International Journal of Cardiology 275 (2019) 70–76

Contents lists available at ScienceDirect

International Journal of Cardiology

journal homepage: www.elsevier.com/locate/ijcard

# Psychosocial situation in adults with congenital heart defects today and 20 years ago: Any changes?

Alina Kronwitter [1], Siegrun Mebus [1], Rhoia Neidenbach [1], Oktay Tutarel [1], Peter Ewert [1], Harald Kaemmerer [1], Nicole Nagdyman *,[1]

*Department of Pediatric Cardiology and Congenital Heart Disease, German Heart Centre Munich, Technical University of Munich (TUM), Munich, Germany*

ARTICLE INFO

*Article history:*
Received 4 May 2018
Received in revised form 5 October 2018
Accepted 8 October 2018
Available online 12 October 2018

*Keywords:*
Congenital heart disease (CHD)
Psychosocial situation

ABSTRACT

*Background:* While diagnosis and treatment of congenital heart diseases have improved over the last two decades, data regarding the course of psychosocial parameters is missing.
*Methods:* In a cross-sectional study, 283 adults with congenital heart disease completed a slightly modified questionnaire that was applied in a comparable study twenty years ago. Significant differences between the two populations as well as possible predictors of psychosocial burden for the recent population were sought.
*Results:* Despite the presence of more complex heart defects in the current cohort ($p < 0.001$), both populations exhibited similar values in the Ability *Index*. Furthermore, the current cohort reported significantly improved outcomes regarding school performance, employment, and sports. Regarding psychosocial functioning, the current cohort showed better outcomes in the domains of sadness ($p < 0.01$), independence ($p < 0.01$), understanding ($p < 0.001$), and acceptance ($p < 0.01$) of heart disease. Predictors for a worse psychosocial situation in a multiple regression analysis were anxiety, lack of curiosity, and age over 33. In the current study women, as opposed to men, reported significantly more dissatisfaction with too little information provided about their illness ($p < 0.05$), higher anxiety levels ($p < 0.01$), and heightened illness-connected burden ($p < 0.05$). However, women showed higher levels of independence ($p < 0.01$) and lower alcohol consumption ($p < 0.001$).
*Conclusion:* The psychosocial situation of adults with congenital heart disease has improved over the span of 20 years. However, particular needs and concerns should be addressed individually via doctor-patient communication. The findings here suggest that especially female patients appear to have a higher demand for counselling information, e.g. reproduction issues.



## 1. Introduction

Congenital heart defects are the most common birth defects [1]. The continuous improvement in survival rates of patients with congenital heart disease (CHD) has led to a growing number of adults with CHD, especially those with complex heart defects. This patient group needs special care, especially since adults with CHD have to deal with a variety of non-cardiac difficulties. These can relate to physical exercise, contraception and pregnancy as well as social and psychological problems. Patients with other chronic diseases reach adulthood also more often [2]. In these, socio-economic or psychosocial problems, such as depression, lower self-confidence, poorer outcome in terms of education, occupation and income are common [3–5].

For this reason, the attending physicians should also pay attention to these areas and provide psychological support on a multidisciplinary basis [6].

In 1995, Tintner examined the psychosocial problems of adults with CHD in Cologne [7]. In our study, we aimed to find out whether the patient population and its psychosocial situation have changed over the years by using a similar questionnaire which was used 20 years ago.

## 2. Methods

### 2.1. Patients and study design

A cross-sectional questionnaire-based survey was performed. Participants were adults with CHD who presented in the Department of Congenital Heart Defects (German Heart Center, Munich) for outpatient visits between August 2014 and November 2015. The patients were recruited randomly and consecutively. The study conforms to the principles outlined in the Declaration of Helsinki 1975 and was approved by the Institutional Review Board of the Technical University of Munich (NO. 34/14). Written informed consent was obtained from all study participants.

