**International Journal of Healthcare Sciences** ISSN 2348-5728 (Online)
Vol. 4, Issue 2, pp: (726-731), Month: October 2016 - March 2017, Available at: www.researchpublish.com

# Life Quality of Children with Congenital Heart Disease: Systematic Review

[1]Elaf mohammed albasheri, [2]Jawaher Ibrahim Alqurashi,
[3]Sahar Abdulrahman alyamani, [4]Samaa Majed, [5]Fawziah Ali halawani,
[6]Abdulrahman Alamodi

***Abstract:*** **Congenital heart diseases (CHDs) are considered to be the most common type of childhood abnormality, with a worldwide occurrence of 9.1 per 1000 live births, and are associated in 12% of cases with a chromosomal abnormality, such as Down syndrome. The main aim of this systematic review is to review the literature and including findings concerning quality of life in children with CHD. and to identify the main determinants of quality of life in children with CHD. We conducted a comprehensive review in PubMed, Scopus, and EMBASE which was carried out using the following key-terms: quality of life, congenital, heart defects, children. We included articles published through 2016. the search limited to Only English language articles, and systematic search and control for duplicates led to the initial selected articles was performed. we included all studies were relevant to the topic of this paper. CHD is connected with a high frequency of neuro-developmental delay and psychosocial specials needs with significant influence on all dimensions of QOL of the afflicted child and his member of the family. As a repercussion, the investigation of QOL becomes an essential element in the management of children with CHD and their families. The number of studies on lifestyle in children and teenagers with congenital heart disease has actually increased in the last few years due to increased survival in this population.**

***Keywords:*** **Congenital heart diseases, heart defects.**

## 1. INTRODUCTION

Congenital heart diseases (CHDs) are considered to be the most common type of childhood abnormality, with a worldwide occurrence of 9.1 per 1000 live births [(1,2,3,4)], and are associated in 12% of cases with a chromosomal abnormality, such as Down syndrome. In the Kingdom of Saudi Arabia (KSA), although research studies do not offer accurate information, the occurrence of CHD is reported to be less than 5 per 1000 babies [(5)]. Hereditary heart flaw describes a broad spectrum of basic, moderate, and intricate lesions, brought on by abnormal heart advancement throughout endometrial life, and are typically classified into 2 categories: acyanotic and cyanotic kinds, according to the presence or absence of cyanosis [(3)]. Another classification categorizes CHD into 2 types: simple CHD, such as septal malformations (atrial septal flaw [ASD] and ventricular septal flaw [VSD]; and intricate CHD integrating more than one simultaneous defect, such as the tetralogy of Fallot [(6)]. In KSA, a number of studies concur that VSD is the most common kind of CHD, taking place in one-third of cases, followed by ASD [(5)].

In addition, there is evidence that the existence of CHD can have a direct effect on the child's physical, motor, cognitive, and neurological advancement; nevertheless, the conflicting arise from existing research, concerning quality-of-life concerns in kids with CHD, reveal an absence of conceptual and methodological rigour [(7)]. However, despite any limitations, a number of studies aim to recognize factors of quality of life in this heterogeneous group of patients with cardiac malformations including acyanotic, cyanotic, and obstructive heart defects [(8,9)].

Health-related lifestyle expresses the impact of a persistent disease such as CHD and its treatment on a child's ability to function and to cope in a range of life contexts along with the capability to get fulfillment from physical, mental, and social performance [(10)]. In addition, a variety of disease-specific procedures have actually been developed for usage in kids with CHD, with or without a parent form, and their medical energy has been validated [(11,12)]. Evidently, understanding of the primary determinants of health-related lifestyle in children with CHD might lead to early recognition of children at the greatest risk for impaired health-related quality of life, and it may allow timely interventions to promote health-related quality of life or to prevent negative results on it [(13)].

***Objectives:***

The main aim of this systematic review is to review the literature and including findings concerning quality of life in children with CHD. and to identify the main determinants of quality of life in children with CHD.

## 2. METHODOLOGY

***Systematic review research was performed***

**Search Methods:**

We conducted a comprehensive review in PubMed, Scopus, and EMBASE which was carried out using the following key-terms: ***quality of life, congenital, heart defects, children***. We included articles published through 2016. the search limited to Only English language articles, and systematic search and control for duplicates led to the initial selected articles was performed. we included all studies were relevant to the topic of this paper.

The inclusion criteria were as follows:

articles written in English, original articles, reviews, randomized control studies RCTs, articles that included in their study children with CHD aged under 17 years old. Children with CHD and acquired heart disease or healthy population, and most important criteria for inclusion in this study studies that used the variable quality of life as a measure, and articles that assessed reports of children and/or their parents regarding their quality of life.

