

Stigma and socioeconomic outcomes in epilepsy

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To all the persons living with epilepsy,

ABSTRACT

Epilepsy influences all aspects of life. While the treatment of seizures is the natural starting point in epilepsy care, social aspects of epilepsy need consideration for successful outcomes. The purpose of this doctoral thesis is to investigate the impact of stigma and socioeconomic status in epilepsy. The thesis is based on four studies with different methodological designs. By using data from national registers (Paper I), self-report questionnaires (Paper II), individual face-to-face interviews (Paper III) as well as focus group interviews (Paper IV), stigma and socioeconomic outcomes in epilepsy are investigated from both a quantitative, population level and a qualitative, individual experience level.

The results indicate that higher education and better income levels are not only associated with less severe epilepsy but also to greater access to a neurologist (Paper I). A higher educational level also appears protective against low income and unemployment in epilepsy compared to healthy controls (Paper I).

Within the Swedish population foreign-born people with epilepsy report higher levels of stigma compared with Swedish-born persons with epilepsy (Paper II). Factors that predict higher levels of stigma are seizure frequency, higher levels of anxiety and lower levels of mental health (Paper II). People with epilepsy born outside of Sweden were found to experience multiple stigma that may increase the risk of social isolation and present barriers to epilepsy care (Paper III). Social barriers, stigma and complex medical situations increase the need for support in specialized epilepsy care. A multidisciplinary team that facilitates communication, education, psychological support, and cooperation with external sectors is crucial to support vulnerable persons with epilepsy (Paper IV).

This thesis contributes to our knowledge of stigma, stigma-associated factors, and socioeconomic disparities in epilepsy care in Sweden. The results from Paper I-IV highlight the importance of an individual approach acknowledging patients' social circumstances and the need for multidisciplinary teams in epilepsy care. They further underscore the need for targeted interventions aiming to reduce stigma and improve the support for vulnerable persons with epilepsy.

Keywords: epilepsy, stigma, socioeconomic status

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SAMMANFATTNING PÅ SVENSKA

Epilepsi beror på avvikande elektriska urladdningar i hjärnbarken och manifesterar sig genom epileptiska anfall. När anfällen uppstår är de oftast oförutsägbara, omöjliga att kontrollera och dramatiska upplevelser både för den drabbade och dess närstående.

Epilepsi påverkar många delar av livet så som arbetsliv, privatliv och sociala relationer. Tidigare forskning har visat att personer med lägre socioekonomisk status (SES) oftare har bristande anfallskontroll och större behov av akutsjukvård till följd av anfall än personer med högre SES, samtidigt som de i lägre grad har tillgång till specialiserad epilepsisjukvård. Alla personer med epilepsi löper samtidigt en risk att drabbas av stigma. Stigma innebär att en person förknippas med en stereotyp, separeras från andra människor, förlorar social status och utsätts för diskriminering. Stigma utgörs både av faktisk diskriminerande, negativ behandling och av rädsla för att sådan ska ske. Stigmat i sig försämrar möjligheterna till bra livskvalitet vid epilepsi, bland annat genom att vara associerat med sämre följsamhet till läkemedel och psykisk ohälsa.

För att identifiera personer med ökat behov av epilepsisjukvård och resurser som ingår i ett epilepsiteam behöver sociala riskfaktorer som stigma och SES utforskas. I det här doktorandprojektet undersöks hur SES påverkar tillgång till epilepsisjukvård och andra socioekonomiska utfall, nivåer av skattat stigma, stigma-associerade faktorer och vad stigma kan innebära i en kontext med social utsatthet som för utlandsfödda personer med epilepsi i ett segregerat bostadsområde.

Genom att samköra data från nationella register kunde sambandet mellan SES och förskrivning av antiepileptiska läkemedel från neurolog i Sverige undersökas för vuxna personer med epilepsi. Resultaten visar bland annat att personer med epilepsi med högre inkomst eller utbildningsnivå har mindre allvarlig epilepsi men i högre grad sina antiepileptiska läkemedel förskrivna av en neurolog än personer med lägre inkomst eller utbildningsnivå. Resultaten visar också att en högre utbildningsnivå korrelerar med minskade skillnader i andel arbetslösa och andel låginkomsttagare mellan personer med epilepsi och friska ålders- och könsmatchade kontroller. Detta tyder på att en högre utbildningsnivå kan skydda mot andra negativa socioekonomiska utfall vid epilepsi.

Genom patientenkäter som samlades in på tre olika neurologmottagningar i Västsverige undersökte vi sambandet mellan upplevt stigma, SES, födelseland och psykisk hälsa bland vuxna personer med epilepsi. Det rapporterades högre grad av stigma bland utlandsfödda än svenskfödda, framför allt bland de som kom ifrån länder utanför Europa. De faktorer som var starkast förknippade med högre nivå av stigma var om deltagarna hade haft anfall det senaste året eller inte, högre nivå av ångestsymtom och lägre nivå av skattad psykisk hälsa.

Innebörden av stigma undersöktes genom individuella intervjuer med 25 utlandsfödda personer med epilepsi i ett segregerat bostadsområde. Stigma relaterat till epilepsi, invandring och låg SES verkade hänga samman med en negativ självbild. Samtidigt som stigma relaterat till epilepsi verkade försvåra för deltagarna att integrera sig i samhället kunde stigma relaterat till att vara invandrad utgöra en barriär till epilepsisjukvården. Att hitta och behålla ett arbete framkom vara av särskilt stor vikt för att minska stigmat, både kring epilepsi och att vara invandrad.

I en fokusgruppintervjustudie där vårdpersonal och personer med epilepsi deltog undersöktes erfarenheter och upplevelser av hur sociala faktorer påverkar epilepsisjukvården. I resultaten framkom utmaningar så som sociala barriärer (tex. låg SES eller språkbarriärer), stigma, brist på kunskap om epilepsi i samhället och brist på resurser inom epilepsisjukvården. Resultaten framhöll betydelsen av det multidisciplinära teamet för att stödja sårbara personer i epilepsisjukvården, genom funktioner så som individuell anpassning, kommunikationshjälpmedel, psykologiskt stöd, utbildning och samverkan med externa aktörer (som tex. skola, Arbetsförmedling och Försäkringskassa).

Sammanfattningsvis understryker resultaten av avhandlingen betydelsen av sociala faktors inverkan på utfallet vid epilepsi. Resultaten bekräftar att SES påverkar behovet av och tillgången till vård och stöd vid epilepsi, och att anfallskontroll, psykologiskt stöd och utbildning både för personer med epilepsi, dess anhöriga och allmänheten, är insatser av avgörande betydelse för att minska stigma och stödja sårbara personer med epilepsi. Framtida studier bör fokusera på att utveckla och anpassa verktyg för förenklad kommunikation och kostnadseffektiva patientcentrerade lösningar och interventioner som underlättar tillgång till vård och stöd för sårbara personer med epilepsi.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. **Andersson K**, Ozanne A, Edelvik Tranberg A, Chaplin JE, Bolin K, Malmgren K, Zelano J. Socioeconomic outcome and access to care in adults with epilepsy in Sweden: A nationwide cohort study.
Seizure: European Journal of Epilepsy. 2020; 74: 71-76.
- II. **Andersson K**, Ozanne A, Zelano J, Malmgren K, Chaplin JE. Perceived stigma in adults with epilepsy in Sweden and associations with country of birth, socioeconomic status, and mental health.
Epilepsy & Behavior 2022;136:108886.
- III. **Andersson K**, Strang S, Zelano J, Chaplin JE, Malmgren K, Ozanne A. Multiple stigma among first-generation immigrants with epilepsy in Sweden.
Epilepsy & Behavior. 2021; 115: 107638.
- IV. **Andersson K**, Zelano J, Chaplin JE, Malmgren K, Ozanne A. Challenges in epilepsy care and the importance of multidisciplinary teams: The perspectives of adult patients and their health providers in Sweden. *Manuscript*.

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ABBREVIATIONS

ASM	Anti-seizure medication
CNS	Central Nervous System
EEG	Electroencephalogram
GADS	Global assessment of Disability of Seizures
GASE	Global Assessment of Severity of Epilepsy
HADS	Hospital Anxiety and Depression Scale
ILAE	International League Against Epilepsy
JSS	Jacoby stigma scale
MRI	Magnetic resonance imaging
Neuro-QoL	Quality of Life in Neurological Disorders
NPR	National Patient Register
PROM	Patient-Reported Outcome Measure
PROMIS	Patient-Reported Outcomes Measurement Information System
SES	Socioeconomic status
SUDEP	Sudden unexpected death in epilepsy
WHO	World Health Organization

DEFINITIONS IN SHORT

Epilepsy	“brain disorder characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiologic, cognitive, psychological, and social consequences of this condition” (1).
Seizure	“a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” (1).
Stigma	“the co-occurrence of labelling, stereotyping, separation, status loss and discrimination in a context in which power is exercised” (2).
Socioeconomic status	Individual characteristics of education, occupation, and income (3).
Health	“a state of complete physical, mental and social well-being and not merely the absence of disease” (4).
Health literacy	“a person’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course” (5).

1 INTRODUCTION

Epilepsy is a common neurologic disorder affecting 50 million people worldwide (6) and about 0.6% of the adult Swedish population (7). Epilepsy can be seen as a compound of diverse brain disorders that predispose for generating seizures (8). An epilepsy diagnosis is associated with driving and employment restrictions (9, 10), lifestyle recommendations, treatment with antiseizure medication (ASM), and it is surrounded by stigma (11). Due to the widespread consequences of epilepsy, it is vital that the diagnosis is established on correct grounds. In clinical practice, the establishment of an epilepsy diagnosis can be challenging both for the neurologist and the patient, and misdiagnosis of epilepsy is common (12). In addition, challenges appear due to the great diversity of patients with epilepsy, with different comorbidities and social circumstances resulting in different needs for treatment and support.

A clinical perspective

When a patient presents with a first seizure, the clinician faces diagnostic challenges in 1. differentiating an epileptic seizure from other conditions, 2. judging whether the seizure was symptomatic or unprovoked, and 3. deciding whether ASM treatment is motivated and if there is sufficient information for establishing an epilepsy diagnosis (13). In connection to acute CNS insults of structural, metabolic, toxic, infectious or inflammatory nature, the threshold to generate seizures is lowered and anyone can experience a symptomatic seizure (14). When a patient presents at the emergency department after a first seizure it is crucial to make a careful clinical investigation of acute symptomatic causes that are not epilepsy but require emergency care for other causes.

Epilepsy means an enduring alteration in the brain that increases the risk of recurrent seizures (15) and the diagnosis should be based on individual assessment of seizure recurrence risk (16). In most persons who experience one unprovoked seizure, seizures will not reoccur (13), but after two unprovoked seizures a majority will experience recurring seizures. It is at this point that the epilepsy diagnosis is most commonly established in clinical practice (1).

Seizure control is a strong predictor for quality of life in epilepsy (17-20) and can be achieved in 2/3 of patients (21) within a few years of treatment with ASM. Successful treatment outcomes require adherence to ASM prescriptions, which can be threatened by lacking tolerability (22), but also by fear of adverse

effects, doubt of ASM necessity or other concerns (23). About 30% of patients have drug resistant epilepsy (24). Drug resistant epilepsy is defined as a failure to obtain seizure control after treatment with at least two tolerated and appropriately chosen and used ASM (25). For selected patients with drug resistant focal epilepsy, neurosurgical treatment can be offered and improve the chances of seizure control (26), but a substantial proportion of patients must learn to live with recurring seizures.

Although MRI and EEG are important tools especially in the investigation of underlying causes of epilepsy (13), the most useful tool in all phases of investigating and treating epilepsy is the patient history. The patient history can differentiate a seizure from other causes of transient loss of consciousness such as a syncope or psychogenic non-epileptic seizure (PNES) (27). The patient history is crucial for detecting signs of a focal start of a seizure, choosing appropriate ASM (28), and for making dose adjustments and changes due to individual tolerability. Therefore, any kind of communication barrier or factor that deteriorates the patients' ability to participate increases the risk of incorrect diagnosis and suboptimal treatment in epilepsy.

A patient perspective

The sudden onset, complete loss of control and dramatic appearance of a seizure can be a shocking experience with psychological consequences for the patient, their whole family, and observers. Previously healthy individuals can have difficulties accepting being diagnosed with a chronic condition, take medication, and reevaluating their life prospects, career, marriage, and self-image (29-31).

Due to a lack of knowledge about epilepsy, there are public misconceptions and stereotyped ideas about the manifestation of seizures (32), for example that all suffer from tonic-clonic seizures. In reality there is a great diversity of seizure types and epilepsy conditions (33). Since seizures reflect the localization and propagation of the seizure activity in the brain (34), they can give rise to any kind of symptom depending on what part of the brain that is involved: motor symptoms, sensory symptoms, auditory symptoms, visual symptoms, memory symptoms, etc. Some symptoms can immediately be related to activity in certain brain regions (primary cortex) while other symptoms such as for example complex motor behavior and emotional change, can be more difficult to localize (35). Seizures have a stereotypical presentation within the same person with epilepsy (34), but usually differ between individuals. This diversity can contribute to difficulties for patients in understanding what epilepsy and seizures really are.

Being diagnosed with epilepsy means being exposed to public misconceptions about the condition. Historically, alternative explanatory models of epilepsy such as sorcery, possessions, or the punishment of God were common (36-38). In Scandinavia, epilepsy was explained as a consequence of having disturbed the “hidden people”, i.e. the supernatural beings that were believed to inhabit the woods and the mountains (39). Other misconceptions about epilepsy that still prevail in some countries are that epilepsy is an expression of insanity, mental illness, or mental retardation (40-42).

The lack of knowledge and misconceptions have exposed people with epilepsy to mistreatments. In Scandinavia, before academic medicine began to influence people’s ideas, it was believed that “the falling sickness” could be treated by tearing off and burning the clothes of a seizing person, or by oral intake of urine or blood (39). The lack of knowledge has also influenced legislation and resulted in discrimination and violation of human rights all over the world. Persons with epilepsy have been interdicted to marry, attend public areas, or forced sterilization (43, 44). In Sweden, the interdiction for persons with epilepsy to marry without sterilization was not removed until 1969 (45). Misconceptions and discrimination of persons with epilepsy contribute to making epilepsy a highly stigmatized condition. Being diagnosed with epilepsy therefore means being transformed from a “normal” person to an “epileptic” and the stigma surrounding that label (46).

A diverse patient population

Epilepsy treatment and outcomes are complicated by the high prevalence of comorbid conditions. About 50% have at least one comorbid condition that often require long term treatment and follow up (47). Neurological conditions such as stroke or cerebral tumors are common since any cerebral insult increases the risk of epilepsy (48). Psychiatric comorbidities are overrepresented and there is a bidirectional relationship, they can share risk factors, origin, or be the result of epilepsy (49, 50). The prevalence of psychiatric conditions have been reported being about 36% (51) and 41% (52) in large cohort studies, almost twice as common in epilepsy compared to the general population (52). Depression and anxiety disorders are the most common, with reported prevalence of 17-18% and 11-23% respectively (51, 52) and dementia and psychoses are overrepresented in older populations with epilepsy. Learning disabilities are more common in epilepsy than in the general population (53), and among children with epilepsy there is an overrepresentation of attention-deficit-hyperactivity disorder (ADHD) (54).

Comorbidities need acknowledgement since they cause a majority of deaths in epilepsy (52), can affect seizure outcomes and quality of life (55, 56). For example, reports indicate that persons with epilepsy and intellectual disability, which implies varying degrees of communication barriers, have poorer quality of life (57) and higher mortality rates among patients admitted to in-hospital care (58). Persons with intellectual disability may face additional challenges in the transition from pediatric to adult epilepsy care and in finding living conditions meeting their needs (57).

Consequently, successful outcomes in epilepsy not only depend on the assessments and treatment of the neurologist, but also upon comorbid medical conditions and the patients' social circumstances affecting communication and the possibilities to be involved in their epilepsy care. This thesis focuses on investigating social circumstances that influence outcomes in epilepsy.

2 OUTLINE

The outline of this thesis is as follows:

- **Social aspects of epilepsy** provide a background to the influence of stigma and SES in epilepsy. The first chapter presents the concept of stigma and how it applies to epilepsy. The second chapter describes how SES can influence population health and implications in the context of epilepsy.
- **Rationale**
- **Aims** of Paper I-IV
- **Methodological considerations** discuss the mixed study designs and strengths and limitations of Paper I-IV.
- **Results** from Paper I-IV.
- **Ethical considerations**
- **Discussion** summarizes and discusses the main findings of Paper I-IV in relation to existing literature in the field.
- **Conclusions**
- **Future directions**

3 SOCIAL ASPECTS OF EPILEPSY

3.1 STIGMA

3.1.1 Background

The word stigma derives from the Greek word “*stig*”, meaning “to prick” or “mark” (59). According to the American sociologist Erving Goffman, no attribute is stigmatizing in itself but it becomes stigmatizing when it deviates from our expectations in a certain time and cultural context (60). Goffman argued that persons with deviating attributes that are perceived as negative will either be *discredited* or *discreditable* depending on the visibility of the stigmatized attribute. This distinction matters in the social interaction with “normal people”, i.e. people without any stigmatized attributes. If “normal people” become aware of a stigmatized attribute, it will lead to categorizing of that person as one of a group of people carrying similar stigmatized attributes. There is a tendency to use the stigmatized category as an easily applied explanatory model for any negative events, difficulties experienced and unusual behaviors of the miscredited person, that would otherwise have been overlooked as coincidences or attributable to the situation and not the individual. Thereby, social interactions between discredited and “normal people” tend to become tense since everybody’s attention is drawn to the stigma. The miscredited person will in turn tend to interpret other peoples’ negative actions towards them as manifestations of an attitude towards their stigmatized attribute, i.e. perceived stigma.

