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The epilepsy specialist nurse: A mixed-methods case study on the role and activities

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ABSTRACT

Purpose: To describe the role and activities of epilepsy specialist nurses (ESNs) operating as a team in the setting of a hospital specialising in the diagnosis and management of seizure disorders.
Methods: We conducted a descriptive mixed-methods embedded single case study. We recruited 9 ESNs, 14 of their professional colleagues and 9 'key informants' to analyse their perceptions of the role and activities of ESNs. We collected data through interviews, questionnaires, observations, and documentation. The study was conducted at the Filadelfia Epilepsy Hospital, Denmark.
Results: The team of ESNs offers holistic care to patients and their caregivers regarding the clinical, social, and emotional aspects of epilepsy. The ESNs are integrated in a multidisciplinary team and promote collaboration among the team members. ESNs also contribute to organisational aspects and perform research activities.
Conclusion: A structured group of ESNs can operate effectively and extensively in a specialised hospital setting. Our findings contribute to clarifying the description of the ESN's role, and provide an example of how ESNs can be incorporated into a hospital's organisational structure.

1. Introduction

The epilepsy specialist nurse (ESN) role was first created and described in the United Kingdom in 1988 [1], and has evolved since then. There is still a lack of clarity about the functions that constitute the role of an ESN [2,3], however, ESNs have a complex and multifaceted role as they operate in a range of settings, collaborate with different professional groups, and assist both patients and carers [4–6]. The ESN has been described as "an expert and essential part of the multidisciplinary team" [7] and it is recommended that every person with epilepsy (PWE) should have access to an ESN [8]. Although the training and education requirements for ESNs differ between countries [1], it is expected that anyone undertaking a specialist nursing role is a registered nurse with a minimum of five years' clinical experience [9,10]. Specialist training or graduate programmes have been established in some countries [1,11–13]. The International Council of Nurses [14] states that a specific graduate programme is important to enable nurses to think critically at an advanced level and to support other healthcare professionals in complex clinical scenarios [14].

The role of the ESN is underpinned by the principle of holistic care [3]. ESNs consider all aspects of the patient's life as part of a comprehensive assessment and care process incorporating lifestyle and psychosocial issues [3,15] and aiding diagnosis and treatment [2,16,17]. They offer information, education, and support with regard to clinical, social, and safety aspects [13,18]. These contributions provide patients and carers with the tools to cope successfully with epilepsy [19]. ESNs empower patients [16] by facilitating their autonomy and self-management [13]. ESNs provide continuity of care [20] by they follow patients throughout their lives [3,10,15,21,22] and act as a liaison among primary and secondary care, hospital and home, school or work, and health providers [10,20]. ESNs possess leadership skills and can exert an organisational influence by reviewing and suggesting improvements to services, policies, and guidelines and developing new standards [4,9,15]. ESNs develop knowledge at local, regional, and national levels [9], spread evidence-based practices [15], and participate in research projects [4].

The role of ESNs and the implementation of ESN services are varied and are influenced by organisational contexts and national factors

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[1–3]. The roles and activities of ESNs are often inconsistent between studies. They are frequently described without specific contextualisation [2,4], as a miscellaneous group [1,5,15], or as a niche aspect of broader studies [5,23]. Furthermore, little is known about the implementation of structured groups of ESNs in a specialised hospital setting. More precise information could help to clarify the role and activities of ESNs. Consequently, this study aims to describe the role and activities of ESNs operating as a team in the setting of a hospital specialising in the diagnosis and management of seizure disorders.

2. Methods

2.1. Design

We conducted a descriptive mixed-methods embedded single case study [24], and we adopted a constructivist epistemological approach [25]. A descriptive case study aims for a thorough description of a phenomenon occurring in a real-world context. It uses a narrative framework that provides essential facts about the phenomenon of interest, including relevant background information [24]. The single case structure is recommended when there is a critical case; the ESN group at the Filadelfia Hospital represents such a case. We believe that the presented case is unique as no other description of structured groups of ESNs operating in a specialised hospital has been reported in the literature. The term embedded means that multiple sub-units of analysis are involved [24].

