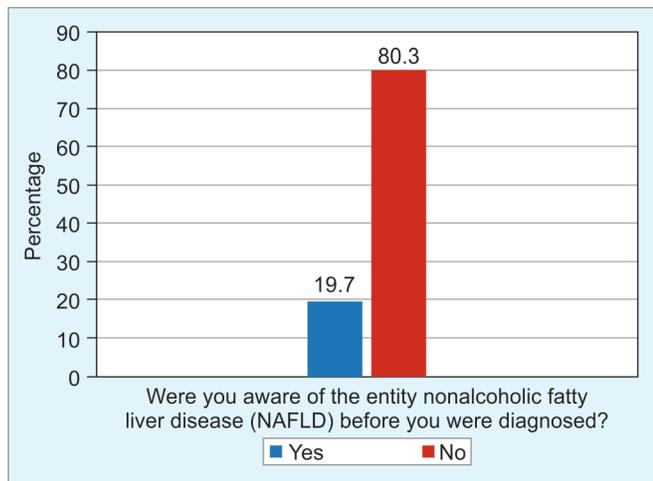


Fig. 1: Patients' awareness of NAFLD before diagnosis

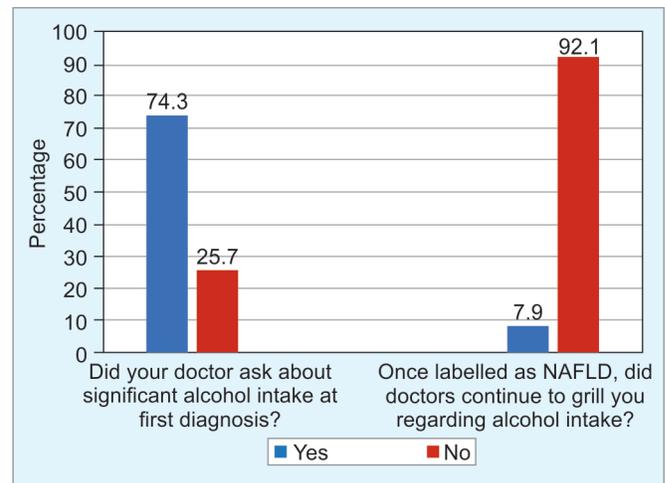


Fig. 2: Pattern of inquiry regarding alcohol intake

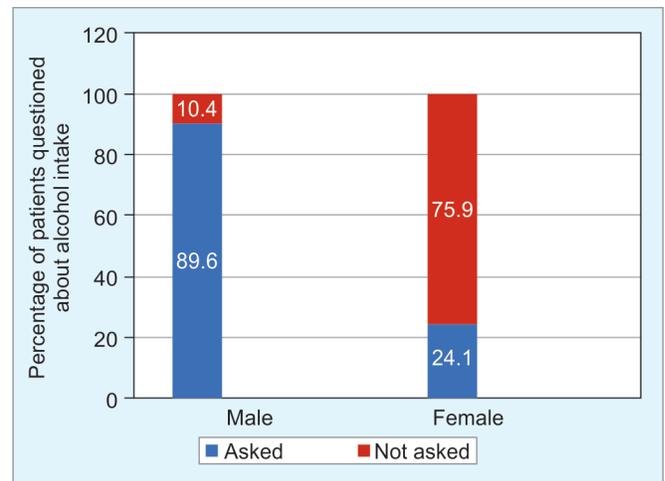


Fig. 3: Gender disparity in questioning about alcohol intake

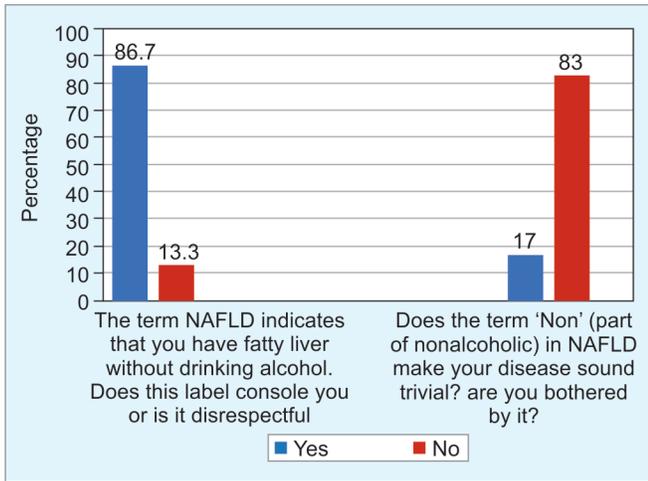


Fig. 4: Patients' sentiments concerning NAFLD

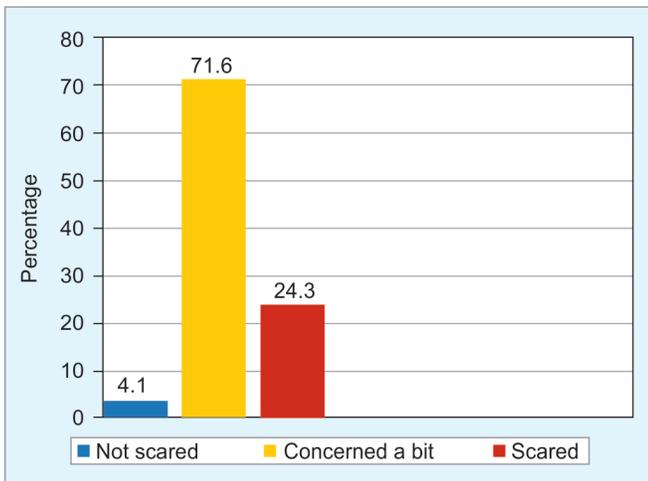


Fig. 5: Patients' concerns regarding the disease

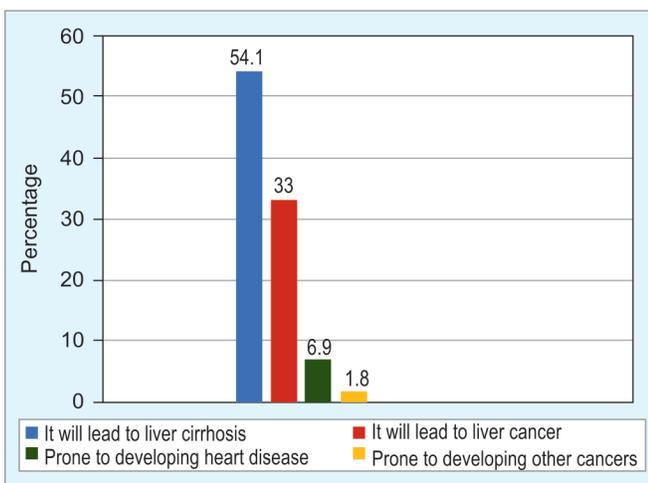


Fig. 6: Patients' reasons for concern

DISCUSSION

Our study has characterized the perceptions and attitudes of South Asian NAFLD patients towards the disease and several aspects of

the name change. Awareness of NAFLD among South Asian NAFLD patients is poor as reflected by the fact that the vast majority of patients had been unaware of NAFLD prior to diagnosis. Attitudes of patients towards NAFLD have been explored in an Asian community-based study earlier which also advocated for the promotion of better awareness regarding NAFLD.¹⁴ Our study shows that most of the NAFLD patients had been asked about significant intake of alcohol when they were first diagnosed. Further, once they had been labelled "NAFLD", the majority of them were not subjected to further inquiry regarding alcohol intake during subsequent visits. However, paradoxically the majority of female patients were never asked regarding alcohol intake at the time of the first diagnosis. This is indicative of the social stigma associated with alcohol among South Asians, and in particular, among female South Asians. Female substance users in India have been shown to suffer from a greater degree of social stigma compared to their male counterparts.¹⁵ With the exception of tribal societies, for women, abstinence from alcohol is a norm in India.¹⁶ This can be attributed to social and cultural norms, religious factors, and patriarchal influences.^{16,17} The different countries of South Asia follow almost the same sociocultural patterns and are bound by similar religious restrictions. Alcohol is still taboo in South Asia and questioning a patient regarding alcohol intake is often considered improper and is responsible for eroding the doctor-patient relationship many a time. These cultural factors and patterns unique to South Asia which play a major role in this kind of peculiar behavior are not encountered in Western societies. Importantly, most of the patients did not find the label "NAFLD" disrespectful and the majority of them thought that the term "Non" in NAFLD did not trivialize their problem. This is quite contrary to the claims made by the proponents of MAFLD who have conveniently overlooked the global variation in NAFLD and the cultural differences across populations. Although a significant proportion of patients were scared of the disease, paradoxically only a small minority were aware of the cardiovascular hazards of NAFLD.

