Validating long term morbidity recording

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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.

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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;[1] secondly, it is comprehensive (it includes all diseases, in all their stages, and in all categories of patients);[2] and thirdly, it is continuous over time.[2] 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,[3] The Netherlands,[4 5] and North America.[6] 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 classifiy 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,[7 8] 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 headache[9] 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

structure. Two aspects of this structure are of particular importance in this respect. Firstly, in the Dutch health care system, the general practitioner has a "fixed" list of patients (the practice population), and, secondly, he or she is the gate keeper of access to specialist medical care. As a consequence, the system collects all morbidity data in a defined population for which specialist medical care is sought.

Each episode of morbidity presented to the general practitioner is recorded, including the cause of death. The general practitioner who diagnoses the episode provides the diagnostic coding. An episode of morbidity is defined according to the international glossary for family practice.[11] Follow up data on already recorded morbidity are not recorded. The morbidity data are stored according to the date of presentation/diagnosis, in relation to the demographic data of the patient (sex, age, social class, and family composition). Registration began in 1967 and has been uninterrupted since. The population of the four practices has been remarkably stable over the years, and as a consequence it is possible to analyse long term individual morbidity. Table 1 details longitudinal studies based on the register.[10 12–17] Longitudinal studies of morbidity in general practice have become the main objective of the register and efforts to secure the validity of the data must be seen in this light.

INTERNAL QUALITY CONTROL OF DATA
Quality control of recorded data involves the following activities.

The diagnostic classification and the diagnostic definitions
At the start of the register in 1967, the only morbidity classification for general practice available was the Dutch translation[18] of the British E-list.[19] For reasons of consistency over time, the classification was not changed when classification more suitable for general practice became available.[7 8] But the list has been made compatible with the International Classification of Health Problems in Primary Care (ICHPPC),[7] and the ICHPPC definitions have been introduced.

The procedure of classifying and coding
Each episode of morbidity is classified and coded by the general practitioner who is involved in the case. This should be done as soon as possible after the consultation, and must reflect the highest level of diagnostic interpretation of the patients' condition. Where there is uncertainty, the classification/coding

may be postponed until more certainty has been achieved (from the natural history of the disease, diagnostic tests, or specialists' assessment).

Training and support of general practitioners
All general practitioners involved in the register have been trained in the use of the classification list and the application of the ICHPPC definitions (using case studies). There is a monthly meeting of all general practitioners to discuss coding problems and to monitor the application of diagnostic criteria. The practice assistants are trained and supervised in collecting the demographic data of the patients.

Completeness of the data
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.[7]

● 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[9] 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 patients with the diagnosis, tension headache.[9]

Diabetes mellitus
For diabetes mellitus the WHO criteria[20] 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,[10] including patients who at the time of study (1989)

Table 2 Continuous morbidity registration Nijmegen. Percentage of clinical features in recorded cases of migraine and tension headache[9]

Features	Recorded cases	
	Migraine	Tension headache
Unilateral location	85	71
Bilateral location	11	29
ICHPPC criteria	85	
Unilateral and:		
4 additional criteria	20	
3 additional criteria	26	
2 additional criteria	26	
1 additional criterion	10	29
Bilateral and 3–4 additional criteria	3	
Photophobia	90	52
Phonophobia	89	64

had died or moved to an other 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.

Table 3 Continuous morbidity registration Nijmegen. Clinical features (%) of classified cases 1967–90 of diabetes mellitus[10]

Number	427	
No clinical data available at time of diagnosis	50	(12)
Only normoglycaemia according to records	61	(14)
Signs/symptoms and (repeated) hyper glycaemia	316	(74)

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[7] 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 rather than under diagnose migraine. That migraine headache and tension headache overlap in their symptoms seems more probable. This underlines the genuine problems of primary care based morbidity databases.

Diabetes mellitus is based on objective criteria, but these have been revised on two occasions in the past 15 years.[20][21] The confirmed diagnostic agreement in three quarters of the cases should be seen in this light. In some cases, no confirmation was possible because clinical data were no longer available from the time of diagnosis. Thus, external confirmation of three quarters of the registered cases in this study is a minimum estimate only. Normal blood glucose concentrations only were frequently found in the records of patients diagnosed as having diabetes mellitus. A variety of factors can (temporarily) increase blood glucose values.[22] Surveys of diabetes mellitus in general practice[23–25] found that in up to 10% of patients under treatment for diabetes, the diagnosis could not be confirmed at the time of survey.

The findings should be considered in the context of the long term data collection. Patients were questioned about features of migraine that in some cases might have occurred more than 20 years before. Furthermore, the practice records were searched for diagnostic tests used at a time when general practice was much more restricted in its laboratory support. Nevertheless, the diagnoses recorded over more than 20 years were largely in touch with today's requirements.

