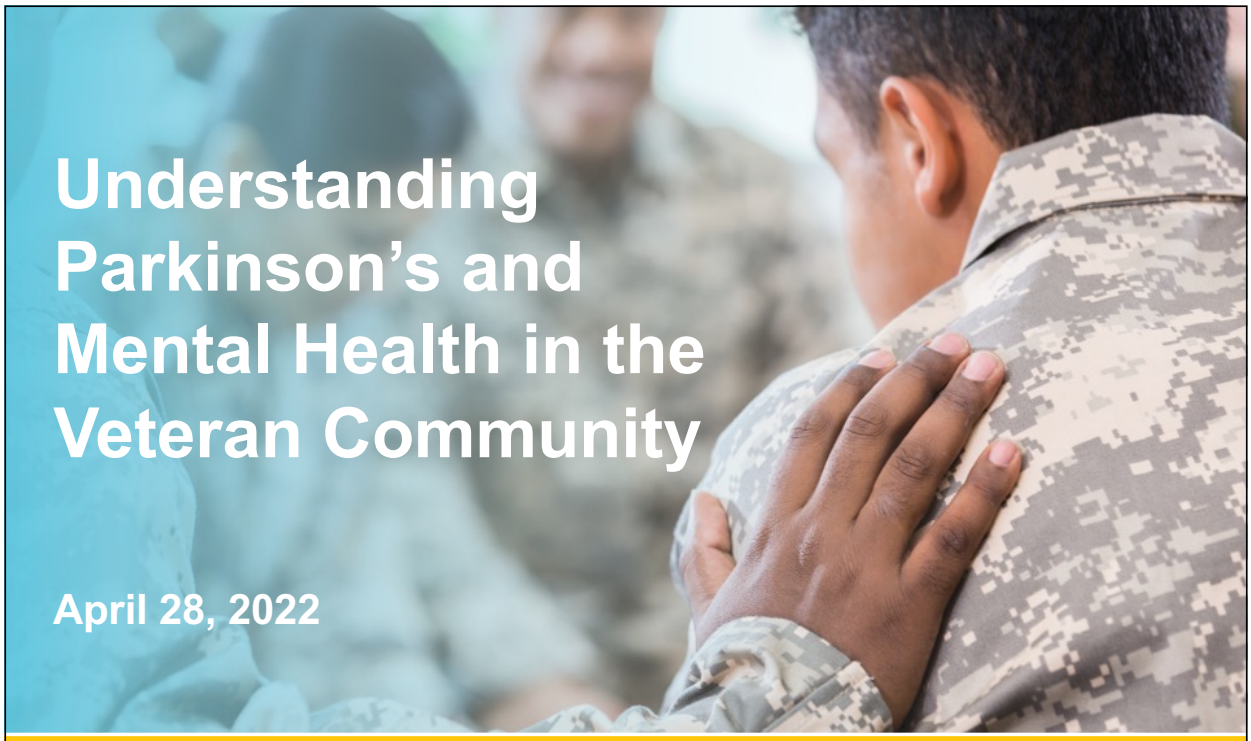


Understanding Parkinson's and Mental Health in the Veteran Community

April 28, 2022

Parkinson's Foundation

VA | U.S. Department of Veterans Affairs

Parkinson's Foundation Veterans Survey

Sheera Rosenfeld
Vice President, Strategic Initiatives
Parkinson's Foundation

Parkinson's Foundation

VA | U.S. Department of Veterans Affairs

Parkinson's Foundation Surveys

U.S. Department of Veterans Affairs

Parkinson's Foundation

Informing Research

- Driven by the experiences of people with Parkinson's disease and their care partners
- Real experiences directly influencing research
- Previous focus areas: Telehealth, Care Access, COVID, Exercise

Getting Engaged

- Your Parkinson's experience matters and informs research
- Join the Parkinson's Foundation Surveys to make sure your voice is heard
- Sign up here: redcap.link/pfsurveys

Survey on Care Experiences for Veterans with Parkinson's

U.S. Department of Veterans Affairs

Parkinson's Foundation

The Why

- More than 19 million veterans in US; less than half receive care through VHA.
- Approximately 110,00 Veterans with Parkinson's disease receive some care through VHA.
- Interest in understanding health status, demographics, and health care usage of veteran's living with PD including those who received care within and outside the VHA.
- Important to understand how and what areas of care can be improved to provide the best possible care for veterans living with PD.

