

Quality of Life of Children with Chronic Kidney Disease

ORIGINAL

Glauce Rocha de Moura Fé¹, Maria Isabelly Fernandes da Costa²,
Wanderson Alves Martins³, Kamila Ferreira Lima⁴,
Priscila Alencar Mendes Reis⁵, Viviane Mamede Vasconcelos⁶,
Mirna Albuquerque Frota⁷, Karla Maria Carneiro Rolim⁸,
Luiza Luana de Araújo Lira Bezerra⁹

Abstract

Introduction: Chronic Kidney Disease has a major impact on a pediatric patient's development. Harmful effects include nutritional changes deriving from a restrictive diet, in addition to systemic manifestations, deficient growth, osseous deformities and chronic anemia. In addition to biological effects, there are psychological and social issues arising from chronic diseases, such as impaired self-image and academic difficulties.

Objectives: To analyze scientific production on the quality of life of children with chronic kidney disease.

Method: Integrative literature review carried out on SciELO, MEDLINE, PubMed databases and the BVS portal, from June to August 2015, using the following controlled descriptors: quality of life, children and chronic kidney disease. Eighteen articles were analyzed based on the inclusion criteria.

Results: Therapeutic modality has a positive influence on the quality of life of children with chronic kidney disease, with patients undergoing hemodialysis being those with the worst scores. Diet restrictions, especially liquid restriction, presence of comorbidities such as anemia, heart disease, short stature and osseous deformities contribute to the negative assessment of patients and caregivers. Poor academic performance is a concern for both children and parents of patients with chronic kidney disease. The presence of family and the participation of the latter in the treatment have a positive influence on these patients' perception about quality of life.

- 1 Doctor. Graduated from the Federal University of Ceará (UFC). Graduate in Nephrology.
- 2 Nurse. M.A. Student in Nursing in Health Promotion by the Post Graduation Program of Universidade Federal do Ceará (UFC).
- 3 Nurse. Post Graduating in Oncological Nursing and in Health Science Teaching by AVM Faculdade Integrada
- 4 Nurse. M.A. Student in Nursing by Universidade Federal do Ceará (UFC)
- 5 Nurse. Doctoral Student in Nursing at the Federal University of Ceará (UFC).
- 6 Nurse. PhD in Nursing by Universidade Federal do Ceará (UFC).
- 7 Nurse PhD by Rouen University, France (CHU/ROUEN) and by the Instituto de Saúde Coletiva (ISC) of Universidade Federal da Bahia (UFBA).
- 8 Nurse. Post Doctorate from the University of Rouen, France (CHU/ROUEN).
- 9 Nurse. Master in Collective Health by Universidade Estadual do Ceará (UECE). Professor at Faculdade Integrada da Grande Fortaleza (FGF).
FGF: Faculdade Integrada da Grande Fortaleza

Contact information:

Luiza Luana de Araújo Lira Bezerra

Address: Rua Dr. Rodrigo Codes Sandoval, 300, Casa 02, Maraponga CEP: 60711-455 Fortaleza, Ceará. Brasil

✉ luizaluana@yahoo.com.br

Conclusion: Children with chronic kidney disease have been presenting low quality of life when compared to the group without chronic disease. Further studies need to be conducted within varied cultural contexts in order to compare results and develop coping strategies with the aim of improving the quality of life of children with chronic kidney disease.

Keywords

Quality of Life; Children;
Chronic Kidney Disease.

Introduction

Chronic diseases have been gaining a prominent role in the health context worldwide. With the adoption of public policies aimed at improving the socioeconomic conditions of populations and reducing the incidence of infectious and contagious diseases, there was a decrease in their prevalence, resulting in the decline of child mortality and rise of chronic conditions among children and adolescents [1].

In this scenario, Chronic Kidney Disease (CKD) is worth highlighting, defined by the presence of renal damage for a period longer than three months, or reduction in Glomerular Filtration Rate (GFR) $<60\text{ml}/\text{min}/1.73\text{m}^2$ for a period longer than three months with or without kidney damage. Renal damage is understood as structural or functional abnormalities in the kidney, with or without GFR reduction, manifested by pathological abnormalities, abnormalities in imaging exams or changes in blood and/or urinary composition. According to the degree of the damage, assessed by GFR, CKD is staged from 1 to 5, with 1 being the lightest and 5 corresponding to patients who need renal replacement therapy [2].

CKD progression depends mainly on the cause of the damage, the time elapsed from the onset of symptoms to the establishment of an adequate treatment – with early detection being of great importance – and the type of necessary treatment. In this sense, compliance with the treatment by patients and, in the case of pediatric patients, by caregivers, is vital.

