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### A questionnaire survey about doctor-patient communication, compliance and locus of control among South Indian people with epilepsy

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#### Abstract

To date, very few studies have investigated patients' views on the information they receive from the doctor concerning epilepsy and its management. Little information is available about the influence of doctor-patient communication and locus of control on the compliance of persons with epilepsy. We investigated, through a questionnaire-interview design, among patients attending the epilepsy clinic of a tertiary referral center in South India, their views about the provision of information by the doctor, and their compliance and locus of control. We also determined the interrelation between doctor-patient communication, compliance and locus of control. Our subjects comprised 200 adult persons with epilepsy, 113 males and 87 females, mean age 30.5 (range 18-67) years. Over one-third of the subjects received from the doctor insufficient information about epilepsy and its treatment. There was a significant positive correlation between effective doctor-patient communication and compliance. A majority of our patients had an external locus of control, which negatively influenced the compliance. Even in a comprehensive epilepsy clinic of a model tertiary referral center in a developing country, a significant proportion of patients do not receive optimal information about epilepsy from the doctor. Knowledge about their disease will encourage people with epilepsy to make informed choices, and achieve better compliance and personal control of their problems. Educating primary and secondary care physicians about the importance of doctor-patient communication in the management of epilepsy and educating the public about the positive aspects of life in epilepsy cannot be overemphasized. © 2000 Published by Elsevier Science B.V. All rights reserved.

Keywords: Epilepsy; Compliance; Locus of control; Developing country; Doctor-patient communication

#### 1. Introduction

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Epilepsy, a chronic disorder characterized by recurrent unprovoked seizures, affects people of

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all ages. A major challenge facing health-care providers today in the management of persons with epilepsy is how to formulate a comprehensive epilepsy educational program. The goal of epilepsy education is to provide the patient and family members with the information needed to enhance their knowledge and to dispel misconceptions about epilepsy, to ensure compliance with treatment, to minimize the effect of this chronic disorder on their daily activities, and to promote optimal quality of life.

Among persons diagnosed with epilepsy, a majority will become free of seizures after appropriate treatment has been initiated (Sander, 1993; Shinnar and Berg, 1996). The maintenance of a seizure-free status necessitates continued antiepileptic drug (AED) therapy and avoidance of precipitating factors. Compliant behavior of a person with epilepsy can be defined as taking AEDs on time and without fail, not manipulating their dosages, and following physician's instructions regarding daily activities such as sleep, avoiding alcohol, driving and swimming (Leppik, 1988). Noncompliance with treatment is a significant problem in epilepsy management; as many as 30-50% of persons with epilepsy are reported to be noncompliant to the extent of interfering with their optimal treatment (Leppik and Schmidt, 1988). Patient education has been shown in several areas of medical practice to be highly effective in improving compliance (Thomson, 1984; Leppik, 1988).

Psychopathology associated with chronic disorders has been linked to subjects' locus of control; individuals with an external locus of control are more susceptible to psychopathology, particularly depression (Hiroto, 1974; Levenson, 1974; Lefcourt, 1982). Persons with epilepsy spend a great deal of time focusing on seizure episodes and the negative consequences of epilepsy (Hermann et al., 1990). Several studies have shown that epilepsy is associated with externality of control (De Vellis et al., 1980; Ziegler, 1981; Ferrari et al., 1983; Hermann and Wyler, 1989; Gehlert, 1994; Amir et al., 1999). Information provides people with epilepsy knowledge of their condition, thereby enhancing their ability to make informed choices and to achieve more personal control (de Boer, 1995).

Consumer satisfaction is now considered as an important part of assessment of health care (Khayat and Salter, 1994). Patients with epilepsy place great importance on having a doctor who is approachable, communicative and knowledgeable and on receiving adequate information about their condition. Patient satisfaction has been shown to influence health outcomes such as compliance with treatment and follow-up visits (Thomson, 1984; Ogden, 1996). Patients have been reported not to comply with advice given if they feel dissatisfied with a consultation (Francis et al., 1969; Freeman et al., 1971; Ogden, 1996).

The patient's satisfaction with the consultation, his understanding and recall of the instructions and advice given can be used as a measure of the quality and effectiveness of doctor-patient communication (Buller and Buller, 1987; Coiera and Tombs, 1998). This is an area of epilepsy research where very little work has been done, even in developed countries, and to our knowledge, none from developing regions.

