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Accuracy of ICD Codes for Persons with Considerable Emergency Department Use for Mental Health Complaints

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The International Classification of Diseases (ICD) is the standard diagnostic tool for clinical, health management, and research purposes, put forth by the World Health Organization. Currently in its 10th version, ICD-11 is expected to release in 2017. Researchers use ICD codes to identify participants for clinical studies and to track healthcare utilization rates, among a variety of other purposes (e.g. to study access, quality, costs, and effectiveness of care, patient comorbidities, incidence of complications, morbidity, and mortality) (O'Malley et al., 2005). Clearly, code accuracy is paramount and existing priorities include assessing diagnostic congruence of ICD codes and medical records (De Coster et al., 2006). From the emerging evidence, we see that at least two ICD codes are needed to accurately identify individuals with confirmed chronic conditions (Goldberg et al., 2013). Yet, researchers continue to use single ICD codes to identify study participants (Krueger et al., 2011).

An ICD code is recorded for each hospital visit. While regulating standards exist to ensure a consistent process, individuals working in hospital medical records departments typically assign ICD codes. These hospital personnel have no patient contact. Through our work, we have come to question the accuracy of ICD coding for persons who rely heavily on emergency care. Most importantly, for frequent presenters with psychiatric issues, given the many manifestations of mental disorders and the complicated psychosocial issues often prompting visits to the emergency department. We suspect that these patients accumulate multiple diagnoses, some of which are not part of their most responsible diagnosis or set of comorbidities. This may contribute to misrepresentation of certain mental disorders in clinical and health services research, ultimately biasing samples and jeopardizing rigour of research results.

Concerned, we sought to answer the question: 'How accurate is diagnostic information (i.e. ICD codes) captured in administrative systems compared to health records (gold standard) for individuals who make multiple visits (≥5 visits annually) to hospital emergency departments for mental health complaints?'

We identified 62 patients with five or more visits to the emergency department for mental health complaints and compared diagnostic information obtained from administrative data (ICD codes) and health records (most responsible diagnosis). The purpose was to assess agreement or instances where diagnoses attributed to a patient matched in the two sources.

We identified a total of 762 ICD codes assigned to the 62 patients during the one-year study period. Of these, there were 48 unique ICD codes: 35 'disorder' codes and 13 'signs, symptoms, and acute/possibly one-time problems' codes (e.g. ICD F31: 'Bipolar affective disorder' versus ICD F30: 'Manic episode'). Per patient, total codes ranged from 4 to 45, unique codes ranged from 1 to 11, and total 'disorder' codes ranged from 1 to 9 – meaning some patients were labeled with as many as 9 mental disorders.

This brief study, which was part of a larger study examining frequent emergency department use for mental health complaints (Vandyk et al., 2013; 2014), also clearly demonstrated that most responsible diagnoses (recorded in health records) were poorly captured by ICD codes in administrative data. In few instances did ICD codes accurately report the *exact* health record diagnosis, and in many cases, disorders that were not part of their most responsible diagnosis or contributing comorbidities were attributed to patients in administrative data. Less than 50% of ICD codes exactly matched the most responsible primary diagnosis and only 7% of cases matched for affective disorders. Furthermore, when assessing the distribution of primary disorders amongst our sample, we saw tremendous variability. According to most responsible diagnoses captured in health records, 34% of the sample had a primary psychotic disorder (13% according to ICD codes), 23% had a primary affective disorder (6% according to ICD codes), 23% had a primary substance use disorder (6% according to ICD codes), 13% had a primary anxiety disorder (21% according to ICD codes), and 8% had multiple primary diagnoses (53% according to ICD codes). Similar discrepancies were also evident when examining comorbidities including personality disorders and substance use.

These findings shed light on the inadequacy of using administrative records alone to identify and study patients who frequently seek mental health care in the emergency department. At times, the transiency of these patients makes it difficult to engage them in research, thus encouraging the use of readily available administrative data. However, if we hope to truly make a difference for these people, we must ensure that study samples are representative of target populations. What may be most misleading is the use of the term 'disorder' in ICD codes. Regardless of chronic condition, researchers exploring the diagnostic information of individuals with high healthcare utilization should use caution when relying on ICD codes, given their propensity to falsely attribute disorders. A clinical diagnosis or the use of a validated diagnostic tool would more appropriately measure the burden of disease in this cohort.

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