

The Burden of Parkinson's Disease on Society, Family, and the Individual

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OBJECTIVE: To examine the burden of Parkinson's Disease (PD) on society, family, and the individual.

SETTING: In-home interviews in Central North Carolina.

DESIGN: A cross-sectional, descriptive study.

PARTICIPANTS: A total of 109 people with PD.

MEASURES: Standard instruments used to assess income, health status, health-related costs, and household activities.

SAMPLE: The sample was weighted toward individuals who were within the first 5 years of post-PD diagnosis.

RESULTS: The total per capita societal burden was approximately \$6000 per year, the greatest single element of which was compensation for earnings loss for those less than age 65. Government insurance covered 85% of our sample. The largest components of family burden were the burden of providing informal caregiving and that of earnings loss. Spouses providing informal care did so a mean of 22 hours per week. Compared with a random sample of older people, our respondents spent much less time on house and yard work.

CONCLUSION: The direct costs of the disease reflect a small portion of the burden. The hidden costs, in the form of lost wages, informal care, and changing roles are substantial. Their magnitude is even more important when we consider that the family generally lives on a fixed income, and the caregiver is an older aged spouse. Medical practitioners will best be able to intervene if they look holistically at the patient with this disease. When treating symptoms themselves, practitioners need to be aware of the high level of pain, fatigue, and depression associated with PD, even in the early stages. The results demonstrate clearly that family relationships are affected early, indicating the importance of providing early referrals to services such as home health, social workers/counseling, and well as PD support groups. *J Am Geriatr Soc* 45:844-849, 1997.

As our population ages, the number of families living with Parkinson's Disease (PD) increases. For individuals older than age 85, PD prevalence is almost three in 100 persons.¹⁻³ Much has been written about the effect of PD on health status.⁴⁻⁶ However, the effect of the signs and symptoms of PD on the stricken individuals and those who love and care for them is much broader reaching than clinical health measures indicate. PD places a burden on the individual with PD, the family, and society. Each step in the deterioration of health influences the family unit's quality of life and its financial status. This occurs in four ways: (1) financial burden on the family and society; (2) burden on the family of caring for the disabled individual; (3) changes in family roles and activities for the stricken individual and caregivers; and (4) changes in cognition and psychology of the individual with PD.

The purpose of this study was to determine the burden of PD in a holistic fashion. We examined the burden of PD in four domains: (1) financial burden to society (i.e., compensated loss); (2) financial burden to the family (i.e., costs not compensated); (3) personal burden (i.e., loss of function, depression, pain); and (4) role changes. To gauge generalizability, we compared our data with other nationally representative databases that include separate information for individuals with and without PD.

METHODS

Sample

Our sample consisted of PD patients living within 30 miles of Duke University in Central North Carolina and was drawn from several sources: participants in other PD studies (158); participants in support groups (7); participants from local nursing homes and VA hospital (10); respondents to newspaper advertisements (29); and referred from others in the study (2). Thirty-eight of the 206 letters were sent to participants who were ineligible: 19 lived too far away, 11 had an unclear PD diagnosis, and eight were deceased. Another 60 people (36%) did not participate because they were too busy (1), did not think they could contribute (1), or were not locatable (29), too ill or had family problems (9), no-shows, (4) or for reasons unknown (2). Overall participation rate was 64%.

Instruments

Duke Survey

The Duke Survey lasted approximately 90 minutes, with an additional 20 minutes with the spouse. Survey questions

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were based on comparison surveys described below. We requested demographic information (e.g., age, sex, race, education, marital status, work status) for the respondents, spouse/partner, children, others who live with them in the home, and unpaid caregivers (Table 1). We asked questions about the health status of respondents, including other chronic conditions, depression, cognition, pain and fatigue, activities of daily living (ADLs; see Table 2), instrumental activities of daily living (IADLs; check Table 2), and PD-specific signs and symptoms. Third, we requested information about hours of informal caregiving received each week, medical services, alterations made to home or vehicle attributable to PD, and special equipment purchased because of PD. These sections included questions on the out-of-pocket cost of each service or alteration and the source of compensation. Fourth, we asked about household work, employment history, and disability. To ascertain wealth and income, we asked about housing wealth, net worth other than housing, and sources and amounts of income. Finally, we asked about the amount of time spent on various activities and hobbies. Spouses were asked many of the same questions as the individual with PD in a separate interview.

