

Original article

## Psychosocial adjustment following relief of chronic narcolepsy

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### Abstract

**Background and purpose:** No previous research has examined the psychosocial adjustment of chronic narcolepsy patients following efficacious pharmacotherapy. In contrast, considerable research has examined the process of psychosocial adjustment following surgical relief of chronic epilepsy. This process can manifest as a clinical syndrome, the ‘burden of normality’, comprising psychological, behavioural, affective and sociological features. The aim of the present study was to characterise the process of psychosocial adjustment of patients with successfully treated narcolepsy and to explore the applicability of the burden of normality.

**Patients and methods:** Thirty-three narcolepsy patients and 31 epilepsy surgery patients were recruited through routine outpatient follow-up at the Austin Hospital in Melbourne. All patients underwent in-depth, qualitative psychosocial assessment using a well-validated semi-structured interview, the *Austin CEP Interview*. They were also administered quantitative measures of anxiety (*State Trait Anxiety Inventory*) and depression (*Beck Depression Inventory-II*).

**Results:** Narcolepsy patients spontaneously reported similar themes of post-treatment adjustment to successfully treated epilepsy patients, including symptoms of the burden of normality. Chi-squared analyses revealed that the two groups differed only on disease-specific factors, reflecting the later diagnosis and treatment of narcolepsy ( $P < 0.05$ ).

**Conclusion:** The results support a general model of adjustment following successful treatment of chronic neurological illness, as the patient discards perceptions of illness and behaviours associated with being ‘sick’ and learns to become ‘well’. Recognition of the burden of normality has important clinical implications for maximising the post-treatment care and outcome of narcolepsy patients.

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**Keywords:** Treatment outcome; Psychosocial adjustment; Narcolepsy; Epilepsy; Burden of normality; Chronic illness; Quality of life

### 1. Introduction

Recent medical and technical advances have played a major role in the relief of chronic, lifestyle-limiting medical illnesses. Examples of procedures that offer patients the chance for alleviation of chronic illness include liver, heart, and kidney transplantation, cardiac surgery, and seizure surgery. Current literature has focused on patient reports of well-being and quality of life following

these procedures. This research has arisen from an increased recognition of the importance of psychosocial issues in maximising treatment outcomes. Interest has also been driven by the need to evaluate the efficacy, cost-effectiveness, and net benefit of new therapeutic strategies to ascertain whether associated increases in health care expenditure are justified [1].

The alleviation of chronic illness has far-reaching and varied implications for those receiving treatment. Successful treatments offer patients the chance of a life without the burdens of physical, social, recreational, or vocational handicaps, and without the stigma and prejudices accompanying their condition. Previous research

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has indicated that achieving these benefits may involve a process of psychosocial adaptation and adjustment. In other words, the successful removal of chronic medical symptoms may not automatically give rise to psychosocial benefits. Outcome is also determined by the way in which the individual manages the process of post-treatment adjustment, which can encompass both positive and negative experiences. A number of studies have described the challenges associated with the post-treatment phase, including outcome following cardiac surgery [2–4], kidney transplantation [5,6], liver transplantation [7], and seizure surgery [8–11].

### 1.1. Psychosocial adjustment following seizure surgery

The most favourable candidates for seizure surgery are those with intractable complex partial seizures and a unilateral temporal lobe focus, for which patients may undergo anterotemporal lobectomy (ATL) [12]. Recent research examining outcome following ATL has shown that seizure freedom does not automatically lead to psychosocial benefits for the patient. A high percentage of patients and families describe adjustment issues associated with the patient's psychosocial transition from chronically ill to 'well' [13,14]. Bladin and colleagues [10,11] have characterised the phenomenology of the post-treatment adjustment process and shown that its features reliably co-occur, forming a psychosocial syndrome known as the 'burden of normality' (Table 1).

### 1.2. The narcolepsy–cataplexy syndrome

Like epilepsy, narcolepsy–cataplexy syndrome is a chronic neurological condition in which the relief of symptoms has been made possible through advances in medical science. The provision of central nervous system (CNS) stimulants to heighten alertness after years of sleepiness allows alleviation of the most disabling feature of the condition, excessive daytime somnolence [15–18].

There is a growing knowledge base of the psychosocial, co-morbid psychiatric, and neuropsychological

difficulties faced by narcolepsy patients [19–26]. In contrast, there has been no single prospective or retrospective investigation of psychosocial adjustment following successful treatment of narcolepsy. As chronic illnesses, narcolepsy and epilepsy share a number of similar features, including irresistible paroxysmal attacks, and deleterious psychosocial, neuropsychological and psychiatric impact [27]. Given that both conditions offer the chance for alleviation of medical symptoms, the nature of adjustment following successful treatment for narcolepsy warrants closer attention.

The primary aim of this study was to characterise the features of post-treatment adjustment in patients with successfully treated narcolepsy using a phenomenological, patient-centred approach. Qualitative methods were used as this information provides a crucial first step in characterising relevant psychosocial issues in new areas of research [28]. A secondary aim was to extend the previous research of Bladin, Wilson, and colleagues [10,11] by examining the relevance of the burden of normality to the post-treatment phase.

## 2. Methods

### 2.1. Participants

The sample comprised 33 narcolepsy and 31 seizure surgery patients. Narcolepsy patients were consecutively recruited through the hypersomnolence outpatient clinic of the Austin Hospital, which receives the majority of referrals of psychosocially disabling narcolepsy from the community. The diagnosis of narcolepsy was made by a senior clinical neurologist using the criteria of the International Classification of Sleep Disorders, Diagnostic and Coding Manual [29], and polysomnogram results. All patients were being treated with CNS stimulants for hypersomnolence (modafinil, methyl phenidate) and cataplexy (clomipramine, venlafaxine).

A pure sample of standard en bloc ATL patients was consecutively recruited through the seizure surgery follow-up and rehabilitation program at the Austin Hospital Epilepsy Outpatient Clinic. This program has a wide

Table 1  
Post-treatment features of the burden of normality

Psychological	Affective	Behavioural	Sociological
Sense of 'cure'	Euphoria	'Overdoing it' – physical, vocational, or social domains	Restructuring family dynamics
Grieving the loss of the illness	Anxiety	Increased sex drive	Hidden agenda of the patient or family for relationship change
Proof of 'normality'	Depression	Shirking behaviours	New vocational horizons
Increased expectations	Fluctuating course of the above	Focus on other somatic complaints	New social horizons
Lack of 'excuse' of the illness			
Sense of 'lost years'			
Need to make up for lost time			

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