

# MEDICAL PRACTICE

## *Process and Outcome*

### Deaths from chronic renal failure under the age of 50

Medical Services Study Group of the Royal College of Physicians

#### Abstract

From a survey of the West Midlands and Mersey Regions and the Grampian Health Board, we found that in 1978 and 1979 some 122 patients with chronic renal failure died in hospital under the age of 50. Of these, 69 had been given dialysis or transplantation, or both, while for many reasons the remainder had been considered unsuitable. While the criteria varied, the reasons given for non-acceptance of cases seemed sound, and in no instance during this particular period was a patient denied dialysis because of a shortage of machines. We think that the public should be aware of these findings and not led to think that if only enough dialysis machines were available death from renal failure would be a rarity.

#### Introduction

During the two years 1978-9 physicians in the West Midlands and Mersey Regions and the Grampian Health Board collaborated with the Medical Services Study Group of the Royal College of Physicians in a survey of medical deaths in hospital of those aged under 50.<sup>1</sup> The populations concerned were roughly five million, two and a half million, and half a million respectively. Altogether 1290 such deaths were assessed by study of the case notes and necropsy reports and with the help of the con-

TABLE 1—Causes of chronic renal failure

	No
Chronic glomerulonephritis	34
Diabetic nephropathy	19
Hypertension	13
Obstructive uropathy	12
Chronic pyelonephritis	8
Polycystic disease	3
Amyloidosis	3
Renal hypoplasia	2
Hyperparathyroidism and idiopathic hypercalcaemia	2
Myelomatosis	1
Analgesic nephropathy	1
Wegener's granuloma	1
Systemic lupus erythematosus	1
Gout	1
Renal tuberculosis	1
Renal vein thrombosis	1
Alport's syndrome	1
Polyarteritis nodosa	1
Congenital familial nephrotic syndrome	1
Uncertain	16
Total	122

sultants concerned, but the overall ascertainment rate was only about half. When death was attributable to chronic renal failure (initially 52 patients), however, we managed by a special effort directed to the nephrologists and transplant surgeons to increase this to 122, and we think that we have now obtained the notes of almost all those who died from this cause in hospital, but those who died at home, some of whom would not have been assessed by a nephrologist, were outside the scope of the investigation. Moreover, a few of the deaths in hospital of people aged under 50 that were not reported to us may have been due to renal failure but in cases under the care of a general physician and not referred to a nephrologist. Such patients would have been missed in this survey, but we do not think that the numbers would have been large enough to have affected our conclusions.

The primary object of the survey was to analyse the deaths from the point of view of selection of cases for dialysis/trans-

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plantation. The project also provided an opportunity to assess the adequacy of dialysis facilities in the three regions and to obtain some information about patients accepted and successfully treated by dialysis/transplantation during the period of the survey.

### Patients studied and results

Table I shows the underlying cause of chronic renal failure in the 122 patients; a little over one-quarter were due to chronic glomerulo-

nephritis and about one-sixth to diabetic nephropathy. Table II gives details of the 69 patients who died during the period of the study and who had been treated by peritoneal dialysis or haemodialysis or transplantation or by a combination of such measures. In some of these treated patients survival was short, often because their unsuitability for dialysis became apparent only after it had been started. Others, who received a transplant, had (once the danger of early rejection had passed) several years of life before them.

Table III shows the remaining patients, who received neither dialysis nor transplantation, and the cause of their chronic renal failure and the reasons why it was considered inappropriate to use such measures. In no case was this due to a shortage of machines.

