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Causes of death in older peritoneal dialysis patients—can we depend on registry reports?

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Abstract
Objectives Despite significant improvements in renal management the mortality associated with dialysis care remains high. Many renal registries report mortality statistics on an annual basis. The objectives of this study were (1) to establish the accuracy of the registered cause of death (CoD) against that determined by a panel of physicians; and (2) to test the feasibility of using the HEMO study CoD classification system in patients on peritoneal dialysis (PD).
Setting Single centre tertiary-care hospital.
Patients and methods Patients were selected from those aged ≥ 65 years who died while receiving PD. The CoD was identified from that registered with the local renal registry, and from clinical records.
Main outcome measures (1) Sensitivity, specificity, positive predictive values (PPV), negative predictive values (NPV) and kappa score comparing registered and extracted CoD. (2) The proportions of deaths in seven categories using two classification systems.
Results A total of 51 patient charts were reviewed. The agreement between the registered and extracted CoD was poor for all causes of death except malignancy. Kappa scores ranged from 0.55 to 1.0 for different causes. PPV were poor for all except malignancy. Comparison of the CoD was highly dependent on the classification method used (e.g., death secondary to infection was 4% and 25% for CORR and HEMO, respectively).
Conclusions The registered CoD for patients who die while on PD is often inaccurate. Different policies for classifying deaths can have a significant effect on the final reports, which show the proportion of deaths attributed to different diseases. Standardization across registries is required.

Keywords Renal registries · Mortality · Peritoneal dialysis · Agreement statistics · Sensitivity · Specificity · Positive and negative predictive values

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Introduction

Despite significant improvements in renal management the mortality associated with dialysis care remains high. Worldwide, annual registries report the causes of patient death allowing clinicians, researchers, and health policy makers to follow trends in disease, compare treatment

effectiveness across regions and set health care priorities [1–7]. Errors arising from registry data can occur at the time of reporting (data quality) or at the time of data analysis (data interpretation), and can impact directly on health care providers and policy makers alike.

Information about the actual cause of death in most registries is collected using a coding system, which can be electronically summarized into broad categories. The proportion of deaths within each of these categories, for example, cardiac, infective or vascular deaths is reported each year. Differences in the methods used to summarize individual patient data can influence the reported mortality statistics, making comparisons across different databases difficult. Both the Canadian Organ Replacement Registry (CORR) [1] and Centers for Medicare and Medicaid Services (CMMS) [8] have similar (though not identical) coding systems. CORR, for example, summarizes data from 52 specific causes of death codes into nine categories (cardiac, vascular, infection, liver disease, gastrointestinal, social, accidental, miscellaneous and unknown). For example, death due to ''hemorrhage -vascular access/dialysis circuit'' is included amongst the vascular category for cause of death. However, sepsis, which arose from a vascular access, would be classified as an infection related cause of death. In the dialysis population deaths attributable to hemodialysis (HD) vascular access complications (e.g., sepsis and infection) are potentially preventable. In the HEMO study, the authors suggested a new classification for death [9]. In their table of Attributable Causes of Death, complications resulting from vascular access or HD were reported as a unique category; septic episodes in association with GI problems or gangrene were reported under GI causes and vascular causes, respectively; and a greater attempt was made to classify cardiac deaths into well-defined causes. We hypothesized that the HEMO study death classification may also be appropriate for the peritoneal dialysis (PD) population.

It is vital that the reported and recorded main attributable cause of death be accurate. Differences between the attributed cause of death taken from death certificates, and that obtained clinically, have been widely reported [10–16]. In an East German population-based study, which took place over a one-year period, 1,023 of 1,060 (97%) of those who died underwent an autopsy [12]. At the time of death the attending physician was asked to assign the cause of death using a standardized system. The pathology team were asked to assign the cause of death using data from the autopsy. The gold standard cause of death was that identified by the pathology team. The results showed that 47% of time the attending physician documented a different cause of death from that determined on autopsy. Differences were significant, and crossed disease categories in at least 30% of cases. Errors were most common in those with complex comorbidity and advanced age. In particular cardiac, metabolic and endocrine diseases were over reported, with infectious, neoplasic and genitourinary disorders being underreported. Such discrepancies are not limited to studies with autopsy diagnoses. The Framingham study reported significant discordance between the cause of death reported on death certificates and that determined by a panelist on clinical review, again noting over reporting of coronary heart disease particularly in those ≥ 80 years of age [14]. In renal disease, data from the HEMO study showed poor agreement with registered causes of death and those determined by a panel of physicians, while data from Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) showed discrepancies between registry data and that recorded on the death certificate [9, 10].

