A Cost Model for Neurological Diseases in Puerto Rico: Parkinson's Disease, Alzheimer's Disease and Huntington's Disease

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> Objective: This article proposes an engineering-economics model to determine the total cost of a neurological disease along its temporal progression. The objective was to develop a planning tool faithful to the reality of this type of ailment as well as to that of Puerto Rico (PR).

> Methods: The proposed model organizes a given neurological disease into 3 progressive phases of deterioration; in each, the model collects the typical associated costs and adjusts them based on their value over time. This way, the total cost of the ailment is calculated and its present-day dollar value expressed. Model verification was carried out using data from Puerto Rico related to Parkinson's, Alzheimer's, and Huntington's diseases.

Results: The method demonstrated here considered Parkinson's disease in PR. Our model calculated a total annual cost of \$64,915 for a patient at the medium stage. This figure is larger than estimates from other authors, which fall between \$41,689 and \$51,600 for the USA. This difference is partially due to the proposed model considering the individual's opportunity cost of the loss of productive years, an original contribution of our work.

Conclusion: A neurological disease is one in which an individual goes through progressive phases of deterioration that will require significant economic resources. The model proposed here is designed across the commonalities between Alzheimer's, Parkinson's, and Huntington's diseases and illustrated using costs from PR. As an additional contribution, it allows the consideration of the opportunity cost of lost productivity, a characteristic that makes it more realistic. [P R Health Sci J 2023;42(2):146-151]

Key words: Cost model, Neurological diseases, Financial planning, Parkinson's disease, Alzheimer's disease, Huntington's disease

cost model for Parkinson's disease (PD), Alzheimer's disease (AD), and Huntington's disease (HD) is presented, herein. Quantifying the cost of living with these neurological diseases matters for planning purposes. For model-building, information pertaining to Puerto Rico (PR) about the expected costs that the three said diseases have in common was used. The explicit consideration of the opportunity cost of lost productivity makes the proposed model more realistic than those developed by others. In this paper, a review of the costs of each ailment, as well as the health costs in PR is presented first, followed by a description of the methodology used to create the proposed model, to then describe how each of the three ailments can be fit into the model's 3-stage framework for cost allocation. The application of the model to PD in PR is presented for verification purposes, followed by a discussion of the results and, finally, the conclusions.

Literature review of Cost information Costs related to Alzheimer's Disease

In 2010, the Alzheimer's Association estimated (1) the average annual cost of care per dementia case to be from \$41,000 to \$56,000 (in the USA). The type and level of care needed for AD changes over time due to its progressiveness (2). The estimated annual costs for long-term care service in the USA for 2020 were \$90,155 for a semi-private room in a nursing home and \$102,200 for a private one (2). Also, on an hourly basis, \$48 for basic services in an assisted living facility and \$23 for a home health aide are normal costs; adult care services are \$75 per day.

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Around 6.5 million of age 65 and older Americans are living with AD (2022). Seventy-three percent of these AD patients are 75 or older, and 1 in 9 is 65 or older (3).

Older AD patients require more skilled health care personnel for their nursing facility stays and home health care visits per year than other older people do (3). AD is the most expensive disease in the USA, costing more than cancer and heart disease, together (4).

Costs related to Parkinson's disease

PD incidence is known to increase with age, but around 4% of PD patients are diagnosed before turning 50 (6). A projection in Kowal et al. indicates that the number of PD patients will double by 2040 (7). The average cost for a PD patient's medication is \$2,500 a year; if therapeutic surgery is required, that could add up to an extra \$100,000 cost per patient (6) in the USA. The economic burden of PD exceeded \$14.4 billion in 2010 in the USA (approximately \$22,800 per patient) (8). Indirect costs, such as those linked to reduced employment, are estimated at \$6.3 billion per year (close to \$10,000 per patient). According to the American Parkinson's Disease Association (APDA), the average yearly cost for a PD patient is \$22,800 (8), including the above mentioned \$2,500 medication cost. PD patients will require 24/7 care as the disease progresses, an option is for the patient to live in a care facility (9), where the patient will incur into a higher cost due the specialized care requirements particular to PD (10).

Physical therapy is recommended for PD patients to improve independence and life quality (11). For patients covered by health insurance, out-of-pocket costs typically consist of a copay of \$10 to \$75 per session or coinsurance of 10% to 50%. When medically necessary, physical therapy can be covered by health insurance (12) due to its proven benefits (5).

