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The Parkinson's Story of a Neurologist with 32 Years of Experience on Parkinson's Disease

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ABSTRACT

As a neurologist who has followed up countless Parkinson's patients over the last 32 years of my fifty-year career; I denied diagnosing myself with Parkinson's disease (PD), although the seldom mild involuntary "twitches" that occurred in the thumb of my right hand over a two-year period, resembled Parkinson's disease tremor. However, when these involuntary contractions became persistent; considering its similarity to characteristic resting tremor in typical PD, the positive effect of dopaminergic medications, the development of levodopa-induced dyskinesias and other non-motor symptoms, it was clear that the PD diagnosis was accurate. This situation naturally caused me anxiety, and for a year and a half, I kept my diagnosis hidden from everyone except a few close relatives. However, with the encouragement of a psychiatrist friend, when I was able to share my condition with my loved ones, I felt a relative reduction in the burden I was carrying and consequently experienced emotional relief. I am still able to carry out my daily activities independently with a rather low dose of medication, and my PD symptoms do not attract noticeable attention.

Keywords: Dopaminergic drugs, dyskinesia, motor symptoms, non-motor symptoms, Parkinson's disease, tremor

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INTRODUCTION

As an experienced neurologist specialized in Parkinson's disease (PD) and other movement disorders, I diagnosed my own Parkinson's disease, which started with very mild symptoms. I have chosen to document my observations and experiences during this journey, providing insights from both a patient's and a specialist's perspective.

Through this review article, I aimed to provide a concise account of my educational background, my professional involvement in the field of Parkinson's disease, the initial symptoms and progression of the disease that I experienced personally, the motor and non-motor symptoms associated with the disease; as well as the psychological impact of the disease during the stages of recognition, acceptance, and internalization.

Education and Professional Life

I completed my medical education at Istanbul Faculty of Medicine, Istanbul University. I performed my assistantship at Department of Neurology, Cerrahpaşa Faculty of Medicine, Istanbul University. In 1989, Prof. Dr. Hayrünnisa Denktaş encouraged us to work on subgroups of neurological diseases because of the large number of faculty members in our clinic. I was an associate professor at the time, and together with Güneş Kiziltan MD, who was a specialist, we established the "Parkinson's Disease and Movement Disorders Group" and started seeing patients in a private outpatient clinic. In the following years, we founded the "Parkinson's Disease Association" in Cerrahpaşa. The association was comprised of expert neurologists, as well as individuals diagnosed with Parkinson's disease and their family members. Gradually, the number of young faculty members within our PD group has grown in our clinic. During our regular meetings, conducted several times each year, we collaborated with neurologists and physiotherapists from the Istanbul Faculty of Medicine, Istanbul University to deliver current medical knowledge about Parkinson's disease to patients and their family members. Additionally, we had developed an informative handbook and pamphlets for our patients. We have regularly revised the handbook and released five editions within a few years. Furthermore, our biannual scientific journal, "Parkinson's Disease and Movement Disorders", which has been published since 1998, featured scientific research conducted by our colleagues on PD and other movement disorders. Also, I have collaborated with my colleagues and the assistants we supervised during in-clinic rotations, on numerous scientific publications in peer-reviewed journals, both Turkish and international.

Highlights

- **In PD, the initial motor symptom may be an intermittent 2–3-beat tremor in one finger.**
- **It may not be possible to make a diagnosis in the early stages of PD that start insidiously.**
- **In PD, non-motor symptoms may appear years before motor symptoms.**
- **Patients diagnosed with PD experience significant anxiety in the early stages.**

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In 1991, I was employed at the Mayo Clinic in Minnesota, Rochester in the USA for six months. During this time, I collaborated with respected neurologists who specialized in movement disorders and dementia. We organized two symposia on PD and movement disorders in 1993 and 1997 and invited the faculty members I worked with at Mayo Clinic to Istanbul.

In the subsequent years, we formed the "Parkinson's Disease Study Group (PDSG)" with the participation of our friends interested in the subject in different cities and started to perform presentations at neurology congresses. We often attended international meetings on movement disorders. Today, under the umbrella of PDSG, the number of members has significantly grown with the active involvement of several neurologists practicing in different cities.

