Gastroscopy with Biopsy—Williams et al.

We are indebted to the Nuffield Committee for making a grant to one of us (S. C. T.) for the purchase of the G.F.B. fibroscope. One of us (D. G. W.) was supported by a research grant from G. D. Searle, who also met some incidental expenses, for which we are grateful. It is a pleasure to acknowledge the help of Dr. A. I. Spriggs and Mr. M. M. Boddington with the cytological examinations. We wish to thank Mrs. Christine Pousford for assistance at the gastroscopical examinations and Mrs. R. Lees for secretarial assistance.

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Psychological Aspects of the Management of Chronic Renal Failure


The treatment of chronic renal failure and the outlook for the patient have changed dramatically in recent years. Patients who have died can now be maintained in reasonably good health by recurrent haemodialysis or by renal homotransplantation, either from living volunteer donors or from cadaveric sources. These new developments have thrown up new problems of management for the medical profession.

The early papers of Scribner et al. (1960), Barber et al. (1963), and Guth et al. (1964) among others, referred to psychological factors briefly and in a relatively superficial way. Rather more extended and detailed accounts of psychological reactions to chronic dialysis were supplied by Brown et al. (1962), Shear et al. (1965), Wright et al. (1966), Sand et al. (1966), and Retan and Lewis (1966). Abstracts have been published by Pollock (1967) on the emotional adjustment of patients after transplantation and by Norris (1967) on personality factors in the performance of dialysis patients. Norton (1967) makes the point that the novelty of the procedure is in a large part responsible for the anxiety felt by patients and staff and that these issues are clearly in the process of resolution.

Commentaries on the psychological problems of renal homotransplantation have been concerned mainly with living donor selection, as, for example, those by Woodruff (1964), Hamburger et al. (1964), and Monnerot-Dumaine (1965). Kemph (1966) drew attention to the unconscious resentment of donors to recipients, while Cramond (1967) described the development of a hostile dependency between recipients and donors.

Ethical and moral issues concerning this whole field of dialysis and transplantation have been dealt with, notably by Lindholm et al. (1963), Scribner (1964), Leake (1964), and Schreiner and Maher (1965), while a Ciba Foundation Symposium was almost entirely preoccupied with these problems (Wolstenholme and O'Conner, 1966).

This paper deals with some of the psychological issues involved in the management of 47 patients in chronic renal failure and of the problems of the psychiatric screening of 20 potential kidney donors seen at the Queen Elizabeth Hospital, Adelaide, South Australia.

Methods

The renal unit, opened in early 1964, provides recurrent haemodialysis for the State with its population of slightly over one million. Initially, only four places were available on the artificial kidney. The number has since been increased to 10. The unit staff comprises a full-time director, two senior medical registrars, a senior house-physician, a junior house-physician, technicians, a trained sister, and trainee nurses. The unit is closely associated with the University of Adelaide's Department of Surgery, which organized the renal homotransplantation programme. Staff on this side of the work consists of a senior research fellow in experimental surgery with the status of reader and two honorary assistant surgeons, together with the usual theatre staff complement and two trained sisters. The psychiatrist, clinical psychologist, and social worker are closely identified with the work, and the psychiatric contribution to patient-care can be understood under the following headings: (1) the initial assessment interview of all patients being considered for inclusion into the renal unit programme; (2) the provision of specific therapy of a psychiatric nature as the need arises for patients in the programme; (3) the interpretation to

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the staff of patients' behaviour, psychological and social needs, and the identifying of and dealing with the problems of transference and countertransference—that is, the role of mediator or catalyst; (4) potential donor selection; and (5) follow-up of recipients and donors.

