

Palliative Care for Parkinson's Disease

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Objectives

- To describe the end-of-life needs of Parkinson's disease patients and their caregivers
- Describe translations of these findings into quality clinical care for people with Parkinson's Disease
- Understand implications for multidisciplinary involvement in PD palliative care (Nutrition, PT, OT, ENT, Speech Therapy, Psychiatry, Psychology)



Definition of Palliative Care

- Support of people with life-limiting illness as they live, until they die.
 - Physical symptom control
 - Avoid iatrogenic effects of treatment
 - Prevent pressure sores, falls
 - Quality of life
 - Dignity
 - Relieve fear, anxiety, depression
 - Caregiver support

The clinical characteristics of PD create challenges to good palliative care

- Parkinson's Disease (PD) is a progressive neurodegenerative disorder
 - Loss of cells from substantia nigra, Lewy body inclusions
 - After ~ 5-10 years dyskinesias, neuropsychiatric problems, increasingly poor response to drug treatments, ongoing or worsening depression.
 - Slower progression for early onset, more rapid for older adults.
 - Average length of life with PD 14.6 (\pm 9.8) years since advent of levodopa*

*MacMahon, 1999

Recognizing When to Transition to a Palliative Approach

- Increasing motor disability with poor response to medication/surgical intervention
- Persistent hallucinations in the absence of drugs that could cause hallucinations
- Dementia, where risk of cognitive compromise outweighs motor benefits of dopaminergics

Negotiating the Transition

- Understand individual preferences for information
- Frequent discussions with patients and family/caregivers
 - Who should initiate these discussions?
 - Multidisciplinary approach could be helpful
- Communicate known limitations of treatment (e.g. drugs will not prevent falls, DBS may not be appropriate intervention in context of significant neuropsychiatric symptoms/ dementia)

Do people die from PD?

- Often not cited on death certificates, neurology textbooks equivocal
- PD was the 14th leading cause of death in the U.S. in 2006 per CDC
- Common cited causes for PD patients include:
 - Fractures, complications from falls
 - Chest and urinary infections
 - Immobility
 - Exhaustion/weight loss
- Goy, Carter, & Ganzini reported (Neurology 2007) on 47 caregivers who described PD as primary cause of death.

Hospice Referral

- MD verifies six months or less remaining lifespan
- No further curative treatment
- Palliative approaches to symptom management, comfort care

Appropriate Hospice Referral

- Significant dysphagia occurs an average 15-24 months before death¹
- Serious neuropsychiatric problems²
 - Hallucinations
 - Confusion
 - Dementia
- PD medications significantly reduced³ due to altered risk/benefit profile
- Weight loss³ – secondary to reduced intake and dyskinesia

¹Miller et al., Arch Neurol 2001;58:259-264; ²Clough & Blockley in Palliative Care Neurology, Voltz et al., eds., 2004; ³Goy, in preparation

End-of-life needs of Parkinson's disease patients and caregivers

Lissa Brod, MD



Motor Complications of Late Stage PD (Hoehn-Yahr Stage 5)

- Freezing
- Rigidity
- Dyskinesia
- Dysarthria
- Dysphagia
- Respiratory problems
- Less response to dopaminergic medicines
- Pain



Nonmotor Complications of Late Stage PD (Hoehn-Yahr Stage 5)

- Cognitive slowing
- Dementia – 40% develop in late stages
- Psychosis/hallucinations
- Depression, anxiety
- Dysregulation of blood pressure
- Dysregulation of bowel/bladder - constipation
- Sleep disturbance

Patient suffering in PD

- Severity of suffering 4 (out of 5) in both Parkinson's disease and related disorders (PDRD) and ALS in the last month of life
 - Difficulty communicating, physical discomfort, insomnia, choking, depression, anxiety, pain
 - Difficulty eating, dyspnea worse in ALS
 - Confusion worse in PDRD

Patient suffering in PD

- Most common concerns in last month, per caregivers: being away from home (9), loss of mobility (7), trouble communicating (7), saying goodbye (7), dying process (confronting death, stopping treatment) (6), loss of independence/control (5).
- Most common concerns in last days/hours, per caregivers: inability to communicate (14), loss of mobility (9), saying goodbye (8), being away from home (6), loss of independence/control (6), confusion (6).



