



## Palliative care for advanced Parkinson disease: An interdisciplinary clinic and new scale, the ESAS-PD

Janis M. Miyasaki\*, J. Long, D. Mancini, E. Moro, S.H. Fox, A.E. Lang, C. Marras, R. Chen, A. Strafella, R. Arshinoff, R. Ghoche, J. Hui

*The Palliative Program for Parkinson Disease and Related Disorders, The Morton and Gloria Shulman Movement Disorders Centre, Toronto Western Hospital, University of Toronto, Canada*

### A B S T R A C T

#### Keywords:

Parkinson's disease  
Palliative care  
Interdisciplinary care  
Pain  
Non-motor management

Palliative care provides a holistic approach to symptom relief using a multidisciplinary team approach to enhance quality of life throughout the entire course of a particular illness. The care team consists of movement disorders neurologist, a palliative care physician, a wound care nurse, a spiritual counselor and a care coordinator. Palliative care concepts were applied to a group of advanced Parkinson disease (PD) patients in a dedicated Palliative Care Clinic.

**Methods:** A modified Edmonton Symptom Assessment System Scale for PD (ESAS-PD) was developed and applied to 65 PD patients at their initial consultation and following recommended interventions. Scores were compared to those of metastatic cancer patients reported in the palliative care literature.

**Results:** The ESAS-PD scores significantly improved after the interventions (56 and 40 respectively,  $p = 0.0001$ ). The most improved items were constipation, dysphagia, anxiety, pain and drowsiness. ESAS-PD scores were not significantly different from metastatic cancer patients' ESAS scores.

**Conclusions:** ESAS-PD is a quick, effective scale for assessment of late stage PD symptoms. Scores are sensitive to intervention, and therefore have potential clinical utility for physicians and other healthcare providers. Advanced PD patients have a similar degree of symptoms as metastatic cancer patients, respond to treatment in a similar way, and therefore should have access to palliative care services.

© 2012 Elsevier Ltd. All rights reserved.

### 1. Introduction

According to the World Health Organization, palliative care uses a multidisciplinary team to integrate the psychological and spiritual aspects of care. Although the primary goals are traditionally seen as relief of pain and distressing symptoms, palliative care should help patients live as actively as possible, experience improved quality of life and this in turn, may positively influence the course of illness. Family members are also the recipients of palliative care to address their distress and help them cope. (<http://www.who.int/cancer/palliative/definition/en/>). This holistic approach to Parkinson disease (PD) has not been previously presented in the published literature. Current concepts for palliation in PD address behavioral and cognitive decline with pharmacologic manipulation, and are assessed using the Unified Parkinson's Disease Rating Scale (UPDRS) [1]. In advanced PD, goals of care may

change for the patient and the family. There are no previously documented programs with an interdisciplinary palliative approach, and no available assessment tools to capture patients' symptoms.

Palliative care, therefore, could begin far earlier than previously conceived. Specifically, end-of-life care is used interchangeably with palliative care by non-medical and healthcare providers, however, end-of-life care is only one phase of palliative care. Palliative care begins when hope for a cure is not possible. Therefore, other chronic illnesses such as end stage renal disease and congestive heart failure are beginning to embrace palliative care approaches. In contrast to chronic illness, end-of-life for cancer patients is perhaps more clearly defined [2]. For those with chronic illness, there is a predictable decline complicated by a precipitous decline from other unpredictable comorbidities such as falls, infections or the addition of other chronic illnesses. These events are often anticipated (such as falls in PD), but are unpredictable. Injuries, infections and other chronic illnesses can result in unexpected death due to the higher risk associated with frailty in advanced PD. Therefore, introducing palliative care at an earlier

\* Corresponding author.

E-mail address: [miyasaki@uhnresearch.ca](mailto:miyasaki@uhnresearch.ca) (J.M. Miyasaki).

stage before an unpredictable crisis situation occurs may help avoid potentially unnecessary interventions such as intubation, ventilation and intensive care unit admissions. Beginning conversations with patients and families allows patients to express their wishes regarding what symptoms are important to them and where and how they wish to die [3]. This approach reduces the burden for families in times of crisis and provides direction that families and healthcare providers can respect.

