Research

JAMA Neurology | Original Investigation

Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders
A Randomized Clinical Trial

Benzi M. Kluger, MD; Janis Miyasaki, MD; Maya Katz, MD; Nicholas Galifianakis, MD; Kirk Hall, MBA; Steven Pantilat, MD; Ryan Khan, MDiv; Cari Friedman, LCSW; Wendy Cernik, BSN; Yuika Goto, MD; Judith Long, MS; Diane Fairclough, DrPH; Stefan Sillau, PhD; Jean S. Kutner, MD

Journal Club 10/22/2021

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WHY IS THIS IMPORTANT?

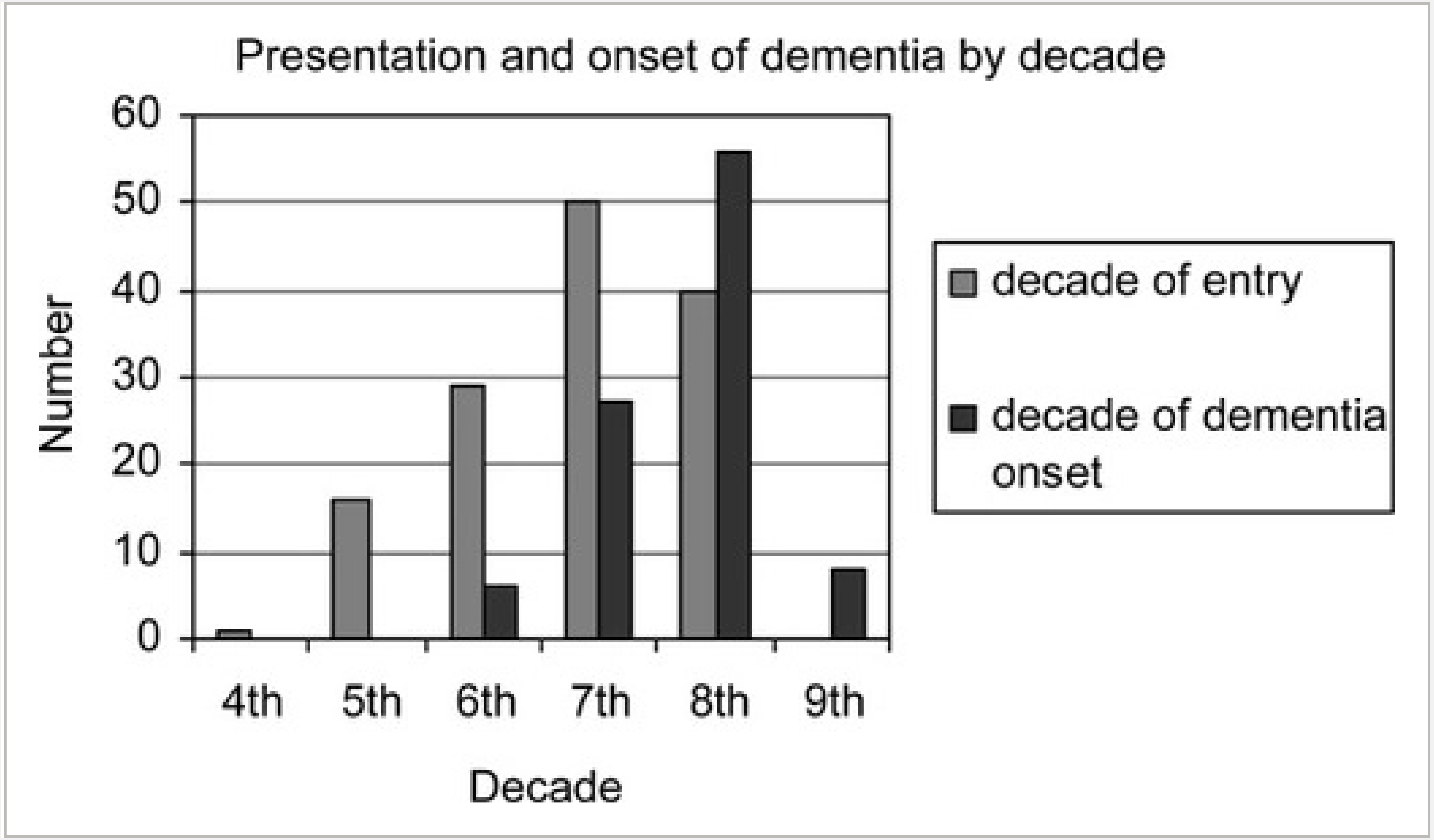
- Parkinson's disease and related disorders (PDRD) affects 1 to 2% of people older than 65 years (will be prevalent in our patient population!)
- The prevalence of PD is increasing and is expected to double by 2030
- It is the 14th leading cause of death in the United States

PARKINSON’S DISEASE

- No curative treatment – chronic illness model
- Mainstay of therapy: managing motor symptoms with dopamine agonists, COMT inhibitors, and MAO B inhibitors
- As disease advances the effect of levodopa begins to wear off and these drugs have side effects

BURDEN OF PDRD

- Burden of PD and PDRD include physical disability, dementia, mood disorder, psychosis, financial hardships
- These symptoms are common and are associated with mortality, quality of life, caregiver distress and nursing home placement
- Over the course of the illness up to 80% of individuals with PD will develop dementia
- People living with PD are also five times more likely to be placed in a nursing home and die in hospitals significantly more often than their age-matched peers



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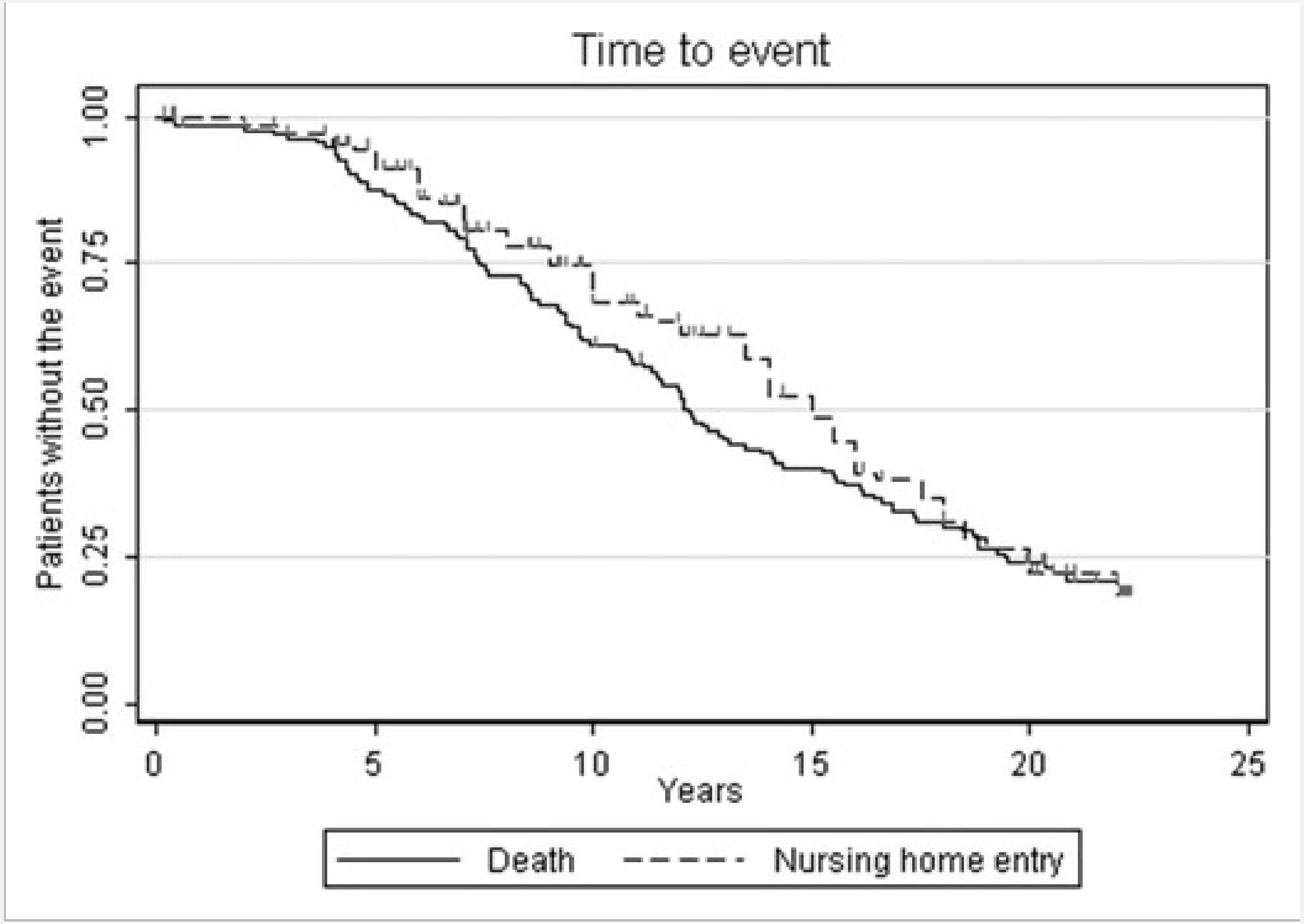

