Please cite this paper as

Higgins A, Downes, C, Varley J, Begley C, Doherty C Elliott N (2019) **Evidence-based** practice among Epilepsy Specialist Nurses in the Republic of Ireland: findings from the SENsE study Journal of Nursing Management; 27:840–847. http://dx.doi.org/10.1111/jonm.12747

Please note that some minor changes may have been made to the paper below in the final publication

Evidence-based practice among Epilepsy Specialist Nurses in Republic of Ireland: findings from the SENsE study

ABSTRACT

Background: The importance of epilepsy specialist nurses (ESNs) delivering evidence-based care to people experiencing epilepsy is without question, yet research into this aspect of the role is relatively sparse.

Aim: To describe how epilepsy specialist nurses in Ireland enact the evidence-based practice dimension of their role.

Methods: A mixed methods study design was used, involving 12 epilepsy specialist nurses working in five units in Ireland, 24 multidisciplinary team members working with them, and 35 people with epilepsy and their family members. Data were collected using individual and focus group interviews, observation and documentary analysis.

Findings: Findings from this study provide empirical evidence that the ESNs were all active to varying degrees in accumulating, translating, applying, generating and disseminating evidence. Whilst all of the ESNs were actively involved in, or were leading clinical audit and service evaluations, and were using findings to improve practice, their research activity was limited and mainly consisted of small-scale unfunded research projects.

Implications for practice and management: ESNs are ideally placed to support a culture of evidence-based practice within and across multidisciplinary teams and services.

Organisations and managers need to support ESNs by ensuring that they have the necessary

resources and competencies to accumulate, translate, apply, generate and disseminate relevant evidence.

Conclusions: The findings showed that ESNs are well placed to promote evidence-based practice among other nurses, junior members of the multidisciplinary team, patients and families. The ESNs' knowledge of epilepsy, their clinical credibility, and the support they received from senior nursing and medical personnel enabled them to act as opinion leaders and role models in relation to evidence-based practice, including the generation of new knowledge through audit and research. Future research should explore the impact of the ESNs' promotion of evidence-based practice on patient and family outcomes.

Keywords: evidence-based practice; evidence dissemination, evidence translation, Epilepsy Specialist Nurse; advanced practitioner, research, audit,

INTRODUCTION

Evidence-based practice (EBP), which originated in the field of medicine, is now central to the practice and vocabulary of all nurses (Jansson & Forsberg, 2016; Veeramah 2016) and considered the 'gold standard' in the delivery of healthcare. There is general consensus that evidence involves the integration of the most valid and current evidence from primary research, systematic reviews and clinical guidelines, with clinical expertise and judgement based on assessment of patient needs, preferences and values (Melnyk, Gallagher-Ford, Long, & Fineout-Overholt, 2014; Reynolds 2000; Sackett, Rosenberg, Gray, Haynes, & Richardson 1996). The quest for EBP is driven by a desire to enhance the quality and reliability of care, and improve both costs and health outcomes (Carrier, 2016), and is especially important for patients with chronic conditions. In addition to difference in duration and severity, chronic illnesses can have a profound impact on the physical, psychological,

social and relational aspects people's lives. Best outcomes are achieved when clinicians select and deliver evidence-based interventions in a manner that is mindful of the person's stage of illness, biographical needs, beliefs and goals, and recognises the importance of the person being an active agent in their own care and wellbeing (Carrier, 2016; Zwar et al. 2014).

Epilepsy is a common chronic neurological condition, occurring equally in men and women, and is not limited by race, gender, geography, age or social class boundaries (Hadjikoutis & Smith, 2005). It is estimated that epilepsy affects 65 million people worldwide and imposes a significant burden on a person's quality of life and emotional well-being as well as education, employment, and psychosocial functioning (Herman & Jacoby, 2009; Sample, Ferguson, Wagner, Pickelsimer, & Selassie, 2006; Schactner & Andermann, 2008). While important scientific advances have been made in the understanding of pathophysiology and in the development of interventions such as pharmacological agents and neuro-surgery (Engel, Pedley, & Aicardi 2008; Kullmann, 2002; Moshé, Ryvlin, & Tomson, 2015), the lives of many people continue to be adversely affected by gaps in service provision and deficits in practitioners' knowledge (Bradley, Lindsay, & Fleeman, 2016). The importance of delivering evidence-based care to people experiencing epilepsy is outlined in the guidelines published by the National Institute of Health and Clinical Excellence (NICE, 2012).

