



International Parkinson and Movement Disorder Society

MDS Health Professional Special Interest Group (HP SIG)

Online Basecamp Meeting

Focus: *Young Onset Parkinson's*

March 3-6, 2017

MINUTES

Present: Julie Carter; Angela Roberts; Clynton Correa; Michelle Tosin; Gila Bronner; Mariella Graziano; Siok-Bee Tan; Jennifer Doran; Elaine Book; Maria Elisa Pimentel Piemonte; and John Dean

Chair: Victor McConvey

Staff Liaison: Samantha Surillo

Co-Chair(s): Hanneke Kalf; and Maria Elisa Pimentel Piemonte

Background & Agenda

Twenty individuals, from across the globe, holding Health Professional (HP) roles in the Movement Disorders and Parkinson's disease (PD) community were invited to participate in the MDS HP SIG Leadership Basecamp Meeting (online) with the intent to have a focused discussion surrounding Young Onset Parkinson's disease (YOPD).

Participants were given 72 hours to submit feedback and suggestions to agenda items put forth by the Chair. The Chair requested Individuals provide feedback, from their unique perspectives / roles in the community, by addressing:

- I. SERVICES AND SUPPORT
 - Are people able to access Multidisciplinary care in your location/region?
 - Do you have a medical / health professional team with a particular interest in Young Onset Parkinson's (YOPD)?
 - Is there capacity to deliver a MD Service responsive to the needs of people with YOPD? i.e. *After hour's clinics/ increased use of virtual or online therapy*
 - What additional support do people with YOPD need? And are they available? i.e. *specific peer Support Groups*
- II. CHALLENGES AND SOLUTIONS
 - Please provide examples of challenges you have observed, experienced by people living with YOPD.
 - What challenges have you, as a health care professional, experienced in planning and delivering care for people living with YOPD?
 - As a health care professional what other challenges have you identified in managing people with YOPD?
 - What strategies have you used or are you aware of to meet these challenges and promote better care?
 - Pregnancy and Parkinson's – there is little published information on managing Parkinson's and pregnancy. Does anyone have any experience they are able to share?
- III. ADVANCED THERAPIES AND TECHNOLOGY
 - Do a greater percentage of people with YOPD get referred /or receive DBS than the typical onset of Parkinson's?
- IV. OTHER INFORMATION
 - Is there any other information you would like to share which may enhance the care provided for people living with Young onset Parkinson's and their families?

Purpose and Aim of focused Meeting on Basecamp

To date, there is little research into how the needs and models of care may differ for people with young onset Parkinson's. In this base camp meeting the group aimed to discuss this issue and share experiences of delivering care and how each meets the needs of people with YOPD.

Introduction to Young onset Parkinson's

Parkinson's occurring in younger people has many challenges over the duration of illness, such as the need to continue working and managing family life and in some cases raising children. For many people living with young onset Parkinson's, there is a need to access a range of health care professionals, often for many years to get the best symptoms management (-V. McConvey).

Welcome & Introductions

The Meeting started with the MDS International Secretariat welcoming group members to the discussion board.

Health professionals whom participated in the online meeting practice in locations such as Portland, OR, USA; Morton Grove, IL, USA; Rio de Janeiro, Brazil; Ramat-Gan, Israel; Esch-sur-Alzette, Luxembourg; Elwood, VIC, Australia; Singapore; Montreal, Canada; Vancouver, BC, Canada; Sao Paulo, Brazil; and Boulder, CO, USA.

Professional roles of participants consisted of ANP/Professor of Neurology; Assistant Professor; Professor(s) of Physical Therapy; Nurse Specialist in Neurological Rehabilitation; Director of Sex Therapy Services; Physiotherapist; Clinical Nurse Consultant; Deputy Director of Nursing (APN); Movement Disorders Clinic Nurse Clinician; Clinical Social Worker; and a Speech Language Pathologist.

Advice and contributions also received from (offline participants) Dr. Tanya Gurevich, MD Neurologist, Director of the Movement Disorders clinic, Tel-Aviv Medical Center, Israel; Dr. Ilana Schlesinger, MD Neurologist, Director of the Movements Disorders clinic, Rambam Medical Center, Israel; and Dr. Simon Israeli-Korn, MD Neurologist, Movement Disorders institute, Sheba Medical Center, Israel.

The following is a synopsis of discussion posts, cumulatively, across the 72-hour meeting period.

Comments and Feedback

I. SERVICES AND SUPPORT

Are people able to access Multidisciplinary care in your location/region?

It was identified that Individuals are able to access multidisciplinary care in the following locations: Portland, OR, USA; London, ON, Canada; Chicago, IL, USA; Elwood, VIC, Australia; Singapore; Montreal, Canada; Vancouver, BC, Canada; and only in big cities across Israel. Some locations also offer access to allied health clinicians and social work support via PD specialty clinics.

