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Refereed paper

Identification of patients with neuropathic pain using electronic primary care records

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ABSTRACT

Background Chronic neuropathic pain is a common condition which is challenging to treat. Many people with neuropathic pain are managed in the community, so primary care records may allow more appropriate subjects to be recruited for clinical studies.

Objective We investigated whether primary care records can be used to identify patients with diseases associated with neuropathic pain.

Method We analysed demographic, diagnostic and prescribing data from over 100 000 primary care electronic patient records in one part of London, UK.

Results The prevalence of diagnoses associated with chronic neuropathic pain was 13 per 1000, with the elderly, women and white patients experiencing the greatest burden of disease.

Conclusion Computerised health records offer an excellent opportunity to improve the identification of patients for clinical research in complex conditions like chronic neuropathic pain. To make full use of data from these records, standardisation of clinical coding and consensus on diagnostic criteria are needed.

Keywords: clinical research, electronic health record, 'medical records systems, computerised', neuralgia, neuropathic pain, prevalence, primary care, treatment

Where this study fits in
- Research into chronic neuropathic pain has mainly involved patients in secondary care.
- Many people with chronic neuropathic pain are managed in the community.
- We demonstrate how information about chronic neuropathic pain and its management can be derived from primary care records.

What this paper adds
- Electronic primary care records are a useful resource for studying chronic neuropathic pain.
- In our diverse population, the prevalence of diagnoses associated with chronic neuropathic pain was 13 in 1000.
- There may be ethnic differences in the epidemiology of neuropathic pain.

Introduction

Neuropathic pain arises 'as a direct consequence of a lesion or disease affecting the somato-sensory system'.[1] It is common and debilitating, with significant societal impact.[2] Despite the availability of efficacious treatments, chronic neuropathic pain remains a challenge to manage.[3]

Most studies of neuropathic pain have taken place in patients referred to secondary care, or in diagnostic subsets.[4] However, as with other chronic conditions, diagnosis and management increasingly occurs in the community. Community prevalence estimates vary from 3.3%[5] to 17.9%[6–8] depending on the methodology, disease subset and population studied, but the overall prevalence among patients presenting to general practice is unknown.[4] Outlining the prevalence of a condition can encourage research into diagnosis and management.[6]

Most general practices in the UK now have computerised medical record systems. These include extensive longitudinal information on diagnoses, physical measurements, investigations, prescriptions and referrals. These records have mainly been used to study conditions such as coronary heart disease, diabetes, hypertension and epilepsy. Despite being complex, multisystem disorders, their indicators tend to be well-recorded. This may be in part due to the financial incentives in the Quality and Outcomes Framework[9] and also because they are better understood and classified, with well-defined coding in electronic patient records.

Electronic primary care records can be used to improve clinical management and research in chronic disease.[10,11] We aimed to determine the feasibility of using primary care records to identify patients with neuropathic pain, and to describe how such patients are managed pharmacologically in primary care.

Methods

Identification of patients with neuropathic pain

Brent is a West London urban area with 55% of its population from non-native ethnic groups.[12,13] The population of Brent is younger and has higher levels of unemployment than the rest of England. Twenty-six of 79 general practitioner (GP) practices in the London Borough of Brent contribute automatically extracted, standardised electronic patient records to a central database. Data from three general practices were not suitable for analysis, leaving data from 23 general practices with a registered population of over 100 000 patients.

Data include demographic and clinical information using READ coding, which is the clinical classification system used in UK primary care.[14] The information extracted from the electronic records allowed patient-level analyses by age, sex and ethnicity. Data were extracted for the 2007 calendar year. The dataset consisted of data files for each of the READ code 5-byte (version 2) chapters A–Z, with additional data files for ethnicity coding and general practice details. Each consultation record contained details of the practice number, local patient identification number, READ code, a 30-character description of the consultation, the date of consultation, and age and sex of patient.

We identified READ code terms for conditions associated with neuropathic pain (Appendix 1) and searched the database for every patient with one or more of those codes in their records. We also extracted records of medications prescribed for these patients.

Data analysis

We examined the prevalence of neuropathic pain diagnoses recorded under various READ code terms, by age, sex, ethnicity, practice and selected co-morbidities.

We also explored the proportion of patients taking various analgesics and how this varied by age, sex, ethnicity and diagnostic group (because the recommended drug class depends on the underlying condition[15]). Data were analysed using Microsoft Excel 2007 and Stata Version 10.

