

Dependency and transfer incomes in idiopathic Parkinson's disease

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ABSTRACT

INTRODUCTION: Idiopathic Parkinson's disease (IPD) is a progressive neurodegenerative disorder affecting approximately 1% of the population above 65 years of age. The aim of this study was to define the estimated Danish IPD population and to elucidate source of income and labour market affiliation for working-age IPD patients.

MATERIAL AND METHODS: IPD cases were included through the Danish Register of Medicinal Product Statistics. The participants had to be alive by the end of 2010 and at least twice have cashed in prescriptions on IPD medication in the 2009-2010 period. Information on employment status and transfer income was retrieved through the DREAM database under the Danish Ministry of Employment.

RESULTS: A total of 7,033 estimated IPD patients were identified. The mean age at time of registration (2010, week 50) was 72 years. Overall, 7% of the IPD patients were employed and 5% were self-supportive. In the working age range (18-64 years), 25% were employed and 10% enrolled in supported employment. Compared with the age-adjusted general population, twice as many IPD patients were outside the ordinary labour market and, furthermore, the proportion receiving anticipatory pension was increased three-fold. The majority (89%) of the patients were living at home with a spouse (59%). 11% were nursing home residents.

CONCLUSION: The working age IPD population was more prone to be outside employment and to receive public transfer income than an age-adjusted population sample.

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Idiopathic Parkinson's disease (IPD) is a progressive neurodegenerative disorder of unknown aetiology. Its prevalence is estimated to approximately 1% in the population above 65 years of age and increasing with age [1, 2]. The estimated number of Danish patients suffering from IPD is 6,000-8,000.

The diagnosis is based on clinical criteria, and cardinal symptoms consists of bradykinesia in combination with resting tremor, rigidity and postural instability [3]. IPD is characterised by loss of dopaminergic neurons in the substantia nigra which results in decreased levels of dopamine. The response on motor symptoms to dopaminergic replacement therapy early in disease course is

beneficial. As the disease progresses, patients experience increasing disability and morbidity. In addition to motor symptoms, patients suffering from IPD may also experience cognitive deficits which often include executive dysfunction (planning, initiation), attention and visuospatial perception as well as memory impairment [4]. Other non-motor symptoms include sleep disturbances, autonomic symptoms as well as co-incident depression.

IPD is more prevalent among the elderly population, but IPD also affects younger individuals and individuals in the working age. The group of young-onset IPD patients has a high percentage of impairment of occupational performance and early retirement as well as psychosocial dysfunction [5]. In addition, both motor and non-motor symptoms may cause a reduction in working capacity, and IPD is generally associated with high socioeconomic costs, measured by direct and particularly by indirect costs, as well as a high degree of utilisation of health-care resources and an overall progressive impairment of health-related quality of life [6-10].

The aim of the present study was to define the estimated Danish IPD population, to investigate labour market affiliation for IPD patients in the working age and to elucidate source of income (public transfer incomes).

MATERIAL AND METHODS

Relevant cases for this study were identified as all Danish citizens who collected anti-Parkinson medication in relevant doses at a pharmacy during the study period. The study is register-based. This design was chosen to achieve a population-based approach and to ensure inclusion of patients in the early stages of disease. Participants were captured through the Danish Register of Medicinal Product Statistics. The register holds information on total sales of medicinal products since 1994 for the primary sector and in 1997 the register was extended to include hospital prescriptions. It is maintained by The State Serum Institute (SSI) and is updated on a monthly basis. In this study, only prescriptions handed out at Danish pharmacies are included.

Participants had to be alive at the end of 2010 and to have redeemed a prescription twice or more for one of the medications shown in **Table 1** in the 2009-2010 period. Prescriptions required an indication of

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 TABLE 1

Classification of pharmaceuticals.