In 2007, we established the Palliative Care Program for PD and Related Disorders at Toronto Western Hospital, Krembil Neuroscience Program. The team consists of a movement disorders neurologist, a palliative care physician, a wound care nurse, a spiritual counselor and a care coordinator. To identify symptoms requiring treatment and follow patients' response to interventions, we adapted the Edmonton Symptom Assessment System (ESAS) [4]. This 10-point scale is the most commonly used scale in palliative care. It includes domains reflecting the holistic approach including tiredness, sense of wellbeing in addition to the traditional symptoms of pain, nausea and shortness of breath. ESAS was designed to be a brief, useful, bedside tool for evaluation of psychological and physical domains of palliative care patients. ESAS is validated in advanced cancer populations and renal dialysis patients [5]. Concurrent validity with other pain and depression scales is also documented [6]. ESAS may also be administered several times during a single day to monitor symptoms.

Of note, treatment of chronic illness shares many goals with palliative care. Alleviation of symptoms and improved quality of life take precedence over "normalcy". Indeed, pain, fatigue and shortness of breath in chronic illness have been associated with lower quality of life, worse functional status and higher mortality [7]. ESAS in end-stage renal disease patients revealed pain and psychological burden from anxiety and depression were under appreciated by care providers [5]. Therefore, translating ESAS for PD patients may help patients and healthcare providers to identify additional symptoms that contribute to disability and suffering.

To address PD specific symptoms and allow comparison to other palliative populations, we added the following clinically relevant symptoms to the scale – constipation, difficulty swallowing, stiffness, and confusion – as a result of a modified Delphi process among 3 movement disorders neurologists. Compared to existing scales such as PDQ-39 or SF-36, the ESAS focuses on symptoms in advanced stage illness, contains 14 items and omits rating irrelevant tasks such as lifting, climbing stairs, carrying groceries [8,9]. We will refer to the scale henceforth as the ESAS-PD. Modifying the original scale to add targeted symptoms is encouraged by the original ESAS investigators to tailor use for specific patient populations [10]. Through administration in our clinic, we aimed to demonstrate that the ESAS-PD documents patients' symptoms not captured in the UPDRS, identifies symptoms requiring intervention, and is feasible in advanced PD.

## 2. Methods

Consecutive patients attending the Palliative Care Program for PD and Related Disorders completed the ESAS-PD independently or with caregiver assistance. The scale can be completed in 5 min or less. Baseline data included age, duration of illness, Montreal Cognitive Assessment Scale (MoCA) [11] score and Katz Independence Score [12] (0–6, 6 being completely independent).

## 3. Clinic activities

Each clinic visit occurs in one clinic room with the team members rotating between clinic rooms. The initial assessment is provided by the care coordinator and discussed with the palliative care physician and movement disorders neurologist. A consensus regarding interventions is obtained. Discussion with the patient

and family includes confirming the important issues/symptoms and reaching a consensus with the patient and family regarding treatment plan. The wound care nurse attends this segment of the appointment to provide input to the treatment plan. At the first appointment, discussion occurs regarding the patient's wishes for care and end-of-life care and Power of Attorney. Patients and families are introduced to advanced directives and if accepted, information brochures are provided for completion. If the patient and family are receptive, a Do Not Resuscitate (DNR) Confirmation Form is provided. This form was developed by the Ministry of Health and Long Term Care Ontario for completion by a doctor or nurse confirming that DNR is in keeping with the patient's expressed wishes and/or that resuscitation given the patient's existing health state is not in the patient's best interests. The completed form allows ambulance and paramedic personnel to respect the patient's wishes if they are called at the time of death. The intake visit requires 1 h with additional time for counseling by the spiritual counselor. Efficiencies are achieved through the use of patient and caregiver completed instruments using an iPad. The second visit occurs at three months and requires 1 h.

Treatment plans include initiating, adjusting or discontinuing medications to address symptoms related to parkinsonism, non-motor complications and pain. Appropriate referrals were made to the Alzheimer Society which has a policy in our province to accept anyone with cognitive impairment, regardless of the etiology and additionally has a close relationship with this program (for social work support and referral to day programs for cognitively impaired patients), day programs, speech language pathology, registered nutritionist, occupational therapy, physiotherapy, Community Care Access Centre (government provided in home care), specialists (psychiatry, orthopedic surgery, neurosurgery, urology), hospice volunteers and palliative care physicians. Given our multicultural population, referrals and links must be language and culture appropriate.

ESAS-PD results for patients comparing the first and second assessments were analyzed using a paired *t*-test.

## 4. Results

One hundred and nine patients were seen by the Palliative Care Program, 65 patients had more than one assessment. The average age was 68 years (46–80 y) with 10 years duration of illness (range 4–33). Mean baseline MoCA score was 11.5 (range 0–27, normal >26).

