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Veröffentlichungsversion / Published Version  
Zeitschriftenartikel / journal article

#### Empfohlene Zitierung / Suggested Citation:

Carlantônio, L. F. M. d., Santiago, L. C., Ribeiro, R. V., & Arcoverde, K. V. P. T. d. S. (2015). An integrative review about the pediatric heart transplant and the aspects of quality of life. *Revista de Pesquisa: Cuidado é Fundamental Online*, 7(3), 2805-2814. <https://doi.org/10.9789/2175-5361.2015.v7i3.2805-2814>

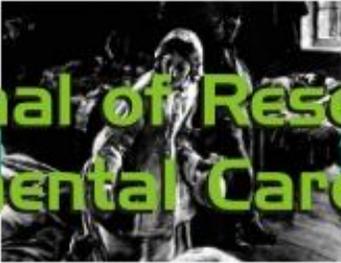
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# Journal of Research Fundamental Care Online

ISSN 2175-5361  
DOI: 10.9789/2175-5361

## REVIEW INTEGRATIVE OF THE LITERATURE

**Revisão integrativa sobre o transplante cardíaco pediátrico e os aspectos na qualidade de vida**

An integrative review about the pediatric heart transplant and the aspects of quality of life

Una revisión integradora acerca del trasplante cardíaco pediátrico y los aspectos en la calidad de vida

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### ABSTRACT

**Objective:** it is an integrative review of literature that aims to review the productions concerning pediatric heart transplant and the aspects of quality of life, summarising the impact of transplantation in this group. **Method:** an integrative review, where there were elected descriptors; tested combinations; conducted a search in the databases; and thematic analysis to examining the findings. **Results:** the cut-out of 68 studies reviewed, 23 were selected, among them only 10 were framed in all criteria, and were analyzed. **Conclusion:** the complex congenital heart diseases can be treated with heart transplantation in some stage of its evolution, without increased mortality or morbidity, evidenced in the fact that medical complications can be controlled. **Descriptors:** Quality of life, Heart transplantation, Child, Nursing.

### RESUMO

**Objetivo:** Trata-se de uma revisão integrativa de literatura que objetiva revisar as produções referentes ao transplante cardíaco pediátrico e os aspectos na qualidade de vida, sintetizando o impacto do transplante neste grupo. **Método:** Revisão integrativa, onde foram eleitos descritores; testados combinações; realizada busca nas bases de dados e análise temática para examinar os achados. **Resultados:** Do recorte de 68 artigos pesquisados, foram selecionados 23, dentre eles apenas 10, se enquadravam em todos os critérios, e foram analisados. **Conclusão:** As cardiopatias congênicas complexas podem ser tratadas com o transplante cardíaco, em alguma fase de sua evolução, sem aumento da mortalidade ou morbidade, fato que evidenciamos nas complicações médicas passíveis de controle. **Descritores:** Qualidade de vida, Transplante de coração, Criança, Enfermagem.

### RESUMEN

**Objetivo:** es una revisión integral de la literatura que pretende revisar la producción relativa el transplante cardíaco pediátrico y los aspectos en la calidad de vida, resumiendo el impacto del trasplante en este grupo. **Método:** revisión integradora, donde fueron elegidos los descriptores; probadas combinaciones; se realizó una búsqueda en las bases de datos; y el análisis temático para examinar los resultados. **Resultados:** del corte de 68 artículos estudiados, 23 fueron seleccionados, entre ellos sólo 10 estaban enmarcados en los criterios, y se analizaron. **Conclusión:** las cardiopatías congénitas complejas pueden ser tratadas con el trasplante de corazón en alguna etapa de su evolución, sin aumento de la mortalidad o la morbilidad, hecho que se evidencia en las complicaciones médicas que pueden ser controladas. **Descritores:** Calidad de vida, Transplante de corazón, Niños, Enfermería.

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## INTRODUCTION

**H**earth transplantation is one of the great advances in medicine in the twentieth century. The first heart transplantation between humans was performed by Barnard in 1967<sup>1</sup>, and in the same year, there was reported the 1<sup>st</sup> neonatal transplantation, when Kantrowitz<sup>2</sup> tried, unsuccessfully, the transplantation in newborn carrier of Ebstein's anomaly.