Table 1. Caregiver Ratings of PDRD (N = 52) Patient Symptoms in the Final Month of Life

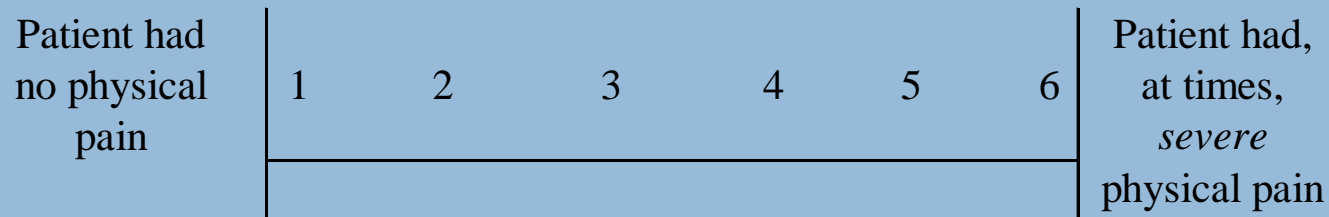
Symptoms	Frequency* (Median, IQR)	N (%) Rated Symptom Moderate or Severe	N (%) Rated Symptom “Quite a Bit,” or “Very Much” Bothersome
Difficulty Eating	3 (2,4)	34 (65)	23 (44)
Difficulty Communicating	3 (2,4)	37 (71)	32 (62)
Physical Discomfort	3 (2,3)	33 (63)	19 (37)
Insomnia	2 (1,3)	22 (42)	16 (31)
Shortness of Breath	2 (1,3)	24 (46)	15 (29)
Choking	2 (1,3)	22 (42)	18 (35)
Confusion	3 (2,4)	32 (62)	22 (42)
Depressed Mood	3 (1,3)	28 (54)	17 (33)
Anxiety	2 (1,3)	28 (54)	18 (35)

* 1 = never, 2 = a few times, 3 = frequently, 4 = almost all the time, 5 = constantly.



Pain in PD

- Musculoskeletal causes
 - Immobility
 - Muscle spasms
- Motor complications
 - Limb rigidity
 - Dystonia
- Nonmotor complications
- Altered nociception from the basal ganglia



