

INTRODUCTION

The Eighth Report of the National Renal Registry (NRR) showed upward trend in patients being taken in for Renal Replacement Therapy (RRT). As in the past years, haemodialysis was the most popular RRT modality chosen. The renal transplant rate has not improved significantly over the years. Of interest and a portend of a better future in transplantation is the number of locally done cadaveric renal transplantation which was the best ever in the year 2000 at 26 transplants. The number of local cadaveric renal transplants though small by comparison to other countries have been increasing over the last few years as a result of concerted efforts by many parties to increase the awareness level amongst the public and medical staff.

The outcomes of RRT particularly haemodialysis have remained the same over the last few years. Whilst the Registry have been able to provide a fairly detailed outcome results for haemodialysis and to a lesser extent CAPD, the same cannot be said for renal transplantation. The data collected for renal transplantation is minimal and catered only at gross outcomes. Detailed data such as incidence of acute rejection, chronic graft nephropathy, serious infections and others are difficult to collect as the process would depend a lot on the doctors' input. The Registry will have to look into ways to overcome this.

This year saw a major change in the way the Registry is being managed. The organisational structure has gone a full cycle and now the NRR is back in the hands of a government agency. We started with the Registry being run by a government department i.e. the Department of Nephrology, Hospital Kuala Lumpur and then it was transferred to the Malaysian Society of Nephrology. In September 2001, an agreement was reached for the Registry to be managed by the Clinical Research Centre (CRC), Ministry of Health (MOH). The running of it will be done by the CRC. The reason for this is that the CRC has interests in doing Health Outcome Studies and they do this through the development of registries. It has excellent facilities to manage large databases including dedicated soft wares, IT experts and statisticians. More importantly it receives funding from the MOH for developing and running registries and thus is able to share its resources with the NRR.

I hope this new arrangement will bring the NRR to greater heights and serve the Nephrology community even better.

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REPORT SUMMARY

1 ALL RENAL REPLACEMENT THERAPIES

- 1.1 At 31st December 2000, 7539 patients were on renal replacement therapy, comprising 6368 on dialysis and 1171 with functioning transplants. 1617 new dialysis patients were accepted in 2000 compared to 1466 in 1999.
- 1.2 The new renal transplant rate was 5 per million population. The overall dialysis acceptance rate has increased to 70 per million population and dialysis prevalence rate 274 per million population.

2 DIALYSIS IN MALAYSIA

- 2.1 Dialysis acceptance rate by state varied between 116 per million state population for Johor Darul Takzim to 25 per million per state population in Sabah.

By age group, dialysis acceptance rate varied between a low of 4 per million child population to a high of 379 per million population for age group 55 to 64 years. Dialysis provision rate for patients older than 65 years was 379 per million population for age. A dramatic increase in dialysis treatment rate was seen in those more than 45 years of age and static for those below 45 years old.

- 2.2 Males made up 57% of all new dialysis patients
- 2.3 Haemodialysis (HD) accounted for 88% of new dialysis acceptance in 2000 of which 87% were accepted in centre HD, and only 1% in office HD. No new patients had been accepted into home HD programme from 1997. 12% of new dialysis patients were accepted into the CAPD programme.
- 2.4 The proportion of patients with unknown primary disease decreased to 29% in 2000. Diabetic nephropathy remained the commonest cause of ESRD accounting for 44%, chronic glomerulonephritis 10% and obstructive uropathy 3 %.
- 2.5 Overall death rate on dialysis remained at 9%; HD death rate was 9%, and CAPD death rate was at its lowest at 12%. 35% of deaths were attributed to cardiovascular causes and 16% to sepsis unrelated to peritonitis. 23% died at home.

