

## **The burden of normality: A framework for rehabilitation after epilepsy surgery**

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### **SUMMARY**

**This paper describes a conceptual framework that generates a modus operandi for rehabilitation after epilepsy surgery derived from regular longitudinal and prospective follow-up of patients and families. The framework focuses on patient experiences of undergoing surgery placed within the context of the family and broader community. It adopts a holistic view of patient care to understand the**

**complex interactions between neurobiological and psychosocial factors that determine surgical outcome in the eyes of the patient, family, and clinical team. It emphasises the importance of anticipating postoperative adjustment issues using a preventive treatment approach.**

**KEY WORDS:** Rehabilitation, Treatment outcome, Epilepsy surgery, Psychosocial adjustment, Quality of life, Chronic illness.

Based on research and clinical experience in our Seizure Surgery Follow-up & Rehabilitation program (Bladin, 1992), we present a conceptual framework for rehabilitation after epilepsy surgery. Most research has focused on rehabilitation for patients who acquire a neurological disability such as stroke or traumatic brain injury (Cooper, 2006). This entails a sudden transition from wellness to chronic disability. Epilepsy surgery patients experience the reverse transition from chronic disability to sudden wellness, giving rise to a different spectrum of rehabilitation needs (Wilson et al., 2001). Principally, we have found that rehabilitation requires a psychological focus nested within the patient's social context, and underpinned by an appreciation of brain–behavior relationships.

The challenges for the epilepsy surgery patient reentering community life have been well described, particularly for employment, social functioning, and driving (Fraser and Thorbecke, 1997). Despite complete seizure relief, not all patients make employment or social gains, and not all perceive their outcome as a complete success (Wilson et al., 2004; Dulay et al., 2006). A multidisciplinary approach to rehabilitation has been highlighted to facilitate patient change and achieve “real life” benefits of seizure

freedom. Equally important is understanding patient and family expectations associated with being rendered seizure free and their impact on perceived outcome (Taylor et al., 2001; Wilson et al., 2004). Considered this way, the process of rehabilitation begins before surgery with preoperative expectations providing insights into the nature of the transition that may lie ahead.

### **THE “BURDEN OF NORMALITY” AS A FRAMEWORK FOR REHABILITATION**

“Being sick is one manner of being. That may not change by removing an epilepsy focus.” (Taylor, 1993, p. 15)

At the core of the transition from chronic disability to sudden wellness lies a change in the patient's self-concept. Before surgery this depends on the extent to which epilepsy defines and limits the individual, from a personal, family and local community viewpoint. After surgery, it reflects the degree to which a change in self-definition is embraced by the patient, and is supported by the family and broader social context. We have found that most patients are eager to discard epilepsy from their self-image, often embracing this change soon after surgery in an attempt to negate perceived stigma and enjoy a lifestyle unrestricted by the sanctions that accompany intractable seizures (Jacoby et al., 2005). Preoperatively patients may allude to this desire through the expectation of being rendered “normal” by

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**Table 1. Features of the burden of normality to canvass in rehabilitation for epilepsy surgery**

Life domain	Features	Common issues for rehabilitation
Psychological	Changes in self-concept ("well self")	Sense of "cure" or "difference" (from self or others) Lack of "excuse" of chronic illness Sense of missed opportunities ("lost years")
Behavioral	Changes in activities	Need to "prove" normality Grieving the loss of epilepsy Need to make up for lost time
Affective	Changes in mood	"Overdoing it" (physical, vocational, social) "Underdoing it" (physical, vocational, social) Other somatic complaints Change in sex drive (typically increased) Nonadherence to anticonvulsants
Sociological	Changes in family dynamics New vocational horizons New social horizons	Euphoria, joy of "cure" Anxiety, increased "pressure" Depression, shame, guilt Frustration, regret Role of the primary carer Attitudes of family members and friends Increased family conflict Educational and vocational programs Employment opportunities, promotion Driving Intimate and nonintimate friendships New social activities and networks

surgery, or the experience of feeling like a "new" or "different" person after surgery (Wilson et al., 2004).

A need to acquire or prove this "normality" can alter the balance of life, and may constitute a significant adjustment for the patient and family after surgery. This is because patient and family expectations of how this normality might be experienced span a range of psychological and social issues that vary in complexity according to the perceived effects of intractable seizures (Wilson et al., 2004). In attempting to achieve this normality, patients may overshoot or undershoot the mark, or they may lack the necessary skills and abilities while no longer having the "excuse" of epilepsy. The psychosocial sequelae of intractable seizures have often been years in the making with effects that continue to reverberate after surgery (Wilson et al., 2001).

The rate at which a patient embraces the transition from chronic disability to sudden wellness may or may not match the rate that is accepted by the family or broader community. A mismatch creates a psychosocial disequilibrium that may lead to patient and family distress and/or dysfunction (Seaburn & Erba, 2003). Alternatively, some patients or carers choose not to embrace this transition or lack the capacity to do so, with significant frustration for all. Feelings of anxiety or guilt may arise within the patient accompanied by a sense of increased expectations or pressure to perform roles and responsibilities that hallmark being "well" (Wilson et al., 2001).

