

PTH-115

COMPARISON OF THE PBC-40 AND PBC-27 TOOLS FOR QUALITY OF LIFE ASSESSMENT IN ENGLISH SPEAKING PRIMARY BILIARY CIRRHOSIS PATIENTS

doi:10.1136/gut.2011.239301.516

D Jones,¹ I Patanwala,^{1,*} J Newton¹ ¹*Institute of Cellular Medicine, Newcastle University, Newcastle upon Tyne, UK*

Introduction The PBC-40 is a patient-derived, disease-specific, quality of life (QOL) measure for Primary Biliary Cirrhosis (PBC). It is the only QOL measure developed using optimal methods in liver disease, that has proven to be of real value in the study of the pathogenesis of important symptoms in PBC, in increasing our understanding of patient experience and as an outcome measure in clinical trials. Derived in an English speaking population it had not, until a recent validation study in Italian and Japanese language groups, been validated in other languages. This study re-examined domain structure using the original PBC-40 items, and proposed an abbreviated form consisting of 27 of the original 40 items with a modification in the domain structure.

Methods To evaluate the English version of the PBC-27 in comparison with the original PBC-40 in a randomly selected group of PBC patients (n=40) and utilising novel versions of both measures developed as experimental tools for use in age and sex matched normal subjects (n=40).

Results The experimental normal subject versions of the PBC-40 and PBC-27 both proved psychometrically robust and were acceptable to control subjects. Unsurprisingly both measures were highly discriminatory between PBC patients and controls for all symptom domains, confirming the utility of both measures for the assessment of QOL in PBC patients. When comparing the discriminatory ability of the two measures between the PBC and control populations, the PBC-40 outperformed the PBC 27 with regards to fatigue (auc 0.8 (0.69–0.91), $p < 0.0001$ vs 0.78 (0.66–0.9), $p < 0.0001$) and cognition assessment (0.74 (0.63–0.86), $p = 0.0001$ vs 0.70 (0.57–0.84), $p < 0.005$) as well as other symptoms domain compared with the combined symptoms and dryness domains of the PBC-27. In contrast, both measures performed equally in discriminating between patients and controls with regard to the social and emotional domains (although in the former instance the PBC-27 was unduly reliant on a single item relating to holiday). In this population there was no difference in completion rates and acceptability between the shorter and the longer measures.

Conclusion The PBC-27 is valid for use in English-speaking populations and is highly effective at quantifying symptoms in English-speaking PBC patients. Any advantages associated with compliance and usability for a shorter measure are, however, outweighed by lowered sensitivity for cognitive and fatigue symptom severity (the two domains with the greatest impact). When compared to the PBC-40 the optimum measure may be a hybrid containing the fatigue and cognitive domains of the PBC 40 and the shortened social domain of the PBC 27.

Competing interests None.

Keywords PBC27, PBC40, primary biliary cirrhosis.