* Corresponding author at: Department of Paediatric Cardiology and Congenital Heart Disease, German Heart Centre Munich, Technical University of Munich (TUM), Lazarettstr. 36, D-80636 Munich, Germany.
*E-mail address:* nagdyman@dhm.mhn.de (N. Nagdyman).
[1] This author takes responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

https://doi.org/10.1016/j.ijcard.2018.10.030
0167-5273/

Inclusion criteria were: CHD, ability to read and complete the questionnaire in German language, and age of 18 and older. Of the 308 randomly selected patients, 25 had to be excluded because of incomplete questionnaire data, leaving us with an eligible sample size of 283. Having distributed 500 questionnaires, we achieved a response rate of 61.6%. These patients' data was compared to the data of 146 patients who filled out the questionnaire twenty years earlier in a comparable setting.

### 2.2. Variables and measurements

The original questionnaire was distributed in a comparable setting in the Department of Congenital Cardiology of the University of Cologne, Germany in 1995 [7].

As over the last 20 years, the use of the internet has become indispensable, the questionnaire was slightly modified, including an additional question of information search on the internet. The questionnaire contained open and closed questions. Patients expressed their own answer on open questions, whereas the closed questions consisted of dichotomous, multiple-choice or rating questions. The latter were scored on a four-point Likert scale from "totally applicable" [1] to "totally inapplicable" [4].

The questionnaire involved nine fields of interest.

1) *Educational level*: Highest graduation degree, school performance and potential problems.
2) *Employment*: current occupation and associated satisfaction as well as occupational burden caused by CHD
3) *Sports and hobbies*: Involvement in sports and its time effort
4) *Insurance status*: Potential difficulties with health or life
5) *Living conditions*: Sociodemographic details as current housing situation
6) *Assessment of health*: Self-perceived health, acceptance of illness, alcohol and nicotine consumption
7) *Medical care*: Information on follow-up screening and satisfaction with clinical care
8) *Sexual health*: Methods of contraception
9) *Psychosocial situation*: Illness-related psychological burden and possible coping strategies

For simplification, answers concerning fields 1 and 2, 4 and 5 as well as 6 and 7 are subsumed in the results part. Gender aspects were analyzed in the 2015 cohort; no comparisons to the 1995 cohort were feasible due to missing data.

### 2.3. Ability Index and congenital heart disease complexity

Diagnosis and Ability Index were verified through medical reports. Ability Index is classified as follows [8]:

*Grade I*: normal life, full time work/school possible, pregnancy possible
*Grade II*: part time work possible, life modified by symptoms
*Grade III*: unable to work, noticeable limitation of activities
*Grade IV*: extreme limitation, dependent, almost housebound

To classify complexity of the CHD, patients were classified "CHD of Great Complexity", "CHD of Moderate Severity" or "simple CHD" on the basis of their diagnosis [9]. As the sample of 1995 had not been categorized this way, the same classification was applied retrospectively in order to guarantee comparability.

### 2.4. Statistical analysis

All data analyses of the Munich population were performed using IBM SPSS Statistics Version 24. Categorical variables are represented by frequencies and percentages. The two-sample *t*-Test was used for age. Group differences (Cologne vs. Munich population) were examined with Chi Square Test or Fisher exact test. Probability values of $p < 0.05$ were considered statistically significant.

Predictors for psychosocial burden were measured in multiple logistic regression with backward elimination. Gender aspects of psychosocial burden were analyzed exclusively in the Munich sample.

## 3. Results

### 3.1. Samples and somatic characteristics

The data of the Munich cohort ($n = 283$) from 2015 were compared to the data of the Cologne cohort ($n = 146$) from 1995. Characteristics of the two cohorts are displayed in Table 1. Diagnoses are sorted by frequency of the 1995 cohort. More than one third of the 2015 cohort (34.2%) presented with other underlying congenital heart disease than the 1995 cohort. Therefore, we show these differing diagnoses in more detail in Table 2. As presented in Fig. 1, the 2015 sample had significantly more CHD of great complexity ($p < 0.0001$). The distribution of Ability Index, however, showed *no* significant difference (Fig. 2). Neither cohort 1995 nor 2015 included a patient with ability index grade IV.

