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From goat-fall to modern epilepsy surgery—the development of epilepsy care in Norway

Karl O. Nakken[1] · Mia Tuft[2] · Oliver Henning[1]
[1] National Center for Epilepsy, Division of Neuroscience, Oslo University Hospital, Oslo, Norway
[2] Neuropsychology Centre, Oslo, Norway

Abstract

Throughout history, epilepsy has been considered a mysterious and unexplained illness. People with tonic–clonic seizures were believed to be possessed by evil spirits, and in Norway, as in many other countries, these people were stigmatized, discriminated against, and often excluded from society. Only in the second part of the 19th century did a shift take place from a magical to a scientific view of the disease. Nevertheless, until the middle of the 20th century epilepsy was confused with psychiatric illness in Norway. Although people with epilepsy today are not stigmatized to the same degree as before, we still have some way to go.

Keywords
Seizures · Mental disorders · Stigmatization · Tonic–clonic convulsions · Superstitions

The history of medicine is full of fallacies of bygone eras. Throughout the years, the deviant has generated fear and unfortunately condemnation. People with odd and sometimes frightening epileptic seizures are no exception.

Living with epilepsy in Norway in earlier times must have been challenging. The causes of the attacks were unknown, and no effective treatment was available. Prejudices were widespread, and exclusion of those affected was common. For example, children with epilepsy were excluded from the regular school system, and for adults it was difficult to obtain paid work. Moreover, according to old Norwegian laws, epilepsy was a valid reason for breaking the marriage vows, and such discriminating laws lasted up until 1969 in Norway [1].

Old Norwegian terms

In accordance with the English *falling sickness*, "fallesyke" has been the most preferred term for epilepsy in Norway. Falling to the ground during a seizure was considered a consequence of sin; it was a fall toward hell.

Another term directly pointing to a tonic–clonic seizure is "krampe" (cramp). A term referring to the magic view of the traditional agrarian society was "fang," best translated as "to be captured or seized." It springs from the notion that a supernatural force caused the attack, and the convulsions were an attempt to get free.

It has been an old Norwegian tradition to name seizures after the sounds the person makes during the seizures, e.g., pig-fall, cow-fall, or goat-fall. If a seizure resembled a fish in death throes, it was termed fish-fall [2]. Burial fall was used if the person lay as if they were dead during the seizure. "Brotfall," "brotfallssott," and "stjarfi" are other old Norwegian terms for epilepsy [3].

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Fig. 1 ▲ A forest troll as Theodor Kittelsen sees it (1892). Theodor Kittelsen (1857–1914) was a Norwegian painter and drafter. He is best known for having illustrated Norwegian folk tales, and many of his trolls and mystical creatures have become icons in the Norwegian consciousness

Fig. 2 ▲ Theodor Kittelsen's perception of "nøkken" (1904)

Supernatural beings as inflictors of epilepsy

In Norwegian folk medicine, there was a belief that magical powers governed people's lives. In rural Norway, it was widely believed that supernatural people inhabited the woods, mountains, and the underground. These "people" had many names, e.g., "troll" (**Fig. 1**), "hulder," "heks," "spøkelse," "tusser," "vetter," "jutul," "nøkken" (**Fig. 2**), "haugfolket," "skrømt," "varulv," "gjenferd." We have a rich fairytale tradition in which trolls play a prominent role. They are mysteries creatures, dangerous but sometimes stupid, and are mentioned as early as the Viking Age. There are even sections in the legislation that were aimed at trolls.

The creatures most often mentioned in the folk tales about epilepsy were "underjordiske," "hulder," and "nøkken." The "underjordiske" were small characters living in a parallel world to our world, but underneath the ground. A "hulder" (from *huld* = hidden) was a supernatural female being, pretty and fair-haired with a cow tail. If you refused to marry her or have sex with her, she could inflict poverty and epilepsy on you [4]. "Nøkken" was a male supernatural creature living in rivers, by waterfalls, in lakes, and wells, who possessed the same powers to cause epilepsy if he was disturbed or annoyed.

It was of utmost importance that such beings were respected. If you annoyed them, they could punish you by inflicting diseases on you. For example, you should avoid building farmhouses on top of the hidden houses of the "underjordiske," or pouring hot water directly on the ground [2]. In that case, they could punish you by making your children get epilepsy.

