



# Individuals' invisible work continues after epilepsy surgery: A qualitative interview study

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## ABSTRACT

**Objective:** How do persons with epilepsy (PWE) experience their everyday lives after epilepsy surgery?

**Methods:** Qualitative thematic interviews were conducted with eight PWEs (30 to 60 years old). They were recruited when coming for post-operative control 1 to 5 years after epilepsy surgery. The interviews were transcribed. They were analysed by thematic analysis and inspired by Goffman who examines everyday life activities as a theatre play.

**Results:** Before surgery, a substantial invisible and hidden work of adjustments was performed to prevent seizures, to secure help from others if seizures occurred, and to protect oneself from others' gaze during a seizure. This invisible work continued after surgery even for those who became seizure-free; but now for the purpose of protecting oneself from relapse of epilepsy. From the participants perspective there was no or minor change in daily activities among those not becoming seizure-free after surgery. In contrast, those who became seizure-free enjoyed the freedom to participate in social activities without planning or restrictions.

**Conclusions:** A striking finding was that daily life after surgery comprises considerably invisible work to protect a social self, and this preventive and protective invisible work continued, although those who became seizure-free were living an ordinary socially healthy life.

## 1. Introduction

Approximately 40% of the epilepsy population has drug-resistant epilepsy and does not achieve freedom of seizure with antiseizure medication (Engel, 2018). An alternative option for treatment is surgery. Only a small proportion of patients with epilepsy (PWE) undergo surgery (Engel, 2018; Rolston et al., 2016; Kaiboriboon et al., 2015), and only after living with epilepsy for multiple years (Doherty et al., 2003). Several studies have demonstrated an increased prevalence of psychosocial difficulties among PWE (Bautista et al., 2014; Saada et al., 2015; Edward et al., 2015; Quintas et al., 2012; Smeets et al., 2007). The long time before surgery can be detrimental to the psychosocial well-being of PWEs, and this can be challenging to reverse after surgery (Edelvik et al., 2015; Ozanne et al., 2016). Even among PWE who successfully became seizure-free after surgery, increased psychosocial and psychological difficulties have been observed (Wilson et al., 2007, 2001; Bladin, 1992). In addition, surgery may have adverse effects, such as neurological problems, memory and concentration difficulties, anxiety, depression, and fatigue (Ozanne et al., 2016; Coleman et al., 2020;

Edelvik et al., 2017; Liu et al., 2015; Benifla et al., 2008). Preoperatively, PWE may expect better self-esteem and increased social participation after surgery (Ozanne et al., 2016). However, studies have shown no improvement in, for example, self-esteem and workability (Bautista et al., 2014; Saada et al., 2015; Edward et al., 2015; Smeets et al., 2007). Accordingly, the life after surgery may not satisfy PWE's preoperative expectancies and purpose of submitting themselves to surgery.

Standardised questionnaires mostly examine PWE's post-surgery experiences. One study showed that patients who committed suicide shortly after surgery had reached good seizure control and improved quality of life scores (Hamid et al., 2010). However, the authors critically reflected that quality-of-life measures only assess overall health and functioning and do not specifically measure, for example, the patient's sense of self-worth, fulfilment of personal expectations and achievements, nor the impacts on daily life and family dynamics. Another study demonstrated that patients might undertake an identity crisis after surgery as they do not recognise themselves without seizures (Ozanne et al., 2016). This indicates that after surgery, patients must adapt to a new everyday life as seizure-free, which may comprise a

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process of renouncing sickness and learning to be healthy. Transitioning from a sick to a healthy person may include a major change in relationships within a family and with others in the social context (Seaburn and Erba, 2003). Reconciling a healthy way of living after being sick for years has been described as the 'burden of normality', which suggests that those who recover from illness adopt cultural norms about how to live as a healthy person (Wilson et al., 2007, 2001). To our knowledge, no study has used qualitative interviews to explore how patients experience changes in daily activities after surgery. We aim to delve into the individual patient's experiences to gain insight into how daily life was practised after surgery.

