AN INTEGRATED APPROACH FOR THE NEUROLOGICAL AND PSYCHOLOGICAL SUPPORT OF PARKINSON PATIENTS

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1. INTRODUCTION

Although symptomatic therapy is available for Parkinson's disease, patients and relatives are faced with continuous severe psychological problems. These psychological problems include: 1. lack of emotional expression, 2. bradephrenia, 3. depression, 4. lack of motivation, 5. social anxiety, 6. stress induced increase of symptoms. The first four of these may be at least in part due to the dopamine deficiency. However, even as part of the primary symptoms they have social and communicative impact for patients and relatives.

Social anxiety and stress induced increase of symptoms on the other hand clearly result from an interaction of somatic and psychological factors. Social anxiety mainly develops in Parkinson's disease as an indirect consequence of the motor symptoms. Patients are afraid of being negatively evaluated in the public, of receiving negative comments etc. Thus, social withdrawal increases and the improvement of neurological symptoms following drug treatment may not be fully exploited on the psychosocial level.

Stress induced increase of motor symptoms is a commonly observed phenomenon in Parkinson's disease. Even minor stressors, mainly social in nature, can have extreme effects and may elicit or increase tremor or rigidity. A patient can be well in one moment, but unable to move in the next when being aware that he has to leave the house in an hour.

Given this situation, patients and relatives have to develop strategies for an emotional balance in the presence of a continuous confrontation with the direct and indirect consequences of the disease. A precondition for developing new psychologically based strategies is an optimum medical treatment.

The integrated approach for neurological and psychological support has the following goals: 1. improving medical treatment for the individual patient, 2. improving psychological coping

and psychosocial adaptation for patients and relatives, and 3. evaluating and improving medical and psychological therapy.

2. INSTITUTIONAL ENVIRONMENT

The integrated approach is built upon cooperation between neurologists, psychologists and the German Parkinson Association (lay organisation). A Neurological Outpatient Unit is provided by the Neurological Department of the University Hospital Großhadern, Ludwig-Maximilians-University Munich (Oertel, Gasser). A Psychological Outpatient Unit has been introduced at the Max-Planck-Institute for Psychiatry in Munich (Ellgring, Seiler, Perleth). The cooperation and the development of the programs has been supported by a grant of the Robert-Bosch-Foundation Stuttgart. The project started in 1988. An important link between patients and the neurological and psychological programs is provided by the lay group "German Parkinson Association" (dPV).

The cooperation between the two outpatient units and the lay group include: - conveyance of patients, - consultation for problematic cases, - integration of medical and psychological results, - conjoint information seminars for patients and professionals.

Neurological Parkinson Outpatient Unit: Tasks provided by the Neurological Outpatient Unit are: 1. checking diagnoses, 2. adjusting medication and 3. providing medical information about the disease on individual basis, in small groups and seminars.

At the specialized unit within the Neurology Department, more than 300 patients are seen per year, most of them several times. Diagnosis, pharmacological treatment and documentation of the clinical course are the main tasks of the unit. During the project, 452 patients have been studied. Coming into the clinic with the (assumed) diagnosis of Parkinson Syndrome. For 259 patients (= 57,2%) the diagnosis "Idiopathic Parkinson Syndrome" was astonished. Adjusting medication included individual counseling of patients and relatives. Medical information is provided by means of seminars for various groups of the medical professions as well as for patients and relatives.

Psychological Parkinson Outpatient Unit: The task of this unit was mainly to develop concepts and procedures for 1. individual counseling, 2. group seminars for psychological coping with the disease, and 3. providing information about relatives and professionals. The goals are - improvement of patients independence, - preventing unnecessary social withdrawal, - alleviate relatives' psychological stress resulting from the neurological and psychological symptoms of the patient. About 100 individuals participated in the offered activities of this unit. In the following, one of these activities, group seminars on stress management for patients, will be described in some detail.

3. GROUP SEMINARS

Patients: 52 Parkinson patients (35 female, 17 male, mean age = 67 years ranging from 48 to 82 years) took part in the

program. Disease lasted from 7,5 years on the average with severity ranging from 1 to 4 on the Hoehn & Yahr scale.

