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Review article

Working capacity of patients with Parkinson's disease – A systematic review

Janneke Koerts^{*,1}, Miriam König¹, Lara Tucha, Oliver Tucha

Department of Clinical and Developmental Neuropsychology, Faculty of Behavioral and Social Sciences, University of Groningen, The Netherlands

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ABSTRACT

Introduction: Parkinson's disease (PD) is characterized by motor and non-motor symptoms and has a median age-of-onset around 55 years. Many PD patients are thus diagnosed before reaching retirement age and it is likely that they are confronted with a reduced working capacity or loss of employment. This systematic literature review gives an overview of the research conducted on work capacity in PD.

Methods: A systematic literature search was performed in PsycINFO and PubMed (Keywords: "Parkinson" or "Parkinson's disease" combined with "employment", "work", "working", "retire" or "retirement").

Results: Thirteen studies were identified and showed that PD patients retired 4–7 years earlier than the general population. Furthermore, 23%–75% of patients report that they retired early because of PD and slowness and fatigue were reported as the most debilitating symptoms in relation to working capacity. Early retirement of PD patients is associated with high societal costs and a high loss of individual lifetime earnings. Although many employed PD patients asked for adjustments at their workplace, their employers did not always support these.

Conclusions: PD has a detrimental effect on working capacity and is associated with high costs. Employed PD patients do not, however, always receive the support they need. It is therefore very relevant that employers and patients are informed about strategies and techniques developed for counteracting symptoms of PD which might support patients to stay in the workforce for a longer period of time.

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1. Introduction

Parkinson's disease (PD) has a median age-of-onset around 55 years [1]. A recent study indicates that 5% of patients are diagnosed before the age of 50 and 30% of patients are diagnosed before the age of 65 [2]. Many PD patients are thus diagnosed before their normal retirement age and are likely to be confronted with a reduced working capacity or employment loss.

PD is characterized by motor and non-motor symptoms, including bradykinesia, rigidity, tremor, sleep disturbances, cognitive impairment and affective disturbance [3]. Possible treatment options include pharmacotherapy, typically encompassing levodopa and dopamine agonists, which can successfully reduce disabling effects of PD in most patients. Nevertheless, levodopa and

dopamine agonists are accompanied by many drawbacks, such as the need for an increased dosage over time as well as debilitating side effects [4]. Symptoms of PD as well as the side effects of pharmacotherapy can thus evolve into employment obstacles.

In high-income countries, the employment rate in the late 2000s for persons with disabilities, including PD patients, was about 40% compared to 75% in healthy individuals [5]. Although these numbers vary between countries, it appears obvious that disabled populations encounter great disadvantages regarding employment [6]. These disadvantages are reflected in reports on income, revealing an average earnings gap of 15% between disabled and non-disabled individuals [5]. Alarming, research in the UK and USA has shown that about half of this wage gap cannot be explained by productivity and human capital factors [7,8] and it has been hypothesized that possible causes for this wide wage gap are strongly related to discrimination and stigmatization [9]. The capacity to work is as much a means for making a living, as it is a necessity for individuals with disabilities to actively fight against exclusion from their social and occupational environment. Moreover, employment and the capacity to work have an influence on

* Corresponding author. Department of Clinical and Developmental Neuropsychology, University of Groningen, Grote Kruisstraat 2/1, 9712 TS, Groningen, The Netherlands.

E-mail address: janneke.koerts@rug.nl (J. Koerts).

¹ Both authors contributed equally to this manuscript.

the emotional well-being of an individual [10]. Research on working capacity of PD patients is limited so far and only a few studies have addressed this topic. This systematic literature review gives an overview of the research conducted on this subject until now, with the goal of shedding light on factors contributing to a decreased working capacity of PD patients and their premature leave from the workforce.

2. Method

A literature search was performed according to the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) encompassing PsycINFO and PubMed. The keywords “Parkinson” or “Parkinson’s disease” were used in combination with keywords such as “employment”, “work”, “working”, “retire” or “retirement”. These combinations generated a total of 5875 records (Fig. 1). An evaluation of records was conducted in order to eliminate duplicates and to determine which papers met the predefined inclusion criteria: a) the paper discussed factors associated with early retirement and/or working capacity and/or b) the study investigated socioeconomic factors, such as (in)direct costs, related to the inability to work or retirement and c) the study included a group of idiopathic PD patients. Reasons for exclusion comprised a) the date of the study, with investigations before 1990

being excluded and b) the language of the paper being other than English. After searching the references of eligible papers for possible additional literature that did not turn up during the database search, thirteen studies were identified (Fig. 1) which included 5014 PD patients in total.

A content analysis approach was applied. The results were organized and extracted in a table format displaying demographics and disease characteristics of the included samples. In addition, primary and secondary outcome measures, the applied statistical analysis and the most important results of each paper relevant for the research questions at hand are described.

3. Results

Nine of the included studies (Table 1) dealt with factors associated with either leaving the workforce or prolonging employment. Three studies investigated (in)direct costs of PD, one study examined the effect of different drug treatments on retirement rates.

3.1. Retirement age

Patients who develop PD before having reached retirement age leave the workforce earlier than the general population. Two

Fig. 1. Flow diagram of systematic literature search [34].

Table 1

Overview of studies included in the systematic review (n = 13).

