

Psychosocial impact of epilepsy in women of childbearing age in India

Sureshababu Sachin¹, Madakasira V. Padma¹, Rohit Bhatia¹, Kameshwar Prasad¹, C. Gureshkumar², Manjari Tripathi¹

¹ Department of Neurology

² Department of Biostatistics, All India Institute of Medical Sciences, New Delhi, India

Received January 7, 2008; Accepted July 12, 2008

ABSTRACT – The aim was to evaluate comprehensively the psychosocial impact of epilepsy in women between 15-40 years of age with epilepsy, compared to those with migraine and healthy, pregnant women. One hundred women with epilepsy, 50 with migraine and 100 healthy, pregnant women were enrolled over a two-year period. The three groups were assessed using questionnaires for quality of life (QOL), coping strategies and caregiver burden. The influence of demographic and seizure variables on these psychosocial outcomes were also assessed. It was found that quality of life was least, and the burden experienced by the caregiver was significantly more in patients with epilepsy ($p < 0.001$). Women with epilepsy relied more on religion/faith as a coping method ($p = 0.021$), and less on problem solving strategies ($p < 0.001$) when compared to those with migraine. When compared to healthy, pregnant women, they more frequently employed religious methods of coping and denial ($p < 0.001$), with significantly less use of problem solving techniques, acceptance, and positive and negative distraction ($p < 0.001$). Less frequent seizures, better education and remission sustained for at least six months, were associated with better QOL. Educational status, frequency of seizures and time elapsed since last seizure emerged as significant determinants of coping behaviour. Low educational status and monthly income of the family contributed significantly to caregiver burden. This study helped to identify the different areas of psychosocial impairment in patients with epilepsy, as well as the contributing factors. Women with epilepsy rarely used constructive coping strategies, and this was found to contribute to their poor psychosocial status and adjustment within the family and society at large.

Key words: epilepsy, psychosocial, quality of life, coping, caregiver burden

Epilepsy refers to a collection of disorders characterized by recurrent seizures, which affect 1-2% of population worldwide. It is the most common neurological problem encountered in India, after headache. A meta-analysis has shown the overall prevalence of epilepsy in India to be 5.59 per thousand and is higher in women than men

(Sridharan and Murthy 1999). Epilepsy is associated with a high prevalence of psychological and social problems, which contribute greatly to the distress caused by seizures, sometimes overwhelming patients and their families. The successful management of epilepsy therefore encompasses the assessment and satisfaction of the psy-

Correspondence:

M. Tripathi
Department of Neurology,
All India Institute of Medical Sciences,
New Delhi, 110 029, India
<drsachins1@rediffmail.com>
<manjari.tripathi@gmail.com>

psychosocial needs of the patient. In the present study, quality of life, coping methods and caregiver burden were the psychosocial outcomes considered.

Women of childbearing age, with epilepsy, are a population with particular issues related to the epilepsy. Psychosocial pathology would be expected to be greatest in women of childbearing age when one considers the stress of marriage, changed circumstances, and childbearing (Aggarwal *et al.* 2006, Santosh *et al.* 2007, Rodrigues *et al.* 2003). Sexual dysfunction (Meador *et al.* 2006, Demerdash *et al.* 1991, Harden 2005) and the risk of teratogenicity with the use of AEDs could also be contributory in this regard (Thomas *et al.* 2001a, Morrell 1998, Holmes *et al.* 2004, Wide *et al.* 2004).

Quality of life (QOL) in epilepsy has been well studied (Baker *et al.* 1997, Vickrey *et al.* 2000, Guekht *et al.* 2007). However, the socio-cultural and economic situation in India presents greater challenges compared to the developed world. The male child is favoured over the female in India and is believed to carry the family lineage forwards. This is reflected in the skewed sex ratio of the country with 93 women for every 100 men (Census of India 2001). Only 55% of women are literate as compared to 78% of men (National Family Health Survey 2007). The average Indian woman bears her first child before she is 22, and has little control over her own fertility and reproductive health. Women do not have sufficient autonomy in decision-making in their personal lives. Lack of proper knowledge, and stigmatization of patients with epilepsy still prevail in Indian society in spite of improvement in education and awareness campaigns. A significant proportion of the Indian population believes that epilepsy is a hindrance to normal education, marriage and employment (Radhakrishnan *et al.* 2000). Many people, especially from the rural areas, resort to alternative forms of therapy or ritualistic practices such as sorcery (Surekha and Sureka 2007, Desai *et al.* 1998). Approximately 12% of people with epilepsy reside in India. The annual economic burden due to the disease is enormous, amounting to 88.2% of the per-capita GNP (Thomas *et al.* 2001b). Since the majority of patients live in rural areas where medical facilities are poor, many receive suboptimal treatment or no treatment at all (Kuruvilla). The treatment gap and discontinuation rates are relatively marked (Das *et al.* 2007), and are greater in women than men (Thomas *et al.* 2006).

