

# Inaccuracy of ICD-9 Codes for Chronic Kidney Disease: A Study from Two Practice-based Research Networks (PBRNs)

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**Background:** Inaccurate use of International Classification of Diseases, Ninth Revision (ICD-9), codes obfuscates registries used for research, resulting in unreliable data and inaccurate measurement of outcomes, and it may contribute to mismanagement of patients. Thus it is important to understand the prevalence of ICD-9 code misuse. We chose chronic kidney disease (CKD) as a condition of interest after several patients recruited for a previous study indicated they did not have the disease, despite the presence of the ICD-9 code (585.x) in their electronic medical record (EMR).

**Methods:** Retrospective chart review of patients with the ICD-9 code for CKD stage 3 (585.3; n = 325). Data were collected from EMRs at 3 primary care practices Buffalo, New York (n = 2), and Kansas City, Kansas (n = 1).

**Results:** Across all practices, 47% of patients with the CKD ICD-9 code did not have clinical indicators for the disease, based on Kidney Disease Outcomes Quality Initiative guidelines.

**Conclusions:** The CKD stage 3 ICD-9 code usage did not accurately reflect the prevalence of disease among this population. This has clinical implications because patients may be treated or receive tests for a disease they do not have. This also presents an important issue for research projects that rely on accurate data from EMRs to identify and recruit patients. (J Am Board Fam Med 2015;28:678–682.)

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Electronic databases are increasingly being used to track and analyze population health outcomes.<sup>1</sup> The ability to track disease longitudinally among large populations is an important innovation for health research and public health. It is imperative, however, to ensure that the International Classification of Diseases, Ninth Revision (ICD-9), codes are reliably accurate.<sup>2,3</sup>

The issue of ICD-9 code accuracy was raised when we developed patient registries using these codes to identify patients with chronic kidney disease (CKD) for an institutional review board–approved qualitative interview study. The study was conducted in a practice in an Upstate New York practice-based research network (UNYNET). Patients identified in this registry were sent a letter inviting them to participate in the study. Several patients responded with alarm, indicating that they did not have CKD. A subsequent manual chart

**Table 1. Demographics of Chronic Kidney Disease (CKD) Stage 3 Patients at Three Residency Teaching Sites**

Characteristic	Total Sample (n = 325)	Buffalo Practice 1 (n = 109)	Buffalo Practice 2 (n = 95)	Kansas City Practice (n = 121)
Female sex	56 (182)	61 (67)	44 (42)	60 (73)
Age (years)				
Mean (SD)	66.8 (13.5)	67.8 (13.4)	63 (12.8)	69.1 (13.5)
Range	32–96	32–96	35–93	34–95*
Race/ethnicity				
Hispanic (any race)	3 (11)	5 (5)	0 (0)	5 (6)
Black	68 (222)	83 (90)	86 (82)	41 (50)
White	25 (82)	10 (11)	14 (13)	56 (58)
American Indian/Alaska Native	0 (1)	0 (0)	0 (0)	0.8 (1)
Asian/unknown/other/decline to answer	5 (15)	3 (3)	0 (0)	10 (12)

Data are % (n) unless otherwise indicated.

\*Data from one patient are missing.

SD, standard deviation.

review verified that several patients did not meet national guideline-based CKD criteria, although their chart contained the ICD-9 code for the disease. We then expanded the study to another UNYNET practice and a comparable practice in the Kansas Physicians Engaged in Prevention Research (KPEPR) network to determine whether the results were unique to our original practice.

ICD-9 coding inaccuracies raise concerns for both clinical treatment and research. Patients with an ICD code for a disease they do not have may undergo unnecessary treatment or tests. In addition, subjects in research studies recruited from registries based on ICD codes may not have the disease in question, compromising the reliability of the findings.<sup>4–6</sup> Although the literature on the accuracy of electronic health records is limited, recent studies suggest that data in electronic health records may not be appropriate for quality reporting.<sup>6</sup>

The objectives of this study were to (1) determine the prevalence of misdiagnosis among patients with stage 3 CKD at the original UNYNET practice site, and (2) to compare this prevalence to that within a similar UNYNET practice and a KPEPR practice.

