Long-Term follow up on Kidney Transplant Patients and Their Families

B M KORSCH, J E GARDNER, R N FINE, V F NEGRETE
Children’s Hospital of Los Angeles, Los Angeles, USA

Some of the gross failures in the rehabilitation of children with end stage kidney disease are partly or wholly rooted in psychosocial malfunction. Traditional methods of paediatric and psychiatric assessment have not predicted which are the patients who are vulnerable and where preventive or therapeutic intervention is needed.

The justification for kidney transplantation in children has been questioned seriously because of the presumed deleterious psychosocial impact on child and family. This study was designed to provide information covering these issues.

PATIENTS AND GRAFTS

Over the past five years (February 1967 - February 1972), 81 transplants have been performed on 69 patients with end stage kidney disease at the Children’s Hospital of Los Angeles. Fifty-one of the 69 children are surviving with a functioning allograft.

Of the 51 patients with functioning allografts 35 were studied carefully for the psychosocial impact of illness and treatment on child and family.

These 35 patients were aged 6 to 16 years at the time of transplantation. The duration of kidney disease varied; only about 20% had an acute onset, all others had evidence of renal insufficiency from birth or for a number of years.

METHODS

A series of tests were used in the follow up study. The California Test of Personality was chosen because of the availability of norms at all the relevant age groups and because it has been tested on large populations; Sarason’s Anxiety Scale was chosen because it seemed as good as any anxiety scale; the Piers-Harris Self Esteem Scale was selected because self esteem seems to be one of the casualties in the course of treatment for end stage kidney disease, and because self esteem has been found to be a significant factor in motivation.
and rehabilitation of patients with all kinds of disabilities. The 'Draw a Person' test was a small attempt to tap non verbal responses.

Data management was completely computerised. A system was devised by which all test results and all information from interviews were keypunched on IBM cards. The data was then processed and stored on magnetic tape for subsequent computer analysis. The system allows for additions or deletions of cases and variables. Updating is maintained by special Fortran programs. This may be accomplished for the complete record, for selected variables on various records, or for an individual datum on a single record. Statistical analyses of the data to date have been limited to certain descriptive and comparative procedures but more sophisticated approaches can be handled with the present system.

PERSONALITY TEST RESULTS

California test of personality  The distribution of personal adjustment scores among the renal patients at the Children's Hospital is not significantly different from normal (Figure 1). The personal adjustment scores of renal patients of Los Angeles were compared to two matched control groups; one a group of 20 patients with cystic fibrosis (matched for sex, age etc) and the other a group of well children the Rochester epidemiologic study of chronic illness by Barry Pless. They were matched by sex, age, social, economic status, ethnicity etc. No significant difference was found between the three samples.

The distribution of social adjustment scores show a high proportion (79%)

Figure 1. Results of California test of Personality, total personal adjustment, in three groups of children: CHLA = renal patients at Children's Hospital of Los Angeles; ROCH = well children in Rochester, study marked height, age and sex; CF = cystic fibrosis, children matched for age and sex.
of patients below the 50th percentile (Figure 2). The probability for this distribution, i.e., for only 21% of the patients to be >50% is 0.01. However, the scores of the transplant recipients were not significantly different from those of the control groups.

The Pier-Harris Self Esteem scale results indicate that the Children's Hospital renal patients have suffered damage to their self esteem (Figure 3).

Having looked at these test results, it becomes of interest to speculate as to their significance and to correlate with clinical findings. There were 11 children who scored at the extreme lower end of the spectrum of all the tests (on the California Test of Personality and on the self esteem scale as well as
the Sarason Anxiety Scale). Three of these had been thought to be well adapted 
and adjusted by all the clinicians on the health team at the time of follow up. 
Two were universally recognised to be maladapted. The remainder were 
usually rated as partially rehabilitated with the physicians tending to rate 
them higher than the other health professionals.

We then looked at four of the most serious clinical problems encountered 
in caring for post-transplant patients to see how they were reflected in per-
sonality test results. We chose obesity, short stature, noncompliance with 
immunosuppressive medicine and psychiatric disturbance. Obesity and short 
stature were not significantly associated with personality disturbances. On 
the other hand, noncompliant patients and those with psychologic problems 
requiring more than the usual support, do include a high proportion of low 
scores on personality testing. It seems that the personality disturbances are 
not reactive to the illness in these children but are part of their pre-illness 
personality. Thus testing could conceivably contribute to predicting this kind 
of problem and suggesting where preventive or therapeutic intervention might 
best be applied.

Another feature of the personality test results is that they were admini-
stered to children more than a year after the most turbulent period of their 
treatment and illness. When the same set of tests were given to three child-
ren who were acutely post-transplant and who clinically seemed well adjusted 
previously, extremely low scores (totals of 10%, 20% and 30%) were obtained. 
This may suggest that personality test results in the renal follow up study 
were as positive as they were because the patients had had time to recover 
from the assault of illness and the treatment programme.

FAMILY INFORMATION

We will not dwell on the descriptive data about the renal families, although 
they are encouraging in that most of the families seemed to have returned to 
pre-illness equilibrium and all but four of the children were attending appro-
priate schools and participating in appropriate activities at home and with 
peer groups outside the home. Instead, we will present a few examples of 
the information obtained from the family interviews on the renal patients and 
two separate matched control groups from Rochester (one containing well 
children and one mild chronically ill children) and their families.

Comparing the data from parent interview in the three groups, the simi-
larities were more striking than the differences. All in all, the families in 
all three groups thought of themselves as cohesive, close to one another with 
channels of communication and interaction open and with probably more co-
hesiveness than most other families. This was true for the renal patients in 
almost the same degree as the two groups from Rochester in that the former 
felt that they spent more time together than the average family, that the child-

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ren could communicate with parents and with one another better than most, that decision making tended to be a family activity rather than unilateral etc. There were very few families who perceived and reported any divisive effects of the illness experienced.

Some effects of the child’s illness on the family were reported on interview. Among others there were: fatigue, decreased social relations for the parents and sibling problems. The persistent problems in the renal families do not differ significantly in frequency from those in the Rochester group with mild chronic illness. However, during the most acute phases of the treatment programme obviously there was more family disorganisation and stress reported in renal than in the control groups.

SUMMARY

The results of this computerised follow up study of 35 children who have undergone renal transplantation, and their families, from the point of view of their psychosocial adaptation shows that although the time period of treatment for end stage renal disease, haemodialysis and kidney transplant causes severe disorganisation of family routines, relationships, education and recreational patterns etc, family equilibrium is usually restored to normal within a year or so after successful transplantation. Likewise, the child’s personality pattern, although probably severely stressed during acute portions of the treatment programme seems to return to pre-illness balance in most instances if the transplant functions and the child’s physical health improves.

The results also show that it is possible to prepare psychosocial data for computer processing as part of the regular protocol for patient study and in such a fashion that comparison and collaboration studies are possible.

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