

*Original article*

## **Psychosocial characteristics and coping skills in children maintained on chronic dialysis**

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**Abstract.** Psychosocial character traits and coping skills were examined in 12 children with end-stage renal failure. Six of the children were maintained on in-center hemodialysis and 6 were treated with home peritoneal dialysis. All of the patients felt a lack of ability to control their lives. The incidence of anxiety, depression, and hostility did not appear to vary from a population of healthy adolescents. Personal and social adjustment scores were, on average, on the 20th percentile. Coping skills appeared to be most influenced by the mode of dialysis treatment. Home peritoneal dialysis patients utilized self-reliance as a coping process more often than their counterparts on hemodialysis. We conclude that children maintained on chronic dialysis therapy demonstrate reasonable psychological adjustment with some differences in social and emotional functioning when compared with healthy children, and that the type of treatment chosen may influence the development of certain coping skills.

**Key words:** Chronic dialysis – Adolescent development

### **Introduction**

Children with end-stage renal failure often require prolonged maintenance dialysis treatment while awaiting kidney transplantation. Although successful in sustaining life, several investigators have suggested that the various forms of mainte-

nance dialysis exact a psychosocial as well as physical toll [1–3]. Indeed, the successful completion of developmental tasks in adolescence may be jeopardized by a chronic illness such as end-stage renal disease (ESRD). ESRD, with its various treatment restrictions and frequent hospital visits, can significantly affect an adolescent's sexual identity and body image, peer relationships, and independence from family ties. Thus, treatment decisions have an effect on both the teenager's psychological development as well as his or her physical health.

The advent of home peritoneal dialysis is an important advance with possible psychological ramifications. Peritoneal dialysis allows the adolescent patient to perform his own dialysis and may enhance feelings of self-control and independence. Similarly, the reduction in the number of in-center or hospital visits could also lead to improvement in an adolescent's peer contacts and in perceived social competency. Consequently, one of the major purposes of this preliminary investigation was to assess psychological functioning in adolescent patients maintained on in-center hemodialysis and home peritoneal dialysis.

Although many authors consider chronic illness to be a potentially destructive force in personality and psychosocial development [4, 5], most objective psychological assessment studies have not revealed significant levels of psychopathology in chronically ill children and adolescents [6]. These studies suggest that most chronically ill children may be considered to be psychologically normal rather than deviant and; thus, the majority of chronically ill children would be expected to cope adequately with daily events and stresses under normal circumstances [7]. However, the recur-

ring symptoms of ESRD lead to an abnormal situation, e.g., hospitalization and/or intrusive medical procedures, which may result in periodic adjustment difficulties. Following the above arguments, it is reasonable to focus research efforts on coping strategies and barriers to adjustment in chronically ill childhood populations [8]. Thus, a second goal of this pilot study was to examine the coping mechanisms utilized by adolescents with ESRD and compare them with those commonly utilized by healthy adolescents.

## Subjects and methods

Twelve patients aged 10 years and older who were followed at the Rhode Island Hospital agreed to enter the study. They ranged from 10 to 19 years in age and were from middle-class families. Six of the children were maintained on chronic in-center hemodialysis and six were maintained on either home continuous ambulatory peritoneal dialysis (CAPD) or continuous cycling peritoneal dialysis (CCPD). The mode of dialysis therapy was selected by the patient and his/her family based on personal preference. The diseases leading to ESRD are depicted in Table 1. Both groups of children were medically stable and ambulatory with only occasional need for hospitalization. Clinical data on most of the patients studied were presented in a previous report [9].

### Instruments

*Nowicki-Strickland children's locus of control scale.* Locus of control, defined as that personality dimension which reflects an individual's attitude about his/her ability to control life events, was measured using the Nowicki-Strickland Children's Locus of Control Scale [10]. Locus of control measures have been used in previous research with chronically ill adolescents and differences have been found between healthy and patient groups, including adolescents with renal disease [6]. Low scores indicate greater feelings of personal (internal) control over life events.

*Piers-Harris self-concept scale.* This instrument was an 80-item self-report which provided a total self-concept score along with six subscale scores [4]. Since chronic illness is believed to influence self-image via physical changes, life restrictions, and disruptions of daily activities, self-concept was an important area to investigate. The Piers-Harris scale has specifically been

used in studies examining the psychological functioning of children with chronic illness and life-threatening diseases such as cystic fibrosis [12] and childhood cancer [13].

