

WELCOME TO EXPERT BRIEFINGS

Do You See What I See? Hallucinations and Delusions in Parkinson's

- The program will begin at the top of the hour
- Meeting attendees will be muted and off video

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Do You See What I See? Hallucinations and Delusions in Parkinson's

James Beck, PhD

Chief Scientific Officer, Parkinson's Foundation

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Our Mission



The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.

We have everything you need to live better with Parkinson's.



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Poll: Getting to Know You



What best describes your connection to Parkinson's disease?

- Person with PD
- Spouse/Partner
- Parent has/had PD
- Other family
- Healthcare Professional
- Physician/Clinician
- Scientist/Researcher
- Nurse/Nurse Practitioner
- Other

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For Your Convenience



Recording

Expert Briefings are recorded and archived on www.Parkinson.org/ExpertBriefings



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Meet Your Expert



Megan Gomez, PhD

- Clinical Psychologist
- Tibor Rubin Medical Center
- Long Beach, California

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Do you see what I see? Hallucinations and Delusions in Parkinson's

Megan E. Gomez, Ph.D.
Staff Psychologist
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Disclosures

- I am a Clinical Psychologist (licensed in State of CA)
- No financial disclosures

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Learning Objectives



1. Understand what Parkinson's-related psychosis is, with particular attention to hallucinations and delusions,
2. Learn how people with Parkinson's and their care partners may be impacted
3. Review strategies for coping and potential medical treatments for troublesome hallucinations or delusions

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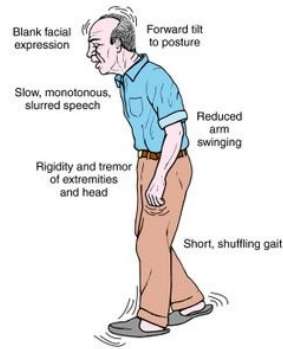
Outline



1. Non-motor symptoms of PD
2. Parkinson's related psychosis
3. Hallucinations and Delusions
4. Impact on PwP and care partners
5. Strategies for coping and potential treatments

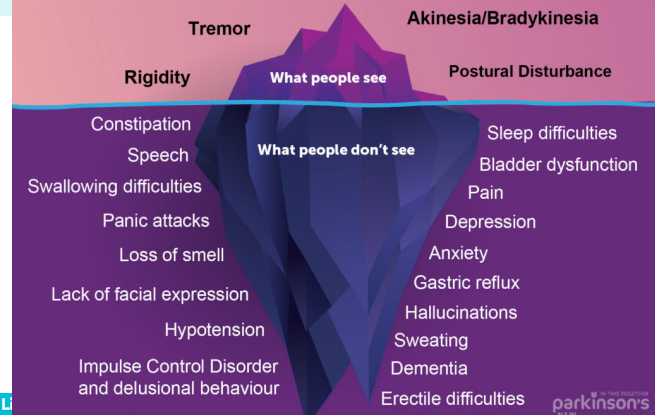
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Parkinson's Disease



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The Parkinson's Iceberg



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Non-motor symptoms of PD



- Some are easier to talk about (loss of smell, eyes, pain)
- Some are more sensitive and harder to discuss (more stigma)
Possibly due to fear of being judged by others, worrying loved ones, feeling self-conscious and embarrassed, feeling shame, feel hopeless
- Tend to avoid discussion, deny symptoms, tend to isolate, reluctant to ask for help

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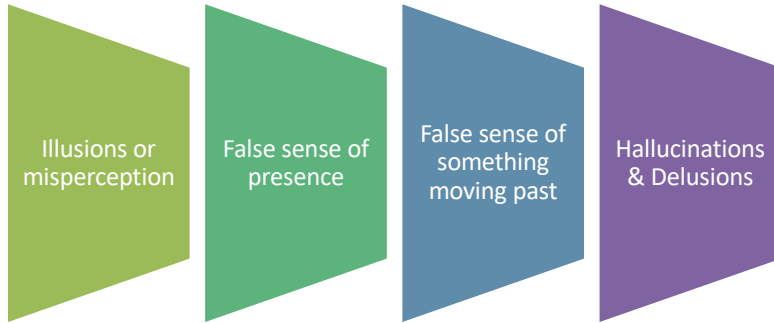
Process



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Spectrum of Severity



Illusion or misperception



False sense of presence



Sensing a presence (stranger or familiar)



False sense of passage



- Fleeting movement in the periphery
- When you look, they are gone



Hallucinations



- Hallucinations are perception-like experiences that occur without an external stimulus.
- They are vivid and clear, with the full force and impact of normal perceptions, and not under voluntary control.

