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Psychosocial Problems in a Renal Unit

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This paper attempts to show something of the interaction between social factors and the response to treatment in patients with chronic renal failure who embark on a programme of recurrent dialysis. The social work involved was carried out on the series of patients reported by Professor Cramond and his colleagues in the three articles preceding this one.

Pilot Study

It was first thought that the main contribution of the psychiatric social worker would come from home visits to observe problems in daily living encountered by the patient and the family. In a preliminary study it was arranged that she should spend two periods of observation of three hours each in the home of a patient who had already been on recurrent dialysis for several months. This approach failed because the original family did not react naturally and persisted in maintaining conventional social behaviour.

Reviewing this experience, it was considered that a patient who had already established good relationships with staff might well feel threatened by the introduction of another person whose function was not directly related to medical treatment. Observation at regular intervals over a long period of time would be necessary for the patient and relatives to feel entirely at ease and to behave naturally. Since the worker's time was limited it was thought that short periods of observation would be of little value. It was therefore decided that the social worker would deal with families referred because of particular psychosocial problems and that home visits would be made only when the practical situation demanded this. This modified approach has proved entirely satisfactory.

Current Programme

Over a period of two years, sixteen patients and three potential donors for renal transplantation were referred to the psychiatric social worker. Of these, fourteen were referred by doctors in the Renal Unit, four were referred by medical social workers and one was referred by the patient's neighbour.

Interviews were mostly of an hour's duration, but occasionally lasted longer. In the initial interview the social worker introduced herself and was careful to make the statement that she was there to help with problems. Her role in the team was expressed in simple terms. One relative, at first interview, asked if she would be allowed to weep and did so. She stated that her son's illness made her realize how much she missed her deceased husband and how hard life was without him. Several weeks later, on a home visit, she asked for permission to talk about her own feelings and said: "I do not know the seriousness of my son's kidney trouble." This was an attempt to deny information which the physician had recently given her. The fact that this mother felt she needed to ask for permission to talk about specific reactions of her own indicated that she had seen the hospital's interest as being concentrated exclusively on the patient.

There was wide variation in the number of times patients were seen. The minimum number of interviews was one, and the greatest amount of time was spent on a patient whose involved psychosocial and economic problems required fifty-one interviews, six visits to the home, one consultation at a bank and one visit to a government welfare agency.

The potential donor for this patient also required much time. He reported that his employer was willing to give him unpaid leave of absence while he recovered from his nephrectomy. The donor's family was dependent on his weekly wage. The surgeon, not wishing them to suffer, asked the social worker to check that the donor's job was not in jeopardy and to investigate the financial position. An approach was made to a number of charities, which each agreed to make a contribution so that the donor's family would receive a sum equivalent to his weekly wage while he was in hospital. While this was being done, further screening tests showed that the potential donor was unsuitable. However, making the necessary arrangements for this one potential donor involved one visit to the employer, two home visits, one interview with the secretary of a charitable organization, eleven letters and fourteen telephone calls. The total amount of time spent on this patient and his potential donor was approximately one hundred and fifty hours. To put it another way, this represents nearly four weeks' work. This would mean that the social worker could only carry a caseload of twelve such patients a year.

The General Response to Crisis

Chronic illness such as this makes demands that may be intolerable for a period of time for even the most stable personality. The speed of adjustment to a radically altered life situation will depend on the maturity of the person and the degree of strength within the family group. All members of the patient's immediate family are affected, not only emotionally but materially as well. In Australia there is no National Health Service and the provision of medical care is a matter for voluntary insurance. The period of benefit is limited to thirteen weeks in any one year, so that very real financial hardship may result from prolonged periods of chronic ill health. Many people in younger age groups with young families take a chance that they will not become ill and do not subscribe to voluntary insurance schemes.

The majority of our patients have experienced loss of status within their community, for example, bankruptcy, change of housing, loss of a business which had been slowly built up and limitation of social living. The reactions to these privations have included depression, shame, anxiety, guilt and anger. These strong feelings have affected the other marriage partner and also children.

Writing of psychosis in parents, Irvine (1961) draws attention to the fact that mental illness is responsible for two major anxieties among families—the anxiety about heredity and the guilt that is experienced about the breakdown of relatives. Our experience with this series of patients suggests that the reactions she has described are valid in this context. The parents become afraid that children may have renal disease, e.g. in our series two out of the six couples with children asked that the latter be investigated to exclude renal pathology.

Mothers of young children early in the dialysis programme are unable to fulfil their mothering role. We have noted that the situation improves as adjustment takes place, but the time for this to happen is of the order of twelve months. It is important therefore that there be arrangements made for the young children to have adequate substitute mothering experiences during that time.

In connection with the total change of life pattern it is noticeable that the same practical situation calls forth entirely different reactions in different personality types. The mature couple will try to do as much as possible to cope with their practical problems, and this sometimes has the paradoxical effect that they are less able to obtain help since they are so controlled. By being less spontaneous they may fail to arouse empathy in various staff members and may in fact be at a disadvantage when compared to the patient who is more active in drawing his needs to the attention of others.

