International Parkinson and
Movement Disorder Society

MDS Health Professional Special Interest Group (HP SIG)

Online Basecamp Meeting
Focus: Cognitive Change in Parkinson's Disease
September 1-5, 2017

ONLINE MEETING SUMMARY

Present: Maseumeh Dashti; Rosemary Gallagher; Deborah Bier; Olawuwo Samuel; Bhanu Ramaswamy; Angela Roberts; Linda Carolina Jaramillo Rojas; Michelle Tosin; Sylvia Liew; Mariella Graziano; Clynton Correa; Vicki Segro; Julia Marie Wood; Courtney Johnson; Siok-Bee Tan; Julie Austin; Ana Aragon; John Dean; and Meg Morris.

Chair: Victor McConvey
Staff Liaison: Samantha Surillo
Co-Chair(s): Hanneke Kalf; and Maria Elisa Pimentel Piemonte

Background & Agenda

Sixty individuals, from across the globe, holding Health Professional (HP) roles in the Movement Disorders and Parkinson's disease community were invited to participate in the MDS HP SIG Leadership Basecamp (online) Meeting.

Online Meeting Intent: to have a focused discussion surrounding Cognitive Change in Parkinson's disease (PD).

Participants were given 5 days to provide feedback to questions put forth by the Chair and Co-chairs. The Chairs requested individuals provide feedback (from their unique perspectives / roles in the community), by responding to the following questions:

1. Is screening for cognitive change part of your assessment or your team assessment, and what disciplines would screen for cognitive change and what is the preferred tool?
   {Q1 Discussion on pages 3 – 7}
2. What strategies do you use to discuss cognitive change with people experiencing it?
   {Q2, pages 7 – 9}
3. What strategies would you use in daily practice to manage the motor impact of Parkinson's? (i.e. Strategy training; Visual/ auditory cueing)
   {Q3, pages 9 – 10}
4. How do you support the psychosocial needs of a person experiencing cognitive change?
   {Q4, pages 10 – 12}
5. Caregivers frequently are significantly impacted when cognitive symptoms become apparent.
   {Q5, page 12}
6. How do you support caregivers in coping with cognitive change in their partner?
   {Q6, page 13}
7. What formal or informal supports are available for caregivers in your practice environment (other than the support you provide)?
   {Q7, page 14}
8. How do you share results from cognitive screening or consequences of cognitive decline during consultation or treatment with the patient, caregiver and other health professionals?
   {Q8, pages 14 – 16}

Purpose and Aim of focused Meeting on Basecamp

This basecamp discussion has the aim of sharing practice on managing both the motor and non-motor impact of Parkinson's on the person with Parkinson's and their caregiver.

Introduction to Cognitive Change in Parkinson's disease (PD)

"Cognitive change is now thought to be a cardinal symptom of Parkinson's disease, with emerging evidence suggesting that some changes may be detectable on diagnosis. While a diagnosis of PD does not guarantee dementia is inevitable it is a significant and often unspoken of fear of many people living with the condition. Identifying cognitive change, developing management strategies and supporting caregivers is frequently a role for health care professionals." *- V. McConvey*

Participant Information

Welcome & Introductions

The Meeting started with the MDS International Secretariat welcoming members of the MDS HP SIG to the discussion board.

Health professionals whom participated in the online meeting practice in locations such as:

> Elwood, VIC, Australia; Isfahan, Iran; Jos Plateau State, Nigeria; Bucaramanga, Colombia; Sheffield, United Kingdom; Rio de Janeiro, Brazil; Singapore; Esch-sur-Alzette, Luxembourg; St. Ives, NSW, Australia; Bath, United Kingdom; Sao Paulo, Brazil; Surrey Hills, VIC, Australia; and various locations throughout the United States of America (USA), including Point Lookout, NY; Concord, MA; Evanston, IL; Narberth, PA; Indianapolis, IN; Englewood, CO; Boulder, CO; among a number of other locations across CO, USA; as well as throughout the state of CA.

Professional roles of participants consist of:

> Neurologist; Movement Disorders Clinical Specialist; Professor(s); Assistant Professor(s) and Lecturer(s) of Physical Therapy, Communication Sciences and Disorders, and Speech and Occupational Therapy; 4th Year Medical Student; Director of Special Populations; Physiotherapist(s) and Senior Physiotherapist; Occupational Therapist(s); Clinical Neuropsychologist; Deputy Director of Nursing (APN); Neurorehabilitation Nurse; Speech Language Pathologist; President of the Association of Physiotherapists in Parkinson's Disease-Europe; Nurse Consultant; Nurse Practitioner; Head of Allied Health; Nurse Advisor, Information Officer, and Counselor; as well as an Admissions Coordinator.

While some participants are independent consultants, private, or tele- practitioners, others work at entities such as:

Parkinson's Victoria;
Parkinson's UK;
Parkinson's NSW Australia;
Isfan Medical University;
University of Jos;
La Trobe University;
University of Sao Paulo;
Universidade Federal do Rio de Janeiro;
Universidad Industrial de Santander;
University of Pennsylvania, Dan Aaron Parkinson's Center, Parkinson's Disease & Movement Disorders Center for Excellence;
Indiana University School of Medicine, Department of Psychiatry, IU Neuroscience Center;
Northwestern University;
New York Institute of Technology;
Singapore General Hospital
Tan Tock Seng Hospital;
SARAH Network of Rehabilitation Hospitals;
ComForCare Senior Services;
Association of Physiotherapists in Parkinson's Disease-Europe; and
Rocky Mountain Movement Disorders Center.

The following is a synopsis of discussion posts, cumulatively, across the 5-day meeting period.

Question 1. Is screening for cognitive change part of your assessment or your team assessment, and what disciplines would screen for cognitive change and what is the preferred tool?

