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Preliminary validation of the NTM Module: a patient-reported outcome measure for patients with pulmonary nontuberculous mycobacterial disease

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ABSTRACT
Introduction: Nontuberculous mycobacteria (NTM) cause chronic, debilitating pulmonary disease. Patient-reported outcomes provide measures of symptoms, functioning and treatment response. Here we describe the preliminary validation of the recently developed NTM Module.
Methods: The study population included Northwest NTM Biobank patients in whom *Mycobacterium avium* complex (MAC) was isolated and who had ever met the 2007 American Thoracic Society/Infectious Diseases Society of America pulmonary disease criteria. The NTM Module was administered at enrolment and 12 months; a subset also completed the Quality of Life Questionnaire–Bronchiectasis (QOL-B). The NTM Module generates four domain scores (0–100; higher scores indicate better functioning) reflecting NTM-specific symptoms (NTM Symptoms, Body Image, Digestive Symptoms and Eating Problems). We described patient characteristics and mean scores, and evaluated psychometric properties, including response to treatment at 12 months, for each domain.
Results: Overall, 203 patients with pulmonary MAC disease were included. Average enrolment scores ranged from 76 (NTM Symptoms) to 84 (Eating Problems). Ceiling effects were observed for Body Image (26% of participants) and Eating Problems (52%). Internal consistency (Cronbach's alpha) ranged from 0.67 (Digestive Symptoms) to 0.89 (Eating Problems). The intraclass correlation for test–retest reproducibility (n=27) ranged from 0.72 (Body Image) to 0.94 (Eating Problems). Patients starting treatment (n=35) had statistically significant increases in scores for NTM Symptoms (+5, p=0.04), Digestive Symptoms (+7, p=0.002), Body Image (+7, p=0.03) and QOL-B Respiratory Symptoms (n=25, +10, p=0.006). NTM Symptoms scores increased by 15 points (p=0.002) in the 16 patients with scores ⩽80 at enrolment.
Conclusion: The NTM Module generally performs well as a valid patient-reported outcome for pulmonary MAC disease and was responsive to MAC treatment.