



# Patients' perspective on current treatment options for Parkinson's Disease



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## ARTICLE INFO

### Keywords:

Parkinson's disease  
Patient perception  
Self-report  
Treatment pattern  
Satisfaction  
Efficacy  
Tolerability  
Survey

## ABSTRACT

To date, current data on the treatment situation of patients with Parkinson's disease (PD) are limited. Therefore cross sectional surveys in 4485 patients and in addition, in office based neurologists, were performed. Patients were questioned about their disease history and current treatment, as well as their therapy satisfaction.

The mean lag time between first diagnosis of PD and the first prescription of medication was in 68.9% of patients less than 3 months, in 15.6% between 3 and 6 months, in 7.1% 7 to 12 months, in 3.3% up to 2 years, and in 3.1% more than 2 years. Patient rated themselves in 9.7% to be in the initial course of PD, 44.3% in a progressed stage and 41.3% in an advanced stage. The success of therapy rated 4.9% as very good, 22.6% as good, 43.4% as satisfactory, 23.0% as unsatisfactory, and 2.1% as poor (4.1% no response).

Treatment success was dependent on motor symptoms in the view of 51.3% of patients, on non-motor symptoms in 6.5%, in 23.4% with cognitive ability, in 57.0% with quality of life and in 21.5% with impairment caused by medication. With respect to current therapy 41.8% of patients were affected by frequency of drug intake, 3.2% by type of administration, 12.3% by number of drugs, 27.7% by unsatisfactory efficacy, and 41.3% by side effects (several answers possible).

Overall, only 27.5% of patients rated their current PD medication as very good or a good, in contrast to the physicians (treatment success very good or good in 75.8%). Physicians named control of motor symptoms (89.7%) and quality of life (86.7%) as key criteria for successful therapy.

In summary, PD patients report deficits in drug treatment. There is a clear need for action with regard to the information transfer to patients (including the explanation of side effects or differentiation of symptoms of the PD) and possibly for a change of the medication schedules including other drugs or combination therapies.

## 1. Background

Parkinson's disease (PD) is one of the most common neurological diseases with a prevalence of approximately 1680 cases per 100,000 individuals [1]. The disease is age dependent causing a further increase of new cases in the next decades [2].

PD is defined by the presence of akinesia and rigidity or resting tremor, and also postural instability. A number of non-motor autonomic and psychiatric symptoms are detectable in all stages of the disease [3]. Even today, the early and correct diagnosis of the disease is not always achieved [4].

Numerous drugs have been approved for the treatment of PD. The most important medication continues to be L-dopa in combination with a decarboxylase inhibitor (benserazide or carbidopa) [5]. The second important approach is dopamine agonists, which are also the drugs of choice in younger patients in the early stage of disease. [6] Furthermore, the COMT inhibitors entacapone, opicapone, and tolcapone are

used in the presence of motor activity fluctuations, [7] the MAO-B inhibitors rasagiline and selegiline, the NMDA antagonists amantadine and bupidine, anticholinergics [8,9] and latterly safinamide [8,10,11].

Regarding different disease manifestations, differences in disease management [12], and the complex treatment options, which also include numerous combination options, it is difficult for patients with PD to compare drugs and to set preferences.

Therefore, the present surveys were initiated with the aim of obtaining a representative picture of the current treatment situation and treatment success for patients with PD in daily practice. The entire picture of drug treatment, not individual preparations, was to be assessed by means of patient self-reports. The patients survey was supplemented by a survey of office-based neurologists treating patients with PD.

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## 2. Methods

The present work was designed as a pair of cross-sectional surveys. Ethics approval was not necessary for this study type. Only anonymous data were analysed and the data protection guidelines were closely followed.

In collaboration with the Deutsche Parkinson Vereinigung e.V. (German Parkinson patient association), the author developed a patient questionnaire with 22 questions. These questions mainly concerned the duration and course of the disease, medical care, drug therapy, efficacy and disadvantages of the treatment.

It was submitted to office-based neurologists and other physicians in all regions of Germany. Patients were eligible for participation if they provided written confirmed consent. They received the questionnaires by the patient association by mail. The questionnaire was to be answered anonymously by the patients without the involvement of their doctors.

Physicians had to be office-based and not linked to a hospital. They were contacted by the patient organisation and asked to fill out a medical questionnaire with 23 questions. They did not assess individual patients, but the overall situation of all Parkinson's patients in their practice.

Patient and physician questionnaires are available in the online supplement.

Study analyses were purely descriptive, and no inferential statistics were performed.

## 3. Results

### 3.1. Patient questionnaire

Of the 4485 participating patients, 966 patients (21.5%) had a disease duration of up to 5 years, 1339 (29.9%) 5–10 years, 1576 (35.1%) 10–20 years and 550 (12.3%) over 20 years (no data: 1.2%).

The time between first-time occurrence of symptoms and the diagnosis was less than 3 months in 914 patients (20.4%), 3–6 months in 986 (22.0%), 6–12 months in 1004 (22.4%), 1–2 years in 796 (17.8%) and more than 2 years in 683 patients (15.2%, missing data: 2.3%).

The diagnosis was made by a neurologist in 3908 patients (87.1%), by a general practitioner in 616 (13.7%), and by an internist in 168 (3.8%) (others specialists: 200 patients, 4.5%).

