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ORIGINAL ARTICLE

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Congenital heart disease patients' and parents' perception of disease-specific knowledge: Health and impairments in everyday life

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Abstract

Background: Children and adolescents with congenital heart disease (CHD) and their families require qualified combined medical and psychosocial information, care, and counseling. This study aimed to analyze CHD patients' and parents' perception of disease-specific knowledge, state of health, and impairments experienced in everyday life, as well as factors influencing these perceptions.

Materials and Methods: Analyses were based on a survey among patients/parents recruited via the German National Register for Congenital Heart Defects (NRCHD). The total sample (N = 818) was divided into four groups: "Children" (176 patients), "Adolescents" (142 patients), "Adults" (269 patients), and "Parents" (231 parents). The patients were stratified into those with simple and those with complex CHD. Descriptive and univariate analyses were performed.

Results: Patients' age and CHD severity were related to self-assessed state of health ($P = .04$ and $P = .02$). In addition, CHD severity was associated with worse impairment in everyday life ($P < .001$). Psychosocial support was related to the self-assessed state of health ($P = .01$) and the reported impairment in everyday life ($P < .001$).

Conclusions: Patients' age, CHD severity, and psychosocial support seem to be related to self-assessed state of health and impairments in everyday life. To evaluate causality beyond associations, the development of patients' and parents' assessments and quality of life during the phase of transition from childhood to adulthood could be investigated by prospective long-term studies.

KEYWORDS
congenital heart disease, impairments, knowledge, parent perspective, perception, psychosocial support

1 | INTRODUCTION

Approximately, 6000 children with congenital heart disease (CHD) are born in Germany every year.[1] The number of patients with CHD is therefore growing steadily[2,3]: more than 90% of those affected today reach adulthood. This can be attributed to the improvements in the diagnosis and treatment of CHD.[2–6]

Patients with CHD can be considered to be chronically ill. As a consequence, as with other chronic illnesses, patients and parents require information regarding underlying conditions, morbidity and mortality risks, and the natural course of the disease. Sufficient disease-specific knowledge may help patients and their relatives to adequately maintain or improve their state of health by adopting an appropriate lifestyle and by attending regular follow-up examinations.

Lifelong chronic illnesses starting at birth require a transition from parent-led care to independently responsible self-care as patients reach adulthood. This presents parents and their growing CHD children with various challenges. The shift requires patients to acquire relevant disease-specific knowledge and hence to realize the impairments associated with the specific form of CHD involved. This so-called transition phase requires special consideration in connection with a child's CHD.[4,6–10]

According to experts' opinion, children and adolescents with CHD, as well as their families, must be provided with qualified combined medical and psychosocial care and counseling.[11,12] The studies on this matter have shown that taking over control of their own health, including acquiring disease-specific knowledge, is an important aspect in patients' development. Apparently, this is often not achieved to the desired extent as it can be gauged from the fact that 50%–75% of patients fail to attend regular specialist follow-up examinations, and thus incurring an increased risk of suffering potentially irreversible complications and increased mortality.[8,13,14]

In 2014, Lesch et al.[8] published the initial results of a nationwide German survey conducted by the German National Register for Congenital Heart Defects (NRCHD) to record the data from the patients and parents. The objective was to assess patients' and parents' strategies to acquire disease-specific knowledge, their subjective assessment of their current level of information, their communication, as well as their assessment of impairments in everyday life owing to the CHD and their situation regarding medical and psychosocial care. Based on this survey, this study aims to investigate the similarities and discrepancies between patients' and parents' subjective perceptions regarding:

1. the subjective assessment of disease-specific knowledge,
2. the assessment of the individual's state of health, and
3. the assessment of the extent of impairment in everyday life.

A further question was how patients' assessments correlate to their age, disease severity, and/or their having received psychosocial support in the past.

2 | MATERIALS AND METHODS

For the recruitment of study participants, the patients' database of the NRCHD was used. Comprising data from more than 52 582 registered patients (as of May 2017) the NRCHD is the largest database of CHD in Europe and is representative of the German cohort of patients with CHD.[15] The study participants were surveyed online. In addition to the data available from Lesch et al.,[8] the present analyses focused on the parents' perspective.