Applying PF Survey Learnings

U.S. Department of Veterans Affairs

Parkinson's Foundation

Calls to Action

- Getting referrals for mental health early is vital for veterans living with PD
- Educating veterans with PD on the type of care they can receive and are eligible for, whether that be through the VHA or not, is crucial
- Findings highlight importance of targeted educational outreach about care best practices for Veterans living with PD beyond VHA's current reach as well as the importance of access to good mental health resources

Research into Action-- Today's Webinar

- Understand and educate veterans with PD community on:
  - ❖ Mental health and symptoms
  - ❖ How to recognize symptoms
  - ❖ Where to go for treatment and support
  - ❖ Why it is so important to talk to one's provider
  - ❖ Awareness of resources in and outside VA

How Veterans with Parkinson's Can Recognize and Manage Common Mental Health Issues

Laura Marsh, MD
Executive Director, Mental Health Care Line, Michael E. DeBakey Veteran Affairs Medical Center
Professor of Psychiatry and Neurology, Baylor College of Medicine

Parkinson's Foundation

VA | U.S. Department of Veterans Affairs

Outline

- Recognition of Mental Health Symptoms in the Context of PD
- Treatment Approaches and Options
- Communication with Your Clinical Team
  - VA-specific resources

U.S. Department of Veterans Affairs

Parkinson's Foundation

U.S. Department of Veterans Affairs

Parkinson's Foundation

Recognition of Mental Health (MH) Symptoms in the Context of PD

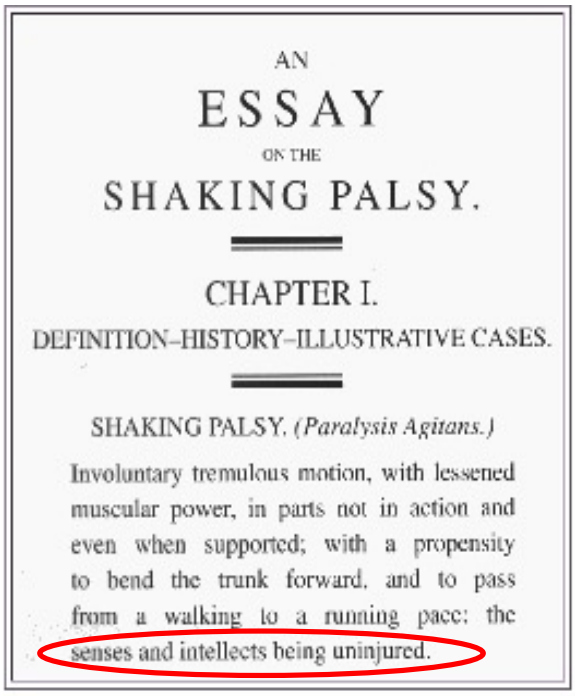
- Context of MH symptoms in PD
- Common MH conditions in PD and their features

Mental Health and PD

U.S. Department of Veterans Affairs

Parkinson's Foundation

- Initially, MH symptoms not recognized as part of PD
- The traditional view of PD did *not* match the lived experience
- Progressive increase in attention to the mental health aspects of PD



AN

ESSAY

ON THE

SHAKING PALSY.

CHAPTER I.

DEFINITION–HISTORY–ILLUSTRATIVE CASES.

SHAKING PALSY. *(Paralysis Agitans.)*

Involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forward, and to pass from a walking to a running pace: the senses and intellects being uninjured.

Mental Health Symptoms *Prior* to PD Diagnosis

U.S. Department of Veterans Affairs

Parkinson's Foundation

Depression

- On average, precedes PD by 4 to 6 years[1]

Anxiety

- Symptoms often coincide with PD onset[5]
- Anxiety disorders present ≤ 20 years before motor signs
  - Associated with eventual development of PD[3]
- 12-year follow-up of 35,000 men:
  - High anxiety, anxiolytic use ~ increase relative risk of PD[3]

[1]Gonera et al 1997, [2]Shiba et al 2000; [3] Weisskopf et al 2002; [4]Williams et al. 2009; [5]Ishihara and Brayne 2006

