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Do self- and proxy-reports of cognitive problems reflect intellectual functioning in children and adolescents with congenital heart defects?

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Aim: Children with congenital heart defects who suffer from cognitive impairments and school difficulties need to be identified as early as possible in order to set appropriate interventions in place that may enhance the school situation and quality of life for these children. Identifying children and adolescents at risk for cognitive difficulties requires specific screening tools. This study assessed such a tool – Pediatric Quality of Life Inventory Cardiac Module subscale: Cognitive Problems – to investigate whether proxy-reported and self-reported cognitive problems were associated with measured intellectual functioning in children and adolescents with congenital heart defects.

Method: The sample consisted of 184 children/adolescents aged 3, 5, 9, and 15 years. The severity of the congenital heart defects diagnoses was categorized into three groups (mild, moderate, or severe) for all age groups. For all age groups, we collected proxy-ratings of cognitive problems and for the 5-, 9-, and 15-year-olds we also collected self-reported cognitive problems. Intellectual functioning was measured with the Wechsler scales. The control variables were socio-economic status and severity of diagnosis.

Results: A strong association was found between the parent's ratings of cognitive problems and the children's and adolescents' results on the Wechsler scales. This association was present for all ages, including the 3-year olds. As for the self-reports an association was only found between the 15-year-olds self-report of cognitive problems and their results on the Wechsler scales.

Conclusions: To identify children with cognitive problems as early as at the age of three years, parent-rated Pediatrics Quality of Life subscale: Cognitive Problems can be used as a screening tool. For 15-year-olds, the self-report ratings can be used as a screening tool. We also suggest a cut off score of 80 for both the 15-year olds as well as the proxy reports. If the score falls below 80 the child should be formally evaluated using standardized test.