Introduction & Background

- Twenty individuals holding Health Professional roles in the community, with an interest in Movement Disorders and/or Parkinson’s disease (from across the globe) were invited to participate in the MDS HP SIG Leadership Basecamp Meeting Online.

- Participants were given 72 hours to submit feedback and suggestions regarding possibilities of developing the scope of an MDS Palliative Care Task Force as well as identifying any people that could positively contribute to shaping palliative care for people living with movement disorders.

- Individuals of the meeting were requested to provide feedback on the following items:
  1. Identify what, or if, Palliative care models exist for Parkinson’s within their location (or a colleagues’);
  2. Identify the key Palliative care needs of a person living with Parkinson’s; and
3. Identify any health care professionals and Physicians (who are MDS Members) who would be interested in contributing to an MDS Palliative Care Task Force.

Welcome

The Meeting started with the International Secretariat welcoming group members to the discussion board and notifying all the discussion was now open on Basecamp to submit feedback.

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

Comments and Feedback

I. **Defining Palliative Care & Essential Elements**

Mariella Graziano initiated dialogue by suggesting the group work on defining exactly what palliative care for Parkinson’s would be. She further suggested the group consider whether or not it refers to the late stage of Parkinson’s disease (PD) or to the end of life situation; adding that she feels the former is more appropriate, but also requesting the group provide their thoughts on the following:

**Late stage criteria to consider:**

- Wheel-chair bound;
- Bed-bound;
- Full-time care required; and
- Problems such as:
  - Difficulty Swallowing; and
  - Advanced cognitive impairments

Elaine Book agreed that a definition is always a good starting place, noting that she recently heard a speaker at the National Parkinson’s Foundation meeting talk about Palliative Care as “the relief of suffering for those with incurable illness and that it needs to be considered along the disease trajectory.”

Regarding key needs of people with PD (in advanced stages), Elaine agreed with Mariella’s suggestions, and added to them for the group to consider:

- Addressing cognitive change;
- Unpredictability; and
- Psychosis for the patient;

It has also been seen as valuable to address the caregiver support issues (with the lengthened time of caregiving), as well as providing bereavement counselling.

Elaine ended with - ultimately, an interdisciplinary approach to palliative care with PD would be ideal.

Susan Heath mentioned that for their Palliative Care model and approach, they provide ‘primary palliative care’ to people with advanced PD that includes a multidisciplinary approach to focus on quality of life and reduction of caregiver stress. The Health Professional staff team encompasses a Movement Disorder
neurologist, clinical nurse, palliative chaplain, and social worker, with a palliative physician as a consultant on complex cases. Susan went on further to identify that key palliative care needs the group should consider are:

- Under-recognition and Under-treatment of symptoms;
- Psychosocial stressors;
- Spiritual wellbeing;
- Advance care planning; and
- Caregiver support.

The HP SIG Chair, Victor McConvey, thanked the group for feedback given and agreed that defining Palliative care for people living with PD and other movement disorders would be a great help for getting the task force started. He further went on to state that, traditionally, Palliative Care models have been developed in response to Cancer in the past, but evidence, to date, seems to reflect that the needs of a person with PD in palliative phase are best met by taking a multi-disciplinary approach and the duration can often be longer.

To help illustrate one model and way of meeting the palliative needs of people living with long term neurological illnesses, Victor provided the group with two PDFs to review (See attachments I and II from V.McConvey).

Although Siok Bee Tan was unable to join the online discussion during the specified time (due to international travel during the time), she emailed the Secretariat that Palliative care is a holistic approach in caring for patients with life-limiting illnesses.

Siok Bee went on further to state that, in Singapore, the aims of palliative care are to meet all needs (physical, emotional, psychosocial, and spiritual), alleviate suffering, and maximize the quality of life for patients and their families. Siok Bee detailed that Palliative care benefits patients with malignancy or non-malignant conditions such as neurodegenerative diseases (i.e. advanced Parkinson’s disease), and who may require control of distressing symptoms.

