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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

Available online 2 September 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; Desnous 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

previous epilepsy research (Loring et al., 2004). Quality of life was evaluated by completing the QOLIE-31 instrument. QOLIE-31 is one of the most commonly applied quality of life instruments in epilepsy and it has good reliability and validity (Cramer et al., 1998). The initial evaluation took place on the day of the admission under electrographic guidance to ensure the absence of subclinical electrographic seizure activity affecting some of the responses. At the time of the testing, the patients were maintained on their home AED(s) and had not been yet sleep deprived with the intent that their answers would be representative of their baseline state in the ambulatory setting.

The caregivers accompanying the PWE also completed questionnaires providing demographic information (age, gender, race, employment, education, marital status, cohabitation). Given the lack of a disease specific questionnaire to assess their burden, the Zarit caregiver burden inventory was used instead. This is the most widely used standardized, validated scale to assess caregiver burden and has been administered previously in various neurological disorders, including epilepsy (Kim et al., 2010; Westphal-Guitti et al., 2007). Caregiver health-related quality of life was assessed by administering the second version of the SF-36 generic questionnaire (SF36v2) (Ware and Gandek, 1998).

Those PWE who subsequently underwent surgery were mailed follow up questionnaires to complete, along with the same caregivers who originally accompanied them to the EMU. For the PWE these questionnaires included the same QOL and psychiatric inventories, in addition to a survey on their postoperative outcome objectively (i.e. seizures per month, AEDs number, potential deficits) and subjectively (i.e. quality of life change, worthwhile surgery). Classification of seizure outcome was based on the system proposed by Engel et al. (1996). The information collected was cross-validated with medical records review from the postoperative follow up visits. For the caregivers, the follow up questionnaires also included the same QOL and burden inventories as preoperatively. In addition, a survey was given on their subjective view on the effect of epilepsy surgery to themselves (i.e. quality of life change, worthwhile surgery, time spent with patient).

For a detailed description of the questionnaires used both for patients and caregivers, please refer to the Appendix.

Analysis

Summary scores were created for all the aforementioned variables and descriptive statistics were applied. Comparison of pre-post scores on the various scales used for both the PWE and the caregivers was done on those participants who had available pre- and post-operative data using paired *t*-test for normally distributed continuous data and its non-parametric equivalent (Wilcoxon signed rank sum test) when appropriate. Comparison between the scale scores of seizure free PWE (Engel Class I) and their caregivers with all others (Engel Class II–IV) was performed using student's *t*-test for normally distributed continuous data, a non-parametric equivalent (Mann–Whitney *U* test) when appropriate, or Fischer's exact test/Chi-square test for categorical data. Statistical significance was set at 0.05.

Table 1 Patients characteristics (N = 26).

Gender (n, % female)	13 (50%)
Age in years (mean ± SD)	37.42 ± 11.60
Race (n, % Caucasian)	25 (96.15%)
Employed (n, %)	18 (69.23%)
Education (n, % some college or higher)	22 (84.62%)
Living situation (n, % living with family or others)	24 (92.31%)
Marital status (n, % married)	13 (50%)
Age of onset of epilepsy in years (mean ± SD)	19.81 ± 13.32
Duration of epilepsy in years (mean ± SD)	17.58 ± 15.38
Type of epilepsy (n,%)	
Partial	6 (23.08%)
Partial with secondary generalization	20 (76.92%)
Epilepsy etiology (n,%)	
Symptomatic	20 (76.92%)
Cryptogenic	6 (23.08%)
Time since surgery in months (mean ± SD)	9.19 ± 3.87

Statistical analysis was performed in STATA 11 (College Station, TX) and SAS 9.3 (North Carolina).

Results

Patient demographics are detailed in Table 1. Out of 30 PWE who originally completed the preoperative questionnaires and underwent surgery, 26 returned their postoperative questionnaires (response rate: 87%). From those, 13 (50%) were male with a mean age of 37 years. The majority were employed (69%), of higher education (85%) and were living with relatives (92%). The mean age of onset of their disease was 20 years of age and the mean duration was 18 years. Pre-operatively, they had on average 4 seizures/month, and they were on average on 2.2 antiepileptic drugs (AEDs). Most PWE suffered from symptomatic partial epilepsy (77%).

