

Chapter 12

A perspective on psychosocial intervention and outcome around epilepsy surgery

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Summary

The initial sections of this chapter review psychosocial outcome studies relating to epilepsy surgery with a highlighting of recent studies from the Bethel Centre, Germany and the University of Washington, Seattle, Washington. Recent years have evidenced renewed interest in psychiatric variables relating to epilepsy surgery and the post-operative period, and also patients' personal attributes (e.g. learned resourcefulness) and the psychosocial context for the surgery event (e.g. the family's emotional affect and level of positivism).

The major focus of the chapter is the description of comprehensive psychosocial interventions, pre- and post-epilepsy surgery. Roles to be assumed by all relevant allied health team members are described in the provision of continuous intervention around the epilepsy surgery event. Representative cases are highlighted from the Bethel and University of Washington epilepsy centres which underscore the range of intervention services provided with an emphasis on effective psychiatric or psychosocial patient engagement.

Introduction

The purpose of this chapter is to review the available literature and clinical experience in relation to mounting an effective comprehensive psychosocial intervention around an epilepsy surgery event in order to improve eventual functional outcome. The existing literature has examined satisfaction with the surgery, quality of life ratings across domains of functioning, psychological and psychiatric gains and losses, changes in employment, etc. We, however, continue to lack synthesis of the available literature and expertise in formulating a more standard psychosocial approach, positively complementing the medical neurosurgical procedure.

Psychosocial outcome findings

There have been several recent reviews in this area (Dodrill *et al.*, 1997; Fraser and Thorbecke, 1997). Dodrill *et al.* (1991) in their review of 17 studies suggested improvement in interpersonal relationships approximately two-thirds of the time, improved employment status (chiefly linked to a seizure free status), and a negative functional impact due to presurgical psychiatric or cognitive impairments. On an overview, however, most individuals improve relative to overall social adjustment.

Fraser and Thorbecke (1997), recent work by Mihara *et al.* (1994), Guldvog *et al.* (1991), and Williams *et al.* (1994) indicate that impact on unemployment needs to be examined carefully. Although underemployment can decrease relatively expediently, it can take some time for actual unemployment rates to drop. Some of the differences in outcome relate specifically to time of follow-up, viz. it can take a number of years for individuals to make integrative vocational gains post-surgery, secure stable employment or profit from post-surgical education. As Mihara *et al.* (1994) indicated, although improvement is often found in one or more areas of psychosocial function post-epilepsy surgery, it is not yet universal in nature. These authors also offer that there may simply be areas of life that are more environmentally determined such as employment or interpersonal functioning, that will require more time to establish gains which are missed in some studies due to an early or the premature timing of follow-up. Work that clearly shows psychosocial gains in areas such as employment (Sperling *et al.*, 1996) or from the University of Washington group (Fraser and Thorbecke, 1997) may simply reflect that follow-up occurred at three or more years post-surgery, giving individuals sufficient time to establish or re-establish themselves at work, chiefly unimpeded by seizures. McLachlan *et al.* (1997) indicate that patient-perceived improved quality of life, in general, may not be observed until after two years post-surgery.

The 1997 review by Fraser and Thorbecke also emphasizes that seizure issues are only part of the concern relative to variables influencing optimal psychosocial outcome post-surgery. Issues related to psychosocial limitations and neuropsychological impairment deserve expanded attention. The Fraser and Thorbecke review indicated that *patients' post-surgery expectations set too high* at the Bethel Centre can have a negative effect on how patients perceive quality of life and experienced depression post-surgery. Derry and Wiebe (2000) have emphasized findings that a patient's personal resources, specifically learned resourcefulness and an internal locus of control, can significantly influence post-surgical psychosocial outcome. These types of individual 'self-capacities' have not really been well addressed, to date, as part of the post-operative adjustment equation.

In sum, the literature is starting to 'move on' from basic examination of satisfaction with surgery or changes in some type of life status to a fuller understanding of the post-surgery adaptation process as a multifactorial construct with implications for helpful intervention. Yagi (1998) again recently indicates that 'preventing seizures through medical or surgical treatment removes only one factor affecting patients' employment prospects and general "quality of life"'. Yagi's recent work and others' cited in the Fraser and Thorbecke review also underscore that surgical intervention with the younger patient is likely to have a more profound positive impact.

