Original article

Psychosocial problems and quality of life in children with chronic kidney disease

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Objectives To assess psychosocial problems in children with chronic kidney disease (CKD) by comparing them with controls and to ascertain the relationship between psychosocial problems and quality of life in these children.

Method A cross-sectional study of children with CKD and healthy children was conducted. The Strengths and Difficulties Questionnaire (SDQ) and the Pediatric Quality of Life (PedsQL) were used to assess psychosocial problems and quality of life, respectively. Self-report and parent-report forms of the SDQ and the PedsQL were completed by children and parents from both groups.

Results Twenty-five CKD patients and 25 healthy controls were enrolled into this study. The major causes of CKD were congenital nephro-uropathies and glomerular diseases. The mean SDQ self-report scores, especially emotional symptoms, of children with CKD were significantly higher than those of controls (p= 0.02). The SDQ scores in the CKD group, reported by parents, were higher in many domains, especially the total score and emotional symptoms (p=0.02 and 0.01, respectively). The PedsQL scores from parent reports in the CKD group were significantly lower than those of the controls, especially the total, psychosocial, and social scores (p=0.01, 0.02 and 0.01 respectively). The relationship between psychosocial problems and quality of life in children with CKD was fair and correlated negatively (r=-0.47, p< 0.05).

Conclusion Children with CKD were at increased risk of psychosocial problems, especially emotional problems, and they tended to have lower quality of life. Appropriate psychosocial intervention may be needed for a better treatment outcome and quality of life for successful transition into adulthood. **Chiang Mai Medical Journal 2014;53(3):127-134.**

Keywords: psychosocial, quality of life, chronic kidney disease, children

Chronic kidney disease (CKD) refers to irreversible kidney damage that can progress to end-stage renal disease (ESRD). CKD is defined by the National Kidney Foundation Kidney Disease and Outcome Quality Initiative (KDOQI) Group[1] as kidney damage lasting for at least 3 months with or without a decreased glomerular filtration rate (GFR), or a GFR of less than 60

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mL/min per 1.73 m^2 lasting for 3 months with or without kidney damage[2]. The KDOQI also classifies severity of CKD into 5 stages, which are valuable for children older than 2 years of age. The incidence of CKD in Europe is approximately 11-12 per million of the age-related population, depending on CKD definition[3]. The incidence of CKD in Thailand is not known[4]. The major causes of CKD are urologic abnormalities (30-33%), glomerulopathies (25-27%), hereditary nephropathies (16%) and renal hypoplasia/dysplasia (11%)[2]. CKD patients who have progressed to end-stage renal diseases require renal replacement therapy (chronic dialysis or kidney transplant).

With improvements in medical management, including nutritional support, recombinant erythropoietin, dialysis techniques, and kidney transplantation; the prognosis of children with CKD has improved substantially[5-7]. Like most chronic illnesses in childhood, CKD has a stressful and lifelong impact on children and their families[8]. Children with CKD experience multiple hospitalization and invasive procedures. The constraints and restrictions from CKD have a significant impact on normal psychosocial development. The medical requirements for children with CKD include dietary restrictions and isolation from their healthy peers[7]. Such interruptions in normal daily life and activities are a likely cause for low self-esteem and low rates of independent living, with reports of little or no close interpersonal relationships in adult survivors of pediatric ESRD. When compared with healthy children, children receiving dialysis revealed increased incidences of depression, behavioral problems, dependency on caregivers, poor school performance, lack of higher education, cognitive delays, and poor social adjustment and peer relationships[7]. Parents of children with ESRD also experience increased stress, decreased support from friends, increased incidences of anxiety and depression, and confusion related to the role of being both parent and medical caregiver, particularly in parents of patients receiving continuous ambulatory peritoneal dialysis (CAPD)[8-10].

