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Supporting and empowering people with epilepsy: Contribution of the Epilepsy Specialist Nurses (SENsE study)

ABSTRACT

Purpose: To explore how Epilepsy Specialist Nurses in the Republic of Ireland enacted their clinical role.

Methods: Qualitative descriptive design that involved individual and focus group interviews, observation and documentary analysis. Data were collected from 12 Epilepsy Specialist Nurses working in five hospital-based epilepsy services in Ireland, 24 multidisciplinary team members, and 35 people with epilepsy and their family members were involved. Data were analysed in NVivo using an inductive and deductive approach.

Results: Epilepsy Specialist Nurses work out of a value base that gives primacy to collaboration, active participation, relationship-based care, and respect for the voices of PWE and family members. They are key players in empowering people to self-manage their illness, Core dimensions of their clinical role includes: performing a comprehensive assessment to inform care and treatment; providing person-centred education; monitoring the impact of care and treatment; providing education to family members and significant others; providing psychosocial care to optimise psychological wellness; co-ordinating care to enhance patients' journey; and quality assuring patient information.

Conclusion: Findings from this study highlight the key role ESNs played as members of the MDT in building and supporting PWE's capacity to self-manage their illness. However, they also indicate deficits in the provision of information on sudden unexpected death in epilepsy and how to disclose a diagnosis of epilepsy by the ESN, as well deficits in their knowledge and confidence in supporting people experiencing significant mental health morbidities.

Highlights:

- Epilepsy Specialist Nurses provide a range of service and clinical roles
- They are central to empowering people with epilepsy to self-manage their illness.
- They require support to increase their competence around mental health morbidities.
- They need to include strategies on how to disclose a diagnosis of epilepsy to others

Key words: Epilepsy, advanced practice, nurse specialists, clinical role, self- management, nursing

INTRODUCTION

Epilepsy is a chronic neurological condition characterised by recurring seizures and estimated to affect 50 million people worldwide (Mameniskiene et al. 2015) with a prevalence of between 5-10 per 1,000 persons (National Institute for Health and Care Excellence (NICE), 2012). Although epilepsy can cause significant health morbidities and negatively impact the person's quality of life, education, employment, and psychosocial functioning (Sample et al. 2006, Schachter & Andermann, 2008; Herman & Jacoby, 2009), with timely, appropriate and supportive clinical care two-thirds of people with epilepsy (PWE) enter long-term remission (Smithson & Hukins, 2008; NICE, 2012). There is increasing recognition that for optimal outcomes to be achieved, care needs to move from the traditional disease model of care where power resides in the clinician as knowledgeable expert, to a more collaborative partnership model that acknowledges the psychosocial context of people's lives and enhances people's ability to self-manage (Kirton et al. 2012). As members of the multidisciplinary team, Hill et al. (2017) assert that epilepsy speciality nurses (ESNs) have a particular clinical expertise that positions them as key players in building PWE's self-efficacy to self-manage.

BACKGROUND

Notwithstanding the mixed evidence in support of the effectiveness of ESN care (Ridsdale et al. 2000; Mills et al. 2002; Ridsdale, et al. 2002; Stephen et al. 2003; Helde et al. 2005; Kengne et al. 2008, Noble et al. 2013; Pfäfflin et al. 2016; Bradley et al. 2016; Higgins et al. 2018), internationally, the ESN is considered an integral part of the epilepsy multidisciplinary care team. Despite this few studies have been undertaken into how exactly ESNs enact their clinical role in practice. While writers indicate that the clinical aspect of the role spans the medical, social, emotional and educational aspects of epilepsy management (Splevings, 2000; Minshall, 2004; Dupras, 2005; Ford, 2012), much of the discussion on the role is based on anecdotal evidence. Only three studies were located that focused on how ESNs enacted their clinical role (Goodwin et al. 2004; Higgins et al. 2006; Hopkins and Irvine, 2012) and all three were UK based. Findings from Goodwin et al.'s (2004) national survey (76 ESNs), Higgins et al.'s (2006) interviews and diary entries (9 ESNs), and Hopkins and Irvine's (2012) focus groups (19 ESNs) identified the following dimensions of the role: assessment, education, psychological support of PWE; caseload management; and running of nurse-led clinics, with varying level of involvement in drug management. While these studies provide

important information, they are limited in terms of the evidence they provide on how ESNs perform their clinical role on a day-to-day basis and are based on one source of data, namely ESNs.

This paper reports on the clinical aspect of the ESN role arising from the Specialist Epilepsy Nurse(s) Evaluation [SENSE] study in the Republic of Ireland. Findings on the leadership and evidence based practice aspects of the role, as well as their impact on care experiences and satisfaction with care are reported elsewhere (Higgins et al. 2019, 2018 a,b).

Methods

To address the research question on the clinical role a descriptive qualitative design was used.

Study sites

Epilepsy services in the Republic of Ireland are provided through a public health system that is free through an income based medical card system for about 30% of the population, subsidised at secondary and tertiary care for the majority of the population and a side by side private health system that provides elective procedures for citizens who pay an additional private healthcare subsidy. Epilepsy services were recently reorganised under the National Epilepsy Care Programme (Health Service Executive, 2014), a government funded investment with the explicate aim to improve access and quality of epilepsy care. The programme employs an ethos of Nurse Specialist led care with an electronic real-time patient health record (EPR) shared across the centres that provide epilepsy services. The study took place in five epilepsy services (four adult services and one children's service) which were purposefully selected from different health areas in the Republic of Ireland because they employed ESNs as part of the MDT. Permission to access each site was given by the Director of Nursing and Medical Consultant.

