Chronic Kidney Disease Often Undiagnosed in Medicare Beneficiaries
*Updated September 2021

Introduction

Chronic kidney disease (CKD) is a costly and increasingly common condition that adds to health risks for vulnerable populations. According to the Centers for Disease Control and Prevention, 37 million adults in the United States have CKD; of those, 90% do not know they have it.[1] CKD is a gradual loss of kidney function. It begins with kidney damage that has no symptoms and can lead to kidney failure, which requires dialysis or a kidney transplant. Early diagnosis and treatment can prevent or delay progression to later-stage CKD. Although most patients with CKD do not progress to kidney failure (also known as end-stage renal disease, or ESRD), CKD has other harmful effects such as increased risk of hypertension, heart disease, anemia, dementia, cancer, and death.

Women are more likely than men to have CKD. Among racial and ethnic groups, Black people are more likely than non-Hispanic whites to have CKD. Evidence also shows that although Hispanics and non-Hispanic whites have about the same rates of CKD, Hispanics have a much higher rate of progressing to ESRD.[2]

Rates of diagnosed CKD in Medicare beneficiaries have increased substantially over time. In 2017, 15% of Medicare beneficiaries over age 65 had CKD.[3] Although there is evidence suggesting that estimates for the number of people with CKD are low, there is limited information about how many cases go undiagnosed and why providers might miss it.

A recent analysis using linked laboratory and claims data examined CKD recognition and severity (stage) in Medicare Advantage (MA) beneficiaries. Race and ethnicity data were obtained from the Medicare Beneficiary Summary File.

Key Findings:

- Less than one-third of Medicare Advantage beneficiaries whose lab results are positive for CKD also had a CKD diagnosis code (27%).

- Although CKD is more likely to be diagnosed at later stages of disease, only 49% of beneficiaries whose lab results identified Stage 3 CKD had a diagnosis code.

- Beneficiaries with lab-identified CKD who saw a nephrologist had 17 times higher odds of being diagnosed with CKD.

- Non-Hispanic black beneficiaries with lab-identified CKD had higher odds of being diagnosed with CKD than non-Hispanic white beneficiaries.

- When disease-stage information is present in both lab and claims data, there is substantial agreement in CKD stage (76%) across sources.

- Linking Medicare diagnosis and lab data greatly improves the ability to identify beneficiaries with CKD.

Data Sources: Medicare Advantage claims and lab values 2014, Medicare Beneficiary Summary File for race and ethnicity.

[1] "Kidney Disease Statistics for the United States | NIDDK," National Institute of Diabetes and Digestive and Kidney Diseases, accessed November 12, 2019, https://www.niddk.nih.gov/health-information/health-statistics/kidney-disease.

[2] Nisa Desai et al., "CKD and ESRD in US Hispanics," American Journal of Kidney Diseases 73, no. 1 (January 1, 2019): 102–11, https://doi.org/10.1053/j.ajkd.2018.02.354.

[3] USRDS, "US Renal Data System 2019 Annual Data Report: Epidemiology of Kidney Disease in the United States" (United States Renal Data System (USRDS), 2019), https://www.usrds.org/2019/view/USRDS_2019_ES_final.pdf.

Importance of Screening and Staging CKD

CKD is diagnosed and monitored through a blood test that measures serum creatinine and a urine test to assess albumin. The disease stage is determined by using results of both tests over a 3-month time period. The estimated Glomerular Filtration Rate (eGFR) indicates how well kidneys are working. This rate is based on a scale of 0 to 100. A higher eGFR means that the kidneys are working well and have less damage. A lower number means more damage. An eGFR of 15 or lower indicates CKD stage 5 (kidney failure).

Figure 1: Stages of Chronic Kidney Disease by eGFR

Stages of Chronic Kidney Disease		eGFR*
Stage 1	Kidney damage with **normal** kidney function	**90 or higher**
Stage 2	Kidney damage with **mild loss** of kidney function	**89 to 60**
Stage 3a	**Mild to moderate** loss of kidney function	**59 to 45**
Stage 3b	**Moderate to severe** loss of kidney function	**44 to 30**
Stage 4	**Severe** loss of kidney function	**29 to 15**
Stage 5	Kidney **failure**	**Less than 15**
* eGFR approximates % of normal kidney function. As kidney disease gets worse, eGFR goes down.		

NOTE: Adapted from the National Kidney Foundation.

In the early stages of CKD (Stages 1–3), care focuses on treating complications and slowing the disease or preventing it from getting worse. In the later stages of CKD (Stages 4–5), care focuses on planning for kidney failure. Early identification of CKD is important for preventing its progression and the possibility that it could worsen other conditions the patient might also have, such as heart disease.