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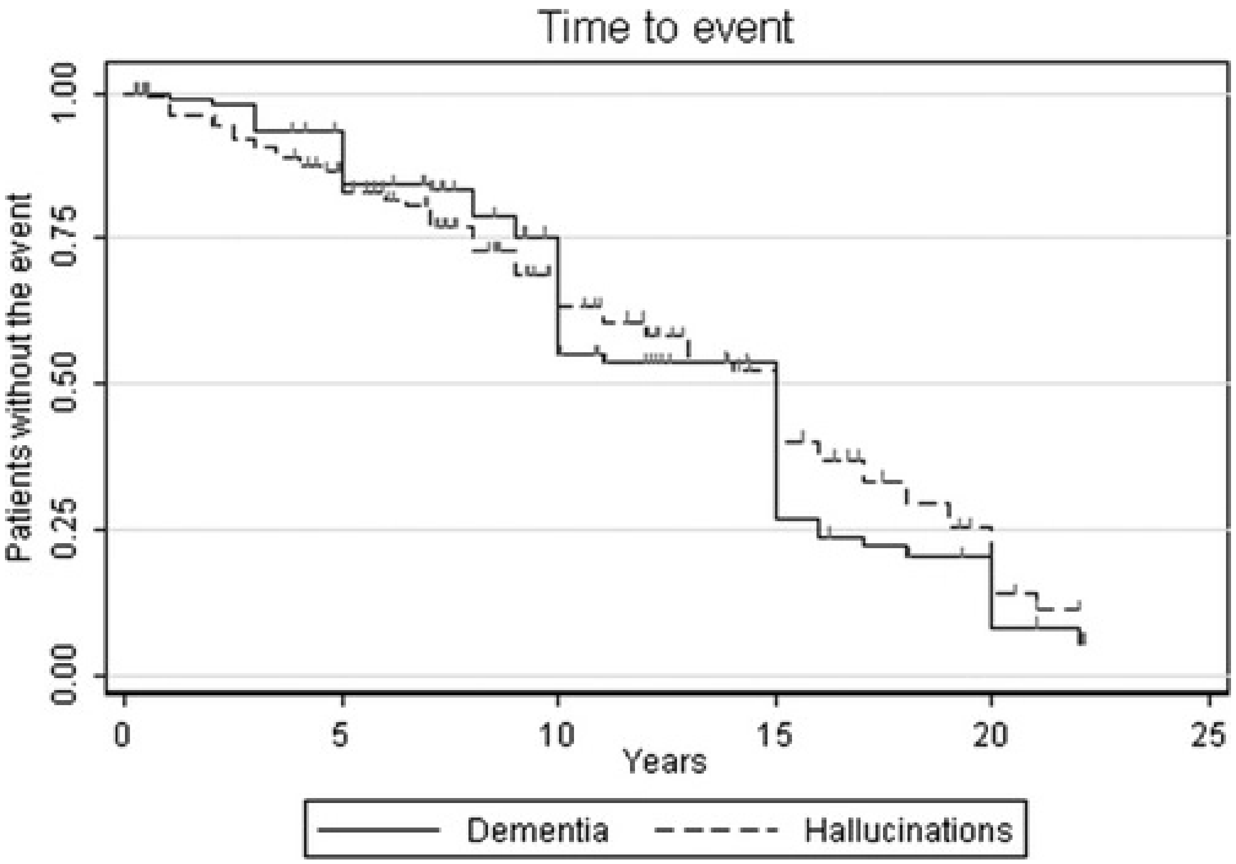

