**Epilepsy in Ireland: towards the primary – tertiary care continuum**

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**Abstract**

**Background:** Epilepsy is a chronic neurological disease affecting people of every age, gender, race and socio-economic background. The diagnosis and optimal management relies on contribution from a number of healthcare disciplines in a variety of healthcare settings.

**Objective:** To explore the interface between primary care and specialist epilepsy services in Ireland.

**Methods:** Using appreciative inquiry, focus groups were held withhealthcare professionals (n=33) from both primary and tertiary epilepsy specialist services in Ireland.

**Results:** There are significant challenges to delivering a consistent high standard of epilepsy care in Ireland. The barriers that were identified are: the stigma of epilepsy, unequal access to care services, insufficient human resources, unclear communication

between primary-tertiary services and lack of knowledge. Improving the management of people with epilepsy requires reconfiguration of the primary-tertiary interface and establishing clearly defined roles and formalised clinical pathways. Such initiatives require resources in the form of further education and training and increased usage of information communication technology (ICT).

**Conclusion:** Epilepsy services across the primary–tertiary interface can be significantly enhanced through the implementation of a shared model of care underpinned by an electronic patient record system (EPR) and information communication technology (ICT). Better chronic disease management has the potential to halt the progression of epilepsy with ensuing benefits for patients and the healthcare system.

**Keywords:** epilepsy, primary care, tertiary care, shared care, electronic patient record

**Introduction:**

Chronic illness is a key feature in the pattern of health for children and adults today because of advances in medical science and technology, medical and nursing care and improved socio-economic conditions. Such advances in medical science have led to improvements in health outcomes and a greater life-expectancy associated with many chronic diseases. It has also led to considerable increases in diagnostic and therapeutic complexity and a consequent additional strain on health care systems. Current models of health service delivery are struggling to meet the existing demand of chronic disease management and are unlikely to cope with demand in the future unless services are reconfigured [1]. To maximise the benefits of medical science advances for the patient while minimising the burden on healthcare systems, there is an international move to transform the way chronic disease is managed [2-6]. Among the recommendations of chronic disease management models is a call for a shared care model that is integrated across organisational boundaries [7] and supported with information communication technology (ICT) [8-10].

Epilepsy is a common chronic neurological disease which affects people of every age, gender, race and socioeconomic background. Characterised by the occurrence of recurrent unprovoked seizures, its prevalence is estimated at between 4.5 and 8 per 1000 [11]. Hence epilepsy is recognised as a major chronic disabling condition with consequent burden on the healthcare system and individuals. There are many different types of epilepsy and its diagnosis and optimal management relies on integration of clinical data from a number of healthcare disciplines in a variety of healthcare settings e.g. community based general practice, secondary and tertiary care. The patient's active participation in managing their condition is important in achieving a good health outcome. The goal of treatment is a reduction or elimination of seizures to enable individuals to lead as productive a life as possible, without significant side effects of therapy. Best practice guidelines for the management of epilepsy make many recommendations regarding the nature and timing of diagnostic and therapeutic intervention [12,13]. For example, the NICE guidelines advise that ‘all people with epilepsy should have a comprehensive care plan that is agreed between the individual, family and/or carers where appropriate, and primary care and secondary care providers. This should include lifestyle issues as well as medical issues’. However, the current fragmented nature of healthcare systems poses a significant barrier to the effective implementation of these recommendations as seen by reports of inconsistent/uncoordinated care, conflicting advice, delays in diagnosis and treatment, and inappropriate investigations [9].

In Ireland the general practitioner (GP) in primary care is normally the first point of contact for people requiring health services. If required the GP will refer the patient to a consultant doctor at the local hospital for secondary care who in turn may refer the patient to a medical specialist in either the same or a different institution for tertiary care. There is no formally recognised expert epilepsy institution and specialist epilepsy care is incorporated into general neurology. However, as it is the only centre in Ireland offering surgical treatment for epilepsy, Beaumont Hospital in Dublin is the main referral centre for complex epilepsy. While a number of Irish neurologists have specialist epilepsy training, this capacity is not fully exploited as expert epileptologists are obliged to also provide general neurology services. Furthermore, an accident of geography means that for some of the population the local hospital includes neurology (with or without epilepsy) services while for others there is no local neurology service. As a consequence there is often no clear distinction between secondary and tertiary care and the number of times people with epilepsy must access the system to have their needs addressed varies throughout the country. For the purposes of the study presented below, tertiary care refers to neurology services in Ireland with a special interest and specifically trained personnel in epilepsy.