The National Health Interview Survey (NHIS)

We compared demographic characteristics of our respondents with those 88 respondents to the 1993 National

Health Interview Survey (NHIS).⁷ The NHIS is a nationwide survey of almost 50,000 households and more than 100,000 civilian, noninstitutionalized individuals that has been conducted annually since 1957. The survey collects basic socio-demographic information and limitations on activity (not comparable to ADLs and IADLs in our survey).

The Panel Study of Income Dynamics (PSID)

The Panel Study of Income Dynamics (PSID), which does not identify those with PD, was used as a national population-based comparison group. The PSID was used to predict earnings that persons with PD might have experienced in the absence of the disease. We phrased financial and demographic questions in the survey identically to those in the PSID. The PSID began in 1968 with a nationally representative set of 5000 families in the United States and has followed all of the individuals living in (and born to) those families. All monetarily expressed values were updated to 1994 dollars, using the "Consumer Price Index - All Items."⁸ Weights were used to generate estimates representative of the United States population.

The Assets and Health Dynamics (AHEAD) Survey.

The AHEAD survey is a national survey of 8100 community-based individuals aged 70 and older conducted by the University of Michigan's Survey Research Center between

Table 1. Comparison of Parkinson's Disease (PD) Sample with Other Data Bases

Variable Description	Sample Means (Persons >48)		
	Total PD Sample	NHIS PD Sample 1993	AHEAD Weighted
Demographics			
Age (mean years)	71.7	69.1	78.0 ^a
Age 45-64 (%)	20.2	10.2 ^b	0.0
Age 65-74 (%)	42.2	29.5 ^c	35.1
Age 75 or more (%)	37.6	47.7	64.9
Female (%)	29.2	40.0	62.1 ^a
Currently married (%)	78.0	58.0 ^a	50.1 ^a
Divorced or separated (%)	5.6	4.5	5.0
Widowed (%)	16.7	28.4 ^c	41.6 ^a
Never married (%)	0.9	8.0 ^b	3.3 ^b
Any children living at home (%)	10.1		
White (%)	94.5	93.2	87.5 ^a
Black (%)	3.7	6.8	10.6 ^a
Other race (%)	1.8	0.0	1.9
Hispanic (%)	0.0	4.5 ^c	4.3 ^a
Education (mean years)	15.1	11.0 ^a	10.9 ^a
Self-rated health			
Excellent or very good health (%)	17.4	14.8	33.4 ^a
Good health (%)	33.0	27.3	30.7
Fair or poor health (%)	49.5	58.0	35.9 ^a
Employment			
Working (%)	8.3	12.5	8.7
Hours worked per year (mean)	189.3		106.6
Total income (1994\$ mean)	37,644	31,403	22,473
Assets (1994\$ mean)	223,927		107,465
Number of Observations	109	88	8223

t tests examine the significance between the Parkinson's sample and NHIS or AHEAD samples.

^aTwo-tailed *t* test significant at 1%.

^bTwo-tailed *t* test significant at 5%.

^cTwo-tailed *t* test significant at 10%.

Table 2. Health Status of People with Parkinson's Disease and Comparison with General Population

Variable Description	Total PD Sample	Good Health	Poor Health	Weighted AHEAD
Duration of disease (mean years)				
Years since diagnosis	5.9	5.4	6.5	
Years since symptoms started	7.1	6.5	7.8	
Symptoms of PD (%)				
Bradykinesia	79.8	69.1 ^a	90.7	
Stiffness	75.0	70.4	79.6	
Speech	71.6	69.1	74.1	
Saliva	60.6	61.8	59.3	
Tremors	45.0	45.5	44.4	
Swallowing	34.3	30.9	37.7	
Bladder	32.4	29.6	35.2	
General condition (%)				
Depression	29.9			15.1 ^a
Cognitively impaired	26.3			22.0
Fatigued	50.9			
Pain	37.6			32.8
ADLs (mean out of 6 possible)	3.2			0.5 ^a
Walking (%)	40.0			19.8 ^a
Dressing (%)	67.9			7.8 ^a
Eating (%)	39.4			4.6 ^a
Sitting (%)	83.3			2.5 ^a
Bathing (%)	29.4			9.0 ^a
Getting out of bed (%)	56.9			6.5 ^a
IADLs (mean out of 3 possible)	1.4			0.8 ^a
Climbing stairs (%)	44.1			3.2 ^a
Walking several blocks (%)	61.7			4.5 ^a
Picking up a dime (%)	34.9			
Walking Aids (% using any)		40.2		18.1 ^a
Number of Observations	109	55	54	8223

t tests examine the significance between the Parkinson's samples and Parkinson's sample and AHEAD:

^aTwo-tailed *t* test significant at 1%; two-tailed *t* test significant at 5%; two-tailed *t* test significant at 10%.

