

Quality of life of children and adolescents with chronic kidney disease: A review of the literature

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Abstract

Background: Chronic kidney disease (CKD) is a risk condition for young patients that can cause psychosocial impairment and psychiatric symptoms. The aim of this literature review was to study the living conditions of children and adolescents with chronic kidney disease and to highlight the difficulties that these individuals are called upon to face on a daily basis. Complementary objectives of this review were to look for factors that may contribute to improving the quality of life of such individuals.

Methods: The literature of the years 2014-2021 was reviewed using the PubMed and Google Scholar databases. The present literature review included studies that refer to the quality of life of children and adolescents with chronic kidney disease and the difficulties they encounter daily.

Results: Approximately 3082 studies were retrieved and further reviewed. After reviewing their title, abstract and full text, 11 studies were selected meeting the inclusion criteria of this review and were used for its compilation.

Conclusions: In most of the selected studies, the prevailing perception was that children and adolescents with chronic kidney disease have a lower quality of life in various areas, compared to their healthy peers. Furthermore, statistics have shown that children with chronic kidney disease face several difficulties on a daily basis, but there are several factors that contribute to the improvement of their daily life.

Keywords: Chronic renal failure; Chronic kidney disease; Childhood kidney disease; Children; Adolescents; Quality of life; Treatment

1. Introduction

Chronic kidney disease (CKD) is a risk condition that can cause psychosocial impairment and psychiatric symptoms. [1] The prevalence of children with CKD worldwide is approximately 82 cases/year/1 million children. [2] International studies show that 10 to 12 children per million of a country's child population will be diagnosed with CKD each year. Chronic renal failure is mainly a hereditary disease. For several years now, healthcare professionals have been using a combination of mechanical support equipment, such as peritoneal dialysis or hemodialysis, and pharmaceutical substances in order to contribute to the treatment of kidney diseases in young patients. However, in the case of a child, it's not enough to just stabilize his health status in order to keep it alive. The main goal of the treatment should be the "restoration" of his/her health and consequently the "restoration" of the "beauty", harmony and quality of his/her life (QoL). [3]

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Therefore, the inclusion of these children in an immediate kidney transplant program may be considered beneficial. Unfortunately, so far in Greece the donation of a kidney from a living donor is mainly carried out with children’s parental donors. It is necessary for the country to pioneer in such procedures, informing and sensitizing its citizens appropriately to initiate organ donation procedures to children with CKD. In a world that is constantly being alienated, people need to have team spirit and social sensibilities, in order to effectively treat chronic diseases as CKD. [3]

The main purpose of this literature review is to study children’s and adolescents’ with CKD QoL, with particular emphasis on the difficulties these individuals face. Complementary objectives of this review are to look for factors that may contribute to improving the quality of life of such individuals.

2. Material and methods

A literature review has been performed for the study of the framework children and adolescents with chronic renal failure live into. The following research questions therefore arise: « What is the impact of chronic renal failure upon children’s and adolescents’ quality of life? ».

