

Article information: <http://dx.doi.org/10.21037/cdt-20-825>

Reviewer #1

The paper deals with the health care perception of adult patients with congenital heart disease (ACHD) in Germany. I think it is a very interesting study giving valuable information on a growing population of patients which requires increasing attention and provision of specialized health care now and in the future.

The results of this analysis, based on questionnaires of 4008 patients, clearly confirm the presence of significant deficits concerning the nature of the CHD and its consequences for their life. Of particular interest are also the details concerning the frequency of non-cardiac comorbidities in these patients. Data regarding the requirement of advice concerning daily life activities, education, pregnancy, occupation and insurance issues confirm the requirement of adequate counseling regarding these issues in specialized centers.

Comment 1: I wonder if it is possible to give details or an estimation on how many data sets were derived from questionnaires of patients presenting at the tertiary referral center, of questionnaires distributed by the insurance company and questionnaires distributed by the National Register of Congenital Heart Defects. I would assume that the level of information should be higher in the patient group presenting at the specialized center.

Reply 1: Thank you for this important comment. Unfortunately, we cannot present these data as the survey was conducted anonymously according to the study protocol and we cannot draw any conclusions as to the respondent.

Reviewer #2

This cross-sectional study is designed to characterize the health care of ACHD in a real world from a patient perspective (patients questionnaire survey). They found that many ACHD are not informed about the ACHD care structures available nationwide, although the patients have a great need for specialized follow-up, advice, and care. Also, most of PCPS did not direct ACHD to ACHD specialists or specialized institutions even cardiac comorbidities of ACHD. This survey was performed in Germany, but similar problems are pending in the other international countries.

This paper is important and informative message to adults with CHD and ACHD specialists internationally.

Abstract

Comment 1: Authors mentioned that almost all of ACHD require lifelong specialized medical follow-up for their chronic heart disease. But there are several different opinions, that is, patients with mild CHD such as patients with repaired ASD, VSD or post PDA division is not necessary for lifelong specialized medical follow-up.

Reply 1: Thank you for this important comment. However, we do agree with this assessment. Even patients who have had simple shunt lesions (e.g., atrial or ventricular septal defects, or patent ductus arteriosus) successfully repaired at an early stage cannot be considered as completely cured;

they may develop relevant sequelae of the underlying disease in later decades. This recent observation contradicts current guidelines stating that patients do not require regular follow-up after shunt closure. [38,39]

- van Riel, A.C.; et al. J. Am. Coll. Cardiol. 2015, 66, 1084–1086.
- van Riel, A.C.; et al. Int. J. Cardiol. 2014, 174, 299–305
- Seidel L; et al. J Clin Med. 2020 Jun 22;9(6):1943. doi: 10.3390/jcm9061943.
- Kaemmerer H; et al. J Clin Med. 2020 May 13;9(5):1456. doi: 10.3390/jcm9051456.

Results

Comment 2: According to the severity of patients, such as severe, moderate or mild CHD, the results of the survey will become a bit different. I speculate that patients with adults with severe CHD dot more appropriate information regarding specialized ACHD center than adults with mild CHD and their PCPS will refer them to specialized ACHD center more often than patients with mild CHD. Also, between male and female, possibly there may be a difference. among different age groups, also?? When we know this, in future target patients for advertisement of specialized institutions for ACHD or ACHD specialists will become much clear for us. If these data are available it is better to show. We will focus on these ACHD.

Reply 2: The reviewer is certainly right. We have the same impression. Therefore, we have prepared a separate paper with special consideration of gender aspects, the underlying cardiac anomalies, degree of severity, the treatment performed, etc, which is currently being submitted.

Results: Section “Need for medical advice and satisfaction with currently available ACHD resources”

Comment 3: Regarding the part, “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”.

Why were these patients satisfied with the CHD-specific care? Authors mentioned current situation is not ideal, so authors should mention some comments on this in the discussion section for further proceed their recommendation in future.

Reply 3: Thank you very much for your critical reflection on that point. Indeed, these findings may seem counterintuitive at first sight. However, they appear plausible because most of the patients are capable of mastering their everyday lives without major restrictions for a long period of time. So, from a life-stage perspective, the supply deficit in ACHD specific care often only becomes noticeable, when these patients eventually develop symptoms and disruptions later in life.

Indeed, our psychologists currently look on the influence of life-stage variables, such as age at diagnosis or years of survival, on patient satisfaction with health care. Unfortunately, the results are not yet available.

For clarification, we add the following sentence:

“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.”

Inserted Literature:

41. Gurvitz, M., et al., *Building quality indicators to improve care for adults with congenital heart disease*. J Am Coll Cardiol, 2013. **62**(23): p. 2244-53.

Comment 4: Reference 28 and 38 are possibly duplicated.

Thank you for your detailed review. In the final document, we found a duplicate of the source by Singh et al. (number 23 and number 38). We have corrected this mistake. The sources have now moved one position.

Comment 5: Reference 35, Number of pages are not described.

Thank you for your detailed review. This source was a duplicate that has been removed. The source was the following one, and it was mixed up because of a publication date confusion.

Kaemmerer, H., et al., *Recommendations for improving the quality of the interdisciplinary medical care of grown-ups with congenital heart disease (GUCH)*. Int J Cardiol, 2011. **150**(1): p. 59-64.