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CHAPTER 2

**Source validation of pancreatitis
related hospital discharge
diagnoses notified to a national
registry in the Netherlands**

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Abstract

BACKGROUND National and regional disease registries are often used for epidemiological studies and validation analyses are scarce. We analysed the reliability of the in the Netherlands used National Information System on Hospital Care (NISHC) to classify admissions for acute and chronic pancreatitis.

METHODS All pancreas related discharge diagnoses notified by the Academic Medical Center to the NISHC were retrieved from a two year time period. A review of multi-disciplinary patient reports was conducted to verify these diagnoses.

RESULTS 284 patients were notified to the NISHC, relating to 483 admissions with 523 pancreas-related discharge diagnoses. Of these diagnoses, 112 were coded as acute pancreatitis, 250 as chronic pancreatitis and 161 were classified as pseudocysts and other pancreas diseases. The positive predictive value for acute pancreatitis diagnosis codes was 77.7% and 46 additional acute pancreatitis diagnoses were identified. Ultimately, leading to an underestimation of the total number of acute pancreatitis diagnoses of 15.8%. The positive predictive value for discharge diagnoses regarding chronic pancreatitis was 83.6% and 57 additional chronic pancreatitis diagnoses were identified. Finally, resulting to an underestimation of the total number of chronic pancreatitis diagnoses of 6%.

CONCLUSION There is a substantial miscoding on a person level of discharge diagnoses of acute and chronic pancreatitis. On a group level, when miscoding between categories is levelled-out, actual numbers of admission are only slightly underestimated.



Introduction

National and regional registries of hospital discharge data are often consulted for epidemiological studies on incidence and prevalence of acute and chronic pancreatitis.¹⁻⁸ The validity of these studies depends heavily on the quality of the national registries as data sources for the estimation of incidence and prevalence rates. Therefore, it is important to ascertain the completeness and accuracy of such registry databases.^{9, 10} It has been suggested that registries of hospital discharge data may be unreliable for acute pancreatitis (AP) incidence estimates, because of an inadequacy of case retrieval using computer linked diagnostic index for acute pancreatitis.¹¹ Another potentially limiting factor is that the commonly used International Classification of Diseases, 9th revision, Clinical Modification (ICD-9CM) codes are not specific for pancreatitis, for example they do not distinguish between alcoholic and biliary causes.⁹ However, such disqualifying note itself may be invalid, as validation analyses of hospital registries related to pancreatitis are scarce.^{1, 3, 10} Only two European studies reported on the validity of diagnosis codes of acute pancreatitis.^{1, 3} Importantly, accuracy data concerning chronic pancreatitis are lacking. In the Netherlands, the National Information System on Hospital Care (NISHC) is frequently used for epidemiological studies. The NISHC is regarded as an unbiased source for epidemiological studies because it does not depend on commercial or financial incentives.¹²

To assess the validity of the NISHC hospital discharge data on pancreatitis we re-examined all discharge diagnoses related to admissions for acute and chronic pancreatitis in the Academic Medical Center between 2002 and 2003 and compared these with data that were originally notified to the NISHC.

Methods

Study population

Since 1963 Dutch hospitalization data are collected in the National Information System on Hospital Care (NISHC). This nationwide database contains anonymous hospital discharge data in academic and community hospitals. The NISHC database is maintained by Prismant, the research and advisory agency for the Dutch Health Care Service. Since 1986 almost all (98%) Dutch hospitals are linked to the NISHC. The case load of pancreatitis is very small in the remaining hospitals that do not report to the NISHC, because these are hospitals specialized at e.g. oncology and rheumatology. Recorded data include, among others, sex, date of birth, number of admission days, mortality, and the primary and secondary discharge diagnoses. The discharge diagnoses are coded in accordance with the ICD-9CM (www.cdc.gov/nchs/icd9). The NISHC receives the discharge diagnoses from in-hospital medical coders. A medical coder extracts diagnoses

from the discharge letter of the treating physician. Since 1992, Prismant improved its internal verification process to optimize the quality of the discharge data. The collected data from pooled hospitals are since then matched yearly with the notified hospital discharge data of the preceding year. Whenever (large) changes in trend or discrepancies are observed, a verification is prompted to verify the notified data. It is not to be expected that in this verification process the original source data are thoroughly verified and validated.

We retrieved and verified all outgoing primary and secondary discharge diagnoses related to admissions (single day treatment and ≥ 1 day of hospital stay) from the Academic Medical Center to the NISHC with ICD codes relating to pancreas disease (ICD-9CM, 577.*) in the period 1 January 2002 until 31 December 2003.

