International Parkinson and Movement Disorder Society

MDS-PAS From Guidelines to Action: Movement Disorders Care Through Regional and Multidisciplinary Collaboration



What We Should Know from the Caregiver Perspective

Prof. Maira Rozenfeld Olchik

Full Professor, PHD, SPL

FONAD
GRUPO DE PESQUISA EM FONOAUDIOLOGIA NAS DOENÇAS NEUROLÓGICAS DO ADULTO

UFRGS
UNIVERSIDADE FEDERAL DO RIO GRANDE DO SUL

HOSPITAL DE CLÍNICAS
PORTO ALEGRE RS

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Living With a Person Who Has Parkinson's Disease: The Spouse's Perspective by Stage of Disease

Julie H. Carter,[1,2] Barbara J. Stewart,[2] Patricia G. Archbold,[2] Iku Inoue,[2] Jeana Jaglin,[3] Meg Lannon,[4] Elke Rost-Ruffner,[5] Marsha Tennis,[6] Michael P. McDermott,[7] Donna Amyot,[8] Ruth Barter,[9] Lisa Cornelius,[21] Carol Demong,[10] Judith Dobson,[11] Jan Duff,[12] Judi Erickson,[13] Nita Gardiner,[7] Lisa Gauger,[19] Peggy Gray,[14] Bernice Kanigan,[15] Barbara Kiryluk,[16] Paula Lewis,[17] Kathie Mistura,[18] Teri Malapira,[19] Mary Pay,[20] Carol Sheldon,[21] Linda Winfield,[22] Kathy Wolfington-Shallow,[23] Kim Zoog,[24] and the Parkinson Study Group

Caregiver burden in PD is not new !!

brain sciences
MDPI

Article

Neuropsychiatric Symptoms in Parkinson's Disease Patients Are Associated with Reduced Health-Related Quality of Life and Increased Caregiver Burden

Hannah von Eichel [1,†], Johanne Heine [1,†], Florian Wegner [1], Sophia Rogozinski [1], Stephanie Stiel [2], Adrian Groh [3], Lea Krey [1], Günter U. Höglinger [1] and Martin Klietz [1,*]

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ELSEVIER

Factors impacting caregiver burden in Parkinson's disease: A systematic review and meta-analysis

Wilfred Wing Fung Sin [a], Lily Man Lee Chan [a], Christine Tsz Ying Ng [a], Edmond Pui Hang Choi [a], Kris Yuet Wan Lok [a], Daniel Yee Tak Fong [a], Jojo Yan Yan Kwok [a,b,*]

[a] School of Nursing, Li Ka Shing Faculty of Medicine, The University of Hong Kong, Hong Kong
[b] Centre on Behavioral Health, Department of Social Work & Social Administration, The University of Hong Kong, Hong Kong

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The Iceberg of Parkinson's Disease

Clinical medicine treats the visible. The invisible drives the burden.

Tremors
Rigidity
Motor Complications
Physical Disability

THE CLINICAL SETTING (WATERLINE)

Apathy
Agitation & Delusion
Caregiver Depression
Psychological Distress

The Narrative Shift:

We assume physical disability drives burden. However, meta-analysis of 30,000+ dyads reveals a radically different reality.

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What we HEALTH PROFESSIONALS can learn from the caregivers??

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01 Getting to know the caregiver and their story

02 The day-to-day experience of caregiving

03 The emotional impact of caregiving

04 Strategies for coping with challenges

05 Support network and relationships with healthcare professionals

06 What they can say to health professionals or other caregivers

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CASE 1:

Patient 83 Years old, 14 Years of disease
H&Y 4
Motor symptoms: rigidity, falls, physical disability.

Dementia (lost of independency)

Dysphagia

Dysarthria

KeyPoints:
Never receive support or information from health professionals





brain sciences

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Article

Neuropsychiatric Symptoms in Parkinson's Disease Patients Are Associated with Reduced Health-Related Quality of Life and Increased Caregiver Burden

Hannah von Eichel [1,†], Johanne Heine [1,†], Florian Wegner [1], Sophia Rogozinski [1], Stephanie Stiel [2], Adrian Groh [3], Lea Krey [1], Günter U. Höglinger [1] and Martin Klietz [1,*]

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FACTORS ASSOCIATED WITH BURDEN

Cognitive changes may increase the need for supervision and assistance.

