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Managing epilepsy in the community: exploring the perspectives of community epilepsy nurse

Implications for practice and research

- Recognising and managing role development is key to delivering quality patient care.
- There is a need for a policy shift towards integrated practices and models of care that help to address the practice gaps.

Context

Epilepsy care is known to have evolved dramatically worldwide, but achieving optimal care remains a challenge. In the field of neurological disorder, epilepsy is one of the most disabling diseases and it has a significant personal, social, and economic impact¹. People with epilepsy often have multiple healthcare needs and the current international healthcare policy advocate the adoption of a holistic approach to provide patient centered care (PCC)¹. The Epilepsy specialist nurse (EN) has a vital role to play within the epilepsy care team and they help to reduce unnecessary use of hospital facilities and enhance the quality of life of the patients.

Methods:

The purpose of this study was to explore the role and responsibilities of ENs within the context of Australian healthcare settings. This study used a 3-stage design involving one-to-one interviews with 12 community based Epilepsy specialist nurses, retrospective analysis of data collected from nurse-led community helpline service and a national focus group. The ENs were recruited from Epilepsy Foundation and Epilepsy Australia through snowballing technique based on informed consent and all the meetings were audio recorded and transcribed verbatim. To aid good practice, ethical approval was granted by the appropriate research ethics committee.

Findings:

The three themes that emerged from this 3-stage study highlighted the diversity in career pathway in terms of the lack of standardised qualifications for the role, lack of specific competence framework for Epilepsy specialist nurses in Australia with minimal opportunities to engage in organisational or cross-sector professional learning. The role of the Epilepsy specialist nurse is diverse and continues to evolve in response to the healthcare environment, the needs of the patients and their families¹. These roles include being an advocate through safeguarding, championing social justice and providing counselling on issues such as stigma and discrimination, relationships, employment, bereavement, and mental health concerns such as depression and suicide¹.

Commentary:

Studies in the UK and Ireland has identified the key role of ENs in fostering patient-centered care, providing quality cost-effective care, and improving the quality of life of patients. With the general focus of shifting care of people with complex long-term conditions to the community, a key function of ENs role is to support the patients through long-term trajectory of epilepsy to reduce the impact of the disease on the affected individuals¹. The findings of absence of national competence frameworks in epilepsy care with limited understanding of

the EN scope of practice is supported by other researchers¹. Another key issue is the lack of enough EN in the community to provide the level and standard of care required. The study showed that the zeal to advance their research knowledge and skills is constrained by heavy workload and funding opportunities.

Factors impacting epilepsy nurse practice include poor integration of this sector into the current models of care, funding parameters, organisational structure, and conflicting priorities. These working practices have implications for skill development, career progression, workforce planning, motivation, and job satisfaction¹⁻². The study added to the findings of earlier studies suggesting the need for increase cross-boundary learning and working for self-development and peer support. This study advocates for more recognition and awareness¹⁻² about the role of Epilepsy specialist nurses. Although, there is no specific national qualification required for the Epilepsy specialist nurse role apart from being a registered nurse, some Epilepsy specialist nurses undertake distance learning in the UK and engage in self-directed learning to upskill themselves.

The three-stage methodology provides rich and detailed narratives, nevertheless, a key limitation of the study is the lack of inclusion of ENs working in the hospital settings. Regardless of this limitation, this study illuminates the knowledge gap in a less widely recognised role of ENs within the Australian community setting. Finally, the role of Epilepsy specialist nurses is well acknowledged and valued by patients, therefore, any measures geared towards developing the role is recommended to address the challenges such as inadequate staffing and lack of national qualification for the role.

References

1. Hutchinson et al (2022) Determining the role and responsibilities of the community epilepsy nurse in the management of epilepsy. *Journal of Clinical Nursing* 2022, 00: 1 – 16.
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