



ADVANCED STAGES OF PARKINSON'S DISEASE

Keiran K Tuck MBBS

Disclosures

- ▶ Honorary Board Member at Parkinson Wellness Project

Outline

- ▶ The PD Hydra
- ▶ Cognitive changes and dementia
- ▶ Mortality
- ▶ Long Term Care and PD

AN
ESSAY
ON THE
SHAKING PALSY.

BY
JAMES PARKINSON,
MEMBER OF THE ROYAL COLLEGE OF SURGEONS.

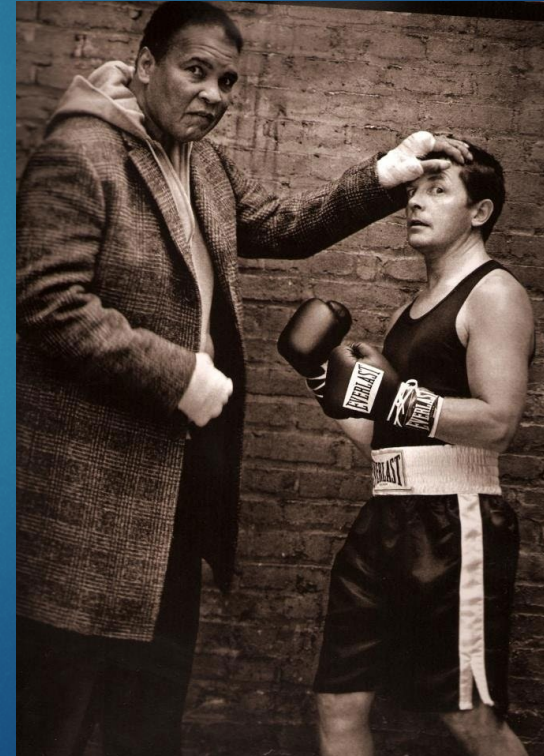
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Cardinal Features of PD

- ▶ Shaking → Tremor
- ▶ Palsy → Bradykinesia
- ▶ Difficulty with gait and falls → Postural Instability
- ▶ ??? → Rigidity



Non Motor Features of PD



Drooling
Olfactory and taste dysfunction
Choking and swallowing difficulties
Nausea and vomiting
Constipation
Fecal incontinence
Bladder dysfunction
Pain
Weight loss & weight gain
Cognitive dysfunction and Dementia
Hallucinations
Depression
Anxiety
Apathy
Sexual dysfunction
Orthostatic hypotension
Excessive daytime sleepiness
Insomnia
REM sleep behaviour disorder
Restless leg syndrome
Leg swelling
Excessive sweating
Diplopia and visual abnormalities
Delusions
Impulse control disorders

But wait... there's more!


- ▶ Caregiver strain
- ▶ Spiritual distress
- ▶ Transportation
- ▶ Relationships with Friends and Family
- ▶ Planning for the future
- ▶ ...

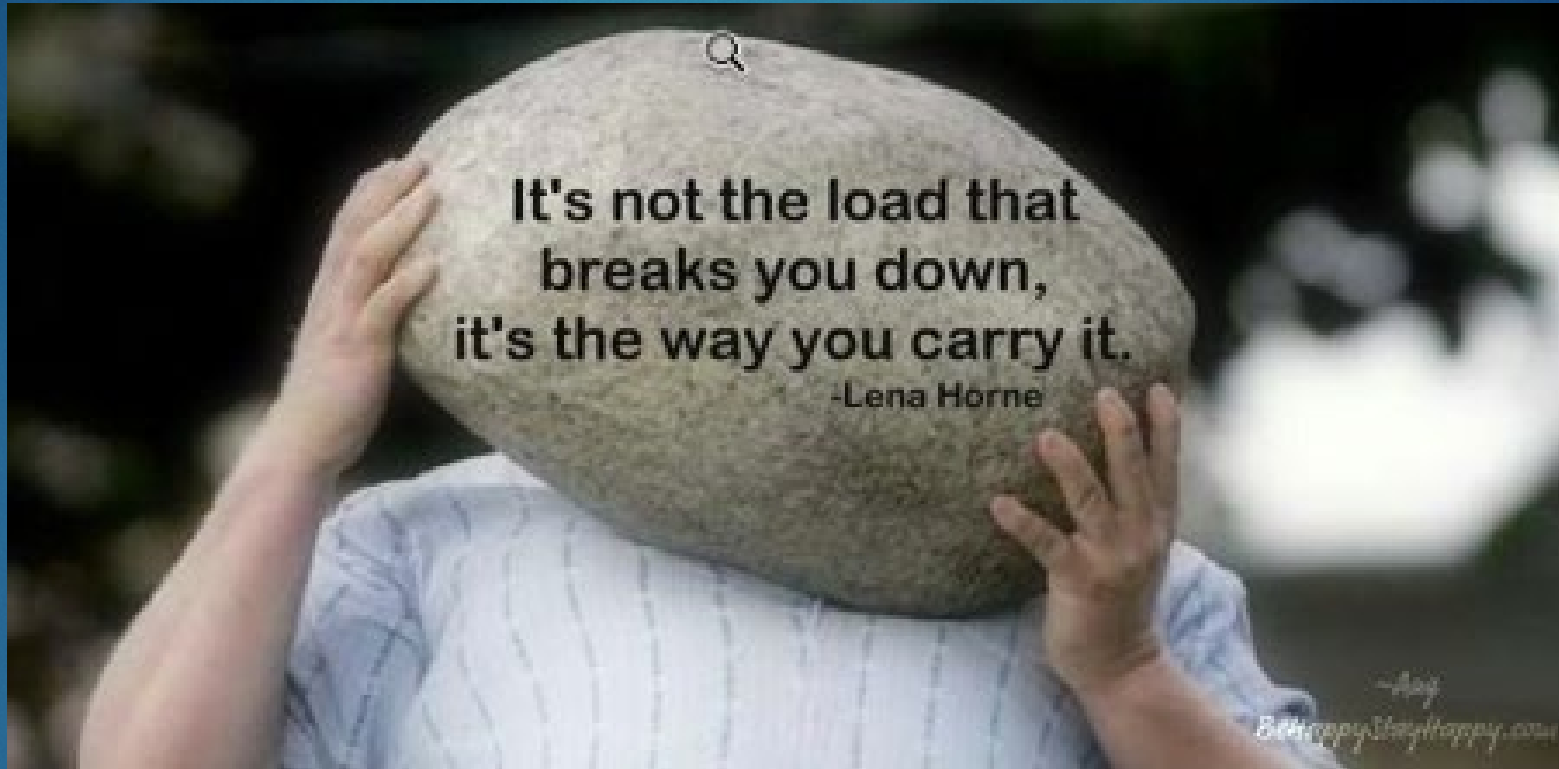
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OVERWHELMED

SURE, I CAN HANDLE THE LOAD. NO PROBLEM.