The “tyranny of the urgent” has resulted in an historical emergence of health systems that respond to the needs of patients with acute conditions better than those with chronic conditions who require on-going care [6,9]. The evidence suggests that effective epilepsy care requires re-shaping of healthcare delivery systems to improve patients’ access to services, increase efficiency and enhance the continuity of care. In recognition of such issues, the Health Research Board (HRB) in Ireland has funded a five year research and development (R&D) programme to examine challenges to epilepsy management in both primary and specialist sectors, and to consider how epilepsy management may be supported by adopting a shared care model. This paper reports on a project which aimed to explore healthcare professionals’ perspectives and experiences of providing epilepsy care for adult patients in Ireland.

**Methods**

To meet the stated aim, there were three objectives:

1. To explore healthcare professionals’ experiences of providing epilepsy care
2. To identify healthcare professionals’ perspectives on the factors that enhance or inhibit the provision of quality epilepsy care
3. To ask healthcare professionals to identify strategies/actions that could address challenges and assist them in their provision of quality epilepsy care.

A descriptive qualitative approach informed by appreciative inquiry was used as the focus was on identifying the issues from professionals’ perspectives without any preconceptions or a ‘blame culture’. There was a need to ensure that participants could talk freely about issues/challenges they encountered on a daily basis in providing epilepsy care. Bringing practitioners together from both primary and specialist services provided rich data as such an event had not occurred before in the epilepsy services in Ireland. Ethical approval to conduct the research was obtained from Beaumont Hospital Ethics (Medical Research) Committee.

***Sampling and recruitment***

Our aim was to enrol information-rich participants who would provide and exchange perspective on a) the role of primary care and b) the role of tertiary care in the management of epilepsy in Ireland. As previously stated, tertiary care in this study refers to neurology services with a special interest in epilepsy care. We also aimed to attract input from Brainwave, The Irish Epilepsy Association, which is the main epilepsy support group for people with epilepsy in Ireland. In this regard the inclusion criteria were to work as one of the following in Ireland:

* a general medical practitioner (GP)
* a general practice nurse working in primary care
* a consultant neurologist with a special interest in epilepsy
* an epilepsy specialist nurse
* patient advocate with Brainwave

It was intended that there would be up to 40 individual participants and that there would be an equal distribution of primary care and tertiary care representatives which would include both doctors and nurses.

Recruitment of primary care participants was facilitated by the Irish College of General Practitioners (ICGP) and the Irish Practice Nurses Association (IPNA). A letter of invitation was provided to the two organisations who in turn forwarded it to their registered members (ICGP membership = 2515; IPNA membership = 451). The letter outlined the research purpose and the format of the planned focus group discussions. Recipients were provided with a form which they were asked to return to the event organisers if they were interested in participating.

A purposive sample of tertiary care representatives was approached and invited to participate. These included consultant neurologists with a special interest in epilepsy and epilepsy specialist nurses. The former were the group of seven consultants from different centres who regularly attend a multidisciplinary epilepsy surgery review meeting at Beaumont Hospital. Epilepsy specialist nurses provided a list of 12 nurses who met the inclusion criteria.

***Focus groups***

It is difficult to organise focus groups with a diverse group of healthcare professionals from different settings due to participants’ clinical commitments. Therefore it was decided to hold a number of concurrent focus groups on a single day. Participants were divided into five groups of six/seven participants so that each group had a mix of healthcare professionals ensuring different perspectives. The focus groups were of 60 minutes duration. Each group was instructed to nominate a time-keeper, a note-keeper and a spokesperson and to discuss the following four topics over 60 minutes: epilepsy care in Ireland; gaps in service provision; challenges to shared care; strategies to meet current challenges. Each group (n=5) was facilitated by a member of the research team which included: one lecturer in health informatics, one lecturer in health policy and management, and three health services researchers. The facilitators’ role was one of active listening and when necessary he/she helped the discussion by introducing additional probing questions [16].

