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Development of a Quality of Life Scale For Children on Chronic Peritoneal Dialysis

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= **Abstract** =

Purpose : The aim of this study was to develop a quality of life scale for children on chronic peritoneal dialysis(QOL-CPD).

Methods : Thirty children on chronic PD at Seoul National University Children's Hospital participated. A healthy control group included 47 elementary school children. Other patients groups are 32 children from the department of pediatric orthopedics and 28 children from the department of child psychiatry. The age range of all children was 7 to 16 years. Preliminary items of the QOL-CPD were developed and administered along with the Korean version of the Children's Depression Inventory(CDI) to all children.

Results : The final QOL-CPD was constructed by excluding those items with a factor loading of less than .20, and the principal axis factor analysis was performed again. The QOL-CPD demonstrated a good internal consistency with a value of .87. The dialysis and child-psychiatric groups showed significantly lower QOL scores compared to the healthy control group. In addition, the dialysis and child-psychiatric groups showed greater difficulties on physical and academic functions. For the CDI, the PD group showed a mild level of depression.

Conclusion : The results of this study demonstrate the clinical utility of a newly developed self-report QOL scale specific for children on chronic PD. (**J Korean Soc Pediatr Nephrol** 2008;12:202-212)

Key Words : Children with end-stage renal disease, PD, Quality of life, Depression, Hopelessness, Negative self-concept

INTRODUCTION

Technical breakthroughs in dialysis and renal transplantation over the past few decades have enabled the long-term survival of children with end-stage renal disease(ESRD). Accordingly, with the long-term survival of these children, the main research focus has been shifting from the prolongation of life to provision of a better quality of life(QOL) with improved emotional and social well-being.

QOL is an essential aspect of human existence. It refers to an overall evaluation of life, both a subjective and objective index of hap-

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piness and the perception of the way one is living life. Ferrans and Power[1] provided a specific definition of QOL as "well-being, satisfaction with life, personal feeling about happiness or unhappiness". Padilla and Grant[2] defined QOL of patients as "what makes life worth living, which includes physical, emotional well-being, concern about body image, social interest, and response to treatment". Furthermore, according to Noh et al.[3], QOL is a subjective perception of well-being by each individual in physical, mental, and socio-economic domains, which consists of the emotional state, self-esteem, physical functioning, and relationships with family and neighbors. While the definition of QOL may vary from one scholar to another, it generally includes the physical, psychological, emotional, social well-being and treatment satisfaction domains.[4]

However, most of the studies conducted thus far have focused on the physical aspects of the quality of life, such as physical functioning and symptoms in patients with chronic renal failure. The psychological and adjustment problems, associated with this group of patients, have been relatively neglected.

In addition, most studies have been limited to adult patients; there are only a few reports that address the QOL in children with ESRD [5, 6]. In fact, empirical studies on the variables that affect the QOL of the children with chronic renal failure are limited, as are the scales for assessing the QOL. Previous studies on children with renal failure showed that psychosocial adjustment and treatment adherence were negatively influenced by depression, anxiety, a sense of hopelessness, as well as poor self-perception and perception by their parents, low family economic status, and the absence of social support[5, 6]. Measurement scales such as 'the Child Health and Illness Profile Adolescent Edition'(CHIP-AE)[7], 'the Children's Health Questionnaire'(CHQ)[8] and 'the Pediatric Quality of Life Inventory'(PedsQL)[9] that have been used to assess the QOL of children with chronic kidney disease, were not developed specifically for children on chronic peritoneal dialysis(PD). Hence, in the present study we have developed a self-report questionnaire to assess the QOL of children, especially those on chronic PD.

Since the QOL is a subjective concept, the perception of children can be different from those of their parents. In addition, parents may base their ratings on comparisons with other children or with their own experiences, which may be susceptible to their emotional state and expectations of their children. Therefore, it is more appropriate to have the children directly assess and report their own QOL. Therefore, we developed a self-report QOL questionnaire for children with ESRD on PD.

