

Parkinson's Disease Psychosis (PDP) with Dr. Christopher Goetz
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Melani Dizon (Director of Education, Davis Phinney Foundation)

Hi, and welcome everybody to Parkinson's disease, psychosis webinar. My name is Melani Dizon. I'm the director of education at the Davis Phinney Foundation. And today I am here with Dr. Soania Mathur and Dr. Christopher Goetz. Hello, thanks for being here. I'm thrilled to have Dr. Soania Mathur here as our moderator. She is a member of our board of directors. She's a former family physician, and she's been living with Parkinson's for over 20 years. She's also a founding member of the PD Avengers. If you don't know what this organization is yet, I highly recommend you check them out. At some point it's PD Avengers.com. It's an initiative to unite a global group of 1 million actively engaged activists, activists, advocates to raise awareness of its mission to end Parkinson's so definitely check that out. It's a really great initiative. We're excited about it. Okay. Soania, take it away.

Dr. Soania Mathur (Moderator):

Good afternoon, everyone. As Mel said, my name is Dr. Soania Mathur. I'm a family physician and Parkinson's patient having been diagnosed well over two decades ago. I have the privilege of serving on the board of directors for the Davis Phinney Foundation. I have the great pleasure of being your moderator today. Today, we're going to be exploring a very important topic. One that is really not addressed frequently enough, perhaps because the symptom is not well known to be an issue amongst patients, or perhaps it's too stressful topic to face. But regardless today, we'll be talking about psychosis in Parkinson's disease, the what, when, why and how, and to help us tackle this really important subject is Dr. Christopher Goetz. Dr. Goetz is a professor of neurological sciences and pharmacology at Rush University Medical Center in Chicago, where he serves as the director of the movement disorder program, and also is the director of the Rush Parkinson's Disease Foundation Research Center. Welcome Dr. Goetz. We're very privileged that you could join us today. Dr. Goetz, maybe we could start off our discussion with actually defining the term psychosis. And how would you describe this group of symptoms?

Dr. Christopher Goetz (Department of Neurological Sciences, Rush Medical College):

Well, psychosis is really a psychiatric term, and we use it in neurology and specifically in Parkinson's disease to refer to kind of a spectrum of abnormalities, the archetype that the most salient feature is usually visual hallucinations, and a hallucination is a false

perception of a missed reality. So that a patient who is wide awake--this is not a bad dream, this is not coming out of dreams-- this is a person who is awake, generally sees something that is not there. And one might think, Oh, that's kind of cute. That's sweet. If it's a little child setting the dinner table, but it's not normal. It's not normal and will not be normal. Nobody's going to convince me that that's cute. It's an abnormality. We understand it. It's very frightening to some people. And it is an alert to the doctor and to the patient that we need to be very cautious about the medications and the state of the disease when hallucinations start.

It can progress to be something else, which is a delusion. And a delusion is a false belief. So that one might think that in the midst of these children, in the house, that you are now a daycare center, or you are in fact, the zoo and you are entertaining these children and the animals are in the backyard. And so you start to think about things that are not true and they don't make any sense. And they frighten the family and there may be a great dichotomy. The patient himself may not be so bothered about it, but the doctor needs to be bothered about it. And the family needs to be able to report to the doctor because unlike most aspects of Parkinson's disease, I can't see the hallucination. So you have to tell me about it right now. I ask about it. Many doctors are not comfortable asking about it, and we need to talk about that. How does one present that in front of the patient? How does the patient come forward without frightening the family? How do you make the doctor comfortable to help you? And I think that's what the focus of this whole hour is going to be.

Dr. Soania Mathur:

Absolutely. Just to step back, how common is psychosis in patients with Parkinson's disease?

Dr. Christopher Goetz:

Well, it depends on the stage of where we stand temporally in the history of the Parkinson's disease. It's not common at all at the beginning of the disease. And in fact, if you have hallucinations and you are within the first year or so of the Parkinson's disease, or if you have hallucinations and you're not even on medicine for the Parkinson's disease, I ask always the question, *Is this the right diagnosis?* Because early in the disease, hallucinations are not common. After 10 years of the disease, about 60% of patients in my practice, and I've studied this over my career in a longitudinal basis, they have some form of hallucinations. So it is quite common. And we have to, as physicians, we have to get used to dealing with it.

Dr. Soania Mathur:

Absolutely. I'm so surprised that it's 60%. That was a lot higher than I thought, because it's really a symptom that we, we just seem to gloss over. And we don't as patients really

don't have enough awareness about it. You mentioned, Dr. Goetz, about the visual hallucinations. Are there other types of hallucinations that patients experience?

