Clinical approach to Quality of life in Children with End-stage renal disease

Min Hyun Cho, MD

Department of Pediatrics, Kyungpook National University Hospital, Daegu

# Running title: QOL in children with ESRD

# Corresponding author: Min Hyun Cho, MD

Department of Pediatrics, Kyungpook National University Hospital

50, Samduk Dong 2Ga, Jung Gu, Daegu

700-721, Republic of Korea

Tel: ++82-53-420-5719

Fax: ++82-53-425-6683

E-mail: chomh@knu.ac.kr
Abstract

Quality of life in addition to various medical problems in children with end-stage renal disease (ESRD) should be objectively assessed to accomplish normal growth and development during childhood. However, unfortunately, studies of QOL in children with ESRD have been not popular yet and there are only fewer suitable assessment tools compared with adults. Recently, disease-specific modules to evaluate QOL in children with chronic disease such as ESRD have been developed. This review was made to introduce these QOL instruments for children and help the clinical application of them.

Keywords: Quality of life, Children, End-stage renal disease

Introduction

Development of renal replacement therapies such as hemodialysis (HD), peritoneal dialysis (PD) and renal transplantation in children with end-stage renal disease (ESRD) has resulted in improved long-term survival\(^1\). However, ESRD influences virtually every organ system and thus, has a major impact not only on morbidity and mortality but also on the quality of life (QOL) of children with ESRD\(^2\).

In general, QOL can be defined as a patient’s sense of well-being and functional outcome within several life domains including physical, psychological status, and social interaction\(^3\). QOL should not be confused with the concept of standard of living, which is based primarily on income. Based on previous studies of QOL, Spilker et al. concluded that QOL is a multifaceted/multidimensional phenomenon and there are next five domains in a conceptual definition of QOL; 1) physical status and functional abilities, 2) psychological status and well-being, 3) social interaction, 4) economic and/or vocational status, and 5) religious and/or spiritual status\(^4,5\)(Fig. 1).
Actually, we, pediatric nephrologists, should confront a lot of medical problems in children with ESRD. These problems consist of general symptoms such as fatigue and malaise, hematologic problems such as anemia and dysfunction of platelet, gastrointestinal problems such as anorexia, nausea and vomiting, electrolyte imbalances such as hyperkalemia, metabolic acidosis, hyponatremia, hyperuricemia and hyperphosphatemia, genitourinary problems, nerve system, endocrine, musculoskeletal, cardiovascular, and dermal problems, etc. Except for these medical problems, however, there are additional problems that we must resolve in children including the change of body image, too many medicines, side effects, psychiatric problems, growth, and development. If we don't have concern about these issues, normal growth and development in these children cannot be accomplished. Kurtin suggested that the definition of success in the care of pediatric ESRD patients should not be limited to mortality rates, but must include the degree to which these children are allowed to grow, develop, and behave in the same manner as their healthy peers\(^6\). The goal of this review was to help the understanding of clinical usefulness of assessment of QOL in children and adolescents with ESRD.

**QOL in adults with ESRD**

The QOL of adults with ESRD has been evaluated more comprehensively than in children. In 1985 Evans et al. evaluated the QOL of 859 patients undergoing dialysis or transplantation. They concluded that transplantation can give better QOL than dialysis because QOL of transplant recipients compared well with that of the general population, whereas patients with dialysis did not work at the similar level as people in the general population\(^7\). In the CHOICE Health Experience Questionnaire (CHEQ) study, the difference of QOL according to dialysis modality in adults with ESRD was evaluated by 36-Item Short-Form Survey (SF-
36) and it was reported that PD can give better QOL than HD in various domains including physical functioning, bodily pain and emotional functioning\(^8\). In 2002, Kidney Disease Outcomes Quality Initiative (K/DOQI) reported that impairment in functioning and well-being are associated with worse outcomes in chronic kidney disease (CKD) and compared with healthy population, dialysis patients tend to have more dysfunctions and limitations of behavior due to more bodily pain, poorer vitality, and poorer general health\(^9\). So, K/DOQI Clinical Practice Guidelines for CKD recommended that patients with glomerular filtration rate (GFR) < 60 mL/min/1.73m\(^2\) should undergo regular assessment for impairment of functioning and well-being\(^9\). In Korea, Park et al. suggested that lower residual renal function is a risk factor for depression and impaired QOL in Korean PD patients\(^10\).

**Pediatric QOL tools**

Up to the present, several pediatric QOL tools have been developed such as these lists; Child Health Questionnaire (CHQ), Child Health and Illness Profile-Adolescent Edition (CHIP-AE), Dartmouth Primary Care Cooperative Functional Health Assessment Charts (COOP), Functional Status II (R) (FSII-R), Pediatric Quality of Life Inventory (PedsQL) and The Vineland Adaptive Behavior Scale (VINELAND).

