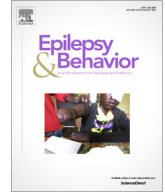




Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Experiences of emotional and psychosocial functioning after frontal lobe resection for epilepsy

Sofia Ljunggren^{a,b,*}, Stefan Winblad^c, Ulla Hällgren Graneheim^{d,e}, Kristina Malmgren^{a,b}, Anneli Ozanne^{b,f}^a Department of Clinical Neuroscience, Institute of Neuroscience and Physiology, Sahlgrenska Academy at Gothenburg University, Blå Stråket 7, SE-413 45 Göteborg, Sweden^b Department of Neurology, Sahlgrenska University Hospital, SE-413 45 Göteborg, Sweden^c Department of Psychology, Gothenburg University, Box 500, SE-405 30 Göteborg, Sweden^d Department of Health Care Sciences, University West, SE-461 32 Trollhättan, Sweden^e Department of Nursing, Umeå University, SE-901 87 Umeå, Sweden^f Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, SE-413 45 Göteborg, Sweden

ARTICLE INFO

Article history:

Received 13 April 2021

Revised 11 May 2021

Accepted 11 May 2021

Available online 1 June 2021

Keywords:

Frontal lobe epilepsy surgery

Emotional function

Psychosocial function

Qualitative content analysis

ABSTRACT

Purpose: Frontal lobe resection (FLR) is the second most common epilepsy surgery procedure in adults. Few studies address neuropsychological consequences after FLR. The aim of this study was to explore patients' and relatives' experiences of cognitive, emotional and social cognitive functioning after frontal lobe epilepsy surgery.

Methods: Semi-structured interviews were held with 14 patients having gone through FLR as adults during the years 2000–2016 and 12 of their relatives. Interviews were audio-recorded, transcribed and analyzed with inductive qualitative content analysis.

Results: Positive as well as negative consequences were described both by patients and relatives. Feelings of relief and an increased capacity to experience emotions of well-being were mainly experienced as related to seizure freedom. A newfound autonomy and a more grown-up identity as opposed to a self-image based on epilepsy was also highlighted. However, results also showed that even for seizure free patients, FLR could give rise to negative experiences, the most prominent of which were mental fatigue, lowered mood and social withdrawal. Coping strategies included planning ahead to avoid mental exhaustion. Over all, respondents considered that the epilepsy surgery had been a risk well worth taking and that positive consequences outweighed the negative ones.

Conclusions: This study shows a range of positive as well as negative outcomes after FLR for epilepsy. The findings indicate that lowered mood and mental fatigue could affect the life situation in a negative way, regardless of seizure outcome. This is important to consider in the preoperative counselling of patients and their families, as well as in the postsurgical follow-up. It is also crucial that the epilepsy surgery team has the possibility to offer rehabilitation and support to families regarding these aspects after surgery.

© 2021 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

1. Introduction

Epilepsy surgery is a well-documented treatment for a selected group of patients with drug-resistant focal epilepsy [1–3]. Frontal lobe epilepsy is, after temporal lobe epilepsy, the second most common surgically treated focal epilepsy. While the cognitive consequences of temporal lobe resections (TLR) have been extensively studied [4–6], there are fewer studies regarding frontal lobe resec-

tions (FLR). There are several possible explanations for this, one of them being that the patient group is heterogeneous regarding resected area within the frontal lobes. Another is that the frontal lobes themselves accommodate a number of various and complex functions that are not easy to assess with neuropsychological tests or rating scales [7,8]. Studies have shown inconsistent results, some pointing toward cognitive improvement in aspects of executive functions if seizure freedom is achieved [9], others showing cognitive stability as the major finding while a minority of patients suffer decline [10–12]. One study pointed out that presurgical depression could be associated with poorer postoperative executive functions [13]. Frontal lobe epilepsy can be associated with deficits in social cognition and emotional functions [14,15] but how this might be affected by surgery has only been the focus of

* Corresponding author at: Department of Clinical Neuroscience, Institute of Neuroscience and Physiology, Sahlgrenska Academy at Gothenburg University, Blå Stråket 7, SE-413 45 Göteborg, Sweden.

E-mail addresses: sofia.ljunggren@vregion.se (S. Ljunggren), Stefan.winblad@psy.gu.se (S. Winblad), Ulla.hallgren.graneheim@umu.se (U. Hällgren Graneheim), Kristina.malmgren@neuro.gu.se (K. Malmgren), Anneli.ozanne@gu.se (A. Ozanne).

a limited number of studies [16]. Existing results point toward improved quality of life after FLR and also lower scores on depression scales and reduced apathy [17–19]. Stability in psychological symptoms measured by personality assessment questionnaires is another finding [20].

