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The Dynamics of Disease Diagnosis: Navigating Neurologic Disorders Without Losing the Focus of Providing Care

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When a person is presenting with signs and symptoms consistent with a progressive condition, it may be tempting to rule-in or rule-out the possible conditions using all of the available information. What happens when comorbid conditions cause the workup, the process of being diagnosed, to be derailed? Are we able to not only see the features of separate conditions clearly but also educate patients and families in a healthy manner that does not cause confusion or catastrophization? Providing space and latitude with room to change our own opinions during the workup can allow caregivers to provide therapeutic support (physical and psychological), along with their efforts in home exercise, advocacy, and behavioral management. When conditions are complicated, it can be helpful to provide advice and interventions directed at those signs and symptoms that are known or are within our scope of practice. As a complementary and parallel approach, practitioners may benefit from seeking counsel with other team members or facilitating an additional referral to investigate and intervene on less-well established signs and symptoms. The collection of conditions known as Parkinsonisms can be among the most complicated conditions that a neurologically-focused practitioner might encounter on a regular (not rare) basis.

Keywords: Parkinson's Disease; Anxiety; Paranoia; Postural Instability; Perseveration

Introduction

MP is a 79 y of diagnosed by one movement disorders specialist (MDS, neurologist specializing in movement disorders) as having Progressive Supranuclear Palsy and by another MDS as having idiopathic adult-onset Parkinson's Disease. These diagnoses were made just over 4 weeks apart with no changes in medication, environment or intervention between the two clinical visits [1]. The patient's history as available in chart review and elaborated by her son (for matters that are not found in an EMR) to include:

- An abusive childhood with physical, sexual and emotional

trauma

- Raising two children with her husband, who passed away decades ago
- A progressive tendency toward paranoia of her surroundings first through non-family connections and spreading inward leaving all but her grandchildren and sparing family members without accusations of intentions to harm, and actual harm
- A parallel tendency toward reclusiveness

. In the past 8-10 months, the patient's mobility has deteriorated, leading to the use of two trekking poles and an increasing frequency of falls. It is estimated that she had fallen three times in the prior 6 months, yet endured 5 falls in the last 30 days [2]. The most recent symptom that MP is both experiencing and is beleaguered-by is her perseveration on pain. At times, she can seemingly have no other thought in her head, no matter the attempts to distract her, than to focus her vaginal pain. While MP is aware that she has undergone extensive examination and testing for her vaginal pain, she is not comforted by the answers that she has received, "... we cannot find anything wrong".

The perseveration becomes burdensome for her son and daughter, the primary caregivers. They are experiencing burnout from the incessant talk about their mother's reproductive organs and genitourinary function. It is at this time that I was called in to consult, under the auspices of helping with her mobility – only onsite to learn of the perseveration [3]. This clinician first encountered MP in a home consultation, June 2025. This in-person visit with MP was at a home that her son owns, where she often resides alone at night, yet with family coming by to visit and provide care during the day. It is during this session that the patient was evaluated using a thorough subjective interview; observation and objective measures of movement transitions; and education regarding her perseveration on pain. The findings of this visit are pasted below in the form of recommendations to the family. These are reflected fully verbatim of what was written to them (substituting references to her family members in place of names) [4].

First visit:

For a multitude of reasons, readers may benefit from this 100% verbatim copy of the post-visit notes sent to the patient's daughter and son:

I have a high degree of confidence that the diagnosis of adult-onset Parkinson's Disease is accurate. Her clinical presentation resonates most with PD of the Postural Impairment Gait Disorder (PIG-D) subtype.

She does not have an apparent tremor

She does utilize facial gestures in a wide range

She does experience both postural impairment (forward-leaning) but also gait disorder (shuffled steps)

She has difficulty with surface transitions (changes in flooring can cause her to freeze)

She has difficulty with changing directions

She appears to have a full range of movements with her eyes in all directions

She has no reported backward falls and does not have a tendency to do so in testing

2. While persons with all forms of PD (PwPD) may also experience cognitive decline, it is most consistent with the PIG-D subtype for people to experience a degree of paranoia. On one of my first

phone calls with (her son), I recall that paranoia may have been an early sign with MP a finding that preceded her motor symptoms. This is not usually the case in PwPD, but can happen, leading me to point #3.

3. MP may be found by a neuropsychologist to have both anxiety and depression. I expect this to be the case, yet acknowledge this is not my area of expertise, as I mentioned to (her daughter) in closing yesterday. It is likely that her paranoia, combined with anxiety and depression are leading to her impaired cognition, as she would not have much room left to pay attention to other people's well-intentioned education and support because her ruminative thoughts from anxiety and paranoia are occupying most of her available attention.

4. MP perseveration on pain is likely a function of her perseveration-anxiety-confusion, combined with a degree of what is known as nociplasticity. She has a default-mode of thinking about pain when she is not otherwise occupied. When a person can be consistently distracted away from their pain for prolonged periods, it is more likely that the pain is more central (emanating from memories and predictions in the mind) than peripheral (emanating from danger to or injury within the body part(s)). Among other things, nociplasticity means that a person's brain has created more "territory" for and attention-to a body part, in a vicious cycle. Neuroplasticity (the brain's dynamic ability to make new connections and learn) can be used to a distinct disadvantage so that pain becomes an expanding theme and the body parts in pain become larger on the internal map of the brain. Noci = pain; plasticity = remoldable and dynamic.