2.1 | Inclusion criteria

The patients aged 10–30 years with the following diagnoses were invited to the survey: atrial septal defect, double inlet ventricle, hypoplastic left heart syndrome, hypoplastic left ventricle, pulmonary valve stenosis with associated lesions/cyanosis, truncus arteriosus communis, and transposition of the great arteries.

2.2 | Group classification

These diagnoses were classified into 2 groups (simple CHD and complex CHD). In accordance with the current recommendations,[16] atrial septal defects were classified as simple lesions and the further diagnoses were combined and classified as complex.[17] The total sample was divided into 4 groups: "Children" = patients aged 10–13 years, "Adolescents" = patients aged 14–17 years, "Adults" = patients aged 18–30 years, and "Parents" = parents of patients who were also willing to take part in the survey. Patients younger than 10 years or >30 years of age were excluded from the survey as the focus was on the transition from childhood to adolescence and adulthood. The parents were asked to participate in the survey to investigate potential differences between the patients' and the parents' perspective.

2.3 | Questions analyzed

2.3.1 | Psychosocial care in the past

Participants were asked whether they had received psychosocial care in the past. Additionally patients who stated that they had not received psychosocial support in the past were asked whether they had desired psychosocial support.

2.3.2 | Rating of level of information

Participants were asked to rate their subjective level of information regarding their CHD on a scale from 1 (not good at all) to 10 (very good).

2.3.3 | Rating of state of health

The patient's state of health or the child's state of health, as applicable, was to be rated on a scale from 1 (very bad) to 10 (very good).

2.3.4 | Rating of impairments in everyday life

Participants were asked to rate the degree of CHD-related impairments in everyday life on a scale from 1 (very limited) to 10 (not limited at all).

2.4 | Statistical analysis

Descriptive data analysis was performed regarding psychosocial support. Univariate analysis was performed to investigate how patients' age, disease severity, and psychosocial support influenced patients' rating of their own level of information (disease-specific knowledge), state of health, and impairments in everyday life. The results were considered statistically significant if they reached a P value of $\leq .05$. In addition, 3 univariate analyses were performed to compare the patients (10–30 years) and their parents regarding the items of "rating of level of information," "rating of state of health," and "rating of impairments in everyday life." The effect size was given as Cohen's d. Statistical analyses used SPSS (version 22; IBM, Armonk, New York, USA).

TABLE 1 Sample composition (N = 818)

	Group 1 (children)	Group 2 (adolescents)	Group 3 (adults)	Group 4 (parents)
Male	75 (42.6%)	53 (37.3%)	107 (39.8%)	51 (22.1%)
Female	101 (57.4%)	89 (62.7%)	162 (60.2%)	180 (77.9%)
Sample size	176 (100%)	142 (100%)	269 (100%)	231 (100%)
Age in years (M/SD)	11.5/1.05	15.4/1.13	22.7/3.52	43.7/6.52

Abbreviations: M, mean value; SD, standard deviation.

3 | RESULTS

The overall response rate was 53%.[8] In total, 1372 patients meeting the inclusion criteria were identified in the database of the NRCHD. Of these 1372 potential study participants, 232 persons were not eligible of different reasons (e.g., death, no address, and incapable of completing the questionnaire). Of the remaining patients (n = 1140), 596 participated in this study. The response rate corrected for persons lost to follow-up was 52.3%. Of the 596 patients, 9 were excluded additionally because of missing values regarding the analyzed questions (final patient sample = 587). The total sample (N = 818) was divided into four groups: "Children" (176 patients), "Adolescents" (142 patients), "Adults" (269 patients), and "Parents" (231 parents) (Table 1). A total of 340 of the patients surveyed (57.9%) had a simple CHD and 247 had a complex CHD (16.2% with a single ventricle).

In preliminary analyses, sex turned out to be statistically insignificant when comparing the groups regarding the assessment of "level of information," "state of health," and "impairments in everyday life." It was thus not considered in any univariate analyses. However, sex is included in the descriptive analyses concerning psychosocial support.

3.1 | Data on psychosocial support

Overall, 38 patients (6.5%) reported psychosocial support in the past. In the "Children" group, 15 patients (8.5%) stated that they had received psychosocial support in the past (male patients with simple CHD = 4.4%, female patients with simple CHD = 6.9%, male patients with complex CHD = 16.7%, and female patients with complex CHD = 10.3%). In the "Adolescents" group, 6 patients stated that they had received psychosocial support in the past (male patients with simple CHD = 12.5%, female patients with simple CHD = 3.3%, male patients with complex CHD = 3.4%, and female patients with complex CHD = 0%). In the "Adults" group, 17 patients (6.3%) reported psychosocial support in the past (male patients with simple CHD = 0%, female patients with simple CHD = 6.5%, male patients with complex CHD = 4.9%, and female patients with complex CHD = 11.4%). In brief, 9.4% of mothers and 7.8% of the fathers stated that their child had received psychosocial support in the past.

