

THE EXPERIENCES OF ADULTS LIVING WITH EPILEPSY:
AN INTERPRETIVE DESCRIPTION

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science (MSc) in Nursing

The Faculty of Graduate Studies
Laurentian University
Sudbury, Ontario, Canada

THESIS DEFENCE COMMITTEE/COMITÉ DE SOUTENANCE DE THÈSE
Laurentian Université/Université Laurentienne
Faculty of Graduate Studies/Faculté des études supérieures

Title of Thesis Titre de la thèse	THE EXPERIENCES OF ADULTS LIVING WITH EPILEPSY: AN INTERPRETIVE DESCRIPTION		
Name of Candidate Nom du candidat	Bilinsky, Laryssa		
Degree Diplôme	Master of Science		
Department/Program Département/Programme	Nursing	Date of Defence Date de la soutenance	April 17, 2015

APPROVED/APPROUVÉ

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Abstract

A qualitative interpretive description study was conducted to explore adults' experiences of living with epilepsy. Adults integrate epilepsy into their daily lives; however, there is dearth of literature that explores their lived experiences. Semi-structured interviews were conducted with nine participants recruited from two health clinics situated in northern Ontario, Canada. The main theme was epilepsy as a temporal journey accompanied by others who knew of their past and present experiences, and future aspirations. The past included the onset of epilepsy and accompanied losses. The present was the balance between threats and well-being. Envisioned future was facilitated by hope. Each subtheme built upon the preceding in an attempt to create well-being and strive towards their envisioned future. Suggestions for nursing practice include fostering understanding in the past, promoting the creation of well-being in the present, and inspiring hope towards the future envisioned life.

Keywords: epilepsy, seizures, adults, lived experiences, interpretive description, well-being, health dimensions, qualitative, nursing, health promotion

Acknowledgements

I would like to express my special appreciation and thanks to my advisor Dr. Montgomery. Her unwavering support and encouragement has allowed me to grow, not only as a researcher, but as a nurse. I would also like to thank my committee members, Professor Mossey and Dr. McCauley for offering me guidance and expressing confidence in my work. I would especially like to thank the nurse clinician for her assistance in the recruitment of participants. Without her, this study would not have been possible.

For the adults who volunteered to share their experiences of living with epilepsy, I am grateful for your time and help answering difficult and personal questions. The study would not have been possible without all of your experiential knowledge.

To mom and dad who have always supported my work, thank you. Without your guidance and continued support I would have never had this privileged opportunity. To Kyle, thank you for always being there for me to listen to my rambling. To David who kept me grounded throughout this process, I am so thankful. Your patient ears and spot-on advice kept me going. To my friends (especially Megan), thank you for allowing me time and for forgiving my preoccupation with my learning. Finally, in remembrance of Amorok, her unconditional love and support greatly contributed to my success in pursuing higher education. Thank you.

Table of Contents

Abstract	iii
Acknowledgements	iv
List of Tables.....	vii
List of Appendices	viii
Chapter 1: Introduction	1
Purpose	2
Rationale.....	3
Significance of the Study	3
Chapter 2: Literature Review	5
Introduction	5
Physical Health Dimension	5
Social Health Dimension.....	11
Emotional Health Dimension	15
Spiritual Health Dimension.....	18
Summary	20
Chapter 3: Research Design and Methodology.....	22
Introduction	22
Methodology	22
Setting.....	24
Sampling.....	24
Data Collection Methods.....	27
Semi-structured interviews.....	27
Unstructured research journaling	28
Documentation.....	29
Data Analysis	29
Rigor.....	32
Epistemological integrity	32
Representative credibility.....	33
Analytic logic.....	33
Interpretive authority.....	33
Ethical Considerations.....	34

Chapter 4: Findings	36
Introduction	36
Past	37
Present	40
Threats to Well-Being	40
Developing a ‘mind-set’	42
Protecting self.....	42
Securing belonging.....	44
Future Life Vision	45
Summary	47
Chapter 5: Discussion.....	49
Introduction	49
Epilepsy as a Life Journey	49
Past	51
Present	55
Future	58
Limitations	60
Conclusions	60
References	62

List of Tables

Table 1 - Participant Profiles.....	26
Table 2 - Data Analysis Steps	30

List of Appendices

Appendix A – Recruitment Poster.....	76
Appendix B – Interview Guide.....	77
Appendix C – Second Interview Themes and Guide.....	78
Appendix D – Seizure Diary.....	79
Appendix E – Seizure Mapping.....	80
Appendix F – Consent Form.....	81
Appendix G – Study Information.....	82

Chapter 1: Introduction

Epilepsy is characterized by “a brief disruption in normal brain activity that interferes with brain function” (Epilepsy Ontario, 2015, para. 3) resulting in a seizure. Epilepsy can be classified in various ways depending on the type and degree of severity. An individual might experience mild seizures, where consciousness is not impaired. Others may experience more severe seizures resulting in loss of consciousness (Hopkins, 1987). There is much variability in the literature, however, in terms of the classification of epilepsy. Epilepsy has been described as a chronic illness, a disease, and a disorder (Fisher et al., 2014; Jacoby, Baker, Smith, Dewey, & Chadwick, 1993). For the purposes of this study, the World Health Organization’s (WHO) definition of epilepsy will be applied: “Epilepsy is a chronic disorder characterized by recurrent seizures” (WHO, 2015, para. 1). Due to the chronic nature of the disorder, the WHO (2014) has recognized epilepsy as a major public health concern. Thus, a global campaign ‘Out of the Shadows’ was established by the WHO, International League Against Epilepsy and International Bureau for Epilepsy to increase public and professional awareness of epilepsy, and “to improve acceptability, treatment, services and prevention of epilepsy” (WHO, 2014). This campaign highlights the need for further epilepsy research to raise awareness at a global level.

Epilepsy affects 1 in every 100 Canadians with 15,500 new cases diagnosed each year (Tellez-Zenteno, Pondal-Sordo, Matijevic, & Wiebe, 2004). In Ontario alone, 70,000 individuals continue to live with epilepsy (Bowen, Snead, Chandra, Blackhouse, & Goeree, 2012). Despite the number of new diagnoses each year, there is a dearth of literature available for newly diagnosed patients to help cope with the realities of living with epilepsy (Bautista, Rundle-Gonzalez, Awad, & Erwin, 2013). In particular, adults struggle to integrate epilepsy into their day-to-day lives as seizure triggers cannot be fully prevented (Bautista et al., 2013; Reid et al., 2012). Individuals can experience the fear of stigmatization, rejection, sense of indignity, loss of

self-esteem, employment insecurity and the inability to live a “normal” life (Hosseini, Sharif, Ahmadi, & Zare, 2013). These struggles have effects on all areas of life including, but not limited to, personal, financial, family, and employment (Buelow, 2001).

As a result, options are limited for health care professionals to find ways to assist those living with epilepsy to increase patient-centred care and overall quality of life. In addition, evidence suggests that adults living with epilepsy have unmet health care needs (Reid et al., 2012). Few guidelines have been established for the care of adults with epilepsy. Guidelines that have been developed, focus on the medical and biological aspects of living with epilepsy (Critical Care Services Ontario, 2014; Scottish Intercollegiate Guidelines Network, 2003). One aspect of the Critical Care Services Ontario (CCSO), however, focuses on patient education and counseling following a diagnosis of epilepsy. The guideline states that this education and counseling is the responsibility of the health care provider. A check list was developed as a guide for health care providers to ensure they have reviewed all health related topics. Exploring the lived experiences of adults with epilepsy will assist in the implementation of this guideline to educate the patient, their families, and health care providers.

Purpose

The purpose of this qualitative, interpretive description study, was to gain insight and understanding about what it is like to live with epilepsy as an adult living in Northern Ontario. The research questions were developed to bring meaning to the lived experiences of adults with epilepsy in order to implement new knowledge into nursing practice. The question addressed in this study is: What are the common ways in which adults describe their experiences of living with epilepsy?

Rationale

Little research has provided insight into the lived experience of adults with epilepsy. Evidence, however, does suggest that nurse interventions are valued by most adults living with epilepsy (Risdale, Kwan, & Morgan, 2003). Patients found that their cognitive and affective levels of self-management were increased when nurses took the time to explain lifestyle changes and challenges surrounding a new diagnosis of epilepsy. It has been recommended that studies examining the lived experience of epilepsy are warranted to bring awareness to community leaders and healthcare providers in order to facilitate future nurse-led interventions and programs for those living with epilepsy (Hosseini et al., 2013).

This study will address the gap in nursing knowledge about the lived experiences of adults living with epilepsy in northern rural settings. Such information could guide nurses in their efforts to promote healthy lifestyle and symptom management. The Canadian Nurses Association (2010) outline health promotion as a nursing competency that focuses on recognizing and valuing health and wellness through the collaboration with clients to develop promotion strategies.

Significance of the Study

This study is one of the first interpretive descriptive qualitative research efforts to provide insights into the lived experience of adults with epilepsy and is the first to include adults living in Northern rural locations. The findings from this study may be useful to adults living with epilepsy in allowing them an opportunity to reflect on their own practices with their epilepsy and gain insight into the experiences of other adults facing similar challenges. The findings may also benefit health professionals to gain a better understanding of how they describe their lived experience with epilepsy and how this impacts their wellbeing. The research findings may thus inform the care and support services offered by health professionals to adults living with epilepsy. The knowledge gained from this study may lead to an increased understanding of the

impact epilepsy has on day-to-day life choices. Further, no studies were found inclusive of adults living with epilepsy in northern and rural Ontario. Residents in rural areas can be described as “at risk” for health disparities (Kurpas, Mroczek, & Bielska, 2014). Difficulties with access to health and social services were found to negatively affect quality of life. These authors also suggest that geographical factors are important in the assessment of health status, health service deficits, and healthcare utilization.

Chapter 2: Literature Review

Introduction

The ‘theoretical scaffolding’ of this study is founded on a descriptive review of relevant theoretical and empirical evidence (Thorne, 2013; Thorne, Kirkham, & MacDonald-Emes, 1997a). To organize and guide the interpretation of the participants’ reports, the concept of holism was selected. Holism is central in health promotion and is described as “fostering physical, mental, social and spiritual health” (Povlsen & Borup, 2011, p. 798). Holistic nursing informs practice on an individual’s social, cognitive, emotional and physical problems. McEvoy and Duffy (2008) describe holistic nursing practice as embracing mind, body and spirit to support wholeness, harmony and healing of the patient as a whole. This chapter will include a description of four holistic dimensions including physical, social, emotional, and spiritual. These dimensions will also be addressed specific to individuals living with epilepsy, which will assist in the development of practical implications for this study’s results (Thorne, 2008).

Physical Health Dimension

The physical health dimension involves biological functions of the body “to live, move, and exist in the world” in order to achieve wellness (Tokpah & Middleton, 2013, p. 82). This health dimension is developed using a combination of regular activity, healthy eating habits, and avoidance of harmful behaviours such as smoking and illicit drug use. In addition to achieving and maintaining a healthy body, physical activity can also improve cognitive and spiritual connectivity. Melton, Hansen, and Gross (2010) conducted a study examining young adults who participated in physical activity programs. The individuals who took part in these physical activity programs described an overall sense of increased health and wellness. The physical dimension and fitness connects mind, body, and spirit (Hales & Lauzon, 2014). The physical dimension also focuses on managing chronic conditions in order to prevent them from

progressing. The following section will describe the diagnostic criteria of epilepsy, the risks involved, and the techniques individuals use in order to manage their disorder including maintaining a medication regime and avoiding seizure triggers.

A person is diagnosed with epilepsy when two or more seizures are experienced that were not provoked by substance abuse, fever, infections or other causes (Engel, 2013). Seizures are divided into two major categories: partial seizures and generalized seizures (Henry, 2012). Within these two categories, however, are many different types of seizures. Partial seizures occur in one part of the brain and can be either simple or complex. In a simple partial seizure the individual remains conscious but may experience unusual sensations or feelings. In a complex partial seizure, the individual might lose consciousness and may display abnormal, repetitious behaviours such as blinking, twitching, and mouth movements. Some individuals with partial seizures experience an aura or an unusual sensation that preludes an impending seizure. The second major category is generalized seizures. Generalized seizures are abnormal neuronal activity in multiple parts of the brain usually resulting in the loss of consciousness. There are many types of generalized seizures including absence (or petit mal) seizures where the person may appear to be staring into space, tonic seizures that cause stiffening of muscles, clonic seizures that cause jerking movements, atonic seizures where the person loses normal muscle tone, and tonic-clonic seizures that cause a mixture of stiffening of the body and repeated jerks (Engel, 2013; Henry, 2012). In addition, individuals may experience both types of epilepsy during a seizure, beginning with a partial seizure and progressing into a generalized seizure. Regardless of the type of seizures experienced, epilepsy can be a disabling disorder affecting day-to-day activities such as work or school. Due to the intermittent nature of epileptic seizures, it is often difficult to obtain a firm diagnosis. Video-electroencephalography (EEG) is the gold

standard for the diagnosis of epilepsy, however, in cases with low seizure frequency this method of diagnosis becomes difficult.

