

# Resilience in children with congenital heart disease: a comparative study with health counterparts

Katharina Köble ,<sup>1</sup> Laura Willinger ,<sup>1,2</sup> Leon Brudy ,<sup>2</sup>  
Renate Oberhoffer-Fritz,<sup>1,2</sup> Peter Ewert,<sup>2,3</sup> Jan Müller <sup>1,2</sup>

<sup>1</sup>Institute of Preventive Pediatrics, Technical University of Munich, Munich, Germany  
<sup>2</sup>Department of Pediatric Cardiology and Congenital Heart Disease, Technical University of Munich, Munich, Germany  
<sup>3</sup>partner site Munich Heart Alliance, German Centre for Cardiovascular Research, Munich, Germany

## Correspondence to

Katharina Köble, Institute of Preventive Pediatrics, Technical University of Munich, Munich, 80992, Germany; [katharina.koeble@tum.de](mailto:katharina.koeble@tum.de)

KK and LW contributed equally.

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## ABSTRACT

**Objective** Resilience is a complex, yet rather unexplored topic in patients with congenital heart disease (CHD). The goal of this study was to assess and compare resilience in children with CHD with healthy controls during the COVID-19 pandemic.

**Design and patients** From June 2020 to June 2021, 124 children with various CHDs (14.6±2.1 years, 49 girls) and 124 matched healthy controls (14.8±2.0 years, 49 girls) completed the Resilience Scale-11 short version.

**Results** Resilience was significantly reduced in children with CHD compared with healthy controls (CHD: 59.0±10.0 vs healthy controls: 64.4±6.5,  $p<0.001$ ). That reduction was prominent in all CHD subgroups except those with left heart obstruction (aortic stenosis and coarctation of the aorta) and patients with transposition of the great arteries. Complex CHD had the lowest resilience of 57.6±8.4 ( $p<0.001$ ) after adjusting for age and sex according to group differences. There was no difference between native CHD and CHD with open-heart surgery (native: 59.5±12.2 vs surgery: 58.8±9.3,  $p=0.758$ ).

**Conclusions** Resilience was reduced in children and adolescents with CHD compared with healthy peers during the COVID-19 pandemic. Children with complex severity appeared to be particularly affected. These findings emphasise continued efforts to provide a holistic and multidisciplinary approach in medical aftercare of these patients and their families.

## INTRODUCTION

Resilience describes a person's ability to cope with, manage or adapt to adverse conditions or experiences.<sup>1</sup> This process hinges upon two critical factors: first, exposure to an unfavourable event, and second, the development of positive adjustments despite enduring severe adversity.<sup>2</sup>

Children with congenital heart disease (CHD) encounter compromised health outcomes from birth and endure chronic illness as they progress into adulthood. The severity of CHD determines the extent of major adversities experienced during early life, including hospitalisation, medical interventions and surgeries.<sup>3</sup> Consequently, patients and their families confront elevated levels of uncertainty as they navigate through life.<sup>4</sup> Additionally, prescribed medication intake, regular clinical visits or the surgical scar on the chest are constant reminders of the congenital condition. Adding to these challenges, the year 2020 witnessed the onset of the COVID-19 pandemic and the ensuing restrictions, constituting yet another significant event that

## WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ All previous literature has focused on resilience in patients with congenital heart disease (CHD) only within their own cohort.
- ⇒ This study aims to close this knowledge gap by comparing patients with CHD under 18 years of age with healthy peers.

## WHAT THIS STUDY ADDS

- ⇒ Resilience was lower in young patients with CHD compared with healthy controls during the COVID-19 pandemic.
- ⇒ Children with complex CHD seem especially to be affected.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ These findings emphasise continued efforts to provide a holistic and multidisciplinary approach in medical aftercare of these patients and their families.

necessitated management. Consequently, the fulfilment of the first critical condition regarding resilience, as mentioned earlier, is apparent. However, whether children with CHD and their families successfully adapt to these adverse circumstances, which encompasses the second critical condition, remains inadequately explored.<sup>5,6</sup>

Previous studies have examined resilience solely within the CHD patient population.<sup>7–10</sup> These studies have revealed a strong correlation between resilience and various domains of health-related quality of life (HrQoL)<sup>7</sup> as well as task-oriented coping mechanisms.<sup>9</sup> In adolescents with CHD, resilience was found to be associated with parental rearing behaviour such as overprotection and control.<sup>8</sup> However, no previous study has compared the resilience of children with CHD with healthy controls. No research on resilience during the COVID-19 pandemic has been identified in the context of children and adolescents with CHD. Therefore, the aim of our study was to compare in a pioneering investigation the resilience of children with CHD with that of their healthy counterparts, specifically during an exceptionally challenging period.

