Journal of Neurology and Neurological Disorders
Volume 10 | Issue 2
ISSN: 2456-5482

Research Article Open Access

Impact of Socioeconomic Determinants on Cost of Care and Quality of Life in Parkinson's disease

Michael Mounié[1, 2, *], **Thavorn Kednapa**[3], **Margherita Fabbri**[4], **Christine Brefel-Courbon**[4], **Jamal Atfeh**[5], **Natalia Del Campo**[4], **Tiago Mestre**[6], **Estelle Harroch**[7], **Tatiana Trouchko**[8], **Laurent Molinier**[1, 2, 9], **Olivier Rascol**[4], **Richard Dodel**[10] and **Nadège Costa**[1, 2]

[1]The Health Economic Unit, Toulouse University Hospital, Toulouse, France
[2]INSERM UMR 1295, CERPOP, Toulouse III University, Toulouse, France
[3]Ottawa Hospital Research Institute (OHRI), The Ottawa Hospital, Ottawa, Ontario, Canada
[4]Clinical Investigation Center CIC1436, Department of Clinical Pharmacology and Neurosciences, Parkinson Expert Centre and NeuroToul Center of Excellence in Neurodegeneration (COEN) of Toulouse INSERM, University of Toulouse 3, CHU of Toulouse, Toulouse, France
[5]Hospices Civils de Lyon, Pôle de Santé Publique, Service d'Evaluation Economique en Santé, Lyon, France
[6]Parkinson's Disease and Movement Disorders Center, Division of Neurology, Department of Medicine, The Ottawa Hospital Research Institute, University of Ottawa Brain and Mind Institute, Ottawa, Canada
[7]Centre Expert Parkinson, Neurosciences department of the University Hospital of Toulouse, CHU Purpan, F-31059 Toulouse, France
[8]University Hospital Center of Toulouse, Toulouse, France
[9]Department of Medical Information, University Hospital of Toulouse, Toulouse, France ;
[10]Chair of Geriatric Medicine and Center for Translational Neuro- and Behavioral Sciences, University Duisburg-Essen, Essen, Germany

[*]**Corresponding Author:** Michael Mounié, 1The Health Economic Unit, Toulouse University Hospital, Toulouse, France, Tel.: +033677708149, E-mail:mounie.m@chu-toulouse.fr

Citation: Michael Mounié, Thavorn Kednapa, Margherita Fabbri, Christine Brefel-Courbon, Jamal Atfeh (2024) Impact of Socioeconomic Determinants on Cost of Care and Quality of Life in Parkinson's disease, J Neurol Neurol Disord 10(2): 202

Received Date: October 20, 2024 **Accepted Date:** November 20, 2024 **Published Date:** November 25, 2024

Abstract

Objective: We aim to investigate the association between socioeconomic determinants, the costs of care, and the Health-Related Quality of Life (HRQoL) of Parkinson's Disease (PD) patients and their caregivers.

Methods: This study is a part of the Integrated Care for PD (ICARE-PD) international study and focuses on patients recruited in 2021, followed over a 3-month period. Demographic, clinical, socio-economic and healthcare consumption data of patients, as well as HRQoL of patients and caregivers, were recorded. The societal perspective was employed to evaluate the cost of PD management. Regression models on costs and HRQoL were implemented to assess factors impacting these outcomes and considering age, gender and severity adjustment.

Results: Socio-economic data were collected for 72 patients, and they were included in the analyses. Informal care constituted the primary component of care, accounting for 3,791€, 66% of the total cost (i.e. €5,706). Informal care costs increase significantly as the HRQoL of both patients and caregivers decreases. Furthermore, a limited impact was observed between socioeconomic characteristics and the cost of management or the HRQoL. No significant impact (p~0.10) were identified between the level of education and the cost of management, and no significant impact was assessed between the level of income and HRQoL.

Conclusion: We have assessed an association between the HRQoL of patients and caregivers, both of which impact care costs, notably when considering the informal care cost. Furthermore, limited associations between patients' socio-economic characteristics, quality of life, and care costs have been estimated. Despite our tempered result, we emphasis the need to implement tailored interventions that address the unique needs of both PD patients and their caregivers, with special consideration given to socioeconomic factors.

Keywords: Parkinson Disease; Costs; Quality of Life; Socioeconomic Determinants

Background

Parkinson’s Disease (PD) represents the second most common neurodegenerative disease accounting for 6 million of PD patients worldwide and 1 million incident cases in 2017 [1, 2]. In France, more than 166,000 PD patients were treated in 2015 and projections have estimated an increase to 260,000 patients by the year 2030 [3, 4]. PD is characterized by both motor and non--motor symptoms that significantly impact the health-related quality of life (HRQoL) of patients and caregivers [5]. A meta-analysis conducted in 2021 revealed a considerable reduction in HRQoL among PD patients compared to healthy controls. The physical function and mental health domains are consistently the most affected [6]. Demographic, socio-economic, and clinical characteristics are among the main factors influencing the HRQoL of PD patients [7]. Informal caregivers play a crucial role in PD care management, bearing a significant burden in providing physical and emotional support to patients, as well as managing out-of-pocket expenses [8]. The HRQoL and emotional burden experienced by caregivers are closely linked with the functional status and HRQoL of PD patients [9, 10].