As key members of the healthcare team, epilepsy specialist nurses (ESNs) have a critical role to play in advancing the evidence-based practice agenda. In addition, international literature on specialist and advanced practice identifies the need for these nurses to be 'knowledge brokers' linking evidence to practice (Gerrish et al. 2011a), 'opinion leaders' influencing front-line nursing staffs' views on evidence (Davies et al. 2006; Kleinpell & Gawlinski 2005)

and be involved in the generation and dissemination of evidence (Begley et al. 2010; Begley, Elliott, Lalor, & Higgins, 2015; Gerrish et al. 2011b). Although a significant body of research exists on nurses' knowledge and attitudes to EBP and the barriers to nurses implementing EBP (Lenung, Trevena, & Waters, 2014; Rycroft-Malone, 2008; Veeramah, 2016; Williams, Perillo, & Brown, 2015), much uncertainty exists about how epilepsy specialist nurses engage with EBP, with literature mainly focusing on the clinical dimension of the role. This paper reports on the EBP aspect of the findings from the Specialist Epilepsy Nurse(s) Evaluation [SENsE] study, a larger study into the role, cost-effectiveness and impact of the ESN role on patient care (Reference after review).

Aim

To describe how Epilepsy Specialist Nurses in Ireland enact the Evidence-based Practice dimension of their role.

METHODS

A case-study design was used to explore the evidence-based practice and research role of ESNs. Case study research is appropriate for studying phenomena in their natural environment (Houghton, Casey, Shaw, & Murphy, 2013).

Data collection

The study took place in five epilepsy services, purposefully selected from different healthcare areas in Ireland. Data were collected using semi-structured individual and focus group interviews, non-participant observation and documentary analysis (Table 1). The interviews were guided by an interview schedule that included questions about EBP. The observation phase involved recording detailed field-notes on the context, actions and factors influencing

EBP. In addition, ESNs were asked to provide documentary evidence to capture the EBP dimensions of their role. Data were collected between 2013 and 2016.

Table 1: Data collection methods and sources

Individual interview	v 12 Epilepsy Specialist Nurses,				
	5 Directors of Nursing/Assistant Directors of Nursing				
	6 Medical consultants				
	2 Clinical Nurse Managers				
	11 Allied Professionals				
Focus group	21 persons with epilepsy				
	14 family members.				
Observation	61 hours of observation				
Documents	Role descriptions, guideline developed, research/audit activity, and				
	publication or conference presentation activity				

Sample

Individual interviews were conducted with 12 ESNs, who were also shadowed by a research team member for two hours, on at least two occasions. All ESNs were female and had a mean of 10.5 years working in the area of epilepsy. Two were Registered Advanced Nurse Practitioners (RANPs), five were candidate Advanced Nurse Practitioners (cANPs) and five were clinical nurse specialists (CNSs). Within Ireland an RANP is a nurse who works as an autonomous practitioner, with four role dimensions: clinical practice, education, leadership and research (Elliott, Begley, Sheaf, & Higgins, 2016). The CNS works with healthcare colleagues in an area of specialist practice, with a leadership remit in education and improving the quality of patient care (National Council for the Professional Development of Nursing and Midwifery (NCNM), 2008).

Individual interviews were conducted with 24 key stakeholders with whom the ESN had direct contact and five focus groups were conducted with people with epilepsy (PWE) and

their family members (n=35). Purposive sampling was used to recruit ESNs and members of the multidisciplinary team (MDT). PWE and family members who were physically well enough to take part, had the ability to give informed consent and were able to hold a conversation in the English language were recruited through convenience sampling (Table 2).

