



Rising to the challenge: Epilepsy specialist nurses as leaders of service improvements and change (SENsE study)



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ARTICLE INFO

Keywords:

Leadership
Change
Service improvements
Epilepsy specialist nurse
Advanced practitioner

ABSTRACT

Purpose: To report the leadership role and change activities of epilepsy specialist nurses (ESNs) in Ireland; findings from the SENsE study.

Method: 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.

Results: Five key areas in which ESNs demonstrated leading on the change agenda were identified. These included: Initiating new clinical practice developments; Building capability within the multidisciplinary team; Developing education programmes and resources for people with epilepsy, family and the public; Exerting influence through membership of committees and lobbying; and Advancing the ESN role.

Conclusion: Though the epilepsy specialist nurse role was first established in the UK in 1988, much of the literature that discusses or describes the ESN role is founded on anecdotal evidence, or focusses on their clinical expertise. Findings from this study provide empirical evidence that the ESNs were involved as key players in leading changes within the services, in the education of others, and the continuous advancement of epilepsy care.

1. Rising to the challenge: Epilepsy Specialist Nurses as leaders of change

All health care systems are challenged by the increasing prevalence of chronic diseases. Epilepsy is a spectrum of disorders that are chronic in nature and if poorly managed can have a significant impact on the person's psychosocial functioning as well as their educational, vocational and occupational aspirations [1,2]. Despite the body of evidence that supports the early and accurate diagnosis of epilepsy in the context of improved outcomes [3], international literature exploring people with epilepsy's (PWE's) experiences of healthcare identify a number of systemic problems, including geographic variation in types of services available, delays in access to specialist services, difficulties in access due to distance and transport issues, poor communication across disciplines and services, and practitioners that lack specialist knowledge and skills in the area of epilepsy [4–8]. In addition, deficits in care have been identified for particular groups, such as pregnant women [9,10]

and people with intellectual disability [11,12]. Within Ireland Varley et al.'s [13] and Bennett et al.'s [14] studies reported similar deficits and inadequacies. Participants in both studies wanted better integration, communication and information sharing between healthcare providers and healthcare sectors, and more efficient and easier access to specialist services and investigations. In addition, there is evidence that many PWE who present at Irish emergency departments are admitted 'when often they could safely receive care and advice and rapid follow-up' at an outpatient service [15]:8.

As the nursing profession constitutes a large part of the healthcare system there is growing recognition that no substantial health care reform can take place without nursing engagement [16]. Indeed Day and Brownie [17]:30 assert that as the largest and most accessible cohort within the health care workforce 'nurses need to be viewed as part of the solution and encouraged to lead and innovate' in the delivery of safe, quality, person-centered, accessible and affordable health care. While all nurses have a critical contribution to make to the reform

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<https://doi.org/10.1016/j.seizure.2018.10.013>

Received 10 August 2018; Received in revised form 5 October 2018; Accepted 25 October 2018

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Table 1
Demographic profile of ESNs.

Employment status	Full time = 10 Part time = 2
Time in current post	Mean = 5.42 years (SD = 5.69)
Time working in epilepsy	Mean = 10.42 years (SD = 6.02)
Time since registration as a nurse	Mean = 20.92 years (S.D = 6.92)
Professional qualifications	Registered General Nurse (n = 12) 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) MSc Epilepsy/advanced practice (epilepsy) (n = 5) 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)
Epilepsy specific qualifications	

agenda, nurses who occupy advanced or specialist roles, because of their expertise and role within the clinical team, are ideally placed to initiate, lead and drive organisational change [18–20]. Though the epilepsy specialist nurse (ESN) is in existence in the UK since 1988 [21] and a number of studies have been undertaken to identify the nature of the role [21–24] or evaluate aspects of the role [25,4,26,3,27,28], the ESN's role as leader and change agent is given scant attention. Despite leadership being identified as one of the five core competencies in the adult epilepsy specialist nurse competency framework designed by the Epilepsy Nurse Specialist Association [29] most of the research focuses on clinical aspects of the role, apart from a brief mention of their leadership role in building knowledge capacity [22,30] and their role in developing standards, policies and guidelines [22].

