A Patient’s Experience of Over One Thousand Haemodialyses
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During the past eight and a quarter years I have been dialysed regularly over 1,000 times in three different countries, in both hospital and home, with treatment techniques which have, in certain ways, varied considerably.

I have given here a brief report on my progress during regular dialysis, mentioned certain problems which I have encountered personally, and discussed some observations.

MEDICAL HISTORY AND EARLY MANAGEMENT

In 1949 (aged 8) proteinuria was first discovered, and an orthostatic cause was diagnosed later after extensive investigation of the renal tract. During the following 13 years the proteinuria persisted and I had recurrent sore

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<th>Table I. Medical history</th>
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<td>1949 (aged 8 years)</td>
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<td>1950 to 1962</td>
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<td>1962</td>
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<th>1962/1963</th>
<th>Conservative management</th>
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<tr>
<td></td>
<td>Hypotensive drugs: methyl dopa (up to 2.5 g/day)</td>
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<td></td>
<td>hydrochlorothiazide</td>
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<td>Protein restriction (20-30 g/day)</td>
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<td></td>
<td>NO salt and water restriction</td>
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<tr>
<td>February 1963</td>
<td>First dialysis in Seattle</td>
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<td></td>
<td>BUN 120 mg/100 ml</td>
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<tr>
<td></td>
<td>Plasma creatinine 20.7 mg/100 ml</td>
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<td>Creatinine clearance: 2 ml/min</td>
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<td>Salt and water overloaded</td>
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throats; but I felt well generally and led a normal and active life. In 1962, I presented with features of chronic renal failure and accelerated (malignant) hypertension.

Early management (10 months) was conservative, and large doses of hypotensive drugs were needed to control my blood pressure. Dietary protein, but not salt and water, was restricted. I had my first dialysis in Seattle in February 1963.

Relevant points are summarised in Tables I and II.

DIALYSIS DATA

![Dialysis Data Diagram]

Figure 1. A = 20 to 24 hours weekly of refrigerated (20°C) recycled tank dialysis.
B = 20 hours weekly of warmed (40°C) single-pass tank dialysis.
C = 28 hours weekly of warmed single-pass dialysis, using both tank and automated central supply systems.
D & E = 30 hours weekly, with individual patient automated dialysate supply
and monitoring unit (mainly 'Dylade' system B)
Number of years of hospital dialysis: 5 years
Number of years of home dialysis: 3.25 years
DIALYSIS TECHNIQUES

The modified two-layer Kii1 dialyser with Cuprophane membranes has been used exclusively, except on one occasion recently, when an AB Gambro disposable dialyser was substituted.

The type of dialysate supply, whether in hospital or in the home, and the hours of treatment per week are shown in Figure 1.

The composition of dialysis fluid has varied considerably through the years. Perhaps the most important changes have been in the concentrations of dextrose (2.0-2.5 g/100 ml to 180 mg/100 ml), calcium (2.5-3.75 mEq/l) and sodium 125-130 mEq/l to 135-140 mEq/l). The dialysate potassium has varied between 0 and 2.5 mEq/l.

Initially fluid removal during dialysis was effected by using high dialysate dextrose concentrations, but for most of the time negative pressure has been employed. As a rule, a blood pump was not used with the external shunt, but more recently one has of course been needed for the external fistula.

COMPLICATIONS OF DIALYSIS (Table III)

In general, hypotension and muscle cramps have been the most common problems. The incidence of these complications has been about the same in hospital as in the home, except recently, during the past year, when hypotension in particular has been more frequent. This is in spite of adjusting the dialysate sodium concentration to 135-140 mEq/l (previously 130 mEq/l).

Table III. Complications and side effects of dialysis

1. Hospital
   Hypotension, headaches, cramps
   Insomnia and apprehension
   Multiple pyrogen reactions
   Bacteriæmia
   Hard water syndrome
   (Shunt infection)

2. Home
   Hypotension, cramps

Technical failures are more common in hospital (ie mechanical problems, blood leaks, clotted dialyser etc)

All of the more serious and potentially dangerous complications have occurred in hospital. These included the hard-water syndrome (without convulsions), Clostridium welchii bacteriæmia, and an episode of brain-stem ischaemia following a technical fault which caused a retrograde injection of a bolus of 0.9 g/100 ml saline up the radial artery at the start of dialysis.
The most painful and temporarily a most unpleasant episode followed the passage of formalin from the dialyser into my blood stream at the start of dialysis in hospital on one occasion.

