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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 Philosophy in Nursing

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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

Chapter 1: Introduction

Introduction

'Cancer, you're awake. I know you can die, but you're awake. I'd prefer something like that … Having epilepsy; you're going into a fit. You don't know if you're going to wake up or die' (Noble, Morgan, Virdi, & Ridsdale, 2013, p. 1027).

Epilepsy is one of the most common neurological disorders with an on-going tendency to have recurrent epileptic seizures and it affects 20,000 to 28,000 people in New Zealand (Bergin et al., 2008). Epilepsy care is not only giving medical treatment for those live with this chronic condition. It is also just as importantly, providing continuous support for people with epilepsy (PWE) when available, nurses take on a significant part in this care. This thesis explores current epilepsy care in New Zealand and nurses' involvement to find out how they are providing the care with an aim of continuous improvement of service to PWE.

The focus of this study is adult epilepsy care. However, in the real settings, there are younger people who can be classified as paediatrics in adult epilepsy care. Therefore, in this thesis, I use the term 'people' or 'person' to describe the clients.

About Epilepsy

History of Epilepsy

Epilepsy is one of the world's oldest acknowledged conditions, with written records dating back to almost 2000 B.C. (Magiorkinis, Sidiropoulou, & Diamantis, 2010; World Health Organization, 2018b). People's view of epilepsy was very different at that time from what it is nowadays. Before the 18th century, epilepsy was regarded as a mysterious disease, for example a sacred disease, herculean disease, supposedly caused by evil spirits, goblins and demons, or linked to witchcraft (Mia Tuft, 2014). As for the treatment, the patient was shoved into a natural opening such as a stone crevice or a hollow tree to transfer the disease into the ground (Mia Tuft, 2014). People also tried other forms of treatment including complete abstinence of food and drink, castration, bloodletting, leeches, craniotomy to release the spirits. They also ingested the ashes from burnt clothing worn during seizures, herbs, various metals, human and animal blood, urine and ground-up human skulls (Magiorkinis et al., 2010; Mia Tuft, 2014). At the beginning of the 18th century, the notion of the 'animal spirits' was gradually shifted towards neural function or 'electrical fluid' in nervous system (Daras, Bladin, Eadie, & Millett, 2008, p. 18). The diagnosis of epilepsy became the presence of both loss of consciousness and bilateral

convulsion. In the 19th century, various clinical symptoms of epilepsy were recognised in broad areas. Theories of the mechanisms of epilepsy at that time became the foundation of today's understanding of epilepsy. Treatment with an antiepileptic drug (AED), potassium bromide, and epilepsy surgery were started around this period (Daras et al., 2008).

Despite scientific understanding of the condition, misunderstanding, fear, discrimination and social stigma have surrounded epilepsy for centuries and still affect PWE in many countries today. For example, in the United Kingdom (UK), until 1971, the annulment of a marriage on the grounds of epilepsy was legal. In the United States of America (USA), denying people with seizures access to restaurants, theatres, recreational centres and other public building was legal until 1970s. Having epilepsy is still a common reason for prohibiting or annulling marriage in both India and China (World Health Organization, 2018b)

Global impact of epilepsy

Epilepsy affects 0.4 to 1.0 % of general population globally, however this percentage increases up to 1.4% in low- and middle-income countries (World Health Organization, 2018b). This is likely because of endemic condition such as neurocysticercosis (infectious parasitic disease in the brain) or malaria, higher incidence of head injuries due to traffic accidents, birth-related injuries, discrepancies in medical infrastructure, availability of preventative health care, and discrepancy in accessible care (World Health Organization, 2018b). Additionally, 80 to 98 % of PWE in developing countries are not treated (Kale, 1997). PWE are known to have higher unemployment rates and lower incomes when compared to similar adults without epilepsy (Ziemba & Drazkowski, 2015). This situation leads to an economic burden and when seizures are not well controlled, the burden grows larger (Megiddo et al., 2016).

Epilepsy treatment

Epileptic seizures are defined as 'the transient clinical manifestation that results from an episode of epileptic neuronal activity' (Shorvon, 2010, p. 1) and the symptoms are varied depending on the type of epilepsy and focus of the seizures. Seizure presentation can be different in each person. There could be motor, psychic, autonomic and sensory phenomena with or without alteration in awareness. The first line treatment for epilepsy is taking antiepileptic drugs (AEDs) to prevent seizure recurrence. There are more than 20 different AEDs with a different mechanism of action. Approximately 70% of people who are on treatment with AEDs obtain good seizure control with no seizures for at least two years (Perucca & Tomson, 2011; World Health Organization, 2018b).

Despite the treatment with AEDs, it may be difficult to obtain good seizure control in some PWE. In these cases, there may be other options for treatment. This is dependent on the cause or

type of epilepsy and availability of the treatment (Shorvon, 2010). Surgery can be a treatment option for certain type of epilepsy, however the benefits and the risks need to be considered for such an invasive treatment (Shorvon, 2010). Other options such as vagal nerve stimulation or cortical stimulation may be beneficial, yet the efficacy and the cost effectiveness are not conclusive and their availability is varied (M. C. Smith, Byrne, & Kanner, 2006). Nowadays, invasive and expensive treatments are performed less due to the development of newer AEDs and also rekindling interests in ketogenic diet (Ye, Li, Jiang, Sun, & Liu, 2015).

Comorbidities and quality of life (QOL)

The International League Against Epilepsy (ILAE) defined epilepsy as "Epilepsy is a disease characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition" (2014, para. 1). Although most PWE maintain reasonably good seizure control by using antiepileptic drugs (AEDs), they could still be affected by comorbidities (Duncan, Sander, Sisodiya, & Walker, 2006; World Health Organization, 2018b). AEDs are a central nerve system depressant and they can cause short or long-term depressive effects on the central nerve system, resulting effects such as fatigue, dizziness, and decreased cognitive function (Aschenbrenner & Venable, 2009). PWE have higher rates of pre-existing conditions compared with the general population. These include autisms, intellectual disabilities, brain injuries, and brain tumours, all of which can complicate the presentation of epilepsy (Selassie et al., 2014). PWE have more incidents of psychiatric comorbidities, such as anxiety and depression compared with people without epilepsy (Azuma & Akechi, 2014; Ettinger, Reed, Cramer, & the Epilepsy Impact Group, 2004; Koh et al., 2014). Additionally, epilepsy seizures can cause injuries such as fractures and burns (World Health Organization, 2018b). Moreover, some PWE are affected by stigma and psychosocial difficulties. People with poor seizure control are more affected by epilepsy as they need constant attention to safety and a stricter lifestyle alteration to minimise seizure recurrence. These PWE would continually search for alternative treatments to gain better seizure control. When seizures are not controlled, PWE have significant challenges in their quality of life (QOL) (Choi et al., 2014).

Epilepsy is understood as a neurological disorder by scientists and doctors, however there is still a lack of knowledge regarding this condition. This lack of understanding can contribute to a negative impact on those living with epilepsy and this possibly leads to discrimination or social isolation for PWE. The circumstance that PWE are living in can affect their QOL. Epilepsy care needs to consider comorbidities and needs to provide support to PWE and their families to minimise any negative effects from having epilepsy.

Background to the study

I have been involved in adult epilepsy care as an Epilepsy Speciality Clinical Nurse over three years in a regional hospital in New Zealand. My position was newly created to provide more nursing support for PWE in areas with limited neurologists' and no nurses' input, because a disparity of epilepsy care and its effect on patients' outcomes were found (Joshi, Watson, Rosemergy, & Jayathissa, 2015). Since I started this role, I have been looking for guidelines for an epilepsy nurses' role, such as details of what kind of care should be provided to PWE and pathways for referral processes to epilepsy nurses. There are some literature and research available on epilepsy nursing overseas, however nothing similar has been conducted here in New Zealand.

I started looking for other specialised epilepsy nurses to find out what they do and how they work in other areas of New Zealand. However, unfortunately I could find only small number of nurses and their roles seemed to be quite different in each centre and from what I do. Some epilepsy care can be provided by neurology nurses and possibly by more generalised nurses such as practice nurses and medical nurses. However, given the large number of PWE and the complexity of the condition, specialised nursing care would be definitely beneficial for PWE. The more I leaned about epilepsy care, the more I started wondering how and by whom the care is delivered to adult people with epilepsy. Therefore, I decided to explore what is happening in this field. Throughout my working experience, I had concerns about epilepsy care: the small number of nurses who are involved, the low profile of this disease within healthcare sectors, the uncertainty around the referral process to access epilepsy nurses, no care guidelines for nursing intervention, and integration of this care.

Small number of nurses

The shortage of nurses in the healthcare system appears to be a common problem in many sectors. However, New Zealand has a higher number of nurses per capita compared with other Organisation for Economic Co-operation and Development (OECD) countries (Zuru & Dumont, 2008). This means the New Zealand population should expect to have equal or more number of nurses in each sector. Given the lack of, or small number of nurses specialising or working in the field of epilepsy in New Zealand is a concern. There is no data available on how many nurses work specifically for neurology and epilepsy services. However, by looking at epilepsy nursing studies of some OECD countries, they seem to have more numbers of epilepsy specialised nurses than we do in New Zealand. Although no published data on exactly how many nurses working in this field, given this small number of nurses, I wondered what kind of epilepsy care PWE were receiving in an area where there is no epilepsy nurse available.

Additionally, there is no epilepsy speciality nurses' network in New Zealand. The nurses seemed to know of each other's existence through their colleagues and meetings or conferences for other neurological conditions. As epilepsy care is a specific area, I do not know how the nurses can update their knowledge or manage when they face a challenging situation, without support from colleagues who are working in the same or similar speciality area.

Low profile of epilepsy care

The low profile of epilepsy among the general public and healthcare sector is known to be a problem (Bergin et al., 2008). My background before this role was in emergency and intensive care nursing and I have to admit that I have never come across nurses giving epilepsy specific care to anyone in more than 20 years of nursing experience. While I started understanding the importance of nursing involvement in epilepsy care, I also noticed that very few of the general public and those in the healthcare sector showed an interest in epilepsy care. Bergin (2008) believes this may be related to the fact that many PWE have social disadvantages although I believe long history of stigmatisms and misunderstanding of the condition contribute to this. While epilepsy is a chronic condition, there is no strong evidence to justify spending money on speciality care by the national health system. Regardless of the reasons, it is clear that epilepsy care needs a higher profile and the current situation of available care and possible barriers should be investigated to raise the profile of epilepsy.

Referral process to epilepsy nurses

There are systems to make referrals to different specialists, such as neurologists, psychiatrists and social workers within and across organisations. However, there is no system to make referrals to epilepsy nurses. The decision of whether a person with epilepsy is seen by a nurse, in my organisation, is up to the discretion of their neurologist. Although I started seeing PWE in my clinic, I was unsure which PWE or at what stage they required my input. In my view, nursing focus and intervention would be different for each patient. For example, for a newly diagnose PWE, I would spend more time on education around what their condition is, the reason for taking medication, safety consideration, and possibly altering their lifestyle to manage seizure control. A person with epilepsy who has a complicated social background will need to have education around self-management skills and access to support in the community. It is important for nurses to spend some time providing education, listening to patient's thoughts, and assessing their needs. According to Blank (2013), unclear referral pathways could lead to people missing out on available services. I was uncertain if all PWE were receiving sufficient care, if any care, or aware of what care is available in our department. Therefore, I wanted to explore if there is any clear system or pathway for when or who involves nurses in the care of each patient and what other centres do about this.

Epilepsy nursing guidelines and standardisation

Guidelines can be broad or more detailed, but to my knowledge there are no guidelines specifically designed for epilepsy nursing in New Zealand. According to Robert's (2011) study, Clinical Nurse Specialist (CNS) roles are described as being a leader, a clinical expert, a coordinator and an educator. This is still too broad to know what epilepsy nurses' role is. Given nurses at other centres work differently, it is clear that there is a lack of standardisation in epilepsy care.

Although guidelines for epilepsy nursing are available overseas, they do not necessarily suit the New Zealand system. More relevant guidelines which work in our system would be helpful for providing optimal care. For example, if a guideline for a referral pathway to epilepsy nurses was developed, neurologists, GPs, and other healthcare providers would know when and how to refer PWE to the nurses. This means that PWE can access epilepsy nursing care seamlessly across New Zealand.

Integrated care

The National Institute for Health and Care Excellence (NICE) states that Epilepsy Specialist Nurses should take the key role to support continuity of care between specialists and generalists, to ensues the PWE have access to community based services and to provide optimal information (National Institute for Health and Care Excellence, 2012). Integrated and coordinated care for epilepsy is recommended to manage comorbidity, to increase QOL, and to provide timely referral and access to the treatments (Koh et al., 2014). There are health care providers in the community including general practitioners and practice nurses. There are also community organisations such as Epilepsy New Zealand, Epilepsy Foundation New Zealand and Epilepsy Waikato Charitable Trust. They offer support to PWE by visiting the PWE and their family, providing information, organising social activities in the community (Epilepsy Foundation New Zealand, 2018; Epilepsy New Zealand, 2018; Epilepsy Waikato Charitable Trust, 2018).

As a hospital based nurse, I need to rely on primary healthcare providers and those community organisations for care of PWE outside of the hospital. The services that PWE are receiving in the community appear to be varied and are often dependent on the area of residence and the organization they contact. There is some communication between hospital care and community care, however the process is unclear and this needs to be investigated.

New Zealand League Against Epilepsy (NZLAE)

A joint campaign 'Bring epilepsy out of the shadows' was launched by the International League Against Epilepsy (ILAE), International Bureau for Epilepsy, and the World Health Organization (WHO) in 1997 to fill treatment gaps. Their aims are: advancing and disseminating knowledge about epilepsy, promoting research, education, and training, and improving services and care for patients, especially by prevention, diagnosis, and treatment (Bergin et al., 2008; Kale, 1997; World Health Organization, 2018b). New Zealand also joined in this campaign by forming New Zealand League Against Epilepsy (NZLAE) in November 2006 (Bergin et al., 2008). At that time, NZLAE was aiming to improve the care of PWE in various ways such as working with the lay group Epilepsy New Zealand to raise the profile of epilepsy in the community, working with both drug companies and the Pharmaceutical Management Agency of New Zealand (PHARMAC) to ensure the medications used worldwide become available in New Zealand, and promoting various researches. The NZLAE also has nurses' involved although there are not many nurses and there are no guidelines about adult epilepsy nursing care at this stage.

Emergence of the research question and research method

The desirable outcomes of this study would be to learn if there are problems with epilepsy care in New Zealand. If so, I need to find out what the problems are, why the problems occurred, and how we can solve these problems. Hence, I chose to conduct a qualitative study using grounded theory method to explore epilepsy care in New Zealand. As the focus of this study is nursing care, I chose to conduct semi-structured interviews with nurses who provide care to adult PWE to collect data.

Significance of the study

Through my working experience as an Epilepsy Speciality Clinical Nurse, there seem to be some problems providing optimal epilepsy care to PWE. Nevertheless, the resource to find out what is happening in epilepsy care is extremely limited as no research has been conducted on epilepsy nursing care in New Zealand. Therefore, this study is significant to explore this unknown area. This topic is clearly relevant to my nursing practice. It is also important given the large population of PWE and the significant impact of the condition on the people, their families, the healthcare system, and society.

Structure of the thesis

This thesis consists of six chapters which follow a logical progression to describe this study. Chapter 1 is the introduction of this study. There is information about epilepsy including its history, treatment and comorbidities. This chapter also outlines the background and significance of this study, and introduces New Zealand's main body of epilepsy care group, NZLAE.

Chapter 2 is a literature review which provides further information about epilepsy care within and outside New Zealand. This chapter contains people's experience of epilepsy, how epilepsy nurses work, what guidelines are available and their feasibility, epilepsy care for certain populations, and a future view of epilepsy care. These topics are all related to each other and understanding these helps to see epilepsy care in a broader view.

Chapter 3 focuses on methodology. I revisit the emergence of the research question and explain the grounded theory approach and the rationale for its use for this study. The theoretical underpinning and data analysis are described. The details of the study method including data collection using semi-structured interviews and data analysis process are also defined. Ethical issues and reflexivity were also included in this chapter.

Chapter 4 and 5 reports the result and analysis of the interviews. Chapter 4 describes the process of substantive coding including open coding and development of categories. Each code is placed into small categories and then these categories are grouped in bigger core categories. Chapter 5 focuses on theoretical coding which analyses relationships between categories and core categories to develop theories. In this chapter 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. During this process, 'the epilepsy care pathway' and 'the negative cycle of epilepsy' were also created to visualise the concepts. Chapter 6 discusses the finding of this research based on the two theories developed. These six chapters are followed by conclusion which includes four recommendations to improve the delivery of epilepsy service.

Summary of chapter one

This chapter presented epilepsy which is the condition that many people have heard of but the history, the reality and its effect on people are not well known. The background of the study including how I chose the topic and the method are explained. Significance of the study and structure of the thesis are also presented.

Chapter 2: Literature Review

Introduction

This chapter reviews the available literature about epilepsy and epilepsy care. There are four components in the chapter. The first part describes the impact of epilepsy on people's quality of life (QOL). The second part focuses on nurses' role and values in epilepsy care. The third part explains epilepsy care for certain populations and conditions. The last part refers to the goal and future view of epilepsy care.

Impact of epilepsy on people's quality of life (QOL)

Epilepsy is not only about seizures. The condition is surrounded by complex issues and there are many factors affecting the QOL. Epilepsy care needs to include providing treatment, education, and continuous support to people with epilepsy (PWE) to improve their QOL.

Seizure frequency and antiepileptic drugs' (AED) side effects

Seizure frequency is generally known to affect QOL of PWE in that people with fewer seizures have better QOL than people with more frequent seizures. Choi et al. (2014) found that people who had been seizure free for more than one year have significantly higher QOL compared with people who have recurrent seizures within one year. Yet, they also found that the frequency itself is not sufficient to know PWE's QOL.

Although the goal of epilepsy treatment is to achieve seizure freedom with minimal side effect (Labiner et al., 2010), approximately 50% of people experience side effects to antiepileptic drugs (AEDs) (Schmidt & Schachter, 2014). However, when the risk of having seizures outweighs the side effect of the AEDs due to severity of seizures and high risk of sudden unexpected death in epilepsy (SUDEP), their choice of treatment is limited. There are many side effects including fatigue, cognitive difficulties, tremor, weight gain or loss. Some of AEDs are mood stabilisers while some cause depression which could lead to suicidal or self-harming ideas and behaviours (Peng, Ding, Li, Mao, & Wang, 2014). Some AEDs have harmful effects when taken long term. For example, phenytoin can cause gum hypertrophy, osteomalacia (softening of the bones), and cerebellar atrophy in long-term. Rarely AEDs can cause serious adverse reactions include acute suicidal ideation or life-threatening rashes such as Stevens-Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN) (Zaccara, Franciotta, & Perucca, 2007). Additionally, some AEDs increase risk of teratogenicity (abnormality in foetus), so the choice of AEDs needs to be made carefully for women of child bearing age.