COGNITIVE IMPAIRMENT

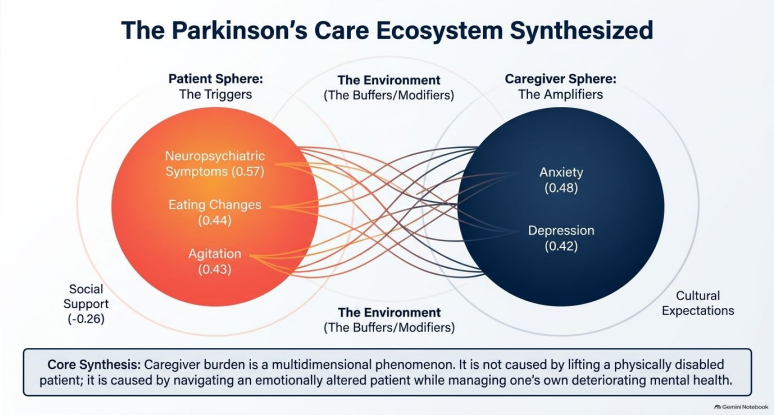
Dementia is associated with greater caregiver burden and poorer caregiver quality of life.

MILD COGNITIVE CHANGES

Mild cognitive impairment may also increase burden; the impact is not limited to dementia stages.

Consider non-motor symptoms when assessing the impact on caregivers.

- Depression and anxiety
- Hallucinations, confusion, and psychosis
- Apathy and other behavioral symptoms



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FACTORS ASSOCIATED WITH BURDEN

Caregiver burden tends to be greater when disease severity and functional disability increase.

EARLIER STAGE

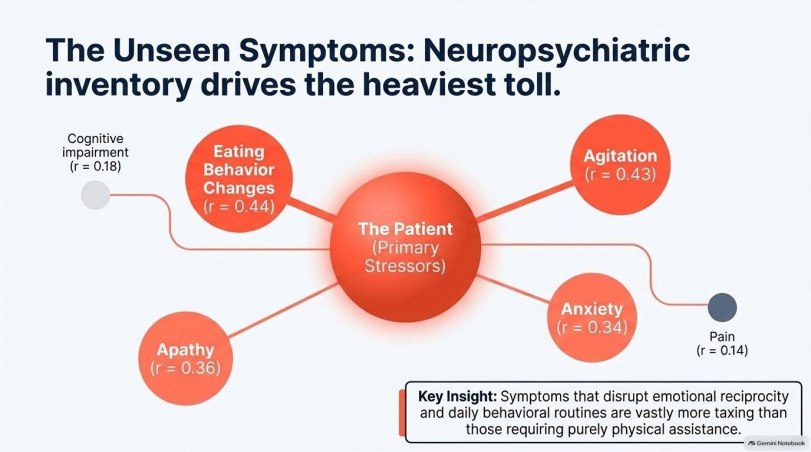
Care demands may be lower.

GREATER DISABILITY

The need for assistance increases.

ADVANCED DISEASE

Caregiver burden tends to be greater.



Motor, cognitive, and psychiatric symptoms also shape the caregiver experience.



Keypoints:
Man as a caregiver

CASE 2

Patient FEMALE
Hard time to get the right diagnosis

5 Years of disease (diagnosis)
H&Y 2
DBS – 1 year ago
Falls (had to go more than once to the hospital)

Hard time to programming DBS (change neurologist 3 times)



Listening to the caregiver perspective

THE PERSON

Who is the caregiver beyond the caregiving role? What matters in their own life?

THE EXPERIENCE

How does care shape daily routines, relationships, emotions, and well-being?

THE NEEDS

What support is available, what is missing, and what should change?

Core principle: the patient and caregiver should be considered together.

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Limited support may be associated with greater burden and exposure to daily demands.

PROTECTIVE FACTORS

WHEN SUPPORT IS LIMITED

Caregivers may face greater demands with fewer opportunities for relief.

SUPPORT RESOURCES

Family and social networks; respite breaks; psychoeducation; training; caregiver-focused interventions.

Social support may buffer caregiver burden

Support should be accessible, ongoing, and tailored to family needs.

Financial condicions



CASE 3

Patient 66

9 Years of disease

H&Y 3

Dysarthia

Dyskinisia

OVERALL HEALTH

Caregiver burden is associated with poorer health indicators.



Caregiving has an impact

CAREGIVER BURDEN

Care demands and disability may increase as Parkinson's disease progresses.

