United States Renal Data System public health surveillance of chronic kidney disease and end-stage renal disease

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The United States Renal Data System (USRDS) began in 1989 through US Congressional authorization under National Institutes of Health competitive contracting. Its history includes five contract periods, two of 5 years, two of 7.5 years, and the fifth, awarded in February 2014, of 5 years. Over these 25 years, USRDS reporting transitioned from basic incidence and prevalence of end-stage renal disease (ESRD), modalities, and overall survival, as well as focused special studies on dialysis, in the first two contract periods to a comprehensive assessment of aspects of care that affect morbidity and mortality in the second two periods. Beginning in 1999, the Minneapolis Medical Research Foundation investigative team transformed the USRDS into a total care reporting system including disease severity, hospitalizations, pediatric populations, prescription drug use, and chronic kidney disease and the transition to ESRD. Areas of focus included issues related to death rates in the first 4 months of treatment, sudden cardiac death, ischemic and valvular heart disease, congestive heart failure, atrial fibrillation, and infectious complications (particularly related to dialysis catheters) in hemodialysis and peritoneal dialysis patients; the burden of congestive heart failure and infectious complications in pediatric dialysis and transplant populations; and morbidity and access to care. The team documented a plateau and decline in incidence rates, a 28% decline in death rates since 2001, and changes under the 2011 Prospective Payment System with expanded bundled payments for each dialysis treatment. The team reported on Bayesian methods to calculate mortality ratios, which reduce the challenges of traditional methods, and introduced objectives under the Health People 2010 and 2020 national health care goals for kidney disease.

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The United States Renal Data System (USRDS), established in 1989, is the largest and most comprehensive national end-stage renal disease (ESRD) and chronic kidney disease surveillance system. It has operated for 25 years under competitive contracting with the National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Division of Kidney, Urologic, and Hematologic Diseases. In its first 10 years, the USRDS Coordinating Center developed standard techniques for calculating incidence and prevalence of treated ESRD, and reported on treatment modalities and basic mortality outcomes in the dialysis and transplant populations. The USRDS focus changed in the third and fourth contract periods toward assessment of cause-specific morbidity and mortality by organ system, thereby expanding the domain of care assessment beyond dialysis therapy delivery.

MORBIDITY AND MORTALITY

Death rates among dialysis patients have been falling 2–3% per year since 2001 (28% reduction), and in 2012 reached a level comparable to rates reported in 1982 (Figure 1), despite other data showing increased complexity of the population after 1983. Over time, causes of death shifted from acute myocardial infarction to heart failure and sudden death (Figure 2), in many ways paralleling changes in mortality in the general population. Acute myocardial infarction as a cause of death decreased in the dialysis, transplant, and general populations.

Although few clinical trials in the dialysis population have shown any benefit of techniques such as increasing the amount of dialysis therapy delivered three times per week or use of high-flux versus lower-flux membranes, the recent Frequent Hemodialysis Network trial showed for the first time that dialysis delivered 6 days per week provided substantial benefit.[1] In the Adequacy of Dialysis Mexico trial, more therapy for peritoneal dialysis patients also did not show a benefit beyond a minimum weekly therapy.[2] These findings led the USRDS to conduct detailed assessments of the broad range of care delivery for heart failure, ischemic heart disease, and valvular heart disease and compare outcomes between prosthetic and porcine valves. Revascularization procedures using surgical interventions with internal mammary artery

grafting, versus stent placement, appeared to be best for dialysis patients, as for the general population.

Medication use changed markedly from reports on the incident and prevalent populations in the 1993–1994 and 1996–1997 Dialysis Morbidity and Mortality Studies[3,4] to full assessment of prescription medications under the expanded Medicare prescription drug benefit, Medicare Part D.[5] Use of statin drugs increased from less than 10% of dialysis patients in the 1990s to 50% from 2007 to 2011.[3] Use of beta blockers, also less than 10% in the 1990s, increased to 65% overall and to 75% in dialysis patients with prior acute myocardial infarction.[5] In dialysis patients with heart failure, use of angiotensin-converting enzyme inhibitors and angiotensin receptor blockers increased fourfold form 50 to 60% in the current era. Along with these changes, use of dialysis catheters also declined under the Centers for Medicare and Medicaid Fistula First program. These changes were associated with substantial decreases in death rates in the prevalent population since 2001 (Figure 1).[6]