In order to gain control over seizures most individuals require lifelong drug treatment (Henry, 2012). More severe types of epilepsy, where seizures cannot be controlled with medications, require surgical treatment. Both medication and surgical approaches consider a person's quality of life and are individualized to consider the risk versus benefit in the treatment of seizures (Engel, 2013). While most people with epilepsy can be treated effectively with medication, about 30% of these individuals are diagnosed with medically refractive epilepsy where seizures do not respond to two or more antiepileptic drugs (CCSO, 2014). Approximately 21,000 Ontarians are diagnosed with medically refractive epilepsy and 9,600 of these people are potential candidates for surgery based on eligibility (i.e. location of cerebral seizure origin) (Bowen et al., 2012). There is an 80% chance that an individual will be seizure-free after surgery, resulting in higher seizure freedom, and improved quality of life (Bowen et al., 2012). Epilepsy surgery, however, is underutilized due to the unawareness of surgical options, and low referral rates. It is estimated that less than two percent of the potential candidate population is assessed for surgical treatment (CCSO, 2014). Recent best practice guidelines have been developed for physicians and healthcare workers in terms of epilepsy treatment options to improve surgical referral rates and assessments (Ontario Health Technology Advisory Committee, 2012).

The most common approach to achieve wellness and decrease seizure frequency is with treatment using medications. In most cases trial-and-error of medication and dose is required to obtain a steady drug concentration to prevent breakthrough seizures (Schulze-Bonhage & Kühn, 2008). There are more than 30 types of antiepileptic drugs that can be prescribed alone or in combination at different dosages depending on factors such as seizure type, lifestyle, age, seizure frequency; and, for women, if she is or will become pregnant. The requirement of daily doses of

antiepileptic drugs is often accompanied with side effects such as weight loss, vomiting, nausea, fever, behaviour changes, depression, drowsiness, headache, and dizziness (Baker, Jacoby, Buck, Stalgis, & Monnet, 1997; Bishop & Allen, 2003; Buelow, 2001; Jacoby, Ring, Whitehead, Marson, & Baker, 2014). In a recent study examining the implications of a diagnosis of epilepsy, the researchers found that medication side effects have a significant negative impact on their quality of life (Jacoby et al., 2014).

Medication side effects have been reported as a major factor that contributes to poor self-management and medication noncompliance (Fraser et al., 2011; Schulze-Bonhage & Kühn, 2008). Side effects that are typically experienced include tiredness, dizziness, blurred vision, headaches. More intrusive impairments in cognition have also been reported, including difficulties with attention, concentration, and even language functions (Schulze-Bonhage & Kühn, 2008). A study that included 165 adults living with epilepsy notes that over 91% of the sample reported having problems with unpleasant side effects from medications, although the researchers do not elaborate on what type of side effects were experienced (Fraser et al., 2011). Compliance to medication was also found to be problematic in a study conducted by Cramer, Glassman and Vincent (2002) who found that 71% of respondents reported having skipped or missed one or more doses of seizure medications. Individuals were nearly three times more likely to miss a dosage as the number of prescribed medications increased. In contrast, a study examining lifestyle management behaviours among 108 adults with epilepsy found that over 90% of the sample had high self-efficacy for taking seizure medications (Kobau & Dilorio, 2003). Further, almost 90% of individuals were able to name their medication and dosage. It is not clear why results differ across these studies, which supports the need for further research in terms of epilepsy and medication compliance.

A diagnosis of epilepsy increases the risk for physical injuries (Asadi-Pooya, Nikseresht, Yaghoubi, & Nei, 2012), especially in those who experience loss of consciousness with no preceding warning symptoms. A recent study examining injuries in patients with epilepsy found that 47% of participants reported having at least one injury during the past 12 months (Asadi-Pooya et al., 2012). These injuries included car accidents (0.4% of patients), soft-tissue injury (43.6% of patients), burns (4.5%), fractures (5.3%), head injury (1.9%), and dental injury (4.5%). Tiamkao and Shorvon (2006) also found 27% of participants reported seizure related injuries including soft-tissue injuries (61%), burns (17%), head injury (14%), fractures (5%) and injuries in water (3%). A European study also found that 60% of all accidents in people with epilepsy were as a result from contusions, wounds and abrasions (Beghi & Cornaggia, 2002).

Life threatening injuries as a result of epilepsy can also occur, however, are far less common. The risk for premature death is increased among people with epilepsy. Almost half of those deaths occur in people with epilepsy who are younger than 55 years of age (Fazel, Wolf, Långström, Newton, & Lichtenstein, 2013). A study that looked at death certificates of people with epilepsy found that the most frequent causes of death were falling (26%) and drowning (10%) (Jansson & Ahmed, 2002). These authors also reported that accidental poisoning is the cause of death in under 10% of the patients. It was also found that epilepsy is under-reported on death certificates; therefore, additional fatalities as a result of a seizure might have occurred but were not reported.

Another cause of death is sudden unexpected death in epilepsy (SUDEP). SUDEP can be described as a “sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in patients with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death” (Nashef, 1997, p. S6). SUDEP is poorly understood, however, the risk for

sudden death in someone with epilepsy is more than 20 times higher than for those without epilepsy (Shorvon & Tomson, 2011). Epilepsy duration and seizure frequency have been found to be two of the most important risk factors for SUDEP. Shorvon and Tomson (2011) found that individuals diagnosed with epilepsy for over 15 years were at nearly double the risk of SUDEP than the wider population of people with epilepsy. In addition, a study examining 1,042 patients with epilepsy found that having more than three seizures per year greatly increases the risk for SUDEP with an odds ratio of 15.6 (95% CI, 10.1 – 24.2) (Hesdorffer et al., 2012). This means that individuals who have more than three seizures a year are 15.6% more likely to experience SUDEP than those who have fewer seizures.

In addition to adhering to prescribed medications, many individuals with epilepsy also avoid seizure triggers in order to gain control at an individual level (Schulze-Bonhage & Kühn, 2008). The avoidance of seizure triggers is described in the literature as a self-management technique to maintain wellness (Walker et al., 2014). The most common seizure triggers are lack of sleep and stress, therefore, developing a daily routine is essential in the avoidance of seizure activity (Schulze-Bonhage & Kühn, 2008). A recent grounded theory study involving in-depth interviews with 22 adults with epilepsy found that the most common self-management behaviours to avoid seizures were using relaxation techniques, avoiding certain foods or stimuli (i.e. flashing lights), and maintaining habitual sleeping routines (Walker et al., 2014). Managing these routines, however, was found to be problematic in a study conducted by Admi and Shaham (2007). The participants expressed a desire to live more spontaneously and disregard their routines. For example, one participant stated, “I really want to get drunk just once in my life” (p. 1184). These behaviours, if acted upon, may threaten the physical wellness of the individual living with epilepsy.

Social Health Dimension

Social health can be defined as the “ability to interact with the people around us as well as our capability to function as a contributing member of society while supporting and helping others to do the same” (Hales & Lauzon, 2014, p. 29). There have been numerous studies that have demonstrated a link between social health and its effect on health problems (Salovey & Rothman, 2003). Individuals who are isolated and less integrated into society are at an increased risk for psychiatric disorders, accidents, tuberculosis and even death.

Two key components of the social health dimension are social support and social bonds (Hales & Lauzon, 2014). Social support refers to the perception that one is loved or cared for by others and valued as a part of a social network (Taylor, 2007). This support can come from multiple sources including partners, relatives, friends, colleagues, community ties, and even pets. Hales and Lauzon (2014) classify social support in several ways. First, informational support is described as an individual who helps another make sense of a stressful event and assists in developing positive resources in order to help cope with it. Next, instrumental support is the provision of tangible services such as financial aid or other specific goods. Finally, emotional support refers to the warmth and nurturing actions towards another in order to provide reassurance that they are valued. The second key component of the social health dimension is social bonds (Hales & Lauzon, 2014). Social bonds refer to the extent of integration and attachment to family, community, and society (Hirschi, 1969). To reduce the risk of unhealthy life choices, four social bonds must be integrated into one’s lifestyle. These include attachment, involvement, investment, and belief. These bonds encourage individuals to participate in social norms to live a socially healthy life.

Within the epilepsy literature, five factors were commonly identified as threats to social health. These factors include stigma, social isolation, loss of employment, being labeled, and

poverty or low income (Admi & Shaham, 2007; Hosseini et al., 2013; Kerr, 2012). Other common topics that will be explored include disclosure and social support.

Despite the number of individuals living with epilepsy worldwide, there continues to be a lack of understanding and basic knowledge surrounding the disorder (Admi & Shaham, 2007; England, Austin, Beck, Escoffery, & Hesdorffer, 2014; Fernandes, Snape, Beran & Jacoby, 2011). Public education and awareness is imperative to repair the perception of epilepsy (England et al., 2014; Fernandes et al., 2011). England et al. (2014) reason that:

With the absence of accurate information, these misperceptions can flourish and reinforce beliefs and behaviors that foster stigma on personal, interpersonal, and societal levels. For full social inclusion of people with epilepsy to occur, the general public needs to have basic knowledge about epilepsy (p. 315).

The goal of public education in terms of epilepsy is to increase knowledge about epilepsy so that individuals will maintain a positive attitude and a sense of comfort while interacting with people who are living with epilepsy (England et al., 2014). These researchers suggest that public health educators play an essential role in the implementation of such awareness campaigns to decrease stigmatizing behaviours within communities and its institutions.

Stigma can be described as deeply discrediting, resulting in the stigmatized individual to be perceived as inhuman (Fiest, Birbeck, Jacoby, & Jette, 2014; Fernandes et al., 2011). Three types of stigma related to epilepsy are well demonstrated in the literature. The first type is “felt stigma”, which refers to feelings of shame and embarrassment by an individual living with epilepsy (Fiest et al., 2014). Viteva (2012) found that nearly half (43.6%) of people with drug-resistant epilepsy and six percent of well controlled people with epilepsy felt stigmatized because of their epilepsy. In a study of public attitudes towards epilepsy, one fifth of respondents agreed that people with epilepsy “have more personality problems than do others” (Jacoby, Gorry,

Gamble, & Baker, 2004, p. 1405). These public attitudes have a negative effect on patients' own perception of epilepsy and threaten their self-identity (Hosseini et al., 2013). These social labels are used to differentiate those with epilepsy from others. This separation can further lead to a disruption of normalcy, resulting in social isolation or rejection (Hosseini et al., 2013; Jacoby, Snape, & Baker, 2005).

Enacted stigma, the actual occurrence of being discriminated against, is the second type of stigma related to epilepsy (Fernandes et al., 2011). Enacted stigma is most commonly reported in terms of low employment rates. A study conducted in the United Kingdom found that 21% of employers reported that employing an individual who had epilepsy would be a major issue (Jacoby et al., 2005). The general public holds several misperceptions that contribute to the stigma associated with epilepsy (England et al., 2014; Fernandes et al., 2011; Fiest et al., 2014). People with epilepsy have been considered impure, mad, and violent, as having abnormal behaviour and as being contagious (Hosseini et al., 2013). In 2002, a survey distributed to high-school-aged adolescents found that 22% were unsure whether epilepsy was a contagious disorder (Austin, Shafer, & Deering, 2002). Another study found that 30% of the population surveys continue to consider epilepsy as a form of mental disease or insanity (Novotná & Rektor, 2002). Recently, a study was conducted on Twitter, a publically available website on which users post comments referred to as a *tweet*, that examined how individuals use the word "seizure" (McNeil, Brna, & Gordon, 2012). Findings indicated that over 40% of "seizure" tweets were metaphorical or ridicule/joke themed.

The final type of stigma related to epilepsy is "courtesy stigma". This term refers to stigma by association where individuals in social or physical proximity to an individual with epilepsy are also stigmatized (Jacoby, 1992). A study by Parfene, Stewart and King (2009) examined hypothetical employees who did not have epilepsy but were associated with a family

member with epilepsy (stigma by association). They found that employees who took a leave within the past year to care for a family member with epilepsy were more likely to experience discrimination in the workplace including, fewer rewards and greater likelihood of being fired even if their work performance was better or equally strong as other employees.

Several studies examined social isolation and rejection in relation to epilepsy and employment (Bishop, Berven, Hermann, & Chan, 2002; Kessler, Lane, Shahly, & Stang, 2012; Majkowska-Zwolińska, Jędrzejczak, Owczarek, 2012; Smith et al., 2009). Being employed is an important factor in “quality of life” and social health (Smeets et al., 2007). In addition to the economic gains, employment contributes to personal identity, social integration, and self-worth. Individuals living with epilepsy are almost five times more likely to report their employment status as ‘disabled’ and ‘unemployed’ compared to those without epilepsy (Kessler et al., 2012). Smith et al. (2009) also found that 54.9% of their study population were unemployed.

