

PERFORMANCE DISORDERS AND QUALITY OF LIFE OF ALBANIAN CHILDREN AND ADOLESCENTS WITH CHRONIC KIDNEY DISEASE

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Abstract

It has been noticed that the interest in the Quality of Life (QOL) of children and adolescent with chronic kidney disease (CKD) in Albania is increasing rapidly. Thus, the aim of this study is to investigate the prevalence of performance disorders and to evaluate the Health-Related QOL (HRQOL) in 130 patients with CKD. To appraise the prevalence of performance disorders and analyze HRQOL, we used the Strengths and Difficulties Questionnaire (SDQ) and Pediatric Inventory of Quality of Life (PedsQL) Core scales as the measuring instruments for both the children and their parents. The CKD group has lower results in nearly all areas of PedsQL. Only the lack of religion was related in a significant way with a lower global HRQOL result (OR= 5.8; P= 0.07). Furthermore, only two factors were related with a lower HRQOL result between the parents: children's age >10 years (OR = 4.9, P=0.026) and the lack of religion (OR= 2.8, P= 0.025). The CKD group showed a higher ratio of performance and emotional disorders in all SDQ fields. Therefore, our results recommend the significance of assessing performance and social impacts of CKD in order to improve the life quality of this pediatric population.

Keywords: Quality of life, dialysis, emotional disorders, chronic renal disease

Introduction

Medical progresses have demonstrated remarkable changes in physical results and essential advancement in survival rates of children with

chronic kidney disease (McDonald 2004). Many restrictions in the life of these children can lead to a moderated social life through hospitalization and absence from school and leisure activities (Kinsella E 2006, Fukunishi I 1995).

WHO defines Quality of Life (QoL) as an “individual awareness of his position in life in the context of the culture and assessment system in which he lives and in relation to his objectives, expectations, standards and worries” (WHOQoL Group 1994). However, the implication of QoL changes from one person to another; hence, it is important to know each individual’s social and psychological characteristics and the area these features are influenced by illness (Ravens-Sieberer U 1998).

While “quality of care” measures are commonly used, there has been a rising trend towards the results becoming more patient-centered and not just based on survival (Campdell A 1976, Taylor RM 2010).

Regardless of the aim of renal substitution therapy, there is little data that specific QoL measures are used in medical practices (Varni JW 2004).

The concern in promoting health-related quality of care has developed with the model of humanization of medicine which has motivated concerns about patients’ satisfaction with medical care, suggesting specific management choices which could be tailored according to patient’s needs and personal choices (Pais-Ribeiro JL 2004, Goldbeck L).

The evaluation of QoL in childhood and adolescence must be guided by subjective and objective evaluation of the child, child’s family as well as the social, economic and cultural conditions (Wallander JL 2001).

Optimal care for the pediatric patient with CKD involves not only medical management, but also the management of psychological and developmental factors that will ensure a pediatric patient’s successful transition in adulthood (Goldstein SL 2007).

Few studies have addressed the issue of clinical and social factors associated with an impairment of HRQOL (Konrad M 2010).

The aim of the study is to investigate the prevalence of behavioral disorders and to evaluate the QoL in 130 patients and adolescents with CKD. Therefore, potential clinical, social and demographic factors associated with behavioral disorders and a lower HRQOL were also assessed.

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This is a cross-sectional study consisting of all CKD patients being followed up at the Pediatric Nephrology Unit, at the University Hospital Centre “Mother Theresa”, in Tirana, Albania.

The sample of the study was provided according to the fact that the participants were of the ages between 2.5-18 years, with a permission

obtained by both the patient and the parent. Also, the patients with severe cognitive and developmental deficit were kept out.

Demographic and clinical data were obtained by a structured interview regarding primary renal disease, CKD phase, comorbidities, medication intake, height and weight measurements and laboratory tests. Social and demographic records such as gender, age, religion, marital status, family income, absence from school and malfunctions related to the treatment were also taken.

The patient behavioral and emotional alteration was assessed by fulfilling the Strengths and Difficulties Questionnaire (SDQ) (Goodman R 1997). The questionnaire comprises of emotional and behavioral problems of the children. SDQ has been demonstrated to be very associated with other well-set up measures (Goodman R 1999). Thus, the subjects were distinguished as anomalous on the total range of indicators and were considered to represent performance and emotional disorders. This description helps in diagnosing the psychiatric problems like depression, and anxiety in which the tool displays a high sensitivity and specificity (Madden SJ 2002).

