

QUALITY OF LIFE IN CHILDREN WITH CRONIC KIDNEY DISEASE UNDERGOING RENAL REPLACEMENT THERAPY; REVIEW

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ABSTRACT

Introduction: Chronic Kidney Disease (CKD) in children will have an impact on the quality of life in children, to be able to continue the growth and development of children with ESRD, renal replacement therapy, dialysis, end renal transplant, is needed. **Purpose:** To identify in the literature studies that evaluate the quality of life in children with CKD undergoing renal replacement therapy and validated instruments in Pediatrics. **Method:** review of the literature with searches conducted in the following database: Medline, Pubmed, Proquest, CINAHL and Cochrane Library databases were searched from 2010 to 2020 in quality of life in children with CKD undergoing renal replacement therapy. Studies were included following criteria (1) quality of life in children with CKD (2) Instruments QOL in children (3) study were included renal replacement therapy: peritoneal dialysis, hemodialysis, and renal transplant. (4) the full-text article was available in English. **Results:** eight studies were included in this review. Included that evaluated the quality of life of children with CKD undergoing renal replacement therapy by means of evaluation instruments of quality of life. **Conclusion:** Quality of Life in Children with various QOL instruments from eight articles concluded that QOL is better in children who have undergone kidney transplantation, compared to children with PD and HD. QOL of children with PD was better than children with HD in all domains

1. Introduction

Children with CKD will result in increased morbidity and mortality and reduce the quality of life of children (Kaspar, Bholah, & Bunchman, 2016). The incidence of CKD increases every year around 11-13% and is a global epidemic problem worldwide and will reduce the quality of life of children and the burden on parents (Alkharashi, 2019). CKD cases in children were estimated at 82 children per million children and 15 children entered the direction of ESRD. ESRD in children only contributes 2% of cases of ESRD in general but causes mortality of nearly 30 - 150%. The life

expectancy of children under 14 years of age with ESRD is only 20 years, so it requires special care (Raj, Patel, & Ramachandran, 2017).

ESRD is a major health problem with an annual rate of occurrence of approximately 5 to 10 children per million (Morales, 2018). The incidence of acute kidney disorders in children in the world increases every year, by 33.7% being hospitalized and 13.8% experiencing death. Chronic Kidney disorders in the United States in 2015 amounted to 1,399 children and increased to 9,800 children in 2017, this number increased seven times from 2015 (CDC, 2017). The incidence in Europe is around 11-12 cases per 1 million children

with a prevalence of about 50-60 cases per 1 million children. National data on the incidence of kidney problems in children in Indonesia have not been found, but based on data from 14 hospitals in Indonesia, it was found that 212 children had kidney failure and were undergoing kidney replacement therapy with a mortality rate of 23.6% (Hidayati, 2018). ESRD in children is a serious kidney disorder that causes death and cardiovascular disorders and causes complications in children such as growth disorders and psychosocial disorders (Clavé et al., 2019).

Quality of life in children with chronic kidney disease is very much influenced by many factors, including the child's perception of disease and adaptation to changes in physical, emotional, social, and school environment (Kelly, 2016). Condition chronic kidney disease can be treated with to the modality of renal replacement therapy: Hemodialysis (HD), Peritoneal Dialysis (PD), and Renal Transplant (RT) (Clavé et al., 2019). Long-term dialysis will limit the child's activities and have a major impact on the child's quality of life (Obiagwu, Sangweni, Moonsamy, Khumalo, & Levy, 2018). World Health Organization (WHO) defines quality of life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (El Shafei, Soliman Hegazy, Fadel, & Nagy, 2018). Objective to identify in the literature studie that evaluate the quality of life in children with CKD undergoing renal replacement therapy end validated instruments in Pediatrics.

2. Methods

Literature Search: Pubmed, Proques, MEDLINE (EBSCO), Chocrane databases were searshed from 2010 to 2020. 191 articles identified in this search end 174 articles excluded after reading title and abstract. 17 articleles selected and included in this review, 9 studies excluded after reading in full, as they did not meet inclusion criteria, 8 articles selected and included in this review.

Autor, year and country	Type of study	No. Of participant's/Age group	QOL of instrument	Type of monitoring	Result
(Dotis et al., 2016), Greece Yunani	cross-sectional study	55 children's 8 and 11 years	The KIDSCREE N-52.	Outpatient	The quality of life of children with CKD was significantly decreased in physical condition compared to the control group.
(Obiagwu et al., 2018), Johannesburg, South Africa.	A cross-sectional study	27 children and adolescent's / age 5 - 25 years	PedsQL ESRD module 3.0	Outpatient	HRQOL in children on hemodialysis was lower than in children undergoing peritoneal dialysis in most domains.
(Morales, P et al., 2018), Lima, Peru	Descriptive, cross-sectional, prospective, observational Study	79 children, age 5 to 17 years.	KINDL	Outpatient	First-time sick children give different experiences to perceptions of the quality of life of children in all dimensions
(Silva, E. M., 2017), Portugal	Descriptive, correlational, and cross-sectional study.	42 children, age 7 to 17 years.	KINDL	Outpatient	Positive perceptions of quality are best in the dimensions of self-esteem and worst in emotional well-being.
(Hooman, 2019), Tehran, Iran	This case-control study.	160 children, / age 18 years	PedsQL™ 4.0™	Outpatient	Children undergoing CAPD had better quality in all domains such as somatic symptoms, emotional symptoms and social functioning
(El Shafei, et al., 2018), Cairo	A cross-sectional study.	55 children / 5 - 18 years.	PedsQL™ 4.0™	Outpatient	Quality of life for children with ESRD was significantly poor in all domains
(ALkharashi, 2019) Jeddah, Kingdom of Saudi Arabia	This cross-sectional study	23 pediatric / aged 2-18 years	PedsQL™ 3.0™	Outpatient	The quality of life of children undergoing peritoneal dialysis was significantly better than children on hemodialysis
(Clavé et al., 2019), France	Prospective national study	32 Adolescent's / 11-17 years.	"Vécu et Santé Percue de l'Adolescent" (VSP-A)	Outpatient	The lowest relationship between life in leisure time doing activities and time dealing with medical staff, maintaining energy and physical well-being is lower in children undergoing hemodialysis

Chart 1 – Characterization of publications according to reference.

