



## How nurses in the UK participate in managing epileptic patients Comment les infirmières au Royaume-Uni participent à la prise en charge des patients épileptiques



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### **Abstract**

This work shows how the effective creation of the Clinical specialist nurse (CNS) in epileptology has proved to be cost effective and beneficial in the management of epileptic patients in the UK. It provides high quality care and facilitates the work in epilepsy clinics. Other comparison studies have highlighted the need of having these specialist nurses in other developed countries as well. Their Role is extremely supportive for the Doctors and Consultants in epilepsy clinics.

**Keywords:** Epilepsy- Nurse Specialist- Management- Care- Community.

### **Résumé**

Cet travail met l'accent sur l'utilité de la création effective de l'infirmière spécialisée dans les cliniques d'épileptologie, ce qui s'est avéré être rentable et bénéfique dans la gestion des patients épileptiques au Royaume-Uni. Il offre des soins de haute qualité et facilite le travail dans les cliniques d'épilepsie. D'autres études comparatives ont mis en évidence la nécessité d'avoir ce type d'infirmières spécialisées dans d'autres pays développés. Leur rôle est très favorable pour les médecins et les consultants des cliniques d'épileptologie.

**Mots-clés:** Epilepsie- Infirmière spécialisée- Prise en charge- Soins- Communauté.

### **Introduction**

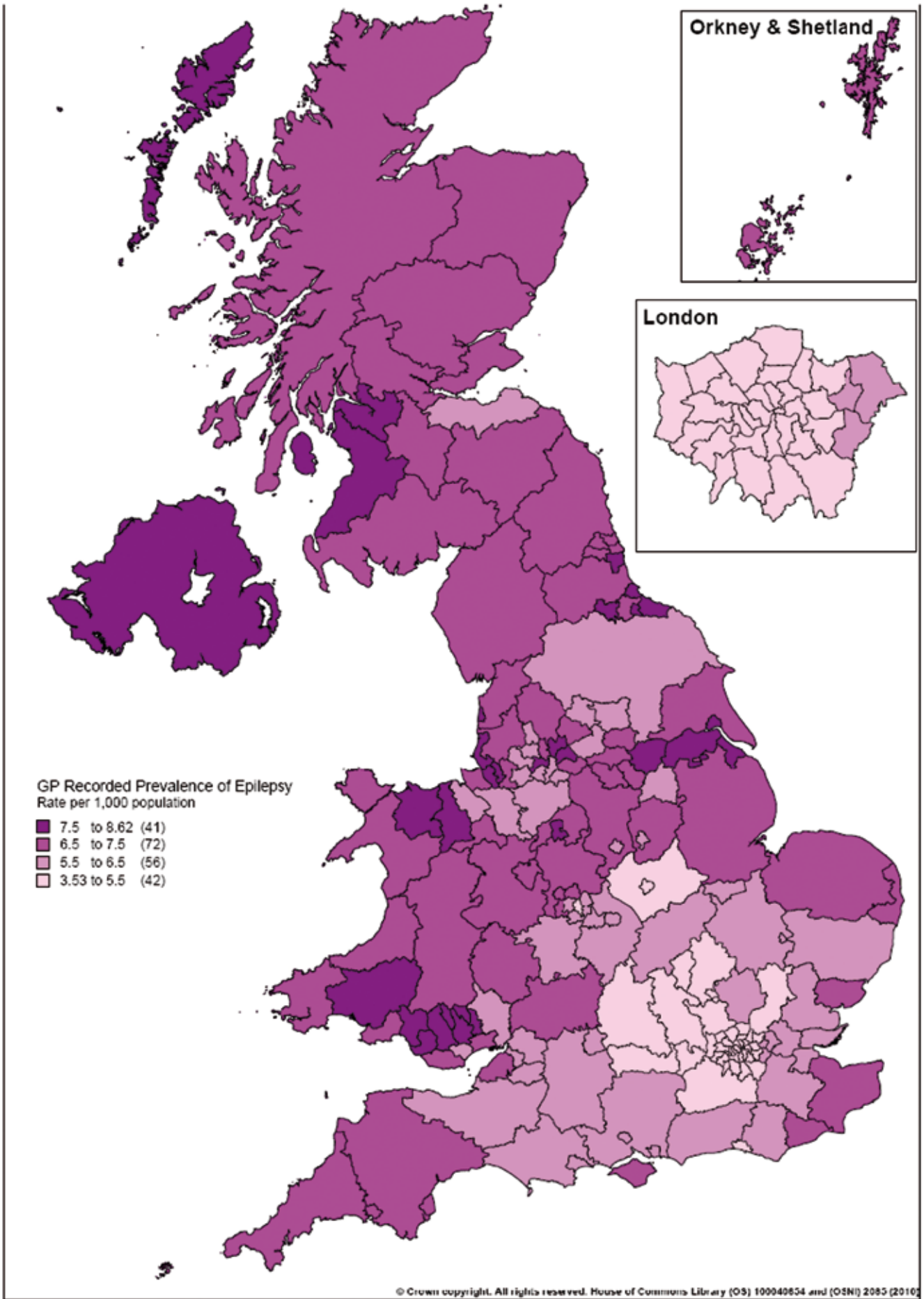
This paper looks at comparative research of how nurses in the UK and other countries manage patients that suffer from epilepsy and the effectiveness of this management and how the Role of the Clinical Nurse Specialist (CNS) nurse assists with this growing population of sufferers. It also highlights the effectiveness and benefits of the developments of these roles.