Coping, and its association with psychosocial and seizure-related variables, have been examined in few studies (Mirnics *et al.* 2001, Goldstein *et al.* 2005, Piazzini *et al.* 2007). The nature and significance of maladaptive coping in epilepsy are yet to be ascertained in the Indian context. The impact of epilepsy on the caregiver and family also needs to be analyzed so that the areas where intervention is required can be identified. Previous studies indicate that the burden of caring for the epilepsy patient leads to stress, stigma, social and psychiatric problems in family members (Thompson and Upton, 1992).

In this study, we tested the hypothesis that women of child-bearing age with epilepsy have greater psychosocial impairment compared to those with migraine and healthy, pregnant women. We also attempted to study the influence of patient and seizure characteristics on the psychosocial outcomes.

Methods and subjects

The participants in this study comprised three groups of women between the age of 15 and 40 years. The study protocol was approved by the Institute's ethics committee, and all information was collected with the consent of patients. The subjects were recruited over a period of two years, from February 2005 to January 2007.

The first group included 100 consecutive patients with epilepsy attending the neurology out-patient department of the All India Institute of Medical Sciences (AIIMS), New Delhi, India. Patients were included if they had; a) two or more unprovoked seizures, b) recurrent seizures for a minimum duration of one year and c) experienced at least one seizure in the last two years. Patients with significant cognitive impairment or physical disability, and confirmed non-epileptic seizures as the primary diagnosis were excluded from the study. Patients were classified as having localization-related or generalized epilepsy based upon the ILAE classification system (Commission on Classification and Terminology of the International League against Epilepsy (ILAE), 1989). The following information was gathered from patients with epilepsy: a) type of seizure, b) age-at-onset, c) duration of seizures, d) seizure frequency, e) anti-epileptic drug (AED) taken, f) obstetric data (number of pregnancies, maternal and foetal outcomes) and g) socio-economic and educational details. Questionnaires to assess QOL, coping strategies of the patient, and caregiver burden were administered to each patient.

The second group consisted of 50 patients who had had a clinical diagnosis of migraine based on the International Headache Society diagnostic criteria (The International classification of headache disorders, 2004), for a minimum duration of one year. Consecutive patients were recruited from the Neurology outpatient department of AIIMS. In this group also, patients were questioned about age-at-onset, duration of illness, treatment received, cost of treatment and socioeconomic/ educational details. They were also given the same questionnaires.

The third group included 100, healthy, pregnant women who were recruited from the antenatal clinic of the same institute. Subjects with co-morbid illnesses were excluded from all three groups. In each group, the key caregiver was regarded as a family member older than 18 years who had cared for the patient for a minimum duration of one year. In the third group, demographic details and obstetric data were collected followed by administration of the same questionnaires. Pregnant women rather than non-

pregnant healthy women were included to provide the possibility of the assessment of burden in a control group.

WHO-QOL (BREF), Hindi version

This is a validated, QOL assessment tool developed at AIIMS, New Delhi especially for use in the Indian setting, comprising 26 items (Saxena *et al.* 1998). The domain scores produced by the WHO-BREF version have been shown to correlate at 0.9 with WHOQOL-100. It includes 26 items: two items from overall quality of life (Q1) and general health (Q2), and one item each from the remaining 24 facets included in the WHO QOL-100. In Q1, the patient was asked how he/she would rate his/her quality of life and in Q2, how satisfied he/she was with his/her physical health. Apart from the Q1 and Q2 scores, quality of life in four domains was assessed: 1) physical, 2) psychological, 3) social relationships and 4) environmental. Higher scores in each domain indicate better quality of life pertaining to that aspect.

Coping check-list (CCL)

It is a comprehensive checklist of coping behaviour and is the first of its kind validated for use in the Indian setting (Rao *et al.* 1989). It comprises 70 items describing a broad range of behavioural, emotional and cognitive responses that may be used to handle stress. The various coping strategies covered are: 1) problem solving; 2) denial; 3) positive distraction; 4) negative distraction; 5) acceptance; 6) religion/faith; 7) social support. A higher score in each domain denotes greater reliance on that specific strategy.