According to a forum on the website Parkinson's News Today, PD patients usually visit their neurologist 2 to 4 times a year (13). Almost all private insurance policies require a copay when visiting a doctor or any other health care provider. A copay for a visit to a primary care physician ranges from \$15 to \$25. The copay for a visit to a specialist will generally run from \$30 to \$50. However, problems requiring comprehensive evaluation—approximately a 40-minute visit—can be as much as \$234 (14).

Costs related to Huntington's disease

In a report from Divino et al. (2013), HD patients were classified by disease stage (early/middle/late) using a hierarchical assessment of severity markers (15). The total annual cost per patient was calculated to be in average between \$4,947-\$22,582 (commercial health insurance) and \$3,257–

\$37,495 (Medicaid) (15).

The majority (73.8%) of late-stage patients covered by Medicaid were receiving nursing-home care, representing the majority (54.6%) of the late-stage-related costs paid out by Medicaid. However, only

40.6% of commercially insured late-stage patients were receiving care from nursing homes, with the associated costs representing only 4.6% of those pertaining to late-stage care. Divino's article states that nursing homes housed more late-stage HD patients (and for more time) on Medicaid than they did the commercially insured counterparts of these patients, which was evidenced by the higher costs incurred by the former and was suggestive of greater disease severity (15).

Information for Puerto Rico

In PR, Triple-S's website (16,17), a local insurance company, showed that the monthly rate of health insurance coverage varied from \$330 to \$480. Depending on the plan selected, the specialist fee ranges from \$15 to \$20 per visit and the hospitalization fee averages \$0 to \$50 per night. According to a study from Sommerlad et al., the annual hospital admission for HD patients' rate was 1.26 admissions/person-year of which 0.90/person-year were emergencies (18).

Triple S's website (16,17) claims that the average fee for an emergency room visit with medical insurance coverage ranges from \$0 to \$50. If laboratory or radiology tests are needed, then the fee paid by the insured patient will be from 30% to 60% of the total cost (19). Beneficiaries with dementia are hospitalized 3.4 times more often than are other elderly beneficiaries, and at 3.2 times the cost to Medicare (14). A recent Gallup Poll showed that 27% of American adults aged 18 years and older reported having been to an emergency room within the last year, including 10% who had made such a visit at least twice (20). Blood work at a laboratory can range anywhere from \$100 for one simple test to \$3,000 for a battery of them. On average, blood work at a laboratory will cost an uninsured patient around \$1,500 (21). Commonly, an insurance company pays either 70% or 80% of a given charge, while the rest is paid out of pocket by the covered individual after the deductible is met (22).

Methods

The method in this research consisted of identifying the data required to design a cost model. Figure 1 shows the associated steps.

Literature related to PD, AD, and HD costs was reviewed for information to derive the common disease stages and cost drivers to create the model. In addition, specific cost data for PR were included. The next step was to identify and define the cost variables. Then, the cost model for neurological disorders was developed (explained below). The last step involved verification. These steps are detailed in the following sections.

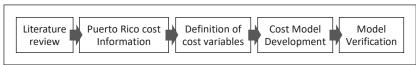


Figure 1. Method. From reviewing the literature on the costs associated with 3 neurological ailments, to gathering information for PR, to building and verifying the cost model.

Cost variables and model definition

Considering the diseases' cost information and the fact that cost varies with disease stage, an engineering-economics model considering 3 stages for each condition was proposed. The 3 stages use severity as their reference (low, medium, and high), in a fashion similar to how Divino et al. handled the issue (15). The cost model comprised individual costs, shown in a diagram in Figure 2 and further detailed in Table 1. The rationale for modeling neurological diseases (AD, PD, and HD) with 3 stages is explained in the following subsections.

Following Table 1, the cost model is the sum of all the costs of disease i at stage j, as shown in equations 1 thru 6.

$$TCij = MI + DC + HS + NC + OC(1)$$

Where:

$$DC = MM + ND (2) \qquad MC = FC + (YL) (3)$$
$$YL = \sum \frac{CF}{(1+r)^n} (4)$$

Where:

TC = total cost, MI = medical insurance cost

DC = disease cost per patient

HS = health service cost

NC = nursing home cost

OC = other costs

MM = cost of patient death

ND = cost of living with the disease

MC = medication costs

FC = funeral costs

YL = present value

CF = cash flow at future time

r =the periodic rate of return or interest

n = number of periods

HC = hospitalization cost

DH = days in hospital

DV = cost of doctor's visit

TD = times visited doctor's office

ER = emergency room cost

TE = times visited emergency room

TT = times in therapy

$$PL = \sum \frac{CF}{(1+r)^n} (5)$$

$$HS = HC(DH) + DV(TD) + ER(TE)$$
$$+ MC + TC(TT) (6)$$

The 3-stage structure adopted for each disease is explained next.