Recurrent, sometimes severe pyrogenic reactions caused considerable distress, and they occurred when both tank and automated individual patient dialysate supply systems were used in hospital. Occasionally spore-bearing micro-organisms, diphtheroids, and *Pseudomonas aeruginosa* have been isolated from samples of dialysis fluid taken at the time of reactions, and blood culture once grew *Clostridium welchii*, but more frequently cultures were sterile. This would suggest that the pyrogen was, in many instances, some substance such as a bacterial product rather than viable bacteria themselves.

After starting on home dialysis, there was an immediate and complete cessation of pyrogen reactions which has continued for the full duration of three and a quarter years, except twice when rigors have recurred. Once they followed routine servicing of the water softener, and since this system has been regularly formalinised, there has been no further trouble.

**BLOOD PRESSURE AND SODIUM INTAKE**

In 1962, when I first presented, my blood pressure (BP) was 240/150 mmHg. Control of hypertension (BP range 160/110 to 200/130 mmHg) was a major difficulty in conservative management, and large doses of hypotensive drugs were needed. Just before dialysis was started, these drugs were completely withdrawn, and for the first time sodium and fluid were restricted; immediately, my BP became less labile and better controlled. Within two to four

![Figure 2. Changing relationship between blood pressure, sodium intake and weight](image-url)
months of starting on dialysis it had come down to normal levels, and I have since remained essentially normotensive (average pre-dialysis BP <160/100).

Initially, and for the first two years, a dietary sodium of 20 to 30 mEq/day was strictly adhered to, but since then it has gradually increased to 60-100 mEq/day. In spite of this change, and the fact that I have been totally anuric for over five years, my average BP between dialyses has continued to fall to lower levels and indeed, postural hypotension is now not infrequent. Moreover, after a loss of weight of 5 kg during the first year of dialysis, there has been a steady gain (Figure 2).

This observation would indicate that eight or nine years ago there was an extreme sensitivity to saline loading which has gradually diminished during the years on dialysis. On occasions recently, saline loading (3-4 kg) between dialyses has been sufficient to cause breathlessness and dilatation of neck veins, but has had little or no effect on BP.

It is also of interest that my plasma sodium (pre-dialysis) has tended to change from the lower to the higher end of the 130-145 mEq/l range, and that I have gradually become less thirsty after eating salty food. This has been particularly apparent when two friends (normal controls) became more thirsty than I after we had a similar meal in an oriental restaurant.

Gleadle et al (1969) noted that in their series of maintenance haemodialysis patients, severe hypertension was often associated with thirst, hypotension, and raised plasma renin concentrations, and that bilateral nephrectomy corrected these abnormalities. It would seem, therefore, that I have reached the situation analogous to the bilaterally nephrectomised one, and in an attempt to confirm this hypothesis, plasma renin studies are being arranged.

PERIPHERAL NEUROPATHY

A peripheral neuropathy, affecting mainly the motor function in the lower legs and causing a waddling gait, was most evident two to four months after the start of dialysis. Nerve conduction studies then showed diminished conduction velocity in the right common peroneal nerve (37 m/sec). The neuropathy improved clinically by increasing the total dialysis time by an extra four hours per week, but nerve conduction remained slightly defective for three to four years.

EXTERNAL SHUNT AND INTERNAL FISTULA

Total experience of the external shunt was eight years. Data is shown in Table IV.

On the whole, I had little difficulty with the external shunt. Only two limbs were cannulated, and there were only two overt infections. During the first eight months of its use, the formation of fibrin plugs at the joints in the U segment, usually occurring three to six hours after the termination of
Table IV. Data on external shunt

Total number of years in use = 8

Arterial cannulae:
- Number in arm = 3
- Number in leg = 1
- Total = 4

Average survival . . . . 2 years

Venous cannulae:
- Number in arm = 7
- Number in leg = 2
- Total = 9

Average survival . . . . 10.8 months

Longest surviving
- Leg arterial cannula for 3 years

dialysis, led to repeated clotting episodes. When regional instead of general heparinisation was used, the incidence of clotting was less (McLeod, 1964). It was our impression that some form of rebound phenomenon was affecting the clotting mechanism, similar perhaps to that noted in the study of heparin and thrombus formation in pigs (Mustard et al, 1963).

Whenever possible, cannula revision was done electively as this produced less psychological stress.

Experience of the internal fistula (right forearm) is only four months and it is therefore difficult to make a true comparison with the shunt. My wife does the venepunctures, and there has been no major complication. Haematoma formation following mispuncture, and infection of the skin at the puncture site have occurred, but neither was serious.

Although I do not feel that the transition from shunt to fistula has made much difference to my well-being, I am prepared to accept that I may prefer the fistula as my experience of it increases which is, I believe, the case for most other patients.