Initial Assessment Interview

The psychiatrist's initial role in the renal unit is to interview in depth each possible candidate for inclusion in the programme of dialysis or dialysis leading to transplantation. The interview attempts to delineate the personality structure of the patient, his or her strengths and resources, preferred patterns of ego defence, and the dynamics of family life as it has affected the patient. The clinical interview, which lasts for 90 minutes to two hours in one or two sessions, is supported by intelligence and psychometric testing (J.H.C.). The information is then assessed and attention is drawn to specific current problems—for example, socio-economic difficulties, the presence of depression, and to family dynamics which may have significance in the renal setting. An example of this is a comment that a patient could be expected to relate better to the senior medical male staff than to the senior nursing female staff because of a close relationship in childhood and adolescence to the father after persistent rejection by the patient's mother, who had seen the patient as an unwanted child.

The personality structure and the ego defences most consistently used are detailed with recommendations on what the illness means to the patient in terms of his or her personality, past experience, and current goals. For example, the staff are warned that the very obsessional patient will be happier and more co-operative if he is kept fully informed, and every detail of procedure must be presented to him. He can be given control of working out some of his own diet sheets, which he will do well because he is so meticulous. Handling of the obsessional patient in this way allows him to feel that he is in control of his own affairs, and as a result he is less threatened by the unfamiliar and frightening environment. Again, recognition of the defence of denial whereby the patient shuts out the unpleasant and unwelcome is important. Understanding of this mental mechanism permits the staff member to be ready to go over specific difficulties again and again or to repeat instructions a number of times over a period without loss of patience or the rejection of the patient as stupid or deliberately uncooperative. The patient cannot be completely understood and supported without awareness of the immediate family and the relationships within it. The initial assessment interview not infrequently brings to light marital unhappiness, difficult parent/child relationships, or financial distress. These matters are further clarified with the help of home visits by the research social worker.

By this time the renal team is able to see the patient in depth and to have some idea of the strength of support he or she will obtain from the family environment, from religious conviction, from constitutional and personality resources, and from the will to live.

This will to live, or patient morale, is invariably affected by the depression which follows as a reaction to significant loss. When patients begin to give up the initial defence of denial they come to appreciate the fact that they have a permanent loss of health, independence, and even status. The future, and this includes the ability to work and to provide, is uncertain. As a natural reaction to these significant and personal losses the patients will grieve and mourn. This sadness, which will colour the clinical picture to varying degrees, may take many months to lift and may move into pathological depression requiring specific therapy.

At the initial interview an opportunity is given to talk about death and the processes of dying. All the patients had faced up to this long before the psychiatric interview. Invariably no one had discussed these issues with them. The way in which the patient discusses dying and his own possible death is useful in assessing the degree of morale, ego strength, and depression. Preferred patterns of handling fear and anger are discussed at this initial interview since both emotions will be frequently encountered during the long course of therapy when things will go wrong and those emotions will be aroused. An awareness of the patient's feelings and an ability to discuss them and to take them out in the open are important matters for the caring staff.

Specific Psychiatric Therapy

The second contribution of the psychiatrist is advice on and help in dealing with crises of a psychological nature as they arise. The psychiatrist, being less involved in the day-to-day running of the renal unit, is more readily able to act as an independent observer and interpreter of patient behaviour. The severe reactive depression experienced by some patients responds well to current antidepressant therapy. On a number of occasions patients have become psychotic for brief periods and an opinion has been sought on deciding the proportionate influence of organic or psychogenic factors. Brief interpretative psychotherapy of a profound reaction to stress has proved extremely effective. The following is an example:

A man aged 42 developed severe tetany and laryngeal spasms after parathyroidectomy for secondary hyperparathyroidism. In the succeeding days he regressed severely and became mute, lay curled up in the fotel position, and was negativistic. The clinical picture of regression suggested a resentful, angry, yet afraid small boy. The therapist commented to the apparently unheeding patient that he was angry, hurt, and frightened and that his recent experiences of terrifying choking and breathlessness might have had their original counterpart in childhood. The therapist indicated that he accepted the fact that the patient was angry with the doctors for allowing this to happen. Slowly the patient was able to respond and with very little difficulty recalled an episode in childhood when he had choked on a fish bone and his parents had been helpless to deal with the crisis. By discussing and accepting his anger and by encouraging him to tell the unit staff how upset and angry he was with what he believed was their failure, the patient rapidly recovered.