- 
- ▶ “The early stages, including problems of motor complications from medications are largely treatable. It is the **later stages...** that are **virtually untreatable at present.**”



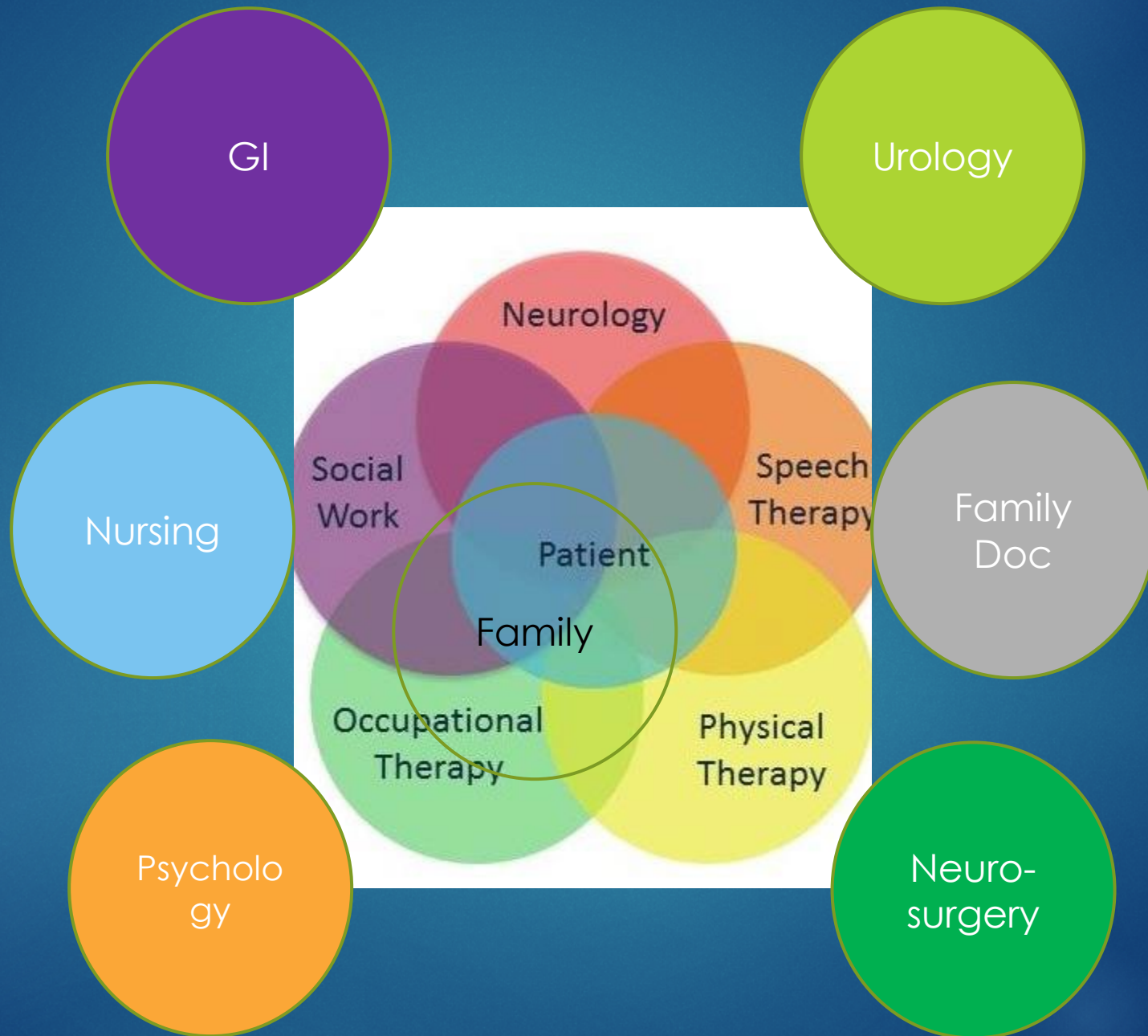
**It's not the load that
breaks you down,
it's the way you carry it.**

-Lena Horne

-Amy
BttHappyStayHappy.com

- ▶ PD management requires a team approach involving patients, families, caregivers and numerous clinicians





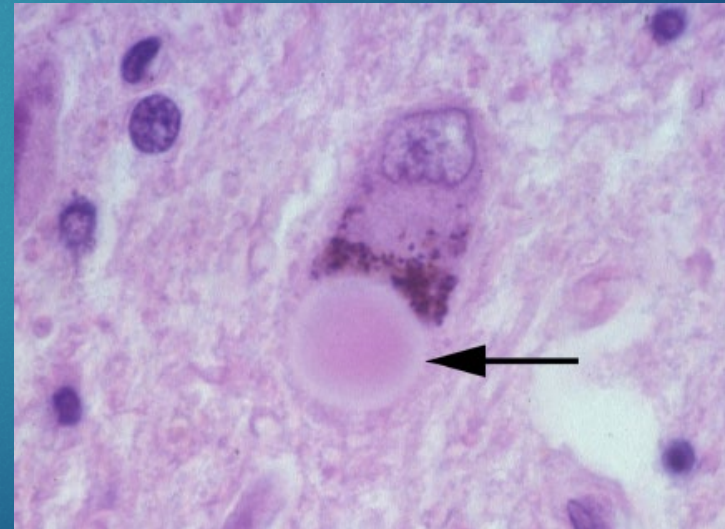
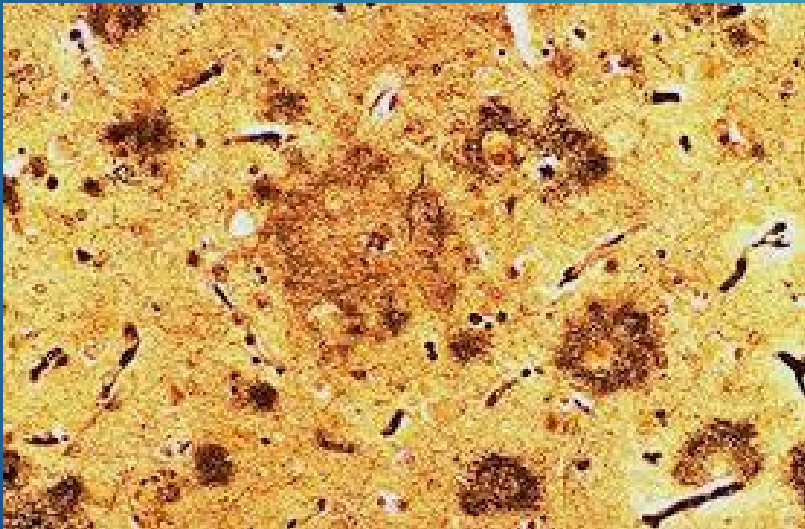
Cognitive Impairment



