Supplement 1 Interview guide

Introduction and illness experience

1. Tell me about your experience with your illness over the past year Provide an example of how it's been going. (Probe for burden, isolation, apathy, etc.)
    a. Has anything become easier or improved in your life overall?
    b. Has anything become more challenging over the past year? Give an example.
    c. Over the past year, have relationships that are important to you changed in any way? Which relationships, and how/in what ways?
    d. How satisfied are you with your care relating to Parkinson disease? Can you elaborate?
        i. Was anything missing?
        ii. What would be helpful from providers?
        iii. What additional services could help improve your quality of life?

2. Some people have told us that there are some things they don't always feel comfortable sharing in medical visits. Have there been times when you held something back from your doctor or didn't share with them or show them something? Why?
    a. Patients: Have there been times when you did this with a care partner or loved one? Why? Probe for burden, shame, independence, etc.
        i. What could your medical team do to help this? Or what could be a good strategy where you would feel safe to talk honestly about this with loved ones or providers?
    b. Care partners: Have you ever held back sharing something with the doctor about the patient's condition? If so, why?
        i. What do you think could be a good strategy to encourage you to talk honestly about your concerns?
    c. I know you were randomized to the ___ arm. How is your experience different in the ___ arm of the study, compared to your previous experiences with neurology care, when it comes to sharing information with providers? (Does this happen with PCP and not study neurologist, vice versa?)
    d. Patients: Do you normally go to your visits by yourself or does someone go with you? Have you ever met with the doctor without your care partner? Is there value in being seen as a couple or an individual?
        i. If yes—how did it benefit you, what did you accomplish?
        ii. If no—what do you think of that?
    e. Care partners: Have you ever met with the doctor without your partner or loved one? Is there value in being seen as a couple or an individual?
        i. If yes—how did it benefit you, what did you accomplish then?
        ii. If no—what do you think of that?
    f. How could the medical team ask about your needs as a couple versus your needs as an individual?
        i. How can we do more for you as a "paired" relationship? (as a couple, as a twosome)
    g. What additional services or support could your medical team provide to care partners? How can we do more for care partners?

3. We are specifically interested in your thoughts about the future.
    a. What is most important to you when thinking about the future?
        i. Have you talked about this with anyone? Who with, about what?
    b. What are you most concerned (worried about) about for the future?

Advance care planning (ACP) or 'Goals of Care' (Canada) section

4. Have you thought about what you want your life or situation to look like as you near the end of life, or when you can tell time is short?
    a. What did you decide on? What decisions did you make? Probe for specific things.
    b. How did you decide what is important to you?

5. Can you tell me about any prior experiences you (or your loved one) have had with future medical planning or advance care planning?
    a. How did it come up? With who?
    b. Did you complete documents, have a discussion, etc.?
        i. Tell me about the documents you filled out.
        ii. What are the goals of this document?
        iii. What are you hoping this document does?
        iv. Do you have any concerns about the document?
        v. Do you feel that your wishes will be followed? Why or why not?
            1. Probe for discussions with family, following through on wishes, how well was the discussion received? Will they follow through?
    c. Did you do anything after this discussion or after completing these documents?
        i. Share with anyone, make copies?
    d. How comfortable were you in discussing ACP?
    e. IF NO EXPERIENCE: Why? Barriers? What would be helpful to overcome this? Who would you want to discuss this with?

6. How important is it to you to take actions related to future medical planning, such as talking about what you want or writing it down? What is the value of ACP to you?
    a. What do you think ACP adds to your life (having had these discussions, OR NOT)? Examples of how your life or your activities look different because of this?
    b. What challenges have you experienced related to this type of planning?
    c. Has anything changed over time, as far as your values and preferences?
    d. What is the risk in not engaging with ACP?

7. Have you ever received ACP educational materials (goals of care in Canada) from a doctor or someone else? Has a medical provider brought up these discussions?
    a. Where else have you gotten information from? (lawyer, website, support group)?
    b. What type of services or information could be provided to help you plan for your future medical care?

[The remaining questions are for participants from any setting, US or Canada]

8. How do you think ACP should be introduced to people with Parkinson disease?
    a. Who should initiate the discussion?
    b. Who should all be involved in the conversation?
    c. When should ACP discussions happen- at what point in the illness journey?
    d. What are your thoughts about discussing this in group medical visits, where you would participate with other patients, care partners and medical providers to discuss common concerns related to Parkinson disease?

9. Now, I'd like to ask specifically about the potential for memory loss or dementia related to Parkinson disease.
    a. Can you tell me how you think about potential memory loss or inability to make decisions for yourself (or for your patient if care partner)? Probe for concerns
    b. How have memory concerns affected (or not) your future medical planning?
    c. Can you describe your experiences talking about current memory changes or future memory loss concerns with your doctor?
        i. Are you able to talk about it with your loved ones?
    d. What has been helpful to these discussions? What could be better/different?

10. For care partners: How involved did you want to be in the ACP decision making process? Why?
    a. How important do you feel it is to know the treatment preferences of the person you care for? Why?
    b. How confident are you in your understanding of what they want?
    c. What kind of things are missing that would help care partners be more involved in ACP processes?

