High cost dialysis and transplantation — dilemmas for nephrologists and nations
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SUMMARY
The linked successes of dialysis and transplantation pose dilemmas for nephrologists struggling to meet the clinical need and for health care planners wondering where to find the resources required. The low rate of acceptance of new patients in the UK compares unfavourably with the service given in other countries. Successful rationing is achieved by a sparse distribution of centres and of specialists and operates through a low rate of referral of patients to nephrologists. Political initiative is beginning to emerge to redress the underprovision of facilities by setting realistic targets before regional health authorities.

INTRODUCTION: DILEMMAS POSED BY SUCCESS
It is the success of dialysis and kidney transplantation during the past 25 years which now poses dilemmas for nephrologists and nations. Renal replacement therapy (RRT) prolongs life for patients who would otherwise die of end-stage renal failure (ESRF). This life is of a reasonable quality and patients have an expectation that RRT will be offered to them if they need it.

The modern treatment of ESRF consists of complementary dialysis and transplantation. Most renal units have available both haemodialysis and peritoneal dialysis. Haemodialysis is carried out both in the hospital unit and by patients in their own homes. Peritoneal dialysis when used for long-term therapy is usually administered as continuous ambulatory peritoneal dialysis (CAPD). Individual patients may experience all these methods of therapy at various times in their careers on RRT. The treatments are thus termed 'integrated'. Reasons for choice of one therapy at a particular time include patient preference as well as medical and domestic considerations. Inevitably, economic factors enter into such deliberations and it is seldom possible to take these decisions for an individual without weighing their effect on the group of patients in a programme.

This paper presents data from the patient registry organised by the European Dialysis and Transplant Association-European Renal Association (EDTA-ERA) to illustrate the differences in provision of RRT in various European countries.1 Mechanisms which ration high cost medical care in the United Kingdom have been investigated.2 Ethical dilemmas for governments which provide health care and for doctors — in this case nephrologists — who dispense it are becoming ever more painful.

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THE COST OF DIALYSIS AND TRANSPLANTATION

RRT is expensive. The price is excessive for poor nations and not without embarrassment for the wealthier. It is a popular misconception that the cost of treatment is the price of a kidney machine. The capital cost of a machine which manufactures dialysis fluid and monitors the dialysis procedure is around £5,000 to £6,000. The revenue implications in terms of consumables — disposable dialysers, blood lines, dressings and drugs — amount to a further £2,000 to £3,000 per annum. In addition there are the overheads of the renal unit and its staff.

Overall costs of the different methods of dialysis and of transplantation in its first and subsequent years are given in Table I. Successful transplantation is obviously the 'best buy'. From this the economic importance of cadaver procurement is evident. However, nearly all patients experience a short or long period on dialysis while waiting for a suitable graft, and dialysis should also be provided for patients whose grafts have failed. A graft carries greater risks for certain patients but risks are diminishing as results improve and its lower cost will encourage doctors to offer transplantation to a wider spectrum of patients with ESRF.

TABLE I

Costs of various methods of RRT (Mancini, 1984)

| Method               | Costs (£)       |
|----------------------|-----------------|
| Hospital haemodialysis| 10,650 - 12,300 |
| Home haemodialysis   | 7,250 - 7,850   |
| CAPD                 | 6,050 - 6,950   |
| Successful transplantation: |         |
| First year           | 5,600 - 6,400   |
| Subsequent years     | 1,600 - 1,850   |

Mean survival exceeds ten years. A clinical decision to admit a patient to an integrated treatment programme therefore obligates approximately £100,000 at present-day prices. Because of good results, the stock of patients in a programme may be expected to continue rising for many years before it reaches a plateau. In no country has the number of patients alive on RRT yet levelled off. It must therefore be predicted that the economic burden in terms of personnel and plant will continue to increase.

The treatment of ESRF began in the 1960s, a period of expanding economies when even the moon was coming within the reach of mankind. In the United Kingdom, central funding was provided by the Department of Health and Social Security (DHSS) to get the programme off the ground. The geographical distribution of centres matched the major concentrations of populations and was a fine advertisement for a nationalised organisation moving in a co-ordinated and imaginative way to bring a new advance in therapy to the population it served. However, health authorities have since learnt that capital grants without an annual increment to meet the revenue implications are often less than welcome.

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The two decades of RRT have witnessed increasing concern at the cost of high technology medicine and the growing proportions of gross national product consumed by health care. Godber has discussed the need to strike a balance in health expenditure between therapy, prevention and support. He advocated compromise to provide the most for the most and not everything for a few. The small number of patients with ESRF whose treatment is readily costed are beginning to be seen as consuming more than their fair share of medical resources. Yet how fair was it that their lives should be held ransom by kidney disease which can only be treated by continuing substitution therapy rather than pneumonia cured with a week's antibiotics or a perforated peptic ulcer corrected by a single operation?

