

**INTERNALIZED STIGMA IN PEOPLE WITH EPILEPSY
IN THE PROVINCE OF SASKATCHEWAN, CANADA**

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By

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Abstract

Background and objective: Goffman defined stigma as a phenomenon in which a person is discredited or rejected by society because of a particular attribute, in a way that spoils their normal identity. It may be related to 'external deformations' such as physical disabilities and diseases, 'deviations of personal traits' such as being unemployed or addicted to drugs, and 'tribal stigmas' based on, for example, ethnicity or nationality. Self-perception is as critical as public attitudes toward people with epilepsy. Therefore, understanding the relationship between factors that play crucial roles in developing and sustaining internalized stigma among people with epilepsy is important to expand our knowledge about these factors. This study aimed to evaluate stigma for Canadian people with epilepsy for the first time using the Internalized Stigma of Mental Illness (ISMI) scale.

Methods: This was a cross-sectional study performed at the Epilepsy Program of the University of Saskatchewan, after approval by the Human Research Ethics Review Board (ID 357). Ninety-three patients were included. Participants were recruited using a non-probabilistic sampling method in a consecutive way. Every patient signed a written consent form. The inclusion criteria were the following: a) patients with focal and generalized epilepsy, b) any consecutive patients attending to the clinics in the established period of study, c) patient must be able to read and understand English, d) patients older than 17 were recruited. The Internalized Stigma of Mental Illness has 29 questions and measures the subjective experience of stigma, with subscales measuring Alienation, Stereotype Endorsement, Perceived Discrimination, Social Withdrawal and Stigma Resistance. Each item has four response options scored from 1 to 4 (1 = not at all to 4 = totally). This scale has been used to assess stigma in mental conditions but has not been used in patients with epilepsy.

Results: Ninety-three patients were recruited. Mean age was 41.9+15 years. Fifty-two patients were males (56%). Sixty patients had focal seizures (64%) (59.6% male vs 70.7% female) , 26 patients were on disability (28%)(26.9% male vs 29.3% female), 35 patients had psychiatric comorbidity (38%)(36.5% male vs 39% female), 30 had depression (32%)(30.8% male vs 34.1% female) , 16 had an anxiety disorder (17%) (15.4% male vs 19.5% female), 22 had somatic comorbid conditions (24%) (28.8% male vs 17.1% female), 59 were seizure-free (63%) (63.5% male vs 63.4% female), 25 patients had drug resistant epilepsy (27%) (25% male vs 29.3% female), 67 were from urban areas (72%), 60 patients were not employed (64%) (61.5% male vs 68.3% female), and 17 had epilepsy surgery (18%) (11.5% male vs 26.8% female). The scores of the Internalized Stigma of Mental Illness were explored in the following groups: DRE (58.4) vs not DRE (60.3) (p-value 0.6), tonic-clonic seizures (63.6) vs not (62.3) (p-value 0.6), focal seizures (62.0) vs not (64.3) (p-value 0.4), disability (67) vs non disability (58.5) (p-value 0.01), epilepsy surgery (62.5) vs not (60.5) (p-value 0.6), presence of depression (65.5) vs not (58.8) (p-value 0.03), presence of anxiety (65.1) vs not (60.1) (p-value = 0.2).

Conclusions: This is the first study in the Canadian population exploring stigma in patients with epilepsy. Using the Internalized Stigma of Mental Illness, we demonstrated that patients on disability and those with psychiatric comorbidity have higher stigma scores. There was no score difference in patients with and without drug-resistant epilepsy. Also, the scores of stigma appeared to be similar among different seizure types. This study will help to understand the complex association of stigma in patients with epilepsy.

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Dedication

I dedicate my thesis:

- To Almighty God, who gave me the strength to finish my thesis despite many obstacles.
- To my parents for their eternal love and encouragement
- To my devoted sister, who has supported me unconditionally, and I could not finish this chapter of my education without her incredible support.
- To my strong and intelligent daughter who is patient with my never-ending, continuing education.

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List of Abbreviations

3T MRI	3-Tesla magnetic resonance imaging
AED	Anti-epileptic drugs
AMB EEG	Ambulatory electroencephalogram
CSF	Cerebrospinal fluid
DRE	Drug-resistant epilepsy
ES	Epilepsy surgery
fMRI	Functional magnetic resonance imaging
HRQOL	Health-related quality of life
ILAE	International League Against Epilepsy
ISMI	Internalized Stigma of Mental Illness
NPHS	National Population Health Survey
PET scan	Positron emission tomography
PWE	People with epilepsy
SEEG	Stereo-electroencephalography
SPSS-13	Statistical Package for Social Sciences-13
VEEG	Video Electrocorticography
VFD	Visual field deficit

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND

Almost 50 million people worldwide have epilepsy, making it one of the most common neurological disorders globally. Many studies have reported that the social impacts of epilepsy are worse than the clinical effects.^{1, 2} People with epilepsy (PWE) experience comorbid illnesses, psychiatric disorders, stigmatization,³ reduced quality of life, higher standards of mortality ratios,²⁻⁴ and, thus, diminished life expectancies.^{4, 5}

Stigma is the phenomenon whereby people with an attribute are discredited by their society and changed from the general population to discounted ones.⁶ Stigma produces a social identity that is degraded by society and can cause status loss, discrimination, and negative a self-concept.⁶⁻⁸ Those who are stereotyped and discriminated against are vulnerable,⁹ are likely to be isolated,^{10, 11} and may not seek help.⁶ Epilepsy is the most common neurological illness associated with stigma due to the fear of being watched and judged by others in public as a result of having uncontrolled seizures.¹²⁻¹⁴ Based on the results of a recent study, PWE suffer from mood disorders more than twice than those in the general population (17% versus 7%).¹⁵ A study in England on adults with epilepsy assessed 14 aspects of psychosocial adjustment to epilepsy. The most concern of PWE was fear of seizures in public and fear of stigma in the workplace. Patients with frequent seizures had less adequate psychosocial adjustment than those with controlled seizures.¹⁶ Undervaluing PWE leads to stigmatization. The results of a recent survey about PWE conducted in the U.S. showed that approximately 50% of the respondents expressed a feeling of fear and depression as their first reaction to the diagnosis of epilepsy. Almost 24% described their fear of social stigma, embarrassment, and helplessness. Children and adolescents diagnosed with epilepsy felt embarrassment or shame more often than those diagnosed later in life.¹³ Participants described

the unpredictability of the next seizure and stigma as the first- and second-worst aspects of having epilepsy, respectively.¹³ A recent study conducted in Turkey found that patients were more likely to be stigmatized if they had low education levels, low income, were unemployed, used three or more antiepileptic drugs, or had frequent seizures.¹⁷ A European study that used a self-completed questionnaire to evaluate the number of PWE who had experienced stigma showed that 69% of participants had felt stigma.¹⁸

The PWE's self-perception is as critical as public attitudes toward those with epilepsy.¹⁹ The assumed causes of the behaviour also contribute to stigma. For instance, in some cultures, such as in some African countries, people believe that epilepsy is caused by evil spirits.¹⁹ The PWE internalize the negative perspectives related to their disease, which can increase their isolation. This phenomenon is known as internalized stigma. Therefore, there is a two-fold process in the stigma procedure: effects from surrounding people and the effects from the inflicted person themselves. The disease also impacts a person's family and society indirectly. The person's opportunities in life become more restricted due to unpredictable seizures, the risk of physical harm, and the consequences of being stigmatized. Internalized stigma can constitute, then, a vicious cycle activated by a person's sense of being different due to the experiences of having a disorder, negatively impacting that person's perceptions, beliefs, emotions, and behaviours.²⁰ These life experiences may cause hurt, anger, hopelessness, and progressive damage to oneself, which can lead to self-devaluation, shame, secrecy, and anticipated rejection, and can seriously affect one's self-esteem. For example, a participant in a study of stigma for patients with psychiatric disorders noted that "being treated as less human because of mental illness sent me into the darkest depression".²¹

Therefore, understanding the relationship between factors that play crucial roles in developing and sustaining internalized stigma among PWE is important to expand the available knowledge regarding these factors. To have a better understanding of the stigma experience of PWE, I briefly discuss the following terms and concepts: the definition of epilepsy; the classification and epidemiology of seizures; the history of epilepsy; the evaluation of stigma; the concept of illness-related stigma; and epilepsy stigma.

1.1.1 Definition of epilepsy

The most commonly used definition of epilepsy in contemporary literature is from the International League Against Epilepsy (ILAE). In 2005, the association presented the following definition of epilepsy: “A disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychiatric, and social consequences of this condition. This definition of epilepsy requires the occurrence of at least one epileptic seizure”.^{22, 23} In 2014, a new operational description of epilepsy was suggested: Epilepsy is a disease of the brain defined by any of the following conditions:

1. A least two unprovoked (or reflex) seizures occurring >24 hours apart.
2. One unprovoked or reflex seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next ten years.
3. Diagnosis of an epilepsy syndrome: Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age, or those who have remained seizure-free for the last 10 years with no seizure medicines for the last 5 years.²⁴

This new definition is an explanation of the 2005 definition, and it may be more practical in natural environments. Moreover, it categorizes epilepsy as a disorder, whereas previous definitions categorized it as a disease.²⁴

Since epilepsy is characterized by frequent seizures, the presence of these seizures is necessary for the diagnosis of epilepsy. In other words, the correct diagnosis of epilepsy can only be made with the correct diagnosis of epileptic seizures. However, an epileptic seizure diagnosis is complicated by the absence of authenticated criteria and depends mainly on eyewitness reports and the knowledge of an experienced epileptologist. Thus, the reported prevalence of epilepsy in developing countries may not be entirely correct.²⁵ The use of various definitions of epilepsy is likely to generate broad variance in epilepsy prevalence estimates within different studies.²⁶ To correctly compare the prevalence of epilepsy in various countries, reviews have to utilize the same definition of epilepsy. Consequently, it might be confusing or incorrect to compare the findings from studies using the 2005 definition to those using the 2014 ILAE definitions of epilepsy.

1.1.2 Definition of epileptic seizures

According to the ILAE, an epileptic seizure is a temporary incidence of signs and symptoms caused by unusual, extreme, or synchronous neurological activity in the brain.²⁷ Abnormal discharges can be confined to a small area of the brain.²⁸ It can cause focal seizures, or it can involve a significant part of the brain and produce generalized seizures that are often complemented by loss of consciousness.²⁸ In the past four decades, several classifications were suggested by the ILAE to promote the use of universal epilepsy definitions for physicians and other health care providers. In 2017, based on the collected medical knowledge, the ILAE suggested two separate classifications for the types of seizures, including a basic classification and an extended classification.²⁷ These classifications are based on three main symptom categories: 1) the area in the brain where the seizure begins; 2) the different impacts of the seizure on the patient's consciousness; and 3) the signs and symptoms that the seizure triggers.

