

# Annual Cost of Care of Parkinson's Disease and Its Determinants in North India – A Cost of Illness Study with Patient Perspective

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## Abstract

**Background:** Parkinson's disease (PD) is a slowly progressive and disabling disorder, so the cost of illness may change with time. We aimed this study to know the annual cost of care of PD in India. **Methods:** After ethics approval, a prospective cohort study was conducted at the movement disorder clinic of tertiary care hospital for 2 years (2014–2016). The outcomes were a description of the total annual direct cost of Parkinson's disease including health care as well as non-health care cost. We also did correlation analysis to know the determinants of the total cost. **Results:** A total of 200 consecutive patients of PD with 141 (70.50%) males and 59 (29.50%) females with a mean age of  $56.84 \pm 10.51$  years were enrolled. The annual Median Direct cost of care was INR 27,315.0 (IQR 13636.6–44908.4), whereas the Indirect cost was INR 21,400 (IQR 9800 – 96800). Cost on drugs (Direct health care) formed 68.50% (Median) of the total Direct cost. Total direct cost formed 11.38% of the Median total yearly income of our patients. Of the direct cost, the Median expenditure on drugs was INR 18,712.8 (8064.0 -30696.0). Only 5% of patients had health care insurance. The total direct cost was determined by the stage of Parkinson's disease and duration of disease ( $P = < 0.01$ ) but not predicted by age, gender, age at onset, and the yearly income of patients. **Conclusion:** Annual cost of care of Parkinson's disease is high and increases with the duration of the disease as well as the progression of the disease.

**Keywords:** Cost of illness, direct cost, indirect cost, Parkinson disease

## INTRODUCTION

Parkinson's disease (PD) is a chronic and degenerative neurological condition that is associated with lifelong disability. Motor dysfunctions/symptoms such as slowness, balance impairment, tremor, freezing, and rigidity are characteristic of PD and nonmotor symptoms such as anxiety, depression, fatigue, constipation, rapid eye movement sleep behavior disorder (RBD), and cognitive impairment are common. Modified Hoehn and Yahr (HY) score is the clinical rating method to determine the stage/severity of motor dysfunction in people with PD. As the disease progresses, people with PD become highly vulnerable to falls and fall-related injuries. The range of symptoms associated with PD signifies that the disease burden to the household (individual and family), health system, and society is usually significant.

Age-adjusted prevalence in the Indian population is estimated to be 52.8 per 1,00,000 population.<sup>[1]</sup> As the life expectancy is improving in India, the number of elderly is also increasing and hence the number of people affected by PD. From the patient's perspective, the disease has a significant economic impact. There is very sparse literature from all over the world and only one study from India regarding the cost of treating Parkinson's disease.<sup>[2-9]</sup> As PD is a chronic disorder, and the expected number of elderly with all chronic diseases is likely to rise, this study may help in formulating data regarding the economic impact of this disorder. From this study, we intend to

estimate the cost of PD to the patient and family, so that in the future, these data can be utilized for better health care policy and planning in the elderly. In India, central as well as state governments have a responsibility to provide social security pensions to the elderly. Recently, PD is included as an individual specified disability category also. The government used to provide fixed disability pension to all disabled/specially-abled persons irrespective of their disability category or disability percentages. We did this study with the aim to know the average annual out-of-pocket (OOP) cost of the individual PD patient.

## METHODS

We conducted a prospective cohort study at the movement disorder clinic of an academic institute and tertiary care