3 HAEMODIALYSIS

3.1 Haemodialysis in Government Centres

- 3.1.1 At 31st December 2000, 2077 patients were on HD in government centres. There was a steady increase of centre HD patients with a corresponding decrease in home and office HD.
- 3.1.2 96% of new patients were accepted into centre HD. 99% of new patients were financed by the government.
- 3.1.3 Death rate was 10% per year. Cardiovascular disorders, infections and deaths at home were the 3 commonest causes of death at 37%, 22% and 16% respectively
- 3.1.4 In 2000, there was a total of 65 government HD centres, 8 run by Ministry of Defence, 3 university hospital centres and the rest under the Ministry of Health.
- 3.1.5 New HD patients in 2000: Modal age-group 45 – 64 years; 59% males, 30% were diabetics, 8% had HBsAg, and 5% had anti-HCV antibodies.
- 3.1.6 Both HD patient and technique survival in government centres at 6 months for 1999 were similar at 91%.
- 3.1.7 Overall, 44% of HD patients were able to work part or full time. 67% had normal quality of life index.
- 3.1.8 **Haemodialysis Practices:** In 2000, 79% were dialysed via wrist AVF, 17% via brachiocephalic fistula. 92% reported no difficulties with their vascular access; only 16% had vascular access complications. Proportion of patients with higher blood flow rates of 300-349 increased from 12% in 1997 to 30% in 2000. Almost all were on thrice-weekly dialysis, 95% on 4 hours per session. Use of cellulosic membrane dialysers decreased further to 31% and synthetic membrane dialyser usage increased to 50%; 83% reused their dialysers six times or more, 14% reused 12 times. Usage of bicarbonate buffer increased to 86%. Median prescribed KT/V increased to 1.5; and a higher proportion of patients (79%) achieved a KT/V of more than 1.3.
- 3.1.9 **Dyslipidaemia in haemodialysis patients:** In 2000, 69% of HD patients had serum cholesterol concentration < 5.3 mmol/l with median at 4.9 mmol/l. 88% had serum triglyceride concentration <3.5 mmol/l with median at 1.7 mmol/l; 94% had serum LDL concentration <5 mmol/l with median at 2.9 mmol/l; and 93% had serum HDL concentration of < 2 mmol/l with median at 1.1 mmol/l.
- 3.1.10 **Renal bone disease:** In 2000, 92% of HD patients were on oral calcium carbonate, only 8% remained on aluminium hydroxide. Use of vitamin D remained at 24%. 36% achieved serum phosphate concentration <1.6 mmol/l; 56% had serum calcium concentration between 2.2 and 2.6 mmol/l, and 18% with iPTH between 100 – 250 ng/l. Median PTH concentration was 77 ng/L.

- 3.1.11 **Blood pressure control:** In 2000, 67% required anti-hypertensive therapy. Of these, 63% achieved systolic blood pressure(BP) < 160 mmHg, and 59% a diastolic blood pressure (BP)< 90 mmHg. Of the 33% not on anti-hypertensive therapy, 87% had systolic BP < 160 mmHg and 78% diastolic BP < 90 mmHg.
- 3.1.12 **Management of anaemia:** In 2000, 92% of patients were on oral iron supplements, IV iron use usage has slightly increased to 7%. 54% of HD patients were on recombinant erythropoietin with 57% on 2000-4000 units weekly. 70% of those without erythropoietin and 69% on erythropoietin injections had serum iron > 10 umol/l. 79% of patients without erythropoietin and 89 % of those on erythropoietin supplements had serum ferritin > 100 ng/l. Only 10% of patients on erythropoietin injections had haemoglobin concentration >12 g/dl, 45% with haemoglobin concentration >10g/dl.
- 3.1.13 **Nutritional status:** 57% of HD patients had serum albumin > 40 g/l with 61% with body mass index of between 18.5 and 25kg/m². 20% had BMI <18.5 kg/m².
- 3.1.14 **Anti-HCV and HBsAg status:** In 2000, patients with anti-HCV antibodies increased to 29%. Proportion with HbsAg remained at 6%.

3.2 Haemodialysis in Non-Governmental Organisation (NGO) Centres

- 3.2.1 At 31st December 2000, 2140 patients were on HD in centres managed by NGOs. 598 new patients were accepted into the programme.
- 3.2.3 Death rate in NGO HD centres was 7% for 3 years to 2000. Cardiovascular disorders, deaths at home and infections were the 3 commonest causes of death at 35%, 26% and 10% respectively.
- 3.2.4 In 2000, there was a total of 59 NGO dialysis centres.
- 3.2.5 New HD patients in 2000: Modal age-group 45-54 years; 58% were males, 46% were diabetics, 5% had HBsAg and 4% had anti-HCV antibodies.
- 3.2.6 HD patient and technique survival in NGO centres at 6 months for 1999 were similar at 96%
- 3.2.7 Overall, 32% of HD patients were able to work part or full time, 26% were homemakers and 11% pensioners. 59% had normal quality of life index.
- 3.2.8 **Haemodialysis Practices:** In 2000, 86% were dialysed via wrist AVF. 94% reported no difficulties with their vascular access; only 11% had vascular access complications. 87% had blood flow rates between 200 and 299 ml/min, 93% were on thrice-weekly and 6% on twice weekly HD. 98% had HD for 4 hours per session. Synthetic membrane usage increased rapidly to 45% in 2000. 41% reused their dialysers six times, 11% reused ten time. Usage of bicarbonate buffer was 99%. Median prescribed KT/V was 1.5; 71% had KT/V more than 1.3.

