The Impact of Renal Failure on the South African Black and his Attitude towards Haemodialysis

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SUMMARY

Four years' experience with haemodialysis in South African Blacks has afforded an insight into their beliefs and superstitions about kidney function and kidney disease, the role of the extended family and the influence of traditional healers on the pattern of management of patients with chronic renal failure. Despite a vastly different cultural background and basic ignorance of biology, their reactions and adaptations to maintenance haemodialysis are closely similar to those reported from modern Western societies.


The South African Blacks of Soweto, Johannesburg, who are catered for by Baragwanath Hospital, are by Western standards relatively unsophisticated, poorly educated (Table I) and indigent (Table II). Their concepts of kidney function and kidney disease differ vastly from those of Whites, and their faith in the traditional witchdoctors, as well as their family relationships, influence the medical management of terminal chronic renal failure (CRF).

Regular haemodialysis is a recent advance in the management of terminal CRF in this community. A great deal of tact, patience and understanding is required in order to teach the patient the principles of renal function and renal disease and to explain what will be required of him while on the programme.

In order to co-ordinate information about patients, a 'team conference' including the renal physician, social worker, head dialysis nurse, junior medical staff and members of other rehabilitation disciplines and agencies has been initiated. Each patient is discussed in detail and professional expertise and knowledge of patients' problems are shared. The knowledge and experience so gained over a 4-year period form the basis of this communication.

Beliefs and Superstitions

The average Black patient does not associate kidney function with urine formation, which is usually attributed to bladder function. The kidneys are rather associated with sexual function and this is usually termed 'the essence of life'. Venereal disease, witchcraft, ancestral wrath and sexual misdemeanours are the common explanations for kidney failure. For example, a man who develops uraemia and oedema is alleged to have had sex with a mourning widow. This is considered serious, as there is a threat of death. The Black medicine man is immediately summoned and a definite ritual is performed or herbs are given. This may give temporary relief, but when the state becomes chronic a physician is usually consulted.

A ritual has to be performed or herbs have to be taken by both husband and wife following the wife's miscarriage or abortion in order to calm down the ancestors. Failure to do so is alleged to cause urinary retention and persistent backache.

Impotence is attributed to venereal disease, overindulgence in sex, sex with older females, and sometimes to witchcraft by wife or consorts.

Driving of a heavy motor vehicle for a prolonged period is discouraged as this is associated with backache and urinary retention.

Patient Selection

The criteria for acceptance in the haemodialysis programme are comparatively liberal. The only patients absolutely excluded are those above the age of 60 years, those with a proven major psychosis and those with a proven systemic disease, the prognosis of which is considered to be less than 5 years.

Initial peritoneal dialysis, while the patient is being assessed, produces extreme discomfort and pain, so that although some patients readily accept the offer of haemodialysis or kidney transplantation, others feel they would
rather not be told of any other form of treatment. Consequently, they refuse treatment and leave hospital; some return later in a deteriorated condition and then accept haemodialysis. A small group of patients never return.

This hesitance on the part of the patient to embark upon a generally acceptable form of treatment is based on a variety of factors. Informing the patient of the diagnosis of terminal chronic renal failure often produces a state of crisis. Choice is limited to haemodialysis, transplantation or death. The Black social structure, through the extended family, assumes major significance. Decision-making devolves upon the patient, his eldest sibling, his parents if they are alive, the husband (in the case of a married woman) and other relatives. The males usually, but not invariably, have the greater authority, but the status and role of each member of the family is clearly defined. Interference by a social worker with family decisions may be resented. The family may react to this intrusion and may influence the patient to abandon hospital treatment and to seek help elsewhere.

In order to help the patient and his family make a decision about haemodialysis, the diagnosis, treatment schedule and requirements from the patient are carefully explained. Difficulty is often experienced in explaining the natural history of chronic renal failure to a layman with very little education and limited knowledge of organ function. He knows nothing about biochemistry and such concepts as loss of renal tissue, electrolyte imbalance and raised blood urea are completely foreign. Moreover, his vernacular has no equivalent terminology to explain these concepts.

The patient may listen attentively while his condition and the times of treatment are being explained, but he will be wondering why this has happened to him and whether witchcraft is not in some way involved.

The patient may have come to hospital to seek a second opinion and help, after the witchdoctor or diviner has failed him, and may find difficulty in reconciling the opinion of the witchdoctor with the present diagnosis. At the back of his mind he may still be clinging to the explanation of aetiology given by the witchdoctor or diviner. The natural history of kidney failure as given by the physician may not be understood. He may be unwilling to express his doubts, for fear of provoking a reaction in the physician (usually White), and may even be reticent in conveying his thoughts and feelings to Black staff members.

