

Review Article

Quality of life in adolescents and young adults with CHD is not reduced: a systematic review and meta-analysis

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Abstract *Purpose:* We performed a systematic review and meta-analysis of observational studies assessing quality of life in adolescents and young adults born with CHD compared with age-matched controls. *Methods:* We carried out a systematic search of the literature published in Medline, Embase, PsychINFO, and the Cochrane Library's Database (1990–2013); two authors independently extracted data from the included studies. We used the Newcastle–Ottawa scale for quality assessment of studies. A random effects meta-analysis model was used. Heterogeneity was assessed using the I^2 -test. *Results:* We included 18 studies with 1786 patients. The studies were of acceptable-to-good quality. The meta-analysis of six studies on quality of life showed no significant difference – mean difference: -1.31 ; 95% confidence intervals: -6.51 to $+3.89$, $I^2 = 90.9\%$ – between adolescents and young adults with CHD and controls. Similar results were found in 10 studies not eligible for the meta-analysis. In subdomains, it seems that patients had reduced physical quality of life; however, social functioning was comparable or better compared with controls. *Conclusion:* For the first time in a meta-analysis, we have shown that quality of life in adolescents and young adults with CHD is not reduced when compared with age-matched controls.

Keywords: CHD; quality of life; adolescents; young adults; outcome

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NEARLY 1% OF ALL CHILDREN ARE BORN WITH CHD.¹ Improved treatment for CHD over the past few decades has dramatically decreased the morbidity and mortality for these patients.^{2–4} As a result of this, ~85–90% of children with CHD currently survive to adulthood.^{5–7} The population of surviving patients with CHD is, thus, increasing by 5%/year. Should this trend continue, there will be more adults than children living with CHD 10 years from now.^{6,8,9}

In examining long-term outcomes in children born with CHD, there has been an increasing focus

on quality of life as a supplement to other outcome measures such as morbidity, mortality, and para-clinical and physiological measures.^{10–12} Quality of life is a multidimensional tool assessing an individual's physical, mental/emotional, and social functioning,¹³ thereby encompassing dimensions that biomedical outcome measures do not.¹⁴

Earlier reviews assessing quality of life in adolescents and young adults with CHD concluded that quality of life was reduced compared with healthy peers.^{15,16} In this review, we have identified several studies not previously included in reviews, thus providing a more up-to-date assessment. Furthermore, this is the first time that a meta-analysis assessing quality of life in adolescents and young adults with CHD compared with age-matched controls has been carried out.

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Materials and methods

This systematic review and meta-analysis was performed with guidance from the Cochrane Handbook of Systematic Reviews,¹⁷ the PRISMA guidelines for meta-analysis and systematic reviews,¹⁸ and the MOOSE guidelines for meta-analyses of observational studies¹⁹ (see Supplementary table 1). Before initiating the study process, the study protocol was registered in the PROSPERO database for systematic reviews (registration number CRD42013005699) (see Supplementary table 2).

Data sources and search strategies

In accordance with recommendations,²⁰ we made a preliminary protocol with a pilot study as the first step. This allowed us to make the appropriate corrections to the study design and search strategy for the final study protocol.

In September, 2013, we conducted searches in the following electronic databases with the help of an experienced health science librarian: Medline, Embase, PsychINFO, and the Cochrane Central Register of Controlled Trials. Furthermore, we manually examined reference lists from all the selected articles and reviews to identify additional studies.

For this review, two independent researchers – M.S. and senior researchers G.T./K.B./J.B./J.R. – performed study and data collection individually. Search citations were screened based on the title and abstracts, and finally the full text was reviewed. Researchers settled disagreements by discussion until consensus. We used medical keywords as well as subject headings and text word combinations for the search. The study flow chart is displayed in Figure 1. An example of a full search string is given in Supplementary file 3.

