Parkinson’s Disease Psychosis

A ROUNDTABLE DISCUSSION

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Parkinson’s disease psychosis (PDP) is defined by the following criteria:

- One or more symptoms of illusions, false sense of presence, hallucinations, and delusions
- A primary diagnosis of PD with subsequent onset of psychosis
- Symptoms that are recurrent or continuous for at least 1 month
- Exclusion of other causes
- Associated features including with/without insight, with/without dementia, and with/without PD treatment

(Ravina et al 2007)

UNDERSTANDING THE PDP PATIENT AND CAREGIVER NEED

**Dr. Goldman:** Parkinson’s Disease psychosis (PDP) is thought to be related to dopaminergic side effects, but clearly it is more than just a medication effect—there are elements of disease and disease progression that may underlie PDP. What do you believe causes PDP?

**Dr. Isaacson:** Over the past several years there has been a shift in how we think about the underlying cause of PDP. In the past we thought PDP to be a side effect of dopaminergic medication, either overmedication or an idiosyncratic reaction to some of the medications, such as the dopamine agonists. More recently, however, it has become apparent that PDP is really part and parcel of the underlying disease process of Parkinson’s Disease (PD).

**Dr. Pahwa:** Patients who have some degree of cognitive impairment are more likely to show signs of PDP. Moreover, if the patient has PDP symptoms, then there is likely some degree of underlying cognitive issues. Advanced PD is more likely to have cognitive impairment, and, therefore, more likely to have PDP.

**Dr. Black:** In addition to medication, there is clearly a “host factor” involved in PDP. This includes age, longer duration of illness, physical impairment, dementia, and history of depression. These tend to be bigger factors than the medication dose.

**Dr. Goldman:** What is the impact and progression of PDP on the patient?
Evidence suggests that dopaminergic therapy may be a causal factor in PDP, but increasing evidence suggests that underlying neurodegenerative processes are also involved. (Holroyd et al 2001)

Dr. Isaacson: A lot of our patients are much more troubled by PDP than we may recognize in the clinical setting. The hallucinations, delusions, and paranoia associated with PDP impact a patient’s general emotional state, their relationships with family and caregivers, and limit daily activities in and out of the home.

Dr. Pahwa: Once cognition begins to worsen or the dementia begins to set in, the patient is certainly going to decline faster than if they didn’t have dementia or cognitive features. Once these symptoms appear, we monitor the patient more closely and discuss it with the patient and family. My concern is that the progression of PD is going to get worse.

Dr. Goldman: Do you think that PDP affects the patient and caregiver emotionally?

Dr. Black: Absolutely. The effect on the patient depends on the features of the hallucinations or delusions that they are having. Arguably, the caregiver may be more affected emotionally. Caregivers may be adjusted to assisting their loved ones with motor symptoms, but now there are delusions and/or hallucinations to deal with as well. It can become overwhelming.

Dr. Isaacson: The stigma that many patients and families attach to the presence of these delusions, paranoia, and hallucinations makes them less likely to talk about PDP or to make use of some of the supportive services that may be available.

Dr. Pahwa: It is easier for patients and caregivers to discuss hallucinations than delusions. Emotionally, delusions are more difficult to address, especially when the patient and caregiver are in each other’s company.

Dr. Goldman: The experience of hallucinations, such as seeing or hearing things that are not truly present, can be very scary or disconcerting to the patient and caregiver, especially at its onset. The emotional impact on caregivers is apparent at clinic visits; caregivers also may ask how to respond to the patient when they are experiencing PDP. Delusions, or false beliefs, regarding infidelity, suspiciousness, or that people are not who they claim to be, can have a profound emotional effect and strain on the relationships between a patient and their spouse and family.

Dr. Black: Some studies are now showing that nursing home placement is more highly associated with the presence of hallucinations than any other factor of PD.

Dr. Isaacson: That is an important point. It is not only placement in a long-term facility, but also the fear of such placement. As patients and their families research PDP, they may learn that untreated PDP often leads to placement in a long-term care facility. This can make it much more difficult to try to get an accurate history because the patient or caregiver will not want to highlight symptoms that may hasten facility placement.

**BREAKING THROUGH THE PSYCHOSIS STIGMA TO IDENTIFY PDP**

Dr. Goldman: Do you think that patients in a routine Parkinson’s visit, even at early stages after diagnosis, should be routinely queried about psychosis?

Dr. Black: I think it is quite helpful to have the assessment of psychiatric side effects of medications or psychiatric symptoms as a standard part of every visit with a patient with PD. For instance, I commonly ask patients, “a lot of people taking Parkinson’s medicines will experience hallucinations, has this happened to you?” When the question becomes part of your routine assessment, patients realize that it is an important point of treatment because they are being asked each and every visit. It can help reduce the stigma of PDP.

