

Misperceptions

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We all misperceive things. A common example is the sensation that the world is turning after we spin ourselves quickly around and then stop suddenly. It can be so severe that we may even fall down. In Parkinson's disease (PD), there are a number of misperceptions that may occur as part of the disease, and may seem puzzling to the patient and the family. The misperceptions usually affect the person with PD (PWP), but there are misperceptions by others concerning the PWP.

Perhaps the easiest to understand is speech. Some PWP perceive their speech as being louder than it really is. This, of course, increases communication problems, and may contribute to the soft speech of PWP. In most cases of soft speech the patient is aware of the softness, but simply can't muster the strength to make the vocal cords vibrate adequately, but in some cases, it occurs because the PWP thinks she is talking louder than she really is. The problem can be remedied by teaching the patient to talk louder than the PWP thinks is "necessary" because it isn't as loud as it seems to the speaker. These PWP need to talk to the world as if they are all deaf.

Many PWP do not perceive spatial relationships as they did before the onset of PD. This occurs in a number of settings, and is particularly important for driving. It is not rare for a spouse of a patient to complain that the patient is never in the center of the lane but always to the right, or to the left, or sometimes too close to the car in front. When confronted, the PWP will disagree and confidently state that the car is, fact, in the middle of the road, even when it isn't. This occurs because of changes in parts of the brain that process visual input, which causes a distortion in what is perceived as the middle, or up or down, causing the PWP to argue, because, to the PWP, the car *is* in the middle, but it really isn't. It is difficult to convince patients of problems such as these when their own personal and repeated experience indicates that they are in the middle of the road. A similar problem occurs in PWP who think they are closer to a chair than they really are so they sit down, and almost miss the chair. Sometimes people will actually miss the chair, and injure themselves.

One of the most surprising mis-perceptions concerns dyskinesias. These are involuntary movements that may be fluid or jerky. They may involve any part of the body, face, head, hands, legs or trunk, and cause the person to look fidgety, like they are dancing in place, or uncomfortable. Michael J Fox suffers from this, so you can see what these movements look like on his TV shows, or you can watch a You Tube video of PWP who suffer from these movements. These are side effects of long term use of L-Dopa and are very common. They are not uncomfortable, although they may look like they are. The surprising observation is that people with this type of movement disorder, whether in PD or any other condition, often perceive the movements as much less than they really are, sometimes not recognizing that they are present at all. Even more surprising is the observation that when patients look in the mirror they do not see the movements, even though they are present, but when they see themselves on video they are usually quite surprised by how prominent the movements are. For unknown reasons, the brain perceives the movements only when they are not occurring at exactly the same time as they really

are, so that the video is perceived accurately, but the live movements are not, even with a mirror. Of further interest is the observation that PWP almost always accurately perceive their tremors.

PWP often feel that they are weak, most particularly in the legs. In a study we performed, 40% of PD patients thought that their legs were weak. Sometimes they felt that their legs were “heavy,” “encased in concrete,” “made out of lead,” “dead,” “wooden,” etc. Yet the legs were not weak. The brain perceives the reduced motor control as being weakness, even though the problem is really reduced control.

I have never heard a PWP report that they move less than other people. In fact, PD patients are almost always “akinetic” to some degree. This means that they have fewer spontaneous movements than other people, which is readily seen in the blink rate. PWP blink less than normal people, contributing to their facial “staring” expression. They also swallow less than others, which is why saliva pools in their mouths, leading to drooling. Thus, PWP do not realize that their immobility is a difference between them and others.

In addition to PWP mis-perceiving themselves they are also not perceived properly by others. This has not been properly studied but the few papers published on this topic indicate that people, including health professionals, have a more negative impression of PWP they haven’t met based purely on their facial expression, viewing them as depressed, angry, less socially involved, less interested and less pleasant based on how “masked” their facial expression is. These impressions were completely unrelated to what the PWP actually was like. This unfortunate problem may underlie difficulties PWP experience relating to people who don’t know them.

There are a number of other mis-perceptions that seem to be more common in PWP than in the general population, and understanding that we all perceive the world differently, and that these differences reflect not only our genetic makeup and our specific experiences in life, but also the changes that take place within our brains as a result of aging or disease processes.