Participants noted use of various cognitive tests when psychological signs or symptoms are present in Parkinson's disease (PD) patients with some Neurologists referring patients out to psychologists (familiar with PD) to complete assessment and other professionals:

- Simply inquiring from the patient mathematical equations (such as what is 1+2?), asking where the patients is along with what the time says to them (before proceeding to other areas of assessment); to others
- Making cognitive screening a part of every visit within their offices, with the professional routinely asking about subtle cognitive changes to both patient and caregiver.

One member identified assuming that cognitive screenings should be done in two important and complementary ways:

1. A formal assessment through formal tests. Noting her team has adopted the Portuguese version of MoCA (following the MDS Task Force recommendation); and
2. A continuous evaluation through the observation of patient behavior and caregiver report; noting in her experience (of more than 20 years in Cognitive Science), many times, there has been a conflict between formal evaluation and cognitive performance in daily life activities.

Members discussed the importance of choosing the right instrument and noted use of the following methods of documentation:

- Montreal Cognitive Assessment (MoCA) [*English, and Portuguese version*]
- MiniMental State Exam (MMSE)
- Subject, Objective, Assessment, and Plan (SOAP)
- Abbreviated Mental Test (AMT)
- Timed Up and Go (TUG)
- Walking While Talking Test (WWT)
- Mini-BESTest (MiniBest)
- Beck Depression Inventory
- Beck Anxiety Inventory
- Addebbrooke's Cognitive Examination-ACE-111 Australian Version A (2012)
- Wechsler Adult Intelligence Scale (WAIS III)
- Cognitive Linguistic Quick Test (CLQT)
- Assessment of Language Related Functional Activities (ALFA)
- Allen's Cognitive Levels (ACLs)
- Rivermead
- Wiscosin
- Clock-Drawing Test (Clock-Face)
- Trail Making Test (Trail A & B)
- Dementia Rating Scale-2 (DRS-2)
- The SCales for Outcomes in PArkinson's disease-COGnition (SCOPA-COG)
- St. Louis University Mental Status Exam (SLUMS)
- The Executive Function Performance Test; and
- The Cognitive Performance Test.

Members agreed professionals should be careful to consider tools':

- Over usage;
- Potential for learning effects (and the various versions that may help mitigate such);
- Adequacy and sensitivity to Mild Cognitive Impairments (MCI);
- Global-measurement-feasibility; and

- Differentiating purposes (i.e. screening vs. assessment)

Considerations when using the Montreal Cognitive Assessment (MoCA)

Members agreed the MoCA is a preferred tool amongst many, with one member noting they always perform the MoCA if there is a cognitive concern – and:

> If the cognitive problems are obvious or appear more advanced, professionals schedule the patient for computer based cognitive testing in-office.
>
> If the cognitive complaints are subtle or complex, professionals send the patient to neuropsychologists for formal neuropsychological testing.

Members agreed the MoCA is a good global measure of cognitive status that is fast and easy to use (10-20 minutes) while also offering more sensitivity to mild cognitive deficits than the MMSE. It was noted the MoCA has been validated and recommended for use in persons with PD (Hoops et al., 2009; Dalrymple et al., 2010; Chou et al., 2010).

One member noted however, that even when the MoCA is taken months apart, they have noticed slight learning effects on PD patients (among others, such as Stroke patients) along with specific learning curves correlating with the amount of education a person may have. However, the member noted they are currently further investigating this.

> Another member noted interest – stating, to date, they have only used the MoCA either as exclusionary criteria or for demographic data. The member further noted they don't know of any other tool to use to test this affect but will be interested to see if MoCA testing over time with the different versions shows whether or not there is a learning effect (while factoring in education level).

Members discussed other challenges and concerns, such as:

- Some countries only allowing usage of some tools for assessment (such as the MoCA-only);
- Professionals being over dependent on- or improperly using- screening tools as assessment tools (i.e. usage of MoCA as assessment instead of screening);
- Considering hearing status of patients (frequently unidentified) and impact on screening tools.

Members added there are also tools that have been created specifically for PD, such as the SCOPA-COG (among others), but they can sometimes rarely be used because of their lack of good normative data for non-PD individuals and when professionals like to use and report a single tool for all groups.

Instrument Usage

Members noted differences in screening and assessment within their individual interdisciplinary teams with some teams having:

- Doctors perform quick screening (where they may use MMSE or AMT);
- Neurologists order adhoc screens (to address memory complaints, during clinic consults) for nurses to routinely perform baseline and annual MMSE/MoCA (and when necessary, referral to the neuropsychologist for cognitive screening);
- A neurologist and psychologist perform the screen together (utilizing the MoCA and MMSE);
- Neurologists typically administer the MoCA and Neuropsychologists primarily handling cognitive testing (seeing patients with PD for both neuropsychological assessment as well as individual psychotherapy);
- An advanced practice nurse perform the screening (with MoCA) where a Neuropsychiatrist may be referred for formal and detailed cognitive tests;
- Counselors, or nurses, perform screening (using the MoCA), acknowledging that anxiety and depression may have an impact on results, having further testing done by counselors and psychologists using the Beck Depression Inventory and/or Addebbrooke's Cognitive Examination-ACE-111 Australian Version A (2012); where, at the discretion of the counselor or psychologist – and depending on results, the MoCA may be repeated after a number of counseling sessions;

- Speech Language Pathologists (SLPs) and OTs perform basic cognitive screening, and neuropsychologists assess cognitive impairment (following a positive screening); and others where, on occasion, OT's would incorporate the Allen's Cognitive Levels (ACLs) into their assessments;
- Occupational Therapists (OT) perform most of the cognitive screening (primarily with tools such as the MoCA); and

    One member noted, as an OT, cognitive screening is a key part of their role in the team environment with speech therapy and MDs screening as well – all, often referring to the neuropsychologist for a more complete assessment of cognitive levels.