Dr. Goldman: What types of questions or conversations can health care professionals employ to screen for a diagnosis of PDP, particularly in a very busy clinic setting with many other issues to cover during the course of a visit?

Dr. Pahwa: I use one question from the new UPDRS (http://www.movementdisorders.org/MDS-Files1/Resources/PDFS/MDS-UPDRS.pdf), which addresses both hallucinations and delusions. This gives me an idea if a patient is having hallucinations and how often they occur. I use this as a starting point to further the discussion, such as the severity of the hallucinations and how they are affecting the patient’s lifestyle. This is particularly useful in the clinic setting.

Dr. Isaacson: I make use of intake questionnaires with some of our clinical assistants querying these symptoms initially. However, I think clinicians should ask patients directly about some of the more important symptoms because they are often minimized on questionnaires.

Few patients (10%-20%) spontaneously report their psychosis symptoms. (Fénelon et al 2000; Fénelon et al 2010)

Dr. Goldman: Do you think there are some ways that are more approachable to ask patients and caregivers about the range of PDP symptoms?

Dr. Black: One question that I think works for many people is to ask: “Is your mind playing tricks on you?” This phrasing reminds me of visual or optical illusions that we all encounter and brings it to a familiar level. Another way to frame the conversation is to tell the patient: “If we prescribe medication for PD, it does not just go straight to the movement part of the brain. It is likely going to affect other parts as well and that is why we ask about these types of symptoms.”

Dr. Goldman: I think it is important to ask about PDP symptoms in a non-threatening and non-judgmental fashion. One el-
mment that helps break down this barrier is educating patients and caregivers about potential drug side effects and common non-motor or neuropsychiatric symptoms experienced in PD so that questions regarding PDP (or even cognition, mood, behaviors, or sleep) do not seem "out of the blue." It is also good to get in the habit of asking about the range of PDP symptoms—hallucinations in non-visual modalities (hearing, feeling, smelling, or sensing things that are not present), misperceptions, illusions, and shadows. When I see PDP patients who also have dementia, it is not uncommon for the caregiver/spouse to nod in agreement when I’ve asked about suspiciousness or infidelity and to express appreciation in learning that these features were actually part of PDP.

Dr. Goldman: What about that relationship between the neurologist, the movement disorder specialist, and the psychiatrist?

Dr. Black: I am fortunate because I work in the same location as the neurologists treating these patients. It is much easier for the neurologist to refer a patient to a psychiatrist in the same office. Many patients are resistant to going to a new office to meet a new doctor. But if I am in the other room, it is much easier on the patient and they are more open to it.

Dr. Pahwa: Unfortunately, there isn’t a psychiatrist in our clinic and I will have to refer the patient for a psychiatrist. However, there is often patient resistance, as mentioned earlier, and there can be a communication barrier regarding treatment with the psychiatrist, especially if we do not regularly work together. I often end up treating the patients with PDP symptoms myself, because of these barriers.

Dr. Isaacson: If a patient is seeing a general neurologist, general practitioner, or internist for their PD and they develop PDP, the health care practitioner will sometimes consider the emergence of PDP to be a sign of end-stage PD and may begin discussions with patients and their families about end-stage disease, facility placement, and hospice care. They are not discussing it as part of the progression of PD itself, but rather as the emergence of an end stage of the disease. This could also contribute to the stigma associated with PDP.

Dr. Goldman: Once the symptoms are at least identified, what is the typical patient’s journey from diagnosis to treatment?

Dr. Pahwa: I first ensure that the patient is not medically compromised, such as having a urinary tract infection. If it is not medical in nature, I will reassess their medicines to see if anything can be changed or discontinued. I also ensure that the patient is consuming enough fluids. Older patients especially tend to not consume enough fluids because of the constant need to urinate.

If neither of these lines of treatment works, I may try medication. However, I hesitate with medication because of adverse effects, such as daytime somnolence and orthostatic hypotension. I have to be convinced that the psychosis is bad enough to initiate treatment.

Dr. Isaacson: There is also brief psychosocial counseling which can be performed by a caregiver daily. Caregivers can be advised to get patients involved with outside activities, day groups, and support groups. These kinds of experiences can be helpful because patients are more socially engaged. But if there’s an underlying psychosis, I think we have to think about treating it medically.

More than 50% of patients with PD are expected to develop psychosis at some time. (Forsaa et al 2010)

Dr. Goldman: Are there certain things that tip the balance as to when to treat?

Dr. Isaacson: In the past, treatment plans have focused on lowering dopaminergic therapy in an attempt to lessen the psychosis. But a decrease in PD medication often worsens motor function. Therefore, a patient could potentially have worse motor symptoms related to the emergence of PDP. If we discontinue or lower some of the medicines we use to treat the motor symptoms of PD, and patient’s motor symptoms worsen, I think that is a signal that we should probably begin an antipsychotic drug instead of reducing dopaminergic medications. The problem is we are so limited in our antipsychotic treatment choices right now that it drives us away from earlier treatment with antipsychotics.

