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BACKGROUND

Patients with fatty liver disease may experience stigmatization due to the disease or associated comorbidities.

AIM

The aim was to understand stigma among NAFLD patients and providers.

METHODS

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

RESULTS

The patient surveys were completed by 475 NAFLD patients [12 countries; 58% USA, 20% Middle East/North Africa (MENA), 20% East Asia] (Figure 1) and the provider surveys were completed by 555 providers (Figure 2).

Figure 1. Demographics of Participating NAFLD Patients

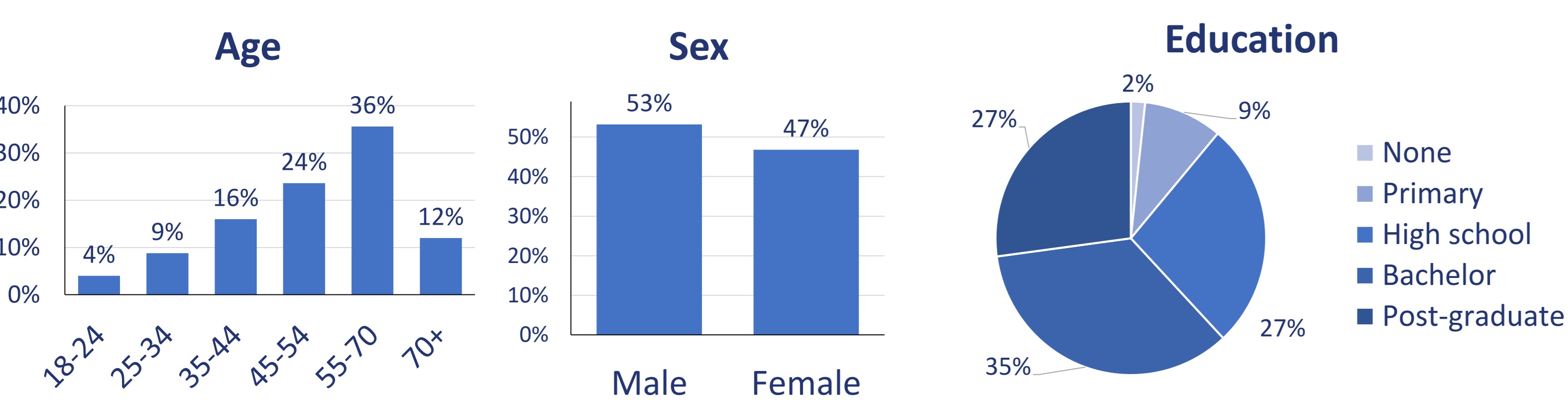
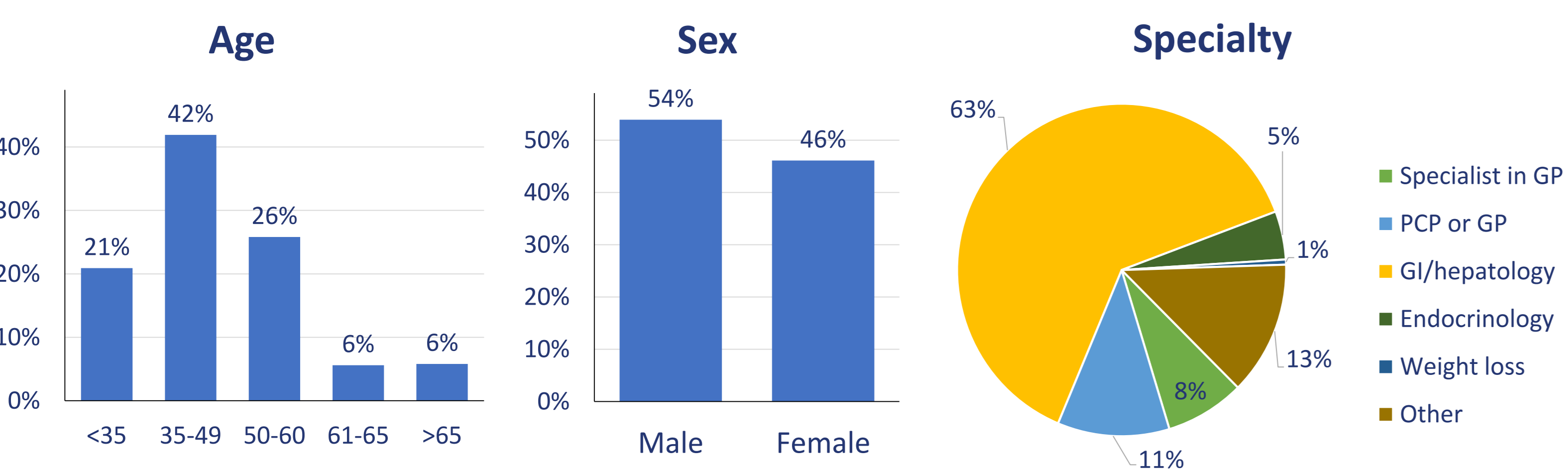