2.2. Context

In contrast to many other regions, there are traditional epilepsy centres in Europe [26] that offer nursing care, medical treatment, schooling, education, and work opportunities for PWE, thus undertaking tasks that are not fulfilled by general hospitals. The European Association of Epilepsy Centers was initiated in 1988 and officially founded in 2001 [27]. It involves 12 highly specialised hospital centres, including the Filadelfia Epilepsy Hospital in Denmark [28] where we conducted this study.

The ESN's role at the Filadelfia Epilepsy Hospital is structurally implemented within the organisation, and the nine ESNs work within multidisciplinary teams in the adult and paediatric outpatient departments. The six ESNs in the paediatric outpatient department take care of both general PWE and those requiring sub-specialty care, such as surgical patients, patients with vagus nerve stimulators (VNS), patients on ketogenic diets (KD), and parents of children with epilepsy. Similarly, the three ESNs in the adult outpatient department take care of both general PWE and those requiring sub-specialty care, including surgical patients, patients with VNS, pregnant women with epilepsy, and PWE with severe intellectual disability (ID). The ESNs are structurally and functionally integrated into the hospital setting as a group of professionals with their own job description and professional requirements. As members of the multidisciplinary teams, they have their own location in the outpatient departments and conduct many unique tasks (e.g. coordination of the care path; liaison between the parties involved in the care process; provision of holistic care to patients and their families, caregivers, municipalities, teachers, and employers). The ESNs coordinate their own activities but collaborate with other staff members. The ESNs role is considered essential, and their professional colleagues and the hospital managers rely on their services.

2.3. Sample

As an embedded single case study, the sampled context was the Filadelfia Epilepsy Hospital and the embedded sub-units of analysis were purposefully selected (Fig. 1). This approach ensured triangulation of data sources and methods.

We recruited three samples. Firstly, we recruited 14 professionals who had worked in collaboration with the ESNs on a daily or weekly basis and thus, had a close relationship with them and knowledge about their work practice; two of these were members of the Danish Epilepsy Society and four were managers. Secondly, we recruited all nine ESNs working at the hospital. Thirdly, we recruited nine 'key informants' using both purposeful and convenience sampling to identify people with unique knowledge on some aspect of the role and activities of the ESNs. This group comprised neurologists, secretaries, research staff, and organisational staff.

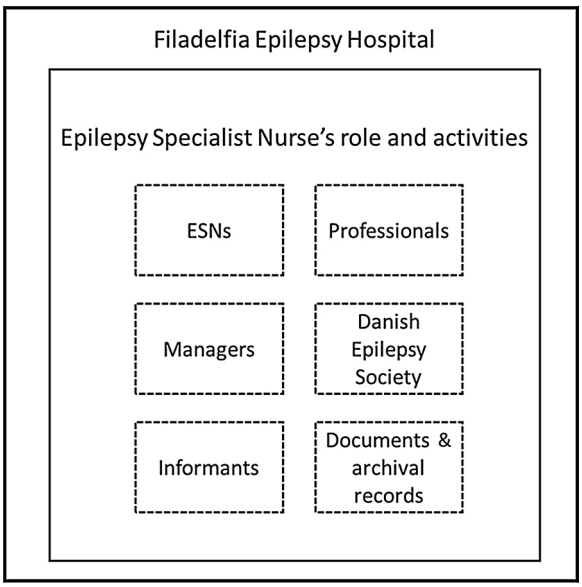

Fig. 1. A graphical representation of the case study involving epilepsy specialist nurses (ESNs).

2.4. Data collection and measurements

We collected data from June 2019 to September 2019 from different sub-units, as summarised in Table 1.

We developed a novel questionnaire to investigate the professionals' perceptions of the role and work of ESNs by modifying an existing questionnaire on feedback from medical colleagues [29] to make it

Table 1
Research objectives, sub-units, and data-gathering instruments.

