

Removing Oneself from the Shadows: A Heuristic Inquiry to Understand the Lived  
Experience of Epilepsy in Young Adult Women and their Epilepsy Disclosure

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## Abstract

Epilepsy is a chronic neurological disorder characterized by recurrent seizures (Stein & Kanner, 2009). The purpose of this study was to understand the essence of being a young woman living with epilepsy using heuristic inquiry (Moustakas, 1990). The research was built upon the assumption that each experience is unique, yet commonalities exist. Five women aged 22 to 28 years living with epilepsy were interviewed. Additionally, the researcher described her life with epilepsy. Participants characterized life with epilepsy as a transformative journey. The act of meeting and interacting with another woman living with epilepsy provided an opportunity to remove themselves from the shadows and discuss epilepsy. Three major themes of seizures, medical treatment, and social relationships were developed revealing a complex view of an illness requiring engaged advocacy in the medical system. Respondents frequently make difficult adjustments to accommodate epilepsy. This study provides a complex in-depth view of life with epilepsy.

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## Abbreviations

(In order of appearance)

PWE = People with epilepsy

ILAE = International League Against Epilepsy

WHO = World Health Organization

QOL = Quality of life

EEG = Electroencephalogram

MRI = Magnetic resonance imaging

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## Chapter 1 – Introduction

Epilepsy is one of the oldest physical disorders known to mankind and (aside from migraines) is the most common neurological disorder among people of all ages around the world (WHO, 2001, Banerjee, Filippi, & Hauser, 2009). As a result, epilepsy has been documented for several centuries and has been pharmaceutically treated since approximately the 1960s (Kale, 1997). It is a chronic neurological disorder generally characterized by the tendency for recurring seizures and is generally diagnosed when at least two unprovoked seizures have occurred in an individual (Stein & Kanner, 2009).

A seizure is defined as an abnormal electrical discharge within a group of neurons in the brain which can lead to various symptoms such as a loss of consciousness, convulsions, muscle stiffness and jerking, staring spells, falls, and delusions, depending on which area of the brain is affected (Wilner, 2003). Epilepsy can be caused by factors such as genetics, brain damage, tumours, birth defects, and brain infections, amongst others; however, the cause cannot be found in the majority of patients that are diagnosed (Wilner, 2003). Through treatment, the majority of people with epilepsy (PWE) can live outwardly normal lives, although many continue to have a fear of future seizures, driving restrictions, a lack of independence, employment and social problems, side effects, adverse reactions to medication, as well as the emergence of cognitive, motor, and psychiatric complications (Sander, 2005). Pharmaceutical interventions with anti-epileptic medications can also cause a wide range of side effects such as drowsiness, behavioural problems, aplastic anemia, leukopenia, dizziness, impaired thinking abilities,

depression, headaches, weight loss/gain, and many more (Schmidt, 2009). In other words, epilepsy can affect every aspect of a person's life.

The ultimate goal of treatment in epilepsy is the minimization of seizures and side effects through pharmaceutical intervention which is often a trial-and-error process between doctors and patients (Schachter, 2000). There are other treatments to epilepsy other than medication, including dietary changes, brain surgery, medicinal marijuana, and brain stimulation devices, but pharmaceuticals are the dominant form of treatment (Stein & Kanner, 2009). There is no known cure for epilepsy and approximately one-third of those diagnosed do not properly respond to medication and are unable to gain seizure management (Schmidt, 2009). Much of the research in seizures and epilepsy tends to lean towards the treatment of seizures and fails to address the many problems in epilepsy that go beyond the physical issues themselves (Mirnics, Bekes, Rozsa & Halasz, 2001, de Souza & Salgado, 2006, Camfield & Camfield, 2007, Smith et al., 2009). There are many physical, psychological, and social problems which can occur at the time of diagnosis and also emerge as the condition progresses, yet little of this knowledge has translated into the clinical setting (Clark, Stoll, Youatt, Sweetman, Derry, & Gorelick, 2010).

Consequently, the majority of treatment continues to focus on the administration and management of medication, while often ignoring or failing to address issues that may arise and affect the patient's social and psychological quality of life (Schachter, 2010).

Epilepsy has been documented for over 4000 years and according to Kale (1997), those years can be summarized as "4000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma" (Kale, 1997, p. 2).

Subsequently, even though humans know much more about epilepsy in the biological, clinical, and neurological fields than they ever have, this has done very little in regards to reducing any misunderstanding about epilepsy around the world. While there have been recent attempts to reduce epilepsy stigma through various awareness raising campaigns and advertisements such as the “Out of the Shadows” campaign formed by the International League Against Epilepsy (ILAE) and the World Health Organization (WHO) there is still a general lack of knowledge about epilepsy around the world (Jacoby, Snape & Baker, 2005). There have been large developments and improvements in medication over the past 60 years to treat and manage seizures; however, many of those affected may still have a poor quality of life (QOL) and often live in silence with their condition (Schachter, 2010). When comparing the progress of epilepsy knowledge and treatment to other less common neurological conditions such as Alzheimer’s or multiple sclerosis, epilepsy is not understood as well (England, Liverman, Schultz & Strawbridge, 2012). While pharmaceutical medication can help many people living with epilepsy, much of society does not recognize that epilepsy is more than just seizures – many can develop coexisting health problems leading to a lower than average quality of life, which may in turn affect their ability to maintain healthy social activities and relationships (England et al., 2012, Collings, 1990, de Souza & Salgado, 2006 & Schachter, 2009, Naess, Eriksen, & Tambs, 2009, Jacoby et al., 2005, May & Pfafflin, 2005). Information collected by England et al. (2012) reported several key messages about epilepsy in today’s society including that more research is needed to improve epilepsy care and prevention, health professionals need to be better informed about

epilepsy, patients, caregivers, and the general population need to be educated more in epilepsy, and that the stigma associated with epilepsy needs to end.

Epilepsy is most often viewed according to biomedicine; therefore the subjective experience of people dealing with illness is often overlooked and therefore misunderstood (Andermann, 2000). As a result, epilepsy has been widely misunderstood throughout history which has led to many untrue beliefs about epilepsy and stigmatization among the individuals it affects (Andermann, 2000). Common generalizations and stigma attached to epilepsy that have developed over time include the beliefs that epilepsy is a punishment for sin, is from demonic possession or witchcraft, is contagious, and is a disease of the brain. All of these are untrue, yet are still believed by many in society (Jacoby, Snape & Baker, 2005, Andermann, 2000). The above information makes it clear that there is a lack of awareness in most of society for what epilepsy is, what it is caused by, how it is treated, and the side effects that tend to come along with it. So why is it that human beings have recognized and documented epilepsy for so long, and yet, much of the general public still does not understand what it really is?

Due to the lack of awareness of epilepsy presented by the public over the past several thousand years, it is no wonder that numerous psychological and social problems can and do occur in PWE. They have many boundaries placed on them including restricted participation in recreational activities, social situations, specific areas of work, and especially the ability to drive, which are often listed as a large concern for QOL in PWE (Drazkowski, 2003). Due to daily restrictions and medical treatment, many PWE can be faced with some very difficult decisions such as whether or not to participate in

certain activities from simple things like riding a bicycle or taking a bath, to more extreme activities like sky diving, consuming alcohol, or taking illegal drugs. Side effects from medication can also cause painful or somewhat debilitating symptoms (Schachter, 2000). As a result, some PWE may also fail to adhere to their treatment prescription.

Medication side-effects and seizure recurrence are often experienced by PWE, which seems to cause many of these people to desire a more active relationship with their doctor to ideally become more informed and involved in treatment decisions (Prinjha, Chapple, Herxheimer & McPherson, 2005). In an effort to be relieved of these clinical issues, PWE may then be faced with decisions that may make them feel better physically and emotionally and perhaps cause them to participate more socially; however, these decisions may conversely affect their health (Drazkowski, 2003). For example, a patient may neglect to take their medication to avoid painful or frustrating side-effects, but this may cause their seizures to no longer be managed. Another example may be the decision to drive and whether or not to report to their physician if they have a seizure in fear of losing their licence to drive. For example, a review by Elliot and Long (2008) indicated almost one in five PWE studied would not honestly report their seizure frequency when it was in a state that required reporting. Meanwhile, Bautista and Wludyka (2006) reported that as many as 24% of people with recurrent seizures may continue to drive. The decision not to report seizures can not only put the patient's life in danger, but also the lives of many others on the road. The ultimate decision PWE may face is how to best manage their own condition (Kucukarslan, Reeves & McAuley, 2008). This may include the decision of which anti-seizure medication to take, if at all, as well as whether or not to

sacrifice cognitive abilities for better seizure management. Conversely, some may choose to take a medication which has fewer side effects, but does not management seizures as well.

Ultimately, I wanted to understand how and why PWE come to the decision to disclose their epilepsy. As a person living with epilepsy, I wanted to know how other PWE come to make decisions in life around their epilepsy and how they weigh benefits from risks. The decision to examine the psychosocial effects of epilepsy through a qualitative analysis was largely based on the literature by Charon (2006) and Charmaz (1999) & (2002). This literature stresses the importance of qualitative inquiry in medicine and how listening to the patient's experience can strengthen treatment and ideally improve their QOL. It seems apparent through such literature that patients desire a doctor that can comprehend what they are going through and therefore stay with them through the course of their illness. Without this practice, medicine may fulfill its technical clinical goals, but such a treatment is far from complete when it does not address the psychological, social, and general life aspects of health (Charon, 2006).

That is why I believed that a study in decision making and epilepsy disclosure conducted by someone who also is diagnosed with the same condition, such as I, may provide an informative conclusion regarding this topic. My role as the researcher will be explained in a much more comprehensive manner in the methods chapter of this study. Aside from research studies that have examined medical treatment decision making and decisions in those with temporal lobe epilepsy, there has been little research involving the

comprehension of decisions in epilepsy from a qualitative, psychosocial perspective (Labudda et al., 2009).

Therefore, the purpose of this research study was to gain an understanding of the essence of life with epilepsy in young adult women. This study attempted to address some gaps in the qualitative literature in epilepsy and result in a creative synthesis providing others with a new perspective of what it means for a young adult woman to live with epilepsy. Research themes addressed topics like the physical, psychological, and social side effects of living with epilepsy, disclosure of this chronic illness, and differences that young adult women experience with epilepsy that others do not. The study looked to answer the following research question:

What is the essence of living with epilepsy in young adult women, and how do these women's experiences with epilepsy relate to my own?

## Chapter 2 – Review of Literature

### Themes in Epilepsy Research

**Physical Effects of Living with Epilepsy.** Epilepsy is defined as a condition characterized by recurrent epileptic seizures of two or more that can be identified using modern medical diagnostic equipment such as an electroencephalograph (EEG) or magnetic resonance imaging (MRI) (Banerjee, 2009). The majority of people diagnosed with epilepsy are treated with pharmacological medications known as anti-epileptic drugs (AEDs) in order to reduce and ideally eliminate seizures, but not cure epilepsy (Schmidt, 2009). In a review conducted by Schmidt, various drugs can cause an early-onset of side effects such as debilitating drowsiness, dizziness, seizure aggravation, gastrointestinal issues, liver failure, hypersensitivity, and rash. Various late-onset side effects of medication cited also included sedation, behavioural problems, psychotic episodes, leukopenia, aplastic anemia, pancreatitis, osteoporosis, weight gain or loss, and several other physical problems (Schmidt, 2009). Some of the most difficult and common physical side effects of epilepsy include migraine (Hinnell, et al., 2010), drug interactions, drowsiness, dizziness, somnolence, central nervous system toxicity, and medication tolerance (Schmidt, 2009). Side effects of epilepsy and/or its treatment can be so debilitating that those treated may not be able to work full-time or perhaps have no social life due to effects such as drowsiness, migraine, memory problems, etc. (Jacoby et al., 1998; Salas-Puig et al., 2009).

In addition to various types of seizures and physical side-effects of treatment, epilepsy has a negative impact on a person's health and health-related behaviours when

compared to its severity and prevalence (Hinnell et al., 2010). It is commonly known that most forms of physical activity and exercise are generally beneficial for overall health and is greatly promoted within our society. Unfortunately, for many decades, children and adults with epilepsy were discouraged from participating in sports and general physical exercise as it was believed that it would be harmful for their seizure management (Arida et al., 2008).

Even though physicians now promote physical activity in PWE, perceptions and the stigmatization that they shouldn't participate in sport and exercise still remains today in society. In addition, research has shown that the populations of PWE in countries between both North America and Europe tend to have a greater risk of being overweight and having sedentary lifestyles due to factors such as depression, perceptions of the effects of physical activity in epilepsy, various anti-epileptic medications, and others (Ben-Menachem, 2007 & Hinnell et al., 2010). Therefore, PWE are generally less active than the average person and as a result, this population could be at risk for other adverse health conditions in addition to their epilepsy.

**Psychological Effects of Living with Epilepsy.** When it comes to the psychological consequences of living with epilepsy, many different problems can arise not only due to the physiology and treatment of it, but also through the social effects of living with epilepsy. Consequently, a person's self-worth can become drastically reduced (Smith et al., 2009). Other common psychological effects include depression, anxiety, pessimism, memory problems, cognitive difficulties, behavioural problems such as anger, irritability, and reductions in perceived management over personal life (Miller,

Kustra, Vuong, Hammer & Messenheimer, 2008; Chaplin, Lasso, Shorvon & Floyd, 1992; Loring, Hermann & Cohen, 2010; Poochikian-Sarkissian, Sidani, Wennberg & Devins, 2008). Many of the psychological issues and/or changes can be a result of the biological domain of epilepsy and its pharmaceutical treatment, but problems like anxiety or decreased self-worth are often a result of social issues related to epilepsy such as stigmatization.

Those affected by epilepsy can experience limited independence and perceived stigma which may cause the perception of their psychological well-being to be negatively impacted (Suurmeijer, Reuvekamp & Aldenkamp, 2001). According to Charmaz (2002), serious illness can also raise questions in someone about their self and identity. As a result, this may cause adults diagnosed with chronic illnesses to question their personal and social identities which were once thought to be already set. Much of this seems to be a result of their treatment and lack of independence, but also due to the lack of public awareness, outward stigma, and objective perceptions of epilepsy, which in turn can affect the patient's subjective perceptions.

According to Smith et al. (2009), perceived stigma in PWE negatively affects a patient's self-efficacy, confidence, happiness, and increases the prevalence of depression. For that reason, their psychological health can decrease not only when recently diagnosed, but also even once their seizures have stopped (Eddy, Rizzo, Gulisano, Roberston, & Cavanna, 2010). This shows that psychological problems in PWE may not necessarily be related to their seizure frequency. Several studies such as those by Naess, Eriksen, and Tambs (2009), Jacoby et al. (2005), and May and Pfafflin (2005) suggest

that in order to improve self-worth, satisfaction, and overall quality of life, public awareness regarding epilepsy must still increase greatly so that both outward and perceived stigma may lessen. In addition, the use of educational and psychotherapy programs could lead to greater self-confidence for not only PWE, but also their family, friends, and caretakers.

While epilepsy is a serious neurological disorder, it should not prevent someone from living a happy, fulfilling life. Therefore, reducing the psychological problems someone with epilepsy may experience is something which not only the patient should work on, but also the health-care system and the general public. This would ideally help those living with epilepsy to live confident, successful, productive, and ultimately happy lives.

**Social Sides of Living with Epilepsy.** One of the main issues in epilepsy which may decrease a patient's quality of life is that of stigma and exclusion (de Boer, 2010). Based on cultural differences and economic circumstances around the world, the social consequences of epilepsy can be vast, including further psychological issues which are often not related to the severity of the disease itself, but instead originate from the concepts of epilepsy and seizures that are held by the public (Jacoby, Snape & Baker, 2005). Attitudes towards PWE are influenced, in part, by the extent of knowledge about the condition (de Boer, 2010). Seizures and epilepsy have been documented for longer than most medical disorders, yet PWE are still viewed with fear, suspicion, misunderstanding, and are subject to stigma (de Boer, 2002).

Through the review of a nineteenth century diary of one woman's experience with epilepsy plus several other historical accounts, Devinsky (2007) stressed the unfortunate and debilitating social stigma of this disorder. These included societal beliefs such as satanic possession, supernatural causes, alcoholism, and insanity; which consequently led many to hide their epilepsy from the public for fear of marital hindrance and social stigmatization in all classes of society. Just under a decade ago, the Governor of Virginia in the United States at the time, issued a formal apology to thousands of people in the state which included many PWE that were forcibly sterilized under the state's eugenics laws since the start of the last century (Finucane, 2003). Meanwhile, Kale pointed out specific events in world history which explicitly show the social stigma and negative attitudes of others that PWE have and continue to face. In this academic paper, Kale (1997) stated:

A survey in Germany in 1996 showed that about 20% of people interviewed thought that epilepsy was a mental disorder; a similar number objected to their children marrying a person with epilepsy. 17 states in the United States prohibited people with epilepsy from marrying till 1956, and denying them access to public places like theatres and restaurants was legal until the 1970's. Discrimination in developing countries is more blatant and widespread. In India, where most marriages are arranged, a girl with epilepsy has little chance of getting married, and a recent survey from Turkey showed that 70% of people thought that epilepsy resulted from supernatural causes. (p. 3)

A good deal of stigma has carried into present day (de Boer, 2010). While much of our society is more educated regarding the basics of seizures and epilepsy, there is still so much the public is unaware of. Sadly, many of the old stereotypes and prejudices still exist. Examples include the belief that epilepsy is a mental illness, causes violent behaviour, aggressiveness, learning disabilities, and that it is even contagious (Alto, Esser & Gordon, 2010, Jacoby, Snape & Baker, 2005).

It is possible that the traditional and historical oppression and stigma faced by PWE over the years has created barriers for them to live happy, healthy lives and in turn, some may feel as if they have been labelled by society as 'disabled' in the physical, emotional, and social senses (Rhodes, Nocon, Small & Wright, 2008). Consequently, self-identities of PWE may become skewed as they are told not to participate in certain activities. Also, epilepsy can take many different forms, so people's experiences are therefore variable, ranging from extreme physical disruption (resulting from frequent and severe seizures) to minimal or even the absence of physical incapacity (Rhodes, Nocon, Small & Wright, 2008). Yet, many of these people may still remain highly 'disabled' by society, perhaps causing psycho-emotional distress.

**Women and Epilepsy.** Epilepsy is a medical condition which does not discriminate. This is because anyone of all ages, ethnicities, socioeconomic statuses, lifestyles, and other dimensions can be diagnosed with epilepsy all around the world and at any time in their lives (Stein and Kanner, 2009). There is a significant difference; however, between men and women who live with epilepsy. Such factors can include can include birth defects in pregnant women depending on their medication choice, problems

with their menstrual cycle, hormonal aggravation of seizure frequency, endocrine dysfunction, decreased effectiveness of oral contraceptives, and sexual dysfunction, amongst others (Meador et al., 2009, Shuster, 1996 & Luef, 2009). In women with epilepsy, especially those of childbearing ages are faced with various other complications and/or difficulties that men are not. Additionally, many women living with epilepsy may face various psychosocial problems in areas such as underemployment (even though many women have higher educations than their male counterparts), as well as problems with romantic relationships, marriage, mood, anxiety, and many others (Gopinath, Sarma & Thomas, 2011).

Gender barriers and discrimination against women still exist today even though major advancement in gender equality has been made over the past century (Michailidis, Morphitou & Theophylatou, 2012). A key example of this is in democratic countries in which gender equality is a fundamental principle, whereby women and men should participate as equals in the social, cultural, and economic aspects of life. Especially over the past 30 years, women in the workplace, especially in managerial and professional ranks, has steadily risen (Michailidis, Morphitou & Theophylatou, 2012).

Okin (1989) argued; however, that gender division, which typically occurs in most families, leads to a socially-created situation that causes women to be in a state that is socially and economically vulnerable. In addition to this, Okin (1989) claimed that such a division of labor begins a cycle that reinforces various inequalities at home and work such that women tend to be the primary caretakers of families; however, the labor market is designed to suit full-time workers. Thus, women who work full-time and are

also primarily responsible for their family's well-being may become marginalized in the workplace as they do not fit the workplace norms on equal terms with men (Okin, 1989).

Such inequalities are shown through a study conducted by Duehr and Bono in 2006 where it was revealed that stereotypes towards women in the workplace have been changing in a positive way over the past few decades; however, many men still hold gender stereotypes against women that are quite similar to previous years. While women are not marginalized or socially suppressed nearly as much as in previous centuries, it is clear that gender stereotypes and disadvantages, especially in the workplace and home, are still very much a part of societies and cultures around the world.

Accordingly, women living with epilepsy, especially of child-bearing ages and ability, not only face difficult challenges in society simply because they are women, but also face various physical and psychological effects and/or challenges that men do not. Again, such factors may include endocrine dysfunction, hormonal aggravation of seizures, mood problems, birth defects due to medication, and an inability to breast-feed infants, amongst others (Gopinath, Sarma & Thomas, 2011). Women who live with epilepsy face various physical, psychological, and social problems that men do not, causing young women's diagnoses and lives to perhaps become more difficult or complicated.

This study examined the lives of young adult women between the ages of 20 and 35 years with the ability to conceive and care for a child, and who have been diagnosed with an active form of epilepsy for at least one year. This sample was appropriate for this study because I am also a young adult woman of child-bearing ability and my research

methodology is that of heuristic inquiry. Heuristic inquiry in qualitative research aims to understand the lived experience of a certain phenomenon (in this case living with epilepsy) by studying those that experience it and comparing it to my own understanding of the same phenomenon (Moustakas, 1990). By studying young adult women, it is also reasonable to believe that social justice issues faced by those living with epilepsy will be illuminated due to the fact, as stated above, that women still face gender inequality today in many aspects.

**Disclosure of Epilepsy.** Since the development of modern medicine, there have been many research studies performed to gain knowledge about epilepsy and the people affected by it; however, the large majority of this research has utilized quantitative measures. As a result, we now know much more about the biology, physiology, and epidemiology of epilepsy than we ever have. Examples of this include that approximately 50 million people around the world are affected by epilepsy at any given time, there are unknown causes for epilepsy prevalence, there are various seizure types such as partial complex, atonic, tonic-clonic, partial simple seizures, etc., and that epilepsy is not prejudiced. Such facts show that epilepsy and seizures have no preference in race, age, gender, socioeconomic status, or culture. Yet, this knowledge has done little in terms of increasing overall public awareness and reducing the stigma around epilepsy and seizures (Banerjee, Filippi & Hauser, 2009).

A significant proportion of PWE underreport their seizures (Darymple & Appleby, 2000). A doctor's ability to treat epilepsy is hindered because of their role in regulating the legal rights of PWE to hold a valid driving licence and even access certain

occupations. Consequently, PWE may not disclose any breakthrough seizures and/or failure with medical treatment to their doctor, in fear of losing their ability to drive and/or perform certain occupations.

A good example of both may be a transport truck driver living with epilepsy that chooses not to report a random seizure to their doctor in fear of losing not only his or her ability to drive, but also their career and income. This decision not to tell their doctor may lead to criminal charges, insufficient medical treatment, further seizures, and may put not only their own health and life in jeopardy, but also those of other people if they choose to continue driving on busy public roadways. Such an example illustrates the difficult decisions PWE may face when choosing whether or not to disclose their seizures and epilepsy. Many PWE chose not to report any seizures to their doctor, especially when it is the duty of the physician to report these people under law to their provincial, regional or state driving organization (Salinsky, Wegener & Sinnema, 1992; Troster, 1997; Bishop & Allen, 2001; Schneider & Conrad, 1980; Dalgin & Bellini, 2008). Accordingly, those people compromise their medical care, driving rights, and the safety of others.

When reviewing the topic of chronic illness disclosure, especially with respect to epilepsy disclosure, Schneider and Conrad (1980) concluded that many people living with epilepsy are not fully in or out of the closet and instead, the closet of epilepsy has a revolving door. In other words, Schneider and Conrad (1980) concluded from their qualitative study that epilepsy disclosure is very situation-specific in places like the workplace, social activities, academic work, and others. They also concluded that being “in the closet” with epilepsy can isolate PWE from one another even further.

A person's willingness to disclose epilepsy varies across many different scenarios in public (Troster, 1997; Lingsom, 2008). It ultimately depended on their subjectively-perceived risk of someone figuring out they have epilepsy and the anticipated consequences of their illness disclosure. Essentially, Tröster (1997) found that participants were more willing to disclose their epilepsy the more they feared the person would be able to detect their illness on their own. In essence, this means that PWE seem to apply a strategy of preventative disclosure whereby they strive to positively influence other peoples' social judgements to delay and ideally prevent any outward stigma (Tröster, 1997).

Charmaz has completed a large amount of research in the area of narrative medicine and as a result, published significant knowledge in the areas of how patients' stories or experiences are expressed. As well, disclosure of chronic illness by patients and how this occurs in society is reviewed in her 2002 article titled "Stories and Silences: Disclosures and Self in Chronic Illness." In this article, she stated that not all personal experiences are stored in memory and they are not all ready to be recalled either. Meanwhile, silence signifies an absence of words and/or emotions, but it may also reflect meanings, boundaries, and rules towards actions or situations (Charmaz, 2002). Ultimately, Charmaz explained that when a person is asked to recall and describe their experiences with illness, they may choose to hide/silence certain things due to how others may perceive them (Charmaz, 2002). As a result, it is very important for researchers to pay attention to not only what is being said by a person, but also to what they aren't saying. In addition, the way that a participant views the researcher or interviewer can

have significant consequences regarding what a person chooses to disclose about their experiences (Charmaz, 2002). Therefore, it is reasonable to conclude that a person living with epilepsy interviewed by another person living with epilepsy could be beneficial in terms of the participant's disclosure of their illness and life, but also in terms of how the researcher observes and interprets the participants' silences, body language, and other non-verbal cues.

A study performed by Dalgin and Bellini (2008) found that employers perceive the employability of people with psychiatric disabilities to be significantly lower than the general population and are generally less likely to be hired than others. Since many people in society believe the stereotype that epilepsy is a mental illness and unfortunately psychiatric complications can become a side-effect for PWE, this is perceived as a significant reason for PWE not to disclose their neurological disorder to a potential or current employer (Dalgin & Bellini, 2008). It is possible that this could also hinder their willingness to disclose epilepsy in other social situations as well, seeing as employment is a rather vital component in the lives of the majority of the world's population.

After reviewing the literature on illness disclosure, especially in epilepsy, it is very subjective and situation-specific. Those studies reviewed; however, were completed among rather general, adult populations and included broad quantitative, as opposed to qualitative research methods. Consequently, there is still much we do not know about young adult women's decisions to disclose chronic illness and in this case, specifically epilepsy.

