Original Article on Current Management Aspects in Adult Congenital Heart Disease (ACHD): Part III

Systematic assessment of health care perception in adults with congenital heart disease in Germany

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Background: The number of adults with congenital heart disease (ACHD) is steadily rising due to increased survival rate and improved medical resources. Accordingly, more than 330,000 ACHD are currently living in Germany. Almost all of them require lifelong specialized medical follow-up for their chronic heart disease, often accompanied by residua, sequelae, or comorbidities. Primary care physicians (PCPs) are a crucial factor in directing patients to ACHD specialists or specialized institutions, but despite all efforts, the number of ACHD under specialized care is low, the lost-to-follow-up rate is high, and the morbidity and mortality is substantial. The present cross-sectional study was designed to systematically characterize the health care of ACHD from a patient perspective, including (I) use of medical care by ACHD, (II) medical counselling needs, and (III) perceived satisfaction with health care.

Methods: The German-wide analysis was based on a 25-item questionnaire designed to address different aspects of medical status and health issues of ACHD from their own perspective, performed between May of 2017 and July of 2020.

Results: A total of 4,008 ACHD (52% female; mean age 41.9±17.2 years) completed the questionnaire. The majority of ACHD (3,524, 87.9%) reported, that they consulted their PCP for non-cardiac health problems, and 49.7% (n=1,991) consulted their PCP also for medical problems associated with the underlying CHD. Almost all ACHD reported a need for medical advice concerning exercise capacity and daily life activities, occupational skills, pregnancy, rehabilitation, genetic counselling, insurance, and retirement. A total of 1,840 (45.9%) patients were not aware of the existence of certified ACHD specialists or centers. Moreover, 2,552 (67.6%) of those surveyed were uninformed about patient organizations for ACHD.

Conclusions: The present study demonstrates that ACHD are largely uninformed about the ACHD care structures available nationwide, although the patients have a great need for specialized follow-up, advice, and care.

Keywords: Adults with congenital heart disease (ACHD); medical health supply; primary health care; general practitioners; primary care physicians (PCPs); congenital heart disease (CHD)

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Introduction

Congenital heart defects (CHD) are defined as gross structural abnormalities of the heart or intrathoracic great vessels that are functionally significant or of potential functional significance. They are the most common isolated organ anomalies, accounting for about 30% of all congenital malformations in Europe (1,2). Prevalence estimations of CHD range from 5.2 to 10.7 per 1,000 live births (3-5). The number of children born with CHD per year is about 6,500 in Germany, 108,000 in Europe, and about 1.35 million worldwide (6-8). While in the 1930s, 80% of children with relevant CHD died in the first years of life, nowadays, more than 90% of CHD patients reach adulthood due to remarkable advances in cardiac surgery, paediatric cardiology, intensive care, and pharmacotherapy (6,9,10). It is estimated that, today, the number of adults living with CHD totals more than 330,000 in Germany, 2.3 million in Europe, and 12 to 34 million worldwide (11-13); the population of "adults with congenital heart defects" (ACHD) now exceeds the number of children with CHD.

Despite the enormous reduction in mortality, all patients with CHD still have a chronic heart condition. In almost all ACHD, anatomic or hemodynamic residua and sequelae exist from the medical intervention, and cardiac and/or non-cardiac comorbidities can develop (14-16). The most common cardiac comorbidities include heart failure, arrhythmia and pulmonary hypertension, aortopathy, and endocarditis, while non-cardiac comorbidities encompass metabolic disorders and endocrinological, hepatic, nephrological, and neurological disease (17-19). Moreover, ACHD frequently experience psychological limitations such as depression, anxiety, or posttraumatic stress disorders (20-22).

In order to ensure adequate care for ACHD, a three-stage care model has been developed in Germany, including an ACHD-specific certification for cardiologists or pediatric cardiologists as well as for specialized centers (23). Within this system, basic medical care should be provided by primary care physicians (PCP), including general physicians, family doctors, internists, and pediatricians who participate in general medical care. These physicians have a central role to play in CHD care, through referral of patients to ACHD-specialized institutions. The second level of care includes, at present, 11 regional ACHD hospitals and practices, in which resident adult or pediatric cardiologists offer services for ACHD as well as close-to-home treatment by ACHD-certified cardiologists. The third level currently includes 20 national ACHD centers for tertiary care, which also provide cardiac surgical care and have specialized outpatient departments (e.g., for Marfan syndrome, pulmonary hypertension, pregnancy, and genetic counselling) (24-28). A total of about 350 cardiologists and pediatric cardiologists are accredited as ACHD specialists in Germany.

