Psychologic and Social Adjustment to Extended Haemodialysis and Renal Homotransplantation in 42 Children

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The experience of suffering from end stage kidney disease, undergoing extended haemodialysis in preparation for homotransplantation and finally the transplant itself with all its sequelae have such drastic implications for the paediatric patient and his family that there has been some doubt as to whether this type of treatment programme should even be offered to patients in this age group. In recognition of this, since its inception, the transplantation team at Childrens Hospital of Los Angeles has worked very closely with a psychologically trained and oriented paediatrician and with public health nurses experienced in research with children's and families' reactions to chronic physical illness.

The aim of emphasising this aspect of the treatment programme was manifold. It appeared desirable to learn as much as possible about the reactions of children and families to this new type of treatment. More important it was thought that if maximal support could be offered to the children and the families in the programme, that some of the far reaching emotional, social and psychologic consequences might be prevented or at least minimised, which would make possible better rehabilitation of the children after homotransplantation.

CLINICAL DATA

Haemodialysis

During the past three years, 42 children and adolescents have undergone more than 3000 haemodialyses (Table I).

Table I. Haemodialysis patient data

| Patients | 42 |
| Ages    | 1½ - 20 years |
| Length of dialysis | ½ - 28 months |
| Deaths | 3 |
Patients are selected for haemodialysis when symptoms of uraemia are uncontrolled by diet, antihypertensive therapy and peritoneal dialysis. Each patient is haemodialysed 3 times weekly for 7 to 8 hours. All patients and families enter the haemodialysis and transplant programme with the concept that a successful transplant is the ultimate goal of the programme, and no child is accepted for chronic haemodialysis only.

Homotransplantation

Thirty-two children have received 35 renal allografts (Table II), 27 of them survive with functioning grafts 1 - 39 months after transplantation.

<table>
<thead>
<tr>
<th>Transplants</th>
<th>35</th>
<th>Rejected</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recipients</td>
<td>32</td>
<td>Died</td>
<td>4</td>
</tr>
<tr>
<td>Ages (years)</td>
<td>2-18</td>
<td>Survival (months)</td>
<td>1-39</td>
</tr>
<tr>
<td>Sources:</td>
<td>live 11</td>
<td>cadaver 24</td>
<td></td>
</tr>
</tbody>
</table>

In the immediate post-transplant period in addition to the numerous medical and surgical complications, 3 children have developed psychiatric problems and 5 children actually stopped taking their immunosuppressant drugs.

Approach to comprehensive care

Since this kind of treatment programme has generally been reported to lead to gross maladjustment and to family disorganisation, comprehensive health care with special attention devoted to the psychosocial aspects has been offered to this group of children. Regular conferences are held with all patients and families with emphasis on maintaining health, family equilibrium and optimal interpersonal relationships, on preventing complications by anticipatory guidance and on dealing with crises as they arise.

Responses to the treatment programme

Family disorganisation, low socioeconomic status and long distance from the medical centre were found in a large proportion of our patient group (Table III).

<table>
<thead>
<tr>
<th>Both natural parents at home</th>
<th>24</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social class</td>
<td></td>
</tr>
<tr>
<td>high</td>
<td>5</td>
</tr>
<tr>
<td>low</td>
<td>10</td>
</tr>
<tr>
<td>Distance from CHLA 10 miles +</td>
<td>33</td>
</tr>
</tbody>
</table>

These have been considered obstacles to successful participation in a complex treatment programme. However, in our experience, the families'
ability to give emotional support to the children has been a more important factor in successful adaptation.

Chronic renal disease with haemodialysis and transplantation, like other chronic illnesses, constitutes a severe stress on the child patient and his family. Like other stressful experiences disease may cause potential family problems to become manifest or may exaggerate emotional disturbance, personality maladjustment or behaviour problems in the child patient. In addition, it has been possible to define some more specific reactions on the part of the child and family that can be predicted to occur in response to certain aspects of the renal treatment programme.

Peritoneal dialysis is frequently the first specific treatment offered to the child. In our experience, this is painful and humiliating especially for the adolescent patient. A few of the children have resented peritoneal dialysis to the extent that they have stated that they would rather die than have another treatment of this type.