Table 2: Demographic profile of ESNs

Employment status	Full-time =10				
	Part-time =2				
Time in current	Mean = $5.42 \text{ years (SD} = 5.69)$				
post					
Time working in	Mean = 10.42 years (SD = 6.02)				
epilepsy					
Length of time	Mean 20.92 years (S.D =6.92)				
since registration					
as a nurse					
Professional	Registered General Nurse (n=12)				
qualifications	Registered Children's Nurse (n=4)				
	Registered Nurse in Intellectual Disability (n=2)				
	Registered Midwife (n=1)				
	Registered Prescriber of Medicinal Products (n=7)				
	Registered Prescriber of Ionizing Radiation (n=1)				
	Registered Advanced Nurse Practitioners (n=2)				
Epilepsy specific	MSc Epilepsy/advanced practice (epilepsy) n=5				
qualifications	Diploma/Postgraduate Diploma in epilepsy care/advanced practice epilepsy				
	care n=6				
	Certificate in Epilepsy n=2				
	Currently completing MSc in Epilepsy/Advanced Practice (Epilepsy) n=3				
Other	Masters in Nursing				
qualifications	BSc in Nursing Studies				
	Post graduate/higher diploma/diploma in: Neuroscience Nursing; Critical				
	Care; Women's Health; Management; Intensive Care				

BSc in Nursing Management
Certificate in: Intensive Care; Anaesthetic room recovery; Infection Control

Ethical considerations

Approval was granted by the university's Research Ethics Committee and all five participating sites. All participants received written and verbal information about the study and gave written consent.

Data analysis

Qualitative data from interview transcripts, observations and documentary evidence were analysed using NVivo 10 (QSR International 2014). Data analysis was undertaken using a framework developed by Gerrish et al. (2007) which comprised five dimensions of 'evidence brokering', namely: accumulating, applying, translating, generating and disseminating evidence. Analysis was undertaken independently by two members of the research team, with final coding agreed by consensus, thus ensuring consistency in data interpretation.

RESULTS

Accumulating evidence to inform practice

According to Gerrish et al. (2007:ix) accumulating evidence involves 'searching out, networking and acting as a conduit for organizational evidence'. All ESNs actively sought evidence from a multitude of sources including participation in a range of educational programmes and initiatives, such as degree programmes (Table 2), conferences/study days, journal clubs and other educational meetings (Table 3).

ESNs also gathered information from published materials including scientific journals, epilepsy-focused websites, and information generated by Epilepsy Ireland. ESNs relied on international guidelines and protocols on epilepsy care, and spoke of accessing NICE guidelines and 'e-journals, databases, clinical summaries, Cochrane Library' (ESN interview). However, a number of ESNs found it difficult to access materials once they had completed their education programmes due to library access ending. To overcome this barrier, some participants used networks with colleagues in other organisations both in Ireland and abroad to avail of literature. ESNs were also observed using the online database http://www.medicines.ie and the British National Formulary (Joint Formulary Committee, 2017).

Experiential knowledge was accumulated through interactions with MDT members, especially consultant epileptologists and neurologists who were research-active. All ESNs and medical personnel spoke of the value of learning from 'observing the (senior medical) interaction with patients in the clinic or during ward round' (Medical personnel interview), as well as the values of 'presenting case studies at multidisciplinary team meeting and learning from the facilitated discussion' (ESN interview). More senior ESNs were also observed mentoring and teaching less experienced ESNs, both within and outside their service.

Applying evidence to clinical practice

Gerrish et al. (2007:ix) define application as the use of 'different types of evidence directly, persuasively or conceptually in their own practice and in promoting the use of evidence among front-line staff'. Frequently ESNs were observed citing research evidence when explaining to patients and families choice of medication, decisions to adjust medication, and rationale for performing certain tests.