Not much is known about patients' own experiences of cognitive or psychosocial consequences of epilepsy surgery, especially not after FLR. Studies that address subjective experiences of epilepsy surgery have mainly focused on TLR, both short- and long term [21,22], others have specifically focused on experiences after epilepsy surgery in childhood [23–26]. This qualitative study aimed to explore both adult patients' and relatives' experiences of cognitive, emotional, and social cognitive functioning after FLR for epilepsy.

2. Materials and methods

2.1. Subjects

Fourteen adult patients (ages 20–64 years, $Md = 40$) who had undergone FLR for epilepsy at Sahlgrenska University Hospital during the years 2000–2016 and 12 of their respective relatives (six parents, five partners, one aunt) were included in the study. Median age at surgery was 29 years following a median duration of epilepsy of 10 years (range 1–25 years). Median time since surgery was 11 years (range 2–15 years). Five of the patients had resections in premotor or supplementary motor area (SMA), four had lateral resections, four had mesial resections and one had an orbital resection. Nine of the patients were male, five were female. One patient had a major complication (sensory and motor deficit in right hand), one had a minor complication (speech difficulties and motor deficit in right hand, which resolved within three months) and one had an overgoing psychosis during the first two years post-surgery. One patient scored above cutoff for depression in the Hospital Anxiety and Depression Scale [27] at the time of the interview. Inclusion criteria for the relative were that he/she had known the patient well before surgery and still had a close relationship with the patient at the time of the study. During the time period studied, 20 patients with frontal lobe epilepsy had been operated, three of whom declined participation and three were unreachable. One of the patients did not have a close relative to ask for participation and in one case practical issues came in between for the relative who was supposed to participate. Ten patients (71%) were seizure free (without aura, ILAE class 1) [28], two had a better seizure situation postoperatively (ILAE class 4) while two had an unchanged seizure situation (ILAE class 5). Four of the six patients who declined participation or were unreachable were seizure free and two had a better seizure situation than preoperatively. Median age at surgery was 28 years following a median duration of epilepsy of 10 years (range 5–35 years). Two of them had mesial resections, two had lateral resections, one had a premotor/SMA resection and one had an orbital resection. Four were female, two were male.

Informed consent was obtained from the participants. They also had the possibility to ask questions about the study and were informed that, if the interview had given rise to further issues to discuss, they would be offered a follow-up meeting with a psychologist. Patients, but not relatives, received a taxable fee of 500 SEK.

2.2. Data collection

The semi-structured interviews included questions covering experiences of cognitive, emotional, and psychosocial changes after epilepsy surgery, how to cope with them, and how quality of life was affected by perceived changes. Example of questions

were “Since surgery, have you experienced any changes regarding your emotional abilities?”, “In what ways have these changes that you have described affected your quality of life?” and “Is there anything in your relatives' “former me”, that is before surgery, that you miss?”. Follow-up questions like “Could you describe more about that?”, “Could you give examples of when you notice this?” and “Would you like to explain how you feel?” were used to deepen the content. See [supplementary information](#) for interview guides. All respondents were interviewed by the neuropsychologist responsible for the study (SL), patients at the hospital (except for one patient who was interviewed by telephone) and relatives by telephone. Interviews lasted 20–62 min, were audio recorded and transcribed verbatim. Data collection was made between January 2016 and October 2018.

2.3. Data analysis

Data were analyzed by qualitative content analysis which is a structured method designed to systematically analyze written or verbal communication [29,30]. Interviews were read several times before the text was divided into meaning units, then condensed and coded [31]. The analysis was inductive, which implies no theoretical framework was used to make meaning of the content but the respondents' own words were leading the analysis [31]. The codes were then sorted according to similarities and differences, abstracted into subcategories and then further abstracted into categories representing the manifest content. Finally, the categories were abstracted and interpreted into a theme representing the latent content [32]. The first (SL) and last (AO) authors conducted the initial selection of meaning units, condensation, coding and a preliminary categorization. Then, to create a wider analytic space and enhance trustworthiness the first (SL), third (UHG), and last authors (AO) jointly reflected on and discussed the meaning of the codes and the naming of categories and theme. Special attention was given to codes and categories upon which the researchers disagreed [33]. As qualitative content analysis is a non-linear process the researchers moved back and forth between the original text and parts of the text during these phases in the analytic process [31,32]. Finally, all authors discussed and reflected on categories and theme until consensus was achieved. The authors had different pre-understanding of the subject, SL and KM had a patient-neuropsychologist/doctor relation with a majority of the patients, AO and UHG were experts in the methodology used and SW had neuropsychological expertise.

2.4. Ethics

Ethical approval for the study was granted by the Regional Ethics Board in Gothenburg (EPN 613-16). We ensured that the work described has been carried out in accordance with the Declaration of Helsinki. Transcribed interviews were deidentified and only accessed by the researchers responsible for the study.