Mental Health Symptoms *at Time of* PD Diagnosis

U.S. Department of Veterans Affairs

Parkinson's Foundation

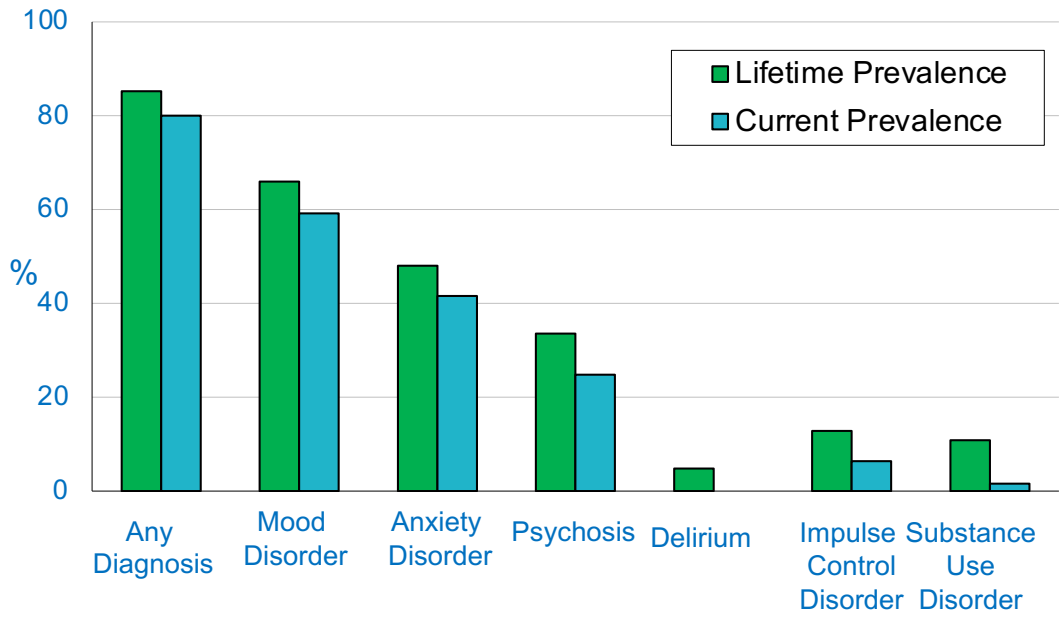
Initial Symptom (n=183)	# Reported
Tremor	129 (70%)
Gait disturbance	21
Stiffness	18
Slowness	18
Muscle pain, cramps, aching	15
Loss of dexterity	14
Handwriting disturbance	9
Depression, nervousness	8
Speech disturbance	7
General fatigue, muscle weakness	5
Drooling	3
Loss of arm swing	3
Facial masking	3

Yahr, 1967

Common Psychiatric Diagnoses in PD

U.S. Department of Veterans Affairs

Parkinson's Foundation



(Mood-PD Study, n=250, MMSE>23)

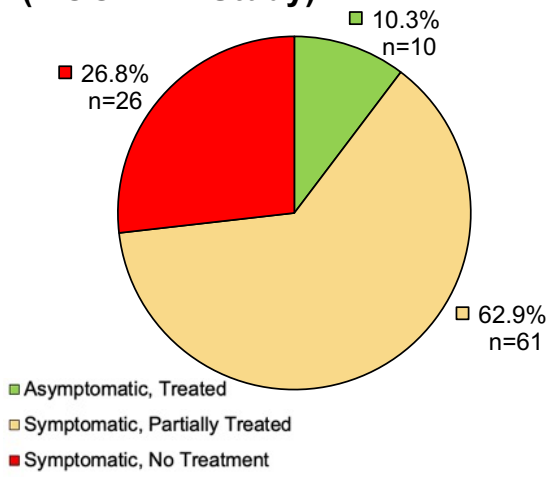
Marsh et al. 2010

MH Issues are Undertreated

U.S. Department of Veterans Affairs

Parkinson's Foundation

Major Depression, n=97 (MOOD-PD Study)



Current symptomatic major depressive episode (n=86)
Duration = 182.4 (218.8) weeks
Range 2-1612 weeks. Median 104 weeks.