Some side effects are better tolerated then others. According to a study by Witt et al. (2013), weight gain and tiredness are tolerated better, whilst psychiatric and cognitive side effects are less tolerated. Tolerability is also related to the efficacy of AEDs. A higher number of PWE with 100% seizure control tolerate side effects better than those with 50% control. Tolerability also correlates with what is happening in the person's life. For example, people for whom driving is very important would take the AEDs despite side effects to stay seizure free. On the other hand, people who are studying and want to maintain their cognitive function as much as possible may refuse to take AEDs due to cognitive side effects (Collins, 2011).

Social stigma

Social stigma is defined as 'loss of societal standing due to the possession of a particular attribute, such as undesirable medical condition which results in restriction beyond that necessary for the condition itself' (Bautista, Shapovalov, Saada, & Pizzi, 2014, P. 46). Beyond just managing their medical condition, social stigma is an on-going challenge for PWE. These stigmas are more obvious in low- and middle- income countries. In Mexico, the general population still have a powerful stereotypical notion linking contamination, danger, sin and madness with epileptic seizures. Due to a lack of legal system to protect human rights of PWE, structural discriminations still exist and this prevents PWE from participating in school and employment (Espínola-Nadurille, Crail-Melendez, & Sánchez-Guzmán, 2014). Espínola-Nadurille et al. (2014) found that PWE in Mexico feel that it is not their epilepsy but other people's attitude limit their lives.

Hosseini et al. (2013) studied patients', their families', and medical staff's perceptions of epilepsy in Iran. The major theme found in the study was that PWE feel loss of self-identity. PWE are ashamed and feel that they are a burden of the family or society. The general public perceive that PWE are mentally and psychologically unstable and some people still believe seizures are associated with evil spirits. PWE experience discrimination and social isolation. Employment is also difficult in that PWE try not to disclose the diagnosis to stay in the employment. (Hosseini et al., 2013)

In New Zealand, PWE have less social stigma compared with the US and the above countries (Collings, 1994). This is partly because there are community organisations that work to improve understanding of epilepsy within the general population. New Zealand's human rights include 'The right to be free from discrimination' which is protected through the Bill of Rights Act in 1990 (Human Rights Commission, 2018). There is no study conducted about social stigma of PWE in recent New Zealand and although the law protects their rights, there are still uncertainties around PWE experience.

Discordance between PWE and care providers

Discordance of perception about the condition and treatment between PWE and their physician is known to contribute to QOL (Choi et al., 2014). Although PWE know that AEDs are necessary treatment to control their seizures, the concerns of side effects from AEDs can influence their decision making for their treatment. Chapman et al. (2014) conducted a study in the UK on patients' perceptions on AEDs. Of 398 PWE who were currently taking AEDs, 55% of them were uncertain if they preferred to take AEDs over risk of having seizures despite 84.9% were accepting the necessity of AEDs. Over a third had strong concerns about the potential negative effects of AEDs. Approximately one-third of PWE who were taking AEDs were categorised in the low adherent group. Low- or non-adherent attitude is believed to be correlated with general beliefs about pharmaceuticals and perceptions of personal sensitivity to medicines. To reduce the discordance, adequate education and assessment of PWE's needs are essential.

Less education and lower income

Education can be challenging task for PWE dues to their underlying cognitive dysfunction, seizures and side effects of AEDs. The pressure to keep up with their education requirements can lead to depression and anxiety (Collins, 2011). For the younger population of PWE who are studying, cognitive function is important for their classroom performance so that they might chose an AED with less sedative effect than better seizure control (Collins, 2011). Interestingly, attitude to teaching staff appears to the most significant education issue rather than academic difficulties (McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004).

PWE also have high rate of unemployment which is partly related to lower level of education (Bautista et al., 2014; Lim, Wo, Wong, & Tan, 2013). Nevertheless, significant numbers of PWE became employed after receiving job training. In US study, 55% of PWE obtained job within six months after completion of the job training (Freeman & Gayle, 1978) and 60% of PWE in Ireland were employed post 6-month job training (Carroll, 1992). However, statistically, with or without employment, PWE are known to have lower incomes than adults with other chronic illness (Ziemba & Drazkowski, 2015).

Safety issues

Safety considerations are an important part of epilepsy education, particularly for people who have seizures without awareness. Safety issues can affect PWE's employment. Ideally, the safety considerations need to be discussed with each employer, however this can be sensitive topic for PWE to stay in their employment. How strictly PWE need to consider their safety is related to their activities and the severity of their seizures. When PWE have frequent seizures,

daily activities such as cooking at home, having a bath, and standing on a stool can be hazardous. Even when seizures are controlled, safety concerns need to be discussed with PWE who are undertaking certain activities. For example, PWE should never swim or undertake water sports by themselves. Leisure activities such as sky-diving and parachuting may have specific guidelines for medical conditions and PWE needs to be aware of these guidance (Collins, 2011).

Safety issues also apply to PWE's fitness for driving. In New Zealand, PWE cannot drive unless they are seizure free for 12 months (NZ Transport Agency, 2012). Healthcare providers are required to let PWE know about the driving rule for their own safety and that of the public. The limited personal mobility and transportation can be barriers to their social life and employment. When providing support to young PWE, it is helpful to advise the driving restriction especially when they are making career choice (Collins, 2011). However, the desire to drive can be a potential motivation for good AED compliance and a healthy lifestyle (Collins, 2011).

Difficulty with transportation affects their ability to receive available support services. A community support organisation in the US, South Carolina Advocates for Epilepsy (SAFE) provides service to improve quality of life for PWE including raising awareness of epilepsy, removing stigmas, providing educational opportunities and social activities in the community. However, more than 50% of PWE reported that traveling and finding time to participate in these social activities and groups are challenging. PWE prefer alternative ways of communication such as using social media and online workshops (Wagner et al., 2015).

Access to general and mental health services

General health is known to influence QOL of PWE as it directly contributes to their ability to function socially and at work or school (Choi et al., 2014). Additionally, local or general infections can trigger seizures, therefore preventing general illness relates to better seizure control. Compared with PWE in US or UK, PWE in New Zealand have higher well-being and this is thought to be due to easier access to healthcare which is publically funded (Collings, 1994).

On the other hand, access to mental health services is not straight forward. PWE have higher rates of psychosocial comorbidity than in the general population and mental health affects their QOL (Choi et al., 2014). Azuma (2014) found 18.6% of 215 PWE had symptoms of depression and within the rest of PWE without depression, 19.3% of them were already medicated for anxiety, insomnia, psychosis, or depression. These psychological comorbidities can be caused by pre-existing brain conditions, social environment, or both. Despite the high rate of

psychiatric comorbidities, accessing mental or behavioural health service in the community is challenging (Wagner et al., 2015).

Effect on family members

Epilepsy also affects family member's QOL. Poor emotional connection with family members is related to severity of seizures and episodes of status epilepticus (Bautista et al., 2014). Family or caregivers experience a high burden of looking after PWE, particularly when the PWE has the following factors: seizure onset was younger than 20 years old, unemployed, family history of epilepsy, not well-controlled epilepsy, and living in rural area (Nuhu et al., 2010). Family members' QOL is closely affected by PWE's knowledge of epilepsy and self-management ability. In Mahrer-Imhof et al. study (2013), QOL of PWE did not affect family members' QOL; on the other hand, QOL of PWE is significantly dependent on QOL of their family members. This suggests that care to family members of PWE is also important to improve QOL of PWE.

Epilepsy Nurses' roles and values

Epilepsy care is complex and specialist nurses working with PWE need appropriate knowledge and skills to provide optimal care. There are no specific guidelines for epilepsy nursing in New Zealand. In other countries where epilepsy nursing is more common, there are guidelines for their roles. According to the National Institute for Health and Care Excellence (NICE), an epilepsy nurse's role is:

> Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of children, young people and adults with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the child, young person or adult, families, carers and, in the case of children, others involved in the child's education, welfare and well-being (National Institute for Health and Care Excellence, 2012,1.8.3).

Optimal skill for epilepsy nursing

The skills and knowledge required for each epilepsy nurse depends on their scope of practice and the requirements of where they work. Although the focus of a nurses' role is different from neurologists, there are studies comparing epilepsy nurses' and neurologists' assessment skills and findings from the assessment to see if nurses' involvement is feasible to improve delivery of clinical care. Paul et al. (2014) explored feasibility of an epilepsy nurse clinic and acceptance by PWE in India. The nurse who ran the clinic was a second year post-graduate neurology nursing

student. She received eight hours epilepsy related didactic training by a neurologist and then observed 20 epilepsy patients in the outpatient department. Then she independently followed up 40 epilepsy patients and discussed each case with the neurologist to get feedback. After this training, she saw 175 patients independently and her clinic was evaluated by questionnaires of patients who were also seen by a neurologist. The nurse's and the neurologist's findings were compared in the following five fields: recognition of seizure type/syndrome, estimating degree of seizure control, need to modify AEDs, need for investigation, and recognition of AEDs adverse effects. As a result, the nurse and the neurologist had 76-94% of agreement in the five fields. The patients' satisfaction score was 37.63 ± 3.26 (full score of 40 and >30 means highly satisfied). Although this study was focused on drug treatment and not 'nursing', Paul concluded that the nurse led epilepsy clinic is feasible and acceptable by PWE.

Similarly, Goodwin (2011) compared the history taking process by an epilepsy nurse specialist (ENS) and a consultant neurologist (CN) at first seizure presentation. Twenty patients (13 females and 7 males) presenting with a suspected first seizure were randomly allocated for clinical review with both ENS and CN in the separate clinic with regardless of order. The ENS and CN agreed on diagnosis in the most cases but both missed important information at times. ENS tends to request more investigations than CN and Goodwin believes that this may reflect the ENS's lack of confidence in patient acceptance of nurses' diagnosis in this relatively new role.

Increasing patients' satisfaction and self-management skills

Epilepsy nurses are thought to be informative, empathetic, taking time to listen to patients, accessible, and supportive to PWE and their families (Noble et al., 2013), Particularly, when seizures are not well controlled, PWE, their main care provider, and GPs also appreciate easy access to specialist advice (P. G. Hosking, 2004). Therefore, epilepsy nursing input in epilepsy care is known to increase patients' satisfaction (Ridsdale, 2000). Hosking's (2002) studied efficacy of an epilepsy nurse specialist (ENS) role by analysing feedback from PWE. The nurse's main role was providing treatment advice, information, and support in a tertiary hospital. These services were provided not only to PWE but also their family members and general practitioners as required. A questionnaire was sent to PWE who had access to the ENS to obtain the patients' feedback and 133 people responded. Approximately a half of the responders showed appreciation or positive feedback about the support provided by the nurse. More than 20% commented they had easier and faster accessibility to specialist's advice and clinic appointments. PWE also commented that they received satisfactory amount of information as the nurse was easy to talk to and gave them enough time to ask questions, and PWE become more confident with antiepileptic medications and trying new medications.

According to Noble et al. (2013), PWE often feel that they have not received enough information about their epilepsy despite having already been diagnosed with epilepsy for many years . The nursing input for providing information, counselling and supporting their self-management was valued for filling the gap of their understanding. Some PWE feel epilepsy nurses specialists (ENS) are considerate and attentive to the broader aspects of their lives. ENS's support can improve PWE's emotional well-being, self-management skills, and confidence in managing their condition.

Noble et al. (2014) conducted a further study on clinical and cost effectiveness of ENS's education to reduce ED visits. The focus of the education was on patients' self-management skills and knowledge of appropriate ED use. Eighty five PWE received two one-on-one education sessions with ENSs plus treatment as usual. The intervention did not lead to a reduction of ED visit, however the patients' hospital stays became shorter, therefore, the intervention did not cost extra in the end. Perhaps, because of the complexity of epilepsy, obtaining quantitative results from one focused intervention to prove the effectiveness of nursing care is not that simple.

Clinical- and Cost- effectiveness of nurses' input in epilepsy care

The results from studies of clinical- and cost-effectiveness are varied. Literature on assessing of nurses' input in epilepsy care is limited. However, specialist nurses' care is more studied and supported to be feasible and effective in common chronic disease management, such as cancer, respiratory disease, and heart disease (Dean, 2010). Bryant-Lukosius et al. (2015) conducted a systematic review on clinical- and cost-effectiveness of clinical nurse specialist-led hospital to home transitional care and showed that involvement of clinical nurse specialists (CNS) improves patients' outcomes, delays re-hospitalisation and reduces hospital length of stay, and re-hospitalisation rates and costs. In a similar study by Kilpatrick et al. (2015), CNS and nurse practitioners input in an inpatient setting showed equal clinical- and cost-effectiveness to care provided by physicians. These results suggest that speciality nurses input can improve overall health outcomes more in the community rather than in hospital settings.

Within a limited epilepsy nursing study, there is a systematic review of epilepsy care by Rajpura and Sethi (2004). This study reports that there is no convincing evidence to relate nursing input in epilepsy care and improvement of patients' outcomes. They also commented that employing nurses is slightly cheaper because nurses' consultations work out cheaper than doctors' consultations. This area is still poorly studied and evidence was limited, thus further research is needed.

Integration of epilepsy care

Integrated care includes improving continuity and coordination of care such as multi-professional collaboration and improvement of primary and specialist care partnership (Fitzsimons, Normand, Varley, & Delanty, 2012). Importance of integration in the healthcare systems has been discussed at different levels. The Institute of Medicine in the United States of America (USA) recommends integrated national approach in epilepsy care (Koh et al., 2014). Integration of the care is also emphasised in chronic disease management (Fitzsimons et al., 2012; Procter, Wilson, Brooks, & Kendall, 2013). However, Proctor et al. (2013) found PWE experience fragmented care because the care is determined by diagnostic categories rather than what the patients need.

Integration of the care is one of the important roles of epilepsy nurses (National Institute for Health and Care Excellence, 2012). Hosking et al. (2002) found that involvement of epilepsy nurse specialist (ENS) can improve the integration of epilepsy care. In particular, efficient coordination and communication between generalists and specialist or primary care and tertiary care can improve diagnosis and referral processes. In New Zealand, healthcare has been challenged due to high fragmentation of the care due to involvement of a wide range of professionals, a lack shared information systems, and poor liaison between health professionals and organisations. However, there is now significant attention on working towards smooth and continuous integrated care (Cumming, 2011).

Rural hospitals

Living in rural area can have negative impact on PWE (Nuhu et al., 2010). When PWE have limited access to transportation, it leads not only to social isolation but also barriers to receiving optimal epilepsy care. Nurses' input is valued in some rural areas with no or limited availability of neurologists. In 2001, nurse-led clinics using telemedicine at two rural hospitals in the UK were commenced to achieve quality epilepsy care (Bingham & Patterson, 2007). Prior to this study, PWE had occasional appointment with a visiting neurologist. However nursing input is thought to be beneficial to PWE, particularly for understanding psychosocial aspects which were important matter for PWE. As organising a joint nurse and neurologist clinic in the rural area was not feasible, an epilepsy nurse carried out monthly epilepsy clinics at each hospital with telephone and/or real-time telecommunication with a neurologist. When the nurse needed further advice on the management of any case, the nurse made telephone contact with the appointed neurologist at the regional neuroscience centre. If necessary, an immediate real-time video-link between the nurse, the patient and the neurologist was made. The acceptability and sustainability was measured by patient satisfaction questionnaire in 2001 and 2003. In 2001, 15% of the patient wanted to see a doctor with or without a nurse, however, the 2003 result

showed 100% of the patients were happy to be seen by a nurse and preferred this rather than previous clinic visit structure.

Epilepsy care for certain population

Adolescents' epilepsy care

Depending on the age, sex and other medical backgrounds, nurses may focus on different aspects of epilepsy care. Adolescence is one of the most rapid phases of human development and adolescents are going through psychosocial and sexual maturity, and development of their capabilities and independence (World Health Organization, 2018a). A diagnosis of epilepsy in adolescence can influence education, socialising, employment, lifestyle, and it needs to be considered as a significant life event. The ordinary needs, concerns, and difficulties associated with being adolescent are more complicated by epilepsy and this could affect their QOL and level of independence (Collins, 2011). Adolescents with epilepsy can be affected by complex psychosocial difficulties, such as social isolation, low self-esteem, a feeling of being different, depression and impaired independence (Thomson, Fayed, Sedarous, & Ronen, 2013). Adolescents may have risk-taking behaviour which leads to poor compliance and misuse of alcohol and/or drugs (Christie & Viner, 2005). They often do not understand long-term consequences of their behaviour as they are more focusing on their relationship with their peers and their self-image (Leather, 2009).

One of the challenges in adolescent epilepsy care is the transition from paediatric care to adult care. In paediatric care, education and discussions for treatment options are carried out to parents while adolescents or young adults with epilepsy are starting to take responsibility for their own treatment (Christie & Viner, 2005). Iyer & Appleton (2013) conducted a survey to study transitional services for adolescents in the United Kingdom (UK). There were 15 epilepsy centres defined as a 'clinic or service that provided joint paediatric and adult supervision of care from paediatric to adult services' to provide epilepsy care to persons with the age between 14 and 20 (Iyer & Appleton, 2013, p. 434). These transition clinics were held between three and 12 times per year. The members of staff in the centres were the consultant paediatric neurologist, consultant adult neurologist, adult nurse specialist, and paediatric nurse specialist. Most patients were seen only once in a transition clinic before being promoted into the adult epilepsy service.

As adolescents are not psychosocially and cognitively developed fully, they might not have an adult's level of understanding or be able to make rational decisions regarding their future (Christie & Viner, 2005). Care providers need to understand this and maintain the engagement with young adult, identify possible psychosocial implications and hold discussions for adult issues such as contraception, pregnancy, driving and employment (Iyer & Appleton, 2013).

Care for older population

Older people have the highest incidence of new-onset epilepsy secondary to stroke, tumour, or cardiovascular incidence (Hesdorffer et al., 2011). Older people have higher risk of having fractures, bleeds, or other injuries when they have a seizure. The result could affect their life style and lead to loss of their independence (Sirven, 2013). Treatment also can be complex as they often have other comorbidities with subsequent treatments prior to the onset of epilepsy. Miller (2014) studied the experience of elderly with epilepsy. She found that self-management was of importance to the older population with epilepsy. The care for this population should then focus on patient-centred epilepsy self-management interventions, such as providing sufficient information and involving the person in decision of treatment and care plans. The outcomes need to be measured in a patient-centred way and it is important to ensure the both patients and care providers agree on their goal.

