



Case Report

Post-lobotomy epilepsy illustrated by the story of Ellinor Hamsun, the daughter of the famous Norwegian author Knut Hamsun

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ABSTRACT

In Scandinavia, at least 11,500 people were lobotomized in the period 1939–1983. Beside grave personality changes, the surgery caused epilepsy in 10–35% of the patients. Moreover, many died due to perioperative bleedings, convulsive status epilepticus or SUDEP.

Most of the stories of these people are anonymous and their post-lobotomy lives are scarcely documented. If it was not for the fact that Ellinor Hamsun (1916–1987) was the daughter of the famous Nobel Prize winning Norwegian author Knut Hamsun, her lobotomy story and the subsequent iatrogenic epilepsy would probably have remained unknown.

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1. Introduction

Lobotomy was introduced by the Portuguese neurologist Dr. Egas Moniz in 1935 as a treatment for grave psychiatric disorders, mainly schizophrenia. Such psychosurgery soon received a widespread usage, and in the period 1939–1983 at least 11,500 people were lobotomized in the Scandinavian countries; about 4,500 in Denmark [1], approximately 4,500 in Sweden [2], and at least 2,500 in Norway [3]. The procedure caused not only serious personality changes, but 10–35% also developed postoperative epilepsy [1–3].

The destinies of lobotomy victims were rarely documented, but Ellinor Hamsun is an exception.

2. The author Knut Hamsun

Knut Hamsun (1859–1952) was a Norwegian author awarded the Nobel Prize in Literature in 1920. He published more than 20 novels, among the most famous are “Hunger” (1890), “Mysteries” (1892), and “Victoria” (1898). His praising of the simple rural life in “The growth of the soil” (1917) is considered a gospel of agriculture and was the main reason he won the Nobel Prize [4].

He was a famous literary stylist, and pioneered psychological literature with techniques of stream of consciousness and interior monolog. Isaac Bashevis Singer claimed the whole modern school of fiction in the twentieth century stems from Knut Hamsun. Knut Hamsun

influenced authors such as Ernest Hemingway, Franz Kafka, Maxim Gorky, Henry Miller and Hermann Hesse.

Knut Hamsun himself was influenced by authors like Jean-Jacque Rousseau [4–6].

In his old age, his reputation was considerably impaired due to his nazi sympathies before and during World War II [6].

3. Ellinor Hamsun

Ellinor Hamsun (1916–1987) was third of four children of Knut Hamsun and his second wife, author and actress Marie Hamsun [7] (Fig. 1). Ellinor grew up at Nørholm, a small place by the Norwegian south coast. She was a beautiful and charming girl, and she did well at school. When she was 13 years old her father took her out of primary school just a few days before her final exam [7]. She was sent to a monastery school in Germany, later to other monastery schools in France and Belgium.

Her father claimed that women were like flowers; they should be cultivated and worshipped and not be bothered by taking exams. They should go abroad, learn languages, become beautiful ladies, and socialize in the higher social circles. Although disappointed, she kept on loving and admiring her father; “there are many kinds of love” she commented [7].

When marrying Knut Hamsun, Ellinor’s mother had to give up her career as an actress. Her bitterness probably had a negative impact on the family atmosphere [4]. From early on, Ellinor struggled to live up to her parents’ expectations. At one occasion, her mother asked her

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Fig. 1. The Hamsun family in 1917. From left to right: Tore, Marie, Arild, Knut and Ellinor. Photo: Anders Beer Wilse. The Norwegian National Library.

not to eat so much if she was later to be an actress. This may have been the start of her lifelong eating disorder.

3.1. Her years in Berlin

In the period 1936–40 she lived and worked as a film actress in Berlin. At that time, she attended a well reputable German acting school (Fig. 2). In 1938, she married a German film director, Richard Schneider-Edenhöhen [8]. Due to his anti-Nazi attitudes, the couple had to be on the run from the Gestapo during the Second World War. He was still able to make some films, but to her great disappointment, Ellinor was not offered any roles in these films. After the war, her husband separated from her and married his secretary.