11. Some people have told us they would like to have a 'roadmap' of their journey with Parkinson disease, which would better prepare them for what to expect down the road. What do you think of this idea?
    a. What would you like to see on the roadmap? What 'markers?' Actionable items

Mortality myth

12. I have a final question about the future related to Parkinson disease. What is your current understanding about how Parkinson impacts mortality?
    a. Has your neurologist talked with you about how Parkinson disease affects life span?
    b. What were you told?
    c. Are you someone who wants to know details about how your disease impacts mortality?
        i. How do you think your care matches this, or doesn't?

Closing questions

13. Given this is part of a research study, what do you think are the most important or valuable outcomes we should measure? (e.g., quality of life, not having to worry about the future, feeling of support from healthcare team, control over health decisions, outlook on disease, care partner stress or support?)
    a. In other words, what is the most important thing we should understand about your illness journey? What would signify improvement to you?
    b. What makes that important to you?
    c. You may remember having completed survey questions, some of which asked about burden and depression. What type of questions do you think we should be asking that capture what is valuable to you (on surveys)?

14. Anything else you want to add that we have not covered in our discussion today? Thank you.

Table S1 Parkinson disease life changes related to palliative care domains

Life changes	Exemplar quotation	Source	Implications and potential decisions
Palliative care domain: physical aspects of care			
Motor symptoms and mobility	Right now, the master bedroom is on the second floor. I'm getting a little nervous going up and down the stairs.	Patient in standard care	Residential changes
Household ability changes (iADLs)	That's why I can't look after my husband at home, [that is] why he had to go to long term care, because he was too ill to be at home. His medical needs are too heavy. He gets medication 11 times a day.	Care partner in standard care	Care partner resources and planning (e.g., home care; respite)
Self-care ability changes (ADLs)	He can fix cereal, but I'm looking forward to a time when he can't do that, and I'm struggling.	Care partner in palliative care	Care partner resources and planning (e.g., home care; facility care)
	That [roadmap] would help me a lot [for] support options at night… if I reach a point where I need help during the night, how is that going to happen? Certainly, all of this doesn't relate directly to my care, but it does relate to her support (care partner).	Patient in standard care	
Palliative care domain: psychological aspects of care			
Anxiety, depression	I don't know what the warning signs are that his depression is taking a turn for the worst or if he's miserable because he can't do things.	Care partner in palliative care	Counseling, support, socialization
Isolation	When do you tell them they can't go out in the community on their own? He made the decision not to drive on his own. Some of those other decisions are hard; he wants to take a bus somewhere and he can't. He would get lost.	Care partner in palliative care	Community resources
Palliative care domain: social aspects of care			
Professional role changes	Cognitive decline at some point is going to become more than inconvenient. I can no longer do the job that I used to do being a tour director. My memory can't support that anymore.	Patient in standard care	Professional retirement
Social interaction changes	I've noticed [with] conversations I try to have with people. I walk around the block each day and five years ago we'd chat about each other. Now, they have learned that I'm hard to hear or that I'm hard to listen to. …The neighbors have learned to turn away from me because it's more of an effort to talk… that reduces my social ability in their lives.	Patient in palliative care	Counseling, support, socialization
Driving ability	In the early days, they'd say that you'd have one side that was worse off than the other, and then I knew I was in this stage when both sides of my body were going, so it's almost like a marker for when I can drive. I can still drive, but not all day…	Patient in standard care	Driving retirement
Living situation needs	Assisted living [should be on the roadmap] and what it's going to cost. I can still do [stairs] but I'm thinking we need to start looking for a place where everything is on one floor. Should we do it now and then have to move again when we go into assisted living, or do we just start looking at assisted living?	Patient in standard care	Residential changes
Palliative care domain: cultural aspects of care			
Navigating medical systems	It's a complex issue how to manage all the things that a person in society would have to take care of... the medical system is so complex that [care partners] spend half the time talking about payments and managing my issues with the insurance.	Patient in standard care	Care partner availability and willingness for care coordination
Care partner role changes	If it gets to the stage where he can't get in and out of bed himself, then I'm going to need a lot of home care. I'm going to need someone to come every day probably because I certainly can't lift him.	Care partner in standard care	Care partner availability and willingness for care coordination
Palliative care domain: end of life aspects of care			
Physician-assisted death	I may get to the point where I can't live alone. Well that's the point in time when I start looking at physician assisted death.	Patient in standard care	Comprehensive advance care planning
Palliative care domain: ethical and legal aspects of care			
Financial planning needs	Financial planning would be crucial to some people with Parkinson: a list of resources and what it's going to cost and what's available.	Patient in standard care	Financial counseling
Safety concerns	I'm realizing the needs are going to be more than physical, and safety is going to be an issue, and how to determine what's safe for him and what's safe for the family. It's all very tricky on a day to day basis… when do you tell a person they can't do something around the house anymore because it would be unsafe for them or for the family?	Care partner in palliative care	Education, support, care partner resources and planning

iADLs, instrumental activities of daily living; ADL, activities of daily living.