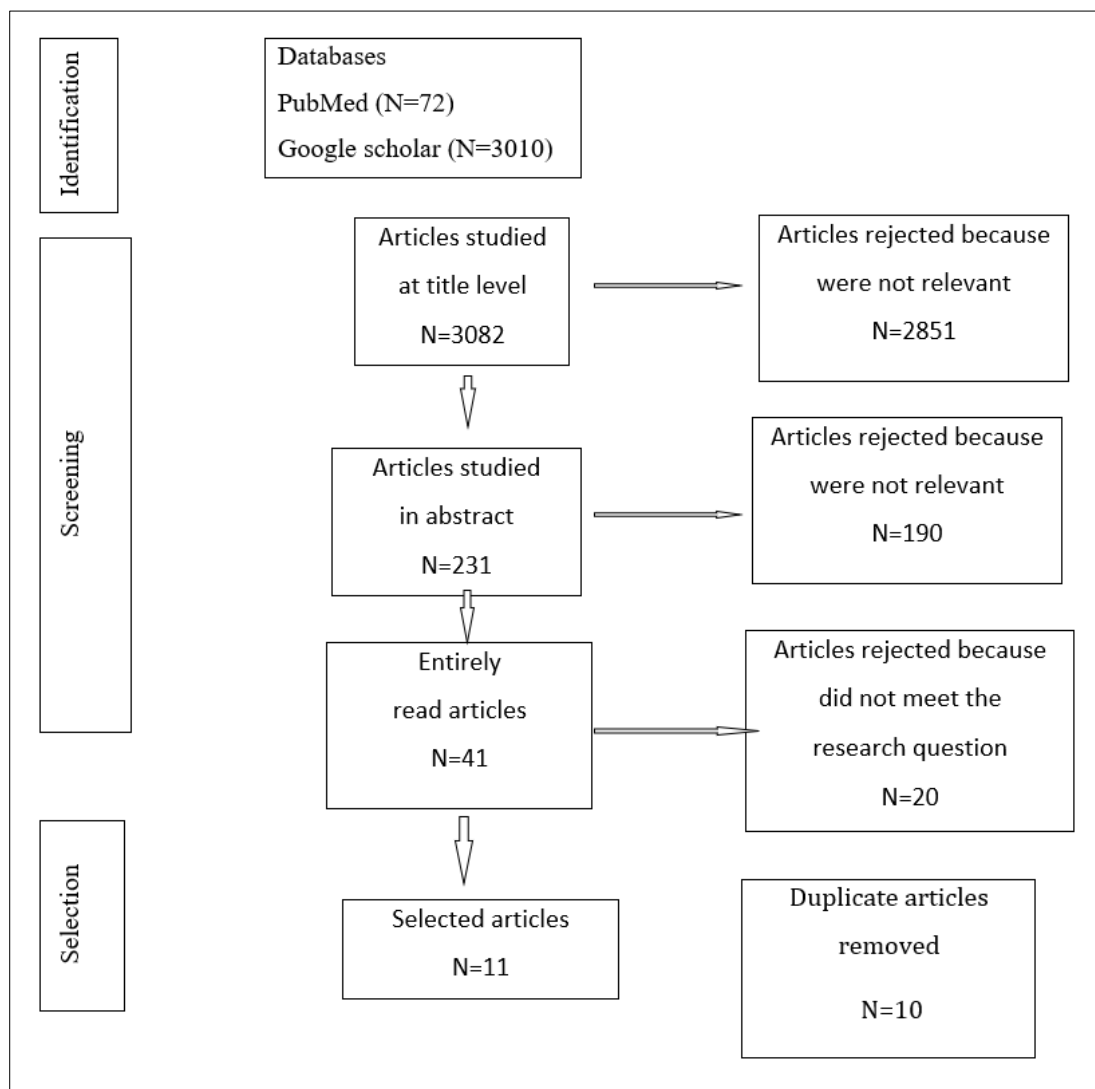


Figure 1 Flow chart according to the method-proposal PRISMA

The data collected in the present bibliographic review are scientific articles that are part of the modern international literature. The articles were searched independently by two researchers in the databases Pubmed and Google Scholar throughout the period from 1/12/2021 to 28/02/2022. These specific medical databases were chosen by the researchers, since they constitute reliable and high-quality databases for academic research, especially in quantitative

science studies. The following keywords were used: «chronic renal failure», «chronic kidney disease», «nephropathy of childhood», «children», «adolescents», «treatment» with the use of Boolean “AND”.

The selection criteria were: a) articles of the previous 8 years (2014-2021) from the searching, b) articles that include primary empirical studies (quantitative and qualitative methodology), c) articles concerning children and adolescents or both (0-18 years of age) with renal failure and d) articles published in Greek or English language. The studies should have been published from 01/01/2014 to 30/04/2022 in Greek (which is the native language of the researchers) or English, while protocols, pilot studies and parts of any research were excluded from the review as well as any kind of review, including meta-analysis, and case studies. The variables selection process was based on the PRISMA method for systematic reviews (Figure 1). In terms of the characteristics of the articles, data such as authorship, year, title, country, aim and methods such as sample size, study designs, measurement tools and main findings were extracted.

