

Overestimation of the diagnosis of eosinophilic colitis with reliance on billing codes



Amanda B. Muir, MD^a, Elizabeth T. Jensen, PhD^b,
Joshua B. Wechsler, MD^c, Paul Menard-Katcher, MD^d,
Gary W. Falk, MD^e, Seema S. Aceves, MD, PhD^f,
Glenn T. Furuta, MD^{g,h}, Evan S. Dellon, MD^{i,j},
Mark E. Rothenberg, MD, PhD^k, and
Jonathan M. Spergel, MD, PhD^a

Clinical Implications

- This retrospective chart review evaluates accuracy in diagnosis of eosinophilic colitis (EC) by examining patients with EC diagnosis codes in major referral centers nation-wide. We found that the isolated use of *International Classification of Diseases, Ninth Revision*/*International Classification of Diseases, Tenth Revision* lacks diagnostic accuracy in EC due to ambiguous codes with overlapping diagnosis.

TO THE EDITOR:

Eosinophilic colitis (EC) is a chronic disease characterized by eosinophil-predominant inflammation of the colon. Studies probing claims data suggest that the prevalence of EC is 1.5 to 2.4/100,000.^{1,2} *International Classification of Diseases (ICD)* and *Systematized Nomenclature of Medicine* codes are classification systems that can be used in the studies of administrative claims data. The Consortium for Eosinophilic Gastrointestinal Disease Research, part of National Institute of Health's Rare Diseases Clinical Research Network,³ planned a prospective multicenter longitudinal study with a projected enrollment of 150 patients over the course of 4 years. However, as of July 2018, only 31 patients have been enrolled over the course of the 3-year enrollment period to date.

To diagnose EC, other inflammatory (inflammatory bowel disease [IBD], allergic proctocolitis of infancy, food protein-induced enterocolitis [FPIES]) or infectious (parasite)

etiologies must be ruled out. Differentiating between these conditions using claims data alone can be challenging because EC and allergic proctocolitis of infancy share the same *International Classification of Diseases, Ninth Revision (ICD-9)*/*International Classification of Diseases, Ninth Revision (ICD-10)* codes and EC and FPIES share *ICD-9* codes (FPIES recently received its own *ICD-10* code in 2015). We therefore hypothesized that ambiguity in *ICD* coding has led to overestimation of the rates of EC.

We performed a retrospective study to assess the accuracy of diagnosis of EC at 8 institutions (5 pediatric and 3 adult hospitals) over the last 3 to 10 years (Table 1). Electronic medical records were searched for all *ICD* codes for EC (*ICD-9*: 558.42; *ICD-10*: K52.82). It is important to note that these codes can be used for other diseases that cause eosinophilia in the colon. Charts were evaluated by one attending physician per institution, looking specifically for comorbid conditions that could provide alternative explanations for colonic eosinophilia (IBD, FPIES, allergic proctocolitis of infancy, malignancy, solid organ transplant, and parasitic infection). Pathology reports were reviewed at each site to confirm eosinophilic infiltrate of the colon (defined as >35 eosinophils/hpf in the rectosigmoid or significant eosinophilic infiltrate noted by the pathologist).

In 5 pediatric hospitals, 501 patients had an *ICD-9/ICD-10* code for EC, but just 38 of 501 (7%) cases met clinical and histopathologic features suggestive of EC. In 3 adult hospitals, there were only 20 patients with an *ICD* code for EC; 11 of 20 (55%) had confirmed EC after chart review (Table 1). This stark difference between the pediatric and adult centers was in large part due to overlapping *ICD* codes for more common pediatric diseases, specifically FPIES and allergic colitis of infancy, both of which shared *ICD-9/ICD-10* codes with EC. In looking at the final diagnosis of patients with the code for EC at 2 pediatric centers (Children's Hospital of Philadelphia and Lurie Children's Hospital of Chicago), we found that most (55%) had either allergic colitis of infancy or FPIES, 9 had inflammatory or immune disease associated with EC (IBD and solid organ transplant), and 2 had mild eosinophilia of the colon not thought to be pathologic (Table 2).