Psychiatric aspects

It is of interest that since the 1997 Fraser and Thorbecke review, there has been a major and more discrete emphasis in the research literature on the *psychiatric aspects* surrounding the

surgical event. Glosser *et al.* (2000) indicate that 65 per cent of epilepsy surgery patients before and after epilepsy surgery had Axis I diagnoses such as depression, anxiety and organic mood disorders. They indicate that the onset of new psychiatric problems in the months directly following the surgery may be as high as 31 per cent. On the whole, however, the severity of psychiatric symptoms was much lower at six months post-surgery than before the operation. A symptom complex, involving mixed features of depression, anxiety, and irritability occurring in episodic cycles, seems to be common in both pre- and post-operative temporal lobe patients. Seizure-free status was highly predictive and confirming of psychiatric and psychosocial adjustment, but there was a slight trend for individuals that were seizure free to develop early but transient psychiatric worsening. Glosser *et al.* (2000) note that elements of anxiety and depression, even for those with no psychopathology pre-operatively, are quite common at six weeks post-surgery. By three months, however, these symptoms will usually resolve. As indicated by Ring *et al.* (1998), anxiety tends to remit at three months while depression can be more resistant. Some stress, if actually controllable, can facilitate psychosocial adaptation.

Derry *et al.* (2000) indicate that a Washington Psychosocial Seizure Inventory (WPSI) elevated emotional adjustment scale score was highly correlated with persisting depression two years after surgery. This correlation was higher for patients of older age, experiencing generalized seizures and pre-operative neurological deficits, with a history of psychiatric illness in the family, and a family history of seizures. Although a post-operative seizure-free status contributed to the prediction of less depression, the pre-operative WPSI emotional adjustment score remained the best predictor of depression level.

It should be noted, however, that pre-existing mood disorders, specifically depression, are certainly not contraindicative of performing the operation. Blumer *et al.* (1998) emphasized that these individuals can be handily treated pre-operatively by one or more antidepressants. A treatment strategy can involve a serotonin selective re-uptake inhibitor (SSRI) being added to a tricyclic drug. Continuation of the psychotropic medication after surgery is recommended. Patients who were seizure free and remained free of depressive symptoms were considered stable within a range of 6 to 18 months post-surgery (Blumer *et al.*, 1998, p. 485).

Psychosocial variables

Since the Fraser and Thorbecke (1997) review, there has also been an increase in research activity relating to a wider range of psychosocial variables examined as impacting psychosocial adjustment. Wheelock *et al.* (1998) underscored that satisfaction with surgery was largely a function of pre-surgical expectations and directly related to expectations for seizure elimination. Derry and Wiebe (2000) move toward a more predictive model of perceived surgical success involving good pre-operative psychological adjustment and self-perceived quality of life, the tendency toward learned resourcefulness, adequate available social support, and low neuroticism. Wilson *et al.* (1999) highlight some of the complexity of perceived success related to psychosocial factors such as positive anticipation of a later change pre-surgically and learning to discard the role of having a chronic disability post-surgery. Langfitt *et al.* (1999) indicate that families' emotional affect predicted patients' social adjustment post-surgery independent of post-operative seizure status and other epilepsy variables. Promoting a positive affective climate within a family and supporting autonomous behaviour for a patient undergoing surgery appear to be very important and warrant further investigation as clinically tested interventions. In closing, the last few years have shown not only an interest in psychiatric variables relating to epilepsy surgery and the post-operative adjustment period, but also in patients' internal personal

attributes and the psychosocial context for the epilepsy surgery event. These findings present areas that can be targeted for tested interventions by allied health and mental health specialists.

Recent studies at the Bethel, Germany and University of Washington epilepsy centres

Several studies are recently underway or have been completed that emphasize the newer psychosocial concerns, developments, and intervention implications around epilepsy surgery. These are reviewed from the Bethel Centre (Germany) and the University of Washington (Seattle) Center.

Bethel Centre

Koch-Stoecker (in Lüders and Comair, 2001) at the Bethel Centre recently conducted a study of 100 patients with temporal lobe epilepsy undergoing surgery. The study focus was on those patients who pre-operatively had an Axis I or Axis II psychiatric diagnosis and their subsequent post-operative course of adjustment. Post-operatively of those *without an Axis I or Axis II diagnosis*, 89 per cent were free of seizure involvement. Of the remaining *with an Axis I or Axis II psychiatric disorder*, only 43 per cent reached seizure free status. In a subgroup with a diagnosis of organic personality disorder, only 10 per cent reached a seizure free status post-operatively.