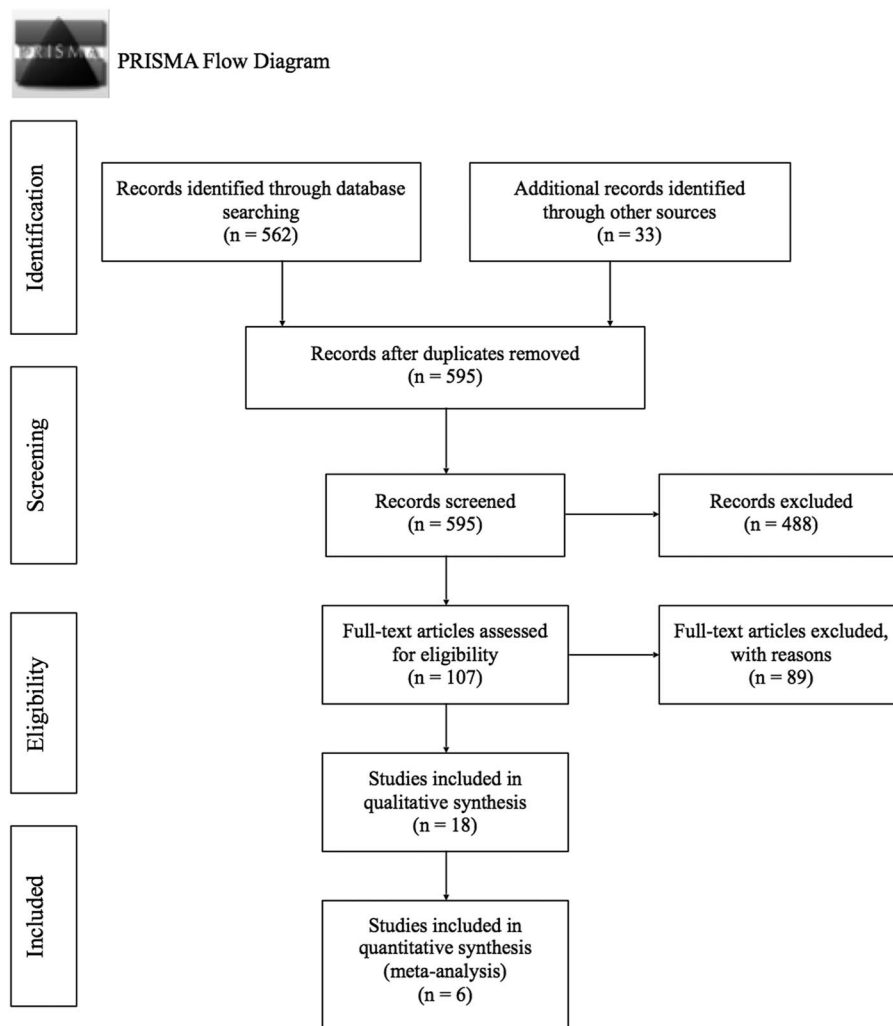


Figure 1.
Study flow selection diagram.

Study eligibility

In the systematic review, we included all quantitative studies that assessed quality of life in adolescents (12–18 years) and/or young adults (19–30 years) with CHD. Acquired heart disease and heart disease associated with genetic disorders were not included. Disease severity was categorised as mild, moderate, or severe according to the classification of Warnes et al²¹ For inclusion in the meta-analysis, studies had to present a quantitative assessment of quality of life preferably on a scale from 0 to 100 with higher scores indicating better quality of life.

Studies were included if >50% of the patients were between 12 and 30 years of age. We also included studies if it was possible to use subgroup data from this specific age group regardless of mean age.

The comparison groups in eligible studies had to consist of healthy age-matched controls from the background population. Studies were also included if they compared outcomes between groups with different types of CHD or if they compared patients with test norms from the background population. Studies were not included if no control group or comparative data were reported.