Patients independently or with input from caregivers were able to complete the ESAS-PD. Scores were distributed through all items of the scale although only 17 patients used the other designation (Table 1). Total scores across all patients for the items reveal that pain, tiredness, depression, anxiety, drowsiness, poor feeling of wellbeing, stiffness, constipation, dysphagia and confusion were most endorsed. The maximum score for ESAS-PD is 140. The mean ESAS-PD score was 56 for the first visit, median score 51 (range 14–107, SD  $\pm$  19.3, 95% confidence interval (CI) 51, 60) and mean score was 40 for the second visit, median 37 (range 9–80, SD  $\pm$  17.2, 95% CI 35–44). The first visit ESAS-PD was significantly higher than the second visit ESAS-PD ( $p = 0.0001$ , 95% CI 10.21). The symptoms responding to most to interventions were dysphagia, constipation, anxiety, pain, drowsiness and other.

## 5. Discussion

A study of metastatic cancer patients documented a modified ESAS score of 47.8/110 [13]. This score is not significantly different from ESAS-PD scores in our patient population with a 95% confidence interval. Thus, as measured by modified ESAS, metastatic cancer patients have similar symptoms and symptom severity

**Table 1**  
ESAS-PD item scores.

	Pain	Tired	Nausea	Depressed	Anxious	Drowsy	Anorexia	Wellbeing	SOB	Other	Stiffness	Constipation	Dysphagia	Confusion
<b>V1</b>														
Median	6	7	0	3.5	3.5	5	3.5	5	2.5	0	7	5.7	3	3.5
Mean	5.2	6.5	1	3.7	3.6	5.4	3.6	4.9	3.3	1.6	5.9	4.7	3.8	3.9
Range	0.10	3.10	0.8	0.8	0.8	0.10	0.10	0.10	0.10	0.9	0.10	0.9	0.10	0.10
SD	3.0	1.8	2.1	2.8	2.7	2.8	3	1.9	3.2	3.2	3.1	2.9	3.3	3.0
<b>V2</b>														
Median	5	6	0	3	3	4	2.5	4	2	0	6	3	2	3
Mean	4.0	5.6	0.8	3.4	2.8	4.5	2.9	4.0	2.4	1.3	6.0	3.6	2.9	3.3
Range	0.9	0.9	0.4	0.10	0.9	0.10	0.10	0.9	0.10	0.9	0.10	0.8	0.10	0.8
SD	2.8	2.4	1.4	3.0	2.6	3.1	2.9	1.9	2.7	2.8	2.8	2.9	2.9	2.4

compared with advanced PD. PD patients and their families must cope with illness for decades and this results in a progressive decreased quality of life for both patients and their informal care providers (often elderly spouses or their children).

All patients were able to complete ESAS-PD independently or with caregiver assistance. ESAS-PD is easily administered and the scale highlights the symptoms requiring investigations, treatment and referral to other healthcare providers [14]. Symptoms not typically elicited in clinical practice were strongly endorsed by patients and caregivers.

## 6. Conclusions

We conclude that ESAS-PD is practical to administer in advanced PD care and is useful in identifying symptoms not typically elicited in routine care. Additionally, the scale is responsive to change in symptoms as a result of treatment. ESAS-PD can help practitioners identify symptoms requiring intervention in this population. Further research should validate ESAS-PD against quality of life measures.

Comparing ESAS-PD scores to ESAS scores for metastatic cancer reveals similar degrees of suffering and also response to interventions that are provided in an interdisciplinary setting. Palliative care should therefore be available to advanced PD populations in a more systematic manner. Optimally, these programs should include a neurologist working in conjunction with existing palliative care teams to provide true interdisciplinary care. The time required for visits are similar to appointment schedules in many movement disorders centres. Hence, interdisciplinary care may be provided through team commitment and through the use of standardized tools such as the ESAS-PD.

## Funding source

Dr. R. Chen received research grants from the CHIR (grant numbers MOP 15128 and MOP 62917), the Michael J. Fox Foundation for Parkinson's Research and the Dystonia Medical Research Foundation. He is supported by a CIHR-Industry (Medtronic Inc.) Partnered Investigator Award (ISI 83213) and holds the Catherine Manson Chair in Movement Disorders.

## Conflict of interest statement

Dr. R. Chen received consulting fees from Medtronic Inc, Allergan, Biovail and EMD Serono, honoraria for speaking from the American Academy of Neurology, the Douglas Mental Health University Institute, Movement Disorders Society, University of Pittsburg, UCLA, funding for travel and honoraria from Merz, provided expert testimony and affidavit in welding related litigations.

