

**PSYCHOSOCIAL ADJUSTMENT OF ADOLESCENTS WITH END-STAGE RENAL
DISEASE**

by

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ABSTRACT

The psychosocial adjustment of nine adolescents with end-stage renal disease (ESRD) was described by two standard psychologic tests; Piers-Harris Self-Concept Scale and Nowicki-Strickland Locus of Control. Life Events were recorded to evaluate the effect of stress at the time of testing. The mean self-concept scores were higher ($p = .009$) for the ESRD adolescents than the normative sample. However, the individual's scores did not differ significantly. The Life Events were comparable to the healthy population for age. The family members were assessed on the Family Assessment Measure (FAM) to assess the influence of family functioning on adolescent psychosocial adjustment. The standardized FAM scores were comparable to a normative sample. Cluster analysis of the ESRD adolescents revealed three groups differing significantly on: self-concept, locus of control, FAM self-rating and number of years from diagnosis to dialysis. Significant differences were maintained across the family members on FAM General Scale and FAM Self-Rating Scale. The adequate psychosocial adjustment of the adolescents with ESRD is consistent with recent studies suggesting that chronically ill children and adolescents do not differ from healthy children. However, the results also suggest that within the study group, a number of individuals may be experiencing problems of adjustment.

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TO THE FAMILIES

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RICHARD, CYNTHIA and JACQUELINE

DEDICATION

To my parents.

NELLY and JOHN OLSEN

To my daughter and my son.

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I. INTRODUCTION

Chronic disorders in childhood are a major challenge to health care providers, as children with chronic physical disorders comprise between five and ten per cent of the population under the age of 16 years (1). For some time there has been concern regarding the psychosocial consequences of chronic diseases which limit normal functioning in children's lives (2-4).

Pless and Roghmann (2) reviewed three epidemiological surveys to identify the psychosocial consequences of chronic illness, and concluded that a high proportion of psychological and social disturbances associated with chronic illness could be attributed to the physical disorder. It was estimated that thirty percent of children with chronic disorders may be expected to exhibit social and psychological maladjustment at some time in their life. They also suggested that increased functional limitation was associated with greater psychosocial maladjustment.

Adjustment to chronic illness has been studied from a variety of perspectives: the most dominant of these is the "personality focused paradigm" (3). Variables which have most commonly been foci of studies are: self-concept, internal-external locus of control, family functioning, life events related to stress and severity of disease. Effects of technology have added another dimension to the study of adjustment in children and adolescents with chronic disorders.

There were a number of methodological differences which limited cross study comparisons. The areas of most difficulty were: sample selection, choice of control groups and

consistency in the choice of instruments.

A. SELF-CONCEPT

Piers and Harris (5) described Rogers' "self-theory" which proposed that adjustment, is in part, a function of the self-concept and self-acceptance. Coopersmith (6) contended that children who ultimately display overt signs of disturbance begin the process by changes in self-concept. In congruence with these hypotheses, Pless and Roghmann (2) advocated assessment of self-concept in chronically ill children, as a measurement of psychosocial adjustment.

A number of studies have included measures of self-concept or self-esteem. McAnarney et al. (7) compared the incidence of psychosocial problems in a group of children with arthritis ($n = 42$) *vs* a group of healthy children ($n = 42$). The investigator included ratings of parents and teachers who completed behavioural checklists. Psychological evaluation of the child included a screening test for intelligence, a measure of self-esteem, two projective tests, an anxiety scale, and two standard general personality measures. Group differences on self-esteem, general personality, and the projective tests, were not significant. However, the overall school adjustment (from teacher-rated behaviours, personality description, and academic performance) revealed that one third of the children with arthropathies scored low as compared to just nine per cent of the control children. Although these findings suggest an increased incidence of adjustment problems among children with arthropathies, the differences were not statistically significant.

A group of black children with sickle cell anemia were compared with a control group of healthy black children on scales measuring self-concept, anxiety, social and personal

adjustment (8). The mean anxiety scores differed significantly between groups, with the normal children demonstrating more anxiety than children with sickle cell anemia. The higher mean self-concept score for the normal children was also significantly different. However, the personality scores did not differ over all, though one sub-scale score "social skills" was statistically significant, with the normal children demonstrating a higher mean score.

Kellerman et al. (9) studied a large group of chronically ill adolescents with various diseases and compared them with healthy adolescents. They chose tests of trait anxiety, self-esteem, and health locus of control. The significant difference between the healthy and ill adolescents on the measure of health locus of control was specific to only some of the illness groups: oncology, cardiac, and renal. The overall comparisons of chronically ill versus healthy adolescents were not significant.

In a study by Smith et al. (10), self-concept, life event scores, and clinical status were examined for the purpose of evaluating the psychosocial function of adolescents with cystic fibrosis. There were no significant differences between the normative scores and the study group on the number of life events reported within the previous year. The self-concept scores suggested "good" adjustment and did not covary with a rating of clinical status. Cowan et al. (11) observed a similar result in a study that included assessment of family adjustment to cystic fibrosis. The locus of control mean score suggested that adolescents with cystic fibrosis, as a group, appear to perceive themselves as being less capable of exerting control over environmental events. The locus of control scores were significantly correlated with perceived social support, total self-esteem, self-acceptance, and defensiveness.

B. LOCUS OF CONTROL

The concept of internal and external control is derived from social learning theory. Rotter (12) explains that "when a reinforcement is perceived by the subject to follow some action of his own but not entirely contingent upon this action the reinforcement is perceived as the result of luck, chance, fate, or as being under the control of others" When the event is interpreted in this manner this belief is labelled *external control*. When the event is perceived to be contingent upon the subject's own behaviour or his relatively permanent characteristics, the behaviour is termed *internal control*.

Nowicki and Roundtree (13) assessed a number of variables; school achievement, popularity, involvement in extracurricular activities, family ordinal position, and I.Q., to determine if they were related to locus of control, in three normal secondary school-age populations. The results on the extracurricular activity measure and locus of control were significantly different for males and females. The female subjects were more involved in extracurricular activities than their male counterparts. Of interest is the trend in family ordinal position; the farther a male adolescent's position is from firstborn, the more likely is he to be an "externalizer", and in the female case the more likely she is to be an "internalizer".