BLOOD TRANSFUSIONS

Up to 1967, I had received a total of about 130 units (each 540 ml) of blood. In order to maintain my haematocrit at 20% or more, transfusion requirements were as high as six units per month in 1964, but fell to one unit per month with better dialysis (Figure 1: B to C). With the adoption of a non-transfusion policy in my dialysis unit, and since changing from twice to three times weekly dialysis (Figure 1: C to D), no further blood has been needed, and my haematocrit now remains at about 25%.

Regular estimation of serum iron has shown a fall from high values
during the period of transfusion to lower values after transfusion ceased (Figure 3).

Because of the very large number of transfusions which I have had in the past, and previously high serum iron levels (with 80% saturation of iron binding capacity), I have not taken iron supplements. However, my serum iron is now low (55 µg/100 ml) with 22% saturation; but recent bone marrow examination showed excess iron stores compatible with those found in transfusion haemosiderosis. Wright et al (1968) found that there was a good response to parenteral iron in anaemic patients with low serum iron levels even in the presence of ample iron stores in the marrow. They postulate that there is inadequate availability and/or utilisation of iron during erythropoiesis in these cases. In view of these findings it would be of interest if my haematocrit rose after parenteral iron, but I am naturally reluctant to have iron supplements if they will merely add to my already substantial store.

WELL-BEING

I have summarised the more important factors affecting a dialysis patient’s well-being in Figure 4. We are affected not only by the factors which are above the dotted line but also by those below it. At different times during the past eight and a quarter years each factor has affected me to a greater or lesser extent.

In this context, the term well-being implies a totally subjective feeling of contentment, and is not something which has been assessed objectively.

Well-being was lowest during the period of conservative management when the dietary restrictions and side effects of the hypotensive drugs became almost intolerable; then a dramatic improvement was felt after dialysis was begun. With better quality of treatment and better health, my physical per-
formance and well-being have improved accordingly. The ability to work full-time has always been a strong motivating force, and since changing from twice to three times weekly overnight dialysis, I have been able to do this. The most notable improvement was when I married and changed from hospital to home dialysis (D to E in Figure 1). As mentioned above, dialysis complications occur less frequently at home; also I feel more secure and have greater confidence in running, with my wife's help, my own dialysis.

We have been fortunate to be able to take holidays abroad, and this facility has provided us with an important and complete change of environment which has always been welcome. We feel that better collaboration between dialysis units in different countries is desirable, so that other patients and their families can also take vacations.

CONCLUSION

For nearly seven years, apart from the time spent on dialysis, I have stayed only two nights in hospital, and for four years I have been working full-time as a hospital doctor or as a postgraduate student.

My way of life is immeasurably preferable now to what it was during conservative management, and it has improved with better treatment. On the whole it is enjoyable and I regard myself fortunate to be able to have dialysis, but the strain can be very great at times, both for myself and my family. I feel that I have progressed possibly as far as I will ever do so, in coming to terms with my dependence on the machine, and in moments of low spirits I find consolation in my belief that new developments with the artificial kidney or a successful renal transplant will provide a better alternative.
ACKNOWLEDGMENTS

I should like to extend my grateful thanks to the large number of people who have helped and encouraged me, including the doctors, nurses and other personnel of the dialysis units in Seattle, Edmonton and the Royal Free Hospital, London.

My wife and parents have given unfailing support.

Dr Stewart Cameron and Dr Rosemary Baillod kindly gave advice on the preparation of the manuscript.

REFERENCES


Pitman Medical, London


Excerpta Medica, Amsterdam.

OPEN DISCUSSION

M McGEOWN (Belfast, Chairman): Thank you Dr Eady. This is a most impressive presentation which must affect us all. It is now open for discussion.

W CATTELL (London): We have heard a great deal about the pros and cons of dialysis and transplantation, the quality of life and so on. Can I, perhaps rather unfairly, ask you, Dr Eady, your feeling at this time regarding transplantation as opposed to dialysis?

EADY: Thank you Dr Cattell. We calculated there was a 99% chance of me being asked this question in the discussion. We know that the quality of life, as Dr Parsons showed, is certainly better for patients with successful grafts. I suppose that I can be considered as a well rehabilitated home dialysis patient but obviously I would prefer to have a successful graft; what are my chances of this? At this time in my career, when I have got to the stage when it is very important for me not to take time off from work due to the competition which we all have to face, I don't want to take the plunge and alter my way of life. The other very important point which worries me is that as a physician having many patients in dermatology who are on systemic steroids, I really have a tremendous aversion to going on long-term steroid therapy. Does this answer your question?