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Multi-method assessment of behavior adjustment in children with chronic kidney disease

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Abstract To describe the psychological adjustment in children with chronic kidney disease (CKD), we studied behavioral problems in 19 patients with CKD stage 5 on regular hemodialysis, 19 patients in the predialysis stage, and 19 control children, using the child behavior checklist (CBCL) and the semi-structured clinical interview for children and adolescents (SCICA). For CBCL scales, the mean score on the internalizing scale was significantly higher in the children on dialysis than in predialysis and control children. No significant differences in the mean scores of the total problem or externalizing scales were found between the groups studied. The mean score of SCICA observed problems and total self-reports were significantly higher in the control group than in the CKD groups. The mean score on total self-report was significantly higher in the control children than in the predialysis group. There were significant positive correlations between SCICA self-report and all CBCL scales. No significant correlations were found between these CBCL and SCICA scales and age, gender, severity of anemia, duration of CKD or the efficiency or the duration of hemodialysis in

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the CKD patients. In conclusion, multi-method assessment of children's adjustment through different informants yields a comprehensive view of child psychopathology in CKD that calls for psychosocial support and early identification of maladjustment.

Keywords Chronic kidney disease · Child adjustment · Child behavior checklist (CBCL) · Semi-structured clinical interview for children and adolescents (SCICA)

Introduction

Chronic kidney disease (CKD) invariably has a stressful and often lifelong impact on children and their families [1-3]. Advances in medical care, including improvements in dialysis and transplantation, have increased the survival rates for children with CKD. Like most chronic illnesses of childhood, CKD seriously affects children's lives as they negotiate the stress associated with disease management and the prospect of a shortened life span [4, 5]. Many researchers have conducted clinical studies to highlight the psychosocial sequelae of CKD in children [6-8]. However, those studies primarily focus on the prevalence of clinically significant distress. Moreover, although they mostly reported behavioral functioning within normal limits, findings of significant differences between children with kidney disease and controls were not consistent. These studies used the standardized behavior measures that are mainly based on parental reports.

Research in pediatric psychiatry has ascertained the strategy of gathering data from multiple informants [9], which has become standard practice in many settings [10, 11]. The aims of our study were: (1) to demonstrate the pattern of psychological adjustment in children with CKD;

(2) to compare the perception adjustment between parents and children, using multi-method assessment; (3) to investigate the possible correlation between behavior profiles and demographic indicators (age, gender), and treatment-related indicators (severity of anemia, duration of CKD and duration and efficiency of dialysis). We used multiple sources of information: the child behavior checklist (CBCL) and the semi-structured clinical interview for children and adolescents (SCICA) to assess behavioral adjustment, to elucidate the inconsistent results of previous research.

Methods

Thirty-eight children with CKD and 19 control children between the ages of 9 years and 15 years were enrolled in the study. Of the patients, 19 had CKD stage 5 and were on regular hemodialysis (dialysis group), and 19 had predialysis CKD (predialysis group). CKD was diagnosed when the creatinine clearance (Crcl) (measured by the Schwartz formula) was <90 ml/min per 1.73 m² body surface area (BSA). Patients were started on dialysis when their Crcl was <15 ml/min per 1.73 m² BSA. None of the previous 38 CKD patients had undergone kidney transplantation. CKD patients were recruited consecutively from those attending the pediatric nephrology unit, Mansoura University Children's hospital, between October 2005 and March 2006. A cohort of 185 children with chronic renal failure (CRF) was followed up in the unit. All patients were taking calcium-based phosphate binders, calcitriol, iron, orally, erythropoietin subcutaneously, and antacids. The comparison group of control children was recruited from children who attended the outpatient clinic for mild illnesses (e.g. respiratory tract infections). None of them had evidence of chronic physical illnesses.

After informed consent from the parents had been obtained, a CBCL form was completed by one of the parents, usually the mother, or by interview with illiterate parents. Then, the pediatric psychiatrist conducted the SCICA with the children. Interviews were carried out in a quiet room near the dialysis room after dialysis settings.