CKD prevalence in studies conducted in Brazil is inferior to that reported in developed countries. A study conducted in São Paulo has estimated a prevalence of 23.4 cases per million in the population with compatible age (pmpca), and in Rio de Janeiro, in 2007, a prevalence of 24 cases pmpac was found – lower numbers when compared to the 84.6 cases pmpac of a similar study carried out the United States, and to the 62 cases pmpac reported in a European study, which included data on 12 countries [3-6].

Harmful effects of CKD include nutritional changes resulting from a restrictive diet, necessary for the control of the disease, in addition to systemic manifestations, deficient growth and osseous deformities, due to calcium metabolism changes and use of medication that contribute to reducing one's final stature, besides chronic anemia. Coupled with biological effects, there are social and psychological issues deriving from chronic diseases, such as depreciated self-image and academic difficulties.

Scientific studies on the quality of life (QL) of pediatric patients with CKD aim to detect relevant aspects relating to biological, social and psychological effects that affect patients and caregivers. Based on such knowledge, it is possible to develop care strategies in order to minimize these effects and promote a better quality of life.

From the above exposed, this study aimed to analyze scientific evidence in the literature on the quality of life of children with chronic kidney disease, determining the content of produced knowledge

and existing gaps in the theme from an integrative review.

Methods

This is an integrative literature review, which contributes to the deepening of knowledge on the investigated object, evidencing conclusions of the literature *corpus* on a specific phenomenon, and allows identifying gaps in the knowledge about the subject being studied [7]. The operationalization of this review comprehended the following stages: theme identification and selection of the research questions, establishment of inclusion and exclusion criteria of the studies, definition of information to be extracted from selected studies, analysis of included studies, discussion of results, and review presentation [8].

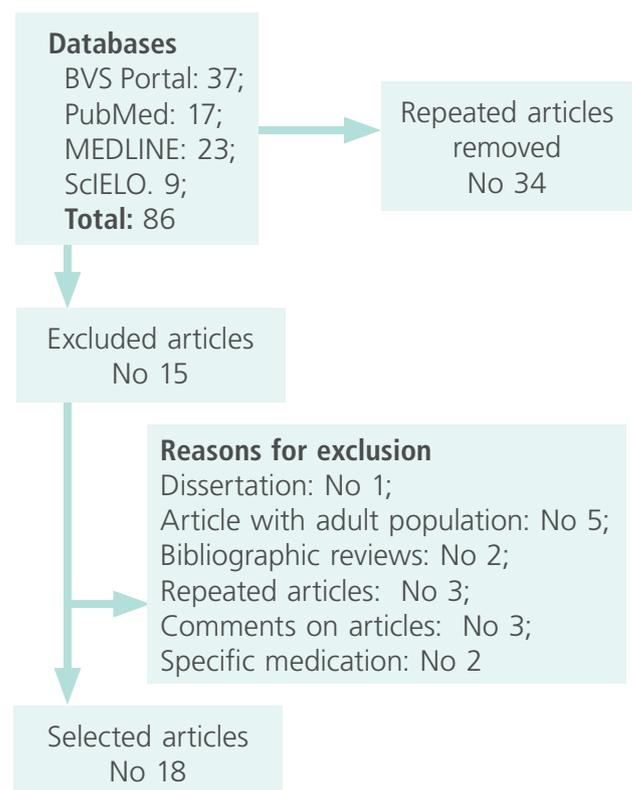
For the present study, the following guiding question was formulated: what evidence is available in the literature on the quality of life of children with chronic kidney disease? The databases used were the Scientific Electronic Library Online (SciELO), the National Library of Medicine (PubMed), the Medical Literature Analysis and Retrieval System Online (Medline) and the Virtual Health Library (*Biblioteca Virtual em Saúde*) (BVS). The descriptors used for the search on the bases were "Quality of Life", "Child" and "Chronic Kidney Disease", extracted from the Health Sciences Descriptors (*Descritores em Ciências da Saúde*) (DeCS) and the Medical Subject Headings (MeSH). The search was done from June to August 2015. The descriptors were combined on each database through the Boolean operator AND, and combining all descriptors at the same time.

Inclusion criteria comprehended articles published from 2009 to 2014 in Portuguese, English and Spanish. This study excluded articles that referred to the validation of quality of life questionnaires for the corresponding languages, that were repeated on the databases, that did not answer the study question, that were conducted with adults, in

addition to theses, review studies, comments and editorials.