Dr. Christopher Goetz:

There are what we call multi-sensory hallucinations. So you can have olfactory hallucinations where you smell strange things that aren't there. You can have auditory hallucinations. They're not common. In schizophrenia, auditory hallucinations are very common and visual hallucinations are rare, but in Parkinson's disease, it's exactly the reverse. They're not very many, well-formed auditory hallucinations, but they still can occur. There can be tactile hallucinations, a very common one is a sense of somebody standing behind you. I sense of presence. We call that presence. There are also some hallucinations that are, you don't actually see something, but you have a sense that there's something over in the side of your vision, like a little puppy dog that runs across. You don't actually see anything, but you just know that little puppy dog ran. They're very minor, but they're important that the doctor knows about them. And that's, if we count those, that's where we get to the 60%. If you say, *Oh, well, I'm only talking about that little child setting the dinner table.* Well, then we're down at 30%. There's a different, so we have to choose what we're going to talk about, but I consider them all together because they are abnormal sensations. And we understand what's going on biochemically in the brain.

Dr. Soania Mathur:

I've also heard the term illusion being used. Is that a term that you're familiar with?

Dr. Christopher Goetz:

Well, in the psychiatric world, illusions are a separate entity from hallucination. An illusion is a misinterpretation of something that is there. For instance, there's a standing lamp in your corner of this very building and it's standing there and it's a lamp and a Parkinson's patient may, while talking to you, actually see a person standing there. The stimulus is the lamp. The misinterpretation is a man. And this happens, especially in the evening when the lights are dim and the shadows are great. And you can see in a couch that has a floral design, suddenly there are little faces in it. Or you see a pattern in the carpet and suddenly there are little animals crawling there, and those are illusions, but it's still, it's taking visual information and aberrantly interpreting it in spite of being fully awake and cognizant. So I link them similarly, but in the psychiatric literature, they tend to separate those two. I think biochemically they're very similar.

Dr. Soania Mathur:

Do people who experience hallucinations recognize that what they're experiencing is not real? Do they retain that insight?

Dr. Christopher Goetz:

When we rate hallucinations, we first ask, are they well formed? Or are they vague? Are they illusions or true hallucinations? Each one getting a little bit worse then, is insight retained or is insight lost? When insight is lost, you will fall a bit off the cliff, because now you can't really participate in suppressing the hallucinations. I think we're going to talk about strategies of how do you suppress your hallucinations? How do you help your loved one suppress his hallucinations? But if he doesn't realize they're hallucinations, it's a, it's a hard task to accomplish. So that switch over from insight to loss of insight is actually pivotal. It's like in Parkinson's disease, the motor aspect, if you start to fall, suddenly the world is very, very different. There's that kind of cliff and it's all going along. But once you start falling, life is very different. Well, once you lose insight into hallucination, life is very different. And then finally that the greatest severity is when there's delusional thinking, as I said before, all right, so there's a spectrum.

Dr. Soania Mathur:

And is there a timeline or a time course that you find that moment, the switch happens?

Dr. Christopher Goetz:

No. I don't think that that's what we, the duration of disease is a very important risk factor for hallucinations, but exactly the time point at which they develop is hard to register. Except I would still argue that in the very first years, if you start having hallucinations and you're not even on medicine or the diagnosis was within the last year or two years, if you've just been diagnosed, the likelihood that you have a different diagnosis is quite high and that needs to be revisited. But otherwise, if this is chronic treatment, this could develop at three years, five years, it may never develop.

What's interesting, I took a patient over a decade ago. I asked 80 patients to participate in a study with a commitment that if they were around and if they still liked me, they would stay in the program for 10 years. And I put them into different categories. Many-- 40 of them--did not have any hallucinations at the time. And others had hallucinations at different severities. And every year we interviewed them and I was just treating their Parkinson's disease. And we saw that over time, more and more patients started to hallucinate. And once you started to hallucinate, there might be a little bit of in and out. But by and large, you stayed a hallucinator. Once you develop that trait, the actual severity might shift, but you still have that trait. So it does. It's the duration of the disease has a lot to do with the propensity for these hallucinations. The actual exposure to medication, while you need in almost all cases to have medication, dopamine medications, to develop hallucinations, the actual dose of the medicine doesn't actually predict whether you will hallucinate or not. It's not that clear cut. It's not, it's not like dyskinesia. Some of the audience will know that what Michael Fox has, all that jerky movement, that directly relates to how much dopamine is floating through the system.

But that's not how hallucinations work. You can have hallucinations when you're completely off and the medicines aren't even working and you're hallucinating. It's not like dyskinesia. It's very, very different.

Dr. Soania Mathur:

Is that relative to the fact that you're on medications in terms of the severity of your disease, or is that due to the medications themselves, do you think?

