The influence of knowledge and Empathy on stigma in epilepsy

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Abstract

Epilepsy is one the most common neurological disorder in the world, however despite this stigma towards epilepsy is still common to this day. T therefore the current study has aimed to examine how knowledge and empathy impacts on individual's level of stigma. The current sample contained (n=240) participants, with (n=115) individuals who have a medical diagnosis of epilepsy whilst (n=125) participants who do not. Individual's empathy levels were measured through the empathy quotient (EQ), whilst knowledge of epilepsy was measured through the epilepsy knowledge profile (EKP), and the level of stigma through the stigma of epilepsy scale (SSE). The results demonstrate that there is no significant correlation between knowledge of epilepsy and the level of stigma in individuals who have epilepsy or who those do not. As well as finding there is no relationship between a certain level of knowledge and internalised stigma amongst individuals with epilepsy. Along with illustrating there is no significant relationship between empathy and stigma towards epilepsy. However individuals with epilepsy displayed a higher level of knowledge than does that do not have epilepsy. The results of this study illustrate that stigma is not affected by knowledge or empathy, therefore more research is needed in determining the exact sources that harvest these stigmatising attitudes would be valuable in preventing and dismantling stigma towards epilepsy.

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Chapter 1.

1.1 Understanding epilepsy

Epilepsy is one of the oldest and most common neurological disorders, occurring in all mammalian species, whilst currently affecting 50 million humans worldwide (Neni, Latif, Wong & Lua, 2010). Epileptogenesis, the development of tissue capable of generating seizures, can affect individuals in both childhood and adulthood (De Boer, Mula & Sander, 2008). Individuals without epilepsy have inhibitory neurons that prevent excess firing of action potentials and electrical messages (McNamara, 1994). In epilepsy, seizures are a result of excessive or excitatory neural activity (Moshé, Perucca, Ryvlin & Tomson, 2015). Seizures are characterised by the transient alteration of behaviour such as uncontrollable movements, loss of awareness and loss of conscious depending on the specific area in the brain that is effected (Chung et al., 2010).The cause of epilepsy differs for individuals along with the frequency of seizures (McNamara, 1994). Seizures can be generalized, which arises through rapidly engaging bilaterally distributed networks which causes absence, myoclonic, tonic, atonic and tonic clonic seizures. Seizure can also be focal where in which thye occur in only one hemisphere, which causes focal aware and focal impaired awareness seizures (Moshé, Perucca, Ryvlin & Tomson, 2015). The most with the most common seizure being tonic clonic seizures (Chung et al., 2010).

1.2 Stigma in epilepsy

Stigma can be noted as being a well-rehearsed concept in literature of epilepsy (Baker, Brooks, Buck & Jacoby, 2000). Over the past 4,000 years, epilepsy has been surrounded by superstition, myth, ignorance and stigma such as attributing the cause of epilepsy to be a demonic possession or divine retribution, which has been followed by 100 years of ignorance, knowledge and stigma. This has led epilepsy to often be associated with prejudice

and discrimination along with psychosocial difficulties (Bandstra, Camfield & Camfield, 2008). A longitudinal study on the attitudes towards individuals with epilepsy was first implemented in 1949, in the hopes to understand the prevalence and cause of social stigma towards epilepsy, across time, this longitudinal study has demonstrated attitudes in the US improving over the span of 30 years (Lim, Lim & Tan, 2011). This is displayed as only 59% of individuals understood epilepsy isn't a form of insanity in 1949, rising to 92% 30 years later. As well as attributing the brain as the cause of epilepsy has increased, with only 20% believing so in 1949, whilst increasing to 36% in 1979 (Caveness & Gallup, 1980). This is also displayed through a decrease of 9% to 6% when asked if they agreed that individuals with epilepsy should be barred from employment (Cui, Kobau, Zack, Buelow & Austin, 2015), or not allowing their children to play with epileptic children decreasing from 34% to 24% (Jacob, Snape, Gus,. 2005). However stigmatizing attitudes are still prevalent, as a study conducted within the Czech Republic found 29% of participants considered epilepsy to be a form of insanity, along with over a 25% of individuals agreeing people with epilepsy have personality issues (Jacoby & Austin, 2007). With a recent study discovering 21% of employers within the UK felt employing people with epilepsy would be a major issue, 78% felt disclosure of their employees epilepsy should be mandatory, even when seizure free for a number of years (Jacoby & Austin, 2007).

Sociologist Erving Goffman's (1963) theory of stigma, notes individuals experience stigmatisation for possessing an attribute that is viewed as different which is undesirable. Reactions from a community to a specific undesirable characteristic reduces individuals' identity (Cohen et al). Durkheim (1964) notes the boundary between normal and deviant requires unity within society to allow the process of stigmatization to occur (Jacoby, Snape & Baker, 2005). Fishbein and Ajzen's (1975) theory of reasoned action, states knowledge influences attitudes, which in turn is a predictor for behaviour. The components of

knowledge, attitudes and behaviour are noted to be important in the process of labelling, discrimination, stereotyping, isolation and loss of status, which in turn can denounce and oppress individuals. These components were also discovered within Link and Phelan stigma concept (Jacoby, Snape & Baker, 2005). Which also emphasises stigmatisation acts as a function of exploitation and domination, norm enforcement and disease avoidance (Phelan et al., 2008).

Additionally studies have argued stigma to be a core biological need to live in effective groups, individuals who are perceived to violate the group's norms of trust, reciprocity and preferred socialisation practices that are potentially threatening to the groups functioning will be stigmatised (Jacoby, Snape & Baker, 2005). Also symbolic threats to a culture or an individual, including moral, physical and health threats. Temkin (1971), aligned with the biological theory when describe

ing the cause of stigma towards epilepsy, questioning if humans are hardwired to see seizures as a treat. Offering an explanation hardwired centre on the fear seizures can invoke in others (Jacoby, Snape & Baker, 2005). Due to the unpredictability, dramatic presentation and impotence it induces, seizures affront social order. By losing control, people with seizures are viewed as reverting back to a primitive state; therefore "atomic terror" is experienced by individuals without epilepsy or who have never experienced a seizure. However, it should be noted that this explanation also relies heavily on powerful stereotypes, through insinuating all seizures are generalised (Ahmad, 2011).

Epilepsy has often been mistakenly viewed as a mental illness, due to historical practices in which Psychiatrists treated epilepsy in poor resourced countries where Psychiatry is currently the most common form of treatment. Along with a variety of similar presentations of epilepsy, meeting the DSM IV criteria such as psychogenic non-epileptic seizures which is

induced by panic disorders, generalized anxiety and depression (Jacoby, Snape & Baker, 2005). Goffman's stigma theory is reflected within biomedical theories towards epilepsy, with violent or criminal behaviour often being associated with epilepsy. The "epileptic personality", was also associated with a range of undesirable attributions such as aggressiveness and hyper sexuality (Fenwick, 1989). This fundamentally flawed theory has further enhanced the stigmatization of epilepsy, as a trans-national study conducted in the Netherlands, Ireland and UK showed 15% of participants believed in the "epileptic personality" (De Boer et al., 1994).

