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# Problems, awareness and practices of caregivers of epileptic patients regarding home management of epilepsy

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## Abstract

**Background**: Epilepsy is the fourth most common neurological disorder which affects people of all ages. Inappropriate management during seizure episodes among the epileptic patients can lead to complications. That is why, it is important for caregivers of epileptic patients to know about the disease and its management. **Objective:** To assess the problems, awareness and practices of caregivers of epileptic patients regarding home management of epilepsy. **Material and Methods**: A descriptive approach was employed. A total of 60 subjects (caregivers) visiting neurology OPD of tertiary care hospital in the month of April 2014 were enrolled. Information profile, details and information regarding problems, awareness and practices of caregivers of epileptic patients were gathered using a validated interview schedule. **Results:** The subjects were in the age range of 18 to 65 years with the mean age of 39.3±12.7 years. Mean duration of care (months) ±SD was 70.4± 87.3. More than half of the caregivers (51.7percent) felt stressed regarding caring for their relative and trying to meet other responsibilities of family and work. Around one fourth of the caregivers (28.3percent) felt that their social life had suffered because they were caring for their relatives. About 3/4th (76.7percent) of caregivers were found to have good epilepsy management practices at home. **Conclusion:** Caregivers' management practices were good among most of the patients but they were experiencing some problems while caring for their relatives because of lack of awareness.

**Keywords:** Epilepsy, caregivers, problems, awareness and practices.

## Introduction

Epilepsy affects an estimated three percent of people during their life time. It is one of the commonest childhood disorder (Smelter, Bare, Hinkle, Cheever, 2009). According to World Health Organization (WHO) in 2004, over 50 million people worldwide suffer from epilepsy and nearly 80 percent of cases occur in developing countries (WHO, 2012). Overall prevalence rate of epilepsy in India in 2003 was 5.59/1000 population with no statistically different rates between men and women of urban and rural residences (Bharucha, 2003). The prevalence of epilepsy in rural Haryana was 4.2/1000 and it was more among males and among young children i.e., six to 15 years (Singh, & Kaur1997).

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Epilepsy has immense effect on lives of patients and their caregivers. Its effect can be characterized in terms of social effect, such as isolation, prejudice and unemployment or in terms of emotional influences such as difficulties in maintaining personal relationships, negative self-image and low self-esteem. The psychological problems experienced by people with epilepsy cause bigger loss to quality of life than seizures themselves (Guitti,Alonso, Migloirini, Azevedo, Cabolco,& Yacubian, 2007).

“Burden of care is a multi-factorial construct which includes emotional, psychological, physical and economic impact as well as related distressing feelings such as shame, embarrassment, anger, feelings of guilt and self-blame. Studies have shown that caregivers of patients with epilepsy have high levels of strains, fears that the illness may cause injury or death as well as concern about what will happen to patients in future when the caregiver will not be available to cater for patients (Nuhu, Yusuf, &Ayilara, 2010)

In a study conducted at a community centre of Chandigarh, the researcher has shown that after proper training the caregivers were capable to act appropriately before and during the epileptic fit in an efficient manner (Kaur, Thakur, &Saini, 2012). Hence, the current study was conducted to assess the problems, awareness and practices of caregivers of epileptic patients regarding home management of epilepsy.

## Materials and Method

The current descriptive study was carried out at neurology OPD of a tertiary care hospital in the month of April 2014 among the caregivers of patients suffering from epilepsy. A total of 60 subjects (patient’s caregivers) were enrolled in the study using purposive sampling technique. Tools were prepared in both Hindi and English languages and content validity was established by the experts in the field of nursing and neurology. The tool contains modified caregiver strain index. The study was approved by institutional ethical committee. Permission for conducting the study was obtained from departmental head of neurology. Written informed consent was taken from the study subjects. Data regarding information profile of the caregivers, details and information regarding awareness and management practices of caregivers of epileptic patients were gathered using structured interview schedule. Modified caregiver strain index was used to assess problems of caregivers. Epilepsy management score amongst the caregivers was categorized into poor (0 to 7), below average (8 to 14), average (15to 21) and good (22to27) based on quartile division. The data was analysed with the help of SPSS 16

## Results

### Information profile of the caregiver

Table 1 depicts the socio-demographic data of the caregivers. The subjects were in the range of 18 to 65 years with the mean age of 39.28±1.3 years. As per age distribution, 30 percent of subjects were in the age group of 15 to30 years and 26.7percent were from 31to40 years. Sixty five percent of subjects were male and 43.3 percent of subjects were educated up to metric. Twenty five percent of subjects were housewives/not working. As per relation, 45 percent of the caregiver’s were parents. As per care duration, 66.7 percent were caring for the last zero to five years and 15 percent were caring for more than ten years. Majority (88.3percent) were staying with patients (Table 1).

