Thorax 1991;46:589–591 589

# Accuracy of diagnostic coding of hospital admissions for cryptogenic fibrosing alveolitis

Ian D A Johnston, Carol Bleasdale, Charles R K Hind, Ashley A Woodcock

### Abstract

To determine the accuracy of diagnostic coding of cryptogenic fibrosing alveolitis, the case notes of 166 admissions to four hospitals were reviewed. These consisted of all admissions that had been coded as "idiopathic fibrosing alveolitis" (ICD code 516.3: 97 admissions) or as "postinflammatory pulmonary fibrosis" (ICD code 515.9: 69 admissions). Of 88 available records of admissions coded as idiopathic fibrosing alveolitis, 70 (80%) patients had definite cryptogenic fibrosing alveolitis, and six (7%) possible cryptogenic fibrosing alveolitis according to predetermined conventional clinical criteria. Only seven (8%) admissions were clearly coded wrongly. Sixty four records were available for patients coded as having postinflammatory pulmonary fibrosis; 16 (25%) of these patients had definite cryptogenic fibrosing alveolitis, a further 12 (19%) had possible cryptogenic fibrosing alveolitis or fibrosing alveolitis with a connective tissue disorder, and the remainder had a very wide range of diagnoses. In this study the idiopathic fibrosing alveolitis (ICD 516.3) code was relatively reliable, but a substantial proportion of admissions coded under postinflammatory pulmonary fibrosis (ICD 515.9) also had cryptogenic fibrosing alveolitis and code 515.9 was of little diagnostic value. The data are inadequate for case finding, though in respect of cryptogenic fibrosing alveolitis may be adequate for planning purposes. There continues to be a need for more medical input into the process of diagnostic coding.

Accurate diagnostic information has long been recognised as important in planning health care provision and in research. Diagnostic information on hospital inpatients was provided by Hospital Activity Analysis in the UK from 1969 until the late 1980s, a system in which clerks coded diagnostic data from discharge summaries written by medical staff. Several studies have pointed to serious shortcomings in the data produced by Hospital Activity Analysis, 12 and this system of data collection has now been replaced by the Korner system, the data being intended to be coded by doctors but still largely coded by clerks. With the advent of resource management into the National Health Service in the

late 1980s, diagnostic information has assumed even greater importance, yet the question of the accuracy of coding does not appear to have been formally re-examined since the early 1980s.

Cryptogenic fibrosing alveolitis is a respiratory disease of unknown aetiology with a median life expectancy of only four to five years from diagnosis.<sup>3</sup> The mortality is increasing.<sup>4</sup> The epidemiology of the disease is poorly understood and indeed only since the introduction of the 9th revision of the International Classification of Disease (ICD) in 1979 has cryptogenic fibrosing alveolitis been allocated a specific code, ICD 516.3.<sup>5</sup> We have been compiling a case register of the disease, and have taken the opportunity to study the diagnostic accuracy of coding of hospital admissions for the disease.

# Methods

All admissions to four hospitals in Nottingham and Liverpool coded under "postinflammatory pulmonary fibrosis" (ICD 515.9), "idiopathic fibrosing alveolitis" (ICD 516.3), and "lung involvement in conditions classified elsewhere' (ICD 517) during the period January 1985-August 1988 were identified from Hospital Activity Analysis and Korner data. Within ICD code 516 there are specific subcodes alveolar proteinosis, haemosiderosis, microlithiasis, and idiopathic alveolitis. Code 517 refers to lung lesions in connective tissue diseases—for example, rheumatoid lung. Code 515.9 is used for other causes of pulmonary fibrosis, the exact wording being "chronic or unspecified cirrhosis, fibrosis, or induration of the lung." The relevant case notes were reviewed by two doctors (IDAJ, CB), who decided whether the patient fulfilled the diagnostic criteria for cryptogenic fibrosing alveolitis, given below, at the time that the patient was discharged from hospital.

The criteria for the diagnostic categories were:

- 1 Definite cryptogenic fibrosing alveolitis Inspiratory basal crackles on auscultation of the chest, lower zone pulmonary radiographic shadowing, and restrictive lung function with no history of appreciable relevant occupational or other exposure to known fibrogenic agents.

  2 Possible cryptogenic fibrosing alveolitis In-
- spiratory basal crackles on auscultation of the chest and lower zone pulmonary radiographic shadowing but no record in the notes of lung function or details of occupational or other exposure.

University Hospital, Nottingham NG7 2UH I D A Johnston

Regional Adult
Cardiothoracic Unit,
Broadgreen Hospital,
Liverpool L14 3LB
C Bleasdale
C R K Hind

Wythenshawe Hospital, Manchester M23 9LT A A Woodcock

Reprint requests to: Dr Johnston Accepted 22 May 1991

- 3 Fibrosing alveolitis (according to the criteria of (1)) associated with a connective tissue disease whose diagnosis was documented in the case notes.
- 4 Definitely not cryptogenic fibrosing alveolitis (that is, not meeting criteria 1-3).