In studies assessing surgical patients with CHD, we included studies where patients had undergone surgery from 1990 to 2013. This period was chosen because we wanted to assess the current patient population and to ensure that time-dependent advances in surgical treatments were minimised.^{2–4}

We excluded studies with parent and proxy reports, because several studies have shown that parent and proxy reports yield different results^{15,22,23} and because we believe that young people should and could answer for themselves. All the eligibility criteria are listed in Table 1.

Quality assessment of included studies

The Newcastle–Ottawa scale was moderated to fit our study design and served to assess the quality of the eligible studies.^{17,24} The Newcastle–Ottawa scale scores each study by assigning 0 to 9 stars and assesses the studies in three domains – selection of patients and controls, comparability between groups, and outcome and follow-up; 0 to 3 stars indicate poor study quality, 4 to 6 stars indicate acceptable study quality, and 7 to 9 stars indicate good study quality.

Statistical analysis

For the meta-analysis, a forest plot was calculated using weighted scores and a random effects model. We chose the random effects model over the fixed effects model because it accounts for the variations between studies,²⁵ which we expected due to inclusion of different types of CHDs. Standardised mean difference was used in the meta-analysis for combining continuous data as we expected different scores to assess quality of life. The degree of heterogeneity across studies was determined using the I^2 -test, with I^2 values of 25 or less, 50, and 75% or greater representing low, moderate, and high inconsistency, respectively; $p < 0.05$ was considered to be statistically significant. All the statistical calculations were performed with the assistance of a statistician using R Statistical and Programming Software (version 2.9.0.) (R Foundation for Statistical Computing, Vienna, Austria).

Results

We identified 562 unique articles (see Fig 1). Of these, 18 studies ($n = 1746$ patients) met the eligibility

Table 1. Eligibility criteria.

	Inclusion criteria	Exclusion criteria
Diagnosis	All types of CHDs	Acquired heart defects and heart defects associated with genetic disorders
Age	>50% adolescents (12–18 years) and/or young adults (19–30 years)	50% or more <12 years and/or >30 years
Time of surgery	>50% underwent surgery from 1990 to 2013	<50% underwent surgery before 1990
Study design	RCTs, case–control, cohort, and cross-sectional with quantitative outcomes	Editorials, comments, qualitative studies, annual reports, systematic reviews
QOL-tool/measurement	Use of a validated, quantitative QOL-tool, and/or questionnaire devised for the study. Self-report for QOL	Parent/proxy-report for QOL
Comparison group	Comparison with a healthy control group, other severity/disease group, or normative data	No comparative data provided
Languages	English, Danish, Norwegian, Swedish	Languages other than English, Danish, Norwegian, Swedish
Text format	Abstract and full-text available	Abstract and full-text not available

QOL = quality of life; RCT = randomised controlled trial

criteria,^{23,26–42} and six studies (n = 328 patients) were pooled in the meta-analysis.^{27,30,31,39–41} All the included studies were cross-sectional studies (n = 14) or retrospective cohort studies (n = 4). The included studies encompassed mild, moderate, or severe forms of CHD. Characteristics of the included studies are displayed in Table 2.

The mean Newcastle–Ottawa Score was 6.8 (range from four to eight) corresponding to acceptable study quality (see Table 2). The detailed scoring for each study is displayed in Supplementary table 4.

All six studies included in the meta-analysis used validated tools that assessed quality of life on a scale of 0 to 100 with higher scores indicating better quality of life. Table 3 displays the different tools for assessing quality of life.

The meta-analysis showed no significant difference in quality of life between adolescents and young adults with CHD and age-matched controls. Standardised mean difference in average scores for quality of life between the two groups was -1.31 with 95% confidence intervals: -6.51 to $+3.89$. Heterogeneity (I^2) was 90.9%, indicating a high degree of inconsistency (see Fig 2).

Of the six studies included in the meta-analysis (n = 328 patients), three studies assessed a mixed population of patients,^{39–41} whereas the other three studies assessed a smaller group of patients with specific forms of CHD.^{27,30,31} Mild, moderate, and severe forms of CHD were represented in the meta-analysis, and interestingly the three studies encompassing severe CHDs^{39–41} were found on both sides of the mean difference (Fig 2).