Maturity and competence have been postulated to be associated with internal locus of control (14). This concept, linked with that of delay of gratification, led Strickland (15) to examine the hypothesis in a study of third, fourth, and fifth grade students. He concluded that children who have come to believe that the events that happen to them are a result of their own behaviour ("internals") choose rewards that are more valuable over time than do those ("eternals"), who believe events that happen to them are beyond their personal

control and understanding.

Strickland (16) reviewed the research on internal and external locus of control, in relation to health attitudes and behaviour. Included in the review were such topics as psychological disturbances, reactions to physical disorders, and psychological responding. The reviewer concluded that any impending or disabling disorder has a varying degree of influence on the responses of the persons faced with the handicap. The severity of the disorder, the age at time of onset, the current status of the patient, the support that the person receives, may all interact to form a complex response.

C. FAMILY FUNCTIONING

The psychosocial adjustment of the child with a chronic disorder may reflect the interactive behaviour of the family support system. Pless and Roghmann (2) stressed the importance of attempting to identify those children with the highest risk of social and psychological maladjustment by measuring family functioning. In a study of children with cystic fibrosis (17), mothers and fathers were asked to rate the family "as it is now", with how they thought their family would be if they did not have an affected child. Assessments of family satisfaction and family adjustment differed significantly when the comparisons were made between the real and hypothetical situation. Parents perceived a higher degree of family satisfaction and adjustment in the hypothetical situation. Vance et al. (18) studied families with children suffering from nephrosis and found the families similar to their matched control families with healthy children. However, the siblings of the children with nephrosis differed significantly in their academic achievement and measures of health. The siblings rated lower on school achievement and health than siblings of healthy controls. The results generally suggested that illness placed less stress

on families than had been assumed.

In a more recent study, Cowan et al. (11) incorporated a number of measures to assess the psychosocial adjustment of the family unit and its individual members over several illness groups, and found that siblings of chronically ill children do seem more likely to experience adjustment or behavioural problems than the siblings of healthy children.

Measures of family functioning, parental self-esteem, and the children's self-esteem, were used to assess the degree of maladjustment in families which included a diabetic child (19). The results of the psychosocial adjustment scale divided the diabetic children into two groups; well-adjusted and maladjusted. Parental self-esteem, family functioning, and the child's self-esteem were significantly higher in the well-adjusted group as compared with the maladjusted group. The results supported the premise that high parental self-esteem may be regarded as the key to family functioning, psychosocial adjustment, and the child's self-esteem. While able to demonstrate significant differences on measures of malaise, depression, and anxiety, between parents of children with renal failure and parents of normal children, Fielding et al. (20) found no suggestion that the children were adversely affected.

D. LIFE EVENTS

Observations of life events, specifically events considered to create stress in one's life, have been the topic of study for many years. Rabkin and Struening (21) reviewed the many approaches to the topic and outlined the specific problems with the existing data. Although a significant correlation had been established between "stressful" life events and illness, there were a number of difficulties related to interpretation. In order to measure

the effect of stress, Holmes and Rahe (22) included desirable and undesirable events, recognizing that both require an adaptive response. Events were assigned a value which was considered to reflect the degree of change required to adapt to the event. This value was referred to as "social readjustment".

Coddington (23-24) studied a normal population of children for the purpose of calculating the amount of social readjustment required of them in their daily lives. They concluded that major social readjustment might be etiologically significant in the case of physical illness. Their conclusion was based on the rationale that resistance to disease depends on the individual's ability to make appropriate adjustments to events.

In an effort to elucidate the impact of stressful events in the lives of adolescents with cystic fibrosis, Smith et al. (10) added another dimension to a Life Events Checklist. Adolescents assigned a positive or negative value to the event. When the number of life events of adolescents with cystic fibrosis were compared with a normative sample, no significant difference was found. However, when the event was considered in relation to clinical profile, the adolescent with the severe disease, and a poor prognosis, experienced significantly more negative events.

Because the life experiences of children suffering from a chronic disorder are as varied and heterogenous as for a normal population of children, it is difficult to measure the effect of stressful events on physical health and psychosocial adjustment.

E. SEVERITY OF DISEASE AND MORBIDITY

A number of investigators have questioned the suggestion that the more severe disease results in greater risk of psychosocial problems. Several studies did not demonstrate severity as a contributing factor to maladjustment and it was suggested that children with marginal or no overt disability, may be at greater risk of psychological maladjustment (7,25). Tavormina et al. (26) concurred that chronically ill children were "more normal than deviant". However Beck et al. (27) cited significant correlations between visibility of handicap, self-esteem, control over destiny, identity stability, and social maturity, as predictive of poor psychosocial adjustment but cautioned that visibility of handicap is only one of several variables which may affect psychosocial functioning. Stein and Jessop (28) studied the relationship between traditional morbidity measures and psychological adjustment of children with chronic illness and found a significant relationship between poor functional status and poor psychological adjustment. They concluded that the data could not support the suggestion that children with mild handicapping conditions have more frequent or serious adjustment problems than those with more serious limitations. However, the investigators were unable to elucidate the important issue of cause and effect between psychological adjustment and health status.

F. EFFECTS OF TECHNOLOGY

Advances in technology have contributed to changes in the care of children with certain chronic disorders, e.g. children suffering from end-stage renal disease who require hemodialysis or peritoneal dialysis to sustain their life. Reichwald-Klugger et al. (29) in a German study, compared children on hemodialysis, treated in the home and treated in hospital. The descriptive study explored a number of variables including physical capabilities, social skills, family life, school activities, and hobbies. The authors concluded

that home dialysis usually provoked more fears of complications and aggressive feelings in the children, and stress in parents, but was superior to hospital treatment because social contacts and school activity could be maintained. De-Nour (30) compared an adolescent group on hemodialysis with an adult group on the same treatment, to study the reaction to dialysis. The study design involved clinical interviews before and after commencing dialysis. The responses differed between the adolescents and the adults, largely in areas difficult for developing adolescents, e.g. peer group relationships, and sexuality.

