

ISPOR Abstract

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Title: A USRDS Retrospective Cohort Study: Epidemiology, Treatment Modalities, and Burden of End-Stage Kidney Disease Attributed to Focal Segmental Glomerulosclerosis (FSGS)

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Objectives: FSGS is a histologic pattern of glomerular damage that results in proteinuria and may lead to end-stage kidney disease (ESKD). This study describes epidemiology, treatment modalities, resource burden, and mortality of ESKD attributed to FSGS in the United States (US).

Methods: We used United States Renal Data System (USRDS) data which includes all patients receiving dialysis or kidney transplant in the US. Patients registered in USRDS in 2008-2018 with FSGS as the primary ESKD cause were included (USRDS registration date as index). Annual prevalence and incidence of ESKD-attributed FSGS were evaluated. Patient characteristics and treatment modalities during the 12 months after index (follow-up) were described. For the subgroup with Medicare at index and during follow-up, healthcare-related utilization during follow-up was described.

Results: From 2008-2018, an average of 2,339 FSGS patients progressed to ESKD annually with approximately 27,600 patients requiring ESKD care each year (average annual incidence rate and period prevalence rate of 7.4 and 87.6 per million US population, respectively). Of 25,699 patients included in the final cohort, median age at ESKD registration was 53 years, 61% were male, 62% white, 33% Black, and 32% full-time employed. 93% started on dialysis, mostly in-center hemodialysis, and 7% received a kidney transplant at ESKD registration. During 12-month follow-up, an additional 7% received a kidney transplant. Among 5,575 patients with Medicare coverage, resource burden was high, with 74% requiring hospitalization and 67% visiting an emergency room (ER). Five-year survival for the final cohort was 71% (95% Confidence Interval: 70% to 71%).

Conclusion: Although rare, FSGS-attributed ESKD in the US is associated with a substantial burden to patients and the healthcare system. Safe, effective, and approved therapies for FSGS would significantly improve the lives of patients and reduce substantial burden to the healthcare system.