



REVIEW ARTICLE

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QUALITY OF LIFE AND ADOLESCENTS WITH HEART DISEASE: AN INTEGRATIVE REVIEW OF LITERATURE

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ABSTRACT

This literature review was aimed at investigating the quality of life (QoL) of adolescents with cardiomyopathy and its associated factors. Pubmed, Scielo, Lilacs and Cochrane databases were consulted in the period between 2010 and 2019, in the languages English, Portuguese and Spanish in the original article format. After analysis, 18 articles were selected. The physical limitation was one of the dimensions identified in terms of changes in QoL of these adolescents, leading to their exclusion from physical activities which require social interaction. School performance was also compromised due to hospitalisations, medical appointments and fatigue as a result of the disease. Some studies showed higher levels of depression, loneliness, stress and low self-esteem in adolescents with heart disease when compared to a healthy group. The social support, the feeling of coherence and the level of knowledge of the pathology demonstrated to be a protection factor, improving the quality of life. The results of this review showed that adolescents with cardiomyopathy present a worse life quality when compared with adolescents without cardiomyopathy.

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INTRODUCTION

Adolescence is established as the period of transition between childhood and adult life, characterised by the many biological, psychological, social, economic and sexual changes which will have a strong impact in the formation of their behaviour (Bardini et al. 2011). Due to various changes faced by teenagers, they require special attention, especially in cases when chronic diseases are present, such as the case of heart diseases (Santos et al. 2015). Heart damage is not always the greatest problem for these individuals, with issues related to survival, incapacity, intolerance to exercise, growth retardation and cognitive development being highly relevant in their lives. Constant hospitalisations, as well as the frequent concerns with social relationships and the impact of self-esteem have a strong influence on the quality of life (QoL) of this population group (Ernst et al. 2018).

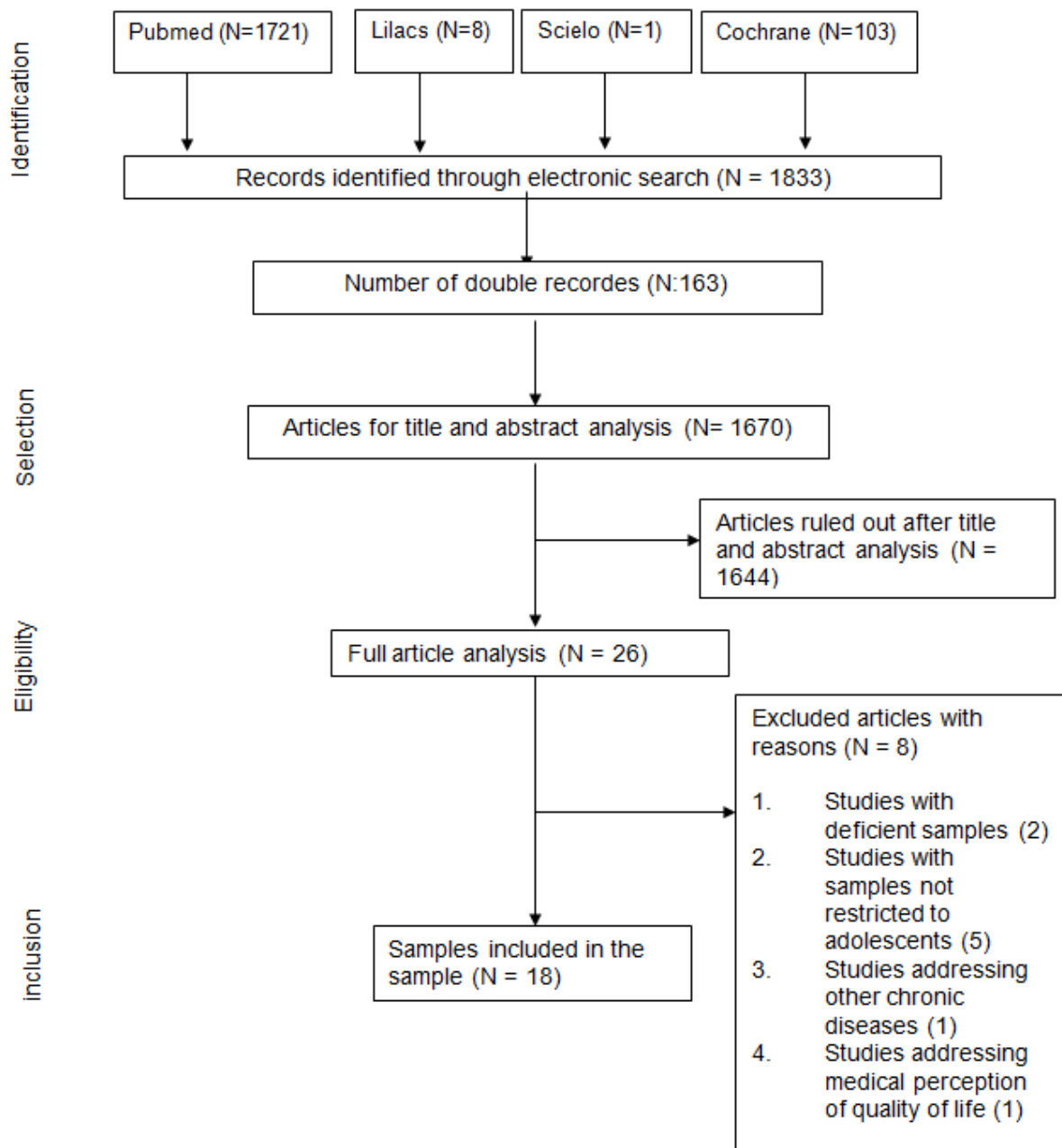
Studies have shown that advances on diagnostic and therapeutic tools, as well as new surgery techniques, advances on extracorporeal circulation and interventional medicine have increased the proportion of adolescent patients with congenital heart disease (CHD) and acquired heart disease (AHD), directly affecting the quality of life of this group (Bertoletti et al. 2015; Uzark et al. 2015). QoL can be defined as the degree of satisfaction with life in general, influenced by the individual perception of certain aspects of life, related or not to health (Seidl et al. 2004; Pereira et al. 2012). As one's quality of life has a great impact on health and well-being, there is a growing interest of various health sectors on the QoL of adolescents, as this is considered a key phase for interventions and lifestyle changes, with this age group being recognised as important facets of global public health (Campos et al. 20008; Wang et al. 2014). Furthermore, chronic diseases have become issues of great interest to researchers, when trying to establish their impact on QoL (Campos et al. 2008; Im et al. 2018). With this

