

Patient-reported impacts of hepatitis B: A novel content analysis study of online forum posts.

Authors:

Lay K¹, Heriveau M^{1,2}, Tu T^{1,2}

¹ The Storr Liver Centre, The Westmead Institute for Medical Research, The University of Sydney and Westmead Hospital, Westmead, NSW 2145, Australia.

² Hepatitis B Voices Australia, Brunswick, VIC 3056, Australia

Background: Patient Reported Outcome Measures (PROMs) capture the impact of a condition from the patient perspective and should include affected communities throughout design and implementation. However, community involvement in developing hepatitis B specific PROMs has been minimal and mostly limited to clinical recruitment, where patients are more likely to be physically symptomatic with advanced disease. We therefore aimed to carry out comprehensive concept elicitation in the broader affected community through the HepBCommunity.org forum.

Methods: We analysed public posts on the forum to assess the relevance of concepts in existing PROMs with the aim of generating a new framework of impacts. Public posts were extracted using Octoparse data scraping software.

Results: Preliminary analysis of HepBCommunity.org forum posts include prominent domains missed by other PROMs including financial impacts, social isolation, difficulty sleeping, and decreased energy. Moreover, existing hepatitis B instruments do not include stigma or use inaccessible language to assess its impacts. Systematic analysis of the posts is ongoing. Posts will be analysed using a deductive coding framework developed from concepts included in existing hepatitis B specific measures. NVivo AI assisted analysis will be used to quantify the frequency of discussion around these concepts. A secondary inductive analysis of random subsamples of posts will be conducted by two independent coders until theme saturation. Following each round of coding, disagreements will be resolved through discussion with the wider research team.

Conclusion: This will be the first study to use social media data to identify quality of life impacts for people with hepatitis B. Many psychosocial impacts of HBV infection are not adequately covered by existing general or disease-specific PROMs. A new measure incorporating the full range of impacts for people with hepatitis B may be warranted to adequately capture the broad range of impacts for people without active liver disease.

Disclosure of Interest Statement: A/Prof T Tu has received funding from Gilead. All other authors declare no conflicts of interest.