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BRAZILIAN PUBLIC HEALTH SYSTEM AND PARKINSON'S DISEASE: ARE THE RESOURCES INVESTED ENOUGH TO MAKE THE TREATMENT VIABLE?

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ABSTRACT

Parkinson's disease (PD) is considered a chronic and degenerative neurological condition that affects mainly elderly individuals, causing significant disabilities and decreased quality of life, the main cause of expenses for the patient, family, caregivers, and the health system. The objective of this study is to estimate the average annual cost per patient who undergoes PD treatment in the Brazilian public health system, and to identify whether the resources made available by public health are significant to make the treatment viable for these patients. The case study, carried out at a university hospital in the city of Niterói (RJ), followed a mixed methods design, with qualitative and quantitative data, obtained through interviews with a sample of 54 patients. The mean annual cost per patient was estimated at US$ 2,904.80 and calculated from the mean and 95% confidence interval obtained. The total cost of treatment would represent 48.51% of the average annual income of the sample, if it were fully financed by the patient, with 23% of this amount falling on the Brazilian public health system. In this case study, it was possible to diagnose that the allocation of resources from the public health system not only includes the main variables of direct cost with the treatment, but also includes the most expensive ones, such as medications and hospitalizations, making the treatment viable for the patient.

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INTRODUCTION

Parkinson's disease (PD) is a chronic and progressive neurodegenerative disease characterized by a decline in motor and non-motor function, and is frequently associated with several complications (Liu, 2021). Classically, among the symptoms of PD are tremor at rest, rigidity, difficulty in walking, balance deficit, bradykinesia, intellectual decline, decreased range of motion, and disturbances in cognition (Marques, 2020). Considered the second most frequent neurodegenerative disease, after Alzheimer's, it affects all populations, regardless of ethnicity, social class, and profession, with a certain predominance in males (Viana, 2021). The chronicity of this condition and the lack of treatment make its projection of burden economic growth substantially in the coming decades, impacting patients and their families, the health system and society as a whole (Prado, 2020). Proportionally to the aging of the population, an increase in cases of chronic diseases, such as PD, is expected, and the discussion about the financial impact of treating these diseases gains relevance (Gil-Prieto, 2016). In Brazil, there is an evident lack of studies on the cost of treating PD, and this gap makes it difficult to assess the economic impacts on the life of the patient and the health system (Silva, 2021). Determining the costs of a disease facilitates the understanding of its impact on society and health systems, assessing its degree of efficiency and understanding how the market tends to organize itself in relation to certain values (Bovolenta, 2017). Therefore, the objective of this case study is to estimate the average annual cost per patient who undergoes PD treatment in the Brazilian public health system, and to identify whether the resources made available by public health are significant to make the treatment viable for these patients.

MATERIALS AND METHODS

Participants: In this case study, intentional non-probabilistic sampling (for convenience) was adopted, composed of patients undergoing PD treatment in a public health hospital in the city of

Niterói, in the State of Rio de Janeiro. The study was submitted to the Ethics and Research Committee of the Universidade Federal Fluminense (UFF) and approved according to Opinion nº 3.687.239. The Free and Informed Consent Term was presented to the patients in the sample before participating in the research. A total of 59 patients were contacted between March and November 2020, during outpatient consultations at Hospital Universitário Antônio Pedro (HUAP). Patients physically or cognitively unable to respond to the questionnaire (n=5) were excluded from the sample. All others agreed to participate in the research, resulting in a total of 54 interviews.

Procedures: The instrument used for this research was a questionnaire, composed of 33 questions, which evaluated the cost of treatment based on the most cited direct cost variables in the literature. This was an observational, cross-sectional, and retrospective case study on the prevalence of the disease, which used the "bottom-up" cost valuation method. The time horizon used was 6 months. The study perspective was carried out first from the patient's point of view, and then evaluated from the point of view of the Public Health System.