The impact on a family of having one of its members suffer from renal disease is to sensitize it to references in the popular press, radio and television and to stories about modern methods of treatment. This means that the medical staff has to be aware of what information is available for people who are at risk.

Meeting the needs of the Patient and the Family

Cramond *et al.* (1967) have drawn attention to the fact that patients invariably become dependent on members of staff. They are sensitive to staff changes and express sorrow when they have become used to a member of staff who has to leave. They sometimes wonder whether the next staff member will understand their illness, and talk about the time it takes to get to know new people.

Patients and their spouses often have intense feelings, both positive and negative, towards their doctors. While some of these are expressions of transference in the analytic sense, others are undoubtedly realistically based. A number of patients and relatives have been impressed by the devotion shown by staff members. One husband, who had been severely rejected by his father and whose usual pattern was to reject authority figures, often expressed admiration for one doctor and the amount of time he gave to patients and relatives. His positive feelings towards the doctor led the husband to obtain treatment for his own illness, which previously he had resisted.

It is more difficult for a patient to express negative feelings even when he considers them justified. "If you tell them to go to hell, they can kick you out of the hospital." One patient said that when he was ill he felt "cheesed off". If he felt this way when well he was accustomed to going for a long drive in the car and getting it out of his system, but he could not do this when he was ill. If he became particularly angry when in hospital he had noticed that he was awkward with the nurses. He could not behave in this way with the doctors, however, "they are too big".

Cramond *et al.* (1967) draw attention to the fact that the strict therapeutic regime deprives the patient of outlets for his tension. One patient became so tense that his physician commented he was "heading for an explosion". During this period the patient, who had had numerous interviews with the psychiatric social worker, approached another social worker about his problems. This approach was rejected, but when the patient was later seen by the original worker he was, with encouragement, able to describe feelings of anger (which he had inhibited) towards one of the medical staff. It was interpreted to him that as he had felt one particular doctor was not sufficiently understanding of his problems, this had led him to think that probably the psychiatric social worker did not care either, and so he had sought out someone else. The patient quickly responded to this explanation and spoke of relief at having his feelings understood.

One of the important roles of the social worker in the programme has been that of a supportive therapist. Although doctors in the Unit have been very careful to ensure that patients know as much as possible about their illness and about the treatment regime, yet some patients find it difficult to ask questions, and all draw conclusions—sometimes faulty—from chance remarks they have overheard. Discussion with the patient or relative of his understanding of the information given him enables distortion to be recognized and dealt with as soon as possible.

Provision of factual information is essential. but sometimes more than this is needed. In some cases a question may be the way of leading up to a number of fears and anxieties, and giving reassurance or an answer to the original question may stop the person from expressing related or deeper anxieties. As an example of this, one wife commented that her mother-in-law had "the same trouble" as the patient. She did not know the medical diagnosis of her mother-in-law, but had observed that her legs became oedematous and that she was on the same type of diet as the patient. She then asked if the condition was hereditary; the social worker responded by enquiring whether the wife had discussed this with the doctor. She had done so, and had been told that kidney disease was not hereditary, but she said she could not believe this. She was afraid that her children might have inherited the condition, and asked if they might have a thorough physical examination. After she had expressed this and many other worries, and these had been accepted, she felt no need to arrange a special examination for the children.

As he was about to leave the room—a time when emotionally significant material is likely to come up—one patient reported that he was now "scared" before coming into hospital each week, and was having cramps "on the machine". During discussion, the physician said that the patient should not be having pain during dialysis, and that any pain was likely to be of emotional origin. At this time the patient had an economic problem for which he required legal advice. He had already been given a form to obtain legal assistance, and when he brought this back at the next interview he specifically drew attention to a question which showed he had had a police offence, and enquired if this would debar him from free legal assistance. It is possible that concern over the need to disclose his appearance in court may have made him more tense and increased any pain he was already feeling.

Denial, as a defence mechanism, is common, particularly in patients who are inhibited and cannot express their feelings. One patient asked if his mother had been crying again and said: "This is the only thing that worries me." The social worker replied that when the patient used these words perhaps he also meant that he was upset about his illness, about his itching feet, his sleeplessness and his frequent epistaxis. The patient agreed with this. This patient's mother later remarked that before his illness he had been an active sportsman. She said: "I think the shock of his illness has locked him inside himself. You hold it inside and it takes something to bring it out." In later interviews this patient returned to the theme of his mother's crying. He felt that it would be good if he could cry himself, but he could not. After some discussion about the importance of expressing feelings, whether in words or by crying, he was able to break down and became aware of great relief. He went on to remark that he was never a person who complained, and that even as a child he did not tell anyone if he was in pain.

