Living as Well as Possible: Introduction to Neuropalliative Care for Parkinson’s and related conditions

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Learning Objectives

1. Define supportive and palliative care.
2. Understand why supportive and palliative care are relevant to ALL people living with Parkinson’s disease.
3. Use a palliative care mindset to improve self-care and resilience.
4. Apply palliative care skills that can improve the care you get from your current healthcare providers.
5. Know when a referral to a supportive or palliative care specialist might help you get an extra layer of support for challenging situations.

Personal Background I

REFLECTIONS: NEUROLOGY AND THE HUMANITIES

The head leads to the heart

Benzi M. Kluger, MD, MS, FAAN

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Personal Background II

1. What is supportive and palliative care?

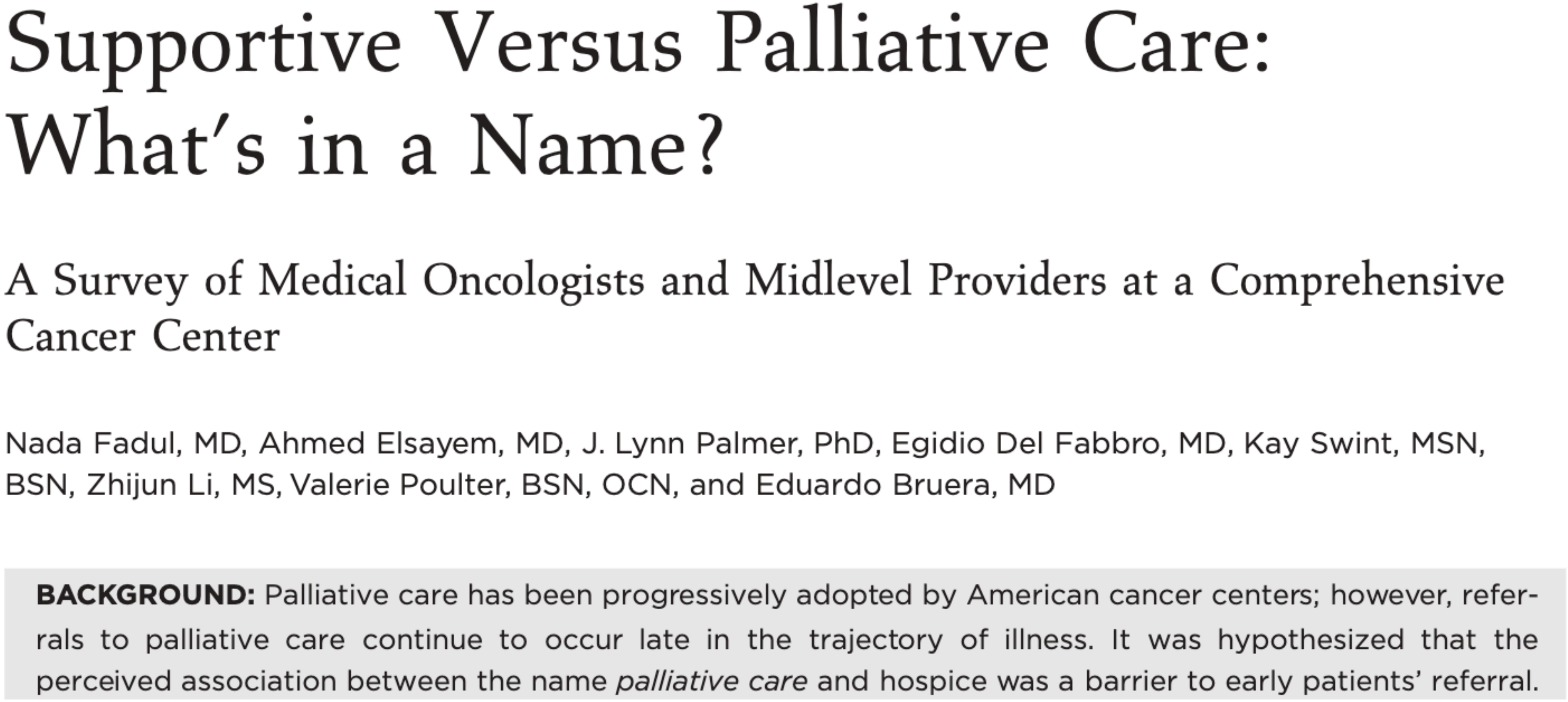
> “Palliative care is about living as well as possible for as long as possible.”