The Impact of Untreated MH Symptoms

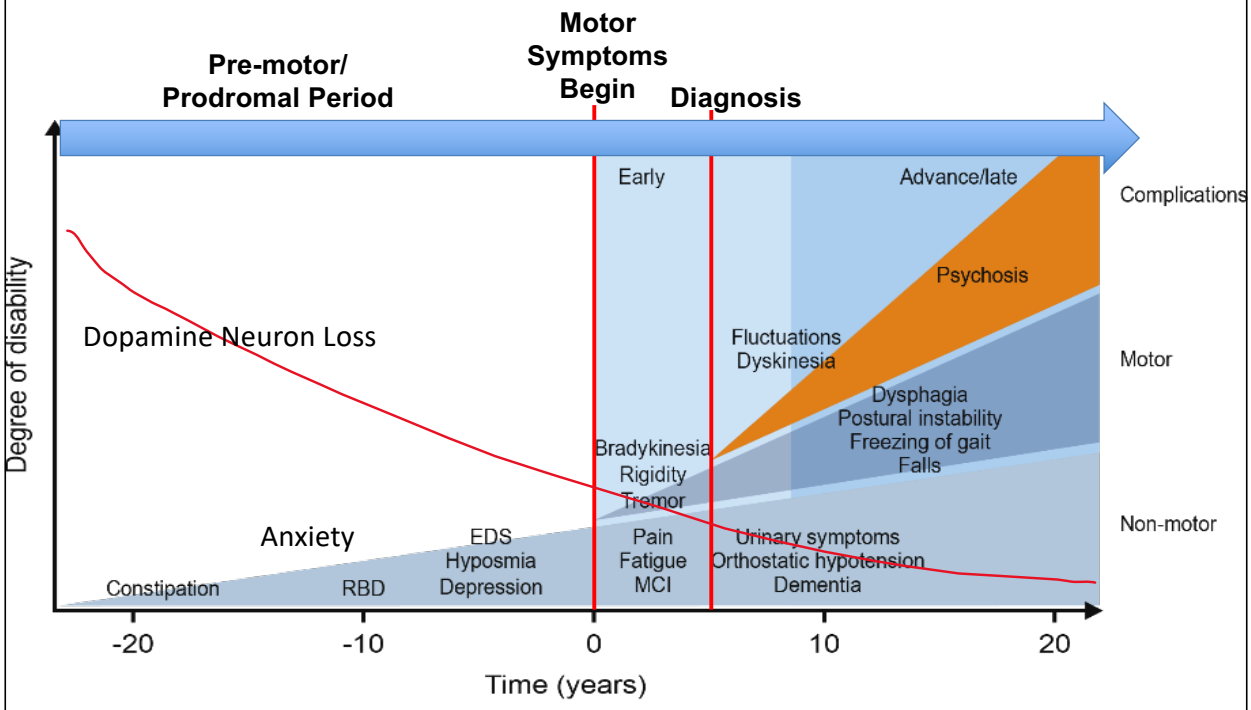
- Greater negative effect on Quality of Life (compared to motor symptoms)
- Aggravates:
  - Motor and cognitive deficits
  - Disability over course of PD
  - Other co-morbid medical and psychiatric conditions
  - Economic strain
  - Caregiving distress
  - Suffering

Palanci et al. 2009; Burn DJ, 2002

Motor and Non-Motor Symptoms Over PD Course

U.S. Department of Veterans Affairs

Parkinson's Foundation



Aarsland D, et al. *Int J Geriatr Psychiatry* 2001; 16:528-536.; Forsaa et al., 2010; Connolly B, Fox SH. *Neurotherapeutics.* 2014;11(1):78-91.; Fénelon G, et al. *Mov Disord.* 2010;25(6):763-766. ; Kalia LV, Lang AE. *Lancet.* 2015;386(9996):896-912.

Recognizing Depressive Disorders

U.S. Department of Veterans Affairs

Parkinson's Foundation

Isolated emotions ≠ Mood Disorder

Depressive disorders vary in severity and type

Major depressive episode DSM-V criteria:

Depressed/sad mood
and/or
Decreased interest/pleasure

Features of PD or Depression	VS	**Features of Depression**
• Appetite/weight changes • Sleep disturbances • Retardation (slowness) • Fatigue or loss of energy • Decreased ability to think or concentrate or indecisiveness		• Psychomotor agitation • Feelings of worthlessness/ excessive guilt • Recurrent thoughts of death, suicidal ideation, or suicidal attempt or plan

Palanci et al. 2009

Recognizing Depressive Disorders

U.S. Department of Veterans Affairs

Parkinson's Foundation

To recognize a depressive disorder, look for the emotional features*

- Persistent sadness
- Decreased interest
- Decreased enjoyment (anhedonia)
- Pessimism
- Hopelessness
- Negative ruminations
- Inappropriate guilt
- Negative view of sense of self
- Morbid and/or suicidal thoughts
- Feeling overwhelmed, anxious, unable to cope
- Irritability

**In mood disorders, emotional features are pervasive or persistent*

The physical symptoms (changes in sleep, appetite, energy level, motor slowness) worsen with active depression, but can be hard to distinguish from changes that occur in PD without depression.