Dr. Christopher Goetz:

Well, if we, we have to kind of deduce this, the dose of medicine that you're currently on does not predict well whether you're hallucinating, if on the other hand, no matter what dose you're on, if I pull back on your medicines, the hallucinations tend to get better. So the first thing the doctor wants to do is to look at the medication schedule and see, is there anything that's optional? Is there anything that was recently added that was kind of fine tuning that you were just trying to make things a little bit better, get rid of those things. More importantly, and more likely is that something else is going on. That the patient is suddenly medically ill, has a urinary tract infection, has pneumonia, or another doctor has introduced a new medicine. So you have to look and say, why did these hallucinations suddenly appear? Or did they suddenly get worse? And make sure there's not a medical explanation before we start looking at our dopamine drugs, but even then, lowering the dopamine drugs will help the hallucinations.

Dr. Soania Mathur:

So what you're discussing, Dr. Goetz, I guess, is what we call delirium, is that correct? That some of the medical aspects of urinary tract infection, pneumonia, and that sort of thing?

Dr. Christopher Goetz:

There can be, but even in a patient with a chronic hallucination syndrome, right. Percolating along and has insight, if he gets just a minor injury, a minor infection, delirium is a kind of extreme case where people are very agitated and they're jumping around and they're screaming and yelling. It's not to that extent, but yes, there can be delirium instances where people get the wrong drug or they get very deeply infected. Those people will hallucinate and then they'll stop hallucinating after you correct the medical problem. The definitions are a little bit tricky medically, but I think you, I think we're all talking about the same concept here, right?

Dr. Soania Mathur:

You mentioned medications, you mentioned stage of disease. Do we know what else might be causing these hallucinations?

Dr. Christopher Goetz:

Well, we know that the trickier, that Parkinson's disease doctors are a small group of people who dedicate their life to Parkinson's disease. And those doctors are almost all very visually skilled because the diagnosis of Parkinson's disease is not done through a blood test. It's not done by listening to the arteries. It's not done by looking at a scan. No, you have to look at your patient. So you have to be very visually savvy. And so in this area of expertise, one would think we would study what we can see. And I can tell you, in my early career, I was interested in hallucinations and my teachers discouraged me. They said don't go in that direction. No, no, no, you do dyskinesia. Do motor fluctuations, do something you can see. Right. And I said, well, but that's not what fascinates me. I want to see what my patients are experiencing, but I have to study it not just with my eyes.

So I have looked at scans of people who are hallucinating and those people who are not hallucinating. It's very hard to get a patient to actually hallucinate in the scanner. Because one of the features that typically promotes hallucinations is a quiet environment, an under-stimulated environment. And that's why hallucinations tend to be in the evening. They tend to be when there is no company around. And so the poor spouse is there with the patient and then things kind of explode. And then the children come over and they say, Mom, what's the big deal? Dad looks fine. And then they go home and then the hallucination starts. So that can be very frustrating. But anyway, I've put the patients into the scanner, and just the fact that they are chronic hallucinators, when I give them visual stimuli, like a little bouncing ball or something for them to look at, they don't handle that information normally.

Dr. Christopher Goetz:

Typically, in a patient without Parkinson's disease, and even a patient with Parkinson's disease who doesn't have hallucinations, we'll take that visual information, and it registers in the back of the brain. That's our visual brain. And the more you stimulate and the brighter the light, and the more bouncing, the more stimulation there is, and I can see it in the visual brain, but it doesn't go anywhere else. It stays in the visual brain. Hallucinators are not able to do that. They get the same information, but it bounces up into the frontal part of the brain and they are handling it completely differently. And our job and when we use medications or we use cues, or we use adaptations, is to keep that information in the back of the brain where it belongs and not to allow it to come up and conjure up new images. So the actual anatomy and the handling of the information is very, very different. And so I tell my teachers, well, look, I can see the hallucination. I can't see it the way the patient does, but I can see it. I'm the scientist. And I can see what's happening in terms of the anatomy of the brain. It's very interesting.

Dr. Soania Mathur:

That's incredibly interesting. Very, very interesting. Have you been able to predict who would become a hallucinator based on it? Is that possible based on these scans?

Dr. Christopher Goetz:

I haven't done that, but I don't know. We don't have evidence that treating prophylactically hallucinations will prevent them. I've done a study where--there's a long heritage of kind of a humorous approach to these hallucinations, where doctors kind of, since they're not comfortable, they call them benign hallucinations. That's a medical term in the Parkinson's literature. *Well, Chris, don't worry. They're just little images. They're just, they're benign, they're benign.* But they are not benign if you say benign in the sense that they will not be progressive. They are progressive. And therefore I've done a study where I looked at patients who had these minor hallucinations, and I said, I'm going to treat them. I'm going to treat you with medication, or I'm going to teach you some of the strategies we use to try and keep them quiet, because I don't want these hallucinations to progress.

And my colleagues, and I work with very smart people, but they're not interested in hallucinations. And they historically, until I published this paper, they historically let their patients percolate along and let them have their hallucinations. *They're called benign. Why would I treat them with a drug that might be toxic? Why would I put them through focusing on their hallucinations?* And in fact, in those patients where I treated them and kept them at a low level, they had a better outcome than those that were just left to continue because it is--and we have to acknowledge this--it is a progressive condition, right? We should not let this go. And therefore, I think that people are a little bit more conscious that this term "benign hallucinations" really should be dropped because it connotes that we don't have to worry about it. I think we do have to worry about it. And we now have treatments.