The child behavior checklist

The CBCL is a standardized instrument for the assessment of a child's behavioral problems. It is suitable for children aged from 4 years to 16 years and can be completed in 15– 17 min by the parents. The instrument is easily applied, and there are many data about its high test–retest reliability and discriminate validity, including the Arabic version [12, 13]. The items of the CBCL are divided into eight domains, each of which takes different aspects of behavior into account: withdrawn, somatic complaints, anxious/depressed state, social problems, thought problems, attention problems, delinquent behavior, and aggressive behavior. Most of the eight domains within the CBCL can be subdivided into two subscales: internalized problems and externalized problems. These two subscales reflect a distinction between inhibited/anxious behavior (internalizing) on the one side and aggressive, antisocial, behavior (externalizing) on the other side. The internalizing subscale is a summation of withdrawn, somatic, complaints, and anxious/depressed state. The externalizing subscale is comprised of aggressive behavior and delinquent behavior [14].

Norms for these standardized questionnaires in the Arab countries have not yet been established. According to the American norms, standardized T scores of 65–69 fall into the 'borderline clinical' range, while scores of 70 and above can be regarded as clinically significant [15].

Semi-structured clinical interview for children and adolescents

The SCICA is semi-structured clinical interview developed for children aged 6 years to 18 years and can be completed in 60-90 min. During this interview, the child is asked questions about the general areas of school, friends, family, relatives, fantasies, and self-perceptions. Brief assessments of academic achievement, fine motor skills, and gross motor skills are also obtained. After the interview has been completed, the interviewer scores the 117 observation items and 107 selfreport items of the SCICA scoring forms. The items of the two scoring forms are aggregated into a profile of empirically derived two broadband syndrome scales. The syndrome scales based on observation items include anxious, withdrawn, attention problems, strange and resistant, and those on selfreport items include anxious, depressed, family problems and aggressive behavior [15]. The SCICA yields also another two broadband internalizing and externalizing scores. The Arabic translation of the SCICA was done by Khater et al. [15] and Newacheck et al. [16], with test-retest reliability and convergent validity similar to those of the original version. A score of ≥ 70 is considered clinically significant. Higher scores mean worse functions.

Statistical analysis

Data were analyzed with Statistical Package for Social Sciences (SPSS) version 11. Qualitative variables were presented as numbers and percentages. The chi-square test was used for comparison between groups. Quantitative variables were tested for normality distribution by the Kolmogorov–Smirnov test. The variables were presented as means \pm standard deviations (SDs). In normally distributed variables, analysis of variance (ANOVA) with Bonferroni multiple comparisons was used for comparison between

groups. For nonparametric variables, the Kruskal–Wallis test was used for comparison between three groups and the Mann–Whitney test was used for comparison between two groups. Pearson's correlation coefficient was used to test correlation between variables (two scales) in CRF of children. A value of $P \le 0.05$ was considered to be statistically significant.

Results

Table 1 shows that the two groups of kidney disease and the control group were comparable for both age and gender. No statistical differences in the duration of renal impairment were noted between predialysis and dialysis patients. However, patients on dialysis had lower serum levels of albumin and hemoglobin than did the predialysis patients. The median duration of dialysis was 14 months, and the median Kt/v value was 1.1.

As shown in Table 2, behavioral profile, according to the CBCL, demonstrates that the mean score on the internalizing scale was significantly higher in the dialysis group than in the control and predialysis groups. The more internalizing problems in the dialysis group were predominantly due to increased scores for the anxious/depression state and somatic complaints. There were no significant differences in the mean scores of either the total problem or externalizing scales between the CKD groups and the healthy group. However, there was a strong trend for patients with CKD to have higher mean scores for total problems (P=0.07). Moreover, it was found that 26.3% of the dialysis group and 5.3% of the predialysis group had scores in the clinical range of the externalizing CBCL score, with no significant statistical difference, while 31.6% of the dialysis group and 21.1% of the predialysis group had scores in the clinical range of the total problem the CBCL score, with no significant statistical difference (data not shown in tables).

According to the SCICA behavioral assessment (Table 3), there was a significant difference in adjustment between the groups of children with and without CKD on the two broadband scales of observed problems and self-report. The mean score of observed problems was significantly higher in the control group than in the dialysis and predialysis groups, mainly for the anxious, attention, strange and resistant categories. Also, the mean score of total self-report was significantly higher for the control group than for the predialysis group, mainly for aggressive behavior and family problems. No significant differences in the mean scores of either the internalizing or externalizing scales were found between the CKD groups and the control group.

Table 4 shows that the positive correlations between the CBCL internalizing, externalizing and total problem scores were significant and that also the correlations between the broadband SCICA scales, total observed, self-report, and internalizing and externalizing scales were significant. Furthermore, there were significant positive correlations between the SCICA self-report and the CBCL internalizing, externalizing and total problem scales. Also, there was a positive significant correlation between the SCICA externalizing scale and the CBCL externalizing scale.

