Presentation of complaints and worth of life in Albanian children and teenagers with CKD

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Abstract

It is observed an elevated interest in the quality of life (QOL) of children with chronic kidney disease (CKD). This study aimed 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 measurement instruments for both the children and their parents. The CKD group had lower results in nearly all areas of PedsQL areas. Only the lack of religion was related in a significant way to a lower global HRQOL result (OR= 5.8; P= 0.07). Only two factors were related to a lower HRQOL result between the parents: children's age > ten 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. Our results recommend the significance of assessing the 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 progress has shown remarkable changes in physical results and essential advances in survival rates in children with chronic kidney disease (1). Many limitations in the life of these children can lead to a moderated social life through hospitalization and nonattendance of school and free time activities (2).

WHO states quality of life (QoL) as an "individual recognition of his status in life in the context of the culture and evaluation system in which he lives and linked to his aims, expectations, standards and worries" (3). However, the implication of QoL changes from one person to another, so it is essential to know each individual's social and psychological features and the area where these features are influenced by illness (4).

While "quality of care" measures are commonly used, there has been a rising trend toward outcomes becoming more patient-centered and not just based on survival (5).

Regardless of the aim of renal substitution therapy, there needs to be more data that specific QoL measures are used in medical practice (6).

The issue of promoting health-related quality of care has developed with the pattern of humanization of medicine, which prompts concerns about patients' satisfaction with medical care, recommending specific management alternatives could be tailored according to patient's needs and personal choices (7).

The evaluation of QoL in childhood and adolescence must be guided by subjective and objective evaluation of the child's family's social, economic, and cultural conditions (8).

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 into adulthood (9).

Few studies have addressed the issue of clinical and social factors associated with an impairment of HRQOL (10).

The study aims to investigate the prevalence of behavioral disorders and to evaluate the QoL in 130 patients and adolescents with CKD. We evaluated significant clinical, social, and demographic components correlated with behavioral disorders and a lower HRQOL, too.

Methods

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

We provided the study sample according to the fact that the participants were aged 3-15 years, with consent obtained by both the patient and the parent. We excluded the patients with severe cognitive and developmental deficiency.

We achieved the demographic and clinical data by a structured interview containing the 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, school nonattendance, and malfunctions are related to the treatment.

We assessed the patient behavioral and emotional alteration by fulfilling the Strengths and Difficulties Questionnaire (SDQ) (11). The questionnaire involved emotional and behavioral problems of the children. SDQ has been demonstrated to be significantly associated with other well-set-up measures (12). The subjects distinguished as anomalous on the total range of indicators were considered to represent performance and emotional disorders. This description helps in diagnosing

psychiatric problems like depression and anxiety, in which the tool displays a high sensitivity and specificity (13).

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 (14). The interviewers who administered the PedsQL and SDQ questionnaires were very skilled, considering the restrictions of the study population.

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

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

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

Medical/Demographic features	**N (%)**
Sex	
Male	75(57.7)
Female	60(42.3)
Main renal disease	
Glomerular diseases	26(19.2)
Cystic diseases	20(14.8)
Congenital nephrotic-uropathies	62 (45.9)
Mixed	27 (20.1)
Stages of CKD	
Stage 2	25 (18.5)
Stage 3	30 (22.2)
Stage 4	17 (12.6)
Stage 5	66 (46.7)
Age at interview (years)	
Median	13.2
Interquartile range (25^{th}-75^{th})	7.6-15.8

The socioeconomic features are shown in Table 2. When we reflected on demographic and socioeconomic features, there was a considerable difference between groups only for mean age, 11.5 (SD = 5.1), 8.3 (SD = 5.3) years for the conservative method and dialysis, when P= 0.002 correspondingly. The family income of the majority of the sample (64.8 %) was three minimum earnings or less, and 34.5% of the families got some financial support from NGOs and the government.

Regarding the education of the patients, a significant part of them, 58(44.6%), had not so far fulfilled the elementary school, 33.6 % declared failing and subsequently repeating a school year, and 44.8 % of them associated the event with medical treatment. Among the patients' mothers, 46 % had yet to finish elementary school. At most, 4% of them had a university education.