Dr. Pahwa: Before I start medication, I ask the caregiver and the patient if the hallucinations are bothersome. If they say no, I will not start treatment. But if the caregiver or patient express that the symptoms are bothersome, I will add a medication.

Dr. Goldman: I think that point is really well taken because it is a spectrum, and I’m sure we all have patients who actually find some of their hallucinations comforting. Sometimes these more comforting hallucinations encompass young children playing outside or a person that the patient remembers fondly sitting in the home. But we also have patients who believe that their spouse is having an affair or there are imposters in their house, or see imaginary bugs on their arms and injure themselves by scratching. There is no one-size-fits-all approach.

IDENTIFYING AND EXECUTING AN EFFECTIVE MANAGEMENT PLAN

Dr. Goldman: What are the management goals of PDP and when do we know we are successful in managing these symptoms for both patients and caregivers?

Dr. Isaacson: One goal is to stop, or at least significantly lessen, the psychosis symptoms. But with that in mind, we must allow continued optimal management of the motor symptoms. I think these two goals are intertwined and have to be considered together when making treatment decisions. When we choose therapies to try to improve psychosis, we also have to ensure we are not going to worsen motor function or create a side effect like somnolence.

Dr. Goldman: Is there a sense of how we target the treatment of PDP? Do we target the severity and frequency or aim to stop the hallucinations or psychosis?

Dr. Pahwa: The ultimate goal is that the hallucinations would go away, but it is not going to happen all the time. It is important to note that we also want to target delusions and sleep disturbances as well.

Dr. Goldman: How do comorbidities, such as cognition, mood, anxiety, and apathy, influence your approach to treatment or querying the patient and their caregiver?

Dr. Black: Typically, I will not change my approach with people who have severe depression and psychosis. However, it would affect things substantially if there is a prior history of a psychotic illness, or a prior history of mania or psychotic depression, because in that case you may not be dealing with the same problem as the more typical patient with PD who has hallucinations beginning in their sixth or seventh decade.

Dr. Pahwa: If I have a patient who has some degree of psychosis, but has a lot of anxiety and insomnia, I am much more likely to treat that patient right away. The reason is that even though the hallucinations may not be that bad, if I can bring the anxiety down or if I can improve the sleep, the psychosis could also improve. So, yes, these comorbidities do play a part when I am thinking about treating these patients.

Dr. Goldman: What if a patient does not have caregiver support? How does that change your approach?

Dr. Pahwa: If a patient does not have a caregiver, it can be very difficult for them, the patient, to come to terms with PDP. Are the worms on the carpet really there or not? A caregiver would help them distinguish between the hallucination and reality. Also, if the patient does not have a caregiver, they are more likely to be in a nursing home or long-term placement facility.

I think my threshold to treat is much lower if there is a caregiver involved because we will have a better understanding of the patient history and know there is support for the patient. Conversely, if a patient comes in from a nursing home needing treatment, there are many more unknowns.

Dr. Goldman: What do you think are the important aspects of patient safety in PDP?

Dr. Black: Safety is one of the most important concerns when you discover psychotic symptoms that are beyond mild or trivial. Clinicians will have to judge the questioning needed based on the context of the PDP symptoms. For instance, you will be asking a lot more of a patient who has persecutory delusions than someone who occasionally sees a spot on the wall or an imaginary bunny run by.

It does happen that a patient with PDP may become aggressively suspicious of something or they may call the police because “people” won’t stop bothering them and they are going to go do something about it next time. These types of circumstances have to be taken into consideration as part of patient management. The sensible step for most doctors would be to refer these patients to the emergency room.

Dr. Goldman: How large is the unmet need in PDP management?

Dr. Isaacson: We have all been frustrated by the lack of awareness and education of PDP in our patients; by the lack of effective treatment options that are easy to use; and by the use of some therapies that can worsen motor symptoms in attempts to treat the PDP.

With a better understanding of PDP as a part of PD and not merely a side effect of dopaminergic medications, we will hopefully enter an era where we can have better PDP treatment options along with increased opportunities to raise the awareness and recognition of this important non-motor problem.

Dr. Pahwa: PDP is a major unmet need in PD. Currently, we do not have any approved medications for this indication. The medications we do use have troublesome side effects, so it weighs heavily on the decision to treat. We are struggling to treat these patients.

Dr. Goldman: There is not only an unmet need in terms of treatment, but also in terms of education and recognition. Even though in recent years we’ve made tremendous gains in motor and non-motor symptoms, there is still so much more that needs to be done.

The whole field of PD has changed over the years. It is recognized as a multisystem disease that has nonmotor elements throughout its whole course. It requires thinking about PD in a different capacity and elevating some of these non-motor symptoms to as important, and in some cases or at some times, perhaps even more important, than motor phenomenon or motor complications.

SUGGESTED READING