We have investigated the views of South Indian people with epilepsy about doctor-patient communication. We also examined the factors that influenced doctor-patient communication, and the interrelation between doctor-patient communication, compliant behavior and locus of control. Our a priori hypothesis was that patients who were well informed about epilepsy were more likely to comply with the doctors' advice and are more likely to have an internal locus of control, compared to the ones who were dissatisfied with the information provided to them.

#### 2. Materials and methods

# 2.1. Area of investigation and medical organization

The state of Kerala, situated in the South-West coast of Indian peninsula, is distinguished from the rest of India by the high degree of literacy (literacy rate 90.6% in 1991; male literacy rate 94.5%, female literacy rate 86.9%) and health awareness of its population (Thankappan and Valiathan, 1998; Zachariah, 1998). Sree Chitra

Tirunal Institute for Medical Sciences and Technology (SCTIMST), situated in Trivandrum, the capital of Kerala, is a tertiary referral center for neurological disorders. The comprehensive epilepsy program of SCTIMST receives patients from all over Kerala and neighboring states. Epilepsy clinics are conducted twice weekly. Each clinic is attended by  $\sim 30$  patients who are examined within a period of  $\sim 3$  h. In addition to two consultant neurologists with special interest in epilepsy, each clinic utilizes the services of a nurse, a medical social worker and a postgraduate student in neurology.

#### 2.2. Patient population and data collection

For this study, we considered 200 consecutive persons aged  $\geq$  18 years who attended the Epilepsy Clinic of SCTIMST with recurrent epileptic seizures and were receiving AEDs. We excluded patients with major mental handicap who were unable to understand and answer the questions. Items included in the questionnaire were developed de novo through a series of semistructured interviews with volunteers and patients, taking into consideration the quality of local medical services and the ability of the subjects to understand and respond, during the pilot phase of the study. The patients were presented with the questionnaire by a research assistant (BG) when they were coming out of the epilepsy clinic after consulting the doctor. The doctors were not aware that the questionnaire was being administered. The questions were administered in the local language, Malayalam, with 'yes' or 'no' answers. The interviewer intervened only to clarify a question when it became evident that the responder had not understood. No attempt was made to prompt the responder by hints or suggesting answers.

The questionnaire (available on request) comprised 57 questions concerning items related to doctor-patient communication, compliance and locus of control. Demographic data and information regarding the duration of epilepsy, seizure types and their frequency, and AED treatment were also gathered.

## 2.3. Description of variables included in the questionnaire

### 2.3.1. Items relating to doctor-patient communication

We inquired the patients' views about how easy the doctor was to talk to, whether the doctor took the patients' views into account and whether the doctor provided sufficient information about epilepsy and its management to test the non-verbal and verbal content of the communication.

#### 2.3.2. Items relating to compliance

The patients were asked whether they were provided with information about the importance of compliance to AEDs and the consequences of noncompliance. We also inquired whether the patient complied with the doctors' advice about AED intake, driving, swimming, and avoiding the factors which can exacerbate seizures such as insufficient sleep and alcohol intake.

### 2.3.3. Items relating to locus of control

We utilized an instrument to measure the general locus of control. These questions have been adopted from Rotter's Internal–External Control of Reinforcement Scale (I–E Scale) (Rotter, 1966). This I–E Scale has been standardized and validated for the local population (Santoshkumar and Thomas, 1992). We adhered to the scoring procedures originally described, with higher scores indicating a more external locus of control (Rotter, 1966). For categorizing the locus of control of subjects with epilepsy as internal, intermediate and external, we used the 33rd and 67th percentiles of the score (0.188 and 0.375, respectively) generated among a group of 206 healthy adult volunteers.

#### 2.4. Statistical analyses

We used standard deviation (SD) to define the dispersion. Student's t test was used to test the mean difference between two groups. The proportion of positive responses out of the number of responses from each patient to the questionnaire was taken as the scores pertaining to an item. These scores being a proportion, ranged from 0 to

1 for the three items, namely doctor-patient communication, compliance and locus of control. Higher scores indicated a better doctor-patient communication, better compliance and an external locus of control. For assessing the association between continuous variables, we used Pearson's correlation. For bivariate analyses, we used Spearman's rank correlation when at least one of the variable is an ordered variable. To compare multiple means of component subgroups, we used one-way analysis of variance (ANOVA). Multiple regression was used for multivariate analysis. A P-value of < 0.05 was considered statistically significant.