Objective	Sub-units	Instruments
To explore the perspectives of the professionals collaborating with the epilepsy specialist nurses at the Filadelfia Hospital, following the propositions (Fig. 2) derived from the literature	Neurologists (n = 3) Nurses (n = 3) Psychologist (n = 1) Social worker (n = 1) Teacher (n = 1) Dietician (n = 1) Managers (n = 4)[a] Members of the Danish Epilepsy Society (n = 2)[b]	Questionnaire Oral discussion Semi-structured interview
To explore the perspectives of the epilepsy specialist nurses at the Filadelfia Hospital on their own role and activities, following the propositions (Fig. 2) derived from the literature	Epilepsy specialist nurses (n = 9)	Questionnaire Oral discussion Observations Field notes
To gain a comprehensive picture and guide on the context and on the role and activities of epilepsy specialty nurses at the Filadelfia Hospital	Informants (n = 9) Internal documents and archival records (n = 59)	Oral discussion Diary records

[a] Among the four managers, one is the social worker mentioned above.
[b] Among the two members, one is a neurologist mentioned above.

relevant to the practice of the ESN. The questionnaire investigated the theoretical propositions of this study (Fig. 2; see the 'Analysis' section below). It comprised 22 items measured on a 5-point Likert scale ranging from 1 (*very poor*) to 5 (*very good*). The results are presented as means and modes. We interviewed the professionals to explore their perceptions about the role and activities of the ESNs with whom they collaborated, as well as the limits and potential of the role of the ESN. We developed an interview guide based on the available literature, previous clinical experience, and discussion with our key informants.

We explored perceptions of ESNs regarding their own professional contribution using a questionnaire that we developed from a validated questionnaire for workplace satisfaction for nurses [30]. The questionnaire comprised 17 items grouped into three components: intrinsic ('how much you enjoy your job'), extrinsic ('doing your job'), and relational ('the people I work with'). Each item was rated on a 5-point Likert scale ranging from 1 (*totally disagree*) to 5 (*totally agree*). The results are presented as means and modes. We added five open-ended questions asking respondents to elaborate on some items. Furthermore, we interviewed the ESNs, asking them to explain and expand their answers to the questionnaire and to describe their activities and roles in more detail.

We generated handwritten field notes based on non-participants' observations of the ESNs' activities with patients during nursing consultations and interprofessional meetings, and participants' observations of the ESNs' activities that did not involve patients, such as office work and discussions with colleagues. We collected diary records and internal documents and held meetings and oral discussions with the nine key informants.

2.5. Analysis

The integration of qualitative and quantitative data allowed a thorough understanding of the role and activities of ESNs at the Filadelfia Epilepsy Hospital. We adopted method and data source triangulation, peer examination, inquiry audit, and thick description [24]. We grounded the data collection and analysis on six main themes derived from the literature [2–4,9,10,13,15–22], which in case study research are called 'propositions' [24] (Fig. 2). To follow a strong analytic strategy, we adopted pattern-matching logic because it is one of the most desirable techniques for case studies [24]. This logic compares an empirically based pattern with a predicted one. If the patterns coincide, the results can help strengthen the internal validity of the case study.

Each interview was audio-recorded, transcribed, and subjected to thematic analysis [31]. We used descriptive codes defined ex ante, except for specific themes that emerged during the study and that we coded ex post. Documents and archival records were critically analysed and integrated with the information obtained from the observations and the informants. We analysed quantitative data with descriptive statistics.

2.6. Ethics and rigour

The study was approved by the competent authorities at the Filadelfia Epilepsy Hospital. Each participant gave written consent for their