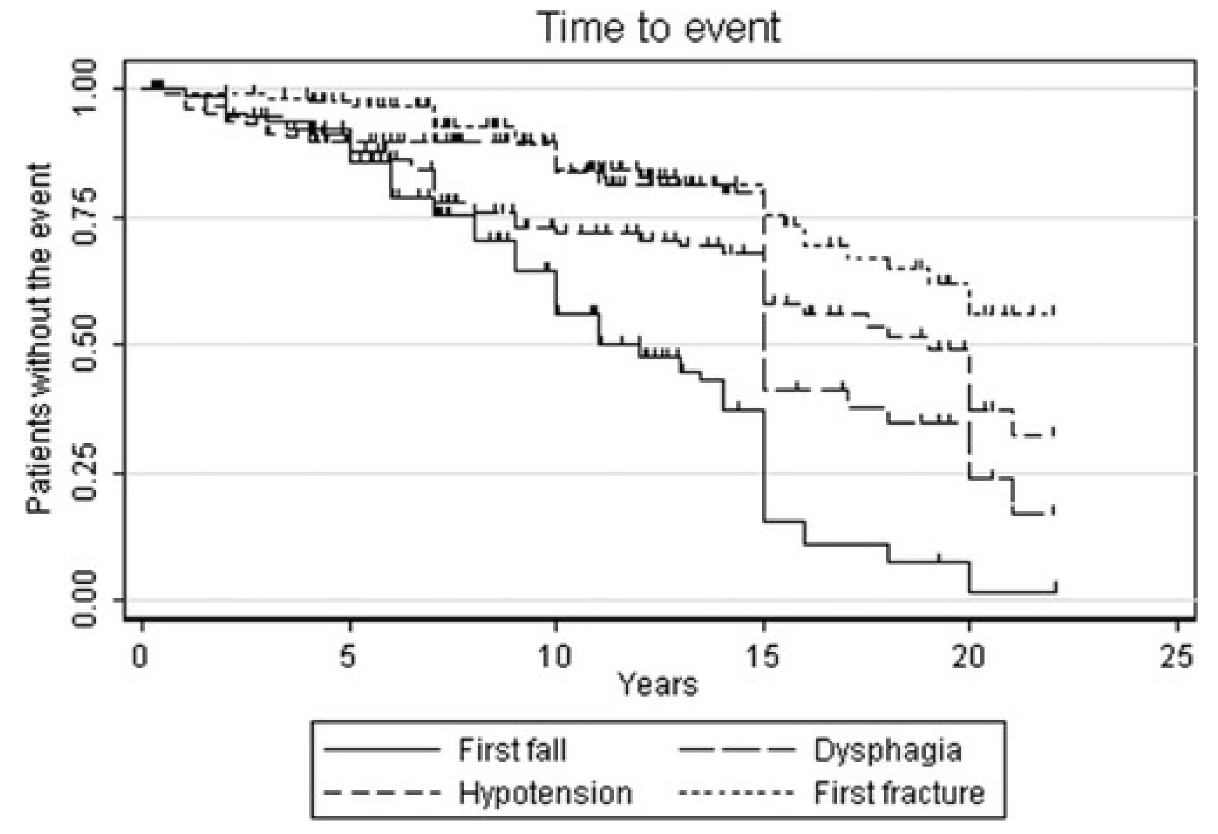

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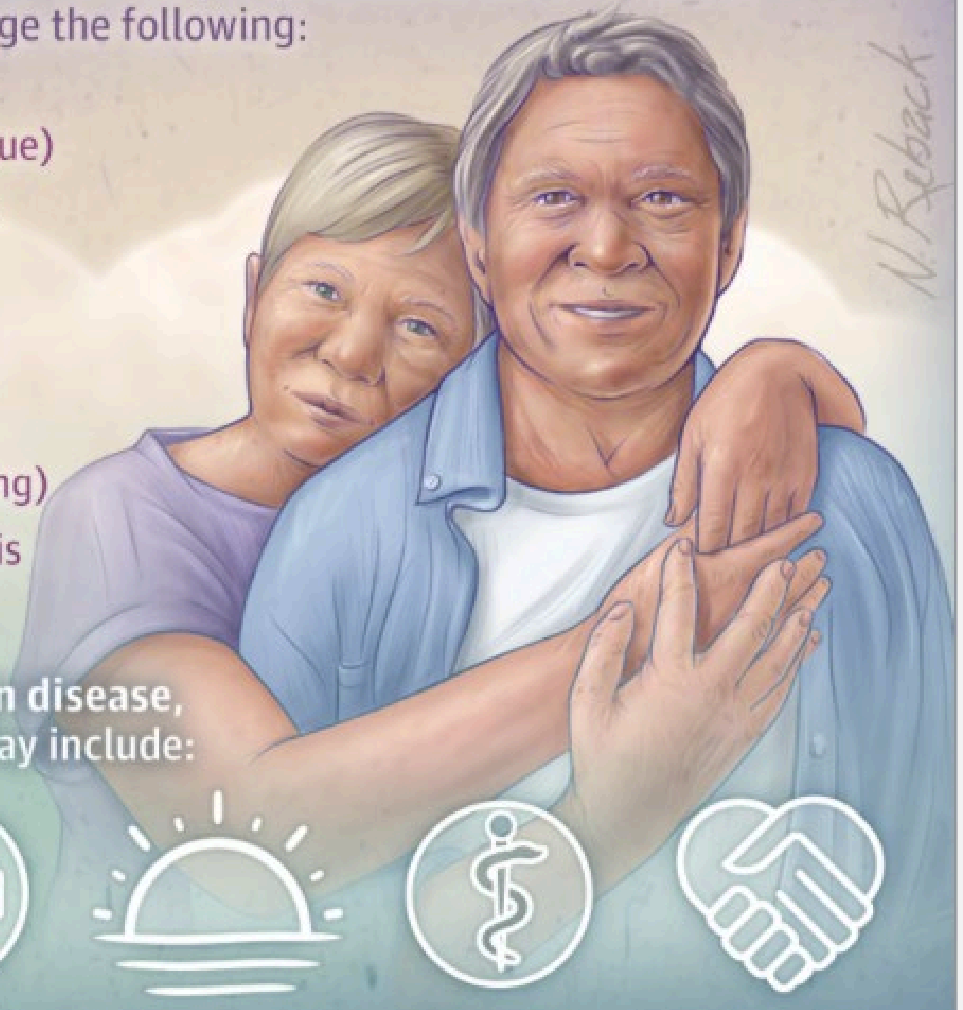
PALLIATIVE CARE IN PDRD

- Current chronic illness care model lacks addressing psychosocial and spiritual concerns; recognition and management of non-motor symptoms; advance care planning; and caregiver support
- Palliative care (PC) aims to improve quality of life (QoL) and reduce suffering in persons with serious illness by addressing medical symptoms, psycho-social issues, and advanced care planning
- PC is frequently equated with hospice care and cancer, though it is now expanding

Palliative care involves a team of professionals who work together to improve the quality of life of seriously ill patients and their families. Palliative care helps manage the following:

- Physical symptoms (pain, constipation, fatigue)
- Psychological challenges (grief, worry)
- Preparing for the future (advance care planning)
- Spiritual support (finding hope and meaning)
- Education about diagnosis (progression)



In a person with **Parkinson disease**, the palliative care team may include:

Neurologist

Nurse

Spiritual guide

Palliative physician

Social worker

WHY ISN'T PC UTILIZED MORE PDRD?

- Patients with PDRD spend less time in and are less likely to be referred to end-of-life palliative care/hospice compared with other advanced diseases
- Several studies suggest end-of-life palliative care/hospice is underused in PDRD, but estimates of use vary considerably, ranging from 0% (in a UK community sample) to 69% (in US nursing homes)
- A multinational review of death certificate data from 2008 revealed that 0% of people with PDRD in New Zealand and 4% in the USA died in hospice

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IS OUTPATIENT PALLIATIVE CARE ASSOCIATED WITH IMPROVEMENTS IN PATIENT OR CAREGIVER OUTCOMES COMPARED TO CURRENT STANDARD OF CARE AMONG PERSONS WITH PARKINSON’S DISEASE?

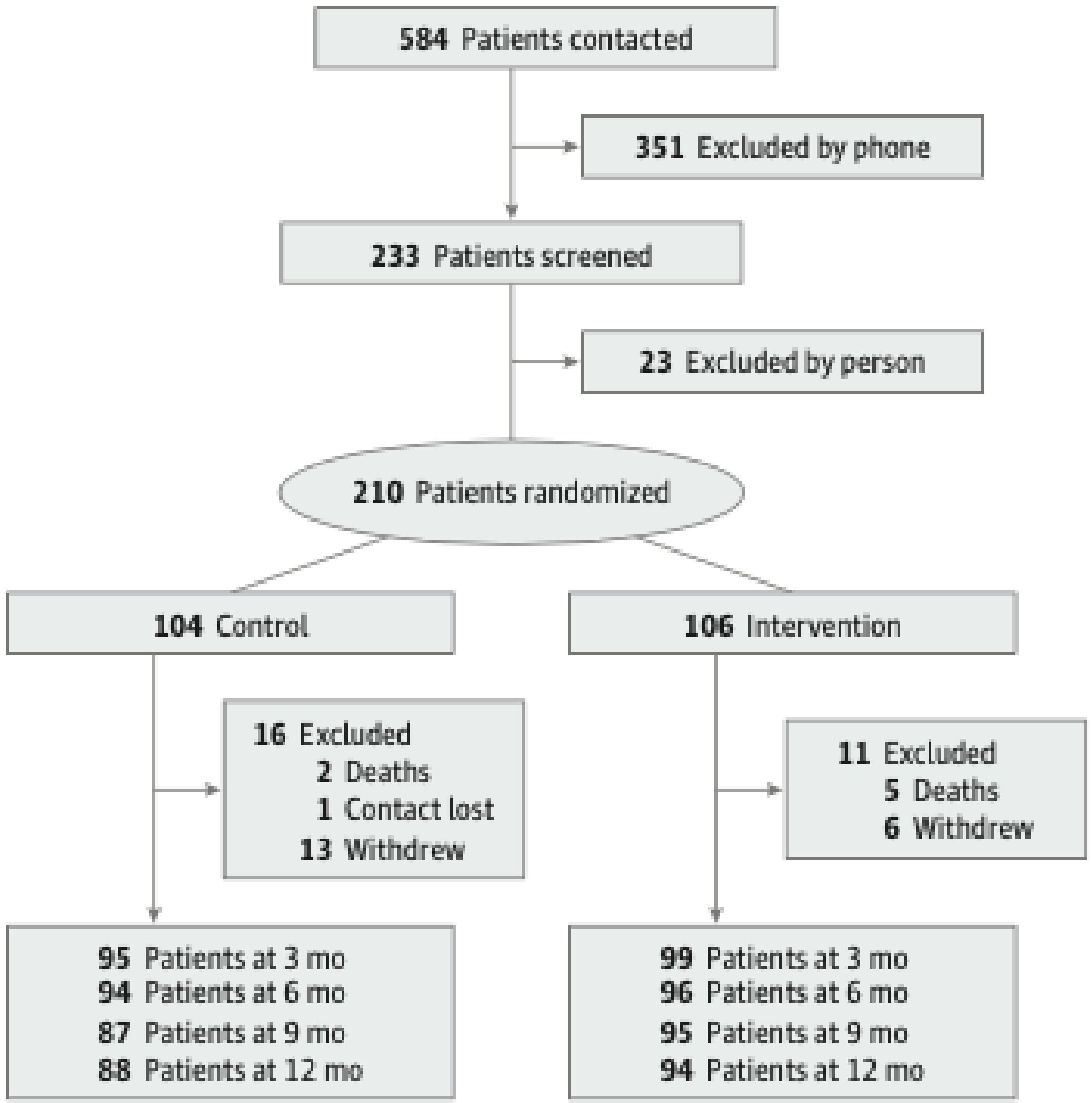
METHODS

- Patient population: Patients with PDRD + their caregivers (if available)
- Study conducted at 3 academic tertiary medical centers
- Nonblinded randomized control trial
- Participants were randomized using a 1:1 ratio and stratified by site, presence of a caregiver, and presence of dementia
- Randomized to either standard care or PC intervention