Burden assessment schedule (BAS)

This is used to assess the burden of care on the key relative or caregiver of chronically mentally ill patients using the process of stepwise ethnographic exploration (Thara *et al.* 1998). Out of the forty items, which are related on a three-point scale, four items were to be answered only by spouse care-givers. Thus, when the total burden was calculated for each patient, it was out of a maximum of 120 for those whose caregivers were spouses and out of 108 for those whose caregivers were family members other than the spouse. Higher scores indicate greater burden experienced by the care-giver. The validity has been established by comparing it with the Family Burden Schedule (Pai and Kapur 1981).

Data analysis

The three groups were compared for significant differences in psychosocial outcomes by multivariate ANOVA. Multiple comparisons between the groups were performed using the Bonferroni method. Association of various patient and seizure characteristics with the outcomes was analyzed by step-wise multiple regression analysis. All analyses were performed using the statistical package, SPSS 15.0.

Results

We studied one hundred women with epilepsy, their age ranging from 15-40 years (mean \pm SD, 24.50 \pm 6.72 years), 50 women with migraine, age ranging from 15-40 years (mean \pm SD 26.20 \pm 7.98 years). We also recruited 100, normal, pregnant women as controls, their age ranging from 19-40 (mean \pm SD 26.24 \pm 3.97 years). The clinical, demographic and socio-economic characteristics of the three groups are shown in *table 1*.

The types of seizure included generalized tonic-clonic seizures in 36%, complex partial seizures in 20%, and multiple seizure types were reported by the remaining 44% of patients. Seizure frequency distribution was as follows: seizure-free for 6 months ($n = 35$), one to five seizures per year ($n = 48$), and six or more seizures ($n = 17$). The median duration since the last seizure was 60 days (range, 1-700 days). Seventy percent of patients were on a single anti-epileptic drug, 26% were on polytherapy, and 4% were not receiving treatment. The data also revealed that of the 72 babies born to patients in the epilepsy group, two had congenital malformations (one had transposition of the great arteries and the other had a cleft lip). The first patient had been receiving 1 400 mg of valproate and the second a combination of 1 000 mg of valproate and 300 mg of phenytoin per day. Folic acid was administered during pregnancy to the first patient, but data are not available regarding the second.

Comparative analysis of the three groups for various psychosocial outcomes

On multivariate analysis by ANOVA, significant differences were found in all of the psychosocial outcomes namely QOL, coping behaviour and BAS (*table 2*). In the *post hoc* analysis, significant differences were obtained in the WHO-Q1, psychological, social, environmental domain scores, and the caregiver burden assessment score between all three groups ($p < 0.001$). The epilepsy group showed the maximum impairment while the healthy, pregnant women were least affected. The WHO-Q2 score was greater in women with epilepsy and in those with migraine compared to healthy, pregnant women ($p < 0.001$). However, the difference in Q2 score between the first two groups was not statistically significant.

The epilepsy group had significantly higher scores for the religion/faith domain compared to the migraine group ($p = 0.021$) and health, pregnant women ($p < 0.001$). The CCL-problem solving score was lower in women with epilepsy compared to those with migraine and healthy, pregnant women ($p < 0.001$). CCL-acceptance, negative distraction and positive distraction scores were significantly lower in women with epilepsy compared to healthy, pregnant women ($p = 0.017$, < 0.001 and 0.033 respectively), but comparable to those of patients with migraine. The CCL-denial score was significantly greater

Table 1. Clinical, demographic and socioeconomic characteristics of the three groups.

		Epilepsy (n = 100)	Migraine (n = 50)	Normal (n = 100)
Age (Years) (Mean±SD)		24.50 ± 6.72	26.20 ± 7.98	26.24 ± 3.97
Education (%)	0-5 th class	21	20	19
	6 th -12 th class	54	53	59
	Graduate and above	25	27	22
Marital status (%)	Unmarried	53	42	0
	Married	47	58	100
Occupation (%)	Unemployed /student	71	68	74
	Employed	29	32	23
Income (per month) (%)	< 30 00 Rs.	46	51	44
	> 3 000 Rs.	54	49	56
Age at disease onset (Mean ± SD)		18.07 ± 6.61	22.72 ± 7.68	---
Duration (years) (Mean ± SD)		6.31 ± 4.92	5.54 ± 4.33	---
Duration of treatment (Mean ± SD)		5.58 ± 4.64	4.83 ± 3.98	---
Cost of treatment per month	For medicines (INR)	484.33 ± 339.13	266.26 ± 228.72	---

Table 2. Comparison of quality of life, coping methods and caregiver burden between the three groups.