## **Qualitative Literature**

When it comes to qualitative literature in epilepsy, a large amount has been dedicated to gaining a better understanding of the experience of living with the neurological disorder. When examining these studies more closely, it is apparent that many have focused on specific aspects. As a result, the research has apparent gaps (Andermann, 2000; England et al., 2012; Linehan, Tellez-Zenteno, Burneo & Berg, 2011). Consequently, there is a strong lack of research which gains a whole picture of what it means to be a person living with epilepsy. We can try and tie the various pieces together to gain an understanding; yet, this still would not capture an accurate representation of the experience of living with epilepsy. Heuristic inquiry, which will be implemented in this study; however, will aim to do just that.

In the research and exploration of the experience of epilepsy, Faircloth (1998) put it into perspective by stating that since the 1970's and 1980's, the majority of the research has remained somewhat stagnant and tends to concentrate on specific themes in the illness, such as stigma. In Faircloth's (1998) narrative study, three separate individuals living with epilepsy were interviewed and through narrative analysis, it was shown that identities and meanings in the experiences of those with epilepsy are highly varied. In an attempt to expand the study of illness, especially in epilepsy, it is suggested that academics step outside their comfort boundaries into other, more in-depth qualitative measures. Since then, unfortunately not much has changed to better understand the experiences in people living with epilepsy.

Many qualitative studies in epilepsy explain the need for less quantitative research methods and instead, more qualitative studies to better understand the experience of life with epilepsy (Sample, Ferguson, Wagner, Pickelsimer & Selassie, 2006, Shostak & Fox, 2012, & Varley, Delanty, Normand & Fitzsimons, 2011). Nonetheless, much of the research in this dimension comes to common conclusions and themes which focus mainly on gaps in healthcare services, stigma, comorbidities, and general life with epilepsy.

### **Phenomenological Research in Epilepsy**

Phenomenology aims to essentially understand the experience of various events in peoples' lives (Moustakas, 1994). Depression is often a co-morbidity of living with epilepsy and as a result, a large portion of the phenomenological research in epilepsy examines the experiences of depression (Seethalakshmi & Krishnamoorthy, 2007). Phenomenological studies in epilepsy relevant to this study; however, include those by Gauffin, Flensner, and Landtblom (2011), Ryan and Raisanen (2012), and Varley, Delanty, Normand, and Fitzsimons (2011), among others. These studies essentially came to similar conclusions in the areas of medical treatment, public stigma, and seizures themselves. Those conclusions were that of fear. Many PWE live in fear everyday not only for their health and safety, but also for their social identity and mood. Another side of living with epilepsy is stigmatization, which has been largely examined; however, Kılinc and Campbell (2009) used the phenomenological approach to give the "power" of knowledge back to the people living with epilepsy by viewing them as the experts. This study found three common themes of embarrassment for having epilepsy: non-disclosure

of epilepsy, misconceptions about the condition, and ultimately, PWE tend to change their social identity in order to avoid stigmatization.

### **Heuristic Inquiry Research in Epilepsy**

Heuristic inquiry is absent in epilepsy research literature and that is why this study attempted to provide the academic community with a new perspective in the experience of epilepsy. Qualitative research in epilepsy can and has shed significant light on the experience of epilepsy; yet, much more can be done to express the essence of the experience of epilepsy. Heuristic inquiry research was an advantage in this qualitative study as I was able to reflect on my own experiences with the subject matter.

## Chapter 3 – Methods

### Research Context

This study represented a partial component of a Master's thesis in the Faculty of Applied Health Sciences, specializing in health and physical education at Brock University in St. Catharines, Ontario, Canada. The rationale for studying the lived experience of epilepsy in young adult women and how that relates to epilepsy disclosure was contingent upon both public and private concerns of the study, as epilepsy is a very common neurological disorder, is quite misunderstood in society, and I have a private connection to epilepsy as I began experiencing seizures in 2009 . The significance and research implications of the latter will be discussed in the Reflexivity and Role of the Researcher sections. Interviews were the primary source of information for this study. The research question that led this study was:

1. What is the essence of living with epilepsy in young adult women, and how do these women's experiences with epilepsy relate to my own?

Heuristic inquiry is a qualitative research methodology which aims to capture the essence of various experiences in life (Moustakas, 1990). It is a branch of phenomenology which is a qualitative research methodology that also aims to understand various experiences; however, heuristic inquiry differs as it not only examines experiences, but also the essence of the experience in which the researcher is already personally familiar with (Moustakas, 1994). In terms of the essence of a particular experience (being a young woman living with and disclosing epilepsy in this case) I

examined the interviews very closely to illuminate any overlooked aspects of the phenomenon (Moustakas, 1990).

This study followed a heuristic inquiry methodology, as described by Moustakas (1990). This is because I hoped to capture the essence of a certain phenomenon; in this case, the essence of life with epilepsy in women of child-bearing age. This methodology allowed for a specific research perspective as I also experience this phenomenon in day to day life.

It should be noted that the grounded theory methodology was considered for this study before heuristic inquiry. This is because it seemed to fit my goals of the study as I aimed to create a new theory regarding the essence of what it means to live with epilepsy. As my perspectives and knowledge grew, however, I realized that heuristic inquiry would provide me with the ideal opportunity to involve myself in the study as well.

### **Theoretical Perspective**

In order to perform proper research, various researchers need to explicate their theoretical perspective. Crotty (1998) defined this as a person's view of the human world and the social lives that occur within it. Meanwhile, Guba and Lincoln (1994) stated that a researcher's particular perspective or paradigm is a set of basic beliefs that represents a worldview and defines the nature of the 'world' to them, their place within it, and the range of possible relationships to their world. Constructivism studies the many realities that individuals construct and the implications those constructions have on their lives and interactions with other people (Patton, 2002). Social constructionism is a perspective that refers to the construction of knowledge about reality, and not the construction of reality

itself (Shadish, 1995b). Constructivism and constructionism, also known as social constructionism are often used interchangeably among scholars; however, Crotty (1998) made an important distinction between the two perspectives when he stated that constructivism points out the different experiences of each of us and suggests that each person's method for making sense of our world is just as valid as any other (Crotty, 1998). Social constructivism; however, emphasizes that our culture has a strong hold on us and shapes the way that we see and feel things that gives us a rather definite worldview. For this study, I assumed a constructivist perspective to better understand young women's experiences with epilepsy.

According to Guba and Lincoln (1994), a constructivist perspective of the world tends to adopt relativist ontology. This is a way that constructivist researchers perceive reality. That is because reality is something that is 'constructed' by their personal experiences and culture that is specific to each person (Willis, 2007). Willis (2007) also used the term antifoundationalism, which essentially claims that there are no "universal truths" for humans. In terms of epistemology, constructivists are nominalists that are very subjective during the experience of social reality and life (Willis, 2007, Denzin & Lincoln, 2011). The rather personal nature of social constructions suggests that individual constructions can only be developed and produced through the interactions between and among the researcher and participants. Such varying constructions must then be interpreted, compared, and contrasted through verbal interchange in order to distinguish a construction that is encompassing of the information collected, as well as more informed than previously related studies (Guba & Lincoln, 1994).

Constructivism, just like any other theoretical research perspective, has several questions which set the foundation for the research study. They can be translated towards whatever topic it is that someone wishes to study in order for the research to follow the constructivist paradigm as closely as possible. Patton (2002) outlined questions in constructivism, such as how have the people in this setting constructed reality? Or for this study, how do young women view their own epilepsy and how it is a part of their life? What are their reported perceptions, accuracies, explanations, beliefs, and worldviews? Or, how do young women think others in society view epilepsy and especially their own epilepsy? Finally, what are the consequences of the constructions for their behaviours and for those with whom they interact? Again, for this study, such a question is, who do these women tell that they have epilepsy? (Patton, 2002). As a constructivist, these questions are the foundation for this thesis study and will lead to a distinctive perspective of the lived experience of epilepsy in young adult women and how that relates to their epilepsy disclosure.

## **Methodology**

Phenomenology is a type of research methodology that has disciplinary roots in philosophy and asks the central question, what is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people? (Patton, 2002). The majority of phenomenological research has been a result of the Duquesne Studies in Phenomenological Psychology, Volumes One to Four, which ultimately explained how interpretation can reveal what is hidden behind a specific objective phenomenon and ideally recognize signs that a person is really feeling understood

(Moustakas, 1994). Van Kaam (1966) derived a general description of feeling understood:

“The experience of “really feeling understood” is a perceptual-emotional Gestalt: A subject, perceiving that a person co-experiences what things mean to the subject and accepts him, feels, initially, relief from experiential loneliness, and, gradually, safe experiential communion with that person and with that which the subject perceives this person to represent (p.325-326).”

On the other hand, Van Kaam (1966) felt that pre-conceived experimental research designs and statistical analysis tend to impose on the participants and may distort, instead of disclose a specific behaviour due to constrained theoretical constructs on what a certain human behaviour truly means.

Meanwhile, heuristic inquiry (or heuristics), is a research methodology that is closely related to phenomenology, but has disciplinary roots in humanistic psychology and focuses exclusively and continually on understanding the human experience (Moustakas, 1994). The central question behind heuristics includes what my experience of this phenomenon is and the essential experience of others who also live this phenomenon intensely (Patton, 2002). In this case, I described my own experiences living with and disclosing epilepsy, then compared and reflected on the information provided by other young adult women that also live with and disclose epilepsy.

The term heuristic comes from the Greek word *heuriskein*, which means to discover or to find, and refers to a process of internal examination whereby one can discover the nature and meaning of a specific experience (Moustakas, 1990). Through

this internal search, one can then develop methods and procedures to further investigate and analyze the specific experience in question. Moustakas (1990) also explained that in heuristic research, the “self” of the researcher is present throughout the entire study to understand the phenomenon with increasing depth, but to also experience a growing self-awareness and knowledge to ideally lead to creative self-discovery. Through this study, I explained and contrasted my experience with epilepsy and how that related to other women of similar demographics in order to ultimately capture the *essence* of living with epilepsy in women of child-bearing ages through a subjective manner. As a result, the methodology which suited this study was that of heuristic inquiry.

Heuristics and phenomenology are closely related as they each attempt to gain an understanding of certain phenomena; however, there are specific differences between each that help to show how heuristics better suits this research study. These are especially highlighted when comparing heuristics to the phenomenological research of the Duquesne studies (Moustakas, 1994):

1. The Duquesne studies focus on a situation in which the experience investigated occurs, while heuristic research is a wide-open investigation whereby the research participant widely and deeply explores the phenomenon. It is rare for only one example or situation to be used to depict the participants’ experience.
2. In phenomenology, the researcher usually pursues descriptions of experience. In heuristics, the researcher seeks to attain self-dialogues, stories, poems, artwork, journals and diaries, and other personal documents that depict the experience, in addition to narrative descriptions.

3. Phenomenological studies look to build structures of the experience; meanwhile, heuristic research aims towards complex depictions that stay close to the individual stories. Heuristic studies culminate in a creative synthesis, while phenomenological studies end with more of a general description of an experience.

At the end of the day, phenomenology ends with the essence of experience, while heuristics preserves the essence of the person in the experience (Moustakas, 1990). Due to the fact that I am a person living with epilepsy that was studying other similar women, heuristic qualitative research was the clear path for this study. This is because I aimed to complete a highly in-depth, personal, and intimate account of the experiences that young adult women with epilepsy face in their daily lives and how their experiences relate to various factors in life.

Heuristic inquiry is arguably still on the periphery of the qualitative approach to research as it is gradually being taken up by scholars, especially in the fields of education, psychology, psychotherapy, counselling, nursing, and theological and transpersonal studies (Hiles et al., 2008, Kenny, 2012). As stated in the literature review, living with epilepsy can negatively affect the social and psychological state for a young adult woman. Thus, heuristics appropriately fit my intentions to illuminate the experience of living with epilepsy. Heuristic inquiry sets out a systematic and transparent methodology for self-inquiry (Hiles et al, 2008); which is what this study followed. However, there was a much greater self-inquiry as I am a young woman with epilepsy that investigated other young women living with epilepsy in order to capture the essence

behind our lives and the way in which we choose whether or not to conceal it from the rest of society.

According to Douglass and Moustakas (1985), heuristic research aims to discover meaning and essence of significant human experiences in everyday life. This specific research therefore fit the framework of heuristic research and was a highly disciplined, yet intimate search to cast light on to what it means for young women to live with epilepsy. Heuristic inquiry challenges the extremes of perceptions. Consequently, a passionate but disciplined approach was needed in order to attain academic credibility (Douglass & Moustakas, 1985). Due to the fact that I have been diagnosed with epilepsy for several years, have become involved in epilepsy advocacy, and have been taught as a graduate student how to conduct ethical qualitative research in applied health sciences, I believe that I was a strong candidate to carry out this heuristic study and ideally emerge with a credible, and enlightening thesis on what it means to be a young adult woman living with epilepsy in our current society. It is important to note; however, that since my personal experiences with the phenomenon are so closely tied to the research in question, I need to acknowledge the qualities of my tacit knowledge and intuition (Moustakas, 1990).

As stated by Kenny (2012), tacit knowing or knowledge, is a highly crucial component to any heuristic study and is essentially part of the basis for all heuristic discoveries. Tacit knowledge, according to Polanyi (1967), is an act of reflection that allows us access to achieve new meaning. When we exercise a skill, we essentially dwell in the various muscular acts that contribute to its purpose, which then leads to a joint

meaning and since all understanding is achieved by indwelling, then all understanding is tacit knowledge (Polanyi, 1967). Essentially, tacit knowledge is not openly expressed; it is instead an implied understanding. I therefore exercised tacit knowing throughout this entire study in order to enlighten the research and analysis.

Through the classic publication “Loneliness”, Moustakas (1961) launched heuristic research to be an organized and systematic form of research to investigate human experience in loneliness when he had to make a decision regarding his daughter’s heart defect and her need for an operation (Kenny, 2012). This research was then continued through explorations in *Loneliness and Love* (1972) and *The Touch of Loneliness* (1975) (Moustakas, 1990). Similar to other forms of research, heuristic inquiry went through continual evolution and was influenced by many other scholars. However, as heuristics evolved, Moustakas was present throughout the whole process to ultimately develop and write *Heuristic Research: Design, Methodology, and Applications* (1990), which is the heuristic publication guiding and influencing the methodology behind this study.

Heuristic qualitative research embodies the phenomenological emphasis on meanings and knowing through personal experience (Patton, 2002). Patton (2002) emphasized that heuristics exemplifies and places at the forefront the way in which the researcher is actually the primary instrument for inquiry, and in doing so, challenges scientific traditions of objectivity. To summarize, heuristic inquiry strongly personalizes research and put my voice and experience at the front and center throughout the study, while still encompassing the experiences of others in order to emerge with a definitive

exposition of the experiential essence of young adult women that live with epilepsy and their choices to conceal or show it in society.

There are several phases when exercising heuristic inquiry. The learning that proceeds the study has a path of its own and the steps of this methodology unfold spontaneously, but are guided at the same time by a strong desire to illuminate the experience in question (Douglass & Moustakas, 1985). There are a series of critical components in heuristics that Douglass and Moustakas organized into a three-phase model that included immersion, acquisition, and realization. They also stated that it is acceptable to change methods or procedures of the study in midstream, in order to connect as closely as possible with the meaning of the phenomenon in question. When Moustakas published *Heuristic Research: Design, Methodology, and Applications* in 1990; however, the phases of heuristic research were expanded to include initial engagement, immersion into the topic and question, incubation, illumination, explication, creative synthesis, and validation (Moustakas, 1990). The updated seven phases of heuristic inquiry shall be used in this study.

In the *initial engagement*, the research begins with the identification of a passionate interest with respect to the important social and universal meanings which have personal implications (Hiles et al., 2008). This required me to participate in frequent self-dialogue and an inner search to help further clarify the research question. I needed to tap into my tacit knowledge in order to help clarify the question and any underlying meanings (Hiles et al., 2008).

Because I had been studying the topic at hand for over five years with my faculty supervisor, the first phase of initial engagement had been ongoing since my first experience with epilepsy. In addition to frequent journaling and inner dialogue, I completed multiple literature reviews in epilepsy, personal narratives, an in-depth interview, and an undergraduate thesis titled “Exploring the Psychosocial Effects of Epilepsy – A Qualitative Inquiry into One young Woman’s Experience” (McGuire, 2010). Since February of 2012, I have served on the board of directors at Epilepsy Niagara. This is a non-profit organization that aims to improve the lives of people affected by epilepsy in the Niagara region. These activities have given me a strong connection to the social aspects of epilepsy and increased her knowledge of how epilepsy affects many different parts of society, in addition to clinical knowledge of the subject. In 2013 I performed a thesis presentation the Mapping New Knowledges Graduate Student Conference at Brock University which outlined the study in an attempt to spread knowledge about epilepsy among the academic community and inform others about the details of this study (McGuire, 2013). These documents were all submitted to Dr. Jarold Cosby; all activities have been completed since the fall of 2009 and have led to this graduate thesis, in addition to a strong sense of academic, social, and tacit knowledge in epilepsy.

The second phase of *immersion* required me to fully engage in as many dimensions as possible that connected to the question of interest (Hiles et al., 2008). This included intense exploration, following trails of information, self-dialogue, self-searching, and facilitation of the tacit dimension of knowing. To some, this is a phase in

the research process which may seem endless or boundless, but it is up to the researcher to remain disciplined and open to the experience so that they may recognize where this phase must end (Hiles et al., 2008). Once again, because I have been trained in qualitative research methods and studied many areas of epilepsy for several years now, I was confident in my ability to know when to remove myself from this research phase.

*Incubation* is the third phase of consolidation, whereby the focus was relaxed so that any emerging ideas could begin to take shape (Hiles et al., 2008). As a result, I took a “time out” from the research and pursue other activities and allow for any ideas or concepts to bloom. Accordingly, I continued my studies, but focused more on my own life and personal activities to allow for tacit knowledge to emerge and lead into the next phase.

The fourth phase of heuristic inquiry known as *illumination* actually occurred naturally and spontaneously in the relaxed and tacit state from the previous incubation phase (Hiles et al., 2008). Consequently, a meeting between both my conscious and the unconscious mind occurred whereby a synthesis of fragmented knowledge emerged out of the various aspects of the phenomenon being studied. To explain this in more manageable terms, the experience of the forgotten name is used. This is when someone is trying to remember a person’s name, but no matter how much they try, they cannot remember. But when the person is in a relaxed state, or doing something completely unrelated, the name enters their mind (Moustakas, 1990). In this phase, there was insight, an emotional connection occurred, and the universal significance was realized (Hiles et al., 2008). It was surely a phase of enlightenment and learning.

Phase five of *explication* added other dimensions of meanings whereby a full unfolding of the experience occurred (Patton, 2002). Through the processes of focusing, self-dialogue, and reflection, the experience in question was depicted and then delineated even further. As a result, new connections were made by further exploration into universal elements and primary themes of the experience of living with and disclosing epilepsy among young adult women.

During such heuristic analysis, I refined any emergent patterns and discovered relationships so that what arose was a depiction of the experience and portrayal of the specific individuals that were involved in the study as participants including myself (Patton, 2002). This analysis required me to draw from my tacit knowledge of living with epilepsy which, as Polanyi (1967) described is knowledge that is deeply internal, personal, and implicit. Since tacit knowing is inherently implicit (Polanyi, 1967), this caused me to acknowledge such personal knowing and bring it forth to the study. This was so the understanding of the experience of living with epilepsy could be brought forward in a creative and personal manner.

Once the previous phases were completed, the sixth phase of *creative synthesis* commenced so that I could communicate the findings of the study in a meaningful way (Patton, 2002). In this process, Patton (2002) explained that it requires the researcher to put together the significant “pieces” that have arisen throughout the study so that they come together into a total experience, which will show the various patterns and relationships that occur for young adult women that live with and disclose epilepsy. The

process of creative synthesis helps to show different perspectives and meanings so that a new vision of the experience can be revealed (Patton, 2002).

The seventh phase of *validation* required me to return to the various interviews I obtained over in order to check that the depiction of the experience of living with and disclosing epilepsy was comprehensive (Hiles et al., 2008). As Hiles et al. (2008) explained that final validation of the research is left to how the research is received by other people, such as my supervisor and committee, and is best established through creative synthesis with others.

In order to illustrate the process of heuristic inquiry research, a short example will be used. Two seemingly opposite experiences with epilepsy will be described to show just how different these epilepsy experiences can be, yet, commonalities can still be found. The first two stages of initial engagement and immersion were already in process with since 2009, as described in the various literature reviews, narratives, presentations, and the my undergraduate thesis (McGuire, 2010, McGuire, 2013). Once interviews with other young adult women began the rigorous process of heuristic inquiry allowed for further progression in each stage. After analysis of each interview transcript, the third phase of incubation occurred whereby common and more obvious themes were explicated. For instance, my original experience with epilepsy included relatively few seizures, which would likely be easier to manage with anti-seizure medication. However, because I have a hyper-sensitivity to those medications, my life was put in jeopardy on more than one occasion when doctors tried to treat me. Meanwhile, a young woman of similar age may have been dealing with multiple uncontrolled seizures which severely

debilitated her life, but when she began treatment with a new-generation anti-seizure medication such as Keppra, her seizures stopped entirely.

The above comparisons of young women's experiences with epilepsy may appear entirely different; however, once the fourth and fifth phases of illumination and explication began, a strong connection could be made between them thanks to the self-realization of tacit knowledge. For example, while my treatment with anti-seizure medication almost killed me, the other female's treatment led to a seizure-free life. The administration of these two women's treatments led to highly different results, yet, our lives were both changed forever when we began taking seizure medication. This and other young women's experiences with epilepsy could then be compared in the sixth phase of creative synthesis to show just how different each case of epilepsy can be from person to person; however, connections, commonalities, and perhaps even kinship can still be found among young adult women living with epilepsy.

It is important to follow Guba's (1981) model of rigor to achieve strong trustworthiness in this study. This included following the four criteria of credibility, transferability, dependability, and confirmability (Guba, 1981). First in credibility, a picture of the phenomenon under scrutiny was presented. Second, transferability was achieved by ensuring that there was enough descriptive information to allow for comparison of the results among other populations and/or situations to ensure variable applicability (Lincoln & Guba, 1985 & Krefting, 1991). Dependability occurred through continued studies by the current research and/or other academics to allow for further exploration of the phenomenon under investigation (Shenton, 2004). Finally,

confirmability occurred by having my faculty supervisor, Dr. Jarold Cosby, review the results and ensure that the findings did not emerge from any personal predispositions (Shenton, 2004 & Guba, 1981).

Trustworthiness was achieved in this study through discussion with my supervisor, Dr. Jarold Cosby, and thesis committee members at Brock University. Since Dr. Cosby and I had been working on this study topic since the fall of 2009, we gained robust insight into the academic dimensions of epilepsy research. I have not only been personally experiencing epilepsy, but over the past several years, have also been trained in qualitative research methods and studied the many social, psychological, and physical dimensions of epilepsy. These experiences have prepared my supervisor and me for an exploration of the experiences of young adult women living epilepsy and its various effects in our society.

Heuristic inquiry is far from an easy research process. In fact, due to the need for it to be highly personal, involved, and rigorous, any researchers that wish to take on such a task should be interested in self-inquiry and want a structured approach to work within but at the same time, not be overwhelmed by the strong possibility for the research to lead to unpredicted avenues of inquiry that may seem to have no end (Hiles et al., 2008). Craig (1978) explained the heuristic research process in the sense that the rigor of heuristic inquiry comes from systematic observation and dialogues with both you and others, in addition to the in-depth interviewing of participants. Consequently, this specific mode of inquiry embraces the chance that one can live deeply and passionately in the

moment, be fully immersed in mysteries and miracles, yet still be engaged in a meaningful research experience.

Other research methods such as grounded theory were considered but not chosen due to my personal relationship with epilepsy. Grounded theory aims to develop a new theory and perspective regarding a specific phenomenon. There are two approaches a researcher can take when applying grounded theory to their studies. Glaser (1992) emphasized induction and emergence of theory from whatever may come into the researcher's mind during their analysis. Meanwhile, Strauss and Corbin (1998) emphasized more of a systematic approach to analysis and trustworthiness. As a result, many qualitative researchers, including Glaser, continue to disagree on how grounded theory should be carried out. When examining the two approaches, it is apparent that this study conformed more to Glaser's approach to grounded theory as I wanted to let the themes and theories emerge on their own as the entire study was carried out. In order to avoid such a debate altogether, it became more apparent that heuristic inquiry would be the best approach for the study methodology. While the fact that grounded theory aims to derive a new academic theory was at first very appealing, it would not allow me to be as close to the study as desired (Glaser & Strauss, 1967). Heuristic inquiry in this study; however allowed for me to incorporate a bit more subjectivity and allow the results to emerge on their own. This allowed me to apply my perspective more to the study when compared to grounded theory.

Accordingly, the qualitative research methodology of heuristic inquiry was the clear choice for someone like me who wished to understand and essentially capture the

essence of the experience of living with and disclosing epilepsy among myself and other people in today's society. Because I am also a young adult woman living with epilepsy, I do not believe that any research methodology other than heuristic inquiry would have suited this study. In fact, I felt that because I am so closely tied to the research in question, I was able to complete a heuristic research study that bring forth new perspectives, accuracies, and insights for what it means to live with epilepsy in our society.

### **Design Strategies**

The nature of the phenomenon of living with epilepsy is one which is very personal and sometimes sensitive; therefore naturalistic inquiry was employed in the study. Close attention was paid to the participants' descriptions and outcomes of the phenomenon being studied. According to Moustakas (1994), the practice of *being with* required me to be present as my own person when compared to the participants, bring in my own knowledge, perspectives, and experience into the relationship all while also listening to the participants' feelings, thoughts, perspectives, and experiences without any manipulation by me during the interviews. This was employed to enrich both the interviews and subsequent analysis in the study.

Empathetic reflection was used in order to ethically and successfully involve a participant in a discussion of the personal phenomenon which we have both experienced (living with and disclosing epilepsy in society). Moustakas (1990) supports the idea and need for empathic approaches in heuristic inquiry as it is important to remain open to oneself as well as the participants. Accordingly, I showed interest in the descriptions and

experiences my participants told me in addition to staying conscious of my own reactions during each interview.