*Multiple affect adjective checklist.* Several dimensions of mood were also investigated in this population. Multiple Affect Adjective Checklist (MAACL) investigates patient anxiety, depression, and hostility [14]. Since the most frequently reported psychological response to dialysis has been depression [15, 16], it was appropriate to measure this function. Similarly, anxiety was also explored, since various complications and treatment procedures may cause distress. Hostility was studied because rebellious, risk-taking behaviors have been seen in adolescents with chronic illness [17].

*California test of personality.* On this particular instrument, personal and social adjustment were collectively defined as feelings of self-worth and the ability to adapt or conform to social mores [18]. Thus, this measure was felt to be an appropriate test of adaptive functioning and was consistent with the view that children with chronic illness function in the area of psychological normality rather than deviancy. The administered test contained 180-items with 12 subscales, 6 in personal adjustment and 6 in social adjustment. Two subscores in personal and social adjustment were derived. Transformation of the scores into percentiles was also done for the dialysis patients and the percentiles were compared with the norms.

*Adolescent coping orientation problem experiences.* Adolescent Coping Orientation Problem Experiences (A-Cope) [19] was a 53-item scale which yielded scores in 12 individual areas reflecting different mechanisms of coping, e.g., self-reliance, avoidance, relaxation, etc. Coping in this instance was defined as those behaviors used to manage hardship in one environment and to relieve the discomfort associated with life changes or difficult life events. The A-Cope scale was specifically employed in this study to investigate coping mechanisms of adolescents with ESRD. Differences in coping styles between peritoneal and hemodialysis patients were assessed. In addition, the scores derived from these individual coping patterns for the chronic dialysis patients were compared with a control group of 25 male and 24 female students attending a local high school. All of the controls for the A-Cope were white and from a middle-class background. The mean age of the controls was  $14.7 \pm 0.6$  years, which was no different from the 12 chronic dialysis patients tested (hemodialysis vs control  $t = 0.07$ ,  $P = 0.947$  and peritoneal vs control  $t = 1.28$ ,  $P = 0.254$ ).

### Statistical analysis

Student's  $t$ -test was employed for analysis of age and treatment time differences. Due to the skewed distribution of the small number of subjects, a nonparametric test, the Wilcoxon signed ranks test, was used to compare the two groups on the various assessment measures. All data reported were expressed as the mean  $\pm$  standard deviation.

Informed consent was obtained from each patient tested and from the parents. The project was approved by the Institutional Review Board of the Rhode Island Hospital.

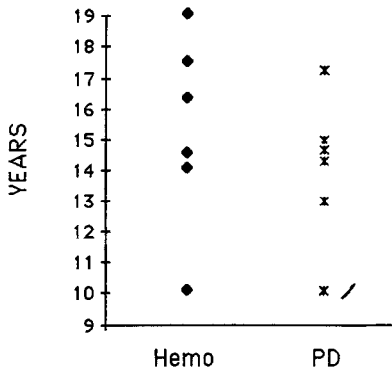
## Results

The mean age of the hemodialysis patients was  $15.3 \pm 3.4$  years, while the mean age in the peritoneal dialysis group was  $14.0 \pm 2.4$  years ( $t = 0.79$ ,  $P < 0.5$ ; no significant difference in age) (Fig. 1).

**Table 1.** Etiology of end-stage renal failure

Diagnosis	Hemodialysis	Peritoneal dialysis
Focal segmental sclerosis	1	2
Medullary cystic disease	–	1
Renal dysplasia/obstruction	1	2
Cystinosis	2	–
Rapidly progressive glomerulonephritis	1	–
Chronic glomerulonephritis	–	1
Anaphylactoid purpura	1	–

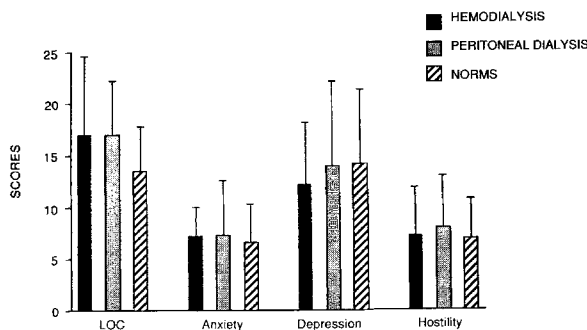
Glomerular diseases produced renal failure in 6 of the 12 patients studied



**Fig. 1.** Age of the patients studied. No significant difference in age exists between the children maintained on hemodialysis and peritoneal dialysis

There were 5 males and 1 female in the hemodialysis group and 4 males and 2 females in the peritoneal dialysis group. All patients were maintained on dialysis for a minimum of 3 months and had been given the choice of dialysis treatment. There was wide variability in the length of time patients were maintained on dialysis in both groups (11 patients ranging from 3 months to 5 years with 1 hemodialysis patient on treatment for 10 years); hemodialysis treatment time  $41 \pm 45$  months and peritoneal dialysis treatment time  $12 \pm 12$  months ( $t = 1.54, P < 0.1$ ; no significant difference in mean treatment time between the two groups).