After the search results were obtained, titles, descriptors and abstracts were read, and articles that addressed the quality of life of children with CKD and that met the period and languages defined were selected. Thus, this investigation obtained as a result 37 articles on BVS; 17 on PubMed; 23 on MEDLINE; and 9 on SciELO. Excluding repeated articles, 34 articles remained. Afterwards, the full material was recovered on electronic means for reading. After the reading of the whole text, 18 articles were selected to be included in the review. Reasons for the exclusion of recovered articles were: one was a dissertation, five articles assessed an adult population, two articles were bibliographic reviews, three were repeated, having titles presented in different languages, three were comments on published articles, and two assessed quality of life related to use of specific medicines. (Figure 1)

Figure 1: Identification of the selection of articles on BVS, PubMed, MEDLINE and SCIELO databases.



Results

Out of the 18 articles included in this investigation, nine were from Europe, three from the United States, one from Asia and six from Brazil. About study design, it was observed that quantitative

researches were more frequent, accounting for 88.8% of all articles that composed this review. Quantitative studies used varying collection instruments such as questionnaires on quality of life validated for pediatric age groups, assessment of

laboratorial and sociodemographic indexes, with applications of statistical analyses. Qualitative studies used questionnaires on quality of life for children and individual interviews, as well as focus groups (**Table 1**).

Table 1. Characteristics and results of selected studies – Fortaleza, CE, Brazil, 2015.

References	Databases and Portals	Origin	Study Type	Median
Riano-Galán I, Málaga S, Rajmil L, Ariceta G, Navarro M, Loris C, Vallo A. Quality of life of adolescents with end-stage renal disease and kidney transplant. <i>Pediatr Nephrol.</i> 2009; 24(8): 1561-8.	BVS	Spain/2009	Cross-Sectional	- Worse health score in patients undergoing dialysis compared to healthy control and transplanted groups. - Short stature has a negative influence on self-esteem and satisfaction with health. - Short stature and anemia score negatively among transplanted patients.
Goldstein SL, Rosburg NM, Warady BA, Seikaly M, McDonald R, Limbers C, Varni JW. Pediatric end stage renal disease health-related quality of life differs by modality: a PedsQL ESRD analysis. <i>Pediatr Nephrol.</i> 2009; 24(8): 1553-60.	BVS	USA/2009	Cross-Sectional	- PedsQL 3.0 ESRD as a good instrument to assess the impacts of CKD and therapeutic modality in children.
Frota MA, Machado JC, Martins MC, Vasconcelos VM, Landin FLP. Qualidade de vida da criança com insuficiência renal crônica. <i>Esc Anna Nery.</i> 2010; 14(3): 527-33.	BVS	Brazil/2010	Descriptive Qualitative / Quantitative	- Categories that emerged from the discourses: Pain at the moment of dialysis, Hospitalization, Limitations of the disease and treatment, Transplant expectation, Family support. -Autonomy was the most compromised domain. More representative dimensions were Leisure and Family.
Aparicio LC, Fernández EA, Garrido CG, Luque A, Izquierdo GE. Calidad de vida percibida por niños con enfermedad renal crónica y por sus padres. <i>Nefrol.</i> 2010; [citado em 14 jul 2016]; 30(1): 103-9.	BVS	Spain/2010	Cross-Sectional	-Worse HRQoL in children undergoing hemodialysis compared to those undergoing peritoneal dialysis and transplanted ones. The most affected domains were physical activity and school attendance. -Greater divergence in QL perception between parents and children aged from 9 to 15 years old.
Buyan N, Türkmen MA, Bilge I, Baskin E, Habera M; Bilginer Y et al. Quality of life in children with chronic kidney disease (with child and parent assessments). <i>Pediatr Nephrol.</i> 2010; 25(8):1487-96.	BVS	Turkey/2010	Cross-Sectional	-Differences in QL perception between children and caregiving parents. Importance of psychological follow-up of children and relatives.