The specialty of the consultant under whose care the patient had been predominantly admitted was also recorded.

## Results

Sixty nine admissions were coded under postinflammatory pulmonary fibrosis (ICD 515.9) and 97 under idiopathic fibrosing alveolitis (ICD 516.3) during the 44 months from January 1985. Only two admissions were coded under 517 and this category is not considered further in this analysis.

The breakdown of admissions into the four diagnostic groups is shown in the table. Of the 64 admissions coded under postinflammatory pulmonary fibrosis (ICD 515.9), 16 (25%) had definite cryptogenic fibrosing alveolitis and 24 (38%) had definite or possible cryptogenic fibrosing alveolitis. The 36 cases coded under ICD 515.9 that we considered to have definitely not had cryptogenic fibrosing alveolitis had a very wide range of probable diagnoses, including old tuberculosis (8), bronchiectasis (4), and fibrosis or radiographic shadowing associated with renal disease (4), occupation (3), cancer (2), radiotherapy (2), eosinophilic granuloma (1), amiodarone (1), sarcoidosis (1), and cryptogenic organising pneumonitis (1). For the remainder there was no obvious diagnosis for the radiographic shadows (5), or the records contained no reference to any fibrotic condition at all (4). The 88 cases of idiopathic fibrosing alveolitis (ICD 516.3) were coded more accurately, 70 (80%) being definite cryptogenic fibrosing alveolitis, and 76 (87%) definite or possible cryptogenic fibrosing alveolitis, with only seven completely wrongly coded. For all 152 admissions for which the case notes were available the total number coded as ICD 516.3 (88) was close to the overall number of admis-

Analysis of case notes

Analysis of case n			
Code 515.9 (postir	iflammatory pulmonary	fibrosis)	
	5 case notes missing		
69 admissions	64 reviewed	16 (25%)	Definite cryptogenic fibrosing alveolitis
		4 (6%)	Fibrosing alveolitis with connective tissue disorder
		8 (13%)	Possible cryptogenic fibrosing alveolitis
		36 (56%)	Definitely not cryptogen fibrosing alveolitis
Code 516.3 (idiop	athic fibrosing alveolitis	)	
	9 case notes missing		
97 admissions	88 reviewed	70 (80%)	Definite cryptogenic fibrosing alveolitis
		5 (5%)	Fibrosing alveolitis with connective tissue
		6 (7%)	disorder Possible cryptogenic fibrosing alveolitis
		7 (8%)	Definitely not cryptogen fibrosing alveolitis

sions with definite cryptogenic fibrosing alveolitis by our criteria (86), irrespective of whether these were coded 515.9 or 516.3. If those patients with "possible cryptogenic fibrosing alveolitis" are also included under cryptogenic fibrosing alveolitis, however (total 100), the 516.3 data underestimated the actual number of cryptogenic fibrosing alveolitis admissions by 14%.

The reasons for miscoding were difficult to assess retrospectively, but included: (a) generally poor recording of the diagnosis in the medical notes; (b) different diagnostic labels (for example, pulmonary fibrosis, idiopathic pulmonary fibrosis and cryptogenic fibrosing alveolitis sometimes appeared in the same case notes); and (c) overinterpretation of medical records by clerks—for example, "CXR? pulmonary fibrosis" as a single comment led to the coding of a case as idiopathic fibrosing alveolitis.

Overall, 51 (58%) of the patients who were coded under ICD 516.3 were under respiratory consultants, compared with only 22 (34%) of those coded under ICD 515.9 (p < 0.001).

# **Discussion**

This study shows that there is substantial miscoding of the diagnosis of cryptogenic fibrosing alveolitis. The category idiopathic fibrosing alveolitis (ICD 516.3) appears relatively reliable, but at least a quarter of patients admitted with postinflammatory pulmonary fibrosis (ICD 515.9) also had cryptogenic fibrosing alveolitis.

What factors can explain these difficulties in coding cryptogenic fibrosing alveolitis? Cryptogenic (idiopathic) fibrosing alveolitis was coded separately for the first time in the 9th revision of the International Classification of Diseases, introduced in 1979.5 This was six years, however, before the first admissions in our study, so the new diagnostic code is unlikely to be responsible for the errors. There was a possibility that the data were being distorted by one clerk or group of clerks in one unit; but the proportion of miscoded admissions appeared broadly similar in all the hospitals, though the number of admissions was too small to permit formal comparisons. There is undoubtedly much semantic uncertainty. While the preferred term in the United States is idiopathic pulmonary fibrosis, cryptogenic fibrosing alveolitis is the usual label applied in Britain, though some clinicians include those cases associated with connective tissue disorder and others do not. Such semantic difficulties are likely to be troublesome for both coding clerks and medical staff and may also explain the use of ICD code 515.9 or 516.3 for fibrosing alveolitis associated with a connective tissue disorder even though there is a clear ICD code, 517, for this condition.<sup>5</sup> Poor medical record keeping and overinterpretation by clerks of tentative diagnoses in the medical notes also contributed to the miscoding.

