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“If I had Parkinson’s”

Introduction

For a young, healthy individual, life with Parkinson’s is hard to imagine. However, 1 in 500 people in the UK face the challenges of this neurodegenerative disorder every day, and that figure is expected to double by 2030. Parkinson’s is pathologically characterised by degeneration of dopaminergic neurones in the pars compacta of the Substantia Nigra of the midbrain, causing a deficiency of the neurotransmitter dopamine. This deficiency manifests clinically as the cardinal symptoms bradykinesia, resting tremor, lead pipe rigidity, and postural instability. Behind these symptoms, individuals face drastic changes in their physical, social and psychological functioning. Although currently incurable, Parkinson’s symptoms can be palliated. Understanding patients’ experience of the disease and its complications is therefore necessary to develop an individualised, holistic and successful strategy. I have tried to identify several milestones on the journey through Parkinson’s which I imagine to be particularly difficult: coming to terms with the diagnosis, a fear of mobility restrictions, the development of incontinence, and planning for the end of life.

“Do I really have Parkinson’s?” Diagnostic Challenges

Parkinson’s causes stress and disruption before patients even know they have it. A history of slow onset tremor, stiffness, and difficulty in starting movements, usually more prominent on one side, should prompt urgent referral. However, the onset of Parkinson’s disease is often insidious with general, nonspecific symptoms. A case cohort study published in the Lancet\(^1\) highlights how, in the years before diagnosis, patients who develop Parkinson’s disease have a higher incidence of non-specific symptoms such as constipation, late-onset depression, anxiety, dizziness, and fatigue compared to healthy controls. It is not uncommon for these to be falsely blamed on age or co-morbidities such as arthritis. Patients therefore often experience 2-3 years with worsening unexplained symptoms, and the anxiety and fear that comes with them.

Even once a clinician settles on Parkinson’s as a likely diagnosis, there is still a great deal of uncertainty for patients except those with the most clear-cut symptomatology. There are no biomarkers, EEG patterns, or functional brain imaging which give a definite diagnosis: the most accurate assessment is made by a neurologist specialised in movement disorders, who refers to the UK Parkinson’s Disease Society Brain Bank Criteria.

If I were told I had Parkinson’s disease, I believe I would struggle to come to terms with the diagnosis. The lack of a definite, objective test would leave too much hope for a different, better
diagnosis, preventing the start of an acceptance process. After years of GP consultations feeling unwell I would want to know if something more could have been done to reach a diagnosis earlier. Most importantly, I would be terrified of progressively losing control over my body and mind. I think Parkinson’s sufferers will always feel this sense of powerlessness, but it can be partially overcome by receiving the right information about the disease.

“Will I end up like those people in the waiting room?”

Parkinson’s motor symptoms eventually become advanced enough to cause severe disability. Impaired dexterity and tremor mean routine tasks like making a cup of tea may become difficult. Rising from chairs or walking short distances can become impossible as patients experience longer periods of being ‘off.’ Postural instability can lead to falls, impacting confidence and independence. The number of patients who have recurrent falls with Parkinson’s isn’t clear, but it has been reported to be as ‘low’ as 18% or as high as 65%. Regardless of how common it is, falls are usually traumatic and violent: the postural instability component of Parkinson’s causes patients to lose balance and their bradykinesia prevents them from adequately protecting themselves as they fall, as one patient describes:

- “In the eighteen months from the time I was diagnosed, I had four or five falls, always landing on my face because of my inability to put out my arms to save myself. So I loosened teeth, my lip had to be stitched, and I had a couple of black eyes.” [Diana]

However, the most pervasive harm caused by a fall is not the immediate trauma, but the fear of falling (FoF) again. FoF in Parkinson’s is more likely in those who have had a previous fall and it is linked to poor quality of life, reduced mobility and social activity, and psychological distress. It is also more likely that those who have a FoF will fall again. The reasons for these links are likely to be complex, but what appears clear is that falls in Parkinson’s are one of the main causes of loss of independence. Even if patients can overcome FoF to the extent that it does not impact their quality of life, many will find it difficult to come to terms with the way others perceive their symptoms. Patients can feel too embarrassed by their symptoms to socialise or be seen in public because of assumptions that are made when someone is seen to be unsteady on their feet and falling over. Indeed, it is not uncommon for Parkinson’s patients to be mistaken as drunk.