Classification	Pharmaceutical	Constituents	ATC code	Dosage
Dopamine	Duodopa	Carbidopa, levodopa	N04BA02	All
	Levodopa/carbidopa	Carbidopa, levodopa	N04BA02	≥ 2 doses/day
	Sinemet	Carbidopa, levodopa	N04BA02	≥ 2 doses/day
	Sinemet depot	Carbidopa, levodopa	N04BA02	≥ 2 doses/day
	Madopar	Benserazid, levodopa	N04BA02	≥ 2 doses/day
	Madopar depot	Benserazid, levodopa	N04BA02	≥ 2 doses/day
	Levodopa/benerazid "Teva"	Benserazid, levodopa	N04BA02	≥ 2 doses/day
	Stalevo	Levodopa, carbidopa, entakapon	N04BA03	All
MAO-B inhibitors	Azilect	Rasagilin	N04BD02	All
	Selegilin	Selegilin	N04BD01	All
	Eldepryl	Selegilin	N04BD01	All
COMT inhibitors	Comtan	Entakapon	N04BX02	All
	Comtess	Entakapon	N04BX02	All
	Tasmart	Tolcapon	N04BX01	All
Dopamine agonists	Apo-go	Apomorfin	N04BC07	All
	Pramipexol	Pramipexol	N04BC05	At least ½ tablet tds
	Pramipexol depot	Pramipexol	N04BC05	All
	Oprymea	Pramipexol	N04BC05	At least ½ tablet tds
	Oprymea depot	Pramipexol	N04BC05	All
	Cabaser	Cabergolin	N04BC06	≥ 2 mg/day
	Cabergolin	Cabergolin	N04BC06	≥ 2 mg/day
	Permax (expired 2011)	Pergolid	N04BC02	≥ 0.25 mg/day
	Pergolid (expired 2011)	Pergolid	N04BC02	≥ 0,25 mg/day
	Sifrol	Pramipexol	N04BC05	At least ½ tablet tds
	Sifrol depot	pramipexol depot	N04BC05	All
	Mirapexin	Pramipexol	N04BC05	At least ½ tablet tds
	Requip	Ropinirol	N04BC04	At least ½ tablet tds
	Requip depot	ropinirol depot	N04BC04	All
	Ropinirol	Ropinirol	N04BC04	At least ½ tablet tds
	Ropinirol depot	Ropinirol	N04BC04	All
Neupro	Rotigotin	N04BC09	All	

COMT = catechol-O-methyltransferase; MAO = monoamine oxidase; tds = ter die sumendum (3 times a day).

Parkinson's disease/Parkinson-related dementia corresponding to indication code 351 or 595. Dopaminergic agents belong to ATC group N04B.

As dopaminergic agents have a few other indications than IPD, such as restless legs syndrome and the rare condition of dopamine-responsive dystonia, cut-off values were used regarding daily dose and number of daily administrations. Criteria concerning classification of medication as well as dosage were established by movement disorder specialist TH. Cases who had only one redeemed prescription for anti-Parkinson medication in the 2009-2010 period were excluded to avoid accidental errors in the register.

Participants were cross-checked in the National Hospital Registry (NHR) by International Classification of Disease (ICD-10) code DG 20.9 (Parkinson's disease) between 1994 and 2010.

Information on educational level was retrieved from the educational attainment statistics, information on marital status and residence through the Population

Statistics Register and information on nursing home residents was retrieved through the Statistics Documentation of the Elderly under Statistics Denmark. Information on co-morbidity was evaluated through the NHR by ICD-10 classification registration for 2009 and 2010.

Public transfer income

Information on dependency status was generated through the DREAM database, which is a longitudinal database within the National Labour Market Authority and Ministry of Employment holding information on Danish citizens receiving public transfer income with weekly follow-ups. The DREAM database was established in 1991 and link data from the Ministry of Employment, the Ministry of Education, the Central Civil Register and the Danish Customs and Tax Administration. Since 2008, the database also holds information on employment status. Data reflect the status of included patients in week 50, 2010.

In order to compare data with the general popula-



TABLE 2

Profile of cases.

