

Psychosocial needs of children undergoing an invasive procedure for a congenital heart defect and their parents

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Introduction.

Up till now, research has focused mainly on psychosocial problems in children with congenital heart disease and their parents, but has largely neglected the need for and implementation of specialized psychosocial care from the parents' and patients' perspectives.

Objective: to investigate the psychosocial needs of both parents of children with congenital heart disease (aged 0-18 years) and patients themselves (aged 8-18 years) in the week before cardiac surgery or a catheter intervention.

Patients: eligible were all consecutive patients (0-18 years), scheduled to undergo cardiac surgery or a catheter intervention in our hospital between March 2012 and July 2013. Psychosocial needs were assessed by a disease specific questionnaire designed for this study, consisting of a 53-item parent version and a 39-item child version (for children >8 years), each covering 5 domains: physical/medical, emotional, social, educational/occupational and health behaviour). 4 items assessed from whom and in what format psychosocial care was preferred. Quality of life was also assessed.

Interventions: if parents/ patients reported a need for psychosocial care, referral to adequate mental health professionals was arranged.

Results: more than 40% of participating parents and more than 50% of participating children reported a need for psychosocial care on each of the five domains. Needs for psychosocial care for parents themselves were highest for those with children aged 0-12 years. Parents and patients report clear preferences when asked from whom and in what format they would like to receive psychosocial care. Quality of life was relatively high for both parents and patients. Psychosocial care interventions in our hospital increased significantly due to implementation of this study.

Conclusions: results show that psychosocial care is rated as (very) important by both parents and children during an extremely stressful period of their life.