Until recently in the Republic of Ireland, the ESN role developed informally and was regulated at a local level; however, with the development of the National Clinical Care Programme in Epilepsy Care (NCPE) [15] a strategic and more defined role for nurses in epilepsy care was outlined. In addition to addressing historic deficits in epilepsy care, a core goal of this programme was the creation of a cohort of ESNs [15]. Within this ambitious plan lay an implicit assumption that the ESNs would demonstrate the leadership ability to effect change within the system as well as implement the organisational change required to enhance care provision for people with epilepsy in the Republic of Ireland through improved access to expert quality care and information across the healthcare system [15]. Given the newness of the role within the Republic of Ireland and the absence of evidence within the literature on the leadership component of the ESN role it was important to explore the degree to which the ESNs rose to the leadership and change challenge implicit within the NCPE. This paper reports on the leadership 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 on patient care. The impact of the role on care experiences, satisfaction with care and quality of life (QoL) is reported elsewhere [28].

2. Methods

The study design used a case study approach, which by definition involves the collection of data within the real-life context of health care [31]. Data were collected from multiple sources using mixed methods.

2.1. Recruitment and sampling

The study took place in five hospital-based epilepsy services that employed ESNs as members of the multidisciplinary team. The five services were purposefully selected from different health areas in the Republic of Ireland; four of the services provided care to adults with epilepsy and one provided care to children. Directors of Nursing and relevant medical consultants in all sites were contacted to seek

permission for access and for their involvement in the study. Participants in the study included ESNs, Directors of Nursing, members of the multidisciplinary team, PWE and family members (See Table 2). Purposive sampling was used to recruit the ESNs and health professionals, and to ensure representation from professions, disciplines, roles and sites. PWE and family members who met the inclusion criteria in terms of being physically well enough to take part, having the ability to give informed consent and being able to hold a conversation in the English language were recruited through convenience sampling. Recruitment of ESNs was facilitated by Directors of Nursing who, with their permission, gave the research team contact details of each ESN. The ESNs in turn assisted with recruitment of members of the MDT, PWE and family members.

2.2. Data collection and sample

Data for the study were collected using interviews (individual and focus group), documentary analysis and non-participant observation, which involved shadowing the ESNs. The interviews were semi-structured in nature and guided by an interview schedule developed by the research team. It was informed by a study previously undertaken on advanced nursing practice in the Republic of Ireland [32] and included questions about the leadership aspect of the ESN role, its impact, and barriers and facilitators to developing and sustaining this aspect of the role. In total 36 individual interviews were conducted with ESNs (n = 12) and with a range of key stakeholders (n = 24) with whom the ESN had direct contact (Table 2). The ESNs who participated were all female, two were Registered Advanced Nurse Practitioners (RANPs), five were candidate ANPs and five were clinical nurse specialists (CNSs). Within the Republic of Ireland an ANP is a nurse who works as an autonomous practitioner, with four key dimensions to the role: namely, clinical practice, education, leadership and research [33]. The CNS works with medical and para-medical colleagues in an area of specialist practice, also with a leadership remit in the area of education and improving the quality of patient care [34]. A more complete demographic profile is available in Table 1.

In addition, five focus groups were conducted with PWE and family members of PWE (n = 35). Each of the 12 ESNs was also intermittently shadowed by a member of the research team for a minimum of two hours, on at least two occasions. In total 61 h of observation took place. In selecting times for observation the researchers endeavoured to capture the range of activities that encompassed the ESN role across the full practice week. During this time the researchers recorded detailed field notes of the context, events, behaviours and interactions that indicated leadership activities, as well as factors influencing leadership actions. These methods were supplemented by the collection of documentary evidence which enabled the research team to capture any leadership dimension of the role that may not have been particularly evident during observation or interviews (see Table 2 for an overview of data

Table 2
Data collection methods and sources.

Individual interview	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, portfolios, committee membership, education or curriculum activity, guideline developed, research/audit activity, and publication or conference presentation activity

collection and sources of data). Data collection was undertaken by two members of the team (AH and JV).

2.3. Ethical considerations

Approval was granted by the university's Research Ethics Committee and all five participating sites. All participants were given written and verbal information about the study. Written informed consent was obtained from all participants, including clinicians, patients, and carers or parents/guardians involved peripherally in observation of care. In addition, the principle of process consent was applied by the researchers at each encounter. Where participants were aged under 18 or were perceived as vulnerable, a parent or guardian was present during any communications and the person's verbal assent and parental/guardian written consent was obtained for observation.

2.4. Data analysis

Using both a deductive and inductive process, data from the interview transcripts, observations and documentary evidence were analysed with the support of NVivo 10 [61]. In combination with generating new codes inductively, a coding template developed from a previous study of advanced nurse and midwifery practitioner leadership roles (the SCAPE study) was used [19,20,35]. Analysis was undertaken by two members of the research team (AH; NE), with final coding and interpretations agreed by consensus.

