

A Report of the Malaysian Dialysis Registry of the National Renal Registry, Malaysia

Y N Lim, T O Lim, D G Lee, H S Wong, L M Ong, W Shaariah, G Rozina, Z Morad

National Renal Registry Malaysia, 2nd Floor, MMA House, 124, Jalan Pahang, 50286 Kuala Lumpur, Malaysia

SUMMARY

The Malaysian National Renal Registry was set up in 1992 to collect data for patients on renal replacement therapy (RRT). We present here the report of the Malaysian dialysis registry. *The objectives of this paper are:* (1) To examine the overall provision of dialysis treatment in Malaysia and its trend from 1980 to 2006. (2) To assess the treatment rate according to the states in the country. (3) To describe the method, location and funding of dialysis. (4) To characterise the patients accepted for dialysis treatment. (5) To analyze the outcomes of the dialysis treatment. Data on patients receiving dialysis treatment were collected at initiation of dialysis, at the time of any significant outcome, as well as yearly. The number of dialysis patients increased from 59 in 1980 to almost 15000 in 2006. The dialysis acceptance rate increased from 3 per million population in 1980 to 116 per million population in 2006, and the prevalence rate from 4 to 550 per million population over the same period. The economically advantaged states of Malaysia had much higher dialysis treatment rates compared to the less economically advanced states. Eighty to 90% of new dialysis patients were accepted into centre haemodialysis (HD), and the rest into the chronic ambulatory peritoneal dialysis (CAPD) programme. The government provided about half of the funding for dialysis treatment. Patients older than 55 years accounted for the largest proportion of new patients on dialysis since the 1990s. Diabetes mellitus has been the main cause of ESRD and accounted for more than 50% of new ESRD since 2002. Annual death rate averaged about 10% on HD and 15% on CAPD. The unadjusted 5-year patient survival on both HD and CAPD was about 80%. Fifty percent of dialysis patients reported very good median QoL index score. About 70% of dialysis patients were about to work full or part time. There has been a very rapid growth of dialysis provision in Malaysia particularly in the older age groups. ESRD caused by diabetes mellitus, despite being a preventable and treatable cause of ESRD - has increased and accounted for more than 50% of incident dialysis patients. Death and survival rates on dialysis are comparable to those from other countries.

KEY WORDS:

End-stage renal disease, Renal replacement therapy, Renal, Dialysis, Database, Registry

INTRODUCTION

The Malaysian National Renal Registry (NRR) collects information on patients with end stage renal disease (ESRD) on renal replacement therapy (RRT) and patients with other

types of kidney diseases in Malaysia. This report presents data on patients on chronic dialysis therapy.

The NRR has its origin in the Dialysis and Transplant Registry established by the Department of Nephrology, Kuala Lumpur Hospital (HKL) in 1992 to collect data from patients on renal replacement therapy within the Ministry of Health (MOH). In order to expand coverage to include non-MOH patients so that the registry may truly claim to be a national one, the running of the NRR was transferred to the Malaysian Society of Nephrology.

The objectives of this paper are:

1. To examine the overall provision of dialysis treatment in Malaysia and its trend from 1980 to 2006.
2. To assess the treatment rate according to the states in the country.
3. To describe the method, location and funding of dialysis.
4. To characterise the patients accepted for dialysis treatment.
5. To analyze the outcomes of the dialysis treatment.

MATERIALS AND METHODS

Patients with ESRD from participating clinical sites who were on dialysis or received renal transplantation were enrolled into the registry. This registry is open to all clinical sites that provide healthcare services for patients with ESRD in Malaysia.

The data collected consists of initial patient notification including - demography, medical history, current treatment modality, source of funding; patient outcome including death, change of RRT modality, moved to another clinical centre; and annual data collection on individual patients on RRT, including medications, dialysis prescription, management of uraemic complications; and annual quality of life (QoL) assessment using the Spitzer's index. In addition, dialysis centre surveys were conducted in December of each year since 1999. This annual cross-sectional survey was carried out to describe the most current level and distribution of dialysis provision at the end of each year, and to determine the completeness of data submission of patients on RRT to the NRR.