TABLE II—Treated patients

Case No	Cause of chronic renal failure	Age	Treatment given	Period under treatment	Cause of death, or where relevant, reasons for cessation of treatment
52	Amyloidosis	32	H	4 weeks	Underlying disease and shunt difficulties
220	Malignant hypertension	45	P H T	1 year	Bacterial endocarditis. Graft rejection
260	Polycystic kidneys. Retroperitoneal lymphoma	34	P	1 week	Retroperitoneal lymphoma
336	Chronic glomerulonephritis	45	H T	34 months	Acute pancreatitis. Graft rejection
337	Chronic pyelonephritis	48	H	33 months	Gastrointestinal bleeding of unascertained cause
338	Obstructive uropathy	40	H	18 months	Bacterial endocarditis
349	Obstructive uropathy	20	P	~1 week	Chronic renal failure. Considered for transplant but deemed unsuitable. Personality disorder. Suicidal attempt
400	Uncertain	48	P H T	6½ years	Chickenpox
491	Chronic glomerulonephritis	47	P	1 week	Staphylococcal septicaemia
549	Chronic glomerulonephritis	48	P	1 week	Myocardial infarction
653	Obstructive uropathy	47	P	1 week	Chronic renal failure. Died 3 days after starting dialysis. Traumatic brain damage. Unable to walk. Low IQ
835	Chronic glomerulonephritis	24	P	1 week	Chronic renal failure. Deaf. Eye removed for pseudoglioma. Very little vision in other eye
841	Chronic glomerulonephritis	46	P H	2 months	Cerebral haemorrhage
R13	Hypertension	46	P	1 week	Pneumonia. Cardiac failure. Had had stroke
1091	Chronic glomerulonephritis	46	H	1 week	Chronic renal failure. Haemodialysis started 2 days before death
1131	Chronic glomerulonephritis	44	P H T	3½ years	Graft rejection. Cardiac failure
1149	Systemic lupus erythematosus	43	P H	13 months	Underlying disease and shunt difficulties
1150	Chronic glomerulonephritis	40	H	19 months	Cerebral haemorrhage while awaiting a transplant
1152	Uncertain	48	P H	4 weeks	Crohn's disease, final cause of death gastrointestinal bleeding
1153	Malignant hypertension	39	P	5½ months	Cardiac arrest
1155	Wegener's granuloma	46	P H	10 months	Underlying disease
1156	Chronic pyelonephritis	46	P H	14 months	Cardiac failure
1157	Polycystic disease	48	P H	8 years	Final cause of death uncertain
1165	Chronic glomerulonephritis	35	H T	6½ years	Two transplants rejected. Died from effects of infection and haemorrhage around second graft
1166	Chronic glomerulonephritis	42	H	6 months	Cardiac arrest
1167	Analgesic nephropathy	28	H	7 months	Complications of repeated surgery for chronic duodenal ulcer. Psoriatic arthritis
1168	Chronic glomerulonephritis	43	P H	3 months	Cerebral haemorrhage. On transplant waiting list at time of death
1169	Carcinoma of ovary. Bilateral ureteric obstruction	45	H	2½ weeks	Carcinomatosis. Dialysed pending diagnosis and attempted surgical extirpation. Thereafter bilateral cyclostomy
1195	Alport's syndrome	30	H T	10½ years	Dialysis encephalitis
1198	Chronic glomerulonephritis	39	H T	3½ years	Cerebral haemorrhage. Graft rejection
1200	Chronic glomerulonephritis	30	P H	20 months	Acute pulmonary oedema
1202	Chronic glomerulonephritis	49	P	1 day	Chronic renal failure. Respiratory infection treated with tetracycline. Dubiously suitable for dialysis on account of anxiety and coronary artery disease