### **Role of the Researcher/Reflexivity**

**Impact of “the self” on the study.** Reflexivity is known as the process of critical reflection on the self as the researcher (Guba & Lincoln, 2011). In this specific study, my reflection significantly impacted how the research process was carried out. This is because my own experiences of being diagnosed and living with epilepsy have directly influenced the purpose, theoretical perspective, methodology, and methods of this study. The first seizure I was aware of was in the fall of 2009 and not long after, I was consequently diagnosed with epilepsy. Since then, I have and continue to experience the many effects of epilepsy. Over the past few years, I feel that epilepsy has become a part of my daily life and I will always have a connection to this neurological disorder. It was specifically the process I went through when I was first being diagnosed that ultimately led me to my graduate studies and this thesis topic.

The rationale for this research, as explicated in the introduction, was based upon the prevalence of epilepsy around the world, and specifically in first-world, western nations. Approximately one percent of the world’s population is diagnosed with epilepsy, which makes it one of the most common neurological disorders faced by people around the world (Kale, 1997). Additionally, the physical, psychological, and sociological impacts epilepsy has on women’s lives, along with a strong lack of understanding of epilepsy in society justified this study (Shuster, 1996, Luef, 2009 & Gopinath, Sarma & Thomas, 2011).

It is my personal experiences with epilepsy, specifically the diagnosis, effects on my daily life, lifestyle adjustments, and studies with Dr. Jarold Cosby over the past few years, which inspired and motivated me to learn more about epilepsy and help others that are diagnosed with it. Living with epilepsy for over five years has lead me to varied medical engagement, physical and psychological issues including migraine headaches, muscle tension, and mood problems, as well as a strong understanding of the lack of epilepsy awareness among society. The nature of my experiences with epilepsy over the past several years in relation to others living with epilepsy gave me strong insight into the different ways epilepsy can impact a person's life and consequently, the disclosure of the disorder to others. These experiences have shown me that each case of epilepsy is different, so the complications and treatments of epilepsy go far beyond the neurological seizures themselves and their pharmaceutical interventions.

When I started experiencing seizures and began the process of being diagnosed with epilepsy, I happened to be taking Dr. Jarold Cosby's "Health and Well-Being" course at Brock University. This was during what was thought to be my fourth and final year in university and I chose to take his course out of personal interest. After suffering my first tonic-clonic seizure during a midterm exam, I missed approximately two months of class and as a result, could not complete all of the five university courses I was taking at the time. Dr. Cosby gave me a chance to achieve his course credit by writing a personal narrative of the experiences I was going through at the time as much of what I was going through, both physically and psychologically, mirrored Dr. Cosby's course material.

This personal narrative (that was completed in December of 2009) was the starting point of my academic studies in the psychological and social sides of living with epilepsy. By describing my experiences in the hospital, school, and at home, I was able to show there are many gaps in the various aspects of research in epilepsy and that care in the diagnosis and management of this neurological condition is highly unstandardized. In order to complete the required number of credits to graduate with a Bachelor of Science degree in kinesiology, Dr. Cosby invited me to complete an undergraduate thesis study in the following fall semester of 2010.

To complete the undergraduate thesis titled “Exploring the Psychosocial Effects of Epilepsy – A Qualitative Inquiry into One young Woman’s Experience,” various forms of information was collected on my experiences with epilepsy over the past few years, in addition to a comprehensive literature review in the various domains of epilepsy (i.e. physical, social, psychological). Information in this study also included a chronological narrative, personal journal, and a two hour interview between Dr. Cosby and me to explain all of the things that were going on in my life since I was diagnosed. As a result, I achieved various forms of pilot evidence to design this study in heuristic inquiry. This is because I was already close to the research in both the personal and academic senses. Consequently, the impact of the self on this study is highly significant as I have not only influenced the design of the thesis, but also strongly impacted results of the study. For clarification regarding the timeline of evidence collection that led to this study, please see Appendix J.

Consequently, I believe that epilepsy is best understood through contextual and subjective meanings. This belief helps to explain the interpretive/constructivist theoretical perspective that guided this study and the highly personal heuristic research methodology that allowed for this research to take place. Additionally, my personal research over the past few years allowed for this study to evolve naturally. That is because I have experienced many personal highs and lows since my first major seizure, which has shown me the difficult physical, psychological, and social effects of epilepsy. These experiences have also caused me to desire better life in epilepsy for not only myself, but others as well. As a result, it is clear that my role as the researcher considerably influenced the purpose, nature, and design of this research study as heuristic inquiry allows for such personal relation to research (Moustakas, 1990).

### **Ethics**

The research conformed to all of the ethical guidelines that are present in the Tri-Council Statement: Ethical Conduct for Research Involving Humans (TCPS), which is clarified in section 8.1 of Brock University's Faculty Handbook concerning research ethics. An application for ethical review of research involving human participants was submitted to Brock University's Research Ethics Board (REB). This study was reviewed and received ethics clearance through the REB at Brock University on February 5, 2014 (13-1149 COSBY). All names and contact information collected were used for the lone purpose of this research protocol. Any identifying information was known solely by me and I followed all REB protocols to ensure confidentiality and anonymity of all participants. Identifying information was not shared with anyone other than Dr. Jarold

Cosby and an anonymity protocol was used to ensure there were no connections between participant information and the interview transcripts. Participants were strongly informed that any and all involvement in the research was strictly voluntary and that they had the right to decline participation at any time. Each participant was verbally informed of these rights during the initial contact with me and again immediately before the official interview began. All participants were also informed of their rights in writing in the informed consent form and confirmation letter.

### **The Interview**

Semi-structured, in-depth interviews are the most widely used interview format and are generally organized around a set of pre-determined open-ended questions so that others emerge as the dialogue between interviewer and interviewee progresses (DiCicco-Bloom & Crabtree, 2006). Polkinghorne (1983) explained that the interview process should include interaction between the researcher and participant in the context of a relationship and in an environment which allows for the establishment of safety and trust. This strongly applied to this study and the interviews which occurred as various aspects of living with epilepsy was discussed, which had the potential to appear sensitive to some of the participants. It was therefore of great importance to establish a trusting relationship between the researcher/interviewer and participant as various feelings and views regarding epilepsy were explored.

In order to allow for significant reflection and comparison during the interviews and analysis portion of the study, I also shared my experiences in epilepsy. This method allowed for the interviews to be very in-depth and rich in information; however, one

cannot choose such a method without identifying possible negative effects as well. The interviewee could have perceived my epilepsy disclosure as either a positive or negative component to the interview. For example, the interviewee may have felt more comfortable discussing their epilepsy, although, they could have also felt pressured to tell me more.

### **Shared Experiences in Illness**

When reviewing the approach this study took in trying to understand the experience of epilepsy in young adult women, one cannot ignore the influence of the primary student investigator on the methods and analysis. In that sense, one must acknowledge the shared experiences in epilepsy between the participants and me. That is because, as stated before, I am a young adult woman living with and studying epilepsy. As a result, the research conformed to the methodology of heuristic inquiry since this process requires the researcher to perform strong self-searching in order to discover the essence of the phenomenon in question (Brooks & Howie, 2008).

Previous research which supports the positive impact of academics with shared or lived-experiences in education and inquiry include a study by Happell et al. (2014) which examined the results of nursing students that had a teacher with previous mental health experience on their perceptions of nursing in mental health. Overall, the research revealed the benefits of having an academic with lived experience of mental health challenges in the promotion of nursing careers in mental health. At the same time, Cleary, Escott, Horsfall, Walter, and Jackson (2014) pointed out benefits of actively involving “consumers” into their relevant research. Essentially, studies including participants as

researchers have a strong potential to improve the quality of the research, in addition to the improvement of individual and health service outcomes (Horsfall, Cleary, Walter, & Malins, 2007). That is why the interviews were approached very calmly and my epilepsy was disclosed to them in a sincere manner while reminding them that they could tell me as much or as little as they desired.

### **Data Collection Procedures**

**Sampling Criteria.** Purposeful sampling was used to select participants with information-rich cases that would help lead to an in-depth understanding of the phenomenon in question (Patton, 2002). At the start of my graduate studies, the idea of studying a more general population of people living with epilepsy was considered to gain a more encompassing perspective in epilepsy disclosure. As my education in qualitative research methods progressed; however, I realized that personal involvement in the study was an inevitable part of the research. After consulting with my faculty supervisor and fellow classmates in applied health sciences at Brock University, it was more feasible to study a smaller population of women for this master's thesis.

Since it was my intention to include my own experience of the epilepsy phenomenon with that of other similar people, it was decided that it was best to focus on young adult women of child-bearing ability between the ages of 20 and 35 years. One should be reminded that young adult women have some different biological factors when living with epilepsy compared to other populations of PWE. These additions can include birth defects in pregnant women depending on medication choice, problems with the menstrual cycle, hormonal aggravation of seizure frequency, endocrine dysfunction,

decreased effectiveness of oral contraceptives, and sexual dysfunction, amongst others (Meador et al., 2009, Shuster, 1996 & Luef, 2009). As well, many women living with epilepsy may face various psychosocial problems in areas such as underemployment (even though many women have higher educations than their male counterparts), as well as problems with romantic relationships, marriage, mood, and anxiety (Gopinath, Sarma & Thomas, 2011).

Similarities between the participants and me included the ability to bear a child as well as being diagnosed and living with an active neurological form of epilepsy for at least one. That is because patients must go through multiple diagnostic tests such as a CAT scan, brain MRI, neurological exam, and the electroencephalogram (EEG) in order to diagnose epilepsy first, then it can take many months to find the right medication to manage the seizures and for the body to become physically used to the treatment (Wilner, 2003). In addition, patients may go through somewhat of a change in identity relating to their epilepsy (Faircloth, 1998); therefore, it was appropriate that the participants had an epilepsy diagnosis for at least one year to ensure they had adjusted significantly to life with epilepsy.

The study population included some participants who have only some experience with epilepsy as an adult and others who have a good deal of experience because the type, frequency, and disabling nature of epilepsy differs dramatically (Jacoby et al., 1998 & Salas-Puig et al., 2009). Thus, participants may have formed a strong career and income, marriage, child-birth, and other significant life events, whereas many others are restricted by their epilepsy and do not experience these life events. In addition, it was

important that the participants did not have psychogenic non-epileptic seizures, as they are not a result of having epilepsy. Instead, they are psychological in nature (Krumholz, 1999).

I chose not to include 18 and 19 year old women, as it is very possible that young women under the age of 20 have not yet experienced many of the essentially “adult” decisions and circumstances, when compared to their older colleagues. For example, 18 and 19 year old women may still leave many of their life’s important aspects such as medicine, finances, and overall health for their parents to manage. Consequently, it can be argued that several of those women likely have not experienced life as an adult quite long enough yet compared to those aged 20 to 35. That is why I chose to use the term “young adult women” instead of just young women.

**Sample Recruiting Procedures.** After receiving clearance from the Brock University Research Ethics Board (File #13-1149-COSBY), participants were recruited through purposeful advertising and word-of-mouth. In other words, invitations were extended to students, staff, and faculty at Brock University as well as the Executive Director of Epilepsy Niagara to advertise among the organization and its affiliates. Anyone who wished to participate could contact me via telephone or email which was provided in all forms of recruitment, and I screened them for their ability to participate and then set up interviews.

During initial contact with a potential participant, I sent the person an official letter of invitation for the research study providing further details of the study (See Appendix D), as well as an informed consent document (See Appendix E). The letter of

invitation and informed consent documents helped to fully explain the purpose and nature of the study, the requirements of participation, and the rights that each potential participant is entitled to. These forms supported potential participants to make an informed decision about participation. If a potential participant expressed a desire to learn more about the study, then I would ask for their telephone number to make contact with them so they may be screened for their ability to fit the requirements for participation. If the woman did fit the study requirements, then I contacted them once again to confirm their participation, setup an interview date, place, and time, and send them a confirmation email. This email included confirmation of their participation date and time, directions to Brock University (if that is where the interview was to take place), on-campus parking, where the interviews were to take place, as well as reminder that participation was voluntary and the study was confidential and ethical (See Appendix F, G & H). If any women did not fit the study's requirements or participation was no longer needed, they were once again contacted via telephone (See Appendix I).

### **Sample**

Participants included five women between the ages of 22 and 28 years that have had an active neurological diagnosis of epilepsy for at least one year. It was imperative that they were of child-bearing age and ability as well, in order to allow for some consistency among the participant sample. In addition, I was a part of the research sample since I contrasted my experience of living with and disclosing epilepsy to the participants that were interviewed. As a result, I have included an interview, chronological narrative, personal narrative and literature reviews regarding my personal and academic

experiences since being diagnosed with epilepsy. I have gone through many other stages and events in life and epilepsy since then. Consequently, I also provided current information for the study in the form of a personal narrative regarding my present and past experiences with epilepsy. According to Moustakas (1994) the process of heuristic inquiry aims to use six to 12 participants in a study to ensure enough information is captured, however, not all heuristic studies must reach this. When there is an appropriate amount of evidence, the range of six to twelve participants may not be needed. This range should be seen as more of a guideline since significant in-depth information was provided through the five women that participated in order to develop the Results and Conclusions and emerge with a perspective of the essence of life with epilepsy.

Charon (2006) explained the benefits of personal and subjective narratives and reflection as they can lead to more in-depth knowledge of what patients go through in illness. Personal narratives/narrative medicine in qualitative research can help to remove the barrier that may exist between patients and researchers. This may help patients open up more in appointments or interviews to provide more personal information and reduce or ideally eliminate the feeling of inferiority. According to Shenton (2004), reflective commentary throughout a study can help the researcher identify emergent themes as a study progresses. Such commentary can also contribute to project evaluation and the addition of questions or study methods to continue to produce legitimate results (Shenton, 2004). Perhaps one of the most pressing reasons for the use of significant reflexivity and personal narratives in qualitative methods is that reviewing and piecing together the past can help make sense of the present and future (Charmaz, 1999). Therefore, the subjective

use of information in the study allowed for a new social relationship between the researcher and participants, the development of trust during the interviews, and ultimately, an in-depth understanding of what life as a young adult woman living with epilepsy is like.

### **Data Collection**

**Researcher Input.** Personal reflective information provided by the author was in the form of both a past and present personal narrative which provided an additional experience of epilepsy to be included with the participant information gathered. This provided information that enriched the Discussion and Conclusions sections of this study (Charmaz, 1999). Charmaz (2002) explained that when the purpose of research is to discover and report patterns of thoughts, feelings, and actions, then the addition of the researcher's own collective story may provide a more compelling argument for the results.

Due to my significant personal experience and relationships in epilepsy, I am fairly adept as an epilepsy researcher. Based on my own struggles with this illness, I also gained insight into its medical and social treatment in society. As a result, reflexivity and subjective reflection in this study are a significant factor in the interpretation and presentation of results.

**Interviews.** Semi-structured, in-depth interviews are the main form of evidence in all forms of phenomenological research, including heuristic inquiry (Cresswell, 2007). As a result, participants were interviewed one-on-one on an in-depth and personal basis. The interviews ranged in time from 45 minutes to 1.5 hours. Each participant was informed

about the security measures in the study to ensure their information would be kept secure and then signed two copies of the informed consent document prior to the interview (one for themselves and one for records), and the interviews did not commence until this was completed.

All interviews took place in the Qualitative Interview Lab at Brock University located in Welch Hall 145. This lab was ideal for interviewing since it is a highly private room which has no windows to cause distraction for the interviewer or interviewee, was secured by a lock code, and off-limits to anyone else during the interview time to ensure total privacy and security during the interview. Furthermore, this lab contained comfortable leather couches and chairs to make the interviewee feel comfortable and ready to discuss the subject matter. The participants were told they could ask to take a break at any time during the interview.

All participants also were given the option to complete an interview at their home (if they lived in the region) or online. Two interviews were completed online while I was in the interview lab and no participants requested an interview in their own home. There was no reward for participating. Participants that completed an interview at Brock University were provided with a \$12.00 stipend for travel.

The interviews were semi-structured around both the day-to-day and significant events of living with and disclosing epilepsy. These events helped to provide the participant's experiences and "stories". As each interview progressed, I relied more on reflective questions to ideally provide an understanding of their experiences living with epilepsy. Refer to Appendix A for the general interview guide. Please note that it is only

a guide and not every question was asked, although all questions were typically eventually answered. Each interview was audio-recorded and transcribed verbatim by me. Upon the completion of the transcription process, over 100 pages of single-spaced interview transcripts were created that provided information about their experiences with epilepsy. All audio recordings and transcripts were kept confidential and secure by storing all files on a secure password-encrypted flash-drive and my personal laptop which was also password-protected. This ensured confidentiality and security for the study.

### **Analysis**

**The Seven Phases of Heuristic Inquiry.** As previously explained, there are seven essential phases in heuristic inquiry that were employed throughout the study to arrive at a result that was both inductive and creative regarding the phenomenon that young adult females experience when both living with and disclosing epilepsy. Those seven phases again are: initial engagement, immersion, incubation, illumination, explication, creative synthesis, and validation (Moustakas, 1990, Moustakas, 1994). Each of these phases were implemented throughout the study and analyzed in order to embrace the discovery of knowledge while still honouring the individuals and their experiences.

***Phase One – Initial Engagement.*** The first phase of heuristic research is the search for a specific topic and question which involves deep passion and connection that calls out to the researcher (Moustakas, 1990). As a result, the principal student investigator had been in the process of heuristic research essentially since she decided to understand the lived experience for young adult women living with epilepsy and how that relates to her own experiences. Heuristics required me to turn inwards and consider my

own experiences to be both personally fascinating and meaningful for sustained research (Moustakas, 1990). This evolution has been documented over the past five years since my epilepsy experience began in the Fall of 2009 through this research involvement, a related undergraduate thesis, personal narratives and journals, papers, and drafts of the research project proposal. The Initial Engagement phase was in a sense, active in my life since my initial experience and diagnosis of epilepsy. As a result, significant time, thinking, writing, and reviewing of the topic and question were devoted to this research study. This previous work has been organized and presented in Table 1 below.

Table 1 – Epilepsy Academia Timeline

Format	Date Completed	Academic Results
Health & Wellbeing course paper – detailed my experiences with epilepsy and related to course material	January 2010	- ignited decision to complete undergraduate thesis in epilepsy with Dr. Jarold Cosby
Personal Interview	October 2010	- Provided information for personal narrative
Personal Narrative in Epilepsy	October 2010	- Provided information for chronological narrative
Chronological Narrative in Epilepsy	November 2010	- Provided information for undergraduate thesis
“Social and Psychological Perceptions of Epilepsy: A Review”	October 2010	- Set academic foundation for undergraduate thesis
Undergraduate thesis: “Exploring the psychosocial effects of epilepsy – A qualitative inquiry into one young woman’s experience”	December 2010	- Led to the decision to complete a Master’s thesis in epilepsy under the supervision of Dr. Jarold Cosby
Literature review in epilepsy: “Epilepsy- Why do we still know so little?”	January 2012	- Set academic foundation for graduate thesis
Thesis Proposal Presentation at 2013 Mapping New Knowledges Conference: “Removing oneself from the shadows: A heuristic inquiry to understand the lived experience of epilepsy in young adult women and their epilepsy disclosure”	April 2013	- Provided information on the organization and preparation of the study - provided audience with a greater understanding of the purpose of the research

*Phase Two – Immersion.* The second phase, Immersion, starts in heuristics once the research question and specifications of it have been identified. (Moustakas, 1990). Moustakas identified that the researcher must be conscious of the research question at all times and become aware of “all possibilities for meaning” (Moustakas, 1990, p.28). I experienced this phase through on-going discussions with my graduate supervisor and fellow classmates, as well as immersive personal thoughts regarding the study phenomenon. It was clear at this point that if I was to study epilepsy, it would be most beneficial to work with heuristics and other young women living with epilepsy to take advantage of my subjectivity surrounding the question and how I could shed light on the subject in a way no other researcher has done yet in this academic area. Immersion was also experienced during the initial engagement with the interviews in order to identify meaning.

One participant was engaged at any given time. The general schedule was to interview a specific participant and immediately transcribe the interview within 48 hours. In between interviews, I reflected on notes taken during the interview and transcription, emails and verbal feedback from participants, as well as major themes the participants placed importance on. As a result, I was intensely immersed in each participant’s quotations, views, and experiences. During this process, I was also in a state of an on-going self-analysis. This caused me to reflect on my personal reactions and identifications/connections to and with the participants’ accounts of the phenomenon in question.

Notes and thoughts regarding any emerging themes, differences, and similarities between the participants and me were reviewed, reflected, and updated on a regular basis after each interview progressed. This allowed me to become increasingly aware of the individual accounts with epilepsy while the larger phenomenon unfolded in the study. Complete immersion in the study was achieved as I was situated in my own apartment in St. Catharines, Ontario or the Qualitative Interview Lab at Brock University.

*Phase Three – Incubation.* The third phase in heuristic inquiry, Incubation, is a time of detachment from the intense immersion of the second phase. Moving away from such strong research immersion allowed for me to internalize the obtained participant information. This allowed me to process the information and find more significant meaning.

Once the interviews were completed and transcribed, I left for a nearly two week family vacation in Harbor Springs, Michigan. During this time period, I was able to break away from the transcripts and let go of all the voices of the participants to allow for all the experiences and perspectives to manifest and grow into different groupings and combinations of themes. The second part of my vacation included a paid trip to Washington, D.C. as I was one of 20 young adults from across North America to attend the Young Adult Epilepsy Summit hosted by The Epilepsy Foundation and the North American Region International Bureau for Epilepsy (IBE). This was a three-day conference for young adults (ages 21-29) affected by epilepsy to come together and share our experiences in epilepsy to ultimately design an epilepsy awareness project to be implemented across North America. The second portion of my “break” from research not

only allowed me to meet other young individuals living with and affected by epilepsy, but it also allowed me to pay witness to real-time phenomenon of being a young adult woman living with and disclosing epilepsy. Additionally, the major themes found in the interviews were reinforced by the young adults at this summit as they were expressed regularly throughout the weekend.

Witnessing firsthand the phenomenon of being a young adult woman living with and disclosing epilepsy gave me significant inspiration and made it easier to let go of the collected information and just live in the moment. Throughout my vacation and summit experience, I would journal any new thoughts or insights; however, I found myself predominately reflecting on my own experiences and how they related to the participants. The witnessing of the phenomenon at the summit caused me to realize just how significant the research themes were and continued to fuel my passion for not only this research study, but also for future studies in epilepsy. The Epilepsy Summit was an enlightening personal experience in itself, in addition to reinforcement of the emergent themes.

***Phase Four – Illumination.*** During the Illumination phase, I returned to conscious awareness of the interviews. According to Moustakas (1990), Illumination is a time “when the researcher is open and receptive to tacit knowledge and intuition” (p.29). In other words, this was a time when the most prominent themes were identified by accumulating new knowledge and perspectives (Moustakas, 1990). This was a full return to the information in order to discover and acknowledge the prominent research themes.

In order to achieve this, I went back to the participant interview transcripts one at a time to build a complete representation of them as individuals. This involved understanding their lived context and perspectives on epilepsy, and their personal experiences with epilepsy disclosure, as well as the intersection of the two. This was done by essentially following the thematic goals of the interview guide. As the interviews progressed, the goal was to understand the participant's experiences, feelings, and decisions towards life with epilepsy. Consequently, the complete perspectives and lived experiences of each individual were gathered and identified.

Once a complete set of the participants' thoughts were organized, I began the process of merging together the complete stories for each person with my voice as the narrator of their perspectives in order to gain tacit knowledge. By honouring the participants' voices and perspectives in life with epilepsy into their story, tacit relevance of individual statements could then emerge later on.

For the practice of self-study, I re-read all of my personal journals, undergraduate thesis, and academic epilepsy articles from the past five years. In addition, I listened to all voice notes I had made since being diagnosed with epilepsy. Consequently, a vast personal reflection was possible that explored my life and thoughts with epilepsy in the academic, professional, and personal everyday dimensions. From these various sources, I was able to design an outline of the major themes of my own experiences and their outcomes that were most prominent in the interviews. During this process, I became especially aware of the differences and similarities between mine and others' perceptions of living with and disclosing epilepsy as the interviews progressed and since attending

the Young Adult Epilepsy Summit. This allowed my documented thoughts to incubate and develop into an expression of myself in the research. This was done while staying mindful not to overindulge in my own story and keep the participants' experiences at the forefront. I did this by constantly reviewing the different transcripts of each participant interview while simultaneously reviewing my own. This allowed me to keep the participants' experiences in mind while also exploring mine. Therefore, there was an equal representation of each participant experience in addition to my own. At this time, I also started considering how different bodies of literature and previous studies in epilepsy helped to inform the emerging themes. To follow the heuristic methodology, review and consideration of various literature was carried out continuously right through to the identification of the essence of being a young adult woman living with epilepsy (Moustakas, 1990).

It is important to know when one is "illuminated." We cannot necessarily go to a quiet place or mountaintop to ponder and discover all meaning. Instead, the process of illumination predominantly occurred through a slow and gradual process. Much of the illumination was unconscious until review of my further interaction with other people outside of the study. I have met many people diagnosed with epilepsy since interviewing the study participants and they continue to illuminate the social interaction that occurs between those who have epilepsy.

Looking back, the single moment where illumination was achieved was when I attended the Young Adult Epilepsy Summit in July 2014. At this conference, I met 19 other young adults living with or close to epilepsy from across all of North America. By

discussing various topics in epilepsy, similar interactions occurred as what was experienced during the interviews. Everyone was extremely open to discussing their epilepsy, sharing their stories, and understanding others. This experience brought the illumination to fruition and made the resulting theory highly conscious in my mind. Such illumination continues to be demonstrated through both my shared and observed experiences among people living with epilepsy. This was when I knew I could move to the next phase of explication to share and explain the concept in detail.

*Phase Five – Explication.* The fifth phase of heuristic study known as Explication required me to move on from theme recognition to the formulation of explanations that are meaningful and more understandable for any person to read this thesis (Moustakas, 1990). As a result, I had to explicate the most prominent themes of the phenomenon of being a young adult woman living with and disclosing epilepsy in North American society. This caused me to narrow the various themes and sub-themes discovered in the Illumination phase into the most important and meaningful characteristics of the phenomenon.

During this phase, the stories that were merged together previously were examined as a whole, all while keeping the individual stories in mind to ensure all participants' voices were included in the final thesis document. Therefore, the individual final themes were placed into a cross case summary to identify and verify the major themes for the whole study to explicate the essence of the phenomenon. Supporting themes were clustered together similar to the individual cases analyses to help make connections between the different final themes of each individual case. It should also be

noted that the supporting themes represent the foundation of the final thesis statements and conclusions.

