Episode 98: How to Talk about Impulse Control Disorders

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Dan Keller: Welcome to this episode of *Substantial Matters, Life, and Science of Parkinson's*. I'm your host Dan Keller. At the Parkinson's Foundation, we want all people with Parkinson's and their families to get the care and support they need. Better care starts with better research and leads to better lives. In this podcast series we highlight the fruits of that research, the treatments and techniques that can help you live a better life now as well as research that can bring a better tomorrow.

As many as one in six people with Parkinson's disease taking a dopamine agonist drug may develop an impulse control disorder during the course of their disease. Examples are compulsive shopping, eating, gambling, sexual activity or involvement in hobbies. These repetitive behaviors often seemingly without purpose can interfere with the person's life causing social, emotional economic health and family issues.

Two keys to avoiding these outcomes are prompt recognition of the impulsive behaviors and effective communication about them often by the care partner or other family members. I spoke with neuropsychiatrist Dr. Greg Pontone of Johns Hopkins University about impulse control disorders, how they may be recognized and ways to bring them up with the person and the neurologist. He first described how the consequences of these behaviors distinguished them from normal behaviors.

Dr. Greg Pontone: Impulse control disorders plainly stated are behaviors, and they can be almost any behavior in the normal repertoire of behaviors, performed to an extent or a frequency which causes distress or problems in their day-to-day life.

Dan: What are some examples?

Greg: The most common examples in Parkinson's disease are pathological gambling, hypersexuality, binge eating. Oftentimes this goes along with compulsive shopping both on the internet and in person.

Dan: When these occur or are suspected, what's the role of the family or care partner in recognizing them and dealing with them?

Greg: I would say that it's equally recognized maybe even slightly more often by the family or a caregiver because the patient may either be embarrassed or rationalize the extent of the behavior or lack insight about how disruptive that behavior is. For instance, sometimes pathological gambling won't be recognized until there's a short fall in an account.

Dan: That's pretty serious.

Greg: Sometimes we've had cases where they've dipped into retirement savings or college savings for children. It can really be destructive and damage trust within a family. Hypersexuality can be a bit more conspicuous. Sometimes you will have a person who just has an increased frequency but other times, there'll be a change in the repertoire of behaviors.

People may have had one sexual preference for most of their life and all of a sudden they want all sorts of alternative sexual behaviors, either from a spouse or partner or they're seeking sexual gratification outside of their normal relationship, their normal intimate relationship. Again, we've seen pretty much a range of behaviors all the way up to very risky and illegal behaviors in that regard.

Binge eating can be a little more difficult because at first, you might just think someone had a midnight snack. Then when you notice the amount of food consumed and the way it's consumed, often the patients will tell us it's conspicuous because they don't necessarily feel hungry. Oftentimes we'll screen for it by asking are you eating for reasons other than hunger? Sometimes people will describe eating in a way where they feel compelled to take mouthful after mouthful.

Compulsive shopping with the internet. It's easy to shop even from home so that one can be tricky but I'll give you an example. We had a gentleman who had a two-bedroom condominium and he purchased 15 art deco lamps. Again, it's usually the amount, disproportionate amount, of things purchased or a lack of clear rationale for what is purchased.

Dan: It seems some of these behaviors can be fairly obvious seeing a bunch of new lamps in a room or that someone has maybe a binge eating disorder, but I would assume some of them are more secretive. People may be embarrassed about them. They could go off and gamble. They can go online and gamble, the hypersexuality, they could be going outside the home. What should people, especially care partners, be on the lookout for?

Greg: That's a great point. The extent and frequency and especially in the face of consequences. When someone is experiencing consequences such as bankruptcy or whatnot and the behavior continues, that's a clear signal but it's very likely that there's a fair amount of these impulse control behaviors that go unrecognized either because the family or the patient can absorb them either financially or in other ways or they're just under the radar because the patient is able to conceal them.

