Brainstorming for Parkinson's Disease (BSPD)

Workshop Summary

June 9-10, 2022

The Brainstorming for Parkinson's Disease Workshop is an exclusive annual workshop, including the best minds in the field of Parkinson's disease treatment and research in Israel. Every year, experienced neurologists specializing in the treatment of Parkinson's disease and leading researchers in the field meet for an intensive 2-day workshop.

During this workshop, the experts discuss key issues in the current and future treatment of Parkinson's disease. This year, we focused on eight essential topics and are proud to present the key points and conclusions for our experts on each one.

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Legal Aspects

Headed by: Prof. Judith Aharon & Prof. Rivka Inzelberg

Parkinson's disease is characterized by motor changes (tremor, muscle stiffness, slow movement, and loss of balance), as well as changes in cognitive functions and behavior, which worsen as the disease progresses.

It is estimated that more than 50% of patients with Parkinson's disease suffer from cognitive decline and as the disease progresses, from dementia and changes in behavior. The cognitive deficits are mainly detected by tasks that test executive functions.

Executive functions are a collection of mental functions that control other cognitive processes (memory, language, visual recognition). They are responsible for the ability to initiate, persist, delay and change reactions and actions and are involved in emotional regulation and social and academic functioning.

Executive functions are essential for planning and making decisions, detecting and correcting mistakes, learning about new situations or actions and dealing with dangerous or complicated situations. Deficits in executive functions may occur with normal or impaired basic cognitive functions.

The functional decline in Parkinson's disease is caused by the impairment of motor function, the impairment of cognitive functions and the behavioral changes. These can be a result of the disease or secondary to the drug treatment.

Patients suffering from moderate or severe cognitive decline often suffer from poor awareness of the severity of their cognitive, behavioral and functional impairments. Therefore, their ability to make informed decisions might be damaged even during early stages on the disease.

Caregivers of patients suffering from cognitive decline are sometimes required to decide whether the cognitive-behavioral impairment enables the patients to continue the activities they performed in the past (such as driving, carrying weapons, managing financial affairs, living independently). They are also required to decide whether the patients are fit and able to make informed decisions regarding the management of their property, medical care, personal and social conduct, and legal matters such as appointing a proxy and drawing up a will. These are dynamic processes that may change over time.

Competence is specific to the action or decision for which it is tested. A person may be competent to perform an action or make one decision and incompetent to perform an action or make another decision. It is not possible to infer one competency from another.

Assessment of competence

Diagnostic tools suitable for assessing cognitive function are not necessarily suitable for assessing competence for decision-making. Competency is usually correlated to the ability to perform executive functions.

The assessment of competence should include four components:

1. **Comprehension:** The patient understands the information presented to him
2. **Evaluation:** The patient is able to evaluate the relevance of the information provided.
3. **Reasoning:** The ability to use information to carry out a logical decision-making process.
4. **Expression:** The ability to express the decision and reason.

Recommendations

1. The patient and his family must be informed about the patient's changing ability to make decisions in light of cognitive decline and behavioral changes early during the course of the disease.
2. Existing legal tools must be made accessible to enable the preservation of the rights and wishes of the patient suffering from Parkinson's disease (durable power of attorney, guardianship, fitness to drive, etc.).

Sleep

Headed by: Dr. Jonathan Reiner & Prof. Yuval Nir

Sleep disturbances are one of the most common non-motor complications of PD and are often debilitating.

There is a broad spectrum of sleep disorders in PD, including the following:

Insomnia- a sleep disorder in which patients have difficulty with falling asleep and/or staying asleep.

RLS/PLMS- restless leg syndrome (RLS) is a common disorder among PD patients that includes episodic jerks of a limb (usually the leg). In many patients with this disorder, the jerks may occur during sleep and are then called **periodic limb movements of sleep** (PLMS). In PLMS, jerks occur every 20 to 30 seconds on and off throughout the night and can cause sleep disturbances.

