Assessing Health Status and Health Care Utilization in Adolescents with Chronic Kidney Disease

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Few validated health status measures have been assessed in children with chronic kidney disease (CKD). The objective was to assess the validity of a generic health status measure, the Child Health and Illness Profile-Adolescent Edition (CHIP-AE), in adolescents with CKD. A case-control study was performed (*1*) to assess scores on the CHIP-AE in adolescents with CKD compared with two control groups of age-, socioeconomic-, and gender-matched peers and (2) to compare health of patients who had chronic renal insufficiency (CRI), were on dialysis, and were posttransplantation. Seven pediatric nephrology centers recruited 113 patients (mean age, 14 yr; 39 CRI, 21 dialysis, 53 posttransplantation). Compared with 226 control subjects, patients with CKD had lower overall satisfaction with health and more restriction in activity. Positively, patients with CKD had more family involvement, better home safety and health practices, and better social problem-solving skills and were less likely to participate in risky social behaviors or socialize with peers who engaged in risky behavior. Patients who received dialysis were less physically active and experienced more physical discomfort and limitations in activities than did transplant or CRI patients. It is concluded that patients with CKD have poorer functional health status than age-matched peers. Among CKD patients, dialysis patients have the poorest functional health status. These results suggest that the CHIP-AE can be used to measure functional health status in adolescent patients with CKD.

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The tremendous cost of treatment for ESRD, with Medicare expenditures exceeding $12.36 billion in 2000, has mandated research that is aimed at determining which treatment options are associated with the best health outcomes and the best value (quality/cost) (1). Patient-based assessments of functional health status and health-related quality of life are an increasingly important aspect of treatment outcomes. Until recently, this research has centered largely on adult ESRD patients, with little research examining treatment choices and patient-based assessments of functional outcomes in pediatric patients with ESRD (2–5). In addition, the health status of adolescent patients with ESRD has yet to be compared directly with a national sample of age-matched "healthy" adolescents. In "Research Needs in Pediatric Kidney Disease: 2000 and Beyond" (6), a task force from the National Institute of Diabetes and Digestive and Kidney Diseases called for prospective studies correlating ESRD treatment with subjective global assessments, *i.e.*, patient-based functional outcomes in children with ESRD. The task force anticipated that this type of study would help in understanding the impact of kidney failure and transplantation on functional health status including social adjustment, graduation from high school, obtaining employment, and achieving supportive social relationships. As a first step in addressing these research gaps, we conducted a cross-sectional study in a prevalent cohort of adolescents with chronic kidney disease (CKD) comparing their functional health status with a school-based control group matched by age, gender, and socioeconomic status (SES). We also evaluated the health care utilization of adolescents who had chronic renal insufficiency (CRI), were on dialysis, and were posttransplantation to examine the relationship of health service use to aspects of health. Health status was measured using the Child Health and Illness Profile-Adolescent Edition (CHIP-AE), a well-validated, multidimensional, generic health status questionnaire (7–11).

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Materials and Methods

Patients

Seven pediatric nephrology centers at tertiary care hospitals in the northeastern United States participated in the study. The study was

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approved by the Institutional Review Board at each of the participating centers. Enrolled patients (*1*) were between the ages of 10 and 18; (*2*) attended one of the participating outpatient clinics during the time of the study period (October 1998 to March 2003); (*3*) had advanced stage 2 or stages 3 to 5 CKD according to the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (estimated GFR <75 ml/min per 1.73 m^2 by Schwartz formula), were receiving dialysis treatment (hemodialysis or peritoneal dialysis), or were stable kidney transplant recipients; and (*4*) were capable of reading English or Spanish at the fourth-grade level (the reading level of the CHIP-AE).

Informed consent was received from all parents or guardians, and assent was received from all youth. Demographic information, laboratory values (hematocrit, albumin, and creatinine), CKD treatment modality, height, and Tanner stage of the adolescents were recorded at the time of enrollment. Information about the adolescents' health care utilization (frequency of hospitalization, emergency room visits, and nonroutine physician visits) during the 6 mo before study enrollment was also collected. Data from the concurrent administration to caregivers of a generic health status tool (Child Health Questionnaire Parent Form 50) was published recently (12,13).