References	Databases and Portals	Origin	Study Type	Median
Heath J, Mackinlay D, Watson AR, Hames A, Wirz L, Scott S et al. Self-reported quality of life in children and Young people with chronic kidney disease. <i>Pediatr Nephrol.</i> 2011; 26(5): 767-73	BVS	UK/2011	Cross-Sectional	-The Generic Children's Quality of Life Measure was used. It emphasizes the need for a questionnaire specifically related to health.
Gerson AC, Wentz A, Abraham AG. Health Related Quality of Life of Children with mild to moderate chronic kidney disease. <i>Pediatrics.</i> 2010; 125(2): 349-57.	BVS	USA/2010	Cross-Sectional	-Worse scores for physical, social, emotional and academic domains compared to healthy children. Low maternal schooling levels associated with worse scores of children with CKD.
Brunelli G, Nogueira PC, Pestana JO, Diniz HD. Quality of life in children on dialysis. <i>Int Urol Nephrol.</i> 2012; 44(5):1515-9.	PUBMED	BR/2012	Cross-Sectional	-CKD relates to worse QL perception as to aspects linked to the practice of sports.
Marciano RC, Soares CMB, Diniz JSS, Lima EM, Silva JMP, Canhestro MR et al. Transtornos mentais e qualidade de vida em crianças e adolescentes com doença renal crônica e em seus cuidadores. <i>J Bras Nefrol.</i> 2010; 32(3): 316-22.	BVS	BR/2011	Cross-Sectional	-Importance of assessing social and behavioral impacts in children with CKD in order to improve QL.
Park KS, Hwang YJ, Cko MH, Ko CW, Ha IS, Kang HG et al. Quality of life in children with end-stage renal disease based on a PedsQLESRD module. <i>Pediatr Nephrol.</i> 2012; 27(12): 2293-300.	PUBMED	Korea/2012	Cross-Sectional	-Children report better QL compared to caregiving parents for domains referring to fatigue, family and social relationship and worries. Longitudinal studies needed.
Kiliś-Pstrusińska K, Medyńska A, Chmielewska IB, Grenda R, Kluska-Józwiak A, Leszczyńska B et al. Perception of Health-Related Quality of Life in Children with Chronic Kidney Disease by the Patients and Their Caregivers: Multicentre National Study Results. <i>Qual Life Res.</i> 2013; 22(10):2889-97.	BVS	Poland/2013	Cross-Sectional	-HRQoL in children with worse CKD compared to the healthy control group. Worse scores observed at initial stages of the disease. Worse scores in children undergoing hemodialysis. Negative view of parents regarding the quality of life of children may have a negative impact on QL in the future and create conflicts between parents and children.
Aparicio LC, Fernández EA, Augusto LP, Izquierdo EG, Garrido GC. Influencia de la situación clínica em la calidad de vida relacionada com la salud de los pacientes pediátricos con enfermedad renal crônica. <i>Nefrologia</i> 2013. 33(1): 61-69.	BVS	Spain/2013	Cross-Sectional	-Results confirm previous studies and contribute to the validation of the TECAVNER questionnaire.
Neul SK, Minard CG, Currier H, Goldstein SL. Health-related quality of life functioning over a 2-year period in children with end-stage renal disease. <i>Pediatr Nephrol.</i> 2013; 28(2): 285-93.	BVS	USA/2013	Cross-Sectional	-Patients subjected to long dialysis periods report worse scores in the emotional domain, which is more evident among females. Concern about appearance mostly reported by females. Parents report worse overall scores and scores related to the disease in older children and those subjected to a longer dialysis period. Parents reported progressive worsening in academic performance.

References	Databases and Portals	Origin	Study Type	Median
Kul M, Cengel KE, Senses DG, Bilginer Y, Uluc S, Baykan H. Quality of life in children and adolescents with chronic kidney disease: a comparative study between diferente disease stages and treatment modalites. Turk J Pediatr 2013. 55(5): 493-9.	PUBMED	Turkey/ 2013	Cross-Sectional	-Children and adolescents with CKD have worse scores as to physical and psychosocial aspects compared to healthy control groups.
Teixeira CG, Duarte MCMB, Prado CM, Albuquerque EC, Andrade LB. Impact of chronic kidney disease on quality of life, lung function, and functional capacity. J Pediatr. 2014; 90(6): 580-6.	BVS	BR/ 2014	Cross-Sectional	-Significant reduction in quality of life and functional pulmonary capacity in children with CKD, influenced by treatment modality, gender and sedentary lifestyle.
Lopes M, Koch VHK, Varni JW. Tradução e adaptação cultural do Peds QL™ ESRD para a língua portuguesa. J Bras Nefrol. 2011; 33(4): 448-56.	BVS	BR/ 2014	Cross-Sectional	-HRQoL of children with stage 1-5 CKD is negatively affected according to age and treatment modality.
Abreu IS, Kourrouski MFC, Santos DMSS, Bullinger M, Nascimento LC, Lima RAG et al. Children and adolescents on hemodialysis: attributes associated with quality of life. Rev Esc Enferm USP. 2014; 48(4): 602-9	BVS	BR/ 2014	Exploratory/ Descriptive	-Seven themes were identified: water and food restriction, limitations related to the treatment, time reserved for the treatment, change in body image related to vascular access and growth, stigma, self-care and transplant expectation.

Discussion

In 1991, the World Health Organization's project on quality of life began (QHOQOL), with the aim of developing instruments for the assessment of quality of life (QL) in several cultural contexts. Considering that the concept of QL relates to an individual's perception on his cultural context, social values, goals and longings, assessment instruments on the subject should approach four domains: physical well-being, psychological well-being, social relations and environment of interaction with others [9]. First, there was the development of instruments for the adult population and, then, for the child population, as well as for children with chronic diseases in several countries. Using these instruments requires observance of copyright laws, validation for the desired language or, in case it has been validated, citing the validation's author [10].

