

Development and psychometric validation of the Greek version of the adult QOL-PCD questionnaire: preliminary results

Phivos Ioannou^{1,2}, Panayiotis Kouis³, Nicos Middleton⁴, Maria Kakkoura³, Margarita Kaliva³, Aristoula Toliopoulou¹, Laura Behan^{5,6}, Jane S. Lucas⁶, Panayiotis K. Yiallourous³

¹ Department of Pediatrics, Hospital "Archbishop Makarios III", Nicosia, Cyprus ² Department of Nursing, Frederic University, Nicosia, Cyprus ³ Medical School, University of Cyprus ⁴ Department of Nursing, School of Health Sciences, Cyprus University of Technology ⁵ School of Applied Psychology, University College Cork, Cork, Ireland ⁶ Primary Ciliary Dyskinesia Centre, University Hospital Southampton NHS Foundation Trust, Southampton, United Kingdom

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 HR-QoL 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).

Table 1: Internal consistency of QoL-PCD scales measured by Cronbach's α and test-retest reliability measured by ICC.

Scale	# Items	Scale Median (IQR)	Cronbach's α	ICC (95% CI)
Physical Functioning	5	80.00 (43.33-93.33)	0.879	0.906 (0.791-0.958)
Vitality	3	66.67 (44.44-77.78)	0.439	0.803 (0.561-0.912)
Emotional Functioning	5	80.00 (63.33-93.33)	0.633	0.889 (0.752-0.950)
Treatment Burden	4	62.50 (41.70-85.40)	0.812	0.652 (0.097-0.866)
Social Functioning	3	33.30 (5.55-61.15)	0.688	0.772 (0.492-0.898)
Role	4	66.70 (58.30-79.15)	0.509	0.895 (0.766-0.953)
Health Perspective	4	50.00 (25.00-62.50)	0.585	0.596 (0.098-0.819)
Upper Respiratory Symptoms	4	58.30 (50.00-83.30)	0.758	0.848 (0.660-0.932)
Lower Respiratory Symptoms	6	61.10 (41.65-72.20)	0.790	0.894 (0.763-0.952)
Hearing Symptoms	2	66.70 (58.35-100.00)	0.648	0.831 (0.623-0.924)

IQR: Interquartile Range, CI: Confidence Intervals



Results

Female patients and older patients as well as patients with lower lung function exhibited lower QOL-PCD scores in general while high correlations for most QOL-PCD scales with SF-36 scales were observed (e.g. for Physical Functioning: $r=0.77$, $p<0.01$).

Table 2: Association of median QoL-PCD scale values with Gender, Age, FEV1 and FVC.

Parameter	Physical Functioning		Social Functioning		Lower Respiratory Symptoms	
	Value	Sig.	Value	Sig.	Value	Sig.
Male	80.00 (53.93-93.33)	0.141	44.40 (22.20-66.70)	0.328	66.70 (50.00-77.80)	0.289
Female	60.00 (33.33-93.33)		27.75 (0.00-55.60)		61.10 (37.50-68.08)	
<33.7 years*	80.00 (53.93-93.33)	0.244	44.40 (33.30-66.70)	0.049	61.10 (44.40-77.80)	0.246
>33.7 years	55.67 (38.33-88.34)		22.20 (0.00-44.40)		58.35 (31.93-66.70)	
<-2 FEV1* Z-Score	53.33 (33.33-80.00)	0.014	22.20 (0.00-44.40)	0.146	50.00 (38.90-63.90)	0.103
>-2 FEV1 Z-Score	90.00 (51.67-93.33)		38.85 (22.20-66.70)		69.45 (50.03-79.18)	
<-1.7 FVC* Z-Score	60.00 (40.00-80.00)	0.210	22.20 (0.00-44.40)	0.125	58.35 (40.28-65.30)	0.304
>-1.7 FVC Z-Score	80.00 (46.67-93.33)		44.40 (22.20-66.70)		66.70 (38.90-77.80)	

*Median Age, Median FEV1 Z-Score, Median FVC Z-score

Figure 1: Scatterplot of QoL-PCD Physical Functioning with FEV1 Z-score and FVC Z-score.