Korsch et al. (31) studied a group of children following renal transplantation. They found that following transplantation, the children displayed no greater psychological disturbance than the two control groups; physically well children and children suffering from another chronic illness. The investigators suggested that the period following the acute event, e.g. the period immediately following transplantation, may be the period of greatest disorganization. Beck et al. (27) studied the young adult survivors of end-stage renal disease on ratings of visibility of handicap, social maturity, and a self-report measure of self-image and found a positive correlation between the years since last transplant and self-esteem. When years, and age since last transplant were statistically controlled, the relationship between visibility of handicap and self-esteem was no longer significant.

G. METHODOLOGICAL ISSUES

Interest in the impact of chronic illness on psychosocial development has dominated the studies in this field. Generally, investigators have considered the chronically ill child and family as vulnerable to or at risk of psychosocial maladjustment, based on the assumption that chronic illness negatively affects psychosocial development and family relationships. The importance of continued research in this area of study is self evident. However, there

are a number of methodological issues which tend to limit the value of the investigations.

1. Internal validity

Generally, a clear statement of purpose was provided which indicated the nature of the study: evaluative, descriptive, etc. (10,18,20,27,28). Of the large number of studies concerned with evaluation of chronically ill children and their families, few have provided a conceptual framework upon which their research questions or hypotheses were based.

a. Design

In most instances the studies were of a descriptive or evaluative nature, and measures were taken on just one occasion with few exceptions. All the investigators acknowledged the need for longitudinal studies to better understand the changing patterns of adjustment to chronic illness.

b. Sample

The selection of a clinical population is an area of potential bias. This bias is apparent in a number of studies where subjects were chosen from clinic populations in large hospitals without reference to prevalence figures. In some instances the clinic population is described, but rarely has the sample been shown to represent the prevailing population in a geographic area. With one exception, Stein and Jessop (28) clearly described the clinic population and its representativeness of the general population. Others have described the entire clinic population by medical diagnosis. Many of the studies involved small numbers (8,10,17-20) and random sampling has rarely been employed; one exception was Stein and Jessop (28).

Studies generally involve heterogeneous groups of chronically ill children. A few investigators have considered homogeneous groups by disease diagnosis (8,10,17-20,25,31). Several investigators attempted to study chronically ill samples on variables other than disease diagnosis. For example, Stein and Jessop (28), and Beck et al. (27), assessed disability, handicap, and visibility of handicap.

c. Controls

Few studies provided a control group matched adequately with clinical subjects. Often "healthy controls" were chosen for convenience, e.g. classes of children from nearby schools. Several studies used well documented data from population studies and surveys as bases for comparison (17,18,31).

d. Instrumentation

In a number of studies, the instrumentation was well described but few provided reliability and validity information. Correlations between instruments are only infrequently reported. There has been consistency over different studies in the choice of instruments designed to measure certain constructs, such as self-concept, locus of control, and life stress. While there has been consistency in constructs under study, there was inconsistent use of specific instruments, e.g. Piers-Harris Self-Concept Scale *vs* Child's Self-Esteem Index, Family Assessment Measure *vs* Family Adaptability and Cohesiveness Evaluation Scales.

e. Analysis

A number of investigators proposed to study their sample by comparing their results with a "control group", data derived from "normal" populations (10,19,20,25,27). In some instances, a matched control group was also incorporated. Generally, correlation measures, analysis of variance, and t-tests have been the statistical methods of choice. In other instances (25,28) non-parametric analysis has been employed. In studies involving large samples regression analysis and analysis of covariance have been the analyses of choice. In only one instance (26) was the level of significance set in relation to the sample size and the number of significance tests.

2. External validity

In the majority of studies reviewed, generalizability of the results have been restricted by limitations of internal validity. Because many studies have employed small samples and descriptive study designs, the investigators have not attempted to generalize their results to populations of chronically ill children and adolescents. While appropriate in studies of small numbers, this limits the application of the results to larger populations.

To investigate the effects of chronic illness on psychosocial development is difficult for several reasons. Children and adolescents with a chronic disease constitute a small proportion of the population of children and adolescents and there is considerable variation within this population. Because of the problem of small numbers in groups identified by disease, heterogeneous diagnostic groups are studied. While this satisfies the problem of small numbers it does not reveal the problems related to specific conditions or address within group differences which may exist, e.g. functional differences, cognitive differences. Also, the underlying assumption of maladjustment has not been satisfied in previous

investigations. To the contrary, the more recent studies suggest that chronically ill children and adolescents do not present as maladjusted judged in comparison with healthy groups.

This study provides a rationale for comparing a homogeneous group of chronically ill adolescents with a normal population. Generally, previous investigations as well as this study, provided information obtained on one occasion. However, the conceptual framework, instrumentation and procedures for analysis provided in this study could readily be employed in a prospective study of homogeneous or heterogeneous groups. Also, the underlying assumption of normality provides the conceptual framework for study of chronic illness by variables other than disease diagnosis.

H. CONCEPTUAL FRAMEWORK

Studies conducted for the purpose of understanding the effect of chronic illness on the afflicted child and family, have generally assumed difficulty with psychosocial adjustment. More recently, McAnarney (32) described an integrated model of adjustment (1) in combination with a model of social maturation (33). The model defined social maturation within the normal patterns of adolescent development and considers the effect of chronic disease on physiological and psychosocial development. Within the context of this model, social maturation implies acceptance of the adolescent by his/her family, peers and society, supporting self-esteem. Also acknowledged is the adolescent's need for independence, developing intimate relationships and planning for the future. The process of "coping" is an intergral part of this model, although it is often poorly defined.

Shapiro (34) developed a similar model which describes the concept of coping in two

contexts; behaviours considered as responses to stressful events, and coping as a process, i.e. coping *vs* not coping. Burish and Bradley (35) defined the process of coping as; "... efforts, both action-oriented and intrapsychic to manage ... environmental and internal demands, and conflicts among them"

Within the context of this study, coping is considered the process of interacting with one's environment producing a measurable response. This response is considered "adjustment", described by Haas (36) as "the ability to get along with others," and to have "... skills necessary to fit ourselves in with others and respond as desired by those around us." Psychosocial adjustment is measured by a positive sense of self, and an emerging sense of control over one's environment. Family functioning is considered an important influence on adjustment.

I. THE PURPOSE OF THE STUDY

The purpose of this study was to describe a group of chronically ill adolescents and their families; to better understand the effect of chronic illness on psychosocial adjustment of developing adolescents, considering the family as an influencing factor in adjustment, and to identify adolescents at risk of developing psychosocial problems, to enable health professionals to plan and provide assistance to chronically ill adolescents and their families.