1.1.3 Basic classification of seizures (Figure 1.)

The basic classification identifies seizures based upon their onset as focal, generalized, and unknown (Figure 1).²⁹ Focal onset seizures are categorized into two classification: aware seizures that do not impair consciousness and impaired awareness seizures that do impair consciousness. Focal seizures are also classified as motor onset and non-motor onset. Generalized seizures are usually complemented by impairment of consciousness. Therefore, they are classified as tonic-clonic (motor) and absence (non-motor). Unknown onset seizures are classified as motor and non-motor.²⁷

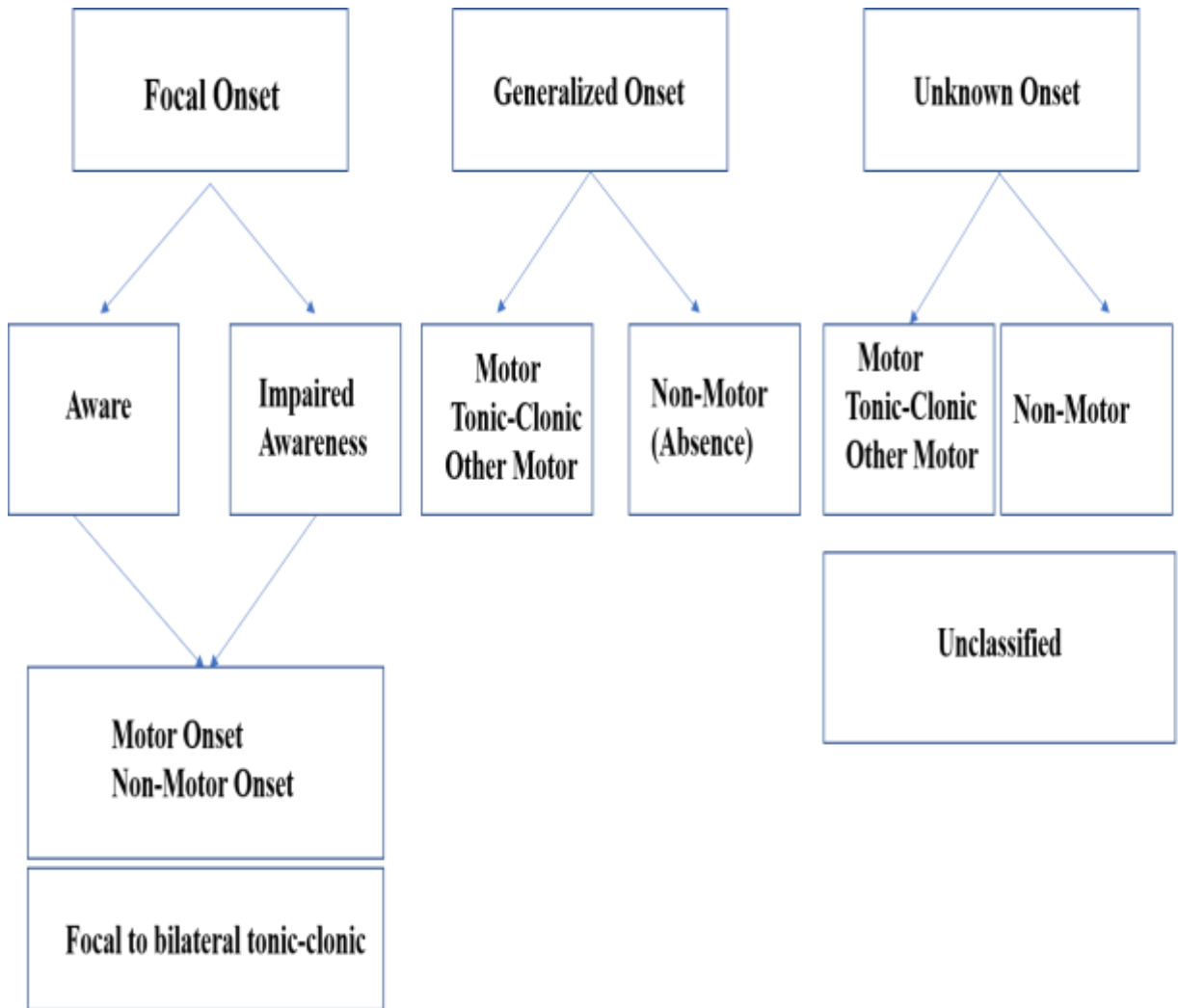


Figure 1. ILAE 2017 Classification of Seizure Types Basic Version ²⁹

1.1.4 Extended classification of seizures (Figure2)

The extended classification was based on the basic version, with extended “motor” and “non-motor” classifications for focal, generalized, and unknown onset seizures. This extension is based on first signs or symptom of seizures.²⁹ Although the basic version appears to be more helpful for physicians, the extended one can help epidemiologists and neurophysiologists because it gives further details for motor or non-motor seizure onset.²⁷ In developed countries, PWE could simply be transferred to emergency rooms, and the main features of epilepsy can be correctly diagnosed. However, in developing countries, many PWE may not get medical care either because they have a fear of revealing their status or because they do not have access to medical services.²⁸ Patients seeking medical attention can only get medical care in emergency rooms. These factors could restrict the accuracy of seizure classification and epilepsy diagnosis. It also causes epileptologists and epidemiological studies undertaken by epileptologists to be highly dependent on witnessed reports/evidence about the seizures.³⁰

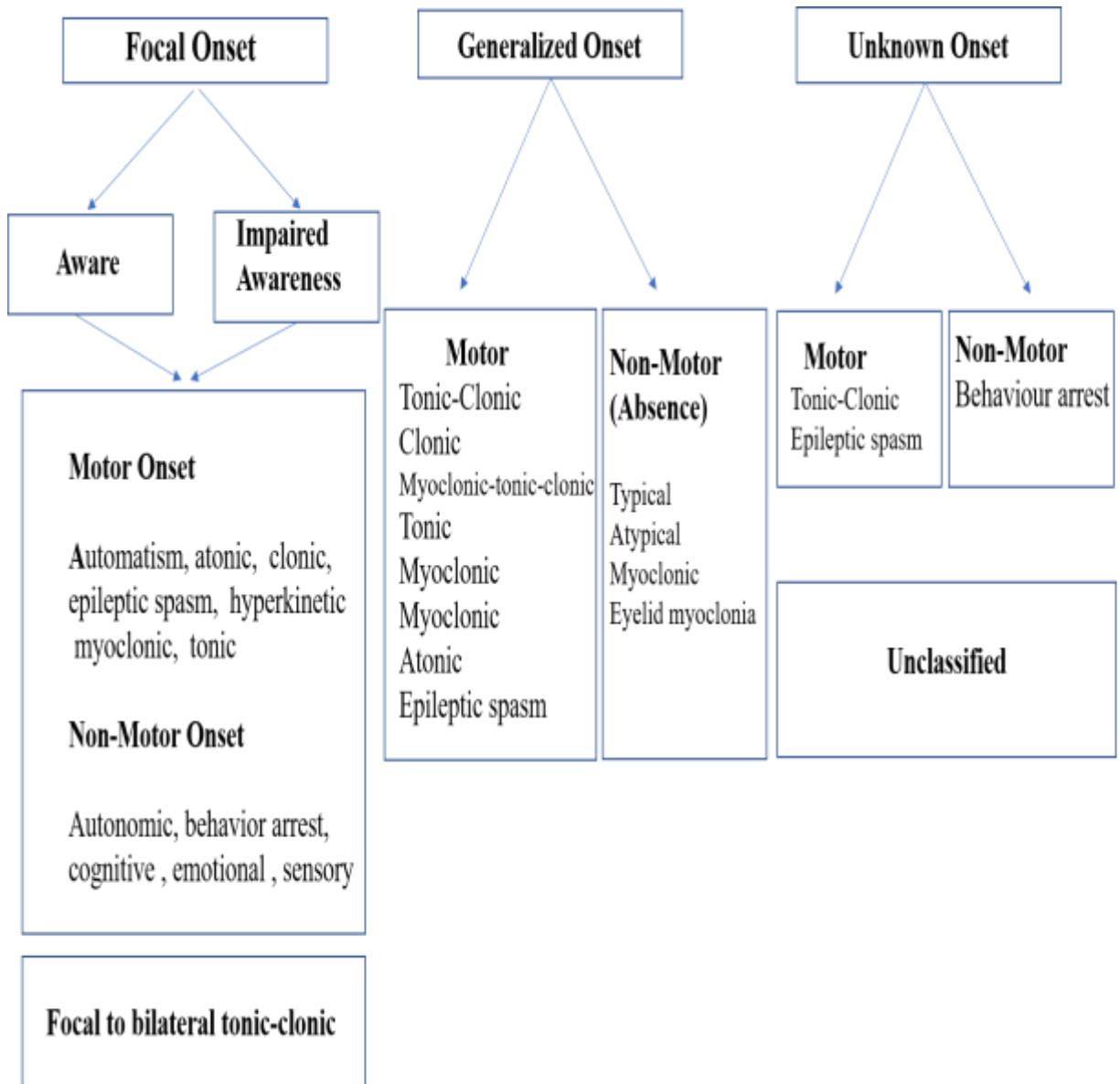


Figure 2. ILAE 2017 Classification of Seizure Types Expanded Version ²⁹

1.1.5 The prevalence and incidence of epilepsy in Canada

The prevalence of epilepsy in Canada differs across studies, but most report that six people per 1,000 have epilepsy (0.6%).³⁰⁻³⁵ Presently, little information regarding the prevalence of epilepsy in various areas of Canada exists. The prevalence of epilepsy in Ontario was almost 6 per 1,000.³⁶ A study done in Manitoba in children between birth and 15 years found an incidence rate of 4.4 per 1,000.³⁷ Recently, Tellez-Zenteno et al.³⁸ identified the prevalence rates of epilepsy that originated from the National Population Health Survey (NPHS)³⁸ and the Canadian Community Health Survey (CCHS).³⁸ The age-adjusted point prevalence per 1,000 people in various Canadian provinces varied from 3.7 to 7.1 based on the NPHS and from 3.0 to 6.9 based on the CCHS. The point prevalence in Ontario was 5.0 (NPHS) and 5.2 (CCHS) per 1,000 people. In Alberta, the prevalence of epilepsy was 4.4 (NPHS) and 5.7 (CCHS) per 1,000 people. In other provinces of Canada, the prevalence of epilepsy varied from 3.7 to 7.1 per 1,000 people. Self-reported epilepsy was more common among people who had low income and education levels, and there were no significant differences between sexes. Unfortunately, there is no similar data available for Saskatchewan.