The aim of this study was to evaluate the current ACHD health care system in Germany from the patient perspective, in order to clarify to what extent ACHD know about and frequent these care structures, which ACHD medical counselling needs are being met, and whether ACHD were satisfied with their perceived health care. We present the following article in accordance with the SURGE reporting checklist (available at http://dx.doi.org/10.21037/cdt-20-825).

Methods

Study cohort

This cross-sectional study was a sub-analysis of a nationwide "VEmaH-registry" (www.vemah.info), the first large-scale attempt to analyze the real-world health care status of ACHD in Germany from the patients' perspective. The analysis was performed between May of 2017 and July of 2020.

The study employed a questionnaire-based survey that was initiated by the Department of Congenital Heart Disease of the German Heart Center Munich, Technical University Munich. Inclusion criteria included the presence of a confirmed CHD, a minimum age of 18 years, and a written declaration of consent. Exclusion criteria were lack of cognitive competence to consent to research and refusal to consent. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013).

The definition of a PCP in the current survey is based on legal requirements. Accordingly, in Germany, primary medical care is provided by all doctors who participate in general medical care. This includes "general practitioners", physicians with basic medical training who are usually the

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Table 1 Socio-demographic variables of the responding adults with congenital heart disease (N=4,008)

Patient information	Values
Age in years, mean ± SD/ median [range]	41.9±17.2/38 [18–97]
Degree of disability, mean ± SD/ median [range]	35.8±32.5/30 [0–100]
Sex, n (%)	
Male	1,807 (45.1)
Female	2,084 (52.0)
Missing data	117 (2.9)
Place of residence, n (%)	
Big city	774 (19.3)
City	589 (14.7)
Small town	923 (23.0)
Rural community	1,562 (39.0)
Missing data	160 (4.0)
Status of insurance, n (%)	
By law	3,700 (92.3)
Private	219 (5.5
None	7 (0.2)
Missing data	82 (2.0)

Big city >100,000 inhabitants; city >20,000–100,000 inhabitants; small town >5,000–20,000 inhabitants; rural community <5,000 inhabitants. N, total number; n, absolute number; SD, standard deviation.

first point of contact for the patient if a medical problem arises, and others who participate in primary medical care, including "specialists in general medicine", "specialists in internal medicine and general medicine", and "specialists in internal medicine".

Data collection procedure and measurements

Several ACHD specialists, epidemiologists, PCPs, and psychologists from different federal states in Germany jointly developed the questionnaire to describe the perceived health care in a large ACHD cohort. The questionnaire comprised 25 questions regarding patient-reported diagnosis, residua, sequelae, and cardiac or non-cardiac comorbidities. Further included were questions concerning health care structures known and used by ACHD, and questions asking ACHD to describe their counselling needs and their perceived satisfaction with their current health care.

Data collection was carried out using a questionnaire addressed to ACHD (≥18 years) presenting at the Department of Congenital Heart Disease and Pediatric Cardiology of the German Heart Center Munich and the Department of Cardiology of the University of Erlangen. Additionally, the insurance company "AOK Bayern" provided the questionnaires to their policyholders with CHD in Bavaria, and the "National Register for Congenital Heart Defects" in Berlin, Germany, invited its members to participate in the study online. All data collection was conducted with the master-approval of the Ethics Committee of the Technical University of Munich, conferred on April 5, 2017 (157/16 S).

Statistical analysis

Descriptive statistical analysis was performed using IBM SPSS Statistics 25.0 (IBM Inc., Armonk, NY, USA) to characterize the study population. Continuous data were expressed as arithmetic mean ± standard deviation (SD), and nominal and categorical variables were expressed as absolute numbers or percentages. The numbers of valid answers given to some questions differed from the total number of the included study participants. This was due to the presence of multiple answers in some cases and missing data in others.

Results

Questionnaires filled in by 4,008 ACHD (52% female) were included in the final data analysis. The estimated response rate could not be determined because the majority of the questionnaires were sent by mail or ACHD were invited to participate online; it could not be determined whether the recipients actually received the mailing or opened the online invitation to participate.

