

Determining the role and responsibilities of the community epilepsy nurse in the management of epilepsy

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Abstract

Aims and Objectives: The aim of this study is to enhance the understanding of the core elements and influencing factors on the community-based epilepsy nurse's role and responsibilities.

Background: Internationally, epilepsy nurse specialists play a key role in providing person-centred care and management of epilepsy but there is a gap in understanding of their role in the community.

Design: A national three-stage, mixed-method study was conducted.

Methods: One-on-one, in-depth semi-structured qualitative interviews were conducted online with 12 community-based epilepsy nurses (Stage 1); retrospective analysis of data collected from the National Epilepsy Line, a nurse-led community helpline (Stage 2); and focus group conducted with four epilepsy nurses, to delve further into emerging findings (Stage 3). A thematic analysis was conducted in Stages 1 and 3, and a descriptive statistical analysis of Stage 2 data. Consolidated Criteria for Reporting Qualitative studies checklist was followed for reporting.

Results: Three key themes emerged: (1) *The epilepsy nurse career trajectory* highlighted a lack of standardised qualifications, competencies, and career opportunities. (2) *The key components of the epilepsy nurse role* explored role diversity, responsibilities, and models of practice in the management of living with epilepsy, and experiences navigating complex fragmented systems and practices. (3) *Shifting work practices* detailed the adapting work practices, impacted by changing service demands, including COVID-19 pandemic experiences, role boundaries, funding, and resource availability.

Conclusion: Community epilepsy nurses play a pivotal role in providing holistic, person-centred epilepsy management. They contribute to identifying and addressing service gaps through innovating and implementing change in service design and delivery.

Relevance to Clinical Practice: Epilepsy nurses' person-centred approach to epilepsy management is influenced by the limited investment in epilepsy-specific integrated care initiatives, and their perceived value is impacted by the lack of national standardisation of their role and scope of practice.

No Patient or Public Contribution: Only epilepsy nurses' perspectives were sought.

KEYWORDS

career trajectory, epilepsy nurses, person-centred care, role diversity, service demands

1 | BACKGROUND

Epilepsy is one of the most common neurological conditions, affecting approximately 50 million people worldwide and causing up to 0.5% of the total disease burden globally (World Health Organisation, 2019). In Australia, an estimated 250,000 people live with epilepsy, with approximately 70% attaining good seizure control with antiseizure medication (ASM) (Deloitte Access Economics, 2020). Compounding the disabling impact of living with epilepsy are the side effects of ASMs, stigma, and economic

impact, which contribute to further physical, behavioural, cognitive, and psychological challenges (Jacoby & Baker, 2008; Peterson et al., 2019; Welton et al., 2020). Hence, both controlled and uncontrolled epilepsy can affect people of all ages and their family members, with far-reaching impacts on the family's psychosocial well-being (Deloitte Access Economics, 2020). In Australia, dealing with the complexity of an epilepsy diagnosis is challenging, under fragmented health and social care systems and inequitable access to care in rural and remote areas (Deloitte Access Economics, 2020; Hutchinson, Herkes, et al., 2020; Hutchinson, Ryder, et al., 2020; Welton et al., 2020).

What does this article contribute to the wider global clinical community?

- Epilepsy nurses are champions at fostering person-centred and holistic care for the person and their family and play a central role in extending care beyond the hospital units and clinic.
- Despite epilepsy nurses playing a key role in identifying and addressing gaps through implementing innovative changes in practice and service delivery in the community, limited investment in epilepsy-specific integrated care initiatives hamper connectivity across the epilepsy care continuum.
- Investing in a specific epilepsy nurse competency framework is fundamental to standardise the level and scope of practice, build capacity and consistency of the epilepsy nurse workforce, improve workforce planning, raise profile and value, and facilitate a clear structure for career development and progression.

1.1 | Person-centred integrated care

Many people living with epilepsy (PLWE) have one or more comorbid chronic health conditions. Consequently, international health care policy reforms promote the adoption of a more holistic approach to epilepsy management and integrated person-centred care (PCC) approach, believed fundamental to improving PLWE, family, and care provider experiences (Hutchinson, Ryder, et al., 2020; Lystad et al., 2020; Power et al., 2020; Sikka et al., 2015). PCC 'represents an approach to improve the quality and cost-effectiveness of care by ensuring that services are well-coordinated around people's needs' (Goodwin et al., 2021, p. 22). However, applying integrated PCC to complex conditions like epilepsy is challenging because of the diverse approaches to the concept adopted across health and psychosocial care, rather than focusing on particular components and policies that contribute to the success of integrated care (Goodwin et al., 2021; Hutchinson, Ryder, et al., 2020).

1.2 | Australian health and social care

Within the Australian context, there is increasing focus on creating health systems that are more integrated, efficient, person-centred, and equitable, to better support the management of chronic conditions, to ensure people remain healthy in the community (Australian Government Department of Health, 2019; NSW Government Health, 2020). Yet despite this commitment, limited cross-sector working and 'siloed' funding models have led to service fragmentation and services being provided and funded inequitably across disability, health, and aged care sectors (Hutchinson, Herkes, et al., 2020; Rapport et al., 2019; Schroeder & Cutler, 2021). In

addition, not-for-profit (NFP) organisations play a significant role in providing services to the community within the purview of each organisations' focus. These NFP organisations may collaborate with healthcare services and research institutions; however, they are external to services funded publicly (Lyons, 2020).

Consequently, in Australia, PLWE and their families report many hurdles navigating fragmented services. They report delays to specialist referral, geographical variations in care and services, ineffective communication, and insufficient knowledge and understanding of epilepsy among care providers in the community and primary care, resulting in an overreliance on specialist tertiary services (Hutchinson, Herkes, et al., 2020; Hutchinson, Ryder, et al., 2020; Lystad et al., 2020; Rapport et al., 2019). Such barriers can contribute to unnecessary hospitalizations, and poor health and psychosocial outcomes (Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018; Hutchinson, Herkes, et al., 2020; Rapport et al., 2019). Those from socioeconomically disadvantaged areas, marginalised, and culturally diverse populations encounter greater inequities and barriers to accessing routine primary health and social care, while being overrepresented in the hospital system (Hutchinson, Herkes, et al., 2020; Mumford et al., 2019). In this context, the nursing workforce has received international attention as significant contributors and leaders of system change towards integrated PCC (Delaney, 2018; World Health Organisation., 2020). More specifically, the epilepsy nurse (EN) has been identified as a key player in the delivery of integrated PCC (Higgins et al., 2020; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018; Hutchinson, Ryder, et al., 2020).