Terms

- ▶ Pseudo-dementia
 - ▶ subjective cognitive impairment caused by a medical or psychological problem
- ▶ Mild Cognitive Impairment
 - ▶ subjective cognitive impairment
 - ▶ lower than normal score on formal cognitive test
 - ▶ no obvious cause
- ▶ Dementia – impaired daily function
 - ▶ Alzheimer's
 - ▶ Lewy Body Dementia
 - ▶ Vascular
 - ▶ Mixed
 - ▶ others

- ▶ Diagnosis of the specific type of dementia is difficult without brain tissue sample
- ▶ Often it doesn't really matter



Incidence

- ▶ Within three years of diagnosis
 - ▶ 25% converted to MCI
 - ▶ 20% converted to dementia while 28% reverted back to a state of normal cognitive function
 - ▶ To me this indicates a large amount of pseudo-dementia
 - ▶ 2% converted to dementia

Prevalence

Movement Disorders
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The Sydney Multicenter Study of Parkinson's Disease: The Inevitability of Dementia at 20 years

Mariese A. Hely, MBBS,^{1*} Wayne G.J. Reid, PhD,¹ Michael A. Adena, PhD, ASTAT,²
Glenda M. Halliday, PhD,³ and John G.L. Morris, MD¹

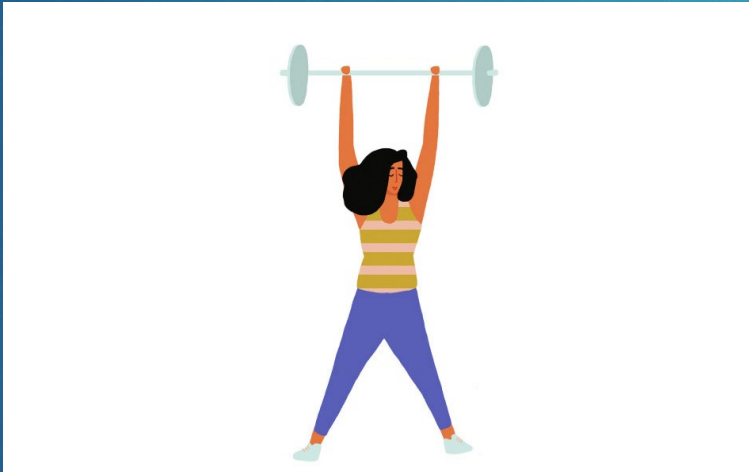
- ▶ Dementia is present in 83%
- ▶ 17 people with dementia had postmortems. 8 had diffuse Lewy bodies as the only cause of dementia, while others had mixed neuropathology.

Risk Factors

- ▶ Atypical parkinsonism
 - ▶ PSP, MSA, DLB, Vascular parkinsonism
- ▶ Hallucinations
- ▶ Greater motor impairment
- ▶ Longer duration of illness
- ▶ Male gender
- ▶ Older age

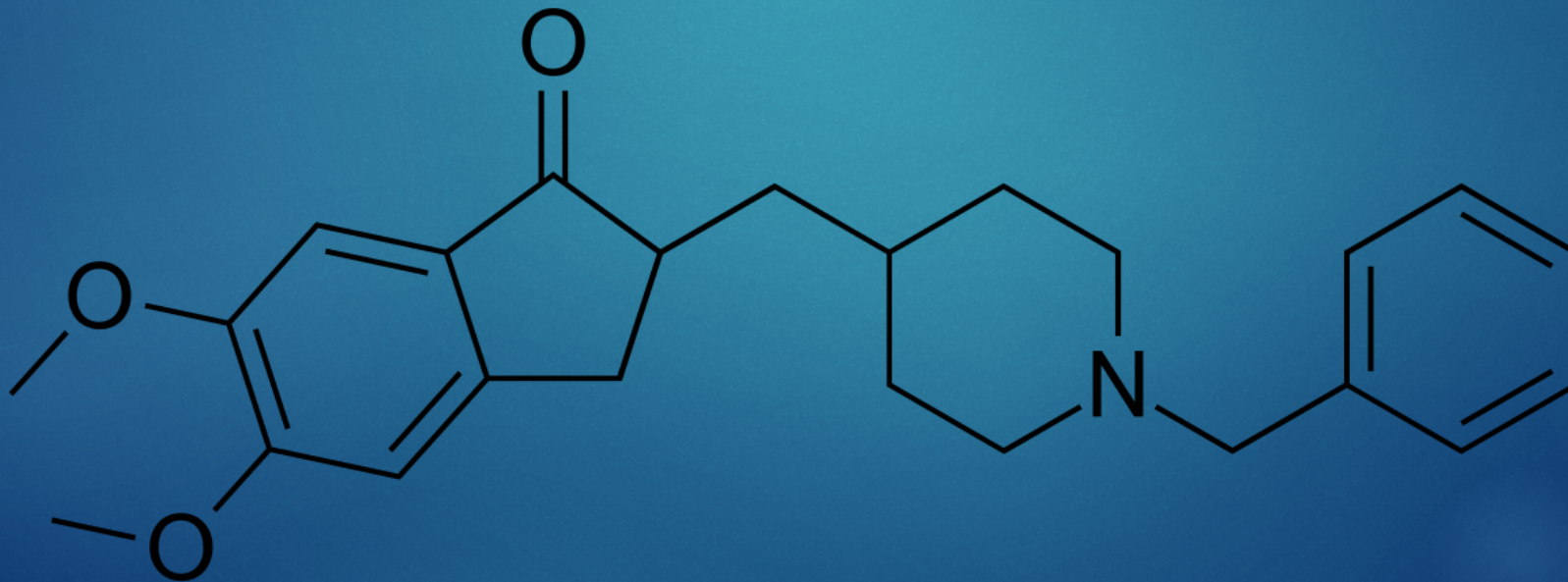
Prevention

- ▶ Exercise
- ▶ Social and mental activity
- ▶ Managing other medical issues



Management - Medications

- ▶ Cholinesterase inhibitors (donepezil, rivastigmine)
- ▶ NMDA receptor antagonist (memantine)
- ▶ Quetiapine, clozapine, pimavanserin (USA)



Management - Lifestyle

- ▶ Happy and Safe
 - ▶ Home safety
 - ▶ Driving safety
 - ▶ Enjoy life
- ▶ Caregiver support
- ▶ Advanced care planning documents



Mortality in PD



Preferences of Patients With Parkinson's Disease for Communication About Advanced Care Planning

Keiran K. Tuck, MBBS¹, Lissa Brod, MD¹, John Nutt, MD¹, and Erik K. Fromme, MD²

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Table 2. Percentage Responding “When Should your doctor discuss”

	At the Time of Diagnosis	During the Next Few Visits	Only When the Disease Worsens	Wait Until I Ask	Never	Unsure
Treatment goals and options	73.2	19.9	4.1	1.6	0	1.2
Symptoms and treatment side effects	73.9	19.7	3.6	2.4	0	0.4
Involving family in disease discussion	56.6	17.3	7.2	15.3	1.2	2.4
Advance care planning documents	25.2	24.8	19.5	12.6	5.7	12.2
Life expectancy	23.8	14.1	25.0	23.8	2.0	11.3
Planning for end-of-life care	13.0	14.2	39.3	20.2	1.6	11.7
Family communication about end-of-life care	12.5	13.3	43.1	17.3	3.2	10.5
End-of-life care options	12.1	9.3	48.4	16.9	0.8	12.5

Table 3. Who Should Ideally Raise These Issues?