## PATIENTS AND METHODS

### Study participants

From June 2020 to June 2021, 124 children with various CHDs (14.6±2.1 years, 49 girls) participated



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in this study at the outpatient clinic of the German Heart Center Munich. Participants were part of the FOOTLOOSE cohort (German-Clinical-Trial-Register-ID: DRKS00018853). During the same time period, 328 healthy control subjects were examined for their resilience at the outpatient clinic of the Department of Preventive Pediatrics at the Technical University of Munich. From this pool, 124 healthy control subjects (14.8±2.0 years, 49 girls) were selected using a computer algorithm for matching.

According to American College of Cardiology (ACC) criteria,<sup>11</sup> the cohort comprised 60 children categorised as having complex heart defects, 33 with moderate defects and 31 with simple defects. Eighty-nine children had undergone one or more open-heart surgery, 35 had native conditions or not undergone open-heart surgery. The various CHDs were classified into five major subgroups: 'left heart obstruction' (n=25), including aortic stenosis and coarctation of the aorta; 'right heart obstruction' (n=29), including tetralogy of Fallot and pulmonary stenosis; 'isolated shunts' (n=27), including atrial/ventricular/atrioventricular septal defect; 'transposition of the great arteries (TGA)' (n=17); and children with 'total cavopulmonary connection' (n=26).

### Resilience Scale-11

Resilience was assessed using the short version of the Resilience Scale (RS-11) by Schumacher and colleagues.<sup>12</sup> There are three different Resilience Scales: a long (RS-25), a short (RS-11) and a very short (RS-5) version, all of which have been shown to be valid, reliable and economical measures for identifying individual levels of resilience.<sup>12-14</sup> The herein used RS-11 is an 11-item form translated and extracted from the Resilience Scale by Wagnild and Young.<sup>15</sup> The questionnaire asks participants to rate the extent to which 11 statements apply to them in general, or in other words, how much their general actions and thinking are described by these statements. For example: 'If I have plans, I pursue them' or 'I usually manage everything somehow'. The 7-point Likert scale ranges from 'I do not agree' to 'I completely agree'. The specific questionnaire can be assessed elsewhere.<sup>12</sup> All of an individual's response items are summed to produce a total resilience score, which can range from 11 to 77. A higher score indicates a higher level of agreement with the stated items, and therefore a higher level of individual resilience.<sup>13</sup>

### Data analysis

Data were analysed using SPSS V.29.0 software (IBM). All data are presented as mean±SD after visual examination suggested the data could be treated as normally distributed. Group differences between healthy controls and CHD were analysed by independent t-test, as normal distribution was given. Subgroup analysis for specific diagnosis (six groups) and defect severity (four groups) was performed using univariate analysis of variance with sex and age as covariates. Results were illustrated showing the estimated mean and the SE of the estimates. Significance level was set at  $p \leq 0.05$ . For multiple comparisons, post-hoc Bonferroni tests were calculated with the p value adjusted according to subgroup size.

## RESULTS

### Comparison of CHD–healthy controls

Patient characteristics and resilience scores are displayed in table 1. In general, children with CHD exhibit a significant reduction in resilience compared with healthy controls (CHD: 59.0±10.0 vs healthy controls: 64.4±6.5,  $p < 0.001$ ). Further subgroup analysis revealed a significant variation in total

**Table 1** Study population

|                                     | n   | Age, years | Sex, female (%) | RS-11     |
|-------------------------------------|-----|------------|-----------------|-----------|
| CHD all                             | 124 | 14.6±2.1   | 49 (40)         | 59.0±10.0 |
| Healthy controls                    | 124 | 14.8±2.0   | 49 (40)         | 64.4±6.5  |
| Left heart obstruction              | 25  | 15.2±1.9   | 6 (24)          | 64.4±6.8  |
| Right heart obstruction             | 29  | 14.5±2.3   | 12 (41)         | 58.0±10.7 |
| Isolated shunts                     | 27  | 14.3±2.0   | 20 (74)         | 57.1±12.6 |
| Transposition of the great arteries | 17  | 14.2±2.4   | 5 (29)          | 58.4±8.5  |
| Total cavopulmonary connection      | 26  | 14.6±2.1   | 6 (23)          | 57.3±8.7  |