The identification of crisis periods during chronic haemodialysis has been one of the psychiatric contributions to the work. For example, the discussion of dreams may give a lead to existing depression, to preoccupations with death, or to very real difficulties with diet. The discovery that many patients had naive or inaccurate concepts of the artificial kidney led to routine reassurance by the staff on such matters as the fear that the breakdown of the pump would lead to the patient's immediate death. Other unspoken anxieties which are now anticipated by explanation and reassurance include the availability of immediate admission from home to hospital if need arises and the disturbing effect on body image of the cushioning facile of patients on cortisone.

Stress Problems

In normal living, day-to-day stress is coped with by such adaptive or defensive devices as eating, the use of tobacco and alcohol, by physical exercise, or in sexual outlets. The patient with chronic renal failure is denied many of these normal methods of coping. The fairly usual pattern of withdrawal and by the loss of libido which accompanies the condition. How then is the patient to cope not only with the stress of the disease and its management but also with his daily life problems? Tension deprived of its usual outlets must find others, which may be more crude, more disturbing, and less economical to the whole organism. Reactions like insomnia, terrifying nightmares, depression of suicidal intensity, and even epileptic seizures have
been considered as such. One patient with preterminal renal failure developed an arthritic condition of knees and elbows. This may have been related to her tension state as the implications of her situation became clearer to her, since her basic personality was one characterized by marked inhibition and overcontrol.

To help patients find a more effective and less harmful relief of tension, relaxation therapy (Jacobson, 1938), a technique easily learned, can offer patients a means of doing something for themselves rather than having something done to or for them.

The treatment by psychological means of individual members of the patient's family who are reacting to the stress of illness in the home has been required occasionally. For example, a young teenage girl, an only child, began to show disturbances of behaviour when her father withdrew from her because of illness and her mother withdrew partly because of reactive depression and partly by reason of having to work. Therapy of the child and her parents directed to the reopening of intra-family communications was required. It has been our experience that the spouses of patients show signs of distress, with anxiety and depressive features predominating, at some point during the treatment programme. In one of our cases the strain on the husband was so intolerable that the marriage broke up even though the patient, after two years on dialysis and after one successful transplantation, recovered very good health. It is important to note that over the years, as the renal unit has built up a library as it were of experiences, the members have become less anxious. The patients coming into the programme are now exposed to a more confident and less anxious team and there has been a significant drop in their anxiety reactions.

Such an experience, where the fear of the unknown leading to emotional disturbances often of a gross nature is replaced by knowledge, competence, and a lowering of levels of anxiety, has been reported in cardiac surgery (Burgess et al., 1967).

Transference and Countertransference

The psychiatrist, because of his training, becomes extremely aware of emotional feeling both in the patient and in himself. He learns that much of our feeling in the here-and-now situation stems from the unremembered or partially recalled happenings in childhood. He is aware, too, that we take into the present situation assumptions, expectations, and prejudices which may or may not be rational. Because of this the patient and the doctor may not share the same set of expectations. In addition, doctors have a stereotype of how a patient ought to behave, while the patient makes certain assumptions about the doctor's role. Since both patient and doctor take to the transaction unconscious and irrational as well as conscious and rational elements, there are many possible opportunities for breakdown in communication. The doctor who as a child learned that failure was followed by withdrawal of parental love may tend as an adult to have an undue need to succeed. Failure leads to a loss of self-esteem. The patient who is not responding to therapy implies failure, and, since personal failure is a loaded problem for the doctor, he brings to the present situation not only his clinical insights but also irrational childhood emotional feelings. This may lead to irritation with the patient, followed by a rise of tension between the patient and doctor, then by reactive behaviour from the patient, and finally by medical rejection. The danger in the situation is that the patient may be withdrawn from the programme as unsuitable because of his inability to co-operate in the highly complex and stressful treatment situation.