Recognition and identification of those who need psychosocial intervention could help to improve health care for children with CKD. It was suggested in the study by Amr et al that multimethod assessment through different informants yields a comprehensive view of psychosocial problems in CKD that calls for support and early identification of maladjustment[11]. Screening tools for psychosocial problems and quality of life assessment are used for this purpose. The Strengths and Difficulties Questionnaire (SDQ) is a tool that is brief and practical for psychosocial problem screening. The health-related quality of life (HRQoL) is useful in assessing the function of children in different areas. The HRQoLs used commonly were the Children's Health Questionnaire, Child Health and Illness Profile-Adolescent Edition, and Pediatric Quality of Life Inventory (PedsQL)[7]. This study aimed to assess psychosocial problems and quality of life in children and adolescents with chronic kidney diseases by compared them with those of controls using self- and parent-reports. The correlation of psychosocial problems and quality of life also was studied.

Material and methods

Children with CKD, who were followed up at the Nephrology Clinic, Chiang Mai University Hospital, were enrolled into this study. The inclusion criteria included an age range from 11 to 18 years, being diagnosed as chronic kidney disease category 3-5 with a regular follow-up for more than 6 months, and able to complete the questionnaire themselves. The children were required to have their parents accompany them and be able to read the Thai language. Since few cases with CKD were being followed regularly, all of those that met the inclusion criteria were enrolled. Healthy children with matched age and gender, and present with their parents at the general out-patient clinic, were enrolled as a control group for comparison. Informed consent and assents were received from all participants. This study was reviewed by the Ethics Committee of the Faculty of Medicine, Chiang Mai University.

Both the children and their parents were asked to complete 2 forms of a questionnaire, the Strengths and Difficulties Questionnaire (SDQ)[12-14] and Pediatrics Quality of Life Inventory (PedsQL)[15-18]. The SDQ is a short-screening tool that assesses psychosocial and emotional problems and strengths among children and adolescents. The psychosocial health problems found by using the SDQ are measured better when reported by both the parents and children themselves. The reliability and validity of the SDQ in identifying psychosocial problems is as good as other instruments such as the Child Behavior Checklist. The SDQ comprises 25 items in a 5-item scale: emotional symptoms, conduct problems, hyperactivity, peer problems, and prosocial behavior scales. The first 4 scales create total difficulty scores, in which higher scores indicate larger difficulties. The prosocial behavior score indicates the strength of children. The PedsQL is a brief, useful, measurement tool that assesses health-related quality of life in children and adolescents who are healthy and those with acute and chronic health conditions. The PedsQL divides 23 items into 4 functioning scales: physical, emotional, social, and school functioning.

Data analysis

Data were analyzed by using the SPSS program. The Chi square or Fisher's exact test was used as appropriate, and the student t-test for comparing between the two variables. Spearman correlation was used to assess the relationship between the SDQ and PedsQL. A p-value of < 0.05 was considered as statistically significant.

Results

Twenty-five patients with chronic kidney diseases and 25 healthy controls were enrolled into this study. The demographic characteristics of the two groups were comparable for both age and gender, as shown in Table 1. Among the 25 children with CKD, the etiologies were congenital nephro-uropathies (9 cases), glomerular diseases (9 cases), cystic diseases (3 cases), and others (4 cases). Eighty percent of the cases were in grade 5 severity, in which GFR was less than 15 mL/min/1.73 m^2, and more than 2 systems were involved. Approximately 60% of the cases required CAPD.

All the symptom scales from the SDQ were higher in the CKD group according to the self- and parent-reports, as shown in Table 2. Only the emotional symptoms reported by self and parents were significantly higher in the CKD group (*p*=0.02 and 0.01 respectively). Regarding the prosocial behavior scale, which indicates the strength of children, both self- and parent-reports showed that the CKD group had lower strength than the controls. The total SDQ score reported by parents in the CKD group was significantly higher than that reported in the control group (*p*=0.02). None from either group met the clinical range of symptom scores.

