

## Research Article

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## Quality of Life and Caregiver Burden Scale in Iranian Children on Continuous Ambulatory Peritoneal Dialysis

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**Introduction:** Chronic kidney diseases are associated with a poor quality of life in patients and their families. Previous studies have shown a three-fold higher rate of exhaustion in peritoneal dialysis compared to hemodialysis patients and their families. Here we studied the quality of life and caregiver's burden of children receiving chronic ambulatory peritoneal dialysis (CAPD) in comparison with other chronic diseases among pediatric patients.

**Materials and Methods:** This prospective case-control survey was conducted between 2013 and 2014 in Ali-Asghar Children's Hospital. The inclusion criteria were age below 18 years and having a chronic disease diagnosed at least six months earlier. The parents of 13 children on peritoneal dialysis (cases) and 160 children with other chronic diseases (controls) were requested to complete the Pediatric Quality of Life Inventory (PedsQL™ 4.0™) appropriate to the patient's age and the Caregiver Burden Scale (CBS). Independent t-test was applied to compare the variables between the two groups. P-values < 0.05 were considered significant.

**Results:** Overall, 353 questionnaires were completed. The CAPD group had a higher mean (SD) score of quality of life in all domains, including somatic symptoms [67 (25.6) vs. 18.5(15.6)], emotional symptoms [71(17) vs. 20.5(15.1)], and social functioning [58(32) vs. 21.3(20)] (p-value<0.001). In addition, the case group had a lower mean (SD) score of caregiver's burden [50(16.7) vs. 80 (13.5)] compared to the control group (P value<0.001).

**Conclusions:** CAPD children and their parents had better a PedsQL™ 4.0™ score and a lower CBS compared to children with other chronic diseases. The most affected area of the quality of life was school functioning in the CAPD group and somatic symptoms in the control group.

**Keywords:** Quality of life; Renal Dialysis; Adaptation; Psychological; Chronic Disease; Child.

**Running Title:** Quality of Life in CAPD Children

## Introduction

Chronic kidney disease (CKD) affects 1%-2% of the pediatric population [1]. The quality of life of the children with CKD may be low and unrelated to the disease stages [1]. Beside specific problems of renal replacement therapy, anemia, hyperlipidemia, hypocalcemia, hyperphosphatemia, uncontrolled blood pressure, short stature, and failure to thrive are common complications of CKD that potentially reduce the quality of life and increase health care needs [2]. A recent study in Gaza strip showed that depression is more prevalent and quality of life is lower in children with ESRD than those with chronic medical problems [3]. Patients with self-care peritoneal dialysis have a higher quality of life and a similar rate of depression and anxiety compared to patients on assisted peritoneal dialysis [4]. Adults CAPD patients have a significantly better quality of life and lower mortality in comparison with hemodialysis patients; however, the quality of life of pediatric patients with CAPD is less studied [5].

The family members of children undergoing dialysis are affected by psychosocial and economic conditions, requiring appropriate interventions [3]. The caregivers of hemodialysis patients have higher rates of anxiety and depression, lower sleep quality, and higher caregiver burden scores compared to renal transplanted patients [6] or the general population [7]. Similar to the quality of life, the caregiver's burden of CAPD patients is less studied compared to renal transplanted and hemodialysis patients. This study was conducted to investigate the quality of life of pediatric patients and the burden of their caregivers in a population of Iranian CAPD pediatric patients.

## Materials and Methods

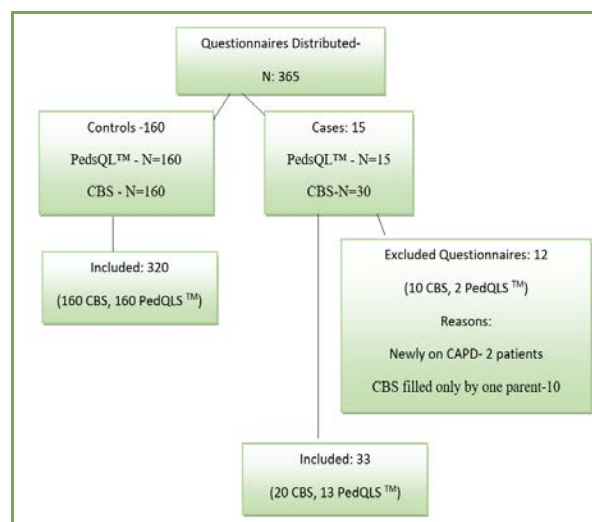
This case- control study was conducted between 2013 and 2014 in a population of patients aged less than 18 years and their caregivers in Ali-Asghar Children's Hospital. The case group included children with end-stage renal disease that were on continuous ambulatory peritoneal dialysis for at least six months. The control group included patients with other chronic diseases and moderate to severe CKD not on dialysis in the six months or more. The caregivers of the patients were asked to complete the Pediatric Quality of Life Inventory (PedsQL™ 4.0™) and the Caregiver Burden Scale (CBS). Informed consent was obtained from caregivers before enrollment. The study adhered to Helsinki principles. The protocol

of the study was approved by Research and Ethic committee of Iranian Society of Pediatric Nephrology (ID number: 22306 dated 23.2.2013). The PedsQL™ 4.0™ measures the health-related quality of life of children and adolescents suffering from acute or chronic health conditions. The PedsQL™ 4.0™ assesses physical, emotional, social, and school or daycare problems. The total score of the Inventory ranges from 0 to 100. It was previously validated in Iranian children [8].