**Table 1**
Patients' characteristics.

| | Sample 1995 | Sample 2015 |
|---|---|---|
| Sex | | |
| Female | 83 (43.2%) | 133 (47.0%) |
| Male | 63 (56.8%) | 150 (53.0%) |
| Age | | |
| Range | 20–71 years | 18–65 years |
| Mean | 33 | 33 |
| Diagnoses | | |
| ASD II | 36 (24.7%) | 8 (2.9%) |
| Coarctation of the aorta | 33 (22.6%) | 24 (8.5%) |
| VSD | 23 (15.8%) | 23 (8.1%) |
| Pulmonary valve stenosis | 22 (15.0%) | 10 (3.5%) |
| ASD I | 12 (8.2%) | 6 (2.1%) |
| Tetralogy of Fallot | 7 (4.8%) | 38 (13.4%) |
| PDA | 3 (2.1%) | 1 (0.4%) |
| ccTGA | 3 (2.1%) | 8 (2.8%) |
| dTGA | 2 (1.4%) | 48 (17.0%) |
| Aortic stenosis | 0 | 20 (7.1%) |
| Others | 5 (3.3%) | 97 (34.2%) |

### 3.2. Educational level and employment

Adults with CHD of 1995 compared to adults with CHD of 2015 tended to have lower educational levels, especially for patients with Ability Index II + III (60.9% vs. 31.5%, $p = 0.0003$). Within the 2015 cohort, patients with Ability I achieved more often university and college degrees ($p = 0.0364$). Employment rates were higher in the 2015 cohort ($p < 0.0001$) with an equivalently higher unemployment rate for the 1995 cohort.

The rate of inability to work decreased over the 20 years period ($p = 0.0006$). Overall, more patients of the 2015 cohort regarded their scholar/occupational situation as "very good" than twenty years earlier ($p = 0.0038$).

An overview of the surveyed fields of interest can be found in Fig. 2.

**Table 2**
Other diagnoses of the 2015 sample.

| Diagnoses | Frequency | Percentage |
|---|---|---|
| Aortic ectasia | 1 | 0.4 |
| Aortic insufficiency | 5 | 1.8 |
| Aortopulmonary window | 1 | 0.4 |
| Atrioventricular septal defect | 5 | 1.8 |
| Bicuspid aortic valve | 5 | 1.8 |
| Cor triatriatum sinistrum | 2 | 0.7 |
| Double chambered right ventricle | 1 | 0.4 |
| Double inlet left ventricle | 2 | 0.7 |
| Double outlet right ventricle | 4 | 1.4 |
| Ebstein's anomaly | 4 | 1.4 |
| Combined aortic vitium | 19 | 6.7 |
| LVOTO | 2 | 0.7 |
| Mitral valve cleft | 1 | 0.4 |
| Mitral valve insufficiency | 1 | 0.4 |
| Mitral valve prolapse | 9 | 3.2 |
| Persistent truncus arteriosus | 4 | 1.4 |
| Pulmonary atresia with VSD | 8 | 2.8 |
| Pulmonary atresia without VSD | 6 | 2.1 |
| Pulmonary ectasia | 1 | 0.4 |
| Shone's Complex | 1 | 0.4 |
| Single ventricle | 1 | 0.4 |
| Subaortic stenosis | 2 | 0.7 |
| Taussig-Bing syndrome | 2 | 0.7 |
| Total anomalous pulmonary venous connection | 2 | 0.7 |
| Tricuspid atresia | 8 | 2.8 |
| Total | 97 | 34.2% |