Due to both formal (i.e., paid care services) and informal (i.e., unpaid care services) care required for PD patients, this disease has a significant economic impact on society as a whole, particularly affecting healthcare insurers, patients, and families. The cost of managing PD is well-documented and increases with the severity of the disease stages [11-15]. A 2021 Swedish study assessed an annual care cost of €15,958, which increased from €5,893 to €99,755 depending on the Hoehn and Yahr (H&Y) stages [16]. Nevertheless, studies considering out-of-pocket (OOP) expenses for formal care and informal care remain sparse. Informal care costs increase with the Hoehn and Yahr (H&Y) stage and are particularly significant in stage IV. The Care of Late Stage Parkinsonism (CLaSP) study aimed to describe the care costs of late-stage PD in six European countries, with results currently available for Germany and Sweden [17, 18, 19]. The 3-month informal care costs for H&Y stages IV and V were approximately €11,000, while direct costs were estimated at €13,719 and €8,749, respectively, in both countries. While the impact of clinical factors (such as disease duration and severity) or demographic factors (such as age and gender) on PD management costs and HRQoL has been extensively studied, the influence of socio-economic factors or caregivers' HRQoL on these outcomes remains underrepresented [16 - 19].

In this study, we hypothesize that socioeconomic determinants impact the cost of care for PD patients, notably through the caregiver and associated informal care cost, and their HRQoL, notably through the additional cumbersome due to financial aspect of the PD. In this context, we hypothesize that patients with lower socioeconomic status incur higher costs of PD care, while those with higher socioeconomic status experience better HRQoL. Therefore, our objectives are to describe the cost of care for PD, considering informal care costs, and to investigate the association between socioeconomic determinants and both the costs of care and HRQoL for PD patients.

Methods

Population and Study Design

This study is part of the Integrated Care for Parkinson's Disease (ICARE-PD) international initiative aimed at addressing the complex care needs of Parkinson's disease in contemporary society [20, 21]. Patients were recruited between February and July 2021 from the Parkinson's disease expert center at the University Hospital of Toulouse in southern France. Eligible participants included patients diagnosed with Parkinson's disease at various disease durations or Hoehn & Yahr (H&Y) stages, proficient in French language. All patients who expressed willingness to participate were included, and no other exclusion criteria were applied.

Data on demographics, clinical (disease history, H&Y stages) and socio-economic factors (educational level, current and former occupation, income source and level), and health-related quality of life (measured using EQ-5D-5L [22]) for both patients and caregivers, along with healthcare utilization over the preceding 3 months were collected through telephone interviews by trained nurses analogously to the “Care of Late-Stage Parkinsonism” (CLaSP) study [18, 19].

Disease severity was determined using a scale developed by the iCARE consortium, derived from the H&Y scale and disease duration. This scale comprises the following categories: 1) Newly diagnosed PD - PD diagnosis by a specialist ≤2 years ago AND H&Y<3; 2) Intermediate stage PD - PD diagnosis by a specialist between 2 and 8 years ago AND H&Y<3; 3) PD with complex care needs - PD diagnosis by a specialist ≥ 8 years ago OR H&Y stages ≥ 3.

Economic Evaluation

Patients were asked to report healthcare consumption for the 3 months preceding the interview. Healthcare consumption included inpatient stays, medical visits (both with general practitioners and specialists), paramedical procedures, medications, medical devices, transportation, home care, and informal care, which encompassed Basic Activities of Daily Living (BADL), Instrumental Activities of Daily Living (IADL), and supervision. The cost components were valued using various data sources which are fully described in the Additional file 1. In France, PD patients are covered under the Long-Term Disease management scheme, which provides nearly 100% reimbursement for PD-related care. Out-of-pocket expenses for reimbursed care are minimal in this context. This study adopts the societal perspective, which encompasses costs reimbursed by the French National Health Insurance (FNIH) as well as informal care costs and any out-of-pocket expenses incurred. Costs were expressed in €2020 and adjusted for inflation using the French annual consumer price index when necessary.

Additional file 1 – e-Table 1: Sources of unit costs

Cost components	Unit	Cost per unit (€, 2020)	Sources
Participant stays (Exact value)			
Hospitalization	Participant stay	12 397.7 (neurology)	French Technical Agency for Medical Information on Hospitalization
	Participant stay	1241.03 (urinary infection)	French Technical Agency for Medical Information on Hospitalization
Consultation (Exact value)			