1203	Uncertain	11	P	4 weeks	Peritonitis and pneumonia. Mentally subnormal but awaiting transplant
1204	Diabetic nephropathy	44	P H	4 weeks	Cardiac arrest. Diabetes 18 years. Severe retinopathy and arterial disease
1205	Chronic glomerulonephritis	20	P H	8 months	Cerebral haemorrhage. Psychiatric instability. No support from parents who were separated. Awaiting transplant
1206	Uncertain	49	H	7 years	Staphylococcal septicaemia. Haemorrhage from fistula. Refused transfusion. Jehovah's Witness. Depressive
1207	Chronic glomerulonephritis	24	P H T	6 years	Cardiac arrest. Graft rejection
1208	Renal hypoplasia	19	H T	3 years	Septicaemia. Graft rejection
1215	Congenital familial nephrotic syndrome	7	H	5 days	Acute pulmonary oedema. On transplant waiting list
1220	Chronic glomerulonephritis	14	H T	2½ years	Chronic renal failure. Graft rejection
1222	Secondary amyloidosis	46	P	4 months	Chronic renal failure. Had chronic osteomyelitis of femur. In cardiac failure and had had stroke
1224	Chronic glomerulonephritis	32	H	1 month	Pulmonary oedema and cardiac arrest
1225	Chronic glomerulonephritis	38	H T	7½ years	Septicaemia. Myocardial infarction
1226	Malignant hypertension	45	P H	6 months	Uncertain. Epileptic, low intelligence. Had had myocardial infarction
1227	Uncertain	30	P H T	1½ years	Cardiac arrest
1228	Chronic glomerulonephritis	47	H T	2½ years	Pneumonia. Shunt difficulties. Two transplants. Psychologically feeble and dependent
1229	Uncertain	34	H T	8 years	Pneumonia. Two failed transplants
1230	Renal hypoplasia	39	P H T	1½ years	Carcinomatosis
1231	Uncertain	35	H T	3 months	Thromboembolism
1232	Uncertain	33	P H	3½ months	Shunt difficulties
1233	Bilateral hydronephrosis	44	H T	3 years	Graft and shunt failure
1234	Uncertain	35	P H T	5 months	Septicaemia. Graft failure
1235	Malignant hypertension	30	H T	7 months	Septicaemia. Pulmonary tuberculosis. Peripheral vascular disease
1236	Chronic pyelonephritis	36	H T	1 year	Graft rejection
1237	Uncertain	27	P H T	4 years	Three grafts rejected. Peripheral vascular disease. Secondary haemorrhage from transplant wound
1238	Chronic pyelonephritis	9	P T	5 weeks	Hypertensive encephalopathy
1239	Hypertension	46	P H	4½ years	Bronchopneumonia
1240	Diabetic nephropathy	22	P T	7 weeks	Pneumonia. Graft rejection. Advanced retinopathy
1241	Malignant hypertension	26	P H T	4½ years	Septicaemia. Three unsuccessful transplants
1242	Chronic glomerulonephritis	40	P H T	1½ years	Chronic renal failure. Graft and shunt failure
1243	Uncertain	45	H T	6 months	Septicaemia
1244	Uncertain	42	H T	5 years	Septicaemia
1245	Chronic glomerulonephritis	43	P H T	1 year	Chronic renal failure. Two failed transplants
1246	Polycystic disease	12	P H T	1 year	Chronic renal failure. Two failed transplants
1248	Chronic glomerulonephritis	15	H	2 months	Pneumonia. Also had cirrhosis of liver and repeated haematemesis for which she underwent gastric transection and splenectomy
1249	Renal calculi	49	P	4 days	Cardiac arrest
1253	Chronic glomerulonephritis	43	H T	1½ years	Septicaemia
1254	Carcinoma of cervix	33	P	3 days	Carcinoma of cervix. Peritoneal dialysis only carried out until diagnosis established
1263	Uncertain	38	H	1½ years	Cardiac arrest. Had severe coronary artery disease

