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Benefits of the epilepsy specialist nurses (ESN) role, standardized practices and education around the world

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ABSTRACT

Epilepsy, often considered as a stigmatizing disease, affects 65 million people worldwide and is frequently associated with comorbidities that increase both direct and indirect costs. The degree of impact on quality of life and the cost of care differs depending on the social and health care organizations in place, political, medico-economic and/or socio-cultural contexts. Across the globe, healthcare is provided by nurses in primary care, urgent or emergency care, and within specialized domains of practice. In Epilepsy the global care could be enhanced by developing standardized nursing education in close collaboration with other caregivers. The impact of epilepsy nursing care has been documented in some developed countries, but the diversity of nursing practices and professional education of nurses raise difficulties in generalizing these findings. Specialized education in epilepsy will improve access, treatment and ultimately the quality of life of patients.

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1. Introduction

Epilepsy is recognized [1] (Robert S. Fisher et al. 2014) as a complex brain disease that requires multidisciplinary

specialized health care and capacity building of health care providers.

The different health care systems worldwide face unique challenges in providing epilepsy care and education in developed and developing nations. Additionally, the lack of

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knowledge of health care providers about epilepsy has been documented as well as delays in obtaining specialized epilepsy care [2] (The Institute Of Medicine –IOM) and the fact that specialized health professionals do not exist (or in too limited number) in certain countries.

Efforts to provide high-quality cost-effective services requires optimizing the contribution of all health care professionals to increase access to and quality of care for people with epilepsy.

The World Health Organization (WHO) approved the resolution entitled “Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge Implication” on the 26th of May 2015.

WHO recommends implementing epilepsy care within the non-specialized primary care system, as an alternative to scarce human resources in developing countries.

Efforts to improve education of nurses have been undertaken by a variety of related organizations.

For example, in the United States, the American Epilepsy Society has an online educational program for nurses new to epilepsy and one focusing on patient safety in epilepsy monitoring units.

The Epilepsy Foundation of America provides training programs for school nurses and other community-based providers. Clinical practice guidelines for nurses have recently been developed by the American Association of Neuroscience Nurses for the care of children and adults with epilepsy. Yet no systematic approach to educating epilepsy nurses globally has been developed, hampering the availability and widespread use of epilepsy nursing expertise in clinical care.

We have an opportunity as a global community to enhance the role of nurses in epilepsy and ensure that all people with epilepsy have in the future access to epilepsy nursing care.

2. Epilepsy nurse role

Across the globe, healthcare is provided by nurses in different capacities. Nurses are found in primary care, urgent or emergency care, and within specialized domains of practice. With the advent of comprehensive epilepsy centers, the nursing role varies in different countries: nurses with specialized knowledge and expertise in epilepsy become integral members of the epilepsy care team [3] (National Association of Epilepsy Centers – NAEC guidelines). In resource-poor settings, nurses are often the only healthcare professional and provide comprehensive disease management and support to patients and families living with epilepsy. Often, nurses will have multiple roles requiring expertise in the provision of epilepsy care, patient/family self-management education, psychosocial care, and clinical research.

Nursing education has evolved with medical knowledge of differing etiologies of epilepsy and seizures, as well as an influx of medications and other therapies used to control seizures. Emphasis has been placed on enhancing the person’s health, by improving access and coordination of care, and assisting the individual with epilepsy and their family to function optimally within constraints of illness.

Epilepsy nurses and their roles can be quite diverse. Depending on the country of practice, educational level, governing laws and many other factors, the scope of nursing practice has great breadth and depth. The epilepsy nurse can work anywhere that one finds people with epilepsy: school, home, clinic, hospital and specialized centers. They may practice as advanced practice nurses, nurse specialists, educators and researchers. They contribute to nursing education, research and clinical practice; they work as part of a multidisciplinary team and as independent practitioners.

In France, for example the occupation of Epilepsy Specialist Nurse covers three terms:

- nurse educators (Bachelor degree) with special training in Therapeutic education. Their title is “Infirmière d’éducation thérapeutique”;
- nurse specialists (Bachelor degree) with experience and special training in epilepsy, clinical reasoning in nursing and concept analysis. Their title is “Infirmières du Protocole de coopération en Epilepsie”;
- advance practice nurses (Masters degree) equivalent in France to “Infirmières de Pratiques Avancées”.