EDS- Excessive daytime sleepiness (EDS) is the tendency to fall asleep during normal waking hours. While inadequate sleep (insomnia for example) is often the cause, Parkinsonian pharmacological treatment (mostly dopamine agonists) may also increase the risk for EDS.

Circadian dysfunction- Circadian rhythms are physical, mental, and behavioral changes that follow a 24-hour cycle. These natural processes, which are often referred to as "sleep/wake cycle" respond primarily to light and dark. When this rhythm is disturbed, which often happens in PD, patients may suffer from either difficulty falling asleep, waking up during the sleep cycle or waking up too early and being unable to fall back to sleep.

RBD- Rapid eye movement (REM) sleep behavior disorder (RBD) is a sleep disorder that is closely associated with PD, and often precedes the disease. REM is a sleep stage in which most dreaming occurs. RBD is characterized by dream-enactment behaviors that emerge during a loss of REM sleep atonia (a muscular inactivation usually occurring during REM sleep). While also impacting quality of

sleep, this disorder my impact the patient's safety as well as the bed-partner's safety. RBD enactments can vary in severity from simple hand gestures to violent acts (like punching and kicking) and thus may cause injuries (both self-inflicted and to the bed partner).

Contributing factors to all sleep disorders are multifactorial:

Disease related causes- may be either motor (e.g. night time akinesia) or non-motor (e.g. anxiety, pain or nocturia).

Treatment-related causes- pharmacologically induced (e.g. agonist related excessive daytime sleepiness and sleep attacks).

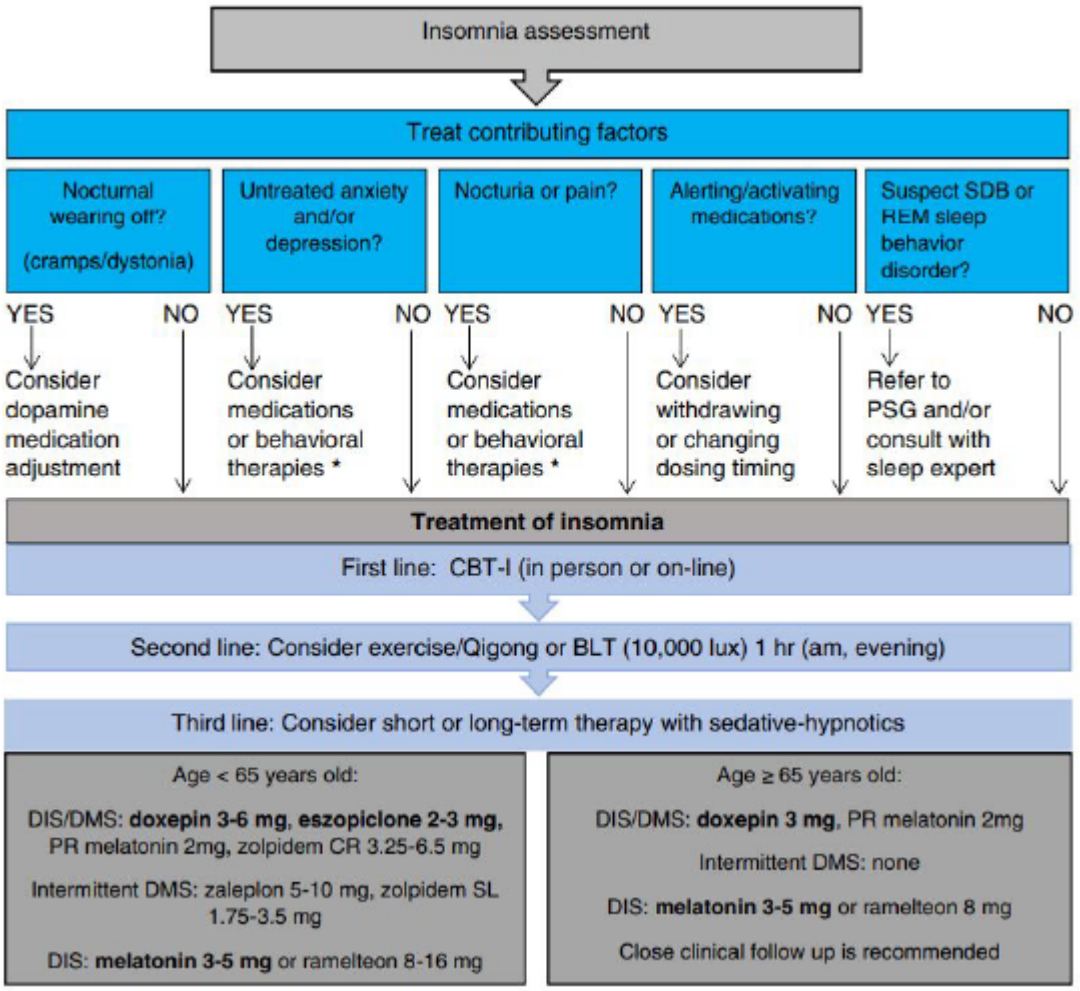
Behavioral causes- lack of exercise, frequent and inefficient napping, etc.