MATERIAL AND METHORDS

Sample and Procedure

Thirty children with ESRD on PD who were attending the pediatric dialysis clinic, Seoul National University Children's Hospital participated in this study. They were 18 boys and 12 girls with a mean age of 12.6±3.7 years. We included only the children on PD because the dialysis modality may have affected the QOL, and PD is the primary modality used in this age group. The mean duration of PD was 42.7±30.4 months. 8 children on PD (27%) had significantly shorter height and lower weight compared to their age norms. The mean height of the children in this group was two standard deviations(SD) below the age norm and their weight was one SD below the age norm. Since growth failure and psychosocial difficulties are common and significant problems of children on chronic dialysis, 32 children with Osteogenesis Imperfecta from the department of pediatric orthopedics and 28 children from the department of child psychiatry also participated in this study as the other clinical group(mean age=12.8±4.5, 11.47±2.7, respectively). The psychiatric group consisted of children who were diagnosed with attention deficit hyperactivity disorder(ADHD) with learning problems. For the healthy control group, 47 children were recruited from an elementary school in Seoul(mean age=11.7±1.6). Since the children were required to read and complete the self-report scales reliably, children in the age range from 7 to 16 years, without reading problems, were included for both the clinical and control groups. There was no significant difference in the mean age among the groups. Informed consent was obtained from all parents of the children before conducting this study. Any human data included in this manuscript was obtained in a compliance with the regulations of Seoul National University Hospital and have therefore been performed in accordance with the ethical standards reported in the 1964 Declaration of Helsinki. The demographic and laboratory data of the children with ESRD are presented in Table 1.

Construction of the Quality of Life Scale for Children on Chronic PD (QOL-CPD)

First, the content domains of QOL-CPD were determined according to the generally accepted definition of quality of life. The content domains thereby included a "Physical Function Domain," an "Emotional Function Domain," an "Academic Function Domain," and a "Social Function Domain." Next, we delveloped the preliminary items for the QOL-CPD that was thought to reflect accurately those domains after a thorough discussion among the investigators. Since the self-report scale for children should be simple and not too lengthy, the preliminary QOL-CPD consisted of 56 items using the 3-point Likert scale.

Measures and Statistical Analysis

The preliminary QOL-CPD and the Korean version of the Children's Depression Scale (CDI)[10, 11] were individually administered to all children. Next, the item-total correlation was obtained for each item to exclude those showing less than a .20 item-total correlation; then principal axis factor analysis was carried out with the remaining items. The final QOL-

Table 1. Characteristics of Children on Chronic PD

Variables	Mean(S.D)	Range
Age(year)	12.6(3.7)	7-16
Hemoglobin(g/dL)	10.6(1.7)	5.3-12.9
Serum albumin(g/dL)	3.99(.41)	3.30-4.70
Residual renal Kt/V	.28(.47)	0.00-1.88
Total Kt/V	2.22(.77)	1.30-5.35
Residual renal CCr (L/week·1.73 m^2)	10.8(17.9)	0.0-66.9
Total CCr (L/week·1.73 m^2)	52.8(15.0)	32.3-89.9

CPD was constructed after a process of excluding those items with the factor loading of less than .20 and then conducting the principal axis factor analysis again. In order to confirm the validity of the newly developed "QOL-CPD", its correlation with the CDI was calculated, and the differences in the mean scores of the QOL-CPD among the children on PD, child-psychiatric and healthy control groups were examined by analysis of variance (ANOVA) for its discriminant validity. The reliability of the QOL-CPD was examined by obtaining the internal consistency coefficient and a 2-week test-retest reliability coefficient. All data analyses were performed with SPSS WIN 12.0.

RESULTS

The QOL-CPD and Its Reliability

After obtaining the item-total correlation coefficients of the data from the clinical and healthy groups and excluding 16 items with an item-total correlation of less than .20, the factor analysis was conducted, and the 40-item "QOL-CPD" was finalized(Appendix). The score ranges of the physical, emotional, academic and social functions are 0-40, 0-16, 0-18, 0-9, respectively. The QOL-CPD showed a good internal consistency with the Chronbach's α of .87. Its test-retest reliability coefficient was .67. As the QOL-CPD includes various items reflecting difficulties in physical, emotional, academic, and social domains, and since the emotional state may vary with time, the reliability of the QOL-CPD developed in this study was considered satisfactory.

Validity of the QOL-CPD

A higher total QOL-CPD score indicates a worse QOL as perceived by the children. The children with Osteogenesis Imperfecta were not included in the analysis because their QOL-CPD mean score was nearly equal to that of the healthy group. The PD and child-psychiatric groups were found to have significantly lower QOL scores compared to the healthy group (mean QOL total score=27.41, $P<.01$, mean QOL total score=27.88, $P<.01$). Specifically in terms of the sub-domains, the PD and child-psychiatric groups reported more difficulties in the physical and academic function domains($P<.01$), while the three groups showed no differences in the emotional and social function domains. Therefore, these results showed that the PD group not only had trouble in physical functioning, but also in learning, similar to the child-psychiatric group. For the CDI, the child-psychiatric group had the highest depression score(17.12) and the PD group had a mild level depression score(12.61)(Table 2).

