



Patients with epilepsy care experiences: Comparison between services with and without an epilepsy specialist nurse

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ABSTRACT

The aim of this study was to determine whether there were differences in experiences of care, satisfaction with care and quality of life between those who were in receipt of care from a service with an epilepsy specialist nurse (ESN) and those who were receiving care from a service that did not include an ESN. A comparative design was used, which involved the completion of a confidential, self-completed survey. The survey was administered to a nonprobability convenience sample of patients with epilepsy who were attending services with an ESN ($n = 244$) and services where the treatment team did not include an ESN ($n = 261$) from each of the four health areas in Ireland. This study found that, in comparison to people with epilepsy (PWE) who attended a service without an ESN, PWE who attended a service with an ESN reported receiving greater amount of information, were more involved in their care, perceived care to be better coordinated, and had greater confidence in the information provided and greater comfort in discussing issues with an ESN. They also reported higher rates of satisfaction with the emotional and practical support offered. Thus, it may be concluded that models of care involving the input of ESNs enhance the quality of epilepsy care and care processes. The findings also emphasize the need to have an ESN as part of the multidisciplinary team.

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1. Introduction

Epilepsy is a common neurological condition with a prevalence estimated to be between 5 and 10 per 1000 persons [1]. Most people with epilepsy (PWE) experience long-term remission and manage their epilepsy through medication, once the most effective regimen is followed. However, a significant number experience ongoing problems in the form of breakthrough seizures or prolonged uncontrolled convulsive activity, which have profound implications for their physiological and psychological well-being as well as other aspects of their lives, including social, educational, and employment [2]. As epilepsy is considered a chronic disease, the authors assert that its management requires a shift from a reactive healthcare system that views the patient as a passive recipient to a model that is proactive and supports the patient to develop knowledge and skills in self-management.

Despite the importance of access to timely coordinated care and early and accurate diagnosis [3], the literature documents many gaps

and unmet needs in the care and treatment of PWE. In a systematic review of satisfaction with care, it was found that PWE are least satisfied with communication, knowledge, and perceived skills of healthcare providers, with a significant number of PWE expressing dissatisfaction with the information provided to them [4]. Studies indicate that, due to time constraints and/or lack of expertise, doctors, neurologists, and other professionals do not comprehensively address essential elements of care with PWE, such as diagnoses, treatments, drug interactions and side-effects, as well as the psychosocial implications of epilepsy [5–8]. Compounding this lack of information is the reticence PWE experience around asking questions of clinicians for fear of wasting their time [5, 8]. A more recent systematic review of unmet needs identified challenges that PWE experience in the availability, accessibility, and acceptability of services [9]. In terms of availability, a lack of specialist services, long waiting times, and insufficient consultation time were reported. Cost of care and challenges around transport were the main issues that impacted on accessibility, with culture, language, and interpreter issues being the primary issues affecting acceptability. Similarly in Ireland, studies of PWE echo international findings, reporting delays in accessing specialist services, a lack of coordinated care and information sharing, inadequate follow-up care, and a belief that general practitioners have insufficient knowledge of epilepsy [10, 11]. Given the evidence of the impact of

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poor quality epilepsy care on mortality, morbidity, and healthcare costs, finding a model of care that addresses epilepsy care deficits is critical. The inclusion of epilepsy specialist nurses within the multidisciplinary team has been proffered as a solution to address some of these unmet needs and challenges [12]. The overall aim of the study reported in the paper was to evaluate the impact of ESN care on PWE's experiences of care, satisfaction with care and quality of life. The core objective was to determine whether there were differences in experiences of care, satisfaction with care and quality of life between those who were in receipt of care from a hospital-based epilepsy service with an ESN and those who were receiving care from an epilepsy/neurology service that did not include an ESN role.

2. Epilepsy specialist nurses

Internationally, the role of the epilepsy specialist nurse (ESN) is recognized as an integral part of the epilepsy multidisciplinary care team. The role is said to encompass facilitating PWE to access services, supporting the coordination of care and providing information, education, and support to PWE and their families [13, 14]. In qualitative studies that have explored the ESN role from the perspective of PWE, the role has been endorsed for providing continuity of care [6, 15–17], increasing the accessibility of care [8, 17, 18], and facilitating greater opportunity to access information and advice [7, 16, 18]. In this regard, ESN care is said to result in enhanced knowledge of epilepsy among PWE and a greater ability to self-manage the condition [7, 8, 17]. The effectiveness of ESN care in terms of the provision of information was demonstrated in Ridsdale et al.'s study, which showed that more advice was provided on epilepsy through nurse-run clinics [19]. Pfäfflin et al.'s study [12] also showed significant improvements in epilepsy knowledge, satisfaction with information and support, and information seeking in the ESN group in comparison to the control group. Nevertheless authors of two systematic reviews conclude that the evidence in support of the effectiveness of ESN care is mixed at best, and is not robust enough to assert that ESN care results in better care or outcomes compared to those receiving standard treatment [20, 21].