The mean age of the included ACHD was 41.9±17.2 (range, 18–97; median 38) with a mean degree of disability of 35.8±32.5 (range, 0–100; median 30). All sociodemographic characteristics of the surveyed patients are summarized in *Table 1*.

The most frequent patient-reported CHDs were aortic valve disease, atrial septal defect, transposition of the great arteries, tetralogy of Fallot, and aortic coarctation (*Table 2*). According to their own statements, 396 (9.9%) patients

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Table 2 Patient-reported type of congenital heart defect (N=4,008)

Type of CHD (multiple answers possible)	n (%)
Aortic valve stenosis/insufficiency	718 (17.9)
Atrial septal defect	544 (13.6)
Ventricular septal defect	508 (12.7)
Transposition of the great arteries	349 (8.7)
Tetralogy of Fallot	340 (8.5)
Aortic coarctation	327 (8.2)
Pulmonary valve stenosis/insufficiency	279 (7.0)
Atrioventricular septal defect	86 (2.1)
Persistent ductus arteriosus	73 (1.8)
Univentricular heart	55 (1.4)
Hypoplastic left heart syndrome	15 (0.4)
Other CHD	681 (17.0)
Missing data	33 (0.7)

CHD, congenital heart disease; N, total number; n, absolute number.

Table 3 Patient-reported cardiac and non-cardiac comorbidities (N=3,985, multiple answers possible)

Comorbidities	N (%)
Cardiac arrhythmias	1,178 (29.6)
Heart failure	514 (12.9)
Mental or intellectual impairment	307 (7.7)
Coagulation disorders	251 (6.3)
Neurological complications	160 (4.0)
Coronary artery disease	154 (3.9)
Pulmonary (arterial) hypertension	148 (3.7)
Thromboembolism	146 (3.6)
Hematologic disorders	109 (2.7)
Infective endocarditis	57 (1.4)
Unknown	210 (5.3)
None	1,600 (39.9)

N, total number; n, absolute number.

listed a combination of more than one defect.

Among 3,985 (99.4%) responses regarding the presence of cardiac and non-cardiac comorbidities, 60% (n=2,408) of the ACHD reported having relevant comorbidities. Most of these indicated cardiac arrhythmia, heart failure, mental or intellectual impairment, coagulation disorders, and pulmonary (arterial) hypertension (*Table 3*).

Patient-reported characteristics of care utilization

The study evaluated the medical contacts between patients and PCPs, differentiating between general medical concerns and medical questions specifically related to the underlying CHD. For primarily non-cardiac medical issues, 87.9% (n=3,524) of the ACHD predominantly consulted a PCP and only 7.2% (n=287) predominantly consulted a cardiologist. In the case of medical questions directly related to the underlying CHD, for their primary consult, 1,991 (49.7%) study participants also consulted their PCP, 1,489 (37.7%) a cardiologist, and 528 (13.2%) another physician. Overall, 1,982 (53.8%) patients consulted the same PCP for both cardiac and non-cardiac health-related issues, and 3,617 (90.2%) participants stated that their treating physicians were informed about the existence of the CHD.

Further questions addressed the referral patterns of the attending PCPs as perceived by the included ACHD. At least 2,269 (56.6%) had never been referred to an ACHD specialist or a specialized institution. Even in the case of cardiac problems, only 1,161 (29.0%) of the surveyed ACHD were referred to an ACHD-specialized institution. Another 221 (5.5%) received a referral from their PCP to an ACHD-specialized institution in order to address complaints that may have been influenced by the underlying CHD.

Patient knowledge and awareness of specialized medical care structures for ACHD

Another important part of the study was to determine the awareness of specific medical care structures for ACHD (*Table 4*). Nearly half of the respondents (1,840; 45.9%) were not aware of any ACHD-specific medical services. In addition, more than half of the surveyed ACHD (2,208; 55.1%) stated that they did not receive sufficient information about such supply structures.

Since patient organizations can provide important support for chronically ill ACHD, the ACHD were also asked about their knowledge in this regard. Only 1,213 (30.3%) participants were informed about ACHD patient organizations, whereas 2,552 (63.7%) were not familiar with such associations.