Dr. Soania Mathur:

I agree, and I think that quality of life is very important and it's not these sorts of psychoses don't just affect the patient, but the whole family and care partner as well, to great extent. You mentioned sort of strategies that patients and their care partners can use when they're experiencing hallucinations. Can we talk a little bit about that?

Dr. Christopher Goetz:

I think it's the most common question I get from families is, *Well, should I just let them be and, and laugh with them and just, you know, not, not correct them per se, because that's kind of demeaning.* And the answer is, I do not want to play into this. This is a hallucination. It's like a dyskinesia. It's like a fall. It's something that we just have to wrestle with. We don't pretend you didn't fall, nor should we pretend that you're not

having a hallucination. So families are very hesitant to confront it, as if dad is going crazy. If you say, *That's a hallucination and we're not going to tolerate that, right? Let's blink again. And there is no child here, Dad, we're not going to play into this.* I think that's very important because otherwise you reinforce it.

You don't want to scold the person. You don't want to be pejorative towards them, but hallucination is not normal. So we say, well, that sounds cute, but it's not a hallucination. And that's the kind of approach. So we don't allow the loss of insight to take any kind of ground at home. It's a hallucination.

The other thing is that you don't even have to do it with words. You could say, gee, if an illusion bleeds into hallucination and these things are more common at night, let's turn the lights on. Let's not allow these shadows to precipitate the problem. So I tend to try and have a little bit of extra stimulation, put the music on, keep the lights on. Don't allow this to be just a quiet time when these hallucinations can pop up because there's no other visual stimulation to keep things active. All right. Some patients would have told me, *If I really blink or move my glasses and really look, I can see, it's not a hallucination. I can put my hand out. And eventually I know that that's a hallucination, cause I put my hand right through it and then I don't have to do it anymore.* And if you need to do that, to do it, not to be ashamed that you're not quite sure, but we don't play into these. It's not safe to play into them.

Dr. Soania Mathur:

What about, Dr. Goetz, when it gets to the other sort of end of the spectrum when we're dealing with delusions, because some delusions are obviously real to patients, and they can't really attend to be convinced that they're not right.

Dr. Christopher Goetz:

Well, at the point, as I said, these, these there's a great continuum here. When a patient is delusional, you and your doctor have to be working together. All right? So your doctor has to guide you. You can't have a delusional patient at home with no intervention. It's not fair because that person is suffering. That is not a fun experience, to lose your sense of what is reality. And that's what a delusion is. It is a loss of reality. That's not fair to patients. All right. Even if it's funny, it's not fair. That's not the person who came to us. That is a medication effect and a disease effect. And we must take responsibility to try and help the patient.

Dr. Soania Mathur:

And what about those people who can become quite agitated or aggressive and defensive those beliefs and how can a care partner deescalate that situation at the moment before they, you know, seek medical attention? Is there any way of reasoning?

Dr. Christopher Goetz:

If a person is agitated, it's probably best to step back and just not engage. Not engage. I wouldn't, if correcting is going to make the person more angry, then you don't want to do that. So you don't enter into that dialogue that I was just talking about which is in fact really relating more to the calmer patient. But an agitated person--whether delusional or not, whether they're having hallucinations or not--an agitated patient, you should step back. All right. And the doctor needs to be involved in that.

The very typical thing, and we haven't talked about this yet, but there's a great overlap of sleep abnormalities and hallucinations. And we want to remember that if you can get a person to sleep, often the hallucinations improve. They don't go away. But sleep deprivation is a very bad thing for hallucinators.

And one of the drugs that is commonly used--we haven't talked about drugs yet-- but one of the drugs that's commonly used is called quetiapine. It's not approved for hallucinations. And the actual clinical trials that have looked at it for hallucinations, have not shown that it is successful, but it's widely used. Mainly in my experience, it puts people to sleep. It lets them sleep and they sleep and then they wake up and they're more alert. They're more cooperative, and they're able suppress their hallucinations. The more cognizant you are, the more insights you have, and of course the better you're going to be at suppressing a behavior you know is not right. Right. And that can make a big difference. So I'm not opposed to the quetiapine usage, but it really is a sleep aid and a good one for our Parkinson's patients.

Dr. Soania Mathur:

Is there any--you're speaking of sleep disorders--is there any relationship with REM sleep behavior disorder?