Caregiver demographics are details in Table 2. Out of 19 caregivers of patients who underwent surgery and completed their preoperative questionnaires, 16 returned their postoperative questionnaires (response rate: 84%). From those, 11 (69%) were female with a mean age of 47 years. 50% were spouses, 37.5% were parents and the rest siblings of the patients. The majority were employed (87.5%) and of higher education (87.5%).

Most of the PWE (78%) underwent an anterior temporal lobectomy (left twice more commonly than right) and

Table 2 Caregivers characteristics (N = 16).

Gender (n, %female)	11 (68.75%)
Age in years (mean ± SD)	47.69 ± 13.02
Race (n, % Caucasian)	15 (93.75%)
Employment (n, % employed)	14 (87.50%)
Education (n, % some college or higher)	14 (87.50%)
Marital status (n, % married)	14 (87.50%)
Cohabitation (n, % living with patient)	16 (100%)

Table 3 Effect of epilepsy surgery on patients.

Surgery type (n, %)			
L ATL			14 (53.85%)
R ATL			7 (23.92%)
Extratemporal			5 (19.23%)
Engel Class (n, %)			
Class I			18 (69.23%)
Class II			6 (23.08%)
Class III			0 (0%)
Class IV			2 (7.69%)
Post-operative deficits (n, %)			1 (3.85%)
QOL change (n, %)			
Better			20 (76.92%)
Similar			4 (15.38%)
Worse			2 (7.69%)
Worthwhile surgery (n, %)			24 (96.00%)
	Before surgery	After surgery	P-value
Seizures per month (median, IQR)	4 (4)	0 (0.125)	<0.001
AED use (mean number of AEDs \pm SD)	2.19 \pm 0.89	1.91 \pm 0.85	0.25
QOLIE-31 seizure worry (mean \pm SD)	47.75 \pm 27.65	69.23 \pm 29.73	0.005
QOLIE-31 overall quality of life (mean \pm SD)	63.84 \pm 21.31	73.65 \pm 15.51	0.04
QOLIE-31 emotional well-being (mean \pm SD)	66.19 \pm 18.79	75.27 \pm 15.60	0.03
QOLIE-31 energy/fatigue (mean \pm SD)	46.73 \pm 21.16	58.27 \pm 19.59	0.01
QOLIE-31 cognitive function (mean \pm SD)	57.29 \pm 22.82	66.56 \pm 22.08	0.04
QOLIE-31 medication effects (mean \pm SD)	57.26 \pm 26.32	68.91 \pm 27.29	0.08
QOLIE-31 social function (mean \pm SD)	55.85 \pm 24.65	71.04 \pm 25.10	0.01
QOLIE-31 overall score (mean \pm SD)	56.96 \pm 16.61	68.66 \pm 14.65	0.003
Beck Depression Inventory (mean \pm SD)	9.81 \pm 7.30	7.61 \pm 6.73	0.26
Beck Anxiety Inventory (mean \pm SD)	11.19 \pm 7.77	7.54 \pm 6.36	0.03

SD, standard deviation; IQR, inter-quartile range; ATL, anterior temporal lobectomy; QOLIE-31, quality of Life 31 questionnaire. Higher score is better for all domains of QOLIE-31 and worse for Beck depression and anxiety inventories.

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 where there was a trend for improvement. Similarly BAI but not BDI scores were statistically better post surgery. Yet, increased variability was observed among individuals, particularly in the psychiatric scales. 96% of the PWE felt that the decision to go through surgery was worthwhile (Table 3).

Caregiver burden and QOL scores also demonstrated variability among participants (Table 4a). 50% of the caregivers stated that their overall time devoted to patient's care decreased after surgery and 50% that it remained unchanged. On average, the ZCBI and the physical component of their QOL (SF36v2, PCS) scores did not significantly vary before and after surgery but the mental component of their QOL (SF36v2, MCS) showed statistically significant improvement. 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 (Table 4b).

On further analysis (not shown), there was no statistically significant effect of epilepsy surgery between the various subgroups based on Engel class surgical outcome, when the

subgroup who enjoyed complete seizure freedom was compared with all the other together.

Discussion

This study corroborates previous reports on improved patient quality of life and patient satisfaction post successful epilepsy surgery but also identifies increased caregiver satisfaction and a positive effect to caregiver quality of life in the psychological domain.