Data collection

Data were collected using individual interviews with 12 ESNs and 24 key stakeholders who the ESNs were in contact as part of their role. The 24 key stakeholders were purposefully selected to ensure representation from disciplines, roles and sites. In addition each ESN was shadowed in practice by a member of the research team for a 2 hour period on at least two occasions. Focus group interviews were conducted with PWE (n=21) and family members (n=14), who were recruited by the ESNs. ESNs were also asked to provide the research team with any documentary evidence on their clinical role such as role descriptions, guidelines and

audits which was also used as a data source. The interviews and observation were guided by schedules developed by the research team (Table 1). Data were collected between 2013 and 2016 by two members of the research team (AH and JV), both experienced nurses and researchers. Greater detail on the recruitment process is published elsewhere (Higgins et al 2018b, 2019).

Table 1 Interview and observation schedules

<p>Interview schedule (ESN and Members of the MDT)</p> <ul style="list-style-type: none"> • Background to role and development of the clinical practice aspects of role • Core aspects of clinical role (assessment, diagnosis, referral for investigation, referral to other MDT members, prescribing medication/tests, changing medication, monitoring side effects, educational interventions, liaising with GPs/others, discharging, coordinating care, • Contribution to patient’s outcome (clinical outcomes, seizure control, waiting times, speed of access, early intervention, adherence to treatment, correct diagnosis, correct procedure, enhanced patient safety, decreased negative incidents, decreased admission rates, shorter length of stay) • Contribution to patient’s psycho/social outcome (increased quality of life, increased patient knowledge, patient satisfaction, enhanced self-management, decision making, decreased anxiety) • Contribution to family outcome (clinical outcomes, waiting times, patient education, shared decision making, adherence to care plan)
<p>Observation schedule (ESN)</p> <ul style="list-style-type: none"> • Services delivered • Context of care (physical environment, MDT members, governance structures) • Assessments/diagnosis (focus, strategies used) • Role in interventions/treatment offered (including clinical investigations/tests medication regime, education, clinics, psychosocial, education) • Engagement with family/carers (frequency, purpose, mediums used) • Referral/liaison (referral to other nurses, doctors, professionals, within and outside service) • Initiating / ending health care episodes (accepting referrals, discharge planning)
<p>Focus group schedule (PWE and Family)</p> <ul style="list-style-type: none"> • Experience of ESN role in relation to assessment, emotional and practical support to manage disease/symptoms, education. continuity of care, referral & access to care • Relationship with the ESN • Satisfaction with communication and care provided: example of good care? Of not-so-good care? • Difference or value-added things (if any) that the care/support of ESN has made.. • Difference in the care/support given by the ESN (if any) compared to care given by other members of the health care team?

Sample

Participants included ESNs (n=12), Directors of Nursing (n=6), medical consultants (n=6), clinical nurse managers (n=2), allied health professionals (n=11), PWE (n=21) and family members (n=14). Table 2 provides further information on the profile of participants, inclusion criteria and the data collection method used with each group.

Table 2: Profile of participants

Data source	Data collection method
Epilepsy Specialist Nurses Gender: Female=12 Employment status: full time = 10; part time = 2 Time in current role: Mean = 5.42 years (SD = 5.69) Time working in epilepsy = Mean = 10.42 years (SD = 6.02). Role profile: Registered ANP ¹ s = 2; Candidate ANPs =5; CNS ¹ = 5; Prescriber of Medicinal Products = 7 Completed or completing Master Degrees (Epilepsy) = 8, Diploma/Postgraduate Diploma/Certificate in Epilepsy = 8	Individual interview 61 hours of observation
Directors of Nursing/ Assistant Directors = 5 Medical Consultants = 6 Clinical Nurse Managers = 2 Allied Professionals = 11	Individual interviews
People with epilepsy = 21 Inclusion criteria: i) physically well enough to take part; ii) able to give informed consent; and iii) hold a conversation in the English language Family members/carers = 14 Inclusion criteria: i) able to give informed consent; and ii) hold a conversation in the English language.	Focus groups x 5
Role descriptions, portfolios, committee membership, education or curriculum activity, guideline developed, research/audit	Documents
¹ Within the Republic of Ireland an Advanced Nurse Practitioner (ANP) is a nurse who works as an autonomous practitioner, holds a Master’s degree or higher and has four key dimensions to the role: namely, clinical practice, education, leadership and research. The Clinical Nurse Specialist (CNS) works with medical colleagues in an area of specialist practice, with a remit for patient care, including education and quality of patient care (NCNM, 2008a,b).	

Data analysis

Prior to analysis the interview transcripts and observational field notes were cleaned, anonymised and prepared for transfer into NVivo 10 (QSR International 2014). All interview and observational data relating to three ESNs were coded and a template of themes developed based on this analysis. Subsequent to this the remaining data, including the focus group and documentary data, were coded separately using the themes identified. To enhance rigor and consistency of coding analysis was undertaken by more than one member of the research team (AH; NE, JV), with final analysis and theme titles agreed based on consensus.

Ethical considerations

Ethical approval was granted by Research Ethics Committees in a University and participating healthcare sites. Written consent was obtained from all participants and verbal consent was obtained from people involved peripherally in the observation of the ESN. Where patients were aged under 18 or were perceived as vulnerable verbal assent was obtained from the person for observation and parental/guardian consent was obtained.

Irrespective of parental consent, children/adolescents who did not wish to be involved were not observed.

RESULTS

Analysis of the findings resulted in the following seven themes:

Table 3: Themes following analysis

- Completing comprehensive assessment to inform care and treatment;
- Providing person-centred education to empower PWE towards self-management;
- Systematic monitoring of impact of care and treatment;
- Providing education to family members and significant others to promote confidence to self-manage;
- Providing psychosocial care to optimise psychological wellness of person and family;
- Co-ordinating care and care-pathways to enhance patients' journey; and
- Quality assuring patient information recorded.

