"It's Not in Your Head": Navigating the Challenges of a Functional Movement Disorder Diagnosis

A Q&A with Katie Kompoliti, MD

Though separate scientific disciplines, neurology and psychiatry frequently cross paths and require both expertise and care from physicians of varying backgrounds. Functional movement disorders represent one of those intersection points, illustrating unique challenges as well as opportunities for care. According to Katie Kompoliti, MD, Professor of Neurology and Director of the Movement Disorders Fellowship Program at Rush University in Chicago, patients with functional movement disorders often easily fall between the cracks of the two disciplines and do not receive the care they require. Ahead, Dr. Kompoliti shares strategies for communicating with patients with functional movement disorders. She also offers insight on how specialists from neurology, the psychiatry/psychology disciplines, as well as rehabilitation specialists, can interface better for the improved care of patients.

What are the challenges of recognizing and diagnosing functional movement disorders?

While most patients with functional movement disorders share a similar symptomatic profile, rendering easy recognition in many cases, diagnosis is more complicated, according to Dr. Kompoliti. "Historically, the diagnosis of a functional movement disorder has been one of exclusion rather than inclusion," she says. "We often have to rule out what we used to call 'organic disease' before we arrive at the diagnosis of functional movement disorders." The basic notion was that there is nothing medically wrong with patients with functional movement disorders, which is why they were defined by what they were not. More recently, she notes, attitudes from leaders in the field have begun to shift in favor of a more positive diagnosis, as reflected in the new round of diagnostic codes. "Whereas previous DSM codes focused on the 'medically unexplained' aspects of functional movement disorders, the new guidelines in DSM-V emphasize the degree to which the patient's thoughts, feelings and behaviors about their somatic symptoms are disproportionate or excessive," says Dr. Kompoliti.

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While the shift away from a diagnosis of exclusion to a diagnosis of inclusion is better in the long-term, it may present unique difficulties for physicians who might not feel comfortable making the judgment call on a positive diagnosis. According to Dr. Kompoliti, the unique challenges of understanding functional movement disorders has increased the burden of disease for patients who often feel like physicians don't know what to do with them. "Patients usually need positive answers and want to know what's wrong with them, instead, patients are often left with the notion that their problems are all in their head," says Dr. Kompoliti. "What we need to convey to patients is that functional movement disorders are not 'in their head,' but are, in fact, in their brain." However, rather than being what Dr. Kompoliti calls "hardware" problems, functional movement disorders are more akin to problems with "software." "When someone has a stroke, you can see where the hardware is damaged. Here you can't see anything structurally wrong with the hardware, but the software—i.e. the way the different parts of the brain communicate with each other—does

not work as it should." In other words, it's a matter of brain functioning, which, according to Dr. Kompoliti, is where the term "functional" movement disorders came from. "This works better than the previous term, psychogenic movement disorders, which was perceived by many patients as derogatory and overemphasized the mind-body separation."

After making the diagnosis, what are next steps in terms of communication with the patient and management?

"Once the diagnosis is clear, informing the patient can be difficult, due to the confusing nature of the diagnosis," says Dr. Kompoliti. The most important step toward a good outcome is that first conversation in which the neurologist delivers and explains the diagnosis. In some instances, if the patient is receptive, it can even be therapeutic. These conversations are not easy to have with patients, though, Dr. Kompoliti admits. "Some do not want to believe that their movement disorder could be functional, and in addition they might feel like we are just passing them off to someone else," says Dr. Kompoliti. "Since functional movement disorders fall between disciplines, many patients often feel that no one is assuming responsibility for their care," she says. Furthermore, "very often they want to continue searching for an alternative explanation."

Thus, neurologists should become more comfortable and confident with these (often complicated) cases and help patients through the first steps of what could be a long journey. "Among other things, neurologists should be prepared to talk about the types of therapy these patients may be receiving in the future," notes Dr. Kompoliti. More recent evidence, she observes, favors cognitive therapy in conjunction with physical rehabilitation therapy to help re-train the body to respond properly. Additionally, many patients with functional movement disorders have untreated or sub-optimally treated psychiatric issues, ranging from depression and anxiety to post-traumatic stress disorder (PTSD). Therefore, a psychiatric referral should be pursued together with a referral to a psychologist and physiatrist.

For patients wishing to continue seeking alternative explanations, Dr. Kompoliti suggests frank guidance. "I often explain that they've likely already undergone many tests, and that more tests will only increase the likelihood of finding a false positive," she says. "Then, I often tell them that this diagnosis is much better than the diagnosis of Parkinson's disease, for example, and that it is time to stop focusing on *why* they have this and start focusing on *how* we can address it." This should open the door to a discussion about cognitive behavioral and physical therapies, which represent the most promising forms of management right now.

PRACTICAL POINTER

When speaking to patients about their movement disorders, emphasize that why they have the disorder is much less important than how to address it. Additionally, reassure patients that this is not a disorder that's "in their head," but is instead in their brain.