Ellinor told a friend that “when I eat it becomes all too much, and to avoid weight gain I put my finger down my throat and throw it all up again” [7]. She never got proper help for her eating disorder. In 1939, a Jewish doctor, Dr. Silberstein, advised her to go home to Norway to get professional help for bulimia. Despite the advice, she chose to continue her acting school, hoping to get roles in German films.

3.2. Psychiatric therapy in Denmark

After her divorce in the postwar period she moved back to Norway. In addition to her eating disorder, she now felt depressed. In 1952 her weight was scarcely 40 kg, and according to her mother she was “unhappy, friendless and looked like the living dead” [8]. Thus, she was sent to Denmark to get professional psychiatric help. During her stays in Danish hospitals she was described as quiet and calm, and her depression was not considered serious. Nevertheless, she was lobotomized twice in Denmark. In 1953, she underwent a standard lobotomy, and in 1956 she was relobotomized, now with a radical procedure.

In the period between the two operations, during a stay in a Danish mental hospital, she was given chlorpromazine for a short period due to what was considered psychosis, most probably a postictal psychosis.

After the second operation her dream about going back to be a film actress was devastated forever. Her Norwegian family did not keep their promise about allowing her to move back to Nørholm and she

spent the remainder of her life, 34 years, in a Danish nursing home in Jylland. She continued to have recurring epileptic seizures, and a friend noted she had a “total lack of initiative” [7].

3.3. Why was she lobotomized?

Knut Hamsun seems to have had a naïve confidence in new medical therapies. Inspired by the Austrian physician Eugen Steinach he himself underwent vasectomy in 1921 believing that such an operation would increase his manhood and delay the aging process [4]. His unlimited trust in the medical profession may have influenced his family [4,8], including Ellinor (Fig. 3).

Why the Danish doctors chose lobotomy in her case is difficult to understand. In retrospect, her symptoms were never so severe as to warrant such a radical procedure.

4. The rational and indications for lobotomy

The aim of a frontal lobotomy was primarily to interrupt or damage limbic-frontal cortical connections, thus interfering with the influence of emotion on the frontal cortex. Both efferent and afferent fibers are damaged in these lesions [9]. After surgery, it was expected that the patients would be less aggressive, experience less anxiety and thus show improved social functioning.

There was a wide variation of surgical techniques. Originally there were three procedures; minimal, standard, and radical [10]. In the minimal procedure the section was cut was placed more anteriorly and was used in patients with predominately affective symptoms. The radical whereas radical lobotomies were extended more posteriorly and medially and were reserved for patients with schizophrenia or those with treatment failures [10].

The American neurologist Walter Freeman introduced and popularized the transorbital lobotomy. He was well-known across the United States and famous for his ad hoc “operating rooms” set up in motel rooms [10,11].

The introduction of the stereotactic technique in the 1950s made it possible to create small precisely placed lesions, particularly in the



Fig. 2. Ellinor Hamsun, unknown date.
The Norwegian National Library.

limbic or paralimbic pathways believed to underlie major affective disorders [9].

In no other parts of the world did the rate of lobotomies reach such high numbers for millions of inhabitants than in the Scandinavian countries [1–3]. Denmark was active in psychosurgery, and here the procedure was called “The white cut” [1].

In the 1950s, at least in Scandinavia, lobotomy was not considered controversial albeit psychopharmacological treatment had become available since 1953 [12]. Although most of those who underwent lobotomy were seriously ill, such as patients with chronic psychosis and aggression, the indications for such surgery were somewhat blurred. From the 1950s up until the 1980s people with a wide range of other diagnoses underwent lobotomy [1–3].

For example in the 1950s people with intellectual disabilities were increasingly lobotomized, and from 1954 this was the largest patient group in Denmark. Children were also lobotomized, including a 6-year old boy that tore things apart and “was impossible to get in contact with” [1].

In Norway, Ørnulv Ødegård, a leading Norwegian psychiatrist, stated that those best suitable for psychosurgery were patients with chronic depression, (i.e. a long-lasting disorder characterized by depression), anxiety, hypochondriasis and restlessness. To achieve an effect on patients with bipolar disorders the surgical section had to be placed posteriorly in the frontal lobe, he claimed. Patients with chronic hypochondriasis, obsessive-compulsive disorder, and those with severe pain were also considered lobotomy candidates. He argued that the effect on schizophrenia was controversial, although this was the patient group most often undergoing the operation [13]. Further he stated that epilepsy patients with aggression could benefit from lobotomy, but “it seems not to work well with imbecile types” [13].

