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Caregiver burden among family members of Parkinson's disease patients using the Zarit Burden Interview: A cross-sectional study

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Abstract

Background: Parkinson's disease imposes a substantial and sustained demand upon family members, yet clinical assessment and treatment remain centred upon motor impairment. Which features of the illness actually burden the caregiver has not been established with confidence, and reviews report inconsistent findings for motor severity. **Objective:** This study measured caregiver burden and determined the relative contribution of motor severity, non-motor and neuropsychiatric symptoms, and the practical context of caregiving. **Methods:** One hundred and eighty patient and caregiver dyads attending a movement disorder clinic were studied. Patients underwent staging, motor examination, cognitive and neuropsychiatric assessment; caregivers completed the Zarit Burden Interview. Predictors were examined by hierarchical regression entered in four blocks, and the unique contribution of each block was tested independently of entry order. **Results:** The mean burden score was 30.32, and 77.8% of caregivers reported clinically significant burden. The full model explained 72.7% of the variance. Non-motor and neuropsychiatric symptoms contributed uniquely, accounting for 24.4% of the explained variance, whereas the unique contribution of motor severity was 1.5% and did not reach significance. Motor severity appeared influential only when it was entered first. **Conclusion:** Caregiver burden is driven predominantly by non-motor features rather than motor severity.

Keywords: *Parkinson's disease, Caregiver burden, Zarit Burden Interview, Neuropsychiatric symptoms, Non-motor symptoms, Hierarchical regression, Family caregiving*

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1. Introduction

Parkinson's disease is a progressive disorder whose management, in most of the world, is undertaken at home by a family member. That person is generally a spouse or an adult child, is rarely trained, is seldom paid, and occupies a role that extends over years and intensifies as the illness advances. The consequences for the caregiver, described collectively as caregiver burden, encompass physical strain, psychological distress, social

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restriction and financial loss, and they are now recognised as an outcome of the disease in their own right rather than as an incidental accompaniment (Zarit *et al.*, 1980; Mosley *et al.*, 2017; Bhattacharjee *et al.*, 2019).

The instrument most widely used to quantify this is the Zarit Burden Interview, a twenty-two item questionnaire yielding a total between zero and eighty-eight, with conventional thresholds separating absent to mild, mild to moderate, moderate to severe and severe burden (Bedard *et al.*, 2001). It is the measure employed in the majority of published studies of caregiving in Parkinson's disease, which permits comparison across settings (Lesley *et al.*, 2025).

What determines the magnitude of that burden is less settled than the frequency of its measurement would suggest. The intuitive expectation is that burden should track the severity of the disease, and since severity is assessed clinically by motor staging and motor examination, it would follow that the most disabled patients impose the greatest burden. The evidence does not support this straightforwardly. A recent systematic review found that disease duration failed to predict burden in the majority of studies examining it, and that findings for motor examination scores were inconsistent, whereas measures of neuropsychiatric disturbance and of dependency in daily activities predicted burden with far greater consistency. Studies addressing neuropsychiatric symptoms directly have reported strong associations with caregiver distress, and this has been observed even in early disease (Martinez-Martin *et al.*, 2015; Leiknes *et al.*, 2010; Schrag *et al.*, 2006).

There is a plausible reason why motor severity might nonetheless appear influential in analyses that report it as such. Motor and non-motor features advance together, so that a patient with advanced motor disease will also tend to have more neuropsychiatric disturbance and greater cognitive impairment (Schapira *et al.*, 2017; Weintraub *et al.*, 2022; Aarsland *et al.*, 2021). Any analysis that enters motor severity without simultaneously accounting for non-motor features will therefore attribute to motor severity a portion of variance that properly belongs to the symptoms accompanying it. Distinguishing the two requires that the unique contribution of each be estimated, which a single simultaneous regression reporting only coefficients does not readily convey.

Clinical assessment in Parkinson's disease is organised around motor function, and treatment is directed principally at it, so that if burden is in fact generated by features that are neither routinely measured nor systematically treated, the caregiver's difficulty will be invisible to the consultation that ought to detect it (Sauerbier *et al.*, 2021). Indian data on this question remain limited, and the few available studies have reached differing conclusions about the primacy of motor severity (Wandrekar *et al.*, 2017; Kumar *et al.*, 2021; Rao *et al.*, 2015).