Treatment rate was calculated by the ratio of the number of new patients or prevalent patients in a given year to the mid-year population of Malaysia in that year, and expressed in per million-population. Annual death rates were calculated by

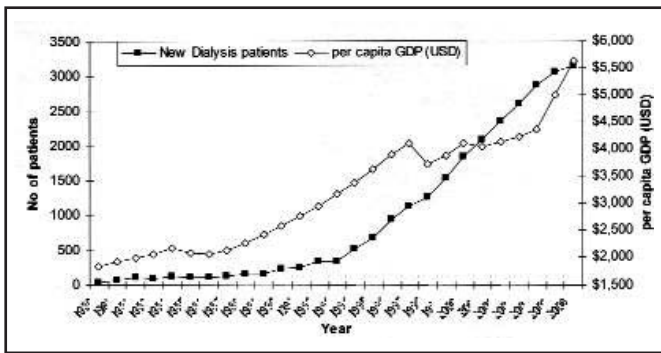


Fig. 1: Number of new Dialysis patients and per capita GDP, Malaysia 1980 – 2006

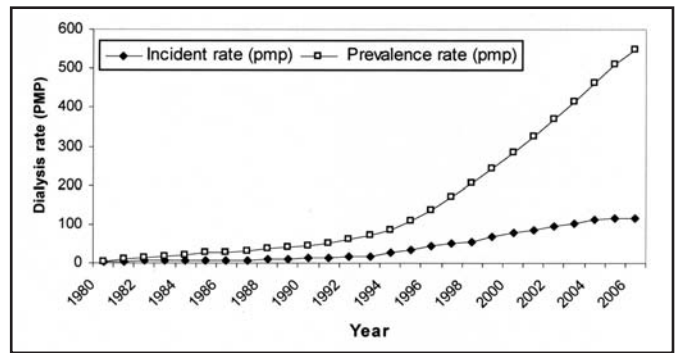


Fig. 2: Incident and prevalent rates of Dialysis patients. in Malaysia 1980-2006

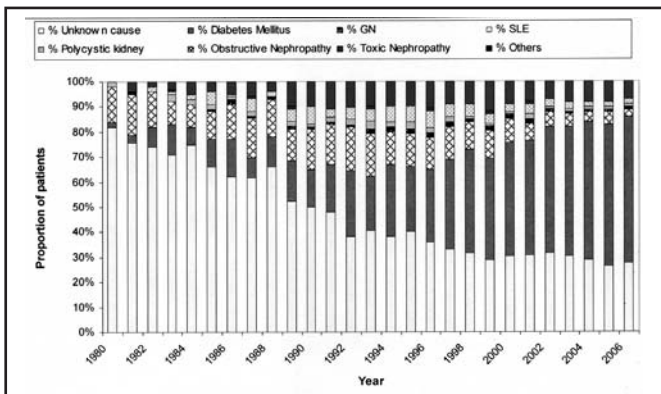


Fig. 3: Primary renal disease in Malaysia, 1980-2006

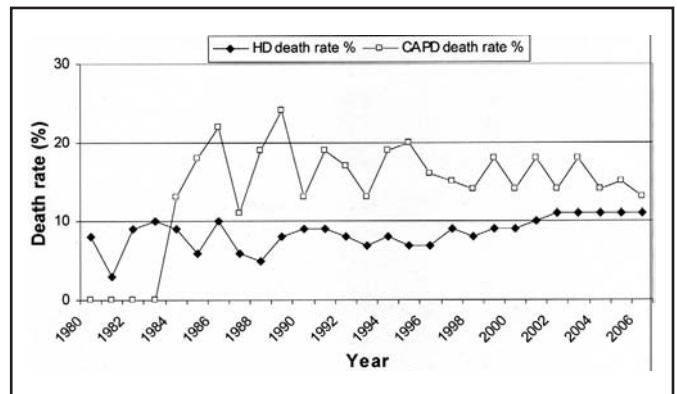


Fig. 4: Death rates on Dialysis in Malaysia, 1980 – 2006

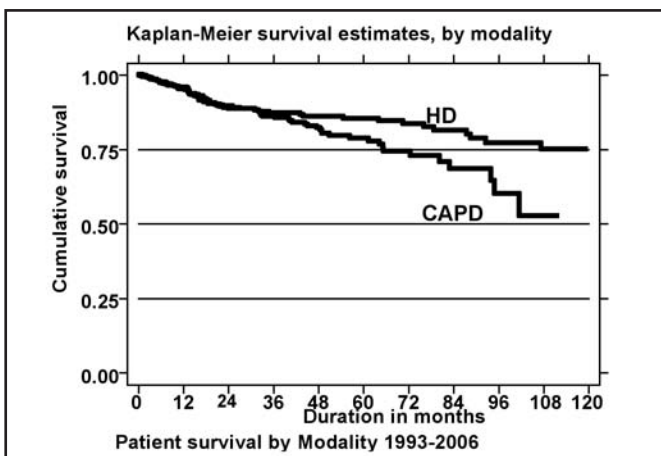


Fig. 5: Unadjusted patient survival by dialysis modality in Malaysia, 1993- 2006

dividing the number of deaths in a year by the estimated mid-year patient population. The unadjusted survival probabilities were calculated using the Kaplan-Meier method, in which the probability of surviving more than a given time can be estimated for members of a cohort of patients without accounting for the characteristics of the members of that cohort. The dialysis patient survival by modality was calculated based on the duration of the patients up to the moment when they switched modality. The duration and modality after switching dialysis modality were censored.

RESULTS AND DISCUSSION

Provision of dialysis treatment in Malaysia Overall and trends

Dialysis therapy in Malaysia was introduced on a rudimentary basis in 1964 mainly to support patients with acute renal failure. Chronic haemodialysis (HD) was introduced in 1969 and the first renal transplantation was performed in Malaysia in 1975. Chronic ambulatory peritoneal dialysis (CAPD) was first introduced into Malaysia in 1981².