3. Results

3.1. Finding contentment in success and setbacks

The theme was derived from the categories below (see [Table 1](#) and text) and illustrates respondents' different as well as shared experiences from frontal lobe epilepsy surgery. Experiences range from very positive outcomes with increased autonomy and more joy in life, illustrated by the category “Increased zest for life”, to descriptions of increased psychological distress, mental fatigue, and social withdrawal which are included in the category “Withdrawal from social interaction”. Respondents have described how

Table 1
Conceptual map of the data including main theme, categories and subcategories.

Theme	Finding contentment in success and setbacks		
Categories	Increased zest for life	Withdrawal from social interaction	Deal with a changed everyday life
Subcategories	Emotional access and feelings of relief A risk worth taking	Loss of energy and lowered mood Reduced ability to experience and express emotion	Plan for shortcomings Thoughts about causality

they coped with the changes to try to find contentment with their new life situation, this is shown in the category “Deal with a changed everyday life”.

3.2. Increased zest for life

Patients described how life after surgery had been more joyful, that they had been able to relax more and experience emotions in a new way. They expressed gratitude and relief for having had the chance to go through this treatment, had dared to take the risk and that it had turned out so well. Relatives agreed that their family members had been more life-affirming since surgery and that they had been able to live a more “normal” life.

3.2.1. Emotional access and feelings of relief

The patients, especially those who became seizure free, described positive emotional changes and increased access to emotions. Increased passion and capacity for joy and pleasure was reported, along with a new capacity to long for things in life. Being able to relax and enjoy things like having a cup of coffee and listening to the birds was described together with decreased fear of seizures and a more optimistic attitude.

“Yes, I find it a bit easier regarding emotions now compared to before. I find it easier to laugh, easier to cry, all sorts of emotions. It is simply easier.” (Patient 1)

They also argued that more energy due to absence of seizures made it possible for them to pay more attention to other people’s emotions and to be able to regulate their own emotions in a better way. Better self-awareness and empathy were also experienced, combined with gratefulness over life and increased maturity leading to better social skills.

The patients thought that they had a slight change in temperament after the surgery, primarily toward a calmer personality. They found it easier to control anger and did not experience restlessness and hyperactivity as much as they used to. This was, by some of them, experienced as a relief. Profound changes in behavior, approaching changes in self-image and personality, as well as a more reflective attitude were described. Patients also found an increased self-awareness and a self-image of themselves as normal, as opposed to being a person with epilepsy.

Relatives also described positive emotional changes. They thought surgery and seizure freedom had made their family members happier, not having to deal with worry about seizures. This was described as resulting in a new independence and sometimes even a partly new identity, a grown-up identity.

“Yes, as most people having known him over a long time say, he is much happier now, and most of all more positive and, yes, full of life.” (Relative 6)

3.2.2. A risk worth taking

Although patients were suffering from increased mental fatigue and other problems post-surgery they were very content with the changes that the surgical treatment had given rise to. This was not solely related to seizure freedom; seizure reduction was also stressed as very meaningful as well as increased autonomy and less fear of seizures. The positive consequences outweighed the

negative ones and they concluded that it had been a risk worth taking. Relatives also thought that negative side effects were worth risking to achieve seizure freedom or reduction and they agreed that the decision to accept surgery was right. They expressed that there had been no alternatives, as quality of life before surgery was heavily affected by severe epilepsy.

“The only thing I miss is some motor function, because I play the guitar, I notice it in particular when I play classical guitar. I miss that a little, but the little that I miss in sensory and motor function I have gotten back thousand-fold by getting rid of the other, so it was a very low price to pay for that, for what it gave.” (Patient 7)

3.3. Withdrawal from social interaction

Patients described that their social lives were maybe the part that was most negatively affected after surgery. This was primarily due to loss of energy, less passion, and curiosity for things in life as well as lowered mood.

3.3.1. Loss of energy and lowered mood

While some respondents experienced positive emotional changes post-surgery, others described the opposite irrespective of seizure freedom. Patients as well as relatives provided descriptions of energy loss, emotional instability, increased irritability, lowered mood, and depression.

“I do believe that the fact that he avoids these grand mal which he had before... it must have affected his quality of life in a very... in a positive way. At the same time, his mood is lowered, or he is a bit duller. Yes, not quite as curious as he used to be. Not as... not as life-affirming as he actually was before. [...] Yes, he is more depressive in a way, I believe.” (Relative 1)

A tendency to isolation and withdrawal from social interaction was present. Lowered self-esteem, sleeping problems and restlessness was described. The decreased mental health was sometimes prominent and under medical treatment. Suicidal thoughts were expressed, related to depression and bitterness over lost years and a feeling of being punished combined with feelings of guilt. Lack of passion for things in life and decreased experience of joy and happiness were emphasized as potential explanations for the lowered psychological well-being. Some thought that the decreased motivation and apathy had led to practical consequences such as not being motivated to seek a job.