    While agreeing the MoCA is more sensitive than the MMSE, the OT identified using SLUMS if the MoCA may have been used recently in another setting.

    The OT further noted, however, there having been a few interesting cases recently with individuals' with significant executive dysfunction who scored 26/30 on the MoCA, where both her and the MD were baffled.

    The OT noted also utilizing:

    - TUG and TUG cog to see the impact in functional mobility and the Trails B for a quick screen; and
    - The Executive Function Performance Test and the Cognitive Performance Test for a look at functional cognition (though, both can be time consuming).

- The physiotherapist within the team consider the impact of cognition on functional mobility (by using TUG at baseline measure, with added motor task and cognitive task to see impact of additional tasks on mobility function)

    It was noted, when a physiotherapist needs to work within limited space (i.e. within patient's homes or when the patient is too unsteady), the WWT test may be used instead as both patient and professional walk from room to room (as part of the assessment).

    It was also identified that cognition issues are sometimes noted if the physiotherapist is doing the MiniBest as part of the assessment, as a dual task test whilst walking.

    Professionals also noted adding the 'Clock-Face' test when cognitive impairment or dementia are suspected and utilizing the Trail A & B test to test visual attention and task switching whilst adding stress (timing the task).

While working in a skilled nursing facility as an SLP, another member noted also liking to use:

- The Cognitive Linguistic Quick Test (CLQT) when they needed more resolution (clinically speaking) because they feel it has good activities including some basic trail making activities as well as other higher level cognitive activities; and
- Parts of the ALFA (Assessment of Language Related Functional Activities), which somewhat crosses over into the area of occupational therapy, because it covers many areas of daily life (including change making, calendar, telephone use, checkbook, financial registers, among others).

One member identified the psychologist and neuropsychologist, within their multidisciplinary team, apply cognitive tools (such as the Beck Depression Inventory, WAIS III, Rivermead, Beck Anxiety Inventory, Wiscosin, and/or Clock-drawing test), while other team-members may use MoCA to assess cognitive functions.

The member noted their multidisciplinary team in Rio de Janiero, Brazil consisting of a:

- Dietician;
- Neurologist;
- Neuropsychologist;
- Nurse;
- Occupational therapist;
- Pharmacist;
- Physical therapist;
- Psychologist;
- Speech therapist; and
- Social worker.

The member added, that - a big challenge in Brazil, however, lies in the fact that the country has different educational levels among its citizens.

> For this reason, the member supposes the cutoff (>26) suggested by this tool, at least in Brazil, should be carefully interpreted.

Working without a Multidisciplinary Team

Some members noted they do not have access to a Multidisciplinary Team, and therefore rely fully on the information the Person with Parkinson's (PWP), the family and sometimes, the referring doctor may provide. The member further noted this is a reality shared by many therapists in the world and further shared her experience as a physiotherapist where:

> Cognitive screening is part of her assessment and continuous treatment, and is taken into account the moment the PWP or caregiver makes the first appointment. The member noted she does not use a specific tool, as she has not found one that fully satisfies her in her daily practice. Adding, she instead uses observation, listing skills, exchanges with the caregiver, and the person's performance at work (when appropriate). Further noting – it can be of great value to spend significant time on first assessment and to take a thorough history.
>
> The member identified stressing physical performance (i.e. increasing the cognitive load via multitasking) as also valuable to identifying emerging cognitive deficits. Further noting, on occasions, people may be screened (outside of her services) by a neuropsychologist, who may mainly utilize the MoCA test for diagnosis (where the report may not convey management recommendations).

Another member noted not currently working with an interdisciplinary team either, and instead working in private practice (primarily tele-practice in CO and CA, USA) where he continues to use the MoCA as part of his initial evaluation; noting it has the best sensitivity and specificity for Parkinson's, having 3 English language versions, and is available for free.

> While highlighting the SLUMS as also free, the member noted finding it to be a bit intimidating for some patients and also not well normed for Parkinson's.
>
> The member added, although they continue to see the MMSE score listed as part of the inclusion of any number of studies, they don't use it in practice for a number of reasons such as the author retroactively charging money for its use in clinical settings (via a submarine patent); and with the MMSE also having been proven to be demonstrably less sensitive and specific for identifying dementia in Parkinson's than the MoCA, the member voiced their hope for the MMSE to be discontinued for clinical and research practice.

Differentiating between Screening and Assessment

There was agreeance that any discipline can screen for cognitive changes if using an appropriate tool with appropriate training; however, one member noted the MoCA and MMSE are screening tools and not intended for use as cognitive assessment tools. Furthermore, both tools are merely intended to indicate potential presence/absence of cognitive impairment (in order to identify the need for further assessment).

Members agreed screening procedures are usually discipline-independent, where anyone can administer (i.e. nursing, physiotherapy, OT, SLP, Audiology, etc.) with some members suggesting the field should be training as many HPs as possible to conduct these types of screenings (to increase the detection of Cognitive Impairment in PD and to facilitate access to appropriate professionals for full assessment of cognitive impairments).

Members noted assessment procedures as requiring a greater degree of training in the valid administration and robust interpretation of results. One member noted this as an important point, identifying a common concern raised in recent years as the overuse (especially in PD) of the MoCA as an assessment tool (when it is actually a screening tool), along with the over dependency on this tool for clinical decision making. While there was no doubt amongst group members that the MoCA is more sensitive/specific than the MMSE for detecting cognitive impairment in PD, it was noted that even in PD it's sensitivity is better than it's specificity (where it may falsely identify individuals as having cognitive impairment when they indeed do not).

Members agreed that, while the MoCA is used as a quick screen for study eligibility and within physician clinical visits – it's utility is limited to that purpose (in some practices), due to it being a screening tool only and not diagnostic.

