

## PW2-9

### **Quality of life in school-age survivors of severe congenital heart disease: results from the UK Collaborative Study of Congenital Heart Defects (UKCSCHD)**

*Day T. G. (1), Dezateux C. (1), Wade A. (1), Bull C. (2), Wren C. (3), Knowles R. (1)  
Institute of Child Health, London, UK (1); Cardiac Unit, Great Ormond Street Hospital for Children,  
London, UK (2); Department of Paediatric Cardiology, Freeman Hospital, Newcastle, UK (3)*

#### Introduction:

As mortality due to congenital heart defects (CHDs) falls, long-term outcomes including health-related quality of life (QoL) attain greater importance. Paediatric QoL has been measured in cardiac outpatient populations using the PedsQL™ questionnaire and impaired psychosocial QoL scores demonstrated. However, previous studies were often limited to instrument validation, comparisons with reference norms or specific CHD types.

Our aims were to (1) compare QoL scores, for a UK-wide cohort of children born with serious CHDs, with a unaffected classmate comparison group and (2) investigate factors predicting lower PedsQL™ scores that may be modifiable through improving care.

#### Methods

Children aged 8-12 years were recruited through the UKCSCHD cohort, a multi-centre study of CHD outcomes involving all 17 UK paediatric cardiac centres. Each child (and their parent) was sent a generic PedsQL™ 4.0 questionnaire and was asked to give a questionnaire to two age- and sex-matched classmates. Information on children with CHDs was also available from a case-note review. Characteristics of respondents with CHDs were compared with all cohort survivors and unaffected children. Using Generalised Additive Models for Location, Scale and Shape (GAMLSS) based on the sinh-arcsinh (SHASH) distribution, univariable and multivariable models were constructed to investigate predictors of PedsQL scores, including individual and family factors, illness severity and participation in peer activities.

#### Results

Data were obtained from 479 affected children (271 boys; mean age 12.1 years) and 467 unaffected children (256 boys; mean age 12.0 years). Compared with unaffected peers, children with CHDs reported significantly lower QoL scores on the PedsQL™ physical, psychosocial functioning and total scales in univariable models ( $p < 0.001$ ). In univariable models, predictors of lower QoL scores in children with CHDs included measures of cardiac severity, non-cardiac illness and special educational needs.

#### Discussion

Children with CHDs in this prospective multi-centre study reported significantly lower physical as well as psychosocial QoL compared to their healthy classmate peers. Clinical management should seek to optimise children's ability to participate fully in peer activities, particularly within the school environment.

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