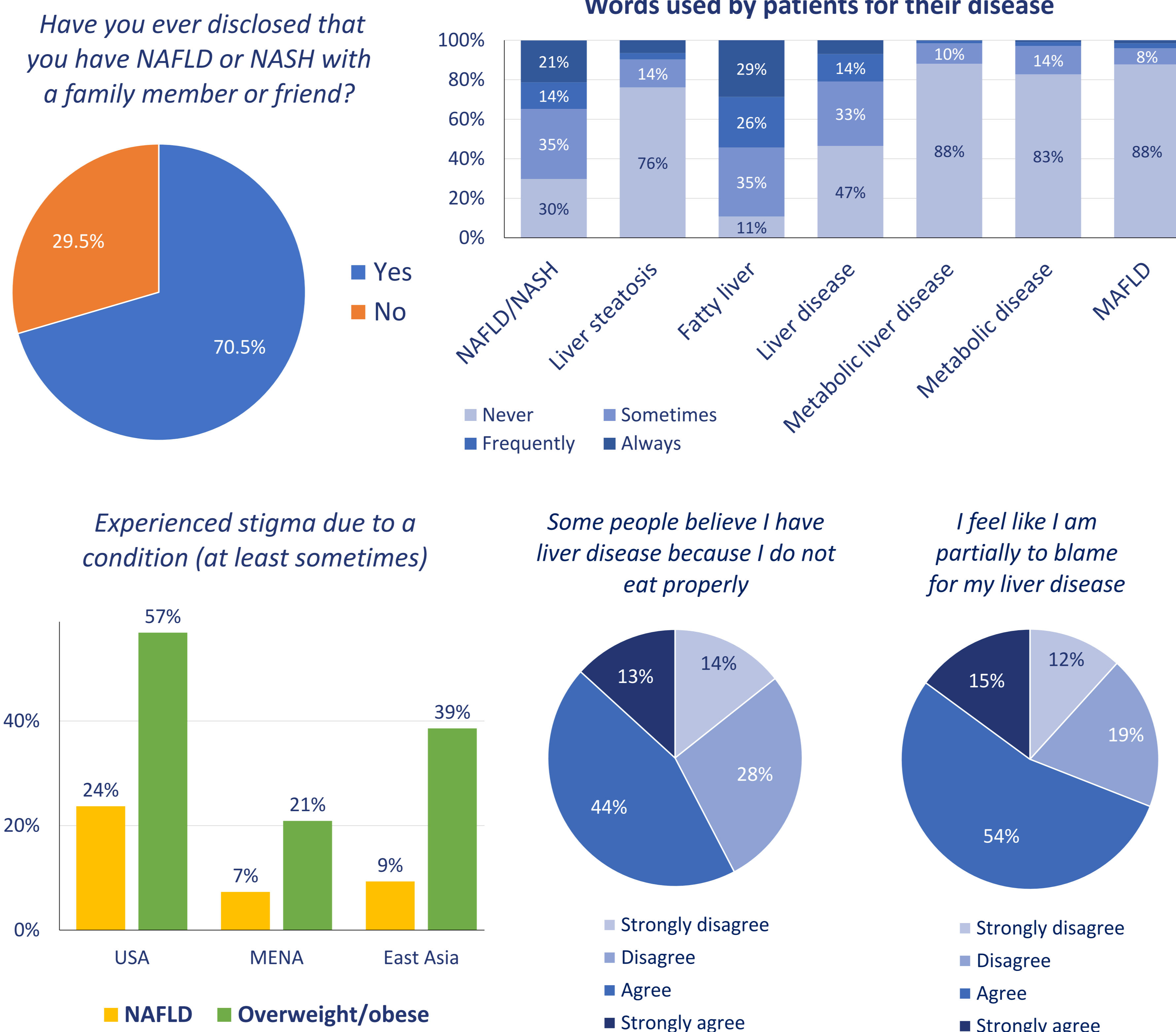
Figure 2. Demographics of Participating Providers



RESULTS

- Of all patients, 71% ever disclosed having NAFLD/NASH to family/friends (Figure 3).
- The words most commonly used by patients were “fatty liver” and “NAFLD or NASH” (35-54%); “metabolic disease” or “MAFLD” were rarely used (never 83-88%) (Figure 3).
- There were 46% who reported experiencing stigma or discrimination (at least sometimes) due to obesity/overweight vs. 17% due to NAFLD (Figure 3).
- The greatest social-emotional burden among NAFLD patients was feeling partially to blame for their liver disease (69% agree) and others believing that they do not eat properly (58% agree) (Figure 3).