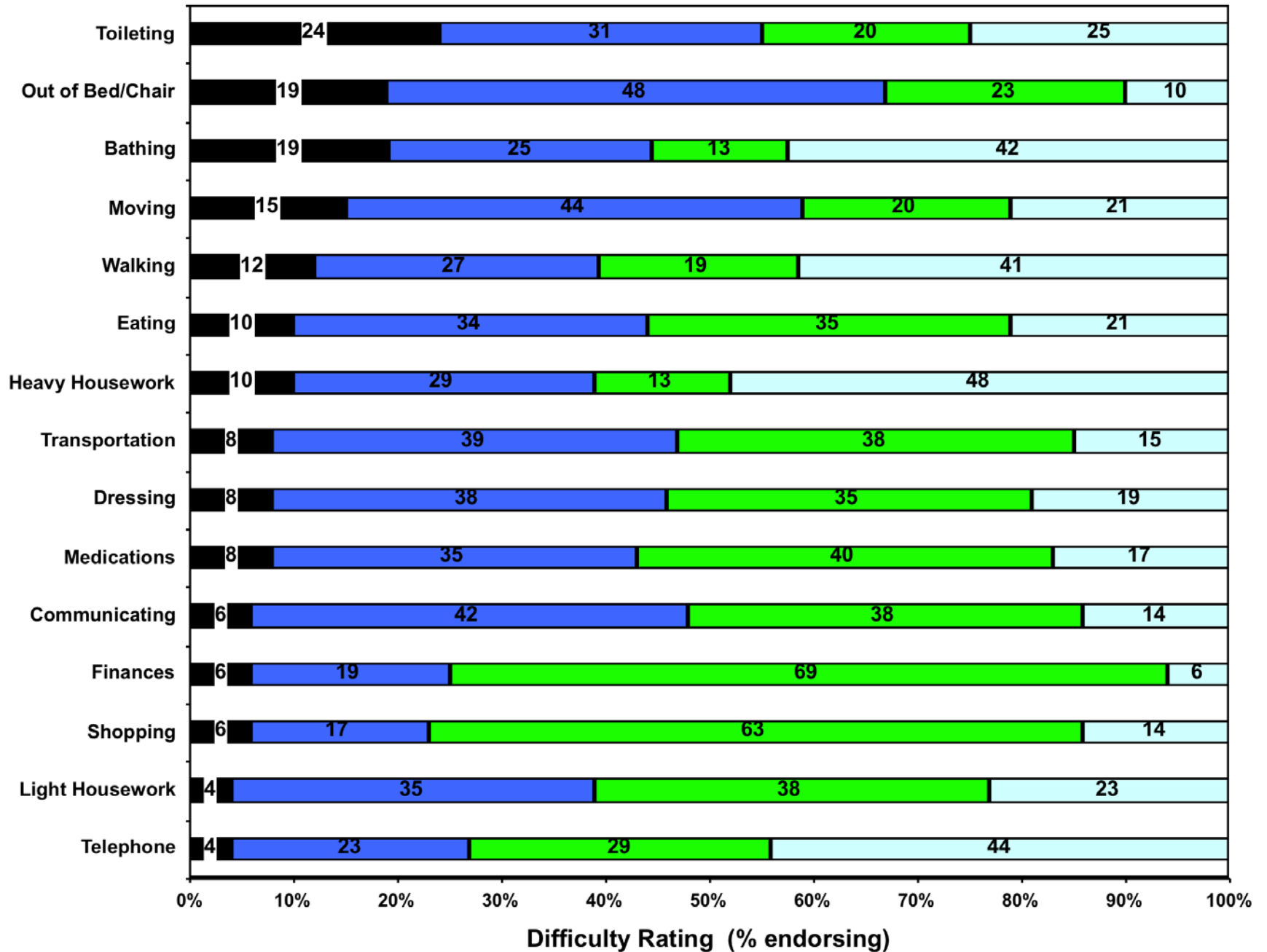
- Median Severity = 4
- 42% (n = 20) rated pain as severe (4-6)
- Of those, 30% (n = 6) received NO pain medication in the last month of life



Caregiver Assistance to Loved One

- Assisted with a mean of 13 possible activities of living in the last months of life, a mean of 6 hours per day.
- Tasks requiring physical effort were rated the most difficult.
- One third or more of respondents did not feel prepared to cope with the stress of caregiving, with the patient's physical needs, or with emergencies.
- High incidence of depression in PD caregivers (46%). No significant difference from ALS caregivers.

Activity



legend

■ Very hard

■ Somewhat-Pretty hard

■ Easy-Not too hard

□ Not done



Long Term Care

- 40% of PDRD patients died while in a skilled nursing or other long term care facility; only one in four died at home.
- 17% of PDRD residents of long term care facilities died without any significant family or friends in attendance, while all who remained at home had at least one significant person with them ($p = .006$).



Goals of Care

- 15% of PDRD caregivers were unable to state loved one's goals of care.
- 48% of the patients were described as unable to make any decisions in the last month of life.
- Caregivers rated less satisfaction with answers received from health care professionals as patient confusion increased in frequency, patients had greater impairment of decision-making ability during the last month of life, and as a trend, when communication problems were increasingly severe.



Goals of Care

- 87% had a health care proxy and 92% had a living will.
- 79% wanted comfort care, 6% life-prolonging.
 - CPR was not performed on any patient,
 - 26% were fed by tube and
 - 30% received some type of breathing support.
- Most (74%) felt wishes regarding medical treatments were followed.

Goals of Care

- When should providers discuss this?
 - Supporting hope vs realistic planning
 - Prognostic uncertainty



Services, Treatments during Final Month

- Fifty-six percent of PDRD caregivers reported that their loved one received hospice care, for a median of three weeks
 - More likely to receive pain medication in hospice.