The caregiver related findings on QOL are difficult to substantiate with previous reports, given their remarkable scarcity and completion in pre-surgical, heterogeneous populations. Outpatient studies performed in the Netherlands identified a trend of decreased mental component of QOL in caregivers of refractory PWE (van Andel et al., 2009). No specific patient or disease characteristic appeared to drive caregiver QOL (van Andel et al., 2009). On the contrary, caregiver self-perceived burden of care (van Andel et al., 2009) and coping style (van Andel et al., 2011) were deemed to be more reliable indicators. Using a control group for comparison, a study of 257 caregivers escorting PWE to outpatient clinics in Sudan revealed lower QOL scores for caregivers who were children of the PWE, female and had

Table 4a Effect of epilepsy surgery on caregivers. Individual scores.

	Change in QOL	Worth-while surgery	Change in time spent	Zarit burden pre	Zarit burden post	SF36PCS pre	SF36PCS post	SF36MCS pre	SF36MCS post
1	Better	Yes	Less	33	5	64	53.1	42.3	54.1
2	Same	Yes	Same	46	52	40.7	50.6	30.2	27.8
3	Better	Yes	Less	21	8	59.5	52.2	60.2	63.2
4	Better	Yes	Same	47	39	31.8	29.4	41.5	33.8
5	Same	No	Same	39	36	46	43.2	40.9	45.6
6	Better	Yes	Less	20	18	61	60.3	37.4	49.4
7	Better	Yes	Less	20	17	53.6	53.2	44.7	54.9
8	Better	Yes	Same	18	28	60.5	60.5	56	56
9	Better	Yes	Less	40	10	55.6	58.9	29.1	41
10	Better	Yes	Less	12	8	52.1	60.6	44	56
11	Worse	Yes	Same	18	35	39.5	42.2	48.2	44.5
12	Better	Yes	Same	17	16	54.7	52.3	53.6	56.7
13	Same	Yes	Same	3	25	60.3	57.3	54.7	49.2
14	Better	Yes	Same	35	35	62.4	65.1	30.9	35.5
15	Better	Yes	Less	16	37	59	57.1	34.2	40.7
16	Better	Yes	Less	16	19	54.7	59	43.7	52.5

SF36v2PCS, physical component summary of version 2 of short form 36 health survey; SF36v2MCS, mental component summary of version 2 of short form 36 health survey.

Higher score is worse for Zarit caregiver burden inventory and better for all domains of SF36v2.

lower education attainment (Ohaeri et al., 2009). In Brazil, Westphal-Guitti et al. compared 50 adolescent and adult PWE with juvenile myoclonic epilepsy (JME) and another 50 with temporal lobe epilepsy (TLE) along with their caregivers (Westphal-Guitti et al., 2007). Mild-moderate caregiver burden was identified. For JME PWE, that burden correlated with poorer emotional, social and physical domains of the caregivers' QOL measured with SF-36, while for TLE PWE, the emotional component was primarily affected (Westphal-Guitti et al., 2007). Another study of 65 PWE-caregiver pairs from Hong Kong identified below average scores on a QOL measure and severe levels of depression in 14% and anxiety in 22% of caregivers (Lee et al., 2002). The authors indicated that seizure severity and age at onset were negatively

correlated with psychosocial adjustment of caregivers; on the other hand, perceived support level had a positive impact in their well-being and quality of life (Lee et al., 2002). Our findings partially concur with the preexisting literature. Similar to Westphal-Guitti et al. (2007) and Tajudeen Nuhu et al. (2010), we were also able to identify modest epilepsy caregiver burden. In agreement with the Brazilian (Westphal-Guitti et al., 2007) and the Dutch group (van Andel et al., 2009), we also recognized heavier impact in the mental component of caregiver QOL.

The patient related findings are borne out by previous reports. Using similar metrics, studies conducted both in the adult (Elsharkawy et al., 2009) and the pediatric population (Elliott et al., 2012) have also shown significant

Table 4b Effect of epilepsy surgery on caregivers. Summary scores.

QOL change (n, %)			
Better			12 (75.00%)
Similar			3 (18.75%)
Worse			1 (6.25%)
Worthwhile surgery (n, %)			15 (93.75%)
Time spent with patient (n, %)			
Increased			0 (0%)
Unchanged			8 (50.00%)
Decreased			8 (50.00%)
	Before surgery	After surgery	P-value
Zarit Caregiver Burden Inventory	25.06 ± 13.04	24.25 ± 13.71	0.82
SF36 Physical Component Scale (PCS)	53.46 ± 9.32	53.44 ± 8.92	0.98
SF36 Mental Component Scale (MCS)	43.22 ± 9.54	47.56 ± 9.75	0.02

SF36v2PCS, physical component summary of version 2 of short form 36 health survey; SF36v2MCS, mental component summary of version 2 of short form 36 health survey.