Epilepsy nurses provide a wide range of care for people and their families living with epilepsy such as: education regarding diagnosis and impact on their lives, promoting independence and living well with epilepsy, and telephone triage providing timely access to advice. The scope of nursing practices has evolved with nurse practitioners now responsible for activities that were previously in the physician’s domain. Many nurses are now able to prescribe drugs, perform diagnostic examinations and prescribe other types of medical treatments, either independently or in conjunction with a physician. Others may focus on providing self-management education and care in a collaborative or independent manner. The epilepsy nursing role also extends beyond direct patient care by providing education to colleagues, communities, and students and leading quality improvement initiatives and research. [4] (Ball J).

3. Scope and burden of epilepsy, economic impact, comorbidities and mortality

Epilepsy affects people of all ages, though the incidence is greatest in young children and older adults. Epilepsy knows no boundaries, affecting people of all races, ethnicities, and socioeconomic groups. Eighty percent of the burden of epilepsy occurs in the developing world.

For example, in some regions 80 to 90% of people with epilepsy receive no treatment at all. Other disparities among regions have been noted affecting treatment access, health care, quality of life, and education [5] (Theodore WH et al., 2006).

In most developed countries, 70% of people with epilepsy can gain seizure control with anti-epileptic medication, but cost and side effects of medications may remain a problem.

In Europe, the direct and indirect health care costs of epilepsy exceed €20 billion per year In the United States, direct

and indirect costs of epilepsy account for \$15.5 billion each year (IOM). Direct medical costs are highest for new patients and in people with refractory epilepsy.

The indirect costs of epilepsy can be difficult to evaluate and encompass quality of life as well as measurable effects on lost productivity and employment. Indirect and direct costs and quality of life are substantially worse in people with uncontrolled epilepsy. Obtaining complete seizure control as early as possible is the first aim. In developing countries, the stigma and lack of awareness of epilepsy leaves people isolated, unemployed and often living in poverty.

The spectrum of comorbidities seen in epilepsy may include somatic, neurological, mental health, cognitive, infectious diseases, physical disabilities, injuries and nutritional disorders [6–10] (IOM; Benbadis SR; Ettinger A; Friedman DE; Gaitatzis A; Margrove K; Mensah SA). Comorbidities have both direct and indirect effects (spectrum of intensity) on a person's health and can have a greater effect on quality of life than epilepsy alone. Health care professionals must be able to incorporate care of comorbidities into routine care of people with epilepsy.

A multidisciplinary and holistic approach by allied health professionals is essential in meeting the complex needs of this population of patients. Nurses are ideally placed to contribute to the screening and detection of comorbidities, such as depression, anxiety or suicidal ideation. Nurses often offer early education and support, which can serve to reduce anxiety and depression.

Premature death in people with pharmaco-resistant epilepsy is 2–3 times higher than that of the general population [11,12] (Gaitatzis and Sander 2013; Nashef L 1997). Sudden Unexplained Death in Epilepsy (SUDEP), the most common cause of death in epilepsy, occurs in 1 of 1000 people with epilepsy, with the occurrence increasing to 1 in 150 in people with uncontrolled epilepsy [13,14] (Smithson, 2014; Tomson, 2008).

Nurses are essential in educating patients, caregivers and families about mortality and the risks of seizures. They are placed to carry out individual risk assessments and support patients to make appropriate choices to minimize their risks and optimize their lives. The long-term supportive relationship between an epilepsy nurse and patient can lead to early recognition of comorbidities that can inform therapeutic choices.

4. Benefits of the epilepsy specialist nurse (ESN) role

ESNs should have extensive knowledge of epilepsy and diversified expertise in the bio-psychosocial field. They participate actively in therapeutic education programs and provide support and advocacy for patients and their families.

Nurses have been known to spend the time needed communicating, on an empathetic level, with their patients/families and contributing to improved quality of life. While a variety of health care providers may be able to assist patients with individual areas, nurses have the particular ability to counsel, intercede and educate in all of the above realms. Nursing community studies contributions in health care and

quality of life [15,16] (Chartrand D, Jurasek L). Time spent educating and counselling the patient and family has been shown to be instrumental in limiting trips to the emergency department, complying with medication management, increasing cost savings and promoting self-esteem and social functioning [17] (Higgins S).

The quality of care and support that specialist nurses offer has been instrumental in reducing unnecessary hospital admissions and readmissions, reducing waiting times, freeing up time to treat other patients, improving access to care, educating health and social care professionals and supporting patients in the community [18,19] (RCN 2010).