The present study was therefore undertaken with three objectives: to determine the magnitude and distribution of caregiver burden among family members of patients attending a movement disorder clinic; to compare the contribution of caregiver characteristics, motor disease severity, non-motor and neuropsychiatric symptoms, and the practical context of caregiving, by entering these as successive blocks in a hierarchical regression; and to establish, by a test independent of the order in which the blocks are entered, which domain accounts uniquely for the burden reported.

2. Materials and methods

2.1. Design and participants

A cross-sectional study was conducted among 180 patient and caregiver dyads attending a movement disorder clinic. Reporting follows the recommendations for observational studies (von Elm *et al.*, 2007). Patients were eligible if they met established diagnostic criteria for idiopathic Parkinson's disease and attended with a family member who had provided unpaid care for at least six months and was principally responsible for that care. Dyads were excluded where the patient had a diagnosis of atypical or secondary parkinsonism, where the caregiver was employed for the purpose, where care was shared equally among several people such that no principal caregiver could be identified, or where either party was unable to complete the assessment.

2.2. Patient assessment

Disease stage was determined by the Hoehn and Yahr scale and motor impairment by the motor examination section of the Unified Parkinson's Disease Rating Scale, both administered by a neurologist during the on state

(Hoehn and Yahr, 1967; Goetz *et al.*, 2008). Neuropsychiatric symptoms were assessed by the Neuropsychiatric Inventory, which quantifies the frequency and severity of disturbances including depression, anxiety, apathy, hallucinations, irritability and disinhibition (Cummings *et al.*, 1994). Global cognition was assessed by the Mini-Mental State Examination and depressive symptoms by the Geriatric Depression Scale (Folstein *et al.*, 1975). Disease duration was recorded from the reported onset of motor symptoms.

2.3. Caregiver assessment

Caregivers completed the 42-item Zarit Burden Interview, administered by interview in the local language by an investigator not involved in the patient's clinical care. Scores were classified by the conventional thresholds as absent to mild for 20 or below, mild to moderate for 21 to 40, moderate to severe for 41 to 60, and severe for 61 and above, and a total exceeding 20 was taken to indicate clinically significant burden. Caregiver age, sex, relationship to the patient and employment status were recorded, together with the mean number of hours of care provided daily, whether the caregiver was the sole provider of care, and whether the household reported financial strain attributable to the illness.

2.4. Statistical analysis

Continuous variables are presented as mean with standard deviation and categorical variables as frequency with percentage, proportions carrying 95 percent confidence intervals by the Wilson method. Associations with burden were examined by Pearson correlation. Predictors were then entered as four conceptual blocks in a hierarchical regression, the increment at each step being tested by the F statistic for change (Petrocelli, 2003). Because that increment depends upon entry order, two further analyses were performed: the unique contribution of each block was computed as the variance lost when that block alone was removed from the full model, and the hierarchy was re-run with the motor and non-motor blocks interchanged (Nimon and Oswald, 2013). Collinearity was assessed by the variance inflation factor, group differences by the Welch t test with Cohen d (Cohen, 1992), and a probability below 0.05 was accepted as significant.

3. Results

3.1. Characteristics of the dyads

Caregivers had a mean age of 48.6 years. Of these, 68.3 % were women and 48.9 % were spouses of the patient, the remainder being adult children or other relatives. Patients had a mean age of 64.2 years, a median Hoehn and Yahr stage of 2.5 and a mean disease duration of 5.5 years. Care occupied a mean of 5.0 hours daily. Sole responsibility for care was reported by 43.9 % of caregivers and financial strain by 38.9 % of households (Table 1).

3.2. Magnitude and distribution of burden

The mean Zarit Burden Interview score was 30.32 with a standard deviation of 12.19, the median was 31 and scores ranged from 0 to 67. Clinically significant burden, defined as a total above 20, was present in 140 caregivers, that is 77.8% of the sample. Table 2 gives the distribution across the conventional categories. Spouses scored higher than adult children and other relatives, 32.5 against 28.2, with a t statistic of 2.41, a probability of 0.017 and an effect size of 0.36.

3.3. Burden across patient strata

Burden rose across strata of motor severity, from 21.0 at Hoehn and Yahr stages 1.0 to 2.0, to 33.7 at stages 2.5 to 3.0 and 38.2 at stages 3.5 to 5.0, with an F statistic of 46.69. It rose more steeply across tertiles of neuropsychiatric symptom burden, from 22.1 in the lowest tertile to 28.3 in the middle and 40.5 in the highest, with an F-statistic of 58.48. Both gradients were significant beyond the 0.001 level (Figure 1).

