What Caring for the Late Stages Can Teach Us about Thriving with Parkinson's *Today*

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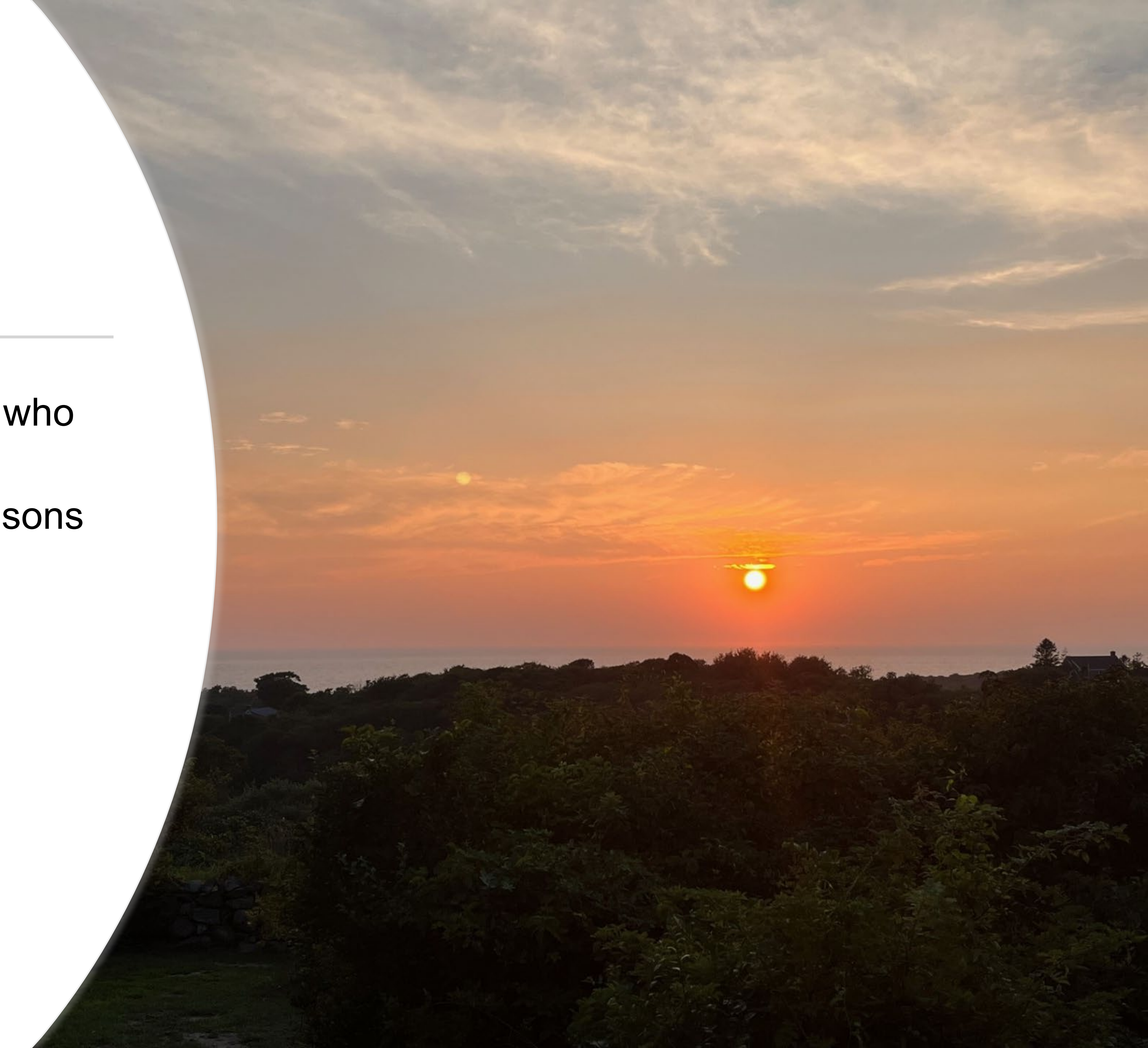
Parkinson and Movement Disorder Alliance
July 30, 2025

On the Horizon

- Stages of Parkinson’s Disease and who we are missing
- Interdisciplinary home visits and lessons learned
- A chicken, an egg, and a confusing umbrella
- Caring for caregivers
- How to PERSEVERE



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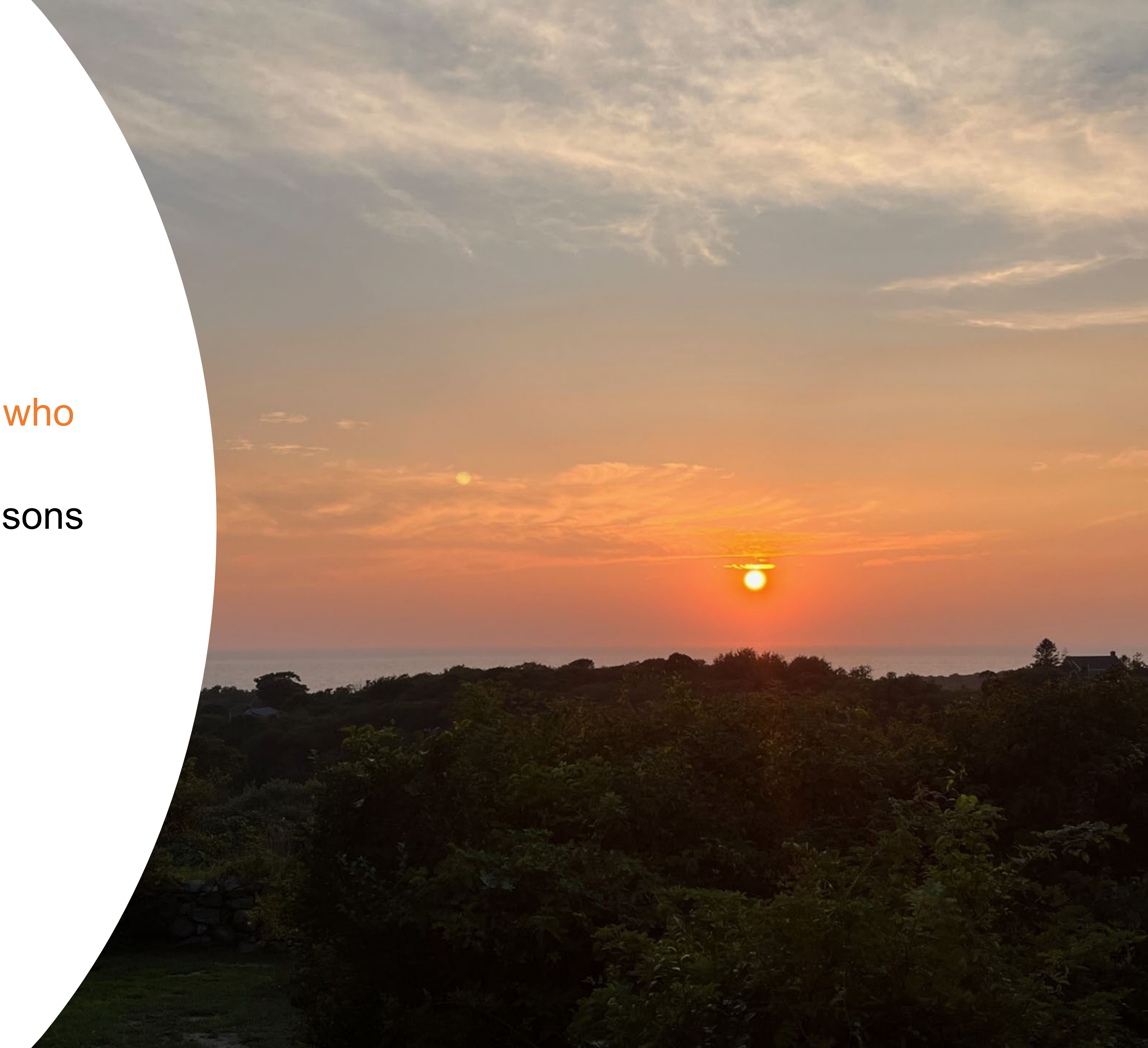
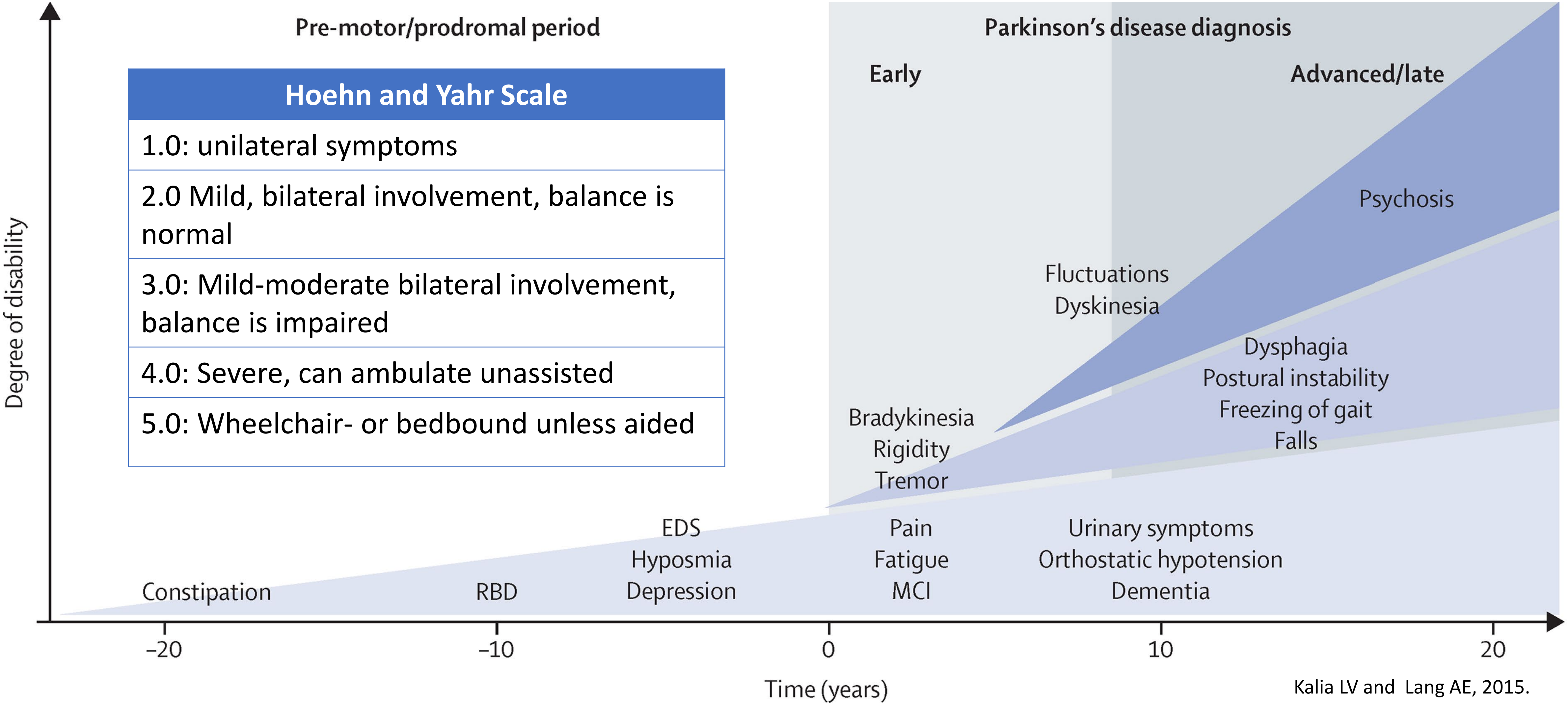


Individuals with advanced PD are understudied



Hoehn and Yahr Scale
1.0: unilateral symptoms
2.0 Mild, bilateral involvement, balance is normal
3.0: Mild-moderate bilateral involvement, balance is impaired
4.0: Severe, can ambulate unassisted
5.0: Wheelchair- or bedbound unless aided

Kalia LV and Lang AE, 2015.

Individuals with advanced PD are underrepresented in research

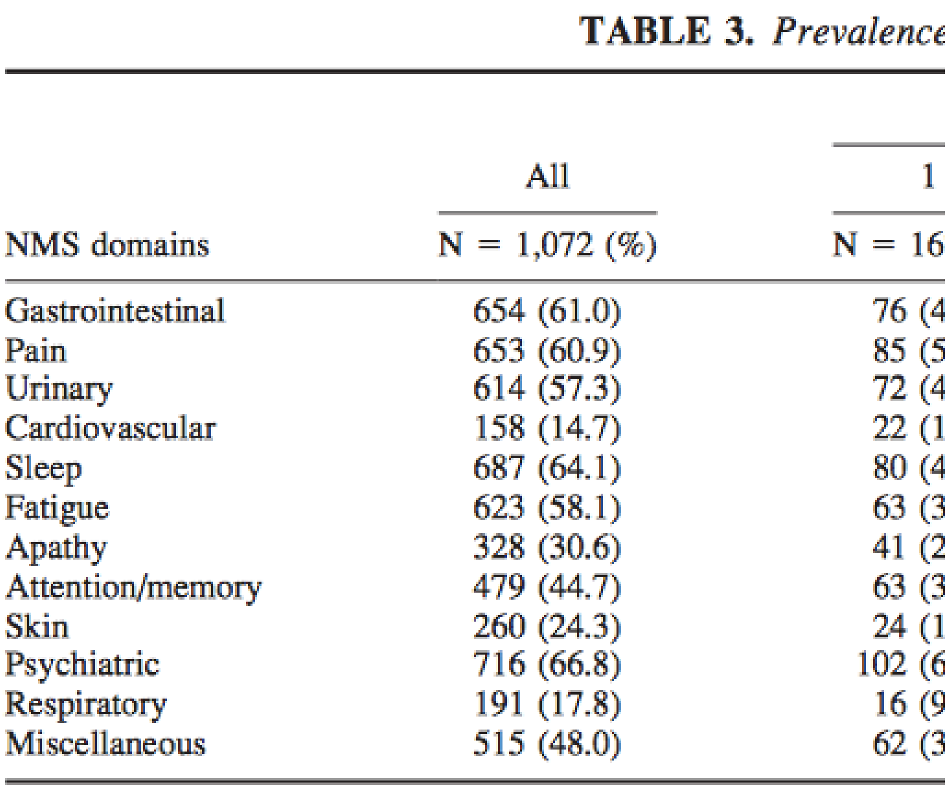
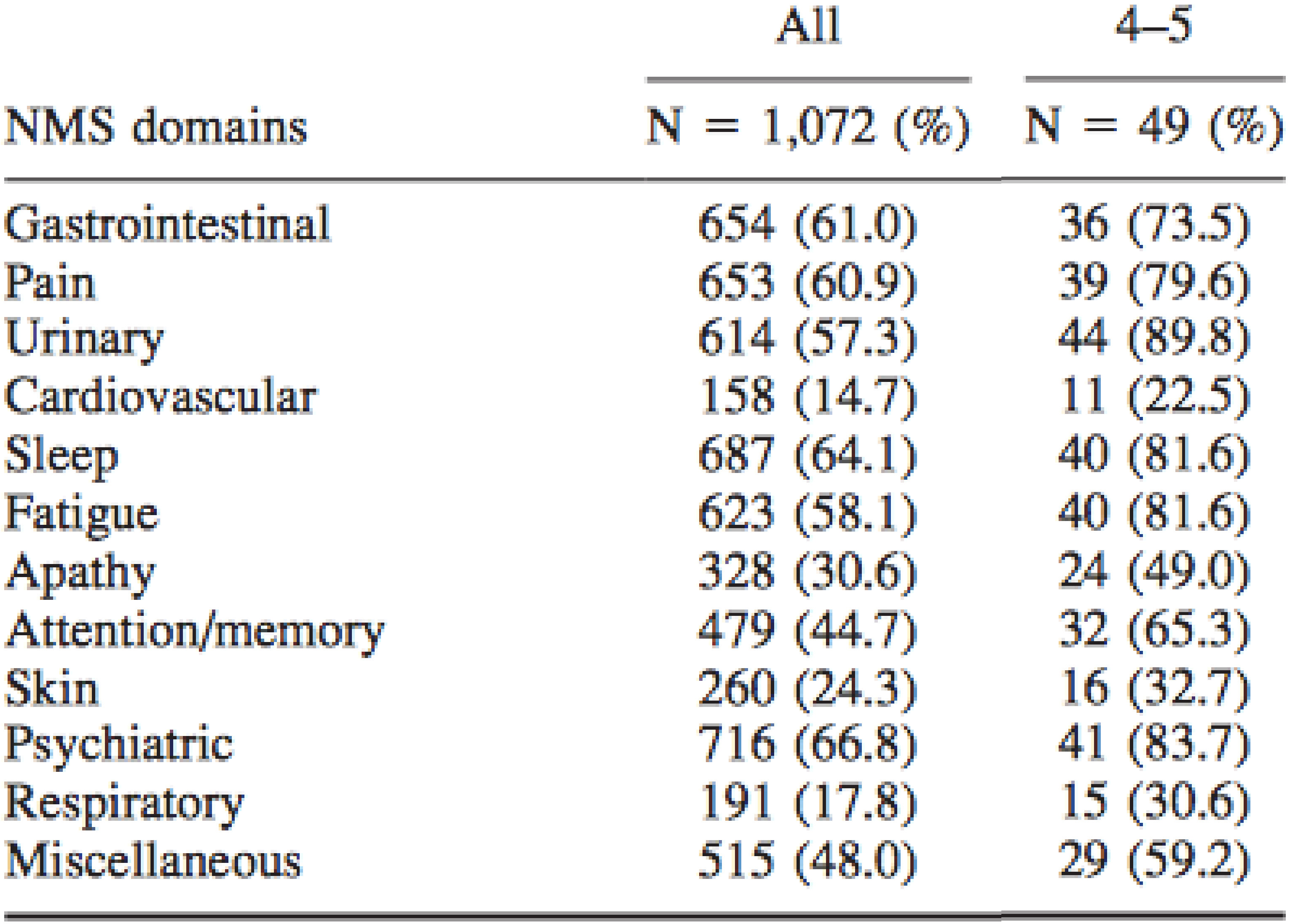