From the PedsQL, all the subscales reported by self and parents were lower in the CKD group, but there was no statistical significance. Only the psychosocial and total quality of life scores reported by parents were significantly lower in the CKD group (*p*=0.02 and 0.01, respectively), as shown in Table 3. Inverse correlations (range 0.26-0.54) between the PedsQ and the SDQ scores, especially the emotional

Table 1. Demographic characteristics of children with chronic kidney diseases and healthy controls

	Chronic kidney disease (n=25)	Healthy controls (n=25)	*p*
Age, year (mean±SD)	(n=25)	p value	0.73
Gender, male (%)	8 (32%)	8 (32%)	1.00
Education, year (mean±SD)	6.42±4.84	7.25±5.18	0.66
Father age, year (mean±SD)	34.45±7.37	38.98±5.31	0.21
Father education, year (mean±SD)	10.50±4.13	10.21±3.95	0.42
Mother age, year (mean±SD)	32.23±6.71	35.34±3.57	0.24
Mother education, year (mean±SD)	9.00±4.06	9.75±4.08	0.48
Family status, couple (%)	22 (88%)	24 (96%)	0.61
Family income, bath (mean±SD)	10,029±3,453	12,329±6,386	0.73
Disease duration, year (mean±SD)	8.7±2.23	NA	

Table 2. The mean Strengths and Difficulties Questionnaire scores between patients with chronic kidney diseases and healthy controls

	Chronic kidney disease (n=25)	Healthy controls (n=25)	*p*
Child self-report			
Emotional symptoms, mean±SD	2.17±0.92	1.94±1.16	0.02
Conduct problems, mean±SD	1.94±0.73	1.56±0.78	0.73
Hyperactivity, mean±SD	1.78±0.73	1.50±0.51	0.18
Peer problems, mean±SD	1.61±0.61	1.11±0.76	0.80
Prosocial, mean±SD	6.67±1.61	8.61±1.24	0.89
Total problems, mean±SD	7.50±1.38	6.11±1.41	0.43
Parent -report			
Emotional symptoms, mean±SD	2.96±1.31	2.04±0.98	0.01
Conduct problems, mean±SD	2.36±1.22	1.60±0.76	0.05
Hyperactivity, mean±SD	1.84±0.75	1.52±0.65	0.91
Peer problems, mean±SD	1.96±0.79	1.12±0.83	0.76
Prosocial, mean±SD	7.08±1.71	8.92±1.19	0.18
Total problems, mean±SD	9.12±2.15	6.28±1.46	0.02

Table 3. The mean Pediatric Quality of Life scores between patients with chronic kidney diseases and healthy controls

	Chronic kidney disease (n=25)	Healthy controls (n=25)	*p*
Child self-report			
Physical, mean±SD	70.64±7.07	73.26±9.00	0.96
Psychosocial, mean±SD	61.47±4.57	73.71±4.48	0.40
Emotional, mean±SD	60.81±9.75	75.85±14.72	0.36
Social, mean±SD	67.48±13.71	80.27±12.14	0.59
School, mean±SD	56.12±12.70	65.00±12.65	0.42
Total score, mean±SD	64.67±2.88	73.55±3.16	0.51
Parent -report			
Physical, mean±SD	62.73±7.76	69.09±6.21	0.37
Psychosocial, mean±SD	57.44±4.62	68.37±4.81	0.02
Emotional, mean±SD	57.82±17.53	70.84±16.19	0.11
Social, mean±SD	62.61±13.43	74.89±13.20	0.01
School, mean±SD	51.89±9.61	59.48±12.10	0.23
Total score, mean±SD	59.28±2.92	68.63±2.79	0.01

and total scores, are shown in Table 4. This indicates that higher psychosocial problem scores correlated fairly with lower quality of life scores.

