World Journal of Advanced Research and Reviews
eISSN: 2581-9615 CODEN (USA): WJARAI
Cross Ref DOI: 10.30574/wjarr
Journal homepage: https://wjarr.com/

(REVIEW ARTICLE)

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Quality of life in children with congenital heart disease (CHD): Systematic review

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World Journal of Advanced Research and Reviews, 2023, 17(01), 425–432

Publication history: Received on 04 December 2022; revised on 10 January 2023; accepted on 13 January 2023

Article DOI: https://doi.org/10.30574/wjarr.2023.17.1.0059

Abstract

Congenital Heart Disease (CHD) is the most prevalent birth defect, with an incidence of approximately 8 per 1000 births. Multiple factors that impact the patient's life and quality of life can cause Congenital Heart Disease to become a chronic condition. It is important to assess the quality of life in children with Congenital Heart Disease (CHD) in order to determine whether the child is experiencing quality of life problems and, if so, which aspects are experiencing problems, so that in addition to overcoming the disease, psychosocial impacts and social interactions with other healthy children are avoided. The purpose of this study is to determine the life quality of children with CHD. This study is a systematic review conducted by searching PubMed, Science Direct, Web of Science, and the Cochrane Library. Literature screening was carried out by looking at the predetermined inclusion and exclusion criteria so that 11 literatures were reviewed. Based on the literature study it was reported that the HRQoL scores of children with CHD were at least as good as or comparable to their healthy peers.

Keywords: Quality of life; Health related quality of life; Child; Congenital heart disease; Systematic review

1. Introduction

Congenital Heart Disease is one of the most common congenital abnormalities found in infants and children and is one of the leading causes of death in the first year of life, accounting for 3% of all congenital malformation-related deaths[1]. Congenital heart disease accounts for 30% of all congenital abnormalities. The incidence of congenital heart disease (CHD) ranges from 6 to 10 cases per 1000 live births in both developed and developing countries[2]. Epidemiological data on Congenital Heart Disease in Indonesia are still limited, but it is estimated to have a prevalence of approximately 8 infants per 1000 live births, with an annual increase of 32 000 cases [3].Congenital Heart Disease can become a chronic condition due to several factors that affect the patient's life, such as the duration of the illness, the severity of the symptoms, the patient's reduced level of activity, and the prognosis, all of which impact the patient's quality of life [4]. Due to limited activity or mobility, restrictions on school, play, family, and social activities, and lengthy treatment, children with congenital heart disease are susceptible to experiencing quality-of-life disruptions. Considering the preceding description, it is crucial to evaluate the quality of life of children with CHD. The purpose of this systematic review is to examine the quality of life of children with congenital heart disease (CHD) so that, in addition to overcoming the disease, psychosocial impacts and social interactions with other normal children do not arise.

Purpose

This systematic review aims to determine the quality of life in children with congenital heart disease. Thus, the research question is how is the relationship between quality of life in children and *Congenital Heart Disease* (CHD)?

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2. Material and methods

2.1. Design

This research is secondary research with a systematic review. The selection of selected literature will be reported according to the PRISMA flow guidelines so that the screening process becomes transparent

2.2. Searching the Literature

Literature search in this study was from four different e-databases, namely PubMed, Science Direct, Web of Science and Cochrane Library using relevant keywords.

2.3. Inclusion Criteria

2.3.1. Inclusion Criteria

- Full text literature (in the period 2018-2022)
- Quantitative research results
- English article
- Research describes the quality of life of children with *Congenital Heart Disease*

2.3.2. Exclusion criteria

- Sources come from Non-Research Studies (Conference papers, book chapters, reports)
- Studies in the form of interventional, qualitative, and systematic or literature review studies

2.4. Assessment of Quality

The Effective Public Health Practice Project's Quality Assessment Tool for Quantitative Studies is used to evaluate the quality of the selected literature (EPHPP). This instrument consists of six general evaluation components: selection bias, study design, confounder, blinding, data collection method, withdrawals, and dropouts. After evaluating each component, it is possible to determine that the overall rating for the literature is strong if there are no weak ratings, moderate if there is one weak rating, and weak if there are two or more weak ratings. We extracted the following information for each study: author, title, literature database, journal, year, edition, volume, numbers, setting, research method, study design, participants, variables, instruments, statistical analysis, analysis of results, and research results summary.

2.5. Data Extraction

The process of data preparation involves transferring key information from the selected literature into specific forms/tables to make it easier for researchers to identify literature.

