



Living as Well as Possible for as Long as Possible: What is Palliative Care in Parkinson's?

*Benzi Kluger, MD, MS
University of Rochester, NY, USA*

Better Lives. Together.

Disclosures



- I have received support for this work from:
- The University of Colorado Hospital Clinical Effectiveness and Patient Safety Grants Program
 - The Veterans Affairs Medical Center Clinical Research to Improve Care Coordination Grants Program
 - National Institute on Aging (K07AG030337; K02AG062745)
 - Parkinson Disease Foundation Conference Grants
 - Patient Centered Outcomes Research Institute (IHS-1408-20134; DI-2019C2-17499)
 - National Institute on Nursing Research/National Institutes of Aging (R01NR016037)

Better Lives. Together.

Outline



- I. Define palliative care, neuropalliative care and hospice.
- II. Identify palliative care needs in Parkinson's disease (PD).
- III. Understand how palliative care can improve outcomes for people with PD and their families.
- IV. Discuss strategies that people with PD and their families can use to access palliative care.

Better Lives. Together.

I. Defining Palliative Care



“Palliative care is about living as well as possible for as long as possible.”

- Steve Pantilat, MD

Better Lives. Together.

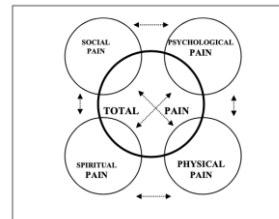
Palliative care was designed to address gaps in our care for persons with serious illness.



- Enhances quality of life
- Offers support to help patients live as actively as possible
- Offers support to family
- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process,
- Addresses psychosocial and spiritual issues
- Is applicable early in the course of illness and in conjunction with therapies intended to prolong life (or function)

Better Lives. Together.

Palliative care agrees that having PD sucks!



Better Lives. Together.

Palliative Care is an approach to addressing suffering.



- Open, honest and compassionate communication
- Develop a roadmap for the future
- Work to manage difficult symptoms such as pain, fatigue and depression
- Provide support around difficult emotions such as grief, worry and guilt
- Promote spiritual wellbeing and work with spiritual challenges such as loss of hope or meaning
- Provide practical support for patients and families in navigating medical systems and home care
- Ensure dignity and comfort, particularly near end of life

Better Lives. Together.

Palliative care is:



- An approach and philosophy of care
- A skillset
- A specialty
- A public health goal

Better Lives. Together.

Palliative Care complements Standard Chronic Care



Chronic Care	Palliative Care
Focuses on disease-related medical symptoms	Focuses on the <i>total pain</i> of serious illness (physical, psychosocial, spiritual, and practical challenges)
Focuses on improving physical health	Focuses on improving overall well-being and reducing suffering
Prolongs life	Affirms & values life, while planning for the inevitable decline of health & end to life.
Focuses on patient	Focuses on person living with illness and their family
Variable use of team approach	Frequent use of interdisciplinary team approach

Better Lives. Together.

The 3-legged Stool



1. Palliative care specialists
2. Community and disease support organizations
3. Primary care providers and non-palliative specialists (e.g. neurologists)



- Kirk Hall

Better Lives. Together.

What is hospice?



Specialized palliative care for persons with a terminal diagnosis (6-month life expectancy)
 Goals are to maximize comfort and time with family and to avoid medical procedures and hospitals
 Hospice includes medical, social and spiritual support
 Hospice is covered by Medicare and all insurances

Better Lives. Together.

II. Palliative Care Needs in Parkinson's Disease



Better Lives. Together.

Palliative needs begin with diagnosis....



Dropping the Bomb: The Experience of Being Diagnosed with Parkinson's Disease

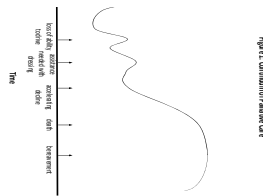
Lorraine J. Phillips, MSN, RN, FNP

This qualitative descriptive study examined the advice people with Parkinson's disease have for someone newly diagnosed. Qualitative content analysis of interview data from 11 persons with Parkinson's resulted in 1 major theme: "Dropping the Bomb." This theme signified sorting through the rubble

and turmoil—relief related to naming the responsible entity and fear related to an ominous forecast for the future.¹⁰ Because the impact of PD on one's life is all-encompassing, understanding the processes people with PD have used to navigate life within the context of this debilitating disease may help others to do the

Better Lives. Together.