**ACTION ITEM:**

The chair and Co-chair will consider all feedback provided and work with the International Secretariat in formulating an appropriate definition for Palliative Care of Parkinson’s disease and identifying essential elements based on suggestions provided.

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**II. Relevant Studies and Articles**

Gila Bronner provided the following article and synopsis for the group to review and consider:

*Palliative and Hospice Services in Israel.* N. Bentur, S. Resnizky, Y. Shnoor (2005)  

**Synopsis of the study:**
Caring for patients at the end of life is becoming a central concern of the health systems. The belief that palliative and hospice services are the most appropriate for the terminally ill, and that everyone has a right to these services at the end of his/her life, is gaining ground in health systems throughout the world, including Israel. However, the idea has yet to gain a firm hold.

This study provides a comprehensive, up-to-date picture of palliative and hospice services in Israel, examines their characteristics, cost, and quality and identifies unmet needs.

Principal Findings of the study (condensed by the Secretariat):

- Although Hospital- and Community-based palliative and hospice services exist in Israel, it is to a very limited extent – treating less than 10% of those who could benefit from it.

- Some Hospital- and Home-based Hospice units rely on multiple sources of financing (such as third-party budgets, sales of services to other health plans, and philanthropic contributions). Consequently, their existence is precarious; which impedes their ability to expand their activities.

- Although it was found that all home hospice units had a multi-professional staff which visited most patients frequently, it was also found that frequency and patterns of care differed significantly across the units.

- A majority of home hospice patients are treated concurrently by other services (primarily community clinics and oncology services in hospitals).

- The average cost per patient of medical services during the last two months of life was significantly higher (almost three times as much) when performed for patients in not-in-home hospice care versus those being treated in in-home hospice units.

- While patients and families were satisfied with home hospice services, a need was expressed for greater emotional and psychological support.

Findings from this study were presented to decision-and-policy-makers in Israel’s Ministry of Health and Health plans as well as other Federations and service providers within the region. The director-general of the Ministry of Health in-turn appointed a committee to provide recommendations for setting guidelines for palliative care – which was later fully adopted by the Ministry. The presentation of this study’s results also spurred the development of a national training program in palliative care; the research team spearheaded by ESHEL and Ben Gurion University continues to be involved in evaluating these processes.

The study highlighted was conducted with the support of a grant from the National Institute for Health Policy and Health Services Research and The Association for the Planning and Development of Services for the Aged in Israel (ESHEL).

Gila suggested individuals visit the web URL provided to learn more information about this study and to read the full article.

Gila went on to state that her colleague, Dr. Dorit Gamus, whom is the Director of Complementary Medicine Service in Gila’s hospital, suggested the HP SIG consider incorporating various techniques into
palliative care. Gila then provided the following article that deals with complementary medicine as part of palliative care in cancer for the group to review and consider.

_Complementary medicine in palliative care and cancer symptom management._

**Synopsis of the Article (condensed by the Secretariat):**

- Complementary and alternative medicine (CAM) varies according to geography, gender, and disease diagnosis.
- The review article focuses on practices belonging to the CAM domains of mind-body medicine, CAM botanicals, manipulative practices, and energy symptom management.
- The article suggests that music therapy, massage, and hypnosis may have an effect on anxiety, and both acupuncture and massage may have a therapeutic role in fatigue.
- The article also suggests transcendental meditation and the mindfulness-based stress reduction can play a role in the management of depressed mood and anxiety.

The group should visit the web URL provided to read the full article and details.

**ACTION ITEM:**

_The HP SIG members will review and read articles provided by Gila Bronner (Israel) and coordinate with the International Secretariat if there are any questions or further thoughts._

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**III. Current Models and Examples of Palliative Care Team Compositions and Approaches**

Elaine Book stated that although they do not have a palliative care program specifically for PD in Vancouver, BC, Canada, they do have a palliative care in-patient program at a number of hospitals and also a well-developed palliative care program in the community. However, not many of her patients have used these resources, so she wonders if it’s because of the mindset of the definition of palliative care being under 6 months of life. Elaine went on further to state that The Canadian Guidelines for Parkinson’s are due to be revised and this would be a great opportunity to address palliative care needs in the guidelines. Elaine’s comments about definition for Palliative care can be found in Section I of these minutes.