1.3 | Epilepsy nurses

Specialist nurses play an important role in psychosocial support, education, treatment, and risk management as well as providing solutions to the challenges faced by PLWE by facilitating greater coordination of care and acting as a communication 'conduit' with other health and social care providers within and across systems (Campbell et al., 2019; Higgins et al., 2020). These solutions provide foundational elements to building and sustaining integrated models of care (Campbell et al., 2019; Cashin et al., 2015, p. 408). ENs are regarded as integral members of epilepsy management teams being ideally positioned to 'act as an expert resource and point of first contact' for PLWE, families and health and social care providers (Campbell et al., 2019, p. 2; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018). ENs also demonstrate leadership skills in advancing their role, driving practice and system change (Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018; Pfäfflin et al., 2016).

The United Kingdom (UK) and Republic of Ireland drive the development of the EN role, promoting the inclusion of ENs in all epilepsy specialist teams through the National Institute of Clinical Excellence, the Scottish Intercollegiate Guidelines Network, and the Irish National Epilepsy Care Programme, although not yet fully

achieved (Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018; Sauro et al., 2015). However, the EN role is not standardised globally and is frequently developed in an ad hoc manner according to specific local requirements and the nurses' level of expertise (Campbell et al., 2019; Locatelli et al., 2021, p. 61). It could be argued that this patchwork emergence has been detrimental to workforce and service development planning, skill and knowledge transferability, career progression, engagement in research and provisioning of resources (Epilepsy Nurse Specialist Association, 2012; Higgins et al., 2020). The ambiguity over terminology used for ENs, qualifications and required experience, scope of practice and workforce training needs is an ongoing concern internationally (Campbell et al., 2019; Pfäfflin et al., 2016; Prevos-Morgant et al., 2019). Research has highlighted evidence gaps on the impact of the EN role supporting PLWE and their families, how support is provided, interprofessional relationships, as well as the barriers ENs faced in navigating fragmented services, and the elements of their role that support 'effective delivery of effective care' (Campbell et al., 2019, p. 46; Epilepsy Nurse Specialist Association, 2012; Prevos-Morgant et al., 2019).

ENs in Australia are employed by health, disability, and community sectors. However, there is a dearth of information regarding the roles and responsibilities of ENs within the Australian community context and a lack of knowledge of how their roles operate and link across sectors. The current study sets out to: (i) Enhance our understanding of the core elements of the EN role and responsibilities in the Australian community context; (ii) Understand the influences on the EN's delivery of care and support for PLWE and their families; (iii) Provide insights into the EN's career pathway, and their training, and education in Australia; and (iv) Clarify ENs contributions during a public health crisis (i.e., COVID-19) to strengthen service responses. It is hoped that the information gathered would have national and potentially global implications for EN role development.

2 | METHODS

2.1 | Ethics approval statement

Ethics approval for this study was granted by Macquarie University (HREC: 52020668117612).

2.2 | Study design

This study outlined three stages; Stage 1 involved one-on-one interviews with ENs; Stage 2 was a retrospective analysis of data collected from a national community helpline (the National Epilepsy Line [NEL]); and Stage 3 was a national focus group with ENs (Rapport et al., 2021). Semi-structured interviews (Stage 1) and one focus group (Stage 3) were conducted with ENs and fieldnotes were documented during both events. This design uses the Consolidated Criteria for Reporting Qualitative research (COREQ) checklist (File

S1; Tong et al., 2007), and provides a rich and detailed, comprehensive dataset to ensure a better understanding of the roles and responsibilities of ENs (Braun & Clarke, 2019). A mixed-methods approach was taken to data analysis, following a convergent parallel design, involving two qualitative stages and one quantitative stage (Creswell & Plano, 2011). Qualitative data were collected and analysed sequentially for Stages 1 and 3, with the early findings of the interview data analysis informing the topic guide for the subsequent focus group, providing further opportunity to clarify, validate, and explore topics arising from the interviews, and embellish meaning between participating ENs (Braun & Clarke, 2019). Stage 2 involved retrospective analysis of Epilepsy Action Australia's (EAA) NEL telephone service data, from March 2019 to August 2020. Quantitative analysis of NEL data was conducted in parallel with the qualitative inquiry.

2.2.1 | Recruitment

Snowballing recruitment was carried out through EAA, the Epilepsy Foundation (EF) and Epilepsy Australia (EA), newsletters and social media networks. Any self-identifying EN working in primary or community care in Australia was eligible to participate. Interested participants contacted the research team via email and had an opportunity to discuss by phone the study and read through the Participant Information and Consent Form. All participants gave signed written consent prior to data collection.

Following preliminary interviews and data analyses, participants were contacted by the research team and invited to participate in a focus group. The purpose of the focus group was to seek clarification regarding issues raised in the interviews, confirm early interpretations of the data, and further explore themes that had emerged from researcher discussions during early analysis. As with the interviews, the focus group was approximately 1 h long and held via videoconferencing. The meeting was audio-recorded and transcribed verbatim.

2.2.2 | Participants

A total of 12 ENs (Table 1) working in the community care sector participated in semi-structured interviews (Stage 1). Four ENs from Stage 1 then attended a focus group as part of Stage 3. Quotes from Stage 1 were assigned individual identification numbers (EN1-12), and quotes from Stage 3 are indicated by 'FG'.

2.3 | Materials and methods

2.3.1 | Demographic questionnaire and interviews

EN participants completed a demographic questionnaire which collected information on age, gender, qualifications, and current employment

TABLE 1 Epilepsy nurse participant characteristic

	Stage 1 interviews	
	n	%
Gender		
Male	-	
Female	12	100
Other/No answer	-	
Age		
≤30years	-	
31–40years	2	16.7
41–50years	3	25
51–60years	6	50
≥61 years	1	8.3
Aboriginal and/or Torres Strait Islander		
Yes	-	
No	12	100
Speak language other than English		
Yes	1	8.3
No	11	91.7
Job title(s) ^a		
Epilepsy Nurse Specialist	5	41.7
Epilepsy Educator	3	25
Licensed Epilepsy Trainer	2	16.7
Clinical Nurse Consultant	2	16.7
Other	1	8.3
Employer		
Not-for-profit epilepsy organisations (2 organisations)	10	83.3
Disability organisation	1	8.3
New South Wales health	1	8.3
Employment type		
Full-time	5	41.7
Part-time (<1.0 FTE)	6	50
Casual	1	8.3
Time in current role		
<5 years	4	33.3
5–10years	3	25
>10years	5	41.7
Mean months	119	
Experience in the field of epilepsy		
≤10years	4	33.3
11–20years	4	33.3
≥20years	3	25
Unknown	1	8.3
Client population		
Adults only	1	8.3

