SHORT COMMUNICATION

Audit on data accuracy of the Malaysian Dialysis and Transplant Registry (MDTR)

Thong Kah Mean, FRCP[1], Maisarah Jalalonmuhali, MRCP[2], Choo Cheh Loo, Bachelor of Software Engineering[3], Yee Seow Yeing, MRCP[4], Rosnawati Yahya, FRCP[4], Philip Navaratnam Jeremiah, FRCP[5], Sunita Bavanandan, FRCP[4], Hooi Lai Seong, FRCP[3]

[1]Nephrology Unit, Medical Department, Hospital Raja Permaisuri Bainun, Ipoh, Malaysia, [2]Renal Division, Department of Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia, [3]National Renal Registry, Malaysia, [4]Nephrology Department, Hospital Kuala Lumpur, Kuala Lumpur, Malaysia, [5]KPJ Ampang Puteri Specialist Hospital, Kuala Lumpur, Malaysia

SUMMARY

Diabetes mellitus is the main aetiology of end stage kidney disease (ESKD) in Malaysia. However, there may be concerns of over-reporting of diabetes mellitus as the cause of ESKD in the Malaysian Dialysis and Transplant Registry (MDTR). The objective of this audit is to assess the accuracy of data collected in the MDTR. There were 151 centres/source data providers (SDP) with a total of 1977 patients included in this audit. The audit showed that 80.2% of doctors' records matched the MDTR data. The results were comparable with published validation studies in other countries.

INTRODUCTION

The Malaysian Dialysis and Transplant Registry (MDTR) of the National Renal Registry (NRR) collects data on all patients receiving kidney replacement therapy in Malaysia. There was a total of 9123 new dialysis patients in 2021, and diabetes mellitus remained the main cause (53.0%) of end stage kidney disease (ESKD), followed by hypertension (33.9%), unknown (4%) and glomerulonephritis/systemic lupus erythematosus (1.9%).[1] The proportion of diabetes mellitus appeared to have declined from 67.4% in 2016. This was probably artefactual due to the over-reporting of diabetes mellitus as the cause of ESKD, which was reviewed upon migration to a new deceased donor kidney transplant allocation system, the Malaysian Kidney Allocation System (MyKAS) in 2020.[2] The new system seeks to achieve the best use of scarce kidneys from deceased donors, applying ethical principles of utility and equity while retaining the principle of justice in the allocation process. Under MyKAS, a diagnosis of diabetes mellitus increases the 'estimated post transplant survival (EPTS)' score, and in effect excludes the patient from listing as a potential kidney transplant recipient. It is therefore important that all attempts are made to confirm the presence of diabetes mellitus.

The objective of this audit is to assess the accuracy of data collected in the MDTR on notification of new ESKD patients, specifically on the diagnosis of diabetes mellitus as cause of primary renal disease (PRD), in reference to patients' medical records.

Adult patients who were initiated on haemodialysis (HD) or peritoneal dialysis (PD) in year 2021 were included in the audit. Paediatric and transplant patients were excluded. A total of 177 centres/source data providers (SDP) were invited. Data collection was carried out from 1st November 2022 to 31st December 2022.

Doctors at each site reviewed the patients' medical records retrospectively and coded as 'Yes' if there was documentation of diabetes mellitus in the medical records, or 'No' if absent. Their results were then compared with the original data of PRD that was submitted by the SDP staff to MDTR.

Sub-group analysis was carried out to analyse the data accuracy according to sectors, HD versus PD, geographical regions as well as types of institution.

Descriptive statistics were used to describe demographics, primary renal disease, and comorbid conditions. Chi square tests were used to make comparisons between matched and unmatched data in subgroup analysis. The alpha level was established as $p \leq 0.05$. SPSS (version 25) and MS Excel were used for all calculations.

