

MOSES: An Educational Program for Patients with Epilepsy and Their Relatives

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Summary: The knowledge of patients with epilepsy about their own condition is poor, and thus the need for educational programs for people with epilepsy has long been recognized. However, no such programs have been established in their routine care. The Modular Service Package Epilepsy (MOSES) now tries to fill this gap for patients in German-speaking countries. The program was developed by a multidisciplinary group (neurologists, nonmedical professional helpers, and representatives of national epilepsy associations) for people with epilepsy older than 16 years, independent of the kind and severity of their epilepsy. MOSES is designed for group education and can be used in inpatient and outpatient settings in epilepsy centers, in clinics, and by neurologists in private practice. The program aims to help patients achieve a better understanding of

their disease, to gain more self-confidence, and to take over responsibility, thus supporting patients to become experts in managing their own illness. Being modular in structure, MOSES includes nine units: living with epilepsy, epidemiology, basic knowledge, diagnostics, therapy, self-control, prognosis, psychosocial aspects, and network epilepsy. MOSES consists of a workout manual for patients and a trainer manual. For potential trainers, special “train-the-trainer seminars” are offered and considered mandatory. About 400 patients have participated in a MOSES training program in Germany, Switzerland, and Austria. The efficacy of the program is currently being evaluated. **Key Words:** Educational program—Epilepsy—Group education—Trainer manual—Workout manual.

No other illness since the beginning of medicine has absorbed doctors and their patients, medical science, and medical thinking of lay people, mythology, and superstition as much as epilepsy. For centuries, epilepsy has been a disorder with a very high degree of stigma and prejudice. Today, many people with epilepsy (PWE) have to face a number of limitations in their daily life. In an epidemiologic study in Germany, more than two thirds of 631 patients reported social restrictions caused by their epilepsy, concerning employment and education, sports and leisure, problems with their partner, contact with friends, and acceptance by others (1).

Within comprehensive therapeutic management of chronic diseases, educational programs for patients are considered to be extremely important. Such educational programs have two main aims: to increase the relevant knowledge about their own disorder, and to strengthen the responsibility of the patients for themselves, with the

consequence of living with as few limitations as possible. For chronic diseases such as diabetes or asthma, such programs have existed for many years. Although the importance of sufficient patient knowledge has been acknowledged by the Commission for the Control of Epilepsy and its Consequences (2), by patients’ organizations (3), and by the European Declaration on Epilepsy (4), efforts for patients with epilepsy have been limited (5–8).

Patient education is urgently needed (9–11), because the knowledge of PWE has shown to be poor regarding diagnosis (12), the purpose of antiepileptic medication (AEDs) and the possible side effects (13), and the causes and possible consequences of seizures (14). Dawkins et al. (15) found that patients with epilepsy knew no more than those without epilepsy about the disorder. Jain et al. (16), reporting on 493 patients attending hospital epilepsy clinics, found ~90% of the interviewed patients wanted to receive more information about epilepsy than had already been given to them. Jarvie et al. (17,18) demonstrated that patients with epilepsy tend to know more about the medical rather than social consequences of their condition, but even the knowledge about medical topics was limited. The social and vocational significance of such poor knowledge should not be underestimated, as only this specific knowledge can help the

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patients to minimize the social and vocational limitations enforced by their illness. Concerning medical therapy, its success is strongly related to the patient's medication compliance, and this can be enhanced by improving the patient's knowledge about his or her disorder (19).

Usually, clinical visits and the dialog between the physician and the patient, leaflets, brochures, and books for lay people seem to be the main sources of information for PWE. However, as shown earlier, these kinds of information obviously do not result in a sufficient knowledge about the management of epilepsy and its consequences in everyday life. Within a group session of a structured educational program, questions arising can be answered, and an exchange with the trainer and with other participants is possible. In a pilot project in Los Angeles, California, U.S.A., such a setting has proved effective in improving the overall understanding of epilepsy, reducing fear of seizures, and improving self-management practices and medication compliance (5). However, as far as we know, such programs have not been established in the routine care of PWE, such as in diabetes or asthma.

For the German-speaking countries the Modular Service Package Epilepsy (MOSES) now tries to fill this gap. It was developed by a multidisciplinary expert group to be able to offer structured, interactive, and modular training for PWE and their relatives.