## Methods

This study entailed a collaboration between 2 PBRNs. We conducted retrospective chart reviews of patients from 2 primary care practices in Buffalo, New York (UNYNET sites) and 1 primary care practice in Kansas City, Kansas (KPEPR site). All 3 sites are residency teaching sites located in low-

income neighborhoods and use a certified electronic medical record (EMR). Two sites treat predominantly African American patients (Table 1).

Patients selected for chart review were adults (>18 years old) with the ICD-9 code 585.3 (CKD stage 3) recorded in their EMR. A registry of these patients was pulled from each practice and given to the research team for analysis.

The Buffalo and Kansas teams used a single chart review protocol to guide data collection (Table 2). The protocol was informed by the Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines, which state that a patient meets criteria for CKD stage 3 if they have had 2 estimated glomerular filtration rates <60 at least 90 days apart or have had 2 albumin creatinine ratios >30 at least 90 days apart. This study was approved the institutional review boards of both the University at Buffalo and the University of Kansas Medical Center.

## Results

Comorbidities and demographics were similar across practices (Table 1). Among the 3 practices, 47% of the patients did not have sufficient evidence recorded in their chart to support the diagnosis of CKD. Similar prevalence of misdiagnosis was found at each practice (Table 3). At the 2 Buffalo sites, test results recorded in the charts were analyzed further (Table 4).

## Discussion

Based on our findings, nearly half of patients in the registries did not have the clinical indicators to

**Table 2. Chart Review Protocol**

ICD-9 Code	585.3
Race/ethnicity	White, African American, Hispanic, or Native American
Age	Numeric value
Body mass index	Numeric value
Two most recent GFR values, with dates	Numeric value*
Two most recent ACR values, with dates	Numeric value*
Diagnosis based on GFR correct?	Yes/No
Diagnosis based on ACR correct?	Yes/No
ACR date	Date
ACR verified? (2 successive ACRs at least 90 days apart)	Dates and values of the 2 ACRs
Comorbidities	
Diabetes mellitus	Yes/no
Hypertension	Yes/no
Congestive heart failure	Yes/no
Sleep apnea	Yes/no
Acute kidney injury	Yes/no
Coronary artery disease	Yes/no

\*Values were recorded only at the Buffalo sites.

ACR, albumin-to-creatinine ratio; GFR, glomerular filtration rate; ICD-9, International Classification of Diseases, Ninth Revision.

support a diagnosis of CKD stage 3, suggesting that registries developed from ICD-9 codes may not accurately represent the prevalence of CKD stage 3 in these practices.

The reasons behind this high prevalence of misdiagnosis cannot be defined by this study. However, this finding raised many questions as to why this may be occurring. Some possible reasons include CKD-specific issues, alternative uses of ICD-9 codes, and challenges inherent in the practices where this study was conducted. These issues are discussed below.

**Table 3. Prevalence of Misdiagnosis**

Site	Patients, n	Prevalence of Misdiagnosis, n (%)
Buffalo practice 1	109	48 (44)
Buffalo practice 2	95	52 (54)
Kansas City practice	121	54 (45)
Total	325	154 (47)

**Table 4. Breakdown of Misdiagnosed Patients\***

	Patients (n)			Prevalence (%)
	Buffalo Practice 1 (48)	Buffalo Practice 2 (52)	Total (100)	
1 Normal, 1 abnormal GFR	19	18	37	37
1 Normal GFR	3	8	11	11
1 Abnormal GFR	6	6	12	12
2 Normal GFRs	19	14	33	33
No recorded GFRs	1	6	7	7
No recorded ACRs	42	18	60	60

\*Data are from the Buffalo sites only.

ACR, albumin-to-creatinine ratio; GFR, glomerular filtration rate.

