

Quality of life in children with kidney transplant: Systematic review

Qualidade de vida em crianças transplantadas renais: Revisão sistemática

La Calidad de vida en niños trasplantados renales: Revisión sistemática

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ABSTRACT

Objective: To identify in the literature studies that evaluate the quality of life in pediatric patients with kidney transplant through use of specific, validated instruments in Pediatrics. **Method:** Systematic review of the literature with searches conducted in the following databases: Medline, PubMed, LILACS, CINAHL, SciELO and Cochrane Library. Main keywords: *Quality of life, Kidney transplantation and Pediatrics*. **Results:** A total of 366 studies were selected and eight observational studies were included that evaluated the quality of life of children with kidney transplant by means of evaluation instruments of quality of life. **Conclusion:** The quality of life of children with kidney transplant is inferior compared to healthy children. The post-transplant period presents better results compared to pre-transplant children. The identification of mental, physical and social conditions related to the quality of life of this population allows for better planning the assistance provided to them.

Descriptors: Quality of Life; Kidney Transplantation; Pediatrics; Nursing; Review.

RESUMO

Objetivo: Identificar na literatura estudos que avaliam a qualidade de vida de pacientes pediátricos transplantados renais através de instrumentos específicos e validados em pediatria. **Método:** Revisão Sistemática da Literatura com pesquisas realizadas nos bancos de dados: Medline, PubMed, LILACS, CINAHL, SciELO e Biblioteca Cochrane. Principais descritores: *Quality of life, Kidney transplantation and Pediatrics*. **Resultados:** Foram selecionados 366 estudos e incluído oito estudos observacionais que avaliaram a qualidade de vida das crianças transplantadas renais por meio de instrumentos de avaliação da Qualidade de Vida. **Conclusão:** A qualidade de vida de crianças transplantadas renais é inferior quando comparadas as crianças saudáveis. O período pós transplante apresentam resultados melhores comparadas às crianças pré-transplante. A identificação das condições mentais, físicas e sociais relacionadas à Qualidade de Vida dessa população abre possibilidades para o melhor planejamento da assistência prestada.

Descritores: Qualidade de Vida; Transplante Renal; Pediatria; Enfermagem; Revisão.

RESUMEN

Objetivo: Identificar en la literatura estudios que evalúan la calidad de vida de pacientes pediátricos trasplantados renales a través de instrumentos específicos y validados en pediatría. **Método:** Revisión Sistemática de la Literatura con investigaciones realizadas en los bancos de datos: Medline, PubMed, LILACS, CINAHL, SciELO e Biblioteca Cochrane. Principales descriptores: *Quality of life, Kidney transplantation and Pediatrics*. **Resultados:** Se seleccionaron 366 estudios e incluyó ocho estudios observacionales que evaluaron la calidad de vida de los niños trasplantados renales por medio de instrumentos de evaluación de la Calidad de Vida. **Conclusión:** La calidad de vida de los niños trasplantados renales es inferior en comparación con los niños sanos. El período post trasplante presenta resultados mejores comparados a los niños pretrasplante. La identificación de las condiciones mentales, físicas y sociales relacionadas a la Calidad de Vida de esa población abre posibilidades para la mejor planificación de la asistencia prestada.

Descriptores: Calidad de Vida; Trasplante de Riñón; Pediatria; Enfermería; Revisión.

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INTRODUCTION

End-stage kidney disease (ESKD) has presented increasing incidence in the pediatric population, often lower than that found in adults. Recent estimates report the occurrence of 84.6 cases per million population with compatible age (pmpca) in the United States of America and 36.6 pmpca cases in Europe. Amongst the few cases described in Latin America, Brazil registers an incidence of 47.4 pmpca cases, with 24 cases in the state of São Paulo and 23.4 in the state of Rio de Janeiro⁽¹⁾.

Various aspects of the lives of children and adolescents are impacted by ESKD, which includes changes in family routine and social conviviality due to specific dietary needs, commitment to dialysis treatment, the presence of invasive procedures, the constant use of specific drugs and hospitalizations required as a result of frequent clinical changes. These factors, among others, lead children and teenagers to acquire emotional, physical and social changes, influencing quality of life (QOL)⁽¹⁾.

