

# The behavior pattern of parents of patients with subacute sclerosing panencephalitis concerning alternative medicine

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The aim of the study was to examine the attitude of the parents of Subacute Sclerosing Panencephalitis (SSPE) patients regarding alternative treatment methods and compare with those of the parents of epilepsy patients. The study comprised 39 SSPE and 53 epilepsy patients who were under follow-up in Gaziantep Children's Hospital. A questionnaire designed to inquire about the knowledge (13 questions) and behavior (11 questions) of parents about alternative medicine methods was given to the caregiver of all patients. The ratio of parents using alternative medicine methods was 29/39 (74.4%) in the SSPE group and 8/53 (15.1%) in the epilepsy group. Less than half of the parents of SSPE patients reported talking about it with their doctors. These results show parents facing a chronic debilitating disease frequently seek benefit from alternative methods. Most define this treatment as complementary to the established medical treatment. However, potential and unrecognized adverse events of alternative methods and their interference with regular medical treatment can be of importance, especially because treating physicians are seldom informed about concurrent use.

**Key words:** subacute sclerosing panencephalitis, epilepsy, questionnaire, alternative medicine, pediatric, parent, children.

Subacute sclerosing panencephalitis (SSPE) is progressive and often fatal encephalitis caused by persistent measles virus infection in the central nervous system<sup>1</sup>. Incidence rates in different parts of the world range between 0.2 to 40 cases per million population per year<sup>2,3</sup>. Current treatments may reduce the progression rate, extend survival, or rarely, result in clinical improvement in only 35-45% of patients<sup>4,5</sup>.

The term "alternative and complementary medicine" comprises all treatment other than scientifically established methods<sup>6</sup>. The usage of complementary and alternative treatment methods is increasing all over the world especially for chronic diseases with high economical and emotional burden<sup>7</sup>. Determining the general tendency of patients or caregivers about alternative treatment methods may increase understanding by doctors who generally disapprove this practice.

We investigated the usage of alternative treatment method for SSPE patients and compared the results with those of epilepsy patients. To the best of our knowledge, this is the first such study on SSPE or any fatal neurological disease in children.

## Material and Methods

### Study design and patient selection

The study comprised 39 SSPE and 53 epilepsy patients who were under follow-up in Gaziantep Children's Hospital. A questionnaire designed to inquire about the knowledge (13 questions) and behavior (11 questions) of parents about alternative medicine methods was given to the caregiver of all patients. The questionnaires were filled out by the parents themselves. The diagnosis of SSPE was made according to clinical and laboratory criteria. All patients had elevated measles IgG titer in the cerebrospinal

fluid. Duration of disease was 48-184 months (median 114 months). Twenty-seven (69.2%) patients were bed-ridden. In the epilepsy group, 31 patients were under monotherapy, 10 were receiving two drugs and the remaining 12 cases were taking three or more drugs for treatment. Cerebral palsy was an associated diagnosis in 13 patients of the epilepsy group.

The study was approved by the local ethics committee and informed consent was obtained from the parents of all participants.

### **Statistical Analyses**

Results were expressed as number and percentage. Comparisons of two groups were performed with Student's *t* test.  $P < 0.05$  was considered as statistically significant. All statistical analyses were performed with the Statistical Package for Social Sciences (SPSS) for Windows 21.0 program.

### **Results**

A total of 39 SSPE (13 female, 26 male) and 53 epilepsy (30 female, 23 male) patients were included in the study. General characteristics are summarized in Table I. Most parents in both groups were primary school graduates with middle- or low-income. Most mothers were stay at home mothers and the primary caregiver for the child.

The knowledge of parents about alternative medicine, as assessed with 13 questions in the questionnaire, showed most parents in both groups knew about at least one type of alternative medicine method (Table II). Knowledge about herbs' effect on health was less prevalent than belief in metaphysical factors' effect. Many parents defined the alternative treatment methods as the last chance where medical treatment is not enough. Very few patients defined the alternative treatment as a first line therapy before presenting to a doctor.

The behavior of parents about alternative medicine was evaluated by 11 questions (Table III). Significantly fewer parents in the SSPE group had been informed about the course of the disease compared with the epilepsy group. Significantly more parents in the SSPE group had applied alternative medicine methods to their child before the diagnosis, and had spent

significantly higher amounts for the alternative methods in the SSPE group compared with the epilepsy group.