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hospital in North India. We enrolled consecutive Parkinson's disease (PD) patients attending the clinic for 2 years (2014–2016) with a diagnosis of PD [diagnosed on the basis of the United Kingdom Parkinson's Disease (UKPD) Brain Bank criteria]. We enrolled patients irrespective of age, gender, and stage of the disease. PD patients with other major neurological and systemic diseases were excluded. The study was commenced after obtaining approval from institutional review board (IRB)/ethics committee (EC). Written informed consent of the participants was taken before enrollment in the study. Information was collected in a format consisting of two parts. In the first part, patients' socio-demographic and disease-related information were collected and in the second part, all expenditure on treatment was collected via face-to-face interview with the patient and/or a caregiver. The severity of the disease was assessed using Hoehn and Yahr staging.<sup>[10]</sup> For direct health care costs, expenditure for drugs and investigations were included. For calculation of direct non health care cost, expenditure of travel and stay and money spent on formal caregiver were included. Expenditure on every visit was calculated by the cost of travel and stay of the patient as well as all attendants accompanying the patient. Indirect cost/productivity losses cost were calculated by wages lost due to travel for hospital visit of self and accompanying person and loss of wages due to reduced income if the patient had to lower his/her activities in a job or refuse promotion/opt for a less paying job due to illness and associated disability. If a productive family member also left his/her job or reduced working hours to look after caregiving of patient, it was also included in indirect cost.<sup>[11]</sup> The intangible cost was not calculated in this study. All costs were calculated based on Rupees (INR) in 2018. Analysis was done using Statistical Package for Social Sciences (SPSS) version 21.0. Categorical variables were presented in number and percentage, and continuous variables were presented as mean ± standard deviation and median (Inter-quartile range). The outcomes were a description of mean/median annual direct cost, indirect cost of care of Parkinson's disease. Total OOP Direct annual cost was calculated by summing direct health care and direct nonhealth care cost. We used correlation analysis to know determinants of Total Direct cost, Direct health care cost, and Direct nonhealth care cost.

## RESULTS

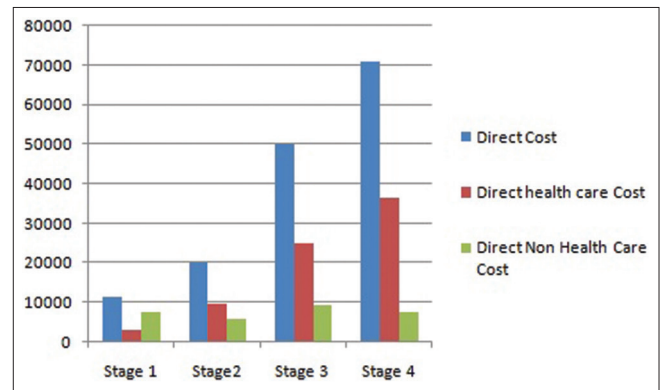
A total of 200 patients with PD were recruited in our study with 141 (70.50%) males and 59 (29.50%) females with a mean age of 56.84 ± 10.51 years. The mean age of males and females were 57.81 ± 10.72 and 54.54 ± 9.71 years, respectively. The mean age at onset of PD was 49.83 ± 10.6 years, and the mean duration of disease was 7.03 ± 4.23 in years. Demographic details are given in Table 1. Most of the patients belonged to stages 2 and 3, forming 149 (74.5%) of patients. Median yearly income [Table 1] of patients was INR 2, 40,000 ((IQR 1, 20,000–4, 80, 000).

The median out-ofOOP direct health cost was INR 27,315 (IQR 13636.6–44908.4), and the median yearly cost on drugs was INR

18,712.8 (IQR 8064–30696) [Table 2]. It increased as the disease progressed [Table 2 and Figure 1]. The percentage of total income spent on drugs also increased with increasing stage of disease [Figure 1] with patients in stages 3 and 4 spending more than one-third of their income on drugs. Median expenditure on travel and stay [Table 1] was INR 1,750 (IQR 300–10000). It was 38% of total expenditure on treatment in stage 1.

Twenty-one (10.5%) patients had to quit their jobs or incurred financial loss due to the disease [Table 1]. The median loss due to this was INR 60,000 (IQR). Seven (3.5%) patients had employed paid caregivers (in stages 3 and 4) [Table 1]. The mean expenditure on this item was INR 6,000 per year. No one from family members changed or quit their job.

Six (3%) patients underwent deep brain stimulation (DBS) surgery for PD. The total median cost at our center was INR 525,000, which included hardware, operation charges, and charges for imaging to localize target and stay in the general ward. Only 10 (5%) patients out of 200 patients recruited in the study had medical insurance [Table 1].