General practitioner	Visit	25	French Healthcare Insurance (GNPA*)
Cardiologist	Visit	51	French Healthcare Insurance (GNPA*)
Neurologist/Psychiatrist	Visit	46.7	French Healthcare Insurance (GNPA*)
Other specialists	Visit	25	French Healthcare Insurance (GNPA*)
Informal care	hour	12.77	The local authority job site**
Paramedical procedures (Mean Γ(shape; scale))			
Nurse	Visit	22.85 Γ(1.38; 16.61)	French Healthcare Insurance (GSB§)
Physiotherapist	Visit	23.5 Γ(22.61; 1.04)	French Healthcare Insurance (GSB§)
Medication (Exact value/daily dose)	Daily dose	From 0.012 to 33.898	French Healthcare Insurance (Drug database)†
Transportation (Mean Γ(shape; scale))			
Ambulance	Trip	97.8 Γ(3.63; 26.98)	French Healthcare Insurance database (GSB§)
Personal vehicle	Trip	19.3 Γ(0.29; 65.63)	French Healthcare Insurance database (GSB§)
Taxi	Trip	53.96 Γ(0.91; 59.09)	French Healthcare Insurance database (GSB§)
light health vehicle	Trip	33.71 Γ(1.94; 17.42)	French Healthcare Insurance database (GSB§)
Medical device			
Non-reimbursed		*Specified by patient*	NA
Reimbursed (Mean Γ(shape; scale))	Walker	99.8 Γ(1.40; 71.2)	French Healthcare Insurance database (GSB§)
	Sleep Apnea	70.2 Γ(2.64; 26.62)	French Healthcare Insurance database (GSB§)
	Wheel chairs I	877.67 Γ(7.69; 114.13)	French Healthcare Insurance database (GSB§)
	Wheel chairs II	72.04 Γ(0.96; 75.1)	French Healthcare Insurance database (GSB§)
	Medical beds	66.7 Γ(0.62; 108.19)	French Healthcare Insurance database (GSB§)
	Apomorphine infusion	663.8 Γ(1.65; 403.46)	French Healthcare Insurance database (GSB§)

[*] *GNPA: General Nomenclature of Professional Acts*

(https://www.ameli.fr/medecin/exercice-liberal/facturation-remuneration/consultations-actes/nomenclatures-codage/ngap; [**]The local authority job site: https://www.emploi-collectivites.fr/grille-indiciaire-territoriale-auxiliaire-soins-principal-1ere-classe/14/42/109.htm ; §GSB: Generalist Sample of the Beneficiaries; †Drug database : http://www.codage.ext.cnamts.fr/codif/bdm_it/index_presentation.php?p_site=AMELI ; Wheel chairs I: electric; Wheel chairs II: manual; Γ : Gamma distribution;

Statistics Analysis

Usual statistics were used to describe baseline characteristics of the PD population. Healthcare consumption was described in terms of the quantity of resource utilization and the associated costs from a societal perspective. For each outcome, the mean cost and the associated 95% confidence interval bootstrapped using bias corrected and accelerated method were implemented. Multivariate analyses were conducted on costs and HRQoL. Generalized gamma regression models with a log link were used to assess variations in costs, while beta regression models were used to assess variations in HRQoL. All models for costs and HRQoL were adjusted for age, gender, and severity

Results

Description of the Population

A total of 72 PD patients participated in the study, with a mean age (SD) of 68.0 (8.1) years and a disease duration of 9.3 (6.9) years. The majority of participants were men (62%) (Table 1).

Table 1: Baseline characteristics of the PD population

	Total population n=72	
Variable	**statistics**	
Age	Years (Mean, Sd)	68,01 (8.1)
Gender	Male (n, %)	45 (62.5)
Duration since disease began (Mean, SD)		9.29 (6.9)
Disease duration classes (n, %)	Advanced (> 8 years)	36 (50)
	Intermediate (2 to 8 years)	26 (36.1)
	Recent (< 2 years)	10 (13.9)
Duration since first appropriate treatment (Mean, SD)		8,86 (6.9)
Hoehn & Yahr stage (n, %)	1	6 (8.3)
	1,5	2 (2.8)
	2	21 (29.2)
	2,5	22 (30.6)
	3	15 (20.8)
	4	5 (6.9)
	5	1 (1.4)
Severity categories	Newly diagnosed PD	9 (12.5)

	Intermediate stage PD	21 (29.1)
	PD with complex care needs	42 (58.3)
Patients with informal care		48 (66.6)
Patient’s HRQoL	Mean (sd)	0.751 (0.24)
	Median (Q1- Q3)	0.841 (0.637 ; 0.897)
Patient’s HRQoL categories	1: HRQoL≥ 0. 8752	25 (34.7)
	2: HRQoL ≥0.7887 & HRQoL<0.8752	24 (33.3)
	3: HRQoL < 0.788	23 (31.9)
Caregiver’s HRQoL	Mean (sd)	0.939 (0.07)
	Median (Q1- Q3)	0.953 (0.932 ; 0.978)
Caregiver’s HRQoL categories	1 : ≥0.95	31 (43.1)
	2 : <0.95	41 (66.9)
Marital Statut (n, %)	Divorced/single	4 (5.6)
	Married/ in relationship/ common law	67 (93.1)
	Widowed	1 (1.4)
Long Term Disease (LTD) scheme (n, %)*		69 (95.8)
Education, (n, %)	High school diploma or lesser	32 (44.4)
	Bachelor's or equivalent	12 (16.7)
	Master's or equivalent	28 (38.9)
Current occupation (n, %)	Employed	6 (8.3)
	Intermediate profession	2 (2.8)
	Retired	58 (80.6)
	Senior executive and intellectual profession	2 (2.8)
	Without professional activity	4 (5.6)
Former occupation (for retired n=58) (n, %)	Craftsman, entreprenor	3 (5.2)
	Employed	28 (48.3)
	Farmer	2 (3.4)
	Intermediate profession	1 (1.7)
	Senior executive and intellectual profession	23 (39.7)
	Worker	1 (1.7)
Current source of income (n, %)	Disability Pension and/or other	7 (9.7)
	Retirement income	43 (59.7)
	Retirement income and other	14 (19.5)
	Salary ± other	8 (11.1)
Level of income (n, %)	< 42 000 €	35 (48.6)