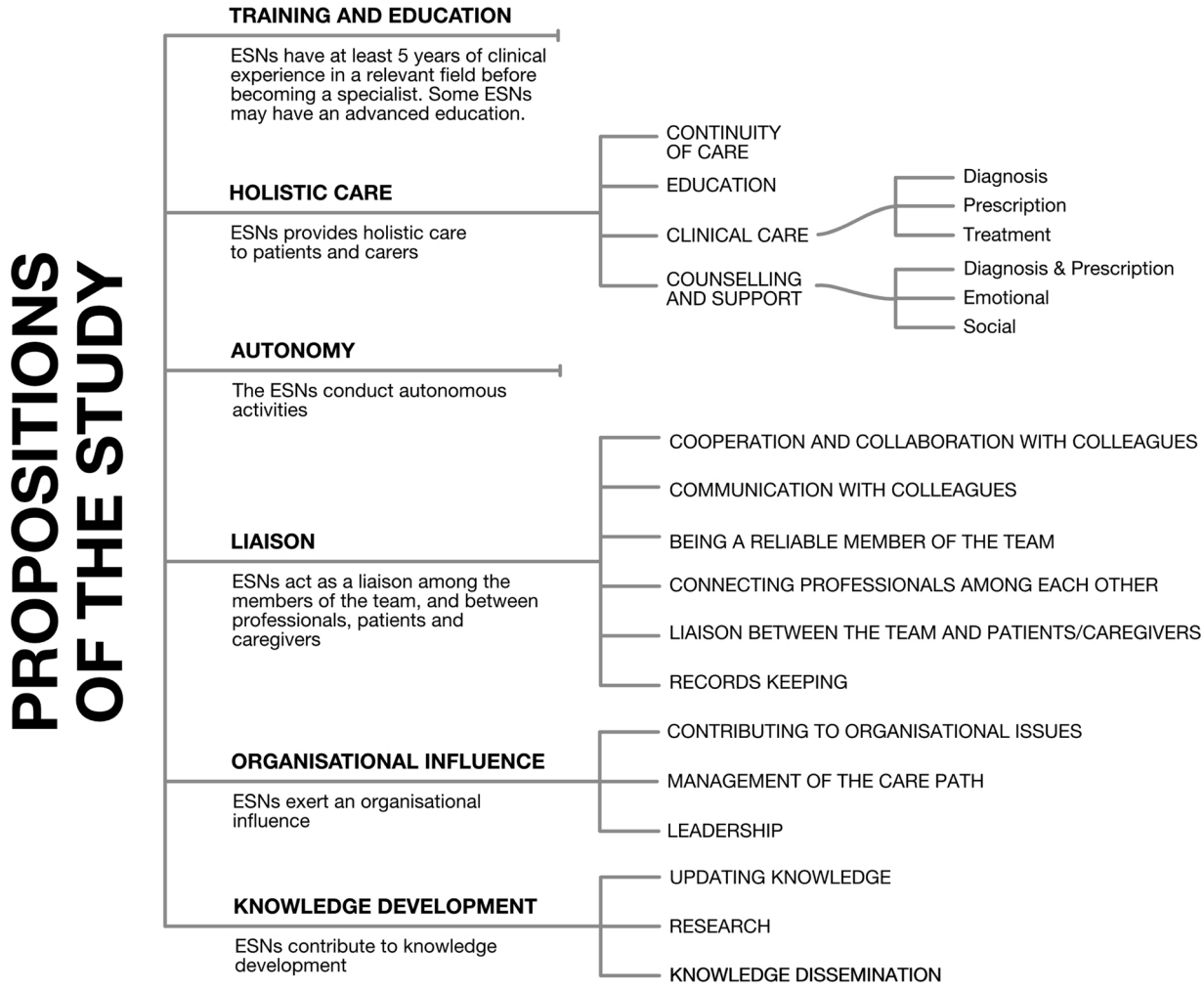

Fig. 2. The three-level propositions for our study. Abbreviation: ESNs, epilepsy specialist nurses.

participation [32]. To ensure construct validity, we triangulated data sources and defined the phenomenon with specific concepts, we asked key informants to review the initial report of the study, and we applied the chain of evidence during all the phases of the study [24]. We did not consider internal validity because it does not apply to descriptive studies, while we supported external validity by referring to the literature and the propositions when presenting our results. Furthermore, we ensured reliability using a case study protocol and database.

3. Results

We analysed the sub-dimensions within each main proposition by triangulating data from multiple sources. Based on the pattern-matching logic, grounding on the main propositions, and the empirical data collected, we present the results of the study for the six identified propositions (Fig. 2).

3.1. Education and training

Before becoming a specialist nurse, the ESNs had between 6 and 30 years (mean = 16) of clinical experience in either the neurological or paediatric field. At the time of the study, they had been working as an ESN from 2 to 22 years (mean = 8). Two of them had master's degrees and advanced education in nursing-related fields such as nursing education, systemic theory/social constructivism, and epilepsy specialist care. Although an advanced education is not mandatory to become an ESN in Denmark, the participants considered it important to have international standards for advanced and specialist nursing practices, and that national competencies should reflect those standards. Indeed, a member of the Danish Epilepsy Society stated that it would be relevant to 'educate ESNs in a systematic way, so that they have a standardised knowledge […] as it happens for medical specialisations'. In her opinion, this would also help employers to know what to expect from the role of an ESN. Indeed, participants noted that an unclear definition of the role of the ESN at the international or national level could lead to difficulties in how the role itself is understood. One ESN stated that 'new team members do not know what the specialist nurses do and what they can ask us about' and that a manager may believe that staff nurses and ESNs are interchangeable 'but they are really not, and it is not good if they are not well prepared on all the aspects a specialist nurse has to deal with. Since it is the managers who decide, they should know our role very well'.