Pre-operative psychoses do not appear to be a contraindication for epilepsy surgery: post-surgery psychoses persisted, but fluctuated a little less dramatically than before surgery. Despite the persistence of the psychotic episodes, these individuals generally still retain only one chronic disability with which to deal following the chiefly positive medical benefits of epilepsy surgery. Post-operative mood disorders tended to be predictable with pre-operative dysthymic or dysphoric syndromes – changing into major depressive episodes and somatoform disorders. They generally respond to antidepressants and tend to remit within a year. Totally reduced anxiety and increased self-esteem appeared to be among the most important changes reported after surgery. Sixty per cent of the group were diagnosed pre-operatively with personality disorders (obviously there is overlap across diagnostic categories of Axis I and Axis II). It appears that those in this category require some careful monitoring. In this category, small subgroups developed chronic psychotic syndromes and delusional psychotic episodes partly linked to their continuing seizures, partly being seizure free. Individuals with organic personality syndromes ($n = 10$ in this group) seemed to have the worst outcome. It appears that these patients need very careful consideration relative to surgery. They tended to have continuing seizure difficulties and post-operatively have complex psychiatric reactivity. A number of these individuals experienced *de novo* psychosis. These findings obviously have a number of clinical implications relative to the importance of psychiatric evaluation pre-surgery and careful weighing of surgery benefit-cost variables.

Thorbecke in nearly the same patient group as analysed by Koch-Stoecker (for the complete study, see Thorbecke, in Lüders and Comair, 2001) looked for changes in specific social domains 2 years after ATL. Significant changes could mainly be observed in driving, accidents for which the person with epilepsy had to visit a doctor, and in qualitative aspects of employment (more responsibility, extension of tasks as compared to the pre-operative situation, etc.). There were, however, no changes in social contacts and in partnership although pre-operatively many of the patients had expected a positive change in these domains (Thorbecke, 1997). Closer inspection of changes in the domain of employment revealed some interesting findings. When looking at changes in qualitative aspects of employment, seizure outcome, cognitive abilities

and personality disorders pre-operatively proved to be significant predictors. When only looking at the 16 of the 103 patients whose employment situation had deteriorated post-operatively, it could be seen that their seizure outcome was much worse than for the whole group, IQ had significantly decreased and psychiatric status had deteriorated. Thorough counselling in respect of what can realistically be expected post-surgery, continuous psychiatric monitoring and if necessary intervention during the pre-post-trajectory, and psychosocial support as needed in the case of employment difficulties would be the implications of the reported findings.

Table 1. Differences pre-post in different social domains

	Pre- (%)	Post- (%)	P
Accidents	31	8	0.0000
Not driving	96	70	0.0000
Not leaving without accompanying person	23	7	0.0002
No sports	65	58	:
Sports under supervision	15	5	0.05
Unemployed	19	15	:
Early disability pension	15	23	:
Unsatisfactory employment situation	64	43	0.0008
Living with parents	39	26	0.0002
Social contacts < 1/week	29	32	:
No partner	48	46	:
OL in the social domain	34.2	38	0.01

University of Washington

To assist in answering some of the important cognitive and psychosocial questions around epilepsy surgery, a study from the University of Washington Epilepsy Center, Seattle is reviewed. This study included both surgically-treated temporal lobe epilepsy patients and a medically-treated comparison group. All patients were at least 16 years at the time of initial evaluation with poorly controlled partial seizures. A total of 108 individuals were subject to cortical resection surgery with follow-up of their pre-surgical multidisciplinary assessment at five years ($n = 74$) or 10 years ($n = 34$) post-surgery. The 'medication treated' comparison patients included 45 persons with 5-year follow-ups and 36 with 10-year follow-ups. None of the medically-treated cases had previously been rejected for surgery, but they had been treated primarily by 'non-epilepsy surgery' oriented neurologists.

The surgical and medical groups did not differ initially with respect to demographic or biological variables, but at the end of the study there was a significant difference in relief from seizures, with 49 per cent of the surgical group being seizure free as opposed to 25 per cent for the medically-treated cases.