Higher score is worse for Zarit caregiver burden inventory and better for all domains of SF36v2.

improvement across nearly all domains of quality of life; an improvement that seems to last in time (Mohammed et al., 2012). Irrespective of methodology, 91% of studies investigating the impact of epilepsy surgery on PWE QOL have yielded favorable results with seizure freedom being the most prevalent postoperative determinant, followed by AED side effects, employment status and psychological function (Seiam et al., 2011). Similarly, the high PWE satisfaction rate seen in our cohort is comparable with rates up to 87% reported in the literature of epilepsy surgery, particularly when seizure freedom was achieved without postoperative deficits (Macrodimitris et al., 2011b). The psychiatric metrics used in our study yielded statistically significant improvement in the anxiety but not in the depression level of the patients. This is also not surprising with the literature showing either improvement or no changes in psychiatric outcome post epilepsy surgery, with seizure freedom and preexisting psychiatric comorbidities being the strongest determinants (Macrodimitris et al., 2011a). The relatively low initial BDI scores and their significant variability in our cohort may provide an alternative explanation for the lack of improvement in patients' depression levels post surgery.

The main strength of the present study is the focus on caregiver, an indispensable component of effective and compassionate care in epilepsy. While previous studies have thoroughly looked into the effect of various therapeutic interventions (medications, implantable devices, surgery) to the patient QOL, the effect of those interventions to family well-being has been largely ignored. This study, albeit at a pilot level, addresses that need in the rubric of epilepsy surgery. Furthermore, the focus was on adult PWE, where most of the caregiver literature is sparse. Both PWE, and caregivers could complete the surveys independently. That prevented potential bias inevitably incurred by proxy-reports in the pediatric post-surgical literature (Elliott et al., 2000). The PWE recruited had well-characterized epilepsy. We monitored and minimized factors that may have interfered with patient's initial testing such as seizures or commonly applied procedures in the EMU (e.g. antiepileptic medication withdrawal or sleep deprivation). Cross-reference with medical records provided an additional checkpoint for accuracy. Several patient- and caregiver-related factors were taken into account when assessing caregiver QOL. In addition to providing QOL scores for groups of PWE and caregivers, we incorporated a subjective assessment of the effect of surgery to the stakeholders of the disease, which at times is more important in individualized clinical decision making and allows for direct comparison across different studies (Seiam et al., 2011).

On the other hand, there are limitations to acknowledge. First, self-reporting nature of the study bears a risk of recall bias. Yet, self-report scales are widely used, cost-effective methods both for diagnostic assessment and for outcome evaluation, albeit admittedly not as exhaustive and objective as standardized cognitive and psychiatric interviews or physiologic sleep recording procedures. Second, the small sample size of caregiver participants may have underpowered us for the detection of additional associations and limited our ability to adjust for potential confounders and pinpoint determinants of caregiver QOL. A larger sample size would have also enabled us to better evaluate

parameters with high degree of variability among individual PWE and caregivers. Third, other patient-associated factors (e.g. changes in driving and financial status, interpersonal relationships, social behavior, cognitive capacity, etc.) and mostly caregiver-related (e.g. social support, financial status, physical and emotional comorbidities, etc.) aspects that may have been significant determinants of their QOL, were not directly addressed. However, they largely constitute components of the QOL and burden inventories used. Fourth, the relatively short follow up period postoperatively and lack of additional long-term data prevented further insight into the evolution of these associations longitudinally. Fifth, not all patients were accompanied by caregivers and not all caregivers participated in the study preoperatively and postoperatively, generating the potential of selection bias. Our response rate was nevertheless high. Sixth, the majority of the PWE suffered from symptomatic temporal lobe epilepsy treated with anterior temporal lobe resection, rendering generalization of this data to the overall population questionable. Moreover, these PWE have traditionally the highest success rates, potentially skewing our results positively and limiting our ability to show a linear trend between different Engel Class subgroups due to the underrepresentation of failures in our study sample. Yet, our sample population characteristics are typical for the majority of surgical candidates (i.e. temporal lobe epilepsy commencing in teens and not being operated until their 30s) (Wiebe and Jette, 2012). Furthermore, the congruence between our patient related outcomes and those reported in the literature enhance face validity and potentially generalizability of our findings. Finally, the absence of a non-surgical patient-caregiver control group to receive an alternative intervention (e.g. medication change or implantable device) limited our ability to directly compare the effect of epilepsy surgery to alternative treatments offered to patients with refractory epilepsy in daily practice.

