A Comparison of Death Records Between the United States Renal Data System and a Large Integrated Health Care System

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In studying treatments and outcomes of end-stage renal disease (ESRD), mortality is a major component of all studies. Thus, the completeness and accuracy of mortality data is paramount in helping researchers to assess ESRD care and to develop interventions targeted at improving survivability or quality of life. This is especially important, as the ESRD population faces one of the highest mortality rates in the nation, and the first few months after ESRD transition are the most critical.[1]

The United States Renal Data System (USRDS) maintains 1 of the largest disease registries in the United States and is a primary source of outcomes data on the U.S. ESRD population. USRDS mortality information is derived mostly from the Centers for Medicare & Medicaid Services Death Notification Form 2746 and Medical Evidence Form 2728 as reported to them by providers.[2] Although a small number of studies have examined the completeness of the mortality data maintained by the USRDS,[3–7] most of this work was done many years ago, some for small subsets of the population, and therefore may not reflect the current state. To address this gap, we performed a retrospective cohort study comparing mortality records from Kaiser Permanente Southern California (KPSC) with the USRDS registry among ESRD patients between January 1, 2007 and December 31, 2016.

KPSC is a large integrated healthcare system that cares for a racially/ethnically and socioeconomically diverse population of 6 million members. It maintains a comprehensive Research Data Warehouse with data from its electronic health record and other sources. Mortality information, including death date, is primarily obtained from the linkage to California State Death Master Files, supplemented by 6 data sources: California State Multiple Cause of Death Master Files, Social Security Administration (SSA) Death Master Files, KPSC hospital and emergency room records, KPSC Perinatal Services System files, KPSC Membership System files, and claims submitted to KPSC from outside facilities or information reported to the Health Plan directly.[8]

In this cohort, KPSC members with ESRD were matched to USRDS data by Social Security Number, name, sex, and date of birth. Demographic characteristics of all matched ESRD patients were collected from KPSC membership databases. Mortality information was obtained from USRDS and KPSC databases to confirm reported death. In the USRDS database, death dates are obtained from several sources including the CMS Medicare Enrollment Database, CMS forms 2746 (Death Notification form) and 2728 (Medical Evidence form), OPTN transplant follow-up form, CROWNWeb database, and Inpatient Claims database.[9] For those with death records in USRDS or KPSC, death date and reporting sources were compared. To evaluate whether the missing records were related to patients' profile, characteristics were compared between patients who had death recorded in both databases and those with death recorded in KPSC only. Student t tests and χ^2 tests were performed for comparisons of continuous or categorical variables separately.

A total of 12,486 ESRD patients between January 1, 2007 and December 31, 2016 from KPSC were linked with USRDS. We identified 4827 death records during this period in either the KPSC or USRDS database. Of these records, 4189 (87.3%) were found in both databases, 609 (12.7%) were found only in KPSC, and 29 (0.6%) were found only in USRDS. The percentage of death records found in KPSC but missing in the USRDS database was consistent each year of the study period (Table 1). In comparing the decedents' characteristics

Table 1. Comparison of death records between KPSC and USRDS among incident ESRD patients in 2007–2016 (N = 4827)

Database of death recorded	Year of death recorded[a]										Total
	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	
USRDS-only	0	0	0	0	0	1	6	3	8	11	29
KPSC-only	12	29	42	54	60	55	74	71	97	115	609
In both databases	86	186	264	343	416	479	504	540	638	732	4189
Percent missing in USRDS if KPSC had recorded death	12.2%	13.5%	13.7%	13.6%	12.6%	10.3%	12.8%	11.6%	13.2%	13.6%	12.7%

KPSC, Kaiser Permanente Southern California; USRDS, United States Renal Data System.
[a]Year of death used the earliest death reported year in KPSC or in USRDS if recorded by both sources, then the recorded year if missing in one source.

between those found in both databases and those found only in KPSC (Table 2), age, sex, and race/ethnicity were similar. A majority (4345; 90.6%) of these ESRD patients were on hemodialysis. Death records missing in USRDS occurred 20.5 (median) months after ESRD initiation. For those who had death records in KPSC but not USRDS, 573 (94.1%) were identified by linking to California death files. It was found that compared to those who had records in both sources, those whose death records were in KPSC but not USRDS included a

higher percentage of patients receiving their last care in hospice or palliative care or having an indication of recovery of glomerular filtration rate and no longer receiving dialysis.

