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The Efficacy of an Educational Treatment Program for Patients with Epilepsy (MOSES): Results of a Controlled, Randomized Study

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Summary: *Purpose:* To evaluate the efficacy of the educational program MOSES (Modular Service Package Epilepsy). It was developed to improve patients' knowledge and understanding about their epilepsy, its treatment, and psychosocial consequences. The program intends to improve patients' coping with the disease, to strengthen self-esteem, and to support patients to become experts in managing their epilepsy.

Methods: A controlled, randomized study design was used to examine the efficacy of MOSES. Patients from 22 epilepsy centers in Germany, Austria, and Switzerland were randomly allocated to either MOSES group (treatment group) or waiting-list group (control group). The 242 patients were aged from 16 to 80 years. The MOSES group (n = 113) completed the questionnaires immediately before the educational course (T1) and 6 months later (T2), and the control group (n = 129), 6 months before (T1) and immediately before (T2) the course. The questionnaires included generic instruments (SF-36, Rosenberg self-esteem Scale, von Zerssen Depression Scale), and epilepsy-specific scales (Restrictions in Daily Life, Epilepsy-Related Fears, Coping with Epilepsy and Adaptation). Depression was used as a moderator variable. Seizure frequency and satisfaction with therapy also were assessed. Multivariate analysis of variance (MANOVA) with repeated measurements and univariate analyses of variance were performed.

Results: The MANOVA showed that participants of the educational program improved significantly. Univariate analyses revealed improvements in knowledge ($p < 0.001$) and coping with epilepsy ($p = 0.004$), whereas important effects of MOSES on other epilepsy-specific measures and on generic questionnaires (SF-36, self-esteem) were not found. Participants of the MOSES program also improved in seizure outcome ($p = 0.041$) and became more satisfied with the therapy [better tolerability of antiepileptic drug (AED) therapy, fewer side effects; $p = 0.014$]. In addition, participants expressed being highly satisfied with the program.

Conclusions: The study clearly indicates the need for patient education. Even patients with a long history of epilepsy and with additional handicaps or diseases benefitted from the MOSES program. **Key Words:** Educational program—Knowledge—Coping—Seizure frequency—Quality of life—Epilepsy-related fears—Self-esteem.

The knowledge of epilepsy patients about their disorder, treatment, and consequences is often poor (1–4). As a patient's knowledge and understanding is related to her or his success in coping with the disease, the need for and importance of epilepsy education was emphasized 20 years ago by The Commission for the Control of Epilepsy and its Consequences (5), but only a few educational programs were developed in the past (6,7). In recent years, the interest in educational programs for patients with epilepsy has been growing, and meanwhile, programs for specific patient groups have been developed in different countries (8–15).

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In memory of Dr. Sibylle Ried, August 29, 1956 to June 14, 2000.

Mainly through the initiative of Dr. Sybille Ried, the patient-education program MOSES (Modular Service Package Epilepsy) was developed (16). It is the first comprehensive program in German-speaking countries. MOSES is an interactive program for people with epilepsy older than 16 years, regardless syndrome, duration, and severity of the epilepsy. It can be used in routine care as well as in other settings (e.g., weekend courses or weekly courses). The teaching methods consider the amalgamation of information, emotions, and performance. Specific didactic tools (e.g., the workout manual, trainer manual, mind maps) were developed. MOSES has a modular structure and includes nine units: living with epilepsy, epidemiology, basic knowledge, diagnostics, therapy, self-control, prognosis, psychosocial aspects, and network. To cover the program, ~14 lessons (60 min each) are necessary.

The aims of MOSES (16) are to improve patients' knowledge about epilepsy, its consequences, and diagnostic and therapeutic measures, and to improve patients' understanding of psychosocial and occupational problems. The patients are encouraged to cope actively with their disease, to live with as few limitations as possible, to participate in the treatment process, and to gain more self-esteem. The program focuses on enhancing the self-help potentials of the patients and on promoting the patients to become "experts" in dealing with their epilepsy. As results, a reduction of psychosocial problems and an improvement of quality of life are expected.

The purpose of this study was to evaluate the efficacy of the Educational Program Epilepsy MOSES. The participants were asked to evaluate the benefit of the program and how to optimize the educational program.

METHODS

Patients and study design

We performed a randomized study with an untreated control group design with pretest and posttest to examine the efficacy of MOSES. Twenty-two epilepsy centers (mainly specialized outpatient clinics) in Germany, Austria, and Switzerland (see acknowledgements) collaborated and offered the educational course through public information and advertisement. Persons who applied were asked to participate in the study (i.e., fill out a questionnaire twice within 6 months). Mentally retarded patients as well patients with acute psychiatric illness, patients with nonepileptic seizures only, and patients younger than 16 years were excluded. MOSES was offered as a 2-day course. All applicants (n = 383) agreed to participate in the study and were randomly allocated to either the MOSES group or to the waiting-list control group (Fig. 1). Patients of the waiting group were invited to attend a course 6 months later. The participants of the MOSES group completed a questionnaire twice, the first time immediately before the educational course (T1) and a second time 6 months after completion of the course (T2). The control group also was asked to complete the questionnaires twice, the first time 6 months before the course (T1) and the second time immediately before the course (T2). Of the previously mentioned 383 patients, 342 returned the first questionnaire, and 250 patients of them also returned the second questionnaire. Even though all persons agreed to participate, 28 persons did not return any questionnaire for unknown reasons.