Prior to discussing the themes, to provide context a brief description of the services provided is offered.

Range of services provided

As part of the MDT, ESNs provided a range of services to children, adolescents and adults attending neurology or dedicated epilepsy services. The ESN caseload comprised a complex and diverse mix of PWE, including: pre-diagnosis patients; people who were seizure-free; had complex refractory epilepsy; had physical and mental co-morbidities; had varying degrees of ID and cognitive impairment; were pre and post neurosurgery; women who were considering pregnancy or were pregnant; and people with psychogenic non-epilepsy seizures. The number and type of clinics provided varied geographically, usually including general epilepsy clinics, in which the ESNs had their own cohort of PWE, as well as rapid access clinics (RACs) and vagal nerve stimulator (VNS) clinics. The RAC facilitated timely assessment and management of patients presenting with seizures to the Emergency Department or GP, while the VNS clinic provided a specialist service for patients post-

insertion of a VNS. Outreach services were provided in some areas to meet the specialist needs of pregnant women with epilepsy, people with intellectual disability (ID) in residential settings and older people living in care homes. In addition, ESNs operated a telephone advice line (TAL), aimed primarily at PWE and their families, although it was also utilised by some healthcare professionals e.g. GPs. This was service-specific in so far as it was only available to PWE who were attending the service where the TAL was offered, as the ESNs had access to their healthcare records.

Completing comprehensive assessment of needs to inform care and treatment (Theme A)

The ESNs believed that effective care required a person-centred approach that incorporated a comprehensive assessment, in collaboration with the PWE and/or family/carers. '*Knowing the whole*' person and having accurate and reliable information on their biography, interests, goals, wishes and context ensured that shared expectations were established and interventions were tailored to each person's unique needs. Thus assessment and '*getting to know*' the person was an iterative process that continued throughout the PWE's attendance at the service, whether the ESN's encounter was face-to-face or by telephone.

The EPR was the primary tool used by ESNs to structure healthcare information collected (Table 4 A1). Despite this systematic approach, the ESNs' questioning style was conversational in nature, allowing the person to tell their story in their own way. To achieve an accurate and succinct seizure history (onset, triggers, auras, seizure types, impact on awareness/consciousness, injury, recovery, headache, and potential triggers) (A2-A3), ESNs commenced by asking the person about their current state or most recent event and worked retrospectively. The ESNs thus not only got a detailed insight into each unique seizure story, but developed an in-depth understanding of the person's life context and any factors that might influence seizure management. ESNs also enquired about all aspects of physical health, especially if the person had a co-morbid physical health problem that might impact on their epilepsy (A4-A5).

Assessment included the wider psychosocial context of the person's life, through a discussion on family, relationships, education, and work (A6). The impact of the diagnosis and resultant subjective (stigma, depression, anxiety) and objective (impact on employment and driving) burden experienced (A7-A8), were assessed as well as lifestyle behaviours (alcohol or other substance abuse) that could impact on seizure control or put the person at risk (A9-A10).

The ESNs obtained a collateral history of seizures from family members, carers, and guardians including from parents of children and family/carers of people with ID or cognitive impairment (A11).

ESNs spent time ‘teasing out’ patterns and organising information to inform problem formulation and subsequent advice or care (A12-A13), leading to decisions on triaging care. As the ESN was the first point of contact for PWE and family they prioritised when to schedule appointments, arrange investigations or make referrals (A14).

The ESNs’ communication, relationship-building, and skill in ‘teasing out’ information to inform subsequent decision-making, were valued by the MDT, particularly the medical personnel (A15-A16).

Providing person-centered education to empower PWE towards self-management (Theme B)

A key aspect of the ESN role was education aimed at empowering PWE to self-manage. Education was applied in a person-centred manner to enable each person to understand their unique experience and note subtle and not-so subtle changes in their condition. Education included information on: epilepsy (causes, seizure types), interventions (medication, VNS, ketogenic diet, surgery), the importance of compliance, side-effects of interventions, lifestyle changes, resources available, and strategies to promote personal safety and minimise risks from seizures, medication side-effects or non-compliance (Table 4 B1- B2).

While the ESNs endeavoured to facilitate PWE to pursue interests and hobbies and live as unrestricted lives as possible, they provided education about potential lifestyle implications and changes needed to avoid dangers and comply with legal requirements (B3–B6). They provided timely information at times of transition, such as moving from childhood to adolescence, sitting examinations, going to college, changing employment, deciding to conceive (pre and post conceptual care) or holidaying (B7-B9).

ESNs also provided education on the role of tests and procedures associated with each person’s ongoing treatment (B10-B11), the purpose and use of the EPR, epilepsy and other support services (B12-B14).

ESNs working in surgery provided education in the preoperative phase to help PWE make informed decisions about surgery. Postoperative education was about giving patients confidence that they could manage post discharge (B15- B16).

Education was delivered during face-to-face encounters in clinics, over the TAL, on wards and through hospital-based group education sessions or in community outreach work, such as information evenings for PWE and their family/carers. Education was incorporated on an ongoing basis into each patient encounter, irrespective of the duration of time the person attended the service. ESNs were aware of the need to translate evidence and terminology into a language that patients understood, but also introduced PWE to the medical language required. ESNs also took account of the impact of distress, medication and other factors on the person's ability to process and recall information, by providing both verbal and written information, and repeating information, and continually checking understanding, to avoid information overload. ESNs always provided PWE with an open invitation to contact them, but they were mindful of the fine balance between providing reassurance and promoting independence (B17).

The more experienced ESNs adopted a coaching more than didactic style, constantly seeking to understand the PWE's perspective and their priorities for learning before engaging in education. Irrespective, most PWE, carers and MDT members affirmed the importance and value of the education provided by ESNs (B18-B19).