	Epilepsy (mean ± SD)/median	Migraine (mean ± SD)/median	Controls (mean ± SD)/median	p-value
WHO-BREF-Q1	3.06 ± 0.86 (3)	3.74 ± 0.83 (4)	4.67 ± 0.57 (5)	< 0.001
WHO-BREF-Q2	2.78 ± 1.03 (3)	2.70 ± 0.99 (2)	4.78 ± 0.44 (5)	< 0.001
WHO-BREF-physical	22.28 ± 4.21 (22.5)	25.86 ± 4.10 (26)	33.64 ± 1.91 (34)	< 0.001
WHO-BREF-psychological	18.86 ± 4.22 (19)	24.62 ± 3.98 (25)	29.0 ± 1.72 (29)	< 0.001
WHO-BREF-social support	0.72 ± 0.19 (0.8)	0.82 ± 0.13 (0.8)	0.96 ± 0.08 (1)	< 0.001
WHO-BREF-environmental	26.94 ± 5.29 (27)	33.78 ± 5.32 (35)	39.24 ± 2.17 (40)	< 0.001
^a CCL-problem solving	3.95 ± 2.94 (4)	6.34 ± 1.59 (6)	6.34 ± 1.99 (6)	< 0.001
^a CCL-acceptance	6.44 ± 2.37 (6.5)	6.98 ± 1.39 (7)	8.94 ± 1.32 (8)	< 0.001
^a CCL-social support	2.81 ± 1.45 (3)	3.16 ± 1.10 (3)	3.09 ± 1.05 (3)	< 0.001
^a CCL-positive distraction	5.10 ± 2.63 (5)	5.28 ± 1.87 (5)	5.89 ± 1.79 (6)	0.032
^a CCL-negative distraction	0.90 ± 1.16 (4)	1.14 ± 1.01 (4)	1.65 ± 0.97 (2)	< 0.001
^a CCL-denial	4.47 ± 2.23 (1)	4.20 ± 2.16 (1)	1.81 ± 1.28 (2)	< 0.001
^a CCL-religion/faith	3.05 ± 1.88 (3)	3.84 ± 1.78 (3)	2.12 ± 1.39 (2)	< 0.001
^b BAS score	56.13 ± 10.26 (56.6)	45.12 ± 8.27 (43.5)	34.92 ± 1.75 (35)	< 0.001

^a CCL-coping checklist.

^b BAS-burden assessment schedule.

in women with epilepsy compared to healthy, pregnant women ($p < 0.001$).

Patients with migraine differed from healthy, pregnant women with respect to CCL-acceptance, denial, negative distraction and religion/faith scores ($p < 0.001$). Group comparisons did not yield any significant difference for CCL-social support.

Factors associated with psychosocial outcomes in epilepsy

Step-wise, multiple regression analysis was performed in group 1 (patients with epilepsy) to determine the factors

that were associated with the various psychosocial outcomes. Frequency of seizures ($\beta = -0.219$, $p = 0.001$) and educational status of patient ($\beta = 0.369$, $p = 0.002$) were found to be associated with the Q1 score; seizure-freedom for six months or more ($\beta = 0.720$, $p = 0.001$) and monthly income of family ($\beta = 0.429$, $p = 0.027$) with the Q2 score; frequency of seizures ($\beta = -0.695$, $p = 0.045$) with the physical domain score; freedom from seizures for six months or more ($\beta = 0.008$, $p = 0.001$) with the psychological domain score; age-at-onset ($\beta = -0.006$, $p = 0.044$) and education ($\beta = 0.071$, $p = 0.007$) with the social domain score; educational status ($\beta = 1.894$, $p = 0.011$),

monthly income ($\beta = 2.677$, $p = 0.009$) and frequency of seizures ($\beta = -0.921$, $p = 0.024$) with environmental domain scores.

Educational status ($\beta = 1.272$, $p < 0.001$), duration of epilepsy ($\beta = 0.011$, $p = 0.005$) and time elapsed since last seizure ($\beta = 0.033$, $p = 0.044$) were associated with the CCL-problem-solving subscore; educational status with acceptance ($\beta = 0.693$, $p = 0.041$), positive distraction ($\beta = 1.159$, $p = 0.002$) and social support ($\beta = 0.696$, $p = 0.001$); marital status with negative distraction ($\beta = 0.470$, $p = 0.043$); and frequency of seizures with religion/faith subscales ($\beta = -0.311$, $p = 0.045$). Education ($\beta = -5.357$, $p = 0.004$) and monthly income ($\beta = -1.558$, $p = 0.046$) were associated with the BAS scores.

Discussion

This study has attempted to compare various psychosocial outcomes in women with epilepsy to women with migraine and healthy, pregnant women. Further, it has also served to determine the relation between these psychosocial outcomes and the patient and their seizure characteristics. The three groups studied differed significantly in all of the psychosocial outcomes, namely QOL, coping behaviour and caregiver burden.