Tools somewhere in-between Screening and Assessment

One member suggested when a quick instrument is required the Dementia Rating Scale-2 (DRS-2) may be a much better instrument (noting there are a few quick ways to assess cognition in all domains). The DRS-2 lies somewhere between a screen and a full assessment, providing not just pass/fail information (notwithstanding, the MoCA having a new memory sub-score with it) but also information on MCI vs. Dementia and severity. Importantly, the DRS-2 can be administered in 20 minutes or less.

Members noted the following regarding the DRS-2, with it having:

- A raw and standardized score profile;
- Both age and education adjusted normative data (If interpreted in the context of the Mayo Older Adults Study);
- Been normed on thousands of subjects (collectively, across more than 10 studies in the last 10-15 years);
- Been well established as a valid and reliable instrument in PD;
- Been recommended over the MoCA (within the MDS task force guidelines);
- PD-specific normative data and cut-off scores (published within at least three articles); and
- Two alternate versions to minimize learning across repeated administrations (and for increasing test-retest reliability).

One member identified her institute as using the DRS-2 instrument almost exclusively as the global cognitive measure in their research studies - followed by more comprehensive testing; also noting a recent publication by van Steenoven et al. (2014), which provides conversion scores specifically for PD among the MMSE, MoCA and DRS-2.

Conclusion

Members identified it being critical that motor control and cognitive impairment be assessed together as most daily activities require a synthesis of both, and further – identified a need for more research studies of people with poor cognition due to most trials having people who score 25/30 or higher on MMSE.

Some members acknowledged following the MDS Task force recommended list of neuropsychological measures that has been published for the purpose of diagnosing (not screening) MCI and Dementia in PD; outlining how this normally involves administering at least two tests per domain (i.e. episodic memory) and interpreting the tests within their published guidelines.

> One member noted when her institute conducts research or clinical testing for the purposes of contributing to a MCI/dementia diagnostic decision - they use the MDS Task Force published instruments almost exclusively.
>
> Furthermore, the only exception being if her team knows they will be re-testing someone within 6-months, then they may substitute a test that has alternate versions for one recommended by the MDS Task Force.

Members re-emphasized the paramount importance for professionals to consider hearing status when interpreting screening/ assessment results. It was noted, people with hearing loss (frequently unidentified) can perform 1-2 points lower on cognitive screening tools (i.e. MMSE; MoCA) due solely to the hearing loss (extra demands to allocate resources in the presence of the hearing loss) and not because they actually have MCI/dementia.

> Members noted there being two recent studies indicating that hearing loss may be more prevalent in PD, than aged matched cohorts as hearing loss is extremely common after the age of 60.
>
> Members further noted that in a typical research protocol, undiagnosed hearing loss can be found (without participant complaints of hearing loss) in 40-50% of PD recruits.

Question 2. What strategies do you use to discuss cognitive change with people experiencing it?

Members agreed that, generally, when people are experiencing cognitive change - they realize they cannot cope with certain tasks anymore or that they are slower and not able to manage their thoughts like they used to, which creates anxiety and fear (where they may try to hide it from themselves and others). Furthermore, members identified how 'the ghost of DEMENTIA,' may haunt the individual, especially with how media and the public may cover the topic (and often).

> **Approaches from a Clinical Neuropsychologist**
>
> One member noted she typically starts with a patient's subjective experience. If they are noticing changes, it's a natural launching point to discuss how the testing is consistent (or inconsistent) with the changes they have observed. Further noting, she will talk about how her job is to determine on testing if the changes they notice look like normal aging or something else, and if something else, what she thinks the cause is and what suggestions she may have for care.

Members across disciplines noted discussing a number of different strategies with patients, such as:

- Identifying education programs with strategies to cope and manage change (for both the person with the diagnosis and their partner/caregiver). Adding, this can range from using commercial Apps (which are already available), to referral to Dementia organizations - if required (which is in advanced cases and will provide greater access to funded services that are not otherwise available).
- Taking each situation one-at-a-time, and especially in cases when it may be related to movement, the professional will try to find a way to manage it with the person or caregiver (and, when necessary, will lease with the referring doctor).
- Inviting patients to compare their current cognitive performance with young people, where the professional will then explain that the expected cognitive decline associated with the aging process may be accelerated by PD.

Another member shared her experience as an OT, where she will perform an in depth clinical interview with the patient and caregiver as well as screening to determine the perception of the individual experiencing cognitive changes and will then relate the results from screening to the functional cognitive changes the individual is reporting. Adding that, often, bradyphrenia is the most prominent concern, so the member will attempt to empower the individual with awareness of the cognitive changes associated with PD and contrast with dementia--which is often the ultimate fear.

> The OT approaches cognitive changes as a normal aspect of PD, educating the individual that PD is not just a movement disorder, while also discussing the changes with the caregiver (with permission of the patient) as well, to stress how functional changes are not just behavioral but related to cognitive changes. Most importantly, the OT immediately gets to work on education in strategies (to help cope with changes and support maintenance of daily function).

Members agreed a good first step is to educate patients and caregivers about the reality of MCI and dementia in their diagnosis as well as to discuss measures to prevent more rapid worsening such as mental and physical exercise. Members noted they stress the importance of recognizing subtle changes early so that treatment can have a greater impact.