I voluntarily retired from Department of Neurology, Cerrahpaşa Faculty of Medicine, Istanbul University on November 1, 2010, and started working part-time at a private medical center. Three years later, I moved to a more institutional medical center and worked for another eight years. Likewise, I often saw Parkinson's patients and occasionally those with movement disorders. During my last year and a half at this institution, I had diagnosed myself with Parkinson's disease and was taking medication, but I never told my colleagues there about my illness. Upon realizing that my handwriting was deteriorating and I was having difficulty filling out patient files even though I was taking my medication regularly, I decided to quit my job on March 1, 2022. The plaque that I received from the Istanbul Medical Chamber on March 14, 2022, commemorating my 50th year of practice as a neurologist, including my residency and faculty membership, confirmed a half-century of professional experience.

Diagnosis and Course of My Parkinson's Disease

Within this section, I will try to provide a comprehensive and sequential account of the progression of my Parkinson's illness. Therefore, it would be appropriate to state that my date of birth is February 5, 1948 which means I am 75 years old. First of all, I would like to briefly talk about my medical background, family history, and the medications I use. I had a caesarean section (06/1986) and two meniscus operations on my left knee (2009 and 2011). I have been taking levothyroxine tab. 75 mg 1×1 for hypothyroidism (Hashimoto's) for about 25 years and metformin tab. 1000 mg 2×1 for type II diabetes since 2012.

There was no history of Parkinson's disease among my parents nor close relatives, and there was no consanguinity between my parents. My mother died of myocardial infarction at the age of 65, and my father died of lung cancer at the age of 92. I lost my brother, who had Hashimoto's disease and type II diabetes, at the age of 67 due to a cerebral ischemic stroke.

Age 70–72: I had tremor-like involuntary contractions of 2–3 beats in the thumb of my right hand about 10 times a year, and although I suspected that some of them might be PD, I naturally hesitated to diagnose myself, since the contractions were not continuous. It was convenient for me to assume that I might have overworked my finger and that they were not tremors.

Age 70: A plastic surgeon friend I met by chance told me that the lower right part of my mouth had shifted downward. I did not dwell on it at the time, but when I looked at my photographs taken at that time, after the diagnosis, I noticed the presence of mild right hemihypomimia, common in patients with the right-sided onset of Parkinson's disease (1) (Figure 1).

Age 71: I was experiencing pain in the anterior femoral area of my right leg during long walks, and I could not understand why.

Figure 1. A minor right hemihypomimia is visible in my photo.

Age 72 (07/2020): One day I was wading into a slightly wavy sea from the shore and fell when the sea level was still between my ankle and my knee, but I was able to get up immediately unassisted. At the time, I could not see the reason for this fall. It was also around that time that I noticed that I was bending forward a lot when I was walking at home and that my slight hunchback, which had been there since childhood, had increased, but I did not know why.

Age 72 (11/2020): One day, when I started to have constant resting tremors in the thumb of my right hand, I realized the diagnosis was PD. The tremor was in the form of flexion and extension of the finger, and its frequency was 4–6 Hz, consistent with PD. As a matter of fact, the diagnosis of PD is often made on the basis of clinical symptoms and is known to start with tremor in approximately 70% of patients (2–5). A few days later, I also had a resting tremor of about 10 beats in the index finger of my left hand, but it did not recur. Thus, I realized that my disease was in Hoehn-Yahr Stage 2 (6). Throughout that two-year period when intermittent-short tremors appeared in my finger and I could not make a diagnosis, I concluded that the disease was in Hoehn-Yahr Stage 1. Based on clinical experience, I had often observed that many patients do not consult a physician at the onset of a tremor in one finger but are diagnosed when the disease progresses and the symptoms become more pronounced. As an expert on the subject, I was able to diagnose the symptoms before they progressed further.

When I discussed my diagnosis of Parkinson's disease with Prof. Dr. Bülent Elibol from our PDSG group by phone, he recommended that I take domperidone tab. 2×1 for one week along with piribedil tab. 50 mg 2×1/2. The tremor completely disappeared with medications. However, I stopped domperidone, which is not recommended for long-term use due to possible cardiac side effects, and after a week, I had to stop taking piribedil because of excessive vomiting. I could not tolerate the drug, probably due to my chronic gastritis. Piribedil is a drug that we often recommend to our patients, especially those with tremors, but I have observed that some of my patients cannot tolerate it because of its gastric side effects.