	% of Respondents Who Say This Person Should Ideally Raise Questions Of ...		
	Life Expectancy	Advanced Care Planning Documents	End-of-Life Care Options
Patient	65.9	74.5	77.6
PCP	27.8	38.9	41.6
Neurologist	50	38.5	42
Should not be discussed	6.7	1.2	1.2
Unsure	16.3	10.9	9.6
n = 252/267 (94.4%)			

Abbreviation: PCP, primary care physician.



Life-sustaining treatment orders, location of death and co-morbid conditions in decedents with Parkinson's disease

Keiran K. Tuck^a, Dana M. Zive^b, Terri A. Schmidt^{b, c}, Julie Carter^a, John Nutt^a, Erik K. Fromme^{c, *}

Place of Death and POLST Use

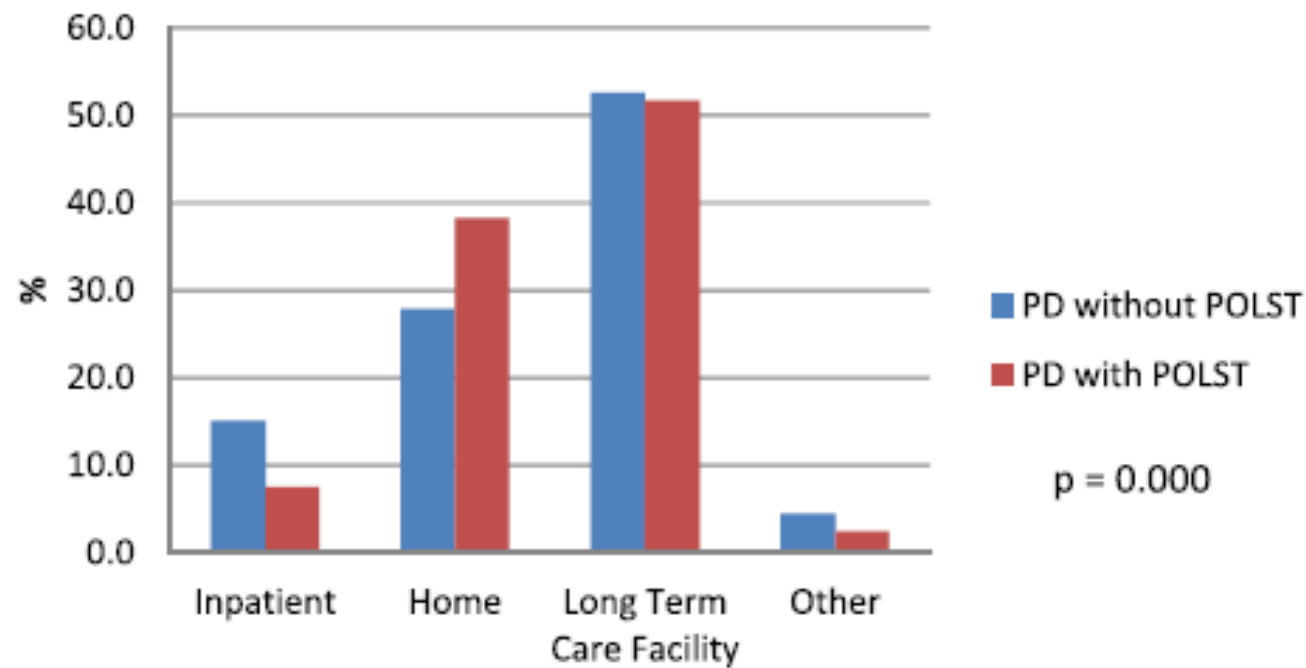


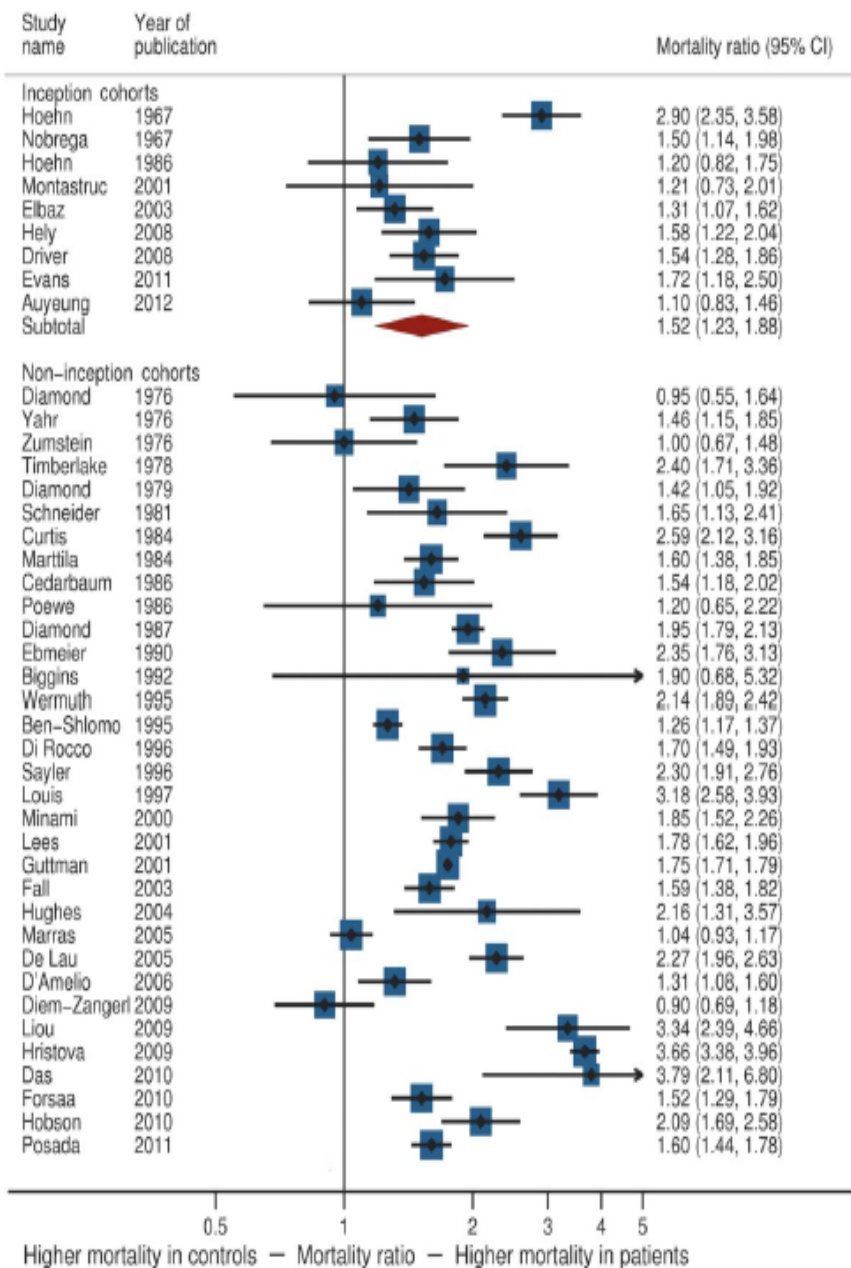
Fig. 1. Place of death and POLST use.