DEVELOPING MOSES

MOSES was developed in four steps. The starting point was the establishment of a multidisciplinary advisory board of neurologists, neuropediatricians, non-medical professional helpers such as social workers, psychologists, medical sociologists, and representatives of the national epilepsy associations. This composition was in accordance with recommendations for developing patient-information materials in which an important demand is "to involve patients throughout the process," and "to involve a wide range of clinical experts" (20). The task of this advisory board was to define the educational aims of MOSES, and to design the basic structure of the program [i.e., to determine the main subjects to be dealt with in the program modules (21)] and the basic didactic concepts. After extended discussions, it was decided that the program should have nine modules, and that didactic materials for learning in small groups should be developed (i.e., a manual for group trainers and a workout manual for the participants). During this phase, and also during steps two and three, active support was given by a pharmacomarketing agency (Agency Dr. Schlegel, Switzerland) well experienced in the development of patient-education materials for other chronic diseases.

In a second step, an executive board, consisting of two epileptologists, a psychologist, a medical sociologist, and

a representative of the German self-help groups was formed from members of the advisory board. The task of this group was the didactic realization of the nine modules. This involved writing the basic information for each module of the workout manual in an easily understandable but nevertheless not too simplified manner, and designing situations for the group teaching process to be outlined in the trainer manual, which addressed not only the informational but also the emotional and attitudinal aspects of epilepsy. This required the development of visual materials with the support of the agency. There was continuous testing during this phase, with the members of the executive board teaching patients and giving them the drafts of the written materials for a first evaluation.

In a third step a pilot study was carried out with a preliminary version of MOSES in 199 patients from nine institutions: six hospital units for PWE, two outpatient clinics; and one private neurologic practice. Modules 1–4 were tested with 124 patients and Modules 5–9, with 75 patients. Between five and 10 patients took part in the teaching groups. All 17 trainers of the pilot study (physicians, nurses, psychologists, social workers, occupational therapists) participated in a train-the-trainer seminar.

Almost all of the patients invited to the pilot study took part. The patients' feedback was gathered by questionnaires. It seemed that the acceptance of the program by the participants and the trainers was excellent (22), although at this time, the final version of the program with colored graphs and pictures was not ready, with only black-and-white copies being available. The executive group met twice with the trainers to discuss shortcomings and possible modifications. There was some criticism from the trainer's perspective. Shortcomings during the test phase included more time needed than planned; the need for a glossary; some questions not close enough to the patient's situation; and unexpectedly strong emotional reactions in some sequences addressing illness-related emotions. However, there was no criticism of the basic structure of the program or the design of the nine modules. A large proportion of the patients thought it advantageous to have a trainer belonging to a nonmedical professional group. The trainers pointed out that the train-the-trainer seminars were very helpful for preparation and moderation of the MOSES learning groups. The result of this interchange was a reshaping of a number of details in both the workout manual and the trainer manual.

In a fourth step, currently ongoing, an evaluation study is being carried out in cooperation with the Gesellschaft für Epilepsieforschung (Society for Epilepsy Research) in Bielefeld; 300 patients will be taking part. It is a randomized, controlled study design, with a group of patients starting immediately with the educational program,

and a waiting group of patients being trained 6 months later. The aim of this evaluation study is to gauge the educational and pharmaco-economic effects of MOSES. The findings of this study are currently being prepared for publication.

AIMS OF MOSES

MOSES wants to support PWE to become experts in managing their own disease, thus trying to change attitudes and behavior, rather than solely imparting theoretical knowledge. For this reason, MOSES uses the different levels of perception: the cognitive level (imparting information), the emotional level (recognizing and discussing emotions), and the level of acting (talking about concrete activities). Compared with individual education or group training with traditional lectures, these different levels of perception can be reached more successfully by learning and training within a small group with the possibility of discussions and sharing personal experiences (6,7). The educational aims of MOSES for the patients and the didactic aims for the trainers are summarized in Tables 1 and 2, respectively.