Assessment of QOL in epilepsy helps one to identify and quantify the physical, psychological, emotional, social and educational aspects of the patient's life. It also assists the care provider to understand the impact of various factors such as seizure activity, sleep, work and home atmosphere, inter-personal relationships etc., and also helps the physician to evaluate the patient's and family's financial need and access to medical facilities (Baker 2002). Several studies have appraised the QOL of patients with epilepsy (Baker *et al.* 1997, Vickrey *et al.* 2000, Guekht *et al.* 2007, Johnson *et al.* 2004, The RESt-1 Group, 2000, Collings 1990). Nevertheless, this aspect needed to be ascertained in the Indian context because regional differences are known to affect psychosocial well-being in epilepsy (Collings 1994). Compared to healthy, pregnant women, WHO-Q1, physical domain, psychological, social and environmental domains were significantly affected in both patient groups. QOL was more significantly impaired in women with epilepsy compared to those with migraine. This could be attributed to psychosocial issues such as stigmatization, abnormal coping behaviour and decreased sexual ability that are more frequently seen in epilepsy (Kale 1997, de Boer *et al.* 2008, Mirnics *et al.* 2001, Damerdash *et al.* 1991). An earlier study comparing QOL in patients with epilepsy to those with multiple sclerosis and diabetes, found that physical well-being was most affected in patients with multiple sclerosis, while emotional well being was equally affected in both MS and epilepsy (Hermann *et al.* 1995).

In the present study, better QOL in patients with epilepsy was associated with lower seizures frequency and remission sustained for at least six months. Several studies have examined the relationship between QOL and seizure frequency and sustained remission from seizures. Most of them have found that QOL was poorer in patients with higher seizure activity (Suurjmeijer *et al.* 2001, Vickrey *et al.* 2000, Guekht *et al.* 2007, Leidy *et al.* 2001, Thomas *et al.* 2005, Djibuti and Shakarishvilli 2003). A higher frequency of seizures leads to apprehension about the disease and its outcome, as well as affecting social functioning, relationships and self-esteem (Harden *et al.* 2007). Jacoby *et al.* (1996) reported that seizure frequency was the single most important determinant of perceived stigma, perceived impact of epilepsy and levels of anxiety and depression in epilepsy. Sustained remission from seizures can positively influence quality of life in many ways. A previous study (Vickrey *et al.* 2000) has shown that the perception of being "normal" had a remarkable impact on all domains of health-related QOL. In addition, it enabled the patient to procure a better education and occupation (O'Donoghue *et al.* 1999, The RESt-1 group 2000), which could indirectly improve the quality of life. Repeated seizures may cause a person to remain at home, reducing her opportunities for social interaction. Medication effects, seizure worry, lack of confidence and low self-esteem are also more commonly observed in patients with frequent seizures (Levin *et al.* 1988, Baker *et al.* 1997).

In the present study, education was found to be an independent predictor of the patients' overall quality of life. This could be because of a better family background and social support, coping abilities, ability to make friends and ending relationships, good knowledge about the disease and its treatment, and confidence regarding career in educated individuals. Djibuti and Shakarishvilli (2003) also found education to be a strong predictor of all aspects of health related QOL (HRQOL) in a similar group of epilepsy patients. The monthly income was linked with the environmental factors determining the QOL. This is to be expected as a good family income would contribute to a better standard of living, better means of transport and better access to medical care.

The specific features of coping behaviour in patients with epilepsy were an important focus of our study. The patient with epilepsy needs to cope with the diagnosis, the uncertainty of the course of the disease, the physical and emotional trauma of recurrent seizures, long term treatment and treatment failures, and, most importantly, the accompanying psychosocial problems. Stigma associated with the disease and the non-availability of good social support systems, when coupled with lack of confidence, low self-esteem and poor interpersonal skills in the patient, leads to a detrimental milieu and the emergence of maladaptive coping (Baker 2002, Elliot and Shneker 2008). In the present study, women with epilepsy were found to rely on religion/faith and denial, and much less on problem-

solving, positive and negative distraction, and acceptance to help them overcome problems and situations in daily life when compared to healthy, pregnant women. Problem-solving strategies were used only sparingly, while using religion to help cope was more dominant in women with epilepsy compared to those with migraine. Earlier studies from the country have shown that nearly half of the patients with epilepsy resort to religious practices or alternative forms of therapy (Sureka and Sureka, 2007, Desai *et al.* 1998). Denial as a coping behaviour in epilepsy has been reported previously with intractable epilepsy (Piazzini *et al.* 2007). A few studies have revealed that patients with epilepsy underuse constructive methods of coping such as active problem solving when compared to the general population (Mirnics *et al.* 1998, Oosterhuis 1999, Piazzini *et al.* 2007). They tend to demonstrate palliative approaches and depressive reactions rather than using problem-directed, active strategies for coping. Krakow *et al.* (1999) reported problem-directed methods as the predominant coping strategy in patients with intractable epilepsy and found maladaptive coping only in depressed individuals. Maladaptive coping has been found to be more pronounced in females compared to males (Oosterhuis 1999).