PARTICIPANTS

- In order to be eligible patients had to be:
  - were fluent in English
  - Over age 40
  - Have probable PD, had another PDRD diagnosis and had moderate to high PC needs based on the Palliative Care Needs Assessment Tool modified for PD

Figure 1. CONSORT Patient Flow Diagram



PALLIATIVE CARE NEEDS ASSESSMENT TOOL

- Focuses on 4 domains
    - Domain 1 - Physical Wellbeing
    - Domain 2 - Social and Occupational Wellbeing
    - Domain 3 - Psychosocial Wellbeing
    - Domain 4 - Spiritual Wellbeing

Section 1a: Red Flags – If present, be alert for unmet palliative care need:	**Y**	**N**
Red flag symptoms? (Persistent hallucinations / ≥2 Falls / Aspiration / Hoehn and Yahr 3 -see guidance for details)		
Admission to residential or nursing care?		
Section 1b: Priority referral for further assessment:	**Y**	**N**
No carer?		

Section 2: PATIENT WELLBEING ***(“Does the patient have……”)***	**Level of Concern**		
Who provided this information? Patient ☐ Carer ☐ Both☐	None	Some/ Potential	Significant
Unresolved physical symptoms? (Motor / Non-motor)			
Unresolved psychological or neuropsychiatric symptoms?			
Problems with daily living activities?			
Spiritual or existential concerns?			
Financial or legal concerns?			
Health beliefs, cultural or social factors making care delivery complex?			
Information needs: Prognosis ☐ Diagnosis ☐ Treatment options ☐ Financial/legal issues ☐ Support services ☐ Social/emotional issues ☐			

Section 3: ABILITY OF CARER OR FAMILY TO CARE FOR PATIENT ***(“Is the Carer / Family…….”)***			
	Level of Concern		
Who provided this information? Patient ☐ Carer ☐ Both☐	None	Some/ Potential	Significant
Distressed about the patient’s symptoms? (Motor / Non-motor / neuro-psychiatric)			
Having difficulty providing physical care?			
Having difficulty coping?			
Concerned about financial or legal issues?			
Experiencing problems that are interfering with inter-personal relationships or functioning?			
Information needs: Prognosis ☐ The diagnosis ☐ Treatment options ☐ Financial/legal issues ☐ Support services ☐ Social/emotional issues ☐			

Section 4: CARER/FAMILY WELLBEING “Carer or family experiencing……..”	**Level of Concern**		
	None	Some/ Potential	Significant
Problems that are interfering with their wellbeing or functioning?			
Grief over the impending or recent death of the patient?			

RED FLAGS – If present consider further assessment by own team +/- SPCS if required

Visual hallucinations –"yes" if hallucinations are formed and persistent. Do not include if associated with inter-current illness or medication change.
Recurrent falls –"yes" if multiple (>2) falls have occurred. Single, isolated falls, even in the context of injury, should not be included here.
Pneumonia / choking – May indicate aspiration and should trigger further palliative review in addition to SLT where appropriate.
Hoehn and Yahr stage 3 (Bilateral disease, mild to moderate disability and impaired postural reflexes) is associated with reduced quality of life.
24 hour care – admission to either residential or nursing care should trigger exploration of further supportive and palliative care needs.
Failure to attend clinic – may indicate physical or social difficulties, change in circumstance or acute admission preventing attendance.

PATIENT WELLBEING

Physical symptoms
- Fatigue, drowsiness, Pain, Constipation, Poor sleep, Urinary urgency, frequency, or incontinence, swallowing difficulty, SOB, Drooling, Spasms.

Activities of daily living
- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
- Do they require more information to maximise their daily function –see below

Neuro-psychiatric / Psychological - "Does the patient have…."
- Thinking or memory problems, which interfere with wellbeing / relationships?
- Hallucination or behavioural issues which require assistance or evidence of psychosis?
- Sustained lowering of mood, tearfulness or guilt? Loss of pleasure in usual activities? Feelings of anxiety, apprehension, anger or fearfulness?
- Is the patient struggling with the implications of, or emotional response to the diagnosis?
- Is the patient requesting a hastened death?

Spiritual/Existential – "Is the patient…."
- Feeling isolated or hopeless?
- Feeling that life has no meaning or that his/her life has been wasted?
- Having difficulty thinking about the future?
- Requiring assistance in finding appropriate spiritual resources or services?

Financial/Legal concerns
- Consider loss of income, costs of treatment, travel expenses, equipment, or future care needs (such as residential care)?
- Is the family socio-economically disadvantaged?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these (e.g. social worker)?
- Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?

Health Beliefs, Social and Cultural – "Does the patient or family…"
- Have beliefs or attitudes that make health care provision difficult – for example believing that palliative / hospice care is not available to them?
- Have communication difficulties – consider language and disease related issues (hypophonia / freezing of speech)?
- Feel socially isolated? If so are they avoiding peer support groups due to concerns such as "downward comparison"?
- Need information passed on to a particular member of the family or cultural group?
- Want information about prognosis to be withheld from the patient, or are they reluctant to discuss prognosis? If so, has this been explored?
- Have logistical difficulties accessing services (distance, transport, cost)?

Information – "Is the patient aware of/that…."
- Available services and do they need assistance accessing these? (e.g. financial /legal assistance, psychological services, support groups, pastoral care.)
- Advance Care Planning (ACP) and have their views / attitudes towards it been explored?
- PD is progressive, incurable and shortens life?
- Does the patient want more information about the course and prognosis of the disease and treatment options?

ABILITY OF CARER OR FAMILY TO CARE FOR PATIENT

Physical symptoms
- Are the patient's physical symptoms causing the carer and/or family distress?

Providing physical care
- Is the carer having difficulty coping with activities of daily living, medical regimes or practical issues such as equipment and transport?
- Have they received all the practical information they require?

Neuro-psychiatric / Psychological – "Is the carer / family…"
- Having difficulty coping with the patient's memory problems, hallucinations or behavioural issues?
- Having difficulty coping with the patient's psychological symptoms (esp. anxiety and depression)?
- Requesting a hastened death for the patient?

Family and Relationships
- Is there any communication breakdown or conflict between the patient and family over prognosis, treatment options or care giving roles?
- Is the patient particularly concerned about the impact of the illness on the carer or family?
- Is the disease having an adverse effect on the relationship between patient and carer? (May wish to consider impact of physical, psychological and personal cares, sexual dysfunction and change to previous roles within relationship.)

Information – "Do/are the carer or family…"
- Require more information about the course and prognosis of the disease and treatment?
- Aware of available services/ need assistance accessing these? (e.g. Financial/legal psychological services, support groups, pastoral care.)