3. Results

3.1. Search Results

This study utilized PubMed, Science Direct, Web of Science, and Cochrane Library to conduct a literature search using pertinent keywords. Initially, this database was searched separately using the Boolean operators " Quality of life " AND " Congenital Heart Disease " AND " Children " OR " Child " OR " Baby " OR " Toddler " OR " Teen " OR " Neonates " to locate literature pertaining to the quality of life of children with CHD. 1150 research articles were obtained through keyword searches. For the process of analyzing the literature in this study, 11 articles that met the inclusion and exclusion criteria were obtained following a screening process. The PRISMA flow chart in figure 1 below shows the search and article selection process.

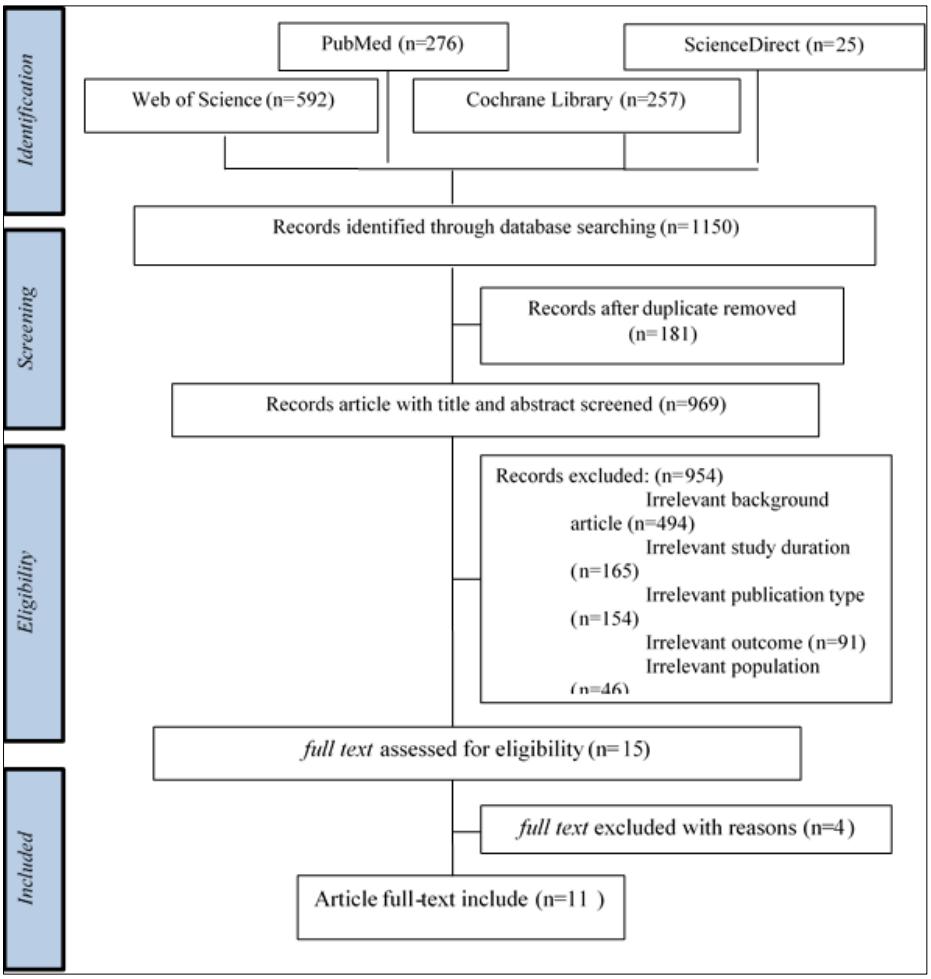

Figure 1 PRISMA Diagram

3.2. Characteristics of the Study

The characteristics of the literature are determined by extracting data from each reviewed piece of literature. There was a total of 4388 participants involved in these studies. The distribution of research areas among the eleven reviewed articles demonstrates that the literature spans numerous regions on the continents of Asia, Europe, and North America. The characteristics of the literature are displayed in Table 1.