...rise and fall throughout the illness journey...



Palliative medicine and end-of-life care. Glover TL, Kluger BM. *Handb Clin Neurol*. 2019;167:545-561.

Better Lives. Together.

...and must include end of life care.



OPEN ACCESS Review

Prognostic predictors relevant to end-of-life palliative care in Parkinson's disease and related disorders: a systematic review

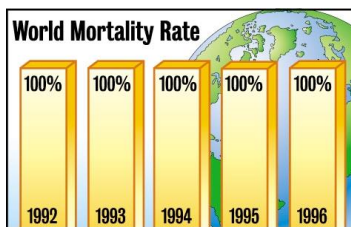
Umer Akbar¹, Robert Brett McQueen,² Julienne Bemsik,² Julie Carter,² Elizabeth R Goy,³ Jean Kutney,⁴ Miriam J Johnson,⁵ Janis M Miyasaki,⁶ Bernd Kluger⁶

ABSTRACT
Parkinson's disease and related disorders (PDRD) are the second most common neurodegenerative disease and a leading cause of death. However, patients with PDRD receive less end-of-life palliative care (EOLPC) and increased mortality^{1,2,7} and financial hardship.¹⁰ Hospital admissions, duration of hospital stay and in-hospital mortality are higher among individuals with PDRD compared with patients with other life-limiting conditions.^{10,11}

KEYWORDS: Parkinson's disease, end-of-life palliative care, prognosis, mortality, financial hardship

Better Lives. Together.

Is not dying an option?



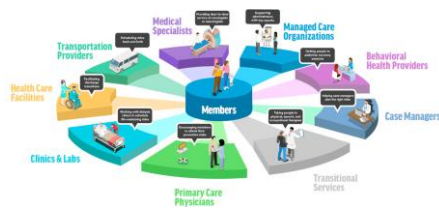
Better Lives. Together.

Need for a Road Map



Better Lives. Together.

Difficulties Coordinating Care



Better Lives. Together.

Medical and Psychiatric Symptoms



Dementia and psychosis
 Depression and Anxiety
 Pain
 Sleep disorders and Fatigue
 Dysphagia and sialorrhea
 Weight loss and nutrition
 Constipation and bladder dysfunction
 Apathy

Better Lives. Together.

Prozac is not always the answer.



Better Lives. Together.

Psychosocial Issues



Difficult emotions
 – Grief, Guilt, Anger, Frustration
 Social isolation and loneliness
 Care partner/family Support
 Effects on relationships
 Cosmetic issues and social stigma
 Financial
 Worries about the future

Better Lives. Together.

Spiritual and Existential Issues



Demoralization
 Challenges to Identity and Personhood
 Challenges to Faith
 Use of spiritual practices for coping and resilience
 Fear of death, decline and dementia

Better Lives. Together.

Future Care Planning



Patients prefer advance care planning soon after diagnosis
 Advance care planning influences place of death
 CURRENTLY, PD patients more likely to die in a hospital or nursing home than at home
 Waiting for the right time for ACP means conversations occur in the ICU without patient's input

Better Lives. Together.

Care Partner Support



Physical Health
 – Sleep
 – Self-care
 – Cardiovascular disease and mortality
 Financial and Social Wellbeing
 – Loss of income and anticipated expenses
 – Loneliness and isolation
 Emotional and Spiritual Wellbeing
 – Grief, guilt, anger
 – Burnout

Better Lives. Together.

III. Palliative Care Improves Outcomes



“I see such a sense of relief on the faces of patients and care partners when they realize what is available to them through palliative care. They know they have a team to help them, they feel their symptoms are better addressed, and their concerns are heard.”