Once the haemodialysis programme has been explained, the patient is left to make his decision. He is free to obtain a second opinion from his relatives, if time permits and if they are close at hand. At this stage the patient may realize his inability to control his destiny and may be unsure what he ought to believe.

Bureaucracy in the hospital may also contribute to this realization. As an inmate of an institution, the patient may sense a lack of control over decisions which could affect his life and over movements from one department to another. His ego as a man, or as a decision-maker, is overlooked. He feels powerless, powerless and isolated, and has a sense of self-estrangement and impotence. There is sharp demarcation in the status of patient and staff, with a great deal of social distance created by the bureaucratic structure of the hospital. The patient sees his physician only during ward rounds. This makes it difficult for the physician to affect the social, cultural and psychological milieu of his patient.

**Reaction to Haemodialysis**

A significant implication for the social worker and the renal unit team is the reaction of the patient and his relatives to haemodialysis. Dialysis is a new concept for the patient. Although he may have accepted admission to the programme, he may wonder how he would tolerate dialysis and how his relatives would react to him. His relatives might in turn wonder how they would react to the patient and what effects his diagnosis and treatment would have on the rest of the extended family. Both patient and relatives might wonder what effect the illness and treatment will have on the patient's employment.

For new patients dialysis can be a frightening experience. The patient observes his blood being led into the artificial kidney machine from his artery and then returned into his vein. He also observes his shunt clamped at the end of dialysis. He may have several kinds of mental images of himself, as not fully human.

**Patient Inter-relationships**

Patients on the dialysis programme usually befriend each other and take a keen interest in one another's progress. They compare notes and give each other moral support. Quite often, inaccurate information or advice is exchanged. When a patient becomes acutely ill or dies, the other patients become disturbed, withdrawn and depressed. They may misinterpret the cause of death and assume that the same fate is in store for them. Patients also tend to model their behaviour on that of other patients. This may be beneficial, but is not infrequently detrimental, to their management.

**Dietary Restrictions**

The patient is carefully instructed about restrictions on fluids and foods, but quite often these are ignored. The patient may have failed to regain the role in his family and in society which he occupied before his illness. Violation of the restrictions imposed on him may be a means of denial of treatment and therefore of illness, or a form of rebellion against his situation. It may also be a means of relieving anxiety or tension.

Acceptance by the patient of the need for long-term haemodialysis does not necessarily imply rejection of the opinions of the witchdoctor or diviner, and the frustration of prolonged treatment may prompt the patient to return to the latter. He could, at this stage, be advised to suspend treatment and to watch the progress of his condition himself.

**Socio-economic Aspects**

Attending for 12 - 18 hours' dialysis per week presents numerous social and economic problems, which may
also have a bearing on the patient's employment. Some employers are unsympathetic, so that patients lose their full-time employment and are compelled to seek part-time jobs. These are difficult to obtain and are not very remunerative. Unemployment benefits are meagre and are not always readily obtainable. Hence, patients fail to meet commitments, and in fact the majority of patients are indigent (Table II).

Another source of insecurity for the patient is the question of the legality of his domicile in Johannesburg. Should he be resident in Johannesburg on the basis of a labour contract, his illness could lead to the loss of his job and, consequently, the loss of his right to remain in the Johannesburg area. The relevant authorities are aware of this problem and are prepared to make concessions in such cases. They have also made housing available for the use of patients referred from other areas for haemodialysis. Despite these privileges, some patients, when told of the implications of long-term dialysis, prefer to return to their rural place of origin. Once such a decision has been made, not even the warning of certain death in a short time will make the patient change his mind.

Domestic Factors

The disorganization and disruption of family life often produces domestic anxieties and crises for the patient on haemodialysis. The patient from outside Johannesburg may be separated from his family for extended periods in order to be close to the treatment centre. He is then unable to travel long distances to attend to kinship matters. The patient who has returned to his former occupation and has dialysis at night will have little time with his family. This often leads to imagined or real neglect of the spouse and children, while the children become more attached to the other, healthy parent. For the same reasons the healthy spouse may desert the patient.

Long-Term Adjustment

The personality of the patient himself is often a major determinant of the course of his treatment. The ideal patient is one who takes an active interest in his condition and his treatment, understands the need for dialysis and attends regularly. He may complain about the long hours of dialysis or restrictions of diet and activity, but he is basically happy. At the other end of the spectrum is the patient who, despite dialysis and improvement in well-being, does not accept the diagnosis or the treatment. As soon as he is discharged for outpatient dialysis, this patient will abscond and never return. Such a drastic step may be based on resentment toward the medical or nursing staff and is often precipitated by a reprimand for dietary indiscretion. It may also be for the purpose of returning to the traditional healers. In an analysis of 63 patients, it was found that 17% of males and 26% of females tended to default from dialysis frequently or to abscond totally from the programme, sometimes after a period of irregular attendance (Table III).