The conflicting claims of preventive measures and transplant surgery are not infrequently the cause of public debate and were the subject of an interesting correspondence in The Times in 1979. I have kept this correspondence on my files and while re-reading it recently found my attention riveted on one letter: " *** is entitled to write at length about prevention being better than cure in medicine as in other things. But I trust he will not overlook a substantial number of people for whom prevention will come too late . . . . " The reason why this letter so caught my eye was the name of the author: unknown to me when he wrote it five years before, he had in recent weeks become my patient and commenced dialysis.

NATIONAL DIFFERENCES IN THE PROVISION OF RRT

The EDTA-ERA Registry has a computer file of almost 150,000 patient records going back to the beginning of dialysis and transplantation in Europe. It is a uniquely comprehensive record of medical endeavour. Tables II and III and Figures 1-5 are derived from this data-base.

### Table II

*Number of centres and of patients per million population (pmp)*

*on 31 December 1983 in various European countries*

|                          | Pop. (millions) | Known centres pmp | Registered patients pmp |
|--------------------------|-----------------|-------------------|-------------------------|
|                          |                 | Haemodialysis     | Peritoneal dialysis     | Graft | TOTAL |
| Benelux*                 | 24.2            | 4.5               | 161                     | 14    | 62    | 237   |
| Fed Rep Germany          | 61.2            | 4.9               | 221                     | 6     | 31    | 258   |
| France                   | 53.4            | 3.9               | 202                     | 17    | 36    | 255   |
| German Dem Rep           | 16.8            | 3.1               | 73                      | 1     | 24    | 98    |
| Irish Republic           | 3.3             | 1.5               | 51                      | 11    | 56    | 119   |
| Israel                   | 3.8             | 6.8               | 220                     | 24    | 57    | 301   |
| Scandinavia**            | 22.5            | 3.9               | 69                      | 21    | 98    | 188   |
| Spain                    | 37.0            | 5.0               | 190                     | 15    | 30    | 236   |
| Switzerland              | 6.5             | 5.2               | 166                     | 28    | 72    | 267   |
| United Kingdom           | 55.9            | 1.1               | 62                      | 23    | 68    | 153   |
| Yugoslavia               | 22.1            | 3.4               | 95                      | 1     | 6     | 103   |

*Belgium, Luxembourg and The Netherlands.

**Denmark, Finland, Iceland, Norway and Sweden.

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Table II shows the number of centres providing treatment and the cumulative stock of patients in each country, each figure being given per million of population to facilitate comparisons. The number of centres is a constraint on patient numbers and the low number of patients in the United Kingdom, only 153 patients per million population (pmp), is obviously related to the restricted number of centres, 1.1 pmp. Average work load per UK centre is thus much greater than in the average European centre indicating that British centres tend to be larger and probably more cost-effective. The stock of patients describes the current work load and the staff and facilities are related to this.

The opportunity for a new patient to obtain treatment is determined by the rate of acceptance of new cases and Table III shows the rates for patients aged under and over 65 in different countries. The low acceptance rate in the UK particularly disadvantages patients aged more than 65.

**TABLE III**

*Rate of acceptance of new patients of all ages and over 65 per million population in 1983 in various European countries*

| Country              | New patients | New patients |
|----------------------|--------------|--------------|
|                      | all ages     | > 65         |
|                      | pmp          | pmp          |
| Benelux              | 52           | 11           |
| Fed Rep Germany      | 56           | 12           |
| France               | 44           | 10           |
| German Dem Rep       | 28           | 1            |
| Irish Republic       | 24           | 1            |
| Israel               | 67           | 13           |
| Scandinavia          | 52           | 8            |
| Spain                | 61           | 7            |
| Switzerland          | 55           | 10           |
| United Kingdom       | 33           | 3            |
| Yugoslavia           | 32           | 2            |

Not only do the constraints operating in the UK limit patient numbers, they also have a marked effect on the distribution of patients between different treatment modalities (Fig 1). Because of the limitation of hospital stations in the UK, patients who can only be treated by hospital haemodialysis (Fig 2) are accepted with reluctance because they might block hospital facilities which are the corridor to home haemodialysis, CAPD, and transplantation. A pattern of selection has emerged in which patients who are capable of independent treatment are accepted.
and those who are not are excluded. However, RRT in elderly and dependent patients has been shown to result in a satisfactory quality of life and worthwhile survival. Their exclusion from therapy in the UK cannot be justified on clinical grounds and can only be attributed to value judgements forced on doctors by the economic constraints under which they work.

Figure 2. Number of patients aged over 65 per million population on RRT in four large European countries according to method of treatment.

Figure 3 shows how the numbers of patients have accumulated year by year on different methods of therapy in the UK. Figure 4 compares the achievements in Northern Ireland. The population of 1.5 million in Northern Ireland is served by

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the single unit whose 25th anniversary is celebrated by this Symposium. The excellent results of transplantation\(^5\) have made a vital contribution here over the years. Unlike practice in the rest of the UK, CAPD has not yet been used extensively to help out hard-pressed hospital haemodialysis.