Hallucinations



Visual
Hallucination



Seeing people
(living or
deceased)
or animals

Auditory
Hallucination



Hearing voices
or music

Olfactory
Hallucination



Smelling odors

Tactile
Hallucination



Feeling something
touching or
moving on the skin

Visual Hallucinations



- Seeing someone sitting in your living room, at the dining table
- Seeing military boot camp in your backyard
- Distorted people or animals
- Figures hovering on the ground
- Spiders on the wall
- Mice darting across the floor
- "Dreaming when you are awake"

Visual Hallucinations



- Small people are common (can be very tiny)
- Can be mischievous or innocently behaving
- Can be small cats, dogs or other animals that run around
- Can be threatening or non-threatening
- People morph to animals
- Cartoon like people
- Dwarf sized people

Auditory Hallucinations



- People doing yard work
- People down the street having a party and playing loud music
- Someone using a drill or chain saw outside
- Hear people living in washing machine
- Hear people under the house or in the attic
- People walking on the roof

Delusions



Delusions are fixed beliefs that are not amenable to change in light of conflicting evidence.

Delusions (themes)



Persecutory
Delusion



Believing someone
is trying to harm,
steal from,
or deceive you

Jealousy
Delusion



Believing someone
is cheating on you

Reference
Delusion



Believing a
song or TV show
is speaking
to you directly

Delusions



- Can cause great deal of distress
- Can cause suspiciousness of those close
- Can cause a violent or angry attitude towards those close
- Can cause conflict in relationships
- Can cause legal/safety problems
- Can cause social embarrassment
- Can cause stress and more social isolation

Fregoli Delusion



The belief that different people are in fact a single person who changes appearance or is in disguise

Cotard's Syndrome



Delusion that one is dead, decaying, does not exist, or has lost their blood or internal organs

Capgras Syndrome



Delusion that a friend, spouse, parent, another close family member, or pet has been replaced by an identical impostor.

Asks wife: Can you please get my wife?
Where is my wife?
You are not my wife!
You are pretending to be my wife.

Othello Syndrome



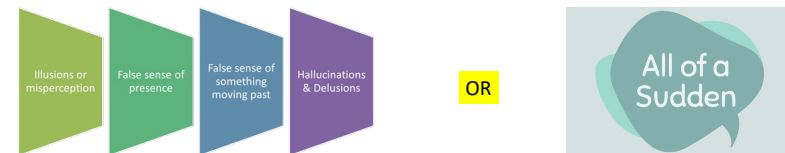
Delusion involving jealousy and characterized by the false absolute certainty of the infidelity of a partner, leading to preoccupation with a partner's sexual unfaithfulness based on unfounded evidence.

Delusions



Caregivers are more likely than PwP to recognize the presence of hallucinations and delusions and may provide important insight.

PD Psychosis vs. Delirium



Delirium

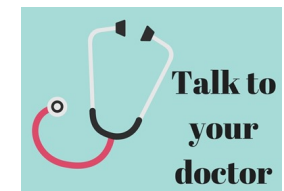


- Confusion/disorientation
- Normal to delirious in **a few hours/days**
- Changes in attention and energy level
- Altered Sleep Wake Cycle
- Hallucinations and/or delusions

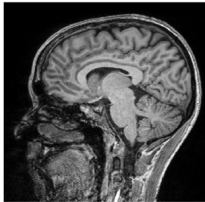
Main Causes of Delirium



- Infections (UTI, pneumonia)
- Medications
- Dehydration
- Substance withdrawal
- Very high/low blood sugar
- Low blood pressure
- Post surgery
- Organ failure



Cause of PD Psychosis



OR



Prevalance



~50% of PwP experience hallucinations or delusions over the course of the disease (could be higher)

~90% of PwP do not proactively tell their physician about it.

Potential Impact



Hallucinations and delusions

- Can be benign and not bothersome
- Can reduce quality of life for PwP
- Can cause safety issues (crawling under the house, moving outside furniture in, rearranging bedroom, fall risks, physical aggression, lack of sleep for household, frequently calling 911)
- Can increase caregiver burden, cost of care, risk of hospitalizations, and placement in long-term care facilities

Medical conditions that can cause psychosis



- Malignant lung neoplasm
- Brain tumor
- Multiple Sclerosis
- Lupus
- Depression
- Bipolar disorder
- Schizophrenia
- Stroke
- Dementia
- Steroid treatment for autoimmune disorders
- PD

Hallucinations



- More common in people with cognitive problems, depression, sleep problems
- Absolute dose in PD medications is not associated with hallucinations.
- Increase in PD medications is associated with hallucinations.
- Most PwP will experience hallucinations after 10 years of diagnosis