(Continues)

TABLE 1 (Continued)

	Stage 1 interviews	
	n	%
Paediatric only	2	16.7
Both adults and paediatrics	9	75
State location		
New South Wales	5	41.7
Victoria	3	25
Queensland	1	8.3
Western Australia	2	16.7
South Australia	1	8.3
Epilepsy specific qualifications obtained		
Postgraduate university courses in the United Kingdom	5	41.7
Epilepsy organisations internal training—Australia	10	83.3
Prescribing course—Ireland	1	8.3
Cannabis Nursing—US	1	8.3
Other work-related non-epilepsy qualifications		
Certificate IV in teaching and training—Australia	7	58.3
Master's in Education	1	8.3

^aCould provide more than one, therefore total > 12.

details. Semi-structured interviews were conducted via videoconferencing and followed a semi-structured interview guide derived from the literature and previous team research (Higgins et al., 2019a, 2019b; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018; Hutchinson, Herkes, et al., 2020; Hutchinson, Ryder, et al., 2020). The interviews focused on the EN's career trajectory, qualifications, and their roles and responsibilities in the community with prompts for ENs to elaborate further on relevant experiences. All interviews averaged 1 h, were audio-recorded and transcribed verbatim. Transcripts were deidentified for data analysis.

2.3.2 | National epilepsy line (NEL) data

The NEL, funded by the Australian Government Department of Health and delivered and managed by EAA, is a free service and the entry point to EAA services, including individual service programs and epilepsy education. Callers can enter the NEL via the 1300 EPILEPSY phone number or electronically via social media, the EAA website, or email. At the time of this study, the NEL used an outsourced service model whereby callers were triaged by a government preferred provider, Medibank Health Service (MHS). MHS registered nurses support a range of helplines, having been trained to answer calls across a range of topics related to epilepsy. Since this research, the NEL operational service model has been adjusted to a new service model (outside the scope of this article).

Information is collected about the PLWE (either from first person or informant report), the reason for the call, and the call outcome (e.g., a referral to an EN for an individual service program). The caller listened to a recorded message and if they proceeded to provide personal details, this was taken as implied consent for their information to be stored in the client management system. For those younger than 16 years of age or those unable to give consent, a legal guardian was required to provide consent. If consent is not given, then ENs provide only general information. All NEL data provided for this study were deidentified by EAA. For this study, only data from telephone calls were included and therefore did not represent the full extent of the contacts made to the NEL.

2.4 | Data analysis

The analysis of the qualitative data began with familiarisation of the dataset. The de-identified interview transcripts were analysed thematically in NVivo 12 by four researchers (QSR International., 1999). The analytical approach was both inductive and deductive, with themes reflecting the explicit content of the data, and assuming a realist perspective (Braun et al., 2019). Codes were synthesised through a series of collaborative and reflexive discussions between researchers and key frames subframes were used to develop an agreed framework for coding all interviews (Braun et al., 2019). The analysis involved an iterative process of refining and adding codes and clustering simple descriptive codes within high-level categories. Data from the focus group were coded deductively using an existing coding framework developed from the interviews.

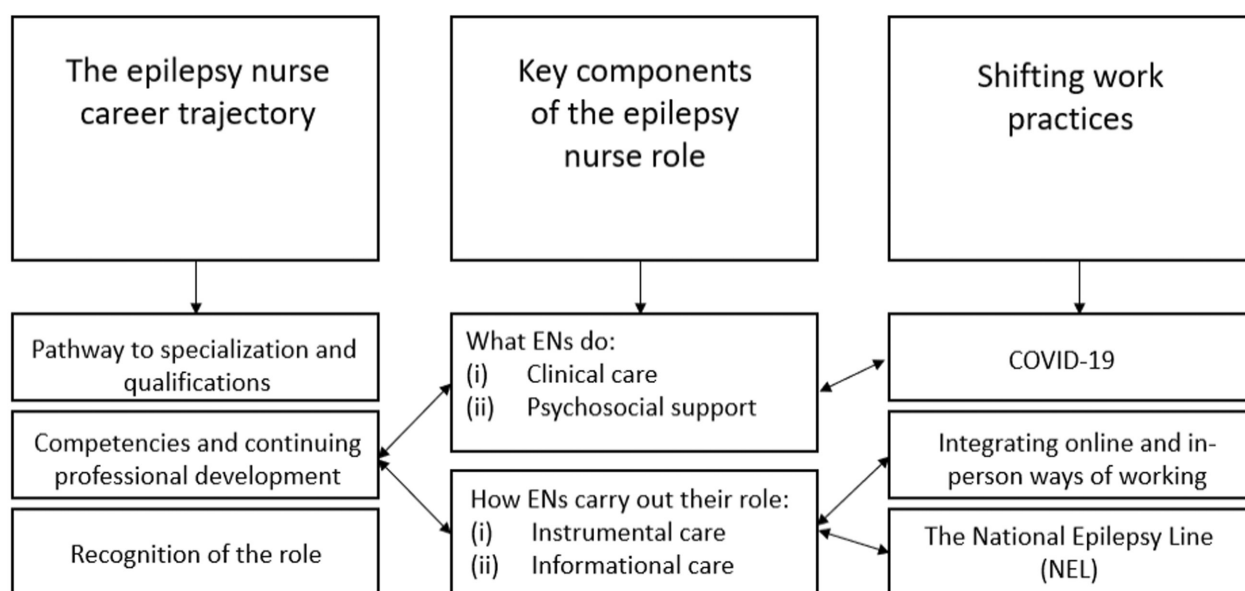
Quantitative data analysis was conducted using SAS® software version 9.4 (Holcomb, 2016). A unique client ID was created to identify repeated calls and the caller's relationship to the client. Descriptive statistics of client characteristics and call-specific information, including presenting need and call outcome, were calculated.

3 | RESULTS

Three key themes emerged, delineating the role and responsibilities of EN specialists in the Australian community context. First, *the epilepsy nurse career trajectory*, which considers qualifications, competencies, and career opportunities for community-based epilepsy nurses. Second, *the key components of the epilepsy nurse role*; encompassing role diversity, responsibilities, and models of practice in the management of living with epilepsy, and experiences navigating complex systems and practices. Third, *shifting work practices*, which explores the adapting work practices of community ENs, impacted by changing service demands, role boundaries, funding, and resource availability. Key themes and related sub-themes are outlined in Figure 1 and described in more detail below.