Systematic monitoring of impact of care and treatment (Theme C)

Another dimension of the clinical role involved the systematic follow-up and monitoring of the impact of treatment on the person's seizure pattern and quality of life. The ESNs monitored the impact of treatments, including VNS and surgery, and the impact of antiepileptic drug (AED) therapy. Whilst the goal of care is always complete seizure control with no side-effects, the ESNs were aware that all interventions could have both positive and negative effects on the person's quality of life. The ESNs' continual monitoring and assessment of the person's response to, compliance with, and any negative impacts of, the medication prescribed (Table 4 C1-C3) ensured early detection of adverse effects.

To assist in monitoring potential side-effects, ESNs undertook neurological assessments (C4-C5), and referred patients for blood tests to measure therapeutic levels of AED therapy or monitor other effects (C6). The seven ESNs who were Registered Nurse Prescribers (RNPs)

could increase, decrease, stop or prescribe medication under agreed prescribing protocols (C7). Those without prescribing authority provided advice to patients on increasing, decreasing or stopping medication, under the guidance of the medical consultant.

Providing education to family members and significant others to promote confidence (Theme D)

A large component of the ESN role involved educating family members and significant others, enabling them to feel confident to support the PWE both psychologically and practically, intervene in an emergency, and seek help or advice from others. ESNs educated family members on all aspects of epilepsy, with specific emphasis on first-aid seizure care, rescue medication and how to summon help (Table 4 D1-D3). As key informants around seizure type and duration, the ESNs educated family members on what to observe and how to keep accurate, up to-date seizure records using either a diary or taking a phone video (D4).

Education took on particular significance for parents of children with epilepsy who spoke of their fears and their need for skills to support their children psychologically (D6). Educating parents to ‘let go’ and support their children at adolescence to self-manage their epilepsy was an important dimension of the ESN’s role (D7).

Similarly, educating family members of people with ID or significant cognitive impairments was central, as in many situations they were supporting the person to maintain independence, manage their medications or access other interventions, such as VNS. Family members were also key providers of collateral information about changes in health status in response to interventions or treatments (D8).

Providing psychosocial care to optimise psychological wellness of person and family (Theme E)

Optimising psychological wellness and adaptation was a critical goal for ESNs. Psychosocial care and support occurred simultaneously with assessment, education and the provision of other treatments. Usually, psychosocial care was about listening, reassuring, providing information and bolstering the person’s or the family member’s motivation and confidence in self-management (Table 4 E1-E4).

There was significant variability in the ESNs’ skill level around assessment and response to more significant mental health morbidities, such as depression, anxiety, substance misuse,

thoughts of suicide or self-harm and working with people who had psychogenic non-epileptic seizures. A number of ESNs indicated a desire for further education, but all engaged with members of the MDT to ensure optimum care and management of these individuals, and advised and/or arranged referrals for patients (E5-E6), despite the challenges they were experiencing with the timely availability of specialist mental health services.

Co-ordinating care and care-pathways to enhance patients' journey (Theme F)

A key function of the ESN role was the co-ordination of care pathways for PWE across complex primary, secondary and tertiary services and across a diverse range of professional groups. The ESNs were valued by PWE, family and members of the MDT for being *'the glue that holds the service together'*, *'the constant within the team'*, *'the gatekeeper in keeping people in their homes'*, *'the point of contact'*, and the person who *'takes the patient on their epilepsy journey'*.

The success of this co-ordination role stemmed from their extensive knowledge of epilepsy services and each patient (Table 4 F1-F3). ESNs coordinated care across MDT teams and departments, prioritised need, improved patient flow and enhanced people's journey through the hospital services (F4-F7).

Co-ordination of care also involved working across different healthcare services (e.g. intellectual disability, mental health, paediatric and maternity), to provide a streamlined care pathway (F8-F10). As ESNs were the first point of contact, they also co-ordinated care between hospital and primary care services (e.g. GP, pharmacy) (F11-F12) and referred patients to a range of services and support organisations in the community (F13).

Quality assuring patient information recorded (Theme G)

ESNs also ensured the quality of information recorded by themselves, and other members of the MDT, in conjunction with their assessment function.. Checking the accuracy of biographical and health care information recorded in the EPR was seen as critical in the reduction of adverse events due to inaccuracy of information, including adverse drug events, as well as ensuring that information was sent in a timely manner to the correct location and correct member of the MDT and that any tests prescribed were carried out in a timely manner (Table 4 G1-G3).

Insert Table 4: Selected evidence to support themes A-G

DISCUSSION

Despite the ESN role being in existence in the UK since 1988 (Goodwin et al. 2004), there is only three studies that have attempted to capture the clinical role (Goodwin et al. 2004; Higgins et al. 2006; Hopkins and Irvine, 2012). This is the first study to our knowledge that used multiple data sources and methods to make explicit the clinical role the ESN plays within the MDT. The findings indicate that the ESNs provide a range of services and interventions to PWE across the age and healthcare continuum, and to people that are considered ‘neglected’ (Hopkins et al. 2010) within epilepsy services, such as pregnant women, people with ID and PWE living in care homes.

To support and empower PWE to self-manage their care, the ESNs complete comprehensive assessments, provide person-centred education and psychosocial care, monitor the impact of care and treatment, co-ordinate care and care-pathways and quality assure patient information. Although these dimensions of the clinical role are similar to other studies (Goodwin et al. 2004; Higgins et al. 2006; Hopkins et al. 2010), our findings make explicit the in-depth processes involved in each dimension. In addition, the research findings reveal that ESNs were aware that best outcomes are achieved when clinicians select and deliver care 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). Thus the ESNs underpinned their practices with the values that gave primacy to collaboration, participation, relationship-based care, and respect for the voices of PWE and family members.