3. Results

While not all of the ESNs involved in the study were leading on the change agenda at the same level, with the leadership dimension emerging as they became more established in their roles, analysis of the findings resulted in the following five key themes: i) initiating new services and practice developments; ii) building capability within the multidisciplinary team; iii) developing education programmes and resources for PWE and the public; iv) exerting influence through membership of committees and lobbying; and v) advancing the ESN role.

3.1. Initiated new services and practice developments (Theme A, Table 3)

Findings indicated that the ESNs identified gaps in services, developed business cases, sourced resources, collaborated with the key stakeholders and sought approval through relevant governance structures to initiate and implement new services, both within and outside their organisation. The ESNs contributed to the development of a comprehensive epilepsy service through developing and expanding nurse-led clinics, such as Vagal Nerve Stimulation (VNS) clinics (Table 3, A1-A3), and Rapid Access Clinics (RACs) (Table 3, A4), new services such as the Telephone Advisory Line (TAL) (Table 3, A5-A8), and outreach clinics for specific patient groups, such as people with intellectual disabilities and pregnant women (Table 3, A8-A10). By decentralising and

localising services, many PWE and their family members did not have to travel large distances to services, which was especially important for PWE who were restricted in terms of transport, physical disability or significant intellectual disability. In doing so ESNs not only improved access to specialist services, but they also reduced the geographic variation in the availability of, and access to, services which had led to considerable inequalities for PWE and their families.

In addition, evidence indicated that the ESNs were active in initiating collaboration with other practitioners, and leading the development and evaluation of care pathways (referral pathways to neurological services, transitions from child to adult services), clinical guidelines (ketogenic diet, buccal midazolam administration) and standard operating procedures (Table 3, A11-A15). In addition to enhancing the quality of care and the patient's journey through the development of guidelines, the emergency department care pathway, together with the RAC and TAL were viewed by members of the MDT and family as an important strategy in reducing hospital admissions and family burden (Table 3, A16-A18). The ESNs were also instrumental in the implementation of the Electronic Patient Record (EPR), a key initiative within the National Clinical Care Programme for Epilepsy in the Republic of Ireland [15]. The ESNs not only promoted its use to MDT members, but they were actively collaborating with developers to enhance the efficiency and effectiveness of the system through the collection of data, the development of new modules, and performing user acceptance tests (Table 3, A19-A20).

3.2. Building capability within the multidisciplinary team (MDT) (Theme B, Table 3)

To enhance the quality of service provision, the ESNs increased the capability of nurses, MDT members and other practitioners, both within and outside of their organisation, through the development and implementation of a range of formal and informal educational initiatives. The ESNs led the development of short educational programmes on various aspects of epilepsy care, and in some instances, secured accreditation and approval from the relevant professional body for formal educational events (Table 4). In addition, the ESNs built capacity and enhanced others' clinical decision-making by providing consultancy on patient care issues to MDT members, GPs and staff from intellectual disability services (Table 3, B1-B7).

3.3. Developing education programmes and resources for PWE and the public (Theme C, Table 3)

While patient education is viewed as key to self-management [13,36] and a central part of the clinical dimension of the role of the ESN, improving PWEs' knowledge and enabling them to take an active role in their own care requires the development of educational resources. Findings suggest that in striving to enhance services for PWE the ESNs identified educational gaps and designed new educational resources and programmes of education to meet the needs of people with epilepsy and their families/carers, such as group education programmes for newly diagnosed patients. The nature and range of educational resources developed by ESNs for PWE and family members are indicated in Table 4. In addition, ESNs led on the dissemination of information to the wider public, including teachers, through organising events and community education/information sessions (Table 3, C1-C3).

3.4. Exerting influence through committees and lobbying (Theme D, Table 3)

Data indicated that ESNs were recognised by people within and outside of the discipline as experts in their area of clinical practice. Consequently, they were invited onto national and international committees where they exerted their influence on issues related to epilepsy

Table 3
Selected evidence related to the themes.

