Blind Spots in Home Dialysis

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Five year survival rates of 60-90% indicate that regular dialysis treatment is an effective means of preserving life in patients with terminal renal failure. Home dialysis, in particular, has proved to be highly successful and offers a satisfactory and economic solution to the problem of availability of treatment for patients awaiting or unsuitable for transplantation (Parsons et al, 1971).

Survival statistics, however, give no indication of the success or otherwise of this form of treatment in returning patients to a reasonably normal way of life. They take no account of residual physical or social handicap nor do they assess the so-called quality of life of these patients. It may be argued that such considerations exceed the prime purpose of RDT which is to maintain life. Alternatively, it may be argued that having achieved survival, it is the duty of the dialysis unit to examine the quality of life provided for these patients.

The Regional Renal Unit at St Bartholomew's/ St Leonard's Hospitals has a five year survival rate of 90%, and home dialysis on Kill dialysers for 30 hours weekly, has long been the treatment of choice. The patients are clinically well and superficially they fulfill the medical staff's expectations of home treatment — that is they are independent of the hospital; they are able to work and to lead virtually normal domestic and social lives (Baillot et al, 1967). When the situation was examined in greater depth, however, it was obvious that there were wide discrepancies between the hospital's concept of home dialysis and the patient's experience of it.

MATERIALS AND METHODS

As part of a study on social rehabilitation, interviews were held with 25 home patients all of whom had dialysed at home for at least six months. The interviews were based on a detailed questionnaire and were conducted by one non-medical member of staff. The patient's spouse or parent was interviewed separately. Of the 25 patients 14 are men, 11 women; 23 are
married and 2 are single. Their ages range from 17-50 years and they have dialysed at home for periods ranging from 6-48 months (Figure 1).

RESULTS

In considering the patients' work record, it emerged that prior to dialysis 22 of these patients were working; 2 were housewives and 1 was a student (Figure 2). On dialysis, 18 are still working; 4 women have given up work to concentrate on the home and one student continues his studies. This gives an 80% success rate in returning patients to work and compares very favourably with other reports (Baillod et al, 1968; Kossoris, 1970).

However, a closer examination of this 'return to work' revealed that only 55% of the patients currently employed had in fact returned to their previous employment (Figure 3) and of these, half had had their jobs modified in some way because of dialysis – no longer doing the heavy work, no longer working overtime, no longer allowed to climb stairs, no longer allowed to take responsibility. This meant that 45% had had to find new work because the demands of dialysis rendered their previous jobs unsuitable. Return to work cannot therefore be equated with return to previous employment or return to previous earning capacity.

One of the main reasons for working is to earn money to support the family unit. The earnings of the 18 patients at work showed an increase in five, no change in six and a decrease in seven. Combined family income
However, is a more significant indicator of the impact of home dialysis on the household (Figure 4). Taking family earnings as a whole, 56% suffered an appreciable drop in income. This difference between individual earning capacity and family earnings was caused by another member of the family working fewer hours, losing overtime payments or ceasing work altogether. The reasons given for this were tiredness and the amount of time taken up with dialysis preparations.

Since reduced family income was attributed to the time needed for dialysis we examined the work load generated by home treatment. All patients use automatic supply units which require little attention and a minimum of work. Dialysis is by Kiil dialysers which are either stripped and rebuilt after each treatment or reused for a maximum of three dialyses. Building the kidney is the main chore but there are many other small tasks which taken together add an average of 8-10 hours per week to the 30 treatment hours. Where there is a wife at home, be she patient or spouse, the dialysis chores can be fitted into the domestic routine without much effort. When both are at work this extra load can be a great burden. In a third of the families interviewed one member other than the patient has given up work
or is working fewer hours because of dialysis. This is, of course, a voluntary reduction in work but giving up work means giving up earnings in a situation where domestic costs are bound to rise.

It has been suggested that under a nationalised health service the cost of home dialysis to the patient is a social one. This is only a half truth. There are concealed financial costs which arise from dialysis treatment and relate to two factors – the need for a separate treatment room and a special diet.

Where there is no spare room the family is involved in the inevitable expense of acquiring one. Only 10 of the families interviewed had sufficient accommodation (Figure 5). Two families moved house privately; six had an extra room built on to their house and seven were re-housed by local housing authorities. Thus 60% of these families incurred expense in obtaining a room for dialysis. Once there is such a room, the dialysis equipment is provided free by the Department of Health and Social Security. Water and electricity are installed by the local health authority who have the power, in certain circumstances, to recover part of the cost from the patient. It is the patient who must supply the bed and bedlinen and, once established at home, he will have extra heating and lighting costs and possibly extra laundry bills. Housekeeping costs inevitably rise with home dialysis.