Among the 4189 death records present in both sources, there was good agreement in date of death (Figure 1). There were 3641 (86.9%) records with exact matches and another 502 (12.0%) matched within a week. Of the 548 death records for which the death date did not match, more than one-half (312; 56.9%) of

Table 2. Characteristics comparison between patients with death reported in USRDS and KPSC and those with death reported in KPSC-only (n = 4798)

Characteristics	Having USRDS death records	Missing USRDS death records	Total	P value
	n = 4189	n = 609	n = 4798	
Age, yr, mean ± SD	68.8 ± 12.1	68.7 ± 12.21	68.8 ± 12.1	1.0
Female	1726 (41.2)	264 (43.3)	1990 (41.5)	0.3
Death reported from ESRD initiation,[a] mo, median (IQR)	25.7 (8.2–48.3)	20.5 (6.9–42.2)	25.1 (8.0–47.5)	0.01
Modality				<0.0001
Hemodialysis	3778 (90.2)	567 (93.1)	4345 (90.6)	
Peritoneal dialysis	404 (9.6)	30 (4.9)	434 (9)	
Transplant	7 (0.2)	12 (2)	19 (0.4)	
Race/ethnicity				0.6
White	1590 (38)	245 (40.2)	1835 (38.2)	
Asian	380 (9.1)	59 (9.7)	439 (9.1)	
Black	882 (21.1)	111 (18.2)	993 (20.7)	
Hispanic	1208 (28.8)	179 (29.4)	1387 (28.9)	
Other	80[a] (1.9)	10 (1.7)	90 (1.8)	
Unknown	49 (1.2)	5 (0.8)	54 (1.1)	
Death-reporting source in KPSC				<0.0001
KPSC hospital	1 (0)	1 (0.2)	2 (0)	
Membership	24 (0.6)	4 (0.7)	28 (0.6)	
California state death master files	4119 (98.3)	573 (94.1)	4692 (97.8)	
Non-KPSC hospital	1 (0)	2 (0.3)	3 (0.1)	
SSA	44 (1.1)	29 (4.8)	73 (1.5)	
Provider				0.01
Large dialysis organization	3470 (82.8)	478 (78.5)	3948 (82.3)	
Other	719 (17.2)	131 (21.5)	850 (17.7)	
Dialysis status				<0.0001
Active	3708 (88.7)	335 (55.2)	4043 (84.4)	
Off dialysis[b]	147 (3.5)	214 (35.1)	361 (7.5)	
Unknown	334 (8.0)	60 (9.9)	394 (8.2)	
Care before death				0.0004
Hospice	313 (7.5)	74 (12.2)	387 (8.1)	
Palliative care	50 (1.2)	8 (1.3)	58 (1.2)	
Other	3826 (91.3)	527 (86.5)	4353 (90.7)	