TABLE 3. *Prevalence*

NMS domains	All N = 1,072 (%)	1 N = 16
Gastrointestinal	654 (61.0)	76 (4
Pain	653 (60.9)	85 (5
Urinary	614 (57.3)	72 (4
Cardiovascular	158 (14.7)	22 (1
Sleep	687 (64.1)	80 (4
Fatigue	623 (58.1)	63 (3
Apathy	328 (30.6)	41 (2
Attention/memory	479 (44.7)	63 (3
Skin	260 (24.3)	24 (1
Psychiatric	716 (66.8)	102 (6
Respiratory	191 (17.8)	16 (9
Miscellaneous	515 (48.0)	62 (3

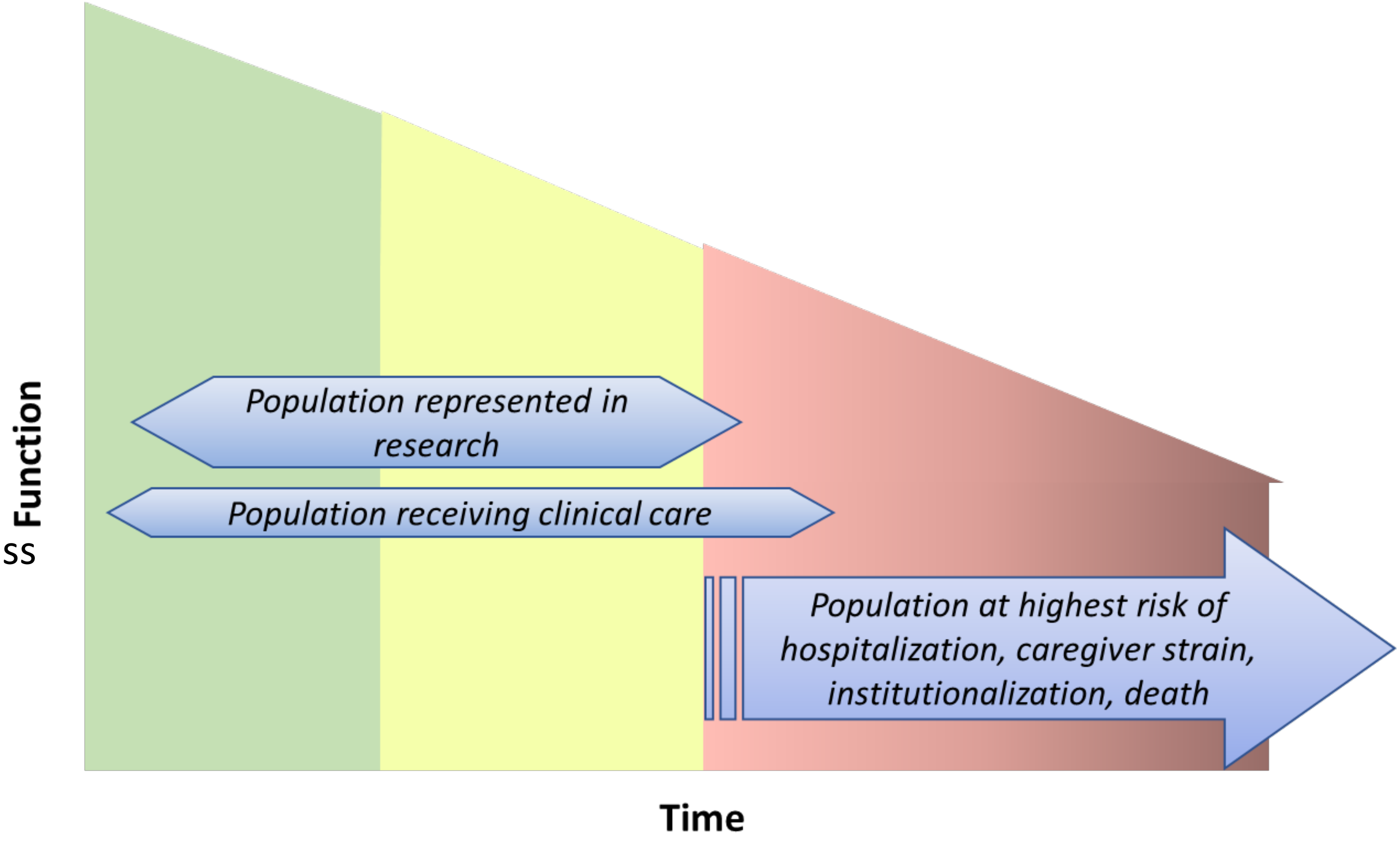


NMS domains	All N = 1,072 (%)	4–5 N = 49 (%)
Gastrointestinal	654 (61.0)	36 (73.5)
Pain	653 (60.9)	39 (79.6)
Urinary	614 (57.3)	44 (89.8)
Cardiovascular	158 (14.7)	11 (22.5)
Sleep	687 (64.1)	40 (81.6)
Fatigue	623 (58.1)	40 (81.6)
Apathy	328 (30.6)	24 (49.0)
Attention/memory	479 (44.7)	32 (65.3)
Skin	260 (24.3)	16 (32.7)
Psychiatric	716 (66.8)	41 (83.7)
Respiratory	191 (17.8)	15 (30.6)
Miscellaneous	515 (48.0)	29 (59.2)

Barone P, et al, 2009.

Late-Stage Parkinsonism

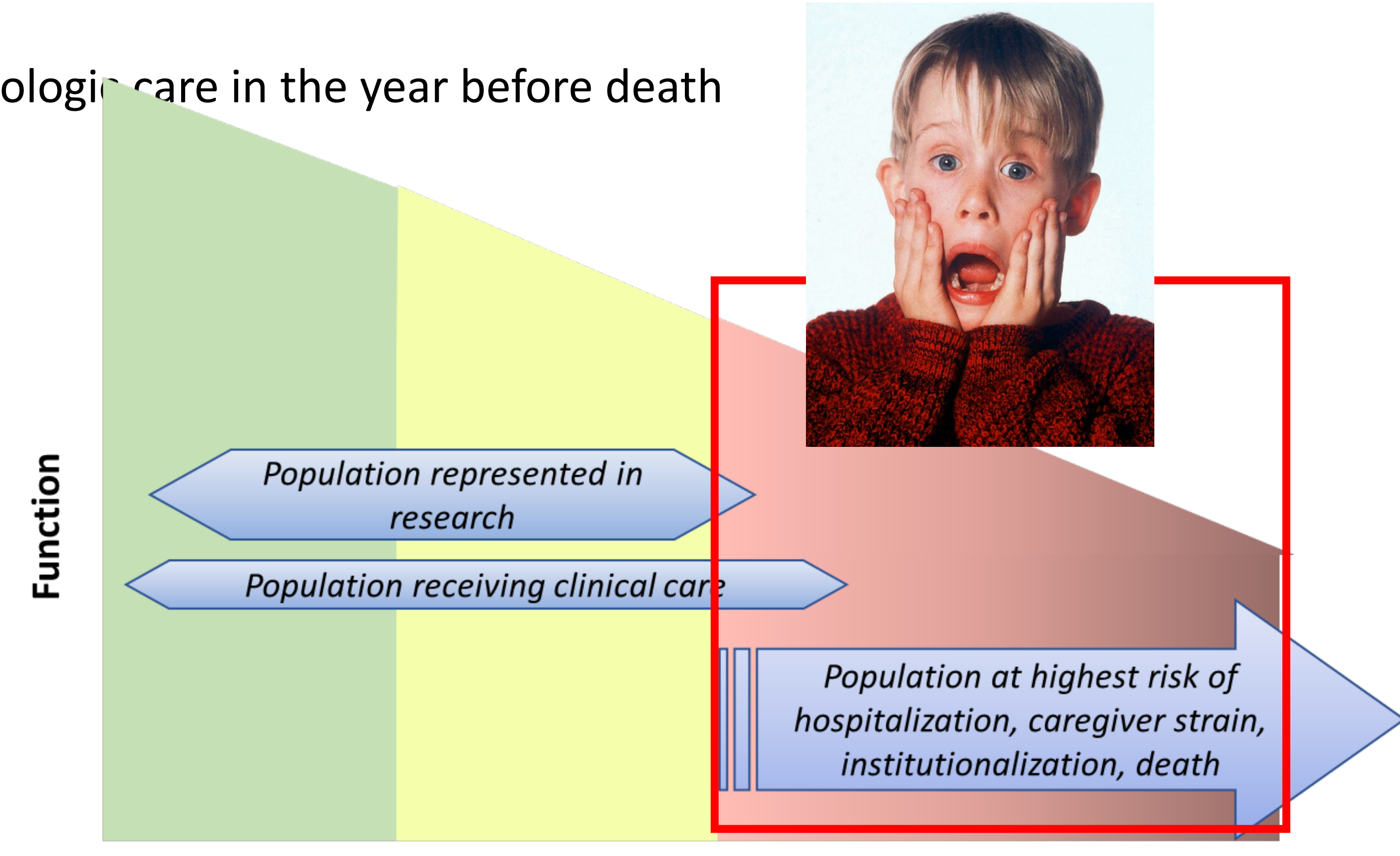
- Operational criteria: HY 4-5, or S&E <50% in ON
- Main clinical features:
  - Motor features:
    - Marked bradykinesia
    - Absent/mild appendicular rigidity
  - Moderate-severe axial impairment:
    - Freezing of gait
    - Falls
    - Moderate-severe dysphagia
  - Non-motor symptoms:
    - Sleep disturbance/daytime sleepiness
    - Urinary disturbance/incontinence
    - Dementia
    - Psychosis
    - Depression
    - Skeletal deformities



Fabbri M, et al, 2020; Fleisher JE et al, 2020.

Where are they? How do we reach them?

- Among 35 million community-dwelling US Medicare recipients followed for 7 years:
  - 8.3 million died (23.7%)
  - 1.2 million institutionalized (3.4%)
    - 37% of institutionalized PwP retain neurologic care in the year before death
  - 4.5 million homebound (12.9%)
    - 43% are impoverished
    - 39% live alone
    - 39% have ≥ 5 medical comorbidities
    - ~30% have dementia
- US PD deaths, 2003 vs. 2017*:
  - Nursing homes: 52% vs. 42%
  - Hospital: 18% vs. 9%
  - Home: 21% vs. 32%
  - Inpatient hospice: 0.3% vs. 8.6%
  - ~4% home + hospice



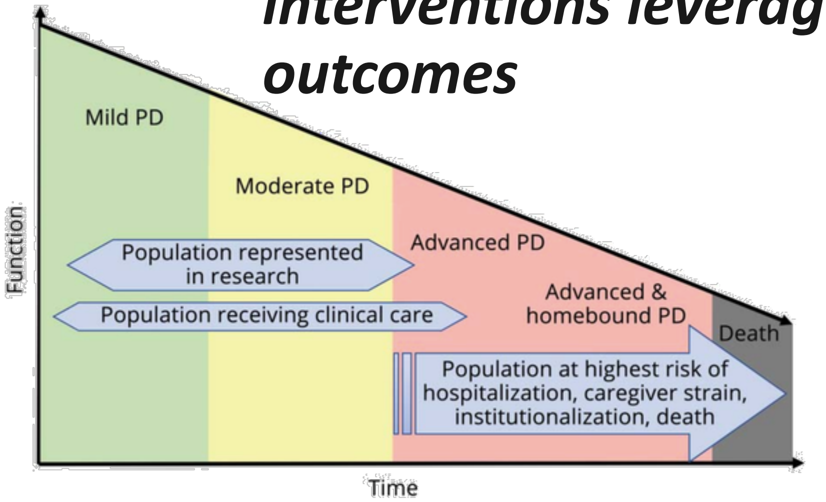
*Based on death certificates

Ornstein KA et al, 2020; Moens K et al, 2015; Fleisher JE et al, 2022; Kumar P et al, 2021; McKenzie ED et al, 2022

Fleisher Lab:

Novel interventions to reach advanced PD and related populations and improve quality of life in those individuals *today*

- **WHO are these individuals and who is supporting them**
- **WHAT are their unique symptoms, barriers, needs**
- **WHY have they have fallen into the "in-between" –** including disease, healthcare system, & social determinants of health
- **HOW do we re-engage them in care, research, advocacy**
- **Unifying hypothesis:** ***Human connection is required to reach these populations and interventions leveraging human connection can change trajectories and health outcomes***



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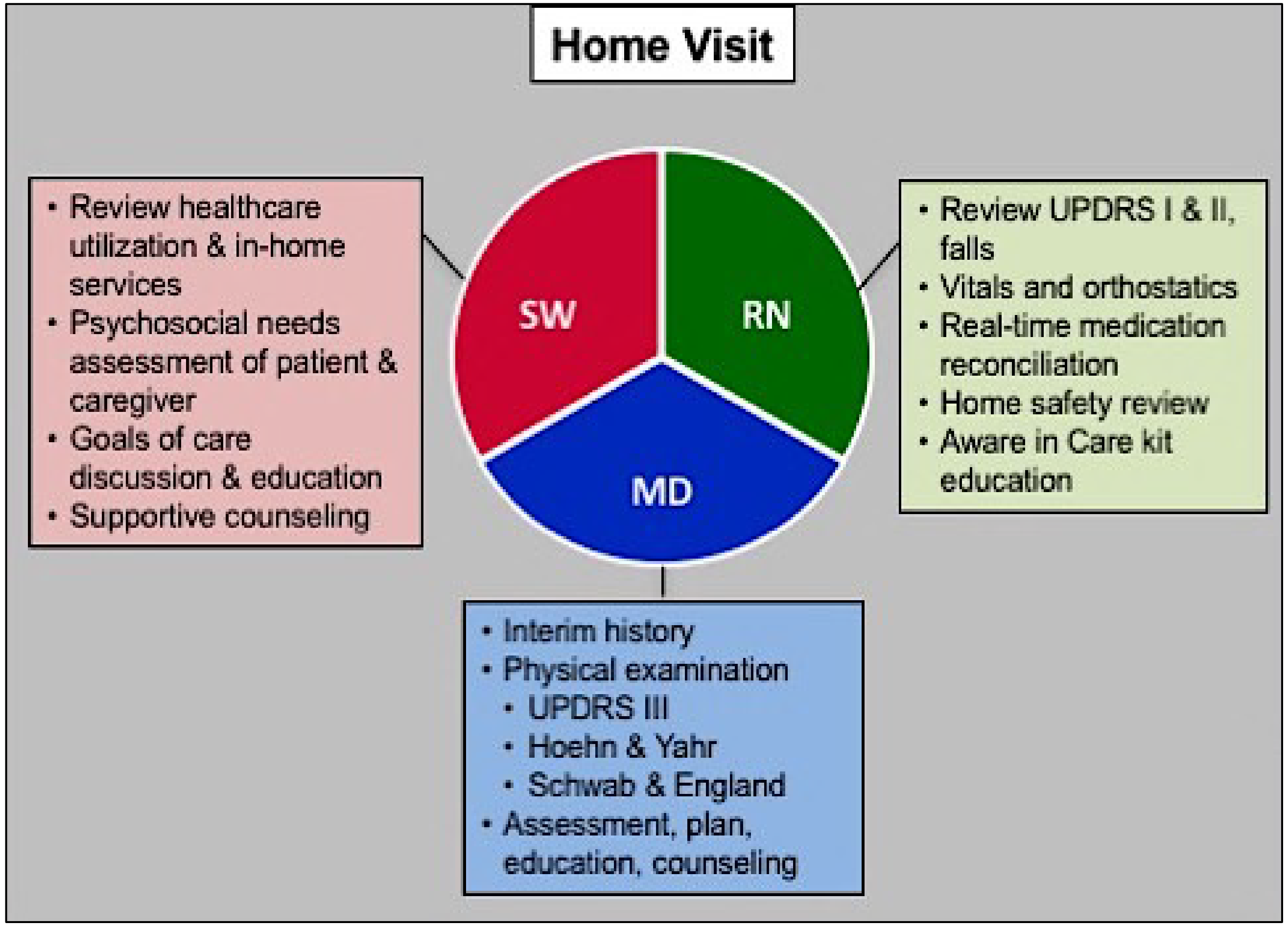
Individuals with advanced PD…
are amenable to home visits & research



Home Visit

- Review healthcare utilization & in-home services
- Psychosocial needs assessment of patient & caregiver
- Goals of care discussion & education
- Supportive counseling

- Review UPDRS I & II, falls
- Vitals and orthostatics
- Real-time medication reconciliation
- Home safety review
- Aware in Care kit education

- Interim history
- Physical examination
  - UPDRS III
  - Hoehn & Yahr
  - Schwab & England
- Assessment, plan, education, counseling