Within Colorado, USA, it was identified that:

- Several movement disorders programs exist in Denver (with full interdisciplinary team care provided);
- the University of Colorado has a palliative care program;
- in outlying regions of Colorado, there are primarily interdisciplinary rehab programs (PT, OT, ST) including
 - a network of 15 programs at Life Care Centers of America (a subacute/skilled nursing company), as well as
 - local hospitals with excellent programs (i.e. Boulder Community Hospital; Exempla Good Samaritan Hospital).
- Overall, access to care in Colorado can be great for some, but minimal in less rural areas.

While it was identified that there is access for people living in Brazil, it was only identified for those in the Northeast and Southeast, as in many other places across Brazil, multidisciplinary care for People with Parkinson's (PwP) do not yet exist. Examples of facilities offering multidisciplinary care in Brazil included the Sarah Network of Rehabilitation Hospitals (in the north- and south- east), and Rehabilitation Centres and Neurological Institutes spread throughout the Country.

While it was identified that specialised services for specific conditions are available in Luxembourg (a very small country), efforts are in their infancy period, though there is increasing Parkinson's awareness in society and health providers.

These increases in awareness can mainly be attributed to consistent international efforts and a recent and well-developed large cohort study on Parkinson's disease and atypical Parkinsonism with clinical and biological assessment.

The emphasis of the cohort research study are at a molecular, cellular and genetic level while care is taken to improve the services available for the Parkinson's population in the country and the region.

On this context, there is not yet a specific Multi-Disciplinary Team (MDT) for Parkinson's in Luxembourg, but the need of specialised expertise recognition and management is growing (and there is confidence it will be available in the future). While YOPD is taken into consideration in Luxembourg, it is not yet a specific group.

So far, specific needs of YOPD in Luxembourg have been taken care of especially when they are cared for by health professionals with a special interest in PD. While there is capacity, presently, to deliver a Movement Disorders service responsive to the needs of the Parkinson's population, in general, there is none specifically for YOPD.

With Luxembourg being a multilingual country and people with YOPD having access to the internet, it is believed this population benefits a great deal when appropriate sources are available in the Parkinson's community online.

It was identified that people from all over the British Columbia Province in Canada are able to access the MDT within the Pacific Research Centre (PRC) in Vancouver; and other teams have formed in a Rehab facility, as well as another outpatient clinic as well. While the PRC do not yet have a team with a particular interest in YOPD, it was identified that The Parkinson Society of BC has increased services to people with YOPD, including an online support group and in person support groups as well.

Do you have a medical / health professional team with a particular interest in Young Onset Parkinson's (YOPD)?

Members of the Group identified a number of facilities that have an interest or special team working in YOPD, where professionals recognize that YOPD needs differ from older PD populations; facilities/communities mentioned include:

- **Oregon Health & Science University** (*Portland, OR, USA*), which
 - accepted 340 new young people with PD (under 60 years old) within the last two years;
 - hosts a young person symposium for people 59 and younger every other year; where there are
 - Topics specific to young people with PD and their families;
 - Panels that have included couples who address issues of relationships, raising children, etc.; and
 - Other panel speakers and referral sources have included Sex Therapists in the community;
 - Symposium is closed with a wine/cocktail reception (a little more 'hip' than you'd find in other settings)
- **Northwestern Medicine** (*Chicago region, IL, USA*), which
 - has a PT clinic focusing on early intervention; which they are
 - working to expand to a multidisciplinary care path; and
 - has a goal of bringing individuals into a routine multidisciplinary approach to PD management early on in diagnosis
- **Neurology Institute of Deolindo Couto, Federal University of Rio de Janeiro** (*Rio de Janeiro, Brazil*), which
 - has many health professionals working together to improve QoL and health conditions of people with YOPD, professionals include a:
 - Neurologist
 - Nurse
 - Nutritionist
 - Occupational therapist
 - Pharmacist
 - Physical educator
 - Physical therapist
 - Psychologist
 - Speech therapist; and
 - Social worker
- **SARAH Network of Rehabilitation Hospitals** (*Brazil*), which
 - provides patient evaluations by an interdisciplinary team
 - offers patients an opportunity to participate in individual and group activities (based on their individual demands/needs)
 - holds weekly meetings to discuss cases among all members of the MDT (providing harmony of actions); and
 - encourages active participation from family to add valued contextualizing and personalized care

- **University of Sao Paulo (Brazil)**, which
 - has many PD patients under the age of 55 years old (making up approx. 20% of their total PD patients)
 - assumes that younger people have showed more interest for specialized care than older people (considering the world prevalence of YOPD)
 - is thought to possibly be associated with a higher level of hope in avoiding the progression of disease

It was also identified that several specific programs for young onset in the Canadian PD community exist (both in Ontario, and within the larger Parkinson Society programs). Additionally, in Montreal, Canada, professionals have noticed an increase in the number of YOPD patients, and so, have been looking to incorporate specific “support” groups and exercise activities more targeted towards them.

Members mentioned in Chicago, IL, USA, there is also a focus on YOPD groups with a key motivator for expanding multidisciplinary care being to try and ensure YOPD individuals have opportunities for early access to cognitive and communication therapies (among others).