October 1993 and March 1994. While the AHEAD survey does not identify PD as a separate neurological disease, the unique characteristics of the survey include its health, functional status, cognitive status, and financial questions. We were able to use this database as a comparison with our PD sample on socio-demographics and health status.

MacArthur

To measure productivity and role loss in our respondents, we used an activities survey instrument validated in the MacArthur Foundation Research Network on Successful Aging.⁹ This research was conducted with 4030 individuals between the ages of 70 and 79 in Durham County, North Carolina, East Boston, Massachusetts, and New Haven, Connecticut.

Analysis

We computed costs attributable to PD during the year before our survey. Cost estimates included expenditures on personal health services and other care, both paid and unpaid, home and vehicle alterations, purchase of special equipment, and earnings loss. Per capita expense per unit of service was calculated as the product of (1) the fraction of individuals in the sample using the service, (2) the mean number of units (e.g., hospital days), and (3) the national mean cost of the unit. Excess cost to individuals with PD was computed by

subtracting per capita cost to the general population from the cost per capita to individuals with PD.

Informal care was defined as care for which no payment is made. If the same respondent received both formal and informal care, the price our survey respondent reported paying per hour for formal care was used as the value of any informal care received. If the respondent received informal care but no formal care, we used a mean hourly wage from the PSID adjusted to 1994 dollars (\$12.95).

Yearly expenses on alterations to home, vehicle, and special equipment were estimated by using the Consumer Price Index and the year in which the expenses were incurred to adjust all expenses in 1994 dollars and, assuming a useful life to be 7 years for equipment, 10 years for a car, and 30 years for a home, equal payments each year over the life of the equipment or alteration and a real interest rate of 3%.

To compute loss in earnings incurred by individuals with PD we derived population-based predicted labor force participation and wage using the PSID sample. This allowed us to estimate what individuals with PD, given their demographic characteristics, would be expected to earn. Gender and age group specific equations were estimated using age, race, and education as explanatory variables for labor force participation; and age, race, education, and religion for wage. Earnings losses were predicted for each individual by subtracting actual hours of work from predicted hours of work

and multiplying by the predicted wage. Compensation for lost earnings included income from unemployment compensation, worker's compensation, veteran's benefits, Supplemental Security Income, Social Security when the respondent or spouse was under the age of 65, and food stamps. We used *t* tests to compare our sample to PD respondents of the NHIS and to the AHEAD surveys.

RESULTS

Representativeness of Survey

Our survey respondents were similar to the NHIS sample with Parkinson's disease in age, gender, race, self-rating of health with the exception of poor health, percent working at the time of the survey, and income (Table 1). Our respondents differed significantly from NHIS respondents only in that our respondents were more likely to be married, have more years of education, and less likely to be Hispanic. While the difference in educational level would be a concern if other information were not available, it is balanced by the similarity in incomes for which education is often used as a proxy. The high education level of our subsample is attributable to the large number of persons with PhD degrees in the area.

Our survey respondents differed from nationally representative samples of those older than age 49 in predictable ways. The AHEAD sample of older people is similar in employment, income, and assets to our sample but rated themselves to be in better health than our sample, even though the AHEAD sample is older.

Overall, we are comforted that our local sample is similar to nationally representative surveys of those with and without Parkinson's Disease in terms of income, assets, and working status. Barriers to health care, social services, and, ultimately, utilization for the samples should be similar because of similar health states.

Parkinson's Disease Signs and Symptoms

Respondents were asked to rate their health subjectively on a 5-point scale from excellent to poor (Table 1). Approximately half of the sample rated their health as fair to poor and half as good or better. Tremors, bradykinesia, and rigidity are the cardinal signs of PD. At least three-quarters of the respondents reported difficulty with bradykinesia and stiffness (Table 2). Nearly half reported tremors that interfered with activities. Difficulty with speech, and lack of saliva were also reported by more than half of the respondents. Our respondents were diagnosed with Parkinson's Disease 6 years, on average, before the survey and 7 years before development of Parkinson's symptoms (range 0 to 30 years for diagnosis).