Patient suggests that she be prescribed a form of treatment that she sourced on the internet. ESN goes through the research evidence for that treatment and discusses when this option would be used, including the pros and cons given her type of epilepsy. (ESN observation)

Patient's mother has concerns around vaccinations (childhood) and epilepsy and the ESN goes over the research evidence specific to this with the mother. (ESN observation)

ESNs also drew on evidence as the basis for clinical decision-making, including when advising more junior nurses or medical personnel.

ESN receives a telephone call from a medical colleague, who is currently reviewing a patient in another department. The patient is known to the epilepsy service and is exhibiting signs of acute psychosis. ESN suggests possible causes of psychosis secondary to recent increase in anti-epileptic drug (AED) therapy using evidence from research and previous experiences with this particular AED. (ESN observation)

[ESN] discusses decision [regarding medication] with Medical Register, explains the rationale supporting her decision with reference to research (has a hard copy of research study in her hand); he is not familiar with the study but affirms her decision.

(ESN observation)

Translating evidence

Translating evidence involves a number of processes including 'evaluating, distilling and interpreting evidence to make it understandable to different audiences' (Gerrish et al. 2007:ix). Most of the evidence used by ESNs had already been distilled into evidence-based guidelines, standard operating procedures (SOPs), and protocols, but those that were involved

in outreach services, such as clinics within the intellectual disability (ID) service, used every face-to-face contact as an opportunity to translate evidence to clinicians within those organisations. In addition, they translated evidence into accessible written materials for patients and family members.

ESN discusses with patient the implication of driving as she has been informed by doctor she cannot drive and is upset. ESN explores why she needs to be able to drive and helps her identify other potential solutions. (ESN observation)

Arrives on ward and meets a patient who is 5 days post-surgery and is being prepared for discharge. ESN uses a booklet prepared by the ESNs to explain what to expect...in the next days, ESN reassures that headache is normal post-surgery for a period, talks about facial swelling using very simple and easy-to-understand terms...ESN draws a picture and gives time for questions. (ESN observation)

Where PWE had cognitive impairments or intellectual disability, the ESNs were constantly employing strategies to enhance communication and facilitate greater understanding.

ESN uses a colour co-ordinated chart of AEDs to assist the patient recall his medication. ESN goes through information a few times slowly and respectfully, until both are happy with level of comprehension and understanding. (ESN observation)

Patient with ID appears to be experiencing multiple types of seizures...ESN classifies seizures into ABCD and writes a simple explanation of each type into the patient's seizure diary and goes through each with family and patient until they are confident they know the difference and how to record in the diary. (ESN observation)

Generating evidence

All ESNs engaged in clinical audit and service evaluations, the majority of which measured the National SOPs for epilepsy practice. Other audits performed focused on nursing activity, service development and staff education, which were then used as a benchmark for evaluating any subsequent changes made (Table 3). Some ESNs collaborated with the MDT in generating evidence from audits, which was aimed at informing future service development.

Table 3: ESN activity

Educational initiatives undertaken by the ESNs from documentary evidence Range of audits from documentary evidence

Study days and short programmes

- Epilepsy and rescue medication train the trainer
- Epilepsy Master classes
- Introduction to Cochrane systematic reviews
- Pediatric epilepsy training course
- Global symposium on dietary treatment of epilepsy
- Epilepsy in people with intellectual disability
- Annual Epilepsy Nurses Study Day
- Developing telephone skills
- Public speaking workshop

In-service education (mandatory)

- Data protection training
- Hand hygiene
- CPR
- Child protection awareness
- Handling and moving
- Fire safety

- Telephone Advisory Service activity (type of call, interaction required and outcome achieved)
- Time taken to triage into ESN service
- Type of education provided to patients on epilepsy
- Information given to patients regarding driving
- Activity of First Seizure Service
- EPR generated discharge letter using an amended Sheffield Assessment Instrument or Letters (SAIL) assessing the readability, safety and quality of the letter content
- Reliability and accuracy of data inputted into the epilepsy-specific Electronic Patient Record (EPR)
- Waiting times for patients in nurse-led clinic
- Percentage of new referrals contacted by ESN within 10 days of receipt of referral to the epilepsy service
- All epilepsy emergence department admissions, their length of stay, their follow-up
- All the out-patient referrals that the consultants receive, the timelines, the details
- Outcomes of Vagal Nerve Stimulator
- Adverse effects of new anti-epileptic medication
- Impact of group education sessions for patients
- Needs of staff for in-service education on epilepsy

