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QUALITY OF LIFE IN CHILDREN WITH CONGENITAL HEART DISEASE: AN INTEGRATIVE REVIEW

[1]Alan Cássio Carvalho Coutinho, [1]Bruna da Silva Oliveira, [1]Lorena Carvalho Braga, [1]Andréa Dutra Pereira and [2]Isaura Leticia Tavares Palmeira Rolim

[1]Mestrandos do Programa de Pós Graduação em Enfermagem, Universidade Federal do Maranhão, Cidade de São Luis, Brazil
[2]Professora Doutora em Enfermagem, Universidade Federal do Maranhão, Cidade de São Luis, Brazil

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ABSTRACT

The Congenital Heart Diseases (CHD) is a heart anatomic malformation which may cause alteration in function and also has a complex etiology without a clear cause. In this context, the investigation of these children's quality of life becomes relevant, since the heart disease brings implications related not only to the physical structure, but also emotional and family.
Objective: The aim of this study is to search scientific knowledge productions about children's quality of life who coping with CHD.
Method: This is a study of integrative review about publications regarding to the quality of life of children who have Congenital Heart Diseases (CHD).**Results:** The search resulted in 506 articles in three different data basis using the descriptor: Child, Congenital Heart Disease and Quality of live in English and Spanish language. Among them only 98 filled the inclusion criteria and they were submitted to applications to the exclusion criteria, resulting only in 21 articles, which were completed analyzed, constituting the final sample of 6 studies that were related to the content.
Conclusion: The studies made to evaluated the quality of life of children with CHD show inconclusive results, possibly because of the methodological and conceptual differences in the researches.

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INTRODUCTION

The Congenital Heart Diseases (CHD) is a heart anatomic malformation which may cause alteration in function and also has a complex etiology without a clear cause. It might consider that CHD is associated to environmental factors as pregnancy diseases (gestational diabetes, rubella, syphilis and others), medicine use, illicit drugs and alcohol use. Moreover, genetics factors lead to chromosomic alteration manifested on Down syndrome, Turner and Klinefelterwhich are more frequently attached to CHD. These factors may happen in the first pregnancy week, where the fetus heart is been formatted (Bastos *et al*., 2013). The incidence of CHD may vary from 0.8% in developed countries to 1.2% in underdeveloped countries.

***Corresponding author:* Alan Cássio Carvalho Coutinho**
Mestrandos do Programa de Pós Graduação em Enfermagem, Universidade Federal do Maranhão, Cidade de São Luis, Brazil

Since 2001, the CHD are the second cause of children death, according to the Mortality Information System of the Ministry of Health from Brazil. The estimated number is about 22.386 newborns and lactating, every year, which need identification, diagnosis and treatment to their heart disease. If we consider the number of conceptions, the incidence of CHD is 5 to 10 times bigger (Santana, 2005). The heart malformation is a congenital anomaly responsible for 3 to 5% of deaths in neonatal period. The early diagnosis is extremely important, since the clinical deterioration is fast and the mortality level is high. About 20 to 30% of children die in their first month of life with cardiac failure or hypoxia crisis (Santana, 2005). Clinically, the heart diseases are classified as acyanotic and cyanotic (Ebaid *et al*., 1993). The acyanotic heart disease needs simpler procedures to be fixed when compared to the cyanotic one. The most commonacyanotic heart diseases are: interatrial and interventricular communication, total or partial atrioventricular septum defect, aortic stenosis, persistence of

the atrial pathway and coarctation of aorta (Jatene, 2002). The acyanotic heart disease has more dangerous because they cause a decrease of hemoglobin level in the arterial blood. The Fallot tetralogy is the most common in this group; other examples are Ebstein anomaly and Eisenmenger Syndrom (Araújo *et al*., 2014). The simple CHD does not need immediate invasive treatment, but a judicious monitoring is indicated. This happens to reduce the deleterious effects of hemodynamic decompensation, indicating an intervention in the best moment for the child. Complex heart diseaseneeds an earlier diagnosis and treatment (Araújo *et al*., 2014). The extension of survival after the birth depends of the heart disease type. The early deaths are caused by the severer anatomic alteration. The children which survive to the first day of life are exposed to the disease progression and to the inherent risks, like: physical development deficit, pulmonary arterial hypertension, fibrosis and myocardial dysfunction, stroke, vascular thrombosis and hemorrhagic accidents; all of them are capable of substantially deteriorate the quality of life (Bastos *et al*., 2013).