Dr. Christopher Goetz:

No. REM is, I mean, REM behavior disorder and, and abnormalities of sleep are common in Parkinson's disease. And REM behavior disorder often precedes the diagnosis of Parkinson's disease, but those are sleep disorders and hallucinations are not nightmares. Many people confuse them. They're not at all. Hallucinations aren't awake phenomenon. Some people say, well it's--and one of my teachers once said--*well, they're just dreams while you're awake*, which is kind of dismissive. And actually

he's not entirely wrong when you look at the sleep wave cycle, but nonetheless, they are not sleep events. The patient is awake. He's not sleeping. And then acting like he's dreaming. These are, these are stereotypic, repetitive visions. In most cases, I've seen the same thing over and over again. All right. If it's in the brain, it's in the brain. It's being activated. It's not random.

Dr. Soania Mathur:

And are there, you mentioned medications being an issue. Are there certain medications for Parkinson's or otherwise that are associated more with hallucinations or delusions?

Dr. Christopher Goetz:

Well, the dopaminergic drugs are associated with hallucinations. So, and the issue here is any drug that we use to treat Parkinson's can cause and aggravate hallucinations. There are a couple that are kind of particular. If you give amantadine at night--mezzanine is a very good drug for Parkinson's disease, but it is a daytime medicine--and patients who take it in the evening and are not properly instructed, or they just want to take it at night-time, in my view, it is kind of a one-way ticket to hallucinations, and people should be careful about that.

Anticholinergic drugs are not used very much but were very much used at the beginning of my career. They have a high propensity to induce what you were calling delirium. And so they can precipitate hallucinations and agitation specifically. Sometimes drugs that are used for urinary incontinence--and they are anticholinergic drugs used for the bladder prescribed by the urologist--oops. They got into the brain and they cause hallucinations. So looking at the whole program and saying, *What does this patient absolutely need to control this Parkinson's* and eliminating other things is a very wise exercise for the neurologist and the family that they have to do it together with the doctor. Don't just randomly decrease. All the dopamine drugs can do this. There is no safe dopamine drug in terms of at least having some risk for hallucinations.

Dr. Soania Mathur:

And that brings up the point that it's nice when medical professionals work together so that your urologist isn't prescribing something that can aggravate your Parkinson's. And that team approach to care is really so successful.

Dr. Christopher Goetz:

Yes, it is. I think we have to thank president Obama in a way, because it was his idea and his administration that developed the electronic chart, and with the electronic chart,

one can sign to allow other doctors to see your medical record so that when I see my patient, I can look up. If he assigned for me to be able to look at his cardiologist and his urologist, I can see those notes and I can see the combined medications. And that is a distinct advantage to taking a comprehensive look at a patient. That's new though. That is not even a decade old.

Dr. Soania Mathur:

That's really true. Now you mentioned quetiapine. It's a medication that's used quite regularly in Parkinson's. What other medications are there to treat psychosis in Parkinson's?

Dr. Christopher Goetz:

There's one. Let's just take a step back for a minute. Psychosis, as I said at the beginning, is a psychiatric term. We use it in neurology, and psychosis is seen in many psychiatric illnesses. And most of those illnesses are treated with agents that block dopamine. Well, we need to augment dopamine to treat the Parkinson's. So while there are many agents that would stop or improve hallucinations, they all make Parkinson's work. So we don't want to allow those agents to be introduced. There is one agent that has been used and there are trials that demonstrate that it is effective, but it does require medication monitoring. And it is not approved by the FDA specifically for this indication, but there's several strong evidence-based studies and that's called clozapine. And it's a very effective drug in my view, but it does require frequent blood work because you have to be looking out that the blood counts do not change, but it is effective in my view, and that is supported by the scientific literature.

There is one drug, one, that is newly approved by the FDA for the treatment specifically of hallucinations or psychosis in Parkinson's disease. That is called pimavanserin (NUPLAZID®) Pimavanserin is very effective in my view. It takes a little time to work, and that's one of the problems. If a patient is agitated and it takes two or three weeks before this medicine really takes its effect--that's my experience; it's not so much written in the drug's pamphlets and everything, but I've seen many patients who abandoned treatment with other doctors because it didn't work over the weekend. Well, it won't work over the weekend. You have to have a game plan to get the patient to sleep and be calmed down for about two weeks while he's getting the pimavanserin into his bloodstream. And you can pull back on that other treatment and see whether the psychosis is under control.

I think that's a good strategy. Patients, families, doctors have to put in a little bit of time and a little bit of trust to reach that good goal, right? And that's where in my experience--now this is not published or anything, but in my experience, I would use the quetiapine

to get them to sleep at night, get them restful. Let the spouse gets some rest. And start the pimavanserin, start it started, get it going, get it going, get it going. And two weeks later, pull back on the quetiapine and unveil that yes, indeed, these hallucinations are getting better. It's that kind of, but that's, you know, that's a month before you're really set and this is a hard thing to do. That's why I don't like to wait until there's a disaster. I tend to treat much earlier.

Dr. Soania Mathur:

So when should patients or their care partners bring their spouses or loved ones in to see you? At what point?

