Importance of GPs for people with epilepsy

A personal view

Dr Jon Dickson, a GP from Sheffield, provides a personal view of the role of GPs in the healthcare management of people with epilepsy. He describes how GPs and epilepsy specialists can work together to improve the care people with epilepsy receive

General practice is the largest medical speciality in the UK. There are 37,000 general practitioners (GPs) (full-time equivalents) and 7,875 general practices in the National Health Service (NHS) in England [Powell and Parkin, 2016; The Kind's Fund, 2016]. The majority of medical consultations in the NHS take place in general practice and nearly everybody in the UK is registered with their local NHS GP. General practice is an essential part of good quality care for people with epilepsy but its role in their care is ambiguous. Epilepsy is complex and there are very few educational materials or training courses for GPs. Many GPs do not feel confident or competent in managing many aspects of epilepsy care. This adversely affects people with epilepsy who may find that their GP is unable to provide the care that they need and that epilepsy services are difficult to access [Dickson et al, 2012].

General practice (also known as family practice internationally) is difficult to define precisely. It means different things in different contexts (nationally and internationally). General practice has been at the heart of the NHS in the UK since its inception in 1948. General practices are not NHS organisations but they are independent contractors to the NHS. The traditional NHS general practice was led by one or more GP partners who owned the premises and ran the business. This is still the *modus operandi* for most general practice but the team of people delivering medical care within the practice has grown especially over the last 10 years. It now includes managers, nurses, pharmacists, paramedics, midwives and physiotherapists. Other recent changes include the number of GPs who are salaried members of staff in a practice rather than partners. They also include the number of GPs working outside traditional general practice in diverse settings such as primary or urgent care centres, hospitals and ambulance services.

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GPs are expert medical generalists [Reeve and Byng, 2017; RCGP, 2012]. The specialism of general practice is not defined by detailed knowledge of, for example, neurology or dermatology, but by focus on the individual patient – the person. The relationship between the individual patient and the doctor is at the heart of general practice and it is based on trust. The commitment of the GP to the individual is maintained regardless of the disease(s) they are affected by. General practice is characterised by proximity to the patients' home, accessibility (available when required without delay) and continuity (provided over many years, often a lifetime). It also places emphasis on context (housing, relationships, employment) and on the wider determinants of health such as smoking, exercise, alcohol and air pollution. It encourages self-care, autonomy, healthy living and primary prevention (immunisation, screening and drug treatment).

Jon Dickson

"Generalist knowledge is characterised by a perspective on the whole rather than the parts, on relationships and processes rather than components and facts; and on judicious, context-specific decisions on how and at what level (individual, family, system) to consider a problem"

Greenhalgh, in McWhinney's Textbook of Family Medicine, 2016, [Freeman, 2016]

GPs use their expertise in assessment, investigation and treatment but they also rely on the expertise of other healthcare professionals (nurses, specialist nurses, consultants etc). They coordinate care from multiple healthcare professionals into a single, coherent and comprehensive package. General practice is the primary point of contact for most healthcare needs for most of most people's lives. General practice is highly valued by patients [Appleby and Robertson, 2016] and it is highly effective [Starfield, 2011; Kringos, 2012]. International evidence shows that national health systems with strong primary care systems are the most effective and the most cost-effective. It also shows that the NHS is one of the best healthcare systems in the world [Davis et al, 2014].

Medicines and multi-morbidity

Most anti-epileptic drugs (AEDs) are initiated by consultants but the responsibility for ongoing prescribing usually rests with GPs. AEDs are complex medicines with diverse and potentially serious side-effects and they have important interactions with other drugs. Adherence to AED regimes is often poor which results in significant loss of efficacy. AEDs are known to have important implications for women of childbearing age, as many interact with contraceptive medications and many can increase the risk of teratogenic effects. Most women go to their GPs for contraceptive advice and for prescribing and fitting of contraceptives such as pills, coils and implants. GPs are often asked to provide pre-conception advice and to assess couples with difficulty conceiving. General practice is also where most community antenatal care is based (led by community midwives).

