

**Lack of Specific Disease Related Medical Health Care in Congenital Heart Disease:  
A Call for Reaction?  
The General Practitioners View**

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Objective: Mortality in children with congenital heart disease (CHD) has decreased significantly in the last decades. Nowadays, more than 90% survive into adulthood. According to estimates, there are currently more than 280.000 adults with congenital heart disease (ACHD) living in Germany. ACHD need specific follow-up, due to a high incidence of cardiac and non-cardiac problems in the long-term course. In Germany, medical follow-up for ACHD is organized in basic treatment through general practitioners (GP) and specific care by ACHD specialized and certified cardiologists and institutions offering maximum ACHD supply. Highly actual data show, that the majority of ACHD (>200.000) is NOT tied to specialized and ACHD-certified physicians and institutions. This study aims to generate "real-life" data regarding the care of ACHD provided by general practitioners.

Methods-Results: A questionnaire-based survey of 541 GP's in Germany was analyzed. According to study results, GP's deal with all types and with any severity grade of CHD, in 58.2 % actually with moderate and severe forms. Even severe problems like heart failure, pulmonary hypertension, arrhythmias or endocarditis are managed by GP. More than 93% of the surveyed treat ACHD older than 35 years. 69.1% of GP's are also taking care of rare hereditary disease. ACHD specific physicians are consulted in only 23.6%. More than 35% of the GP's are not aware of the existing certified clinics/ centers of ACHD. 75.2% of the GP are not informed about the existence of patient initiatives.

Conclusions: ACHD centers and specialists are inadequately perceived or consulted, despite the increasing rate of cardiac or non-cardiac complications of CHD during adult life. Although GP's have to guide ACHD to provide adequate diagnosis, treatment and preventive measures, they are insufficiently informed about the certificated ACHD-specialists or -facilities. A better awareness of the problems concerning follow-up in ACHD should be created, to optimize their care and, as a result, to reduce morbidity and mortality.