Mortality in Parkinson's Disease: A Systematic Review and Meta-analysis

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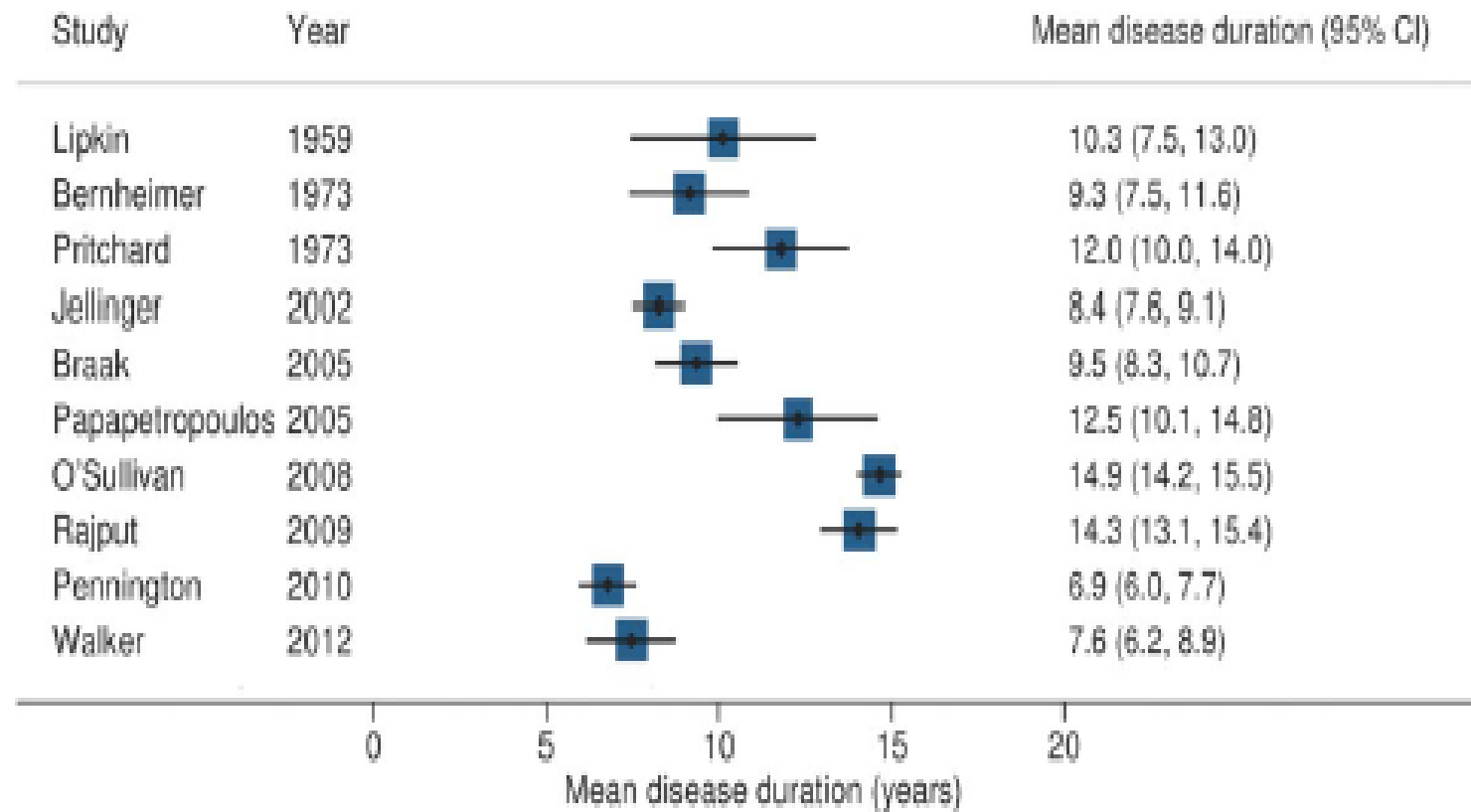


FIG. 4. Meta-analysis of time from disease onset or diagnosis to death in a retrospective series of deceased patients using a DerSimonian and Laird random effects model. The I^2 heterogeneity statistic is 97.4%; a pooled estimate is therefore not presented. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]

- ▶ median age at death was 83 years (range 47-101 years)



- 
- ▶ Although patients presenting with idiopathic parkinsonism have reduced survival, the survival is highly dependent on the type and characteristics of the parkinsonian disorder. Patients with Parkinson disease presenting with normal cognitive function seem to have a largely normal life expectancy

Predictors of Survival in Patients With Parkinson Disease

Allison W. Willis, MD; Mario Schootman, PhD; Nathan Kung, MD; Bradley A. Evanoff, MD, MPH; Joel S. Perlmutter, MD; Brad A. Racette, MD

- ▶ Retrospective cohort study of 138 000 Medicare beneficiaries with incident PD who were identified in 2002 and followed up through 2008
- ▶ Thirty-five percent of PD cases lived more than six years.
- ▶ Sex and race significantly predicted survival:
 - ▶ female (HR 0.74, 0.73– 0.75)
 - ▶ Hispanic (HR 0.72, 0.65–0.80)
 - ▶ Asian (HR 0.86, 0.82–0.91)
- ▶ Dementia/cognitive impairment, diagnosed in 69.6% of cases, most often in Blacks (78.2%) and women (71.5%), was associated with a greater likelihood of death (HR 1.72, 1.69–1.75).