3.4. Bivariate associations

Burden correlated most strongly with the Neuropsychiatric Inventory score at 0.704. The Hoehn and Yahr stage followed at 0.634, the daily hours of care at 0.587 and the motor examination score at 0.559. Cognition was inversely correlated at -0.285. Neither caregiver age nor disease duration was significantly associated with burden (Table 3).

Table 1: Characteristics of caregivers and patients (180 dyads)

Characteristic	Value
Caregiver age (years), mean $\pm$ SD	48.6 $\pm$ 12.4
Female caregiver, n (%)	123 (68.3)
Spouse caregiver, n (%)	88 (48.9)
Caregiver in employment, n (%)	84 (46.7)
Patient age (years), mean $\pm$ SD	64.2 $\pm$ 9.1
Disease duration (years), mean $\pm$ SD	5.5 $\pm$ 3.6
Hoehn and Yahr stage, median (range)	2.5 (1.0 to 5.0)
UPDRS motor examination, mean $\pm$ SD	28.1 $\pm$ 12.4
Neuropsychiatric Inventory, mean $\pm$ SD	14.6 $\pm$ 10.6
Mini-Mental State Examination, mean $\pm$ SD	26.4 $\pm$ 3.1
Daily hours of care, mean $\pm$ SD	5.0 $\pm$ 2.4
Sole caregiver, n (%)	79 (43.9)
Financial strain reported, n (%)	70 (38.9)

Table 2: Distribution of caregiver burden by conventional Zarit Burden Interview category

Category	n	Percentage	95% CI (%)
Absent to mild (0-20)	40	22.2	16.8 to 28.8
Mild to moderate (21-40)	97	53.9	46.6 to 61.0
Moderate to severe (41-60)	41	22.8	17.3 to 29.4
Severe (61-88)	2	1.1	0.3 to 4.0

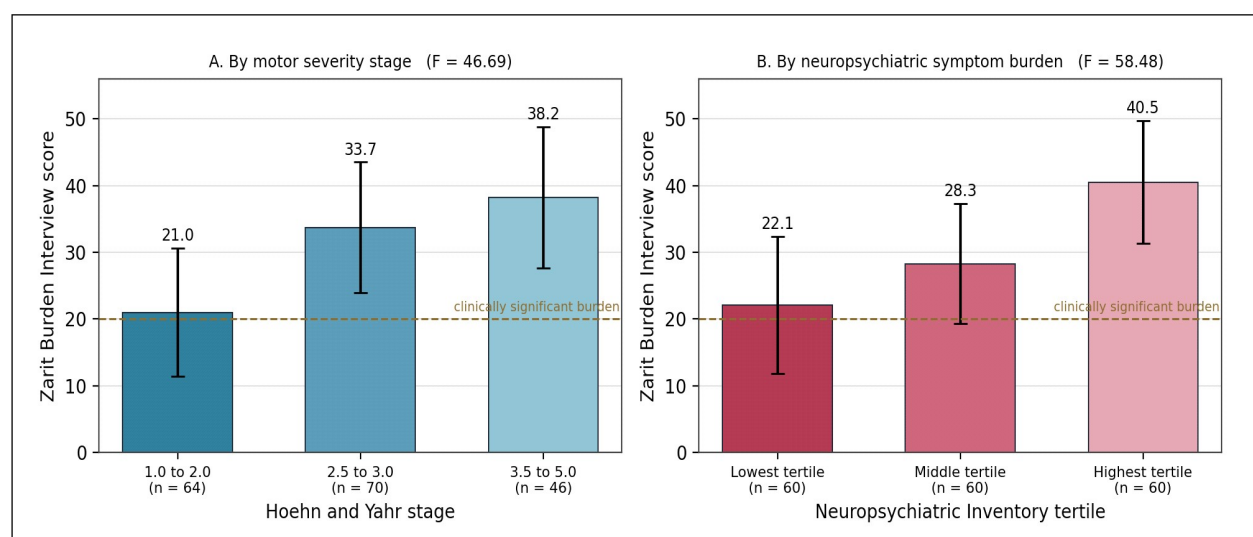
**Figure 1: Caregiver burden across strata of motor severity and of neuropsychiatric symptom burden. The broken line denotes the threshold for clinically significant burden**

Table 3: Bivariate correlation of the Zarit Burden Interview score with patient and caregiver variables