What we generally tell people is if that if there's any substantial change in behavior that's causing distress or problems that it should be discussed with the neurologist or the doctors helping to take care of the Parkinson's. It's one of those things where I think it's important to educate both the patient and their caregiver because like I said there's various reasons that it goes unrecognized because often these will just be an extrapolation of an existing behavior.

For instance, if you have a patient who's been playing the lottery that their whole life and all of a sudden now instead of buying two tickets a week, they're buying 25 or 200, it could be that type of a change. Making that link between Parkinson's and certain Parkinson's medications with the caregiver and patient I think is the crucial link. Because even when they are recognized, sometimes people fail to associate these with Parkinson's or Parkinson's disease treatments, and they don't know where to go for help.

Dan: How does one approach the person who is exhibiting these behaviors especially a family or care partner? Are there tools or techniques to approach them without causing animosity?

Greg: That's tricky. With many of these behaviors, there is embarrassment or in the case of hypersexuality, there can be privacy issue or a concern for privacy or even deviance for some of the behaviors that we've seen. What we generally recommend is just having a very clinical open discussion. We'll usually start with the patient and then we'll invite the family member or care partner into the room and we'll continue the discussion.

Then sometimes we'll ask permission to interview the care partner, spouse or family member separately and then piece it together that way. In all situations we ultimately try to bring the conversation back to the entire group so that individuals don't feel as if they're breaking alliances within their family or within their partnership.

Dan: Is that reasonable to approach the person, exhibiting the behaviors to say listen these can be associated with medication, this is not a character flaw, a personality thing but it's something that's really a side effect?

Greg: Absolutely. That's probably one of the most important messages is that once we recognize one of these behaviors, we try to make the association with the disease and the medications and let the person know especially if it's a new behavior that this isn't something where they have fallen down or should be embarrassed about. I think that helps undo some of the stigma in one of the barriers to seeking care is to normalize it in the context of the ongoing medical therapy.

Dan: How important is the family or care partner in communicating what they see to the healthcare team?

Greg: I would say crucial in the majority of cases. There's a fairly substantial literature in Parkinson's disease of the care partner or family member recognizing the impulse control disorder before the patient or even if the patient recognizes it, the care partner being the one that comes to the clinician because the patient either is too embarrassed or lacks insight into the severity of the problem. I think we've always operated using the model where we involve at least the main caregiver or a partner in the home.

Dan: How are impulse control disorders different from bipolar disorder mania or hypomania where shopping may be a sign of that too?

Greg: The distinction between impulse control disorders and bipolar mania or bipolar hypomania of real interest, I think right now, because it may be on the same spectrum of behavioral disorder. For instance, it could be that these are just a component process within mania. Mania is usually in this hyper-excited state with minimal sleep, lability of mood, in addition to some impulse control disorders, whereas impulse control doesn't necessarily have those other components.

What we have definitely seen is that in people who have either a recognized bipolar disorder in addition to Parkinson's or an unrecognized bipolar disorder, we've seen dopamine agonists and levodopa to some extent trigger manic and hypomanic episodes in these individuals. The question of whether it's a part of that same spectrum is a valid one. I think the difference between the two is that mania and hypomania include many more symptoms and behavioral changes. Like I said, the reduction in sleep and the severe mood change.

Dan: Are there other behaviors that are not necessarily impulse control disorder but might be tip-offs to something going on that people in contact with the person with Parkinson's should recognize? These might be behavioral biomarkers even though they're not the thing itself.

Greg: Yes, absolutely. One of the things, especially when people might be using a bit more of the medication than they're actually prescribed, but not necessarily are things like punding, which is a repetitive semi purposeful behavior done over and over again. One example would be reordering the kitchen again and again and again, without clear purpose of why you're moving things around. We've had punding that included just writing a series of random numbers to fill a page. Again, that type of repetitive behavior, it can even be more sophisticated, like performing parts of a typical hobby again and again, repetitively in a very driven way.