#### 3. Results

### 3.1. Demographic characteristics

The 200 persons with epilepsy comprised 113 males and 87 females, mean age 30.5 (range 18–67) years. Eighty patients had primary generalized seizures, 95 had partial seizures with or without secondary generalization and in 25 patients the type of seizures were undetermined at the time of study. The duration of epilepsy ranged from 3 months to 40 years; 100 patients had had seizures for  $\geq$  10 years. Five patients were attending the SCTIMST epilepsy clinic for the first time. The demographic and clinical characteristics of our patients are summarized in Table 1.

Table 2 shows the responses to selected questions during the semi-structured interview which are detailed below.

## 3.2. Patients' overall satisfaction about doctors' communication skills

A majority of our patients were impressed by the doctors' nonverbal and verbal communication skills and described the doctor as easy to talk to, listened to them adequately and conveyed enough information about epilepsy. However, over onethird of patients felt that they were provided with insufficient information about epilepsy.

### 3.3. Communication concerning epilepsy

Sixty-five percent patients felt that they were informed about the type of their epilepsy and its etiology. While a majority of patients agreed that they were briefed about the effectiveness of AEDs, 39% did not know about their adverse effects. Information about how the seizures can influence the quality of life and how to overcome the seizure-related handicap, why special investigations were ordered and their cost-effectiveness, and prognosis of epilepsy were poorly communicated.

Table 1 Clinical characteristics of 200 persons with epilepsy<sup>a</sup>

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Gender	Males 113, females 87
Age (years)	Range: 18–67. Mean ± SD: 30.5 ± 10.9 Median: 27
Duration of epilepsy (years)	Range: 0.25–40.0 Mean ± SD: 10.7 ± 7.1 Median: 10.0
	n (%)
Type of seizures	
Generalized	80 (40.0)
Partial	95 (47.5)
Uncertain	25 (12.5)
Antiepileptic drugs	
Monotherapy	153 (76.5)
Polytherapy	47 (23.5)
Seizure frequency	
$\geq 1$ per month	43 (21.5)
$\geq 1$ per 6 months	28 (19.0)
≥1 per year	42 (21.0)
Seizure free $\geq 1$ year	87 (43.5)
Number of clinic visits	
1	5 (2.5)
2–5	92 (46.0)
6–10	50 (25.0)
≥11	53 (26.5)
Education	
Illiterate	3 (1.5)
Primary school	3 (1.5)
High school	85 (42.5)
College/technical	109 (54.5)

<sup>&</sup>lt;sup>a</sup> SD, standard deviation.

Table 2
Patients responses to selected items in the questionnaire<sup>a</sup>

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Statement	Positive response (%)
When I entered the consultation room, the doctor told me to sit down	98.5
In addition to inquiring about my disease, the doctor asked about my general well being	71.5
Doctor gave me adequate description about my disease, its cause and treatment, and how I can live a comfortable life	65.0
Doctor used several terms which I did not understand	21.0
The doctor explained to me the usefulness of AEDs in the control of seizures	82.0
The doctor informed me about the adverse effects of AEDs	61.0
The doctor did not tell me the likelihood of seizure control and whether I will ever be cured of epilepsy	46.0
The doctor told me about the risks of driving	50.0
I take the prescribed AED(s) regularly and in time	95.5
Although the doctor told me not to drive, I occasionally drive my vehicle	50.0
I have been told to be regular in food intake and avoid alcohol and I comply with these advises	91.0
Since I am free of seizures for the last few months, I think there is not much of a problem if I miss some of the AED doses	32.0

<sup>&</sup>lt;sup>a</sup> AED, antiepileptic drug.

### 3.4. Compliance

The majority of our patients adhered to regular intake of AED and complied with advice about sleep, and food and alcohol intake. Nearly 86% of them were aware that they should not manipulate the dose of AED of their own. They also sought the help of family members to ensure regular AED intake. One-third felt that there is no harm in occasionally missing an AED dose, if the seizures are under control. A significant proportion of patients did not know and hence did not

comply with the usual advice about driving, swimming, brushing the teeth and travelling.

### 3.5. Influence of patient characteristics on doctor-patient communication

Table 3 depicts the relation between patients' satisfaction and the clinical and demographic characteristics. Patients with better educational and economic status judged the communication they received more favorably. The seizure frequency and an external locus of control negatively influenced the level of patient satisfaction. Age, gender, religion, marital status, duration of epilepsy and the seizure type did not influence patients' perception on doctor-patient communication.

