Validating long term morbidity recording

Chris Van Weel

Abstract

Study objective – To assess the validity of diagnosis made in a general practice based morbidity recording from 1967–90.

Design – Clinical features of patients with a diagnosis of migraine headache and diabetes mellitus were compared with international diagnostic criteria for these conditions. For migraine headache the International Classification of Health Problems in Primary Care (ICHPPC) definition was used, while diabetes mellitus was defined according to World Health Organization (WHO) criteria.

Setting – The continuous morbidity registry of the Department of General Practice and Social Medicine, University of Nijmegen, has been recording data from four general practices (12,000 patients) continuously since 1967. The database is used for longitudinal clinical research.

Patients – All patients with migraine headache and living in the practice area at the time of study and matched controls with tension headache received a questionnaire asking about ICHPPC criteria symptoms of migraine. The medical records of all patients with diabetes mellitus at the time of diagnosis were compared with WHO criteria.

Main results – In 85% of patients with migraine headache, the questionnaire confirmed the ICHPPC defined criteria. Twenty nine per cent of the matched controls reported migraine features.* In 74% of the patients with diabetes mellitus the diagnosis was made in agreement with the WHO criteria: in 12% no clinical information from the time of diagnosis could be traced.

Conclusions – The diagnoses of migraine headache and diabetes mellitus in the registry largely agreed with international criteria. The quality control of recorded data is satisfactory, and the registry might serve as a model for other primary care based databases.

(The table: Epidemiol Community Health 1995;49(Suppl 1):29–32)

Health care related databases are widely used in epidemiological research on health and disease in the community. General practice provides medical care in the community and needs, for its research and development, health care related information. Three features in particular single out general practice care. Firstly, it is directed at individuals, in a defined community; secondly, it is comprehensive (it includes all diseases, in all their stages, and in all categories of patients); and thirdly, it is continuous over time. As a consequence, databases for general practice research should provide information on individuals' health on a community level, with emphasis on everyday illness, and on individual morbidity over time.

In the past, general practice has developed databases on individual health problems in the community – particularly in the UK,7 The Netherlands,15 and North America.9 The strength of these data lies in their reflection of the community's medical needs and demands. On the other hand, the often ill defined conditions are difficult to classify and exact classification may have limited consequences for treatment and management. The validity and reliability of community health care related databases are therefore a point of concern. The development of proper classifications for primary care,14 with primary care oriented definitions,7 has been a major step forward in this field, but is insufficient in itself to guarantee the recording of valid and reliable data.

This paper described the oldest still functioning morbidity registration in general practice in The Netherlands – the continuous morbidity registry of the Department of General Practice and Social Medicine, University of Nijmegen. The aim was to assess the validity of recorded diagnoses. Two conditions – migraine headache and diabetes mellitus – were analysed.

Methods

The study analysed recorded cases of migraine headache9 and diabetes mellitus.10 Each case recorded in the database was compared with external criteria for these two conditions. The comparison was made by researchers who where not concerned with the data collection for the registry.

THE DATABASE: GENERAL FEATURES

The continuous morbidity registry is a network of four general practices in the Nijmegen region (seven general practitioners). The network has monitored morbidity in general practice on a continuing basis since 1971 (in two practices since 1967). All new episodes of illness are recorded, including diagnoses made after referral. The database is used to analyse general practice morbidity and morbidity trends since 1971, and as an index for the recruitment of groups of patients for additional research. The practices’ population is about 12,000 patients and has been stable over the years. The relevance and the limitations of the register are directly influenced by the Dutch health care
Van Weel

Table 1  Longitudinal studies 1988-94, continuous morbidity registration Nijmegen

- Prognosis of childhood morbidity
- Early childhood respiratory morbidity and asthma in adolescence
- Breast feeding and morbidity
- Comorbidity in asthma/chronic obstructive pulmonary disease
- Morbidity and mortality in non-insulin dependent diabetes mellitus
- Morbidity and mortality in non-insulin dependent diabetes mellitus

The practice assistants supervise the transfer of the coded data to the Department of General Practice and Social Medicine, where analysis takes place. By comparing the patients' files and the patients' coded diagnoses, the assistants monitor the completeness of the data.