Those patients and parents who had not received psychosocial care in the past were subsequently asked if they would have wished to have this option for themselves or their child. With a proportion of 13%, adult patients with simple CHD were the group with the highest frequency regarding the desire for psychosocial support. In addition, 8.7% of the parents stated that they would have welcomed such an option (mothers: 10% and fathers: 3.9%).

3.2 | Rating of level of information

Parents assumed their own level of knowledge about the child's CHD to be good to a significantly higher degree than the patients themselves did ($d = 0.633$; $P < .001$) (Tables 2 and 3).

Regarding the rating of the individual's own disease-specific knowledge (rating of level of information), significant differences in mean value with a small effect size ($d = 0.22$; $P < .05$) were found between the "Children" group and the "Adults" group. Children assumed their level of information to be significantly lower than the adult patients did. Further comparisons between age groups were not statistically significant (Tables 3 and 4).

No significant differences were found between patients with simple and complex CHD or between patients with or without psychosocial support in the past, regarding the rating of the person's own level of information (Tables 3 and 4).

3.3 | Rating of the state of health

Significant differences between parents and patients were found regarding the rating of the child's or the person's own state of health, respectively ($d = 0.178$; $P < .05$). Thus, parents rated their child's state of health significantly better than the patients themselves (Tables 2 and 3).

In addition, there were significant differences in mean value with a small effect size ($d = 0.281$; $P < .01$) between the "Adolescents" group and the "Adults" group regarding the rating of the person's own state

TABLE 2 Descriptive statistics of the subjective rating of level of information, state of health, and impairments in everyday life

Question	Group	Mean value (SD)	N
Rating of level of information	Patients	6.95 (2.365)	581
	Parents	8.36 (1.836)	229
Rating of state of health	Patients	8.86 (1.716)	583
	Parents	9.15 (1.386)	230
Rating of impairments in everyday life	Patients	8.57 (1.958)	581
	Parents	8.96 (1.750)	230

Abbreviations: SD, standard deviation; N, sample size.
[a]The sample sizes may differ owing to missing values (unanswered questions).

TABLE 3 Results of the univariate analyses

Groups compared	DV	*df*	*T* value	*d*	*P* value
Patients	Rating of level of information	533.797	−9.051	0.633	.000
	Rating of state of health	515.688	−2.559	0.178	.011
Parents	Rating of impairments in everyday life	466.760	−2.765	0.205	.006
Children (10–13 years)	Rating of level of information	310.109	−1.697	0.188	.091
	Rating of state of health	308.081	−0.787	0.085	.432
Adolescents (14–17 years)	Rating of impairments in everyday life	313	−0.720	0.085	.472
Children (10–13 years)	Rating of level of information	438	−2.274	0.22	.023
	Rating of state of health	441	1.773	0.176	.077
Adults (18–30 years)	Rating of impairments in everyday life	439	2.272	0.25	.024
Adolescents (14–17 years)	Rating of level of information	405	−0.369	0.039	.712
	Rating of state of health	360.805	2.925	0.281	.004
Adults (18–30 years)	Rating of impairments in everyday life	316.622	3.090	0.312	.002
Patients with simple CHD	Rating of level of information	579	−0.148	0.013	.882
	Rating of state of health	581	3.742	0.312	.000
Patients with complex CHD	Rating of impairments in everyday life	461.853	7.244	0.625	.000
Patients after psychosocial support	Rating of level of information	577	0.187	0.034	.852
	Rating of state of health	39.931	2.645	0.598	.012
Patients without psychosocial support	Rating of impairments in everyday life	39.601	3.929	0.895	.000

Abbreviations: CHD, congenital heart defect; *d*, effect size; *df*, degree of freedom; DV, dependent variable.

of health. Adolescents thus rated their state of health significantly better than did the adult patients. Further comparisons of age groups were statistically insignificant (Tables 3 and 4).

