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Chapter 21

Vocational Outcome

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As national interest increases in the benefits of the surgical treatment of epilepsy, a growing area of concern is whether the operation has a significant benefit on the occupational lives of patients. This chapter reviews the existing literature on vocational outcome following epilepsy surgery, overviews recent research data from a comprehensive study at the University of Washington Regional Epilepsy Center, and suggests steps toward improving vocational and other functional outcome for patients undergoing the operation.

This chapter concerns itself principally with changes in competitive vocational functioning. Explicitly, as a function of the operation, are the patients actually better able to work on a competitive remunerative basis within the labor market? It is important to maintain this perspective because this is often not the perspective that is maintained in a number of studies within existing research. It can be helpful to document subtle work-related changes, but an emphasis of our research should be focused on whether the surgery and encompassing psychosocial intervention are really making a change in patients' ability to financially support themselves within the local labor market. It is only by clarifying what actually occurs around the surgical intervention that we can better formulate rehabilitation programs and plan interventions that will better complement the increasing effectiveness of the surgical operation on a client's medical functioning (see Chapter 18).

Literature Review

A number of studies have assessed vocational relevance of epilepsy surgery using a diverse number of outcome measures [1-13]. Review of these studies indicates a number of consistent difficulties in attempting to assess whether surgery has made a significant functional difference. These issues include the following:

1. Younger patients (who are often students) are grouped with older patients, and it is difficult to assess whether vocational changes are a function of the intervention or simply occur within the course of social maturation.
2. Working criteria do not always relate to paid competitive employment and include homemaker categories, sheltered work activity, and other subjective ratings of employment functioning.

A review of these studies suggests that the work by Augustine et al. [1] may present an accurate picture of what generally occurs. This 1984 study followed 32 surgical patients at four status points: 2 years before the operation, 1 year postsurgery, 2 years postsurgery, and the latest year postsurgery follow-up available. While the number of patients employed on a full-time basis increased from 14 to 23, the number underemployed decreased from eight to zero. Unemployment, however, remained basically constant. Vocational gains were made, therefore, chiefly by the underemployed. Patients did not progress vocationally unless they had some vocational involvement prior to the surgery.

In this study, there were no significant differences in seizure-related variables (seizure reduction, use and serum levels of anticonvulsant drugs, or medication compliance) in employed or unemployed groups. As compared with the employed, however, the unemployed group appeared to have significantly more nondominant side resections (Chi-square significant,

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$p < .01$). Although similar to the employed group on verbal intelligence quotient (IQ) scores, the unemployed group evidenced a "dull normal" performance IQ compared with an average performance IQ for the employed group. This unemployed group had consistent performance IQ deficits both before and after the operation. Although a relatively small sample size ($n = 9$), the unemployed group had a significantly higher number of moderate to severe psychiatric disorders, legal difficulties/substance abuse histories, and a preoperative history of disability income (all Chi-square significant, $p < .01$).

There is also a consistent trend in the literature that improvement in psychosocial functioning to include occupational activity can be limited to individuals who become essentially seizure-free [7,9]. Although not congruent with the findings of Augustine et al. [1], work at our center by Hale et al. [13] supports the value of seizure-free status on vocational functioning. This study involved 54 surgery patients (44 temporal lobe and 10 other surgical sites). Table 21-1 reviews preoperative and postoperative groups by seizure status. It is apparent that only the seizure-free group achieved a significant gain within the vocational functioning category. It is of interest, however, that 2 years postsurgery there appeared to be no significant change relative to independent living. Since these study participants averaged 28 years of age, it may be particularly difficult to alter established dependent behaviors.

Other studies at our center [4] showed basically no significant employment gains from presurgery to

postsurgery for a group of 51 temporal lobe resection patients (27 right temporal lobe and 24 left temporal lobe). This study, however, did not control for seizure status, specifically the seizure-free category. These patients were interviewed 1-4 years postsurgery.

In sum, the available research suggests that epilepsy surgery is not making a significant contribution to employment functioning except for those patients who are on the employment track prior to surgery, albeit underemployed, and those achieving a seizure-free status. It is also probable that psychiatric functioning, receipt of financial subsidy, and below-average cognitive functioning—particularly in the motoric and visual/spatial abilities areas—also influence employment outcome. Patients with fewer concerns in these areas are better able to mobilize their resources.