Along with the tremor, I also developed hypersalivation, which bothered me a lot. We used to offer our patients a spray containing ipratropium bromide, an asthma medication that we used to take advantage of the dry mouth side effect, but it did not work for me.

In the treatment of PD, the patient's age is taken into consideration when choosing the medication. In the early stages prior to approximately 60–65 years of age, dopamine agonists such as piribedil in two to three daily doses, long-acting pramipexole in a single dose, or monoaminooxidase-B inhibitors such as rasagiline in a single dose are recommended. In older individuals and in patients of any age at the advanced stage of the disease, levodopa, the most potent medication in terms of symptomatic relief, is administered. However, I preferred adjuvant medicines due to the mild nature of my symptoms and their ease of use. I did the following treatment trials without consulting anyone, based on my own decision. When I took rasagiline tab. 1×1 alone, the tremor disappeared, but because I used mirtazapine tab. 45 mg for insomnia, I developed serotonin syndrome, and my blood pressure increased to 170/100 mm. Hg, therefore I stopped the drug again. I did not take mirtazapine for the next 10 days, and my blood pressure returned to normal. Subsequently, when I started using pramipexole tab. ER 0.375 mg 1×1 and increased it to 0.750 mg 1×1 after a week, it was again very effective on tremor, but I had to stop the drug after 20 days when I was constantly dizzy even though my blood pressure was normal. After all these trials, which lasted 1.5 months from the onset of the tremor, levodopa remained as the only suitable medication for my age. When I started levodopa/benserazide tab. 100/25 mg 4×1/2, the tremor disappeared again. In fact, Levodopa is a bit troublesome to use. This is due to the fact that after taking the medication, you should wait for a minimum of 45 minutes before eating; and if a protein-rich meal has been consumed, you should wait for at least 2 hours. If these guidelines are not followed, levodopa, an amino acid, competes with the amino acids derived from protein-containing foods when crossing to the brain, resulting in a minimal amount of levodopa reaching the brain. This may also impair the absorption of levodopa from the gastrointestinal system. Additionally, it is recommended to take 4 doses at intervals of 4–5 hours throughout the day at the beginning of treatment. According to today's medical knowledge, I am obliged to use levodopa for the rest of my life. I would like to emphasize that due to the above-mentioned characteristics, I have to wake up at 9:00 a. m. every morning to take the medication, and my social life is also partially negatively affected. On the other hand, it was pleasing that the pain in the front part of my right leg, which appeared while walking, was relieved with the treatment.

I was only able to explain the diagnosis to my daughter about 20 days later, "so as not to upset her." She was very surprised and, of course, very upset that I had this disease, as I was a physician who had practiced PD for many years. Around that time, I also shared the diagnosis with my dear psychiatrist friend, Prof. Dr. Şahika Yüksel, whom I have known since my high school years.

During that period, I also developed arterial hypertension and was taking irbesartan/hydrochlorothiazide tab. 150/12.5 mg 1×1. Similarly, I was taking rosuvastatin tab. 5 mg 1×1 for high cholesterol and triglycerides. Brain MRI revealed a small number of subcortical small ischemic gliotic foci, and brain MR-angiography revealed an asymptomatic aneurysm with a diameter of 3–4 mm in the right ophthalmic artery. I also underwent a hysterectomy in January 2022 with the diagnosis of uterine cancer (gastric type) due to a very small bleeding mass detected during a routine annual check-up. The physicians decided at the council meeting that there was no need for chemotherapy or radiotherapy.