We have seen repeatedly a deterioration of patient behaviour when a favourably disposed member of staff has temporarily absent. The staff member returns to find a crisis situation with which he has to deal, and in his resulting anxiety or extra work the patient gains extra attention and has “punished” the staff member for abandoning him. Our social worker, who had spent hours sorting out the complicated financial affairs of one couple, returned from her fortnight's leave to find the patient had bought a secondhand car on hire-purchase and was once more in difficulties.

The team members themselves are highly individualistic, with their own preferred methods of dealing with anxiety and tension. Their professional training varies widely, as do their routes to the goal of patient-recovery. This must and does at times lead to tension within the team. Assumptions that seem self-evident to one by reason of his background, experience, and professional training may not appear so to another, trained in a different way with a different value system. The psychiatrist, with his specialist training, can help to keep open lines of feeling communication. This does, however, require on the part of the staff a degree of sophistication and a willingness to look at themselves. For the psychiatrist it requires, in addition, humility, tact, and concern.

Selection of Donors

It has always been realized by workers in this field that if living volunteer donors were used they must be physically and mentally healthy, free from undue pressure, and emotionally stable. There have been, however, some references in the literature to undesirable pressures being put on families to provide donors and of some long-term difficulties in later relationships (Holmes, 1964; Kemph, 1966; Cramond et al., 1967).

In this unit the decision to consider a patient as a candidate for renal transplantation is primarily a medical and surgical one, but all recipients have had extensive psychiatric and psychological assessments. Once the decision is made that the patient is suitable for transplantation a senior member of the team discusses the realities and the implications of the procedure in the clearest and most factual way possible. Risks are outlined, as are the current world results, though it is stressed that these are of little value in predicting the outcome in the individual case. The unit screens all those who wish to be considered as donors, but the final decision regarding who the donor will be rests with the unit personnel. To minimize time losses and expense, a six-point “fail” screening regimen has been devised. The more time-consuming, expensive, and potentially hazardous investigations are left to the end. If the potential donor successfully completes the early tests he is seen by the psychologist and psychiatrist separately. Each reports independently, and in this way bias and possible contamination of opinion is minimized.

The main task of the psychiatrist is to elucidate conscious and unconscious factors which might be detrimental to the donor's subsequent mental health if allowed to sacrifice a kidney. This means that the dynamics of the relationship with the patient and with other family members must be well understood. Evidence for proneness to mental illness and the potential donor's commitments to other people are examined. For all donors, but particularly for those unrelated by blood or marital ties, the psychiatric interview has to exclude any psychopathological motive of exhibition or sacrifice. Religious or altruistic motives have to be assessed as completely as possible for depth of principle.

Grounds for Rejection

In general we have recommended rejection of a donor when we have found good evidence of mental illness in the family, mental breakdown in the potential donor, or personality disorder with marked antisocial behaviour and a tendency to abuse alcohol or drugs. Unconscious resentment of the patient by the donor—for example, clear-cut sibling rivalry—and
marked ambivalence of donor to patient, as, for example, between a son and a previously rejecting father, or mother to an unwanted son, have been grounds for rejection. The following is an example:

A bachelor aged 22 was the eldest of a family of four by five years. The father was unsuitable as a candidate by reason of heart disease but suggested that his wife volunteer. From the beginning of the interview the wife's ambivalent feelings were clear. "After all," she said, "I have a sick husband and three children. He is on a pension and I have to go out to work." By stating that she had three of a family instead of four she seemed to have dismissed the patient. Her conversation was liberally sprinkled with such words as "duty," "ought," and "must." "If anything happened, what would become of the others if I was unable to go out to work? What a waste it would be if it failed." She also reported the recent onset of symptoms indicative of depression and anxiety. The history showed that the patient was a wartime baby, conceived a month before the father was posted overseas and just after both the mother's parents had died. The mother had clearly been depressed and had been unable to form a loving bond with the patient, whom she had always found difficult, awkward, and ill-timed.