## 3.6. Influence of doctor-patient communication on compliance

Table 4 illustrates the attributes of compliance. There was a significant positive correlation between compliant behavior and a good doctor-patient communication (r = 0.2148, P = 0.002). While the number of visits to our epilepsy clinic positively correlated with compliance (r = 0.1859, P = 0.008), seizure frequency had a negative correlation with compliance (r = -1831, P = 0.009).

Table 3
Relation between doctor-patient communication and demographic and clinical characteristics of the patients

Variable	Measure of association	P-value
Age	0.0449a	0.528
Gender	$-0.0281^{b}$	0.091
Religion	ANOVA <sup>c</sup>	0.356
Marital status	ANOVA	0.439
Educational status	0.1488 <sup>d</sup>	0.043
Economic status	0.1885 <sup>d</sup>	0.008
Duration of epilepsy	$-0.0644^{a}$	0.365
Seizure frequency	$-0.1582^{d}$	0.025
Seizure type	ANOVA	0.603
Locus of control	$-0.2278^{a}$	0.001

<sup>&</sup>lt;sup>a</sup> Pearson's correlation coefficient.

<sup>&</sup>lt;sup>b</sup> Two-tailed *t* test.

<sup>&</sup>lt;sup>c</sup> ANOVA-based on one-way analysis of variance.

<sup>&</sup>lt;sup>d</sup> Spearman's rank correlation coefficient.

Table 4
The attributes of compliant behavior

	Measure of association	P-value
Bivariate models		
Age	$0.0749^{a}$	0.297
Gender	$0.0010^{b}$	0.957
Education	$0.0289^{c}$	0.696
Seizure frequency	$-0.1831^{c}$	0.009
Monotherapy/polytherapy AED(s) <sup>d</sup> regimen	0.0144 <sup>b</sup>	0.499
Number of clinic visits	0.1859 <sup>c</sup>	0.008
Doctor-patient communication	0.2148 <sup>a</sup>	0.002
External locus of control	$-0.1620^{a}$	0.022
	Regression coefficient (b)	
Multivariate model		
Number of clinic visits	0.0330	0.002
Doctor-patient communication	0.2355	0.005
External locus of control	-0.0744	0.093

<sup>&</sup>lt;sup>a</sup> Pearson's correlation coefficient.

In the multivariate model, an effective doctor-patient communication and the number of clinic visits were strongly associated with a better compliance. There was no relationship between the following variables and compliance in bivariate or multivariate analyses: age at onset and duration of epilepsy, gender, educational status, and monotherapy/polytherapy AED regimen.

# 3.7. Locus of control and its influence on compliance

The mean I–E score for the patient group was towards external locus of control range  $(0.355 \pm 0.214)$  when compared to that of the normals  $(0.287 \pm 0.204)$  (P < 0.001) (Table 5). A majority of our patients had their I–E scores > 67 percentile of the scores of the control subjects (Table 5). There was a significant negative correlation between I–E scores and compliant behavior in the bivariate analysis (r = -0.1620, P = 0.022), indicating that noncompliance was positively associ-

ated with a more external locus of control (Table 4). There was a trend in the multivariate model also for an external locus of control to negatively influence the compliant behavior, however, this trend did not attain statistical significance (b = -0.074; P = 0.093) (Table 4).

#### 4. Discussion

Doctor-patient communication and its influence on compliance till to date have received very little attention from epilepsy researches. Doctorpatient communication is a two-way process, a shared responsibility, necessary to improve both doctor's attitudes and those of their patients (de Boer, 1995; Ogden, 1996). To our knowledge, this is the first study among persons with epilepsy from a developing country which inquired about patients' views about doctor-patient communication. Very little research has been done in this area of epilepsy care even in developed countries. Buck et al. (1996) examined in the UK the views of 677 persons with epilepsy, who responded to a postal questionnaire, about the provision of information concerning the management of their condition. The opinions of patients about communication concerning epilepsy and its treat-

Table 5
The locus of control of epilepsy patients compared to control subjects<sup>a</sup>

	I–E scores (mean ± SD)	P-value
Control subjects $(n = 206)$	$0.287 \pm 0.204$	< 0.001
Epilepsy patients $(n = 200)$	$0.355 \pm 0.214$	
Percentage distribution		
Locus of control	Patients	Controls
Internal $(n = 46)$	23.1	41.3
Intermediate $(n = 63)$	31.7	22.3
External $(n = 91)$	45.2	36.4
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<sup>&</sup>lt;sup>a</sup> SD, standard deviation; I-E, Internal-External locus of control.

<sup>&</sup>lt;sup>b</sup> Two tailed t test.

