

### How to counsel parents after prenatal diagnosis of congenital heart disease? A multidisciplinary approach to develop a questionnaire.

*Kovacevic A. (1), Simmelbauer A. (1), Starystach S. (2), Elsässer M. (3), Sohn C. (3), Müller A. (1), Bär S. (2), Gorenflo M. (1)*

*Department of Paediatric and Congenital Cardiology, Heidelberg University Hospital, Heidelberg, Germany (1); Max Weber Institute for Sociology, Ruprecht Karls University Heidelberg, Heidelberg, Germany (2); Department of Gynecology and Obstetrics Heidelberg University Hospital, Heidelberg, Germany (3)*

**Objectives:** To develop a questionnaire suitable to assess parental needs for counselling after prenatal diagnosis of congenital heart disease (CHD) in the fetus.

**Methods:** The questionnaire was developed by paediatric and fetal cardiologists, maternal fetal medicine specialists and sociologists based on literature research and analysis of daily practice. Likert scaled and open-ended questions are combined with socio-demographical data. The questionnaire ends with an open-ended question asking for feedback and additional remarks. The feasibility of the questionnaire was pre-tested on six individuals. The revised version was pilot-tested on 17 parents.

**Results:** Median gestational age at fetal diagnosis and first counselling was 28+4 weeks. At time of data collection all children were alive at a median age of 337 days. Response rate was 89.5 %. The pilot-test reliability of the dependent variable's dimensions and the sorrows itemset shows good consistency as shown by high values for the reliability coefficient Cronbach's alpha of > 0.7 (Table 1). Analysis of the open questions showed that parents evaluated the questionnaire as good and perceived it as a chance to participate in the treatment of their child.

**Conclusions:** The questionnaire measures reliably and validly parental needs for counselling after prenatal diagnosis of CHD in the fetus. This newly developed tool enables us to measure counselling success not only in the dimension of transfer of medical information but also in the dimensions of trust in medical staff, transparency regarding the treatment process, coping resources, and perceived situational control. A multidisciplinary approach, in particular including social science, seems feasible as theoretical and methodological effort is essential for constructing adequate tests. We plan to carry out factor and cluster analyses to find typical subgroups of parents, which can be distinguished in terms of the characteristic value of the dependent variable effective counselling.

<b>Dimension</b>	<b>Cronbach's alpha</b>
Transfer of medical knowledge	0.857
Trust in health personnel/medical staff	0.891
Transparency regarding the treatment process	0.914
Coping resources	0.706
Perceived situational control	-
Sorrows (item 4 excluded)	0.949

Table 1: Internal consistency of the questionnaire's subscales (reliability).