STANDARD CARE VS PC INTERVENTION

- Standard care was provided by the patient’s primary care physician and a neurologist
- PC intervention: Standard care + outpatient PC
  - palliative care visits were performed in person or by telemedicine every 3 months with further supplementation at discretion of PC team
  - Team included: palliative neurologist with informal training (included workshops, providing lectures, shadowing) in PC, a nurse, social worker, and chaplain with PD experience; and a palliative medicine physician
  - Typical visit duration was 2-2.5 hours and addressed nonmotor symptoms, goals of care, anticipatory guidance, difficult emotions, and caregiver support

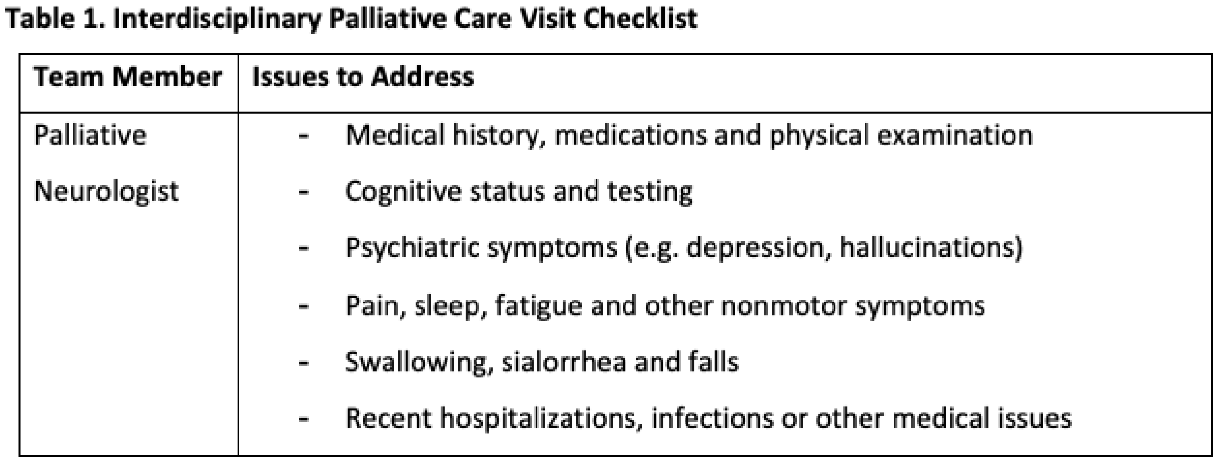
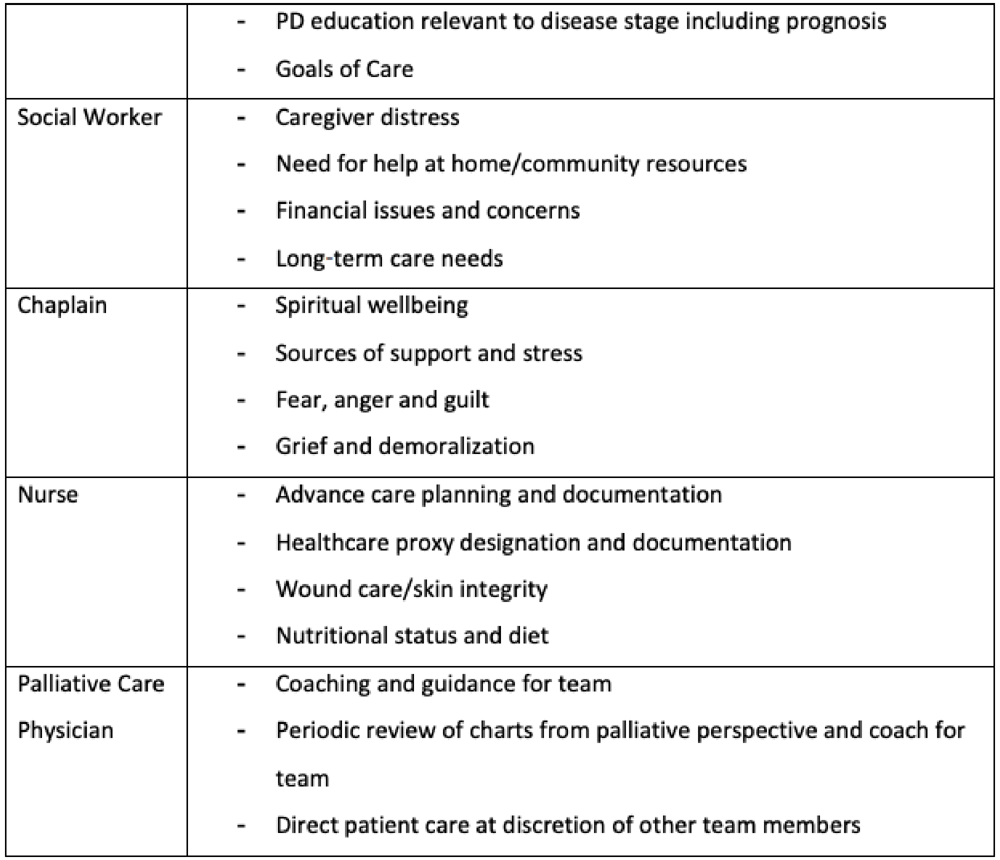


Table 1. Interdisciplinary Palliative Care Visit Checklist

Team Member	Issues to Address
Palliative Neurologist	- Medical history, medications and physical examination - Cognitive status and testing - Psychiatric symptoms (e.g. depression, hallucinations) - Pain, sleep, fatigue and other nonmotor symptoms - Swallowing, sialorrhea and falls - Recent hospitalizations, infections or other medical issues



	- PD education relevant to disease stage including prognosis - Goals of Care
Social Worker	- Caregiver distress - Need for help at home/community resources - Financial issues and concerns - Long-term care needs
Chaplain	- Spiritual wellbeing - Sources of support and stress - Fear, anger and guilt - Grief and demoralization
Nurse	- Advance care planning and documentation - Healthcare proxy designation and documentation - Wound care/skin integrity - Nutritional status and diet
Palliative Care Physician	- Coaching and guidance for team - Periodic review of charts from palliative perspective and coach for team - Direct patient care at discretion of other team members

PRIMARY OUTCOMES

- Coprimary outcomes included: change in patient quality of life and caregiver burden
- Change in patient quality of life was measured by Quality of Life in Alzheimer's Disease (QoL-AD) scale
  - 13-item scale in which patients (and caregivers, if present) rate items from poor to excellent (score range, 13-52, with 13 indicating poor QoL and 52 indicating excellent QoL)
- Caregiver burden measured using 12 item Zarit Burden Interview at 6 months
  - score range, 0-48, with 0-10 indicating no to mild caregiver burden, 11-20 indicating mild to moderate caregiver burden, and 20-48 indicating high caregiver burden)

Outcome Measure	Domain of Interest
Quality of Life Alzheimer's Disease (QOL-AD)[47]*	Patient Quality of Life (Primary Outcome)
Zarit Burden Interview (ZBI)[43] *	Caregiver Distress (co-Primary Outcome)
Edmonton Symptom Assessment Scale revised for Parkinson's disease (ESAS-PD)[48]*	Patient Overall symptom burden
Hospital Anxiety and Depression Scale (HADS)[49]*	Patient and Caregiver Mood
Parkinson Disease Questionnaire (PDQ-39)[50]*	Patient Health Related Quality of Life
Functional Assessment of Chronic Illness Therapy-Spiritual Wellbeing (FACIT-SW)[51]*	Patient and Caregiver Spiritual Wellbeing
Prolonged Grief Questionnaire (PG-12)[52]*	Patient and Caregiver grief (sense of loss)
Unified Parkinson Disease Rating Scale (UPDRS)[53]	Patient Motor symptom Severity
Semi-structured Qualitative Interview (see Table 3)*	Patient and Caregiver recommendations for optimizing services provided and delivery methods
Hospitalizations, emergency room visits, home health services, nursing home placement	Health Service Utilization Survey