When failing renal function and peritoneal dialysis have reduced patient and family to a low ebb as far as hope and general state of mind are concerned, the idea of haemodialysis is seen as the only possible hope. From conversations with other families on the haemodialysis programme prospective patients and their families realise that this type of treatment makes possible greatly increased well-being for the child and return to near normal activity. After several haemodialysis treatments, some children spontaneously state that they had actually forgotten what it felt like not to be in pain and tired and sick all the time. They are delighted with their own improvement. Parents are surprised and pleased as they note their children's increased activity, renewed interest in school and re-emergence of pre-illness personality traits.

For a period of time this general improvement continues. However, with complications such as shunt infections or clotting in addition to the practical problem of returning to the centre 3 times a week, both child and family become increasingly dissatisfied with life dependent on the haemodialysis machine and impatient for the transplant.

Prior to transplantation in our programme most children have their own kidneys removed. This procedure, which the staff views as a step toward the goal of transplantation is perceived quite differently by the families. Especially disturbing to the children is the idea of no urine production, and it may be difficult for parents to accept the severity of the disease even when the organs involved are about to be removed.

The next landmark and the most important one to child and family is, of course, the kidney transplant. This again is anticipated with mixed feelings, although hope and optimism predominate. The negative aspects of contemplating transplantation are for the child primarily the fear of any surgery,
anaesthesia, and pain. With the parents there is a more sophisticated awareness of the dangers implicit in the operation and the questions concerning the prognosis of the transplanted kidney. In addition, donor selection may become a major psychologic problem. In our programme only the natural parents or adult siblings are considered as possible donors. Every effort is made to accept only those donors who are enthusiastic and eager to give a kidney. Repeated conferences and consultations are offered concerning this problem and an 'out' is provided in order to minimise guilt feelings should the potential donor decide not to donate the kidney. In the case of cadaver kidneys, there are grave questions regarding the source of the kidney. Often the children resent the idea of receiving a kidney from someone of the opposite sex and they also have a certain amount of fantasy and concern about the circumstances under which the kidney was donated.

Although the reactions manifested during haemodialysis had been anticipated, in the initial post-transplant period the team has been confronted unexpectedly with severe and far-reaching psychologic, social and emotional ramifications in almost all of the patients. Immediately after the transplant the acute physical discomfort and pain overshadow many other concerns. For the patients who have received cadaver kidneys, the delay in urine production creates a great deal of anxiety in the child, family and staff. The initial production of urine signifying that the cadaver kidney is functioning is greeted by everyone with elation. However, we have learned that many serious obstacles are still ahead. The initial psychologic setback occurs if the child requires further haemodialysis, especially when some kidney function has been achieved. Complications, especially those involving ureteral and/or bladder leaks, have necessitated additional surgery and caused the children to be anxious and depressed.

In addition to the anxiety created by physical complications and failure of the kidney to function promptly, periods of acute rejection are usually fraught with anxiety on the part of all concerned, including the staff members. Parents and children are not always aware of the ominous import of abnormal chemistries and subtle physical findings, but they usually catch on when steroids have to be increased to treat rejection.

Finally, there are many difficulties associated with steroid therapy. The children's appetites are tremendous; they overeat and gain excessive weight and develop typical cushingoid facies and acne. Five adolescents (4 girls and 1 boy) became so depressed with their appearance, which to them was grotesque, that they stopped taking their medications. One girl even became so depressed that she attempted suicide. She is presently undergoing intensive psychotherapy.

Unrelated to the physical problems encountered by the children, there are often periods of doubt, anguish and confusion created by widely publicised
incidents and information in the news media. The staff has found it necessary to keep well abreast of what is appearing in print so as to be able to deal with parental and patient anxiety as it arises.

We have found that through the regularly scheduled conferences of team members with the families, a relationship of mutual trust and ease of communication is established prior to transplantation, which greatly facilitates the support of child and family through the arduous period after transplant. However, the level of support from family members appears to be the most important factor in successful adaptation to the programme.

REFERENCES

Richmond, J. B. (1958) in 'The psychology of medical practice'. (Ed) M. H. Hollender. Saunders, Philadelphia