in mind, this study is aimed at investigating the quality of life of cardiomyopathic adolescents, as well as the factors that influence it. Therefore, a systematic literature review was used as a research strategy to identify the existing evidences in the literature concerning this subject.

METHODOLOGY

The methodology of this study consisted in the review based on the following guiding question: “Which factors affect the quality of life of adolescents with heart diseases?”. This review was based on an analysis of publications of articles indexed in the following databases: the National Library of Medicine (Pubmed), Latin American Health Sciences Literature (Lilacs), the Scientific Electronic Library Online (SciELO) and the Cochrane Library. To adequately refine the search, articles published in the languages English, Portuguese and Spanish were defined as search criteria, with abstracts available in the above-mentioned databases.

A publication year between 2010 and 2019, as well as the articles that answered the guiding question and included the age group between 10 and 19 years old were also used as search criteria. The descriptors used in the advanced search were “Adolescents”, “Quality of life”, “Cardiovascular Diseases”; recognised in the Mesh and Desc vocabulary lists. Repeated studies in these databases, as well as those classified as literature review and those that were not in the format of a scientific article, such as guidelines, letters, editorials, theses and dissertations, were excluded from this selection. Following the exclusion of the repeated studies, a *peer review* was carried out, filtering the studies in terms of their titles and abstracts. The articles with titles and abstracts that did not contain the subject searched were also excluded. The articles that filled the inclusion criteria were selected for a complete reading of the text, enabling the selection of articles included in this revision. In all steps, any disagreements were cross-checked by a third reviewer (Flowchart 1).



Flowchart 1. Identification of the component studies of the final sample

RESULTS

As a result of crossing the descriptors, 1,721 articles were obtained in Pubmed, 1 in Scielo, 8 in Lilacs and 103 in Cochrane, with a total of 1,833 articles. Following the analysis, 163 articles were excluded due to repetition, with 1,670 being tracked after the reading of titles and abstracts. In this step, 1,644 were excluded as their titles and abstracts did not contemplate the subject searched, with 26 studies being read in their entirety, resulting in 18 articles included in the present synthesis. Following the analysis and synthesis of the data, the articles selected were organised and arranged in Table 1 according to the author, year of publication, country of origin, age group, tools used to evaluate the QoL, study design, type of heart disease, factors associated to the quality of life and classification of the quality of life.