Table 1 Data on the characteristics of the literature reviewed

No	Authors	Details
1.	[5](Neil Derridj et al, 2022)	Article title: *Quality of Life Children Born with a Congenital Heart Defect*
		Venue: Greater Paris Area, France
		Study design: Prospective Cohort Study
		Time: 2013-2021
		Number of participants: 598 children with CHD
		Research results: The average total HRQoL score of children with CHD is good. mean total *self-reported* and psychosocial scores were significantly lower in the *no isolated CHD group* compared to *isolated CHD* (73.9 ± 0.4 vs 75.8 ± 0.2 [P < .001] vs 91.9 ± 0 .4 vs 92.3 ± 0.2 [P < .001]), whereas there was no difference for physical scores. The mean total *parent-reported scores* in the physical and psychosocial domains were significantly lower for *non-*

		isolated CHD compared to the *isolated CHD group* (70.9 ± 1.5 vs. 82.7 ± 0.6 [P < 0.001], 76.5 ± 1.9 vs 89.5 ± 0.6 [P < 0.001], and 68.1 ± 1.4 vs 79.1 ± 0.6 [P < .001]
2.	[6](Heye Kristina N et al, 2019)	Article title: *Health-related quality of life in preschool age children with single-ventricular CHD*
		Venue: *Pediatric Heart Centre,* University of Giessen, Germany (Center A). Zurich University Children's Hospital, Switzerland (Center B).
		Study design: Prospective two-center cohort study
		Time: August 2012 and July 2015
		Number of participants: 46 children with single ventricular CHD and biventricular CHD
		Results: Overall, the health-related quality of life of the population was good. Cronbach's indicates that all subscales of the Preschool Pediatric Cardiac Quality of Life Inventory have acceptable to excellent internal consistency: total score: 0.94; physical: 0.85; emotional: 0.70; social: 0.85; therapy: 0.73; and functional: 0.67. Children with single ventricular CHD have a comparable quality of life to those with biventricular CHD.
3.	[7](Karen et al, 2020)	Article title: *Quality of life in children with infrequent congenital heart defects: cohort study with one-year of follow-up*
		Venue: Cardiovascular Referral Center, Bogotá , Colombia
		Study design: cohort study
		Time: August 2016-September 2018
		Number of participants: 112 children with CHD with their parents
		Results: At the early stage, there was no statistically significant difference between children's (median = 74.4, IQR = 64.1–80.4) and parents (median = 68.4, IQR = 59.6–83.7) scores on the generic module (p = 0.296). In contrast, initial cardiac module scores differed significantly between children (median = 79.6, IQR = 69.7–87.4) and parents (median = 73.6, IQR = 62.6–84.3), p = 0.019. At one year of follow-up, scores for the common module did not differ significantly (p = 0.332) between patients (median = 72.8, IQR = 59.2–85.9) and parents (median = 69.9, IQR = 58.5–83.7) Patients (median = 75.0, IQR = 67.1–87.1) had significantly higher cardiac module scores than parents (median = 73.1, IQR = 59.5–83.8), p = 0.034.
4.	[8](Manu Raj et al, 2019)	Article title: *Health-related quality of life (HRQOL) in children and adolescents with congenital heart disease: a cross-sectional survey from South India*
		Venue: Amrita Institute of Medical Sciences and Research Centre, Kochi, Kerala, South India
		Study design: cross-sectional
		Time: January 2013-June 2016
		Number of participants: 308 children with CHD and their parents, 719 healthy children as a control group
		Results: The median (IQR) total generic HRQoL of self-reported for children with CHD was 71.7 (62.0; 84.8) and for the control group 91.3 (87.0; 95.7). The rates reported by parents for CHD and controls were 78.3 (63.0; 90.5) and 92.4 (87.0 ; 95.7). Adjusted median difference were −20.6 (99% CI −24.9 to −16.3, p<0.001) for self-reported and −14.1 (99% CI −16.7 to −11.6, p<0.001) for total HRQOL person-reported parents between children with CHD and controls.
5.	[9](Giulia Amodeo et al, 2022)	Article title: *Health-related quality of life in Italian children and adolescents with congenital heart diseases*
		Venue: Department of Cardiology Children's Hospital "Bambino Gesù" Rome, Italy
		Study design: cross-sectional study