The Sydney Multicenter Study of Parkinson's Disease: The Inevitability of Dementia at 20 years

Mariese A. Hely, MBBS,^{1*} Wayne G.J. Reid, PhD,¹ Michael A. Adena, PhD, ASTAT,²
Glenda M. Halliday, PhD,³ and John G.L. Morris, MD¹

- ▶ only 14/30 (47%) still see their neurologist after 20 years

Nursing Homes



Parkinson's disease and nursing home placement: the economic impact of the need for care

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^aDepartment of Neurology and ^bThe Norwegian Centre for Movement Disorders, Stavanger University Hospital, Stavanger; ^cInstitute of Medicine, University of Bergen, Bergen; and ^dDepartment of Mathematics and Natural Science, University of Stavanger, Stavanger, Norway

Table 2 Patients with Parkinson's disease (PD) compared with controls at baseline and during 12-year follow-up

	Patients with PD	Controls
Number at baseline	108	864
Males/females (%)	49/51	49/51
Age at baseline in years (SD)	73.8 (7.6)	73.8 (7.6)
Admitted to nursing home at baseline (%)	15 (14)	24* (2.8)
Home-dwelling at baseline (%)	93 (86)	840* (97.2)
Number during follow up	93	840
Admitted to nursing home during study period (%)	49 (52.7)	211* (26)
Age at admission in years (SD)	78.9 (5.5)	84.4* (5.4)
Time from baseline to admission in years (SD)	4.9 (2.9)	6.14* (3.6)
Time from admission to death in years (SD)	2.9 (2.6)	1.2* (1.5)
Surviving and home-dwelling (%)	16 (17.2)	353* (42)
Died during study period (%)	70 (75.3)	442* (53)
Died in nursing home (%)	42 (85.7)	172 (82)
Died at home (%)	28 (30.1)	270 (32.4)
Age at death in years (SD)	80.5 (5.3)	82.7* (6.4)

* $P < 0.05$.

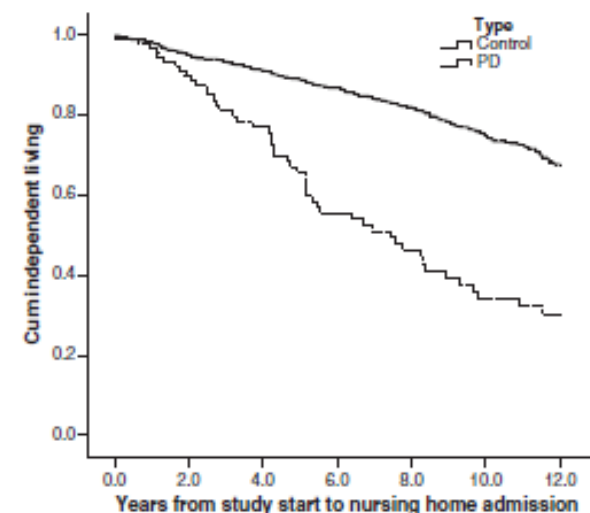


Figure 1 Kaplan-Meier curves for time to nursing home placement for patients with Parkinson's disease (PD) and control individuals.

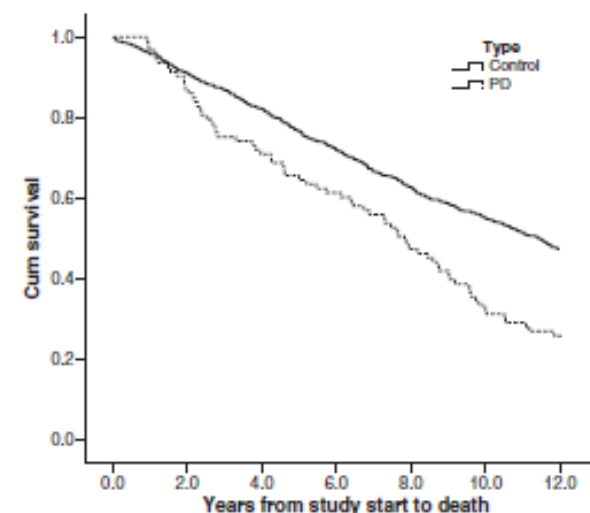


Figure 2 Kaplan-Meier survival curves for patients with Parkinson's disease (PD) and control individuals.

What happens in Nursing Homes





JAMDA

journal homepage: www.jamda.com

Original Study

Perspectives on Parkinson Disease Care in Dutch Nursing Homes




Anouke van Rumund MD^{a,*}, Nico Weerkamp MD^b, Gerrit Tissingh MD, PhD^b,
Sytse U. Zuidema MD, PhD^c, Raymond T. Koopmans MD, PhD^d,
Marten Munneke PhD^{a,e}, Petra J.E. Poels MD, PhD^a, Bastiaan R. Bloem MD, PhD^a

► Survey of 15 nursing home residents and their caregivers in the Netherlands

Table 3
Examples of Related Codes and Quotes Categorized by Core Theme

Core Theme	Code	Quote
Emotional support and empathy	Lack of support/empathy for patient	"An actual talk about emotional aspects is not possible there. And I certainly need that, really, a little support and empathy." (Patient, male 78 years)
Organization of care	PD nurse as mediator between nursing home and neurologist	"So I think there would be a faster feedback to the neurologist through a PD nurse." (PD nurse)
	Involvement of neurologist	"In a late stage the neurologist is not involved anymore." (PD nurse)
	Staff occupancy	"They need to work harder because they get less staff members and, well, they do their best but there is not enough money and not enough time. And they are unable to hire new ones because there is no money for it anymore." (Patient, female 79 years)
Staff knowledge	Medication given too late	"Yes, here I'm always struggling to get my medication in time." (Patient, female 79 years)
	Medication combined with proteins	"They are not aware that it works like that, that medication and food can't be taken at once." (Patient, female 70 years)
	Lack of PD knowledge among nurses	"And what really bothers me is that PD knowledge is just poor." (Spouse, female)

PD, Parkinson disease.



Conclusions: PD care in Dutch nursing homes is suboptimal according to residents, informal caregivers, and health care workers. Three core areas for improvement were identified, including greater attention for psychosocial problems, improved PD-specific knowledge among nursing home staff, and better collaboration with hospital staff trained in movement disorders.



Diagnostic accuracy of Parkinson's disease and atypical parkinsonism in nursing homes

N.J. Weerkamp^{a,b}, G. Tissingh^a, P.J.E. Poels^b, S.U. Zuidema^c, M. Munneke^b,
R.T.C.M. Koopmans^d, B.R. Bloem^{b,e,*}

**Table 1**

Diagnostic changes in 53 of 258 nursing home patients.