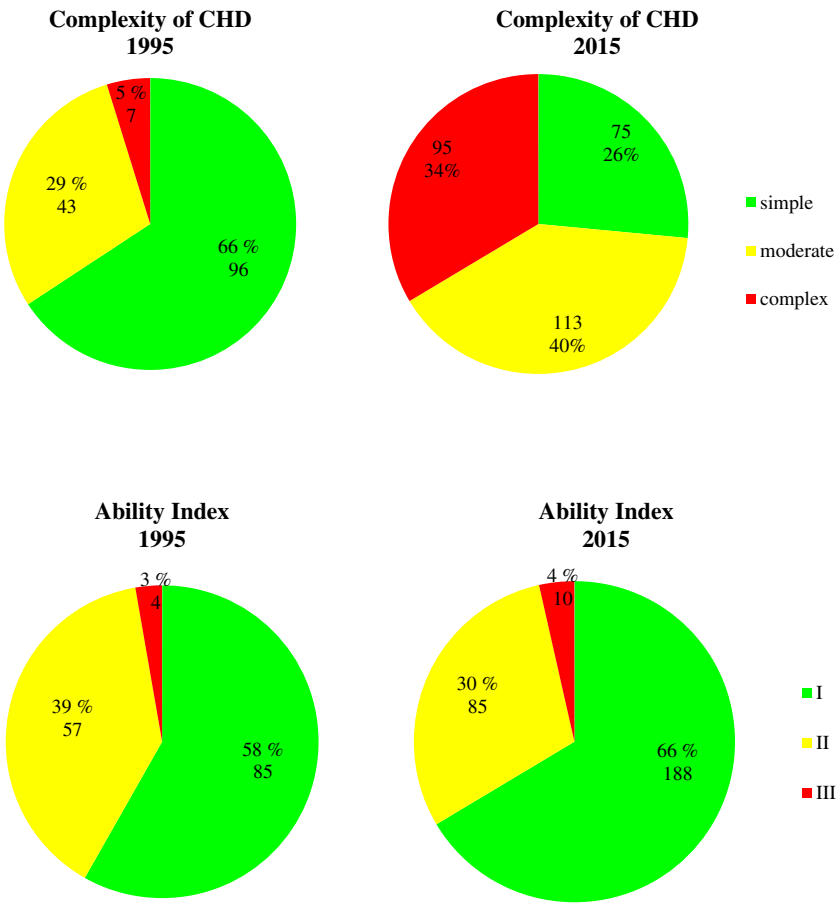


**Fig. 1.** Comparison of CHD Complexity and Ability Index.

### 3.3. Sports and hobbies

In 2015, significantly more adults with CHD exercised several times per week compared to 1995 (43.0% vs. 29.5%, $p = 0.0120$). Patients with Ability Index II reported to feel light restrictions during physical exercise, which was significantly more common in 2015 than in 1995 (72.4% vs. 37.0%, $p = 0.0018$), while in the cohort of 1995 severe restrictions were reported during exercise.

### 3.4. Insurance status and living conditions

In 2015, patients with limitations (Ability Index II and III) were accepted by life insurance companies more often than twenty years earlier ($p = 0.0256$). No significant difference was found for patients in Ability class I.

Compared to 2015, the cohort of Cologne tended to live more often with a partner (76.7% vs. 60.7%), and more independently from their parents (12.4% vs. 23.2%) ($p = 0.0044$).

### 3.5. Assessment of health and medical care

Despite more complex heart defects, the 2015 cohort indicated to feel "healthy and physically capable" significantly more often ($p = 0.0039$). Accordingly, the older cohort stated to be "neither healthy nor physically capable" more often ($p < 0.0001$). Better health over the span of 20 years was mainly reported by patients with Ability Index I ($p = 0.0002$).

In both cohorts, patients with Ability Index III underwent follow-up check-ups at least once per year. For patients with Ability Index II and I, however, frequency of annual check-ups increased over the years. 45.7% of the 1995 and 80.4% of the 2015 patients with Ability I had check-ups at least once a year ($p = 0.0272$), as well as 66.1% of the 1995 and 92.8% of the 2015 patients with Ability II ($p < 0.0001$).

Whereas a significant decrease of cigarette consumption could be observed over twenty years ($p = 0.0082$), alcohol consumption remained unchanged among patients.

### 3.6. Sexual health

The choice of contraception methods shifted over the years. Condoms were reported to be used more often in the recent cohort (27.6% vs. 4.1%, $p < 0.0001$). Furthermore sterilization as contraception method was named less often in 2015 ($p = 0.0003$). There was no significant difference regarding the use of contraception in general. Lack of information provided about pregnancy was criticized by 10.2% of the patients in the 2015 cohort, but not in the 1995 cohort.