DISCUSSION

Evaluating the QoL of adolescents has been a great challenge, as they usually undergo a series of biological, psychological and social changes that impact their perception of QoL, being widely acknowledged that the QoL in adolescence has an influence on well-being in adult life (Coutinho *et al.* 2016). Researches on this subject are still limited, typically analysing adolescents in combination with children or adults. It is observed that 61.1% (Wang *et al.* 2006; Kwon *et al.* 2011; Janiec *et al.* 2011; Koopman *et al.* 2012; Pulgaron *et al.* 2013; O'Byrne *et al.* 2013; Coelho *et al.* 2013; Heusch *et al.* 2014; Uzark *et al.* 2015; Li *et al.* 2017; Sleeper *et al.* 2017) of the articles found consist of samples of adolescents in combination with other age groups.

Table 1. Distribution of articles by author and year, origin, age group, instrument for QoL evaluation, study design, type of heart disease, factors associated with quality of life and quality of life classification

Author, Year	Country of origin	Age	Instrument	Kind of study	Heart disease	Factors that influence quality of life	Quality of life
Ernst, <i>et al</i> (2018)	USA, England	9-15	PCQLI	Crosscutting	CHD	Number of surgeries, medical appointments in the past year, medications; complexity of the disease; educational impairment and psychological factors.	Worse
Im, <i>et al</i> (2018)	South Korea	13-19	PCQLI	Crosscutting	CHD	Presence of siblings; bad economic status; parental protection.	Better
Sleeper, <i>et al</i> (2017)	USA	7-16	Functional Status II	Longitudinal	Cardiomyopathy	Late diagnosis; good socioeconomic level; left ventricle size; high risk of death; presence of transplantation.	Worse
Li, <i>et al</i> (2017)	China	5-15	PedsQLTM 4.0	Longitudinal	CHD	Interventionist treatment by cardiac catheter.	Better
Neal, <i>et al</i> (2015)	USA	13-16	CHQ	Crosscutting	Tetralogy of Fallot	Attention deficit disorder; reduced left ventricular ejection; left ventricular diastolic dysfunction; number of surgical interventions	Worse
Uzark, <i>et al</i> (2015)	USA	13-25	PedsQL	Crosscutting	CHD	Knowledge deficit.	Better
Bertoletti <i>et al</i> (2015)	Brazil	10-18	KIDSCREEN-27	Crosscutting	CHD	Presence of clinical symptoms.	Worse
O'Byrne, <i>et al</i> (2014)	USA	8-18	PCQLI	Crosscutting	TA	Frequent hospitalisations; need for cardiac reintervention.	Worse
Wang <i>et al</i> (2014)	Australia	12-20	Paediatric Quality of Life Inventory 3.0-Cardiac	Longitudinal	CHD/ AHD	Adolescent knowledge of their health condition; level of social support; feeling of optimism and feeling of coherence.	Better
Heusch <i>et al</i> (2014)	Germany	7-18	ModuleHRQoL	Crosscutting	CHD	Ability to develop structures to cope with unfavourable health conditions.	Better
Coelho, <i>et al</i> (2013)	Portugal	12-26	WHOQOL-Bref	Crosscutting	CHD (complex)	Social support; scar from cardiac surgery; number of hospitalisations; concern with signs and symptoms of illness and dropping out.	Worse
Pulgaron <i>et al</i> (2013)	USA	8-17	Miami Pediatric Quality of Life Questionnaire	Crosscutting	Cardiac arrhythmias	Low submission rate to cardiac surgery; good parent-child relationship and solid family structure.	Better
Schaefer <i>et al</i> (2013)	Germany	11-16	KIDSCREEN	Crosscutting	CHD	Socioeconomic status; cardiopulmonary and postoperative circulation time and neurological abnormalities.	Worse
O'Byrne <i>et al</i> (2013)	USA	8-18	PCQLI	Crosscutting	CHD	Operative reintervention.	Worse
Koopman <i>et al</i> (2012)	Netherlands	9-23	WAICD	Crosscutting	Cardiac arrhythmias	Lack of health security; get tired easily and worry about the need for invasive treatments (ICD)	Worse
Janiec <i>et al</i> (2011)	Poland	8-18	KIDSCREEN-27	Longitudinal	Mitral Valve Prolapse	Frequency of clinical symptoms.	Worse
Kwon <i>et al</i> (2011)	USA	8-18	PedsQL	Longitudinal	Tetralogy of Fallot	Exercise capacity and functional status.	Better
Looman <i>et al</i> (2010)	USA	2-18	PedsQL	Crosscutting	Velocardiofacial Syndrome	Physical, social and emotional challenges.	Worse