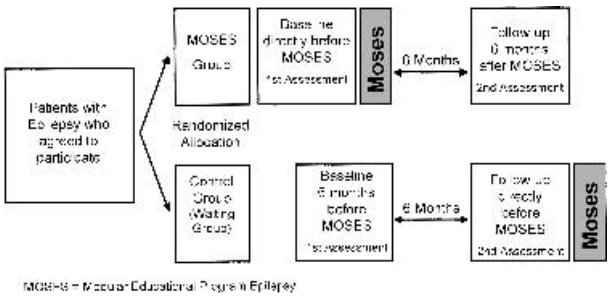

FIG. 1. Study design: controlled, randomized study design with repeated measurements.

Questionnaires were anonymous and were returned to the Epilepsy Research Foundation directly. Eight patients had to be excluded from evaluation because of violation of inclusion criteria (one patient was younger than 16 years, and one patient was demented and not able to complete the questionnaires) or violation of study protocol (six patients, who were allocated to the MOSES group, did not attend the course or returned the first questionnaire after attending the educational course).

The final sample included 242 patients aged from 16 to 80 years who had completed the questionnaires twice. The MOSES group comprised 113 participants; the control group, 129 participants. The demographic and clinical data of the patients are summarized in Table 1. Statistical analyses revealed no significant differences between the MOSES group and the control group in respect to demographic and clinical data, with the only exception of duration of epilepsy ($p = 0.034$; two-sided Mann–Whitney test). The patients of the control group had a longer duration of epilepsy compared with the MOSES group (18.2 vs. 13.5 years; median). A considerable proportion of participants had additional disabilities/diseases (35.1%).

Questionnaires

Generic instruments, epilepsy-specific questionnaires, and specific questionnaires developed for the evaluation were selected in cooperation with the MOSES Development Group to ensure that the questionnaires covered the aims of the program.

Generic Instruments: Health-Related Quality-of-Life, Self-Esteem, and Depressive Mood

Health-related quality-of-life (QOL) was assessed by the German version of the Short-Form 36 (17). The SF-36 is a generic QOL questionnaire, sometimes used when the health status of patients with epilepsy should be compared with other patient groups or with the general population (18–20).

Rosenberg self-esteem Scale (21) consists of 10 items (five negatively and five positively polarized items), each rated on a 4-point scale. It was used in studies with patients with epilepsy (22,23).

The Depression Scale D-S' by von Zerssen (24) was used to measure levels of depressive mood. Subjects were asked for ratings of 16 items on a 4-point scale. The reliability and validity of the D-S' has been demonstrated (24). Recent studies indicated that depressive mood assessed by the D-S' scale was highly correlated with self-reported quality of life (25) and coping patterns regarded as maladaptive in patients with epilepsy (26). Depressive

TABLE 1. *Demographic and clinical characteristics of treatment and control group*

Demographic characteristics	Control group	Treatment group
Gender, n (% female)	73 (56.6%)	65 (57.5%)
Age, (yr) mean ± SD (range)	38.4 ± 13.5 (16–80)	37.5 ± 13.7 (16–77)
Education level, n (%)		
Student (school)	7 (5.4%)	10 (8.8%)
Drop-out	6 (4.7%)	3 (2.7%)
Special school for disabled[a]	8 (6.2%)	5 (4.4%)
Secondary school final certificate	41 (31.8%)	36 (31.9%)
Intermediate school final certificate	40 (31.0%)	35 (31.0%)
General higher qualification	27 (20.9%)	24 (21.2%)
Employment, n (%)		
Employed	57 (44.2%)	40 (35.4%)
Self-employed	1 (0.8%)	2 (1.8%)
Unemployed	18 (14.0%)	8 (7.1%)
Vocational training	3 (2.3%)	6 (5.3%)
Student	6 (4.7%)	15 (13.3%)
Housewife/man	9 (7.0%)	8 (7.1%)
Retired	27 (20.9%)	23 (20.4%)
Other	8 (6.2%)	11 (9.7%)
Clinical characteristics		
Age at onset of epilepsy (yr), 25%–50%–75% percentiles (range)	8.25–15.0–26.0 (0–70)	8.5–17.0–30.0 (0–68)
Duration of epilepsy (yr) 25%–50%–75% percentiles (range)	8.5–18.2–29.6 (1–61)	4.7–13.5–26.2 (1–54)
Type of Epilepsy, n (%)		
Focal	81 (62.8%)	71 (62.8%)
Generalized	20 (15.5%)	23 (20.4%)
With focal + generalized signs	3 (2.3%)	0 (0.0%)
Undetermined	23 (17.8%)	16 (14.2%)
No data available	2 (1.6%)	3 (2.7%)
Type of seizures, n (%)		
Simple partial	57 (44.2%)	45 (39.2%)
Complex partial	56 (39.8%)	46 (40.7%)
Tonic–clonic	59 (45.7%)	58 (51.3%)
Absence	11 (8.5%)	3 (2.7%)
Myoclonic	0 (0.0%)	1 (0.8%)
Tonic	3 (2.3%)	5 (4.4%)
Undetermined	21 (16.3%)	16 (14.2%)
Frequency of seizures in past 6 mo, n (%)		
No seizures	35 (27.1%)	23 (20.4%)
1–2 seizures	15 (11.6%)	17 (15.0%)
3–5 seizures	24 (18.6%)	21 (18.6%)
≥1 seizure per mo	30 (23.3%)	21 (18.6%)
≥1 seizure per wk	22 (17.1%)	17 (15.0%)
≥1 seizure per day	1 (0.8%)	11 (9.7%)
Treatment with antiepileptic drugs, n (%, yes)	125 (96.9%)	110 (97.3%)
Treatment with other drugs, n (%, yes)	33 (25.6%)	30 (26.5%)
Comorbid conditions, n (%, yes)	45 (34.9%)	40 (35.4%)

[a] Participants who had visited a special school for disabled were included only if they had sufficient reading and writing skills to follow the course.

mood was considered in our study as a moderator variable and not as an efficacy parameter. We did not expect that a 2-day educational program could essentially improve depression. However, the level of depressive mood could influence the effects of MOSES.