Analyses were conducted comparing the health status of the adolescents with CKD with the health status of adolescents from the Starfield *et al.* (14) CHIP-AE standardization sample. In addition, the health status of a contemporaneously collected CHIP-AE public school sample was compared with the health status of the CKD sample. In both analyses, the CHIP-AE control groups were developed by selecting teens that had the same gender, SES, and age (±1 yr) as the CKD adolescents. An assessment of the relationship between health status and health care utilization of CKD adolescents was also completed.

Measurement of Health Status

The CHIP-AE, developed by Starfield *et al.* (7,15), is a self-report questionnaire that consists of six domains (Satisfaction, Discomfort, Resilience, Risks, Disorders, and Achievement) and 20 subdomains (see Table 1) that together comprehensively assess health status. Instrument

Table 1. Conceptual description of CHIP-AE domains and subdomains

Domain	Subdomains
SATISFACTION: Composed of elements of satisfaction with one's health and one's self, includes perceptions of well-being and self-esteem as well as the respondent's overall perceptions of his or her own health and attitudes toward it.	**Satisfaction with Health:** Overall perceptions of and beliefs about one's health
	Self esteem-self concept, satisfaction with self
DISCOMFORT: Examines physical and psychological feelings. Symptoms reflect illness experience, which describes the manner in which people monitor their bodies and define and interpret their symptoms.	**Physical Discomfort:** Assesses physical feelings and symptoms reflecting discomfort.
	Emotional Discomfort: Assesses feeling and symptoms of emotional discomfort.
	Limitations of Activity: Assesses restrictions of activity as manifested by absence from school and reductions in normal activities as well as specific limitations in mobility.
RESILIENCE: Includes states and behaviors that are known to reduce the likelihood of subsequent illness or injury. Resilience assesses aspects of positive health characterized by the existence of resources and patterns of behavior.	**Family Involvement:** Reflects amount and time of family activities and whether the child reports the presence of a supportive adult
	Physical Activity: Asks about strenuous activities such as running and involvement in team sports. In past 4 wk, how many sit-ups, how far did you walk at any one time without resting and without getting tired? Longest time you ran without stopping?
	Social Problem-Solving: Assesses respondent's preferences for solving difficult social situations.
	Home Safety and Health: Includes items in the home that reduce the likelihood of harm, such as a smoke detector
RISKS: Includes states and behaviors that are known to heighten chance of ill health or injury.	**Individual Risks:** Risky activities that the adolescent is currently doing (smoking, drinking, etc.)
	Threats to Achievement: Assesses negative behaviors that threaten to disrupt social development, such as lying, cheating, disobeying at school
	Peer Influences: Risky activities of friends (How many of your friends smoke, drink, etc.)
DISORDERS: Assesses both mental and physical illnesses as well as injuries and impairments.	**Acute Minor Disorders:** Colds, tonsillitis, sprains
	Acute Major Disorders: Pneumonia, broken bones, hepatitis
	Recurrent Disorders: Ear infections, asthma, allergies
	Long-Term Medical Disorders: Arthritis, diabetes, epilepsy
	Long-Term Surgical Disorders: Scoliosis, vision and hearing problems
	Psychosocial Disorders: Speech, eating, learning problems
ACHIEVEMENT: Assesses the extent to which social role expectations have been met in a developmentally appropriate manner.	**Academic Achievement:** How does teen do in school. In past two school years, has respondent received award or prize at school, been on the honor roll, failed a subject, etc.
	Work Achievement: Score not computed if respondent does npt work. For last month, asks about how often teen was late for work, absent from work, etc.

[a]CHIP-AE, Child Health and Illness Profile-Adolescent Edition. Adapted from CHIP-AE manual.

scoring has been standardized so that "average" health is represented by a score of 20 and a SD of 5 for each domain and subdomain. Higher scores denote better health and less impairment. Computerized entry and scoring of the CHIP-AE data were completed by research staff familiar with the *Manual for the CHIP-AE* (16). The psychometric properties of the CHIP-AE have been evaluated comprehensively, and the instrument has been found to be a reliable and valid tool for adolescents in the community and in special populations (9,11,17–19).