While it was identified that there are no teams that specialise in YOPD within Australia, it was mentioned there has been considerable interest in the issues surrounding YOPD in the psycho-social research community with several research thesis and PhD’s written on the subject. While there are no specialist Healthcare Professional Services for this in Australia, there are a number of specialised social support groups (i.e. Young onset, and Young men’s groups); many of these groups have grown organically and so are small discrete groups.

It was identified in Singapore that the MDT looks into all aspects of PD, not just YOPD; though, there is a support group at Parkinson Society Singapore (PSS) that caters to YOPD. Within one tertiary hospital in Singapore, there is also a growth group for patients with PD, but not at regular intervals. Additionally, there are hospital-based support groups in major restructured hospitals in Singapore where most individuals with YOPD will either hop-around to the various support groups or to PSS to learn more about PD. However, most YOPD patients in Singapore are not keen to attend due to various reasons (i.e. unable to take time off, access to online resources, or they still have relatively good control of their PD).

While there was no one identified as focusing specifically on YOPD in Colorado, it was mentioned that a number of exercise professionals and physical therapists have designed high intensity exercise programs in the State, which may be appropriate for people with YOPD.

Is there capacity to deliver a MD Service responsive to the needs of people with YOPD? I.e. After hour’s clinics/ increased use of virtual or online therapy

At the Neurology Institute of Deolindo Couto, Federal University of Rio de Janeiro in Brazil, staff offers a WhatsApp service to patients and caregivers to clarify doubts related to treatment; however, the service is unusual as the institute meets with patients twice a week.

Limitations exist at the University of Sao Paulo, where they are unable to offer care after 6 PM, though they have invested in providing educational programs by internet as well as exercise programs based on home-based exercises, which are supervised via monthly visits.

In Colorado, on case-by-case basis’, some therapists are known to schedule appointments to accommodate people for as early as 7 AM to as late as 7 PM.

Within Israel, the National Health service (which is free for all) enables services in the morning and afternoon. The hospitals within Israel are usually planning the multidisciplinary treatment of patients in considerable time, trying to make waiting lists as short as possible; while evening services can be provided, they are usually private and may be costly.

Although some professionals in the group are licensed and practice in Tele-medicine (within the USA), they identified the growth in the area of virtual/ online therapies as being very slow due to a number of reasons, including:

- Issues with Reimbursement (Medicare does not cover tele-medicine); and
- A bit of a technological divide (older population and less technologically savvy)

Participants identified this as being an area that requires more attention, and while recognizing the need to move toward more online programming, members did not specify an awareness of any concerted efforts to do so yet.

What additional support do people with YOPD need? And are they available? i.e. specific peer Support Groups

Participants of the group identified the following:

- Genetic counselling regarding PD
- Specific Support groups
- Lay groups (like the Parkinson Resources of Oregon, whom have support groups specific to young persons)
- Special “orientation” groups for people with YOPD and their spouses
- Targeted (child-friendly) education materials for both the PwP and their families
- Individual meetings of Social workers and nurses with spouses of people with YOPD
- Specific annual education conferences
- Psychological support (hard for individuals receiving a diagnosis of neurodegenerative disease early in life); and
- Social support to understand/obtain their fundamental social rights

One member of the group mentioned a crucial issue to be discussed by Health Professionals as being to determine the most appropriate (non -surgical/-pharma) treatments for younger patients as well as best strategies to delivering other types of treatments, as the discussion is less advanced in comparison to pharmacological or surgical treatments for younger patients. Based on the experience of a PT, it was identified that exercise programs are more challenging to develop in groups among other important focuses, like programs for sexual orientation, providing psychological support in overcoming decreased self-esteem, and (overall) increasing the capacity to cope within the person with YOPD.

It was also identified that some YOPD patients have reported that having more social events, rather than "support" groups would be beneficial, as they appreciate sharing with others the same age and life stage as them (Not so much to support each other but to socialize). An example of this can be seen in Montreal, Canada, where J. Doran identified having a YOPD-group that have created their own meetings, where they get together once a month in a pub, restaurant, or bowling, rather than meeting in a room to sit around a table. It was noted that people with YOPD find these social get-togethers to be more reflective of their life and how they are trying to live it.

Another member of the group agreed, noting the one YOPD support group they are aware of in Colorado do not meet formally, but rather have a rotating engagement at someone's house.

II. CHALLENGES AND SOLUTIONS

Please provide examples of challenges you have observed, experienced by people living with YOPD.

Participants identified that while there are some systemic changes that may improve the situation in the future, the poor visibility of people with YOPD compounds the feelings of uncertainty. However while not officially sanctioned there is often added effort by a range of clinicians providing care. It was also mentioned that it is legislated that individuals cannot be removed from their employment because of disability and the onus falls to the employer to find alternative work if the Parkinson's diagnosis means the individual can no longer continue in their present role.

It was also identified that some key problems for individuals with YOPD is related to one of their key advantages; because they are younger and typically more fit, they have significantly more reserve and often spend the first several years avoiding addressing the disease head on; and, having a negative support group experience often compounds this problem.

One member of the group identified this as being problematic as they feel this is a population, if reached expeditiously, they may be able to help the most and guide on the right path.