Care for women at childbearing age

Epilepsy care for women of childbearing age can be complex. The option for treatment is limited because some AEDs interact with contraceptive or hormone replacement therapy and some AEDs increase a risk of major congenital malformation. For certain women, their seizures can fluctuate with their hormone changes (McIntosh & Jette, 2014). Once a woman becomes pregnant, their AED dose might need to be titrated as drug serum levels can fluctuate with pregnancy. Vomiting with morning sickness can also alter the levels (Lizama & Crawford, 2014). Pregnant women are required to have regular blood tests and clinic follow ups for closer surveillance. During labour, delivery and the 24 hour postpartum period, the risk of seizures is higher, occurring in 2-4% of women (Lizama & Crawford, 2014). Pregnant women often feel increased need for emotional, physical, and financial support during pregnancy and support from family members, specialists, and support groups are important (Qiang, Nyhof-Young, D'Souza, & Bui, 2016).

Refractory epilepsy

Despite the development of newer AEDs and appropriate drug treatment, approximately one in three PWE have refractory or drug-resistant epilepsy (Schmidt & Loscher, 2005). People with refractory epilepsy often face frequent alteration of their AEDs and the dose (Kwan & Brodie, 2000). When PWE are going through the alteration of their treatments, they sometimes experience AED side effects or paradoxical reactions and have more seizures (P. G. Hosking, 2004). However, access to specialist's consultation is limited and complex treatment needs are not often addressed (P. G. Hosking, 2004). Hosking (2004) observed a new service provided by epilepsy nurse specialists (ENS) involved in refractory epilepsy care in the UK. This system

provided PWE and GPs free access to ENS for information and treatment advice via telephone. Sixty percent of PWE contacted ENS and their main reasons for contacting the nurse were side effects of AEDs and ongoing seizures. ENS telephone consultations also provided an opportunity to clarify their treatment needs and review their life style to minimise seizure occurrence. As a result, advice for alteration of AEDs, improving compliance, and/or reviewing their lifestyle to minimize seizures was made as required. Regular follow-up by a specialist can optimise care and minimise morbidity and mortality therefore ENS involvement can make a significant improvement in refractory epilepsy care (P. G. Hosking, 2004).

Psychogenic non-epileptic seizures (PNES)

Psychogenic non-epileptic seizures (PNES) resemble epileptic seizures without the characteristic of electrical discharges associated with epilepsy (Valeta, 2017). People with PNES are regularly seen in epilepsy clinics and it is estimated to occur 2 to 33 per 100,000 in the general population (Benbadis, 2011). PNES are often related to stress, emotions, and past psychological experiences (Valeta, 2017). They are commonly misdiagnosed as epileptic seizures and not responding to AEDs (Benbadis, 2011). The diagnosis is made with video electroencephalography (EEG) and approximately 50% of people with PNES stop having attacks when they are diagnosed (Valeta, 2017). The outcome is generally good if diagnoses is made early and psychiatry or psychology treatment is provided (Valeta, 2017). For early diagnosis, communication and teamwork with care providers including neurologists, epilepsy nurses, and EEG technicians, is important and after the diagnosis, smooth referral to a psychologist or psychiatrist would be valuable (Hall-Patch et al., 2009). During this diagnosis and treatment process, epilepsy nurses can provide seamless referral process and general support for people with PNES which leads to better outcome.

Sudden unexpected death in epilepsy (SUDEP) and status epilepticus (SE)

There are several detrimental outcomes of epilepsy. Sudden unexpected death in epilepsy (SUDEP) occurs 0.81 in 100,000 general population and 1.16 cases per 1,000 epilepsy population (Thurman, Hesdorffer, & French, 2014). The physiological mechanisms underlying SUDEP are poorly understood. The highest incidents occur in the 30’s and 40’s age group and there are strong correlations with tonic-clonic seizures, increased frequency of seizures, long duration of seizures, poor adherence, poly-pharmacotherapy, nocturnal seizures, and complication with psychiatric illness (Devinsky, 2011; Thurman et al., 2014; Watkins, Shankar, & Sander, 2018).

Even though some articles recommend discussing about SUDEP with PWE as a preventative strategy, it is a difficult topic to bring up to patients and their families. This situation puts

healthcare providers in a dilemma whether to discuss the risk. Miller et al. (2014) explored reasons for healthcare providers to discuss SUDEP or not with PWE and their family members. The reasons for discussing were their practical and moral accountability, proactivity and reactivity to patients' decision making for self-management, and patient advocacy. The reasons for not discussing were waiting for the right timing, moral accountability as the mechanism of the complication is poorly understood, all epilepsy treatment were ineffective and there are no other treatment options left, and there is not enough information materials or guidance to discuss SUDEP. The healthcare providers felt that the process of discussing SUDEP needs to be standardised however, the discussion timing and environment depends on each PWE. Therefore, the question is still unanswered and this topic needs to discussed further among health providers as a part of epilepsy care.

Status epilepticus (SE) has a high mortality rate of approximately 10-20% and morbidity of 40-50% (Neligan & Walker, 2016). People can have convulsive SE or non-convulsive SE. Convulsive SE is a serious emergency and is described as continuous or recurring seizures without a return to baseline mental status (Abend et al., 2014). Non-convulsive SE can have varied symptoms such as delirium, psychiatric disturbances, aphasia, or coma. Because of this non-specific presentation, the diagnosis and treatment can be delayed (Audenino, Cocito, & Primavera, 2003).

The current definition of convulsive status epilepticus by the Neurocritical Care Guideline is 'five minutes or more of (i) continuous clinical and/or electrographic seizure activity or (ii) recurrent seizure activity without recovery (returning to baseline) between seizures' (Brophy et al., 2012, P. 5). SE used to be 'fixed and enduring' seizure or a seizure with 'sufficient length'. This ambiguous length of time was 30minutes with the rational that neuronal injury may occur after 30 minutes of ongoing seizure activity (Working Group on Status Epilepticus, 1993). However, seizure lasting longer than five minutes are likely to be prolonged and treatment to terminate the seizure is required, therefore the current definition of SE is longer than five minutes (Trinka et al., 2015). This new definition leads to faster intervention including giving rescue treatment in the community such as buccal midazolam and rectal diazepam. For the safe use of these medications in the community, education to care providers becomes an important part of the role of the epilepsy nurses (Hartman, Devore, the Section on Neurology, & Council on School Health, 2016).

Where is epilepsy care heading to?

The three aims of 'Epilepsy: Out of the Shadows': advancing and disseminating knowledge about epilepsy, promoting research, education, and training, and improving services and care for patients, especially by prevention, diagnosis, and treatment (Bergin et al., 2008, p. 2) continues to apply to New Zealand epilepsy care. Although these aims are broad, all healthcare providers who are involved in epilepsy care need to work on these aims.

There are also more specific recommendations provided by the National Institute for Health and Care Excellence's (NICE) for epilepsy care. They are recommending that 'all adults having a first seizure should be seen as soon as possible by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs' (National Institute for Health and Care Excellence, 2012, 1.4.5.). NICE also recommends that all PWE have an accessible point of contact with specialist services and have a comprehensive care plan which is formulated with the person, family members, and primary and secondary care providers. (National Institute for Health and Care Excellence, 2012, 1.8.1, 1.8.2). These recommendations are not easy to achieve with limited resources, however healthcare providers can work towards them.

Because of the limitation of resources to provide optimal epilepsy care, more efficient and effective alternative methods of delivery are required. Telephone clinics are known to be cost effective and easier to manage a higher number of PWE (P. Smith, 2016). Telephone clinics are suited for people with established epilepsy as they seldom need physical examination. The length of a telephone clinic appointment is shorter than a face-to-face clinic as downtime is reduced with no waiting, entering, or sitting down (P. Smith, 2016). If it is possible to facilitate, video consultation can be another option as it can be easily done via social media or mobile phone applications. These options are particularly preferred by PWE who are not able to drive, or live far from the hospital (Wagner et al., 2015). Providing support via social media communication and website can be alternatives (Wagner et al., 2015).

Telemedicine in rural area was described earlier in this chapter. Online based digital health is also becoming more and more advanced. Lack of computer and/or the Internet access used to be the biggest barrier, however this situation is improving rapidly (Hixson, Van Bebber, & Bertko, 2015). For example, The Managing Epilepsy Well Network in the US, established in 2007, have developed e-Tools and online interventions to improve self-management skills for PWE, their families, and health care providers (Shegog et al., 2013). Six online tools were designed and they can facilitate patient-centred care, community-based education and management, and self-managing skills. Online based tools overcome financial and transportation barriers to provide access to epilepsy care for homebound PWE.

In New Zealand, there is variety of use of technologies to improve healthcare for various health conditions. For example, adherence to asthma preventer medicine was significantly improved by using a text message programme in a study of Petrie et al. (2012). Mobile phone-based intervention, mHealth have variety of interventions such as depression prevention intervention and smoking cessation intervention (Whittaker, Merry, Dorey, & Maddison, 2012). There are online information and phone applications to help managing epilepsy (Health Navigator New Zealand, 2018).

As health care resources are limited, the utilisation of technologies needs to be increased in future for epilepsy care to be delivered more efficiently to a wider population. Technology is continuously advancing. Healthcare providers need to be creative and bring new ideas to improving epilepsy care.

Summary of chapter two

The first section of this chapter presented an updated classification of epilepsy which is important for treatment options and standardisation of epilepsy care. The next section of the chapter focused on the patients' and families' experience with epilepsy. This part highlighted discordance between patients and healthcare providers, and complexity of epilepsy. Third part of the chapter was about epilepsy nursing guidelines, efficacy, and integration of the care. The fourth part described specific epilepsy care to certain populations: adolescents, elderly and women at childbearing age. SUDEP and SE were described including care and prevention. In the last section of this chapter, ideas for future epilepsy care are presented. By the literature review, there is clearly a lack of studies of epilepsy care and the nurses' role within the care in New Zealand. I will go on to discuss the methodology in the next chapter.

Chapter three: Methodology

Introduction

This chapter describes the theoretical underpinning of the methodology, data analysis, and method applied for this study. It includes a description of grounded theory method and the rationale for its choice, details of data analysis process and each step of the research method, are addressed.

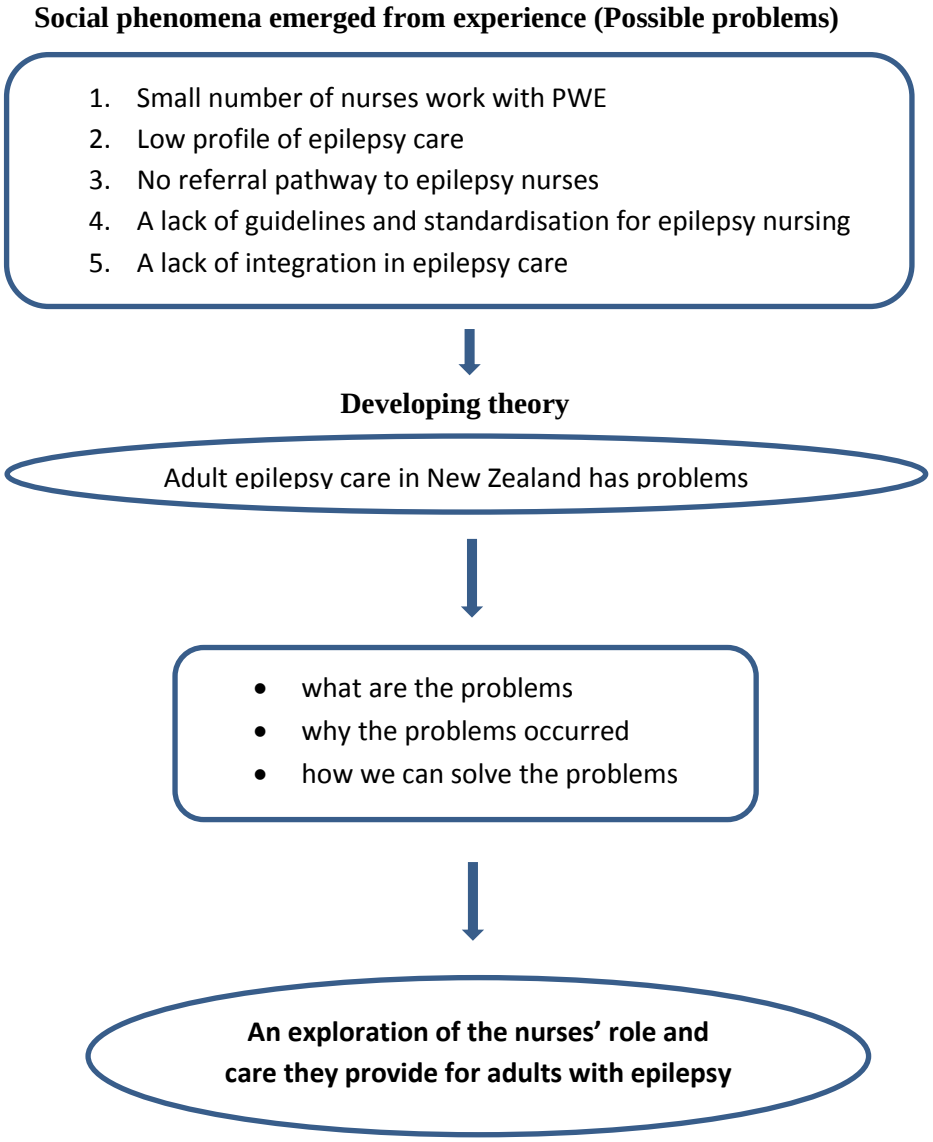
Theoretical underpinning

Emerge of the research question

Before going through the details of the research methodology, it is important to revisit how the research question emerged. I had five concerns that I recognised in epilepsy care within my experience that seem to be occurring (social phenomena) and they are: the small number of nurses working with people with epilepsy (PWE), low profile of epilepsy care, no referral pathway to epilepsy nurses, a lack of guidelines and standardisation for epilepsy nursing, and a lack of integration in epilepsy care. Despite these concerns, it is not grounded in facts and research in this area is needed. Therefore, a developing theory 'Adult epilepsy care in New Zealand has problems' is developed. The purpose of this study is to explore epilepsy nursing care in New Zealand to see what issues there are, how they developed and what we can do to address them.

The environment where health professionals work is incredibly complex with constantly advancing treatment, increasing specialities, involvement of multi-disciplinary providers, and the focus on individual needs. To understand the social phenomenon surrounding epilepsy care, a systematic approach was required. In order to study the whole complex environment, the research question needs to be as broad as possible. Hence, my research became a qualitative study to explore the nurses' role and care they provide for adult with epilepsy.

Diagram 1: Emergence of the research question



What is qualitative research?

Qualitative research is a general broad term covering several different methodologies that have many similarities (Barroso, 2010). Qualitative research aims to develop concepts of social phenomena in natural settings, the setting people live in every day, not in experimental settings (Pope & Mays, 1995) and it helps us to see the world through the eyes of other (Barroso, 2010). Qualitative research begins by recognising and accepting there is a variety of different ways of making sense of the world. In nursing research, qualitative methods focus on the whole of human experience and aim to understand health beyond traditional quantitative measures of isolated concepts (Barroso, 2010). Qualitative research is looking for the meanings seen by individuals living in the experience, accepting their view of the world rather than that of researchers (Jones, 1995). Among the multiple different qualitative study methods, I chose the grounded theory method.

Brief history of grounded theory methods

Grounded theory methods were developed by American sociologists, Barney Glaser and Anselm Strauss in 1960's (Charmaz, 2008). By the 1960's quantitative methods dominated with beliefs in scientific logic, objectivity and truth. However, a division between theory and research started growing (Barroso, 2010). Nurse scholars moved on from using quantitative research which did not answer research questions, to conducting qualitative studies to obtain the best answers to their research question (Barroso, 2010). At that time, quantitative research theory led by the logic-deductive model of research has rarely lead to new theory construction (Charmaz, 1996). Glaser and Strauss challenged and articulated explicit analytic procedures, and changed the tradition by setting clear guidelines for conducting qualitative research (Charmaz, 1996). Through influence from Blumer and Park at the University of Chicago, Strauss further adopted both the realistic philosophical practice with emphasis on studying procedure, action and meaning, and Chicago's traditional ethnographic research (Charmaz, 2008). Nowadays, grounded theory methods have been widely adopted in many sectors including nursing.

Rationale for using grounded theory method

One of the main characteristics of grounded theory in this study is that in this method, theories and concepts emerge not only from the data but also systematic interpretation occurs during the course of the research (Charmaz, 2008; Strauss & Corbin, 1994). Analysis simultaneously starts with data collection procedures and the data includes the whole research environment (Charmaz, 1996). The concerns that I had at the beginning of this research were 'guiding interests' and that was already a part of data to develop concepts through the research process. The data analysis in this method can lead to subsequent data collection. The hallmark of grounded theory method is that the researcher develops analytic categories directly from the data and this makes the researcher stay closely connected to what is happening in the empirical world grounded in the study (Charmaz, 1996). Rich data from grounded theory research provides a thorough knowledge of the empirical world and helped me to discern what participants really mean and how they express their experience.

Data collection and data analysis for grounded theory

Theoretical sampling and data collection

Theoretical sampling is the process of identifying who and what data should be collected. In grounded theory, who become participants and what data needs to be collected should be emerge from the developing theory (Skeat, 2011). According to Charmaz (2006), the aim of theoretical sampling is to refine the idea of saturation of concepts rather than increasing the size

of sample. In this study, the developing theory is 'Adult epilepsy care in New Zealand has problems' which is connected to the social phenomenon that emerged from my experience and the focus of the phenomenon was nursing care. Therefore, the participants became nurses who provide care to adults with epilepsy. The data collection method became semi-structured interviews and the details of rationale and method will be explained in the later section of this chapter.

Navigation of analysis process

Once all the data is collected, coding and analysis processes start. Strauss & Corbin (1990, p. 57) described coding as 'broken down, conceptualized, and put back together in new ways … a central process by which theories are built from data'. Coding is the core process in grounded theory methodology and the codes emerge as the researcher studies the data (Charmaz, 1996). The initial step of the analysis is substantive coding which is the procedure of conceptualising the empirical substance of the data in which the theory is grounded (Holton, 2010). Substantive coding process begins with line-by-line open coding of data and then comparing incidents to each other in the data. Line-by-line coding minimises the researcher missing important data (Holton, 2010). There are no limitations on numbers or length of codes. The researcher codes the data as many as s/he likes and asks questions of the data. The codes then will be placed into categories to describe, name, and classify the phenomenon.

During the analysis, constant comparison between the codes, categories, and new incidents (new codes and new categories) is required to verify if the data is relevant and continues to be relevant to emerging categories (Skeat, 2011). This process also helps to build and prove the emerging categories by describing their properties and dimensions (Holton, 2010). During this process, memo writing becomes important. Memo writing helps researcher's ideas about coding, categories, and emerging themes to be documented and provides an audit trail of each step of the study (P. Wong, Liamputtong, & Rawson, 2017). Memo writing is also useful in reflexivity by presenting written evidence of progression of ideas and conceptual analysis process (P. Wong et al., 2017).

This constant comparison process eventually takes the researcher to 'saturation of data'. Data saturation is accomplished when little or new data is being generated and new data can fit into the already developed categories (Skeat, 2011). Therefore, data saturation is not dependant on the number of participants but on who are the participants. For this study, the number of participants was very small and this process of comparison of the codes and categories is significant to reach data saturation as close as possible.

