Understanding Parkinson’s and Mental Health in the Veteran Community

April 28, 2022

Parkinson’s Foundation Veterans Survey

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Vice President, Strategic Initiatives
Parkinson’s Foundation
Parkinson’s Foundation
Surveys

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

The Why
• More than 19 million veterans in US; less than half receive care through VHA.
• Approximately 110,000 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

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
Outline

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

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

- 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

Mental Health Symptoms *Prior to PD Diagnosis*

**Depression**
- On average, precedes PD by 4 to 6 years

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

Mental Health Symptoms at Time of PD Diagnosis

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

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

Marsh et al. 2010
MH Issues are **Undertreated**

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

- 26.8% (n=26) Asymptomatic, Treated
- 10.3% (n=10) Symptomatic, Partially Treated
- 62.9% (n=61) Symptomatic, No Treatment

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

Palanç et al. 2009; Burn DJ, 2002

### 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

### Motor and Non-Motor Symptoms Over PD Course

Recognizing Depressive Disorders

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**
- Appetite/weight changes
- Sleep disturbances
- Retardation (slowness)
- Fatigue or loss of energy
- Decreased ability to think or concentrate or indecisiveness

**Features of Depression**
- Psychomotor agitation
- Feelings of worthlessness/excessive guilt
- Recurrent thoughts of death, suicidal ideation, or suicidal attempt or plan

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Palanci et al. 2009

Recognizing Depressive Disorders

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)


Prevalence of Anxiety Disorders in PD

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Panic disorder</td>
<td>13 – 30</td>
<td>5</td>
<td>8</td>
<td>4</td>
<td>1.5/1</td>
</tr>
<tr>
<td>Specific Phobia</td>
<td></td>
<td>16</td>
<td>-</td>
<td>-</td>
<td>5.5/5.5</td>
</tr>
<tr>
<td>GAD</td>
<td>0 - 40</td>
<td>4</td>
<td>3</td>
<td>21</td>
<td>0.8/1.6</td>
</tr>
<tr>
<td>Social phobia</td>
<td>15</td>
<td>7</td>
<td>13</td>
<td>10</td>
<td>3.7/4.5</td>
</tr>
<tr>
<td>Agoraphobia</td>
<td>-</td>
<td>1.6</td>
<td>-</td>
<td>16</td>
<td>-/2.3</td>
</tr>
<tr>
<td>Post-traumatic stress disorder</td>
<td>-</td>
<td>0</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anxiety Dis NOS</td>
<td>-</td>
<td>22%*</td>
<td>-</td>
<td>11%**</td>
<td>-</td>
</tr>
</tbody>
</table>

*DSM-IV-TR; **Based on NPI anxiety subscale cut-off >3
Distinguishing Features of Anxiety Disorders

+ 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

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

<table>
<thead>
<tr>
<th></th>
<th>Prevalence (n=160 PDP)</th>
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</thead>
<tbody>
<tr>
<td><strong>Hallucinations</strong></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>98%</td>
</tr>
<tr>
<td>Auditory</td>
<td>97%</td>
</tr>
<tr>
<td>Tactile</td>
<td>48%</td>
</tr>
<tr>
<td>Olfactory</td>
<td>23%</td>
</tr>
<tr>
<td></td>
<td>16%</td>
</tr>
<tr>
<td><strong>Delusions</strong></td>
<td>76%</td>
</tr>
<tr>
<td>Stealing</td>
<td>33%</td>
</tr>
<tr>
<td>Not my house</td>
<td>29%</td>
</tr>
<tr>
<td>Infidelity</td>
<td>29%</td>
</tr>
<tr>
<td>Abandonment</td>
<td>26%</td>
</tr>
<tr>
<td>Imposter Spouse</td>
<td>20%</td>
</tr>
</tbody>
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### PD Medication Related Mood Syndromes

- **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

Motor
- Dyskinetic
  - On
  - Off

Mood
- Happy
- Neutral
- Sad/Anxious

Fluctuating Motor State

Levodopa dosing

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

## Behavior Control and Behavior Disorders

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Prevalence</th>
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</thead>
<tbody>
<tr>
<td>Pathological Gambling</td>
<td>3-8%</td>
</tr>
<tr>
<td>Hypersexuality</td>
<td>2.5%</td>
</tr>
<tr>
<td>Pathological Shopping</td>
<td>0.4-1.5%</td>
</tr>
<tr>
<td>Punding</td>
<td>1.5-14%</td>
</tr>
<tr>
<td>Compulsive Dopaminergic Med Use</td>
<td>3.4-4%</td>
</tr>
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### Treatment Approaches and Options
Optimal MH Treatment (VHA or Non-VHA)

- 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

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?

**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

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**Is your treatment a MESS?**

**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
- 4% Lifetime suicide attempt
- 22.7% Suicide/death ideation
- PD deaths by suicide ~ General population
- Rates in Veterans not known
- Suicidality associated with Major Depression

**Risk of harm/violence to others**
- Increased risk with
  - dementia/agitation
  - psychosis

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1Weintraub 2009; 2Kostic 2010; 3Shepard MD et al JNNP 2019
Is your treatment a MESS?

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

No one can un-fire a firearm.

For someone in crisis, a locked firearm can mean the difference between a tragic outcome and a life saved.

Watch an informational video and learn more at VeteransCrisisLine.net

To obtain gun locks, email Corey Terhune: corey.terhune@va.gov

U.S. Department of Veterans Affairs

Veterans Crisis Line
1-800-273-8255

Confidential chat at VeteransCrisisLine.net or text to 838255
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
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

Me + Self Care + Professional Care + Community = Whole Health
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

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
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

Resources

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

Fact Sheets and Publications
Get the resources and information you need to start living a better life with Parkinson’s.
Parkinson.org/PDLibrary

PDGENEratation
Parkinson’s Foundation national initiative offering genetic testing for Parkinson’s-related genes and counseling at no cost.
Parkinson.org/PDGeneration

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

Newly Diagnosed Kit
Designed to help you get started on your journey to living well with PD.
Parkinson.org/NewlyDiagnosed

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

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VA Resources

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

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
Online resource featuring hundreds of Veterans telling their stories about overcoming mental health challenges.
Thank you for joining us!

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