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The effect of epilepsy surgery on caregiver quality of life

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Received 21 April 2013 ; received in revised form 28 July 2013; accepted 14 August 2013

KEYWORDS

Caregiver;
Quality of life;
Burden;
Epilepsy;
Surgery;
SF36v2

Summary

Purpose: Epilepsy surgery has been shown to improve patient quality of life (QOL). Little is known about its effect on caregiver QOL.

Methods: The study population comprised of 26 persons with epilepsy (PWE) who underwent long term video EEG monitoring at Massachusetts General Hospital for presurgical evaluation along with 16 caregivers. The PWE completed epilepsy directed QOL (QOLIE-31) and psychological (Beck depression-BDI and anxiety inventory-BAI) questionnaires before and after surgery. Their participating caregivers completed generic health related QOL (SF36v2) and disease burden (Zarit caregiver burden inventory-ZCBI) questionnaires before and after surgery. Demographic data for all participants and disease/surgery related data for the PWE were collected. Statistical analysis was performed to compare PWE and caregiver QOL before and after surgery.

Results: Mean patient age was 37 years. Most (77%) suffered from symptomatic partial epilepsy for approximately 18 years prior to surgery, averaging 4 seizures per month and 2.2 antiepileptic drugs (AEDs). 78% of them underwent an anterior temporal lobectomy and the rest extra-temporal resections. On follow up at approximately 9 months, 69% had a surgical outcome of Engel class I, 23% of class II and 8% class IV. Postoperatively, the PWE remained on average on 1.9 AEDs. There was a statistically significant improvement for both the aggregate QOLIE-31 score and all its subscales (except for medication effects) as well as the BAI scores. 96% of the PWE felt that the decision to go through surgery was worthwhile. Mean caregivers age was 47 years. Half of them were spouses to the PWE and the majority of the rest their parents. 50%

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of them stated that their overall time devoted to patient's care decreased after surgery and 50% that it remained unchanged. The mental component scale (SF36v2, MCS) of caregiver QOL showed statistically significant improvement. ZCBI score and the physical component scale of their QOL (SF36v2, PCS) did not significantly vary before and after surgery. 75% of caregivers deemed their QOL better post surgery vs 19% similar. 94% of the caregivers felt that the decision to go through surgery was worthwhile.

Conclusions: Successful epilepsy surgery has a positive impact not only to patient QOL but also to their caregiver. To the best of our knowledge, this is the first pilot study to systematically address the impact of epilepsy surgery on caregivers providing additional support to epilepsy surgery as the optimal treatment modality in carefully selected patients. These findings call for further investigation on the caregiver quality of life in epilepsy and for its inclusion in the treatment plan and quality indicators for epilepsy surgery.

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Introduction

Epilepsy is chronic, paroxysmal and often devastating condition afflicting nearly 4–10 per 1000 people in developed countries (Hauser et al., 1991; Picot et al., 2008). Despite major pharmacologic advances in the past two decades, up to 22.5% of persons with epilepsy (PWE) still suffer from drug resistant epilepsy (Picot et al., 2008). For many of these, surgery is proven to be the best therapeutic alternative (Wiebe et al., 2001).

There is increasing interest in more global outcomes of epilepsy surgery, beyond the traditional focus on mere seizure control (Spencer and Huh, 2008). As pointed out by Tellez-Zenteno et al. in their meticulous review of long-term non-seizure outcomes after epilepsy surgery (Tellez-Zenteno et al., 2007), Penfield and Paine were pioneers also in identifying the need to know the effect of surgery "on the happiness of the patient and friends" (Penfield and Paine, 1955). Patient quality of life (QOL) is a major indicator of epilepsy care and is therefore consistently included in resective (Wiebe et al., 2001) and non-resective (Fisher et al., 2010; Morrell, 2011) surgical treatment trials for medication intractable epilepsy. Caregiver QOL though is a relatively neglected field of epilepsy research, despite the identified disease burden to the caregivers (Karakis et al., unpublished data) and their crucial role in care provision and decision making. Most of the current literature on caregiver burden and QOL stems from parents of children with epilepsy (Asato et al., 2009; Camfield et al., 2001; Cushner-Weinstein et al., 2008; Desnoux et al., 2013; Ferro and Speechley, 2009; Gallop et al., 2009; Hoare, 1993; Kim et al., 2010; Lv et al., 2009; McNelis et al., 2007; O'Dell et al., 2007; Ramaglia et al., 2007; Snead et al., 2004; Taylor et al., 2011; Terra et al., 2011; Williams et al., 2003) and in adults most studies are conducted in the outpatient setting and outside the United States (Lee et al., 2002; Ohaeri et al., 2009; Tajudeen Nuhu et al., 2010; Thompson and Upton, 1992; van Andel et al., 2009, 2011; Westphal-Guitti et al., 2007). There is a doleful paucity of postsurgical data on caregiver quality of life.

In response to this gap of attention to the caregiver in epilepsy, this pilot study is the first to assess the effect of epilepsy surgery on caregiver QOL. The practical ramifications of the findings are also discussed along with future directions.

Methods

Participants

This is a longitudinal study conducted between September 2009 and June 2011 at Massachusetts General Hospital (MGH). Adult PWE admitted electively to the Epilepsy Monitoring Unit (EMU) for continuous video-EEG monitoring were asked to participate by completing a series of questionnaires. Patients were excluded if they were non-English speakers or if they were unable to comprehend and complete the questionnaires independently due to cognitive impairment. The caregivers who accompanied them were also asked to complete questionnaires. Caregiver was defined as the family member who was primarily responsible for providing every-day care for the PWE. Every-day care was loosely defined as the time devoted to everyday activities where caregiver participation was indispensable including AED provision, outpatient and emergency department visits and driving for any patient-related activity. A total of 126 PWE and 48 caregivers completed the questionnaires. Following their EMU evaluation, those PWE who suffered from medication refractory epilepsy and were deemed to be good surgical candidates were offered surgical intervention. Post-operatively, these PWE and their caregivers were sent follow up questionnaires to complete. The current study focused only on those patients who underwent surgery and completed the postoperative questionnaires along with their caregivers. The study was approved by the institutional review board.

Questionnaires and procedures

The participating PWE completed questionnaires providing demographic (age, gender, race, employment, education, living situation and marital status) and epilepsy related (age of disease onset, disease duration, average number of seizures per month in the past year, number of AEDs) information. The information collected was cross-validated with medical records review and with additional electroencephalographic and radiological data collected during the admission as part of the presurgical evaluation. Anxiety and depression levels were measured by completing the Beck anxiety (Beck et al., 1988) and Beck depression (Beck and Steer, 1993) inventory respectively. Both have been used in

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