Treatment:

Sleep hygiene- a behavioral approach which clinicians should educate patients on. The guidelines of sleep hygiene include:

- Stimulants- avoid stimulants (like caffeinated drinks) at least 6 hours before bedtime.
- Food & liquid intake- avoid excessive food and liquid intake at night
- Regular schedule- maintain a regular sleep schedule
- Electronic devices- switch off electronic devices that have a screen (cell-phone, tablet, laptop, etc.)
- Use a proper bed- use beds for your sleep. If you cannot sleep get out of the bed for a brief time period.
- Avoid naps (if necessary) - avoid sleep naps if you have a difficulty falling asleep at night.
- Clock watching- avoid obsessive clock watching
- Bedroom- keep bedroom cool, dark and comfortable.
- Lights- seek out bright light in the mornings and avoid them during the evening.

Insomnia treatments guidelines- follow the MDS insomnia treatment guidelines, which recommend the first and second lines of treatment to be behavioral (and specifically recommend CBT as a first line and exercise as a second line), with only the third line including pharmaceutical treatment . Please see the attached guidelines for more details:



RLS/PLMS:

May have a great impact of QOL. Diagnosis should be established via careful history taking and patient interview. Treatment may be commenced to patients with persistent and debilitating symptoms.

Treatment includes -

- Assessment for iron levels and treating via iron supplementation.
- adjustment of dopamine this treatment to avoid sudden fall in dopamine levels at night which may be a contributing and aggravating factor. Adding nighttime treatment with Sinemet for patients already on Levodopa treatment or nighttime dopicar may be helpful. Whereas previous guidelines supported the administration of dopamine agonists such as ropinorole and pramipexole, current first line approach suggests treatment with gabapentoids such as Pregabalin or gabapentin at appropriate doses.

RBD:

- Diagnosis should be established via patient's interview and overnight lab-based polysomnography.
- If significant and affects patient and cater safety and QOL then consider treatment.

- Avoid aggravating medications such as SSRIs
- Treat with either Clonazepam or with Melatonin.
- Treatment with Melatonin may be safer in patients as is not a sedative. Shown to be useful in doses up to 12mg; therefore, consider increasing dose if commenced in 2mg in small increments.

Home-Based Monitoring

Headed by: Prof. Jeff Hausdorff & Prof. Anat Mirelman

Home-based monitoring has become part of most people's daily lives, as we are all caring devices monitoring much of our behavior and movement (like smartphones and smart-watches) throughout the day. Additionally, devices that are able to monitor more complex behaviors and physiological data are becoming smaller, portable and more user-friendly. Using this always- advancing technology to monitor symptoms has a vast potential in patients' diagnosis and care.

Home based monitoring can potentially provide greater accuracy and richer data sets. It is highly available, fairly simple to use and can increase patients' and caregivers' engagement.