ESRD, end-stage renal disease; IQR, interquartile range; KPSC, Kaiser Permanente Southern California; SSA, Social Security Administration; USRDS, United States Renal Data System.
[a]Using KPSC reported death date.
[b]Includes those whose kidney function recovered and those who opted not to continue dialysis.
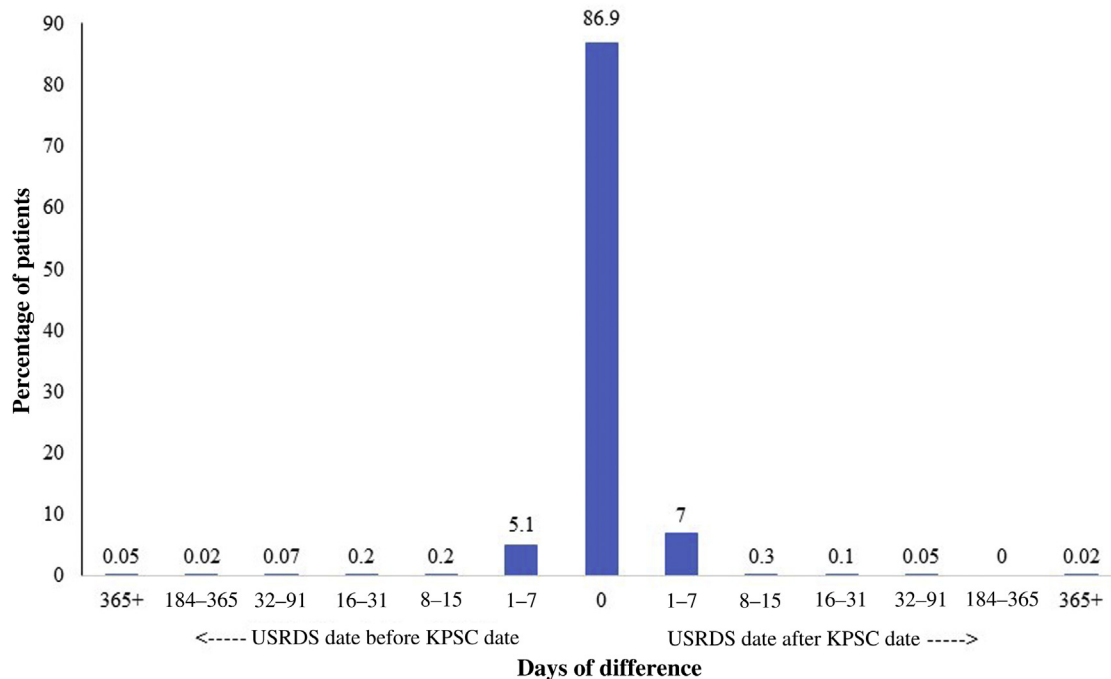Data are n (%) unless otherwise noted.

Figure 1. Death recorded days of difference between Kaiser Permanente Southern California (KPSC) and United States Renal Data System (USRDS) among those with death reported in both databases (N = 4189). Figure does not include the 638 cases with missing death record in either KPSC or USRDS database.

the USRDS death dates occurred after the KPSC death date, and 236 (43%) URDS death dates occurred before the KPSC death date.

These data suggest that the death records in the USRDS are largely complete and accurate but that there is room for improvement. Table 1 shows a steady increase in the number of KPSC deaths compared to those in USRDS, particularly after 2013, suggesting that there may be a potential time lag. However, the percentage of deaths is relatively constant and therefore probably represents underlying demographic changes and growth in the KPSC ESRD cohort. Indeed, we found that over a 10-year period, 86% to 90% of KPSC death records had corresponding USRDS records; of these, 87% of the death dates matched. The missing USRDS records could have important implications for conclusions drawn about ESRD care and management. If these were systematically missing for certain subsets of patients, such as those who recovered glomerular filtration rate after ESRD initiation or chose not to continue dialysis, the resulting bias could misinform questions about specific treatments or approaches. In addition, inaccurate death dates, as suggested in these data, could result in an underestimate of medium- and long-term survival.

These data are similar to those from 2 USRDS studies in the early 1990s. One study found that the USRDS database was 88.6% complete when compared with the Michigan Kidney Registry; however patients with Medicaid, Veterans Affairs, or private insurance were excluded from the USRDS database.[7] The other study showed 90% completeness when compared to a small random sample of 90 medical records in a 1-year period and death dates matched for only 83% of 95 cases.[6] Thus, it appears that 2 decades later, little has changed in terms of completeness.

An important potential limitation to consider for this study is that although the match between KPSC and USRDS is probably very accurate, KPSC death records are identified through both internal and external sources. The latter are derived from probabilistic matching algorithms, linking electronic health record information to vital statistics records. That being said, KPSC's internal quality control data suggest a high degree of accuracy (data not shown). It is also important to keep in mind that USRDS data are obtained from multiple sources and that inaccuracies can occur within any of those sources. In addition, the results found in this study may not be generalizable to other populations such as those in institutions or states with additional reporting restrictions or privacy considerations.

In conclusion, our study suggests that although it is largely complete, USRDS mortality information could be improved. This might be accomplished through the use of vital statistics data, such as the National Death Index (NDI), which has recently been made available to National Institutes of Health—supported investigators at no cost,[S1] via an interagency agreement. The resulting improvement in USRDS data quality may serve researchers and patients better.

DISCLOSURE

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AUTHOR CONTRIBUTIONS

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)
Supplementary References.

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Validation of Prognostic Index for Allograft Outcome in Kidney Transplant Recipients With Transplant Glomerulopathy

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