Theme A	Initiated new services and practice developments
A.1	The nurses on their own initiative, led on the setting up the VNS clinic here [service that didn't have a VNS clinic]... we now have about twenty patients coming... people had to travel to [names a service some distance away]. It's a real addition to the service. (Medical personnel interview)
A.2	There's a new process in place in terms of the VNS clinic...that was done solely by the nurses, led out by the nurses. (DoN Interview)
A.3	[The VNS clinic] is a great service, it has made a difference for families and PWE as well, travelling, so it's local and they don't have the big journeys... because PWE used to have to travel to Dublin before this. (ENS interview)
A.4	There are a certain cohort of PWE that avoid ED [emergency department] by having the nurse specialist, they might have come in [to ED] because they're not feeling well, they've a headache and it's to do with their epilepsy, that can be managed through their clinic, they [ESNs] fit them in there [rapid access clinic], so they're not admitted. (DoN interview)
A.5	Having that port of call [TAL], being able to ring them up and if you've a bad weekend or a Wednesday or a Thursday night, you have someone to ring, you know there's somebody who knows their [PWE] form. (Focus group family member)
A.6	It's great to know that...if you have any fears. You don't have to make an appointment with the doctor, you can just lift the phone [TAL] and ask to talk to somebody, you know. (Focus group family member)
A.7	So when I pick up the phone [TAL] and I'll get [name of ESN]. It's just such a relief, it means everything. You know because when you're going through those really, really dark days it's just nice to get that bit of sunlight from them. And that's, that's what I feel; you know it means everything to me. (PWE focus group)
A.8	[The Outreach service] has been extremely positive for the residents [ID], particularly for some of our residents who may find it difficult to travel for one reason or another. Or to sit in an outpatients department for two hours, remember we are a little bit outside of Dublin. So by the time you get there, you're probably looking at, you're looking an hour, an hour and a half. Both ways and then an extended waiting period in an outpatients department. (Medical personnel interview)
A.9	Evidence of collaboration with intellectual disability services to develop an "outreach clinic" at a long term care ID service that targets the care and management of people with epilepsy with ID. (Documentary evidence)
A.10	The information that she has given some of the PWE [pregnant women] within the [outreach] clinic and subsequently in the home environment in relation to the need to continue and perhaps changing treatment, has prevented the mum being on inappropriate medication in pregnancy... I think [ESN] has prevented death in some women who wanted to stop their medications because they were pregnant, she has made a real impact on this type of risk, getting these women off some medications] and on to more suitable medications. (Medical personnel interview)
A.11	Care pathways for Emergency Department patients presenting with a seizure... was developed by the ANPs [in Epilepsy]. (DoN interview)
A.12	Led the development of a protocol for administration of Buccal Midazolam liquid for patients at home or patients with ID in care settings so family and practitioners can administer medication safely. (Documentary evidence)
A.13	Developed Standard Operating Procedure (SOP) for nursing care of VNS patient in association with colleagues in UK. Developed SOP for telephone advisory service, and one for discharge planning. (Documentary evidence)
A.14	Development of an Epilepsy Nurse Phone Triage form. A document to capture both epilepsy and no epilepsy information at initial contact with the patient. (Documentary Evidence)
A.15	[Name of ESN] was instrumental in developing the guideline and care pathway for care of pregnant women with epilepsy. She wrote the guideline and I had very little to add when she gave it to me, again she knew what was needed and is working at national level so she is very informed. We then sent the guideline to the obstetrician group for approval. That guideline will be used nationally. (Medical personnel interview)
A.16	If a child came into A&E with bad seizures, [ESN] will go down, and she will sort them out, it's sorted. So the neurology registrar, or the neurology SHO [senior house officer], doesn't necessarily have to go down and manage that patient. [ESN] can go down and she will take all of their history, go through everything, make a plan for those PWE, avoid them being admitted, if feasible." (MDT interview)