Statistical Analyses

T tests were used to assess mean differences on the CHIP-AE domains and subdomains between the CKD patients and their matched control subjects. One-way ANOVA was used to assess mean differences on the CHIP-AE domains and subdomains among CKD patients who had CRI, were on dialysis, and were posttransplantation. One-way ANOVA was also used to assess the relationship between health care utilization and health status. In all analyses, $P < 0.05$ was considered significant.

Results

A total of 113 CKD patients (age range, 10 to 18 yr; mean, 14.2; SD, 1.9) were enrolled into the study at one of the seven collaborating centers. Demographic characteristics, primary causes of CKD, Kidney Disease Outcomes Quality Initiative stage, and treatment group classification of the study population are presented in Table 2. Adolescents with CRI accounted for one third of the sample. Four of the seven participating sites systematically collected information regarding the number of eligible patients who were not enrolled in the study. These four sites contributed 78% of the study sample. A total of 120 adolescents were eligible for enrollment, and 73% were enrolled in this study.

Table 2. CKD patient demographics ($n = 113$)[a]

Characteristic	%
Age (yr)	
10 to 14	55
15 to 18	45
Race	
white, not Hispanic	60
black, not Hispanic	25
Hispanic	7
other	8
Gender	
male	64
female	36
SES	
higher	34
middle	34
lower	32
Cause of renal disease	
congenital renal or urologic anomaly	33
chronic glomerulonephritis	18
FSGS	13
systemic autoimmune disease	5
polycystic kidney disease	5
uncertain	4
renal failure with other congenital anomalies	4
other	17
K/DOQI stage (GFR)	
I (≥90 ml/min per 1.73 m^2)	16
II (60–89 ml/min per 1.73 m^2)	29
III (30–59 ml/min per 1.73 m^2)	24
IV (15–29 ml/min per 1.73 m^2)	14
V (<15 ml/min per 1.73 m^2)	17
Treatment group	
CRI	34
dialysis	19
transplant	47

[a]CKD, chronic kidney disease; SES, socioeconomic status; FSGS, focal segmental glomerulosclerosis; K/DOQI, Kidney Disease Outcomes Quality Initiative; CRI, chronic renal insufficiency. SES was determined by calculating a composite index on the basis of adolescent report of maternal and paternal education, maternal and paternal employment status, and eligibility in free school lunch programs.

Comparison of Health Status of Adolescents with CKD and Adolescents from the Control Sample

A comparison of CHIP-AE scores between the CKD patients and their matched control subjects is presented in Table 3. In the comparison of the CKD patients' scores with those of their matched control subjects, statistically significant differences were found within all of the Risks subdomains (Individual Risks, Threats to Achievement, and Peer Influences) and all of the Resilience subdomains (Family Involvement, Physical Activity, Social Problem-Solving, and Home Health and Safety). In addition, statistically significant differences were found within the subdomains of Overall Satisfaction with Health, Acute Major Disorders, and Long-Term Surgical Disorders, with CKD patients endorsing less overall satisfaction of health, more acute major disorders, and more long-term surgical disorders than matched control subjects. Positively, statistically significant differences were observed between CKD patients and their matched control subjects on the Emotional Discomfort subdomain, with the CKD patients endorsing fewer feelings of emotional discomfort than their matched control subjects.

Although statistically significant differences are important to note, Riley *et al.* (20,21) reported that a score differential of 3 points (0.6 SD) is correlated with meaningful clinical differences. Using this more stringent criteria, CKD patients' functional health is comparable to that of their peers except in the area of physical activity, where they report being less physically active than control group adolescents. CKD patients additionally demonstrated clinically significant higher scores in areas of health status that reflect fewer risk-taking behaviors, more avoidance of health risks, and less involvement with peers who engage in risky behavior.