Horowitz and Cohen [14] and Horowitz et al. [5] indicate some of the more subtle concerns that are more difficult to document. Following dramatic seizure improvement or relief, some patients can be undergoing dramatic identity reformulations, which interfere with the ability to focus on a work transition. Other difficulties include a preexisting inadequate personality or inadequate personality secondary to the early onset of a more severe type of seizure disorder, and retarded rates of development or maturation secondary to the disability. In order to document the effects of these types of variables, we need to embark on more comprehensive and discreet evaluation prior to surgery. It is important to better clarify

Table 21-1. Comparison of Psychosocial Functioning Preoperatively and Two Years Postoperatively*

Variable	Before Surgery		After Surgery		t
	Mean	SD†	Mean	SD	
Seizure-free					
Vocational status	2.45	.80	2.73	.63	-2.10‡
Independent living	1.45	.91	1.50	.91	-1.00
Overall	3.95	1.46	4.23	1.38	-2.28‡
Significantly Improved					
Vocational status	1.43	1.28	1.14	1.29	.76
Independent living	.78	.97	.86	1.03	-1.00
Overall	2.21	2.01	1.86	1.75	.94
Not Significantly Improved					
Vocational status	1.33	1.19	1.44	1.20	-0.58
Independent living	1.28	.96	1.39	.92	-0.74
Overall	2.61	1.54	2.83	1.76	-0.96

*Coding Note:

Vocational status: 0 = unemployed; 1 = token employment; 2 = part-time employment; 3 = full-time employment.

Independent living: 0 = fully dependent; 1 = semi-independent; 2 = independent.

Overall functioning score combines the vocational status and independent living scores.

†SD = standard deviation.

‡ $p < .05$.

the role played by obvious and more subtle variables in movement toward work and a greater range of functional life activity. Without careful documentation of these variables, it is more difficult to develop timely and effective interventions.

Current Research at the University of Washington Epilepsy Center

A comprehensive effort is currently being made at our center to examine the effects of epilepsy surgery at 5 and 10 years postoperation with the inclusion of matched controls. For our purposes, we review only the available vocational data. Homemakers were excluded from the study because it is difficult to assess the support that they receive within the home or their actual functional level.

Table 21-2 reviews comparative vocational data at 5-year follow-up between surgical patients and matched controls. Controls were patients with intractable partial seizures who were being medically managed on anticonvulsants. There were 39 surgical patients and 24 controls. For the surgical group, 21 patients were working before and after the surgery, whereas 11 patients were not working either presurgery or postsurgery. Fifteen of the people that were working presurgery and postsurgery indicated improved functioning on the job, whereas six indicated that their employment functioning was about the same. Among the controls, only six were working presurgery and postsurgery, and five of the six indi-

cated improved functioning during this period of time. Numbers in the other vocational categories are very small. It is of interest that in the surgical group, however, three individuals were working after surgery but not before. Ratings of employment functioning were scored as follows: 1 = decreased functioning, 2 = functioning the same, or 3 = functioning improved. These ratings were related to the consistency of their competitive employment, salary increases, more responsible job tasks, a greater range of tasks, or actual job promotions.

In Table 21-2, student transition to work was examined separately. There were only two students in the surgical group, one going to full-time work and one going to full-time subsidy. The control group, however, appeared to be doing reasonably well, with only two of the nine in a sheltered work category at 5 years after initial evaluation. The other seven students were either working or continuing within a school program.

Table 21-3 reviews findings on 17 surgical patients 10 years postsurgery and on 24 matched controls. Of four surgical patients working before and after surgery, all four indicated improved employment functioning on the job. Of seven individuals who did not work before and after the surgery, four indicated the same employment functioning, whereas three indicated reduced employment potential.

Among the 10-year controls, although seven were working before and 10 years after initial evaluation, their perception of their employment functioning was not as positive as that of the surgical group. Only two

Table 21-2. Five-year Follow-up

	Surgical Patients Work Status: Before and After Surgery				Controls Before and After Initial Evaluation			
	Vocational Functioning Level*			No.	Vocational Functioning Level*			No.
	1	2	3		1	2	3	
Working before and after	21	6	15	6		1	5	
Not working before and after	11	9	1	5		4	1	
Working before/not after	4		1	3	2		1	
Working after/not before	3		3	1		1		
	39	4	15	20	15	2	6	7
Student status:†	One working full-time, one on government subsidy				Four working full-time, one working part-time, two in marginal/sheltered work, two in continuing school programs			

*Coding Note:

Vocational functioning level: 1 = work functioning has deteriorated; 2 = work functioning is the same; 3 = work functioning has improved.

