

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

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Abstract

Context: 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.

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)

Objectives: The aim of this study was to introduce palliative care at an earlier stage before an unpredictable crisis situation occurs which may help avoid potentially unnecessary interventions.

-To provide an assessment tools to capture patients' symptoms, which is not captured in the UPDRS, and is feasible in advanced PD.?

Methods: A modified Edmonton Symptom Assessment System Scale for PD (ESAS-PD) was developed and applied to 65 PD patients at their initial consultation (1st visit) and following recommended interventions (3 months). The scale can be completed in 5 min or less. Baseline data included age, duration of illness, Montreal Cognitive Assessment Scale (MoCA) score and Katz Independence Score (0-6, 6 being completely independent). Scores of ESAS-PD were compared to those of metastatic cancer patients reported in the palliative care literature.

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). ESAS-PD results for patients comparing the first and second assessments were analyzed using a paired t-test.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 19.3, 95% confidence interval (CI) 51, 60) and **mean score was 40 for the second visit**, median 37 (range 9-80, SD 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). A study of **metastatic cancer patients documented a modified ESAS score of 47.8/110**. This score is not significantly different from ESAS-PD scores in our patient population with a 95% confidence interval. Metastatic cancer patients have similar symptoms and symptom severity compared with advanced PD.

Conclusion: ESAS-PD is practical to administer in advanced PD care and is useful in identifying symptoms not typically elicited in routine care. ESAS-PD can help practitioners identify symptoms requiring intervention in this population. 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.

Strengths: Clinically relevant study with clinical significant result. It is one of the first papers that touch this issue. A quick and effective scale for assessment of late stage PD symptoms has been developed.

Weaknesses: Small sample size. Lack of longitudinal follow up to better define the ideal frequency of the assessment . In advance PD there is a cognitive function involvement as well which may cause difficulty of understanding the assessment . The interventions were made based on subjective measures . Selection bias (Age) does this work for early onset PD? .

Relevance to palliative care: 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. It is hoped that 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 .This approach reduces the burden for families in times of crisis and provides direction that families and healthcare providers can respect , and avoid potentially unnecessary interventions such as intubation, ventilation and intensive care unit admissions.