Making sure the data saturates in each step of coding is important because this will lead to theoretical saturation which is the final phase of the analysis. This is the stage where there are no new categories or concepts arising from further data collection or analysis and final theories will emerge (P. Wong et al., 2017). This theoretical saturation can be achieved by theoretical coding process where the relationship between substantive codes, categories and core categories are compared and conceptualised. Theoretical codes are flexible and they can be either implicit or explicit (Glaser, 2005).

Theoretical sensitivity

According to Glaser & Holton (2004, 3.1), theoretical sensitivity is 'the ability to generate concepts from data and to relate them according to normal models of theory in general, and theory development in sociology in particular, is the essence of theoretical sensitivity'. Holton (2010) states that analytic temperament and competence are required for theoretical sensitivity. Analytic temperament helps the researcher to keep analytic distance from the data, regression, and confusion and manage to facilitate processing of the conceptual emergence. The researcher's professional back ground, experience, and knowledge can help the researchers to understand significance in the data and become more sensitive to connection between concepts (P. Wong et al., 2017). Relevant literature can also enhance theoretical sensitivity in that it is recommended to carry out literature review prior to the analysis process (Thornberg, 2012).

Ethical issues

This study is a master's thesis and the ethical approval was obtained from the Massey University Ethics Committee (Appendix A). All the participants received the information about the study (Appendix B) and were requested to sign an informed consent (Appendix C) prior to the participation to the study. Verbal and written assurance for protecting the anonymity of individuals and their employers were given to the participants. Additionally, the ability to refuse or withdraw from the study without any penalty was explained.

Ethical consideration was given to participants during interviews by confirming they are comfortable to be interviewed, showing respect for their responses, making sure the communication was clear in both ways in that participants understood my questions and I took their answer accurately.

There is potential risk of the participants and their employer's anonymity as the topic is such a specific area and there are not many participants. To maintain their confidentiality, every effort will be made to de-identify data such as assigning pseudonyms to all the participants and de-identifying their work place. I was the solo analyst of the data and there was no other person could identify the participants.

The interviews were held in my private house in Wellington and a clinic room at the Neurology Outpatient at Wellington Regional Hospital. During the interviews, I made sure that there was no one around me and the participants for the privacy. The record data has been kept in my personal computer with password log in for security.

Consideration for indigenous population

This study focuses on the general population and the percentage of Māori involved in the research is expected to be a minority. Therefore, the research can be carried out in a contemporary mainstream situation (Woods, 2015).

Research methods

Sampling

The first aim was to find epilepsy nurses to enrol in the study. Snowball sampling technique was used to locate possible participants. This technique is based on using social networks to find people who can share knowledge and experiences within the topic in common. When the researcher does not know the numbers of possible participants, location, and how to contact them, this is a good technique to use (Holloway & Wheeler, 2010). The limitation of this technique is that the result could come from a small community and it leads to a lack of variety in social context as they share the same community. However, desirable participants for this study are from such a specific community (neurology or epilepsy) and the above limitation would be minimal.

I contacted neurology or epilepsy nurses who I know of by email, and asked them if they knew other nurses working for people with epilepsy (PWE). I also contacted 14 epilepsy field workers from Epilepsy New Zealand to ask the same question. The epilepsy field workers work with PWE in the community and they liaise with primary, secondary, and tertiary care providers as needed (Epilepsy Foundation New Zealand, 2018). Their service gives a good geographic cover of New Zealand. All 14 workers responded to me to report epilepsy or neurology nurses they knew about.

The inclusion criteria for the study is being New Zealand Registered Nurse and providing care to adults with epilepsy at hospital based outpatient clinics regardless their job titles. Medical outpatient nurses are excluded although they sometimes see PWE, because their roles are thought to be too broad for this study. Paediatric epilepsy or neurology nurses were also excluded as paediatric care is totally different from adult care.

One epilepsy nurse and two neurology nurses who have focus on epilepsy care were identified as the possible participants. There are also four general neurology nurses identified who

possibly provide epilepsy care, however, how much they were involved in epilepsy care was uncertain at that point. I sent invitations for participation to all of those nurses. Even if the nurses did not spend much time with PWE, their view of epilepsy care would provide valuable data. Of seven nurses who were located and invited, four had agreed to participate in this study. During the course of interviews, I also asked all the participants if they could think of any other possible participants and one nurse was identified. However, she did not agree to participate at the end.

Data collection

Rationale for adopting semi-structured interview

I chose to do semi-structured interviews for data collection. Interviews were chosen as they allow in-depth, real-life information to be collected. There are open-ended questions and closed-questions. While open-ended provide narrative answers in responders' own words which the researcher could not predict, closed-ended answers are fixed responses such as finite numbers and respondents provided the closest number to the correct response (Sullivan-Bolyai & Bova, 2010). The purpose of this research was to explore epilepsy care and open question would be suited to obtain broad answers. However, there are five potential problems recognised prior to this research which also need to be explored. Therefore, both open and closed questions in semi-structured interviews were used for data collection.

Interview method

Telephone interviews were adopted for this study because they are a practical, convenient as well as a trustworthy method, to obtain reliable and comparable qualitative data (Novick, 2008). Despite the absence of visual cues, telephone interviews can provide a familiar and relaxed environment for respondents and they are able to disclose sensitive matters (Novick, 2008). There is no strong evidence suggesting that telephone interviews produce less quality data compared with face-to-face interviews (Novick, 2008). It is also practical because participants for this study live in different parts of New Zealand and traveling for a face-to-face interview would be expensive and time consuming.

With the four nurses who participated, I ended up conducting two telephone interviews, one interview by the Skype, and one face-to-face interview. This is because I provided options for different ways to be interviewed and they were the participants' preference. Each interview took between 45 and 60 minutes and they were all audio-recorded. The audio data was transcribed into word documents for data analysis.

Data analysis

Data analysis started with line-by-line open coding to find emerged codes, and then these codes were allocated into categories. These categories were continuously compared with newly emerged codes and categories. Six core categories were developed, they were:

1. Many PWE are not receiving optimal epilepsy care in New Zealand
2. There are challenges in epilepsy nursing
3. Epilepsy care is inconsistent
4. Education opportunity for epilepsy nurses is limited
5. There is a lack of integration in epilepsy care
6. What we can do for future/ideal epilepsy care

Then the relationships and concepts between these categories were studied and through this theoretical coding process, 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.

Reliability and validity of the study

In general terms, once research data is analysed and presented, how useful the results are depends on its reliability or validity. While reliability means if the result is replicable or generalisable, validity is if the findings are accurately answering to the research question (Golafshani, 2003). One of the key processes in grounded theory method is continuous comparison of incidents and generating new properties. The incidents include new codes, categories, and concepts emerged from the empirical data and they compared with already created categories and concepts. The researcher needs to make sure that these categories and concepts were emerged from the original data by the constant comparison therefore the relevance between categories, concepts, theories and the original data can be maintained (Golafshani, 2003). Because the original data was obtained with an aim to answer the research question, this process is ensuring the validity of the research. This constant comparison is also important to ensure the reliability of the study. When the codes, categories, concepts and theories were constantly compared, the idea will eventually reach interchangeable stage (Skeat, 2011) and this is called theoretical saturation (Golafshani, 2003). The number of incidents or codes in each category is not as significant because the required sample sufficiency is up to theoretical saturation (Skeat, 2011). In summary, as long as continual comparing incidents and letting concepts and theories emerge from empirical data, the results are valid and reliable.

Limitations

As a novice researcher, there is a risk that I do not reach outside existing theory and produce rather mundane conceptual theory. There are some limitations to this research. The very small number of participants is obvious and this makes it difficult to generalise the results. However, this small number of nurses is also a valuable data in grounded theory method. My personal working experience can bias the analysis as I was a solo researcher in this study. Yet, again, I believe that my thoughts and experience are also relevant in this study topic and important data. Continuous comparison of all the data and their relationships to develop concepts and theories would help to minimise the bias and to make the result more valid.

Interviewing only nurses can limit the understanding of epilepsy care as a whole. Epilepsy care is not only provided by nurses but also GPs, emergency physicians, neurologists, medical consultants, epilepsy field workers, social workers, etc. More importantly, there is no data collected from PWE which means the results are one sided. To understand broader view of epilepsy care, exploring other stakeholders and PWE would be useful.

Reflexivity

Reflexivity is 'the journey of learning that we underwent as field researchers' (Palaganas, Sanchez, Molintas, & Caricativo, 2017, p. 426). Reflexivity is the process where researchers review each step of their own research subjectivity and this is essential part of qualitative research (Green & Thorogood, 2009).

As I described earlier in this chapter, I had concerns about the epilepsy care that we are providing to PWE in New Zealand. I felt that epilepsy nurses are almost invisible apart from small number of patients we saw. I struggle to understand how other PWE live without nursing input and if epilepsy nurses are making any difference in epilepsy care. This created uncertainty of my professional career. Therefore, I decided to undertake this study for me to understand where I stand and where I am going from here.

I am a solo researcher and working in the environment of the research topic. I have my own views about epilepsy care which has been built through my work experience and my personal life. This is inseparable from the content of this study. I have assumptions based on my political values and subjective impressions. These can affect every stage of the research and the end result. However, in qualitative studies, this connection between the researcher and the world studied, and assumptions coming from the researchers are accepted as it is an inevitable part in the research process (Green & Thorogood, 2009).

Additionally, in grounded theory method, this inseparable connection can be valuable data rather than being a compromised and disregarded bias. My experience and thoughts are important in this study because they developed the foundation of my research question. During the analysis, I could constantly come back to where I started to maintain relationship between the question, codes, categories, and theories. Grounded theory method was appropriate choice of research method as my experience is valued in the research and the result will be beneficial to my epilepsy nursing career.

Study dissemination

This study is only the beginning of implementing of ideal epilepsy nursing care in New Zealand. During this study, I developed the concept of 'the negative epilepsy cycle', 'the epilepsy care pathway' and recommendations that can help to improve delivery of epilepsy service. After the completion of this research, I will look for opportunities to present and disseminate the findings. As per the two developed theories, I would like to work on building guidelines for standardised care and try to raise epilepsy nursing profile.

Summary of chapter three

This chapter presented the theoretical underpinning of the research methodology. The rationale for adopting qualitative research using grounded theory method and data collection method was explained. I also described the step-by-step method to demonstrate that this study is following the correct path of the grounded theory method. The details of data analysis process, ethical issues, limitations, and reflexivity were discussed. Study dissemination was also explained.

Chapter Four: Coding and categories development

Introduction

The goal of this study was to develop substantive theories to explore phenomenon around epilepsy care in New Zealand. The next two chapters present results from four interviews and the analysis process. This chapter presents a brief introduction to the study participants. This is followed by explanation of the process of substantive coding and development of categories and core categories. The left side of the following tables show codes emerged from the interviews and the right side shows categories. At the end of this substantive coding, six core dategories were identified. All direct quotes are written in *italics*.

Introduction to the study participants

Before this study started, I had only a vague understanding of the participants' role and I obtained more details during the interviews. Participant #1 is an epilepsy nurse. Her main role is organising clinical investigations, neurology meetings, and epilepsy surgery matters, and communicating with people with epilepsy (PWE) and their family members as required. Participant #2 is a neurology clinical nurse specialist (CNS) and time she can spend for PWE is minimal. She works part-time and within her limited time carries out a nurse-led clinic for patients with multiple sclerosis (MS) and Parkinson's disease but not with PWE. She communicates with PWE as required, mainly over the phone. Participant #3 is an epilepsy and MS nurse specialist who sees PWE regularly in her clinic. She also stays in touch with PWE by phone calls and emails in between clinics. Participant #4 is a neurology CNS and she has allocated time to carry out the first seizure clinics where diagnosis of epilepsy is made. This is the only involvement she has in epilepsy care.

Substantive coding process

The interviews were transcribed into word documents. Then the documents were analysed by line-by-line open coding and memos were taken. All the data was broken into small phrases and words to analyse the significance and codes were identified. The emergent codes were placed into categories, and furthermore, these categories were assembled into bigger categories. The following tables show the codes and categories. During this process, codes and categories were constantly compared to ensure their relevance.

Many PWE are not receiving optimal epilepsy care in New Zealand

There are not many epilepsy nurses

Codes	Categories
"*never met an epilepsy nurse to see how that role went*" (#3), "*We don't have dedicated epilepsy nurses"* (#4), *"We just don't have neurology nurses"* (#4), *"I know there are lot of regions don't have that (nursing) resources"* (#3), "*we need more staff*" (#2), "*a lot of places in my understanding … they don't have epilepsy nurses there*" (#3)	There are not many epilepsy nurses
"*There is no support from the hospital and took a lot of argument and finally we get that position allocated one then*" (#4). "*We are playing a bit of political game*" (#2), "*There is no money in the health board*" (#2), "*They are not looking to increase my role*" (#2)	A lack of support and funding

The small number of nurses was already a clear phenomenon at the beginning of this research. The participants are aware that there are not many nurses, however, there are no signs of increasing numbers or hours of nurses for epilepsy care.

Nurses do not have enough time to work with PWE

Codes	Categories
"*a big full(-time)*" (#1), "*all (my time is spent) for epilepsy*" (#1), "*I just work longer hours and I get behind*" (#1), "*(certain clinical investigation) takes a lot of time … takes all day … take the whole week out*" (#1), "*I'm too busy*" (#1), "*I couldn't see them all anyway*" (#1), "*it's got so busy and I haven't got time to sit*"(#1), "*(workload) grown too big*" (#1), " *I don't have much (time) to see that anymore*" (#1), "*it became unmanageable … I couldn't get stuff done"* (#3)," *I don't so much do clinical nursing to see with the epilepsy ones*" (#2), "*it could be better but it takes*	Nurses do not have time

more time" (#2), "*We can't get extra hours"* (#4), "*trying to get more hours to do that (more nursing input in epilepsy care)"* (#2), *"It (epilepsy clinic) was too much over my other work"*(#4)*, "probably 10% (of my working hours on epilepsy care)"* (#2), *"I just don't have the ability (time)"* (#2), "*there are just so many patients*" (#3), "*(I) don't have time to follow everyone up*" (#2), "*I don't have enough hours*" (#2), "*It's not enough time*" (#2), "*I could be used a lot more if I had more hours*" (#2), "*I'm busy enough with what I'm doing*" (#1), "*I just can't. I haven't got the time*" (#1), "*It's not enough time*" (#2), "*I'm always behind*" (#1), "*I do think that increase resource would be good*" (#3), "*There is no time really for a proper care*" (#4)	
"*We almost becoming too accessible*" (#3), "*The more available you become, the more people expect of you, and the more angry that you can't provide it*" (#4), "*We've taken our email off (our name care) so we … can filter some things*" (#3), "*we can focus more on patients that really need to have our care*" (#3), "*They can text, they can email me*" (#2), "*trying to make myself available as much as possible for them*" (#2)	Accessibility to the nurses

The nurses who work in neurology departments do not have enough time or limited allocated time to work with PWE. The epilepsy nurse who works full time, given the frequency of use of phrase "I don't have time", it is clear that she does not have sufficient time to complete her tasks and she regularly works overtime. The other three nurses look after people with other neurological illnesses as well as epilepsy and they need to prioritise who needs more care within their limited working hours. They also feel that their allocated time for epilepsy care is not enough to provide what they would like to do. Particularly, they commented that there is no time for sitting down with patients to provide good education, meeting with community fieldworkers, or attending a clinic to learn more about epilepsy.

Furthermore, concerns were voiced about nurses being too easy to access and this increasing their already busy workload. In particular, patients contact nurse #3 asking her to change appointment schedules or addresses, and asking for repeat prescriptions which they should get from their GP. She has removed her email address from her business card hoping to filter out

some of the non-nursing work. It is too early to see the effect of this action at this stage. On the other hand, nurse #2 provides more options for contacting her including phone, text message, and email for easier access.

There is no one to provide care that epilepsy nurses do

The interventions that epilepsy nurses provide such as patients education and follow-ups are not carried out by anyone else apart from the epilepsy/neurology nurses. This means, if the nurses cannot do this, PWE are not receiving these services. Especially, education after first seizure was a concern of the participants because a lack of education can lead to poor seizure control and affect their quality of life (QOL).

Codes	Categories
"*There is nobody that could do it*" (#1), "*you are managing a whole thing*" (#1), "*I have to (do it)*" (#1), "*nobody*" (#1) "*When I see them (PWE) further down the track … they've never seen them (first seizure information) before*" (#1)	No one to do the job that epilepsy nurses are doing

PWE are having difficulties

All the nurses agreed that PWE are facing a lot of difficulties. Because seizures can alter their awareness and control of the body, PWE cannot drive unless they are seizure free for more than 12 months in New Zealand. Even when they start driving, if they have one seizure, they have to stand down from driving for another year. This limits where, when and how PWE can go independently. In the area with no or minimal public transport, even going to a hospital appointment becomes a challenge without other people's support. Moreover, if PWE are in a position of looking after family members, this situation affects how the whole family lives.

Some PWE also have difficulty with getting or staying in employment. There are many things that they can or cannot do for safety reasons. For example, going up a ladder, using or operating heavy machinery, and going into water by themselves are hazards they should avoid. Because of these limitations, some PWE are forced to change their jobs. If they cannot find alternate employment, an epilepsy diagnosis becomes a life changing sentence. The nurses feel that epilepsy is still not well accepted in society and that PWE cannot get employment in the same way as people without epilepsy. This whole situation creates difficulty in PWE's lives and affects their and family member's QOL.

Codes	Categories
"*It's (the public transport) not a good service at all*" (#4), *It's quite difficult for people especially if they can't drive to get there*" (#4), "*(the public transport is) awful with almost no public transport*" (#4)	Difficulty going around independently
"*that is a whole tragedy for young people*" (#4), "*I cannot wait for those driverless cars*" (#4), "*They (PWE) would be house bound*" (#4), "*It is quite difficult saying … you can't drive*" (#4), "*It is very difficult*" (#4)	Impact of not driving
"(epilepsy is) not a glamorous kind of illness to have" (#2), "*would get a different look*" (#3), "*They are put down the list when it comes to the job*"(#3), "*(epilepsy) needs to be more normalised*" (#3), "*even our laws discriminate against (PWE)*" (#3), "*There are stigmas around epilepsy*" (#2), "*(diagnosis of epilepsy) is really sad*" (#4), "*they (PWE) are not seen as urgent*" (#2), "*Some people won't tell anybody because they are afraid of stigma*" (#3), "*It's an unfair system*" (#2) "*People who have socially acceptable ailments wouldn't get discriminated anywhere as much*" (#3)	PWE are socially discriminated and the condition is not well understood
"*People becoming more aware of that (epilepsy)*" (#3), "*They say …'I told so and so, they know what to do*'" (#3)	Understanding of epilepsy is changing
"*GP is expensive*" (#2), "*They tend to go straight to ED (Emergency Department) instead of going to their GP*" (#2), "*knowing it's a pseudo medical endorsement*" (#2), "*their needs are actual desperate needs*" (#4), "*these are the people that I have the most concerns for*" (#4)	PWE have financial difficulties

This difficulty of getting paid work leads them to financial hardship, especially when PWE are the main person to support the family. As public healthcare services are limited, epilepsy treatment can be very expensive for them. One nurse shared a story that she was involved in.

