Safety and quality of life after a multidisciplinary cardiopulmonary rehabilitation program implementation in children and young adults with complex congenital heart disease and their families

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Introduction and objectives
Cardiac rehabilitation programs (CRP) constitute a potential therapeutic tool for post operated complex congenital heart disease (CHD) patients.
We implemented a multidisciplinary CRP for children and adults with complex CHD. We sought to study its safety and to determine its impact on perception of health and quality of life in our patients and their families.

Methods
24 patients (13 male), 7 children (8-14yo) and 17 young adults (15-35yo).
CHD included 8 post operated Tetralogy of Fallot, 1 Fontan stage, 8 TGA (4 arterial switch, 4 atrial switch), 3 PAIVS, 2 truncus arteriosus, 2 DORV.
We designed a customized cardiopulmonary rehabilitation program. Variables analyzed included quality of life, psychological tests (SF-36, STAI, BDI, Peds QoL for children and relatives) and ergospirometry. Every week our patients received one psychological session and they completed their tests before and after CRP.

Results
After a mean of 21.5±4 training sessions we observed statistically significant improvement in VO₂ %predicted (p<0,05).
Psychological pre-tests indicated a normal startpoint regarding quality of life, stress and depression, independently of the severity of the disease of our patients. Quality of life questionnaire did not reveal significant changes, which might be explained by study design (excluding highly symptomatic patients for safety with > 50% in NYHA I).
Data revealed that mental dimension of their quality of life was more affected than the physical one. Relatives had a more pronounced perception of the severity of the cardiopathy compared with their children.
No adverse effects described.

Conclusions
A tailored CRP in children and young adults with complex CHD raised significantly their oxigen consumption, which is an indirect marker of an improvement in their quality of life.
Our patients described their quality of life, stress and depression indicators as normal, despite the severity of their disease. Their relatives objetified a worse perception.
We propose CRP as an useful and safe tool to improve CHD functional capacity and perception of health