Epilepsy-specific instruments: Restrictions in Daily Life, Epilepsy-related Fear, Stigma, and Mobility and Leisure

The scale, Restrictions in Daily Life Due to Epilepsy, comprises 12 items regarding independent living, mobility, partnership, family, friends, and physical and emotional health [e.g., Do you feel restricted due to epilepsy (a) in relations to friends? (b) in sports, leisure time, hobbies?]. Impairment is rated in each domain on a 5-point scale, from "extremely" (100) to "not at all" (0). The scale Epilepsy-related Fears" comprises 11 items regarding aspects of physical consequences of seizures (brain damage, death, etc.) and social consequences (rejection by others, embarrassing situations, etc.). For each item (e.g., Are you afraid of rejection because of seizures?), patients rated the extent to which they were afraid on a 4-point scale, from "yes, very much" (100) to "no, not at all" (0). Both scales were reported in detail elsewhere and had been proven to be consistent, reliable, and valid (27,28). The "Stigma" scale (29) comprises five items (e.g., Do others think you are less intelligent because of your epilepsy?), which required a no (0) or yes (100) response. The total scores of these scales were calculated as mean value and ranged from 0 to 100; higher values reflected a higher extent of impairment, epilepsy-specific fear, or perceived stigma.

The scale "Mobility and Leisure" contains 10 items (e.g., Do you use public transportation alone?) and is a subscale of a questionnaire developed especially for people with severe epilepsy (30). It measures daily performance and mobility (e.g., using public transport, driving a bike) and leisure activities (sports, hobbies), from "daily" (100) to "never" (0). The total score was calculated as mean value and ranged from 0 to 100; higher values reflected a higher extent of activities.

Instruments developed for the evaluation study: Epilepsy Knowledge, Coping with Epilepsy, and Adaptation to Epilepsy

A short scale was developed to assess epilepsy-specific knowledge (see Appendix). The 19 items were grouped into two parts: part I (10 items) was presented at both times; part II (nine items) was presented only at the second assessment. It could not be ruled out that participants who answered the questionnaire immediately before the MOSES course would pay attention especially to the items of the epilepsy knowledge scale during the course. For that reason, a second list of items (part II) was presented only at follow-up. Some items were similar to those of the "Epilepsy Knowledge Profile" (E.K.P.-G.) developed by Jarvie et al. (2). In contrast to the E.K.P.-G., we used three answer categories ("true," "false," or "I don't know") instead of two categories, because participants should not be forced to decide whether a statement was true or false if they did not know the answer.

The Scale "Coping with Epilepsy and Adaptation" comprises 21 items grouped into three subscales: Active Coping (e.g., I have lost hope to live a normal life.), Ability to Express Emotions (e.g., I find it hard to speak with my friends about my epilepsy.), and Information seeking (e.g., I know whom to ask if I have problems with my epilepsy.). An exploratory factor analysis confirmed the assignment of most items to the subscales. This questionnaire was developed especially for the evaluation study because existing scales did not cover some important aims of MOSES. Patients rated the extent of agreement with the items on a 5-point scale, from "I agree completely" (100) to "I disagree completely" (0). The total score was calculated as mean value and ranged from 0 to 100; a high value indicated that the patient had problems in coping adequately with his or her epilepsy.

Psychometric properties of the epilepsy-specific questionnaires and of those instruments particularly developed for the evaluation study are reported (see Table 2). Cronbach's α and test–retest reliability (intraclass correlation coefficient; ICC) were calculated (31,32). The baseline values of the total group (N = 235) were used to investigate the internal consistency (Cronbach's α) of the scales. The test–retest reliability was checked only in those participants of the control group without a change (n = 70) in seizure frequency.

Seizure frequency and contentedness with drug therapy

Seizure frequency was assessed according to six categories: 0, no seizures (sz.) in the last 6 months; 1, one to two sz. in the last 6 months; 2, three to five sz. in the last 6 months; 3, one or more sz. per month; 4, one or more sz. per week; and 5, one or more sz. per day. Furthermore, patients judged the tolerability (1, no side effects; 2, only slight; 3, moderate, but tolerable; 4, severe side effects, not tolerable) and efficacy of drug therapy (1, no more sz.; 2, marked reductions of sz.; 3, slight reduction of sz.; 4, no reduction of sz.). A symptom list was used to assess specific and unspecific side