The CHQ consists of 12 domains of health status (physical functioning, limitations in schoolwork and activities with friends, general health, bodily pain, discomfort, limitations in family activities, emotional/time impact on the parent, impact of emotional or behavior problems on school work and other daily activities, self-esteem, mental health, behavior, family cohesion and change in health) and is suitable for children aged 10-19 years\(^11\). The CHIP-AE is 6 domain/153 item self-report instrument (discomfort, satisfaction, disorder, achievements, resilience and risk) and sensitive to age, gender and socioeconomic influences\(^12, 13\). The COOP chart system has 6 domains of health status including physical fitness,
emotional feeling, school work, social support, family communication, and health habits

The VINELAND is suitable for evaluating both handicapped and non-handicapped persons from birth to age 19 years unlike the other QOL instruments. PedsQL 4.0 Generic Core Scale created by Dr. Varni is a 23-item generic health status instrument that assesses five domains of health including Physical, Emotional, Psychosocial, Social and School functioning in children and adolescents ages 2-18 years.

Although these modules have internal reliability and clinical validity and can be completed easily by children and their parents, they have some limitations because they were not disease-specific module. After then, Varni and his colleagues have developed disease-specific modules to assess QOL in children with chronic diseases such as ESRD, asthma, cancer and rheumatoid arthritis.

The 34-item PedsQL 3.0 ESRD Module developed in 2002 includes 7 scales: (1) General Fatigue (4 items), (2) About My Kidney Disease (5 items), (3) Treatment Problems (4 items), (4) Family and Peer Interaction (3 items), (5) Worry (10 items), (6) Perceived Physical Appearance (3 items), and (7) Communication (5 items). This module consists of 4 age categories of 2-4, 5-7, 8-12 and 13-18 years. The scales are composed of both the child self-report and parent-proxy report formats for children aged 5 to 18 years and a parent-proxy report format for children aged 2 to 4 years. Items are reverse-scored and linearly transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0). Higher scores indicate better HRQOL. In our previous study, we translated the original English version of the PedsQL 3.0 ESRD into new Korean version based on the guideline of linguistic validation provided by the original developer (Mapi Research Trust, on behalf of Dr. James W. Varni, copyright owner in the PedsQL™).

**Studies of QOL in children with ESRD**
Unfortunately, there are few studies of QOL in children with ESRD because first, it is very
difficult to obtain suitable questions for children and second, proxy assessment is always
needed. Initially, there are several limited studies of qualitative status in children with ESRD
instead of typical QOL. Morton et al. reported that living with parents, lack of experience of
close relationship, lack of educational qualifications and unemployment were more common
in young adults with ESRD\textsuperscript{22).} In other study, 30 percent of adolescents with ESRD were
neither enrolled in an educational program nor were employed \textsuperscript{23).} 
Recently, there have been several attempts to quantitate in systematically analyzable terms,
the net outcome of a disease and its treatment on the patient’s perception of his/her ability to
live a useful and fulfilling life during childhood. In 1994, Kurtin et al. created parent-
completed questionnaire validated in the Children’s Health and Quality of Life Project and
suggested that less compliant adolescents consistently reported more pain and poorer general
and mental health than more compliant adolescents, as well as lower family involvement \textsuperscript{6).} It
was also reported that QOL scores of children with ESRD were considerably lower than
healthy controls\textsuperscript{24).} In addition, Marciano et al. suggested that children with chronic kidney
disease showed a higher proportion of behavioral and emotional disorders and there was a
negative correlation between the presence of behavior and emotional disorders and QOL
score\textsuperscript{25).} 
There have been several studies of difference of QOL between treatment modalities such as
dialysis and transplantation in children with ESRD. According to study of QOL in children
with ESRD using CHIP-AE, transplantation can produce improved physical activity, better
work performance, more satisfaction, and less discomfort compared with dialysis\textsuperscript{26).} In other
study using PedsQL module, transplant patients reported better physical and psychosocial
health than dialysis patients\textsuperscript{24).} In addition, pediatric kidney transplant recipients also reported
a higher QOL score than other published studies of chronic illness cohorts\textsuperscript{27).}
Some studies have been reported the difference of QOL between child-self and parent-proxy reports. McKenna reported that caregivers score their children lower in almost all categories than the child-self reports\textsuperscript{28}. On the other hand, Goldstein et al. reported that although parent-proxy reports show a positive impact from renal transplantation on the majority of QOL domains compared with dialysis, child self-reports show non-significant differences in favor of renal transplantation\textsuperscript{29}. Therefore, Buyan et al. concluded that parent-proxy scores on the QOL were not equivalent to child-self scores and that evaluating both children’s and parents’ perspectives were important\textsuperscript{30}.

Co-morbidities including cardiovascular, gastrointestinal, endocrinologic, hematologic and neurologic disorders can be also one of the significant factors to decide the QOL in children with ESRD. Especially, hypertension, diabetes and cardiovascular disorders have been regarded as the leading co-morbidities in developing countries\textsuperscript{31}. Khan et al. classified patients into high, medium and low risk groups according to co-morbidity and age and reported the significant difference of patients’ perception of health score among the 3 risk groups\textsuperscript{32}.