Mariella Graziano mentioned that while Models of Palliative care with well-equipped units and a proficient multidisciplinary team are very welcome and necessary, she cannot refer to a model in her area of Luxembourg, as there is not one yet (despite the need). However, Mariella would like to raise the consideration of how necessary this would be for people living in isolated regions and small countries – where realistically speaking, people with different conditions are cared for in the same place and the staff requires to understand all the specific needs. Mariella has suggested, once formed - the MDS Palliative Care task force address this as an agenda item.

Clynton Correa, from Brazil, added that although Brazil only has 30 palliative care clinics distributed in 26 states (and mainly located in capitals); these centers offer services in public and private hospitals only.
However, these centers are not specifically for patients with PD and appear to be more geared towards patients with different types of cancer. Similar to Mariella’s regions’ situation, Brazil does not seem to have any palliative care centers specialized in Movement Disorders.

Additionally, Clynton mentioned that the theme for Brazil seems to be a lack of discussion with Students about this in the Brazilian Therapy Courses specifically. With this being the case, it is a challenge for the Brazilian Government to include this topic in Brazilian Health Systems due to such a lack of focus on this topic although interesting.

John Dean talked about a number of his patients (over the years) who ultimately pursued hospice when the better choice may have been palliative care with more rehabilitation professionals involved in the process. As a Speech Language Pathologist, he felt implications for swallowing as individuals approach the stage of their disease when they may pursue a palliative approach can loom large (which he feels would add a role for SLP’s to contribute input on such a task force).

John also noted three palliative care programs specifically focused on Movement Disorders that he is aware of in North America and suggested drawing on the expertise from people in these programs in order to avoid reinventing the wheel; programs identified are listed below:

- University of Toronto, Canada
- Oregon Health & Science University (OHSU) in Portland, OR, USA
- University of Colorado, under the direction of Dr. Benzi Kluger

John went on further to state that he had attended a presentation by Dr. Benzi Kluger last year wherein he took away an advantage of Dr. Kluger’s program was the benefit of having a discussion about some of these topics early in the process as a way of opening the door to the conversation later on. However, it is advised that this be handled with care and sensitivity as when folks are first diagnosed it can be overwhelming in itself and could frighten people away if not presented well initially.

Susan Heath who works at a Parkinson’s Disease, Research, Education, and Clinical Center (PADRECC) added that at her center in California, they started a Palliative Care clinic (slowly) about four years ago and called it “supportive care clinic.” Their current model of staff has a social worker, chaplain, nurse, and physician on board. They will soon be having someone from the field of Psychiatry join as well. Her clinic’s palliative care team has been mentored by their hospital’s palliative team. Additionally, their colleagues at the Veterans Affairs, who also work at the University of California, San Francisco (UCSF) have recently created a Palliative Care clinic and are taking part in a funded, multi-center study to evaluate the outcomes/satisfaction of such a specialized care clinic and compare with those patients who are in regular movement disorders clinics and receive the “usual care.”

Outside of the San Francisco PADRECC facility, where Susan is staff, there are five other PADRECC facilities throughout the United States (which are in Philadelphia; Richmond; Houston; West Los Angeles; and Seattle/Portland). Additionally, Consortium Centers are also available throughout the USA, which are VA clinics that offer specialized PD and Movement Disorder specialty care to veterans who cannot travel to a PADRECC. More information about PADRECCs and Consortium Centers can be found online at www.parkinsons.va.gov.