The period between the diagnosis of the PD and the initial prescription of PD drugs was less than 3 months in 3088 (68.9%) of patients, 3–6 months in 701 (15.6%), 6–12 months in 317 (7.1%), 1–2 years in 149 (3.3%) and more than 2 years in 138 patients (3.1%, no data: 2.1%).

A total of 433 patients (9.7%) were in the initial stage of the disease, 1986 (44.3%) in the intermediate stage and 1850 (41.3%) in the advanced stage (no data: 4.8%).

In 4323 patients (96.4%), the first PD drug had been prescribed by a neurologist, by a general practitioner in 140 patients (3.2%), and by an internist in 41 patients (0.9%) (other: 1.0%).

At the time of survey participation, 4344 patients (96.9%) saw a neurologist, 380 (8.5%) a general practitioner, 70 (1.6%) an internist and 50 (1.1%) a general physician (other: 0.9%).

268 patients (6.0%) were cared for by a specially trained Parkinson nurse/assistant (no data: 2.8%).

The quality and efficacy of the available PD drugs were assessed to be very good by 206 (4.6%) of the patients, as good by 1287 (28.7%), as satisfactory by 1450 (32.3%), as not satisfactory by 707 (15.8%) and as poor by 646 (14.4%) (no data in 4.2%) (Fig. 1).

Initially, 2403 (53.6%) of the patients used only one PD drug (monotherapy) (missing data at 4.3%). This was L-dopa in 1741 patients (38.8%) and another, unspecified drug in 2398 (53.5%, no data in 7.7%).

A change to combination therapy occurred in 615 patients (13.7%) within one year, 942 (21.0%) after 1–3 years, 291 (6.5%) after 3 to 5 years, 5–10 years at 114 (2.5%) and more than 10 years at 44 (1.0%) (not applicable in 8.9%) (Fig. 2).

L-dopa was prescribed as monotherapy in 402 patients (8.9%), 1430 (31.9%) with another drug, and 2217 (49.4%) with several other medications (no response 9.7%). The above-mentioned combination partners for L-dopa are shown in Fig. 3. Dopamine agonists were mentioned in 1824 patients (40.7%), followed by amantadine in 1291 patients (28.8%), approximately equal to entacapone, rasagiline and selegiline (13 and 14% respectively). 2696 patients reported stable L-dopa therapy (60.1%, 15.7% not reported).

Treatment success for PD was rated as very good by 218 patients (4.9%), as good by 1012 (22.6%), as satisfactory by 1947 (43.4%), as not satisfactory by 1031 (23.0%), and as poor by 93 (2.1%) (4.1% not stated) (Fig. 4). Success of therapy was associated by 2302 patients (51.3%) with drug effect on motor symptoms, by 290 (6.5%) on non-motor symptoms, by 1050 (23.4%) on the perceptive capacity, by 2555 patients (57.0%) on quality of life and by 963 (21.5%) on medication impairment (Fig. 5).

2986 patients (66.6%) reported impairment of their mobility (no data at 4.8%). 1652 of the affected patients (36.8%) indicated that the treating physician had therefore considered a change of therapy.

Regarding the current therapy, 1875 patients (41.8%) felt impaired by the frequency of use, 145 (3.2%) by type of application, 553 (12.3%) by multiple medication, 1243 (27.7%) by insufficient efficacy and 1852 (41.3%) by side effects (Fig. 6).

### 3.2. Physician questionnaire

A total of 271 doctors participated in the physician survey. On average, they saw  $143 \pm 212$  PD patients per quarter. A PD assistant was available in 14.8% and a PD nurse in 9.6% of the offices. 61.3% of physicians stated that they considered the available treatment options for the care of their patients in the early phase adequate, compared to 25.1% in the late phase of the disease. Therapy was started as monotherapy in 75.0% of the patients (L-dopa at 42.9%), and after 1 to 4 years by further medication completed. Dopamine agonists (94.8%), entacapone (77.1%), rasagiline (70.9%) and amantadine (51.3%) were mentioned as preferred combination partners.

Physicians reported wearing off and/or fluctuations in 32.6% of the patients, and in slightly more than half of the affected patients they considered for this reason a change of therapy.

Physicians described numerous symptoms of PD as “not satisfactorily treatable” (80.8%), in particular tremor (73.8%), freezing (61.3%), neuropsychiatric disorders (54.2%), gastrointestinal disorders (55.0%) and cardiovascular disorders (49.8%).

Regarding the treatment success of PD therapy (from physician's view), in particular motoric symptoms (89.7%) and quality of life (86.7%) were noted as key factors. The treatment outcome was classified as predominantly very good (18.8%), predominantly good (56.8%) or predominantly satisfactory (21.8%). Patients with PD were mainly affected by adverse reactions (61.3%), the frequency of drug intake (57.6%), insufficient efficacy (38.8%) and multiple medications (38.0%). The type of application did not play a significant role (3.7%).

## 4. Discussion

The present results of detailed surveys of patients and neurologists provide a comprehensive picture of the treatment modalities and the treatment satisfaction of patients with PD who were treated predominantly by neurologists.

Surveys are an important tool for assessing the experiences, attitudes, and attitudes of sufferers to their PD [12–16]. In a US study, patients were highly satisfied, especially when treated by neurologists who specialized in PD. [14] However, patients' self-reports are usually

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