Significant differences in mean value with a small effect size ($d = 0.312$; $P < .001$) were found between patients with simple CHD and patients with complex CHD regarding the rating of their own state

TABLE 4 Descriptive statistics of subjective rating of level of information, state of health, and impairments in everyday life[a]

Question	Group	Mean value (SD)	N
Rating of level of information	Children (10–13 years)	6.60 (2.456)	174
	Adolescents (14–17 years)	7.04 (2.190)	141
	Adults (18–30 years)	7.13 (2.376)	266
	Patients with simple CHD	6.94 (2.455)	337
	Patients with complex CHD	6.97 (2.239)	244
	Patients having received psychosocial support	6.89 (2.299)	38
	Patients not having received psychosocial support	6.97 (2.363)	541
Rating of state of health	Children (10–13 years)	8.97 (1.869)	175
	Adolescents (14–17 years)	9.11 (1.312)	140
	Adults (18–30 years)	8.65 (1.779)	268
	Patients with simple CHD	9.08 (1.708)	338
	Patients with complex CHD	8.55 (1.682)	245
	Patients having received psychosocial support	7.97 (2.187)	38
	Patients not having received psychosocial support	8.93 (1.631)	543
Rating of impairments in everyday life	Children (10–13 years)	8.73 (1.986)	175
	Adolescents (14–17 years)	8.89 (1.759)	140
	Adults (18–30 years)	8.29 (2.006)	266
	Patients with simple CHD	9.06 (1.714)	337
	Patients with complex CHD	7.89 (2.070)	244
	Patients having received psychosocial support	6.97 (2.635)	38
	Patients not having received psychosocial support	8.68 (1.850)	541

Abbreviations: CHD, congenital heart defect; SD, standard deviation; N, sample size.
[a]The sample sizes may differ owing to missing values (unanswered questions).

of health. Patients with simple CHD rated their state of health significantly better than did patients with complex CHD (Tables 3 and 4).

A medium effect size was found by comparing the patients who had received psychosocial support in the past and those who had not ($d = 0.598$): the patients who had received psychosocial care rated their state of health as significantly worse than did patients who had not received psychosocial support ($P < .05$) (Tables 3 and 4).

3.4 | Rating of impairments in everyday life

Parents rated the perceived impairments in everyday life that their children face to be significantly lower than did the patients themselves ($d = 0.205$; $P < .01$) (Tables 2 and 3).

Significant differences in mean value with a small effect size ($d = 0.25$; $P < .05$) were found between the children and the adult patients regarding the rating of impairments faced in everyday life. Children rated the impairments faced in everyday life significantly lower than did adult patients (Tables 3 and 4).

Similarly, the adolescent patients rated the impairments they faced in everyday life significantly lower than did the adult patients ($d = 0.312$; $P < .01$). Further comparisons of age groups were statistically insignificant (Tables 3 and 4).

Regarding the assessment of impairments in everyday life, significant differences with a medium effect size were also found between the patients with simple CHD and the patients with complex CHD ($d = 0.625$; $P < .001$): the patients with simple CHD rated impairments faced in everyday life as significantly lower than did the patients with complex CHD (Tables 3 and 4).

Furthermore, patients who had received psychosocial support in the past rated the impairments they faced in everyday life significantly higher than those who had not received such care ($d = 0.895$; $P < .001$) (Tables 3 and 4).

4 | DISCUSSION

This study aimed to investigate patients' and parents' assessment of their own disease-specific knowledge, the patient's/child's state of health, and impairments faced in everyday life. The patients of different age groups, CHD lesion severity, and potential psychosocial care/support in the past were examined. In addition, parents' assessment was recorded and compared to that of the patients. For this purpose, descriptive as well as univariate analyses were conducted. The main findings of the study were that patient age, CHD severity, and psychosocial support seem to be related to self-assessed state of health and impairments in everyday life.

4.1 | Data on psychosocial support

Only a minority of 6.5% of patients had received psychosocial support in the past. It is not surprising that patients with complex CHD had slightly more access to psychosocial support; however, even these highly compromised patients did so only in a small proportion of cases. Highlighting the potential benefits of receiving such care to parents and patients may increase its acceptance and facilitate the implementation of psychosocial care in the routine follow-up of patients with CHD. Improved multidisciplinary care (including psychological support) should be advocated especially during the vulnerable transition phase to avoid loss to follow-up and associated long-term complications.[18,19]

Regardless of CHD severity, female participants (patients/mothers) reported having desired psychosocial support approximately 3 times as often as male participants (patients/fathers). The results of a study by Areias et al.[20] suggest that women with CHD, as well as CHD patients with poor school performance and low social support, have greater difficulties regarding psychosocial adjustment and show a more negative perception of their quality of life. Against this background, our findings regarding psychosocial support seem plausible and should be considered in clinical practice.