†Student status relates to follow-up of individuals who were students at the time of surgery or initial clinic evaluation.

Table 21-3. Ten-year Follow-up

	Surgical Patients Work Status: Before and After Surgery				Controls Before and After Initial Evaluation			
	Vocational Functioning Level*				Vocational Functioning Level*			
	No.	1	2	3	No.	1	2	3
Working before and after	4			4	7	2	3	2
Not working before and after	7	3	4		8	1	7	
Working before/not after					3	2	1	
Working after/not before					1		1	
	11	3	4	4	19	5	12	2
	Student status:† Four working full-time, one working part-time with full-time school, one on government subsidy				Student status:† One working full-time, four on government subsidy			

*Coding Note:

Vocational functioning level: 1 = work functioning has deteriorated; 2 = work functioning is the same; 3 = work functioning has improved.

†Student status relates to follow-up of individuals who were students at the time of surgery or initial clinic evaluation.

indicated improved functioning, whereas three indicated no change in employment functioning and two indicated a decreased level of employment functioning.

Review of student performance 10 years after surgery or initial evaluation shows an interesting trend. Five of the six students who had surgery moved to full-time work or a full-time school and part-time work program, and only one student made the transition to subsidy status. Among the five students within the control group, four students were on subsidy status, and only one had found full-time work. The patients who were students at the time of surgery appeared to be adapting considerably better than the controls. This may support the early benefit of the surgery on these students' rate of development and occupational gains. It will be of interest to examine vocational differences at 10-year follow-up between surgical patients and controls as the patients evaluated increase through the duration of our study. It may require 10 years of follow-up in order to have a more accurate picture of the vocational impact of the surgery.

Steps in Creating Functional Change

For clients without significant cognitive, emotional, and personality deficits, significant intervention will still be required in order to achieve functional life changes among the adult population. Several authors [5,15] have emphasized that although patients may be relieved of seizure concerns, many have learned to live with the disability and in a number of cases have

adopted the identified patient role within the family structure. Horowitz et al. [5] emphasize that this can be a critical period of time in which the counseling therapist and other team members must use their resources to assist the patient in the effort to identify reformulation, reevaluation of assets and deficits, and establishing new patterns of interaction with family, friends, and coworkers (if the person is working).

During the early phases of postoperative rehabilitation, individuals may go through a number of changes. In an earlier study at our center, Hurley et al. [4] indicated that 41% of surgery patients endure some negative emotional or cognitive difficulties in the first postoperative year. These are primarily emotional, involving depression, anxiety, apathy, and irritability. Most of these, however, appear to be reactive and related to changes in seizure status, dealing with new expectations and other such factors, and primarily seem to resolve in the initial postoperative year or years.

These data do suggest a significant subgroup of patients who go through a series of psychosocial changes. Horowitz et al. [5] suggest that these changes can be both intrapersonal and interpersonal. On an intrapersonal basis, patients may be waiting to see if improvement will be maintained, reappraising their abilities, dealing with the polarities of great expectations and the acceptance of the operation's failure if it does occur, giving up an assumed patient role, and so forth. Some individuals have difficulty adjusting and begin to substitute symptoms, become depressed, deny change, and cling to their established disabled person role.

Rehabilitation team members, family, friends, and other associates are challenged to both continue support and make some reasonable expectations for change on the part of the patient. This can be a delicate balancing interaction between the continuance of support, with the establishment of realistic goals and expectations for the patient relative to increased household and work responsibilities.

As previously reported [16], a small group of patients (four in the earlier University of Washington series) experienced a postoperative psychotic incident, primarily an atypical psychosis with paranoid ideation. These patients, although not having a prior hospitalization, had limited social support, experienced seizures of very early onset, were improved but not seizure-free, and had some history of community counseling or therapy. These patients were treated as having transient psychosis at the University of Washington Neurology or Epilepsy Center service. Following a period in which their seizures were stabilized by medication, the patient and family were educated relative to the probable transient nature of this illness. These individuals gradually returned to work, initially using a volunteer work experience with gradual transition to paid part-time and full-time work. They were coached relative to handling emotionally stressful events on the job and referred to a community support group and therapist. In all cases, these individuals stabilized and were able to maintain independent living and employment without being subject to a label of mental illness through referral to a psychiatric institution. A major effort was made to frame these incidents as acute and transient difficulties and to avoid chronic disability.