TABLE 1. Confirmed cases of EC at each institution

Hospital type	Institution	Years of chart review	ICD-9/ICD-10 coded EC patients (n)	EC Diagnosis confirmed (n)
Pediatric	The Children's Hospital of Philadelphia	4	44	1
Pediatric	Cincinnati Children's Hospital	10	228	29
Pediatric	Rady Children's Hospital San Diego	3	32	2
Pediatric	Children's Hospital of Colorado	6	185	5
Pediatric	Lurie Children's Hospital of Chicago	4	12	1
	Total pediatric		501	38
Adult	Hospital of the University of Pennsylvania	8	9	3
Adult	University of North Carolina Hospital	3	10	7
Adult	University of Colorado Hospital	8	1	1
	Total adult		20	11

TABLE II. Final diagnosis of pediatric patients with EC diagnosis code at The Children's Hospital of Philadelphia and Lurie Children's Hospital of Chicago

No. of patients	Final diagnosis
16	FPIES
15	Allergic colitis of infancy
9	Inflammatory/immune disease with EC (irritable bowel syndrome, transplant)
6	Normal pathology with symptoms of colitis
5	No biopsies obtained (irritable bowel syndrome final diagnosis)
2	EC
2	Colitis with mild eosinophilia
1	Eosinophilic gastroenteritis

These data underscore the importance of establishing both clinical-histopathologic definitions and specific *ICD* codes for EC. Collins et al⁴ proposed that in addition to exclusion of other inflammatory conditions, 100 eos/hpf in cecum/ascending colon, 84/hpf in transverse/descending colon, or 64/hpf in rectosigmoid represent pathologic eosinophilia of the colon. However, these definitions are yet to be clinically validated or adopted by the pathology or gastroenterology communities, and are currently used only for research purposes; indeed arriving at a consensus criteria is a goal of Consortium for Eosinophilic Gastrointestinal Disease Research. The lack of diagnostic criteria presents clear limitations for the utilization of the *ICD-9/ICD-10* code in identifying true cases of EC.

Although use of claims databases has distinct advantages such as the ability to capture a large population in geographically diverse areas, there is the risk of misclassification due to lack of granularity of patient data. For example, in the studies assessing EC prevalence, pathology reports were not available in the administrative/insurance claim databases.^{1,2} These studies defined an EC case according to the presence of 1 or more instances of *ICD-9/ICD-10* codes for EC, and with exclusion of cases with certain comorbid conditions that could explain eosinophilia (eg, IBD).^{1,2} The positive predictive value of using administrative claims data for identifying EC cases may be further improved by following the approach of case ascertainment in other gastrointestinal conditions. For example, for IBD, *ICD* codes alone were not sufficient to accurately describe the population, but when combined with IBD-specific pharmaceutical claims, accuracy was improved.⁵ Likewise, in Barrett esophagus, *ICD* codes overestimate prevalence, with only 27% of coded patients having the disease.⁶ In both IBD and Barrett esophagus, there are diagnostic criteria and treatment algorithms that complement *ICD* data. However, in the case of EC, there is broad symptomatology, no therapeutic or diagnostic guidelines, and nonspecific *ICD* codes. Ultimately, using administrative/insurance claims databases for purposes of examining eosinophilic gastrointestinal disorders will necessitate identifying not only *ICD* codes but also procedure codes

(for colonoscopy and biopsy), pathology interpretation codes, exclusion of codes for competing conditions, and perhaps exclusion of infants younger than 1 year to exclude proctocolitis of infancy.

In summary, we have found that diagnostic codes for EC overestimate the diagnosis, especially in pediatric populations, consistent with a recent report.⁷ Establishing clinical-histopathologic guidelines and distinct *ICD* codes for EC will allow for better estimation of disease prevalence and will inform future clinical and translational studies involving eosinophilic gastrointestinal disorders.

^aCenter for Pediatric Eosinophilic Diseases, Division of Gastroenterology and Hepatology & Nutrition, Children's Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, Pa

^bDepartment of Epidemiology and Prevention, Wake Forest University School of Medicine, Winston-Salem, NC

^cEosinophilic Gastrointestinal Diseases Program, Division of Gastroenterology, Hepatology, and Nutrition, Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, Ill

^dDepartment of Gastroenterology and Hepatology, University of Colorado, Denver, Colo

^eDepartment of Medicine, Division of Gastroenterology, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pa

^fDivision of Allergy, Immunology, Departments of Pediatrics and Medicine, University of California, San Diego, Rady Children's Hospital, San Diego, La Jolla, Calif

^gDigestive Health Institute, Children's Hospital Colorado, Aurora, Colo

^hGastrointestinal Eosinophilic Diseases Program, University of Colorado School of Medicine, Aurora, Colo

ⁱCenter for Esophageal Diseases and Swallowing and Center for Gastrointestinal Biology and Disease, Division of Gastroenterology and Hepatology, Department of Medicine, Chapel Hill, NC

^jUniversity of North Carolina School of Medicine, Chapel Hill, NC

^kDivision of Allergy and Immunology, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio

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Corresponding author: Amanda B. Muir, MD, The Children's Hospital of Philadelphia, 3615 Civic Center Blvd, Abramson Research Center 902E, Philadelphia, PA 19104. E-mail: muira@email.chop.edu.

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