The level of involvement in research varied across individuals and organisations. Some ESNs were involved at the level of recruiting participants for research while others collected data on larger MDT research studies. Two ESNs, accredited at RANP level, were making applications for funded research as Principal Investigator, co-applicant or collaborator. The majority of other research projects undertaken by ESNs in a lead capacity were small-scale, unfunded projects, as part-requirement of academic programmes or conducted in response to local clinical needs. ESNs were positive about their role in generating evidence through audit and research, but reported finding it challenging to enact this aspect of their role due to 'the time constraints of clinical practice and running and developing services' (ESN interview). The majority of ESNs also perceived themselves as inexperienced in research and lacking the skills to design research studies, seek funding or appraise literature in a systematic way, especially statistical information and language used in quantitative research. Some senior medical personnel believed that the absence of a strong research culture within the wider MDT also impacted on the ESNs.

'If research is the discovery of new things, we haven't done a lot of that... When there is a busy clinical service, it [doing research] is difficult...this would be a potential criticism say of my own service...it is hard for the ESNs to develop a significant research component to their work, when we're [medical team] not doing it either.' (Medical personnel interview)

Disseminating evidence

ESNs used a range of formal and informal strategies to disseminate evidence to PWE, family members, healthcare practitioners and the wider public. Both within and outside their services the ESNs disseminated evidence to practitioners through MDT meetings, ward meetings, impromptu encounters, in-service education days, and formal education programmes on

epilepsy and epilepsy literature. ESNs also disseminated evidence from their audits to senior management personnel through monthly or annual reports or during meetings with them. ESNs presented evidence generated through their audits and research at conferences, mainly national but some international (American Academy of Neurology conference and American Epilepsy Society conference). Some ESNs also published research on Epilepsy Ireland's website and in their newsletter, and in professional magazines, but clinical demands impacted on dissemination activities.

DISCUSSION

The importance of ESNs delivering evidence-based care to people experiencing epilepsy is paramount and there is a growing consensus within the literature that nurses at speciality and advanced practice level have a responsibility to provide leadership in the area of evidence-based practice and reduce the gap between the generation of evidence and implementation in the real world context (Kleinpell & Gawlinski, 2005). Whilst some writers allude to the ESN's role in research and audit (Dupras, 2005; Foley, Oates, Mack, & Fox, 2000; Higgins, 2008), to our knowledge, this is the first study that comprehensively documents how ESNs, particularly ESNs in Ireland, enact the EBP dimension of their role.

Just ten years ago Kring (2008) noted that specialists, when competent in EBP, can leverage their roles as expert practitioners, consultants, educators and support EPB in their organisation. More recently, Begley et al. (2010:262) suggest that 'with support, nurses in specialist or advanced practice posts can be extremely influential in their specialist area of practice locally, nationally and internationally'. Findings from this study clearly demonstrate that the ESNs were all active to varying degrees as 'knowledge brokers' and 'knowledge managers' (Gerrish et al. 2011a, b) by accumulating, translating, applying, generating and

disseminating evidence. In contrast to nurses in many other studies, who tended to privilege evidence derived from work-based activities, such as clinical experience or from interaction with senior nursing or medical colleagues (Gerrish, Ashworth, Lacey & Bailey, 2008; Jansson & Forsberg, 2016; Spenceley, O'Lear, Chizasky, Ross, & Estabrooks, 2008; Thompson et al. 2001), the ESNs in the SENsE study not only drew on these resources but also used formal educational programmes and continuing professional development opportunities (study days/conferences). In addition, in line with the findings on ANPs in other studies (Begley et al. 2015; Gerrish et al. 2011b; Profetto-McGrath, Smith, Hugo, Taylor, & El-Hajj, 2007) they accessed peer-reviewed evidence from literature specifically tailored to their speciality, and evidence synthesised by others, such as NICE guidelines. ESNs also used their role as opinion leaders, educators and role models, by acting as 'conduits' for the translation of evidence (Thompson et al. 2001) for front-line clinical nurses, junior MDT members, patients and family members.