The coding problems may, however, to a large extent reflect the difficulties inherent in making a diagnosis of cryptogenic fibrosing

alveolitis. Though this may be made histologically, in practice it is usually made clinically. We did not record biopsy procedures in this study but in our current register of patients with cryptogenic fibrosing alveolitis only about a third had had any attempt at histological diagnosis made and only 8% had had an open lung biopsy.6 The diagnostic criteria in the present study reflect standard clinical practice and are very similar to those used in previous detailed surveys of the disease.3 The diagnosis may still remain uncertain, however, and such difficulties are likely to be more prominent for non-specialists and junior staff. Although care is needed in extrapolating from the limited data we present from hospitals in two locations, there is no reason to suspect that radically different results would be obtained elsewhere. It seems inescapable that consultants will routinely need to perform or supervise the coding or at least the recording of an accurate diagnosis if these coding errors are to be minimised.

We did not set out to investigate the accuracy of the ICD 515.9 code for diagnoses other than cryptogenic fibrosing alveolitis. Nevertheless, some of the other admissions coded as 515.9 should clearly have been coded differently. The ICD definition of code 515.9, postinflammatory pulmonary fibrosis, is archaic and the very wide range of diagnoses under this code not only underlines the extent of miscoding but renders code 515.9 almost worthless for diagnostic purposes.

Despite earlier reassurances about the validity of Hospital Activity Analysis data,7 some authors subsequently drew attention to persistent problems in the diagnostic accuracy of these data.12 The present study suggests that, despite an increasing need for more accurate data, accuracy has not improved over the past decade. Our data may underestimate the inaccuracy of current diagnostic coding, as we were unable to assess the extent to which the diagnosis of cryptogenic fibrosing alveolitis may have been missed altogether and coded under neither ICD 516.3 nor 515.9. The period over which we studied admissions with cryptogenic fibrosing alveolitis spanned the changeover from Hospital Activity Analysis to Korner data collection. The number of errors was too small to permit formal comparisons between the two systems, though there was no clear difference. It could, however, be argued that, although the data are inadequate for case finding, the total number of admissions coded as 516.3 provided a good enough estimate of overall numbers of patients with cryptogenic fibrosing alveolitis and that the data might therefore still be useful for planning and resource management.

We were surprised by the comparatively small proportion of patients with cryptogenic fibrosing alveolitis admitted under respiratory consultants, though some admissions were clearly for unrelated problems, such as surgical procedures. Cryptogenic fibrosing alveolitis has a serious prognosis3 with some potential for therapeutic intervention8; respiratory physicians may need to take a higher profile in the management of the disease.

In summary, the extent of the miscoding uncovered in this study is unsatisfactory. If, as seems likely in the light of earlier work, such errors are to be found across the whole range of diagnoses, there must be serious concern about the use of such data for resource allocation, audit, and research. There is a continuing need for greater medical input into the process of coding.9

We thank Professor H R Anderson for helpful comments.

- 1 Rees JL. Accuracy of hospital activity analysis data in estimating the incidence of proximal femoral fracture. BMJ 1982:284:1856-7.
- 2 Whates PD, Birzgalis AR, Irving M. Accuracy of hospital activity analysis operation codes. BMJ 1982;284:1857-8.
- 3 Turner-Warwick M, Burrows B, Johnson A. Cryptogenic fibrosing alveolitis: clinical features and their influence on survival. Thorax 1980;35:171-80.
- 4 Johnston IDA, Britton JR, Kinnear WJM, Logan RFA. Rising mortality from cryptogenic fibrosing alveolitis. BMJ 1990;301:1017-21.
- 5 World Health Organisation. International classification of diseases 1975, 9th revision. Geneva: WHO, 1977.
- 6 Bleasdale C, Johnston IDA, Gomm SA, Woodcock AA, Evans CC, Hind CRK. Management of idiopathic pul-monary fibrosis in the United Kingdom in the 1980s [abstract]. Am Rev Respir Dis 1990;141:A50.
- 7 Martini CJM, Hughes AO, Patton VA. A study of the validity of the Hospital Activity Analysis information. Br J Prev Soc Med 1976;30:180–6.
- 8 Johnson MA, Kwan S, Snell NJC, Nunn AJ, Darbyshire JH, Turner-Warwick M. Randomised controlled trial comparing prednisolone alone with cyclophosphamide and low dose prednisolone in combination in cryptogenic fibrosing alveolitis. *Thorax* 1989;44:280-8.

  9 Earlam R. Korner, nomenclature, and SNOMED. *BMJ*
- 1988;296:903-5.