

Parkinson's Disease Psychosis: Out from the Shadows

Introduction

When I was in medical school, the symptoms of Parkinson's Disease I learned were contained in the acronym T.R.A.P— Tremor, Rigidity, Akinesia, and Postural instability. I was taught very little having to do with the many non-motor symptoms that are a part of PD. But since the 1960s, with the introduction of carbidopa-levodopa, along with other subsequent medications, neurologists have gotten increasingly better at managing the motor symptoms of PD. For most people with PD nowadays, the limiting factors in achieving their maximum quality of life are the non-motor symptoms, such as fatigue, cognitive dysfunction, anxiety, and Parkinson's Disease Psychosis (PDP).

What is psychosis?

• Psychosis is a broad term that may refer to a number of different types of symptoms, but always includes some sort of “break with reality.”

• Illusions

- Misinterpretations of something that is actually in the environment.
- Examples include mistaking a balled-up sock as a mouse or seeing a snake out of an electrical cord.

• Hallucinations

— When someone experiences a sensory perception (sight, sound, touch, smell, taste) that did not occur at all (not just misperceived like illusions). In PDP these are usually visual in nature but can occur with any of the 5 senses. Examples include:

- Visual hallucinations: seeing a person, pet, or other animal that's not there.
- Tactile (touch) hallucinations: feeling an object something in an empty hand.
- Auditory hallucinations: hearing one's name called.

• Passage and Presence

- These are two types of experiences that are a sort of “pre-hallucination” that usually begins early in PDP, and do not correspond directly to one of the 5 senses.
- “Presence” is the feeling that someone/something is in the room or house, when there is not.
- “Passage” is the feeling that someone/something has passed by the person, and usually seen only in peripheral vision.

• Delusions

- False beliefs that are not able to be changed or reasoned with despite sufficient evidence to the contrary.
- Examples include spousal infidelity, paranoia, or a belief that food is rotten or poisoned.

What causes PDP?

- It used to be believed that PDP was solely due to side effects of some medications used to treat Parkinson's, but later research found that the effect of medications can contribute, but don't tell the whole story.
- The same degenerative process that damages dopamine neurons in the movement parts of the brain also harms the functioning of other parts of the nervous system, including those which our perceptions and beliefs.

Why hasn't PDP been talked about more?

- Despite its prevalence, studies indicate that 80-90% of people who have PDP do not spontaneously report their symptoms to a healthcare provider.
- It may be difficult or embarrassing for someone with PDP to discuss the thoughts and feelings that they're having. They may not have wanted to be judged as “crazy.” Or perhaps they may simply have not realized it was relevant— I can imagine someone in this situation thinking, “Why would my neurologist care if I have rats in my house?”

- There was no FDA-approved medication for PDP prior to 2016. Given the complexity of managing Parkinson's with limited appointment times, the lack of good treatment options could have decreased the priorities for providers to proactively screen.
- Your healthcare provider may assume there's no problem with psychosis unless you bring it up.

Why is PDP important?

- Hallucinations and delusions are a common cause of arguments and cause tension between the person with PDP and their family members, worsening everyone's quality of life.
- Paranoia could cause someone to refuse to eat or take medications.
- Even hallucinations that are not troubling to the person could increase fall risk if they alter their movements to compensate for something that is not there.
- Compared to people with PD who do not have psychosis, PDP can result in increased rates of hospitalizations and long-term care placement.

What can I do?

- Don't wait to seek treatment for PDP until it's an emergency
 - Not everyone needs to be treated with a medication at the first sign of symptoms but waiting until they progress too far can cause significant distress for the person with PD or their friends and family.
- Proactively advocate for yourself and keep an open conversation with your healthcare providers
 - Talk to your healthcare provider about any experience that is outside of the norm.
 - Keep a journal of symptoms, side-effects, and questions that you want to remember to tell your provider. Appointments are often spread out
- Poor eyesight and poor lighting can increase the frequency of illusions.
 - Keep things well-lit in the evening to reduce shadows in the low light.
 - Reduce patterns in the house by using plain/monochromatic bedspreads, curtains, carpet, etc.
 - Increase contrast, particularly between thresholds (one room to another). Accent walls help PD patients a lot by increasing contrast between one wall and another.
- Some over-the-counter medications for allergies or colds that contain antihistamines can also increase risk of psychosis. Talk with your provider about which medications are appropriate for you.

What can my provider do for PDP?

- Educate you on what to expect, what to look out for, and answer your questions.
- Teach you about cognitive behavioral strategies and coping skills to manage your symptoms while insight is retained.
- Consider adjusting certain medications you may be taking that can contribute to PDP.
- Prescribe antipsychotic medications, if appropriate. There are dozens of antipsychotic medications on the market, but only 3 have been found to have a risk-benefit ratio in people with Parkinson's that is acceptable for common use. Each varies in the amount of evidence of effectiveness and general safety profile.
 - Clozapine ("Clozaril") has been proven effective but has safety concerns requiring specialized monitoring. It is not FDA-approved for PDP.
 - Quetiapine ("Seroquel") has been proven ineffective in 4 out of 5 clinical trials, but is commonly prescribed because it has only mild-moderate safety concerns, without need for specialized monitoring. It is not FDA-approved for PDP.
 - Pimavanserin ("Nuplazid") has been proven effective, and only mild-moderate safety concerns without need for specialized monitoring. It became the first FDA-approved treatment for PDP in 2016.

My loved one talks/yells or fights in their sleep— is this psychosis?

- Sleep disorders are also a common non-motor symptom of Parkinson's, and many people with PD experience what's called "R.E.M. Behavior Disorder." When people without PD dream (the Rapid Eye Movement, or

R.E.M. phase of sleep), our eyes move rapidly, but the body temporarily pauses the activity most of the other muscles in the body. This can break down in PD, and the sleeping person begins involuntarily responding to their dreams. This is not an example of psychosis.

Who is more likely to develop PDP?

- About 50% of people with PD develop psychosis as some point in the illness, but we don't have great ways to predict who those people will be. However, in general, some risk factors for later development of PD are: older age of person, longer time since developing PD, and overall severity of PD.
- As discussed, R.E.M. behavior disorder itself is not psychosis, but it can be a risk factor for PDP.

Should I try to convince them what they're seeing/believing isn't real?

- Early on, the person is generally able to accept that what they're experiencing is a hallucination, and not based in reality. They may develop techniques to determine this themselves or could work with a counselor to do so. However, as the psychosis progresses and their cognition begins to decline (another nonmotor symptom of PD), this insight is lost. Delusions usually develop later in the course of the illness, and almost by definition, leave little room for insight.
- This is one of the most common questions I get and there isn't much research-based evidence to guide this topic, but for the families I've worked with, later on, when insight is lost, trying to correct a hallucination or delusion is more likely to provoke a fight than accomplish anything positive.
- Instead try to just remain calm and validate their distress without agreeing with them. Examples of statements that may work in this situation are "that must be so stressful" or "I'm so sorry you're going through that" or "I know how much that bothers you".

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