A Registry of Patients with End Stage Renal Disease — the Experience at Hospital Sultanah Aminah, Johor Baru

L.S. Hooi, MRCP
Department of Medicine, Hospital Sultanah Aminah, Johor Baru

Summary

A registry of patients with end stage renal disease was started from 1st January 1990 at Hospital Sultanah Aminah, Johor Baru. There were 126 patients in 1990 and 129 in 1991. The peak age was 31 to 60 years old; males outnumbered females 1.5:1. Forty-three to fifty-six percent presented with small kidneys. Seventeen to twenty percent of patients had diabetes mellitus. In 1991, the racial distribution of patients was Malay: 50.4%, Chinese: 39.5%, Indian: 7.8% and others: 2.3%. The incidence of end stage renal disease in Johor Baru district was 79 per million per year in 1990 and 86 per million in 1991.

Key words: End stage renal disease, registry.

Introduction

"The true incidence of renal disease in Malaysia is not known."[1]

End stage renal disease (ESRD) is defined as advanced chronic renal failure requiring renal replacement therapy.

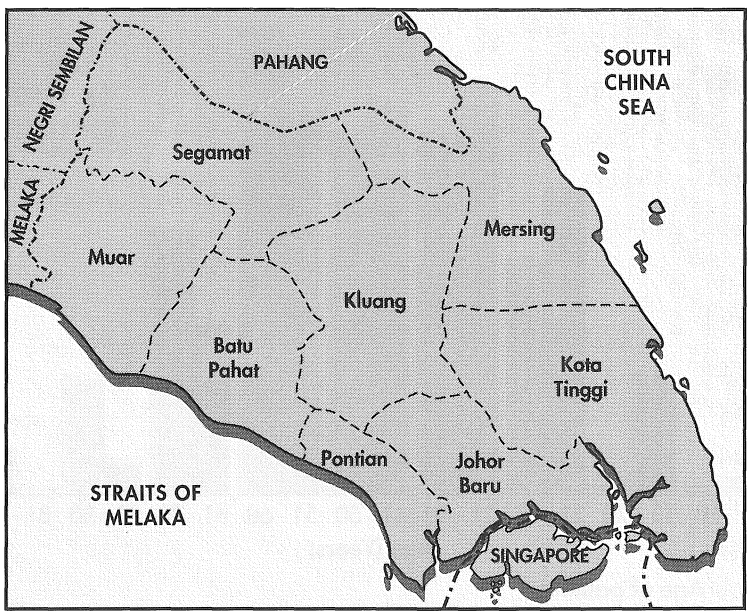

Fig 1: Map of Johor state with district boundaries.

Hospital Sultanah Aminah (HSAJB) has 960 beds[2] and serves as the general hospital for the district of Johor Baru (population 700,000)[3], being also the tertiary referral centre for Johor state (population 2.1 million)[3] (Fig 1).

A registry of patients presenting with ESRD to HSAJB with data from 1st January 1990 to 31st December 1991 is reported. The registry contributes to patient well-being by helping in planning for dialysis and transplantation.

Materials and Methods

All patients presenting to HSAJB with ESRD were reported in 2 time periods: 1st January 1990 to 31st December 1990 and 1st January 1991 to 31st December 1991.

Patients started on centre, home and 'acute' hemodialysis and continuous ambulatory peritoneal dialysis have records in the hospital's hemodialysis unit; patients presenting to paediatric and medical wards and intensive care units were identified via the peritoneal dialysis register, which was started in 1989. Patients with acute renal failure were excluded.

The data were recorded and analysed using a database programme with 14 variables on a 286 IBM compatible personal computer.

Results

The results for 1990 and 1991 were similar. There were 109 new patients in 1990 and 103 in 1991.

Age and sex

The peak age group was 31 to 60 years; 65.1% were in this group in 1990 and 64.6% in 1991. The mean age was 41.8 years in 1990 (age range 4 to 72 years) and 48.8 years in 1991 (age range 17 to 87 years) (Fig 2).The sex distribution is shown in Fig 3. The male to female ratio was 1.8:1 in 1990 and 1.5:1 in 1991.