Studies have suggested that primary care physicians are uncomfortable with or unaware of the KDOQI guidelines for CKD, especially with patients in the early to moderate stages of the disease.<sup>7-9</sup> KDOQI guidelines state that a patient meets criteria for CKD stage 3 if they have had 2 estimated glomerular filtration rates <60 at least 90 days apart or have had 2 albumin creatinine ratios >30 at least 90 days apart.<sup>10,11</sup> Thus, accurate diagnosis relies on 2 abnormal lab tests observed in the appropriate time frame. However, our findings suggest that physicians may be diagnosing CKD after only 1 abnormal test result. Furthermore, many of the misdiagnosed patients had normal or insufficient test results, suggesting that physicians may be diagnosing based on factors not supported by the KDOQI guidelines<sup>12</sup> (see Table 4).

Another explanation for our finding involves the use of ICD-9 codes in ways other than to signify a diagnosis. ICD-9 codes may be used by practitioners to signify a “working diagnosis,” to allow a test or procedure to be covered by a patient’s insurance or to increase reimbursement for the practice.<sup>1,13</sup> Billing staff may add or modify codes for the same reasons.

This high prevalence of CKD misdiagnosis that we observed might be related to the characteristics of the practices where we conducted chart reviews. All 3 practices are residency teaching sites in family medicine. Residents may be even less comfortable with CKD guidelines than attending physicians, leading to more inaccurate diagnoses.<sup>7</sup> In addition, residency practices experience less continuity of care because of student turnover. Reduced continuity of care could contribute to the perpetuation

of an inaccurate diagnosis in the EMR because physicians may be unlikely to question a diagnosis made by a previous provider. These practices also are located in low-income neighborhoods where physicians treat patients with complex medical and social problems. These competing demands could potentially distract physicians from guideline-concordant CKD diagnosis for patients in the early stages of the disease.

Although we cannot yet determine the reasons behind this issue, it has important implications for both research and patient care. Electronic databases built from registries of patients with certain diagnoses, as tracked by ICD-9 codes, are increasingly used for research.<sup>4,13</sup> If a large percentage of these ICD-9 codes, such as the ones found in this study, do not reflect the actual presence or prevalence of disease, the research findings will be skewed. Outcomes research may be tainted and irreproducible if the patients identified in these registries do not have the disease in question.<sup>4</sup>

In addition, if the prevalence of misdiagnosis we observed in this patient cohort is present in other populations, thousands of patients may be mismanaged. This creates an enormous patient safety problem, since patients may be receiving unnecessary tests and/or treatments. For example, a patient treated with an angiotensin-converting enzyme/angiotensin receptor blocker for an erroneous diagnosis of CKD may be unnecessarily exposed to the risk of hyperkalemia, a serious adverse event.

This study has several limitations. First, we reviewed only charts of patients who already had a diagnosis of CKD stage 3. Our study did not investigate patients who met criteria for CKD but did not have a corresponding ICD-9 code in their records. The under-recognition of CKD is a well-documented problem, which is why we were surprised to find evidence of overdiagnosis among this population.<sup>8</sup> The clinical data from a limited population ( $n = 325$ ) makes it difficult to determine the reasons behind our findings. A strength of this study, however, was that we were able to find similar results among 3 separate practices in 2 different regions of the country. The practices we chose had similar patient populations, and all 3 were residency teaching clinics. We believe this is a strength of our study. Our findings suggest, however, that these results might be replicated in practices similar to those we studied. This would implicate thousands of misdiagnosed patients. More research

needs to be done to determine whether these findings are reproducible in a broader range of primary care practices. If this is confirmed, practices similar to those we studied may be affected. Further research should be undertaken to uncover the reasons behind the high prevalence of misdiagnosis, and initiatives should be developed to address this issue.

## Conclusion

Nearly half of the patients diagnosed with CKD stage 3 in these 3 primary care practices did not meet diagnostic criteria based on national, evidence-based guidelines. Although further research needs to be done to determine the underlying causes of this finding, it presents serious implications for both research and clinical practice in an environment increasingly reliant on reliable electronic data.

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