Fleisher JE, et al. J Am Geriatr Soc. 2018 Jul;66(6):1226-1232

There can be MANY symptoms as PD advances…

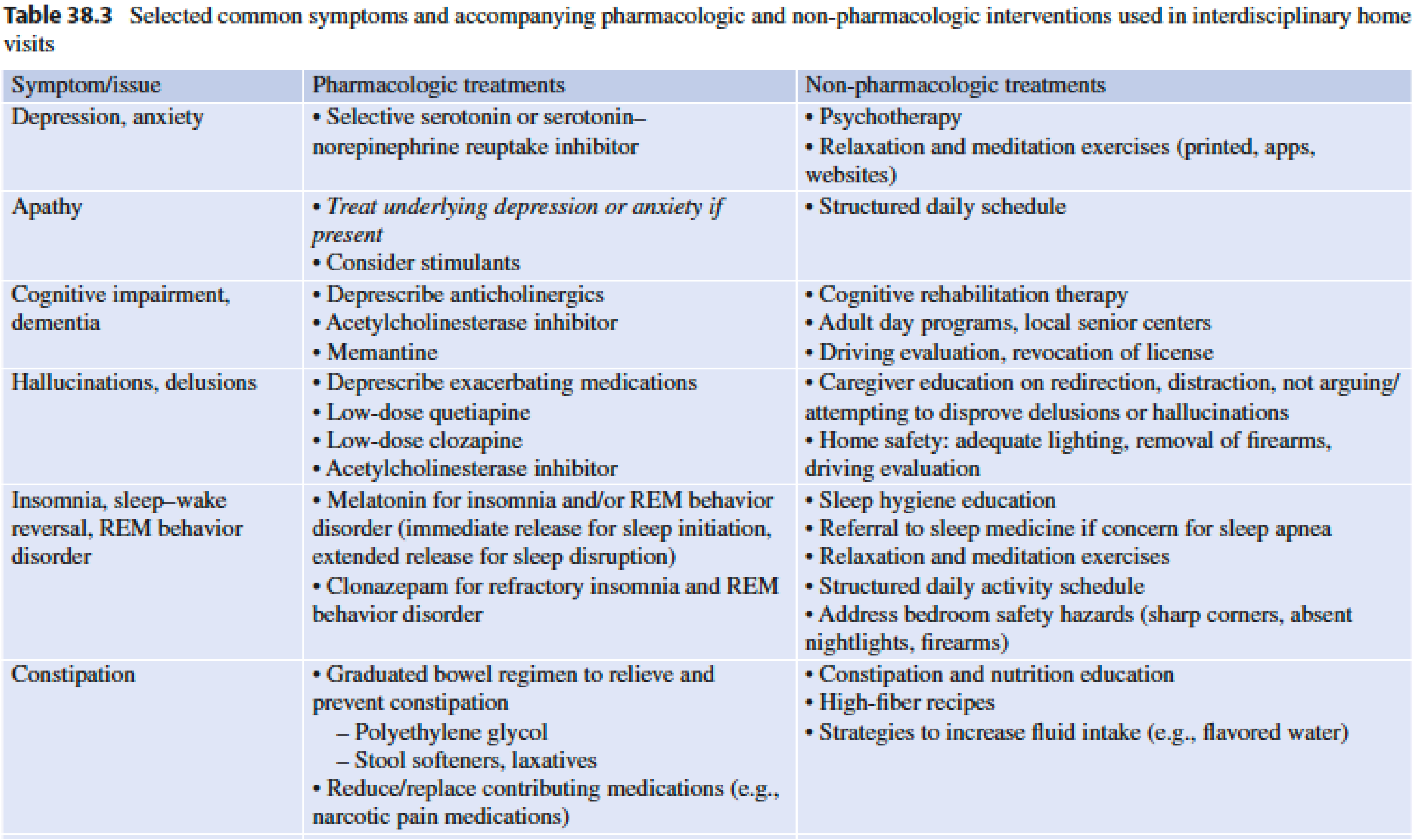
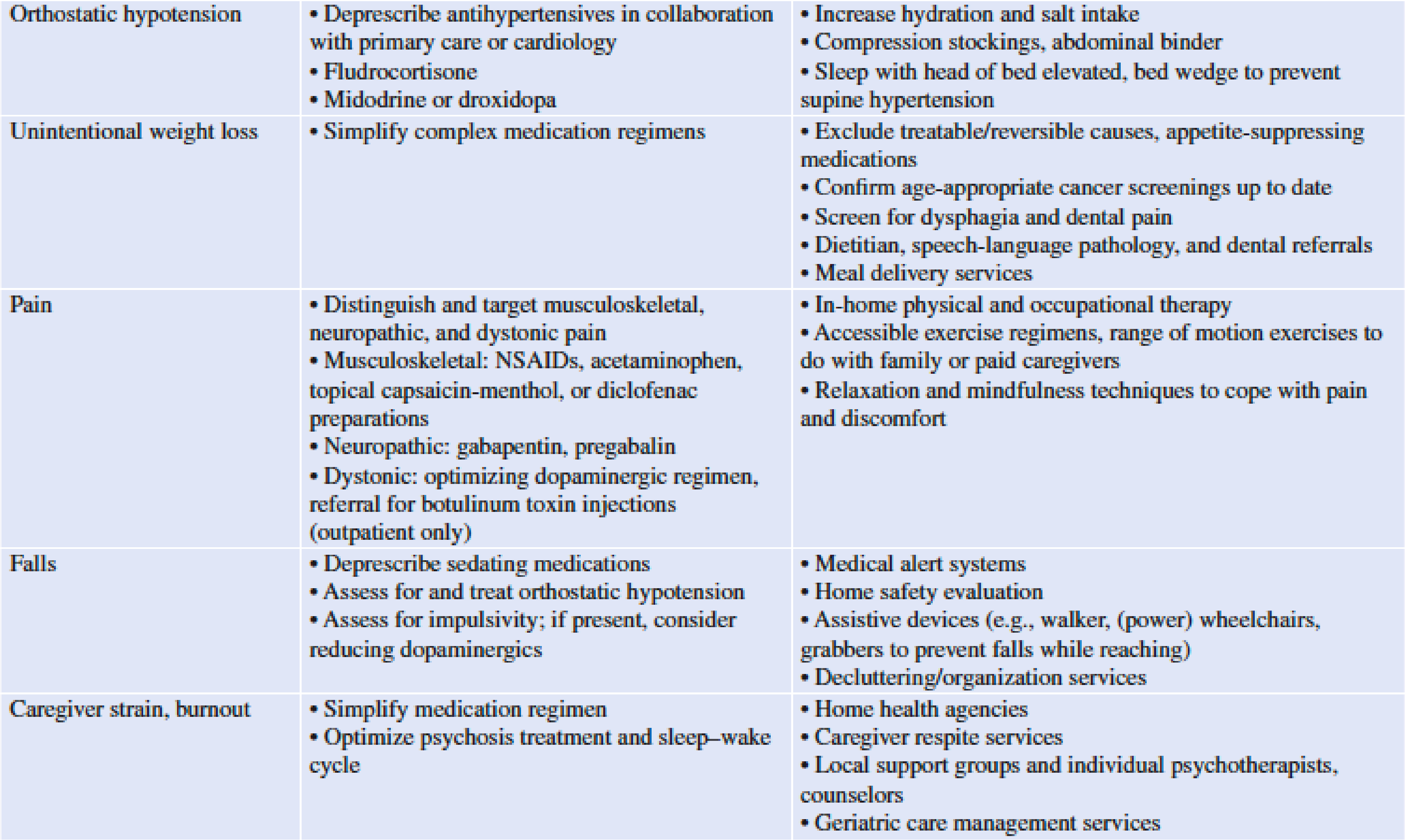


Table 38.3 Selected common symptoms and accompanying pharmacologic and non-pharmacologic interventions used in interdisciplinary home visits

Symptom/issue	Pharmacologic treatments	Non-pharmacologic treatments
Depression, anxiety	• Selective serotonin or serotonin–norepinephrine reuptake inhibitor	• Psychotherapy • Relaxation and meditation exercises (printed, apps, websites)
Apathy	• *Treat underlying depression or anxiety if present* • Consider stimulants	• Structured daily schedule
Cognitive impairment, dementia	• Deprescribe anticholinergics • Acetylcholinesterase inhibitor • Memantine	• Cognitive rehabilitation therapy • Adult day programs, local senior centers • Driving evaluation, revocation of license
Hallucinations, delusions	• Deprescribe exacerbating medications • Low-dose quetiapine • Low-dose clozapine • Acetylcholinesterase inhibitor	• Caregiver education on redirection, distraction, not arguing/attempting to disprove delusions or hallucinations • Home safety: adequate lighting, removal of firearms, driving evaluation
Insomnia, sleep–wake reversal, REM behavior disorder	• Melatonin for insomnia and/or REM behavior disorder (immediate release for sleep initiation, extended release for sleep disruption) • Clonazepam for refractory insomnia and REM behavior disorder	• Sleep hygiene education • Referral to sleep medicine if concern for sleep apnea • Relaxation and meditation exercises • Structured daily activity schedule • Address bedroom safety hazards (sharp corners, absent nightlights, firearms)
Constipation	• Graduated bowel regimen to relieve and prevent constipation – Polyethylene glycol – Stool softeners, laxatives • Reduce/replace contributing medications (e.g., narcotic pain medications)	• Constipation and nutrition education • High-fiber recipes • Strategies to increase fluid intake (e.g., flavored water)

Fleisher, J.E., Woo, K., Chodosh, J. (2024). In: Malone, M.L., Boltz, M., Macias Tejada, J., White, H. (eds) Geriatrics Models of Care. Springer

…and nearly *all* can be treated* with medications and non-medication strategies



Orthostatic hypotension	• Deprescribe antihypertensives in collaboration with primary care or cardiology • Fludrocortisone • Midodrine or droxidopa	• Increase hydration and salt intake • Compression stockings, abdominal binder • Sleep with head of bed elevated, bed wedge to prevent supine hypertension
Unintentional weight loss	• Simplify complex medication regimens	• Exclude treatable/reversible causes, appetite-suppressing medications • Confirm age-appropriate cancer screenings up to date • Screen for dysphagia and dental pain • Dietitian, speech-language pathology, and dental referrals • Meal delivery services
Pain	• Distinguish and target musculoskeletal, neuropathic, and dystonic pain • Musculoskeletal: NSAIDs, acetaminophen, topical capsaicin-menthol, or diclofenac preparations • Neuropathic: gabapentin, pregabalin • Dystonic: optimizing dopaminergic regimen, referral for botulinum toxin injections (outpatient only)	• In-home physical and occupational therapy • Accessible exercise regimens, range of motion exercises to do with family or paid caregivers • Relaxation and mindfulness techniques to cope with pain and discomfort
Falls	• Deprescribe sedating medications • Assess for and treat orthostatic hypotension • Assess for impulsivity; if present, consider reducing dopaminergics	• Medical alert systems • Home safety evaluation • Assistive devices (e.g., walker, (power) wheelchairs, grabbers to prevent falls while reaching) • Decluttering/organization services
Caregiver strain, burnout	• Simplify medication regimen • Optimize psychosis treatment and sleep–wake cycle	• Home health agencies • Caregiver respite services • Local support groups and individual psychotherapists, counselors • Geriatric care management services

Fleisher, J.E., Woo, K., Chodosh, J. (2024). In: Malone, M.L., Boltz, M., Macias Tejada, J., White, H. (eds) Geriatrics Models of Care. Springer

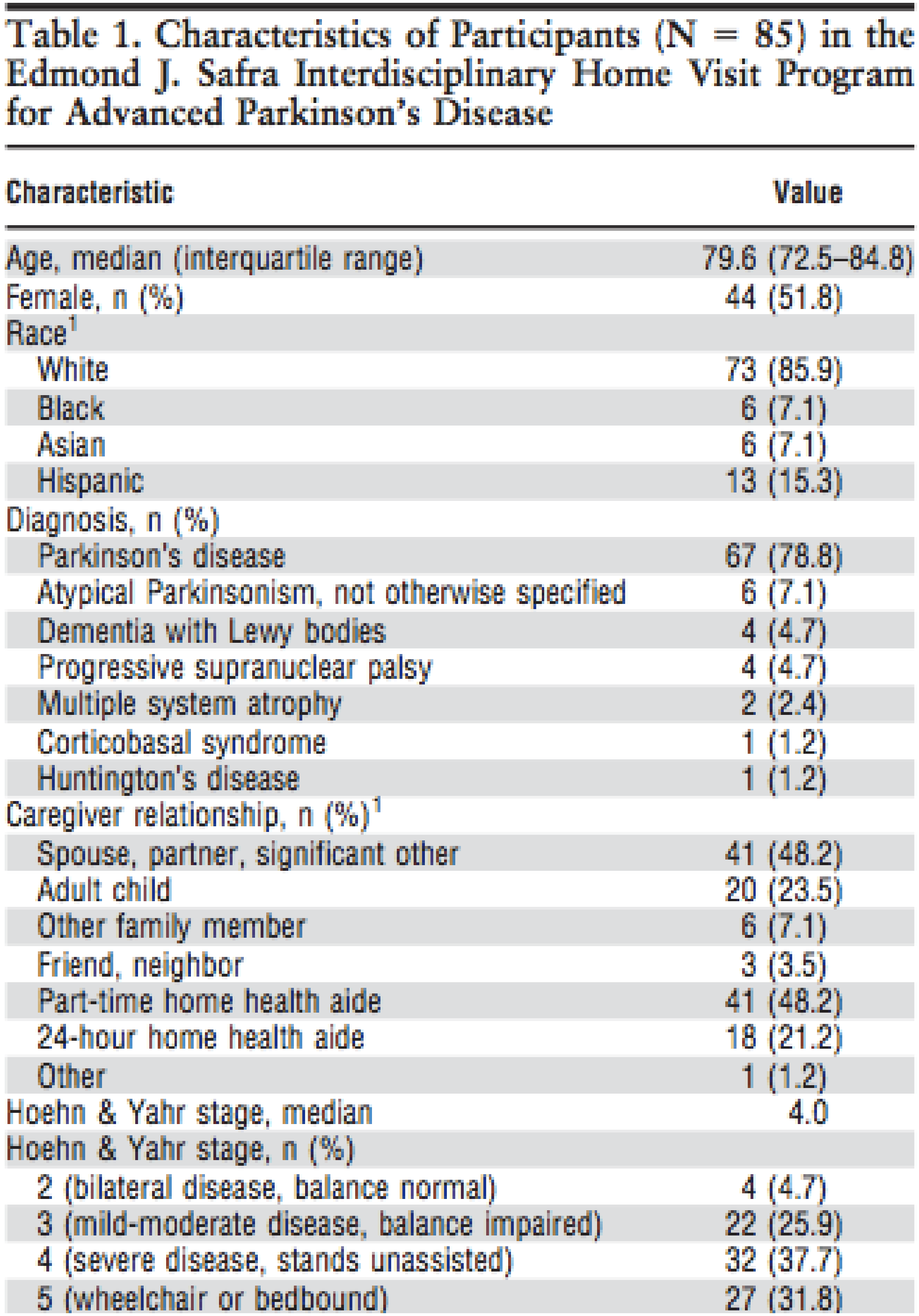


Table 1. Characteristics of Participants (N = 85) in the Edmond J. Safra Interdisciplinary Home Visit Program for Advanced Parkinson's Disease

Characteristic	Value
Age, median (interquartile range)	79.6 (72.5–84.8)
Female, n (%)	44 (51.8)
Race[1]	
White	73 (85.9)
Black	6 (7.1)
Asian	6 (7.1)
Hispanic	13 (15.3)
Diagnosis, n (%)	
Parkinson's disease	67 (78.8)
Atypical Parkinsonism, not otherwise specified	6 (7.1)
Dementia with Lewy bodies	4 (4.7)
Progressive supranuclear palsy	4 (4.7)
Multiple system atrophy	2 (2.4)
Corticobasal syndrome	1 (1.2)
Huntington's disease	1 (1.2)
Caregiver relationship, n (%)[1]	
Spouse, partner, significant other	41 (48.2)
Adult child	20 (23.5)
Other family member	6 (7.1)
Friend, neighbor	3 (3.5)
Part-time home health aide	41 (48.2)
24-hour home health aide	18 (21.2)
Other	1 (1.2)
Hoehn & Yahr stage, median	4.0
Hoehn & Yahr stage, n (%)	
2 (bilateral disease, balance normal)	4 (4.7)
3 (mild-moderate disease, balance impaired)	22 (25.9)
4 (severe disease, stands unassisted)	32 (37.7)
5 (wheelchair or bedbound)	27 (31.8)

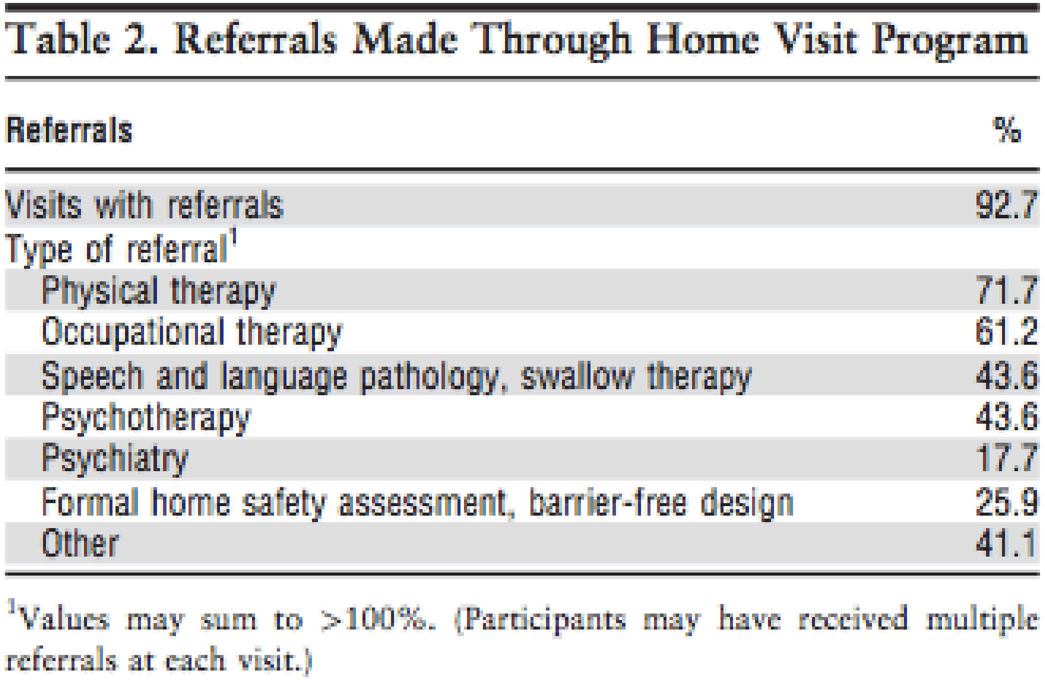


Table 2. Referrals Made Through Home Visit Program

Referrals	%
Visits with referrals	92.7
Type of referral[1]	
Physical therapy	71.7
Occupational therapy	61.2
Speech and language pathology, swallow therapy	43.6
Psychotherapy	43.6
Psychiatry	17.7
Formal home safety assessment, barrier-free design	25.9
Other	41.1

[1] Values may sum to >100%. (Participants may have received multiple referrals at each visit.)