RESULTS

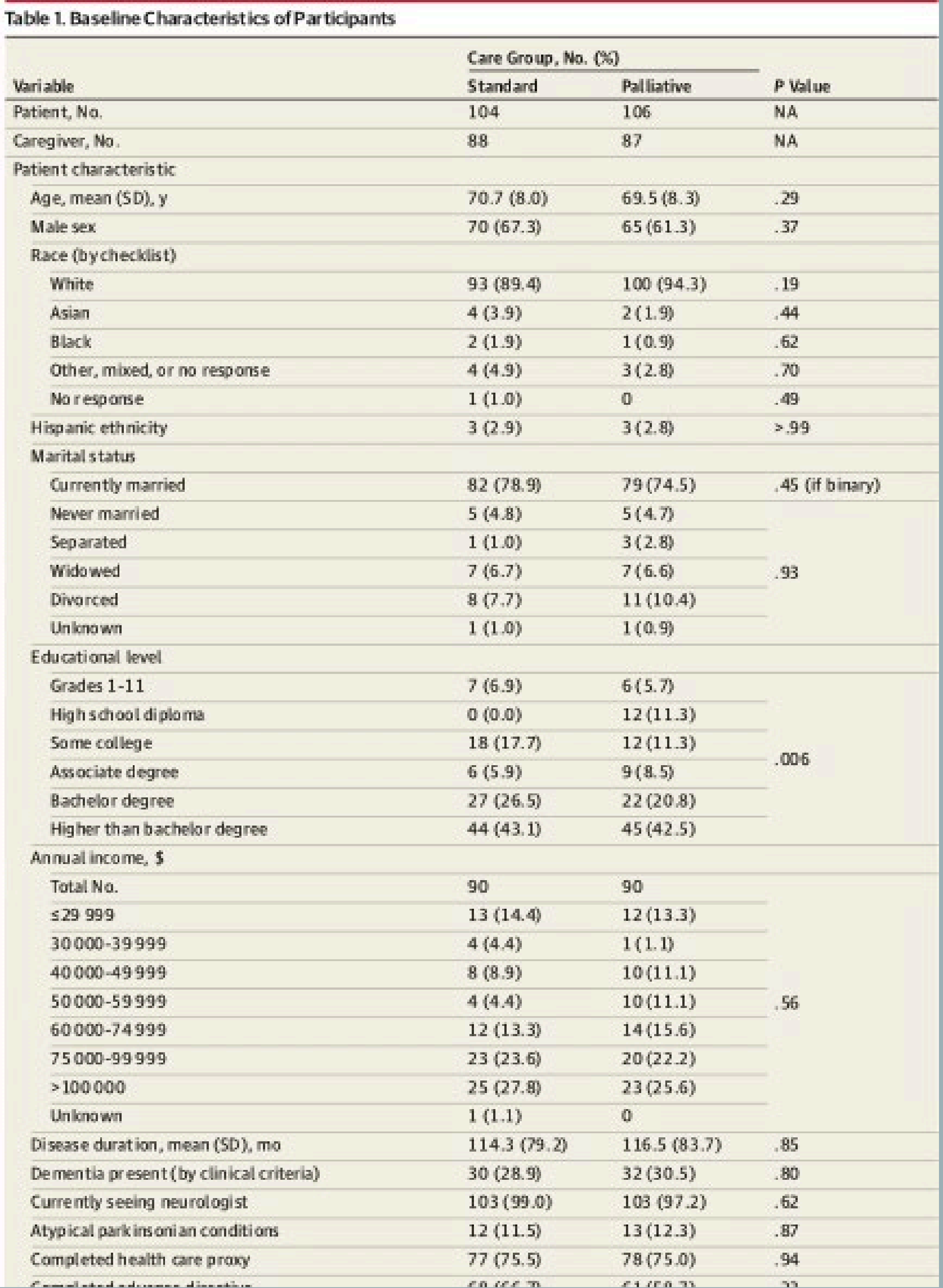


Table 1. Baseline Characteristics of Participants

Variable	Care Group, No. (%)		P Value
	Standard	Palliative	
Patient, No.	104	106	NA
Caregiver, No.	88	87	NA
Patient characteristic			
Age, mean (SD), y	70.7 (8.0)	69.5 (8.3)	.29
Male sex	70 (67.3)	65 (61.3)	.37
Race (by checklist)			
White	93 (89.4)	100 (94.3)	.19
Asian	4 (3.9)	2 (1.9)	.44
Black	2 (1.9)	1 (0.9)	.62
Other, mixed, or no response	4 (4.9)	3 (2.8)	.70
No response	1 (1.0)	0	.49
Hispanic ethnicity	3 (2.9)	3 (2.8)	>.99
Marital status			
Currently married	82 (78.9)	79 (74.5)	.45 (if binary)
Never married	5 (4.8)	5 (4.7)	.93
Separated	1 (1.0)	3 (2.8)	
Widowed	7 (6.7)	7 (6.6)	
Divorced	8 (7.7)	11 (10.4)	
Unknown	1 (1.0)	1 (0.9)	
Educational level			
Grades 1-11	7 (6.9)	6 (5.7)	.006
High school diploma	0 (0.0)	12 (11.3)	
Some college	18 (17.7)	12 (11.3)	
Associate degree	6 (5.9)	9 (8.5)	
Bachelor degree	27 (26.5)	22 (20.8)	
Higher than bachelor degree	44 (43.1)	45 (42.5)	
Annual income, $			
Total No.	90	90	
≤29 999	13 (14.4)	12 (13.3)	.56
30 000-39 999	4 (4.4)	1 (1.1)	
40 000-49 999	8 (8.9)	10 (11.1)	
50 000-59 999	4 (4.4)	10 (11.1)	
60 000-74 999	12 (13.3)	14 (15.6)	
75 000-99 999	23 (23.6)	20 (22.2)	
>100 000	25 (27.8)	23 (25.6)	
Unknown	1 (1.1)	0	
Disease duration, mean (SD), mo	114.3 (79.2)	116.5 (83.7)	.85
Dementia present (by clinical criteria)	30 (28.9)	32 (30.5)	.80
Currently seeing neurologist	103 (99.0)	103 (97.2)	.62
Atypical parkinsonian conditions	12 (11.5)	13 (12.3)	.87
Completed health care proxy	77 (75.5)	78 (75.0)	.94