Negative stigmatizing attitudes vary amongst different countries as South Korea showed 18.1-50% of negative based attitudes whilst Thailand showed 17.3%, India 5.0-10.8% and Tanzania 51.0% (Lim, Lim & Tan, 2011). Studies in Iran found epilepsy to be perceived as an incurable disease leading individuals with epilepsy to be isolated, often affecting individuals (Riasi, Rajabpour Sanati & Ghaemi, 2014). Previous studies have identified four main attitudes which contributed to the outcome of stigma, such as safety concerns, work, social role and negative stereotypes (Roberts & Aida Farhana, 2010). Pryor and Reeder's (2011) recent research model of stigmatization categorised public stigma as the core of the model, representing the people's cognitive, affective and behavioural reactions to someone that may have stigma towards a condition. (Bos, Pryor, Reeder & Stutterheim, 2013)

1.2.1 Effects of stigma in epilepsy

The World Health Organization discovered social consequence to be the primary obstacle for individuals with epilepsy, as worldwide misconceptions contributed to discriminatory practices against individuals with epilepsy (Chung et al., 2010). A cross cultural study found 51% of respondents felt stigma associated with their epilepsy, 49% with epilepsy did not (Baker, Brooks, Buck & Jacoby, 2000). History reveals the social effects people with

epilepsy endured. In the United Kingdom individuals who suffer from the neurological disorder were forbidden from marrying until 1970, in the United States eugenic sterilization was practiced until 1960s. As well as having preventing marriage and prohibiting entry to certain public areas. Legislations based on centuries of stigma have either been replaced or still exist in many third world countries (Chung et al., 2010). Current research in Estonia found epilepsy to influence job opportunities, emotional health and social functioning in society. Similar results were found in China, in addition effects on marriage, family, moral and social prospects were also found (Fernandes et al., 2011). Studies have found Individuals with epilepsy in developing countries suffer higher rates of unemployment and social isolation (Fernandes et al., 2007). A cross cultural study of 5,000 participants, also found stigma impacted individuals self-esteem, the ability to gain employment, to form and maintain relationships which has correlated with an increase in developing depression and anxiety (Yousuf, Shahar, Azarisman, Rosle & Tin, 2018).

Illness related stigma often has greater effects than the illness itself on psychological well-being, economic status, social interaction along with overall health; stigma can also interfere with access to early diagnosis, treatment and healthcare access (Thomas & Nair, 2011). Pryor and Reeder's (2011) recent research model of stigmatization, represents the effect stigma has on individuals with epilepsy. Self-stigma reflects social and psychological impact of being exposed to public stigmatization often leading to internalized stigma through one's own negative beliefs about their condition (Bos, Pryor, Reeder & Stutterheim, 2013).

Internalised stigma in epileptic individuals arises from their knowledge, government policies, social support, cultural beliefs and personal beliefs towards epilepsy; their ability to deal with their seizures contributes to the stigma they perceive. Individuals who believe their epilepsy is caused by brain conditions such as trauma had a lower level of stigma towards the condition than individuals who believed the cause to be hereditary. Individuals who did not

have knowledge of the pathogenesis of their disease have been shown to feel inferior to others, leading individuals to adoption of negative coping strategies to deal with the situation such as concealing their condition (Guo et al., 2012).

Research found that some individuals with epilepsy socially withdraw due to guilt or shame, which can surpass the realms of the physical impact of epilepsy (Mlinar et al., 2016). Individuals who experience stigma in their youth, associated with development of negative psychosocial outcomes such as symptoms of depression, poor self-esteem and behaviour problems (Funderburk, McCormick & Austin, 2007). Research on individual's subjective view of the effects of stigma display that individuals viewed themselves as opposite to what they perceive as normal, therefore continually reviewing and reconstructing their sense of self as a way of gaining control (Fernandes et al., 2011).

1.3 Knowledge and stigma of epilepsy

Knowledge has consistently shown to be a key factor in determining levels of stigma and combating stigma towards epilepsy. Roberts and colleagues (2010) study employed knowledge based interventions in countering stigma through the use of a first aid educational video. The study found post-intervention stigma scores lowered across two domains through the increase of knowledge. Personal fear and social avoidance decreased by 20%, with risk and safety concerns found a 2%. These results show indications of the effectiveness of enhancing knowledge and decreasing stigmatizing attitudes. (Roberts & Aida Farhana, 2010). Another study also implemented an educational video on epilepsy, which was presented to children ages 9-11, results display a significant increase in general knowledge along with a decrease in stigmatizing attitudes (Brabcova, Lovasova, Kohout, Zarubova & Komarek, 2013). However, a conflicting study by Kim and colleagues (2003) found no significant reduction in stigma towards epilepsy in rural Korea, through the use of a public education

campaign in the form of lectures and group discussions. Findings show that the information campaign was effective in dismissing superstitious preconceptions surrounding epilepsy, but did not prove useful in altering deep rooted prejudices with 89% pro-intervention object marriage to a person with epilepsy along with 33% believing epileptic individuals should not have children (Kim .,et al 2003). This may also be due to decision theory; individuals have difficulty taking in negative information, therefore disregard the information (Jacoby, Snape & Baker, 2005).

A current research study on teacher's attitudes and knowledge towards epilepsy there was a significant association between knowledge and attitude score towards epilepsy. A significant variable in identifying poor attitudes was poor knowledge, not having a family members with epilepsy, unawareness of PWE circumstances (Al-Hashemi et al., 2019). A similar study found higher self-reported knowledge, higher level of education to have more positive attitudes and a higher degree of knowledge (Neni, Latif, Wong & Lua, 2010).

A UK public study used the ABLE scale to measure stigma levels towards epilepsy, which showed 10% had negative attitudes whilst 59% had positive attitudes and 30% with very positive attitudes. Whilst displaying an average score of 77% in the knowledge of epilepsy, through accessing the relationship between knowledge and stigma, incorrect responses to commonly known information was associated with higher levels of stigma, suggesting the reduction of stigma is significantly impacted by increasing knowledge (Holmes, Bourke & Plumpton, 2019). A similar study emitted to the American public in 2004, researched perceivers who were exposed to knowledge about epilepsy that was biased or incorrect, showing a correlating to the development of negative stereotypes, increasing the likelihood of negative attitudes (Baxendale & O'Toole, 2007). Janson (2017) study discovered 20% of students believe epilepsy is caused by emotional strain, 1 in 5 had misconceptions in seizure first aid along with 22% of students who would not date individuals with epilepsy (Jansen et

al., 2017). Study of nurses in japan, overall had a high rate of correct responses, however 29.8% incorrectly responded "place something inside the mouth". (Nishina & Yoshioka, 2018). Proving misconceptions are still present to this day.

Study also showed less knowledge and personal contact with someone with epilepsy correlates with poor attitudes. Misconceptions such as epilepsy is a form of insanity, being untreatable, contagious, a form of mental illness had the most significant effect on levels of stigma (Lim, Lim & Tan, 2011). Previous research has noted the reversal of stigma had logical foundations, with stigma in epilepsy fear is almost fundamental. Knowledge and understanding are noted as being powerful in combating fear and stigma (Fernandes, Snape, Beran & Jacoby, 2011).