There were 151 (118 HD, 33 PD) centres/SDP from 12 out of 16 states/federal territories in Malaysia which participated in the audit, of which 139 were from the Ministry of Health (MOH), eight were from the Ministry of Education (MOE) and four were private HD centres. A total of 1977 patients were included, and their medical records were reviewed. Median age was 54.2 years (IQR 40.4, 62.7), 52.1% were male and 63.4% were on PD. Table I compares the characteristics of SDP and patients of the cohort we audited with the non-audited cohort in MDTR.

The audit showed that 80.2% of the doctor's record matched the MDTR data (Table II), with 0.6% of patients having untraceable records (missing data). There were 45.7% of patients with documentation of diabetes mellitus in the doctor's record and MDTR also confirmed the primary aetiology of kidney disease was diabetes mellitus.

There were 326 (16.5%) patients in which doctors documented the presence of DM, but MDTR did not indicate

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Corresponding Author: Thong Kah Mean
Email: thongkmean@gmail.com

Table I: Baseline characteristics of the audited and non-audited cohorts

	Audited cohort (n=151 SDP)	Non-audited cohort (n=752 SDP)	MDTR cohort (n=903 SDP)
Number of centres (SDP)			
Number of HD centres (SDP)	118	737	855
Number of PD centres (SDP)	33	15	48
Number of centres (SDP) according to geographical distribution			
West Malaysia			
East coast	46	93	139
West coast	59	605	664
East Malaysia	46	54	100
Number of centres (SDP) according to sectors			
MOH (Ministry of Health)	139	56	195
MOE (Ministry of Education)	8	4	12
MOD (Ministry of Defence)	0	5	5
NGO (Non-government organizations)	0	159	159
Private	4	528	532
Number of centres (SDP) according to types of institutions			
Tertiary institutions	31	6	37
Secondary institutions	105	132	237
Free-standing clinics	15	614	629
New dialysis patients in 2021			
Number	1 977	7 129	9 106
Age of patients (median, years)	54.2	59.1	58.3
Male patients (%)	52.1%	53.9%	53.5%
Patients on HD (%)	36.6%	94.9%	82.2%
Patients on PD (%)	63.4%	5.1%	17.8%

SDP: source data provider

Table II: Matching of doctors' records with Malaysian Dialysis and Transplant Registry (MDTR) data

	Matched result		Unmatched result	
	Dr's record: Yes; MDTR data: Yes	Dr's record: No; MDTR data: No	Dr's record: Yes; MDTR data: No	Dr's record: No; MDTR data: Yes
Patients (%)	904 (45.7%)	683 (34.5%)	326 (16.5%)	53 (2.7%)
Total patients	1587 (80.2%)		379 (19.2%)	

Untraceable/missing data: 11 (0.6%)

DM as the PRD. Further analysis showed that 123 (out of 326) patients had documentation of diabetes mellitus as 'co-morbidity' in the MDTR.

Sub-group analysis (Figure 1) showed that private centres or free-standing clinics had lower rate of matching data ($p < 0.05$) whereas no differences were detected among HD or PD centres/SDP, nor different geographical regions.

This is the first audit of accuracy of reported data in MDTR and it showed that 80.2% of the doctor's records matched the MDTR data. The results were comparable with other published validation studies. A pilot audit of the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) reported that the PRD data was correct for 86.3%.[3] The overall rate of accurate data entry of the Hong Kong Renal Registry was 81%.[4] Canadian Organ Replacement Register validation study reported a rate of 70.9%[5] and the United States Renal Data System (USRDS) validation result of 59.5%.[6]

In the group of unmatched results (Table II), 326 (16.5%) patients had documentation of diabetes mellitus in the doctor's notes, but MDTR did not reveal diabetes mellitus as the PRD. Although this could be due to inaccurate data submission, another explanation was related to diabetic patients having other causes of ESKD (e.g. glomerulonephritis, autosomal dominant kidney disease, etc). In this group of patients, further analysis showed that 123 (6.2%) patients had a record of diabetes mellitus as co-morbidity in MDTR, but PRD due to other causes. We believe the number may be higher, as it is not compulsory to report co-morbidity to NRR. Hence, the 'true' data inaccuracy of the MDTR was likely lower than 19.2% as shown in this audit. There were 2.7% of patients with an MDTR record as 'Yes' (diabetes mellitus as PRD) but the doctor's record did not concur. This small group of patients would require necessary correction in the MDTR to avoid being de-listed as kidney transplant recipients in MyKAS.