P = Peritoneal dialysis. H = Haemodialysis. T = Transplantation.

TABLE III—*Untreated patients*

Case No	Cause of chronic renal failure	Age	Survival after onset of end-stage renal failure	Reasons for not offering dialysis or transplantation
40	Diabetic nephropathy	23	3 weeks	Uncooperative patient. Dialysis requested by physician but deemed inappropriate by nephrologist
48	Chronic glomerulonephritis	46	2 weeks	Severely arteriopathic. Duodenal ulcer. Dialysis requested by physician but patient thought unsuitable by nephrologists
59	Diabetic nephropathy	39	5½ weeks	Blind. Peripheral neuropathy. Perforating ulcer of foot. Physician requested dialysis but nephrologist declined
82	Myelomatosis	35	1 month	Myelomatosis
116	Idiopathic hypercalcaemia	13	6½ months	Severe mental subnormality. Congenital heart disease. Multiple other congenital abnormalities
158	Obstructive uropathy	43	< 1 week	Severe chronic psychotic illness. Had been in a mental hospital for many years
182	Diabetic nephropathy	43	10½ months	Blind. Insulin dependent diabetes 21 years. Other diabetic complications
272	Diabetic nephropathy	48	3½ months	Insulin dependent diabetes 28 years. Question of dialysis/transplantation not raised
282	Nephrotic syndrome. Focal glomerulosclerosis	4	2½ months	Age. Parental irresponsibility
313	Diabetic nephropathy	32	5½ months	Severe retinopathy and neuropathy. Question of dialysis/transplantation not raised
317	Chronic glomerulonephritis	49	2 weeks	Question of dialysis/transplantation not raised
324	Malignant hypertension	39	5 months	Question of dialysis/transplantation not raised
327	Diabetic nephropathy	48	3 months	Retinopathy. Peripheral vascular disease. Had had stroke
346	Uncertain	7	4½ weeks	Malignant brain tumour. Ventriculocaval shunt
381	Malignant hypertension	47	4½ weeks	No mention of dialysis/transplantation. Was under the care of a nephrologist
387	Diabetic nephropathy	48	3½ months	Considered for haemodialysis but deemed unsuitable as he had had a myocardial infarct, had severe retinopathy, and had no home
446	Diabetic nephropathy	23	2 weeks	Orphan. Neuropathy. Severe retinopathy and poor vision
503	Chronic glomerulonephritis	48	3 months	Alcoholism. Anxiety, depression, and hysteria. Referred to a nephrologist who considered her unsuitable
526	Chronic glomerulonephritis	18	< 1 week	Died due to an anaphylactoid reaction to urografin
548	Diabetic nephropathy	42	5½ months	Blind due to retinopathy. Obese
558	Uncertain	47	2 weeks	Severe rheumatoid arthritis. Had had bilateral hip replacement and knee synovectomy. Dialysis/transplantation not raised
606	Malignant hypertension	43	3 months	Very unintelligent. Dialysis/transplantation not mentioned
639	Diabetic nephropathy	30	1 year	Severe retinopathy and very poor vision. Coronary artery disease. Oedema. Dialysis/transplantation not raised
640	Diabetic nephropathy	45	9 months	Blind. Severe neuropathy. Myocardial infarction. Obese. Separated from wife and family
678	Chronic pyelonephritis with calculi	49	2 months	Multiple sclerosis. Confined to wheelchair and with an indwelling catheter
759	Chronic pyelonephritis with calculi	33	6 weeks	Blind and mentally subnormal
779	Diabetic nephropathy	32	2½ months	Severe retinopathy and oedema. Not considered suitable for long-term dialysis by nephrologist
791	Diabetic nephropathy	43	< 1 week	Was hypertensive and died from cerebral haemorrhage before dialysis/transplantation considered
799	Obstructive uropathy	49	3 weeks	Also had fibrosing alveolitis from which she died with a blood urea of 36 mmol/l
873	Diabetic nephropathy	47	4 months	Severe neuropathy and retinopathy. Very poor vision. Coronary artery disease. Duodenal ulcer
888	Hypertension	47	10 months	Coronary artery disease and cardiac failure. Cerebrovascular disease. Transitional cell carcinoma of bladder. Anxiety and depression. Obese. Not worked for 10 years
R7	Malignant hypertension	45	< 1 week	Coronary artery disease and cardiac failure. Died within 24 hours of second admission from acute pancreatitis
R27	Chronic glomerulonephritis	38	3 months	Very uncooperative patient and husband. One nephrologist thought her unsuitable for dialysis/transplantation another accepted her but she discharged herself
983	Chronic pyelonephritis	47	< 1 week	Undiagnosed neuropsychiatric illness necessitating an indwelling catheter. She died from <i>Escherichia coli</i> septicaemia
1051	Diabetic nephropathy	41	4 months	Severe retinopathy. Question of dialysis/transplantation did not arise
1096	Chronic glomerulonephritis	29	< 1 week	Cardiac arrest shortly after arrival at hospital. Only seen general practitioner 3 days previously
1151	Diabetic nephropathy	42	2 weeks	Had neuropathy, oedema, hypertension, and coronary artery disease. Accepted for dialysis or transplantation but suffered a fatal myocardial infarct before this could be started
1154	Hypertension	39	2 years	Fistula established and transplant planned but degree of chronic renal failure never justified dialysis or transplant. Final cause of death uncertain
1196	Diabetic nephropathy	49	7 years	Mentally subnormal. Peripheral vascular disease. Had had leg amputated
1209	Chronic glomerulonephritis	34	1 month	Spoke no English. Fistula inserted but unsatisfactory because of severe arterial disease
1210	Chronic glomerulonephritis	49	5 months	Coronary artery disease. Deemed unsuitable for dialysis/transplantation by nephrologist
1211	Renal vein thrombosis	46	3 months	Severe nephrotic syndrome. Dialysis/transplantation not considered
1214	Uncertain	41	6 months	Spoke no English. Pulmonary tuberculosis. Psychological instability
1216	Bladder neck obstruction	12	2 years	Spina bifida. Hydrocephalus. Spitz-Holter valve. Very little leg movement
1217	Secondary amyloidosis	33	15 months	Widespread tuberculosis. Spoke no English
1219	Bladder neck obstruction	9 months	1 month	Spina bifida. Very little leg movement
1221	Nephropathy due to gout	42	1 year	Mentally subnormal. Only relative very elderly mother
1223	Polyarteritis nodosa	41	2 months	Cerebral involvement. Died myocardial infarction
1247	Hyperparathyroidism	46	6 months	Osteoclastoma of mandible
1250	Chronic pyelonephritis	39	3 months	Multiple sclerosis. Wife cardiac invalid
1251	Renal tuberculosis	46	1 week	Renal tuberculosis. Ileal conduit. Stroke
1252	Chronic glomerulonephritis	40	1 week	Severe chronic psychotic depression and personality disorder
1264	Renal calculi	22	2 months	Renal dwarf. Long history of repeated operations for stone with secondary abscess and fistula formation