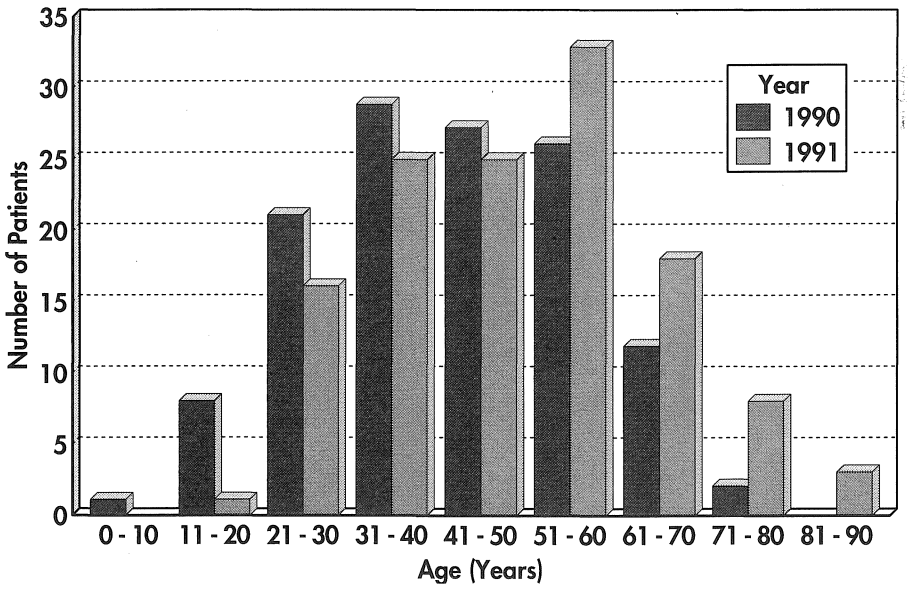

Fig 2: Age of patients.

Place of origin

The patients came from the 8 districts of Johor state (Fig 1). The population of each district in 1991 was as follows[3]:

Johor Baru	705,432
Muar	302,947
Batu Pahat	295,474
Kluang	224,950
Segamat	178,266
Kota Tinggi	174,188
Pontian	129,702
Mersing	63,338
Total	2,074,297

About 50% of patients were from Johor Baru (Fig 4). In 1990, 56 new cases were from Johor Baru and the corresponding number was 61 in 1991. As HSAJB is the largest hospital in the district, being the only one with a nephrology section, most patients with ESRD presented here. This gives the minimum incidence of ESRD in the district of Johor Baru as 79 per million per year in 1990 and 86 per million per year in 1991.

Patients with ESRD presented in about the same racial proportion as the general population. 56.4% in 1990 and 43.8% in 1991 presented with small kidneys. This is defined as kidneys less than 9 centimetres in length bilaterally on ultrasound (in adults). Most of this is probably due to chronic glomerulonephritis. Diabetes mellitus was a major cause (17.5% in 1990 and 20.2% in 1991).

The diagnosis of adult polycystic kidneys was made by physical examination, ultrasound of the enlarged kidneys and family history (autosomal dominant inheritance).

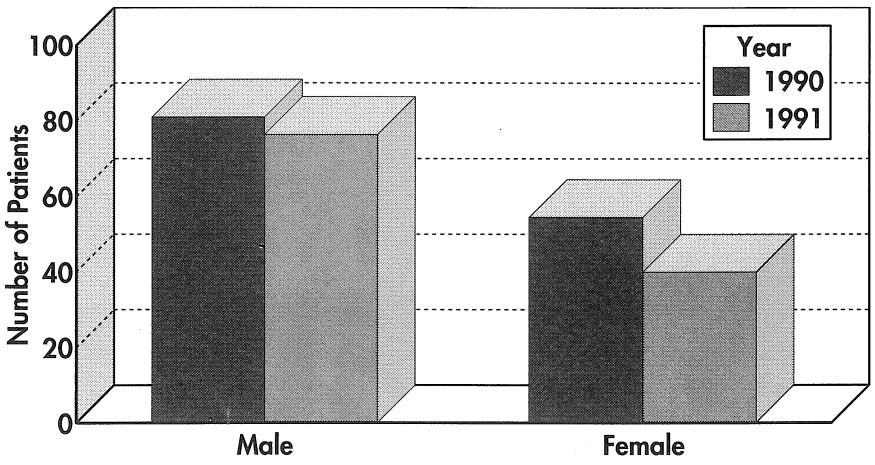

Fig 3: Sex of patients.