Pursuant with the purpose of this study the following questions were examined: 1. What is the extent of psychosocial problems in adolescents with ESRD, described by examining their; self-concept rating, perceived control over their environment and self-rating within the family? 2. What is the relationship between psychosocial adjustment of ESRD

adolescents and family functioning, described by family members ratings on three dimensions; general rating of the family, self-rating and rating of relationships between family members? 3. Are there subcategories of adolescents with ESRD vulnerable or at-risk of developing psychosocial problems?

To estimate the magnitude of effects of end-stage renal disease on the developing adolescents and their families, normative data was employed as a basis of comparison in the analysis. Socioeconomic factors were considered for degree of influence on family functioning.

II. METHODS

A. SUBJECTS

All nineteen children with end-stage renal disease (ESRD) attending the Renal Clinic, British Columbia's Children's Hospital, Vancouver, B.C., over a ten month period, were asked to participate in the study. The children were on hemodialysis or continuous peritoneal dialysis (CAPD). All children on CAPD in British Columbia are referred to the Renal Clinic for medical management. Information on the number of children on hemodialysis in the province was not available. Nineteen adolescents and their families were informed of the study objectives by the attending nephrologist. Six families declined and thirteen agreed to participate. Four of the consenting families were ineligible for the following reasons; one due to language problems, one child had a previous unsuccessful transplant and two children were transplanted after consent was obtained, but prior to being interviewed. The resulting sample of adolescents was nine: five males and four females. Informed consent was obtained from parents, in accordance with the requirements of the Research Advisory Committee, British Columbia's Children's Hospital and the Behavioural Sciences Screening Committee for Research Involving Human Subjects, University of British Columbia.

B. PROCEDURE AND SETTING

All family members, over the age of ten and living at home, were invited to participate, and none declined. The resulting sample included nine ESRD adolescents, eighteen parents, and twelve siblings. One parent provided demographic information for each family. Both parents completed a Life Events Scaling for Recency of Experience (37). All members of the family completed the Family Assessment Measure (FAM) including

General Scale, Self-Rating Scale and the Dyadic Relationship Scale (38). The ESRD adolescents completed the Piers-Harris Self-Concept Scale (39), Nowicki-Strickland Locus of Control (14) and the Life Events Record (24). The information was obtained in a single two hour session in the home. Instructions were provided by the investigator or research assistant.

C. INSTRUMENTS

1. Piers-Harris Self-Concept Scale

The Piers-Harris Self-Concept Scale, "The Way I Feel About Myself" (39) is an 80 item self-report instrument designed for children over a wide age range. The items are simple declarative statements, e.g. "I am an important member of my family", requiring a "yes" or "no" answer. Internal consistency for the scale ranges from 0.78 to 0.93 and test-retest reliability of 0.72. Norms were established based on 1183 public school children, ranging from Grade 4 to Grade 12 (mean 51.84, SD 13.87). The means and standard deviations are available by school grade: 4, 6, 8, 10 and 12.

2. Nowicki-Strickland Internal-External Locus of Control

The Nowicki-Strickland Internal-External Locus of Control Scale for Children (14) measures the relative internal-external attribution of control as rated by the children and adolescents. One total score is derived from the 40 yes/no questions. Higher scores represent more external control. Norms were derived from a sample of 1017, mostly caucasian elementary and high school students from four different communities. Means and standard deviations are available for males and females by grade level. Estimates of internal consistency by the split-half method were $r = 0.63$ (grades 3-5); $r = 0.68$ (grades

6-8); $r = 0.74$ (grades 9-11); and $r = 0.81$ (grade 12). Test-retest reliabilities sampled at three grade levels were $r = 0.63$ for grade 3, $r = 0.66$ for grade 7 and $r = 0.77$ for grade 10.

3. Family Assessment Measure

The Family Assessment Measure (FAM) (38,40) is a self-report instrument that provides quantitative indices of family strengths and weaknesses. FAM is composed of three scales, each with seven subscales: task accomplishment, role performance, communication, affective expression, involvement, control, values and norms. The General Scale (50 items) focuses on the family as a system and includes two additional scales: social desirability and defensiveness. The Dyadic Relationships Scale (42 items) examines relationships between specific pairs of individuals. The Self-Rating Scale (42 items) taps the individual's perception of his/her functioning in the family. Internal consistency estimates were based on a heterogeneous sample of 475 families ($n = 933$ adults, $n = 502$ children) tested at various health and social service settings in a large urban area. The reliability estimates are: General Scale 0.93 (subscale range - 0.65 to 0.87), Dyadic Relationships 0.95 (subscale range - 0.64 to 0.82), Self-Rating 0.89 (subscale range - 0.39 to 0.67) in adults. The reliability estimates for children are comparable to estimates provided for adults.

A multivariate comparison of problem and nonproblem families discriminated the groups on four functions ($p < .001$) with the two major discriminators being Role Performance and Involvement *vs* Social Desirability and Denial. Normative data are provided based on a sample of 247 adults and 65 normal adolescents (less than 18 years of age). Raw score transformations (T scores) are provided. Cowan et al. (11) reported Family Adaptability

and Cohesiveness Evaluation Scales (FACES II) to be correlated with total FAM scores for mothers and fathers ($r = 0.42$; $r = 0.47$, $p < .001$), establishing cross-measure validity.

4. Life Events Record

Life Events Record (23,24) adapted for children was based on the Social Readjustment Rating Scale (22), to estimate the psychological adjustment the average child undergoes in the course of a year. The weighted values for Life Events, 'Life Change Units', were determined for a sample of 3526 children attending preschool, elementary, junior and senior high school. Forms were designed for the four groups to reflect appropriate activities for age and grade. Correlation coefficients between groups based on age, social class, race and sex, revealed no differences between groups, except for age.

5. Life Events Scaling for Recency of Experience

Life Events Scaling for Recency of Experience (37) for use with adults, is comprised of 32 items, weighted for recency of event. The weights were assigned to each item to reflect the overall severity of the event as well as impact over time. The scores range from zero, for the person who has experienced none of the events, to several hundred points for the person who has recently experienced several events with high severity weightings.