The continuous morbidity registry provides data for longitudinal clinical research in general practice. Efforts are made to safeguard the quality of recorded data and this strategy has resulted in satisfactory data. This study may indicate what should be done to guarantee the quality of general practice based data recorded in daily patient care.

1 Hart JT. Reactive and proactive care: a crisis. *Br J Gen Pract* 1990;40:4–9.
2 Anonymous. *Rapport van de subcommissie Gezondheids(zorg)wetenschappen.* Amsterdam: Koninklijke Nederlandse Academie van Wetenschappen, 1991. (Report of the subcommittee Health(care)sciences.)
3 Royal College of General Practitioners, Office of Population Censuses and Surveys and Department of Health and Social Security. *Morbidity statistics from general practice. Third national study, 1981–82.* London: HMSO, 1986.
4 Department of General Practice/Family Medicine. *Morbidity figures from general practice. Data from four general practices 1978–1982.* Nijmegen, The Netherlands: Nijmeegs Universitair Huisartsen Instituut, 1985.
5 Lamberts H. *Morbidity in general practice. Diagnosis-related information from the monitoring project.* Utrecht, The Netherlands: Huisartsenpers, 1984.
6 Green LA, Wood M, Becker L, *et al.* The ambulatory sentinel practice network: purpose, methods and policies. *J Fam Practice* 1984;18:275–80.
7 Classification Committee of WONCA in collaboration with WHO. *ICHPPC-2 defined* (International classification of

health problems in primary care). 3rd ed. Oxford: Oxford University Press, 1983.

8 Lamberts H, Woods M, eds. *ICPC. International classification of primary care.* Oxford: Oxford University Press, 1987.

9 Bartelink ML, van de Lisdonk EH, van den Hoogen HJM, Wollersheim H, van Weel C. Migraine in family practice: relevance and influence of sex hormonal status. *Fam Med* 1993;25:331–6.

10 de Grauw W, van de Lisdonk EH, van den Hoogen HJM, van Weel C. Cardiovascular morbidity and mortality of type-2 diabetes patients. *Diabetic Med* 1995;12:117–22.

11 WONCA. An international glossary for primary care. *J Fam Pract* 1981;13:671–81.

12 van den Bogaard C, van den Hoogen HJM, Huygen FJA, van Weel C. The relationship between breast-feeding and early childhood morbidity in a general population. *Fam Med* 1992;23:510–5.

13 van den Bogaard C, van den Hoogen HJM, Huygen FJA, van Weel C. Is breast best for children with a family history of atopy? The relation between way of feeding and early childhood morbidity. *Fam Med* 1993;25:471–5.

14 Kolnaar BGM, van den Bosch WJHM, van den Hoogen HJM, van Weel C. The clustering of respiratory diseases in early childhood. *Fam Med* 1994;26:106–10.

15 Kolnaar BGM, van Lier A, van den Bosch WJHM, Folgering H, van Herwaarden C, van den Hoogen HJM, van Weel C. Asthma in adolescence and young adults: relationship with early childhood respiratory morbidity. *Br J Gen Pract* 1994;44:73–8.

16 van den Bosch WJHM, van den Hoogen HJM, Huygen FJA, van Weel C. Morbidity in early childhood: family patterns in relation to sex, birth order and social class. *Fam Med* 1993;25:126–30.

17 Bottema 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.* [Morbiditeitsclassificatie voor gebruik door huisartsen, ontleend aan de Engelse z.g. 'E-lijst']. Utrecht: Dutch College of general practitioners, 1963.

19 Eimerl TS. Organized curiosity. A practical approach to the problem of keeping records for research purposes in general practice. *J R Col Gen Pract* 1960;3:246–52.

20 World Health Organisation. Report of the *Expert Committee on Diabetes Mellitus.* WHO Technical Report 727. Geneva: WHO, 1985.

21 World Health Organisation. *Second Report of the WHO Expert Committee on Diabetes Mellitus.* Technical Report Series 646. Geneva: WHO, 1980.

22 Marble D, Krall LP, Bradley RF, Christlieb PR, Soeldner JS, eds. Diagnosis and classification of diabetes mellitus and the non-diabetic meliturias. In: *Joslin's diabetes mellitus.* 12th ed. Philadelphia: Lea and Febiger, 1985:339–40.

23 Reenders K, de Nobel E, van den Hoogen HJM, Rutten GEHM, van Weel C. Diabetes and its long-term complications in general practice: a survey in a well-defined population. *Fam Pract* 1993;10:169–72.

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: Eramus University Rotterdam, 1989. (Thesis) [Summary in English].

25 Patchett P, Roberts D. Diabetic patients who do not have diabetes: investigation of register of diabetic patients in general practice. *BMJ* 1994;308:1225–6.