The relationship between unemployment and epilepsy is not new. Jacoby (1992) studied the effect on the ability of people with epilepsy to attain and maintain employment. These results showed that 32% of the participants felt that it was more difficult to get a job because of their epilepsy. It is not clear in the literature, however, whether unemployment stems from employer rejection or self-imposed rejection for fear of disclosure and discrimination. For example, a recent study found that three quarters of the general population felt comfortable working with a person with epilepsy and believed they should be a valued employee (Majkowska-Zwolińska et al., 2012). Despite this positive assertion, only 55% of participants disclosed their diagnosis with their co-workers and 64% disclosed to their employer. Participants felt the need to conceal their diagnosis for fear of being discriminated against or losing their job.

Rätty and Wilde-Larsson (2011) found that disclosing the diagnosis to others had positive effects on individuals living with epilepsy. Participants felt there was no need to fear seizures

once the diagnosis was disclosed to significant others, family, friends and co-workers. Social support can come from these various sources, however, individuals are careful when selecting who they choose to tell (Admi & Shaham, 2007). This decision about who to tell is based on the ability of the listener to be empathetic, and the ability to maintain an equal relationship to decrease the likelihood of discrimination (Admi & Shaham, 2007). Most individuals reported that their parents and siblings know about their diagnosis, however, disclosing to others (including employers and potential partners) involved personal thoughts and deliberations (Sample et al., 2006). Participants feared repercussions from employers and loss of relationships or discrimination from potential partners as a result of their epilepsy.

Other studies have found that seeking social support as a management strategy is used less frequently (Piazzini et al., 2007). Buelow (2001) found that some individuals living with epilepsy avoid social situations such as work and school as a coping mechanism. Respondents avoided social situations as a reactive technique to protect self in response to others. Participants described this as a “self-protective management strategy” (p. 265). Some individuals living with epilepsy choose not to engage in social support in an attempt to normalize their disorder and to be considered a person rather than an epileptic (Monzoni & Reuber, 2009; Rätty & Wilde-Larsson, 2011). Admi and Shaham (2007) found that actual life experiences influenced individuals with epilepsy to either disclose or conceal their diagnosis. Participants who had mostly positive experiences were more likely to freely disclose compared to those who have had negative experiences in their lives.

Emotional Health Dimension

Emotional health consists of feelings and moods (Hales & Lauzon, 2014). Emotions arise when people “engage in (or even think about) behaviour” (Friedman & Silver, 2007, p. 118). The

study of emotions and stress was examined by Richard Lazarus, a psychologist, who was an early pioneer in behavioural sciences (Lazarus, 1991). He identified four emotion categories including:

1. Emotions that result from loss, harm, or threats (e.g. fear, anger);
2. Emotions resulting from benefits (e.g. joy, delight);
3. Borderline emotions (e.g. hope, compassion); and
4. Complex emotions (e.g. love, grief) (Hales & Lauzon, 2014, p. 28).

Lazarus (1991), however, states that emotional lives are complex and multiple emotion categories are often experienced within the same situation.

The actions of an individual are greatly influenced by emotions (Räty, Soderfeldt, & Wilde-Larsson, 2007). These emotions can be accompanied by physiological and behavioural changes, therefore, the physical and emotional dimensions can be described as having a reciprocal relationship. According to Lazarus (1991), emotions are also a part of the coping process as a means to monitor change, stimuli and stress from the environment; “emotions express the personal significance of what the person experiences” (Räty et al., 2007, p. 390).

Further, emotions can be described as a motivating factor to take action for long-term management efforts. The most commonly reported topics within the emotional dimension include anxiety, fear, depression, and suicidal ideation in adults living with epilepsy.

Emotional distress including anxiety, fear, and despair, has many implications for individuals, especially those with epilepsy who live with seizure unpredictability. It is well documented that negative emotions are often correlated with higher levels of stress (de Souza & Salgado, 2006). A study examining anxiety in people with epilepsy found that over 46% of participants described epilepsy as a stressor leading to anxiety (de Souza & Salgado, 2006). This stress becomes increasingly problematic for individuals living with epilepsy who are at a higher risk for psychological distress such as depression and suicidal ideation (Sahar, 2012).

One qualitative study was found in the literature that describes the experiences of individuals living with epilepsy using emotions. (Räty et al., 2007). Half of the participants ($n = 47$) reported that epilepsy has a negative effect on their daily lives. The most commonly reported emotions included anxiety, despair and fear. These findings were similar across other quantitative studies that examined the prevalence of mood and anxiety in people with epilepsy (de Souza & Salgado, 2006; Räty, Larsson, Starrin, & Larsson, 2009; Sahar, 2012). Räty, Soderfeldt, and Wilde-Larsson (2007) found that individuals experienced anxiety in four ways. First, individuals expressed anxiety about having a seizure in public and being revealed as someone with epilepsy. This led to anxiety about the effects seizures would have on social factors such as friendships and work situations. Anxiety was also expressed in terms of possible negative side effects from antiepileptic medications. Finally, anxiety was described by women in terms of pregnancy and parenthood (Räty et al., 2007). Women thought that medications and epilepsy would harm the fetus and had anxiety about being a “good parent.” Participants in one study describe fear in terms of causing harm to themselves during a seizure as a result of being alone (de Souza & Salgado, 2006). The fear of stigma is also prevalent in the epilepsy literature (Hosseini et al., 2013). Social labels and stigmatization leads to fear of rejection and the loss of self-identity.

Depression is another prevalent psychiatric comorbidity in people with epilepsy that is described in the literature (Bautista & Erwin, 2013; Schulze-Bonhage & Kühn, 2008). In a Canadian population-based analysis, people with epilepsy have a 17.4% lifetime prevalence of a major depression compared to 10.7% in the general population (Tellez-Zenteno, Patten, Jetté, Williams, & Wiebe, 2007). Similarly, a survey conducted in the United States found that people with epilepsy were two and a half times more likely to have a major depression (Kobau, Gilliam, & Thurman, 2006). Loss of control that is characterized by the unpredictability of seizures is a major psychological factor that leads to depression (Schulze-Bonhage & Kühn, 2008).

Depression coexisting with epilepsy can not only decrease quality of life, but can also lead to poor seizure control and failure of medical treatment adherence (Bautista & Erwin, 2013).

Depression has been associated with the use of wishful-thinking (Räty et al., 2009; Upton & Thompson, 1992). Upton and Thompson (1992) found that individuals who utilize wishful thinking have higher levels of depression, lower self-esteem and more difficulty adjusting and accepting epilepsy in their daily lives.

Risk for suicide is an outcome of the previously described depression and anxiety. A large population study examining suicide cases, reported that individuals who have epilepsy are at a three times higher risk for suicide compared to the general population (Christensen, Vestergaard, Mortensen, Sidenius, & Agerbo, 2007). A recent meta-analysis that included 74 articles examined the standardized mortality ratio (SMR) of individuals with epilepsy. SMR is expressed as a percentage that quantifies the increase or decrease in mortality of the study cohort compared to the general population (Bell, Gaitatzis, Bell, Johnson, & Sandler, 2009). These researchers found the SMR to be 3.3 (95% CI: 2.8 – 3.7). A smaller review conducted in the United States found that approximately 12% of people with epilepsy are at a high risk of suicide compared with less than one and a half percent in the general population (Jones, Butler, Thomas, Pevelar, & Prevett, 2006).

Spiritual Health Dimension

Hales and Lauzon (2014) define spiritual health as “our ability to identify our basic purpose in life and to experience the fulfillment of achieving our full potential” (p. 29). Spiritual health includes:

1. A belief in what some call a higher power, in someone or something that transcends the boundaries of self;
2. A strong sense of values, morals, and ethics;

3. Recognizing individuality and self-worth;
4. A deep understanding of the interconnectedness of humans with each other and with nature; and
5. Sharing the virtues of hope, faith, and forgiveness (Hales & Lauzon, 2014, p. 29).

Ross (1995) argues that spiritual integrity is a basic human necessity. A spiritually healthy individual may or may not follow a specific religion. Spirituality is a “human propensity to search for significance in life by way of concepts that transcend the tangible and transmit vitality and significance to events in life” (Tedrus, Fonseca, De Pietro, & Mendes, 2013, p. 386).

Spirituality supports positive reinterpretation of disease, enhances collaboration of treatment, and helps an individual adjust to illness (Giovagnoli, Meneses, & de Silva, 2006). Spirituality will be examined in terms of spiritual connectedness and how this impacts the healing and recovery processes influencing health outcomes in adults living with epilepsy.

Very few studies have focused on spirituality as an independent dimension in people living with epilepsy. Most studies dealing with spirituality include the use of spiritual healing (i.e. complementary therapies), relationships between seizures and mystical states, and the personality of patients in terms of religiosity and personal destiny (Giovagnoli et al., 2006). Only two studies were located that focus specifically on the spiritual dimension of adults living with epilepsy (Giovagnoli et al., 2006; Tedrus et al., 2013). Both studies demonstrate the importance of the spiritual dimension in individuals living with epilepsy.

Researchers in Italy examined the role of spirituality of 32 adults with epilepsy and found that the use of awe and transcendence along with other spiritual facets including spiritual connectedness, meaning and purpose in life, faith, death and dying, hope and optimism, and inner peace all were significantly correlated with quality of life total scores (Giovagnoli et al., 2006). The researchers encourage the reconceptualization of quality of life to include individual

spirituality and its role in patient identity. Similar results were found in a larger study that examined the correlation between spirituality and quality of life in adults living with epilepsy (Tedrus et al., 2013). These authors examined the role of spirituality in 110 adults with epilepsy and found that adults typically utilize positive spiritual coping methods leading to an increased quality of life. Researchers from both studies indicated the need for future studies examining spirituality in adults living with epilepsy.

Hope is one aspect of spirituality that has been studied more frequently within the epilepsy literature. Elliot, Lach, and Smith (2005) found that individuals with epilepsy utilized a sense of hopefulness in the pursuit of a “normal” life. They support the use of hope to strive towards an idealized state of normalcy as it creates a positive process to reach wellness. Hope was most commonly described as it relates to a decrease in seizure frequency or to reach seizure freedom in the future (Ismail, Wright, Rhodes, & Small, 2005; Rätty et al., 2009). The belief for a better, more controlled future, is fueled by hope (Hofgren, Chaplin, Norlin-Bagge, Carlsson, & Malmgren, 1998).

Summary

Adults living with epilepsy face unique challenges within each health dimension (physical, social, spiritual, and emotional). These health dimensions are not independent of each other, but are interrelated and integrated into the lives of adults with epilepsy. Each dimension relates to one another and influences the perceptions of living with epilepsy. The physical dimension includes the diagnosis, treatment and medical aspects of epilepsy. Individuals experience unpredictability and loss of control as a result of their seizures. Control is sought through use of medication and/or surgical interventions. The second health dimension described is the social dimension. It is evident that the social dimension is a complex network of factors that can impact the lives of people with epilepsy. Social labelling, exclusion and social isolation

can all contribute to and are a result of the stigma that is embedded within this dimension (Kerr, 2012). Next, the emotional dimension reports emotions as a direct result of epilepsy; these include anxiety, despair and fear. These emotions increase the risk for depression and suicidal ideation. The final health dimension, the spiritual dimension, is less understood within the epilepsy literature; however, recent studies have determined that spirituality is important for the reconceptualization of quality of life and personal identity (Tedrus et al., 2013). It is evident in the literature that epilepsy is a multifaceted disorder that affects all aspects of life. Gaining knowledge and understanding of how adults with epilepsy describe their lived experiences could assist the nursing community to address the needs of patients and improve care.

Chapter 3: Research Design and Methodology

Introduction

According to Thorne (2013) generating nursing knowledge is not “to control, or to claim truths” (p.296), but to inform professional practice through understanding unique cases of health and illness experiences. To this end, her model of research praxis includes ‘directionality’ to guide the researcher in making sense of patterns given the context of human variation (Thorne, 2013). This chapter outlines interpretive description as an approach to ascertain individuals’ perspectives of living with epilepsy.

Methodology

The purpose of this qualitative study was to explore and describe the lived experiences and perceptions of adults with epilepsy. Qualitative research originates from the social sciences as a method to study human phenomenon that cannot be otherwise quantified, specifically when interpretation and human subjectivity are involved (Thorne, 2013). The interest in a qualitative research approach in nursing is suitable when the research aim is to “grasp and sense the lived experience of their clients, to enter into the life world that these people inhabit, and to understand the basic social processes that illuminate human health and illness events” (Thorne, 1997b, p. 288).

Popularized qualitative methods, such as phenomenology, grounded theory, and ethnography, are borrowed from other social sciences and do not always align with nursing’s unique domain of inquiry, therefore, a new method was developed (Thorne, Kirkham, & MacDonald-Emes, 1997a). Thorne, Kirkham, and MacDonald-Emes (1997a) developed a noncategorical methodological approach known as interpretive description. Interpretive description is a type of qualitative approach specific for the discipline of nursing and is presented as a way to respond to the needs of nurses to inform clinical practice (Thorne, 2008). Interpretive

description has two main objectives: (1) to describe and explore meaning of events or experiences; and (2) to place analysis in the clinical setting. Qualitative research methodologies align with particular paradigms including ontology, epistemology and methodology understandings of inquiry to guide actions. As a logic model, interpretive description is influenced by the naturalistic, constructed and contextual elements of human experience. That is, its philosophical underpinnings include: (1) multiple, complex, subjective realities that only can be examined holistically; (2) a priori theory is not available to capture the multiple realm that is likely to be encountered; and (3) the knower and known are inseparable. (Thorne, Kirkham, and O'Flynn-Magee, 2004).