6. Clinical measures/Demographic data

A clinical profile of the ESRD adolescents related to diagnosis, age at time of diagnosis, date commencing and duration of dialysis, school progress, number of hospitalizations and plans for transplantation, was compiled from the renal clinic records. On the basis of this information, two clinical measures were calculated and included in the analysis; *Time 1* -

time in decimal years from diagnosis to the commencement of dialysis, *Time 2* - time in decimal years spent on dialysis.

Demographic data was provided by one parent per family, on the level of parental education, ethnic group and employment.

D. DATA ANALYSIS

Hierarchical Grouping Analysis (41) was used to group ESRD adolescents. The cluster analysis performs a grouping which reflects "natural" similarities among cases; that is, groups are formed such that cases are similar in their profiles of scores over several variables. The (N) sets of scores are compared over a series of (K) keys combining cases so as to minimize an overall estimate of variation within groups. Interpretation of results is based on the examination of two indices produced at successive stages of clustering: an *error index* giving the estimate of variation which indicates the relative error increase associated with decreasing the number of groups by one, and the *selection index* which aids in determining the most reliable number of groups. These indices were evaluated and formed the basis for judging the the most suitable classification of cases.

The scales chosen as keys for grouping were: the Piers-Harris Self-Concept Scale, Nowicki-Strickland Locus of Control Scale, FAM-Self Rating, Life Change Units and two variables constructed to reflect ESRD status: Time 1 - length of time from diagnosis to the commencement of dialysis, Time 2 - duration of time on dialysis. These two variables were considered as possible influences on adjustment. Pearson's correlation coefficient was used to analyze associations between variables prior to cluster analysis.

Following cluster analysis, one-way analysis of variance was performed to analyze the difference between group means. A *post hoc* analysis of the significantly different group means was calculated using the Scheffé method.

For the scales which had been normed on general populations, additional analysis had to be conducted. Weighted means and pooled variances over the means and standard deviations of the normal populations comparable to the study, were calculated (42).

In order to meaningful describe *individuals'* scores on the major scales, each person's raw score was transformed to a Z score by subtracting the norming sample mean from the individual's raw score, then dividing the resulting deviation score by the normative sample standard deviation.

III. RESULTS

Thirteen of nineteen families attending the renal clinic, consented to participate. Of the thirteen families, four were ineligible for reasons described earlier. The remaining nine families constituted 42% of the total available clinic population and 69% of the consenting sample. All family members, living at home at the time of the interview, completed the questionnaires, with two exceptions: two siblings under the age of ten and one adolescent with ESRD who did not complete the dyadic relationship scales. The sample was comprised of: 9 adolescents with end-stage renal disease (ESRD)[†], 9 fathers (mean age = 50.3 years), 9 mothers (mean age = 46.5 years), 9 older siblings (mean age = 19.7 years), 3 younger siblings (mean age = 13.7 years).

A. CLINICAL CHARACTERISTICS

Clinical characteristics of the 9 adolescents are given in Table 1, presented on the following page. The data for this clinical profile were extracted from the renal clinic records.

B. PIERS-HARRIS SELF-CONCEPT

The mean score on Piers-Harris Self-Concept Scale (63.44 ± 11.25) was compared with normative data (52.96 ± 13.24) for a comparable sample by age.[‡] The Z score ($Z = 2.37$) was significant ($p = .009$), suggesting that adolescents as a group, rated themselves higher on self-esteem than the average in a normal population. When individual's scores were transformed (Z scores; 0 ± 1), significant differences ($p = <.05$) were not attained.

[†] One adolescent was in permanent foster care of an intact family.

[‡] The weighted mean and pooled variance was calculated over the means and standard deviations of a normal population, comparable to the study sample (42).

Table 1. Clinical Characteristics of Adolescents with End-Stage Renal Disease

Characteristic	Classification
Age (mean \pm SD)	16.5 \pm 2.21
Sex	5 male, 4 female
Age at diagnosis (mean \pm SD)	7.9 \pm 5.35
Age dialysis started (mean \pm SD)	14.1 \pm 3.93
Duration of time on dialysis (mean years \pm SD)	2.4 \pm 2.27
Type of dialysis	
CAPD†	4
Hemodialysis	5
Condition	
Acquired	5
Congenital/Familial	4
Prepared for transplant	6 yes 3 no
Hospitalized in prior year	5 yes 4 no
School progress	
At expected grade for age	4
1-2years behind	5

† Continuous Ambulatory Peritoneal Dialysis.

C. NOWICKI-STRICKLAND LOCUS OF CONTROL

The mean score on Nowicki-Strickland Locus of Control (11.44 ± 4.19) was compared on standard scores by age and sex, with normative data (13.07 ± 4.85); the difference was not significant.