Underpinning our study is a theoretical assumption that patients' experiences are created through dynamic, dialectic interactions between a person, illness, her/his engagement in daily life in various social contexts and situations, as well as cultural norms and expectations in our society (Lupton, 2012; Burr, 2003). Personal experiences are understood to be fluid in terms of being continuously shaped and reshaped over time due to what happens with a person and his/her life and illness. Furthermore, a person's present experiences are believed to intertwine with a person's prior life experiences (Kleinman, 1988). Indeed, falling sick is a disruptive event in people's lives where daily activities, habits, social identities, and roles can be considerably disturbed (Bury, 1982; Cassell, 2004). Similarly, to become seizure-free from surgery might be experienced as a disruptive event in a person's life (Seaburn and Erba, 2003). To manage a new and changed situation, either as sick or cured, a person should recreate a coherence between prior and present life prospects, preferences, and social selves (Mengshoel and Feiring, 2020). Accordingly, personal healing or recovery includes biographical, everyday life, and identity work (Corbin and Strauss, 1985). The present study focuses on how everyday life was lived after epilepsy surgery. Through former PWE's concrete descriptions of activities performed during an ordinary day, we assumed that it becomes evident how life, social roles, and identities unfold, and thereby, how prior illness experiences and epilepsy surgery may intertwine with a patient's present experience of daily life. Presently, we intend to interview a heterogeneous sample of patients with various experiences to reach an overall understanding of the phenomenon lived everyday life after surgery. Consequently, our research question is how PWE experience their everyday lives after epilepsy surgery.

## 2. Methods

### 2.1. Study design and ethics

The present study applied an explorative qualitative interview design. During the analysis and presentation of our findings, we focused on maintaining the confidentiality of the participants, as there are few patients undergoing epilepsy surgery in Norway. Our study concurs with the Declaration of Helsinki of ethical principles for medical research, and the study was approved by the Norwegian Regional Medical and Health Research Ethical Board (ref. no. 2018/508). The participants' names are fictitious and used to show that various participants informed our analysis.

### 2.2. Participants

The participants were recruited at a Norwegian specialised hospital for epilepsy among individuals coming for post-operative control. A ward nurse who did not participate in the study group informed potential participants about the study orally and in writing and asked if they were willing to participate. The participants had to be fluently Norwegian-speaking men and women aged 20 to 60 years who had undergone surgery for their epilepsy 1 to 5 years earlier. The participants were included consecutively as they came for post-operative control, and those interviewed varied concerning personal backgrounds, age, gender, employment status, educational and family

backgrounds, and the success of becoming seizure-free. Individuals with severe cognitive problems were excluded based on the evaluation of the nurses at the ward where the patients were hospitalised for control assessments. Those who volunteered for the study were approached by the first author (HML), but three were not interviewed as one had a seizure at the time, and two others had a short stay and a busy program before they departed from the hospital.

### 2.3. Qualitative interviewing

The interviews were conducted by the first author (HML). Beforehand, a thematic interview guide was prepared to address two major themes: how individuals experienced and lived their daily life before surgery for the purpose of contextualizing postoperative experiences, and thereafter, to explore more extensively their experiences of lived daily life activities after epilepsy surgery. They were asked to concretise their experiences by describing what they did during an ordinary day. In addition, the interview guide included detailed questions, which were used as a reminder for the interviewer in case the individuals did not address these issues spontaneously. The researcher pursued the role of being an active listener. The opening question was general: Can you please tell me what epilepsy was like before surgery? Then, more specific questions followed by asking the participants to describe the activities they were engaged in on an ordinary day during epilepsy and at present after surgery. At the end of the interviews, the researcher summarised what she had heard to let the participants correct or nuance the information (Kvale et al., 2009). This often led to further explanations and examples of experiences related to everyday life situations. The interviews were audio-recorded and transcribed verbatim by the interviewer.