Dr. Christopher Goetz:

I ask about hallucinations at every single appointment. Now I'm interested in them and I think it's important to treat them, but there is no appointment that is made because of hallucinations. And you have to have them in order to talk about them. I ask about them all the time and I tell people, I'm only asking, just like I ask about dyskinesia, because they can happen. It doesn't mean it's on the conveyor belt. You may never get them, but I want to know about them if they are starting, because I want to alert you of strategies that will help us keep them under control. I think that the pimavanserin company (NUPLAZID®) has put all a lot of ads on the television and they were highly criticized by patients and by doctors that they were alarmist, but at least it got it into the working vocabulary. People started talking about this. But they were kind of scary. And they're not--there's no reason to be scared about it. There's just a reason to be informed about it. There's a big difference.

Dr. Soania Mathur:

Is psychosis a prognostic factor, would say Parkinson's disease?

Dr. Christopher Goetz:

Well, I think that it's a quality of life issue. If we get them under control and the patient's no longer bothered by it, it doesn't have any consequences. It doesn't mean if you developed hallucinations that you're going to fall off a cliff. It means that if you develop hallucinations, I need to treat them so that your quality of life is protected and you can go on with things. We can treat hallucinations. I think more serious is really problematic cognitive decline because, well, we don't have the best of treatments for that. So what do we do when that starts? We try to treat. That's not the way hallucination--we can treat the hallucinations. Just give us a chance. But I won't know about it if the patient doesn't speak up.

Dr. Soania Mathur:

Right. And that's where education comes in for the patients as well, because unlike dyskinesia, which are now pretty well known, really, it's not spoken about enough. I agree. There's a few questions from the listeners that I want to put forward. One person's asking is Parkinson's psychosis the same as LBD or Lewy body dementia.

Dr. Christopher Goetz:

No. They have the same potential import in terms of this, the hallucinations in Lewy body dementia are similar in that they're visual, but Lewy body dementia, by definition, is a condition that starts with cognitive problems, often with hallucinations. And delusions are a particularly early problem and more of an issue than visual hallucinations. As I said in the Parkinson's disease hallucination spectrum delusions are at the end, but in Lewy body dementia, delusional thinking--thinking that my house has turned into a used car dealership, that my wife is unfaithful to me that, that the children are plotting and they got my bank account--those kinds of delusional thoughts are very common in Lewy body dementia, but cognitive problems predominant so that you don't have the insight. You lose that because you don't have the cognition. So under the microscope, the two conditions may look similar at the end because there are Lewy bodies in the cortex and there are Lewy bodies in the brainstem, so they look under the microscope similarly, but their timeframe is quite different. So there could be some overlap, but typically we think of those as very different clinical conditions. Though they are treated similarly.

Dr. Soania Mathur:

So the medications that work for one work for the other?

Dr. Christopher Goetz:

They do, they do by and large in the patients with Lewy body dementia. We often use a cognitive enhancing medicine because they also have so much cognitive problems. Parkinson's patients with hallucinations may have very good cognition. They may not, but they may. Where you can't have Lewy body dementia without being demented. That's part of the definition.

Dr. Soania Mathur:

Speaking of medications, you mentioned about amantadine being taken at night as being an issue with some patients. Someone's asking what about Gocovri, which is given at night.

Dr. Christopher Goetz:

Okay. That's a brand name, for people who are not familiar. That is a brand name of a protein-bound form of amantadine. So that it's very, very, very slowly secreted. So I don't count that. I was talking about standard amantadine that kicks in and works. And if you take it at nighttime, it's working while you're asleep and it can cause a lot of very vivid dreams. And if you wake up, you can have hallucinations out of those dreams. So, now, the long acting forms of amantadine are not included in my statement. I don't think even with the Gocovri studies that they had an increased risk of hallucinations. So I don't mean in any way to bad mouth them at all. Right. It's an old drug with a new formulation.

Dr. Soania Mathur:

Do antidepressants affect the risk of hallucinations, someone wants to know.

Dr. Christopher Goetz:

No, not to my knowledge, no.

Dr. Soania Mathur:

Someone was also wondering about the effect of anxiety. She mentioned that her husband, when he gets anxious, tends to hallucinate more. Is that a known contributor to the frequency of hallucinations?

Dr. Christopher Goetz:

No. I mean, they're different; there's so many different forms of the hallucination. I don't think there's any pattern that would say that anxiety leads to more hallucinations. Some patients are very calm and they're hallucinating because they actually--those hallucinations are familiar to them. I mean, there may be, you know, little puppy dogs and things, and they're not concerned, but the family is very anxious about it so that it can take all issues. Treating anxiety, I don't think, is going to stop hallucinations. All right. I think that that's a separate issue. If a patient is having hallucinations and becomes anxious, because they're frightening, and there people out in the front yard and they don't belong there, then you get anxious, but that's a secondary form of anxiety, not a primary form.

Dr. Soania Mathur:

Right. Does DBS change the frequency of hallucinations or the occurrence of hallucinations?

