

# Estimation of health-related quality of life in children and adolescents with congenital heart disease by subjective and objective method

Maja Batinica<sup>1</sup>, Daniel Dilber<sup>2</sup>, Jadranka Božikov<sup>3</sup>, Hana Matković<sup>4</sup>, Matea Melsa<sup>4</sup>, Ivan Malčić<sup>2</sup>



<sup>1</sup> Children's Hospital Zagreb, Department of Pediatrics, Cardiology Unit, Klaićeva 16, Zagreb, Croatia;

<sup>2</sup> University of Zagreb, School of Medicine and University Hospital Centre Zagreb, Department of Pediatric Cardiology, Zagreb, Croatia;

<sup>3</sup> University of Zagreb, School of Medicine, Andrija Štampar School of Public Health, Zagreb, Croatia;

<sup>4</sup> University of Zagreb, School of Medicine, Zagreb, Croatia

**INTRODUCTION:** In adult medicine it's established that exercise tests and health-related quality of life (HRQOL) instruments should be used together to get an appropriate overview of the health status of patient with congenital heart disease (CHD). Information on that in children is lacking.

**OBJECTIVES:** To compare perception of health-related quality of life (HRQOL) between patients with congenital heart disease (CHD) and their parents, and both with cardiopulmonary exercise testing (CPET) parameter - peak oxygen uptake (pVO<sub>2</sub>) - as the best represent of exercise capacity and cardiopulmonary fitness.

**PARTICIPANTS AND METHODS:** A cross-sectional, single-centre, observational study was performed on 38 patients aged 8 to 18 years (20 M, 18 F), with various CHD, under routine follow-up. Previous Fontan procedure have had 13% of patients. Patients and their parents completed a HRQOL questionnaire - PCQLI™. We analysed answers on the general health perception item, given at 5-point Likert scale, and subscales: Disease Impact (physical functioning) and Psychosocial Impact (psychological and social functioning). Afterwards, CPET with Bruce treadmill protocol was performed under same conditions, conducted by one of the authors. Descriptive and inferential statistics were used for data analysis, including calculation of Spearman's correlation coefficients between patients' and parents' HRQOL scores and for the comparison of HRQOL scores with pVO<sub>2</sub>.

**RESULTS:** To describe the study group, mean pVO<sub>2</sub> were compared with reference values of healthy pediatric population, local and from the literature; by Student's t-test, patients value was significantly lower (p<0.01) for both gender.

Excellent matching of self- and parent-estimated health-related quality of life was found (Table 1 and Figure 2).

Peak oxygen uptake correlated significantly with all scores - Disease Impact, Psychosocial Impact, Total score (sum of Disease Impact and Psychosocial Impact) - of patients and of their parents (p<0.05) (Figure 1).

All scores increase linearly with pVO<sub>2</sub> up to pVO<sub>2</sub> =<40 ml/kg/min, when they meet their plateau.