In the majority of cases the patient falls between these two extremes. He may be completely passive, so that al-

<p>| TABLE III. ANALYSIS OF ATTENDANCE FOR HAEMODIALYSIS OF 63 PATIENTS |
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<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
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<tbody>
<tr>
<td>Total</td>
<td>36</td>
<td>27</td>
</tr>
<tr>
<td>Defaulters</td>
<td>4 (11.0%)</td>
<td>7 (26.0%)</td>
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<tr>
<td>Absconders</td>
<td>4 (11.0%)</td>
<td>1 (4.0%)</td>
</tr>
<tr>
<td>Both</td>
<td>6 (17.0%)</td>
<td>7 (26.0%)</td>
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though trusting the medical and nursing staff and social worker, he shows no interest in his condition or in the activities of the renal unit. His attitude may, however, be negative rather than passive, so that the need for a small operation may be sufficient for the patient to refuse further treatment or to abscond. Even worse and more frustrating to the attending staff is the patient who seems to have no insight into his condition. He will not adhere to dietary or fluid restriction, nor will he attend regularly for haemodialysis. Then there is the patient who co-operates in treatment but will not return to work although potentially fully rehabilitated.

DISCUSSION

It has become increasingly obvious that patients in terminal chronic renal failure are subject to tremendous psychological stresses and require major expenditure of psychic energy, in order to adapt to the strains of their illness and the necessary medical procedures. In addition, some degree of organic mental impairment has been stated to be present in all, or nearly all, patients with chronic renal disease, although this is not a universal finding. The adaptation of a patient to long-term haemodialysis and the degree of his eventual rehabilitation are profoundly affected by these psychological and intellectual burdens. The South African Black is at a further disadvantage by virtue of his cultural and family background, his beliefs and superstitions, his low educational level and his socio-economic problems. Nevertheless, the reactions to haemodialysis among this group of patients were not strikingly different from what has been reported in the British and American literature for (presumably) fully Westernized patients, who were predominantly or wholly Caucasian.

A great deal of effort has been directed toward defining those factors in a patient's psychological make-up which would assist in the prediction of his responses and degree of adaptation to long-term haemodialysis. Our patients were not studied in such detail, but it appeared that sophistication, intelligence or education were not necessarily prerequisites for adaptation to, or compliance with, the dialysis regimen. It was also not possible to define any medical or social background variables which correlated with adjustment to treatment.

Once on the programme, the dialysis patient is subject to numerous stresses, both physical and psychological. Our patients are certainly subject to these stresses, but they also have to reconcile their illness and its treatment with their preconceived ideas about kidney function. In addition, they have to cope with the relationships of the extended family and the influence of faith-healers and
denial, as well as the socio-economic stresses related to employment and legality of domicile. And all this adjustment must take place in the hospital environment, where the language spoken is not the patient’s mother tongue.

The emotional reactions of patients on haemodialysis have also been well defined. The main defences appear to be those of denial, displacement, isolation, projection and reaction formation. Prior to starting dialysis the patient experiences feelings of sadness, helplessness and anxiety. Long-term responses may be in the form of regression, related to dependency on the doctor, the nurse or the social worker, depression related to damaged self-esteem, and denial which may be adaptive or maladaptive. Our experience with Blacks on haemodialysis is that their reactions and responses are very similar to those described by others. Denial is commonly encountered and not infrequently results in the patient refusing entry to the programme or defaulting. Distortions of body image, where the patient thinks of himself as part of a machine or where he endows the machine with human qualities, were also observed in this study. Although overt suicide has not been encountered, other acts, which may be interpreted as self-destructive, have occurred. Overtly aggressive behaviour seldom occurs, but lesser degrees of aggression may be the explanation for dietary indiscretions, non-adherence to instructions and poor compliance with the dialysis regimen in some patients. We would, however, agree with the view that a major problem with the unco-operative patient may lie with the unrealistic expectations of the staff, which re-inaforce his recalcitrance to treatment.

CONCLUSIONS

The average South African Black patient with terminal chronic renal failure who requires haemodialysis has a social, cultural and educational background vastly different from that of Whites. Despite these differences the stresses to which he is subject while on a haemodialysis programme are similar, and his responses to these stresses are alike.

From the point of view of the attending physician, however, there are many differences in the approach required. A great deal of tact and understanding is necessary, a detailed explanation of all procedures is essential, and patience is required while the patient, the family and the social worker deliberate on the decision whether to accept the offer of long-term haemodialysis.

Once on the programme, the patient often becomes extremely dependent and, once again, patience, tact and understanding are needed in order to gain the requisite cooperation of the patient for the strict requirements of chronic haemodialysis.

REFERENCES


Books Received: Boeke Ontvang


