

Dialysis Patients' View on Health Care Reform

As America's largest dialysis patient organization, Dialysis Patient Citizens (DPC) is proud to represent over 23,000 pre-dialysis and dialysis patients and their families. On a wide variety of issues, we seek to ensure that the patients' point of view is heard and considered by policy makers so that continued progress may be made in the quality of care and life for patients with kidney disease. DPC agrees many changes are needed to improve health and medical care in the United States and wants to ensure policy makers understand the unique situation dialysis patients face so reform measures may incorporate the special needs of patients with chronic kidney disease (CKD).

Background and Facts:

Approximately 27 million Americans have CKD, half a million have progressed to end stage renal disease (ESRD) and over 354,000 of those with ESRD require dialysis to stay alive. Patients with kidney failure typically receive dialysis treatments three times per week at an outpatient clinic for about four hours per treatment. While home modalities such as home-hemodialysis and peritoneal dialysis exist, they are often underutilized or not available in all areas, and many patients may not be a candidate for these treatments for several reasons.

Many changes in the way kidney care is delivered in America have evolved over the past several decades, beginning with Medicare coverage of end stage renal disease (ESRD) in 1972. Dialysis is paid for by Medicare for most patients, even if they are under 65. For low-income patients, Medicaid may supplement Medicare's 80% payment, or if the patient does not qualify for Medicare they may receive Medicaid coverage for their treatment. This is not guaranteed, however, as Medicaid coverage of ESRD is up to the states. While steps have been taken to improve Medicare reimbursement for dialysis, the payment still falls short of what it actually costs clinics to provide the treatment. Medicare reimbursement will continue to fall short even under the enactment of the bundled payment structure passed in the 2008 Medicare Improvements for Patients and Providers Act (MIPPA). It is for these reasons that patients with private insurance plans serve as a safety net for those with only Medicare or inadequate insurance coverage. Those patients who have private insurance as their primary coverage for the first 36 months of dialysis enable providers to operate clinics in both profitable locations and economically depressed locations.

Dialysis is expensive, but it is a life sustaining treatment that affords many individuals with longer quality lives they would not otherwise have. DPC acknowledges the high cost of dialysis care and believes there are many options available to reforming kidney care that can result in savings while also improving the health and quality of life for kidney patients. While health care reform is being undertaken, we hope the following areas of care are improved or protected – ensuring that dialysis patients can receive the highest quality of care and maintain the best quality of life possible.

Education and Public Awareness

ESRD is a largely preventable chronic disease. Early education can help patients slow or halt the progression of CKD and in some cases avoid ESRD. National public awareness campaigns aimed at patients with diabetes and high-blood pressure, the two leading causes of kidney disease, can help educate people about the need to better manage their current conditions and to monitor their kidney function—all with the hope of preventing CKD. For those who may already have CKD and not know it, access to public awareness campaigns, coupled with kidney screenings, can identify individuals with CKD before their disease progresses.

MIPPA took initial steps towards decreasing the progression of CKD by creating a CKD education benefit for those who are current Medicare beneficiaries in stage IV of kidney disease, before the onset of ESRD. Additionally, pilot projects were created for public awareness campaigns and screenings. DPC looks forward to the implementation of both programs under Secretary Sebelius' leadership. We also hope to see similar education initiatives expanded to the non-Medicare population and public awareness campaigns launched nationwide.

Access to Care

For patients who lose complete function of their kidneys, dialysis or transplantation becomes necessary for them to continue living. Quality of life is improved when dialysis patients have:

- The ability to choose the modality that is consistent with their individual needs;
- Access to centers that are convenient to travel to;
- Access to centers that provide the best quality care;
- Access to centers that are open during hours that permit patients to plan dialysis around their lives, rather than having to plan life around their dialysis schedules;
- The ability to choose their frequency of treatments in order to maximize the benefits;
- Access to centers where patients can receive continuity of care, from their physicians and the rest of the dialysis care team.

When reimbursement for dialysis care becomes more constrictive, the trade-offs that occur often impact patients' access to care. If reimbursement to dialysis providers is lowered by either the government or by private insurers, patient access to dialysis may be hindered. Currently many patients already have difficulty securing transportation to and from their dialysis appointments, particularly in rural areas. Having dialysis clinics in the communities where they are most needed and having access to home dialysis is vital for to patients' ability to comply with their treatment. Any policies that would change Medicare and Medicaid reimbursement or impact private payer reimbursement should take into consideration the unique impact on access to care for dialysis patients.

Patient Centered Health Care Model

DPC believes patients, in consultation with their physicians, should decide their best course of treatment. Patients should be well-educated and well-informed about all treatment options

available and be equal partners in their care. As part of our mission, DPC seeks to advance self care. Empowering patients to become more involved in their care through education and information leads to better clinical outcomes and improved quality of life for patients.