Increased survival of patients with chronic diseases because of advances in therapeutic and diagnostic modalities led to a need to question how the QL of these individuals would be. Health Related Quality of Life (HRQL) instruments became, then, necessary.

The development of questionnaires for pediatric patients with CKD, study object of this article, came to assist in the conduction of studies in this area. Studied aspects include general fatigue, perception on the disease, problems in the treatment, interaction with family and friends, worries, perception on physical appearance, and communication [11].

The selected studies, in general, compared the scores of children with CKD to those of groups with healthy children; scores obtained among children with CKD undergoing different treatment modalities assess the impact of morbidities related to the

disease and the results obtained through answers from the children themselves and their caregiving parents.

Comparative studies about QL among children with CKD and control groups show tendency for worse scores among groups with CKD. A study conducted with 81 children who had CKD, in different types of treatment, and 901 healthy children, in the control group, observed no significant difference between the transplanted group and the healthy one, with the health-related score being lower in the group of children subjected to dialysis compared to transplanted and healthy ones [7]. Another study verified worse scores as to self-esteem, physical perception and physical activities within the group with CKD compared to the control group [12]. Likewise, another research assessed worse scores for all domains among children with CKD compared to control group, with results being attributed to a greater perception of emotional and behavioral disorders in the CKD group [13].

A Polish study that assessed 203 children with CKD found worse scores for all domains in comparison with the control population, with emphasis on poorer academic performance, regardless of the disease staging [15]. Two studies were conducted in Turkey; both scores of children with CKD were worse when compared to those of control groups [15-16].

A study conducted in São Paulo, in which 64 patients were assessed, found worse HRQL for physical, social and academic domains in the CKD group, in addition to negative influence of treatment modality on the group undergoing hemodialysis and conservative treatment [17]. A study conducted in the United Kingdom found no significant changes between studied and control groups, neither between different treatment modalities [18]. Differences between studies may be related to the use of different assessment instruments. A research that used the Generic Children's Quality of Life Measurement (GCQ) did not include aspects related to health status [17].

As for treatment modality, there are children undergoing conservative treatment, peritoneal dialysis, hemodialysis, and transplanted ones. Transplanted patients report better health-related QL than other groups do [12]. Lower scores are seen in patients undergoing hemodialysis [16].

The advent of automatized peritoneal dialysis allows the treatment to be performed generally at home, daily and during the night. Hemodialysis requires the patient to go to the specialized center three days a week and stay there for three hours. Thus, children are deprived of regular activities, interaction with friends and family for long periods. There is need for a strict dietary control, which includes food and liquid restriction so the patient stays healthy between hemodialysis sessions. The need for liquid restriction is reason for concern for both children and parents, as seen in qualitative studies [18].

In large centers, the long distance between hemodialysis places and one's home seems to contribute to worse QL perceptions. Children and parents need to wake up early and face heavy traffic until reaching their destination [16]. Treatment periodicity, with shorts intervals, changes family dynamics, negatively influencing the relationship of caregivers with their healthy kids, and their leisure life. Trips are not allowed, even if for short periods. Changes in body image are also present in children and adolescents undergoing hemodialysis. The presence of peritoneal catheter, hemodialysis catheters and the arteriovenous fistula often places patients in the position of "ill" through the eyes of others. It is worth highlighting that adolescents are more vulnerable to these variables [18, 19].

The relationship between presence of comorbidities such as anemia, osseous deformities, heart disease and short stature were assessed by some authors. Another research found worse scores as to physical discomfort in transplanted patients with anemia and hematocrit >35%, relating them to improved physical activity and functionality. Patients with short stature scored lower as to satisfaction,

presenting low self-esteem and little satisfaction with their health [7].

Presence of heart disease had a negative influence on HRQL in a study conducted in Madrid. Osseous deformities affect the autonomy of patients, having a negative influence on HRQL [12]. A research addressing the QL of children with CKD associated with lung capacity, respiratory muscle strength and functional capacity found better QL in patients that exercised, who presented better pulmonary rates [20]. Follow-up of children with CKD must emphasize not only aspects related to the disease itself, as multidisciplinary assistance, early diagnosis and compliance with treatment tend to reduce the presence of comorbidities.

Questionnaires on QL in children are applied to patients and caregiving parents. There was tendency for a more negative assessment by parents in comparison with that of children [15, 21]. When applied to secondary caregiving relatives, it was also observed that the latter would have a more positive assessment on the HRQL of children than the primary caregiving relative did [14].