Interpretive description acknowledges the construct and context of health-illness experience and allows for shared realities (Thorne et al., 1997b). Thorne, Kirkham, and O'Flynn-Magee (2004) further describe this as a relationship where, “the inquirer and the ‘object’ of inquiry interact to influence on another; indeed, the knower and known are inseparable” (p. 5). From a disciplinary perspective, nursing does not stop at the simple telling of a phenomenon, but is always drawn toward the “so what?” Thorne’s (2008) interpretive description design will be used to make sense of patterns and variations in the experiences, beliefs, attitudes and opinions of persons with epilepsy. This understanding will guide nurses’ capacity to couch “epilepsy” within the realm of being human.

Interpretive description has been used by nurse researchers from diverse specialties to study multiple human health experiences across the lifespan. For example, Duggleby, Bally, Cooper, Thomas-MacLean, and Doell (2012) used this approach to examine experiences of male spouses of women with breast cancer. These authors rationalized that this approach was the most suitable approach because it “values the perspective of those living with the experience and acknowledges the constructed contextual nature of the human experience” (p. 401). Further, the researchers

were hopeful that using an interpretive description approach would generate practice relevant findings for nursing science. Although there are recent qualitative studies involving children, adult, and family experiences of living with epilepsy (Thompson, Kerr, Glynn & Linehan, 2014; Tonberg, Harderg, McLellan, Chin & Duncan, 2015), none of the identified studies used interpretive description.

Setting

The location of this study was two neurology clinics located in two Northeastern Ontario communities. In the community with a population of nearly 160,000 there is one clinic servicing an estimated 20 adults. In the second community of less than 45,000 residents, there is a regularly scheduled clinic with a visiting neurologist for approximately 80 adults with epilepsy. The geographical location of each clinic offered a context not specifically addressed in the reviewed evidence. The service's location was important given its potential influence on unique features of individual cases (Thorne, 2013). Travel to the smaller community was not without risk as the main access road is a narrow two-lane highway; a former logging truck road. It is well documented that the health needs and available resources for individuals living in smaller and rural environments differ greatly from those living in densely populated urban settings (Butow et al., 2012). Difficulties in accessing health services increase the risk for health disparities for those with epilepsy.

Sampling

The population of interest were adults diagnosed with epilepsy who accessed the services of the two clinics. The sample method was purposive; the identification of 'key informants' who willingly describe and explain what is happening and why it is happening (Thorne, 2008). Purposive sampling, an information-orientated method, was appropriate for this study given its orientation to reveal patterns from the insights of individuals with day-to-day with epilepsy. With

purposive sampling, a response to the posed question is possible based on a “virtue of some angle of the experience that they might help us better understand” (Thorne, 2008, p. 90).

Interpretive description does not imposed a set sample size. Rather, Thorne (2008) suggests that sample size is dependent on the nature of the study phenomenon and the state of the science (Thorne, 2013; 2008). At the beginning of the project, to solicit multiple and diverse perspectives, the projected sample size was at least 15 individuals with epilepsy. The resultant sample size, however, was nine individuals. As a result, the level of theoretical development may be limited yet appropriate to begin the work of understanding a novel nursing practice situation (Thorne, 2013). Sample inclusion criteria included adults: (1) over the age of 18; (2) self-identified as receiving a diagnosis of epilepsy in at least the past year; (3) English-speaking and able to read English; (4) receiving services at one of the two northern clinics for at least one year; and (5) willing to provide informed consent. The exclusion criterion was an adult who had drug- or alcohol-induced seizures. The socio-demographic profile of the sample is presented in Table 1. This information was extracted from their narrative accounts of living with epilepsy.

Adults living with epilepsy are described as a “hidden” population (Admi & Shaham, 2007). Therefore, to assist with recruitment, I sought the support of a clinic’s service provider during the conduction of the study. The service providers perceived that clients would be interested in such an initiative especially since they were aware of some who have lived with epilepsy most of their adult lives. In one clinic, the health provider was willing to draw attention to the study recruitment poster (Appendix A) in the office. In the other clinic, the health provider offered to contact a few individuals who met the inclusion criteria to introduce the study.

Table 1 - Participant Profiles

Participant	Age	Seizure Type	Profile
John	40-50 years	TC	John was diagnosed during his childhood and has been seizure free for almost 30 years. During this time he has been married with four children. He has had a positive attitude during his remission and feels an overwhelming sense of need to support and encourage other people who might be struggling with epilepsy.
Jake	40-50 years	TC, PC	Jake was diagnosed during childhood due to an illness. He sometimes experiences daily seizures and keeps a seizure diary to track his events. He is married with one child. Though he describes himself as having an extreme level of epilepsy, he remains positive in his day-to-day life. He is very vocal about his disorder.
Tom	40-50 years	TC, PC	Tom was diagnosed at a young age due to an accident. He experiences multiple seizures daily and is a regular visitor to the emergency department. He lives alone and struggles to integrate epilepsy in his day-to-day life.
Doug	30-40 years	TC, PC	Doug was diagnosed at a young age and has been seizure free for almost four years. He is married and a father of two young children. He is frustrated with his lack of employment and does not like to stay home alone.
Claire	>50 years	PC	Claire was diagnosed in her adult years. She has been seizure free for two years. She is divorced and a mother of three adult children. She is a private individual who does not want everyone to know about her disorder. She regrets not returning to school.
Beth	<30 years	TC	Beth was diagnosed at a young age. She experiences monthly seizures but strives for independence. She is a University student.
Ellie	>50 years	PC	Ellie was diagnosed in her adult years and experiences daily seizures. She is married and has two adult children who live in another city. Loss was a concept embedded throughout her story.
William	<30 years	Nocturnal	William was diagnosed later in life due to an accident. He continues to experience monthly seizures during the night. He has two children who do not reside with him. He is determined to take control of his epilepsy and return to work.
Carlos	30-40 years	TC	Carlos was diagnosed later in life due to an accident. He had been seizure free a couple of years. He lives with his mother. He is passionate about his work and is careful when integrating epilepsy into his routine.

TC = Tonic-clonic seizures; PC = Partial Complex seizures

Data Collection Methods

Data was collected during the months of June 2014 to November 2014. Participants interested in the study contacted myself or gave permission to the service provider for me to contact them directly. The initial contact consisted of four objectives: (1) to introduce myself as the researcher; (2) to explain the purpose of the study; (3) to explain the participant's role in the study; and (4) answer any questions. Of the 10 initial contacts, nine were willing to participate in data collection.

Interpretive description has no limits on the type of data sources that may be used to address the research question (Thorne, 2013). The guiding principle is using methods that will facilitate understanding human health experiences for shaping professional practices (Thorne, 2013). The three data collection methods used in this study were: (1) semi-structured interviews; (2) unstructured research journaling; and (c) documentation offered by participant.

Semi-structured interviews

Semi-structured interviews involved the implementation of guide questions (Appendix B) in a flexible manner to promote participants' sharing of their account (DiCicco-Bloom & Crabtree, 2006). With flexibility, there is an increased likelihood that the participant engages as an 'informant' rather than a 'respondent'. (Richards & Morse, 2007). As informants, participants' contributed insights that were not apparent in my review of the evidence. The flexible structure allows the researcher to be guided by experts, to delve into the personal and social matters described by the participant (DiCicco-Bloom & Crabtree, 2006).

Each participant engaged in one initial, audio-recorded interview of 60 minutes. Prior to initiating the interview, I engaged participants in social conversation. Often participants were curious about my interest in this particular topic and northern Ontario. This type of inquiry was not unexpected. As insiders, they may have been respectfully inquiring about my position to the

topic. Once the participant expressed they were ready to begin, the audio-recorder was turned on. The interviews were conducted at the location of the participants' choice. Often, this included a local coffee shop in each of the two communities. The duration of the initial interviews ranged from 30 to less than 90 minutes.

All but one participant were willing to have a second 30 minute interview to assist me in comprehending their stories. Thorne (2013) recommends repeat interviews to inform evolving interpretations through increasing the depth of clarifying questioning. Four participants were interviewed a second time. Participants re-consented prior to commencing the interview. The second interview allowed the participants to follow up on stories and clarify their ideas from the first interview. A list of common themes that were embedded into each initial story was presented during the second interview (See appendix C). These themes were grouped into two categories: (a) things that help manage epilepsy, and (b) things that do not help manage epilepsy. Each participant was given time to reflect on the two grouped themes prior to commencing the audio-recorder. Once the participant expressed their readiness to begin, the audio-recorder was started. Participants began the interview by agreeing and/or refuting the themes that were extracted from the first interviews. An interview guide (See appendix C) was used in addition to the list of common themes to promote further discussion. The interview location was chosen by the participant. Two participants chose to meet at the original meeting location from the first interview. The other two participants were not able to meet in person and instead completed the interview via telephone.

Unstructured research journaling

Unstructured journaling was used throughout the duration of the research process. Journaling consisted of observations or conversations that were taking during the interview that

can yield useful information during data analysis (Thorne, 2013). Excerpts from my journaling are presented below:

Participant arrived eager to begin interview even before I again explained the purpose of the study. He described himself as open and wanting to tell his story to everyone. He was enthusiastic to show me his binder of medical documentations. His organization of records was apparent. He often paused during the interview and lost his spot in conversation. He blamed his bad memory.

Documentation

Documentation authored by participants was the third data collection method. Previous evidence shows that some individuals living with epilepsy may use documents such as bibliographic materials, images, and personal record of seizure events as a coping tool; therefore, it was important to include this data source (Schulze-Bonhage & Kühn, 2008). Further, such documents may uncover experiential health phenomena not explicit during interviews (Thorne, 2008). One participant shared documentation directly related to his lived experience. Documents that were included were seizure diary excerpts (See appendix D), an autobiography draft, and seizure mappings (See appendix E).

Data Analysis

Within 24 hours of an interview, data was transcribed verbatim by myself to record and represent nuances and gestures. Undertaking verbatim transcription increased my familiarity with and “hearing” of the data. Transcribing one’s own data also allows the researcher to become familiar with the data and knowing each case intimately (Thorne, 2008). Transcripts were printed and read through.

Research questions using an interpretive description design “draw meaning from interpretation among and between patient accounts and allow for both pattern recognition and

variance detection throughout the research process” (Thorne, 2013, p. 298). This analysis approach allows the mind of the researcher to “ponder, challenge, chew on, wrestle with and massage pieces of data until they can be formed into parts that seem individually and collectively to tell us something we did not know previously” (Thorne, 2013, p. 301). Table 2 illustrates the steps that were used during the data analytic process.

Table 2 - Data Analysis Steps

Steps	Application
Data preparation	Data was obtained from each participant and transcribed verbatim.
Reacting to data	Re-read transcription and used highlighting to get a feel of the initial data and hunches.
Dividing the data	I extracted main ideas and topics from each individual transcript and inserted these into an Excel spreadsheet to help me see the overall picture of “what is happening?”
Comparing the data	I searched for similar words across all other transcripts. Then I inserted those main topics into an Excel spreadsheet to easily compare and contrast.
Generation of Categories	Once I integrated all nine participant interviews into my excel sheet, I began to break down the main ideas and code in Microsoft Word. Unstructured journal excerpts were also included. Initially I had over 50 codes. I printed all coding from each transcript to analyse individually. Emerging categories were constantly compared in relation to others during this stage of analysis.
Grouping the data	The initial categories and codes were then grouped thematically. For example, terms such as feeling “alone”, “worry”, “unhappy”, and “anxiety” made up the theme of “stressors”.
Refining the data	In consultation with my committee members, the initial patterns were refined and provided the framework for the second interviews with select participants.
Integrating additional data	The final transcripts, including second interviews, were analysed following the previously described steps.
Abstracting the data	All data was abstracted in an attempt to represent the description and interpretation of a pattern. In consultation with my committee members, we employed diagrams, figures, and narratives to make sense of and depict the phenomenon.

Within the next few days transcripts were re-read and audio-recordings were heard to ensure accuracy and expose anything that may have been missed during the initial transcribing. A written analysis was then conducted which included jotting down marginal memos and highlighting in colour preliminary hunches in terms of potential themes. Large sections of texts were analysed rather than smaller phrases and words to generate an overall picture of “what is happening” (Thorne, Kirkham, & MacDonald-Emes, 1997a, p. 174). Probing questions such as “‘what is happening here?’ and ‘what am I learning about this?’ will typically stimulate more coherent analytic frameworks for interpretive description” (Thorne et al., 1997a, p. 174).