Variable	r	95% CI	p
Neuropsychiatric Inventory score	+0.704	+0.622 to +0.771	<0.001
Geriatric Depression Scale	+0.479	+0.357 to +0.584	<0.001
Daily hours of care	+0.587	+0.482 to +0.675	<0.001
Mini-Mental State Examination	-0.285	-0.414 to -0.144	<0.001
Hoehn and Yahr stage	+0.634	+0.538 to +0.714	<0.001
UPDRS motor examination	+0.559	+0.449 to +0.652	<0.001
Caregiver age	+0.057	-0.090 to +0.202	0.448
Disease duration	-0.124	-0.265 to +0.023	0.098

3.5. Hierarchical regression

The four blocks collectively explained 72.7% of the variance in caregiver burden. The overall model was statistically significant, $F(13, 166) = 34.05$, $p < 0.001$, with an adjusted R^2 of 0.706. The maximum variance inflation factor was 3.2, indicating no substantial multicollinearity. When entered sequentially, caregiver characteristics explained 5.3% of the variance, while motor disease severity contributed an additional 40.1%. Non-motor and neuropsychiatric symptoms explained a further 19.8%, and care-context factors added 7.4%. Each incremental contribution after the first block was statistically significant ($p < 0.001$) (Table 4).

Table 4: Hierarchical regression of the Zarit Burden Interview score, showing the increment attributable to each block in the order of entry

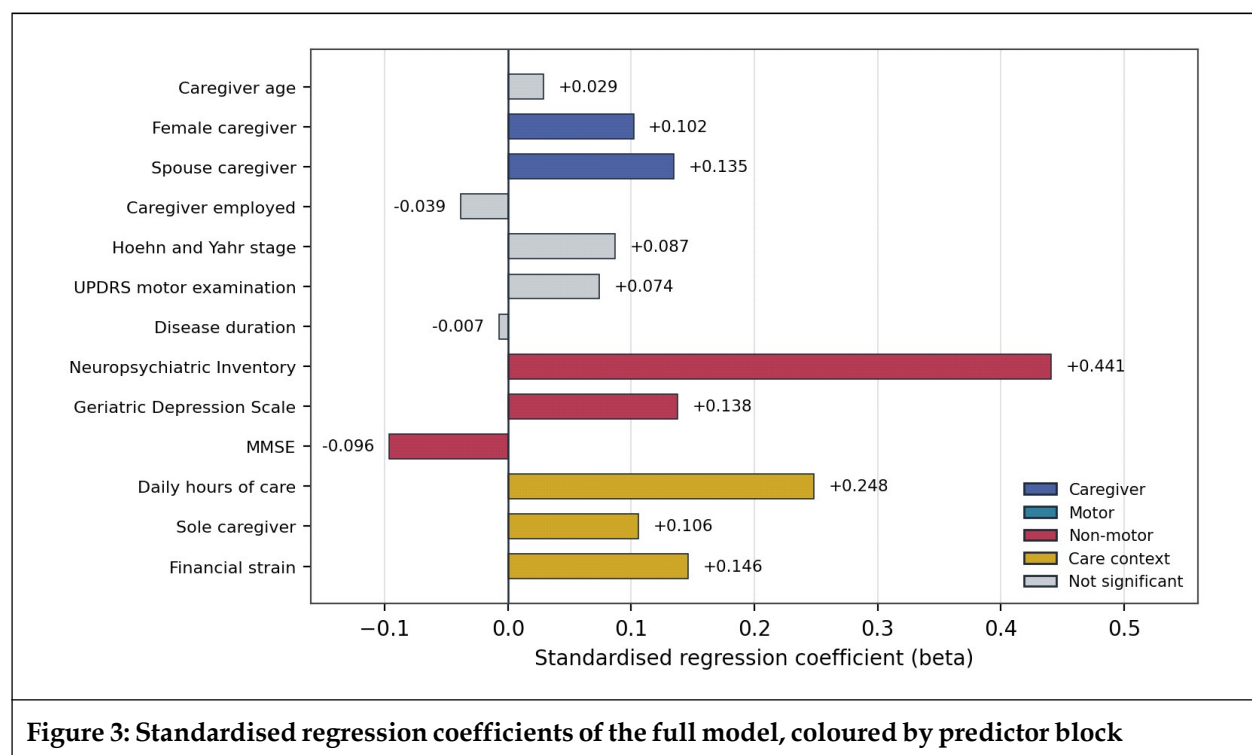
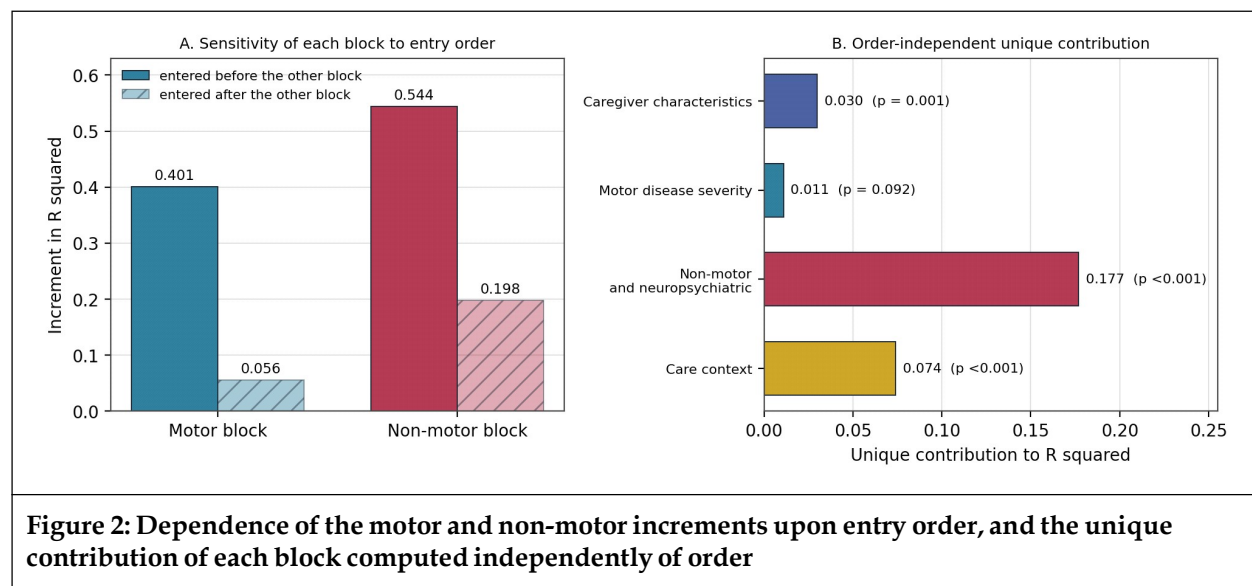
Block	R ²	Increment	F change	df	p
1. caregiver characteristics	0.053	0.053	2.46	4, 175	0.047
2. motor disease severity	0.455	0.401	42.19	3, 172	<0.001
3. non-motor and neuropsychiatric	0.653	0.198	32.20	3, 169	<0.001
4. care context	0.727	0.074	15.08	3, 166	<0.001