- Malenna Sumrall, PhD

Better Lives. Together.

Palliative care needs contribute to quality of life.



Movement Disorders

RESEARCH ARTICLE

CLINICAL PRACTICE

Defining Palliative Care Needs in Parkinson's Disease

Benur M. Kluger, MD, MS^{1*}, Jo Shultuck, MA², Julie Blank, MS, PhD³, Kelly Sebring⁴, Wallace Jones⁵, Fabian Brunetti⁶, Isabel Faimont, MS⁷, Daniel W. Bowles, MD⁸, Stefan Sillou, PhD⁹, David B. Bealton, MD, MPH⁹

ABSTRACT: Objectives: Palliative care addresses the suffering of patients and families affected by progressive illness through the management of medical symptoms, psychosocial issues, and spiritual concerns. Although there is an emerging interest in applying palliative care to Parkinson's disease (PD), potential palliative care needs have not been systematically investigated in PD patients. Our primary objective was to determine the prevalence of clinically significant symptomatic, psychosocial, and spiritual issues in PD and understand their

Better Lives. Together.

Palliative care directly addresses what really matters to people living with serious illness.



- Family
- Integrity and dignity
- Having a road map for the future
- Symptom control
- Joy
- Comfort and control near the end of life

Better Lives. Together.

Palliative Care is the Future of Medicine



- Medicine is increasingly becoming patient and person-centered
 Palliative care is essential to achieving the goals of medicine:
- the relief of pain and suffering caused by maladies
 - the care and cure of those with a malady and the care of those who cannot be cured
 - the pursuit of a peaceful death
- Palliative Care ties into Medicine's Quadruple Aim
- Improve the patient experience
 - Reduce cost
 - Improve population health (including health equity)
 - Increase joy in practice

Better Lives. Together.

To improve care near in advanced illness, start at the time of diagnosis.



©Universal Press Syndicate. Original work by Bill Watterson. Originally published on 1992-05-21.

Better Lives. Together.

Advance directives reduce hospital deaths.



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

Keiran K. Tuck^a, Dana M. Zive^b, Terri A. Schmidt^{b,c}, Julie Carter^d, John Nutt^e, Erik K. Promme^{f,g}

^a Department of Neurology, Oregon Health & Science University, Mail Code 0912, 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, USA
^b Department of Emergency Medicine, Oregon Health & Science University, 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, USA
^c Palliative Care Service, Mail Code 1186, Oregon Health & Science University, 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, USA

Better Lives. Together.

Integrated & embedded outpatient palliative care can improve outcomes in PD.



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

Berislav M. Klager, MD; Jari M. Myasnik, MD; Maya Katz, MD; Nicholas G. Galliani, MD; Kirk Hall, MBA; Steven Pantilat, MD; Ryan Khan, MD; Carl Friedman, LCSW; Wendy Cerink, BS; Yuko Goto, MD; Judith Long, MS; Diane Faroughi, DPH; Stefan Sillau, PhD; Jean S. Kubner, MD

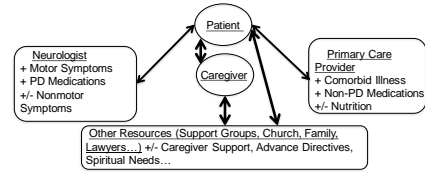
IMPORTANCE Parkinson disease and related disorders (PDRD) have consequences for quality of life (QoL) and are the 14th leading cause of death in the United States. Despite growing interest in palliative care (PC) for persons with PDRD, few studies are available supporting its effectiveness.

OBJECTIVE To determine if outpatient PC is associated with improvements in patient-centered outcomes compared with standard care among patients with PDRD and their caregivers.

Editorial
Supplemental content

Bet

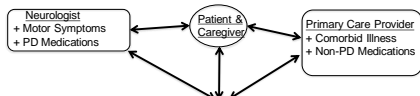
Our current model of chronic disease management has several gaps.