STRUCTURE OF MOSES

Modules

MOSES, as its name suggests, has a modular structure with nine modules covering the following topics:

1. *Living with epilepsy* teaches patients to recognize and express emotions associated with the diagnosis of epilepsy, to understand that coping with epilepsy is sometimes a long-lasting process, and to enhance and improve their coping strategies.
2. *Epidemiology* contains information about the prevalence and age-related incidence of epilepsy. Some PWE, from the past and present, outstanding in arts or science, or leading an everyday life like the majority of people without epilepsy, are introduced.
3. *Basic knowledge* informs about the causes and pathophysiology of epilepsy as well as about different types of seizures.

TABLE 1. Educational aims of MOSES: for the patients

Educational aims	
1	To get to know and understand the disease and its consequences
2	To learn to cope with the disease
3	To understand the diagnostic and therapeutic measures and to take over an active part in the treatment process
4	To gain a better understanding of psychosocial problems and occupational aspects
5	To learn to become autonomous
6	To become the "ambassador of one's own disease"
7	To lead an everyday life with as few limitations as possible

TABLE 2. Didactic aims of MOSES: for the trainers

Didactic aims	
1	To promote the active training of the patients
2	To support empathical relation with other participants
3	To create an interesting and varied learning atmosphere

4. *Diagnostics* deals with important diagnostic tests [electroencephalography (EEG) and magnetic resonance imaging (MRI)] and explains their value in the diagnosis of epilepsy. The importance of an accurate observation and description of seizures, as well as the documentation of seizures and results of diagnostic tests by the patients is emphasized. Included are exercises for describing and documenting one's seizures.
5. *Therapy* discusses the major aspects of therapy, such as aims of therapy, the need for active cooperation, guidelines for pharmacotherapy, and an overview of AEDs. The need for active cooperation and ways to explain one's therapy to others are discussed. This is a very extensive module, so parts of its contents (e.g., details about all licensed AEDs) are not completely presented during the lesson, but should be worked through by the patient at home.
6. *Self-control* concentrates on all kinds of measures for self-control of seizures, such as recognition and avoidance of individual seizure-provoking factors, or active interruption of auras by using counter-measures.
7. *Prognosis* presents chances of entering remission, as well as chances and risks of discontinuation of AEDs after achieving seizure control. Possibilities and strategies in the case of continuing seizures also are discussed.
8. *Psychosocial aspects* is a very extensive module, so that again parts of it have to be worked through by the patient at home. It focuses on the consequences of epilepsy on quality of everyday life and vocational integration, on the improvement of self-esteem and social contacts, and on possibilities of support and rehabilitation.
9. *Network epilepsy* provides addresses and hints about where and how to find assistance, and information about self-help groups, legal regulations, and institutions. This module is not presented in a lesson.

As mentioned earlier, cognitive, emotional, and behavioral aims are included in all units, the different modules having different priorities (e.g., modules 3, 4, and 5 emphasizing the imparting of knowledge, and modules 1, 7, and 8 emphasizing emotional aspects).

Training materials

The training materials of MOSES consist of two parts: the workout manual (23) for patients and the trainer manual including teaching material. Within the workout manual for the patients, a separate booklet for each of the nine modules is provided. An additional booklet contains an introduction to the program, a glossary, and references. Each booklet of the workout manual has two purposes. First, it provides text and illustrations with full information about the topic being covered by that module. Second, it is for use by the patients during the lessons and thus tries to integrate them actively into the teaching process. For this purpose, there are pages with prestructured windows displaying the questions, thesis, or scales under discussion, where the patients may give their answers or express their opinions or write individual notes.

The trainer manual contains text and illustrations identical to those in the workout manual of the patients, including the small windows with the questions, thesis, etc., but with suggestions for answers. It thus serves as a basic textbook for the trainers. Besides this, it provides didactic tools, comments, and additional information for each lesson (24). The didactic tools include "mindmaps" as visual methods to organize the participants' answers, "scales" to gain a measure of the patients' opinions of the size of a problem, and "theses" as a tool to provoke reflections on a specific problem. Several transparencies contain prepared information on specific subjects, such as addresses of epilepsy institutions or examples of typical EEG abnormalities.

The workout manual (23) can be bought in bookshops, but not the trainer manual. It will be handed to each trainer participating in one of the train-the-trainer seminars. Besides these materials, during the MOSES sessions, therapeutic aids such as a tablet dispenser, an emergency card, a seizure calendar, and also the "Diary E(epilepsy)" (25) are demonstrated as tools to enable patients to cooperate reliably in the therapy and to document the course of their epilepsy.