In 2012, we published a cross-sectional study of the Korean translations of the PedsQL ESRD Module comparing child self-reported and parent-proxy–reported HRQOL of children with ESRD based on a national-wide pediatric ESRD registry, the so called ‘The Korea Pediatric CKD registry’\textsuperscript{21}. Participants included children aged 2 to 18 years who received maintenance dialysis treatment or renal transplant care for at least 6 months and their parents. Total 92 pediatric patients (HD 11, PD 44 & transplant 37) were enrolled. We reported that patients with PD had better QOL than HD in several domains (including Treatment problems in the child self reports, About my kidney disease and Worry in the parent proxy reports) and transplant patients had better HRQOL than dialysis patients in one domain of the child-self report (Treatment problems) and in two domains of the parent proxy reports (About my
kidney disease and Worry). However, there were no significant differences in the total QOL scores of the child self reports between the peritoneal dialysis and transplant patients.

**Summary**

Compared with adults, studies of QOL in children with ESRD have been not popular yet. However, we should consider that assessment of QOL can be essential to achieve normal growth and development in children with chronic diseases including ESRD. In addition, although various assessment tools for children have been recently developed, the optimized QOL instrument in our country should be developed to overcome the language problems and cultural gap. A larger, longitudinal prospective study is needed in the future.

**References**


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Fig. 1. Five domains in a conceptual definition of quality of life. Modified from Spilker$^{4,5}$.
### Appendix: PedsQL 3.0 ESRD Module child-self report item content (Korean version)\textsuperscript{21}

<table>
<thead>
<tr>
<th>Scales</th>
<th>Items</th>
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</thead>
<tbody>
<tr>
<td>1) 일반적인 피로감 (General fatigue)</td>
<td>1. 나는 피곤하다 2. 나는 육체적으로 악하다 (강하지 않다) 3. 나는 너무 피곤해서 내가 하고 싶은 일을 할 수 없다 4. 나는 너무 피곤해서 친구들과 시간을 보낼 수 없다</td>
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<tr>
<td>2) 내 신장병에 관하여 (About my kidney disease)</td>
<td>1. 나는 얼굴이 부었다 2. 나는 어지럽다 3. 나는 머리가 아프다 4. 나는 목이 마르다 5. 나는 쥐가 난다</td>
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<tr>
<td>3) 치료하면서 생기는 문제 (Treatment problems)</td>
<td>1. 나는 약 먹는 것을 기억하기가 힘들다 2. 나는 약을 먹고 나면 기분이 좋지 않다 3. 나는 액체로 된 약을 먹기가 힘들다 4. 나는 먹고 싶은 음식을 먹지 못할 때 속상하다</td>
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<tr>
<td>4) 가족 및 교우 관계 (Family and peer interaction)</td>
<td>1. 나는 다른 사람들이 내 병을 이해하지 못할 때 힘들다 2. 나는 치료(투석) 때문에 가족들과 무언가를 함께 할 수 없다 3. 나는 치료(투석) 때문에 친구들과 함께 하는 운동에서 제외된다고 느낀다</td>
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<td>5) 걱정 (Worry)</td>
<td>1. 나는 약물치료가 잘 되고 있는지 걱정이다 2. 나는 수술 받는 것이 걱정이다 3. 나는 오랫동안 아플까 볼 걱정이다 4. 나는 입원해야 볼까 볼 걱정이다 5. 나는 내 혈압이 걱정이다 6. 나는 약을 안 먹으면 아플까 볼 걱정이다 7. 나는 체중이 걱정이다 8. 나는 젊어졌어 볼 걱정이다 9. 나는 주사바늘에 쏘이는 것이 걱정이다 (예, 주사, 혈액검사, 정맥주사) 10. 나는 혈액검사 결과가 걱정이다</td>
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<td>6) 보여지는 신체 모습 (Perceived physical appearance)</td>
<td>1. 나는 다른 사람들이 내 흉터를 보는 것이 싫다 2. 나는 또래만큼 나이 들어 보이지 않는다 3. 나는 내 악이 내 모습을 변화시켜 당황스럽다</td>
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<td>7) 의사소통 (Communication)</td>
<td>1. 나는 내가 치료과정에서 느낀 점을 의사나 간호사에게 말하기가 어렵다</td>
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<td>2. 나는 의사나 간호사에게 질문하기가 어렵다</td>
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<tr>
<td>3. 나는 내가 치료과정에서 느낀 점을 병원의 다른 사람들(예, 영양사, 사회복지사)에게 말하기가 어렵다</td>
<td></td>
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<tr>
<td>4. 나는 내 병을 다른 사람에게 설명하기가 어렵다</td>
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<tr>
<td>5. 나는 내가 치료과정에서 느낀 점을 부모에게 말하기가 어렵다</td>
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