The incidence of recurrent seizures is greatest during the first year of life and decreases during childhood and adolescence. During the first year of life, the incidence rates are highest in the first month (3.18 per 1,000 newborn infants).³⁹ The cumulative (incidence) rate of epilepsy by age of 15 is nearly 0.8%.⁴⁰ Many studies have shown that the incidence rate of epilepsy is higher in boys.^{35,39,41} However, this sex difference varies by age. Before the age of five, incidence rates are between 30% and 60% higher in girls, although rates have a tendency to be 10% to 20% higher in boys through later childhood and youth.^{40,42}

1.1.6 History of epilepsy and development of stigma

The word epilepsy is taken from the Greek *Epilepsia*, which can be divided into *epi* (upon) and *lepsis* (to get hold of or seizure).⁴³ Epilepsy was linked with religion and even devilish possession. In antiquity, people referred to epilepsy as the sacred disease because people believed that seizures came from an attack by devils or that the ideas experienced by PWE during seizures were guided by the gods. For example, animists believed that epilepsy was an attack by an evil spirit, but the disturbed person might be respected as a shaman through these strange experiences.⁴⁴

The relationship of epilepsy to stigma extends far back into the past and throughout several cultures. In many cultures, PWE have been stigmatized, rejected, and isolated. Biomedical descriptions for epilepsy changed these previous magical definitions, but the new theories further created opportunities for stigma, with many studies connecting epilepsy to aggressive or criminal behaviour, unusual sexual activity, hereditary degeneration, and a particular “epileptic personality”.⁴⁵ These descriptions have strengthened adverse stereotypes and prolonged stigma.⁴⁶

Public misconceptions about epilepsy can also contribute to stigma and social disability. Inaccurate descriptions of epilepsy in the media have been a part of the problem. Krauss et al.⁴⁷ surveyed English-language media between 1991 and 1996 to study the general stories regarding epilepsy and found 210 stories. The participants were medical doctors and researchers, (43%) general public resources, (22%) patients and their families, (18%) relatives of persons with epilepsy (11%), and corporate entities (5%). The stories contained personal images about controlling epilepsy, new medication therapies, non-drug therapies, and scientific progress. Almost 31% of the stories included mistakes, severely overstated the benefits of treatment (9%), or overstated the risks of seizures (5%).⁴⁷ PWE themselves were often sources of wrong information about the condition. Long et al.⁴⁸ showed that 30% of patients thought that epilepsy

is a psychiatric disorder or is contagious; 41% believed that it would be appropriate to put an object in a patient's mouth during a seizure, and 25% supposed that pregnant patients must stop taking antiepileptic drugs. The patients' ages, duration of epilepsy, and levels of education did not affect their perspectives regarding epilepsy.

The extent to which a person with epilepsy feels stigmatized can be associated less to the severity of seizure than to what is experienced in society and work environments. In a study of 445 PWE conducted in 1980, the perception of stigma significantly depended on whether the person had suffered discrimination in employment and life restrictions because of epilepsy.⁴⁹ Parents' attitudes and behaviours around epilepsy are critical contributors to their children's perceptions of what it means to have epilepsy and of stigma. One study reported that parents who think that their children will be stigmatized because of epilepsy mention that their children have more behavioural issues and social problems than parents who do not share these opinions.⁵⁰ Furthermore, children with epilepsy with overprotective parents have more behavioural issues compared to those who do not have overprotective parents.⁵¹ The behavioural problems of children with epilepsy are not affected by the type of seizure or frequency, but more by their parents' perception of stigma, limitations, and level of control. Another challenge is that parents of children with epilepsy might feel that their children's disease is affecting them. In one study, almost 33% of parents saw themselves, instead of their child, as having been "thrown off balance" by their children's epilepsy.⁵¹

1.1.7 The concept of illness-related stigma

Goffman described stigma as a phenomenon in which an individual is discredited by society because of a specific attribute, in a way that spoils their normal identity.⁵² It may be related to "external deformations" such as physical disabilities and diseases, "deviations of personal traits"

such as being unemployed or dependent on drugs, or “tribal stigmas” such as a different ethnicity or nationality.⁵² Crocker, Major, and Steele described stigma as the possession of an attribute that conveys a social identity that is devalued in a particular social context.⁵³

Scambler and Hopkins⁵⁴ noted that patients with epilepsy experienced felt stigma (e.g. patients feeling embarrassed about the condition) and enacted stigma (e.g. patients experiencing discrimination or social exclusion). Their model highlighted three areas: 1) the sense of felt stigma that people experience when confronted by a diagnosis; 2) the impact of concealing the condition; and 3) the disruption that this felt stigma may result in, which can be even greater than when stigma is enacted externally.⁵⁴

With mental illness, there are three different levels of stigma: social stigma; structural stigma; and internalized stigma.⁵⁵ Social stigma occurs because of negative stereotypes, prejudices, and discrimination, causing the “us” versus “them” effect, whereas structural stigma involves institutional policies and procedures that limit people’s access to their rights. Research has consistently demonstrated that stigma affects the psychiatric and social wellbeing of people with mental illness by reducing their social opportunities.⁵⁶ The stigma of mental disease is evoked by symptoms (e.g. psychiatric symptoms, social skills deficits, physical look, and labels) that frighten the public.²⁰ The perception of being devalued and rejected on the basis of the marks or symptoms associated with a mental disease can lead to stereotype agreement (i.e. endorsing the same stereotypes perceived to be common in society) , self-prejudice, and self-discrimination, persisting even after the symptoms have disappeared.⁵⁷ Therefore, the negative consequences of stigma occur when, once stigmatized, a person internalizes these generally accepted views, endorsing, and applying negative stereotypes to themselves.⁵⁷

1.1.8 Methods to identify and measure stigma in different studies

Stigma among PWE can be discovered in a wide variety of ways, such as self-report or by the use of validated scales, which will be debated in this section.

The Internalized Stigma of Mental Illness (ISMI) questionnaire is very well validated to measure stigma in patients with psychiatric conditions. The instrument has 29 questions and measures the subjective experience of stigma, with subscales measuring Alienation, Stereotype Endorsement, Perceived Discrimination, Social Withdrawal and Stigma Resistance. This scale has been used to assess stigma in mental conditions but has been used in patients with epilepsy.^{55,58}

The Stigma Scale of Epilepsy was recently developed⁵⁹ This is a multiple-choice questionnaire which quantifies the degree of stigma perceived by adults in different contexts (attitudes and behavior towards PWE, perception and feelings regarding seizures, social aspects associated with having epilepsy).⁵⁹ The scale has 24 items distributed in five domains, and each item has four response options scored from 1 to 4 (1 = not at all, 2 = a little, 3 = a lot, 4 = totally).⁵⁹ The results are transformed into 0 to 100 points. Perception of stigma increases with score. This scale explores aspects of stigma related with seizures and social aspects in PWE, which is different to the ISMI that explores internalized stigma. The internal consistency of the Stigma Scale of Epilepsy showed α Cronbach's coefficient 0.88 for patients with epilepsy from epilepsy clinics and 0.81 for patients without epilepsy in the community.^{59,60} The authors who created the questionnaire reported that the Stigma Scale of Epilepsy had satisfactory content validity and high internal consistency and allowed the quantification of the perception of stigma by patients and people from the community. They suggested using the Stigma Scale of Epilepsy in interventional studies, such as mass media campaign in minimizing the negative facets of stigma.

The Public Attitudes Toward Epilepsy scale includes 14 items, assessed on a five-point Likert scale; the questionnaire had good internal consistency and construct validity. Items on the scale contain the statements “People with epilepsy should not marry,” “People with epilepsy should study in a special school,” and “People with epilepsy should not participate in social activities”.⁶¹ After analysis the factors, two scale domains were found, the personal and the general domains.⁶¹ This scale was used in a Malaysian study evaluating student’s attitudes towards PWE.⁶² The result of the study showed that students were more positive in comparison to the general population towards PWE in the general domain.⁶²

In 2012, the Kilifi Stigma Scale for Epilepsy was established to evaluate the perceived stigma score in PWE.⁶³ This 15-item questionnaire uses Likert-type questions to measure perceived stigma and was validated within Kenya using self-report by adults with epilepsy.

1.1.9 The stigma experience of PWE

Research about PWE’s life experiences across the world consistently shows quality of life deficiencies, including higher rates of unemployment, lower levels of income, lower levels of education, decreased numbers of marriages, and lower rates of well-being. The scope to which stigma contributes to these impairments is presumed rather than recognized. Nonetheless, epilepsy stigma and its connection with other outcomes continue to be a significant focus for research.

Stigma negatively impacts health by affecting access to health care and by causing psychosocial stress to the physiological problem of disease. PWE’s quality of life is adversely affected by the stigma surrounding the disorder. A study by Suurmeijer et al.⁶⁴ used questionnaires to evaluate health functioning and social/psychological experiences of 210 PWE from four neurological clinics in the Netherlands. These patients showed symptoms of depression, anxiety, isolation, problems with adjusting/coping, and felt stigmatized which had a significant impact on

their quality of life. These experiences were not different between patients with mild epilepsy and those with severe epilepsy. Another study compared the responses of PWE in several European countries about their quality of life.¹⁸ It showed that the perceived influence of epilepsy and feelings of stigma were significantly different between countries. While patients in Spain and the Netherlands had the lowest feelings of stigmatization, respondents in France felt the most stigmatization. The authors suggested that their results emphasized the variable experiences of PWE among different countries and cultures. The Centers for Disease Control and Prevention (CDC) in the United States evaluated data on health-related quality of life (HRQOL).⁶⁵ PWE had a noticeably lower HRQOL compared to those without epilepsy. Almost 50% of PWE were in poor health, compared to almost 19% of those without epilepsy.⁶⁵

Stigma and lower HRQOL related to epilepsy have significant economic effects. Epilepsy's impact in the United States is approximately \$12.5 billion each year.⁶⁶ Also, the household income of PWE is 93% of the median household income in the United States.¹³ Birbeck et al.⁶⁷ analyzed the social and economic effect of epilepsy on a stigma score in Zambia. The result showed that PWE who had a lower social and economic status and had significantly higher stigma scores compared to those with a higher social and economic status.

Epilepsy stigma negatively affects economic and employment opportunities. PWE were less likely to graduate from high school than those without epilepsy. A study in the United States showed just 64% of PWE graduated from high school; in comparison, the overall high school graduation rate was 81.7%.¹³ Only, 20% of PWE graduated from college compared to the general population at 23%.¹³ Thus, if a PWE was unable to complete their education, the long-term outcomes of educational deficiency will definitely have an effect on that individual even if epilepsy begins in adulthood. PWE have a 25% unemployment level, and almost 64% of those connect their

unemployment to epilepsy: for patients with uncontrolled seizures, the unemployment rate is 50%.