3.2. Holistic care

ESNs support patients and carers in a multidimensional way, offering holistic care through several sub-dimensions. When ESNs and professionals were asked 'To what extent do the ESNs provide holistic care?', both groups agreed that ESNs provide continuity of care (means: ESNs = 4.9, professionals = 4.6; modes: ESNs = 5, professionals = 5), education to patients and carers (means: ESNs = 4.9, professionals = 4.7; modes: ESNs = 5, professionals = 5), clinical care (means: ESNs = 4.9, professionals = 4.7; modes: ESNs = 5, professionals = 5), and counselling and support to patients and carers (means: ESNs = 5.0, professionals = 4.6; modes: ESNs = 5, professionals = 5).

ESNs not only consider seizures and the patients' needs; they also adopt a holistic approach. They take a comprehensive view of the clinical, social, and emotional situations of patients and caregivers and provide care for all those dimensions. Several participants highlighted the difference between the holistic care provided by ESNs and the narrower focus of other professionals, as stated by a paediatric ESN:

> Nursing, and especially specialist nursing, is about trying to paint a picture of the future that has been destroyed when the patient got sick. Patients have to paint another picture of another future and I help them to do that. A part of that is knowing what to do with the illness, but another part is about building another life, that could be just as good, hopefully, as their life before the diagnosis.

During specialist nursing consultations, ESNs start investigating what patients and carers are most concerned about and how epilepsy affects their lives (e.g. worries about social life, fear about the side effects of antiepileptic drugs, and emotional burden). ESNs believe it is fundamental to listen actively to patients and to what their individual problems and needs are, so they devote time and attention to these issues in an empathetic meeting. ESNs can then proceed with the provision of specific education, guidance, and treatment. Indeed, patients are sometimes not worried about the same issues that professionals consider to be relevant. For example, professionals may be more focused on seizures, follow-up, treatments, or adherence to prescriptions. In contrast, patients and carers may feel more anxious about going out, meeting new people, feeling isolated, being a burden to their family, remembering to take their medications, being aware of the social support they can receive, or the rights they should have in the workplace.

ESNs provide care during follow-up through face-to-face nursing and telephone consultations for both general patients and sub-specialty patients. The duration of these consultations varies depending on the patients' needs. Nursing consultations within a sub-specialty usually last about 1 h, general nursing consultations about 45 min, and telephone consultations about 30 min. In addition to scheduled telephone appointments, ESNs have regularly allotted times for when their telephone lines are open (paediatric ESNs: three times a week for 1 h each; adult ESNs: every day for 1 h). They follow-up patients to manage new treatments, to titrate drugs previously prescribed by the neurologists, to check blood tests, and to assess quality of life and coping strategies. They inform and educate patients with VNSs about the device, and regulate it. They keep patients on KD motivated, educate them about diet types, and check how they and their caregivers are coping with the treatment. They inform candidates for surgery and their caregivers about how the surgery works and discuss their concerns; after the surgery, ESNs counsel them on practical daily issues. ESNs also provide continuity of care in transitional phases of life – for example, when transitioning from childhood to adulthood, and changing schools or employment.

ESNs not only educate patients and caregivers about epilepsy itself but also on how to adapt their lifestyle to cope with epilepsy. The professional colleagues reported how the multidisciplinary team considers ESNs the most appropriate specialists to provide holistic education. The professionals emphasised that ESNs have multidimensional competencies and knowledge about epilepsy and the various services available. ESNs teach parents how to be 'better parents' to their child with epilepsy and counsel them on how to face the difficulties of having a child with epilepsy; these endeavours limit the negative effects on the couple's relationship. ESNs also educate children about the epilepsy of their parents. Moreover, ESNs provide formal education to professional caregivers and schoolteachers who have PWE in their institutions. ESNs collaborate to create educational material covering a vast body of clinical, emotional, and practical issues.

