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Reduced health-related quality of life in older patients with congenital heart disease: A cross sectional study in 2360 patients

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ABSTRACT

Objective: Health-related quality of life questionnaires are frequently used to involve patients' impressions and feelings in the outcome evaluation. In patients with congenital heart disease (CHD) methodological heterogeneities, assessment in different age and diagnostic groups led to controversial findings. This study aims to give a comprehensive answer to the health-related quality of life in patients with CHD.

Patients and methods: From July 2001 to June 2013, 2360 patients (1058 female, 28.6 ± 11.2 years, range 14–75 years) with various kinds of CHD underwent a quality of life assessment with the SF-36 questionnaire and underwent a cardiopulmonary exercise test as part of their routine follow-up.

Results: Physical component summary score (PCS) develops from 96.1 %predicted in patients younger than 20 years, to 96.2 %predicted in patients aged 20 to 30 years, 92.3 %predicted in patients aged 30 to 40 years, and 92.6 %predicted in patients 40 years or older ($r = -.114$; $p < .001$). The decline was more prominent in the mental component summary score (MCS) declining from 104.1 %predicted in patients younger than 20 years, to 103.4 %predicted, 99.9 %predicted, and 97.5 %predicted ($r = -.132$; $p < .001$). Exercise capacity was impaired with 80.1 ± 23.0 %predicted and also declined slowly with age ($r = -.084$; $p < .001$).

Conclusions: Health-related quality of life in patients with CHD is progressively reduced in older age-groups. The decline is small, but more prominent in the mental components. This should be considered in the interpretation of studies, and strategies have to be developed to reduce this effect in future.

1. Introduction

Advances in diagnosis, surgical treatment and medical management have led to a dramatic increase in survival of infants and children with congenital heart disease (CHD). This resulted in a still increasing number of adolescents and adults with CHD [1]. As a result, the focus in long-term follow-up studies changed from a quantitative point of view on survival and redo procedures, to a more functional perspective involving hemodynamics, exercise performance and especially quality of life [2,3].

However, the concept of quality of life is in debate. There are several questionnaires: for healthy people and for patients; as well as generic and disease specific ones. In general, the more disease specific they are, the better is the sensitivity in treatment studies, but the more they leave the primary goal to measure quality of life. The disease specific instruments mainly ask for typical symptoms and resemble more a perceived health status than real quality of life which is defined as "satisfaction with life" [4]. Generic multidimensional "health-related quality of life" (HRQoL) instruments are somewhere intermediate. They include domains that are a pure perceived health status, as well as domains closer to quality of life [5]. Therefore, we have chosen for such an instrument, the SF-36. In clinical outcome studies, it is an optimal addition to a cardiopulmonary exercise test (CPET). CPET objectively measures aerobic capacity which is considered the best substitute for cardiovascular fitness. On the other hand, the SF-36 covers physical, psychological, and social limitations as well as their impact on daily life. Whereas the domain of Physical Functioning as perceived health status correlates at least weakly with aerobic capacity [6], the self-reported domain of Mental Health closely resembles quality of life.

Assessing HRQoL in patients with CHD is important and frequently used to involve patients in the process of decision making especially before high risk procedures to evaluate how much the patient feels limited by his/her cardiac condition, as well as in the outcome evaluation [7,8]. Also for prenatal counseling of future parents awaiting a child with a congenital heart defect, information regarding the patients short- and long-term HRQoL is of major interest for the decision whether or not to terminate the pregnancy [9].

Meanwhile, many studies have evaluated HRQoL of life in children, adolescents [10–13] or adults [3,14–20] in general, as well as with specific heart defects [11,21–26] or after a specific intervention [27–29].

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They found coping strategies, denial mechanisms and pathways like the sense of coherence [2,30] to mediate HRQoL. However, methodological heterogeneities, different age groups and specific congenital heart diseases led to controversial findings [7,8]. Moreover, the majority of those studies evaluated younger patient groups. Data from older patients reaching an age beyond forty years were missing.

Therefore, this cross-sectional report aims to give a comprehensive answer to the HRQoL of patients with CHD with regard to their age and diagnosis.

2. Patients and methods

2.1. Study subjects

We retrospectively analyzed our database of subjects referred for a cardiopulmonary exercise testing (CPET) in our institution from July 2001 to June 2013. All CPET were accompanied by a HRQoL assessment. Most patients were routinely recruited to CPET for evaluation of their functional status from our outpatient department and were not tested in cardiac decompensation to avoid a sampling bias towards a lower HRQoL. Less than 10% were inpatients, expecting surgery or heart catheterization.