The main causes of ESKD in the pediatric population are chronic glomerulonephritis, urological malformation (posterior urethral valves), renal dysplasia and CKD of unknown etiology, however the most frequent are septicemia, acute kidney injury, diarrhea, malaria and hemolytic uremic syndrome. Other factors such as high blood pressure, obesity and low birth weight are also regarded as a cause for the development of ESKD⁽²⁻³⁾.

Kidney transplantation (KTx), besides being considered the most effective treatment for end-stage kidney disease, compared to dialysis methods, allows for better quality of life, and, in the case of a pediatric population, improvement in neuropsychomotor development. In addition, it is an internationally accepted procedure which improves survival rate^(1,4).

In pediatric populations, kidney transplantations present variations each year. According to data from 2014 of the Brazilian Association of Organ Transplantation (ABTO), the number of transplantations was 13.3% higher than the previous year. In 2015, it decreased by 5 percent compared to 2014. In 2016, 310 transplantations were conducted (5.8 per million population (pmp), which means there was a decrease of 2% compared to 2015. This considering that 380 children (7.2 pmp) were added to the transplantation list, whereas children who effectively had transplantation were 310 (81.5%)⁽⁵⁾.

It is worth mentioning that the QOL of patients with transplant depends on several determining factors, among them: age at the time of transplant, nutritional factors, duration of dialysis before transplantation, education level, adherence to drug treatment, among others⁽⁶⁾.

The QOL can be measured through the use of generic and specific instruments, where generic ones can be used for both healthy children and those with a chronic disease, while the specific assess the QOL of sick children⁽⁷⁾.

Studies show that the higher the psychological suffering, the lower the adherence to treatment. On the other hand, there is a deficiency in the literature for studies that address the subject with regard to quality of life and the pediatric patient with kidney transplant in particular⁽⁸⁾.

In this sense, this research aims to contribute to the improvement of the evaluation and valorization of the use of these instruments in children who performed KTx as essential part of nursing care and care planning, and identify in the literature studies

that evaluate the quality of life in pediatric patients with kidney transplant through specific, validated instruments in Pediatrics.

OBJECTIVE

To identify in the literature studies that evaluate the quality of life in pediatric patients with kidney transplant through use of specific, validated instruments in Pediatrics.

METHOD

This is a systematic review based on the steps established by the Cochrane Collaboration⁽⁹⁾.

The keywords used in the search of scientific articles were:

quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields] AND ("kidney transplantation"[MeSH Terms] OR ("kidney"[All Fields] AND "transplantation"[All Fields]) OR "kidney transplantation"[All Fields] OR ("renal"[All Fields] AND "transplant"[All Fields]) OR "renal transplant"[All Fields] AND ("pediatrics"[MeSH Terms] OR "pediatrics"[All Fields] OR "pediatric"[All Fields]) AND ("kidney diseases"[MeSH Terms] OR ("kidney"[All Fields] AND "diseases"[All Fields]) OR "kidney diseases"[All Fields] OR ("kidney"[All Fields] AND "disease"[All Fields]) OR "kidney disease"[All Fields])

Figure 1 – Terms specific to the electronic search

The following databases were consulted: Medical Literature Analysis and Retrieval System Online (Medline)/National Library of Medicine (Pubmed) from January 1966 to June 2018, Literatura Latino-Americana de Ciências da Saúde (LILACS) from January 1982 to June 2018, Scientific Eletronic Library Online (SciELO) from June 1998 to June 2018, Cumulative Index to Nursing and Allied Health Literature (CINAHL) from January 1981 to June 2018, and Cochrane Library, from January 2007 to June 2018.

For the search strategy applied, the publication year of studies was not predetermined, as filtering the date of publication of the studies presents no usefulness, since quality of evidence is not inherently related to the publication date.

The inclusion criteria for article selection was the indexing in the databases aforementioned, the papers being available in English, Spanish or Portuguese. At first, reading of the publication title was made, then careful reading of the abstract, in order to verify the adequacy of the inclusion criteria described above.

In cases where the title and abstract were not sufficient to define the topic researched, the publication in full was sought, in order for all criteria to be applied and for the articles that answered the guiding question to be selected.