“Earlier, I was just sad. Now the depression has more of a cognitive character, I mean the memory, I can’t localize where I am, I have difficulties to concentrate, difficulties starting with things, I don’t have the engine inside me any more – I am not precisely depressed as in sad but things just crash.” (Patient 5)

“Yes, he behaves more... he is more aggressive, or becomes angry and irritated faster and, yes, compared to what he was like before, because he was a very calm person before surgery.” (Relative 11)

Less spontaneity was described, often because of reduced energy. Mental fatigue led to a more withdrawn life style and some patients felt as if they were much more tired than their friends, forcing them to decline social contact and happenings. Being

unable to take part in social life because of chronic headache and phonophobia was also mentioned. They described themselves as more boring persons now, compared to before surgery, but the degree of acceptance of the needed life style change varied. There were descriptions of changed values in life, as a way of accepting the reduced energy and that could also be a relief. Focus shifted from the wider social arena to the closest family and that could be accompanied by gratitude that the family was there and could make smaller things in life meaningful. Other respondents, patients as well as relatives, described the energy loss as consistently negative and expressed sadness over the reduced capacity to take part in social activity.

“He has become more withdrawn, in the past he had more friends and so forth. [...] When we meet friends, I am the one who makes it happen”. (Relative 7)

3.3.2. Reduced ability to experience and express emotion

Reduced passion and capacity to experience joy and happiness were tough changes post-surgery. Knowing what you used to like but not experiencing the same joy while doing it led to less activity and a more withdrawn life. The ability to experience any emotions was decreased, leaving a feeling of numbness or emptiness.

“...before I experienced a lot of feelings myself, I mean feelings of joy inside and things like that. [...] This is all gone now, I mean.” (Patient 11)

Relatives also noticed that their family members seemed more emotionally flat after surgery. They missed the joy in their relatives, leaving an uncertainty about how they felt. A common answer to the question if it was something they missed in their family member after surgery was that they missed “the happy person”. Some of them had a rather straight-forward communication with their relative about this while others just felt that their family members were less happy now.

“Yes, [if I miss anything] it would be those, as I call them, true laughs, sort of this spontaneous joy.” (Relative 5)

Reduced empathy was described, not as a totally new phenomenon but as an increase in existing difficulties since the surgical treatment. This led to social withdrawal and a shameful feeling of being different. By contrast, there was also a fear of how other family members were affected by the reduced empathy. Thus, it was not a question of reduced insight but a notion that empathic abilities used to be more developed and experienced.

3.4. Deal with a changed everyday life

This category comprises how respondents dealt with the perceived changes, mentally and in a very concrete way through alterations in behavior. It became obvious that they had different ways of handling the new situation and that they attributed the changes in behavior and emotion to various things.

3.4.1. Plan for shortcomings

Patients who experienced changes in behavior, emotion, or cognition described how they managed this. The themes that emerged were to a large extent related to the experience of having less energy. Patients felt that they have had to become better at planning ahead, so that they could foresee how much activity they could manage in a week for example. Concrete schedules of planned activities were mentioned as a way to manage apathy and motivation difficulties. It was also about saying no and being better at prioritizing oneself, which in turn was dependent on an acceptance for the reduced energy. They thought that they had

become better at “living in the moment” and not taking life for granted. Memory strategies, mostly introduced by relatives, were a vital part of everyday life post-surgery.

“It is more that I have to plan my life very much. If I know that I am going to do something in the evening, I have to rest for a while to manage.” (Patient 10)

“It’s just that you maybe have to push him a bit more.” (Relative 7)

3.4.2. Thoughts about causality

Reflecting upon whether experienced changes in emotion, behavior, or values really were related to surgery was a common theme among the respondents. Some speculated that aging was maybe just as important in changing energy potential and social outgoing behavior, while others were quite certain that it was the mental fatigue after the surgical treatment that was the explanation. Humbleness and more developed empathy as a result of increased life experience was discussed as well as increased maturity and insight. The patients also touched the subject that their brains never had been healthy, due to the etiology behind the epilepsy, and that emotional or social cognitive deficits may have been there before surgery. This reflects different ways of dealing with the perceived changes where certain respondents tended to reduce the importance of the surgery and others instead blamed the surgical treatment for negative side effects. To sum up, some respondents thought it was difficult to know which changes were due to having undergone brain surgery and which would have happened anyway as part of life.