Anxiety Disorders in PD

- **'Clinically significant'**
- ***Not* understandable reaction PD**
  - Onset before PD diagnosis
- **Occur:**
  - Co-morbid or independent condition with depressive, other MH disorders
  - As secondary anxiety symptoms
    - Consequence of cognitive deficits/impairments
    - Symptoms of a primary depressive disorder
- **Several Types (typical and PD-specific):**
  - Episodic (Panic Disorder)
  - Situational (Phobias)
  - Continuous (Generalized Anxiety, PTSD)
  - PD-Specific (Wearing-off anxiety/panic)

Kummer et al. 2008; Maricle et al. 1995, Witjas et al. 2002, Arabia 2007

Prevalence of Anxiety Disorders in PD

Category / %	Prior studies	Pontone 2011	Dissanayaka 2010	Leentjens (2011)	Population NEMESIS/ NCS
Panic disorder	13 – 30	5	8	4	1.5/1
Specific Phobia		16	-	-	5.5/5.5
GAD	0 - 40	4	3	**21**	0.8/1.6
Social phobia	15	7	13	10	3.7/4.5
Agoraphobia	-	1.6	-	16	-/2.3
Post-traumatic stress disorder	-	0	-	-	-
Anxiety Dis NOS	-	**22%***	-	11%**	-

*DSM-IV-TR; **Based on NPI anxiety subscale cut-off >3

Distinguishing Features of Anxiety Disorders

U.S. Department of Veterans Affairs

Parkinson's Foundation

+ Excessive

- Apprehension
- Worry
- Anticipation of the negative
- ***Avoidance***
- Overly-detailed
- Emotional Reactivity
- Fearfulness
- Somatic concerns
- Ruminative

But *Not* Pervasive

- Guilt
- Sadness
- Decreased self-worth
- Lack of interest
- Morbid thoughts

The above are features of depressive disorders

Apathy

U.S. Department of Veterans Affairs

Parkinson's Foundation

- **Prevalence**
  - ~30% as a feature of a depressive disorder
  - ~10% as an independent disorder
- **Clinical Features**
  - Loss of motivation
  - Emotional indifference
  - Reduced goal-directed activities
  - Can be associated with cognitive changes
  - Patients with primary apathy do *not* complain

Weiss and Marsh, 2009

Emotionalism / Pathological Crying

- **Prevalence**
  - 40-50% in PD
  - Associated with Depressive Disorders, Delirium, side effect of benzodiazepine-type medications
- **Clinical Features**
  - Heightened, excessive sentimentality/tears
  - Inappropriate, unmotivated, involuntary
  - Precipitated by a variety of emotions
  - Social embarrassment/phobic avoidance

PD-Psychosis
Hallucinations and Delusions

- **Prevalence**
  - Depends on definition of psychosis, PD, cognitive impairment
  - ~8% - 40% report rates
  - Over time, symptoms become persistent and progressive
- **Increased Risk**
  - Certain PD and other CNS-active meds
  - Age
  - PD Progression
- **Prognosis**
  - Improved with education/awareness, newer antipsychotics
  - Major clinical and caregiver challenge

Types of Hallucinations in PD

Minor 'Hallucinations'
- Presence – Vivid sensation
- Passage – Brief visions in peripheral field
- ± Illusions – sensory distortions

Hallucinations (with/without insight)
- Formed/Complex versus Unformed
- Visual, Auditory, Olfactory, Gustatory, Somatic/Tactile/Cenesthetic

PD-Psychosis
Hallucinations and Delusions

U.S. Department of Veterans Affairs

Parkinson's Foundation

Rates and Types of Hallucinations & Delusions in Treatment-Seeking PD Patients

	Prevalence (n=160 PDP)
Hallucinations	98%
Visual	97%
Auditory	48%
Tactile	23%
Olfactory	16%
Delusions	76%
Stealing	33%
Not my house	29%
Infidelity	29%
Abandonment	26%
Imposter Spouse	20%

US and European Olanzapine trials for PD-Psychosis Chou KL et al. *Clin Neuropharmacol.* 2005;28:215-219