Total, n	7,033
<i>Gender, %</i>	
Male	57
Female	43
<i>Distribution on age, %^a</i>	
18-39 yrs	0
40-49 yrs	2
50-59 yrs	9
60-64 yrs	11
65-69 yrs	16
70-74 yrs	19
75-79 yrs	19
80-84 yrs	14
85-89 yrs	7
≥ 90 yrs	2
<i>Ethnicity, %</i>	
Danish	96
Immigrants/descendants of immigrants	4
<i>Education, %</i>	
Elementary school	40
High-school	2
Vocational education	36
<i>Higher education:</i>	
Short-cycle	3
Medium-cycle	13
Long-cycle	6
<i>Residency, %</i>	
Nursing home	11
<i>At home:</i>	
Living alone	30
Living with spouse	59

a) Distribution on age sums to 99% due to round-down.

tion, corresponding data from a random sample including 20% of the Danish population were retrieved. An indirect age-standardisation was done within the group from 18 to 64 years of age to adjust for the distribution of age within the IPD group.

All analyses were carried out by author NA who used the research facilities at the Statistics Denmark.

Trial registration: not relevant.

RESULTS

A total of 7,033 patients were identified through the Danish Register of Medicinal Product Statistics according to the established inclusion criteria. By linking the 7,033 cases with the NHR, 3,727 patients were identified as discharged from a hospital with a primary diagnosis of Parkinson's disease (DG20). For the remaining 3,306 patients, this was not the case. There were 4,009 men (57%) and 3,024 (43%) women. The mean age was 72 years. Data on their distribution on age, ethnicity, edu-

cational level, marital status and residency are presented in **Table 2**.

Patients represent the elderly population, and 78% were above 65 years of age at the end of 2010 (week 50) and presumably retired from labour activities. A total of 2% were under the age of 50 years and in total 22% were in the working age (18-64 years).

The patients' level of education reflects the population in general taking into account their age profile.

The majority (89%) were living at home with only 30% of these living alone. In total, 11% of the IPD patients were nursing home residents, although this only applies to 2% of those under 65 years of age. In the IPD population older than 65 years of age, 13% were nursing home residents. This number was 25% for patients above 80 years. The IPD patients have a high degree of co-morbidity, and 71% of the patients had a contact in 2009- 2010 in the NHR distinct from DG20.9 concerning hospitalisation or treatment in an outpatient clinic.

Income status and transfer income

Overall, 5% of the IPD population was self-supportive and presumably employed, and an additional 2% were employed in supported employment. A total of 78% were receiving public retirement pension, and 9% were receiving anticipatory pension. 3% were receiving early retirement benefits.

Sub-group analyses on the patient population (18-64 years) available to the labour market showed that 25% were self-supportive and 10% were employed in supported employment. A total of 43% were receiving an anticipatory pension. A small percentage (4%) was receiving sickness benefits, and 16% were enrolled in the early retirement programme. In total, 75% of the patients aged 18-64 years were receiving public transfer income. The highest proportion of self-supported patients divided by age was found in the age group from 40-49 years and 50-59 years with 31%, descending to 24% in the group under the age of 40 years and 19% over the age of 60 years. Statistics on employment compared with the Danish population in general are presented in **Figure 1**. A description of public transfer incomes is shown in **Table 3**.

Although the proportion of anticipatory pension and supported employment recipients was higher, sickness benefits did not differ between the two groups.