Dr. Christopher Goetz:

Well, we are concerned very much about that. And most centers that I know including ours would not take a patient to DBS who has active hallucinations. The issue here is that you're putting electrodes, one or two, into the brain. And we don't like to do that in patients with psychiatric issues because we don't, we're not too comfortable that we are, might be playing into those problems. So that is, that's usually an exclusionary criteria for DBS. Whether it's should be, and whether we have, we did a series with the Calusa patients get better, the one thing we can say is that we lower the medicines typically after we do DBS. So could you get around the hallucinations? That simply has not been studied. I would be very cautious because it's irreversible, that electrode is in the brain. I don't like hallucinations. And if I felt I approved of surgery and the hallucinations got better after surgery and I can't do anything about it as a doctor, I would feel very guilty. So I have not recommended in that direction at all.

Dr. Soania Mathur:

Okay. That's good to know. Any distinction, Dr. Goetz, between YOPD, Young Onset Parkinson's Disease, versus older onset of Parkinson's, as far as the susceptibility to hallucinations?

Dr. Christopher Goetz:

Well, age and duration of disease are two factors that are associated with hallucinations. And so when we talk about young onset at any one time, if you do a cross section, most young onset patients are still going to be young. So they haven't had a long duration, but there are young onset patients in my practice. And they've been in my practice for my full career, for 40 years. So they are still at risk for having hallucinations because they've had long duration disease. I think that those young onset patients who survive, they are at a higher risk because they've had longer disease.

Dr. Soania Mathur:

And I'm not familiar with this syndrome, perhaps you are, but someone's asking about Capgras syndrome.

Dr. Christopher Goetz:

Capgras syndrome is not recognizing people, but those are--those are issues, usually that's not hallucinations, those are not recognizing people. And it's usually seen with strokes. But they're strokes that involve the posterior part of the brain, so those are vascular problems. And remember in Parkinson's disease, the blood vessels are normal. It's the nerve cells that have been damaged, but the fiber tracks and the blood vessels, those are the origin of other neurologic conditions, but not Parkinson's.

Dr. Soania Mathur:

Not Parkinson's, okay. There is one patient or person listening who says that their brother takes too much of his medication. I'm thinking he must mean dopaminergic medication and he's able to move so that he can move better. Or maybe he just loses his track and takes too much medication. Is there anything that they can do to help him at the time that he's hallucinating to come down from his episode? I guess we've kind of discussed that.

Dr. Christopher Goetz:

Alright. So, so let me turn it back to you. If I've explained myself, you could get to first base on that answer. What would you do?

Dr. Soania Mathur:

I would tell them that the hallucination, it depends on if he's agitated or not.

Dr. Christopher Goetz:

He's not agitated. He has taken medicine and now he's hallucinating.

Dr. Soania Mathur:

You would tell him he's hallucinating. You wouldn't accept it.

Dr. Christopher Goetz:

Right? You say, Derek, that's a hallucination. Let's turn on the lights. Let's turn on the radio. Let's together, let's kind of overstimulate this situation and dismiss those false images. And if that, if you're seeing things, people out on the patio, I'm turning on the

porch lights. But if we have to, if you want to get on the phone and talk to the children, do that, all right. Let's stimulate this and get rid of these hallucinations because they are not what we want.

Dr. Soania Mathur:

Redirecting their attention. There are a few questions about this because I think this is sort of an issue that comes up quite frequently with delusions, but what can care partners do when their loved one is having delusions about infidelity?

Dr. Christopher Goetz:

Well, it's a horrible situation because it's, even though we understand it, cognitively it hurts. It hurts terribly. And I have that personal experience. My father had a neurologic disease, not Parkinson's, but it got to a point where he didn't recognize me. And I know that that's just his disease, but it still hurts. It still hurts. Your heart breaks. And so this is an instance where somebody is accusing you, and what do you do? And try to face this. This is where the doctor really has to help the patient. You cannot endure this alone and this must be treated.

And I've had families who said, Oh, but Dr. Goetz, you know, you're, you're such a professor. It embarrasses us to have to tell you about these, what life is like at home. I said, But how can I help you if I don't know? And so that's a sense of a call out to all our patients in the audience that your doctor is willing potentially to help you, but he can't guess. And if those things are happening, I find that the doctor's appointment is often a very good place to bring those things up because it's neutral. And you say, Dear, I know this is a hard thing for us to have this conversation, but I'd rather have it in front of Dr. Goetz than at home by ourselves. And it hurts me when you say that I'm seeing another man. It hurts when this happens. And I don't know quite what to do. Maybe Dr. Goetz can help us.

And that kind of conversation alone--and then as I ended, I said, All right, in the future, if this happens, I'm giving you permission--I'm giving your wife permission to say, *Remember what you and your doctor said, that we understand it. And it's part of the Parkinson's disease, but we don't have to like it. We don't have to like it. And it hurts me when we talk this way.* And to be able to say it in preparation--and then it comes back on me. And families, they say, I'm not there, but they say, we use your name almost every day, Dr. Goetz, because it takes the pressure off of them to say it and brings it back into a medical context.