The parents' negative view may affect the children's perception of themselves, leading them, for instance, to believe they are unfit for exercises and keeping up with school activities. Qualitative studies about the theme could clarify the difference in perception between parents and children.

The presence and participation of both parents in the treatment is of great importance, since sociability among children with present parents is better when compared to that of children of single or divorced parents [22].

Poor academic performance was reason for concern in several studies, even in those centers where patients are tutored at the very place of treatment [12, 16, 18, 19, 23]. Frequent absences due to hemodialysis sessions, frequent doctor visits and examinations regularly may have an influence in this sense, which would not explain the poorer academic performance among children with CKD undergoing conservative treatment.

The higher proportion of behavioral and emotional disorders in children with CKD, associated with other variables such as presence of anemia and physical limitations, may be explanatory. It is an important aspect in the follow-up of pediatric patients with CKD, since poor education influences one's long-term social and economic life in adulthood [13, 23, 24]. Thus, there is a need for more in-depth studies about reasons for these children's poor academic performance.

Only one longitudinal study was included in this review. A group of 53 patients aged between two and 18 years old were followed up for a period of two years, with at least two assessments on different occasions. Some aspects changed over the progress of the treatment. The longer the dialysis time, the worse the patients' emotional assessment. Girls were the most affected ones, especially when it comes to physical changes imposed by the disease and the effects in their appearance. According to parents, the longer the dialysis time, the worse the assessment of social, emotional, physical and academic aspects. Children tend to feel more tired while performing everyday tasks. Their relationship with family and friends is compromised, as a consequence of all time spent on issues related to the disease. Progressive worsening in academic performance affects parents and patients [19, 25].

Worse HRQL was reported among assessed patients who had a chronic condition diagnosis and were subjected to dialysis more abruptly, as well as their respective parents when compared to those who had undergone conservative treatment first. The study did not include children with cognitive incapacities that hindered the filling of the questionnaire. Longitudinal studies allow for a dynamic assessment of patients in the course of the treatment and as age advances. They also allow assessing the impact of applied measures, in order to improve the QL of these patients and respective caregivers. Although the application of questionnaires on QL to chronic patients is recurring and mandatory in

the United States, country where the study was conducted, little has been published on the matter [19, 26, 27].

Six studies conducted in Brazil were analyzed [4, 11, 13, 16, 20, 23], being four quantitative and two qualitative. Among them, two were carried out in the Northeast, one in the South and three in the Southwest. By definition, QL relates to cultural, social and economic aspects connected to individuals and their environment. Because Brazil is a large country, the five regions presented varied sociodemographic aspects as to population, demographic density, education, GDP, access to health services, among others. Thus, there is need for regionalized assessments that encompass these differences. The validation done for Portuguese of QL assessment instruments aimed at the pediatric population and specific instruments for children with CKD can promote the interest of professionals in this subject [16].

Conclusion

Children with CKD have poorer QL when compared to those without chronic disease. Dietary restrictions, especially liquid restriction, presence of comorbidities such as anemia, heart disease, short height and osseous deformities contribute to the negative assessment of patients and caregivers. Treatment modality has an influence on the QL of these children as well, and those undergoing hemodialysis are the ones with the lowest scores. The presence and participation of families in the treatment has a positive influence on the QL perception of these patients.

An important aspect to be studied in children with CKD is poor academic performance, in the sense of clarifying causes and developing strategies in order to minimize the effects. Conducted studies aim at a result/diagnosis that involve immediate effect and/or long-term actions. There is a lack of longitudinal studies to follow up patients during growth and evolution of the disease and that assess the results of effected measures in order to improve QL.

In Brazil, little has been studied about the QL of children with CKD. Encouraging the application of questionnaires on QL at centers for the treatment of children and adolescents will promote regionalized knowledge about these patients. Qualitative studies can evidence other relevant aspects for the population such as religiosity and specific cultural characteristics of each region.

Abbreviations

- Chronic Kidney Disease: CKD
- Glomerular Filtration Rate: GFR
- Scientific Electronic Library Online: SCIELO
- National Library of Medicine: PUBMED
- Medical Literature Analysis and Retrieval System Online: MEDLINE
- Biblioteca Virtual em Saúde (Virtual Health Library): BVS
- Descritores em Ciências da Saúde (Descriptors for Health Sciences): DECS
- Medical Subject Headings: MESH
- The World Health Organization Quality of Life: WHOQOL
- Health Related Quality of Life: HRQL
- Quality of Life: QL
- Generic Children's Quality of Life Measurement: GCQ

References

1. Stieffge-Krunke I. Diabetic Adolescents and Their Families: Stress, Coping and Adaptation [Internet]. 2014 [citado em 14 jul 2016]. Disponível em: <http://www.cambridge.org/cambridgeuniversitypress>.
2. Hogg RJ, Furth S, Lemley KV, Portman R, Schwartz GJ, Coresh J et al. National Kidney Foundation's Kidney Disease Outcomes Quality Initiative, Clinical Practice Guidelines for Chronic Kidney Disease in Children and Adolescents: evaluation, classification and stratification. *Pediatrics*. [Internet]. Jun 2003 [citado em 14 jul 2016]; 6(1): 1416-21. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/12777562>.
3. 15th Congress of the International Pediatric Nephrology Association. *Pediatric Nephrol* 2010; 25(9): 1779-2004.