Thorne, Kirkham, and O’Flynn-Magee (2004) state that during the earliest coding process breadth is more useful to examine and re-examine data for a range of alternatives. Thus, groups of data with similar characteristics (i.e. ideas of supports) were examined in the earliest organizing process. These groups were input into an Excel spreadsheet as headings with supporting sections of transcripts below. As more data became available, these groups continuously evolved and shifted with new underlying ideas. Often, data was grouped into more than one group. Data searches were then completed within each group to generate common ideas and patterns. For example, terms such as feeling “alone”, “worry”, “unhappy”, and “anxiety” can make up the idea of “stressors”. As these ideas began to take shape, relationships were tested through reflection. Thorne (2008) supports testing relationships through a reflective step by asking questions such as, “What pieces of the puzzle am I beginning to see?” and “What do they tell me about the puzzle as a whole?” (p. 160). Identifying data, grouping them into patterns, and “considering relationships between the pieces and patterns are all aspects of the complex inductive reasoning process through which you move closer to something that could constitute findings” (Thorne, 2008, p. 163). These relationships that emerged were used to help interpret the findings.

Rigor

Issues of rigor and credibility were considered in the creation of this interpretive description study. According to Thorne (2004), credibility of interpretive description findings move beyond the trustworthiness and transferability of data. Rather, the credibility of findings are as a result of the analytic decisions that are presented within the “larger picture” (p. 15). Thorne describes four evaluative criteria that are applied to enhance credibility in interpretive description studies (Thorne, 2008). These include epistemological integrity, representative credibility, analytic logic, and interpretive authority. Each criterion will be further examined below.

Epistemological integrity

Epistemological integrity is the demonstration of a defensible line of reasoning “from the assumptions made about the nature of knowledge through to the methodological rules by which decisions about the research process are explained” (Thorne, 2008, p. 224). In other words, the research question must be consistent with the epistemological approach and interpretation strategies. In interpretive description studies, the research question should not only describe a phenomenon of interest but should also interpret the phenomenon. Associations, patterns, and relationships are often terms used to interpret the phenomenon. The research question for this study was: What are the common ways in which adults describe their experiences of living with epilepsy? The question is in alignment with an interpretive description design due to my interpretation of the phenomenon in terms of common patterns across the experiences to inform clinical practice. As previously stated, this interpretive description study used inductive reasoning to uncover socially constructed patterns in terms of living with epilepsy. As a result, my decisional strategies throughout the interpretation was informed by this epistemological standpoint. Using inductive reasoning, I focused on making sense of the daily life of adults living with epilepsy to develop patterns in the experiences.

One individual experienced a seizure during the first and second interview. Another participant experienced a seizure during the second interview. Seizures appeared to be complex absent seizures in nature lasting from approximately five seconds to up to two minutes. During this time, the audio-recorder was paused. Once the participant regained control, I expressed my concern and asked them if they would like to postpone the interview until a later date. Both of them explained that this was “normal” and were willing to continue the interview to completion. To witness their seizures and immediate recovery was an unexpected source of experiential knowledge.

Representative credibility

Representative credibility is the demonstration that the theoretical phenomenon claims of a study are consistent with the study sample (Thorne, 2008). The phenomenon of interest for this study is living with epilepsy. The study participants were adults diagnosed with epilepsy who had experiential knowledge about their condition. Therefore, the sample is representative of living with epilepsy.

Analytic logic

Analytic logic is an indication that the researcher followed an inductive manner for the analysis of the data (Thorne, 2008). An audit trail of the themes and categories is a principle used to ensure analytic logic is maintained. An audit trail allows for an outside researcher to follow the reasoning pathway. For this study, comments in my reflective journal guided the study in terms of generating themes and patterns in the data that were inductively analyzed to interpret living with epilepsy.

Interpretive authority

Interpretive authority assures that the researcher was not biased in the interpretation and analysis of the data (Thorne, 2008). For this study, bias was reduced by maintaining a journal of

how I developed thoughts and analysis of the data. Another way in which authority was enhanced was by the presentation of interpretations with the participants in a follow up interview. Overall themes that emerged from the data and my journal were summarized and shared with the participants. The purpose of this check was to clarify data pertaining to further interpretations without imposing bias.

Ethical Considerations

Ethical issues were carefully considered in the planning and implementation of this study. Written informed consent was obtained from the participants before each interview began (See appendix F). Participants were assured that they would remain anonymous and all data collected was confidential information. Pseudonyms were used for each participant during the interview, in transcription data and all written reports of the study. Approval was received from the Laurentian University Research Ethics Board (REB) to conduct this study. Ethical approval from each clinic was also obtained.

Prior to initiating the first interview, the researcher also provided a study information sheet to each participant (See appendix G). The study information outlined the purpose of the study, tasks involved and the benefits and risks of the study. The participants were assured that they would remain anonymous throughout the duration of the study and that participation in the study was completely voluntary. They were informed that they could withdraw from the study at any time or refuse to answer any questions without penalty. The main risk to participants in this study was the possibility of emotional distress due to the sensitive topics covered during the interviews, therefore, strategies were developed in the event that a participant showed signs of distress. These strategies included:

1. Validate their experience;

2. Remind the participant of their right to not divulge information if not comfortable and to withdraw from the study without penalty;
3. Offer the participant the option of terminating the interview;
4. If requested, reschedule the interview; and
5. If necessary, in consultation with participant, facilitate contact with his/her primary health care provider.

Chapter 4: Findings

Introduction

In this chapter the findings are presented and described with supporting participant data. Participants described living with epilepsy as a temporal journey accompanied by others who knew of their past and present experiences, and future aspirations. In each of the three stages, participants described involvement of trustworthy others whose presence supported their safety and well-being. Participants' description of their past experiences included their epilepsy diagnosis and associated losses. In the present, participants described daily and purposeful actions undertaken to create well-being. In addition, their lives in the present were influenced by the underlying threat of seizure occurrence. Within the present, participants sustained their day-to-day actions for well-being in the hope of achieving enhanced future well-being – their life vision. Collectively the three phases of living with epilepsy are succinctly stated by a participant: “You don't come out, you don't go through all of this and come out the other end and not be different.”

The findings will be presented relative to each of the three identified stages of life with epilepsy. These stages are not discrete entities that were experienced exclusively in a unidirectional manner. Rather, participants described how they simultaneously thought about their past, lived in their present, and thought about their future. Reflecting upon past experiences assisted participants to make meaning of their current lives and hold on to hope for the future. As one participant explained:

I started taking some new medication and it seemed to really help me out a lot to decrease my seizures. Then all of sudden, I had a few very bad seizures that set me back quite a bit...I hope the new dosage will work.

Past

Participants clarified that their present and future experience were influenced by their past. The past comprised of the onset of their epilepsy and the resulting losses. Five participants, who lived with epilepsy since childhood, were able to recount specific details of the circumstances that precipitated the onset of both their diagnosis and their losses. The presence of epilepsy was “all of a sudden,” “unexpected,” a source of “frantic confusion,” and “a life changing” event. Four participants, who were diagnosed with epilepsy as adults, described its onset as “unbelievable” and “overwhelming”. As one participant stated:

When it was first explained to me I thought I was being diagnosed with cancer. That’s what it felt like, I guess. I thought it was the end of my world. Like I have this disease and everything’s going to come to an end.

Most participants identified a specific precursor to their diagnosis. These were identified as the presence of a tumour, a head injury, or “blood poisoning throughout my whole body.” The identification of the precipitating factor for epilepsy seemed particularly relevant in forming an understanding of the implications, including the presence of seizures and loss. The inability to contextualize “being told you are an epileptic” generated initial and lingering distress. For example:

I’m still sitting here less than 10 years from the date of diagnosis. My family doctor told me. I really don’t even have a complete clue about what’s really wrong with me. It’s a long struggle.

For some, the initial manifestation of their illness symptoms was ambiguous. One participant explained:

I first started having numb tingly feelings and nobody really, even the doctor didn't call it seizures. The doctor started doing more of a work up ... I saw a neurologist who said, 'Those numb tingly sensations are seizures.'

Following the diagnosis, participants described multiple losses in terms of developmental opportunities. Their sense of self became fractured by the presence of symptoms. Epilepsy was described as "loss, loss, loss ... loss of me." Early memories of daily and milestone events such as birthdays or family celebrations were "washed away." Many participants described the aspects of their life were "pretty much gone from memory." Therefore, participants relied on others to "fill in the blanks" as their memories were "erased".

When recounting their past, participants described how their career aspirations became unattainable following the diagnosis of epilepsy. For those individuals this was a substantive loss of their planned self-identity. As several participants stated: "I wanted to be a [profession] ... because of the seizures ... it was a loss of me"; "I used to have high hopes of being a doctor"; "I wanted to be a mechanic"; and "I lost my job. ... I could hear a person talking to me, but I couldn't answer. After I went home, I was informed that the employer had to give me extended time off."

In the past, the participants' unfamiliarity with epilepsy was described as a loss of control over one's body. In illness, they perceived themselves as powerless; "when a seizure hits, you are totally at its mercy." The potential risk of becoming unconscious "at anytime and anywhere" made it necessary to adopt a lifestyle that optimized the involvement of a trusted individual who was available to witness and intervene during a seizure event. When accompanied by a significant other, there was a perception that their safety needs would be met. After receiving the diagnosis, one participant explained that:

... my mother held onto me with such a grip. She wouldn't let me out of the house alone.

She watched like a hawk.

Being “forced” to rely on others became a type of surrogate self-control. Genuine self-control was not possible during a seizure. In order to re-establish control, participants relied on their companions' actions during the seizure and account of the event. Such information lessened the distress of seizure induced loss of control. A participant recalled:

One day as I got onto the bus I had a seizure. I was not aware that I was having the seizure. I did not know what I was doing at all. I, however, was quite fortunate that I had a friend with me at that time. He knew about my seizures. After I got home, about 10 to 15 minutes later, I had come out of my seizure and my friend told me what all had taken place.

To lessen the risk of seizures, participants' lives became highly structured. Trusted others, often family members, regularly assessed the participants' vulnerabilities and need for necessary accommodations relative to their day-to-day expectations and activities, such as participating in education, employment, and leisure activities. “Everything required planning ahead.” The freedom to “live in the moment,” to engage or pursue interests became restricted. For example:

I used to take 10 pills at a time. When you have to take this much medication it was hard to take them in front of people or in certain places ... I missed a lot of opportunities.

Planning involved strategic inclusion of reliable others. In some circumstances, this was not always possible. In the past, participants shared stories about being avoided by “fearful” others, including friends, upon whom they could not depend to be present in case they had a seizure. For example, “when I was younger, my friends doodled off because they were kind of nervous of me seizing so often. Everyone would be kind of nervous about an epileptic seizing so many times a day”; and “I was not able to do much on my own in school so other students did not

want to be friends with me.” For many, the practices to ensure safety were best implemented by vigilant family members. This contributed to a limited social network. Relationships with others outside their familial circle often diminished, especially when stigmatized as “a freak.”

Several participants shared experiences of losing their right to drive and retain or obtain their desired employment. Unable to secure these resources for independence “imposed” an increased reliance on family members for more than physical safety. In such circumstances, they depended upon family for transportation and supplementary income. One participant described the removal of a license as “taking candy from a child.” In the rural context of this study, public transit was not readily available. Without a driver’s licence, the constant “reliance on others” to simply “get around” caused frustration. In the past, the intrusiveness and unpredictability of epilepsy required modifications to how they once lived their lives.

Present

The second stage, labeled the present, involved maintaining a balance between threats to and actions for well-being. With the passage of time and new experiences, however, participants became knowledgeable about how to manage their environment and adopted actions to mediate seizure risks. Two participants continued to experience daily seizures while others reported less than 10 per month (Appendix E). The primary threat was specific to the unpredictability of a seizure event. A seizure had the potential to disrupt their acts of well-being. These acts included developing a mind-set, protecting self, and securing belonging outside their immediate family. In the present, participants described a cyclical dynamic between threats and actions, harm and harm reduction, to create well-being.

Threats to Well-Being

Seizure unpredictability was characterised by four elements: severity, timing, location, and impact to well-being. Each participant had experienced a range of seizure severity and some

were cognizant of the possibility of the impending seizure being more dangerous than the last. As one participant explains:

...there is always the change that a simple partial seizure can progress into a more complex seizure. That is the danger. At any time it can decide to turn into a grand mal or something more complex.

The timing of their seizures was “not regular” and “sporadic.” In an instant, a seizure could induce a significant change in health status. As described by one participant, “one minute I’m watching a movie. The next minute I’m in the back of an ambulance.”

Seizures were also not situation-specific. They could occur “anywhere”: home, yard, sidewalk, street, restaurants or stores. The potential harm is dependent on both the timing and location of a seizure event. For example, “I’m sometimes found on the ground having convulsions”; “I could be walking across four lanes of traffic”; and “because I have so many seizures a day, well loss of consciousness, I almost died. I almost became wheelchair bound.”

Not knowing when, where or the potential severity of a seizure event was worrisome for participants. The passage of time between seizures was spent “thinking to myself when my next seizure will be, wonder when it happens, where’s it’s going to be”. This anticipated worry was particularly heightened when they were unaccompanied:

When I’m alone I am most scared because I think ‘what if I have a seizure? What if my [family member] comes home and finds me on the floor bleeding? Being on my own is a scary thing.

To counter this worry, participants engaged in daily threat reducing behaviours and actions in partnership with others. These actions include developing a “mind-set”, protecting self, and securing belonging.