Meta-analyses could only be performed on sum scores for quality of life. It was not possible to perform a meta-analysis on subdomain scores due to large heterogeneity in reporting styles.

A total of 12 studies were not included in the meta-analysis because they lacked sufficient data, and therefore could not meaningfully be pooled with the other studies in the meta-analysis. Examples include insufficient reporting of quantitative raw data^{32,35} and use of alternative quality-of-life scales.^{34,38} All 12 studies were cross-sectional studies or retrospective cohort studies that used validated tools based on self-reporting to assess quality of life. The 12 studies covered the whole spectrum of CHD from mild to severe forms, including both surgically corrected anomalies and anomalies that did not require surgical intervention. See Table 2 for details of the included studies.

A total of 8 out of 12 studies concluded that quality of life in adolescents and young adults with CHD was comparable with age-matched controls,^{26,28,29,32,34,36,38,42} two other studies reported that quality of life was comparable or better

in adolescents and young adults with CHD.^{23,33} In contrast to these findings, one study reported that quality of life in adolescents and young adults with CHD was reduced compared with age-matched controls.³⁵

A total of seven studies reported that the severity of CHD was negatively associated with quality of life.^{26,28,32–34,37,42} In contrast to this, four studies reported that the severity of CHD did not have an impact on quality of life.^{23,38,40,41}

No studies specifically compared quality of life between adolescents (12–18 years) and young adults (>18 years), and adequate subgroup analyses were not possible due to heterogeneity in the study design. In nine studies encompassing adolescents, seven studies^{23,26,27,31,32,38,39} found better or comparable quality of life, whereas two studies^{35,41} found worse quality of life. In six studies encompassing young adults, the numbers were five^{29,33,36,40,42} and one,³⁰ respectively.

When looking at the different domains of quality of life, four studies^{30,35,36,40} reported that CHD affected physical domains, for example, resulting in diminished physical activity.³⁰ In contrast to these findings, two studies reported that there was no association between exercise capacity and quality of life.^{27,33}

Social functioning in adolescents and young adults with CHD was comparable with or was even better compared with age-matched controls in five studies.^{32,34,35,39,40} In accordance with this, two studies highlighted that social support plays a positive and important role for the overall quality of life.^{34,40}

A total of four studies reported that high scores of quality of life were positively associated with higher achievement in the educational system and higher levels of education in adolescents and young adults with CHD.^{28,39,40,43}

Discussion

In the present meta-analysis, we found that quality of life in adolescents and young adults born with CHD is not reduced compared with healthy age-matched controls. To our knowledge, this is the first time that a meta-analysis assessing quality of life in adolescents and young adults has been carried out. We found it clinically meaningful and relevant to pool the six selected studies in the meta-analysis, because these studies included similar age groups, similar types of CHDs, and used a validated quality-of-life tool with identical or similar scales to assess quality of life. Owing to heterogeneity in study design and reporting methods, further quantitative subgroup analyses were not possible; however, we found that studies

Table 2. Characteristics of studies included in systematic review and meta-analyses.