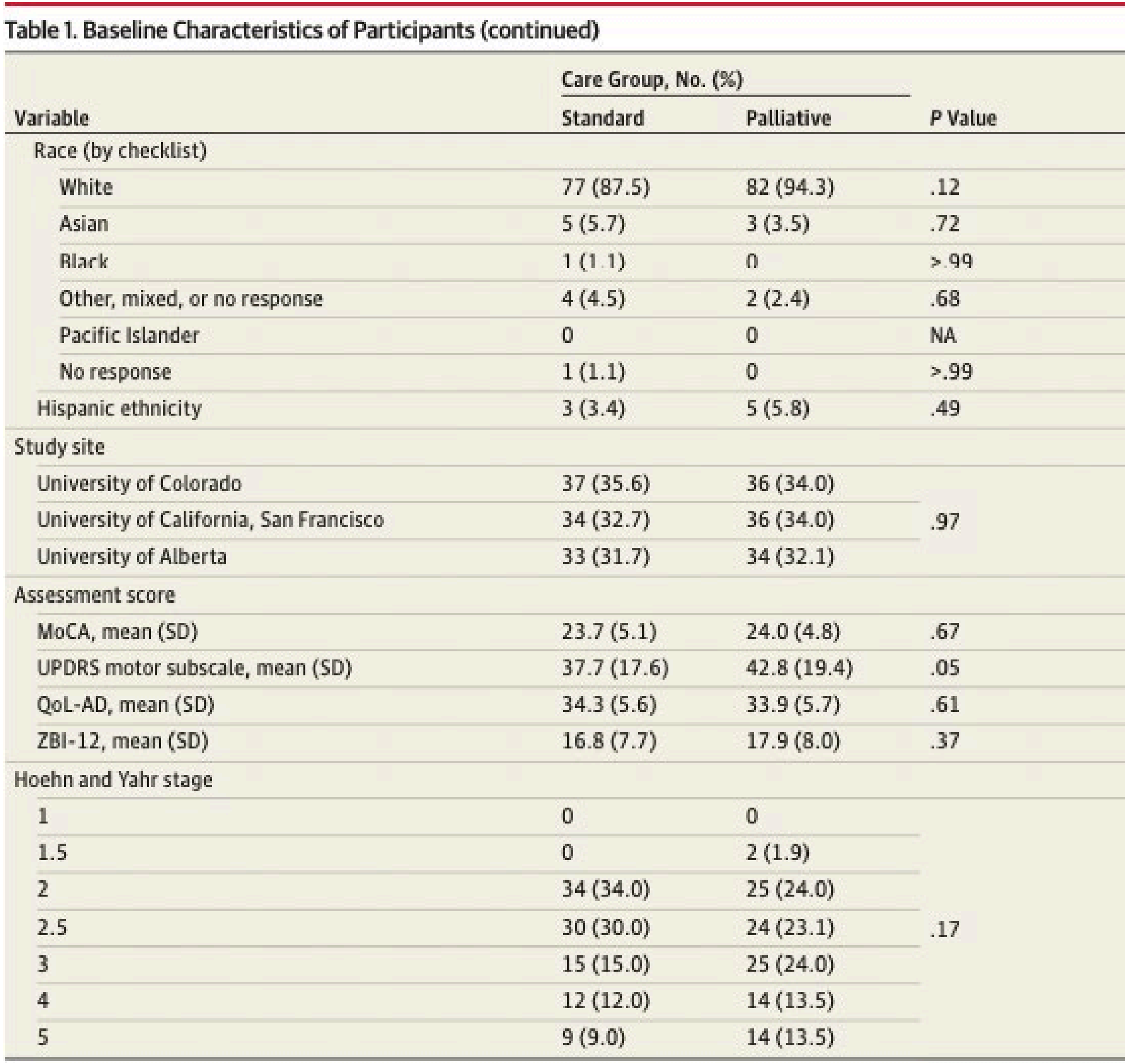


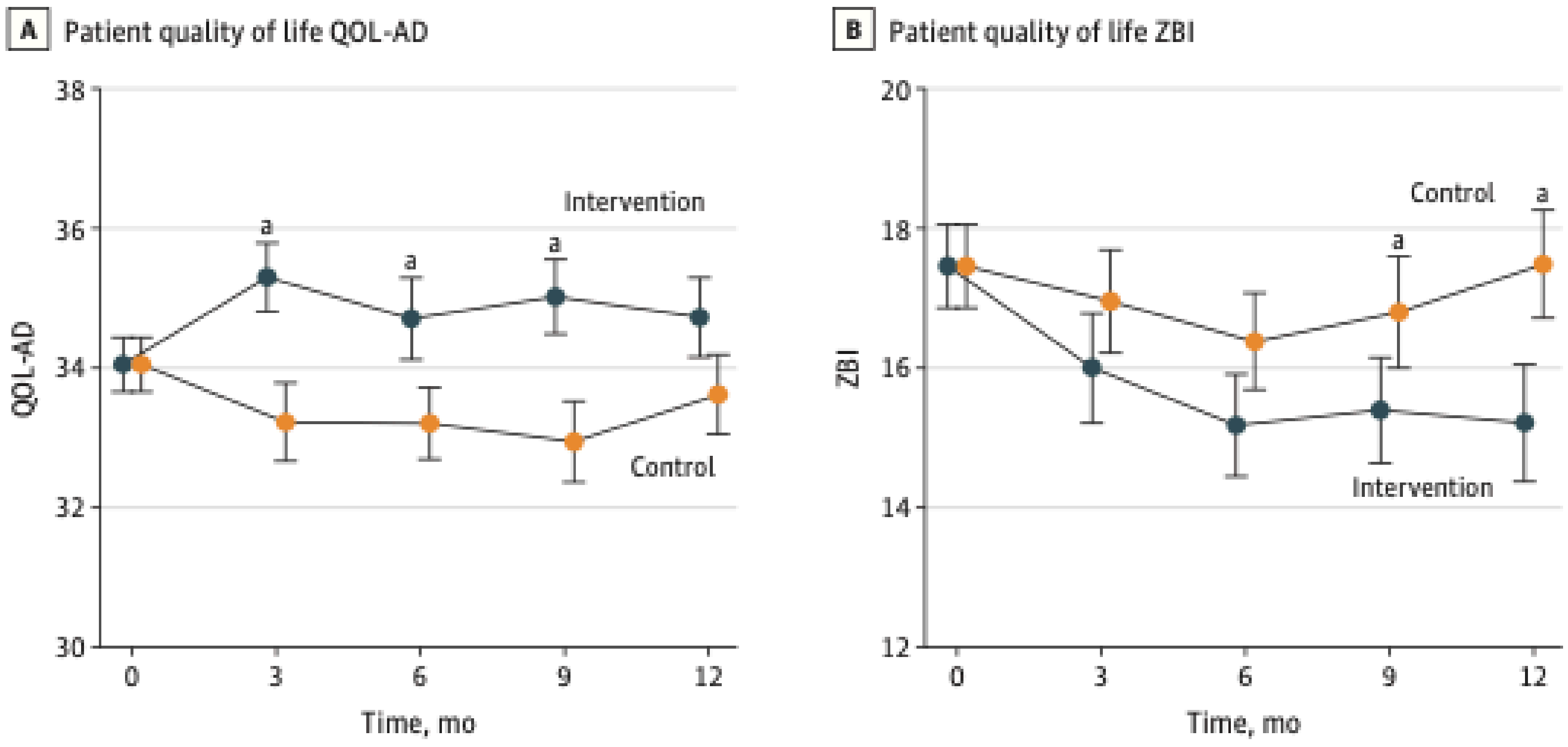
Table 1. Baseline Characteristics of Participants (continued)

Variable	Care Group, No. (%)		P Value
	Standard	Palliative	
Race (by checklist)			
White	77 (87.5)	82 (94.3)	.12
Asian	5 (5.7)	3 (3.5)	.72
Black	1 (1.1)	0	>.99
Other, mixed, or no response	4 (4.5)	2 (2.4)	.68
Pacific Islander	0	0	NA
No response	1 (1.1)	0	>.99
Hispanic ethnicity	3 (3.4)	5 (5.8)	.49
Study site			
University of Colorado	37 (35.6)	36 (34.0)	.97
University of California, San Francisco	34 (32.7)	36 (34.0)	
University of Alberta	33 (31.7)	34 (32.1)	
Assessment score			
MoCA, mean (SD)	23.7 (5.1)	24.0 (4.8)	.67
UPDRS motor subscale, mean (SD)	37.7 (17.6)	42.8 (19.4)	.05
QoL-AD, mean (SD)	34.3 (5.6)	33.9 (5.7)	.61
ZBI-12, mean (SD)	16.8 (7.7)	17.9 (8.0)	.37
Hoehn and Yahr stage			
1	0	0	.17
1.5	0	2 (1.9)	
2	34 (34.0)	25 (24.0)	
2.5	30 (30.0)	24 (23.1)	
3	15 (15.0)	25 (24.0)	
4	12 (12.0)	14 (13.5)	
5	9 (9.0)	14 (13.5)	

THINGS TO NOTE

- Predominantly male and Caucasian
- High percentage of dementia patients in both arms (28.5% in standard group vs 30.5% in PC intervention group)

Figure 2. Patient-Reported and Caregiver-Reported Outcomes



A, Patient-reported outcomes. QoL-AD indicates Quality of Life in Alzheimer Disease Scale.

B, Caregiver-reported outcomes. ZBI-12 indicates Zarit Burden Interview 12-item scale. Error bars indicate the SE.

[a] Points with significant group differences in the primary adjusted model.