Developing a ‘mind-set’

In the present, participants described their ‘mind-set,’ a cognitive disposition to engage in a meaningful existence. This positive outlook evolved as a means to cope with the unpredictability of seizure events. This strategy was supported by close family and friends. In the company of others it was “easier to think positively”. For some participants, a positive ‘mind-set’ was developed among others:

My family, they’ve done and some others, kept me thinking positive. It’s a 50-50 balance.

The wonderful [family member] keeps my positive attitude going, she is quite inspirational.

Too much negative thinking produced inner stress and increased the risk of a seizure event:

The more seizures I have will be caused by stress.

I find it I’m stressed, then my seizure frequency does go up

Participants’ current perception of epilepsy was that it was not a disability. They believed that being disabled refers to persons with physical limitations. As participants clarified:

...in my view, people who have lost their sight, lost their hearing, or who are missing a limb are disabled.

...when your legs stop working ... being in a wheelchair... that is a disability. I am walking, physically I am fine.

There is a residence for people with wheelchairs in my town. I see them driving. I can’t drive, but I think, oh well, I am walking to the bus stop. It could be worse.

Protecting self

Participants engaged in harm-reduction practices to protect themselves from seizures. In the present, they were cognizant of seizure triggers and threat-reducing lifestyles. Their overall

goal was to adopt a “normal” or “regular” lifestyle in a purposeful manner. “You can have a life even if you have seizures”; a testament to their courage. For one participant:

It is difficult to go through my daily routine with always having seizures, but it’s still possible. I try to keep a schedule of what I plan for each day and try to do it. I don’t say I am going to do it and then say, ‘Oh, maybe tomorrow.’ I actually make sure I do it ... this makes me feel better and makes my day more productive.

Participants were mindful of sources of stress, therefore, purposefully minimized their exposure to seizure triggers such as non-negotiated medication changes, lack of sleep and relaxation, use of alcohol, and environmental hazards. Common identified environmental stressors that participants strategically avoided were noise and lights. This was illustrated by two participants:

I do not want epilepsy to stop me from doing anything. I know there are places, however, that do not accommodate to me so why go there? I do not need to be there. There are other places. There are other things to do.

Being driven at night is a challenge. I have to make sure that I do not look outside because lights even headlights and brake lights may be too bright in the dark.

Another form of stress was if a health provider, “did not listen.” Participants feared that this would cause a potential impending seizure event. Therefore, participants involved themselves in a range of enjoyable leisure activities to reduce stress as they focused their attention and energy:

It gives me something to focus on. I can relax doing it. I don’t have to worry about being, like, I don’t have to be stressed out that it has to be done right away or anything it’s just, well, it’s like any other hobby, if you’re doing it, a hobby, it’s supposed to be fun, something that you enjoy, not stress you out.

Protecting self was facilitated through creation of a social system. Trustworthy others, immediate family, individual and group peer support, positively influenced their desires to move beyond self to inclusion in their identified community.

Securing belonging

In the present, the influence of significant others, not the diagnosis of epilepsy, impacted capacity to live a well life. Participants encountered others who believed that the diagnosis inferred that they were “unable to do anything” or “needed to be overprotected.” In such circumstances, others did not understand their abilities. Participants clarified that like others, they had “bad days” and this was not a symptom of epilepsy. Rather, it was an aspect “of living your life.” The participants’ immediate and extended family network continued to be a reliable source of support (Appendix D). Participants realized that they had a role to “stay well.” As a valued member of the family, a participant shared:

If it wasn’t for my children, I do not know if I would be involved really. They make me keep going and so I must always be there for them. This is probably the best way to explain it. Honestly.

In order to “live life well”, participants stressed the importance of securing social supports. Outside of their family, participants spoke positively of long-standing friendships that were initiated prior to and after their diagnosis. Friendships affirmed their self-worth, self-confidence, and sense of belonging. One participant clarified:

My friend is one of the people that got me to where I’m at today because I had someone to cling onto, as a friend. Not as a parent, as a friend. He had a tremendous effect on my self-esteem because I was not alone. I had someone to be talking to as a friend versus a parent.

Their friends were accepting, available “to do things together,” and “know what is going on” so that if necessary, they can intervene during a seizure. The presence of significant others countered the potential threat. One participant explained:

I think everyone with epilepsy should have a few friends that know what’s going on because if you don’t have friends and have a seizure ... nobody is there to call an ambulance or bring you to the hospital.

Being with others who were also living with epilepsy promoted their belonging.

Some participants had attended peer support groups, a resource that allowed them to share their struggles, successes, and expertise. “Being in the same boat” lessened their sense of isolation, their belief that “I was the only one” in relation to an experience. As one participant clarified:

If you’re going through something and someone else is going through it, you have a sense of ‘wow I can share this with this person.’ I can honestly open up because they know what I’m talking about versus just another person sort of looking at like you’ve got three eyes.

The exchange of informational, emotional, and social support was described as beneficial and inclusive:

...to see how other people with epilepsy work it out, to hear what they are going through, to understand what medications they are using and if it is working for them, and think about what it means for me.

Future Life Vision

All participants shared their hopes for the future. Hope flourished in the company of others, rather than “when you are alone.” Their individualized future life visions were influenced by their present ways of being and reparation for past losses. Participants were “on guard” for their next seizure but were continuously hoping for the best. All participants hoped that their incidence of

seizures would decrease or become non-existent; the dosage of medication would decrease and they would be becoming increasingly integrated into their communities through innovations with medical science and engineering, employment accommodations, and advanced public education.

The hope for advanced pharmacological and surgical medical treatments held the promise of more predictable seizures and decrease the negative effect on memory. That is, their current and “frequent medication adjustments” to lessen the threat of a seizure would become a past “reality” in light of new medical discoveries. The focus on seizure management would not be as central to their future lives. In terms of surgical interventions, one participant hoped for:

...medical advanced computer controlled laser surgery. I am willing to go for it if it can be done. I am willing to go on a list because I hope to decrease my convulsions.

Some participants hoped for technological advances in order to lessen frequency and improve memory. One participant explained:

...maybe they will come out with a memory chip into my brain for my short term visual spatial memory. You never know eh? Advancements. Come out with one terabyte microchip.

Most of the participants also had hopes for paid employment. Only two of the participants were working at the time of the interviews. The ability to obtain full time employment symbolized purposefulness and security. As described by participants:

I hope I get a job I just applied to. I am crossing my fingers, my toes, and my eyes because it's full-time for a long term.

...hopefully one of these days something is going to change and I can return to work because I've been out of work for just over a few years now.

I hope to get a well-paying real decent job. Not just any job, but one that I really want to do because of my skills.

The ability to drive also suggested further independence and health. As a participant described:

Eventually I hope to get a driver's license. You never know. The way technology is going there may be a car that drives itself and I just have to tell it where to go.

Most participants hoped for increased education surrounding the diagnosis for both the community and others living with epilepsy. Invitations to share their epileptic experiences were well received by most of the participants. Such an opportunity was considered as venues for educating and inspiring others. In public forums, they wanted others not to personalize "others turning you down" and to be reassured that "life has a new beginning with epilepsy." They described a duty to help others who they considered to be not as well. Further, the participants hoped to increase public awareness of epilepsy to reduce the public's misconceptions of people with epilepsy. For one participant:

I'm not a shy person talking about my epilepsy and there's a lot of people that really appreciate that. I don't just give them pamphlets. I share what I have gone through in different situations with my seizures.

Their educational and outreach efforts were framed from a "capable despite struggling with uncertainty" orientation. Through sharing how they have developed a life in the presence of the threat of seizures, participants believed others could "turn things right around" for "positive change" and well-being.

Summary

This chapter described and illustrated adults' experiences living with epilepsy. Participants described their experience as a temporal life journey beginning with the onset of diagnosis towards achieving their life vision. Participants described stages along the life journey in terms of the past, living in the present, and future aspirations. Their past included the onset of epilepsy and their subsequent losses. In the present, participants described the threat of seizure

unpredictability and their purposeful actions to create well-being. These actions were grouped into three major themes including keeping a ‘mind-set’, protecting self, and securing belonging. These themes were interrelated to facilitate the understanding of how adults live with epilepsy and how they reach their future life vision. Participants simultaneously reflected on past experiences, while using actions to create well-being, to assist in the development of hope for a meaningful future life.

Chapter 5: Discussion

Introduction

In this chapter, the findings will be discussed in light of relevant literature. Interpretive description was developed for nursing research built upon the foundation of pre-existing knowledge. As a result, current references to literature will be included. To date, there is very little research conducted examining the lived experiences of adults with epilepsy. The research that has been conducted has been predominately quantitative work. The purpose of this study was to examine how adults describe their experiences of living with epilepsy in a Northern rural setting. This study's findings provide important information on adults' experiences with epilepsy, which can allow nurses to better understand the needs of those living with epilepsy. This chapter also integrates the implications for nursing practice and nursing research. Subsequently, the chapter discusses the limitations of the study and conclusions.

Epilepsy as a Life Journey

The participants in this study guided the interviews in a chronological manner suggesting that living with epilepsy is a life journey beginning with the onset and striving towards their life vision with stages along the way. This life journey was separated into three sections: the past, present, and future. Each section built upon the last to inform their life choices. Though the life journey towards wellness was sequential, participants often moved backwards and forwards between the stages. This notion is similar to other chronic illness models that suggest individuals move throughout various stages of chronicity with the threat of reverting back to the first stage of their passage to defining a new life (Fennell, 2003). These results reveal that the participants do not emphasize their epilepsy as a medical phenomenon but as a psychosocial one. Further, epilepsy itself is not central to how they live their life. This finding is similar to the research of Admi and Shaham (2007) who found that the management of epilepsy and how it impacts lived

experiences changes over time based on the development and understanding of epilepsy, and the accumulation of life experiences.

The journey of living with epilepsy can also be described as a “trajectory”. Corbin and Strauss (1992) developed the Trajectory Framework in an attempt to assist nurses in understanding the chronic illness experience, to integrate relevant literature about chronic illness, and to guide future nursing models for practice, teaching, research, and policy making. Corbin (1998) defined a trajectory as “the course of an illness over time, plus the actions of clients, families and healthcare professionals to manage that course” (p.3). The illness trajectory begins at the onset of pathophysiological changes and outlines six phases individuals experience before reaching death. Strategies used within each individual’s life shape the trajectory to take into account their uniqueness (Jablonski, 2004). There are nine phases of the chronic illness experience within the trajectory framework and are conceived as a continuum, not linear. Individuals may move between phases, regress to prior phases or plateau for a period of time. No studies were found using this framework to examine epilepsy, however, studies examining other chronic conditions such as renal disease, stroke, and multiple sclerosis have utilized the framework (Lubkin & Larsen, 2006). In this study, participants described their experiences similarly to this trajectory framework.

The results of this study may help guide nurses in terms of caring for individuals along their life trajectory. Understanding the phases that adults with epilepsy experience offers a framework that enables nurses to “move beyond the bio-medically oriented concepts of nursing practice, towards a holistic approach to the provision of nursing care” (Kralik, 2002, p.153). Using the knowledge gained from each phase along the trajectory, nurses will be better prepared to develop individualized and relevant care plans to promote health and well-being.

In order to better understand the experiences of adults living with epilepsy and to help direct nurses who work with these adults, nurse researchers should continue to conduct studies that examine the experiences of adults with epilepsy and how they live with their condition. Additionally, focus should be emphasized on conducting qualitative studies. Qualitative research has value in the exploration of complex human behaviours and deepening the understanding of illness (Johnson & Waterfield, 2004). Therefore, qualitative nursing research would enrich the meaning of epilepsy as a phenomenon using people's own personal narratives.

Past

The emerging themes that accompanied the past experiences of adults living with epilepsy were a sense of overwhelming confusion, lack of control and loss of self. The life trajectory began with the onset of epilepsy and the confusion that accompanied the diagnosis. Corbin (2001) describes the diagnosis of a chronic illness as the "trajectory onset". The trajectory onset includes the appearance of symptoms and diagnosis. During this phase the goal of management is to form a trajectory plan and begin to discover an understanding of the diagnosis. Participants in this study who did not understand their diagnosis were more likely to struggle in their day-to-day life. This finding is similar to a study that examined epilepsy patients' conceptions of epilepsy (Räty et al., 2009). These researchers found that individuals produced their own answers as to why they suffer from epilepsy. They theorize that an unknown cause of epilepsy could increase feelings of uncertainty and loss of control.

No other studies were located that has examined the onset of epilepsy as a precursor for how individuals choose to live their present day life. This concept, however, was evident in other chronic illness literature. For example, a study examining barriers to diabetes management found that individuals who were more knowledgeable about their diagnosis were more likely to employ self-management techniques (Persell et al, 2004). This finding illustrates the importance for

nurses to ensure patients living with epilepsy understand their condition, including the precipitating factors associated with their diagnosis, thus facilitating acceptance and self-management techniques to create well-being.