Reference, country (year)	Study design	Description of study population	Disease severity	Age (mean and/or age interval)	Description of controls	Quality-of-life tool	Tabular narrative	Newcastle-Ottawa scale
Tahirović et al, ³⁹ Bosnia Herzegovina (2011)	Cross-sectional	32 patients with mixed types of CHD	Mild, moderate, severe	13–18 years	32 age-matched controls	Pediatric Quality of Life Inventory 4.0	QOL was significantly better compared with controls	7
Teixeira et al, ⁴⁰ Portugal (2011)	Cross-sectional	74 patients with mixed types of CHD	Mild, moderate, severe	18.7 (12–26 years)	Portuguese background population	WHOQOL-BREF	QOL was better compared with controls but not significantly better	7
Spijkerboer et al, ²⁵ Netherlands (2008)	Cross-sectional	84 patients with mixed types of CHD	Mild, moderate, severe	11–17 years	731 age-matched controls	Youth Self-Report modeled after the Child Behavior Checklist	QOL was similar or better compared with controls	7
Kwon et al, ³¹ United States of America (2011)	Cross-sectional	20 patients with Fallot	Severe	12.4 (8.4–18.7 years)	401 controls	Pediatric Quality of Life Inventory 4	QOL was similar compared with controls	6
Brothers et al, ²⁷ United States of America (2009)	Cross-sectional	25 patients with surgical repair of anomalous aortic origin of a coronary artery	Mild, moderate	12.5 (approximately)	963 age-matched children	Pediatric Quality of Life Inventory 4	QOL was similar compared with controls	6
Spijkerboer et al, ³⁸ Netherlands (2006)	Historical cohort	55 patients with mixed types of surgically corrected CHD	Mild, moderate, severe	12–15 years	1246 age-matched controls	TACQOL	QOL was generally similar compared with controls	6
D'Ukedem et al, ²⁹ Australia (2009)	Cohort	36 patients with single-ventricle CHD	Severe	21.6	Age-matched controls from Dutch SF-36 study	Short Form 36	QOL was generally similar compared with controls	6
Berkes et al, ²⁶ Hungary (2010)	Cross-sectional	63 patients with invasive treatment for CHD	Mild, moderate, severe	13–18 years	100 age-matched controls from the background population	Pediatric Quality of Life Inventory	QOL was generally similar compared with controls	7
Pike et al, ³⁶ United States of America (2012)	Cross-sectional	54 patients with single-ventricle (Fontan operation)	Severe	Mean 26 (15–50 years)	66 age-matched controls	Short Form 36 and Satisfaction with Life Scale	QOL was generally similar to controls	7
Overgaard et al, ⁴² Denmark (2011)	Cross-sectional	62 patients with surgically corrected single-ventricle	Severe	22 (18–20 years)	172 age-matched controls	Short Form 36 and Linear Analog Scale	QOL was generally similar to controls. More severe CHD was associated with worse QOL	7

Table 2. *Continued*

Reference, country (year)	Study design	Description of study population	Disease severity	Age (mean and/or age interval)	Description of controls	Quality-of-life tool	Tabular narrative	Newcastle-Ottawa scale
Loup et al, ³³ Switzerland (2009)	Cross-sectional	152 patients with VSD, Fallot, and transposition of the great arteries	Severe	26 (15–37)	Age-matched controls from Swiss SF-36 study	Short Form 36	QOL was similar or better compared with controls	7
Larsen et al, ³² Denmark (2010)	Cross-sectional	239 patients with mixed types of surgically corrected CHD	Mild, moderate, severe	13.1	288 age-matched controls	Generic Child Health Questionnaire	Functional health was similar compared with controls	7
Gierat-Haponiuk et al, ³⁰ Poland (2011)	Cross-sectional	30 patients with surgically corrected VSD- and ASD-shunts	Mild, moderate	24.6 (18–36)	30 age-matched controls	EuroQoL 5	QOL was worse compared with controls	7
Manilhot et al, ³⁵ Canada (2009)	Cross-sectional	68 patients surgically corrected for single-ventricle (Fontan operation)	Severe	13 (10–20)	37 healthy siblings	Pediatric Quality of Life Inventory	QOL was worse compared with controls	6
Uzark et al, ⁴¹ United States of America (2008)	Cohort	140 patients with mixed types of CHD	Mild, moderate, severe	13–18	1060 age-matched controls	Pediatric Quality of Life Inventory 4.0	QOL was worse compared with controls	8
Luyckx et al, ³⁴ Belgium (2012)	Cohort	398 patients with mixed types of CHD	Mild, moderate, severe	14.7 (14–18)	The same 398 patients after 9 months	Linear Analog Scale	More severe CHD was associated with worse QOL	8
Simko et al, ³⁷ United States of America (2005)	Cross-sectional	124 patients with mixed types of CHD	Mild, moderate, severe	26	Same 124 patients – comparison between the different types of CHD	Sickness Impact Profile	More severe CHD was associated with worse QOL	7
Cohen et al, ²⁸ Israel (2007)	Cross-sectional	90 patients with mixed types of CHD	Mild, moderate, severe	15 (12–18)	87 age-matched controls	TAAQOL-CHD	More severe CHD was associated with worse QOL	7