It was also mentioned that sometimes this is also compounded if an individual with YOPD happens to encounter an inexperienced therapist who uses the standard assessments without the realization that someone younger and more fit may 'ceiling out' on many of the common tools with data specifically for Parkinson's such as the Berg balance test or the time to go.

M. Tosin responded by asking others in the group, "from what age do we consider YOPD?" noting an inability to find consensus in cited studies, with some considering 'young' to be those 21-39 or under 55 (Golbe, Neurology 1991), (Mehanna R, et al. Parkinsonism Relat Disord. 2014), (Pagano G, et al. Neurology. 2016), (Stern, et al Arch Neurol. 1991), (Špica, et al. J Neurol. 2013).

Based on age, M. Tosin made the following parallel between the challenges and the solutions for each:

- In late-onset PD, symptoms may be potentiated by common morbidities in the elderly (urinary, intestinal, sexual, imbalance, falls, depression, dementia ...), with an impact on their safety and quality of life (Špica, et al., J Neurol 2013).
- In young-onset PD, symptoms may be potentiated by the prolonged duration of illness and drug treatment (dyskinesias, motor fluctuations, dystonia, anxiety, depression, sleep problems...), which impact on the role played in society and family (Mehanna R, et al., Parkinsonism Relat Disorder, 2014).

Many of the group felt Motor and non-motor challenges that affect patient's work, relationships, and family are common in most people with YOPD. Members further identified how people with YOPD tend to live with social embarrassment and possible retrenchment/ loss of job opportunities if their employer or colleagues find out about their disease diagnosis. One of the most frequent complaints of people with YOPD consists of difficulty in community walking, and the concern to avoid other people noticing some of their PD symptoms appears to be more prevalent in the younger populations.

Individuals with YOPD are often faced with existing family roles as either breadwinner/ homemaker but unable to carry out these roles due to physical limitations and the disease process. Individuals are often in denial of diagnosis, with preferences to try alternative medication/ therapy to improve PD symptoms instead and are worried about DBS complications, cost and potential failure.

As professionals caring for people living with YOPD, other members of the group identified a number of challenges they have observed for those affected by YOPD, such as:

- Stigma around the illness
- the length of the illness and the economic impact it has on the individual and family (Vocations may need to be changed and income and future income is often jeopardised adding to uncertainty)
- Accepting the disease diagnosis and openly talking about it in public
- Going public/ Disclosing the diagnosis to family, spouse, children, friends, and colleagues
- Employment Ability/ Work accommodations (i.e. needing to leave work due to the disease; keeping their jobs or staying in the same job position; etc.)
- Managing both home and work
- Maintaining their same role in their family dynamic or society
- Managing family life/ and impact on family members
- Raising children
- Financial stability/challenges
- A spouse who may be working and has many other responsibilities
- Peer support
- Increased health care needs and associated costs
- Reduced access to interventions/ therapy services (typically scheduled not at convenient times that fit within their life schedules not allowing them to get the help they need)
- Inability to make it to frequent multidisciplinary appointments due to not being able to take time off work
- Mobility changes
- Physical appearance changes (i.e. drooling, especially for women)
- Overcoming the anxiety aroused by the diagnosis
- Exploring how to stay active and continue usual life, including social life
- Coping with the fear of the unknown
- Attending a support group where the person with YOPD is the youngest in the room, being in the presence of people with much more advanced disease, becoming frightened and often not returning until a problem shows up

All members of the group agreed there are many challenges on how the condition is affecting the PWP and their particular social situation.

Additionally, members of the group identified a lack in a number of areas for individuals with YOPD, including:

- Available information around sexuality/intimacy challenges;
- Support around 'stigma' associated with medication routines
- Family-based specific programs that includes children (i.e. how to talk about PD; remaining active in school activities)
- Access to social work and family counselling services
- Understanding and an over-generalization of the concepts around 'care giving' or 'care partner' (which have unique considerations in a young-onset population and differ from older onset populations)

While there is no scientific evidence to support it, one member of the group suggested that higher frequency of abuse of levodopa in people with YOPD may also be more common; where in one facility, it was noted that some may use extra doses of medication to increase their confidence in public environments.

Another interesting observation shared included an HP having heard from several women with YOPD about the role of their menstrual cycles and the potentially significant negative influence YOPD has on their symptoms. Often, it can take them completely out of commission for several days every month. Group members mentioned, while that's not something they have ever read in a book, a lack of access to this kind of gender-specific knowledge for YOPD could be a real barrier to optimal care.

What challenges have you, as an HP, experienced in planning and delivering care for people living with YOPD?