Pregnant women were especially vulnerable

For a long time, there was an opinion that pregnant women were especially vulnerable to diseases caused by supernatural powers. To prevent the unborn child from developing epilepsy, the women should avoid stepping over fences that had fallen down and avoid seeing someone cutting down a woven piece of cloth. This imagery was based on the magical principle of similarity; like the falling fence, the child contracted the falling illness [5]. If a pregnant woman saw a fish being slaughtered, the child was at risk of getting fish-fall [2]. In a novel by Knut Hamsun, the winner of Nobel Prize in Literature in 1920, it appears that if a pregnant woman saw a hare, the child risked being born with hare shards [6].

Advice to alleviate the disease

Prayers and rituals

In Norway, as in other parts of the world, for many centuries epilepsy was considered the work of the devil. Thus, exorcism performed by priests was the logical treatment of such a demonized disease. Reading the Lord's Prayer during an ongoing attack was particularly effective. Another piece of advice was to read the Lord's Prayer and Ave Maria three times a day and drink wine mixed with peony root for a month.

Wise-Knut had epilepsy

Blood was long considered to have antiepileptic properties. Knut Rasmussen Nordgarden (1792–1876), named "Wise-Knut," a well-known Norwegian clairvoyant in the 19th century, most probably had temporal lobe epilepsy (**Fig. 3**). In 1820, he was recommended to eat either three slices of bread, each with three drops of blood from sick people, or the heart of a viper captured in the spring before the cuckoo crows [7].

For those with epilepsy, drinking the blood of an executed criminal was considered to have a healing effect. The same applied to powdered skulls [4].

Elk hooves and cemetery soil

If you had epilepsy, you were advised to bathe in water that flowed north. Remedies that were considered to have seizure-protecting or seizure-reducing properties were crushed pearls mixed with chips of reindeer or elk hooves, mustard seeds, juniper berries, and smearing cemetery soil on the patient's forehead [3].

According to Norwegian folklore, to avoid epilepsy one should not use eider down duvets or pillows because the down had fallen from the eider [8].

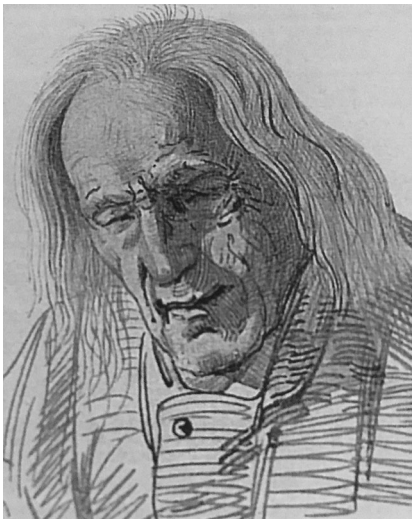

Fig. 3 ▲ Wise-Knut, a Norwegian clairvoyant with temporal lobe epilepsy, drawn by Christian Skredsvig in 1874. Christian Skredsvig (1854–1924) was a Norwegian painter and writer

Fig. 4 ◀ The main house of the farm after the conversion into an epilepsy colony

Goats were associated with epilepsy

For inexplicable reasons, there was a belief that there was a connection between goats and epilepsy. People with epilepsy were to neither eat goat meat or drink goat milk, nor lie on goatskins.

The healing properties of water from St. Olav's springs

One of Norway's most legendary kings was Olav the Saint (993–1030). He was the one who Christianized Norway, and after he fell at the battle of Stiklestad in 1030, he was declared a national saint. He has given rise to many water sources, and if you drank from one of Olav's springs, you could get rid of epilepsy.

Sneaking

"Passing through" was practiced in Norway to combat epilepsy. It involved pulling the sick person through a natural opening in nature, e.g., a natural grown hole in the trunk of a tree. Such trees were rare and made them magic objects. The sneaking was to take place in absolute silence, preferably on a Thursday evening, and it was to be repeated three times [2].

A special seizure knot

According to traditional Norwegian folk medicine, knots were seen as synonymous with conjuring disease. Many sick people wore a woolen thread tied around their wrist. For people with epilepsy there was a special "seizure knot" [9].

Putting the disease in the ground

Putting a disease to the ground was a well-known principle in Norwegian folk medicine. For example, you could stuff the clothes of a child with epilepsy into a doll and then lay the doll out in the terrain. The idea was that the supernatural people, the "underjordiske," would take the doll and thus also the disease [10].