Fleisher JE, et al. J Am Geriatr Soc. 2018

Homebound women outnumbered men and were more likely to be alone

Partnership/Caregiver trends

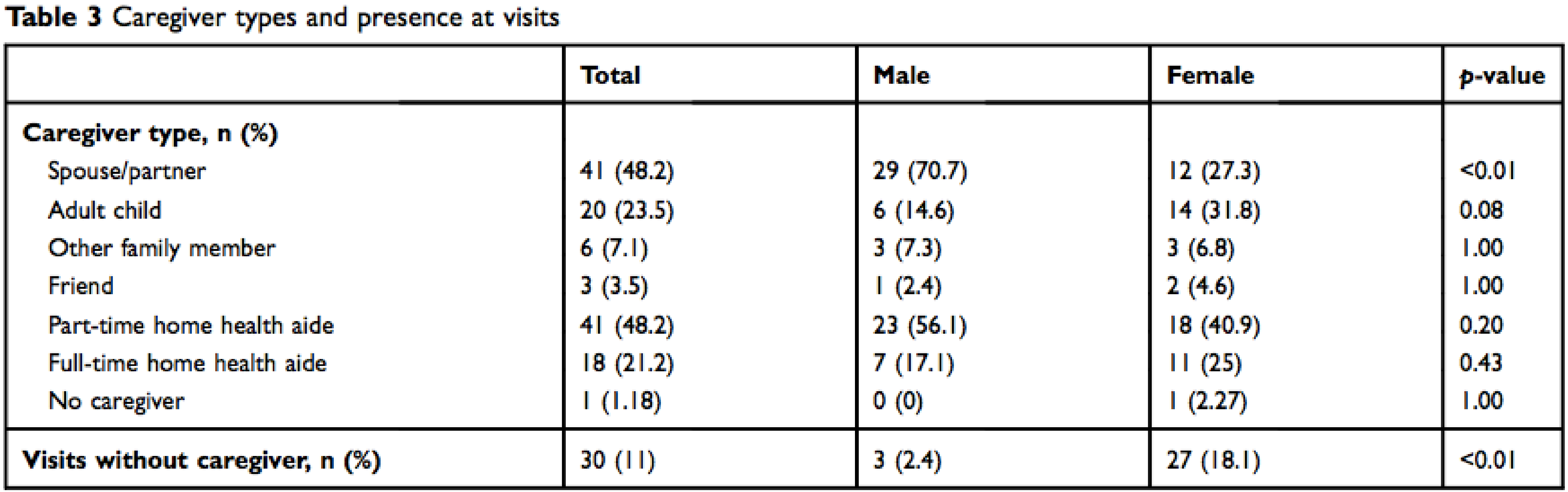
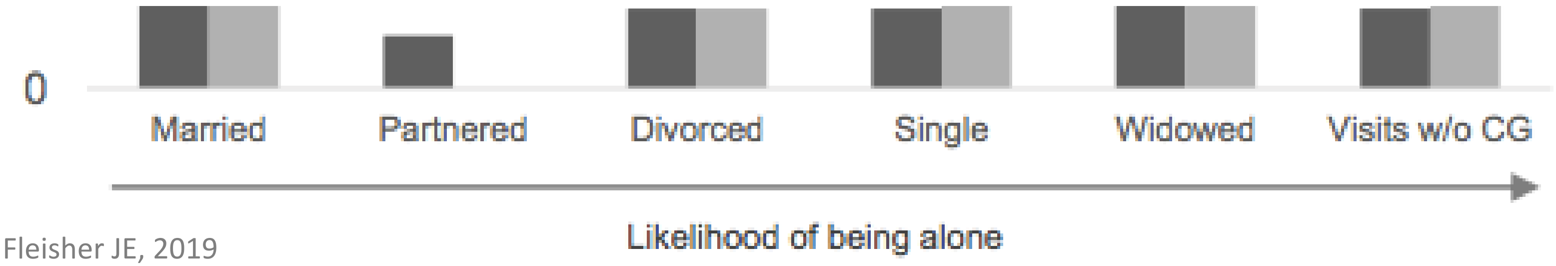


Table 3 Caregiver types and presence at visits

	Total	**Male**	**Female**	***p*-value**
Caregiver type, n (%)				
Spouse/partner	41 (48.2)	29 (70.7)	12 (27.3)	<0.01
Adult child	20 (23.5)	6 (14.6)	14 (31.8)	0.08
Other family member	6 (7.1)	3 (7.3)	3 (6.8)	1.00
Friend	3 (3.5)	1 (2.4)	2 (4.6)	1.00
Part-time home health aide	41 (48.2)	23 (56.1)	18 (40.9)	0.20
Full-time home health aide	18 (21.2)	7 (17.1)	11 (25)	0.43
No caregiver	1 (1.18)	0 (0)	1 (2.27)	1.00
Visits without caregiver, n (%)	30 (11)	3 (2.4)	27 (18.1)	<0.01



Nwabuobi L and Fleisher JE, 2019

Home visits stabilized quality of life over one year, despite disease progression

- Subset of prior cohort (n = 27):
  - PD only, MMSE >20 at visit 1
  - Four visits in ~12 months
- Outcomes:
  - Mean UPDRS mentation score worsened from 2.9 to 4.3 ($p = 0.02$)
  - Mean UPDRS motor score worsened from 34.4 to 42.5 ($p < 0.001$)
  - Mean UPDRS total score worsened from 60.5 to 72.3 ($p < 0.001$)
  - **No significant changes in any of 8 quality of life domains studied** (p = 0.19-0.85):
    - NeuroQoL domains: Stigma, fatigue, depression, anxiety, emotional and behavioral dyscontrol, positive affect and well-being, ability to participate in AND satisfaction with social roles and activities
  - No significant change in acute healthcare utilization ($p = 0.15$)
  - Caregiver strain worsened (n = 10, MCSI mean 17.1 to 23.2, $p = 0.04$)
    - Among three caregivers who withdrew after visit 1, MCSI mean 42, severe range

Fleisher JE, et al. *Neurol Clin Pract* 2020

Limitations & Takeaways

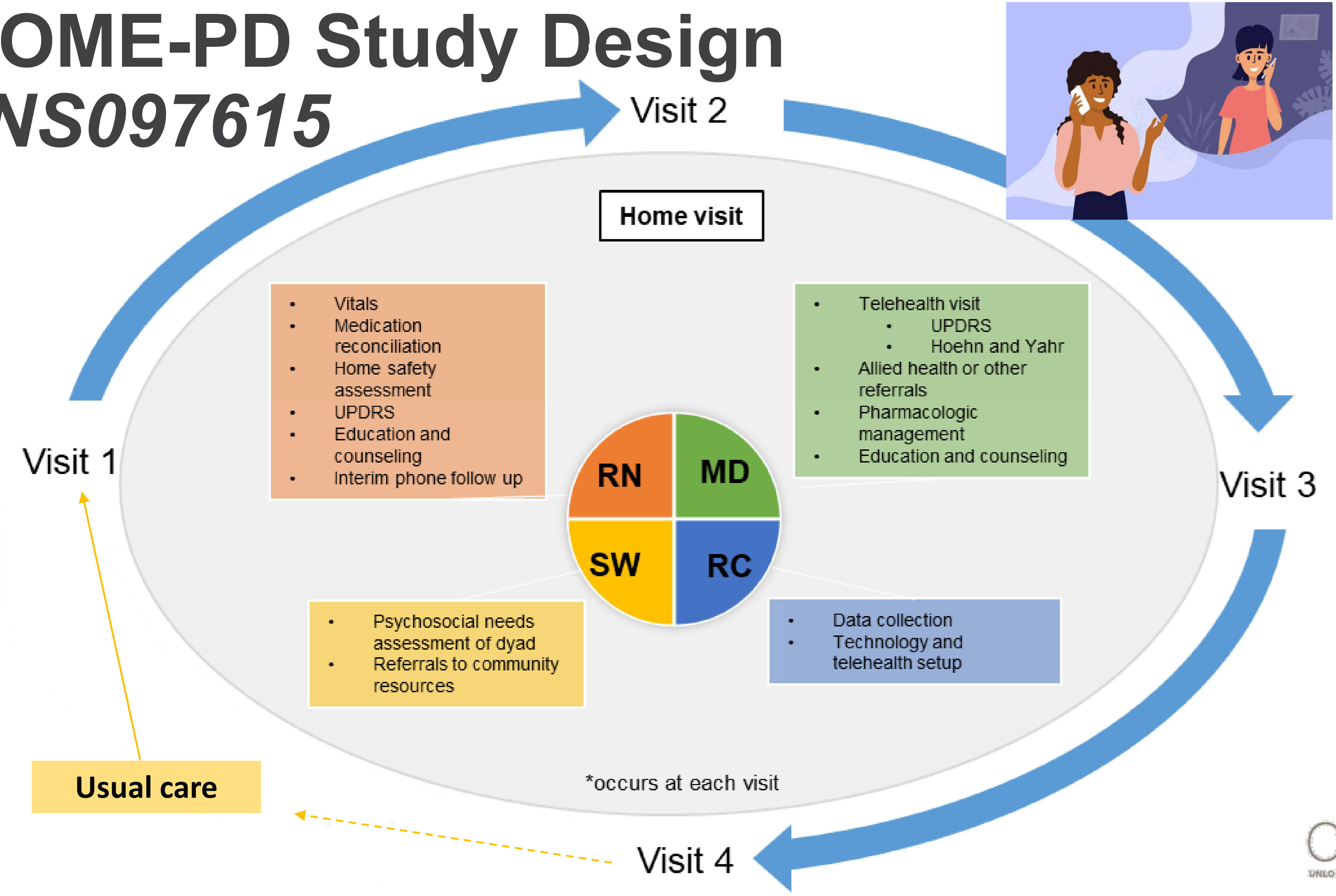
- Heterogeneous population
- Single center; NYC-specific?
- Sustainability, cost
- No control group
- Outcome measures
- Caregiver strain

- Prospective study, 65 dyads, 4 visits
- Parkinson's Disease *only, ± dementia*
- Single center, larger catchment area, suburban, rural
- Pared down in-person team
- Matched controls from Parkinson's Outcome Project
- Parkinson's Disease specific: PDQ-39 at V1 & V4
- Dyads only; nested trial of caregiver peer mentoring
- RN + coordinator in-home, MD + SW in office, low-profile, self-contained telemedicine

Beck CA, et al. Neurology. 2017 Sep 12;89(11):1152-1161.
Cook EJ, et al. BMC Health Serv Res. 2016;16:137.
Peek ST, et al. Int J Med Inform. Apr 2014;83(4):235-248.

IN-HOME-PD Study Design

K23NS097615



Visit 2

Visit 3

Visit 4

Visit 1

Home visit

- Vitals
- Medication reconciliation
- Home safety assessment
- UPDRS
- Education and counseling
- Interim phone follow up

RN

MD

SW

RC

- Telehealth visit
  - UPDRS
  - Hoehn and Yahr
- Allied health or other referrals
- Pharmacologic management
- Education and counseling

- Psychosocial needs assessment of dyad
- Referrals to community resources

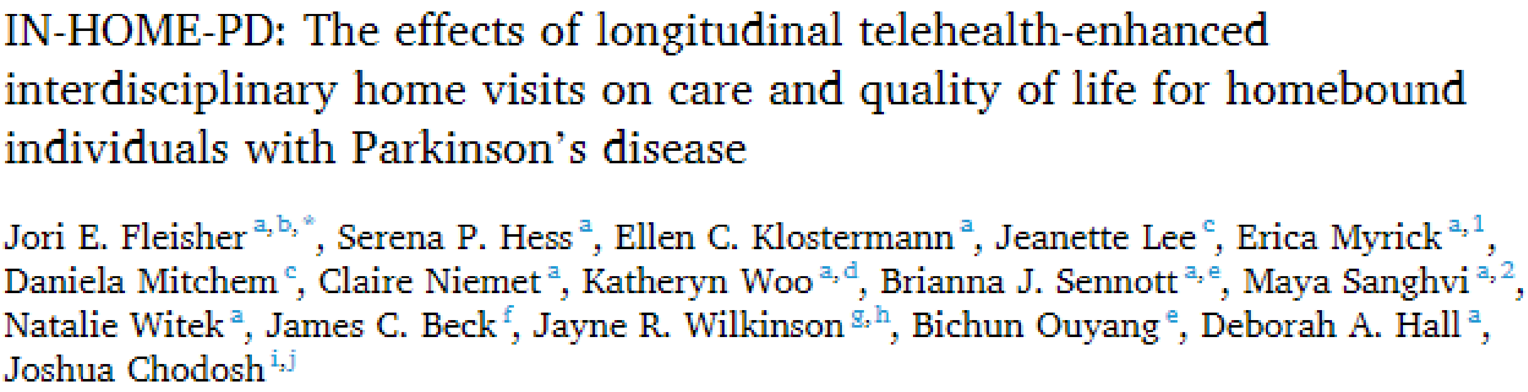
- Data collection
- Technology and telehealth setup

*occurs at each visit

Usual care

NIH NINDS

curePSP
UNLOCKING THE SECRETS OF BRAIN DISEASE®



IN-HOME-PD: The effects of longitudinal telehealth-enhanced interdisciplinary home visits on care and quality of life for homebound individuals with Parkinson's disease

Jori E. Fleisher[a,b,*], Serena P. Hess[a], Ellen C. Klostermann[a], Jeanette Lee[c], Erica Myrick[a,1], Daniela Mitchem[c], Claire Niemet[a], Katheryn Woo[a,d], Brianna J. Sennott[a,e], Maya Sanghvi[a,2], Natalie Witek[a], James C. Beck[f], Jayne R. Wilkinson[g,h], Bichun Ouyang[e], Deborah A. Hall[a], Joshua Chodosh[i,j]

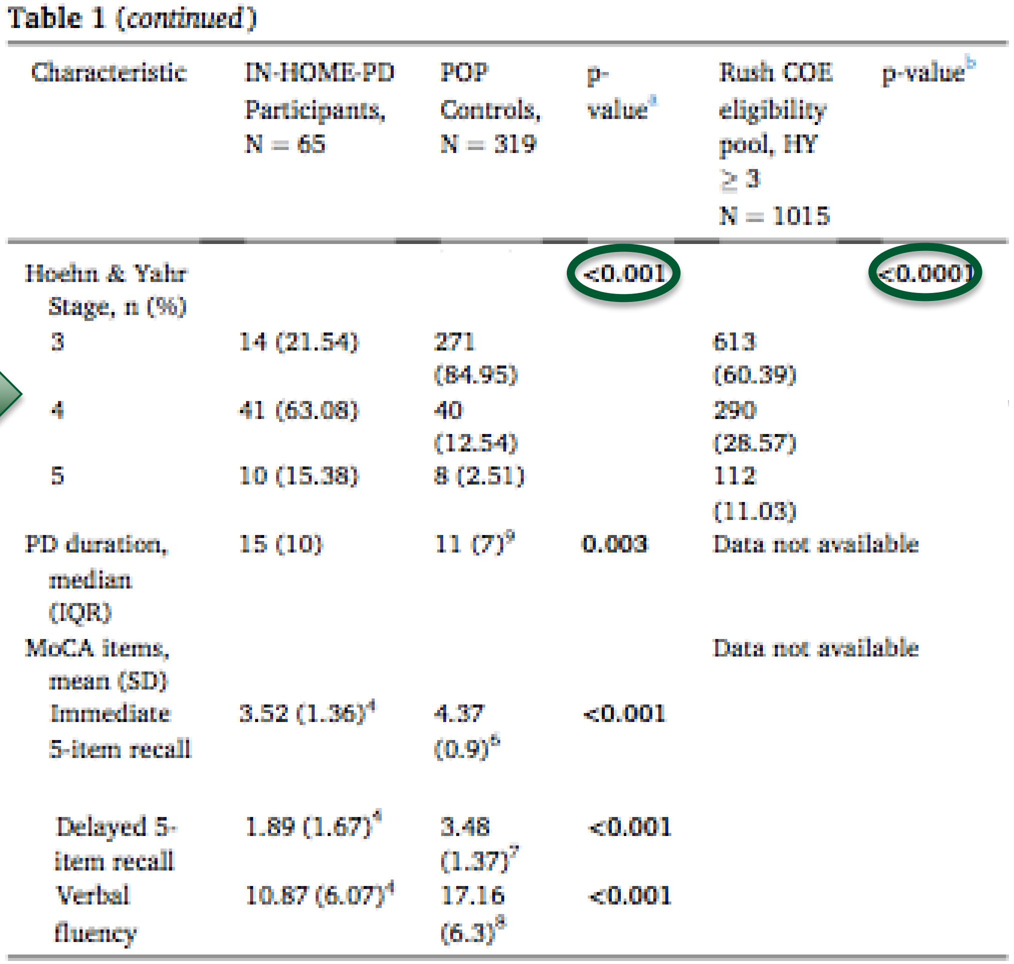


Table 1 (*continued*)