Emotional adjustment, mood and family background are considered to be the most important factors for predicting the coping style in patients with epilepsy (Mirnics *et al.* 1998, Lehrner *et al.* 1999, Krakow *et al.* 1999, Amir *et al.* 1999). Among the seizure-related variables, only the presence of severe seizures has been proved to have an influence on coping (Mirnics *et al.* 1998, Oosterhuis 1999). Although the psychosocial factors underlying coping were not evaluated in the present study, our results show that social- and seizure-related factors, although contributory, are not strongly predictive of the coping style. However, among the patient and seizure characteristics that were studied, educational status emerged as the single most important determinant of constructive, coping behaviour in women with epilepsy. Better education places the patient in a stronger position to tackle her problems by being able to adopt strategies such as problem-solving, acceptance, social support and positive distraction. Frequency of seizures was associated with reliance on faith and religion. This suggests that inefficacy of medical treatment prompts patients to rely on alternatives such as astrologers and ritualistic practices. Only a weak association was found between time elapsed since last seizure and marital status. This emphasizes the role of psychosocial intervention, in addition control of seizures, in helping effective coping in patients with epilepsy.

Even though the whole family is involved in the care of the patient, the major brunt is borne by one "key caregiver". Sometimes, he/she may not get enough assistance from rest of the family and it is important to direct the research efforts and clinical interventions towards the "key caregiver". The person who assumes the care-giving role

continues to do so over years, without transferring it to somebody else in the family. This is particularly true in our cultural context, where providing care to an ailing family member is seen as a 'moral' duty, and transferring the responsibility of care to another person/institution is not well received by society. In the present study, burden was also significantly greater for the caregivers of women with epilepsy compared to those with migraine and healthy, pregnant women. This supports the findings from previous studies in this regard (Thompson and Upton 1992, Ellis *et al.* 2000). The care-giver is faced with the challenge of devoting his/her time and attention to the care of the patient, often with low levels of support from outside of the family unit. This precludes him/her from caring for the rest of the family and also affects work, leisure, social activities and health. The diagnosis of epilepsy often wrecks a family's hope, and a series of negative reactions follow especially in the person primarily looking after the patient. These may include anxiety, depression, a tendency to concealment and sometimes social isolation (Thompson and Upton 1992, Anderson 1990). In the case of the spouse being the care-giver, the reduced ability of the patient to perform her duties in the household and occasional sexual dysfunction can create stress and marital discord. Parent caregivers are mostly apprehensive about education, employment and future marriage of the patient as well as of her siblings (Levin *et al.* 1988). Further studies need to examine the contribution of coping behaviour, stress and QOL in the caretaker to better understand the basis of care-taker burden. Education and monthly income were associated with the BAS scores. Improved education and income would help reduce the burden on the family because, as found in our analysis so far, it helps the patient to cope better with her disease as well as making her feel more secure in terms of career, marriage and social life.

This study is unique in that it compares the psychosocial outcomes of women with epilepsy of childbearing age with those with migraine and healthy, pregnant women. The presence of a control group and a large sample size adds strength to the study. The differences between the three groups in the main outcome measures were statistically significant. The limitation of this study was that healthy, pregnant women were used as controls, and pregnancy can have a positive or negative impact on the psychosocial status of any woman (Mancino *et al.* 2005, Melender and Lauri 2001). This group was also not matched for marital status when compared to the other two groups. Pregnant women from the obstetric clinic were chosen in order to create a homogenous group in which burden assessment also could be performed. This study emphasizes the importance of a comprehensive approach to seizure management, with special attention to psychosocial factors, which would lead to targeted interventions. The caregiver and the family should also be counselled for effective implementation of the management plan. □

Disclosures. The authors report no conflicts of interest. The study was not supported by any financial grant.