In Parkinson's disease (PD), this is especially important, as these devices can follow the fluctuations characterizing this disease.

How close are we to routinely including wearables and home monitoring in PD clinical trials?

Can home monitoring devices be used as clinical outcome assessment? Can they truly reflects how an individual feels, functions or survives? Can it be used to assess the efficacy of a treatment being tested? We discussed both the potential of using this technology and the gaps and obstacles that still exist.

The assessment tool needs to evaluate **functioning in patients' daily life** (e.g., ambulation), and be **meaningful to patients.** Meaning- what significantly affects patients' daily lives **in their perspective** is the most important to be monitored and assessed. Which symptoms have more significant effect on a patient's quality of life differs between individuals and between different stages of the disease.

Following an extensive survey of PD patients, in different stages of the disease, reporting what are the most bothersome symptoms, we examined the level of evidence of 6 areas of home- based monitoring.

	Level of evidence
Voice / speech	Fair
Sleep	Fair
Gait/ postural control	Fair
Autonomic function	Poor
Tremor / dyskinesia	Good
Cognitive function	Poor

How close are we to routinely including wearables and home monitoring in the everyday clinical care of people with PD?

We discussed what clinicians would like to gain from home based monitoring, to enable the use of data derived from home monitoring devices in medical assessment and treatment in PD patients:

- Voice recording before DBS: Voice can be easily monitored using smartphones and can be analyzed for both physical aspect (loudness, speed) and content (cognition, psychiatry). This may enable to assess the patient's compatibility to DBS and the post-procedural side-effects.
- Signs of progression over time and response to medication: Crucial for patient care and very under-addressed
- Home assessment of autonomic symptoms: Symptoms such as drooling, nocturia , constipation, sexual dysfunction, sweat, HTN / orthostatism can be very meaningful for the course of treatment, yet there is lack of evidence from home based monitoring for these symptoms.
- Dyskinesia and tremor recording should be patient specific: As tremor can occur in different body parts and have different patterns, tremor recordings should be personalized (i.e., personalized monitor placement and a personalized algorithm).
- For gait: information should be provided as scores: Definitions such as shuffling, freezing-of-gait, falls and their characteristics.
- Measures of macro and micro are both relevant: Both macro measures (activity, overall movement, number of transitions, sedentary behavior etc.) and micro measures (freezing-of-gate, on-off, dopa responsiveness, a-symmetry, etc.) are relevant for clinical assessment.
- Environmental aspects are also important in the context of gait: Recognizing where and\or when the freezing-of-gait and\or falls are more likely to occurs.

Gaps and recommendations in home-based monitoring:

1. Multimodal seems promising and more comprehensive.
2. Serious gaps that need research: progression, response to intervention, prognosis.
3. Use the advantage of the large body of data to understand variance between patients, to enable future personalization.
4. Add/ collect normative data from non-PD - elderly, with and without additional ageing disease (sarcopenia, diabetics, etc.)
5. Sharing of data / standardization and harmonizing across studies/ collaboration between different groups in the same area and open sharing of data from clinical trials.

Cannabis

Headed by: Dr. Nirit Lev and Dr. Saar Anis

In recent years, there is a constant increase in the administration and consumption of cannabis and cannabinoids among PD patients. While many PD patient either use cannabis prescribed by their neurologist or self-medicate, the usage of cannabis in PD is still highly controversial. The demand for cannabis increases, yet, there is a lack of clear recommendations for the administration of cannabis, making it difficult for neurologists to determine both the right dosage of cannabis and the right concentration of active ingredients (mostly CBD and THC) for the treatment of different symptoms.

In our discussion group we discussed the gaps in knowledge preventing the creation of such recommendations and the possible steps we recommend to close this gap to enable clear guidelines. This, we believe, will aid in a better and more precise care for our patients.