The clinical care provided by ESNs is articulated in the dimensions of diagnosis, prescription, and treatment in the various sub-specialties (PWE candidates for surgery, PWE with VNS or on KD, PWE who are pregnant or have severe ID, and parents of children with epilepsy). While the clinical diagnosis is a medical responsibility, ESNs contribute to its correct formulation – for example, by identifying concomitant factors and differential diagnoses. While ESNs do not prescribe new antiepileptics, they manage the posology of the already prescribed antiepileptics. They prescribe investigations, such as blood tests and electroencephalography (EEG), and consultations with other professionals, such as psychologists or social workers. Furthermore, ESNs offer recommendations regarding the beginning, change, or end of treatments and actively collaborate in managing many of the aspects of treatment.

ESNs detect, counsel, and support patients and caregivers regarding the management of the physical, social, and emotional dimensions of epilepsy. As stated by a neurologist: 'The specialist nurses act as a sort of filter of simple problems. And they take some time to deal with these problems. They can do it easily, avoiding that these problems get more complicated'. Paediatric ESNs counsel adolescents regarding school and learning difficulties and issues with friends and parents. They also counsel and support schoolteachers by explaining how hard it is for the child to be in the school and clarifying what triggers the seizures, answering their questions, and offering help and suggestions. ESNs counsel and support parents on how to behave for their child's well-being and their own wellness. The daily concerns of parents could be about a wide range of aspects: medication-related issues, sleep patterns, the influence of stress, or alcohol. ESNs also have an understanding of the social aspects that can influence the quality of life of PWE. If the patient seems unaware of how the context may affect them, the ESN 'will always take the whole situation into account, voicing it for the patients and nudging them, taking time and energy to explain it to patients and making them reflect over it, for example, by saying: Would it perhaps be possible that you ask your office to start one hour later in the morning?'

3.3. Autonomy

ESNs have a wide degree of autonomy (means: ESNs = 4.7, professionals = 4.6; modes: ESNs = 5, professionals = 5) in various activities, also when working in a team. They autonomously conduct nursing consultations, provide education, manage admission programmes within their specialty, schedule consultations, and manage some aspects of the VNS, KD, and pharmacological therapies. As an ESN explained, '[For an ESN], autonomy means deciding what needs to be done immediately and what can wait, what can be handled independently and what needs to be discussed with another colleague, which means knowing your own limits'. However, some ESNs participating in the study believed that a lot of autonomy is not always a benefit and that working in a team and sharing decisions are relevant and helpful aspects. The ESNs considered that finding a balance between autonomous work and teamwork was very important and believed that everyone should respect this balance.

3.4. Liaison

ESNs have a relevant role in all the sub-dimensions of the liaison proposition (Fig. 2). The liaison role of ESNs was rated with a mean of 4.6 by ESNs and 4.5 by professionals, with a mode of 5 by both groups. The team in which ESNs work may be composed of ESNs, neurologists, dietitians, psychologists, social workers, teachers, nurses, secretaries, physiotherapists, and occupational therapists.

ESNs act as glue for the various clinical, social, educational, and emotional dimensions. They support and improve the connection and communication among the members of the team, between the team and patients and caregivers, and between the team and external professionals (such as teachers in schools). ESNs are considered by their colleagues to foster effective collaboration. As one dietitian described, 'The specialist nurses are like 'connetting threads': they have a holistic view of things, they connect different parties, and they know what is going on. They know what the next step is and what to do'. Indeed, ESNs are seen as role models by the other professionals in the team. The ESNs and their professional colleagues believed that effective communication occurs among all the members of the team in daily, weekly, and monthly meetings. However, ESNs believe the communication among themselves could be improved to enable sharing of their experiences and addressing doubts in their specialist nursing practice (ESNs rated the item regarding the communication among ESNs with a mean of 2.75 and a mode of 2). The professional colleagues considered ESNs to be reliable members of the team and that they improve the amount of information the team has regarding patient-related issues, thereby helping to formulate the correct diagnosis and treatment and to improve the amount and quality of information that patients will receive. Moreover, ESNs are perceived as go-to people by most of the team members because they provide answers to most of their doubts and questions, or else they know whom to ask.