The results of previous studies[5, 6] have shown that among all symptoms of depression, hopelessness and a negative self-concept yielded more negative influences on the psychosocial adjustment of children on dialysis. Therefore, we totaled the hopelessness and the negative self-concept items of the CDI separately and examined their correlations with the QOL-CPD scale. As a result of Pearson product-moment correlation analysis, in the PD group, the scores of hopelessness and negative self-concept showed significant correlations with the QOL-CPD total score(r=.47,

Table 2. Means and Standard Deviations of the Scores of the QOL-CPD and CDI for the Three Groups.

	PD[1] (n=30)	Psychiatric disorder[2] (n=28)	Normal[3] (n=47)	F	Post-hoc(Turkey)
QOL total score	27.41(10.11)	27.88(11.11)	19.54(8.27)	9.22**	
Physical function	14.98(5.91)	12.67(7.04)	8.51(4.05)	10.41**	1, 2>3
Emotional function	4.78(2.44)	5.54(2.61)	4.76(2.45)	.98	1, 2>3
Academic function	6.30(4.38)	7.17(4.20)	4.10(3.63)	5.88**	1, 2>3
Social function	2.36(.99)	2.51(.92)	2.17(1.03)	1.06	2>3
CDI total score	12.61(5.42)	17.12(8.04)	11.51(6.10)	4.69*	

( ) standard deviation; QOL quality of life; CDI Children s Depression Inventory. In Post-hoc analysis, 1 refers to the PD group, 2 to the psychiatric disorder group, and 3 to the normal group.
*P<.05, **P<.01

Table 3. Correlation Coefficients of the QOL-CPD and CDI Scores

	Physical function	Emotional function	Academic Function	Social function	QOL total score
CDI total score	.24*	.61**	.46**	.33**	.50**

QOL-CPD the Quality of Life Scale for Children on Chronic PD; CDI Children s Depression Inventory.
*P<.05, **P<.01

P<.01; r=.42, *P*<.05, respectively). That is, the more hopeless, and the more negative the self-concept, the worse the QOL score. In the child-psychiatric and healthy control groups, the QOL-CPD total score was not significantly correlated with either hopelessness or negative self-concept scores(r=.15, r=.29 for the child-psychiatric group; r=.27, r=.28 for the healthy group).

Although the CDI total score was the highest in the child-psychiatric group, there was no significant correlation between the CDI total score and the QOL score, and there was no significant correlation between the hopelessness or negative self-concept score and the QOL score. Considering that the child-psychiatric group in our study consisted mostly of ADHD children, such a high CDI score appears to be due to their emotional problems such as depressive mood rather than a negative self-concept or hopelessness. On the other hand, the children on PD seem to suffer more from increased hopelessness and a negative self-concept, causing low QOL experiences.

The Pearson product-moment correlation coefficients between the QOL-CPD and the CDI scores for all children were calculated and were found to range from .24 to .61, which were all significant(Table 3). These results confirm that the QOL-CPD developed in our study may be a valid and reliable instrument for assessing difficulties in physical, emotional, academic, and social function domains in children on PD.

The QOL-CPD scores were not significantly correlated with the duration of PD, and the clinical and laboratory data, including height and weight SDS scores, hemoglobin, albumin, residual renal Kt/V, total Kt/V, residual CCr, and total CCr.

DISCUSSION

As anticipated, the QOL of children on PD was found to be significantly lower than that found in their healthy counterparts. While the difficulties in emotional and social function domains were not significantly higher than those of the child-psychiatric group, the children with ESRD on PD were found to have more difficulties due to physical symptoms and learning problems at a level similar to the child-sychiatric group. Considering that the child-psychiatric group consisted of ADHD children with learning and emotional problems, assistance with the academic problems, in addition to the medical treatment for physical symtoms, appears to be important for improving the QOL of children with ESRD on chronic PD.

Children on chronic PD are very likely to experience difficulties with school adjustment due to school absence for hospital visits and the limitations on participating in school activities, as well as their distractibility and diminished attention span due to uremia[12,13]. In Korea, where the educational expectations of the parents for their children are very high and a university diploma is a prerequisite for a better marriage and employment, individualized educational programs or tutoring is necessary to assist the psychosocial adjustment and prevent the development of problems on later for children on PD.

Children with ESRD often suffer from growth retardation. In the present study, 8 children on PD(27%) showed growth retardation. The mean weight and height of children on chronic PD were one and two SD below the age norms, which likely resulted in the feeling of inferiority with regard to their body image, thus leading to a negative self- concept. Since the QOL of children on chronic PD worsens with increasing feelings of hopelessness and a negative self-concept, children on chronic PD need not only assistance for their physical symptoms and learning difficulties, but also support for building a more positive self-image.