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
Armstrong et al. (2014), United States of America	Data from hospital database: 511 patients were employed at initial visit (baseline); n = 419 had follow-up data. Two groups: 1. Employed: PD patients employed at follow-up (n = 195; follow-up = 3.7 years (SD = 2.7)) Age: M = 56.2 (SD = 9.6) Education: 80% college-educated Gender: 82% male 2. LWF: PD patients who left the workforce (LWF; n = 224; follow-up = 3.1 years (SD = 2.3)) Age: M = 58.9 (SD = 10.1) Education: 79% college-educated Gender: 68% male	1. Employed: Disease Severity: H&Y: M = 2.6 (SD = 0.8); UPDRS total: M = 30.2 (SD = 13.0); UPDRS motor: M = 21.7 (SD = 9.8) PD Duration: M = 2.8 years (SD = 3.8) 2. LWF: Disease Severity: H&Y: M = 2.6 (SD = 0.9); UPDRS total: M = 32.3 (SD = 15.9); UPDRS motor: M = 22.1 (SD = 11.1) PD Duration: M = 2.8 years (SD = 3.8) Dementia: No differences between groups regarding dementia according to MMSE	1. Employed: All patients are employed at follow-up. No further information provided (e.g. about full- versus part-time) 2. LWF: 67% retired, 26% on disability leave, 13% lost job	<ul style="list-style-type: none"> To identify baseline features that are associated with unemployment (LWF). Student's t-tests were used to compare groups regarding the following variables: income, marital status, disease characteristics (UPDRS total and motor, H&Y, PD duration), emotional factors (BSI-18: anxiety, depression and somatization), cognition (MMSE), QoL/general health status (SF-12, CIRS-G) and ADL and IADL level of functioning (OARS) Multivariate analyses were performed for the same variables including a correction for age, gender and disease duration. 	<ul style="list-style-type: none"> Patients who left the workforce were more often female, had a lower income, a longer disease duration and were older at baseline than patients who were employed. LWF patients reported more symptoms of depression, anxiety, overall psychiatric distress and worse mental health related quality of life than employed PD patients.
Banks & Lawrence (2006), United Kingdom	PD patients who were either of working age or in paid employment were included and completed questionnaires (n = 339). Age: M = 54.6 (range = 27–75) Twenty-four patients also took part in one-to-one interviews. Two groups: 1. Employed: PD patients in paid employment (n = 103) Age: M = 52.8 Gender: 31.1% male 2. Unemployed PD patients not in employment (n = 236) Age: M = 55.6 Gender: 68.9% male	1. Employed Age at diagnosis: M = 48.6 Time since diagnosis: M = 4.2 Time since first symptoms: M = 6.2 2. Unemployed: Age at diagnosis: M = 47.0 Time since diagnosis: M = 8.6 Time since first symptoms: M = 10.5	1. Employed: All patients are employed. No further information provided (e.g. about full- versus part-time employment) 2. Unemployed: 74.6% retired because of PD, 6.8% retired because of age, 2.5% retired for health reasons other than PD, 7.2% were homemakers, 6.4% were unemployed and 1.3% carried out voluntary work.	<ul style="list-style-type: none"> To determine the impact of PD on employment from the patients' perspective. T-test and χ^2 tests were used to compare groups regarding the following variables: severity of symptoms (SF-36 and undefined questionnaires). Furthermore, a descriptive analysis was used to summarize the answers to the questionnaires and the one-on-one interviews. 	<ul style="list-style-type: none"> The number of working years was inversely associated with age at diagnosis. Of all included patients only 15.3% worked for more than five years post-diagnosis. Patients who retired due to PD showed lower scores on all scales of the SF-36 (physical function, role-physical, bodily pain, general health, vitality, social function, role-emotional and mental health) compared to employed PD patients. Of all included patients 81.5% reported that their symptoms affected their ability to work. The following symptoms were reported in relation to carrying out their work tasks: tiredness and slowing down (45.8%), difficulties writing (30.8%), difficulties using keyboard and other fine motor skills (25.6%), tremor (24.2%), impaired memory and lack of concentration (14.1%), speech problems (11.0%), difficulty walking (9.3%), poor balance (9.3%), stiffness (7.9%), pain (5.7%), visual problems (2.2%), inability to deal with stressful situations (11.5%), lack of confidence (7.0%), anxiety or panic attacks (4.4%) and depression (3.1%). Within the group of patients who retired because of PD, the proportion of patients who worked in manual jobs was similar to the

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Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
					<p>proportion of patients who worked in non-manual jobs.</p> <ul style="list-style-type: none"> • Of all included patients 18.2% asked their employer to make adjustments at work; 73.8% of these patients reported that their employer had been supportive. Patients with a supportive employer remained longer in the workforce post-diagnosis than patients with an unsupportive employer. • No association was found between either the number of GP or outpatient appointments, or having access to a multi-disciplinary team and duration of employment post-diagnosis. • Within the group of patients who retired because of PD, those who reported that their decisions relating to pharmacotherapy were influenced by how they thought it would affect their ability to work worked longer post-diagnosis than patients who did not consider the impact of pharmacotherapy on the ability to work. • No association was found between satisfaction with current financial situation and employment status. Patients who were employed were, however, more worried that they would not have enough money in the future than unemployed patients.
Dodel et al. (1998), Germany	Eight patients in each H&Y stage (n = 40) who were followed for a 3-month period. Age: M = 60.9 (SD = 10.0) Gender: 67.5% male	Duration of disease since onset of symptoms: M = 11.5 (SD = 6.4) Age at symptom onset: M = 50.1 (SD = 12.7) Duration of disease since diagnosis: M = 9.5 (SD = 5.9) Time between symptom onset and start of treatment: M = 2.3 (SD = 2.8)	Of patients included in the study 15% was in workforce and 85% had retired. In 50% retirement was related to PD, in 41% retirement was unrelated to PD and for 9% of patients data was unavailable.	<ul style="list-style-type: none"> • To determine the costs caused by care and treatment of PD patients in Germany. • At study inclusion all patients completed a standardized questionnaire focused on general health, history of PD, drug intake, use of medical services and socioeconomic status. Furthermore, all patients were assessed with the complete UPDRS and H&Y. • During a 3-month follow-up period patients completed a weekly questionnaire focused on direct and indirect medical costs and non-medical costs. • 95% confidence intervals were calculated to determine estimates of difference. 	<ul style="list-style-type: none"> • Mean time between disease onset to time stopped working was 7.4 years (SD = 3.9); women retire somewhat earlier (M = 5.0; SD = 2.6) than men (M = 8.6; SD = 3.8). • Mean retirement age in men was 50.7 years (SD = 6.1) and 50.3 years (SD = 6.8) in women compared to 57.9 years for the total German population. • PD patients younger than 60 years of age received a lower monthly income (with women receiving less than men) compared to people of a similar age. This difference was not found for PD patients aged 65 years and older. • Male patients with a higher educational level (i.e. at least high school) and a

Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
					higher income had a higher probability of working at the time of the survey, as is true for men in the general population.
Gustafsson et al. (2015), Sweden	Two groups: 1. Working-aged (i.e. <68 years of age) PD patients (n = 1432) Age: Median = 63 (QR = 58–65) Education (men/women): Primary school: 25.4%/28.2%; Vocational school: 18.2%/13.0%; Secondary school: 22.9%/23.5%; University: 32.0%/34.0%; Missing: 1.5%/1.4% Gender: 64.0% male 2. Age and gender matched controls without PD (n = 1135) Age: Median = 63 (QR = 58–66) Primary school: 25.6%/24.3%; Vocational school: 18.3%/12.3%; Secondary school: 22.0%/23.9%; University: 33.2%/38.8%; Missing: 0.9%/0.7% Gender: 60.5% male	1. Working-aged PD patients Time since diagnosis (men/women): Median = 6.0 (QR = 3.25–10)/Median = 7.0 (QR = 3–11) Age at diagnosis (men/women): Median = 55 (QR = 49–59)/Median = 54 (QR = 49–59) 2. Age and gender matched controls without PD: NA	1. Working-aged PD patients Work full-time (men/women): 20.0%/10.5% Work part-time (men/women): 21.3%/21.4% Disability pension full-time (men/women): 45.3%/46.6% Disability pension part-time (men/women): 9.4%/11.1% Unemployed (men/women): 5.3%/3.9% Income (men/women (Euro, thousands): M = 36.6 (SD = 21.4)/M = 27.5 (SD = 16.7) 2. Age and gender matched controls without PD Work full-time (men/women): 50.5%/39.1% Work part-time (men/women): 15.0%/21.0% Disability pension full-time (men/women): 24.9%/22.8% Disability pension part-time (men/women): 3.2%/3.6% Unemployed (men/women): 5.1%/3.8% Income (men/women (Euro, thousands): M = 41.7 (SD = 32.9)/M = 31.1 (SD = 14.2)	<ul style="list-style-type: none"> To study the associations between socioeconomic situation and subjective QoL in patients with PD in a large population-based cohort. Particular attention is paid to work-related challenges and possibilities for improvement. A questionnaire was designed specifically for this study which was separated into parts regarding 'present' and 'past' (i.e. past = before diagnosis for patients with PD or 10 years ago for controls). The following factors were included: living conditions, family, vocational situation, leisure, health and self-assessment of well-being from different points of view. Subjective QoL was assessed using 4 domains of the LiSat-11 (life as a whole, employment situation, financial situation and leisure). Work characteristics were investigated using 11 questions from Karasek's Job Content Questionnaire. Participants who reduced work time or stopped working due to PD were asked to rank their symptoms in relation to interference with work on a scale from 1 to 10. Descriptive statistics (numbers and percentages) were used for categorical data. Differences between groups were determined using χ^2, t-tests or Mann-Whitney U test. Binary logistic regression analysis was used in each group to determine which factors were associated with the opportunity to work 	<ul style="list-style-type: none"> Within 5 years after diagnosis: full-time employed: 28.6%, part-time employed 24.3%; 5–9 years after diagnosis: full-time employed: 15.2%, part-time employed: 23.5%; ≥ 10 years after diagnosis: full-time employed: 6.1%, part-time employed: 18.2%. More patients (38.2%) than controls (14.7%) reported dissatisfaction with work situation. More patients (36.2%) than controls (13.2%) experienced work demands that exceeded their limits, with no within-group differences between full- and part-time employed subjects. Within both groups combined having PD, unemployment and the perception that work exceeded one's capacity were negative predictors of life satisfaction. Within the PD group longer disease duration also had a negative influence on life satisfaction. 59.1% of patients reported that they reduced working hours or stopped working due to their disease. Interfering symptoms: stiffness and/or slowness of movement (44.5%), stress intolerance (35.6%), sleep disturbance/fatigue (23.8%) and tremor (22.7%). 12.8% of patients reported that their employment situation had not changed. 33.7% of patients received help from their employer, 14.4% reported that they did not receive the help from their employer that they needed. Help from a vocational rehabilitation unit was used by 30.8% of patients and 14.7% requested help but did not receive. Within both groups combined having PD resulted in a reduced chance to work. Among PD patients disease duration and receiving vocational rehabilitation affected the opportunity to work.

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Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
Jasinska-Myga et al. (2012), United States of America	Prospective cohort of PD patients able to work (i.e. the ability to work in a job with physical/social requirements) or to live independently at baseline visit (n = 495 total group; n = 303 patients were still able to work) Age at first visit: Median = 71 (min/max = 38/93) Gender: 68% male Length of follow-up: Median 4.0 (min/max = 92 days/12.7 years)	Disease Severity: H&Y > 2: 27%, UPDRS tremor: Median = 2 (min/max = 0/18), UPDRS rigidity: Median = 7 (min/max: 0/16), UPDRS bradykinesia: Median = 14 (min/max = 0/39), UPDRS instability: Median = 2 (min/max = 0/2), UPDRS dyskinesia %>0: 16%, UPDRS motor total: Median = 25 (min/max = 0/64) Age at PD onset: Median = 66 (min/max = 16/90) Disease duration (in months): Median = 45 (min/max = 2/621) History of depression: 31% Current depression: 12% Family history of PD: 15% Intellectual impairment: 6%	Employment situation at baseline was not reported.	<ul style="list-style-type: none"> To examine the association between patient characteristics, disease information and loss of the ability to work and to estimate the future likelihood of losing the ability to work. Demographic, historical and clinical information was collected. The inability to work was determined after a routine semi-structured physician-based interview. Severity of disease was evaluated with the modified H&Y and modified UPDRS motor score including additional items for arm swing and dyskinesia. The complete sample was divided into four groups: (1) Age ≤ 70 years and median symptomatic disease duration ≤ 4 years, (2) Age ≤ 70 years and median symptomatic disease duration > 4 years, (3) Age > 70 years and median symptomatic disease duration ≤ 4 years and (4) Age > 70 years and median symptomatic disease duration > 4 years. Within each group the Kaplan-Meier method was used to estimate the proportion of patients still able to work after baseline visit. Relative risks and 95% confidence intervals resulting from Cox proportional hazards regression models adjusted for age and disease duration were used to determine the associations between baseline characteristics and the ability to work. 	<ul style="list-style-type: none"> Estimated proportions of patients still able to work 5 years following baseline visit: Age ≤ 70 and disease duration ≤ 4: 88%, Age ≤ 70 and disease duration > 4: 66%, Age > 70 and disease duration ≤ 4 years: 58%, Age > 70 and disease duration > 4: 43%. Estimated proportions of patients still able to work 10 years following baseline visit: Age ≤ 70 and disease duration ≤ 4: 44%, Age ≤ 70 and disease duration > 4: 26%, Age > 70 and disease duration ≤ 4 years: 8%, Age > 70 and disease duration > 4: 3%. An increased risk of future inability to work was observed in patients with intellectual impairment, H&Y score > 2, higher UPDRS instability score and higher UPDRS motor total score. Increased age and increased disease duration were associated with an increased risk of inability to work.
Johnson et al. (2011), United States of America	Subjects were selected from a database of health insurance and disability claims based on the following criteria: (1) being in the database for at least 1 year at start of study, (2) aged between 18 and 64 years, (3) being actively employed when being entered in the database (baseline). All subjects were followed for three years after start of study. Four groups: 1. Naïve patients (n = 278): PD patients who just received the diagnosis. Age: M = 53 (SD = 7), Median = 54 (25 th –75 th percentile = 50–58) Gender: 74.8% male 2. PDAAD (n = 28): PD	All PD patients (group 1 and 2 combined): Age at diagnosis: M = 53 Dementia and comorbidities: Exclusion of patients with comorbid dementia, Alzheimer's disease, schizophrenia, bipolar disorder and psychosis and patients using anti-psychotics.	All subjects who were included in this study were actively employed at baseline.	<ul style="list-style-type: none"> Costs related to components of income loss (i.e. excess rate of early retirement and earnings conditional of remaining employed) are analyzed using the human capital method. Income losses for people aged 45, 55, 65 and 75 years who are newly diagnosed with PD are simulated. The following variables were taken from the database: employment status, wage, insurance type and demographic information (i.e. age, sex, geographic region of residence, Charlson Comorbidity Index and co- 	<ul style="list-style-type: none"> Employment rate naïve PD patients: baseline = 100%, year 1 = 90%, year 2 = 77%, year 3 = 63%, study end = 58%; control group naïve PD patients: baseline = 100%, year 1 = 93%, year 2 = 86%, year 3 = 81%, study end = 75%; Hazard ratio = 2.08. Employment rate PDAAD patients: baseline = 100%, year 1 = 57%, year 2 = 39%, year 3 = 34%, study end = 34%; control group PDAAD patients: baseline = 100%, year 1 = 93%, year 2 = 87%, year 3 = 79%, study end = 74%; Hazard ratio = 5.01.

Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
	<p>patients with Ambulatory Assistance Device (i.e. wheelchair or walker). Age: M = 53 (SD = 6), Median = 55 (25th–75th percentile = 50–59) Gender: 71.4% male</p> <p>3. Control group without PD matched 10:1 to the naïve group (n = 2780). Age: M = 53 (SD = 7), Median = 54 (25th–75th percentile = 50–58) Gender: 74.8% male</p> <p>4. Control group without PD matched 20:1 to the PDAAD group (n = 560). Age: M = 53 (SD = 6), Median = 55 (25th–75th percentile = 50–59) Gender: 71.4% male</p>			<p>morbidities and sequelae of PD that could be identified in medical claims).</p> <ul style="list-style-type: none"> Survival analysis determined the time to early retirement, Kaplan Meier analysis descriptively plotted survival curves, a Weibull accelerated failure time model calculated the association between the likelihood of early retirement over those for PD patients versus controls, a Cox proportional hazards model was used to determine the hazard ratio of early retirement associated with PD, differences in earnings between PD and non-PD were calculated with the Wilcoxon rank sum tests, lifetime earnings loss for PD patients was simulated using Bureau of Labor Statistics data. 	<ul style="list-style-type: none"> No differences in earnings between employed subjects with and without PD. Naïve PD patients: average estimate of lost income over the year prior to diagnosis to 3 years after diagnosis is 18%. Each year revenue losses increased by an average of 43%. PDAAD patients: average estimate of lost income over the year prior to use of AAD to 3 year after is 84%. All patients with PD: Simulated lifetime earnings loss revealed total loss of 39.1%, 17.6%, 2.7% and 0.2% for those diagnosed at age 45, 55, 65 and 75, respectively.
Keränen, et al. (2003), Finland	<p>Consecutive outpatients with PD (n = 260). Age: M = 66.5 (SD = 10.6) Gender: 53.1% male</p>	<p>Disease Severity: H&Y ≤ 2: 60.1%; H&Y > 2: 39.9% Duration of PD from diagnosis: M = 4.3 (SD = 4.4) Duration of PD from start of symptoms: M = 6.0 (SD = 4.3) Levodopa users: 77.1% Patients with motor fluctuations: 28.3% Duration of motor fluctuations: M = 2.5 (SD = 2.3)</p>	<p>10% of patients were working full-time and 65% had retired. Of those who had retired 22.7% retired early due to PD.</p>	<ul style="list-style-type: none"> To estimate the total costs-of-illness (including early retirement due to PD) to society and to calculate the association between total costs-of-illness, QoL and PD severity. To determine the impact of different cost components (including early retirement due to PD) on the total cost burden. The following factors were assessed: disease severity (H&Y in ON state, presence or absence of motor fluctuations), QoL (15D, EQ-5D, PDQ-39). Costs-of-illness were studied retrospectively by using several resources: hospitalization, other inpatient care, outpatient visits, rehabilitation outside hospitalization periods, formal home care, PD medication, informal home care, early retirement due to PD. Cost-of-illness are presented as means or medians. Spearman rank correlations were used to determine the association between costs, H&Y and PD severity. Mann-Whitney U test and Wilcoxon test were used to compare costs and QoL respectively of patients with and without motor fluctuations. 	<ul style="list-style-type: none"> Of the total annual costs, direct costs accounted for 41%, early retirement accounted for 43% and informal home care for 16% of costs. Retirement age of those who retired due to PD: M = 52.8 (SD = 6.7) which was 5–6 years earlier than the total population in Finland who retire at 58–59 years. Costs-of-illness (including early retirement due to PD) were related to PD severity. All costs were higher in patients with motor fluctuations compared to patients without motor fluctuations.
Korchounov et al.	PD patients in full-time employment with age of	PD duration (months): M = 57 (SD = 10)	All patients were full-time employed at the beginning of	<ul style="list-style-type: none"> To determine if the combined use of levodopa 	<ul style="list-style-type: none"> Six patients who used levodopa and placebo

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Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
(2006), Russia	onset before 60 years, PD duration of at least 3 years, current use of levodopa monotherapy, no prior use of entacapone, minor motor fluctuations or dyskinesias, H&Y between 1.5 and 2.5 (n = 30). Age: M = 55.4 (SD = 3.5) Gender: 53% male	Dementia & Depression: Patients with MMSE score < 24 and/or a BDI score > 10 excluded	the study with equal distribution between groups of professionals and physical laborers.	and entacapone compared to the use of levodopa alone can preserve the ability to remain in full-time employment of PD patients. <ul style="list-style-type: none"> Design: (1) Screening period at least 8 week before start of study: all antiparkinsonian medication other than levodopa was withdrawn, levodopa treatment was individually optimized, (2) After stabilized levodopa use for at least 4 weeks patients were randomized to receive 200 mg entacapone or matching placebo with each levodopa dose, (3) Patients were followed during a 2 year period, if necessary levodopa dose was adjusted to optimize patient care and employability. Six patients (three in each group) stopped participation during study period. The following variables were measured throughout the study period: loss of employability, annual absenteeism due to PD, general absenteeism The following variables were assessed at baseline and at study end: ADL scale of UPDRS, motor fluctuations, "best on" and "worst off" score on sum of seven items of UPDRS motor (finger tapping, hand movements, pronation/supination, foot tapping, arising from chair, walking and rest tremor), dyskinesia severity and duration. Three days before baseline and final assessment patients received a self-assessment diary to rate daily wearing-off duration and daily dyskinesia duration. Means and SDs were calculated, groups were compared using Mann-Whitney U test and Fischer's exact test, Kaplan-Meier survival analysis was used to determine the probability to retire in both groups. 	retired during study period compared to two patients who used levodopa and entacapone. <ul style="list-style-type: none"> Mean survival time from disease onset till retirement was 71.5 months (SD = 9.4) for patients on levodopa and placebo and 90.5 months (SD = 2.4) for patients on levodopa and entacapone. Annual medical absenteeism was half the rate in patients on levodopa and entacapone compared to patients on levodopa and placebo. ADL disability scores worsened in patients on levodopa and placebo. This decline was not present in patients on levodopa and entacapone. No differences between groups regarding decline on "best on" and "worst off" scores. Dyskinesia severity score was lower in patients treated with levodopa and entacapone compared to patients treated with levodopa and placebo.
Martikainen et al. (2006), Finland	All members of the Finnish Parkinson Association not older than 65 years (n = 1343). Questionnaires of n = 937 patients returned and were analyzed.	Duration of symptoms: Median = 7.3 (QR = 4.3–11.3) Time since diagnosis: Median = 5.0 (QR = 2.3–9.2) Disease Severity: Median H&Y = 2	In workforce (n = 205, 21.9%): Full-time: 11.9% Part-time: 4.1% Unemployed: 1.1% Studying: 0.1% Sick leave: 4.7%	<ul style="list-style-type: none"> To determine how PD affects the capacity to work. Questionnaire consisting of 25 questions focusing on several aspects of disease and work. One question focused on the impact of 	<ul style="list-style-type: none"> Age of full- or part-time working patients: Median = 55 (QR = 51–59). Compared to Finnish population the percentage of working PD patients was

Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
	Age: Median = 59 (range = 29–65) Gender: 54% male		Retired (n = 637, 71.8%): Disabled because of PD: 36.6% Disabled because of PD and other disease: 5.4% Disabled because of other disease: 12.1% Other cause of retirement: 17.7% No information provided: 6.3%	symptoms of PD ("Please estimate the five most disturbing symptoms which interfere with your performance."). A self-estimated H&Y scale assessed severity of PD. • Logistic regression was performed to determine the influence of different factors on continued employment. Factors that were significantly associated with working capacity were used in multivariate analysis (covariates: age, disease severity, gender, duration of career, position in work and adjustments in work). The Kaplan Meier life-table method was used to calculate cumulative retirement after established PD diagnosis.	lower after 40 years of age: 16% versus 71%. • Most PD patients who were working had a mild disease (median H&Y = 1). 34% of working PD patients reported a H&Y score between 2 and 4. Retired PD patients: Median H&Y = 3. • Percentage of working PD patients decreased rapidly during first 3 years after diagnosis: from 42% to 15%. • Full-time working PD patients: Median duration of disease since diagnosis = 2.0 years (range: 4 days–14 years), Median age = 54. Part-time working PD patients: Median duration of disease since diagnosis = 4.3 years (range not reported), Median age = 59. • 82% of full-time working PD patients and 92% of part-time working PD patients reported that PD worsened their working capacity. Some adjustments were made for 31% of full-time working PD patients and 45% of part-time working PD patients. 21% of both full- and part-time working PD patients wished further adjustments and 31% of them preferred retirement. • According to working PD patients fatigue is one of the most harmful symptoms. • Short disease duration, young age, low H&Y, white collar type of work and adjustments at work were associated with preserved working capacity. • PD patients who received disability pension (n = 343) worked a median of 1.7 years after diagnosis, range is 0–14 years. • Median age for retirement due to PD is 54.3 years, which is 6 years earlier than the general Finnish population. • Adjustments at work were used more often among patients who continued to work for more than 5 years compared to patients who retired within 1 year post diagnosis.
Murphy et al. (2013), Ireland	PD patients (n = 88) diagnosed at age ≤ 65 years with current age ≤ 75 years	Age of onset of first PD symptom: Median = 54 (range = 19–65) Age PD diagnosis:	Currently employed: 25% Full-time: 15% Part-time: 10% Not working prior to PD	• To determine time from onset of first symptom of PD to loss of employment	• Average age of retirement was 58 years for males and 61 years for females (63.5

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Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
	Age: Median = 64 (range = 33–75) Gender: 61.4% male	Median = 56 (range = 24–65) PD duration from onset: Median = 8 (range = 0–30) PD duration from diagnosis: Median = 6 (range = 0–29) Dementia: Patients with MMSE score < 27 excluded	diagnosis: 19% Stopped working after diagnosis: 56% Becoming unemployed: 19% Retirement: 36%	and to identify influencing factors. <ul style="list-style-type: none"> To identify demographic information, disease history and occupation related factors that may prolong working time. To determine which problems are perceived by patients and to identify useful interventions. The following features were assessed: health status (SF-36), demographic information, disease and employment history, type of work, main challenge at work, suggested interventions. To compare employment rate among PD patients compared to general Irish population age- and gender-matched standardized unemployment ratios were calculated, survival analysis was used to determine time from onset of PD to loss of employment, log-rank tests and cox regression were used for further analysis. 	and 65 years in Irish population respectively. <ul style="list-style-type: none"> Standardized unemployment ratios were higher in males with PD of 45 years and older compared to age-matched males without PD; no differences were found for females. Rates of employment reduce rapidly with time from PD onset. Median time to loss of employment is 7 years (95% CI = 4.8–9.2). Approximately 88% of patients remained working after the first year, 40% after 5 years and 14% after 10 years. Time from PD onset to loss of employment was increased with early age of onset and early age of diagnosis. Median time to loss of employment was 10.0, 7.0 and 2.0 for patients with onset before the age of 50, from 51 to 59 and 60 to 65 respectively. Time from PD onset and diagnosis to loss of employment was prolonged in patients who reported high vitality. Greatest difficulties according to patients who worked after diagnosis (n = 71): slowness (21%), fatigue (18%) and tremor (18%). Of patients currently employed 77% made adjustments in work. Of patients who became unemployed or who retired because of PD 68% indicated that adjustments would have helped them to stay longer in the workforce. The following changes were reported as most useful: changes in work schedule, type or work and more time to complete tasks.
Schrag & Banks (2006) ^a , United Kingdom	Data of two separate studies at the Institute of Neurology (IoN; n = 151) and of a survey commissioned by the UK Parkinson Disease Society (PDS; n = 308) was used. Only patients with age of onset before 65 and with a known employment history were included. Gender: IoN: 62% male PDS: 96% male	Age at onset: IoN: M = 48 PDS: M = 45 Disease duration: IoN: M = 10.6 PDS: M = 8.9	Full-time employed (IoN/PDS): 11%/17% Part-time employed (IoN/PDS): 8%/11% Retired at normal retirement age (IoN/PDS): 10%/5% Retired early (IoN/PDS): 52%/56% Unemployed: (IoN/PDS): 16%/5% Housewives: (IoN/PDS): 4%/6%	<ul style="list-style-type: none"> To provide realistic and naturalistic data on the mean time to, and age of, loss of employment in PD. To determine factors that are related to earlier loss of employment Since patients might be included in the IoN studies as well as in the PDS survey, results were presented separately. Data are presented in a descriptive manner including absolute numbers 	<ul style="list-style-type: none"> The rate of full- and part-time employment was much lower in patients with PD compared to the UK population. The number of patients working full- or part-time decreased with increasing disease duration. Disease duration >5 years and working full-time (IoN/PDS): 6%/10%; Disease duration > 5 years and working part-time (IoN/PDS): 7%/7%. Disease duration >10 years

Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
				and percentages. Mann-Whitney and Kruskal-Wallis tests are used to compare groups and Spearman rank correlations are used for correlational analysis. Survival analysis was used to determine duration of employment after PD diagnosis. The UK population (published by the National Office for Statistics) was used for comparison.	and working full-time (IoN/PDS): 2%/6%; Disease duration > 10 years and working part-time (IoN/PDS): 5%/3%. <ul style="list-style-type: none"> Time to loss of employment (PDS only): Median = 4.9 years (range = 0–17). Stopped working after disease duration of 5 years (PDS only): 46%; Stopped working after disease duration of 10 years (PDS only): 82%. Patients with a younger age of onset had a longer disease duration till loss of employment than older patients. No differences were found regarding time to loss of employment between sexes, different types of work, different environments (urban vs. small town vs. rural), between those living with a partner or alone and between those with and without coresident children below the age of 20.
Schrag et al. (2003), United Kingdom	1. Age of onset before 50 (n = 75) Age: M = 53.7 (SD = 9.4) Gender: 44% male 2. Age of onset after 50 (n = 66) Age: M = 66.5 (SD = 7.0) Gender: 38% male	1. Age of onset before 50 Age at onset: M = 40.9 (SD = 6.4) Disease duration: M = 12.4 (SD = 8.6) H&Y: M = 2.3 (SD = 1.0) Schwab and England: M = 6.5 (SD = 2.4) Treatment: 41% levodopa, 8% no antiparkinsonian drugs, 13% one antiparkinsonian drug, 15% two antiparkinsonian drugs, 39% more than two antiparkinsonian drugs, 12% stereotactic surgery. 2. Age of onset after 50 Age at onset: M = 58.0 (SD = 7.0) Disease duration: M = 8.8 (SD = 5.6) H&Y: M = 2.2 (SD = 1.2) Schwab and England: M = 7.1 (SD = 2.2) Treatment: 35% levodopa, 11% no antiparkinsonian drugs, 10% one antiparkinsonian drug, 20% two antiparkinsonian drugs, 25% more than two antiparkinsonian drugs, 0% stereotactic surgery.	1. Age of onset before 50 Unemployed because of disability for more than 6 months: 56% Of all retired patients 97% retired early Employed full-time: 14% Employed part-time: 7% Housewives: 3% 2. Age of onset after 50 Unemployed because of disability for more than 6 months: 7% Of all retired patients 73% retired early Employed full-time: 5% Employed part-time: 8% Housewives: 8%	<ul style="list-style-type: none"> To determine the impact of PD on the lives of patients with disease onset before age 50 compared to patients with an age of onset after 50. The following measures were used: QoL (PDQ-39, EQ-5D), motor severity (self-reported H&Y and Schwab and England scale), ADL (ADL questionnaire), depression and anxiety (BDI and BAI), perception of stigmatization (modified Stigma scale), self-esteem (Self-esteem scale), coping strategies (Ways of Coping Checklist), Marital satisfaction (Marital Satisfaction Scale), social support (Short Social Support Questionnaire). Independent t-test, Mann-Whitney tests and χ^2 tests were used to compare groups. 	<ul style="list-style-type: none"> More patients in the young-onset group were unemployed for more than 6 months due to disability and retired early compared to the older-onset group. Young-onset PD patients reported higher levels of depression and stigmatization than older-onset PD patients.
Zesiewicz et al. (2007), United States of America	PD patients diagnosed before age of 60 (n = 68) Age: M = 58 Gender: 57% male Education: 75% of patients had at least some college or post-graduate education	Age at diagnosis: M = 49 Disease duration: M = 9.5 Dementia: Patients with MMSE score < 25 were excluded	Employed outside the home: 96%	<ul style="list-style-type: none"> To explore PD patients experience with Social Security Disability Insurance (SSDI) which is provided when employed patients can no longer work due to a medical condition. 	<ul style="list-style-type: none"> 67% of patients were eligible to apply for SSDI and 89% of those eligible applied for it. On average patients applied for it 5 years after diagnosis. Patients who applied for SSDI were more often in jobs that included public

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Table 1 (continued)

Authors, year of publication, country of origin	Sample(s)	Disease characteristics	Employment situation	Aim of study	Main findings
				<ul style="list-style-type: none"> Demographic data, disease history and information about applying and receiving SSDI were collected during an interview. A 30-item questionnaire was used to determine employment history (including date of initial and subsequent SSDI application, reason for application and date of disability award). Subsequent structured telephone interviews were used to retrospectively identify symptoms that contributed to work disability. All data was described in a descriptive manner. 	<p>speaking or manual labor than those who did not apply.</p> <ul style="list-style-type: none"> 88% of patients were successful in obtaining SSDI. Reasons for not applying: early retirement (24%), application process too complicated (21%), not knowing how to apply (12%), never thought about applying (13%), did not think they were sick enough for application (10%), reluctant to admit to being disabled (8%), did not want government involvement in live (6%), did not think they would get it and therefore did not try (4%) and concerns about legal costs for the process (2%). 82% of patients felt that they were too disabled to work full-time after M = 3.4 years after diagnosis (SD = 4). Symptoms that contributed to the inability to work: fatigue (49%), stiffness (47%), tremor (38%), bradykinesia (35%) and medication side effects (including sleepiness; 6%).

Note: SF-12 = 12-Item Short Form Health Survey; 15D = 15 Dimensional QoL measure; SF-36 = 36-Item Short Form Health Survey; ADL = Activities of Daily Living; BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory; BSI-18 = Brief Symptom Inventory 18; CIRS-G = Cumulative Illness Rating Scale for Geriatrics; EQ-5D = EuroQoL QoL questionnaire; GP = General Practitioner; H&Y = Hoehn & Yahr scale; IADL = Instrumental Activities of Daily Living; IoN = Institute of Neurology LiSat-11 = Life Satisfaction Questionnaire 11; LWF = Left the WorkForce; MMSE = Mini Mental State Examination; NA = Not Available; OARS = Older Americans' Resources and Services Scale; PD = Parkinson's disease; PDAAD = PD patients with Ambulatory Assistance Device; PDS = Parkinson Disease Society; PDQ-39 = Parkinson's Disease Quality of Life Questionnaire; QoL = Quality of Life; QR = Quartile Range; SSDI = Social Security Disability Insurance; UPDRS = Unified Parkinson's Disease Rating Scale.

^a Data described in this study is also partly described in Banks & Lawrence (2006) and Schrag et al. (2003).

Finnish studies revealed that PD patients stopped working about 5–6 years earlier than the general Finnish population [11,12]. A German study found that PD patients leave the workforce approximately seven years earlier than the German average [13], while an Irish study found that PD patients retire 4–5.5 years earlier than the Irish population [14]. Regarding gender differences, inconsistent results were found. One study reported that women with PD retired approximately 3.5 years earlier than men [13], while another study indicated that male PD patients retired 3 years earlier than female patients [14].

3.2. Number of PD patients in the workforce

Compared to healthy individuals, PD patients reported more often dissatisfaction with their work situation and experiencing work demands that exceed their abilities [15], which might lead to a decreased life satisfaction [15]. Furthermore, 23%–92% of patients reported that PD worsened their work capacity or that they retired early because of their disease [11–13,16]. A direct consequence of early retirement of PD patients is that the percentage of working patients compared to the number of working individuals in the general population is much lower. For example, after the age of 40 16% of patients are working compared to 71% of the general Finnish

population [12] and male patients older than 45 years have a significantly lower employment rate than age-matched males in the Irish population (i.e. 74% of patients was unemployed compared to an expected unemployment rate of 47% based on the Irish population [14]).