TYPICAL OUTCOMES - GOOD: Motor Symptom Control
FAIR: Nonmotor Symptom Treatment
POOR: Advance Care Planning, EOL Care, Caregiver Support, Psychosocial & Spiritual Needs

Better Lives. Together.

We hypothesized that team-based palliative care would address these gaps.



OUTPATIENT INTERDISCIPLINARY PALLIATIVE CARE TEAM
Physician (Nonmotor symptom, prognosis); Nurse (Nutrition, Home care, Advance Directives); Social Work (Caregiver Support, Finances); Chaplain (Spiritual Wellbeing, Grief Counseling)

IMPROVED OUTCOMES: Patient quality of life, Caregiver Support, Nonmotor Symptom Burden, Grief and other difficult emotions, Spiritual Wellbeing, Advance Care Planning, Healthcare Utilization, End-of-life Care

Better Lives. Together.

Palliative care improves outcomes that matter to persons with neurologic illness & their families.



- Improved patient quality of life
- Improved care partner quality of life
- Improved sense of guidance, support and clarity

Better Lives. Together.

IV. How to Get Palliative Care



“You are braver than you believe, stronger than you seem, and smarter than you think.”

- Winnie the Pooh (A.A. Milne)

Better Lives. Together.

You are part of the healthcare team!



- No one is more invested in your health than you are
- Activated patients and families get better care
- You have opportunities to shape the care you receive

Better Lives. Together.

Opportunities to make your care palliative

- Create a checklist
- *Invisible symptoms*
- *Emotional Needs*
- *Care partner support*
- *Advance care planning*
- Ask important questions
- Let your team know your values
- Get referrals or second opinions

Better Lives. Together.

34

You can change your illness journey by including the positive in your approach.

DEFICIT NARRATIVE

- Focus on what's broken
- Reliance on experts
- Manage symptoms
- Reduce caregiver burden
- Anticipate decline

ASSET NARRATIVE

- Focus on what's working
- Build self-efficacy
- Explore personal strengths
- Increase caregiver meaning
- Seek opportunities to grow

Better Lives. Together.

We have sufficient evidence to establish palliative care as a new standard of care for PD.

Parkinson's Foundation Launches Palliative Care Program Across U.S. Centers of Excellence

Funds awarded by the Patient-Centered Outcomes Research Institute

MIAMI & NEW YORK – August 11, 2020 – The [Parkinson's Foundation](#) is partnering with the University of Rochester Medical Center, a Parkinson's Foundation Center of

Better Lives. Together.

Neuropalliative care can be operationalized around 5 measurable and actionable pillars.

1. Annual advance care planning conversations.
2. Systematic assessment and management of nonmotor symptoms.
3. Recognition and support for emotional and spiritual concerns.
4. Routine assessment and support for family care partners.
5. Timely referral to specialist palliative care and hospice.

Better Lives. Together.

Become an activist.

- Parkinson's Advocates In Research (PAIR)
- Community projects and support groups
- Being a voice to change policy

 Parkinson's Disease

www.nature.com/npjparkd

COMMENT **OPEN**
Palliative care for Parkinson's disease: suggestions from a council of patient and carepartners

Kirk Haal¹, Mahenna Sumari², Gill Thelen³ and Bernd M. Kluger⁴ on behalf of the 2015 Parkinson's Disease Foundation sponsored "Palliative Care and Parkinson's Disease" Patient Advisory Council

Better Lives. Together.

There is still much work to be done.



Better Lives. Together.

INPCS Mission and Vision



Mission: To raise standards of care for all people affected by neurologic illness.

Vision: A world where high quality, person-centered supportive care for persons affected by neurologic illness is the rule rather than the exception.

Better Lives. Together.

Take Home Points



The goal of palliative care is to live as well as possible for long as possible.

Persons living with PD and their families have palliative care needs.

Palliative approaches to care can improve outcomes important to patients and families.

People with PD are critical members of the healthcare team.

PWP can advocate for palliative and supportive approaches in their care.

Better Lives. Together.