Alzheimer's Disease

Seven phases are recognized in AD (23), which can be fit into the 3 general stages in this work. In the first phase, patients do not present signs of the disease. Patients in the second phase begin to develop memory problems, such as misplacing objects or

forgetting names. It is during the third phase when difficulties become apparent: performing tasks, remembering names, losing objects, and increased anxiety, among others (23,24). These first 3 phases were grouped together into what is considered the low stage. The main costs for this stage are medical appointments, insurance, productivity loss (PL), and medication. In the fourth phase, patients are unable to perform complex tasks, such as solving mental challenges or even paying bills (24). During the fifth phase, gaps in the memory and thinking are present. These 2 phases were grouped together as the medium stage. The main costs for this stage are caregiving assistance, PL, medical insurance and appointments, hospitalizations, and some therapy. In the sixth phase, the patient begins to experience personality and behavior changes that can include delusions, hallucinations, anxiety, agitation, obsessive behavior, and the loss of will. The last phase comprises the inability to carry on a conversation, the need for help with most daily functions (including personal care), and muscle rigidity; furthermore, a marked disconnect between body and brain becomes noticeable (24). These 2 last phases were grouped into the high stage. The main costs for this stage are nursing home care, medication, therapy, and those grouped

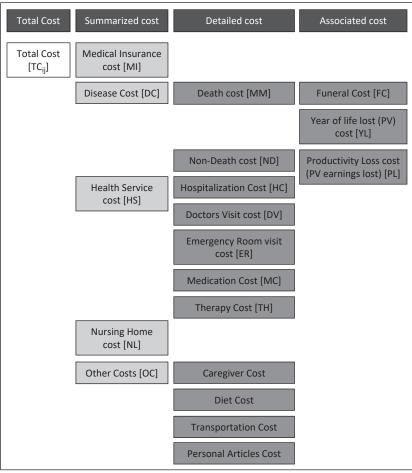


Figure 2. Representation of the Cost Model for Neurological Disorders. The figure represents all main costs (in light gray) and sub costs (in dark gray) associated with the total cost model for a neurological disorder.

Table 1. Definition of variables for the cost model

Variable	Definition	Variable	Definition
i	1, 2, 3: type of disease (1 = PD; 2 = HD; 3 = AD)	HS	Health service costs
j	1, 2, 3: stage of disease <i>i</i> (1 = low; 2 = medium; 3 = high)	HC	Hospitalization costs
TCij	Total cost of disease <i>i</i> at stage <i>j</i>	DH	Days spent in hospital
MI	Cost of medical insurance	DV	Doctor's visit costs
DC	Cost to the patient with the disease	TD	Times visited doctor office
MM	Cost of a patient's death	ER	Emergency room visit costs
FC	Cost of funeral services	TE	Times visited emergency room
YL	Present value of years of life lost (opportunity cost); years of life lost caused by the disease	MC	Medication and prescription costs
AE	Average earnings	TH	Therapy costs
ND	Cost of living with the disease	TT	Times in therapy
PL	Productivity loss, present value of earnings lost due to productivity		
	reduction	NC	Nursing home costs
AD	Non-productive days (days absent		
	from work)	OC	Other costs (includes diet, transportation, caregivers, personal articles, walkers, x-rays, laboratories, electronic beds, etc.)

as "other" costs. Depending on the nature of a given case, a cost may or may not be included in the specific calculation.

Regarding the opportunity cost of PL, it is present at all the stages and increases proportionally to the stage. The death costs (funeral expenses and years of life lost) might be present at any stage. Medical insurance cost may or may not be present at all the stages (depending on whether the patient is insured by a government or private medical plan).

Table 2. Costs considered in model verification

Parkinson's Disease

PD has 5 characteristic phases (25). In the proposed model, the low stage consists of phases 1 and 2, the medium stage includes phase 3, only, and phases 4 and 5 make up the high stage. In the low stage, symptoms begin to appear (25) and include tremors, movement difficulties, walking problems, and poor posture, among others. This stage mainly requires medical appointments. In the medium stage (25), loss of balance is one of the main symptoms, resulting in falls that could potentially lead to emergency room visits and increased medication costs. Patients at this stage have problems eating, getting dressed, and performing daily activities. This stage is associated with higher costs for emergency room visits and medical appointments because of the increased frequency of both. Furthermore, this stage includes the added costs of caregivers as well as diet, transportation, personal items, and therapy. Patients at the high stage (25) may experience hallucinations and delusions and have trouble standing or walking by themselves. These patients are not able to live alone, and nursing care becomes a necessary major cost. All other costs are present at this stage, as well. In all the stages, medical insurance costs are added if the patient has coverage. Having medical insurance decreases medical costs. Additionally, opportunity cost is present in all the stages and increases with stage progression. Death, funeral, and years-of-life-lost costs could be incurred at any stage.