## Discussion

That there is a substantial group of patients with chronic renal failure who are unsuitable for long-term dialysis or transplantation or in whom the procedures are contraindicated from the outset is clear from tables II and III and is well known to most doctors. On the other hand, we think that the general public is under the impression that patients with renal failure die only because of a shortage of dialysis machines and of kidneys for transplantation. They do not appreciate that the basic illness is by no means always primarily renal, and that the nature of the underlying disease may mean that the patient has not long to live whatever is done; nor do they realise that even successful treatment commonly includes episodes of infection, graft rejection, and difficulty with vascular access sites. Diabetes mellitus in particular exemplifies these problems (see table II, cases 1204 and 1240), and the policy on diabetics varies in different parts of Britain.

The Mersey and West Midlands regions have low rates of dialysis per million of population,<sup>2</sup> possibly because in these regions more general practitioners may think that facilities are inadequate and therefore a higher proportion of patients than elsewhere are never assessed by a nephrologist; this may in part explain why we found no shortage of dialysis facilities during the period of analysis. Nevertheless, the picture may well have changed, as an increasing number of older patients are now being accepted for treatment, though the use of continuous ambulatory peritoneal dialysis<sup>3</sup> (when its role has been fully assessed) may meet this increased need. The extent to which facilities for dialysis and transplantation should be extended to later age groups is a policy—or ethical—decision,<sup>4</sup> and this and other matters relating to this paper were discussed in a recent leader in the *Lancet*.<sup>4</sup> The *Lancet* thought that economic pressures led clinicians to reject patients for treatment without realising that it was the pressures that were influencing their decision. We find this difficult to believe, particularly

because in the King's study<sup>5</sup> there were considerable differences in the rejection rate within the relatively well off metropolitan regions. The whole difficult area of the management of chronic renal failure is also discussed in two publications from the Office of Health Economics.<sup>2,6</sup> All we report here is what happened in the three localities surveyed. In our discussions with the nephrologists economic pressures were specifically not blamed and the patients seem to have been assessed purely on clinical grounds. But doctors differ in their assessment of the management of many chronic conditions, and different schools of thought tend to arise in different areas (the King's study<sup>5</sup> particularly highlights this).