5. How to help, in reverse order, starting with pain.

A. Neurons that fire together, wire together. MP needs to experience more time talking about something other than pain, moving her body so that she is not focused on pain, participating in engaging experiences that distract her from ruminating on pain. The more time she can have out of talking, the more "territory" in her brain we can begin to take back and the less-likely that her only and all thoughts default to pain.

- a. Family works with MP to create a list of pleasant topics. "What would you rather talk about when we are hearing from you that you are in pain?"
- b. Use this list immediately and extensively to redirect her.
- c. Will she be able to eventually "forget" that she used to talk so much about pain? It is possible, but unlikely this will be the only successful strategy.
- d. Movement should distract from pain.
- e. Crafts and activities that she enjoys may distract from pain: card games, puzzles, drawing, knitting, cleaning.
- f. Education. She is still able to learn, despite the demands on her attention. Include her in this plan, as I stated above, "What would you rather talk about when we are hearing from you that you are in pain?". She would benefit from knowing that

you are hearing about her concerns regarding pain, and not ignoring her, but are rather helping her brain move on to a topic that she has chosen.

B. Walking. The most succinct advice is to have MP focus on taking “The fewest steps possible from point A-B”, in a game-like fashion. While it can be temporarily helpful for her to try to “think big” or “take big steps”, she may lose focus on this as compared to the “I am winning” sense that can come from an activity that is numbers-based. Meaning, she may not always know if she is taking big steps, but she will keep the sensation at the end that she has “won” and it was based on her performance. Recall that she went from 23 steps to 15, to 13 to 11 in our time yesterday, traversing the very same hallway (distance and environment) each time.

C. Continuing through a change in flooring or crossing through an open doorway. In either case, MP has demonstrated success when she does NOT try to look down, step through, or force herself to persist, but rather when she directs her attention well-into the next room or to a destination far from the immediate flooring transition.

D. Turning to sit down upon arriving at a destination. As was demonstrated today, AA is benefited by cues to “walk to the chair, but don’t think about sitting down...just walk to it and stop.” Then/thereafter she can begin to turn. Her turn is best accomplished by freeing-up the hand closest to the surface, putting both canes in the other hand, and beginning the turn...now that the walk is over.

I realize that this is nearly a chapter of information already, but it is my succinct start to “How to best help MP. This information was received very well by her family. They followed the plan as best as could be expected, to their collective benefit. MP began to attend local physical therapy one and two times per week. Her mobility improved, fall frequency declined, and she began to speak of her pain syndrome less and less. When I came back out to see AA just two months later, she was now rarely perseverating on pain. However, she was in another unrelated crisis. As I arrived to the home, so did she and her daughter, by car. AA was standing by the passenger side of the car, unwilling to go into the home and unwilling to get back in the car. She expressed being fearful of her daughter, and reported that her daughter had both hit and punched her in this car ride, which her daughter denied [5, 6].

MP daughter admitted that she did raise her voice with her mother because she could not stand her, “...incessant rant” that, “everyone was against me’...that. ‘They were plotting to put me in a home’...and that, ‘they never loved me.’” I had arrived that day prepared to offer practical strategies to distract MP from ruminating on pain. My goal was to increase the amount of time that would pass since the last time her attention turned to the painful body part, weakening the connection and the assumed (nociplastic enlarging representation of such, within her brain. This box of distractions served little use on that particular day, yet was ultimately very helpful for family management of the patient, hence it is included within this case report to benefit readers and their future patients.

TheraScoop under-desk lateral-pedal bike

- A deck of conversation cards
- A set of brain game cards
- A Rubik’s cube
- Two handheld puzzles (one with a marble inside a clear maze-like container; another with a set of 5 metal chain-like links to be assembled/disassembled)
- A deck of bird species cards
- A flip chart of US Presidents and facts (handheld)
- A light hand strength/grip strength tool
- A deck of concentration cards - circa 1978

Shortly after the second visit, MP was evaluated by a local neuropsychologist that diagnosed her with Symptomatic Symptom Disorder. For most, this is considered within the umbrella of Functional Neurologic Disorders. She was prescribed and was started on Celexa (citalopram), a selective serotonin reuptake inhibitor (SSRI). As MP is stabilizing on Celexa, she is additionally regularly participating in skilled outpatient physical therapy (PT) 1-2x/week. Her fall frequency has reduced, with no falls reported on many weeks. At the most recent report from her son, MP’s frequency of perseveration on pain has improved significantly as well [7, 8].

While her caregiving needs remain elevated overall, and variable, this case report details the importance of:

- An accurate diagnosis may include leaving some signs or symptoms unresolved
- No singular diagnosis must explain all of a person’s symptoms to be correct
- An appreciation that the biopsychosocial elements of a patient’s life can influence the phenotypic expression of most any disease
- While working toward a diagnosis, it is important to stabilize the patient (and caregivers), by providing care that adds-value
- Comprehensive care includes listening to the patient and family, and educating them with the known - and the unknown
- Multidisciplinary care can often provide added value to the effectiveness of each professional’s plan of care.

Acknowledgement

None.

Conflict of Interest

No conflict of interest.

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