1.3.1 Knowledge and internalised stigma in individual with epilepsy

Previous studies have found people with epilepsy have a higher degree of knowledge regarding their disorder than the general public (Long, Reeves, Moore, Roach & Pickering, 2000) as they are more likely to know different forms of epilepsy, information regarding procedures during a seizure and the etiology of epilepsy, however 25%-35% felt they have not receive adequate information (Peterson et al., 2019). Lack of knowledge is found to be most prevalent within developing countries, as findings in India show 25% of individuals had little understanding of the ethology of epilepsy, along with 9% believing the cause to be evil spirts. Studies in Tanzanian discovered 40% of people with epilepsy believe it to be infectious (Long, Reeves, Moore, Roach & Pickering, 2000). Whilst in Ethiopia, 32% of people with epilepsy did not know the cause of epilepsy, with 2% attributing epilepsy to be punishment for their sins. These individuals displayed higher internalised stigma than individuals who answered correctly (Kassie, Duguma & Kebede, 2014). A similar study also found that respondents with poor knowledge of their neurological disease had negative

attitudes (Yousuf, Shahar, Azarisman, Rosle & Tin, 2018). In addition internalised stigma was found within 64% children lacked who knowledge of what causes their seizures (Austin, Perkins & Dunn, 2014).

1.4 Empathy and stigma

Empathy is critical in enabling the ability for individuals to share experiences, emotions and needs, which promotes the use of pro-social behaviour critical for interpersonal and societal roles (Riess, 2017). The ability to resonate and perceive others suffering requires cognitive, emotional, moral and behavioural capacities to respond to others suffering. An emotional connection is not required in empathy unlike sympathy (Cohen, Quintner, Buchanan, Nielsen & Guy, 2011). The cognitive components of epilepsy are traditionally characterised as a multi-dimensional concept containing both affective and cognitive components. The cognitive component is conceptualised as a person's ability to identify with another individuals emotions, affective empathy is conceptualised an emotional component of empathy defined by their ability to share feelings and emotions (Neumann, Chan, Wang & Boyle, 2016).

A study measured empathy through empathy quotient short form and adult attachment styles via questionnaire in order to determine level of stigma towards mental illness. Adult attachment had less influence than empathy in determining stigma (Webb et al., 2016). In other research, empathy and moral reasoning have been shown to be frequently negatively correlated with stigma and prejudice. As empathy is a natural buffer against stigma (Gerdes, 2011). Another study emitted simulation auditory and visual hallucinations, experienced by individuals with schizophrenia. Participants displayed an increase in empathy towards individuals with schizophrenia by through experiencing the hallucination that People with schizophrenia live with. (Ando, Clement, Barley & Thornicroft, 2011)

Few research studies have covered the correlation between empathy levels and stigma related chronic illness and schizophrenia however, no research has directly correlated how empathy, may impact stigma levels towards epilepsy.

1.5 Rational

This study will investigate the correlation between knowledge and stigma levels. Many studies have found the lack of understanding about epilepsy to be the main contributor to negative attitudes (Vodopić, 2017). With higher medical knowledge of epilepsy being correlated with better psychological adjustment to epilepsy and lower perceived stigma amongst people with epilepsy (Lim, Wo, Ahmad & Tan, 2013). Along with finding insufficient, knowledge about epilepsy has been correlated with negative beliefs and attitudes, along with a higher tendency to stigmatize the condition (Riasi, Rajabpour Sanati & Ghaemi, 2014).

This study will also investigate epileptic individual's knowledge their own condition correlating with internalised stigma levels; studies found the perception of stigma is closely associated with current knowledge of condition (Austin, Perkins & Dunn, 2014).

This study will investigate how empathy effect stigma levels, as previous research has focused on empathy correlation with mental health and chronic illness. Studies also found a correlation between high empathy levels with low levels of stigma toward individuals with disability, terminal illness, chronic pain and mental illness (McKenna et al., 2012).

This study will finally investigate if individuals with epilepsy have a higher level of knowledge and lower level of stigma, than those who do not, as previous studies found individuals with epilepsy higher degree of knowledge (Long, Reeves, Moore, Roach & Pickering, 2000). This hypothesis will also investigate if individuals who have friends and

family with epilepsy have will have the higher level of knowledge and lower level of stigma, than those who do not. As previous studies found poor attitudes and poor knowledge was higher in individuals who do not family members with epilepsy (Al-Hashemi et al., 2019).

1.5.1 Research aims and objectives

This study aims to investigate if certain levels of knowledge affects individuals' stigma score towards epilepsy. Along with aiming to assess if individuals with epilepsy score on knowledge correlates with internalised stigma. As well as investigate how certain levels of empathy affects individuals stigma in regards to epilepsy. The final aim of the study is to access if knowledge and stigma are different in those that have epilepsy and those who don't, along with having friends or family with epilepsy and those who do not.

1.5.2 Hypothesis

1   Individuals who obtained higher scores on the epilepsy knowledge questionnaire will have a lower stigma score towards epilepsy.

2   Individuals with epilepsy who have higher rates of knowledge in regards to epilepsy, will have lower levels of internalized stigma.

3   Individuals with higher levels of empathy will have a lower stigma score toward epilepsy.

4   Individuals with epilepsy and those who know people with epilepsy will have a higher level of knowledge and lower level of stigma, than those who do not.

Chapter 2. Methods

2.1 Participants

The current studies sample consisted of 159 females and 81 males, totalling 240 participants. This included a sample of 115 participants with a medical diagnosis of epilepsy, along with 125 participants who do not have epilepsy. This sample was gathered from the 26th of December 2018 to the 2nd of March 2019. Participants were recruited and selected through a non-probability sampling technique called convenience snowball sampling, along with a target sample of individuals with epilepsy. This was conducted through the use of social media such as Facebook and Reddit, where individuals had the ability to share the questionnaire to other pages and social media platforms. The target sample was acquired through the use of specific Facebook and Reddit pages dedicated to individuals with epilepsy. To avoid vulnerable populations, an inclusion criteria was present, participants were required to be over the age 18, with full mental capacity to ensure individuals were giving informed consent, along with willing to share knowledge, views and opinions through valid scales and questionnaires on the matter of epilepsy. Personal information such as participant's names and email addresses were not collected to retain data anonymity.

2.2 Design

This study is classified as a quantitative, with the implementation of a cross-sectional, correlation design as this study explores the relationship between variables. The variables of interest were level of knowledge towards epilepsy, stigma towards epilepsy and level empathy. With knowledge and empathy being the predictor variables, towards level of stigma within hypothesises.

2.3 Measures

Data was gathered anonymously through the use of Survey Monkey, an online server dedicated to the creation of surveys and the collection of data. Within the questionnaire an information sheet was first provided to the participants stating the nature of the study, followed by informing participants of their rights. The questionnaire was comprised of four sections (1) demographic, (2) Stigma scale of epilepsy, (3) Empathy quotient, (4) Knowledge of epilepsy questionnaire. All questions within each section were mandatory. Within the demographics questionnaire, participants were required to select their gender (Male or Female), input their age through numeric value, as well as selecting their level of education (None, Primary, Secondary, Undergraduate, Postgraduate and Ph.D.). Along with informing if they had a medical diagnosis of epilepsy, and family/friends with epilepsy, to which participants had the option to select yes or no.

The first scale participants were required to answer (SSE) Stigma scale of epilepsy (Fernandes, Salgado, Noronha, Sander & Li, 2007) a self-report measure of stigma towards epilepsy, which was originally conducted on individuals with and without epilepsy. The SSE displays high internal consistency and content validity with a Cronbach coefficient of (a=0.88) for individuals with epilepsy and (a=0.81) for those without. This scale measures stigma through 5 questions with 24 items, each of the 24 items are rated on a four-point Likert scale (not at all = 1, a little = 2, a lot = 3, totally = 4). With no presence of reverse coding. The total scores range from 0 to 100, with higher scores indicating there is stigma towards epilepsy whilst lower displaying there is no stigma towards epilepsy.