> *We had one girl who came off her treatment and was going to try natural path and all that kind of stuff. … I was able to talk to our consultant about that and we've gone from*

there to getting her into the clinic. I rang her, just to find out and where she should be at the treatment. Ended up she couldn't afford GP and in the interim we are always to say "go to see GP" but she couldn't afford it (#2).

On the other hand, nurse #3 found some positive changes. She found that PWE started talking more about their condition to their friends and employers. She has the feeling that understanding of epilepsy is improving in the general population.

There are challenges in epilepsy nursing

Care nurses provide

Nurses are working with PWE providing mainly education and follow-ups. The first seizure education is one of the most important nurses' role and all participants carried out this education. It includes explaining about epilepsy, treatment and how to manage or how to live with this condition. #2 does not have time to do face-to-face education with PWE, therefore she put information together to give away for people who are newly diagnosed with epilepsy. For other nurses, they try to sit down and go through education with PWE and their families however, there are still many PWE without appropriate education. There are other departments such as the Emergency Department (ED) who hand out first seizure information. Not all participants mentioned that their ED provides this service and details of how accurately the information is provided is uncertain in this study.

Along with this education, the nurses feel that PWE also need support around sharing their experience of having seizures and diagnosis. Listening to patients' feelings is often a time consuming process, but nurses try to do it either face-to-face or via telephone. This is the kind of care that if epilepsy nurses do not do, no one else can. Nurses expressed their concerns for people who are diagnosed but have not been seen by an epilepsy nurse because they would not have the same level of support.

Codes	Categories
"*there is still a lot of lack of knowledges (about epilepsy)*" (#3), "*They (PWE) don't have education about what to do during a seizure*" (#1), "*you don't hear much about it (epilepsy)*" (#3), "*there are still a lot of fear of the unknown with epilepsy*" (#3)	Lack of epilepsy education
"*My main thing with epilepsy is education*" (#3), "*(education is) only helping them (PWE) to adapt to this new diagnosis but also forward planning*" (#3)	Education to PWE is important
"*there is a talk about driving, there is a talk about*	All nurses provide first seizure

employment, there is a talk about where they can go for help" (#4), "*I talk about seizure thresholds and what can mild seizure thresholds*" (#4), "*I put the kit together*" (#2), "*first seizure education things (are) really really important*" (#1), "*It is important that nurses should talk to them*" (#1), "*I send them (first seizure information) to everybody*" (#1), "*nurses should be involved in particularly … in first seizure*" (#1),	education in some form
"*people who have … first seizures… are sent home and may not have … given the fist seizure documentation*" (#3), "*A first seizure sheet of information … are usually given to them in ED*" (#4)	Possible gap of delivering first seizure education
"*They often just have a cup of tea and just talk about their experience of the first generalised convulsion, care's experience*" (#1), "*When they are starting treatments and needing to know about taking medications and drinking and sleeping and all of that*" (#2), "*I do get nervous for those who were suddenly sent home after having an often devastating experience happen to them*" (#3), "*They want to tell me everything ever happened to them in their lives*" (#4)	Sharing experience of PWE

Reasons PWE contact epilepsy nurses

Main reasons for PWE to contact epilepsy nurses are they have a breakout of seizures or side effects from antiepileptic drugs (AEDs), and request a letter from their neurologist for returning to drive. Ability to contact nurses can provide more opportunities for PWE to ask questions even after clinic consultations. There are also many cases that nurses can manage remotely. The nurses think this is very important support for PWE.

Codes	Categories
"*A breakthrough of seizures*" (#1), "*they have side effects*" (#1), "*they might want to come off the medications*" (#1), "*about return to drive*" (#1), "*If they (PWE) don't understand something, they've got a contact to call*" (#2), "*they think about things and come back if they have questions*" (#2), "*it the medication changes, they need to phone back within whatever the time begin acceptable*" (#4), "*I get a lot of those*	Reasons PWE contact epilepsy nurse

calls (about driving) … they yelled sometimes" (#1), "*if there is any problems*" (#4)	
"*just providing another level of support*" (#2), "*having a nurse available… saves patients' worries*" (#2), "*Just give them a chance to …ask questions*" (#2), "*Definitely good to know you've got people there to support you*" (#2)	Nursing input from nursing prospective
"*(I do) lots of phone calls … so a lot of follow-ups*" (#2), "*I do a lot of phone work and manage people over the phone*" (#1), "*they don't need to be seen for all the time but phone works well*" (#1), "*(I) look at what they are on, what their levels are*" (#1),	Nurses do a lot of phone follow-ups

High "did not attend (DNA)" rates

There is a high rate of PWE who do not come to hospital appointments. A nurse thinks more young men tend to 'did not attend' (DNA) their clinic appointment. The reasons can be because of the difficulty of transportation to get to the hospital without driving. It also could be the PWE is thinking that they would be told that they cannot drive because of epilepsy if they come to the clinic and therefore they do not come.

Whatever the reason is, PWE who do not attend their clinic appointment miss out on educational opportunities which can lead to a lack of knowledge and poor seizure control. Nurses have concerns for these PWE and try to contact them but some just do not engage with the healthcare system.

Codes	Categories
"*There are very big number of people who do not attend their clinic appointments*" (#4), "*There are a higher proportion of young men who did not attend their clinic appointment than other people*" (#4), "*They might DNA (did not attend)*" (#3), "*it's the demographic*" (#4)	High DNA rate
"*a lot of then struggle with transport*" (#2), "*They can't get in here (hospital)*" (#3), "*They worry about the driving situation. They think if they don't come, then nothing is going to happen*" (#4), "*It's quite difficult for people especially if they can't drive to get there*" (#4)	Possible reasons for DNA
"*They end up with lack of knowledge and lack of follow up*" (#3), "*A number of our patients … have other social issues that also impact on their ability to … take control*	Consequence of lack of knowledge

of their lives" (#3), "*a lack of knowledge makes it a lot more difficult to manage themselves*" (#3), "*(a lack of knowledge makes it more difficult) to talk about epilepsy openly with their peers or in their work environment*" (#3)	
"*If some people don't engage (with healthcare), it's often type of person*" (#2), "*There are a lot of reasons why people live under the radar*" (#2), "*They just don't want the engagement with the healthcare service*" (#2)	Some PWE do not want to engage with healthcare service.

Epilepsy care is inconsistent

Nurses work very differently

Codes	Categories
"*We work very very separately*" (#3), "*It's (the work) not defines enough to do*" (#1),	Nurses work differently
"*We were scoped*" (#1), "*(I am) there to go (person)*" (#1), "*My job is not defined*" (#1),"*I don't have a job description*" (#1), "*I don't have a contract for that (Epilepsy Nurse Specialist)*" (#1), "*(the neurology department) tried to look at what they really wanted to do*" (#3), "*get a better nursing role to trying meet those needs*" (#3), "*the one really needing nursing input (was) epilepsy*" (#3), "*How about starting first seizure clinic as trial?*" (#4), "*if the doctors wanting it here, I organise*" (#1), "*(I'm a) main servant*" (#1), "*I'm guided by really what the neurologists want*" (#2), "*I started helping … just organisation and stuff*" (#1), "*I started managing the meeting*" (#1)	Nurses' role is dependent on what their neurology department want to do
"*They (neurologist) don't usually invite me to see then (PWE)*" (#1), "*We may not know about it (first seizure presentation)*" (#3), "*I'm not invited*" (#1), "*They (doctors) often don't (give nurse's contact to PWE)*" (#1), "*doctors particularly don't want me to see them (PWE) anyway*" (#1), "*at times, our resource isn't used as effectively as it could be*" (#3)	Nurses are missing out on opportunities to meet and provide nursing interventions to PWE

Although the participants are all epilepsy or neurology nurses, there is certainly not much link between each nurse's roles and the consistency of nursing care throughout the country. This difference in the roles appears to be connected with what their neurology department want nurses to do or how the nurses started their role. While #3 and #4 are employed to provide epilepsy care and they have allocated time for their role, #1 started doing tasks that the department required. Because the work she was involved in was related to epilepsy, the title of 'epilepsy nurse' was given later. #2 is a part-time neurology nurse and she needs to prioritise her work. As her department wants more of her input into the other neurological conditions, she cannot provide much epilepsy care.

Additionally, the nurses' opportunities to meet PWE are very varied and it is dependent on a doctor who saw a patient. When the doctor does not let a nurse know about the patient, there is no way that the nurse can provide nursing intervention and subsequently, the patient is missing out on valuable care and support.

Nurses' network

There is no epilepsy nurses' network or close relationships in-between epilepsy/neurology nurses. Three participants know what the strong relationship between specialised nurses is because they are also involved in nursing care for other neurological conditions such as multiple sclerosis (MS) and Parkinson's disease. They have much closer relationships with MS or Parkinson's nurses and find epilepsy nurses do not have the same level of relationship. They think the difference is because of the funding availability. There is pharmaceutical companies' grant-in-aid available for regular meetings and conferences for MS and Parkinson's disease nurses however, the grant does not seem to be available for epilepsy care.

Codes	Categories
"it's quite isolating" (#2)*, "you are quite isolated"* (#2) *"My relationships on the epilepsy side are far inferior"* (#3)*, "I would like to go and see you, see what's going on, what's the best of doing thing"* (#4)*, "Having nursing network could be very valuable thing"* (#2)*, "the newer ones could learn from the more experiences nurses"* (#2), "*It's good to know what other area is doing*" (#2), "*better nursing network would support*" (#2)	There is no strong relationship between epilepsy nurses.
"*I do (communicate) with them (other neurology nurses) more for MS side of things"* (#2)*, "that's the very well*	Nursing network and education is well set up for other neurological

*setup network", "I communicate with *** Parkinson's nurses"* (#4)*, "I have a far closer relationship with my colleagues who work with people with MS"* (#3)*, "MS side of my work is a lot stronger"* (#3)*, "we get a lot more education with MS"* (#3)*, "my education for MS wise, I have, I know, my networks"* (#3)*, "I've got a strong network there"* (#3)*, "We have regular teleconferences"* (#3)*, "we now have a meeting once a year with MS nurses"* (#3)*, "Like Parkinson's, we have a nurse education (conference) most years"* (#4),	conditions
"*there is not much pharma(ceutical companies) involved with epilepsy*" (#3), "*funding is the huge part of that (poor epilepsy network)*" (#3)	Lack of funding to have strong network

All participants are interested in an epilepsy nurses' network but the level of their interest is varied. This is likely related to their role and study opportunities they have in their department. Because they work very differently, some of them are not sure how much in common they have in epilepsy care. The nurse who has limited local education is more keen to have a strong connection with other nurses than the nurse who has regular teaching sessions in her department.

Disparity of epilepsy care around the country

There are smaller hospitals around the country with no neurology department. These hospitals appeared to have visiting neurologists from larger hospitals. It is uncertain which District Health Boards (DHBs) and hospitals do or do not have neurology services including facilities for clinical investigations. Even when there are many neurologists in a large neurology department, when they work in other hospitals, it reduces the workforce of the neurology department. In a smaller hospital with minimal facilities for neurology service, having clinical investigation done is another challenge. Delay or lack of investigation can lead to mis- or delayed diagnosis. There is no sign of nursing satellite care input in those hospitals apart from occasional phone calls that some nurses receive from outside of their DHB.

Codes	Categories
"No (neurology department) in *** and *** … our doctors go from here to there" (#1), "*It's nice to have (EEG) in the hospital*" (#2), "*(There is) disparity around the country*" (#2), "*(neurology clinics is once) every 8 weeks*" (#2), "*You don't have access to the services that you do in another area*" (#2), *"(EEG is done) like a garage in the back of someone's house*" (#2), "*Really really difficult get them (PWE) into (clinical investigation in a bigger hospital)*" (#2)	There is disparity of epilepsy care around the country

Education opportunity for epilepsy nurses is limited

All the participants have their own way of learning about epilepsy such as learning on the job, from neurologists, the Internet, or university study. However, it is not the same as learning 'epilepsy nursing' and the nurses are interested in learning more about 'epilepsy nursing'. Some have more opportunities than others and this is linked to availability of education sessions and funding support. Nurses who work in larger neurology departments seem to have more opportunity to learn during their work time compared with nurses who work in smaller departments. However, it is clear that there are not many formal education opportunities for the nurses in New Zealand. There is overseas training and conferences available but they can be very expensive. There is some study funding available, however they are often not enough to cover the whole study and the application process can be challenging and daunting for some.

Codes	Categories
" *I think there should be a postgraduate study on epilepsy*" (#3), "*I haven't got time to do it (learning in epilepsy clinic) anymore*" (#1), "*It doesn't seem to have the greatest education opportunity*" (#2), "*You can't get education need locally*" (#2), "*you are not going to get (education) locally*" (#2), "*something lack in*" (#2), "*I couldn't get onto it (university epilepsy study)*" (#3), "*(joining) epilepsy formal education … is very challenging*" (#3) *"I think it would be very nice if there were more education for nurses*" (#4), "*don't have the same level of education*" (#4), "*(challenge is) the level of my understanding, knowledge*" (#2), "*The more I*	A lack of epilepsy education for nurses

work with epilepsy, the more I don't know" (#1), "*I had very little knowledge of epilepsy when I started the clinics*" (#4),	
"*It can be challenging to keep yourself up to date*" (#3), *"(sit in … epilepsy clinic) was a huge learning thing*" (#1), "*I learned about epilepsy on the way*" (#1), "*we kind of lean on the job*" (#2), "*working around amazing neurologists for many odd years, I've got a lot of knowledge*" (#1), "*I went on the Internet*" (#4), "*started studying my master's*" (#2), "*a lot of the education was a very much kind of seat of the pants, really*" (#3), "*just leaning on the job and seeing where you can go with it*" (#2)	Nurses are trying to find way of self-education
"*That would be so nice if it was a epilepsy nurse education day*" (#4), "*I would like to go some of the conferences*" (#3), "*I would like to know more of pregnancy updates*" (#3), "*What's the update of SUDEP*" (#3),	Nurses want more education
"*We don't get CME (the continuing medical education funding)*" (#3), "*dot every i and cross every t to see if we can get funding. Even then we are not guaranteed it*" (#3), "*I think it (funding difficulty) makes it (study) harder*" (#3), "*nurses in different area get CME*" (#3), "*just getting the funding for those sort of things (education sessions) is difficult… there is no such support*" (#2)	Difficulty getting funding for nurses study
"(education and knowledge) is going to just be a help to the patients" (#2), "*helps them (PWE) to get better outcome*" (#2)	Nurses education is for the nurses and for PWE

There is a lack of integration in epilepsy care

Neurology department is overloaded

Neurology departments around the country seem to be overloaded with the large number of patients. There are perceptions that some hospitals are more overloaded than others. The reasons for this could be a lack of workforce, inefficient care, too many patients, or a combination of

these. Although the details are uncertain in this study, this is causing early discharges and a long waiting time for a specialist appointment. This situation could lead to a lack of epilepsy care and poor seizure control.

Codes	Categories
"lots of patients waiting for a follow-up"(#2)*, "so overdue follow up"*(#2)*, "Because of the overload"*(#1)*, "tend to discharge more to bring down the numbers"*(#2)*, "Many follow-ups waiting on the book more than anything"*(#1)*, "we do here so many neurology patients"*(#1)*, "we don't have enough neurologists"*(#4)*, "There isn't a lot of appointment"*(#2)*, "we are limited in terms of spaces"*(#2) *"They (epilepsy patient) need to be fitted in over increased my hours"* (#1), "*very short of neurologists*" (#4), "*a huge burden on the technicians*" (#4), "*It's very difficult one (appointment) to get into*" (#2), "*Time of the neurologists is a premium really*" (#2), "*If they just want a follow up, they do get flicked back (to GP) unfortunately*" (#2)	Neurology is overloaded

Epilepsy education to other healthcare providers

Epilepsy nurses also provide education to other healthcare providers. While some education is for specific clinical investigations or treatment, some is about general epilepsy and treatment. The participants found that epilepsy and epilepsy care is still not well understood even among healthcare providers. One of the participants felt that departments that deal with more with acute care do not show much interest in epilepsy care compared with departments managing chronic illnesses. The reason is uncertain however, given the fact that some healthcare providers do not know much about epilepsy care and nurses' involvement, those acute areas are possibly not aware of the value of epilepsy nursing.

Codes	Categories
"*I teach … to the ward nurses" (#1), "Looking seizures, looking at what we do well, what we don't do well*" (#1), "*I also do the education around midazolam*" (#1),	Education to other healthcare providers is required
"*Even giving education like … I've offered our service to places like*	Some health

***, and they've not taken up on that*" (#3), "*Places like … hospice or rehab have requested education sessions and they are interested but I've found it's interesting that some acute places don't*" (#3), "*epilepsy is not their (some neurologists) interest*" (#1)	professionals are not interested in epilepsy
"*One of my colleagues said to me, 'don't you just tell them to take their meds and that's it?'*" (#3)	Lack of knowledge in healthcare providers

GP's role in epilepsy care

When seizures are under control, PWE are often under the care of their GPs. For complex cases such as pregnancy or refractory epilepsy, GPs make referrals to neurology. Some GPs contact epilepsy nurses directly to ask questions. Epilepsy/neurology nurses do not communicate with GPs or practice nurses on a regular basis, but they can communicate appropriately if required.

Codes	Categories
"*GP manage (epilepsy) fine*" (#1), "*They (PWE) are mostly … looked after by their GP*" (#2), "*They (PWE) are under their GP*" (#1), "*Lots of them (PWE) are looked after by general practitioners*" (#2)	GP can manage stable PWE in the community
"*I think most of GPs haven't got ability to do that (changing AEDs)*" (#1), "*(GPs) are very anxious about doing it (changing AEDs)*" (#1), "*often I can manage things over the phone with GPs*" (#1), "*if they (PWE) continue to have refractory seizures … they need to come back*" (#1), "*GPs are quite keen to get the patients seen*" (#4), *"(GP refers) complex cased … pregnant women*" (#2), "*a lot of GPs ring me and ask what they should be doing*" (#1)	GPs need specialist input on complex cases

Relationship with community organisations

Communications between the nurses and community organisations appear to be varied. #2 has close relationship with a fieldworker from an epilepsy organisation. She makes referrals to the organisation and has regular meetings. #1 used to meet with fieldworkers however, as she has become too busy, she does not have these meetings any longer. Yet, she still makes referral to the organisations regularly.