Late age 74 (12/2022): The few friends who knew about my illness and my daughter advised me to follow up with another experienced physician. So, I went to see Prof. Dr. Haşmet Hanağasi from our PDSG group. He saw mild bradykinesia on my right side and a slight decrease in associated movements on the right arm while walking. He said there was no rigidity and found my balance normal. When I considered my doctor's examination and my own assessment together, I found the total score of the motor section of the Unified Parkinson's Disease Rating Scale (UPDRS) to be 14 (7,8). He slightly increased the dose of levodopa/benserazide tab. 100/25 mg to 3/4, 1/2, 1/2, 3/4, still four times a day. For hypersalivation, he suggested timolol maleate eye drops applied on the tongue, which can be effective in most patients, but unfortunately, it had no effect on me. Dr. Haşmet Hanağasi stated that my condition was generally good and that it would be advisable for me to go for a follow-up examination every 6 months.

Age 75 (05/2023): I was doing quite well with the treatment. However, involuntary flexor contractions similar to dystonia started in the second and third toes of my right foot, particularly persistent in the afternoons and evenings. I considered these contractions as levodopa-induced dyskinesia as the neurodegenerative process progressed in the disease (9), and I started amantadine tab. 100 mg 1×1/2 at noon, and when I increased it to 1×1 after one month, these contractions significantly decreased.

My routine blood test in June 2023 was normal, except for a slightly high fasting blood sugar level of 115 mg/dL. My semi-annual abdominal US and smear examinations (07/2023), as well as mammography and breast US (10/2023) were all normal.

Non-Motor Symptoms

It is known that Parkinson's patients may have many non-motor symptoms in addition to motor symptoms (4,10). However, without motor symptoms, clinical diagnosis of the disease is unlikely in patients with only these problems. Upon confirmation of the diagnosis of PD, I thought that my insomnia, which had been ongoing for 20 years, might be a presymptomatic, non-motor manifestation of the disease. This is due to the fact that, according to recent studies, it is accepted that the presymptomatic phase of the disease, which leads to motor symptoms, may be as long as 20 years (11,12). Additionally, it has been found that there is up to a 50% loss of hypocretin neurons in the brain in patients with insomnia (13). The symptoms that I personally noticed in myself, but only recognized that they were non-motor signs of the disease after making the diagnosis of PD, are as follows:

1. **Insomnia:** Difficulty in falling asleep started when I was 50. When some of the sleep medications I tried were ineffective, I used alprazolam tab. 0.5 mg 1×1 until I was 70 years old. In the following years, when the effect of alprazolam was insufficient, I added mirtazapine tab. 45 mg and melatonin tab. 5 mg. Since last year, I have needed to increase the dose of alprazolam tab. to 1 mg and sometimes 1.5 mg. In October 2023, a colleague suggested that I stop consuming cola after 2:00 pm. My sleep improved considerably after this suggestion, when I used the previous medications as half tablets without melatonin. I also tried zopiclone tab. 7.5 mg, which is recommended as being effective on its own. Unfortunately, I could only use it for three days due to severe nausea and hypertension, despite its positive impact on my insomnia.
2. **Excessive sweating:** It appeared at the age of 70, before my diagnosis of PD, and still persists. I slept under a sheet during winter and used the heater on very low, for reasons I could not understand at the time.
3. **Pain:** As I mentioned earlier, about a year before the diagnosis, I had pain in the anterior femur area of my right leg while walking.
4. **Constipation:** This was a problem that occurred intermittently for about 12 years prior to diagnosis. Since it has been continuous for the past two years, I have to take one spoon of lactulose syrup every few days.

Psychological Effects of the Illness

I have attempted to describe the development of my Parkinson's disease in detail above. I suspected PD five years ago when I had intermittent involuntary movements in the thumb of my right hand but refused to accept it. When I developed persistent resting tremor at the end of two years, coupled with an increase in my forward-leaning posture a few months before the tremor and other non-motor symptoms, I concluded that I had clinically definite PD and started treatment with the support of a neurologist friend. This whole process naturally caused me a lot of anxiety and stress, and I did not want to accept the diagnosis. I would like to emphasize that when patients, especially those at an early age, are diagnosed with PD, they develop extreme anxiety, which is justifiable and I have come to understand better after going through this process.