A.17	We are able to access information over the phone [TAL] and have contact with the doctors, through nurses that know what they are talking about [it] means we [ID patient and carer] have less trips to the hospital. (Allied health professional interview)
A.18	"[Telephone advice line] reduced the amount of people needing to come to out-PWE...they don't have to travel...a lot of PWE that can't drive so it's a lot of hassle for them, they need to get somebody to come with them, they need to have a day off work, they need to, safety, travelling, if they're having increased seizures and stuff, they're on a bus on their own, so it saves that. The [ESN] will go through the problem on the phone if they can and certainly won't put an unnecessary journey on the patient if they can avoid it. (DoN interview)
A.19	I think from the time that the ANP started with us, it was then that the EPR was rolled out, she [ESN] literally ran with it.(Medical personnel interview)
A.20	We use the Electronic Patient Record, and the nurses [ESN] really champion that, and run that, and they are instrumental in also making sure that the NCHDs [Non-consultant hospital doctors] use it properly...the nurses here have embraced it very strongly... I think we would be using it a lot less if the nurses hadn't advocated for it. (Medical personnel interview)
Theme B	Building capability within the MDT
B.1	[ESN] give another perspective on what the patient might be going through, what the best approach to managing the patient. which is very helpful...She tends to steer my decision quite a bit. (Medical personnel interview)
B.2	The man [person with ID] had severe kidney issues... he was having lots of seizures, so I [manager of ID service] rang [ESN] about the seizures, ... she give us the other angle, which helped prevent his seizures, didn't change his medication, but got him treated for something that was adding to the seizures... hugely educational... (Allied health professional interview)
B.3	The [ESNs] have shown great initiative, so there has been new driving regulations in relation to epilepsy...and the ESNs had a session where they... they summarised and discussed the driving regulations...that was very helpful to be able to discuss them. (Medical personnel interview)
B.4	ESN rings GP who has left a voice message on the TAL. ESN asks GP about her prescribing and reason for her deciding to increase certain medications for patient in a care home. ESN cautions about increasing without adequate assessment and stresses importance of monitoring effect of increase before making further changes. (ESN observation)
B.5	The SHOs and the interns in particular ask the epilepsy nurse specialist things about patient care that ...I think they are very grateful to have the help of the epilepsy nurse specialists...to educate them. (Medical personnel interview)
B.6	ESN is interrupted by SHO who is seeking advice about a patient who wants to reduce medication and is seizure free for a number of years. ESN advises the SHO on the importance of patient making an informed decision and knowing that if she reduces and experience a seizure this will have implications for driving/insurance, which is important to her as she [PWE] has small children. ESN goes through the medication and woman's history in detail with the SHO, explaining the importance of presenting information clearly and ensuring the patient understands implications. (ESN observation)
B.7	Some of my calls [telephone advisory line] during the week are from GPs and the ID services. GPs ring us directly querying medications...Especially in pregnancy, they deal with us, they liaise with us a lot. (ESN interview)
Theme C	Developing education programmes and resources for PWE and the public
C1	Evidence of delivering epilepsy-specific information sessions regionally at the request of Epilepsy Ireland to patients, families, and schools. (Documentary evidence)
C2	We're creating an information pack for teachers in primary schools. (ESN interview)
C3	I was at an Epilepsy Ireland night recently and it was just specifically aimed at young people. And it was nurse [ESN] who came in giving us a talk...she was discussing employment for us... the legalities around finding employment ...how to come around that aspect ...you don't have to discuss personal, your personal epilepsy story and history. (PWE focus group)
Theme D	Exerting influence through committee membership and lobbying
D.1	Invited to join 2011 curriculum group who developed M.Sc. in Epilepsy. (Documentary evidence)
D.2	Invited by NMBI onto Accreditation Committee as clinical expert for ANP epilepsy and ANP neurodegenerative disorders/ motor disorders. (Documentary evidence)
D.3	Invited to expert round table discussions with pharmaceutical companies – to comment on different medications. (Documentary evidence)