Table 4. Correlation between the Strengths and Difficulties Questionnaire score and the Pediatric Quality of Life scores in patients with chronic kidney diseases

	Total problems	Emotional symptoms	Conduct problems	Hyperactivity	Peer problems	Prosocial
Self-report PedsQL						
Total score	-0.47*	-0.28*	-0.07	-0.37*	-0.19	-0.04
Physical	-0.33*	-0.30*	-0.05	-0.18	-0.16	-0.04
Psychosocial	-0.48*	-0.33*	-0.04	-0.25*	-0.01	-0.03
Emotional	-0.29*	-0.31*	-0.05	-0.25*	-0.06	-0.05
Social	-0.31*	-0.29*	-0.02	-0.23*	-0.14	0.04
School	-0.45*	-0.26*	-0.04	-0.30*	-0.12	0.02
Parent-report PedsQL						
Total score	-0.54*	-0.29*	-0.32*	-0.59*	-0.19	-0.08
Physical	-0.37*	-0.32*	-0.07	-0.35*	-0.38*	-0.05
Psychosocial	-0.51*	-0.36*	-0.04*	-0.39*	-0.03	-0.04
Emotional	-0.30*	-0.34*	-0.12*	-0.03*	-0.08	-0.09
Social	-0.31*	-0.33*	-0.25*	-0.23*	-0.18	-0.08
School	-0.46*	-0.26*	-0.32*	-0.32*	-0.12	-0.01

*≤ 0.05

Discussion

This study found that children with CKD were at increased risk of psychosocial problems, especially emotional ones. They also tended to have lower quality of life. As most children with CKD in this study were in grade 5 severity and required CAPD, there was great impact on the children's daily activities and life in general. There also were limited functions and activities with their peers as well as a stressful life. Fadrowski et al found that a decline in the kidney function of children with CKD was associated with decline in quality of life, particularly physical functioning[19]. Children with CKD were at risk of poor psychosocial adjustment when greater impairment was caused by illness[20]. Furthermore, when compared with previously published norms, the study by Gerson *et al* reported children with mild to moderate CKD having poorer overall HRQoL[21].

The psychosocial problems assessed by the SDQ were higher in children with CKD than in the control group according to both self- and caregiver-reports. Only the emotional symptoms and conduct problem scores were significantly higher than controls. The study of Amr M *et al* found that the mean internalizing score from the Child Behavior Checklist was significantly higher in the children on dialysis than in predialysis patients and controls[11]. No difference in the mean externalizing score was found between the groups studied.

The findings in this study of lower quality of life in children with CKD than in controls were consistent with studies by Goldstein SL, *et al*[7,22], Riano-Galan I, *et al* [23], Buyan N, *et al*[24], and Maxwell H, *et al*[25]. Patients with CKD, both kidney transplant recipients and dialysis patients, had lower scores in all quality of life subscales than the controls, except for physical well-being[24]. The kidney transplant recipients had better quality of life than the dialysis patients. However, the study by Heath J, *et al*, found no significant difference between the mean Generic Children's Quality of Life Measure scores of patients with CKD in various treatment modalities and age groups[26]. The parent-proxy report scores on the QoL are not always equivalent to the child-self report scores[24]. In this study, children reported higher quality of life than the parents did, which was similar to the study by Nuel *et al* that confirms the importance of evaluating both children's and parents' perspectives[27]. The overall QoLs as well as emotional functioning, which are rated lower by parents than by their children, can be found in cases of children with chronic diseases. This may derive from parental over protectiveness and thus hamper the child's development of self-esteem and, as a result, inflict burden on the parents[28]. There were negative correlations between the psychosocial problems and quality of life of children with CKD. Correlations assessed by parents were slightly higher than those determined by the children themselves.

This study assessed psychosocial problems together with quality of life in children and adolescents with CKD. Information was received from both self- and parent-reports that were compared with a control group. Different informants gave a comprehensive view of the psychosocial health of the children with CKD in order that early identification and psychosocial support could be given. The quality of life in children with CKD also was correlated with the psychosocial problems from the SDQ scores. However, there were some limitations in the study. Firstly, the small sample size was due to some patients being too sick during the study time, some did not have a regular follow-up, and others did not meet the inclusion criteria. Secondly, this study was from one tertiary care center, therefore, the findings could not be generalized. Thirdly, subgroup analyses on the impact of various stages of disease or treatment modalities on psychosocial problems and quality of life were not possible, due to the small sample size. Lastly, information was from the children and their parents, whereas reports from a school would provide more accurate data.