Table I
No of Cases

Year	1990	1991
New cases	109	103
Brought over from previous year	17	26
Total	126	129

Table II
Race of patients

Year	1990		1991		Johor population 1990[4]
Race	Number	(%)	Number	(%)	%
Malay	68	(54.0)	65	(50.4)	57.2
Chinese	45	(35.7)	51	(39.5)	36.2
Indian	9	(7.1)	10	(7.8)	6.4
Others	4	(3.2)	3	(2.3)	0.2
Total	126	(100.0)	129	(100.0)	(100.0)

Patients with ESRD presented in about the same racial proportion as the general population.

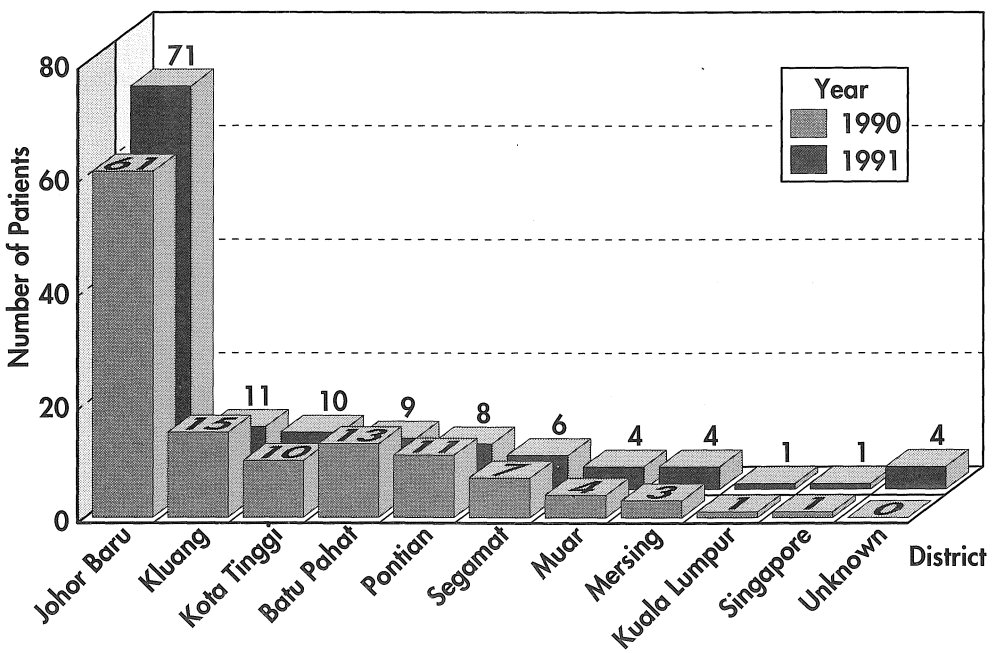

Fig 4: District of origin.

The 6 patients who had gout presented with small kidneys on ultrasound, history of passing stones in the urine and ingestion of analgesics. One had tophaceous gout, the rest recurrent gouty attacks in the big toe with raised serum uric acid (>440 mmol/l). These patients may have analgesic nephropathy but this was not proven by biopsy or radiology.

Three of the patients with renal calculi had urological operations done for stones before suffering from ESRD; the rest had renal stones proven by ultrasound.

Vesico-ureteric reflux in 2 patients was confirmed by micturiting cystourethrogram and the patient with renal tuberculosis had 3 operations for ureteric strictures with histological and microbiological confirmation of TB.