The second scale used within this study was the empathy quotient (EQ) short form version (Loewen, Lyle & Nachshen, 2010) containing eight items, which measure participant's empathy levels. This scale was derived from the condensed empathy quotient twenty-two item version (Wakabayashi et al., 2006), which was produced through an analysis of the original sixty-item empathy quotient (Cohen & Wheelwright, 2004). Through the use of

Wakabayashi data, items of the highest principal factor loadings were selected. Allowing the eight item scale to still retain a high internal reliability at (a=.76) within the original paper. Items 1-4 presented the use of scores (slightly agree =1, strongly agree=2, slightly disagree =0, strongly disagree =0). Items 5-8 require reverse coding by the researcher, to ensure an accurate score. Individual's total scores can range from 0-16, with higher scores indicating a greater empathic capacity whilst lower score indicate lower empathic capacity.

The final questionnaire presented to participants, was the (EKP) Epilepsy Knowledge Profile/Questionnaire (Jarvie, Espie & Brodie, 1993), containing 34 statements questioning participants knowledge regarding their medical knowledge of epilepsy. With the original containing an additional 21 items on social knowledge of epilepsy, we chose not to include these items, similar to previous studies (Doughty, Baker, Jacoby & Lavaud, 2003) due to overlapping with the (SSE). Each question is provided with a "True" or "False" answer. For the purpose of this study, only items relating to medical aspects of epilepsy were used in the (EKP), therefore the possible scores ranged from 0 to 34. With the lower scores indicting little knowledge of epilepsy whilst higher scores indicate a greater knowledge of epilepsy. The original paper performed an internal consistency analysis and found an alpha coefficient of (a=0.63) with an inter-class correlation of 0.88.

2.4 Procedure

All participants who clicked onto the online link through Facebook or Reddit were first presented with an information sheet. In an effort to minimise the likelihood of issues or distress from arising therefrom, the information sheet addressed the nature of the study by displaying what objectives the research aimed to achieve. Along with the overview of questionnaires they will be asked, what they measure as well as the approximate time to

complete them being 8-12 minutes. The inclusion criteria was also presented, such as being 18 years of age and volunteering to participate.

Participants were informed of their confidentiality, as no identifiable details such as names or addresses were taken as well as being informed about the process of retention and disposal of data and their ability to withdraw after submission. Contact details of the researchers and supervisor was provided for individuals with questions related to the research, along with organisations such as Epilepsy Ireland and Jigsaw. To grant their informed consent, participants were required to click the "yes" option to a statement to participate within the study. By doing so the participant were then forwarded onto the scales and questionnaire as they had given consent to partake in the study. See Appendix (D) for the information sheet and consent form.

Participants were first presented with the demographics questionnaire, where participants imputed their gender, age, level of education, if they had a medical diagnosis of epilepsy along with if they had friends or family with epilepsy. This was then followed by the Stigma scale of epilepsy questionnaire, which continued onto empathy quotient, and then to epilepsy knowledge questionnaire. A debriefing form was then presented once participants completed the questionnaire, to further reinstate the nature of the study along ensuring participants to contact the researcher if they had any enquires about the study of use of data. See appendix (E) for debriefing form.

The link was available from the 26th of December to the 2nd of March. All individual responses were collectively saved under a CSV file, and the data was entered into IBM SPSS Statistics 24.0 for statistical analyses.

Chapter 3. Results

3.1 Descriptive statistics

Reliability statistics

Reliability statics was conducted on the two scales and one questionnaire employed within this study, the stigma scale of epilepsy (Fernandes, Salgado, Noronha, Sander & Li, 2007), empathy quotient of 8 items (Loewen, Lyle & Nachshen, 2010) and the Epilepsy knowledge questionnaire (Jarvie, Espie & Brodie, 1993). The stigma scale of epilepsy contained 24 items, displayed high reliability by achieving a Cronbach's Alpha of (a =0.87). The empathy quotient scale contained 8 items to which achieved a Cronbach alpha of (a=0.72). The final questionnaire used within the study was the epilepsy knowledge questionnaire which contained 34 items, allowing it to achieve a Cronbach Alpha of (a=0.68).

Table 1

Reliability statistics for variables

Variable	No. of items	Cronbach's Alpha (a)
Stigma scale of epilepsy	24	.87
Empathy quotient	8	.72
Knowledge of epilepsy	34	.68

N=240

3. Frequencies.

Table 2. Displays frequency statistics of the categorical variables and their findings. The categorical variables within this study are demographics, which include gender, level of education, diagnosis of epilepsy and knowing other individuals with epilepsy.

Table 2.

Frequencies for the current sample of Individuals that have/don't have epilepsy each demographic variable (N = 240)

Variable	Frequency	Valid Percentage (%)
Gender		
Male	81	33.8
Female	159	66.3
Education		
Primary	5	2.1
Secondary	62	25.8
Undergraduate	111	46.3
Postgraduate	59	24.6
Ph.D.	3	1.3
Medical diagnosis of epilepsy		
Have epilepsy	115	47.9
Do not have epilepsy	125	52.1
Friends or family with epilepsy		
Yes	109	45.4
No	131	54.4

Descriptive statistics

Descriptive statistics for all continuous variables is presented within tables 3 and 4. Normality of the data was assessed through reviewing histograms and Q-Q plots for each variable. In each histogram a straight line was present indicating a normal distribution of data; this has been supported through an inspection of Q-Q plots as no extreme outliers were present within any of the questionnaires.

Table 3

Descriptive statistics of all continuous variables within the total sample

Total sample	Mean (95% Confidence Intervals)	Std. Error Mean	Median	SD	Range
Age	33.99(32.53-35.45)	.74	34	11.47	16-63
Stigma scale total score	51.70(50.49-52.91)	.62	51	9.53	12-52
Empathy quotient total score	9.70 (9.24-10.16)	.24	10	3.12	6-15
Epilepsy Knowledge questionnaire total score	27.72 (27.28-28.16)	.22	28	3.42	4-18

Table 4

Descriptive statistics of all continuous variables within individuals who have epilepsy and those who do not.

	Have epilepsy		Does not have epilepsy	
	Mean	SD	Mean	SD
Age	32.64(31.07-34.22)	8.52	35.23(32.83-37.63)	13.5
Stigma scale total score	52.29(50.59-53.99)	9.20	51.16(49.42-52.90)	9.83
Empathy quotient total score	9.13 (8.45-.9.81)	3.69	10.23(9.62-10.85)	3.47
Epilepsy Knowledge questionnaire total score	29.04 (28.54-29.55)	2.72	26.50(25.87-27.13)	3.56

3.2 Infernal statistics

All hypotheses were tested using Pearson's product-moment correlation. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity.

Hypothesis 1: Individuals who have higher scores on the epilepsy knowledge questionnaire will have a lower stigma towards epilepsy.

The relationship between stigma and knowledge within the total sample was investigated using Pearson product-moment correlation coefficient. There was a weak, negative correlation between the two variables ($r = -.07$, $n = 240$, $p < .24$) that was not significant. This indicates that the two variables share approximately 0.5 % of variance in common. Results indicate that higher levels of knowledge is not associated with lower levels of stigma.

The relationship between stigma and knowledge in non-epileptic individuals showed a small, negative correlation between the two variables ($r = -.10$, $n = 125$, $p < .28$) that was not significant. Results indicate that higher levels of knowledge is not associated with lower levels of stigma.