Cumulatively, members of the group identified a number of strategies professionals may use to discuss cognitive change with people who may be experiencing it, including:

- Taking the time to sit with the patient and explain the significance of the tests and why professionals are looking at it in relation to expectations of interventions (such as physiotherapy);
- Finding alternative ways to communicate 'screening for dementia' to the patient by having a broader dialogue about mentioned levels of forgetfulness;
- Ensuring professionals take extra care to highlight all motor and non-motor symptoms to relevant parties;
    - Educating the family and patient on these symptoms of Parkinson's (placing emphasis on the cognitive change)
    - Highlighting the impact of non-motor symptoms on daily activities (such as falls and safety); and
    - Exploring with the family on appropriate referrals to other allied health professionals
- Talking through any subjective complaints and trying to pull apart what might be typical for aging (i.e. difficulty remembering names) and what is not typical for aging;
- Recommending further tests (if they only have the MoCA results);
- Discussing with the Patient (that in PD) the number of considerations that contribute to cognitive changes (which require both medical work-up, and further testing);
- Working with the physician and the patients' families to reassure them that cognitive changes in PD are not necessarily predictors of dementia (noting that for some individuals these changes remain mild over the duration of the disease - and for others they progress to a full dementia);
- Providing reassurance that professionals have team-based interventions that can help support the individual with PD and their families (that include both behavioural and some pharmaceutical options); and
- Providing education on coping with dementia, and discussing ways to slow down the process (with small numbers of patients referred to hypnotherapy clinics, to reduce anxiety and maintain calmness to improve MCI).

Members agreed they feel having an honest conversation with the binomial provides both the patient and families:

- Empowerment with knowledge about the disease; and
- The ability to discern the current condition and prognosis.

Members agreed professionals should create and establish a bond and trust between the patient/family before undertaking this approach while also considering the life expectancy of the binomial.

Some members in the group identified that, these days, they find that individuals with PD are so savvy to this issue - that (although never easy) this is a much easier discussion than it was a decade ago. It was further identified that most people have the prototypical picture of Alzheimer's dementia in mind when they think about dementia, and it is important for professionals to remove the stigma from the word dementia.

Members further noted that while some individuals with PD will also develop Alzheimer's disease, the dementia in PD is different and it is important to help people with PD understand the differences and what their symptom profile may most be like.

Others in the group stated feeling this as still being a difficult conversation to have, where they may tend to focus more on tools for addressing specific issues rather than actually talking about the implications of cognitive change and what progression might look like. The member further noted, as an SLP, they try to direct their attention towards finding solutions and leave it to the doctor to have a more in-depth discussion about the implications of potential cognitive changes.

Overall, members agreed they will explain to their patients that they can experience cognitive impairment; and for this reason, feel it is even more important to develop therapeutic strategies including a multidisciplinary team (i.e. psychologist, neuropsychologist, physical therapist, occupational therapist, nurse, pharmacist, neurologist, among others) as all health professionals perform specific assessment to screen the cognitive function to interpret the results and, ultimately, to suggest appropriate therapies for each patient.

Question 3. What strategies would you use in daily practice to manage the motor impact of Parkinson's?

When discussing what strategies professionals use in daily practice to manage the motor impact of Parkinson’s, one member of the group specified her team first making sure the patient is treated adequately with medications. Then if motor problems such as freezing of gait are present, her team will discuss basic management techniques along with sending the patient to physical therapy. The member noted her team also encourages caregivers to attend therapy to learn safe cueing techniques as well.

Another member noted, as an SLP, finding it beneficial to provide reinforcement for many of the cueing and safety interventions that have been introduced by physical and occupational therapy, where his sessions typically focus on communication (and to a lesser extent, swallowing) deficits where he is often able to incorporate information and instructions from other disciplines as part of the activities as well.

Other members within the group specified generally utilizing the following strategies in their daily practices to help manage the motor impact of Parkinson’s:

- Cueing (visual and proprioceptive);
- Music cues through ear buds (auditory cues);
- A combination of strategy training (visual and auditory cues for management of freezing of gait and akinesia);
- Movement strategy training (incorporating sensorimotor/amplitude re-calibration for improved functional mobility and transfers in daily tasks, including grasp and manipulation of clothing and fasteners);
- Goal setting;
- Light tip canes;
- Visual tricks to reduce freezing in doorways;
- Home adaptation;
- Routine organization;
- Exploration of motor and non-motor potential;

- Positive reinforcement and relaxation techniques;
- Training the caregiver in all strategies and cues (to promote carryover outside of the clinic);
- Intense practice of strategies with gradually reduced auditory cues and increasing challenges with cognitive dual tasks (to promote learning and carryover);
- Encourage enrollment in **Rock Steady!**
- Recommend videos (such as **Delay the Disease**) or other stretching/functional movement programs on television or YouTube individuals may do from home (depending on what may make sense for the individuals' access needs);
- Referral to an OT for further assessment; and
- Exercise and specific programs that use goal setting, visualization and auditory cueing, such as:

    PD Warrior (Physiotherapy), which is particularly useful for those with a diagnosis around two years and has proven to be effective.

    Punchin' Parko's, which has been of assistance in helping to regain balance and co-ordination in those severely affected and is an alternative for those that are newly diagnosed.

Members noted also talking about the role of multitasking in things like walking and talking and increased fall risk when distracted, etc. Members agreed on typically utilizing a combination of all the aforementioned strategies in a manner that best meets the needs of the individual.

Breaking it down by Stages, Complexity Levels, and Session Types

Some members further specified utilizing attentional cues and amplitude high intensity exercises (in early stages), visual cues (in moderate stages), and empowerment of caregivers (in moderate-to-late stages).

Members added they may have Multidisciplinary team involvement in the care (including a psychologist and OT for specific interventions).

Another member shared strategies from his interdisciplinary team's experience, where, similarly, they will adopt dual tasks combining motor and cognitive tasks in a manner that is dependent of the complexity level (i.e. easy, moderate or difficult). For patients with higher cognitive impairment this strategy is limited to maintain/improve cognitive function. Thus, from the earliest stage of the disease, it is important to include cognitive challenges associated with motor training. Furthermore, the member noted that his team also promotes weekly social activities including cognitive tasks (such as singing in a circle, dance, etc.).

Other members noted the strategies utilized would depend on the reason the professional is assessing the person; noting for those seeking 1 on 1 sessions, they will use attentional strategies if the individual has the memory and insight to keep these up under stress (usually when timing is an issue). Professionals also noted if a cue has to be taught to another to take in information and ask questions, it can be helpful for patients to come with a spouse or family member (which is often the case).

