

Kizilbash SJ, Evans MD, Chavers BM, Kashtan C. Racial disparities and trends in kidney transplant outcomes in patients with Alport syndrome. *Clin Nephrol.* 2021 Oct 12. doi: 10.5414/CN110649. Epub ahead of print. PMID: 34642018.

Summary by Clifford E. Kashtan, MD

Background

The success of kidney transplantation is measured by two major outcomes: the length of time that patients survive after transplant (patient survival) and the time it takes for transplanted kidneys to fail (graft survival). We have known since the 1990s that patient survival and graft survival rates after kidney transplantation for Alport syndrome are very good, and are as good as or superior to patient and graft survival rates for patients with kidney failure due to other causes. There are two major reasons for the superior outcomes of kidney transplantation in people with Alport syndrome. First, heart disease is a major cause of death after kidney transplantation, and people with Alport syndrome usually have good heart function when they are transplanted. Second, Alport kidney disease does not come back in the transplanted kidney, unlike some other important causes of kidney failure.

Patient survival and graft survival after kidney transplantation have progressively improved over the past 30 years, due to advances in diagnosing and treating post-transplant infections and in the effectiveness of anti-rejection medications, along with other improvements in the care of transplanted individuals. The care of people with chronic kidney disease has also improved, with increased attention to early diagnosis and the use of treatments like angiotensin converting enzyme inhibitors to delay the onset of kidney failure and the need for dialysis and kidney transplantation. At the same time, researchers have discovered that the benefits of improved care of people with chronic kidney disease and kidney transplants are unequally distributed in the United States, with Black and Hispanic populations showing outcomes that are inferior to the White population.

We undertook our study to examine the trends in patient survival and graft survival after kidney transplantation for Alport syndrome in the United States over the past 30 years. Using the Scientific Registry of Transplant Recipients (SRTR), a database of all transplanted patients in the United States, we found 3794 patients with Alport syndrome who received a first kidney transplant between 1987 and 2017. The data collected for each patient included age at transplant, race, gender, date of death, date of transplant loss (return to dialysis or re-transplantation) and history of diabetes or hypertension.

Our analysis of this data showed that:

1. Black and Hispanic patients were significantly younger than White patients at the time of kidney transplant. The mean age at transplant was 28.3 years for Black patients, 28.7 years for Hispanic patients and 36.5 years for White patients.
2. The age at kidney transplant increased significantly over time for White patients, but not for Black or Hispanic patients.

3. Graft survival improved significantly over time. However, graft survival was significantly lower in Black patients than in Hispanic or White patients. Black patients were also more likely to die during the 10 years after kidney transplant than White or Hispanic patients.

These results are encouraging in some ways, but also indicate areas for improvement. The increase over time in age at transplant for White patients supports the argument that kidney failure in Alport syndrome can be delayed, and is in agreement with a recent study of transplanted Alport syndrome patients in Europe. However, the fact that Black and Hispanic patients are significantly younger than White patients when they get transplanted, and that this difference has shown no sign of decreasing, is disturbing. Although our study was not designed to determine the causes of these differences, data from other studies suggest that disparities in access to effective care of kidney disease is likely a contributing factor.

Another encouraging result is the improvement in graft survival following kidney transplantation for Alport syndrome, which corresponds to increases in graft survival in kidney transplant patients overall. But here again Black patients had significantly poorer graft survival than White patients. Differences in access to care and in long-term insurance coverage for anti-rejection medications are likely contributing to the disparities we observed. Lifetime coverage of anti-rejection medications by Medicare, set to go into effect in January 2023, may alleviate this problem, at least in part.

We hope that this study will motivate nephrologists to act proactively to diagnose Alport syndrome in patients with hematuria, regardless of race assignment or ethnicity, and to start treatment according to published recommendations when a diagnosis of Alport syndrome is confirmed. Advocacy groups like the Alport Syndrome Foundation and the National Kidney Foundation can increase their outreach efforts to Black and Hispanic patients. Additional measures to increase access to effective and affordable care, such as extension of Medicaid coverage in all states, lowering the age of Medicare eligibility, or universal health insurance coverage, are beyond the capabilities of individual nephrologists but would ultimately make the benefits of advances in the care of Alport syndrome accessible to all.