**Figure 1:** Distribution of various types of cost in comparison to four stages of Parkinson's disease

**Table 1: Baseline characteristic of Parkinson patients**

Baseline Variables		n=200
Age (years)		56.84±10.51
Gender	Male	141 (70.50%),
	Female	59 (29.50%)
Duration of illness (years)		7.04±4.23
Age at onset of disease (years)		49.83±10.6
Median (IQR) Annual income		2,40,000 (1,20,000-4,80,000)
Patients underwent DBS surgery		6 (3%)
Patients have Paid caregiver		7 (3.5%)
Patients have Insurance		10 (5%)
H & Y Stage of disease		1
2	73 (36.5%)	
3	76 (38.0%)	
4	39 (19.5%)	
Direct cost		27315.0 (13636.6-44908.4)
Direct health care cost		18712.8 (8064.0-30696.0)
Indirect Cost		60000 (13500-225000)
Mean±SD; Frequency (Percentage), Median (Inter-quartile range Q1–Q3)		

We did correlation analysis to know the determinants of total OOP Direct cost of Parkinson's patients [Table 3]. We correlated independent variables like age, age at onset, duration of disease, stage of disease, and income against dependent variables as total Direct cost, Direct health care cost, and Direct nonhealth care cost. Out of all, duration of disease and stage of disease were significantly correlated with total OOP direct cost ( $P < 0.01$ ) [Table 3]. Direct health care costs were driven mainly by the duration and stage of the disease but also by older age. Expenditure on stay and travel was significantly correlated with the duration of disease and older age.

## DISCUSSION

In general, the mean age of our patients was younger than their western counterparts by more than one decade. This is an observation in several of our publications and other centers from India.<sup>[2,12,13]</sup> It may be a true reflection of an earlier age of onset of PD in India or a reflection of selection bias of cases attending tertiary care centers in India. However, our informal inquiry from other neurologists in private sector hospitals also provided similar observations. This implies that the PD patients in India are relatively young, and most of them are still gainfully employed. Though, 45 (24.50%) patients were housewives but were contributing gainfully to the upkeep of the family. The range of annual income was quite wide INR 12,000–36, 00,000 indicating wide economic disparity among our cohort. This figure is more than the projected per capita income of an Indian.<sup>[14]</sup>

Expenditure on drugs also increased exponentially with an increase in severity of disease (assessed by H&Y stage). This finding is consistent with observations of other studies.<sup>[5,6]</sup> Percentage of total income spent on drugs also increased with increasing stage of disease [Table 2 and Figure 1] with patients in stages 3 and 4 spending more than one-fifth of their income on drugs which poses a huge economic burden on the whole family. Expenditure on travel to our hospital/institute

and stay to show in the outpatient department was higher in stage 1 as compared to other stages (72.11% of the total direct cost of care). This could be due to more frequent hospital visits in the early stage of disease or visits of more patients in early-stage even from far off places including other states who come to our center to get confirmation of diagnosis because of non-availability neurologists/specialists in their vicinity adding to cost of travel and stay in the city away from home.

Another striking finding in our study was the very low percent of our patients had health care insurance (only 5%). This finding is consistent with the other Indian study.<sup>[2]</sup> In the absence of health care insurance, patients have to pay for their treatment from their pocket, which imposes a huge economic burden on the family. The median financial loss due to lost wages was INR 21,400. This is a substantial amount, forming 8.9% of their income, and also posed an additional burden on the family. Procedures like DBS are beyond the reach of the average population, and it is hard for them to afford these procedures without some financial help from external sources. Six patients in our cohort underwent DBS surgery. One patient paid it out of his pocket, whereas the rest received reimbursement from a government agency as they were government employees.