Another patient used the interviews mainly to discuss his involved economic problems, debts contracted during his illness, the difficulties of finding a new home near the hospital and how to obtain equipment recommended by his physician. On his fifth interview the patient came from the ward to the social worker's office wearing pyjamas and dressing-gown, looking like a vulnerable and pathetic little boy. Although his declared intention was to discuss one particular practical issue, he stayed in the office for an hour, expressed a number of fears and anxieties and spoke about his expectation of life. He understood from the physician that no one could tell him how long he would be all right—it might be for a week, or a month, or for twelve years. He would not want his wife to be burdened with repayments for their house if he died, so he and his wife had decided they should sell their present home. After talking about the possibility of death the patient recounted several dreams which had upset him and said these unpleasant dreams might be due to the fact that he was taking drugs. This was accepted, but, knowing that the patient was to be discharged soon, the comment was made that it would be natural for the patient to be apprehensive about going home and how he was likely to manage away from the security of the hospital. This provided an opportunity for the patient to talk about his irritability and his fear that the children might get on his nerves. He then asked if he could be visited at home before he returned to work in a fortnight. This was arranged and the patient seemed reassured and less anxious.

This particular patient had numerous admissions to hospital. At his fifteenth interview he came without appointment. Much of the hour's discussion was concerned with liking and disliking people in his life outside the hospital, and the problems he had in relationships with hospital staff and patients. During the sixteenth and seventeenth interviews the patient again spoke about his financial position and his plans for the future. He hoped to make a large profit from selling his house and intended to buy expensive presents for his wife and children. Much of this discussion seemed to be wishful thinking, and when the social worker spoke of the need to obtain more factual information, he modified his proposed expenditure considerably. He was then able to bring up difficulties in the ward where he felt the Sister was "always on his back" although in fact the situation was one of misunderstandings on both sides.

The patient's problems and his unrealistic expectations were discussed with his physician, who felt it was essential for the patient to face the truth. He thought the patient might become depressed—which in fact did happen—but that it would be better for him to have this reaction at the present time instead of later when he was having his transplant.

At a joint interview the patient and his wife were given factual information about the financial position and about additional benefits the patient could obtain now that he was in receipt of an invalid pension. His wife had a realistic attitude and the patient was influenced by this. He revealed that much of the information about mortgages had already been given to him by the bank and it seemed that his previous grandiose plans for presents for the family had been a reaction to problems in the ward.

The patient went on to say that the previous week had been a bad one for him. He was tense because selling his house meant giving up all he had worked for and gained in the last seven years. He spoke at length about his depression and tension. "Things you think of in hospital, dreams and thoughts that come into your mind —it is just like a big spring inside you and you're going to bust. Everybody seems to be against you but they are not. You lie there and think about your wife and children walking across the road and getting run over. You think of the worst . . . think of your past life . . . the bad things you have done."

As this patient slowly worked through his problems he was able, by the twenty-third interview, to voice appreciation of the help given by one religious organization to his family and to suggest that in future he could use the hospital car for transport from his home, leaving the ambulance for people more seriously ill than he was.

By the twenty-eighth interview the patient and his wife had had all their debts reduced and were able to balance their budget. This patient showed his hostility to the loss of his relationship with the social worker on the occasion of her annual holiday when he confessed, on her return, that he had taken on further financial commitments. An incident such as this illustrates that transference may be as important in a patient with physical illness as it is in a psychiatric patient. This account clearly demonstrates the need for social workers to be skilled in therapeutic transactions.

Activity versus Inactivity

Much of modern medicine consists of the patient having things done *to* him, and his role has been traditionally passive. There are advantages in bringing the patient's family more actively into problems of treatment, especially in the management of chronic illness. Our policy has been to ensure that the patient and family are as fully briefed as possible. This is helpful to all patients, but is of particular importance in the management of patients who have marked obsessional or paranoid traits of personality.

In order to maintain the patient's confidence he is encouraged as early as possible to look after his own affairs. Early in the illness he may require assistance with his official correspondence. His temporary feelings of inadequacy are recognized and accepted. In addition to help with practical problems, something can be done for him as a gift. Later he can be encouraged to do more for himself. This diminishes tension in the home; tension arising from guilt in the patient and hostility in the spouse. In the words of one patient: "I felt more at ease at home, not so much in the way I was earning more money, but there was a feeling about being earning again. It's a mixed feeling, a feeling of self-importance again. Even though I was tired and I'd had it, I felt one hundred per cent. better in myself." He slept without sedation and was less irritable. He no longer worried about dialysis once he was employed. Even his small son had commented on his improvement. It is obviously important for members of the team to consider carefully how much the patient can do for himself, since this leads to a change of self image, reflecting more positive aspects of the personality.

SUMMARY

An account is given of the role of the social worker in a renal unit operating a recurrent dialysis and a renal homotransplantation programme. Over a period of two years, nineteen patients and potential donors were referred to the social worker because of specific psychosocial problems. Eight patients required minimal help, but others had extremely involved social, economic and emotional difficulties which required numerous interviews in the hospital, the home and visits to social agencies. As an example, work with one patient and a donor for the patient involved sixty-three interviews as well as innumerable letters and telephone calls.

The purpose of this paper is to show something of the psychosocial problems involved and what they mean to the patient, to the family and to the treatment team. They can be extremely complex, time-consuming and expensive and require a favourable social worker: patient ratio.

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