Members noted for those they are screening in class sessions, such as within PD Warrior activities at their clinics, the motor impact is managed through exercise complexity.

Members concluded that besides cueing, cognitive strategy and dual-task training, they feel that regardless of the situation - education about the possible impact of cognitive decline in daily life activities, including the increased risk of falls is a key point in the treatment.

Question 4. How do you support the psychosocial needs of a person experiencing cognitive change?

When trying to support the psychosocial needs of a person experiencing cognitive change, one professional identified applying the International Classification of Functioning, Disability and Health (ICF) model while also recognizing the person's role within society. This professional will also emphasize with the patient on their loss of function and role, then support them via exercise prescription and caregiver training with appropriate handling skills, while also helping the individual to explore referral to their local Parkinson society, support group or other allied health professionals for further support.

The clinical neuropsychologist of the group noted some patients she sees for evaluation wish to stay on with her for psychotherapy, while also referring patients to local support groups through the Indiana Parkinson Foundation, among other non-profits; with some patients having their spouse or family members attend the sessions (with them) for additional support.

One member noted, as a tele-practitioner, they often find themselves helping to locate resources that can provide psychosocial support, particularly by working with someone over the Internet. The member will try to help the individual identify helpful sources of information, possible relief and assistance, while also identifying red flags for unnecessary interventions or services.

Members noted when PWPs experience cognitive decline professionals may recommend psychosocial support activities, such as:

- Patient support groups (including, local, in-hospital, and through local churches); as well as
    - Engagement in patient associations (where they may be able to offer fantastic support for family and patients through several activities including singing, dancing, and painting classes beside typical support groups);
- Caregiver workshops;
- Parkinson Society workshops; and
- Activities like Rock Steady, PD Warrior (Physiotherapy), or Punchin Parko's (offering PWPs an opportunity to be a member of a team of people, giving them a sense of normalcy)

Within one member’s interdisciplinary team, if any member of the team thinks there is a need for psychosocial support they refer the patient to the appropriate professional within their team – such as any of their psychologists, neuropsychologists or the social worker.

Other participants noted if the discussion and needs of the person are without their remit or time availability, they will work closely with their local Branch of their region’s charity (such as Parkinson’s UK), so the individual may have referral points into the Branch events for social support (where patients can learn a lot from one another). Professionals noted they also refer patients to varied National Health Service (NHS) provisions, either directly or via the person’s medical practitioner.

Recognizing the Importance of Family Participation & Ongoing Need for HP Support

Others within the group noted providing the freedom to discuss the person’s doubts, showing the perspective of using compensatory strategies, minimizing anxiety about losses and emphasizing the importance of family participation in the process.

Agreeing the psychosocial and caregiving needs of a family living with PD and cognitive decline changes over time, members noted the importance for professionals to realize that this is not an intervention at one point in time - but that individuals and families will require ongoing support from their Health care professionals. Furthermore, strategies to mitigate symptoms and counseling needs will constantly change.

Some members identified supporting families and individuals as a joint unit. Further noting, that once MCI and dementia are in the picture, the focus of intervention should be on the family unit - not the isolated individual (noting this as being a well-researched area in the dementia literature, at large). Members noted how this requires thinking about strategies and interventions from the perspective of what works for the individual and what works for the family based on their needs.

Overall, members agreed it is important to provide education for the patient, family, and caregiver.

One member shared her experience as an OT, where she facilitates a weekly ‘cognitive fitness class’ to promote social interaction for individuals experiencing cognitive changes. The OT will vary the format and activities weekly to incorporate exercise involving cognitive dual task and challenges, mindfulness and social cognitive games and activities supported by education in strategies for word retrieval, memory, executive function, etc.

> Participants are encouraged to (and willingly) discuss any issues they are having and to ask any questions they have—allowing them the opportunity to mentor and share with each other. As part of the group activities, a book club organizes every other month around a book selected by the group. The groups often select books that are also movies (to be inclusive of those who may be having difficulty reading) and are asked to come with one question/topic to discuss with amongst one another (promoting ownership).

Members noted some centers with social workers also offer free counseling services where professionals may often refer patients and/or family for support. When these services are available, professionals identified encouraging participation while also providing resources within the support groups, as well as recommending online webinars and exercise groups (for PD).

Members went on to identify how interventions can be any combination of:

- Strategy training (communications, memory, tasks, etc.);
- Environment modification;
- Implementation of technology;
- Individual and joint counseling sessions;
- Individual and joint support groups;
- Working with physicians to evaluate the impact of medication changes;
- Education;
- Exercise programs (for: mood/cognition; the caregiver to reduce burden; and the person with dementia to maintain function); as well as
- One on one involvement to address conversation/ communication breakdowns resulting from cognitive-linguistic changes associated with dementia in PD.

Others in the group suggested application of some therapies, such as Cognitive Behavior Therapy (CBT), early on might also be helpful noting that depression and anxiety are important to both recognize and treat (which are common in people with cognitive impairment).

Members agreed, while the PWP is still able to contribute to these decisions, they will frequently engage in discussions (with the support of relevant professionals) around advanced planning that aligns with the wishes of the person with dementia. Members noted also advocating strongly for keeping the person with dementia engaged in their care for as long as possible and proceed to do so by interceding and supporting patients within their medical visits, and more importantly – training family members to be this support for the individual with PD and dementia.

Professionals also identified trying to support psychosocial needs by decreasing the emotional and practical load of cognitive impact, often with the approach of advising the person to reduce their working hours (if he or she is working), and consider contacting a social worker or getting help at home (which may often depend on Parkinson’s stage and family support available).

Question 5. Caregivers frequently are significantly impacted when cognitive symptoms become apparent.