Modalities of treatment

Living related donor renal transplants numbered 8 in 1990 (6.4%) and 7 in 1991 (5.4%). The 1 year graft and patient survival in this small series is 100%.

A larger number of patients presented with living unrelated donor renal transplants done in India on a commercial basis (17 in 1990 and 20 in 1991). The numbers are predicted to drop in the next few years with bad publicity of the poor outcome[5,6]. Four of these patients have presented to HSAJB with human immunodeficiency virus infection in 1991; one has AIDS (Acquired Immunodeficiency Syndrome)[6].

A moderate number of patients were offered centre and home hemodialysis, 30 (23.8%) in 1990 and 20 (15.5%) in 1991.

Table III
Causes of ESRD

Year	1990		1991	
Cause	Number	(%)	Number	(%)
Small kidneys	71	(56.4)	56	(43.4)
Unknown	17	(13.5)	35	(27.1)
Diabetes mellitus	22	(17.5)	26	(20.2)
Polycystic kidneys	1	(0.8)	3	(2.3)
Renal biopsy proven glomerulonephritis:		(4.8)		(1.6)
Focal sclerosis	3		1	
End stage kidney	1		1	
Focal proliferative GN	1		0	
Lupus nephritis	1		0	
Others:		(7.0)		(5.4)
Gout	2		4	
Renal stones	4		2	
Vesico-ureteric reflux	2		0	
TB of the kidneys	1		1	
Total	126	(100.0)	129	(100.0)

The number on continuous ambulatory peritoneal dialysis (CAPD) is small, as the CAPD programme was started in HSAJB in 1992.

A large number of patients on 'conservative treatment' were lost to follow-up and the outcome was unknown after diagnosis. Some are on treatment in private hospitals. A more vigorous attempt at tracing them is necessary. This is hampered by their being scattered over an area of 18,941 square kilometres.

Overall, 54.8% of patients were known to have received definitive treatment in 1990 and 48.8% in 1991 (Fig 5).

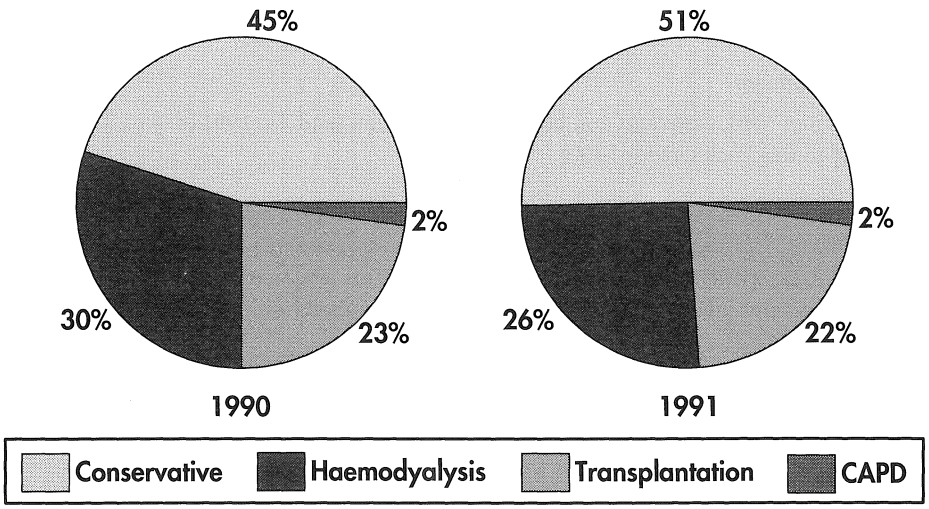

Fig 5: Modalities for treatment of ESRD.

Outcome of treatment

The outcome is as of 31st December of each of the years analysed (Fig 6).