**RATIONING OF RRT IN THE UK**

All British nephrologists testify to the pressure under which their units are operating but it seems that they very seldom have to turn away patients whom they consider suitable for treatment and certainly never at the anticipated rate of 25 patients per unit per year. Is the need for treatment less in the UK? There is no evidence that the incidence of ESRF is lower in the UK than in other European countries. Then, where are the untreated patients? What is happening to them.\(^6\)

The answer lies in the mechanism of access to specialised services under the National Health Service. The patient cannot refer himself directly to the specialist who he deems will help him most. Hospital specialists only see patients at the request of their general practitioners. It is therefore possible that treatment rate is controlled by the physician who first diagnoses ESRF when he decides whether or not to refer a patient. The 'gatekeeper' could be the primary care physician but it seems more likely that it will be the consultant in the hospital where the diagnosis is made. Chronic renal failure requires only a biochemical test of the blood to make the diagnosis but before that is done it can masquerade under many clinical presentations since uraemia causes diverse symptoms. Moreover, approximately one-third of all patients with ESRF have followed an insidious course and present as acute uraemic emergencies, often requiring dialysis within a few days if not hours. Because of the low ratio of renal units to population in the UK, the patient has a four-out-of-five chance of being diagnosed in a district general hospital without a nephrologist or a renal unit. If he is to be treated he must be referred to another hospital, perhaps 50 miles or more distant from his home.

To test this explanation for the low treatment rate of ESRF in the UK we circulated a questionnaire containing 16 brief patient histories to a random selection of general practitioners and consultant physicians and to all nephrologists in the UK.\(^2\) The respondents were asked whether they thought each of the cases suitable for dialysis and/or transplantation. All the cases had complicating medical and domestic problems mitigating against successful good quality life on RRT. A significantly higher (\(p < 0.001\)) number of the 16 cases was rejected by both consultant physicians (7.4 ± 0.2) and general practitioners (6.9 ± 0.3) than by nephrologists (4.7 ± 0.3). Interestingly, the ranking of patients according to suitability produced a close correspondence between the three groups of doctors suggesting that factors other than specialist knowledge determined 'negative selection'.

The same questionnaire was also sent to colleagues in Europe and North America asking them to circulate it amongst primary care doctors and non-nephrologists. Negative selection averaged 0.3 of the 16 cases in North America, 3.6 in Western Europe and 7.5 in Eastern Europe, suggesting that decisions of British consultant physicians reflect an assessment of facilities for RRT in the UK on a par with the health services of communist countries.

Some of the unsolicited letters received with the questionnaires were particularly enlightening. Whereas we were told that in Europe and the USA a specialist nephrologist would virtually always have been consulted about the decisions, one
British consultant physician wrote: "... I worked at my local renal unit in a junior capacity some years ago. I have always referred on merit and not based on what I know to be the facilities locally but I have made the value judgements as to who is meritorious myself ... the decision is mine rather than my local renal unit's ... ".

It may be thought commendable that individual doctors can shoulder such a responsibility. That they can do so at all probably owes much to the social structure of our country and the traditional paternalism of our learned professions. In the face of such a system, which patients are likely to get through to the renal unit? The young and beautiful, certainly. The articulate and aggressive, possibly. Those whose families, parents, children and friends will take up their cause. The request for a second opinion is a rarely exercised privilege under the NHS. Media publicity suggests that it should be invoked more often. 7 In the meantime, a rough and ready system of triage is at work maintaining a delicate equilibrium between clinical need and available facilities. In shielding their patients from the anguish of being turned down for treatment, NHS doctors are making decisions on out-of-date criteria. It appears likely that this mechanism for rationing the demands on high technology, high cost medicine and surgery also regulates referral in other specialities.

**IMPROVING THE SERVICE FOR PATIENTS WITH ESRF**

As a physician caring for patients with ESRF and because of my involvement with the EDTA-ERA Registry, I cannot do other than act as advocate for the cause of RRT in the UK. Physicians in this field have taken a great deal of trouble to catalogue their achievements and to assess the quality of life of their patients in an objective manner. The costs of treatment can be readily identified. The components of the cost-effectiveness equation are known. Other areas of high cost care will need to collect their own data.8 The dilemmas as to which patients should be selected for treatment and how much resource should be allocated to each area will continue to be debated.

At the present time it is acknowledged that the rate of acceptance of new patients in the UK is too low. The DHSS is setting a target of 40 new patients per million of population 'by 1987'. The chances of therapy for a British patient would then be raised to the level of those currently available in Greece and Portugal, but would still be inferior to those in West Germany, France, Italy and Spain and many other small Western European countries. The current rate of increase in acceptance rate seems likely to realise this target, possibly without additional centres being opened (Fig 5). More imaginative is the target of the Secretary of State for
Health for Wales who has announced his intention to treat 50 patients pmp. Subsidiary renal units are being opened in Wales to accomplish this and the experiment in the Principality will be watched with great interest by the rest of the UK.

Northern Ireland has no plans, so far as I know, to augment its single renal unit which has made such a famous contribution over the last 25 years. Perhaps limited facilities could be used more intensively, by the institution of an overnight programme,9 and perhaps the addition of CAPD to the treatment options will ease the pressures under which Dr McGeown and her staff are serving the population of Ulster. Good luck for the years ahead!

ACKNOWLEDGEMENTS
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