Due to the advantages of passing as “normal” in the eyes of other persons, most persons who are *discreditable*, i.e., potentially miscredited if their stigmatized attribute is revealed, will often try to conceal their stigmatized attribute. As a result, information control becomes essential in all social interactions. This is problematic when trying to form deeper and more intimate relationships where people are expected to share hidden shortcomings about themselves. The stigmatized person may feel false or misleading when concealing the stigmatized attribute. If the information leaks out, there is a high risk that others will reject the individual as being someone who is not the person they thought they were.

The stigmatizing attribute tends to also apply to people associated with the individual. “Normal people” being together with a stigmatized person can feel that they are “contaminated” by the stigma, which may explain why people tend to avoid contacts or interrupt existing relationships with a stigmatized person. Thereby, social isolation can both be a strategy to perform information control to avoid discrimination and the discriminatory result of the stigmatized attribute.

3.1.2 Effects of social isolation

Social isolation imposes a stress that has been associated with poorer mental (61), and physical health, as well increased all-cause mortality (62). Historically, being included in a social group has been crucial for finding food and protection, for reproduction and survival (63). Signs of approval from people with high social status seem to activate reward systems in the brain such as dopamine firing in the midbrain (64). In contrast, social rejection seems to activate the same cortical brain areas as when we experience physical pain (65). Social isolation further seems to activate a craving for social interaction similar to the craving for food after fasting (66). Thereby, social interaction can be understood as a basic need, and social isolation as a state of deficiency with potential health consequences.



“Solitude” in watercolor by Malin Andersson.

3.1.3 Effects of stigma

By stigmatizing people with deviating attributes, “normal people” can gain power and resources, consolidate social norms, and maintain health. This can be achieved through exercising oppression, discrimination, by excluding people who do not correspond to the social norms and excluding people with unhealthy appearance (67). For the stigmatized persons, the stigmatization process includes several steps of being labelled, stereotyped, separated from others, and of losing social status (68). These are key elements of stigma that become significant in a disadvantaged power situation that allows them to unfold, for example in a situation of low SES (68). Scambler described felt stigma as feelings of shame and the fear and anticipation of negative treatment and discrimination and distinguished it from enacted stigma which is composed by actual experiences of negative treatment and discrimination (69). The discrimination can be direct (e.g. a person is denied employment because of epilepsy), more subtle (e.g. restricted career possibilities within a certain company because of epilepsy), or occur as an intrinsic form. The intrinsic form of stigma discrimination occurs when the stigmatized person perceives other people’s negative prejudices of them, starts doubting themselves and adjusts their behavior to avoid uncomfortable social interactions. The intrinsic stigma discrimination results in a reduced self-esteem, constricted social networks, social disadvantages, and impaired chances of career development, etc. (70). Thereby, stigma influences chances in life and contributes to social disparities in the population (71).

3.1.4 Stigma in epilepsy

In accordance with Goffman’s description of stigma (60), people with epilepsy often conceal their epilepsy to avoid being miscredited and exposed to enacted stigma (72). Epilepsy is a condition where seizures can be sudden and impossible to control and there is a constant risk of unintentional transformation from a *miscreditable* to a *miscredited* person. Epilepsy is surrounded by more stigma than many other chronic conditions. This can be related to several factors. For example, that the underlying reason for epilepsy can be difficult to understand, that seizures can be impossible to control, the disruptiveness of social interaction, unaesthetic appearance of seizures, other peoples’ perceptions of danger and if the affected person is held responsible

for developing epilepsy (73). In some cultures, the stigma of epilepsy can affect the life chances of whole families. It can lead to “courtesy stigma” where families keep their family member with epilepsy in and the epilepsy a secret (73). As long as people conceal their epilepsy to avoid enacted stigma, the extent to which people with epilepsy are really exposed to discrimination cannot be fully assessed (46).

There are two common approaches in research on epilepsy stigma: qualitative studies investigating the meaning of stigma and quantitative studies assessing the levels of experienced stigma and associated factors. Despite differences in study designs and cultural context, qualitative studies worldwide report certain features of stigma in epilepsy that seem essential. They include feelings of shame, being treated differently, and separated from others, being overlooked, not trusted the same responsibilities as others, being associated with a stereotype, being considered less intelligent and capable than others, and a desire for normalcy (74-79).

A wide range of factors have been reported being associated with higher levels of stigma in epilepsy, which can be divided into epilepsy-related, social factors, and psychosocial factors (80-91). Epilepsy-related factors that have been associated with higher levels of stigma include seizure type (tonic-clonic seizures) a higher frequency and severity of seizure, having seizures in public, a higher number of ASM and non-adherence to ASM (82-86, 89). Social factors that have been associated with higher levels of stigma include lower income, shorter education, poorer school performance, unemployment, driving inability, not being married, and younger age at epilepsy onset (82, 85-88, 90, 91).

Psychosocial factors such as a lack of social support, social isolation, and psychiatric comorbidities have also been associated with higher levels of stigma (85, 88). Concealing epilepsy increases the stress of controlling seizures and information about epilepsy, which has been described as the “hidden distress model” (92). The constant anticipation of negative reactions can create a state of constant vigilance, that can enhance anxiety and stressful reactions (91). This could explain why stigma has been associated with anxiety and depression in clinical studies of persons with epilepsy in both high- and low-income countries around the world (91, 93-97).

Otherwise, the extent to which persons with epilepsy report experiences of stigma and the associated factors differ in studies across countries and cultural contexts (80). Some argue that seizure frequency is the most consistent predictor of stigma across countries (98) while others have found that comorbid depression can be an even stronger predictor (99). The explanation to the varying study results could be differences in resources and knowledge, differences in cultural beliefs and values, and differences related to health-care traditions and systems (100), but also differences in study designs and methodology, for example the use of different scales to assess stigma.

Regardless, a key element in understanding stigma in a certain context is to acknowledge the possible complexity of intersecting stigma (101). Intersecting stigma means that several stigmatized attributes, related to health conditions and/or social characteristics like race, gender, social class sexual orientation etc., can present simultaneously within the same individual and change the meaning of stigma (102). For all stigmatized attributes there are drivers and facilitators that determine whether stigma occurs. The experiences and manifestations of intersecting stigma affect health outcomes through intermediate effects on justice and access to care on an individual level, and laws, media, and health care on an organizational level (102).

Knowledge about intersecting stigma in epilepsy is missing. In the context of obesity, persons with low SES have been found to be surrounded by fat phobia and desire for social distance to a greater extent than persons of high SES (103). In the context of epilepsy, foreign-born persons may simultaneously experience racial stigma (104) and people with comorbid psychiatric conditions can experience a double stigma related to that (105). The stigma surrounding psychiatric conditions also consist of stereotypes, status loss and discrimination. The double stigma can lead to a vicious circle where persons with epilepsy hide their symptoms of anxiety or depression to avoid being stigmatized further (105) and deteriorate health outcomes.

3.2 SOCIOECONOMIC STATUS

3.2.1 Background

Differences in SES cause health disparities in all populations (3). That is because people with high SES have access to resources such as knowledge, money power, prestige and social connections that minimize the risk of disease and the consequences of disease once it occurs (106). Higher SES provides flexible resources that can be used in any context and time. Therefore, health disparities persist and accumulate over the life course (107). SES has an influence on all the conditions where people are born, grow up, live, and work, that contribute to health or disease in a population (106). It includes our living environment, social networks, lifestyle, and health literacy. Health literacy is particularly important for making conscious health promoting decisions, both in everyday life and in a clinical health care setting, and to access health care (5). Health literacy is closely related to educational attainment, but also to cognitive skills and knowledge of specific medical conditions (108).

A pronounced stratification of income has been associated with mortality in a population regardless of the actual income levels within that population (109). In high-income countries with little income stratification like Sweden, mortality inequality is more related to wealth than income (110). Unemployment is associated with poorer health outcomes compared with employment, but the qualification of the employment matters too. There is an inverse relationship between mortality risk and occupational grade (111). Low SES occupations are more commonly insecure, associated with high work strain, low personal control, exposure to environmental hazards, poor nutrition, and chronic stress. Exposure to such factors increases the risk of chronic diseases through intermediate mechanisms like elevated cholesterol levels and poorer glucose control etc. (107).

3.2.2 SES in epilepsy

Globally there is a greater burden of epilepsy in low-income countries (112-114) and in low-income populations within high-income countries (115-118). The prevalence of epilepsy in American low-income households was found to be 1.9% compared to 1.0% in the general population (119).

Persons with epilepsy have lower educational level compared to the general population (120). Recurrent seizures in childhood have been associated with a decline in academic performance (121) and poorer social skills (122). Epilepsy presenting in childhood can also decrease the likeliness to complete higher studies (123). Income levels are lower among persons with epilepsy compared to the general population (120). Adults with epilepsy in the USA more often have difficulties affording medication, and transportation to medical appointments than those without epilepsy (124).

Persons with epilepsy are more commonly unemployed and more often have low skilled manual jobs than the general population (125). Epilepsy can prevent people from getting the job of their choice, and uncontrolled seizures can cause sick-leave or work disability (126). However, a review of employment rates among persons with epilepsy found no differences among persons with controlled and uncontrolled seizures (127) indicating that there are other important factors. Persons with epilepsy may face restricted career possibilities, unnecessary work restrictions, and stigma at the workplace (128). Those with low-skilled jobs are more likely to be exposed to professional disadvantages, and be dismissed from work because of their epilepsy (129).

Because of this socioeconomic vulnerability, persons with epilepsy may be more exposed in times of economic recession. A large-scale American study found a significant increase in suicide rates among persons with epilepsy in 2010 compared with the general population and speculated whether that could be a consequence of the economic crisis in 2008 (130). The corona virus disease 2019 (COVID-19) lead to a transition to telemedicine (up to approximately 40% of all consultations for epilepsy) (131) that implied barriers to epilepsy health care. The health care barriers such as costs of technical device, unreliable access to the Internet in remote living areas, or patients not being up to date with technical device may have affected persons of low SES to a greater extent (131).

3.2.3 SES, severity of epilepsy and access to care

Low SES has been associated with non-adherence to medication (120) and there are indications that persons with epilepsy of low SES generally suffer from a more severe epilepsy, with a higher frequency of uncontrolled seizures and hospitalizations because of epilepsy (132, 133). Social deprivation of the residence area has been associated with more emergency department visits (134, 135), higher mortality in epilepsy (136) and SUDEP (137). Poor health literacy, closely related to low SES, has been correlated with increased seizure frequency and mortality in epilepsy (138).

At the same time, low SES has been associated with poorer access to specialized epilepsy care. A reduced proportion of patients residing in low-income residential areas receive care from an epilepsy specialist or neurologist (139). Persons with low SES have been found to have their ASM prescribed by a neurologist to a lesser extent, less frequently undergo epilepsy surgery and wait longer for epilepsy surgery compared with persons of higher SES (140-143). A national cohort-study of adult epilepsy patients in Sweden found that higher education, income, and residence in large cities was associated with a higher proportion of patients who received care from a neurologist (141).

Racial and ethnic minorities with epilepsy are acknowledged to constitute a socioeconomic vulnerable group of patients in the USA (144), with reports of more severe epilepsy compared to non-minorities (145, 146). Black people with epilepsy were also found to be less likely to see a neurologist than their white counterparts (147, 148). In Sweden, there is no tradition of categorizing people into races. Foreign-born persons statistically have lower SES and have reported poorer health than the native-born population (149). First-generation immigrants face social challenges through the disruption of social, private and professional networks and loss of contextual factors (150) and also face barriers to access health care (151). Therefore, foreign-born persons with epilepsy can be considered to form a particularly vulnerable group of patients.

4 RATIONALE

In the heterogeneous group of persons with epilepsy, successful treatment outcomes rely on health care as well as individual medical and social factors. There is evidence that social factors such as SES, country of birth and stigma influence outcomes in epilepsy and that this influence differs across countries. However, knowledge of the implications of SES and stigma in epilepsy in Sweden is not updated or missing.

A national cohort study of adults with epilepsy found SES disparities in access to epilepsy care in Sweden between 1998 and 2005 (141). No similar study has been performed since. In addition, knowledge of how different socioeconomic outcomes interrelate in epilepsy compared to the general population is missing. This knowledge is important to improve understanding of possible “protective” factors for socioeconomic outcomes among persons with epilepsy.

While there is a growing literature on the meaning of epilepsy stigma from globally different settings, there is a lack of knowledge of the meaning of epilepsy stigma in Sweden and it has not been investigated among foreign-born persons with epilepsy. Improved understanding of epilepsy stigma and associated factors in Sweden, especially among vulnerable persons with epilepsy such as persons with low SES or foreign-born persons, is crucial for knowing how to adapt and improve their support in epilepsy care. This knowledge is needed for designing efficient and meaningful interventions aiming to increase support and reduce the stigma for vulnerable persons with epilepsy in the future.

5 AIM

The overall aim of this thesis is to investigate the influence of stigma and SES in epilepsy and access to epilepsy care. The specific aims for each separate studies included in the thesis are:

- I. To investigate socioeconomic correlations with access to specialized epilepsy care and other socioeconomic outcomes in epilepsy.
- II. To investigate the correlation between perceived stigma and country of birth, SES, and mental health in adults with epilepsy in Sweden.
- III. To investigate the meaning of stigma among immigrants with epilepsy in Sweden.
- IV. To explore the effects of social factors on epilepsy care from the double perspective of persons with epilepsy and their care providers and provide knowledge for the development of future interventions to meet the social disparities that exist in epilepsy.

6 METHODOLOGICAL CONSIDERATIONS

Mixed methods research designs have become more frequent in medical research as it offers powerful tools to investigate complex processes in health and health care (152). This thesis is founded on a compound of four studies with different methodological designs, strengths, and limitations. An overview of the applied methods is described in Table 1. For practical and detailed descriptions of the different methods that were applied, please see each attached manuscript (Paper I-IV). This chapter will focus on broader aspects of the applied study designs and separately discuss the strengths and limitations for Paper I-IV.

Table 1. Description of the methods applied in Paper I-IV.

	Design	Data	n=	Analysis
I	Retrospective cohort study	National registers	126 406	Statistical
II	Cross-sectional cohort study	Questionnaires	161	Statistical
III	Qualitative	Individual interviews	25	Hermeneutic analysis
IV	Qualitative	Focus group interviews, correspondence	21	Qualitative content analysis

6.1 Paper I

The first study is a retrospective national cohort study based on data from Swedish quality registers (Table 2).

Table 2. Registers included in Paper I.

Register	Register holder	Extracted data
National Patient register (NPR)	National Board of Health and Welfare	Diagnoses from in-hospital and specialized out-hospital epilepsy care
Swedish cause of death register	National Board of Health and Welfare	Registered deaths
Swedish prescribed drug register	National Board of Health and Welfare	Prescribed ASM
Swedish national epilepsy surgery register	Swedish Neuro registries, Anna Edelvik Tranberg	Admission to epilepsy surgery
Integrated database for labor market research (LISA)	Statistics Sweden, Population and Welfare Department	Income, educational level, employment status, marital and civil status

National registers

National registers offer unique possibilities to conduct clinical research. The registers are enabled by the Swedish system of assigning a unique 12-digit personal identification number (PIN) to all citizens. The PIN is used by most public and private sectors in the Swedish society for identification, registration, and documentation of individual data, not least in health care.

The National Patient Register (NPR) is held by the National Board of Health and Welfare and aims to provide statistics for analyzing health development in the population, improve prevention and treatment of diseases, and evaluate and contribute to the development of health care in Sweden. It contains information of all cases of in-patient care since 1964, with full coverage since 1987, and information of specialized out-patient care since 2001. Information of primary health care is not included (153), which results in a low sensitivity for diagnoses in the NPR of medical conditions that are primarily being followed there (154). The NPR is often linked and combined with other national registers for research purposes.

All medical dispensations from Swedish pharmacies that require valid prescriptions for being purchased are automatically reported to the Swedish eHealth Agency and registered in the Swedish Prescribed Drug register (155). The Swedish cause of death register contains data of causes of death and is based on the information from medical death certificates issued by licensed physicians (156). The Swedish national epilepsy surgery register provides population-based data of admission to and outcomes of epilepsy surgery (157).

Information of SES was retrieved from the Integrated database for labor market research (LISA) (158). LISA was launched in the 1960's as a national response to the rising numbers of sick leave in the Swedish population. The database links data from data sources such as the Swedish Social Insurance system, the Swedish public employment service and the Swedish Education register (159). Most medical researchers use LISA to retrieve information about education, sick leave, and unemployment.

Definition of epilepsy

To define epilepsy, we used the recommended definition by the ILAE Commission on Epidemiology report (160) as a single ICD-10 code of G.40 in the NPR. The same definition of epilepsy was also applied in Paper II-IV.

Measuring SES

SES is a compound of different interrelated factors and different factors may be more or less accurate measures of SES in different settings. In countries with a pronounced income stratification, income may be an important SES measure, since income-stratification is associated with higher mortality in the population regardless of the actual income levels (109). In the Swedish population, mortality inequality has been more closely associated with wealth than income (110), but data of wealth is difficult to retrieve. Since Sweden is a welfare country with little income stratification compared with many other countries, education may be a more important SES measure than income or wealth.

When assessing SES through employment status, the qualification of the employment matters too. There is an inverse relationship between mortality risk and occupational grade (111) and low SES employments are more often associated with poor working conditions such as high work strain, low control, exposure to toxic substances, and chronic stress (3). Detailed information of occupational grade is however not available in national registers.