3.1 | The epilepsy nurse career trajectory

This theme highlighted the diversity in career trajectories of the nurses interviewed, in part a product of the lack of standardisation in requisite qualifications to becoming an EN in Australia. The diversity of roles and pathways was clearly reflected in the array of job



Themes are interrelated and consider the broader context of working in the community, including barriers to the role: Siloed practices, funding models, governance structures, and conflicting values and priorities.

FIGURE 1 Key themes and related sub-themes

titles held by ENs, which included 'epilepsy nurse specialist' ($n = 5$), 'clinical nurse consultant' ($n = 2$), 'epilepsy educator' ($n = 3$), and 'licensed epilepsy trainer' ($n = 2$). There is no competency framework specific to ENs in Australia and purportedly minimal formal opportunities for nurses to participate in cross-sector or organisational professional learning and development. Nurses expressed the sentiment that more recognition and awareness is needed for their role as a means of increasing their effectiveness in supporting PLWE and others affected by epilepsy. This could be achieved through professional unity and advocacy. Subthemes relating to the career trajectories were (i) *Path to epilepsy nursing qualifications*, (ii) *Competencies and continuous learning opportunities*, and (iii) *Recognition of the role of the epilepsy nurse*.

3.1.1 | Pathway to specialisation and qualifications

Most ENs described some prior exposure to epilepsy through their nursing roles in neurosciences, paediatrics, learning disabilities, and special disability schools, but many had '*never really delved deep into epilepsy*' (EN10). A few had an education background, which attracted them to the education roles within epilepsy organisations. However, a career in epilepsy was often not planned and several ENs commented on how they '*fell into epilepsy*' (FG, EN8). For some, having lived experience with family members or caring for PLWE prompted their interest in the area.

No specific national qualifications were outlined as a prerequisite to the EN role, other than being a registered nurse. ENs working for epilepsy organisations all completed a Certificate IV in Training and Assessment (Cert IV TAE) as a prerequisite for teaching and educational roles. All ENs completed epilepsy education courses which were developed and administered by their employing epilepsy organisation before or at the commencement of employment. Some ENs engaged in distance learning in the UK, however, these courses were only available to university-trained registered nurses (RNs). A comment made in the FG that '*there's a real lack of educational opportunities [in Australia] for nurses*' compounded by the '*tyranny of distance*' was met with strong agreement.

3.1.2 | Competencies and continuing professional development

The lack of a specific competency framework was a common topic of discussion, with ENs noting that standards and professional competencies would help to structure and support career progression across hospitals and community settings. The Chief Nursing and Midwifery Officers Australia outline four core competencies as part of the 'Strong Model' (Ackerman et al., 1996), namely, clinical practice, education, strategic planning, and research (Cashin et al., 2015; Chief Nursing & Midwifery Officers Australia., 2020). In practice, however, flexibility was evident in the role of the community EN, and many prioritised their clinical role. Varied engagement was evident

in the other three domains, influenced by clinical workload, funding availability, specific skills, and opportunities. Education was another primary focus, with some ENs heavily involved in developing educational resources and programs, and others engaged with the delivery of education to families, schools, community, disability groups, and others. Senior ENs in managerial positions were involved in specific organisational strategic planning, '*writing policy and procedures*' (EN10), and leading organisational change through developing models of care and service delivery and engaging in research activities. While there was a strong desire among participants to upskill in research, these opportunities were often limited and impacted by clinical workload.

Most ENs described their learning as self-directed. Learning from peers, and other health care professionals (HCPs), particularly hospital-based HCPs with clinical expertise in epilepsy, was invaluable and vital for keeping up-to-date on best practice. Some community nurses retained a connection to the hospital system through casual employment, to maintain their nursing skills and the opportunity for continuous professional learning. Connecting with hospital-based HCPs created valuable epilepsy learning opportunities as '*a lot of us (ENs) hadn't had that exposure in the hospital setting and needed to understand more about what goes on*' (EN4) but was challenging with the current fragmentation and limited cross-boundary working opportunities. ENs valued peer support, which was often in the form of informal meeting for providing advice and support, while formal, cross-organisational, or cross-sector engagement was minimal.

3.1.3 | Recognition of the role of epilepsy nurses

A strong need was identified to promote greater recognition for their valuable role in supporting PLWE and their families. Across primary, community, and tertiary sectors, ENs encountered a lack of awareness from HCPs about their role, including their qualifications and clinical expertise, which limited the potential for cross-sector engagement, the building of trusting relationships, and the development of shared-care practices. To address this barrier, ENs believed that leadership from nurses themselves alongside championing from other HCPs (e.g., epileptologists and neurologists) was necessary to advocate for their role. There was also concern regarding the '*mis-match of not enough nurses to present the level of care (needed)*' (EN 7) in the absence of professional unity and efforts to bolster the EN workforce.

3.2 | The key components of the epilepsy nurse role

Two interrelated sub-themes were identified that reflect the key components of the multifaceted, diverse community EN role and responsibilities; First, exploring *what ENs do* in providing important clinical care and psychosocial support, and second *how ENs carry out their role* through specific support elements that are instrumental

TABLE 2 Defining core elements of the EN role

Core elements	Definitions
What ENs do	
Clinical care	The provision of epilepsy-specific nursing care and support related to individual health needs.
Psychosocial support	Providing reassurance, encouragement, and understanding to PLWE and their families, to support psychosocial wellbeing.
How ENs carry out their role	
Instrumental support	The specific and explicit ways that holistic care and support is provided to PLWE and their families, which includes care coordination and connecting people to organisations and different specialists.
Informational support	The provision of epilepsy education, information, and guidance to a diverse group of people on a wide range of topics.

(coordination, connection, advocacy and building trusting relationships) and informational (education, resources, digital technology) (Table 2). EN7 summed up the multifaceted, diverse role of ENs:

'[You are] their social worker, you're the counsellor or you're a marriage counsellor, if you like, in that you're managing their behavioural issues, you manage for their child, you're managing health issues, medication, problems with the doctor, problems with the teacher, you know, you're the intermediary between the teacher who's not supporting their child in the classroom from their perspective. So, you wear all those hats all the time.' (EN7)

The way care was delivered varied across organisations, consisting of in-person meetings, telehealth (email, telephone, helpline, and videoconferencing), and social media. Some ENs worked within a multidisciplinary team (MDT) and others worked as sole practitioners within their specific organisation.