During the onset of epilepsy, nurses should focus on education and the careful planning of health trajectory. The complex treatment options and plans may be overwhelming for patients, especially those who are experiencing the onset of epilepsy. Previous studies have found that epilepsy patients valued the time spent with nurses in order to facilitate understanding for diagnosis, tests, risk management and taking their medications (Ridsdale et al., 2003). In addition, education is needed pertaining to the onset of epilepsy and precipitating factors. It was evident that individuals experienced confusion and uncertainty at the time of their diagnosis. Only when the participants understood what epilepsy meant for them could they begin to accept and develop strategies to successfully live with epilepsy. Bradbury and Miller (2010) suggest that understanding past experience results in meaningful orientation towards the future. Therefore, patient education at the onset of the diagnosis might alleviate some uncertainty, allowing for a smoother transition to life with epilepsy.

Following the onset of epilepsy, participants described a loss of self. Miczo (2003) describes chronic illness with fluidity that is met with great emotional responses resulting in a threat to self-identity. Galvin (2005) also considers a change of identity as a result of chronic illness. This loss of identity occurs after the onset of diagnosis and the realization that life will be changed. Conceptually, loss has been defined as “any situation in which a valued object is rendered inaccessible, or is altered in such a way that it no longer has qualities that render it valuable” (Buck, 1984, p. 337). Loss of self was related to the lack of independence experienced when newly diagnosed. Families become protective of their child experiencing a chronic illness and much more involved in their day-to-day lives (Akre & Suris, 2014).

Few studies have examined the loss experienced specific to adults with epilepsy. One study, however, was found that had some aspects of loss including loss of self, and loss of independence (Räty & Wilde-Larsson, 2011). These authors described patients' perceptions of living with epilepsy and found that loss of control hinders one from living an ordinary life. They found that individuals described their struggle with this loss, however, they did not associate the loss within a trajectory framework. Another study examined loss in 67 individuals living with epilepsy through qualitative methods (Jacoby et al., 2014). These researchers found that loss is a key concept in epilepsy's impact on lived experiences. This finding is similar to the experiences of the participants in the current study who describe loss as having a substantial impact on how individuals live and create actions for well-being in their day-to-day lives. In addition, the researchers support the notion that loss does not necessarily lead to a decreased quality of life (Jacoby et al., 2014). Instead, epilepsy can be "neutralized by replacement with valued others" (p. 60). Participants in the current study described that loss had a negative effect on their sense of self, though, did not relate this to their quality of life. Participants did, however, emphasize the importance of valued others along their life journey in order to regain some sense of self.

The development of self when it becomes fractured is a nursing intervention that may be implemented for individuals who are newly diagnosed. Regardless of the losses participants describe, nurses are in a position to promote health and self-development by finding an alternative in order to regain a sense of self. Whitehead (2006) supports this claim in the examination of the redevelopment of identity for individuals with chronic fatigue syndrome/myalgic encephalomyelitis. This author found that lived experience follows a trajectory in order to reconstruct self-identity. Nurses should be sensitive to this reconstruction and facilitate ways to achieve self-identity under the new life circumstances. Kralik (2002) suggests relationship-building between nurses and individuals is the first step to map context and

identify values to gain mutual understanding of their clients' values and expectations. As a result, nurses and clients can work together towards creating a path to reconstruct ordinariness and a new self-identity. In addition to the nurse-client relationship, the importance of a social network is also evident in order to “fill in the blanks”. Exploring the social lives and relationships of the client can allow the nurse to fixate on someone for whom the patient can find safety and begin to reconceptualise a new self-identity.

Self-identity issues secondary to chronic illness can also impact self-care behaviours and self-management capacity (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). A case study by Tilden, Charman, Sharples, and Fosbury (2005) found that a woman with diabetes was only motivated to manage her illness once she confirmed her identity was separate from her diabetes. In order to promote self-care, nurses can assist the individual with epilepsy to understand that epilepsy itself is not their “identity.” If this is facilitated early in the diagnostic stage, individuals might become better adjusted as they move along their life trajectory. People with epilepsy must establish a new sense of self when integrating chronic illness into their lives. Though the process of separating identities was not explicated by the participants in the current study, epilepsy was described as intrusive, resulting in a loss of self. Nurses are in a position to help people with epilepsy adjust to their illness, to separate their identity from epilepsy in order to integrate self-care and management strategies, and to re-establish independence.

Balancing dependence and independence was a commonly reported experience by the participants. Whittemore and Dixon (2008) describe this as individuals not wanting to be a burden on others. Dependency on others results in a loss of spontaneity. In the rural context, dependency on others is increasingly difficult given the limited support systems that are already a barrier to health (Molinari & Bushy, 2012). To seek medical care, individuals living in rural locations are likely to travel more than 30 minutes to reach their usual source of care. In addition,

extensive medical treatment requiring surgical intervention can be several hours from their community (Molinari & Bushy, 2012). Given that the individual with epilepsy is unable to drive, family members and friends are relied upon to transport these individuals to medical appointments. As such, epilepsy becomes increasingly intrusive in the lives of all those involved.

Present

The emerging theme during the present phase along the life trajectory was living and hoping for the best while knowing the threat of a seizure is continuously present. Individuals live through the creation of well-being, however, threats to this well-being cause turmoil in their lives. Threats to this creation of well-being were largely related to the unpredictability of seizures. This finding is consistent with current epilepsy literature that has found unpredictability to be one of the most troubling aspects of living with epilepsy (Hosseini et al., 2013). The idea of living with epilepsy, knowing that at any moment you might lose control, has an influence on how one chooses to live and act in order to create and/or maintain well-being. One study found that the unpredictability of seizures was more disabling than the seizures themselves (Rhodes et al., 2008). Further, the authors found that participants imposed restrictions because of the risk for social embarrassment, accident or injury as a result of a seizure. This finding is echoed by the current study where participants described the influence their epilepsy has on their life choices.

Participants in the current study made efforts to integrate epilepsy into their life context in order to create well-being and a “well life.” Adjustment to chronic illness has been described as “the fluctuating tension between living a life and living an illness” (Whittemore & Dixon, 2008, p. 10). Consequently, illness integration is nonlinear and unpredictable. This notion is related to the participants’ experiences of living with constant threats while attempting to create well-being. Paterson (2001) describes this process as “illness in foreground” or “wellness in the foreground.” “Illness in foreground” occurs when an individual living with chronic illness is absorbed by the

illness; “wellness in foreground” occurs when an individual envisions opportunities and successfully integrates illness into their life. In terms of epilepsy, the period of time between seizures can be described as “wellness in the foreground” where individuals are living with increased independence and freedom; however, when a seizure occurs the illness becomes “in the foreground” and the individual becomes, once again, absorbed by epilepsy. The promotion of healthy life choices in order to decrease seizure frequency is integral for the individual to live a well-life. Decreasing the frequency, or eliminating seizures results in more time spent with ‘wellness in the foreground’. As such, nurses can educate patients on seizure triggers and develop plans (e.g. medication routines and sleeping patterns) to lessen the risk for seizures in the future

In the present, social networks were important for people with epilepsy to create well-being. Individuals sought belongingness from others in an effort to integrate themselves back into their community. Current evidence suggests that attention to the physical aspects of a chronic illness alone is not adequate in order to integrate the illness into one’s life successfully (Whittemore & Dixon, 2008). Attention to social aspects of living with a chronic illness is equally important in the creation of well-being. Similar to the participants’ experiences, Whittemore and Dixon (2008) found that individuals with a chronic illness are supported by family and friends to provide emotional wellness and companionship. Additionally, these authors found that family members also provide instrumental support in terms of activities of daily living such as running errands and maintaining the home. Securing belonging can also have implications on self-management behaviours (Gallant, 2003). This author found that greater levels of social support relate to better self-management behaviours.

Nurses can assess the social networks of individuals with epilepsy in order to promote self-management strategies. Education should focus on incorporating skills and successfully managing interpersonal relationships (Gallant, 2003). Promoting social support networks can be

challenging in rural communities because of geographic and social isolation (White, 2013). In an effort to solve these issues, nurses can leverage other health professionals in the community to mobilize the program. In addition, nurses can promote community engagement through local organizations and businesses (e.g. pharmacies) to assist in the mobilization of the health program or challenge and to increase community awareness. Nurses should develop health programs consistent with the rural community norms and values and draw upon community resources to develop a health system-community partnership (Kilpatrick, 2009). Community engagement leads to better health outcomes for rural residents.

During the present stage, nursing interventions should focus on the promotion of health within the individuals' psychosocial domains. Health promotion is a process that enables individuals to improve their own health and gain control of their life (WHO, 2009). In order to reach a state of well-being, nurses must assist individuals to identify aspirations, to satisfy needs, and to cope with their environment. Hornsten, Lindahl, Persson, and Edvardsson (2014) developed health promotion dialogues as a strategy to promote healthy lifestyles. The authors found five themes that motivated participants to adopt healthy lifestyles: "Guiding patients vs. pressuring them; Adjusting to patients vs. directing the conversation; Inspiring confidence vs. instilling fear; Motivating and supporting patients vs. demanding responsibility; and lastly, introducing emotionally charged subjects or avoiding them" (p. 235). Nurses may utilize these mindfulness dialogue techniques to assist in promoting psychosocial health in adults living with epilepsy. Participants in the current study described their experience with developing a positive mindset. Nurses may use motivational interviewing in order to assist individuals struggling to adopt a positive mindset (Hornsten, Lindahl, Persson, & Edvardsson, 2014).

It is important, however, that psychosocial health promotion interventions must be sensitive to rural populations (Davis-Smith et al., 2007). For example, an effective heart health

promotion program offered condensed timeframes in order to ensure its completion before the seeding of crops in a small farming town (Ebbsen et al., 1997).

Future

The future phase along the trajectory of life was described as the participants' life vision. Hope was embedded within this trajectory in an attempt to reach their future life vision and mediated how the individual managed epilepsy. Current epilepsy literature also considers hope to influence the experiences of living with epilepsy (Shostak & Fox, 2012). These authors found that adults with epilepsy are hopeful when looking towards their future: "People with epilepsy express confidence that the lives and life chances of people with epilepsy have improved – and will continue to improve – over time" (p. 362). This notion was similarly described by the participants in the current study who suggested that their lives are improving and that they hoped for continued well-being in order to reach their life vision, whether it be obtaining a driver's license, returning to work, or increasing public awareness.

In contrast, Rätty and Wilde-Larsson (2011) found that hope had a negative impact on the lived experiences of adults with epilepsy. These researchers found that participants described hope as losing faith where each time a seizure occurred hope was "dashed to the ground over and over again" (p. 1998). Participants in the current study, however, were adamant that without hope, you will lose faith: "hope's always one thing, you can't ever let go of that". This contradictory finding is interesting since demographic characteristics and settings were similar to the current study (Rätty & Wilde-Larsson, 2011). It is clear that further research is required to understand how hope influences the lived experiences of adults with epilepsy.

Towards the promotion of an envisioned future self, nurses can play a role in inspiring hope. Hope was found to be an integral piece for individuals to look towards their future and shape their actions to create well-being. Miller (2000) developed a model to help nurses inspire

hope in chronically ill patients. This model helps guide nurses caring for people with epilepsy to develop nursing strategies specific to epilepsy. One aspect of inspiring hope, as described by the model, is to enhance control for the patient by providing skills to manage and care for themselves. The adults living with epilepsy in the current study believed they should play an active and equal part in their treatments including making independent treatment decisions and having all aspects of their care explained. As nurses, taking a more active role in assisting adults with epilepsy to become part of their treatments is vital to patient quality care.

Environmental progress in terms of public education was also a common hope for the future. A lack of understanding and basic knowledge surrounding epilepsy reinforces beliefs that foster stigma and misperceptions (England et al., 2014; Fernandes et al., 2011). Public health nurses are in an ideal position to increase public education surrounding epilepsy. Awareness campaigns similar to the Out of the Shadows established by the WHO (2014), would benefit communities and increase public education, treatment, and services. These campaigns would be especially beneficial in rural communities where health disparities exist (Balamurugan, Rivera, Sutphin, & Campbell, 2007). These authors suggest that health campaigns can increase awareness for not only the illness but also for the rural community itself. Increased attention to the rural community might assist in the recruitment of medical professionals to bridge the gap between rural and urban health disparities.

Participants in the study also addressed medical and engineering advancements they hoped would lessen their seizure frequency, medication dosage, and assist in regaining their independence. No study was found that explored specific hopes of adults living with epilepsy. Further research is warranted to determine the needs of this population as the medical field advances.

Limitations

A major limitation of this study is related to sampling. Difficulties in sample recruitment persisted throughout the research process despite continuous efforts in the promotion of the study. As a result, a smaller sample size was obtained. More interviews would have contributed additional data for the study. Another limitation was the sampling technique. The experience of those who agreed to participate in the study may vary from those who did not wish to participate. For example, the experience of individuals who were struggling with epilepsy, or those who have had experienced negative implications (e.g. stigma) might have been less likely to participate. It is possible that these individuals could have reported experiences quite different than those who self-identified. Finally, the sample lacked some diversity in terms of seizure diagnostic length. All individuals but one have had epilepsy for more than 20 years. It would be interesting to examine the experiences of individuals who have been newly diagnosed in order to validate the findings in terms of the life trajectory that was generated in this study.