- 3.2.9 ***Dyslipidaemia in haemodialysis patients:*** In 2000, 65% of HD patients had serum cholesterol concentration < 5.3 mmol/l with median at 5 mmol/l. 86% had serum triglyceride concentration <3.5 mmol/l with median at 1.9 mmol/l.
- 3.2.10 ***Renal bone disease:*** In 2000, 92% of HD patients were on oral calcium carbonate, only 3% were on aluminium hydroxide. Proportion on active vitamin D supplements dropped to 22%. 32% achieved serum phosphate concentration <1.6 mmol/l; 61% had serum calcium concentration between 2.2 and 2.6 mmol/l and only 10% with iPTH between 100 – 250 ng/l. Median PTH concentration was 27 ng/L.
- 3.2.11 ***Blood pressure control:*** In 2000, 67% required anti-hypertensive therapy. Of these, 55% achieved systolic BP < 160 mmHg, and 59% diastolic BP < 90 mmHg. Of the 31% not on any anti-hypertensive therapy, 75% had systolic BP <160 mmHg and 77% diastolic BP < 90 mmHg.
- 3.2.12 ***Management of anaemia:*** In 2000, 56% were on recombinant erythropoietin with 58% on 2000 units weekly and 37% on 2000 – 4000 units weekly. 76% without erythropoietin and 67% on erythropoietin injections had serum iron > 10 µmol/l. 91% of those on erythropoietin had serum ferritin of > 100 µg/l. 32% of patients on erythropoietin had haemoglobin concentration >10 g/dl with only 6% > 12 g/dl.
- 3.2.13 ***Nutritional status:*** Proportion of patients with serum albumin concentration of >40 g/l was 39% in 2000. 59% had body mass index of between 18.5 and 25 kg/m² with 19% with BMI <18.5 kg/m².
- 3.2.14 ***Anti-HCV and HBsAg status:*** In 2000, 20 had anti-HCV antibodies, 6% were positive for HBsAg.

3.3 Haemodialysis In Private Centres

- 3.3.1 At 31st December 2000, 1513 patients were dialysing in private dialysis centres. 518 new patients were accepted for HD in private centres.
- 3.3.3 Death rate in private centres was 9% in 2000. Cardiovascular disorders, deaths at home and infections were the 3 commonest causes of death at 36%, 28% and 10% each respectively.
- 3.3.5 New HD patients in 2000: Modal age-group > 54 years; 56% were males, 52% were diabetics, 4% had HBsAg, 4% had anti-HCV antibody
- 3.3.6 HD patient survival in private centres at 6 months for 2000 was 97%, technique survival 96%.
- 3.3.7 In 2000, 28% were able to work full or part time, 26% were homemakers. 53% had a normal quality of life.

- 3.3.8 **Haemodialysis Practices:** In 2000, 80% were dialysed via wrist AVF, 15% via brachiocephalic fistula. 93% reported no difficulties with their vascular access; only 12% had vascular access complications. 87% had blood flow rates between 200 and 299 ml/min. Only 67% were on thrice-weekly dialysis, 32% only had twice weekly dialysis. 79% had 4 hours for session, 10% 4.5 hours. The majority – 78% used cellulosic membrane dialysers; only 19% used synthetic membrane dialysers. 8% did not reuse dialysers, 88% reused their dialysers at least three times. Usage of bicarbonate buffer was 89%. Median prescribed KT/V was 1.4; 67% had KT/V more than 1.3.
- 3.3.9 **Dyslipidaemia in haemodialysis patients:** In 2000, 66% of HD patients had serum cholesterol concentration < 5.3 mmol/l with median at 4.9 mmol/l. 86% had serum triglyceride concentration <3.5 mmol/l with median at 1.7 mmol/l.
- 3.3.10 **Renal bone disease:** In 2000, 84% of HD patients were on oral calcium carbonate, only 3% were on aluminium hydroxide and 33% on active vitamin D supplements. 31% achieved serum phosphate concentration <1.6 mmol/l; 56% had serum calcium concentration between 2.2 and 2.6 mmol/l and 23% with iPTH between 100 – 250 ng/l.
- 3.3.11 **Blood pressure control:** In 2000, 68% required anti-hypertensive therapy. Of these, 52% achieved systolic BP < 160 mmHg, and 59% diastolic BP < 90 mmHg.
- 3.3.12 **Management of anaemia:** In 2000, 63% were on recombinant erythropoietin with 30% on 2000 units weekly and 59% on 2000 – 4000 units weekly. 34% of patients on erythropoietin had haemoglobin concentration >10 g/dl with only 6% with haemoglobin concentration \geq 12 g/dl.
- 3.3.13 **Nutritional status:** Proportion of patients with serum albumin concentration of >40 g/l was 30% in 2000. 61% had body mass index of between 18.5 and 25 kg/m² with 17% with BMI <18.5 kg/m².
- 3.3.14 **Anti-HCV and HBsAg status:** In 2000, 23% of patients had anti-HCV antibodies, 5% were positive for HbsAg.

4. CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)

- 4.1 At 31st December 2000, 638 patients were on CAPD. There were 204 new CAPD patients of which 94% were funded by the government.
- 4.3 In 2000, death rate on CAPD was low at 12%; transfer to HD 10%. Death at home, cardiovascular disorders and sepsis were the main causes of death accounting for 28%, 27% and 21% respectively. CAPD peritonitis accounted for 13% of deaths. The main cause of transfer was peritonitis at 62% followed by membrane failure.
- 4.4 There were 15 CAPD centres all within the government sector.
- 4.5 New CAPD patients in 2000: Modal age-group 45-54 years; 47% males, 36% were diabetics, 3% had HBsAg, 4% were anti-HCV antibody positive.
- 4.6 CAPD patient and technique survival at 6 months for year 2000 were 95% and 92% respectively.
- 4.7 Overall, 22% of CAPD patients were able to work part or full time. 31% were homemakers and 15% full time students. Only 5% had normal quality of life index.
- 4.8 **CAPD Practices:** In 2000, 98% were on standard CAPD dialysis regime; 39% used the usual Baxter disconnect system; 61% on a disconnect system by Braun. 96% had 4 exchanges per day and 95% were on 2-litre exchanges
- 4.9 **Dyslipidaemia in CAPD patients:** In 2000, 40% of CAPD patients had serum cholesterol concentration < 5.3 mmol/l with median at 5.8 mmol/l. 79% had serum triglyceride concentration <3.5 mmol/l with median at 2.1 mmol/l.
- 4.10 **Renal bone disease:** In 2000, 79% of CAPD patients were on oral calcium carbonate, only 2% were on aluminium hydroxide and 15% on active vitamin D supplements. 51% achieved serum phosphate concentration < 1.6 mmol/l; 58% had serum calcium concentration between 2.2 and 2.6 mmol/l and 18% with iPTH between 100 – 250 ng/l. Median PTH values were lower than government HD patients at 43 ng/L.
- 4.11 **Blood pressure control:** In 2000, 78% of CAPD patients required anti-hypertensive therapy. Of these, 76% achieved systolic BP < 160 mmHg, and 56% diastolic blood pressure < 90 mmHg. Of the 22% not on anti-hypertensive therapy, 91% had systolic BP < 160 mmHg and 76% a diastolic BP < 90 mmHg.
- 4.12 **Management of anaemia:** In 2000, 63% of patients on CAPD were on recombinant erythropoietin with 53% on 2000-4000 units weekly and 35% on 2000 units weekly. 21% still received blood transfusions. 75% of patients without erythropoietin and 73% on erythropoietin injections had serum iron concentration of >10 umol/l. 80% of those without erythropoietin and 82% on erythropoietin had transferrin saturation > 20%. 86% of those with and 90%

without erythropoietin had serum ferritin concentration > 100 ng/l. 37% of CAPD patients not on erythropoietin had haemoglobin concentration >10 g/l and 12% had haemoglobin concentration of >12% compared to 39% and 9% respectively for those on erythropoietin. Generally haemoglobin concentrations for both groups of patients have improved over the years.

- 4.13 **Nutritional status:** 19% of CAPD patients had serum albumin > 40 g/l compared to 57% of government HD patients. 53% had body mass index of between 18.5 and 25 kg/m². 24% had body mass index <18.5 kg/m².
- 4.14 **Anti-HCV and HBsAg status:** The viral hepatitis serological status of CAPD patients were constant over the years at 2-3% for positive HbsAg and 5-6% for antiHCV antibodies.