### **Discussion**

In this general assessment of the attitude of parents about alternative medicine methods, we observed a significant difference between SSPE and epilepsy groups: 75% vs. 20%. This result could be expected due to the progressive and debilitating nature of SSPE and the absence of any proven treatment. Moreover, the educational level and economic status of parents were lower in the SSPE group, which may also contribute to this difference. Interestingly, 7/29 parents who used alternative treatment methods reported to be advised by the doctors about this method. Fortunately, adverse events were reported in only 2 cases and 26/29 parents (89.6%) were defining alternative treatment as complementary to medical treatment. There was no difference between groups regarding the presence of adverse events and general opinion of parents about this treatment modality.

This is the first study evaluating the behavior of parents of SSPE patients about alternative treatment methods. More studies have been reported about epilepsy. In one from Turkey in which the parents of 202 epilepsy patients were interviewed face-to-face, 27.7% reported used alternative treatment including 6.9% who started it at the suggestion of their doctor<sup>8</sup>. In our study, 8 of 53 (15.1%) parents of the epilepsy group applied alternative treatment methods and none of them reported this having been suggested by their doctor. In fact, the figures in our study are in general lower than those in the literature. Peebles et al.<sup>9</sup> evaluated the prevalence, characteristics, and demographic patterns of alternative medicine use in 92 patients with epilepsy and reported 24% of patients were using these methods. Recently, Lagunju et al.<sup>10</sup> applied a standardized questionnaire to caregivers of 175 children with epilepsy: 56.6% had a history of alternative medicine usage, of which 1/3 in combination with prescribed anti-epileptic drugs, and 17.1% reported adverse effects. The use of alternative medicine was less frequent in our epilepsy group: this may be related to the less severe nature of epilepsy compared to SSPE, and also

Table I. General Characteristic of Study Participants.

	SSPE (n=39)	Epilepsy (n=53)	p
Age (years)	16.07 ± 1.73	15.58±1.02	0.12
Pollster (%)			0.07
Mother	21 (53.8)	31 (58.5)	
Father	15 (38.5)	22 (41.5)	
Other	3 (7.7)	0	
Gender (F/M)	13/26	30/23	0.39
Mother's education (%)			0.01
None	7 (17.9)	5 (9.4)	
Primary School	28 (71.8)	36 (67.8)	
Secondary School	2 (5.1)	9 (16.9)	
High School	0	1 (1.8)	
University	2 (5.1)	2 (3.6)	
Mother's occupation (%)			0.07
Office	1 (2.6)	1 (1.8)	
Worker	0	5 (9.0)	
Employer	0	1 (1.8)	
Homemaker	38 (97.4)	46 (86.8)	
Father's education (%)			0.10
None	5 (12.8)	1 (1.8)	
Primary School	25 (64.1)	29 (54.7)	
Secondary School	4 (10.2)	9 (16.9)	
High School	4 (10.2)	11 (20.7)	
University	1 (2.6)	2 (3.6)	
Father's occupation (%)			0.001
Office	5 (12.8)	7 (13.2)	
Worker	8 (20.5)	38 (71.7)	
Employer	23 (58.9)	7 (13.2)	
Unemployed	3 (7.7)	0	
Care giver (%)			0.24
Mother	34 (87.2)	47 (88.7)	
Father	1 (2.6)	5 (9.0)	
Other	3 (7.7)	1 (1.8)	
Economic situation (%)			0.005
Good	4 (10.2)	4 (7.2)	
Middle	10 (25.6)	33 (62.3)	
Lower middle	12 (30.7)	10 (18.0)	
Low	12 (30.7)	6 (10.8)	
Health Insurance (%)			0.001
None	8 (20.5)	3 (5.4)	
Superannuation fund	8 (20.5)	3 (5.4)	
Social security	8 (20.5)	38 (71.7)	
Distinctive fund	6(15.4)	2 (3.6)	
Private insurance	7 (17.9)	1 (1.8)	
National*	0	6 (11.3)	
Area of residence (%)			0.09
Village	5 (12.8)	9 (16.9)	
Town	8 (20.5)	18 (33.9)	
Province	23 (58.9)	25 (47.2)	

\*Equivalent to Medicaid in USA.