Tearing the clothes off a person having a seizure, burning them, and then making the sufferer eat the ashes was also a treatment option [11].

Epilepsy treatment in Norway anno 1908

In the journal of the Norwegian Medical Association from 1908, there was a brief article on epilepsy treatment. The author warned against eating meat and salt, drinking coffee and alcohol, and smoking tobacco. He recommended bed rest, a lacto-vegetarian diet, bromide salts, baths, and veronal (a barbiturate). "Appropriate stools" were considered important [12].

The legd system

In the 19th century, a distinction was made in Norway between the worthy and the unworthy poor. Children, the elderly, and the disabled who were unable to work were considered worthy and entitled to public support. Poor people who were able to support themselves were considered unworthy and had no right to support.

At the countryside, many of those with epilepsy went on "legd" between farms. The legd system, introduced as early as in the 16th century, was a duty the farmers had toward the poor [13]. Those on "legd," including many with epilepsy, received board and lodging on the farm and participated in the farm work to the extent that they were able to. They could stay at the same farm for up to 1 year. Children with epilepsy could also be on "legd," or they were placed in foster care.

In the cities, many people with epilepsy lived in poorhouses or dollhouses where they received little or no treatment. They were at the very bottom of society's ladder, and a disease such as epilepsy were seen as particularly shameful.

