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The Global Survey of Disease Burden and Stigma in NAFLD

Zobair M. Younossi, Yusuf Yilmaz, Jian-Gao Fan, Ming-Hua Zheng, Khaled Alsawat, Saleh A. AlQahtani, Mohammed El-Kassas, Laurent Castera, Jesus Funuyet, Manuel Romero-Gómez, Vincent Wai-Sun Wong, Shira Zelber-Sagi, Sombat Treeprasertsuk, Alina M. Allen, Hirokazu Takahashi, Takumi Kawaguchi, Sven Francque, Marlen I. Castellanos Fernández, Ajay Duseja, Jörn M. Schattenberg, Patrizia Burra, Patrizia Carrieri, Marco Arrese, Mary Rinella, Ashwani K. Singal, Stuart Gordon, Michael Fuchs, Wayne Eskridge, Naim Alkhouri, Kenneth Cusi, Rohit Loomba Jane Ranagan, Achim Kautz, Janus P. Ong, Marcelo Kugelmas, Yuichiro Eguchi, Moises Diago, Phil Newsome, Ming Lung Yu, Lynn Gerber, Brian Lam, Lisa Fornaresio, Fatema Nader, Linda Henry, Andrei Racila, Pegah Golabi, Maria Stepanova, Jeffrey V. Lazarus and the Global NASH Council

Background: NAFLD can be associated with disease burden and stigma to both the patients and providers.

Aims: To understand the disease burden and stigma among NAFLD patients and their healthcare providers.

Method: Members of the Global NASH Council created two surveys about experiences and attitudes toward NAFLD and related terms (68-items patient and 41-items provider survey).

Results: The surveys were completed by 895 NAFLD patients from 19 countries and 629 providers [64% GI/hepatologists, 23 countries]. Of all patients, 64% ever disclosed having NAFLD to family/friends; the majority used word was “fatty liver” (82% at least sometimes) while “metabolic disease” or “MAFLD” were rarely used (never by 83-88%). There were 35% who reported experiencing stigma or discrimination (at least sometimes) due to obesity/overweight but only 12% due to NAFLD. From the Liver Disease Burden (LDB) part of the patient survey (35 items, 7 domains; range 1-4, higher scores indicate greater burden), the total mean burden score was the highest in patients from the USA (1.97 ± 0.57), the lowest in Middle East and North Africa (MENA) region (1.74 ± 0.53). The Stigma domain score was also the highest in the USA (2.51 ± 0.71), the lowest in MENA (1.84 ± 0.60). In multivariate analysis adjusted for country of enrollment, independent predictors of higher total LDB and Stigma scores included female sex, living outside of an urban region, history of weight loss due to medical reasons, having ≥ 2 chronic comorbidities, and having severe fibrosis or cirrhosis ($p < 0.05$). Regarding how various diagnostic terms were perceived by patients, there were no substantial differences between “NAFLD”, “fatty liver disease”, “NASH”, or “MAFLD”: the most popular response was being neutral (neither comfortable nor uncomfortable: 45%-60%). In contrast, provider discomfort while taking care of patients with NAFLD was primarily related to the perceived patients’ lack of willpower for lifestyle changes and taking care of their diabetes (43-48%). Furthermore, 40% of providers believed that the word “fatty” in the name of the disease was stigmatizing for patients (similar across regions and specialties) while 35% believed that the term “non-alcoholic” was stigmatizing (more commonly in the MENA region and among GI/hepatologists). Finally, 45% of providers (49% GI/hepatologists vs. 36% other specialties) believed that a name change may reduce the disease stigma.

Conclusions: Perception of NAFLD disease burden and stigma varies between patients, providers, and regions of the world. There is evidence that stigma is more associated with obesity than NAFLD and that women are more concerned than men.