What are Psychosocial Needs of Children and Adolescents undergoing an Invasive Procedure for a Congenital Heart Defect and their Parents? A Cross-sectional Cohort study

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

Methods: Inclusion: 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 considering five specific domains (physical/medical, emotional, social, educational/occupational, health behaviour) were measured by a disease specific questionnaire. Additionally, parents and patients were asked from whom and in what format they would prefer to receive psychosocial care. Quality of Life (QoL) was also assessed.

Interventions: if parents and/or patients reported a need for psychosocial care, referral to health care professionals in or beyond our hospital was performed.

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. QoL was relatively high for both parents and patients. Psychosocial care interventions in our hospital increased significantly due to the 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.