	Between 42000€ and 144 000€	37 (51.4)

[*] Special scheme allowing 100% of PD related care reimbursement

The mean HRQoL of PD patients was 0.75, while that of caregivers was 0.94. Patients were distributed across all H&Y stages, with the majority falling between stage 2-3 (about 80%), and a large proportion of patients had an advanced disease duration (> 8 years). According to the severity classification used, 12.5% were classified as "newly diagnosed PD", 58.3% were in the “Intermediate stage PD”, and 29.1% had “complex care needs PD”. The study population was well-educated, with over 38.9% of patients holding a Master's degree or equivalent. The majority of PD patients were retired (81%) and had retirement incomes (79%), among which a significant proportion having been employed (48%) or in senior executive and intellectual professions (40%). Finally, half of the group had an income of less than €42,000, while the second half had an income between €42,000 and €140,000.

Economic Analysis

According to the societal perspective, the mean cost management of a PD patient amount to €5,706 for 3 months follow up (Table 2).

Table 2: Three-months quantity and costs (€2020) description according to cost components

	Quantity	**Costs**
	Mean [95 IC]	**Mean [95 IC]**
Inpatient stays	0.1 [0 ; 0.1]	550 [176 ; 1533]
Consultation	3.6 [3 ; 4.1]	129 [111 ; 160]
General practitioner	1.5 [1.2 ; 1.7]	37 [31 ; 43]
Specialist	1.9 [1.6 ; 2.5]	84 [71 ; 110]
Neurologist	1.5 [1.2 ; 2]	69 [56 ; 96]
Other Specialists*	0.5 [0.3 ; 0.8]	16 [10 ; 32]
Other consultations**	0.2 [0 ; 0.5]	8 [3 ; 24]
Paramedical acts	20 [15.9 ; 24.2]	515 [420 ; 645]
Orthophonist	4.7 [2.8 ; 7.4]	125 [79 ; 217]
Physiotherapist	16.6 [13.4 ; 19.8]	386 [308 ; 463]
Others paramedical acts***	0.2 [0.1 ; 0.5]	4 [1 ; 12]
Medications	-	292 [205 ; 468]
LTD for PD care	-	223 [169 ; 358]
Not in LTD for PD care	-	69 [22 ; 294]
Other medications†	-	34 [19 ; 56]
Medical Device	0.3[0.1 ; 0.5]	172 [61 ; 464]
Transportation	2.6 [2.3 ; 2.8]	207 [157 ; 375]
Personal vehicles	1.6[1.3 ; 1.7]	109 [88 ; 139]
Medical vehicles	0.6 [0.3 ; 0.9]	28 [15 ; 47]
Other transporation‡	0.4 [0.2 ; 0.7]	71 [23 ; 233]

Informal care¥	296.9 [217.9 ; 395.8]	3791 [2794 ; 4972]
BADL	80.9 [58.4 ; 114.1]	1033 [735 ; 1464]
IADL	117.3 [86.5 ; 164.5]	1498 [1070 ; 2068]
SuperVision	98.6 [63.3 ; 157.6]	1260 [785 ; 2086]
Home Care	4.7 [2.1 ; 10.7]	63 [27 ; 177]
Nurse	4.2 [1.7 ; 10.1]	57 [22 ; 165]
Meal	0.1 [0 ; 0.3]	1 [0 ; 4]
Life assistant	0.3 [0 ; 1]	4 [0 ; 13]
TOTAL	-	5706 [4533 ; 7562]

PD: Parkinson Disease; LTD: Long Term Disease; CI: BCA 95% Confidents intervals ;Other Specialist*: Urologist, cardiologist, physiatrist ; Other consultations**: non-conventional care (acupuncture, naturopath) ; Others paramedical acts***: Speech therapist, Osteopathist ; Other medications† : medication not allowed for reimbursing; Other transportations‡ : Taxi, train…; ¥: frequency in hour; No quantity for medication due to the method of valorization ;

Informal care represents the main cost component, accounting for 66% of the total cost (i.e. 3,791€). Informal care is provided for IADLs with 117 hours per patient, resulting in €1,498, followed by Supervision care with 99 hours per patient, leading to €1,260, and BADL care with 81 hours per patient, resulting in €1,033. Informal care costs are followed by inpatient stays (i.e., €550), although only 4 patients required an inpatient stay, paramedical acts (i.e., €515), and medication costs (i.e., €292).