EXTERNAL VALIDATION OF THE RECORDED DATA
The validity of the recorded data was studied for two conditions – migraine headaches and diabetes mellitus.

Migraine headache
This was defined according to the ICHPPC criteria.
- Recurrent episodes of unilateral headache with either/or
  - Nausea/vomiting,
  - Aura,
  - Neurological (visual) disturbances,
  - Family history of migraine, OR
  - Recurrent episodes of bilateral headache with three or more of the above features.

All patients with the diagnosis migraine who were still on the practice list at the time of study (1990) were selected from the register. They were invited to complete a mailed questionnaire detailing the features of their headache. For each migraine patient a sex, age, and practice matched control was selected from the register matched control was selected from the register. They were invited to complete a mailed questionnaire detailing the features of their headache.

Diabetes mellitus
For diabetes mellitus the WHO criteria were applied:
- Symptoms (thirst, polyuria, pruritus, weight loss);
  AND
- Raised blood glucose concentrations (fasting values >6.7 mmol/l or two hours after meal >11.1 mmol/l).
  OR
- In the absence of symptoms, a raised blood glucose value (as defined) on two occasions.

The data for all patients on the register in whom diabetes mellitus had been diagnosed between 1967 and 1989, were analysed including patients who at the time of study (1989)
had died or moved to another area. The diagnostic criteria applied at the time of diagnosis were reconstructed from their medical files.

Results

MIGRAINE HEADACHE (TABLE 2)

There were 150 patients who had been diagnosed as having migraine headache and were still registered with the practice at the time of the study. The questionnaire was returned by 140, of whom 85% confirmed the diagnostic criteria. The matched controls with tension headache had migraine features that met the ICHPPC migraine criteria in 29% and photophobia or phonophobia were reported in more than 50%.

DIABETES MELLITUS (TABLE 3)

There were 427 cases recorded but no clinical data could be traced in 50. In another 61, normal blood glucose values only were found in the records. Diabetes mellitus according to the WHO criteria was present in 316 (74%). This included all cases diagnosed after 1985.

Discussion

The continuous morbidity registry applies strict rules to control the quality of collected data. An external comparison of the recorded cases of migraine headache and diabetes mellitus with international diagnostic criteria showed satisfactory agreement – in most cases of recorded migraine headache and in three quarters of the cases of recorded diabetes mellitus the criteria could be confirmed. Both migraine headache and diabetes mellitus provide problems of their own in coding of morbidity. Migraine is a diagnosis based entirely on the information provided by the patient and represents his or her perception of signs and symptoms. The finding that about one in three of the controls with tension headache reported migraine-like symptoms and more than half of them had migraine associated signs of photophobia and phonophobia could point to a lack of sensitivity in general practitioner diagnosed migraine. On the other hand, a diagnosis of migraine will usually be more easily accepted by patients than one of tension headache, which suggests a psychosocial rather than a somatic background of the disorder. Consequently, the general practitioner might tend to over-diagnose migraine than one of tension headache, which suggests a psychosocial rather than a somatic background of the disorder. Consequently, the general practitioner might tend to over-diagnose migraine. On the other hand, a diagnosis of migraine will usually be more easily accepted by patients than one of tension headache, which suggests a psychosocial rather than a somatic background of the disorder. Consequently, the general practitioner might tend to over-diagnose migraine than one of tension headache, which suggests a psychosocial rather than a somatic background of the disorder. Consequently, the general practitioner might tend to over-diagnose migraine.


17 Botterman BJAM. Diagnosing chronic non-specific lung disease in general practice [Diagnostiek van CARA in de huisartspraktijk]. Amsterdam: University of Amsterdam, 1993. (Thesis)

18 Anonymous. Morbidity classification for general practitioners derived from English E-list. [Morbiditeitsscijferatie voor gebruik door huisartsen, ontleend aan de Engelse z.g. 'E-list']. Utrecht: Dutch College of general practitioners, 1963.


24 Verhoeven S. Behandeling, controle en metabole instelling van patiënten met diabetes mellitus type-II en de prevalentie van late complicaties bij deze patiënten. Rotterdam: Erasmus University Rotterdam, 1989. (Thesis) [Summary in English].