Once the cross case summary was complete, a cross case analysis was performed in order to conceptualize cross case themes that were based upon the supporting themes of the cross case summary. Multiple specific themes then began to emerge in the summary. Those included a seizures, medical treatment, and social relationships. Subthemes were then developed under each of the major three themes.

***Phase Six – Creative Synthesis.*** This was the section of the analysis whereby I moved from the final themes to a write up and a final statement that outlined the meanings of the experiences for the participants involved (Smith et al., 2003). This required me to translate each of the final themes into a narrative account, so that the themes could be explained, illustrated, and justified. According to Smith et al. (2003), this final section of the analysis clearly distinguishes between what the participants said and the researcher's interpretation of it. Before writing this section, I spent significant time thinking of and interpreting the various ways to conceptualize and present each of the final themes as different (but interconnected) ideas that build upon each other.

***Phase Seven – Validation.*** In order to complete the final stage of heuristic inquiry, I had to return to the information on multiple occasions to ensure that the depiction of the experiences were comprehensive, vivid, and accurate. Validation or trustworthiness was further enhanced through review of the manuscript by Dr. Jarold Cosby, the graduate supervisor. Even further validation occurs through the internal and external thesis defenses. Final validation will occur depending on how the research is

received through avenues such as publication and presentation. By sharing the creative synthesis with others, the trustworthiness of the heuristic research is established (Moustakas, 1990).

## Chapter 4 – Results

Chapter four contains descriptive biographies of the primary researcher (myself, Suzanne) and the participants Amy, Anne, Daisy, Katie, and Karen. The biographies help to give the reader information about the lives of the participants and the circumstances that surround their experience of life as a young woman with epilepsy. These biographies consist of all pertinent information including demographics and any other relevant information the participants provided to help to understand and contextualize their experience of life with epilepsy and how that ultimately determined their epilepsy disclosure among various people in society. These descriptions are meant to be accessible to the reader and essentially ‘story-like’. That is so the reader can have a greater understanding of the context of the participants’ lives and experiences with epilepsy as young adult women. In order to keep the stories clear and concise for the reader as well as consistent with the heuristic methodology, the biographical experiences of each participant are voiced through the primary researcher (Moustakas, 1990). In that sense, I served as the narrator for each participant. When the thesis is written in this way, it helps to set the tone for the remaining chapters to give a clear picture of the essence of being a young adult woman living with and disclosing epilepsy in current society (Moutakas, 1990).

Pseudonyms were assigned to all participants to ensure their identities remained anonymous. Some information regarding the participants’ lives, family, and friends were also omitted to keep their personal information confidential. For example, the names of home cities, well-known places of work, schools, etc. were taken out so their identities

were not revealed. Meanwhile, the details and information regarding my own life have been kept intact to make sure my own experiences remain transparent.

It should also be recognized that there were some differences in the various participant accounts in terms of the volume of information presented and the depth of their details. This does not mean there is preference for one participant over another. Instead, it is an honest account of the amount of detail, clarity, and understanding of their experience from the interviews (Johnson, 2007).

### **Participant Stories**

**Suzanne.** I was born and raised in Sault Ste. Marie until I graduated high school at 17 years of age and moved to St. Catharines, Ontario to attend Brock University for a Bachelor of Science in the field of kinesiology. Little did I know that my life would change forever in my fourth year of studies during a biomechanics midterm exam. All I can remember is solving the various physics problems in the test, then the next thing I knew, I was waking up with a paramedic beside me telling me that I just had a seizure. October 26<sup>th</sup>, 2009; it was a day that I can barely remember and yet, will never forget. This was the beginning of my journey with epilepsy that has had a great impact on the person I am today and who I will continue to become.

Who knew that a day at school would turn into a whirlwind of events over the next several years, which, as I write this thesis, continues to evolve and affect my life in ways I never thought possible? Once I was officially diagnosed with idiopathic generalized epilepsy in January 2010, I faced many challenges to not only complete my undergraduate degree at Brock University, but to also choose whether or not to take

medication for my seizures. This is because I have anti-convulsant hyperactivity disorder to most anti-epileptic medications. This of course was not discovered until my life was put in jeopardy on two separate occasions- not by seizures- but by the doctors and nurses who treated me. I was told that I had a second seizure in the ER and so they intravenously gave me Dilantin or Phenytoin, a very powerful anti-seizure medication. Little did they know I was severely allergic to this medication and my body could not properly metabolize it. The doctor then gave me another medication called Keppra or Levetiracetam (which I was also allergic to) and I went into anaphylactic shock. After being diagnosed with epilepsy, I learned that anti-seizure medication should not be given to a person until they are diagnosed with epilepsy or another type of seizure disorder. So the doctors and nurses treating me basically did the opposite. One would think by now that seizure treatment would be standardized and well-known, but as I learned from the interviews in this study, it certainly is not.

Before I knew it, my driver's licence was suspended, I was being referred to a local neurologist, and I had to travel the Niagara Region for multiple tests, such as an electroencephalogram (EEG) and a brain MRI. It was easy to arrange an EEG; however, I could not receive an MRI until over three months later. My parents and I were afraid that I may have had a brain tumour or lesion and so we decided to go straight to Buffalo, New York where we paid over \$500 to get the scan that same day. It was expensive, but something had to be done.

Thankfully, the MRI was clear and I did not have any anatomical problems with my brain. Instead, I have excess electrical activity in my brain neurons causing me to be

diagnosed with epilepsy and psychomotor seizures. It took quite some time before that diagnosis was reached as the first neurologist I was referred to in St. Catharines basically told me he wasn't sure what to do and that I should get a second opinion from another doctor. There one was problem though; he didn't refer me to anyone else. I literally had to use my professional connections to start seeing Dr. Joseph Bruni in Toronto, Ontario as the original neurologist basically abandoned me and left me to deal with my medical situation on my own.

Dr. Bruni was able to come to the conclusion after careful review and consideration of my medical files that I actually have a strong hypersensitivity to virtually all anti-seizure medications. This is a condition known as anticonvulsant hypersensitivity disorder or AHD. As a result, I started taking the medication Clobazam or Frisium, which has the lowest rate of side-effects, but because I am literally sensitive to those medications, I have multiple life-altering side effects. Those include constant tension headaches, short-term memory loss, severe drowsiness and lack of stamina, among many others. I was told that it is ultimately my choice if I want to take this medication, but when you are dealing with dangerous seizures that could put one's life in jeopardy, that didn't really feel like a choice. While my seizures are not fully managed and may never be, medication still makes a difference in the number of seizures I have and brings me significant mental comfort. I don't want to live with such strong daily side effects, but I also don't want to be paranoid that I could have a seizure at any moment.

Looking back at the past several years, it has been an emotional, physical, and psychological rollercoaster ride. This is likely due to the fact that my body has had a very

difficult time adjusting to my medication, but also because I have refused to let epilepsy stand in my way. That is why I turned my diagnosis into this chance to study the lived experience of epilepsy in young adult women at Brock University for a Master's degree in Applied Health Sciences and ultimately, to educate others about this neurological condition. Now that my master's degree is complete, I plan to continue advocacy work in epilepsy both voluntarily and through a career as well. I joined the Board of Directors for Epilepsy Niagara in early 2012 to start making a difference in the epilepsy community and want to continue to help the organization for as long as I can. That is because I believe regional groups like them can make a strong and positive impact on society and how others view epilepsy.

Currently, my life is challenged by epilepsy as I have poor stamina, suffer from severe chronic headaches, and some short-term memory loss. As a result, I sleep much more than a 26 year old woman should, take painkillers all too often, lose my train of thought a lot, and cannot always work a regular "nine to five" schedule. Thankfully my schooling allowed for a flexible schedule, but I am rather concerned about how I will be able to perform in my future career. It is the effects of my anti-seizure medication that challenge my daily life more than the epilepsy itself. Not only do I need to deal with medication side effects, but the social effects of epilepsy cannot be ignored. Over the past five years, I found it very difficult to have a romantic relationship. I was constantly trying to feel physically and emotionally better and it was as if nothing else mattered. I felt alone and isolated and unfortunately some of those feelings continue today. I fight a very constant battle with epilepsy, however, it has made me a stronger person today.

Not only is epilepsy very misunderstood by the general public, it is also highly stigmatized as I have learned through both academic reviews and personal experience. While I have been the subject of some initial stigma around epilepsy, I have not been as affected by prejudice against epilepsy compared to many other people. As a result, I openly disclose my epilepsy in the public and wear it with pride to hopefully teach others that there is no reason to think any less of anyone who has epilepsy. As a whole, epilepsy is simply a neurological condition that causes a person to have recurrent seizures. I firmly believe that we as a society must dispel the myths about seizures that still exist to this day; epilepsy is not contagious, not demonic possession, does not make you mentally handicapped, is a neurological condition and not mental, and you should never put a spoon in someone's mouth during a seizure.

As the past several years have gone by, there is no doubt that my life has changed dramatically. My journey to fully comprehend the implications and outcomes of being a young adult woman living with and disclosing epilepsy truly began to be understood once I began my academic journey at Brock University to complete my undergraduate degree and then become a Master's student under the supervision of Dr. Jarold Cosby.

**Adrienne.** Adrienne is a 22-year old woman currently working as a restaurant server and was diagnosed with juvenile myoclonic epilepsy a few years ago after an uphill battle with the first neurologist she was referred to. Her first seizure happened when she was drinking with friends. She woke up on the ground and her friends called an ambulance to help. Once the ambulance and paramedics arrived, they simply brushed the seizure off by coming to the conclusion that she was "just dehydrated." Approximately

18 months later; however, Adrienne had a second seizure which caused her to hit her head on the bathtub in her washroom at home. She had no warning and once she came to, all she remembered was her boyfriend screaming (except she couldn't recognize who he was at the time).

As a result, her driver's licence was suspended, she was referred to a local neurologist, and just like me, and she soon started to feel like a significant part of her independence as a young woman was taken away. Once she saw the local neurologist, she asked for a referral to another doctor because he just kept increasing her dosage of the anti-seizure medication Tegretol without having any seizure reduction or benefit. She also said that this doctor was rude to her and as a result, felt like he couldn't wait to send her to another doctor.

Once Adrienne was referred to another neurologist in another city approximately two hours away, she was told that the first electroencephalogram (EEG) performed on her was actually misinterpreted. After having a second EEG under the supervision of her new doctor, she was diagnosed properly and prescribed correct medication that now manages her seizures. It took approximately one year for her to be properly diagnosed with epilepsy and treated using the medication Keppra with no significant side effects that interfere with her daily life. In addition, she admires her doctor as he listens to her during check-ups and takes into account her actual life with epilepsy, not just the medical diagnosis itself.

Adrienne has now been seizure-free for over two years and recently gained back the legal ability to drive. Once getting her driver's licence back, she felt like she had her

independence as a young woman again. It was not an easy journey for Adrienne to deal with her epilepsy, as she suffered from terrible seizure-related anxiety issues. When walking to the downtown bus terminal, less than one block away from her apartment, she would become paranoid about having a seizure in public and her heart would start to race as she feared going to work. Thankfully, Adrienne has a female cousin that is also living with epilepsy. Therefore, when talking to her cousin, she felt more comfortable discussing her epilepsy and they even joke around about it together. This helped her feel normal again and she expressed how lucky she was to have such a close relationship with this cousin, in addition to having no treatment side effects.

It has not been as easy for Adrienne to discuss her epilepsy with other people in her life, especially her boyfriend (now ex-boyfriend), close friends, and mother. When she would tell her friends about her seizures and how to follow proper first aid if she did have one, it was like they did not take her seriously enough and would immediately ask if they should grab her tongue when it happened. She said they would also fail to recognize her inability to drive and even say she should do it anyway.

Her boyfriend at the time also did not understand why she would get so tired and did not respect the fact that she would have seizures at night and needed to rest. Adrienne thought they had a very strong relationship together; however, she felt like her life with epilepsy interfered with their connection and ultimately led to its demise. This was reinforced even more as Adrienne's boyfriend cheated on her with her best friend while she was in the process of being diagnosed. She is no longer dating that man or friends with the other woman anymore.

Relationships with her mother and father have been (and even continue to be) tested when it comes to Adrienne having epilepsy. That is because she feels like her mother is very over-bearing as she text messages and calls Adrienne multiple times a day to make sure she is ok and it frustrates Adrienne significantly. It makes her feel like a child because even though her seizures have been managed for over two years now, her mother still checks up on her just as much. During her initial appointments with her neurologist, Adrienne's mother would join her and even answer the doctor's questions for her, only further reinforcing her feelings of dependence on others. She is thankful that she has a mother who cares so much, but also thinks her mother needs to back off at times and just let Adrienne live her life. When it comes to discussing her epilepsy with her father, Adrienne expressed that she felt some disconnect in their relationship as he could not even talk about it without her father crying. He just couldn't talk about the seizures and epilepsy with her.

In terms of being a young woman living with epilepsy, Adrienne expressed that she does feel things are different for females compared to males. That is because her seizures seem to revolve around her monthly hormonal cycle like "clockwork." Additionally she has already spoken to her doctor about pregnancy in the future and the complications that can surround it. Even though Adrienne has no plans to become pregnant with her boyfriend anytime soon, she can't help but think about the complications that could arise from having epilepsy and a child at the same time.

Looking to the future, Adrienne is excited as she feels that her current medication, Keppra, has given her life back. She isn't scared about having seizures

anymore and is back to the person she was before the epilepsy and seizures began.

Adrienne was very thankful to be able to discuss her epilepsy with me and became a bit emotional towards the end of the interview. She felt as if she had made a new friendship the day we spoke.

**Amy.** After hearing about my research, Amy was very willing to participate and share her journey with epilepsy over the past few years. She went through a very tiring diagnosis process which caused her to seek better medical help approximately two hours away from her hometown. Amy was diagnosed about six years ago with catamenal epilepsy when she was roughly 20 years old. She is now 26 years old and currently works as an employment counsellor after completing a four year undergraduate degree in psychology and then two years in college studying social work.

Amy's specific form of epilepsy is catamenal, in the sense that her seizures tend to revolve around her monthly hormonal cycle and are triggered once a month by those hormone changes around her period. She used to be able to predict down to the day when she was going to have seizures. Medical professionals did not believe her when she told them this; however, as they just brushed her off and said she is simply a stressed out university student. Therefore, Amy had to fight the medical system to see a neurologist that understood this.

Looking back, Amy started having small seizures as early as high school when she described having small twitches that were very random. She knew something wasn't right and went to a nearby hospital where they told her to simply "deal with it." Then one day in the summer after her first year of university, she asked her father to drive her to

work instead of taking her own car as she just didn't feel right. On the way to work, she then had a tonic-clonic seizure and found herself waking up in her father's car going the other way back home after taking her to the emergency room, but she had no memory of being there. She only remembered being very disoriented and tired. Both Amy and I were able to understand and share in the experience of having no memory whatsoever of the event. She just remembered going to work and the next thing she knew she was back at home.

Amy was not fully diagnosed with epilepsy until about four years later after seeking the help of several neurologists. Because the doctors would not believe her when she told them her seizures revolved around her period, she had to take the research into her own hands by keeping a seizure journal, recording how she felt, and printing out various research articles explaining catamenal epilepsy and how the birth control shot can help some women manage their seizures. She had to basically beg her doctors to let her try that treatment and it wasn't until she was referred to another neurologist back in her hometown that she was allowed to try it.

Amy was correct about the nature of her epilepsy and since starting the birth control shot every three months, she has been seizure free for over two years. In addition, she takes a low daily dose of the medication Keppra with minimal side effects. The Keppra serves as a form of backup protection if her birth control shot fails to fully manage her seizures. Amy respected the doctors and their opinions, but expressed that most of them would not listen to her and felt somewhat belittled by medical professionals. She expressed that she knows how she feels more than anyone else.

Amy is now able to drive again; however she could not for several years. As a result, her family had to transport her to various medical appointments across the province and help her with daily tasks that required her to be driven somewhere. She is very thankful to have such a caring family that was so willing to help out as she knows that many other people in our society are unfortunately not surrounded by such similar caring family members and friends. She feels for those who do not have the same help she did when being diagnosed and having to travel so much.

When asked to describe epilepsy in one word, Amy expressed that it is “complex”. By this, she means that everyone who has epilepsy is different and just because a certain medication works on one person, does not mean it will work for everyone. She enjoys hearing about other people’s experiences and reactions with epilepsy to get a better understanding of just how complex and different life with epilepsy can be.

Even though Amy has been seizure-free for over two years now, she still has significant anxiety about having more seizures, especially after having one while driving a few years ago. Since then, she’s been seizure free again, but feels like her ‘expiry date’ is coming anytime soon. In that sense, she thinks that she can only stay seizure-free for so long before another tonic-clonic seizure must break through. As a result, Amy stays in close contact with her parents, checking in with them multiple times a day, even though she now lives on her own. Her fear of seizures is exacerbated when she discloses her epilepsy to other people in her life. That is because they make her think about the serious consequences that can result from seizures. Before some people asked what would

happen if she hit her head from a seizure or hurt herself, she was not thinking about such things. When other people would tell her about those consequences; however, Amy couldn't get such thoughts out of her head and only became more anxious and fearful of the unknown. She became trapped in this circular process as the anxiety continued to feed itself and grow larger.

Amy is not the only person in her life that worries about her epilepsy as her parents will ask how she is doing every day to make sure she is ok. She couldn't help but express that her independence often feels belittled and insignificant. Amy lives by herself, but still sees her parents every day. While she feels like her parents are overbearing, she reminds herself that she is lucky to have such a caring family.

Amy described how difficult it was to date men and until she met her current boyfriend, was rather reluctant to tell other men that she had epilepsy. One young man even told her that her condition was too significant and simply did not want to deal with it in his life. As a result, she did not tell her current boyfriend that she had epilepsy until several weeks of dating. He was upset at first because she did not say anything before, but Amy asked him to try and put himself in her shoes- then he might understand. She even reported that some people have told her that her seizures weren't being caused by hormones. Instead, she said that several people she has come across with her epilepsy just say that she's "just being too emotional" or "too much of a woman", which simply isn't true.

When asked about any future plans to have a family and children, Amy responded by saying she definitely would like to start a family in the years to come; however, she

cannot help but think about the possible negative consequences of caring for a child. Her doctor even told her that pregnancy may actually help to get her hormones (and therefore seizures) under better management. Yet, Amy cannot help but think she will drop her baby and

also chooses not to hold other young babies that her friends have because she doesn't want to be responsible for dropping their child. As Amy discussed the topic of pregnancy and child care, she became a bit more worried and couldn't help but think of all the possible negative effects, such as passing medication through breastfeeding, becoming sleep deprived, and as a result, putting her child's life in danger. As such, she has a rather pessimistic about having a child because of her epilepsy.

Looking to the future, Amy certainly has some fears about living with epilepsy and especially being a mom. In addition, she is rather reluctant to try new things such as zip lining and vacationing in other countries. Frustrations about small things she could not do such as take baths, go to concerts with strong light shows, and go on rollercoaster rides bother her sometimes just as much as the epilepsy itself. She is a strong woman but she was a bit upset when explaining those frustrations. Even though she has no desires to try some of the things a person with epilepsy should stay away from, she can't help but think that it simply isn't fair; if she did want to ride a rollercoaster, perform adrenaline sports, etc., she simply could not. We connected significantly and were able to vent out some of our similar frustrations to each other. There is no doubt that Amy has not let any of those feelings or experiences stop her from becoming a successful employment

counsellor and now fights for equality in epilepsy by advocating for more public awareness about seizures.

**Daisy.** Daisy is a 28 year old woman currently attending university to obtain her Ph.D. and was diagnosed approximately six years ago with juvenile myoclonic epilepsy. In 2008 she was awarded a scholarship to study psychology in Canada after moving from her home country in Southeast Asia. At the time, she did not know she had epilepsy and it wasn't until she participated in a sleep deprivation research study that her diagnosis turned out "by accident." When asked how she was diagnosed, she stated that it was in fact a "very convoluted answer." That is because she probably was having seizures as early as 10 years of age; however, this was not recognized until after her diagnosis.

About half of the way through the sleep study, Daisy was eliminated from participating as one of the research students said she was "acting weird." Then, no more than two months later, she was speaking with her teacher and then entered into an absence seizure in which she just "zoned out." Her teacher told Daisy that she had an absence seizure, but she wouldn't believe her as she does not remember her seizures. However, she cooperated with her teacher and went to the hospital. After returning from hospital, Daisy asked the sleep study professor for her sleep study data and that is when her professor took her into her office and told her she had epilepsy based on the EEG sleep data.

Thanks to her academic connections, Daisy was able to be diagnosed within one month of entering into the sleep research study. Contrary to all of the other women involved in this study, Daisy had a very fast and efficient diagnosis process, but in a

sense, she still had to be in the ‘right place and right time’ to identify her epilepsy. Things were complicated more once Daisy was medicated to manage her seizures. She was given a fairly common dosage of the medication named Topamax. In addition to strong drowsiness, Daisy had major difficulty in the understanding and processing of the English language because it is her third language. After returning home for some time and visiting a doctor in her home country, he determined that because she is of Asian descent, her body metabolizes medication differently compared to the majority of people treated in Western style medicine. As a result, she was on too much medication and had her dosage reduced once returning to school in Canada.

After receiving a lower, more proper prescription of Topamax, Daisy has come to peace with her epilepsy and doesn’t let it define her. She is very active and has significantly reduced seizures that she is unaware of unless she wakes up in pain. At times, she even forgets she has epilepsy until she is reminded by her inability to drive a motor vehicle. Because she was diagnosed with epilepsy as an adult; however, Daisy believes that it has been a bit easier to cope with her lifestyle adjustments and is also very thankful for being in the field of academia. That is because she believes medical conditions such as epilepsy can be more accepting in academics as her teachers gave her more time to complete her work and everyone at her job in psychiatry was trained and educated in epilepsy and seizure first-aid. She even found a “silver lining” in the whole experience as her grades actually went up after receiving proper treatment.

Daisy is a highly educated individual that has learned a great deal about epilepsy since being diagnosed and was very enthusiastic about participating in this research

study. Even though she has not necessarily been the subject of major epilepsy stigma like me, she has formed significant opinions on epilepsy in society and ultimately wants a better public voice for people living with epilepsy. When it comes to disclosure of her epilepsy in society, Daisy doesn't really force the fact that she has epilepsy on others except for safety purposes in places like school, work, sports, etc. The majority of people she interacts with on a daily basis already know she has epilepsy and therefore she doesn't feel like she needs to say much about it. Even though she acknowledges her epilepsy and tells other people when she needs to, Daisy insists that epilepsy does not define her.

**Katie.** Katie is a 28 year old woman who is married, has children, and lives with generalized epilepsy. Katie's first seizure was at 16 years of age when she was at a party with friends drinking underage. She thought at the time this was an isolated incident and therefore swore everyone who witnessed that first event to secrecy. About one year later, she had a second seizure and was then diagnosed with epilepsy. Katie believes her seizures are aggravated by changes in her hormonal cycle each month, but her doctor cannot find exactly where her seizures are coming from or why they happen.

Katie has had many seizures in her lifetime in both very private and public places. She has to laugh at some of the instances where she had a seizure, or else she may let sadness overcome her at times. When she was diagnosed with epilepsy, some of her family members actually wanted her to hide her epilepsy; however, Katie believes in "putting it out on the table" for not only safety reasons, but also because it is "a part of"

her. She does not tell absolutely everyone she meets that she has epilepsy, but believes in being honest about it if you are to spend any significant amount of time with her.

When asked about her independence, Katie expressed that she is thankful to have a very loving husband that will take her anywhere she needs to go. Although, she still feels very restricted in her ability to go places and do things at times. In addition, she can't help but feel emotional and sorry for herself after some of her seizures. Anxiety is a significant part of Katie's life as she gets very nervous doing simple things like walking her dog down the street. She can't help but wonder what would happen if she had a seizure and was out alone. It is a major source of anxiety in her life as she was also in denial of her epilepsy diagnosis for several years.

Katie has been unable to find a proper anti-seizure treatment that she can handle and manages her seizures, but believes that day is yet to come. Becoming pregnant and nursing did reduce her seizure frequency somewhat. This only furthers her belief that her menstrual cycle affects her seizures. When Katie was pregnant she couldn't help but feel even more anxious as she would often fear falling on her stomach and hurting the baby. Thankfully, such a thing did not happen, but it plagued her thoughts during pregnancy and unfortunately has not gotten any better since having children. If anything, Katie has become increasingly conscious of her seizures and their possible consequences.

Katie's epilepsy can be a stressful factor in her marriage as well. At times, Katie can't help but feel her husband is too overbearing and worried about her safety. For example, when searching for their current home, they put a lot of thought into what the stairs should be like, if any. That is because Katie's husband will insist on walking up the

stairs behind her in fear that she will have a seizure and fall. Katie knows that is just her husband caring about her at the end of the day, but she can't help but feel too dependent at times. Her worry of future seizures and having her health put in jeopardy only exacerbates such anxiety as she cannot bear the thought of dying from a seizure and leaving her family, but still cannot stop the thoughts from entering her mind.

Before this interview, Katie had not met another person living with epilepsy, let alone another young woman with it. As a result, she was very comforted by my statements and willingness to listen to her. We developed a significant bond within minutes of meeting each other. That is because she was very enthusiastic to meet me was very thankful to have someone to talk to about her epilepsy and have them understand.

**Carly.** Carly is also a 28 year old married woman that is currently a Ph.D. student at a prestigious university. She was diagnosed with partial epilepsy approximately two years ago but looking back, has in fact been having seizures for the past three years. Her epilepsy diagnosis is not set in stone; however, as standard EEG's cannot seem to localize in her brain where the partial seizures that generalize into tonic-clonic events are coming from. As a result, she needs to be admitted to an epilepsy monitoring unit (EMU) once again to perform a 24-hour video EEG where she will ideally have a seizure and then have her epilepsy properly diagnosed. Carly is not the only participant to have an evolving diagnosis as several other women interviewed had to see several physicians over the period of one or more years to achieve proper diagnosis. I also relate strongly to her evolving diagnosis as it was originally thought that I simply had a generalized diagnosis of epilepsy that was essentially over my whole brain. After being admitted to the EMU at

Toronto Western Hospital back in September, it is now apparent after five years that I actually have a highly localized form of right temporal lobe epilepsy and may in fact be a strong candidate for epilepsy surgery.