Validation NISHC

To validate the hospital discharge diagnoses all available multi-disciplinary reports were thoroughly reviewed including hospital charts, radiological reports, laboratory data, endoscopic reports, surgery, pathology and autopsy reports.

As mentioned earlier, the NISHC encodes all diseases of the pancreas in accordance with the ICD-9CM [table 1]. The main group of pancreas diseases consists of five related subgroups: 577.0 Acute pancreatitis; 577.1 Chronic pancreatitis; 577.2 Cyst and pseudocyst of pancreas; 577.8 Other specified diseases of pancreas and 577.9 Unspecified disease of pancreas. The NISHC registers per hospital admission one primary discharge diagnosis and up to nine secondary discharge diagnoses. This may have important implications. When for example a patient with Crohn's disease develops an attack of acute pancreatitis induced by azathioprine during hospital admission, Crohn's disease may be registered as the primary discharge diagnosis and acute pancreatitis as a secondary discharge diagnosis. In this validation analysis, secondary diagnoses are defined as complications or consequences of the primary diagnosis during the actual admission, or diagnoses from a patients' medical history that play an actual role during the admission, but are not the primary diagnosis.

For proper validation of the discharge diagnoses, the specific pancreas diseases were strictly defined. The discharge diagnosis of acute pancreatitis was defined as a clinical picture with acute epigastric pain combined with a serum amylase or lipase value of more than three times the upper limit of normal, and in the absence of any feature of chronic pancreatitis.¹³⁻¹⁶ The diagnosis of chronic pancreatitis (ICD-9CM; 577.1) was defined on a clinical picture of recurrent or chronic epigastric pain, weight loss, or steatorrhea, and/or functional evidence of pancreatic insufficiency and/or typical findings at imaging tests (ultrasound, radiography, computed tomography, endoscopic retrograde cholangiopancreatography (ERCP), magnetic resonance cholangiopancreatography (MRCP) or endoscopic ultrasound) and/or a typical picture at laparotomy or histological examination.¹⁷⁻¹⁹ An exacerbation of chronic pancreatitis (with or without a serum amy-



Table 1 *Diseases of the pancreas according to the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9CM) (www.cdc.gov/nchs/icd9)*

ICD-9CM Pancreas diseases codes	Description
577.0 Acute pancreatitis	<p>Abscess of pancreas</p> <p>Necrosis of pancreas:</p> <ul style="list-style-type: none"> • acute • infective <p>Pancreatitis:</p> <ul style="list-style-type: none"> • not other specified • acute (recurrent) • apoplectic • hemorrhagic • subacute • suppurative <p>Excludes:</p> <ul style="list-style-type: none"> • mumps pancreatitis (072.3)
577.1 Chronic pancreatitis	<p>Chronic pancreatitis:</p> <ul style="list-style-type: none"> • not other specified • infectious • interstitial <p>Pancreatitis:</p> <ul style="list-style-type: none"> • painless • recurrent • relapsing
577.2 Cyst and pseudocyst of pancreas	
577.8 Other specified diseases of pancreas	<p>Atrophy of pancreas</p> <p>Calculus of pancreas</p> <p>Cirrhosis of pancreas</p> <p>Fibrosis of pancreas</p> <p>Pancreatic:</p> <ul style="list-style-type: none"> • infantilism <p>Necrosis:</p> <ul style="list-style-type: none"> • not other specified • aseptic • fat <p>Pancreatolithiasis</p> <p>Excludes:</p> <ul style="list-style-type: none"> • fibrocystic disease of pancreas (277.00-09) • islet cell tumor of pancreas (211.7) • pancreatic steatorrhea (579.4)
577.9 Unspecified disease of pancreas	

lase or lipase value of more than three times the upper limit of normal) was classified as a recurrent or relapsing chronic pancreatitis.

A pseudocyst was defined as a fluid collection in the parenchyma of the pancreas originating after an attack of acute pancreatitis or in the course of chronic pancreatitis. This definition implies that the discharge diagnoses pseudocyst (ICD-9CM; 577.2 Cyst and pseudocyst of pancreas) is frequently accompanied with a primary or secondary discharge diagnosis of acute or chronic pancreatitis.

Statistics

In this validation study descriptive statistics were used. The validated data were considered to reflect the true hospital discharge status. To assess the possible epidemiological impact of the discordant discharge diagnoses, the net effect of over- and underreporting was related to the actual number of pancreatitis discharge diagnoses according to the AMC validated database as gold standard. Only positive predictive values (PPV) for the original notification to the NISHC of both acute and chronic pancreatitis discharge diagnoses could be calculated. Sensitivity, specificity, negative predictive values, and accuracy could not be reliably calculated; some true cases with acute or chronic pancreatitis might not have been encoded by the AMC as pancreatitis related and therefore might not have been notified to Prismant as ICD-9CM 577.* primary or secondary discharge diagnoses.