Although CKD usually gets worse, it does not affect all patients at the same rate. Racial and ethnic minorities are more likely to progress from CKD to kidney failure and progress more rapidly than non-Hispanic whites.[4] For example, non-Hispanic blacks with lab results similar to non-Hispanic whites are almost five times more likely to progress to ESRD.[5] Early identification and treatment of CKD can slow its progression. Improved diagnosis and staging of CKD allow for better treatment and management through controlling blood pressure and blood glucose (high blood glucose indicates diabetes), reducing albumin in the urine, eating a healthy diet and maintaining a healthy lifestyle.

[4] Deidra C Crews et al., "Disparities in the Burden, Outcomes and Care of Chronic Kidney Disease," Current Opinion in Nephrology and Hypertension 23, no. 3 (May 2014): 298-305. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4126677/

[5] Bruce Horowitz, "Epidemiology of Hypertension in CKD – Advances in Chronic Kidney Disease," accessed November 21, 2019, https://www.ackdjournal.org/article/S1548-5595(14)00149-9/fulltext.

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2

Research showed that primary care providers correctly recognized stage 4 CKD in a test case only 63% of the time.[6] Misdiagnosis of CKD stage is a barrier to slowing disease progression and addressing consequences such as heart disease. A CKD diagnosis of an earlier stage, compared to lab results, may contribute to a delay in referral to a nephrologist (kidney specialist). Additionally, diagnosis prior to kidney failure allows for planning for renal replacement through either transplant or dialysis.

Improved awareness of CKD in primary care along with involvement of a nephrologist can lead to more effective treatment, drug safety, patient-centered treatment decisions, and better patient outcomes.[7] The sooner CKD is detected, the sooner the provider can diagnose the disease stage, actively monitor its progression, administer treatment and refer the patient to specialists.[8, 9]

Methods

To examine recognition of CKD and agreement of disease stage in MA beneficiaries, this study linked lab data and claims data for analysis. In a sample of beneficiaries identified with CKD from lab tests in 2014, beneficiaries had clinical recognition if they also had an ICD-9 diagnosis code indicating CKD in the year prior to or the year after the lab test. This study then examined the extent of agreement in CKD disease stage between lab tests and diagnoses codes. These analyses of MA enrollees align with a study based on 2011 Medicare Fee-for-Service (FFS) data that was recently published in BMC Nephrology (2019).[10]

Definitions

- **Lab Identified CKD** refers to patients who have serum creatinine lab values indicating CKD.
- **Clinical Recognition** refers to patients who have a diagnosis code indicating CKD in claims data. Clinical recognition was assessed for patients with lab-identified CKD.
- **Staging Agreement** refers to patients whose lab identified CKD stage matches their CKD stage diagnosis code.

Data Source	Description
Medicare Advantage Claims Data	2013–2015 MA claims from OptumLabs® linked with outpatient lab values processed by a national laboratory data vendor. Race and ethnicity data were obtained from the Medicare Beneficiary Summary File. The study included beneficiaries continuously enrolled in medical benefits whose labs had serum creatinine test results in 2014 [n=167,524] to examine CKD recognition via diagnoses. A subset with diagnosed CKD of a specific stage (n=35,460) were used to examine CKD staging agreement between lab values and diagnoses after excluding 121,888 enrollees without a CKD diagnoses and 10,176 with CKD stage 1 from lab data (due to small numbers) or beneficiaries with a CKD diagnoses of unknown stage.

[6] "Percentage Correctly Identifying CKD and Recommending Referral to Nephrologist," Centers for Disease Control and Prevention, accessed November 1, 2019, https://nccd.cdc.gov/ckd/detail.aspx?QNum=Q268#refreshPosition.

[7] "A Risk Based Approach to Improving Management of Chronic Kidney Disease – 2012 | AHRQ National Resource Center; Health Information Technology: Best Practices Transforming Quality, Safety, and Efficiency," Agency for Healthcare Research and Quality (AHRQ), accessed November 12, 2019, https://healthit.ahrq.gov/ahrq-funded-projects/risk-based-approach-improving-management-chronic-kidney-disease/annual-summary/2012.

[8] "Effect of 2 Clinical Decision Support Strategies on Chronic Kidney Disease Outcomes in Primary Care: A Cluster Randomized Trial," Carroll, J.K., Pulver, G., Fox, C.H, accessed November 15, 2019, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6324427/

[9] "A Risk Based Approach to Improving Management of Chronic Kidney Disease – 2012 | AHRQ National Resource Center; Health Information Technology: Best Practices Transforming Quality, Safety, and Efficiency."