Patients' HRQOL was evaluated using the Pediatric inventory of Quality of life Core Scale that encloses physical, emotional, social and school performance based on focus groups and cognitive discussions (Varni JV 2002). The interviewers which administered the PedsQL and SDQ questionnaire were very skilled considering the restriction of the study population.

The statistical analysis was carried out using the SPSS statistical package version 17 (SPSS Chicago, IL). The continuous data were represented as the median and the interquartile range (IQR), or as the mean and standard deviation when it is suitable. The Mann-Whitney and Kruskal-Wallis test were used for non-parametric variables. Therefore, Chi-square test was applied for binary variables and logistic regression for multivariate analysis.

The main baseline clinical and demographic characteristics are summarized in Table 1.

Table 1. Medical/demographic feature of the patients with CKD

Medical/Demographic features	N (%)
Sex	
Male	72(55.4)
Female	58(44.6)
Main renal disease	
Glomerular diseases	25(19.2)
Cystic diseases	18(13.8)
Congenital nephro-uropathies	61 (46.9)
Mixed	26 (20.1)

Stages of CKD	
Stage 2	23 (17.7)
Stage 3	27 (20.8)
Stage 4	16 (12.3)
Stage 5	64 (49.2)
Age at interview (years)	
Median	13.0
Interquartile range (25 th -75 th)	7.8-16.0

The socioeconomic features are shown in Table 2. When we reflected on demographic and socio-economic features, there was a considerable difference between groups only for mean age, which was 11.7 (SD = 5.3), 8.3 (SD = 5.2) years for the conservative method and dialysis, when P= 0.001 correspondingly. The family income of the majority of the sample (60.7%) was three minimum earnings or less and 39.2% of the families got some financial support by NGO-s and from the government.

Regarding the education of the patients, the great part of them 58(44.6%) had not so far fulfilled the elementary school; 31.2% failed and subsequently repeating a school year, and 49.5 % of them associated the event to the medical treatment. Among the mothers of the patients, 43% had not yet finished elementary school and not more than 3% of them had a university education.

Table 2. Cultural and socioeconomic features

Cultural and socio-economic features of the patient	N (%)
Parent's civil status	
Married	78 (60%)
Separated, widowed, others	52 (40%)
Family profits	
≤ 3 minimum salary	79 (60.7%)
≥ 3 minimum salary	51 (39.3%)
Patient education level	
Kindergarten	6 (4.6%)
Partial elementary school	58 (44.6%)
Entire elementary school	5 (3.8%)
Deficient secondary school	32 (24.6%)
Partial higher education	9 (6.92%)
Special school	3 (2.3%)
Not applicable (years)	17 (13.1%)
Family religion	
Muslim	92 (70.7%)
Orthodox	31 (23.8%)
Absence of religion/others	7 (5.5%)

Table 3 illustrates the outcomes of PedsQL survey from the patients and their parents. Hence, a significant difference among the QoL evaluated by the patients and the parents concerning the curative modality was not noted. Nevertheless, the CKD group had significantly lower scores in nearly all characteristics compared to the control group. The only exclusion was in the emotional area in the PedsQL accomplished by the children, which did not achieve a statistically significant difference among patients and controls.

Table 3. Quality of life of the children and adolescents with CDK based on PedsQL survey

PedsQL statement	Conservative (mean \pm SD)	Dialysis (mean \pm SD)	P value	Total n; (mean \pm SD)	Control group (mean \pm SD)	P value
PedsQL parents						
Emotional	61.2(\pm 23.5)	64.7(\pm 18.6)	0.275	65.9(\pm 21.6)	80.47(\pm 11.5)	<0.0001
Psychosocial	69.7(\pm 17.4)	67.8(\pm 17.3)	0.798	71.8(\pm 17.5)	88.26(\pm 7.62)	<0.0001
Physical	76.1(\pm 22.8)	70.3(\pm 25.2)	0.628	75.7(\pm 21.8)	96.82(\pm 3.59)	<0.0001
Educational	59.4(\pm 20.7)	62.5(\pm 27.9)	0.176	63.7(\pm 22.6)	90.75(\pm 10.78)	<0.0001
Total	72.3(\pm 16.6)	70.3(\pm 18.6)	0.572	72.8(\pm 16.9)	91.64(\pm 5.66)	<0.0001
PedsQL children						
Emotional	68.5 \pm 14.6	64.9 \pm 11.3	0.587	68.8 \pm 14.7	73.04 \pm 16.28	<0.0001
Psychosocial	75.4 \pm 12.7	73.7 \pm 11.8	0.876	75.1 \pm 11.8	84.77 \pm 9.52	<0.0001
Physical	81.7 \pm 14.8	78.6 \pm 16.3	0.478	81.7 \pm 13.9	95.76 \pm 5.67	<0.0001
Educational	68.6 \pm 18.5	67.4 \pm 13.7	0.903	68.3 \pm 17.6	87.25 \pm 11.2	<0.0001
Total	77.4 \pm 11.5	74.6 \pm 10.8	0.582	76.8 \pm 11.3	87.59 \pm 6.28	<0.0001