However, clinical application of neonatal transplantation due to the pioneering Bailey that in 1984<sup>3</sup> performed the first xenotransplantation in a child with hypoplastic left heart syndrome (HLHS).

According to the Brazilian Association of Organ Transplantation - ABTO, there were conducted in Brazil, from January to December 2011, a total of 160 heart transplants from deceased donors, and 28 of these pediatric patients. Of these 28 pediatric transplants, 7 occurred in the age group of 0 -5 years old, 9 aged 6-11 years old and 12 in the age group of 12 - 17 years old.<sup>4</sup>

In this perspective, the application of heart transplantation in the pediatric area has enabled survival and improved quality of life in a group of children with complex and refractory cardiomyopathies.

However, the process for heart transplantation brings difficulties, ranging from fitness profile to the availability of compatible organ. Thus, pediatric patients are those with reduced prospects for obtaining organs in a timely manner, especially at the lower weight and the reduced availability of compatible donors. His prognosis is quite reserved and mortality in the short term, waiting for a compatible organ, reaches 20%, reaching up to 31% in children aged less than 6 months old.<sup>5-6</sup>

On this front, the success of infant heart transplant means ensuring the survival of patients with heart disease and allow them to develop their daily activities with quality. Thus, the infant heart transplantation represents an increase of survival and quality of life of transplant.<sup>5</sup>

Quality of life is self-esteem and personal well-being and includes a number of aspects, such as functional ability, socioeconomic status, emotional state, social interaction, intellectual activity, self-care, family support, the state itself health, cultural, ethical and religious values, lifestyle, satisfaction with the job and with daily activities and the environment in which we live.<sup>7</sup>

There is concern by health professionals with the quality of life of human beings, especially with children's cardiac transplant recipients, as they require strict care and greater family and health care team.

The initial arguments, set up, allow us to then signal that the understanding and mastery of the impact of heart transplantation in the quality of life of pediatric patients

becomes a sufficiently interesting subject from the point of view of a problem/phenomenon to be investigated in the context of nursing research, on which we develop.

There is a need to know the universe of studies published about the attempt to provide children with heart disease live longer through the heart transplant. This brings the reasoning for the quality of life of these children since the heart transplant be an extremely stressful alternative, requires discipline and constant self-care.

Based on the growing trend around the proposed theme, it is important to consider its specific purpose to collaborate so that the health care process results in benefits for both users and for professionals. Therefore, we defined as a study object "pediatric heart transplant and the quality of life."

In order to review the related productions pediatric heart transplant and aspects of quality of life, became the question: How is shown in scientific production aspects related to quality of life of children undergoing heart transplantation?

The purpose of this article is to review the productions for the pediatric heart transplant and aspects of quality of life, as a contribution through subsidies for nursing care to this group.

## METHOD

The study is characterized as an integrative literature review. Integrative review is the broadest type of review research because it allows the simultaneous inclusion of experimental and non-experimental research, combines empirical and theoretical literature data and incorporates a wide range of purposes: to define concepts, theories review, review evidence and the examine methodological issues of a specific topic.<sup>8</sup>

The development of an integrative literature review occurs in six distinct stages: issue identification and research questions, sampling or literature search, categorization study, evaluation of the studies included in the literature review, interpretation of results and synthesis of knowledge evidenced in articles analyzed or presentation of the integrative review.<sup>9-10</sup>

Therefore, we proceeded to a literature integrative review to the object "pediatric heart transplant and the quality of life" from the content of accessible references. The choice and combination of the following descriptors: heart transplant AND quality of life, heart transplantation AND quality of life and trasplante de corazón AND calidad de vida.

The publications were identified in the following databases: LILACS; BDEF; SciELO and PubMed. Inclusion criteria were: scientific articles indexed in national and international journals published in English, Spanish and Portuguese, from January 2002 to 2012 and that addressed the pediatric heart transplant and somehow brought the quality of life.

Exclusion criteria were: Articles that did not address the issue in the manner indicated by the researchers; text not indexed in the specified databases; articles without

summary available in databases that were indexed, and cannot be purchased the full article for free, with the researchers' access to the portal of Higher Education Personnel Training Coordination Foundation (CAPES).