3.6. Unique contribution and the effect of entry order

Computed independently of entry order, the unique contribution of non-motor and neuropsychiatric symptoms was 0.177, representing 24.4% of the explained variance, with an F-statistic of 35.94 and a probability below 0.001. The unique contribution of motor disease severity was 0.011, representing 1.5%, with an F-statistic of 2.18 and a probability of 0.092, which did not reach significance. Care context contributed 0.074 and caregiver characteristics 0.030, both significant. When the hierarchy was re-run with the motor and non-motor blocks interchanged, the motor increment fell from 0.401 to 0.056. The non-motor increment rose from 0.198 to 0.544 (Figure 2).

3.7. Predictors in the full model

In the full model the Neuropsychiatric Inventory score carried the largest standardised coefficient at 0.441. The daily hours of care followed at 0.248, financial strain at 0.146, the Geriatric Depression Scale at 0.138 and spouse relationship at 0.135. The Hoehn and Yahr stage at 0.087, the motor examination score at 0.074 and disease duration at -0.007 did not reach significance once the remaining variables were accounted for. Figure 3 shows the coefficients grouped by block.



4. Discussion

Burden was common and substantial in this sample, more than three quarters of caregivers reporting a score in the clinically significant range. The more consequential finding, however, concerns its determinants. Motor severity, which is the axis along which Parkinson's disease is staged, examined and treated, made almost no unique contribution to caregiver burden once the non-motor and neuropsychiatric features accompanying it were taken into account.