“It feels like I had more energy before, at the same time I was considerably younger.” (Patient 3)

“And it is always so hard to attribute things; what comes from surgery, what comes from medication, how do all these parts contribute?” (Relative 6)

4. Discussion

This study shows that patients and relatives experience a range of positive outcomes after FLRs for epilepsy. Patients described feelings of relief and an increased capacity to experience emotions of well-being, mainly related to seizure freedom. A newfound autonomy and a more grown-up identity as opposed to a self-image based on epilepsy was also highlighted. Even patients who did not become completely seizure free could experience relief if seizures were milder and/or if seizure frequency was lower. Feelings of gratitude and a more reflective attitude were described, partly leading to increased self-awareness and a better capacity to handle difficult emotions. However, our results also show that even for seizure-free patients, FLR can give rise to negative experiences where the most prominent ones regard mental fatigue, lowered mood and social withdrawal. Respondents described that patients suffered from apathy and fatigue and that they seemed less happy than before. Respondents agreed though that the surgical treatment was a risk worth taking and that the positive consequences outweighed the negative ones. Patients and relatives also described how the differences in energy level, mood, and emotion had affected daily life and that coping could include reducing the amount of leisure activities as well as planning ahead to avoid mental exhaustion.

4.1. Findings regarding negative experiences after FLR

Previous studies regarding quality of life and social functioning after epilepsy surgery have shown mainly positive results [2,34].

This is also the case after FLR [17–19]. These findings are partly supported by our study and mainly described as related to seizure freedom or seizure relief. Seizure-free patients could after reorientation establish a new sense of self without epilepsy and develop a perceived “normal” identity. However, results also emerge which are associated with negative experiences during the aftermath. These include lowered mood, social withdrawal and less energy to participate in daily life or leisure activities. To the authors’ knowledge, this is the first report on negative experiences after FLR. Dissatisfaction with seizure-free patients’ social functioning after TLR has however been described by both patients and their families [35]. These negative experiences might be associated with the concept *burden of normality*, i. e., related to the new life situation in which expectations and demands rapidly change when a person becomes seizure free and therefore by others regarded as healthy [36–38]. Coleman et al. [21] recently found that this kind of reorientation in life is described as crucial during the first five years after epilepsy surgery and after that most of the patients have adapted to the new life situation. Since the majority of patients in our study were interviewed more than five years post-surgery, the negative experiences described cannot be attributed to a reorientation phase but understood as more long-term. Findings from this study highlight that individuals having undergone FLR can have emerging difficulties which need consideration in daily life and might affect psychosocial function in partly different ways than being affected by epilepsy did. It also highlights the need to focus on coping strategies and involvement of family members in the rehabilitation process to avoid unrealistic demands and relational conflicts.

Depression, fatigue, and apathy can be hard to distinguish from one another as they are all a part of the same spectrum of symptoms which can arise in relation to neurological disease or neurosurgical treatment [39]. This study does not aim to clarify how these symptoms should be understood but emphasizes that further studies are warranted as these domains recur in a majority of the interviews. Knowledge about fatigue after neurological disease and brain surgery has improved over the last decades [40–42] although it is still hard to measure or fully understand its consequences. One possibility is that the experience of fatigue might reduce the possibilities to engage in social activities which in turn can lead to social isolation and lowered mood. If fatigue influences mood and sociability in this way, this may provide an understanding of the experiences of reported negative social consequences by patients and family members.

Negative experiences were commonly reported even though the proportion of seizure-free patients was high in this study population (71%), compared to what is normally reported in FLR outcome studies [43,44]. This is an important finding since patients and relatives tend to focus on the chances of seizure freedom and there could be a tendency to hope and believe that the majority of the patients’ problems would resolve if seizure freedom is achieved. It is also worth to comment on the fact that the majority of the negative experiences were related to mood and fatigue while there were few descriptions of cognitive impairment from both patients and relatives. Neuropsychological studies regarding FLR have pointed toward cognitive stability at group level whereas subgroups might experience problems with executive functions and language abilities [10,11,45]. Findings from this study can be interpreted to support cognitive stability through the lack of descriptions of cognitive problems among both patients and relatives. Furthermore, the focus from both patients and relatives on emotional and social cognitive difficulties suggests that standardized neuropsychological assessment might not be enough to grasp the kind of difficulties experienced after FLR.