Hypothesis 2: Individuals with epilepsy, who have higher scores on the epilepsy knowledge questionnaire, will have a lower stigma towards epilepsy

The relationship between stigma and knowledge in individuals with epilepsy showed a small, negative correlation between the two variables ($r = -.12$, $n = 115$, $p < .20$) that was not significant. This indicates that the two variables share approximately 1.4% of variance in common. Results indicate that within individuals with epilepsy higher levels of knowledge are not associated with lower internalised stigma.

Through investigating hypothesis 1 & 2, other groups and the variables of stigma and empathy were investigated.

There was a non-significant, negative correlation between stigma and knowledge in individuals that have friends or family with epilepsy ($r = -.14$, $n = 109$, $p < .16$) that was not significant. This indicates that the two variables share approximately 2% of variance in common. Results indicate that higher levels of knowledge are not associated with lower levels of stigma in individuals that have friends or family with epilepsy.

There was non-significant, negative correlation between stigma and knowledge in individuals who do not have friends or family with epilepsy ($r = .01$, $n = 131$, $p < .91$). This indicates that the two variables share approximately .01% of variance in common. Results indicate that higher levels of knowledge are not associated with lower levels of stigma in individuals that do not have friends or family with epilepsy.

Hypothesis 3*:* Individuals with higher levels of empathy will have a lower stigma score toward epilepsy.

There was a weak, negative correlation between the two variables ($r = -.03$, $n = 240$, $p < .60$) that was not significant. This indicates that the two variables share approximately .09% of variance in common. Results indicate that higher levels of empathy is not associated with lower levels of stigma.

Through investigating hypothesis 3, other groups and the variables of stigma and empathy were investigated.

There was a weak, negative correlation between stigma and empathy in individuals with epilepsy ($r = -.03$, $n = 115$, $p < .683$) that was not significant. This indicates that the two

variables share approximately .09 % of variance in common. Results indicate that higher levels of empathy is not associated with lower levels of stigma.

There was a weak, negative correlation between stigma and empathy in individuals without epilepsy (r = -.014, n = 125, p < .88) that was not significant. This indicates that the two variables share approximately .02% of variance in common. Results indicate that higher levels of empathy is not associated with lower levels of stigma.

There was weak, positive correlation between stigma and empathy in individuals who have friends and family with epilepsy(r = .07, n = 109, p < .48) that was not significant. This indicates that the two variables share approximately .05% of variance in common. Results indicate that higher levels of stigma are not associated with lower levels of knowledge.

There was small, negative correlation between stigma and empathy in individuals who did not have friends or family with epilepsy (r = -.15, n = 131, p < .08) that was not significant. This indicates that the two variables share approximately 2.3% of variance in common. Results indicate that higher levels of empathy is not associated with lower levels of stigma

For hypothesis 4, a two way analysis of covariance was conducted: to test if, individuals with epilepsy and those who know people with epilepsy will have a higher level of knowledge, empathy and lower level of stigma, than those who do not. Three separate two-way ANOVAs were conducted, the interaction effect of knowing individuals with epilepsy and having epilepsy were measured on knowledge, stigma and empathy. Figures 1, 2, 3 displays the results of the ANOVAs conducted.
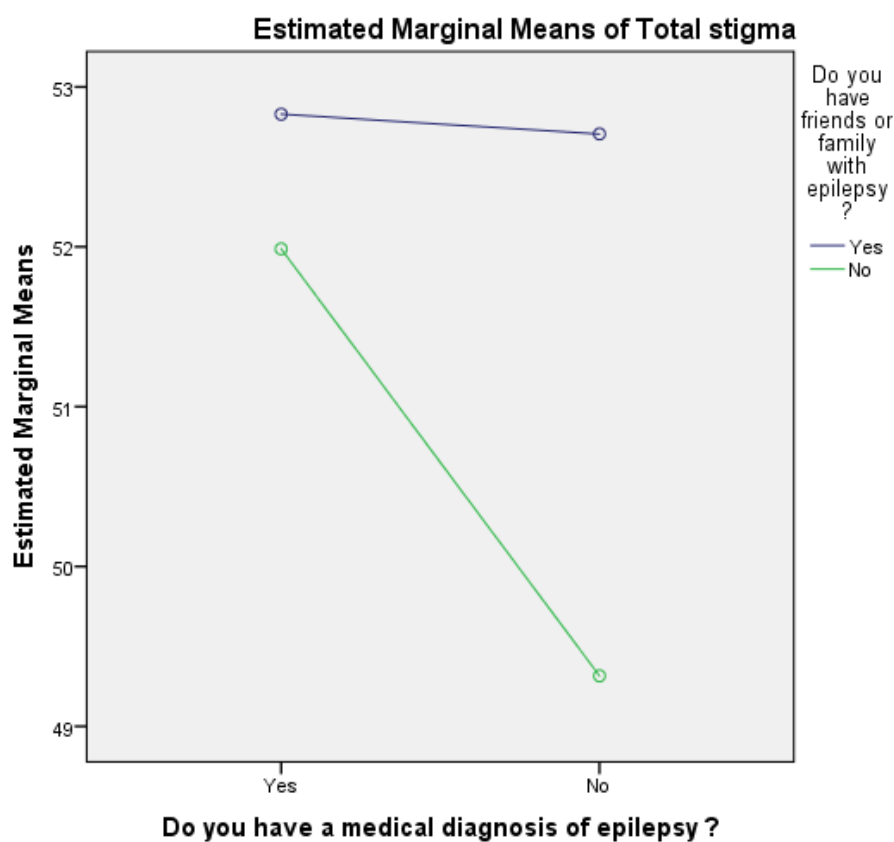
Figure 1- Knowledge
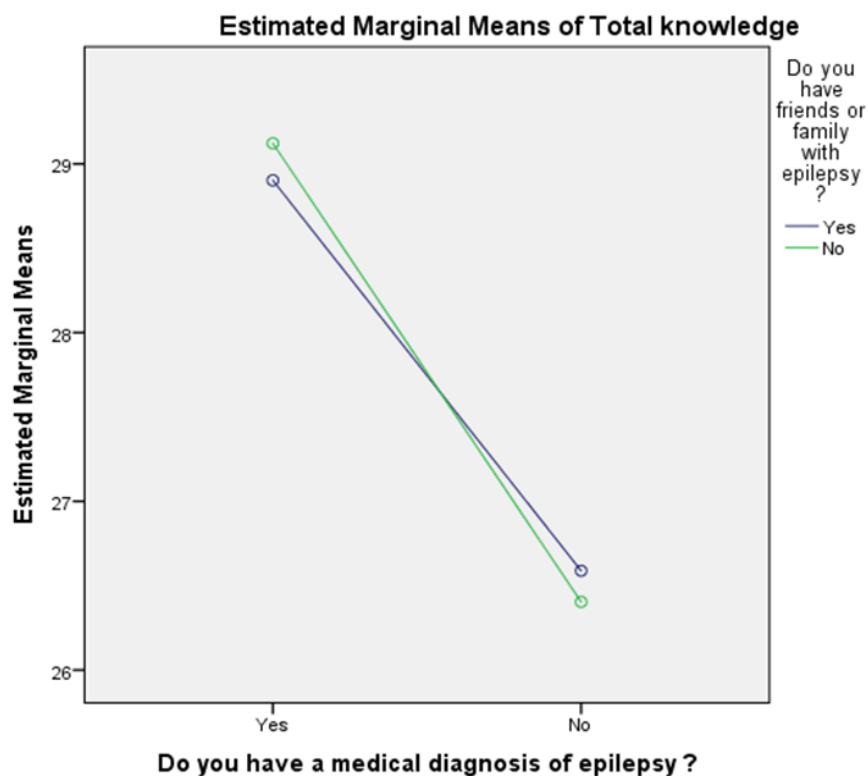
A two-way between groups analysis of variance was conducted to explore for: (1) differences in having epilepsy, and knowing individuals with epilepsy, on levels of knowledge, and (2) to examine the effects of having epilepsy on levels of knowledge, along with if it is effected by knowing individuals with epilepsy. Initial findings indicated a violation of the assumption of homogeneity of variance (p = .007) therefore a new alpha level of .01 was selected to determine statistically significant effects.