References

- Agarwal P, Mehndiratta MM, Antony AR, et al. Epilepsy in India: nuptiality behaviour and fertility. *Seizure* 2006; 15: 409-15.
- Amir M, Roziner I, Knoll A, et al. Self-efficacy and social support as mediators in the relation between disease severity and quality of life in patients with epilepsy. *Epilepsia* 1999; 40: 216-24.
- Baker GA, Nashef L, van Hout BA. Current issues in the management of epilepsy: the impact of frequent seizures on cost of illness, quality of life, and mortality. *Epilepsia* 1997; 38 (Suppl. 1): S1-S8.
- Baker GA. The psychosocial burden of epilepsy. *Epilepsia* 2002; 43 (Suppl. 6): 26-30.
- Collings JA. International differences in psychosocial well-being comp: A comparative study of adults with epilepsy in three countries. *Seizure* 1994; 3: 183-90.
- Collings JA. Psychosocial well-being and epilepsy: an empirical study. *Epilepsia* 1990; 31: 418-26.
- Commission on Classification and Terminology of the International League Against Epilepsy. Proposal for revised classification of epilepsies and epileptic syndromes. *Epilepsia* 1989; 30: 389-99.
- Das K, Banerjee M, Mondal GP, et al. Evaluation of socio-economic factors causing discontinuation of epilepsy treatment resulting in seizure recurrence: a study in an urban epilepsy clinic in India. *Seizure* 2007: 601-7.
- de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy Behav* 2008; 12: 540-6.
- Demerdash A, Shaalan M, Midani A, et al. Sexual behavior of a sample of females with epilepsy. *Epilepsia* 1991; 32: 82-5.
- Desai P, Padma MV, Jain S, et al. Knowledge, attitudes and practice of epilepsy. Experience at a comprehensive rural health services project. *Seizure* 1998; 7: 133-8.
- Djibuti M, Shakarishvili R. Influence of clinical, demographic, and socioeconomic variables on quality of life in patients with epilepsy: findings from Georgian study. *J Neurol Neurosurg Psychiatry* 2003; 74: 570-3.
- Ellis N, Upton D, Thompson P. Epilepsy and the family: a review of current literature. *Seizure* 2000; 9: 22-30.
- Elliot J, Shneker B. Patient, caregiver, and health care practitioner knowledge of beliefs about, and attitudes toward epilepsy. *Epilepsy Behav* 2008; 12: 547-56.
- Goldstein LH, Holland L, Soteriou H, et al. Illness representations, coping styles and mood in adults with epilepsy. *Epilepsy Res* 2005; 67: 1-11.
- Guekht AB, Mitrokhina TV, Lebedeva AV, et al. Factors influencing on quality of life in people with epilepsy. *Seizure* 2007; 16: 128-33.
- Harden CL, Maroof DA, Nikolov B, et al. The effect of seizure severity on quality of life in epilepsy. *Epilepsy Behav* 2007; 11: 208-11.
- Harden CL. Sexuality in women with epilepsy. *Epilepsy Behav* 2005; 7 (Suppl. 2): S2-S6.
- Hermann BP. The evolution of health-related quality of life assessment in epilepsy. *Qual Life Res* 1995; 4: 87-100.
- Holmes LB, Wyszynski DF, Lieberman E. The AED (anti-epileptic drug) pregnancy registry: a 6-year experience. *Arch Neurol* 2004; 61: 673-8.
- International Institute for Population Sciences and Macro International (2007-09-09). Third National Family Health Survey. International Institute for Population Sciences.
- Jacoby A, Baker GA, Steen N, et al. The clinical course of epilepsy and its psychosocial correlates: findings from a U.K. Community study. *Epilepsia* 1996; 37: 148-61.
- Johnson EK, Jones JE, Seidenberg M, et al. The relative impact of anxiety, depression, and clinical seizure features on health-related quality of life in epilepsy. *Epilepsia* 2004; 45: 544-50.
- Kale R. Bringing epilepsy out of the shadows. *Br Med J* 1997; 315: 2-3.
- Krakow K, Bühler K, Haltenhof H. Coping with refractory epilepsy. *Seizure* 1999; 8: 111-5.
- Lehmer J, Kalchmayr R, Serles W, et al. Health-related quality of life (HRQOL), activity of daily living (ADL) and depressive mood disorder in temporal lobe epilepsy patients. *Seizure* 1999; 8: 88-92.
- Leidy NK, Elixhauser A, Vickrey B, et al. Seizure frequency and the health-related quality of life of adults with epilepsy. *Neurology* 2001; 57 (11 Suppl. 4): S69-S73.
- Levin R, Banks S, Berg B. Psychosocial dimensions of epilepsy: a review of the literature. *Epilepsia* 1988; 29: 805-16.
- Melender HL, Lauri S. Security associated with pregnancy and childbirth—experiences of pregnant women. *J Psychosom Obstet Gynaecol* 2001; 22: 229-39.
- Mancino P, Melluso J, Monti M, et al. Preparation for childbirth in different cultures. *Clin Exp Obstet Gynecol* 2005; 32: 89-91.
- Meador KJ, Baker GA, Finnell RH, et al. NEAD Study Group. In utero antiepileptic drug exposure: fetal death and malformations. *Neurology* 2006; 67: 407-12.
- Mirmics Z, Bekes J, Rozsa S, et al. Adjustment and coping in epilepsy. *Seizure* 2001; 10: 181-7.
- Morrell MJ. Effects of epilepsy on women's reproductive health. *Epilepsia* 1998; 39 (Suppl. 8): S32-S57.
- O'Donoghue MF, Goodridge DM, Redhead K, et al. Assessing the psychosocial consequences of epilepsy: a community-based study. *Br J Gen Pract* 1999; 49: 211-4.
- Oosterhuis A. Coping with epilepsy: the effect of coping styles on self-perceived seizure severity and psychological complaints. *Seizure* 1999; 8: 93-6.
- Pai S, Kapur RL. The burden on the family of a psychiatric patient: development of an interview schedule. *Br J Psychiatry* 1981; 138: 332-5.
- Piazzini A, Ramaglia G, Turner K, et al. Coping strategies in epilepsy: 50 drug-resistant and 50 seizure-free patients. *Seizure* 2007; 16: 211-7.