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Table 4 Knowledge and awareness of specific care structures for adults with congenital heart disease

	n (%)
Patients' knowledge about ACHD-specific care structures (multiple answers possible)	
Aware of ACHD-certificated pediatric cardiologists in private practice	969 (24.2)
Aware of ACHD-certificated cardiologists in private practice	771 (19.2)
Aware of certified hospitals or centers for ACHD	1,044 (26.0)
No awareness of certified hospitals or centers for ACHD	1,840 (45.9)
Satisfaction with level of knowledge on ACHD-specific care facilities	
Sufficient information obtained	1,213 (30.3)
Insufficient information obtained	2,208 (55.1)
"I don't know"	587 (14.6)

ACHD, adults with congenital heart disease; n, absolute number.

Need for medical advice and satisfaction with currently available ACHD resources

Since the individual needs of the affected patients in different life situations are of great importance in the follow-up of ACHD, their need for counseling was specifically queried. The following issues were indicated by the respondents as ones for which they needed counselling: exercise capacity (n=1,377, 34.4%), daily life activities (n=1,281, 32.0%), rehabilitation (n=1,105, 27.6%), types of education (n=865, 21.6%), occupational skills (n=844; 21.1%), genetic counselling (n=796, 19.9%), driver's license (n=715, 17.8%), and aerobic capacity (n=681, 17.0%). Concerning pregnancy, 1,196 (29.8%) of the total cohort stated a need for medical advice. The counselling demand by women was age-dependent: 49.1% of those between 18–20 years, 58.2% of those between 20–30 years, and 51.1% of those between 30–40 years. In addition, more detailed information and advice was requested on health insurance by 1,178 (29.4%) respondents, on life insurance by 1,144 (28.5%), on retirement issues by 1,260 (31.4%), and on disability certificates by 869 (21.7%).

Despite all deficiencies, the surveyed ACHD were for the most part satisfied with their general medical care and even with the CHD-specific care. Although 2,208 (55.1%) of the ACHD were not sufficiently informed about the existing structures, 3,134 (78.2%) rated the current care situation as either "very good" or "good".

Discussion

Worldwide, ACHD pose a challenge to healthcare providers who care for this patient population. The number of ACHD is continuously rising, a trend that is expected to continue beyond the second half of this century. Almost all of them are chronically ill due to residua, sequelae, and complicating comorbidities. To achieve an adequate quality of life and long-term survival, many of them need proper medical care throughout their lifetime.

While children with CHD are usually competently guided by pediatric cardiologists for years, many CHD patients have to switch in early adulthood to regular adult cardiologists, who are often not specifically trained in CHD (24,25,29). At this time, there is a considerable loss of follow-up, partly because patients are not interested in constantly dealing with their chronic disease, or feel that they are not understood by their surrounding and treating physicians, and partly because some patients refuse further medical or surgical interventions (30-32).

This is a worldwide problem that poses a challenge to all healthcare providers. Despite all efforts, the care of ACHD is still dissatisfying, as indicated by recent data from the accredited ACHD centers in Germany, which are capable of ensuring competent, holistic care for ACHD. Although appropriate care can only be provided by experienced ACHD cardiologists, only 22,000 out of the estimated 330,000 ACHD living in Germany are under ACHD-accredited cardiological follow-up provided in an accredited ACHD center (33,34). The number of ACHDs in the care of certified cardiologists is not available, but from the personal experience of the authors, it is also likely to be small.

The current study is the first to assess, from the patients'

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perspective, health care under real-world conditions in a large CHD population: 4,008 ACHD in Germany. The study sought to determine (I) how well care-structures are known and used by ACHD, (II) which medical counselling needs ACHD have, and (III) whether ACHD are satisfied with their perceived health care.

The large number of ACHD included in the current study illustrates that, due to recent advances in modern medicine, today even patients with severe CHD, who were considered to have no realistic chance until a few decades ago, survive into adulthood. The patient-reported outcome comprises data on almost all types of CHD, from the more common and simple (e.g., septal defects, congenital valve anomalies, aortic coarctation, or tetralogy of Fallot) to very complex CHD (e.g., native or operated transposition of the great arteries, univentricular heart, or hypoplastic left heart syndrome). The cohort also included all age groups, ranging from 18 to 97 years (median 38 years).

The role of cardiac and non-cardiac comorbidities in ACHD

A recent single-center study of 800 consecutive ACHD from our institution showed that 95.6% of ACHD had relevant non-cardiac comorbidities (19). Singh *et al*. described an even higher number within their nationwide health record analysis of 255,355 ACHD in the United States (22). These recently published data suggest that many ACHD are not sufficiently aware of and informed about their health condition and its consequences. The current study data also confirm the importance of cardiac and non-cardiac comorbidities, which were present in 60% (*Table 3*) (n=2,408) of ACHD, including heart failure, cardiac arrhythmias, pulmonary (arterial) hypertension, other organ disorders, and mental or intellectual impairment.

