Editorial: rapid assessment of health related quality of life in PBC - no excuse not to ask. Authors' reply

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We read with great interest Dr Gulamhusein and Dr Jackson's editorial about our paper on the development and validation of PBC-10 as a short and valid questionnaire that can be used as a simple screening tool of symptom burden in patients with PBC.[1,2] The PBC-10 was derived from the original PBC-40 questionnaire[3] using rigorous statistical analysis of the extensive UK-PBC Research Cohort database to select the smallest number of items that represent the majority of the PBC-40 scores. The 10 items of the PBC-10 covered all domains of the PBC-40 and explained more than 95% of the variance of the questionnaire scores.

The editorial highlighted that PBC-10 was not evaluated in patients with PBC treated with new agents such as obeticholic acid (OCA) or fibrates. However, the focus of our study was to develop and psychometrically validate a short tool to measure the quality of life in patients with PBC. The quality of life questions were completed by patients at a time when those treatments were not available. Flooring effect of a questionnaire is observed when more than 15% of patients score the lowest possible score.[4] Most patients in the UK-PBC cohort had stable and less severe symptoms. Therefore, flooring effect was observed with PBC-10. Quality of life questionnaire validation is an ongoing process. Therefore, as new treatment options are emerging in PBC, more validation studies will be needed to assess the QoL of patients using different treatments as well as to further evaluate the flooring effect of PBC-10.

The editorial recognises that symptom burden in PBC often goes unrecognised and an easy-to-use bedside tool such as PBC-10 is very much needed. From a patient perspective, improving health is reflected in the improvement of their symptoms. With a move towards shared decision making and patient-centred care there is growing recognition of quality of life assessment as a key component of a holistic approach to patient care.

We recommend using PBC-10 for clinical screening in primary biliary cholangitis. The simplicity, validity and reliability of the PBC-10 make it a strong candidate for PBC clinical registries and databases, and in audits that assess the efficacy of new treatments in PBC

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