Costs Calculation: Costs were calculated for the period of 6 months prior to the interview and extrapolated to 1 year. The values were described in dollars (US$). The research on the value of medical consultations, as well as other cost variables that fall within the public health system, was carried out in the database of the Brazilian Ministry of Health (www.datasus.gov.br), consulting the Public Health System, Management of the Procedures, Medicines and OPM Table (SIGTAP). Access to the portal was performed on 01/16/2022, to update the values. In cases where private therapists were hired, consultation fees were obtained directly from the professionals. For the other variables, the patient was directly questioned about the values practiced.

Statistical Analysis: The statistical description of the data was performed using tabular methods (statistical tables and summary information tables), graphs and parametrics. Parametric methods include, for categorical variables, absolute frequencies, and proportions (relative frequencies or percentages). Since the normality of numerical data sets, assessed by the Kolmogorov-Smirnov test, was rejected, comparisons between two independent groups of numerical variable data will be carried out by the Mann-Whitney test. If the two sets of data are matched, the Wilcoxon test will be used. Comparisons of three or more groups of independent data will be performed using the non-parametric Kruskal-Wallis test, which, if it produces a statistically significant result, will have multiple comparisons to identify groups of different behaviors proceeded by the Mann-Whitney test, with correction Bonferroni for statistical significance. The total annual cost was estimated by calculating the mean and the 95% confidence interval (CI) obtained by fitting a generalized linear model with a gamma probability distribution and logarithmic linkage function. The significance level adopted for statistical decisions in the application of statistical tests was $\alpha = 0.05$, so that conclusions for which the p-value is less than or equal to 0.05 ($p < 0.05$) were considered statistically significant. Statistical analyzes were supported by Microsoft Excel application and R statistical software version 4.0.3.

RESULTS

Men represented 64.8% of the sample, 50% of patients had completed elementary school, 88.9% were retired, 48.1% of patients had an H&Y score of 3 or 4, and 82.6% of patients were diagnosed with PD for at least 5 years. The average monthly income of the sample R$2,455.00 (US$498.92). The distribution of the average half-yearly cost with the treatment of PD, considering the direct cost variables, are described in Table 1 with values in dollars (US$) and in Table 2 with percentage values. The study sample, although composed of patients undergoing treatment in the Brazilian public health system, presents values associated with costs distributed in two categories: private costs and public costs. Medicines are the most frequently

accumulated direct cost variable, and Hospitalizations have a high cost attributed to the public health system due to the profile of the sample. No patient interviewed reported a case of hospitalization in a private hospital. The high cost of home care falls directly on the patient since the public health system does not offer this type of service. Although reported by only 5 patients (9.3% of the sample), it is the third variable with the highest cumulative cost distribution identified in this research. Fundamental as non-pharmacological therapy, the Auxiliary Treatments had a high number of prescriptions among the investigated patients (79.6%). However, 41.9% of patients who were indicated for these treatments did not actually undergo them, due to difficulties in scheduling these therapies in the public health system. Among the most frequently prescribed treatments, Physiotherapy and Physical Activity stand out. The variables "Consultations" and "Exams", fundamental for the treatment and monitoring of the evolution of PD, do not have a great representation in the total cost of treatment (1.1% and 0.6%, respectively).

Other variables, such as "Adaptations in the residence", use of "Special equipment" and "Transport" presented interesting biases that hampered the calculation of their respective average costs, and this fact certainly underestimated the total cost estimate with these variables. The total annual cost was estimated by calculating the mean and the obtained 95% confidence interval (CI), fitting a generalized linear model with a gamma probability distribution and logarithmic linkage function. The following variables were considered: Category (private or public), Transport, Consultations, Home Care, Hospitalizations, Surgeries, Auxiliary Treatments, Medications, Examinations, Stage of Disease Progression and Age. These variables were the result of a step-by-step variable selection process, which sought the best combination to explain the total cost. A "0" (zero) expenditure was assigned for surgery and hospitalization in the complementary six-month forecast, considering the rare probability of the patient undergoing two surgeries for the treatment of PD in 1 year. As, in this research, all hospitalization cases were directly related to the surgeries performed for the treatment of PD, the attribution of the value "0" (zero) for the cost with this variable was also necessary. In addition, variables such as food, adaptations in the residence and use of special equipment represent a small contribution to the total cost and were used by few patients, so it was decided not to consider them. These data revealed an average annual cost of US$2,904.08 per patient (US$2,215.50 – US$3,594.10), as described in Table 3.