Current medical care for ACHD

Unfortunately, many ACHD are unaware that they suffer from a chronic disease, and both patients and their PCPs lack awareness of the importance of lifelong follow-up for CHD, not only in severe, but also in mild or moderate, cases (24,35,36). Based on the analyzed data, it is obvious that PCPs are the first contact person for ACHD for general medical questions, regardless of the patient's age, sex, or type or severity of the CHD. Moreover, PCPs are also the first advisors if medical problems related to the patients' CHD arise. This is in accordance with data from a recently published study of 767 PCPs in Germany, conducted by our center. We found that more than 83% of the surveyed PCPs cared for ACHD, but for most of them (75%), ACHD accounts for less than 1% of their entire patient population (28).

Importantly, ACHD do not tend to visit their PCP for routine check-ups and before any medical problems arise. This is important, since many ACHD often do not correctly perceive their health status and newly emerging disease complications. This is a decisive issue, as the PCP is the main contact person who should sharpen CHD patients' awareness and emphasize the importance of regular follow-up visits with a congenital cardiologist. Indeed, the current data reveal that ACHD primarily consulted their PCP for non-cardiac medical issues (87.9%; n=3,524), which may aggravate the natural course of the patients' CHD, as well as for medical questions directly related to the underlying CHD (49.7%; n=1,991). The PCPs are usually (90.2%; n=3,617) informed about the existing CHD of their patients. However, since ACHD account for only a very small proportion of their patient population, many PCPs are not fully aware of the special needs and treatment requirements of ACHD and lack clinical experience with the long-term problems of this vulnerable patient group (28).

Difficult to understand are the referral habits of the PCPs as perceived by the ACHD who participated in this study. Even in the case of cardiac problems, the surveyed ACHD were only exceptionally referred to an ACHD-specialized institution (29.0%; n=1,161) and at least 56.6% (n=2,269) had never been referred to an ACHD specialist or a specialized institution. In fact, recent data show that less than 25% of PCPs in Germany involve ACHD-specialized physicians in their ACHD treatment (28). When PCPs do refer their ACHD for further cardiological care, they usually refer them to general cardiologists, who are for the most part not specifically trained to treat ACHD. This is far from ideal. Considering the broad variety of CHD and its associated conditions, the different natural course of each CHD case, and the large number of treatment options, it is impossible to determine an adequate cardiac status and treatment regime for an adult with CHD without being specifically trained in ACHD care (37). PCPs and general cardiologists must bear in mind that the cardiac and non-cardiac problems in ACHD may differ significantly from those in patients with acquired heart disease. The diagnosis and management of these medical problems, as well as their

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early and correct detection, is essential (38). Therefore, ACHD strongly benefit from specialized management, which reduces morbidity and mortality (36).

Knowledge and awareness of specialized resources for ACHD

Nearly half of the respondents (n=1,840; 45.9%) were unaware of the nationwide available ACHD-specific care facilities. In addition, only 30% (n=1,213) of the surveyed ACHD (n=2,208; 55.1%) felt sufficiently informed about the existing ACHD-specific care facilities. Moreover, only a minority (n=1,213, 32.2%) of the questioned ACHD were familiar with ACHD patient organizations, which can often provide important support and valuable information for chronically ill ACHD and their health care needs.

Counselling needs among ACHD, and future aspects

A particular challenge in ACHD care is the tremendous demand among ACHD for advice that goes beyond the purely medical scope. When inquired in detail, the majority of ACHD stated major consultation needs concerning exercise capacity and daily life activities, pregnancy (age-dependent) and genetics, education and occupational skills, rehabilitation, and/or insurance issues. To advise ACHD on these issues, health care professionals require a great deal of expertise and experience going far beyond the competence of a generally trained PCP or general cardiologist. With respect to these issues in particular, the support of patient organizations can be extremely beneficial.