- Scientific research about cannabis in PD is scarce. While results from studies in animal models looked promising, clinical studies in humans are inconclusive.
- There are no formal recommendations from the American or European neurological societies.
- For the creation of clear recommendations, it is essential to encourage further research, to learn about the effectivity and side effects of the treatment.
- These studies should be controlled trials - including control groups, with a selected and controlled strain with high levels of THC or CBD or a balanced combination, to avoid the high variability in the cannabis strains used by patients.
- We believe these studies are very feasible in Israel, because of the high compliance of patients and the relatively high number of patients with medical cannabis permits.

- We recommend establishing a database of patient monitoring, enabling pharmacovigilance, which includes efficacy and safety. It is possible to contact the Ministry of Health and the medical cannabis unit, to combine this data with the database of Parkinson's patients in Israel.
- Generally, follow-ups on patients treated with cannabis is conducted every six months in the first year, and once a year in the following years.
  In view of the older age of Parkinson's patients and their frailty, it seems that a closer follow-up is needed, especially at the beginning of treatment. The clinical impression is that most of the side effects or terminations of treatment are in the first few weeks of treatment. Such follow-up can be conducted with the aid of family practitioners.
- To create guidelines, because of the lack of scientific-based recommendations, it was proposed to conduct an expert survey.

Psychosis

Headed by: Prof. Ramit Ravona & Dr. Ilana Schlesinger

While PD is a multi-symptomatic disease, including many non-motor symptoms, both research and treatment of this disease focuses mostly on motor aspects. Psychiatric symptoms in PD are especially disabling and generally under-addressed. Among the most common psychiatric phenomena of PD is psychosis, considered by many the most dramatic and behavior altering psychiatric cluster of symptoms. These symptoms, which disconnect patients from their surroundings, are very disabling, creating a significant burden on both the patients and their caregivers.

Psychosis in PD has slightly different characteristics than what is addressed as psychosis in “classic” psychiatry. The American Neurological Society defined **Parkinson’s Disease psychosis** not to only include **hallucinations** and **delusion**, but also to include **presence hallucinations** (more mild hallucinations, such as believing someone is next to me) and **illusions** (when a sensory stimulus is present but is incorrectly perceived and misinterpreted).

Psychosis in PD is surprisingly common- with an estimation of **60-80% of patients experiencing psychosis** during their disease duration. With disease progression and cognitive decline, the psychosis aggravates- starting with minor illusions, progressing to hallucinations with insights, than to hallucinations without insights, and eventually to delusions (often paranoid delusions).

The main risk factor for psychosis in PD are as following:

- Older age
- Longer duration of illness
- Severity of motor symptoms
- Presence of sleep disturbances

- Cognitive impairment
- Daily levodopa equivalent dose
- Dose of dopamine receptor agonists

The mechanism of psychosis in PD is unknown, with studies linking psychosis to several possible mechanisms- including neurotransmitter dysfunction, aggregation of Lewy bodies, genetic susceptibility and white matter changes.

Anti-Parkinsonian medications may not be sufficient or necessary contributors to PD psychosis, since psychotic symptoms can present in drug naïve patients. All dopaminergic agents have been found to be associated with incident visual hallucinations (which are the most common form of psychosis in PD), yet these studies did not control for other established risk factors (like disease severity or cognitive impairment).

Encountering a patient with psychosis, we must first eliminate other possible causes or aggravators- infections, medications, metabolic disorders, head trauma etc. Once eliminated, we establish the diagnosis of PD psychosis by a differential diagnosis between delirium, PD and dementia of Lewy body disease.

<u>Anti-Parkinsonian medication adjustment recommendations</u>

Reduce or stop medications if possible (without worsening motor symptoms) in the following order:

- Anticholinergics
- Amantadine
- Dopamine agonists
- MAO-B inhibitors
- COMT inhibitors
- Levodopa (last resort)

Any withdrawal of dopaminergic agents should be achieved slowly to **avoid rebound motor symptoms or dopamine agonist withdrawal syndrome.**

Other, non-pharmacological methods should also be considered:

- Provide a stable and adapted surrounding (familiar persons and objects, adapted communication)
- Maintain hydration and nutrition
- Correct and maintain sleep-wake cycles
- Avoid sensory deprivation (hearing aids and glasses)

- Detect and treat medical precipitators (lab tests, blood pressure, ECG, etc.)