The quality of life is defined as an internal experience of satisfactions and wellbeing associated to the life process. About the children quality of life, the protection and promotion represented challenges which the amplitude and complexity go thought the ones that the public health stablishes as a solution (Davim *et al*. 2008). The reaction of each child facing the adverse experience shows that there is a level of individual adjustment and facing style that is related to the perception about quality of life. Thus, it is important consider the repercussion of physical, psychological and social which follow the CHD and effect the children's quality of life (Bertoletti, *et al*., 2014). Otherwise, it is clear that the children who have the life affected by the CHD suffer several changes in their life style and quality of life that include therapeutic demands, judicious clinical control and recurrent hospitalization. In this context, the investigation of these children's quality of life becomes relevant, since the heart disease brings implications related not only to the physical structure, but also emotional and family. Showing a repression of the children's right of enjoy the appropriated quality of life, which also will affect their wellbeing in their adult's life (Vieira; Dupas; Ferreira, 2009). The aim of this study is to search scientific knowledge productions about children's quality of life who coping with CHD.

MATERIALS AND METHODS

This is a study of integrative review about publications regarding to the quality of life of children who have Congenital Heart Diseases (CHD). The literature integrative review is a method that has the aim of synthesizes the results about the theme or question, in a systematic and embracive way. It is called integrative because offers amplified information about the problem/content, constituting knowledge body (Ercole; Melo; Alcoforado, 2014). To make the integrative literature review were followed these steps: 1) the research question was selected; 2) criterion of inclusion and exclusion were defined; 3) It was made table with the studies selected, considering all the features in common; 4) critical analysis of the found studies, identify the differences and conflicts; 5) results interpretation and 6) report the found evidences (Ganong, 1987). Considering the high prevalence of children with CHD, it was created the question: "What are the available evidences in the literature about quality of life of children who have CHD?" To effective article search, it was used these data basis accessed by Health Virtual Library: LILACS, MEDLINE and ScieELO.

About the descriptors, it was used the terminology in health consulted on Health Science Descriptors (DeCS/Bireme), which identified the respective descriptors: Heart defects, congenital, cardiopatíascongénitas, quality of life, calidad de vida and child; niño. The inclusion criteria to develop the integrative review were: scientific articles that had completed texts published from 2007 to 2016, which included children aged until 12 years and with CHD. Also available in the data basis selected, published in Portuguese, English and Spanish and with the abstract available on internet.

It was excluded the paid publications, letter-answered studies type, editorial, abstracts of annals, dissertation, thesis, papers of graduate conclusion, articles of integrative or narrative review, publications that were doubled in other data basis, case studies and primary studies that do not mention the topic or that do not answer the guiding question. The studies which were included in this research were pre-selected by the judgment of title and abstracts.

Table 1. Characterization of articles considering the title, author, magazine publication and year

Articles	Titles	Authors	Magazine Publication	Year
1	Exercise capacity, quality of life and daily activity in the long-term follow-up of patients with univentricular heart and total cavopulmonary connection	Jan Muller, Florian Christov, Christian Schreiber, John Hess e Alfred Hager	European Heart Journal	2009
2	Neurodevelopmental outcome, psychological adjustment and quality of life in adolescents with congenital heart disease	Christina Schaefer, Michael Von Rhein, Walter Knirsch, Reto Huber, Giancarlo Natalucci, Jon Caflisch, Markus A. Landolt, Beatrice L.	Developmental medicine & Child Neurology	2013
3	How good is a good fontan? Quality of life and excercise capacity of fontans without arrhythmias	Yves d'Udekem, Michael M. H. Cheung, Stella Setyapranata, Ajay J. Iyengar, Patrícia Kelly, Naomi Buckland, Leeanne E. Grigg, Robert G. Weintraub, Alasdair Vance, Christian P. Brizard e Dan J. Penny	Journal at the Society of thoracic surgeons	2009
4	Functional health status of adolescents after the fontan procedure – comparison with their sibilings	Cedric Manlhiot, StevanKnezevich, Elizabeth Radojewski, Geraldine Cullen-Dean, Willian G Willianse Brian W. McCrindle	Journal Canadian of Cardiology	2009
5	Patient-reported quality of life outcomes for children with serious congenital heart defects	Rachel L Knowles, Thomas Day, Angie Wade, Catherine Bull, Christopher Wren, Carol Dezateux	Arch dis Child	2014
6	Calidad de vida em pacientes portadores de cardiopatías congénitas	Maria Elisa Castillo,Lida Toro R., Pamela Zelada P., Fernando Herrera L., Rodolfo Garay V., Alex Alcántara P., Myriam Ferreiro C., Daniela Agusti	RevistaChilena de Cardiologia	2010