4.2. Clinical implications

This study contributes in several ways to increase the knowledge upon which the epilepsy team relies when patients are counseled prior to surgery. It contributes with important data regarding patients’ and relatives’ experiences after FLR, data which are not easily obtained from standardized neuropsychological testing or from medical follow-up. To take a decision about undergoing brain surgery is probably one of the toughest and most important decisions an individual faces in his or her life with epilepsy, recently described as a major turning point in life [21]. The epilepsy surgery team must provide as much information as possible to facilitate this decision and to assure that the patient can get a perception of what life might be like after surgery. This is a complex process which demands a lot from the epilepsy team but also from the patient. Multivariate regression models have identified factors that predict cognitive decline after TLR [46–48], which can be of great value when discussing before surgery potential cognitive costs at an individual level with patients and relatives. However, when it comes to FLR no such models are available, reflecting the dearth of cognitive follow-up studies for this patient group. One study points out that presurgical depression predicts a larger degree of executive dysfunction after FLR [13] which might reflect the impact emotional status has on this patient group. In line with our findings, a thorough psychiatric assessment is needed both before and after surgery to delineate which of the symptoms described could be perceived as depression and treated, to optimize experienced outcome. The possibilities to predict individualized cognitive outcomes after TLR have also given rise to work on cognitive rehabilitation and *prehabilitation* [49]. This last concept includes preparing the individual to manage expected cognitive deficits post-surgery e. g., by adapting strategies before the surgical treatment. Regarding FLR, the situation is much more difficult because of the lack of long-term follow-up studies and prediction models. Rehabilitation is despite this just as important to highlight since the symptoms described in this study may not be easily understood or evident if not explored. Therefore, follow-up visits need not only to include neurological and cognitive but also psychiatric and psychosocial assessments.

4.3. Strengths and limitations

This study gives an important contribution to the knowledge about experiences of outcome after FLR. A strength of the study is that both the patients’ and the relatives’ perspectives are described, and that they in major parts are concordant. This is important to point out as frontal lobe injuries are known to be associated with problems with insight and self-awareness [7], which does not seem to hold for this study. Furthermore, the qualitative method, with questions regarding subjective experiences, allowed variations in outcomes to appear and descriptions of symptoms to be captured, that are not easily characterized by available rating scales and tests.

The study also had several limitations. Time from surgery to interview varied since the inclusion period spanned over 16 years, and therefore patients’ memories of how life was before surgery might be quite variable. This is somehow reflected upon by the respondents themselves. Since time from surgery to interview differed we cannot distinguish short-term experiences from long-term but a majority of the interviews were held more than five years post-surgery, a time frame that has been suggested to delimit the initial reorientation phase [21]. Another limitation is that the majority of the patients were seizure free, and therefore the results may not be quite transferable to FLR cohorts with a higher proportion of non-seizure-free patients.

4.4. Future studies

Future studies need to further explore emotional and social cognitive consequences of FLR for epilepsy as well as longitudinal cognitive outcomes. Exploring the emotional outcomes related to anatomical subgroups of FLR as well as onset age and etiology of the epilepsy would be highly interesting and would also facilitate personalized counseling and rehabilitation further. Results from qualitative studies like the present could also be a basis for the development of questionnaires focusing on aspects that are not easily grasped by existing methodology.

5. Conclusions

Frontal lobe resections for epilepsy could give rise to a range of positive outcomes regarding emotional well-being and autonomy. These outcomes were mainly but not exclusively related to seizure freedom or substantial improvement. However, even when seizure freedom was achieved, negative experiences such as mental fatigue, lowered mood, and social withdrawal were described by both patients and relatives. These are difficult but important issues to discuss in the presurgical counseling to make sure that an informed decision about undergoing epilepsy surgery is taken. It is also crucial that the epilepsy surgery team has the possibility to offer rehabilitation and postoperative counseling to help patients and families to cope with possible negative side effects that may persist even long-term.

6. Ethical publication statement

We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to thank all of the patients and relatives who participated in this study and medical secretary Lotta Beaird for transcription of most of the interviews.

Funding

This work was supported by grants from the Swedish State under the agreement between the Swedish Government and the County Councils, the ALF-agreement (grant ALFGBG-723151) and from the Gothenburg Foundation for Neurological Research and the Margarethahemmet Foundation.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2021.108077>.