**Table II. Knowledge About Alternative Medicine.**

	SSPE (n=39)	Epilepsy (n=53)	p
Did you know any alternative medicine methods before the diagnosis? (%)			0.01
Yes			
Herbal	5 (12.8)	13 (24.5)	
Thermal	3 (7.7)	5 (9.4)	
Prayer	3 (7.7)	8 (15.1)	
Massage	7 (17.9)	2 (3.6)	
Hypnosis	0	1 (1.8)	
Others	2 (5.1)	0	
No	16 (41.0)	21 (39.6)	
No idea	3 (7.7)	3 (5.4)	
Did you know about herbal tea before? (%)			0.05
Yes	7 (17.9)	9 (16.9)	
No	16 (41.0)	34 (64.1)	
No idea	16 (41.0)	10 (18.0)	
Do you think that "Herbals may change the effects of drugs?" (%)			0.49
Yes	4 (10.2)	8 (15.1)	
No	9 (23.1)	14 (26.4)	
No idea	26 (66.6)	31 (58.5)	
Do you think that "Herbals may be harmful?" (%)			0.47
Yes	6(15.4)	10 (18.0)	
No	7 (17.9)	14 (26.4)	
No idea	26 (66.6)	29 (54.7)	
Do you think that "Metaphysical factors may affect health?" (%)			0.03
Yes	21 (53.8)	31 (58.5)	
No	2 (5.1)	14 (26.4)	
No idea	16 (41.0)	8 (15.1)	
Do you think that "Positive beliefs may help the body to be healthier?" (%)			0.001
Yes	20 (51.2)	48 (90.5)	
No	5 (12.8)	4 (7.2)	
No idea	14 (35.9)	1 (1.8)	
Do you think that "Alternative treatment may cause delays in obtaining medical treatment?" (%)			0.001
Yes	10 (25.6)	31 (58.5)	
No	5 (12.8)	16 (30.2)	
No idea	24 (61.5)	6 (11.3)	
Do you think that "Alternative treatment may be the last chance where medical treatment is not enough?" (%)			0.001
Yes	20 (51.2)	36 (67.9)	
No	2 (5.1)	16 (30.2)	
No idea	17 (43.6)	1 (1.8)	
Do you think that "Stressful patients have more severe diseases more commonly?" (%)			0.012
Yes	29 (80.5)	51 (96.2)	
No	4 (10.2)	1 (1.8)	
No idea	6 (15.4)	1 (1.8)	
Do you think that "Alternative treatment methods should be tried before seeing a doctor?" (%)			0.001
Yes	3 (7.7)	8 (15.1)	
No	24 (61.5)	43 (81.1)	
No idea	12 (30.7)	2 (3.6)	
Do you think that "Alternative treatments may only be used for mild diseases but not for severe ones?" (%)			0.001
Yes	15 (38.5)	21 (39.6)	
No	5 (12.8)	25 (47.1)	
No idea	19 (48.7)	7 (13.2)	
Do you think that "Alternative treatments are as effective as drug treatment?" (%)			0.004
Yes	8 (20.5)	21 (39.6)	
No	6 (15.4)	12 (22.6)	
No idea	26 (66.6)	20 (37.7)	
Do you think that "Alternative treatments prepare the body for protection and drug treatment?" (%)			0.001
Yes	5 (12.8)	17 (32.0)	
No	6 (15.4)	30 (56.6)	
No idea	28 (71.8)	6 (11.3)	