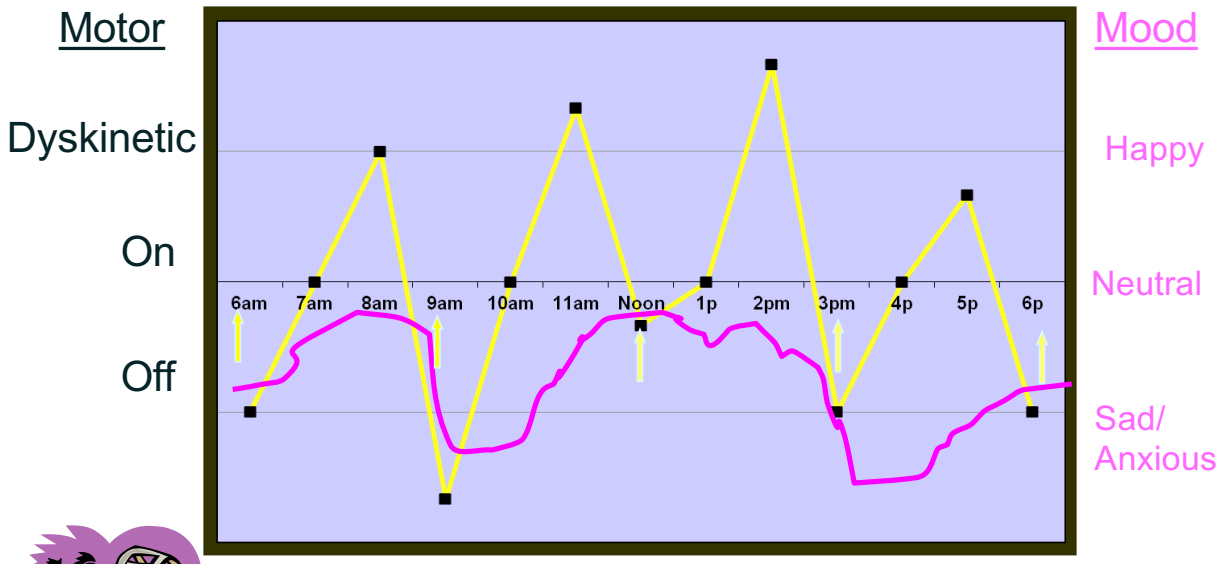
PD Medication Related Mood Syndromes

U.S. Department of Veterans Affairs

Parkinson's Foundation

- **Early Morning Off (EMO) States** (Rizos, 2014)
  - Anxiety, low mood
  - Urinary urgency, drooling
  - Paresthesias, dizziness
- **Dopamine Agonist Withdrawal Sd (DAWS)** (Rabinak & Nirenberg, 2010)
  - Anxiety, panic attacks
  - Depression, dysphoria
  - Suicidality, agitation, irritability
  - Insomnia, fatigue, dizziness
  - Nausea, diaphoresis, pain
  - Orthostatic hypotension
  - Drug cravings
- **On-Off Motor and Non-Motor Fluctuations** (Racette 2002)

PD-Specific Motor and Mood Fluctuations



Non-Motor Fluctuations

Dysautonomic

Drenching sweats, hot sensation, flushing, dry mouth, dyspnea, dysphagia, constipation, distal cold sensations, excessive salivation, urinary urgency, visual complaints, palpitations, bloating, chest pain

Cognitive/Psychiatric

- Slowed thinking, mental hyperactivity, impaired memory, mental emptiness
- Off-Anxiety (81%), Off-depression (63%), On-hypomania (24%), irritability, psychosis

Sensory/Vegetative

Fatigue, akathisia, tightening sensations, tingling, pain

Witjas et al, Neurology 2002; 59: 408-413; Racette et al., J Neuropsychiatry Clin Neurosci 2002; 14: 438-442.

Impulse Control and Behavior Disorders

U.S. Department of Veterans Affairs

Parkinson's Foundation

Behavior	Prevalence
Pathological Gambling	3-8%
Hypersexuality	2.5%
Pathological Shopping	0.4-1.5%
Punding	1.5-14%
Compulsive Dopaminergic Med Use	3.4-4%

Voon, V. et al. Arch Neurol 2007;64:1089-1096.

U.S. Department of Veterans Affairs

Parkinson's Foundation

Treatment Approaches and Options

Optimal MH Treatment
(VHA or Non-VHA)

U.S. Department of Veterans Affairs

Parkinson's Foundation

- Emphasizes that MH treatments are *only* effective when pursued!
- Targeted, Individualized, & Collaborative
- Employs Multidisciplinary Interventions
- Uses *multiple* types of Interventions
  Pharmacologic & Non-pharmacologic

Case Study

U.S. Department of Veterans Affairs

Parkinson's Foundation

70-yo Veteran with PD, History of PTSD, Major Depression, and Alcohol Use Disorder (AUD)

New Onset Panic Attacks—Possible Treatment Options

Collaborative: 24-hour diary (0100 to 2400), hourly recordings
- Mood, Anxiety, Sleep, PD, Meds, Circumstances
- Adjust PD meds if non-motor fluctuations, ? DBS candidate

Education/Support to facilitate a healthy med/daily schedule

Behavioral Interventions
- Stop-gap approaches (Breathing, distraction)
- Mindfulness training
- Rehab therapies—OT, PT, Speech Rx

Specific Psychotherapies
- Cognitive Behavior Therapy for anxiety (in-person/virtual)
- PTSD- or Panic disorder specific psychotherapy
- Cognitive bias Modification

Medical/Medications: Add or adjust antidepressant if ++ Depressive symptoms; ?rTMS or ECT; ? AUD treatment

Pontone et al,AJGP 2013; Chen & Marsh 2014; Dissanayaka et al, 2015

Is your treatment a MESS?