Huntington's Disease

For HD, the 3 stages correlate directly with the phases that are presented (15). In the low stage (27), the major symptoms may include minor involuntary movements, a subtle loss of coordination, difficulty thinking through

complex problems, and perhaps some depression, irritability, and/or disinhibition. HD patients who are at the medium stage lose the ability to drive and in many cases work (27). They may no longer be able to manage their finances or perform household chores, but they should still be able to eat, dress, and attend to personal hygiene (with assistance). Voluntary motor tasks may become increasingly difficult for people at this HD stage, chorea may be

Туре	Cost calculation details	Formula	Yearly cost
МІ	Average monthly fee for medical insurance x 2	$MI = 12 \times (\frac{(330+480)}{2})$	\$4,860.00
MC	Average medication cost/year	MC = 2,500	\$2,500.00
HC	Average hospitalization cost/night x Average days/hospitalization x Times hospitalized/year	HC = 75 x 7 x 4	\$2,100.00
DV	Doctor visit, average cost x Average visits/year	DV = 4 x 15	\$60.00
ER	Emergency room, average cost x Average visits/year	ER = 3.43 x 15	\$51.45
TH	Average therapy cost x Average # of therapist visits	TH = 3 $\left(\frac{(10+75)}{2}\right)$	\$127.50
OC (care giver)	•	OC = 75 x 52 x 5	\$19,500.00
OC (lab tests)	Laboratory test cost x Percentage not covered by insurance	C = 1,500 x 0.3 O	\$450.00
OC (x-rays)	Average radiology costs	$OC = \left(\frac{(13+265)}{2}\right)$	\$139.00
OC (personal articles)	Diaper cost	OC = 2,160	\$2,160.00
OC (diet)	Average diet cost/day x days/year	OC = 20 x 365	\$7,300.00
PL ,	Present value (interest rate, number		
	of payments, payment amount(s))	PL = PV (0.0075,12,- 2244.58)	\$25,666.58
TC	TC = MI + MC + HC + DV + ER + TH + OC + YL	TC = 4860+2500+2100+60 +51.45+127.50+19500+450 +139.00+2160+7300+25666.58	\$64,914.53

Abbreviations: TC: total cost; PV, present value; YL, years lost

marked, and swallowing and weight loss may become problematic (27). At this stage, difficulty balancing can lead to falls. Medication costs are also present at this stage. When at the high stage (27), patients require assistance in all activities of daily living. For all stages, medical insurance might be present, decreasing some of the other costs mentioned. Opportunity cost is present at all the stages and increases with stage progression. Death, funeral, and years-of-life-lost costs could be incurred at any stage.

Model verification and results

For verification purposes, the estimates available in the literature were used to compare the cost of a patient at the medium stage of PD, with the cost obtained using our model for the condition at that stage. It was assumed that the average patient would receive daily visits from a caregiver, as that patient would not be able perform every task alone at this stage. This individual would have medical insurance and be 60 years old (average age provided by the Parkinson's Foundation) (26).