The findings of this study have implications both for clinical practice and research paradigms. In clinical practice, physicians should aim towards a collaborative model of health care delivery that incorporates the caregiver into their assessment and treatment frame in an effort to eventually improve the patient's QOL. Previous studies on caregivers of patients with dementia have corroborated that potential (Pinquart and Sorensen, 2006). Further, advocacy groups should include caregiver feelings and needs into their agenda. In addition, expert opinion panel reviews and national clinical guidelines should further emphasize caregiver QOL as one of the core quality measures in the evaluation and management of epilepsy (Pugh et al., 2007). Finally, the positive impact of epilepsy surgery on the family as a whole identified in this study provides further support to its utility as the optimal treatment in carefully selected PWE. In the research field, the focus of investigation should expand to incorporate the family well-being. Caregiver QOL both for the adult and the pediatric population should be further characterized longitudinally and its determinants need to be elucidated. This way, during presurgical counseling, in addition to currently used patient related factors, caregiver/family related factors could enter the equation of identifying PWE at risk for poor psychosocial outcome (Langfitt et al., 2007). Clinical trials on medication and intervention based epilepsy treatments should incorporate

caregiver epilepsy burden and QOL as surrogate measures. For that reason, epilepsy specific QOL measures need to be created and validated for caregivers of PWE. As also underscored by the recently published Institute of Medicine report on epilepsy, there is need for rigorous research in this understudied field (Hesdorffer et al., 2013), and funding agencies should consider this important issue.

Conclusion

Epilepsy surgery, when successful, can improve not only patient quality of life, but also caregiver quality of life, particularly in the emotional realm. These findings call for further investigation of the caregiver quality of life in epilepsy and for its inclusion in the physicians' treatment plan and epilepsy surgery outcome measures.

Conflict of interest

None of the authors has any conflict of interest to disclose related to this project.

Acknowledgements

I confirm that I have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Presented in part at the 2012 American Epilepsy Society Meeting in San Diego.

Appendix. Questionnaires details

Beck anxiety (Beck et al., 1988) and Beck depression (Beck and Steer, 1993) inventory: These are 21-item inventories that assess the presence and degree of affective, cognitive, motivational and psychomotor components. Each item is scored 0–3 and the aggregate score is 0–63. Higher scores depict higher levels of psychopathology (Depression: 1–10: normal, 11–16: mild depression, 17–20: borderline depression, 21–30: moderate depression, 31–40: severe depression, >41: extreme depression; Anxiety: 0–21: very low anxiety, 22–35 moderate anxiety and >36 high anxiety).

Quality of life in epilepsy 31 (QOLIE-31) (Cramer et al., 1998): The 31-item self-administered questionnaire has seven subscales: seizure worry, overall quality of life, emotional well-being, energy/fatigue, cognitive function, medication effects and social functioning. A score ranging from 1–100 is obtained from each subscale with higher scores indicating better quality of life.

Zarit caregiver burden inventory (Zarit et al., 1980): This is a 22-item inventory derived from the original 29-item inventory. The 22 items evaluate the effect of disease on the caregiver's quality of life, psychological suffering, financial difficulty, shame, guilt and difficulty in social and family relationships. Scores range from 0 to 88 with higher scores indicating higher burden (<20: little or no burden, 21–40: mild to moderate burden, 41–60: moderate to severe burden, 61–88: severe burden).

SF-36 generic questionnaire-version 2 (SF36v2) (Ware and Gandek, 1998): This is a generic QOL instrument that assesses eight health concepts (physical functioning, role limitation caused by physical problems, bodily pain, general health perception, vitality, social functioning, role limitation caused by emotional problems, mental health). Scores standardized to norms and weighted averages are used to create a summary physical component summary (PCS) and a mental component summary (MCS) composed by the first and last four of the aforementioned health concepts respectively. All health dimension scores are standardized to normal by employing a linear transformation of data originally scores on a 0–100 scale. Norm-based scores have a mean of 50 and a standard deviation of 10 in the general US population. Therefore, any score <50 for any health dimension and component scale falls below the general population mean and each point represents 1/10th of a standard deviation.

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