

The clinical and psychometric validation of a questionnaire to assess the quality of life of adult patients treated with long-term parenteral nutrition.

Janet P. Baxter, PhD, Scottish Home Parenteral Nutrition Managed Clinical Network, Ninewells Hospital and Medical School, Dundee, UK.

Peter M. Fayers, PhD, Division of Applied Health Sciences, University of Aberdeen, Aberdeen, UK and Department of Cancer Research and Molecular Medicine, NTNU, Trondheim, Norway.

Alastair W. McKinlay, MBChB, Department of Gastroenterology, Aberdeen Royal Infirmary, Aberdeen, UK.

Home parenteral nutrition (HPN) is an established treatment for the management of patients with chronic intestinal failure. No quality of life assessment tools have been developed and validated specifically for this patient population, and previous studies have used generic instruments or techniques not validated in HPN. The assessment of quality of life (QOL) should produce clinically relevant data reflecting patients' issues. The HPN-QOL[®] was designed to assess the QOL of HPN patients. The purpose of this study was to test the hypothesised scale structure of the questionnaire with regard to reliability and validity in a sample of patients. *Methods:* A provisional questionnaire was prepared following recognized guidelines and then subjected to field-testing. The questionnaire was administered to 100 adult patients receiving HPN. Psychometric tests examined the reliability and validity of the questionnaire, and patients' debriefing comments were analysed. *Results:* The provisional questionnaire was adapted using evidence from quantitative and qualitative analysis. Multi-trait scaling analysis and face validity refined the questionnaire to 48 items. Compliance rates were high and the questionnaire was well accepted. *Conclusions:* A method of objectively assessing the QOL of patients treated with HPN has been developed. The HPN-QOL[®] has been rigorously prepared and demonstrates psychometric and clinical validity to assess the QOL of long-term HPN patients.