### 3.7. Psychosocial situation

Several fields of psychosocial burden were studied. Significant differences resulted in the following fields: in 1995, patients stated to be sad more often than in 2015 (33.9% vs. 21.5%, $p = 0.0058$). They also admitted less acceptance of their illness (22.1% vs. 11.3%, $p = 0.0034$). Patients of the 2015 sample felt to be better informed about their illness (97.3% vs. 84.7%, $p < 0.0001$) and stated to be more independent (91.3% vs. 81.8%, $p = 0.0054$). The following fields showed no significant difference between both cohorts: anxiety (31.4% vs. 25.0%), frequent rumination (41.2% vs. 48.5%), social contact to other patients with heart diseases (23.3% vs. 17.0%), introversion (31.9% vs. 25.0%), curiosity

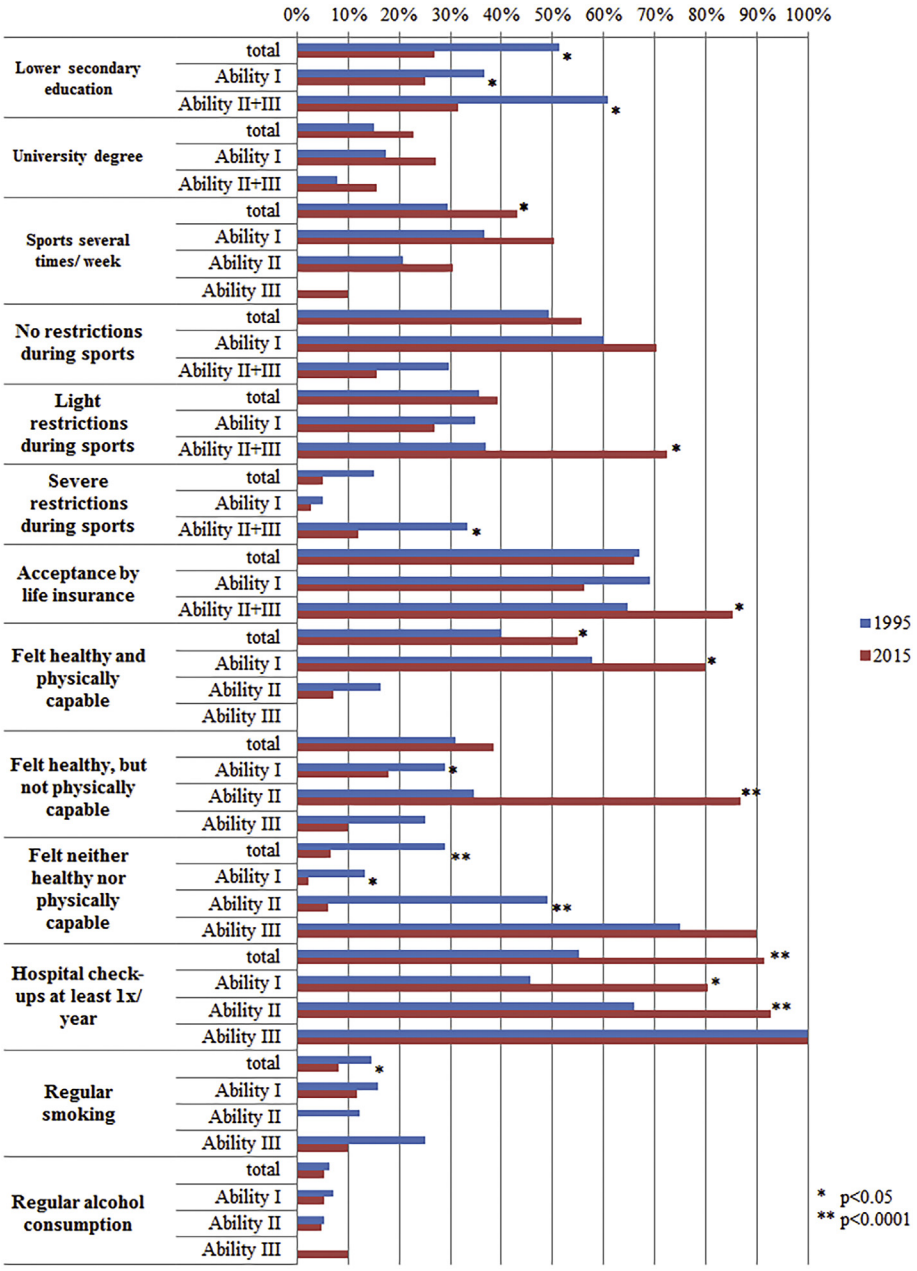


**Fig. 2.** Overview of selected surveyed fields of interest. The given percentages do not add up to 100% because they were calculated within each Ability index group separately.

(88.4% vs. 91.6%), assertiveness (77.3% vs. 83.5%), and impatience (35.6% vs. 33.0%).

Regarding problems, 61.1% of the older cohort reported *missing physical strength and symptoms*, while this was mentioned in 38.6% of the recent cohort. The second most named problem in both cohorts was *anxiety regarding future*, 23.3% in 1995 and 34.8% in 2015. In 2015, further concerns related to *uncertainties of pregnancy* and *possible inheritance*, *drug taking*, *disadvantages in society* and *operation scars*. In 1995, patients reported to be burdened because of *operation scars*, *chronicity of illness*, *drug taking*, *missing information*, *compassion of fellows* and *financial strain*.

Strengths and coping strategies patients named altered in the two cohorts. Whereas in 1995 30.6% reported *acceptance of illness* and 25.8% *optimism*, 52.7% named *optimism* and 19.4% *routine with the illness* in 2015. Other coping strategies by the 1995 cohort were *social support*, *denial* (both 16.1%), *check-ups* and *hobbies*, and by the 2015 cohort *denial* (14.5%) and *social support* (10.9%).

A change regarding who is burdened most (patient vs. relative) was observed: patients of the 1995 cohort regarded their relatives as most burdened. Patients of the 2015 sample, however, regarded themselves as most burdened. The difference was significant in patients with Ability Index I ($p = 0.0029$) and II ($p < 0.0001$).

