

Outcomes of the PDF CCRA: a workshop to address maintaining cognitive function in Parkinson's

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Objectives

1. To define unmet needs related to cognitive changes in PD
2. To review evidence for non-pharmacological interventions to maintain cognitive health in PD
3. To form recommendations for people with PD for maintaining cognitive health and dealing with cognitive changes that may occur
4. To form recommendations for health care professionals for addressing cognition in their PD patients as early as diagnosis

Background:

In 2013, the Parkinson's Disease Foundation (PDF) launched the Community Choice Research Award (CCRA), designed to advance research in areas that were identified as unmet needs within the PD community. People with Parkinson's (PWP) and care partners (CP) were asked "what areas of research do you think scientists should be focusing on in order to make an impact in the PD community?" In 2015, over 300 people from eight countries responded with ideas. One unmet need identified by many PWP and CP was addressing cognitive problems in PD and how to maintain cognitive function for as long as possible. As a result, the PDF organized a working group of multidisciplinary experts to address this need.

The working group and workshop

The group, chaired by Jennifer G. Goldman, consisted of 19 researchers, which included movement disorder neurologists, cognitive neurologists, psychologists, neuropsychologists, social workers, nutritionists, nurses, and researchers who study aging and cognition. In addition, 6 members of the Parkinson's community (3 people with PD and their care partners) were also part of the group.

The workshop covered 9 topics:

1. Defining cognitive issues in PD
2. Cognitive impairment in PD
3. Cognitive aging
4. Clinical measures of cognition
5. Physical exercise
6. Cognitive exercise
7. Nutrition
8. Caregivers and PD cognitive issues
9. Decision-making capacity



Needs within the PD community

Need #1: Information early on

Through discussions at the workshop as well as a post-workshop questionnaire, we asked PD community members what they wished the doctor had told them at different stages of their PD regarding cognitive changes they may experience (responses from PWP (n=3) and CP (n=2)).

Overwhelmingly, nearly all respondents indicated a lack of information being given about cognition and PD early on in the disease. Below are three responses:

"I wish that they stated that it was a possibility and discussed more about it. I only got information on the motor symptoms." -PWP

"I wish that the doctor might have mentioned some changes to be watchful for so I could be aware and helpful." -CP

"That cognitive changes could be one of the results of the disease." -PWP

Need #2: Knowing what to expect

Several responses indicated a need for knowing how fast cognitive changes will occur and what they will look like.

"I am familiar with the changes that occur in the executive function area, and I have lived with elderly parents in a nursing home with dementia, but what can I expect in between?" -PWP

Need #3: Resources and support

People with PD also felt that they were not offered enough resources early on to help deal with cognitive changes they were experiencing.

"I would have liked to have more resources about cognitive impairment and a conference with a social worker when first diagnosed so planning could be started." -PWP

"... Patients should be asked if they would like to meet with someone that can help them process any changes they are coping with..." -PWP



Recommendations: People with PD

The working group was given a post-workshop questionnaire to identify recommendations for PWPs to be proactive in their cognitive health.

For early to mid-stage PD:

1. Exercise according to American Heart Association guidelines
2. Stay active socially; join a support group
3. Engage in cognitive training exercises
4. Learn coping strategies with an occupational therapist
5. Nutrition can affect cognition; try a Mediterranean diet
6. Take your time when doing tasks and do not multitask
7. Communicate with family and friends if you are struggling

For advanced PD:

Keep following the above recommendations, PLUS:

1. Develop a highly structured daily routine that you follow
2. Consider the use of medication for cognitive impairment
3. Have an advanced directive in place (living will, treatments)
4. For care partners-- take care of your own health as well
5. For care partners-- seek out support such as counseling



Recommendations: Health care providers

For health care professionals working with people with Parkinson's, in addition to communicating the above recommendations to their patients, the group also suggests the following:

1. Provide information at diagnosis re: cognitive aspects of PD
2. Follow-up appointment a few weeks later to answer questions
3. Be honest with regard to what changes can be expected
4. Refer to neuropsychologist for baseline cognitive testing
5. Have cognition assessed regularly
6. Refer to OT, PT, speech language, social worker, and nutritionist
7. Depression and anxiety can affect cognition; evaluate patients
8. Broach the subject of advance planning with patients

Future directions

The working group is currently writing a paper reviewing the evidence for these interventions and identifying key issues and gaps in knowledge that should be addressed moving forward, both for cognition research as well as care.

The group also plans to have these recommendations published so that they are available to everyone in the PD and health care communities.