Models on Costs

The impact of educational level, patient's, and caregiver's HRQoL on costs is summarized in Figure 1. Due to the limited sample size and the high variability in costs, we observed large confidence intervals. Nevertheless, we noticed that patients with a Bachelor's degree or equivalent educational level are associated, at a 0.10 significance level, with a cost increase compared to patients with a High school diploma or lower (RR=1.95, CI=[0.92; 4.15], p=0.087). There is no significant difference between the higher and lower educated. Patient HRQoL is highly linked to costs, with costs increasing as HRQoL decreases (RR=1.69, CI=[0.94; 3.05] p=0.084; RR=2.55, CI=[1.27; 5.13], p=0.011). Finally, despite caregivers' HRQoL remaining high, caregivers in the worst 2-quantiles category are associated with 2.05 (CI=[1.31; 3.23], p=0.003) higher management costs compared to caregivers in the best category. HRQoL is heavily correlated with informal care frequency and thus informal care costs, explaining these impacts. Current or past occupation ("Level 1: Employed" vs "Level 2: Senior executive and intellectual profession" vs "Level 3: others") and level of income had no impact on costs.

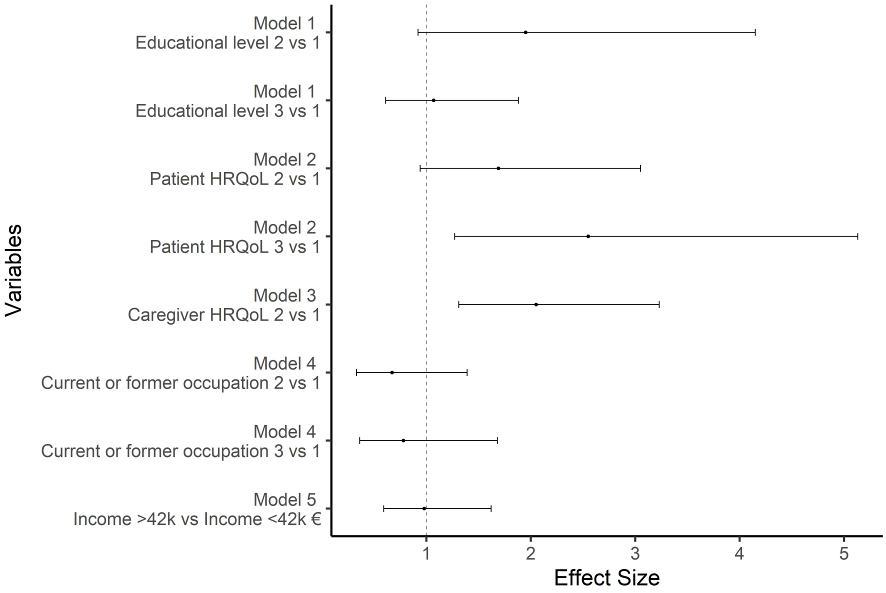

Figure 1: Impact of Educational level, patients and caregiver quality of life, occupation and income on costs

Models on Patient's HRQoL

The educational level, level of income (<42k vs >42k), and current or past occupation had no effect on the patient's HRQoL (Figure 2). Male patients have a higher HRQoL compared to women (RR=1.68, CI=[1.08; 2.62], p=0.022), and the older the patients are, the lower their HRQoL is (RR=0.97, CI=[0.94; 1], p=0.028). Finally, caregivers with the lowest HRQoL are associated with lower HRQoL in patients (RR=0.60, CI=[0.39; 0.92], p=0.018).

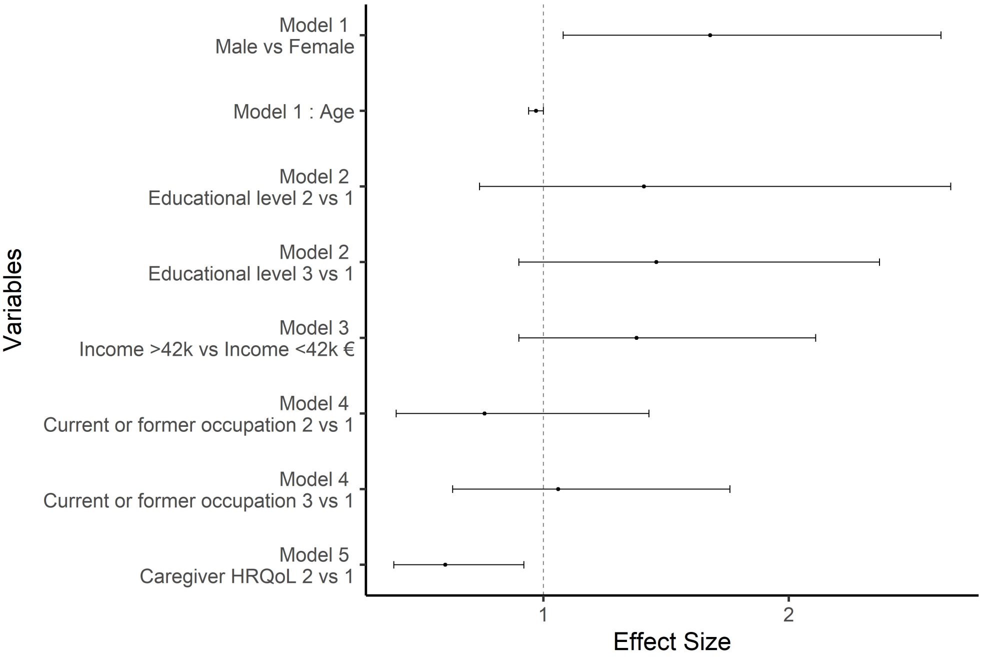

Figure 2: Impact of gender, age, educational level, income, occupation and caregiver quality of life on patient quality of life