4. Nogueira PCK, Feltran LS, Camargo MF, Leão ER. Prevalência estimada da doença renal crônica terminal em crianças do estado de São Paulo. *Rev Assoc Med Brasil*. Jul/Ago 2011 [Internet] [citado em 14 jul 2016]; 57(4): 443-9. Disponível em: <http://www.scielo.br/pdf/ramb/v57n4/v57n4a20.pdf>.
5. Collins A, Foley R, Herzog C, Chavers B, Gilbertson D, Ishani A et al. Excerpts from the US Renal Data System 2009 Annual Data Report. *Am J Kidney Dis* 2010;55(1 Suppl 1):S1-420, A6-7.
6. Van der Heijden B, Van Dijk P, Verrier-Jones K, Jager K, Briggs J. Renal replacement therapy in children: data from 12 registries in Europe. *Pediatr Nephrol* 2004;19(2):213-21.
7. Riano-Galán I, Málaga S, Rajmil L, Ariceta G, Navarro M, Loris C, Vallo A. Quality of life of adolescents with end-stage renal disease and kidney transplant. *Pediatr Nephrol*. [Internet]. Aug 2009; [citado em 14 jul 2016]; 24(8): 1561-8. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/19475433>.
8. Mendes KDS, Silveira RCCP, Galvão CM. Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem. *Texto Contexto Enferm*. [Internet] Out-Dez 2008; [citado em 14 jul 2016]; 17(4): 758-64. Disponível em: <http://www.scielo.br/pdf/tce/v17n4/18.pdf>.
9. The WHOQOL Group. World Health Organization. WHOQOL: measuring quality of life. Geneva: WHO; 1997.
10. Souza JGS, Pamponet MA, Souza TCS, Pereira AR, Souza AGS, Martins AMEBL. Instrumentos utilizados na avaliação de qualidade de vida de crianças brasileiras. *Rev Paul Pediatr*. [Internet] Mar 2014 [citado em 14 jul 2016]; 32(2): 272-8. Disponível em: http://www.scielo.br/pdf/rpp/v32n2/pt_0103-0582-rpp-32-02-00272.pdf.
11. Lopes M, Koch VHK, Varni JW. Tradução e adaptação cultural do Peds QL™ ESRD para a língua portuguesa. *J Bras Nefrol*. [Internet] 2011 [citado em 14 jul 2016]; 33(4): 448-56. Disponível em: <http://www.scielo.br/pdf/jbn/v37n2/0101-2800-jbn-37-02-0158.pdf>.
12. Aparicio LC, Fernández EA, Garrido CG, Luque A, Izquierdo GE. Calidad de vida percibida por niños con enfermedad renal crónica y por sus padres. *Nefrol*. [Internet] 2010; [citado em 14 jul 2016]; 30(1): 103-9. Disponível em: <http://previous.revistanefrologia.com/revistas/P1-E43/P1-E43-ES.pdf>.
13. Marciano RC, Soares CMB, Diniz JSS, Lima EM, Silva JMP, Canhestro MR et al. Transtornos mentais e qualidade de vida em crianças e adolescentes com doença renal crônica e em seus cuidadores. *J Bras Nefrol*. [Internet] Jul/Set 2010 [citado em 14 jul 2016]; 32(3): 316-22. Disponível em: <http://www.scielo.br/pdf/jbn/v32n3/v32n3a14.pdf>.
14. Kiliś-Pstrusińska K, Medyńska A, Chmielewska IB, Grenda R, Kluska-Józwiak A, Leszczyńska B et al. Perception of Health-Related Quality of Life in Children with Chronic Kidney Disease by the Patients and Their Caregivers: Multicentre National Study Results. *Qual Life Res*. [Internet] Dec 2013 [citado em 14 jul 2016]; 22(10):2889-97. Disponível em: <http://link.springer.com/article/10.1007/s11136-013-0416-7>.
15. Buyan N, Türkmen MA, Bilge I, Baskin E, Habera M; Bilginer Y et al. Quality of life in children with chronic kidney disease (with child and parent assessments). *Pediatr Nephrol*. [Internet] Aug 2010; [citado em 14 jul 2016]; 25(8): 1487-96. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/20383649>.
16. Lopes M, Ferraro A, Koch VH. Health-related quality of life of children and adolescents with CKD stages 4-5 and their caregivers. *Pediatr Nephrol*. [Internet] Jul 2014 [citado em 14 jul 2016]; 29(7): 1239-47. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/24577804>.
17. Heath J, Mackinlay D, Watson AR, Hames A, Wirz L, Scott S et al. Self-reported quality of life in children and Young people with chronic kidney disease. *Pediatr Nephrol*. [Internet] May 2011 [citado em 14 jul 2016]; 26(5): 767-73. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/21327779>.
18. Abreu IS, Kourrouski MFC, Santos DMSS, Bullinger M, Nascimento LC, Lima RAG et al. Children and adolescents on hemodialysis: attributes associated with quality of life. *Rev Esc Enferm USP*. [Internet] 2014 [citado em 14 jul 2016]; 48(4): 602-9. Disponível em: <http://www.scielo.br/pdf/reeusp/v48n4/0080-6234-reeusp-48-04-601.pdf>.
19. Neul SK, Minard CG, Currier H, Goldstein SL. Health-related quality of life functioning over a 2-year period in children with end-stage renal disease. *Pediatr Nephrol*. [Internet] Feb 2013 [citado em 14 jul 2016]; 28(2): 285-93. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/23052652>.
20. Teixeira CG, Duarte MCMB, Prado CM, Albuquerque EC, Andrade LB. Impact of chronic kidney disease on quality of life, lung function, and functional capacity. *J Pediatr*. [internet] Nov-Dec 2014 [citado em 14 jul 2016]; 90(6): 580-6. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/24950475>.
21. Park KS, Hwang YJ, Cko MH, Ko CW, Ha IS, Kang HG et al. Quality of life in children with end-stage renal disease based on a PedsQLESRD module. *Pediatr Nephrol*. [Internet] Dec 2012 [citado em 14 jul 2016]; 27(12): 2293-300. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/22832667>.