It was identified, from a physiotherapist's perspective, that people with YOPD seem to have more problems than the older populations when it comes to having adequate time available to invest in their rehabilitation programs where they tend to push themselves further in daily activities leading to increased levels of fatigue and frustration. Other participants mentioned:

- Individuals being in a 'not needing care-upon-diagnosis' mind-set, particularly if they are in the "honeymoon period" with medications
 - Due to higher level of function, sometimes YOPD patients have a low level of understanding of the potential significance of certain symptoms and require coaching in order to participate in treatment
- Building scientific evidence to guide the therapeutic decision about the best strategies to support people with YOPD
- Helping people who do not have adequate disability coverage
 - Sometimes public system funding isn't enough (especially in expensive cities; i.e. Vancouver)
- Manpower, funds and clinic space
- No one-stop service centre
- Not having a good couples therapist who understands about PD in young people, specifically:
 - Talking about couples issues, role changes, intimate issues, intimate and sexual role changes;
 - Helping individuals in sharing their fears for the future, and planning in advance, when the person with YOPD still feels strong and capable, and how they would like to manage their intimate relationships;
- Various aspects of sexuality and sexual behaviour
- Gender issues (important for HPs and physicians to better understand in order to help)
- A therapist who can work with children who have a parent with PD;
- Restrictions around service access based on organization-imposed limitations;
- Narrow perspectives of how PD is taught within allied health training programs (such that the focus or model of PD presented rarely includes the YOPD client – as such, new graduates have a very limited understanding of this population)
- Not being able to tell them the future or answer some of the biggest questions, such as "Will I be able to work until I am 65?" or "How will I support my family?"
- Low attendance in organizing virtual evening meetings via Google Hangouts (to accommodate work-schedules)

From a Neurologists perspective, some key challenges people with YOPD face are having a more difficult time with the decision to start levodopa treatment, and the effect of dopamine agonists on driving.

A key issue for YOPD identified in Australia is viability within the large Government funded Health Care System where clinicians deliver care; however, there is no recognition within the broader system that this group may need a specialised response. A recent policy has been to introduce the National Disability Insurance System in Australia, which is a major government reform that focuses on the support of people with a disability (it is self-directed and aims to be patient focused).

Within its roll out, it has provided additional services to people with YOPD, but some early issues have been the system is not responsive to the progressive nature of PD and requires the individual to know what their needs are.

Others from the group felt it is quite challenging to handle people with YOPD who have high social status and high level of education, which they felt was likely due to the self-proud, where patients often refuse treatment or refuse help from psychiatrists/ or psychologists when they experience problems. These challenges, among others, pose tremendous stress to patient's, their caregivers, and family members.

As a health care professional what other challenges have you identified in managing people with YOPD?

Participants of the group identified the following:

- To gain their confidence and trust long term. They search desperately for a cure, and look for many solutions, which at times are not realistic, but as a professional, you need to learn to support and act when the time is right.
- Limited community support for those who are keen to continue working.
- Lack of financial support for YOPD.
- Lack of training of new skills to remain employed for people with PD.
- Progressive nature of disability affecting employment.
- Family relationship is often affected (Without the support from family members, YOPD may face much difficulty in overcoming the problems).
- Working within limited constraints; such as following the “Guideline for PD treatment,” determined by the National Health System in Brazil, which only includes pharmacological and surgical treatment; however- health professionals have been working hard to change this guideline.
- Difficulty involving kids and teenagers in supportive care of parents with YOPD
- Many other therapists having a lack of information about early indications of deficits; missing simple tricks to uncover deficits, like adding a cognitive dual task to a simple task (such as the timed up and go)
- Other tools being largely unknown among many therapists (regardless of them having extensive Parkinson’s specific training, including certification in a branded approach as well as ATTP training)
 - Though, because the main focus in the past has been on older populations (where Medicare is a preferred source), access to individuals with young onset diagnosis seems to be somewhat less common than would be at large university-based movement disorders clinics

What strategies have you used or are you aware of to meet these challenges and promote better care?

Members of the group offered strategies they have used in the past or are aware of in meeting special challenges and promoting better care in people living with YOPD; these included:

- Investing in chats for education and support (with adequate approaches for kids and teenagers)
- Trying to be as flexible as possible
- Using telephone appointment times so all know when they can reach one another instead of playing phone-tag
- Keeping a list of young people diagnosed so professionals may utilize to foster an informal peer support network;
- Offering newly diagnosed workshops that
 - provides an opportunity for the professional to personally see and talk to people who are young and diagnosed; and also
 - provides the person with YOPD a variety of resources in their community
 - i.e. Brain Grant Foundation (caters to YOPD and focuses on exercise and nutrition)
- Incorporating family systems principles (working with the whole family unit when establishing priorities and goals to address in intervention)
- Including children within the therapy process
- Taking on the role of being an advocate for the client, establishing a 'network' of information providers for them
- Organizing a clinical meeting at least once a week with the purpose of discussing cases of the patients among health professionals; topics may include:
 - Identifying patients without social benefits (i.e. drugs free of charge, income tax exemption, etc.)
 - Identifying patients in need of psychological support among other demands

In Singapore, the Parkinson Society Singapore (PSS) and the National Neuroscience Institute were identified as creating a Community Care Partnership Program to train Community Partners within Singapore (Community Hospital, Nursing Homes, Rehab centres, Day care centres, among others).

Twice a year, they offer the program to train healthcare workers on how to care for PwPs. In addition, rehab training for community partners are offered by Speech Therapists, Occupational Therapists, and Physiotherapists to manage motor and non-motor symptoms during on-job training. A key strategy focused on is to encourage the patient to participate in more social activities and learn rehabilitation skills; there is also a Home visitation program to detect and understand patient’s coping at home.