3.2.1 | Clinical care

The community EN's clinical role focused mainly on the management of more complex epilepsies including seizure first aid, risk, and crisis management, and developing seizure management plans (SMPs), also known as epilepsy management plans, and/or emergency medication plans. ENs had expertise across a range of specialty areas related to epilepsy including paediatrics, Sudden Unexpected Death in Epilepsy (SUDEP) and grief, the epilepsy surgical pathway, and new epilepsy diagnosis management. ENs provided education and training to PLWE and families on medication management and side effects, and emergency medication administration. Some routine nursing care was specified, such as administering medications and reporting seizures, but this was more relevant to those working in disability group homes.

Generally, there was a shared view among ENs that their clinical role involved an increasing amount of 'desk' duties and less in-person treatment and care. For example, all ENs were involved in developing and reviewing individual SMPs with PLWE, family members, and their treating team. These plans *'are tailored to each individual and clearly outline how their seizures can be effectively managed, when to*

seek emergency help, etc.' (FG). ENs would also liaise with pharmacists and general practitioners to ensure all prescribed medications were suitable for PLWE's required method of administration. Most ENs felt SMPs and EMPs should be completed as routine practice similar to people living with conditions such as diabetes, asthma, and anaphylaxis. These plans could also serve as a catalyst for PLWE and families in accessing support and services, by highlighting individual and family care and support needs. However, ENs also noted significant inefficiencies with how SMPs are implemented across Australia, namely that *'every organization develops their own plan'* (EN12). The multiple templates in use across Australia could result in PLWE, families, work, and schools having several versions of an SMP on file—potentially undermining its purpose in providing clear and up-to-date guidance.

Client electronic medical records (EMR) were shared within a given organisation, but there was minimal collaboration or data sharing across organisations or with hospitals. Only one EN had access to EMR across both inpatient and outpatient settings that linked to a specific network of hospitals. ENs commented that the client's diagnosis was often unclear, and yet, *'from a nursing point of view'* (EN11) they needed this detailed clinical information as they are accountable for the information and advice they provide. With client consent, ENs could request access to medical information, but these processes took time and could delay care and support provision.

3.2.2 | Psychosocial support

The provision of psychosocial support was a large component of the EN's role in enhancing person-centred care. EN5 noted *'So as a nurse now, I do quite a lot of psychosocial support'*, and *'on some days I am pretty much like a social worker'*. The range of psychosocial support and advocacy provided varied among ENs and organisations. Most ENs described taking on aspects of psychosocial support, with some having access to counsellors and social workers within their organisation, whereas others sourced psychosocial support external to their organisation. Even though the EN's role was not considered a crisis service, at times nurses needed to reprioritise their workload

to support the PLWE and/or family members through the provision of acute emotional support and guidance.

The scope of psychosocial support provided by the nurses commonly included counselling on a range of areas such as living with epilepsy, experiences of stigma and discrimination, relationships, family, employment, palliative care, bereavement, COVID-19, and mental health concerns such as depression, anxiety, psychosis, stress, and suicide. Nurses helped in the management of these negative experiences to improve social inclusion and equity. Employment was another common challenge facing PLWE that ENs helped to address, particularly around workplace discrimination and seizure management. Other instances of service navigation included writing letters of support to housing agencies to help PLWE obtain suitable and safe housing. While ENs would refer clients for formal psychological support, they maintained a role in providing psychosocial support specifically related to epilepsy experiences, as these could not be separated from their clinical duties.

Nurses highlighted the importance of building a trusting relationship with PLWE and their families where *'you become a part of, you know, their support, strong, close support network over a period of time as well'* (EN2). In some cases, these strong relationships and bonds between nurses and PLWE and their families began in infancy, when a child was first diagnosed, and remained through to adulthood. The transition from paediatric to adult services was seen to be a particularly challenging time for families, who may *'feel like they have been tipped off a cliff'* (EN12) as the level of support lessens. Nurses perceived that PLWE and their families require *'constant people they can trust...helping them navigate'* (EN12) services and support, as needs change across the lifespan.

ENs reported frequently adopting an advocacy role, becoming a voice for PLWE and their families across many situations. For example, EN10 described becoming an advocate in situations where families *'might be in dire straits'* or at times when they cannot access effective medications or when they need urgent safe housing. For those PLWE with no or limited communication with their families, the nurses were *'like their family members'* (EN9), helping to ensure their healthcare and well-being needs were met. Advocacy roles were complex and involved the *'act of safeguarding, apprising, valuing, mediating, and championing social justice'* (Abbasinia et al., 2020, p. 148). This role was fulfilled through improving self-management, epilepsy knowledge and linking PLWE with appropriate care providers.

3.2.3 | Instrumental support

There was a consensus among ENs that the timely sharing of knowledge and improving understanding was an important part of their role. ENs positioned themselves as *'translators'*, helping PLWE and families to better understand the clinical information provided by other HCPs. ENs viewed themselves as particularly skilled in drawing out information and providing the time and space for PLWE and their families to share their concerns. EN2 revealed her dismay when clients would say things like *'I've learned more from you (EN) in 20 min,*

30 min, an hour, whatever it is that I've spoken with you than I have in the last three years since my child's been diagnosed', but these comments were testament to the importance of their role as a communicator.

One EN used the metaphor of hub and spokes in a wheel to describe their function as a single point of contact (hub) for PLWE and families to access support (spokes) across a complex health system and an array of community-based services. Other ENs described how they worked as part of a multidisciplinary or nursing team acting as a *'conduit'* (EN10), liaising and coordinating care and support with hospitals, other HCP services, and support agencies. ENs provided support navigating different processes across sectors (i.e., health, disability, aged care, employment, and education). Supporting PLWE and their families in the processes of applying for disability funding was becoming a major role of the ENs. This process required ENs to liaise with a range of other support professionals to facilitate applications related to epilepsy.

ENS acknowledged the diversity of responses to the support provided. Despite encouraging active engagement from clients, some people still required more *'spoon feeding'* (EN10), and *'hand-holding'* (EN12). Others just required pointing in the right direction, or reassurance in knowing that an EN will be there in times of need, to support them as required. Empowering and providing people with the necessary tools and skills to take more control of their lives was seen to be an extremely valuable and extensive part of their role.