Our two objectives were to conduct a pilot study in a Toronto PD population to establish the accuracy of the registered cause of death against that determined by a panel of physicians; and to apply the HEMO study Attributable Causes of Death classification system to patients on PD.

Methodology

Patient population

Subjects were recruited as part of a study looking at mortality rates in older female diabetic patients on PD [17]. All subjects were treated with PD at the University Health Network Peritoneal Dial-

ysis Unit over the period August 1986–March 1999. Patients had all been on PD for a minimum of 1 month.

Method used to determine registered attributable cause of death

Registered data on the main attributable cause of death were obtained from the Toronto Region Dialysis registry. In our unit, deaths are reported to the local dialysis registry (The Toronto Region Dialysis Registry) on a weekly to monthly basis. The cause of death is determined by chart review; clinical information from the physicians involved with the direct care of the patients; and review of biochemical and lab testing. During the whole study period, and presently, coding is done by one of two permanent registered nurses familiar with both the patients' clinical history and the coding system. If the patient death occurred while in hospital additional information is available from the cause of death documented by the physician certifying the death. These data are electronically forwarded to the national dialysis registry (Canadian Organ Replacement Register, CORR) on an annual basis. Unlike CORR data, the Toronto Region Dialysis Registry retains the actual patient names in addition to demographic data and information on the cause and date of death. Thus named data are accessible to physicians involved directly with the care of the patient (in accordance with the agreements between the registry and the centers). Patient name, date of first renal replacement therapy, date of death and the date of birth were used to link registered and clinical data.

Method used to determine clinically identified cause of death

Clinical data for each patient was obtained from the electronic and paper charts. All data, including ECG's, laboratory results, X-rays etc. were reviewed and a final cause of death agreed on by a panel of two clinicians (SM and SVJ). Disagreements, between the two reviewers, about the cause of death were resolved by discussion. The cause of death was classified using both CORR and HEMO study codes at the time of data extraction.

Statistical analysis

The codes used to identify the registered cause of death codes were electronically translated into codes used by the HEMO study classification (available on request). Agreement statistics to evaluate the accuracy of the registered cause of death with that extracted by the panel of physicians included the sensitivity, specificity, positive and negative predictive values and the kappa statistic for each of the diagnostic categories. The clinically extracted cause of death was used as the gold standard.

Descriptive comparisons between the results showing mortality using the CORR classification and those using the HEMO system were made. The degree of agreement was confirmed using the kappa statistic.

Results

A total of 51 patients were identified. The patients had a mean age of 78.8 ± 8.8 years at the time of death, with a median survival on PD of 29 months (quartiles 15–44 months). Comorbidity characteristics have been described elsewhere [17]. Death was most commonly secondary to cardiac causes (Table 1). One patient died after a HD related vascular access infection. This patient had been recently switched from HD to PD and was awaiting access removal. Three patients died as a result of PD peritonitis-related sepsis, and one as a result of bowel strangulation in relation to encapsulating peritoneal sclerosis .

Accuracy of registered data

The agreement between the registered and extracted cause of death was poor for all main attributable causes of death except malignancy. Within the four cardiac related diagnoses (myocardial ischemia and infarction; arrhythmia related; heart failure and other) the kappa scores ranged between 0 and 0.38 suggesting any agreement was by chance alone (Table 2). However, when all cardiac-related deaths were grouped together, the sensitivity, specificity,

Table 1 Causes of death as registered

	Frequency	Percent
Cardiac arrest (cause unknown)	10	19.6
Malignancy	5	9.8
Uncertain/not determined	4	7.8
Myocardial ischaemia/infarction	4	7.8
Cachexia	4	7.8
Cardiac failure	3	5.9
Acute respiratory distress	3	5.9
Septicaemia	3	5.9
Therapy ceased	3	5.9
Cerebrovascular accident	2	3.9
Infection	2	3.9
Multisystem failure	2	3.9
Other	2	3.9
Pulmonary infection (bacterial)	1	2.0
Tuberculosis (except lung)	1	2.0
Withdrawal (pt request)	1	2.0
Encapsulating peritoniteal sclerosis	1	2.0

positive and negative predictive value and the kappa score increased to 0.76, 0.94, 0.87, 0.89 and 0.83, respectively. This suggests that individuals completing the registration documents correctly identify the cause of death to be cardiac related but incorrectly sub classify them.