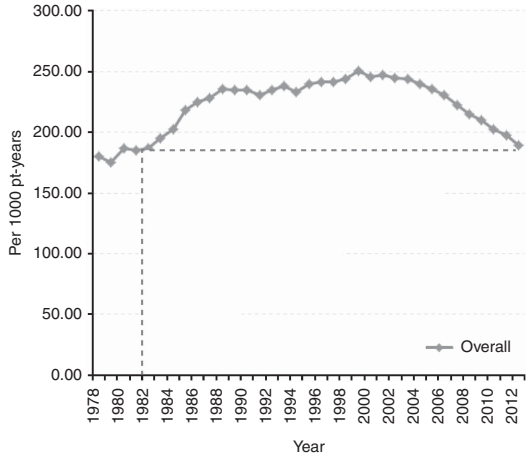

Figure 1 | Trends in prevalent dialysis death rates. pt-years, patient-years.

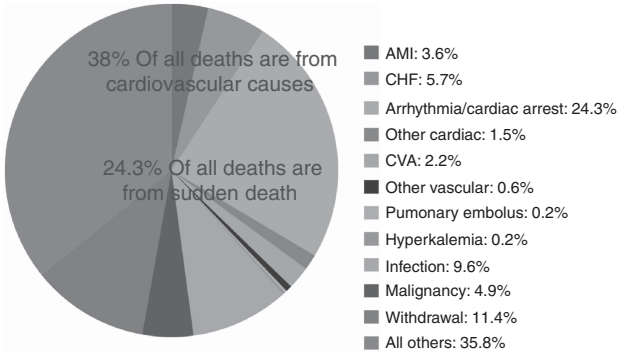

Figure 2 | Causes of death in incident dialysis patients, 2009–2011, first 180 days.[5]

Infectious complications presented serious problems (Figure 3); highlighting these in detail over many years helped bring back the Centers for Disease Prevention and Control's dialysis unit infection control surveys, which had stopped in 2002. Additional organ-specific assessments centered on infectious complications related to use of dialysis catheters and their event rates. Placement rates for catheters, fistulas, and grafts were tracked through physician service claims. Catheter and graft placements decreased markedly through 2011 (Figure 4).

Prior studies on death risk after infectious complication[7] contributed to these findings. Infectious hospitalizations were not reduced to the extent that mortality was. Rates of infectious hospitalizations increased in hemodialysis patients during the time of highest dialysis catheter use, but failed to decline once catheter use declined. This is a source of major concern. Infectious hospitalization rates for peritoneal dialysis patients did not change (Figure 5). This lack of progress needs greater attention to reduce infectious complications.

Each Annual Data Report presented data on morbidity and treatment, including the changes in anemia treatment due to clinical trials showing adverse cardiovascular events when hemoglobin levels were targeted to above 12 g/dl (Figure 6).

GRAPHIC LAYOUT OF THE ANNUAL DATA REPORT

These findings were shown in a graphic format that the USRDS developed to advance the presentation of data describing the ESRD population and public health surveillance to the public, Congressional committees, the National Institutes of Health, the Centers for Medicare and Medicaid Services, the White House, and nephrologists and dialysis providers.

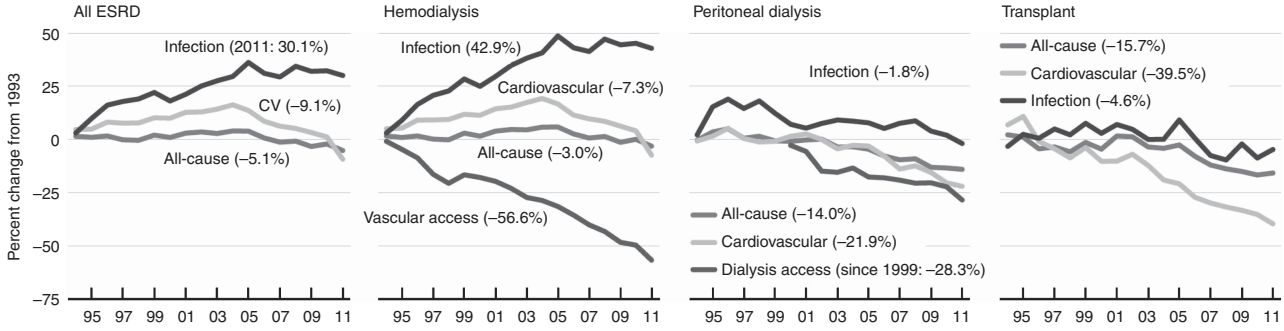

Figure 3 | Change in adjusted all-cause and cause-specific hospitalization rates, by modality. CV, cardiovascular; ESRD, end-stage renal disease.[5]