The NHS is the National Health Service it is a service that provides health care to all British Citizens based on the need for health care rather than whether they can pay for it. The service was born on the 4th of July 1948 and it was the first in the world to provide care based on citizenship rather than on funding. In the early 30s and 40s, thousands of people were dying from curable diseases and infections babies were dying before their 1st birthday from preventable illness and health care was considered a luxury. This is why the NHS was born, patients were not discriminated on wealth or race or class it was free for all. Although the NHS has suffered due to cash flow, it has changed the lives of millions of people. Every person

living in the UK Pays taxes a percentage of that goes to the NHS to keep it going, whether you are unemployed or in full time work every one pays towards it [1]. Within the UK, approximately 600,000 people suffer from epilepsy (Epilepsy UK). This approximates one in every 103. The national institute of Clinical Excellence (NICE) have created a framework that entails a 9 and 17 step guideline of managing patients from diagnosis to management [2]. Although Epilepsy affects quite a large proportion of adults and children Health care professionals still needs more educational support in managing this condition in the community. Basic training is given during basic life support and intermediate life support training nationwide. In the UK Approximately 70 % of people that suffer, epilepsy may be seizure free with the right medication according to Epilepsy Action. For the remaining 30% of suffers who medication is of no benefit there are other options, like brain surgery, Vagal Nerve Stimulation or Ketogenic Diet [3]. The role of the Community Nurse is very important as 90% of patients epileptic episode normally presents itself in the community [4]. The Clinical Nurse Specialist (CNS) has a pivotal Role in the education of Care Givers and community services that care for this client group, their input is a vital to the delivery of quality care and the provision of quality of life. NICE. The reason the role of Epilepsy Specialist Nurse (ESN) was created as this deemed a financial sense as the ESN manages the patients in between consultations with the consultant or DR and this will reduce the amount of: A + E attendance; the unnecessary calls, errors in diagnosis of epilepsy and reduce the hospitalization of patients delays (Figure 1).

### **Benefits to NHS are:**

Reducing cost by using cost effective Nursing time and Less Use of Gp Consultant time, Evidence based practice, Effective anti-epileptic drug prescribing by ESN, improved communication between secondary care and primary care hence creating better Patient care pathways [4-6]. Guys and St Thomas's Hospital in London conducted a controlled trial where 251 patients above 15 years of age who were on anti-epileptic medication, or recently diagnosed with epilepsy and had recently had an episode in the last 2 years. Who also met the criteria and completed the questionnaire. The trial showed that out of the 251 patient's 127 were randomised to a nurse of which 83% of those patients attended the nurse led clinic and 28 correspondences were sent to Patient's own GP making recommendations for drug changes and epilepsy management. Also highlighted in this comparative study