Dr. E. Moro has received honoraria from Medtronic for consulting services and lecturing, honoraria from TEVA for lecturing, and research support from CurePSP, St. Jude Medical and CIHR.

Dr. J.M. Miyasaki has received Research Grants from Medivation 2010, Teva 2012, Abbott 2012; Consultancy fees from Merz 2012, Ontario Drug Benefits (Ministry of Health and Long Term Care), UCB 2011; and Speaking fees from Teva 2012.

Dr. A. E. Lang has served as an advisor for Abbott, Allen Therapeutics, AstraZeneca, Avanir Pharmaceuticals, Biovail, Boehringer-Ingelheim, Cephalon, Ceregene, Eisai, GSK, Lundbeck A/S, Medtronic, Merck Serono, Novartis, Santhera, Solvay and Teva; received honoraria from Teva; received grants from Canadian Institutes of Health Research, Dystonia Medical Research Foundation, Michael J. Fox Foundation, National Parkinson Foundation and Ontario Problem Gambling Research Centre; received publishing royalties from Saunders, Wiley-Blackwell, John Hopkins Press and Cambridge University Press; and has served as an expert witness in cases related to the welding industry.

J. Long, A. Strafella, R. Arshinoff and J. Hui have nothing to declare.

Authors Mancini, Fox, Marras and Ghoche have all declared no Conflict of interest.

## Acknowledgments

The authors acknowledge the support of the Rosati Family and NORUS and the National Parkinson Foundation who supported the development of the Palliative Care Clinic and conduct this research. We also acknowledge the administrative assistance of Ms. R. Ortiz in preparation of this manuscript.

## Appendix A. Supplementary material

Supplementary data related to this article can be found online at <http://dx.doi.org/10.1016/j.parkreldis.2012.06.013>.

## References

- [1] Martinejo-Martin P, Gil-Nagel A, Gracia LM, Gomez JB, Martinez-Sarries J, Bermejo F. Unified Parkinson's disease rating scale characteristics and structure. The cooperative multicentric group. *Mov Disord* 1994;9:76–83.
- [2] Stone P, Kelly L, Head R, White S. Development and validation of a prognostic scale for use in patients with advanced cancer. *Palliat Med* 2008;22:711–7.
- [3] Ayyar A, Varman S, De Bhalldraithe S, Singh I. The journey of care for the frail older person. *Br J Hosp Med (Lond)* 2010;71:92–6.
- [4] Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton symptoms assessment system (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991;7:6–9.
- [5] Davison SN, Jhangri GS, Johnson JA. Longitudinal validation of a modified Edmonton symptom assessment system (ESAS) in hemodialysis patients. *Nephrol Dial Transplant* 2006;21:3189–95.
- [6] Vignaroli E, Pace EA, Willey J, Palmer JL, Zhang T, Bruera E. The Edmonton symptoms assessment system as a screening tool for depression and anxiety. *J Palliat Med* 2006;9:296–303.
- [7] Hewitt J, Smeeth L, Bulpitt CJ, Tulloch AJ, Fletcher AE. Respiratory symptoms in older people and their association with mortality. *Thorax* 2005;60:331–4.
- [8] Peto V, Jenkinson C, Fitzpatrick R, Greenhall R. The development and validation of a short measure of functioning and well being for individuals with Parkinson's disease. *Qual Life Res* 1995;4:241–8.

- [9] Ware Jr JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;30:473–83.
- [10] Nikolaichuk C, Watanabe S, Beaumont C. The Edmonton symptoms assessment system: a 15-year retrospective review of validation studies (1991–2006). *Palliat Med* 2008;22:111–22.
- [11] Nasreddine ZS, Phillips NA, Bedirian V, Charbonneau S, Whitehead V, Collin I, et al. The Montreal cognitive assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc* 2005;54:695–9.
- [12] Lang PO, Meyer N, Heitz D, et al. Loss of independence in Katz's ADL ability in connection with an acute hospitalization: early clinical markers in French older people. *Eur J Epidemiol* 2007;22:621–30.
- [13] Follwell M, Burman D, Le L, et al. Phase II study of an outpatient palliative care intervention in patients with metastatic cancer. *J Clin Oncol* 2009;27:206–13.
- [14] Brechtl JR, Murshed S, Homel P, Bookbinder M. Monitoring symptoms in patients with advanced illness in long-term care: a pilot study. *J Pain Symptom Manage* 2006;32:168–74.