The relationship between the number of patients that remain in the workforce and the duration of the disease differs between studies, which appears at least partly to be due to the sample included. In a group of Finnish PD patients under 65 years of age it was found that the percentage of employed patients dropped from 42% to 15% during the first three years post-diagnosis [12]. Murphy et al. [14] included a group that was diagnosed at age ≤ 65 years with current age ≤ 75 years and showed that approximately 88% of patients were still working one year post-diagnosis. This number dropped to 40% five years after diagnosis and to 14% ten years post-diagnosis with a median time to loss of employment of seven years. These numbers were lower in the study of Banks & Lawrence [16], who only included patients that were either of a working age or in paid employment and reported that only 15.3% of PD patients were still in the workforce five years post-diagnosis. Jasinska-Myga and colleagues [17] examined the number of PD patients in the workforce in more detail by taking the age of patients into account. They examined a prospective cohort of patients in the USA who were still

able to meet the physical or social demands of their job and estimated that five years following baseline visit, 88% of patients with an age lower than 70 years and a disease duration of less than 4 years was still able to work. This number dropped with increasing age and increasing disease duration to 43% in patients who were older than 70 years and who had a disease duration of more than 4 years [17]. These findings are consistent with several other included studies showing negative associations between age, disease duration and time in employment after disease onset [e.g. 12,14,15,18,19]. Two studies made a distinction between full-time and part-time employment. In a Swedish sample of working aged patients, it was found that within five years after diagnosis 28.6% of patients were still full-time employed, which dropped to 15.2% five to nine years post-diagnosis and to 6.1% ten years post-diagnosis. The following results were found concerning part-time employment respectively: 24.3%, 23.5% and 18.2% [15]. In a sample of PD patients living in the UK with age-of-onset before 65 years and with a known employment history, full- and part-time employment rates were lower. Five years post-diagnosis, 6–10% had a full-time job while 7% had a part-time job; ten years post-diagnosis only 2–6% worked full-time and 3–5% worked part-time [20]. When comparing the number of employed PD patients who just received the diagnosis to PD patients who use an Ambulatory Assistance Device (e.g. a wheelchair), it was found that the latter group was at higher risk of becoming unemployed (hazard ratio 2.08 vs. 5.01 respectively [21]). Finally, it was demonstrated that 67% of a sample of patients who were diagnosed before the age of 60 were eligible for Social Security Disability Insurance which provides insurance benefits to employees who can no longer work due to their medical condition [22].

3.3. Motor symptoms

When studying symptoms that have a debilitating effect on the ability to work, several of the included studies ($n = 7$) showed that motor symptoms have an adverse effect. Jasinska-Myga et al. [17] included PD patients in different disease stages and revealed that a high postural instability score, a Hoehn and Yahr (H&Y) score higher than 2 and a high total score on the Unified Parkinson's Disease Rating Scale were significant predictors of future loss of employment. Similar results were found by Martikainen et al. [12] who showed that most employed patients had a mild disease severity (i.e. median H&Y = 1), while retired patients had a more severe disease severity (i.e. median H&Y = 3). Also when taking a different approach by asking patients which symptoms affected their ability to work, motor symptoms were often mentioned. The most debilitating motor symptom according to patients is slowness (reported by 21%–45.8%), followed by stiffness (7.9%–47%), tremor (18%–38%), fine motor skills (25.6–30.8%), speech problems (11.0%), difficulties walking (9.3%) and poor balance (9.3% [15,16,22]). Consistent with these findings is a study showing that patients who retired because of PD reported a more severely impaired physical functioning and higher levels of bodily pain than employed patients [16]. Furthermore, it was demonstrated that patients who applied for Social Security Disability Insurance were more often in jobs that required public speaking and manual labor compared to patients who did not apply [22]. Banks & Lawrence [16], however, showed that within the group of retired PD patients, the proportions of patients who worked in manual or non-manual jobs was similar. Furthermore, even though one study indicated that white-collar type of work was positively correlated with the ability to stay employed for longer [12], other studies failed to replicate this finding [14,16].

3.4. Non-motor symptoms

Six of the included studies also took non-motor symptoms into account. According to 18%–49% of patients, fatigue is the most debilitating non-motor symptom in relation to the ability to work, followed by stress intolerance (11.5%–35.6%), impaired memory and concentration (14.1%), lack of confidence (7.0%), anxiety and panic attacks (4.4%), depression (3.1%) and visual problems (2.2% [12,14–16,22]). Also when directly comparing PD patients who left the workforce to patients who are still employed, it was found that the former group reported more symptoms of depression and anxiety, a higher level of psychiatric distress, a decreased mental health related quality of life, a lower vitality and more difficulties with social and emotional functioning than employed patients [16,18]. Consistent with these findings, Schrag and colleagues [19] revealed that young-onset PD patients reported more symptoms of depression than older-onset patients.

3.5. Treatment

Neither the number of appointments with the general practitioner or the specialist in the outpatient clinic nor the accessibility to a multi-disciplinary team had an influence on the duration of employment post-diagnosis [16]. However, patients who reported that decisions regarding pharmacotherapy were influenced by how pharmacotherapeutic changes might affect their ability to work, worked longer post-diagnosis than patients who did not take the impact of pharmacotherapy into account [16]. Indeed, when patients were asked to name factors that influenced their ability to work, 6% reported that they were limited due to medication side effects [22]. Surprisingly, only one study directly examined the effects of medication on the ability to work [23]. Korchounov and colleagues [23] included thirty full-time employed PD patients who were treated during a 2-year period with either levodopa and entacapone or levodopa and a placebo. The results indicated that the combination of levodopa and entacapone had a more positive effect on the ability to work compared to the use of levodopa and a placebo, i.e. patients who used levodopa and entacapone worked longer post-diagnosis, retired less often and showed a lower annual medical absenteeism than patients who used entacapone and a placebo [23]. No study examined the effects of non-pharmacological treatments; only Gustafsson et al. [15] reported that vocational rehabilitation might have a positive effect on the ability to work.

3.6. Adjustments at workplace

Adjustments at the workplace appear to have a positive effect [12,14–16]. The number of patients who requested and received adjustments differs, however, between studies. Murphy and colleagues [14] observed in their sample that 77% of employed patients made adjustments at the workplace, while 68% of unemployed or retired PD patients indicated that adjustments at work would have helped them to stay longer in the workforce. Lower numbers were reported by Gustafsson and colleagues [15] who found that 33.7% of patients received help from their employer, while 14.4% suggested that they did not get the help they actually needed [15]. According to Banks & Lawrence [16], only 18.2% of patients asked for adjustments at the workplace, which were not supported or granted by employers in 26.2% of cases. When distinguishing between full-time and part-time working, Martikainen et al. [12] found that 31% of full-time working and 45% of part-time working PD patients received some adjustments at their workplace. Twenty-one percent of full- and part-time working patients wished, however, further adjustments and 31% would

like to retire [12]. Only one study asked patients which changes at workplace they consider as most helpful. According to patients, changes in the work schedule and type of work as well as the freedom to use more time to complete tasks were experienced most useful [14].

3.7. Direct and indirect costs

Keränen et al. [11] found that the direct costs of PD to society, such as hospitalization, and medication, covered up to 41% of the total cost burden of PD. Indirect societal costs of PD were even higher, with early retirement due to PD making up for 43% of the total costs. Employed PD patients were more worried that they would not have sufficient money in the future compared to unemployed patients [16]. These worries are supported by findings showing that patients who left the workforce had a lower income than employed patients [18]. Also, patients who were younger than the age of 60 received a lower monthly income than individuals without PD of a similar age [13]. Differences regarding income were, however, not found for patients aged 65 years and older [13] and between employed individuals with and without PD [21]. Loss of earnings, however, appears to depend strongly on the age-of-onset with simulated loss of lifetime earnings increasing from 0.2% in patients diagnosed at the age of 75 years to 39.1% in patients diagnosed at the age of 45 years [21].