QUALITY OF LIFE

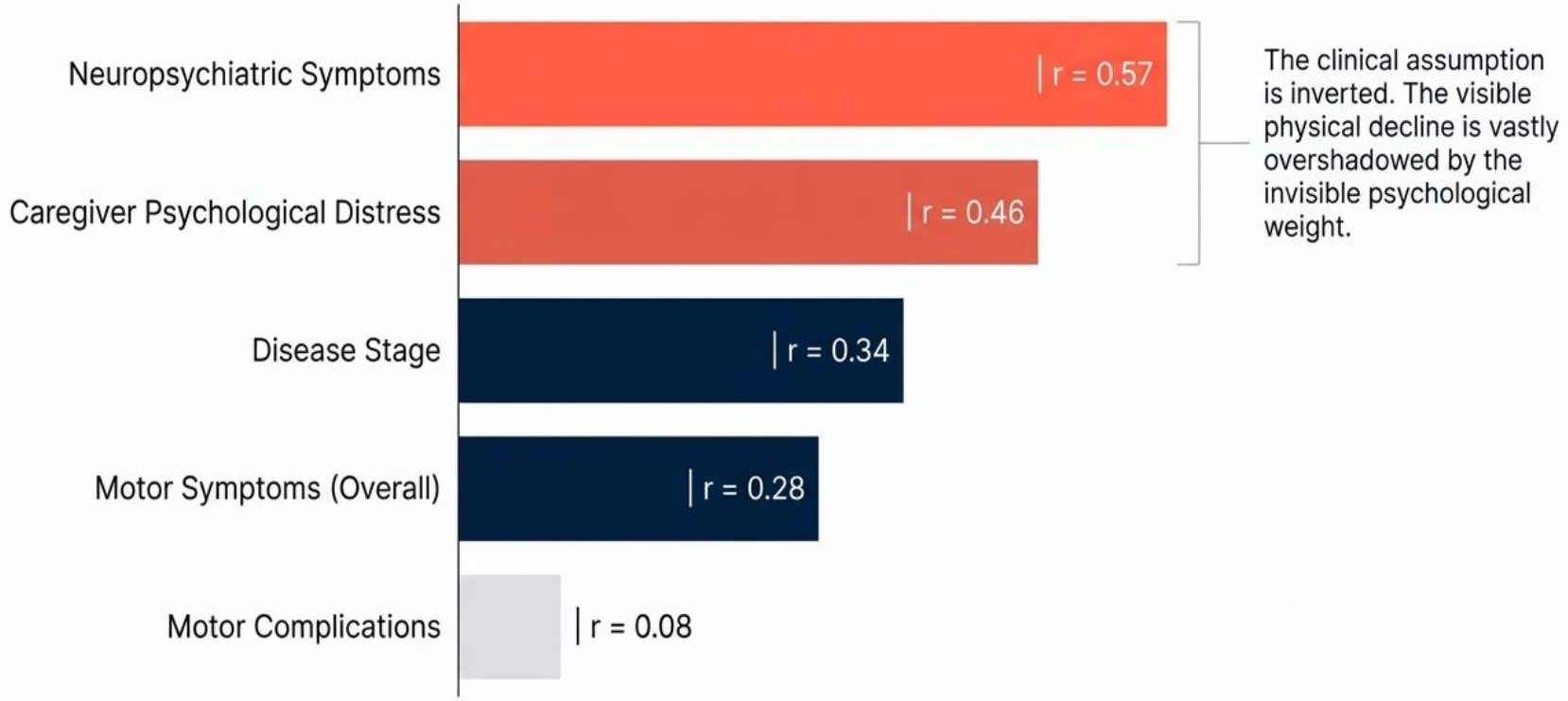
Greater burden is associated with poorer caregiver quality of life and well-being.

PSYCHOLOGICAL DISTRESS

Distress is particularly relevant alongside motor, cognitive, and neuropsychiatric symptoms.



The 'Mind Over Motor' Revelation: Psychological factors dominate caregiver burden.



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Caregiver-focused interventions

The evidence identifies useful or promising approaches; responses may vary across caregivers.

Psychoeducation

Information and guidance about Parkinson's disease and caregiving.

Training

Skills for specific caregiving demands.

Cognitive behavioral therapy

A promising approach to distress and burden.

Respite and social support

Reduce continuous demands and strengthen resources.