Foreign-born persons who have immigrated to Sweden are included in the national registers as soon as they become citizens and receive a PIN. It is however not possible to retrieve data of country of origin for immigrated persons since registration of ethnic origin is illegal in Sweden (161). People registered as immigrated in LISA in one county can either have immigrated from abroad or moved from another county within Sweden.

Strengths and limitations

Since reporting to the national registers is mandatory, there is a high coverage reliability of the included registers. Using national registers offers opportunities to study large cohorts, in this study it was possible to include the national population of adult persons with epilepsy. The fact that the register data is collected nationwide and without regard to the purpose of any specific research study has the limitation that the data may not always be adequate for a specific study, however it also decreases the risk of selection bias. This is a strength in this study because it reduces the risk of excluding patients of underserved groups that are otherwise commonly overlooked or difficult to include in research studies. Like all register-based studies, there is a risk of reporting bias. For example, acute symptomatic seizures could have been misdiagnosed as epilepsy in the NPR. We did however not include cases with single seizures (ICD-code R56.8X) in the study.

6.2 Paper II

This cross-sectional cohort study aimed to investigate levels of self-reported stigma and associations with SES, country of birth and mental health. The study is based on self-report questionnaires with background questions and validated scales.

In a chronic condition like epilepsy, without disease modifying medical treatment and where health care ultimately aims to improve patients' quality of life, there is a need for reliable patient-reported outcome measures (PROMs). PROMs are designed to measure patient symptoms, functioning and quality of life in order to assess the effects of a medical condition and the health care provision, both in clinical settings and research studies (162).

The quality of a certain PROM can be assessed through different criteria. Recommended quality criteria include content validity, internal consistency, reproducibility and floor and ceiling effects (163). Content validity assesses how well the items in a scale measure the concept they are intended to measure. Assessing the content validity can be facilitated by clear descriptions of the measurement aim, target population, the concept measured, and how the items were selected. Internal consistency is the extent to which theoretically related items in a scale co-vary indicating that they measure the same concept. Internal consistency can be calculated with Cronbach's alpha. A high Cronbach's alpha indicates a strong relationship between the items and a value of 0.70-0.90 has been suggested as criterion of good internal consistency (163). Reproducibility concerns the consistency of results in repeated measurements in individuals with a stable condition and can be measured by repeated testing in the form of a test-retest. Floor or ceiling effects are present if more than 15% of participants score the lowest or highest value of a scale. This may indicate that the scale is inadequate for accurate measurement of the population at the extreme ends of the scale (163).

As a standard outcome measure for stigma in Paper II we applied the Neuro-QoL stigma short form. Neuro-QoL is a PROM originally developed by the American National Institute of neurological disorders and stroke (NINDS) to assess health-related outcomes in bilingual (Spanish/English) adult and pediatric populations in the USA (164). Neuro-QoL focuses on neurological conditions and has been validated in both adult (165) and pediatric (166)

cohorts with epilepsy in the USA. The internal consistency has been calculated to 0.86-0.96 and the test-retest range to 0.57-0.89 (165). The questions in the Neuro-QoL stigma short form are concept specific but not specifically related to epilepsy. Therefore, we also applied the Jacoby stigma scale (JSS) with three items that are specifically related to epilepsy. The JSS was initially developed for a stroke cohort and adapted and validated for epilepsy in the 1990's in a British population with epilepsy in remission (46) and has thereafter been commonly used to assess stigma in epilepsy (99, 167-169).

To assess mental health, we applied the long and frequently used hospital anxiety and depression scale (HADS) and the newer Patient-Reported Outcome Measurement Information System (PROMIS) Global Health form v1.2. HADS is a 14- item questionnaire developed to detect symptoms of anxiety (seven items) and depression (seven items) in a patient population without previously established psychiatric conditions (170, 171). PROMIS questionnaires and the associated assessment center are the development of an initiative of several universities in the USA supported by a grant from the American National Institutes of Health. The aim of this initiative was to create a standardized and validated set of item banks to measure patient-reported outcomes and evaluate and compare health care provision (172). The PROMIS system contains PROMs for physical, mental, and social health, in alignment with the WHO definition of health (4). The development of a certain PROM within PROMIS follows a series of systematic steps. A specific domain of interest is chosen, and qualitative measures are used to generate items to measure this domain. When a pool of items is created, the items are calibrated using item response theory (IRT) through large field tests. A scoring system is developed as a norm for the general population in the USA, using t-score metrics where 50 is the mean value with 10 as the standard deviation (162). PROMIS scales are specific to certain domains, but not specific diseases.

Strengths and limitations

Using scales (Neuro-QoL, PROMIS) that have been developed with mixed methods and validated in large field tests increases the reliability and validity of the scales. Recruiting patients from three neurology out-patient departments, including a regional and suburban daycare hospital, allowed inclusion of patients who are rarely included in research studies compared with patients at university hospitals. Although patients can be referred to a certain hospital

regardless of their residential area within the Region, most patients reside in the same area as the hospital that they attend. The cohort can thereby be considered to reflect areas with different sociodemographic characteristics: a large city, a socioeconomic deprived suburb to a large city, and small town/rural areas.

The provision of questionnaires in both Swedish, English and Arabic, which has been acknowledged as the most frequently spoken minority language in Sweden (173), allowed participation of persons from immigrant populations. Translation of the questionnaires into more languages may have increased the diversity of the sample but this was not possible due to a lack of time and resources.

In order to minimize the burden on the participants and increase the frequency of response some background questions addressing comorbidities or other characteristics known to be important in relation to stigma, such as physical disabilities, sexual orientation, and transmittable diseases (102) could not be included. This however creates a limitation in that we cannot know for sure, when applying domain-specific scales, whether the results reflect stigma related to epilepsy or to other stigmatized factors that were not accounted for in the study. We did apply a disease-specific stigma scale (JSS) in addition to the domain-specific stigma scale (Neuro-QoL). For both scales the reported levels of stigma skewed to the bottom end, indicating strong floor effects and raising questions of the usefulness of these scales to capture the whole range of stigma symptoms within the Swedish context. Decades have passed by since the development of the JSS, and it is possible that persons with epilepsy as well as people in general experience less stigma today. It is also possible that scales including questions of a potentially sensitive nature like experiences of stigma lead to an increase in missing data and a decrease in recruitment. It should also be noted that the COVID-19 pandemic contributed to the recruitment challenge of this study.

Another limitation of the study concerns the impossibility to conduct a drop-out analysis. It is, therefore, not possible to determine whether our cohort is representative of the population, and this limits the generalizability of the results.

6.3 Paper III

This qualitative study aimed to investigate the meaning of stigma among foreign-born persons with epilepsy. The study is based on 25 individual face-to-face interviews with foreign-born adults with epilepsy attending a neurology out-patient department in a socially deprived neighborhood. The interviews started by informing the participants about the purpose of the study and what the interview would be about (i.e. experiences of living with epilepsy). Open-ended questions were used, for example: “-How did your life change after you had your first seizure? How did you experience that? What did that mean to you? Please explain”. Interviews proceeded until data was considered rich in content and no new information was forthcoming. Recruitment to the interviews proceeded until new interviews repeated what had appeared in the former interviews and data collection was considered to be saturated.

To gain knowledge of what stigmatization means to foreign-born persons with epilepsy, we applied a Gadamerian inspired hermeneutic approach (174) in the analysis of Paper III. A hermeneutic approach is appropriate to apply when the analysis aims to increase knowledge and a deeper understanding of the text’s underlying meaning.

Gadamer did not provide a practical method for understanding, he aimed to clarify the conditions for the process of understanding. A fundamental idea in hermeneutic interpretation is that understanding emerges first when the meaning of the whole text resonates in the meaning of the details. Thereby, hermeneutic interpretation is characterized by a constant movement from parts of the text to the text as a whole. This movement is often referred to as the “hermeneutic circle” (174).

Preunderstandings

Gadamer stated that all persons interpret new information through their preunderstandings. Preunderstandings are formed by our previous experiences and knowledge, and no interpretation is possible without it. Through the confrontation of what we perceive as familiar and what is new to us, we gain knowledge and move the horizons for what we understand further away. Consequently, our preunderstandings are transformed, and new questions can arise (174).

Disclosing preunderstandings is meaningful to provide transparency of the perspective from which data has been interpreted, and necessary to increase credibility of the researcher (175). During the time of my PhD- studies, my preunderstanding of stigma and of persons with epilepsy has changed, from scarce theoretical knowledge and no clinical experience of epilepsy to a resident physician in neurology who is beginning to collect clinical experience of meeting and treating persons with epilepsy. Throughout the performance of Paper III, I gained new insights into epilepsy related stigma from each interview, which contributed to a changed understanding of the subject. However, it is necessary to recognize that it is never possible to fully “put oneself in another person’s shoes”, due to each person’s unique experiences.

Strengths and limitations

A strength of this study has been finding reoccurring themes despite the great heterogeneity of the cohort, indicating that some aspects of stigma can be experienced by anyone in this context (epilepsy and immigration). Meanwhile, it is important to acknowledge that this study investigated individual experiences which are not representative of whole populations, neither when it comes to epilepsy stigma nor when it comes to experiences of immigration. The transferability of the findings should be questioned and performed with careful consideration to the specific context where the interviews were performed.

When interviewing persons with other mother tongues than Swedish or when using the assistance of an interpreter, there is always a risk of misunderstanding and misinterpretation due to language barriers. The interviewer tried to avoid misunderstandings by facilitating communication as far as possible by not using complex language and by confirming the participants answers through repeating and rephrasing. Despite these efforts it should be acknowledged that language barriers were still evident.

Another limitation of this study is the lack of information of the reason for immigration. Although the interviews indicated that most had arrived as refugees, formally collecting this information would have been meaningful since stigma and experiences of immigration are likely to change if participants arrived as refugees or immigrated for career opportunities. This distinction

matters since refugees and persons immigrating for other reasons may have different socioeconomic and psychosocial vulnerability.

6.4 Paper IV

Focus-group interviews offer opportunities to produce knowledge and find solutions where the discussions and interaction between participants have synergetic effects. Compared to individual interviews, focus-group interviews shift the focus away from the interviewer and put the participants' interaction with each other as the main source of new information. While focus-groups may be less appropriate when aiming to investigate phenomenon of a sensitive nature, they are a useful method to increase and gather knowledge of provision of care for future interventions (176). In this study, we conducted focus-group interviews with adults with epilepsy and health professionals working with epilepsy care. Focus-group interviews with two or three people in the patient sample were considered to be acceptable both given the difficulty securing participation and that it would be more effective given the complexity of the topic (177). Small groups would also maintain the fundamental characteristic of a focus group by providing interactive discussions (178). The transcribed text from the interviews was analyzed step-by-step with qualitative content analysis with an inductive approach and focusing on the manifest content, as it has been described by Elo and Kyngäs (179).

Strengths and limitations

The focus-groups with health professionals were conducted first and due to the ongoing COVID-19 pandemic at the time, the interviews were held via Zoom. Although participants were experienced in using Zoom for digital medical appointments during the pandemic, the virtual format may have deteriorated the interaction between participants in the focus-groups. On the other hand, in contrast to the patient groups, the participating health professionals knew each other which is likely to have facilitated the group discussion. A transition to online focus groups was important to ensure continuous research during the pandemic (180). The patient focus-groups were performed later and could be conducted face-to-face in a separate room at each respective site.

To improve the chances of providing valuable knowledge that can be used in future clinical interventions it was important to involve patients and health care professionals in the whole process (181). By conducting focus-group interviews with patients and health professionals, the double perspective on epilepsy care could be investigated. Another strength was the enrollment of

participants from neurology out-patient clinics with different demographical characteristics, resources, and structure in organization of care.

We aimed to include patients with different ages, backgrounds, and SES. Five to seven patients had accepted participation prior to each focus-group interview. A reminder of the interview was sent via email a few days prior to the interview. Despite this only two to four patients participated in each focus-group interview, and of these, none were foreign-born. The cohort of participating patients was not representative of socially vulnerable persons with epilepsy but the participation of health care professionals treating all patients with epilepsy provided a broader perspective. Due to the small sample size, the results cannot be judged representative of all persons with epilepsy or health professionals working with epilepsy.

6.5 Trustworthiness and validity in qualitative research

Trustworthiness refers to different factors that can improve the quality in qualitative research and include credibility, dependability, confirmability and transferability (182). The credibility refers to the degree the applied method is appropriate to investigate the specific research question. Dependability refers to the circumstances where the study has been conducted and the stability of data over time and underscores the importance of transparency of the conditions where the study was conducted. Confirmability describes to what extent the findings can be considered “neutral” and not overshadowed by the researcher’s own prejudices. The transferability refers to the extent the findings can be valid in other contexts outside the context where the study was performed. Considering these factors, and clarifying the circumstances of the researcher, of the conditions where the research studies were conducted and providing a detailed description of the process of analysis can thereby improve the quality of qualitative research.

Triangulation

To reduce the subjectivity and bring nuance and dimension to the interpretation, triangulation can be a useful tool in qualitative analysis. Observer triangulation means that more than one author separately conducts the analysis (183). Thereafter, they meet to discuss the findings and agree on a consensus. The aim is not that every researcher reproduces the exact same

results, but to search for knowledge of different nature. Still the triangulation with the searching for contradictions and rival explanations can be considered as part of a validation. In both Paper III and IV, the analyses were mainly performed by the doctoral student, but a certain degree of observer triangulation was performed together with the main tutor (AO) who had also read the interviews, participated in discussions, and agreed on a consensus.

Reflexivity

Reflexivity is important to avoid that the researcher bias, i.e. the researcher's prejudice and expectations of the results, overshadow and prevent new findings in qualitative research. Reflexivity is an approach where the researcher actively confronts with his-or her own prejudices and remains capable of questioning and doubting his- or her own interpretations. Eliminating researcher bias on the interpretation in qualitative analyses is not possible. Instead, a reflexive approach and considering how the researcher's influence has influenced the interpretation should be maintained to produce new knowledge (183).

It is also important to acknowledge how the circumstances and characteristics of the researcher may have influenced the data collection. In Paper III, the interviewer (me) was a white, native-born women and physician (although not involved in the care of the participant patients) and the interviews were held in a separate room at the same neurology department where the participants received epilepsy care. It is possible that these circumstances might have influenced the participants to express more loyalty and that they would have shared different experiences together with a person who were foreign-born like them. On the other hand, being interviewed by a person with the same cultural background could have reminded participants of the misconceptions about epilepsy in their home country and prevented them from sharing their experiences (It appeared in Paper III that some participants did not want interpreters with the same cultural background for this reason).

All participants in Paper III spoke another mother tongue than Swedish. To avoid misunderstanding and misinterpretation, the interviewer repeated participants' answers throughout the interviews, like "-If I understood you correctly, what you mean is that...". This repetition and confirmation was also applied during the focus group interviews for Paper IV. In Paper IV, the participants were given the opportunity to correct, adjust or complement their

answers by being sent a written summary of the results by mail. The comments that were sent back from participants were acknowledged and led to editing of the results.

7 ETHICAL CONSIDERATIONS

All studies obtained ethical approval from different Regional Ethics boards in Sweden (839-16, 464-18, 2020-00328 and 2021-04041). In Paper I, all data from national registers was cross-referenced and anonymized before we were given access to them. The process of planning and performing study II-IV was guided by the Declaration of Helsinki (184). The health of patients shall always be a physician's first consideration, in health care as well as when patients participate in research studies, especially when involving vulnerable persons like foreign-born and/or persons with low SES. Careful consideration was made to ensure safety and confidentiality of all participants.

All participants received oral and written information about the voluntary basis of participation. The risk remains that patients attending a certain neurology department or health professionals felt obliged to participate since the person asking for participation was one of their health providers or colleagues. All participants were informed that their decision to participate or not would not in any way interfere with or influence their care and support for their epilepsy or their employment at the clinic. All participants were informed that all information they gave in interviews or questionnaires was confidential also vis-à-vis their health providers or other colleagues and were reminded of this confidentiality in the beginning of each interview.

There is always a risk that questions about epilepsy and stigma can provoke negative feelings for persons living with epilepsy. To safeguard the wellbeing of the patients, all patient participants received information of the possibility to receive psychological support by health professionals and received written contact information to the principal investigator if they needed this support following participation. Careful attention was paid to any signs of distress. There was professional support available on site, but this did not become necessary. Questionnaires, digital files with the transcribed interviews and written informed consent forms were stored in a locked drawer in a locked room at the Institute of Health and Care Sciences. To ensure confidentiality of participants in online focus interviews, they were not recorded in the Zoom software but on a separate voice recording device. All voice recordings were deleted after transcription. Careful considerations were made in the manuscript writing not to present information that could reveal the identity of participants.

8 RESULTS

8.1 PAPER I

In Paper I, socioeconomic correlations with access to specialized care was investigated in national registers. During the years 2000-2015, the Swedish adult population with epilepsy consisted of 126 406 cases. Three age-, gender- and community-matched controls were selected per case, resulting in a total of 379 131 healthy controls. The mean age for the total cohort was 63.1 years (\pm 21.9) and 52.9% were male. Compared with the controls, the cases with epilepsy had a higher prevalence of comorbidities like brain tumor (8.0% vs. 0.4%), cerebrovascular disease (17.9% vs. 1.9%), intellectual disability (2.7% vs. 0.1%), psychiatric comorbidities (14.8% vs. 7.6%) and dementia (2.9% vs. 1.2%).