ASD = atrial septal defect; QOL = quality of life; VSD = ventricular septal defect

Table 3. Characteristics and selected raw data of studies included in meta-analyses.

Reference, country (year)	Description of study population	Disease severity	Age (mean and/or age interval)	Quality-of-life tool	Newcastle-Ottawa scale	Number of patients (a)	Mean QOL patients (b)	SD patients (c)	Number of controls (d)	Mean QOL controls (e)	SD controls (f)
1 Uzark et al, ⁴¹ United States of America (2008)	Mixed types of CHD	Mild, moderate, severe	13–18	Pediatric Quality of Life	8	140	80.88	13.51	1060	85.49	12.04
2 Brothers et al, ²⁷ United States of America (2009)	Patients with surgically repaired anomalous aortic origin of a coronary artery	Mild, moderate	12.5 (approximately)	Inventory 4 Pediatric Quality of Life Inventory 4	6	25	84.9	12.6	963	83	14.8
3 Gierat-Haponiuk et al, ³⁰ Poland (2011)	Repaired ASD and VSD	Mild, moderate	24.6 (18–36)	Pediatric Quality of Life	7	30	79	9.1	30	88.5	9.6
4 Kwon et al, ³¹ United States of America (2011)	Patients with Fallot	Severe	12.4 (8.4–18.7 years)	Inventory 4 Pediatric Quality of Life	6	20	85.3	13.1	401	83	14.8
5 Tahirović et al, ³⁹ Bosnia Herzegovina (2011)	Mixed types of CHD	Mild, moderate, severe	13–18 years	Inventory 4 Pediatric Quality of Life	7	39	89.4	12.4	32	83.9	14.6
6 Teixeira et al, ⁴⁰ Portugal (2011)	Mixed types of CHD	Mild, moderate, severe	18.7 (12–26 years)	Inventory 4 WHOQOL-BREF	7	74	72.47	15.89	315	71.51	13.3

ASD = atrial septal defect; QOL = quality of life; VSD = ventricular septal defect

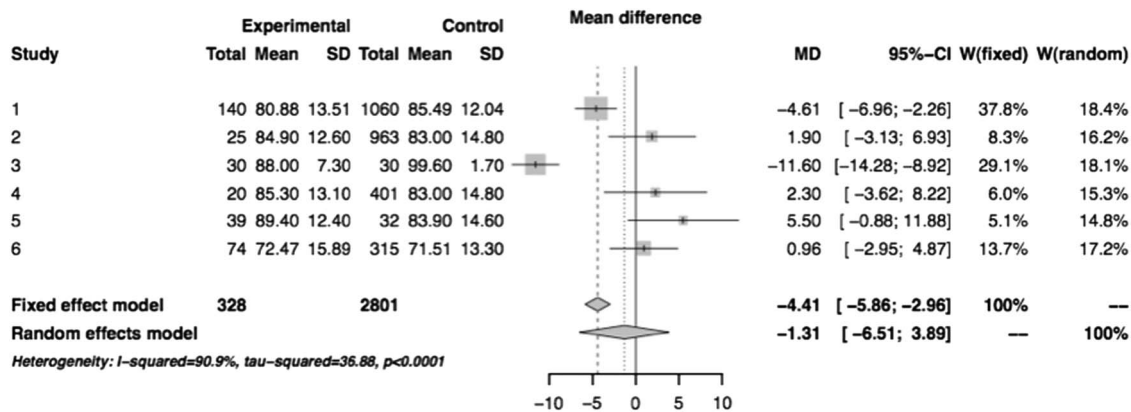


Figure 2.