PedsQL 4.0= Pediatric Quality of Life Inventory; WHOQOL-BREF= Self-report Questionnaire; CHQ = Child Health Questionnaire; PCQLI= Pediatric Cardiac Quality of Life Inventory; WAICD = Worries About (WA)ICDsScale; HRQOL Health-related quality of life; Congenital heart disease (CHD) and acquired heart disease (AHD); TA = Truncus arteriosus communis.

It was verified that 72.22% of the studies Koopman *et al.* 2012; Schafer *et al.* 2013; Pulgaron *et al.* 2013; O'Byrne *et al.* 2013; Coelho *et al.* 2013; Neal *et al.* 2015; Bertoletti *et al.* 2015; Uzark *et al.* 2015; Ernst *et al.* 2018; Im *et al.* 2018) were cross-sectional evaluations, only revealing the association between the variables but with no cause and effect relation; thus, any conclusions should be interpreted with caution. In addition, considering that adolescence is a period of great changes and instabilities, a longitudinal assessment would help identify the critical moments concerning the transition from childhood to adolescence and their relationship with the QoL and heart diseases. The different methodologies used lead to some discrepancies in terms of the sociodemographic and clinical variables and their influence on the QoL.

Among the inclusion criteria established, only one study on the subject was carried out in Brazil [4], while 5 articles were from Europe (Janiec *et al.* 2011; Koopman *et al.* 2012; Coelho *et al.* 2013; Schafer *et al.* 2013; Heusch *et al.* 2014, 8 from the United States of America (Looman *et al.* 2010; Kwon *et al.* 2011; Pulgaron *et al.* 2013; O'Byrne *et al.* 2013; O'Byrne *et al.* 2014; Neal *et al.* 2015; Uzark *et al.* 2015; Sleeper *et al.* 2017), 2 articles from Asia (Li *et al.* 2017; Im *et al.* 2018), 1 from Oceania (Wang *et al.* 2014) and 1 article with a British and North-American sample (Ernst *et al.* 2018). Among the heart diseases analysed, CHD was the most prevalent (Coelho *et al.* 2013; Schafer *et al.* 2013; O'Byrne *et al.* 2013; Heusch *et al.* 2014; Uzark *et al.* 2015; Bertoletti *et al.* 2015; Ernst *et al.* 2018; Li *et al.* 2017; Im *et al.* 2018), followed by AHD, which was addressed in combination with CHD in 1 article (Wang *et al.* 2014). Considering the fact that AHD is more associated with socioeconomic and living conditions, this can be the determining factor in terms of the low frequency of research on these pathologies in developed countries.

The evaluation of the quality of life can be carried out using generic (Koopman *et al.* 2012; O'Byrne *et al.* 2013; Pulgaron *et al.* 2013; Schafer *et al.* 2013; Coelho *et al.* 2013; Heusch *et al.* 2014; Wang *et al.* 2014; Bertoletti *et al.* 2015; Uzark *et al.* 2015; Li *et al.* 2017; Sleeper *et al.* 2017; Ernst *et al.* 2018; Im *et al.* 2018) or specific tools (Looman *et al.* 2010; Kwon *et al.* 2011; Janiec *et al.* 2011; O'Byrne *et al.* 2014; Neal *et al.* 2015). Specific tools evaluate the QoL under a certain condition or in the scenario of a particular disease, being more sensitive to changes over time. On the other hand, generic tools assess the general population or compare this population with one that has a specific disease. These tools have the disadvantage of not specifically targeting the adolescent age group, although they also reduce the sensitivity to specific problems resulting from cardiomyopathies, as no clear distinction between the symptoms is possible (Wang *et al.* 2014). Nevertheless, it can be stated that there has been progress in terms of the assessment of the QoL in children and adolescents with cardiomyopathy. The generic tool of the Pediatric Quality of Life Inventory (PedsQL) was combined with a cardiac component. Marino *et al.* 2009 created the Pediatric Cardiac Quality of Life Inventory (PCQLI), which is applicable for children and adolescents with ages ranging between 8 and 18 years old, with a version for parents. This tool was recently validated in Brazil by Lopes *et al.* 2018.