The first time Carly recognized she had a seizure was when she was home alone one night while her husband was at his bachelor party. At the time she did not know it was a seizure as she had very little knowledge about epilepsy and seizures, so she truly thought she just fainted. Looking back, it was in fact a generalized tonic-clonic seizure as she felt terrible afterwards and said she felt like she was terribly hung over- the aches and pains were so bad.

As Carly was referred to a local neurologist, she became frustrated with the doctor's care as he didn't believe she was truly having seizures. This was only because she did not bite her tongue during them. It wasn't until she suffered a very major seizure that she was admitted to the hospital and the EMU it had. While recovering from her previous major seizure in the EMU, she had a second on camera and with the EEG electrodes glued on her head. It was then clear that she did in fact have epilepsy and was rather relieved to have a diagnosis in addition to being referred to a neurologist in that same hospital. Since then, Carly has been treated with the medications Lamotrigine and Topamax; however, her seizures are still not fully managed and she suffers from two to three partial complex seizures a month in addition to a recent increase in generalized tonic-clonic seizures.

Since Carly's seizures have increased in previous months, she began taking Topamax which helps her seizure management a bit more, but gives her very debilitating

side effects. She insists on using the nickname “dopamax” for the medication as she literally feels “doped up.” As a result, Carly has had to take a temporary leave of absence from her doctoral education program. It was a bit of a fight at first as she is close to finishing her doctorate; however, she eventually gave in and came to the conclusion that it was for the best to ensure her health. That is because she is very drowsy most of the time as that is a common side effect of many medications, but she also described difficulty with language expression as well. This has significantly affected her abilities to remember certain words and complete her sentences at times. Carly described this as “a disconnect from what I’m thinking and what comes out of my mouth.” Even though she knows it is a side effect of her medication, she can’t help but get frustrated and “feel stupid” as a result.

Since being diagnosed with epilepsy, Carly has gained a great deal of knowledge surrounding epilepsy and is quite aware of the social stigma around it. While she has not been the direct subject of stigma, she knows other people have which motivates her to want to help others living with epilepsy. Carly couldn’t help but express how the relationship with her parents has changed in some ways since she has been diagnosed with epilepsy. Because her family lives very far away, her parents had only heard of Carly having seizures until recently when they came to visit her. After they witnessed her have a seizure for the first time, Carly’s parents were very shocked and told Carly that “it was as if they saw me in a different way.”

Carly's epilepsy has also caused some stress in her marriage in the past as sometimes she and her husband will argue over her safety and tensions will build. However, they try not to let it frustrate them too much. There is no doubt that Carly's epilepsy and safety has at times, been a point of contention in their marriage. Carly wants to one day have a child, but also can't help but feel anxious about her baby's safety and how her epilepsy may affect her childcare. That is why she hopes to soon be readmitted to the EMU at the hospital so the doctors may come up with a more conclusive epilepsy diagnosis so she could get better treatment one day.

When it comes to disclosing her epilepsy to others, Carly is fine with telling people she has seizures, but only in the right context. She believes it is very situation-specific and not all scenarios call for her to disclose. Epilepsy is not something Carly is embarrassed about, but she doesn't go around introducing herself to others and saying she has epilepsy along with her name. Carly is hopeful about the future and is now feeling better so that she may continue her academic studies and live a happy seizure-free life, but cannot help but be all too realistic about her condition.

**Participant Summary.** All of the participants interviewed in this study were young individuals that were very interested in discussing their epilepsy. None of the participants were over the age of thirty; however, two of them were married and one had children. Each of the women expressed their dismay with the stigma surrounding epilepsy and how awareness in society needs to increase. While each participant's experience with epilepsy was different from diagnosis to continued and changed treatment, I could not help but relate to nearly everything they said in terms of emotions

and/or opinions surrounding epilepsy. Whether or not a participant chose to hide or show their epilepsy, I could understand their reasons for doing so based on my own experiences with epilepsy.

### **Theme Development**

All participants were living with epilepsy for at least two years. Two of the participants had fully managed epilepsy in the sense that their anti-seizure medication completely managed their seizures from recurring for a period of at least one year. This did not mean that their epilepsy was cured as the underlying susceptibility to neurological seizures still existed. The other four women interviewed, including myself, have unmanaged epilepsy in the sense that they have not been able to find a medical treatment such as medication or surgery to completely manage their seizures. Varied forms of epilepsy existed among the participants including juvenile myoclonic epilepsy, catamenal epilepsy, idiopathic generalized epilepsy, and partial epilepsy; however, all participants have suffered from at least one tonic-clonic seizure in their lifetime. Tonic-clonic seizures, as described before, are also known as grand-mal seizures which include static neurological muscle tension, followed by repetitive muscle contractions. While there are other forms of seizures based on the specific type of epilepsy one lives with, tonic-clonic seizures are often known as the “stereotypical seizure” which makes sense as they are also the most publically visible compared to other forms.

In some cases, the participants’ epilepsy developed during childhood/teen years while in others, their epilepsy did not develop until they were already living as a young adult woman. Regardless of when epilepsy developed, it was chronic and continues to

affect all participants' daily lives. All women that participated, including myself, are taking some form of anti-seizure medication and one participant receives a birth control shot every three months as well to manage her seizures.

Subtheme #1.1 "Fear of Future Seizures" was apparent with all participants; even in the participants that had fully managed seizures. As a result, Subtheme #1.2 "Social Anxiety" followed with examples not only in public places, but also in the home. Based on the literature and length of time epilepsy has been studied and witnessed by human beings, the epilepsy diagnosis has been standardized as described by Bruni (1995). However, Subtheme #2.1 "Varied Diagnosis Processes" showed that such standardized procedures were not uniform because the process of being diagnosed with epilepsy differed significantly from participant to participant. Only one of the six participants was diagnosed with epilepsy in the standardized procedure within just over one month of her first seizure. All other participants were not diagnosed and treated for epilepsy until a minimum of six months after their first witnessed seizure. After being diagnosed with epilepsy and treated, the many effects of epilepsy began to set in for all participants. These included various physical, social, and psychological effects that were not experienced before their seizures and/or treatment started. As a result, Subtheme #2.2 "Medical Treatment Side Effects" was distinguished.

Due to the fact that people with unmanaged epilepsy cannot legally drive in Canada, in addition to various other restrictions and fears, Subtheme #2.3 "Lack of Independence" was all too apparent. As you will see in the literature review, this follows various other research studies in epilepsy. This led to the development of Subtheme #2.4

“Frustration with the Medical System” as the majority of woman interviewed, including myself, had to seek the help of more than one neurologist to eventually become properly diagnosed and treated. Three of the six participants, including myself, also had to travel a minimum of 1.5 hours outside of their hometown to receive proper treatment.

Each woman that contacted me was very determined to discuss their epilepsy experiences and how others see them. Subtheme #3.1 describes this as a “Surprised by Stigma” as all participants expressed their experiences in society and how the public seems to misunderstand epilepsy. Furthermore, this emphasis on the social stigma of epilepsy was fueled by their own experiences with seizures witnessed by various people in their lives such as family members, friends, employers, doctors, teachers, and many others.

Upon review of the interviews and after personal reflection, Subtheme #3.2 “Varied Experiences, Similar Understanding” was apparent as each participants’ personal experiences with epilepsy were different. Although, we, could all relate to those differences with an underlying understanding of the hardships and injustice many people living with epilepsy can and do face. Even if one of the participants did not have the same experiences with specific aspects of life with epilepsy, such as medication side effects, when compared to me, and vice versa, we could all relate to many of the hardships and struggles each other went through. During each interview, we were all able to even joke about epilepsy-specific aspects such as losing the ability to drive and forgetting names, words, and/or sentences because of medication side effects.

Such connection and understanding significantly contributed to Subtheme #3.3 “Development of Fictive Kinship.” Fictive kinship is described by Woodward and Jenkins (2011) as “strong emotional ties between individuals across various groups” and occurs among non-blood relationships. Theme #3.3 is one of the most prominent Subthemes in the study as it was developed with all participants. This theme is reinforced further by me as I have experienced similar connections with other people living with epilepsy that were not involved in this study. Upon identification of this theme, personal reflection, my attendance to the North American Young Adult Epilepsy Summit, and admission to the Epilepsy Monitoring Unit at Toronto Western Hospital resonated even further with me as I have developed similar fictive kinship ties with many other individuals living with epilepsy- not just other young adult women. Subtheme #3.4 “Epilepsy Disclosure” was apparent not only from the interviews, but also more so from the feedback I received once the interviews had been completed. This was due to the fact that I was told by various participants vocally and through email that they felt somewhat “empowered” to talk about their epilepsy after speaking with me. Finally Subtheme #3.5 “Patients Studying Patients” was present throughout the study as I could relate to virtually everything the participants told me in relation to their epilepsy. In addition, several participants expressed their gratitude for knowing that someone who has epilepsy is studying it.

In order to reinforce the themes presented, I provided various personal quotations at the end of each theme section, designated as ‘Suzanne’, and/or as a paraphrased summative response to a theme. The quotations were taken from a collection of essays,

research papers and personal communication with my academic supervisor over the past five years. These themes were also reinforced after attending the Young Adult Epilepsy Summit as some of the other attendees expressed how much more comfortable they felt talking about and disclosing their epilepsy during and after the summit. Table 1 outlines each of the themes including a theme description and notes on the theme development. The themes are numbered primarily for convenience in identifying and do not necessarily reflect the order in which they emerged.

Table 2 – Outline of Themes

Theme #	Theme Name	Theme Description
1	Seizures	- The aspect of having seizures composed a significant amount of the interview time
1.1	Fear of Future Seizures	- All participants said they were or are currently afraid to experience more seizures, especially if their seizures were unmanaged, or they were pregnant/caring for their child - Fear of hurting themselves or others
1.2	Social Anxiety	- Developed anxious feelings around public seizures - Anxiety across various private and public experiences or thoughts with seizures
2	Medical Treatment	- All participants received medical treatment for their seizures resulting in various effects on their lives
2.1	Varied Diagnosis Processes	- Diagnosis time periods to epilepsy were highly varied & unstandardized
2.2	Medical Treatment Side Effects	- All participants experienced at least one major side effect from their medication(s) - Significantly affected their lives due to factors like pain, drowsiness, headache, difficulty in the processing and expression of language, etc.
2.3	Lack of Independence	- Several participants expressed how their lives were limited in some way or another - All women stated frustration with the inability to drive, both previously and presently
2.4	Frustration with Medical System	- Due to problems/delays in diagnoses, five of the six participants often had an increase in frustration and anger with the public medical system - Frustration increased also when proper treatment could not be found
3	Social Relationships	- Various aspects of the participants lives and social relationships were affected by their seizures and epilepsy diagnosis - All participants contacted the researcher and were very enthusiastic about participation - Each woman was eager to be interviewed and have their voice heard
3.1	Surprised by Stigma	- Participants expressed their dismay with public misunderstanding and stigma in epilepsy - Wish for better education in epilepsy

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Table 2 – Outline of Themes		
Theme #	Theme Name	Theme Description
3.2	Varied Experiences, Similar Understanding	<ul style="list-style-type: none"> <li>- All participants had unique experiences with epilepsy</li> <li>- There were many differences and similarities across their experiences</li> <li>- Even if the researcher and/or participant didn't have the same experiences with epilepsy, they could still identify with the other person's feelings and/or comfort the other in some way</li> </ul>
3.3	Development of Fictive Kinship	<ul style="list-style-type: none"> <li>- Fictive kinship is a non-blood form of kinship that can develop between people with some type of commonality</li> <li>- Fictive kinship was developed between the researcher and all participants as conversation around epilepsy and life was very fluid</li> </ul>
3.4	Epilepsy Disclosure	<ul style="list-style-type: none"> <li>- A participant's epilepsy disclosure did not depend on good or bad experiences</li> <li>- A person is not fully in or out of the shadows – their disclosure varies from situation to situation</li> </ul>
3.5	Patients Studying Patients	<ul style="list-style-type: none"> <li>- Once fictive kinship was established, the participants were more comfortable discussing their epilepsy and some expressed their motivation to be more confident with their epilepsy after contact with the researcher</li> <li>- This provided the opportunity to study life with epilepsy in an very in-depth manner</li> </ul>

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**Theme #1 – Seizures**

**Subtheme #1.1 - Fear of Future Seizures.** All participants involved in this study including myself, fear from time to time the very real and likely possibility for future seizures- all except for Daisy. Because Daisy is a very confident and intelligent woman that has her seizures almost under management and the few that she does have, are in her sleep. The remaining women made a point of explaining their past and present fear of having more seizures and what that could mean for them or their families. Even the two participants that did have managed epilepsy (Carly, Katie) still could not help but discuss their worry of having seizures. “I’m terribly scared that I will die for some reason or I guess death caused by a seizure. And leaving my family, that causes me fear all of the time.” (Katie)

I don’t really feel like I can do what I want to do. I mean I’m at a place now where my seizures aren’t controlled and I’m having a lot of side effects from my medication. So I’m at peace with the fact that I have epilepsy, but I would definitely like better seizure control and I would like to find a better medication without the strong side effects like what I’m getting in my Topamax. (Carly)

But then I also have fears. I think to myself “can I be home alone with the kids?” Like, can I hold the kid? Right now, I see friends with their babies and they’re like, do you want to hold the baby? “No, because I really don’t want to be responsible for dropping your child when I have a seizure.” That’s what I’m thinking in my head. So that’s fearful to me, um, the whole holding the baby and

what happens, if that. So what if I'm along with a kid and I have to take them to the hospital. Like in a moment of stress, and stress is supposed to make it worse right. So it could be a trigger. So if I'm stressed out...what happens? (Amy)

Daisy was the one exception to this theme as she has good management of her seizures and the few that she does have are usually just in her sleep. As a result, she sometimes even forgets she has epilepsy. However, while she tries not to worry, she can't help but be a bit afraid for her possible future baby. As a result, a similar fear exists:

My main concern for being a woman with epilepsy is getting pregnant on my meds. That could be bad as the chances to have a natural birth are a bit lower for me. I try not to worry about it though. (Daisy)

It should be noted that when asked about having seizures, Daisy did have to think about the answer for over 30 seconds before responding.

One of my biggest fears then became having another seizure in public and embarrassing myself again. (Suzanne)

**Summary.** Due to the fact that epilepsy is a neurological condition which leads to recurrent seizures (Bruni, 1995), patients living with epilepsy can become very fearful and worried about having them. This was highly evident in the research as all participants except Daisy discussed their common fear of having seizures and in a sense, living with epilepsy. I related to all of their answers regarding fears of seizures as I have gone through multiple processes of full seizure management to totally unmanaged seizures. Looking at all of the information collected, the topic of having seizures composed a significant portion of the interview time. Even in the participants that have their seizures

almost or fully managed their experiences with seizures were discussed throughout the study.

**Subtheme #1.2 - Social Anxiety.** Based on the foundation which the previous theme of a “fear of future seizures” set, the social anxiety that came along with having seizures and epilepsy was the next logical theme in this study. Subthemes 1.1 and 1.2 in a sense, go hand-in-hand as their fears naturally caused significant anxiety in their lives from having seizures and choosing whether or not to disclose their epilepsy to others. Their fears surround the physical consequences of having seizures in society.

As you will see from the following quotations, anxiety is a very prominent theme in the lived experience of being a young woman with epilepsy:

I definitely get a bit of anxiety even just walking the dog, I'm very aware of my surroundings because I'm afraid that if I have a seizure, I hope, like if I saw someone on the street, I immediately think what would they do if I had a seizure right now? (Katie)

I feel very anxious, to be honest. I've actually been at a state where I was seizure free for about a year and a half. And then I was driving and had a seizure while driving. Since that thing happened, to me now I feel like I'm just waiting for the ball to drop. I'm just waiting for it to happen and I think the more I go (seizure-free), the more I'm just waiting for it to happen. Because I was a year and a half before and now I'm two years. So now is my expiry date supposed to happen any time soon? And I think that is my biggest struggle now. When I was having

seizures I felt more at peace because then it was, “ok this is what I have.” Where right now it’s like, “Do I? Don’t I? Do I? Don’t I? It’s hard! Like ahhhh!” I’m very anxious now, I find about it. (Amy)

Even though it’s such a short walk to the bus terminal, I would get such bad anxiety sometimes that I wouldn’t want to go to work...”What if I had a seizure right now just waiting for the bus?” Then my heart would start to race.

(Adrienne)

Once again, Daisy was the only exception to this theme of social anxiety as it is strongly related to the previous theme of a fear of future seizures. She does not necessarily condone living in fear as she does not fear her well-managed seizures, but she does recognize why some people may experience anxiety, and therefore promotes more positive thinking:

Many of the bad images and stereotypes in epilepsy today are still self-reinforced and some people may feel that they have a certain entitled behaviour. Maybe it’s not you’re seizures; it’s your attitude... “There’s a silver lining if you look for it.”

(Daisy)

Not only do my seizures and medical side effects stress me out every day, but this condition and its poor treatment over the years has put a great deal of stress on my friendships, family, and romantic relationships. Sometimes I just can’t take the pain each day. (Suzanne)

*Summary.* Overall, each participant could relate to the social anxiety that living with epilepsy and having seizures can cause both from direct and indirect experiences in their lives. This theme of social anxiety is strongly tied to the previous theme of a fear of future seizures. This is due to the stress that can occur from past, present, and future seizures. Also, based on the answers of several participants, thinking about previous seizures can cause stress around the possible consequences of future seizures. This can develop as you will see in Carly's quote above, into a feed-forward cycle of anxiety from the thought of seizures to an increase in current seizures fueled by that same anxiety.

## **Theme #2 - Medical Treatment**

**Subtheme #2.1 - Varied Diagnosis Processes.** Based on the information gathered from this study, it is evident that there is a strong disconnect between the recommended diagnosis and treatment procedures doctors should follow in epilepsy compared to what actually happens in the emergency room or doctor's office. Each of the participants told of their experiences with the medical system and the road to an epilepsy diagnosis. All processes were different and complex in their own ways instead of following a common diagnosis pathway in medicine. Consequently, the time it took to achieve a proper epilepsy diagnosis varied from one month, to four years and counting. Carly has had to wait a significant period of time to get a proper diagnosis and treatment. It is known that her brain has epilepsy; however, her diagnosis is still evolving after more than two years of treatment as her epilepsy is very complex and cannot be localized:

It was a little bit complicated. First I saw my family doctor and she referred me to a neurologist. The neurologist I saw was in my community and he was not the greatest. Like, I really didn't like him. But he decided because I didn't bite my tongue but I have seizures, he was not convinced that they were seizures. So he wanted me to get an MRI before he diagnosed it as epilepsy. This was the thing, and of course there's a huge waiting list for MRI's right? Like a huge waiting list. And so in the meantime, he was like, "I don't want to put you on medication because medication can be really hard on your body." So in the meantime he was leaving me having seizures because I wasn't biting my tongue. He did send me for an EEG, but there wasn't any abnormal activity because I didn't have a seizure during the EEG....So finally, I was kind of fighting with him about that but he really just wasn't budging on it. So finally I had a really major seizure where I ended up going to the emergency room where they admitted me to the hospital and from there a bed opened up in the monitoring unit....while I was there, I guess I had a seizure in the monitoring unit and they diagnosed me there. So, sort of a weird way to diagnosis. (Carly)

Um I going to say like 3 or 4 years, maybe? I went through my family doctor here, and then they referred me to someone at (hospital name removed for confidentiality purposes), and with my past experiences at (hospital), I thought they were a great hospital, but with my jerks, I felt like it was just a "deal with it" and with epilepsy, you don't just deal with it. So then I was referred to another

person in Hamilton who then told me that she didn't feel qualified enough for my case. So then she referred me to someone in London and with all the specialists its time right? Like a lot of time. (Amy)

He`s an ass, he`s so rude. I had to ask for a second opinion because he just kept upping my dose of Tegretol with no control...He just never made me feel good...I had to ask for a second opinion as I wasn't getting results...it was like he couldn't wait to get me off of his hands. (Adrienne)

I definitely can relate to the epilepsy diagnosis process as I was given the medication Dilantin and then Keppra, which I was highly allergic to. Also, my local neurologist didn't know what to do with me for treatment and said I should get a second opinion. I respected his statement to see another doctor; however, he did not refer me to anyone else. I had to use personal contacts to start seeing a neurologist in Toronto in the summer of 2014.

*Summary.* It is clear that there was not a standardized diagnosis process in epilepsy care for the participants, as Daisy was diagnosed quickly, while the rest took varying amounts of time. As a result, many of the participants explained their frustration with the medical system, which leads into the fourth theme.

**Subtheme #2.2 - Medical Treatment Side Effects.** More frustration with medicine can develop as one's journey with epilepsy continues, especially when it comes to medication side effects and their consequences in daily life, as the medicines work directly on a person's brain to essentially calm it down, resulting in a vast array of

physical effects. Daisy's comment about her treatment side effects was very blunt, but full of information about her day to day life, especially when she was receiving too high a dose of Tegretol: "I felt like I was high all of the time." She then went to add more about the depth of her side effects:

My medication affects my menstrual cycle and makes me feel like I'm pregnant half of the time. I get my period only about three times a year, have nausea, vomiting- like morning sickness. My main concern for being a woman with epilepsy is getting pregnant on my medication. That would be bad because the chances to have a natural birth are lower. (Daisy)

As Carly's life with epilepsy has evolved, so has her epilepsy and therefore the frequency of her seizures. Since adding a second medication (Topamax) to her epilepsy treatment regime, the side effects and their intensity have been so unbearable, that she has had to take time off from school. She knows she is a smart woman, but she can't help herself from feeling terrible about her current state at times:

At first it was really bad, but now I'm starting to adjust to it. I'm a little bit worried. I'm taking a leave of absence from my program right now and I am a Ph.D. student, so when I started on it (Topamax), I had a really hard time remembering basic words. I would have these little moments where I would be trying to remember things like "dog." So it is getting a lot better now, but I have trouble with memory. Sometimes I think there's a disconnect between what I think and then what comes out of my mouth. I just feel a little stupid... (Carly)

The first medication he described supposedly controlled generalized seizures well, but had more pronounced side effects. Meanwhile, the second choice was the opposite whereby it generally showed fewer side effects, but did not always control seizures as well. Because I had such violent reactions to the first two medications I was given, I chose the second drug called Clobazam. I kind of felt like it would be the lesser of two evils. (Suzanne)

*Summary.* When examining the theme of medical side effects, significant levels exist. Those include the choices of which treatment or medication, if at all a young woman should take in an attempt to manage and ideally eliminate their seizures. It is a significant decision in a young woman's life and for the majority must be made multiple times during the course of their treatment. The side effects of anti-seizure medications can be rather intrusive on a young woman's health and well-being in terms of the side effects, strengths, effectiveness, and tolerability.

Another dimension of the medical treatment of epilepsy in young adult women which resulted largely due to the intrusiveness of medication on a participant's life was the evolution of their treatment, quality of life, and overall productiveness. Medication side effects can be so strong that they physically intrude on a participant's life and even command it. For example, side effects such as drowsiness, headaches, nausea, etc. can cause someone to be physically limited in the amount of work they can perform, the information they can learn, and the overall production they can make in their lives. The more difficulty a participant had with anti-seizure treatment, the more likely they were to make the decision to change treatments and see the components of

their life with epilepsy evolve. In summary, the medical treatment of epilepsy in young adult women is a strong component of their lives and in some cases can significantly alter it.

**Subtheme #2.3 - Lack of Independence.** Another very prominent theme in this study was the independence that is lost when a person is diagnosed with epilepsy. The lack of independence that commonly comes along with epilepsy in this research is largely due to the loss of personal safety from seizures and the inability to legally operate a motor vehicle. Driving and independence were strongly related to each other as a topic in epilepsy discussion. The following quotes help to illustrate how the participants' epilepsy can lead to a common lack of independence both subjectively and objectively.

Katie was diagnosed with epilepsy before she received her driver's licence and therefore never had to go through the process of having her licence suspended by her doctor and the government. At the same time, she could not help but relate her inability to drive a car back to her feelings of lacking personal independence to do various things in life:

Luckily I never had my licence taken away from me. I have friends who drove so I just was slow in getting it. So I just never got it, but being a mother of two children and on maternity leave, I really notice it. Someone has to take me to and from work if I'm working. I can't just run out to the store during the day with the kids if I need something. We always have to wait for my husband to be home so we can all do it together or he can go out on his own and at times, I feel very restricted. (Katie)

Amy also described the frustration that comes along with having epilepsy and the restrictions it places on her independence:

“Right now I’m really lucky because I live down the street from my job. BUT, what if I move? I always have to think to myself, ‘location!’ Like I need to be on a bus route, right?” (Amy). “Yeah it’s true and it’s one of those things where no, I don’t have a desire to, but if I wanted to, I couldn’t.” (Amy)

We paid the thousand dollars or whatever it costs to get into Disney, realized I couldn’t do anything, so we just walked around and left! Like it was just one of those things where you’re like “Really?” like and that’s where it hits you. It’s not an everyday thing but there are moments where you’re like, “this sucks.” Like yes I’m thankful for how great it’s been because some people can’t even go like a minute without having a seizure or other crazy things like that. But then you get these other things where it’s like” ah this sucks!” (Amy)

Daisy has a good life in the sense that she has good seizure management and will sometimes forget she has seizures, but she can’t help but be affected by the social consequences of life with epilepsy:

“I don’t let it bother me, except for when I can’t drive or go swimming alone.” (Daisy)

At the same time, Carly is not happy with the restrictions some people think that epilepsy places on their independence. It is like she feels the loss is an intrusion on who she is as a person:

It bothers me when people make assumptions about what I can or can't do, even though some of their assumptions may be right...I would prefer it if I am the one who decides what my limits are instead of making those choices for me....With family members, I know their actions come from a place of concern, but sometimes I would like them to realize that I am an adult and I can make my own decisions. (Carly)

“One thing my husband wanted was for me to get a helmet to wear around the house. I was like ‘That’s not gonna happen!’ It’s like a symbol of lost identity” (Carly).

Adrienne, at the same time, described just how she felt once her driver’s licence was reinstated after becoming seizure-free:

Life was hard without a car. I bussed everywhere and would cry to myself as I think sometimes “I hate my life”, but then I know it could be worse. I didn’t let it get the best of me, but when I found out I could drive again, I cried and felt like I had my independence back. (Adrienne)

At the time, I could barely stay conscious, let alone realize what the consequences would be for losing my licence. Not only did I lose the ability to drive my first car I acquired only months before, but I lost much of my new found independence, and therefore happiness. (Suzanne, 2010)

**Summary.** It is evident that all participants feel like their lives and who they were as a person was intruded upon significantly when they were diagnosed and proceeded to live with epilepsy. Consequently, it can be stated that the lived experience of epilepsy in

young adult women is meaningfully connected to a feeling of lost independence and restrictions put on their lifestyles. This was even more apparent after reviewing the interview portions that included the participants' inability to drive. As a result, one can conclude that epilepsy both physically and emotionally takes away from a young adult woman's independence in society. In addition, the ability to legally operate a motor vehicle is a strong component of a young adult woman's independence in our Western society.