“It happened last night as well”

Urinary disturbances in Parkinson’s are usually related to urge incontinence, and caused by detrusor hyperreflexia. Unfortunately, this non-motor symptom is made more unbearable by motor deficits
in Parkinson’s. Despite the feeling of urgency, patients are often unable to move quickly enough to the bathroom. ‘Being caught short’ is particularly likely at night, when detrusor contractions coincide with a time when patients have not taken their medication and are ‘off.’

Constipation affects 50-60% of Parkinson’s patients and is the quintessential example of a vicious cycle: patients may become constipated as a direct result of dopamine deficiency, or as a side effect of Levodopa, or because their motor symptoms hamper them from getting up and pouring themselves a glass of water. In turn, because of the pharmacokinetics of Levodopa, the drug’s efficacy is reduced as patients’ bowels become impacted. Their symptoms consequently worsen and they are less able to stay hydrated. Particularly concerning is the fact that constipation tends to accompany other Parkinson’s complications. For example, patients who have a FoF are among the most likely subgroups to develop constipation. Constipation in Parkinson’s has been shown to significantly reduce health related quality of life and, when it leads to faecal impaction and spurious diarrhoea, is one of the main causes of nursing home admissions in patients with Parkinson’s.

If I had Parkinson’s, developing incontinence of bladder or bowel would be one of my biggest fears, probably because the word ‘incontinence’ is associated with negative images of the demented or inebriated. Society outside the healthcare profession neither understands nor accepts it. This stigma understandably prevents many patients from seeking help, and the problem is compounded by the fact that Parkinson’s main demographic (men over 60), represents the part of the population which is least likely to open up to doctors about embarrassing medical issues. Bladder and bowel disturbance secondary to Parkinson’s therefore not only isolates patients socially, but from healthcare services.

“Can I have a good death?” End of life issues

The words long-term neurodegenerative disorder implicitly tell that there is no escape from the worsening of symptoms. If I had Parkinson’s I would worry about how I would die. NICE guidelines recommend that patients with Parkinson’s and their carers have the opportunity to discuss end-of-life issues with relevant health professionals. However, a Parkinson’s UK Clinical Audit reported that end-of-life discussions were documented in only 27% of patients with advanced Parkinson’s disease. This data can be explained considering that death is still considered a taboo. A 2014 survey on GPs attitudes towards discussing end-of-life care, found that one in four GPs are reluctant to talk about death with their terminally ill patients. The survey highlighted an even worse attitude amongst the general public: only 6% of 2055 interviewed people had written down their wishes, and 51% of people did not know their partners end-of-life wishes. This ‘pass the
buck’ attitude is not only detrimental for doctors, who will bear the burden of important life or death decisions, such as artificial feeding or withdrawing antibiotic treatment, but, most importantly, it is detrimental for the loved ones left behind.

**Conclusion**

Throughout this essay I have analysed the aspects of Parkinson’s disease that would matter the most to me if I had been diagnosed with it. However, there are a myriad of other equally important symptoms, feelings, and social issues which others may see as a priority. What I have learned from writing this essay is that Parkinson’s disease is as many diseases as there are patients diagnosed. If I did develop Parkinson’s disease, then given the average age of diagnosis, it would likely be the year 2055. My hope for that time is, of course, a cure. However, if unachievable, what I would value the most, and what I believe too many of today’s patients do not have, is an easy, fast, fair access to health care and social services.

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References


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