Psychosocial Evaluation and Management in Haemodialysis and Transplantation

G. DeVEBER and D. J. MACDONALD
Toronto Western Hospital, Departments of Medicine and Psychiatry, University of Toronto, Canada

In a four year period the unit I describe has undertaken dialysis in 54 patients, 34 of whom have come to successful transplantation. Psychiatric and social work involvement first began three years ago when the medical staff recognized that the major problems emerging in patient management were of emotional origin, and were of such significance that the further operation of the unit was in jeopardy unless intervention occurred.

At that time there were few guide lines in medical, psychiatric or social work literature to indicate what steps could be taken in establishing psychosocial support to a dialysis unit. As we studied the complex conflict-laden situation that end stage renal disease presents to a patient and his family, we discovered that the breakdown of an individual’s normal coping mechanisms could be expected in many patients who had experienced no previous breakdown and that the whole spectrum of neurotic, psychotic and behavioural reactions under extreme stress could result. The response to stress was not confined to the patient alone. As a rule the whole family is caught up in the illness — in its profound effect both on the patient and on the family structure. In addition, the process of chronic dialysis, the anticipation and materialization of transplantation are further sources of extreme emotional uncertainty. We realized that for intervention to be effective it must involve both the individual and the family and required a multidisciplinary team for its functioning.

Even laymen today almost universally recognize that kidney disease if severe can lead to death. The personal anticipation of death — that I too must die, and that I now suffer a disease which will cause my death, comes universally as a shockingly destructive realization. In that many victims are young adults in the prime of life, an intense frustration, sense of loss, and hostility is engendered which may be dealt with in a variety of ways. Most commonly one sees a depression with anxiety — a feeling of extreme
helplessness and lostness — accompanied by sudden withdrawal of feeling investment in those most close and from the pursuits which formerly occupied the interest and attention. Behind the depression is a feeling of rage — that such a catastrophe should be allowed to happen to me — which may or may not reach conscious awareness. If rage is denied and projected, it takes the form of a sense of persecution, a tendency to blame the gods, or fate, or the doctors for the condition; this is described as 'paranoid projection'. If acted out, the rage takes the form of a passive or active rebelliousness or irritability in the refusal of dietary or fluid restrictions, in inadequate self-care, in opposition to staff or next of kin, or in assertive antisocial behaviour.

Whatever the reaction, it tends to take the form which the patient's pre-existing personality structure dictates. The response is an understandable reaction in that person to the tragedy of the loss of self and future. Likewise in the family the emotional response to the crisis situation may also take any of these forms. They vary from over-protectiveness to complete rejection, with many complex mixtures. Following the initial shock, confusion and individual reaction to the new reality a long period of working through begins, a period of critical readjustment for all concerned, a period when depression, denial or acting out can have fatal consequence. This is usually within the stage of chronic dialysis.

Recognizing the urgent need for intervention during dialysis, the necessity of support, reality testing and education, we developed a psychosocial team approach at Toronto Western Hospital. I would like to comment upon its constitution, its function during initial assessment, and in its supportive intervention; then to comment on the evolution of a patient self-help group; finally to suggest some basic requirements in a psychosocial team approach.

The Assessment Team is composed of:

- Physician in Chief + Resident Staff (3)
- Social Work Supervisor + Students (4)
- Staff Psychiatrist + Resident
- Immunologist
- Urologist

Initial Assessment
Prior to, or shortly after, the patient's first admission for peritoneal dialysis a psychiatric and social work evaluation is done.

The psychiatric assessment includes an extensive psychiatric history and a study of the mental status, the purpose of which is to obtain a longitudinal and cross sectional view of the patient's emotions. Three purposes are served by this experience:

1. the establishment of a therapeutic relationship with the patient
2. the grasp of the patient's psychodynamic posture — that is, his
personal strengths and characteristic ways of dealing with anxiety.

(3) the evaluation of his present reaction to the life-threatening illness with the possibility of intervention if mood or behavioural changes are remarkable.

Simultaneously a social worker interviews the patient and his family, attempting to gain an understanding of the family structure and the response of individuals to the patient's illness. The worker thereby establishes an empathic contact with the relatives so that their feelings can be expressed, their questions raised, and their emotional, economic and domiciliary problems dealt with. Frequently a home visit is made in the course of the initial assessment.