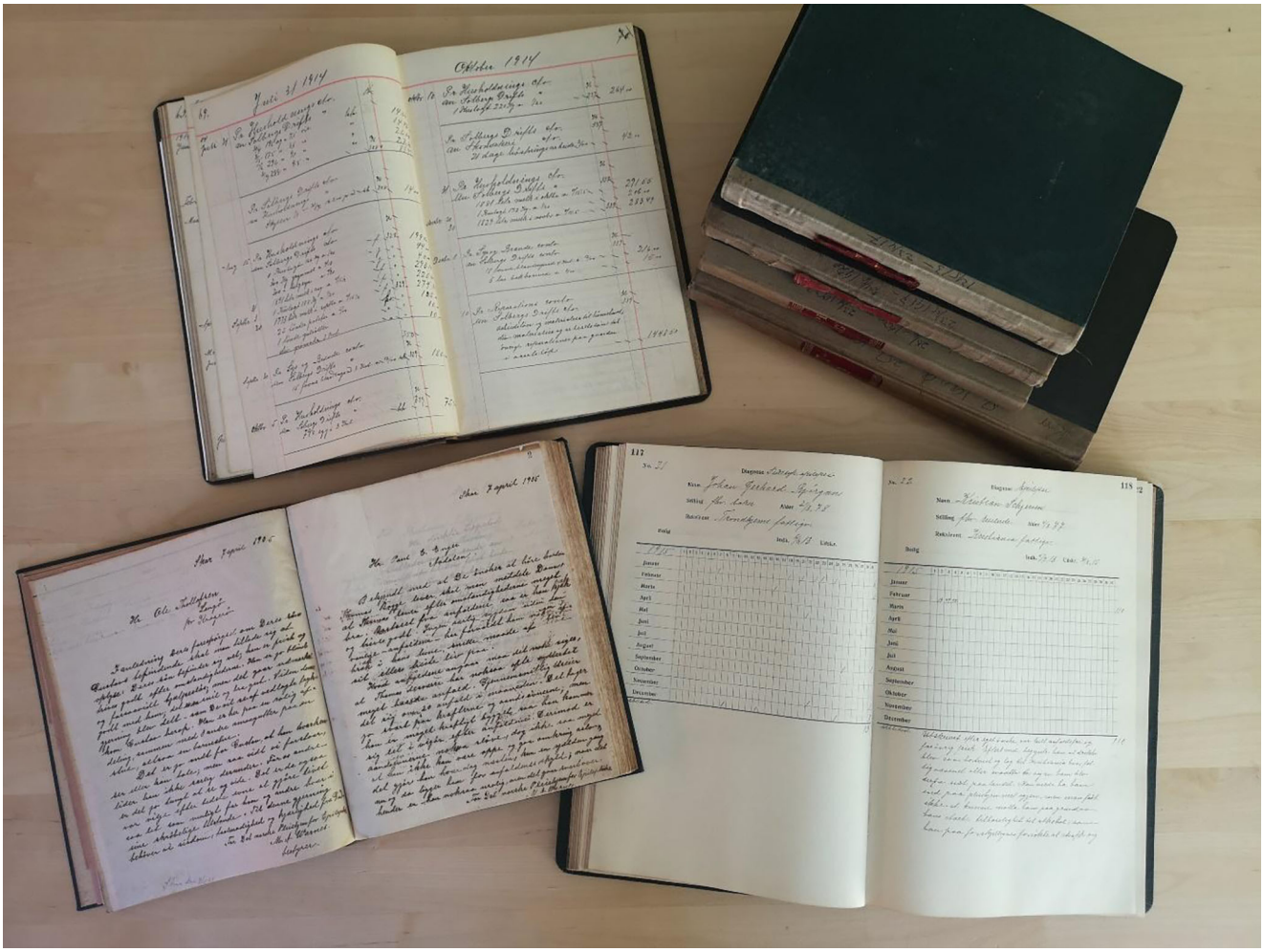

Fig. 5 ▲ The accountant ledgers, correspondence copies, and seizure diaries from the first years of the colony

Epilepsy was long confused with psychiatric illness

In the 19th century, a mixture of people with mental illnesses, developmental disabilities, and epilepsy were placed in the newly established asylums. Although tonic–clonic seizures admittedly were recognized as epilepsy, focal attacks with anxiety, strange behavior, or hallucinations were long interpreted as symptoms of a psychiatric illness in Norway.

Tryggve Andersen (1866–1920), a Norwegian author, is an illustrative case. He wrote an autobiographical novel in 1900, *Mod Kvæld* (*Towards Night*; [14]), in which the main character had episodes of vivid visual hallucinations, just like the ones the author had himself. Andersen became aware of having epilepsy only after 1900. Before that time, he had interpreted the episodes as symptoms of a mental hereditary illness.

Erik Holk, the main character in the novel, wakes up at night and sees a face at the end of the bed: "His nose was big and strong, his cheeks wan and hollow, and he smiled mockingly." He speaks to the figure but realizes soon that the face is not real. He could also have diurnal attacks in which he sees himself as a Lilliput, i.e., seizures with micropsia. The description of the seizure semiology fits with a focal epilepsy originating from right temporal–occipital region [15].

Søren Bloch Laache (1856–1941), a legendary Norwegian medical professor, published the first Norwegian textbook in neurology in 1923. There, he claimed that epilepsy is a neurosis—and a very serious one [16]. In those days, patients with epilepsy were referred to psychiatric hospitals, and there they received the diagnosis "insania epileptica" [17]. The seizures were considered an escape from a difficult life situation or a consequence of repressed sexuality [18].

Establishment of an epilepsy colony outside Kristiania (now Oslo)

In several European countries, epilepsy colonies were established in the latter half of the 19th century. The colonies, most often located in the countryside, came about on the initiative of philanthropists linked to a Christian humanist movement originating in Germany.

In 1895, inspired by these colonies, the deacon Ludvig Waale (1861–1932) established a small epilepsy institution in Kristiania (now Oslo). When it soon became clear that the institution was too small for the purpose, the deacons' association bought