- Steve Pantilat, MD

Essential Elements of Palliative Care (from the World Health Organization)

- 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 emotional, social and spiritual issues
- Is applicable early in the course of illness and in conjunction with therapies intended to prolong life (or function)

Palliative care is Supportive care.



Supportive Versus Palliative Care: What's in a Name?

A Survey of Medical Oncologists and Midlevel Providers at a Comprehensive Cancer Center

Nada Fadul, MD, Ahmed Elsayem, MD, J. Lynn Palmer, PhD, Egidio Del Fabbro, MD, Kay Swint, MSN, BSN, Zhijun Li, MS, Valerie Poulter, BSN, OCN, and Eduardo Bruera, MD

BACKGROUND: Palliative care has been progressively adopted by American cancer centers; however, referrals to palliative care continue to occur late in the trajectory of illness. It was hypothesized that the perceived association between the name *palliative care* and hospice was a barrier to early patients' referral.

The 3-legged Stool model of Palliative Care

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

- Kirk Hall

The Role of PWP and Family in Palliative Care: Person-Centered

- Palliative care is based on conversations and dialogue.

- Patients and family are essential to understand:
- What values should drive care.
- What aspects of the illness are causing the greatest suffering.
- What opportunities exist for living well (e.g. joy, meaning, and love).

The Role of PWP and Family in Palliative Care: Person-Driven

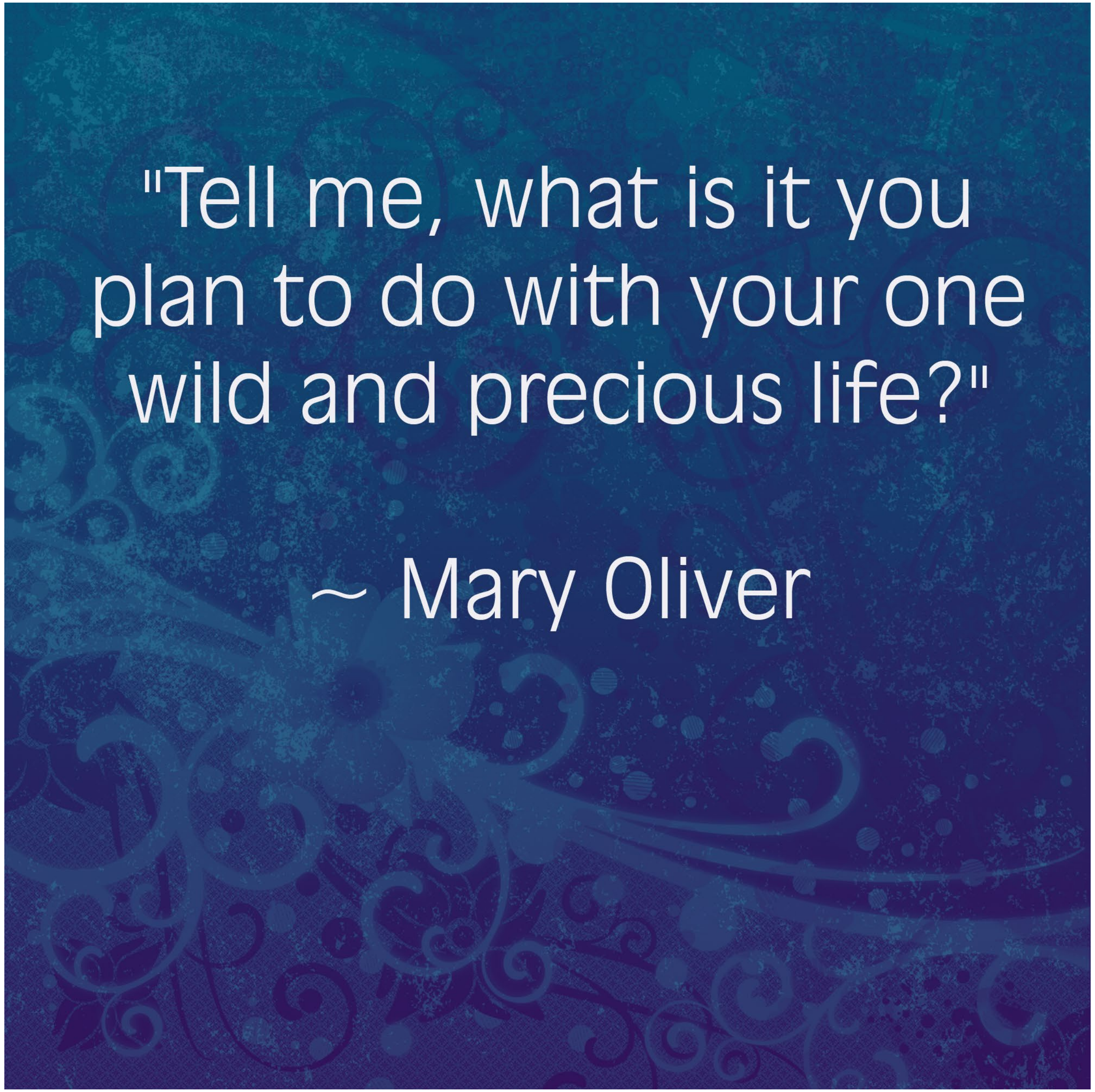
- **You have the power to improve the care you receive**.