It was through time spent ‘*getting to know the person*’ and the meaning they attached to their epilepsy and treatment, that ESNs were enabled to integrate individual biographical differences, beliefs, and goals into the plan of care, and deliver interventions in a person-centred and flexible manner. Whilst the ESNs were, on their own admission, more skilled in the physical and medical aspects of assessment, care and treatment, findings do suggest that they were endeavouring to address severe mental health morbidities within the limits of their competence and were challenged by deficits in the availability of timely specialist mental

health services. Addressing mental health morbidities in a timely manner, an area that is not always prioritised for PWE (Ridsdale et al. 1999; Varley et al. 2011; Noble et al. 2013), is important as not only can mental health issues directly impact compliance with treatment, but they can also increase the negative impact of epilepsy on quality of life and clinical outcomes (Kanner, 2003; Clancy et al. 2014).

In the context of epilepsy, education of the PWE is considered critical if self-management is to be achieved (Ridsdale et al. 1999; Helde et al. 2003; Doughty et al. 2003; Mameniskiene et al. 2015). Knowledge of epilepsy reduces fear associated with seizures, and enables PWE to make informed decisions regarding treatment, adapt positively to their diagnosis and educate others about epilepsy (Couldridge et al. 2001; Helde et al. 2003; Doughty et al. 2003; May & Pfäfflin, 2005). Findings from this study indicate that the ESNs considered education central to their clinical role. For the ESNs involved, education was not just about providing written and verbal information, but also about building the person's confidence and motivation to use their skills and knowledge to take control over their life and enable self-care and self-management.

Within the literature families/carers of PWE are reported as receiving low levels of practical and emotional support, and often lack the critical information needed to support PWE, including information on first-aid seizure management and side-effects of anti-epileptic drugs AEDs (Kendall et al. 2004; McEwan et al. 2007; Lewis et al. 2010). Findings from this study suggest that the ESNs provided education to all families and carers, including parents of children with epilepsy and carers of people with ID or cognitive impairment. Notwithstanding this, two aspects of education that were not evident within this study was the provision of information on sudden unexpected death in epilepsy and information on how to disclose a diagnosis of epilepsy to others. These are significant omissions in light of the guidelines (NICE, 2012; SIGN, 2018) and other literature (Lewis, 2011; Pembroke et al. 2017) that stresses their importance.

Literature on PWEs' experience of service provision within Ireland and elsewhere report delays in accessing services, poor integration between services, and a lack of communication between healthcare providers (Mahendran et al. 2017; Bradley et al. 2016; Varley et al. 2011; Bennett et al. 2016). Similar to other studies, the ESNs in this study were frequently the first point of contact for PWE and family members (Scrambler et al. 1996; Sarkissian & Wennberg, 1999; Mills et al. 2002; Kirton et al. 2012); consequently, to ensure that PWE, in

the majority of situations, experienced seamless care and did not fall through the ‘cracks’ of a busy and stretched service, the ESNs were not only referring and triaging PWE within the epilepsy service, but were improving continuity of care and transition care across the primary, secondary and tertiary interface.

LIMITATIONS

The finding of the study need to be read in the context of the following limitations. The findings are from one country where contextual factors and the small sample size may limit generalisability internationally. In addition the ESNs involved were all well-educated clinicians and experienced in epilepsy care. The involvement of the ESNs in recruitment of members of the MDT, PWE and family members may have biased the sample. While data were triangulated using multiple data collection methods and sources, and analysed by more than one researcher there is the potential for observer bias during observations. As the study was nationally funded, there is also a risk that participants, in a desire to ensure a positive evaluation, projected a more positive view of the ESNs’ clinical role.

CONCLUSION

Maximising outcomes for PWE requires an engaged and informed patient with knowledgeable clinicians that have a high of degree of epilepsy-specific knowledge as well as the skills to build partnerships, provide evidence-based interventions and assess, monitor and co-ordinate care in a responsive and flexible manner. Findings from this study highlight the key role ESNs played as members of the MDT in building and supporting PWE’s capacity to self-manage their illness. The findings can support educators to develop the competency of future ESNs as outlined in the competency framework (ENSA 2012); however, they do highlight the need for ESNs to include information on sudden unexpected death in epilepsy and disclosure when educating PWE. The findings also highlight the need to support ESNs to increase their competence in relation to significant mental health morbidities, as well as the need to develop specialist mental health services to ensure timely access.