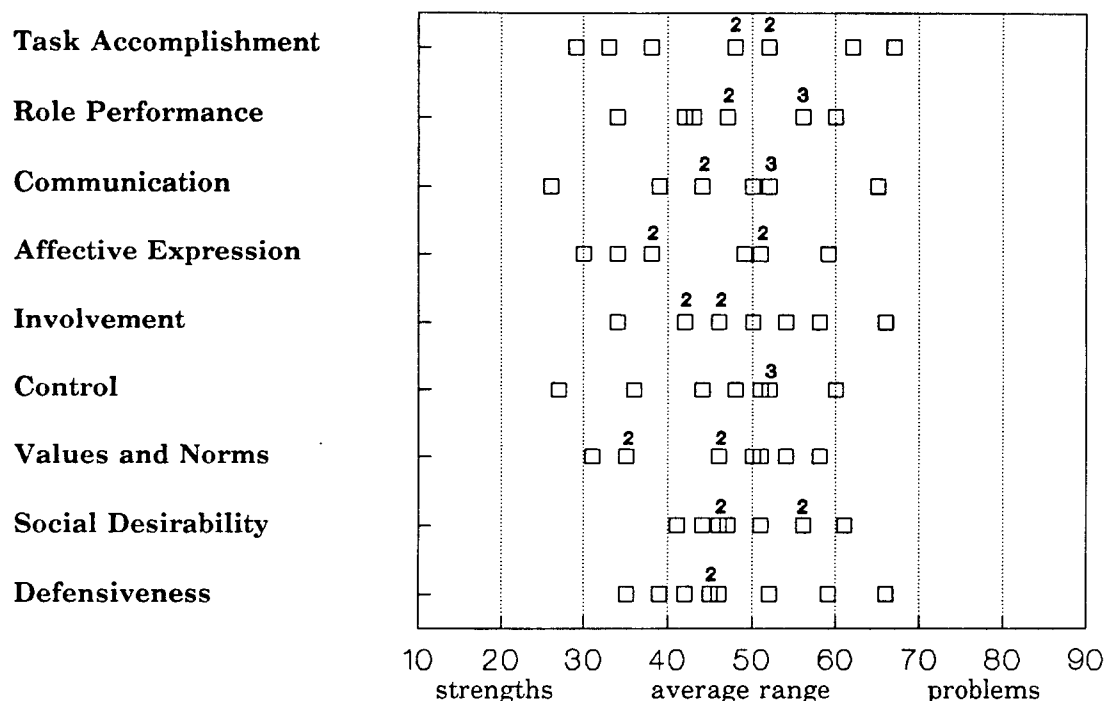
D. LIFE CHANGE EVENTS

Life Change Units (182.11 ± 84.65) were also compared on standard scores, with a normal sample (182.77 ± 123.52) by age. There was no significant difference between adolescents with ESRD, and a healthy normal population.

E. FAMILY ASSESSMENT MEASURE

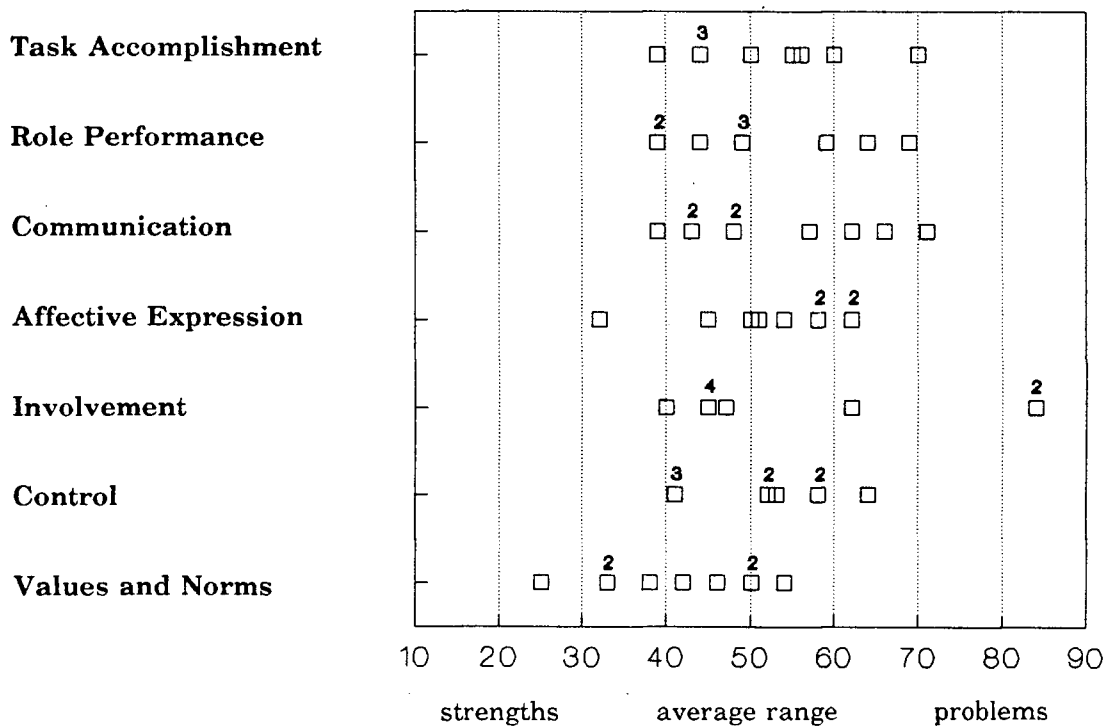
The mean T scores for FAM General Scale and Self-Rating Scale for all family members, were within normal range (50 ± 10). However, individual subscale scores exceeded the normal range in a number of instances.

The variability among ESRD adolescents in FAM General Scale scores, is shown in Figure 1. Five scores were above the average range, suggesting problems within the family system.

Figure 1. FAM General Scale Variability Among Adolescents with ESRD

2;3 — number of cases with the same score.

Figure 2 shows the variability among adolescents with ESRD on their performance within the family system. Ten scores were above the average range, which suggests that these individuals viewed themselves as performing poorly within the family. The most common areas presenting potential problems were: task accomplishment, role performance, communication, and involvement.

Figure 2. FAM Self-Rating Scale Variability Among Adolescents with ESRD

2;3;4 — number of cases with the same score.

Pearson correlations revealed associations between means of family members on General Scale-subscale scores shown in Table 2. Other family members did not differ significantly on these or other subscales.

Table 2. Correlation Coefficients Between Family
Members on FAM General Scale-Subscale Scores

Subscale/Family members compared	r	p
Task Accomplishment		
ESRD adolescents & mothers	0.865	.001
Role Performance		
Fathers & mothers	0.661	.023
Communication		
ESRD adolescents & fathers	0.768	.008
Affective Expression		
ESRD adolescents & mothers	0.635	.033
ESRD adolescents & fathers	0.673	.023
Mothers & fathers	0.798	.005
Involvement		
Fathers & mothers	0.710	.016
Values and Norms		
ESRD adolescents & mothers	0.807	.004
Social desirability		
ESRD adolescents & fathers	0.675	.023

F. CLUSTER ANALYSIS

Using the six grouping variables as criteria, the nine adolescents clustered into three groups. To investigate and characterize differences between groups, one-way analyses of variance were conducted (Table 3). The cluster means of the significantly different variables, provided distinguishing characteristics which formed the basis for describing three levels of psychosocial adjustment among the nine subjects. The three levels ranged from high-average to low-average: on self-concept, locus of control, FAM self-rating scores, and the length of time calculated from diagnosis to dialysis. The three clusters were defined by their level of psychosocial adjustment as follows: H = high average (n = 2) presenting higher self-concept, more internal control, healthier level of functioning within the family, and a longer period from diagnosis to dialysis, L = low-average (n = 2) presenting with lower self-concept, less internal control, higher self-rating within the family in the direction of problems, and a shorter period from diagnosis to dialysis and M = mid-average (n = 5).