When caregivers are impacted by cognitive symptoms becoming apparent, members identified often offering for individuals to attend Parkinson support groups within their individual communities. Individuals noted local Branches of charities (such as Parkinson’s UK or Alzheimer Association) within their countries often running Caregiver support groups, which are open to all and provides opportunities for caregivers with similar issues to meet and discuss assistance challenges. Members noted the Alzheimer Association often provides caregivers with educational information about Lewy Body Dementia (LBD) and Pervasive Development Disorders (PDD), with the Lewy Body Dementia Association also having some materials (which can be a good resource for people who are dealing with that serious manifestation as well).

Another member shared their experience as an SLP, where they often provide guidance about the best way to communicate with someone experiencing cognitive changes as well as recommendations for other ways to support them (such as reducing distractions at mealtimes, etc.). The SLP also directs individuals to materials from one of the national nonprofits as a resource.

Most members identified feeling strongly that the sharing of experiences, and not just knowledge from professionals, can be supportive for affected individuals. Furthermore, participants agreed non-health groups provide an essential forum from which people build friendships and social connections, as well as cross the boundaries of support needs professionals cannot manage.

Others in the group sympathized how at first experience, the perception can be very confusing, and may often be interpreted as laziness, carelessness, lack of interest or self-love, however, when cognitive loss begins to impact the patient's safety – the family is forced to face the irreversible symptom. Members reiterated how education about the cognitive changes in Parkinson’s is important for the caregivers while also offering referral to other professionals to help empower them with good handling skills.

Question 6. How do you support caregivers in coping with cognitive change in their partner?

When discussing how professionals may support caregivers in coping with cognitive change in their partner, members noted some of the first strategies as being to:

- Raise awareness that the cognitive impact is part of PD (educating the caregivers on how the changes to behavior and function may be linked to cognitive changes), where it will need to be managed not ignored;
- Help caregivers to manage the impact of cognitive decline in the patient's routine while also offering emotional support for the role exchange in the family;
- Not take the cognitive changes as the caregiver's only responsibility to cope with;
- Work to establish goals in collaboration with the patient and caregiver to enable strategy training (to support improved communication and functional performance); as well as
- Train the caregiver in cues, organizational strategies, and help them to understand all resources available (to empower caregiver and promote collaboration between patient and caregiver).

Members identified specific strategies as mainly done through functional goal setting, agreeing it can be most useful when decided with the involvement of the person and caregiver. Professionals noted also advising caregivers to take breaks and join a support group. One member noted she is currently working to develop an interdisciplinary caregiver support program to provide education, training, resources, and tools to enable optimal wellness for the caregiver.

Others identified providing referral onwards when they feel their discussion with the caregiver is insufficient. Some within the group identified also speaking at local meetings to encourage open dialogue – where some caregivers will just listen, and others will talk as well, which in essence, professionals within the group feel – allows caregivers an opportunity to better understand the 'why' of behavior change as a result of Parkinson's.

Others in the group recommend Dementia caregiver training, visiting websites they feel may be helpful to the caregiver (such as Michael J Fox), providing handouts about cognitive changes in PD, and often recommend the individual obtain (or offering to borrow them) a copy of Joseph Friedman's *"Making the Connection between brain and behavior: Coping with PD."* Members noted also recommending the *"Third Thursday Webinars"* on the Michael J Fox website along with upcoming local conferences.

One member will also refer her patients to the lecture series about topics in PD her Neuroscience Center has just started.

Some members identified offering caregivers counseling from diagnosis, as professionals recognize these individuals can be more affected than the person with the diagnosis. Education and telephone support are offered as well, with caregivers encouraged to participate in exercise programs for their own wellbeing (adding - to this end, some centres have the ability to provide this in a separate area).

Another member shared her approach as a nurse specialist in neurorehabilitation, where she provides care to the binomial noting she always focuses her interventions on both of the two components helping them through individualized and personalized guidance, and considers life contexts as well as individual needs. The nurse specialist noted informing individuals that participation in group activities may also help individuals in sharing experiences and in relieving the burden of care.

Another member shared his experience in respect to tele-practice, where he often refers caregivers to local support groups as well as national nonprofits (which often provide good resources). The member added that – in Colorado, USA, the regional Parkinson's nonprofit had a social worker that was willing to do in-home visits, noting – however, the social worker has now transitioned to assist the palliative care program at the University of Colorado instead.

> The member further noted when they were previously serving as founder and Director of a Colorado Parkinson's network, the network was not only involved with many of the local support groups but they also taught classes and exercise programs where many exercise classes operated as not only opportunities for fitness but also support.

Another resource this member noted referring to quite frequently was a set of videos produced by **CurePsP** that features a physical therapist working through a number of common daily activities in the home environment.

> The videos provide guidance for safe ways to navigate the home environment and are particularly relevant because many of the activities are somewhat out of the scope of practice (of an SLP). The member noted ostensibly, however, preference that individuals work with a PT or OT as well (in order to directly address potential issues).

The member noted awareness of MDS producing some consumer content but has yet to implement it into practice.

Question 7. What formal or informal supports are available for caregivers in your practice environment?

Members discussed the formal and informal supports available for caregivers in their practice environments, noting differing experiences by country, where within:

Brazil
Patient associations and rehabilitation centers play an important role in this context with an additional increase of reliance on social networks (in recent years), with families, more than patients, using this feature.

Formal support: may be offered by some hospitals, providing a booklet with information about many topics concerning the health and social conditions (mental/physical health, physical condition, social rights, and self-care). Participating hospitals may also offer a course (every month) for any person (including patients and caregivers) interested in the topic; the course explains the role of the multidisciplinary team regarding PD. Additionally, there is a large online education program, which offers education and support for patients, caregivers, and families.

Informal support: may be offered as get-togethers for socializing (national campaign for PD; Christmas' celebration, Carnival time, St. John's celebration, etc.).

Singapore
There are various resources, such as monthly support group meetings in hospitals, Parkinson society-organized local events, caregiver training workshops, and discussion sessions.