Globally nursing is often the first line of entry to the healthcare system. In resource-poor countries, the majority of healthcare is provided in remote communities where nurses or traditional healers may be the only care providers. Nurse often have close ties with the community and may impact the care of people with epilepsy in different ways.

An epilepsy education, awareness and advocacy program implemented in Africa and Central America demonstrated the impact of epilepsy nurses. This program was developed collaboratively with partner countries, national nursing organizations with the support of the Ministries of Health to educate nurses with varying scope of practice about epilepsy (Jurasek 2012–2016).

Epilepsy education and advocacy training was provided over a 1–5 day course (varied on support in each region). Significant positive outcomes were demonstrated such as: educating other nursing colleagues; negotiating simple health messages via radio to improve community awareness of epilepsy; providing education to schools which lead to changing policies allowing children with epilepsy to attend school; educating local community leaders; initiating a community epilepsy group; and incorporating the Beyond Epilepsy Program into nursing curriculum (Jurasek, 2012–2016).

This initiative highlights potential benefits of specialized nursing education.

5. Standardized education

Research has identified gaps in health professionals' knowledge about treating epilepsy and its comorbidities and in their level of confidence in doing so (IOM, p231).

The goal of epilepsy nurse education is to provide a program that will enhance nursing knowledge, competency and confidence in nurses. There needs to be formal assessments and evaluations to ensure standardization across international and educational boundaries. Completion of such courses may lead to specialization or may remain as part of a more generic role [20] (Pfafflin et al., 2016).

Entry-level qualifications to become a specialist nurse can vary dependent upon the nursing scope of practice in various countries. Graduate nursing programs for advanced practice nurses and clinical nurse specialists in the United States are generally two years in length and offer specializations in acute or primary care with neurological specialization. Certifications may be available in general areas, such as family practice, pediatric, acute care, or neuroscience nursing but epilepsy

specific certification is lacking. Guidelines for comprehensive epilepsy centers in the United States require centers providing medical and surgical epilepsy care have a nurse specialist in epilepsy as part of the multidisciplinary care team (Labiner 2010).

Specialized education in epilepsy, for the most predominant healthcare providers globally will improve access, treatment and ultimately the lives of those living with epilepsy. Competencies will be established by expert nursing consensus. Definition of various nursing roles will be clarified and therefore can be adapted to align with scope of practice within countries. Core content of the program will be defined and expanded upon to create a meaningful and usable program, which could be delivered via various modalities dependent upon local needs and resources. Program evaluation and research will be embedded in this initiative at the onset in order to determine effectiveness and impact. This is an amazing opportunity to empower our global epilepsy nursing community, increase epilepsy awareness and improve patient outcomes.

6. Conclusion

Patients followed up by epilepsy specialist nurses recognize and address previously unidentified problems, including misdiagnosis, overmedication and lack of awareness of drug side effects [21] (Macdonald et al., 2000).

Epilepsy nurses play an important role in the care of people with epilepsy. The positive impact of the presence of epilepsy nursing has been documented in published research in some countries and anecdotal and clinical experience has supported the use of epilepsy nurses in many areas. A formalized structure and process is needed to create opportunities for collaboration between epilepsy nursing professionals working across different countries including nursing research and standardized epilepsy nurse education.

In the UK, epilepsy nurse competencies have been established as a framework to develop nurses from novice through to expert level of practice [22] (Leavy et al., 2013), but these have not yet been promoted worldwide and would need further elucidation for different regions and health care systems.

In France, standardized practices in therapeutic education led to the creation of a National Reference of healthcare skills. This specific approach follows adults' and children's different life periods [23] (Prévos-Morgant et al., 2014). In a second time, this led to the creation of an Epilepsy nurse commission of the French League Against Epilepsy which aims is to standardize epilepsy nurse practices. In France, a law on Advanced Nursing Practices, published on the 18th July 2018, will support the new epilepsy specialist nurse role.

Competencies are important to set and maintain skills and knowledge and ensure performance can be bench-marked. The competency dimensions are also relevant to non-specialist professionals and could be very pertinent to those countries that do not recognize 'specialist nurses' or use other health care workers to provide epilepsy support. A consensus of nursing competencies in epilepsy that could be adapted globally would be a critical step towards standardizing and expanding nursing roles in epilepsy care.

Epilepsy nurses have been key in developing procedures and protocols to ensure the appropriate and safe use of rescue medications to prevent seizure emergencies, hospitalizations and possible death.