### 2.4. Data analysis

The transcribed data material was subjected to thematic analysis (Clarke and Braun, 2018). First, the transcripts were read several times by HML to become familiar with the contents. During this reading, it became obvious that the data material included rich information about daily life activities and challenges in the form of concrete limitations in doing activities, as well as engaging in a more dubious process to manage. For analysing these issues further, we were inspired by Goffman (Vårt, 1992), who examines what people do in everyday life as a theatre play; where activities are performed to pursue roles at the frontstage and visible to the public, and in contrast, other activities that may take place backstage and hidden from the public gaze. Therefore, we asked the following analytical questions to the data material: What activities were performed frontstage and backstage before and after surgery? In the further analysis, information addressing our analytic questions was extracted from the data material and sorted into concrete descriptions of everyday life situations and how they managed challenges before and after surgery. The extracts were coded and clustered into categories. An overarching understanding gradually emerged in writing our analysis, and the analytic themes were refined several times. Although the analysis is described as a linear process, the process moved between the whole data material and the coded descriptions to preserve the contextual meaning throughout the analysis and writing process. In this process, the reflexivity was enhanced by the researchers' different professional backgrounds (occupational therapist, nurse, and physiotherapist) and by our various theoretical competencies within activity theory in occupational therapy, phenomenology, and social interactionism.

## 3. Results

### 3.1. Presentation of the informants

Five men and three women aged between 30 to 60 years were

interviewed. Four were married, three were divorced, and one was single. All, except one individual, were parents to small children, teenagers, or adults with own children. Five participants were seizure-free, and three had some seizures after surgery. The three patients who were not seizure-free experienced reduced seizure frequency and milder seizures in terms of shorter duration that did not lead to convulsive seizures. They continued to use anti-epileptic medication, for further medical information, see Table 1.

All informants underwent neuropsychological tests pre- and post-operatively, as well as mental health assessments for anxiety and depression. Pre-operatively, the intelligence and memory tests indicated medium to high normal range, with varying memory challenges. Post-operatively, the tests were unchanged for most patients, but some showed improvement or persistent impairments. Three reported depressive symptoms which were not new, and two of whom still had seizures after the operation.

At the time of the interviews, three were fully employed (two seizure-free), four worked about 70–80% (three seizure-free), and one continued to be out of work. The time since surgery was 1 year ( $n = 12$  years ( $n = 4$ ), or 5 years ( $n = 4$ ). For three patients, it was their second operation after a prior surgery 10 to 20 years earlier.

### 3.2. Invisible and hidden work to prevent seizures before surgery

To contextualize the individuals' experiences of everyday life after surgery, they were asked to go back in time and describe what an ordinary day was like before surgery. They talked about how epilepsy intruded on their daily activities in various ways. The seizure episodes occurred unpredictably, making their life situation hazardous. Some experienced warnings ahead of seizures and could, to some extent, prepare for it, while others experienced no warnings, and they had to be on constant guard to be prepared in case a seizure should happen. In both cases, the patients had a seizure plan, performed risk assessments, and adjusted their daily life habits and routines to prevent seizure events. However, even though they planned activities to ensure there was someone present to assist them if they lost consciousness during a seizure, they were simultaneously uncomfortable with the thought that people around them should detect that they had epilepsy. Thus, they put great efforts in both the work to prevent possible events of seizures and to camouflage their epilepsy for people around them. These efforts were concealed from others, and therefore, the work became invisible to others. This invisible, hidden work required energy. In particular, the energy costs were high among those who did not tell people close to them that they had epilepsy and constantly strived to disguise their illness. The following quote captures this alertness and effort:

*I wasn't very bothered (about epilepsy). But you had the feeling that now there's going to be a seizure, even though it wasn't coming. It was distressing because you feared it should happen when you're out among others. (Kjetil)*