Codes	Categories
"*a lot of people do appreciate the support that provided by the fieldworker in the community*" (#2), "*They can offer them different community based support that we can't do in the hospital*" (#2), " *a shame really (that I don't have time to meet fieldworkers regularly)*" (#1), *"(epilepsy organisations) mainly are for social issues*" (#1), "*She (the fieldworker) is amazing. She goes to visit patients, she helps them … she really one person working on her own*"(#4), "*I refer lots of them (PWE)*" (#1), "*It is very important to establish a communication line between the hospital and community*" (#3)	Role of the community organisations
"*We do make quite a few referrals (to the fieldworker)*" (#2), "*It's not a close relationship*" (#4), "*That is a really good referral to make*" (#2), "*I've got a good network with my fieldworkers*" (#2), "*I'm a hospital nurse so whether thing in the community done, but that's not my field or knowledge*" (#4), "*I do catch up with her probably every 6 months maybe or over the phone every few months*" (#2), "*we have a very good relationship with the fieldworkers*" (#3), "*We should have more formalised meetings with the community teams*" (#3)	Nurses' relationships with community fieldworkers are varied
"*I don't think the community based services are as resources as it could be in the ideal world*" (#3), "*There is some dysfunction in the epilepsy organisation*" (#3), "*I think care in *** is not well coordinated*" (#4), "*that is a pity because it works so much better when was a good coordination between the societies*" (#4), "*They (epilepsy organisations) are falling out there*" (#4), "*We have two field officers and two separate epilepsy societies … with very different outlook on what field officers position is involved*" (#4), "*It's quite disconnected with the care*" (#4)	Possible dysfunction in community organisation

#4 does not have a close relationship with fieldworkers but she provides information about the organisation in case PWE need support in the community. This varied communication between hospital nurses and community organisations suggest that there are no guidelines for continuity of the care.

Disorganisation or dysfunction of the community organisations was highlighted by two nurses who work in different parts of New Zealand. This seems to be affecting the fieldworkers' performance and possibly relationships between hospital nurses and community care. The features of community fieldworker's role were not a part of this study; however, this area can be

studied further to understand epilepsy care especially in the areas where there is no nurse involvement.

What we can do for future/ideal epilepsy care

Nurses are aware that the epilepsy care they are providing is not enough. They are thinking of 'if there was enough time' or 'if there are more nurses', what they would like to do. Nurses would like to be involved in epilepsy care from first seizure presentations and whenever patients are admitted to a hospital. Regular follow-ups, easier access to epilepsy nurses and integration of the care between hospital and communities, are the gaps that nurses would like to fill. For more efficient care, tele-clinics and/or telephone clinics are on the list to be developed. Furthermore, improvement in information technology (IT) systems and culturally sensitive care are on the nurses' wish list.

Codes	Categories
"*We have these dreams of what we'd like to do but … won't be practical or not able to happen*" (#2), "*Seeing all patients presented with first seizures and being invited to see patients in the ward*" (#1), "*I would expect epilepsy patient to be contacted if not seen once a year*" (#4), "*I would like to see an epilepsy nurse in the neurology department with the same sort of a good access that we have to the neurologists*" (#4), "*You all coordinating the care right through to the general practice, field officers and hospital, all working together. That's I would like to see*" (#4) , "*if my role was to be increase, we talked about me seeing some of the follow-ups*" (#2)	Ideal epilepsy care
"*We are trying to set up … a telehealth, like a remote with the patients somewhere with a phone, and be able to conduct interviews*" (#4)	Plan for the future
"*Our computer system … is hopeless. Absolutely hopeless*" (#4)	IT system needs to be improved
"*I'd like to get more of the cultural side involved*" (#3), " *I remember having a patient … she said … 'this is a very white way of dealing with things"*" (#3), "*Could be done better to work with people of your culture*" (#3)	Culturally sensitive care is required

Summary of Chapter Four

This chapter presented the findings from the interviews. The first step of substantive coding with open coding and comparison process and development of categories were presented. These categories were further placed into core categories and there are six core categories developed. They were

1. Many PWE are not receiving optimal epilepsy care in New Zealand
2. There are challenges in epilepsy nursing
3. Epilepsy care is inconsistent
4. Education opportunity for epilepsy nurses is limited
5. There is a lack of integration in epilepsy care
6. What we can do for future/ideal epilepsy care

These core categories and their relationship are further studied to develop theories in the next chapter.

Chapter Five: Theory development

Introduction

This chapter describes theoretical coding and development of the theory process. It involves creating relationships between categories and six core categories which were explained in the previous chapter.

Category one: Many PWE are not receiving optimal epilepsy care in New Zealand

Significant shortage of nurses

It is clear that there are not many nurses working with people with epilepsy (PWE) and this is one of the biggest gaps in epilepsy care in New Zealand. All participants, without exception, mentioned that they are too busy to provide the level of care that they would like to deliver. Additionally, frequently repeated "*I don't have time*" emphasises the significance of this issue. The nurses feel that there are too many patients and it is obvious that there are more nurses needed to cover the numbers of patients. They also think that they need more time allocated for epilepsy care and nurses are doing too much work that is irrelevant to nursing. The combination of minimal number of nurses and limited time to spend on epilepsy care is causing a significant lack of epilepsy nursing care. Furthermore, no one else delivers the care that the nurses are providing. This means PWE are not receiving adequate epilepsy care.

In the interviews, the nurses commented that "*there is no money*", and "*It's a political game*". As these comments came from different DHBs, this indicates that the New Zealand health care system is generally not interested in increasing resources in this field. Neurology departments seem to 'fight for the position' to get more nurses, however an increase in nursing hours or position does not seem to be happening. It is possible that the health care system is not aware of the value of epilepsy nurses' input. Epilepsy nursing is still an understudied area and there is no research conducted in New Zealand to present the rationale for having more epilepsy nurses. Given the fact that many healthcare workers are not aware of epilepsy care suggests that the profile of epilepsy nursing is low. Epilepsy nurses need to raise their profile to increase in resources.

Effects of driving restriction and high 'did not attend (DNA)' rates

The nurses who participated are aware of the difficulties that PWE have. One of the challenges that PWE have is standing down from driving. There is public transport in bigger cities but there are many places with no public transport in New Zealand. This difficulty of traveling independently has been problematic for many of the PWE. Some people have difficulty

commuting to their work which can affect their employment situation. If they are living in an area with no transport, they lose their independence and potentially are house bound. Because of this, some of them struggle to attend their hospital appointment and this is part of the reason that PWE have high 'did not attend (DNA)' rates.

High DNA is also related to sensitivity that they feel around their condition. When people don't want to discuss their epilepsy, they avoid coming to hospital appointments. Unfortunately, this is a pointless battle because regardless of whether they come to their clinic appointment or not, stopping driving is mandatory as per the New Zealand Transport Agency's (NZTA) regulation. Additionally, missing out on clinic appointment means they miss out on valuable education about living with epilepsy including the reason for taking medications, lifestyle to avoid seizures, safety considerations, and where to go for help in the community. This can lead to poor understanding and management of epilepsy. Although nurses cannot help their situation, the importance of coming to an appointment should be explained when the patient was referred to neurology. Unfortunately, there is currently no system to provide this kind of education to PWE unless they meet epilepsy nurses. To improve this situation, epilepsy nurses need to develop a relationship with areas where people present after having their first seizure such as general practitioners (GP) and emergency departments (ED), to let the staff know about epilepsy care and the nurses' role.

Stigma and discriminations

There are also barriers for PWE with social acceptance of epilepsy. Although human rights are protected by the law in New Zealand (Human Rights Commission, 2018), PWE still experience stigma and discrimination around epilepsy. The participated nurses have observed that epilepsy is not a "*socially acceptable ailments*" or "*a glamorous kind of illness to have*." However, one participant noted that the understanding of epilepsy among the general public is changing. PWE are more openly talking about epilepsy. People around them are more aware of this condition and what to do if someone has a seizure.

Unfortunately, the discrimination still remains and it becomes more critical when PWE are trying to get a job. People who developed epilepsy who happen to be working with heavy machinery or working in places that involve going to heights, struggle to stay in employment. In these cases, the main reason for employment loss is related to safety concerns rather than discrimination however, the situation of not having employment remains. This difficulty of finding paid work leads to financial difficulties which can cause fewer visits to the GP and poor compliance due to high cost of GP visits and medications. This situation leads to poor seizure control and lower quality of life (QOL). PWE are not only dealing with psychological challenges with these barriers but also difficulty in maintaining QOL.

Category two: There are challenges in epilepsy nursing

Although all participants work differently, they share many similarities in relation to ideas of optimal epilepsy nursing care. One of the most important nursing inventions is education for patients and their families. In particular, all nurses spoke about first seizure education. This is the education that nurses give or would like to give, to patients who are newly diagnosed with epilepsy. It contains important information such as seizure first aid, reasons for taking drugs, and safety considerations. This education should be given in a timely manner, however the nurses are missing their opportunities. This is because the nurses are not notified about the patients by a doctor who saw the patient or the nurses do not have enough time to meet the patient. The reasons for not being notified by the doctor are uncertain in this study. However, it is clear that there is no guideline or pathway for when to involve nurses and what nurses' roles are in the care.

For nurses, first seizure education is a very important opportunity to meet the PWE and their family to offer general support, contact details, and listen to what they have experienced. Having a seizure can be a very scary and traumatic event and nurses would like to offer the patient the opportunity to share their experience to help them to come to turn with the condition. Main reasons that PWE contact nurses are: worsening seizure control, side effects of antiepileptic drugs (AEDs), and requesting a letter for driving. Apart from driving, difficult seizure control and experiencing drug side effects can occur anytime in the PWE's life. Nurses feel that most PWE need continuous care, therefore the nurses provide their contact details, so they can contact the nurse when concerns arise.

Mostly, communication between PWE and nurses is done by telephone and emails. Nurses sometimes control how PWE can get hold of them. One nurse gives only her land line but not her mobile number because she often needs to be at her computer to see the patients' record when they call and she does not want to be interrupted by patients all the time. Another participant thinks that she has been receiving too many phone calls and emails so that she struggles with her workload. Sometimes, they contact her for administration matter or something not related to epilepsy and she removed her email address from her name card recently. Easy access to a specialist is helpful to PWE however, it needs to be used appropriately and all patients should be instructed around when it is appropriate to contact nurses.

Nurses' epilepsy education has various values. Clinical based education is for PWE to manage their condition. Nurses can discuss the reasons to take medications, maintaining good compliance, regular blood test, lifestyle to avoid seizures, and safety considerations. Some education focuses on better QOL, includes that the nurses go through social background and life

style, and discuss with PWE about what they would like to achieve. Another type of education is more to raise epilepsy awareness. Epilepsy nurses can provide education sessions to the general public, to schools, or to employers of PWE as required. However, this education in the community is mostly carried out by community organisations. Again, there is no guideline on what are epilepsy nurse's responsibility and the role of fieldworkers'.

Category three: Epilepsy care is inconsistent

There are no guidelines for standardised epilepsy nursing in New Zealand. It is apparent that the nurses' roles are dependent on what each neurology department wants to achieve. This is clear evidence that care provided to PWE across the country by nurses are all different. The nursing role and the value of nurses' input in epilepsy care needs to be more acknowledged within neurology departments and the nurses need to work to raise the epilepsy nursing profile. Developing guidelines for detailed standardised epilepsy care is fundamental to promoting epilepsy nursing.

Among epilepsy/neurology nurses, there is no strong relationship across the country. Having a speciality nurses network could be very useful for promoting an understanding of what others do as part of their practice, sharing their experiences, and updating their knowledge. This is apparent in networks for other neurological conditions. There is pharmaceutical company involvement and they support nurses' education, therefore the nurses' can attend conferences or study days regularly and developed close relationships. However, the same networking is not happening for epilepsy nursing and this is thought to be due to the lack of funding which is the biggest barrier to establishing the nurses' network. Other factors may contribute this are the small number of nurses, lack of motivation, or lack of leadership. Unless a nurses' network is established, it will be difficult to standardise epilepsy care.

Epilepsy care also appears to be different around the country. A shortage of specialist care does not apply to only epilepsy, however the lack of epilepsy care in rural areas is a noticeable problem. Neurology departments in bigger cities provide satellite clinics in smaller areas however, the city neurology departments are already overloaded and the service provided to rural areas is very limited. Consequently, PWE are struggling to be seen by a neurologist. Epilepsy care that PWE are receiving in rural areas is unknown as there are no nurses who travel to rural areas.

One way of dealing with overloaded PWE, neurology departments are trying to discharge patients to GPs as soon as they can. The GP can manage stable PWE, but once their condition becomes complicated, a specialist's input is required and patients need to be referred back. Some neurology departments are in the process of managing this problem by providing more

efficient care such as telephone clinics and telehealth. It is too early to know how feasible it is to carry out these cares and their effectiveness.

Category four: Education opportunity for epilepsy nurses is limited

Epilepsy/neurology nurses would like more education for epilepsy care. They feel their knowledge is limited and not updated. The nurses have their own way of learning such as undertaking postgraduate studies, learning on the job, and attending journal clubs. However, they would like 'epilepsy nursing' education. As it is such a specific topic, the opportunities for education are limited. There is no epilepsy nursing study day in New Zealand. Some nurses attend overseas' conferences, however, the high cost for these education sessions is a barrier for nurses. The study funding is limited and although the funding is available, the application process can be difficult and there is no guarantee for the application to be accepted.

The nurse in the smaller hospital felt her opportunity for education was very limited and she would like to learn more. A nurse in one of the bigger centres has a regular journal club and is learning constantly from neurologists. However, she is still keen to learn more about the nursing side of the care. One participant is keen to learn all the updates in epilepsy care as well as caring for people from different cultures. Although each nurse's interests are slightly different, they all agree that they would like to have a good nursing network to learn about epilepsy nursing and support each other.

Category five: There is a lack of integration in epilepsy care

There are epilepsy organisations which support PWE in the community. In some areas, PWE epilepsy engage with fieldworkers from these organisations and are well supported. On the other hand, there are areas with less support. Epilepsy organisations in the community provide general support to PWE including psychosocial problems, however the detail of their work was not explored in this study. In the interviews, the nurses mentioned that there are some discrepancies within the organisations. Additionally, the relationship between the nurses and these organisations is varied and some nurses do not have much relationship with local community organisations. The reason for the lack of relationship seems to be related to a lack of nurses and a lack of time for the nurses to have regular meeting. Despite this, the nurses agree that a good relationship with community organisations would be beneficial for epilepsy care.

While the communication between nurses and epilepsy organisations is rather random, relationships between GPs and practice nurses appears to have a better structure. PWE with stable medications and reasonable seizure control can be well looked after by GP. GPs sometimes contact epilepsy nurses for advice or discussion when the situation becomes more complex such as seizures becoming difficult to control, patient is pregnant, or PWE have side

effects from antiepileptic drugs. GPs can also be directly in contact with neurologists, therefore there was no issue raised.

Neurology departments are generally overloaded. However, discharging PWE to GP care to reduce the waiting list is not the best solution for unstable PWE. If the care between hospital and community is linked well, it would reduce miscommunications and frustration, and create seamless care. Nurse can take a pivotal role here, however a guideline or pathway should be created for this process.

Integration of care is also needed within hospital care. Epilepsy does not seem to be a well-known condition and even some healthcare workers do not know what epilepsy care is. To be fair, I did not know what epilepsy nurses' roles are until I started this role and I never met anyone who provided epilepsy care in my more than 20 years of nursing career. Epilepsy nursing care is very specific and providing epilepsy education to others in the health sector is another important role of the epilepsy nurses. However, the interest in learning about epilepsy care appears to be varied and depends on each sector. Interestingly, there is a tendency that acute practice areas are not interested in epilepsy nursing care as much as areas that provide chronic care. The reason is uncertain, though learning about chronic conditions may not be the best interests in the acute settings. Regardless of the reason, epilepsy care needs to be understood more in the acute areas as they could play a part of important role in epilepsy care.

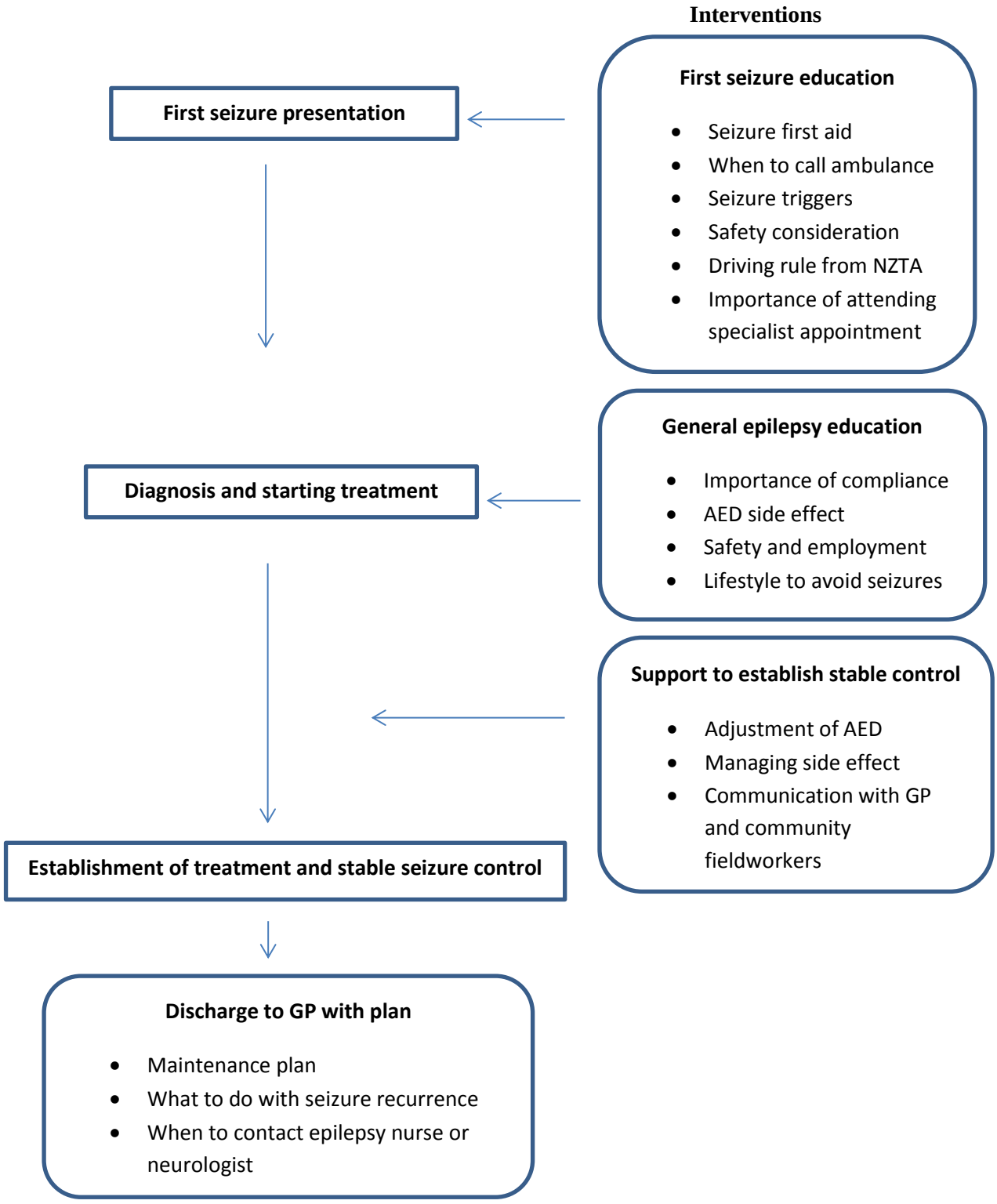
Category six: What we can do for future/ideal epilepsy care

All participants think that there are gaps in epilepsy care. Some of the problems are not easily solved, such as small number of nurses and high workload of neurology departments. Nevertheless, nurses are thinking ahead and working towards providing more efficient and effective care. Providing basic standardised epilepsy care to more PWE is one of the first priorities. Nurses mentioned about telehealth or telephone consultation to provide their service to PWE living a distance from hospitals. However, once the care is more established, better information technology (IT) systems and more cultural sensitivity input were stated by the participants for better practice.