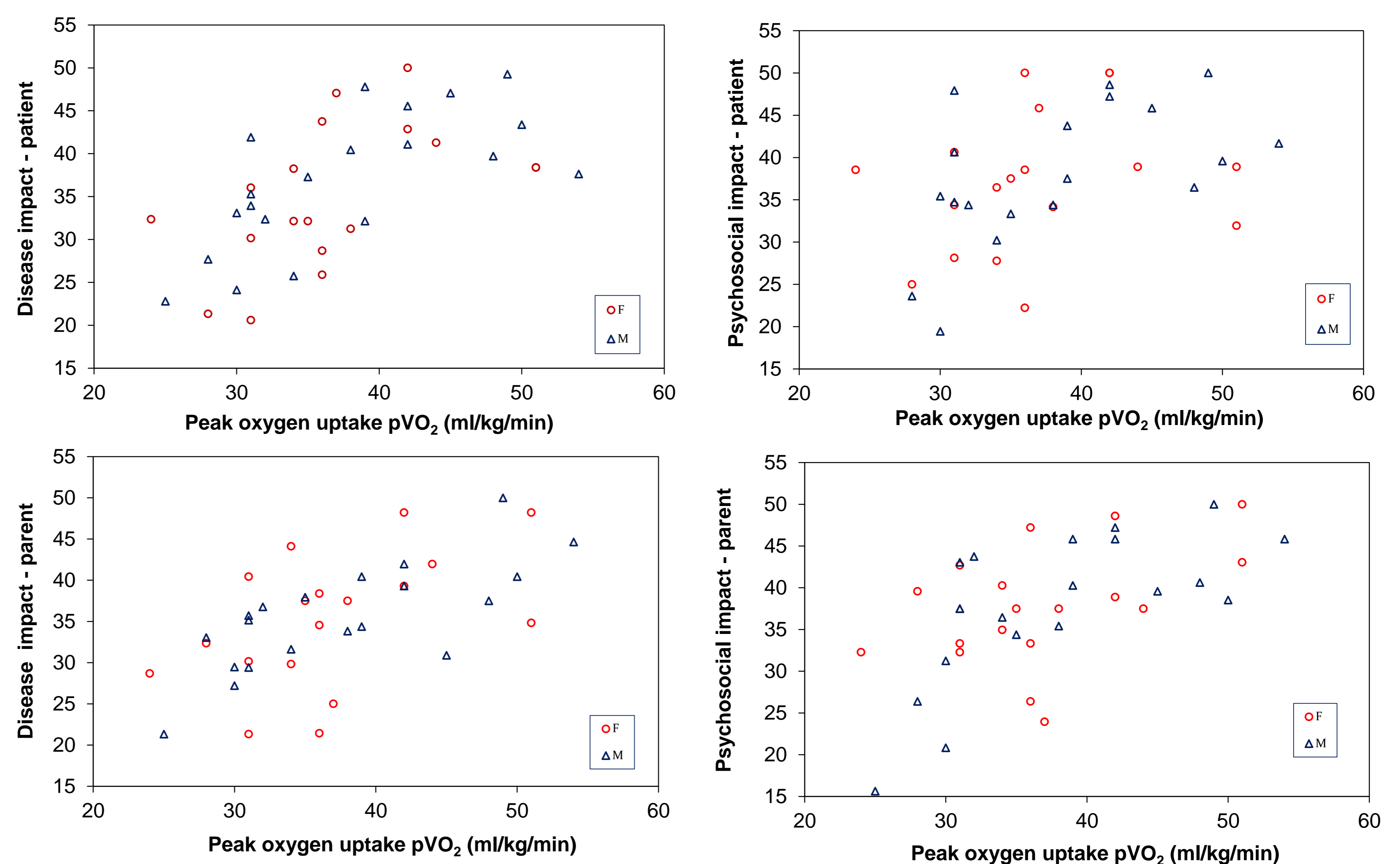


Figure 1. Comparison of self- and parent-reported QOL with peak oxygen uptake from a CPET.

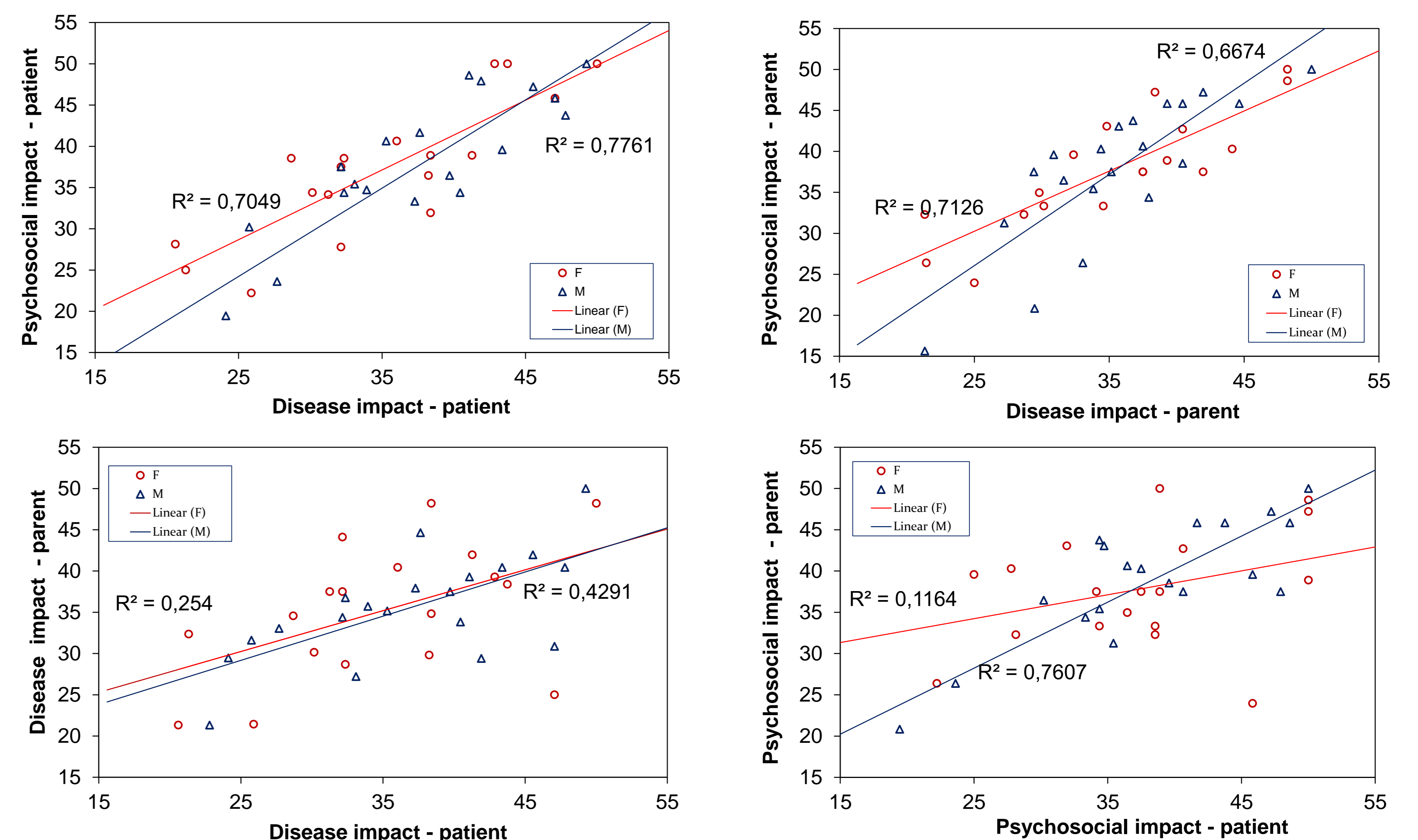


Figure 2. Matching of self- and parent-estimated disease impact and psychosocial impact.

Table 1. Matching of self- and parent-estimated HRQOL (health perception: 1 - excellent, 2 - very good, 3 - good, 4 - fair, 5 - poor).

Patients answers	Parents answers					Total
	1	2	3	4	5	
1	8	2	1			11
2	1	6	2	1		10
3		4	10	1		15
4			1	1		2
5						
Total	9	12	14	3		38

**CONCLUSIONS:** In general, our patients had reduced exercise capacity. Peak oxygen uptake was in good correlation with the perception of all aspects of health, made by patients and by their parents: better perception of health mainly means better pVO<sub>2</sub>. So, complementary usage of these two methods should get an comprehensive overview of the health status of young patients with CHD, as it's already established in adult medicine.