<sup>&</sup>lt;sup>c</sup> Spearman's rank correlation coefficient.

d AED, antiepileptic drug.

ment was examined through a telephone interview in four European countries: France; Germany; Italy; and Spain (ISIS Research, 1994).

Before interpreting the results of our study, the influence of the organization of care on doctor—patient communication, methodological issues, and the limitations of our data need to be highlighted.

### 4.1. Influence of the organization of care

The quality of care is markedly influenced by the *structure* (type of facility, the administrative organization, and the qualification of the providers) and process (the technical and interpersonal skills of the physician and other providers, and the medical interaction) of the health care system (Baker et al., 1998). Doctor-patient communication in a set-up like ours (see, Section 2) with an optimal organization for a comprehensive epilepsy care is likely to be far superior compared to the usual secondary and tertiary health care facilities in developing countries where hundreds of patients are disposed of within a brief period by doctors with no special experience in epilepsy and with little assistance from nurses or medical social workers. In the survey of British patients' experiences with their care of epilepsy, whereas 62% of patients examined by a neurologist or epilepsy specialist believed they had received the right amount of information, only 45% of those examined by a general hospital doctor agreed to this (Buck et al., 1996).

#### 4.2. Methodological considerations

A semi-structured personal interview method was used in our study, whereas the data were gathered through postal questionnaires in the British study (Buck et al., 1996) and by telephone questionnaires in the four-nation European survey (ISIS Research, 1994). Respondents are known to answer differently in face-to-face interviews compared to postal or telephonically administered questionnaires (Antonak and Rankin, 1982). The interview method generally produces more socially acceptable answers (Iivanainen et al., 1980). The socio-cultural and educational diversity of the

respondents further complicates the comparison of the data from different surveys.

#### 4.3. Limitations of our study

Patients are referred to our tertiary referral center from primary and secondary care facilities in this geographical region. Therefore, we see more 'difficult to control' epilepsy patients. It is difficult to quantify the extent to which previous consultations have influenced the response to our questionnaire. This study was undertaken in a geographical area with a population well known for their high level of literacy and health awareness (Zachariah, 1998). It is very unlikely that the results of our study can be extrapolated to other parts of India or to other developing regions. The South Indian population still holds the medical profession in high esteem. Out of respect for the doctors, patients may often respond in a way that they believe they should respond rather than what they actually believe. Furthermore, our questionnaire has not been validated for the local population.

We relied on patient interviews to measure compliant behavior which may be inaccurate and biased (Gordis et al., 1969; Mushlin and Appel, 1977). However, alternate measures of compliance such as serum AED assays and pill counts have their own deficiencies and provide information only about AED intake and not about other aspects of compliance (Leppik, 1988).

### 4.4. Doctor-patient communication: perception and reality

Our results are remarkably similar to European studies which inquired about patients' views about provision of information concerning epilepsy and its management (ISIS Research, 1994; Buck et al., 1996). In the UK survey, 38% of patients examined by a neurologist or epileptologist did not consider that they received the right amount of information about epilepsy (Buck et al., 1996). In the four-nation European study involving persons with epilepsy from France, Germany, Italy, and Spain, 38% of patients said that the side effects of AED treatment were never

mentioned to them (ISIS Research, 1994). Thus, over one-third of patients in different studies, including ours, reported that they received insufficient information about epilepsy and its treatment.

In the British study (Buck et al., 1996), patients who reported having regularly visited their doctor were more likely to have discussed clinical aspects of epilepsy care compared to those who did not have such an arrangement. Whether the patient consulted the same doctor each time they went to the clinic did not influence the communication in the British survey (Buck et al., 1996). In our epilepsy clinic, each time the patient may be seen by the same or by a different doctor; however, we did not investigate the influence of this factor on doctor—patient communication.

Previous studies have shown that demographic characteristics modify levels of patient's satisfaction (Jacoby, 1989; Khayat and Salter, 1994; Buck et al., 1996). In the British study (Buck et al., 1996), women and younger people were less likely to be satisfied with their epilepsy care than men and older people. By contrast, in our inquiry, age and gender did not influence the views of patients about doctor-patient communication. As in the British study (Buck et al., 1996), our patients experiencing frequent seizures expressed more dissatisfaction with the consultation. Our patients with better educational and economic status understood the information provided to them better than the less privileged ones. The inconsistencies between various studies may be related to the socio-cultural and educational diversity between the populations investigated.