For the comparison, the cost of medical insurance (16,17)was set at \$405 per month; the average monthly payment was from \$330 to \$480. The medication cost per year was \$2,500, as stated in E. Downward's article for ParkinsonsDisease.net (26). The hospitalization cost was \$2,100 per year, based on a stay of 4 days per hospitalization, 7 hospitalizations per year (14), with an average hospitalization fee of \$75 per night (14). The cost of an emergency room visit was calculated using the average fee of such a visit with medical insurance coverage, \$15 per visit and 3.43 visits per year, on average (14), totaling \$51.45 per year. The cost of a doctor's visit for an insured person is \$15 (19), and this individual will see his or her doctor an average of 4 times per year (14), for a yearly cost of \$60. The radiology cost (classified as an "other cost" [OC]) is from \$138 to \$265 (excluding esophagus radiology [\$595] and Upper Gastrointestinal with small bowel views and air contrast [\$1,139]). Assuming a patient needs x-rays in at least 1 of the emergency room visits, the average radiology cost will be \$201.50. Assuming that at least 1 blood laboratory test (OC) is needed, the cost will be the average laboratory cost of \$1,500 times 0.30, which is the fraction that the insured person is responsible for, according to Walk-In Lab, an online source for laboratory testing (21). The cost for personal articles (discussed in the Financial Post) includes equipment to make a home comfortable and safe, such as electric beds (\$3,000 to \$5,000), walkers (\$100 to \$450), a bath lift (\$1,200), and ramps (\$200 to \$8,000) (29). Using the lower estimates, we calculated that the cost for personal articles would be \$4,500. Additionally, the cost of adult diapers is approximately \$2,160 per year for these patients (31). The equipment cost could be applied at any stage, and in different years of the patient's life, so it was not included in this specific situation. In this case, using a daily caregiver minimizes transportation cost; therefore, this cost was not included. A unique diet at \$20 per day results in a total of \$7,300 per year.

The physical therapy cost for insured people goes from \$52.50 to \$75 (12). The total cost is the average fee for 2 visits per year,

\$127.50. To calculate nursing home costs per year, the amount of \$75 per day was used (2) for a total of \$19,500 per year.

PL was calculated using 0.75% as the interest paid per period, which is the USA rate as presented by the Trading Economics website in 2016 (32). The payment used was the average monthly salary in PR in 2016 (\$2,244.58) (33). The periods used were 36 months in duration since the average age of PD patients is 60 years (28) and the average retirement age in both the USA and PR is 63 (34). This means that the average PD patient will lose at least 3 years of working time/productivity. According to the Trading Economics website, the PL cost is \$25,666.58 per year. These costs were used as examples; the total cost could change depending on the specific patient and his/her stage of the disorder. Medical insurance could also have an influence on the cost, as could the patient's being in a nursing home, the presence of a caregiver, or the need for surgical intervention(s).

The average cost for a patient with a dementia disorder was estimated to be from \$41,000 to \$56,000 per year in the USA (1). A study performed by Miele et al. (8) included only nursing home and medication costs, yielding an estimate of \$22,800 per year. The model proposed by this study yielded an annual cost of \$64,914.53. This is higher than the others because it explicitly considers PL cost. If this additional cost is ignored, the estimated total cost would be \$39,247.95, which reasonably compares with those of previous studies. This study was carried out using data from PR and the USA; other locations may have different cost drivers.

Conclusion

A cost model was developed to calculate the annual average costs incurred by patients with neurological diseases. Depending on the stage of the disorder, these costs may vary. Based on the data obtained using the proposed formulation and the costs already available in the literature, the yearly average annual cost for a PD patient at the medium stage was estimated to be \$64,914.53. All the costs were obtained from 2016 through 2020, thus some variations are to be expected. This article was created with the intention of postulating a cost model that could be continually updated and improved.

Resumen

Objetivo. Este artículo propone un modelo de ingeniería económica para determinar el costo total relacionado con una enfermedad neurológica en su progresión temporal. El objetivo es desarrollar una herramienta de planeación fiel a la realidad de este tipo de enfermedades, así como a la realidad de Puerto Rico (PR). Métodos. El modelo propuesto organiza una enfermedad neurológica en tres etapas progresivas de deterioro. Para cada etapa, el modelo recoge los costos típicos asociados y los ajusta considerando el valor del dinero a través del tiempo. De esta manera, se calcula el costo total para la enfermedad expresando

el dinero en tiempo presente. Para la verificación del modelo se utilizaron datos de las enfermedades de Parkinson, Alzheimer y Huntington relacionados con PR. Resultados. El método se demuestra considerando la información para la enfermedad de Parkinson en etapa media, para lo cual el modelo calcula un costo de \$64,915 anuales en PR. Esto es mayor que los estimados de entre \$41,689 y \$51,600 en los Estados Unidos. Esta diferencia es debida parcialmente a que el modelo propuesto considera el costo de oportunidad por pérdida de años productivos de la persona, un aspecto original de nuestro trabajo. Conclusión. Una enfermedad neurológica presenta etapas progresivas de deterioro que requieren de recursos económicos significativos. El modelo aquí propuesto está diseñado considerando las semejanzas entre las enfermedades de Alzheimer, Parkinson y Huntington ilustrado con costos en PR. Contribuye, además, la posibilidad de contabilizar el costo de oportunidad por la pérdida productividad, lo cual lo hace más realista.

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