No significant correlations were found between total problems CBCL scores and either SCICA self-report or

Table 1 Characteristics of the children studied (KW Kruskal-Wallis test)

Characteristic	Dialysis (n=19)	Pre-dialysis (n=19)	Controls $(n=19)$	Significance ^a
Gender				
Boys/girls	11/8	13/6	9/10	$\chi^2 = 1.7, P = 0.4$
Age (years)				
Mean \pm SD	12.3±3.5	10.3 ± 3.1	11.6 ± 3.8	F=1.6, P=0.2
Serum albumin (g/dl)				KW $\chi^2 = 37.3$
Mean \pm SD	3.2 ± 0.12^{AB}	$3.4\pm0.16^{-\mathrm{BC}}$	4.2 ± 0.6 ^{AC}	P<0.0001
Serum creatinine (mg/dl)				Z=5.3
Mean \pm SD		$2.7{\pm}0.7$	$0.3 {\pm} 0.1$	P<0.0001
Serum hemoglobin (g/dl)				KW $\chi^2 = 23.0$
Mean \pm SD	7.9 ± 0.96 AB	9.3±1.3 ^{BC}	12.1±3.1 ^{AC}	P<0.0001
Duration of renal impairment (months))			
Median (minimum-maximum)	20 (1-125)	17.5 (5–52)		Z=0.4, P=0.67
Duration of dialysis (months)				
Median (minimum-maximum)	14 (1–54)			
Kt/v				
Median (minimum-maximum)	1.1 (0.73–2.93)			

^A Dialysis vs control; ^B dialysis vs predialysis; ^C pre-dialysis vs control

^a Mann–Whitney test or KW test

Scale	Dialysis (mean±SD)	Predialysis (mean±SD)	Controls (mean±SD)	Significance ^a
Withdrawn	63.47±12.79	57.0±7.9	54.42±3.06	KW $\chi^2 = 4.3$, $P = 0.12$
Somatic complains	70.05 ± 8.99 A	67.0±9.98 ^B	51.37±4.09 AB	KW $\chi^2 = 29.1, P < 0.0001$
Anxious/depressed	$64.47 {\pm} 8.87$ AB	58.26±8.29 ^A	53.79±3.97 ^B	F=10.1, P<0.0001
Social problems	$57.58 {\pm} 6.49$	57.95±10.79	55.37±4.97	KW $\chi^2 = 1.1$, $P = 0.6$
Thought problems	57.95 ± 6.57	58.79±8.24	54.53±3.26	F=2.4, P=0.1
Attention problems	57.0±6.82	55.95±6.86	54.24±4.87	KW $\chi^2 = 1.2, P = 0.5$
Delinquency problems	55.16±11.78	55.37±8.12	55.65±4.47	KW $\chi^2 = 0.6$, $P = 0.75$
Aggressive behavior	54.21±11.47	56.47±8.64	55.16±5.54	KW $\chi^2 = 0.15$, $P = 0.93$
Internalizing	67.37±7.83 AB	58.47±13.38 ^A	52.37±5.52 ^B	F=11.98, P<0.0001
Externalizing	$47.84{\pm}21.8$	51.0±13.84	52.16±9.66	F=0.37, <i>P</i> =0.7
Total problems	$57.95 {\pm} 8.46$	56.84±12.71	51.11±6.64	F=2.77, <i>P</i> =0.07

Table 2 Behavior assessment according to the CBCL in the children studied (KW Kruskal-Wallis test)

^A Dialysis vs control; ^B dialysis vs pre-dialysis

^a Bonferroni multiple comparison or Mann-Whitney test, as appropriate

total observed scores and age, gender, severity of anemia, duration of CRF or the efficiency or the duration of hemodialysis in CKD patients.

Discussion

A child's serious illness or disability can place psychological and social burdens on both the child and the family [17]. Epidemiologic data show that children with chronic health conditions have higher rates of mental health problems than children without such conditions [18]. In this study we aimed to provide insight into these problems in children with CKD, which has received little research attention. To the best of our knowledge, no similar studies have been carried out on children with CKD in our locality.

Our multi-method assessment of child functioning provided information on the adjustment of children's behavior in the CKD subgroups compared with that in control children. The multi-method assessment included the gathering of information from multiple informants, utilizing the commonly used parent report measure (CBCL) and a standardized child interview measure (SCICA).

