Introduction

Disease specific Health Related Quality of Life (HRQoL) measures are key instruments in monitoring disease progression and treatment efficiency. The QOL-PCD is a recently developed HRQoL instrument for Primary Ciliary Dyskinesia (PCD). Originally developed in English, the QOL-PCD is available in parent proxy, child, adolescent and adult versions. The aim of this study was to investigate the metric properties of the Greek version of the questionnaire among adult PCD patients.

Methods

In cooperation with the QOL-PCD developers, forward translations to Greek and backward translation to English were carried out. Translation was followed by cognitive interviews in 12 adult PCD patients and the final version underwent psychometric validation. Validation included assessment of the internal consistency, test-retest stability, construct and convergent validity. Internal consistency was assessed by Cronbach’s alpha coefficient in terms of the overall and sub-scales. Test-retest reliability was assessed by repeat administration of the QOL-PCD questionnaire after 10-14 days and calculation of the intra-class correlation (ICC). Construct validity was assessed by comparing different groups of patients (discriminated by gender, age and lung function) based on a priori hypotheses. Convergent validity was evaluated by examining associations between the QOL-PCD and the generic SF-36 HRQoL questionnaire.

Results

QOL-PCD questionnaires were administered to a consecutive sample of 29 adult PCD patients. Moderate to good internal consistency was observed (Cronbach’s α: 0.44–0.88 across sub-scales) and test-retest reliability assessment demonstrated good repeatability for most scales (ICC: 0.65 – 0.91 across sub-scales).

Conclusions

The adult version QOL-PCD has been translated according to international guidelines resulting in a cross-culturally validated Greek version which exhibited good metric properties in terms of internal consistency, stability, known-group and convergent validity. Validation will continue as more patients complete the questionnaire.