TABLE 2. *Scales and questionnaires*

Scales and questionnaires references	No. of items	Range[b]	Psychometric properties[c]
Epilepsy Knowledge Scale[a] (Part I + II), see appendix	9 + 10	0–100	Total: Cronbach's alpha = 0.72; Part I: Cronbach's alpha = 0.45; ICC = 0.70; Part II: Cronbach's alpha = 0.57
Coping with Epilepsy[a] 3 Subscales; Active coping, Ability to express emotions, Information seeking	21	0–100	Total scale: Cronbach's alpha = 0.81; ICC = 0.70 Subscales: Cronbach's alpha = 0.54–0.77; ICC = 0.51–0.77
Restrictions in Daily Living Due to Epilepsy (27)	13	100–0	Cronbach's alpha = 0.90; ICC = 0.83
Mobility and Leisure (behavior) (30)	8	0–100	Cronbach's alpha = 0.63; ICC = 0.83
Epilepsy-related Fear (27)	12	100–0	Cronbach's alpha = 0.88; ICC = 0.80
Stigma (29)	5	100–0	Cronbach's alpha = 0.79; ICC = 0.71
SF-36 (17) 8 Subscales: Physical functioning, Role-physical, Bodily pain, General health, Vitality, Social functioning, Role-emotional, Mental health	36	0–100	Mental component[d]: ICC = 0.76, Physical component[d]: ICC = 0.50 Subscales: Cronbach's alpha = 0.80–0.92; ICC = 0.44–0.77
Self-esteem (Rosenberg) (21)	10	0–3	Cronbach's alpha = 0.90; ICC = 0.77
Depressive Mood Scale (D-S′) (24)	16	0–48	Cronbach's alpha = 0.89; ICC = 0.83

[a] The "Epilepsy Knowledge Scale" and the "Coping with Epilepsy" scale were developed especially for the evaluation of the MOSES program (Research scales).

[b] Range; range of theoretically possible values, 0–100 means that high values were desirable, 100–0 means that low values were desirable.

[c] Cronbach's alpha computed for the total group; ICC, Intraclass correlation coefficient computed for the participants of the control group without changes of the seizure frequency (n = 70).

[d] Mental and physical component were computed as weighted sum of the eight subscales.

effects of antiepileptic drugs (AEDs) during the past 6 months.

Evaluation of the MOSES Program by the participants

In addition, 111 participants of the MOSES program answered a short questionnaire to evaluate the program and the procedure of training (see Table 4).

Statistical methods

Multivariate analysis of (co-)variance (MANOVA) with repeated measurements and univariate analyses of variance were performed. To investigate whether the moderator variable "depression" and other variables (e.g., age, gender, educational level, or duration of epilepsy) interacted with the effect of MOSES, the differences of before-minus-after values of the outcome measures were analyzed by using MANOVA, including these variables as factors or covariates. Nonparametric tests (Wilcoxon test, χ^2 test) were used to check differences among groups at baseline. For statistical and psychometric analyses, we used SPSS for Windows (Version 9.0; SPSS Inc., Chicago, IL, U.S.A.).

RESULTS

Effects of MOSES on knowledge and psychosocial aspects

The MANOVA indicated that MOSES had a significant impact on the outcome measures (highly significant Group × Time interaction and Time effect, cf. Table 3). The univariate tests revealed improvements in Epilepsy knowledge, especially regarding medical aspects and inadequate self-limitations, and Coping with epilepsy, whereas no significant effects (group or interaction effects) of MOSES were confirmed on other outcome measures (Table 3).

Knowledge

In contrast to the control group, the MOSES group showed a significant improvement in knowledge, part I

TABLE 3. *Outcome scores (mean ± SD) at baseline (first assessment) and follow-up*

	Control group		Treatment group		*F* score (p)		
	Baseline	Follow-up	Baseline	Follow-up	Group × time	Time	Group
Primary outcome measures (MANOVA)					4.30[a]	9.60[a]	1.26
Epilepsy Knowledge Scale I	46.44 ± 16.09	48.50 ± 19.39	43.03 ± 17.10	54.62 ± 17.08	21.47[b]	44.02[b]	0.46
Coping with Epilepsy (total score)	58.29 ± 15.31	59.92 ± 14.58	59.70 ± 16.41	65.60 ± 16.64	8.35[c]	25.82[b]	3.52 (0.062)
Subscale a) "Active coping vs. resignation"	49.81 ± 22.84	52.06 ± 21.33	51.99 ± 23.11	56.67 ± 22.63	1.20	9.79[b]	1.54
Subscale b) "Ability to express emotions"	56.97 ± 21.33	58.27 ± 18.89	58.50 ± 21.17	64.46 ± 22.11	5.15[d]	1.261[a]	2.41
Subscale c) "Information Seeking"	68.09 ± 16.65	69.42 ± 16.15	68.32 ± 16.84	75.69 ± 17.23	8.43[b]	17.46[a]	2.95 (0.087)
Restrictions in Daily Living	33.97 ± 22.50	28.34 ± 20.59	31.57 ± 21.68	29.55 ± 21.42	2.64	11.77[b]	0.05
Mobility and Leisure Behavior	43.21 ± 15.25	44.59 ± 15.40	42.34 ± 15.30	43.04 ± 14.31	0.32	2.95 (0.087)	0.42
Epilepsy-related Fear	45.34 ± 22.32	42.90 ± 23.07	41.90 ± 22.13	39.98 ± 21.42	0.04	4.86[d]	1.32
Stigma	24.61 ± 33.35	25.32 ± 32.14	17.77 ± 25.95	19.20 ± 29.66	0.06	0.55	3.08 (0.080)
SF-36 mental component	42.22 ± 10.98	42.46 ± 11.75	43.74 ± 10.70	43.69 ± 11.51	0.05	0.02	0.99
SF-36 physical component	50.84 ± 9.23	52.00 ± 8.70	49.88 ± 9.55	50.39 ± 9.37	0.12	3.21 (0.075)	0.94
Self-esteem (Rosenberg)	1.81 ± 0.65	1.88 ± 0.71	1.83 ± 0.70	1.91 ± 0.71	0.02	0.89	0.77
Secondary outcome measures (ANOVA)							
Seizure frequency scale	2.90 ± 1.48	2.74 ± 1.62	3.23 ± 1.64	2.77 ± 1.64	4.22[d]	18.4[b]	0.081
Contentedness with therapy a) Tolerability of AED	2.03 ± 0.85	2.10 ± 0.82	2.20 ± 0.86	2.05 ± 0.88	6.11[d]	0.61	0.30
Contentedness with therapy b) Efficacy of AED	2.19 ± 1.01	2.04 ± 0.92	2.46 ± 1.07	2.15 ± 1.11	1.73	14.00[b]	2.28
Moderator variable Depressive Mood Scale (D-S′)	13.94 ± 8.73	13.63 ± 8.99	12.49 ± 8.97	12.22 ± 8.86	0.00	0.59	1.71

[a] $p < 0.0001$; [b] $p < 0.001$; [c] $p < 0.01$; [d] $p < 0.05$; p values >0.05 and <0.1 are given in brackets; *F* scores from univariate ANOVA analyses.