It is our view that the transition from chronic disability to sudden wellness principally underpins the psychosocial challenges that arise following epilepsy surgery. These challenges play out in different life domains, affecting how the individual thinks, feels, behaves, and interacts socially, including the desire to pursue new vocational and social opportunities, and driving. The challenges are inter-related and constitute a "syndrome" of regularly occurring psychosocial issues that centre around the meaning of becoming well. The burden of normality encapsulates this syndrome under one rubric or framework that informs rehabilitation (see Table 1).

### Alternate psychosocial trajectories after epilepsy surgery

For patients who have only minimally incorporated epilepsy into their self-identity, the transition from "illness" to wellness may be relatively smooth without significant burden of normality. Alternatively, patients experiencing seizure recurrence may initially struggle with issues of self-identity (i.e., Am I sick or well?) but ultimately show no transition to wellness if seizure frequency remains largely unchanged. In these patients there may be significant disappointment and a sense of "failure" (Bladin, 1992), with resignation towards ongoing seizures and frustration over the perceived "ineffectiveness" of medications and continued restrictions on independence. Also pertinent is the case where the perception of one disability is replaced by another after surgery. For example, the acquisition of a physical or cognitive disability associated with a neurosurgical complication (Popovic et al., 1995), or a *de novo* diagnosis of a psychiatric condition such as depression (Wrench et al., 2004). This case counters the preoperative argument that "it can't get any worse," with patients and families expressing anger or regret at undergoing surgery and a desire to return to the preoperative status quo. In these patients, rehabilitation may need to follow a more traditional model of acquired disability.

### The role of neurobiological factors

Rehabilitation of epilepsy surgery patients must take into account brain functioning and its expression at a cognitive, affective, and behavioral level. Two models of the comorbidity of mood and behavioral difficulties after epilepsy surgery point to the complexity of neurobiological and psychosocial interactions. The first considers changes in mood and behavior to arise directly from the transition from chronic disability to sudden wellness that potentially applies to all patients irrespective of seizure localization or the site of surgical resection. Neurobiological factors play an important role in mediating seizure outcome, but only affect mood and behavior indirectly via the patient's perception of surgical success and the extent of burden of

normality. The second model presupposes a neurobiological mechanism related to seizure localization or resection that directly underpins changes in mood and behavior (Kanner, 2006; Wilson et al., in press). Examples include mood disturbance or changes in sexual functioning following disruption of limbic system structures after mesial temporal resection. These models are not mutually exclusive, rather their effects may be compounded in given patients. Neurobiological factors can heighten the risk of mood and behavioral changes in patients following epilepsy surgery either directly or indirectly, and may act as preoperative markers of these changes (Wilson et al., in press).

Extra-temporal surgery is less likely to render patients seizure-free (Télez-Zenteno et al., 2005) producing a less dramatic transition from chronic disability to wellness. Extra-temporal surgery may also pose specific risks to cognition with resection of eloquent cortex, providing a direct neurobiological mechanism for changes in patient thinking and behavior. The burden of normality provides an overarching framework for rehabilitation after epilepsy surgery as it allows the complex interactions between neurobiological and psychosocial factors to be taken into account.

### Rehabilitation in the clinical setting

The process of rehabilitation begins before surgery, with patient and family expectations providing a crucial baseline for understanding outcome (Taylor et al., 2001). Our goal is to anticipate the extent of patient and family adjustment after surgery using a detailed, face-to-face psychosocial assessment to gain an understanding of the way epilepsy has affected the patient and family over the lifespan. This includes canvassing the extent to which epilepsy forms part of the patient's identity and has dictated the structure and functioning of the family, as well as its perceived advantages and disadvantages, views about surgery, and post-operative expectations. It provides an opportunity to proactively address unrealistic expectations and prepare patients and families for changes that may lie ahead as part of the adjustment process.

The treating clinical team discuss key psychosocial issues that relate to the decision to offer the patient surgery. Identified issues are then incorporated into the patient's rehabilitation plan and addressed as part of routine treatment. This can include linking patients into appropriate vocational and social services in preparation for the postoperative period, and proactively treating mood and psychosocial adjustment difficulties. The latter recognizes that patients who are poorly adjusted before surgery often show adjustment difficulties after surgery (Wilson et al., 2001). We advocate a proactive rehabilitation approach that pre-empt negative outcomes and enhances positive outcomes, ideally to promote a seamless transition for the patient and family.

After surgery, our rehabilitation program includes regular multidisciplinary reviews for at least two years with

patients and family members that is coordinated by a Senior Clinical Neuropsychologist (Wilson et al., 2004). The focus of these reviews varies with the needs of the patient and family but invariably canvasses the ability to live without epilepsy and features of the burden of normality in the context of seizure outcome. Liaison with members of the patient's broader social community is also common, particularly employers and vocational services. Buttressing our detailed face-to-face psychosocial reviews is the pivotal role of an Epilepsy Nurse Clinician who provides a triage service via regular phone follow-up of patients. This service is particularly vital for patients and families who live in geographically remote locations.

## CONCLUSIONS

We propose that the broad psychosocial changes of the burden of normality provide an essential framework for rehabilitation after epilepsy surgery with an understanding of the neurobiological and psychological bases of the patient's behavior nested within the broader context of the family, community, and culture. This framework views the patient and family members as active agents in rehabilitation that primarily revolves around the transition from chronic disability to sudden wellness. It provides an approach to the assessment and counseling of patients and families to assist patients in maximizing their outcome and truly benefiting from seizure relief.

### Disclosure of Conflicts of Interest

The authors have declared no conflicts of interest.

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