New- and rejected diagnosis within parkinsonian spectrum (n = 31)	Parkinsonism and PD rejected (n = 22)
<i>PD newly diagnosed (19)</i>	<i>Parkinsonism rejected (17)</i>
<ul style="list-style-type: none"> - Parkinsonism → PD (9) - VP → PD (3) - MSA → PD (2) - 'falls' → PD (1) - AD → PD (1) - DLB → PD (1) - VD → PD (1) - 'frontal dementia' → PD (1) 	<ul style="list-style-type: none"> → AD (5) → hypertonia after stroke (4) → contractures (2) → lumbar stenosis (1) → polyneuropathy (1) → hypertonia in MS (1) → multimorbidity (1) → head titubation (1) → ET (1)
<i>DLB newly diagnosed (5)</i>	<i>PD rejected (5)</i>
<ul style="list-style-type: none"> - AD → DLB (2) - MSA → DLB (2) - 'dementia' → DLB (1) 	<ul style="list-style-type: none"> → AD (1) → myoclonus eci (1) → orthopedic (1) → stroke (1) → akathisia (1)
<i>MSA newly diagnosed (2)</i>	
<ul style="list-style-type: none"> - 'falls' → MSA (1) - parkinsonism → MSA (1) 	
<i>PSP newly diagnosed (1)</i>	
<ul style="list-style-type: none"> - DLB → PSP (1) 	
<i>PD/MSA rejected (4)</i>	
<ul style="list-style-type: none"> - PD → parkinsonism (3) - MSA → parkinsonism (1) 	

The diagnosis in italics represents the groups of diagnosis newly made or rejected. All diagnosis behind the arrows (→) represents the individual new diagnosis made in the study.

VD = vascular dementia ET = essential tremor MS = multiple sclerosis VP = vascular parkinsonism.

MSA = multiple system atrophy AD = Alzheimer's disease PSP = progressive supranuclear palsy.

Motor Profile and Drug Treatment of Nursing Home Residents with Parkinson's Disease

Nico J. Weerkamp, MD,*[†] Sytse U. Zuidema, MD, PhD,^{‡||} Gerrit Tissingh, MD, PhD,* Petra J. E. Poels, MD, PhD,[†] Marten Munneke, PhD,[†] Raymond T. C. M. Koopmans, MD, PhD,[‡] and Bastiaan R. Bloem, MD, PhD^{†§}

JAGS 60:2277–2282, 2012

- ▶ 73 nursing home patient with PD
- ▶ 87% were H+Y 4 or 5

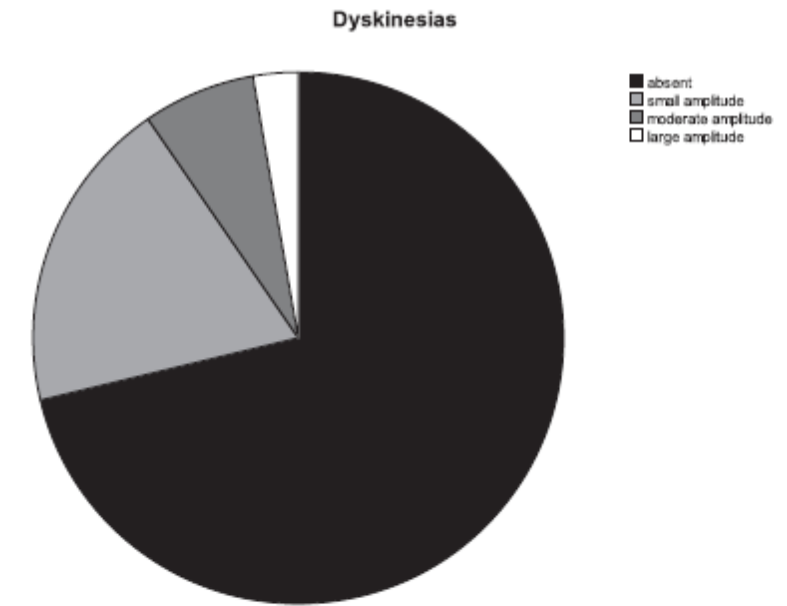


Figure 1. Presence and severity of dyskinesia.

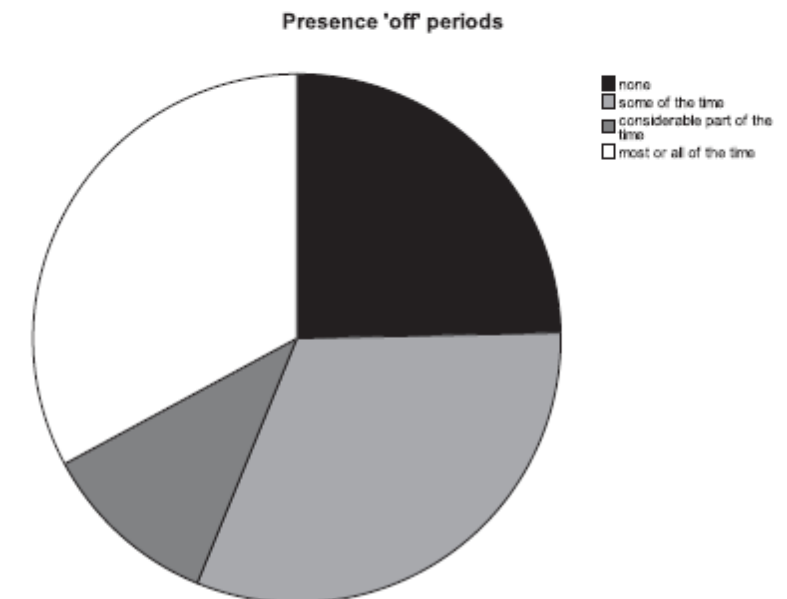



Figure 2. Presence and severity of "off" periods.

- 
- ▶ Poor QOL for PD in NH
 - ▶ PDQ-8 higher than outpatient cohorts
 - ▶ PDQ mainly driven by NMS

Nonmotor Symptoms in Nursing Home Residents with Parkinson's Disease: Prevalence and Effect on Quality of Life

Nico J. Weerkamp, MD,*† Gerrit Tissingh, MD, PhD,* Petra J.E. Poels, MD, PhD,†
Systse U. Zuidema, MD, PhD,‡ Marten Munneke, PhD,† Raymond T.C.M. Koopmans, MD, PhD,§
and Bastiaan R. Bloem, MD, PhD||

JAGS 61:1714-1721, 2013

Table 1. Participant Characteristics and Drug Treatment (N = 73)

Characteristic	Value
Age, mean ± SD	78.7 (6.4)
Female, n (%)	40 (55)
Disease duration, years, mean ± SD	10.1 (7.3)
Length of stay, months, mean ± SD	22.5 (27.1)
Hoehn and Yahr stage, n (%)	
2	1 (1)
3	8 (11)
4	28 (38)
5	36 (49)
Taking levodopa, n (%)	67 (92)
Taking dopamine agonist, n (%)	15 (21)
Levodopa equivalent dose, mg, mean (range)	673 (0-1,600)
Taking antidepressants, n (%)	18 (25)
Taking atypical antipsychotics, n (%)	25 (34)
Taking cholinesterase inhibitors, n (%)	21 (29)
Taking anticholinergics, n (%)	9 (12)
Taking benzodiazepines, n (%)	31 (42)

SD = standard deviation.

