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Disease perception and knowledge about their disease of children with congenital heart defects and their parents

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Introduction:

Due to the residuals and sequelae of corrective or palliative surgeries patient with congenital heart disease (CHD) are a chronically ill population. The knowledge of their illness and what it implies, both for children and for adolescents, and for their parents, is a key factor in promoting a good health attitude.

Objective:

To evaluate disease perception and knowledge in children, adolescents with CHD and their parents, and whether the degree of understanding is related to age and sex.

Patients and Methods:

85 children 8 years or younger (39,3% girls), 70 from 9-18 years (45% girls) with various CHD and 200 parents participated in this cross sectional study in a Tertiary Pediatric Cardiac Centre over a 6 month period. The questionnaire comprised 15 items that can be grouped to 4 domains: name and nature of heart disease its treatment and prognostic, impact of heart disease on quality of life and daily life, perception of disease and social relationships

Results:

43.8% of patients know the name of their CHD (39.3% ≤8 years, 50% 9-18 years) versus 77.5% parents ($p<0.001$). But 93.3% of the patients have no understanding of their heart defect (≤8 years: 100%, 9-18 years: 85%) compared to 48.5% of the parents ($p<0.001$). 72.3% of patients believe that they will be cured but only 40% of parents believe that their children will be cured ($p<0.001$). 52.2% of patients (≤8 years: 15.4%, 8-19 years: 100%) considered their illness not a problem in terms of social relationships compared to 94% of parents ($p<0.001$).

There was no disagreement in terms of that the children or adolescents with CHD can live the same daily life as their healthy peers (≤8 years: 84.6%, 9-18 years: 89.5%, parents: 79.7%, $p=0.45$). Also in wellbeing children, adolescents and parents responded similarly to the question "I am (my child) not feeling well" (≤8 years: 7.4%, 8-19 years: 5.3%, parents: 12.9%, $p=0.36$)

Conclusion:

There is a need to intensify CHD-related education to promote a better perception and knowledge of CHD and thus optimize and improve the health behavior of patients.