Disclosure of interest

The authors declare that they have no competing interest.

REFERENCES

- [1] Fisher R, Acevedo C, Arzimanoglou A, Bogacz A, Cross H, Elger C, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia* 2014;55(4).
- [2] Institute of Medicine (Institute of Medicine). *Epilepsy across the spectrum: Promoting health and understanding*. Washington (DC): National Academies Press (US); 2012.
- [3] Labiner DM, Bagic AI, Herman ST, Fountain NB, Walczak TS, Gumnit RJ. Essential services, personnel, and facilities in specialized epilepsy centers – revised 2010 guidelines. *Epilepsia* 2010;51(11):2322–33.
- [4] Ball J. Maxi nurses: advanced and specialist nursing roles; 2005, https://www.rcn.org.uk/_data/assets/pdf_file/0006/78657/002756.pdf.
- [5] Theodore WH, Spencer SS, Wiebe S, Langfitt JT, Ali A, Shafer PO, et al. *Epilepsy in North America. A report prepared under the auspices of the global campaign against epilepsy, the international bureau for epilepsy, the international league against epilepsy, and the world health organization*. *Epilepsia* 2006;1–23.
- [6] Benbadis SR, Allen HW. An estimate of the prevalence of psychogenic non-epileptic seizures. *Seizure* 2000;9:280–1.
- [7] Ettinger A, Reed M, Cramer J, Epilepsy Impact Project Group. Depression and comorbidity in community-based patients with epilepsy or asthma. *Neurology* 2004;63(6):1008–14.
- [8] Friedman DE, Kung DH, Laowattana S, Kass JS, Hrachovy RA, Levin HS. Identifying depression in epilepsy in a busy clinical setting is enhanced with systematic screening. *Seizure* 2009;18(6):429–33.
- [9] Margrove K, Mensah S, Thepar A, Kerr M. Depression screening for patients with epilepsy in a primary care setting using the patient health questionnaire-2 and the neurological disorders depression inventory for epilepsy. *Epilepsy Behav* 2011;21(4):387–90.
- [10] Mensah SA, Beavis JM, Thapar AK, Kerr M. The presence and clinical implications of depression in a community population of adults with epilepsy. *Epilepsy Behav* 2006;8(1):2213–20.
- [11] Gaitatzis A, Sander JW. The mortality of epilepsy revisited. *Epileptic Disord* 2004;6(1):3–13.
- [12] Nashef L. Sudden unexpected death in epilepsy; terminology and definitions. *Epilepsia* 1997;38(suppl 11):S6–8.
- [13] Smithson WH, Colwell B. Sudden unexpected death in epilepsy: addressing the challenges. *Curr Neurol Neurosci Rep* 2014;(12):502.
- [14] Tomson T, Nashef L, Ryvlin P. Sudden unexpected death in epilepsy: current knowledge and future directions. *Lancet Neurol* 2008;7(11):1021–31.
- [15] Chartrand D. The psychosocial challenges of epilepsy and the role of the clinical nurse specialist. *Soins Pédiatr Pueric* 2015;283.
- [16] Jurasek L, Ray L, Quigley D. Development and implementation of an adolescent epilepsy transition clinic. *Am Assoc Neurosci Nurse* 2010;42(4):181–9.

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- [17] Higgins S, Lanfear JH, Lewis S, Goodwin M. Quantifying the role of the nurse specialist in epilepsy. Data from diaries and interviews. *BJNN* 2006;2(5.).
- [18] RCN. Specialist nurses: changing lives, saving money; 2010 Fletcher M (2011)http://www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf 3.
- [19] RCN Factsheet: specialist nursing in the UK February 2013.
- [20] Pfafflin M, Schmitz B, May TW. Efficacy of the epilepsy nurse: results of a randomised controlled study. *Epilepsia* 2016;57(7):1190-8.
- [21] MacDonald D, Torrance N, Wood S, Wormersley J. General practice-based nurse specialists-taking lead in improving the care of people with epilepsy. *Seizure* 2000;9(1):31-5.
- [22] Leavy Y, Goodwin M, Higgins S, Myson V. The adult epilepsy specialist nurse Competency Framework. (ESNA 2012).
- [23] Prevos-Morgant M, Petit J, Grisoni F, André-Obadia N, Auvin S, Derambure P. A national framework for educational programs in epileptic patients, children and adults. *Rev Neurol (Paris)* 2014;170(8-9):497-507.