[10] Clarissa J. Diamantidis et al., "Lab-Based and Diagnosis-Based Chronic Kidney Disease Recognition and Staging Concordance," BMC Nephrology 20, no. 1 (September 14, 2019): 357, https://doi.org/10.1186/s12882-019-1551-3.
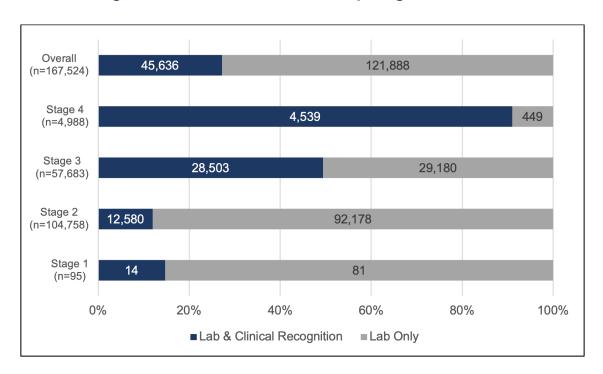
This study analyzed the population of MA beneficiaries who had lab-identified CKD via two abnormal serum creatinine lab values. Patient factors associated with clinical recognition of CKD were identified. This population with lab-identified CKD was then split into two groups: 1) MA beneficiaries whose claims had an ICD-9 CKD diagnosis code and 2) MA beneficiaries whose claims did not have an ICD-9 CKD diagnosis code. For patients that had a CKD diagnosis code, the stage between the beneficiary's lab results and diagnosis codes (CKD stage agreement) was compared. Stage agreement was defined as a beneficiary having an ICD-9 CKD diagnosis code indicating the same stage as the lab-identified CKD stage in the year before or after the lab test.

Results

CKD is Under-Recognized in Medicare Beneficiaries Across All Stages

Figure 2 shows CKD recognition rates overall and by stage for MA beneficiaries. CKD is under-recognized in MA populations across all stages of CKD. Among all beneficiaries with CKD, only 27% (46,144 of 170,576) with lab-indicated CKD also had diagnosis codes indicating CKD. Although this result compares favorably to the earlier study of Medicare FFS beneficiaries which found that 12% of beneficiaries had CKD recognition, it means that over 70% of MA beneficiaries whose lab tests indicated CKD were not diagnosed with CKD.

Figure 2: Clinical Recognition and Lab Identification, by Stage

NOTE: This stacked bar chart shows the number and proportion of MA beneficiaries with lab-identified CKD who had clinical recognition versus lab recognition only, by CKD stage (1-4).

Study results also show that clinical recognition of CKD varies by disease stage. Later stages are more likely to be recognized. Even so, the analysis found that only 49% of people with stage 3 CKD based on lab results had a documented CKD diagnosis.

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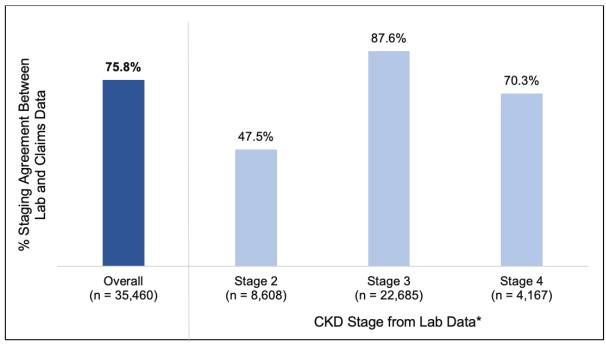Paid for by the U.S. Department of Health and Human Services.

4

Factors Associated with CKD Recognition

Clinical recognition of CKD was more likely for beneficiaries with higher CKD stages, those who had seen a nephrologist, had multiple chronic conditions or were non-Hispanic black. MA beneficiaries with Stages 3 and 4 CKD had 5.6 and 23.4 times greater odds, respectively, of having clinical recognition when compared to beneficiaries with stage 2 CKD. Beneficiaries who had seen a nephrologist had 17 times greater odds of having clinical recognition than beneficiaries who had not seen a nephrologist. Also, beneficiaries with greater comorbidity burden (based on the Charlson comorbidity index) were more likely to have clinically recognized CKD than beneficiaries with a lesser comorbidity burden. Among racial and ethnic groups, non-Hispanic black beneficiaries were more likely than non-Hispanic white beneficiaries to have clinically recognized CKD.