Patients showed few cognitive or psychosocial changes in the medically treated sample. Cognitively, there was also very little in the way of general cognitive change in the surgical group, as has been previously demonstrated by Hermann and Wyler (1988).

As consistent with previous literature, there were some significant changes in the area of verbal memory for individuals who had surgery on the same side as speech (usually the left). This is

illustrated in Fig. 1 which portrays changes on the Wechsler Memory Scale (Form 1) logical memory scores with the 5- and 10-year surgery groups combined.

It is not always appreciated, however, that cognitive changes after resection surgery are linked to changes in post-operative seizure frequency. Figure 1 reveals this difference. Individuals becoming entirely seizure free after surgery showed a slight but likely 'tolerable' memory loss 5 or 10 years post-surgery. Likewise, individuals who demonstrated worthwhile improvement in seizure frequency (at least 75 per cent improvement) also showed a slight loss in verbal memory. Persons, however, with less than 75 per cent seizure relief showed a prominent loss of memory.

With respect to emotional and psychosocial functioning, the results from this study are not fully detailed here, but have been presented elsewhere (Hermann, 2001). These results also indicate that on the Minnesota Multiphasic Personality Inventory (MMPI) and the Washington Psychosocial Seizure Inventory (WPSI) significant improvement was noted when patients were rendered seizure free; moderate improvement realized when there is at least 75 per cent relief from seizures, and no change when less than a 75 per cent relief from seizures have been experienced. These results were quite systematic and they do not differ from those in the cognitive area in the presented figure.

The surgical group vocational outcome, in relation to this study, has been presented previously (Fraser and Thorbecke, 1997), as compared to the medication comparison group, the surgery patients gained both in the number of weeks worked at follow-up and hourly salary versus the medical comparison group. Of marked note, however, was the fact that the medical comparison group was actually losing ground in the number of weeks worked during the follow-up period while the surgical group was increasing weeks in work engagement and moving ahead. The findings were even more dramatic for individuals who were students at the time of surgery versus those in the medical comparison group. At follow-up 90 per cent of the individuals in the student surgical group were working versus 47 per cent of the student medical comparison group.

The implications of the Bethel psychiatric study related to the surgery would indicate the importance of careful and detailed psychiatric evaluation for surgery patients as to individual risks, as to patient-family-member interactions, and as to the need for initiation of optimal therapy regimens. Psychiatric assessment and intervention receive scant attention at most centres and appear to be truly important not only in relating to psychosocial adjustment, but also to seizure outcome status. Medical patients at the University of Washington did not show any marked cognitive change from the surgery group. Cognitive loss, specifically relating to verbal memory, appeared mainly slight in the seizure free and seizure improved (at least 75 per cent seizure reduction) groups. It is of interest, however, that persons with less than a 75 per cent relief in seizures showed a prominent memory loss. The results might suggest that not only was there removal of some functional tissue related to memory functioning at the time of surgery, but also that at least some of the epileptogenic area had been missed. Findings relating to emotional and psychosocial status on the Washington Psychosocial Seizure Inventory show a close linkage between seizure status and psychosocial improvement. Findings in relation to employment and psychosocial status may be clearer in the University of Washington series versus some other studies because the 5- and 10-year follow-up time frames are relatively 'distant' from the time of operation and not spread out over several years including the immediate follow-up period, as found in much of the prior research.

Pre- and post-surgical intervention

Although there has been a consistent emphasis in the literature on post-operative psychosocial intervention or rehabilitation, the concept here really should be *active* pre- and post-surgical allied and medical health intervention personnel in order to maximize the medical benefits of the operation. A number of points relating to pre-operative assessment, planning and preliminary intervention were made in the prior review by Fraser and Thorbecke (1997). It seems at this juncture that it may be more important to talk about both pre-and post-operative intervention as a function of specific allied health disciplines.