The interaction effect between knowing and having epilepsy was not statistically significant, $(F_{(4, 236)} = .227, p = .63)$. The main effect for having epilepsy was significant and of a large magnitude $(F_{(4, 236)} = 35.1, p = .00,$ eta-squared $= .13)$. The main effect for knowing individuals with epilepsy was not significant based on the newly selected alpha level, the effect was of a small size $(F_{(2, 82)} = .002, p = .96,$ eta-squared $= .00)$.
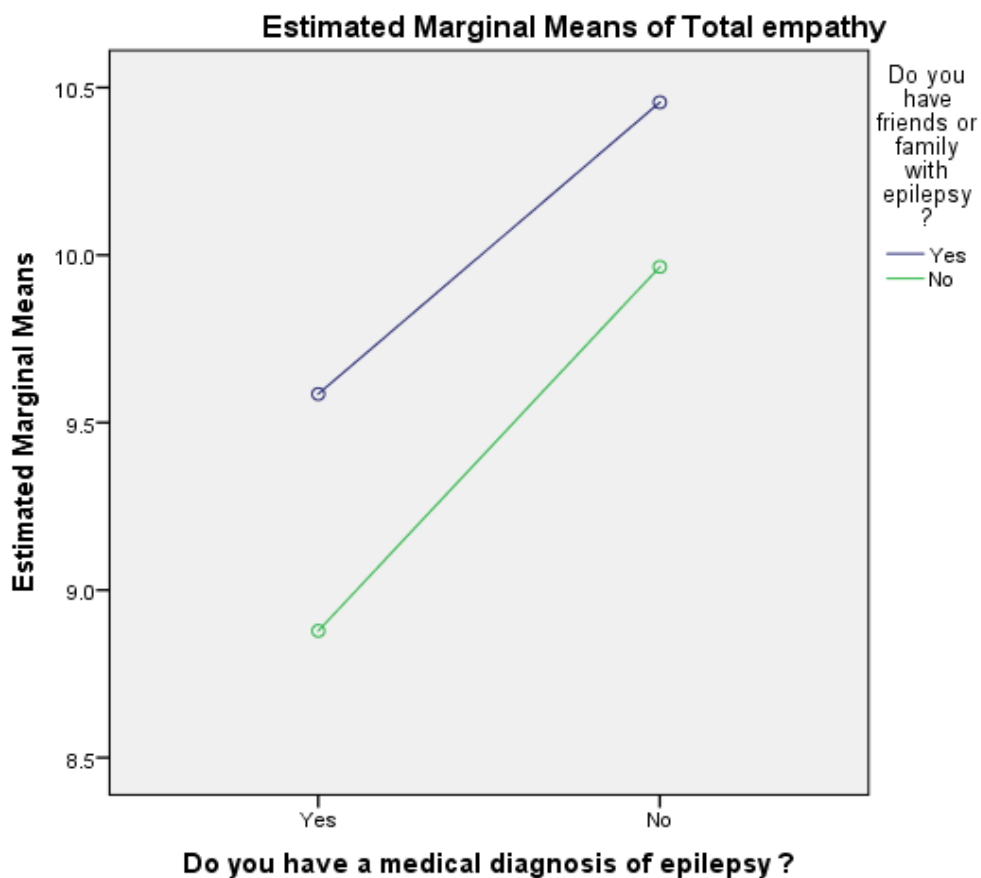
Figure 2- Stigma

A two-way between groups analysis of variance was conducted to explore for: (1) differences in having epilepsy, and knowing individuals with epilepsy, on levels of stigma, and (2) to examine the effects of having epilepsy on levels of stigma, along with if it effected by knowing individuals with epilepsy. Initial findings indicated a violation of the assumption of homogeneity of variance (p = .79) therefore a new alpha level of .01 was selected to determine statistically significant effects.

The interaction effect between having epilepsy and knowing individuals that have epilepsy was not statistically significant, ($F_{(3, 236)}$ = 1.03, p = .31). The main effect for having epilepsy was not significant and of a small magnitude ($F_{(2, 236)}$ = 1.23, p = .27, eta-squared

= .005). The main effect for knowing individuals with epilepsy was not significant based on the newly selected alpha level however the effect was of a small size (F (3, 236) = 2.83, p = .09, eta-squared = .01).

Figure 3- Empathy

A two-way between groups analysis of variance was conducted to explore for: (1) differences in having epilepsy and knowing individuals with epilepsy, on levels empathy and (2) to examine the effects of having epilepsy on levels of empathy, along with if it effected by knowing individuals with epilepsy. Initial findings indicated a violation of the assumption of homogeneity of variance (p = .13) therefore a new alpha level of .01 was selected to determine statistically significant effects.

The interaction effect between having epilepsy and knowing individuals with epilepsy was not statistically significant, (F (3, 236) = .05, p = .82). The main effect having epilepsy was not significant and of a small magnitude (F (3, 236) = 4.24, p = .04, eta-squared = .02). The main effect for knowing an individual with epilepsy was not significant based on the newly

selected alpha level however the effect was of a small-to-moderate size (F (3, 236) = 1.6, p =

.21, eta-squared = .07).

Chapter 4. Discussion

The current study investigated knowledge and empathy relationship with stigma towards epilepsy. The findings of the first three hypotheses were not supported, conflicting with previous research; however the fourth hypothesis was partially supported. Interestingly the vast majority of studies have reported a lack of knowledge amongst the general public, however this study found knowledge to be quite high with the average score being 28 out of 34. Overall the general population showed high levels of knowledge whilst displaying average levels of stigma and empathy.

The **first hypothesis**, states "Individuals who obtained higher scores on the epilepsy knowledge questionnaire will have a lower stigma score towards epilepsy". Through conducting a separate pearson correlation analysis on the total sample and individuals who do not have a medical diagnosis of epilepsy, a negative relationship was found in both tests. Adhering to previous research however the correlations were not significant, therefore the hypothesis is rejected. This finding, contradicts previous literature as studies have found knowledge and stigma to have a significant negative relationship, the majority of previous studies on stigma in epilepsy have found the publics attitudes and their knowledge are negatively correlated (Bishop & Boag, 2006). Along with a study in Spain find individuals with low knowledge of epilepsy had higher rates of stigma (Wu et al., 2008).

However the current studies results align with findings in south Korea, as information campaigns did heighten individuals level of knowledge towards epilepsy however did not alleviate any level of stigma towards the neurological disease (Kim,. et al, 2003). Findings from a qualitative study, asked participants with average to high knowledge why individuals with epilepsy are subjected to stigmatisation. The prevalent statements attributed this to epilepsy being seen as a public health risk, hurting other individuals, as well as fear and

ignorance (Jacoby, Gorry, Gamble & Baker, 2004). Overall it should be noted that certain attitudes are deep rooted and may be unchanged to additional knowledge. Knowledge is often suggested in combating any form of stigma, however the finding within the current suggests otherwise, previous theories attributed the cause of stigma in epilepsy to be due to unexpected seizures conflicting with behavioural social norms (Jacoby & Austin, 2007).