Results

The age–sex distribution of the patients in the database was similar to that of Brent and London. Ethnicity was recorded for 49% of patients; the ethnic distribution reflected the Brent population accurately.

Prevalence of disorders likely to be associated with neuropathic pain

Of the 105 877 patients with valid age and sex data, 1390 had at least one neuropathic pain-associated diagnosis; an overall prevalence of about 13 per 1000 patients. There were 33 separate terms used for neuropathic pain-associated disorders; the most common terms were herpes zoster and its subcodes (Table 1). The majority of codes were recorded for the elderly and women (Table 2). Prevalence varied by ethnicity, with the highest prevalence in white patients (Figure 1).

The number of patients with a diagnosis likely to be associated with neuropathic pain varied between practices, from 1 to 205 (median = 34, interquartile range = 20–71). Recorded prevalence varied from 1.8 per 1000 to 39.6 per 1000 patients. Five hundred and seventy-four (44%) patients had one or more of the following co-morbidities: asthma, atrial fibrillation, coronary heart disease, cerebrovascular disease, depression, hypertension, heart failure or osteoporosis.

Prescribing analysis

In total, 1089 patients (86%) had been prescribed at least one drug used for neuropathic pain since their diagnosis. This suggests that most of the identified patients therefore had some degree of pain. When we examined medication use by diagnostic group, over

Table 1 Number of patients by READ code term

Condition	Number of patients	Condition	Number of patients
Acute painful diab neuropathy	1	Herpes zoster + oth.CNS complic.	2
Asymptomatic diab neuropathy	26	Herpes zoster + other CNS compl.	70
Cerv disc disord + radiculopathy	2	Herpes zoster + other spec comp	2
Chron painful diab neuropathy	13	Lu disc prolapse + radiculopathy	31
Cx disc prolapse + radiculopathy	3	Nerve/spinal cord injuries	2
Disc prolapse + radiculopathy	1	Ophthalmic herpes zoster infec	11
Geniculate herpes zoster	9	Polyneuropathy	7
Glossopharyngeal neuralgia	2	Polyneuropathy in diabetes	76
Heredit.periph.neuropathy NOS	1	Polyneuropathy + herpes zoster	1
Herpes zost. dermatitis eyelid	1	Postinfectious polyneuritis	1
Herpes zoster	895	Postzoster neuralgia	24
Herpes zoster + unsp. complic.	2	Th disc prolapse + radiculopathy	1
Herpes zoster NOS	88	Trigeminal neuralgia NOS	44
Herpes zoster iridocyclitis	3	Trigeminal neuralgia OS	3
Herpes zoster keratoconjunctiv	4	Zoster encephalitis	1
Herpes zoster ophthalmicus	16	Other chronic pain	30
Herpes zoster + ophthalmic comp.	17		

Table 2 Number of patients with READ codes associated with neuropathic pain by age group and sex, and prevalence per 1000

Age group (years)	Total no. patients	Males	Females	Prevalence per 1000
0–14	31	20	11	0.18
15–24	69	33	36	0.50
25–34	87	44	43	0.38
35–44	109	56	53	0.60
45–54	165	68	97	1.24
55–64	261	125	136	2.88
65–74	265	126	139	4.06
75 +	274	114	160	5.35

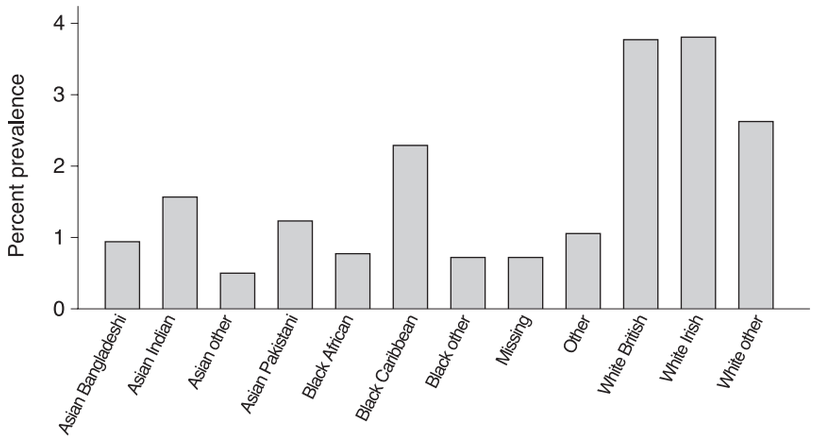

Figure 1 Prevalence of pain-associated codes by ethnic group

Table 3 Patients on medication by diagnostic group

Diagnostic group	Number of patients	Number (%) on any drug from List A	Number (%) on any drug from List B
Herpes zoster	1038	328 (31.6)	816 (78.6)
Diabetic neuropathy	109	46 (42.6)	97 (89.8)