Table 3. Prevalence of Individual Non-Motor Symptoms Scale Items

Item Number and Symptom	n (%)
4. Fatigue	56 (78.9)
22. Urgency ^a	51 (75.0)
17. Forget things or events	49 (69.0)
10. Seem sad	47 (66.2)
8. Lack motivation	45 (63.4)
19. Saliva	45 (63.4)
3. Daytime sleep	43 (60.6)
7. Lost interest surroundings	43 (60.6)
23. Frequency ^a	40 (58.8)
24. Nocturia ^a	39 (57.4)
16. Concentration	40 (56.3)
6. Restless legs	38 (53.5)
9. Feel nervous	38 (53.5)
5. Difficulty falling asleep	37 (52.1)
18. Forget to do things	36 (50.7)
1. Light headedness	34 (47.9)
21. Constipation	34 (47.9)
20. Swallowing	30 (42.3)
12. Difficulty experiencing pleasure	27 (38.0)
11. Flat mood	25 (35.2)
15. Double vision	25 (35.2)
13. Hallucinations	17 (23.9)
27. Pains	17 (23.9)
30. Excessive sweating	15 (21.1)
14. Delusions	14 (19.7)
29. Weight change	13 (18.3)
28. Taste or smell	8 (11.3)
25. Interest in sex	4 (5.7)
26. Problems having sex	4 (5.7)
2. Fainting	4 (5.6)

^aThe urinary domain was incompletely collected in three residents because of an indwelling catheter.

Death in Nursing Homes



Predictors of mortality among nursing home residents with a diagnosis of Parkinson's disease

Hubert H. Fernandez^{1,2 ADEF}, Kate L. Lapane^{3 ABCDE}

- ▶ 3-year mortality rate = 50%.
- ▶ Independent predictors of death:
 - ▶ **Advanced age** (relative rate (RR) 2.22; 95% confidence interval (CI) 1.99–2.47, for patients 85+ years),
 - ▶ **male** gender (RR 1.73; 95% CI 1.60–1.87),
 - ▶ severe **functional impairment** (RR 1.81; 95% CI 1.53–2.13)
 - ▶ **cognitive impairment** (RR 1.54; 95% CI 1.38–1.72),
 - ▶ **vision** problems (RR 1.25; 95% CI 1.20–1.57),
 - ▶ pressure **ulcers** (RR 1.25; 95% CI 1.14–1.37),
 - ▶ congestive **heart failure** (RR 1.49; 95% CI 1.35–1.65),
 - ▶ **diabetes mellitus** (RR 1.22; 95% CI 1.11–1.35)
 - ▶ **pneumonia** (RR 1.39; 95% CI 1.09–1.77)
 - ▶ African-Americans and other minority groups were less likely to die relative to white PD residents.

Nursing home and end-of-life care in Parkinson disease

- ▶ Retrospective cohort study
- ▶ 469,055 elderly Medicare beneficiaries with a diagnosis of PD (ICD-9 codes 332 (Parkinson disease) or 332.0 (paralysis agitans)
 - ▶ Those with a secondary code such as secondary parkinsonism (332.1) or other degenerative diseases of the basal ganglia (333.0) were excluded from analysis.
 - ▶ 24% (n = 113,668) had claims consistent with residence in a LTCF

Table 2 Demographic and clinical characteristics of LTCF and community-dwelling individuals with Parkinson disease^a

Characteristic	Community (n = 355,387)	LTCF (n = 113,668)
Race		
White	326,862 (92.0)	104,866 (92.3)
Black	17,013 (4.8)	6,433 (5.7)
Asian	3,918 (1.1)	839 (0.7)
Hispanic	7,594 (2.1)	1,530 (1.3)
Sex		
Male	181,190 (51.0)	47,472 (41.8)
Female	174,197 (49.0)	66,196 (58.2)
Age, y		
65-69	37,418 (10.5)	4,570 (4.0)
70-74	64,666 (18.2)	11,295 (9.9)
75-79	90,600 (25.5)	22,360 (19.7)
80-84	87,138 (24.5)	31,578 (27.8)
85+	75,565 (21.3)	43,865 (38.6)
Comorbid medical diagnosis^b		
Atrial fibrillation	47,551 (13.4)	16,923 (14.9)
Dementia	104,199 (29.3)	74,930 (65.9)
Myocardial infarction	12,140 (3.4)	3,872 (3.4)
Congestive heart failure	107,951 (30.4)	47,248 (41.6)
Colorectal cancer	7,343 (2.1)	2,375 (2.1)
COPD	59,225 (16.7)	24,228 (21.3)
Diabetes mellitus	85,819 (24.1)	28,352 (24.9)
Hip fracture	18,168 (5.1)	14,086 (12.4)
Ischemic heart disease	124,064 (34.9)	53,859 (47.4)
Stroke/TIA	74,709 (21.0)	34,466 (30.3)

Abbreviations: COPD = chronic obstructive pulmonary disease; LTCF = long-term care facility. Data are n (%).


^a Among all fee-for-service Medicare beneficiaries older than 65 years (year = 2002).

^b According to the Centers for Medicare & Medicaid Services Chronic Condition Warehouse.

Sex and age ratios consistent with other LTCF data

Hospice Utilization

- ▶ Almost 85% (n = 80,877) of nursing home residents with PD died between January 1, 2003, and December 31, 2005.
- ▶ Hospice care was utilized by 54.2% (n = 43,805) of the decedents
- ▶ A logistic regression model determined that neurologist-treated patients were more than twice as likely to receive hospice care before death (AOR 2.35, 95% CI 2.24–2.47).

- 
- ▶ Neurologist-treated patients were also healthier:
 - ▶ Lower odds of dementia (AOR 0.41, 95% CI 0.40–0.42),
 - ▶ Lower odds of hip fracture (AOR 0.74, 95% CI 0.70–0.77),
 - ▶ Lower odds of congestive heart failure (AOR 0.67, 95% CI 0.65–0.70)
 - ▶ Lower odds of diabetes (AOR 0.68, 95% CI 0.65–0.70)
 - ▶ Lower odds of ischemic heart disease (AOR 0.78, 95% CI 0.76–0.80)
 - ▶ Lower odds of stroke/TIA (AOR 0.69, 95% CI 0.67–0.72).

Summary

- ▶ PD is a complex life threatening illness
- ▶ A large proportion of people with PD end up in Nursing Homes
- ▶ Nursing home care may be inadequate
- ▶ As part of an interdisciplinary team, neurologists can make a difference in end-of-life care

Questions?