### 3.8. Gender differences in the 2015 cohort

Due to the lack of original data from 1995, only the data of the 2015 cohort were analyzed for gender differences. Women showed greater dissatisfaction of provided information concerning the illness than men ($p = 0.0142$). Female patients also reported higher anxiety levels ($p = 0.0100$) and insomnia problems ($p = 0.0235$). While male patients described their family and friends to be more burdened than themselves, women stated themselves as the most burdened person regarding their illness ($p = 0.0368$). Females were more independent than males ($p = 0.0066$). Alcohol was consumed less by women ($p < 0.0001$).

### 3.9. Predictors of psychosocial burden

In the multivariate logistic regression analysis with backward elimination, three variables remained as predictors of psychosocial burden. Greatest odds were for patients with heightened anxiety (2.81 increased risk). Patients who denied being curious (lack of interest) had a 2.76 times elevated risk for psychosocial burden. Finally, patients over the age of 33 showed a 1.92 times elevated risk.

## 4. Discussion

It is worth emphasizing that although patients of the actual population showed more complex heart defects, Ability Index did *not* differ significantly from the other group interviewed 20 years ago. It can be assumed, that due to better diagnostic and therapeutic methods the health status, even in more complex CHD patients, is similar.

Furthermore, it is noteworthy that neither the 1995 nor the 2015 study cohort included patients with ability index IV. We speculate that these patients felt so uncomfortable with their situation that they avoided the participation in the study.

Over a time period of 20 years we observe a shift of the severity in the adults with CHD population who address to a CHD center. While in 1995 patients had mainly simple or moderate CHD, twenty years later the majority presented with moderate and complex CHD. It seems that the adults with simple lesions do not see the necessity to visit a CHD center, have their check-ups at a regular cardiologist, a general practitioner or even skip their regular examinations. Therefore, the spectrum of treatment in a supraregional center for patients with CHD might have shifted over the years to patients with more complex heart defects.