Assessment

It is very important that these patients be carefully assessed cognitively and psychosocially as a complement to effective surgical intervention. Assessment includes neuropsychological and psychiatric interviews and testing, functional academic testing, vocational interest assessment, and work values identification, and may include the use of work samples. This assessment not only identifies those patients who may have more adjustment difficulties but also enables the establishment of reasonable postoperative goals toward which progress can be made even before the surgery.

Framing Intervention

To truly bring about a successful rehabilitation, the surgery may be conceptualized to the patient and

family members as only part of the intervention that may render them more successful within their personal lives. Nonmedical team members such as the counseling psychologist, neuropsychologist, vocational counselor, recreational therapist, social worker, and recreation specialist can provide clients with a profile of their assets and areas of deficit as they approach the surgery. Patients and their significant others can be securing information about different job or work goals prior to the surgery. Based on seizure frequency, individuals can be placed on volunteer or even temporary paid work as they approach the surgical event (if they are not working at the time of surgery). They can explore reasonable living alternatives as well as community activities in which they have a greater potential for participation postsurgery. For clients with a longstanding patient role within the family and community, gains made in social interaction skills through volunteer work or involvement in organized community activities can be immensely helpful in improving employment potential. Improved socialization skills can compensate, to some degree, for even cognitive limitations within the employment market.

Based on response to the surgery, these community activities may need to proceed slowly in the immediate postoperative period. Some patients, however, can again begin to pick up on a fuller range of life activities relatively early in the postoperative period and make significant progress toward achieving new work, independent living, and social goals.

Functional Goals

It is important to emphasize that functional goals are established through review of assessment data as well as through interaction with the patient and family members, members of the interdisciplinary team (neurosurgeon, neurologist, neuropsychologist, rehabilitation counselor, social worker, etc.). Based on the client's progress, these goals may have to be reformulated, but if they are not set it is more likely that the client will not make a functional change because of established life patterns, anxiety over barriers that need to be overcome, and/or currently existing financial subsidy. If a patient has significant neuropsychological, emotional, or other deficits, these areas of concern will require more careful interdisciplinary team attention.

Utilization of the Rehabilitation Team

Surgery for epilepsy should be conducted within a team framework in order to optimize functional outcome. For many neurosurgical groups, there may be

no social worker, vocational rehabilitation counselor, or other nonmedical team members. If this is the case, the activities of these professionals should be secured on a consultant basis from the community and coordinated by a nursing care coordinator or a social worker. For a majority of clients, it appears unlikely that these operations will result in substantial functional improvement (even if relief from seizures is experienced) unless a team or coordinated psychosocial intervention is made.

Maintaining Functional Gains: The Continuing Role of Psychotherapy and Education

As clients begin to make progress, it will be important that the primary therapist or counselor (psychologist, rehabilitation counselor, etc.) maintain contact with the client and family. There is often a tendency to regress to previously established roles that are not conducive to maintaining functional life progress. As more of these operations are performed, it would become valuable to establish 1- to 2-week psychoeducational programs for clients and family members that will provide more information about the patients' new medical status, the world of work, restructuring of their family interactions, emotional support as they challenge themselves with new expectations, and so on. Epilepsy associations may be of assistance in developing self-support groups for postsurgical patients. In considering the extent of change that will be required in the lives of many of these patients, however, it would behoove medical facilities conducting these operations to establish a short-term psychoeducational program as a basis for the rehabilitation effort. At times, family members can be more resistive than patients to establishing more functional rehabilitation goals within the lives of their sons or daughters. It may require a very comprehensive effort to really bring about change.

Summary

This chapter reviews a number of concerns related to vocational and, to some degree, other functional life changes following epilepsy surgery. Certain groups appear to be making postsurgical vocational and psychosocial progress, but these tend to be individuals who were already on a vocational track prior to the surgery, were students, or generally were of a higher cognitive level and better integrated psychosocially. Total relief of seizures can be a factor affecting vocational change, but findings are inconsistent and may

be related to presurgical functioning. This will not be the case among the majority of individuals undergoing this operation. Consequently, the onus of bringing about successful changes in daily life functioning as a complement to seizure resolution rests on the staff of our medical facilities or the consulting teams that these facilities can draw from the community. Although further research is ongoing at our center and at others, existing data suggest that we are not yet able to effect the changes that are necessary to maximize these individuals' functional capacities as a complement to their usually improved medical status. Continuing research at our center should be helpful in further clarifying salient variables related to functional surgical outcome and the interrelationships among these variables.

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