¹³ Employment discrimination is a considerable burden for many PWE. While the Americans with Disabilities Act tried initially to address this discrimination, judicial rulings have indicated that PWE do not have protection against unfair employment practices. ⁶⁸ A study in Sweden showed that almost 35% of PWE experienced employment problems. ⁶⁹ Nearly 9% of PWE were unemployed, and almost 16% received disability compensation. Moreover, patients with controlled seizures had a higher employment rate than those with uncontrolled seizures. Almost fifty percent of patients with uncontrolled seizures had experienced job problems. Patients who were diagnosed with epilepsy at a younger age were more likely to feel employment discrimination. This survey proposes that if epilepsy starts early, employment discrimination can be a severe issue that results in rising underemployment rates and limited job opportunities. ⁶⁹ Employment status can be correlated to felt stigma in PWE; those patients who have been unemployed are most likely to be stigmatized. ⁷⁰⁻⁷² The result of a recent study in Australia showed almost 50% of PWE who have a job reported unfair treatment in the workplace. ⁷¹ In Iran, PWE who are unemployed also described higher levels of stigmatization compared to those who are employed. A low educational status was also connected with high levels of felt stigma. ⁷²

A study explored the association between stigma scores and psychological outcomes in a group of children with epilepsy. ⁷³ The children's experience of stigma was evaluated using the Child Stigma Scale ⁷⁴ that contained questions about the attitudes and reactions of their friends and the issue of revelation. While there were significant relationships between stigma scores and self-confidence and behaviour problems, there was not a substantial relationship between stigma scores and social competence or ability to effectively handle social interactions. A recent study that was done among PWE in an ethnic minority group living in England provided qualitative data about

their experience of stigma and discrimination. Participants were mostly concerned about people's lack of knowledge about their disease and about having unpredictable seizures in public areas.⁷⁵ psychiatric comorbidities, such as anxiety and depression, were common in PWE, and the one item constantly described as being related with greater feelings of stigma in PWE was the existence of psychiatric symptoms, such as depression and anxiety.^{70, 75, 76} A study done among PWE in Korea showed that the rate of felt stigma was higher in patients with psychiatric symptoms than those without psychiatric symptoms.⁷⁶

In several studies, participants mentioned the issue of marriage as central to the experience of stigma and prejudice.⁷⁷ Fear of facing negative perspectives in their community caused PWE to be socially isolated.⁷⁸ A study done in India emphasized the significant impact of epilepsy stigma on marriageability.⁷⁹ Around half of the 85 women with epilepsy in the study hid their epilepsy from their husbands before marriage, and around 90% of them considered that social discrimination was especially noticeable toward women with epilepsy.⁷⁹ A study in Cameroon showed that epilepsy stigma reduced people's abilities to have normal social activities and decreased their perceived social value. Moreover, the results, like those in other studies, showed that the experience of stigmatization and social rejection impacted their marriage, education, and employment.⁸⁰

An evaluation of the stigma scores in PWE in Bulgaria found that while nearly half of people with drug-resistant epilepsy (DRE) reported being stigmatized, only 5.7 % of patients with well-controlled epilepsy reported being stigmatized.⁷⁵ Almost 30% of patients with DRE mentioned that the reason for their feeling of stigmatization was their epilepsy; stigmatization was also correlated with depression and mental illness.⁷⁵

1.1.10 Recent studies of Public Attitudes Toward Epilepsy (PATE)

In addition to the social attributes of stigma, many studies around the world have shown that even though PATE has improved considerably, negative beliefs about its causes and outcomes remain to inform popular concepts, resulting in continued misunderstandings and harmful attitudes. The result of a recent survey of 1850 people showed that epilepsy caused substantial levels of discrimination in education (by 36%), social relationships (by 47%), and employment (by 64%).⁸¹

However, social discrimination had less impact on marriage and family relationships. Additionally, the stigma scores varied considerably by education, socioeconomic status, and sex^{57, 82-85}. A previous study in Pakistan used a 117-question questionnaire about personal attitudes and beliefs about epilepsy, causes and alternative treatments, a different way for controlling epilepsy and seizures, and social attitudes toward epilepsy.⁸⁶ The participants were 83 PWE, 83 family members of PWE, and 166 people who lived in the village. Stigmatizing attitudes were frequently reported. The study evaluated the misbeliefs about epilepsy and showed that almost 42% of respondents thought epilepsy had unnatural origins, between 38% and 57% believed epilepsy was contagious, and between 14% and 44% believed epilepsy could be transmitted by saliva.⁸⁶ Most respondents in another study done in Pakistan considered epilepsy a treatable disease, and they also believed that PWE could be educated and do daily activities. However, most of the respondents did not want to marry a person with epilepsy, and almost 30% believed that PWE could not make a contribution to society and must be separated from others.⁸⁷ A study done by Chomba et al.⁸⁸ analyzed the beliefs and attitudes of health care providers in Zambia as part of a sequence of studies that also engaged teachers⁸⁹, priests,⁹⁰ and police officers.⁹¹ The results demonstrated that people who had more formalized training and had graduated recently had higher

levels of knowledge about epilepsy.⁸⁸ High levels of education related to higher social acceptance. Nearly all employees realized that epilepsy was a non-contagious and chronic disease that needed long-term treatment.⁸⁸ Almost 30% identified epilepsy as a neurological disorder. Fernandes et al.⁸⁵ noticed that education could increase knowledge and enhance attitudes among school teachers toward their students with epilepsy. The results of a study conducted among a Turkish population showed that the score of stigma was higher in males than in females because of the particular nature within the Turkish society, men were widely considered as the breadwinners of the family.⁵⁷

1.1.11 Intervention to eliminate stigma

Having access to optimal medical care and the correct information are the best antidotes to mitigate stigma. Education has an affect not only on the individual, but also on the entire community, involving family members, friends, teachers, employers, health insurance providers, the media, and politicians. Researchers indicated that, during the early stages of epilepsy, psychosocial outcomes were closely linked to the level of medical care,¹⁶ suggesting that controlling seizures quickly decreases perceived stigma. Stigma needs to be addressed as soon as possible. Reducing the adverse effects of low self-esteem and misunderstandings regarding epilepsy may make it more difficult when wrong beliefs are not tackled throughout early childhood and continue into adolescence. For teenagers, epilepsy could cause problems and pressures in addition to those that usually accompany the teen years of life. Almost 23% of teenagers with epilepsy had depression (27% of females and 18% of males).⁹² The severity of depression was strongly related to the teenagers' attitude toward epilepsy.⁹² Thus, the Epilepsy Foundation and the CDC are creating a program to enhance the lives of teenagers with epilepsy.⁶⁸ The aim of the program was to work with teenagers with and without epilepsy to decrease the psychosocial

symptoms from seizures, working from the assumption that attitudes can be changed easily when they are changed in early life.

Increasing knowledge about epilepsy can be helpful in improving self-esteem among PWE. Due to misconceptions and knowledge gaps about epilepsy, various programs can be setup with the purpose of increasing knowledge and decreasing negative public attitudes towards epilepsy.⁹³

Regulations and laws have the potential to shape behaviour that can eventually change attitudes. The Americans with Disabilities Act (ADA) was effective in USA since 1990 and later amended in 2008. This is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. Based on this law, people with disabilities have the same rights and opportunities as everyone else. Information about the Americans with Disability Act and legal prerequisites to verify disability is accessible from the Epilepsy Foundation website⁶⁸. Even for patients with controlled seizures, employers and supervisors may discriminate against them because they have a misbelief that the individual with epilepsy is substantially impaired due to the seizures.⁶⁸ The Supreme Court, in its recent decisions, has required that patients with controlled epilepsy must exhibit a substantial disability, such as substantial impairment in ability to work or to be considered as disabled. In other words, if seizures persist or if the patient is limited due to other neurological symptoms or medication-related side effects, that person is considered to be disabled.⁶⁸

Courts have assessed epilepsy as a disability under state and federal antidiscrimination laws. Nevertheless, recent Supreme Court rulings indicate that patients with controlled seizures can not be labeled as disabled, even though epilepsy may cause stigma and restrict their job opportunities.⁶⁸ However, PWE usually leave the workforce because of problems related to their seizure

situations, and they are often underemployed because of their education level and abilities.^{13, 66, 69} Even patients with controlled seizures may be discriminated against by employers who wrongly think that the PWE have a disability. In its recent judgments, the Supreme Court noticed that patients with controlled epilepsy had to be considered as disabled in spite of treatment.⁶⁸ Therefore, if seizures continue or if patients are restricted due to other neurological disorders or the side effects of medication, such as amnesia or fatigue, those patients are disabled. Moreover, employment problems may arise for PWE whose driver's licenses are suspended.

In conclusion, epilepsy can be categorized by an enduring tendency to generate epileptic seizures and by their neurological, cognitive, psychiatric, and social outcomes.⁹⁴ PWE are usually seen as having a mental disorder and creating social disturbances.⁶⁸ Consequently, their quality of life is significantly decreased when compared to the general population. The implications of epilepsy in terms of morbidity, mortality, quality of life, and stigma vary across the world, depending on community-based health, cultural, and economic backgrounds.⁹⁵

1.2 Statement of the problem

Based on the 2010 and 2011 Canadian Community Health Surveys, approximately 139,200 Canadians reported having been diagnosed with epilepsy, with an age-standardized incidence of 62 per 100,000 person-years in Saskatchewan.^{38, 96} For Indigenous people, the age-standardized incidence of epilepsy was 122 per 100,000 person-years, nearly double the rate of epilepsy in the general population.⁹⁶

Almost 16% of the population in Saskatchewan have identified as being Indigenous.⁹⁷ Various studies have shown that Indigenous peoples have more health and social difficulties (e.g. family violence, racism, stigmatization) in comparison with other Canadian ethnic groups.^{98, 99}

Stigma has never been measured in PWE in Canada. This study aimed to evaluate stigma in PWE in Canada for the first time using the Internalized Stigma of Mental Illness (ISMI). This study explored the aspects of stigma in PWE from the psychiatric aspects to the patient and family perspective. This study also helped to identify risk factors for stigma in PWE. Subsequently, it may provide better information for healthcare systems and policymakers to improve the health status of PWE by recognizing stigma and its social impacts.

1.3 Hypothesis and objectives

We hypothesized that the internalized stigma score will be higher in PWE with psychiatric comorbidity than those without it.

The specific objectives are:

1. To evaluate the stigma scores for PWE using the ISMI
2. To identify risk factors for stigma in PWE

2 CHAPTER 2: METHODS

2.1 Basic study design

This is a cross-sectional comparative study. This study aimed to evaluate stigma using the Internalized Stigma of Mental Illness (ISMI) scale in Saskatchewan, Canada. This study will help programs to be designed to target internalized stigma.

