

MP2-2

Are Adults with Congenital Heart Defects adequately supplied in Medical Care?

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Objective:

The number of Adults with Congenital Heart Disease (ACHD) in the western world is steadily rising. Nearly all ACHD have relevant residua and sequelae, requiring life-long follow-up. At least in Germany, the majority is NOT tied to a certified ACHD specialist or centre. For cardiac and noncardiac problems, ACHD consult general practitioners (GP), who are, however, frequently not qualified to manage congenital heart disease (CHD). This may put ACHD at risk and may adversely affect morbidity and mortality. Moreover, opportunities of initiating preventive care are mostly missed. The current study provides an overview of primary health care of ACHD in Germany for the first time.

Methods and Results:

A questionnaire-based survey of 116 ACHD (48.3% female, mean age of 34.8 ± 12.5 years) and 126 GP's (35.7% female, mean age 54.6 ± 9.1 years) was analyzed.

Results of GP's:

All ACHD consult GP's for noncardiac problems. 69% of the GP's also treat specific ACHD related cardiac problems. In up to 62% GP's consult (paediatric) cardiologists, but ACHD-specialists in only 25.4%.

63.5% of the GP's are not informed about the existence of ACHD facilities.

GP's deal with all CHD types and severity grades, in 58% even with moderate/severe forms.

Management tasks include heart failure, arrhythmias, endocarditis, pulmonary vascular disease and impeding comorbidities. GP's offer advice in social medical aspects and preventive measures, although specifically unskilled.

Results of ACHD:

41.1% of ACHD are uninformed about specific medical facilities, although suffering from significant side effects (arrhythmia, heart failure, pulmonary hypertension). ACHD-support groups are unknown in 44%. 70% of the ACHD surveyed need advice about exercise capacity, insurance, occupational skills and/or pregnancy. In 90%, patients' needs concerning daily life questions and preventive measures are underprovided.

Conclusion:

GP's have to guide ACHD with cardiac -/noncardiac problems to provide adequate diagnosis, treatment and preventive measures. According to study-results, ACHD and their caregivers are insufficiently informed about ACHD facilities. Experts and centres must become more visible and cooperate stronger with GPs to provide modern management in treatment and therapy.