That punding and hobbyism are two things that we'll often see in conjunction with people who have impulse control disorders. Then again, to the extent that impulse control might track with higher levels of dopamine, we've also seen it occur along with dyskinesia, peak-dose dyskinesia that choreiform hyperkinetic movement, we see as a complication of Parkinson's therapy. To some extent, we've seen it associated again with mood lability. People who might have some pressure to speech and be just a little bit high emotionally, and that can be high in terms of a little grandiose and overly excitable all the way to irritability and brittleness of mood.

Dan: What's the prevalence over the course of the disease that impulse control disorders would occur?

Greg: Right now, the best evidence is probably from a meta-analysis, which is a collection of several studies all boiled down together for one conclusion. That estimate gives us right around 14%. I think the official estimate was 13.6% of people with Parkinson's who are treated with dopaminergic therapy, most often dopamine agonists will have an impulse-controlled disorder at any given time. It could be that up to four or 5% will have more than one impulse control disorder at the same time.

Dan: Does it matter how long the impulse control disorder has existed for a good outcome or stage of the disease or what predicts a successful outcome?

Greg: That's tricky. There isn't a whole lot of literature or evidence to support what I'm about to say. This is more anecdotal, but there are different types of impulse control disorders that we talked about the pathological gambling, the hypersexuality, binge eating, and compulsive shopping. The way that I think about what predicts success is, how biologically or intrinsically reinforced the behavior is more so than when it started or the duration. All those are probably important to some extent, but let me give you the example. Pathological gambling, once it starts, let's say it was triggered by Parkinson's and a dopamine agonist, but now that it's started it's self-reinforcing and we found that pathological gambling is probably trickier to treat and resolve than some of the others.

Hypersexuality seems to be more biologically driven. Oftentimes when we reduce or stop the dopamine agonist, for instance, that seems to cool off more quickly because it's more directly potentially motivated by the dopamine than by the self-perpetuating and reinforcing nature of the behavior itself. Again, I think we need to do more

research to understand what predicts a better course of any behavior. The longer you do it, the more it's habituated - the more chances for it to be reinforced. I think in general, it'll turn out that duration is important. We haven't demonstrated that necessarily conclusively in the literature, but I think the sooner you can recognize them and stop them, the better in general your outcomes are going to be.

Dan: Have we missed anything important or interesting to add?

Greg: No, I think you covered all the main ones, your point about how important is the family and caregiver, I can't tell you how many times the patient's done it for five years before it comes to light from a concerned caregiver.

Dan: They just were waiting for it to pass, I guess, I don't know.

Greg: Yes, or sort of rationalizing it. I can give you a common scenario that's actually come up a number of times in the instance of gambling. People will say, look, they got diagnosed with Parkinson's and let him have his fun. Then as gambling expenditures, mount and mount and mount, they keep saying, "He can't do this. He can't do that anymore. At least he can have some fun gambling." They rationalize it and it really can get out of hand that way. Even in full daylight when the caregiver family member is aware of it, this really is a unique disorder.

Dan: Very good. I appreciate it. Great information. Thank you.

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For more on today's topic. Listen to our podcast with Dr. Mark Groves called clinical issues behind impulse control disorders. You can find lots more information by searching our website at parkinson.org for impulse control, including a fact sheet called Impulse Control and Parkinson's Disease. In it is a section on what to do if you suspect you have impulse control problems. Some suggestions are to keep a diary of your medications, and when you take them, and to note any changes in your mood, behavior, and physical responses. This will be useful when talking with your doctor. Medication adjustments can often alleviate impulsive behaviors if they did not exist prior to using the medication.

If you have questions about today's topic or anything else having to do with Parkinson's, our information specialists can provide answers in English or Spanish. You can reach them at 1800-PD-INFO. News and updates about future events and resources are available by joining our email list at the bottom of our website's homepage. If you want to leave feedback on this podcast or any other subject, you can do it at parkinson.org/feedback. If you enjoyed this podcast, be sure to subscribe and rate and review the series on Apple Podcasts or wherever you get your podcasts.

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