From 6542 examinations in our database, we excluded 1044 patients younger than fourteen, 411 healthy controls and 608 patients with mental retardation, syndromes or language barriers (Fig. 1). During that period of time we also had 2199 follow-up examinations. Only the most recent examination was included in our statistical analysis. Finally 2360 patients (1058 female, 1302 males; 28.6 ± 11.2 years old) with a HRQoL assessment were included. According the disease severity classification of the ACC [31] the defects were mild in 328 patients, moderate in 633 patients and complex in 1138 patients. The missing 261 patients with miscellaneous CHD were not assigned to the ACC groups. The detailed assignments to the diagnostic groups are presented in Table 1.

2.2. Health-related quality of life (HRQoL)

The medical outcome study 36 item short form (SF-36) was used. It has an acceptable internal consistency and has proven useful in various specialties of medicine without any bias for symptoms of a specific disease [32,33]. The SF-36 measures eight health constructs with scores ranging from 0 (worst) to 100 (best) with two to 10 items per construct and one single item about health transition. The German version of the self-report form with a window of four weeks was used. Individual age- and sex-related reference values were drawn from the German evaluation study [32,33]. All values are presented in percentage of the predicted reference (%predicted). The scores of HRQoL (0–100) are only displayed in the supplemental material 1 and 2.

2.3. Cardiopulmonary exercise test (CPET)

All patients underwent a symptom limited cardiopulmonary exercise test on a bicycle ergometer in upright position as previously described [11].

In short, after a 3 minute rest to define baseline, patients had a 3 minute warm-up without load, followed by a ramp wise increase of load with 10, 15, 20, or 30 W/min depending on the expected individual physical capacity estimated by the investigator. With this protocol a cycling duration of about 8 to 12 min after warm-up should be reached. The end of the CPET was marked by symptom limitation and was followed by a 5-minute recovery period, with the first 2–3 minute cycling with minimal load and 2 minute rest.

The exercise test featured a breath-by-breath gas exchange analysis using a metabolic chart (Vmax 229, SensorMedics, Viasys Healthcare, Yorba Linda, California). Peak oxygen uptake ($\dot{V}O_2$) was defined as the highest mean uptake of any 30-second time interval during exercise. Reference values for age, body mass, body height, and gender, expressed in "% predicted" were calculated like previously described [30].

2.4. Data analyses

All descriptive data were expressed as mean ± standard deviation.

First, actual HRQoL scores were compared with the individual reference values by a paired *t*-test. After that only the values in %predicted were used for furtzer analyses. For the primary research question, whether there is a decline in HRQoL with proceeding age, Pearson's correlation was calculated to find associations between age, the physical and mental component summary of HRQoL and finally exercise capacity. Differences in between the diagnostic subgroups were tested with a one-way analysis of variance with Bonferroni post-hoc test.

All analyses were performed using SPSS 21.0 software (IBM Inc, Armonk, New York, USA). *P*-values <0.05 in a two-sided analysis were considered significant.

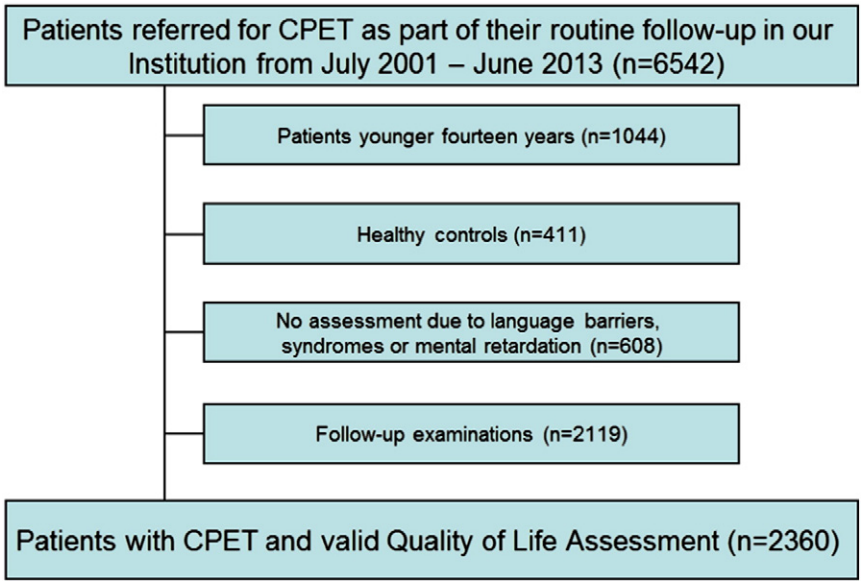

Fig. 1. Patient inclusion.