management. Also highlighted in this comparative study was that in over a fifth of the patient's she saw she was able to pick up on possible improvements on drug regime, and also the drug compliance by patients who were being seen by the (ESN) and patients reported more knowledge was gained by visiting the Nurse. This is indicative of how the nurse specialist clinic can significantly improve the level of drug compliance and epilepsy management of these patients, which in turn can increase their quality of life [7,8]. The (WHO) World Health Organisation conducted a study in 2005 to ascertain the amount of trained allied professionals who are care providers for patients suffering from epilepsy in various countries. They looked at Africa, America, Asia, Europe, Eastern Mediterranean, Western Pacific and the World. The Study showed that 19732 Neurological Nurses, Psychiatrists, Social Workers are providing care in the responding countries. Nurses were highlighted as providing care to 56.5% of the responding countries that were in the study. While the average number of Nurses per 100,000 inhabitants in Europe is 0.19 and South Asia is 0.03. The average number of Nurses per 100,000 inhabitants involved predominantly in care of epilepsy in low income countries is 0.07 and for middle and high income countries is 0.11 [9]. Pilot Nurse Led Clinics were set up in rural health districts in Cameroon, to manage four Chronic conditions which included; Diabetes, Hypertension, Asthma and Epilepsy. This was used as a setting for the study. The international and local countries guidelines were identified and the study and setting were adapted to the countries circumstances. Nurses were trained in each of the specific areas and medication was provided and made readily available for the trials. The outcome of the Study showed that 46 Nurses attended course updates in the following year, and the pilot encouraged 3-4 separate clinics to become operational in other rural areas, by this time 925 patient's had been recorded as registered under the clinics which indicated in a 68.5% increase from the beginning of the pilot scheme. The conclusive outcome of the pilot indicated that Nurse led Clinics in the rural areas of Sub Saharan Africa were positively the better option to overcome the physician shortages that were faced and other issues relating to access to health care. This was also indicative of a pathway to promote better quality of life [10, 11]. Relatively few studies of epilepsy-associated stigma have been conducted in Africa, where much of the world's burden of epilepsy exists. In sub-Saharan Africa (SSA), particularly in rural regions.

Epilepsy is a burden on close families, socially psychologically and physically as these affected individuals are not medically reviewed rather seen as possessed of some sort, which indicates further health promotion is needed in order for these stigma's to go away add few words that sp nurses are missing and also in some countries neurologists are very rare [12]. This study showed that for disorders like Epilepsy Nurses play pivotal roles in the provision of care in the primary care setting, including liaison services. But importance of the appropriate training is needed to provide adequate care

with facilities at reach, to provide high quality standards of care. As you can see, there is a huge difference in the number of nurses in low-income countries than there are in high-income countries [9].

### **Authors informations**

Previous research identifies loss as a key concept for our understanding of the impact of chronic illness. In this in-depth qualitative study, we explored the utility of the concept of loss and loss replacement as a means of gaining a fuller understanding of the implications of a diagnosis of epilepsy for overall quality of life (QOL). Potential participants were identified from the database of a large UK-based randomized controlled trial of antiepileptic drug treatment for new-onset epilepsy and selected using purposive sampling methods. In-depth interviews were conducted with 67 people; interview material was analysed thematically. Our findings confirm 'loss' as a key concept in understanding epilepsy impact. Participants cited profound physical and social losses, and the links between these and psychological loss were clearly articulated. Informants described two main processes via which the linked losses they experienced occurred: personal withdrawal processes and externally enforced processes. Seizure control was integral to restoring psychological well-being and a sense of normality but was only one of a number of influences moderating the degree of loss experienced following seizure onset. Our work emphasizes that people with epilepsy (PWE) require active support for their continued engagement or reengagement in roles and activities identified as central to their psychological well-being and overall QOL. Achieving this requires a multiagency approach to drive forward key strategies for reduction of the negative impacts of epilepsy and to engender a sense of normality in the context of a condition often experienced as placing the individual outside the socially determined parameters of the 'normal' [12]. Various Countries throughout the globe conduct Conferences and Workshops to support the Allied Professionals or Doctors involved in managing and the treatment of Epilepsy For example in Slovenia in July 2013 there is an advocate workshop conference being held to help teach the care givers strategic steps in to managing patients with epilepsy via person centred approach. If you are under 35, the admission is free, showing them coping mechanism, raising awareness and promoting the research in to epilepsy as so few are done in a comparative method.

### **Conclusion**

The UK and America are very fortunate to have such specific roles in comparison to other countries including Europe, as an ENS nurse isn't an option in some of these countries, as the role of a nurse is varied, i.e. the nurse is always seen as the Doctors assistant, or does what she is told. However, this is not the case in the UK, America the nurse has a great amount of autonomy, and clinical decisions are based on evidence-based practice which is why the Nurse led clinics are such a great success.

They benefit the Service providers by being cost effective and innovative and reduce the increased pressures that originally would leave appointments with Doctors un-bookable, now they are able to free up capacity so that DR and nurses are sharing the work load.

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