Table 4: Selected evidence to support themes A-G

Theme A: Completing comprehensive assessment of needs to inform care and treatment	
A1	<i>I [ESN] use the EPR [epilepsy-specific Electronic Patient Record] as my guide because it's [EPR] very encompassing... move through their epilepsy history, how frequent their seizures are... look at anything else going on, provoking factors in their life that might make their seizures worse. (ESN interview)</i>
A2	<i>ESN does a detailed seizure history of last seizure, presence of warning, duration, time (night/day), feeling, photosensitivity; to help patient answer on triggers give examples of possibilities e.g. tiredness, stress. (ESN observation)</i>
A3	<i>ESN introduced herself as this was her first time meeting the patient in person. ESN confirmed a number of details including, GP, medication regime, recent seizure activity, epilepsy history, family history, childhood illness history, trauma history, birth history. (ESN observation)</i>
A4	<i>You'd talk about sleep, exercise, diet, different things about their lifestyle. (ESN interview)</i>
A5	<i>ESN asks about general health history including asthma, hypertension, sleep, explains that monitoring bone health is part of [ESN] role. (ESN observation)</i>
A6	<i>What they're doing with themselves, are they living on their own, are they in college or are they working, driving, , make sure you've discussed those support issues with them." (ESN interview)</i>
A7	<i>Some people struggle with how they developed epilepsy...it's kind of like a post-traumatic stress... some people find it very hard or maybe just in denial, but you would ask and talk about coping strategies." (ESN interview)</i>
A8	<i>Psychological issues, how are they getting on, mood, any memory problems, you have to consider all of those aspects every time you have that clinical encounter. (ESN interview)</i>
A9	<i>You have somebody who's drinking too much, or you've someone that's taking drugs that would affect their seizures. (ESN interview)</i>
A10	<i>Particularly teenagers, young adults, drug abuse, they'll tend to admit it more as we [ESNs] tease things out ... you have to ask about that. (ESN interview)</i>
A11	<i>Does a detailed seizure history with parents (son has ID). Asks about seizure types, changes in seizure frequency, medication dosage, compliance, side-effects, quality of life (alertness, communication). ESN asks focused questions and translates technical terms into lay terms with examples to help family identify seizure type. (ESN observation)</i>
A12	<i>Does detailed history of when symptoms appeared (drowsiness, drooling) as she [ESN] is trying to get a picture if some of the patient's symptoms is related to seizure activity, the medication prescribed, or something else. To help she names each drug and the side-effects and questions about each drug's side-effects separately. (ESN observation)</i>
A13	<i>When person rings the TAL] we ...go into the nitty gritty of why this [increase in seizures] is happening, is it something new, how long, have they missed medications, are they good at taking medications, have they any infections or any other reasons for causing increased seizure activity." (ESN interview)</i>
A14	<i>When you get a call, you have to triage call, you have to make sure that this person doesn't need to be dealt with immediately. Can you wait for the GP? Can they wait to come in for an appointment? Do they need to go to casualty? So you are constantly making sure you don't miss something." (ESN interview)</i>

A15	<i>We see a lot of the patients [PWE] who have learning disabilities, severe learning disability, associated behavioural disorders, and it can be very tricky trying to tease out is it the medication, or is it seizures, or something else that is making it difficult for them [PWE] ... and the nurses [ESNs] are particularly good at teasing those things out...</i> (Medical Consultant interview)
A16	<i>They [ESNs] know the formal support networks, the informal support networks ... family stressors, other dynamics happening in a family that might impact on their epilepsy and until you get to know a patient you're not going to know those things</i> (Allied health professional interview)
Theme B: Providing person-centered education to empower PWE towards self-management	
B1	<i>You are there to enhance and improve their knowledge of their condition and how to manage it...Our [ESN] responsibility is ensuring that they know everything about epilepsy, about seizures, how to identify seizures, the risks, know about all about their medication, when and how to take them, possible side-effects, the importance of compliance, rescue medication.</i> (ESN interview)
B2	<i>They need to know if they have a side-effect not to jump straightaway and stop taking the medications because that could cause rebound seizures.</i> (ESN interview)
B3	<i>You want people to lead as normal a life as possible but there is some changes that they'll have to make, like driving or occupational changes.....You'd also talk about alcohol, swimming, safety and how to protect a baby.</i> (ESN interview)
B4	<i>[ESN] informs patient of driving regulation, also discusses his recent stroke and motor ability. ESN explains that he will need a driving assessment done as it is not just the epilepsy that is the issue but also the physical weakness and motor ability.</i> (ESN observation)
B5	<i>ESN discusses safety precautions with a patient (82 years old very active man accompanied by his wife). Her discussion centres on baths, ladders and garden safety.</i> (ESN observation)
B6	<i>ESN discussed lifestyle implications with patient [young male]; focuses on socialising and alcohol, the importance of sleep and how to manage stress.</i> (ESN observation)
B7	<i>ESN rang me recently and said, do you want me to have a chat with [names daughter] about contraception. I said, yes you do it. ...I know if I mention anything [about contraception] she's, 'uh, please!'. Whereas, she'd [daughter] chat to her [ESN].</i> (FM focus group)
B8	<i>Education in pregnancy is a big thing, we go through everything. A lot of the concern would be the medicines...and the potential harm for that baby... some medications can be teratogenic to the unborn... one big question is 'will I have a seizure in labour?' so it might take an hour the first time you discuss with a woman... you give them written information to read as well.</i> (ESN interview)
B9	<i>ESN discusses work with a woman who recently commenced a job after long period of unemployment. The woman is anxious about the impact of medication on her memory. ESN discusses this and explores how stress and anxiety can exacerbate memory issues. ESN also discusses contraception as woman is currently in a relationship, they discuss the option of an IUD and ESN gives information on the pros and cons of having IUD inserted, procedure for insertion, and provides information on a local woman's clinic.</i> (ESN observation)
B10	<i>I had surgery. Before I had it I went through loads of tests. The girls [ESNs] explained all the tests and gave me confidence.</i> (PWE focus group)
B11	<i>Part of our role is being there for the patient, helping them understand why they're getting more regular blood tests</i> (ESN interview)
B12	<i>ESN explains the role and function of the EPR to patient and his wife. ESN also gives them an information leaflet on the EPR to take home and read.</i> (ESN observation)
B13	<i>Depending on need, you tell PWE about Epilepsy Ireland, linking them in to brain injury services. It's constant education, there's a new Epilepsy Ireland toolkit available to people, engage them with that and the local services.</i> (ESN interview)