In the prescribing of treatment for kidney failure and its resulting co-morbid conditions, DPC believes the government should not interfere in the patient-provider relationship by placing financial barriers to receiving optimal care. DPC is committed to payment reform and understands the need to reign in health care costs. However, cost containment programs should not prevent patients and doctors from working together to determine the best course of treatment for a patient's kidney failure and other co-morbid conditions.

Coordinated Care

As part of our mission, one way DPC seeks to improve the quality of life for dialysis patients is by strengthening partnerships between patients and caregivers. This relationship is important not just for the provision of kidney care but also for patients' overall health. Patients with CKD often develop multiple co-morbid chronic conditions that are difficult to manage. As a result, they are frequently hospitalized. It can be difficult for patients to ensure that proper communication is occurring between their nephrologist, other physician specialists, hospitals, dialysis facilities, and nursing homes, and strong relationships among caregivers is key.

DPC believes patients should play a vital role in the coordination of their care, but patients need the support of the provider community, technology providers, and insurers to improve communication and sharing of information that results in optimal and efficient care. Coordinating care for CKD patients can slow the progression of CKD, reduce hospitalizations, prevent co-morbid conditions and better manage co-morbidities for those already suffering from multiple diseases. DPC looks forward to reviewing and contributing input on proposals of coordinated care for kidney patients.

Medicare Equality and Private Insurance

Currently, Medicare ESRD beneficiaries are barred from participating in Medicare Advantage plans, and in many states beneficiaries are also excluded from secondary coverage under Medicare, called Medigap plans, if they are under 65 years of age. Unfortunately, ESRD patients are also nearly always ineligible from obtaining private insurance coverage due to their pre-existing condition. Unless they had private coverage prior to being diagnosed with chronic kidney disease, patients are unlikely to obtain the secondary coverage needed to pick up the remaining costs of care Medicare does not pay for. Absent any changes in the private sector rules, Medicare Advantage and Medigap plans would be the only way for patients, who don't qualify for Medicaid, to obtain 100% coverage for their health care. We believe access to these Medicare plans for ESRD patients is vital and patients should not also face the same inequalities under Medicare they face in the private sector.

DPC believes patients with ESRD should be afforded the same coverage opportunities as the general Medicare population. Having access to Medicare Advantage and Medigap plans can

help patients better afford the care they critically need. While patients should be well educated on the benefits and pitfalls of each plan, ultimately the decision on coverage should lie with the patient.

Medicaid ESRD Coverage

While most states cover some ESRD costs for Medicaid beneficiaries, it is not a benefit that states are mandated to cover. Approximately 40% of ESRD Medicare beneficiaries are dual eligible for Medicaid as well as Medicare. DPC believes Congress should require all states to cover ESRD treatment, therefore providing a way for low income patients to be fully insured and able to afford life-sustaining treatment.

Medicare Immunosuppressant Coverage

Individuals that receive an organ transplant must take immunosuppressant drugs to reduce the likelihood their body will reject the transplanted organ. Failure to take this medication after a kidney transplant significantly increases the risk of rejection and results in the need for an individual to receive dialysis to continue living.

Currently the Medicare End Stage Renal Disease (ESRD) program pays the majority of dialysis and transplantation costs for eligible ESRD patients, but only covers immunosuppressant drugs for thirty-six months following a transplant. With the annual cost of these drugs averaging \$17,000 a year, patients must find a way to pay for their medications. State and pharmaceutical assistance programs offer some relief, but are not available to all patients. Patients who are unable to pay for the medications are often forced to discontinue their use, resulting in kidney rejection and a return to Medicare covered dialysis treatments at an annual cost of nearly \$71,000 per patient. Many patients find these high medication costs a barrier to seeking transplantation as an option.

DPC believes that all ESRD transplant recipients should receive immunosuppressant drugs under Medicare Part B for the life of their transplant, not just the first thirty-six months. Extending the current benefit beyond thirty-six months would result in a net savings to Medicare, provide transplantation as an affordable option to more patients, and ensure that those individuals in whom Medicare invested can continue to receive the necessary drugs to reduce their chance of rejection.

Health Disparities

Minorities, when compared to whites, are much more likely to progress to end stage renal disease and often spend more time on transplant waiting lists. If implemented nationwide, many of our above suggested policy improvements such as education and public awareness, patient centered care, and coordinated care may go a long way in improving the disparities that exist in the care and outcomes of chronic kidney disease patients. However, research suggests other factors may play a role in these disparities. Further research is needed to discover why minorities receive differing courses of treatment and have different outcomes when compared to whites with similar conditions.

Conclusion

DPC believes recognizing the special needs of kidney patients and incorporating measures specific to this unique population into health care reform will lower the number of individuals who reach ESRD and also provide for the best quality of care and quality of life for those who do progress to kidney failure. Contrary to its name, End Stage Renal Disease does not necessarily have to mean the end of life. Many patients can enjoy long, productive, quality lives while on dialysis. We hope health care reform options will continue to allow for dialysis care to be delivered in the areas where it is most needed, while also incorporating our suggestions for new ways to improve kidney care in America.