5. RENAL TRANSPLANTATION

- 5.1 At 31st December 2000, there were 1171 functioning renal transplants
- 5.2 Of 111 new renal transplants in 2000, 14 were from living related donors, 26 from cadaveric donors done locally- the highest ever; 8 from commercial living non-related donors; and 58 from commercial cadaveric donors.
- 5.3 In 2000, 2% of transplant recipients died and 2% lost their grafts. Sepsis and cardiovascular diseases were the commonest cause of death. Rejection accounted for 68% of graft loss.
- 5.4 There were 41 centres of follow-up for renal transplant recipients.
- 5.5 Modal age group for new transplant recipients in 2000 was slightly older at 45-54 years; 66% were males, 14% diabetics; 4% were HBsAg positive and 6% had anti-HCV antibodies at the time of transplantation.
- 5.6 Six month patient survival in 2000 was 98% and graft survival was 91%.
- 5.7 Overall, 73% of transplant recipients were able to work part or full time, and 17% were homemakers. 95% had normal quality of life index.

METHODS

1. COVERAGE

There were 198 dialysis centres in Malaysia as at 15th November 2000, of which 181 reported data to the Registry. Thus, centre coverage has increased to 91%. We assessed completeness of patient ascertainment by comparing the number of patients registered on the Registry patient database at end of year 2000 and patient census data obtained independently from the annual centre survey at 15th November 2000. Based on the patient prevalence estimates calculated from these 2 independent sources of data (274 versus 316 patients/million population), we estimated the patient ascertainment rate by the Registry to be 87%.

2. STATISTICAL ANALYSIS

Kaplan Meier method¹ was used to estimate probability of survival and log rank test used to compare survival function. Technique failure is defined as occurrence of death or transfer to another modality of dialysis. Similarly, graft failure is defined as occurrence of death or returned to dialysis.

Annual death rates were calculated by dividing the number of deaths in a year by the estimated mid-year patient population.

For summarising continuous laboratory data, we have moved away from calculating summary statistics like mean, standard deviation and instead plot the cumulative frequency distribution graph. We are following the approach used by the UK Renal Registry². Cumulative distribution plot shows a listing of the sample values of a variable on the X axis and the proportion of the observations less than or greater than each value on the Y axis. An accompanying table gives the Median (50% of values are above or below it), upper quartile (UQ, 25% of values above and 75% below it) and lower quartile (LQ, 75% of values above and 25% below it). Other percentiles can be read directly off the cumulative distribution plot. The table also shows percent of observations above or below a target value, or with an interval of values; the target value or interval obviously vary with the type of laboratory data.. For example, target value for prescribed KT/V is ≥ 1.3 and that for haemoglobin is ≥ 10 and ≤ 12 g/l. The choice of target value is guided by published clinical practice guidelines, for example, the DOQI guideline; or otherwise they represent consensus of the local dialysis community.

In contrast to other results reported in this report, Tables 2.12 and 2.13 are based on centre survey data rather than individual patient data reported to the Registry. This is to provide an up to date information on patient and centre census in the country and thus overcome the inevitable time lag between processing individual patient data and subsequent reporting of results. The survey was conducted between 20th November and 20th December 2000. Centre response rate to the survey was 99.5% (197/198 responded). Standard error estimates are not reported because no sample was taken. Results on distribution by state are also expressed in per million-population since states obviously vary in their population sizes. State population data are based on 2000 census population

projection. It is very difficult to estimate the amount of cross boundary patient flow; this source of error is therefore not accounted for in computing state estimates. However, we minimise the bias by combining states (Selangor and Wilayah Persekutuan, Kedah and Perlis) based on geographical considerations. HD treatment capacity is derived by assuming on average patients underwent 3 HD sessions per week and a centre can maximally operate 2.5 shifts per day. A single HD machine can therefore support 5 patients' treatment. Obviously HD treatment capacity is calculated only for centre HD. The ratio of the number of centre HD capacity to number of centre HD patients is a useful measure of utilisation of available capacity. Only 1 centre did not respond. As the objective of this analysis is to estimate the total amount of dialysis provision in the country, we obviously cannot simply ignore the missing data and confine the analysis to available data. We therefore imputed the missing data based on regression imputation model and guided by the imputation principles described by Little³. The imputation model included sector (public, NGO or private), state, year of operation, number of dialysis personnel. These are well known correlates of level of dialysis provision in a centre. The imputations are then drawn by predictive mean matching³. Each centre with missing data was match with each respondent on its predicted values. We then use the data of the centre with the closest match to impute the missing data.

References:

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2. UKRENALREG 1998 UK Renal Registry, Bristol, UK.
3. Little RJ. Missing data adjustments in large surveys. *J Business Econ statistics* 1988;6:287-301