**Subtheme #2.4 - Frustration with Medical System.** Due to the previous theme and the following participant quotations, the theme of frustration with the medical system stood out from the first interview and followed throughout the study. It was common for those who had a frustrating diagnosis with epilepsy to also become frustrated with their doctor(s) after diagnosis had been achieved. Attaining proper treatment caused a great deal of mental and physical frustration for all of the people interviewed. Timing in our public health care system and the issue of wait times for medical appointments was a strong point of contention for Katie. In addition, she did not appreciate the fact that her physician was not communicating with her enough:

It took several weeks after her EEG before we could get another appointment with the doctor to get the results. When we finally did see the doctor, he said everything is fine, it all came back normal. He just assumed we knew, but we didn't... My stomach was churning it was so stressful. (Katie)

Similarly, Adrienne had to do much of her own research in epilepsy treatment and even had to suggest a specific treatment for her to try:

I printed out studies and had a book saying we were looking into women with seizures with their period. It's like, "Look! Can I try this? Can I go on this?" And he was like, "It's not you, it's stress." So then there was a gentleman, I can't remember his name. He was in Toronto and he did the study. So I said can you please refer me to him for a second opinion? So I went to him for a second opinion and he again said, "You know what, it's too soon in the study. We can't tell you where you're at." So then I thought, "Okay, maybe I'm making progress but I don't know." (Adrienne)

Because I'm Asian, my body metabolizes medication differently compared to Caucasians. So after returning to my home country for some time, I saw my doctor there and he said that I was on too high of a dose which makes sense because I felt like I was high all of the time (Daisy).

A few days later my original appointment with the neurologist finally arrived. This proved to be a very unsatisfying visit; however because all he really told me was to go get some more tests done. So sure enough, I found myself going to receive both an MRI and EEG. Thankfully, the MRI showed no physical problems with my brain, although the EEG was not so clear. This led the neurologist to the conclusion that I should get a second opinion. So great, I just went through one month of hell essentially for an inconclusive diagnosis? Well that's just great (Suzanne).

*Summary.* The final subtheme of frustration with the medical system is a significant result of the previous subthemes in seizures. This was also significantly dependent on the success of the patient's anti-seizure medication and treatment. As previously stated, all participants had to change their anti-seizure medication at least once. Some even had to do their own research on epilepsy, suggest alternative treatments to their doctors, travel hours outside of their hometown, and ask for referrals to other specialists in hopes of having a better doctor-patient relationship. Generally, the medical treatment of epilepsy is a highly significant factor in understanding the lived experience of being a young adult women living with epilepsy.

### **Theme #3 - Social Relationships**

**Subtheme #3.1 - Surprised by Stigma.** All of the participants had varied experiences in epilepsy from diagnosis, to starting a family and so on; however, one thing was clear after each interview. No matter how easy or difficult these young women's lives with epilepsy is or was, they all expressed a strong desire for increased public awareness in epilepsy in addition to better standardized care. It was clear early on in the study that each of the young women experienced at least one form of the misunderstanding of epilepsy in public society. While some of the examples below are direct and others are indirect forms of misunderstanding or stigma, they all express a general lack of knowledge about epilepsy among the public, which is very consistent with my own experiences. For example:

Sometimes people will make assumptions and say like, "Well I guess you can't ride a bike or drive," and while those assumptions are true...often it is ignorance.

So I can take those opportunities to re-educate them that it's not a big deal.

(Carly)

I think a lot of the time people don't take that into consideration when they see or say things. Or maybe they'll say, "Oh you're being emotional," or they worry about you being emotional and having a seizure. It's like they don't realize how hurtful those statements can be I guess. And I think that is where the awareness needs to be put. That and I guess the whole stigma thing is dumb. (Amy)

I think that when you look at some kids with epilepsy is more serious, like for those who have to wear helmets, I think it reinforces stereotypes. Like, you don't hear from the people who are doing well with epilepsy. Many of the people who speak about epilepsy may give it the wrong voice. So many bad images and stereotypes are self-reinforced still in epilepsy today. We need a better voice in epilepsy. (Daisy)

"While much of our society is more educated regarding the basics of seizures and epilepsy, there is still so much the public is unaware of. Sadly, many of the old stereotypes and prejudices still exist" (Suzanne).

*Summary.* The main motivation behind the participants' willingness to be involved in this research was their dismay with the many societal stereotypes and lack of education there is around epilepsy. I can attest to the magnitude of which they all believe this as I could physically feel the passion and hear it in their voices when

speaking to misunderstanding in epilepsy and how it needs to change. While they all tried not to let the stigma affect them, each woman could not help but come across some example or another whether it may be direct or indirect. This motivated each participant to desire more education and awareness in epilepsy, especially when it comes to stereotypes.

**Subtheme #3.2 - Varied Experiences, Similar Understanding.** The following theme helps to explicate the common understanding and connection that can develop between young adult women when they meet and discuss epilepsy. All of the participants had different, yet common experiences with epilepsy. Not all of the exact details of each experience are similar, but they allow for the participants to gain a strong understanding of what other young women go through. Looking back, I was able to relate to the participants' emotions surrounding their experiences more than the physical details of the experiences themselves.

Amy was rather educated in the complexity and unique nature of epilepsy prior to the interview. Also, she explicated her interest in sharing in those stories:

I guess one would I think of is complexity. It's just so, like everybody has a different story. You can talk to 10 people that have epilepsy and we're all different. It all is different for us. We have all different experiences. Some of us can do different things. Some of us can't and it's just interesting hearing everybody's story and just seeing how complex it is and how you just can't even explain it for everybody and it almost scares me a bit in just how complex it is!

(Amy)

Katie meanwhile, used the analogy of disconnected relatives as a way to describe our understanding of each other's stories due to the fact that we are each young adult women living with epilepsy:

Yeah it's kind of like when you hear about long lost relatives or you do the ancestry search and they're like sixteenth cousins, but for some reason they still feel a connection. Commonality is family and our commonality is an unfortunate one, but still one. (Katie)

Another aspect of this theme is shown through Carly's quotation:

I've learned a lot about epilepsy itself...to be honest, this may sound weird, but prior to being diagnosed with epilepsy I hadn't realized that there was a real social stigma against it. I didn't hold a stigma against it and I just thought of it kind of being like an illness or a disease like cancer or like diabetes. So that was actually interesting for me to find out. I actually haven't felt a personal stigma from other people, although now I can see it in the media. (Carly)

Carly was fairly unaware of epilepsy and the physical and social issues that come along with it. That was until she too was diagnosed with epilepsy just over two years ago. After experiencing epilepsy, Carly then began to really understand what being a young woman living with epilepsy was all about. While I am not a big fan of grapefruit, I strongly understand and relate to the following statement about the restrictions that epilepsy places on us: "You miss the little things in life that you can't have because of the epilepsy and meds. Like, I love grapefruit, but I can't have that" (Adrienne).

Daisy has good management of her seizures and therefore sometimes forgets she even has epilepsy, but like all other participants including myself, she remains connected to its limitations when she is reminded that she cannot legally drive or swim safely:

I don't let my epilepsy define me. Sometimes I forget I have epilepsy because my meds control the seizures so well, except for when I still have an occasional sleep one. I basically just remember that I have it when I can't drive. It doesn't bother me except for driving and swimming. (Daisy)

**Summary.** Based on the interviews, it is evident that even though each young woman has a different lived experience of epilepsy; it is relatively easy for young adult women living with epilepsy to strongly understand and relate to other similar women like myself. I was personally able to understand or relate to all of the statements made by the participants. Even though I may not have experienced some of the same scenarios as the other participants, I could still strongly relate based on my own experiences and knowledge of epilepsy. Instead of connecting with the exact same physical experiences, I tended to connect more by understanding the emotions that can come along with those experiences. Based on the feedback I received from the participants, it was also evident that they too could understand the experiences I told them about myself. I did this to help get their discussion moving with each question by providing a personal experience of mine that related to the interview question. As a result, I put my experiences on the table in an effort for the participants to do the same. Whether or not they experienced the same or similar situations, all women interviewed in this study agreed with much of what I had

to say, just as I did the same for them. This theme of different experiences, but similar understanding is the foundation for the next theme of fictive kinship.

**Subtheme #3.3 - Development of Fictive Kinship.** According to Duben (1982), fictive kinship is defined as non-blood relationships that have highly familial properties.

Essentially, kinship is the study of family relations; however, fictive kinship is a term used for strong relationships between non-family members in various dimensions of society and culture. The development of this theme came to me after reviewing the research interviews, participant feedback, and feelings of strong social bonding and understanding with each participant during and after the interviews. The following quotations help to explicate my reasons for this theme development: “You’re boosting my confidence...I’m going to walk upstairs now like a rock star” (Katie). “It’s so complex and yeah, most people have different cases but you know at the same time, we all get it! Ha-ha!” (Amy). “You’ve got to have it to get it” (Daisy).

Carly started an online blog about life with epilepsy. Since its creation, she has received some great feedback and thanks from many anonymous people also living with epilepsy that give her thanks: “My blog is also nice because people know what’s going on. It’s taken a load off in some ways” (Carly). Carly was also invited to attend the North American Young Adult Epilepsy Summit this past summer where we set up a meeting and bonded very well by the second day of the conference. Discussion came very naturally between the two of us and also led to various constructive thoughts used for projects developed at the summit.

*Summary.* Meeting each participant and discussing our experiences with epilepsy together helped to develop a strong social connection between myself and each young adult woman. While I too had a unique process of diagnosis and treatment for epilepsy, I still had similar roadblocks in life, improper or ineffective medications, dismay with physicians, etc. This was largely in part due to our similar understanding of epilepsy and seizures. The more people I meet that live with epilepsy, the more I realize that we have many experiences and opinions to share with each other. I can personally say that it is a rather rewarding process. By going through the various stressors involved in diagnosis and life with epilepsy, people living with epilepsy have a strong basis to develop a fictive kinship relationship. In that sense, an individual living with epilepsy can choose to meet others with epilepsy in an attempt to improve their relationships and have a better view on their neurological condition. Social relationships between individuals living with epilepsy should be promoted as a result. Furthermore, there may be great potential to use such predisposition for social relationships in qualitative research as researchers may gain a better understanding of what it is really like to live with epilepsy. Such a technique may be of significant advantage in this field.

**Subtheme #3.4 - Epilepsy Disclosure.** When the topic of epilepsy disclosure came up in each interview, all participants stated that they would tell someone they had epilepsy to ensure their safety. However, it is not something they go around advertising to others either. When discussing various social situations, all participants inferred that their epilepsy disclosure was very situation-specific and that it would depend on whether or not someone absolutely needed to know about their seizures. Consequently, applied a

strategy when disclosing their epilepsy. The following quotations help to emphasize their feelings toward epilepsy disclosure:

Now I feel very comfortable. At first I was not completely sure how to approach it, but I think because I was diagnosed later in life and suddenly, it was very hard to hide it in a way...So it was very difficult to tell people at first...it was very difficult at first, how much I wanted to tell people, but over time I've kind of figured it out for myself (Carly).

"I can understand why others don't disclose due to various issues" (Daisy)

"Overall, I am very comfortable disclosing my epilepsy to others, but at the same time, It's not something I show off either. I find it really depends on who you are with and where you are." (Suzanne, various voice notes from 2010-2014)

**Summary.** Based on the above information, it is apparent that epilepsy disclosure is a complex process and strategies are used to decide when to disclose and when not to. While the interview process meant to make the young women more comfortable to speak about epilepsy, the amount of epilepsy disclosure was higher than originally thought. Based on my experiences with each participant in the interviews, I have to admit that they felt quite comfortable speaking about their epilepsy with me. The feedback I received from the participants and also some of the people who also attended the North American Young Adult Epilepsy Summit confirmed their motivation to discuss epilepsy not only with another young adult living with epilepsy, but to also speak about it more among general society.

**Subtheme #3.5 – Patients Studying Patients.** A social relationship for people living with epilepsy is an important component of the participants' lives. During contact, each woman explained their gratitude for my determination to complete this research and essentially have the patient's voice captured and explicated to other academics. Even more so, the participants explained how happy and excited they were to meet and speak with me about their epilepsy. Adrienne described her strong willingness to participate as follows: "You have no idea how good it is going to feel to get this all off my chest...It makes me happy to be able to talk about it" (Adrienne). Meanwhile, Katie described her enthusiasm: "I emailed you the day that I received the newsletter and invitation to participate" (Katie).

In addition, she was eager to speak to someone different about her epilepsy:

It's not that I hide it, because I don't. So I don't share my story at all with anyone because I feel like they might not care. So why tell them? Then my family and my parents have been here for it all so it's not like I retell them the story. I want to talk about it but sometimes I feel like I don't have anyone I can talk to. (Katie)

"I want to have my experience heard and I think my experience has a lot to do with my social circles." (Carly)

Even individuals who could not participate in this study gave me feedback on how important they felt this research was to help people living with epilepsy. The parent of a child sent me an email after seeing my research advertisement and expressed their opinion. This anonymous person stated:

Congratulations Suzanne! I wanted to wish you luck in completing your thesis. I know the information you gather from young women will make a difference for many in understanding epilepsy. I come from a parent perspective on the issue and with a 21 year old son diagnosed two years ago. Your thesis will also provide families with some background in understanding what he is going through. It is always good to get your type of info rather than just the medical side. Just wanted to wish you the best in your efforts! (Anonymous)

**Summary.** Whether the participants wanted to speak about their epilepsy for therapeutic reasons or to donate to academic research, all participants wanted their voices to be heard. This is in large part due to the fictive kinship that was developed during the interviews as the discussion of epilepsy came very easily. In addition, the interviews were completely confidential which no doubt attributed to their open discussion of epilepsy; however, it was due to the feedback I received both during and after the research interviews that I knew the fact I am also a person living with epilepsy helped make the participants a bit more comfortable to disclose their experiences. This theme resonated strongly among the research based on the following quotations. “Knowing someone else with epilepsy helps make it more normal and easier to talk about- even joke about” (Adrienne). “You have to have it to get it” (Daisy). Katie is also fairly comfortable disclosing epilepsy to others, although, she couldn’t help but explain why she used to hide it in the first place:

“After we ended our chat I realized how good it made me feel to speak with you. I somehow felt stronger and more confident after speaking with you. Thank you” (Katie).

“I feel like this could be the start of some great friendships” (Suzanne, Young Adult Epilepsy Summit, 2014).

**Summary.** Overall, the commonality of living with epilepsy eased the interview process and provided a basis for more eager and in-depth discussion of epilepsy. Consequently, I feel that there is a strong representation of the patient perspective in this study. This helps to show the benefits of having people living with epilepsy studying other similar individuals. Therefore, the idea of ‘patients studying patients’ is supported in this study.

## Chapter 5 – Discussion

The lived experience of being a young adult woman with epilepsy was characterized by changes in their awareness of social stigma surrounding epilepsy, highly varied medical diagnosis processes, frustration with the medical system, fear of seizures and anxiety, treatment side effects, and lack of personal independence. These common characteristics of the varied experiences of being a young adult woman living with epilepsy set the foundation for the ability to relate to and understand each other's experiences through the physical and emotional dimensions. The discussion and understanding of the lived experience by other young adult women in addition to me therefore allowed for the development of primary fictive kinship. Finally, the establishment of understanding and relation in the epilepsy experience built the bridge for young adult women to disclose their epilepsy openly with the researcher.

The objectives of this study were to further understand the lived experience of being a young adult woman living with epilepsy and to emerge with an explanation of what the essence of life with epilepsy is. Therefore, in the sections that follow, all emergent themes from the analysis were examined together with the previous literature review to clearly and succinctly articulate each participant's experience with epilepsy. This helped to facilitate an improved understanding of the lived experience of being a young adult woman living with epilepsy, show how the similar experience of living with epilepsy can lead to an increase in overall epilepsy discussion, and suggest topics in need of further research. The study's limitations are then discussed at the end of the chapter.

### **Managed vs. Unmanaged Epilepsy**

The lived experience of epilepsy did not seem to be controlled by whether or not a young adult woman has her seizures presently managed. Two of the five women in this study had their seizures currently managed completely while the remaining three participants and I have not been able to achieve full seizure freedom with treatment. The two women that did have their seizures managed felt as if they had more independence, primarily due to the fact that they were cleared by the Ministry of Transportation and can now legally operate a motor vehicle. But because they too experienced the suspension of their driver's licence for two years or more, they were still able to strongly relate to their previous experiences without the ability to drive. Even though they could drive, their epilepsy still felt like a strain on their personal independence and safety.

Such indifference for epilepsy management over a patient's quality of life support the conclusions of Park et al. (2010) who stated that adverse effects of seizure medications were much more likely to have a negative impact on a patient's quality of life and well-being than the actual seizures. Lloyd, McIntosh, and Price (2005) also found that the adverse effects of medications can be much more difficult to deal with when compared to seizure frequency or management. In addition, they discovered that some people with epilepsy (PWE) will trade away seizure management for fewer side effects. This is reasonable to assume in the participants of this study as the negative effects of medications were discussed during each interview; however, it was hardly the center of discussion. Instead, the participants focused more on the social sides of living with epilepsy and magnified its importance when compared to their medication side effects.

It is important to note that seizure frequency and management did not define their rate of epilepsy disclosure in society. Instead, the participants applied a strategy when disclosing their epilepsy. That is, there is no one they will absolutely not tell they have epilepsy; however, it is not something they go around telling everyone about. The participants have no issue disclosing their epilepsy for safety reasons and ultimately, wanted their experiences with epilepsy to be heard. It is important that future research continues to aim for a reduction in seizure frequency; however, this thesis shows that research should be devoted less to comparative studies designed to understand the differences in the lives of people with managed versus unmanaged seizures and instead focus on their lives with epilepsy as a whole and their experience as a person living with epilepsy.

### **Fear of Future Seizures & Social Anxiety**

One of the main issues in epilepsy which may decrease a patient's quality of life is that of stigma and exclusion (de Boer, 2010). Based on cultural differences and economic circumstances around the world, the social consequences of epilepsy can be vast. These include further psychological issues that are not necessarily related to the severity of the epilepsy itself, but instead originate from the concepts of epilepsy and seizures that are held by the public (Jacoby, Snape & Baker, 2005). Attitudes towards PWE are influenced, in part, by the extent of knowledge about the condition, or lack thereof (de Boer, 2010). Seizures and epilepsy have been documented for longer than most medical disorders, yet PWE are still viewed with fear, suspicion, misunderstanding, and are subject to stigma (de Boer, 2002). Consequently, the theme of seizure fear and

anxiety is all too common in PWE as the uncertainty of seizure frequency and social stigma can lead to a significant decrease in their happiness and confidence in life.

All participants expressed a fear of future seizures and how those seizures can cause them to become anxious about the future and consequences of possible seizures. These results fall in line with research performed recently by Heersink, Kocovski & Denomme (2014) at Wilfred Laurier University. People were asked to think about a scenario where one would have a seizure at a party. This proved to be anxiety-provoking and it did not matter whether or not they told anyone previously if they had epilepsy. Although this scenario was artificial in nature, the thought of having seizures and being judged by others caused the participants to become fearful, afraid, and very socially anxious. This also supports other research (Gauffin, Flensner & Landtblom, 2011, Ryan & Raisanen, 2012, & Varley, Delanty, Normand & Fitzsimons, 2011) which has found that PWE live in fear everyday not only for their health and safety, but also for their social identity and mood. As a result, young adult women living with epilepsy simply do not want to have seizures, especially outside of their homes and in the public-eye.

There is no doubt that young adult women living with epilepsy find importance in seizure management in their daily lives as it can affect a patient's well-being significantly (Sander, 2005). All participants expressed some anxiety around their seizures and could relate to that of other people living with epilepsy as well. The major component of fear in epilepsy among the participants emerged from the experience and thought of childbearing. Not only did the participants become anxious for their own safety when asked to think about their seizures, but also for the safety of their potential child. One

participant also brought up the thought of sudden unexpected death in epilepsy (SUDEP) and leaving her family behind which chilled her to the core. As a result, it can be said that young adult women not only become fearful and anxious when thinking about having seizures and epilepsy, but they can also worry significantly for individuals other than themselves such as their current or future children. Such social attributions in epilepsy and parenting for young women who have children should be further examined to determine how such anxiety levels for themselves and others may affect their quality of life and possibly parenting skills when living with epilepsy.

### **Varied Diagnosis Processes**

The research strongly supported the conclusions of Rhodes et al. (2008) who stated that epilepsy can take many different forms. The current thesis sheds new light on this concept, revealing that people's experiences are variable, ranging from extreme physical disruption (resulting from frequent and severe seizures), to minimal or even the absence of physical incapacity. That is because all participants had different experiences with their initial seizures, diagnostic testing, and treatments. Instead of the participants' physicians following a standard, regularly practiced regime of medical care for epilepsy, all of the women in this study, including myself, experienced mixed forms of medical diagnosis and treatment. The diagnosis process varied for the participants from one month, to several years and counting. At the same time, the participants took a combination of six different medications and one form of birth control to try and reduce their seizure frequency, while side effects ranged from virtually nothing to significant

mental and physical disruptions including language difficulties, mental concentration, drowsiness, lethargy, and headaches.

In this study, the varied diagnosis processes contributed directly to the various experiences they presented during each interview. Medically, all participants went through the similar test of an electroencephalogram (EEG) to help diagnose their epilepsy; however, the amount of secondary and tertiary methods used during their diagnosis was highly varied. One participant only required a basic EEG to fully diagnose her seizures and epilepsy. Meanwhile, I and all other participants required at least one secondary test/method or more to properly diagnose them. One woman did not even show any abnormal electrical activity in her tests which led to a significant delay in proper diagnosis and treatment.

### **Treatment Side Effects**

The adverse effects of anti-seizure medication for epilepsy treatment can arguably be the most difficult and debilitating part of living with epilepsy (Tebb & Tobias, 2006, Perucca, 2008, Schmidt, 2009, Hinnell et al. 2010, Jacoby et al., 1998 & Salas-Puig et al., 2009). Anti-seizure drugs can cause an early-onset of side effects such as debilitating drowsiness, dizziness, seizure aggravation, gastrointestinal issues, liver failure, hypersensitivity, and rash. After taking a medication for a significant amount of time, various late-onset side effects of medication can also develop including sedation, behavioural problems, psychotic episodes, leukopenia, aplastic anemia, pancreatitis, osteoporosis, weight gain or loss, and several other physical problems (Schmidt, 2009). Some of the most difficult and common physical side effects of epilepsy include migraine

(Hinnell, et al., 2010), drug interactions, drowsiness, dizziness, somnolence, central nervous system toxicity, and medication tolerance (Schmidt, 2009). Side effects of epilepsy and/or its treatment can be so debilitating that those treated may not be able to work full-time or perhaps have no social life due to these side effects (Jacoby et al., 1998; Salas-Puig et al., 2009).

The main side effects from the medicinal treatment of seizures in the study population varied from being virtually unnoticeable to major disruptions in mental concentration, language, alertness, and physical pain. While not all of the participants currently suffer from adverse medication effects, they all have some significant experience with strong side effects at some point or another in their diagnosis and treatment of epilepsy.

### **Lack of Independence**

Surmeijer, Reuvekamp and Aldenkamp (2001) found that people who have epilepsy can experience limited independence and perceived stigma in society. This can cause the perceptions of their own well-being to become skewed and negatively impacted (Suurmeijer, Reuvekamp & Aldenkamp, 2001). Also, one of the main issues in epilepsy that can lower a person's quality of life is stigma and exclusion (de Boer, 2010).

This research supported the findings by de Boer (2002) and others in the sense that the participants all felt like epilepsy was an intrusion on their independence in some way or another. The most prominent factor that negatively affected a young woman's own view of their personal independence and ability was the inability to legally drive a motor vehicle. All participants had their driver's licences suspended by the government

when first diagnosed with epilepsy as this is the law; however, two of the five women interviewed had their seizures managed for over two years which allowed them to legally gain the ability to drive once again. When they received their licences back, they both explained how thankful they were and how it in a sense gave them back their full independence. At the same time, each participant felt somewhat limited by the fact that they could not drive presently or in the past. This confirms the research by Drazkowski (2007) who found that driving can have a significant impact on a person's quality of life and when people living with epilepsy can have their seizures managed and legally gain back the ability to drive, their perceived quality of life can increase significantly.

Overall, the participants communicated how their epilepsy has ultimately been a negative impact on their lives and personal independence. Not only was their physical and social independence limited due to major factors like the inability to drive, but they also felt as though their personal ability to do other smaller things in life such as eat certain foods, go on theme park rides, take baths, or other things were taken away by their diagnosis of epilepsy and its treatment. As a result, it can be difficult for young women living with epilepsy to maintain both their perceived and actual independence as an adult, wife, and parent.

### **Frustration with the Medical System**

Throughout their experience of living with epilepsy as a young adult woman, participants would find themselves becoming frustrated with their diagnosis process and/or the treatment they were receiving, whether it was the proper treatment or not. This was due to delays in attaining both a proper epilepsy diagnosis, and then the proper

medication(s). As a result, such delays often led to an increased feeling of frustration and disdain for the medical system. These frustrations were somewhat linked to their level of seizure management, but more so, it was their experiences with specialists and medication effects that truly caused their faith in the medical system to drop.

All participants except for Daisy had some delay or another when being diagnosed with epilepsy, resulting in uncertain and changing diagnoses. Sample et al. (2006) found that PWE often experience delays in their epilepsy diagnosis and must search for proper help. This thesis provided important insights in to the this process, as the participants had to take their treatment into their own hands and confront their own physicians with their frustrations to achieve a better epilepsy diagnosis and collaborate to create a more effective and less intrusive treatment in their daily lives.

Debate and tension with their neurologists came along strongly with this theme of frustration with the medical system. That is because all participants except for one have had to go through at least two different neurology specialists until they found one that was willing to listen to them more, treat them properly, and take a specialized approach to their epilepsy. It is clear from the participants' emotions and frustrations with our medical system that much still needs to change in the area of epilepsy care and treatment. These findings provide new information and support for the research by Schachter (2010) who concluded that numerous challenges in the diagnosis, treatment and social management of epilepsy still need to be solved so that no person with epilepsy is limited by the condition.