In Ireland, in recognition of the relationship between quality services and health outcomes, the National Clinical Care Programme in Epilepsy (NCPE) [22] was charged with addressing the historic deficits in epilepsy care. As part of a range of policy and system changes to improve access to person centered epilepsy care the NCPE recommended that every PWE have access to an ESN. In Ireland, an ESN has specialist education and expertise in epilepsy, plays a key role in the management and support of people with epilepsy across primary, secondary, and tertiary care, and may be working as a clinical nurse specialist (CNS) or an advanced nurse practitioner (ANP). The CNS is defined as a nurse who works in an area of specialist clinical practice, works closely with medical and paramedical colleagues, educates colleagues, and improves the quality of patient care through audit and research [23]. An ANP is defined as a nurse who is an autonomous practitioner, responsible for advanced levels of decision-making, managing a patient caseload, demonstrating clinical and professional leadership, and advancing clinical practice through research. An ANP holds a Master's degree in nursing or a higher degree, which contains substantial modules related to advanced practice in the specific area of expertise [24].

Given the ESN role is said to focus not only on clinical/medical aspects of epilepsy, but also on providing information and support to patients through educational and therapeutic work to enable them to self-manage and cope with the challenges presented in every aspect of life, be it social, educational, or vocational, it was important to assess how well this role is responding to the holistic needs of PWE. With a view to informing future developments in relation to the role in Ireland, and supported by Epilepsy Ireland and the Health Research Board, the Specialist Epilepsy Nurse(s) Evaluation [SENSE] study set out to identify the role and cost-effectiveness of the ESNs and to evaluate their impact on patient care. This paper reports some aspects

of the findings and focuses on differences in care experiences, satisfaction with care and quality of life (QoL) between PWE attending a service with an ESN and those attending a service that did not include an ESN.

3. Methods

3.1. Research design

A comparative, cross-sectional survey design was adopted to achieve the objective of determining differences in PWE's experiences of care between services with and without ESNs.

3.2. Survey

Data for the study were collected using a confidential, self-completed survey. This method was selected as it is a relatively easy and cost-effective means of obtaining structured information from participants, while its anonymity minimizes the potential for socially desirable responses [25, 26].

The survey collected information on patients' demographic characteristics and epilepsy profile, and examined patients' experiences of the care provided in relation to information provided on epilepsy (21 items), involvement in care (6 items), coordination of care (4 items), continuity of care (3 items), comfort with and confidence in care (4 items), whether treated with dignity and respect (2 items), impact of care on health and well-being (1 item), and satisfaction with emotional and practical support (2 items). The 21 items on information provided were focused on the nature of epilepsy and their own epilepsy (4 items); medical aspects of epilepsy (9 items); social aspects of epilepsy; (3 items) and safety aspects of epilepsy (4 items). One item related to information on pregnancy and was only applicable to the female participants.

Some of the items included in the questionnaire were adapted from the survey used within the Specialist Clinical and Advanced Practitioner Evaluation (SCAPE) study [27–30], a national evaluation of clinical specialist and advanced nurse and midwife practitioners in Ireland, while others were developed by the research team. People with epilepsy were asked to rate their experience of care provided by the ESN, or, in the case of the non-ESN sites, the provision of care from health practitioners, which is mainly neurology specialists or medical consultants with expertise in epilepsy. Most questions contained Likert response categories ranging from 1 ('strongly disagree') to 5 ('strongly agree'), with the exception of the two questions on practical and emotional support, which used a ten-point scale ranging from 1 ('Not at all satisfied') to 10 ('completely satisfied'). Higher scores indicated a more positive perception of the issue being measured.

The survey also included the Quality of Life in Epilepsy (QOLIE)-10-P, an adaptation of the QOLIE-10 [31] to assess the impact on patients' quality of life. The QOLIE-10-P requests participants to rate the degree to which a number of epilepsy-related issues have impaired their quality of life over the past 4 weeks. Items include seizure worry, overall quality of life, emotional well-being, energy/fatigue, cognitive function, medication effects, social function, and overall distress. The final score ranges from 0 to 100 with a higher score indicating better quality of life. Permission to use copyright questionnaires was obtained before use.

3.3. Sample and recruitment

As there was no national database of PWE, the survey was administered to a nonprobability convenience sample of patients with epilepsy who were attending services with an ESN and services where the treatment team did not include an ESN from each of the four health areas in Ireland. To be included in the survey patients had to have a diagnosis of epilepsy, be aware of their diagnosis, be attending a service (with or without an ESN) for one year or more, be over 18 years of age, and not have an intellectual disability or dementia to the level that they would not be able to self-complete the survey.

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