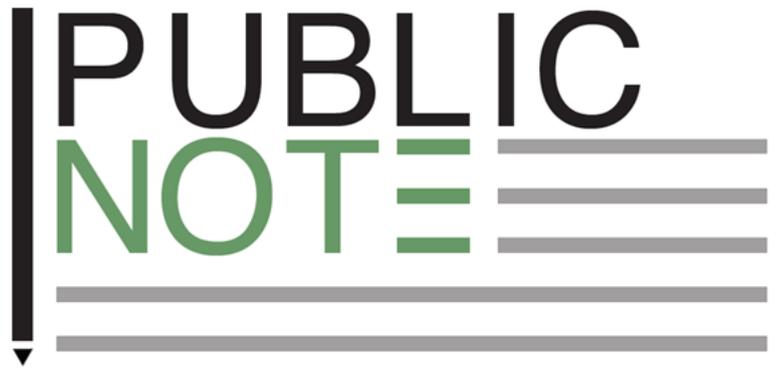


Parkinson's Disease and Employment

David Vorbau



Parkinson's disease (PD) is the second most common neurodegenerative disease and yet the consequences for sufferers, in particular on their professional life, are hardly discussed in public life. This article aims to draw attention to a topic that has received far too little attention and therefore discusses the relationship between Parkinson's disease and employment. The various sections first explain PD itself, then relate the disease to the ability to work, followed by highlighting the enormous socioeconomic and psychological consequences for patients, and finally discuss an outlook focusing on possible improvements to the current situation. This text will clarify that people with PD face severe socioeconomic and psychological burdens and need societal support to minimize them. So why is it of interest that you as a reader know about it? Well, because everyone is individually in a position to improve the situation for the people affected.

Lessons for Practice

- As Parkinson's patients are even more disturbed by others' perceptions of the symptoms than by the symptoms itself, each individual can try to make a Parkinson's patient feel comfortable in a professional environment to reduce the psychological pressure on the patient.
- As an employer, offer your support and try to create a work environment where people with Parkinson's can feel comfortable and reach their full potential.
- Parkinson's patients are impaired in many ways, both psychologically and physically, in the way they can do their work, but despite all this, this problem is communicated far too little in society. Therefore, try to discuss this issue with your friends and family to raise social awareness.

Keywords: Parkinson's disease, employability, chronic illness

In 1817, James Parkinson wrote a short treatise on a condition he had observed in six acquaintances. He speaks of involuntary tremors and diminished muscle strength - the birth of Parkinson's disease (PD) (Barnett, 2016). Nowadays, PD is the second most prevalent disease in the neurodegenerative field (Poewe et al., 2017). PD occurs when neurons in the substantia nigra - the part of the brain responsible for motor control - stop working effectively (Smith, 2016). The causes of PD are largely unknown (Poewe et al., 2017). PD manifests in motor and non-motor symptoms. Most common are involuntary tremors, slower movements, stiffness, and loss of balance (Smith, 2016). Although mostly older people get diagnosed with PD, about 30% of patients are under the age of 65 (Gustafsson, Nordström, Strähle & Nordström, 2015). With a large number of PD patients still being of working age, it is of particular interest to investigate the relationship between PD and employment.

After the preceding short introduction of PD, it is important to look at how it actually affects the ability to work. Both types of symptoms have a significant impact and reinforce each other. PD patients report that the biggest challenges at work are slowness, fatigue, and tremors (Murphy, Tubridy, Kevelighan & O'Riordan, 2013). As a result, patients often face work demands that exceed their capacity (Gustafsson et al., 2015). This manifests itself, for instance, in a struggle with writing (Murphy et al., 2013). The cognitive and psychological problems are generally less considered but are relevant in the context of PD and work (Martikainen, Luukkaala & Marttila, 2006). For example, physical disability was often cited as the biggest factor in difficulties at work. Yet, it was not the symptom itself, but the perception others might have, which was most disturbing for PD patients (Murphy et al., 2013). Other psychological challenges at work include depression, anxiety, and insecurity (Akhmadeeva, Magzhanov, Tayupova, Baitimerov, & Khidiyatova, 2018). Building on the challenges posed by symptoms, PD patients reported missing support from employers and supervisors (Murphy et al., 2013).

The impact of PD on the ability to work leads to significant socioeconomic consequences for the patient. These consequences include a lower employment rate and lower income compared to people without PD (Gustafsson et al., 2015). This significant loss of earnings also translates into a reduced pension (Martikainen et al., 2006). On average, PD results in the loss of a specific occupation within less than 10 years of disease onset (Schrug & Banks, 2006). According to Murphy et al. (2013), only 14% of patients continued to work 10 years after the first symptoms. Studies also show that the retirement age for PD patients was about 4 to 6 years younger compared to the general population (Murphy et al., 2013; Martikainen et al., 2006). These socioeconomic consequences contribute significantly to the total cost of the disease (approximately 20,000 euros per year) (Murphy et al., 2013).

The burden that PD patients have to bear goes beyond the financial costs. Psychological and cognitive problems are significant in the context of PD and work. Job loss can lead to social isolation, a lack of meaning and purpose (Martikainen et al., 2006). In numbers, more than 80% of those who had stopped working due to PD were dissatisfied with their employment status (Murphy et al., 2013). Patients who remain employed find it difficult to meet the challenge of a balanced employment situation (Gustafsson et al., 2015). Since the employment situation influences life satisfaction for working-age individuals, people with PD are at an increased risk of being dissatisfied with life (Gustafsson et al. 2015). Depression occurs in an average of 40 to 50% of patients with PD and anxiety in 17 to 43%. With job loss, the odds of depression and anxiety increase (Akhmadeeva et al., 2018).

After focusing on PD's impact on employment, it is helpful to examine some approaches for improving patients' situations at work. Various studies show the importance of support by employers for working PD individuals (e.g. Gustafsson et al., 2015). Among people with PD, the chance of work was greater for those who had received help from their employers (Gustafsson et al., 2015). Studies state that adjustments changing the content and amount of work or the schedule appear to be effective (Martikainen et al., 2006; Murphy et al., 2013). However, it was also shown that employers struggled to help patients and appeared to be unsure of what changes are needed (Murphy et al., 2013). Murphy et al. (2013) state that education for employers is needed to address this issue. Educational programs are also necessary for PD patients, creating awareness for their rights and what helping resources are available (Murphy et al., 2013).

To conclude, the consequences of PD on the employment situation of patients are enormous. The burdens PD patients have to cope with are socioeconomic as well as psychological. Employers in particular must be held accountable to improve the condition of working-age PD patients.

A note from the author

Hi, I'm David Vorbau, a student at University College Groningen from the Rijksuniversiteit Groningen. I am in an interdisciplinary liberal studies program where I focus especially on social scientific, society-related topics. In the course of my studies, I also wrote this paper on the issue of Parkinson's patients in the work environment in the first year of my studies. Due to my grandmother's illness, I was confronted with Parkinson's syndrome and its effects at an early age. This triggered an interest in me not only to find out more in this respect, but also to share this inherent motivation and awareness with others. I think it is a topic that is unfortunately addressed far too little and far too reserved. In the future, I can imagine working in the public health sector and thus influencing such health, social and interdisciplinary issues.



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