To evaluate the stability of the observed differences, we compared the CKD group to a second, contemporaneously collected CHIP-AE public school sample. As in the first analysis, statistically significant differences were found between the CKD sample and the second control group on the Overall Satisfaction with Health subdomain ($P < 0.001$), all of the Risks subdomains ($P < 0.001$), and three of the four Resilience subdomains (Family Involvement, Physical Activity, and Social Problem-Solving; $P < 0.05$). Clinically significant differences between the CKD sample and the second control group were also replicated.

Table 3. Mean CHIP-AE domain/subdomain scores, CKD patients and control subjects

CHIP-AE Domain/Subdomain Scores (Mean [SD])	CKD Patients ($n = 113$)	CHIP-AE Control Subjects ($n = 226$)
Satisfaction domain	19.0 (4.38)	20.0 (5.20)[a]
overall satisfaction with health	18.4 (4.93)	20.2 (5.20)[b]
self-esteem	19.9 (4.19)	19.9 (5.04)
Discomfort domain	21.0 (4.35)	20.2 (5.29)
physical discomfort	20.0 (4.65)	20.3 (4.95)
emotional discomfort	20.8 (3.96)	19.8 (5.36)[c]
limitation of activities	21.0 (4.47)	20.3 (5.18)
Resilience domain	21.0 (4.84)	20.2 (4.81)
family involvement	21.1 (4.07)	19.8 (5.00)[c]
physical activity	17.3 (4.64)	20.7 (4.70)[d]
social problem-solving	21.4 (5.04)	20.0 (5.04)[c]
home safety and health	24.1 (4.35)	20.1 (4.62)[d]
Risks domain	25.7 (2.47)	19.8 (5.19)[d]
individual risks	27.8 (2.58)	19.9 (4.96)[d]
threats to achievement	22.9 (2.61)	19.8 (5.23)[d]
peer influences	24.0 (3.69)	19.8 (5.28)[d]
Achievement domain	very small *n*	very small *n*
academic performance	20.8 (4.72)	20.0 (4.89)
work performance	very small *n*	very small *n*
Disorders domain	17.5 (6.17)	19.7 (4.83)[b]
acute minor	19.5 (5.51)	19.7 (4.97)
acute major	17.7 (5.31)	19.6 (4.10)[b]
recurrent	19.3 (5.57)	19.4 (4.76)
long-term medical	18.7 (6.51)	19.9 (3.98)[a]
long-term surgical	16.5 (8.48)	19.5 (4.11)[b]
psychosocial	19.2 (5.73)	20.4 (5.01)[c]

[a]$P < 0.10$, [b]$P < 0.01$, [c]$P < 0.05$, [d]$P < 0.001$ in *t* test. Higher scores indicate better health.

Comparison of Health Status of CRI, Dialysis, and Transplant Patients

Table 4 displays the mean CHIP-AE scores for the CKD sample stratified by renal treatment modality. Statistically significant differences in physical discomfort, limitations in activities, and physical activity were observed among the transplant, CRI, and dialysis patient groups, with the transplant and CRI patient groups endorsing less physical discomfort, fewer limitations in activities, and more physical activity than the dialysis patient group. Statistically significant differences in satisfaction with health were observed between the transplant and dialysis patient groups, with the transplant patient group endorsing better overall satisfaction with health than the dialysis patient group. The dialysis patient group reported poorer adherence to home safety practices than the transplant or CRI patients. A stepwise increase in physical activity was observed, indicating that CRI patients are more physically active than transplant patients and both groups (CRI and transplant) are more physically active than dialysis patients. All of the above-referenced statistically significant differences are of sufficient magnitude to infer clinically significant differences in health status (*i.e.*, mean differences ≥ 3 points).

Health Care Utilization among Adolescents with CKD

Construct validity was evaluated by assessing the association between health care utilization and CHIP-AE subscale scores that would be expected to vary as a function of impaired health status (Satisfaction with Health, Physical Discomfort, Limitations in Activities, and Physical Activity). We hypothesized that increased hospitalizations, emergency department visits, and nonroutine health care visits would be associated with poorer satisfaction with health, more physical discomfort, more limitation in activities, and less physical activity. CKD patients were grouped into one of three health care utilization categories (no use, low use, or high use), and the group means were evaluated using ANOVA (Table 5). The observed relationships between increased health care utilization and impairment in health status support the construct validity of the CHIP-AE.