3.2.4 | Informational support

The perceived contrast between hospital and community-based ENs was highlighted by EN7, saying *'So, I guess we've got a different role where we could help out when they (hospital-based staff) get those complicated ones that want a lot of help in the community rather than just about epilepsy and just about epilepsy information'*. Having widespread knowledge and expertise was important to cater to the holistic needs of a diverse population living with epilepsy, but it was a demanding task to keep up-to-date on the clinical advances, availability of services, new technologies, etc. Importantly, as noted by EN10, *'you need to know what resources are out there.... to guide your patients'*.

ENs identified educational gaps and developed resources and/or facilitated group education programs, either face-to-face or online, which focused on providing general information about epilepsy including management, risks, safety, SMP, emergency medication, etc. Practical training on emergency medication administration was also delivered to small groups in schools, aged care facilities, disability organisations, people's homes, and workplaces. These training sessions had been predominantly delivered face-to-face, but adapting the sessions allowed a move to online webinars during COVID-19 restrictions.

The development of new programs and resources was believed to be challenging, particularly engaging with diverse populations. One EN5 reflected on their experience with an outreach program to an indigenous community, stating, *'I think our programmes probably*

didn't really suit the way that they wanted to receive the information'. Nurses agreed that responding to local needs, diverse populations and understanding cultural context was essential and that 'one size does not fit all' (EN5) when it comes to the resources and programs they develop. Only one EN had experience delivering small group education to a culturally and linguistically diverse population, working closely with a professional interpreter to provide essential cultural context throughout.

3.3 | Shifting work practices

Three subthemes were linked to the theme of *shifting work practices*, these were: *Integrating online and in-person ways of working*, *COVID-19*, and *Nurse-led helpline*. These subthemes explored the changes in EN work practices in response to demand for services across a large geographical area, funding models, increase in the use of digital technology, and the COVID-19 pandemic.

3.3.1 | Integrating online and in-person ways of working

Most ENs reported a preference for in-person interaction with clients, yet acknowledged that their increased use of telehealth had likely enabled more equitable access to epilepsy support for PLWE across Australia. In general, it was reasoned that a hybrid approach was a good compromise and did not adversely impact their capacity to provide high-quality support and care.

In the past, ENs in epilepsy organisations had opportunities to be part of the 'hub' (EN2), more involved in the MDT epilepsy hospital-based clinics, which prompted meetings with PLWE and their families. This helped to raise awareness of the epilepsy organisations' community role and improved referral practices to these organisations. There was a concern among ENs that referrals to epilepsy organisations could be impacted by their lack of visibility and presence in clinical settings. Most ENs strongly preferred working with an MDT in their clinical role, improving their access to, and sharing of knowledge and information. One EN who worked across both health and community sectors was considered a valuable member of the health-based MDT, and an important link across sectors. Working remotely and outside the health system, the nurses had reduced opportunities to form incidental connections, build relationships, and promote awareness of their services to those in the acute health sector, some of whom 'don't know a lot about community services' according to EN7. Although deemed worthwhile by ENs this level of in-person involvement was hard to maintain, with limited funding and time restraints.

Several ENs reported that their workload had increased rapidly as a by-product of switching to telehealth. This was attributed to a perceived greater availability of ENs and increased expectations of PLWE, as well as the time burden associated with following-up clinicians via email, requesting access to medical information and navigating complex systems.

3.3.2 | COVID-19

Reflecting on changes to their work practices over recent years, several ENs described the transition to increased use of telehealth began around 2017, purportedly due to increasing demand for services coupled with limited resources and funding for travel. The delivery of telehealth services was more cost-effective for reaching a dispersed population across a large geographical area. EN8, for example, noted the fortuitous timing 'of converting to online so that we could offer face-to-face and online and here we are now with COVID and lockdown, and we've already been doing this, our role didn't change'. Whilst many organisations were compelled to make the rapid shift to remote working and online services in response to the COVID-19 pandemic from early 2020 onwards, the ENs reported minimal disruption to their work during Australia's COVID-19 restrictions and lockdowns. An exception to this was the experience of EN9, who described working for a disability organisation, and only delivering face-to-face nursing care to people living with severe disabilities. EN9's role had not changed throughout COVID-19 but the pandemic created additional demands around infection control measures, and limited community interactions when not at work.

3.3.3 | Nurse-led helpline

These results are from the outsourced triage model only, provided by MHS. There were 1621 calls to EAA's NEL recorded over 18 months from March 2019 to August 2020, serving 1349 PLWE. The NEL predominately received calls from PWLE themselves (68.6%), as well as parents of children with epilepsy (26.5%) (Table 3). Over one-third of calls (36.5%) had a health or medical-related presenting need. This included calls related to the medical aspects leading to a diagnosis of epilepsy, as well as any medical condition in addition to epilepsy, and included non-epileptic seizure activity. The next most common presenting need was seizure history or management, accounting for 30% of calls. This category included calls related to treatment and management of seizures, such as seizure first aid and lifestyle factors leading to self-management (Table 4).

For more than one-third of calls (36.5%), the information and support provided by the NEL nurse was sufficient to meet the needs of the caller, with follow-up deemed necessary. However, one in two callers (50.1%) (Table 3) was referred to EAA's Individual Service Programs for ongoing support by an EN. The most common call outcome differed by caller groups; with 61.3% of calls made by parents regarding their child with epilepsy referred to an Individual Service Program, compared with 45.1% of calls made by PLWE calling about themselves (data not shown).

The frequency of calls—including from repeat callers—demonstrates the significance of the helpline as a resource for accessing general epilepsy information and advice, and as a referral pathway to EAA ENs for those needing more specific information and support.

TABLE 3 NEL client characteristics (n = 1349), from March 2019 to August 2020^a

	n	%
Gender of client		
Female	837	62
Male	512	38
State of caller		
Unknown	2	0.2
New South Wales	586	43.4
Victoria	277	20.5
Queensland	205	15.2
South Australia	89	6.6
Northern Territory	8	0.6
Western Australia	135	10
Tasmania	22	1.6
Australian Capital Territory	25	1.9
Relationship of caller to client		
Caller has a parent with epilepsy	9	0.7
Caller has a child with epilepsy	357	26.5
Caller has epilepsy	926	68.6
Other (e.g., friend, colleague)	57	4.2
Age group of client		
<5 years	91	6.8
5–17 years	228	16.9
18–39 years	398	29.5
40–59 years	446	33.1
>60 years	186	13.8
Any disability recorded		
None recorded	1042	77.2
Yes	307	22.8

^aThis is not a unique caller query. There were 17 callers who contacted the NEL for both themselves and another person.