2.2 Location of study

The study was carried out between 2018 and 2019 at the Saskatchewan Epilepsy Program after the Human Research Ethics Board approval (ID 357). The Saskatchewan Epilepsy Program was started in 2007 and located at the Royal University Hospital (RUH) in Saskatoon, Saskatchewan, Canada. The program assesses approximately 1200 patients per year and maintains a database of all patient records. This program provides clinical and supports services for PWE who are referred from healthcare clinics throughout the province.¹⁰⁰ These services include inpatient Phase I and Phase II monitoring with depth electrodes, neuromodulation (deep brain stimulation and vagus nerve stimulation), a single seizure clinic for patients with new onset seizure, ambulatory electroencephalogram (AMB EEG) capability, video electrocorticography (VEEG), brain stimulation, 3-Tesla magnetic resonance imaging (3T MRI), functional magnetic resonance imaging (fMRI), positron emission tomography (PET) scan, and epilepsy surgery (ES)¹⁰¹. About 300 patients have been assessed for ES since 2007, of which 30% received surgical treatment.¹⁰⁰

2.3 Participants

1.1.12 Inclusion criteria

This study used the following inclusion criteria:

- a) Patients with focal and generalized epilepsy from RUH (between 2018 and 2019)

- b) Any consecutive patients attending the clinics in the study period
- c) Patients who could read and understand English
- d) Patients between 18 and 79 years old

1.1.13 Exclusion criteria

The following exclusion criteria were used:

- a) Patients with any significant psychiatric condition or intellectual disability (ID) who were unable to fill out the questionnaires.
- b) Age less than 17 years old or more than 79 years old

2.4 Description of tools

1.1.14 Socio-demographic and clinical datasheet

A socio-demographic and clinical data sheet was used to collect some primary information regarding participants' socio-demographic variables and clinical history, which included gender, age of onset, type of epilepsy, date of the last episode, type of seizure, number of seizures, family history, treatment history, etiology of seizures, number of antiepileptic drugs, and type of surgery. Seizure frequency was asked in order to categorize patients as being seizure-free or to note the number of seizures per year and the number of seizures per month. Psychiatric comorbidity was collected from the patients' charts. Somatic comorbidity included allergies, back problems, arthritis, migraine, sleep apnea, hypertension, asthma, heart disease, thyroid conditions, stomach ulcers, and diabetes.

1.1.15 ISMI scale

The Internalized Stigma of Mental Illness (ISMI) Scale built by Ritsher et al.²³ assesses the internalized stigma score in patients with a mental health disorder. The ISMI Scale, which has 29 questions is a self-report questionnaire. It has been used to assess stigma in mental health

conditions but has not been used with PWE. ISIM measures the subjective experience of mental health stigma, with subscales measuring “Alienation” (6 questions), “Stereotype Endorsement” (7 questions), “Discrimination Experience” (5 questions), “Social Withdrawal” (6 questions), and “Stigma Resistance” (5 questions). Each question has four response options scored from 1 to 4 (1 = not at all to 4 = totally). The “Alienation” subscale assesses the personal experience of being less important than other members in society. The “Stereotype Endorsement” subscale assesses the level that participants agree with common stereotypes about PWE. The “Discrimination Experience” subscale is comprised of five questions that describe the participant's perception of the way that others treat him or her. The “Social Withdrawal” subscale involves statements such as “I do not socialize as much as I used to, because my epilepsy might make me look or behave weird”. The “Stigma Resistance” subscale assesses the rate of struggle with being stigmatized. The ISMI scale was modified for the study of PWE.

A pilot study was conducted with 30 patients to evaluate the feasibility and reliability of the epilepsy version of ISIM. The questionnaire pilot study reported an internal consistency of 0.87. Overall, the internal consistency of the questionnaire was assessed by Cronbach's alpha coefficient, and an alpha equal to or greater than 0.70 was considered satisfactory. The internal consistency score for the entire scale of ISIM for epilepsy was 0.91, the score for the Alienation subscale was 0.67, the Stereotype Endorsement subscale score was 0.81, the Discrimination Experience subscale score was 0.80, the Social Withdrawal subscale score was 0.84, and the Stigma Resistance subscale score was 0.47.⁷²

Patients from outpatient clinics of the neurologists working in RUH were recruited. The aim was to recruit 100 individuals aged 17 to 79 years old. The program assesses approximately 1000 patients per year and therefore a good maximum sample size was around 10% of the patient

population. However, in the process of data cleaning, seven patients were excluded from the study, because of unfinished questionnaires. Oral consent was requested from all participants before potential participation in the study. If participants decided to continue after having received the explanation of the study's purpose, they were invited and subsequently signed the written consent. The participants were also told that the requested information would be stored confidentially and would not be used for any commercial or business purposes. The participants were invited to complete the ISMI questionnaire, which was given to them by a research assistant that had been trained by Dr. Miranzadeh Mahabadi. In addition, the following information was obtained from patients' charts: socio-demographic characteristics; type of epilepsy; type and frequency of seizures; years of evolution; drugs that the patients were using; imaging findings; criteria of DRE; list of comorbid conditions; and, previous epilepsy surgery.

2.5 Statistical analysis

The statistical analyses were undertaken with using the Statistical Package for Social Sciences-13 (SPSS-22). Descriptive statistics (mean, frequencies, and proportions) were applied to describe demographic and clinical characteristics. The mean, standard deviation, and range to describe the scores of the stigma scales in the population were used. The independent t-test was used to compare the scores of the stigma scales between variables of interest such as the presence of DRE, frequency of seizures, presence of psychiatric comorbidity, disability, type of seizures, and seizure syndrome. A Chi-square test was used to determine whether independent variables (all categorical) were distributed differently between those below and above the midpoint. First, a simple logistic regression was performed for each independent variable with the outcome of interest being identified (severity of stigma) (data was not shown). Based on the simple analysis, variables with a p-value of less than 0.2 or those with clinical importance were included in a multivariate logistic

model. The strength of association was determined by the odds ratios (OR) and 95% confidence intervals (CI).

This study was approved by the University of Saskatchewan's Behavioural Research Ethics Board (ID 357, issued October 22, 2018) prior to beginning the study.

3 CHAPTER 3: RESULTS

3.1 General consideration

This was a cross-sectional comparative study. This study aimed to evaluate stigma using the Internalized Stigma of Mental Illness (ISMI) Scale in the province of Saskatchewan, Canada. The study was carried out at the Saskatchewan Epilepsy Program located at Royal University Hospital (RUH) in Saskatoon, Saskatchewan, Canada and aimed at recruiting 100 adults aged 17 to 79 years. The ISMI questionnaire with 29 questions was used. Each question had a score of between 1 to 4. Thus, the stigma score can range between 29 and 116.

3.2 General characteristics of the sample

As presented in Table 1, one hundred patients were recruited. Mean age was 41.9+15 years. Fifty-two patients were males (56%). Sixty patients had focal seizures (64%) (59.6% male vs 70.7% female) , 26 patients were on disability (28%)(26.9% male vs 29.3% female), 35 patients had psychiatric comorbidity (38%)(36.5% male vs 39% female), 30 had depression (32%)(30.8% male vs 34.1% female) , 16 had an anxiety disorder (17%) (15.4% male vs 19.5% female), 22 had somatic comorbid conditions (24%) (28.8% male vs 17.1% female), 59 were seizure-free (63%) (63.5% male vs 63.4% female), 25 patients had drug resistant epilepsy (DRE) (27%) (25% male vs 29.3% female), 67 were from urban areas (72%), 60 patients were not employed (64%) (61.5% male vs 68.3% female), and 17 had epilepsy surgery (18%) (11.5% male vs 26.8% female).

Table 1. General characteristics of patients with epilepsy in Saskatchewan Epilepsy Program.

	Saskatchewan N=93
Age (\pm SD)	41.91 (<u>+15.01</u>)
Gender	
Male	52 (55.9%)
Female	41 (44.1%)
Current residence	
Rural area	26 (28%)
Urban área	67 (72%)
Civil state of patent	
Single	41 (44.1%)
Married	45 (48.4)
Separated	6 (6.5%)
Widowed	1 (1.1%)
Yearly income	
45,916 or less	24 (25.8%)
45,916 to 142,353	7 (7.5%)
142,353 to 202,800	1 (1.1%)
More than 202,800	2 (2.2%)
Education level	
No certificate, diploma or degree	6 (6.5%)

High school diploma	43 (46.2%)
Apprenticeship or other trade certificates	16 (17.2%)
College diploma	13 (14%)
University below bachelor's	3 (3.2%)
Bachelor's degree or higher	12 (12.9%)
Currently employed	
Yes	33 (35.5%)
No	60 (64.5%)
Disability of patient (mental or physical disability)	
Yes	26 (28%)
No	67 (72%)
Type of epilepsy	
Generalized epilepsy	33 (35.5%)
Focal epilepsy	60 (64.5%)
Seizure free	
Yes	59 (63.4%)
No	34 (36.6%)
Years of the evolution of epilepsy mean (\pm SD)	
Mean	15.4 \pm 12.8
<10 years	44 (47.3%)
\geq 10 years	49 (52.7%)

Epileptic syndromes (%)	
Symptomatic/structural	38 (40.9%)
Cryptogenic/ unknown	26 (28%)
Idiopathic/genetic	29 (31.2%)
Status epilepticus	
Yes	12 (12.9%)
No	81 (87.1%)
Drug-resistant epilepsy	
Yes	25 (26.9%)
No	55 (59.1%)
Undetermined	13(14%)
Seizures per year (group)	
None	63%
One or more	37%
Seizures per month (group)	
None	77%
One or more	23%
Number of AEDs ¹ (group)	
0	1 (1.1%)
1	32 (34.4%)
2	47 (50.5%)
3	9 (9.7%)
4 or more	4 (4.3%)

Epilepsy surgery	
Yes	17 (18.3%)
No	76 (81.7%)
Type of epilepsy surgery	
Lobectomy	16 (17.2%)
Lesionectomy	1 (1.1%)
Psychiatric condition	
Yes	35 (37.6%)
No	58 (62.4%)
Total Somatic comorbidity	
	22(23.7%)
Use of illegal drugs	
Yes	13 (14%)
No	80 (86%)

3.3 The score of stigma in people with epilepsy

1.1.16 The comparison of internalized stigma score in PWE by different social demographic characteristics (Table 2.):

The mean of score for stigma in males and females were 63.4 ± 13.3 and 61.9 ± 12.01 , respectively ($P = 0.5$). There was no significant difference in the mean score between participants who lived in urban and rural areas ($P = 0.4$). The mean score among employed PWE was 57.7 ± 14.2 , and those who were unemployed was 62.73 ± 14.5 ($P = 0.1$). There was no significant difference in stigma scores between PWE that were married and those that were single ($P = 0.2$).

Table 2. Reported score of internalized stigma in PWEs with different social demographic characteristics.

		Score		P-value
		Mean	SE	
Gender	Male	61.7	2.1	0.5
	Female	59.9	2.1	
Current residence	Rural	62.7	3.0	0.4
	Urban	60.2	1.7	
Employment	Yes	57.7	2.4	0.1
	No	62.73	1.8	
Education status	Heigh school diploma or less	61.06	2.1	0.9
	College diploma or university degree	60.84	2.1	
Marital status	Single	62.5	2.2	0.2
	Married	59.3	2.0	

SD= Standard Error, $P < 0.05$ = statistically significant.

