Fifty Years of a National Program for the Treatment of Kidney Failure

Fifty years ago, on October 30, then-President Richard Nixon signed the Social Security Amendments of 1972, which created the End-Stage Renal Disease (ESRD) program. In extending Medicare benefits to people with kidney failure regardless of their age, this landmark legislation availed universal health care coverage for most persons with kidney failure.

Technological innovations in the treatment of kidney failure combined with a political movement to expand the role of government in health care begot the 1972 legislation. In the 1950s kidney transplant had emerged as a treatment option. By the early 1960s, innovations in dialysis machines and vascular access made it possible to treat chronic uremia with dialysis. These technological breakthroughs transformed kidney failure from a terminal illness into a treatable chronic condition. Although the first long-term dialysis center opened in 1962, most patients with kidney failure could not afford dialysis.

As new dialysis and transplant therapies emerged, enactment of the Medicare entitlement program in 1965 generated momentum toward building a national health system. In this context, the need to ration limited dialysis resources conflicted with commonly held moral sentiments. A 1962 LIFE magazine feature titled "They Decide Who Lives, Who Dies" helped to frame the dilemma through the vivid depiction of a "God committee" tasked with rationing limited dialysis care. The controversial selection processes included consideration of demographics, geography, past and projected occupational performance, and an assessment of moral character. Every congressional body between 1965 and 1972 introduced a bill to expand the government’s role in the financing of treatments for catastrophic kidney disease.1

In 1966, the White House convened an expert committee to review government obligations in the treatment of kidney failure. The ensuing Gottschalk committee report called for a federally assisted national program to provide dialysis and kidney transplant care.2 The report also contained one of several projections that grossly underestimated the future size of such a program.3 Debate over a US ESRD program in the House Ways and Means Committee briefly attracted national media attention when a patient with kidney failure underwent dialysis on the floor of Congress. Yet passage of the ESRD program would ultimately go largely unnoticed by the broader public, overshadowed by the 1972 presidential election.

For individuals with kidney failure, the ESRD program was transformative. By 1980, there were 58,000 patients receiving lifesaving treatment through the program, with enrollment growth averaging 22% per year. Enrollment growth spanned wide ranges of age, sex, and race, reflecting benefits across broad segments of the US population.4 Currently, more than 700,000 patients with kidney failure have Medicare coverage.5

Early success in providing access to dialysis and transplant care coincided with concerns about program costs. Enrollment growth quickly exceeded original forecasts. By 1980, Medicare was spending $1.2 billion per year on the ESRD program.4 An initial attempt to control increasing dialysis costs occurred in 1981 when Medicare bundled all payment for the dialysis procedure into a composite rate. This per-treatment rate remained relatively fixed in nominal terms during the next 30 years, with reimbursement decreasing after adjusting for inflation. Lawmakers have also controlled costs through the Medicare Secondary Payer statute by requiring that private insurers serve as primary payers for up to 30 months after the onset of kidney failure.6

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monitoring of quality and the development of quality assessment and assurance systems.  

With this goal, agencies within the US Department of Health and Human Services joined forces to make data on patients with kidney failure available to researchers through a national dialysis registry, the US Renal Data System. Subsequent public-private partnerships led to a series of quality initiatives, including the development of national practice guidelines, and quality assurance activities. The Fistula First Initiative heralded an increase in arteriovenous fistulas for patients undergoing dialysis. Increased surveillance and quality initiatives coincided with gradual reductions in adjusted mortality among patients with kidney failure.

Despite past efforts to maintain quality and limit cost growth, major care gaps remain. Since the ESRD program’s inception, proponents of home dialysis have deplored the underuse of these modalities. Meanwhile, near-universal dialysis coverage may incentivize overtreatment with dialysis. Increasing evidence suggests that some of the sickest patients who start dialysis could instead benefit from active conservative management. A growing body of evidence also suggests that some patients who are new to dialysis may be able to safely undergo a hemodialysis regimen that includes fewer than the standard 3 treatments per week. Near-universal access to kidney failure treatment contrasts sharply with widespread limitations in access to preventive chronic kidney disease (CKD) care. This contrast is particularly poignant as it relates to racial disparities. Black patients face faster rates of CKD progression due, in part, to limited access to CKD care. In 2019, 33% of all patients receiving dialysis were Black individuals.

Value-based payment reforms aim to address cost and quality challenges within the health care system. With the federal government being the primary payer for the care of kidney failure, dialysis has been at the forefront of the transition to value-based payment. A 2004 reform to the system of capitated payments to nephrologists for outpatient dialysis care represented one of the first national policy responses to a call by the IOM for value-based payment to help in crossing the quality chasm. In 2011, the first nationally mandated pay-for-performance program (the ESRD Quality Incentive Program) began evaluating dialysis facilities on a series of quality metrics. More recently, the 2019 Advancing American Kidney Health initiative built on prior efforts to create a dialysis-focused alternative payment model (APM) through 6 new kidney care APMs that encourage home dialysis, kidney transplant, and advanced CKD care. It remains unclear whether dialysis-focused value-based payment initiatives will address outstanding cost and quality gaps. To date, substantial improvements in quality have not been observed.

The US ESRD program is entering a time of transition, in which new challenges and disruptions interact with the transition to value-based payment, with uncertain consequences. One major challenge has to do with the structure of the dialysis industry. Dialysis markets have become highly concentrated and remain dominated by for-profit facilities. Both characteristics may be associated with reduced quality of care and could either help or impede value-based payment reforms. A second challenge involves a changing payer mix. Beginning in 2021, patients with kidney failure became eligible to enroll in Medicare Advantage plans. Meanwhile, by allowing some private health insurers to designate all dialysis facilities as secondary payer. Social Security Administration. Accessed October 25, 2022. https://www.ssa.gov/OPE/Home/ssact/title18/1862.htm.

It is unclear how these changes to the financing of dialysis will affect care delivery and reform efforts. Finally, it is unclear how the development of new technologies will affect dialysis quality and costs. Recently, the introduction of a new injectable drug for the treatment of mineral and bone disease led to an increase in the dialysis base payment. If additional technologies have similar effects, growth in per-treatment dialysis costs could reignite, potentially offsetting benefits from the new technologies.

In summary, during its first 50 years the US ESRD program has provided critical access to lifesaving care for many patients with kidney failure while it has undergone a series of reforms as policy makers aim to control costs and maintain quality. Challenges in balancing cost and quality will persist as the program enters the second half-century of its existence.

REFERENCES