The study illustrated that assessment of the effect of CKD on the adjustment of children's behavior measured by the CBCL revealed a similarity between the CKD and control groups in total behavior problems. Mean scores for both groups indicated typical functioning.

In our study the chronically ill families and children may have had typical rates of functioning because most of them had been living with their illness for more than 1 year. After families and children have been managing their illness for a year or more, their levels of functioning may have stabilized, returning to levels more characteristic of the period before diagnosis [19]. Some studies have shown that symptoms of depression are common as early as 1 month to 3 months after diagnosis of pediatric illness and that 4–14% of children are clinically depressed at that time [20, 21].

Table 3 Behavior assessment according to the SCICA in the children studied (KW Kruskal-Wallis test)

SCICA scale	Dialysis (mean±SD)	Predialysis (mean±SD)	Controls (mean±SD)	Significance ^a
Anxious/depressed	50.95±8.54	49.47±8.96	49.89±8.52	F=0.15, <i>P</i> =0.9
Anxious	53.42±8.17 ^A	50.11±9.8 ^B	61.26±7.61 AB	F=9.01, <i>P</i> <0.0001
Family problems	47.05±8.16 ^A	46.58±6.94 ^B	56.63±6.68 AB	F=11.5, P<0.0001
Withdrawn	55.63±8.79	49.95 ± 9.04	55.37±7.07	F=2.8, <i>P</i> =0.07
Aggressive behavior	49.0±8.3 ^A	47.84±11.93 ^B	58.26±9.77 ^{AB}	F=6.1, <i>P</i> =0.004
Attention	41.32±4.9 ^A	40.58±6.06 ^B	47.84 ± 7.96 AB	KW $\chi^2 = 13.7$, $P = 0.001$
Strange	45.37±7.16 ^A	45.53±6.94 ^B	59.47 ± 7.72 AB	F=23.5, <i>P</i> <0.0001
Resistant	52.47±9.66 AB	45.05 ± 5.88 ^{AC}	62.0±10.02 ^{BC}	KW $\chi^2 = 25.6$, $P < 0.0001$
Internalizing	52.16±8.79	45.63±16.33	54.05 ± 8.45	F=2.7, P=0.08
Externalizing	43.47±11.18	39.11±10.93	36.0±6.64	F=2.8, <i>P</i> =0.07
Total observations	49.79±12.17 AB	40.16 ± 6.57 ^{AC}	60.47±11.26 ^{BC}	F=16.9, <i>P</i> <0.0001
Total self-report	51.89±13.17	41.95±14.48 ^B	59.89 ± 8.84 ^B	F=9.6, P<0.0001

^A Dialysis vs control; ^B dialysis vs predialysis; ^C predialysis vs control

^a Bonferroni multiple comparison or Mann–Whitney test, as appropriate

Table 4 Inter-correlations between the measures of adjustment in the children with CRF

Measure	CBCL internalizing	CBCL externalizing	CBCL total	SCICA self-report	SCICA observed	SCICA internalizing
CBCL externalizing	0.48*					
CBCL total	0.66***	0.43**				
SCICA self-report	0.39*	0.39*	0.39*			
SCICA observed	0.1	0.3	0.02	0.62***		
SCICA internalizing	0.16	0.22	0.01	0.39*	0.57***	
SCICA externalizing	0.3	0.34*	0.36*	0.68***	0.64***	0.12

Significant correlation at:

* P=0.05, **P=0.01, ***P≤0.001

The first year of illness was the highest risk period for depression in a 10-year prospective longitudinal study of juveniles with diabetes [22]. Abd El-Azim et al. found that Egyptian parents not only employed more religious defense mechanisms than Western patients did in such a stressful situation, but also went a step further, considering the outcome of treatment, whether good or bad, to be the will of Allah, thus greatly minimizing the anxiety provoked by thinking of the bad outcome of CKD [23].

The more internalizing problems in the dialysis group were most probably due to increased scores on the subscales of anxiety/depression and somatic complaints. Garralda et al. compared psychiatric adjustment in children with that in predialysis and hemodialysis CKD patients and control children. They reported higher internalizing symptoms for children in the illness groups [7]. Further studies to explore the difference in coping mechanisms between parents from different cultures may be of value. Fielding et al. documented that the stress associated with CKD and its prolonged and intensive treatment may adversely affect the psychological well-being of children with the disease [24]. High stress, as well as children's feelings of hopelessness, concerns about self-worth and perceived competencies and maladaptive attribution style may contribute to the elevated levels of depression among patients with CKD [25]. Studies of behavioral adjustment in children with other CKDs such as nephrotic syndrome [18], kidney transplantation [8], and other chronic physical illnesses that do not affect cerebral functions [17], demonstrated that those patients, like ours, were particularly prone to emotional symptoms rather than antisocial behavior.