Both hemodialysis (mean =  $17.0 \pm 5.2$ ) and peritoneal (mean =  $17.0 \pm 7.6$ ) dialysis patients fell into the external locus of control category as defined by the developers of the scale [10] with no statistical difference existing between the mean scores ( $z = 0.08; P = 0.93$ ). Piers-Harris self-concept scores in our patients were similar to age-ad-



**Fig. 2.** Test scores for the Nowicki-Strickland children's locus of control scale and multiple affect adjective checklist. No significant differences exist between the two dialysis groups. Both dialysis groups test in the external locus of control category. Test norms are provided for comparison

**Table 2.** California Test of personality adjustment scales

	Hemodialysis	Peritoneal dialysis
	Percentile rank	Percentile rank
<b>Personal adjustment</b>		
Subject		
1	10	30
2	10	5
3	5	20
4	20	40
5	50	60
6	60	5
Mean percentile	26	27
<b>Social adjustment</b>		
Subject		
1	20	20
2	20	1
3	1	20
4	20	20
5	<sup>a</sup>	30
6	30	20
Mean percentile	18	18
<b>Total adjustment percentile rank</b>		
Subject		
1	20	20
2	20	5
3	2	20
4	20	30
5	<sup>a</sup>	50
6	40	10
Mean percentile	20	23

<sup>a</sup> Subject 5 in the hemodialysis group did not complete this portion of the test.

Data were computed with an  $n = 5$  in this subset. Percentile rank scores are depicted for all 12 patients. Only 3 of the 12 children achieved a 50th percentile rank for personal adjustment and none of the patients tested received scores at the 50th percentile rank on social adjustment

justed norms (hemodialysis  $51.2 \pm 18.9$  vs peritoneal  $57.2 \pm 12.2$ ;  $z = 0.32, P = 0.75$ ). Anxiety (hemodialysis  $7.2 \pm 2.8$  vs peritoneal  $7.3 \pm 5.3$ ;  $z = 0.16, P = 0.89$ ), depression (hemodialysis  $12.2 \pm 5.9$  vs peritoneal  $14.0 \pm 8.2$ ;  $z = 0.08, P = 0.94$ ), and hostility (hemodialysis  $7.2 \pm 4.7$  vs peritoneal  $8.7 \pm 5.0$ ;  $z = 0.64, P = 0.52$ ) scores were also similar in our two groups of patients. Figure 2 depicts graphically the locus of control, MAACL data, and normative data for comparison.

Individual patient California Test of Personality personal and social adjustment scores with the appropriate percentile ranks are depicted in Table 2. No significant differences in either personal or social adjustment mean scores were observed be-

**Table 3.** Adolescent coping scales

	Hemodialysis Mean $\pm$ SD	Peritoneal dialysis Mean $\pm$ SD	Controls ( <i>n</i> = 49) Mean $\pm$ SD
Ventilation	13.3 $\pm$ 4.2	14.8 $\pm$ 5.4	13.8 $\pm$ 3.7
Low-level activity*	20.7 $\pm$ 5.3	28.0 $\pm$ 2.3	18.5 $\pm$ 3.9
Self reliance*	15.8 $\pm$ 1.2	18.3 $\pm$ 2.0	18.6 $\pm$ 2.4
Emotional connections	17.7 $\pm$ 3.7	18.3 $\pm$ 5.4	10.6 $\pm$ 2.7
Family problem solving	16.7 $\pm$ 4.8	17.5 $\pm$ 5.5	14.0 $\pm$ 3.2
Avoidance	7.5 $\pm$ 1.6	7.2 $\pm$ 2.7	8.2 $\pm$ 2.6
Spiritual support	5.5 $\pm$ 2.8	7.5 $\pm$ 3.6	4.2 $\pm$ 1.1
Friendship*	4.3 $\pm$ 1.0	6.7 $\pm$ 2.7	4.6 $\pm$ 1.9
Professional support	3.5 $\pm$ 0.8	5.2 $\pm$ 1.9	3.4 $\pm$ 1.4
High-level activity	10.7 $\pm$ 3.1	11.8 $\pm$ 4.3	8.9 $\pm$ 2.0
Humor	7.0 $\pm$ 2.2	7.2 $\pm$ 2.0	3.7 $\pm$ 1.4
Relaxation	11.3 $\pm$ 2.6	11.0 $\pm$ 3.8	10.3 $\pm$ 2.3