DISCUSSION

The cost analysis study carried out in this research is initially presented from the patient's perspective, since data collection in the quantitative phase was carried out through interviews with patients with PD, who undergo treatment in the public health system (Hospital Universitário Antônio Pedro – HUAP). Using a retrospective time horizon of 6 months through the "bottom-up" valuation method, and considering the prevalence and direct cost variables, an annual cost forecast was made with the treatment of PD. From this analysis, it is understood that there is no statistically significant difference between the share of cost to the public health system and to the patient in the calculation of total annual direct costs (according to Wilcoxon's test). However, in order to meet the objective of this work, it is understood that a more in-depth analysis is necessary to diagnose whether the allocation of public resources in health includes the main variables of Direct Cost with the treatment of chronic diseases, such as the PD. Given the profile of the sample, it was expected that some variables, mainly those of Direct Health Costs, would concentrate their expenditure on public health. In this research, we had 100% of the costs borne by the public health system in the variables "Medical visits", "Surgery", "Hospitalization" and "Exams". This trend should not be extrapolated due to the size and characteristics of the sample, but it is an important characteristic of this research, and shows an important contribution in the treatment of PD, considering the cost category adopted (direct costs).

Table 1. Distribution of the 6-months costs of PD treatment

Costs (US$)	Categorie		Total
	Private	Public	
Direct medical costs			
Medical visits	0.0	1,100.9	1,100.9
Medications	17,987.2	20,452.4	38,439.6
Secondary treatments	8,803.8	840.1	9,643.9
Surgery	0.0	3,707.2	3,707.2
Hospitalizations	0.0	22,346.7	22,346.7
Caregiver services	13,656.8	0.0	13,656.8
Medical exams	0.0	621.7	621.7
Direct nonmedical costs			
Transport	776.4	0.0	776.4
Food	3,901.9	0.0	3,901.9
Home adaptations	2,040.4	0.0	2,040.4
Equipment to facilitate locomotion	1,225.2	0.0	1,225.2
Total	48,391.7	49,069.0	97,460.7

Table 2. Distribution of total semi-annual cost by direct cost variable and categories (percentage values)

Variable (percentage values)	Category		Total (%)
	Private (%)	Public (%)	
Direct medical costs			
Medical visits	0,0	2,2	1,1
Medications	37,3	41,7	39,6
Secondary treatments	17,9	1,7	9,7
Surgery	0,0	7,6	3,8
Hospitalizations	0,0	45,5	23,0
Caregiver services	28,4	0,0	14,10
Medical exams	0,0	1,3	0,6
Direct nonmedical costs			
Transport	1,6	0,0	0,8
Food	8,1	0,0	4,0
Home adaptations	4,2	0,0	2,1
Equipment to facilitate locomotion	2,5	0,0	1,3
Total	100,00	100,00	100,00

Table 3. Estimated means and 95% CIs for the total annual cost of Parkinson's disease (US$)

Categories	Mean US$ (95% CI)	Total Cost (%)
Private	1,532.1 (1,087.1- 1,977.0)	82,734.7 (52.8)
Public	1,372.7 (958.5 -1,786.9)	74,127.8 (47.2)
Total	2,904.8 (2,215.5 - 3,594.1)	156,862.5