Data collection was performed using a previously set table and included: author, title, year, research question, general objective, specific objective, theoretical framework, methodological approach, location, subject, sample, data collection technique, the time of collection, analysis, method, results, discussion, conclusion and prominent narrative passages (described contents that came closest to the object of study). The thematic content analysis<sup>11</sup> was the method to examine the data. We used the abbreviation (A) for articles.

The selected studies were critically evaluated, seeking to determine their methodological quality. So were assigned evidence levels that followed the classification proposed by Melnyk and Fineout-Overholt.<sup>12</sup>

## RESULTS AND DISCUSSION

As search results there were obtained 68 articles. Then there were read the titles and abstracts by both researchers, resulting in a sample of 23 articles. We performed the selection of articles in full, first in the database which have been properly selected and later in CAPES portal with the help of a librarian. At this stage resulted in 12 articles in full, 2 articles discarded after its correct reading observed not it is the study of the subject.

Thus, 10 indexed scientific articles were reviewed in international journals. Of the 10 articles analyzed, the highest production was concentrated in the years 2005 and 2009, with an average of two articles per year.

When the research designs were analyzed two articles (20%) were found of quasi-experimental design. Non-experimental design items totaled 8 (80%), 3 of the descriptive / exploratory (30%), 4 prospective (40%) and expert opinion (10%).

Regarding the strength of evidence 3 articles have evidence level III (30%), 3 articles have evidence level IV (30%), 3 articles have evidence level VI (30%) and 1 product was rated the level evidence VII (10%).

**Table 1: researched articles in databases**

Identification of the article	Complete reference
A1	Wray J, Radley-Smith R. Beyond the first year after pediatric heart or heart-lung transplantation: Changes in cognitive function and behavior. <i>Pediatric Transplant</i> 2005;9:170-177.

A2	Green, A., McSweeney, J., Ainley, K., Bryant, J. Comparing parents' and children's views of children's quality of life after heart transplant. <i>Journal for Specialists in Pediatric Nursing</i> . 2008; 14: 49-58.
A3	Olausson, B., Utbult, Y., Hansson, S., Krantz, M., Brydolf, M., Lindstrom, B., Holmgren, D. Transplanted children's narratives of daily living: Children's narratives about their lives following transplantation. <i>Pediatric Transplantation</i> . 2006; 10: 575-585.
A4	Green, A., McSweeney, J., Ainley, K., Bryant, J. In my shoes: Children's quality of life after heart transplantation. <i>Progress in Transplantation</i> . 2007; 17: 199-208.
A5	Sanjiv, K., Gandhi, MD., Charles, E., Canter, MD., Agnieszka Kulikowska, MD., Charles, B., Huddleston, MD. Infant Heart Transplantation Ten Years Later—Where Are They Now? <i>Ann Thorac Surg</i> 2007;83:169 –72.
A6	Uzark, K., Spicer, R., Beebe, DW. Neurodevelopmental Outcomes in Pediatric Heart Transplant Recipients. <i>The Journal of Heart and Lung Transplantation</i> 2009; 28: 1306-11.
A7	Ari RJ, Luis GQ, Charlene MTR, Irina AD, Gwen AMN, James C, RegS, Bryan VA, David BR, Ivan MR. Outcomes after heart transplantation in children under six years of age. <i>Pediatric Cardiac</i> 2011fev/mar; 10 (1): 1016.
A8	Wray, J; Lunnon-Wood, T; Smith, L; Orrells, C; Iguchi, A; Burch, M; Brown, K; (2012) Perceived quality of life of children after successful bridging to heart transplantation. <i>J Heart Lung Transplant</i> , 31 (4) 381 - 386.
A9	Wray J, Radley – Smith R. The occurrence of depression in pediatric patients before and one year after heart or heart-lung transplantation. <i>J Heart Lung Transplant</i> 2004oct/nov; 23 (3): 1103 – 1110.
A10	Pollock-BarZiv SM, Anthony SJ, Nieldra AI, Dipchand AI, & West LJ. Quality of life and function following cardiac transplantation in Adolescents. <i>Transplantation Proceedings</i> . 2003; 35: 2468-2470.