Adverse effects from medication and slow diagnosis processes were the main sources of frustration for the participants when recalling their experiences with epilepsy. The frustration could be heard in their voices when discussing their diagnosis and consequential treatments. This is a common source of frustration for these people as they want to be more involved in their medical treatment (Gauffin et al., 2011, Varley et al.2011, & Prinjha, 2005). This is reasonable as Sofaer and Friminger (2005) stated that patients in our health scare system should be educated about appropriate expectations for care and therefore motivated to judge the quality of care they are receiving. In the current study, each of the participants were strongly involved with their doctors and if they were not, they expressed their desire to be more involved in their epilepsy treatment and care.

### **Surprised by Epilepsy Stigma**

Due to the various issues and adverse effects that can arise from having epilepsy and being treated, it makes sense that the participants recruited for this research were very willing to provide information (Risdale, 2009). This motivation was strongly tied to their awareness of the misunderstanding and stigmatization of epilepsy in society. Hence, the theme “Surprised by Epilepsy Stigma” arose from the interviews

All participants discussed the strong lack of knowledge in epilepsy and social stigma that results still from that misunderstanding. This falls in line with Banjeree, Filippi, and Hauser (2009) who inferred that knowledge about seizures has done relatively little in terms of increasing public awareness and reducing stigmatization of epilepsy. It is possible that the traditional and historical oppression and stigma faced by PWE over the years has created barriers for them to live happy, healthy lives and in turn,

some may feel as if they have been labelled by society as 'disabled' in the physical, emotional, and social senses (Rhodes, Nocon, Small & Wright, 2008).

The stigma still attached to epilepsy may be why Schilz et al. (2013) reported a significant demand by PWE for counseling services to help them deal with their epilepsy. The research from this study supports this statement as the participants also wanted to have their voice heard and found it somewhat therapeutic to discuss their epilepsy with me. This supports the notion that the participants were motivated to be involved in the research as it is possible that they were reaching out for someone to talk to and in a sense, receive some form of counseling by speaking about it.

Based on the reactions of the participants to volunteer for this study, it is apparent that young adult women do in fact wish there was more qualitative research in epilepsy that allows them to have their voices heard and make a difference in society for the better. This is reasonable to understand as approximately one percent of the world's population is diagnosed with epilepsy, making it one of the most common neurological disorders faced by humans of all ages around the world (Kale, 1997). These participants were aware of how common epilepsy was in society, but did not necessarily know anyone else living with epilepsy before they contacted me. While I did advertise the study as a chance to meet and discuss epilepsy with other young adult women like themselves, they all seemed to contact me with great enthusiasm to meet someone else with epilepsy.

### **Varied Experiences, Similar Understanding**

In this study, all of the participants involved had varied experiences with epilepsy. This confirms the research by Faircloth (1998) who completed a narrative study in epilepsy. In this, three separate individuals living with epilepsy were interviewed and through narrative analysis, it was shown that identities and meanings in the experiences of those with epilepsy are highly varied. Faircloth (1998) then suggested that researchers step outside of their comfort zones more in order to gain a more thorough and in-depth understanding of epilepsy. That is why I felt that I would have the ability to obtain in-depth information when it comes to the lived experience of being a young adult woman with epilepsy. Not only do I have epilepsy, but due to my previous research and knowledge, I also felt that I was more able to understand the essence and meaning of what the participants told me.

Ultimately, there is a strong potential for researchers to study medical conditions which they also live with. Narrative and qualitative research allow for researchers to gain a very in-depth understanding of certain phenomena by not only interacting with the target audience, but also by self-reflection and thought (Charmaz, 2002). This leads into the next theme discussion which explains the development of fictive kinship between me and the participants and how that kinship may lead to an increase in epilepsy disclosure and comfort in public epilepsy discussion.

### **Fictive Kinship**

According to Fisek (2010), fictive kinship is the feeling of familial relations and connection across non-blood related individuals in various societies and cultures. When

individuals face times of stress together in situations such as soldiers at war or refugees in camps, they can bond in significant ways, even if they do not know each other (Woodward & Jenkins, 2011). The traditional view of kinship, as described by Read (2012) is a system of relations based on marriage and reproduction. Meanwhile, fictive kinship tends to occur in cultures and is defined more by the terms used to describe their fictive non-blood kin. For example, the way we, as individuals in western society express a familial term for brother or sister is for family members only. Meanwhile, in other cultures across the world and even micro-cultures in various societies may use those familial terms to describe people who have experienced life together or in similar ways and thereby consider them to be “like family” (Read, 2012).

In that sense, there is reason to believe because the participants and I all have the commonality of the epilepsy experience, that the foundation for the development of fictive kinship and connection was set through this experiential dimension. Due to experiences with the participants and personal experiences with epilepsy over the past five years (especially the past six months), I have bonded significantly with other people I have met that also live with epilepsy.

Fictive kinship resonated strongly throughout the study from the first interview to the last, and beyond. It was very easy to develop an understanding and relation to each other’s experiences and as a result, new friendships have been formed. A young adult woman's amount of epilepsy disclosure in society is not necessarily related to their personal experience with seizures and epilepsy. Instead, when young adult women meet and discuss their epilepsy, their disclosure can increase among each other, and society.

Epilepsy discussion came very easily during the interviews with all participants. Not only did they feel more comfortable discussing epilepsy with another young woman, but some also even felt empowered to discuss their epilepsy more in public society. A major factor in their comfort was possibly due to my ability as an interviewer; however, all participants were eager to discuss their experiences. The combination of their eagerness and the researcher's interview skills likely provided an atmosphere for comfortable discussion.

According to Duben (1982), the kinship idiom is the use of kinship terms in order to facilitate social interactions between non-kin and even strangers, especially in the contexts of social differentiation. In other words, the kinship idiom is a concept put into practice in which those who do not know each other, but still share some sort of common connection, are brought together to share their experiences and allow for significant social relationships to develop. Kinship terms such as brother, sister, father, etc. can be used among non-kin to invoke family-like relationships (Fisek, 2010). Ultimately, the kinship idiom can be used to create a code across which to relate (Fisek, 2010).

When discussing the use of the kinship idiom to help facilitate interactions between different genders, Fisek (2010) stated:

. . . . Cast oneself into the familial sphere and invite her to be kin by addressing her as a virtual relative and thereby crossing over the adversarial gap into familial hierarchic intimacy. It is understood that the invocation of fictive kinship involves more than a resolution of the tension of relating to a stranger—it brings with it as well a morality of mutual rights and duties based on an assumption of altruism.

Once such a nonjudgmental meeting ground is established, the kinship invocation can be ignored and an encounter between two subjectivities can be enjoyed. (p. 53)

While Fisek is primarily discussing gender relations in Turkish society, a similar understanding can be applied to people living with epilepsy in Western society. In that sense, when the common connection of being a young adult woman living with epilepsy is used as a basis for young women to meet each other, they have a nonjudgmental and highly understanding ground that is established. Therefore, fictive kinship may develop between young adult women living with epilepsy for which strong relationships can increase.

Based on the results from this study, it can be said that significant fictive kinship was established between the researcher and young adult women that participated. This concept resonated with me as I have experienced other similar situations with people living with or affected by epilepsy. For example, when I attended the North American Young Adult Epilepsy Summit in July 2014, I was put in a conference room with 19 other young adults like myself from across North America to share our experiences in epilepsy, discuss major issues in epilepsy today, and ultimately develop an epilepsy awareness campaign. Not only did we all connect virtually immediately, but we were also able to use our understanding of epilepsy as a bridge to facilitate discussion.

It can be said therefore, that the kinship idiom was in a sense used for this summit meeting to facilitate social interaction. That is because we all had the common association of epilepsy and used it as a vehicle to bond, make new friendships, identify gaps in epilepsy understanding and care, and ultimately use that knowledge to help other

young adults like us. This meeting was a significant success and more is yet to come from our discussion and campaign design to improve epilepsy awareness in North American society. When two young adult women living with epilepsy meet each other and discuss their lives, significant social relationships can develop between them. Fictive kinship resonated strongly throughout the study from the first interview to the last, and beyond. It was very easy to develop an understanding and relation to each other's experiences and as a result, new friendships have been formed. A young adult woman's amount of epilepsy disclosure in society is not necessarily related to their personal experience with seizures and epilepsy. Instead, when young adult women meet and discuss their epilepsy, their disclosure can increase among each other, and society. Epilepsy discussion came very easily during the interviews with all participants. Not only did they feel more comfortable discussing epilepsy with another young woman, but some also even felt empowered to discuss their epilepsy more in public society. A major factor in their comfort was possibly due to my ability as an interviewer; however, all participants were eager to discuss their experiences. The combination of their eagerness and the researcher's interview skills likely provided an atmosphere for comfortable discussion.

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### **Epilepsy Disclosure**

Dalrymple and Appleby (2000) studied seizure disclosure towards their doctor as they wanted to understand how honest PWE are about whether or not their seizures are managed. Upon completion of their study, it was found that a significant proportion of PWE underreport their seizures. Strong factors for why epilepsy is not always disclosed include the fact that physicians have a legal responsibility to know of any breakthrough seizures and/or failure with medical treatment in a patient's epilepsy and therefore report this to the Ministry of Transportation in Ontario to ensure the suspension of their driving licence until their seizures are managed and they can safely drive again (Dalrymple & Appleby, 2000). As a result, seizures and/or epilepsy are not always disclosed in society out of fear of losing their ability to drive and/or be stigmatized (Salinsky, Wegener & Sinnema, 1992).

When reviewing the relation of epilepsy disclosure with the young adult women's experience with epilepsy in life, there was not a significant relationship between good or bad experiences and the amount each participant chose to disclose. Instead, their choice to disclose was very situation-specific. This strongly supports the notion that people living with epilepsy are not fully in or out of the 'epilepsy closet' as stated by Schneider and Conrad (1980). They also stated that when choosing to stay "in the closet" and hide epilepsy, people may become more isolated from meeting others with epilepsy. That is

why there was an increase in epilepsy disclosure and comfort when interacting with the researcher.

The research confirmed the notion made by Troster (1998) who stated that the concept of epilepsy disclosure is not a door which is completely open or closed. Instead, epilepsy disclosure is more like a “revolving door” whereby people living with epilepsy use strategies to decide whether or not to disclose their epilepsy. All of the participants involved stated that there is no one they absolutely will not tell that they have epilepsy; however, it is not a condition which they go around disclosing to everyone in society. The main motivation behind epilepsy disclosure for the young women was that of safety. In that sense, if the participants felt for some reason that they may have a seizure or their safety may be in jeopardy one day from a seizure, they were more likely to disclose their epilepsy. This finding resonated strongly with all participants in the study and for me as well.

I like to think that I keep my epilepsy disclosure very open despite some very bad experiences with epilepsy and seizures; however, as I have learned through the Analysis and Discussion portion of this study, I too use the same disclosure strategy for my epilepsy. I try to disclose my epilepsy very openly in public and without shame in hopes of promoting open disclosure and discussion among other people living with epilepsy, although, it is not a topic that I introduce immediately when meeting someone new and unless my safety warrants it.

Due to the fact that all participants had varied experiences with epilepsy, specific ways of experiencing epilepsy do not ultimately determine how a young adult woman will disclose their epilepsy in society. Instead, situation-specific strategies are used by young women to decide when epilepsy disclosure is appropriate in their lives as suggested by Troster (1998).

### **Patients Studying Patients**

The statement made previously in Chapter Two regarding the benefit of having a young adult woman living with epilepsy interview other similar women was in fact an advantage in this study. Consequently, I was able to closely interact and identify with the participants in their experiences and emotions. I received feedback at the end of the interviews as well as further communication after that reinforced their fictive kinship and gratitude for completing this study. It is reasonable to conclude that the fact I am living with epilepsy and interviewed other young women that have epilepsy did make them more comfortable to discuss and disclose their epilepsy and seizures. This notion supports the concept of patients studying patients. In that sense, if a researcher living with a specific medical condition were to study other similar people living with the same condition, a greater understanding of the concept may occur. In addition, participants may feel more comfortable disclosing and discussing their epilepsy. Therefore, in order to show further evidence that using researchers living with medical conditions that study similar individuals may be an advantage in research, another person living with epilepsy should perform a second similar study. It would also be beneficial for a male to complete a similar research study to interview other men about their epilepsy. Future research in

similar methods could show that academics need more in-depth understandings of various phenomena in medicine and social studies and that this may be achieved by patients studying other patients. This may lead to a greater and more complex understanding of experiences not only in epilepsy, but various other medical and social conditions.

### **The Epilepsy Management Model**

Upon final review of the interviews and analyzed themes, it can be seen that the three themes of seizures, medical treatment, and social relationships are components of the Epilepsy Management Model. Seizures make up a significant part of epilepsy; however, it is not the neurological condition itself. Instead, seizures are how epilepsy presents itself and the goal of medical treatment is to manage and even eliminate the presentation of seizures. Even when seizures have been managed for years through medication, surgery, or any other form of treatment, there is still the underlying condition and the possibility of further seizures.

Concurrently, the effectiveness and tolerability of the medical treatment of seizures is not guaranteed as shown in the interviews. All participants had to change their medications for more tolerability, better seizure management, or both. While a person living with epilepsy can be given the choice of which treatment to take, their responses and overall results to the medication still cannot be managed. Medication is not the only form of treatment for epilepsy. Yet, it is predominantly used in the medical system as the go-to form of treatment. Accordingly, all participants in this study received some form of

pharmaceutical treatment to attempt to manage their seizures. As a result, medical treatment is the second component of the Epilepsy Management Model.

Meanwhile, social relationships can develop from interacting with other people living with epilepsy. A young adult woman can choose to bring other people into their lives that live with epilepsy and have that develop into a significant relationship. As seen from the study, fictive kinship between two unrelated people who have epilepsy can progress fairly easily and the discussion of epilepsy can become fluid. Such social relationships may help a person better adjust to life with epilepsy as these people may be able to share in their experiences and comfort each other.

While not all of the participants had their seizures fully managed, they had all come to terms with their circumstances as people living with epilepsy to lead productive lives. Therefore, based on the research, the interaction of seizures, medical treatment, and social relationships surrounding epilepsy comprise the three components of epilepsy management. By acknowledging their predisposition to seizures, the effects of their medical treatment, and the social relationships that can be developed through the discussion of epilepsy and seizures, epilepsy may be better managed.

### **Trustworthiness**

The trustworthiness of research results is an important strategy in this study in order to legitimize the results. To achieve this in qualitative research, triangulation must occur through one or more of the different forms including methods triangulation, triangulation of information, analyst triangulation, and theory or perspective triangulation. Triangulation helps the study achieve trustworthiness during the analysis

phase (Patton, 2002). This was achieved through multiple processes involving the four criteria of credibility, transferability, dependability, and confirmability, in addition to interaction and review with the researcher's graduate supervisor.

Credibility was achieved through the identification of the researcher's training, experience, and perspective. Due to the fact that the researcher is also diagnosed with epilepsy, she has a strong connection to the subject both personally and professionally. In addition to personal experiences with epilepsy, the researcher has gained perspective in the many ways that people with epilepsy live their life through education and volunteerism in the subject. By working with other people diagnosed with epilepsy, she has achieved multiple perspectives other than her own about what it is like to have seizures and epilepsy. As a result, credibility is present.

Transferability must be achieved in research to allow for the findings to be applied in various situations other than the exact one being studied (Patton, 2002). If the knowledge obtained cannot be transferred to other studies and situations, it is of less value. As a result, a thick description was applied in order provide in-depth details of how the research findings came to be (Lincoln & Guba, 1985). In that sense, the context of the research study was described in detail to show the intentions of the study, its evolution, and development. (Denzin & Lincoln, 2011). Rather than simply reporting the findings of the study, context and meaning was applied to give more insight into how the findings occurred. Consequently, this study may be applied to other situations involving epilepsy and other chronic diseases. It is possible that the "Epilepsy Management Model" could be used in not only young women living with epilepsy, but also other age groups

living with the same or different medical conditions to help them understand and accept their circumstances and become more open to discussing it.

Dependability also needed to occur to ensure trustworthiness in this study. This was done by showing the consistency of the information and results of each participant interview (Lincoln & Guba, 1985). Various quotations and answers by the participants were strongly related in their meaning and feelings. Additionally, Dr. Jarold Cosby examined the process and product of the research study to perform an external audit. As a result, the findings of this study are a dependable perspective in epilepsy research.

Meanwhile, confirmability was achieved by having the researcher's graduate supervisor review the entire thesis draft document. The purpose of this was to evaluate the accuracy of the study and whether or not the findings, interpretations, and conclusions are in fact supported by the information collected (Lincoln & Guba, 1985). Upon formal review by Dr. Cosby, confirmability was achieved and explicated in the Discussion and Conclusions. Feedback from Dr. Cosby helped lead to better findings regarding the disclosure of epilepsy information among young adult women living with epilepsy. Based on the study information, both the researcher and Dr. Cosby came to the same conclusions about the research in that epilepsy is more related to social relationships as opposed to specific past experiences with seizures. As a result, the conclusions of this study have been deemed trustworthy and confirmed for rigor.

### **Study Limitations, Challenges, and Values**

In this reflexive account, this study's limitations, challenges, and values, are discussed. First, I will share the challenges that I faced from obtaining study participants

to the process of conducting heuristic research with diverse representative information. Secondly, I will discuss the limitations of this research which includes the contextualized findings, subjective perspectives, cautions about making generalizations about the research findings. Third, I will discuss the values or delimitations of this research by taking another look at the people who participated in this study and why, as well as how this research can help to fill in some of the missing information from the patient's perspective of living with and disclosing epilepsy.

The heuristic research process was especially rigorous for someone like me as I am a young adult woman both living with and studying epilepsy. What I found to be most difficult during my research was handling my own perspective and being sure not to over-represent myself or my own perspectives in the lived experience of being a young adult woman living with and disclosing epilepsy in current North American society. It was important to make sure that my own perspectives was not more important than those of the participants. It was the heuristic process of writing, stepping back from it, and then re-writing a few times which helped me to identify and express the most important information from the interviews without over or under-representing myself and the participants.

Another challenge which delayed the research process was the ability to obtain the appropriate number of participants. This was not expected as connections and arrangements were made with local, regional, and provincial epilepsy support service groups to spread the word about this research and encourage woman to participate. In addition, several potential participants that contacted the researcher in the first place to be

interviewed did not end up responding to their official invitations and valuable research time that could have been used to obtain other participants was lost. There could be many reasons as to why it was a challenge to obtain enough participants from being unwilling or afraid to speak about their epilepsy with someone else, to having a busy life and simply not having the time to participate. There is not enough information; however, to identify exactly why this research roadblock occurred; however, the Epilepsy Management Model is clearly suggestive based on the evidence that without the binding of social relationships, people may not be able to properly manage their epilepsy. On the other hand, it was beneficial to be able to identify with many of the experiences and feelings that the women shared with me as I have also felt and experienced many of the similar, if not same things, in epilepsy. Consequently, I feel that their stories are well represented.

After standing back from the interviews during the incubation phase, it became apparent that symbolic interactionism was achieved. This is due to the verbal interactions that could be observed in the interview transcripts. The interactions of the participants showed the researcher what their beliefs about epilepsy and life were. In order for these people to disclose their epilepsy and “remove themselves from the shadows,” they needed to interact with people similar to them. In this situation, that meant speaking about their lives with another person living with epilepsy.

While there were differences between perspectives, experiences, and opinions, my significant study of epilepsy over the past five years helped me to understand them and explicate their views strongly. I believe that the interviews were proficient in eliciting

memories, feelings, and emotions of the phenomenon. Even though there were various challenges working with heuristic methodology in this subject, the results demonstrate the strong depth of knowledge that heuristic research can achieve.

This thesis was written with the intention of providing the reader with sufficient information about each participant as well as a clear depiction of the research process that lead to the findings. Such would allow for the reader to make an independent decision as to whether or not the research findings would be applicable to their own situations. Contextualized research such as this can have its limitations; however, the many different pathways to knowledge and understanding can be highlighted to show how personal lived experiences can significantly impact their perspectives. Therefore, this study contributes to the understanding of the complex experience of being a person living with epilepsy to ideally lead to a more patient-centered approach to treating and assisting those who have epilepsy.

It should also be addressed that there is the potential for this particular group of participants to be different and have had experiences with epilepsy out of the norm. The particular relationship, understanding, and sense of connection shared by the researcher and participants is likely very common among many young women living with epilepsy. This specific conclusion was reinforced in my research when I attended the North American Young Adult Epilepsy Summit in Washington D.C. July 25<sup>th</sup>-27<sup>th</sup>, 2014. Men and women between the ages of 21 and 29 years all living with and affected by epilepsy came together for this specific summit and at the end, expressed how happy they were to have met each other. They understood each other, and they all wanted to stay connected,

including me. This was a group of 20 male and female young adults all living with or affected by epilepsy from across North America and the theme of social relationships and connection was mirrored. As a result, it will be beneficial to study this phenomenon further, but with both genders and different age groups.

It should be noted that the participants involved in this study were relatively similar in the sense that they were all well-educated young women living in the mid to high socioeconomic status range. All participants were Caucasian (except for one who was of South Pacific descent) and in their twenties. As a result, the study sample was highly specific and may not be generalizable to all young adult women living with epilepsy. There were not any gender-specific themes in the research.

The women chosen to participate in this study were selected on a first-come first-serve basis. It should also be noted I had a small relationship with two of the study participants prior to their participation. Initially I met one participant through her volunteer work with Epilepsy Niagara. In this short meeting, she was elected to the Board of Directors and then I asked if she wanted to participate. This was the only interaction that occurred prior to the interview. The other young woman I had a prior relationship with involved someone I met at the Young Adult Epilepsy Summit. During this time, the participant had light to moderate verbal interaction with me over the three days of the Summit. At the end of Summit, she was asked if she wanted to participate. All other participants were unknown prior to their contact and resulting study involvement. Looking back, I am content with the participants that volunteered to share their perspectives and stories.

If this research were to be completed again, I would encourage a more diverse sample of young adult women with a more broad range of advertising in addition to a change in the methods to allow for group interviews and significant person-to-person interaction. Group interviews would help to facilitate further discussion about epilepsy and ideally reinforce the theory that people living with epilepsy can achieve better management of their condition through the interaction of their seizures, medical treatment, and social relationships.

### **Summary of Research Findings**

- 1.) The essence of life with epilepsy is a transformative journey that can alter a young adult woman's perceptions of personal relationships, independence, the medical system, and public society. This is ultimately because the participants expressed experiences which involved shifts in their family, friends, and romantic relationships, personal feelings of independence, issues and frustrations in medical diagnosis and treatment, and understanding of the social views of epilepsy. The lived experience with epilepsy is a changing one that evolves over time and continues even after a young woman can reduce her seizure frequency.
- 2.) Seizures influence a person's life with epilepsy in many ways; however, they are not the single factor for determining the essence of such life.
- 3.) The medical treatment of seizures can affect a person's life in many ways beyond just seizure management. The side effects of anti-seizure medications can be very debilitating and contribute significantly to the management of epilepsy and a person's view of their

life. A participant's amount of seizure management was not the only determining factor in managing epilepsy.

4.) When two people living with epilepsy meet each other and discuss their lives, significant social relationships can develop between them.

5.) There is a strong potential for the expansion of research in the lived experiences of not just epilepsy, but also with many other medical conditions. Having the patient's perspective in medical care can be extremely valuable and is a voice which needs to be listened to more in research.

## **Chapter 6 – Conclusions**

After reviewing all of the evidence from this study and exploring the various experiences with epilepsy between researcher and participants, the essence of living with epilepsy is that it is a transformative journey for people to be diagnosed and live with epilepsy. This is because all of the participants did not choose one factor or circumstance to define their epilepsy. Instead, they acknowledged that there are several components to life with epilepsy and their lives are much different now than when they were first diagnosed. Being diagnosed has altered their views about epilepsy and society. All of the participants were aware of what seizures were prior to being diagnosed, but as their condition progressed, they began to understand how much of society views seizures and epilepsy in the sense that it is highly misunderstood and stigmatized. Based on the analysis, epilepsy management is a constantly evolving process that shapes a person's life in multiple dimensions.

Whether a participant currently had their seizures managed or not, it did not affect the amount in which they disclose their epilepsy in society. Instead, it is believed that it was the act of meeting and interacting with me, the researcher, who is also a young adult woman living with epilepsy, that allowed for fictive kinship to develop and ultimately increase their comfort in discussing epilepsy.

While there were commonalities among participants and me in life with epilepsy, it should also be noted that every participants' experience and ultimate journey with epilepsy were all different. Each woman including myself went through very different diagnosis processes that ranged from one month to five years. Some women had a very

efficient and quick diagnosis to epilepsy, while others had to seek out better care on their own accord. It should be noted that all participants lived in Canada where public provincial health care systems are in place. No women involved in this research study live in a private health care system. In such public health care systems, citizens are referred to other health care professionals through the provincial network and the patient does not have to do much other than show up for medical appointments and follow their doctors' orders. In this study, myself and four of the five women interviewed had to actively seek out better medical care to be properly diagnosed with epilepsy and ultimately treated to ideally achieve seizure freedom. All young women involved were currently taking one or more anti-seizure drugs and one of the participants also receives a birth control shot once every three months to keep her hormones balanced and seizures managed. Two of the participants were seizure-free through treatment while the remaining four women including me were currently receiving treatment, but did not have full seizure freedom.

Upon the development and identification of the social relationships between each participant I interacted with, it was clear that there could be significant applications for this evidence. The concept of fictive kinship between young adult women living with epilepsy was reinforced once the interviews were complete and the final manuscript of this thesis was being written. I had the chance to attend the North American Young Adult Epilepsy Summit in Washington, D.C. where I interacted and worked with 19 other young adults living with or affected by epilepsy to develop a social media campaign for epilepsy awareness that will be released in the months to come. Not only did we all

connect within minutes of meeting each other, but when asked what we would take away from the Summit, all of us expressed how grateful we were to meet each other and two women even expressed that they were more comfortable speaking about their epilepsy after the weekend.

In addition, I had the chance to be admitted to the Epilepsy Monitoring Unit at Toronto Western Hospital where I had multiple electrodes glued all over my head for a 24 hour video electroencephalogram and stayed there for two weeks to achieve a more accurate epilepsy diagnosis and ultimately determine if I was a surgical candidate. Even in the dense, busy hospital I was able to interact very well with the other individuals in the room. We were all able to comfortably discuss our epilepsy and even laugh at the various medication side effects we had. It was a true test of patience as I was very anxious to be released in the second week of admission; however, it opened up my eyes to the possibility of future heuristic research to understand the lived experience of being admitted to an epilepsy monitoring unit.