Hallucinations



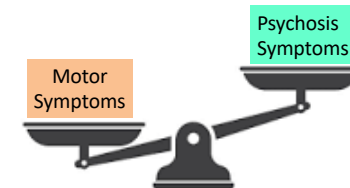
- Even with insight it is a hallucination, can still be distressing
- Hallucinations can occur occasionally or be constant
- Can be progressive and disabling
- Can be demoralizing and fragmenting to home life

Hallucinations



Less likely to occur when stimulated
More likely to occur when alone, not engaged
More likely to occur at nighttime (dark)
More likely to occur with vision problems

Trade-offs



Medication adjustments



- Discuss your symptoms with your medical providers
- Elimination of non-essential medications
- Reduction in necessary medications
- Start medication to help treat hallucinations and delusions

Advances in treatment



- More attention to the topic of hallucinations and delusions is PD.
- More clinical assessment and discussion
- More research and drug therapies
- Some antipsychotics worsen PD motor symptoms by blocking dopamine receptors and can cause side-effects
- Pimavanserin (Nuplazid) has been FDA approved to PD psychosis – some PwP experience full resolution of symptoms, others have some improvement, others don't experience improvement

Things to consider



- Sudden change vs gradual, progressive
- New medications
- Hallucinations commonly start when PD medications are increased
- Hallucinations can improve with reduction of PD medications
- Error in current medications

Things to consider



- PwP who experience hallucinations or delusions may become more restless or emotional (fearful, angry, suspicious, agitated)
- PwP who experience hallucinations or delusions may change their routine or behavior (controlling, monitoring/checking, moving items, being watchful, on guard)
- PwP who experience hallucinations or delusions may lose confidence, self-esteem (anxious)

Things to consider



- New environments can increase hallucinations/delusions
- Travel
- Hotel
- Hospital
- New home
- New room

Acknowledge symptoms



PwP who experience hallucinations or delusions may try to keep these experiences a secret from family or medical providers

- Fear of being judged
- Fear of being labeled "crazy"
- Fear of being put on another medication
- Fear of being institutionalized
- Fear of having drivers license taken away
- Fear of restrictions or lack of autonomy

Values



What matters most to you?
What impacts your quality of life?
What symptoms are most distressing to you?
What symptoms are most distressing to your family caregiver(s)?
What functions are most important to you?

What the PwP can do



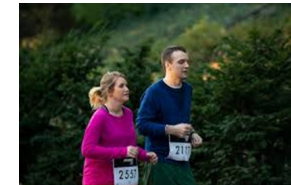
- Focus on your sleep
- Focus on your cognition
- Focus on your physical activity/exercise
- Allow/encourage your family caregiver to take breaks and practice self-care
- Environment: keep room lit, declutter
- Calming: music, photos, pets, reassurance, written letter, voice recording, physical affection, physical activity.

Tips for caregivers



- "These are not real; They are a medication side-effect. You are not going crazy"
- Don't try to rationalize. Leave the room if needed. Don't argue.
- Orient the person (calendar, photos, post-it notes)
- Don't shame
- Keep a routine
- Ask for help from a person that they respond well to
- Remove weapons
- Safety planning – risk assessments
- ER for acute onset, regular medical provider for slow, gradual onset

Self-care for the caregiver



Self-care for the caregiver



- Acknowledging Your Feelings and limitations
- Talking to someone or write down your feelings in a journal
- Identify biggest sources of stress and frustration in the caregiving experience
- Identify problems that within your control and those that are not.
- Forgive yourself for not being perfect.
- The dyad's prior interpersonal patterns play a significant role in how caregiving affects the individual.
- Maintain social connection
- Practice stress management skills
- Early practice to prevent caregiver burnout



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2024 Expert Briefings



Wednesday, March 13

**Research Update:
Working to Halt PD**

Wednesday, April 10

**Understanding Pain
in Parkinson's**

Wednesday, May 8

**Trouble with Zzz's: Sleep
Challenges with Parkinson's**

Wednesday, September 11

**Solving the Challenge of
Apathy in Parkinson's**

Wednesday, October 9

**More Than PD: Managing
Multiple Chronic Conditions**

Wednesday, November 13

**What's On Your Mind? Thinking
and Memory Changes in
Parkinson's**

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Before You Go...



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

EXPERT BRIEFING EVALUATION

Page 1 of 1

1. What best describes your connection to Parkinson's disease (PD)?

- ☐ Person with Parkinson's
- ☐ Spouse / Partner
- ☐ Parent has / had Parkinson's
- ☐ Other family of person with Parkinson's
- ☐ Friend of person with Parkinson's
- ☐ Healthcare Professional
- ☐ Other

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