8.1.1 Severity of epilepsy

The number of hospitalizations due to epilepsy and the number of prescribed ASMs were assessed as indicators of severity of epilepsy. A larger proportion of persons in the lowest income level were hospitalized one or more times because of epilepsy compared with persons in the highest income level (6.8% vs. 2.6%, $p < 0.001$) and a similar difference was observed across education levels (Figure 1A and 1B). It was significantly more common to be prescribed ASM in polytherapy (two or more ASM) in the lowest income group compared with the highest (49.5% vs. 26.2%, $p < 0.001$). This difference was similar but less pronounced in the comparison of the lowest and highest educational groups (42.7% compared to 33.7%, $p < 0.001$).

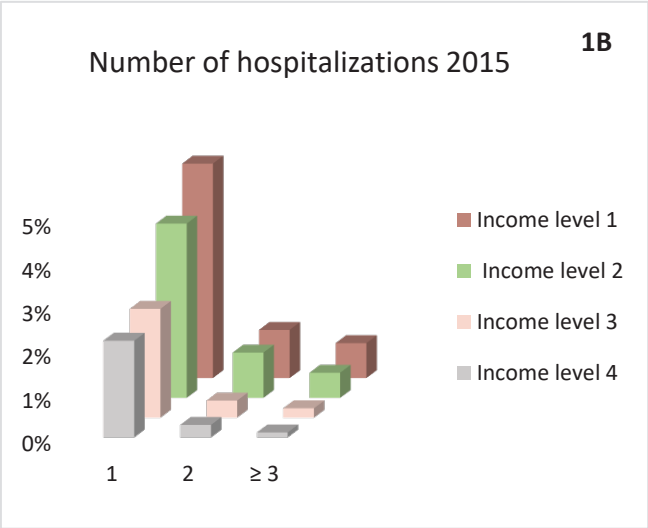
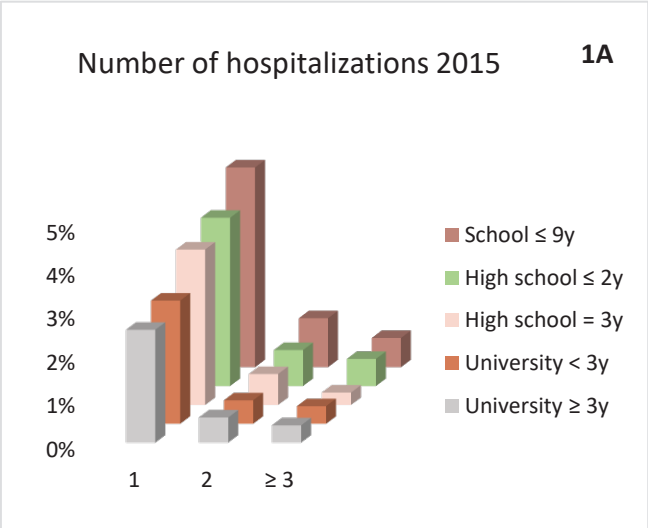


Figure 1. Severity of epilepsy assessed by hospitalizations because of epilepsy in the year 2015 in relation to income (1A) and education (1B). Mantel-Haenszel, $p<0.001$ (1A and 1B).

8.1.2 Access to specialized epilepsy care

People of working age with a registered diagnosis of epilepsy within the last five years, who did not have a registered diagnosis of intellectual disability were included in the analysis (n=31036). In the highest educational level 91.2% had an ASM prescription from a neurologist compared with 78.3% in the lowest educational level ($p<0.001$). A similar difference was seen across income levels (Figure 2A and 2B). There was no significant difference in representation in the Swedish national surgery register across educational levels (1.5% across all educational levels), but it was twice as common in the lowest compared with the highest income level (2.1% versus 1.0%, $p<0.001$).

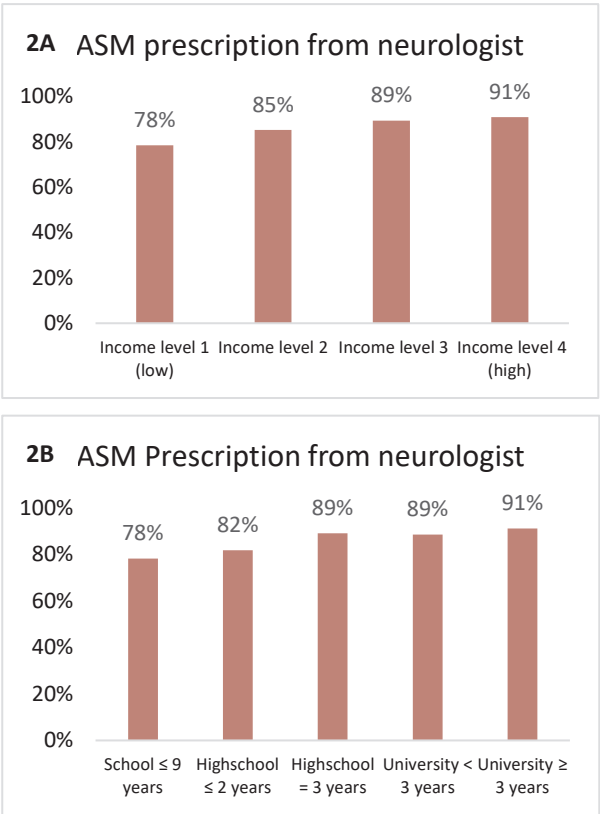


Figure 2. Access to specialized epilepsy care assessed through prescriptions of ASM from neurologist in relation to income (2A) and education (2B). Mantel-Haenszel, $p<0.001$ (2A and 2B).

8.1.3 Socioeconomic outcomes

The interaction effect of educational level with employment status and with low income was also investigated, comparing cases with epilepsy and controls. Low income was defined as having a yearly income below the median income level of the controls. Unemployment and low income were more common among cases than controls and in the lowest educational level compared with the highest. However, the difference between cases and controls was significantly reduced (interaction effect, $p < 0.001$) with higher educational level, both for employment and low income (Figure 3A and 3B).

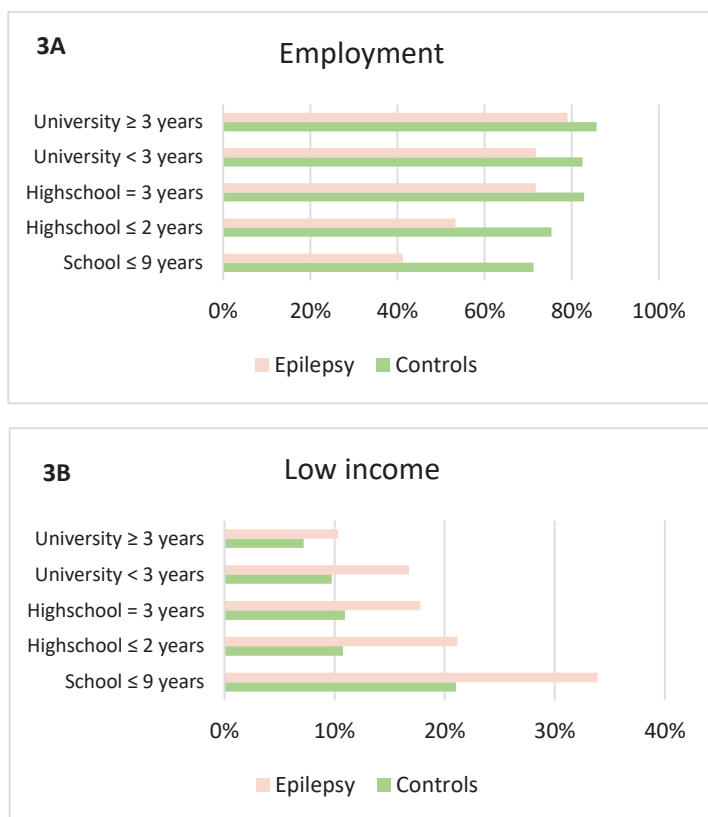


Figure 3. Unemployment and low income in relation to educational attainment in cases and controls. Interaction effect, $p < 0.001$ (3A and 3B).

8.2 PAPER II

Paper II investigated the levels of self-reported stigma and associated factors among native- and foreign-born adults with epilepsy. A total of 161 adults with epilepsy were included in the cohort, of which 56.5% were women, 28.0% had some level of College or University education, 45.3% were working either full or part time and 71.4% were born in Sweden. 54.7% reported having had one or more seizures in the past year and 58% reported tonic-clonic seizures as their predominant seizure type.

8.2.1 Levels of assessed stigma

The Neuro-QoL stigma scale was applied as the main outcome measure for stigma. The median Neuro-QoL stigma score was 48.3 points in the total cohort and the distribution was skewed towards the lowest end of the scale (Figure 4).

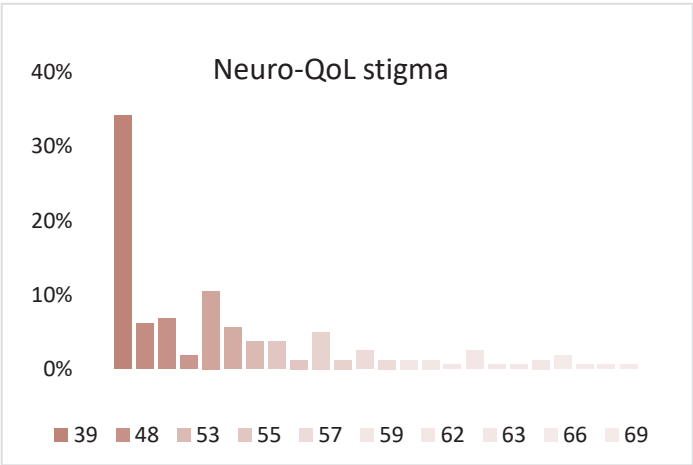


Figure 4. Distribution of reported Neuro-QoL stigma score.

8.2.2 Factors associated with higher levels of stigma

Foreign-born participants reported a significantly higher stigma score compared to native born participants, and especially participants born in countries outside of Europe (mean stigma score for native-born: 47.0, foreign-born in Europe: 49.8 and foreign-born outside of Europe: 52.3, $p=0.003$) No significant difference in reported stigma scores were found in different age-sex- educational and occupational groups. Participants who had experienced seizures during the last year reported a higher stigma score than those who had not (mean stigma scores for 0 seizures: 44.0, 1 seizure: 50.9 and 2 or more seizures: 52.4, $p<0.001$). Public seizures were associated with a higher stigma score (public seizures: 50.9, no public seizures: 44.7, $p= 0.035$). A higher stigma score was associated with reporting a more severe and disabling epilepsy (GASE > 5 points, GADS >5 points), poorer mental health (PROMIS Mental Health score <40 points) and more symptoms of anxiety (HADS anxiety ≥ 11 points, and depression (HADS depression ≥ 11 points).

All factors associated with higher stigma scores at the 0.05 significance level were included in a multiple regression analysis. The only factors that remained significant to explain a variation in Neuro-QoL stigma score were PROMIS Mental Health, HADS anxiety and the number of seizures last year (Table 3).

Table 3. Variables explaining variation in Neuro-QoL stigma score. Stepwise Multiple regression.

	Constant (95% CI)	p-value	R-square	p-value
Model 1			0.31	<0.01
HADS anxiety	0.89(0.67-1.11)	<0.01		
Model 2			0.43	<0.01
HADS anxiety	0.71(0.50-0.91)	<0.01		
Seizures last year	6.06(3.96-8.15)	<0.01		
Model 3			0.47	<0.01
HADS anxiety	0.43(0.15-0.70)	<0.01		
Seizures last year	5.89(3.85-7.92)	<0.01		
PROMIS Mental Health	-0.21((-0.35)-(-0.07))	<0.01		

Variables entered in the equation: seizures in the past year, public seizures, country of birth, GASE, GADS, HADS depression, HADS anxiety, PROMIS Mental Health.

8.3 PAPER III

Paper III investigated the meaning of stigma among foreign- born persons with epilepsy through individual face-to-face interviews. The cohort included 25 foreign-born adults with epilepsy of which 15 were female. Participants originated from 18 different countries of which most were low-income countries in Africa or in the Middle East. The average time they had lived in Sweden was 10.2 years and the average age at the time for immigration was 24.3 years. Tonic-clonic seizures were reported by 88% as their predominant seizure type.

The meaning of stigma in this context is summarized by the main theme “a fight to be appreciated as a person and member of society” and by the themes and subthemes presented in Table 4 and in the text below.

Table 4. “A fight to be appreciated as a person and member of society” illustrated through themes and subthemes

Struggling with a negative self-image	Searching for strategies to build self-confidence
Feeling shame and guilt	Seeking social support
Feeling unvalued	Informing others
Being weak and less capable	Concealing the epilepsy
Being the strange and crazy one	Finding and maintaining employment
Distancing oneself from the stereotype	

8.3.1. Struggling with a negative self-image

The participants struggled with a negative self-image, both related to having epilepsy and to being an immigrant and living in a socially deprived neighborhood. Epilepsy was considered a ‘bad disease’ in some of the participants’ home countries and associated with strong feelings of shame. Shame could be related to the label of epilepsy and to seizure related symptoms. The shame could affect the whole family, making the person with epilepsy feel guilty.

Actual experiences of broken engagements, divorce, or discrimination at work due to epilepsy, or anticipated fear of such events was reported as the cause of feelings of being unvalued by other persons. Those who lived in a socially deprived neighborhood described how being separated from people in other neighborhoods also made them feel unvalued by the society.

Some participants described difficult experiences of the migration process and from the home country of war, poverty, homelessness etc. Being confronted with having epilepsy in addition to this vulnerability made participants struggle with a self-image of being weak and less capable than others. Other people contributed to this feeling by not trusting them with responsibilities because of their epilepsy. To be treated differently because of epilepsy seemed to signal to the participants that they were strange. Some had been considered as crazy in their home countries because of their epilepsy. Fear of being seen as strange or crazy could also relate to having culturally different customs compared to native-born Swedes. Mental health problems were told being surrounded by misconceptions of being crazy in some of the participants home countries. Therefore, some participants chose to conceal their symptoms of depression or avoided meeting with the psychologist to avoid being considered crazy by other people.

Participants distanced themselves from the description of their seizures and the stereotyped image of a person with tonic-clonic seizures, since they felt that it did not reflect who they really were as persons. Some participants further expressed a fear of being associated with a stereotyped image of an immigrant, terrorists, or Islamic extremists and of being discriminated against in health care due to their foreign origin.

8.3.2 Searching for strategies to build self-confidence

To avoid feelings of stigma, it seemed important to reduce misconceptions and negative attitudes by e.g. inform family members, friends, colleagues, and others about the disease and how to act in case of seizures.

Some participants chose to conceal their epilepsy to avoid different treatment or discrimination, for example when applying for work. However, secrecy about epilepsy increased the worry about the epilepsy being revealed. Staying at home minimized the risk of having seizures in public but resulted in social isolation. Social isolation was expressed often as a result of epilepsy stigma, which seemed to be amplified by the reduced social network because of immigration.

Employment seemed crucial to build self-confidence as a capable person, reduce feelings of being weak or unvalued and to break the social isolation. Participants underlined the importance of being given the chance to work part time and of focusing on their capacities instead of disabilities.

8.4 PAPER IV

Paper IV investigated social influence on epilepsy care from the perspectives of persons with epilepsy and their health providers (neurologists, nurses, and a health care counselor). The study was based on focus-group interviews from three different out-patient neurology clinics in the southwest of Sweden.

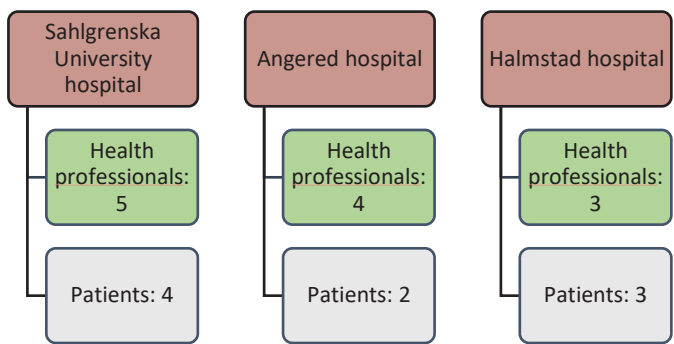


Figure 5. Cohort of Paper IV.

The results of Paper IV highlight common challenges in epilepsy care and important functions of the multidisciplinary team that can provide support for socially vulnerable patients (Figure 6).

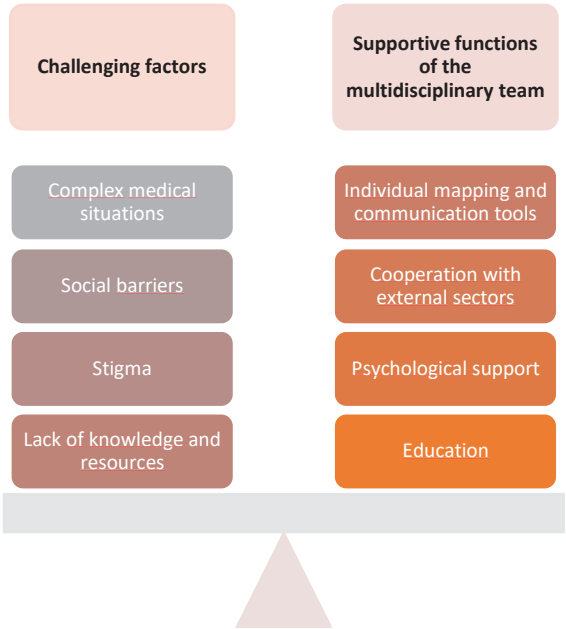


Figure 6. Categories and subcategories describing the results of Paper IV.

8.4.1 Challenging factors

The often complex medical situations in epilepsy, with seizures, adverse drug events, etc. in combination with a high prevalence of neurological and psychiatric comorbidities impose challenges in epilepsy care.