***Table 1.*** Information profile of the caregiver (n= 60)

| Variables | Frequency | Percentage |
|---|---|---|
| Age(years)*<br>15-30 | 18 | 30.0 |
| 31-40 | 16 | 26.6 |
| 41-50 | 13 | 21.7 |
| 51-70 | 13 | 21.7 |
| Gender<br>Male | 39 | 65.0 |
| Female | 21 | 35.0 |
| Education<br>Illiterate | 07 | 11.7 |
| Primary | 14 | 23.3 |
| Matriculate | 26 | 43.3 |
| Secondary | 10 | 16.7 |
| Graduate and above | 03 | 5.0 |
| Occupation<br>Labourer | 11 | 18.3 |
| Govt. job | 14 | 23.3 |
| Business | 07 | 11.7 |

| **Variables** | **Frequency** | **Percentage** |
|---|---|---|
| Agriculture | 09 | 15.0 |
| Student | 04 | 6.7 |
| House wife/not working | 15 | 25.0 |
| Relation with patient | | |
| Mother-father | 27 | 45.0 |
| Child | 5 | 8.3 |
| Husband-wife | 13 | 21.7 |
| Brother sister | 7 | 11.7 |
| Others** | 8 | 13.3 |
| Duration of care (months)** | | |
| <12 | 16 | 26.6 |
| 12-60 | 24 | 40.0 |
| 60-120 | 11 | 18.3 |
| >120 | 09 | 15.1 |
| Staying with patient | | |
| Yes | 53 | 88.3 |
| No | 07 | 11.7 |

*Mean age (years) ±SD: 39.3±12.7; Range: 18-65

**Mean (months) ±SD: 70.4±87.3; range: 1-360** *friend, cousin

### Problems of caregivers of epileptic patients

Table 2 highlights the problems of caregivers of patients. Because of caring for their relative (epileptic patient) 51.7percent of caregivers always felt stressed and meeting responsibilities for their family or work was disturbed. Embarrassment was felt by 16.7percent of the caregivers because of the behaviour of their relative. Sixty five percent of subjects were scared of their relative's future. In 61.7percent of subject's social life was never affected because of caring for their relative. Nearly half of the caregivers (46.7 percent) always felt shortage of money for taking care of their relative. In 76.7 percent of subjects difficulty was never felt in taking care of their relative for a long time. Majority of subjects (91.7percent) felt that they should do more for their relative. Most of subjects (98.3 percent) felt they could do a better job in caring for their relative. Overall 90 percent of subjects never felt burdened in caring for their relative.

***Table 2.*** Problems of caregivers of the epileptic patients (n= 60)

| **Problems of caregivers** | **Always** | **Sometimes** | **Never** |
|---|---|---|---|
| Feel stressed because of caring for your relative and trying to meet other responsibilities for your family or work. | 31(51.7%) | 3(5.0%) | 26(43.3%) |
| Feel embarrassed over your relative's behaviour. | 10(16.7%) | 3(5.0%) | 47(78.3%) |
| Afraid of what the future holds for your relative? | 39(65.0%) | 4(6.7%) | 17(28.3%) |
| Feel that your social life has suffered because you are caring for your relative. | 17(28.3%) | 6(10.0%) | 37(61.7%) |
| Feel that you don't have enough money to take care of your relative in addition to the rest of your expenses. | 28(46.7%) | 4(6.7%) | 28(46.7%) |
| Feel that you will be unable to take care of your relative much longer. | 9(15.0%) | 5(8.3%) | 46(76.7%) |
| Feel you should be doing more for your relative. | 55(91.7%) | 2(3.3%) | 03(5.0%) |
| Feel you could do a better job in caring for your relative. | 59(98.3%) | 1(1.7%) | - |
| Overall how burdened you feel in caring for your relative. | 4(6.7%) | 2(3.3%) | 54(90.0%) |

### Management practices of caregivers (Table 3 and figure 1)

Table 3 presents management practices of the caregivers. They are discussed under the headings i.e., at the time of seizure and after the seizure episode.