At present all our patients are first treated by peritoneal dialysis during which an extensive knowledge of the entire situation becomes available. It provides treatment staff with invaluable information prior to the commitment that cannulation signifies. It allows a team to select those patients who will prove treatable during the usually lengthy process of haemodialysis and permits the anticipation of problems before they arise.

Supportive Intervention

Having established contact with the patient from the beginning, the psychiatrist is not viewed as a frightening figure, rather as another member of the team. Similarly the social worker being well known from the beginning, forms a very important early link with the hospital and the treatment staff for relatives. Her visit to the family in the home establishes rapport, and gives her a personal grasp of the home conditions and feeling relationships between family members.

As the period of haemodialysis is frequently protracted while a suitable cadaver or living related donor is found, the day-by-day support of the patient is crucial. This is a period of chronic uncertainty, of fluctuating mood and frequent complication. As the nursing staff provides an attentive supporting community for the patients, it is obvious that their own morale and interpersonal relationships are critical. Frequently the nursing personnel are caught in the problem of having to discipline, cajole, or chastise patients who abuse their dietary and fluid restrictions, or who otherwise act out in protest against their unfortunate condition. Reactive hostility may emerge, the nurses being caught in an angry battle with those who depend on them for their survival. The recognition of death wishes for patients in nurses who attend them leads to profound guilt and may produce rapid staff turnover unless dealt with actively. We have found it essential to have an hour and a half weekly meeting for all the disciplines to share all relevant information, to deal with emotional issues arising both in patients and in the staff who care for them, and to resolve emotional conflict between staff members.
Self help through group involvement

As the unit philosophy developed we came to the recognition that for discipline among patients to be effective it must be self-initiated. Working also on the premise that the person who best understands the patient's problem is a fellow patient, we suggested the establishment of a patient meeting, with a neutral leader who was not one of the medical team. On a voluntary basis, all patients were led weekly by a hospital chaplain trained in group therapy in an hour long meeting, the ostensible purpose of which was educative. It was hoped, however, that the group would also promote interpersonal relationships and mutual help between patients so that common concerns and emotional difficulties could be shared and alleviated. When issues raised in the group indicated areas of factual uncertainty experienced by the patients, they were encouraged to ask members of the treatment team to give explanatory lectures. For example, an internist was asked to speak on tissue typing and the rejection mechanism, the dietitian to explain the complicated dietary restrictions. As an end result, the patients began to educate, discipline and correct each other so that the burden of instruction and personal initiative was removed from the treatment team, in particular from the nursing staff. For example, the patient group most effectively confronted a male patient who filled his pockets with sausage rolls after each dialysis; his acting out resulted in immediate behavioural change. This conflict previously had been a source of helpless frustration among the nurses.

Social interaction was accompanied by emotional support. Feelings of anger, frustration and depression were freely expressed and as a result of the group acceptance individuals were able to overcome their sense of isolation and anxiety. Finally as a result of group experience a number of outings with family members were arranged among patients to which the staff was invited, and a monthly newspaper was produced giving details of personal interest, new recipes for preparing restrictive diets and articles on relevant subjects such as rejection and tissue typing. Operating on the assumption that an informed patient is more likely to be a co-operative patient, the staff supported and encouraged the group process. Patient morale improved remarkably, acting out behaviour was greatly curtailed, and a strong cohesiveness developed between patients and their individual families, and between patients and the treatment staff. Discharged transplanted patients now frequently refer to their previous relationship on the unit as being members there of a new family - an experience of great support, personal warmth and growth. We feel that the patient group has been responsible for patients developing attitudes of self-reliance, independence, and mutual support to their significant betterment.

For a psychosocial team to work effectively a number of basic requirements are needed:
(1) an interested and available psychiatric service which is accepted
in partnership by the medical staff
(2) a social work service providing a flexible approach to patients
and their families
(3) a team approach to the patient which involves both him and the
family from the earliest contact
(4) a weekly sharing experience for all members of the multi-
disciplinary team to promote open and direct communication of
fact and feeling
(5) an assessment period on peritoneal dialysis for the collection
and collation of relevant data
(6) a patient group leader, preferably not a member of the treatment
team, to give direction to the patient meeting
(7) a suitable room adjacent to the dialysis unit for group and team
meetings.

We feel that the establishment of a psychosocial team approach has
enabled the unit to deal effectively with the predictable social and emotional
reactions to renal disease, dialysis and transplantation. The more informed
a team can be with respect to the patient's total situation, the more effec-
tively it can deal with issues arising during treatment.