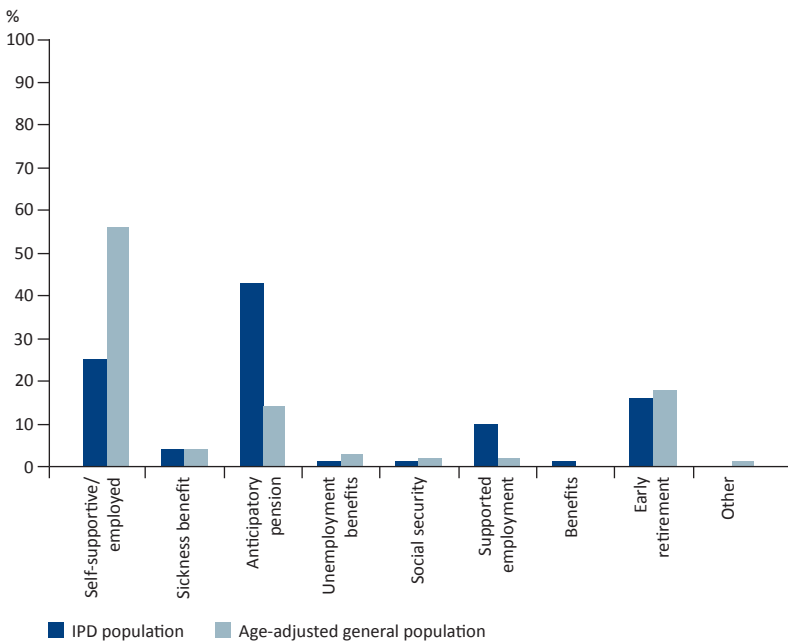
Sub-group analysis on the IPD population (18-64 years) registered in the NHR with an admission under DG 20 was less likely to be self-supportive (19%) and more likely to receive anticipatory pension (49%) than cases without an admission (34%).

DISCUSSION

In this study, we evaluated the dependency status and

FIGURE 1

Employment and dependency status: IPD population and general population, 18-64 years.



IPD = idiopathic Parkinson's disease.

public transfer incomes in the estimated Danish IPD population. To our knowledge, this is the first time data on this issue have been presented.

Results identify IPD as a disease that is mostly prevalent in the elderly population, which is reflected by the fact the majority of participants were receiving public retirement pension. Overall, 95% of the IPD patients were receiving public transfer income. Among working age persons, one third were affiliated to the labour market, but twice as many IPD patients were outside the ordinary labour market, and the proportion receiving anticipatory pension was increased three-fold compared with an age-adjusted population sample. In IPD patients with a prior IPD-related hospital admission, the proportion was even higher than in IPD patients with no admission.

The marked difference in employment may not only be due to motor deficits and physical constraints. The neuropsychological and neuropsychiatric symptoms associated with IPD presumably contribute considerably, with cognitive impairment being among the most prevalent factors. A recent prospective study in a cohort of IPD patients found that age, duration of disease, morbidity (higher United Parkinson's Disease Rating Scale (UPDRS) score and Hoehn and Yeah stage) were associated with an increased risk of future loss of ability to work. The same study also reported a 3.5-fold increased

TABLE 3

Description of transfer incomes.

Transfer income	Transfer income (Danish translation)
Employed – self-supported. No transfer payment ^a	I arbejde – selvforsørgende
Public retirement pension ^b	Folkepension
Sickness benefits ^c	Sygedagpenge
Anticipatory pension ^d	Førtidspension
Unemployment benefits ^e	Dagpenge
Social security ^f	Kontanthjælp
Supported employment ^g	Fleksjob
Benefits ^h	Ledighedsydelse
Early retirement ⁱ	Efterløn

- a) No public transfer income. Presumably the person is employed and self-supportive;
 b) A public benefit administered to Danish citizens over the age of 65 years;
 c) The patient is sick-listed by the employer and receiving sickness benefits.
 d) Anticipatory pension is a social security service provided to persons aged 18-64 years whose capacity to work is substantially reduced due to physical, mental or social reasons.
 e) The person is registered as unemployed by the Public Employment Service. In order to receive unemployment benefits, the patient has to be a member of an unemployment insurance fund.
 f) Social security is administered by the municipalities if the patient is unable to support him-/herself.
 g) Supported employed assist persons with disabilities in being able to be employed in the ordinary labour market on reduced time.
 h) Benefits covers a special benefit provided to persons who have been approved for supported employment, but who are not yet employed.
 i) The early retirement programme offers the opportunity to retire early. The programme is financed by the Danish state and personal contributions.

risk of future loss of ability to work in patients with intellectual impairment at baseline [11]. Withdrawal from the labour market may presumably add to morbidity and may be connected with a decreased quality of life, social implications and may interfere with family life, especially in the young IPD patients [5].