Characteristic	IN-HOME-PD Participants, N = 65	POP Controls, N = 319	p-value[a]	Rush COE eligibility pool, HY ≥ 3 N = 1015	p-value[b]
Hoehn & Yahr Stage, n (%)			<0.001		<0.0001
3	14 (21.54)	271 (84.95)		613 (60.39)	
4	41 (63.08)	40 (12.54)		290 (28.57)	
5	10 (15.38)	8 (2.51)		112 (11.03)	
PD duration, median (IQR)	15 (10)	11 (7)[9]	0.003	Data not available	
MoCA items, mean (SD)				Data not available	
Immediate 5-item recall	3.52 (1.36)[4]	4.37 (0.9)[6]	<0.001		
Delayed 5-item recall	1.89 (1.67)[4]	3.48 (1.37)[7]	<0.001		
Verbal fluency	10.87 (6.07)[4]	17.16 (6.3)[8]	<0.001		

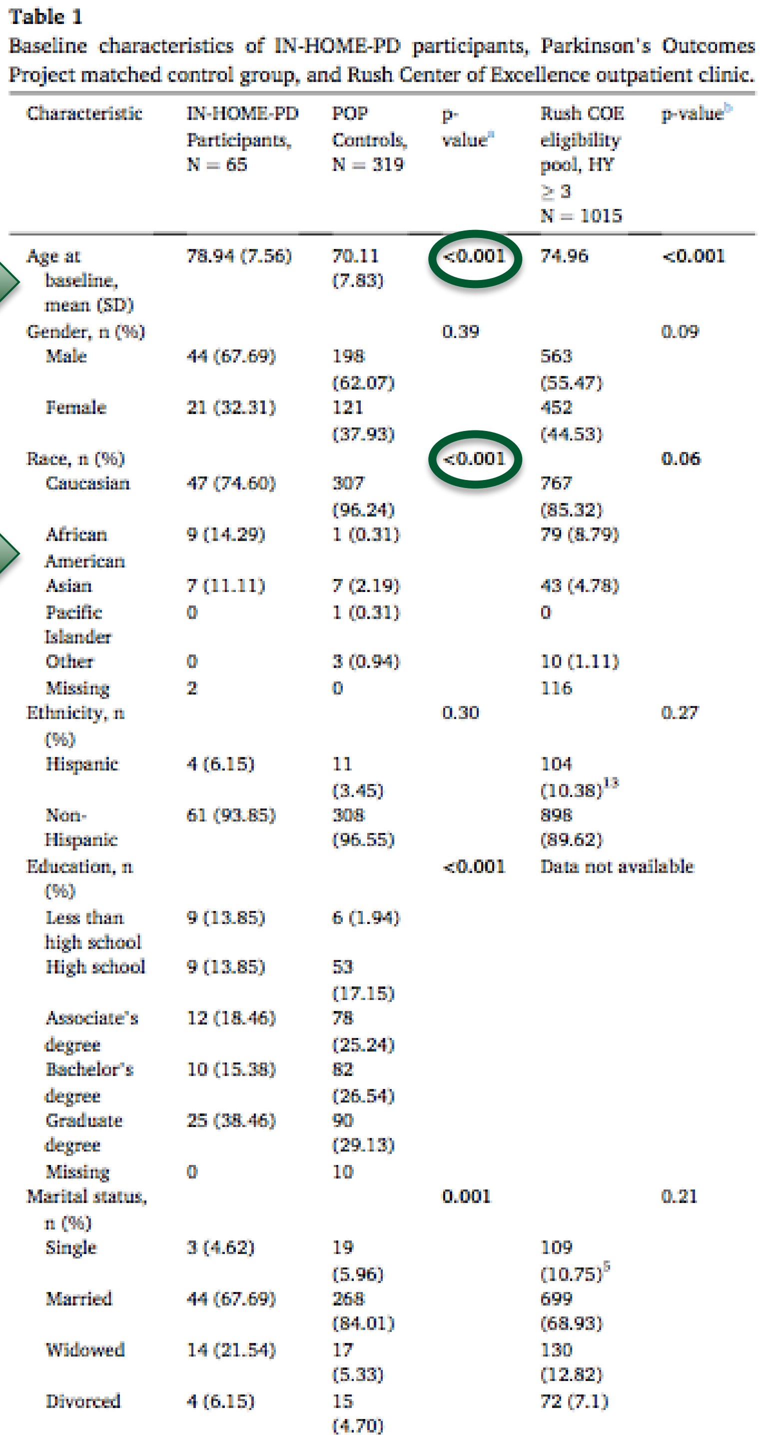
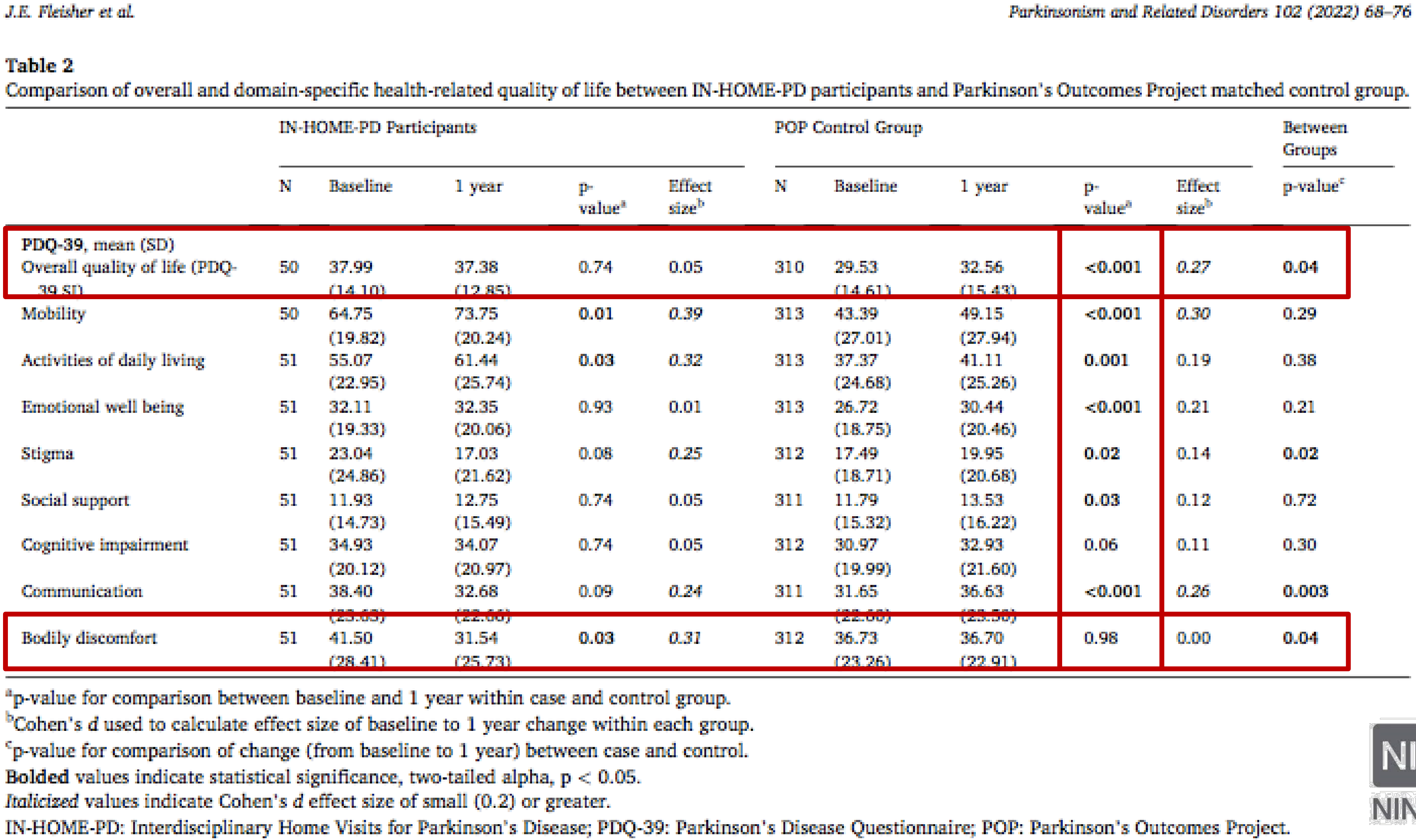


Table 1

Baseline characteristics of IN-HOME-PD participants, Parkinson's Outcomes Project matched control group, and Rush Center of Excellence outpatient clinic.

Characteristic	IN-HOME-PD Participants, N = 65	POP Controls, N = 319	p-value[a]	Rush COE eligibility pool, HY ≥ 3 N = 1015	p-value[b]
Age at baseline, mean (SD)	78.94 (7.56)	70.11 (7.83)	<0.001	74.96	<0.001
Gender, n (%)			0.39		0.09
Male	44 (67.69)	198 (62.07)		563 (55.47)	
Female	21 (32.31)	121 (37.93)		452 (44.53)	
Race, n (%)			<0.001		0.06
Caucasian	47 (74.60)	307 (96.24)		767 (85.32)	
African American	9 (14.29)	1 (0.31)		79 (8.79)	
Asian	7 (11.11)	7 (2.19)		43 (4.78)	
Pacific Islander	0	1 (0.31)		0	
Other	0	3 (0.94)		10 (1.11)	
Missing	2	0		116	
Ethnicity, n (%)			0.30		0.27
Hispanic	4 (6.15)	11 (3.45)		104 (10.38)[13]	
Non-Hispanic	61 (93.85)	308 (96.55)		898 (89.62)	
Education, n (%)			<0.001	Data not available	
Less than high school	9 (13.85)	6 (1.94)			
High school	9 (13.85)	53 (17.15)			
Associate's degree	12 (18.46)	78 (25.24)			
Bachelor's degree	10 (15.38)	82 (26.54)			
Graduate degree	25 (38.46)	90 (29.13)			
Missing	0	10			
Marital status, n (%)			0.001		0.21
Single	3 (4.62)	19 (5.96)		109 (10.75)[5]	
Married	44 (67.69)	268 (84.01)		699 (68.93)	
Widowed	14 (21.54)	17 (5.33)		130 (12.82)	
Divorced	4 (6.15)	15 (4.70)		72 (7.1)	



J.E. Fleisher et al. Parkinsonism and Related Disorders 102 (2022) 68–76

Table 2

Comparison of overall and domain-specific health-related quality of life between IN-HOME-PD participants and Parkinson's Outcomes Project matched control group.

	IN-HOME-PD Participants					POP Control Group					Between Groups
	N	Baseline	1 year	p-value[a]	Effect size[b]	N	Baseline	1 year	p-value[a]	Effect size[b]	p-value[c]
PDQ-39, mean (SD)											
Overall quality of life (PDQ-39 SI)	50	37.99 (14.10)	37.38 (12.85)	0.74	0.05	310	29.53 (14.61)	32.56 (15.43)	**<0.001**	*0.27*	**0.04**
Mobility	50	64.75 (19.82)	73.75 (20.24)	**0.01**	*0.39*	313	43.39 (27.01)	49.15 (27.94)	**<0.001**	*0.30*	0.29
Activities of daily living	51	55.07 (22.95)	61.44 (25.74)	**0.03**	*0.32*	313	37.37 (24.68)	41.11 (25.26)	**0.001**	0.19	0.38
Emotional well being	51	32.11 (19.33)	32.35 (20.06)	0.93	0.01	313	26.72 (18.75)	30.44 (20.46)	**<0.001**	0.21	0.21
Stigma	51	23.04 (24.86)	17.03 (21.62)	0.08	*0.25*	312	17.49 (18.71)	19.95 (20.68)	**0.02**	0.14	**0.02**
Social support	51	11.93 (14.73)	12.75 (15.49)	0.74	0.05	311	11.79 (15.32)	13.53 (16.22)	**0.03**	0.12	0.72
Cognitive impairment	51	34.93 (20.12)	34.07 (20.97)	0.74	0.05	312	30.97 (19.99)	32.93 (21.60)	0.06	0.11	0.30
Communication	51	38.40 (23.63)	32.68 (22.66)	0.09	*0.24*	311	31.65 (22.66)	36.63 (23.50)	**<0.001**	*0.26*	**0.003**
Bodily discomfort	51	41.50 (28.41)	31.54 (25.73)	**0.03**	*0.31*	312	36.73 (23.26)	36.70 (22.91)	0.98	0.00	**0.04**

[a] p-value for comparison between baseline and 1 year within case and control group.

[b] Cohen's *d* used to calculate effect size of baseline to 1 year change within each group.

[c] p-value for comparison of change (from baseline to 1 year) between case and control.

Bolded values indicate statistical significance, two-tailed alpha, $p < 0.05$.

Italicized values indicate Cohen's *d* effect size of small (0.2) or greater.

IN-HOME-PD: Interdisciplinary Home Visits for Parkinson's Disease; PDQ-39: Parkinson's Disease Questionnaire; POP: Parkinson's Outcomes Project.

On the Horizon

- Stages of Parkinson’s Disease and who we are missing
- Interdisciplinary home visits and lessons learned
- A chicken, an egg, and a confusing umbrella
- Caring for caregivers
- How to PERSEVERE

Lewy Body Dementia (LBD):

- **Attention, judgment, & visual perception problems** are more prominent earlier; memory loss may occur later in the disease
- **Hallucinations are common**, especially repetitive visual hallucinations
- **Misidentifying familiar people is common** ("Capgras syndrome")
- **REM sleep disorder**—acting out dreams during sleep—is very common
- **Autonomic nervous system problems** (drops in blood pressure, constipation, trouble with temperature regulation, and urinary incontinence) are common

Alzheimer's Disease (AD):

- **Memory loss** is more prominent earlier; repetitive questions, forgetting recent events and names of people are all common
- **Hallucinations are uncommon**, especially early
- **Forgetting familiar people is common,** less likely to think people are imposters
- REM sleep disorder is uncommon in AD
- Autonomic problems are uncommon
- AD is more common in women; LBD is more common in men

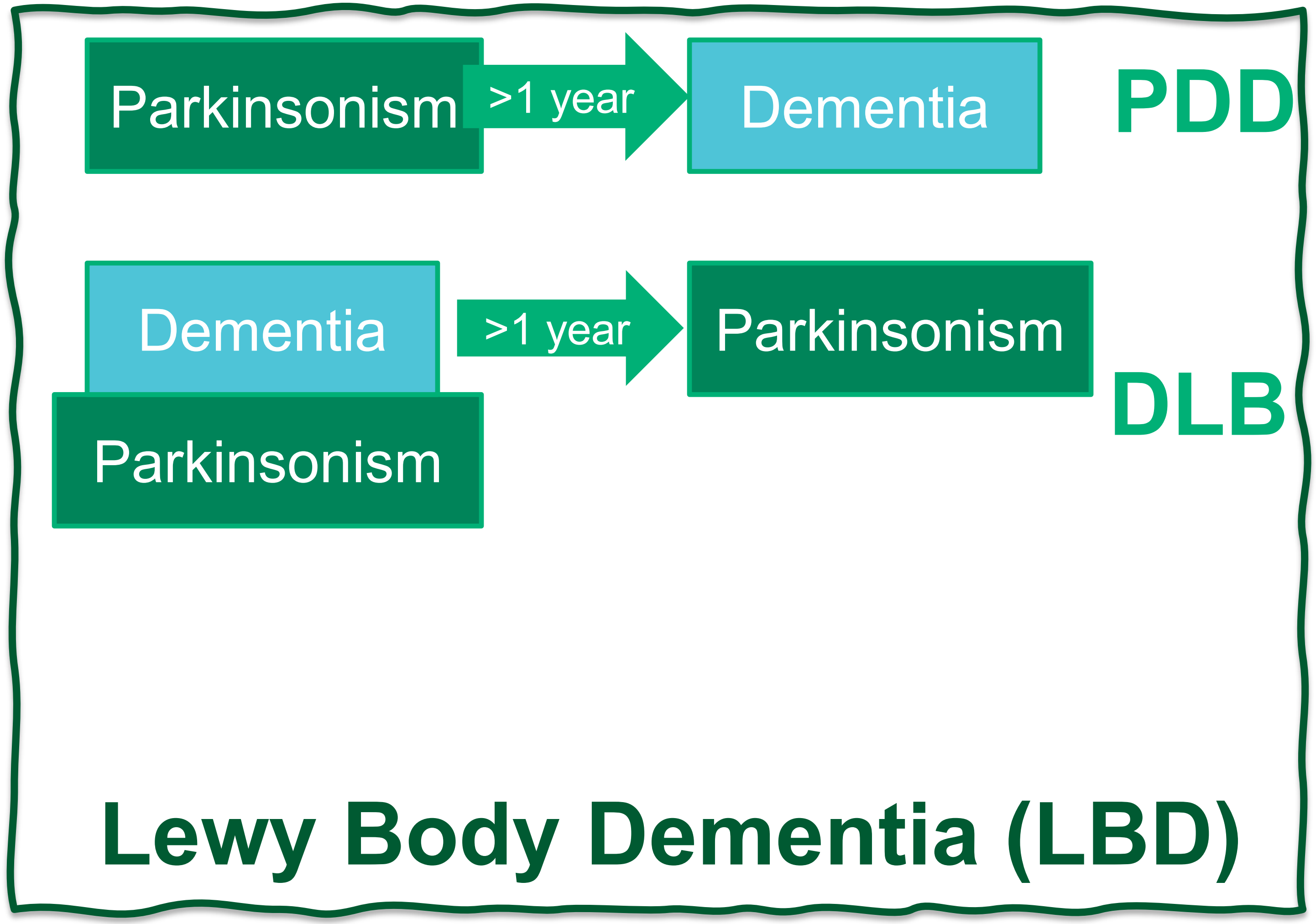
Lewy Body Dementia:
A Tale of Semantic Confusion