Ongoing prescribing of AEDs requires an understanding of the indication of the drug, how to assess its effectiveness and side-effects, and how to take appropriate action if the regimen is suboptimal. The British National Formulary (BNF), the resource that most GPs use to guide prescribing, can be unhelpful for AEDs. Dose and titration schedules are often poorly described and do not reflect the standard practice of epilepsy specialists. The BNF describes blood test monitoring for some drugs that is not considered necessary by most specialists. The process of titration of AEDs is time-consuming and titration led by GPs is arguably unfeasible given current workload pressures [The King's Fund, 2016]. Many Clinical Commissioning Groups (CCGs) have traffic light systems to guide GPs as to which drugs are suitable for independent GP prescribing and which require specialist input [The Sheffield Area Prescribing Group, 2018]. Many areas also have shared care protocols (SCP) (care shared between GPs and hospital specialist) to support GPs in this role and to clarify responsibilities between the GP and the specialist. But

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these documents are often long, contain detailed and complex information and are difficult to access during busy clinical sessions. A working knowledge of over 25 commonly used AEDs is a challenge for GPs. This leaves them with clinical, ethical and financial concerns (including the cost of medical indemnity) about taking responsibility for AEDs. In practice, there is concern that many long-term prescriptions of AEDs are infrequently reviewed and under-supervised.

Multi-morbidity refers to the presence of more than one long-term health condition. As the population ages and treatments for previously life-shortening conditions improve, multi-morbidity is becoming increasingly common [Barnett et al, 2012]. The most common long-term conditions are cardio-metabolic disorders (hypertension, diabetes, obesity, ischaemic heart disease), mental illness (most commonly anxiety and depression) and chronic pain [Wallace et al, 2015]. Many people with epilepsy have multiple long-term conditions and many are taking multiple medications which may interact and may have cumulative side-effects.

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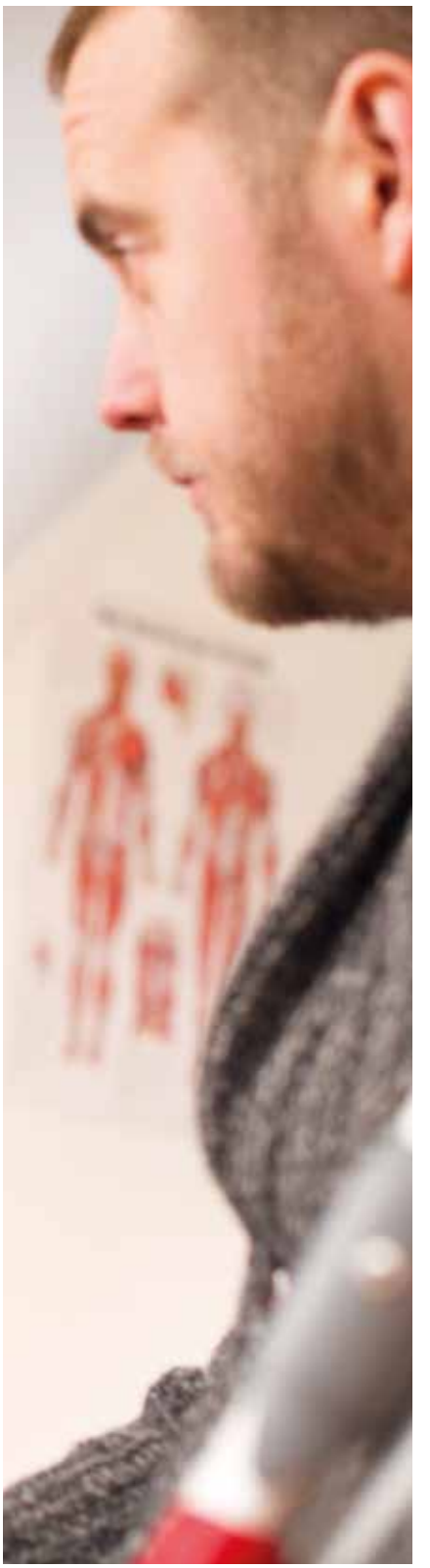
Multi-morbidity affects the majority of elderly patients, many of whom are frail and have conditions which span multiple specialities. Much of the evidence-base underpinning national clinical guidelines comes from populations who are not representative of patients with multi-morbidity. The guidelines, therefore, have limited and often unknown applicability for these patients. The impact of care from specialists who focus their interventions on a single body system is limited and the role of the medical generalist comes to the fore. It includes synthesising multiple health problems into a single formulation, deviating from clinical guidelines in the best interest of the individual and focussing on care of the person not the disease. Providing responsive care close to home, including within the patients' homes, is of special importance in people who are elderly and frail, disabled or socially isolated.

Mental illness is one of the most common long-term conditions and it is a common comorbidity among people with epilepsy. Mental illness requires a holistic approach to treatment, including regular follow-ups, an intimate knowledge of the patient, and a combination of psychological and medical treatment. GPs manage the majority of mental illness in the NHS, especially depression and anxiety. They therefore have a crucial role in the treatment of patients with epilepsy who have these conditions.