Anti-psychotic medications should be considered for patients with troublesome hallucinations or delusions despite anti-Parkinsonian medication adjustments. If antipsychotic drugs are deemed necessary, preferred agents in patients with PD include quetiapine, clozapine and pimavanserin. All three agents have a low likelihood of exacerbating Parkinsonism, in contrast to the first-generation antipsychotics as well as other second-generation antipsychotics such as risperidone and olanzapine.

- **Quetiapine-** A widely used antipsychotic for dopaminergic-induced psychosis. Quetiapine is sedating, and this property can be taken advantage of with evening/bedtime dosing to target exacerbation of confusion and psychosis with nightfall ("sundowning") and comorbid insomnia, when present. In some cases, evening/bedtime dosing is sufficient to control daytime psychotic symptoms and dosing during the day is required as well.
- **Clozapine-** Clozapine is underutilized because of the burdensome requirement of hematologic monitoring (weekly to biweekly blood counts are required to monitor possible granulocytopenia, caused in 1-2% of patients), but it is probably the most effective of the second-generation antipsychotics in for PD psychosis. Because of the high effectivity of clozapine, neurologists should be able to directly administer clozapine to PD patients.
- **Pimavanserin-** A second-generation antipsychotic drug, with a clinical effect starting after ~6 weeks of use. It is approved by the FDA but not in Europe, so it is commonly used in the US, but is still uncommon in Israel. As more US- Israeli dual citizenships patients are using this medication, Israeli neurologist should be aware of the indication of use, administration and the possible adverse effects.

Falls

Headed by: Prof. Nir Giladi & Dr. Gilad Yahalom

Falls are a significant cause of disability, lost independence and reduced quality of life in people with PD. It is also a significant possible cause of death among these patients. We believe that the fall risk of patients should be assessed at each clinic visit and if it will be routinely done, it can aid in the prevention on falls in a very effective manner.

To do so, we propose a quantified fall risk score that can be easily assessed during the already short clinical visit.

The Parkinson's disease fall risk scale (PDFR)

Item	score
H&Y	1-2=0 3-4=1
Fall history	No=0; Yes=2
Presence of FOG	No=0; Yes=1
Cognitive state	Normal=0 Decreased =1
TUG sec	< 13 sec=0 >13 sec= 1
Total	0-6

Low risk: PDFR=0-1, Moderate risk: PDFR=2-3, High risk: PDFR=4-6

Almost all tests are already part of the clinical routine examination, except time-up-and-go, which we believe should be added in the clinical examination of every PD patients, and will add valuable information about the patient's condition.

Additional risk factors and their monitoring:

- **Orthostatic hypertension**: A major risk factor that should be routinely monitored. Ideally- will be done in the physician's office, but since it is a highly time-consuming test in a short clinical visit and clinical visits can be infrequent for proper monitoring we recommend an at-home patient self-monitoring. The patient will be asked to lay down for 5 minutes, stand up for 3 minutes and report his\hers blood pressure after each position using a diary and do so routinely at home. This data can be later submitted to a physician that will decide on the necessity of autonomic lab tests.
  Orthostatic hypertension should be treated aggressively- physicians should avoid offending drugs (like rasagiline and dopamine agonists) and prescribe anti orthostatic hypertension drugs.
- **Visual disturbances:** An under-addressed and significant risk factor. We should increase awareness of the impact visual disturbances like cataract and diplopia can have on the risk for falls among both patients and medical stuff. We recommend a close monitoring of such disturbances and an adjusted treatment, if needed:
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  - Neuro-ophthalmologic evaluation to subjects with increased fall risk (including an assessment of high-level visual functions like depth perception).
  - Pay attention to drugs with potential negative effect on visual function (like anti-cholinergic drug)
  - Behavioral modification among patients (create a safer environment, walking aids, higher awareness while walking etc.)
  - Treat aggressively

- **Sleep disturbances\ OSA (Obstructive sleep apnea) -** sleep disturbances, and OSA in particular are high risk factors for falls, despite being modifiable. We should increase the awareness of both patients and clinicians on the importance of sleep disturbances. Sleep studies should be done to all patients at early stages of the disease and treat aggressively and monitor throughout the course of the disease.