1.1.17 The comparison of the internalized stigma scores in PWE by different epilepsy types and seizure types (Figure 3):

The difference in stigma scores between participants with drug-resistant epilepsy and those with drug-responsive epilepsy was not statistically significant. (58.4 vs 60.3, $P= 0.6$). The difference between participants who have had status epilepsy and those who have not was significant (58.9 vs 61.2, $P= 0.6$). Although there were differences in the mean of scores between participants with focal epilepsy and those without, these differences were not significant. ($P= 0.4$). The mean score among patients with generalized epilepsy was 63.6 ± 2.5 , and among those without generalized epilepsy was 62.3 ± 1.8 ($P=0.6$). There was no significant difference in stigma scores between participants who were seizure-free and those that were not ($P= 0.7$).

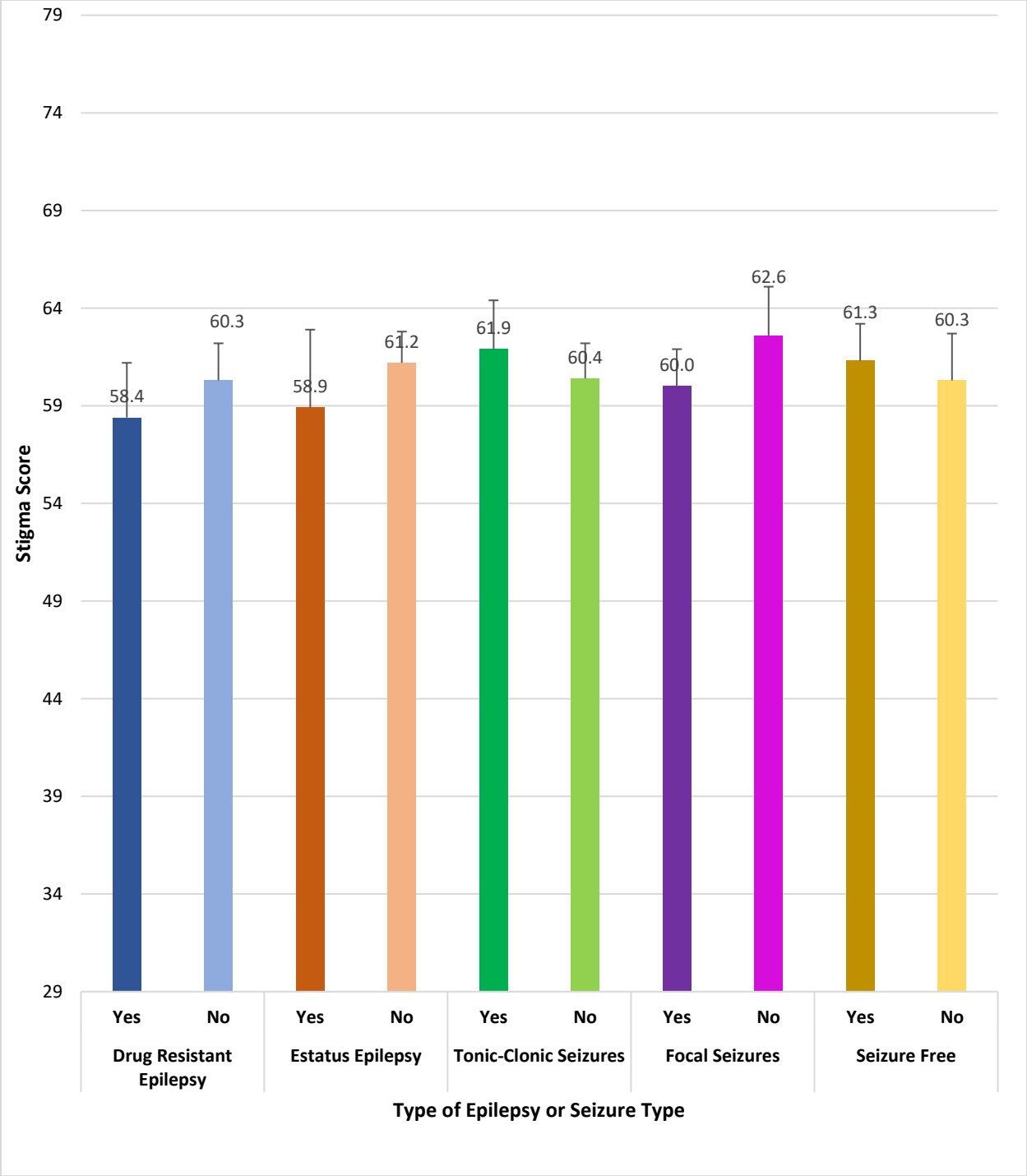


Figure 3. The internalized stigma scores in different types of seizures and epilepsy.

1.1.18 The comparison of the internalized stigma scores in PWE by different types of treatment (Figure 4):

The difference in stigma scores between participants who have had epilepsy surgery and those that had not was not statistically significant. (62.5 vs 60.5, $P=0.6$). The difference between participants who took one antiepileptic drug and those taking two or more antiepileptic drugs was marginally significant using independent sample t-test (57.5 vs 62.7, $P=0.09$).

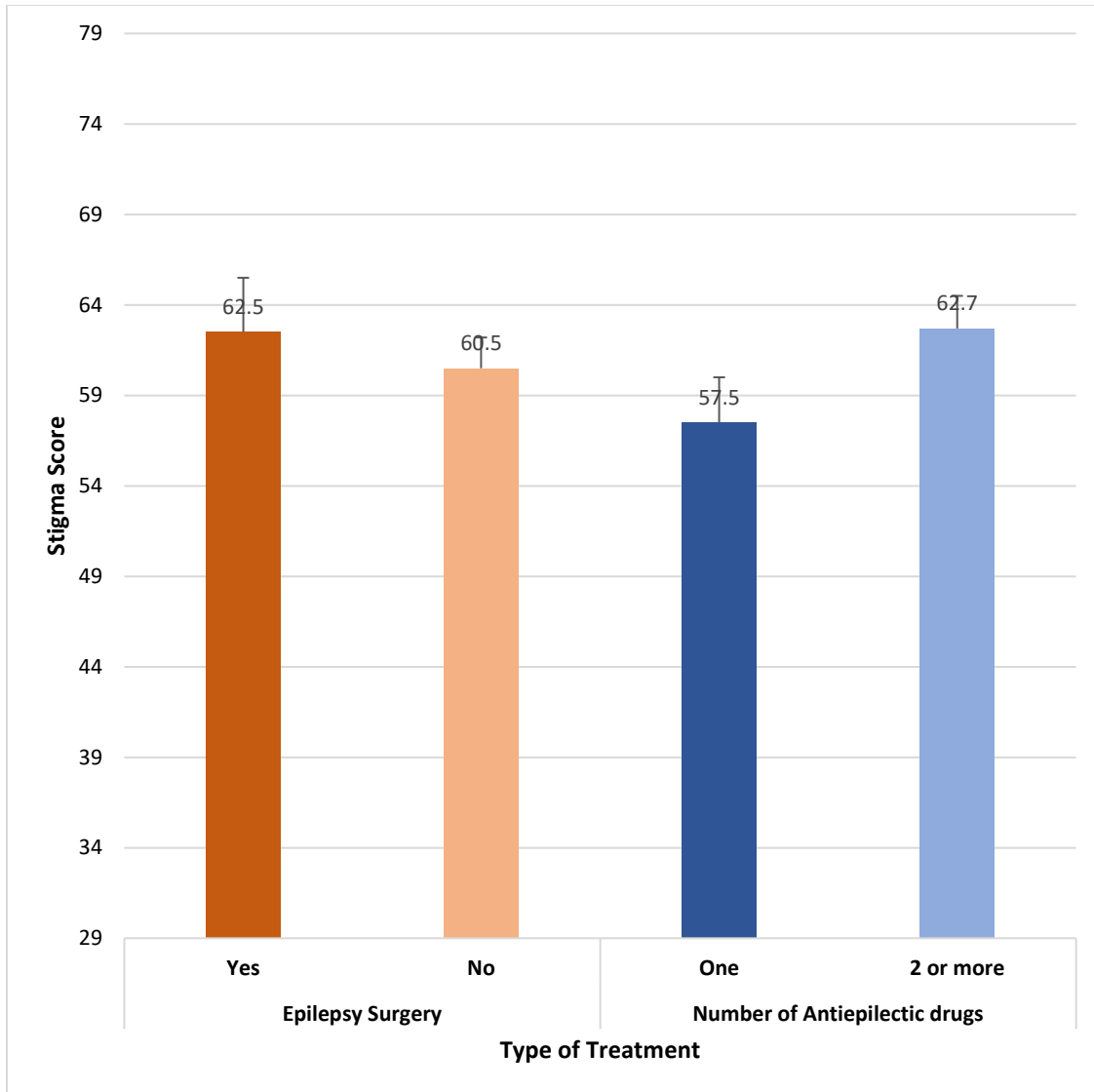


Figure 4. Relationship between the scores of the internalized stigma and different types of treatment.

1.1.19 The comparison of the internalized stigma scores in PWE by different somatic and psychiatric comorbidity (Figure 5):

There were significant differences in stigma scores in participants with disability (67 vs 58.5, $P=0.01$), and psychiatric disorders (65.4 vs 58.2, $P= 0.02$) compared to those without these health conditions. Although the difference of stigma scores between participants with depression and those without was statically significant with $P= 0.03$, the difference of stigma scores was not significant in participants with anxiety and without anxiety. ($P= 0.2$) The difference between participants who had somatic comorbidity and those without was marginally significant. (65.7 vs 59.4, $P = 0.07$).