Results

Between 1 January 2002 and 31 December 2003 the AMC reported 284 patients to the NISHC with a pancreas disease related discharge diagnosis. These 284 patients generated 483 hospital admissions and 523 pancreas disease related discharge diagnoses. Of these 523 discharge diagnoses, 112 were coded as acute pancreatitis (ICD-9CM; 577.0); 250 as chronic pancreatitis (ICD-9CM; 577.1) and 92 as pseudocysts (ICD-9CM; 577.2). The remaining 69 discharge codes were classified as other specified and unspecified diseases of the pancreas (ICD-9CM; 577.8 and 577.9) [table 2].

Acute pancreatitis

The PPV of the NISHC discharge diagnoses regarding acute pancreatitis was 77.7% (87/112) [Table 2]. The 25 falsely registered and thus over-reported acute pancreatitis discharge diagnoses, consisted of 15 (60%) chronic pancreatitis diagnoses (ICD-9CM; 577.1) and 10 other diagnoses. In this latter group there were 3 acute pancreatitis diagnoses (ICD-9CM; 577.0), but all diagnosed in the past and not relevant during the actual admission. The other 7 discharge diagnoses were not 577.* related ICD-9CM codes.



Table 2 Overview of number of NISHC and Academic Medical Center validated discharge diagnoses

		AMC validated				
		AP	CP	PC	Other#	
NISHC	AP	87	15	-	10	112
	CP	32	209	-	9	250
	PC	1	1	89	1	92
	Other	13	41	1	14	69
Total		133	266	90	34	523

NISHC= National Information System on Hospital Care; AMC= Academic Medical Center; AP = Acute Pancreatitis (577.0); CP = Chronic Pancreatitis (577.1); PC= Pseudocyst (577.2); Other = 577.8 and 577.9 pancreas disease ICD-9CM codes. # 577.* and other ICD-9CM codes

Importantly, an additional 46 (under-reported) acute pancreatitis diagnoses were identified which were originally miscoded into other categories (577.1, 577.8 and 577.9), amounting to a total number of 133 discharge diagnoses (87+46). Ultimately, the net effect of over- and under-reporting leads to an underestimation of the total number of discharge diagnoses for acute pancreatitis of 15.8% (21/133).

Chronic pancreatitis

The PPV of the NISHC discharge diagnoses regarding chronic pancreatitis was 83.6% (209/250) of admissions. The 41 falsely registered and thus over-reported chronic pancreatitis discharge diagnoses consisted of 32 (78%) acute pancreatitis diagnoses (ICD-9CM; 577.0) and 9 other diagnoses. This latter group consisted of one acute pancreatitis diagnosis (ICD-9CM; 577.0) diagnosed in the past but not relevant during the actual admission and 8 discharge diagnoses without 577.* related ICD-9CM codes.

An additional 57 (under-reported) chronic pancreatitis diagnoses were identified, which were initially miscoded into other categories (577.0, 577.8 and 577.9), amounting to a total number of 266 diagnoses (209+57). Ultimately, the net effect of over- and under-reporting leads to an underestimation of the total number of discharge diagnoses for chronic pancreatitis of 6% (16/266).

Discussion

In this validation study we show that there is a substantial miscoding of discharge diagnoses of acute and chronic pancreatitis on the level of individual hospital admissions.

The PPV for acute and chronic pancreatitis discharge diagnosis codes are 77.7% and 83.6% respectively. The PPV for acute pancreatitis discharge diagnosis codes is in accordance with the results of two former, but limited validation studies.^{1, 3} Eland et al. performed, as a part of a retrospective study in which incidence rates of acute pancreatitis in the Netherlands were assessed, a restricted validation analysis. Data were retrieved from 101 patients who were reported to the NISHC with a discharge diagnosis code for acute pancreatitis.¹ They report a PPV of 82.2% for acute pancreatitis discharge diagnosis codes. This percentage was similar for the years 1985, 1990, and 1995. Floyd et al. found in their validation analysis among 99 Danish patients an overall PPV of 82% for correctly recorded diagnosis of a first episode of acute pancreatitis (95% confidence interval, 72.8-88.9).³