22. Kul M, Cengel KE, Senses DG, Bilginer Y, Uluc S, Baykan H. Quality of life in children and adolescents with chronic kidney disease: a comparative study between diferente disease stages and treatment modalites. *Turk J Pediatr*. [Internet] Sep-Oct 2013 [citado em 28 ago 2016]; 55(5): 493-9. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/24382529>.
23. Frota MA, Machado JC, Martins MC, Vasconcelos VM, Landin FLP. Qualidade de vida da criança com insuficiência renal crônica. *Esc Anna Nery*. [Internet] Jul-Set 2010 [citado em 14 jul 2016]; 14(3): 527-33. Disponível em: <http://www.scielo.br/pdf/ean/v14n3/v14n3a14.pdf>.
24. Goldstein SL, Rosburg NM, Warady BA, Seikaly M, McDonald R, Limbers C, Varni JW. Pediatric end stage renal disease heath-related quality of life differs by modality: a PedsQL ESRD anlysis. *Pediatr Nephrol*. [Internet] Aug 2009 [citado em 28 ago 2016]; 24(8): 1553-60. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/19421787>.
25. Gerson AC, Wentz A, Abraham AG. Health Related Quality of Life of Children with mild to moderate chronic kidney disease. *Pediatrics* [Internet] Feb 2010 [citado em 28 ago 2016]; 125(2): 349-57. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/20083528>.
26. Brunelli G, Nogueira PC, Pestana JO, Diniz HD. Quality of life in children on dialysis. *Int Urol Nephrol*. [Internet] Oct 2012 [citado em 28 ago 2016]; 44(5): 1515-9. Disponível em: <http://www.ncbi.nlm.nih.gov/pubmed/21870089>.
27. Aparicio LC, Fernández EA, Augusto LP, Izquierdo EG, Garrido GC. Influencia de la situación clínica em la calidad de vida relacionada com la salud de los pacientes pediátricos con enfermedad renal crônica. *Nefrologia*. [Internet] Jul 2013 [citado em 28 ago 2016]; 33(1): 61-69. Disponível em: <http://www.revistanefrologia.com/es-publicacion-nefrologia-articulo-influencia-situacion-clinica-calidad-vida-relacionada-con-salud-los-pacientes-X0211699513002668>.

Publish in International Archives of Medicine

International Archives of Medicine is an open access journal publishing articles encompassing all aspects of medical science and clinical practice. IAM is considered a megajournal with independent sections on all areas of medicine. IAM is a really international journal with authors and board members from all around the world. The journal is widely indexed and classified Q2 in category Medicine.