***Analysis***

Data reduction was conducted during the focus group as the note-keeper within each group summarised and manually recorded in bullet point format the issues raised by participants. Following the focus group session a plenary assembly was conducted so that the individual groups could share the key points of their discussion. At the plenary session, feedback from each group was presented by their spokesperson and further discussion was facilitated. A note-keeper for the plenary session summarised and recorded the plenary discussion manually into a word-processor. All the data gathered, from each focus group and at the plenary session, were compared and contrasted to identify major categories which were then collated into three themes.

**Results**

In total 33 individuals (82% of the original target) agreed to participate in the focus groups. Of these 52% represented primary care and included 14 general practitioners and 2 practice nurses and 1 hospital based GP liaison nurse. Thirty-six percent represented the specialist care setting including 5 neurologists/epileptologists, 1 junior hospital doctor, and 6 epilepsy/neurology specialist nurses. The remaining 12% were 3 nurses from learning disability services, and 1 patient advocacy group representative.

Table 1 presents the key themes and categories from the analysis of the focus group data.

***Gaps in epilepsy care in Ireland***

According to participants, patients encounter poor access to epilepsy clinics, and experience lengthy waiting times. It seems that there is a geographic variation in availability and access to epilepsy services leading to considerable inequalities for patients with epilepsy and their families. Similarly, the public or private status of a patient (i.e. those with private health insurance) was perceived as causing inequities. It was thought that patients and families with private health insurance or better financial stability had better and faster access to care. Likewise, there was a perception that more proactive patients and parents manage to get faster access to care and treatment. Participants noted that there is poorer access to adult epilepsy clinics compared to paediatric clinics. At the same time it was noted that the transition from paediatric to adult services required special attention and that there is a need to develop adolescent specific services as epilepsy can be a life-time condition.

In terms of human resources there was general agreement that the current lack of adequate numbers of epilepsy nurse specialists and neurologists with expert training in epilepsy are leading to deficits in epilepsy care in Ireland. Also there is a need for additional clinical and administrative support to facilitate quality care. The concept of “reasonable delay” in waiting time to see a neurologist was discussed. Even when patients manage to see a neurologist, they then encounter difficulty accessing required clinical investigations for their condition.

Poor communication was seen as resulting in deficiencies in advice conveyed to general practitioners (GPs) about their patient after referral to the specialist service. The slow transfer of information between specialist services and primary care, and vice versa, contributes to inadequate communication. Similarly, participants believed that poor follow-up arrangements results in many patients being lost to follow-up after being seen by hospital based service. Non-computerised medical practices were seen as contributing to the gap in communication and transfer of information between services. The potential of electronic communication for exchanging information and advice between healthcare providers was acknowledged. It was suggested that telephone advice provided by specialist epilepsy services could be very useful for GPs.

A lack of knowledge and confidence to manage epilepsy among practitioners at the primary care level was identified. Although participants recognised that international and UK best practice guidelines for epilepsy care exist, they questioned their appropriateness in the Irish context. The lack of Irish guidelines and protocols was considered a drawback. Similarly, patients understanding of, or ability to understand, their epilepsy was considered to impact on care and to sometimes result in unrealistic expectations. Some participants believed that epilepsy remains a taboo subject as many patients feel socially stigmatised. This stigma contributes to epilepsy and its care not being spoken about and consequently not receiving the social or political attention it deserves.

*[Insert Table 1 here]*

***Challenges to moving towards a shared epilepsy care model***

The concept of sharing epilepsy management between the primary and specialist health care sectors was discussed. Although most participants felt that a shared model of care could improve on the challenges identified earlier, there were barriers that would need to be overcome to implement such a model in Ireland. Overall, participants thought that more human and financial resources and changes in organisational structure of health care delivery would be required to implement a shared care model.