We have also recommended rejection when we judged that the potential donor's commitments towards his wife and family, for example, were so great as to make the risks and hazards of nephrectomy unwarrantable.

To date 29 patients have been admitted to the transplantation programme, and 19 of these have had the operation carried out. For these 19, 67 potential donors were examined and 28 reached psychiatric assessment. Of these 28, only 12 were thought to be suitable psychologically. They completely understood the outcome and consequences of their act.

In this programme, if potential donors are to be rejected on psychological grounds, the decision is given to the surgeon (P. R. K.). They are not informed of the psychological grounds for rejection but are told there is an incompatibility to the patient. Provision is made for donors to withdraw at any time, the reason being kept confidential from the other members of the family. As a result of our follow-up of donors and recipients we are in no doubt that careful psychiatric and psychological screening is essential if undesirable sequelae are to be avoided after nephrectomy.

Follow-up of Recipients and Donors

This follow-up can be divided into two parts. Firstly, the process of adjustment to transplantation, and in particular to the relationship that develops between recipient and donor, is described. Secondly, the process of adjustment of recipients from living donors is contrasted with that of recipients of cadaver kidneys.

So far 19 transplantations have been carried out. Of these eight were from living donors; three of the patients have since died, but the others are alive and working, the longest survival being three years. One of the patients had a graft from a living donor, which was rejected, and later had a successful cadaveric graft. Eleven patients have had cadaveric grafts; two grafts failed and were rejected, and one of these patients has since successfully been regrafted from a cadaver. One of the cadaver patients has died and the longest survival is 19 months. We have followed up five pairs of living recipients and their donors. All these donors except one were blood or marital relatives of the patient. In four cases we have found evidence of a mutual hostile dependency arising. This has ranged from very marked in one case to minimal and transient in another. The paradigm appears to be that both donor and recipient become something of heroes for their extended family and local community. Both are seen together, both are congratulated together and praised for their courage and in some cases natural environment serves to reinforce the sense of obligation on the part of the recipient towards the donor, and makes the donor prize his gift even more. As a result each becomes involved in the personal life of the other. The recipient has a gift for which he can never pay; the donor has a need to overprotect his gift, lest it be abused and spoilt. Both become irritable one with the other. This is followed by feelings of guilt and a need to undo or expiate. This situation becomes very acute at times of the anniversaries.

This sequence of events is of relatively little consequence if the original relationship was sound and free of ambivalence and mutual concern to the patient. However, where psychiatric screening has failed to diagnose potential disease the hostile dependency can become a considerable problem. In our only case where the relationship is producing major difficulties, the donor, who was an acquaintance and unrelated to the recipient, is drinking heavily and habitually, and the recipient is chronically anxious and depressed. Both dislike living "in each other's pockets," yet neither can break from the other.

At least the patient who has a transplant from a cadaver is not continually reminded of an obligation. One other important point that has emerged at follow-up which has relevance for donor selection is the sex of the donor. In one of our series a female was allowed to give a kidney to her recipient brother. It was noted in his history that as a child he had shown some evidence of confusion of sexual identity. The presence of the female organ vaguely connected with the reproductive system in his body seemed to upset something, and this has been held in check by his marriage and his ability to father two children. While no harm was done in this case, the implications are clear and should be used as a guide in future donor selection. With the exception of the donor mentioned above, all have done well and have come to no harm. It is of more than passing interest to note that, of the eight donors from whom kidneys have been taken, two have been involved in vehicle accidents. Both, fortunately, were wearing safety belts, but both had anxiety states for a short time afterwards when they appreciated the threat to the remaining kidney.