30% of patients in these groups received a medication from List A, considered more appropriate for neuropathic pain (Table 3).

Discussion

Principal findings

This study showed that patients with a diagnosis likely to be associated with chronic neuropathic pain can be identified using electronic primary care records. How-

ever, there was marked interpractice variation in coding; this mirrors findings in studies of other chronic conditions.[16]

Implications for practice

Case findings can be used to help meet national recommendations for the management of neuropathic pain[17] through planned care, reviews and clinical audit.[10,11] Records can also be used to identify people with neuropathic pain for use in service planning, provision and research.

Interpractice variation suggests under-recording of diagnoses, which will become more important as the prevalence of neuropathic pain is expected to increase because of an ageing population.[18] Hence, further epidemiological, clinical and therapeutic studies will be needed. Primary care records provide a unique opportunity for such population-based research because they cover a large population, are representative because of the high degree of registration with GPs in the UK, and in some practices provide near-complete information on illness, treatments, outcomes and use of healthcare services.[19]

Comparison with other studies

Prior surveys found prevalences of 3.3%[5] and 8.2%[8] in their populations. Toth *et al*[6] report a 17.9% prevalence in a telephone survey of 1207 randomly sampled Canadians. This figure was higher than our and previous studies, and may be explained by their use of DN4Q, a validated questionnaire for chronic pain with neuropathic symptoms. However, it has proved difficult to obtain representative samples in surveys, for example because participants self-select or were chosen for convenience.

Hall used the UK General Practice Research Database to calculate the incidence of four syndromes associated with chronic neuropathic pain.[4] Our study suggests that the prevalence could be calculated in this way too, albeit with a wider range of search terms. In line with our findings, each of these previous studies also found the highest prevalence of chronic neuropathic pain in older patients and women.

Limitations of the study

This was a cross-sectional study in an ethnically diverse, urban area. Although the sample was representative of the area, different rates might be expected in other settings. The search terms did not include phantom limb pain but the incidence is about 1.5 per 100 000 person years, suggesting that this diagnosis would be too uncommon to pick up in our sample.[4] We also did not include carpal tunnel syndrome as the treatment approach usually differs from other neuropathic pain syndromes. Other conditions omitted include chemotherapy induced neuropathy, complex regional pain syndrome, HIV sensory neuropathy, neuropathy secondary to tumour infiltration, post-mastectomy pain and chronic painful neuropathies due to central nervous system conditions such as following stroke, spinal cord injury, multiple sclerosis and Parkinson's disease.

We did not control for medication use for alternative indications, for example, patients taking amitriptyline for depression rather than pain. However, depression is a common co-morbidity with neuropathic pain. Similarly, future searches should incorporate measures to account for anticonvulsants that were not prescribed for pain management.

Although database searches do not identify subjects who have not presented to the medical system, the severe symptoms and effect on quality of life make it likely that patients would be known to primary care, especially in the UK where many of the treatments are available only on prescription.

Further research

If practices maintain a neuropathic pain disease register, further work can compare the identification rates with control practices and estimate the deficit in prevalence. More patients may also be identified if medication records[20] and other non-diagnostic data[21] are used in the search strategy.

Electronic primary care records could also be used to analyse the longitudinal treatment history of individuals with neuropathic pain to examine, for example, how long patients are on suboptimal treatment before a beneficial drug or combination is found. Even patients taking an effective class of drug are often given suboptimal doses;[3] an analysis could be constructed to investigate this in UK primary care. Longitudinal primary care records will also be valuable in studies exploring the longer term outcomes of neuropathic pain, particularly the psychosocial sequelae which are currently less well delineated.