(Table 1, Fig. 2). At follow-up, the MOSES group also had higher scores on the knowledge scale, part II, than did the control group (59.2 ± 19.9 vs. 65.0 ± 18.8, F = 5.37; p = 0.021).

Coping with epilepsy

The educational program had a significant effect on the scale, Coping with Epilepsy (total score), especially on the subscales Ability to Express Emotions and Information Seeking (significant Group × Time interactions, cf**.** Table 3). MOSES had no significant impact on the subscale Active Coping vs. Resignation; however, an improvement was seen in both groups (significant Time effect, cf. Table 3).

Effects of MOSES on seizure frequency and contentedness with AED therapy

The MOSES group also improved significantly in seizure frequency compared with the control group (Group × Time interaction, p = 0.041). Nineteen percent of the MOSES group improved markedly in seizure frequency (≥2 points on the seizure frequency scale; cf. Table 1) compared with 7.2% of the control group, whereas 4.8% of the control group deteriorated markedly in seizure frequency compared with 1.8% of the MOSES group (cf. Fig. 3). The percentage of patients without seizures or with only few seizures (one to two seizures) in the past 6 months increased in the MOSES group from 35.4 to 50.4% (+15.0%); in the control group this improvement was less pronounced (from 38.7 to 45.8%, +7.1%). Conversely, the percentage of patients with a high seizure frequency (weekly or daily seizures in the past 6 months) decreased in the MOSES group from 24.7 to 18.6% (-6.1%) and to lesser degree in the control group (from 17.9 to 15.6%, –2.3%). Moreover, the MOSES group improved significantly in contentedness with treatment; the tolerability of AED therapy especially improved (fewer side effects; Group × Time interaction, p = 0.014).

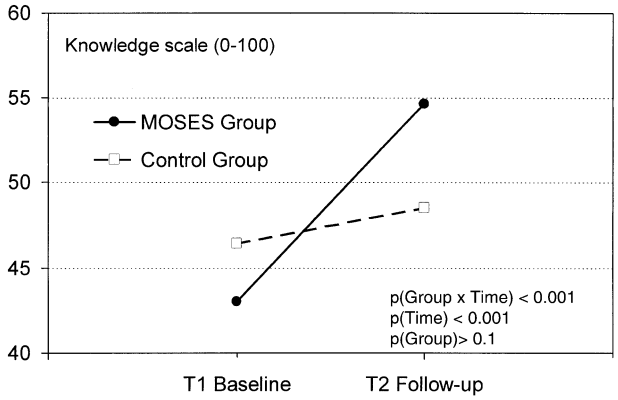

FIG. 2. Effect of MOSES on knowledge: In contrast to the control group, the MOSES group showed significant improvement in knowledge. Answer categories of the knowledge questionnaire: "true," "false," "I don't know." Only correct answers were counted.

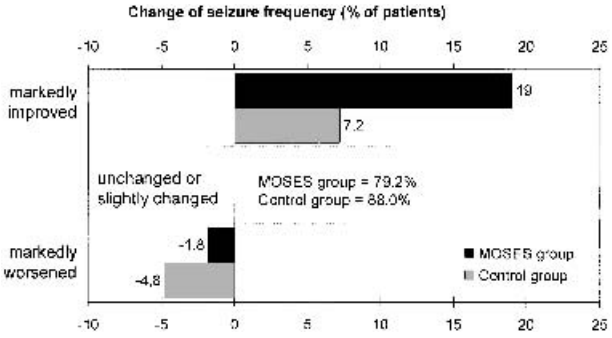

FIG. 3. Change of seizure frequency in MOSES group and control group. "Markedly" improved or worsened means a change in seizure frequency of two classes or more classes (see Table 1).

Influence of the moderator variable Depressive Mood and other variables

About 24.3% of the participants of the MOSES group and 29.2% of the control group reached scores higher than the 95% percentile of the reference population on the scale Depressive Mood. Depressive Mood (scores at baseline) was highly correlated (p < 0.01) with some outcome measures [e.g., mental component of the SF-36 (r = –0.73), self-esteem (r = –0.67), restrictions due to epilepsy (r = 0.54), coping with epilepsy (r = 0.55), epilepsy-related fears (r = 0.45), and perceived restrictions due to epilepsy (r = 0.46). However, MOSES had no significant effect on depressive mood (Table 3).

Participants were assigned according to their baseline values to a group with high scores on the depressive mood scale (>95% percentile) and a group with low and moderate scores (<95% percentile). Univariate ANOVA with the factors Group (MOSES vs. control group) and Depressive Mood (high vs. moderate and low) indicated that participants with high Depressive Mood scores gained more from the MOSES program with respect to Restrictions in Daily Life (interaction of Group × Depressive Mood F = 4.97; p = 0.027) and Epilepsy-Related Fear (interaction of Group × Depressive Mood, F = 4.34; p = 0.038) in contrast to those with low or moderate scores on the Depressive Mood scale. Regarding Coping with Epilepsy, the effect of the factors Group (F = 8.61; p = 0.004) and Depressive Mood (F = 7.01; p = 0.009) was significant, but not the interaction of both (F = 0.11; p = 0.74). No significant impact of the moderator variable was observed on the pre–post changes of other outcome measures.