Since those early days, the RRT scene in this country has changed dramatically. In 1980 there were only 59 patients on dialysis. Since then the number of patients has increased exponentially to almost 15,000 in 2006 as shown in Figure 1. The dialysis acceptance rate increased from 3 per million population in 1980 to 116 per million-population in 2006 and the prevalence rate from 4 per million to 550 per million-population respectively (Figure 2). The reason for the rapid increase in the RRT population in this country is no doubt due to the rapid economic growth Malaysia has experienced in the last two decades, as shown in Figure 1 coupled with the increasing awareness among the Malaysian public and politicians of this lethal disease³. This has resulted in more funds being channeled for dialysis therapy both through public donations as well as subsidies from the government.

Geographic distribution

The economically advantaged states of Malaysia i.e. Pulau Pinang, Melaka, Johor, Perak, Selangor, Wilayah Persekutuan

of Kuala Lumpur, and Negeri Sembilan had much higher dialysis treatment rates compared to the less economically advanced states and this trend persisted throughout the study period. Pulau Pinang had the highest treatment rate at 181 and Sabah the lowest at 56 per million in 2006.

Method, location and funding of dialysis

In the 1980's so-called home- or office-HD (HD carried out at home or in the work-place) made up a third to half of new dialysis treatment. Since the mid 1990's the proportion of new patients started on home HD has been almost negligible and 80-90% of new patients were accepted into centre HD. The proportion of patients accepted into the CAPD programme increased in the early 1990's to about 22-24%, plateau in the mid 1990's; and decreased in the late 1990's to a low of 10 to 11% since 2000. This trend reflected the prevailing conditions and funding of the ESRD programme.