- Patients and families can drive care by:
- Setting the agenda for visits.
- Bringing up important topics and tough conversations.
- Letting providers know their preferences for information.
- Requesting referrals.

What is hospice?

- Hospice is palliative care specifically focused on persons nearing the end of life.
- In the United States, hospice is a benefit covered by Medicare and all insurers for persons with a life expectancy of 6 months or less.
- Hospice is a service that is generally provided in your home or place of residence.
- The goals of hospice are to maximize comfort and avoid hospitalizations.

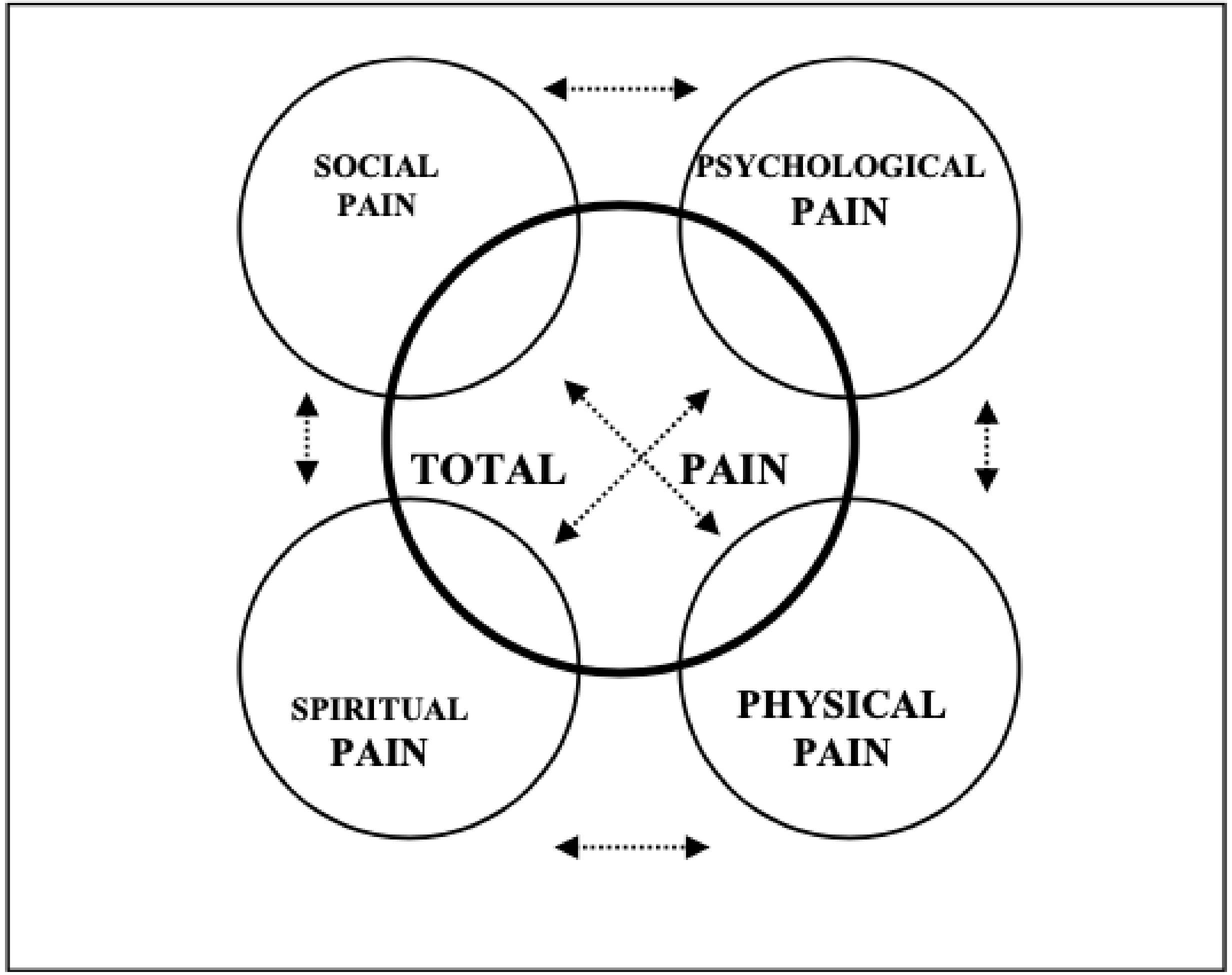
2. Why is palliative care important for all people living with Parkinson’s?