Forest plot of quality of life in adolescents and young adults compared with age-matched controls. Each horizontal line represents a study and the raw data of each study are displayed. In the graph, each study is represented by a box whose size correlates to the weight of the study, whereas the line through the box represents the 95% confidence intervals. Studies located on the left side of the mean difference line report worse quality of life in patients versus controls, whereas studies on the right side of the mean difference line report better quality of life in patients. The diamond at the bottom of the graph is the meta-analytic summary that shows no significant difference in quality of life between patients and controls as the confidence intervals cross the mean difference line. Study 1: Uzark *et al.*,⁴¹ United States of America (2008); Study 2: Brothers *et al.*,²⁷ United States of America (2009); Study 3: Gierat-Haponiuk *et al.*,³⁰ Poland (2011); Study 4: Kwon *et al.*,³¹ United States of America (2011); Study 5: Tahirović *et al.*,³⁹ Bosnia Herzegovina (2011); Study 6: Teixeira *et al.*,⁴⁰ Portugal (2011).

encompassing severe CHDs were found on both sides of the mean difference in the forest plot, indicating that severe CHD is not necessarily associated with worse quality of life.

The result from the meta-analysis is supported by similar findings in the systematic review of the remaining 12 studies, where 10 out of 12 studies reported that quality of life in adolescents and young adults with CHD was similar or better compared with age-matched controls. In contrast, only 1 out of the 12 studies reported that quality of life in adolescents and young adults with CHD was worse. We found no difference in quality of life when comparing adolescents and young adults with CHD.

When looking at the studies that found worse quality of life in patients with CHD, an explanation for these findings may be reduced physical activity compared with controls based on the conviction of having some sort of undefined disability.³⁰ This may be caused by being treated as handicapped/ill by their family and the society.^{30,41} Living with the conviction of having some sort of disability and being treated like an ill/handicapped person by the society might also explain a general feeling of insufficiency.^{30,41} There may be a small subgroup of patients with severe heart disease, and thus impaired level of functioning and/or quality of life – for example, young patients in palliative care.

When looking at the subdomains of quality of life, we found that a majority of studies reported that patients with CHD had worse quality of life in the physical domains compared with controls. On the other hand, a majority of studies found that

adolescents and young adults with CHD had comparable or even better social functioning compared with age-matched controls.

Strengths and weaknesses

Our study includes an exhaustive and reproducible search strategy according to a registered protocol. In addition, the included studies comprised all types of CHDs and covered studies from a geographically large area, thereby making the results relevant for a mixed, general population of adolescents and adults with CHD. Finally, the present review included several studies published within the last few years, thus providing an up-to-date long-term assessment of quality of life in adolescents and young adults with CHD.

There are several limitations to our analysis. The overall estimate of the meta-analysis should be interpreted with caution, as the total number of included studies in the meta-analysis was relatively small and the degree of heterogeneity was high. In addition, the heterogeneity between studies may complicate direct comparisons across studies; however, we believe that our eligibility criteria resulted in a group of selected studies that in many ways were comparable, also seen from a clinical point of view. Another limitation was that almost all the studies were cross-sectional studies, ranking in the lower end of the evidence hierarchy; however, to our knowledge, no additional cohort or case-control studies currently exist in this field. The meta-analysis included studies using scales from 0 to 100. Therefore, some studies

were not included in the quantitative analysis but were only included in the systematic review. Finally, the average quality of the included studies was acceptable when rated based on the Newcastle–Ottawa scale; however, there exists no official threshold for distinguishing between poor-, acceptable-, and good-quality studies.