## 3. RESULTS & DISCUSSION

***Life of Quality (QoL) of Children with CHDs:***

We identified a very large meta-analysis study [14] that evaluate the impact of CHDs on children life quality and this research study showed results as follows: (a) A significant percentage of kids experienced mental maladjustment according to their moms and dads; (b) research studies on self-reported PA indicate an excellent result; (c) the studies on QoL suggest an impaired QoL for some children in particular for those with more severe heart disease; (d) parental reports of mental maladjustment were associated with severity of CHD and developmental delay. And concluded a significant proportion of survivors of open-heart surgery for CHD are at risk for mental maladjustment and impaired QoL. Future research study has to focus on self-reports, QoL data and teenagers.

One essential cross-sectional research study [15] was carried out between May 2014 and August 2015, including kids aged <16 years, and followed-up at King Abdulaziz University Hospital, Jeddah, Kingdom of Saudi Arabia for CHD. Involving 180 children (104 [57.8%] males; suggest age ± standard deviation [SD] = 5.65 ± 4.8 years). Concluded that, Congenital heart diseases impact all elements of QOL of patients and their households, and are connected with high comorbidity. Social and psychological assistance and education for patients and their moms and dads are important factors for enhancing QOL.Main scores and evaluation results of QoL are summarized in (**Table1**) [15]

**Table1. Impact of congenital heart disease (CHD) on quality of life (QOL) of mothers, according to being exclusive care-givers or not. [15]**

| Mother's QOL parameter | Mother exclusive care-giver | | Total | *P*-value |
|---|---|---|---|---|
| | Yes (group A; n=156[a]) | No (group B; n=24[b]) | | |
| *BIS* | | | | |
| *Level of impact* | | | | 0.405 |
| Low | 99 (63.9) | 18 (62.07) | 117 | |
| Medium | 26 (16.8) | 4 (13.79) | 30 | |
| High | 30 (19.35) | 2 (6.9) | 32 | |
| *PIS* | | | | 0.469 |
| *Level of impact* | | | | |
| Low | 102 (65.4) | 18 (78.26) | 120 | |
| Medium | 42 (26.9) | 4 (17.39) | 46 | |
| High | 12 (7.69) | 1 (4.38) | 13 | |
| *SIS* | | | | 0.305 |
| *Level of impact* | | | | |
| Low | 112 (71.8) | 20 (83.3) | 132 | |
| Medium | 34 (21.8) | 2 (8.3) | 36 | |
| High | 10 (6.41) | 2 (8.3) | 12 | |
| *Spiritual life* | | | | 0.007* |
| Improved | 78 (50.6) | 3 (13.0) | 81 | |
| Unchanged | 73 (47.4) | 19 (82.6) | 92 | |
| Worsened | 3 (2.0) | 1 (4.4) | 4 | |
| *Social activities impacted* | | | | 0.014* |
| No | 101 (66.0) | 20 (90.9) | 121 | |
| Yes | 52 (34.0) | 2 (9.1) | 54 | |
| *GIS* | | | | |
| *Level of impact* | | | | 0.465 |
| Low | 105 (67.7) | 18 (78.3) | 123 | |
| Medium | 44 (28.4) | 5 (21.7) | 49 | |
| High | 6 (3.9) | 0 (0) | 6 | |

[a,b] Total sample size was not reached for all parameters because of unanswered questions, BIS - biological impact score, PIS - psychological impact score, SIS - social impact score, GIS - global impact score, * significant result (*p*-value =<0.05)

According to one methodical evaluation research study [16] analysis, kids with CHD are a high risk population for impaired quality of life due to major functional disabilities. In this context, a range of determinants of the quality of life are determined together with a number of possible barriers concerning its evaluation. To this end, it seems that sense of coherence, reconciliation with the disease and/or its restrictions, and compliance with treatment are locations that have to be checked out in more depth in relation to quality of life. Physical and psycho-social domains seem to be more affected in children with CHD [16]. In a number of included studies [7,17,18,19,20,21], kids and with moderate or intricate CHD reported lower quality of life than those with less-severe cardiac problems or healthy kids; [17] however, this does not seem to be the case. Kwon et al [18] reported that quality of life in kids and adolescents with fixed tetralogy of Fallot was not analogous to the severity of their residual disease. Sears et al [19] reported that medical severity and implantable cardioverter defibrillator discharges did not appear to have an unfavorable result on children's lifestyle, and other studies concluded that medical seriousness of CHD may even have a favorable impact on children's quality of life. A closer take a look at all these studies will expose that frequency and severity of signs together with physical restrictions and parental constraints must be considered as more crucial factors of health-related lifestyle, due to the problems they trigger in life, than the intricacy of the medical condition [7,20,21].

