



Lack of accuracy of the international classification of disease, ninth (ICD-9) codes in identifying patients with encephalitis

Mohammed Samannodi¹ · Michael Hansen² · Rodrigo Hasbun¹

Received: 10 January 2019 / Revised: 1 February 2019 / Accepted: 3 February 2019 / Published online: 7 February 2019
© Springer-Verlag GmbH Germany, part of Springer Nature 2019

Dear Sirs,

The International Classification of Disease (ICD) codes are used worldwide and are usually collected and comprised in administrative databases. These data are a valuable source of information for both inpatient and outpatient healthcare encounters. ICD-9 codes have been widely used in studies utilizing large national databases that evaluate the clinical epidemiology of encephalitis in the United States [1]. Many studies have showed that ICD-9 codes have different accuracy in other diseases [2–4]. To our knowledge, this is the first study in the United States to evaluate the diagnostic accuracy of ICD-9 codes in encephalitis.

We conducted a retrospective study of all adults with an ICD-9 discharge diagnosis of encephalitis. The study was collected from 17 hospitals from the Memorial Hermann Health (MHH) System and Harris Health System (HHS) in the Greater Houston area between March of 2010 and July of 2015. Medical records were reviewed independently by two physicians and were determined to be accurately classified as encephalitis if they met the definition established by the international encephalitis consortium [5]. The UT Health Committee for the Protection of Human Subjects, the Memorial Hermann Hospital Research Review Committee,

and the Harris Health Research Committee approved the study.

A total of 1241 cases were identified with an ICD-9 discharge diagnosis code of encephalitis. 777 patients were collected from Memorial Hermann Health System (MHH) and 464 patients were collected from Harris Health System (HHS). After a detailed chart review, we found the most common cause identified was not having a central nervous system infection in 580 (46.6%) patients. A total of 326 of 580 (56.2%) were from MHH system and 254 (43.8%) were from HHS. Sepsis due to non-CNS related infections was the most common example of misclassification. A total of 244 of 1,241 (19.6%) patients were correctly coded as having encephalitis with significant differences between both health systems ($P < 0.001$, see Table 1). A total of 110 (14.2%) were from MHH and 134 (28.8%) were from HHS. Other frequent causes of miscoding were: hospital acquired meningitis in 148 (11.9%), community-acquired bacterial meningitis in 101 (8.1%), aseptic meningitis in 72 (5.8%), fungal meningitis in 68 (5.4%), tuberculous meningitis in 25 (2.0%), and parasitic meningitis in 3 patients (0.2%) (Table 1).

Discussion

Large studies have relied on administrative databases to identify, describe, and analyze various diseases. Because of the frequent use of these types of databases in the research field, we decided to assess the accuracy of ICD-9 codes for encephalitis cases. In our study, we ascertained the accuracy of ICD-9 codes by reviewing the medical records to determine if they met the definition of encephalitis on admission or during their hospital course. Out of 1,241 medical records, only 244 patients (19.6%) met the definition of encephalitis. Conversely, the majority of incorrectly coded cases were due to non-CNS related infections. This lack of accuracy can significantly impact the reliability of large studies of encephalitis that are based on ICD-9 codes. Another recent

This study was presented at the Infectious Diseases Society of America in San Francisco, CA on October 8th, 2018 as a poster presentation with interim findings. The poster's abstract was published in "Poster Abstracts" in Open Forum Infectious Diseases, Volume 5, Issue suppl_1, 26 November 2018, Pages S130, <https://doi.org/10.1093/ofid/ofy210.335>.

✉ Mohammed Samannodi
Rodrigo.Hasbun@uth.tmc.edu

¹ Division of Infectious Disease, Department of Medicine, McGovern Medical School at University of Texas Health Sciences Center, 6431 Fannin St. 2.112 MSB, Houston, TX 77030, USA

² Department of Family Medicine, Baylor College of Medicine, Houston, TX, USA

Table 1 Correct clinical diagnosis in 1,241 patients between our two health systems with a discharge diagnosis of encephalitis by ICD-9 codes

Diagnosis	MHH patients <i>n</i> (%)	HHS patients <i>n</i> (%)	Total patients <i>n</i> (%)
Non-CNS infection	326 (42)	254 (54.7)	580 (46.6)
Hospital acquired meningitis	147 (19)	1 (0.2)	148 (11.9)
Encephalitis	110 (14.1)	134 (28.9)	244 (19.6)
Bacterial meningitis	92 (11.8)	9 (1.9)	101 (8.1)
Aseptic meningitis	29 (3.7)	43 (9.3)	72 (5.8)
Fungal meningitis	53 (6.8)	15 (3.2)	68 (5.4)
Tuberculous meningitis	18 (2.3)	7 (1.5)	25 (2.0)
Parasitic meningitis	2 (0.3)	1 (0.2)	3 (0.2)
Total	777 (100)	464 (100)	1,241 (100)

ICD-9 an International Classification of Disease, Ninth, *CNS* Central Nervous System, *MHH* Memorial Hermann Health, *HHS* Harris Health System

**P* value <0.001 in all factors between the two health systems

study done in Denmark evaluated 3 ICD-10 codes for herpes encephalitis and documented a positive predictive value of 58% raising also concerns with accuracy [6].

Between the two health systems, we found that HHS encephalitis ICD-9 codes (28.8%) were more accurate than MHH (14.2%). In addition, we found significant differences between the other miscoding causes, which are detailed in Table 1. We found that physicians in the HHS had more accurate descriptions of the discharge diagnosis that could account for these differences. Alternatively, this difference could also be in part due the coding staff and institution.

Conclusion

ICD-9 codes have poor reliability in identifying patients with encephalitis, leading to concerns about the accuracy of large nationwide studies that utilize them to identify patients.

Funding Grant A Starr Foundation.

Compliance with ethical standards

Conflicts of interest All authors have no conflicts of interest.

References

1. Hasbun R, Rosenthal N, Balada-Llasat JM et al (2017) Epidemiology of meningitis and encephalitis in the United States, 2011–2014. *Clin Infect Dis* 65(3):359–363
2. Johnson EK, Nelson CP (2013) Values and pitfalls of the use of administrative databases for outcomes assessment. *J Urol* 190(1):17–18
3. Baldereschi M, Balzi D, Fabrizio VD et al (2018) Administrative data underestimate acute ischemic stroke events and thrombolysis treatments: Data from a multicenter validation survey in Italy. *PLOS One* 13(3):e0193776. <https://doi.org/10.1371/journal.pone.0193776>
4. Jetté N, Reid AY, Quan H, Hill MD, Wiebe S (2010) How accurate is ICD coding for epilepsy? *Epilepsia* 51(1):62–69. <https://doi.org/10.1111/j.1528-1167.2009.02201.x>
5. Venkatesan A, Tunkel AR, Bloch KC, Luring AS, Sejvar J, Bitnun A, International Encephalitis Consortium et al (2013) Case definitions, diagnostic algorithms, and priorities in encephalitis: consensus statement of the international encephalitis consortium. *Clin Infect Dis* 57(8):1114–1128. <https://doi.org/10.1093/cid/cit458>
6. Jørgensen LK, Dalgaard LS, Østergaard LG et al (2016) Validity of the coding for herpes simplex encephalitis in the Danish National Patient Registry. *Clin Epidemiol* 31 8:133–140