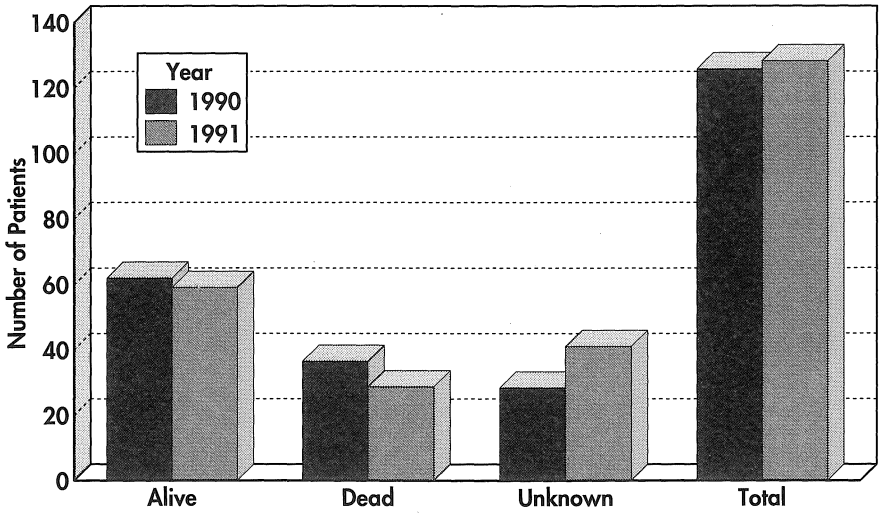

Fig 6: Outcome of treatment.

The mortality rate was 28.6% in 1990 and 22.5% in 1991.

Discussion

This computerised registry represents 100% reporting of patients with ESRD presenting to 1 regional general hospital (HSAJB) for 2 years. The registry is ongoing and the idea could be extended first to general hospitals and then to other hospitals and dialysis centres. The contribution to health planning in the provision of comprehensive treatment for ESRD is one justification. This is true of successful registries, e.g., those in Europe (EDTA since 1964)[7], Australia and New Zealand (ANZDATA since 1977)[8], Canada (since 1981)[9] and the United States of America (USRDS since 1988)[10].

Sixty-five percent of the patients were in the economically active age group 31 to 60 years old. This parallels the youth of the general population[4], in contrast to USA where 38% of patients treated were more than 65 years old (1988)[11], median age 61 years (1989)[12] and Australia where 48% of new patients were more than 55 years old, median age 54 years (1990)[8].

The minimum incidence of ESRD in the Johor Baru district is 86 per million per year for 1991. For the other districts of Johor, incidence is not calculated as some patients presented to local hospitals. A registry is being started in district hospitals from 1992.

The incidence rate for Johor Baru could be extrapolated to the urban areas of the rest of Malaysia. The limitation is whether the incidence is different in the rural population.

In 1990, Singapore had an incidence of ESRD of 96 per million[13], while in Australia it was 55 per million[8]. Other figures are, USA: 166 in 1989[14], Japan: 135 in 1988, Canada: 80 and United Kingdom: 70, in 1989, approximately[12].

As with the study in 1982 by Suleiman *et al*[15], more than half the patients presented with ESRD with no known cause. In this series it was not routine to biopsy small shrunken kidneys and the underlying pathology is not known. The symptoms of chronic renal failure are non-specific and many patients present at an advanced stage. HSAJB is a tertiary referral centre and some patients were managed in other hospitals until symptomatic. There is also the problem of patients trying traditional cures first and seeking medical treatment as the last resort. In this group of patients nothing much can be done to prevent or retard the renal failure.

Diabetes mellitus accounted for 20% of patients. The prevalence of diabetes in Malaysia is 4%[16] and renal failure is a major complication[16,17]. Seven out of twenty two patients in 1990 and 8/26 patients in 1991 with diabetes and ESRD presented at more than 60 years of age. Diabetes as a cause of renal failure is 31% in USA (1988)[11], 20% in West Scotland in 1990[18] and 14% in Australia (1990)[8].

These results compare with those from Singapore[13]: chronic glomerulonephritis 30%, diabetes 25%, chronic pyelonephritis 10%, kidney stones 4%, polycystic kidney 2%, others 4%, unknown 25%.