A conceivable reason for the scepticism of parents and patients regarding the psychosocial support might be fear of stigmatization owing to receiving this kind of support and might explain the lack of uptake of psychosocial support.[21] One possible healthcare implication could be to assess all CHD children for their need for psychosocial support and to offer this option broadly to the CHD community. In the best of cases, timely psychosocial support and, if needed, psychotherapy, may then prevent later psychological issues and illnesses associated with high morbidity and cost-intensive treatment.

4.2 | Rating of level of information

Parents considered themselves to be generally well informed about their child's heart disease. In contrast, patients assumed their knowledge to be considerably lower. These results indicate that, regardless of age, patients report significantly less knowledge about their disease than do their parents. The practical implication of these results should be considered. Although it appears plausible that, up to a certain age, parents are better informed than their children, patients should, with increasing age, become the experts on their own disease. The fact that whether the subjective assessment of their own level of information is also reflected by actual knowledge remains to be investigated in future studies. Both CHD severity and psychosocial support do not seem to influence the assessment of disease-specific knowledge to any extent.

4.3 | Rating of the state of health

Parents rated their children's state of health as significantly better than the children themselves. In addition, adult patients rated their own state of health worse than did children and adolescent patients.

The studies have shown that the transition phase involves a change in everyday tasks and challenges, the life situation, and the increasing necessity to take on responsibility for one's own health care.[4,6–10,18,19] The assumption that, by experiencing this, adult patients are increasingly aware of the limitations imposed by their disease (thus rating their state of health more negatively or arguably more realistically) seems plausible. Similarly, the fact that patients with complex CHD rate their state of health as significantly worse than those

with simple CHD is also comprehensible, considering the added physical burden owing to the disease severity.

At first glance, particularly the observation that patients who had received psychosocial support in the past assess their own state of health as significantly worse than patients without such psychosocial support appears paradoxical. Rather, we speculate that psychosocial care/support helping patients focuses on their well-being and state of health leads to a more conscious and realistic assessment of their own health situation. Future prospective studies are to further investigate this matter to clarify the causality between receiving psychosocial care/support and well-being.

4.4 | Rating of impairments in everyday life

Parents rated the impairments their children faced in everyday life as significantly lower than did the CHD patients themselves. Adult patients rated the impairments in everyday life as significantly higher than did younger patients. These findings strengthen the need to provide adult patients with targeted care and support. The worsening assessment of impairments in everyday life can be potentially explained by disease progression leading to greater impairment with age and by an increased general burden and reduced protection by the environment in later life (e.g., the need to make career choices, physical activity, and family planning).

5 | LIMITATIONS

As a cross-sectional study, this investigation by definition does not allow any conclusions as to causalities. Furthermore, the information given regarding level of information (disease-specific knowledge), state of health, and impairments in everyday life reflects the subjective assessment of those surveyed and is therefore not objective.

6 | CONCLUSIONS

This study gives a first insight into the subjective assessment of CHD patients and their parents regarding their level of information (disease-specific knowledge), state of health, and impairments in everyday life. This allows correlations to be identified between patients' subjective assessment, their age, CHD severity, and history of psychosocial support. To further assess temporal changes in subjective assessment of impairment and quality of life of patients with CHD during the transition phase, prospective long-term studies are needed. Special attention should be paid to the question of whether providing easily accessible psychosocial support that is independent of the disease severity might be an effective measure to encourage patients' adequate adjustment to their individual conditions on a behavioral as well as on a psychological level.

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CONFLICT OF INTEREST

None.

ETHICS

All procedures performed in the studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

AUTHOR CONTRIBUTIONS

Conception and design of study: Lesch, Specht, Bauer
Acquisition of data: Lesch, Specht, Bauer
Analysis and/or interpretation of data: Helm, Kempert
Drafting the manuscript: Helm, Kempert
Critical revising of the manuscript: Helm, Kempert, Körten, Lesch, Specht, Bauer

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