Although there are only a few studies on psychiatric disorders among children on chronic dialysis, these reports have demonstrated that children with ESRD are at high-risk for psychiatric disorders such as depression, anxiety and adjustment disorders. According to Fukunishi and Kudo's study[14], 17 of 25 (65.4%) Japanese children with ESRD on chronic PD were found to have psychiatric disorders. Sixteen percent of British children with ESRD on home dialysis had psychiatric disorders[15]. Bakr et al.[16] found that adjustment disorders were the most common (18.4%) among children with ESRD on regular hemodialysis, followed by depression(10.3%) and neurocognitive disorder(7.7%).

The results of our study revealed that the children on chronic PD not only had trouble in physical and academic functions similar to the child-psychiatric group, but also had a mild level of depression by the CDI score. However, the level of depression experienced by the children on PD was not as severe as anticipated. Such a result can be considered as a positive sign attributed to treatment adherence and psychosocial adjustment. Since the children on PD in our study showed good treatment adherence, they may have thereby shown only a mild level of depression. However, another interpretation might be possible. Children on chronic PD may develop a denial defense to cope with the emotional problems that accompany their chronic medical illness.

The QOL-CPD scores were not significantly correlated with the duration of PD, and the clinical and laboratory data, including height SDS, weight SDS, hemoglobin, albumin, and the scales of PD adequacy. These results are consistent with those of Bakr et al.[16], which did not show significant correlations among psychiatric disorders, age, gender, severity of anemia, duration of chronic renal failure, and duration of hemodialysis. They interpreted these findings as suggesting that psychiatric disorders in children on dialysis could be better explained by the difficulties encountered in living with chronic renal failure rather than by such demographic and physical factors. However, the absence of a significant relationship between psychiatric disorders and physical factors might be due to the small number of patients studied.

The limited number of patients available for study is one of the shortcomings of the present study. Unlike adults, it is actually difficult to recruit a large number of children on chronic PD in the age range of 7 to 16 years. Further studies are required to confirm the reliability and validity of the scale developed in this study using other already existing QOL instruments for children, and to examine its clinical utility in children on chronic PD, with a larger number of children. Omission of individual interviews to assess the difficulties in physical, emotional, academic, and social functions as well as treatment satisfaction of the children on chronic PD may be another limitation of this study.

However, despite such limitations, this study tried and provided a self-report QOL scale specifically developed for children on chronic PD, and the results demonstrated a relatively high reliability and validity.

한글요약

만성 복막투석 아동용 삶의 질 척도 개발

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목 적 : 본 연구에서는 만성 복막투석 아동용 삶의 질 척도(Quality of Life Scale for Children on Chronic Peritoneal Dialysis: QOLCPD)를 개발하였다.

방 법 : QOLCPD문항 개발을 위한 자료수집을 위해서 서울대학교 어린이병원에서 복막투석 중인 30명의 만성 신부전 환아가 본 연구에 참여하였다. 타 임상 집단으로 28명의 소아정신과 장애 아동과 32명의 소아정형외과 아동이 연구에 포함되었고, 정상 통제집단으로는 초등학교에 재학중인 47명의 아동이 참여하였다. 연구대상 아동들의 연령범위는 7세-16세였다. 56개의 예비문항으로 이루어진 QOLCPD와 한국판 아동용 우울척도(CDI)를 모든 아동들에게 개별적으로 실시하였다.

결 과 : 수집된 자료에 대해 주축 요인분석을 실시하여 문항-전체 상관이 낮고 요인부하량이 .2이하인 16문항을 제외시켜서 총 40문항으로 이루어진 최종 QOLCPD를 개발하였다. QOLCPD의 신뢰도 계수인 Chronbach's α는 .87로 양호한 수준이었다. 복막투석 집단과 소아정신과 아동 집단

은 정상 집단에 비해 더 낮은 삶의 질 총점을 보였다. 특히 두 집단은 삶의 질 영역 중 신체적 기능과 학업 기능에서 정상집단에 비해 낮은 점수를 보였다. 복막투석 집단의 CDI 점수는 경한 우울 수준에 해당되었다.

결 론: 자기보고형 만성 복막투석 아동용 삶의 질 척도는 임상적 유용성이 있는 것으로 나타났다.

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APPENDIX

Quality of Life Scale for Children on Chronic PD (the QOL CPD)

The following statements are about what you may have experienced in your life. Please read each item and check "not at all", "a little"(once or twice a week), or "very much"(almost everyday) according to what you've experienced during the past 1 month.

