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’, neur- algia, neuropathic pain, prevalence, primary care, treatment
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 occur 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

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.

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.

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.

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.

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\textsuperscript{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>
<thead>
<tr>
<th>Condition</th>
<th>Number of patients</th>
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<tr>
<td>Acute painful diab neuropathy</td>
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<td>26</td>
</tr>
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<td>Cerv disc disord + radiculopathy</td>
<td>2</td>
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<tr>
<td>Chron painful diab neuropathy</td>
<td>13</td>
</tr>
<tr>
<td>Cx disc prolapse + radiculopathy</td>
<td>3</td>
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<td>9</td>
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<tr>
<td>Glossopharyngeal neuralgia</td>
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<tr>
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<td>Herpes zoster + other CNS compl.</td>
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<td>Lu disc prolapse + radiculopathy</td>
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<td>Nerve/spinal cord injures</td>
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<td>Polyneuropathy in diabetes</td>
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<td>44</td>
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<td>Zoster encephalitis</td>
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</tr>
<tr>
<td>Other chronic pain</td>
<td>30</td>
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</table>
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 pain17 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 al6 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 neuromas 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 records20 and other non-diagnostic data21 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; 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). 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.

ACKNOWLEDGEMENTS

We thank the 26 general practices that participated in the study, and Mike Sievwright and the NHS Brent database team for their help.

REFERENCES


FUNDING

Financial support for this analysis of data from the database was provided by Pfizer. The Applied Research Unit is a part of the Public Health Department
within NHS Brent, which also funds the database. Imperial College London is grateful for support from the National Institute for Health Research Biomedical Research Centre scheme; and the National Institute for Health Research Collaboration for Leadership in Applied Health Research & Care scheme. We are also grateful for past support from the Medical Research Council and the Engineering and Physical Sciences Research Council. The views expressed in this article are those of the authors.

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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Accepted September 2011

Appendices

Appendix 1 READ codes used and their text labels

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<th>READ Term</th>
<th>READ Code</th>
<th>READ Term</th>
<th>READ Code</th>
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</tr>
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<td>Nerve/spinal cord injuries</td>
<td>SJ...</td>
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<td>F366</td>
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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.