The **second hypothesis** states "Individuals with epilepsy who higher rates of knowledge will have lower levels of internalized stigma". This hypothesis was fully rejected as there was also a non-significant negative correlation between knowledge and internalised stigma in individuals with epilepsy conflicting with findings of previous literature, with mean scores of knowledge quite high whist stigma score ranging at average. The current studies finding does not adhere to the vast majority of previous finding within this field. As research has found that respondents with poor knowledge of their neurological disease had negative attitudes (Yousuf, Shahar, Azarisman, Rosle & Tin, 2018). Especially those with lower self-efficacy, lack of support and information for seizure management (Austin, Perkins & Dunn, 2014). A cross-cultural study, Swedish subjects reported a significantly lower level of internalised stigma than the Iranian patients due to higher levels of knowledge (Forsgren, Ghanean, Jacobsson & Richter, 2013). As well as a previous studies also finding children with a lack of knowledge towards epilepsy, had experienced internalised stigma to a higher degree than children with high knowledge (Austin, Perkins & Dunn, 2014).

However the current studies findings might suggest that internalised-stigma is influenced by the exposer of public stigmatization, which has been shown to enhance one's own negative beliefs about their condition (Bos, Pryor, Reeder & Stutterheim, 2013). As few studies have found that despite having a high degree of knowledge of their neurological disease, attitudes of others have been shown to contribute to interpersonal stigma (Sands & Zalkind, 1972). The negative views associated with the disorder can cause public devaluation, shame, which

can trigger the application of negative stereotypes to one self (Ghanean, Jacobsson & Nojomy, 2013). A study of individuals with schizophrenia used other methods other than knowledge to reducing internalised stigma which included sharing illness experience, self-acceptance and the use of CBT to challenge beliefs about stigma. Which was showed to be more effective in combating and preventing internalised stigma rather than knowledge (Mittal, Sullivan, Chekuri, Allee & Corrigan, 2012). Therefore findings within the current study show there may be other causes for internalised stigma, as people's perceptions may have a greater influence on internalized stigma than having adequate knowledge of their neurological condition, however more research need to confirm.

Additional tests which were not hypothesised were run on individuals who have friends and family with epilepsy and those who do not. The findings were also insignificant, with a negative correlation.

The **third hypothesis** states "Individuals with higher levels of empathy will have a lower stigma score toward epilepsy". The current studies findings show there is no significant correlation between empathy and stigma in epilepsy, along with displaying a negative relationship with little variance. These findings are not consistent with previous literature, as studies have shown that empathy has a significant effect on the behaviours and attitudes against stigma, with individuals with lower levels of empathy having higher levels of prejudice (McFarland, 2010). Recent research on empathy and stigma in schizophrenia, used methods of inducing empathy through the simulation of auditory and visual hallucinations, found individuals who had heightened levels of empathy had reduced stigma towards the condition greatly (Ando, Clement, Barley & Thornicroft, 2011). As well as theories suggesting empathy may directly address the central feeling and evaluation components of the attitudes (Batson et al., 1997).

Although a large number of studies support that individuals with low levels of empathy tended to show higher stigmatizing attitudes (Batson et al., 1997). There are similar findings to the current study, although limited. Recent research has found mental health professional had less stigma than non-health professionals, however empathy levels where the same amongst the two groups (Gateshill, Kucharska-Pietura & Wattis, 2011). Theories propose that empathy is typically felt for individuals, rather than a certain group of people. Feeling empathy towards a certain individual may increase value or concern however this may not be generalised. Having empathy towards an individual within a stigmatized group may lead to personalization; as feelings towards an individual within the group may be an expectation however the feeling towards the group is unchanged (Batson et al., 1997).

Additional tests which were not hypothesised were run on individuals with and without epilepsy as well as on individuals who have friends and family with epilepsy and those who do not. The findings were also insignificant with little variance.

The **fourth and final hypothesis** states "Individuals with epilepsy and those who know people with epilepsy will have a higher level of knowledge and lower level of stigma, than those who do not" Our findings suggest that individuals with epilepsy do have a higher degree of knowledge than individuals who do not, aligning with previous studies. Which have shown people with epilepsy have a higher degree of knowledge regarding their disorder than the general public, by having a higher degree of knowledge on the etiologic of epilepsy, different forms, causes and procedures (Long, Reeves, Moore, Roach & Pickering, 2000). This legible as knowledge and understanding of their own neurological disease is important as it gives individuals with epilepsy the ability to cope with daily life (Coker, Bhargava, Fitzgerald & Doherty, 2011). However having friends or family with epilepsy showed no statistically significant effect on level of knowledge. Conflicting with previous studies, as findings show parents of children with epilepsy, showing a higher rate of knowledge than

parent who did not have children with epilepsy (Hirfanoglu et al., 2009). The current study found stigma levels in individuals with epilepsy are not significantly different to individuals who do not have epilepsy. In addition there also was no statistically significant difference between those who know individuals with epilepsy and those who do not. However previous research suggests that not having family members with epilepsy correlates with a lower awareness of people with epilepsy's circumstance's therefore have poorer attitudes (Al-Hashemi et al., 2019).

4.2 Strengths and limitations within the current study

The current study has a number of limitations. First and foremost this being the use of self-reporting scales to measure levels of empathy and stigma, as this relied heavily on an individual's introspective ability. In which during personal evaluation individuals may have select incorrectly despite their best efforts to be accurate and honest. As well as induce a response bias. Along with secondly different forms of measurements have been used within previous studies such as questionnaires for individual's knowledge of epilepsy. Each questionnaire varies in its level of difficulty; therefore accurately comparing scores is difficult. Along with there being different forms of measurement used in previous studies for empathy and stigma, In addition the stigma scale of epilepsy, seems to incorporated both individual's perception of stigma in epilepsy along with their own stigmatizing attitudes therefore its questionable whether this measure accurately obtained individuals level of stigma towards epilepsy. Finally, it should be noted that the study had a total of 47 questions in which required attention and active thinking, especially within knowledge of epilepsy questionnaire, therefore there is a possibility some may have lost attention and guessed or randomly selected their answers.

As this study possesses a number of limitations, there are also strengths. As a suitable number of 240 participants, with a diverse age group ranging from 18-81, as well as 115 participants having a medical diagnosis of epilepsy allowing for an appropriate sample size for hypothesis 2. Secondly this study has contribution to research of stigma in epilepsy, as no previous study has examined empathy influence on stigma in epilepsy. As previous studies were only conducted on stigma in mental illness such as schizophrenia (Ando, Clement, Barley & Thornicroft, 2011). With research of empathy and stigma being limited, the contribution of this study was necessary. Finally as this questionnaire was online participant's had privacy and comfort to complete the questionnaire in any suitable location.

4.3 Recommendations for future research

For future research, as discussed within limitations, studies may gain more accurate results of stigma in epilepsy through a different scale than the one employed within the current study, As the current scale (SSE) seemed to incorporate the individual's perception of stigma as well as their own stigmatizing attitudes. Along with this we would recommend the use of the empathy quotient twenty-two scale (Wakabayashi et al., 2006) instead of the eight item version, as a higher accuracy would be obtained.