This paper is only about death, and the brighter side of the story is that during the two years 108 new patients under 50 in the Mersey Region and 18 in the Grampian Area were accepted for dialysis or transplantation, while in the much larger West Midlands Region 186 transplants were carried out and 170 patients were accepted for dialysis and many of these did well.

Our overall impression is that during the period of analysis there was no shortage of equipment and the selection of patients was competent. Our criticisms relate chiefly to the poor harvesting of kidneys, which is discussed in the accompanying paper.

We are greatly indebted to the nephrologists and transplant surgeons in the three regions for permitting us to study their case notes and for helping us to compile this paper. We also thank the many other physicians whose patients have been included in this survey and Sir Douglas Black, FRCP, who gave such valuable criticisms.

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## References

- <sup>1</sup> Clarke CA, Whitfield AGW. Deaths under 50. *Br Med J* 1978;iii:1061-2.
- <sup>2</sup> Office of Health Economics. *Renal failure: a priority in health?* London: OHE, 1978.
- <sup>3</sup> Anonymous. CAPD for chronic renal failure. *Lancet* 1980;iii:1172-3.
- <sup>4</sup> Anonymous. Ethics and the nephrologist. *Lancet* 1981;i:594-6.
- <sup>5</sup> Parsons V, Lock P. Triage and the patient with renal failure. *J Med Ethics* 1980;6:173-6.
- <sup>6</sup> Office of Health Economics. *End-stage renal failure*. London: OHE, 1980.

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# Donation of kidneys

## Medical Services Study Group of the Royal College of Physicians

### Abstract

**A survey of deaths from medical causes among hospital inpatients aged under 50 years in three health regions provided details of 1168 such deaths not caused by renal failure. Kidneys for transplantation were obtained from only 20 of these patients. In another 18 cases permission was refused or donation was impracticable. Ninety-eight of the deaths were due to subarachnoid haemorrhage and 38 to primary cerebral tumour, yet kidneys were obtained from only 11 and one of these patients respectively. Patients dying from subarachnoid haemorrhage are particularly suitable for donating their kidneys, but there is still a shortage of kidneys for transplantation because they are not harvested efficiently.**

**Doctors seem to be reluctant to ask relatives' permission to remove kidneys, and the arrangement of a donation is time consuming. Because transplant surgery is recognised as a specialist sphere, surgeons in other specialties may be reluctant to remove kidneys and come to rely on one transplant team covering a wide area. In an area such as Grampian, where a small population is served by one hospital containing all the major units, including accident and emergency and renal departments, it may be easier to arrange prompt donation and transplantation.**

### Introduction

Previous papers<sup>1,2</sup> have described the investigation of medical deaths in hospital in patients aged under 50 that was carried out during 1978 and 1979 by the Medical Services Study Group of the Royal College of Physicians in collaboration with the physicians in the Mersey and West Midlands regions and the Grampian Health Board (see also accompanying paper, p 283). One of the interests arising from the survey was to consider the number of potentially transplantable kidneys in relation to those actually transplanted.

### Patients studied and results

There were 1168 deaths in our survey which were not due to renal failure. Although this number represented an ascertainment rate of only about 50% we think it is likely to be a random sample as regards kidney donation.

Kidneys were obtained from transplantation from only 20 of the 1168 patients. The relatives of another eight gave consent, but hypotension, infection, or other factors made donation impracticable. In 10 cases permission was refused. Only about a third of the participating hospitals made successful or unsuccessful attempts to obtain kidneys, and among this third one intensive care unit provided five of the successful donations and four of the refusals. Among the 1168 deaths were 98 due to subarachnoid haemorrhage. Only 11 of these cases provided kidneys, and the mean age of the donors was 36.9 years (range 9-49) compared with a mean age of 30.4 years (range 22-44) in the other nine donors. There were also 38 patients who died from primary cerebral tumour, but the kidneys of only one of these were obtained for transplantation.

### Discussion

The Minister of Health stated in February 1980 that over 1000 patients in England were awaiting renal transplants<sup>3</sup> and by November 1980 this had risen to 1900, and the *Panorama*

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