Application of HEMO study classifications to PD data

To evaluate the effect of adopting the HEMO study classification of cause of death, we condensed the cause of death categories into seven main groups (cardiac, vascular, infection related, malignancy, dialysis related, unknown and other). Using the HEMO coding system resulted in a larger number of deaths being attributed to vascular disease. In many of these situations, patients had been suffering from severe peripheral vascular disease with evidence of gangrene. In each, the final event had been vascular disease related septicemia. When the HEMO study classification was further modified to reclassify PD-peritonitis and death secondary to encapsulating peritoneal sclerosis as being dialysis related deaths, there was a significant increase in the number of deaths attributable to dialysis related complications.

Discussion

This study is the only study of PD patients that compares the registered and extracted cause of death. Our data confirm reports from other populations, showing that the registered cause of death is often inaccurate [9–12]. None have specifically looked at PD patients and therefore, included causes of death unique to PD patients. Our study has shown that illnesses specific to PD (e.g., PD peritonitis; encapsulating peritoneal sclerosis) that may result in death must be included in the HEMO study coding system before it can be generalized to studies, which include PD patients. The data presented here demonstrate the importance of worldwide standardization in reporting the cause of death. By simply adopting

Table 2 Table showing agreement between different classifications systems

Cause of death	Registered classification	Extracted classification	Sens	Spec	PPV	NPV	Kappa
IHD	4	3	0.33	0.94	0.25	0.96	0.23
CHF	3	0	0.00	0.94	0.00	1.00	0.00
Arrhythmias	0	2	0.00	1.00	N/A	0.96	0.00
Other cardiac	10	10	0.50	0.88	0.50	0.88	0.38
CVA	2	2	0.50	0.98	0.50	0.98	0.48
PVD	0	11	0.00	1.00	N/A	0.78	0.00
Resp	4	2	1.00	0.96	0.50	1.00	0.65
Malig	5	5	1.00	1.00	1.00	1.00	1.00
GI	0	4	0.00	1.00	N/A	0.92	0.00
Infection	6	4	0.50	0.91	0.33	0.96	0.34
HD vasc access	0	1	0.00	1.00	N/A	0.98	0.00
Other	13	6	1.00	0.84	0.46	1.00	0.56
Unknown	4	1	0.00	0.92	0.00	0.98	0.03

a different coding system we were able to dramatically reduce the proportion of patients who died from infection, but increase the prevalence of vascular disease as a cause of death. As such differences in international reporting can be artificially created.

Two important issues arise as a result of this pilot project:

First we believe that deaths should be reported by a trained observer. In most circumstances, it is the physician involved with the direct clinical care of the deceased patient who reports the death and determines the cause of death. In Canada, for example, the physician signing the death certificate is asked to list the most likely cause of death and contributing factors. Few, if any, physicians are trained in death certificate completion and consequently few complete them accurately [18]. We propose several solutions: that the registration of the attributable cause of death be done by a trained data clerk (as with ICD9 coding clerks); that nurses and physicians receive training to increase reporting accuracy or that registry requirements for cause of death be simplified and a structured algorithm be devised (and tested) to improve cause of death coding.

The second important issue arising from our data is that simple changes in definitions of cardiac, infectious or vascular deaths can result in marked demographic swings. Assuming similar differences across registries exist, we believe that the International Federation for Renal Registries, with the help of leading registry organizations across the world, should standardize death reporting to facilitate accurate comparison across registries.

There are several limitations to this study. We chose to perform a pilot study with a relatively small sample size limiting the precision of the sensitivity and specificity estimates. We believe the thrust of our results to be correct, as they reflect the findings of similar larger studies in other populations [9–11]. All the data were gathered from a single University based academic centre. Data were not drawn from any of the community hospitals allowing for a possible centre effect. In teaching hospitals, like our own, there are a number of trainees who may be less familiar with identification of an accurate attributable cause of death. Pervious studies have shown that the accuracy of reporting increases with increased training, although to a small extent. One could therefore, assume that in community hospitals, where fewer junior residents are involved with patient care, the accuracy of reporting is higher. In our own centre, only specialist trainees in nephrology are involved with the PD unit, and therefore, physician inexperience is unlikely to have influenced the results. Furthermore, our data on death rates, and causes, were similar to national demographics reported by CORR on an annual basis.

A major strength of our study was that we were able to perform accurate data linkage. Clinical and registered data were easily matched using four parameters including name, date of birth, date of first dialysis and date of death. The causes of death, obtained from the registry data, are however, consistent with national reports suggesting a limited amount of bias.

In conclusion, we believe that with simple modifications the HEMO study death classification can be adapted for use in PD patients. We also conclude that the accuracy of registered deaths is low for PD patients, and that some thought needs to be directed to a system allowing more accurate completion of the cause of death.

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