3. Results

Using the keywords and the inclusion criteria, a total of 3082 studies were identified from the selected search engines included in the final phase of the review. In particular, 72 articles emerged from ‘PubMed’ and 3010 from ‘Google Scholar’. Following the PRISMA guidelines, in the first phase of the selection, 3082 articles were examined based on their title, and 2851 of them were excluded. The remaining 231 articles were examined based on their summary and 190 were further removed. In the second phase, the remaining 41 articles were examined based on their full text and 20 of them were excluded. Furthermore, and after the exclusion of 10 duplicate articles, the remaining 11 complete articles were included in the final review. In their references no article was found that met the criteria for inclusion in the study by manual searching. The strategic study of the literature is presented in the flow chart (Figure 1).

A total of 1603 young patients participated in the 11 surveys included in the review. The studies were conducted in 11 different countries around the world. Three studies were conducted in Europe (Greece, Netherlands, Germany, Belgium, United Kingdom), two in Asia (South Korea, Indonesia), one in Oceania (Australia, New Zealand), two in Africa (Egypt) and three in South America (Brazil). All surveys were performed on young patients aged from 1 to 18 years, required parental approval/consent and have been published between 01/01/2014 and 30/4/2021. Caregivers and/or healthy peers concerned almost half of the studies (5/11, 45.5%), and the majority were cross-sectional studies (8/11, 72.7%), while one was a descriptive study with mixed methods and one was a double blinded prospective randomized trial. The studies included in the review model are presented in Table 1.

Table 1 Study characteristics

Study	Participants	Aim of study	Study design	Data collection methods	Results
Lopes et al., (2014, Brazil) [4]	64 children/adolescents with chronic kidney disease (CKD) stage 4-5, 1-18 years old and 64 healthy peers with their caregivers	The description of HRQoL of children and adolescents with CKD stage 4 (pre-dialysis) or stage 5 (dialysis/transplantation) and their primary caregivers, and compared to a healthy control group. The evaluation of the association between the primary caregivers HRQoL scores and selected laboratory biomarkers of the patients and their primary caregivers	Cross-sectional, descriptive, comparative and analytical study.	PedsQL™ 4.0, Short Form-36 (SF-36) Selected CKD laboratory parameters	Patients reported a deleterious impact on physical capacity and on social and school activities. A negative influence on emotional aspects was reported by older patients, but not by their PC. Hemodialysis, followed by peritoneal dialysis, had a more negative impact on patients' physical functioning domain.
Moreira et al., (2015,	28 children and adolescents with pre-	The investigation of the resilience, QoL and anxiety and depressive	Cross-sectional	Wagnild & Young Resilience Scale	The CKD patients were referred to mental health professionals

