Neurology Asia 2011; 16 (Supplement 1) : 31 – 33

Psychosocial outcomes of newly-diagnosed epilepsy

Sarah J Wilson

Psychological Sciences, The University of Melbourne, and Comprehensive Epilepsy Program, Austin Health, Victoria, Australia

Abstract

It is well-established that the diagnosis of a chronic or life-threatening illness typically gives rise to significant adjustment issues, as an individual seeks to make the necessary changes to lifestyle and self-perceptions to accommodate the diagnosis. Despite this, an understanding of the psychosocial adjustment process surrounding newly-diagnosed epilepsy is only beginning to emerge, with available evidence suggesting that management of this process may significantly impact longer-term medical and psychosocial outcomes.

INTRODUCTION

Advancing our understanding of the natural history and treatment of epilepsy is best derived from prospective, community-based outcome studies that follow individuals from the time of diagnosis over the long-term. This allows identification of different trajectories of outcome, including those patients who will ultimately become medically intractable (and may require surgery), versus those who will go into remission, or be controlled by anti-epileptic drugs (AEDs). To date, a dominant focus following the new diagnosis of epilepsy has been to identify predictors of seizure outcome, with research indicating that the risk of seizure recurrence decreases with time, but that ultimately up to 30% of individuals fail to respond to medical treatment.[1] There has been considerably less research of predictors of other outcomes, such as patient AED use, cognitive, psychiatric, or psychosocial functioning.

In the adult medical literature, it is well-established that the diagnosis of a chronic or life-threatening illness typically gives rise to significant adjustment issues, as individuals seek to accommodate the illness into their lifestyle and self-perceptions.[2] Despite this, we are only beginning to understand the adjustment process surrounding the new diagnosis of epilepsy and the potential psychosocial trajectories to which this gives rise, including how these trajectories might interact with medical outcomes. This research has the potential to identify patients at varying levels of risk across a range of outcomes, including patients at 'high risk' for poor outcomes across multiple measures. It also promotes the search for neurobiological and psychosocial predictors of outcome, enhancing our understanding of the interplay of factors that creates the greatest or least risk for a given patient, and providing insight into the psychological processes involved in adapting to ongoing illness.

PSYCHOSOCIAL ADJUSTMENT AT DIAGNOSIS

At the time of diagnosis, life expectancy has been reported as reduced, particularly in people who develop seizures before the age of 40.[1] There is an increased risk of suicide shortly after diagnosis, and elevated rates of co-morbidity and psychosocial difficulties.[3] In 2008, Jacoby and Baker reviewed the small number of existing studies examining psychosocial issues in newly-diagnosed epilepsy and linked their implications for overall quality of life (QOL) to the clinical course of seizures. This indicated that following only one or a few seizures, there is an initial dip in QOL that then returns to baseline levels, whereas when seizures become intractable, the QOL trajectory may worsen or have a more fluctuating course influenced by treatment and seizure control. While the second trajectory is not surprising, the first raises the important question, *What are the psychological processes that underlie the dip in QOL after a first seizure?* Or stated another way, *What is the experience surrounding diagnosis like for the patient?*

Initial answers to these questions come from work by Velissaris *et al*.[4] They undertook a prospective, longitudinal study of a cohort of 90 adult patients using both qualitative and

Address correspondence to: Sarah Wilson, Psychological Sciences, The University of Melbourne, Parkville, Victoria, 3010, Australia. Telephone: +61-3-8344-6377; Fax: +61-3-9347-6618; e-mail: sarahw@unimelb.edu.au

quantitative methods to profile psychosocial adjustment and outcome trajectories from the time of diagnosis. They identified two groups of patients with distinct adjustment features and psychosocial trajectories, who differed in their psychological experience at the time of diagnosis. The first group (55%) described a pervasive sense of loss of control (LOC), characterised by increased vunerability and mortality, grappling with why the seizure occurred, a fear of seizure recurrence and lowered mood, and a sense of loss of physical control. Diagnosis was experienced as a time of trauma and major life change, similar to the psychological sequelae often described following unexpected traumatic life events (such as natural disasters or the diagnosis of terminal illness). This psychological reaction likely accounts for the reported dip in QOL following a first seizure, and contrasts with the experience of the second group (45%) who reported a more limited psychological reaction. This group reported few, if any, features of LOC, and subsequently followed "less volatile" psychosocial and medical trajectories (Figure 1).

PROFILING TRAJECTORIES AND PREDICTING OUTCOMES

Psychosocial trajectories from the time of diagnosis centered around a psychological process of restoring perceived control. This included patient attempts to reduce the likelihood of seizure recurrence and generally improve health and lifestyle behaviours, as well as mental efforts to keep the seizure in perspective, trust in the efficacy of AEDs, and maintain normality in daily life. These attempts meant that most patients showed a return to normal psychological functioning within three months following their initial review, however the pervasive LOC group employed a much broader range of cognitive and behavioural coping strategies to regain control. This led to the paradoxical effect of an improved sense of self (greater self-confidence and increased control) in members of the pervasive group that is consistent with reports of psychological growth following a crisis[4], and was not experienced by the limited LOC group (Figure 1).