USE OF MOSES

Contexts in which MOSES can be offered

MOSES was designed to be used in epilepsy centers, in epilepsy outpatient clinics, and by neurologists in private practice, having a focus on treating patients with epilepsy. It is possible that these fields of application will be extended in the future (for example, by using MOSES for training in self-help groups).

People with epilepsy who will gain from participating

MOSES was conceived for PWE who are older than 16 years, independent of the kind, severity, and duration of their epilepsy. Relatives also may take part. A partici-

pant should be able to follow in a concentrated way a teaching lesson of 90 min and to write notes. As training in small groups offers a lot of advantages (sharing experiences with other people, taking the other participants as models to learn from, motivating each other), MOSES is specifically developed for this learning situation. Ideally the number of group participants will be between seven and 10, maximum 12, with one or two trainers working interactively with the group.

Adaptation of modules to the heterogeneity of the learning group

The possible heterogeneity of such a group was considered when designing the educational program. The intensity of the teaching can be modified according to the composition, interests, and motivation of the group of patients to be trained. The group can include, for example, newly diagnosed patients as well as patients with a long-standing epilepsy, and patients with different levels of previous information and education. Some parts may be skipped over, others may be extended, and some well-informed patients may function as cotrainers. Thus, the participants in MOSES have the opportunity to share their experiences and to learn from each other. During the pilot study and up to now, as far as motivation of the patients and group interactions is concerned, it has proved effective to start with the module "living with epilepsy."

Because of the possibilities of different institutions and settings offering MOSES, different timetables for the program must be considered: for example, 2 h every Thursday evening for 8 weeks, or weekend courses, or two meetings per week for inpatients aiming to complete MOSES in 3–4 weeks.

For use in Switzerland and Austria, some amendments, especially to module 8 "psychosocial aspects," and module 9 "network epilepsy" had to be made to give correct information on legal aspects to the patients of these countries.

Recruitment of patients and trainers

It is of paramount importance to find motivated trainers who will take part in a train-the-trainer seminar to learn the interactive approach necessary for group work. To become a MOSES trainer, participation in one of these seminars is obligatory. There are often nurses, social workers, psychologists, occupational therapists, or EEG assistants who are interested in extending their field of activity to patient education. A trainer should have some experience in moderating for a group. For MOSES this would mean the ability to keep the balance between emotional/attitudinal learning and information uptake, to correct misconceptions at the appropriate moment, and to keep an eye on the group process to give every participant an opportunity for discussing his or her questions.

To recruit the patients to be trained, a publicity cam-

campaign for MOSES is necessary. Contacts with physicians who treat PWE to inform their patients, short advertisements in newspapers or special epilepsy journals, leaflets, posters, and so on are suitable. Here the institution that intends to offer the program will receive support from the MOSES secretariat, being linked with EUREPA, the European Epilepsy Academy.

FIRST EXPERIENCES WITH MOSES

Since autumn 1998 MOSES has been available for use in Germany, Switzerland, and Austria. The experience is based on the previously mentioned pilot study with 199 patients. As mentioned in this study, the acceptance of the program by the participants and the trainers was excellent (22). It could be demonstrated that MOSES is suitable not only for patients with normal cognitive abilities but also for those having some learning difficulties. Independent of the duration of their illness, all participants gained from the program. MOSES had many positive effects on the patients' involvement in the treatment process; for example, they asked more questions about their epilepsy at the doctor rounds, they continued to discuss various related topics among themselves, they made contact with self-help groups, and they asked for more written information concerning epilepsy.

There will be more systematic results on the effects of MOSES on the participants' behavior from the ongoing evaluation study.

PERSPECTIVES

MOSES is the first element of a comprehensive educational program package. In the near future, it is planned, with reference to the existing program, to develop an educational program for families having a child with epilepsy. Furthermore there are ongoing activities for a program "MOSES for kids."

Meanwhile there is an international interest concerning the MOSES program, for example, in England, Denmark, Netherlands, France, and Hungary. To use MOSES in other countries, it will be necessary to translate the program and to add (with the support of a national advisory board) country-specific amendments.

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