U.S. Department of Veterans Affairs

Parkinson's Foundation

Meds/Medical
Education
Skills
Support

M – Add/Adjust/Optimize/Adhere Medications

- Identify and treat medical conditions, delirium
- Adjust meds causing cognitive/psychiatric problems, motor sx
- Consider other somatic treatments (Psychiatric Meds, DBS, rTMS, ECT)
- No Benzodiazepines, anticholinergic, antihistaminergic

E – Education

- Educational Programs
- Lifestyle Interventions, Home Evaluations

S – Skills

- Psychotherapies
- Rehabilitative Therapies: PT, OT, ST, RT, KT
- Clinic & Home-based Evals and Treatment

S – Social Support, Support Groups

- Support + Exercise + Fun: Singing, Yoga, Dance, Boxing, etc.
- Caregiver Needs: Home Care, Respite, Support

Is your treatment a MESS?

U.S. Department of Veterans Affairs

Parkinson's Foundation

Meds/Medical
Education
Skills
Support

and attentive to

Safety
Falls
Harm to self or others

S – Safety in PD

Suicidal ideation and Suicide Behaviors

- 28% Death ideation
- 11% Suicide Ideation[1]
- 4% Lifetime suicide attempt
- 22.7% Suicide/death ideation[2]
- PD deaths by suicide ~ General population[3]
- Rates in Veterans not known
- Suicidality associated with Major Depression[3]

Risk of harm/violence to others
Increased risk with

- dementia/agitation
- psychosis

[1]Weintraub 2009; [2]Kostic 2010; [3]Shepard MD et al JNNP 2019

Is your treatment a MESS?

U.S. Department of Veterans Affairs

Parkinson's Foundation

Safety & Suicide Prevention

S – Safety in PD

Advance Safety Planning

- Awareness of distressing triggers, symptoms, thought
  - Identify + internal coping actions to take to reduce symptoms
  - Identify + external coping actions to take to avoid if in crisis

Suicide Prevention Measures

- Time + Distance are on your side
- Ask if concerned, stay with person
- Lethal Means Counseling
  - Use gun locks for routine safety
  - Temporarily remove weapons, other lethal means based on MH status
- +++Treatment of MH conditions
- Psychotherapies specific for suicidality
- Veterans Crisis Line: 1-800-273-8255

Communication with Your Clinical Team

Talking about MH Issues

Mental health, like any other medical condition, impacts overall physical health and well-being

- Clinicians *may not* realize MH issues are important or relevant if you don't bring them up and you don't appear different from usual
- Identify concerns you want to address at an appointment
  - If MH issues are your greatest concern, bring those up first!
  - Call if you experience changes in your MH. Don't wait for an appointment weeks to months away. Many times, there is a quick fix (e.g., urinary tract infections, medication side-effect)
- Best practices involve regular screening for MH symptoms
  - Find out what screening tools are used by your clinical team. If that tool isn't picking up on your problem, make sure the team knows so a different tool can be used to track your targeted issue.
- Tips for starting a conversation about MH issues with your clinical team

VA Whole Health Program

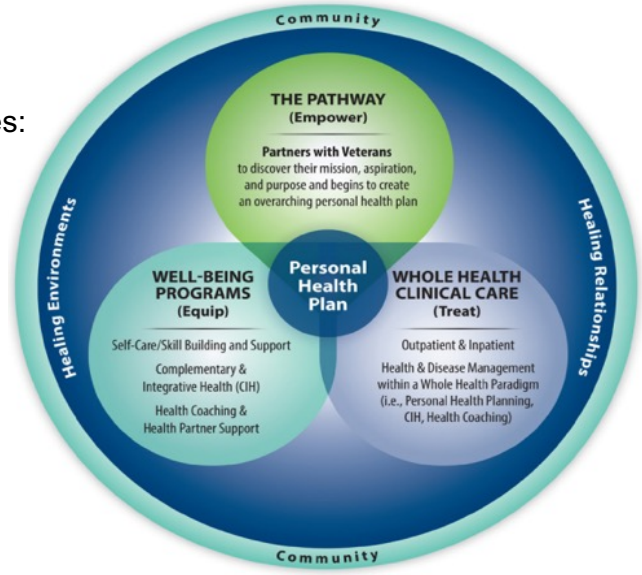
U.S. Department of Veterans Affairs

Parkinson's Foundation

Transforming VA Healthcare Delivery: The Whole Health System of Care

Promote Whole Health Principles focused on patient goals and maximizes:

- Motion/Exercise
- Nutrition
- Sleep
- Spiritual Well-being
- Relationships and other Social Supports