Brazil) [1]	dialysis CKD and 28 healthy sex- and age-matched peers	symptoms in children and adolescents with pre-dialysis CKD and the comparison to the values of healthy controls.		Pediatric Quality of Life (QoL) Inventory 4.0 Child Depression Inventory Self-report for Childhood Anxiety Related Disorders.	more frequently than the controls. Patients exhibited higher scores for separation anxiety and a higher frequency of clinically significant depressive symptoms. They also had lower overall QoL scores and poorer scores for the psychological, educational and psychosocial subdomains of QoL instruments. There was a negative correlation between anxiety and depressive symptoms and all domains of QoL.
Dotis et al., (2016, Greece) [5]	55 patients 8-18 years of age, with CKD, renal transplantation and end-stage renal disease compared to 55 healthy peers of the same age group.	The record of the HRQoL of children in Greece with CKD on peritoneal dialysis (PD) or a renal transplant	Cross-sectional	KIDSCREEN-52 (Greek version)	Physical well-being of all ill children was significantly lower, while ill children of 8-11 years of age showed better social acceptance compared to healthy peers.
Baek et al., (2017, S. Korea) [6]	376 children with CKD	The evaluation of the quality of life (QoL) of Asian children with pre-dialysis chronic kidney disease (CKD) and the investigation of the factors influencing the QoL of children with CKD	Cross-sectional.	PedsQL 4.0 Generic Core Scale Module	In child self-reports, male patients had better QOL than female patients in Physical, Emotional, and School Functioning categories. Furthermore, growth parameters showed a significantly positive correlation with the QOL score in all categories.
Heath et al., (2017, United Kingdom) [7]	71 children with CKD	The evaluation of a generic and renal-specific self-report QoL scale, the assessment of children's attitudes towards living with CKD and the proposition of an appropriate tool for future individual clinical use or departmental audit	Cross-sectional	Generic Children's QoL Measure (GCQ) PedsQL 3.0 End Stage Renal Disease Module (PedsQL) Child Attitude Toward Illness Scale (CATIS)	Generic QoL, disease specific QoL and attitudes towards CKD did not vary by CKD stage, age, time since diagnosis or duration of current treatment. Gender was not associated with QoL. Pre-emptive transplant patients had more positive GCQ and PedsQL scores ($p < 0.05$ for each). Scores on all scales were moderately correlated ($r = 0.35-0.59$)

Splinter et al., (2018, Netherlands, Belgium, Germany) [8]	192 young patients aged 8-18 with end-stage renal disease	The assessment of HRQoL across three renal replacement therapy modalities (preemptive transplant, non-preemptive transplant, and dialysis) in comparison with the healthy norm and other chronic health conditions, and the investigation of related patient factors	Cross-sectional	PedsQL™ Generic Core Scales 4.0 (PedsQL™)	Patients had significantly lower mean scores and consequently higher proportions of impaired HRQoL on almost all domains compared to the healthy norm and other chronic health conditions. Patients with a preemptive transplant only reported higher scores on physical health compared to the other treatment modalities. Having comorbidities was the most important determinant associated with lower HRQoL scores.
Francis et al., (2019, Australia-New Zealand) [9]	375 children and adolescents between 6 and 18 years of age with CKD	The comparison of quality of life (QoL) among children and adolescents with different stages of chronic kidney disease (CKD) and the determination of the factors associated with changes in QoL	Cross-sectional.	Health Utilities Index 3 score	QoL for those with CKD stages 1-2 (n=106, median 0.88, IQR 0.63-0.96) was higher than those on dialysis (n=43, median 0.67, IQR 0.39-0.91, p<0.001), and similar to those with kidney transplants (n=135, median 0.83, IQR 0.59-0.97, p=0.4) or CKD stages 3-5 (n=91, 0.85, IQR 0.60-0.98). Reductions were most frequent in the domains of cognition (50%), pain (42%) and emotion (40%). The risk factors associated with decrements in overall QoL were being on dialysis (decrement of 0.13, 95% CI 0.02 to 0.25, p=0.02), lower family income (decrement of 0.10, 95% CI 0.03 to 0.15, p=0.002) and short stature (decrement of 0.09, 95% CI 0.01 to 0.16, p=0.02)
Pardede et al., (2019, Indonesia) [2]	112 children aged 2-18 years with CKD	The assessment of the QoL in children with CKD and its relationship with duration of diagnosis, severity, and related demographic factors	Cross-sectional	PedsQL™ generic score scale 4.0	The school and emotional aspects were the lowest score parameters studied. Factor related to QoL children with CKD were length of diagnosis >60 months (P = 0.004),