In this present study, the cause of miscoding on a patient level mostly originated from the misclassification of acute pancreatitis as chronic pancreatitis and vice versa. Sixty percent (15/25) of the falsely coded acute pancreatitis diagnoses should have been classified as chronic pancreatitis and 78% (32/41) of the falsely coded chronic pancreatitis codes should have been classified as acute pancreatitis. Apparently, the allocation of acute versus chronic pancreatitis causes considerable confusion and is not performed according to uniform criteria. However, consensus reports are available in which the features of acute and chronic pancreatitis are clearly defined and which may be strengthened further if more information becomes available concerning the pathogenesis and the natural history of pancreatitis.^{17, 20, 20, 21} In the process of reporting discharge codes to the NISHC there are two potential sources of error: first the *physician* composing the discharge letter in which the diagnostic investigations, treatment outcome and overall conclusions are discussed, and secondly the *medical coder* filtering diagnoses from the discharge letter and translating these into ICD-gCM based discharge codes (primary and secondary) to report to the NISHC. The medical coder is dependent on an accurate interpretation and clear presentation of the diagnoses by the clinician. Therefore, classifications by the medical coder of discharge letters that do not contain accurate information and uniformly stated diagnoses are a potential source of error.

Which proportion of errors in discharge diagnoses can be attributed to either the physician or the medical coder was not a part of the present study. It could be anticipated that there would be less errors if the physician reports discharge codes directly to the NISHC. In 2005, a registration system has been introduced in the Netherlands in which discharge diagnoses are reported by physicians. This new registration system has been introduced nationwide to control and manage health care finances and is called 'Diagnose Behandeling Combinatie' (DBC) (translation: Diagnosis Treatment Combination).²² This DBC system is not meant to replace the NISHC, for the time being they will probably coexist for the foreseeable future. DBCs are defined as the whole set of diagnostic and therapeutic interventions in an individual patient with a typical clinical representation or diagnosis starting from the first consultation until discharge. Each



registered DBC provides the hospital/physician with pre-calculated financial reimbursement which is based on the average costs of medical care in patients with a comparable diagnosis. Each DBC is characterized by a diagnosis which is derived from the International Classification of Diseases, 10th edition (ICD-10). In which way information on disease diagnosis is truly representative of discharge diagnoses and is biased for example by financial incentives (selecting a more expensive DBC) is unclear. Moreover, physicians are allowed to choose from a pre-selected set of ICD-10 diagnoses and, depending on the local situation, in some instances there is an extra re-coding from items selected by physicians into a final DBC code. Also, different selections by physicians may be recoded into one DBC which may be readily apparent to administrators but not to physicians.

The proportion of pancreatitis related hospital admissions during which patient die, could not be estimated from this validation study in which both, primary and secondary discharge diagnosis codes of pancreatic diseases (ICD9-CM, 577.*) were evaluated. Admission-related death as registered within the NISHC cannot be linked specifically to a particular primary or secondary discharge diagnosis. In-hospital, pancreatitis related death however, may be modest. Andersson et al. retrospectively studied hospital mortality for acute pancreatitis during 1994-2003 in a centre with a restrictive attitude to surgery.²³ They identified 22% of all admissions for acute pancreatitis to involve cases of severe acute pancreatitis, 9% of which mortality-related. Hence, hospital mortality for all cases of acute pancreatitis may amount to 2%. Hospital mortality for chronic pancreatitis may be far below this figure, given its recurrent nature.

The important question remains if the pancreatitis related discharge diagnoses reported to the NISHC are valid enough to use for epidemiological studies. The underestimation of the total number of admissions for acute and chronic pancreatitis amounts to 15.8% and 6% respectively. With these figures in mind and with the notion that there may also be some (unknown) degree of underreporting because some hospital admissions are unrightfully not coded as pancreatitis cases, the NISHC may serve as a relatively reliable source for large scale epidemiological surveys regarding the incidence and prevalence of acute and chronic pancreatitis. When data over time are compared and relative changes are studied, this may even be more true as miscoding may be relatively constant at different points in time, although this has not been formally assessed in this study nor in other surveys. If records are filtered to exclude duplicate diagnoses entries of individual patients, NISHC data could serve a dependable source to calculate incidence and prevalence rates of acute and chronic pancreatitis in the Netherlands. Although our validation study is, in absence of international administrative databases almost by implication, restricted to a national registry, other epidemiological studies may benefit from our approach when assessing the validity of the administrative data. National registries elsewhere may be hampered by similar validity issues as pointed out in this paper. National and international epidemiological studies reporting on incidence and prevalence of acute and chronic pancreatitis can be validly compared, only if the

accuracy of the used administrative data has been assessed. Prediction studies too may benefit from better validated registries. For instance, severe acute pancreatitis has been reported to be more frequent in obese patients; those patients developed more systemic and local complications.²⁴ If one is interested in determining the risk for (repeat) hospitalization in these patients, accurate identification and classification of admissions as pancreatitis-related would be a prerequisite for further study. Hence, more validation studies, preferably internationally oriented and prospectively designed, are needed.

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