Hospice

- Satisfaction with hospice care was at the top of the ranking for satisfaction with health care (24 of the 29 who received hospice were satisfied or very satisfied).
- Among the patients enrolled in hospice, increasing severity of complicated grief was correlated with satisfaction with hospice ($p = .002$).
- Increasing satisfaction with information provided about symptom management was associated with greater satisfaction with hospice services ($p < .01$).

What Would the Ideal Palliative Care Clinic Look Like for Parkinson's Disease?

Teresa Mangin, MD

Challenges Addressed by a Palliative Approach

- Unrealistic expectations on the part of patients and caregivers
- Caregiver burden
- Existential suffering
- Pain
- Psychosis
- Dysphagia and nutrition
- Communication problems
- Constipation
- Medication management

Members of the Ideal Palliative Care Team

- The patient
- Caregivers and families
- Nurse
- Social Worker
- Physicians – neurologist, palliative care specialist, psychiatrist, others
- Speech therapist
- Physical and occupational therapists
- Psychologist
- Nutritionist
- Chaplain



Unrealistic Expectations

- Breaking the news that PD may result in death
- Helping families plan for inevitable decline in function
- Teaching the limits of medications and their specific roles
 - Tension between motor and cognitive function

Caregiver Burden

- Screening for caregiver strain or burden in clinic
- Providing support
 - Asking about this at each visit
 - Peer support over the phone if unable to leave pt
- Facilitating home help, both formal and informal
- Day programs for patient
- Offering programs geared toward caregivers (cognitive behavioral therapy, support groups)



Existential Suffering

- “a perceived threat to the integrity of the self, helplessness in the face of that threat, and exhaustion of psychosocial and personal resources for coping” -EJ Cassell
- Expressed by patients as feelings of hopelessness, futility, meaninglessness, remorse, death anxiety
- Leads to suffering and frustration on the part of the family



Existential Suffering: Some Truths

- This is normal and need not be totally controlled.
- There is no effective drug therapy.
- It leads to frustration in families and providers.
- Recognition of the factors involved in the individual patient helps to understand how to meet their needs.
- Relieving the suffering of the patient helps caregivers and providers.
- There is a distinction between fear of the dying process and fear of being dead.



Existential Suffering

- Treatment of attendant symptoms of pain, anxiety, depression, etc.
- Acceptance commitment therapy (ACT)
 - Branch of cognitive behavioral therapy
 - Incorporates mindfulness, acceptance, commitment and behavior change strategies to improve psychological flexibility
- Preserving patients' dignity



Pain

- Fear of pain is a common source of distress.
 - Relief of pain may take precedence over prolongation of life.
 - Reassure patient that his/her wishes will be honored and that pain will be controlled.
 - Identify and address fear of pain medications.
- Pressure sores
- Dystonic pain
 - May consider botulinum toxin injections
- Musculoskeletal pain
 - ROM exercises
- Ideally, have a pain management specialist in clinic with the neurologist.
 - Toronto Western Hospital



Management of Psychosis

- Streamlining medication regimen
- Reduction of dopaminergic medications
- Communicating with care facilities about preferred medications in PD
- Do not be afraid of clozapine!
- Psychiatry referral

Dysphagia

- ENT speech therapy for modified barium swallow
- Rehab speech therapy for teaching management strategies (chin tuck)
- Clarifying patient's wishes if swallowing is unsafe
- Discussion of and referral for G-tube if necessary and desired
- Nutrition consult

Communication Problems

- Often multifactorial in nature due to hypophonia, cognitive problems, bradyphrenia
- Lee Silverman Voice Therapy
- Enlisting speech therapist for communication board, other tools
- Allowing sufficient time for patient to respond

Medication Management

- Identifying priorities with respect to medication
- Simplifying regimen
- Eliminating medications that can contribute to cognitive side effects
- Educating about role of various medications (including those that are relatively contraindicated in PD)
- Strategies for medication reminders

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