The CBS, which is a self-assessment tool, contains 22 multiple choice questions on a Likert scale with a total score ranging from 22 to 88. The scores could be used quantitatively or divided into little-to-no, mild, moderate, or severe burden. The Persian version of the CBS was previously validated with acceptable internal consistency [9]. Data are presented in mean, standard deviation, standard error of mean and median or percentage. All variables were tested by the Kolmogorov-Smirnov test for normal distribution. The Mann-Whitney U test or independent-t test was used accordingly. P-values less than 0.05 were considered significant.

## Results

As shown in Figure 1, 365 questionnaires were completed by 175 families (15 cases, 160 controls). In the case group, both parents of eight patients participated, of whom one family had a twin on CAPD due to congenital nephrotic syndrome. Only mothers completed the questionnaires in the rest of case group and in the control group.



**Figure 1.** Flowchart of filled in questionnaires

The demographic data of the subjects are presented in Table 1.

**Table 1.** Demographic data of the study groups

variables	Case (n=13)	Control (n=160)	p- value
Age (yr), mean(SD)	6.85(3)	8.45(4.7)	NS
Age classification, n (%)			0.05
< 5yr	4(31)	40(25)	
5-8yr	5 (38)	40(25)	
8-12yr	0	40(25)	
13-18yr			
Gender, male, n(%)	9(69)	79 (60)	NS
Underlying disease, n (%)			<0.05
Endocrine disorder	0	24(15)	
Metabolic	0	17(10)	
disorder	0	3(1)	
DM			
Hypothyroidism	0	20(12.5)	
Hematologic disorder	0	38(23)	
Acute leukemia			
Anemia	5(38)	17(10)	
/Thalassemia	5(38)	8(5)	
Renal disorder	0	5(3)	
RUTI/CAKUT /NB	3(23)	0	
NS/FSGS/CNS			
CKD –moderate	0	19(11)	
PKD/ ciliopathy			
Neurologic disorders:	0	6(3)	
Epilepsy		3(1)	
GI disorders:	0		
Cystic fibrosis			
Failure to thrive			
Duration of disease , mean(SD)	2.9 (0.8)	>6 months	
Age of responder, mean(SD)			NS
Mother	35.8 (6)	34.3(4.7)	
Father	37.8(2.7)		

Table 2 shows the score of quality of life, its various domains, and CBS in both groups of CAPD children and other chronic disorders. Comparison of the quality of life between the two groups revealed that CAPD children had a significantly better quality of life ( $P<0.001$ ). However, school functioning was not good in either group. The parents of children on CAPD had lower exhaustion compared to the parents of children suffering from other chronic disorders ( $P<0.001$ ).

## Discussion

The result of our study revealed that children on dialysis had a better quality of life and lower CBS compared to other chronic diseases but they had a lower score in the education domain. Marciano et al found that children with chronic kidney disease, regardless of receiving renal replacement treatments, had a lower health-related quality of

life, which was significant in the age group above 10 years and those without religious beliefs [10].

**Table 2.** Comparison of Quality of life and caregiver burden scale of families of children on CAPD an children with other chronic disorders

	Case n-13	Control n-160	p- value	95% CI*
PedQLS	234 (15)	103.2 (4.5)	<0.001	-157 to -104.5
Somatic symptoms, mean (SE)	67 (5.7)	18.5 (1.23)	<0.001	-60.7 to -38.3
Emotional symptoms, mean (SE)	70.9 (3.7)	20.5 (1.2)	<0.001	-57.6 to -43.3
Social functioning, mean (SE)	58 (7.1)	21.3 (1.6)	<0.001	-51.9 to -21.5
School functioning, mean (SE)	38 (7.6)	43 (1)	0.52	-11.2 to 21.1
CBS, mean (SE)	49.9 (3.7)	80 (0.35)	<0.001	23.2 to 37.8

CI\*: Confidence Interval

CAPD every 6 hours or more is one of the reasons for decreased school attendance in Iran. Depression is more prevalent and the score of quality of life is lower in Taiwanese caregivers [11]. Lopes et al found discrepancies between the reported QOL of caregivers and children on dialysis [12]. Avsar et al compared the psychiatric symptoms and CBS of 113 caregivers of children on CAPD and renal transplant. They revealed that renal transplant improves sleep quality and reduced anxiety, stress, and CBS [13].

The exhausted parents with feelings of grief and self-blame dedicate the majority of their time to care for their ESRD children, a factor that might be neglected in the assessment of children with ESRD and has a great impact on the couple's mutual relationship.

Meanwhile, the parents of children with chronic diseases other than CAPD had lower scores in all domains and lower CBS scores.

We believe that periodic assessment of CKD children and their caregivers using these questionnaires could help detect the domains of a lower performance, find the self-imagination of children, and discover their parents' exhaustion earlier.

The limitations of this study were the small sample size of CAPD children, lack of hemodialysis and transplant children, including unhealthy cases in the control group, and not completing the questionnaires by both parents.

### Conclusions

In conclusion, CAPD children and their parents had a better PedsQL™ 4.0™ score and a lower CBS compared to other chronic diseases. The most affected area of the quality of life was school functioning in the CAPD and somatic symptoms in the control group.

### Conflict of Interest

Authors declare that they have no conflicts of interest.

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