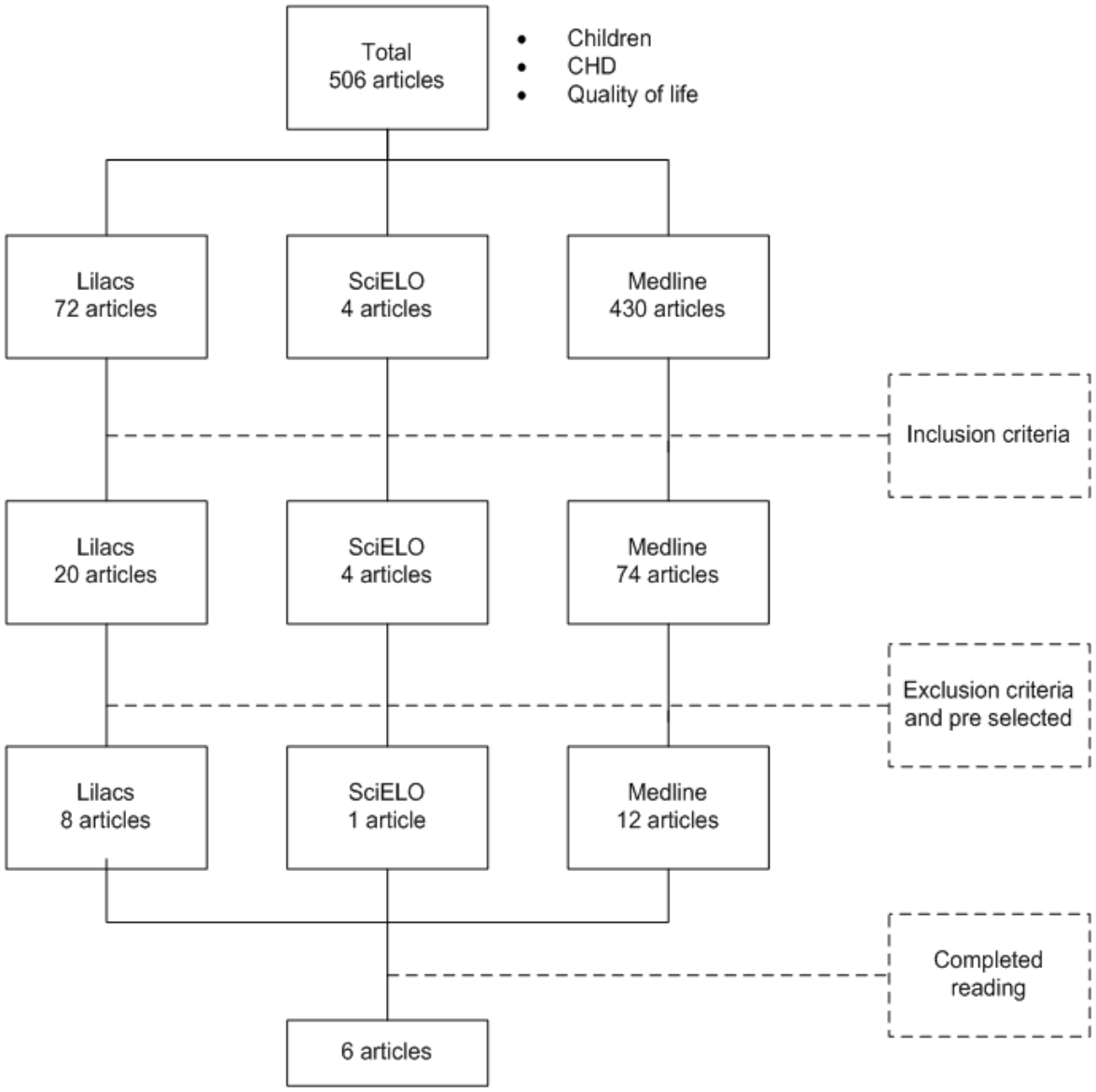

Image 1. Synthesis of the three first steps on the integrative review about children`s quality of life with congenital heart disease. São Luís, 2017

After the pre selection, the articles were completed analyzed to guarantee that they would fill the inclusion criteria, confirmed the selection, organization and the data tabulation according to the title, aims, methodologic lineation and results. The found content during the critical analysis were grouped according similar topics to discussion of the results and evidences found.