Development of epilepsy care pathway

All nurses works differently, mostly part-time, and there are many gaps in our care for PWE. However, all nurses seem to have similar view on what would be a good epilepsy care. With these pieces of ideas and information, the following epilepsy care pathway is developed.

Diagram 2: Epilepsy care pathway



As per the diagram, first seizure education needs to be provided at first seizure presentation to provide valuable information and for PWE's safety until they are seen by a specialist. Once the diagnosis is established and treatment is started, further education and support is required until the treatment is established and seizures are reasonably controlled. This is often the period that PWE need to have regular contact with epilepsy nurses. This period could be a few weeks if the choice of AED was effective for the patient or could be years for someone who has difficulty with controlling seizures. Once their treatment is established, PWE can be looked after by GP. It is important that each patient and GP knows the plan for what to do when seizures recur and when to refer the patient back to neurology.

The theme development

There are connections between the above six categories. The first three categories: many PWE are not receiving optimal epilepsy care in New Zealand, challenges in epilepsy nursing, and epilepsy care is inconsistent, are reflecting problems/gaps in the current epilepsy care. The next three categories: education opportunities for epilepsy nurses are limited, there is a lack of integration in epilepsy care, what we can do for future/ideal epilepsy care describe more phenomena in epilepsy care rather than problems.

The gaps in epilepsy care seem large and it would take a lot of effort and time to fill. One of the main causes of these gaps is a lack of guidelines for standardised epilepsy nursing. Nurses have many challenges in epilepsy care and most of them appear to be related to a lack of guidelines. To improve the current situation, guidelines needs to be developed in each step of epilepsy care and disseminated to have consistency throughout the country. Therefore, the first theory became '**Epilepsy care in New Zealand is far from ideal due to the lack of guidelines for nursing practice**'. Having guidelines with feasible pathways for epilepsy care will potentially improve the consistency of epilepsy care. However, the reality is that there are not many nurses in this field and it is clear that developing guidelines within such a small group of nurses is a huge task.

The other three categories describing phenomenon of epilepsy care indicates that the profile of epilepsy nursing is very low. The value of epilepsy nursing needs to be shown by presenting evidence and promoting nursing care in order to receive support from management. Raising the profile of epilepsy is one of the goals of New Zealand League Against Epilepsy (NZLAE) and epilepsy nursing profile also needs to be raised. Hence, the second theory is '**If the profile of epilepsy nursing is raised in New Zealand, delivery of the epilepsy care would improve**'.

Raising the profile of epilepsy nursing includes more research to be conducted in this field and actively providing information about epilepsy nursing. This will provide evidence to the healthcare system, lead to more support to increase nursing workforce and support for nursing

education. This process also helps nurses to develop guidelines for standardised care. Furthermore, healthcare providers would be aware of the nurses' role and value in epilepsy care which helps care integration. Raising epilepsy awareness in the general public can help with normalising epilepsy and promoting acceptance in society so that PWE would have less stigma and discrimination. This also improves the knowledge of seizure first aid in general and PWE can feel safer in the public space.

Summary of chapter five

This chapter presented six categories emerged from the previous chapter and describes the details. The process of the theoretical coding of relating each category is explained. During this process, the diagram for 'the epilepsy care pathway' was developed. At the end, two theories emerged: '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'. In the next chapter, I will discuss how these theories can be utilised to understand current care and improve epilepsy services.

Chapter Six: Discussion

Introduction

In this chapter, I discuss the findings of this study based on the 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**'. It presents the problems of current New Zealand epilepsy care are and suggests the probable causes of this situation. This process provides a clearer view of what is happening and this clarity of the situation guides us to think what nurses can do to improve overall epilepsy care.

Epilepsy care in New Zealand is far from ideal

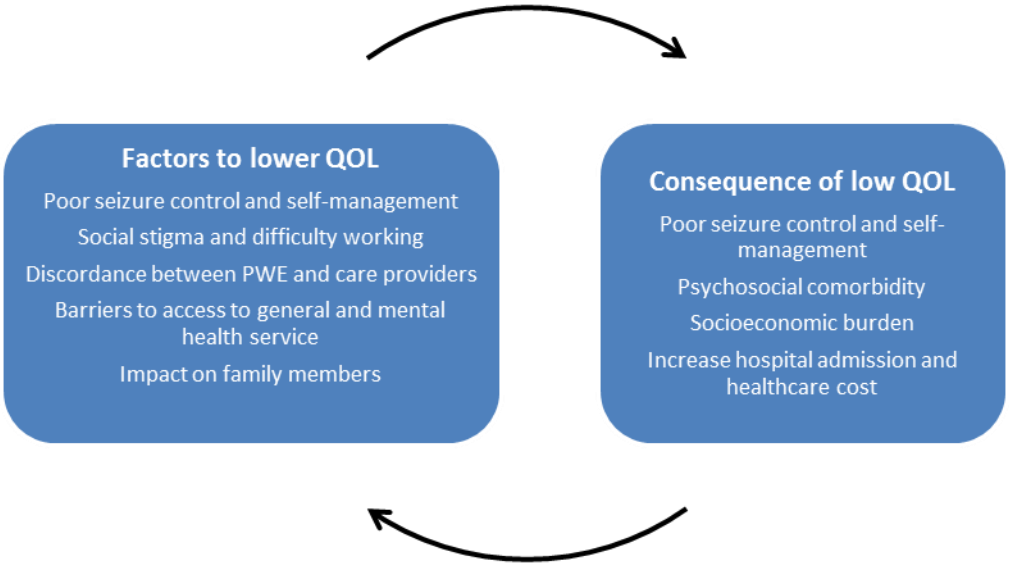
It is clear that New Zealand does not have enough nursing workforce in epilepsy care. This problem was noticeable even before this study was started as I extensively searched for epilepsy nurses throughout the country and struggled to find them. After the interviews, all the nurses agreed that there are not enough nurses here in New Zealand. It is difficult to estimate ideal numbers of epilepsy nurses to provide optimal care. In the United Kingdom (UK) which has population of approximately 65 million, there are 250 epilepsy specialists nurses (Hopkins & Irvine, 2012). In comparison, it is obvious that the number of epilepsy nurses in New Zealand is significantly low. Additionally, the existing nurses feel that they do not have enough time to provide adequate service to people with epilepsy (PWE). This is partly caused by a lack of guidelines for the epilepsy nurse's role resulting in that nurses spend some of their time on non-nursing duties at times. However, it is clear that there are not enough nurses. Most nurses work part-time on epilepsy care and each centre struggles to provide more nurses' hours for epilepsy care.

A lack of nursing workforce in epilepsy care means that many PWE are missing out on nursing care. Many PWE may not know that such services are available or have the opportunity to receive the service. When PWE want to know about epilepsy, but did not have any nursing support, we can only speculate that they may have searched about epilepsy through available resources such as General Practitioners (GPs), community organisations, or online, or are living with lack of knowledge and support. Finding out information and about services with no assistance is challenging. PWE can end up with a lack of information. Receiving appropriate timely information could improve their quality of life (QOL).

Negative cycle of epilepsy

Through this research, I tried to link nursing interventions to PWE and the effect on their epilepsy and QOL. There are many factors which can impact QOL of PWE and these factors are also negatively affected by the low QOL. Therefore I came up with this negative cycle of epilepsy.

Diagram 3: Negative cycle of epilepsy



Interventions to manage factors to lower quality of life (QOL)

To stop this negative cycle, epilepsy care should aim to manage these QOL lowering factors. The following table shows what kind of interventions can help each factor.

Table 1: Interventions to manage factors to lower quality of life (QOL)

Factors lowering QOL of PWE	Possible interventions
Poor seizure control and self-management	• Education and support to improve self-management skills to control seizures • Encouragement to increase motivation • Close monitoring and pursuing optimal treatment with PWE • Good engagement with PWE • Support for lifestyle alteration
Social stigma and difficulty working	• Raising epilepsy profile • Education to general public

	• Having close relationship with community supporters • Adequate treatment to control seizures and manage the side effects • Encouraging and supporting systems for job training
Discordance between PWE and care providers	• Adequate assessment of patients' needs • Providing sufficient information • Involving PWE in the decision making process
Barriers to access to general and mental health services	• Integration of the care • Making sure PWE has access to available services
Impact on family members	• Education and support for family members

There is no rule that nurses are the ones to provide these interventions, however, the person who can provide this care needs to have optimal skills and knowledge and the epilepsy nurses are well suited for this role. Currently these interventions are not well provided due to the lack of workforce and guidelines. Once guidelines are developed, they need to be disseminated to appropriate sectors.

There are also areas with no available specialist including epilepsy nurses in less populated areas. In such areas, the condition of PWE is likely managed by GPs. However, GPs would struggle to provide sufficient care particularly for refractory epilepsy and complex cases (Dalrymple & Appleby, 2000; Keikelame, Hills, Naidu, de Sá, & Zweigenthal, 2012). In New Zealand, the fact that GPs contact epilepsy nurses shows those GPs appreciate nursing input in epilepsy care. How GPs are managing PWE in the area where there is no epilepsy or neurology nurse remains unknown in this study.

Josh et al.(2015) found a higher incidence of sudden unexpected death in epilepsy (SUDEP) in a region with fewer specialists, both neurologists and nurses, compared with a region with more specialist care in New Zealand. Although the pathophysiological mechanism of SUDEP is unclear, epilepsy speciality care aims to provide good seizure control, seizure monitoring, education to patients and family members, and support for comorbidities such as psychiatric and alcohol related issues because these cares may reduce the risk of SUDEP (Miller, Young,

Friedman, Buelow, & Devinsky, 2014; Watkins et al., 2018). Therefore, this lack of nursing care is not only just leading to low QOL of PWE but also it could shorten their lives.

Barriers providing education for PWE and their family members

Providing information, training and support is a key role of epilepsy nurses (National Institute for Health and Care Excellence, 2004b, section 1.3). The National Institute for Health and Care Excellence (NICE) recommends adults with epilepsy should receive appropriate information and education about all aspects of epilepsy to help them cope with the diagnosis (National Institute for Health and Care Excellence, 2004a, section 1.2).

This study showed some consistency in New Zealand epilepsy education. However, there are some barriers to provide education. The fact that nurses do not have enough time to provide an adequate amount of education is one of the barriers. Particularly education for altering life style and self-management is time consuming. In the Noble et al. (2014) study, 90 minutes of education intervention was found to be too brief to change self-management skills. To be able to provide optimal education, nurses need to take time for each PWE. Appropriate working environment, such as an allocated block of time and private space for education, is required. At this stage, the nurses who carry out nurse-led clinics in New Zealand have this opportunity. However, for other nurses who do not have enough time allocated, the delivery of education at optimal timing is a big challenge. The nurses' education should be promoted and given higher priority in epilepsy care.

The timing of initiating education with PWE is also important in epilepsy care to initiate education. However, seeing a patient at the ideal time is challenging. In many cases, first seizure presentation is either in the Emergency Department (ED) or with a GP, who then refers to a neurologist. The government target waiting time for a specialist appointment is within four months (New Zealand Government, 2018). Therefore it may be several months between the first presentation and receiving adequate education for their safety. To be able to provide timely first seizure education, it needs to be provided by a staff in ED or GP. Therefore, it is important for epilepsy nurses' to update ED staff and GPs with the first seizure education materials and to make sure the referral pathway to is clear for all healthcare provides involved in epilepsy care.

Furthermore, once PWE are seen by a neurologist and diagnosed with epilepsy, the patient should be offered the nurses' education service. Following diagnosis with epilepsy, the person and if appropriate, family will need further education including what epilepsy is, the role of antiepileptic drugs (AED) and side effects, self-management skills, prognosis, risk management, and psychosocial issues. The nurses know that it is critical that the provision of education is appropriate and timely. For example, education around pregnancy and epilepsy should be

provided to all women of childbearing age before they become pregnant to reduce risk of teratogenicity due to antiepileptic drugs. This kind of education needs to be explained when they are diagnosed.

Providing education also becomes a challenge when PWE do not engage with healthcare professionals. The high 'did not attend (DNA)' rate of PWE seems to be multifactorial. It is important not to be judgemental as everyone has their own reason for DNA and this needs be understood by the healthcare providers. When the person does not engage with hospital care, making a referral to a community organisation can be an option. PWE might feel more comfortable being in their familiar environment and it would also be convenient for people with transport difficulties.

To overcome or reduce these barriers to providing valuable education to PWE, again, guidelines need to be established and disseminated. In particular, it is important that these guidelines are shared between hospitals and community care to avoid confusion and to provide seamless care.

Nurse-led clinics and standardisation of epilepsy nursing

Nurse-led clinics are where experienced nurses work independently or interdependently from neurologists to assess, evaluate, and provide health counselling for patients (F. Wong, K. Y. & Chung, 2006). Epilepsy nurse-led clinics internationally are diverse. Some nurses are involved in diagnosis and clinical investigations, providing regular follow-ups to assess efficacy and side effects of AEDs, and prescribing medications, while others have more focus on patient education and general support (Bingham & Patterson, 2007; Hosking, 2003; P. G. Hosking, 2004; Noble et al., 2014; Pascual et al., 2015; Paul et al., 2014). Overall, epilepsy nurse-led clinics are largely valued for improving patient outcomes, patient satisfaction, and access to specialist care (National Institute for Health and Care Excellence, 2013; Noble et al., 2013; Randall, Crawford, Currie, River, & Betihavas, 2017). Much of the focus on nurse-led clinics has previously been the reduction of neurologist's workload (Bingham & Patterson, 2007; Hopkins & Irvine, 2012). Some New Zealand neurology departments recognise that nurses can do certain work to reduce neurologists workload. While this situation may be convenient for these departments, it should be recognised that there is a need for patient education and continuity of general support by the nurses. As this care can only be provided by nurses, they should not lose sight of this over more medically focused care (Hopkins & Irvine, 2012).

In this study, two of the participants provided some form of nurse-led clinics, however what they do in those clinics appears to be quite different. One nurse carries out first seizure clinic, diagnoses epilepsy, organises clinical investigations, and provides first seizure education; while the other nurse carries out follow-ups and provides general support for PWE and their families.

Interestingly, the former does not do any follow-ups with PWE and feels this is the main gap in her centre's epilepsy care. On the other hand, the nurse in the latter clinic has concerns that because nurses are not involved in a person's first seizure presentation or diagnosis, early nursing intervention is lacking in her centre. Nurse-led clinics are a significant part of epilepsy care and developing guidelines for the nurses' roles in epilepsy care would be a necessary step.

Epilepsy nursing in less populated area

Nurses' challenges are various as their roles and working environments are different. In a hospital with a smaller population, the neurology clinical nurse specialist (CNS) faces difficulty in organising clinical investigations due to the lack of services available. Hospitals in a bigger city may have an advantage of easier access to specialist consultations and clinical investigations. The neurology CNS in smaller areas also struggles to secure time to provide epilepsy nursing care because she is working part-time and the only neurology CNS to cover all neurological conditions in a large geographic area. She provides her contact number to PWE and offers support if she can, however there is no time for regular follow-ups.

In a smaller hospital, it appears that PWE tend to be discharged to a GP from specialist care more often than urban hospitals. This is due to the smaller number of neurologists available, and the fact that epilepsy can often be managed by a GP. The relationship between the nurse in smaller hospital and primary healthcare workers, such as general practice nurses, does not seem to exist due to a lack of time. Although the nurse in this study acknowledged that hospital and community care should be integrated, she just does not have time to manage epilepsy care in this way. This hospital also has satellite hospitals with occasional neurologist's visit but there is no nursing support available.

Another challenge in less populated areas is that PWE cannot drive unless they are seizure free for 12 months with or without medications (NZ Transport Agency, 2012). This makes it difficult for PWE to travel to the hospital for their appointments as public transport in very limited in rural areas. In response, some patients do not disclose their seizures correctly due to the concerns for their fitness for driving (Dalrymple & Appleby, 2000) or just try not to engage with the healthcare.

Some overseas rural areas tackle this problem by providing specialist consultation via a remote telecommunication system or by setting up nurse-led satellite clinics (Bingham & Patterson, 2007). In New Zealand, no epilepsy nurses can travel to manage satellite nurse-led clinics at this stage given even tertiary hospitals are having difficulties in providing sufficient epilepsy nursing care. However, epilepsy nurses providing medication advice, information, support and time to discuss issues via telecommunication is proven to be an effective and safe system to

improve patients' access to specialist care (Hosking et al., 2002; P. Smith, 2016). Additionally, use of digital health is growing and using online tools to manage health for chronic conditions including epilepsy is supported to provide satisfactory care (Hixson et al., 2015; Mhurchu et al., 2014). Exploring this kind of system would be helpful in rural areas.

Integration of care and the pivotal role of nurses

Integrated care is a system of healthcare delivery with advanced coordination of multidisciplinary care within and across organisational boundaries (Fitzsimons et al., 2012) to improve patients' experience and achieve greater efficacy and value from the health care system (Health Navigator New Zealand, 2017). To be able to provide efficient and effective care to PWE, integration between specialists, primary health providers, community supporters, and other multidisciplinary carers is important.

When nurses are involved in epilepsy care, they can play a pivotal role in interdisciplinary liaison by supporting specialists, GPs, and other community services. Nurses can provide advice and information on epilepsy related medical and social issues and training. The New Zealand healthcare system provides GPs with relatively easily access to specialists, with whom they can usually communicate as required (Cervin Media, 2017). All participants in this study seem to communicate with GPs and practice nurses as required to report their assessments, interventions and concerns about their mutual patients. Some GPs also contact epilepsy nurses directly for advice on adjustment of antiepileptic drugs or to discuss other epilepsy related issues.

The nurses' communication with other specialities, such as psychiatrist and social workers, is different in each centre. One participant usually communicates with other specialities and refers PWE to other services, whereas another participant believes that it is a GP's role and usually does not make referrals to other speciality areas. The reason for this difference appears to be related to where each neurology department defines their role and, again, there is no standardisation of roles when multiple disciplines are involved in care.