RESULTS

By means of the keywords presented in Figure 1, 366 primary studies were found, namely: 260 in PubMed, 50 in LILACS, 20 in CINAHL, 36 in SciELO and 0 in Cochrane Library. Through reading of title and abstract, 32 studies were selected, all of them

available in English. After reading these studies in full, eight articles met the inclusion criteria and were thus selected for this research, as described in Figure 2.

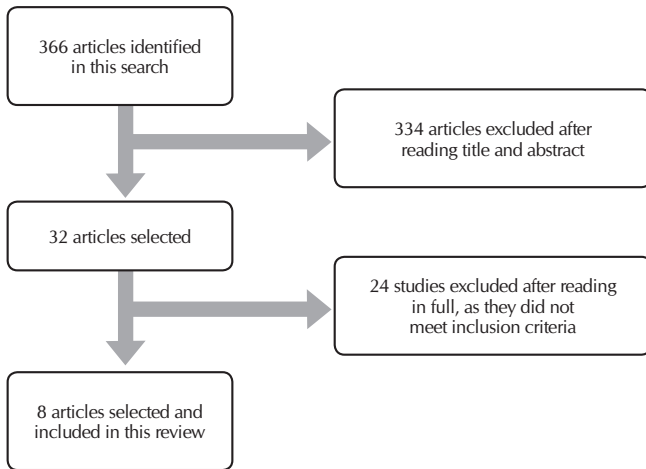


Figure 2 – Flowchart regarding selection and identification of studies by following PRISMA recommendations (<http://www.prisma-statement.org/>)⁽¹⁰⁾

The characterization of the studies is presented in Chart 1. Characterization of studies is presented in Chart 1. Clinical guidelines based on systematic reviews of randomized and controlled clinical trials were adopted:

- I. Evidence from at least one controlled and well-designed randomized clinical trial;
- II. Evidence from well-designed clinical trials without randomization;
- III. Evidence from well-designed cohort, cross-sectional and case-control studies;
- IV. Evidence from systematic review of descriptive and qualitative studies;
- V. Evidence from a single descriptive or qualitative study;
- VI. Evidence from the opinion of authorities and/or from reports of expert committees.

The articles included in this review had observational design with follow-up period from pre-kidney-transplantation and until post-kidney-transplantation with interval of 6 months to 4 years after operation and average period of post-operation follow-up of 2 years and 6 months. All eligible articles were published between 2009 and 2017, and half of them were conducted in Europe. The age range of participants was from 2-18 years, 52.5% of participants were male.

Chart 1 – Characterization of publications according to reference, study type, thematic considerations and level of evidence

Publication, year and country	Type of study	No. of participants/ Age group	QOL instrument ^{††}	Type of monitoring	Result	Level of evidence
Park Ki-Soo, et al, South Korea, 2012 ⁽⁷⁾	Observational Cross-sectional	92/2-18 years	PedsQL 3.0 ESRD module	Outpatient	Transplant patients presented better QOL compared to under dialysis treatment. There was no difference in total QOL scores between PD* and KTx** according to the children's report.	III
Bamford J, et al, United Kingdom, 2016 ⁽⁸⁾	Observational Cohort Study	31/3-18 years	PedsQL 4.0	Outpatient	The biggest concerns regarding transplantation for children and adolescents are: physical appearance, physical discomfort, pain, and damaged social relations.	III
Oborn H., et al, 2016, Sweden ⁽¹¹⁾	Observational Cross-sectional	59/8-18 years	DISABKIDS37 KIDSCREEN-27	Outpatient	There was no difference in QOL when comparing populations with kidney transplant and pediatric population in general.	III
Yadav P, et al, 2017, India ⁽¹²⁾	Observational Cross-sectional	62/ < 18 years	WHOQOL-BREF	Outpatient	KTx** had beneficial effect in all areas assessed.	III
Anthony et al, 2010, Canada ⁽¹³⁾	Observational Cross-sectional	23/2-18 years	VAQOL and General Health/ PedsQL	Outpatient	Compromised areas were: physical appearance, symptoms, difficulty in family interaction and school disruption.	III
Buyan N, et al, 2010, Turkey ⁽¹⁴⁾	Observational Case-control	211 /4-18 years	KINDL [®]	Hospital	The analysis of patients with ESKD [†] (PD* + KxT**) showed lower scores on all subscales compared to the control group, except for physical well-being.	III
Dotis J, et al, 2016, Greece ⁽¹⁵⁾	Observational Case-control	55/8 to 18 years	KIDSCREEN-52	Outpatient	Children with ESKD [†] presented scores of physical well-being lower than healthy children.	III
Diseth TH, et al, 2010, Norway ⁽¹⁶⁾	Observational Case-control	38/2 to 19 years	SDQ, PedsQL, GHQ	Hospital	Children with kidney transplant and parents had significantly lower QOL ^{††} scores in all areas, except for emotional functioning.	III