CKD Staging Agreement Across Lab and Claims Data

This study examined CKD stage agreement for the 35,460 MA beneficiaries who had CKD stage documented in both lab and claims data. Figure 3 shows the rates of CKD stage agreement between lab and claims data sources. Overall, 76% of beneficiaries had consistent staging in diagnosis codes and lab data. This result aligns with previous Medicare FFS results, which found a 70% CKD staging agreement across diagnosis and lab data.[11] The agreement rate varied by stage, with generally higher rates for later stages of CKD and lower agreement for CKD stage 2. Figure 3 does not include an additional 10,176 beneficiaries with CKD stage 1 from lab data (due to small numbers) or beneficiaries with both lab- and claims-based evidence of CKD who had "unknown stage" designated. This may reflect the lack of incentives in MA plans to code specific CKD staging.

Figure 3: CKD Stage Agreement between Lab and Claims Data

*Stage 1 excluded due to small numbers.

[11] Clarissa J. Diamantidis et al., "Lab-Based and Diagnosis-Based Chronic Kidney Disease Recognition and Staging Concordance," BMC Nephrology 20, no. 1 (September 14, 2019): 357, https://doi.org/10.1186/s12882-019-1551-3.

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5

Conclusions

These findings have important implications for health care policy and providers:

- **There is a major opportunity to improve diagnosing of CKD.** Because CKD is progressive, early identification creates the opportunity for initiating treatment, managing other existing diseases and slowing CKD progression. The analysis found that over 70% of Medicare beneficiaries whose lab results indicate CKD did not have a diagnosis code for CKD. The lack of a diagnosis code does not always mean that CKD was not clinically recognized, but these results point out a clear need to improve documentation of CKD.

- **Failure to diagnose advanced-stage CKD is a problem.** Results indicated that MA beneficiaries at later stages of CKD are more likely to be clinically recognized, but 51% of beneficiaries with stage 3 CKD remain undiagnosed. Patients diagnosed at a late stage of CKD may have limited options for preventing kidney failure and may "crash" into dialysis through a health crisis rather than planning to start dialysis.

- **Clinical recognition of CKD is more likely for beneficiaries who are at later stages of CKD and who have had a visit to a nephrologist.** This finding is not surprising, since CKD symptoms increase at later stages, but it highlights the importance of access to nephrologists, which can have a positive effect on delaying the progression of disease and preparing for renal replacement therapy.

- **Clinical recognition of CKD is more likely for black MA beneficiaries than white MA beneficiaries.** This may reflect clinician awareness that racial and ethnic minorities experience higher rates of risk factors for kidney disease such as diabetes and hypertension and that they experience higher rates of kidney failure than white populations.

- **Staging of CKD is largely consistent across diagnosis and lab data.** Analyses found substantial overall agreement in CKD staging across lab values and diagnoses. This finding highlights the importance of lab data to monitoring progression of CKD.

- **Lab data significantly improve the ability to identify patients with CKD.** This study confirmed previous findings on CKD recognition in Medicare FFS beneficiaries by combining lab values and diagnostic coding. Results suggest that using ICD-9 based diagnosis codes to identify patients with CKD is inadequate and significantly under-identifies patients with CKD. Linking Medicare claims data to lab results would greatly enhance data for future analyses.

These analyses confirm previous findings of under-diagnosing of CKD, suggesting that there is great value to systematically linking laboratory and claims data for Medicare beneficiaries. Access to longitudinal data that includes lab and diagnosis codes would improve the ability to identify CKD to study its progression and to pinpoint areas for improvements in care.

Data Acknowledgement

This study used de-identified administrative claims and electronic health record (EHR) data from the OptumLabs Data Warehouse (OLDW). The database contains longitudinal health information on enrollees and patients, representing a diverse mixture of ages, ethnicities, and geographical regions across the United States. The claims data in OLDW includes medical and pharmacy claims, laboratory results and enrollment records for commercial and Medicare Advantage enrollees. The EHR-derived data includes a subset of EHR data that has been normalized and standardized into a single database. Study data were accessed using techniques compliant with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and, because this study involved analysis of pre-existing, de-identified data, it was exempt from Institutional Review Board approval.[12]

About the Authors

Matthew L. Maciejewski is with Duke University School of Medicine and US Department of Veterans Affairs, Health Services Research and Development. Karen Onstad is with the National Committee for Quality Assurance and serving as an OptumLabs Visiting Fellow. Loida Tamayo is with the Centers for Medicare & Medicaid Services Office of Minority Health.

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Disclaimer

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CMS Office of Minority Health
7500 Security Blvd
Baltimore, MD 21244
HealthEquityTA@cms.hhs.gov
go.cms.gov/cms-omh

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7