Parental needs and factors affecting counseling success for prenatal congenital heart disease

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Objectives:
To explore parental needs and affecting factors for counseling success after prenatal diagnosis of congenital heart disease (CHD).

Methods:
Counseling success after prenatal diagnosis of CHD was measured in five dimensions (Transfer of Medical Knowledge; Trust in Medical Staff; Transparency Regarding the Treatment Process; Coping Resources; Perceived Situational Control) by a pretested standardized questionnaire. Likert scaled and open-ended questions are combined with sociodemographic data. Data analyses were conducted with regard to influencing factors and correlations by IBM SPSS® V. 25.

Results:
59 individuals (n=38 female, n=21 male) were interviewed in a tertiary medical care center. Gestational age at diagnosis and first parental counseling was 28+5 weeks (median). Parental counseling was performed overall 4 times (median), mainly by pediatric cardiologists (85%) and/or MFM specialists. Overall counseling was successful in 45.3% and satisfying in 52.8%; 1.9% of parents were dissatisfied. Counseling was less successful for the dimensions “Transfer of Medical Knowledge” and “Perceived Situational Control”. Success rates were higher if additional written information or adequate web sources were provided. Length of consultation was positively correlated to counseling success for the dimensions “Transfer of Medical Knowledge” (r=0.278*), ”Transparency Regarding the Treatment Process” (r=0.330*), and “Perceived Situational Control” (r=0.210). However, the absolute number of parental consultations had no effect on counseling success in any dimension. Interruptions during consultations were negatively correlated to the dimensions “Trust in Medical Staff” (r=0.258*) and “Transparency Regarding the Treatment Process” (r=0.203). If cardiac diagnosis was graded as high-risk CHD overall counseling success was lower. The presence of chromosomal abnormalities (n=7) had no effect on any dimension. If parental mother tongue was different from the language the counseling was conducted, success rates were lower for ”Transfer of Medical Knowledge”, ”Trust in Medical Staff” and ”Coping Resources”.

Conclusions:
These data indicate that parents after fetal diagnosis of CHD need uninterrupted counseling of adequate duration. In addition, written information or links to adequate web sources seem necessary, ideally in the parental mother tongue. High-risk CHD needs more attention for counseling. Further analyses of sociodemographic factors are necessary to identify parental needs for counseling. The mid-term goal is to propose evidence-based guidelines.