There was no significant difference between the assessment of the children and the parents on the kind of cure. When we evaluated the CKD group to healthy controls, it resulted to a higher ratio of performance and emotional disorder in nearly all areas of SDQ (Strengths and Difficulties Questionnaire). In the univariate analysis, there was no significant difference among medical, demographic, and socio-economic variables in the parents' questionnaire.

The fascinating findings is the strong connection between the occurrence of the performance and emotional disorders and the low HRQOL (health related quality of life), as appraised by the parents PedsQL statement.

In this study, we estimated the QOL and the prevalence of emotional and performance disorders in a pediatric population with CKD. We found a significant destruction of their QoL and a higher prevalence of emotional and performance disorder than in healthy controls. Many studies using PedsQL 4.0 have demonstrated Generic Core Scales with the same results (Goldstein SL 2006, Mckenna AM 2006) like Varni et al, who compared HRQOL among ten chronic disease groups comprising 96 children with ESRD (end-stage renal disease). In our study, there was no important difference in both parents or children with HRQOL scores between the CKD cure modalities in

contrast with other studies in which children presented lower HRQOL scores (Goldstein SL 2006).

Some social and demographic factors were associated with lower HRQOL results in the statistical analysis. The majority of families in our study were of low socio-economic level, but this was not associated with lower HRQOL results or a higher prevalence of performance disorders in CKD children in contrast with Fielding et al (Fielding D 1999). The multivariate analysis confirmed that parents and children who were reported to belong to the Muslim religion scored higher in almost all PedsQL areas. Some studies have showed a defensive religious effect on morbidity and mortality and on depressive indicators and general psychological distress in chosen populations (Levin J 2005). Therefore, these findings suggest to many patients and their families other religious resources to navigate and overcome the spiritual challenges that arise in their experience of illness (Sloan RP 1999, Curlin FA 2005).

Our outcomes reveal that the pediatric CKD patients contributing in our survey had a higher ratio of performance and emotional confusions in nearly all areas of SDQ questionnaire than healthy controls. Hence, there are a few studies that illustrate the prevalence of these disorders in children and adolescents with CKD, with contrasting results (Bakr A 2007, Fukunishi I 1995).

Medical requisites for children with CDK comprising of dietary constraints and dependence on dialysis may separate them from their healthy friends (Hooper SR 2009, Soliday E 2000). Children with CKD show neuro-cognitive insufficiencies, and developmental restrictions such as postponed sexual maturation, bone deformities and short figure (Slickers J 2007, Falger J 2008).

As a consequence, children need self-esteem adjustments which may require isolation from their friends. However, in our study there was no significant difference in the prevalence of performance disorders between the CKD treatment modalities.

Thus, our study had some restraints in terms of the questionnaire used which was not precise for CKD patients and known as the cross-sectional character of the study; therefore, it is unattainable to assume the causality from the outcomes of the statistical analysis.

Conclusion

Finally, we found probable prognostic aspects of impairment of HRQOL in the pediatric CKD population. Regarding Madden et al (Curlin FA 2005), assessing the emotional and psychological impact of CKD and its cure is a significant step in the progress of a less invasive and more individual care for the patients.

This study is the primary challenge to create relations among performance and emotional disorders and QOL. Our results are another step forward in supplying the health professionals that assist these patients with the medical sustain to recognize and treat the psychosocial obstacles for promoting better clinical management and better QOL in this population. The awareness is focused in a multidisciplinary group approach to pediatric CKD for the care of these children that are engaged with complex medical, nutritional, and emotional problems (Bell L 2007, Maxwell H 2010, Menon S 2009). Therefore, prospective studies are required in the future to identify predictors of QOL in children and adolescents with CKD.

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