The other factor mentioned by all the patients was the cost of the diet. This highlights one of the paradoxes of dialysis. The aim of the treatment is

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<th>40%</th>
<th>ROOM AVAILABLE</th>
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<tr>
<td>60%</td>
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<tr>
<td></td>
<td>EXTRA ROOM BUILT 6</td>
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<td></td>
<td>REHOUSED BY LOCAL AUTHORITY 7</td>
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Figure 5. Provision of spare room

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<tr>
<th>WEEKLY FOOD EXPENDITURE PER HEAD</th>
<th>U.K. 1971</th>
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<tr>
<td>NATIONAL AVERAGE</td>
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<tr>
<td>R.D.T. DIET</td>
<td>£4.20</td>
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Figure 6. Weekly food expenditure
to return patients to a normal way of life. This includes using normal food, although it has to be cooked differently. To maintain a high Calorie intake it is necessary to use many foods which are expensive but because they are ‘ordinary’ foods there is no means of subsidizing them on medical grounds. The average weekly expenditure on food in Britain in 1971 was £2.30p (National Food Survey 1971). The average weekly cost of an RDT diet in East London in 1971 was £4.20p (Figure 6). The difference of almost £2 must be borne by the patient.

When considering the social restrictions imposed by RDT, the conventional wisdom is that well dialysed home patients are able to lead virtually normal social lives. Detailed interviews revealed, however, that a major limiting factor to an active social life was tiredness and lack of energy. This in part resulted from lack of sleep. To return to work patients must dialyse overnight. They must also be able to sleep during the night and to enable them to do so the equipment is designed to be fail-safe. In practice, however, only 10 of these 25 well established home patients were able to sleep on dialysis nights (Figure 7). A similar pattern emerged for their helpers. The reasons given for this insomnia were discomfort through not being able to move easily and, above all, anxiety about the equipment. The implication from this is that patients are not convinced that the equipment is entirely fail-safe.

A striking example of this was the patients’ anxiety about the level of blood in the bubble trap. Blood level monitors have not been used in the Unit. This decision was based on the assumption that with good dialysis technique, the hazard of a sudden fall in blood level resulting in air embolism was negligible. What was not realised was the importance attached to the level of blood in the bubble trap during home training. The result was that while patients were quite confident in the fail-safe mechanisms of temperature, conductivity and the like, they were chronically worried about a fall in blood level. In some cases the patient or spouse deliberately wakened each hour throughout the night solely to check the level of blood in the bubble trap. We are now firmly convinced of the need for a bubble trap monitor,

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<th>Patients</th>
<th>Good Sleep</th>
<th>Little Sleep</th>
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<td>10</td>
<td>15</td>
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<th>Helpers</th>
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<td>12</td>
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Figure 7. Sleep on dialysis nights
principally to give a sense of security during treatment and thus remove one obstacle to sleep.

Social rehabilitation, particularly in home treatment, involves not only the patient but his wife and family. One of the problems of home dialysis is to encourage independence and yet avoid domestic strife. Traditionally, the emphasis in training has been to encourage self sufficiency in the patient and to make him independent of the institutional protection of the hospital. A possible consequence of this approach is that the patient finds it difficult to admit to faults or problems at home lest they be taken as signs of inadequacy. He thus becomes an unreliable witness.

The practice at this Centre is to review the patient at regular but infrequent intervals. It has proved extremely valuable to encourage the spouse to accompany the patient on these occasions. In this way a number of cases have come to light where the patient appeared to be dialysing successfully but was doing so only at the expense of considerable disruption of family life. By consulting a 'second opinion' on the progress of home dialysis, it may be possible to identify social discord and take appropriate action before major problems develop.

DISCUSSION

These are some of the 'blind spots' in our home dialysis programme which came to light as a result of detailed discussions with the patients. Having identified these problems, how can they be resolved? As regards work the important point to be recognised is that more often than might be expected a change of employment is necessary and patients must be advised accordingly. With prolonged survival retraining schemes may have to be considered.