Conclusions

The findings of this study illustrate the lived experiences of adults with epilepsy. Adults described a life journey with epilepsy that included three chronological themes: past, present and future. The past consisted of the onset of epilepsy and loss as a result of the diagnosis. The present included living with threats and the actions utilized to create well-being. Hope was embedded as the theme in achieving a future life vision. These findings demonstrate a movement from a focus of biomedical care to a more psychosocial interpretation of lived experience by adults with epilepsy. Nurses are advocates for their patients in terms of including them in all medical care options and decisions. Patient education is an additional aspect of nursing strategies to help inspire hope and promote positive actions to create well-being while being sensitive to

their future life vision. Future research examining the lived experience of adults with epilepsy will hopefully raise awareness and education within professional nursing practice.

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Laurentian University's Research Ethics Board approved this study.

Appendix B – Interview Guide

1. Describe your experience with epilepsy.
2. What is it like living with epilepsy?
 - a) What would a normal day look like?
3. How would you describe epilepsy's impact on your life?
4. What does well-managed mean?
5. What sorts of challenges do you face because of epilepsy?
 - a) How do you deal with these challenges?
6. Do you seek any services to deal with epilepsy? (I.e. support groups, doctors, etc.)
7. Would you like health professionals to discuss coping methods as part of your health treatments?
 - a) Would it help in dealing with a diagnosis of epilepsy?
8. What advice would you give to someone who was struggling with epilepsy?
9. Is there anything else you would like to tell me that I might have missed?

Appendix C – Second Interview Themes and Guide

Things that help manage epilepsy:

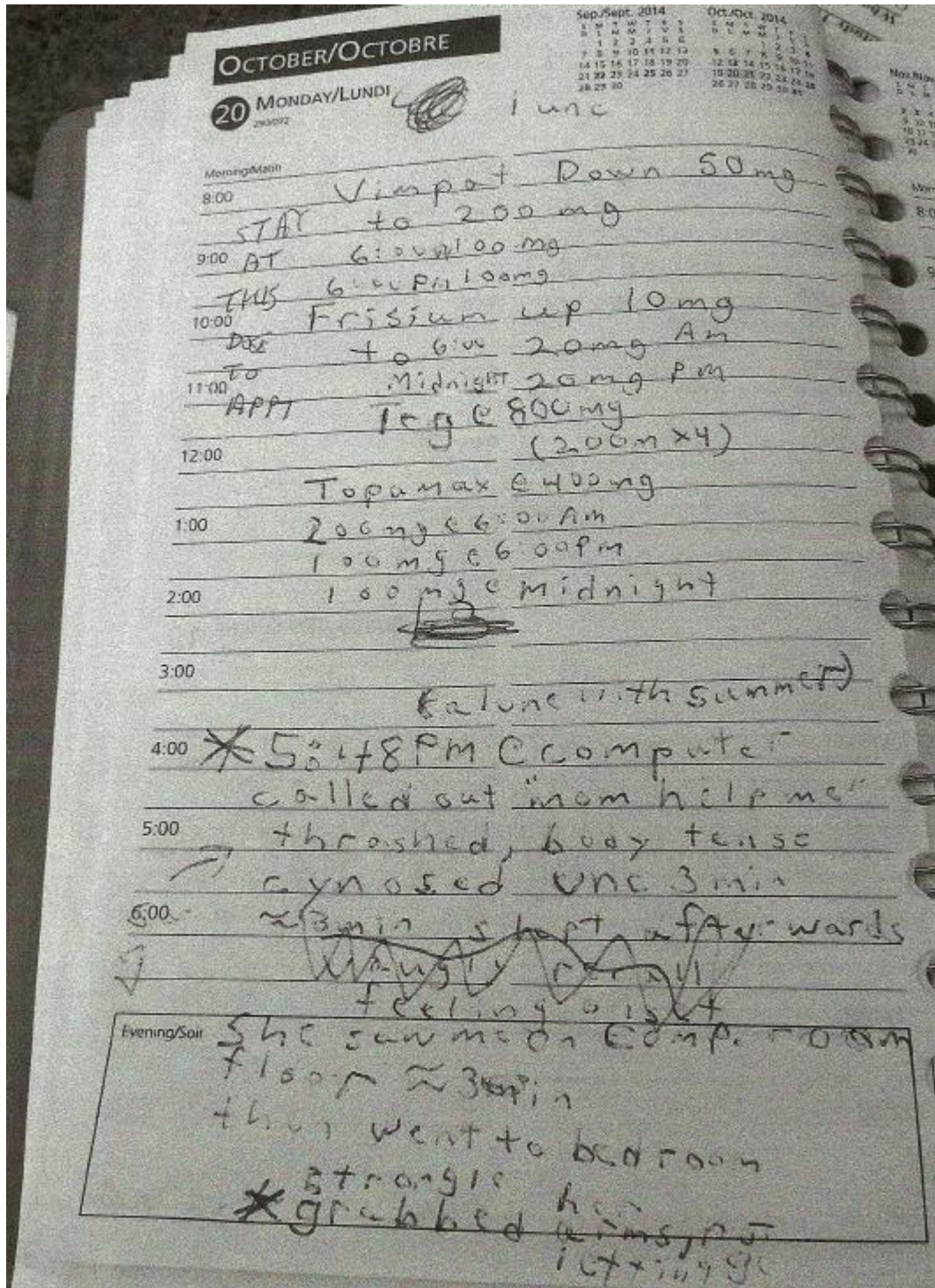
- Positive way of thinking
- Hope
- Don't give up attitude
- Support systems (e.g. family, friends, other)
- Hobbies
- Sharing your experience

Things that don't help manage epilepsy:

- Fear
- Stigma
- Exclusion from society/public
- Loss (e.g. loss of job, loss of driver's license, loss of friendships)
- Being alone
- Unpredictability

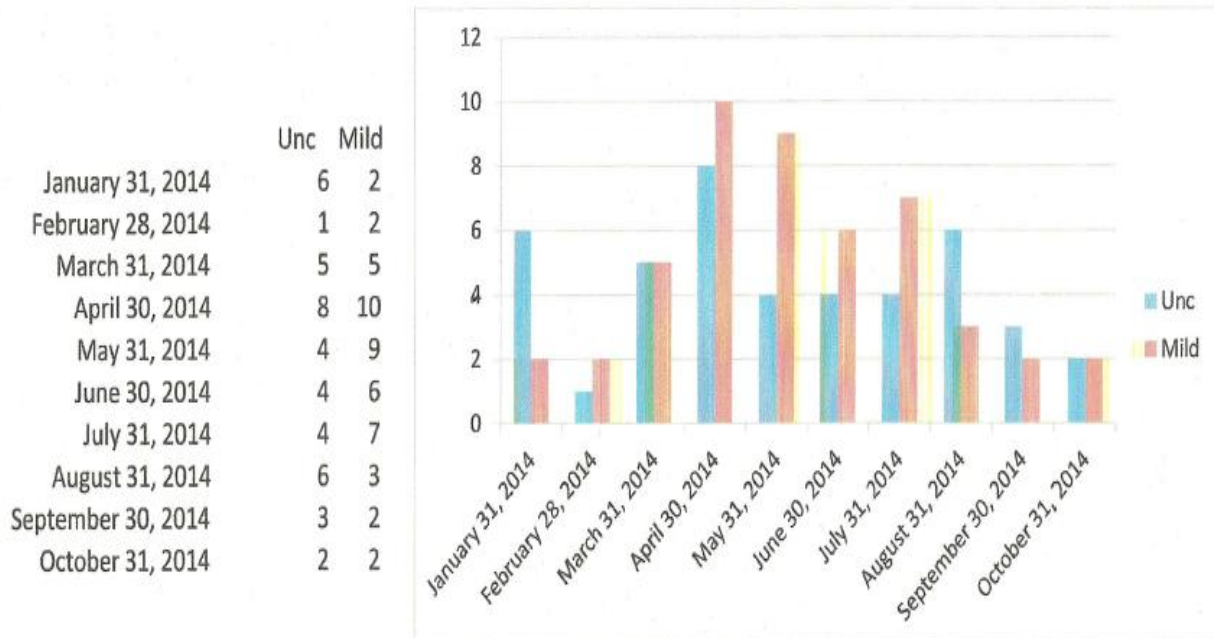
1. These are some of the topics/themes that I've found across most stories shared. Would you agree with some of these topics? Do you disagree?
2. What are things that help you manage the risks you face due to your epilepsy? Do you do anything independently to help manage?
3. What are things that hinder or are a barrier in managing the risk epilepsy has in your life?
4. Do you hope for anything in the future for yourself?

Appendix D – Seizure Diary



Appendix E – Seizure Mapping

2014 Seizure Graph for Dr. [REDACTED]
cc Dr. [REDACTED] Neurological Institute



Medication Originally on, 800mg Tegretol, 40mg of Frisium
Vimpat just brought up to 300mg on the day of June 19 with
20 mg of frisium

Since the increase of Vimpat, there has been a significant increase of side effects in areas such
as headaches; memory loss, and now I am also developing a weakness in my limbs. And psychological tension

Starting Sept 20th, Vimpat was brought back down to 250mg/day along with Frisium to go up to 30mg a day
along with 800mg-Tegretol, and 400mg Topamax for 2 weeks. 2 weeks later I am to go down another 50mg
with the Vimpat and up another 10mg on the Frisium for the following month and meet with him in November.
I felt a decrease in headaches already at the 250mg level and others who witnessed stated my behaviour was
much better and was remembering things better at this level already, I went an 18day stretch clear of seizures,
afterwards, I had 1mild, then 1 unc the next day then 1 very mild one 10 days later. After that (Oct 20) m
Vimpat was brought down to 200mg/day 2X100mg, upping the Frisium to 40mg (20mg-6:00AM, 20mg-midnight,
800mg-tegretol (4X200mg), 4X100mg Topamax)

Appendix F – Consent Form



1. I have read the information about the study being conducted by Laryssa Bilinsky, a graduate nursing student at Laurentian University, as part of her graduate thesis.
2. I understand that my participation in this study is voluntary and confidential. If I agree to participate in this study, I may withdraw from the study at any time. I have the right to refuse to answer any questions.
3. I understand that by agreeing to participate or not participate in this study, the care that I will receive today and in the future will **not** be affected.
4. I understand that when the findings are presented or published I personally will not be identifiable. All information I share is confidential.
5. All my questions about this study have been answered to my satisfaction.
6. I am aware that if I have any questions regarding my participation in this project I can contact Laryssa Bilinsky (lm_bilinsky@laurentian.ca; 705-675-1151 or 1-800-461-4030 extension 3818), Dr. Montgomery (pmontgomery@laurentian.ca; 705-675-1151 or 1-800-461-4030 extension 3818), or Laurentian University Research Ethics (705-675-1151 or 1-800-461-4030 extension 2436; ethics@laurentian.ca).

I would like to receive a summary of the study results: (please circle your answer)

Yes No

If **YES**, where would you like the results sent:

Contact Information: _____

I would like to participate in an interview with the researcher: (please circle your answer)

Yes No

If **YES**, how would you like to be contacted?

Email address: _____

Telephone number: _____

By signing my initials on the following line, I have read the above statements and freely consent to participate in this research study:

Appendix G – Study Information



Study Title: The Experiences of Adults Living with Epilepsy

Who I Am: My name is Laryssa Bilinsky; I am a graduate student attending Laurentian University in Sudbury, Ontario. As part of my program I must conduct a research study under the supervision of a nursing faculty member.

Purpose of the study: You are invited to take part in this study that is looking at how people live with epilepsy and how this affects everyday life.

Tasks involved in this study: If willing to participate, your involvement will include at least one but no more than two audio-recorded interviews lasting approximately 40-60 minutes at your convenience.

Benefits and Risks: You may not personally benefit from participating in this study but the information you provide may benefit planning of services for others in the future. There are no known risks anticipated with your sharing of knowledge or experiences about coping practices.

Participation in this study is voluntary: Participation is completely voluntary. Your choice to participate or not participate in the study will **NOT** influence the care you will receive at the community clinic. You have the right to withdraw at any time or refuse to answer any of the questions during the interview.

Confidentiality: Any identifying personal information that you share will not be recorded for this study. Your medical records will **NOT** be used for this study. You will be assigned a code name. All data collected will be kept in a locked filing cabinet in a locked office at Laurentian University. The data will be saved for a total of seven years and at that time it will be shredded at the University. Results of this study may be published or presented but at no time will you be personally identified.

Contacts: If you have any questions about this study please contact the student researcher Laryssa Bilinsky (lm_bilinsky@laurentian.ca; 705-675-1151 or 1-800-461-4030 extension 3818), faculty supervisor Dr. Montgomery (pmontgomery@laurentian.ca; 705-675-1151 or 1-800-461-4030 extension 3818), or a Laurentian University Research Ethics Officer, who has no attachment to the research team (705-675-1151 or 1-800-461-4030 extension 2436; ethics@laurentian.ca).

The research ethics boards at Laurentian University has approved this study.

Please keep this information sheet for your records.