

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

**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
Philosophy in Nursing**

at Massey University, Wellington, New Zealand



COLLEGE
OF HEALTH
TE KURA HAUORA TANGATA

Kinuko McCarthy

2018

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.

Acknowledgement

Although I was the solo researcher for this thesis, this study was not accomplished alone. I would like to thank all of the nurses who agreed to participate and share their thoughts and experiences in this study. I am in eternal gratitude to Professor Annette Huntington for your continuous support and encouragement throughout this project.

I am indebted to all field officers from Epilepsy New Zealand for helping me during sampling stage on this study. I would like to thank the Wellington Neurology Department and the New Zealand League Against Epilepsy for their financial support for this thesis.

I wish to express my sincere thanks to my colleagues and friends who supported and encouraged me throughout the study, particularly those who helped with my English.

And last but not least, special thank you to my husband Ged and three children for supporting me through this long journey.

Kinu McCarthy

June 2018

Table of Contents

ABSTRACT	i
ACKNOWLEDGEMENTS	ii
TABLE OF CONTENTS	iii
ABBREVIATIONS	ix
CHAPTER ONE: Introduction	1
Introduction	1
About epilepsy	1
History of epilepsy	1
Global impact of epilepsy	2
Epilepsy treatment	2
Comorbidity and quality of life (QOL)	3
Background to the study	4
Small number of nurses	4
Low profile of epilepsy care	5
Referral process to epilepsy nurses	5
Epilepsy nursing guidelines and standardisation	6
Integrated care	6
New Zealand League Against Epilepsy (NZLAE)	7
Significance of the study and study design	7
Emergence of the research question and research method	7
Structure outline of the thesis	8
Summary of chapter one	8

CHAPTER TWO: Literature Review	9
Introduction	9
Impact of epilepsy on people’s quality of life (QOL)	9
Seizure frequency and antiepileptic drugs’ (AED) side effects	9
Social stigma	10
Discordance between PWE and care providers	11
Less education and lower income	11
Safety issues	11
Access to general and mental health services	12
Effect on family members	13
Epilepsy nurses’ roles and values	13
Optimal skill for epilepsy nursing	13
Increasing patients’ satisfaction and self-management skills	14
Clinical- and cost-effectiveness of nurses’ input in epilepsy care	15
Integration of epilepsy care	16
Rural hospitals	16
Epilepsy care for certain population	17
Adolescents’ epilepsy care	16
Care for older population	18
Care for women at childbearing age	18
Refractory epilepsy	18
Psychogenic non-epileptic seizures (PNES)	19
Sudden unexpected death in epilepsy (SUDEP) and status epilepticus (SE)	19
Where is epilepsy care heading to?	21

Summary of chapter two	22
CHAPTER THREE: Methodology	23
Introduction	23
Theoretical underpinning	23
Emergence of the research question	23
What is qualitative research?	24
Brief history of grounded theory methods	25
Rationale for using grounded theory method	25
Data collection and data analysis for grounded theory	25
Theoretical sampling and data collection	25
Navigation of analysis process	26
Theoretical sensitivity	27
Ethical issues	27
Consideration for indigenous population	28
Research methods	28
Sampling	28
Data collection	29
Rationale for adopting semi-structured interview	29
Interview method	29
Data analysis	30
Reliability and validity of the study	30
Limitations	31
Reflexivity	31
Study dissemination	32

Summary of chapter three	32
CHAPTER FOUR: Coding and categories development	33
Introduction	33
Introduction to the study participants	33
Substantive coding process	33
Many PWE are not receiving optimal epilepsy care in New Zealand	34
There are not many epilepsy nurses	34
Nurses do not have enough time to work with PWE	34
There is no one to provide care that epilepsy nurses do	36
PWE are having difficulties	36
There are challenges in epilepsy nursing	38
Care nurses provide	38
Reasons PWE contact epilepsy nurses	39
High “did not attend (DNA)” rates	40
Epilepsy care is inconsistent	41
Nurses work very differently	41
Nurses’ network	42
Disparity of epilepsy care around the country	43
Education opportunity for epilepsy nurses is limited	44
There is a lack of integration in epilepsy care	45
Neurology department is overloaded	45
Epilepsy education to other healthcare providers	46
GP’s role in epilepsy care	47
Relationship with community organisations	47

What we can for future/ideal epilepsy care	49
Summary of chapter four	50
CHAPTER FIVE: Theory development	51
Introduction	51
Category one: Many PWE are not receiving optimal epilepsy care in New Zealand	51
Significant shortage of nurses	51
Effects of driving restriction and high ‘did not attend (DNA)’ rates	51
Stigma and discriminations	52
Category two: There are challenges in epilepsy nursing	53
Category three: Epilepsy care is inconsistent	54
Category four: Education opportunity for epilepsy nurses is limited	55
Category five: There is a lack of integration in epilepsy care	55
Category six: What we can do for future/ideal epilepsy care	56
Development of epilepsy care pathway	57
The theme development	58
Summary of chapter five	59
CHAPTER SIX: Discussion	60
Introduction	60
Epilepsy care in New Zealand is far from ideal	60
Negative cycle of epilepsy	61
Interventions to manage factors to lower quality of life (QOL)	61
Barriers providing education for PWE and their family members	63
Nurse-led clinics and standardisation of epilepsy nursing	64
Epilepsy nursing in less populated areas	65

Integration of care and the pivotal role of nurses	66
Becoming a point of contact	67
Education for epilepsy nurses	68
Raising profile of epilepsy nursing	70
Research required	70
Future epilepsy nursing care	71
Summary of chapter six	72
CONCLUSION	73
Recommendations	73
REFERENCES	75
Appendix A: Ethics notification	82
Appendix B: Participant's information sheet	83
Appendix C: Participant's consent form	86

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