Parkinsonism

- Bradykinesia (slowness)
- Rigidity (stiffness)
- Tremor
- Balance changes

Dementia

- Changes in attention, concentration, decision making, visuospatial processing
- Fluctuations in alertness
- Hallucinations



Parkinsonism → >1 year → Dementia **PDD**

Dementia + Parkinsonism → >1 year → Parkinsonism **DLB**

Lewy Body Dementia (LBD)

The (in)evitable triggers for hospitalization and death

- **Leading causes of hospitalization:**
  - Falls
  - Urinary incontinence or infection
  - Dehydration ± metabolic derangements
  - Neuropsychiatric issues: hallucinations, delusions, agitation, depression, anxiety, dementia
  - **Caregiver strain**

- Once hospitalized, individuals with PD and Lewy Body Dementia have excess iatrogenic injuries, longer lengths of stay

- ***Hypothesis: Many episodes of acute care utilization are preventable or manageable at home, if recognized early***
  - **Doing so requires an educated, engaged, observant caregiver**

Ornstein KA et al, 2020; Moens K et al, 2015. Fleisher JE et al, 2022;
Kumar P et al, 2021; McKenzie ED et al, 2022

On the Horizon

- Stages of Parkinson’s Disease and who we are missing
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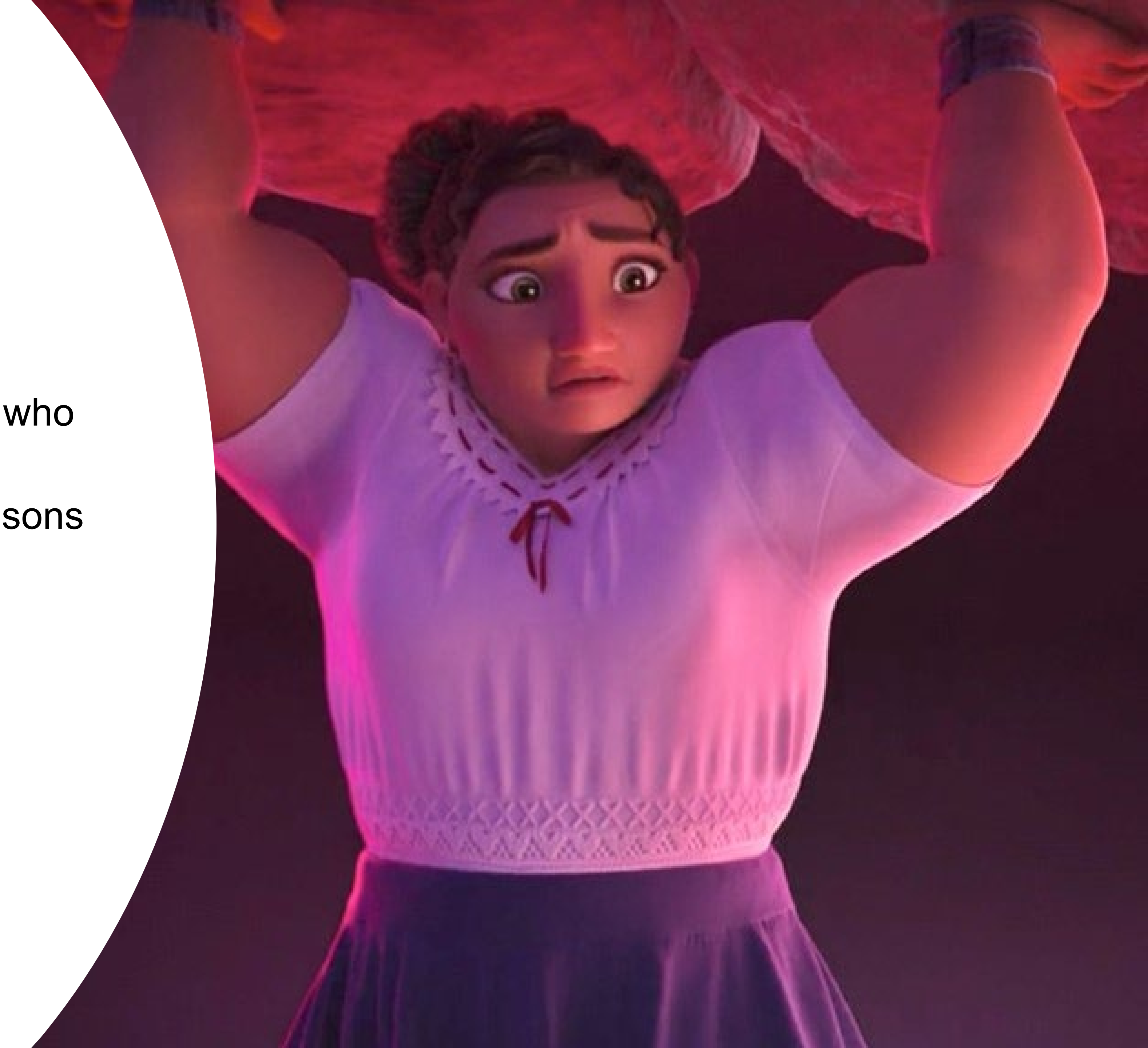
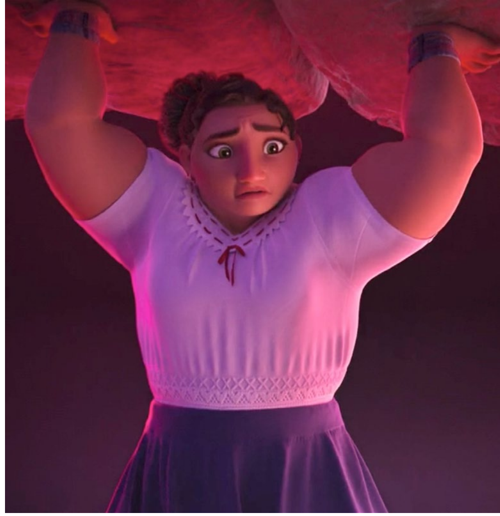


Parkinson’s & LBD Caregivers: Overburdened, understudied



- >83% of community-dwelling people with PD or LBD rely on unpaid caregiving from family members → **18.5 billion hours of care valued at $232 billion**
- PD/LBD family caregivers have higher caregiver strain, burden, and depression than caregivers of people with Alzheimer’s Disease and related dementias
  - Combined deterioration in motor, cognitive, neuropsychiatric, and non-motor domains, plus unpredictability, motor & cognitive fluctuations

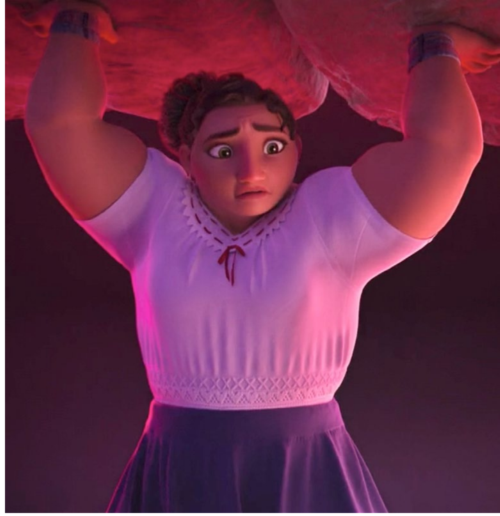
Corbett A et al, 2012; cdc.gov/aging/caregiving/Alzheimer; Svendsboe et al, 2016; Roland KP et al, 2019; Martinez-Martin P et al, 2019; Spears CC et al, 2019; Corey KL and McCurry MK, 2018; Riffin C et al, 2022.

Prevalence of Comorbidities Among Current Lewy Body Dementia Caregivers, by Age Group

Comorbidity Prevalence Among Current Caregivers, n (%)	All (n=182)	Age 18-44 (n=11)	Age 45-54 (n=11)	Age 55-64 (n=48)	Age 65-74 (n=70)	Age 75-84 (n=38)	Age 85+ (n=4)
High blood pressure	70 (38.5)	1 (9.1)	4 (36.4)	15 (31.3)	29 (41.4)	18 (47.4)	4 (36.4)
Depression	68 (37.4)	5 (45.5)	6 (54.5)	21 (43.8)	28 (40.0)	7 (18.4)	1 (25.0)
Back pain	68 (37.4)	5 (45.5)	5 (45.5)	15 (31.3)	27 (38.6)	13 (34.2)	3 (75.0)
Other medical problems	56 (30.8)	4 (36.4)	3 (27.3)	16 (33.3)	19 (27.1)	12 (31.6)	2 (50.0)
Osteoarthritis or degenerative arthritis	53 (29.1)	2 (18.2)	2 (18.2)	13 (27.1)	17 (24.3)	17 (44.7)	2 (50.0)
Heart disease	24 (13.2)	0	0	4 (8.3)	17 (24.3)	7 (22.6)	1 (25.0)
Constipation	24 (13.2)	2 (18.2)	2 (18.2)	5 (10.4)	12 (17.1)	2 (5.3)	1 (25.0)
Diabetes	16 (8.8)	0	0	8 (16.7)	5 (7.1)	2 (5.3)	1 (25.0)
Ulcer or stomach disease	16 (8.8)	0	0	5 (10.4)	7 (10.0)	3 (7.9)	1 (25.0)
Rheumatoid arthritis	15 (8.2)	0	0	3 (6.3)	8 (11.4)	3 (7.9)	1 (25.0)

Fleisher JE et al, 2022

Parkinson's & LBD Caregivers: Overburdened, understudied



- **Caregiver strain independently increases person's risk of hospitalization & nursing home placement**
- No effective PD or LBD caregiver interventions to date
- Among dementia caregiver interventions, only costly, multimodal approaches demonstrate benefit
- **Paid caregivers:**
  - Not covered by insurance, including Medicare or hospice
  - Extremely expensive (~$US 30+/hour, or ~$5,000/week)
  - High demand, low supply
  - High turnover & burnout pre-COVID, worse post-COVID
  - Minimal to no training in dementia, PD, end-of-life care

…not a sustainable option for most

Corbett A et al, 2012; cdc.gov/aging/caregiving/Alzheimer; Svendsboe et al, 2016; Roland KP et al, 2019; Martinez-Martin P et al, 2019; Spears CC et al, 2019; Corey KL and McCurry MK, 2018; Riffin C et al, 2022.

Home visits are insufficient to change caregiver strain alone

Home Visit Pilot Study:

- Among 10 caregivers over 1 year, strain increased from mild to moderate (17.1 to 23.2, p = 0.04)
- Among 3 who withdrew, median V1 baseline was 42 (range 29-55) suggesting severe strain
- Conclusion: home visits aren’t enough to mitigate caregiver strain

Peer mentoring

- **Initially in Alzheimer's Disease caregivers**:
  - Former caregivers paired with current caregivers, mixed quantitative results, strong qualitative data supporting benefits for mentors & mentees
- **Peer mentoring has subsequently led to improved outcomes among:**
  - Trauma survivors
  - Individuals with kidney disease
  - Sedentary older adults
  - Young adults with neurologic disorders
  - Family caregivers of people with cancer
  - Bereaved parents of children who died from cancer

Charlesworth G et al, 2016; Charlesworth G et al, 2017; Greenwood N and Habibi R, 2014;
Walshe C et al, 2020; Zwaima A et al, 2022; Perry E et al, 2003; Stevens Z et al, 2015;
McKenzie G et al, 2022; Husted Nielsen I, et al, 2022.

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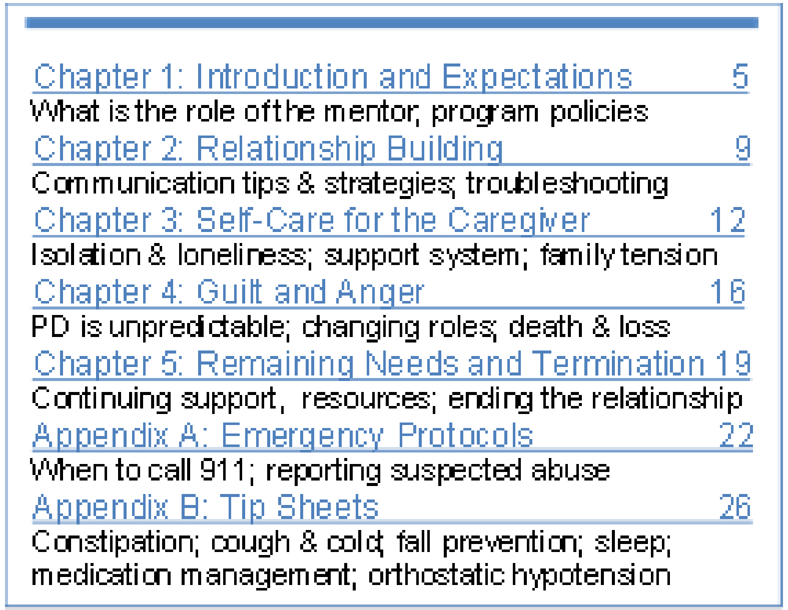
- Conclusion: home visits aren't enough to mitigate caregiver strain

K23 IN-HOME-PD: Home Visit + Peer Mentoring Pilot:

- 65 patient-caregiver pairs receiving 4 visits over 1 year
- 34 experienced caregivers, 6 hours of training to become **peer mentor**
- Caregiver matched with a peer mentor for 16 weeks (between V2-V3)



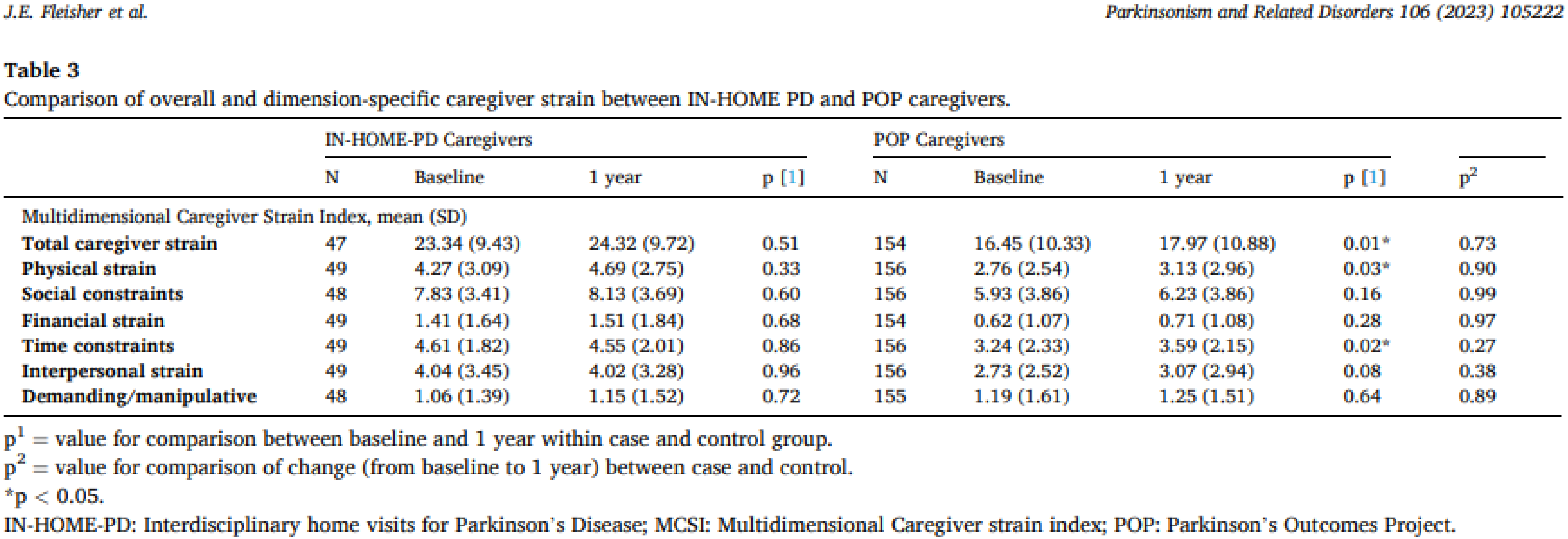
Chapter 1: Introduction and Expectations 5
What is the role of the mentor; program policies
Chapter 2: Relationship Building 9
Communication tips & strategies; troubleshooting
Chapter 3: Self-Care for the Caregiver 12
Isolation & loneliness; support system; family tension
Chapter 4: Guilt and Anger 16
PD is unpredictable; changing roles; death & loss
Chapter 5: Remaining Needs and Termination 19
Continuing support, resources; ending the relationship
Appendix A: Emergency Protocols 22
When to call 911; reporting suspected abuse
Appendix B: Tip Sheets 26
Constipation; cough & cold; fall prevention; sleep; medication management; orthostatic hypotension

IN-HOME-PD Caregivers:
Greater baseline strain than non-equivalent controls, stable over one year

NIH NINDS

curePSP
UNLOCKING THE SECRETS OF BRAIN DISEASE®

- 34 former or active experienced caregivers completed training
- 51 of 61 eligible caregivers of homebound PD participants enrolled in mentoring, 3 withdrew
- Median of 11 calls in 16 weeks, 30 minutes' duration (IQR 20-45); mean satisfaction 91/100



J.E. Fleisher et al. *Parkinsonism and Related Disorders 106 (2023) 105222*

Table 3

Comparison of overall and dimension-specific caregiver strain between IN-HOME PD and POP caregivers.