Dr. Soania Mathur:

Right. And what do you advise care partners, Dr. Goetz, in terms of their own self care? And is that really important in these situations?

Dr. Christopher Goetz:

Well, I think it is. I think that care partners are enduring an awful lot and it's, it's not their Parkinson's disease. Parkinson's disease belongs to the patient, and they are partners in it, but it's not their Parkinson's disease. And I don't want them to think it's their Parkinson's disease. They are partners in this, but they still have to look after themselves, and their health matters.

And so these kinds, I think that one of the very hard things about the COVID pandemic is that it's isolated people. They're not able to kind of powwow. They're not able to go out and say, you know, sit in the park. And then somebody sits down and said, *Oh, you know, would you listen to my story?* And just be able to talk to people. Because we've been forcibly telling people to stay indoors. Now we're out. But even that, it's hard. We haven't gotten really over this. And being able to communicate and to share is in fact important, I think to the caregiver's health and that you keep a certain autonomy that this is not, this is not, this psychosis is not mine. It's not mine, I'm a partner in it, but it still isn't mine. And I draw that distinction very strongly. And I also charge my patients saying, *This is your Parkinson's. So when the lights are turned on, you have to try to suppress those hallucinations. I don't want them.* And we work together on this.

Dr. Soania Mathur:

Right, team approach. We're starting to come towards the end of our hour. I just want to ask you something. In general, when people hear the word psychosis, that conjures up some fear in their minds, that they might experience that sort of complication of their disease. Their care partner may feel some sort of stigmas associated with it. And what words of advice would you give to those patients?

Dr. Christopher Goetz:

It is a reality that in every other area of medicine, one doctor's specialty takes care of an organ. So if you have bone problems, only orthopedic doctors are specialists. And if you have a liver problem, only a hepatologist is skilled to take care of it. But the brain is managed by both neurologists and psychiatrists. And there is a great dichotomy. There's a split. And there is definitely a fear element if there is a psychiatric manifestation of a neurologic disease. And somehow if it's psychiatric, it somehow tears worse, even though it's due to a neurologic condition. What I've tried to do in my group is we have a psychiatrist on our staff. If our patients need depressive symptom relief, if

they need anxiety symptom relief, I don't send them to a psychiatrist like they're being spanked. They simply see the psychiatrist who's part of our team.

And that has made a huge difference in allaying some of the anxiety that somehow this is a different problem. It's all the same problem that people have been trained to have different specialties. I think we'd simply have to--and this is something that goes for a long time in terms of education--that having psychiatric manifestations of a neurologic disease is not a sign of weakness. It's not a sign of some kind of additional problem. It's all part of the neurologic disease. And I agree that that is a very hard product to sell in the general environment, right? And most doctor's offices do not have a psychiatrist. So you're being sent out, you're being rejected. You know, *I don't deal with that. Go see a psychiatrist, which is, Oh my gosh, what am I going to do? Wait in a waiting room with crazy people?* That's the advantage of having a psychiatrist on our staff. It's the same waiting room you're called in. It has none of the stigma. And I think that we have to sort of use that model in our minds if we don't have it in our offices, but I've done it specifically to address that very issue.

Dr. Soania Mathur:

Oh, and I think that's really vital, and it's such an important message for people to learn that this is just part of your disease. It's part of it. And it's just like you would complain or let your physician know. But any other symptom that you're experiencing in your disease, it's the same thing. We need to sort of push that stigma or idea of what we think it is aside.

Dr. Christopher Goetz:

I would say that patients have told me that when they've told their other doctors--it's on their face, that the doctor doesn't want to deal with it. The doctor doesn't want to deal with that. Let's go back to your tremor. Let's go back to your falls. Let's go back to...Doesn't want to, so there's some medical education as well. And I've worked very hard at the international level to make sure that our movement disorder and Parkinson's specialists are comfortable with this as well. And there's a good amount of education to come because the patients often they come, but they have to be embraced. If you start saying something like this, the doctor has to look at you and say, well, tell me more. And if they don't, if they say, *Oh, let's get, let's get back to that tremor*, you're silenced. Then what do you do? You go home in fear. So, so it works all ways. All right. Let's, that's why these are good discussions.



Dr. Soania Mathur:

Absolutely. Dr. Goetz, thank you so much for your insight. It is greatly appreciated. And thank you everyone for joining us today. I hope that you found your time with us helpful and educational. We'll be sending you a link for the recording of this webinar in the next few days that you can share with others and we encourage you to do so. And always remember, you may not have control over your diagnosis, but how you face the challenges that this diagnosis brings is really yours to determine. So focus on optimizing your quality of life, educate yourself, empower yourself, and celebrate your daily victories.

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