Low SES, poverty, a lack of schooling (including inability to read and calculate) and lacking basic knowledge of the body posed specific challenges in epilepsy care. Persons who have emigrated from another country seemed especially affected due to poor language proficiency or knowledge of the organization of Swedish health care. This could lead to misunderstandings, missing medical appointments and non-adherence to medication. A hierarchy in the doctor-patient relationship was described by patients as a social barrier that could prevent the patients from sharing thoughts or asking questions.

Participants reported repeated experiences of perceived and enacted stigma in epilepsy. Having seizures was experienced as shameful and some preferred to conceal their epilepsy to others. Health professionals told of recent cases of enacted stigma, where patients had unjustifiably been dismissed from work or mistrusted by their colleagues because of their epilepsy. A lack of knowledge about epilepsy in society, such as the police mistaking epilepsy for substance abuse or an incorrect judgement of patients' working ability by the Social Insurance Agency had led to feelings of insecurity and mistrust.

A lack of resources resulted in prolonged intervals for follow-up visits and reduced possibilities to provide psychological support and make educational efforts. The importance of resources for securing an epilepsy nurse with more time to monitor particularly vulnerable patients was highlighted.

8.4.2 Supportive functions of the multidisciplinary team

Close cooperation between the neurologist, nurse, psychologist, and other paramedical professionals in the multidisciplinary team was considered by the health professionals as the key to find solutions to challenging factors in epilepsy care. To provide individualized support, knowing the patients and understanding their experiences and approach to epilepsy was considered to be crucial. This was illustrated by medical appointments being scheduled as longer and more frequent, so that the effects of social barriers, intellectual disability or other complex factors could be explored.

Written information about prescriptions and explanatory pictures had been used to facilitate communication with patients with intellectual or language limitations. Screening instruments were suggested as needed to detect symptoms that were not frequently asked about. Participants further described a wish for digital applications that could improve knowledge and facilitate medical adherence.

The cooperation with external sectors was described as slow and inefficient when trying to improve support for vulnerable patients with epilepsy. The need for educational initiatives to improve public, patients' and relatives' knowledge about epilepsy was expressed. Increasing patients' knowledge about epilepsy was said to be empowering and reducing the stigma. Educating relatives could further diminish the relatives' stress and worries and improve their ability to provide social support.

The nurse could provide stability by being an accessible contact person in the multidisciplinary team. It was recognized that social isolation and feelings of loneliness could be experienced by any person with epilepsy, and this could increase the need for psychological support, both for the person with epilepsy and for relatives.



"Conversations" in watercolor by Malin Andersson.

9 DISCUSSION

9.1 Paper I- Socioeconomic disparities in access to epilepsy care

In Paper I, we investigated associations of SES, measured by levels of income and education, with different markers of severity of epilepsy and access to specialized care. The main findings were that persons with lower education or lower income levels had more severe epilepsy and were at the same time less likely to have their ASM prescribed from a neurologist compared with persons with higher educational or income levels who had less severe epilepsy. The results from our cohort of adults admitted to specialized epilepsy care from 2000-2015 validate the findings of SES disparities in the Swedish national cohort in 1998-2005 reported by Mattsson et al. (141). In Mattsson's study, the proportion of patients with ASM prescriptions from a neurologist in different educational groups ranged from 37.2-65.6 %, in comparison to 78.3-91.2 % in our study. However, some differences in selection criteria make direct comparisons difficult, e.g., the Mattsson study included status epilepticus (ICD code G.41) and demanded prescription of ASM at two different time points to define epilepsy. They did not exclude patients with intellectual disability in their analyses who more often receive care from general practitioners.

The representation in the Swedish national surgery register was twice as high in the lowest income group compared to the highest (2.1% vs 1%) which probably reflects more severe epilepsy among these patients. Likewise, newer generation ASM were more commonly prescribed to persons of low SES, which could point to a more severe epilepsy. However, the differences were small across the different SES groups which could indicate that persons of higher SES are offered newer ASM as a treatment option earlier. In a related study that is not included in this thesis, it was found that prescriptions of Valproic acid, (an ASM with teratogenic affects that should not be prescribed to women of fertile age unless certain criteria are met) were more commonly prescribed to women of fertile age with low SES in Sweden (185) further indicating SES disparities in epilepsy.

In Paper I, a higher educational level was associated with a decreased difference between persons with epilepsy and healthy controls in proportions with low income and unemployment. Higher education thereby appears to be an important protective factor against other socioeconomic disadvantages in

epilepsy. These findings highlight the importance of supporting young persons with epilepsy in accomplishing higher education thus possibly avoiding manual jobs where epilepsy may be considered a negative indication for employment.

9.2 Why do persons with epilepsy of low SES have reduced access to a neurologist in a welfare state like Sweden?

Sweden has relatively few practicing neurologists. In 2019 the number of neurologists was estimated to 45 per million inhabitants (186) compared to the European median of 79 (187). It is possible that persons with low income more often reside in rural areas where the accessibility of neurologists is particularly poor. Another reason can be the association between low SES and low health literacy, meaning that persons of low SES can have difficulties in demanding and accessing health care services. Poor health literacy has previously been associated with underutilization of health care services (138). In addition to having knowledge advantages, persons with higher education and social class may also feel more comfortable with participating in decisions about their health (188). Other unknown factors may contribute to SES disparities and need to be investigated in further studies.

9.3 Paper II and III- Stigma and associated factors

Paper II investigated perceived stigma and associated factors through patient-report questionnaires. The main findings were that foreign-born persons with epilepsy, especially persons born outside of Europe, reported higher levels of stigma than native-born. Factors that remained significant in explaining variation of reported levels of stigma were having had one or more seizures during the last year, more self-reported symptoms of anxiety and poorer self-assessed mental health. Differences were found among different educational and occupational groups, but they were non-significant. However, this could perhaps be explained by the relatively small sample size (n=161).

Seizure- frequency was found to be the most important factor to explain variations of stigma, while no significant difference was seen in different seizure-types. In the existing literature, both seizure frequency (81) and seizure-type (83) has been associated with stigma, but seizure frequency has long appeared to be the most determining factor (189, 190). Seizure-free

patients can also experience stigma (191). In Paper II self-reported symptoms of anxiety and poorer mental health significantly explained some of the variation of reported stigma. These findings correspond well to previous reports of associations between stigma and mental health (91, 93).

We reported a mean stigma t- score of 48.3 points (sd.=8.1), which is below the normative mean used internationally based on the general American population. All scales that were used in Paper II had been translated and undergone cognitive debriefing in the Swedish context. Meanwhile, neither the Neuro-QoL questionnaires nor the PROMIS have been developed for a Swedish general population. The comparability of the levels of reported stigma and mental health in Paper II and the general American population where the scale was developed is limited and such comparisons were not the aim of the present study. However, further validation of the Neuro-QoL and PROMIS scales in the general Swedish population would facilitate usage and interpretation of those scales in clinical research in Sweden in the future.

Paper III investigated the meaning of stigma among foreign-born patients with epilepsy attending a daycare hospital situated in a socially deprived suburb. Most participants originated from low-income countries in Africa and the Middle East. The results highlighted multiple aspects of stigma related to epilepsy, to being an immigrant and to being in a low SES group and how it could negatively influence the self-image. The participants applied different strategies to overcome the stigma and build self-confidence, by either disclosing their epilepsy and inform others about their situation, or to conceal epilepsy and by trying to find and maintain employment.

Despite the culturally heterogenous sample of participants in Paper III we found reoccurring traits of epilepsy stigma corresponding to previously conducted qualitative studies of stigma in epilepsy, both in Sweden (192, 193), and elsewhere (74-76, 79). This points out that some traits of epilepsy stigma are general and can be experienced by any persons with epilepsy regardless of the country or cultural context. This idea aligns with the reports from a recent literature review of stigma in epilepsy by the ILAE (194).

Foreign-born persons reported higher levels of stigma than native-born in Paper II, but this difference did not remain significant in the multiple regression model. This indicates that higher levels of stigma within this group

of patients could be explained by other interrelated factors, such as for example lower SES (149) or mental health. At the same time, foreign-born persons with epilepsy may experience the additional stigma related to being an immigrant, stigma related to race or ethnicity (102) or stigma related to lower SES (149). As with misconceptions about epilepsy, foreign-born persons from low-income countries may also carry with them misconceptions about mental health conditions increasing the stigma around both conditions. Results from Paper III indicate that persons with epilepsy may conceal mental health problems to avoid further stigma, which is unfortunate and calls for careful measures to identify mental health problems and psychiatric comorbidities without increasing the stigma.



“Wake-up call” in watercolor by Malin Andersson.

Even though our results from Paper II did not indicate a significant association between perceived stigma and education level or financial capacity, our results from Paper III indicate that stigma related to social deprivation indeed can increase stigma in epilepsy. This finding is in line with other research, for example a German study of adult persons with epilepsy in urban Berlin that found associations between socially deprived neighborhoods and perceived stigma in epilepsy (195). An American study also found associations of SES and epilepsy-related stigma (96) but the differences did not remain significant when adjusting for symptoms of depression and anxiety. To what extent SES affects stigma in epilepsy remains unclear and needs to be investigated further in future studies, preferably considering all possible contributing stigmatizing factors and in a larger cohort.

Importantly, statistically significant associations from observation studies do not tell us anything about causation. In the context of epilepsy and SES, we cannot know whether it is the seizures or other epilepsy related factors that lead to lower SES through negative effects on education, occupation etc., or whether low SES leads to non-optimal use of health care services and thereby poor management of epilepsy. It is also important to acknowledge that multiple risk factors can be interrelated, having a substantial effect on clinical care. This needs to be investigated further in future studies. The underlying reasons why a relatively higher proportion of persons with epilepsy are found in studies that identify lower SES populations (120) can have unlimited inter-individual variations. National registers cannot provide this information, and that is one reason why qualitative studies can contribute with valuable knowledge in this field.

9.4 Paper IV- Social influence, challenges, and support in epilepsy care

The main findings of Paper IV highlighted barriers in epilepsy care such as complex medical situations, social barriers, stigma and a lack of knowledge and resources. The findings underscored the importance of the multidisciplinary epilepsy team in supporting vulnerable patients through individual assessment, facilitating information, cooperation with external sectors (such as primary and pediatric care, schools, employers, and the Social Insurance system etc.), provision of psychological support, and education. The findings correspond well to the WHO intersectoral global action plan on epilepsy and other neurological disorders (196), and highlight the need for resources to secure the implementation of the Swedish National Guidelines for Epilepsy Care (197) that were far from being fulfilled in the evaluation report from 2021 (198). Most importantly, all neurology out-patient clinics treating persons with epilepsy should have access to a multidisciplinary epilepsy team with a nurse dedicated only to epilepsy patients. Failing to adhere to the national guidelines will preserve, or in the worst-case increase, SES disparities in epilepsy care since it is most likely the additional support for the most vulnerable persons with epilepsy that is being restrained.

9.5 How can we reduce stigma and increase the support for vulnerable persons with epilepsy in Sweden?

Stigma in epilepsy can be the result of seizures, public misconceptions and negative attitudes or be an indicator of poor mental health and/or lacking knowledge of epilepsy that is probably more common among persons with low SES. Treating seizures must remain the number one priority in epilepsy care. In addition, health professionals could play an important role in reducing the burden of epilepsy by detecting and treating comorbid psychiatric conditions, providing psychological support, and participate in educational efforts to increase knowledge about epilepsy among patients, their relatives and in the public sector (194).

9.5.1 Treating psychiatric comorbidities and providing psychological support

Neglecting to treat psychiatric comorbidities in epilepsy like symptoms of depression causes unnecessary suffering and can even waste resources by an exaggerated health resource utilization (199). The limited availability to psychiatric and psychological support within the epilepsy team is a common problem and contributor to the under-recognition and lack of treatment of psychiatric comorbidities in epilepsy (200). A basic condition for screening for depression and anxiety in epilepsy are established routines for how to treat persons when the conditions are detected. The ILAE recently published recommendations for the treatment of unipolar depression in epilepsy (201). It is recommended that investigation of depression in epilepsy should be approached step-by-step and include multidisciplinary health professionals. Psychological interventions and/or selective serotonin reuptake inhibitors (SSRI) are recommended as first-line treatment for mild to moderately severe unipolar depression in epilepsy. However, the report does not provide recommendations as to which specialists (neurology, psychiatry, etc.) should provide the treatment. Opinions differ when it comes to the question of who is best suited to treat anxiety and depression in epilepsy. It has been suggested that neurologists should be able to treat at least mild to moderate depression, while severe depression should be referred to specialist psychiatric care (202). There are indications that persons with epilepsy and depression or anxiety prefer neurologists to psychiatrists to prescribe their medical treatment for depression or anxiety (203). However, many neurologists are uncomfortable with treating depression and anxiety due to a lack of experience of treating such conditions. In Sweden, mild to moderate symptoms of depression and anxiety are often treated in primary care, but there are no established routines for referral to the general practitioner. Routines for screening and treating depression and anxiety in epilepsy needs to be established. Such routines should preferably be developed in agreement with primary and psychiatry care for efficient cooperation. Even for patients without an established psychiatric comorbidity, the results from Paper II-IV underscore the importance for persons with epilepsy of being offered psychological support. The availability to psychologists in the multidisciplinary teams needs to be increased.



“Support” in watercolor by Malin Andersson.

9.5.2 Stigma-reducing interventions and efforts for improved support

The ILAE recently published a review of previous stigma-reducing interventions (204). Most of the 30 identified stigma-reducing interventions were educational and a majority targeted people without epilepsy. The overall quality of the interventions was poor, and most had failed to apply validated measurement instruments. Previous interventions to support self-management in epilepsy in the entire socioeconomic strata have mainly focused on increasing knowledge by providing education to persons with epilepsy (204-208). This has had some mixed success. MOSES was a two-day educational program developed for adults with epilepsy in German-speaking countries (205). After six months evaluation, a significant improvement was seen in tolerability to medication, seizure-control, better coping with epilepsy and knowledge about epilepsy (209). A similar intervention, SMILE, applied the same concept but adapted the program for the British population, and only included adults with epilepsy with two or more recent seizures. When they evaluated the outcomes after 12 months no significant improvements were found (206).

It is possible that receiving too much information at once can be overwhelming and lead to “information overload”, especially for persons with low health literacy. A research group in Chicago tried to overcome this issue by developing an online educational platform called PAUSE to learn your epilepsy (208). The intention was to provide accessible and reliable information that was easy for patients to understand regardless of their educational level, and that the information was available whenever patients needed or had time for it. Patients with lower scores for self-management and quality of life before the intervention were found to improve more after the intervention than patients who had higher scores before the intervention, indicating a more pronounced effect of the intervention among socioeconomically and psychosocially vulnerable patients.

The Managing Epilepsy Well (MEW) network in the USA has developed interventions to promote psychosocial support in epilepsy (UPLIFT) that were adapted for underserved populations such as racial minorities and socially deprived groups (210). This distance group intervention provided psychosocial support for Blacks and Hispanics with epilepsy. One of the findings was the importance of keeping the language simple to facilitate understanding. While

some patients preferred physical meetings with a support person, it was highlighted that distance/telephone contact and support increased accessibility and reduced transportation barriers.

The above-mentioned interventions provide valuable information and take-home messages that could contribute to making a similar intervention in the Swedish context more successful. The ILAE recommends that future stigma-reducing interventions should explore theories of stigma that transcend individual conditions, engage the community of persons living with epilepsy in the development and implementation of the intervention, and use existing validated measurement tools, instead of developing new ones (204).

Providing information in different languages is important if the intervention is to include foreign-born persons. Using simple language and explanatory images could improve accessibility for persons with low educational attainment. The results from Paper IV highlighted a wish for communication tools and online digital platforms for educational purposes. However, accessibility of the technical device used for such purposes need to be secured also for persons of low SES to avoid excluding vulnerable patients for whom the intervention is aimed to support.

Regardless of what a stigma-reducing intervention consists of, considering the above mentioned factors is crucial to improve inclusivity, and the intervention needs to target both the public, persons with epilepsy and their families in order to be successful (73).

10 CONCLUSIONS

As long as persons with epilepsy have seizures and prejudices and misconceptions about epilepsy prevail, the stigma around epilepsy will continue to cause suffering and mediate negative psychological and socioeconomic effects. Stigma and SES remain important determinants of health that need consideration in epilepsy care.

This thesis has investigated the impact of stigma and SES in epilepsy in Sweden. The compilation of research studies has contributed with updated knowledge of persisting socioeconomic disparities in epilepsy care. It has contributed with new knowledge of stigma-associated factors among persons with epilepsy in Sweden and of the meaning of stigma in a context of epilepsy, immigration, and social deprivation. Furthermore, it has contributed with knowledge of the challenges and facilitating factors in the provision of epilepsy care from the double perspective of patients and health providers, which has not been reported before.

Knowledge of stigma and stigma-associated factors is necessary for improved understanding of the specific situations where stigma exist and where patients need additional support. This knowledge is crucial for designing efficient and meaningful stigma-reducing interventions and for increasing support for vulnerable persons with epilepsy.

Seizure control must remain the priority in epilepsy care, being a determining factor for all aspects of health in epilepsy including stigma. In addition, detecting and treating psychiatric comorbidities like anxiety and depression, and providing psychological support and education represent important measures to reduce the stigma in epilepsy. The multidisciplinary team is essential in the provision of care and support for vulnerable persons with epilepsy. Therefore, it is crucial that the Swedish National Guidelines for Epilepsy are being followed.

FUTURE DIRECTIONS

The results from this thesis highlight the need for stigma-reducing interventions and interventions that improve support for vulnerable persons with epilepsy in Sweden.