\*  $P < 0.05$  PD vs Hemo, see text for additional statistical analyses. Peritoneal dialysis patients are more likely to employ low-level activity, self-reliance, and personal friendship as coping processes than their counterparts maintained on hemodialysis

tween hemodialysis and peritoneal dialysis patients (hemodialysis personal adjustment  $53.3 \pm 9.3$  and social adjustment  $44.5 \pm 12.3$  vs peritoneal dialysis personal adjustment  $53.7 \pm 5.2$  and social adjustment  $53.3 \pm 4.6$ ;  $z = 0.40$ ,  $P = 0.69$  for personal adjustment and  $z = 0.09$ ,  $P = 0.93$  for social adjustment). Perhaps of greater interest, when all of the chronic dialysis patients were analyzed as a whole, only 3 of 12 children achieved a 50th percentile rank (average) or above for personal adjustment. None of the individuals studied received scores at the 50th percentile rank on the social adjustment scale.

The mode of dialysis treatment may have influenced adolescent coping mechanisms as tested by A-Cope (Table 3). In the 12 categories measured, statistically significant differences between the two groups were noted in low-level activity (e.g., going to the movies) ( $z = 2.17$ ,  $P < 0.03$ ), self-reliance ( $z = 2.28$ ,  $P < 0.03$ ) and use of friendship ( $z = 2.29$ ,  $P < 0.02$ ). Thus, patients maintained on peritoneal dialysis were more likely to use low-level activity, more likely to show self-reliance, and more likely to develop friendships than their peers on hemodialysis. Table 3 also compares both sets of patients with data gathered from a control group of 49 healthy adolescents similar in age and socioeconomic status.

Since the hemodialysis and peritoneal dialysis patients were not significantly different on the remaining nine coping strategies measured by the

A-cope, all 12 of the dialysis patients as a group were compared with the controls in those nine areas. Statistical differences were noted between the dialysis patients and controls in the following coping strategies; dialysis patients were more likely to employ emotional connections ( $z = 4.54$ ,  $P < 0.001$ ), family problem solving ( $z = 2.79$ ,  $P < 0.005$ ), spiritual support ( $z = 2.26$ ,  $P < 0.02$ ), professional support ( $z = 2.08$ ,  $P < 0.05$ ), high-level activity ( $z = 2.52$ ,  $P < 0.01$ ) and humor ( $z = 4.55$ ,  $P < 0.001$ ).

## Discussion

The small number of subjects studied meant that a rather substantial difference between the means of each dialysis group had to be present if statistical significance was to be achieved. Thus, it might have been possible to detect some differences between the two groups on the measures employed with a larger sample. The small numbers also preclude studying a more homogeneous age group of patients which would enhance the ability to draw specific conclusions. Lastly, all patients elected the type of treatment they desired. Many of our findings may reflect psychological factors which influenced the selection of dialysis treatment. The opportunity to select the form of treatment may have led to greater feelings of control over the illness for both groups. Such selection may be an important psychological process, diminishing much of the emotional distress associated with chronic illness (anxiety, depression, hostility) [20, 21].

Only self-report measures were used in this study. Although self-report measures are more objective than certain other psychological measures, response bias and response shifts may influence the data acquired. Self-report instruments may also be subject to patient denial. Denial of difficulties has been found in adolescent chronic illness populations [22]. By minimizing the distress produced by the disease and its treatment, denial may even be adaptive for this population [23].

All the patients studied demonstrated external scores on the locus of control measure. Although peritoneal dialysis allows some greater control over certain aspects of the adolescent's life, e.g., social contacts, home activities, etc., these activities may not override the fact that control over general health remained tied to the receipt of medical care, be it in-center or home dialysis. The external locus of control demonstrated in our patients also has been observed in adult chronic he-

modialysis patients [1]. The external scores found in this study and in studies with adults do not necessarily indicate psychological problems but may reflect a reasonable self-perception on the patient's part given the nature of the illness and its treatment [6].

