

Improving Care for People with Parkinson's Disease

Joyce Oberdorf, National Parkinson Foundation President and CEO
Peter Schmidt, PhD, National Parkinson Foundation Vice President, Programs
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“My mother has been in the ICU since Friday with pneumonia due to aspiration, which they are guessing is due to her Parkinson's. She has been intubated and our current concern is that she has been unable to take her Parkinson's meds. When she is alert, she has severe movements and has to be sedated to calm her body down. If she is constantly sedated, how will she get strong enough to get off the breathing machine? The ability to control her Parkinson's is key to all this. We are looking to you for help, as there is no Parkinson's specialist here.”

--A son's e-mail to the National Parkinson Foundation, November 2009

Parkinson's disease is the second most common neurodegenerative condition, affecting between 1 and 1.5 million people in the United States and an estimated four to six million worldwide. The average age of diagnosis is 60 although between 10 and 15 percent are “young Onset” patients diagnosed in their 30's and 40's. The prevalence of the disease is expected to increase substantially in the next decades due to the aging of the population. The economic burden of Parkinson's has been estimated as \$23 billion annually in the United States, and projected to increase to \$50 billion by the year 2040. In addition, the cost of care increases exponentially with the progression of the disease. The leading causes of death and disability of people with Parkinson's disease are aspirational pneumonia and debilitation due to falls.

Management of the health of the Parkinson's disease patient, many of whom live decades with the disease and have one or more comorbid conditions, is frustratingly complex, especially for community-based primary care physicians.

Because of the complexity of the disease, research has shown that care process and treatments improve when Parkinson's patients are under the care of a movement disorder specialist (a neurology sub-specialty). While care under general neurologists is typically not as comprehensive, it still ranks higher than that received under primary care physicians, most of whom do not have sufficient population of Parkinson's patients to be truly expert in managing this debilitating disease. In addition, most hospital and ER staffs are not sufficiently versed in the disease—a critical issue for an aging group that experiences more (and longer) hospitalizations than the general population. The areas with the greatest gap in care are: initial diagnosis, and diagnosis and treatment of non-motor aspects of the disease.

At present, there are not enough trained movement disorder specialists to treat every Parkinson's patient in the U.S. Given the cost constraints of the current healthcare system, such a system would be unsustainable.

Unmet Needs in Parkinson's Care

The NPF mission seeks to address significant unmet needs in Parkinson's care. Not only is there lack of definition or standardized measures of quality care in Parkinson's disease, but there is limited *systematic* and scientifically sound research on high quality care. As a result, *care models are poorly defined* and the *impact of many care interventions is poorly understood*. Innovations are often limited to single Center studies with small number of participants and limited chance to impact or improve care more broadly in the field.

Moreover, non-motor Parkinson's symptoms, including depression, anxiety, apathy and impulse control disorders, have only recently been recognized as strongly impacting quality of life and increasing caregiver strain. Yet, *non-motor symptoms are often poorly treated*, with limited understanding of best clinical practices for treating non-motor symptoms. Advancing stages of the disease pose significant challenges, with complications including dementia, psychosis and debilitating cognitive changes.

In addition, innovations in care are limited by the lack of scientific evidence and validation of new care interventions which would improve quality of life and perhaps even longevity for middle- to advanced-stage Parkinson's patients and their families. Up to 50 percent of Parkinson's patients are seen by primary care physicians or general neurologists, with significant error rates in diagnosis. *Community-based physicians often have inadequate knowledge of current assessment or treatment of Parkinson's disease*, including its complex, varied, unpredictable course and its effect on virtually every aspect of a person's life. *PD is often enough under-diagnosed* or misdiagnosed. There is *an insufficient supply of PD-trained allied health professionals*, many of whose interventions can improve quality of life.

The Need: Cost-Effective Models to Improve Care

What is needed is a systematic approach to improving care for all Parkinson's patients that seeks to leverage and disseminate models of exemplary care practiced by leading movement disorder specialists across the U.S. to help close the gap in care, at a reasonable systemic cost. Such an effort would not only benefit Parkinson's patients, but could serve as a model of the cost-effective elevation of care management of complex chronic condition in an aging population, with applicability to many other conditions.

Focus on Improving Care

The National Parkinson Foundation is focused on this mission of improving the quality of care for Parkinson's patients. Backed by the powerful resources of its Center of Excellence network, NPF is in a unique position to lead the charge to define and develop measures of high quality care and promote top-notch science of care research. As part of this effort, NPF is:

- » Developing a large-scale Clinical Practice Patient Database to collect longitudinal information on every Parkinson's patient in NPF Center of Excellence network. This database has been successfully piloted at six NPF Centers of Excellence in the U.S and Canada. NPF intends to collect information across the U.S., Canada and in selected international settings to cross-fertilize models of quality care that are related to improved care outcomes (quality of life and longevity);
- » Creating consensus on what works in Parkinson's care interventions, translating innovations and state-of-the-art science into everyday clinical practice by publishing scholarly papers, holding consensus conferences, and widely disseminating patient-centric clinical "guidelines".
- » Funding research to support evidence-based medicine decisions and affect health policy, particularly in the United State;
- » Advocating for changes in US healthcare reimbursement paradigms that work to the disadvantage of Parkinson's patients.

NPF is implementing the same data-driven approach to clinical care that has proven effective in improving outcomes in cardiovascular disease and cystic fibrosis. By defining and developing sound measures of quality care, building evidence-based best practices and innovations in Parkinson's care, and then disseminating the information and serving as advocates, NPF plans to drive quality care improvement and continuously "raise the bar" for Parkinson's care.

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