B14	<i>ESN is a source of information for community supports other than epilepsy. ESN provides advice re accessing the community OT and physiotherapy as patient [who is in a wheelchair] would like to get a wheelchair that is easily transported in the car. (ESN observation)</i>
B15	<i>They [ESNs] understand the surgery, the benefit of surgery, how the surgery happens,so when the decision for surgery is made at the conference [MDT discussion]... she [the ESN] takes over, and communicates with the patient... explains about surgery, help them with that decision-making process... puts the things in process whereby they are prepared for surgery. But it is deeper than that, she creates the mental and psychological environment to support the patient to accept that decision and go forward for surgery. (Medical Consultant interview)</i>
B16	<i>ESN visits patient in ward who is post-surgery. She explains to the woman that she doesn't want her to worry when dressing is removed and wants her to be aware that swelling will be present, and what it feels like to the touch. She supports the woman to gently touch the area and feel the swelling that is currently present and note what it feels like when touched, suggesting that it feels spongy to touch. Also talks to her about the colour of the scar and what to expect in the next few days. Gives her time to ask questions and answers questions slowly checking the woman understanding. Sits closely, touching her arm gently, reassuring her continually. Also leaves written information leaflet about postoperative experience that she and colleague has developed. (ESN observation)</i>
B17	<i>Sometimes there is a risk that patients become dependent. Instead of making a decision themselves or planning themselves they run absolutely everything by the epilepsy nurse. So that's a balance. On the whole I think self-management is really important ... I think epilepsy nurses encourage people to be self-manage their disease but there is a risk that we encourage patients to become very dependent on us.(ESN interview)</i>
B18	<i>They [ESNs] are a huge knowledge reservoir and a huge support to people with epilepsy and their families. (Medical Consultant interview)</i>
B19	<i>She [the ESN] came over to the house. Spent a couple of hours answering all my questions and informing me, what was normal and what wasn't. I found that very very helpful. (PWE focus group)</i>

Theme C: Systematic monitoring of impact of care and treatment

C1	<i>You need to monitor the seizure frequency since they were last at the clinic or since the last medication change, has seizure frequency changed, if so how many, the duration, the intensity. (ESN interview)</i>
C2	<i>[names ESN] is full-time checking, ringing me, checking is the medication suiting me, listening to me. Making sure my seizure diary is complete (PWE focus group)</i>
C3	<i>The consultation is a telephone follow-up on a recent OPD visit. The ESN has a conversation with the mother of patient with ID about AEDs and the impact of recent changes. The change has reduced seizure activity but the patient has developed gastrointestinal upset. As the ESN explores and asks questions it becomes apparent that the gastrointestinal upset has pre-dated the change. The ESN goes into detail about the objectives of the treatment and long-term goals, and need to conduct a risk versus benefit examination in respect of 'side-effects versus seizures'. Explains potential treatment options to the patient based on her knowledge of the patient, her knowledge of AED therapy and advises the patient's mother re GIT upset and informs her that a letter will be sent to the patient's GP to make suggestions for follow-up. (ESN observation)</i>
C4	<i>I would do is a neuro assessment for the side-effect profile of the medication so I'd go through like any tremor, check their gait, check their pupils, any nystagmus." (ESN interview)</i>
C5	<i>ESN completes a neurological assessment (hand tremor, heel to toe walking). Explains that it is to check for toxicity of medication. Checks chart to check if liver function tests have been done recently. Bloods not done recently so gives choice to patient, return to GP or get test done in hospital today. (ESN observation)</i>
C6	<i>ESN explains to patient that her tremor may be a side-effect of her medication, suggests that they do</i>

C7	<p><i>a blood test to check blood levels of the drug. ESN explains to patient the reason for the test and what it may tell her. (ESN observation)</i></p> <p><i>ESN discusses blood serum levels of AED and discusses with the patient the rationale for increasing her medication. The patient agrees with this and they have a further discussion of how, when and why the patient should get a repeat blood serum level done. (ESN observation)</i></p>
Theme D: Providing education to family members and significant others to promote confidence to self-manage	
D1	<i>My mother was shown how to give [names rescue medication] to me (PWE focus group)</i>
D2	<i>ESN goes through procedure for giving rescue medication with husband (wife is post- surgery), so he knows what to do if required in an emergency and who to contact (ESN observation)</i>
D3	<i>They (parents) need to know what a seizure looks like, because they keep the records, so we put effort into teaching them. (ESN interview)</i>
D4	<i>When there is an uncertain around diagnosis, the [ESN] advises the partner or the sister or the mother to video [what they see] on their phone, because it is the sister or the mother that sees something, so that if there is something going on, and it is uncertain that is advice she (ESN) will give... they need to know what to do ... they need to know what are the things to be watching out for, that could lead to an intervention or prevents something significant.” (Medical Consultant interview)</i>
D5	<i>She’s [ESN] giving me tools to deal with my child...she enables you to cope...she gives you the confidence and the reassurance that you can help your child [when he has seizure]. Whereas, your consultant tells you he should be on X, Y, Z drugs. These might be the side-effects, they might keep the seizures away. very medically based. The nurse has a dual affect, she has the knowledge medically but she also helps you cope. (FM focus group)</i>
D6	<i>They [ESN] educate parents... spend the time as they're the person that reassures the child if they have a seizure and they're the point of contact if the child is having problems in school because he's had seizures, so they're counselling the parents (DoN interview)</i>
D7	<i>The relationship they've built up with the child and the parent means they are well placed to influence the parent to start letting go, start giving the child more responsibility around managing their epilepsy in the context of normal adolescence. (DoN interview)</i>
D8	<i>Patient (young man with ID) had VNS inserted recently. ESN explains to patient and parents what this is and how it works, She involves patient and giving time to parents to ask questions. Explains to parents and patient the procedure she is going to use to activate the device. Ensures they have understanding before proceeding, ...goes through the 'does and don'ts' of using the device and explores with them when they think is the best time to give a 'booster dose' based on seizure times. Reassures family that if anxious to ring the TAL and she or a colleague will ring back and go through any concerns they have so they don't have to travel if at all possible. Reassures them that she will be in a position to assess if they need to visit clinic. (ESN observation)</i>
Theme E: Providing psychosocial care to optimise psychological wellness of person and family	
E1	<i>The nurses [ESNs] are the people who pick up a lot of the psychological difficulties... they're [ESNs] the ones who are on the phone on a very regular basis... they're the ones at the coal face. That would be identifying any behavioural, emotional, or cognitive difficulties, they're [ESNs] talking to the parents [of children with epilepsy] on a very regular basis and they know the patients really well. (Allied health professional interview)</i>
E2	<i>I thought my child was going to die... so I needed to speak to someone ... somebody who's got that knowledge and can calm you down... the most important thing for me was getting to speak with [names ESN]. (FM focus group)</i>
E3	<i>ESN [on TAL to a male patient] discusses medication and seizure history, which leads into a discussion about patient commencing third level education in the next week. Asks about his fears and explores anxieties, and reassures him that he can contact her to talk at any time. (ESN observation)</i>