The high cost of hospitalizations, already identified in previous costs studies, was also the variable with the highest cost in this study. However, the causes for such hospitalizations differ from the results found in other studies. A systematic review performed by Koay et al.[8] pointed as the main reasons for acute hospital admission in patients with PD: falls, deterioration of motor and non-motor symptoms of the disease, cardiovascular events and infections, especially urinary and respiratory tract infections. The incidence of falls is also cited by Fundament et al.[9] and Fletcher et al.[10] as largely responsible for cases of hospitalization among patients with PD. In this research, the main cause of hospitalizations cited by patients were surgeries performed for the treatment of PD. Although only 11 patients underwent surgical interventions, some had postoperative complications and had to extend their hospital stay, which significantly increased costs with this variable. As for the incidence of falls, reported by 31.5% of the patients in this sample, no case resulted in hospitalization or the need for medical care. The cumulative distribution of costs by variable (with Medications, Hospitalizations, Home Care and Auxiliary Treatments responsible for 86.4% of the total costs) had already been previously identified in the literature. In a study carried out in Australia, with the objective of estimating the annual cost of treating PD from the perspectives of the family, the health system and society [11], the authors found that two-thirds of the burden on the healthcare system was related to hospitalizations, with medical and pharmacological services contributing significantly to the total costs. The study had a sample of 87 patients, assisted by the public and private health systems of that country. In another study, carried out by Zhao et al.[12], the authors identified pharmacotherapy and home care as the main components of total cost.

The sample consisted of 195 patients treated at the Movement Disorders Center of the National Institute of Neurosciences in that country. The high cost of medicines was also observed by Bovolenta et al. (2017) in a study of a similar nature, carried out with patients also assisted by the public health system in the city of São Paulo. In this study, the authors identified that antiparkinsonian drugs were responsible for 25% of the total cost (both drugs provided by the public health system and those purchased by patients). The public policy on medication distribution and the medication booklet offered by the Brazilian public health system for the treatment of PD provide a representative support to the patient, although it still may not seem ideal for all cases Much of the drug cost attributed to the patient in the results of this research reflects the treatment of comorbidities associated with PD, as many of these drugs (53.8%) were not available in the "Aqui tem Farmácia Popular" program and could not be purchased for free. Considering the sample studied, it is possible to identify that 47.2% of the average annual cost of treatment is aggregated to the public health system.

This represents a significant contribution to the patient's budget, given the socioeconomic characteristics of the sample. When considering the average monthly income of the sample of R$ 2,455.00 (US$ 498.92), an average annual income of R$ 29,460.00 (US$ 5,987.04) is estimated, inferring that the average annual cost with estimated PD treatment (see Table 3) would represent 48.51% of this income if it were fully funded by the patient. Of this amount, it can be inferred that 23% (US$ 1,372.70) is borne by the Brazilian public health system.

CONCLUSION

The scenario of population aging and the increase in spending on the treatment of chronic degenerative diseases associated with this aging process puts the Sustainability of Health Systems, both Public and Supplementary, at risk. Such systems are impacted by PD, as the highest incidence of the disease is concentrated in older age groups.

In the study environment contemplated by this case study, for example, it was possible to observe a high cost of medicines and hospitalizations subsidized by the Brazilian public health system, which corroborates the data collected in the literature review. Although methodological procedures were used to provide security for the analyses, such as the use of multiple methods of data collection and analysis, there are limitations in the research. The nature of the study, in itself, is already a considerable difficulty. Retrospective analysis, in a time horizon of 6 months, working with an elderly population (or caregivers of these patients), is susceptible to providing misleading or inaccurate data. In addition, there were cases where patients did not remember the amounts spent, which underestimates the analysis in a cost study. As proposals for further research, we suggest replicating this study in a larger sample, with the possibility of generalizing the results. In addition, it is worth comparing this cost analysis between patients undergoing treatment in the public and private sectors. An analysis of the economic impacts of treatment, through a study of costs of the same or similar nature, would also be interesting in the context of supplementary health. Finally, given the importance of studying the costs of treating diseases, the relevance of studies with other cost categories (indirect and intangible) should be highlighted, in order to reinforce the understanding of the problem.

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