**Table III.** Evaluation of Behavior Pattern of Parents About Alternative Medicine.

	SSPE (n=39)	Epilepsy (n=53)	p
Were you informed about the disease by your doctor? (%)			0.45
Yes	26 (66.6)	41 (77.4)	
No	3 (7.7)	3 (5.6)	
No idea	10 (25.6)	9 (16.9)	
What do you know about the course of the disease? (%)			0.01
Fast recovery	0	14 (26.4)	
Slow recovery	8 (20.5)	19 (35.8)	
Variable	12 (30.8)	9 (16.9)	
No idea	19 (48.7)	11 (20.7)	
Time passed after the diagnosis (%)			0.19
2-6 months	10 (25.6)	22 (41.5)	
7-12 months	5 (12.8)	8 (15.1)	
13-24 months	3 (7.7)	6 (11.3)	
>25 months	21 (53.8)	17 (32.1)	
Did you apply any alternative medicine method to your child before the diagnosis? (%)			0.01
Yes	9 (23.1)	1 (1.8)	
No	30 (76.9)	52 (98.2)	
Did you apply any alternative methods after the diagnosis? (%)			0.001
No	10 (25.6)	45 (84.9)	
Herbal treatment	3 (7.7)	2 (3.6)	
Charm	1 (2.6)	5 (9.0)	
Sepulcher	1 (2.6)	0	
Whiff	1 (2.6)	2 (3.6)	
Massage	3 (7.7)	0	
Other	5 (12.8)	0	
Two of them	5 (12.8)	0	
More than two	11 (28.2)	0	
Who suggested you to use alternative treatments? (%)			0.002
Mother-mother in law	5 (12.8)	3 (5.4)	
Neighbor	2 (5.1)	0	
Friend	1 (2.6)	4 (7.2)	
Doctor	7 (17.9)	0	
Pharmacist	1 (2.6)	1 (1.8)	
Other	5 (12.8)	0	
Two of them	3 (7.7)	0	
More than two	5 (7.7)	0	
What was the reason of using alternative treatment methods? (%)			0.001
Treatment	10 (25.6)	5 (9.0)	
Trying	3 (7.7)	0	
Stop progression	2 (5.1)	0	
Psychological treatment	1 (2.6)	1 (1.8)	
Other	3 (7.7)	0	
Two of them	5 (12.8)	1 (1.8)	
More than two	5 (12.8)	1 (1.8)	
Did you talk to your doctor about this treatment? (%)			0.02
Yes	13 (33.2)	0	
No	16 (41.0)	8 (15.1)	
Did you get any benefit from this treatment? (%)			0.42
No	7 (17.9)	1 (1.8)	
Yes, a bit	9 (23.1)	2 (3.6)	
Yes, highly.	5 (12.8)	1 (1.8)	
I have just started	0	1 (1.8)	
I am not sure	8 (20.5)	3 (5.4)	
Did you see any adverse event from this treatment? (%)			1.00
Yes	2 (5.1)	0	
No	27 (69.2)	8 (15.1)	
What is the method of traditional treatment for you? (%)			1.00
Together with classical treatment	26 (66.6)	6 (11.3)	
Without classical treatment	3 (7.7)	2 (3.6)	
How much money did you pay for this treatment? (%)			0.06
None	7 (17.9)	4 (7.2)	
1-50 TL (≈1-16\$)	1 (2.6)	1 (1.8)	
51-150 TL (≈17-50\$)	3 (7.7)	1 (1.8)	
>150 TL (>50\$)	18 (46.2)	1 (1.8)	

higher educational level of the parents in the epilepsy group. Alternative treatment methods were regarded as an addition to medical drugs in most SSPE (26/29) and epilepsy (6/8) patients. This indicates a high degree of reliance of parents to their doctors. Tonekaboni et al.<sup>11</sup> reported that 44% of 133 parents or relatives of epileptic children had used alternative methods either alone or in combination with other treatments and only 16.7% of these parents had discussed this matter with their children's physicians. In our study, 13 of 29 parents in SSPE group and none of the 8 parents in the epilepsy group informed their doctors about using alternative treatment methods. Al Asmi et al.<sup>12</sup> reported that 73.3% of their 101 participants were using alternative treatment methods. Similar to ours, the most common types of alternative treatment methods reported were under the "mind-body" type (incantations and incense) and herbs. They also reported an association of using alternative treatment methods with unemployment, having basic school education and low family income<sup>12</sup>. In our study population, the educational levels and family income rates of parents were in the lower range and this may be one of the reasons of high application rates of alternative medicine methods in the SSPE group.

Very recently, Hartmann et al.<sup>13</sup> studied 164 parents and reported that 13% stated that they used alternative medicine methods in their child. The main reason of using alternative medicine was reported as the adverse events associated with anti-convulsant medications. Among those 21 parents, ten parents described positive effects of alternative medicine on seizure frequency and 12, on the general condition of their child. In our study, the main reason for using these methods was "treatment" in both groups. The benefit rates of these agents reported by 14/29 in SSPE group and 3/8 in epilepsy group are similar to those reported by Hartman et al.<sup>13</sup> Differences between results of different studies may be related to cultural differences, educational level, time after diagnosis (parents becoming more interested in these treatment methods in time), and the importance of alternative treatment methods for investigators, patients or caregivers.

There are some limitations to be emphasized

in this study. The first one is that the questionnaires were filled out by the parents and then collected by the doctors during interview, which might have caused under-reporting. Results may be different in studies where the physician is blind to the answers. On the other hand, even with this drawback we observed a high usage of alternative and complementary methods, especially in SSPE. This may be associated with the lack of effective treatment, discouragement, and loss of expectations from medical approach that may affect the parental behavior and the results point to need for more professional help and support for such particular disease groups.

SSPE is a chronic debilitating disease where as high as 75% of parents of SSPE patients use alternative treatment methods for their children. Most of the parents define this treatment as complementary for the traditional drug treatments. However, less than half of the parents of SSPE patients reported that they had talked with their doctors about this condition. The results suggest that parents need more support and information by the medical staff. Larger studies are warranted with different patient groups to define the general behavior pattern of parents of SSPE patients about alternative treatment methods. Moreover, the interference of this treatment with the regular treatment needs to be considered and treatment doses adjusted accordingly.

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