The recent work cited here by Koch-Stoecker at the Bethel Centre and other literature has stressed the importance of *psychiatric assessment and potential intervention*. As emphasized by Savard and Machanda (2000), all individuals with known or suspected psychopathology should be subject to a full and up to date psychiatric assessment using structured psychiatric assessment instruments such as the Structural Clinical Interview for the DSM IV (SCID), Minnesota Multiphasic Personality Inventory-II (MMPI-II), etc. A major focus according to Taylor and Hermann (1997) is to provide a rich data bank to show that no harm is likely to occur, estimate the probability of negative mental states arising in the period after surgery and to provide advisement, to identify existing psychiatric deficits with estimations of improvement post-surgery and, finally, to show that these aims are compatible with those of the individual and his or her significant other(s). Savard and Machanda (2000) suggest that the challenge is 'to better identify those patients for whom surgical intervention will resolve or improve seizures, without leading to functional psychiatric disability' (p. 48). Blumer *et al.* (1999) indicate certain medications, particularly for depression, should be initiated pre-surgery once the salient concerns are identified. At many centres, psychiatric assessment and planning/initial interventions are the missing or weak link.

Neuropsychology has a multiplicity of roles in pre-operative assessment and planning. As Taylor and Hermann (1997) indicate, the neuropsychologist offers prognoses regarding post-operative quality of life, works with the neurosurgical team to minimize post-operative cognitive deficits, and provides evaluations of estimated long-term outcome. The neuropsychologist will often focus specifically on concerns related to language and memory (utilizing the Wada testing as necessary) in order to negate or minimize impact on these cognitive functions. As part of a neuropsychological battery, the neuropsychologist will often administer the MMPI-II, the WPSI, a general measure of psychosocial status (helpful in predicting post-operative depression), and one of the quality of life instruments (Vickrey *et al.*, 1992). The neuropsychologist provides direct input not only to the physician or operating neurosurgeon, but to all members of the team to include the neurosurgeon, vocational rehabilitation counsellor, psychiatrist, social worker and clinical nursing staff. This is a professional who has the best databank for obtaining an objective perspective on current psychosocial status.

The role of the physician in pre-operative assessment and planning is critical and underemphasized. The physician not only provides to the patient and significant others the nature of surgical treatment, risk, duration of treatment, surgical treatment limitations, and expected results; but can provide other information that is just as relevant. The physician can help the social worker, the neuropsychologist and others to understand the family's expectations and provide some realistic feedback to the family relative to the fact that life may be improved even if seizure free status or dramatically improved seizure status is not attained. It can be highly encouraging and reinforcing if the patient understands that even a reasonable seizure reduction can improve life

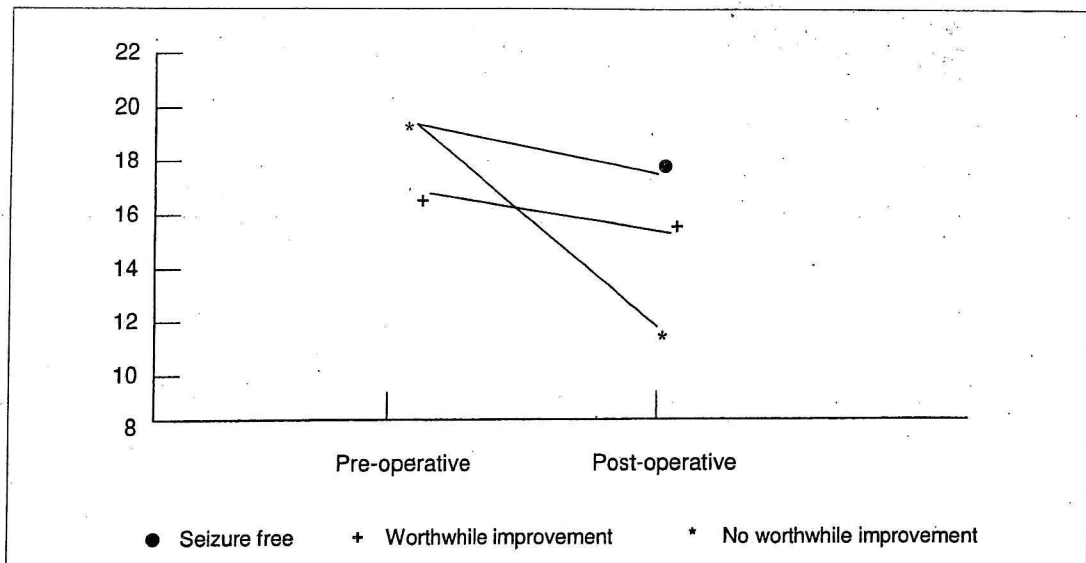


Fig. 1. WMS verbal scores and seizure relief: surgery on speech side ($n = 51$)

functioning; they will tend to be less frustrated if the 'ideal seizure outcome' is not achieved. The physician can also collaborate with the neuropsychologist and other staff in presenting a 'timetable' relative to the sequence of pre- and post-operative activity, limitations for pain control, possible neurological and medical complications, overview the possible occurrence of post-operative mood fluctuations, and underscore that psychosocial adjustment and gains will occur in a graduated method during the post-operative period.