RESULTS

The search resulted in 506 articles in three different data basis using the descriptor: Child, Congenital Heart Disease and Quality of live in English and Spanish language. Among them only 98 filled the inclusion criteria and they were submitted to applications to the exclusion criteria, resulting only in 21 articles (1 SciELO, 8 LILACS, 12 Medline), which were completed analyzed, constituting the final sample of 6 studies that were related to the content (Image 1). About the language, two articles were published in Portuguese, six in English and one in Spanish. The article extraction and analyze were effectuated through of the identification of the articles and their authors, year and magazine publication (Quadro 1).

The information were synthesized in a table with methodological features as search lineation, objective, approach tool and results), according Table 2. It was used the abbreviation (A) to organization and presentation of articles in the following table.

DISCUSSION

While the quality of life of the adult population has been investigated in the last years, among the children and teenagers is a current reality (Rezende *et al*, 2008; Bertoletti *et al*, 2014). The articles were found in this search showed the evaluation in quality of life, mainly, through validated tools. These tools are divided in aspects that talk about physical activity, daily activity and social interactions. Among these tools, two articles were used *SF-36 (Medical Outcomes Study 36 – Intem short – Form Health Survey)*that is a multidimensional questionary formatted by 36 items, encompassed in 8 scales and domains, which are: functional capacity, physical aspects, pain, health general condition, vitality, social, emotional and mental health aspects.

Table 2. Characterization of the articles according to the lineation, objectives, tools and results

Article	Lineation	Objectives	Approach tool about quality of life verification	Results
A1	Transversal Study	Search the capacity of exercise, quality of life, daily activities and its interaction with anuniventricular heart with total cavopulmonary connection.	SF-36questionaries'(to children aged≥ 14 years); CF-87questionaries'(to children aged from 8 to13 years old).	Children showed good results in all variables addressed in two questionnaires, especially in physical, behaviors and social area.
A2	Cohort Study	Compare the neurological development, psychological and quality of life adjustment in teenagers with CHD.	Kidscreen 27	The children with CHD do not have significant differences in their quality of life during scholar age when compared with children who do not have CHD. The children's parents with CHD identify the difference in physical wellbeing in the same relation with the others, which is not recognized to them.
A3	Analytic study	Knowing the quality of life and exercise capacity of patients submitted to surgeries of Fontan without arrhythmia	SF-36 questionaries'	The patients with Fontan have a normal perception of quality of life diverging of what is found in the literature. There is no statically relation between quality of life and capacity of exercise.
A4	Case control study	Compare the functional health situation of the patients with Fontan with or without siblings; Evaluate if there are differences between patients with Fontan, their siblings and associated factors	Pediatric inventory of quality of life; CF-87	Patients with siblings were significantly low in many domains in physical and functional aspects than the ones without siblings. The patients submitted to Fontan had results significantly lower than their siblings in all the aspects (physical, emotional, social, scholar functional). However, the psychosocial domain was comparable to their siblings, suggesting any level of coping
A5	Retrospective cohort study	Compare the quality of life reported by the patients related to quality of life of children with CHD and classmates who do not have the disease; Investigate the demographic and clinical factors that influence the quality of life.	Pediatric invitatory of Quality of Life (PedsQL)	The teenagers from 10 to 14 years old with serious CHD reported quality of life significantly lower than to their classmates without the disease. Cardiac intervention, non-scholar period, regular use medication and non-cardiac were associated to lower quality of life. The physical activities offer positive benefits to theirpsychosocial functional.
A6	Case control study	Study about the children's quality of life with CHD, on the individual and familiar point of view, with the aim in three specifics areas: scholar activity, daily activity and family interaction.	The specific questionnaire that evaluate the scholar activity, daily activity and family interaction	In general, the perception of the patient's quality of life does not differ significantly of the healthy group, but there are some activities limitations in physical and daily ones with the increase of the disease complexity.

It shows a final score from 0 to 100 (using the Raw Scale calculation), where the 0 is the worst quality of life/general health condition and 100 is the best quality of life/ general health condition. On articles, A1 and A3 that used this tool showed that the domains and scores close to 100. Thus, the self-perception of quality of life was considered satisfactory, normally interacting with family environment, excepted for the reduced physical capacity, as was mentioned in A1. Other tool used to evaluate the quality of life of children with CHD was *Child Health Questionnaire* (CHQ-CF87).This questionnaire evaluates the physical, psychological and social components. It was develop for children (age equal or superior to five years old) and teenagers. There are sub classifications of this questionnaire to parental fill and self-fill for children aged above ten years old, included the dimensions: physical capacity, health global perception, mental health, global behavior, impact of physical inability in social, emotional and behavior level, pain and discomfort, impact of the disease in the country and impact in the family activities limitation. The scores were converted to scale from zero to 100. The highest score indicate the best quality of life and health condition (Araújo; Dourado; Ferreira, 2015).