					female (P = 0.019), and middle school (P = 0.003). More than half of the children with CKD have disturbance of QoL in general from parental reports (54.5%) and children's reports (56.3%). Length of diagnosis >60 months, female, and middle school education were all related to the QoL children with CKD
Rotella et al., (2019, Brazil) [10]	48 children and adolescents with ESKD	The investigation of the emotional repercussions and quality of life (QoL) associated with end-stage kidney disease (ESKD) in children and adolescents undergoing hemodialysis or a kidney transplant	Descriptive study with mixed methods	Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0)	The total score was higher in the transplanted patients and their caregivers, suggesting a perception of better QoL after kidney transplantation. In the specific aspects of the questionnaire, physical capacity was considered superior by children who underwent transplants, and their caregivers. There were no differences between the groups in the emotional, social and school aspects.
Abd-Elmoneim et al., (2019, Egypt) [11]	32 children with CKD from 8 to 12 years of age	The investigation of the effects of progressive resistance exercises on quality of life and functional capacity in pediatric patients with chronic kidney disease	Double blinded prospective randomized trial	Paediatric Quality of Life Inventory (PedsQL™) generic core scale (Arabic version) The six-minute walking test (6MWT)	Statistically significant improvements in the post-test quality of life and functional capacity in the Exercise group (p<0.05) were found. The Standard Care group showed significant decrease of quality of life and non-significant change was recorded regarding their functional capacity (p<0.05). The post-test comparison between the two groups revealed significant difference in favor of the Exercise group in all measured variables.

Darwish et al., (2021, Egypt) [12]	250 children with CKD and 250 healthy peers	The comparison of QoL in diseased and healthy children and the investigation of factors associated with QoL score in children with CKD	Cross-sectional comparative study	Pediatric quality of life inventory (PedsQL) 4.0	Healthy children achieved statistically significant higher mean PedsQL in all domains of quality of life in all domains of PedsQL. Children on conservative treatment achieved statistically significant higher scores in all domains of PedsQL than those on dialysis. There was no statistically significant difference in all domains of PedsQL regarding the severity of CKD. Children receiving hemodialysis reported lower scores in all dimensions of QoL than children on conservative treatment.
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4. Discussion

The main purpose of this literature review was to highlight the living conditions of children and adolescents who suffer from chronic kidney disease, with particular emphasis on the areas of life in which difficulties and low quality are presented. At the same time, there was a search for treatment methods and factors that could contribute to improve the quality of life of children and adolescents burdened by chronic kidney disease.

In most of the studies collected, the results showed that children with chronic kidney disease, regardless of disease stage and method of treatment, reported a lower quality of life compared to their healthy peers. More in detail, the study by Lopes et al (2014) showed that the patients' quality of life was significantly lower than that of healthy participants and their caregivers, regarding physical, social, and school functioning. Furthermore, in the same study it was found that patients who underwent any form of hemodialysis reported a lower quality of life than those who received conservative treatment. [4] A lower quality of life of the patients was also found from the results of the study by Splinter et al (2018). The findings of the study led to the conclusion that regardless of the treatment method, patients had significantly lower quality of life in almost all dimensions, compared to healthy children. From the same study, it emerged that patients with preventive transplantation reported better physical health, compared to patients who underwent other treatment methods. [8] In addition, there was one more study that revealed that participants with prophylactic transplant had significantly higher overall quality of life than those who underwent other treatments, as typically reported in the Heath et al (2017) study of children with chronic kidney disease of stages 3-5. [7]

Dotis et al (2016) found that at ages 8-18, children with kidney disease report lower physical well-being. At the same time, children with chronic kidney disease on peritoneal dialysis rated better their mood and feelings about the relationship with parents and home life, as well as their financial resources, compared to children with chronic kidney disease of stages 1-4. [5] Differences in the quality of life of children with kidney disease, depending on the stage of the disease, were studied by Francis et al (2018) who aimed to compare the quality of life between children and adolescents being in different stages of chronic kidney disease. According to their study, quality of life for people with chronic kidney disease of stages 1-2, was, as expected, better than that of people on hemodialysis and similar to people with kidney transplant or chronic kidney failure of stages 1-3. [9] The study by Baek et al (2017) had a similar goal, as they tried to evaluate the quality of life of children with chronic kidney disease and to reveal the factors that influenced their quality of life. Parents' reports, as well as children's self-reports, showed better quality of life in boys in most dimensions. The reasons that contributed to this result were difficult to explain. However, two could be the possible causes: the difference in the age distribution of patients, and sociocultural factors. In particular, the gender difference by age seemed to vary, especially during childhood and adolescence, thus the results of quality-of-life studies would be likely to differ according to the age distribution of the enrolled patients. Furthermore, there were significant differences in

the scores of the parents in all categories, depending on the stage of chronic kidney disease. However, in children's reports there was no difference in quality-of-life scores with respect to disease stage. [6]