Studies have shown that some factors influence the QoL of cardiomyopathic adolescents (Pike *et al.* 2012; González-Gilet *et al.* 2012), such as the number of interventions, functional limitations and emotional support. Accordingly, these authors

investigated the influence of these variables and indicated the existence of distinct, and sometimes contradictory, findings. The need of invasive treatments and frequent hospitalisations / interventions were identified as the main factors that have a negative influence on the QoL of cardiomyopathic adolescents (Koopman *et al.* 2012; Coelho *et al.* 2013; O'Byrne *et al.* 2013; O'Byrne *et al.* 2014; Neal *et al.* 2015; Ernst *et al.* 2018). Pulgaron *et al.* 2013 demonstrated the relationship between the low submission rates to heart surgery and a good quality of life. Physical challenges, the presence of clinical symptoms and the fact of being easily tired were also pointed out as negative influences on the QoL (Koopman *et al.* 2012; Bertoletti *et al.* 2015). Due to the effects of heart diseases on the ability to exercise and the interactions between the cardiovascular and respiratory systems during activities that require physical effort, it does not come as a surprise that physical limitations have been identified as one of the factors responsible for impacting the QoL of adolescents (Carvalho *et al.* 2009; Marino *et al.* 2009; Kwon *et al.* 2011; González-Gil *et al.* 2012; Pike *et al.* 2012). Besides these limitations, these adolescents often feel excluded from activities that require social interaction, but involve physical efforts, which can cause a feeling of sadness and outbreak (Carvalho *et al.* 2009).

Several studies (Marino *et al.* 2009; Neuner *et al.* 2011; Luyckx *et al.* 2012; Pike *et al.* 2012; Wang *et al.* 2014) have revealed that living with a heart disease has many psychosocial consequences, given that teenagers have the highest levels of depression, loneliness, as well as greater levels of psychological stress and low self-esteem when compared with a healthy group. Longitudinal surveys (Kwon *et al.* 2011; Janiec *et al.* 2011; Wang *et al.* 2014; Sleeper *et al.* 2015; Li *et al.* 2017) show how these problems remain for a while as a negative predictor of QoL and are not easily visible to external observers, such as parents and health professionals (Luyckx *et al.* 2012). This finding was verified by Landolt *et al.* 2008 and Spijkerboer *et al.* 2006, who evaluated the QoL of adolescents with AHD through the Child Quality of Life Questionnaire (TACQOL) instrument. This instrument has a specific version for adolescents and parents, which evaluates the quality of life of their children. The results have shown that adolescents reported to have worse QoL when compared to the report from parents. One possible explanation for this difference can rely on the fact that the perception and meaning of QoL can vary among individuals in response to many factors. Adolescents may still not have the cognitive abilities to interpret certain life experiences, with their judgements being strongly influenced by recent incidents, such as hospitalisation and surgery. In contrast, parents, when assessing the quality of life related to their children's health (HRQoL), despite being influenced by feelings and tensions regarding the precarious health conditions of their children, demonstrated good strategies to cope and handle the problem.

In turn, the perception of the QoL of adolescents by health professionals was also addressed in some selected studies (Marino *et al.* 2009; Teixeira *et al.* 2011; Pike *et al.* 2012; Luyckx *et al.* 2012). Emotional factors, such as anxiety due to the divorce / separation of parents during hospitalisation, the fear of the procedures or of needles, difficulty in understanding the reason for being hospitalised were among the most reported. It is worth pointing out that these professionals are limited to the contact with the patients only during hospitalisation, when stressful situations and criticisms unfold, which will mostly have an effect on the psychological