		Time: January to December 2018
		Number of participants: 498 children with CHD
		Results: The average generic total QoL was 78.19 (SD=12.63) and the average condition-specific total QoL was 78.82 (SD=11.66) Mother-reported total patient-generic QoL averaged 79.22 (SD=15.48) and total patient-specific QoL averaged 73.17 (SD=13.80). A total patient-generic QoL of 82.17 (SD=14.78) and an average patient-specific QoL of 76.51 (SD=13.80) were reported by fathers.
6.	[10](Hamouda Abassi et al, 2020)	Article title: *Health-related quality of life in children with congenital heart disease aged 5 to 7 years: a multicenter controlled cross-sectional* study
		Venue: Montpellier University Hospital, France and St-Pierre Institute, Palavas-Les-Flots, France
		Study design: *prospective cross-sectional study*
		Time: April 2019
		Number of participants: 124 children aged 5-7 years with CHD and 125 healthy children aged 5-7 years as the control group
		Results: No significant difference was found between children with CHD and control group children in self-reported total HRQoL scores (73.5±1.2 vs. 72.8±1.2, respectively, P=0.7). Mother-reported HRQoL was lower in the CHD group than in controls for total score (76.1±1.1 vs 81.1±1.1, P=0.002, respectively), and in all dimensions (P<0.05) except for emotional function. Father-reported HRQoL was lower in the CHD group than in the controls for total scores (79.2 ± 1.2 vs 83.7 ± 1.1, respectively, P = 0.006), physical functioning, school functioning, and psychosocial functioning.
7.	[11](Tamay Sercelik et al, 2018)	Article title: *Life quality of children with congenital heart diseases*
		Venue: Celal Pay University S of Medicine, Division of Pediatric Cardiology, turkey
		Study design: cross-sectional
		Time: August 2015
		Number of participants: 40 cyanotic CHD children and 40 a cyanotic CHD children aged 6-16 years
		Research results: The average total QoL score is good. The total quality of life subscale, emotional well-being and *self-esteem subscale* were significantly lower in children with cyanotic *congenital heart disease* (p=0.02, p=0.007, p=0.006). The total quality of life subscale was significantly lower in children with medical and surgical treatment.
8.	[12](Barbara Reiner et al, 2018)	Article title: *Quality of life in young people with congenital heart disease is better than expected*
		Venue: Department of Pediatric Cardiology and Congenital Heart Disease, Deutsches Herzzentrum München, Technische Universität München, Munich, Germany
		Study design: cross-sectional
		Time: July 2014 and May 2017
		Number of participants: 514 children with CHD and 734 normal children
		Results: Children with CHD scored at least as high as healthy children on HRQoL (CHD: 78.6±9.8; healthy: 75.6±10.1; P<0.001). This suggests that the level of quality of life in children with CHD is reported to be comparable to that of their healthy peers
9.	[13](Aguilar-Alaniz et al, 2021)	Article title: *Quality of life of children and adults following cardiac surgery for congenital heart disease*
		Venue: Miguel Hidalgo Centennial Hospital, Mexico
		Study design: cross-sectional

		Time: June 2017 – January 2018
		Number of participants: 40 children with CHD and 80 healthy children as a control group
		Results: patients with cardiac surgery gad better QoL indexes than healthy controls ($p<0.0001$). the difference was greatest in moods and emotions, autonomy, and parent relations.
10.	[14](Angeles Fuertes et al, 2020)	Article title: *Longitudinal Health-Related Quality of Life Assessment in Children with Congenital Heart Disease*
		Venue: Department of Pediatric Cardiology and Congenital Heart Disease, German Heart Center Munich, Germany
		Study design: *Longitudinal Study*
		Time: July 2014 to February 2020
		Number of participants: 317 children aged 6-18 years with CHD
		Research result: At baseline, HRQoL was 78.7 9.3. HRQoL did not change over time during the follow-up (0.03 [–0.01–0.07]; p = 0.195). In a linear mixed model, CHD severity, diagnostic subgroup, age, BMI, surgical history, and gender were not associated with a change in HRQoL over the course of the follow-up period. Only older children (–0.48 [–0.85––0.11]; p = 0.010) had a lower HRQoL. Identical trends were observed for BMI (–0.19 [–0.41–0.03]; p = 0.099).
11.	[15](Saavedra et al, 2020)	Article title: *Health related quality of life in children with congenital heart disease that undergo cardiac surgery during their first year of life*
		Venue: University General Hospital, Buenos Aires, Argentina
		Study design: cross-sectional observational study
		Time: August 2017 and December 2018
		Number of participants: 31 children with CHD aged 2-4 years who had undergone cardiac surgery and 62 healthy children
		Research result: There are no statistically significant differences (p = 0.1) between the HRQOL Total Scale Scores of children with congenital heart disease and healthy children. However, lower scores were observed with statistically significant differences in social (p=0.0092) and school (p=0.0001) scales.