My psychiatrist friend Şahika Yüksel stated in a professional manner that my anxiety might be high in the early stages but would relatively decrease over time. I was really worried because I was well aware of the course of Parkinson's disease, a progressive neurodegenerative disease, and what to expect in the future. I avoided sharing my illness with my acquaintances at that time for some reason and continued to work for another year and a half at the private medical center where I worked two days a week, with my diagnosis that I "kept secret as if it were a contagious disease" because I had no noticeable symptoms with the medication I was taking. I find it difficult to explain my effort to hide the diagnosis at the time; perhaps I did not want to arouse pity or attract the attention of others.

Şahika Yüksel supported me to open up, emphasizing that it was wrong to hide my diagnosis from everyone and it could be shared with others like many other illnesses. So, a year and a half after the diagnosis, I began the process of occasionally revealing to my relatives that I had Parkinson's disease. Indeed, as I shared the diagnosis with others, I felt as if the burden was lifted off my back. Şahika, a few other friends who knew about my illness, and my daughter kept emphasizing that it would be more objective and comforting if I stopped being my own doctor and followed up by a PD specialist. I realized that by actually sharing the responsibility and entrusting myself to an experienced professional, my anxiety was significantly reduced.

Consequently, I came to the conclusion that I had to accept the onset of motor symptoms at the age of 70, being aware that Parkinson's disease is seen in approximately 1% of individuals over 65. It was also a relative consolation for me that my disease was not one of the "Parkinson plus" syndromes with a rapid progressive course that renders patients disabled in a short period of time.

Current Status

Based on the symptoms I have described in detail above, my disease is clinically compatible with the diagnosis of Parkinson's disease responsive to dopaminergic drugs. While there is currently no medication that slows down the progression of the disease, there are medications that provide symptomatic relief. I would like to emphasize that the relatively low dose of levodopa has been helpful.

I am still independent in my daily life and often take long walks. However, while I agree with recent scientific observations that confirm exercise slows the progression of the disease (14), I must admit that I have neglected to exercise regularly. Sometimes, especially when holding a heavy object, I get a slight tremor in both hands. I have been a bit slow getting up from low seats and getting out of the car in recent months, but I do not require assistance. I find it difficult to open my knees after sitting for a long time, so I often get up and walk to overcome this problem. I have also been observing lately that I sit a bit slumped (en bloc), especially in low seats. Although my right foot got stumbled on the carpet a few times at home, I kept my balance and never fell.

In Parkinson's disease, the partial decrease in serotonin and noradrenaline in the brain can lead to the emergence of depression in many patients. I speculate that my lack of depressive mood may be related to the antidepressant effect of the mirtazapine I use for insomnia.

It has been stressed in extensive controlled studies conducted in recent years that the presence of type II diabetes in patients with PD may be a "prodromal" risk factor in the development of the disease (15,16). Similarly, in a controlled study with numerous PD patients, it was found that hypothyroidism and long-term use of levothyroxine could also be a risk (17), and the prevalence of PD was found to be high in patients with hyperthyroidism (18) as well as hypothyroidism. The fact that I also have diabetes and hypothyroidism, as I mentioned earlier, can perhaps be considered in this respect.

Drugs used for hypersalivation in the form of locally acting drops did not help me. However, I would also like to point out that even without using them, my issue shows an increasing and decreasing course over a period of several months. Due to this situation, I try not to sleep on my back, as I think it might be risky.

The impact of my illness on my social life is also quite evident. I consistently need to keep track of my medication times during the day and organize my daily life according to the intervals in which I can eat. Therefore, my entire social life, appointments, and meetings are shaped according to my medication schedule. Furthermore, I avoid attending events that require sitting for long periods of time, such as movies, theaters, concerts, and long journeys, since I have difficulty getting up after prolonged sitting. Unfortunately, entering the sea from the shore is no longer in my vacation plans due to the risk of losing my balance. I also tend to avoid situations that can cause balance problems in general.

Acknowledgment: After the diagnosis, I have observed that the sincere and affectionate behavior of my daughter, Asli Aykanat, and my son-in-law, Emre Aykanat, towards me has increased even more and they have been making every effort to assist me in every possible way. I am also grateful to both of them for their help in the preparation of this article. Additionally, the professional support of my dear psychiatrist friend Şahika Yüksel, whom I have known since our high school years, was crucial and invaluable, particularly in overcoming my anxieties during the diagnosis process. I would like to express my endless gratitude to her as well.

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