The ESNs were very positive about their research role, but their research activity was limited and mainly consisted of small-scale unfunded research projects, with some involved in recruitment or data collection on larger MDT research studies. This finding is similar to findings from other studies involving advanced practitioners (Begley et al. 2015; Gerrish et al. 2011a, b). Positively, however, all the ESNs were actively involved in, or were leading clinical audit and service evaluations, and most importantly were using findings from the audits to improve the patient experience by arguing for changes, with formal dissemination at national and international fora apparent. Within the literature, irrespective of country, nurses report various factors that hinder their ability to implement EBP, including lack of knowledge and skills to conduct research and appraise literature (Begley et al. 2015; Gerrish et al. 2011b; Rycroft-Malone, 2008; Veeramah, 2016), lack of support from managers, resistance from nursing and medical colleagues, lack of time, insufficient resources and lack of autonomy to

change practice (Hutchinson and Johnston, 2006; Kuuppelomäki & Toumi, 2005; Rycroft-Malone, 2008; Veeramah, 2016). Whilst some ESNs in the SENsE study did mention difficulties in accessing library resources and databases, and all mentioned the challenges of competing demands and workloads, lack of autonomy or lack of support from managers or medical colleagues were not barriers identified. In fact, the ESNs were very positive about the support they received from nursing management and medical consultants in relation to education and audit. In addition, they were all very positive about the level of autonomy they had to lead and implement changes, with concomitant benefits to patient care.

IMPLICATIONS FOR FUTURE RESEARCH

Now that there is clear evidence of the ESNs' competency in accumulating, translating, applying, and to some degree generating and disseminating evidence, future research should explore the impact of their promotion of EBP on patient and family outcomes.

LIMITATIONS

Although the triangulation of methods and the use of a template framework for data analysis enhanced the robustness of the findings the short duration of observation and the subjective nature of data recorded on the documents analysed may have influenced the findings. Although informative, the PWE's and families' data were limited to comments on the translational dimension of the ESN role.

CONCLUSION

A review of the research evidence on the EBP aspect of the ESN role is relatively sparse which has implications for informing policy-makers and educators in relation to role development and preparation. The findings of the SENsE study support the view that ESNs are well placed to promote EBP among other nurses, junior members of the MDT, patients

and families. There is no doubt that their belief in the value of EBP, their knowledge of epilepsy, their clinical credibility, as well as the support from senior nursing and medical personnel enabled them to act as opinion leaders and role models in relation to EBP, including the generation of new knowledge.

LINKING EVIDENCE TO ACTION

- ESNs are ideally placed to support a culture of EBP within and across multidisciplinary teams and services, and their skills should be maximised.
- Organisations and managers need to support EBP by ensuring ESNs have the necessary resources and competencies to accumulate, translate, apply, generate and disseminate relevant evidence.
- Future research should explore the impact of the promotion of EBP on patient and family outcomes.

ACKNOWLEDGEMENTS

The SENsE study was funded by a grant from Epilepsy Ireland and the Health Research Board Ireland (Grant No. MRCG/20125).

ROLE OF THE FUNDING SOURCE

The funding source of the study had no role in the study design, data collection, data interpretation, in the writing of the report, or in the decision to submit the article for publication. Epilepsy Ireland, who are part-funders, provided assistance in the advertising and recruitment of sites by sending information letters/emails to medical consultants about the study.

CONFLICTS OF INTEREST STATEMENT

There are no known conflicts of interest associated with this publication.

ETHICAL APPROVAL

Prior to commencing the study ethical approval was obtained from the Faculty of Health Sciences Research Ethics Committee of the university where the researchers were employed and local research ethics committees in each study site.

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