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Insight into adult epilepsy care in New Zealand:
An exploration of the nurses’ role and care they
provide for adults with epilepsy

A thesis presented in partial fulfilment of the
requirements for the degree of Masters of
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Abstract

Epilepsy is one of the most common neurological disorders that has an on-going tendency for reoccurring seizures. It is estimated to affect between 20,000 and 28,000 people in New Zealand (Bergin, Sadleir, & Walker, 2008). Epilepsy care includes not only giving treatment but also providing continuous support to people with epilepsy (PWE). Nurses have the potential to play a significant role in epilepsy care by providing education and support to PWE and their families. Through my working experience as an Epilepsy Speciality Clinical Nurse, I recognised issues in epilepsy care and I found out that there have been no studies in New Zealand relating to a nurse’s role and care of PWE. This is why I decided to undertake study of and exploration of the nurses’ role and care they provide for PWE.

Grounded theory methodology was adopted to explore adult epilepsy care by interviewing nurses who provide care to PWE. Data was collected using semi-structured interviews by telephone, Skype, or face-to-face from the nurses. The data was analysed by open coding, development of categories, and theoretical coding. During this process, the epilepsy care pathway and the negative cycle of epilepsy diagrams were developed. At the end of the analysis two theories ‘Epilepsy care in New Zealand is far from ideal due to the lack of guidelines for nursing practice’ and ‘If the profile of epilepsy nursing is raised in New Zealand, delivery of the epilepsy care would improve’ were developed. The findings are discussed in relation to these two theories and consequently four recommendations: creating guidelines, building epilepsy nurses’ network, promoting more research on epilepsy nurses’ role and their value in epilepsy care, and increase utilisation of digital technologies, were made to improve the delivery of epilepsy care in New Zealand.
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Abbreviations

AED: antiepileptic drugs
CNS: clinical nurse specialist
DHB: district health board
ED: emergency department
EEG: electroencephalography
ENS: epilepsy nurse specialist
GP: general practitioner
ILAE: International League Against Epilepsy
MS: multiple sclerosis
NICE: National Institute for Health and Care Excellence
NZTA: New Zealand Transport Agency
NZLAE: New Zealand League Against Epilepsy
PHARMAC: Pharmaceutical Management Agency of New Zealand
PNES: Psychogenic non-epileptic seizure
PWE: people with epilepsy
QOL: quality of life
SJS: Stevens-Johnson syndrome
TEN: toxic epidermal necrolysis
UK: United Kingdom
USA: United States of America
WHO: World Health Organization