Discussion

Our study supports the well-known fact that informal care is the most important component of care costs in PD management within the societal perspective, followed by inpatient stays. We found a negative association between informal care costs and patient's and caregiver's HRQoL. Thus, socioeconomic characteristics (level of education, income, current or past occupation) have limited impact on costs or HRQoL. Only trends at the significant boundary of a 10% risk were found to lead to higher costs in PD patients with higher education levels. To our knowledge, no study has assessed the impact of socio-economic characteristics on these outcomes (i.e. cost and HRQoL). Despite tempered results, we provide additional information to emphasis the need for implementing tailored interventions for PD patients taking into account their caregivers, and with special consideration given to socioeconomic factors.

The lower the patient's and caregiver's HRQoL, the higher the costs of management. Given that informal care represents the vast majority of cost management, these results are consistent. Furthermore, we have estimated that patients with a Bachelor's degree or equivalent have management costs that are twice as high as patients with a high school diploma or lower. This group of patients requires the most informal care and also incurs significant expenses reimbursed by the FNHI. To our knowledge, our study is the first to examine the effect of socioeconomic status on informal care time and costs in PD patients. A study conducted in 2022 in several European countries showed that lower individual socioeconomic resources, including education, income, and wealth, are associated with a higher incidence of informal care provision for older adults and can exacerbate social inequalities [23]. Furthermore, another study focused on the impact of socioeconomic status on the life satisfaction of caregivers of older people and found that informal care provision was negatively associated with the life satisfaction of older adults [24]. It is important to emphasize the impact of socioeconomic status on caregiving time and costs in order to highlight the differences in caregiving burden according to socioeconomic position and to anticipate future care needs of PD patients.

When considering only the costs reimbursed by the FNHI, we observed no impact of patient HRQoL on costs, while a low caregiver's HRQoL led to a two-fold increase in costs (Additional file 2). The cumbersome care management of patients with neurodegenerative disorders, such as PD, affects caregivers more than patient HRQoL, which is accustomed to it [25]. Nevertheless, no significant effect of higher cost management was identified (at the significance boundary of 0.10 threshold, RR=2.11, CI: [0.85; 5.21], p=0.111 and RR=1.73, CI: [0.88; 3.38], p=0.116) for patients in the higher education categories (Additional file 2). It is well-known that higher socioeconomic groups usually have better clinical management [26]. A higher educational level improves access to healthcare and consequently impacts the cost of care reimbursed by health insurance [27]. Highly educated PD patients in our population appear to be more capable of utilizing healthcare services for preventive care and medical follow-up, including visits to neurologists, physiotherapists, speech therapists, and medication when necessary, as well as inpatient care [28]. However, this result should be interpreted with caution because we note that a large portion of our population belongs to a mild or high socioeconomic group. This trend is consistent with findings from other studies, as patients with a lower socioeconomic status are less likely to participate in clinical studies [29, 30].

Additional file 2 – e-Table 2: Models focusing on cost reimbursed by the health insurance

Variable		RR [CI], p
Model 1 : Caregiver HRQoL	>0.95	1
	<0.95	2.11 [1.22; 3.64], p=0.010
Model 2 : Educational level	*Short-cycle tertiary education or lesser*	1
	Bachelor's or equivalent	2.11 [0.85; 5.21], p=0.111
	Master's or equivalent	1.73 [0.88; 3.38], p=0.116

Models 1 & 2 adjusted on age, sex and severity. Only costs reimbursed by the French Nation Health Insurance are considered.

Men were found to have a better HRQoL estimate than women, even after adjusting for age and severity. Among PD patients, women more frequently experienced dyskinesia, depression, and anxiety, whereas men were more affected by tremors or mild motor impairment, which may explain this difference [31]. Depression is the strongest determinant of low HRQoL and may account for the gender effect [32]. Furthermore, depression and fatigue affect women's HRQoL even in the early stages of PD, which explains the burden on HRQoL experienced by women in our data [33]. As expected, there is also a correlation between the HRQoL of PD patients and that of their caregivers [9, 10]. As the disease progresses, patients and caregivers increasingly experience stress and depression [34]. Ultimately, factors such as education level, current or past occupation, and income level did not have a significant effect on HRQoL. However, being financially comfortable may offer advantages in coping with the challenges of the disease. Out-of-pocket expenses for alternative therapies (such as osteopathy or psychology) may be more accessible and less stressful for both the patient and the caregiver; however, we were unable to demonstrate this in our population (higher income level: RR=1.29, CI=[0.85;1.97], p=0.2303). Furthermore, findings from the literature suggest that income is positively associated with HRQoL, particularly due to the social networks that can be accessed for care [35].

