

“Presence Hallucinations” in PD Patients

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THE BEHAVIORAL ASPECTS of Parkinson’s disease (PD) are as fascinating as they are problematic. Until the late 1980s the only non-motor problem in PD that attracted any significant interest from physicians was depression. Even neurologists could see that a lot of their PD patients were



depressed. But, of course, why shouldn’t they be? But some raised the question of whether the depression was reactive, that is, a normal response to a progressive, incurable, potentially disabling disorder, or whether it was intrinsic to the disease, a foreordained process directly related to the loss of neurons in a particular location in the brain. At that time, some attention, albeit very little, was paid to the problem of medication-induced psychosis, dementia and a host of other problems, most of which were not recognized.

Hallucinations occur in about 20–30% of medication-treated PD patients, and these tend to be fairly stereotypic. They are usually visual, and half as often auditory, mostly in the context of co-existent visual, and considerably less often tactile, olfactory or gustatory. They are generally without emotional content, unlike hallucinations that occur in schizophrenia and other primary psychotic disorders. Some are pleasing, like the baby my patient saw

every evening, “who was such a good baby. He never made a sound,” or the tiny people another patient saw who looked like small Christmas ornaments. Some authorities have employed the label of “minor” hallucinations to those that occur only transiently in the peripheral visual

field, but are never seen directly. These are usually perceptions of shadows, cats or dogs running by, but disappear when looked at directly, and to a peculiar sensation, called “presence hallucinations.” These are not really hallucinations, as they do not occur as a false perception in one of the five special senses. These are the feelings that there is someone or something behind or to the side. They are never sensed as threats. The patient does not worry about being attacked. The person or animal is never hiding. The patient turns to see who or what is there, but there is nothing. Hence there is a strong feeling of a “presence.” As best I know, this is transcultural, although I am not aware that it has been studied, so I am unsure. The feeling resolves if the medications are reduced or an antipsychotic medication is given.

As noted above, the sense of presence is not an hallucination. It is classified with the actual hallucinatory phenomena, but in the category of “minor” hallucinations. It is a unique phenomenon.

Although there may be occasional patients with a psychotic delusion that they have an angel, or devil, watching over them, or an invisible twin, in PD, the patients don’t know who is present, and are neither frightened, worried or pleased. The presence is neither reassuring, nor threatening. And, although I believe it may be unique to PD, there are two settings in which a sense of presence has been described, but the phenomena are quite different. A sense of presence is well described in the recently bereaved, who continue to feel the presence as if the person was still alive. This sensation may last a long time, but apparently is most commonly present early on. The second scenario, sometimes called “the third person factor,” occurs in people who have had near-death experiences, and have been led by an unseen person to safety. The survivor may consider the unseen presence an angel or not, but generally not a psychotic experience. The presence is not felt again but is credited with the successful overcoming of a life-threatening event.

The perception of a presence, like the perception of an illusion, or even a fleeting hallucination, are experiences that we’ve all had. We’ve all turned to see who was in the room with us when there was no one there. We’ve seen an image at a distance that we think is a boy walking a dog but it turns out to be fire hydrant as we get closer. Or we’ve answered a door, having heard a knock,

but there is no one there. These are all part of normal existence and only become medical phenomena when they become overly common, or overly real. In PD, “presence hallucinations” have been identified in untreated patients in a single report. They are otherwise associated with use of the medications for treating motor dysfunction in PD, and are considered a milestone on the road to the development of PD psychosis. Yet, these patients always know this is unusual, never think these are “real” experiences, and are never bothered by the experience. It’s simply an odd experience.

I have no idea what the underlying

pathophysiology is. This is not a process that has been studied. I recently encountered a PD patient who reported that she had a feeling of presence, but only on her left side, just out of view. This is interesting, suggesting a degree of focality to the pathophysiology. I am fascinated by this phenomenology but, in truth, I don’t actually think it is a very important clinical observation, other than for reassuring patients and their doctors that it is a not uncommon experience for treated PD patients.

One of the many rewards of practicing medicine is to share the world of our patients, often quite different in so many ways than our own. ❖

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