Sex, age, and duration of epilepsy did not interact with the effect of the educational program.

Evaluation of MOSES by the participants

The evaluation of MOSES through the participants reflected a high degree of contentedness with the educational program (cf. Table 4).

TABLE 4. *Evaluation of the educational program MOSES by the participants*

Question[1]	Very much	Much	Somewhat	Little	Nothing	Missing
Have you learnt something new in the educational program MOSES?	22 (19.8%)	51 (45.9%)	29 (26.1)	7 (6.3%)	1 (0.9%)	1 (0.9%)
Does MOSES help you to cope with your epilepsy in daily life?	13 (11.7%)	42 (37.8%)	34 (30.6%)	16 (14.4%)	3 (2.7%)	3 (2.7%)
	Completely	Rather yes	Indifferent	Rather not	In no case	Missing
Does MOSES fulfill your expectancies?	41 (36.9%)	53 (47.7%)	12 (10.8%)	3 (2.7%)	2 (1.8%)	0 (0.0%)
Would you recommend MOSES to other patients with epilepsy?	77 (69.4%)	29 (26.1%)	4 (3.6%)	0 (0.0%)	1 (0.9%)	0 (0.0%)
	Very good	Good	Moderate	Poor	Very poor	Missing
How do you judge MOSES all in all?	54 (48.6%)	49 (44.1%)	7 (6.3%)	0 (0.0%)	1 (0.9%)	0 (0.0%)

DISCUSSION

Methodologic aspects

We used a randomized, controlled design to investigate the efficacy of the educational program MOSES with a waiting group as control group. Improvements also were seen in the control group and contributed to a significant time effect in some epilepsy-specific measures (Table 3); this underlines the importance of a control group. One reason for these improvements might be that the patients of the control group continued treatment in specialized outpatient clinics and stayed highly motivated to participate in the program as well.

The rate of responders at follow-up was relatively high in the MOSES group and in the control group (71.8 and 78.0%, respectively, of those who answered the first questionnaire at baseline). As nonresponders may be a source of bias, we checked whether responders, who returned both questionnaires, differed in respect to demographic and epilepsy-related data and in outcome measures at baseline from nonresponders, who returned the first questionnaire only. No significant differences were observed at baseline, except that nonresponders were significantly younger than responders in both groups (MOSES group, 31.3 ± 9.8 vs. 37.1 ± 13.8 years; $p = 0.026$, two-sided Mann–Whitney test; control group, 31.7 ± 11.4 vs. 38.0 ± 13.4 years; $p = 0.008$). Furthermore, nonresponders of the control group had fewer seizures ($p = 0.043$), lower scores on the scale Depressive Mood (10.5 ± 7.6 vs. 13.8 ± 8.8, raw scores; $p = 0.038$) and higher scores on Self-esteem (2.08 ± 0.56 vs. 1.81 ± 0.66; $p = 0.024$), suggesting that nonresponders had less severe epilepsy and were less impaired in emotional well-being.

At baseline, the demographic and epilepsy-specific data and outcome measures of the responders of the MOSES and the control group were largely comparable, with the exception of duration of epilepsy (Tables 2 and 3). Thus randomization was satisfactory, and the observed effects of the educational program could not be explained by different baseline values.

During the planning of the study, we had some doubts whether existing scales and QOL questionnaires were sufficiently sensitive and appropriate to assess the intended effects of MOSES. Our results indicated that these doubts were well founded. The effect of MOSES was most pronounced on the scales Epilepsy-specific Knowledge and Coping with Epilepsy, which were especially developed for the evaluation study.

Previous cross-sectional studies (18–20,23) had shown that subscales of the SF-36 are valid in respect to patient groups with different seizure frequencies and with or without side effects of AEDs. Compared with the German reference population, the participants in our study had significantly ($p < 0.01$) lower (0, worst; 100, best) scores on the SF-36, especially on physical role functioning (women, 67.8 vs. 80.4; men, 68.0 vs. 87.3), vitality (women, 47.0 vs. 60.6; men, 53.9 vs. 66.2), social functioning (women, 72.4 vs. 87.0; men, 75.2 vs. 90.1), emotional role functioning (women, 64.6 vs. 92.1; men, 69.3 vs. 92.1), and mental health (women, 59.8 vs. 76.6; men, 64.0 vs. 76.6) at baseline. This points to the influence of epilepsy on emotional functioning and on QOL. However, we could not demonstrate a significant impact of MOSES on the SF-36 or on its subscales. The question remains whether epilepsy-specific QOL scales would be more responsive to effects of an educational program. Birbeck et al. (33) compared the generic measures SF-36 and SF-12 with the epilepsy-targeted measures QOLIE-89 and QOLIE-31 with respect to detecting change over time. They concluded that epilepsy-targeted QOL measures might be preferable to generic ones in longitudinal studies.

Efficacy of the MOSES program: improvement of epilepsy-specific knowledge

In accordance with previous studies (e.g., 4), our results clearly indicate the need for educational interventions independent of the duration of epilepsy or age. The high percentage (~54%) of incorrect answers (false answers and "I don't know" answers) in the Knowledge Scale at baseline in both groups demonstrated deficits in knowledge of patients. At first glance, it is not remarkable that an educational program improved epilepsy-specific knowledge, but two facts should be kept in

mind: the period of time between the educational course and the second assessment was ~6 months, and long-term memory could be impaired in patients with epilepsy (34,35). Furthermore, it was not possible to check whether all topics of the knowledge scale were discussed during the 2-day program. These might be reasons that some participants improved only slightly in epilepsy-specific knowledge.