Our findings on the Piers-Harris scale suggested that the restrictions and disruptions of daily activity did not adversely affect self-image. Self-concept test results from children and adolescents with other chronic illnesses have been reported to be similar to those from healthy adolescents [6, 12]. Given the body disfigurement in many of our patients (e.g., short stature), denial most likely was employed when questions concerning body image were asked.

The results obtained on the MAACL suggest that dialysis treatment did not influence the level of anxiety, depression, and hostility demonstrated by our patients. The mean scores on these measures were similar to those obtained by the control population. Although one might predict that children maintained on home dialysis might be more anxious due to less frequent medical staff contacts, we did not find this to be the case. In general, the 12 patients surveyed were not chronically anxious; this corresponded with the previous finding that adolescents with chronic illness often did not report higher levels of anxiety [6].

The rather low level of depression noted in this study was somewhat surprising in light of the fact that depression is quite common in adult ESRD patients [15, 16]. Two points can be made here; one should not uniformly extrapolate findings from the adult patient to the pediatric patient, and depression often may not be elicited from self-report measures in pediatric patients with chronic illnesses [6]. It may be better to compare our group with other adolescent chronic illness populations rather than adult patients with ESRD. The low scores on the measure of hostility indicate that our patients did not demonstrate some of the rebellious and angry feelings frequently noted in adolescent patients with a chronic illness.

Probably the most interesting findings in this preliminary investigation were those involving psychological adjustment and coping. Measures of psychological difficulties (anxiety and depression) did not reveal differences between the dialysis groups or between the patients and available norms. However, our patients did receive scores on the California Test of Personality (a measure of psychological adjustment) substantially below the average. On the personal adjustment scale (a

measure of self-reliance, sense of personal worth, feeling of belonging, and withdrawing tendencies), only 3 of the 12 subjects reached the 50th percentile, with the entire group average at the 26.5 percentile for a normal adolescent population. Thus, a decrease in functioning in dialysis patients and patients with other childhood chronic illnesses may well be found when measures devised for assessing adjustment and life quality are employed rather than measures designed for detecting emotional difficulties. Even more substantial deficits were noted on the social adjustment scale (a measure of social skills, school relations, community relations, etc.), where none of the 12 patients received a score at the 50th percentile. Overall, the dialysis patients obtained scores averaging in the 18th percentile. Such social deficits in children with chronic illness may be more profitable areas for investigation and intervention than assessment of emotional problems [24].

Differences between the peritoneal and hemodialysis groups were noted on three coping styles of the A-Cope. Peritoneal dialysis patients employed the coping style of self-reliance to a greater degree than the hemodialysis patients. Whether this observation can be explained by the active part played by patients on home peritoneal dialysis treatment or whether it was a function of pre-existing personality characteristics cannot be answered here. Children and adolescents maintained on peritoneal dialysis were more likely to rely on close personal friendships as a coping mechanism when compared with children maintained on hemodialysis. Hemodialysis patients generally require a full 4 h of treatment 3 times per week, and these treatments occur during "prime time" waking hours. Thus, one may infer that these children did not have the same time to establish close personal friendships as patients maintained on home peritoneal dialysis. In addition, peritoneal dialysis patients engaged in more "low-level" activities (attending movies, watching television, reading, playing video games) than hemodialysis patients. Once again, this could be related to a greater amount of available time to participate in such activities.

Taken as a whole, our chronic dialysis patients appeared to use different coping strategies than the healthy adolescents given the A-Cope who served as controls. The dialysis patients tended to forge more emotional bonds both within and outside the family unit (e.g., dialysis staff, spiritual leaders) than the controls. What was somewhat surprising was the use of high-level activity in our patients. Either denial was present here or these

patients attempted to overcompensate for their limited physical abilities. The use of humor as a coping process was clearly a positive factor in dealing with chronic renal failure.

This study is a preliminary examination into the psychosocial function of a special group of patients. Further studies are needed, perhaps including structured interview techniques and larger numbers of patients, in order to draw more concrete conclusions.

*Acknowledgements.* This project was supported in part by a research grant from Abbott Laboratories. The authors wish to acknowledge Mrs. Charlene McGloin for her secretarial skills and editorial advice, as well as Dr. Lewis Reisman and Mrs. Alice Toscano Turner for their assistance.

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Received July 17, 1987; received after revision November 30, 1987; accepted March 17, 1988