3. Results

Based on the eight articles reviewed, it says that the quality of life of children with CKD has decreased the quality of life in several dimensions, including physical well-being, psychological well-being, mood and emotions, self-perception, autonomy, parental relations and home life, financial resources, peers and social support, school environment and bullying (Dotis et al., 2016). Articles come from eight different countries including Greece, South Africa, Peru, Portugal, Iran, Cairo, Saudi Arabia and France and published articles in 2016, 2017, 2018 and 2019. Type of study in this review article, four articles using a cross sectional study, two articles mix methods with a descriptive and cross sectional study, one article with a case study end one article using a prospective national study. The age range of children experiencing CKD from eight articles was between 2 years and 25 years. The number of participants in each article ranged from the lowest to 23 children and the highest to 160 children. Instruments to measure the quality of life of children used in

the eight articles using The KIDSCREEN-52, the Pediatric Quality of Life Inventory (PedsQL) End Stage Renal Disease module version 3.0 (PedsQL ESRD module 3.0), PedsQL™ 4.0™, KINDL and “Vécu et Santé Perçue del’Adolescent” (VSP-A).

The research was conducted on outpatient care for children who performed dialysis. From the eight research articles, it was found that children who had CKD and had experienced ESRD, renal replacement therapy was performed to replace kidney function, namely hemodialysis, peritoneal dialysis and transplantation. Of the three kidney replacement therapies used by children, transplantation is the best kidney replacement therapy for the child's quality of life, other kidney therapies such as hemodialysis (HD) and peritoneal dialysis (PD) are still under transplantation. The quality of life of children who had undergone renal replacement therapy in all domains as measured using a questionnaire on the quality of life in children resulted in Physical well-being of all studied children was significantly lower compared to Control Group. The health-related quality of life (HRQOL) was lower in most domains in the HD group compared with the PD group. The mean HRQOL scores of the children with ESRD on dialysis were significantly lower for both child. QOL is very influenced by the age of experiencing illness so that the quality of life of children varies widely. Children had a positive perception of quality of life. The Self-Esteem dimension was the best perceived, and the Emotional well-being dimension was the worst perceived. The CAPD group had a higher mean (SD) score of quality of life in all domains, including somatic symptoms, emotional symptoms and social functioning.

Discussion:

The quality of life for children with CKD who are undergoing kidney replacement therapy such as dialysis and kidney transplantation has a lower quality of life than healthy children. Low quality of life in children is built by many factors such as frequent hospitalization, painful medical procedures, absence from school, and restriction of activities that result in negative

behaviors and emotions in children (El Shafei et al., 2018). Children with CKD reported a lower quality of life than children in the general population, physical and psychological condition was bad. children who underwent peritoneal dialysis reported better quality of life on the dimensions of mood and feelings, relationships with family and parents and sources of costs compared to children undergoing hemodialysis (Dotis et al., 2016). Several studies have provided an overview of low average HRQOL scores in children with ESRD who are undergoing HD or PD and children who have received a kidney transplant Children with ESRD are more often unable to participate in routine activities with friends because of the nature of the disease, which affects the physical, emotional and psychosocial aspects of life (Obiagwu et al., 2018).

The instruments used to measure the quality of life of children with CKD vary widely, this is very much influenced by what will be measured regarding the quality of life of children. Instrumen quisionari “Vécu et Santé Perçue del’Adolescent” (VSP-A) scribes QoL in 10 dimensions : energy-vitality, psychological well-being, relationships with friends, leisure activities, relationships with parents, physical well-being, relationships with teachers, school performance, body image and relationships with medical staff (Clavé et al., 2019). PedsQL ESRD module 3.0, this questionnaire consists of 34 items on 7 scales: general fatigue, about my kidney disease, treatment problems, family and peer interaction, worry, perceived physical appearance, and communication (Alkharashi, 2019). PedsQL™ 4.0™ it includes four domains covered by 23 questions: physical domain, emotional domain, social domain, and school domain (El Shafei et al., 2018). The KINDL® questionnaire measures children’s quality of life and is composed of 30 questions, distributed into seven dimensions of quality of life: Physical well-being, Emotional well-being, Self-esteem, Family, Friends, School, and Disease (Silva, E. M, 2017).

The KIDSCREEN-52 questionnaire measures ten dimensions, including physical well-being, psychological well-being, moods and emotions, self- perception, autonomy,

parental relations and home life, financial resources, peers and social support, school environment and bullying (Dotis et al., 2016). The choice of instruments to measure the quality of life of children depends on what researchers want to measure, as the five instruments described above are described for measuring the quality of life of children with CKD. Each instrument measures the same domain and there are different domains with different number of questions. To maintain the quality of life of children with CKD with ESRD, doing one of the renal replacement therapy is an option that must be lived by children and their families.

4. Conclusions

Quality of Life in Children with various QOL instruments from eight articles concluded that QOL is better in children who have undergone kidney transplantation, compared to children with PD and HD. QOL of children with PD was better than children with HD in domains. The selection of QOL instruments varies greatly, this is adjusted to the QOL to be measured in children with CKD.

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Conflicts Of Interest

None declared

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