Data presented as mean±SD (%).  
RS-11 is rated on a scale of 11–77, with higher values indicating higher resilience.  
CHD, congenital heart disease; RS-11, Resilience Scale-11.

resilience score based on CHD diagnosis and severity (both  $p < 0.001$ ). Post-hoc analysis indicated that both simple and complex CHD demonstrated significantly lower total resilience scores compared with healthy controls, as shown in figure 1. Patients with right heart obstruction (n=29,  $p = 0.003$ ), isolated shunts (n=27,  $p = 0.001$ ) and total cavopulmonary connection (n=26,  $p = 0.002$ ) showed significantly reduced resilience compared with healthy controls (n=124). There was no significant difference in resilience compared with healthy controls in patients with left heart obstruction (n=25,  $p = 0.99$ ) and patients with TGA (n=17,  $p = 0.065$ ; see figure 2). No differences were observed in relation to surgical status (native: 59.5±12.2 vs surgical: 58.8±9.3,  $p = 0.758$ ).

## DISCUSSION

Our analysis is the first evaluation of resilience in paediatric patients with CHD compared with healthy controls. Children with CHD showed diminished resilience compared with their healthy counterparts, particularly those with more complex heart defects. Furthermore, the specific diagnosis seems to affect resilience in this cohort.

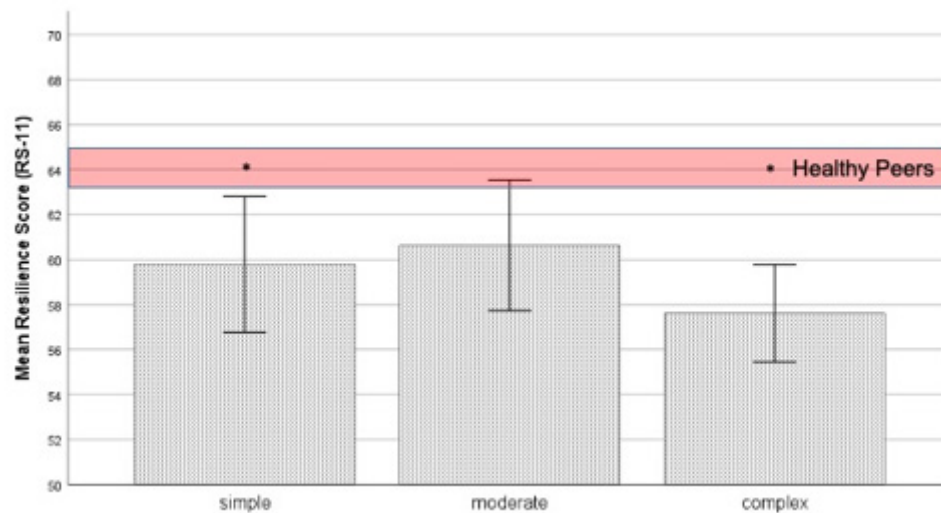
### Resilience in children with CHD

Resilience is a complex, multifactorial concept to analyse and is closely related to environmental and economic factors as well as past life experiences.<sup>9</sup> While there has been considerable research examining the relationship between sense of coherence and HrQoL in patients with CHD,<sup>16-19</sup> exploration of resilience in patients with CHD remains relatively unexplored.

Norm data on resilience measured by the RS-11 in healthy children were published by Kocalevent and colleagues in different age groups in 2015. Resilience value in the age group 14–24 was 60.4±10.8.<sup>13</sup> However, the results are not directly comparable with our CHD cohort. Therefore, we collected data from healthy control subjects in which both groups were examined at the time of COVID-19 and are therefore more comparable.

A previous study has shown that adolescents with CHD have better resilience than adolescent blood cancer survivors.<sup>20</sup> As CHD is a paediatric disease that, compared with cancer survivors, can be treated right after birth, knowledge of the positive and negative sides of their disease helps patients to cope better with adverse conditions such as surgeries and hospitalisation.<sup>20 21</sup>

Resilience is also affected by parental rearing behaviour. Mental health of parents has been shown to be a crucial factor of HrQoL in children with CHD.<sup>22</sup> Moon and colleagues indicated lower resilience in adolescents with CHD who were either over-protected, rejected, controlled or punished.<sup>8</sup>