"Tell me, what is it you plan to do with your one wild and precious life?"

~ Mary Oliver

The “Total Pain” of Serious Illness



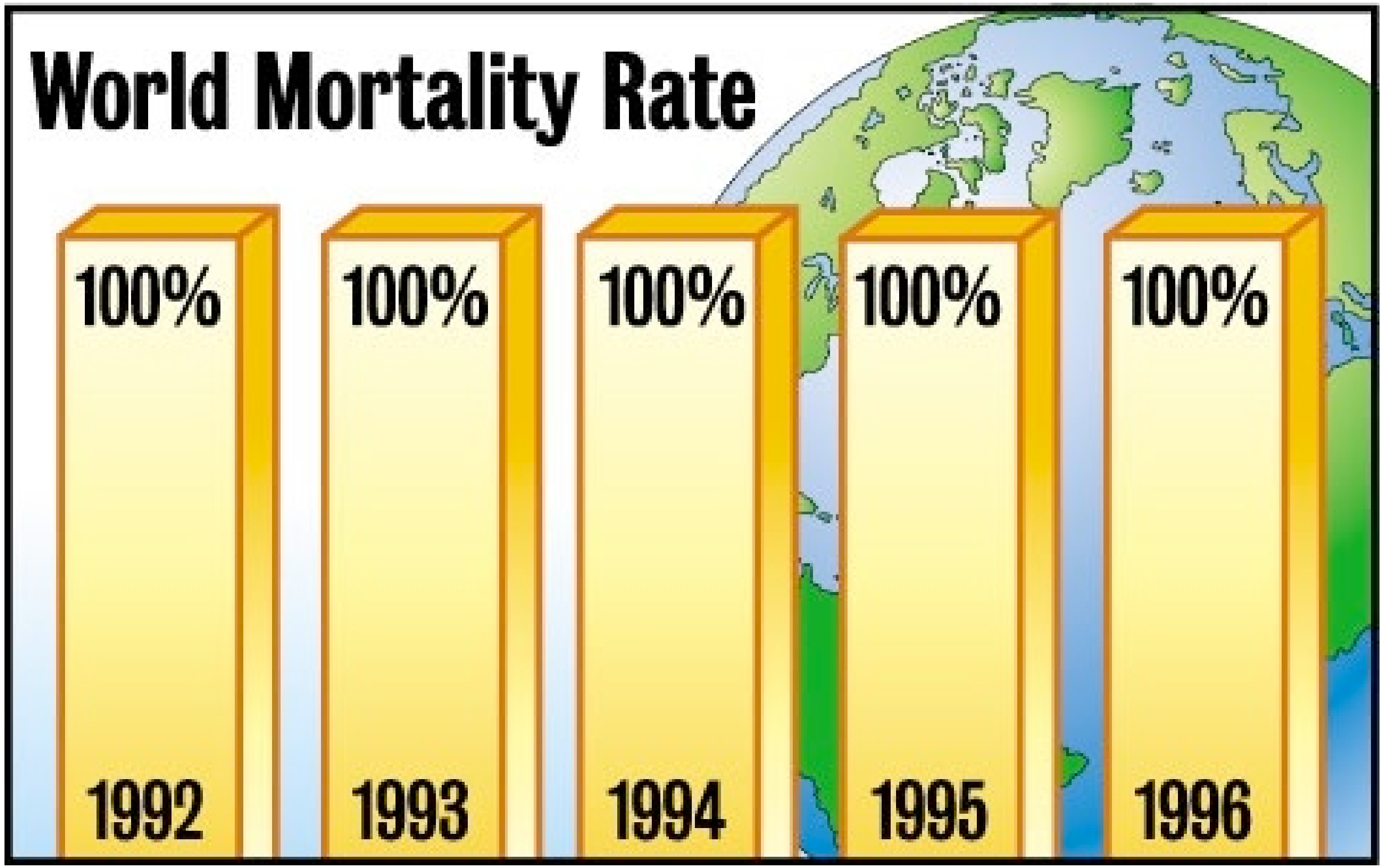
The Total Pain of Parkinson’s Disease

1. Physical: motor symptoms, nonmotor symptoms
2. Emotional: depression, anxiety, grief, worries, frustration