Making sure that PWE have access to available community based services is one of the epilepsy nurse's roles. Communications between the nurses and community supporters, such as fieldworkers from epilepsy organisations, also appeared to be varied. The role of fieldworkers was not investigated in this study. Field workers' main role is providing education, general support for PWE and family members, and organising social groups in the community (Epilepsy New Zealand, 2018). While two of the participants meet fieldworkers on regular basis, another nurse communicates with the fieldworkers over the phone and refers her patients, but does not have enough time for regular meeting. Epilepsy nurses commonly take on a role for

communicating with fieldworkers. Without nurses' involvement, there would be no communication between hospital and community care.

The demands placed on the small number of epilepsy nurses and this makes communication with larger number of epilepsy fieldworkers in New Zealand difficult. There is also possible fragmentation and a lack of coordination within fieldworkers' organisations which disrupts the relationships between hospital care and community care. Developing closer relationship with community organisation could be beneficial to epilepsy care. Additionally, community fieldworkers can provide some of the education that epilepsy nurses provide. As stated before, education is time consuming intervention and if their education and nurses' education can link together, it would be more efficient. More details of the fieldworkers' role and how they work in the community needs to be studied further.

Becoming a point of contact

Becoming a point of contact for a neurology department is necessary to take the pivotal position in integrated care. Also, having a point of contact would be a very helpful service for PWE. Epilepsy is a chronic condition and PWE needs on-going care provided either by GPs or hospital specialists. In this study, three nurses provide their phone numbers and some give email address to PWE. When epilepsy treatment is commenced, often a surveillance care is required to adjust AEDs to optimal dosage and monitor side effects until the patient is on the stable treatment. During this process, having a speciality point of contact can provide timely and safe treatment adjustment. Additionally, epilepsy nurses can make sure that PWE have access to available community services. This is particularly very useful when PWE cannot obtain a timely neurology appointment.

Most of the nurses meet PWE when a neurologist thinks nursing input is required and subsequently invite the nurse to meet the patient. This ambiguous timing of meeting with PWE creates concern about missing opportunities to initiate nursing intervention and provide an early point of contact. This situation could lead to uncontrolled seizures and possibly more hospital admissions. It is not uncommon for these nurses to meet patients who have had epilepsy for many years, and report that they do not know much about epilepsy because they have missed out on sufficient education and support in the past. Yet again, having guidelines to make sure all PWE have adequate education and the importance of this should be understood by all healthcare providers.

Providing a point of contact could however results in increasing workload for nurses. Giving PWE information about how to contact the nurse directly assist with easier access to specialist care rather than going through the GP or searching for one particular nurse through the entire

hospital system when there is a problem or concern. Nurses are usually friendly, sympathetic and easier people to communicate with for patients (Cleary & Edwards, 1999). This assists with putting the PWE as ease however it could also, in some instances, result in patients becoming more demanding. Nurses are facing a dilemma of wanting to support PWE by giving easier access but they are sometimes too busy to meet their demand. One nurse feels that she became 'too accessible' for PWE and this resulted in increased workload thereby this disrupting her epilepsy clinical work. The access to the nurse seem to become easier particularly with email contact as PWE can send messages any time and as long as they like. The department dealt with this challenge by removing the email address from her business card. It is too early to assess the effect of this action at this stage. This problem also could be avoided if patients are informed when and for what they should contact the epilepsy nurse when they meet for the first time.

Education for epilepsy nurses

The epilepsy/neurology nurses are self-educating mainly on their job about epilepsy. Learning through the job is one of the common methods and especially learning from neurologists or epileptologists would provide a benefit for nurses. However, this is clinically orientated learning and it is different from epilepsy nursing. These learning opportunities also depend on where the nurses work. In a smaller hospital with one busy neurologist, the learning opportunity is minimal compared with a nurse in a bigger hospital with multiple neurologists and many ongoing speciality investigations.

Apart from self-directed learning, the learning opportunities are very limited for the nurses. There is no epilepsy nursing meetings or study days in New Zealand. Some nurses go to international conferences, while some do not have the ability to attend such costly conferences. Some of the nurses experience frustration around the time-consuming and challenging process for funding applications. Overseas conferences are mostly valuable and useful, however some of the conference topics may not relevant to New Zealand nursing care especially if it is related to overseas policies and healthcare systems. Epilepsy care in New Zealand should be regularly discussed among New Zealand nurses.

Educational needs change and it depends on individual experience. When a nurse starts in an epilepsy nursing role, s/he need to learn basic epilepsy care including epilepsy pathophysiology, treatments, what education should be provided, etc. Once the nurse has more experience, s/he has to develop skills to keep updating their knowledge constantly. In most cases, nurses who take epilepsy/neurology nursing roles, already have certain knowledge, skills, a background of postgraduate qualifications, and certain years of experience (Roberts, 2011). Although all the participated nurses are qualified for their roles, their continuing education opportunities are limited. There is no standardised system to keep updating their epilepsy nursing knowledge and

skills. While some centres have regular meeting with neurologists or provide opportunities for nurse to attend conferences, learning opportunities are very limited for some, especially in centres in rural area. Over all, there is no regular education system to update epilepsy care for nurses in New Zealand.

A speciality nurses' network can provide opportunities to exchange ideas, to develop greater understanding of epilepsy nursing, to raise epilepsy care profile, to inform and mentor more junior nurses, to gain knowledge through education, development, research and collaborative ventures. It would also be helpful to develop stronger links and relationships between different centres (Taylor & Whayman, 2009). A good nursing network can definitely impact epilepsy nurses practice and improve overall epilepsy care. There are epilepsy nurse networks in the UK, Australia, and Canada (Canadian Epilepsy Nurses Group (CENG), 2016; Epilepsy Action Australia, 2017; ESNA - Epilepsy Nurses Association, 2018) but not in New Zealand.

The reasons for this lack of epilepsy nurse network can be put down to the very small number of epilepsy nurses, difference in their workstyles and a lack of leadership. It is a challenge to put a group together when all nurses work differently because their varied interests and the relevance to their roles become problematic. Additionally, some nurses are working part-time and nurses are always very busy so that they do not have sufficient time to organise and built strong nursing networking. In this study, while some nurses showed interest in nurses' network and regular meetings, another nurse did not think it would be beneficial for her.

Another factor which makes it difficult to hold regular meetings is a lack of funding. The New Zealand Nursing Organisation (NZNO) states 'If nursing in New Zealand is to be adequately educated to work to its potential, it is essential that post-registration nursing education, fit for purpose and adhering to these principles, is put in place and funded' (Brinkman, 2010, p. 6). However, in reality, while there are many potential sources of funding are available, many nurses are unaware of these resources and/or hit more barriers during the application process. It can be time consuming and frustrating to the point that nurses struggle to complete the application process. For nurses working with other neurological conditions, such as multiple sclerosis and Parkinson's disease, there are proactive funding support by pharmaceutical companies for nurses' regular meetings and conferences. Within this study, it is uncertain if any of the participated nurses approached any organisations including pharmaceutical companies, asking for funding to have epilepsy nurse meetings. Given the potential of benefits from having nursing network, this is certainly an area needs to be investigated further and improved.

Raising profile of epilepsy nursing

Epilepsy nursing profile is clearly low in New Zealand even within neurology departments. One participant commented that she is not usually invited by neurologists to see PWE in their ward. This issue was not raised as a major concern by the participant, however it undoubtedly disrupts nursing care by not giving any opportunity for PWE to meet the nurse who could provide support and helpful interventions to live with epilepsy. It is unclear if this is due to the different idea of valuing epilepsy nurses input or just a lack of communication. Epilepsy care is becoming more specialised even within neurology (Grainger et al., 2016) and a department with many neurologists will likely have specialists in specific neurological conditions. Therefore, those neurologists who do not specialise in epilepsy may not show an interest in epilepsy care. Despite this, if they are consulting PWE, they need to know, at the least, what epilepsy nursing care is available in their department and its value for patients' outcomes.

The New Zealand League Against Epilepsy (NZLAE) is trying to raise the profile of epilepsy (Bergin et al., 2008), epilepsy nursing is not a well understood nursing role. However many gaps in epilepsy care can be attributed to this lack of understanding. When the value of epilepsy nursing is recognised by the healthcare system, there is a greater chance of increasing nursing workforce and funding support for education. If other healthcare providers know what epilepsy nurses' roles are, it would help to integrate care efficiently and seamlessly.

Research required

There are many areas within epilepsy care requiring guidelines and to achieve this, nurses need evidence-based backup from the literature. Guidelines are available in the literature, yet these guidelines need to be applicable to the New Zealand setting. Undoubtedly, research in New Zealand epilepsy care is very limited and further research is required to be able to develop guidelines of epilepsy care.

Epilepsy nursing research is limited internationally and there is no study within New Zealand as mentioned before. Some literature shows that evidence relating to the benefit of epilepsy nursing care is not strong (Rajpura & Sethi, 2004), although epilepsy care is very complex in that it is questionable if the benefit should be measured by quantitative data such as seizure frequency and hospital admission rate or not. Regardless, there is no doubt that conducting more research in New Zealand would be beneficial to promote epilepsy nursing care. In order to present robust evidence to management to demonstrate the value of epilepsy nursing more research is definitely required.

Although the importance of further research is understood, it would be still be a challenge for nurses to undertake it within their practice. Goodwin et al. (2004) pointed out that epilepsy

nurses tend to put more of their attention on education and clinical practice but not on the research because nurses focus on more familiar tasks. The nurses know the benefit of nursing input in epilepsy care, such as improving patients' healthcare experience, QOL. This leads to better outcomes, reduction of healthcare cost, and socioeconomic improvement. Benefits of this need to be emphasised to be supported by management to increase the nursing workforce. For the nurses' voice to be heard by neurologists, organisations, the public and the healthcare system, more robust research needs to be done by nurses for improving nursing care.

Future epilepsy nursing care

Overall, in New Zealand there is a substantial gap in terms of meeting standards of epilepsy care from the best-practice. Therefore, more efficient and effective ways of providing nursing care need to be developed despite the shortfall of nursing workforce.

Utilisation of digital technology can be a very useful tool to improve epilepsy care nationwide. For example, consultation with specialists on a digital platform is becoming more and more popular and feasible (Bingham & Patterson, 2007; P. Smith, 2016). Also, delivering health information via the Internet and social media is becoming more common. However, the existence of a large amount of unreliable or incorrect information on the Internet can be problematic and create more confusion and frustration for PWE. Epilepsy nurses need to develop the skills to filter unreliable information and direct PWE to more trustworthy information. Additionally, as the population using smart phones is increasing (Research New Zealand, 2015), utilising phone applications for education, self-management, or seizure monitoring can be an optimal option, particularly for the younger generations (Watkins et al., 2018).

PWE find that communicating with other PWE to share their experiences can be helpful although transportation issue may prove a hindrance for many PWE to attend a face-to-face meeting. A virtual society where PWE can communicate with others with similar medical conditions and support each other without traveling could be less of a barrier and possibly be as helpful as face-to-face meetings. Of course, there are many processes that need to be thought through before this technology can become feasible in the practice. However, technology should be better utilised to improve the current situation and more health professionals including nurses need to be involved in this kind of project for future epilepsy management.

Summary of Chapter Six

This chapter discussed the findings based on the 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. 'The negative cycle of epilepsy' was developed during the analysis and also the interventions to manage factors to lower quality of life (QOL) were discussed. In this chapter, the necessity of developing guidelines and raising epilepsy nursing profile, hence requirement for more researched in this area was discussed. Additionally, utilisation of digital technology for more efficient and effective care delivery was described for future epilepsy care.

Conclusion

This research was undertaken to explore and understand current adult epilepsy nursing care in the New Zealand context by interviewing nurses who are involved in epilepsy care. This topic arose from my working environment as an Epilepsy Speciality Clinical Nurse and the challenges I faced and saw. Furthermore, I recognised that there was a lack of research about epilepsy nursing globally and none in New Zealand. There is a need to find out what nurses do and how epilepsy care is delivered to people with epilepsy (PWE). During this research, I gained greater insight and possible problems in epilepsy care. To recognise and obtain valuable data, a systematic approach was required and grounded theory method was adopted.

The perceived problems at the beginning became clear when I started searching possible participants as there are hardly any nurses providing epilepsy care. Eventually, four nurses agreed to participate and the interview results highlighted many gaps in current epilepsy care. Through the data 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. In addition, 'Epilepsy care pathway' and 'The negative cycle of epilepsy' were also developed during the analysis process and nursing interventions required for better service delivery were described. Developing guidelines and raising the epilepsy nursing profile are the main targets to improve epilepsy care and as an additional tool, improvement of utilisation of digital technologies was suggested. The following is the summary of recommendations to improve epilepsy care service.

Recommendations

1. Create guidelines – There are no comprehensive guidelines for epilepsy nursing in New Zealand. To provide standardised care, evidence based comprehensive guideline for epilepsy care and epilepsy nurses' roles need to be developed.

2. Building epilepsy nurses' network – Specialist nurses' networks are beneficial for nurses to learn and update their knowledge, share their experience, and provide standardised care. Although it seems to be difficult to find funding sources to have regular meetings, an effort should be made to pursue funding source and possible alternative ways to have regular communication.

3. Promoting more research on epilepsy nurses' role and their value in epilepsy care – Epilepsy nursing is still an understudied area and more research is required to present robust

evidence. This would help nurses to not only develop guidelines but would also raise the nursing profile which could lead to more support from the healthcare system.

4. Increase utilisation of digital technologies – Epilepsy care is already struggling to deliver optimal service and given the large population of PWE, the available technologies need to be utilised. Nurses need to be creative and familiarise themselves with the technologies to provide more efficient and effective care.

These recommendations are for nurses, however nurses are not the only professionals working with PWE. All healthcare providers involved in epilepsy care including managers, neurologists, GPs, community healthcare providers and other healthcare speciality areas need to work together to achieve better epilepsy care.

The whole journey of this qualitative research was very interesting and helpful for me to understand my role, improve my provision of the care, what other nurses are thinking about current situation, and overview of New Zealand's epilepsy care. I was aware of some of the problems prior to the study, but there are many uncertainties and these prevented me from speaking out or acting on them. Although existing problems are large, the insight into epilepsy care and what to do to improve the service are so much clearer. This study definitely gave me the pathway and encouragement to move forward to improve epilepsy care. I hope this study also helps other healthcare providers to acknowledge the epilepsy nursing role and to work together towards improving future epilepsy care in New Zealand.

I conclude this thesis with my favourite quote from this study.

"*To be fair, a part of our job is to educate people to let them know that there is often a light at the end on the tunnel. … You can lead a life that you would like to lead*" (#3).

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Appendix A: Ethics notification

Date: 20 March 2017

Dear Kinuko McCarthy

Re: Ethics Notification - **4000017422 - Insight into epilepsy care in New Zealand (NZ): An exploration of the nurse's role and care they provide for adults with epilepsy**

Thank you for your notification which you have assessed as Low Risk.

Your project has been recorded in our system which is reported in the Annual Report of the Massey University Human Ethics Committee.

The low risk notification for this project is valid for a maximum of three years.

If situations subsequently occur which cause you to reconsider your ethical analysis, please contact a Research Ethics Administrator.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

A reminder to include the following statement on all public documents:
"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director - Ethics, telephone 06 3569099 ext 86015, email humanethics@massey.ac.nz. "

Please note, if a sponsoring organisation, funding authority or a journal in which you wish to publish requires evidence of committee approval (with an approval number), you will have to complete the application form again, answering "yes" to the publication question to provide more information for one of the University's Human Ethics Committees. You should also note that such an approval can only be provided prior to the commencement of the research.

Yours sincerely

Dr Brian Finch
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840
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Appendix B: Participant's information sheet

Insight into epilepsy care in New Zealand: An exploration of the nurse's role and care they provide for adults with epilepsy

INFORMATION SHEET

Researcher Introduction

My name is Kinu McCarthy and I am a student at Massey University in the Master of Nursing. I also work as an epilepsy specialty clinical nurse at Wellington Hospital Neurology Department. For my master's thesis, I am conducting a qualitative study to explore current epilepsy care provided by nurses to adults with epilepsy (AWE) in New Zealand.

Project Description and Invitation

I would like to invite you to take part in a study on exploring epilepsy nursing in New Zealand. Whether or not you participate in the study is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect any work related matters. This information sheet will help you to decide if you would like to participate in the study.

The main purpose of this study is to explore and understand what adult epilepsy care is provided by nurses. My motivation behind this is there are hardly any studies that have been conducted in this area in New Zealand. I am interviewing epilepsy or neurology nurses who work at hospital based clinics and discussing about their role and cares provided to AWE. The interview will be a semi-structured interview by Skype or phone and the conversation will be recorded for analysis.

I would like to know anything about epilepsy care in New Zealand. For example, I will ask you what kind of care you provide to AWE, the way you communicate with AWE and any organisations you work with to provide epilepsy care. I will also ask about challenges and thoughts you may have about epilepsy care in New Zealand.

Participant Identification and Recruitment

The participant will be a New Zealand registered nurse who currently provides care to adults with epilepsy at hospital based clinics. Medical outpatient nurses are excluded as their roles are too broad for this study. Paediatric epilepsy or neurology nurses are also excluded.

Project Procedures

If you chose to participate in the study and sign the consent form, you will be contacted by me to decide an interview time by email. Please be aware that the interview time needs to be in your own time (not during your working hours). Each interview is expected to be up to one hour long.

The risk of taking part of this study is a small possibility of exposing your personal information. To protect your personal information and privacy, I will de-identify data, assign pseudonyms, limit collection and use of personal information, and de-identify your work place and titles. The benefit of being in this study on the other hand, gives an opportunity to explore and think through your epilepsy care and become a part of project which potentially will improve current epilepsy care in New Zealand.

This study is financially supported by Wellington Hospital Neurology Department and New Zealand League against Epilepsy. However, there is no conflict of interest in this study.

Data Management

Semi-structured Skype interviews will be recorded by a voice recording device. The recorded data will be given to a transcriber who has signed for confidentiality of the study. The transcript will be returned to you for checking and editing. Then the data will be stored in my personal computer with password security until the completion of master's thesis.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to

- decline to answer any particular question
- ask for the recorder to be turned off at any time during the interview.
- withdraw from the study at any point of time during participation until the transcript has been checked and returned
- ask any questions about the study at any time during participation
- provide information on the understanding that your name will not be used unless you give permission to the researcher
- be given access to a summary of the project findings when it is concluded

Project Contacts

If you have any enquiries, please do not hesitate to contact

Researcher: Kinu McCarthy [redacted]

Supervisor: Professor Annette Huntington, Massey University, a.d.huntington@massey.ac.nz

Appendix C: Participant's consent form

Insight into epilepsy care in New Zealand: An exploration of the nurse's role and care they provide for adults with epilepsy

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: ..... **Date:** .....

Full Name - printed .....