We compared those reporting "good" health (including good, very good, and excellent) with those reporting "poor" health (including fair and poor) (Table 2). The only significant difference in symptoms was bradykinesia. Furthermore, there was little difference in years since diagnosis of those reporting good health compared with those reporting poor health.

General Health Status

Depressive symptoms were reported by 30% of our sample. This is similar to PD respondents of other published studies^{10,11} and significantly more than in the general older population represented in the AHEAD survey (Table 2).^{12,13}

Half the sample experienced debilitating fatigue. Levels of cognitive impairment and pain were similar to AHEAD. Our respondents experienced significantly more difficulty with ADLs and IADLs, and were more likely to utilize a walking aid than the older AHEAD sample.

As was expected, respondents reporting to be in fair to poor health were significantly ($P < .05$) more likely to have problems with slow movements, all ADLs with the exception of getting up from a sitting position, all IADLs, and were more likely to use walking aids (not shown). Those reporting to be in good to excellent health were significantly less likely to be women, had higher education, and were more likely to be doing housework.

Societal, Family, and Personal Burden of Parkinson's Disease

Societal Burden

Societal expenses include all compensated costs. Some type of government insurance covered 85% of our sample, including 81% receiving Medicare, 5% receiving Medicaid, and 14% receiving CHAMPUS (these categories were not mutually exclusive). All of the respondents, including those less than age 65, had some form of insurance at the time of the interview. However, in the past, insurers had denied coverage to 16% of our sample because of a preexisting condition.

The total mean societal burden per individual with PD was approximately \$6000 per year (Table 3), with the greatest single element being compensation for earnings loss. Mean compensated earnings loss was highest for those less than age 65, approximately \$9000. Interestingly, compensated healthcare cost differences between those reporting poor health versus those reporting good health were quite small (\$4500 vs \$3800). The largest per capita compensated health care costs were physician visits and hospital expenses. Physician visits cost society an average of \$1324 per year per respondent with PD. Ninety-nine percent of our sample visited the physician at least one time in the 12 months before the interview, with the mean number of visits being 18 per year or more than one visit per month. This compares with a mean of five physician visits per year for the AHEAD sample. A total of 26% of our respondents had in-patient hospitalizations during the 12 months before the interview, with an average length of stay of 2 days. This compares with 23% of AHEAD respondents. Ten individuals in the sample were in a nursing home at the time of the study, compared with less than 1% of the AHEAD respondents, and 42% of our respondents visited other health professionals such as chiropractors, physical, occupational, and speech therapists, and mental health professionals.

All respondents purchased prescription medications, with a mean number of prescriptions filled per year of 50 (4 per month). Almost half of the cost of prescriptions was covered by insurance. Formal care was received by only 8% of the respondents, which explains the low per capita cost (under \$300).

Family Burden

The largest components of family burden were not direct health care costs, but the burden of providing informal caregiving and earnings loss (Table 3). More than one-third of our respondents received informal care. Almost half of those reporting to be in poor health reported receiving informal

Table 3. Societal, Family and Personal Burden of Parkinson's Disease (Annual 1994 \$)

Social		
Hospital expenses		1292
Doctor visits		1324
Visits to other health professionals		590
Rx Drugs		505
Formal Care		293
Special Equipment/Alterations		22
	Subtotal	4026
Compensated Earnings loss		2089
	Societal Total	6115
Family		
Hospital expenses		231
Doctor visits		264
Visits to other health professionals		28
Rx Drugs		556
Formal Care		21
Domestic Help		316
Special Equipment/Alterations		242
	Subtotal	1418
Informal Care		5386
Earnings Loss		12082
	Family Total	18886
	Total Dollar Value	25001
Personal		
Annual hours of housework		326.4
Annual hours of yardwork		22.8
Total home production hours (Annual)		349.2

Includes: physical, speech, and occupational therapy.

*Visits to mental health professional, and nursing home stays.

caregiving. Of those who received informal care, the caregiver, usually the spouse, provided an average of 22 hours of care per week. Mean age of spouses was 69. The physical burden of providing such care for the older Parkinsonian spouse is great. When we monetize informal caregiving, it is, with the exception of income loss, the single most expensive element of burden attributable to PD.