There was performed overall thematic grouping of items and found 12 tracks. However, five themes were categorized and analyzed, namely: a) behavioral changes at home and at school; b) survival; c) neurological development; d) cognitive function; e) perspective of parents and children across the heart transplant. The choice of the five themes was to test those directly discussed the object of study.

### Behavioral changes at home and at school

In general, surveys show that children who pass through the heart transplant have a small level of behavioral difficulties at home and at school.

What was partially evidenced by the study A1, where points indicative of behavior at home problem. There is also a degree of involvement in school behavior, seen by the author, but as no difference of the problems faced at school by healthy children.

Noting that the increased risk of child transplanted tend to deterioration in school performance, wins grounding in the time spent on hospitalizations giving means to school late. In addition to the research evidencing overprotective parents and anxious that do not allow the child post transplanted mixing or participate in education groups or daycare.

In this sense, findings of 6 (60%) of selected articles from this perspective (A1, A2, A4, A5, A7 and A8), indicate that the impact of transplant psychosocial put additional

burden on these patients, as many were concerned about the conflict symptoms (eg. fatigue, cosmetic change due to immunosuppressive drugs, sleep disorders, pain).

### Survival

Articles sample, A3 and A6 investigated the survival of patients after heart transplantation. The studies confirm the fact that the potential consequences due to heart transplant survival ranging from graft failure, severe infection prevention and early detection of acute rejection.

In contrast, the hope of these children to survive to become adults becomes a lofty goal and perhaps a little unrealistic given result observed in the older age groups. Adults undergoing heart transplant have a survival rate of approximately 50% at 10 years after transplantation, with the most common cause of coronary transplant vasculopathy death.

In A7 study shows that children who undergo heart transplantation, especially those with coronary disease are at high risk for adverse outcomes. Adverse outcomes including failure to thrive, frequent rehospitalization, frequent disabilities can, and frequent mental, language and motor delays.

With these findings cannot be said that the evidence is that the survival curve continues a trend of steady decline, because as seen several factors influence the success of heart transplantation and so the expected survival.

### Neurological Development

Although some factors such as better physical functioning, there is still the idea that the pediatric heart transplant survivors may face challenges in developing after transplantation.

Articles of the sample A8, and A10, searched on specific neurological development, showing that recipients of pediatric heart transplantation have intelligence scores on average, although significantly smaller than normal pediatric patients or healthy controls.

In these studies, it is clear the risk for development or cognitive deficit is greater in these patients. There are suggesting delays in the ability to use the spoken language of communication (ie, expressive language) and difficulties with speech articulation in heart recipients. One possible explanation is that these children are sometimes hospitalized for long periods during childhood, when much knowledge is acquired.

In the survey A1, suggesting that the restrictions limit the child social interactions and the impact that the development of speech and social skills, resulting in poorer performance in these areas for transplant patients compared to the healthy group. The etiology of speech and language delays remains open to debate.

About half of heart transplant recipients of studies emphasized that topic had deficits visual motor or lower working engine. This rate is much higher than seen in the general population, indicating the substantial risk to the poor coordination of movements of the hand and wrist that are often necessary to write and draw.

Given the high risk of difficulties with motor and visual skills, children who undergo heart transplantation should be given to the possibilities of being referred for an

occupational therapy assessment in the months after medical stabilization to assess the need for occupational therapy interventions, as that studies show that children can benefit from this therapy.

Through the results of the studies, it is noticed that most children are active and able to participate in activities appropriate to the age after heart transplantation. As regards the Intelligence Quotient (IQ), has obstacles to evaluate it, because the samples are of inappropriate size and it is understood that this ratio suffer influences of the environment.

### **Cognitive Function**

Three sample articles, A3, A6 and A9 studied on cognitive function. The majority (73%) of patients who survived nearly a decade after heart transplantation showed psychological functioning within normal limits. While most patients seemed to work well, it is interesting to note that 25% of patients had difficulties of emotional adjustment at some point during the treatment of heart transplant.

