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

Fuertes Moure A., Mariño García P., Martínez Bendayán I., Pérez Castro M.V., Sánchez Martínez M.E., Rueda Nuñez F.
Hospital Materno-Infantil Teresa Herrera A Coruña, Spain

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.