Table 3. Analysis of Variance of Differences
Among the Three Clusters on Six Grouping Variables

Variable	F(df)	Scheffé†	Cluster means		
			M	H	L
Piers-Harris Self-Concept	6.349(2,6)*	H > L	65.8	73.0	48.0
Locus of Control	12.874(2,6)**	L > M,H	10.0	8.5	18.0
Life Change Units	0.948(2,6)NS				
FAM Self-Rating	49.560(2,6)**	L > M,H	51.2	39.3	59.6
		M > H			
Time 1 ‡	8.228(2,6)*	H > M,L	4.8	13.6	2.1
Time 2 ††	1.973(2,6)NS				

† Scheffé Procedure denotes pairs of groups significantly different at <.05 level.

‡ Time from diagnosis to dialysis.

†† Time on dialysis.

* p <.05.

** p <.01.

Additional analyses was conducted on FAM scores of all family members. The cluster membership of family members was determined by the previous cluster analysis of the ESRD adolescents, i.e., all family members related to the ESRD adolescents falling into the mid-average (M) adjusted group, are assigned to group M. Of the analyses conducted on the data obtained from the individual family members, on FAM general, self-rating and dyadic scales, only the variables presented in Table 4 reached significance ($p = <.05$). These analyses included analysis of variance of FAM general, and of self-rating subscale scores. Analyses of the dyadic scales included all the individual family members rating all the other members of family, e.g. mother rating all.

Table 4. Significant Results of Analysis of Variance of Family Members
by Clusters on FAM Scales

Variable	F(df)	Scheffé†	Cluster means		
			M	H	L
FAM General Scale					
Overall rating	4.080(2,36)*	L > H	49.2	46.5	56.7
Subscale-defensiveness	4.675(2,36)*	H > M	40.9	50.2	47.5
FAM Self-Rating Scale					
Overall rating	3.966(2,36)*	L > H	51.3	46.6	56.0
Dyadic Relationships					
ESRD adolescents rating All	6.657(2,24)**	M,L > H	50.9	40.1	52.7
All rating ESRD adolescents	5.611(2,27)**	M,L > H	53.6	45.1	57.7

† Scheffé Procedure denotes pairs of groups significantly different at <.05 level.

* p <.05.

** p <.01.

G. SOCIOECONOMIC, SELF-RATING AND STRESS SCORE COMPARISONS

Parental factors such as; life-events stress of the parents, FAM self-rating scores, level of education, and socioeconomic level, were investigated using Pearson correlation coefficient. The correlation between mothers' and fathers' stress scores was 0.764 ($p = .008$). Fathers' level of education negatively correlated with fathers' stress scores -0.733 ($p = .012$). The socioeconomic level (43) was not associated significantly with the parents scores. However, the socioeconomic level was unavailable for 2 families.

H. INTERTEST ASSOCIATIONS

Table 5 shows the correlation between the Self Concept, Locus of Control with FAM Self-Rating mean score and subscale scores. The association between the overall FAM Self-Rating score with the Piers-Harris scores and the Nowicki-Strickland scores was $r = -0.72$ ($p = .014$) and $r = 0.68$ ($p = .022$), respectively, with healthy self-rating associated with high levels of self-esteem and more internal control. The correlation between FAM Self-Rating subscale; Role Performance and Piers-Harris was $r = -0.76$ ($p = .009$) with low self-esteem associated with problems of role performance. The same comparison can be drawn for the correlation between FAM Self-Rating subscale; Involvement and Self-Concept; the lower one's self-esteem score the higher the involvement score, in the direction of problems.

Table 5. Correlation Coefficients Between Self-Concept, Locus of Control, Life Change Units, and FAM Self-Rating Scores

Measure	Self-Concept	Locus of Control†	LCU
FAM Self-Rating subscales			
Task Accomplishment	-0.189	0.460	0.137
Role Performance	-0.756**	0.677*	0.209
Communication	-0.435	0.543	0.136
Affective Expression	-0.298	0.073	0.553
Involvement	-0.745*	0.615*	0.208
Control	-0.828**	0.591*	0.332
Values and Norms	-0.260	0.333	0.566
Overall rating	-0.721*	0.678*	0.354

† Higher scores denote externality on the Locus of Control scale.

* $p < .05$.

** $p < .01$.

The correlation between Piers-Harris Self-Concept scores and Nowicki-Stickland Locus of Control scores ($r = -0.78$, $p = .007$) associated high self-esteem with more internal control.

IV. DISCUSSION

Social maturation of the healthy adolescent is described by Mc Anarney (32) as one of: experiencing good feelings about self, acceptance by family, peers, and society, developing independence and planning for the future. Adolescence is a period of physical and psychosocial development which may be influenced by a variety of factors. Chronic illness has been assumed to be one of these factors, interrupting or interfering with normal growth and development. The study of social maturity in adolescents' afflicted with a chronic illness, has focused on psychosocial adjustment by studying personality traits (3).

A paradigm for analysis of psychosocial adjustment to chronic illness in the adolescent period, assumes a positive sense of self and control over one's environment. This in turn is considered as the influence of the family system providing acceptance and support. The family system may be influenced by external factors, e.g. economic factors, parental education. Within this paradigm, this sample of adolescents with end-stage renal disease appear to have made an adequate psychosocial adjustment to their illness. This result is consistent with more recent studies which suggest that the presence of chronic illness does not produce psychosocial maladjustment (9-11,17,26,27).

A. SELF-CONCEPT

The mean self-concept scale scores for the adolescents demonstrate higher self-esteem than the normal population, but individual scores are comparable to the norms for age. In an appropriate manner, the adolescents may view themselves as different, as suggested by the six of nine positive responses to the statement, "I am different from other people".

B. LOCUS OF CONTROL AND LIFE EVENTS

The adolescents with ESRD perceive themselves as more internal, capable of exerting control over their environment. Nowicki and Strickland (14) postulated internal control to be an indication of maturity and competence. Despite the adolescents' total dependence on an external source, (e.g. dialysis) for survival, they exhibit well developed internal control. The relationship between self-concept and locus of control scores, further supports this concept of maturity, as the "self" is enhanced by the degree of perceived control over the events that prevail in daily life. Life stress, as indicated by the life change units was similar to normal, healthy adolescents.