Observation: *Peritoneal Dialysis; **Kidney transplant; † End-stage kidney disease; ††Quality of life

The level of evidence of included studies is concentrated on score III studies with descriptive cross-sectional, cohort, case-control design.

A total of 32 studies were identified and eight were included in which specific, validated instruments in Pediatrics were used for assessing QOL in children with ESKD at various treatment stages, conservative, dialysis, pre-transplantation and post-transplantation.

The tools covered: five dimensions: physical well-being, psychological well-being, autonomy and parental relationships, social support and peer relations and school environment. A variety of testing instruments was found⁽¹¹⁾.

The instruments identified were: PedsQL, KINDL, KID-SCREEN, DISABKIDS, WHOQOL-BREF. These were developed with the purpose of analyzing the responses of children facing kidney therapy substitution, through multiple domains⁽⁷⁾.

All studies compared QOL of children with kidney transplant by comparing them with healthy peers (children)^(7-8,11-16).

In categorizing the QOL in children with ESKD under dialysis and those who were subjected to KTx, studies reported a lower QOL in children undergoing dialysis compared to children with kidney transplant. Since children with ESKD presented associated factors such as anemia, hindered growth and weight gain, this created more concern with body image and deficiency in QOL, whereas children with kidney transplant reported a better quality of life⁽¹¹⁾.

DISCUSSION

The QOL in children with ESKD is a subject barely studied in Brazil and in the world, and its incidence is increasing in the pediatric population.

The ESKD affects many systems and organs and thus has great impact on mortality, both in terms of physical and emotional well-being of the child, demonstrating the importance in highlighting the integrality of care⁽⁴⁾.

In contrast to research on QOL in the adult population, few studies with children and adolescents performed, especially when using representative samples, which reflects the level of evidence from studies that addressed the topic in Pediatrics. A portion of the studies identified focuses on the analysis of prevalence, which results in a low level of evidence, and the rest of the studies identifies risk factors as meaning better evidence and strong impacts of findings.

Studies have shown that children with kidney transplant and ESKD were compromised physically and psychologically compared to the pediatric population in general, particularly regarding concern with body image and decreased QOL⁽¹¹⁻¹⁶⁾.

When comparing girls and boys, girls presented a lower index in total score as well as in independence, social inclusion and emotion⁽¹¹⁾.

Quality of Life in post-transplant children was shown to be similar to the pediatric population in general; however, when compared to patients under dialysis, patients with transplant presented superior QOL^(7,12). When comparing the QOL of children with kidney transplant to children who were on the waiting list for KTx, a beneficial effect of transplantation was observed in all areas evaluated⁽¹³⁾.

The perception of QOL of children regardless of the treatment modality for ESKD was better compared to the evaluation of parents, especially in the areas of general fatigue, family and peer interaction and concern^(7,8,11-14,16). PedsQL data revealed that the concern parents present related to the social function of their children was not observed on the children themselves⁽⁸⁾.

Many QOL measures for children are available, however, the development of reliable and valid instruments to assess QOL is still limited and requires validation in order to be applied in our population. Some measures are specific to the disease, whereas others are generic⁽⁴⁾.

The survival rate of patients affected with end-stage kidney disease improved significantly thanks to therapies associated with kidney transplant techniques. Studies show that KxT allows for the survival of kidney grafting at about ten years in 85% of transplants⁽¹⁴⁾.

Studies point out that the most difficult challenges after KTx are related to mental health in children and adolescents as compared to a healthy child, amongst these difficulties depression, generalized, social and health anxiety, concerns with body image, sleeping difficulties, disorders and pain. It is worth mentioning that all these difficulties can negatively impact the participation of these children and adolescents in everyday life and school routine, reflecting onto an impaired quality of life⁽¹¹⁻¹⁶⁾.