4 | DISCUSSION

PLWE have a right to equitable access to PCC interventions that are affordable and tailored, as recommended by the World Health Organization (2018). Epilepsy services should be implemented in a way that supports effective and efficient PCC and practices of integrated care, to optimise PLWE, family and provider experiences, improve health outcomes and deliver cost-effective health care (Bradley et al., 2016; Goodwin et al., 2021; Hutchinson, Ryder, et al., 2020; Sikka et al., 2015; Varley et al., 2020). This study addresses a gap in knowledge, drawing attention to the less widely recognised yet pivotal practices of ENs working in the Australian community setting and their valuable multifaceted role in optimising service delivery. The ENs' perspectives and insights resonated with experiences described in the international literature (Campbell et al., 2019; Higgins et al., 2019a, 2019b; Locatelli, 2019). This is particularly in relation to working practices, with the absence of

TABLE 4 Call characteristics (n = 1621)

	n	%
Presenting need (see Appendix A for definition)		
Health, medical	592	36.5
Seizure history, management	486	30
Emotional, social	137	8.5
Other	112	6.9
Learning, education	107	6.6
Daily living	80	4.9
Employment	69	4.3
Recreation, leisure	38	2.3
Outcome		
Refer to EAA Individual Service Program	812	50.1
Home care advice	592	36.5
Seek pharmacist advice	66	4.1
Other	56	3.5
See a doctor soon	50	3.1
Attend ED immediately	35	2.2
Activate emergency services contact number	10	0.6

national competency frameworks in epilepsy care, standardised speciality practice and job titles, and limited understanding of the EN scope of practice. Ultimately, this can impact skill development, career progression, and workforce planning (Epilepsy Nurse Specialist Association, 2012; Gardner et al., 2016; Higgins et al., 2019a, 2019b; Locatelli et al., 2021; Manzanares et al., 2021). ENs who predominantly work in the NFP sector faced additional challenges in their role working with a disconnected network of care and siloed governance structures across Australia related to the fragmented health and social care systems (Higgins et al., 2020; Schroeder & Cutler, 2021).

Despite significant hurdles to overcome, community ENs demonstrated their expertise and role value by taking a holistic and comprehensive view of the social, emotional, and clinical factors that impact PLWE and their families (Higgins et al., 2019a, 2019b; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018; Locatelli et al., 2021; Pfäfflin et al., 2016). ENs adapted their organisation's practices, according to financial restraints, to respond and address workload demands, people's needs, and gaps in service provision in a manner that focussed on equity and inclusivity.

4.1 | Crucial role of epilepsy nurses

The common thread throughout this study was the crucial role ENs play as champions in fostering PCC. This includes knowing how to overcome and navigate hurdles to practice in a person-centred way that emphasises coordinated epilepsy care and supports PLWE across the care continuum, in line with evidence-based practices (Delaney, 2018; Higgins, Downes, Varley, Doherty, et al., 2018;

Higgins, Downes, Varley, Tyrell, et al., 2018; Power et al., 2020; World Health Organization, 2018). Adopting a holistic approach to care is necessary to optimise the EN role and an important principle of nursing practice globally, which involves advocacy, timely access to clinical and psychosocial support, and knowledge-sharing to facilitate shared decision-making (Higgins et al., 2019a, 2019b; Locatelli et al., 2021; Zonneveld et al., 2020). ENs reported the drive and motivation to tackle unmet need across care pathways including, but not limited to, new diagnosis and complex epilepsy management, as well as the ability to work in speciality areas such as SUDEP. As seen in other studies, the ENs participated in the development and greater accessibility of services and support, increasing the scope of educational initiatives, and embracing digital technology to keep PLWE safe and limit health and social disparities based on locality, culture, and family situations (Higgins et al., 2019a, 2019b; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018). The embracing of digital technology prior to the global COVID-19 pandemic was clearly advantageous to PLWE, families and ensured continuity of care whilst facing public health recommendations such as physical distancing (Kuroda, 2021).

ENs remain focused on what matters to PLWE and their families and empower them to actively manage epilepsy as best they can. This resonates with the research, which highlights a commitment to building strong relationships with PLWE and their families and provide informational and advocacy support (Campbell et al., 2019; Higgins et al., 2019a, 2019b; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018). These factors have been shown to fundamentally contribute to a better quality of life, and reduction in hospital admissions and associated costs (Higgins et al., 2019a, 2019b; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018; Mumford et al., 2018). Ultimately, the ENs demonstrate a set of unique characteristics, both individually and professionally, that support their important advocacy role with PLWE and families, and the consequential positive impact on job satisfaction and motivation (Abbasinia et al., 2020; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018).

4.2 | Factors impacting epilepsy nurse practice

EN interventions were focused on the PLWE and families' priorities and preferences, which they argued helped to ease the burden on primary and acute health sectors and reduce health care costs (Higgins et al., 2019a, 2019b; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018). However, optimal use of the services of NFP ENs in Australia is currently problematic, primarily as a result of the poor integration of this sector into current epilepsy models of care, particularly within the health sector (Lyons, 2020). Siloed practices, funding models, governance structures, and conflicting values and priorities are said to restrict connected, collaborative practices across organisations and sectors, impacting PCC, which is perceived as the core foundation of

integrated care (Goodwin et al., 2021; Hutchinson, Ryder, et al., 2020; Zonneveld et al., 2020). A recent review by Hutchinson, Herkes, et al. (2020) noted integrated models of care in epilepsy are slowly developing, but research in the UK and Ireland has highlighted the vital role that ENs play in supporting 'the best value care for all people living with epilepsy, in the right place, at the right time, sharing the best available information' (Health Services Executive, 2016, p. 9; Hutchinson, Ryder, et al., 2020; Varley et al., 2020). At the same time, the ENs from those research studies identified poor coherence impacts the sharing of timely clinical information and the ability to respond to the complex demands and needs of PLWE and their families (Campbell et al., 2019; Locatelli et al., 2021).