### 3.3. Visible, ordinary activities and social self after surgery

The informants who became seizure-free expressed a substantial change that was expressed by statements like 'I've got a new life' or 'I've got my life back' again. This implied that they took up valued activities from life before epilepsy or engaged in new activities they found great pleasure in doing. They did not have to take any reservations to prevent seizures anymore. For example, they could go to the store whenever they wanted, run wherever and whenever they wished, and drive a car instead of being a passenger. Furthermore, they could now look after their children without a seizure plan and be safeguarded by the presence of others. The changes are exemplified in these quotes:

For a while, I had to stop running. Because when I came home from the forest and didn't remember more than a fraction of the jogging

trip, I started walking along the road instead. But after the surgery, I started running in the forest again. (Ragnhild)

For me, it's therapy (to do activities). I can get in the car and go for a walk, play music, and enjoy myself. It's been my life all along, and now I can do it again. (Håkon)

A new form of freedom accompanied the transition to ordinary activities after becoming seizure-free. They no longer needed to plan and organise their everyday activities, nor did they depend on others to feel safe. By doing meaningful activities in 'normal' ways, they met their preoperative expectations, but a bonus was their enjoyment of the new-won flexibility in daily life that they prior to epilepsy had taken for granted. They realised that they had spent much energy preventing and worrying about seizures. Now, the released energy was channeled into engaging in prior and new meaningful activities. For this reason, ordinarily, taken-for-granted everyday activities had a new valuable meaning to them, and they experienced that this had transformed their prior passive life role into a more active one, as exemplified by quoting Jacob:

*All worries are gone. I was afraid to go out. I was afraid of new challenges. Now, if I want to go out, I'll go out .... After the surgery, it's a new life; I turned five (years since surgery) in May. I don't go and wait or am afraid of having a seizure. I'm more confident in myself. I work as usual. I live in the village and can use the car to go to visit without preplanning. I've started climbing and hiking in the mountains again without needing assistance from people to get there. I kind of feel like life is more normal (Jacob)*

Their engagement in activities, for example, sports and looking after their children, were visible to others, and so were their increased working time; they were taking on more responsibility and sometimes their careers advanced.

In contrast, such an increased engagement was not seen among those still having seizures. Although those who did not become seizure-free after surgery experienced fewer and less severe seizures, they found the unpredictability of seizures equally difficult. Consequently, they had performed minor or no changes in their everyday activities after surgery. In other words, their everyday life remained more or less unchanged, as described by Vidar:

*The frequency of seizures has somewhat decreased, but I have the same type of seizures and the same type and amount of medication that I had previously. So, the surgery didn't make much change for me. (Vidar)*

Strikingly, despite different outcomes of surgery, everyone emphasised that their motivation to undergo surgery was linked to a wish to return to work or increase their vocational life schedule. They characterised health as being able to work 100%, and if not, this meant being fully or partially disabled, which assaulted their social self. Thus, engagement in social activities and being fully employed had broad meanings to them as one woman uttered, 'it is important to get rid of the stamp on my forehead that says disabled'. Nevertheless, their relationship to epilepsy differed among those being seizure-free as some said, 'I don't have epilepsy anymore', while others said, 'I'm still an epileptic, but I don't have seizures'.

### 3.4. Surgery and new-won healthy life have costs

Those being seizure-free said that they might have had episodes of headaches before surgery, but after surgery, either such episodes had become more frequent or occurred as a new experience. In contrast, the headache was not mentioned by those still experiencing seizures. Several participants said that their memory could have been a challenge before surgery, but now after surgery, their memory had worsened. This was experienced by both those who became seizure free and those who did not. For example, it had become more difficult to remember names, messages, and appointments and recall memories. Such difficulties had a