Future directions for this research may include using larger, more diverse study samples to examine the experience of living with epilepsy. Based on this research; however, the concept of more gender-specific and cross gender studies in epilepsy and with women and should be accomplished by the academic world to further understand the lived experience of epilepsy. Not only should young adult women be interviewed to gain more knowledge about epilepsy, but other similar groups such a young men, children, and seniors may be interviewed to help reinforce and expand this current area of study. To show the resonance of fictive kinship between people living with epilepsy, other

researchers like me living with epilepsy should perform similar studies. Young male researchers living with epilepsy studying other young men who have epilepsy, for example, may yield similar results to this study. In addition, parents of children with epilepsy would no doubt bond strongly over a researcher that also has a child living with epilepsy. As a result, there are various avenues for this research to expand into.

In the meantime, there is strong potential for these findings to be applied within our society and ultimately work towards improving the lives of individuals living with epilepsy. The idea of patients studying patients is emphasized in these conclusions as it was demonstrated in this study that the commonality between me and the participants (living with epilepsy) allowed for the development of social relationships (Fisek, 2010). The potential for social relationships allowed for a greater understanding of what people living with epilepsy go through. In addition, participants may feel more comfortable discussing their health with a researcher who shares the same medical condition. Not only is there the potential for greater insight into the phenomenon being studied, but this may also set the foundation for people living with epilepsy to develop various social relationships with other people living with this condition.

If we were to develop connection services for anyone living with or affected by epilepsy, they would have the chance to meet each other and bond over their commonalities. Duben (1982) defined the kinship idiom as the usage of kinship terms to facilitate social interactions among non-kin and even strangers to invoke actual kinship. While the majority of fictive kinship studies and the kinship idiom take place outside of North American society, they help to show how the use of kinship terms like brother,

sister, etc. can invoke significant interaction, friendship, and possibly develop into another family (Fisek, 2010).

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Appendix A

## Appendix A

### Interview Guide

Please, introduce yourself and tell me a bit about your life and who you are.

- What was your initial experience with epilepsy like? (How long did it take to be diagnosed?)
- What type of epilepsy/seizures do you have? What treatment do you currently receive, if any?
- Since being diagnosed, what have you learned about epilepsy in general?
- How do you feel about the current state of your epilepsy?
- What specific qualities or dimensions of living with epilepsy stand out for you?
- What types of events, situations, and specific people do you relate your epilepsy to?
- When you look back on your life, which specific feelings and thoughts stand out in your mind when it comes to being a woman living with epilepsy?
- Looking at your life right now, what specific feelings and thoughts stand out when it comes to being a woman living with epilepsy?
- When you look to the future, what feelings and thoughts are generated when it comes to your life with epilepsy as a woman?
- What physical, social and/or psychological shifts have occurred during your life with epilepsy?
- What types of experiences in your life have affected your awareness of living with epilepsy?
- Who do you talk to about your epilepsy?

- Who don't you talk to about your epilepsy?
  - Is there anything else you would like to add/say?
  - Thank you for your time and willingness to share your experiences in epilepsy with me.
- \*Questions based upon the heuristic interview questions as outlined by Moustakas (1990, 48).

Appendix B

## Appendix B

**The Stages of Heuristic Inquiry***The 6 phases of heuristic inquiry*

Phase	Processes
1. Initial Engagement	Discover an intense interest /passion that is personal to the researcher. Develop research question.
2. Immersion	Researcher lives with the question. Become very close to question to understand it.
3. Incubation	Retreat from the question. Develop tacit knowledge & intuition beyond immediate awareness (i.e. the forgotten name).
4. Illumination	Researcher is now open to tacit knowledge & intuition. Awaken to new dimensions of the experience to uncover meanings & essences.
5. Explication	Full examination of what has come to consciousness. Core themes developed & ready to be put together into a whole experience.
6. Creative Synthesis	Self-search, intuition, tacit knowledge to express essences of the phenomenon in a specific & comprehensive manner.

Moustakas (1990).

Appendix C

## Appendix C

**Telephone Communication Script Number One**

P = Potential Participant;

I = Interviewer

I - May I please speak to [name of potential participant]?

P - Hello, [name of potential participant] speaking. How may I help you?

I - My name is Suzanne McGuire and I am a Masters student in the Faculty of Applied Health Sciences at the Brock University. I am currently conducting research under the supervision of Dr. Jarold Cosby on the experience of living with epilepsy in young women. (If they were referred by another person) I recently received your telephone number from (say name of contact). Would you be interested in learning more about the study?

P - No. (Thank them for their time and wish them goodbye)

OR

P-Yes

I - Excellent, as part of my thesis research, I am conducting interviews with young adult women ages 20 to 35 to help discover their views on the experience of living with and disclosing epilepsy. Therefore, the purpose of this study is to learn about what it is like to be a young woman living with epilepsy. Before we proceed any further, I need to ask a few quick questions to verify specific demographic factors; how old are you? (P answers) When were you first diagnosed with epilepsy? (P answers) What type of epilepsy do you have? (P answers) Can you physically bear a child? (P answers) Thank you.

(If P does not fit required demographics) Unfortunately, we require specific types of participants and you do not meet the requirements to participate in this study. I apologize for this inconvenience and thank you for your time. Goodbye.

OR

(If P does fit required demographics). Excellent, I would like to speak with you about your life and epilepsy. Is this a convenient time to give you further information about the interviews?

P - No, could you call back later (agree on a more convenient time to call person back).

OR

P - Yes, could you provide me with some more information regarding the interviews you will be conducting?

I - Ok, here is some background Information:

- I will be undertaking interviews starting this summer.
- The interviews will be conducted in the Health Decisions Lab at Brock University located on 500 Glenridge Avenue in St. Catharines, ON, Canada.
- The interview will last approximately forty-five minutes to one hour and would be arranged for a time convenient to your schedule.
- Involvement in this interview is completely voluntary and you can choose to withdraw at any time.
- The interview questions are quite general (for example, Do you recall when your first seizure was?). Interview questions will also be open ended to allow for detailed answers and semi- structured around critical events of the epilepsy experience and psychological and social connections to epilepsy disclosure.
- You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview at any time.
- With your permission, the interview will be audio digitally recorded to facilitate collection of information, and later transcribed for analysis.
- All information you provide will be considered confidential.
- Two weeks after the study has been completed you will be mailed a one page summary of the research results.
- The information collected will be kept in a secure location and disposed of by December 2015.
- With your permission, I would like to mail or email you an information package which has all of these details along with contact names and numbers on it to help assist you in making a decision about your participation in this study.

P - No thank you, I am not interested. (Thank them for their time and wish them goodbye)

OR

P - Sure (decide on method of mailing and obtain contact information from potential participant i.e., mailing address or email address).

I - Thank you very much!

- If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please feel free to contact Dr. Jarold Cosby at 905-688-5550 Ext. 5340
- I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics. However, the final decision about participation is yours. Should you have any comments or concerns resulting from your

participation in this study, please contact the Brock University Research Ethics Officer (905-688-5550 ext. 3035, reb@brocku.ca)

- I will call you in 3 to 5 days to see if you are interested (or still interested) in being interviewed. Thank you very much for your time. Once again, if you have any questions or concerns please do not hesitate to contact me by phone at 905-688-5550 ext. 5340 or by email, sm06ef@brocku.ca.

P - Good-bye.

I- Good-bye

Appendix D

## Appendix D

**LETTER OF INVITATION**

October 2013

**Title of Study:** Removing Oneself from the Shadows: A Heuristic Inquiry to Understand the Lived Experience of Epilepsy in Young Adult Women and their Epilepsy Disclosure.

**Principal Student Investigator:** Suzanne McGuire, Graduate Student, Department of Kinesiology, Brock University

**Faculty Supervisor:** Dr. Jarold Cosby, Associate Professor, Department of Kinesiology, Brock University

Brock University's Health Decisions Lab would like to invite you to participate in a research project about the experience of being a young woman living with epilepsy. The purpose of this research project is to give you an opportunity to share epilepsy life story. I will be conducting in-person interviews with a selection of volunteers in an attempt to understand the impact of the epilepsy experience on the disclosure of your neurological condition to your family, friends, physician, co-workers, and others in life.

The interview will last approximately 45 minutes to 1 hour.

Your participation will provide information that will help contribute to an improved understanding of the personal experience of epilepsy in young women. This will help us improve our success with treating, managing, and improving epilepsy and our awareness of it in the future. This is a single-sited project as all interviews will be conducted at Brock University, at 500 Glenridge Avenue, in St. Catharines, ON, Canada. Your involvement in this study is strictly voluntary and you have the right to refuse participation at any time.

Upon completing your interview, you will be compensated \$12.00 for your participation and to cover any parking or transit fees you may incur.

Please read the informed consent form for more information regarding the risks and benefits of participating in the study, the feedback you are entitled to receive as a participant, and the procedures to ensure the confidentiality of your participation in the study. If you have any further questions regarding this study, feel free to contact Dr. Cosby or me at a time convenient for you.

If you have any questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext. 3035, reb@brocku.ca).

Thank you.

Sincerely,  
Suzanne McGuire  
Brock University Graduate Student  
905-933-5875  
sm06ef@brocku.ca

Dr. Jarold Cosby  
Assistant Professor  
905-688-5555 ext. 5340  
jcosby@brocku.ca

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (REB# 13-114 - COSBY).

Appendix E

## Appendix E

**Informed Consent Form**

Date: October 2013

Project Title: Removing Oneself from the Shadows: A Heuristic Inquiry to Understand the Lived Experience of Epilepsy in Young Adult Women and their Epilepsy Disclosure

Principal Student Investigator:  
Suzanne McGuire, Graduate Student  
Faculty of Applied Health Sciences  
Brock University  
(905) 933-5875; sm06ef@brocku.ca  
jcosby@brocku.ca

Faculty Supervisor:  
Dr. Jarold Cosby; Professor  
Faculty of Applied Health Sciences  
Brock University  
(905) 688-5550 Ext. 5340;

**INVITATION**

Brock University's Health Decisions Lab would like to invite you to participate in a research project about the experience of being a young woman living with epilepsy. The purpose of this research project is to give you an opportunity to share your epilepsy life story.

**WHAT'S INVOLVED**

As a participant, you will be asked to complete an interview with the researcher. Interviews will be audio digitally recorded and transcribed verbatim. Interviews will be one on one and conducted at Brock University on 500 Glenridge Avenue, in St. Catharines, ON, Canada. Interviews will focus on the experience of your life with epilepsy and how it relates to the disclosure of your neurological condition to your family, friends, physician, co-workers, and others in life.

Questions will be semi-structured around "major events" of the epilepsy experience (e.g. when you had your first seizure, when you first received treatment, etc.). Altogether, the interview is an exciting chance for you to share your story and have your voice heard. Participation will take approximately 45 minutes to 1 hour of your time in addition to travel time to from and the interview. Only one interview is required.

**POTENTIAL BENEFITS AND RISKS**

Possible benefits of participation include the opportunity to tell your experience of living with epilepsy, the opportunity to see an interpretation of the meaning of your experiences and to understand your experiences in relation to other young female participants living with epilepsy. You will also contribute to an improved understanding of the psychological and social connections to epilepsy disclosure, thus, helping us improve our success with treating, managing, and improving epilepsy and our awareness of it in the future.

There also may be risks associated with participation as reflecting on troublesome experiences may result in increased feelings of emotional stress. However, you are given the opportunity to avoid answering any questions you feel uncomfortable with. Furthermore, the principal student investigator has formal training in qualitative interviewing and responding to epilepsy, and is well prepared to manage such risks.

For your information, here are a few academic and professional resources that discuss epilepsy. Epilepsy Canada (<http://www.epilepsy.ca/en-CA/Home.html>) is a non-profit organization whose mission is to enhance the quality of life for persons affected by epilepsy, while a list of local support organizations and an opportunity to connect with other people living with epilepsy are available on the Canadian Epilepsy Alliance website at (<http://www.epilepsymatters.com/>).

For a more advanced and informative inquiry you may wish to seek out "Epilepsy" by Gonzalo Alarcon, Lina Nashef, Helen Cross, Jennifer Nightingale, and Stuart Richardson.

- This is a comprehensive handbook which guides the reader through all aspects of epilepsy, both practical and academic, covering aspects of diagnosis and management of the patient. The book appeals to a wide audience by teaching a simple but highly practical method to approaching the classification and diagnosis of epilepsy, and then provides patient-centred information on pharmacological and non-pharmacological management. Alarcon, G., Nashef, L., Cross, H., Nightingale, J. & Richardson, S. (2009). *Epilepsy*. Oxford, NY: Oxford University Press.

Finally, the International League Against Epilepsy (ILAE) is the world's preeminent association of physicians and other health professionals working towards a world where no persons' life is limited by epilepsy. ILAE is made up of over 100 countries around the world that work together to ensure that health professionals, patients and their care providers, governments, and the public world-wide have the educational and research resources that are essential in understanding, diagnosing and treating persons with epilepsy. They offer a variety of resources, committees, academic journals, newsletters, and links to the World Health Organization for people living with epilepsy. For more information you can visit their website at (<http://www.ilae.org/>).

### **CONFIDENTIALITY**

The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, anonymous quotations may be used. The anonymity of participants both during the conduct of the research and in the release of its findings will be secured through the use of encoded numbers and pseudonyms. Data collected during this study will be stored in a desk drawer which will be secured by lock and key and electronically on a computer hard drive, which will be secured by user name and password. Data will be retained until the completion of the project after which time all hard copies of information will be shredded and all electronic copies of interviews and participant information will be erased. Access to this data will be restricted to Suzanne

McGuire (principal student investigator) and Dr. Jarold Cosby (faculty supervisor). However, if you wish to access your interview transcript, you can do so by contacting either Suzanne McGuire or Dr. Jarold Cosby via telephone or email. All requested transcripts will be delivered within twenty-four to forty-eight hours of the request; however all interview transcripts will be destroyed and subsequently no longer available for request after the study has been completed. The estimated time of completion for this study is *February 2015*.

### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled. To withdraw from the study you must contact the principal student investigator via telephone or email before the study has been completed and submitted for publication or for presentation at conferences. After the study has been submitted for publication you will no longer be able to withdraw your information from the study. The estimated time of completion and submission for publication is February 2014.

### **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. A one page summary of the results will be mailed to all participants two weeks after the study has been completed. You are also entitled to view a full length copy of the thesis and may do so by requesting a copy from either the principal student investigator or principal investigator via telephone or email. All academic papers will be mailed within one week of the request.

### **CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact the principal investigator or the faculty supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (13-114 - COSBY). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

### **CONSENT FORM**

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Appendix F

## Appendix F

**Telephone Communication Script Number Two**

P - Potential Participant;

I- Interviewer

I - May I please speak to [name of potential participant]?

P - Hello, [name of potential participant] speaking. How may I help you?

I - Hi, this is Suzanne McGuire from the Health Decisions Lab at Brock University. I am calling to confirm that you reviewed the forms I emailed you and that you are still interested in participating in the study?

P - No I am not (thank them for their time and wish them goodbye).

OR

P - Yes I am.

I - Excellent (agree on an interview time) I will email you a confirmation letter which will provide you with directions to Brock University, where on Campus the interviews will be conducted, where you can find parking, the time and date of the interview, as well as a cell phone number you can contact me with.

I would like to remind you once more that participation in this study is strictly voluntary and it is your right as a research participant to withdraw from the study at any time without penalty. Also, the information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, anonymous quotations may be used. The anonymity of your participation both during the conduct of the research and in the release of its findings will be secured through the use of encoded numbers and pseudonyms.

Finally, I would like you to confirm that you have agreed to participate in the study as described in the informed consent form and that you have made this decision based on the information you have read in the Information-Consent Letter. Also I would like you to confirm that you have had the opportunity to receive any additional details about the study and understand that you may ask questions in the future and may withdraw this consent at any time up until the point of publication.

Can you confirm these details?

P - No I cannot (inform them that they cannot participate in the study until they can confirm these details and arrange for them to contact you via email or telephone when they can confirm these details)

OR

P- Yes I can.

I - Excellent, you will be receiving your confirmation letter shortly via email. Good bye.

P- Good bye.

Appendix G

## Appendix G

**Confirmation Letter**

Day/Month/Year

Dear (name of participant),

This letter is to remind you of your interview on living with epilepsy at Brock University on (date/time of interview). The interview will take place in the Health Decisions Lab located in Welch Hall, room number WH 145.

Parking is provided in Visitor Parking (Lot D) near the Walker Complex. Please call me at 905-933-5875 when you arrive on campus and I will come meet you at the Schmon Tower. I will be wearing a red lanyard on my neck which will have my name on it.

Brock University is located on 500 Glenridge Avenue, St. Catharines, ON. Use this information to find exact directions to the campus through [www.mapquest.com](http://www.mapquest.com).

You are asked to be on campus fifteen minutes before your interview time. If at any time you get lost and/or cannot find parking lot D than please call me at 905-933-5875. For an easy way to find parking lot D please refer to the Brock University Campus Map I have provided for you.

I would like to take this opportunity to once again remind you that your participation in this study is strictly voluntary and you have the right to withdraw from the study at any time without penalty.

Once you have completed the interview with me at Brock University, you will be compensated \$12 for your time and any travel fees you may incur. The compensation will be given to you in the interview lab before you leave.

Finally, I want to thank you for your cooperation and for volunteering your time.

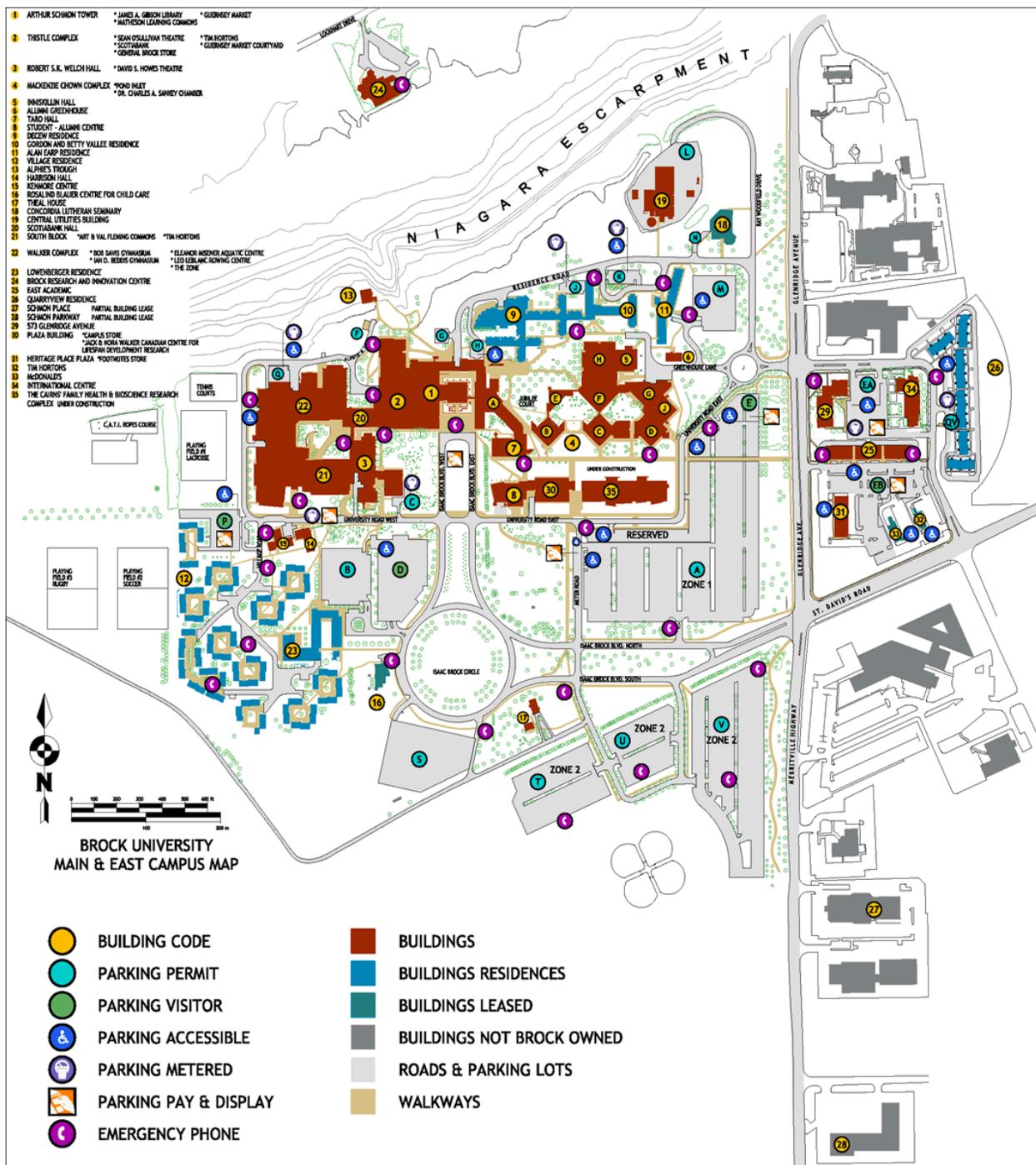
I am looking forward to our interview.

Sincerely,  
Suzanne McGuire

Appendix H

Appendix H

Brock University Campus Map



For the full interactive version of this map, please go to:

<http://www.brocku.ca/blogs/campus-map/>

Appendix I

## Appendix I

**Telephone Communication Script Number Three**

P - Potential Participant;

I – Interviewer

I - May I please speak to [name of potential participant]?

P - Hello, [name of potential participant] speaking. How may I help you?

I - Hi, this Suzanne McGuire from the Health Decisions Lab at Brock University. I regret to inform you that all positions to participate in the study on the experience of being a young woman living with epilepsy have been filled. However, additional volunteers may be called upon in the event that a participant withdraws from the study before or after their designated interview time. Would you like me to contact you if another participation position becomes available?

P - No thank you (thank them for their time and wish them goodbye).

OR

P - Yes I would.

I - Excellent, I want to thank you for your time and consideration. I will contact you in the event that a participant withdraws from the study. This may be any time between now and next fall. Goodbye.

P- Goodbye.

Appendix J

## Appendix J

**Personal Research Timeline – Suzanne McGuire***Personal Information in Epilepsy that this Research Study Builds Upon*

Time Period	Information Collection	Results
Fall 2009 – initial seizures & treatment	Research-supported self-reflection in Dr. Cosby's class	<ul style="list-style-type: none"> <li>- Personal experiences in epilepsy strongly mirrored course material (i.e. disease coping, psychological effects of illness, etc.)</li> <li>- doctors &amp; nurses did not properly follow epilepsy diagnosis/treatment procedures; experienced a strong lack of knowledge in epilepsy among general public &amp; medical professionals</li> </ul>
October 2010	Personal narrative in experiences with epilepsy	<ul style="list-style-type: none"> <li>- revealed the negative physical, psychological &amp; social effects of living with epilepsy for over a year</li> <li>- emphasized personal struggles</li> </ul>
October 2010	Personal interview with Dr. Cosby	<ul style="list-style-type: none"> <li>- highly in-depth explanation of the various life-altering experiences in epilepsy</li> <li>- allowed for me to then complete a chronological narrative</li> </ul>
November 2010	Chronological narrative	<ul style="list-style-type: none"> <li>- stepped back and became the researcher to analyze the personal interview and self-reflection</li> <li>- allowed for a more objective explanation of my experiences in epilepsy</li> </ul>
December 2010	Undergraduate thesis titled "Exploring the Psychosocial Effects of Epilepsy – A Qualitative Inquiry into One young Woman's Experience"	<ul style="list-style-type: none"> <li>- showed the various gaps in the psychological and social domains of epilepsy research</li> <li>- emphasized the injustices that resulted from improper treatment, misunderstanding, and personal struggles in epilepsy</li> </ul>
September 2011-present	Personal journals	<ul style="list-style-type: none"> <li>- have been journaling my experiences in life since I was diagnosed with epilepsy</li> <li>- recorded personal events, feelings, thoughts, and opinions all relating to my life and epilepsy</li> </ul>

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Fall 2009- present	Leisure-oriented research reviews	- since the start of my experiences with epilepsy, I have been reviewing research papers; both qualitative and quantitative studies exploring as many research dimensions as possible in epilepsy - now am very knowledgeable in epilepsy
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Appendix K

## Appendix K

**BROCK UNIVERSITY**  
Department of Kinesiology

**Research Study Advertisement**

**Study Title: Removing Oneself from the Shadows: A Heuristic Inquiry to Understand the Lived Experience of Epilepsy in Young Adult Women and their Epilepsy Disclosure**

**Principal Investigator: Dr. Jarold Cosby, Associate Professor, Department of Kinesiology**

**Principal Student Investigator: Suzanne McGuire, MA Candidate–Applied Health Sciences**

**INVITATION**

Brock University's Health Decisions Lab would like to invite you to participate in a research project about the experience of being a young woman living with epilepsy. The purpose of this research project is to give you an opportunity to share your story of what it is like to live with epilepsy.

**WHO CAN PARTICIPATE?** Females between the ages of 20 and 35 years that are diagnosed with any form of epilepsy. Seizures may be controlled or uncontrolled. Must also have the physical ability to conceive and give birth to a child.

**PARTICIPATION IS VOLUNTARY:** You can withdraw at any time and are not required to answer any questions you do not wish to.

**WHAT'S INVOLVED**

As a participant, you will be asked to complete one interview with the researcher. The interviews will be one on one and conducted at the Health Decisions Lab in Welch Hall 145 at Brock University on 500 Glenridge Avenue, in St. Catharines, ON, Canada. This is an exciting chance for you to share your story and have your voice heard. Participation will take approximately 45 minutes to 1 hour of your time.

**REWARD?** Participants who qualify and complete the interview will be compensated \$12.00 to cover any parking or regional transit fees.

**Who do I contact if I have questions about participation in the study?** If you wish to have further information about this study, you can contact either the principal student investigator, or her faculty supervisor from the information listed below.

**Principal Student Investigator:**

Suzanne McGuire, Graduate Student  
Department of Kinesiology  
Brock University  
sm06ef@brocku.ca  
(905) 933-5875

**Faculty Supervisor:**

Dr. Jarold Cosby, Assistant Professor  
Department of Kinesiology  
Brock University  
jcosby@brocku.ca  
(905) 688-5550 Ext. 5340

This research study has received ethical clearance from Brock University's Research Ethics Board (REB# 13-114 – COSBY).