A lead nurse, social worker, psychologist, or vocational rehabilitation counsellor can also be involved in the general assessment of psychosocial status and planning. A number of instruments are available in order to better understand a patient's sense of personal responsibility for improved medical status and an individual's level of learned resourcefulness (Affleck *et al.*, 1987; Rosenbaum, 1980). The above referenced measures appear to have promise in predicting post-surgical psychosocial adaptation, but more importantly can be used to target individuals who will require more 'personal responsibility' information and support of autonomous steps. As emphasized by Wilson *et al.* (1999) and Langfitt *et al.* (1999) it is important that one professional with psychosocial expertise really reviews with the individual and family members the patient's anticipation for positive change post-surgery, proclivity to discard a 'sick' or disability role, the level of positive emotional affect within the family, and finally, level of support toward the patient's autonomous behaviour.

It would seem of value that if there is a dominant negative emotional affect within the family, that family coaching might occur by a social worker, psychologist, or other mental health specialist toward positive behaviours (e.g. using a warm voice tone, appropriate physical or eye contact, attentive listening, reassuring others, respectful disagreement, or positive use of humour) and less negative behaviours (e.g. abrupt vocal tone, sarcasm, etc.). Family member support of a patient's autonomy can also be coached to include optimistic statements, compliments on independent behaviours toward goal achievement, etc. versus behaviours such as hostile criticism and intrusiveness. This seems especially important in those patients not having become completely seizure free (Langfitt *et al.*, 1999).

Finally, a lead social worker, mental health practitioner, or even vocational rehabilitation counsellor can engage with the client and family in a goal attainment scaling procedure as developed by Kirusek and Sherman (1968) through which goals across different domains of life functioning are clearly established and scaled relative to desirability of outcome. This type of effort also enables the initiation of planning and preliminary action steps, even pre-surgery and provides a more objective framework for clients to function within as they 'discard disability' pre- and post- the operative procedure. At the Bethel Centre, Thorbecke and colleagues encourage patients to scale levels of expected post-operative functioning in the various life domains (independent living, school functioning, social functioning, interpersonal relationships, etc.) on a scale of 1 to 10. This provides a simple, graphic format in which the patient can establish expectations which can be reviewed in detail. The planning and action steps follow in order to reach expected goals.

Using these types of goal planning or outcome scaling methods, members of the allied health team can begin to initiate intervention and action step activity prior to the surgical event. In the vocational arena, as an example, an individual could be provided with a vocational rehabilitation assessment, have career informational interviews completed, and have (actually initiated) specific job training pre-surgery with a 'break' for the surgical event.

In conclusion it seems that the pre- post-operative trajectory is a complex process in which a multidisciplinary medical-psychosocial team should be present in the background monitoring the patients way, and supporting her/him and the family in a preventive and curative way if difficulties arise.

Case vignettes

Case 1: Jonathan – University of Washington Epilepsy Center, Seattle

Jonathan came to the University of Washington Epilepsy Center in July of 1996 from Florida to visit his mother and begin a new life. He was experiencing multiple monthly temporal lobe seizures. His financial status was challenged. His work history in Florida fluctuated wildly to include some cooking, bar bouncer, bartender, home health aide, and significant periods of unemployment and personal wandering. Although sober from alcohol for several years, he still experimented with several street drugs/marijuana exclusive of heroin. Jonathan was quite emotionally distraught and irritable in early meetings with centre staff, but he decided to focus on making his life better and gradually making gains in various life domains.

