ANTICIPATING NEEDS THROUGH THE PARKINSON’S JOURNEY: RESEARCH PERSPECTIVES

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DISCLOSURES

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BACKGROUND

Parkinson's disease (PD) is a slowly progressive neurologic disease.

Anticipatory guidance – The practice of proactive counseling about future disease progression and planning head.

Prior research demonstrates unmet needs for anticipatory guidance among people with PD (PWP) and care partners.

Little known about:

- specific PWP or care partner needs
- neurologist views

STUDY DESIGN

Semi-structured interviews

- 17 people with PD
- 14 care partners
- 11 neurologists

Interviews recorded and transcribed verbatim

Analysis is currently ongoing

Preliminary themes identified

SAMPLE QUESTIONS – PWP AND CARE PARTNERS

Do you feel that you have adequate information about what to expect in the future?

- If not, who do you wish gave you that information?

If you have a neurologist, have you ever talked with them about how life might change in the future because of PD?

- If yes, please tell me about this conversation.
- If no, do you wish you had or would you be interested in doing so in future?

What aspects of PD-related changes over time do you think neurologists should talk to patients and their care partners about before they happen?

SAMPLE QUESTIONS - NEUROLOGISTS

What is your general practice with regards to talking with patients and care partners about what to expect over time with PD?

Are there aspects of PD that you think patients and care partners are often surprised by or unprepared for?

In your opinion, what are the barriers to counseling patients and care partners about what the future will look like with PD and how to prepare for it?

PWP AND CARE PARTNER DEMOGRAPHICS

PWP	Care Partners
Age, mean = 70.8 years	Age, mean = 66.7 years
Time since PD diagnosis = 7.8 years	Time caregiving = 4.4 years
64.7% male	78.6% female
100% white	92.9% white
	71.4% spouse of PWP

THEME 1

PWP and care partners do not routinely discuss future disease progression with their neurologists.

Margaret (PWP): I guess I've never really talked about that with my doctor, as far as what can I expect in five years or ten years, or what should I plan for.

Betty (Care partner): That would have been nice, but no one did.

THEME 2

PWP and care partners desire actionable information about future disease and symptom progression.

Jennifer (PWP): And I've been to Russia and Estonia and lots of places, and I enjoy that. Am I gonna be able to continue to do that? Am I gonna be able to continue to teach at a national level…? How much longer can I do that?

Karen (Care partner): I think at each of the stages…as the doctor sees that there's changes, and these changes are going along the line of more of the disease process…They need to talk about it and say "Hey."

THEME 3

PWP and care partner preferences for timing and content of anticipatory guidance vary.

Matthew (PWP): Very early, to allow as much time as possible to put things in place and consider things appropriately.

Elizabeth (Care partner): I think the right time is when the motor skills start to decline…When you can't do things for yourself, that's the time to start that discussion.

THEME 4

PWP and care partners seek information from support groups, online resources, and their families and social circles.

Richard (PWP): I've observed what my peers in the boxing class have dealt with. And the various combinations of symptoms that they have. Everybody has something in common, but not all the same. And to varying degrees.

Sandra (Care partner): I am inundated with information, do a lot of reading. We are very blessed to have this new network…[in our city] because we're getting a lot of good information from their programming.

DEMOGRAPHICS - NEUROLOGISTS

Age, mean = 42.4 years

Years in practice, mean = 10.2 years

81.8% female

63.6% white; 27.3% Asian; 9.1% black

81.2% movement disorders specialist

90.9% academic practice

THEME 1

Anticipatory guidance is woven into discussion of new PD diagnoses.

Amanda: When I make the diagnosis, I give them a broad-brush overview of general prognostic information about Parkinson's disease, progression, et cetera, because I've had too many instances of people coming back…And it's almost like they didn't expect it to get worse.

THEME 2

There are multiple barriers to routine anticipatory guidance in PD.

Steven: I think a lot of times patients may wish to speak about the future or have curiosity about it, but…clinicians sort of dread the conversation.

Ashley: I'd say time, you know, with clinic work we're only allotted a certain amount of time, and so I oftentimes will find 30 minutes is just not enough time with our PD patients, especially if they're really struggling. But I feel like there's always an obligation from our medical system to see more and more patients over time, and you don't really spend the quality time with people.

THEME 3

Team-based care facilitates anticipatory guidance in PD.

Paul: We do have palliative care physicians here that we work with. One that's actually neuro-specific, so he does help with some of these additional conversations.

Stephanie: I find that the patients really tend to respond well when the nurses talk to them about this…We have a nurse navigator who sees patients both with movement and neuropalliative. And that has been extremely helpful.

THEME 4

Neurologists want education to improve anticipatory guidance in PD.

Emily: Say I'm going to the [Movement Disorders Society] or [American Academy of Neurology] or something, if that was a session, I would actually find myself wanting to join in on that.

Donna: I do think though that it's a skill that every neurologist should have, to be able to have these conversations and give this guidance.

LIMITATIONS

Most neurologists were academic movement disorders specialists.

Most neurologists were in early career.

Most PWP and care partners were recruited from academic movement disorders center and surrounding well-resourced community.

PWP and care partners may be experiencing less burden compared to broader population.

NEXT STEPS

Ongoing data analysis to finalize themes

Intervention development

- Not reliant on clinic time or support staff that are not universally available
- Maybe something that could be delivered by peers, at least in part

Further study to assess the intervention’s feasibility and acceptability

Later studies would assess the interventions efficacy

- Preparedness for caregiving
- Self-efficacy
- Illness uncertainty or perceived adequacy of information scales

QUESTIONS OR COMMENTS?

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