Second Follow-up

The second follow-up compared the recipients of kidneys from living donors with those from cadavers. We have seen eight who had kidneys from living donors and 10 from cadaveric sources. One patient has experienced both, while another patient has had two kidneys from cadaveric sources. In general, the majority of the patients would appear, on retrospective, to prefer a cadaver kidney. Rather surprisingly, there was little evidence to show any disturbance of aesthetic feeling at having tissue from a dead person grafted into the living body. The only patient who was very disturbed by the thought of a cadaveric kidney was a highly obsessive patient who had the misfortune to have to wait for a fortnight for the accident victim to die. This gave him too much time to reflect on what he considered the moral issues involved. All the living recipients and families were grateful to the relatives of the deceased patient for the second chance of life.

In the adjustment period after transplantation all patients are aware of the disturbance to their body image. In general, the recipients take from two to six months to become accustomed to the disturbance of body image relating to the grafted kidney, but eventually all have become aware of its presence. All consciously protect the site of operation, and even two years later automatically cover it if threatened by a blow. Libido takes from three weeks to six months to return. A number of patients used the word "frightening" when describing the first attempts at intercourse after operation, and comparison with a small matched series of patients who had intracardiac surgery showed that the fear of damage from the effect of intercourse was greater in the patients who had experienced this experience. The fear occasioned at intercourse appeared to be for physical and mechanical reasons rather than profound genital or sexual ones.
Most feel that they have been given a second chance and that they should do something worth while. The majority sensibly see this as giving more of themselves to their family and neighbours. Perhaps the most interesting happening is that the great majority of both patients and donors have grown with the experience. They report a greater enjoyment of the simple but essentially real pleasures of life; they have become more tolerant of other people, less critical, and more accepting. After about a year some of them have even begun to appreciate that the experience, grim though it was, has been necessary to them in order to attain this new and worth-while maturity.

Social Worker’s Contribution

Traditionally the psychiatric social worker and the psychiatrist have always worked in close co-operation, and the skills and insights of the psychiatric social worker are of inestimable value in the renal unit. Most of our patients, at a time when they are least able to make the mental and physical effort required, have to make far-reaching economic decisions. Jobs are lost through the illness, and the patient loses status with the financial loss. Wives may have to go out to work, so that young families have to be sent to or are looked after by relatives. Houses have to be sold and alternative accommodation found near the hospital. Hire-purchase debts have to be reorganized to meet the new and lowered income. Family members turn to the psychiatric social worker for help, so that counselling becomes an important matter. This means that the psychiatric social worker has to be a fully co-opted and informed member of the unit. A number of families required more than 100 hours of the social worker’s time before the complex tangles of financial and legal needs were sorted out. In the face of such a case-load the need for adequate finance for the staffing of such units must be well appreciated.

Summary

This paper has attempted to distil the many varied experiences gained over the past three and a half years. As programmes develop and numbers of patients and staff increase in the face of technical expertise, we must never lose sight of the complex emotional and social needs of the patient and his family.

The psychiatric management of 47 patients in chronic renal failure undergoing treatment with recurrent haemodialysis, leading in 19 cases to homotransplantation from both living donors and cadaveric sources, is described, as are the problems of the psychiatric screening of 28 potential donors. The psychiatric contribution includes the initial assessment interview, the provision of specific therapy as the need arises, the interpretation to the staff of the problems of transference and countertransference, and the follow-up of recipients and donors. Anxiety levels both for patients and for staff in the programme diminished as experience was gained over the three-year period and crises became fewer. Selection of living donors requires a dynamic understanding of interpersonal relations, since a hostile dependency may ensue. There is evidence that the total experience leads to a greater maturity in the patient who adapts best. As programmes develop and numbers of patients and staff increase in the face of technical expertise, we must never lose sight of the complex emotional and social needs of the patient and his family.

Our thanks are due to the members of the nursing and technical teams of the Renal Unit at the Queen Elizabeth Hospital, Adelaide, South Australia, who have been involved in this work since it began.

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