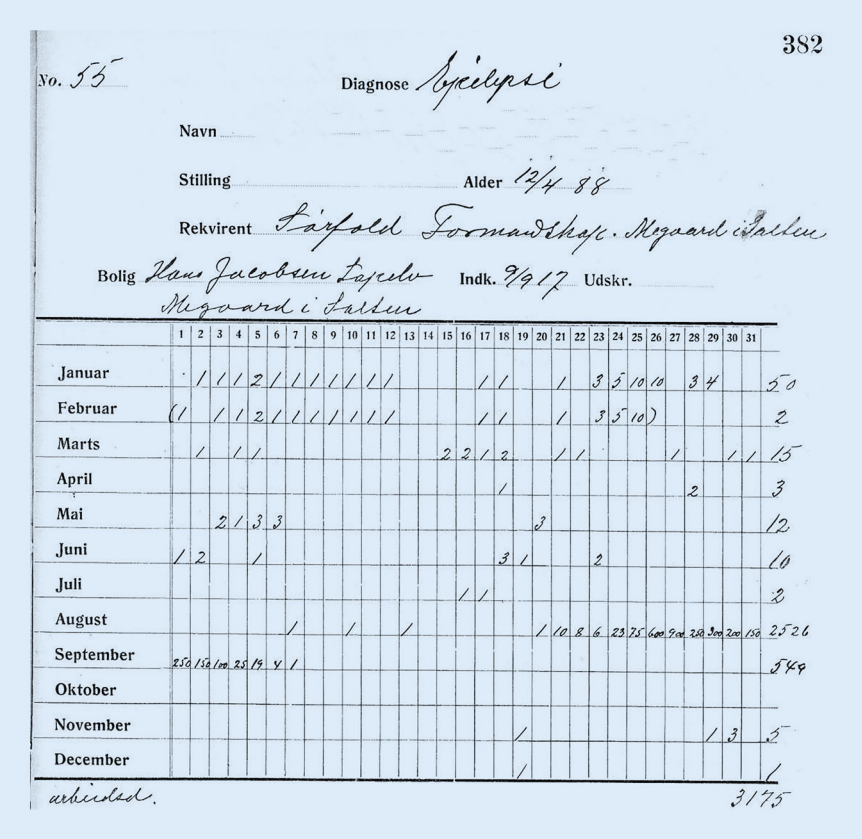

Fig. 6 ▲ Seizure diary of a 29-year-old male patient who in 1918 survived after having had 3072 seizures during a period of 19 days

a farm in Bærum, just outside Kristiania. In 1913, this farm, consisting of 500 acres, was converted into an epilepsy colony with 64 patients (◘ **Fig. 4**).

Overall, 80% of the admissions to the colony were financed by the state, while relatives paid for the remaining 20% [19]. Due to great financial difficulties, the deacons chose to transfer the colony to the state in 1920 [20]. Some years ago, by chance, we discovered copies of the handwritten correspondence from the institution administrator from the first years, the accounting ledgers, and meticulously registered seizure diaries for the patients admitted to the colony (◘ **Fig. 5**).

Frequent seizures and high mortality rate

The patients participated in the farm work to the extent that they were able. During the first 2–3 decades, the finances at the institution were marginal, and there was a shortage of personnel. Some employees found it a great strain to witness the poverty the patients lived under. Women and men lived in separate buildings, and when arguments arose, which was not rare, some could be put in isolation [20].

A seizure calendar was kept for each patient. Some patients had extremely frequent seizures. For example, in August 1918 a male patient had 2526 seizures. The seizures were not sub-classified as we do today, but most of them were probably of the tonic–clonic type (◘ **Fig. 6**).

During the period 1913–1919 there was on average 8.5 deaths (4–24 deaths) per year. As no seizure-stopping drugs were available at that time, many of the patients died in convulsive status epilepticus. The particularly high mortality in 1918 (24 deaths) was mainly caused by the Spanish flu [19].

For most patients, epilepsy was not the only problem

In addition to severe epilepsy, most patients had problems of cognitive, psychiatric, and/or behavioral nature. In retrospect, it is difficult to determine what caused many of the behavioral abnormalities described; the epilepsy etiology, ictal events, postictal psychosis, comorbidities, side effects of the drugs, or something else [19].

About a patient who was hospitalized for 4 months in 1915, it is recorded: "He had to be discharged due to violent behavior. Lately he had to be tied up because he hurt himself. He bit his left little finger, so it had to be amputated." Why this patient behaved violently was not mentioned. The hospital conditions were horrible, and people lived on top of each other.

Few treatment options at first

The majority of patients were treated with bromide salts, mainly potassium bromide. The bromide salts could curb the seizure tendency, but the price was often high. The side effects, called "bromism," could be very debilitating. Most frequently these were fatigue, apathy, mental sluggishness, nausea, drooling, severe acne, pustules and ulcers, irritability, acting out, and even psychosis. Some patients were described as profoundly lethargic. Bromide acne on the face was called "facies epileptica" [19].

After phenobarbital became available in Norway in the 1920s, the patients were offered a mixture of one or two, i.e., a combination of bromide salts and phenobarbital in different mixing ratios. Right up to 1970 they were also given bromide baked into bread (see ◘ **Table 1**).

The bread was to be eaten within 7 days, equally in the morning and evening. The treatment should continue for at least 3 years [21]. A patient recounted during an interview to the local newspaper that he was given bromide bread at the age of 13 (in 1939), and that he recovered completely [22].