*Patients’ preferences for specialist care*

Patients’ attitude to shared care was considered a potential barrier to implementing the model. It was suggested that patients might prefer to communicate with the specialist in epilepsy care rather than the generalist at primary care level. Such attitudes may also vary depending on the insured (public or privately) status of the patient.

*Need for clearly defined roles and formalised clinical pathways*

A lack of formalised clinical pathways outlining multidisciplinary plans of care to support clinical management of epilepsy was also considered a barrier. For example, a requirement for pre-clinic assessment to support shared care was discussed. Such pre-clinic assessment would result in patients attending the specialist epilepsy service carrying appropriate investigation results thus ensuring optimum value from the clinical encounter.

Clear accountability in terms of healthcare provider roles in a shared care model was identified as essential. Participants referred to medico-legal consequences of indistinct roles and responsibilities and felt these would need to be unambiguous for the different healthcare sectors sharing epilepsy management. It was felt that the locus of care for an individual patient should be with a designated clinician. Enhanced education and training in epilepsy management for primary care providers was identified as a requirement to advance shared care.

The two different concepts of management and diagnosis were considered. There was a general opinion that epilepsy diagnosis should be made at specialist care level and that once a diagnosis and care plan were established, ongoing management could be dealt with by the GP service. However, the timing and nature of the follow-up care itself required clear guidelines. Participants also believed that shared care of epilepsy should promote nurse-led services. In this regard, much of the follow-up epilepsy management at primary care could be taken on by general practice nurses with support from their epilepsy specialist nurse colleagues in the specialist centres. This approach would require strategies to ensure the confidence of patients and public in such nurse-led services.

*Need for additional resources*

While shared care was thought to have the potential to enhance care, participants felt that implementation of the model would require additional resources. Geographical inequities were considered a significant barrier to implementing a shared care model for epilepsy. From the GP perspective, shared care was considered achievable in group practices of four or more GPs but not as realisable in single GP practices. Participants also conjectured that the model would bring an increased work-load to GP practices that could not be catered for without improved support from the specialist services and improved communication between the health care sectors involved. Furthermore participants felt that the current healthcare system provided no incentive to reshape services. It was particularly felt that GPs would require incentivisation to adopt a key role in the management of epilepsy patients. Related to this was a discussion regarding the cost to patients in a shared care model. For example, participants wondered how remuneration for services would be managed in the current Irish medical card system.

Participants believed that advancing a shared care approach required that, where appropriate, more epilepsy management needs to be devolved to the primary care sector. To achieve this requires that a number of GPs with a special interest and additional training in epilepsy care be identified in different regions of the country and that these GPs would become focal points for epilepsy care at primary level. This should be supported by access to GP helplines and rapid access clinics provided by a centre of excellence. Associated with this is an identified need for more community based epilepsy nurse specialists to help share the responsibility of epilepsy care across healthcare sectors. The idea of establishing a national network of epilepsy care centres staffed by trained epilepsy doctors, nurses and allied health professionals received support in the discussions. This network would be supported by ICT infrastructure and provide timely access to specialist epilepsy opinion, advice and service to patients, their families and healthcare providers.

***Sharing information – role of ICT***

Information communication technology (ICT) was considered an important ingredient in enhancing communication and sharing of information between the healthcare sectors to facilitate the shared care of patients with epilepsy. In this regard, participants identified a need to improve the computer literacy of healthcare providers and to ensure that appropriate ICT systems are deployed with adequate and available technical support. Participants believed that shared care would require an ability to share patient records between care providers and across organisational boundaries. The need for primary care to have access to information from hospitals in a timely fashion was stressed. Likewise, computer based drug management systems were also considered as having potential to enhance epilepsy care.

While ICT was viewed as a key factor in improving continuity of care, the structure of the current epilepsy service was considered to pose a significant challenge to implementing electronic patient records. Already stretched resources mean that there are significant time constraints on services with little or no leeway for healthcare workers to participate in healthcare reform projects. Despite the advantages, there was also a recognised need to achieve “buy-in” for an ICT facilitated structure of care with assured security and performance of computerised systems.