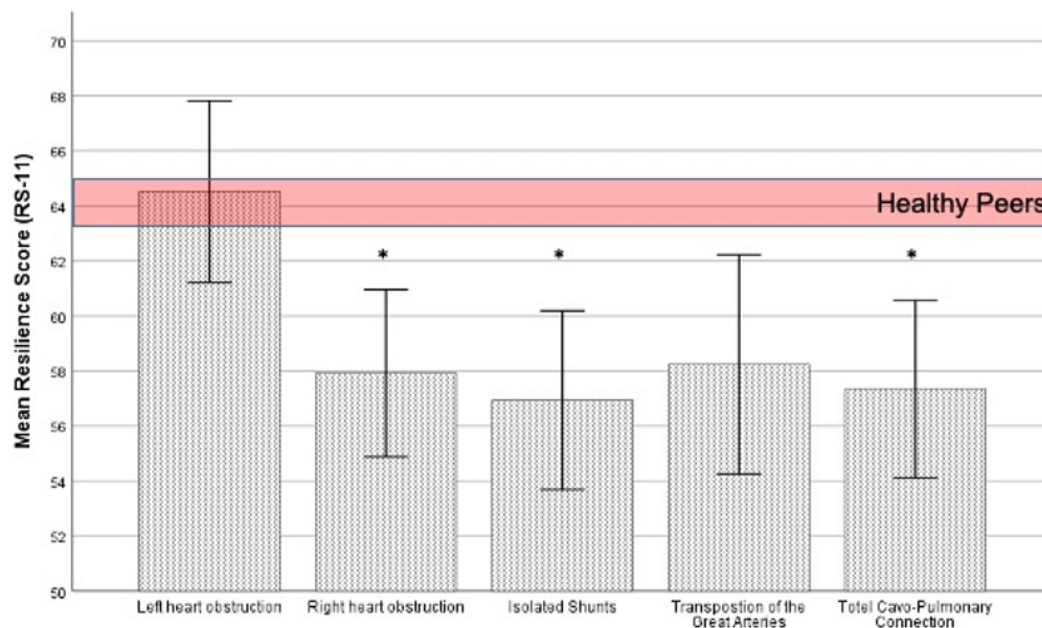


**Figure 1** Comparison of total Resilience Scale (RS)-11 score according to congenital heart disease severity classes with healthy peers corrected for age and sex. RS-11 is rated on a scale of 11–77, with higher values indicating higher resilience. The graph shows the estimated mean and the SE of the estimates of the severity classes. The red area characterises the reference range of the healthy peers. \*Significant  $p < 0.017$  adjusted for multiple testing.

This study represents the first attempt to assess the influence of disease severity on resilience among children with CHD, revealing that those with complex CHDs exhibited lower resilience scores. Similar results were also reported on HrQoL in children with CHD. Specifically, children with cyanotic cardiac disease and complex diseases experienced poorer psychological well-being, which was associated with a higher number of hospital admissions and cardiac surgeries.<sup>23</sup>

In terms of CHD subgroups, this study revealed diminished resilience in patients with right heart obstruction, isolated shunts and total cavopulmonary connection compared with healthy controls, whereas patients with left heart obstruction and TGA

exhibited resilience levels similar to those of healthy controls. Given the limited existing knowledge in resilience among CHD subgroups, results were also compared with studies investigating HrQoL and psychological functioning, as a strong relationship has been reported. Our findings align with a study from DeMaso and colleagues from 2014, which reported favourable resilience in adolescents with TGA, despite noting reduced psychological functioning and attention deficits in these patients.<sup>24</sup> Frigiola and colleagues reported similar HrQoL levels to healthy controls in children after repaired tetralogy of Fallot,<sup>7</sup> classified as right heart obstruction in our study, but our findings indicated diminished resilience in this group. Similar patterns were observed



**Figure 2** Comparison of total Resilience Scale (RS)-11 score according to congenital heart disease subgroups with healthy peers corrected for age and sex. RS-11 is rated on a scale of 11–77, with higher values indicating higher resilience. The graph shows the estimated mean and the SE of the estimates of the subgroups. The red area characterises the reference range of the healthy peers. \*Significant  $p < 0.010$  adjusted for multiple testing.

in patients with ventricular septal defects, classified as isolated shunts in this study, who exhibited relatively normal psychological traits compared with healthy controls in a previous study,<sup>25</sup> but showed reduced resilience in our investigation. Interestingly, patients with isolated shunts showed the lowest resilience compared with other CHD diagnoses. Underlying reasons are not yet understood and need further investigation. Overall, it is essential to explore differences in resilience among CHD subgroups, as well as identify underlying causes in further studies to ensure optimal aftercare for patients.