An epileptic regime

At the colony, "the epileptic regime" was applied, i.e., the patients should live calm and regular lives without great stress. Rest breaks took place during the day; the more attacks, the more rest. Fasting and fluid restriction were also applied. Because the patients should not have more than one liter of liquid a day, some patients com-

Table 1 Recipe for "epileptic bread" at the colony
Quarter kilo of wheat flour
Quarter kilo of collected wheat
30 g of sodium bromide
Yeast and water
The dough must be kneaded and fermented

plained that their mouth was so dry that they could hardly swallow food [18]. To counteract drug-induced fatigue, the patients should drink 0.10–0.30 g of caffeine in the morning.

Neurologists from the National Hospital in Oslo were responsible for the medical treatment at the colony, and in the 1930s professor Monrad-Krohn introduced handwritten medical records for each patient.

Gradual transformation from an epilepsy colony to a modern epilepsy hospital

The colony's first medical director, Georg F. Henriksen (1904–1981), was well qualified for the task. He had trained as both a psychiatrist and a neurologist and studied epileptology for 1 year with William Lennox at Framingham in the United States. During his tenure (1955–1974), thanks to his efforts and increased prosperity in Norwegian society, the colony was gradually transformed into a modern epilepsy hospital. The hospital acquired its own children's ward in 1955, its first EEG machine in 1957, a laboratory for therapeutic drug monitoring in 1969, and a long-term monitoring (LTM) unit (telemetry) in 1974. In 1975, the hospital had 184 beds: 34 for residential care, 36 for children, and 114 for adolescents and adults.

In recognition that epilepsy is more than seizures, in 1975, the name of the institution was changed from the National Hospital for Epileptics to the National Center for Epilepsy, and multidisciplinary teams were established according to the comprehensive care model [18]. A new children's department was opened in 1996, and an epilepsy-monitoring unit (EMU) with ten beds was inaugurated in 2006.

As part of a National Health Reform, the epilepsy center merged with the National Hospital in 2001. In 2009, after a reorganization of the health service in the southeastern part of Norway, the center became a separate institution under the umbrella of Oslo University Hospital.

Two nursing homes for people with severe epilepsy

In the 1960s, two nursing homes for people with severe epilepsy were established in the southern part of Norway, which is most densely populated. Those admitted to these homes all had additional problems of neurological, cognitive, and/or psychiatric nature. One of these homes (Kure farm) was closed down in 2009, while the other (Røysumtunet) is still in operation with about 90 beds. Epileptologists from the epilepsy hospital supervise the patients here [18].

In 1980, the national health authorities decided that the epilepsy hospital should no longer have residential care, and some of the 34 remaining patients were transferred to these nursing homes.

Development of epilepsy service around the country

Academic medicine is relatively young in Norway. In 1817, the first Norwegian doctor graduated from the Royal Fredrik's University in Kristiania. Unlike most other countries where neurology sprang from psychiatry and neuropathology, Norwegian neurology has its roots in electrotherapy. At the National Hospital in Kristiania, electrotherapy was so widely used that in 1858 a separate electrotherapist was employed [3]. At this hospital, the first Norwegian neurological department was established in 1918, and it became the country's only neurological department for the next 50 years. In the period 1952–1978, this department had a subdivision for epilepsy diagnostics [23].

In the 1950s and 1960s, pediatric and neurological departments were established at the country's largest hospitals, and most people with epilepsy were diagnosed, treated, and followed up there. Before a neurological service was established around 1970 in the three most northern counties, a "travelling epileptologist" (Wollert Krohn) met their needs.

Cases where the diagnosis was uncertain, or in which seizures were difficult to control, were referred to the nearest university hospital or to the National Epilepsy Hospital.

Drastic increase in available anti-seizure medications

After phenytoin was discovered in 1937, the majority of Norwegian patients with epilepsy were treated with a combination of phenobarbital and phenytoin. The majority of patients used a standard dose; 100 mg phenobarbital and 300 mg phenytoin daily. In the 1970s and 1980s there was a shift in the pharmacological treatment, as carbamazepine became the drug of choice for those with focal epilepsy, while valproate became the preferred treatment for those with generalized epilepsy.