Our survey clearly shows that the term "NAFLD" destigmatizes patients of the taboo associated with alcohol use. Repeated questioning and grilling of patients about alcohol intake is humiliating to patients. Most patients found the term "NAFLD" consoling and did not feel that it trivialized their problem. It is obvious that the label of "NAFLD" will protect them from persistent and humiliating questioning about alcohol intake.

In a survey by Alem et al.,¹⁸ a significant proportion of Egyptian patients were found to express dissatisfaction with the term NAFLD. The apparent reason professed for this was the presence of "alcohol" in NAFLD, which is associated with stigma in Egyptian culture. This logic seems to be primarily flawed and raises concerns about the methodology of the survey. To begin with, the presence of the term "nonalcoholic" in NAFLD should effectively destigmatize a patient, especially in cultures where alcohol is taboo and it is inexplicable why patients would find the presence of "nonalcoholic" disturbing. On the contrary, patients are expected to express serious dissatisfaction with the term "MAFLD" which, by definition, would include the intake of significant amounts of alcohol and also leave room for repeated questioning about alcohol intake during subsequent consultations. Second, since most patients are unaware of NAFLD in the first place, it is highly probable that they were totally ignorant of the implications of a change in nomenclature. Therefore, the results of this particular survey don't really lend any credence to the call for a name change.

Our study demonstrates the fallacies in the claims by the proponents of MAFLD. The change in the name of any disease entity has got major implications for both physicians and patients.¹⁹ Considering the enormous burden of NAFLD and the peculiarities

associated with disease perceptions among South Asians, it would have been prudent to study these aspects of the disease before rushing forward with the name change. The cultural diversity across populations and the sensitivities of South Asian patients cannot be ignored.

Our study highlights the glaring lack of awareness among patients regarding NAFLD. The need of the hour is spreading awareness of the entity among patients, educating them about the implications of the disease, and developing treatment strategies. It would vastly benefit both the patient community and hepatologists if global collaborative efforts were launched creating networks across countries and populations; our understanding of the disease would greatly increase while patients would be greatly benefitted.

CONCLUSION

A change of name for any medical entity has got enormous ramifications for both patients and physicians. Arbitrarily doing so without a convincing reason would do more harm than good in the long run. Proponents of MAFLD must take into account the global diversity in NAFLD and the peculiarities specific to different populations before going ahead with the name change. It is amply clear that these attempts at changing the name would do nothing to move the field forward. It would benefit not only NAFLD patients but also the hepatologists engaged in research on NAFLD if collaborative efforts were launched worldwide to understand the entity better and devise therapeutic strategies.

Clinical Significance

The attempt by a panel of experts to change the nomenclature of NAFLD to MAFLD is bound to have significant clinical implications. It would be an abject denial of all the evidence gathered in NAFLD research over decades and would also move the field backward as it would not be possible to reconcile previous results with new findings. Additionally, at the level of the individual patient, it would create great confusion since studies that have used MAFLD criteria have included patients with alcohol consumption up to 60 g/day. This would also create problems in pinpointing diagnosis and devising management protocols and algorithms.

Our study assumes great clinical significance since it evaluates the perspectives of patients in South Asia who constitute a significant proportion of the global NAFLD population. The response is a clear "No" to name change, thereby reaffirming the primacy of patients' attitudes and beliefs before contemplating a change of this scale and magnitude. The term "NAFLD" is comforting to patients, destigmatizes them, and is acceptable to the vast majority of South Asian patients. This would also lead to greater participation of patients not only in NAFLD research but also in devising preventive strategies and community programs.

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