There is a consensus of the importance of empowering patients with epilepsy with knowledge and of increasing knowledge about epilepsy in society to reduce misconceptions and stigma. Therefore, educational efforts are needed that target both the patients, their relatives, and the public sectors. Another important issue concerns the importance of providing psychological support to patients and their relatives, and to detect and treat comorbid psychiatric conditions in epilepsy to avoid further stigma.

There is no universal solution to how to develop meaningful and efficient interventions. Importantly, interventions must be developed within the specific context where they are to be used. Both persons with epilepsy (including vulnerable persons such as foreign-born persons and persons of low SES) and health professionals must be involved in the process. Failing to include vulnerable persons in the development of interventions aiming to support them risk being inefficient. Furthermore, it is crucial that all social circumstances and possible risk factors for vulnerable persons with epilepsy are taken into account (211, 212). Further studies that clarify the social circumstances that contribute to socioeconomic disparities in epilepsy, and of how to provide meaningful psychological support for persons with epilepsy would be valuable.

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REFERENCES

1. Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia*. 2014;**55**(4):475-82.
2. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health*. 2013;**103**(5):813-21.
3. Adler NE, Newman K. Socioeconomic disparities in health: pathways and policies. *Health Aff* (Millwood). 2002;**21**(2):60-76.
4. World Health Organization. WHO remains firmly committed to the principles set out in the preamble to the Constitution: WHO; 1946 [cited 2022 05-10-2022]. Constitution]. Available from: <https://www.who.int/about/governance/constitution>.
5. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health*. 2012;**12**:80.
6. Fiest KM, Sauro KM, Wiebe S, Patten SB, Kwon CS, Dykeman J, et al. Prevalence and incidence of epilepsy: A systematic review and meta-analysis of international studies. *Neurology*. 2017;**88**(3):296-303.
7. Forsgren L, Beghi E, Oun A, Sillanpää M. The epidemiology of epilepsy in Europe - a systematic review. *Eur J Neurol*. 2005;**12**(4):245-53.
8. Fisher RS vEBW, Blume W, Elger C, Genton P, Lee P, Engel J Jr. Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia*. 2005.
9. Beran RG, Devereaux JA, Buchanan D. Some legal aspects of epilepsy. *Epilepsy Behav*. 2020;**111**:107244.
10. Brown S, Bird J. Continuing professional development: medico-legal aspects of epilepsy. *Seizure*. 2002;**11** Suppl A:68-74; quiz 3-4.
11. de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy & Behavior*. 2008;**12**(4):540-6.
12. Oto MM. The misdiagnosis of epilepsy: Appraising risks and managing uncertainty. *Seizure*. 2017;**44**:143-6.
13. Krumholz A, Wiebe S, Gronseth GS, Gloss DS, Sanchez AM, Kabir AA, et al. Evidence-based guideline: Management of an unprovoked first seizure in adults: Report of the Guideline Development Subcommittee of the American Academy of Neurology and the American Epilepsy Society. *Neurology*. 2015;**84**(16):1705-13.
14. Beghi E, Carpio A, Forsgren L, Hesdorffer DC, Malmgren K, Sander JW, et al. Recommendation for a definition of acute symptomatic seizure. *Epilepsia*. 2010;**51**(4):671-5.

15. Fisher RS, van Emde Boas W, Blume W, Elger C, Genton P, Lee P, et al. Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia*. 2005;**46**(4):470-2.
16. Zelano J. Recurrence risk after a first remote symptomatic seizure in adults: Epilepsy or not? *Epilepsia Open*. 2021;**6**(4):634-44.
17. Alanis-Guevara I, Peña E, Corona T, López-Ayala T, López-Meza E, López-Gómez M. Sleep disturbances, socioeconomic status, and seizure control as main predictors of quality of life in epilepsy. *Epilepsy Behav*. 2005;**7**(3):481-5.
18. Mrabet H, Mrabet A, Zouari B, Ghachem R. Health-related quality of life of people with epilepsy compared with a general reference population: a Tunisian study. *Epilepsia*. 2004;**45**(7):838-43.
19. Stavem K, Loge JH, Kaasa S. Health status of people with epilepsy compared with a general reference population. *Epilepsia*. 2000;**41**(1):85-90.
20. Reyes-Miranda A, Chan S, Gowda S, Kean J, Cramer JA, Pugh MJ. Assessing the personal impact of epilepsy in a population-based cohort of Veterans. *Epilepsy Behav*. 2020;**106**:107047.
21. Kwan P, Brodie MJ. Early identification of refractory epilepsy. *N Engl J Med*. 2000;**342**(5):314-9.
22. Sunny AA, Iyer RS, Kumaran SG, Bunshaw NG, Shanmugham K, Govindaraj U. Affordability, availability and tolerability of anti-seizure medications are better predictors of adherence than beliefs: Changing paradigms from a low resource setting. *Seizure*. 2020;**83**:208-15.
23. Chapman SC, Horne R, Eade R, Balestrini S, Rush J, Sisodiya SM. Applying a perceptions and practicalities approach to understanding nonadherence to antiepileptic drugs. *Epilepsia*. 2015;**56**(9):1398-407.
24. Sultana B, Panzini MA, Veilleux Carpentier A, Comtois J, Rioux B, Gore G, et al. Incidence and Prevalence of Drug-Resistant Epilepsy: A Systematic Review and Meta-analysis. *Neurology*. 2021;**96**(17):805-17.
25. Kwan P, Arzimanoglou A, Berg AT, Brodie MJ, Allen Hauser W, Mathern G, et al. Definition of drug resistant epilepsy: consensus proposal by the ad hoc Task Force of the ILAE Commission on Therapeutic Strategies. *Epilepsia*. 2010;**51**(6):1069-77.
26. Malmgren K, Edelvik A. Long-term outcomes of surgical treatment for epilepsy in adults with regard to seizures, antiepileptic drug treatment and employment. *Seizure*. 2017;**44**:217-24.
27. Reuber M, Chen M, Jamnadas-Khoda J, Broadhurst M, Wall M, Grünewald RA, et al. Value of patient-reported symptoms in the diagnosis of transient loss of consciousness. *Neurology*. 2016;**87**(6):625-33.
28. Gavvala JR, Schuele SU. New-Onset Seizure in Adults and Adolescents: A Review. *Jama*. 2016;**316**(24):2657-68.

29. Kılınç S, van Wersch A, Campbell C, Guy A. The experience of living with adult-onset epilepsy. *Epilepsy Behav.* 2017;**73**:189-96.
30. Pembroke S, Higgins A, Pender N, Elliott N. Becoming comfortable with "my" epilepsy: Strategies that patients use in the journey from diagnosis to acceptance and disclosure. *Epilepsy Behav.* 2017;**70**(Pt A):217-23.
31. Elliott N, Pembroke S, Quirke M, Pender N, Higgins A. Disclosure strategies in adults with epilepsy when telling, "I have epilepsy": The How2tell study. *Epilepsia.* 2019;**60**(10):2048-59.
32. Baxendale S. Epilepsy on the silver screen in the 21st century. *Epilepsy Behav.* 2016;**57**(Pt B):270-4.
33. Fisher RS, Cross JH, French JA, Higurashi N, Hirsch E, Jansen FE, et al. Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology. *Epilepsia.* 2017;**58**(4):522-30.
34. McGonigal A. Semiology and Epileptic Networks. *Neurosurg Clin N Am.* 2020;**31**(3):373-85.
35. Bonini F, McGonigal A, Trébuchon A, Gavaret M, Bartolomei F, Giusiano B, et al. Frontal lobe seizures: from clinical semiology to localization. *Epilepsia.* 2014;**55**(2):264-77.
36. Obeid T, Abulaban A, Al-Ghatani F, Al-Malki AR, Al-Ghamdi A. Possession by 'Jinn' as a cause of epilepsy (Saraa): a study from Saudi Arabia. *Seizure.* 2012;**21**(4):245-9.
37. Mameniškienė R, Puteikis K, Carrizosa-Moog J. Saints, demons, and faith - A review of the historical interaction between Christianity and epilepsy. *Epilepsy Behav.* 2022;**135**:108870.
38. Bou Nasif M, Koubeissi M, Azar NJ. Epilepsy - from mysticism to science. *Rev Neurol (Paris).* 2021;**177**(9):1047-58.
39. Tuft M, Nakken KO, Kverndokk K. Traditional folk beliefs on epilepsy in Norway and Sweden. *Epilepsy Behav.* 2017;**71**(Pt A):104-7.
40. Awad A, Sarkhoo F. Public knowledge and attitudes toward epilepsy in Kuwait. *Epilepsia.* 2008;**49**(4):564-72.
41. Diamantopoulos N, Kaleyias J, Tzoufi M, Kotsalis C. A survey of public awareness, understanding, and attitudes toward epilepsy in Greece. *Epilepsia.* 2006;**47**(12):2154-64.
42. Demirci S, Dönmez CM, Gündoğar D, Baydar CL. Public awareness of, attitudes toward, and understanding of epilepsy in Isparta, Turkey. *Epilepsy Behav.* 2007;**11**(3):427-33.
43. Lee P. Has disability discrimination legislation changed the legal framework for epilepsy in the United Kingdom? *Seizure.* 2010;**19**(10):619-22.
44. World Health Organization. Epilepsy: World Health Organization,; 2019 [cited 2021 19th October 2021]. Fact sheet]. Available from: <https://www.who.int/news-room/fact-sheets/detail/epilepsy>.

45. Cronlund A. Epilepsi- en omfattande historia: Neurologi i Sverige; 2020 [cited 2022-11-02]. Available from: <https://www.neurologiisverige.se/wp-content/uploads/2020/12/Epilepsi-historia.pdf>.
46. Jacoby A. Felt versus enacted stigma: a concept revisited. Evidence from a study of people with epilepsy in remission. *Soc Sci Med*. 1994;**38**(2):269-74.
47. Keezer MR, Sisodiya SM, Sander JW. Comorbidities of epilepsy: current concepts and future perspectives. *Lancet Neurol*. 2016;**15**(1):106-15.
48. Yoshimura H, Tanaka T, Fukuma K, Matsubara S, Motoyama R, Mizobuchi M, et al. Impact of Seizure Recurrence on 1-Year Functional Outcome and Mortality in Patients With Poststroke Epilepsy. *Neurology*. 2022;**99**(4):e376-e84.
49. Hesdorffer DC, Ishihara L, Mynepalli L, Webb DJ, Weil J, Hauser WA. Epilepsy, suicidality, and psychiatric disorders: a bidirectional association. *Ann Neurol*. 2012;**72**(2):184-91.
50. Löscher W, Stafstrom CE. Epilepsy and its neurobehavioral comorbidities: insights gained from animal models. *Epilepsia*. 2022.
51. Tellez-Zenteno JF, Patten SB, Jetté N, Williams J, Wiebe S. Psychiatric comorbidity in epilepsy: a population-based analysis. *Epilepsia*. 2007;**48**(12):2336-44.
52. Gaitatzis A, Carroll K, Majeed A, J WS. The epidemiology of the comorbidity of epilepsy in the general population. *Epilepsia*. 2004;**45**(12):1613-22.
53. Lhatoo SD, Sander JW. The epidemiology of epilepsy and learning disability. *Epilepsia*. 2001;**42** Suppl 1:6-9; discussion 19-20.
54. Dunn DW, Austin JK, Harezlak J, Ambrosius WT. ADHD and epilepsy in childhood. *Dev Med Child Neurol*. 2003;**45**(1):50-4.
55. Johnson EK, Jones JE, Seidenberg M, Hermann BP. The relative impact of anxiety, depression, and clinical seizure features on health-related quality of life in epilepsy. *Epilepsia*. 2004;**45**(5):544-50.
56. Boylan LS, Flint LA, Labovitz DL, Jackson SC, Starner K, Devinsky O. Depression but not seizure frequency predicts quality of life in treatment-resistant epilepsy. *Neurology*. 2004;**62**(2):258-61.
57. Chiang S, Moss R, Meskis MA, Vogel-Farley V, Sullivan JE, Patel AD, et al. Impact of intellectual and developmental disability on quality-of-life priorities in adults with epilepsy. *Epilepsy Behav*. 2021;**123**:108282.
58. Liao P, Vajdic CM, Reppermund S, Cvejic RC, Srasuebkul P, Trollor JN. Mortality rate, risk factors, and causes of death in people with epilepsy and intellectual disability. *Seizure*. 2022;**101**:75-82.
59. Scambler G. Health-related stigma. *Sociol Health Illn*. 2009;**31**(3):441-55.
60. Goffman E. Stigma. Den avvikandes roll och identitet.: Studentlitteratur AB, Lund; 2014.

61. Wang J, Lloyd-Evans B, Giacco D, Forsyth R, Nebo C, Mann F, et al. Social isolation in mental health: a conceptual and methodological review. *Soc Psychiatry Psychiatr Epidemiol*. 2017;**52**(12):1451-61.
62. Leigh-Hunt N, Bagguley D, Bash K, Turner V, Turnbull S, Valtorta N, et al. An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*. 2017;**152**:157-71.
63. Strang P. att höra till: Natur och kultur; 2014.
64. Bhanji JP, Delgado MR. The social brain and reward: social information processing in the human striatum. *Wiley Interdiscip Rev Cogn Sci*. 2014;**5**(1):61-73.
65. Eisenberger NI, Lieberman MD, Williams KD. Does rejection hurt? An fMRI study of social exclusion. *Science*. 2003;**302**(5643):290-2.
66. Tomova L, Wang KL, Thompson T, Matthews GA, Takahashi A, Tye KM, et al. Acute social isolation evokes midbrain craving responses similar to hunger. *Nat Neurosci*. 2020;**23**(12):1597-605.
67. Link BG, Phelan J. Stigma power. *Soc Sci Med*. 2014;**103**:24-32.
68. Link BG, Phelan JC. Conceptualizing Stigma. *Annual Review of Sociology*. 2001;**27**:363-85.
69. Scambler G. Re-framing Stigma: Felt and Enacted Stigma and Challenges to the Sociology of Chronic and Disabling Conditions. *Social Theory & Health*. 2004;**2**(1):29-46.
70. Link BG, Phelan JC. Stigma and its public health implications. *Lancet*. 2006;**367**(9509):528-9.
71. Link B, Hatzenbuehler ML. Stigma as an Unrecognized Determinant of Population Health: Research and Policy Implications. *J Health Polit Policy Law*. 2016;**41**(4):653-73.
72. Atadzhanov M, Haworth A, Chomba EN, Mbewe EK, Birbeck GL. Epilepsy-associated stigma in Zambia: what factors predict greater felt stigma in a highly stigmatized population? *Epilepsy Behav*. 2010;**19**(3):414-8.
73. Jacoby A, Snape D, Baker GA. Epilepsy and social identity: the stigma of a chronic neurological disorder. *Lancet Neurol*. 2005;**4**(3):171-8.
74. Molavi P, Sadeghieh Ahari S, Fattahzadeh-Ardalani G, Almasi S, Karimollahi M. The experiences of Iranian patients with epilepsy from their disease: A content analysis. *Epilepsy Behav*. 2019;**96**:109-13.
75. Sleeth C, Drake K, Labiner DM, Chong J. Felt and enacted stigma in elderly persons with epilepsy: A qualitative approach. *Epilepsy Behav*. 2016;**55**:108-12.
76. Keikelame MJ, Swartz L. "I wonder if I did not mess up....": Shame and resistance among women with epilepsy in Cape Town, South Africa. *Seizure*. 2018;**61**:50-6.
77. Rawlings GH, Brown I, Stone B, Reuber M. Written accounts of living with epilepsy: A thematic analysis. *Epilepsy Behav*. 2017;**72**:63-70.

78. Kuramochi I, Horikawa N, Shimotsu S, Hiwatashi T, Watanabe M, Okazaki M, et al. The self-stigma of patients with epilepsy in Japan: A qualitative approach. *Epilepsy Behav.* 2020;**109**:106994.
79. Benson A, Lambert V, Gallagher P, Shahwan A, Austin JK. "I don't want them to look at me and think of my illness, I just want them to look at me and see me": Child perspectives on the challenges associated with disclosing an epilepsy diagnosis to others. *Epilepsy Behav.* 2015;**53**:83-91.
80. Baker D, Eccles FJR, Caswell HL. Correlates of stigma in adults with epilepsy: A systematic review of quantitative studies. *Epilepsy & Behavior.* 2018;**83**:67-80.
81. Shi Y, Wang S, Ying J, Zhang M, Liu P, Zhang H, et al. Correlates of perceived stigma for people living with epilepsy: A meta-analysis. *Epilepsy Behav.* 2017;**70**(Pt A):198-203.
82. Ezeala-Adikaibe BA, Achor JU, Aneke E, Ijoma U, Onodugo OD, Orjiokwe C, et al. Pattern and determinants of self-reported enacted stigma among rural dwellers living with epilepsy attending a tertiary health facility in Enugu State Nigeria. *Seizure.* 2018;**56**:60-6.
83. Tedrus G, Pereira RB, Zoppi M. Epilepsy, stigma, and family. *Epilepsy Behav.* 2018;**78**:265-8.
84. Lee SA. Felt stigma in seizure-free persons with epilepsy: Associated factors and its impact on health-related quality of life. *Epilepsy Behav.* 2021;**122**:108186.
85. Yeni K, Tulek Z, Bebek N. Factors associated with perceived stigma among patients with epilepsy in Turkey. *Epilepsy Behav.* 2016;**60**:142-8.
86. Luna J, Nizard M, Becker D, Gerard D, Cruz A, Ratsimbazafy V, et al. Epilepsy-associated levels of perceived stigma, their associations with treatment, and related factors: A cross-sectional study in urban and rural areas in Ecuador. *Epilepsy Behav.* 2017;**68**:71-7.
87. Bautista RE, Shapovalov D, Shoraka AR. Factors associated with increased felt stigma among individuals with epilepsy. *Seizure.* 2015;**30**:106-12.
88. Karakaş N, Sarıtaş S, Aktura S, Karabulutlu EY, Oruç FG. Investigation of factors associated with stigma and social support in patients with epilepsy in Turkey: A cross-sectional study. *Epilepsy Behav.* 2022;**128**:108572.
89. Henning O, Johannessen Landmark C, Nakken KO, Lossius MI. Nonadherence to treatment regimens in epilepsy from the patient's perspective and predisposing factors: Differences between intentional and unintentional lack of adherence. *Epilepsia.* 2019;**60**(5):e58-e62.
90. Adewuya AO, Oseni SB, Okeniyi JA. School performance of Nigerian adolescents with epilepsy. *Epilepsia.* 2006;**47**(2):415-20.
91. Rafael F, Houinato D, Nubukpo P, Dubreuil CM, Tran DS, Odermatt P, et al. Sociocultural and psychological features of perceived stigma reported by people with epilepsy in Benin. *Epilepsia.* 2010;**51**(6):1061-8.