Finally, ESNs are in contact with several departments and various professionals and managers, and they are believed to connect professionals among each other (professionals: mean = 4.3; mode = 5), as stated by a manager, 'The specialist nurses move around the whole organisation like nobody else does […] and I think that they help provide information on a crisscross. I think they do that more than the rest of us do'. In addition, ESNs facilitate the connection between the team and the patients. Given that many of the professionals on the team do not have the same availability to talk directly to the patients and carers, the specialist nurses are usually the primary point of contact. Besides connecting the team and patients within the Filadelfia Hospital, they link the team and patients with external parties such as schoolteachers, municipal social workers, workplace employers, and institutions. ESNs counsel the external parties to facilitate the proper management of PWE. During the interviews, the professional colleagues described the records of ESNs as 'thorough', 'comprehensive', 'clear and precise', and 'very informative'. These records allow every professional in the team to get the patient's full story.

3.5. Organisational influence

ESNs are involved in different organisational aspects at various levels (means: ESNs = 4.4, professionals = 4.5; modes: ESNs = 5, professionals = 5). ESNs participate in reviewing guidelines and procedures; in creating and updating educational material; in implementing projects, such as 'family-focused nursing care', aimed at involving the whole family in the care process; and the 'transitional care' project, aimed at supporting paediatric patients towards adulthood. Moreover, the participants often reported that ESNs manage the care paths for patients by coordinating the clinical, social, organisational, and individual aspects. A neurologist stated that ESNs have a 'bird's eye' view and see the patient's whole situation more than anybody else, 'combining the scientific and practical considerations'.

The leadership role of ESNs is sometimes neglected and mistaken for managerial competencies. However, ESNs with advanced education or longer experience appear to be more influential and guide both people and processes. Nursing managers stated that ESNs can lead themselves and their own work by organising and managing it without external guidance. Other nurses, professionals, and managers considered ESNs to be role models for guidance and development. For example, Filadelfia Hospital holds an annual Nursing Symposium, where the participants (including ESNs) reflect on a theme and develop strategies to address it. Some of the topics of the nine nursing symposia organised over the years have been 'The treatment of chronic patients' (2014), 'When the epilepsy patient's treatment process and everyday life have to be united' (2018), and 'Family-focused nursing for PWE' (2019). All interested professional groups in Denmark are welcome to join these events.

3.6. Knowledge development

ESNs are continuously updating their knowledge, especially in their sub-specialties, contribute to research activities and spread of knowledge among their colleagues (means: ESNs = 4.4, professionals = 4.4; modes: ESNs = 5, professionals = 5). ESNs develop and update their knowledge through interprofessional communication and meetings, as well as regular participation in courses, conferences, and journal clubs. Moreover, ESNs are encouraged by the hospital to pursue individual opportunities for professional development. ESNs are involved in nursing research projects and participate in clinical trials coordinated by other professionals. Most of the nursing research projects are managed by a research nurse, two development nurses (of which, one is also an

ESN), and an ESN, all with master's degrees. Examples of the nursing projects conducted or co-managed by ESNs investigate the implementation of a seizure monitoring app, the potential benefits for patients and organisations of ESN service, the effect of a ketogenic diets on patients' lives, the importance of involving healthy siblings in a child's epilepsy surgery path, the challenges of coping with epilepsy and parenting, and the value of being introduced to an ESN.

ESNs spread their knowledge to their colleagues inside the Filadelfia Hospital and other external professionals, such as schoolteachers from schools and institutions, social and occupational therapists, and nurses from other hospitals. This occurs both informally during daily work and through formal, structured approaches such as weekly and monthly meetings, the annual Filadelfia Hospital Nursing Symposium, and courses run by the educational department (where some ESNs also teach). Moreover, ESNs actively participate in national and international congresses through posters and oral presentations.

In conclusion, as a neurologist said, 'if the epilepsy specialist nurses were missing, a part of care would also be missing' because, as a nursing manager explained, 'epilepsy is more than tablets and seizures. It is about what is all around the patient, and these things are very important for patients. The specialist nurses can take care of everything that sorrounds seizures and can do it with a high level of quality'.