Table 2. Cultural and socioeconomic features

Cultural and socioeconomic features of the patient	N (%)
Parent's civil status	
Married	75 (60%)
Separated, widowed, others	60 (40%)
Family profits	
≤ 3 minimum salary	74 (54.8%)
≥ 3 minimum salary	61 (45.2%)
Patient education level	
Kindergarten	7 (5.18%)
Partial elementary school	59 (43.7%)
Entire elementary school	6 (46.15%)
Deficient secondary school	32 (23.7 %)
Partial higher education	9 (6.66%)
Special school	4 (2.96%)
Not applicable (years)	18 (13.33%)
Family religion	
Muslim	85 (62.9 %)
Orthodox	37 (27.4%)
Absence of religion/others	13 (9.3%)

Table 3 illustrates the outcomes of the PedsQL survey from the patients and their parents. There is no significant difference among the QoL evaluated by the patients and the parents concerning the curative modality. Nevertheless, the CKD group had significantly lower scores in nearly all characteristics than 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 ±SD)	Dialysis (mean ±SD)	P value	Total n; (mean ±SD)	Control group (mean ±SD)	P value
PedsQL parents						
Emotional	62.2(±22.6)	63.6(±17.5)	0.275	65.9(±21.6)	80.47(±11.5)	<0.0003
Psychosocial	67.4(±17.2)	64.8(±17.3)	0.798	71.8(±17.5)	88.26(±7.62)	<0.0004
Physical	73.4(±21.9)	70.3(±25.2)	0.628	75.7(±21.8)	96.82(±3.59)	<0.0002
Educational	56.8(±20.2)	62.5(±27.9)	0.176	63.7(±22.6)	90.75(± 10.78)	<0.0001
Total	72.4(±15.8)	70.3(±18.6)	0.572	72.8(±16.9)	91.64(± 5.66)	<0.0002
PedsQL children						
Emotional	68.5 ± 14.6	64.9±11.3	0.587	68.8±14.7	73.04±16.28	<0.0003
Psychosocial	75.4 ± 12.7	73.7±11.8	0.876	75.1±11.8	84.77±9.52	<0.0002
Physical	81.7 ± 14.8	78.6 ± 16.3	0.478	81.7±13.9	95.76±5.67	<0.0001
Educational	68.6 ± 18.5	67.4±13.7	0.903	68.3±17.6	87.25± 11.2	<0.0001
Total	77.4 ± 11.5	74.6±10.8	0.582	76.8±11.3	87.59±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 in 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, or socioeconomic variables in the parents' questionnaire.

Discussion

The fascinating finding is the strong connection between the occurrence of performance and emotional disorders and the low HRQOL (health-related quality of life), as appraised by the parent's 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 significant destruction of their QoL and a higher prevalence of emotional and performance disorders than in healthy controls. Many studies using PedsQL 4.0 have demonstrated Generic Core Scales with the same results (15,16) as 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 critical difference between parents or children with HRQOL scores between the CKD cure modalities in contrast with other studies in which children presented lower HRQOL scores (17).

Some social and demographic factors were associated with lower HRQOL results in the statistical analysis. Most families in our study were of low socioeconomic 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. (18). The multivariate analysis confirmed that parents and children who reported belonging to the Muslim religion scored higher in almost all PedsQL areas. Some studies have shown a defensive religious effect on morbidity and mortality, depressive indicators, and general psychological distress in chosen populations (19). These findings suggest that many patients and their families and other religious resources can navigate and overcome the spiritual challenges that arise in their experience of illness (20,21,22).

Our outcomes reveal that the pediatric CKD patients contributing to our survey had a higher ratio of performance and emotional confusion in nearly all areas of the SDQ questionnaire than healthy controls. There are a few studies that illustrate the prevalence of these disorders in children and adolescents with CKD, with contrasting results (23,24).

Medical requisites for children with CDK comprising dietary constraints and dependence on dialysis may separate them from their healthy friends (25,26). Children with CKD show neuro-cognitive insufficiencies and developmental restrictions such as postponed sexual maturation, bone deformities, and short figures (27,28).

Consequently, children state self-esteem adjustments, which may lead to isolation from their friends. However, in our study, there was no significant difference in the prevalence of performance disorders between the CKD treatment modalities.

Our study had some restraints in terms of the questionnaire used that needed to be more precise for CKD patients, and knowing the cross-sectional character of the study, it is unattainable to assume the causality from the outcomes of the statistical analysis.

Conclusions

Finally, we found probable prognostic aspects of impairment of HRQOL in the pediatric CKD population. Regarding Madden et al. (29), assessing the emotional and psychological impact of CKD and its cure is a significant step in progressing 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 on a multidisciplinary group approach to pediatric CKD for the care of these children that engages complex medical, nutritional, and emotional problems (30,31,32). Prospective studies are required to identify predictors of QOL in children and adolescents with CKD.

Author's Contribution: Both authors have given the same contribution and have to be considered as first authors.

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