A vocational assessment was completed, neuropsychological assessment added, and psychological and substance abuse work-up performed pre-surgery. He subsequently decided to work toward a job plan for becoming a warehouseman with computer skills. A neuropsychological evaluation determined that he had good language skills, but overall was on the cusp of the lower third of the population cognitively. There were no particularly strong cognitive abilities other than language. Jonathan began work 6 h per week as a church custodian and engaged in both individual and group therapy at a local mental health centre. As his seizures did not remit following an anticonvulsant regimen, he was evaluated by medical staff culminating in his candidacy for epilepsy surgery. Even before the surgery, Jonathan began part-time work as a warehouse person and formal training at a technical college. He also continued his engagement in psychotherapy and secured federally subsidized housing in the community. Positive leisure time activities included a weekly physical conditioning programme.

The surgery was very successful, leaving Jonathan virtually seizure free. He completed the

warehouse training programme at the local technical college and was encouraged by his teacher to advance to training in auto parts. He continued to improve his computer literacy throughout this time period. He never skirted dealing with his personal issues either, continuing to engage in both individual and group therapy thus promoting his further adjustment. Two years later after finishing the auto parts training programme, Jonathan was employed as an auto parts specialist by a Nissan dealership in the Seattle area. He has moved out of public housing and relinquished his federal Social Security pension. Most recently, he became engaged to a woman he's known for several years through his work-out facility. Jonathan is an excellent example of someone who profited from neurosurgical, psychological, and a vocational intervention. His initial assessment and planning steps started before the surgical event. Despite some early post-surgery anxiety, he never seemed to emotionally fluctuate widely, probably due to the context of the structured, progressive plan in which he was involved.

Case 2: Mrs. O – Bethel Centre

Mrs. O, a 40-year-old woman with a paranoid personality structure lived in an extremely unsatisfactory family situation. She felt excluded and humiliated by her husband, her mother and her grown-up daughter, and was full of mistrust and suspicion. She suffered from psychomotor seizures elicited by a right temporal sclerosis. Her decision to have epilepsy surgery grew from her desire to reach harmony within her family or at least to demonstrate that she was an independent, successful woman, superior to her family members.

The pre-surgical psychiatric trials to discuss her goals and to reach a more realistic view about post-operative possibilities ended up in paranoid fantasies that her husband (whom she had never brought to the epilepsy centre for family counselling) 'may have advised the psychiatrist by phone'. It required much sensitivity to maintain the contact with her, and finally she was operated on with a vague concept of possible difficulties after surgery.

Her post-operative behaviour was that of a radical personal redefinition of 'being healthy and well'. She went home proudly, but as expected she encountered unchanged negative family relationships. Although she seemed partly to realize that, despite freedom from seizures, she still had her deficits and faults, she presented herself as powerful and tried to 'force' psychosocial success. At that time she stayed in an ambivalent contact with her psychiatrist, always reproachful for many reasons, but in urgent need of support. When she failed the practical driver's license test, she attributed it to an intrigue of her husband whom she suspected to have poisoned her. She developed an acute paranoid psychosis, but refused any kind of antipsychotic medication. Finally, she was psychiatrically hospitalized and medicated against her will. After that treatment, and under continuous antipsychotic medication, she started to accept that to set up a new life would only be possible step by step and require patience and would take more time than she had expected. Still she did not fully accept prescribed interventions (although she had started a series of psychotherapeutic interventions in her hometown with much reluctance), but she continued her irregular phone calls to our psychiatrist in order to get feedback or to search for advice.

The psychiatric concept was to 'let her have her own way' in some manner and at the same time lead her forward to stability by offering her support in the emotional evaluation and structuring of daily conflicts. She finally managed to drive her own car, travel around, or go shopping on her own, etc. without telling her family about her activities. She reneged on her plans for a job and decided to enjoy her independent life. She is now off antipsychiatric medication. She still lives in disharmony with her family, but she has been successful in defining her borders; she

cooks her own meals, and has her own separate rooms. Her daughter has left for a job in a foreign country. She still has her complicated personality structure and provokes psychosocial conflicts, although she has learned to behave more gently. The most important operation consequence, beside her freedom of seizures, is her pride that she has overcome difficulties on her own.

This case is an example that a careful and supporting accompaniment of patients around the operation may sometimes be the only effective therapeutic measure to relative success. Most professional psychiatric ideas of active interventions (family counselling before surgery, talking about her expectations, antipsychotic medication) were torpedoed. Countering the professionals' versions of optimal therapeutic interventions, some patients need to take their own routes to independence.