At present, treatment for ESRD in Malaysia is not universal, due to financial, social and medical constraints[1]. The statistics from an accurate ESRD registry would be useful in the setting-up of a cadaveric donor renal transplant programme and in planning for more dialysis units. Other benefits include providing data for financial and clinical audit and research.

Conclusion

A registry using a computer database is a feasible way of studying patients with end stage renal failure in a large general hospital and for computing epidemiological data.

Acknowledgement

I thank the Director General of Health, Malaysia, Dato' (Dr) Abu Bakar bin Suleiman for permission to publish this paper.

Table IV
Outcome in detail

Year	1990	1991
Conservative treatment, alive	9	10
Conservative treatment, died	23	21
Conservative treatment, unknown	25	35
Centre hemodialysis, alive	10	6
Home hemodialysis, alive	16	10
Home hemodialysis, died	2	0
Awaiting home hemodialysis, alive	0	2
Awaiting home hemodialysis, died	2	2
Private hemodialysis, alive	3	3
Private hemodialysis, died	3	4
Private hemodialysis, unknown	2	6
Renal transplant, Malaysia, alive	8	7
Awaiting renal transplant, died	4	1
Renal transplant, India, alive	16	19
Renal transplant, India, died	1	1
CAPD, alive	0	2
CAPD, died	1	0
CAPD, unknown	1	0
Total	126	129

References

1. D'Cruz F, Chandrasekharan N. Renal disease in Malaysia; problems and prospects. Med J Malaysia 1990;45 : 88-91.
2. Taklimat, Hospital Sultanah Aminah, Johor Baru, 1992.
3. Department of Statistics Malaysia, Kuala Lumpur. Population and Housing Census of Malaysia, 1991.
4. Department of Statistics Malaysia, Kuala Lumpur. Current Population Estimates, Peninsular Malaysia, 1990.
5. 70 who went to India for kidney grafts developed complications. The Straits Times, Singapore 1991; March 13.
6. Kidney patients urged to seek advice first. The Star, Malaysia 1991; November 15.
7. Wing AJ, Brunner FP. Twenty-three years of dialysis and transplantation in Europe: experiences of the EDTA registry. Am J Kidney Dis 1989;14(5) : 341-6.
8. Disney APS (ed). ANZDATA Report 1991. Australia and New Zealand Dialysis and Transplant Registry. Adelaide, South Australia.
9. Posen GA, Jefferey JR, Fenton SSA, Arbus GS. Results from the Canadian renal failure registry. Am J Kidney Dis 1990;15(5) : 397-401.
10. Excerpts from United States Renal Data System 1991, Annual Data Report; Executive Summary. Am J Kidney Dis 1991;18(5Suppl2) : 9-16.
11. Levinsky NG, Rettig RA. The Medicare end-stage renal disease program. N Engl J Med 1991;324(16) : 1143-8.
12. Excerpts from United States Renal Data System 1991, Annual Data Report; X. International comparisons of ESRD therapy. Am J Kidney Dis 1991;18(5Suppl2) : 93-5.
13. Woo KT. Treatment options in end stage renal failure. Renal Transplantation Update 1990. Singapore Urological Association.
14. Excerpts from United States Renal Data System 1991, Annual Data Report; III. Incidence and causes of treated ESRD. Am J Kidney Dis 1991;18(5Suppl2) : 30-7.
15. Suleiman AB, Jeyeindran S, Morad Z, Kong CT. Outcome of patients with chronic renal failure: review of patients presenting over a one-year period. Med J Malaysia 1984;39 : 225-8.
16. Mustaffa E. Diabetes in Malaysia: problems and challenges. Med J Malaysia 1990;45 : 1-7.
17. Khalid BAK, Rani U, Ng ML, Kong CT, Tariq AR. Prevalence of diabetes, hypertension and renal disease amongst railway workers in Malaysia. Med J Malaysia 1990;45 : 8-13.
18. McMillan MA, Briggs JD, Jumor BJR. Outcome of renal replacement treatment in patients with diabetes mellitus. Br Med J 1990;301 : 540-4.