Six predictors of the psychosocial trajectories were identified. Members of the pervasive LOC group were more likely to be older, less educated women in a relationship, with a psychiatric history and no previous undiagnosed epileptic events. Their pervasive reaction led to more volatile trajectories, including heightened risk of seizure recurrence at 3-month follow-up, particularly in a subgroup of patients reporting increased symptoms of anxiety and depression at the time of diagnosis (Figure 1). This subgroup experienced poorer psychosocial outcomes, including greater mood disturbance, fear of recurrence, and a deterioration in sense of self.[4] Their specific trajectory supports the bi-directional relationship between depression and seizures previously reported in the literature and the view that the two may share pathogenic mechanisms.[5]

Given the evidence that perceived LOC influences subsequent psychosocial and medical trajectories, Velissaris *et al*[6] also examined its impact on cognition. At the time of diagnosis,

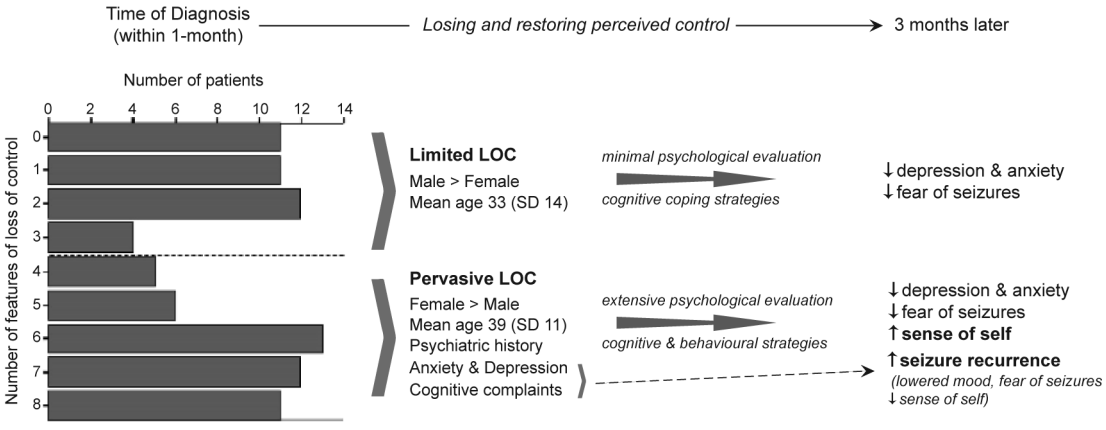

Figure 1. The process of adjustment surrounding newly-diagnosed epilepsy and subsequent psychosocial trajectories. At the time of diagnosis (within 1 month of a first seizure), the eight features of loss of control (LOC) included a sense of vulnerability and mortality, grappling with why the seizure occurred, subjective mood deterioration and fear of seizure recurrence, the experience of trauma and major life change, and loss of control over one's body.

almost 50% of patients believed some aspect of their cognitive functioning had been compromised by a first seizure, which was not related to objective attentional processing. Rather, a pervasive psychological reaction influenced the longitudinal course of cognitive complaints. In contrast to the less volatile trajectory of the limited LOC group, the pervasive group reported significantly more cognitive complaints at diagnosis that declined over time, but were mediated by mood. Notably, patients with seizure recurrence reported more cognitive complaints *prior to* recurrence, again mediated by mood. This is consistent with recent research identifying a subgroup of newly-diagnosed patients who were cognitively compromised at baseline.[7] It suggests that patients presenting with extensive cognitive complaints at the time of diagnosis may benefit from neuropsychological assessment and treatment for mood and adjustment issues, which may help to prevent seizure recurrence. The strong 'cognitive' presentation of the pervasive group may also partly explain why mood disorders are often under-recognised in epilepsy[8], as their symptoms can be easily attributed to other factors.

CONCLUSIONS

The time of diagnosis is a critical landmark from which span a number of possible psychosocial and medical outcome trajectories. Psychosocially, individuals generally fare well after one or a few seizures, however the time of diagnosis poses a risk based on the psychological reaction of the patient, that can be akin to a traumatic response. A pervasive sense of loss of control gives rise to more volatile outcome trajectories, with increased risk of mood disturbance, cognitive complaints, and seizure recurrence, but greater perceptions of psychological growth in patients employing effective coping strategies. This research provides initial insight into the psychological processes involved in adjusting to newly-diagnosed epilepsy and its ongoing treatment. It provides us with important clinical information for prognostic counseling, and helps identify medical and psychological predictors of outcome that may be targeted for early treatment interventions. Because psychological adjustment in the early phases of an illness is a strong predictor of future adjustment, further studies investigating the long-term outcomes of newly-diagnosed epilepsy should take the initial psychological reactions of patients into account.

ACKNOWLEDGEMENTS

This research was funded by an ARC Linkage Project Grant (LP0453690), GlaxoSmithKline Australia, and The University of Melbourne. GlaxoSmithKline had no direct involvement in this research and the author has no conflict of interest to declare.

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