4. Discussion

PD has a detrimental influence on the capacity to work. Patients retire several years earlier than individuals without PD; a trend that has been demonstrated in different countries including Germany, Ireland and Finland [11–14]. The capacity to work appears to decrease relatively rapidly in the first years after diagnosis [12,14–17,20]. The number of years patients work post-diagnosis depends, however, on the age-of-onset, with a younger age-of-onset being more often associated with a longer duration of employment post-diagnosis than an older age-of-onset [12,14,16,20]. The number of PD patients that still work five to ten years post-diagnosis differs strongly between studies, which is at least partly caused by the fact that the studies described in this review used different in- and exclusion criteria.

Both motor and non-motor symptoms have a negative influence on the ability to work, with slowness and fatigue being the most debilitating symptoms according to patients [15,16,22]. However, also other symptoms were frequently mentioned such as stiffness, tremor, fine motor skills, stress intolerance, impaired memory and concentration and symptoms of depression and anxiety [15,16,22]. Furthermore, even though some studies indicated that patients with manual occupations experienced more limitations than patients in non-manual jobs or in white-collar types of work [12,22], other studies could not confirm these findings [14,16]. Therefore, when assessing and advising PD patients regarding the ability to work both motor and non-motor symptoms need to be taken into account. This is particularly relevant since PD is a heterogeneous disease with large inter-individual differences [24,25]. It is therefore likely that the extent to which a certain job can be performed depends on the interaction between job demands and the presence of specific symptoms.

Not much is known about the effects of treatment on the capacity to work of PD patients. Even though patients reported that taking a possible negative influence of changing their medication scheme into account has a beneficial effect on the ability to work, only one study directly examined the effects of pharmacological treatment [23]. This study provides some evidence that the use of levodopa and entacapone allows patients to stay longer in the

workforce than patients treated with levodopa and a placebo [23]. However, only a small group of patients was included in this study [23] and more research on the effects of pharmacological treatment is urgently needed. Similar applies to the effects of Deep Brain Stimulation of the subthalamic nucleus (STN-DBS) on working capacity: The EARLYSTIM study, for example, showed that STN-DBS in patients younger than 60 years, with a recent onset of motor complications and a mild-to-moderate impairment in occupational functioning, had a positive effect on quality of life, including mobility, emotional well-being, stigma and bodily discomfort [26]. Of equal importance are studies focusing on non-pharmacological treatments aiming at compensation and adaptation, since it was assumed that vocational rehabilitation might have a positive effect on work capacity [15]. Furthermore, there is a strong need of PD patients for adjustments at the workplace [12,14–16]. To what extent patients ask for adjustments at their workplace appears to differ between countries. There are no studies comparing matched samples of PD patients from different countries regarding their requests for workplace adjustments, but the percentages reported in different studies (with different samples) appear to vary. For example, it seems that PD patients from Ireland ask considerably more often for adjustments than patients from the UK (Ireland: 77%; UK: 18.2%). It remains unclear whether the percentages reported for each country are reliable or caused by differences in disease, job characteristics, national health services, social legislations or knowledge of patients regarding their national health service and their rights for support. Unfortunately, not all employers support their employees with PD, which might be caused by the fact that strategies and techniques developed for counter-acting symptoms of PD are barely known to patients and employers. The Job Accommodation Network [27] gives useful advice on how to accommodate employees with PD, such as providing ergonomic workstation designs or writing aids. Furthermore, simple solutions, such as automatic door openers, can make a big difference and are often more cost-effective than hiring new personnel. Also, introducing flex work or giving patients the opportunity to use resting areas, may relieve burden of patients since they might maintain their productivity [27]. Better workplace adjustments and an individually tailored application of (non-)pharmacological treatments appears crucial since early retirement covers a large part of the indirect societal costs of PD [11]. Accommodations could also have a positive effect on patients' well-being, because employed PD patients expressed their worries about a future lack of income when they are not able to work anymore [16]. As younger patients are more likely to still be part of the workforce, it is not surprising that the loss of lifetime earnings is significantly higher in patients diagnosed at a relatively young age-of-onset compared to patients with an older age-of-onset [21].

Despite only thirteen studies have been performed so far on the topic of work capacity in PD, the results provide reasonable insight into work related issues patients are confronted with. However, it has to be pointed out that many aspects of relevance have not been considered so far. First, most studies use a dichotomous approach to defining work capacity by dividing patients into an employed and an unemployed group [11,16,18]. Only few studies used a more detailed approach by distinguishing between full- and part-time employment and between different types of unemployment (e.g. 'retired because of PD', 'retired because of age' [12–15,19,20]). None of the studies provide, however, a tool that can be used to assess work capacity. Work capacity is not similar to being employed or not, since unemployed patients might be able to work and may be without a job for other reasons than the inability to work. Moreover, employed PD patients might experience a reduced capacity to work and may be on sick leave for undefined periods of time. By definition, capacity encompasses ability, skills, knowledge,

accomplishments, adequacy and competence. A detailed assessment tool should therefore be developed for future research in order to assess whether or not an individual with PD is able to work. By creating an overview of a patient's strengths and weaknesses, adjustments can also be applied in a more specified manner.

Second, several of the included studies used questionnaires that were specifically designed for the study. Since the psychometric properties of these questionnaires were not examined is not clear whether reliable and valid results were obtained.

A third major drawback of the studies is that none assessed cognitive functioning of patients in an objective manner. The integrity of cognitive functions such as memory, attention and executive functioning is a crucial prerequisite of many different types of work. Cognitive impairment is, however, a frequent symptom of PD with approximately 25% of newly diagnosed PD patients already showing cognitive impairment [28] and with the majority of patients presenting impairment sometime during the course of the disease [29,30]. It is therefore of utmost importance to take cognition into account, preferably in a large prospective longitudinal study on work capacity of patients with PD. In this context, psychometric assessments of cognition should be performed next to a registration of patients' self-reports as objective and subjective evaluations of cognition have been shown to assess different aspects of functioning [31].

Finally, a topic that is rarely addressed in research on PD and that appears particularly relevant in the context of working capacity, is stigmatization. Especially young PD patients report higher levels of stigmatization compared to older patients [19], since they often feel that they do not get the support and understanding they deserve. Consequently, young PD patients might become less willing to discuss the work related difficulties they experience and might not ask for adjustments as they fear rejection or a lack of empathy. Stigmatization and particularly self-stigma (i.e. internalization of a 'new degraded identity' by the individual [32]) and public stigma (i.e. negative stereotypes about out-group members [33]) thus need to be addressed more often in the context of the working capacity of patients with PD.

In conclusion, patients with PD retire earlier than the general population and both motor and non-motor symptoms contribute to a reduced working capacity. Early retirement is associated with high societal costs and, at an individual level, a younger age-of-onset is associated with a higher lifetime earnings loss. Many employed PD patients ask for adjustments at their workplace. However, these are not always supported or granted by their employers. It appears to be particularly relevant that employers and colleagues of PD patients as well as patients themselves are informed about (1) health issues related to PD and their possible consequences and (2) strategies and techniques developed to counteract motor and non-motor impairments of PD in order to enable patients to remain in the workforce for a longer period of time. Furthermore, more research is needed on the working capacity of PD patients, e.g. no tools are available to assess the capacity to work, cognitive functioning has not been taken into account and stigmatization might be a factor that has a major negative influence on the work situation of PD patients and might prevent them from asking support.

Conflicts of interest

None.

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