Treatment

Prevention is key- Trying to prevent (or at least postpone) the first fall should be our primary goal. To do so we should treat risk factors before the first fall.

- **Monitor closely-** Clinicians should monitor risk factors and label all patients for their risk fall.
- **Educate patients-** Clinicians should educate patients about their risk falls and discuss fall prevention strategies.
- **Decrease risk of severe injury due to falls-**
  - **Vitamin D-** Prescribe Vit D 2000 iu to all patients with increased fall risk.
  - **Bone density-** Suggest bone density study to patients with increased fall risk.
- **Exercise-** Prescribe exercise as a drug from day one on.
- **Cognitive protection-** Try to modify or attenuate cognitive decline.
- **Physiotherapy\ rehabilitation-** Patients with increased fall risk should be referred to physiotherapy\ rehabilitation. Treatment should be individualized to the patient's specific risk factors.
- **GaitBetter (intensive motor-cognitive rehabilitation) -** Should be recommended every 6-12 months to subjects with increased fall risk.

Genetics

Headed by: Dr. Lior Greenbaum & Dr. Avner Thaler

The benefit of offering genetic testing as a routine practice in PD is not clear. We agree that genetic testing has important contribution for research (mainly p.G2019S variant in *LRRK2* and *GBA* pathogenic variants). Ideally, this test should be accessible for PD patients and their unaffected relatives who are interested in getting tested, mainly since there are ongoing gene-specific clinical trials, and additional trials are expected to start soon. Overall, the basic (first tier) tests should be performed by the movement disorder clinics. Since positive results are expected in 30% of Ashkenazi Jews and about 10% of non-Ashkenazi Jews, some committee members advocate for genotyping only Ashkenazi Jews, while others suggest to test everyone irrespective of ancestry.

Written informed consent for testing is mandatory. We strongly encourage that all patients are informed about the genetic testing results. This should be done by either the referring neurologist during a conversation with the patient, in the setting of a clinic visit or by phone, or by a designated clinician with experience in PD-genetics (if the referring clinician is not comfortable with counseling about PD-genetics). In this conversation, basic information about the diagnosis, the inheritance pattern with reduced penetrance (approximately 10-30%, according to the specific variant), recurrence risk in offspring, and options for future clinical trials should be conveyed. The GBA related risk for offspring needs to be discussed and conveyed as well. We recommend that the Israeli movement disorder society will develop, publish and distribute educational material about genetic counseling and testing with all relevant information for clinicians, patients and relatives, as a basic reference. The Tel Aviv medical center team suggests to start working on this, based on their previous experience and material from the international PDGENE study. Patients who ask for more detailed information and those who require counseling regarding family planning should be referred to formal genetic counseling.

It seems that most movement disorder specialists prefer sending DNA for sequencing of a comprehensive PD gene panel (up to dozen genes), usually as part of research protocols (e.g., ROPAD) at no cost for the patients. However, the yield beyond *LRRK2* and *GBA* may be limited. The little benefit of an expanded gene panel should be balanced by the reporting of variant of uncertain significance (VUS) that may cause distress and unnecessary follow-up examinations. Of note, the key research studies for PD-genetics do NOT report VUSs. For example, neither ROPAD nor PDGENE report VUS, and VUSs are reported only by selected labs in clinical testing.