If the significant factor in the loss of family income is the time taken preparing for treatment this can be reduced by automated equipment and disposable dialysers which are both cheap and efficient. Much of the increase in family expenditure is directly related to the need for a separate treatment room. This will remain a problem until the equipment is miniaturised to allow its use unobtrusively in a normal bedroom. Dietary costs relate to the insistence on a very high Calorie intake. As an experiment we have reduced the Calorie content of the diet with no ill effect to the patient but an appreciable saving in costs. The problem of tiredness and lack of energy is a major one contributed to by sleeplessness and by anaemia. Chronic anaemia remains one of the outstanding unresolved medical problems of RDT. Sleeplessness, however, can be more readily dealt with when it relates to lack of confidence in equipment. It is perhaps salutary to reflect that in the design of fail-safe devices the criteria are all too often set by the physician with little regard to patient acceptability.

It can be argued that these are refinements and exceed the aim of RDT
which is to maintain life. But it is precisely when that aim is successfully achieved and the patient is able to work and to resume normal life that the quality of that life becomes important. By adopting a 'consumer approach' to home dialysis we have come to modify and, we believe, improve our practice in a number of ways. We would submit that the traditional view of medicine concerning itself only with the immediate success or failure of treatment can no longer be accepted and that, in a very particular way, dialysis highlights the social and economic consequences of medical decision making.

REFERENCES

Kossoris, P. J. (1970) 'An exploration of the employment problems encountered by haemodialysis and kidney transplant patients.' The Kidney Foundation of Northern California

OPEN DISCUSSION

A C KENNEDY (Glasgow, Chairman): Thank you for this high powered look at life on home dialysis, compared with the low powered scan we had in the previous paper. What happens in Europe? This paper is now open for discussion.

W DRUKKER (Amsterdam): I wanted to emphasise that you need a bubble trap alarm with an electromagnetic clamp on the venous line, otherwise you still have a danger.

GORDON: I think we accept this.

A R LAVENDER (Hines, Illinois): I would like to compliment Dr Gordon on a very carefully documented and important paper. For some years a number of us interested in hardware in this field have been particularly concerned with the need for further simplicity and reduction in size of equipment, and I think if you look at Dr Gordon’s paper carefully you will see that what we need is the provision of very simple, easy to use, safe equipment that anyone who can drive an automobile can operate without danger or fear of operation. When we reach the point where one can drive a dialysis machine more safely than you can drive in Florence, I think we have probably achieved a great deal, and I would like to emphasise the need for this equipment.
GORDON: I can only agree.

KENNEDY: You'll accept that there is a certain mortality with automobiles also, of course!

J W CZACZKES (Jerusalem): I would like to make a comment on the question of caloric intake. We have a group of patients in whom, because of cultural background, we have been unable to give the sort of high calorie diet we thought necessary, and during the last two or two and a half years it emerged that in spite of the low calorie intake, they are doing quite as well as others. Now we have actually stopped pushing patients against their will to take a high calorie diet.

KENNEDY: This is confirmation that you can give your patients rather fewer calories.

F ADLER (San Francisco): I was wondering about the work load, which you indicated took the majority of patient time. Do your patients store their kidneys and, if so, how often do they reuse? With our patients, I don't think this takes the majority of home time.

GORDON: Well, we use KiiI dialysers and some of the patients reuse them for a maximum of three times: therefore the dialyser is built once a week. Some of them choose to build it every time after each dialysis.

ADLER: Did you find any difference between those that were rebuilt, as opposed to those that were stored, as to preparation time?

GORDON: Yes, there is a reduction in time, of course, if you reuse that makes a great difference.

J R de PALMA (Los Angeles): I think there is another blind spot that might be exposed. Until about 1969 we used KiiI dialysers, but because with this dialyser you are dialysing patients from 28-34 or even 36 hours a week, we investigated the use of disposable dialyser coils. Since 1969 we have used coil dialysers for a total of 18 hours per week, which saves appreciably in time, which is probably the most precious thing that a patient loses when he is placed on regular haemodialysis. I would suggest that with the high efficiency dialysers we are presently investigating, we will probably drop the total dialysis time per week to 12 hours: that is three times 4 hours a week.

GORDON: I think this would be a major contribution. Any way in which we
can reduce the amount of time patients have to be on the machine is welcome and I am sure disposable kidneys will help.

GIACCHINO (Italy): I wish to know if in the home the patients use arterio-venous fistulae and whether they have any difficulties putting needles in the vessels. Do they do this by themselves, or with some relative?

GORDON: Almost all our home patients are using a fistula. I think we have two shunts still, but everyone else is on a fistula and practically all the patients put in their own needles. There are one or two cases where the spouse does the needling, but we try always to encourage the patients to needle themselves, and by and large this is very successful.