E4	<i>They [ESNs] see patients where it may be more important to discuss psycho-social issues with the patient [PWE] or with the relative that are not to do with the diagnosis or to do with the specific treatment, but they impact... I think the nurses are fantastic with this. (Medical Consultant 1 interview)</i>
E5	<i>She sent me to counselling to try and help me through [crisis in life and suicide thoughts] ...but she also helped me to come to terms with being diagnosed [with epilepsy] ... because I was in the middle of college and then being diagnosed, just in exam period time. (PWE focus group)</i>
E6	<i>We[ESNs] do a lot with psychiatry. There is a big over-lay with psychiatry in epilepsy ...so we would get onto the GP, arrange for urgent psychiatric involvement, while we don't directly refer ...we have often typed letters, got [neurology consultant] to sign it and faxed it to the [psychiatric] consultant or the GP or the child and adolescent mental health services. (ESN interview)</i>
Theme F: Co-ordinating care and care-pathways to enhance patients' journey	
F1	<i>The epilepsy nurses have an almost trans-disciplinary function, knowing what everybody does, and what everybody can contribute. (Allied health professional interview)</i>
F2	<i>Because of her knowledge of how the epilepsy system works, and knowing nurses in [names hospital around the country] she is able to ease the pathway of information between us and the primary epilepsy medical carer and vice versa....She [ESN] has the phone numbers, the contacts, she's meeting these people on an ongoing basis, so any of the really problem cases, she is able to provide a conduit for multidisciplinary care. (Medical Consultant interview)</i>
F3	<i>The team is changing, there'd be a different registrar, and there'll be a different SHO... so [by having the ESN] you're not talking to somebody different all the time. (PWE focus group)</i>
F4	<i>When problems arise the ESN they can pick up the phone and speak to the neurologist, so patient care, or changes in seizure behaviour is brought to the neurologist's attention sooner and then it can be acted upon. (DoN interview)</i>
F5	<i>[ESNs] decide to have the VNS clinic for people with ID at the beginning of the general epilepsy clinic to minimize travel and waiting time for PWE and ID. As a consultant is present for the epilepsy clinic and if patient coming to the VNS clinic require a medication review that requires consultant input it can happen on same visit. Thus PWE and families are saved from having to have 2 separate visits, and having to take extra time off [work]. (ESN observation)</i>
F6	<i>Patient is due into hospital for a scan – [ESN] also organises blood test and ECG forms and leaves at reception for [patient] to collect so can have test all done all on the one day, this prevents patient having to return to hospital on another occasion. [ESN] phones patient to tell her about leaving forms for blood test, ECG, and [her contact] phone number at reception (ESN observation)</i>
F7	<i>When patients come in through ED with the presentation of a seizure ... ED staff can call us, we'll come down and liaise with the registrar...it helps the flow of the patient either they are admitted or discharged. (ESN interview)</i>
F8	<i>The ESNs liaise with us [intellectual disability services] in relation to tracking different people's seizures, and then they liaise with the neurologist with regard to the medications...[ESNs] are able to tell us from the information we give them, whether they [PWE] need a sooner appointment or send us down prescriptions. (Allied health professional interview)</i>
F9	<i>ESN suggests a neuro-psychology referral to a specialist neurology centre [for a patient who had developed epilepsy following head trauma from fall]. ESN prepares the letter for referral following the consultation. (ESN observation)</i>
F10	<i>They've [ESNs] got more involved with the smoother transition of children from paediatric services into adult services and that is very much nurse-led.o" (DoN interview)</i>
F11	<i>[ESN] wrote letter to the patient's GP to ask that he/she organise a Dexascan locally, so patient did</i>

	<i>not have to travel a long distance.. (ESN observation)</i>
F12	<i>I rang [ESN] - [name of child] had a seizure in school. Within an hour, there was a new prescription being faxed to the pharmacy. (FM focus group)</i>
F13	<i>We're [ESN] dealing with people with very complex issues ... trying to see which way you can signpost or direct them to the right services ... because they come with all sorts of problems that might not be related to epilepsy... so you refer them back to either their GP or direct people to Epilepsy Ireland, the voluntary organisations, link them in to brain injury services. (ESN interview)</i>
Theme G: Quality assuring patient information recorded	
G1	<i>Explains about EPR and reassures patient about confidentiality. Explains that she needs to double check other information to make sure letters are going to the GP's correct address. (ESN observation)</i>
G2	<i>I want to make sure the patient is still at the same address, that this is still their phone number, making sure that I have all those details, they still with that GP.(ESN interview)</i>
G3	<i>It's important that you go through and check the investigations, is there any outstanding tests, has any test been missed, you go through the medications to make sure that there's no mistakes [in recording], because you can find mistakes or things missed. (ESN interview)</i>

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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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