

Hepatic Encephalopathy: A Diagnosis for the Individual but an Experience for the Household

Jeremy Louissaint, MD¹ and Elliot B. Tapper, MD^{1,2}

Abstract: Hepatic encephalopathy (HE) is a common complication of cirrhosis that results in unpredictable neuropsychiatric symptoms and increases the risk of death and disability. In the current issue of *Clinical and Translational Gastroenterology*, Fabrellas et al. report on a qualitative study that assesses the psychological impact of HE on both patients and their informal caregivers. Both patients and caregivers report diminished quality of life driven by disruptive anxiety and feelings of fear and sorrow. There is a need to optimize therapy for encephalopathy and to address the shared psychological impact of HE experienced by both patients and caregivers.

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THE WEIGHT OF HEPATIC ENCEPHALOPATHY: HEAVY AND SHARED

Although it presents with a spectrum of severity, even the presence of minimal hepatic encephalopathy (HE) impacts every aspect of a patient's life. HE disrupts one's sleep, driving, daily functioning, and earning potential and carries with it the burden of repeated hospitalizations and diminished survival (1–4). Unsurprisingly, these effects on the patient spill over and affect the quality of life (QoL), health, and functioning of one's caregivers (5). Measuring patient- and caregiver-reported outcomes in cirrhosis provides essential insights into the subjective impact of the disease (6). However, our understanding of contributors to the psychological burden of HE remains incomplete. Missing from the literature are the voices of those experiencing the debilitating consequences of HE. Fabrellas et al. extends our knowledge of the scale and scope of the burden of HE on patients and their caregivers with an important study that gives voice directly to those who are affected (7).

STUDY FINDINGS

Using a mixed-methods study design, the authors enrolled 15 patients with a history of HE and their informal caregivers to complete validated QoL scales (Medical Outcomes Study Short Form 36 and, additionally for caregivers, the Zarit Burden Index). In all areas of the physical and mental components of the Medical Outcomes Study Short Form 36, both patients and their caregivers reported markedly lower health-related QoL scores compared with established norms. Caregiver burden was also exceedingly high (mean Zarit Burden Index 51). Semistructured interviews revealed high expressions of fear, anxiety, sorrow, and

anger in nearly half of patients and in one-third of their caregivers. Even more alarming was the disclosure from most participants that the entity of HE was unknown to them before its actual occurrence. In summary, this informative data provide us with 3 major opportunities to improve the care we deliver to patients and their caregivers (Table 1).

IDENTIFYING AT-RISK PERSONS

Improving the burden of HE begins with proper identification of those at risk so that we can prepare patients and mitigate known precipitants. This starts with risk stratification, which includes the use of scores such as the Bilirubin–Albumin–Beta-Blocker–Statin score and screening for covert HE with tools such as the Animal Naming Test or EncephalApp Stroop (8,9). In addition, routine care for persons with cirrhosis should include frequent review of medications and efforts to minimize risky medications, such as benzodiazepines, opiates, and proton pump inhibitors (10,11). Finally, nutritional interventions to achieve protein targets (e.g., 1 g/kg actual bodyweight) are recommended to reduce the risk of sarcopenia and forestall HE episodes (12).

REDUCING RISK

Secondary prophylaxis of HE relies on both pharmacologic and nonpharmacologic strategies. Lactulose, rifaximin, and optimized nutrition all reduce the risk of recurrent HE and improve patient-reported outcomes (13,14). However, as highlighted by Fabrellas et al., treatment must also address the psychological burden experienced by patients and their caregivers. Clinicians should inquire about, validate, and address the worries and fears experienced by their patients. When indicated, clinicians should

¹Division of Gastroenterology and Hepatology, University of Michigan, Ann Arbor, Michigan, USA; ²Gastroenterology Section, VA Ann Arbor Healthcare System, Ann Arbor, Michigan, USA. **Correspondence:** Elliot B. Tapper, MD. E-mail: etapper@umich.edu.

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Table 1. Reducing the psychological burden of hepatic encephalopathy

| Targets | Tools | Interventions |
|-------------------------------------|----------------------------------------------------------------------------|-----------------------------------------------------------------|
| Risk identification | Testing | Primary prophylaxis of overt HE (e.g., trial lactulose) |
| | Paper-and-pencil testing (psychometric HE score) | Standardized educational handouts |
| | Point-of-care testing (animal naming test, EncephalApp) | |
| | High-risk groups | |
| | Low albumin, high bilirubin, and portal hypertension (ascites and varices) | |
| | Patient-reported outcomes (falls, poor sleep, and poor quality of life) | |
| | Education | |
| | Ensure understanding of the natural history of cirrhosis | |
| Risk reduction | Review medications | Limiting/deprescribing risky medications when safe |
| | Avoid benzodiazepines, opiates, and proton pump inhibitors | Ensure daily protein intake of 1 g/kg actual bodyweight per day |
| | Nutritional screening | |
| | Characterize food intake | |
| | Assess for weakness/frailty (e.g., timed chair stands) | |
| | Loss of appendicular muscle mass | |
| Burden reduction after a HE episode | Optimized medical therapy | Education on lactulose dose adjustment |
| | Lactulose | Nutritionist consultation |
| | Rifaximin | Referral for psychotherapy, social work |
| | Micronutrients (e.g., zinc) | |
| | Macronutrients (protein) | |
| | Nonpharmacologic | |
| | Stress reduction, mindfulness | |

HE, hepatic encephalopathy.

then refer patients and their caregivers for counseling and consider interventions, such as mindfulness training, that improve mood, sleep, and caregiver burden (15). Additional, scalable interventions are also needed. We, for example, have launched a randomized controlled trial to assess the impact of resilience training and emotional disclosure through keeping a diary on caregiver burden (16).

EDUCATION

Fabrellas et al. also found that patients and caregivers felt totally unprepared during the first occurrence of HE because of minimal or no awareness of HE being a complication that they were at risk of experiencing. Although striking, this is consistent with other studies. When assessed, patient's knowledge regarding the natural progression of cirrhosis is consistently low; however, improvement can be achieved through structured patient education (17,18). Similarly, there is a need for education of frontline

providers to improve the recognition of covert encephalopathy in order to promote both timely referral and treatment.

CONCLUSION

The time is now to recognize the deleterious effects of HE on patient- and caregiver-reported health-related QoL. After identification, we must implement treatment strategies that not only address the disease but also reduce the burden placed on the household.

CONFLICTS OF INTEREST

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