Table 2. Differences in Primary and Secondary Outcomes Between Groups

Outcome Measure	Time, mo	Standard Care Group		Palliative Care Intervention Group		Difference Between Groups[a]	
		Estimate (95% CI)	*P* Value	Estimate (95% CI)	*P* Value	Estimate (95% CI)	*P* Value
QOL-AD	6	−0.84 (−1.68 to 0.01)	.05	0.66 (−0.43 to 1.75)	.23	1.87 (0.47 to 3.27)	.009[b]
	12	−0.43 (−1.37 to 0.50)	.36	0.68 (−0.38 to 0.73)	.21	1.36 (−0.01 to 2.73)	.05
QOL-AD caregiver perspective on patient	6	−1.40 (−2.38 to −0.43)	.005	2.09 (0.93 to 3.25)	<.001	2.82 (1.46 to 4.17)	<.001[b]
	12	−0.76 (−1.75 to 0.23)	.13	1.81 (0.72 to 2.90)	.001	1.93 (0.51 to 3.36)	<.001[b]
ZBI	6	−1.08 (−2.28 to 0.12)	.08	−2.28 (−3.38 to −1.18)	<.001	−1.62 (−3.32 to 0.09)	.06
	12	−0.02 (−1.32 to 1.37)	.97	−2.25 (−3.56 to −0.94)	.001	−2.60 (−4.58 to −0.61)	.01[b]
ESAS-PD	6	−0.45 (−3.86 to 2.96)	.80	−6.81 (−10.46 to −3.15)	<.001	−7.15 (−11.89 to −2.41)	.003[b]
	12	−0.73 (−4.97 to 3.51)	.73	−9.66 (−13.52 to −5.80)	<.001	−8.27 (−13.90 to −2.64)	.004[b]
PDQ-39	6	−1.20 (−3.57 to 1.18)	.23	−3.04 (−5.13 to −0.94)	.009	−2.63 (−5.72 to 0.46)	.10
	12	−0.34 (−2.66 to 1.97)	.09	−3.04 (−5.46 to −0.94)	.005	−4.05 (−7.25 to −0.84)	.01[b]
UPDRS motor score	6	2.15 (0.04 to 4.27)	.05	−2.98 (−5.79 to −0.18)	.04	−5.98 (−9.54 to −2.43)	.001[b]
	12	2.45 (−0.36 to 5.26)	.09	−1.38 (−4.78 to 2.02)	.42	−3.91 (−8.38 to 0.56)	.09
MOCA	6	−0.14 (−0.82 to 0.55)	.69	0.17 (−0.55 to 0.90)	.64	0.17 (−0.88 to 1.22)	.75
	12	−1.05 (−1.78 to −0.32)	.005	0.14 (−0.57 to 0.85)	.70	1.36 (0.34 to 2.38)	.01[b]
HADS, depression	6	−0.20 (−0.73 to 0.32)	.44	−0.34 (−0.97 to 0.30)	.29	−0.57 (−1.40 to 0.25)	.17
	12	0.12 (−0.45 to 0.69)	.66	−0.33 (−0.92 to 0.25)	.26	−0.52 (−1.33 to 0.29)	.21
HADS, anxiety	6	−0.73 (−1.35 to −0.11)	.02	−1.19 (−1.71 to −0.68)	<.001	−0.66 (−1.44 to 0.13)	.13
	12	−1.42 (−2.04 to −0.80)	<.001	−1.30 (−1.91 to −0.69)	<.001	0.12 (−0.71 to 0.95)	.78
PG-12	6	−0.68 (−2.05 to 0.68)	.32	−2.63 (−3.91 to −1.35)	<.001	−2.24 (−4.15 to −0.60)	.02
	12	−1.31 (−2.73 to 0.11)	.07	−2.61 (−3.92 to −1.31)	<.001	−1.80 (−3.75 to 0.14)	.07
FACIT-SW	6	1.10 (−0.29 to 2.49)	.12	1.17 (−0.01 to 2.35)	.05	0.71 (−1.12 to 2.55)	.44
	12	2.30 (0.76 to 3.83)	.004	0.61 (−0.83 to 2.04)	.40	−1.65 (−3.69 to 0.40)	.11
FACIT-SW, meaning	6	0.41 (−0.04 to 0.87)	.08	0.23 (−0.26 to 0.71)	.36	0.16 (−0.53 to 0.84)	.65
	12	0.61 (0.08 to 1.14)	.02	0.42 (−0.17 to 1.00)	.16	−0.00 (−0.77 to 0.77)	.99
FACIT-SW, peace	6	0.65 (0.07 to 1.23)	.03	0.57 (0.03 to 1.11)	.04	0.14 (−0.64 to 0.93)	.72
	12	1.09 (0.48 to 1.70)	.001	0.17 (−0.48 to 0.83)	.60	−0.87 (−1.71 to −0.02)	.04
FACIT-SW, faith	6	−0.00 (−0.76 to 0.76)	.99	0.36 (−0.23 to 0.94)	.23	0.50 (−0.48 to 1.48)	.32
	12	0.53 (−0.19 to 1.24)	.15	0.04 (−0.52 to 0.61)	.88	−0.54 (−1.46 to 0.38)	.25
Patient CGIC	6	−0.46 (−0.72 to −0.19)	.001	0.29 (−0.01 to 0.59)	.06	0.85 (0.44 to 1.27)	<.001[b]
	12	−0.59 (−0.87 to −0.30)	<.001	0.41 (0.08 to 0.75)	.02	1.21 (0.78 to 1.64)	<.001[b]
Caregiver HADS, depression	6	−0.20 (−0.68 to 0.29)	.42	−0.36 (−0.99 to 0.28)	.27	−0.49 (−1.32 to 0.34)	.25
	12	0.47 (−0.17 to 1.12)	.15	−0.26 (−0.85 to 0.34)	.40	−0.90 (−1.83 to 0.03)	.06
Caregiver HADS, anxiety	6	−0.52 (−1.21 to 0.16)	.13	−1.21 (−1.90 to −0.52)	.001	−1.06 (−2.11 to −0.02)	.05
	12	−0.40 (−1.13 to 0.34)	.29	−0.68 (−1.37 to 0.02)	.06	−0.43 (−1.46 to 0.61)	.42
Caregiver FACIT-SW	6	−0.27 (−1.42 to 0.89)	.65	0.68 (−0.57 to 1.94)	.28	1.48 (−0.22 to 3.18)	.09
	12	−0.90 (−2.12 to 0.31)	.14	0.42 (−0.81 to 1.66)	.50	1.79 (−0.00 to 3.59)	.05
Caregiver FACIT-SW, meaning	6	−0.05 (−0.47 to 0.38)	.83	0.03 (−0.37 to 0.42)	.90	0.19 (−0.38 to 0.76)	.51
	12	−0.41 (−0.87 to 0.05)	.08	−0.09 (−0.54 to 0.36)	.69	0.41 (−0.25 to 1.07)	.22
Caregiver FACIT-SW, peace	6	0.11 (−0.56 to 0.78)	.75	0.75 (0.15 to 1.34)	.01	1.00 (0.12 to 1.88)	.03
	12	−0.14 (−0.71 to 0.43)	.63	0.67 (0.08 to 1.27)	.03	1.06 (0.21 to 1.90)	.01[b]
Caregiver FACIT-SW, faith	6	−0.24 (−0.78 to 0.31)	.39	−0.09 (−0.74 to 0.56)	.78	0.08 (−0.83 to 0.98)	.86
	12	−0.26 (−0.95 to 0.42)	.44	−0.21 (−0.75 to 0.33)	.43	0.10 (−0.87 to 1.06)	.84
Caregiver CGIC	6	−0.75 (−1.04 to −0.46)	<.001	−0.05 (−0.41 to 0.30)	.76	0.72 (0.27 to 1.17)	.002[b]
	12	−0.81 (−1.11 to −0.50)	<.001	0.36 (−0.07 to 0.79)	.09	1.20 (0.68 to 1.72)	<.001[b]

Abbreviations: CGIC, Clinical Global Assessment of Change; ESAS-PD, Edmonton Symptom Assessment Scale–Parkinson's Disease; FACIT-SW, Functional Assessment of Chronic Illness Therapy–Spiritual Wellbeing; HADS, Hospital Anxiety and Depression Scale; MOCA, Montreal Cognitive Assessment; PG-12, Prolonged Grief 12-item scale; QOL-AD, Quality of Life Alzheimer's Disease scale; UPDRS, Unified Parkinson's Disease Rating Scale Motor Subscore; ZBI, Zarit Burden Inventory.

[a] Treatment effects and *P* values based on adjusted model.

[b] Significant under false discovery rate ($\alpha = .05$) adjustment for 44 treatment effects.

DISCUSSION

- This study showed comparative advantage to outpatient PC compared with standard care in patients with PDRD for several outcomes
- Persons randomized to receive integrated PC had better quality of life, improved symptom burden
- Integrated PC group also had higher rates and quality of advance directive completion
- Possible benefit to caregiver burden, although these results were only significant in the primary analyses at 12 months

DISCUSSION CONT.

- Global symptom burden was improved among participants in the PC intervention group
- Could this be due to systematic approach to detection of nonmotor symptoms? As nonmotor symptoms are not frequently mentioned by patients
- Reduction in symptom burden could also be due to deprescribing
- This population is heterogenous and it is possible that outcomes may not apply to all subgroups or that important outcomes for particular subgroups are missed

LIMITATIONS

- It was conducted at academic centers that had experience in providing PC for patients with PDRD but could the model be implemented in other clinical settings?
- PC intervention is time-intensive and resource-intensive. Will outpatient settings find it cost effective?
- Study could not be double-blinded, and therefore, biases may exist
- Not a diverse population
- Black box approach – how can we really tell what was effective in the PC intervention group?

QUESTIONS?

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THANK YOU!