4. Discussions

The distribution of research areas among the eleven reviewed articles demonstrates that the literature is dispersed across multiple regions in Asia (Turkey and South India), Europe (France, Italy, Colombia, and Germany), and the United States (Argentina and Mexico). South India is classified as a developing nation, whereas Turkey, France, Italy, Colombia, Germany, Argentina, and Mexico are classified as developed nations. This classification is determined by four factors: (1) life expectancy; (2) expected years of schooling; (3) average years of schooling; and (4) per capita gross national income. The reviewed literature does not include any nations in the category of poor nations. Therefore, this literature cannot describe the global quality of life. According to prior research, socioeconomic status influences the quality of life of CHD patients [16]. Poverty was associated with low results in several QoL dimensions; poor participants scored lower on physical function than non-poor participants [16]. The results of this study can be used as a reference for further research on the relationship between socioeconomic status and quality of life in children with CHD.

Several topics were discussed based on the review of 11 articles, including 5 articles discussing the relationship between quality of life in children with Congenital Heart Disease and healthy or normal children [8,10,12,13,15], 2 articles discussing quality of life in children with CHD according to patient age group [6,11], 3 articles discussing the relationship between quality of life for children with CHD and the type of CHD severity[5,9,14], and 1 article about the relationship between perceived quality of life between children with CHD and caregivers [7].

The HRQoL evaluation is conducted by examining 2 main modules and several sub dimensional scales. Analysis of the relationship between the quality of life of children with CHD and healthy children was obtained from five reviewed articles. The review results from one article showed significant results that children with *uncorrected* CHD had a lower quality of life compared to their healthy peers [8]. The results of the review of two other articles showed that children with CHD who had received treatment had a better quality of life than their healthy peers [12,13]. Meanwhile, the results of the study of the other 2 articles showed that the results of *self-reported* quality of life scores in children with CHD were comparable or as good as their healthy peers [10,15]. Children with cyanotic CHD have a lower quality of life than those with biventricular CHD. This could be due to the severity of symptoms, the number of operations or surgeries, the high rate of drug use and the limitations in daily life in cyanotic children[11]. Children undergoing isolation interventions had a lower QoL than those who were not. Parents' experiences can lead them to show anxiety-related behaviors towards their children (overprotection , anxious attachment) As a result, this can affect their children's perception of QoL[6].

Analysis of the relationship between the quality of life of children and CHD according to the patient's age group was obtained from the two reviewed literature. In one article it was found that children with CHD in the age group 14-17 years had a lower QoL score compared to the group aged 7-13 years. It should be noted that low scores in the older age group were obtained only during the early stages, during follow-up it was found that the QoL scores in the older age group were good, which means that children with CHD at an older age can develop similarly to the group of children younger[14]. The results of a study by Angeles Fuertes et al in particular are important for clinical practice and future research because they highlight the importance of quality of life assessment in routine clinical practice. This is particularly important for patients aged 5 to 7 years, during the transition from home to primary school and adolescents to support the development of body image and adherence to medical processes[9].

Analysis of the relationship between perceptions of quality of life of children with CHD and their caregivers was obtained from a review of the literature. there is one article that discusses the relationship between children's perceptions of quality of life with CHD and their parents[7]. In both the general and cardiac modules of PedsQL 4.0, children with five different CHD diagnoses had lower QoL perceptions. This difference in perceived QoL may be attributable to patients' expectations regarding their social, cognitive, and intellectual abilities versus those of their parents or caregivers [7]. Given the increased survival of patients with CHD, HRQoL is starting to become part of this population's long-term care plans. This HRQoL assessment will lead to planning new health policies, social and psychological support, selecting individually appropriate interventions, reducing hospitalization and medical costs, and bringing patients and their relatives to increase their productivity. So it can be said that HRQoL evaluation is very important for the follow-up of chronic patients [8,10,12,13,15].

5. Conclusion

Almost all of the research indicates that the value of quality of life in children with CHD, as measured by the total HRQOL scale score, is good or positive. These quality-of-life levels may reflect recent medical advancements in CHD screening and treatment. It is hoped that this research will improve health services by promoting early corrective treatment of CHD, thereby reducing the burden of CHD on HRQoL.

Compliance with ethical standards

Acknowledgments

We appreciate that everyone’s contribution to the group is critical to our achievement.

Disclosure of conflict of interest

No conflict of interest.

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