Moreover, Julie Carter stated that a little over a year ago, her group started a Palliative Care outpatient clinic for Parkinsonism at OHSU. The team at OHSU consists of a nurse, physical therapist, speech therapist, social worker, and any-one of their neurology clinicians (NP, PA, or MD). Julie’s team sees
patients two half days a month and all members see each family and then consult prior to giving the family a joint plan of care. The group has found this approach to be very effective, however they have been struggling with capacity. At this time, after patients have seen her team 1-3 times, they return to the neurology provider even though it would be ideal and best if her team continued to manage them. Julie also mentioned they gather a number of forms/data prior to the visit for review.

Julie went on further to state that she is also involved in a “working group” in Palliative Care. The group’s goal is to identify “gaps” in research and currently has a number of initiatives that are moving forward. Folks identified by Susan Heath in Section IV have been confirmed by Julie as part of the aforementioned working group.

Siok Bee Tan also added in her email that in Singapore, the Singapore Hospice Council (SHC) serves as an umbrella body that incorporates all voluntary organizations that provide hospice and palliative care services.

In Singapore, there are currently four in-patient hospices;

- Assisi Hospice;
- Dover Park Hospice;
- Bright Vision Hospital; and
- St. Joseph’s Home and Hospice.

And five home hospice services:

- HCA Hospice Care;
- Assisi Hospice;
- Metta Hospice Care;
- Agape Methodist; and
- Singapore Cancer Society.

Siok Bee went on further to state that both Assisi Hospice and HCA Hospice Care provide hospice day care services where patients who require minimal assistance can participate in activities. To date, most acute hospitals provide palliative care services, however, there is no dedicated Movement disorders specific palliative care. Siok Bee ended her email with her support and hope that the HP SIG leaders convene a team to discuss a dedicated movement disorders palliative care approach.

ACTION ITEM:

The chair and Co-chair will consider all feedback provided and work with the International Secretariat in formulating an appropriate suggestion of Palliative Care professional representation across disciplines, as well as, format of care. The suggestion will then be submitted to the MDS Officers for consideration in forming an MDS Task Force for Palliative Care of Parkinson’s disease.
IV. Suggestions and Recommendations: Professionals, Colleagues, or Volunteers

After reviewing feedback and comments, Ruth Hagestuen stated that since palliative care in PD requires an interdisciplinary team, she is hoping the group will be able to propose several people from different disciplines and different regions of the world. Ruth went on further to state that she believes Julie Carter would be ideal for serving on such a task force, as she runs a Palliative Care Program and gave a presentation to the HP SIG at the last Congress in San Diego regarding the development of the program. Ruth feels we can learn so much from one another across disciplines and cultures so representation from around the world would certainly enrich the discussions.

• Elaine Book suggested Pam Palmentera as a potential valuable resource. Pam is a Social Worker at Northwestern University specializing in PD with a background in Palliative Care.

• Outside of Dr. Benzi Kluger, John Dean also suggested MDS consider getting in contact with the Social Worker associated with the Parkinson’s Association of the Rockies, as she is a part of the Palliative team at the University of Colorado. John mentioned she may be willing to be part of the conversation or least have a discussion with others about some of these topics.

Susan Heath suggested that if a task force is started, she would recommend the following folks as having experience in this area:
  • Maya Katz and Nick Galifianakis (whom are both from SFVA and UCSF);
  • Benzi Kluger;
  • Janis Miyasaki; and
  • Julie Carter (whom has recently started a similar clinic at OHSU).

Gila Bronner suggested Dr. Sandra Benizri from the Sheba Medical Center in Israel as someone who would be willing to serve on the Task Force. Dr. Benizri is one of the Neurologists Gila works with in the PD unit and would be willing to cooperate by providing updates on their oncological model.

ACTION ITEM:
The chair and Co-chair will consider all feedback provided and work with the International Secretariat in formulating an appropriate list to suggest to the MDS Officers of individuals that may be willing to serve on the MDS Task Force for Palliative Care of Parkinson’s disease and Movement Disorders.

Meeting Adjourned.

Respectfully submitted,
Samantha Surillo
International Secretariat
MDS Health Professional Special Interest Group
International Parkinson and Movement Disorder Society (MDS)