92. Scambler G, Hopkins A. Generating a model of epileptic stigma: the role of qualitative analysis. *Soc Sci Med.* 1990;**30**(11):1187-94.
93. Olley BO. Psychosocial and seizure factors related to depression and neurotic-disorders among patients with chronic epilepsy in Nigeria. *Afr J Med Med Sci.* 2004;**33**(1):39-44.
94. Yıldırım Z, Ertem DH, Ceyhan Dirican A, Baybaş S. Stigma accounts for depression in patients with epilepsy. *Epilepsy Behav.* 2018;**78**:1-6.
95. Tombini M, Assenza G, Quintiliani L, Ricci L, Lanzone J, Ulivi M, et al. Depressive symptoms and difficulties in emotion regulation in adult patients with epilepsy: Association with quality of life and stigma. *Epilepsy Behav.* 2020;**107**:107073.
96. Leaffer EB, Hesdorffer DC, Begley C. Psychosocial and sociodemographic associates of felt stigma in epilepsy. *Epilepsy Behav.* 2014;**37**:104-9.
97. Peterson CL, Walker C, Shears G. The social context of anxiety and depression: exploring the role of anxiety and depression in the lives of Australian adults with epilepsy. *Epilepsy Behav.* 2014;**34**:29-33.
98. Baker GA. People with epilepsy: what do they know and understand, and how does this contribute to their perceived level of stigma? *Epilepsy Behav.* 2002;**3**(6s2):26-32.
99. Tombini M, Assenza G, Quintiliani L, Ricci L, Lanzone J, De Mojà R, et al. Epilepsy-associated stigma from the perspective of people with epilepsy and the community in Italy. *Epilepsy Behav.* 2019;**98**(Pt A):66-72.
100. Forsgren L, Ghanean H, Jacobsson L, Richter J. On the experience of stigma by persons with epilepsy in Sweden and Iran--a comparative study. *Seizure.* 2013;**22**(9):748-51.
101. Turan JM, Elafros MA, Logie CH, Banik S, Turan B, Crockett KB, et al. Challenges and opportunities in examining and addressing intersectional stigma and health. *BMC Med.* 2019;**17**(1):7.
102. Stangl AL, Earnshaw VA, Logie CH, van Brakel W, L CS, Barré I, et al. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Med.* 2019;**17**(1):31.
103. Makowski AC, Kim TJ, Luck-Sikorski C, von dem Knesebeck O. Social deprivation, gender and obesity: multiple stigma? Results of a population survey from Germany. *BMJ Open.* 2019;**9**(4):e023389.
104. Morey BN. Mechanisms by Which Anti-Immigrant Stigma Exacerbates Racial/Ethnic Health Disparities. *Am J Public Health.* 2018;**108**(4):460-3.
105. Mula M, Kaufman KR. Double stigma in mental health: epilepsy and mental illness. *BJPsych Open.* 2020;**6**(4):e72.
106. Phelan JC, Link BG, Tehranifar P. Social Conditions as Fundamental Causes of Health Inequalities: Theory, Evidence, and Policy Implications. *J Health Soc Behav.* 2010;**51**(1_suppl):S28-S40.

107. Cockerham WC, Hamby BW, Oates GR. The Social Determinants of Chronic Disease. *Am J Prev Med.* 2017;**52**(1s1):S5-s12.
108. Stormacq C, Van den Broucke S, Wosinski J. Does health literacy mediate the relationship between socioeconomic status and health disparities? Integrative review. *Health Promot Int.* 2019;**34**(5):e1-e17.
109. Lynch J, Smith GD, Hillemeier M, Shaw M, Raghunathan T, Kaplan G. Income inequality, the psychosocial environment, and health: comparisons of wealthy nations. *Lancet.* 2001;**358**(9277):194-200.
110. Katikireddi SV, Niedzwiedz CL, Dundas R, Kondo N, Leyland AH, Rostila M. Inequalities in all-cause and cause-specific mortality across the life course by wealth and income in Sweden: a register-based cohort study. *Int J Epidemiol.* 2020;**49**(3):917-25.
111. Marmot MG, Rose G, Shipley M, Hamilton PJ. Employment grade and coronary heart disease in British civil servants. *J Epidemiol Community Health* (1978). 1978;**32**(4):244-9.
112. Global, regional, and national burden of epilepsy, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2019;**18**(4):357-75.
113. Carpio A, Bharucha NE, Jallon P, Beghi E, Camprostrini R, Zorzetto S, et al. Mortality of epilepsy in developing countries. *Epilepsia.* 2005;**46** Suppl 11:28-32.
114. Beghi E, Hesdorffer D. Prevalence of epilepsy--an unknown quantity. *Epilepsia.* 2014;**55**(7):963-7.
115. Us Centers For Disease C, Prevention Epilepsy P. About one-half of adults with active epilepsy and seizures have annual family incomes under \$25,000: The 2010 and 2013 US National Health Interview Surveys. *Epilepsy & behavior* : E&B. 2016;**58**:33-4.
116. Heaney DC, MacDonald BK, Everitt A, Stevenson S, Leonardi GS, Wilkinson P, et al. Socioeconomic variation in incidence of epilepsy: prospective community based study in south east England. *Bmj.* 2002;**325**(7371):1013-6.
117. Hesdorffer DC, Tian H, Anand K, Hauser WA, Ludvigsson P, Olafsson E, et al. Socioeconomic status is a risk factor for epilepsy in Icelandic adults but not in children. *Epilepsia.* 2005;**46**(8):1297-303.
118. Kaiboriboon K, Bakaki PM, Lhatoo SD, Koroukian S. Incidence and prevalence of treated epilepsy among poor health and low-income Americans. *Neurology.* 2013;**80**(21):1942-9.
119. Epilepsy in adults and access to care--United States, 2010. *MMWR Morb Mortal Wkly Rep.* 2012;**61**(45):909-13.
120. Burneo JG, Jette N, Theodore W, Begley C, Parko K, Thurman DJ, et al. Disparities in epilepsy: report of a systematic review by the North American

- Commission of the International League Against Epilepsy. *Epilepsia*. 2009;**50**(10):2285-95.
121. McNelis AM, Dunn DW, Johnson CS, Austin JK, Perkins SM. Academic performance in children with new-onset seizures and asthma: a prospective study. *Epilepsy Behav*. 2007;**10**(2):311-8.
 122. Tse E, Hamiwka L, Sherman EM, Wirrell E. Social skills problems in children with epilepsy: prevalence, nature and predictors. *Epilepsy Behav*. 2007;**11**(4):499-505.
 123. Wiebe S, Bellhouse DR, Fallahay C, Eliasziw M. Burden of epilepsy: the Ontario Health Survey. *Can J Neurol Sci*. 1999;**26**(4):263-70.
 124. Tian N, Kobau R, Zack MM, Greenlund KJ. Barriers to and Disparities in Access to Health Care Among Adults Aged ≥ 18 Years with Epilepsy - United States, 2015 and 2017. *MMWR Morb Mortal Wkly Rep*. 2022;**71**(21):697-702.
 125. Smeets VM, van Lierop BA, Vanhoutvin JP, Aldenkamp AP, Nijhuis FJ. Epilepsy and employment: literature review. *Epilepsy Behav*. 2007;**10**(3):354-62.
 126. Chaplin J. Vocational assessment and intervention for people with epilepsy. *Epilepsia*. 2005;**46** Suppl 1:55-6.
 127. Wo MC, Lim KS, Choo WY, Tan CT. Employability in people with epilepsy: A systematic review. *Epilepsy Res*. 2015;**116**:67-78.
 128. Chaplin JE, Wester A, Tomson T. Factors associated with the employment problems of people with established epilepsy. *Seizure*. 1998;**7**(4):299-303.
 129. Scambler G, Hopkins A. Social class, epileptic activity, and disadvantage at work. *J Epidemiol Community Health*. 1980;**34**(2):129-33.
 130. Tian N, Cui W, Zack M, Kobau R, Fowler KA, Hesdorffer DC. Suicide among people with epilepsy: A population-based analysis of data from the U.S. National Violent Death Reporting System, 17 states, 2003-2011. *Epilepsy Behav*. 2016;**61**:210-7.
 131. Cross JH, Kwon CS, Asadi-Pooya AA, Balagura G, Gómez-Iglesias P, Guekht A, et al. Epilepsy care during the COVID-19 pandemic. *Epilepsia*. 2021;**62**(10):2322-32.
 132. Begley CE, Basu R, Reynolds T, Lairson DR, Dubinsky S, Newmark M, et al. Sociodemographic disparities in epilepsy care: Results from the Houston/New York City health care use and outcomes study. *Epilepsia*. 2009;**50**(5):1040-50.
 133. Begley C, Basu R, Lairson D, Reynolds T, Dubinsky S, Newmark M, et al. Socioeconomic status, health care use, and outcomes: persistence of disparities over time. *Epilepsia*. 2011;**52**(5):957-64.

134. Puka K, Smith ML, Moineddin R, Snead OC, Widjaja E. The influence of socioeconomic status on health resource utilization in pediatric epilepsy in a universal health insurance system. *Epilepsia*. 2016;**57**(3):455-63.
135. Magnusson C, Zelano J. High-resolution mapping of epilepsy prevalence, ambulance use, and socioeconomic deprivation in an urban area of Sweden. *Epilepsia*. 2019;**60**(10):2060-7.
136. Wilson DA, Malek AM, Wagner JL, Wannamaker BB, Selassie AW. Mortality in people with epilepsy: A statewide retrospective cohort study. *Epilepsy Res*. 2016;**122**:7-14.
137. Cihan E, Hesdorffer DC, Brandsoy M, Li L, Fowler DR, Graham JK, et al. Socioeconomic disparities in SUDEP in the US. *Neurology*. 2020;**94**(24):e2555-e66.
138. Bautista RE, Glen ET, Shetty NK, Wludyka P. The association between health literacy and outcomes of care among epilepsy patients. *Seizure*. 2009;**18**(6):400-4.
139. Szaflarski M, Wolfe JD, Tobias JGS, Mohamed I, Szaflarski JP. Poverty, insurance, and region as predictors of epilepsy treatment among US adults. *Epilepsy Behav*. 2020;**107**:107050.
140. Li X, Sundquist J, Sundquist K. Socioeconomic and occupational risk factors for epilepsy: a nationwide epidemiological study in Sweden. *Seizure*. 2008;**17**(3):254-60.
141. Mattsson P, Tomson T, Eriksson O, Brannstrom L, Weitoft GR. Sociodemographic differences in antiepileptic drug prescriptions to adult epilepsy patients. *Neurology*. 2010;**74**(4):295-301.
142. Rubinger L, Chan C, Andrade D, Go C, Smith ML, Snead OC, et al. Socioeconomic status influences time to surgery and surgical outcome in pediatric epilepsy surgery. *Epilepsy Behav*. 2016;**55**:133-8.
143. Samanta D, Ostendorf AP, Willis E, Singh R, Gedela S, Arya R, et al. Underutilization of epilepsy surgery: Part I: A scoping review of barriers. *Epilepsy Behav*. 2021;**117**:107837.
144. Szaflarski M. Social determinants of health in epilepsy. *Epilepsy Behav*. 2014;**41**:283-9.
145. Pisu M, Richman JS, Martin RC, Kim Y, Kratt P, Clements K, et al. Diagnostic tests and neurology care for Medicare beneficiaries with seizures: differences across racial groups. *Med Care*. 2012;**50**(8):730-6.
146. Szaflarski M, Szaflarski JP, Privitera MD, Ficker DM, Horner RD. Racial/ethnic disparities in the treatment of epilepsy: what do we know? What do we need to know? *Epilepsy Behav*. 2006;**9**(2):243-64.
147. Saadi A, Himmelstein DU, Woolhandler S, Mejia NI. Racial disparities in neurologic health care access and utilization in the United States. *Neurology*. 2017;**88**(24):2268-75.

148. Kharkar S, Pillai J, Rochestie D, Haneef Z. Socio-demographic influences on epilepsy outcomes in an inner-city population. *Seizure*. 2014;**23**(4):290-4.
149. Hjern A. Migration and public health: Health in Sweden: The National Public Health Report 2012. Chapter 13. *Scand J Public Health*. 2012;**40**(9 Suppl):255-67.
150. Rechel B, Mladovsky P, Ingleby D, Mackenbach JP, McKee M. Migration and health in an increasingly diverse Europe. *Lancet*. 2013;**381**(9873):1235-45.
151. Hanssens LGM, Detollenaere J, Hardyns W, Willems SJT. Access, treatment and outcomes of care: a study of ethnic minorities in Europe. *International Journal of Public Health*. 2016;**61**(4):443-54.
152. Feters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. *Health Serv Res*. 2013;**48**(6 Pt 2):2134-56.
153. Socialstyrelsen. Patientregistret: Socialstyrelsen; 2018 [updated 2022-08-17; cited 2022 2022-09-21]. Available from: <https://www.socialstyrelsen.se/statistik-och-data/register/patientregistret/>.
154. Rizzuto D, Feldman AL, Karlsson IK, Dahl Aslan AK, Gatz M, Pedersen NL. Detection of Dementia Cases in Two Swedish Health Registers: A Validation Study. *J Alzheimers Dis*. 2018;**61**(4):1301-10.
155. Wettermark B, Hammar N, Fored CM, Leimanis A, Otterblad Olausson P, Bergman U, et al. The new Swedish Prescribed Drug Register--opportunities for pharmacoepidemiological research and experience from the first six months. *Pharmacoepidemiol Drug Saf*. 2007;**16**(7):726-35.
156. Brooke HL, Talbäck M, Hörnblad J, Johansson LA, Ludvigsson JF, Druid H, et al. The Swedish cause of death register. *Eur J Epidemiol*. 2017;**32**(9):765-73.
157. Edelvik A, Rydenhag B, Olsson I, Flink R, Kumlien E, Källén K, et al. Long-term outcomes of epilepsy surgery in Sweden: a national prospective and longitudinal study. *Neurology*. 2013;**81**(14):1244-51.
158. Ludvigsson JF, Svedberg P, Olén O, Bruze G, Neovius M. The longitudinal integrated database for health insurance and labour market studies (LISA) and its use in medical research. *Eur J Epidemiol*. 2019;**34**(4):423-37.
159. Statistikmyndigheten SCB. Longitudinell integrationsdatabas för sjukförsäkrings- och arbetsmarknadsstudier (LISA): Statistikmyndigheten SCB; [cited 2022 2022-10-26]. Available from: <https://www.scb.se/LISA/>.
160. Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, et al. Standards for epidemiologic studies and surveillance of epilepsy. *Epilepsia*. 2011;**52** Suppl 7:2-26.
161. Sveriges Riksdag. Personuppgiftslag (1998:204). 1998.

162. Broderick JE, DeWitt EM, Rothrock N, Crane PK, Forrest CB. Advances in Patient-Reported Outcomes: The NIH PROMIS(®) Measures. *EGEMS* (Wash DC). 2013;**1**(1):1015.
163. Terwee CB, Bot SDM, de Boer MR, van der Windt DAWM, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology*. 2007;**60**(1):34-42.
164. Cella D, Nowinski C, Peterman A, Victorson D, Miller D, Lai J-S, et al. The Neurology Quality-of-Life Measurement Initiative. *Archives of Physical Medicine and Rehabilitation*. 2011;**92**(10, Supplement):S28-S36.
165. Victorson D, Cavazos JE, Holmes GL, Reder AT, Wojna V, Nowinski C, et al. Validity of the Neurology Quality-of-Life (Neuro-QoL) measurement system in adult epilepsy. *Epilepsy Behav*. 2014;**31**:77-84.
166. Lai JS, Nowinski CJ, Zelko F, Wortman K, Burns J, Nordli DR, et al. Validation of the Neuro-QoL measurement system in children with epilepsy. *Epilepsy Behav*. 2015;**46**:209-14.
167. Tombini M, Assenza G, Quintiliani L, Ricci L, Lanzone J, Di Lazzaro V. Epilepsy and quality of life: what does really matter? *Neurol Sci*. 2021;**42**(9):3757-65.
168. Mroueh L, Boumediene F, Jost J, Ratsimbazafy V, Preux P-M, Salameh P, et al. Quality of life and stigma in Lebanese people with epilepsy taking medication. *Epilepsy Research*. 2020;**167**:106437.
169. Yeni K, Tulek Z, Simsek OF, Bebek N. Relationships between knowledge, attitudes, stigma, anxiety and depression, and quality of life in epilepsy: A structural equation modeling. *Epilepsy Behav*. 2018;**85**:212-7.
170. Snaith RP, Zigmond AS. The hospital anxiety and depression scale. *Br Med J (Clin Res Ed)*. 1986;**292**(6516):344.
171. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983;**67**(6):361-70.
172. Cella D, Yount S, Rothrock N, Gershon R, Cook K, Reeve B, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Med Care*. 2007;**45**(5 Suppl 1):S3-s11.
173. Parkvall M. Språken. Den nya mångfalden: Makadam förlag; 2019 [cited 2021 24th October 2021]. Det nya Sverige · Riksbankens Jubileumsfonds årsbok 2019]. Available from: https://www.rj.se/globalassets/rj-arsbocker/rj2019-2_spraken_den_nya_mangfalden.pdf.
174. Gadamer H-G. Truth and method. 2nd ed: Bloomsbury Academic; 2013. 623 p.
175. Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res*. 1999;**34**(5 Pt 2):1189-208.