(continued on next page)

Table 3 (continued)

D4	Reviewer of all SOPs developed as part of the strategic reform of epilepsy services in Ireland via the National Epilepsy Programme. (Documentary evidence)
D5	[ESNs]. are involved in nursing practice guidelines...contribute to general guidelines...around hand medication managements, nurse prescribing, they'd be involved in writing up the guidelines..." (DoN interview)
D6	[Name of ESN] was instrumental in developing the guideline and care pathway for care of women with epilepsy. In fact she wrote the guideline and I had very little to add when she gave it to me, again she know what was needed and is working at national level so she is very informed. We then sent the guideline to the obstetrician group for approval. That guideline will be used nationally, so she had a big input into that. (Medical personnel)
D7	They liaise between you and the consultant because not all the time you get too long to talk to the consultant. (PWE focus group)
D8	Having them [ESNs] there is fantastic particularly when you've forgotten what questions to ask when you're in with the consultant and you go back and go 'oh I should have asked' ... very, very useful. (PWE focus group)
D9	Development of a patient council to feed into the development of information leaflets and other developments in relation to epilepsy. (Documentary evidence)
D10	[ANP has] written to Departments of Education and Health to advocate for support for people being put off road for hardship funding. (Documentary evidence)
D 11	I couldn't put a price on the help that they [ESNs] have given. Cos I'm due to go to [names hospital], And it was thanks to [ESNs] that I got the appointment because they kept pushing. (PWE focus group)
Theme E	Advancing the ESN role
E1	Development of the curriculum for Advanced Nursing Practice in Epilepsy. The evidence supports her role in initiating and developing the course and developing the stand alone epilepsy module (Level 9) in collaboration with epileptologists/neurologists throughout Ireland. (Documentary evidence)
E2	Member of curriculum development group for MSc in Advanced Nursing Practice in Epilepsy care. Teaches and is responsible for setting the final assessment in clinical competency for epilepsy care module. (Documentary evidence)
E3	Candidate ANP seeks advice from RANP on a patient with a history of substance misuse and epilepsy. RANP is familiar with patient. (ESN observation)
E4	You're asking [ANP candidates] the questions...to assess their knowledge. You're looking for what they may not have asked [the PWE] and you're listening for what they did ask. You're looking at the clinical notes and making sure that they've interpreted and analysed everything. You're then helping them make their own decision while...at times, saying, 'have you considered X,Y and Z?' To make sure that they are making the correct decisions, learning the right way... Creating a culture of knowledge, creating a culture of decision-making, because they're novices on this pathway. (ESN interview)
E5	Candidate ANP went to [name of hospital] to work and shadow RANP before setting up own VNS clinic. (ESN observation)
E6	We've had to bring the [RANPs] from [name of hospital] down over the EPR ... we've received a lot of support. (Candidate ANP interview)
E7	Evidence of presenting workshops on the ESN role nationally. (Documentary evidence)

service provision, clinical policy, practice and professional development (Table 3, D1-D6). Table 4 also indicates the breadth and types of memberships held.

Another way the ESNs fulfilled their leadership role and exerted influence was through advocacy, which involved developing opportunities and processes for the voices of PWE to be represented. The ESNs not only enhanced PWE autonomy by providing information on choices and options, but they supported PWE and family members to communicate with the health care team (Table 3, D7-D8), developed a patient council (Table 3, D9), and lobbied at local and national levels for better services for PWE and their families (Table 3, D10-D11).

3.5. Advancing the ESN role (Theme E, Table 3)

A range of data sources showed that the two ESNs at ANP level demonstrated leadership by advancing the ESN role in the Republic of Ireland. As well as establishing and contributing to the first Master's level educational Programme in Epilepsy in the Republic of Ireland through curriculum development, lecturing, and assessment of clinical competency (Table 3, E1-E2); these two ESNs were also involved in mentoring and supporting candidate ANPs to develop the requisite clinical competencies to register as ANPs with the nursing registration board in the Republic of Ireland (Table 3, E3-E4). ESNs further built-up capacity by helping candidates to develop new nurse-led services, and implement national epilepsy policies (Table 3, E5-E6). In addition, they were instrumental in ensuring new ESNs were integrated into existing epilepsy services through the provision of information workshops on the ESN role for healthcare organisations (Table 3, E7).

4. Discussion

The few international studies available on the role of the ESN have focused on the clinical practice component of the role [21,22], with a significant dearth of literature on the leadership and change component. This study addresses this neglected area and to our knowledge is the first study that demonstrates the important ways in which ESNs enact their leadership role at patient, service, national, professional and cross boundary levels. As leaders and change initiators, the ESNs in this study enhanced what the Institute of Health Care Improvement called the triple aims of health care, namely: better care, better health, and better value [37,38]. As self-directed and motivated individuals, the

ESNs improved the availability of and accessibility to specialist epilepsy services by developing and expanding services. In doing so they not only reduced the health disparities in epilepsy care across the country, but they helped decrease the emotional and economic burden on families who had to travel long distances to access services. The expansion of services to people with ID is especially important given the deficits in care identified in the literature and evidence that people with ID and epilepsy have greater prevalence of multiple comorbidities and higher rates of multiple anti-epileptic drug use [11,12,39], which make care and treatment decisions more challenging.

In addition to enhancing access, the ESNs were conscious of the increasing emphasis on the concept of 'expert patient' [40,41] and the importance of knowledge to user-led self-management [13,36], which is perhaps particularly important in pregnancy. A review of 12 studies of women with epilepsy reported they had limited knowledge of essential aspects of pregnancy and childbirth, and had not received information on these issues. In particular, they wanted more information on anti-epileptic drugs before planning a pregnancy [42], a key area for which these ESNs had developed an educational resource (Table 4). Findings from this study suggest that in striving to eschew paternalistic practices and enable PWE to take an active role in their care, the ESNs were not just using educational resources developed by others, but were in many cases leading the design of epilepsy education programmes and resources for patients, families, and the public.