References

- [1] Wiebe S, Blume WT, Girvin JP, Eliasziw M. A randomized, controlled trial of surgery for temporal-lobe epilepsy. *N Engl J Med* 2001;345(5):311–8.
- [2] Fiest KM, Sajobi TT, Wiebe S. Epilepsy surgery and meaningful improvements in quality of life: results from a randomized controlled trial. *Epilepsia* 2014;55(6):886–92.
- [3] Engel Jr J, McDermott MP, Wiebe S, Langfitt JT, Stern JM, Dewar S, et al. Early surgical therapy for drug-resistant temporal lobe epilepsy: a randomized trial. *JAMA* 2012;307(9):922–30.
- [4] Andersson-Roswall L, Engman E, Samuelsson H, Malmgren K. Cognitive outcome 10 years after temporal lobe epilepsy surgery: a prospective controlled study. *Neurology* 2010;74(24):1977–85.
- [5] Baxendale S, Thompson P. Red flags in epilepsy surgery: Identifying the patients who pay a high cognitive price for an unsuccessful surgical outcome. *Epilepsy Behav* 2018;78:269–72.
- [6] Baxendale S. Long-Term cognitive outcomes after epilepsy surgery in adults. In: Malmgren K, Baxendale S, Cross JH, editors. Long-term outcomes of epilepsy surgery in adults and children. Switzerland: Springer; 2015. p. 71–83.
- [7] Stuss DT. Functions of the frontal lobes: relation to executive functions. *J Int Neuropsychol Soc* 2011;17(05):759–65.
- [8] Ardila A. On the evolutionary origins of executive functions. *Brain Cogn* 2008;68(1):92–9.
- [9] Helmstaedter C, Gleißner U, Zentner J, Elger CE. Neuropsychological consequences of epilepsy surgery in frontal lobe epilepsy. *Neuropsychologia* 1998;36(7):681–9.
- [10] Ljunggren S, Andersson-Roswall L, Rydenhag B, Samuelsson H, Malmgren K. Cognitive outcome two years after frontal lobe resection for epilepsy - a prospective longitudinal study. *Seizure* 2015;30:50–6.
- [11] Busch RM, Floden DP, Ferguson L, Mahmoud S, Mullane A, Jones S, et al. Neuropsychological outcome following frontal lobectomy for pharmacoresistant epilepsy in adults. *Neurology* 2017;88(7):692–700.
- [12] Bremm FJ, Hendriks MPH, Bien CG, Grewe P. Pre- and postoperative verbal memory and executive functioning in frontal versus temporal lobe epilepsy. *Epilepsy Behav* 2019;101:106538.
- [13] Dulay MF, Busch RM, Chapin JS, Jehi L, Najm I. Executive functioning and depressed mood before and after unilateral frontal lobe resection for intractable epilepsy. *Neuropsychologia* 2013;51(7):1370–6.
- [14] Farrant A, Morris RG, Russell T, Elwes R, Akanuma N, Alarcón G, et al. Social cognition in frontal lobe epilepsy. *Epilepsy Behav* 2005;7(3):506–16.
- [15] Giovagnoli AR, Franceschetti S, Reati F, Parente A, Maccagnano C, Villani F, et al. Theory of mind in frontal and temporal lobe epilepsy: cognitive and neural aspects. *Epilepsia* 2011;52(11):1995–2002.
- [16] Halley SA, Wrench JM, Reutens DC, Wilson SJ. The amygdala and anxiety after epilepsy surgery. *Epilepsy Behav* 2010;18(4):431–6.
- [17] Winslow J, Hu Bo, Tesar G, Jehi L. Longitudinal trajectory of quality of life and psychological outcomes following epilepsy surgery. *Epilepsy Behav* 2020;111:107283.
- [18] Walther K, Dogan Onugoren M, Buchfelder M, Gollwitzer S, Graf W, Kasper BS, et al. Psychosocial outcome in epilepsy after extratemporal surgery. *Epilepsy Behav* 2018;81:94–100.
- [19] Mah L, Swearer J, Phillips CA, Benjamin S. Reduction in apathy following epilepsy surgery. *Neuropsychiatr Dis Treat* 2019;15:1679–84.
- [20] Prayson BE, Floden DP, Ferguson L, Kim KH, Jehi L, Busch RM. Effects of surgical side and site on psychological symptoms following epilepsy surgery in adults. *Epilepsy Behav* 2017;68:108–14.
- [21] Coleman H, McIntosh A, Wilson SJ. A patient-centered approach to understanding long-term psychosocial adjustment and meaning-making. 15 to 20years after epilepsy surgery. *Epilepsy Behav* 2020;102:106656.
- [22] Bladin PF. Psychosocial aspects of epilepsy and of epilepsy surgery. *Clin Exp Neurol* 1992;29:49–61.
- [23] Ozanne A, Verdinelli C, Olsson I, H. Graneheim U, Malmgren K. Parental experiences before and long-term after their children's hemispherotomy - A population-based qualitative study. *Epilepsy Behav* 2016;60:11–6.
- [24] Ozanne A, Verdinelli C, Olsson I, Edelvik A, H. Graneheim U, Malmgren K. Callosotomy in children - Parental experiences reported at long-term follow-up. *Epilepsy Behav* 2018;86:91–7.
- [25] O'Brien J, Gray V, Woolfall K. Child and parent experiences of childhood epilepsy surgery and adjustment to life following surgery: A qualitative study. *Seizure* 2020;83:83–8.
- [26] Ozanne A, Graneheim UH, Ekstedt G, Malmgren K. Patients' expectations and experiences of epilepsy surgery—A population-based long-term qualitative study. *Epilepsia* 2016;57(4):605–11.
- [27] Zigmund AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67(6):361–70.
- [28] Wieser HG, Blume WT, Fish D, Goldensohn E, Hufnagel A, King D, et al. ILAE Commission Report. Proposal for a new classification of outcome with respect to epileptic seizures following epilepsy surgery. *Epilepsia* 2001;42:282–6.
- [29] Krippendorff K. Content analysis: an introduction to its methodology. Thousand Oaks, CA: SAGE; 2013.
- [30] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24(2):105–12.
- [31] Graneheim UH, Lindgren B-M, Lundman B. Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Educ Today* 2017;56:29–34.
- [32] Lindgren B-M, Lundman B, Graneheim UH. Abstraction and interpretation during the qualitative content analysis process. *Int J Nurs Stud* 2020;108:103632.
- [33] Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health* 2012;40(8):795–805.