As the educational level might interact with the increase of knowledge, we considered the educational level as an additional factor. The corresponding ANOVA (significant interaction of Group × Education, $p = 0.023$) indicated a more pronounced increase in knowledge in participants with a medium educational level compared with those with a high level (general higher qualification) or low level (special school, dropouts). The baseline values of the knowledge scale also revealed an influence of the educational level (Fig. 4A and B). No effects of educational level on other outcome measures were observed.

Improvements in coping with epilepsy

Participants of the MOSES program improved significantly in relevant aspects of coping with epilepsy. The educational program was successful in providing information and possibilities for gathering and finding information by oneself. Thus it supported the active role of the patient in dealing with his or her disease. Communication with others, especially about the emotional aspects, is another important issue, which improved in the MOSES group. The interactive components and the encouragement to discuss the issues in the training group are methods of supporting emotional adaptation. However, no significant effect was seen on the subscale Active Coping versus Resignation, which was highly correlated with the Depression scale ($r = 0.62$; $p < 0.01$) in the MOSES group. A recent study using the D-S scale indicated as well that maladaptive coping patterns (e.g., "depressive coping") were correlated with depression and a poor psychosocial adaptation (26).

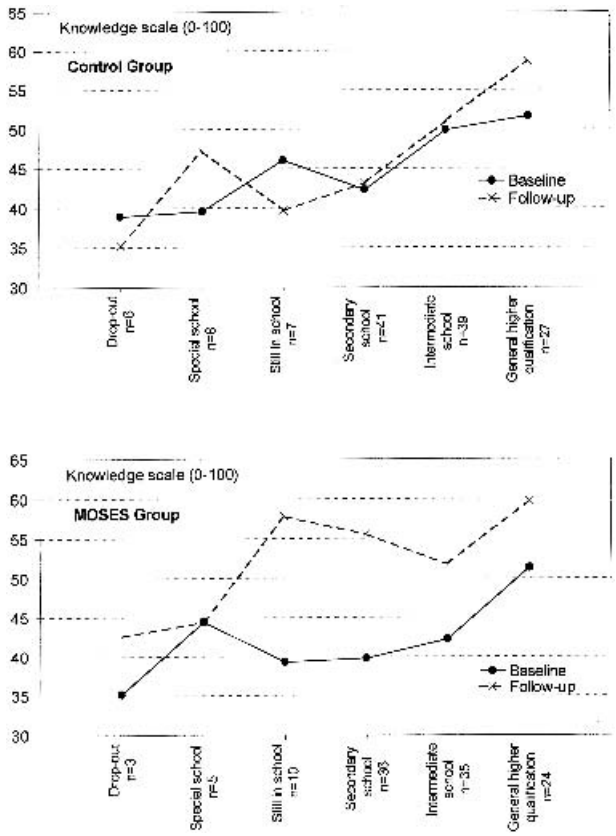

FIG. 4. The effect of MOSES on knowledge is dependent on the educational level.

Effects of MOSES on seizure frequency and contentedness with AED therapy

An aim of MOSES was that patients should better recognize seizures (also auras and simple focal seizures) and should accurately record their seizures. Thus we could not rule out that participants would record even more seizures than before because of a changed awareness or recording of seizures. Despite this, the participants of the educational program reported significantly fewer seizures compared with the control group. We assume that the MOSES program led to an improvement of compliance and to an adjustment of lifestyle. The SEE program (6) demonstrated that an educational program could improve compliance. However, it is a limitation of our study that compliance (e.g., serum concentrations of AEDs) was not assessed. The MOSES program emphasizes the recognition of precipitating factors and the use of seizures-control methods, which also might have led to a reduction of seizures.

We observed a better contentedness with therapy, especially better tolerability of AED therapy. An explanation might be that the patients learned to differentiate better between side effects of AEDs and unspecific complaints not related to AEDs. Perhaps the patients were encouraged to talk with their doctors about their side effects and got more information about side effects. Comparing the frequency of reported side effects, unspecific complaints (e.g., headache, tiredness) decreased more clearly than did specific side effects of AEDs (e.g., tremor, ataxia).

There were slightly more AED changes (of dose or kind of AED) during the past 6 months in the MOSES group compared with the control group (59.3 vs. 49.6%). However, neither in the MOSES group nor in the control group were AED changes significantly ($p > 0.1$) related to changes in seizure frequency and contentedness with therapy (efficacy and tolerability). Including the variable AED Changes as additional factor did not explain the

better outcome in respect to seizure frequency and side effects.

Evaluation of MOSES by the participants

In accordance with other studies (8–10,15), the majority of the participants in the educational program expressed their appreciation for the received information and reported an improvement in coping with their epilepsy (cf. Table 4). The evaluation of the FEP (5-day epilepsy program) by using a "one group posttest only design" indicated that these effects last even over several years (15).

Comparison with other studies

The Sepulveda Epilepsy Program SEE is a 2-day educational program for adult patients with epilepsy, which was evaluated in a similar controlled study design in outpatients (6). Yet the scales used in the SEE study are only partially comparable to ours. Helgeson et al. (6) reported improvements especially in fears of death and of brain damage, hazardous medical self-management practices, and a global reduction in misinformation and misconceptions. We observed an improvement in epilepsy-specific knowledge, too, but no significant reduction of fear of death and of brain damage caused by seizures. This might be explained by considerably lower baseline values in our study ["Are you afraid of dying during a seizure?" (yes, 14%); "Are you afraid that your seizures could damage the brain?" (yes, 32.8%)].