Over-reporting of diabetes mellitus in the past could be due to changes in the classification of diabetes as the PRD. In 2017 data collection migrated from a paper-based system to an electronic NRR, and it allowed more than one PRD. The NRR office adjudicated discrepancies in the data submitted to determine the PRD. For example, if the PRD was recorded as unknown and patient had diabetes mellitus as the secondary cause or co-morbidity, the PRD was amended to diabetes mellitus. However, since year 2021, only one cause of PRD is accepted. If PRD was unknown and diabetes mellitus is

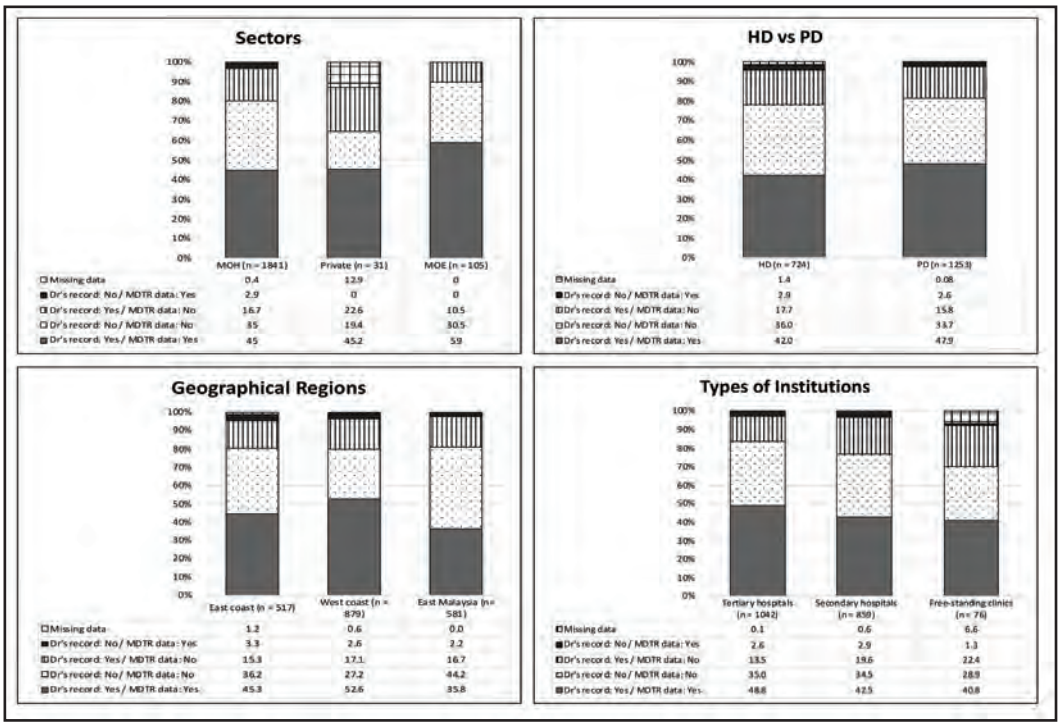

Fig. 1: Sub-group analysis according to sectors, dialysis modalities, geographical regions and types of institution

included in comorbidity at notification, 'unknown' PRD is maintained.

We recognise that our study has a both limitations and strengths. This limited audit involved mostly centres from MOH and MOE, although a large number of incident HD patients were in private HD centres. Although 63.4% were PD patients as opposed to 17.8% in MDTR, we audited 118 HD centres and 33 PD centres. We covered 12 states in Malaysia.

Our results were comparable with published validation studies in other countries. Strategies to improve data quality are on-going. These include providing guidance for diagnosis of diabetic nephropathy, educating staff in data submission and requiring a doctor to verify "primary renal disease" upon submitting data to MDTR.

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CONFLICT OF INTEREST

There is no conflict of interest or competing financial interests.

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