Considering the high demand for medical advice with regard to pregnancy, as an example, it is strongly recommended to advise ACHD early about their options and medical or genetic risks, including regarding contraindications and appropriate and effective contraception. Because of pregnancy-related hemodynamic changes, interdisciplinary care must be offered and organized in advance. Particularly in such cases, PCPs must urgently fulfil their responsibilities and refer all ACHDs to specialized ACHD cardiologists, regardless of the severity of the diagnosis and in spite of a subjectively good state of health (11,39,40).

Despite all deficiencies, ACHD were for the most part satisfied with their general medical- and CHD-specific care. Although this finding may seem contradictory at first sight, most patients report a moderate degree of disability in their daily lives and may therefore not necessitate ACHD specialized care for a long period of time. From a life-stage perspective, their supply deficit often only becomes evident, when they eventually develop symptoms and disruptions later in life (31,41).

Changes resulting from the current study data

As an immediate response to our present study, educational campaigns have been launched nationwide on television, the general press, and the Internet, supported by the German Heart Societies, patient organizations (e.g., German Heart Foundation, Herzkind e.V.), and even with the support of the pharmaceutical industry. In addition, other medical specialties, including general medicine, internal medicine, intensive care medicine, rehabilitation medicine, gynecology and obstetrics, genetics, psychology and psychiatry, sociology, nutrition, and sports medicine, are increasingly obtaining information at conferences and congresses in the context of scientific seminars.

Future aspects of medical care for ACHD

In the future, modern health care for ACHD will require better education and increased awareness among PCPs, ACHD health care providers, insurance companies, and within the ACHD patient population itself about ACHD-specific problems and special needs. Health care for ACHD should encompass patient education as part of their disease management, individually adapted to the patients' medical counselling needs. There is increasing evidence that many ACHD need support concerning psychological difficulties, dietary patterns, and exercise capacity in their daily life (35,42,43). Therefore, it is of particular importance to individually advise ACHD on these demanding issues in order to prevent a high proportion of comorbidities that could be caused by unhealthy lifestyle habits, and to give ACHD the chance to take more responsibility in their own lives (44).

For all these purposes, the support of the nationwide available patient organizations is critical.

Study limitations

The data collected are based exclusively on patient-reported outcomes. Therefore, no validation of the diagnosis with respect to comorbidities was carried out. It is also not

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possible to say why some patients chose to fill out the study questionnaire while others rejected it. In addition, patients were permitted to utilize help from another person in completion of the questionnaire (partially or entirely), and this may have introduced bias into the data.

A selection bias should be considered, as most of the questionnaires were handed out to ACHD undergoing treatment at a tertiary care center. Hence, it can be assumed that the study collective differs from the general ACHD collective, concerning severity and overall awareness of lifelong necessary follow-up. It can be assumed that ACHD who are in continuous follow-up in a tertiary care center are probably more actively interested in ACHD topics, and these patients were more prone to participate in the study. Therefore, it is possible that, in reality, ACHD without specific follow-up are even less aware of CHD-related issues and existing ACHD resources. As a result, those ACHD for whom the lost-to follow-up problem is particularly relevant are probably underrepresented in the present collective survey.

Finally, the generalization of the conclusions to the primary care of ACHD in other countries is only possible to a limited extent.

Conclusions

In the future, specialized ACHD care has to consider all available treatment options, individually adapted to patients' needs and provided by specially trained ACHD health care professionals.

The results of the present study showed that many ACHD are not sufficiently aware of and informed about their health condition and its consequences, particularly regarding the need for lifelong follow-up. Many are also not sufficiently informed and/or unaware of existing ACHD health care facilities, despite the high rate of cardiac and non-cardiac co-morbidities and the immense amount of medical counselling needs among ACHD.

In addition to patient awareness, awareness of PCPs must be increased regarding the specific needs of ACHD, so that all contemporary treatment options are provided to improve the quality of life of ACHD and to prevent further disease burdens. A timely referral to a congenital cardiologist or a specialized ACHD facility may help to prevent or delay major complications in the natural course of the disease.

Finally, the presented data can be exemplary for the development of corresponding ACHD structures in other countries.

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study employed a questionnaire-based survey that was initiated by the Department of Congenital Heart Disease of the German Heart Center Munich, Technical University Munich. Inclusion criteria included the presence of a confirmed CHD, a minimum age of 18 years, and a written declaration of consent. Exclusion criteria were lack of cognitive competence to consent to research and refusal to consent. All data collection was conducted with the master-approval of the Ethics Committee of the Technical University of Munich, conferred on April 5, 2017 (157/16 S).

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