In accordance with the SEE program, which did not significantly improve emotional problems (e.g., depression, anxiety) and aspects of QOL, MOSES had no significant impact on comparable domains (depressive mood, SF-36). In contrast, the evaluation of a psychoeducational program among Nigerian adult patients with epilepsy stated a significant decrease in level of depression and measures of neurotic disorders (13). It is questionable whether the cultural background, the program, and the design (e.g., small samples, shorter follow-up period) were comparable.

Temporary results of an evaluation of a 2-day program for people with epilepsy and their partners in Dianalund Epilepsy Hospital (10) revealed that "the participants thought that their knowledge on epilepsy was better" and "felt that they had learnt something which helped them better to cope better with epilepsy in daily life." There was a tendency for improved social function (subscale of SF-36), whereas no significant changes in QOLIE-31 were observed.

Limitations of a 2-day educational program

Our data confirmed that depressive mood disorders are frequent in patients with epilepsy (25,26,36). Regarding severe emotional disturbances, it is not unexpected that a weekend seminar had only a limited effect, but an educational program could give hints about how and where patients with such problems can get support and professional help.

We agree with other authors (6,15) that organizing follow-up sessions and initiating local self-help groups might intensify the effects of an educational course, especially of a 2-day program. The number of participants in our study who had contact to a self-help group increased only slightly in the MOSES group from 15 (13.3%) to 17 (15.0%) and decreased in the waiting group from 27 (20.9%) to 24 (18.6%). Despite the relatively small numbers, the data indicated a tendency that contact with a self-help group at follow-up enhanced the effect of the educational program not only in Coping with Epilepsy, but also reduced more clearly Perceived Restrictions to Epilepsy and Depressive Mood. This is in accordance with a previous study that demonstrated that self-help groups are a "highly positive factor in rehabilitation, diminishing depression significantly regardless of their type of seizure and medications" (36).

For methodologic reasons, the training was performed as a 2-day seminar, but it may be favorable to spread the course over a longer time. This allows the participants to intensify the emotional confrontation with the epilepsy (e.g., with epilepsy-related fears). Patients could exchange their practical experience of the newly acquired knowledge with other participants. Parts of the program are developed for private study with feedback rounds afterward. Such feedback, the opportunity for practice, and the chance to express emotions are likely to enhance the efficacy of the program. We assume that the nonsignificant effects of the program on the epilepsy-specific scales were less a problem of sensitivity of these scales than of packing the total course into a weekend's time.

Temporary results of the study of the Dianalund Epilepsy Hospital (10) revealed that improvements were seen particularly in participants who had had epilepsy for <5 years. Comparing patients with a long and short duration of epilepsy (≤5 years vs. >5 years' duration of epilepsy), we could not confirm this observation. Nevertheless, it is reasonable to offer patients an educational program as soon as possible after the beginning of epilepsy.

CONCLUSION

The study clearly indicates the need for patient education. Many patients have deficits regarding their knowledge of epilepsy, psychosocial and emotional problems, and report restrictions due to their epilepsy.

The educational program MOSES is an effective component of comprehensive care, especially in improving knowledge and active coping with epilepsy. In some domains (e.g., epilepsy-related fears, restrictions in daily life due to epilepsy), an effect was not confirmed. These aspects, which are integral parts of MOSES, should be

more stressed by the trainers in the use of the program and its realization. It is noteworthy that in the MOSES group, the seizure frequency was reduced, even though most of the participants had had long-standing epilepsies and received specialized treatment before. The participants evaluated the educational program positively, not only in regard to an increase of knowledge, but in coping with epilepsy in daily life.

Educational programs such as MOSES should become a standard service in specialized epilepsy care. That the interventions are brief and inexpensive also should make them attractive to health economists.

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APPENDIX. *Epilepsy Knowledge Scale (Part I and II)*

Part	Questions	Yes	No	I do not know
I	People with epilepsy should avoid strenuous work because this can provoke seizures.	□	■	□
	An EEG can always prove the diagnosis of epilepsy.	□	■	□
	People with epilepsy are as capable as other people.	■	□	□
	All people with seizures should avoid working with open machinery.	□	■	□
	Every seizure destroys a number of nerve cells in the brain	□	■	□
	People with seizures should not swim without an accompanying person.	■	□	□
	All people with epilepsy should avoid flashing or strobing lights (e.g., disco lights, TV or computer screens).	□	■	□
	In most cases, doctors can control epileptic seizures with medication	■	□	□
	If your seizures are controlled for some months, you can reduce the dose of antiepileptic medication.	□	■	□
II	All people with epilepsy have similar symptoms.	□	■	□
	If a patient expects a seizure, he/she should take an additional dose of antiepileptic medication.	□	■	□
	On job application, a patient should always disclose his/her epilepsy condition.	□	■	□
	People with epilepsy can take an active part in sports.	■	□	□
	An epileptic seizure always results in loss of consciousness.	□	■	□
	People whose seizures only happen during sleep may hold a driver's license.	■	□	□
	Everyone can have a seizure, given the appropriate circumstances.	■	□	□
	Blood samples can be used to measure the concentration of antiepileptic medication in the body.	■	□	□
	Epilepsy is a symptom of mental illness.	□	■	□
	If persons with epilepsy drive, they must inform the driving authorities about their condition.	□	■	□

■ correct answer.