

# More than a Movement Disorder: Applying Palliative Care to Parkinsons Disease

<https://neurodegenerationresearch.eu/survey/more-than-a-movement-disorder-applying-palliative-care-to-parkinsons-disease/>

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### Country

USA

## Title of project or programme

More than a Movement Disorder: Applying Palliative Care to Parkinsons Disease

## Source of funding information

NIH (NINDS)

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## Start date of award

15/09/2016

## Total duration of award in years

5

## The project/programme is most relevant to:

Parkinson's disease & PD-related disorders

## Keywords

Palliative Care, Movement Disorders, Caregivers, Parkinson Disease, Telemedicine

## Research Abstract

Project Summary/Abstract: Parkinson's disease (PD) is the second most common neurodegenerative illness affecting approximately 1.5 million Americans and is the 14th leading

cause of death in the United States. PD is traditionally described as a movement disorder with characteristic motor symptoms (e.g. tremor). However, more recent research demonstrates the impact of nonmotor symptoms such as pain, depression, and dementia on mortality, quality of life (QOL), nursing home placement and caregiver distress. Regarding models of care for PD, evidence suggests that care including a neurologist results in lower mortality and nursing home placement than care solely from a primary care physician. Unfortunately, there is also significant evidence that many of the needs most important to PD patients and their caregivers (e.g. depression, planning for the future) are poorly addressed under current models of care. Palliative care is an approach to caring for individuals with life-threatening illnesses that focuses on addressing potential causes of suffering including physical and psychiatric symptoms, psychosocial issues and spiritual needs. While developed for cancer patients, palliative care approaches have been successfully applied in other chronic progressive illnesses including heart failure and pulmonary disease. To date there have been minimal attempts to apply these principles to PD although evidence suggests that PD patients' unmet needs under current models of care may be amenable to palliative care. A small but growing cadre of centers offer outpatient palliative care for PD with early evidence of efficacy and a randomized trial of an academic-based outpatient palliative care is underway led by investigators on this proposal. While this work is critical to forwarding this field, further work is needed to provide a model that can be widely disseminated. The current proposal addresses this gap by assessing the effectiveness and feasibility of a novel community-based intervention that empowers community neurology practices to improve care for PD patients and caregivers through palliative care training, coaching and telemedicine resources. We hypothesize that this intervention will improve patient QOL and caregiver burden and will prove feasible and acceptable to community providers. Our Specific Aims are to: 1) Determine the a) effectiveness and b) feasibility of a novel community-based outpatient palliative care intervention for PD.; 2) Describe the effects of a this intervention on patient and caregiver costs and service utilization; and 3) Identify opportunities to optimize community-based palliative care for this population by: a) describing patient and caregiver characteristics associated with intervention benefits; and b) through direct patient, caregiver and provider interviews. Innovations of our approach include a novel model of providing disease-specific community-based palliative care not dependent on limited palliative specialist resources, a stepped-wedge trial design and use of telemedicine resources to provide multidisciplinary care. The research is significant because it will create a foundation for future community-based dissemination studies in PD and the broader field of palliative care.

## **Lay Summary**

**Project Narrative:** Parkinson's disease (PD) is a chronic neurodegenerative illness which affects 1-2% of people over age 65 and is associated with disability, reductions in quality of life, caregiver distress, pain, fatigue, dementia and increased mortality. While PD is typically managed using a chronic disease model focused on motor symptoms (e.g. tremor), palliative care offers an opportunity to improve quality of life for patients with PD and their family caregivers by addressing potential causes of suffering not well met in current models of care including advance care planning, non-motor symptoms, psychosocial issues, caregiver distress and spiritual needs. This proposal will build upon work by members of this research team to conduct a pragmatic clinical trial of a novel community-based palliative care model for PD delivered by providing additional training and telemedicine support of community neurologists with the specific objectives of determining whether: a) this community-based intervention improves patient quality of life or caregiver distress; and b) this approach is feasible to

disseminating palliative services more widely to PD patients and their families.

**Further information available at:**

**Types:**

Investments > €500k

**Member States:**

United States of America

**Diseases:**

Parkinson's disease & PD-related disorders

**Years:**

2016

**Database Categories:**

N/A

**Database Tags:**

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