The article A1, that used the *CHQ-CF87*, found correlation with mental health condition, represented to anxiety and depression; and the children below 9 years old had less score related to physical activity. The publication A2, used the tool *KIDSCREEN-52*, a questionnaire of self-fill, that take 10 to 15 minutes to be answered. It was developed a European project to measure ten dimensions: health and physical activity, feelings, general mood condition, self-perception, free time, family and its environment, economic aspects, friends, scholar environment, learning and bullying. This tool may be organized in five dimensions in this case called KIDSCREEN-27 (well physical and psychological being, autonomy and family, social support and scholar context) (Gaspar *et al*., 2014). The participants with CHD related similar quality of life when compared to health children in the same age; The quality of life checked through self-perception was better than the noticed in country that were reported bigger problems in the in the physical wellbeing. This parent's view suggests that limited view specifically to the gravity of the children's health condition.

The articles A4 and A5 used the inventory called *Pediatric Quality of Life Inventory* (PedsQL) that consisted in a group of applicable scales to health population as the population with chronic and acute pathologies. The evaluated dimensions are: physical, emotional, social and scholar functional. It is constituted for a total of 23 questions, taking about 4 to 5 minutes to be answered. The analysis of the results may be done through the total result and two sub results: one about an specific physical health and other related to psychosocial health. The answer is organized in scale like Likert with five options. As the scores for dimensions are showed in a positive orientation scale ofzero (worst Quality of life) to 100 (best quality of life) (Araújo; Dourado; Ferreira, 2015). About the production A4, it was possible to observe that the patients who had siblings and were submitted to the cardiac surgery had lower score if related to other children in the same condition, otherwise, without siblings, also low scores are relate. On A4 production, it may possible observe that patients who have sibling and were submitted to cardiac surgery had lower scores when compared to children in the same condition, however, the ones that do not have siblings also had lower scores in relation to their own sibling in all the domains. This result might be related to a bigger impression of physical limitation with self-perception of children with CHD when compared to their siblings.

However, the psychosocial domain was comparable to their siblings, suggesting any coping level. This fact demonstrates as children's ability in get adapt in their experiences and the way they interpreted will have impact in their quality of life. The reactions of each child facing these adverse experiences, as coping the disease, show the level of individual adjustment and facing styles that were related to their perception about quality of life (Rezende *et al*., 2008; Bertoletti *et al*., 2014). These productions show that the cardiac intervention, non-scholar life period, use of medication and comorbidities non cardiac were independently related to quality of life. Children with serious HCD have a lower quality of life than their health classmates. Furthermore, the sport practical may offer a positive benefit to biopsychosocial function. The production A6 evaluated the quality of life through their own formulary that had three topics: scholar and daily activities and family life. The children were evaluated in this study were compared to healthy children in the same scholar age, not been found significantly difference in relation to scholar degree (grade perception and scholar performance). In relation to physical activity, the parents had a better perception of limitation in relation to the self-perceptionof children with heart disease. There are significant differences related to the moderate physical efforts to the intense ones among children with light and severe CHD. The children's perspective related to the family life does not show any significant difference when compared to the healthy children. The struggle to define the quality of life became a constant challenge, mainly in the building of the validated and trustful tools that included all the dimension and perception of an individual in growing stage. The measurement of quality of life related to health became one important indicator in clinical tests, strategies to improve the clinical practice, research and evaluation of health service been important to the children identification with bigger need (Rezende *et al*., 2008; Bertoletti *et al*., 2014).

Conclusion

The studies made to evaluated the quality of life of children with CHD show inconclusive results, possibly because of the methodological and conceptual differences in the researches. The methods differences among the studies, as lineation, inclusion criteria, used evaluation tools, following up and outcome measures make the results comparison harder. The number of studies related to cardiopatic children's quality of life has increase lately because of the increase of their survival. However, the quality of life still low in order to be conclude. The studies show contradictories results and, currently, it possible to observe the tendency to investigate factors as family style, social support and coping strategies to better understand the quality of life of these patients

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