dimensions. There is a great difference from the perception of parents, given that they are also present outside of the hospital environment and in other contexts; thus, being able to identify the physical and social dimensions as the most undermined (Marino *et al.* 2009). Studies have demonstrated that social support has a positive impact on QoL, contributing to the social and psychological components, favouring the adaptation to the disease and even the compliance to treatment (Landolt *et al.* 2008; Teixeira *et al.* 2011; Pike *et al.* 2012; Luyckx *et al.* 2012; Rassart *et al.* 2013; Wang *et al.* 2014). According to Teixeira *et al.* 2011, school performance can be affected by cardiomyopathies due to frequent hospitalisations, medical appointments and fatigue as a result of the pathology. Spijkerboer *et al.* 2006 also points out that some individuals with CHD have difficulties in understanding arithmetic, reading, writing and in visual-motor integration. For Landolt *et al.* 2008, extracorporeal circulation, often inherent to cardiovascular surgeries, is associated to poor blood circulation which can lead to neurological damage, with a consequent neurocognitive neurodevelopment, thus, causing a worse QoL in this respect.

It is important to point out that there were some disagreements in the searches regarding the findings on quality of life. Some studies observed a reduction in the QoL of adolescents with heart disease when compared with the general public, which can be partly due to the physical limitations reported (Landolt *et al.* 2008; Luyckx *et al.* 2012). On the other hand, other researches have also reported an improvement on the QoL of adolescents with cardiomyopathy (Apers *et al.* 2013; Wang *et al.* 2014). This improvement can be justified by the premature adaptation of these youngsters to the adverse events caused by the disease, promoting a better coping capacity, reinforcing the theory that the QoL of this population is not proportional to the severity of the disease. Wang *et al.* 2014, Neuner *et al.* 2011, Luyckx *et al.* 2012, Apers *et al.* 2012 and Apers *et al.* 2013, when studying cardiomyopathic adolescents, stated that a strong positive predictive for QoL over time is the Sense of Coherence (SOC), whose concept was developed to explain why people may have different reactions when faced with similar stressful events. Those with a strong SOC tend to be more resistant and capable of seeking a solution to cope with a certain problem. Therefore, SOC represents a protection factor, related with success in face of everyday issues, thus promoting a better QoL.

As previously mentioned, the number of surgeries, the duration of extracorporeal circulation, the hospitalisation length and the use of medications have a significant effect on QoL. These variables reflect a greater impairment on the functional status, as well as a greater degree of severity of the disease (Janiec *et al.* 2011; O'Byrne *et al.* 2013). Authors that studied more than one type or sub-type of cardiomyopathy revealed no relationship between these variables and QoL (Spijkerboer *et al.* 2006; Landolt *et al.* 2008; Marino *et al.* 2009; Lu *et al.* 2010; Neuner *et al.* 2011; Lu *et al.* 2012; Wang *et al.* 2014). Another factor pointed in the studies was the lack of understanding of the disease among adolescents (Wang *et al.* 2014). A good knowledge of cardiomyopathy can be related to lower anxiety levels, as well as less complications and a better psychological functioning, thus improving QoL, as healthy behaviours are adopted when managing the pathology. Simon *et al.* 2008, on their study on heart transplant adolescent patients, reinforced the need of a dialogue between transplanted patients and health professionals regarding

immunosuppressive medications, their collateral effects and possible plans to mitigate the impact of transplant on the physical and psychological functioning of these patients.

Conclusion

The results of this review showed that adolescents with cardiomyopathy have a worse quality of life when compared with adolescents without the disease. It was possible to verify that the perception of QoL of adolescents is influenced by factors such as the number of interventions, functional limitations, type of treatment and emotional support. By observing some studies, the variables physical, or even psychosocial, impairment was noticed, as well as some disagreements in terms of the sociodemographic and clinical variables and their influence on the QoL. These discrepancies are associated with the different methodologies used, such as the study design, inclusion and exclusion criteria, as well as the type of instrument used to evaluate the QoL, cardiomyopathy and even the sample follow-up period. The assessment of the QoL of this population can be used to establish priorities and identify possible problems, improving communications and monitoring changes over time or the response to treatment. Health professionals, through appropriate interventions, should take into account the perception of patients and their families on the quality of life, aimed at supporting the psychosocial and physical development of these adolescents, as well as reinforcing their capacity of coping with the challenges that they will face.

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