Components of Proactive Health and Well-Being

U.S. Department of Veterans Affairs

Parkinson's Foundation

Summary

MH conditions and symptoms occur over the course of PD

- Including before PD is diagnosed

Variety of MH conditions, each with distinguishing features

- People with PD may have more than one

MH conditions are treatable

- When treated (many options and approaches), overall experience of PD improves, and people live a better quality of life

VA Mental Health Resources

Uniform Mental Health Services Act

Outpatient Psychiatric Care and Psychotherapy Services

- Primary Care-Mental Health Integrated Care
- General Mental Health (Specialty MH care)
- Subspecialty programs for Substance Use, PTSD, Serious Mental Illnesses, Geriatric Psychiatry, Neuropsychiatry
- In-person and Virtual treatment
  - Extensive evidence-based psychotherapy options, including for PD

Additional Resources

- Inpatient psychiatric hospitalization
- Vocational Rehabilitation Services
- Homeless & Housing Services
- Chaplain Services
- Palliative Care
- Home-based Primary Care
- Social Work Services
  - Home Assistance
  - Caregiver Support Program

Veteran Service Centers
(Vet Centers)

U.S. Department of Veterans Affairs

Parkinson's Foundation

For Veterans of:
- Combat zones and/or
- Any era who experience sexual trauma while serving active duty

Provide Community-Based Counseling
- Readjustment counseling re military experiences, mild challenges to severe PTSD.
- Bereavement counseling for parents, spouses, children of Armed Forces Personnel/Reservists/National Guard who died in service to our country.
- Individual, group, couples & family counseling.
- Substance abuse assessment and referral.

No 5-Year Eligibility Limit

Care is Coordinated with the VA
- Records are confidential & not directly accessible by VA staff

Question & Answer

Tracy Weistreich, PhD, RN
Nurse Executive, VHA National Center for Healthcare Advancement & Partnerships

Laura Marsh, MD
Executive Director, Mental Health Care Line, Michael E. Bakey Veteran Affairs Medical Center
Professor of Psychiatry and Neurology, Baylor College of Medicine

Patrick Welch, PhD
Sgt. U.S. Marine Corps (Ret)

Amanda Janicke, LCSW
Helpline Information Specialist, Parkinson's Foundation

Parkinson's Foundation

VA | U.S. Department of Veterans Affairs

Parkinson's Foundation Resources

U.S. Department of Veterans Affairs

Parkinson's Foundation

National Helpline

Speak with Parkinson's specialists and get help finding local PD healthcare professionals.

1-800-4PD-INFO

Helpline@Parkinson.org

Monday – Friday 9am to 7pm ET

Information for Veterans

Visit Parkinson.org/Veterans to find information and resources specific to the veteran community, like our **FAQ Guide**.

Fact Sheets and Publications

Get the resources and information you need to start living a better life with Parkinson's.

Parkinson.org/PDLibrary

Newly Diagnosed Kit

Designed to help you get started on your journey to living well with PD.

Parkinson.org/NewlyDiagnosed

PDGENEration

Parkinson's Foundation national initiative offering genetic testing for Parkinson's-related genes and counseling at no cost.

Parkinson.org/PDGeneration

Aware in Care Hospital Safety Kit

Includes tools and info for people with PD to share with hospital staff during a planned or emergency hospital stay.

Parkinson.org/AwareInCare

VA Resources

U.S. Department of Veterans Affairs

Parkinson's Foundation

Veterans Crisis Line

1-800-273-8255 PRESS 1

Confidential chat at VeteransCrisisLine.net

Or text 838255

Coaching into Care

Program for families and loved ones of Veterans, helping them encourage the Veteran in their lives to seek support.

Call 888-823-7458

MAKE THE CONNECTION

www.MakeTheConnection.net

Online resource featuring hundreds of Veterans telling their stories about overcoming mental health challenges.

PADRECCs and Consortium Centers

parkinsons.va.gov

Mental Health Resources

VeteransCrisisLine.net/ResourceLocator

Whole Health

va.gov/wholehealth

VA Virtual Hope Box App

Homeless Services

va.gov/homeless or 877-4AID-VET

Post-Traumatic Stress Disorder (PTSD)

ptsd.va.gov

Community Provider Toolkit

mentalhealth.va.gov/communityproviders

VA Suicide Risk Mgmt Consultation Program

Email: SRMconsult@va.gov

Thank you for joining us!

U.S. Department of Veterans Affairs

Parkinson's Foundation

Your feedback is important to us.
Please complete our evaluation after the close of this webinar.

A recording of today's program, a copy of the slides, and a list of resources will be emailed to all registrants within a few days.

For questions, contact Emily Buetow at ebuetow@parkinson.org