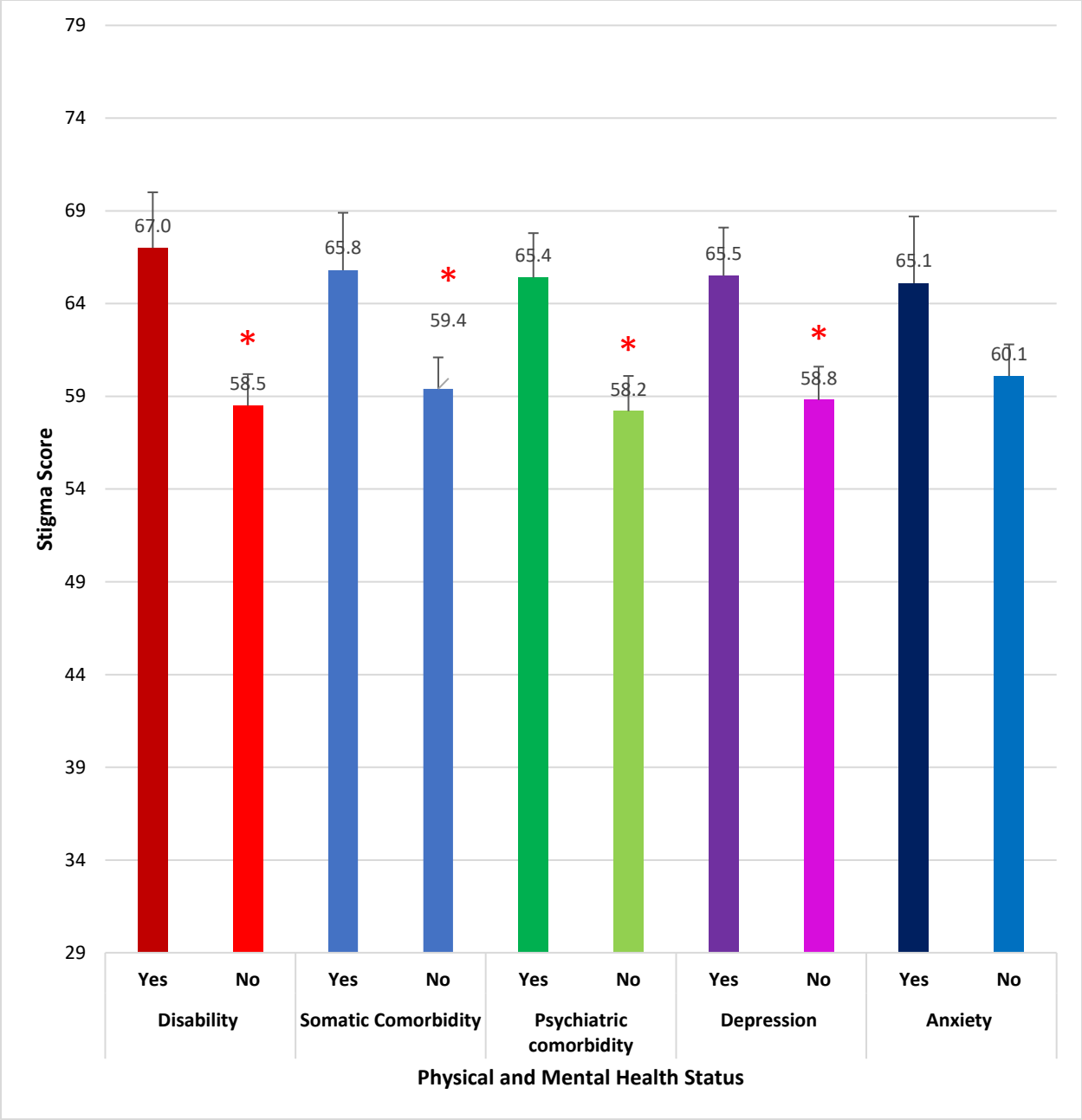


Figure 5. Relationship between internalized stigma scores and psychiatric symptoms, and somatic comorbidity in PWE.

1.1.20 Prevalence of internalized stigma in percentages (Table 3):

The answers to the various questions of the questionnaire are described in Table 3.

Ritsher et al.²⁰ defined patients with high levels of internalized stigma as having an average score over the 2.5 midpoint on a scale of 1–4. Utilizing the midpoint of the scale demonstrated that a total of 23.7% of patients had a score equivalent to or above 2.5. Using the midpoint of the scale in five subscales suggested that 42.4% of participants had a score equivalent to or above 2.5 for Alienation, 7.6% for Stereotype Endorsement, 26.1% for Discrimination Experiment, 29.3% for Social Withdrawal, and 64.1% for Stigma Resistance.

Based on my data, as I hypothesized, the stigma score appeared to be higher in PWE with psychiatric comorbidity than those without it.

Table 3. Prevalence of internalized stigma in percentages.

	Strongly disagree %	Disagree %	Agree %	Strongly agree %
Alienation				
I feel out of place in the world because I have epilepsy	25	27.2	40.2	7.6
Having epilepsy has spoiled my life	29.3	33.7	27.2	9.8
People without epilepsy could not possibly understand me	32.6	38.0	20.7	8.7
I am embarrassed or ashamed that I have epilepsy	31.5	25.0	30.4	13.1
I am disappointed in myself for having epilepsy	34.8	18.5	27.2	19.5
I feel inferior to others who don't have epilepsy	27.2	34.8	23.9	14.1
Stereotype Endorsement				
Stereotypes about epilepsy apply to me	28.3	43.5	22.8	5.4
People can tell that I have epilepsy by the way I look	62	28.3	7.6	2.1

Persons with epilepsy tend to be violent	39.1	44.6	16.3	0.0
Because I have epilepsy, I need others to make most decisions for me	47.8	28.3	16.3	7.6
People with epilepsy cannot live good, rewarding life	57.6	32.6	5.4	4.4
Persons with epilepsy should not get married	78.3	21.7	0.0	0.0
I cannot contribute anything to society because I have epilepsy	56.5	37.0	4.3	2.2
Discrimination Experience				
People discriminate against me because I have epilepsy	26.1	32.6	32.6	8.7
Others think that I cannot achieve much in life because I have epilepsy	27.2	47.8	21.7	3.3
People ignore me or take me less seriously just because I have epilepsy	30.4	34.8	27.2	7.6
People often patronize me or treat me like a child just because I have epilepsy	25.0	40.2	21.7	13.1
Nobody would be interested in getting close to me because I have epilepsy	38.0	47.8	12.0	2.2

Social Withdrawal				
I do not talk about myself much because I do not want to burden others with my epilepsy	20.7	33.7	25.0	20.6
I do not socialize as much as I used to because my epilepsy might make me look or behave “weird”	28.3	28.3	29.3	14.1
Negative stereotypes about epilepsy keep me isolated from the “normal” world	27.2	42.4	21.7	8.7
I stay away from social situations in order to protect my family or friends from embarrassment	43.5	38.0	10.9	7.6
Being around people who do not have epilepsy makes me feel out of place or inadequate	39.1	45.7	8.7	6.5
I avoid getting close to people who do not have epilepsy to avoid rejection	41.3	39.1	15.2	4.4
Stigma Resistance (reverse-coded items)				
I feel comfortable being seen in public with a person who is known to have epilepsy	13.0	9.8	46.7	30.5

In general, I am able to live my life the way I want to	10.9	18.5	40.2	30.4
I can have a good, fulfilling life despite my epilepsy	6.5	12.0	47.8	33.7
People with epilepsy make important contributions to society	2.2	6.5	40.2	51.1
Living with epilepsy has made me a tough survivor	3.3	16.2	52.2	28.3

1.1.21 Description results for risk factors associated with stigma (Table 4):

The percentage of males with stigma scores above the midpoint was significantly higher than the percentage of females (72.7 vs 27.3). The percentage of PWE with disability was significantly higher in the stigma scores above the midpoint than in participants with stigma scores below the midpoints. ($P= 0.04$). The percentage of participants with depression and psychiatric comorbidity was significantly higher in the group with stigma scores above the midpoint than the group with stigma scores below the midpoint. [54.5 vs 25.7 ($P= 0.01$), 59.1 vs 31.4 ($P=0.02$), respectively].

Table 4. Description results for risk factors associated with stigma.

		Midpoint (%)		P-value
		< 2.5	>2.5	
Gender	Male	50	72.7	0.06
	Female	50	27.3	
Current residence	Rural	25.7	36.4	0.3
	Urban	74.3	63.6	
Employment	Yes	38.6	27.3	0.3
	No	61.4	72.7	
Focal Seizure	Yes	67.1	59.1	0.4
	No	32.9	40.9	
Generalized Seizure	yes	34.3	45.5	0.3
	No	65.7	54.5	
Disability	Yes	22.9	45.5	0.04

	No	77.1	54.5	
Depression	Yes	25.7	54.5	0.01
	No	74.3	45.5	
Anxiety	Yes	14.3	27.3	0.1
	No	85.7	72.7	
Psychiatric comorbidity	Yes	31.4	59.1	0.02
	No	68.6	40.9	
Somatic comorbidity	Yes	21.4	31.8	0.2
	No	78.6	68.2	
Estatus epilepsy	Yes	14.3	9.1	0.6
	No	85.7	90.9	
Seizure free	Yes	61.4	68.2	0.5

	No	38.6	31.8	
Epilepsy surgery	Yes	20.0	13.6	0.6
	No	80.0	86.4	
Number of AEDs	One	37.1	22.7	0.4
	>2	50.0	54.5	

1.1.22 The final multivariable logistic regression model (Table 5):

PWE with depression were three times more likely to have stigma scores above the midpoint than PWE without (OR_{adj}: 3.18, 95% CI: 1.03-9.80, $P=0.04$).

Table 5. Adjusted odds ratios (95% CIs) for stigma among PWE associated with selected risk factors

Variables		Adjusted odds ratio (95% CIs)
Gender	Male	1
	Female	2.55 (0.81-8.05)
Disability	No	1
	Yes	3.88 (0.88-16.95)
Depression	No	1
	Yes	3.18(1.03-9.80)
Current residence	Urban	1
	Rural	2.51(0.72-8.72)
Employment	No	1
	Yes	0.88(0.23-3.40)
Seizure free	No	1
	Yes	1.67(0.51-5.48)
	No	1

Epilepsy surgery	Yes	0.41(0.08-1.92)
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The OR for each variable in model is adjusted for every other variable shown in the table.

4 CHAPTER 4: DISCUSSION

In the present study, I aimed to identify the internalized stigma in PWE and to evaluate the relationships between comorbidity of chronic diseases, disability, epilepsy type, seizure frequency, and the stigma score among PWE. The ISMI questionnaire was initially created to examine internalized stigma scores in patients with mental health disorders, but it was found that the questionnaire could be helpful in assessing the internalized stigma scores in PWE. The concepts examined by the questionnaire were understood by the English-speaking participants.

A significant difference in stigma scores was found between PWE with or without psychiatric conditions. Specific to this study, a strong positive relationship was found between depression and stigma. Depression was also a significant independent predictor for stigma scores among PWE. Participants who had a disability or who had somatic comorbidity had significantly higher stigma scores than participants who were not considered to have a disability or somatic comorbidity. There were no differences in terms of stigmatization according to sex, employment status, residential status, seizure type, or frequency of seizures among PWE.