**Table 1**  
Pre-operative and post-operative information.

Name	Etiology (cause)	Seizure classification & ASM	Pre. op. status work, license & independence	Surgery details	Post.op Seizure classification, Engel, ASM	Post op. status Year, work, license & independence
Per	Focal epilepsy (Structural cause, left temporal lobe, hippocampus sclerosis)	<u>Seizure:</u> FIAS FTC <u>ASM:</u> Yes	<u>Work:</u> Work incapacity <u>D.License:</u> No <u>Independence:</u> Low	Extended hippocampus & prehippocampus resection	<u>Engel:</u> IV <u>Seizure:</u> FIAS FCT <u>ASM:</u> Yes	<u>Post op. 1 year:</u> <u>Work:</u> Work incapacity <u>D.License:</u> No <u>Independence:</u> Low <u>Post op.5year:</u> <u>Work:</u> Full time & increased responsibility <u>D.License:</u> Yes <u>Independence:</u> High
Jakob	Focal epilepsy (Cause unknown)	<u>Seizure:</u> FIAS FTC <u>ASM:</u> Yes	<u>Work:</u> Fulltime job <u>D.License:</u> No <u>Independence:</u> Moderate	Left temporal lobe resection	<u>Engel:</u> IA <u>Seizure:</u> SF <u>ASM:</u> Yes	<u>Postop.5 years:</u> <u>Work:</u> Part time 75-80% <u>D.License:</u> Yes <u>Independence:</u> High
Vidar	Focal epilepsy (Cause unknown)	<u>Seizure:</u> FAS FIAS <u>ASM:</u> Yes	<u>Work:</u> Work incapacity <u>D.License:</u> No <u>Independence:</u> Moderate	Right temporal resection	<u>Engel:</u> IV <u>Seizure:</u> FAS FIAS <u>ASM:</u> Yes	<u>Postop. 2 years:</u> <u>Work:</u> Work evaluation <u>D.License:</u> No <u>Independence:</u> Moderate
Håkon	Focal epilepsy (Cause unknown)	<u>Seizure:</u> FIAS FTC <u>ASM:</u> Yes	<u>Work:</u> Work incapacity <u>D.License:</u> No <u>Independence:</u> Moderate	Excision of cavernoma Right temporal	<u>Engel:</u> IA <u>Seizure:</u> SF <u>ASM:</u> Yes	<u>Postop.5 years:</u> <u>Work:</u> Part time 75-80% <u>D.License:</u> Yes <u>Independence:</u> High
Kjetil	Focal epilepsy, (Structural cause)	<u>Seizure:</u> FAS FIAS <u>ASM:</u> Yes	<u>Work:</u> Fulltime <u>D.License:</u> No <u>Independence:</u> High	Re-resection Right temporal lobe	<u>Engel:</u> IA <u>Seizure:</u> SF <u>ASM:</u> Yes	<u>Postop.2years:</u> <u>Work:</u> Fulltime <u>D.License:</u> Yes <u>Independence:</u> High
Ragnhild	Focal epilepsy (Structural cause)	<u>Seizure:</u> FAS FIAS FTC <u>ASM:</u> Yes	<u>Work:</u> Part time 80% work <u>D.License:</u> No <u>Independence:</u> Moderate	Right temporal lobe resection	<u>Engel:</u> IA <u>Seizure:</u> SF <u>ASM:</u> Yes	<u>Postop. 5 years:</u> <u>Work:</u> Part.time 80% & increased responsibility <u>D.License:</u> Yes <u>Independence:</u> High
Eva	Focal epilepsy (Cause unknown)	<u>Seizure:</u> FIAS FTC <u>ASM:</u> Yes	<u>Work:</u> Part time 50% work <u>D.License:</u> No <u>Independence:</u> High	No access to data	<u>Engel:</u> No access to data <u>Seizure:</u> SF <u>ASM:</u> Yes	<u>Postop. 5 years:</u> <u>Work:</u> Part time 70-80% <u>D.License:</u> No <u>Independence:</u> High
Lene	Focal epilepsy (Structural cause, hippocampus sclerosis)	<u>Seizure:</u> FIAS FTC <u>ASM:</u> Yes	<u>Work:</u> Adjusted work 80% <u>D.License:</u> No <u>Independence:</u> Low	Re-resection Right temporal	<u>Engel:</u> III <u>Seizure:</u> FIAS <u>ASM:</u> Yes	<u>Postop.2 years:</u> <u>Work:</u> Adjusted work 80% <u>D.License:</u> No <u>Independence:</u> Low