Quality Outcomes Framework

The Quality Outcomes Framework (QOF) was introduced in general practice in the NHS in England in 2004 at the same time as the new GMS (General Medical Services) contract. It remains the key framework for providing standards and remuneration for the assessment and management of chronic diseases in general practice. NICE has been responsible for advising NHS employers on QOF since 2009. In 2004, epilepsy was one of the diseases included in QOF.



"If general practice fails, the whole NHS fails"

Roland and Everington, 2016, BMJ

Practices were expected to focus on four epilepsy 'indicators':

1. Maintain a register of patients with epilepsy
2. Review their seizure frequency
3. Record seizure freedom (yes/no)
4. Provide conception, contraception and pregnancy advice to all women of childbearing age

No comprehensive studies were ever conducted on the effect of the epilepsy QOF indicators on patient care. There is evidence that rates of annual review for people with epilepsy increased from less than 20% to over 90%, which seems positive. But there was scepticism among GPs that they had the time, knowledge and skills to make the required reviews meaningful [Minshall and Neligan, 2014]. Epilepsy was removed from QOF (except the requirement to keep a disease register for epilepsy) in 2014. Without a national strategy to replace it, this seems to signal relegation of epilepsy in the priorities of the NHS which has caused concern among people with epilepsy and their advocates.

Garekeepers

General practice is a high-capacity speciality. Small changes in the proportion of general practice consultations which result in referral to secondary or tertiary care can quickly overwhelm the lower capacity secondary or tertiary specialities. The role of GPs as 'gatekeepers' to secondary and tertiary care is therefore very important for the effectiveness and efficiency of the NHS. The majority of new referrals to specialised epilepsy clinics come from GPs but this is the tip of the iceberg. Most healthcare needs of people with epilepsy are optimally managed exclusively in general practice. When problems arise that cannot be managed in general practice the input of specialists is required. Traditionally, this has been through out-patient appointments but arguably these appointment systems are inflexible and focussed on hospital processes rather than the needs of patients. Telephone advice by way of a single short phone call may be all that is required. But this is often not available and an appointment in an out-patient clinic weeks or months away is the only option.

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Syncope with brief convulsions is a common reason for referrals from general practice to neurology and epilepsy clinics. NICE provides clear guidance on the assessment of transient loss of consciousness (TLOC). It states that specialist input is not usually required for '…people with a firm diagnosis… of uncomplicated faint, situational syncope, orthostatic hypotension.' But within the constraints of a 10-minute GP appointment, with limited training and expertise and without access to telephone advice, GPs often feel the need for referral to specialist clinics.

In contrast to many chronic diseases such as asthma, COPD and diabetes, very few general practices have a GP with a Special Interest (GPwSI) in epilepsy. The British Chapter of the ILAE has a GP Society which meets regularly but there are less than 30 members who regularly attend. There are specific challenges for GPs who may be inclined to developing epilepsy as a special interest:

- Epilepsy has a lower prevalence than most of the chronic diseases which GPs tend to focus on (which are often part of QOF)
- The lack of an objective biomarker for active epilepsy and seizures is problematic
- Key investigations such as MRI and EEG have traditionally not been available to GPs

None of these are insurmountable but to develop a significant workforce of GPwSIs in epilepsy would require a multi-faceted approach involving multiple organisations. A competency framework for GPwSIs in epilepsy has been published [Epilepsy GPwSI Stakeholder Group, 2007]. But, in contrast to GPwSIs in dermatology, this was never followed-up with measures to support GPs developing epilepsy as a special interest. These could include

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an accredited training programme, the opportunity for GP supervision or mentoring by epilepsy specialists, and endorsement or investment in the role by commissioners and other stakeholders.

Conclusions

Over many decades, multiple reports by clinicians, politicians and charities have highlighted variability in the quality of care for people with epilepsy and significant deficiencies in many geographical regions in the UK [Dickson et al, 2015]. Unfortunately, many of the problems highlighted over 30 years ago still persist today. Among epilepsy specialists, one detects a frustration about the perceived disengagement of GPs. In general practice, one feels that there is a fatalism about lack of access to specialist services, long waits for appointments, and sub-optimal outcomes for people with epilepsy. None of the problems are insoluble but the solutions require closer working between general practice and epilepsy services. This will require sustained effort and the support of politicians, local healthcare leaders and third sector organisations.

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"Knowing is not enough; we must apply. Wishing is not enough; we must do."

Johann Von Goethe

Epilepsy Action offers a training course for primary care nurses. For more information, visit: *epilepsy.org.uk/training/primary-care-nurses*

Further reading

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