3. Social: loneliness, isolation, changes in role
4. Spiritual: hopelessness, challenges to faith, change in identity
5. Practical: can I afford future care, transportation, coordination across doctors

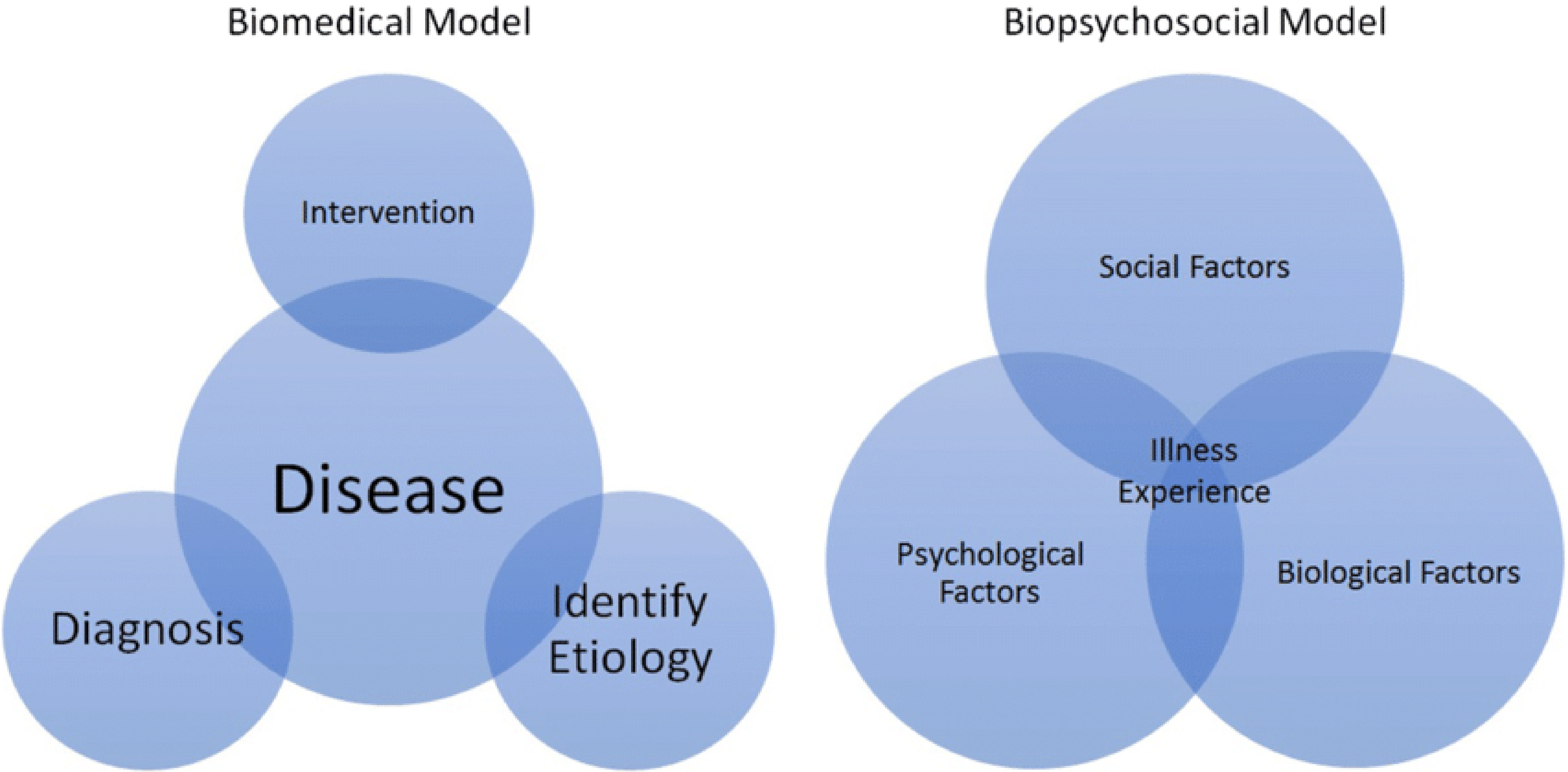
Find the positive without denying the negative.