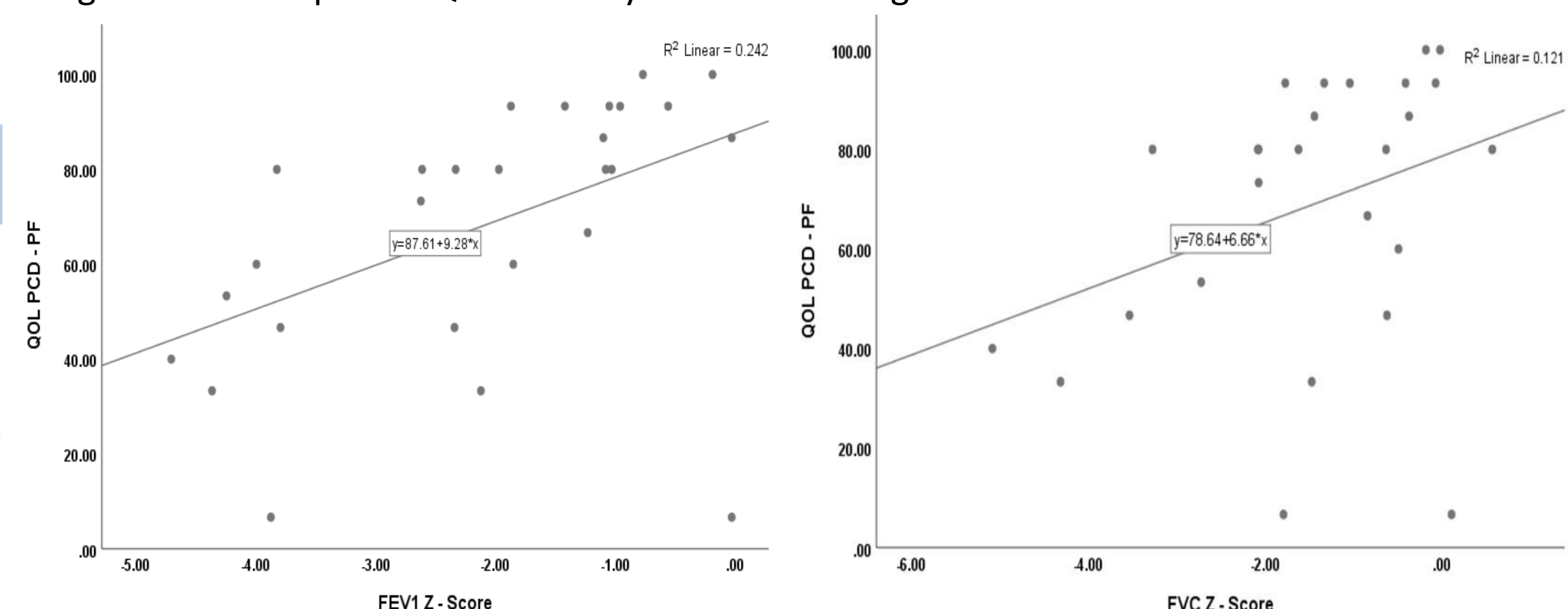


Table 3: Pearson correlation coefficients between scales from QoL-PCD and the generic SF-36 HRQoL questionnaire

	SF36 Physical Functioning	SF36 Role Physical	SF36 Bodily Pain	SF36 General Health	SF36 Vitality	SF36 Social Functioning	SF36 Role Emotional	SF36 Mental Health
Physical Functioning	0.771*	0.678*	0.336	0.264	0.624*	0.678*	0.632*	0.614*
Vitality	0.795*	0.679*	0.518*	0.196	0.665*	0.707*	0.731*	0.542*
Emotional Functioning	0.675*	0.514*	0.421*	0.167	0.707*	0.672*	0.577*	0.706*
Treatment Burden	0.082	-0.108	-0.006	-0.117	-0.065	-0.082	-0.052	-0.001
Role	0.426*	0.412*	0.446*	0.152	0.347	0.470	0.355	0.320
Social Functioning	0.372	0.255	0.284	0.194	0.202	0.232	0.161	0.240
Health Perspective	0.217	0.185	0.258	0.342	0.093	0.154	0.045	0.097
Upper Respiratory	0.620*	0.658*	0.412*	0.560*	0.621*	0.548*	0.449*	0.540*
Lower Respiratory	0.618*	0.680*	0.682*	0.618*	0.687*	0.587*	0.537*	0.699*
Hearing Symptoms	0.118	0.196	0.111	0.237	0.029	0.113	0.162	-0.080

*Significant at the 0.05 confidence level, Highlighted cells correspond to a-priori assumed positive relationships

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.

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