It was identified at the SARAH network in Brazil, YOPD patients:

- participate in physical activities with physical educators (such as strength training and balance, basketball, and swimming);
- see physiotherapists (for gait exercises and video game therapy) and have time with a dance teacher
- are evaluated and guided by nurses (to assist with medication adherence, independence and safety in ADL, intestinal and bladder symptoms);
- see psychologists (for symptoms of humor, cognition and coping);
- have access to speech therapists, and
 - pedagogues (for strategies to compensate difficulties in writing),
- have an art teacher and a neurologist.

All members of the interdisciplinary team within SARAH are responsible to guide patients for fundamental social rights, because they do not offer services from a Social worker. Lastly, it was identified that the SARAH network does not have virtual or online therapy yet, but believe it is to come in the future.

From a neurologist's perspective, the following strategies were identified as having been utilized in Israel:

- (1) Education of patients, giving detailed explanations.
- (2) One orientation session in groups of YOPD, getting to know the multidisciplinary HP team, and sharing with them the different aspects and nuances of YOPD.
- (3) Offering immediate "crisis intervention" if needed.
- (4) Education and advocacy for PD in the community, and among the neurologists in the community.
- (5) The Israeli PD association has recently opened a special unit targeted for activities with YOPD.

In the field of intimacy and sexuality, some of the best tools mentioned that individuals may consider pursuing are:

- (1) giving information which contributes to stress reduction, couple relaxation;
- (2) giving permission to ask, to consult with professionals and to make appropriate changes without feeling like a disabled person/couple;
- (3) giving practical advice and treatment in case of sexual dysfunction;
- (4) increasing the emotional, courting, loving aspects in the couple's life; and
- (5) giving special attention to the spouse's needs.

It was agreed by group members that more education is better. One member added that this population represents a very small percentage and suggested the group consider instead, raising the bar for overall quality of care by dividing better treatment to women. Noting that although women are not as well represented in population, they tend to live a lot longer and traditional medicine continues to treat women in studies as simply "smaller men" without recognizing some of the significant differences between the genders and how that might impact care. While not particularly relevant to this topic, the group member wanted to point out that less than 5% of people with Parkinson's are diagnosed before the age of 40 and overall numbers for young onset range between 10-15%.

Pregnancy and Parkinson's – there is little published information on managing Parkinson's and pregnancy. Does anyone have any experience they are able to share?

J. Carter identified working with Dr. Nutt a number of years ago in publishing a case report regarding lactation and levodopa which was revisited in a recent journal club; findings determined it is safe to nurse if only on levodopa.

Other members of the group identified having limited perspectives and knowledge in this area due to lack of care-giving exposure, however, it was identified that past client-males with YOPD have identified a concern around passing on genetics of PD and feeling they did not have enough information in the specified area. It was suggested though, for people with YOPD who are planning to have children or are already pregnant, the most important need being to understand the medication adjustment.

G. Bronner shared the following case report, from her Neurologist-colleague, about a pregnant female patient who has delivered a healthy baby on duodopa treatment: <https://www.ncbi.nlm.nih.gov/pubmed/25262534>

One member identified within Australia, that there have been some people with YOPD who have experienced pregnancy with PD and it is usually well supported by both Neurology and anti-natal services; though these numbers are low and support is provided on a case-by-case basis.

As a Social Worker, E. Book identified working with couples (where one spouse has PD) whom are interested in having children; wherein her role has been to provide supportive counselling as they navigate the decision.

III. ADVANCED THERAPIES AND TECHNOLOGY

Do a greater percentage of people with YOPD get referred /or receive DBS than the typical onset of Parkinson's?

Participants identified that this does not seem to be the case in practice at OHSU in the USA, within the SARAH Networks, nor services provided at the Federal University of Rio de Janeiro in Brazil, but individuals did identify thinking the notion to be growing while others confirmed yes (in Singapore and Israel, particularly). Other members of the group identified, in their experience, and at clinics they have been involved with, this notion appearing to be true. One member of the group did not agree that more YOPD are being referred for DBS than in the general PD population.

- In Luxembourg, there is a tendency to recommend DBS earlier on, but overall, people with YOPD are reluctant to have DBS.
- In Australia, it is more likely that a person with YOPD will be able to access publically funded DBS (not as selection criteria, but rather as something that organically occurs).

It was mentioned from a Neurologist's perspective, there are feelings that many people with YOPD are interested in DBS (and not advanced therapies). A member of the group specified an interest in breaking this observation up and possibly seeing the difference in YOPD interest/ pursuit in surgery and other advanced therapies (such as pumps).

In Sao Paulo, Brazil, it was identified that people with YOPD have showed a greater interest in DBS than others; which is thought to possibly be associated with a high expectation for cure as many people with YOPD have specified searching for information online and coming across videos which show the surgery as such. Thus, it is very important to clarify the purposes, potential side effects, and any possible limitations of this kind of treatment to better educate the public and relevant parties.

