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Supplementary data

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Lucy Gracen^{1,2}
 Kelly L. Hayward^{1,2}
 Katharine M. Irvine³
 Patricia C. Valery^{1,4}
 Elizabeth E. Powell^{1,2,*}

¹Centre for Liver Disease Research, Faculty of Medicine, Translational Research Institute, The University of Queensland, Brisbane, QLD, Australia

²Department of Gastroenterology and Hepatology, Princess Alexandra Hospital, Brisbane, QLD, Australia

³Mater Research, Translational Research Institute, Brisbane, QLD, Australia

⁴QIMR Berghofer Medical Research Institute, Herston, QLD, Australia

*Corresponding author. Address: Level 5, West Wing, Translational Research Institute, 37 Kent Street, Woolloongabba, Brisbane, Queensland, 4102, Australia.

E-mail address: e.powell@uq.edu.au (E.E. Powell)



Stigma and care avoidance in people with unhealthy alcohol use: A call for research and action

To the Editor:

The article by Schomerus *et al.*¹ on the stigma associated with alcohol-related liver disease and its impact on healthcare provides a lucid, profound, and timely analysis of an under-addressed topic in the field of liver disease care. The very real consequences of stigma and the need for interventions to reduce its impact continue to be neglected. This affects the cascade of care, not only for unhealthy alcohol use and liver disease, but also for associated comorbidities.² Moreover, as the authors underline, public stigma reinforces the vicious circle between self-stigma, delayed care and social inequities. As has already been observed for obesity and associated liver disease, this vicious circle is nourished by social media marketing and social inequities, which are the main drivers of unhealthy alcohol use.

We also share the argument that a dynamic model of individual and social responsibility – where greater alcohol use disorder (AUD) severity calls for greater emphasis on social responsibility – can reduce labelling and associated stereotypes against people with unhealthy alcohol use. This model also facilitates problem recognition and helps increase self-awareness that the risk to health grows as the level of alcohol use increases.

Nevertheless, there are some points that we would like to underline which require further research and/or implementation

science. First, as Schomerus *et al.* indicate, there is a severe lack of quantitative studies providing estimates for the association between self-stigma and care avoidance in people with unhealthy alcohol use. The only review to date reporting such estimates was based on a heterogeneous group of people with mental health problems.³

People with AUD are greatly concerned by self-stigma as they also experience an extreme form of stigma known as dehumanization⁴ (*i.e.*, denial of one's membership in humanity). Accordingly, the strength of the association between self-stigma and care avoidance in this population could be even stronger than in other groups.

We would like to provide novel unpublished data about this relationship. In the French intervention study ETHER,⁵ which recruited 92 people with AUD in sites offering either a community-led intervention or specialised services for substance use disorders, we measured patient-reported outcomes at enrolment using a phone-based interview based on a standardised questionnaire. Among other information, the interview included the completion of the Substance Use Stigma Mechanism Scale (SU-SMS) questionnaire, which included 2 scores of anticipated and internalized (or self-) stigma.⁶ Using a negative binomial regression model based on enrolment data, we found that people with severe levels of self-stigma had an almost 6-fold higher risk of care avoidance (incidence rate ratio [IRR] = 5.67; 95% CI 1.10–29.25; *p* = 0.038) than those with no or low

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self-stigma. Preliminary results about the effect of ETHER's community-led intervention on alcohol-related harms showed significantly reduced self-stigma ($p < 0.05$) with respect to the control group (standard care).

As stigma is a central issue in liver care,^{1,2} we need more estimates of this type, as well as an effect estimate of anti-stigma interventions on care avoidance and their impact on other liver-related outcomes. Moreover, it is essential to use mathematical modelling to forecast outcomes of multi-level interventions for people with alcohol-related liver disease. Modelling can help guide policy making and public health funding decisions to ensure improved liver outcomes and survival through investment in the most cost-effective combined interventions. Introducing the effect of stigma and anti-stigma interventions when modelling liver disease progression needs to become a major focus for innovation in our future research agenda. To date such studies are scarce.⁷

Second, as dehumanization severely affects self-stigma, it requires more complex interventions – including social support measures – to reduce related harms. Paradoxically, low-threshold sites where peers deliver education and social support to reduce self-stigma and increase self-empowerment are scarce and are not adapted for people with unhealthy alcohol use. The evaluation of the effectiveness of social support and educational interventions delivered in community-led sites on patient-reported outcomes and care using an implementation science approach is also a major research need.

Third, further research to assess to what extent incentives, medical training, and social contact anti-stigma interventions targeting primary care physicians, can improve the AUD cascade of care is required before one can recommend the transfer of AUD screening and care (or referral to care²) to the primary care setting.

There is still a long way to go in the comprehensive incorporation of stigma assessment and anti-stigma interventions in the health setting, in research, and specifically in modelling in the field of liver disease. We thank Schomerus *et al.* for their key contribution which highlights the need for these actions and paves the way to promote research on this all too neglected liver care issue.

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Conflicts of interest

PC received research funding by MSD and Intercept unrelated to this work. The other authors declare no conflicts of interest.

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Authors' contributions

Patrizia Carrieri: Conceptualization, Methodology, Supervision, Writing - Original draft, Writing - Review and Editing, Funding acquisition. Tangui Barré: Conceptualization, Validation, Writing - Review and Editing. Morgane Bureau: Investigation, Project administration, Writing - Review and Editing. Fabienne Marcellin: Conceptualization, Validation, Writing - Review and Editing. Abbas Mourad: Methodology, Formal analysis, Writing - Review and Editing.

Supplementary data

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Patrizia Carrieri
Tangui Barré
Morgane Bureau
Fabienne Marcellin*
Abbas Mourad

Aix Marseille Univ, INSERM, IRD, SESSTIM, Sciences Economiques & Sociales de la Santé & Traitement de l'Information Médicale, ISSPAM, Marseille, France

*Corresponding author. Address: SESSTIM, Aix-Marseille Univ, Faculté de Médecine 3è étage, rue Jean Moulin, 13005 Marseille, France.
E-mail address: fabienne.marcellin@inserm.fr (F. Marcellin)