Discussion

This study sought to compare the functional health status of adolescents with CKD with the functional health status of age-, gender-, and SES-matched school-based adolescents. The CHIP-AE, a generic health status survey tool, was used to assess satisfaction with health, discomfort (physical, emotional, and limitations of activity), health states and behaviors that reduce the risk for adverse health outcomes (family involvement, physical activity, and home safety and health), mental and physical illness, and role functioning (academic and work achievement).

Significant differences between the CHIP-AE scores of the CKD patients and their school-based matched control subjects were found within the majority of areas of health status measured (Table 2). Compared with the control group, the CKD patients demonstrated lower overall satisfaction with health. Our data suggest that limitations in activity, rather than physical and/or emotional discomfort, account for the observed relative dissatisfaction.

The Resilience domain of the CHIP-AE, which assesses patterns of behaviors and resources that have previously been associated with reduction in health morbidity, also reflected some interesting differences between CKD patients and non-CKD peers. CKD patients scored higher than the control group in the Resilience subdomain of Home Safety and Health, reflecting a greater attention to aspects of the home and environment that reduce the likelihood of harm. In addition, statistically significant differences between the CKD patients and the control group were observed on the CHIP-AE Risks domain and all of the Risks subdomains. The higher scores of CKD patients in the Individual Risks subdomain (a measure of current risky health behavior such as smoking and drinking), the Peer Influences subdomain (a measure of friends' current risky health behavior), and the Threats to Achievement subdomain (a measure of negative social behavior such as lying, cheating, and disobedience at school) reflect increased risk avoidance by adolescents with CKD. These findings suggest that adolescents with CKD refrain from certain risky behaviors (smoking, drinking, etc.) in greater numbers than do adolescents in the control group, that the friends of the CKD patients engage in risky behavior less often than friends of the matched control group, and that CKD patients engage in less behavior that is disruptive to social and academic achievement than do the control group adolescents. Similar observations have been reported in other groups of children with chronic illness (9,14,22,23).

As expected, the CKD patient group reported more acute

Table 4. CHIP-AE domain/subdomain scores for CKD patient groups: CRI, dialysis, transplant[a]

CHIP-AE Domain/Subdomain Scores (Mean [SD])	CRI Patients ($n = 39$)	Dialysis Patients ($n = 21$)	Transplant Patients ($n = 53$)
Satisfaction domain	19.1 (4.70)	16.9 (3.27)[c]	19.7 (4.31)
overall satisfaction with health	18.8 (5.19)	15.93 (5.02)[c]	19.0 (4.49)
self-esteem	19.6 (4.19)	18.8 (4.64)	20.5 (3.95)
Discomfort domain	21.8 (3.97)	17.9 (5.33)[b,c]	21.5 (3.73)
physical discomfort	20.1 (4.25)	16.5 (5.54)[b,c]	20.9 (3.93)
emotional discomfort	21.6 (3.79)	19.2 (4.34)	20.9 (3.80)
limitation of activities	21.6 (3.68)	18.6 (4.88)[b,c]	21.6 (4.61)
Resilience domain	22.6 (4.44)	18.7 (4.94)[b]	20.6 (4.80)
family involvement	21.7 (3.31)	21.2 (3.83)	20.7 (4.64)
physical activity	19.3 (4.93)	14.2 (3.30)[b,c,d]	17.0 (4.18)
social problem-solving	21.7 (4.57)	21.6 (5.49)	21.2 (5.27)
home safety and health	24.7 (3.68)	21.6 (5.02)[b,c]	24.5 (4.28)
Risks domain	25.7 (2.27)	25.7 (2.73)	25.7 (2.58)
individual risks	27.7 (2.70)	28.0 (1.74)	27.9 (2.80)
threats to achievement	23.1 (2.07)	22.8 (2.12)	22.8 (3.11)
peer influences	23.9 (3.47)	24.3 (4.65)	24.1 (3.50)
Achievement domain	very small n	very small n	very small n
academic performance	21.7 (4.36)	19.2 (5.24)	20.8 (4.71)
work performance	very small n	very small n	very small n
Disorders domain	17.5 (6.17)	19.7 (4.83)	16.9 (6.42)
acute minor	19.2 (5.42)	18.6 (4.74)	20.0 (5.88)
acute major	16.6 (5.15)	19.4 (4.61)	17.8 (5.57)
recurrent	20.0 (5.98)	19.5 (4.41)	18.8 (5.71)
long-term medical	18.1 (7.28)	19.4 (5.28)	19.0 (6.40)
long-term surgical	17.8 (7.18)	15.6 (10.12)	15.9 (8.72)
psychosocial	19.8 (5.92)	17.5 (6.80)	19.4 (5.08)