176. Halcomb EJ, Gholizadeh L, DiGiacomo M, Phillips J, Davidson PM. Literature review: considerations in undertaking focus group research with culturally and linguistically diverse groups. *J Clin Nurs*. 2007;**16**(6):1000-11.
177. Richard A. Krueger MAC. Focus groups. A practical guide for applied research.: SAGE Publications Inc.; 2014.
178. Jayasekara RS. Focus groups in nursing research: methodological perspectives. *Nurs Outlook*. 2012;**60**(6):411-6.
179. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;**62**(1):107-15.
180. Pocock T, Smith M, Wiles J. Recommendations for Virtual Qualitative Health Research During a Pandemic. *Qual Health Res*. 2021;**31**(13):2403-13.
181. Ensuring Value in Research. Guiding principles 2021 [2022-01-28]. Available from: <https://evir.org/our-principles/>.
182. Connelly LM. Understanding Research. Trustworthiness in Qualitative Research. *MEDSURG Nursing*. 2016;**25**(6):435-6.
183. Malterud K. Kvalitativa metoder i medicinsk forskning: Studentlitteratur AB, Lund; 2011. 286 p.
184. World Medical Association. WMA DECLARATION OF HELSINKI – ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS: WMA; [2022-01-28]. Available from: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.
185. Andersson K, Ozanne A, Bolin K, Tomson T, Zelano J. Valproic acid and socioeconomic associations in Swedish women with epilepsy 2010-2015. *Acta Neurol Scand*. 2021;**143**(4):383-8.
186. NEURO. Neurorapporten 2019: NEURO; 2019 [cited 2022 2022-11-16]. Available from: <https://neuro.se/media/7799/neurorapporten-2019-digital.pdf>.
187. Zelano J, Klecki J, Christensen J, Tomson T, Malmgren K. The provision of epilepsy care across Europe 2017: A 17-year follow-up survey. *Epilepsia Open*. 2019;**4**(1):144-52.
188. Waitzkin H. Doctor-patient communication. Clinical implications of social scientific research. *Jama*. 1984;**252**(17):2441-6.
189. Jacoby A, Baker GA, Steen N, Potts P, Chadwick DW. The clinical course of epilepsy and its psychosocial correlates: findings from a U.K. Community study. *Epilepsia*. 1996;**37**(2):148-61.
190. Dalrymple J, Appleby J. Cross sectional study of reporting of epileptic seizures to general practitioners. *Bmj*. 2000;**320**(7227):94-7.
191. Choi EJ, Lee SA, Jo KD, Yim SB, No YJ, Kwon JH, et al. Factors contributing to concerns of persons living with epilepsy. *Seizure*. 2011;**20**(1):14-7.
192. Rätty LK, Wilde-Larsson BM. Patients' perceptions of living with epilepsy: a phenomenographic study. *J Clin Nurs*. 2011;**20**(13-14):1993-2002.

193. Blomberg K, Brorson L-O, Stenninger E, Eriksson M. Fifty-year follow-up of childhood epilepsy — Social, psychometric, and occupational outcome. *Epilepsy & Behavior*. 2019;**96**:224-8.
194. Kwon CS, Jacoby A, Ali A, Austin J, Birbeck GL, Braga P, et al. Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy-Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy. *Epilepsia*. 2022;**63**(3):573-97.
195. Hohmann L, Berger J, Kastell SU, Holtkamp M. Perceived epilepsy-related stigma is linked to the socioeconomic status of the residence. *Front Public Health*. 2022;**10**:952585.
196. World Health Organization. Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 – 2031: World Health Organization;; 2021 [cited 2022 13-10-2022]. Available from: <https://www.who.int/publications/m/item/intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders2022-2031>.
197. Socialstyrelsen. Nationella riktlinjer för vård vid epilepsi: Socialstyrelsen; 2019 [cited 2022 16-10-2022]. Available from: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2019-2-8.pdf>.
198. Socialstyrelsen. Nationell utvärdering av vård vid epilepsi Socialstyrelsen; 2021 [cited 2022 16-10-2022]. Available from: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2021-1-7161.pdf>.
199. Cramer JA, Blum D, Fanning K, Reed M. The impact of comorbid depression on health resource utilization in a community sample of people with epilepsy. *Epilepsy Behav*. 2004;**5**(3):337-42.
200. Lopez MR, Schachter SC, Kanner AM. Psychiatric comorbidities go unrecognized in patients with epilepsy: "You see what you know". *Epilepsy Behav*. 2019;**98**(Pt B):302-5.
201. Mula M, Brodie MJ, de Toffol B, Guekht A, Hecimovic H, Kanemoto K, et al. ILAE clinical practice recommendations for the medical treatment of depression in adults with epilepsy. *Epilepsia*. 2022;**63**(2):316-34.
202. Elger CE, Johnston SA, Hoppe C. Diagnosing and treating depression in epilepsy. *Seizure*. 2017;**44**:184-93.
203. Munger Clary HM, Croxton RD, Snively BM, Brenes GA, Lovato J, Sadeghifar F, et al. Neurologist prescribing versus psychiatry referral: Examining patient preferences for anxiety and depression management in a symptomatic epilepsy clinic sample. *Epilepsy Behav*. 2021;**114**(Pt A):107543.
204. Austin JK, Birbeck G, Parko K, Kwon CS, Fernandes PT, Braga P, et al. Epilepsy-related stigma and attitudes: Systematic review of screening

- instruments and interventions - Report by the International League Against Epilepsy Task Force on Stigma in Epilepsy. *Epilepsia*. 2022;**63**(3):598-628.
205. Ried S, Specht U, Thorbecke R, Goecke K, Wohlfarth R. MOSES: an educational program for patients with epilepsy and their relatives. *Epilepsia*. 2001;**42** Suppl 3:76-80.
206. Magill N, Ridsdale L, Goldstein LH, McCrone P, Morgan M, Noble AJ, et al. Self-management education for adults with poorly controlled epilepsy (SMILE (UK)): statistical, economic and qualitative analysis plan for a randomised controlled trial. *Trials*. 2015;**16**:269.
207. Streltsov NA, Schmidt SS, Schommer LM, Zhao W, Tosteson TD, Mazanec MT, et al. Effectiveness of a Self-Management Program to Improve Cognition and Quality of Life in Epilepsy: A Pragmatic, Randomized, Multicenter Trial. *Neurology*. 2022;**98**(21):e2174-e84.
208. Pandey DK, Dasgupta R, Levy J, Wang H, Serafini A, Habibi M, et al. Enhancing epilepsy self-management and quality of life for adults with epilepsy with varying social and educational backgrounds using PAUSE to Learn Your Epilepsy. *Epilepsy Behav*. 2020;**111**:107228.
209. May TW, Pfäfflin M. The efficacy of an educational treatment program for patients with epilepsy (MOSES): results of a controlled, randomized study. Modular Service Package Epilepsy. *Epilepsia*. 2002;**43**(5):539-49.
210. Quarells RC, Spruill TM, Escoffery C, Shallcross A, Montesdeoca J, Diaz L, et al. Depression self-management in people with epilepsy: Adapting project UPLIFT for underserved populations. *Epilepsy Behav*. 2019;**99**:106422.
211. Bauer GR. Incorporating intersectionality theory into population health research methodology: Challenges and the potential to advance health equity. *Soc Sci Med*. 2014;**110**:10-7.
212. Hancock A-M. When Multiplication Doesn't Equal Quick Addition: Examining Intersectionality as a Research Paradigm. *Perspectives on Politics*. 2007;**5**(1):63-79.

APPENDIX

1. Background questions (Paper II).
2. Neuro-QoL and Jacoby stigma scale (Paper II).
3. PROMIS Global Health v1.2 (Paper II).
4. Hospital Anxiety and Depression Scale (Paper II).

Bakgrundsfrågor

1. Kön: ☐ Kvinna ☐ Man ☐ Icke- binär

2. Ålder:

☐ 18-24 år ☐ 25-29 år ☐ 30-39 år
☐ 40-49 år ☐ 50-59 år ☐ 60-64 år
☐ 65-74 ☐ 75 år eller äldre

3. Civilstånd:

☐ Ensamstående ☐ Gift eller sambo ☐ Särbo
☐ Separerad ☐ Skild ☐ Änka/änkling/efterlevande partner

4. Har du högskole- kandidat eller magisterexamen?

☐ Ja ☐ Nej

5. Vilken är din högsta avslutade utbildning? Obs! Ange endast ett alternativ

☐ Saknar grundskoleutbildning (eller motsvarande)
☐ Grundskola, låg-mellanstadium (eller motsvarande)
☐ Grundskola, högstadium
☐ Gymnasieutbildning/ Yrkesskola (eller motsvarande)
☐ Högskola/Universitet (eller motsvarande)

6. Arbetsstatus:

☐ Heltidsanställd ☐ Hemarbetande, sköter hushållet
☐ Deltidsanställd eller tillfällig anställning ☐ Studerande
☐ Egenföretagare ☐ Pensionerad
☐ Arbetar inte pga funktionshinder eller
långtidssjukskriven (mer än 3 månader) ☐ Tjänstledig eller föräldraledig
☐ Arbetssökande
☐ Annat _____

7. Om du plötsligt skulle hamna i en oförutsedd situation där du på en vecka måste skaffa fram 15 000 kronor, skulle du klara det?

☐ Ja

☐ Nej

8. Postnummer _____

9. Hur många vuxna ingår i ditt hushåll?

☐ 1 vuxen/ensamboende

☐ Flera vuxna

10. I vilken typ av bostad bor du?

☐ Bostadsrätt/egen villa eller radhus

☐ Hyresrätt

☐ Andrahandsboende

☐ Servicehus/servicelägenhet

☐ Inneboende/studentlägenhet

☐ Annat boende

☐ Är bostadslös

11. Födelseland: _____

12. Antal år levda i Sverige:

☐ 0-11 månader

☐ 1-5 år

☐ Mer än 5 år

☐ Hela livet

13. Huvudspråk som talas hemma?

☐ Svenska

☐ Arabiska

Annat _____

14. Mitt allmänna hälsotillstånd de senaste tre månaderna har...

☐ Förbättrats

☐ Varit oförändrat

☐ Försämrats

Frågor om din epilepsi

15. Vilken/vilka typer av epileptiska anfall har du oftast?

- ☐ Fokalt anfall utan medvetandepåverkan (ex. ryckningar, svettning, ändring i lukt, smak, syn, plötslig känsla av glädje/rädsla)
- ☐ Generella tonisk-kloniska anfall (medvetandeförlust och ryckningar i hela kroppen)
- ☐ Fokalt anfall med medvetandepåverkan (ex. osammanhängande tal, förvirrad, plockar, vandrar, kan gå över till ett toniskt-kloniskt anfall)

16. Hur många år har du haft din epilepsidiagnos? _____

17. Hur ofta har du epileptiska anfall:

- ☐ Inget det senaste året ☐ Ett anfall det senaste året ☐ Mer än ett anfall det senaste året

18. Har du anfall som andra människor ser?

- ☐
- Ja
- ☐
- Nej

19. Har du haft ett epileptiskt anfall offentligt, tex i stan?

- ☐
- Ja
- ☐
- Nej

20. Har någon någonsin ringt en ambulans när du hade epilepsianfall?

- ☐ Ja ☐ Nej

Besvara varje påstående genom att kryssa en ruta per rad.

På sistone....	Aldrig	Nästan aldrig	Ibland	Ofta	Alltid
På grund av min sjukdom har vissa människor <u>undvikit mig.</u>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
På grund av min sjukdom har jag känt mig <u>utesluten från sociala inbjudningar.</u>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
På grund av min sjukdom har människor <u>undvikit att titta på mig.</u>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Jag har känt mig generad på grund av <u>min sjukdom.</u>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
På grund av min sjukdom verkade vissa <u>människor obekväma med mig.</u>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Jag har känt mig generad på grund av mina <u>fysiska begränsningar.</u>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
På grund av min sjukdom har folk varit <u>elaka mot mig.</u>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Vissa människor har agerat som om det var <u>mitt fel att jag har den här sjukdomen.</u>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Stigma-skalan

Nedan följer några påståenden om hur du känner med eller mot andra människor. Sätt ett kryss för det alternativ som passar dig bäst.

På grund av min epilepsi:	JA	NEJ
(a) Jag känner att vissa människor är obekväma med mig.	<input type="checkbox"/>	<input type="checkbox"/>
(b) Jag känner att vissa människor behandlar mig som en sämre person.	<input type="checkbox"/>	<input type="checkbox"/>
(c) Jag tycker att vissa människor föredrar att undvika mig.	<input type="checkbox"/>	<input type="checkbox"/>

Besvara varje fråga eller påstående genom att markera ruta per rad.

	Utmärkt	Mycket bra	Bra	Någor-lunda	Dålig/t					
Hur tycker du att din hälsa är i allmänhet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Hur tycker du att din livskvalitet är i allmänhet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Hur tycker du att din fysiska hälsa är i allmänhet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Hur tycker du att din psykiska hälsa är i allmänhet, inklusive humör och förmåga att tänka?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Hur trivs du med dina sociala aktiviteter och relationer i allmänhet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Hur klarar du dina vardagliga sociala aktiviteter och roller (i familjen, på arbetet eller med andra) i allmänhet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
	Helt och hållet	I stor utsträckning	I viss utsträckning	I liten utsträckning	Inte alls					
I vilken utsträckning klarar du dina vardagliga fysiska aktiviteter, t.ex. att promenera, gå i trappor, bära matkassar eller flytta en stol?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
De senaste 7 dagarna...	Aldrig	Sällan	Ibland	Ofta	Alltid					
Hur ofta har du besvärats av känslomässiga problem, t.ex. att du känt dig orolig, nedstämd eller lättirriterad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
	Inte alls	Lite	Måttligt	Mycket	Extremt					
Hur trött har du känt dig i genomsnitt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Hur har din smärta varit i genomsnitt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	1	2	3	4	5	6	7	8	9	10
	Ingen smärta								Värsta tänkbara smärta	

HADS självskattningsformulär

Läs igenom varje påstående och sätt ett kryss i den ruta som bäst beskriver hur du har känt dig den senaste veckan. Fundera inte för länge på dina svar, din spontana reaktion inför varje påstående är förmodligen mer korrekt än ett svar som du tänkt

1. Jag känner mig spänd eller nervös:

- ☐ Mestadels
- ☐ Ofta
- ☐ Av och till
- ☐ Inte alls

2. Jag uppskattar fortfarande saker jag tidigare uppskattat:

- ☐ Definitivt lika mycket
- ☐ Inte lika mycket
- ☐ Endast delvis
- ☐ Nästan inte alls

3. Jag har en känsla av att något hemskt kommer att hända:

- ☐ Mycket klart och obehagligt
- ☐ Inte så starkt nu
- ☐ Betydligt svagare nu
- ☐ Inte alls

4. Jag kan skratta och se det roliga i saker och ting:

- ☐ Lika ofta som tidigare
- ☐ Inte lika ofta nu
- ☐ Betydligt mer sällan nu
- ☐ Aldrig

5. Jag bekymrar mig över saker:

- ☐ Mestadels
- ☐ Ganska ofta
- ☐ Av och till
- ☐ Någon enstaka gång

6. Jag känner mig på gott humör:

- ☐ Aldrig
- ☐ Sällan
- ☐ Ibland
- ☐ Mestadels

7. Jag kan sitta stilla och känna mig avslappnad:

- ☐ Definitivt
- ☐ Vanligtvis
- ☐ Sällan
- ☐ Aldrig

8. Allting känns trögt:

- ☐ Nästan alltid
- ☐ Ofta
- ☐ Ibland
- ☐ Aldrig

9. Jag känner mig orolig, som om jag hade "fjärilar" i magen:

- ☐ Aldrig
- ☐ Ibland
- ☐ Ganska ofta
- ☐ Världigt ofta

10. Jag har tappat intresset för hur jag ser ut:

- ☐ Fullständigt
- ☐ Till stor del
- ☐ Delvis
- ☐ Inte alls

11. Jag känner mig rastlös:

- ☐ Världigt ofta
- ☐ Ganska ofta
- ☐ Sällan
- ☐ Inte alls

12. Jag ser med glädje fram emot saker och ting:

- ☐ Lika mycket som tidigare
- ☐ Mindre än tidigare
- ☐ Mycket mindre än tidigare
- ☐ Knappast alls

13. Jag får plötsliga panikkänslor:

- ☐ Världigt ofta
- ☐ Ganska ofta
- ☐ Sällan
- ☐ Aldrig

14. Jag kan uppskatta en god bok, ett TV- eller radioprogram:

- ☐ Ofta
- ☐ Ibland
- ☐ Sällan
- ☐ Mycket sällan