Marino et al [22] discovered that quality of life outcomes in kids and teenagers with intricate CHD were statistically considerably forecasted by executive performance, gross motor capability, and state of mind. Goldbeck and Melches [23] commented that the combination of medical and social tension had the greatest negative effect on the quality of life in the infected child or adolescent, no matter its intensity. A family with adequate resources can cope much better and limit the negative results on the quality of life, even with a serious disease condition. Social support stands as an essential variable that promotes adaptation to the disease [24]. In conclusion, in children with CHD, the severity of CHD, in sense of the medical signs and the number of surgical procedures or health interventions, appeared to have a minimal impact. To this end, Jackson et al in their meta-analysis concluded that teenagers with CHD did not differ in emotional working from healthy controls; nevertheless, they acknowledged a pattern for degree of sore intensity to moderate psychological performance. They concluded that differences in psychological functioning might exist throughout lesion seriousness, and people with reasonably extreme lesions are emotionally thriving [25]. In the appropriate literature, a multitude of basic and disease-specific instruments have actually been used to examine quality of life using self-reports and/or proxy reports [26,27,28]. Goldbeck and Melches [29] noted that, in the medical setting, the combination of various viewpoints permits a more detailed evaluation of lifestyle, as parental reports cannot replace child reports or vice versa.

***Factors associated with quality of life in children with CHD:***

In general, the frequency of scientific symptoms and practical status of the child with CHD had a fantastic influence on health-related quality of life [7]. Individualization from the family and autonomy appear to be essential indications of cope amongst adolescents and help adolescents enhance their self-esteem and their general understanding of quality of life [7]. In overall, 14 (n=14) research studies examined factors that were related with quality of life in children with CHD. In this context, physical constraints due to impaired physical performance, lower activity levels, lower maximum oxygen uptake, and parental or treatment restrictions have a direct impact on children health related quality of life [20,21]. In addition, deficits in neurodevelopmental result in kids with CHD are related to bad scholastic efficiency, regular school misses, feelings of seclusion, and social incompetence that impact straight numerous measurements of health-related lifestyle [20,21]. Furthermore, depressive state of mind seemed to have a favorable correlation with lower physical and psycho-social lifestyle. A research short article reported that quality of life in children is affected by lower socioeconomic status and serious CHD, as both factors appeared to produce cognitive issues [30]. In a recent study, the findings recommended that family income, as a socio-economic status step, has the greatest influence on health-related quality of life [31]. A prospective research study reported that lifestyle in teenagers with CHD, examined in two periods, is forecasted by viewed health status, socio-economic status, and parental support [32]. A various research study that utilized measurement of 3 periods in the same study population [33] suggested that depressive symptoms and isolation impact adversely the quality of life in teenagers with CHD. Paternal support was found to impact positively the internalizing symptoms and quality of life in this population. Characteristically, a study examined the effect of oral health on quality of life in infants with CHD. Oral health appeared to affect quality of life in infants with CHD, while their moms and dads were discovered to be guiltier and upset about their child's oral health and dental issues compared to the basic population [34]. In a current research study, it was kept in mind that parental mental health moderates the efficacy of workout training on health-related quality of life in adolescents with CHD [35].

In comparison with other persistent diseases in childhood, it seems that children with CHD face an impact on their health-related lifestyle similar to the effects of asthma, weight problems, and end-stage kidney disease, whereas the effect of mild CHD estimates the effect of diabetes mellitus [20]. Numerous factors seem to be connected with quality of life, but the findings in the literature are undetermined. In our analysis, a number of factors that influence and/ or identify the measured quality of life in children and teenagers with CHD are described. In adolescence, measured lifestyle was found to be anticipated by perceived health status, sense of coherence, and adult assistance [36]. The existence of solitude and depressive signs in teens with CHD appeared to have an unfavorable effect on their quality of life [37]. In contrast, the presence of stronger sense of coherence, much better viewed physical health, adult assistance, and family consistency were discovered to affect favorably their quality of life and internalized signs [36,37,38]. On the other hand, determined lifestyle, concerning parental assistance, was found to be adversely impacted by period of bypass, hospitalization and length of health center stay, medication need, and unfavorable family relationships [39].

## 4. CONCLUSION

CHD is connected with a high frequency of neuro-developmental delay and psychosocial specials needs with significant influence on all dimensions of QOL of the afflicted child and his member of the family. As a repercussion, the investigation of QOL becomes an essential element in the management of children with CHD and their families. The number of studies on lifestyle in children and teenagers with congenital heart disease has actually increased in the last few years due to increased survival in this population. Research studies reveal conflicting results, and currently, there is a tendency to investigate factors such as adult designs, social support and coping methods to much better comprehend the lifestyle in these patients. All these variables that engage in the understanding of quality of life are difficult to comprehend by a single measuring instrument.

Health care political leaders and companies associated with health care are invited to examine regular, clinically based cost-efficacy, and to expand the care technique to include non-medical care, providing concern for the improvement of the QOL of these children and their families. It is commonly accepted that quality of life in kids with CHD should be examined inning accordance with age, disease intensity, reputation of the disease, and personality functions. The associated literature recommends that the quality of life in kids and teenagers with CHD is similar with the quality of life in normative/healthy population, when the disease-induced restrictions are controlled and compliance with treatment is satisfying.

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