While advocacy is implicit in many nursing codes of practice [43], it is regarded as a key role of all nurses [44] and a competence for advanced practitioners in Ireland [45]. Bar Hosking et al. [46], citing advocacy as one of the roles of the ESN, there is very little discussion of the ESNs' advocacy role. The findings of the SENsE study adds to the literature in this area by highlighting how the ESNs were enabling PWE to have a voice through enhancing their health literacy, were acting as a communication bridge between the PWE and the health care team, as well as developing opportunities and processes for the voices of PWE to be represented at local and national level.

Notwithstanding the centrality of education and advocacy in enabling PWE to self-manage their condition [47,48], as with other chronic diseases, safe and effective decision-making in relation to referral, diagnosis, treatment and management rely on having competent practitioners in primary, secondary and tertiary care [49]. In addition to leading on educational developments for PWE, findings indicate that the ESNs were also leading on educational capacity building initiatives

Table 4
Overview of educational interventions, committees.

Educational interventions	Educational resources developed by ESNs	Membership of committees
<p>Written information</p> <ul style="list-style-type: none"> ● Shedding light on epilepsy ● Anti-epileptic medication. ● Epilepsy surgery & referral process. ● Epilepsy competency pack <p>In-service seminar</p> <ul style="list-style-type: none"> ● Epilepsy awareness ● Medication and side-effects ● Management of epilepsy and ID ● Documenting seizure activity. ● Ketogenic diet ● Buccal midazolam ● Epilepsy first aid ● New driving regulations <p>Teaching undergraduate & post-graduate education programmes</p> <ul style="list-style-type: none"> ● Epilepsy-related care (e.g. pregnancy & epilepsy) <p>One day course</p> <ul style="list-style-type: none"> ● Range of topics including buccal midazolam ● Epilepsy and acute seizure management <p>Education session</p> <ul style="list-style-type: none"> ● Epilepsy awareness & administration of buccal midazolam <p>Journal club presentation</p> <ul style="list-style-type: none"> ● New epilepsy information Ward-based session ● Epilepsy first aid ● Care of patient during seizure ● Recording seizure activity. ● Epilepsy surgery and post-operative care <p>Continuing education forum within hospital</p> <ul style="list-style-type: none"> ● Epilepsy-related care ● EPR <p>Presentation at conferences and seminar events</p> <ul style="list-style-type: none"> ● Epilepsy ● Glasgow coma scale and neurological assessment <p>Facilitating clinical learning through being ‘shadowed’</p> <ul style="list-style-type: none"> ● Epilepsy care and service delivery ● Role of ESN 	<p>Patient Information</p> <ul style="list-style-type: none"> ● Vagal Nerve Stimulation ● Wada test ● Video EEG/Epilepsy monitoring unit (EMU) ● Epilepsy surgery ● SUDEP ● Epilepsy nurse TAL ● Nurse triage service ● Anti-epileptic medication ● How to administer buccal midazolam ● Pharmacological information relating to pregnancy and anti-epilepsy drugs (AEDs), breastfeeding and AED therapy and side-effects of AED therapy in the new born. ● Pharmacological information for teenagers and young adults. ● Self-care plan post – epilepsy surgery ● Coping with seizures: Information for patients with an oral tumour ● Living well with epilepsy ● Ketogenic diet ● Folic Acid administration ● Brain tumour patient passport ● Seizure diary <p>Family/friends/other Information</p> <ul style="list-style-type: none"> ● What to do in the event of a seizure ● Teachers pack developed in conjunction with Epilepsy Ireland 	<p>Local Committee membership</p> <p>Epilepsy-specific</p> <ul style="list-style-type: none"> ● Epilepsy Steering Group ● Epilepsy EPR Group ● Transitional Care Framework Development Committee. <p>Non-epilepsy-related</p> <ul style="list-style-type: none"> ● Healthcare Records Committee ● Nurse Advisory Committee (Advancing Nurses’ Development Committee) ● Clinical Governance Committee ● CNS Committee ● Conference Committee <p>National/Regional Committee membership</p> <p>Epilepsy-specific</p> <ul style="list-style-type: none"> ● Lead Nurse on the National Care Programme ● Irish Epilepsy Nurses’ Group ● National Epilepsy EPR Steering Board ● EPR National Governance Board ● ESNs from all regions involved in SOP Development Working Groups ● Regional Epilepsy groups (Mid-West, Mid Leinster, Dublin North East, South) <p>Non-epilepsy-related</p> <ul style="list-style-type: none"> ● ANP National Association ANP Regional Committee ● West/North West Hospital Group (WNWHG) which meet quarterly to discuss matters/challenges arising in clinical nurse/midwife specialist roles <p>International Committee membership</p> <ul style="list-style-type: none"> ● UK Epilepsy Specialist Nurses Association

involving the wider healthcare workforce, both within and outside their own organisation. This finding is important given the many unmet needs that PWE experience in relation to education and service provision [5–8,13,50,60].

