Towards the Development of Integrated Epilepsy Services: An Audit of Documented Epilepsy Care

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Abstract

Effective chronic disease management (CDM) requires the ready availability and communication of accurate, clinical disease specific information. Using epilepsy as a probe into CDM, we report on the availability and reliability of clinical information in the primary care records of people with epilepsy (PWE). The medical records of 374 PWE from 53 general practices in the Mid-West region of Ireland were examined. Confirmation of an epilepsy diagnosis by a neurologist was documented for 132 (35%) patients. 262 (71%) patients had no documented evidence of receiving specialist neurology review while 149 (40%) had not been reviewed by their GP in the previous two years for their epilepsy. Significant variation in documentation of epilepsy specific information together with an inadequacy and inconsistency of existing epilepsy services was highlighted.

Introduction

In common with many countries, gaps in quality and safety together with spiralling costs are driving a programme of health service reform in Ireland. Chronic disease management (CDM) is a key reform priority aimed to enhance health service outcomes. The existence of commissioning, illness experience, improved health outcomes and cost-effectiveness are facilitators to sharing and exchanging clinical information across traditional organisational boundaries could be explored. In addition, the study would reveal if the data to assess quality of epilepsy care delivered by GPs is readily available in current healthcare records.

Electronic patient records (EPR) have been recognised as key to supporting healthcare transformation. Traditional paper record, EPRs can improve the quality, safety and efficiency of healthcare processes and delivery. Such an EPR has been implemented by the Epilepsy Programme at Beaumont Hospital and is having a positive effect on the care of PWE. Being web-based, the epilepsy EPR has the potential to support a national network of epilepsy care. By providing access to authorised clinicians beyond Beaumont Hospital it can become a central hub that facilitates integration of services both within and across healthcare agencies. As the majority of GP practices in Ireland are computerised, there is potential to facilitate this integration by interfacing GP IT systems with the epilepsy EPR. A first step in configuring the epilepsy EPR to support a national network of care is to assess the readiness of existing clinical IT systems to adopt the technology. Therefore the purpose of this study was to examine the nature of information documented in the primary care records of PWE. By examining what GPs record about PWE, barriers and facilitators to sharing and exchanging clinical information across traditional organisational boundaries could be explored. In addition, the study would reveal if the data to assess quality of epilepsy care delivered by GPs is readily available in current healthcare records.

Methods

The study was conducted in the Mid-West region of Ireland which includes Limerick city and County, Clare, and North Tipperary (population approximately 361,000). Until the appointment of a consultant neurologist to the region approximately two years ago, neurology services were totally inadequate and there was no specialist epilepsy care available in the Mid-West. All registered GPs in the Mid-West region of Ireland (n=215) received a written invitation to participate in the study. Under the supervision of a senior GP with a special interest in epilepsy care, four trainee GPs audited the records of PWE at participating practices using a pre-designed proforma specific to epilepsy. The research ethics committee of the ICGP approved the study.

Results

Profile of participating general practitioners

Of the invited participants (n=215), fifty-three (25%) agreed to participate. Sixty-five invited GPs (30%) declined to participate while ninety-seven GPs (45%) did not respond to the letters of invitation. In total, thirty-six GP practices were visited due to time constraints, and a swine flu outbreak restricting non-essential visits to GPs. Participating practices were mid-sized (58%), urban (52%) and computerised (76%). GPs did not maintain an epilepsy register (92%) or integrate an automatic recall system for PWE (94%).

Profile of audited records

The primary care records of 374 PWE were audited. While gender was evenly distributed, the majority (85%) were greater than 26 years of age and were registered General Medical Scheme (GMS) patients. A majority did not have their occupation (57%), use of alcohol (51%) or tobacco (53%) documented.

Documentation of epilepsy information

Table 1 summarises the documented epilepsy information. First seizure activity was well documented (87%) however, seizure frequency, classification and aetiology were not consistently recorded (Table 1). 242 patients (68%) had their epilepsy diagnosis confirmed by various health professionals or had no documented record of where or by whom the diagnosis originated. A diagnosis confirmed by a neurologist was documented for 132 patients (35%). Epilepsy specific information relating to tests and investigations were not documented for over half the PWE (Table 1).

Documentation evidence of integrated epilepsy care

Over 70% of patients had not received a neurology review within the past 2 years nor was there evidence of their care being coordinated with specialist epilepsy services. Information specific to patient compliance with advised treatment regime and/or life-style modifications was infrequently documented (Table 2).

Documentation of Anti-epileptic Drugs (AEDs)

The majority of patients (92%) were taking at least one, while 145 (43%) were taking two or more AEDs. The most commonly prescribed AEDs included Carbamazepine, Valproate Chronic, Valproate and Lamotrigine. Documentation relating to Buccal Midazolam use and/or information regarding prior AED efficacy was rarely available. 82 (22%) patients were women of childbearing age (16-50 years) with 33 (44%) currently taking Valproate. Information specific to epilepsy care during pregnancy was unavailable (66%) as was evidence of integrated neurology review (76%).
Discussion
This study provides insight into the availability of data to support optimal management of chronic disease in primary care in Ireland. It revealed a disturbing lack of data recorded in the primary care records of PWE. It is clear that without proper resources and adequate access to secondary care services GPs have great difficulty delivering and appropriately documenting the delivery of the desired standards of care. Furthermore, this has considerable consequences for establishing and implementing interoperable health record systems designed to share and exchange the clinical information required to support integrated, high quality patient care. A dependable description of the frequency and nature of epilepsy patient review by GPs could not be established by this audit suggesting that interaction between Irish GPs and PWE is reactive and unplanned. Best practice guidelines for the care of PWE recommend regular planned patient review while on long-term AED therapy to assess seizure control in response to medication, side-effects or any adverse events. However, the implication from this evaluation is that AED prescription renewal, which may take place twice or three times a year, occurs without clinical assessment by the GP. Proactive primary care for PWE is not currently the norm in Ireland.

Inconsistency in the documentation of clinical information in the healthcare records of PWE demonstrated in this study must impact on quality of care. The adoption of electronic records like the epilepsy EPR can facilitate improvements in information quality, and its sharing and exchange between primary care and specialist services. EPRs can enhance care by providing standardised templates that prompt clinicians to ask appropriate clinical questions and store the required information. Additionally, they can support enhanced communication between healthcare providers thus improving continuity and standardisation of care.

Some limitations to this study are acknowledged. For example, a sampling bias may have occurred as participating practices self-selected and others declined or ignored the invitation (69%). Respondents may have a greater than average interest in epilepsy and are keen to gain insight and/or develop knowledge on how to better manage PWE. Nevertheless the number together with the balance between urban and rural practices means that the study sample is reflective of the general population of GPs in Ireland. This study provides insight into the management of chronic disease within the primary care sector in Ireland. It indicates that primary care services for PWE in Ireland are lacking. The highlighted problems of poor clinical documentation are not exclusive to epilepsy nor to primary care services. Within the effort to reform CDM in Ireland exists an opportunity to improve clinical information management that can support quality and safety of patient care as well as delivery of cost effective health services. Information technology is a powerful tool waiting to be exploited in this campaign.

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