This study has several limitations. The main ones include the small size of the population and the fact that patients were recruited from the Parkinson's expert center at the University Hospital, which may not be representative of the overall PD population. Recruited patients may have a higher socioeconomic status than the general Parkinson's disease population, with improved access to care due to the urban setting and multidisciplinary approach of the expert center. Firstly, we may underestimate the association between education or income, HRQoL, and costs. Once a patient is included in the expert center, their management may be similar regardless of their socioeconomic status. PD patients treated in expert centers receive more supervised follow-up, and educational level has little impact on their management. Secondly, patients in expert centers generally have higher levels of severity or are in more advanced stages of the disease. Therefore, we may overestimate the costs of formal or informal care. Furthermore, participants in our study have higher educational backgrounds, which may lead to an underestimation of the impact within the lower category. However, adjustment models were implemented to more accurately assess the true impact of the parameters studied, particularly by considering the severity scale in each model. Causality models should be implemented to more accurately assess the impact of socioeconomic factors on both the cost of care and HRQoL. However, a larger population size, a more representative sample, and complete information on patients and caregivers' data are needed.

In conclusion, low HRQoL in patients or caregivers is synonymous with a deteriorated PD, which has an impact on care costs from a societal perspective, notably due to informal care. According to our data, socioeconomic factors have limited impact on societal cost and only trends to a costlier management was estimated for higher educated groups. Finally, we have highlighted the link between patients and caregivers HRQoL and that female PD patients HRQoL are more impacted by the PD. Interventions must be individually designed to support both patients with PD and its caregivers, such it represents a burden. Particular attention must be given according to patient’s socioeconomics factors which may impact both access to care and quality of life.

Declaration

Ethics Approval and Consent to Participate

Not Applicable

Consent for Publication

Not Applicable

Availability of Data and Materials

We cannot share individual data nevertheless upon acceptable request we may share aggregated data.

Competing Interest

Mounie M., Kednapa T., Brefel-Courbon C., Atfeh J. Del Campo N., Mestre T., Harroch E., Trouchko T., Molinier L., Rascol O., Dodel R., and Costa N. have no financial disclosures to report. Fabbri M. reports honoraria to speak from ABBVie, Bial, Orkyn and International Movement disorder Society (MDS), consultancies for LVL médical and Bial.

Funding

This is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND - www.jpnd.eu (list of national/regional organisations who are funding project, by country, in alphabetical order, e.g., France, Agence National de la Recherche; United Kingdom, Medical Research Council.

Authors' Contributions

All authors have made substantial contributions to (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it, (3) final approval of the version to be submitted.

Acknowledgements

Not Applicable

References

1. Ou Z, Pan J, Tang S, Duan D, Yu D, Nong H, Wang Z (2021) Global Trends in the Incidence, Prevalence, and Years Lived With Disability of Parkinson's Disease in 204 Countries/Territories From 1990 to 2019. Front Public Health, 9:776847.

2. GBD 2017 Disease and Injury Incidence and Prevalence Collaborators (2018) Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet, 392:1789-1858. Erratum in: Lancet, 393.

3. Moisan F, Kab S, Moutengou E, Boussac-Zerebska M, Carcaillon-Bentata L, Elbaz A (2018) Fréquence de la maladie de Parkinson en France. Données nationales et régionales 2010-2015. Saint-Maurice: Santé publique France, 69p.

4. Wanneveich M, Moisan F, Jacqmin-Gadda H, Elbaz A, Joly P (2018) Projections of prevalence, lifetime risk, and life expectancy of Parkinson's disease (2010-2030) in France. Mov Disord, 33:1449-1455.

5. Juneja A, Anand K, Chandra M, Deshpande S, Dhamija R, Kathuria P, Mahajan R (2020) Neuropsychiatric Symptoms and Caregiver Burden in Parkinson's Disease. Ann Indian Acad Neurol, 23:656-660.

6. Zhao N, Yang Y, Zhang L, Zhang Q, Balbuena L, Ungvari GS, Zang YF, Xiang YT (2021) Quality of life in Parkinson's disease: A systematic review and meta-analysis of comparative studies. CNS Neurosci Ther, 27:270-279.

7. Hendred SK, Foster ER (2016) Use of the World Health Organization quality of life assessment short version in mild to moderate Parkinson disease. Arch Phys Med Rehabil, 97:2123-2129.e2121.

8. Carrilho PEM, Rodrigues MA, de Oliveira BCR, da Silva EB, Silva TAAL, Schran LDS, Mendes M (2018) Profile of caregivers of Parkinson's disease patients and burden measured by Zarit Scale: Analysis of potential burden-generating factors and their correlation with disease severity. Dement Neuropsychol, 12:299-305.

9. Martínez-Martín P, Benito-León J, Alonso F, Catalán MJ, Pondal M, Zamarbide I, Tobías A, de Pedro J (2005) Quality of life of caregivers in Parkinson's disease. Qual Life Res, 14:463-472.

10. Martinez-Martin P, Rodriguez-Blazquez C, Forjaz MJ, Frades-Payo B, Agüera-Ortiz L, Weintraub D, Riesco A, Kurtis MM, Chaudhuri KR (2015) Neuropsychiatric symptoms and caregiver's burden in Parkinson's disease. Parkinsonism Relat Disord, 21:629-634.

11. Lökk J, Borg S, Svensson J, Persson U, Ljunggren G (2012) Drug and treatment costs in Parkinson's disease patients in Sweden. Acta Neurol Scand, 125:142-147.