### At the time of seizure episode

At the time of having seizure, majority (98.3%) of caregivers used to provide calm environment. All 100percent placed the patient at firm surface. About 60percent put pillow under the head of the patient, if patient is on the floor just before seizure. Among the caregivers, 87.7percent always loosen tight neckwears of the patient to ease breathing. All (100%) of subject removed sharp objects and wipe off oral secretion. Majority (91.7%) of the caregivers stayed with patient till recovery and did not allow crowd (93.3%) near the patient. Seventy percent of the caregivers never used to put anything (spoon, key) in patient's mouth during seizure. Majority (85%) of the caregivers waited for the seizure episode to pass off on its own and 91.7percent did not shout near the patient. About 71.7percent of the caregivers did not give anything to patient to drink during seizure. Majority (93.3percent) avoid restraining the patient. More than half (58.3%)) did not hold patient to prevent injury during fits. Around 81.3per cent were not in the practice of using onion or shoes to make the patient conscious. Maximum caregivers took patient to hospital if the patient did not regain consciousness within five minutes of seizure, if seizure activity lasted more than five minutes or patient got injury.

**After seizure episode**

Majority (95.0%) usually observe whether the patient breathes normally or not, 55percentmostly give side lying position and 86.7percent let patient sleep, majority (98.3%) made patient comfortable, 85percent explained that patient about his condition like what had happened to him, and 81.7 percent asked questions from patient to check their orientation Scoring has been done by using quartile method.

***Table 3.*** Management practices of the caregiver (n=60)

| **Management by caregivers** | **Yes** | |
|---|---|---|
| What you do when patient had seizure | Frequency | Percentage |
| Provide calm environment | 59 | 98.3 |
| Place the patient on a firm surface | 60 | 100 |
| Remove the pillow, if patient is on bed | 35 | 58.3 |
| Put a pillow below the head of patient, if he/she is on the floor | 36 | 60.0 |
| Loosen tight neckwear to ease breathing | 52 | 87.7 |
| Remove any sharp or solid object that the patient may hit during the fit like knife, scissors, and needles etc. | 60 | 100 |
| Wipe out secretions coming from mouth, if any | 60 | 100 |
| Stay with the patient until the recovery is complete | 55 | 91.7 |
| Make crowd near the patient | 04 | 6.7 |
| Put anything into the mouth of patient like spoon or keys | 18 | 30.0 |
| Wait to pass fit by its own | 51 | 85.0 |
| Shout near the patient | 05 | 8.3 |
| Give anything to the patient to drink during fit | 17 | 28.3 |
| Restrain the patient | 04 | 6.7 |
| Hold the patient because he can injure himself as well as you | 25 | 41.7 |
| Make patient conscious by smell of onion or shoe if patient is unconscious | 11 | 18.3 |
| When do you think the patient needs to go to the hospital? | | |
| The patient is not conscious within 5 minutes of seizure stopping | 52 | 86.7 |
| The seizure activity lasts more than 5 minutes or a 2nd seizure quickly follows | 58 | 96.7 |
| Patient is injured | 59 | 98.3 |
| Patient is pregnant or has diabetes | 60 | 100 |
| When you know or believe it to be the person's first seizure | 60 | 100 |
| What do you do after the fit | | |
| See whether he/she breathes normally or not | 57 | 95.0 |
| Give side lying position | 33 | 55.0 |
| If the patient goes to sleep then let him sleep | 52 | 86.7 |
| Make the patient feel comfortable | 59 | 98.3 |
| After the fit tell the patient what had happened to him | 51 | 85 |
| After the patient becomes normal ask him about the date, time and place for checking his orientation | 49 | 81.7 |

Figure 1 presents management practices of caregivers of epileptic patients. Scoring of management practices was done by using quartile method. There were 27 questions asked to assess home management practices of epileptic caregivers. Among the caregivers 76.7percent were having good management practices and 23.3percent had average management practices of epilepsy at home with score of 15 to 21.