Referrals to community ENs are currently non-standardised and ad hoc, despite ENs being ideally placed to 'bridge the gap' across fragmented services (Campbell et al., 2019). This limited integration has created ongoing inefficiency, while duplication of services and resources places additional demands on the whole workforce, service sustainability and greater health care costs with uncoordinated care being 35% more expensive (Higgins et al., 2020; Owens, 2010). ENs throughout the study highlighted varying interorganizational working relationships, privileging the health sector as the 'lead organisation', influencing partnerships and allocation of resources across networks and systems. This resonates with Dewulf et al (2018), who noted this can impede shared decision-making, collaboration, and cross sector partnerships (Auschra, 2018, p. 11; Dewulf & Elbers, 2018). There is a much-needed fundamental shift in policy to develop more integrated practices and models of care that help address the current gaps in PCC and support (Higgins et al., 2019a, 2019b; Higgins, Downes, Varley, Doherty, et al., 2018; Higgins, Downes, Varley, Tyrell, et al., 2018; Hutchinson, Herkes, et al., 2020; Power et al., 2020).

4.3 | Lack of professional unity and ambiguity of epilepsy nurse role

There was a consensus among ENs about lack of professional unity and ambiguity of the EN identity, variations and inconsistencies in job titles impacting career progression and workforce planning across all sectors (Gardner et al., 2016, p. 62; Leary et al., 2017). Standardised nursing titles are protected by law in Australia, with only the nurse practitioner classified as 'practicing at an advanced level'. Other specialist titles, such as clinical nurse specialist, consultant, or educator, are neither protected nor standardised (Nursing and Midwifery Board, 2019). Yet developing standards for professional practice in nursing is shown to improve credibility of career pathway, improve job satisfaction, enable employers to support and promote career development, design continual professional development opportunities, and monitor performance, all of which are lacking at a national level (Epilepsy Nurse Specialist Association, 2012; Leary et al., 2017). These benefits align with more recent international research demonstrating the need to create national competencies and to adopt competency frameworks to effectively standardise EN roles and improve teamwork and collaborative practices (Epilepsy Nurse Specialist

Association, 2012; Prevos-Morgant et al., 2019). However, transferring developed EN competencies to an Australian context and delineating levels of competencies as in the UK, would be currently challenging due to lack of integrated practices across sectors and varying funding models (Epilepsy Nurse Specialist Association, 2012).

The lack of any formal education and the gap between formal and informal education routes was another contributor to educational challenges for ENs, evidenced by no epilepsy-specific post graduate education opportunities in Australia, despite the education requirements of advanced practice nurses nationally and internationally (Gardner et al., 2016; Higgins et al., 2019a, 2019b). Clinical experience and interactions or consultations with more senior nurses and HCPs were limited. However, those interactions that do take place are said to emphasise the growing importance of informal workplace learning (Higgins et al., 2019a, 2019b). The lack of integration and work demands has impacted ENs' research opportunities, despite evidence indicating the ENs' support for evidence-based practices and their enthusiasm to increase their involvement in this area (Higgins et al., 2019a, 2019b). The ENs involved in this study perceived barriers to greater visibility, educational and research opportunities, and upskilling, which were seen to be based on their limited numbers across Australia, as well as limited cross-sector learning and continual education opportunities in epilepsy that could further promote connected and collaborative practices.

5 | STRENGTHS AND LIMITATIONS

This is the first article to explore the role of the community EN in Australia. Critical knowledge was obtained on the EN role and responsibilities through in-depth individual qualitative interviews, followed by a focus group. This format allowed for a detailed exploration and reflexive member-checking of the emerging themes.

A notable limitation of the current study was the non-inclusion of ENs working specifically in the hospital setting, therefore not representing the perspectives and roles of nurses across the whole of epilepsy services. Also, the perspectives of users of the EN services and those health and social care providers working alongside ENs were not included which limits a more comprehensive understanding of the full impact of their role. The inclusion of all these perspectives would provide a more extensive representation of the EN role and responsibilities in future studies. Furthermore, the data obtained from the NEL helpline provided important information on caller and call characteristics. More specific information about topics discussed with the EN would have been beneficial in understanding epilepsy information needs. However, this was outside the scope of the data that was available for this research study.

6 | CONCLUSION

This study contributes to the limited knowledge and understanding of the experiences, roles, and responsibilities of community

ENs in Australia. The study findings highlight ENs pivotal role in improving understanding and reducing the impact of epilepsy on the person and their family, with specific key competencies demonstrated such as knowledge, skills, and attitudes. However, their role is affected by the lack of investment in a specific EN competency framework, to standardise their level and scope of practice. If addressed, this could help build capacity and consistency of the EN workforce, improve workforce planning, raise their profile and value among HCPs, PLWE and families, and facilitate and provide a clear structure for career development and progression. Despite ENs key contribution to identifying and addressing gaps through innovating and implementing change in the way nurse services are delivered, their role is influenced by the limited investment in epilepsy-specific integrated care initiatives. To optimise the EN role and PCC provided, there is an urgent need to explore ways to breakdown existing complex sector and organisational boundaries, develop epilepsy clinical guidelines to guide collaborative practices and partnerships, and facilitate better communication, to ensure all PLWE receive person-centred, cost-effective and efficient integrated epilepsy care, irrespective of location, social and financial position, in Australia.

7 | RELEVANCE TO CLINICAL PRACTICE

This study provides evidence of the significant issues that impact community ENs role. It draws attention to the need for greater commitment in developing collaborative and integrated work practices across sectors to improve PLWE and family outcomes and experiences. Investment in developing a competency framework to standardise level and scope of practice is important to build capacity, raise role value, and structure career progression.

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CONFLICT OF INTEREST

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the information reported in this article.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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APPENDIX A

Definitions of presenting inquiry to NEL (Table 4).

Health/medical relates to any medical condition in addition to epilepsy; as well as the medical aspects leading to a diagnosis of epilepsy. Also relates to non-epileptic seizure activity.

Seizure history/management relates to treatment to manage seizures including seizure first aid and lifestyle factors leading to self-management.

Recreation/leisure relates to choice of leisure activities being impacted by epilepsy (e.g., inclusion in community activities/ fear

of accessing certain activities/ not being able to drive to leisure activities).

Employment any issue related to employment including under-employment, gaining or maintaining work, transport to employment.

Learning/education relates to any preschool, school or further education inquiry. Also includes ongoing adult learning and associated aspects such as memory.

Emotional/social relates to any intra-personal or interpersonal inquiry including aspects of independence, e.g., anxiety/depression/

lack of general independence due to epilepsy and relationships including family systems.

Daily living/independence relates to daily living activities that are impacted by epilepsy, e.g., memory affecting capacity to do daily tasks (dressing, washing, cooking, cleaning, shopping), frequency of seizures meaning daily living tasks cannot be completed, seizures impacting independence, e.g., bathing/sleeping alone.

Other any other inquiry not listed above.