Case 3: Ralf G. – Bethel Centre

When Ralf G. came to the monitoring unit he was 32 years old, having three to nine psychomotor seizures per month. In the first years after the onset of his epilepsy (about 20), they were preceded by a warning, which had disappeared after a medication change some months ago. Now he could fall with seizures occurring when he applied for jobs, during interviews, and when he was emotionally rattled.

Ralf had successfully passed a university entrance qualification only a few days after his epilepsy started. He entered university and acquired a diploma in economics by age 25. However, he was not successful in finding a stable position, and when he came to our centre he had already been unemployed for more than two years. He had sent more than 300 application letters and had about 25 job interviews (when discussing this subject a seizure occurs which takes approximately 10 min until full reorientation).

During his university studies, and also during his efforts to find a job Ralf had lived, with one short interruption, in the house of his parents, the reason for which had been his poor finances. He was completely dependent on his parents, got 'pocket money' from them on a weekly basis, and he had no friends. He previously had good contacts with his classmates in his university training, but he had not kept them. He had never had a girlfriend although he hoped for one.

The monitoring showed an angioma in the left posterior temporal lobe with interictal and ictal sharp waves and a seizure semiology congruent with this finding. Some months later Ralf underwent a resection, left temporal posterior, and never had a seizure or an aura since. Before surgery he defined his main aims as to find employment, to live independently from his parents, and to find a significant other. In the first six months after surgery Ralf, after a short euphoric episode, fell into a deep depression which lasted about 3 months. Nevertheless, he started with vocational retraining as an industrial manager initiated by our centre. He had great difficulties in the theoretical part of the training because of surgery-related memory problems. However, he was highly successful in the more practical training tasks because his attention and concentration had significantly improved.

Ralf at first continued to live with his parents, but tried however to live more independently in the house, whereby much conflict with his mother then arose. He cleaned the windows of his room by himself and began to clean his clothes in the washing machine. His mother however insisted on doing the shopping together with him and did not allow him to use his bicycle without her presence. One year before finishing his vocational training he found his own flat about one mile from his parents' house. His mother came to support him at the flat which often

ended in an outburst of rage against her. An evaluation by our psychiatrist showed that during the course of his illness Ralf had become an overly-controlled person whose compulsive perfectionism hindered him in managing his household tasks adequately. He attributed his feelings of inadequacy to his mother, being the personification of structured functioning in household tasks. To clear this complicated relationship, a psychotherapeutic intervention was initiated.

After Ralf had been seizure free for one year he began actively to look for a girlfriend. The only contacts outside his family until then had been in his self-help group. But now he felt that this was no longer his reference group and he tried to find contacts outside the group. This however was completely unsuccessful, and finally Ralf came into partnership with a woman from the self-help group who had also become definitely seizure free. He started biking without any accompaniment or only with his partner and, for the first time in his life, he travelled with her to Italy.

Ralf finished his vocational training (successfully) although with severe difficulties in tasks demanding strong memory involvement and, afterwards, had difficulties finding an adequate job. He has been an employee in the administration of a sheltered workshop for several years, a job which he secured through an employment initiative of his labour exchange's rehabilitation department.

Asked what had changed after surgery, Ralf answers: 'There started a new life after surgery, and I have attained my three goals – employment, independent living, and bonding with a significant other. However, I continue to be a person with disability – at least on some days. I can only hold a job in which the environment accommodates to my individual limitations, i.e. quickly finding the right words and retaining things in my memory.'

Conclusion: new directions

This chapter has emphasized the components of effective psychosocial intervention around the epilepsy surgery event. It drew upon current research findings that stress concern about psychiatric variables and better understanding patients' personal psychosocial attributes in order to improve their post-operative adaptation. Hopefully, we are on the brink of a period in which more comprehensive and targeted psychosocial intervention will become common as a complement to the epilepsy surgery procedure.

The challenge for centres performing epilepsy surgery is the financial support of allied health team members who can perform these interventions or to educate and construct a team of community-based consultants who can likewise provide these services. We are at a juncture where the need for psychosocial intervention can no longer be ignored. These operations, particularly for adults, if performed in isolation from psychosocial assessment/intervention, will often result in 'no change' in functional living status or even a 'regressive' patient profile.

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