Mean scores alone do not fully characterize the functioning of our patients according to the CBCL, as it was found that 26.3% of the dialysis group and 5.3% of the predialysis group exhibited scores in the clinical range on the externalizing scale. Similar results were reported by Soliday et al., who reported that approximately 15% of

children with CKD scored above clinical cutoff values on the CBCL externalizing scale [19]. In Egypt, Okasha et al. reported that behavior disorders represented 5% (in 1967) and 8.2% (in 1990) of diagnoses in all children attending the out-patient psychiatric facilities of the Ain Shams University Hospitals in Cairo [26].

We may question why a higher proportion of the dialysis group had externalizing scores in the clinical range. It is suggested that some adolescent patients respond to the dependency conflict between the dialysis machine and the caretakers by adopting an attitude of bravado and rebelling against medical and social authorities. This rebelliousness is often expressed as non-compliance with the dialysis treatment and dietary regimens or acting-out behavior in the school, hospital, the dialysis unit, or within the family [27].

Concerning the child interview measures, children with CKD reported few psychological difficulties on the four SCICA broadband scales of observed, self-report, internalizing and externalizing problems. Those finding are not unique to our patients. Many studies utilizing self-reports in children have consistently reported lower levels of distress, depression, and behavioral problems in children with cancer than in healthy peers [28, 29]. Moreover, Phipps and Steele documented that repressive adaptation is also characteristic of children with chronic physical illnesses [30].

Many postulations may explain these findings. It might be, of course, that the positive self-reports of children with CRF may be a valid reflection of their exceptionally high level of functioning [28]. An alternative explanation, which we favor, is that these findings are a reflection of the lowend specificity problem and that the self-reports of children with CKD are biased in some way toward minimization of distress [29]. Self-report scales fail to differentiate between the two groups. The adaptive style paradigm, developed initially by Weinberger [31], provides an heuristic model for evaluation of individuals who report low levels of psychological distress. This study provides a clear replication of previous findings, that parents reported higher levels of overall and internalizing problems for their children, although such differences were small and fell in the range between normal behavior and clinical distress in children with CKD, than did the mothers of healthy controls [8, 19].

The finding that clinicians infrequently note increased anxiety in children with CKD is also observed in the study by Klinnert et al., who found that maternal reports revealed more internalizing and total behavior problems in children with asthma than in controls, while child interview yielded no differences between groups. Parents may have a lower threshold than clinicians for detecting psychological distress in children [32].

Data showing the correlations between the measures indicate that the parental report and the child interview report are related. This inter-correlation provides evidence of consistency in children's behavioral problems across the parent and child interview reports. Comer and Kendall found low-to-moderate concordance rates among different informants [33]. The meta-analysis by Achenbach et al. reported only a modest overall correlation (r=0.22) between children's and other informants' reports [34].

We did not find any significant correlations between the presence of psychiatric disorders and a number of factors such as age, gender, severity of anemia, duration of CKD, or the efficiency or duration of hemodialysis, in CKD patients. This means that the presence of these disorders is more likely explained by the difficulties encountered in living with CKD rather than by these demographic or physical factors.

This study revealed that, on child interview measures, children with CKD probably have fewer behavioral adjustments than do children who do not have CKD. The parents of children with CKD reported more internalizing disorders in their offspring, generally along the anxiety/depression and somatic problem spectrum.

The patterns of functioning found in this study for the same children, with parent reports providing one view and reports by external observers providing another, illustrate the importance of utilizing different measurement approaches for understanding the problems faced by children with CKD. No one measure provides the true picture of children's psychological adjustment, but rather different measures and different informants provide information about separate facets of children's functioning.

Despite the small sample size, our study identified the behavior problems in children with CKD along different sources of information. Physicians need to arrange and implement appropriate interventions to provide the optimal care for children with kidney disease. Screening for behavioral problems in children with CKD, especially internalizing problems, should be integrated into the routine workup of these patients, so that any deviation may be picked up early. Further studies on larger numbers of patients are recommended, so that these results may be clarified.

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