Conclusion

The current study provides new findings on the level of impact knowledge and empathy have on stigma in epilepsy. The findings have illustrated there is no correlation between knowledge towards stigma in epilepsy in individuals with and without epilepsy, as well as empathy having no significant relationship toward stigma in epilepsy; Moreover, the data has shown individuals with friends and family did not differ significantly in their level of

knowledge or stigma. However individuals with epilepsy have been found to have a higher degree of knowledge than those who don't, however do not have a lower level of stigma. These findings are important as they show that despite there being a high level of knowledge in both the general public and individuals with epilepsy; however it should be noted that use of different scales may suggest other finding. Therefore further research would be beneficial in finding the exact sources that harvests stigmatising attitudes to enable prevention and dismantle stigma towards epilepsy.

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Appendices

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Appendix A - Epilepsy stigma scale of epilepsy (SSE)

Instructions: Please indicate the number on the following scale that best illustrates your opinion about epilepsy: 1 -Not at all, 2 -A little , 3 -A lot, 4 -Totally.

1.   Do you think that people with epilepsy are able to control their own epilepsy?

1-4

2.   How would you feel when you see an epileptic seizure?

Scared

Fear

Sadness

Pity

3.   Which difficulties do you think people with epilepsy have in their lives?

Relationships

Work

School

Friendships

Sexual

Emotional

Prejudice

4.   How do you think that people with epilepsy feel?

Worried

Dependent

Incapable

Fearful

Ashamed

Depressed

The same as those without epilepsy

5.   In your opinion, the prejudice in epilepsy will be related to

Relationships

Marriage

Work

School

Family

Appendix B

Empathy Quotient short-8 questions

Please rate how strongly you agree or disagree with the following statements

1= Slightly agree, 2= Strongly agree, 3= Slightly disagree, 4= Strongly disagree

1. I find it easy to put myself in somebody else's shoes.

2. I am good at predicting how someone will feel.

3. I am quick to spot when someone in a group is feeling awkward or uncomfortable.

4. Other people tell me I am good at understanding how they are feeling and what they are

thinking.

5. I find it hard to know what to do in a social situation.

6. I often find it hard to judge if something is rude or polite.

7. It is hard for me to see why some things upset people so much.

8. Other people often say that I am insensitive, though I don't always see why.

Appendix C

 Epilepsy Knowledge Profile – medical aspects of epilepsy (Correct answer in bracket)

(1) Epilepsy is always caused by brain damage (FALSE)

(2) Epilepsy is not infectious (TRUE)

(3) Epilepsy is a symptom of mental illness (FALSE)

(4) All people with epilepsy have similar symptoms (FALSE)

(5) Almost anyone can have a seizure given the appropriate circumstances (TRUE)

(6) An EEG can be used to help diagnose epilepsy (TRUE)

(7) If an EEG is abnormal, this is a definite sign of epilepsy (FALSE)

(8) An EEG is designed to detect electrical activity from the brain (TRUE)

(9) All people with epilepsy lose consciousness during seizures (FALSE)

(10) An epileptic seizure can be described as a temporary lack of oxygen to the brain (FALSE)

(11) Some seizures may last for a matter of seconds and not be noticed by others (TRUE)

(12) All seizures affect both sides of the brain (FALSE)

(13) Certain forms of brain damage always cause epilepsy (FALSE)

(14) A normal EEG means that you do not have epilepsy (FALSE)

(15) For most people, doctors can effectively treat epilepsy with drugs (TRUE)

(16) All those who start drugs for their epilepsy have to take them for life (FALSE)

(17) Increasing the dose of antiepileptic drugs increases the chances of side effects (TRUE)

(18) An epileptic seizure can be described as an abnormality in the function of nerve cells in the brain (TRUE)

(19) For antiepileptic drugs to be successful, they must be taken regularly (TRUE)

(20) If you forget to take antiepileptic drug for a day, it is usually OK to take two doses together (TRUE)

(21) Some people get a warning or feeling shortly before a seizure (TRUE)

(22) Blood samples can be used to measure the concentrations of antiepileptic drugs in the system (TRUE)

(23) People taking a combination of antiepileptic drugs are more likely to have side effects than are those taking only one (TRUE)

(24) Most people's seizures are well controlled soon after starting regular drug treatment (TRUE)

(25) It is always helpful to take extra doses of antiepileptic drugs when not feeling well (FALSE)

(26) If seizures stop with antiepileptic drugs, this means your epilepsy has been cured (FALSE)

(27) Few people with a diagnosis of epilepsy are taking antiepileptic drugs (FALSE)

(28) Some people have been taught to control their seizures by psychological methods (TRUE)

(29) There is no need to continue taking antiepileptic drugs if your seizures stop (FALSE)

(30) Brain surgery is still used as a method of preventing seizures (TRUE)

(31) Most mothers taking antiepileptic drugs are able to breastfeed (TRUE)

(32) Too much alcohol may make seizures more likely (TRUE)

(33) Most seizures result in brain damage (FALSE)

(34) Stress may cause some seizures (TRUE)

Appendix D

Introduction and consent sheet

The objective of the study

The main objective of this study assesses how the general population's knowledge and empathy levels correlate with certain levels of stigma towards epilepsy.

Along with identifying within the epileptic community if knowledge and empathy correlate with internalised-stigmatizing attitudes towards epilepsy.

Overview of the study

This study consists of four sections:

1. Your socio-demographic information
2. Questions to measure the population's perception of epilepsy
3. Questions to measure your empathy skills
4. Questions to measure your knowledge of epilepsy.

In total there will be 53 questions, which will take you around 10-15 minutes to fill out.

Benefits of study

This study will help the epileptic community in understanding how significant empathy and knowledge are in determining levels of internalised stigma along with the general public level of stigma.

Risks of study

If participants are uncomfortable with the questions asked, you are able to exit the questionnaire without the submission of data.

Requirements for participation

-Must be 18 years of age

-Volunteer to participate

-Individuals who are willing to share their knowledge and attitudes on the matter of epilepsy through questionnaires.

Confidentiality of participants

-Individuals who wish to part-take in this study will remain anonymous, no identifiable details are required for this study.

-Participants have the ability to halt input of information and withdraw from the study without any implications.

-Due to anonymity, data cannot be withdrawn after submission.

-The researchers hold the responsibility for the collection, retention, and disposal of the data obtained.

-No secondary party will have access to data collected.

-Data obtained through this study will remain in the National College of Ireland's database for 5 years, to which will then be destroyed.

Contact information

If individuals have any quires about this study, please contact mine or my supervisor's email

below
Student researchers email: x16349151@student.ncirl.ie
Supervisors email: Matthew.Hudson@ncirl.ie

<u>Services</u>
Please contact services below if you wish to gain any further information regarding epilepsy
or wish to speak to a helpline
Epilepsy Ireland - (01) 455 7500 / https://www.epilepsy.ie
Jigsaw Ireland - (01) 472 7010 / https://www.jigsaw.ie/

Appendix E

Thank you for agreeing to participate in this study, which aims to investigate knowledge and
empathy influence on the level of stigma in epilepsy.

Participants rights and confidentiality
-As stated previously individuals who wish to part-take in this study will remain anonymous, no identifiable details were required for this study.
-Participants had the ability to halt input of information and withdraw from the study without any implications.
-Due to anonymity, data cannot be withdrawn after submission.
-The researchers hold the responsibility for the collection, retention, and disposal of the data obtained.
-No secondary party will have access to data collected.
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Additional reading
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