In conclusion, both self- and parent-reports showed that children with CKD were at increased risk of psychosocial problems, especially emotional ones. These patients also tended to have lower quality of life. Psychosocial screening and CKD group support would help psychosocial adjustment for children and families. Appropriate psychosocial intervention may be needed for better treatment outcome and quality of life. Children who have CKD require close, coordinated medical attention from a primary care pediatrician, pediatric nephrologists, and other pediatric subspecialists in order to ensure successful growth into adulthood and reaching their highest potential.

Conflicts of interest: none

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ปัญหาจิตสังคมและคุณภาพชีวิตของเด็กที่เป็นโรคไตเรื้อรัง

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วัตถุประสงค์ เพื่อประเมินปัญหาจิตสังคมในเด็กที่เป็นโรคไตเรื้อรังเปรียบเทียบกับเด็กกลุ่มควบคุม และประเมินความสัมพันธ์ระหว่างปัญหาจิตสังคมกับคุณภาพชีวิตในเด็กที่เป็นโรคไตเรื้อรัง

วิธีการวิจัย เป็นการศึกษา cross-sectional ในเด็กที่เป็นโรคไตเรื้อรังและเด็กสุขภาพดี โดยใช้แบบประเมิน Strengths and Difficulties Questionnaire (SDQ) และ Pediatric Quality of Life (PedsQL) เพื่อประเมินปัญหาจิตสังคมและคุณภาพชีวิต โดยเด็กและผู้ปกครองจากทั้งสองกลุ่มตอบแบบประเมินทั้งสองชนิด

ผลการศึกษา ผู้ป่วยโรคไตเรื้อรังจำนวน 25 คนและเด็กกลุ่มควบคุมสุขภาพดีจำนวน 25 คนเข้าร่วมการวิจัยนี้ สาเหตุส่วนใหญ่ของโรคไตเรื้อรังเป็นความผิดปกติของไตและทางเดินปัสสาวะแต่กำเนิด และโรคไต glomerular พบว่าคะแนนเฉลี่ยของแบบประเมินปัญหาจิตสังคม SDQ ที่เด็กตอบด้วยตนเองโดยเฉพาะด้านอาการทางอารมณ์ของเด็กที่เป็นโรคไตเรื้อรังสูงกว่าคะแนนของกลุ่มควบคุมอย่างมีนัยสำคัญ (p =0.02) คะแนน SDQ ในเด็กที่เป็นโรคไตเรื้อรังที่ตอบโดยผู้ปกครองสูงกว่าหลายด้านโดยเฉพาะคะแนนรวมและด้านอาการทางอารมณ์ (p=0.02 and 0.01, ตามลำดับ) ส่วนคะแนนคุณภาพชีวิต PedsQL ที่ตอบโดยผู้ปกครองในกลุ่มเด็กที่เป็นโรคไตเรื้อรังต่ำกว่าคะแนนของกลุ่มควบคุมอย่างมีนัยสำคัญโดยเฉพาะคะแนนรวม ด้านจิตสังคม และด้านสังคม (p=0.01, 0.02, 0.01 ตามลำดับ) พบว่ามีความสัมพันธ์เล็กน้อยและไปในทางตรงข้ามกันระหว่างปัญหาจิตสังคมและคุณภาพชีวิตในเด็กที่เป็นโรคไตเรื้อรัง (r=-0.47, p <0.05)

สรุปผลการศึกษา เด็กที่เป็นโรคไตเรื้อรังเสี่ยงต่อปัญหาจิตสังคมโดยเฉพาะปัญหาด้านอารมณ์และมีแนวโน้มที่มีคุณภาพชีวิตต่ำกว่า ดังนั้น การให้การช่วยเหลือทางด้านจิตสังคมอาจมีความจำเป็นเพื่อให้ผลการรักษาและคุณภาพชีวิตดีขึ้นสำหรับการปรับตัวเข้าสู่วัยผู้ใหญ่ได้อย่างสมบูรณ์ **เชียงใหม่เวชสาร 2557;53(3):127-134.**

คำสำคัญ: จิตสังคม คุณภาพชีวิต โรคไตเรื้อรัง เด็ก