Interestingly, our results are contradictory to previous reviews that reported a reduced quality of life in adolescents and young adults with CHD compared with age-matched peers.^{15,16} In comparison with the findings of Dahan-Oliel et al,¹⁶ the reason for our contradictory results may be that Dahan-Oliel et al¹⁶ included studies with patients who had undergone surgery before 1990. Thus, the surgery and the postoperative care might not meet today's standards and might result in a reduced long-term outcome reflected in the domains of quality of life.^{2–4} Latal et al¹⁵ only included patients who had undergone open-heart surgery with the expectation of more patients in the severe disease category. In contrast, we included mild, moderate, and severe types of CHD. Moreover, our study included 12 studies published between 2008 and 2013 that were not available to Latal et al¹⁵ who conducted their review in 2008. Finally, Latal et al¹⁵ allowed both self-reporting and proxy reporting for quality of life, whereas we included only studies with self-reporting of quality of life. In comparison with the findings in the systematic review by Fteropoulli et al,⁴⁴ we found similar results, as Fteropoulli et al concluded that the quality of life of adult CHD patients is compromised in the physical domain compared with their healthy counterparts. In contrast to this – and again in accordance with our findings – no differences were found in relation to the psychosocial and environmental/occupational domains.

An explanation for our somewhat surprising and counter-intuitive finding has been previously investigated in other studies,^{9,45} finding three possible coping mechanisms: “The disability paradox”⁴⁶ referring to the idea that people living with a chronic condition may experience good quality of life if they accept their impairment; “Sense of coherence”, which can positively affect an individual's perception of quality of life by feelings of high comprehensibility, manageability, and meaningfulness;⁴⁷ and “Response shift”, which is the change in the meaning of one's self-evaluation as a result of a change in internal standards and values.⁴⁸ Another explanation for our results is a possible under-representation of severe CHD in the meta-analysis, where four of the six studies predominantly included mild-to-moderate CHDs; however, these studies also included severe CHDs, whereas one other study included severe CHD only. In terms of generalisability of our results, it is

important to stress that mild-to-moderate CHD is far more common than severe CHD.

Most likely, a smaller group of patients with severe forms of CHD will have impaired quality of life in adolescence and adulthood; however, some of these patients may still have a better quality of life than that previously considered. Therefore, the present review can assist physicians in giving a more up-to-date view regarding the future when counselling patients and their parents.

When comparing our results with previous reviews,^{15,16,44} we believe that there is a tendency towards improving quality of life in adolescents and adults with CHD over the last few decades; however, continuous follow-up and vigorous efforts should be made to further improve the quality of life for these patients, especially in the physical domains of quality of life, where the adolescents and adults with CHD scored lower than age-matched controls. Lower physical quality of life has definite health implications. It is, therefore, of great importance to promote physical activity in this population, especially to promote a healthy lifestyle during adulthood. In addition, previous studies have found that quality of life is positively correlated with a low level of anxiety and depression, a good knowledge of the cardiac condition, adequate social support, and a strong sense of coherence.⁴⁹ Furthermore, it has previously been stressed that participation in age-expected activities such as education, having a job, participating in recreational and social activities, developing intimate relationships, and living independently are important supplemental measures of how this group of patients is doing.^{50,51} It is, therefore, highly important that comprehensive transitional programmes are developed and implemented addressing these issues. Hopefully, the upcoming results from the APPROACH-IS study can help shed light over these important issues.⁵²

For the first time in a meta-analysis, we have shown that quality of life in adolescents and young adults with CHD is not reduced when compared with age-matched controls. The findings in the qualitative assessment where the majority of studies reported that quality of life in adolescents and young adults living with CHD was comparable with age-matched controls support this result. In subdomains, it seems that patients had reduced physical quality of life; however, social functioning was comparable or better compared with controls.

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Conflicts of Interest

None of the authors have any potential, perceived, or real conflicts of interest.

Supplementary materials

To view supplementary material for this article, please visit <http://dx.doi.org/10.1017/S104795111500181X>

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