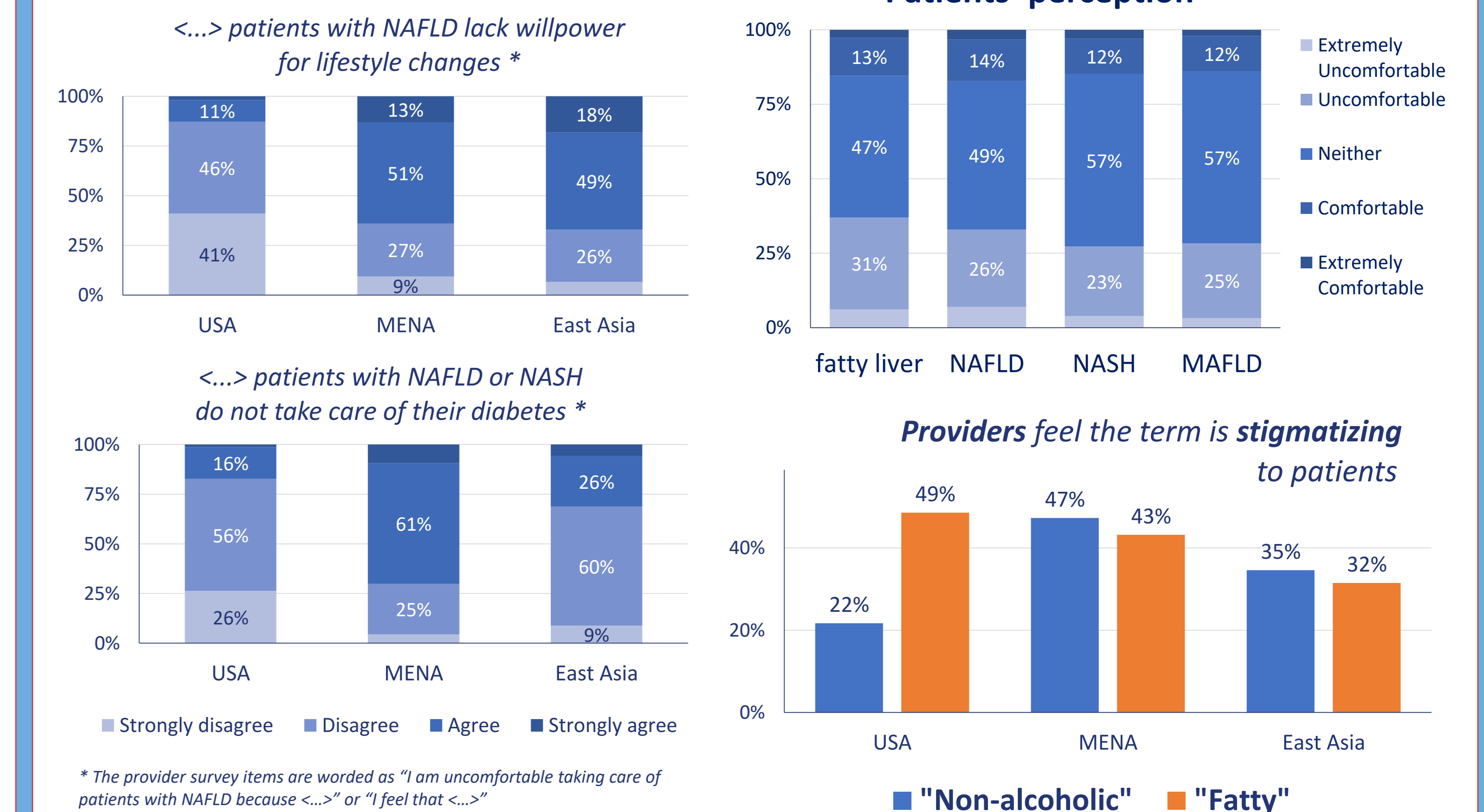
Figure 3. Disease Burden Reported by NAFLD Patients



RESULTS

- Providers believed that lack of patient motivation (70%) and of effective communication (62%) were the biggest obstacles to weight loss discussions.
- Furthermore, provider discomfort was related to perceived patients' lack of willpower for lifestyle changes and taking care of their diabetes (45-49% providers; 13-17% USA vs. 64-70% MENA, 31-67% East Asia) (Figure 4).

Figure 4. Providers' Experience with NAFLD Patients



* The provider survey items are worded as "I am uncomfortable taking care of patients with NAFLD because <...>" or "I feel that <...>".

- Regarding how diagnostic terms are perceived by patients, there were no substantial differences between “NAFLD”, “fatty liver disease”, “NASH”, “MAFLD” (Figure 5).
- Among providers, 42% (49% USA, 43% MENA, 32% East Asia) believed that the term “fatty” in the name is stigmatizing, while 38% believed that the term “non-alcoholic” is stigmatizing, more commonly in MENA (47%) (Figure 5).
- Finally, 54% of the providers (58% GI/hepatology vs. 42% others; 46% USA, 59% MENA, 51% EA) believe that a name change for NAFLD may reduce stigma.

CONCLUSIONS

- Perception of NAFLD stigma varies according to patients, providers, geo-geographic location and sub-specialties.
- NAFLD patients reported the term obesity to be more stigmatizing than NAFLD.