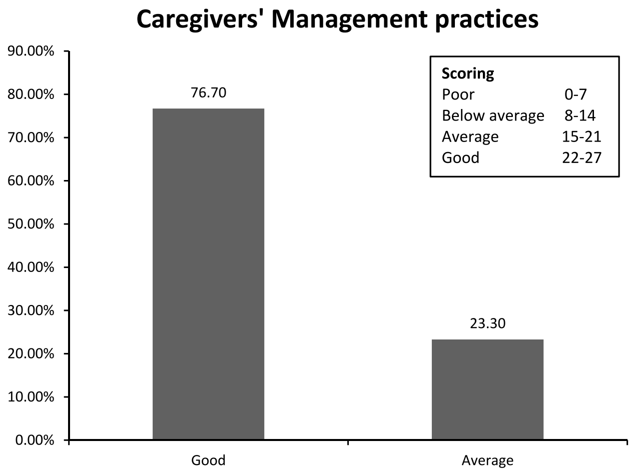

***Figure 1.*** Management practices of caregivers

## Discussion

World Bank ranks epilepsy among top five of all non-communicable diseases (Birbeck, 2012).It affects physical, social and psychological status of the patient (Baker, Jacoby., Buck, Stalgis,& Monnet, 1997). Epilepsy is an unpredictable, often chronic and debilitating disorder that impacts not only those bearing with it but also those who care for them (Karakis, Cole, Montouris, luciano, Meador, & Piperidou, 2014). It results in burden and decreased quality of life amongst the caregivers. Burden may result in feelings of shame, panic, and tenseness. These ultimately can interfere with caregivers' bodily and emotional well-being and disturbed routines (Guitti et al 2007). As per caregivers' distribution in the current study, around 56.6 percent were in 15 to 40 age group, 45percent were the parents and 65percent were male caregivers. However, in a study maximum (67%) were more than 40 years of age, mean age of the caregivers was 43.6 ±9.5 years and 62 percent were parents of patient, 53 percent were mothers and 83.1 percent were employed (Nuhu, Yusuf, & Ayilara, 2010).

Present study revealed that more than half (51.7%) of the caregivers felt stressed between caring for their relatives and trying to meet other responsibilities for family or work, 65percentwere afraid regarding future of patients. Repeated seizure attacks may challenge the coping ability of the caregiver. This may also involve frequent hospital visits and hence increase cost, close monitoring of patients at home (with less time for other responsibilities). This is similar to previous report among caregivers of patient of a study which revealed that51.9 percent caregivers felt burdened while caring for epileptic patient. Objective burden refers to changes in household routine, family or social relations, work, leisure and physical health; while subjective burden consists of subjective distress among relatives, including impact on mental health (Nuhu, Yusuf, & Ayilara 2010). In another study conducted by Guitti et al among100 caregivers of adolescent and adult patients with epilepsy, the mean age of caregivers was 46.18±13.20 years, 68.75 percent were female caregivers. More than half (58.34%) were spouse, 70.83 percent were employed and 81.25 percent were educated up to college and beyond level of education, 79.17 percent were married. There was mild to moderate burden found on caregivers of patients in both groups. Zarit Burden interview average score for caregivers of patients with juvenile myoclonic epilepsy was 25.5 and 30.7 for temporal lobe epilepsy (Guitti et al 2007).

Current study revealed that overall management practices of caregivers (76%) during seizure were good. During seizure majority (98.3%) of caregivers used to provide calm environment. All 100 percent place patient at firm surface. Sixty percent put pillow under the head of the patient, if patient is on the floor just before seizure occurred. All (100%) subjects removed sharp objects and wiped out oral secretions. Majority (85%) of the caregivers waited for the fit to pass off on its own. Majority (93.3%) avoided restraining the patient. In spite of good management practices of caregivers the current study highlighted some wrong practices such as 46.7percent of the caregivers do not loosen neck clothing of the patient, 28.3percent gave water to drink, 41.7percent held the patient during fit, 18.3 percent made patient conscious by shoes smell and45percent did not give side line position to patient immediately after the seizure. A study conducted at same institute i.e. National institute of nursing education, PGIMER, Chandigarh, 71 percent of caregivers were able to demonstrate excellently how to manage stage of aura. Majority (87%) of subjects were able to perform the dos (what all should be done) during seizure episode in an excellent manner.

About 77percent of the subjects had knowledge when to hospitalize the patients. About 67 percent had full knowledge about don’ts during fit (Kaur, Thakur, Saini, 2012).

## Conclusion

The caregivers of epileptic patients were experiencing less problems while caring for their relatives. The practices of managing epilepsy were good amongst majority of the caregivers. However, some wrong practices were also practiced by a few. There is a need for conducting more studies on caregivers of patients with epilepsy. These will help in generating evidences which will ultimately impact on the care of patients suffering from epilepsy.

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