Abbreviations:

- FAS: Focal aware seizure
- FIAS: Focal impaired awareness seizure
- FTC: Focal to bilateral tonic-clonic (Focal to generalized tonic-clonic seizure)
- SF: Seizure-free
- ASM: Anti-seizure medication
- The Engel Epilepsy Surgery Outcome Scale:
- Engel IA: Completely Seizure free since surgery
- Engel III: Noticeable reduction in seizure frequency, at least 50% reduction on all seizures.
- Engel IV: There is little or no improvement in seizure frequency or severity post-surgery.

greater impact on everyday activities after surgery than before. For some participants who did not achieve seizure freedom, but experienced improved seizure condition, enhanced assistance for daily tasks was still necessary due to increased memory challenges, as exemplified by Lene:

*I didn't have trouble recognising things before, but it has happened sometimes now. The fact that I've read what's on the package, but I can't understand. So, I read the word, but I don't understand the meaning of it. (Lene).*

Also, the new-won healthy life situation related to being seizure-free had its costs. It was demanding to live up to their own and others' new expectations of them, as expressed in this quote:

*I work 75–80%, and when I get home, I must sleep for two or three hours. I'm fine after some sleep, but I go to bed at half past ten. It's not possible to go to bed at eleven. So, I need a lot of sleep, why that's so, I don't know. But it's just like that, and I must cope with it. (Håkon)*

The adverse effects of brain surgery in the form of headaches and impaired memory had an impact on daily activities and implications for their management. Even positive changes in everyday life activities and feelings of the new-won freedom related to becoming seizure-free had costs related to own and others' expectations. To fulfil a life as healthy may move individuals to the outer limit of their capacity.

### 3.5. Invisible, preventive, and protective work continues after surgery

All the PWEs in this study performed a considerable amount of invisible work to prevent episodes of seizures before epilepsy surgery. This did not change after surgery, and both those becoming seizure-free and those not successfully cured continued to perform invisible work for preventive and protective purposes after surgery. Everyone found it important to preserve their prior routines of regular intake of anti-epileptic medication and uphold a regular lifestyle. Life situations continued to be evaluated and adjusted to limit stress. Thus, they cohered to old routines by following the clock for the intake of drugs, having regular meals, making sure to get enough sleep, and being careful with the intake of alcohol. Even for those being seizure-free, it was important to do so as there were still some worries residing in the background about a risk of becoming ill again. They also shared an uncertainty with those still experiencing seizures about what the worsened or new episodes of headaches meant, and they took precautions as they believed headache was a possible warning sign of either a seizure or relapse of epilepsy, as expressed in these quotes:

*I have never been bothered by headaches before. What made me sceptical was that I felt most of the pain on the side I had surgery (Jakob).*

*I get tired quickly, I do, and I was before the surgery too. I may have become better after surgery at stopping when I feel that now it is enough. It is because I do not want to return to where I was before (Ragnhild)*

Despite the patients being ambivalent about whether the memory difficulties represented a problem, they referred to specific activities in everyday life where they compensated for impaired memory. After surgery, they, for example, wrote memory notes and installed notifications on their mobile phones. Also, they had received test results for neuropsychological assessments at the hospital, but they were uncertain how to deal with the challenges in everyday life. They did their best to disguise and compensate for it, as exemplified in this quote:

*I've lost a little bit of grip on keeping track of names. It was revealed in that test after two years. It came out in the test that I was bad at remembering names. You work out some strategies in relation to the placement of colleagues in meetings, but then a colleague can change the seating, and then it just becomes a mess to me. So, I feel like that's a little bit stressful. (Ragnhild)*

For those being seizure-free, the purpose of the invisible work had

changed from preventing a seizure to preventing a relapse of epilepsy. For the others, the purpose was still to prevent seizures but also to maintain the improvements that they had achieved after surgery. Thus, the invisible and hidden work performed preoperatively was, to a great extent, sustained after surgery, and now the invisible work might also include managing difficulties with memory and episodes of intense headaches.