In a study carried out in Indonesia by Pardede et al. (2019), a significant correlation was observed between the average level of education and the quality of life of children. This finding may be because in middle school patients were going through their adolescence, which can be considered a vulnerable period. Therefore, it is possible that difficulties faced by the children during their adolescence also affected their quality of life. Furthermore, in the same study, children reported that female gender was related to the quality of life of children with chronic kidney disease. [2] The effect of factors, such as socioeconomic class, height and disease duration, on the quality of life of children with kidney disease was examined by Darwish et al (2020). In this study, a negative correlation was found between high quality of life and low socioeconomic class, short stature, and shorter disease duration. [12]

Moreira et al (2015), in their study regarding the mental dimension of quality of life, demonstrated that sick children sought more often the help of mental health professionals, compared to healthy children. This finding was also associated with patients' overall poorer quality of life and lower performance at school and in social and psychosocial domains. At the same time, patients showed a higher frequency of depressive symptoms. [1] Finally, regarding the functional capacity of children with chronic kidney disease and its connection with their quality of life, the findings of Abd-Elmonem et al (2019) can be considered important. This study showed significant improvements in the quality of life and functional capacity of the children in the group that participated in various physical activities, while the group that did not participate in such tests showed a significantly reduced quality of life. [11] There is a perception that there is improvement in the quality of life of children and adolescents, and also in their families as well, after kidney transplantation. This is actually proven through the study of Rotella et al (2019). In the quality-of-life questionnaires, the overall score was higher in transplant patients and their caregivers, a finding that suggests a recovery in the quality of life of children with kidney disease after receiving a transplant. There were no significant differences between groups in emotional, social, and school dimensions. But caregivers of transplant patients perceived a significant difference in their children's quality of life at school. [10]

Limitations of the study

The present systematic review is characterized by some limitations. Firstly, the electronic search of the articles was done in only two databases, PubMed and Google Scholar, and included studies published only in Greek and English. Furthermore, studies published before the specified period (2014-2021) were excluded from this review. At the same time, included studies are characterized by heterogeneity in terms of their design, data collection tools and the population under study. Finally, another limitation of this review is the lack of assessment of the quality of the studies used.

5. Conclusion

Research findings suggest that the quality of life of children and adolescents growing up with chronic kidney disease is clearly lower than that of healthy peers, and there is a progressive deterioration of quality of life with age. At the same time, a higher incidence of depression has been observed in these children, who in fact very often show feelings of loneliness, sadness, fatigue and weakness. The quality of life and especially the dimension of physical well-being can be dramatically affected in children with chronic kidney disease, regardless of the stage of the disease they are going through. On the other hand, in the first years of school, children with chronic kidney disease seem to feel more accepted socially than their healthy peers. Furthermore, overall quality of life in domains such as pain and emotion is significantly lower in children undergoing hemodialysis compared to children with earlier chronic kidney disease and those who have undergone a kidney transplant. Despite research results state that transplantation improves some aspects of quality of life, no differences are observed between renal replacement therapies regarding the emotional impact of kidney disease in children and adolescents. In addition, the quality of life of children with chronic kidney disease before hemodialysis is affected by several factors, such as gender, glomerular filtration rate, socioeconomic status, comorbidities, anemia, growth retardation and behavioral disorders. Finally, in order to improve the quality of life for children and adolescents, it is important that both them and their caregivers understand the effects of these factors and implement appropriate interventions.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest.

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