12. Findley LJ, Wood E, Lowin J, Roeder C, Bergman A, Schifflers M (2011) The economic burden of advanced Parkinson's disease: an analysis of a UK patient dataset. J Med Econ, 14:130-139.

13. von Campenhausen S, Winter Y, Rodrigues e Silva A, et al. (2011) Costs of illness and care in Parkinson's disease: an evaluation in six countries. Eur Neuropsychopharmacol, 21:180-191.

14. Noyes K, Liu H, Li Y, Holloway R, Dick AW (2006) Economic burden associated with Parkinson's disease on elderly Medicare beneficiaries. Mov Disord, 21:362-372.

15. Marquez M, Sanchez K, Guzman S, Soto H, De Sarachaga A, Cervantes A, Rodriguez M (2016) Estimating the out-of-pock-

et expenses and transport, caregiver, home adaptation and/or special equipment acquisition costs associated with Parkinson’s disease. Value Health, 19.

16. Hjalte F, Norlin JM, Kellerborg K, Odin P (2021) Parkinson's disease in Sweden: Resource use and costs by severity. Acta Neurol Scand, 144:592-599.

17. Norlin J, Hjalte F, Kruse C, Dodel R, Rosqvist K, Odin P (2022) Quality of life and resource utilization: Swedish data from the Care of Late-Stage Parkinsonism (CLaSP) study. Acta Neurol Scand, 145:743-752.

18. Kruse C, Kretschmer S, Lipinski A, Verheyen M, Mengel D, Balzer-Geldsetzer M, Lorenzl S, Richinger C, Schmotz C, Tönges L, Woitalla D, Klebe S, Schrag A, Dodel R (2021) Resource utilization of patients with Parkinson's disease in the late stages of the disease in Germany: Data from the CLaSP study. Pharmacoeconomics, 39:601-615.

19. Kruse C, Lipinski A, Verheyen M, Balzer-Geldsetzer M, Schade-Brittinger C, Wittenberg M, et al. Care of Late-Stage Parkinsonism: Resource utilization in the late-stages of the disease in five European countries. Mov Disord (In Press).

20. Mestre TA, Kessler D, Côté D, et al. (2021) Pilot evaluation of a pragmatic network for integrated care and self-management in Parkinson's disease. Mov Disord, 36:398-406.

21. Mestre TA (2023) Addressing complex care in Parkinson disease in contemporary society. iCARE-PD.

22. Herdman M, Gudex C, Lloyd A, Janssen M, Kind P, Parkin D, Bonsel G, Badia X (2011) Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Qual Life Res, 20:1727-1736.

23. Brandt M, Kaschowitz J, Quashie NT (2022) Socioeconomic inequalities in the wellbeing of informal caregivers across Europe. Aging Ment Health, 26:1589-1596.

24. Quashie NT, Wagner M, Verbakel E, Deindl C (2021) Socioeconomic differences in informal caregiving in Europe. Eur J Ageing, 19:621-632.

25. Andreakou MI, Papadopoulos AA, Panagiotakos DB, Niakas D (2016) Assessment of health-related quality of life for caregivers of Alzheimer's disease patients. Int J Alzheimers Dis, 2016:9213968.

26. Veugelers PJ, Yip AM (2003) Socioeconomic disparities in health care use: Does universal coverage reduce inequalities in health? J Epidemiol Community Health, 57:424-428.

27. Donahoe JT, McGuire TG (2020) The vexing relationship between socioeconomic status and health. Isr J Health Policy Res, 9:68.

28. Zajacova A, Lawrence EM (2018) The relationship between education and health: Reducing disparities through a contextual approach. Annu Rev Public Health, 39:273-289.

29. Price KN, Lyons AB, Hamzavi IH, Hsiao JL, Shi VY (2021) Facilitating clinical trials participation of low socioeconomic status patients. Dermatology, 237:843-846.

30. Alegria M, Sud S, Steinberg BE, Gai N, Siddiqui A (2021) Reporting of participant race, sex, and socioeconomic status in randomized clinical trials in general medical journals, 2015 vs 2019. JAMA Netw Open, 4.

31. Crispino P, Gino M, Barbagelata E, Ciarambino T, Politi C, Ambrosino I, Ragusa R, Marranzano M, Biondi A, Vacante M (2020) Gender differences and quality of life in Parkinson's disease. Int J Environ Res Public Health, 18:198.

32. Heller J, Dogan I, Schulz JB, Reetz K (2013) Evidence for gender differences in cognition, emotion, and quality of life in Parkinson’s disease? Aging Dis, 5:63-75.

33. Yoon JE, Kim JS, Jang W, Park J, Oh E, Youn J, Park S, Cho JW (2017) Gender differences of nonmotor symptoms affecting quality of life in Parkinson disease. Neurodegener Dis, 17:276-280.

34. Kumar H, Ansari S, Kumar S (2022) Association between nonmotor symptoms and gender in Parkinson's disease: A meta-analysis. Mov Disord Clin Pract, 9:466-472.

35. Song Y, Su F, Shi X, Lu S (2023) Exploring gender-specific differences in the association between depression and cognitive impairment in Parkinson's disease. J Neurol, 270:3305-3316.