## 4. Discussion

Four themes emerged from the analysis. The contextualizing theme 'Invisible and hidden work to prevent seizures before surgery' illuminates a regulation of life to prevent seizures, a plan to secure help from others if becoming unconscious during a seizure, and a plan to hide a seizure from others if it eventually happens. After surgery, 'Visible ordinary activities and social self' displays that those free of seizures could take up activities again, and they felt a new form of freedom and flexibility. However, the theme 'Surgery and a new-won healthy life has costs' is showing that surgery may lead to new or more intense headaches and impaired memory that they need to manage. Moreover, a new-won healthy life may bring individuals to the limits of their capacities. 'Invisible preventive and protective work continue after surgery' describes how they prevent and protect themselves from new seizures or relapse of epilepsy, manage headaches and memory difficulties, and maintain an acceptable social self.

Chronic illnesses often intrude and disturb an individual's everyday life (Bury, 2005; Charmaz, 1991). This was also the case before epilepsy surgery, as described by this study's PWE. Regulation of daily life was performed, and we argue that a social self is constructed or shaped by engagement in social activities. A regulated way of living can become observable to people around, and this can have consequences for a person's social self. Thus, our findings confirm that epilepsy has implications for personal identity (Kilinc et al., 2018; Dewar et al., 2020). Adding to former studies, our findings also reveal the considerable invisible and hidden work PWEs do to manage their illness and protect a social self. This hidden work comprises planning how to prevent seizures, manage if it occurs, and at the same time, keep an eventual seizure out of sight to others. Patients' actions to prevent disease flares are also noticed among patients with other chronic illnesses (Charmaz, 1991; Tollefsrud and Mengshoel, 2020). Protecting a body from failure is important for people's functioning in society (Radley, 2004), and a person must maintain body control in social settings (Nettleton and Watson, 1998).

However, the ambiguity in PWEs' dependency on others seems to stand out in our study. On the one hand, they have to plan to get assistance from other people if they lose their consciousness during seizures, and on the other hand, they have a strong wish to protect and hide from the sight of others. For those not becoming seizure-free, this work continues after surgery. For those becoming seizure-free, in the process of adjusting to a seizure-free living, much invisible work continues now to prevent becoming ill again in the future and, secondly, to enable living as healthy people. In both cases, the individuals put efforts into protecting a social self, in the form of concealing an unfavourable illness and keeping up with the ideals of a self as a healthy person who is in control of their own body and contributes on equal terms as other citizens in society. Thus, we recognise 'the burden of normality' as described by Wilson et al (Wilson et al., 2007).

Epilepsy is diagnosed and made visible through deviations in EEG signals. However, for the public, epilepsy first becomes visible through seizures that may frighten or be negatively interpreted by others. For people in general, as described by our interviewees, epilepsy strongly means something is wrong in the brain. The observable cramps during a seizure may remind people about 'madness' portrayed in movies, and the cramps also contaminate a cultural ideal that a person should be in control of their body. This concurs with a recent study suggesting that PWEs may protect a self or identity by separating oneself from the body

and, therefore, consider the brain an objective thing that switches on and off (Kılınç et al., 2018). However, this objectification will not protect the patients against the sights of others and how others consider the situation. Studies show that the fear of social stigma is a strong factor incriminating emotional well-being among PWEs (Kwon et al., 2022; Bautista et al., 2015). Thus, in meeting the public gaze, intriguing questions can be raised about a social self concerning how others perceive a person. Like outlined by Sontag (Sontag, 1990), a person living with HIV/AIDS may need to protect oneself from both the illness and those around, and by hiding the illness, a social self can be preserved. In line with this, our findings indicate that when a seizure goes public, it becomes a source of shame and stigma. Thus, our results suggest that a person must perform visible and invisible illness preventive work, everyday life regulating work, and biographic, protective work. Furthermore, these endeavours seem to be closely interconnected. In the case of those being seizure-free after surgery, our findings concur with Frank's (Frank, 1995) notion that being cured of cancer implies entering a remission society where an individual must live with the worries of falling ill again and a moral obligation to take precautions to avoid it.