Epilepsy, which is a chronic neurological disorder, may have a major influence on social competence, family relationships, and social stigma; therefore, it is likely to reduce the quality of life for PWE and their caregivers.^{46, 67, 102-104} It was clear that the social problems and quality of life implications for PWE could provide more significant challenges than the severity of the seizures. Diagnosis of epilepsy was likely to be interpreted negatively, which resulted in an overwhelming feeling of shame.¹⁰⁵ PWE often worried about negative reactions and attitudes from others and developed a special “epileptic identity,” which was strengthened by these feeling.¹⁰⁶ Not all PWE experienced stigma, but in those who felt stigma, it was significantly related to learned helplessness, depression, anxiety, impaired physical health, other health problems,

diminished self-esteem, and reduced life satisfaction. Perceived stigma can be a significant predictor of quality of life, accounting for more of the differences in the quality of life scores than clinical variables. PWE with high levels of felt stigma also experienced greater challenges with managing treatment regimes and medication compliance.⁴⁶

PWE were considered to be at a higher risk of psychiatric symptoms than those without epilepsy. Increased levels of depression had been reported to be a common psychiatric symptom in PWE.¹⁰⁷⁻¹⁰⁹ In this study, the connection between stigma and depression in PWE was examined. This psychiatric problem was considered to be related to the stigma of epilepsy.¹¹⁰ A study of Hispanic PWE showed a significant relationship between depression and stigma.¹¹¹ The results of recent studies demonstrated that PWE who experience depression report higher levels of stigmatization.^{75, 112-117}

Somatic comorbidities, including medical, psychiatric, and cognitive conditions,¹¹⁸ are common in PWE, and they have significant implications for diagnosis, treatment, and quality of life.¹¹⁹⁻¹²¹ One study reported that almost 40% of adults with epilepsy suffer from one or more additional neurological diseases¹²² that negatively impact the quality of life and signify a considerable burden to the individual and those around them.¹⁴ Our results indicated that more than 23% of PWE also reported one or more of the following: arthritis; migraines; sleep apnea; hypertension; heart disease; thyroid conditions; stomach ulcers; and/or, diabetes. These comorbidities significantly increased the prevalence of stigma in this population. People with disabilities are among the most vulnerable in any society. This vulnerability is more evident among PWE who have hidden their disabilities. Similar to our results, physical disabilities, e.g., paralysis and hemiplegia, and cognitive disabilities e.g. memory impairment and learning disabilities, that are under-recognized and under-treated in PWE can be the most significant factors leading to

stigmatization, discrimination, reduced levels of education, and restricted occupational opportunities.^{14, 123, 124}

Although in this study, there was no significant association between participants' levels of education and employment status and stigma scores. A recent study reported a significant relationship between low educational status, employment opportunities, and stigma in PWE.¹²⁵ The fact that it can be unsuitable for PWE to have some types of jobs adds complexity to studies attempting to understand employment issues for PWE. In regions with an especially high burden of epilepsy stigma, the predominant types of jobs were more likely to require manual labour in agriculture or construction that may put PWE in danger if a seizure happened.¹²⁶ At the heart of employment inequalities for PWE lie problems with accessing education. If a person with epilepsy is unable to complete their education, the long-term outcomes of educational deficiency will affect that individual even if epilepsy begins in adulthood.

When it comes to the type and frequency of seizures, while many other studies similar to this one reported no significant association between the type and frequency of seizures with felt stigma,⁶⁴ some studies found a strong relationship between type and frequency of seizures and the levels of stigma.^{127, 128}

It was clear that while specific habits may vary from country to country, discriminatory attitudes, and prejudicial behaviour toward PWE were common across the globe, and that there was a need for interventions to decrease PWE's experiencing stigma. The stigma of epilepsy was a considerable part of the psychological burden of epilepsy worldwide, but there are ways to decrease it. The first pertains to PWE themselves, who need support to cope with negative stereotypes and diminish their experience of stigma. Epilepsy associations use systematic and comprehensive programs and interventions that provide support and information to politicians and

campaign for better services and less discrimination for their members.¹²⁹ Individual support planning for PWE can be one of the best ways to develop resourcefulness and strength in putting the stigma of their condition aside by increasing knowledge, as the lack of it can increase an affected person's sense of stigma.^{127, 130} Policies are also needed, inclusive of providing education, information, and support, and increasing the level of contact between PWE and people without epilepsy to change negative public attitudes.

The main strength of this study was that as a result of their being only one provincial epilepsy program in Saskatchewan, this province was able to facilitate population-based analysis and study health-care utilization patterns better than most other, similar jurisdictions. Also, the length of the follow-up and the quality of clinical data available for the area were key strengths.

A limitation of this study was the potential generalization of this data to other regions; however, comparative analyses might prove helpful for validation. The cross-sectional design cannot provide a good basis for the analysis of the variables that can be measured as affecting the internalized stigma scores. Furthermore, ISIM Scale only assesses internalized stigma without considering aspects of psychiatric comorbidity. Therefore, there is a need to use a scale that not only can assess aspects of the PWE, family and the community, but can also consider aspects of psychiatric comorbidity on measuring internalized stigma among PWE. Moreover, exclusion of PWE with the significant psychiatric conditions may have had an effect on measuring internalized stigma score. Completed questionnaires depended upon the participants' ability and their willingness to share information and might be considered a limitation. Therefore, different factors, such as motivation and tiredness, could have affected the results. The sample size in this study may have also been a limitation.

5 CHAPTER 5: CONCLUSION

This was the first study in Canada exploring stigma in PWE. Using the ISMI Scale, the study identified that both patients on disability and patients with psychiatric comorbidity have higher stigma scores. The scores were not different in patients with and without DRE. Also, the stigma scores were not different between types of seizures. This study will help to explain the complex association of stigma in PWE.

This study can be helpful in forming the foundation in designing a new scale to measure stigma in PWE. The ISIM Scale only assesses aspects of the PWE, family, and the community but does not consider aspects of psychiatric comorbidity. So, this study could be helpful in being able to identify some risk factors associated with stigma in PWE, and future studies could create a new questionnaire that could not only measure internalized stigma in PWE, but also be a scale that ascertains stigma in PWE epilepsy focusing on aspects of the disease like seizures and impact of the family. Also, an open-ended questionnaire and qualitative study could be useful in developing a better understanding of how those with epilepsy perceive themselves and how they interact with society.

Appendix A. Internalized Stigma of Mental Illness Questionnaire (ISMI).²⁰

Internalized Stigma of Mental Illness Inventory (ISMI)

We are going to use the term "mental illness" in the rest of this questionnaire, but please think of it as whatever you feel is the best term for it. For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

	Strongly disagree	Disagree	Agree	Strongly agree
1. I feel out of place in the world because I have a mental illness.	1	2	3	4
2. Mentally ill people tend to be violent.	1	2	3	4
3. People discriminate against me because I have a mental illness.	1	2	3	4
4. I avoid getting close to people who don't have a mental illness to avoid rejection.	1	2	3	4
5. I am embarrassed or ashamed that I have a mental illness.	1	2	3	4
6. Mentally ill people shouldn't get married.	1	2	3	4
7. People with mental illness make important contributions to society.	1	2	3	4
8. I feel inferior to others who don't have a mental illness.	1	2	3	4
9. I don't socialize as much as I used to because my mental illness might make me look or behave "weird."	1	2	3	4
10. People with mental illness cannot live a good, rewarding life.	1	2	3	4
11. I don't talk about myself much because I don't want to burden others with my mental illness.	1	2	3	4
12. Negative stereotypes about mental illness keep me isolated from the "normal" world.	1	2	3	4
13. Being around people who don't have a mental illness makes me feel out of place or inadequate.	1	2	3	4
14. I feel comfortable being seen in public with an obviously mentally ill person.	1	2	3	4
15. People often patronize me, or treat me like a child, just because I have a mental illness.	1	2	3	4
16. I am disappointed in myself for having a mental illness.	1	2	3	4
17. Having a mental illness has spoiled my life.	1	2	3	4
18. People can tell that I have a mental illness by the way I look.	1	2	3	4
19. Because I have a mental illness, I need others to make most decisions for me.	1	2	3	4
20. I stay away from social situations in order to protect my family or friends from embarrassment.	1	2	3	4
21. People without mental illness could not possibly understand me.	1	2	3	4
22. People ignore me or take me less seriously just because I have a mental illness.	1	2	3	4
23. I can't contribute anything to society because I have a mental illness.	1	2	3	4
24. Living with mental illness has made me a tough survivor.	1	2	3	4
25. Nobody would be interested in getting close to me because I have a mental illness.	1	2	3	4
26. In general, I am able to live my life the way I want to.	1	2	3	4
27. I can have a good, fulfilling life, despite my mental illness.	1	2	3	4
28. Others think that I can't achieve much in life because I have a mental illness.	1	2	3	4
29. Stereotypes about the mentally ill apply to me.	1	2	3	4

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Appendix B. Patient Sociodemographic Questionnaire.

STIGMA EPILEPSY		SOCIODEMOGRAPHIC	
1. Identification number: _____		2. Collection date ___/___/_____	
3. Age: _____		4. Gender: ___Female ___Male	
5. Current residence ___Rural zone ___Urban zone	6. Civil state ___Married ___Single ___Separated ___Widow ___Other	7. Education level: ___None ___Elementary sch ___High school ___College ___University ___Master ___PhD	8. Monthly income (dollars) ___0.00 – 150 ___151 – 400 ___401 – 650 ___651 – 1500 ___> 1501
	9. Currently employed: YES <input type="checkbox"/> NO <input type="checkbox"/>		10. Disability: YES <input type="checkbox"/> NO <input type="checkbox"/>
HISTORIA DE EPILEPSIA			
11. Epilepsy years of evolution: _____		12. Epilepsy type: Focal <input type="checkbox"/> Generalized <input type="checkbox"/>	
13. Seizures type (Choose all the type of seizures) <u>Focal seizures</u> ___Focal aware ___Focal impaired awareness ___Motor onset ___Non motor onset ___Focal to bilateral tonic-clonic <u>Generalized seizures</u> ___Absences ___Myoclonus ___Clonic seizures ___Tonic seizures ___Tonic clonic seizures ___Atonic seizures Unknown _____	15. Lobe ___Temporal ___Frontal ___Parietal ___Occipital ___Insular	14. Seizure frequency ___Seizure freedom (0) ___Number of seizures per year ___Number of seizures per mon	
	16. Epileptic syndrome ___Idiopathic/genetic ___Symptomatic/structural ___Cryptogenic/unknown	17. Etiology ___Perinatal hypoxia ___Hippocampal sclerosis ___Cortical development malformation ___Benign tumor ___Malign tumor ___Cranial trauma ___CNS infection ___Vascular ___Genetic (generalized) ___Other: _____	
18. Status epilepticus YES <input type="checkbox"/> NO <input type="checkbox"/>			
19. Drugs resistant epilepsy (according ILAE criteria) YES <input type="checkbox"/> NO <input type="checkbox"/>	20. Number of antiepileptic drugs: _____		21. Epilepsy surgery: YES <input type="checkbox"/> NO <input type="checkbox"/>

22. Type of surgery: ___ Lobectomy ___ Lesionectomy ___ Callosotomy ___ Disconnection ___ Other		
23. Has the patient received any other treatments ___ Ketogenic diet ___ Vagal Nerve stimulation ___ Deep brain stimulation ___ Other? _____		
PSYCHIATRIC CONDITIONS		
24. Psychiatric conditions		
Depression	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Psychosis	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Behavior problems	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Anxiety	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Other, specify _____	YES <input type="checkbox"/>	NO <input type="checkbox"/>
26. Other comorbidity:		
Allergies ____, Back problems ____, Arthritis ____, Migraine ____, Sleep apnea ____, Hypertension ____, Asthma ____, Heart disease ____, Thyroid conditions ____, Stomach ulcers ____, Diabetes ____, Other: _____		
26. Use of drugs Yes _____ NO _____ Specify drug or drugs:		

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