	IN-HOME-PD Caregivers				POP Caregivers				
	N	Baseline	1 year	p [1]	N	Baseline	1 year	p [1]	p^2
Multidimensional Caregiver Strain Index, mean (SD)									
Total caregiver strain	47	23.34 (9.43)	24.32 (9.72)	0.51	154	16.45 (10.33)	17.97 (10.88)	0.01*	0.73
Physical strain	49	4.27 (3.09)	4.69 (2.75)	0.33	156	2.76 (2.54)	3.13 (2.96)	0.03*	0.90
Social constraints	48	7.83 (3.41)	8.13 (3.69)	0.60	156	5.93 (3.86)	6.23 (3.86)	0.16	0.99
Financial strain	49	1.41 (1.64)	1.51 (1.84)	0.68	154	0.62 (1.07)	0.71 (1.08)	0.28	0.97
Time constraints	49	4.61 (1.82)	4.55 (2.01)	0.86	156	3.24 (2.33)	3.59 (2.15)	0.02*	0.27
Interpersonal strain	49	4.04 (3.45)	4.02 (3.28)	0.96	156	2.73 (2.52)	3.07 (2.94)	0.08	0.38
Demanding/manipulative	48	1.06 (1.39)	1.15 (1.52)	0.72	155	1.19 (1.61)	1.25 (1.51)	0.64	0.89

p^1 = value for comparison between baseline and 1 year within case and control group.

p^2 = value for comparison of change (from baseline to 1 year) between case and control.

*$p < 0.05$.

IN-HOME-PD: Interdisciplinary home visits for Parkinson's Disease; MCSI: Multidimensional Caregiver strain index; POP: Parkinson's Outcomes Project.

Learning to PERSEVERE

per·se·vere

/ˌpərsəˈvir/

Peer Mentor Support and Caregiver Education in Lewy Body Dementia

- Focus groups of former mentors, former mentees, and *de novo* PD & LBD family caregivers to review & revise curriculum
- ENTIRELY virtual; opened recruitment nationally in partnership with LBDA & PF email lists & Facebook groups
- Trained 36 new mentors virtually from across the US
- Recruited 30 new mentees; matched mentors & mentees by preferences using card sorting exercise
- Pairs communicated by phone or videoconference using revised curriculum for 16 weeks

Easily available online resources…
aren't enough and are too hard, time-consuming to find

Weeks	Social Support Topics	LBD Mastery Topics
1-2	Introductions, expectations, goal setting	Top concerns of mentee/goals for mastery
3	Relationship building, top concerns	Falls, fall prevention
4-5	Caregiver strain and related outcomes	Home safety and **resources for aging-in-place**
6-7	Support system, isolation, loneliness	**Depression, anxiety, apathy**
8-9	Self-care for caregiver	**Hallucinations & delusions**
10-11	**Guilt and anger, changing roles**	**Constipation & orthostatic hypotension**
12-13	**LBD unpredictability**	**Sudden changes**/infections – detection, management; **advocating** in the ER/hospital
14-15	**Anticipatory grief**, remaining needs, goal-setting for future	**Advance directives** – planning & starting the conversation
16	Reflecting on PERSEVERE, concluding mentor relationship	Review sudden changes, fall prevention & home safety, non-motor symptoms, presence of advance directives

Mentor training and support

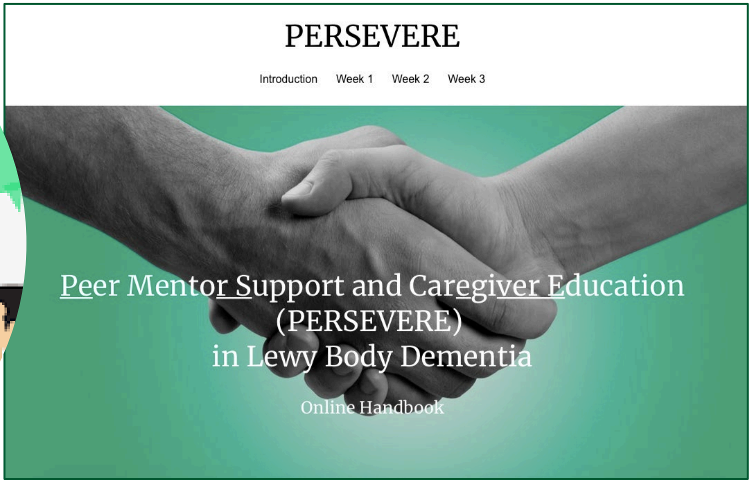
- **Training:**
  - Six-hour synchronous Zoom training session, covering key topics in PD & LBD, active listening, safety protocols, role plays
  - Q&A session with prior mentors
- **Matching:**
  - Mentees and mentors expressed preferences for matching parameters (gender, age, time zone, role concordance, experience with grief); matched to optimize mentee & mentor preferences
- **Support:**
  - Monthly mentor-only Zoom conferences, facilitated by study team RN or SW: successes, challenges, mentor-to-mentor peer support
  - Office hours with access to RN and study coordinators for individual mentoring relationship questions

Despite active caregiving demands or bereavement, LBD caregivers prioritized *Learning to PERSEVERE*

- 30 mentor-mentee pairs completed 424 calls (15 calls/dyad, median 45 min)
- 100% found calls useful; 100% would recommend to other LBD caregivers
- 90% of mentors would serve as mentors in future
- **50% of mentees would serve as mentors in future**

Results of Stage Ib: Learning to PERSEVERE (2020-2021)			
Assessment	**Baseline mean (SD)**	**Post-mentoring mean (SD)**	**p-value**
Mentor Outcomes : n = 30			
LBD Knowledge Test	55.83 (13.34)	64.72 (12.70)	**0.01**
Dementia Attitudes Scale	120.97 (11.76)	121.60 (11.81)	0.66
Mentee Outcomes : n = 28			
LBD Knowledge Test	50 (10.14)	56.85 (14.88)	**0.02**
Pearlin Mastery scale	32.46 (7.57)	33.04 (6.82)	0.58
Dementia Attitudes Scale	104.25 (13.58)	111.57 (9.38)	**0.001**
Geriatric Depression Scale	5.0 (3.76)	4.22 (3.19)	**0.04**
Zarit Burden Interview – Short form	23.18 (8.25)	22.18 (8.52)	0.30

Applying community-based participatory research & user-centered design to optimize training and content



PERSEVERE

Introduction Week 1 Week 2 Week 3

Peer Mentor Support and Caregiver Education
(PERSEVERE)
in Lewy Body Dementia

Online Handbook

Structural feedback from multiple participants: Continue weekly office hours with social worker, monthly mentor support calls, e-newsletters for retention; create an LBD webinar for mentees; make each module one week long with resources *in* module vs. appendix; digitize handbook; shorten intervention from 16 to 12 weeks (limit conflicts with holidays & vacations); add content on nursing facilities, hospice, grief, brain donation, burnout.

Balas JS et al, 2021; Hess SP et al, 2022

On the Horizon

- Stages of Parkinson’s Disease and who we are missing
- Interdisciplinary home visits and lessons learned
- A chicken, an egg, and a confusing umbrella
- Caring for caregivers
- How to PERSEVERE

PERSEVERE

PEER MENTORING
SUPPORT AND CAREGIVER
EDUCATION

A Research Study Designed for *YOU*

PERSEVERE: Randomized Controlled Trial of Peer Mentoring Support and Education for Lewy Body Dementia Family Caregivers

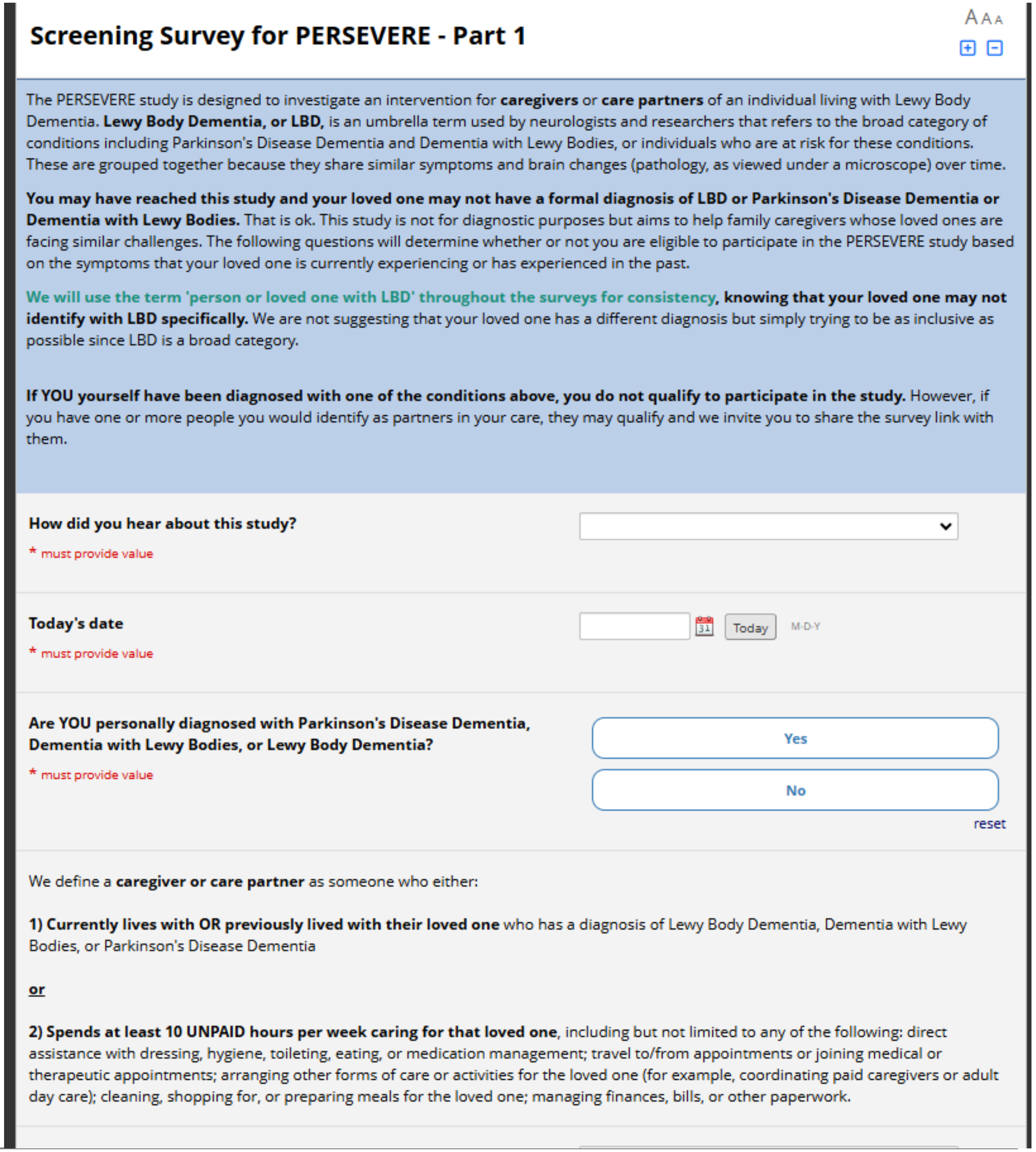
- PERSEVERE is a **national, NIH-funded** study testing an educational program for family caregivers of people with cognitive changes, hallucinations, OR dementia due to Parkinson's or Lewy Body Dementia
- Current and past family caregivers may participate
- Experienced caregivers ($\geq$ 3 years' caregiving or loved one has passed) will be trained as peer mentors to support caregivers earlier in the caring journey
- **All participation is virtual**; biweekly surveys are completed online

Can a disease-specific, caregiver-centered intervention help *you…and* your loved one?

Study overview:

- **Virtual format,** completed at a time that is convenient for you
- **9 months** of bi-weekly surveys
- **Experienced (3 or more years) or former caregivers → Peer mentors**
  - Will be trained virtually by study team and paired with a caregiver mentee for 12 weeks of weekly mentor check-ins
- **Caregivers whose loved ones have had cognitive changes <3 years:**
  - Half will be assigned to the active intervention group
  - Half will be assigned to the lighter intervention group
- **Everyone receives weekly, disease-specific, practical guidance through a 12-week curriculum with resources and activities, plus stipends for participation**

https://redcap.link/PERSEVERE1



Screening Survey for PERSEVERE - Part 1

The PERSEVERE study is designed to investigate an intervention for **caregivers** or **care partners** of an individual living with Lewy Body Dementia. **Lewy Body Dementia, or LBD,** is an umbrella term used by neurologists and researchers that refers to the broad category of conditions including Parkinson's Disease Dementia and Dementia with Lewy Bodies, or individuals who are at risk for these conditions. These are grouped together because they share similar symptoms and brain changes (pathology, as viewed under a microscope) over time.

You may have reached this study and your loved one may not have a formal diagnosis of LBD or Parkinson's Disease Dementia or Dementia with Lewy Bodies. That is ok. This study is not for diagnostic purposes but aims to help family caregivers whose loved ones are facing similar challenges. The following questions will determine whether or not you are eligible to participate in the PERSEVERE study based on the symptoms that your loved one is currently experiencing or has experienced in the past.

We will use the term 'person or loved one with LBD' throughout the surveys for consistency, knowing that your loved one may not identify with LBD specifically. We are not suggesting that your loved one has a different diagnosis but simply trying to be as inclusive as possible since LBD is a broad category.

If YOU yourself have been diagnosed with one of the conditions above, you do not qualify to participate in the study. However, if you have one or more people you would identify as partners in your care, they may qualify and we invite you to share the survey link with them.

How did you hear about this study?
* must provide value

Today's date
* must provide value

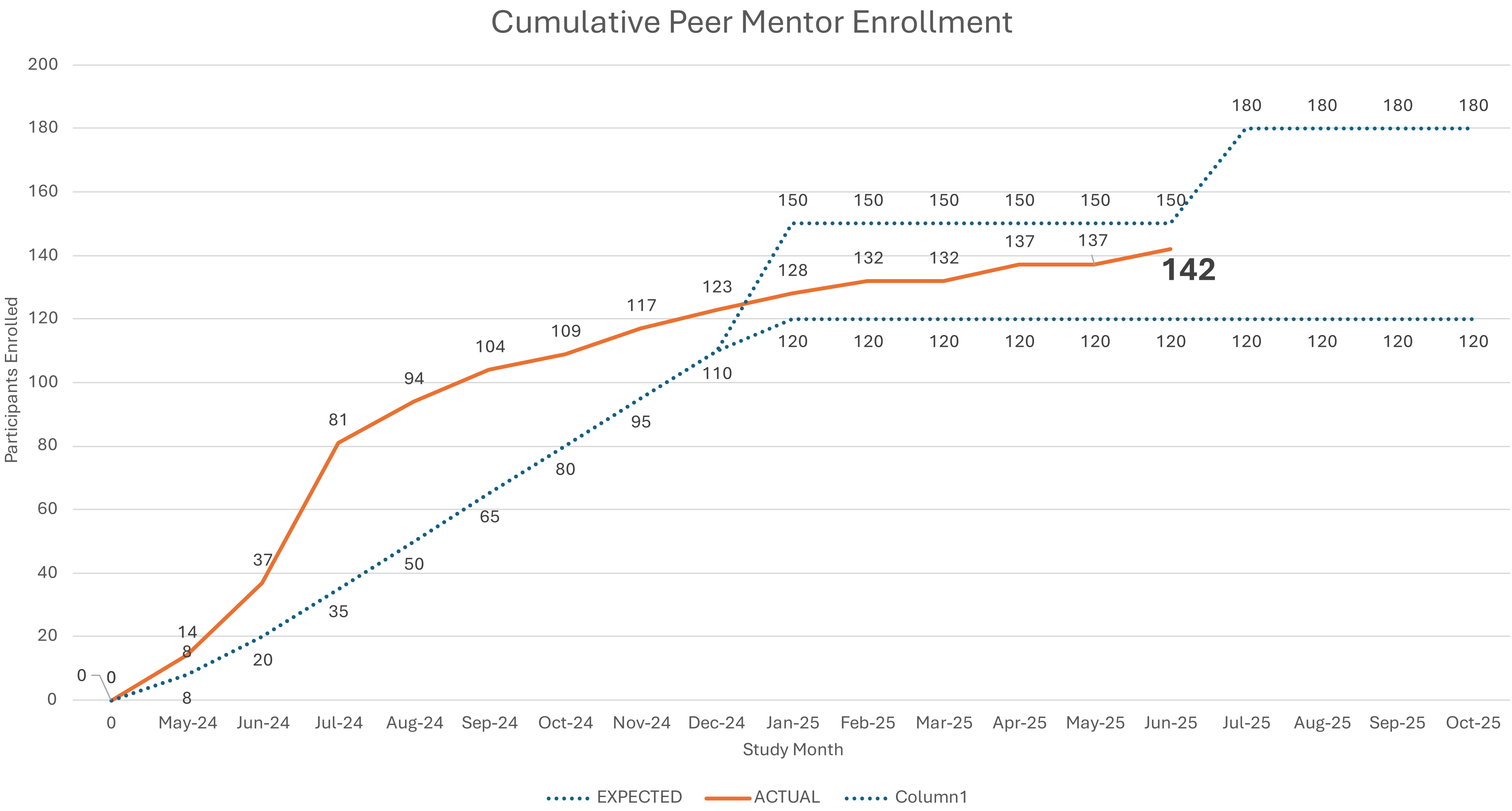
Are YOU personally diagnosed with Parkinson's Disease Dementia, Dementia with Lewy Bodies, or Lewy Body Dementia?
* must provide value

We define a **caregiver or care partner** as someone who either:

1) Currently lives with OR previously lived with their loved one who has a diagnosis of Lewy Body Dementia, Dementia with Lewy Bodies, or Parkinson's Disease Dementia

or

2) Spends at least 10 UNPAID hours per week caring for that loved one, including but not limited to any of the following: direct assistance with dressing, hygiene, toileting, eating, or medication management; travel to/from appointments or joining medical or therapeutic appointments; arranging other forms of care or activities for the loved one (for example, coordinating paid caregivers or adult day care); cleaning, shopping for, or preparing meals for the loved one; managing finances, bills, or other paperwork.