Tips for Identifying Functional Movement Disorders

As functional movement disorders are increasingly a positive diagnosis rather than a diagnosis of exclusion, neurologists should be aware of the signs and symptoms that may contribute. Below are the traditional points that can help clue you in to a presentation of a functional movement disorder. Some of these you may see with traditional movement disorders, but when you put them all together they signal a functional movement disorder:

- Onset is often abrupt, with patient achieving maximal disability shortly thereafter
- Patients are normal in between flare-ups and have spontaneous remissions
- Movement disorder increases with attention and decreases with distraction
- Slowness, when present, has a deliberate quality. Changes in tremor frequency and amplitude are prominent
- Functional disability is sometimes out of proportion with physical examination
- The disorder is difficult to classify and doesn't follow traditional anatomy or nosology of movement disorders
- The disorder can be unresponsive to multiple medications

—Katie Kompoliti, MD

What would you like to see happen in coming years regarding the management of functional movement disorders. What do you think is realistically achievable?

One thing that Dr. Kompoliti would like to see improve is the state of inpatient rehabilitation for functional movement disorders. "It is getting more and more difficult to get patients admitted," she says. Nevertheless, the benefits are pronounced for folks who are able to have an intensive inpatient stay followed by outpatient therapy. "While the patient is admitted, we can also introduce them to

cognitive behavioral therapy and involve a psychiatrist who can help optimize their psychiatric medications." Unfortunately, when patients are discharged back into the community, follow-up is usually inadequate. "The main difficulty for patients when they go back into the community is finding psychologists who are comfortable treating them."

In addition to developing more stringent protocols and procedures for physical and psychological rehabilitation through admission and treatment, Dr. Kompoliti notes that increased awareness and interdisciplinary communication will be needed to help these patients through the process. "Treating individuals with functional movement disorders is outside the comfort zones for many clinicians and other disciplines, including physical therapists." Therefore, more visibility and courses about functional movement disorders at psychiatric and rehabilitation society meetings are necessary to increase awareness and build the expertise needed for the team-based approaches required to care for these patients, according to Dr. Kompoliti.

What do you want your colleagues to take home about care for patients with functional movement disorders?

According to Dr. Kompoliti, communication with patients and their families is the most essential component of successful diagnosis and management. "Many patients do not buy the diagnosis you give them, so how you explain the diagnosis can make all the difference," she says. Moreover, the conversation is different than any other typical conversation you might have when diagnosing another neurological disorder. "Many of these patients have psychiatric illnesses, such as PTSD, chronic depression and anxiety, while others refuse to believe they have psychiatric ailments."

When explaining the diagnosis, Dr. Kompoliti notes that context is key. "Tell them that this is the best news they could have received today." The next step, then, is to emphasize the mechanism, for which the hardware/software analogy can be very helpful. "The brain is fine structurally; it's the connections between different brain areas that are not functioning properly."

But often the most difficult aspect of this conversation is that the take-home message for a lot of patients may be that they are doing this to themselves and their families, says Dr. Kompoliti. "The way you respond to their concerns and emphasize that this is like any other disease and what is happening is beyond their conscious control is important." For this reason, Dr. Kompoliti believes it is important to take the time to walk the patient through each step of the process and how you arrived at the diagnosis.

A Patient's Guide to Dissociative and Functional Symptoms

When discussing the diagnosis, Dr. Kompoliti recommends directing patients to NeuroSymptoms.org, which offers a patient guide to dissociative and functional symptoms. "The content is geared toward functional patients, specifically with helping them accept the diagnosis and understand that they are not responsible for their disorder," says Dr. Kompoliti. Featuring well researched text and video content by a team of neurologists from the University of Edinburgh, the site is a good resource of not only information for patients but also hope. "Every time I direct a patient to the site, they come back and feel much better about their diagnosis," she says.

Then, it's important to listen to and validate their concerns while re-emphasizing key points. "Sometimes, patients will say, 'Just because you don't recognize this problem, that doesn't mean that it doesn't exist.' It's important to validate the emotion and reasoning behind statements like this, while again emphasizing that 'unexplained medical symptoms' represent a larger umbrella of symptoms that don't follow typical disease presentations, cannot be explained according to known rules of anatomy and physiology, and that there is no single therapy or procedure that can fix them."

Arguably the most important step in the entire process is to let the patient know that you believe in them, says Dr. Kompoliti. "Sometimes, no matter what you tell them, they may walk out thinking that their doctor told them 'it's all in their head,' but you have to emphasize that this is not in their head but their brain, that they are not doing this to themselves, and that they are not responsible. In fact, they are the victims."

Patients should also know that they are not alone and that functional movement disorders are actually common. They can also feel hope that since the brain is not damaged, their disorder can be reversed, though it may take great commitment. "These things may sound easy, but they are not," she says. ■

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