### Resilience in times of COVID-19

The underlying survey of this study was carried out in June 2020 while the SARS-CoV-2 epidemic kept the world in suspense. Chronically ill patients generally have a higher risk of infection, which is why they are also at higher risk of developing a more severe COVID-19 infection, possibly associated with cardiac involvement.<sup>26 27</sup> Thus, the fear of an infection in this cohort might have been higher. In a qualitative thematic analysis in the form of semistructured interviews conducted from July 2020 to August 2021, Steiner and colleagues reported an increase in stress and health-related anxiety or depression among adults with CHD.<sup>28</sup> Children with chronic illness are known to be more likely to develop psychosocial problems in such pandemic situations.<sup>29</sup> Furthermore, the resilience of parents plays a crucial role in shaping the resilience behaviour of their children.<sup>30</sup> Resilience is not, as previously thought, innate, but develops dynamically through the interaction of individuals and their environment and is thus not constant, but changes over time. As it is dependent on experience and events, the COVID-19 pandemic, with its associated constraints, may have affected the resilience of a large proportion of the population.<sup>31</sup>

### Clinical implication

Disease knowledge is likely to translate to the belief that a patient can control their health condition, an internal health locus of control.<sup>20</sup> As a result, meaningfulness and manageability are not only key concepts of resilience,<sup>2</sup> but can also serve as psychosocial protective factors as the medical experience of a patient with complex CHD shows.<sup>21</sup> Patient education should therefore be a centrepiece in the medical and psychological aftercare in patients with CHD.

Also, psychiatric illnesses, such as depression or mood and anxiety disorders, are increased in adult patients with CHD,<sup>32 33</sup> during the COVID-19 pandemic.<sup>28</sup> Primary caregivers need to increasingly take into account the psychological needs of patients and families impacted by CHD. In response, it has been shown that interventions can improve resilience in patients with complex CHD.<sup>10</sup> Patients with CHD rely on lifelong routine medical care where cardiac and psychosocial demands need to go hand in hand.<sup>27</sup> In the end, patients with CHD are more than just a heart with a defect, but humans with their own worries and fears.<sup>21</sup>

### Limitations

At our outpatient clinic, we primarily attend to patients requiring specialised medical aftercare, predominantly those with moderate and complex CHD. However, it is important to acknowledge that this patient population may not be fully representative of the general CHD population, which is largely composed of individuals with milder severity. Our analysis would have further benefited from additional anthropometric information as well as demographics, such as socioeconomic and

psychosocial background. Although previous studies reported a strong relationship between resilience, HrQoL and mental health, this study did not include data on these topics. This should definitely be considered in future studies. Further investigations might also indicate differences in resilience between CHD subgroups. Furthermore, we did not take into account the parental point of view, which might have given additional information and not only the intrinsic view.

### CONCLUSION

Children with CHD showed reduced resilience compared with healthy peers, particularly in patients with complex CHD. Future prevention programmes should not only focus on physical activity promotion, but also on psychological aftercare. These findings emphasise the ongoing necessity for a comprehensive and multidisciplinary approach in the medical follow-up care of these patients and their families.

**Collaborators** Shared authorship with author no 2 Laura Willinger.

**Contributors** JM was responsible for conception and design of the study and for data monitoring and integrity and was the guarantor of this study. KK, LB and LW sampled the data. KK, LW and JM analysed the data and drafted the manuscript. RO and PE supported in acquisition of the patients, and gave important input for revising and improving the quality of the manuscript. All authors have read and approved the final version of the manuscript.

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**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** This study involves human participants. Written informed consent was obtained from participants and their parents or legal guardians after providing them with the study protocol. The study was conducted in accordance with the Declaration of Helsinki (revised 2008) and approved by the local ethical board of the Technical University of Munich (project number: 314/14).

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**Data availability statement** Data are available upon reasonable request. Data are available upon reasonable request from the corresponding author.

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### ORCID iDs

Katharina Köble <http://orcid.org/0000-0002-4113-8773>

Laura Willinger <http://orcid.org/0000-0002-8577-4480>

Leon Brudy <http://orcid.org/0000-0001-8700-3324>

Jan Müller <http://orcid.org/0000-0002-7530-2025>

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