***Influencing change***

Having considered gaps in current epilepsy care in Ireland, agreeing that a shared care model could enhance continuity of care, and identifying barriers to re-shaping services, the participants identified requirements for influencing change. There was a general consensus that change could only be effected if there was political will to do so. Participants noted that reconfiguring health services for the benefit of individuals with epilepsy would need to be driven at government or ministerial level. There was a call for an Irish epilepsy audit to more fully understand the nature and scope of related health care needs. It was suggested that a taskforce on epilepsy care in Ireland, mandated to improve services for patients with epilepsy and their families, be established and that clinicians and patient advocacy organisations must agitate for political support. Engaging with health economists to sell the case for enhancing epilepsy care was proposed. Again the need to motivate the different healthcare sectors to institute change was considered.

In addition to this, improvements could only be realised with additional education and training, the development of a well resourced national centre of epilepsy excellence for Ireland, and the deployment of effective information technology systems. The establishment of a centre of excellence for epilepsy care in Ireland was proposed. This centre would be staffed by experts in epilepsy care, have high quality facilities, be the leader in epilepsy care for the country and provide support, advice and service to patients, their families and other healthcare providers. Related to this was identification of the need for more Irish based epilepsy research. Education to raise awareness and understanding of epilepsy was thought to be important in influencing change. This includes enhanced and continuing medical education with study days and workshops for health care providers as well as for patients and the general public.

**Discussion**

It is clear that healthcare professionals working at the epilepsy primary–tertiary care interface face many challenges in delivering effective care and there was general consensus with the concept of re-shaping services for the benefit of patients and their families. In Ireland, epilepsy is not considered a special case but subsumed in the overall national needs for neurology services. By comparison, in the UK an all-party parliamentary group on epilepsy has become a very positive influence on epilepsy policy, while an action plan for improving services for people with epilepsy has been produced by the Chief Medical Officer of their Department of Health [17,18]. Furthermore, the new UK General Medical Services (GMS) GP contract that came into effect in April 2004 includes a financial reward for the delivery of quality care in epilepsy. Under this contract GPs receive remuneration on the basis of the rate of medication review they conduct for their patients with epilepsy [18,19]. This incentivisation together with GP education in the diagnosis and management of epilepsy has been reported to significantly improve review and seizure remission rates as well as a reduce admissions to the accident and emergency department [20].

The focus group participants felt that sharing care across the primary–specialty interface has the potential to improve outcomes in epilepsy, and equally recognised significant hurdles to be overcome to influence change and implement a new model of care. Despite this support for shared model of care, a recent review of the effectiveness of shared care for the management of chronic disease (which did not include epilepsy) concluded that there was insufficient evidence to support the introduction of shared care into clinical practice [22,23]. However, length of follow-up in the studies examined may account for the lack of evidence and the authors recommend further research to test the effectiveness and sustainability of different models of collaboration across the primary care–specialty care interface. Therefore, the introduction of shared care should be accompanied by ongoing monitoring and evaluation so that continuous improvement goals and objectives are set with the aim of achieving an optimal model of epilepsy management for Ireland.

Poor communication, the need for access to shared medical records and more timely exchange of information between the healthcare sectors were repeatedly mentioned by participants as was the role of ICT and electronic patient records in alleviating these concerns. In a computer modelled ten year projection, Bu et al., (2007) demonstrated that ICT enabled management of diabetes, including diabetes registries, decision support systems and patient self-management systems, has the potential to improve healthcare processes, delay diabetes complications and reduce healthcare costs [22,23]. The potential of ICT for reducing error, improving outcomes, and controlling costs is recognised [22]. However, it should not be seen as a panacea for the problems of modern medicine [24]. On-going research and development is required to design and deploy effective health ICT systems that are best for patient care and to truly evaluate their impact on the structure, process and outcome for quality patient care. The socio-technical interface of ICT in healthcare must be carefully managed to realise the promise of improved healthcare yield[25]. Furthermore, because of a perceived increased risk of health information leakage in ICT enabled health care, data protection is critical as people are understandably sensitive about the confidentiality of their health status.