They also had family functioning scores were within the normal range. In the context of higher severity scores of side effects and a greater number of congenital heart disease diagnosed, although limited by the lack of a second accompanying measure setting, this observation again supports the resilience of children facing the difficulties of heart transplantation.

In only one study, A9, medical severity was found to be a less important factor than the operating family determines post-transplant setting, but the authors feel the need to expand the capacity to develop risk factor models, to examine the different patterns of emotional functioning over time and considering the periods of development time.

Finally, the studies do not examine this perspective other possible risk factors such as styles of individual and family coping or deficiencies of neuropsychological, which can alter cognitive functioning.

### **Perspective of parents and children facing the heart transplant**

In trying to understand the experiences and perceptions of parents and children in relation to heart transplantation, A2 reports it emphatically. Most speeches of children were positive about their lives and valued the normal aspects of life (doing what children do and be with friends and family).

Although they were aware of his heart to be transplanted, did not want this fact to dominate their lives and worked to avoid keeping the focus to the disease. Such coherence and evidence from studies, A1 and A10, reflect that children have shift perspectives, and prefer to value aspects of their lives to keep welfare at the forefront.

Many of the negative factors related to the transplant were identified by the children in the studies, such as pain and limitations, which forced a temporary change foreground on welfare in the foreground disease.

However, the children identified many positive factors such as supportive relationships and appropriate developmental activities that support the well-being to the fore, including normal childhood activities, family relationships and the transplant team, development of favorite school activities.

In this study (A1), children describe negative feelings about their appearance, but not directly compare their appearance to that of their peers. Some children reported difficulty in keeping up with colleagues in physical activities and highlighted some being unable to eat food you can eat their peers. If evidence in this study, the fact that children are more focused on their own disability than on different feeling.

In the perspective presented by parents who report the transplant process as a struggle. Often prone to describe this fight as negative impacts children, and not fully appreciate the transplant, perhaps because they believe that the best prognosis balances distress.

Parents and children agreed on the most important issue that affects children, described as restricted activities. Nevertheless, the parents described perhaps unnecessary restrictions, such as not allowing the child to play in a restaurant playground because of fear of infectious diseases. In addition, both (A1 and A10) reported that children showed decreased resistance to their peers who interfered with participation in desired activities.

Some reports in the present study may indicate that parents recognize how important a normal childhood, however, its normal value as perceptions of healthy children reference makes it difficult not restrict your child to activities.

Furthermore, since most children do not remember their pre transplantation life, their life after transplantation was probably normal to them.

What to parents becomes more difficult, as they followed every fight they set. These discussions have made it clear that parents feel responsible for the health of their children, mainly through monitoring and surveillance.

## CONCLUSION

The complex congenital heart disease can be treated with heart transplantation at some stage of its evolution, with no increase in mortality or morbidity, a fact that we noted in the medical complications and post-transplantation survival approached by the articles.

The complications following pediatric heart transplant are mostly subject to medical control and are not limiting factor for patient survival. This survival in the medium term has improved and can be currently considered as very good points searches.

The family and social reintegration of transplanted children can, in most cases, justifying the adoption of this form of treatment turn out to be essential in the perspective of transplant.

Thus, we can consider that when thinking about quality of life working together to pediatric patients receiving a heart and his family, allows the expression of experiences, anxieties, conflicts that interfere or are triggers of possible complications, favoring the relationship between the team and the child or adolescent, so that we can promote better development of frameworks, through better design of patient/professional values.

Despite the quality of life after pediatric heart transplant today be one, there is no doubt, given the above, the importance of implementing, increasingly, these interdisciplinary efforts, in order to ensure fairer approach to the pediatric patient values and family, thus ensuring more favorable conditions for their recovery and resolution of problems that arise in the course of long-term medical treatment.

Highlighting that research in this area is still limited and incipient is highlighted by the limited size found for sample and the level of evidence of the analyzed articles. Where any article presented evidence level I, demonstrating excellence in production, with the best finish found the level III for only 3 (30%) of the sample articles.

It is understood that it is necessary to unite efforts of interest groups in research and expand research and studies addressing the quality of life across the pediatric heart transplant.

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Received on: 04/06/2014  
Required for review: No  
Approved on: 10/02/2015  
Published on: 01/07/2015

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