- Meaning: religion, family, values
- Love: family, friends, community
- Hope: for a cure or better care, for personal goals, for loved ones
- Joy: simple pleasures (food), travel, friendship, movies…

People can die from complications of Parkinson’s disease.



We must raise and change standards of care.

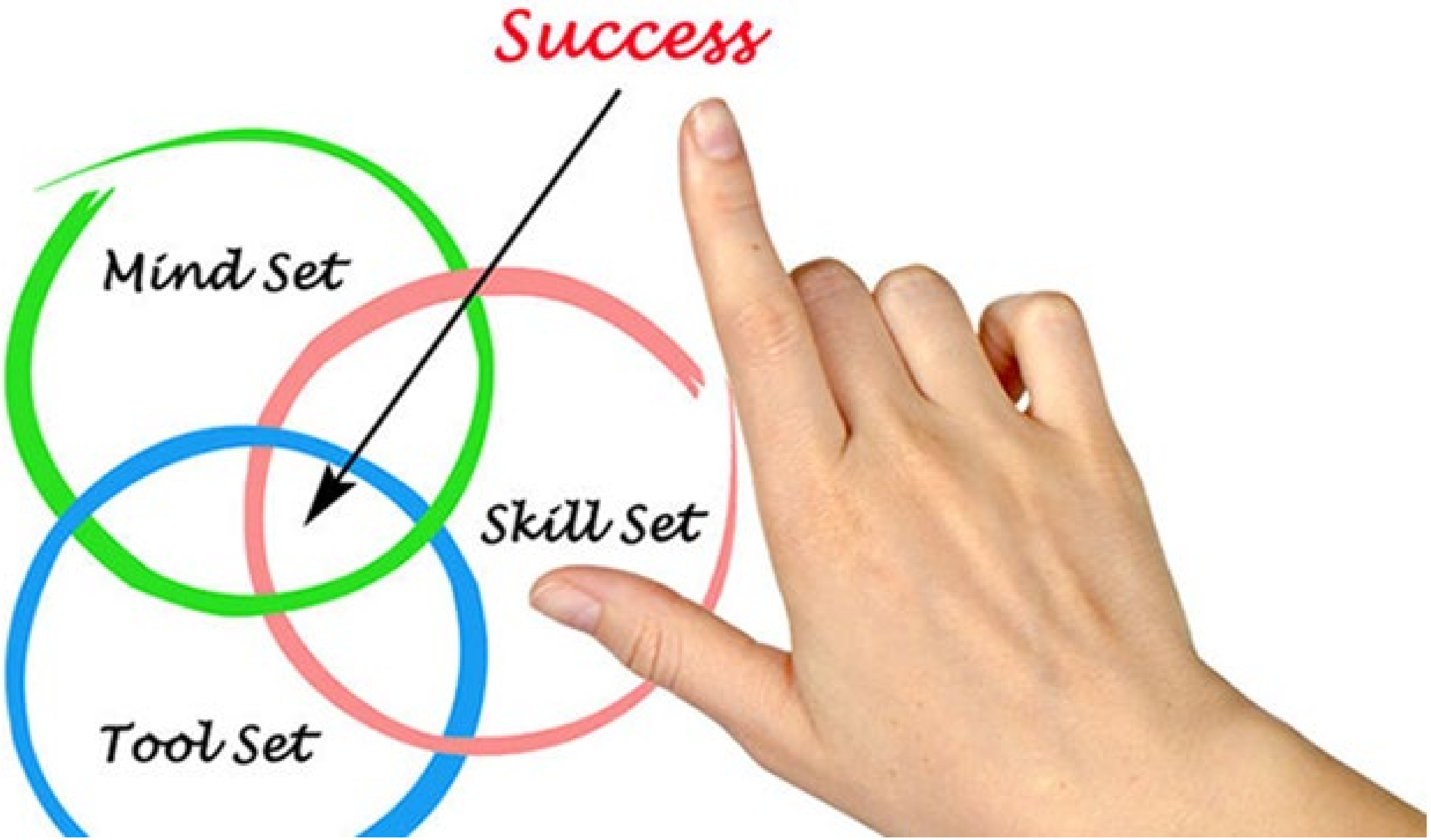


The 5 Pillars of Team-based Palliative Care for Parkinson’s Disease

Systematic screening and comprehensive support for:

1. Nonmotor symptoms
2. Care partners
3. Challenging emotions and spiritual wellbeing
4. Advance care planning
5. Timely referrals for specialist palliative care and hospice

3. Self-care and the Palliative Mindset



Applying the palliative care mindset to living with Parkinson's disease: reduce suffering

1. What are your sources of suffering?

a. Can you name those things that are toughest for you?

b. What options do you have for cure, coping or compassion?

Applying the palliative care mindset to living with Parkinson's disease: increase joy

2. What are your opportunities for joy?

a. What strengths, values, loves, and joys do you carry into this illness?
b. How can you stay connected to these important parts of you you are and what you value to your current situation?
c. Are there ways to adopt or adapt to stay connected or new opportunities to explore?

Applying the palliative care mindset to living with Parkinson's disease: find your people

3. Who in your personal and healthcare community can you turn to to share your suffering and celebrate your joy?

a. On the healthcare side: doctors, nurses, social workers, chaplain, therapists…

b. On the personal side: friends, family, spiritual community, neighbors, support group…

4. Getting more from your healthcare team with a palliative care skillset and toolset.

Using the 5 pillars to improve your care.

PILLAR	SKILL	TOOL
1. Nonmotor symptoms	Set the agenda for your visits	Symptom checklist
2. Emotional and Spiritual Support	Go outside of the medical model	Counseling and peer support
3. Preparing for the future	Start important conversations	Question prompt list
4. Family support	Ask for what you need	Caregiver checklist
5. Specialist Palliative care & Hospice	Get an extra layer of support	Referral to resources in your community

Using the 5 pillars to improve your care.

PILLAR	SKILL	TOOL
1. Nonmotor symptoms	Set the agenda for your visits	Symptom checklist

- ✓ Pain
- ✓ Sleep, fatigue
- ✓ Constipation, urination
- ✓ Depression, anxiety
- ✓ Change in weight or appetite
- ✓ Nightmares, hallucinations, change in personality
- ✓ *Could any of my symptoms be side effects of medications?

Using the 5 pillars to improve your care.

PILLAR	SKILL	TOOL
2. Emotional and Spiritual Support	Go outside of the medical model	Counseling and peer support

- Chaplains
- Spiritual community
- Psychologist
- Mental health counselors
- Social work
- Support groups
- Friends and family

Using the 5 pillars to improve your care.

PILLAR	SKILL	TOOL
3. Preparing for the future	Start important conversations	Question prompt list

- What is the best case, worst care or most likely scenario for how my Parkinson’s may progress?
- What symptoms may indicate that my Parkinson’s is progressing? (What should I be looking out for?)
- How can I and my family be better prepared for the future?
- I would like to complete paperwork to put my future wishes in writing (health care proxy, living will, advance directive)

Using the 5 pillars to improve your care.

PILLAR	SKILL	TOOL
4. Family support	Ask for what you need	Carer checklist

- Self-care
- Emotional, social and spiritual support
- Being prepared for the future
- Caregiving skills
- Help at home

Using the 5 pillars to improve your care.

PILLAR	SKILL	TOOL
5. Specialist Palliative care & Hospice	Get an extra layer of support	Referral to resources in your community

You have the right to request referrals to other specialists and for second opinions.

5. Need an extra layer of support: Getting a referral for supportive or palliative care

What does specialist palliative care do?

- Help with challenging symptoms like pain and fatigue
- Provide support around difficult but normal emotions like grief, worry and frustration
- Explore spiritual or religious issues associated with having a serious illness like hopelessness or loss of meaning
- Provide support for family members and caregivers
- Talk about the big picture, including a road map for the future
- Coordinate care across multiple providers
- Clarify your goals and how your values can drive your care

The Supportive Care Team

- Palliative medicine or neuropalliative care specialist
- Social Worker
- Nurse
- Chaplain
- Mental Health Counselor
- Psychologist
- Home Health Services