Our results are in keeping with the few previously published studies concerning loss of employment and IPD. Hence, one study reported a mean age of retirement of 55.8 years in the IPD population available to the labour market compared with an overall population-based retirement age of 62 years, and a mean time to loss of employment of 4.9 years from diagnosis [12].

The majority of IPD patients are living at home with a spouse or partner, and a total of 11% are nursing home residents. The need for care varies with disease stages. But since a substantial part of the IPD patients are living at home, a focus on the uncompensated caregivers within the family is important. One study evaluated the impact of living with an IPD patient on the uncompensated non-professional caregivers and found reduced life space and high frequencies of early retire-

ment, sick leave and patient-care related part-time work [13]. Furthermore, an efficient home care nursing system is even more urgent in the part of the IPD population who are single and living at home.

Diagnosing IPD can be challenging since the diagnosis relies on clinical criteria. Patients may have a shorter or longer preclinical period before being diagnosed with Parkinson's disease, and IPD has a broad range of differential diagnoses. IPD patients are being treated in different settings and can be followed in the primary sector (by a practicing neurologist or GP), in an outpatient clinic or in a tertiary centre such as a Movement Disorder Clinic. The patients are presumably most likely followed in the primary sector early in the uncomplicated stages of the disease. Inclusion through medical prescriptions was used to ensure inclusion of this segment of the IPD patients. This group is important to include as the group of patients early in disease is presumably more likely to be eligible to participate in labour-marked activities. Referring only to ICD-10 codes from hospital and outpatient clinics data would bias results towards the IPD group in late disease with increased severity of motor impairment and co-morbidity. Furthermore, some patients may be misclassified in the NHR.

The study has several limitations. No medical record review of patients was performed. This caveat was dealt with by excluding patients with other indications than IPD on the prescription or with a dosage not likely to be compatible with IPD. Some IPD patients may be newly diagnosed and collected medication only once; and for some patients receiving dopaminergic medication in 2010, the diagnosis may later have been revised. No data were collected on the duration of disease, severity of disease and time of diagnosis to characterise the IPD group outside the labour market.

Some patients suffering from atypical Parkinsonism, like multiple system atrophy, corticobasal degeneration, progressive supranuclear palsy or dementia with Lewy bodies, will be present in the material. These diseases are relatively infrequent and they are characterised by a poor Levodopa response, but also with an increased morbidity. Based on previous studies with review of medical journals on IPD patients, this group is believed to cause bias [14]. Furthermore, some patients may suffer from vascular Parkinsonism. The results were compared with the results of an age-adjusted population sample but not adjusted for gender. The authors are aware that since IPD it slightly more prevalent in men than in women in the present material, this will cause minor bias.

In summary, IPD is a disease associated with high socio-economic costs, and the results of this study emphasised that IPD is associated with indirect costs due to loss of working capacity. Strategies to ensure optimal

treatment in specialised outpatient clinics focusing on motor as well as non-motor symptoms, social aspects concerning family support and employment may help to improve health-related quality of life (HR-QOL) in IPD patients in the working age [7]. Data reflect the fact that IPD is a progressive disease with deficits that make it difficult for Parkinson patients to maintain an affiliation with the ordinary labour market.

CONCLUSION

Based on the Danish Register of Medicinal Product Statistics, the Danish IPD population is estimated to count 7,033 individuals in late 2010. IPD was associated with reduced affiliation with the labour market. Compared with the age-adjusted general population, twice as many IPD patients were outside the ordinary labour market and, furthermore, the proportion receiving anticipatory pension was increased three-fold.

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