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Characterizing psychosocial outcome trajectories following seizure surgery

Sarah J. Wilson [a,b,*], Peter F. Bladin [a], Michael M. Saling [a,b], Philippa E. Pattison [b]

[a] *Comprehensive Epilepsy Program, Epilepsy Research Institute, Austin Hospital, Melbourne, Australia*
[b] *Department of Psychology, School of Behavioural Science, University of Melbourne, Melbourne, Australia*

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Abstract

Purpose. We have developed a new approach to characterizing psychosocial outcome after seizure surgery that allows us to identify diverse individual trajectories as well as subgroups of patients with similar outcomes.

Methods. Eighty-nine anterior temporal lobectomy (ATL) patients were recruited through our Seizure Surgery Follow-up and Rehabilitation Program. The Austin CEP Interview was used to measure psychosocial adjustment presurgery, at discharge, and 1, 3, 6, 12, and 24 months postsurgery. Patient outcome trajectories were characterized across this time frame using a profile-focused form of dual clustering that leads to a lattice representation.

Results. Two major, distinct outcome subgroups were identified. Fifty-eight percent (58%) of patients reported good outcomes, characterized by improved family dynamics, enhanced vocational and social functioning, and driving by 24 months postsurgery. A range of trajectories led to these outcomes, including the experience of early postoperative adjustment difficulties. In contrast, 31% of patients perceived their outcomes as poor, reporting affective disturbance at 12 months and difficulties discarding sick role behaviors. Early anxiety served as a marker of poor outcomes, while resolution of early anxiety and vocational change at 12 months were indicators of good outcomes at 24 months. The remaining 11% of patients reported minimal adjustment features.

Conclusions. For the majority of patients, seizure surgery gives rise to an evolving process of postoperative adjustment that leads to distinct outcome trajectories. Our approach questions the clinical sensitivity of health-related quality of life measures that average across patients to provide a unitary measure of outcome. Although preliminary, the findings have implications for postoperative treatment, including the identification of markers of longer-term outcomes.
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Keywords: Epilepsy surgery; Surgical outcome; Psychosocial adjustment; Quality of life

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1. Introduction

Medical research has witnessed the rapid growth of health outcome research and the development of standardized, psychometrically validated measures of patient health-related quality of life (HRQOL) to assess the impact of medical diagnostic techniques and treatments. The development and implementation of standardized HRQOL measures, typically in the form of structured paper-and-pencil questionnaires, have been considered an advance in outcome research methodology. The same set of variables can be used to compare the HRQOL of different patient populations, or to assess the impact of an intervention on a specific patient group by comparing HRQOL before and after treatment [1–4].

Outcome studies have commonly employed cross-sectional group research designs where the average score taken at a single time point is used to reflect the HRQOL of the group as a whole. This information can serve as a global outcome indicator and potentially guide the allocation of resources to various patient

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[*] Corresponding author. Fax: +61 3 9347 6618.
E-mail address: sarahw@unimelb.edu.au (S.J. Wilson).

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populations [5], but is perhaps less useful to the treating clinician who must deal with each patient and his or her family on an individual basis. The treating clinician requires a detailed understanding of the factors relevant to the health trajectory of a particular patient and whether she or he may benefit from a given intervention. Cross-sectional group research does not reveal these individual trajectories; it averages across both good and poor outcomes and provides limited clues about which factors are most relevant in effecting positive change for an individual. In other words, cross-sectional group studies assume that outcome is relatively homogeneous within groups and unchanging across time, rather than a dynamic, individually based process that unfolds over time. Reflecting this, standard psychometric data analytic techniques have typically been employed that impose an a priori structure on the data rather than allowing the range of potential outcomes to emerge through an empirically derived approach.

For these reasons, the inclusion of alternative research methodologies is required to broaden the approach of outcome research. Longitudinal follow-up is important to assess the evolution and longer-term effects of treatment outcome. This can be coupled with data analysis techniques that identify the trajectories of individuals or subgroups of patients in a larger population using an empirically derived approach [6,7]. Data collected at the clinical coalface, such as patient self-reports and family- and clinician-based observations, are best used to characterize the phenomenology of outcome for a given individual and to identify factors that may be predictive of longer-term treatment effects [8].

The present study provides an example of this alternative approach to outcome research. Based on detailed patient and family reports, we have previously described the clinical phenomenology of postoperative psychosocial adjustment of patients undergoing surgery for the treatment of chronic epilepsy [8–10]. In particular, we have identified an important psychosocial syndrome, known as the "burden of normality." Our conceptualization of this syndrome comprises clinical features that arise as manifestations of an underlying process of adjustment, and which can be assigned to various psychosocial domains (see Table 1). This process unfolds dynamically over time, and involves primarily the individual discarding roles associated with chronic epilepsy and learning to become well. Our previous research [8–10] suggests that the ability of the patient and family to manage this process can ultimately give rise to widely differing treatment outcomes, despite surgical success at the pathophysiological level (i.e., seizure freedom).

Table 1
Clinical features of the burden of normality

Psychological	Sense of "cure," proof of normality, increased expectations, the "lost years"
Behavioral	Excessive activity, increased sex drive, shirking and/or somatic complaints
Affective	Mood elevation, anxiety, depression
Sociological	Restructuring family dynamics, new vocational and social horizons

The aim of the present study was to model the outcome trajectories of patients following seizure surgery in terms of psychosocial adjustment and symptoms of the burden of normality. In particular, we used a profile-focused form of dual clustering that explicitly characterized the range of observed patient outcome profiles over a 2-year follow-up period. This aim served the broader goal of improving our clinical understanding of the nature of posttreatment adjustment following the effective relief of chronic epilepsy, including the identification of individual trajectories and patient subgroups with diverse outcomes.

2. Methods

2.1. Participants

Patients constituting the sample of this study have been previously investigated and described in detail, and form part of a larger, nationwide study of Australian anterior temporal lobectomy (ATL) patients referred to our Comprehensive Epilepsy Program for seizure characterization [8]. This nationwide study was designed to characterize the phenomenology of psychosocial issues surrounding seizure surgery and the impact of these issues on posttreatment outcomes [8–10]. A consecutive series of 100 ATL patients were drawn from the larger nationwide sample. All patients had undergone ATL for the control of complex partial seizures of temporal lobe origin, according to the preoperative protocol and surgical technique previously described [10,11]. All operations were performed from May 1990 to April 1993. Three patients were excluded from the study because of incomplete data (3% dropout rate), and an additional seven were excluded because they underwent seizure surgery more than once. One of these patients underwent two operations in less than 12 months of the sampling period of the study and, thus, was effectively excluded twice. This resulted in a total sample of 89 prospectively assessed patients (see Table 2).

Table 2
Characteristics of the patient sample

Sex	37 male, 52 female
Mean age	32.9 ± 11.3 (range 9–59)
Side of epileptogenic focus[a]	46 left, 43 right
Marital status[b]	41 single, 42 partnered
Employment status[b]	40 gainfully employed, 43 unemployed
Mean age of epilepsy onset	11.2 ± 9.5 (range 0–36)

[a] Side and site of epileptogenic focus were determined using the method outlined by Bladin [10].

[b] These data do not include children under the age of 18.

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