This finding requires careful statement because it is easily overstated. Motor severity was not unrelated to burden; its bivariate correlation with the burden score was 0.634, which is substantial. The claim is narrower and more precise: that this association is very largely attributable to variance shared with neuropsychiatric disturbance and cognitive impairment, and that once those are accounted for, motor severity retains a unique contribution of 1.5% which does not attain significance. A patient with advanced motor disease does indeed impose a greater burden, but the analysis indicates that this is because such a patient also tends to be apathetic, depressed, hallucinated or cognitively impaired, rather than because of the motor impairment as such.

The methodological demonstration accompanying this deserves emphasis in its own right, since it bears upon how the existing literature should be read. Entered second in the hierarchy, the motor block produced an increment of 0.401 and would have been reported as the leading determinant. Entered after the non-motor block, the identical variables produced 0.056. Nothing about the data changed between these two analyses, only the order of entry, and the difference represents variance that the two blocks share. Since hierarchical regression assigns shared variance to whichever block is entered first, a study that enters motor severity early, as is natural when motor features are regarded as the primary manifestation of the disease, will report motor severity as the principal determinant of burden as an artefact of that decision. This offers a plausible explanation for the inconsistency the systematic review identified, in which motor examination scores predicted burden in some series and not in others.

The findings otherwise accord closely with the published record. The mean burden score of 30.32 lies within the range reported for clinic populations and above the 11.77 recorded in a South Indian series composed predominantly of ambulant patients in early disease, a difference consistent with the more advanced stage of the present sample. The absence of any association with disease duration reproduces the majority finding of the systematic review, in which eight of twelve studies examining duration found it not to predict burden. The primacy of neuropsychiatric symptoms reproduces the conclusions of several independent series, including work showing that caregiver distress is associated with neuropsychiatric problems even in early disease, and the observation that the mood and apathy domain is the strongest predictor of quality of life in large international cohorts. Greater burden among spouses than among adult children is likewise a recurrent finding, plausibly attributable to co-residence, to the absence of respite and to the loss of the reciprocal relationship that the illness entails (Vatter *et al.*, 2018; Grun *et al.*, 2016; Santos-Garcia and de la Fuente-Fernandez, 2015).

The care-context block, which accounted uniquely for 7.4% of the variance, deserves attention disproportionate to its size because its constituents are the most readily altered. The daily hours of care, sole-caregiver status and financial strain were each independently associated with burden, and none is a property of the disease. Respite provision, the recruitment of a second family member into the caregiving role, and assistance with the costs of medication and travel are interventions that require no advance in the treatment of Parkinson's disease and could be delivered through existing services.

Several implications follow for practice. Neuropsychiatric assessment should form part of the routine review of a patient with Parkinson's disease rather than being reserved for those in whom disturbance is volunteered, since it is these features and not the motor examination that predict the difficulty experienced at home. The caregiver should be assessed as well as the patient, and the Zarit Burden Interview is brief enough for clinic use, with a screening version available where time is limited. Reassurance derived from good motor control should be offered cautiously, since the present findings indicate that a patient may be well controlled motorically while the household is under considerable strain. And where burden is identified, the intervention most likely to relieve it in the short term concerns the context of care rather than the disease itself.

5. Conclusion

More than three quarters of family caregivers of patients with Parkinson's disease attending a movement disorder clinic reported clinically significant burden, and burden was greater among spouses than among other relatives. The determinants of that burden were not those by which the disease is conventionally staged. Non-motor and neuropsychiatric symptoms accounted uniquely for approximately a quarter of the explained variance, whereas the unique contribution of motor severity was 1.5% and did not attain significance, and disease duration was unrelated to burden altogether. Motor severity appeared to be the leading determinant only when it was entered into the hierarchy before the non-motor block, which demonstrates that its apparent influence reflects variance shared with the neuropsychiatric and cognitive features that accompany advancing disease rather than the motor impairment itself. The practical context of caregiving, comprising the hours of care provided, sole responsibility for it and financial strain, contributed independently and is the domain most amenable to intervention. Routine neuropsychiatric assessment of the patient, formal assessment of the caregiver, and practical support directed at the circumstances of care together constitute a response proportionate to the burden documented here.

Ethical approval

The study was approved by the Institutional Ethics Committee (approval number.....) and was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained separately from every patient and caregiver, with consent from a legally acceptable representative where capacity was in question.

Conflicts of interest

The authors declare that no conflict of interest exists in relation to this work.

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Data availability

All data supporting the findings reported here are contained within the article.

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