C. FAMILY FUNCTIONING

The family members shared similar opinions about the family, comparable to average families. There were individual differences that suggest certain families may be at risk of family dysfunction. The self-reports also confirm the members view of themselves, as contributors to the family process. If considered individually, several scores were in the low problem range, which may indicate the need for intervention. The interesting associations between fathers, mothers and ESRD adolescents, in areas of communication, affective expression, task accomplishment, suggests a common perception of family which may be interpreted as strength, contributing to psychosocial development. As adolescence is often a period of ambivalence, seeking more independence (35), this congruence among parents and ESRD children may suggest a higher level of maturity for age due to the challenge of illness. However, the converse may be true, that the illness creates a situation which encourages dependency and delayed social maturation. The fact that other members of the family do not share these perceptions to the same degree, may indicate problems.

The overall results supporting adjustment of the adolescent with end-stage renal disease, does not negate the element of risk to certain families and individuals. Cluster analysis divided the ESRD adolescents into three groups, differing on self-esteem, locus of control, FAM self-rating and the number of years elapsed from diagnosis to dialysis. The three groups ranged from high-average to low-average psychosocial adjustment with the former presenting higher self-esteem, more internal control, and healthier level of functioning within the family. The period from diagnosis to commencing dialysis was also longer for high-average adjusted group. It is conceivable that the longer time from diagnosis to dialysis afforded the family the opportunity to develop strengths and skills to cope with with the event of dialysis. However, Fielding et al. (20) did not find differences between children with renal failure (progressing towards dialysis) and their families, compared with children in end-stage renal failure (on dialysis) and their families. It is also possible that a shorter period between acute events, or nearer the acute event, may contribute to greater disorganization (33).

Further analyses of all family members, identified by group according to ESRD adolescent membership, continued to support the differences between levels of psychosocial adjustment. The family members perceived the family system and their functioning within the family, in the direction of problems or strength. This consistency between the most extreme groups, strongly supports family functioning as contributing to adjustment in the adolescent with end-stage renal disease. Lewis et al, (44) also concluded that family functioning is an important mediating variable to consider in psychosocial adjustment, and suggested that family functioning may be more important than the illness itself.

The group differences were also evident in two of the many combinations of family relationships: the ESRD adolescent's relationship with other members of the family, and the relationships of the family members with the ESRD adolescent. The fact that this difference is sustained over the families, could be an indication of a family response to the individual with a chronic illness. Of particular importance in this study, is the participation of both parents. Although the response singles out the individual, a supportive family environment would provide an atmosphere of support and acceptance. A similar comparison can be drawn for a weak family system, the family environment is unable to respond to the extra needs of the individual with a chronic illness and is overtaxed, contributing to problems. Therefore, when family resources are limited the adolescent may indeed be at-risk.

Interestingly, there were no group differences among other members of the family, e.g. mother rating her relationship with other members of the family, etc. These results suggest an interaction between family members and the adolescent, which differs in some respect to the interaction between other members of the family. Again, this suggests that chronic illness in the family does affect the family system in some manner, which may be a reflection of both internal and external resources of the family. The results support the integrated model of adjustment (1) and the paradigm of adjustment, which assumes a healthy self-concept influenced by a supportive family system and the "self" as more self-governing.

D. LIMITATIONS OF THE STUDY

While the results of this study are provoking, the problems accompanying this area of study must be borne in mind. The entire population of chronically ill children and adolescents is a small proportion of the total population of children and adolescents. Because small samples are inherently a problem, studies are often conducted on heterogeneous illness groups. This study, which investigates the psychosocial adjustment of a homogeneous group of adolescents, is limited by its small sample size. Given that the consenting sample is less than 50% of the available sample, the question of selection bias cannot be ignored. However, almost all the available adolescents participated in the study. Although this sample did not constitute the total population of ESRD adolescents within the province, results can be generalized to adolescents within this clinic population.

While the variables chosen to measure psychosocial adjustment are consistent with previous studies, the issue of their appropriateness has not addressed. It is assumed that the measures chosen will reveal differences between chronically ill and healthy adolescents. Recent studies are questioning this lack of difference, and for this reason, sensitivity of the measures should be considered in future studies. A further limitation of this study is the single assessment which does not reveal the changing nature of the chronic illness, adolescent development or the required readjustment. While life change units were calculated, they do not indicate the state of health or disease control, at the time of the assessment. Further information related to overall functioning, such as academic success, peer, and social involvement would enhance the psychosocial profile.

Parental and sibling self-concept, may have provided more conclusive evidence for the family as a mediating variable. It would be illuminating to study family functioning across other illness categories as well as in non-illness situations, e.g. behaviour problems, dependency related problems, etc.

E. CONSIDERATIONS FOR FURTHER STUDY

The principal purpose in the care of chronically ill children and adolescents is to improve their quality of life. To this end, investigations which consider the process of normal development in the context of the problems of chronic illness, are required. While it is necessary to continue descriptive, quantitative studies, strategies to increase the sample size, such as multi-center studies, need to be utilized.

Qualitative studies, designed to allow for naturalistic inquiry, would benefit clinicians and the chronically ill alike. In particular, replicated case study designs are well suited to clinical practice. This is particularly so in the care of children and adolescents followed in a clinic situation. Repeated measures of clinical data related to the management of the disease, are already monitored by the the clinician. It is one progressive step further, to incorporate measures which provide the clinician with evaluative information regarding the effects of illness on physical and psychosocial development.

The study of family resources and how they affect the adjustment of the family in times of crisis, may contribute valuable information to planners of programs caring for individuals with chronic illness.

There is a need to evaluate the contribution of clinic programs in the process of psychosocial adjustment. Generally, the specialized clinic team is viewed as an integral component in the effective management of chronic illness. However, this aspect of care requires ongoing evaluation and self-examination, to understand the effectiveness and efficacy of this approach.

These results support the premise that psychosocial adjustment in chronically ill adolescents, can be studied in the context of normal patterns of adolescent development. To understand the adolescents' needs in this context will assist them in retaining their rightful place in society. Therefore, to focus attention on the successful passage through adolescence to adulthood would reap benefits for the chronically ill, and subsequently, society.

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