Luxembourg
For face-to-face exchange, patient associations in the country and groups (in the greater region) are available, and increasingly information via Internet and social media (especially caregivers' blogs) are successfully used.

United States
Some University centers offer caregiver support group meetings that can be attended in-person or via phone, free counseling services, social work support (as needed), with some even offering an annual caregiver retreat at a local arboretum with speakers and sessions to support the needs of caregivers. Online support groups are also encouraged.

Question 8. How do you share results from cognitive screening or consequences of cognitive decline during consultation or treatment with the patient, caregiver and other health professionals?

Members agreed, they will usually talk to patients and caregivers after the examination of cognitive functions or during clinical consultation. Most members noted providing face-to-face feedback to the patient regarding their performances on testing (and family, if desired by the patient).

Professionals will talk to the patients, caregivers, and other HPs about:
- How testing is interpreted (based on norms);
- The cognitive domains tested;
- The strengths and weaknesses on testing;
- Any appropriate diagnoses (i.e., MCI, PDD); as well as
- Any recommendations professionals may have.

Some members will include the full interdisciplinary team, where specific health advice may be offered when a decline in cognitive function affecting any life domain of the patient is observed.

Participants noted that feedback is often shared immediately following a test so the person understands why the test was performed. It was identified, for those doing the assessment as part of a larger battery of tests (i.e. to screen for appropriateness of the PD Warrior program), individuals receive a report at the end detailing what was found, plus an opportunity to discuss findings. Then, with the individual's permission, the report is sent to the individual's General Practitioner.

Other members noted they may often email over any reports and write to colleagues whom may be taking over the care of the individual.

Other strategies mentioned include:

- Always attempting to relate the information to changes in function, which the patient and caregiver are usually aware.
- Discussing the possible need for increased organizational strategies, cues/reminders from the caregiver, and the potential impact on tasks such as driving and medication management.
- Sharing results directly with the therapy team to promote collaboration on cueing strategies, carryover expectations and to determine supports needed.
- Generally contacting the MD and social worker via email to discuss needed supports or safety concerns.
- Having neuropsychologists review results with the patient and caregiver in person.

One member noted in her experience, she has found it better to be more direct in a supportive fashion then "dance around" the topic of MCI or dementia – trying to involve the caregiver in the entire process of screening, testing, and treating.

Honesty is best – but with sensitivity (and no 'dancing').

Members reiterated the importance to be honest when sharing results, further highlighting how important it is to communicate with the patient and clarify that a cognitive screen is just a flag that further assessment is required and a failed screening does not diagnostically confirm that someone has MCI or dementia.

One member shared her experience as an Assistant Professor of Communication Science and Disorders, where, on multiple occasions, she has watched people come into her University for testing who believed they had dementia (because they were told this following a cognitive screen) when indeed they did not have either MCI or dementia (adding, the opposite can also be true).

> The member noted how:
>
> - One of these individuals was experiencing low blood pressure episodes relating to PD medication;
> - Another had hearing loss; and
> - Others have had a UTI that when resolved, resolved their cognitive issues.
>
> In all these cases, individual driving privileges had been revoked and families were preparing for a dementia course – and five years after these episodes, these individuals still showed no sign of dementia (although, having cognitive changes typical of PD).
>
> The member reiterated, the importance:
>
> - To communicate the limitations of professionals' tools; and
> - Of further testing for diagnostic/treatment planning
>
>   When clients decline during treatment, the same is true. This could be 'real' cognitive decline as a harbinger of dementia - but there could also be a medical explanation for the decline.
>
> Another member agreed that Dementia and driving is a hot topic her team will often discuss and if there are any concerns then they always refer to occupational therapy for an adaptive driving assessment.

Members agreed frequent communication with the physician and nurse is key to rule out any medical causes for changes in cognition before concluding that it is a progressive process.

One member noted they will share this information in order to highlight the losses and, above all, the compensatory strategies needed at time of discussion, taking special care of the family while also engaging other professionals in the process.

Examples of this may include discussing the potentiality of cognitive deficits or behavioral changes with the:

- Physician - as consequence of the use of medications;

- Psychologist - as consequence of depressed mood; or
- Family - as consequence of the disorganized routine.

Other members will share this information via:

- The treating neurologist or physician;
- Clinic consults;
- Multidisciplinary Team Meetings;
- Online Hospital documentation system(s);
- The EMR;
- Email exchange;
- Memo updates to other health professionals;
- Written reports; or
- Telephone.

Working as a Tele-Practitioner

Another member noted they typically send their reports directly to the physician signing the orders via secure email or HIPAA-compliant fax (for health information privacy regulations). Despite this member's work with tele-practice, they noted preference in sending a paper copy of any documents at the conclusion of treatment (as, although they have a HIPAA compliant email set up, most of their patients do not). This individual will also put documents into a secure online folder for the patient to access during treatment but won't typically keep the folder available on the cloud after treatment has concluded (noting this as primarily due to the service being expensive and only adding to the potential for breach by leaving it in the cloud).

Members of the group closed discussion with thanks to one another for sharing experiences

One member within the group identifying as an AHP Learning Advisor for Parkinson's UK (as well as Independent OT) working with Parkinson's UK national Parkinson's research and patient support organization developing learning pathways for OTs, PTs, and SLPs commended the fantastic scope expressed by all contributors (of the online meeting) - of the management strategies, rehabilitative interventions, support for caregivers and belief in the possibilities for improving the day to day lives of People affected by Parkinson's; further encouraging everyone to keep up the good work and consider sharing gems of expertise beyond the group.

All members thanked one another for sharing experiences and for participation in an enriching and truly global discussion.

Online meeting adjourned.

Respectfully submitted,

Samantha Surillo
MDS International Secretariat
MDS Health Professionals Special Interest Group (MDS HP SIG)
International Parkinson and Movement Disorder Society (MDS)