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Navigating Caregiver Burden in Parkinson's Disease

Caregiver burden in Parkinson's disease increases significantly as motor disability, cognitive decline, and neuropsychiatric symptoms worsen in patients. Addressing caregiver well-being requires a dual approach combining routine screening, structured training, psychological support, and social resources alongside patient care.

Primary Drivers of Caregiver Burden



Disease Severity & Cognitive Decline

Advanced motor impairment and dementia are leading predictors of increased caregiver strain.



Patient Neuropsychiatric Symptoms

Depression, anxiety, psychosis, and hallucinations significantly heighten caregiver psychological distress.



Caregiver Mental Health & Isolation

Pre-existing caregiver distress and lack of social support further exacerbate overall burden.

Evidence-Based Support & Interventions

Integrated Dual Care Model

Effective interventions simultaneously target patient symptom management and caregiver mental health.



Routine Screening & Assessment

Clinical care should systematically screen caregivers for depression, strain, and coping capacity.





Targeted Education & CBT

Psychoeducation, cognitive behavioral therapy, and skills training effectively reduce caregiver strain.

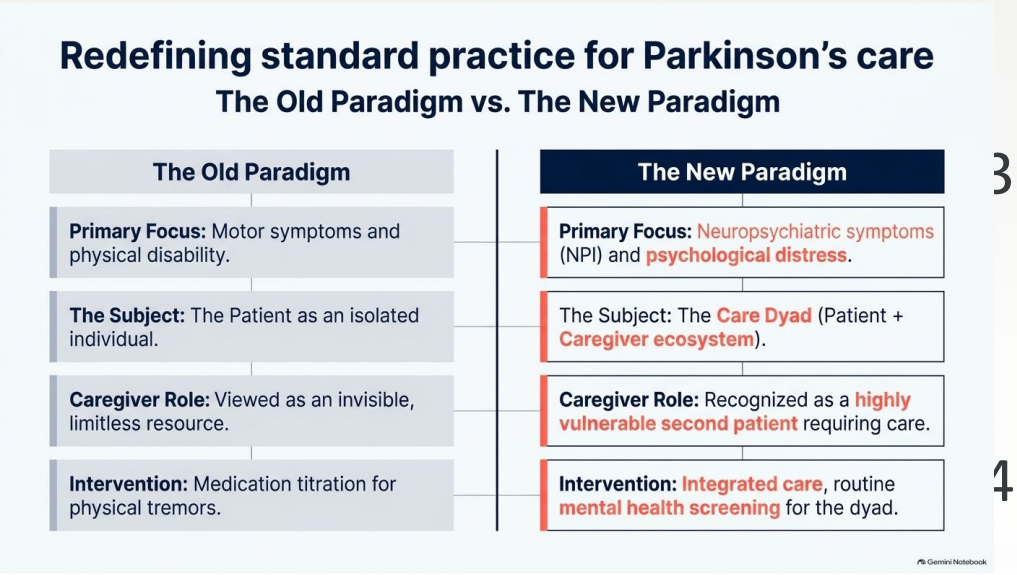
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The patient and caregiver should be considered together.



1. Routinely screen for caregiver burden and distress.
2. Recognize caregiver health and well-being as part of comprehensive care.
3. Assess the patient's motor, cognitive, and neuropsychiatric symptoms.
4. Integrate caregiver support into the management of patient



Recommendations for practice

Translate evidence into an individualized understanding of family needs.

- Routinely screen for caregiver burden and distress.
- Assess the patient's motor, cognitive, and neuropsychiatric symptoms.
- Prioritize families facing advanced disease, cognitive impairment, or psychosis.
- Integrate caregiver support into the management of patient symptoms.
- Recognize caregiver health and well-being as part of comprehensive care.

Redefining standard practice for Parkinson's care

The Old Paradigm vs. The New Paradigm

The Old Paradigm	The New Paradigm
Primary Focus: Motor symptoms and physical disability.	**Primary Focus:** Neuropsychiatric symptoms (NPI) and **psychological distress**.
The Subject: The Patient as an isolated individual.	The Subject: The **Care Dyad** (Patient + **Caregiver ecosystem**).
Caregiver Role: Viewed as an invisible, limitless resource.	**Caregiver Role:** Recognized as a **highly vulnerable second patient** requiring care.
Intervention: Medication titration for physical tremors.	**Intervention:** **Integrated care**, routine **mental health screening** for the dyad.

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The patient and caregiver should be considered together.



References

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Thank you!!

Contact: molchik@hcpa.edu.br