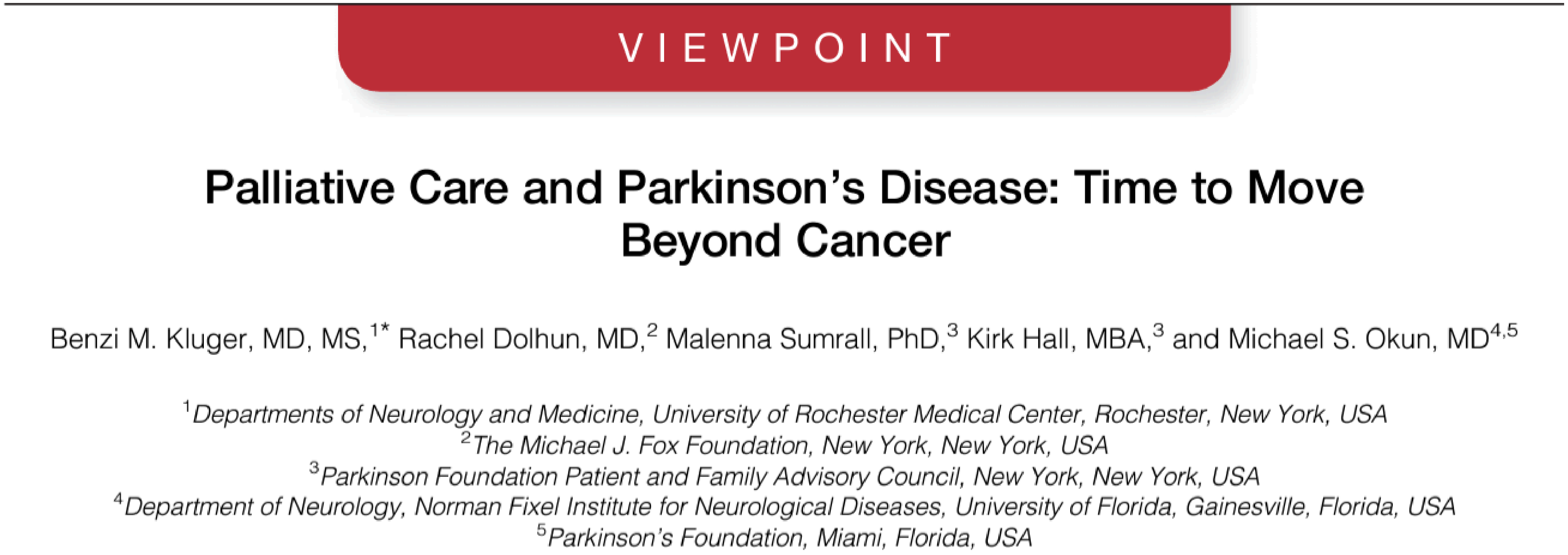
When to consider a referral for a palliative care specialist?

- Can be at any point in your Parkinson’s journey
- Difficult to control nonmotor symptoms (e.g. pain)
- Struggling with difficult emotions (e.g. grief)
- Struggling with severely limited quality of life
- Care partner or family distress or need for more support
- Guidance needed for planning for the future, discussing road map or prognosis
- Difficulties coordinating care across providers

When to consider a referral to hospice?

- Your primary goal for care and treatment is comfort
- You would not want to go the hospital if you developed pneumonia or other infection
- You would like to maximize your time at home (or your current residence) and with family/friends
- You would like an alternative to future ED visits, hospital stays or calling 911
- You and your family could benefit from an extra layer of medical support

Activism and Advocacy: Palliative Care and PD



VIEWPOINT

Palliative Care and Parkinson's Disease: Time to Move Beyond Cancer

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Activism and Advocacy :
Raising standards of care for Parkinson’s

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

The COPE-PD Study

- Community
- Outreach for
- Palliative
- Engagement
- The goal of COPE-PD is to:
  - Document the struggles patients and families living with PD face
  - Develop a new model of care to improve outcomes for people getting care in community settings
- We have partnered with amazing and caring neurologists across the US to make this vision a reality!

You have the power to change care!

GRASSROOTS
ADVOCACY

COPE-PD

INPCS
INTERNATIONAL NEUROPALLIATIVE
CARE SOCIETY

Parkinson's
Foundation

Take Home Points

- Palliative/supportive care is a person and family-centered approach to improving quality of life for serious illness.
- Palliative care addresses many important dimensions of care that are often overlooked.
- You can use palliative care concepts to improve the care you receive, to prepare for the future and to live well today.
- Specialist palliative care or hospice can provide an extra layer of support for advanced illness, challenging situations and near the end of life.