## 4.5. Influence of communication on compliant behavior

Noncompliance is a major factor contributing to suboptimal control of epileptic seizures (Trostle et al., 1983; Leppik, 1988). The consequences of noncompliance can be enormous because of an increased number of seizures resulting in an increase in direct medical costs and physical injury to self and others. Although indirect, a clinically useful and easy method to measure compliant behavior is through a questionnaire—interview

(Leppik and Schmidt, 1988; Trostle, 1988). A significant factor that may lead to noncompliance is insufficient education regarding medication regimen and apprehension about AED adverse effects (Leppik, 1988).

We observed a significant correlation between doctor-patient communication and compliance. Our findings support Ley's model of compliance, which claimed that compliance can be predicted by a combination of patient satisfaction with the process of consultation, understanding of the information given and recall of this information (Ogden, 1996). Multiple visits to the doctor, as expected, enhanced the communication, thereby a better compliant behavior. We observed a negative correlation between seizure frequency and compliance. Perhaps poor compliance increases seizure frequency, or poor seizure control reduces trust in the medical system and the will to comply with it. It is important to note that, in our multivariate model, the two variables associated with a better compliant behavior were doctor-patient communication and the number of clinic visits.

### 4.6. Influence of locus of control on compliant behavior

Locus of control, as defined by Rotter (1966), denotes individual's perception of causality, with internal locus of control indicating the perception of ability to control events in one's life, whereas external locus of control indicates that the person believes his or her life is controlled from without by such factors as fate, luck, etc. Individuals with epilepsy, as a group, exhibits a more external locus of control relative to other chronic illness groups (De Vellis et al., 1980; Ziegler, 1981; Ferrari et al., 1983; Hermann and Wyler, 1989; Gehlert, 1994; Amir et al., 1999). This replicable phenomenon was observed in our group of persons with epilepsy as well. Persons with epilepsy spend a great deal of time focusing on their epilepsy and its negative consequences (Gehlert, 1994). Externality of control and learned helplessness have been implicated as casual factors in the development of psychosocial problems in epilepsy (De Vellis et al., 1980; Ferrari et al., 1983; Hermann et al., 1990).

We noticed that patients with an external locus of control were more dissatisfied with the consultation. Furthermore, an external locus of control negatively influenced the compliant behavior. Establishing a link between doctor-patient communication, perceptions of control and compliance is difficult. Like locus of control, compliance is a complicated and multidimensional attribute (Leppik 1988; Gehlert, 1994). One's belief in one's capabilities has been shown to predict positive health-related behaviors in individuals with epilepsy (Dilorio et al., 1992). Negative attributional styles associated with external locus of control may enhance noncompliance (Wallston et al., 1987; Dilorio et al., 1992).

Pessimistic attributional style may be alterable through interventions (Foresterling, 1985). Amir et al. (1999) showed that the quality of life of persons with epilepsy can be improved by counseling and treatment aimed at reinforcing their self-efficacy and locus of control. It may be assumed that education about epilepsy received during early childhood may help individuals to develop a more internal control, positive attributional style and a better compliant behavior.

## 4.7. Implications of our results on epilepsy care in the developing world

Over three-fourths of the 40 million persons with epilepsy in the world reside in developing nations (World Development Report, 1993; Pedley and Kale, 1996). There are only 400 neurologists for the 5.4 million persons with epilepsy in India, i.e. one neurologist for 13 500 persons with epilepsy (Mani, 1998). Nearly 70% of epileptic population of India reside in rural areas, while 100% of neurologists practice in urban areas (Mani, 1998). A majority of persons with epilepsy in India and other developing countries are therefore treated by primary and secondary care physicians without specific training or expertise in this disorder. The situation may not be much different even in developed countries. A recent study in the UK showed that only 6% of patients with active epilepsy had ever attended a specialist epilepsy clinic (Hart and Shorvon, 1995).

A majority of patients with epilepsy in developing countries are seen in facilities with poor infrastructure for optimal doctor-patient communication. Epilepsy clinics in a developing country set-up have to cater to a large number of patients with very limited skilled personnel. Overcrowding of patients and the consequent overburdening of the service providers make the time available for individual patients very limited. In such time as is available, the provision of clinical services takes up more time rather than the patients' need for information.

Public education ought to be undertaken through attractive posters, pamphlets, television and radio programs, and articles in lay press. These should highlight the medical aspects of epilepsy, therapeutic potential in epilepsy, AED and life style compliance, and positive aspects of life in epilepsy. Knowledge about their disease will encourage people with epilepsy to make informed choices, and achieve more personal control, compliant behavior and a better quality of life.

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