4. Discussion

We aimed to thoroughly describe the contribution that a structured group of ESNs makes to care and treatment in a hospital setting. To the best of our knowledge, this is the first study to do so. Our findings describe how a structured group of ESNs can function effectively in a specialised hospital context. ESNs offer truly holistic care to patients and their carers with regard to clinical, social, and emotional aspects of epilepsy, while also being well-integrated into the wider multidisciplinary team.

All the ESNs in our sample had more than 5 years of experience, which is consistent with the expected requirements for a nurse to become a clinical specialist nurse [9,10]. Some of the ESNs also had master's degrees, while others relied on extended clinical experience and incidental training, which on a formal level only makes them 'specialised' nurses [14] rather than 'specialist' nurses. A master's degree is not mandatory to be an ESN at the Filadelfia Hospital, and epilepsy specialist training does not yet exist in Denmark. Nevertheless, some participants felt that the vague definition of the role and its requirements hinders understanding and implementation of the ESN approach. Similarly, the existing literature suggests that a standardisation of the role of the ESN would promote the planning process and improve patient safety and quality of care [9]. The distinctive role of ESNs in providing holistic care [3,13,15] was confirmed by our results. We have no other structured group of ESNs to compare with, but other studies [1,7] are in line with our results showing that ESNs have varying degrees of autonomy through holding nurse-led clinics and working within multidisciplinary teams. In contrast to previous studies [1,23], these two activities are not mutually exclusive at the Filadelfia Hospital. Consistent with the literature [10,20], ESNs act as references and provide links within the multidisciplinary team.

Similarly to other studies [4,9,16], ESNs exert an organisational influence by reviewing guidelines and procedures, creating and updating educational material, implementing projects, and coordinating the care paths of patients. Contrary to previous research [9,15], the leadership traits of ESNs did not emerge clearly in our study. This can be due to an imperfect understanding of the role and a lack of non-clinical advanced skills by ESNs who do not possess an advanced education. Furthermore, other professionals and the overall organisation do not seem to expect leadership traits from ESNs. Consistent with the literature [4,9,15], the ESNs in our sample develop their knowledge and share it with the multidisciplinary team. Contrary to previous studies and competency frameworks [9,15], most of the ESNs in our study participate in clinical trials but not always in nursing research. This is probably due to their primary clinical focus, high clinical workload, and, sometimes, lack of specific research competencies and advanced education.

4.1. Strengths and limitations

Our results may be not directly transferable to other setting as the Filadelfia Hospital is a specialised epilepsy hospital. However, the results may provide further support for the development and implementation of the role of ESN in other contexts. In the absence of validated questionnaires relating to ESN, we developed two new questionnaires; however, the use of previously validated questionnaires would have increased the validity of the collected data. The wide variety of data sources and mixed-methods approach have jointly strengthened the validity of this study.

5. Conclusion

This study has shown how a group of epilepsy specialist nurses has been incorporated in a structured way into a hospital setting, allowing the provision of an extensive and integrated service. Our findings provide an example for others who may wish to develop the role of the ESN in other contexts through a group of ESNs and not as a solitary presence. This case study could also inform the development of specialist nurses' groups for other chronic medical conditions and in non-hospital settings, such as community healthcare services. Although we recognise that countries have different regulations, educational approaches, and health service organisations, it is important to clarify the role and activities of the ESN at an international level and then adapt it to the specific national context. Wider dissemination about the role of the ESN would improve understanding and implementation, and future directions should consider how to harmonise and regulate the various nursing roles [12,33,34].

Further research is needed to explore the perceptions of patients and families of the ESN service [22], possibly comparing them with those of patients not receiving care from ESNs. It may also be useful to analyse the role and activities of ESNs in other epilepsy centres and other contexts to identify similarities and differences, and to compare the clinical, organisational, and economic outcomes of settings with and without ESN services. It would also be relevant to investigate how to further evolve and improve the role of the ESN where it is already implemented and how to disseminate knowledge about the role of the ESN to potential stakeholders.

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Declaration of Competing Interest

The authors report no declarations of interest.

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