Procedure: Training sessions were conducted once a week for two hours over a period of five to eight weeks. Each session lasted for 120 minutes. A total of 7 seminars with 5 to 10 participants was held. During the first two of these seminars the concepts were tested. Results on the last 5 seminars including 34 patients (17 female, 17 male) are reported here.

Components of Psychological Intervention: During the seminars, the following topics were dealt with: 1. Behavioral analysis of problematic situations, 2. Training and application of relaxation, 3. Cognitive restructuring, 4. Stress management. Between seminar sessions, the components had to be practiced.

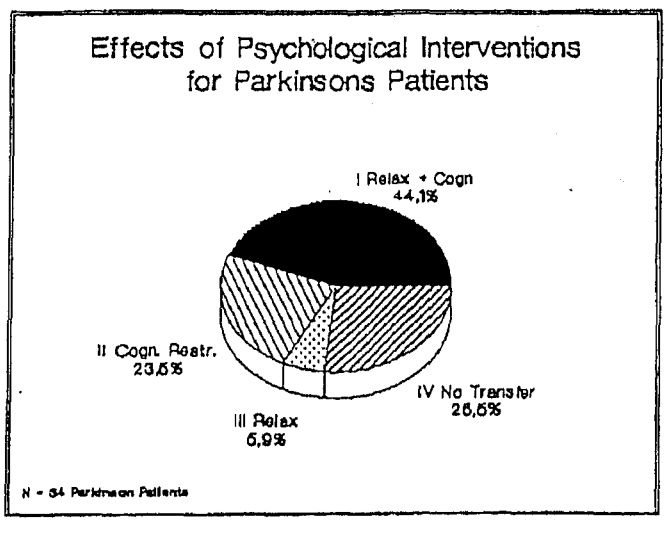
Evaluation of Seminars: The effects of the intervention were individually assessed by means of interviews 6 to 8 weeks after the seminars. Criteria were a) the application of relaxation in critical situations and b) the application of positive self instructions. The interviews served to evaluate whether effects had persisted and generalization had taken place.

4. RESULTS

All patients indicated at the end of the seminars as well as in the interviews one month later that the exchange with other patients during the seminar about their psychological situation was very important to them.

Drop out and Continuity: There were no drop outs during the seminars. Few patients were absent once or twice due to an infection. Because of a booked holiday, one patient could participate on three occasions only but insisted to participate nevertheless. 23 out of 34 patients indicated that they would like to have a further seminar. 15 of the patient keep continuous contact with the psychological outpatient facility.

Transfer of Techniques in Everyday Life: Relaxation technique and/or positive self instructions are used effectively by 25 out of 34 patients one month after the seminars (see Fig.1). The degree of success was determined as follows: Level I: The patient uses ralaxation and positive instruction for coping with problems in everyday life and/or coping with the disease. Level II: Successful usage of cognitive restructuring. Level III: Successful usage of relaxation for stress management. Level IV: Neither relaxation nor concept of positive cognitions can be used for daily problems or coping with the disease.



From those 15 patients who

effectively used relaxation and positive self instructions, 11 developed new strategies in coping with the disease. As an example, one patient tries to do things on his own, where before he always waited for help. He used situational analysis, experiments with his behavior thus adjusting his sense of self efficacy. He actively asks for help without anxiety in those situations where he regards it as necessary.

In contrast, only 1 out of the 9 patients who neither gained from relaxation nor from cognitive restructuring was able to expand his "psychological and behavioral domain". Nevertheless, for 4 patients out of these nine, the seminar was an important change out of daily routine.

5. CONCLUSION

Psychological intervention can provide considerable help for a substantial part of Parkinson patients. The main target is coping with stressful social situations. Relaxation and cognitive restructuring together with situational behavioral analysis and training of social skills specifically adapted to the disease are the main strategies.

Various problems remain open at the moment, like the maintenance of motivation which is especially critical for Parkinson patients.

Parkinson's disease is a neurological disease with a known pathological substrate and a therapy which is effective at least for several years on a symptomatic level. The symptoms are tightly connected with psychological emotional and cognitive processes. Moreover, patients and relatives have to cope with symptoms which strongly influence social interaction. And they have to cope together with this situation over a period of ten or twenty years. Thus not only for the patient but also for the health of the relatives, psychological aid is urgently needed. We suggest to integrate psychological approach into the neurological diagnosis and treatment.