Almost all CAPD patients were found in government centres. Before 1990, the majority of patients received HD therapy in government centres. Since the mid 1990's, the three main providers of dialysis namely government, non-governmental organisations and the private sector each provided a third of all HD therapy. Hence, in the 1980's the government provided three-quarters of the funding for dialysis. This amount has decreased to about half since the mid 1990's.

Characteristics of patients accepted for dialysis treatment

Demographics

In the 1980s new dialysis patients were disproportionately male. Since then, as treatment provision increased markedly, the proportion of female patients steadily improved. This initial convergence in male and female treatment rates implied that there had been a gender bias in dialysis provision in the early years of chronic dialysis treatment in Malaysia when dialysis provision was scarce and males were preferentially treated. We believe this reflects a cultural bias which placed greater value on male life, rather than a conscious decision on the part of nephrologists or policy makers. The consistent treatment gap noted in the last ten years between men and women accepted for dialysis suggests that this is a true reflection of the difference in ESRD incidence between the two sexes rather than any conscious or unconscious bias in treatment allocation

In the 1980s, patients aged 25 to 45 years comprised more than 50% of all new patients accepted for chronic dialysis therapy. Since the 1990s, older patients more than 55 years accounted for the largest proportion of new dialysis patients. Dialysis treatment rates were static for those less than 55 years of age but continued to increase for those over 55. In 2006, the dialysis incident rate for age < 15 years was 5 per million age related population, 26 for those 15 to 24 years, 595 in age group 55-64 years and 710 per million age related population in those >65 years old. Hence with increasing availability of dialysis therapy, the older age group with the highest incidence of ESRD has benefited the most.

Causes of ESRD

As shown in Figure 3, in the initial years of dialysis therapy, when younger patients without diabetes mellitus were selected for dialysis, the largest known cause of ESRD was chronic glomerulonephritis and diabetes mellitus accounted for less than 10%. Since the 1990's diabetic nephropathy has been the main known cause of ESRD and accounted for more than 50% of new ESRD from 2002.

Outcomes of dialysis treatment

Death and Patient survival on dialysis

Figure 4 shows that the annual death rates in patients on HD had been below 10% prior to 2000 but have increased to 11% for the last five years. Patients on CAPD have consistently higher death rates compared to patients on HD but these rates have now averaged about 15%. In contrast, the death rate in the USA was 20 per 100 patient-years for HD and 17 for CAPD, and the UK where death rate was 18 per 100 patient-years^{3,4}.

The increase in annual death rate that is similar to the higher death rate in the USA may reflect a greater intake of older patients onto dialysis rather than suboptimal care of these patients.

As shown in Figure 5, the unadjusted 5-year patient survival on both CAPD and HD was about 80%. After five years, patient survival on HD was better than on CAPD. This difference remains even with adjustment for age and diabetes mellitus. This contrasts with data from the USA, Canadian, Australian and the UK registries which show that CAPD appeared to have a better survival compared to haemodialysis^{3,4}. The fact that more CAPD patients switched to haemodialysis and not vice versa may explain the difference between the two modalities.

Quality of life (QOL) and work related rehabilitation on dialysis.

Fifty percent of dialysis patients reported median QoL index score of 9 or 10, (10 being the highest Spitzer QoL score). Older patients and diabetics reported lower median QoL index score but there was no difference between QoL scores by gender. Patients on CAPD reported higher median QoL index score compared to those on haemodialysis. About 70% of dialysis patients were able to work full or part time, 30% were not employed for health related reasons.

CONCLUSION

The Malaysian dialysis registry has demonstrated the rapid growth of dialysis provision in this country. This has been particularly dramatic in the older age groups. It has noted the unequal distribution of dialysis provision in the various states of this country. It has also shown that diabetic nephropathy leading to ESRD is on the rise and worryingly accounts for more than 50% of all incident dialysis patients. Hence prevention of ESRD is eminently achievable with better management of diabetes mellitus. Deaths and survival on dialysis is comparable to data from other countries.

The time has come to take a closer look at the quality of dialysis provision.

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