- [34] Edelvik A, Taft C, Ekstedt G, Malmgren K. Health-related quality of life and emotional well-being after epilepsy surgery: A prospective, controlled, long-term follow-up. *Epilepsia* 2017;58(10):1706–15.
- [35] Mihara T, Inoue Y, Watanabe Y, Matsuda K, Tottori T, Hiyoshi T, et al. Improvement of quality-of-life following resective surgery for temporal lobe epilepsy: results of patient and family assessments. *Jpn J Psychiatry Neurol* 1994;48(2):221–9.
- [36] Wilson SJ, Bladin PF, Saling MM. Paradoxical results in the cure of chronic illness: the “burden of normality” as exemplified following seizure surgery. *Epilepsy Behav* 2004;5(1):13–21.
- [37] Kemp S, Garlovsky J, Reynders H, Caswell H, Baker G, Shah E. Predicting the psychosocial outcome of epilepsy surgery: A longitudinal perspective on the ‘burden of normality’. *Epilepsy Behav* 2016;60:149–52.
- [38] Mehmood S, Dale C, Parry M, Snead C, Valiante TA. Predictive coding: A contemporary view on the burden of normality and forced normalization in individuals undergoing epilepsy surgery. *Epilepsy Behav* 2017;75:110–3.
- [39] Douven E, Köhler S, Schievink SJ, van Oostenbrugge R, Staals J, Verhey FJ, et al. Temporal associations between fatigue, depression, and apathy after stroke: results of the cognition and affect after stroke, a prospective evaluation of risks study. *Cerebrovasc Dis* 2017;44(5–6):330–7.
- [40] Johansson B, Berglund P, Rönnbäck L. Mental fatigue and impaired information processing after mild and moderate traumatic brain injury. *Brain Inj* 2009;23(13–14):1027–40.
- [41] Johansson B, Rönnbäck L. Mental fatigue and cognitive impairment after an almost neurological recovered stroke. *ISRN Psychiatry* 2012;2012:686425.
- [42] Palm S, Rönnbäck L, Johansson B. Long-term mental fatigue after traumatic brain injury and impact on employment status. *J Rehabil Med* 2017;49(3):228–33.
- [43] Samuel P J, Menon RN, Chandran A, Thomas SV, Vilanilam G, Abraham M, et al. Seizure outcome and its predictors after frontal lobe epilepsy surgery. *Acta Neurol Scand* 2019;140(4):259–67.
- [44] Xu C, Yu T, Zhang G, Wang Y, Li Y. Prognostic factors and longitudinal change in long-term outcome of frontal lobe epilepsy surgery. *World Neurosurg* 2019;121:e32–8.
- [45] Sarkis RA, Busch RM, Floden D, Chapin JS, Kalman Kenney C, Jehi L, et al. Predictors of decline in verbal fluency after frontal lobe epilepsy surgery. *Epilepsy Behav* 2013;27(2):326–9.
- [46] Baxendale S, Thompson P, Harkness W, Duncan J. Predicting memory decline following epilepsy surgery: a multivariate approach. *Epilepsia* 2006;47(11):1887–94.
- [47] Busch RM, Hogue O, Kattan MW, Hamberger M, Drane DL, Hermann B, et al. Nomograms to predict naming decline after temporal lobe surgery in adults with epilepsy. *Neurology* 2018;91(23):e2144–52.
- [48] Ljunggren S, Andersson-Roswall L, Imberg H, Samuelsson H, Malmgren K. Predicting verbal memory decline following temporal lobe resection for epilepsy. *Acta Neurol Scand* 2019;140(5):312–9.
- [49] Baxendale S. Cognitive rehabilitation and prehabilitation in people with epilepsy. *Epilepsy Behav* 2020;106:107027.