If the patients had epilepsy prior to the surgery, most became worse, but there were also examples of patients who became seizure free (!) [11].

5. Side effects

In the early stage of psychosurgery the attention was mainly drawn to a symptom relief, while a more comprehensive evaluation of the treatment was ignored. However, it was soon evident that these operations were not only associated with serious perioperative complications, but

60–70% developed what was later termed a “frontal lobe syndrome”. This implied apathy, loss of initiative, cognitive failure, irritability, impaired judgment, inappropriate behavior, and reduced capability to structure daily life [1,10]. Peri- and postoperative mortality rate varied due to different surgical techniques and was reported to be 6–27% [1–3,14].

Additionally, 10–35% suffered from post-operative epilepsy [1–3]. A similar percentage was reported from the United States of America [11]. The portion may have been higher, as many patients were sent home after the surgery and received no follow-up care. had no follow-up. This occurred despite the fact that after traumatic brain injuries may produce epilepsy more than 10 years later [15].

However, brain lesions caused by head trauma and lobotomy are not quite comparable. The brain tissue is damaged differently. Lobotomy was “blind surgery” involving the frontal lobe. The risk of developing iatrogenic focal epilepsy increased with surgery near motor cortex, perioperative complications, previous brain disease, young age, and more than one operation [11]. Some patients were operated four times [1]. After the introduction of stereotaxy, increasing minimalism, and greater sophistication of the surgical procedures, the rate of post-surgical epilepsy declined [16].

Soon after her first lobotomy, Ellinor experienced an epileptic seizure. Although a detailed description of her seizure semiology in the medical records is incomplete, she seems to have had frontal lobe epilepsy with frequent focal to bilateral convulsive seizures. Her convulsions always started with a scream, and sometimes she had seizure clusters consistent with seizures of frontal lobe origin [7].

6. Discussion

Lobotomy represents a dark chapter in the history of medicine. Today it is easy to condemn this kind of surgery as a horrible mutilation of man's highest function. Not only was the symptom relief most often doubtful, but the price paid by the patients was all too high as the mortality rate was unacceptable and a significant number ended up with permanent personality changes and iatrogenic epilepsy.

Why Denmark, Norway and Sweden had such high rates of lobotomies, and continued with this practice for such a long time, is hard to explain. The mass media in Scandinavian may have glorified the treatment



Fig. 3. Ellinor Hamsun admiring her father Knut Hamsun.
Photo: Anders Beer Wilse. The Norwegian Folk Museum.

[17]. Moreover, insufficient follow-up of the patients may have contributed to lack of awareness of the serious side effects. Alternatively, information on the side effects may have been actively withheld by the authorities and health personnel [12,18,19]. Today it is difficult to understand why health professionals failed to adjust their practices after several critical studies were published internationally. The story of lobotomy in Scandinavia will hopefully serve as a warning against not continuing a harmful medical practice.

Ellinor Hamsun underwent two lobotomies despite having an eating disorder and minor psychiatric problems. She became a victim of Denmark's liberal psychosurgery practice. The consequences were disheartening; she was institutionalized most of her adult life suffering from recurring epileptic seizures and serious personality changes. Her destiny was in many ways similar to Rosemary Kennedy, the younger sister of John F. Kennedy [10].

The Norwegian government decided in 1990 that a selected committee should investigate the destiny of those lobotomized in Norway. In 1996 it was decided that all those who had been lobotomized could apply for an economical appraisal. About 500 persons received such an appraisal [20]. Ellinor Hamsun died 9 years before this decision was made. Similar appraisals have not taken place in Sweden and Denmark.

7. Conclusion

Ellinor Hamsun (1916–87), the daughter of the famous Norwegian author Knut Hamsun, was lobotomized twice in Denmark in the 1950s due to an eating disorder and depression. Thus, she became one of Scandinavia's many psychosurgery victims. After the surgery she developed frontal lobe epilepsy and grave personality changes. She spent the last 30 years of her life in a nursing home in Denmark.

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