The NHS Care Records Service use the Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT) instead of READ codes.[22] SNOMED CT codes map to definitions more accurately in other chronic conditions such as diabetes.[23] When primary care records are uploaded to the Care Records Service, it would be interesting to see if any additional subjects are captured using these codes from the same population. In Europe, the main primary care

coding system is the International Classification of Primary Care (ICPC).[24] This could be used to compare rates of neuropathic pain in similar populations and suggest genetic or environmental trends; it may also have implications for future coding software choices in the UK.

Conclusion

The study illustrates that data from electronic primary care records can be used to study neuropathic pain in a wider population than in previous studies. We have shown that to make full use of this valuable resource, we need to improve the completeness and standardisation of coding in primary care records.

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ETHICAL APPROVAL

The Brent Local Research Ethics Committee approved the use of anonymised patient-level data from the database (REC Reference Number 08/H0717/46).

CONFLICTS OF INTEREST

This study was funded by Pfizer. KT and MF were employees of Pfizer when this project was carried out.

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Appendices

Appendix 1 READ codes used and their text labels

READ Term	READ Code	READ Term	READ Code
Acute painful diab neuropathy	F3720	Herpes zoster + oth.CNS complic.	A5310
Asymptomatic diab neuropathy	F3722	Herpes zoster + other CNS compl.	A531.
Cerv disc disord + radiculopathy	N12zH	Herpes zoster + other spec comp	A53x.
Chron painful diab neuropathy	F3721	Lu disc prolapse + radiculopathy	N12C2
Cx disc prolapse + radiculopathy	N12C0	Nerve/spinal cord injuries	SJ...
Disc prolapse + radiculopathy	N12C.	Ophthalmic herpes zoster infec	A5323
Geniculate herpes zoster	A5311	Polyneuropathy	F366.
Glossopharyngeal neuralgia	F321.	Polyneuropathy in diabetes	F372.
Heredit.periph.neuropathy NOS	F360z	Polyneuropathy + herpes zoster	F3744
Herpes zost. dermatitis eyelid	A5320	Postinfectious polyneuritis	F3701
Herpes zoster	A53..	Postzoster neuralgia	A5315
Herpes zoster + unsp. complic.	A53y.	Th disc prolapse + radiculopathy	N12C1
Herpes zoster NOS	A53z.	Trigeminal neuralgia NOS	F301z
Herpes zoster iridocyclitis	A5322	Trigeminal neuralgia OS	F301.
Herpes zoster keratoconjunctiv	A5321	Zoster encephalitis	A5314
Herpes zoster ophthalmicus	A5324	[X]Other chronic pain	Ryu70
Herpes zoster + ophthalmic comp.	A532.		

Appendix 2A Medications used for all prescription analyses except those shown in Table 2

Amitriptyline, Aspirin, Nefopam, Benolirate, Buprenorphine, BuTrans, Capsaicin, Carbamazepine Celebrex, Co-codamol, Co-codaprin, Co-proxamol, Co-dydramol, Codeine, Dextromoramide, Diconal, Diclofenac, Dihydrocodeine, Emflex, Fentanyl, Meptid, Methadone, Morphgesic, MXL, Oramorph, Oxcarbazepine, Oxycontin, Oxynorm, Papaveretum, Pentazocine, Pethidine, Preservex, Rheumox, Seractil, MST, Oxycodone, Gabapentin, Pregabalin, Paracetamol, Palladone, Sevredol, Temgesic, Tramadol, Transtec, Trileptal, Zomorph.

Appendix 2B Medications used in analysis presented in Table 2

List A medications

Amitriptyline, Buprenorphine, Bu Trans, Capsaicin, Carbamazepine, Cymbalta, Duragesic Duloxetine, Fentanyl, Gabapentin, Lidocaine, Lyrica, Morphine, Morphgesic, MST, MXL, Neurontin, Nortriptyline, Oxcarbamazepine, Oxycodone, Oxycontin, Oxynorm, Oromorph, Pregabalin, Sevredol, Temgesic, Versatis, Tramadol, Zomorph.

List B medications – all drugs in list A plus

Aspirin, Benolirate, Celebrex, Co-codamol, Co-codaprin, Co-proxamol, Co-dydramol, Codeine, Dextromoramide, Diconal, Diclofenac, Dihydrocodeine, Emflex, Meptid, Methadone, Nefopam, Papaveretum, Pentazocine, Pethidine, Paracetamol, Palladone, Preservex, Rheumox, Seractil, Transtec.