After surgery, for those who become seizure-free, the increased engagements in ordinary life activities became noticeable for family and friends as they also became included in the new-won engagements. For these participants, this meant regaining a usually taken-for-granted freedom to decide what mattered to them, and this freedom was highly appreciated and enjoyed. Now, they could perform social activities free from having a seizure plan and participate in activities on equal terms as their family and mates. Unfortunately, this was not the case for those still experiencing seizures. Nevertheless, despite variability in the outcomes of surgery, all patients continued to spend a lot of energy on the invisible preventive work: being careful to get enough sleep, regulating daily life stress, and regularly eating to either prevent seizures or relapse of epilepsy. Thus, after achieving a cure from a longstanding disease, similarly to those having experienced a heart attack (Stevens and Thomas, 2012), epilepsy continues to reside in the background in terms of enhanced attention to bodily signals to take illness precautions. Thus, the new or more intensive headaches and impaired memory after surgery can have a double meaning: something concrete that must be relieved and managed here and now, but also a signal of a plausible future-threatening illness that must be prevented.

The trustworthiness of a qualitative study depends on the clarity of descriptions and coherence between how a study is conducted, theories underpinning the interviews and steps of analysis, and presentation of the results. We have tried our best to develop a clear and coherent description of our study. Our various theoretical understandings are a strength and helped us to raise critical questions during the analysis of the data material, and to the interpretation of the findings. Furthermore, we had a rich and nuanced data material from eight patients differing in age, gender, life situations and outcomes of surgery which is important for the trustworthiness of the findings. However, a qualitative study cannot claim that experiences of everyday life after surgery is similar in other samples. But we succeeded to reveal an aspect of everyday life for patients with epilepsy that at beforehand was not recognized, i.e. the role of invisible work in everyday life among patients with epilepsy seizures that continued after surgery also among those becoming seizure-free. We cannot claim that the phenomenon of invisible work is fully understood, but the analysis revealed a phenomenon occurring among all informants. We consider that this finding is transferable to both other PWE and several other patient groups that have to protect themselves from aggravation of illness or relapses of illness after being cured from disease.

Our findings have clinical implications by pointing out the close interactions between the ill body, daily activities, and threatened social self. It is important to understand the ongoing personal recovery work is including a great invisible and hidden work to protect oneself from illness and maintain an acceptable social self. This means that health

professionals should recognise this complexity, talk about it with their patients, and approach it in consultations. They may even inform and prepare PWEs before surgery about changes in daily life and the continuation of invisible work after surgery as a part of a prehabilitation framework for epilepsy (Baxendale, 2020). Furthermore, more research is needed to understand personal recovery processes after epilepsy surgery, especially regarding managing cognitive challenges and balancing new-won resources and expectations for a healthy life.

In conclusion, daily life with epilepsy is characterised by visible and invisible work to prevent illness, protect a social self, and regulate and adjust everyday life. After surgery, this preventive and protective invisible work continued even for those being seizure-free and engaged in ordinary activities to participate on equal terms in social life as healthy individuals.

#### CRediT authorship contribution statement

**Letèn Helene Myklebust:** Writing – original draft, Writing – review & editing, Formal analysis, Methodology, Data curation, Project administration, Resources, Visualization. **Karterud Hilde Nordahl:** Writing – original draft, Writing – review & editing, Formal analysis, Supervision. **Mengshoel Anne Marit:** Writing – original draft, Writing – review & editing, Formal analysis, Methodology, Resources, Supervision.

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No conflicts of interest to declare.

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