### 4.1. Educational level and employment

Interestingly, both patient groups had a higher educational level compared to the respective general population [10,11]. Over the course of twenty years, both, the normal population and patients with CHD have attained higher educational attainment levels, but the difference remained.

Patients with more severe physical limitations were also able to reach higher educational levels in 2015 than in 1995. The fact that 2015 population's educational attainment levels were higher than those of 1995 can certainly be explained by the general rise in educational attainment levels within twenty years. A large follow-up study over a period of up to 45 years from Finland also showed a good educational level of adults with CHD compared to the general population [12]. Conversely, many other studies conclude that CHD have a negative impact on cognitive and educational performance and education [13–16]. A possible reason for the good academic performance of patients can be that due to physical limitations in childhood and adolescence, sport and exercise were rather dispensed in favor of increased mental activity or learning. Furthermore, the socio-economic status of the parental home can also play a role.

Unemployment rate fell significantly over the span of twenty years (19.4% vs. 2.6%). However, due to geographic and socio-economic disparity, the unemployment figures of the respective regions have to be considered. Thus, the unemployment rate of the Cologne population was higher than the average for Germany (9.4%) and North Rhine-Westphalia (10.5%) in 1995 and of the Munich population lower than the average for Germany (6.4%) and Bavaria (3.6%) in 2015 [17–19]. The positive results of the current study are in contrast to data from literature [20,21]. Crossland et al. showed that 33% of adults with CHD were unemployed, while 25% had been unemployed for more than a year. The rate of unemployment in adults with CHD was significantly higher than in the control group. However, career advice in this patient group was significantly associated with employment. Still, adults with CHD were given advice against a certain occupation more often [22]. Coping strategies and compensation mechanisms among better health might be responsible for the good employment rate of the Munich population. Again, educational background of the parents could influence the results.

### 4.2. Exercise and health behavior

As in the two patient groups, sports awareness has increased in the general population in Germany over the years [23]. In comparison to the general German population, patients of the 2015 cohort exercised even more often. There is a clear link between sporting behavior and education [24]. As mentioned above, adults with CHD in the actual population showed a higher level of education, which may contribute to the more active sporting behavior.

Despite the positive results, it is still important to encourage patients with CHD to do exercise at an early stage. In children with CHD, 31.9% showed severe disturbances of motor development, compared to 5.5% of healthy peers. Parental overprotection may be a reason for this developmental disorder [25]. Moola et al. showed that young patients exercised less often despite the belief that sport was important for their health. Fears and exclusion have led to a low self-efficacy of the young people and thus further decreased the value attributed to physical activity [26]. Belief in self-efficacy, rather than severity of the cardiac disease, is the most influential factor in determining whether or not adolescents will engage in sports [27]. Self-efficacy is the belief of an individual to be able to effect a change in the situation through his/her own actions [28].

### 4.3. Medical and sexual health

The fact that patients of the 2015 cohort had follow-up check-ups more often might contribute to the better health of this population. Risk factors for loss to follow-up among children and young adults with CHD were one or more missed cardiology appointments in the past as well as lack of awareness of the need for follow-up. On the other hand, higher income, recent catheterizations and medical record documentation of the need for follow-up were protective [29]. It can be assumed that higher income in the Munich cohort may play a role due to different demographic background. The treatment of patients with moderate to highly complex heart defects should be coordinated by a tertiary center for CHD. Close cooperation and consultation between general practitioners, cardiologists and adults with CHD centers is essential [30].