In one-way ANOVA with *post hoc* Tukey's significant difference test: [b]CRI > dialysis ($P < 0.05$);[c]transplant > dialysis ($P < 0.05$); [d]CRI > transplant ($P < 0.05$). Higher scores indicate better health.

Table 5. Relationship between CHIP-AE subscale scores (mean, SD) and health care utilization 6 mo before study entry

	No. of CKD Patients in Analysis[a]	Overall Satisfaction with Health	Physical Discomfort	Limitation of Activities	Physical Activity
Nonroutine health care use (no. of visits)					
0	87	18.9 (4.6)[b]	20.6 (4.3)[b]	21.6 (4.3)	17.5 (4.7)
1–2	5	17.3 (4.9)	19.8 (3.6)	22 (0.7)	16.3 (4.4)
>2	7	14.2 (3.7)	16.5 (4.4)	17.4 (6.4)	15.4 (4.3)
Emergency department use (no. of visits)					
0	99	18.9 (4.4)[c]	20.4 (4.2)[b]	21.4 (4.2)	17.3 (4.7)
1	5	12.6 (5.5)	15.3 (4.5)	17.2 (6.6)	16.6 (5.6)
≥2	3	15.4 (6.8)	18.9 (2.9)	20.3 (0.8)	14.1 (3.3)
Hospital use (days in hospital)					
0	87	18.5 (5.1)[b]	20.2 (4.9)	21.5 (4.3)	17.9 (4.7)[b]
<7	10	18.5 (5.1)	17.8 (3.8)	17.1 (6.0)	14.1 (2.9)
≥7	15	17.9 (4.1)	20.1 (3.3)	21.4 (2.2)	16 (4.0)

[a]Some patients had missing health care utilization data and/or some missing CHIP-AE data.
[b]$P \leq 0.05$, [c]$P \leq 0.001$ by ANOVA.

major and long-term surgical disorders than the control sample. Among the CKD patients, markers of poor health were highest for adolescents who were on dialysis. Coupled with the observation that dialysis patients reported less satisfaction with their health, more physical discomfort, more activity limitations, and less physical activity than transplant and CRI patients, our results suggest that certain subscales (domains) on the CHIP-AE may be useful for clinicians to assess health outcomes within clinical environments that treat children with CKD.

Our study has several limitations. (*1*) As our study was cross-sectional, we cannot infer a causal relationship between dialysis treatment and poorer functional health status as measured by the CHIP-AE. (*2*) It is possible that adolescents with poorer health were less likely to be candidates for early transplantation and therefore were more likely to remain on dialysis; the differences in health status measurements on the CHIP may have been a function of this factor. (*3*) As the CKD patients all resided in the northeastern United States, the sample may not be representative

of children with CKD from other parts of the United States. A longitudinal assessment of children with CKD is under way by our research group to assess the changes in health status as a function of changes in health and as a function of time.

Although the use of a generic health status questionnaire proved informative for this comparison of the self-assessed health status of CKD patients and a school-based control group, it is likely that details that could better inform treatment decisions could be obtained with the addition of a disease-specific health status questionnaire. The information gathered during this study can contribute to the development of a CKD instrument that allows adolescents to report on more aspects of health related to kidney function. The medical and surgical status of adolescents with CKD clearly has an impact on their level of social role functioning and the resources that they have available to meet the challenges of living with CKD and becoming well-functioning adults. It is important for the functional health outcomes of CKD treatments to be studied and applied carefully to clinical practice guidelines for adolescents.

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