In addition to building capacity within the wider MDT by supporting the development of candidate ANPs, the aim that every PWE in Ireland would have access to an integrated model of care that is ‘national, population based, multidisciplinary, collaborative and predominately nurse-led’ [15]:19 was being realised. These findings also demonstrate how the ESNs were responding to the wider national discourse around using their advanced expert knowledge to educate members of the health care team in the quest for better health outcomes [45], an area of leadership that does not appear to be emphasised in the international literature on advanced nursing practice [51,19,52].

The sharing of clinical information in a timely manner, within and across organisations, is viewed as key to achieving effective disease management [53,15]. Despite the existence of the Electronic Patient Record (EPR), its adoption into clinical practice is often slow to materialise as it involves an inter-relatedness of human, organisational and technological systems [36,54]. Although the socio-technical nature of the change involving health informatics projects is increasing, findings

from this study clearly indicate the important role of the ESN in driving and supporting the implementation of the EPR. Although the NCPE [15] merely envisioned their role as users of the system, findings from the SENsE study indicate that they took a lead role in integrating the EPR into services, monitoring data entry and coordinating feedback on its use, thus enabling the person responsible for its development and national roll-out to improve the efficiency and effectiveness of the system.

Salmond and Echevarria [55]:12 assert that ‘to be major players in driving change nurses need to understand the factors driving change, the mandates for practice change and [have] the competencies (knowledge, skills and attitudes) needed for system wider success’. Findings from the SENsE study clearly indicate that the ESNs had the knowledge and skills necessary to initiate change, the negotiation and political skills required to build and sustain relationships to effect the changes, and the ‘know how’ to navigate the complexity of the health care system for the benefit of patients and families. There is no doubt that their years of experience within the health care environment and epilepsy care, coupled with their educational backgrounds meant that they were ideally positioned to identify gaps in services and lead on developing a comprehensive epilepsy service that enhanced the quality of the patient’s care journey and quality of care received. These findings

support the centrality of nursing leadership in ensuring service provision is terms of better access, enhanced patient journey, improved outcomes, and more productive and collegial working relationships and environments within services [56,20,32,33,57,58]. In addition, the findings have the potential to be used as a template to inform further research into the leadership component of the ESN role, as well as acting as indicators to support educators to develop the leadership competency of future ESNs as envisioned in the competency framework [29].

5. Limitations

Although the study provides new evidence on the leadership role of the ESN there are some methodological limitations that need to be considered when reading the findings. The generalisability of the findings beyond the five centres involved is limited by the relatively small sample size of ESNs involved. In addition, the ESNs involved in the study were very experienced clinicians with a range of academic qualifications which no doubt enhanced their leadership potential. While analysis was performed by more than one researcher and data was triangulated using multiple data collection methods and sources [59], there is potential for bias in the analysis, including observer bias during the observation. There is also the potential that those interviewed projected a more positive view of the ESNs leadership activity in a desire to ensure a positive evaluation. While documentary analysis was informative in terms of accessing information not evident during interviews and observations, all records are limited to some extent by the subjective view of the recorder and the time available to capture a detailed as opposed to a shorthand account of events. The short duration of the observation also limited the frequency of the leadership activities observed. In addition, the involvement of the ESNs in the recruitment of members of the MDT, PWE and family members may have biased the sample.

6. Conclusion

A review of the research evidence on the leadership and change 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 SENSe study through the use of multiple data types and sources provides empirical evidence that the ESNs were involved as key players in leading changes within the services. Although some were engaging in a wider range of leadership activities than others, the findings demonstrate that the ESNs were enacting their leadership role at both a strategic and patient-level, and were negotiating change across disciplinary, managerial and organisational boundaries. Not only were they improving accessibility to specialist epilepsy care and improving the knowledge and competence of practitioners to provide evidence-based care, some were actively supporting the development of the next generation of epilepsy specialists.

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.

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.

Conflicts of interest statement

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

Acknowledgements

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

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