Item	Not at all	A little	Very much
1. I feel dizzy.			
2. I sometimes feel nausea or throw up.			
3. I feel shortness of breath after exercise.			
4. I get cramps			
5. I am not gaining weight.			
6. I often feel tired.			
7. I feel itchy.			
8. My mouth is dry.			
9. I sometimes have headache.			
10. I get cold and shivery.			
11. My hands and feet feel numbness.			
12. I can't fall asleep easily.			
13. I have no energy.			
14. I am not growing.			
15. My chest hurts.			
16. It feels like my body smells.			
17. I have no appetite.			
18. My skin is dry.			
19. My limbs are weak.			
20. Treatment is difficult to stand.			
21. My appearance is worse than others.			
22. I get easily irritated.			
23. I feel sad and depressed.			
24. I get worrisome and anxious without clear reasons.			
25. I think that I'll be happier in the future than now.			
26. More good things than bad will happen to me.			
27. I get angry about my situation.			
28. I feel that I'm different from others.			
29. It takes more time for me to finish my work than other students.			
30. Writing has become more difficult than before.			
31. Reading books has become more difficult than before.			
32. It is difficult to concentrate.			
33. Many times, I need helps from others with my school works.			
34. I am worried about whether I could do the school works well.			
35. I often forget what I've learned.			

36. I don't answer well to the questions at school.			
37. I lack the perseverance to finish my task.			
38. There are times when I feel rejected from my family members or friends.			
39. I'm afraid that others might find out about my disease(or treatment).			
40. I have family members or friends who help me with my activities.			

< 부록1 >

만성 복막 투석 아동용 삶의 질 척도

이 름:
성 별:
연 령: 세
학 력: 학교 학년

다음은 여러분들이 생활하면서 경험할 수 있는 문항들로 이루어져 있습니다. 다음의 문항들을 읽고, 지난 한 달 동안 자신에게 해당되는 문항에 대해 전혀 그렇지 않다 (0), 약간 그렇다"(1), 상당히 그렇다 (2) 중에서 해당하는 곳에 체크 (V" 표시) 해주시기 바랍니다.

신체기능	문항 1-20	
정서기능	문항 21-28	
학업기능	문항 29-37	
사회적 기능	문항 38-40	
삶의 질 총점		

*문항 25,26,40은 역으로 채점함.

문 항	전혀 그렇지 않다	약간 그렇다	상당히 그렇다
1. 어지러운 적이 있다.			
2. 간혹 속이 울렁거리거나 토한다.			
3. 운동을 하면 숨이 차다.			
4. 몸에 쥐가 난다.			
5. 체중이 늘지 않는다.			
6. 자주 피곤하다.			
7. 가려움증이 있다.			
8. 입안이 건조하다.			
9. 간혹 머리가 아프다.			
10. 춥고 떨린다.			
11. 손발이 저린다.			
12. 잠이 잘 안 온다.			
13. 기운이 없다.			
14. 키가 크지 않는다.			
15. 가슴이 아프다.			
16. 몸에서 냄새가 나는 것 같다.			
17. 식욕이 없다.			
18. 피부가 건조하다.			
19. 팔, 다리의 힘이 약하다.			

20. 치료 받기가 힘들다.			
21. 내 외모가 남보다 못하다.			
22. 쉽게 짜증이 난다.			
23. 슬프고 우울하다.			
24. 공연히 걱정이 되고 불안하다.			
25. 나는 미래가 지금보다 더 행복할 것이라고 생각한다.			
26. 나에게는 나쁜 일보다 좋은 일이 더 많이 생길 것이다.			
27. 내 처지로 인해 화가 난다.			
28. 내가 다른 사람들과 다르다고 느낀다.			
29. 급우들에 비해 과제를 끝마치는데 시간이 오래 걸린다.			
30. 예전보다 글씨 쓰기가 힘들다.			
31. 예전보다 책을 읽기가 힘들다.			
32. 주의 집중하기가 어렵다.			
33. 학습 과제를 수행할 때 다른 사람의 도움을 받아야 할 때가 많다.			
34. 학교 공부를 잘 해낼 수 있을지 걱정이 된다.			
35. 배운 것을 자주 잊어버린다.			
36. 학교에서 대답을 잘 못한다.			
37. 과제를 마치는데 끈기가 부족하다.			
38. 가족이나 친구들로부터 거부당한다고 느낄 때가 있다.			
39. 치료를 받고 있는 것을 다른 사람들이 알까 두렵다.			
40. 활동할 때 가족이나 친구들로부터 도움을 받는다.			