

Commentary

Parkinson's Inside Out

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Much of our current understanding of Parkinson's disease (PD) is based on largely objective criteria and concentrates on the more overtly visual, and thus quantifiable, aspects of the condition. In contrast, the patient experience of PD is inherently subjective and, in many respects, is poorly reflected in the criteria used to diagnose and to treat the condition.

Recent reflections on Parkinson's disease (PD) have led to the conclusion that it is a highly complex disease when considering not only the motor, but also the accompanying or even preceding non-motor symptoms. It has been suggested that the currently defined symptomatology might reflect many different underlying patterns of pathology in brain that were previously unrecognised.

Although the current medical diagnosis remains based primarily on motor symptoms, non-motor symptoms are increasingly being considered as key components of the illness. In future, this new perspective based on both motor and non-motor components of PD will lead to a revision of diagnostic criteria and therapeutic approaches.

Based on the personal experience and testimonies of people with Parkinson's, it is increasingly apparent that the diagnosis and treatment of the disease has a more profound effect on an individual patient and their personality in later life than had been previously realised – a phenomenon which has been largely ignored but which causes pronounced influences on their social environment and even the relationship with the care-giving professionals.

It seems obvious that a conceptual difference in their perception of PD exists between patients and their treating physicians and healthcare team. Patients perceive the disease from a personal and introspective viewpoint that many outside struggled to comprehend. The physician's perspective, by comparison, is detached and to a certain degree impersonal which may be necessary to enable a diagnosis, to initiate treatment and to deal with the inevitable decline in function with time.

Although the physician's perspective inevitably predominates, these two views of PD are, in essence, opposite sides of the same coin: the physician knows what the disease *looks* like while the patient knows what it *feels* like. Each perspective on its own provides a partial picture of PD. Supposedly, the two concepts do not exist independently and in fact, may amplify one another. To truly understand what having PD means requires reflection from both directions and in order to generate a full or at least a more comprehensive picture of the disease both viewpoints need to be integrated.

A unique approach to achieving a truer, more complete, picture of what it means to have PD, might be obtained from the experiences of healthcare professionals and neuroscientists who, in addition to their professional expertise, also have PD. Accordingly, a small group of people was brought together who have PD and have thus experienced how it feels from the inside to receive a diagnosis of PD and then to pass through the health care system. The group

(entitled Parkinson's Inside Out) was convened by JS and DS and is moderated by PJ. The combined life experiences of the group were as neurologist, neurosurgeon, pain specialist, general physician, physiotherapist, psychologist, speech therapist, nurse, dietician and neuroscientist. The group ranged in age from 40 to 70 with personal experience of Parkinson's ranging from 5 to 20 years. There was an almost equal split of male and female members. The group therefore collectively has professional expertise that encompasses many of the disciplines PD patients commonly encounter and personal experience derived from being a PD patient. In essence, the group provides both inside and outside insights. Surprisingly, a think tank of this nature has never, to our knowledge, previously been convened.

The group was inaugurated in September 2014 with initial support from UCB pharmaceuticals and has met for two workshops over the last year. These were very insightful and often moving as participants shared a number of their personal experiences regarding various aspects of the disease and the life that goes with it. The first meeting covered all aspects of personal experiences prior to and after diagnosis and treatment. Based on these discussions, three main aspects based mainly on personal experiences were chosen to be dealt with in depth during a second meeting:

- Pain – a highly prevalent condition in all stages of the disease with a large influence on the quality of life of patients, but under-recognized and rarely addressed by treating physicians (and also researchers): what features of pain or pain subtypes are unique to Parkinson's and how does the experience of pain differ in PD?
- Sleep disturbances – also a highly prevalent condition with a large impact on daily functioning and quality of life, but recognized by physicians and to a certain extent treatable: what are the differences between sleep issues in PD and non-PD?

- Impulse control disorders (ICDs) – a variety of mainly unpleasant and often disturbing personality changes which may develop prior to or after treatment of Parkinson's with their prevalence being highly variable/controversial. Besides the personality changes, the social impact of that condition can be very dramatic including not only the patient but the whole personal environment.

Many insights on these topics accrued from the openly shared experiences of scientifically or medically educated individuals, in particular on ICDs that are clearly underestimated and under reported. The group committed to communicating this joint experience to provide an inside-out perspective on living with PD and going through the healthcare process.

The first formal report of the group's workshops is the article by Georg Stenberg, submitted for publication in this journal and discussing impulse control disorders from both inside and outside perspectives. It is anticipated that other publications will follow as the group turns its attention to other facets of PD. The intention always is simply to provide a more complete picture of PD and one which it is hoped will better inform our clinical colleagues and contribute to improved practice. We also hope and anticipate that these insights may also prove useful in the direction of clinical research.

Future plans for the group include the presentation of findings at the forthcoming World Parkinson Congress in Portland, Oregon in September 2016. In addition to presenting their existing findings at a number of posters, the group will also host an interactive workshop on Monday 19th September 2016 prior to the main WPC meeting. The future intentions for the group are that it should find a consultative niche, providing informed comment to clinicians and researchers interested in patient centred research and treatment issues.