Cumulative Peer Mentor Enrollment
Participants Enrolled
200
180
160
140
120
100
80
60
40
20
0
Study Month
0
May-24
Jun-24
Jul-24
Aug-24
Sep-24
Oct-24
Nov-24
Dec-24
Jan-25
Feb-25
Mar-25
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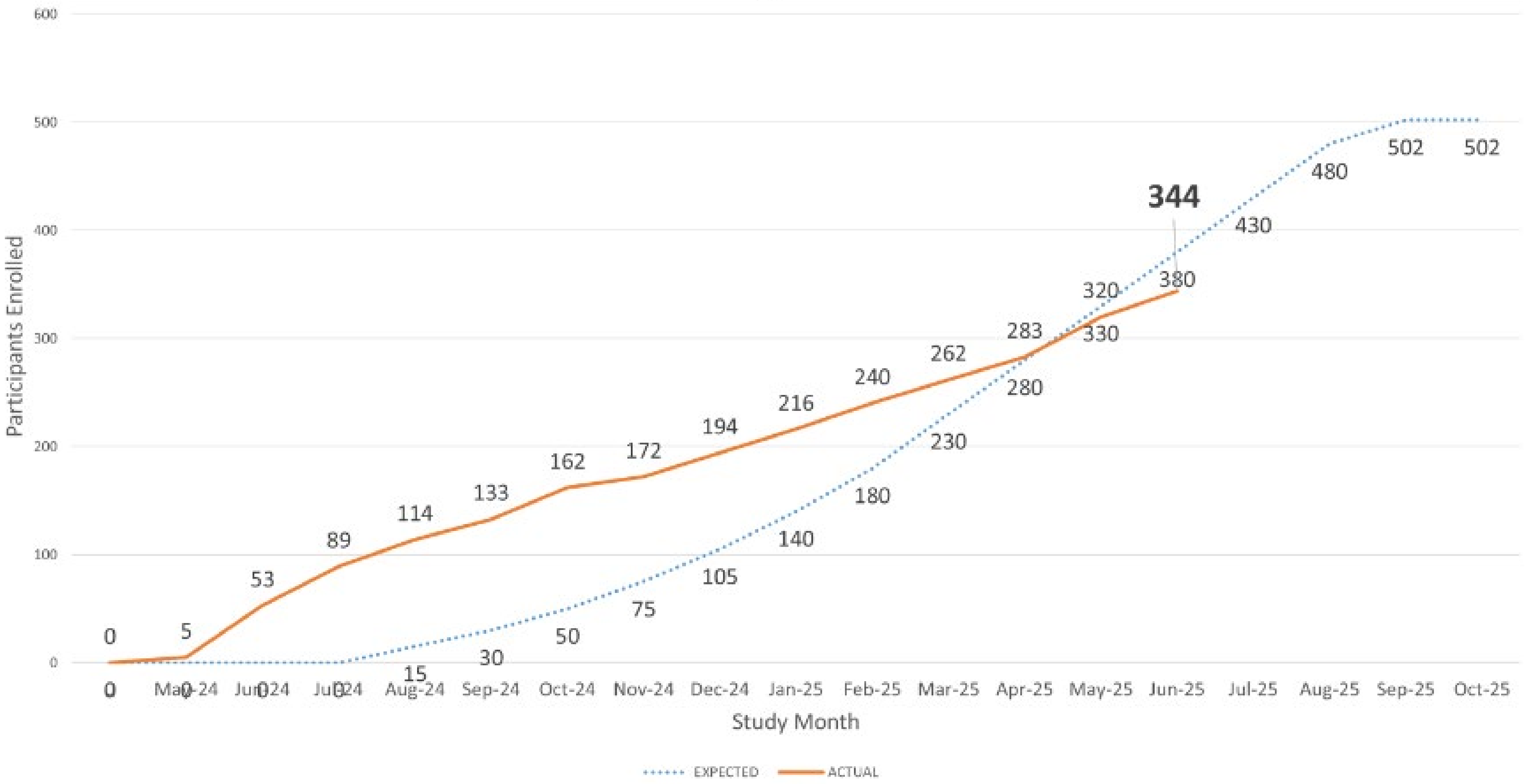
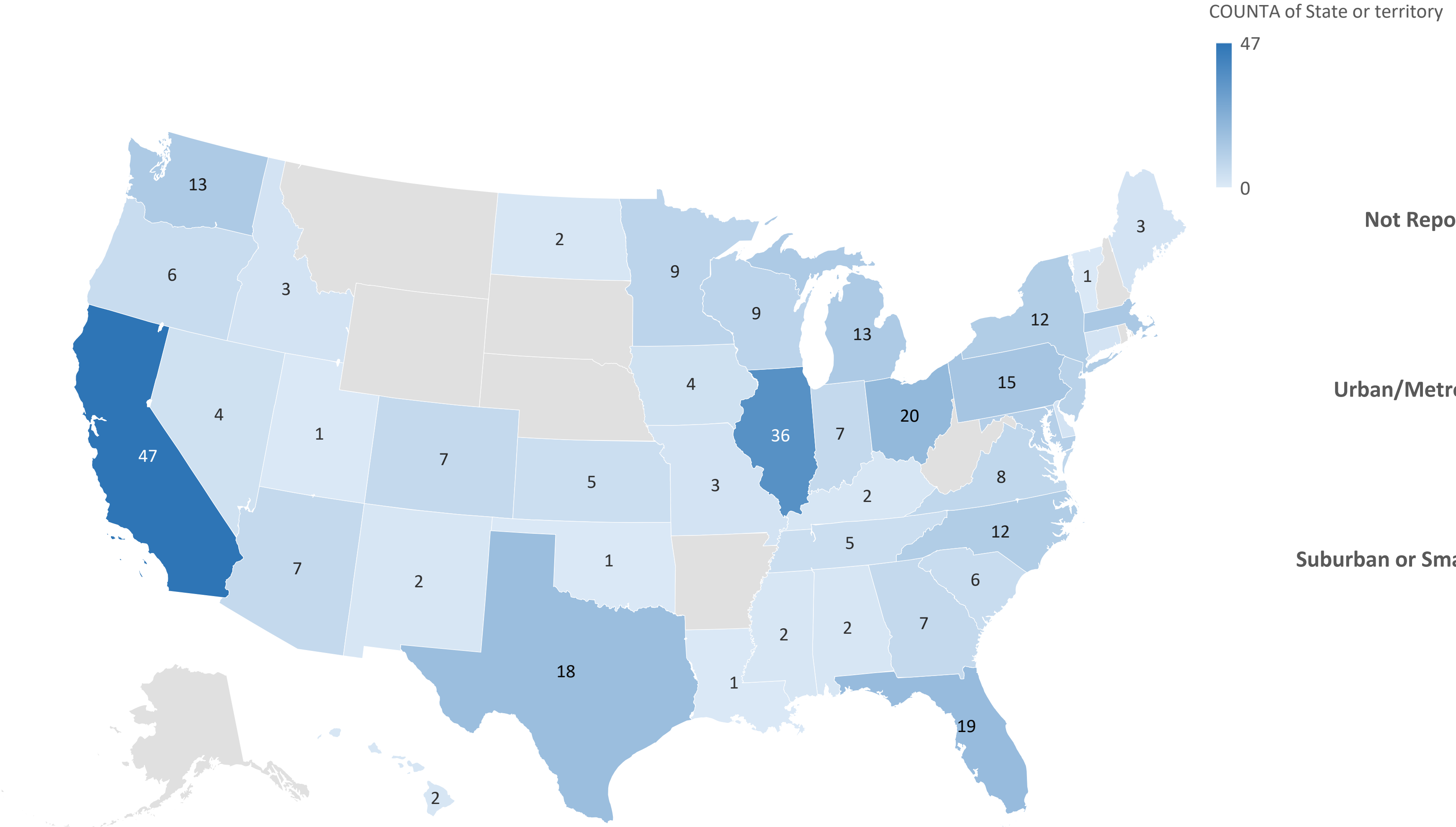
Column1

Cumulative Caregiver Enrollment



Enrollment by State



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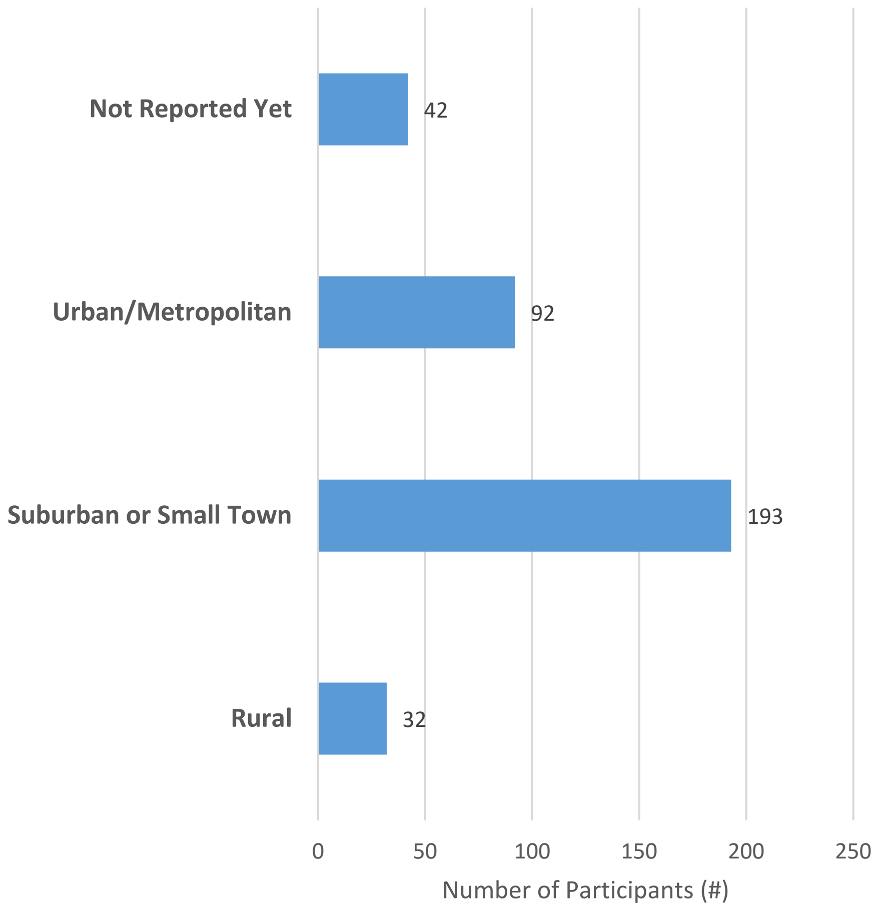
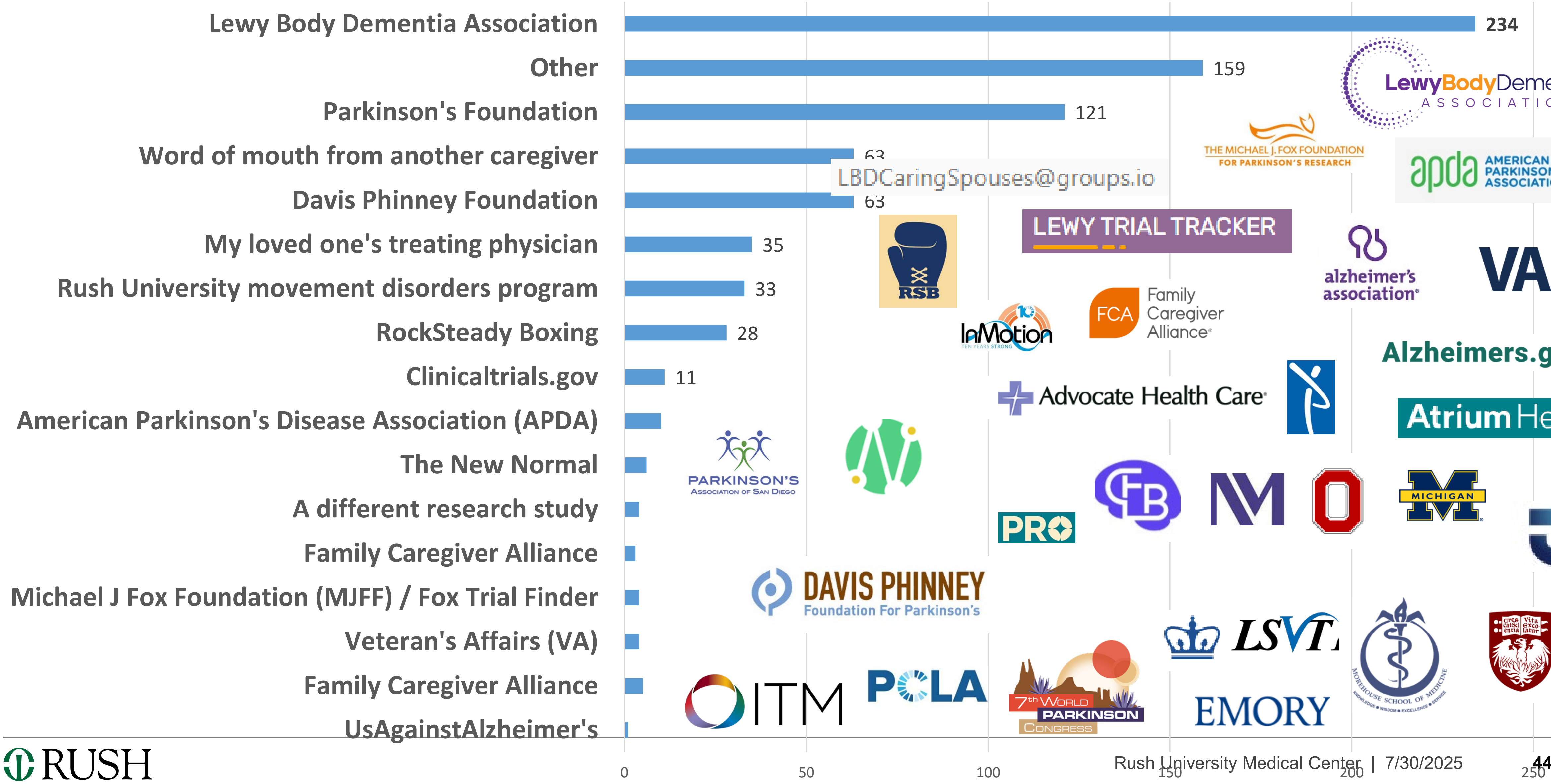
Enrollment by Geographic Area



Where did you hear about us?



LBDCaringSpouses@groups.io

LEWY TRIAL TRACKER

PERSEVERE

PEER MENTORING
SUPPORT AND CAREGIVER
EDUCATION

Interested in learning more or participating?

- Scan the QR code to the left!
- Visit https://redcap.link/PERSEVERE1 to watch a video with more information about the study
- Listed on clinicaltrials.gov, Fox Trial Finder, alzheimers.gov, LBDA.org, The New Normal
- **Email us directly at** persevere@rush.edu
- **Follow us! The.persevere.study** on TikTok & Instagram

Conclusions & Takeaways

- Individuals with advanced PD are understudied, underrepresented in research, amenable to clinical care and research, and benefit from comprehensive care that can stabilize and even improve symptoms and quality of life
  - **Takeaway 1: NO ONE with PD is past the point of help and the medications don't stop working**
- Lewy Body Dementia is an umbrella term, covering PD Dementia and Dementia with Lewy Bodies
  - **Takeaway 2: Terms are confusing but recognizing cognitive changes leads to better management today and in the future – hope *is* on the horizon!**
- There are identifiable—and potentially preventable or manageable—causes of hospitalization in PD & DLB
  - **Takeaway 3: Any sudden change in your PD symptoms *isn't usually PD* – think infection, dehydration, and take action!**

Conclusions & Takeaways

- PD and LBD family caregivers have higher strain & burden than caregivers for individuals with Alzheimer's Disease
  - **Takeaway 4: Caregiver strain is common, real, and a risk factor for hospitalizations and nursing home placement…but potentially modifiable with peer mentor-led educational intervention**
- Despite high strain and burden, caregivers willingly share invaluable lived experience + mentor newer caregivers, who improve their own knowledge and attitudes
  - **Takeaway 5: Until our healthcare system changes, one of the biggest sources of caregiver support & wisdom is in connecting with *others* on this journey**
- Word-of-mouth referrals from one caregiver to another have been a big driver of PERSEVERE recruitment
  - **Takeaway 6: You are not alone, you know more than you think you do, and you can make this journey better for others who follow**

Acknowledgments

NYU Home Visit Program & Rush IN-HOME-PD Patients, Families, and Peer Mentors

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- Neha Kramer MD, Sarah Mitchell Chen, LCSW, Kristin Gustashaw RD, Grace Hong RN, Dirk Labuschagne MDiv MPH

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