In this study, we estimated the economic burden of disease on productive population, who presented to our center, a tertiary care center. When we compare direct cost in our cohort (2014) with other studies Table 4 (Supplementary Data), we observe that cost in the US (2008) was about 28 times higher than in our population, whereas in Sweden<sup>[6]</sup> it was almost six times higher. Direct cost was two times our cost in China.<sup>[4]</sup> A similar study from India in 2006<sup>[2]</sup> calculated drug-related cost which was about half of our estimates in 2014. Difference from the previous Indian study could be due to an increase in gross national income over these years or an increase in the price of all commodities including drugs. Treatment for PD remains out of reach for patients in resource-poor countries

**Table 2: Description of various costs in Parkinson disease stages wise**

H & Y Stages of PD (N=200)	Total Direct Cost (INR)	Direct Health Care Cost (INR)
Stage 1 (N=12)	11350 (4847.81-17852.20)	3165 (2537.72-3792.28)
Stage 2 (N=73)	20324.52 (14970.46-25638.58)	9811.02 (8305.77-11316.29)
Stage 3 (N=76)	50238.03 (36560.41-63915.65)	24922.05 (22847.22-26996.89)
Stage 4 (N=39)	71108.33 (44453.29-97763.38)	36577.56 (32612.38-40542.75)
Mean (95% CI)		

**Table 3: Description of Spearman correlation among various costs and independent variables**

Independent Variables	Direct Cost	Direct health care Cost	Direct Non Health care Cost
Age	0.11 (0.10)	0.19** (<0.01)	-0.14* (0.05)
Age at Onset	-0.06 (0.43)	0.01 (0.94)	-0.17* (0.01)
Duration of illness	0.47** (<0.01)	0.52** (<0.01)	0.14* (0.05)
Income	0.12 (0.09)	0.14* (0.04)	0.02 (0.76)
Stage of Disease	0.66** (<0.01)	0.81** (<0.01)	0.03 (0.63)

Spearman correlation coefficient, rho ( $P$ -value)

**Table 4: (Supplementary Data), Comparison of the direct cost of treating PD in other countries (recent studies)**

Study	Sweden (6), 2002	China (4), 2006	India, (2) 2006	USA, (8) 2012	Our Study
Direct cost (USD)	2900	917	203.3	12,800	455.25

like ours. Our study had only one patient in stage 5. A low number of patients in H&Y stage 5 is possibly due to difficulty in bringing the severely disabled patient to the hospital, highlighting the disabled unfriendly environment (roads, buses, trains, etc.) in our country. Hence, patients with severe disease are under-represented in this study, and economic burden on patients with severe disease may not be reflected in this study.

Secondly, a significant amount of time spent by a spouse or other family members on care is also an important finding in our study and could be well more useful and personalized than any nurse in a western setting; nevertheless, quantification and importance of such time are difficult to assess is underestimated.<sup>[15]</sup> It is also a significant emotional drain for the family member providing care.

Most patients pay for their medicines, which amounts to almost 6.72% of their annual income. The burden of PD is considerable in our country, and the magnitude of problem increases in view of the paucity of the universal health care system and lack of specialist health care at village/district level as well as lack of movement disorders specialists who can diagnose and take care of the patients locally, hence necessitating avoidable expenses on frequent traveling and staying in a city outside their own. As PD is not a curable disease and no treatment is available to stop its progression, it has life-long economic implications for the patient, family, and society. It becomes imperative for government to take the initiative to provide universal health insurance, patient/elderly/disabled-friendly environment and improving infrastructure, and provide specialists for early diagnosis and proper management at all levels of health care. Our study has limitations. OOP cost may vary from our estimates if patients took generic medications or drugs procured under any government-free medication scheme. We did not include patients of advanced stages and patients with comorbidities, so their OOP may even be higher than our estimates.

## CONCLUSIONS

The annual cost of care for Parkinson's disease is high and increases with the duration of the disease as well as the progression of the disease. To reduce the economic burden of PD care, further interventional studies should target disease progression, other methods of care like teleconsultation, the policy of free drug schemes, and essential drug lists. Meantime disability measurement in PD should take into account both duration and disease staging. Social support level should be based on the economic burden of disease and disability which are determined by the duration of disease and stage of the disease.

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Nil.

## Conflicts of interest

There are no conflicts of interest.

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