- Radhakrishnan K, Pandian JD, Santhoshkumar T, *et al.* Prevalence, knowledge, attitude, and practice of epilepsy in Kerala, South India. *Epilepsia* 2000; 41: 1027-35.
- Rao K, Subbakrishna DK, Prabhu GG. Development of a Coping Checklist: A preliminary report. *Indian J Psychiatry* 1989; 31: 128-33.
- Rodrigues M, Patel V, Jaswal S, *et al.* Listening to mothers: qualitative studies on motherhood and depression from Goa, India. *Soc Sci Med* 2003; 57: 1797-806.
- Santosh D, Kumar TS, Sarma PS, *et al.* Women with onset of epilepsy prior to marriage: disclose or conceal? *Epilepsia* 2007; 48: 1007-10.
- Saxena S, Chandiramani K, Bhargava R. WHOQOL-Hindi: a questionnaire for assessing quality of life in health care settings in India. World Health Organization Quality of Life. *Natl Med J India* 1998; 11: 160-5.
- Sridharan R, Murthy BN. Prevalence and pattern of epilepsy in India. *Epilepsia* 1999; 40: 631-6.
- Sureka RK, Sureka R. Knowledge, attitude and practices with regard to epilepsy in rural north-west India. *Ann Indian Acad Neurol* 2007; 10: 160-4.
- Suurmeijer TP, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. *Epilepsia* 2001; 42: 1160-8.
- Thara R, Padmavati R, Kumar S, *et al.* Burden assessment schedule. Instrument to assess burden on caregivers of chronic mentally ill. *Indian J Psychiatry* 1998; 40: 21-9.
- The International Classification of Headache disorders. 2nd ed. *Cephalalgia* 2004; 24: 1-160.
- The REST-1 Group. Social aspects of epilepsy in the adult in seven European countries. *Epilepsia* 2000; 41: 998-1004.
- Thomas SV, Deetha TD, Nair P, *et al.* Fewer women receive tertiary care for epilepsy in Kerala State, India. *Epileptic Disord* 2006; 8: 184-9.
- Thomas SV, Indrani L, Devi GC, *et al.* Pregnancy in women with epilepsy: preliminary results of Kerala registry of epilepsy and pregnancy. *Neurol India* 2001; 49: 60-6.
- Thomas SV, Koshy S, Nair CR, *et al.* Frequent seizures and polytherapy can impair quality of life in persons with epilepsy. *Neurol India* 2005; 53: 46-50.
- Thomas SV, Sarma PS, Alexander M, *et al.* Economic Burden of Epilepsy in India. *Epilepsia* 2001; 42: 1052-60.
- Thompson PJ, Upton D. The impact of chronic epilepsy on the family. *Seizure* 1992; 1: 43-8.
- Vickrey BG, Berg AT, Sperling MR, *et al.* Relationships between seizure severity and health-related quality of life in refractory localization-related epilepsy. *Epilepsia* 2000; 41: 760-4.
- Wide K, Winbladh B, Kallen B. Major malformations in infants exposed to antiepileptic drugs in utero, with emphasis on carbamazepine and valproic acid: a nation-wide, population-based register study. *Acta Paediatr* 2004; 93: 174-6.