We are at the dawn of a new age in healthcare with a shift from medical paternalism, more knowledgeable and better informed patients, and burgeoning health care costs driving healthcare transformation programmes. The potential of personalised medicine continues to grow with pharmacogenomics promising more individually tailored and safer anti-epileptic drug and other therapies [26]. Its adoption into clinical care will require the integration of the individual’s molecular and clinical information which will be dependent on substantial cooperation between a variety of medical disciplines. In addition, a move towards personally controlled health records (PCHR) will enable patients to manage their own health data [27,28]. Large corporations such as Google and Microsoft are aiming to offer on-line repositories which will allow patients to store, retrieve, manage and share their health data. The success of such initiatives will give rise to a transportable medical record that can be available via the internet to authorised healthcare providers at any location. Thus negating the need for paper records, patients are able to share their data with multiple doctors and health care service providers [28] to engage them in their optimum health care. Control over their health data may put patients more in command in health care delivery with consequences for the way healthcare is structured and in how information and communications technologies are utilised [29].

***Limitations of the study***

In order to attract approximately 20 primary care representative, a letter of invitation was sent to almost 3000 individuals. While this approach may seem excessive we purposely spread the net wide for the following reasons. Targeting GPs and practice nurses with a special interest in epilepsy was not simple as the professional groups (ICGP and IPNA) did not have a register of such interest. In addition it was anticipated that clinical commitments might limit availability to attend the focus group meeting. However, it is not clear why those primary care representatives who participated decided to do so as this question was not explicitly asked and we recognise that this approach to recruitment may not have been ideal. By comparison 6 of the 7 consultant epileptologists and 6 of the 12 epilepsy nurse specialists who were invited did participate. Although invitees were not asked the reason for their participating or not participating, clinical and personal commitments are thought to be the cause of not attending.

In this study the experience of health professionals working in the primary and specialist care sectors in relation to epilepsy services in Ireland was explored. The experience of the journey through the health care system from the perspective of Irish people with epilepsy was examined in a separate investigation (manuscript in preparation). It may be effective to incorporate all points of view in a single study by bringing patients, healthcare professionals as well as healthcare managers together in a joint workshop.

**Conclusion**

This examination of the primary-tertiary care continuum for epilepsy in Ireland revealed a need to shift from the current fragmented healthcare system to a shared care model for the benefit of the patient with epilepsy and their families. Furthermore, the aging of the population and the advent of improved therapies indicate a need to reform our healthcare structures to more adequately meet current and future chronic disease management needs. The shared care model may help in the integration of care across organisational boundaries thus contributing towards a structured seamless web of care for patients with epilepsy. Sharing of information is essential for quality disease management. Electronic patient records accessible to authorised healthcare professionals at any location that incorporate decision support with links to evidence based clinical practice guidelines may facilitate improvements in communication and help in optimising care. However, effecting the necessary changes cannot happen at once and a realistic action plan mapping out at least a ten year programme of work is required to develop a more integrated approach to epilepsy care in Ireland. For example, improved communication between the primary care and specialist care sectors might be advanced within a shorter time-frame than will reducing geographic inequities, training and education of additional personnel in epilepsy care, or the elimination of the stigma associate with epilepsy. A policy response from government together with a commitment of required resources is necessary to drive the change. While the focus was on epilepsy care provision and the setting is Ireland, the implications from this study may be applicable to other chronic diseases and other countries.

Table 1. Key themes and categories

|  |  |  |
| --- | --- | --- |
| **Gaps in epilepsy care in Ireland** | **Challenges to moving towards a shared care model** | **Influencing change** |
| * Access to services * Service inequities   1. Geographic   2. Paediatric/Adult   3. Public/Private healthcare * Human resources * Communication between healthcare sectors * ICT infrastructure * Professional education & training * Irish best practice guidelines * Stigma associated with epilepsy | * Patients expectations * Definition of shared care * Role clarity * Lack of formalised clinical pathways * Advanced education and training * Incentivisation * Accountability and medico-legal issues * Additional resource requirements * ICT and information sharing | * + - * Political drive required       * Irish audit of epilepsy       * Establish a taskforce       * Clinicians and patient representative groups agitate for change       * Irish centre of excellence       * Irish based epilepsy research       * Awareness raising       * Enhanced and continuing medical education |

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