IV. OTHER INFORMATION

Is there any other information you would like to share which may enhance the care provided for people living with Young onset Parkinson's and their families?

A member of the group suggested, from the professional's point of view, when it comes to the individual person with YOPD or group, key areas that should be acknowledged are having experience, patience, and a good listening ear for the Patient and their families. Working in the context of a MDT approach, communication with professionals is key, together with patient empowerment; with the latter needing to effectively give the person with YOPD ownership of their care and appropriate tools to achieve their goals, especially if it is to make themselves understood by other health professionals or health providers.

It was also suggested that efforts be made for technology to be more humanized and promoted as a safety net not only for the management of impairments and decreased activities of daily living, but also to help the person with YOPD to maintain a role in Society. Another member of the group suggested that integrated care and mindfulness practices also be considered.

A. Roberts mentioned to the group, that one of the most informative comments she has received lately was from a research colleague who has YOPD, who in a large research meeting, recently became very upset at the use of the term care partner/caregiver and the groups' emphasis on including this into their research protocol.

From a non-married individuals' perspective, the person with YOPD felt this assumption is overemphasized and does not like the automatic assumption that individuals need (or will ever require) a care partner. Notwithstanding the importance of considering care partner's (as clearly I think this is necessary as my research is partially in this area), I thought the individual's reflection around the 'assumptions' that are made around the role of /need for a care partner - particularly in the YO group - was an important one to consider.

Members of the group agreed with A. Roberts thoughts on this matter.

C. Correa mentioned at his institute, they offer talks for patients, caregivers and family as well as a booklet containing information from a multi-professional approach, iterating the importance of highlighting that YOPD or PD diagnosis is not a death sentence and should not impose limits for any patient. It was further highlighted how important it is for patients to discover new possibilities and abilities which can be seen as a challenge.

A number of links were also shared to enhance the care provided for people living with YOPD and their families:

- Northwest Parkinson's Foundation (some noted this as superior content to others)
<https://nwpf.org/>
- Living Well Message from the Davis Phinney Foundation
<https://www.davisphinneyfoundation.org/living-well/>
- The American Parkinson Disease Association (APDA)
<https://www.apdaparkinson.org>

APDA has been producing young onset materials over the years with a chapter approach.

<http://www.apdaparkinson.org/national-young-onset-center/symptoms/>

- AMPARO Network:
<http://neuromat.numec.prp.usp.br/content/neuromat-network-empower-persons-parkinsons-disease-shaping-therapeutic-1>
- Viver bem com Parkinson (Living well with Parkinson's, Brazil):
<http://vivabemcomparkinson.com.br>
- SARAH Network:
<http://www.sarah.br/en-us/a-rede-SARAH/nossas-unidades/unidade-rio/>

Other Links shared:

- <http://www.parkinson.org/understanding-parkinsons/what-is-parkinsons/young-onset-parkinsons>
- <https://www.parkinsonrockies.org/early-onset>
- <https://www.nursingtimes.net/young-onset-parkinsons-disease-a-guide-to-care-and-support/205289.article>

A member of the group suggested considerations in setting up a database of patients (PD patients and Dystonia) that are pregnant and delivered during the advanced therapies, especially DBS treatment, in order to assess the DBS effect on pregnancy, on the fetus development, on delivery and the child's development.

It was mentioned that in Australia, there is a conscious offer to raise the visibility of YOPD by the NGO sector, and often, when raising profile of Parkinson's in the community, case studies of people living with young onset PD are featured highly. There is also a bi annual Young onset Conference delivered by Parkinson's Victoria as a national event. Every state based organization in Australia also has a network of Young Onset Support groups.

G. Bronner shared, as a Sex Therapist, she feels there is a scarcity of information about female sexual and intimate issues and their effect on the male partner.

In Brazil, it was identified that there is no access to treatments based on cannabis for PD; however, individuals at the University of Sao Paulo have observed a growing interest in this issue with people with YOPD (which may be due to information online).

Members agreed that increasing options for information, support, and networking for this group would be valuable, as well as, for their spouses and children; sometimes spouses of YOPD are not seen as care partners and their needs may go unaddressed. Similarly, many PWP do not want to involve their children in the PD process and education in this area with PWP could be valuable to facilitate healthy adaptation for the whole family.

A member of the group shared that David Sangster, a person living with young onset Parkinson's (in London) has been doing some online support groups (recent notification provided below):

Join the #youngpdnetwork for LIVE pd related discussion, post questions and comments - enjoy the festive spirit!
#parkiechat

Watch the LIVE Stream from 8.30-8:55PM (UK)

<https://youtu.be/WfdAhF5ytv0>

To join the group and take part click the group link below!

<https://plus.google.com/communities/10336806113806472865-8>

V. PATIENT INTERVIEWS

The following entails Question and Answer, (Q & A) with two patients from a Health Professional within the group.

- (2) Patient Interviews
 - Interview #1: 44 year old man, diagnosed 18 months ago
 - Interview #2: 47 year old female, diagnosed at age 40

Patient Interview 1: 44-year-old man, diagnosed 18 months ago

Q: Do you have a medical / health professional team with a particular interest in Young Onset Parkinson's (YOPD)?