Children with kidney transplant reported significantly less mental and physical wellbeing, the result persisting even after controlling sex and age in multivariate analysis. Kidney transplantation is the preferred therapy for children with ESKD and it is generally expected to improve health and QOL⁽¹⁰⁾.

It should be noted that a kidney transplant may limit the daily life of the child, especially in the early years after the intervention, with things such as the need for immunosuppressive therapy, side effects, and risk of infection require frequent examinations and rejection. Moreover, the decrease independence of the child may reflect the overprotection of parents and health professionals, decreasing QOL⁽¹⁰⁾.

A study conducted in India indicates a deterioration of sleep and less participation in extracurricular activities in children with kidney transplant. Another important finding was the relationship of parents with domestic responsibilities, showing a neglect of duties at home and suppression of social activities, as well as a feeling of hopelessness and stress⁽¹¹⁾.

It is noteworthy that only with the subscales of physical well-being, self-esteem and friends, the totals of QOL in KTx were significantly higher compared to peers under peritoneal dialysis (PD). It is also worth mentioning that there were no significant differences between the scores of disease perception in groups PD and KxT⁽¹⁶⁾.

It has been observed that, the higher the suffering, the lower is adherence to drug treatment, which suggests that psychological well-being may impact directly on the long-term outcome of a transplant. For such, maintaining psychological well-being has positive implications for the therapeutic result⁽¹⁵⁾.

Studies show that adolescents have the highest rates of non-adherence to medication in the treatment after Pediatric kidney transplantation, with increases in rates of graft failure, starting at 11 years of age and reaching a peak between the ages of 17 and

24 years⁽¹⁷⁻¹⁸⁾. The findings support the idea that a specific age group requires specialized care due to complex transformations, marked by a physical development preceding emotional maturity, often with deficits and organizational skills, risk perception and logical reasoning which evolve over time⁽¹⁹⁾.

Another aspect relevant to the commitment of non-adherence to medication as related to interferences in quality of life would be inappropriate parental relationships, ineffective communication between parents and patients or between doctor-patient, and signs of depression/anxiety⁽¹⁷⁻¹⁹⁾.

Aspects that contribute to risk factors for non-adherence to necessary drug therapy, intentional or not, and strategies to improve adherence are generally effective if they involve a combined approach of health education, parental involvement, self-monitoring, reinforcement and troubleshooting⁽¹⁷⁾. An international consensus on the non-adherence of immunosuppressive medication stressed the need to study non-adherence consequences and risk factors, making an urgent appeal to the development of randomized clinical trials and new studies to test interventions and improve adherence to transplantations in the adolescent population of high risk⁽²⁰⁻²¹⁾.

The choice of instrument for assessing QOL during childhood must meet the criteria of reliability and understanding from the public. The instruments analyzed in this study are not available for use in Brazil and require translation and adaptation for the Portuguese language⁽⁸⁾.

In countries with high indexes of children with ESKD and with higher number of transplants, like the United States and Brazil, we did not find studies that addressed this subject.

Study limitations

Few studies with children and adolescents having representative samples were found, which affects the level of evidence from

the studies that addressed the subject in Pediatrics. The instruments used in the studies included are not validated in Brazil.

Contributions to the field of nursing, public health or public policy

This study encourages discussion on the need for frequent assessments of QOL in patients with kidney transplant and their parents. The results found will be able to guide healthcare assistance through the identification of the mental, physical and social conditions associated with QOL of this population, in order to assist in fighting against this disease and provide better conditions for their transition to adulthood.

CONCLUSION

This systematic review of the literature allowed to identify studies that evaluated the QOL of pediatric patients with kidney transplant, among which different instruments were used.

The main evidence found as that quality of life of children with kidney transplant is inferior compared to healthy children. When comparing children with end-stage kidney disease, we identified that post-transplantation children present better results compared to indexes of pre-transplantation children. The identification of mental, physical and social conditions associated with the QOL of this population allows professionals to rethink the health assistance offered to patients, assisting them in order to achieve a better therapeutic outcome. This way, they are able to acquire better adaptation and coexistence with changes, creating their coping strategies for facing the limitations imposed by this chronic condition.

This study points to the need for further research in order to assess the QOL of the pediatric population with ESKD, as well as the need to implement specific instruments.

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