The current study revealed the need for better counselling regarding the topic “pregnancy”. How well patients with CHD were informed about pregnancy and contraception by their physicians was the subject of several studies. It turned out that many women with CHD do not have sufficient knowledge of safe contraceptive methods [31,32]. A lack of education in patients with CHD can lead to an increased risk during pregnancy for both mother and child [33]. Guidance about contraception and pregnancy needs to be improved. Counselling about the possibility to become pregnant, about the patient's individual risk factors caused by her CHD as well as the potential complications during pregnancy needs to be addressed. Therefore, education should begin in adolescence and pre-conceptional counselling and care during pregnancy should be accompanied by a multidisciplinary team of gynecologists and experienced cardiologists, anesthetists and obstetricians [34–36].

### 4.4. Psychosocial situation and gender aspects

In 2015, significantly more patients reported to be informed about their CHD than in 1995. Still, several studies show a lack of diagnosis and disease specific knowledge and education in patients with CHD [37–39]. In 2015, male patients were significantly more satisfied with their disease specific education than women. This result correlates with the previously mentioned poor information regarding pregnancy.

Predictive factors for psychosocial stress in the statistical model were: *anxiety*, *lack of interest/lack of curiosity*, and an *age over 33 years*. Loss of interest can be a symptom of Depressive Disorder or a Depressive Episode [40]. Similar results were also obtained by Enomoto et al. in 2015 who compared two age groups of adults with CHD in Japan. It was found that the group of patients over the age of 30 suffered significantly more often from possible anxiety disorders or depression. In addition, patients over 30 years of age were significantly more likely to have a negative perception of the disease compared to the other age group [41]. Increased anxiety and depressive disorders among patients with CHD are often described in the literature [42,43]. The fact that female patients of the 2015 population mentioned to be anxious significantly more often than men is also in accordance with the statement of female patients that they saw the greatest burden on themselves and not on their family. A predictor for a worse psychosocial situation among young adults (18–26 years) was female sex. In younger patients (12–17 years) female sex was also a predictor of somatic complaints. Social support was very important in improving the quality of life [44].

Female patients in 2015 considered themselves to be the most burdened, while men attributed the greatest burden to their family and friends. This correlates with the statement that female patients also suffered more from a lack of disease specific information and anxiety.

Nevertheless, the knowledge that the family also suffers from their illness can play a serious and additionally stressful role for both patient groups. Several studies have shown that relatives of patients with CHD face psychosocial problems [45–49]. Therefore, it is important to also address the relatives during therapy and to inform them about offers for support in the clinical setting as well as self-help groups.

In the current study, female participants reported to be more independent than males. This fact can be associated with other gender aspects: through greater independence female patients assume more responsibility for their own illness. A follow-up study showed that patients with CHD tended to live less independently than people of the same age. This was especially observed in male patients with moderate and highly complex CHD [50].

### *4.5. Study limitations*

This study has some limitations: Better self-perceived health and psychosocial situation may influence each other. Furthermore, a selection bias may also be present, since only those patients in Munich who have undergone check-ups regularly have been evaluated and may be expected to have a higher level of education. Furthermore, different socio-demographic factors of the two cohorts may have an impact on the results. Psychosocial situation was not measured with a standardized questionnaire. In order to generate a more reliable image on psychosocial situation, patients who are not seen regularly, but are filed by the hospital, should be addressed likewise.

## 5. Conclusion

Diagnostic and therapeutic progress over the past 20 years as well as an improved organization of care by CHD-specialized cardiologists and centers seems to lead to a shift to more complex adults with CHD. Higher degrees and an improved occupation situation on the one hand, sport attitude and modified health awareness on the other hand follow a trend which can be observed in the general population over the last two decades. Education in sexual matters and pregnancy are still insufficient. Adults with CHD have an increased risk for psychosocial problems, especially female patients. Social support and personal acceptance of the disease are important resilience factors.

Career and sport counselling are an important part in the medical care of adults with CHD. Especially the topic of contraception and pregnancy should play a more important role during medical check-ups, not only the cardiologic examinations. Relatives of adults with CHD need sufficient support, too.

## Disclosure of grants or other funding

We declare that no grants or other funding were used for this study.

## Conflict of interest

The authors have no conflicts of interest to disclose. All authors of this manuscript declared that they comply with the Principles of Ethical Publishing in this journal. All authors take responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

## Acknowledgements

None.

## Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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