A: Dr. Kluger is my neurologist, but not sure what the question is really getting at.

Q: What additional support do people with YOPD need? And are they available? i.e. specific peer Support Groups

A: The biggest need I see is programs (i.e., exercise and support groups) that meet outside of normal business hours. Most or all of us are still working, and find it difficult to duck out of the office in the middle of the day.

Q: Please provide examples of challenges you have observed, experienced by people living with YOPD.

A: See note above, regarding time. The second piece I'd say is a feeling of double isolation-- I'm in a subset of the population that has PD, and an even smaller subset of the PD population that is under 65-- sometimes that can make me feel more "alone".

Q: What strategies have you used or are you aware of to meet these challenges and promote better care?

A: Regarding the class times, I guess my "strategy" is to just take more non-PD specific exercise classes after work, realizing it's not a perfect solution but better than nothing.

Q: Is there any other information you would like to share which may enhance the care provided for people living with Young onset Parkinson's and their families?

A: If boxing were offered 4 days/week outside of normal working hours, I'd be at that class every time. I love it and I believe it's one of the best things I can do to help beat this thing called Parkinson's :).

Patient Interview 2: 47 year-old female, diagnosed at 40

Q: Do you have a medical / health professional team with a particular interest in Young Onset Parkinson's (YOPD)?

A: Yes - Dr Giroux

Q: What additional support do people with YOPD need? And are they available? i.e. specific peer Support Groups

A: Support Groups

Q: Please provide examples of challenges you have observed, experienced by people living with YOPD.

A: We are at the stage of life where we are parents to young children and still in our income earning years. Retirement is still a long way off. Medical costs can be crippling. We have to think not only about disability but how to live our lives with this disease the best way we can. Financial information comes too late: many of us don't apply for disability (maybe because we are still trying to be normal?) until it's too late (there is a time limit for applying for disability) and if you're under age 50 you must prove that there is NO WORK at all you can do; after age 50 the requirements loosen and you only have to prove you are unable to continue the kind of work you have been doing. And find time to exercise! There is an abundance of support for the newly diagnosed, but a lack of information for those who are in the middle stages of the disease, probably because no one shares the same symptoms.

Q: What strategies have you used or are you aware of to meet these challenges and promote better care?

A: Winging it!

Q: Pregnancy and Parkinson's – there is little published information on managing Parkinson's and pregnancy. Does anyone have any experience they are able to share?

A: Does the pregnant immune system switch encourage PD to emerge? What effect do hormones have?

I was diagnosed at age 40 (2010) but symptoms emerged four years earlier. My thumb started shaking 6 weeks after Jack was born (2006), so I guess that was the start of my symptoms. I was incredibly anxious - swiffing my floors 3 times a day - and had a panic attack. I was diagnosed with postpartum thyroiditis and given propranolol, which controlled the tremor and anxiety for another two years, masking the PD. After Patrick's birth in 2009, he breastfed for a year. Once he stopped and my hormones dropped off, it was Emergency on Planet Liz. The tremor came back, I was losing hair, the anxiety returned, and I was diagnosed with Hashimoto's Disease, an autoimmune disease of the thyroid. I've been pretty stable since then with Synthroid (synthetic thyroid hormone). I was also borderline low on Vitamin D, and my A1c hovered around 5.9. I've periodically been anemic too. I have all my blood tests, about every 5 months, since then.

Because of the anemia, my gyn was watching uterine fibroids, which caused excessive bleeding every month and found a large ovarian cyst, and after watching it for 3 months (it did not get smaller), she removed the cyst, left ovary and uterus. I kept the right ovary for the hormone protection, and Dr. Giroux encouraged me to keep some hormones if I can.

I went through 6 weeks of recovery, but to my surprise my anemia did not improve. I had sudden severe abdominal pain and the ER discovered another ovarian cyst, and a twisted ovary - which all occurred in the six weeks post surgery. I had emergency surgery to remove the second cyst, and they discovered it had adhesions to my bowels. The right ovary was removed too.

So: no more hormone protection. Dr. Giroux says she is not a hormone expert so to follow my ob/gyn advice. The ob/gyn put me immediately on hormone replacement therapy; the Estradiol patch, but only until I'm 50. How does the ob/gyn determine the dose? By my symptoms, which amount to hot flashes.

My functional medicine doctor, on the other hand, tested all my hormones and how my system gets rid of them. If my system has trouble getting rid of estrogen, should we be adding more? The tests showed that my body's methylation (MHTRF) system is working and getting rid of estrogen appropriately. I am in the midst of researching all my options for hormone replacement therapy, and none of my doctors will give me any real advice, no one knows whether HRT is right vs. bioidentical hormones. But they all agree I am too young to have no hormones at all.

There is a clinic in AZ, Sotto Pelle, treating PD symptoms with bioidentical testosterone with encouraging results.

The Secretariat ended the meeting and thanked all for their thoughts and participation.

Meeting Adjourned.

Respectfully submitted,

Samantha Surillo
MDS International Secretariat