Since the introduction of vigabatrin in 1993, a great number of new anti-seizure medications (ASMs) have come on the Norwegian market. Thus, today it is possible to tailor drug treatment to each patient far better than before. However, despite the many new drugs, the proportion of patients with drug-resistant epilepsy has not decreased, indicating that there is still a need for a specialized epilepsy hospital.

The start of epilepsy surgery in Norway

In the period 1947–1949, a Norwegian surgeon, Kristian Kristiansen (1907–1993), stayed with Wilder Penfield in Montreal in Canada. With Penfield he published a book on seizure semiology and the localizing value of the initial ictal phenomena [24]. In 1949, Kristiansen was the one who introduced epilepsy surgery in Norway—at Ullevål Hospital in Oslo. For many years, he was the only one in Norway to perform such interventions. On his initiative, intraoperative electro-corticography was introduced in the 1950s, and he became a driving force behind the establishment of neuroradiology, neurophysiology, and neuropathology in Norway. Kristiansen worked closely with Henriksen at the epilepsy hospital.

The number of patients operated on for epilepsy was rather modest in the next 2–3 decades. When Kristiansen retired in 1977, epilepsy surgery was centralized to two institutions: the National Hospital in

Oslo and the National Epilepsy Hospital in Bærum [18].

After introduction of computed tomography (CT) in 1974, and especially magnetic resonance imaging (MRI) in 1987, it became possible to detect epileptogenic lesions in the brain far better than previously. It ushered in the possibility of surgery for several patients who had earlier been assessed as inoperable.

The surgical processes are carried out at Neurosurgical Department of the National Hospital, while the majority of the preoperative assessments and the postoperative follow-up take place at the epilepsy hospital. In the past 3–4 decades, 20–40 patients have undergone surgery for epilepsy every year in Norway [25].

To identify the precise localization of the ictal onset zone, EEG registrations from intracranial electrodes have been employed in the past 2–3 decades; at first with subdural strips and grid electrodes, and later with depth electrodes, which are inserted under stereotactic MRI guidance.

Since 1993, vagus nerve stimulation has been offered to Norwegian drug-resistant epilepsy patients who are not suitable for surgery. To alleviate seizures, about 25 patients receive a vagus nerve stimulator every year in our country [26].

Epilogue

In Norway, the view and treatment of epilepsy was mainly characterized by magic and superstition before the last half of the 19th century, and there was no organized epilepsy care.

After Ludvig Waale's modest start in 1895, the quality of Norwegian epilepsy care has gradually improved. Although most of today's epilepsy patients receive treatment locally, there is still around one third of the population, in Norway about 12,000 patients, with difficult-to-treat epilepsy who are in need of a specialized hospital. Many of these patients are not only struggling with recurrent, unpredictable seizures, but also with the many psychosocial consequences of the disease. Thus, they are in need of comprehensive and multiprofessional care.

During the past 100 years, attitudes toward epilepsy in Norwegian society have gradually improved. The prejudices are not as pronounced as before, and it is not as shameful or stigmatizing to have epilepsy today as it was in earlier times. Nevertheless, we still have some way to go [27].

Corresponding address

Karl O. Nakken
National Center for Epilepsy, Division of Neuroscience, Oslo University Hospital
Oslo, Norway
karln@ous-hf.no

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Declarations

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Zusammenfassung

Von der Fallsucht zur modernen Epilepsiechirurgie – Entwicklung der Epilepsieversorgung in Norwegen

Schon immer im Laufe der Geschichte galt die Epilepsie als eine geheimnisvolle und unerklärliche Krankheit. Man glaubte, Menschen mit tonisch-klonischen Anfällen seien von bösen Geistern besessen, und in Norwegen – wie in vielen Ländern – wurden diese Menschen stigmatisiert, diskriminiert und oftmals aus der Gesellschaft ausgeschlossen. Erst in der zweiten Hälfte des 19. Jahrhunderts vollzog sich ein Wechsel von der magischen zur wissenschaftlichen Sichtweise der Erkrankung. Trotzdem wurde in Norwegen bis in die Mitte des 20. Jahrhunderts die Epilepsie mit einer psychischen Erkrankung verwechselt. Obwohl Menschen mit Epilepsie heutzutage nicht mehr im gleichen Maße stigmatisiert werden wie früher, sind wir noch nicht im Ziel.

Schlüsselwörter
Anfälle · Psychische Krankheiten · Stigmatisierung · Tonisch-klonische Konvulsionen · Aberglaube