It is important to emphasize that PD is usually a multifactorial disease with polygenic architecture. Thus, beyond the first tier testing discussed above, there is usually no need for routine genetic counselling and testing for all patients (beyond the above mentioned panels that include *LRKK2* and *GBA*). However, it should be specifically offered for patients with known mutations in the family, early onset PD, in families with multiple affected individuals or for patients with unusual disease presentation. These individuals should be referred for genetic counselling. Of course, any patient and family member has the right to approach this counselling, if they like.

The results of the genetic testing are usually documented in the patient medical files, but this can harm the patient's privacy and conflict with law. More precise guideline should be provided by the Israeli Ministry of health and other professional associations, at a national level.

Advanced-Stage Patients

Headed by: Dr. Yair Zlotnik & Dr. Meir Kestenbaum

Most conferences and consortiums address the early stage, mid-stage and advanced stages of PD, but the very-advanced stage, which almost all patient get to, is under-addressed. Here we chose to address this sensitive stage of the disease, emphasizing that patients at all disease stages should be cared and treated.

Firstly, one must differentiate between the advanced-stage patients, who are usually candidates for invasive procedures, and the very-advanced stage patients. To do so, we defined who qualifies as a very-advanced stage patient.

- Cognitive - Significant cognitive decline, hallucinations and delusions are uncontrollable.
- Functional- Nursing in all ADL functions. Completely incontinent.
- Motor - complete immobility, confinement to a wheelchair or multiple falls, significant swallowing difficulties with reduced caloric and fluid intake, aspirations.
- Autonomic - orthostatic hypotension resistant to treatment to the point of inability to stand.
- Disease complications - pressure sores, recurrent pulmonary infections, recurrent fractures, etc.

A patient does not have to comply with all criteria listed above. If a patient complies with one or more of these criteria to a degree of a very significant disability, not enabling the patient to perform most or all daily functions, he\she can be defined as a very advanced stage patient.

Home- based hospice

Home-based hospice, provided by the HMO's, consists of palliative treatment within a patient's home, and is given to terminally ill patients. In Israel, terminally ill patients are defined as those who are assumed to have up to 6 months to live. Yet, several other diseases are included- including advanced dementia and very significant functional deficits, making many very-advanced PD patients eligible for this treatment.

We recommend to define every advance-stage patients as suitable for home-based hospice. The service can be approved for very advanced PD patients, yet many therapists and caregivers are unaware of this

option. **We recommend doctors and other therapists to increase awareness among patients and their caregivers, as this service can significantly aid them.**

This service includes a holistic treatment for pain, pressure sores, fluids, salts and oxygen, as well as psycho-social support. It is given by skilled professionals who are experts in end-of-life care (a doctor, a nurse and a social worker). It is given in the patient's home, making it more convenient for him\her. This service can minimize hospitalizations and clinic visits and can greatly aid the caregiver.

Anti- Parkinsonian treatment

Pharmacological treatment

Two approaches arose, with no consensus:

1. Some physicians recommend gradual reduction and discontinuation of all non levo-DOPA based antiparkinsonian therapies. Additionally, a gradual reduction in DOPA dose in patients with psychosis, as long as there are no side effects to such reductions (pain, rigidity etc.).
2. Other physicians recommend continuation of current treatment, as long as there are no side-effects, since the treatment can have positive effects, alleviating motor symptoms and pain.

Invasive treatment- If a patient is already treated with duo-DOPA or DBS, and this treatment alleviates pain and motor symptoms- it should be continued

PEG treatment- a treatment enabling administration of nutrients and medicines directly to the digestive tract. It can aid in patients with problems of swallowing or aspiration. This treatment should be discussed by the therapist with the patients and caregivers.

Should we continue to treat these patients in a movement disorder clinic?

- Attempts should be made to transfer the main treatment to other, more suitable practitioners (psychogeriatricians, geriatricians, palliative care physicians).
- It is advisable to try to reduce the frequency of appointments at the movement disorder clinic.
- Leave an opening for communication with the movement disorder clinic (such as by phone) to prevent a feeling of abandonment by a patient and caregivers.
- Families who insist to continue follow-up at a movement disorder clinic should not be denied this option.

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