The mean uncompensated earnings loss for our sample was approximately \$12,000. To examine earnings loss more closely, we stratified our sample by those under age 65 and those 65 and older. The range in earnings loss was great for those under age 65, approximately \$39,000 per year. Women aged 65 and older lost \$5000 per year, and men in this age group lost a mean of \$6500 per year. Earnings loss for those aged 65 and older comes predominately from lower sources of income, probably a result of less income at the time of retirement. Although the compensation for earnings loss was the largest component of societal burden, compensation is small relative to the amount of loss.

Family burden measured in terms of health care expenses paid was approximately one-third the cost to society (Table 3). The largest expense to the family was paying for prescrip-

tion medications. Informal care was received by 34% of the respondents (45% of the respondents in poor health and 24% in good health).

Personal

We found that our respondents spent a mean of 326 hours on housework per year and 23 hours on yard work per year. This compares with the MacArthur study of older individuals, which found those who were high functioning performed an average of 739 hours of housework and 210 hours of yard work per year.¹⁴ The MacArthur study found low functioning individuals performed an average 512 hours of housework and 86 hours of yard work per year, still much higher than our sample. The differences hold even when we take into account differences in the gender distribution of our samples.

DISCUSSION

The results of this study illustrate that the greatest burden of PD is not financial but personal. Our cross-sectional sample included participants ranging from the early stages of the disease to late stages, with a mean time since diagnosis of only 6 years. It has been estimated that since the institution of levodopa, 9% of patients with the disease are disabled or dead within 1 to 5 years, 21% between 6 to 10 years, and 37.5% at 11 to 15 years.¹⁵ Thus, our sample was weighted toward persons in the early stages of the disease. Few of the respondents in our sample resided in nursing homes so we were unable to estimate the cost during the most expensive years of the disease. It will be important to establish the cost of PD in the early years of the disease versus later in the disease. The hidden costs in the form of lost wages and informal (non-reimbursed) care are substantial, even for people in the early stages of the disease course. Their magnitude is even more impressive when we consider that this is a disease of older people. These individuals are often on a fixed income, meaning that the effect of paying for home care, medications, and other out of pocket expenses extract a larger toll on this age group than on younger people. The caregiver often is a spouse, who in our sample had a mean age of 69, and may also have health limitations that further compound the burden of care giving.

With respect to the burden of the symptoms of PD, our sample was similar to others in the literature. We compared symptoms of those participants who reported "good health" compared with those who reported "poor health." It is noteworthy that the one PD symptom that differentiated the two groups was bradykinesia. This is consistent with literature that suggests that bradykinesia is the most debilitating symptom of PD.¹⁶

Symptoms of depression were high in this sample, consistent with previous reports. In addition, a significant proportion of these respondents reported pain and debilitating fatigue. Although pain is reported generally in the older population, the symptoms may be compounded by the presence of PD. Neither pain nor debilitating fatigue are generally recognized as major symptoms of PD. Healthcare professionals involved with patients who have PD need to understand the relationship of depressive symptoms, pain, debilitating fatigue, and the overall symptoms of PD, as well as the neurophysiological pathology of PD. Healthcare professionals need to treat these symptoms aggressively because they may be contributing factors in the patient's overall level of disability.

The psychological/cognitive ramifications of PD were only crudely assessed in the current study. A full appreciation

of psychological/cognitive issues with respect to burden of PD requires an in-depth investigation. Comparisons with the MacArthur data⁹ indicate that this sample is limited in the amount of yard and house work that they can do, suggesting the inevitable role changes engendered by PD.

In summary, this is a preliminary investigation designed to look at the burden of PD in a holistic manner. Medical practitioners will best be able to intervene if they look holistically at the patient with this disease. When treating symptoms, practitioners need to be aware of high levels of pain, fatigue, and depression associated with PD, even in the early stages. While these are not the cardinal signs of PD, they appear to be quite prevalent and do influence the mental health of both PD patients and their family. Treatment of these symptoms may help patients to cope better with the disease, even when rigidity, tremor, and other cardinal signs are worsening. The results clearly demonstrate that family relationships are affected early, emphasizing the importance of providing early referrals to services such as home health and social workers/counseling, as well as PD support groups. Because we found such a high burden in these early stages, a full appreciation of the burden of this disease will be enhanced by a longitudinal study of this cohort. We expect the burden in all areas to increase as the disease progresses.

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