



From Mobility to the Mind: A look at dementia in Parkinson's disease

Brief prepared for the Senate Standing Committee on Social Affairs, Science and Technology

May 2016

For more information contact:

Jacquie Micallef

Sr. Manager, Public Affairs and Partnerships

Parkinson Canada

316 - 4211 Yonge Street, Toronto, ON M2P 2A9

P: 1-800-565-3000; ext. 3501

Jacquie.Micallef@parkinson.ca www.parkinson.ca

Introduction

Parkinson's is a neurodegenerative disease of the brain that touches almost every aspect of daily living including: movement, mood, speech, ability to smell, eating and drinking, sleep, and cognitive impairment.

Parkinson's disease is commonly treated through drug therapies; however, evidence shows that access to a range of different therapies is vital. Exercise, dietary changes, physiotherapy, speech and occupational therapies, as well as counselling have been shown to improve the health and wellbeing of people with Parkinson's disease.

Parkinson's is an incredibly challenging disease to manage. People with Parkinson's have the highest rate of prescription drug use compared to other neurological conditions. Many people with the disease must take upwards of 50 pills a day, on a regimented basis, to be able to function. Over time, the benefits of medication become less effective at controlling symptoms associated with Parkinson's disease, and in some cases become the cause of undesired side effects, like involuntary movements (dyskinesia).

More recently surgical treatments such as Deep Brain Stimulation (DBS) – the implanting of electrodes in the brain – have surfaced as an invasive treatment option for the small number of people (5-10%) with Parkinson's disease who qualify. This therapy, like drug treatment, is not curative and targets symptom management – rather than addressing the underlying cause of the disease.

There is no known cure for Parkinson's disease.

In Canada today, Parkinson's disease is the second most common neurodegenerative disorder and affects more than 100,000 Canadians. Over the next 15 years, the number of Canadians diagnosed with Parkinson's is expected to increase by 65%. Each day 28 people in Canada are diagnosed with Parkinson's and by 2031 that number will increase to 51 people a day.

Although Parkinson's is the second most common neurodegenerative disorder, next to Alzheimer's disease and dementia, it is growing at the same staggering rate as the top condition. This is due to the steep increase in the incidence of Parkinson's disease in individuals over the age of 65; which makes up 85% of the population with Parkinson's.

Parkinson's disease and dementia

Parkinson's disease is most commonly characterized as a disease causing motor symptoms (i.e. tremors, rigidity); however in more recent years we have begun to increase our understanding of the non-motor symptoms associated with the disease – one of those symptoms is dementia. Dementia in Parkinson's is often experienced as a package that includes depression and anxiety, apathy, and psychosis (visual hallucinations).

Dementia in Parkinson's disease occurs most commonly in the advanced stages of the disease and in those with an older age of onset. On the other hand it is important to note that Mild Cognitive Impairment reportedly affects up to 30% of people in the early stages of Parkinson's disease. Recently, Parkinson Canada received health administrative data from Ontario that shows as of 2013 nearly 30% of Ontarians with Parkinson's disease also had a co-existing diagnosis of dementia. We are working with our other provincial partners across the country to gain this level of understanding of the Parkinson community in each region.

In 2012, the first Canadian Guidelines on Parkinson's disease were approved. The Guidelines include a section on dementia and offers the following information specific to people with Parkinson's disease:

“Older age at onset and initial hypokinesia/rigidity should be used to predict earlier development of cognitive decline and dementia”, and;

“Older age of onset, dementia, and decreased dopamine responsiveness may be used to predict earlier nursing home placement as well as decreased survival”.

It's noteworthy that the Guidelines shed light on the different markers and approaches to dementia in Parkinson's disease – a response to dementia cannot be “one size fits all”.

Parkinson Canada is currently working with our Medical Advisory Committee and other partners to develop updated Guidelines for Parkinson's disease, which will be sure to bring forward new information and evidence on dementia in Parkinson's disease.

In 2012, Parkinson Canada partnered with McGill University on the development of a guide for patients and a guide for clinicians on the non-motor symptoms of Parkinson's disease. The purposes of the Guides are to increase the understanding and awareness of risk factors and treatment options for non-motor symptoms in Parkinson's disease. In regards to dementia, the Guide offers the following information: “common symptoms of cognitive impairment in Parkinson's include problems with attention and planning. Often, people are unable to follow a complicated conversation. Some notice trouble making decisions. It can also take a longer time to formulate thoughts. Solving complex problems can be a challenge. Memory can also be impaired. However, serious memory problems (as seen in Alzheimer's) are less common, and hints or clues are often enough to stimulate memory”.

In Ontario, Parkinson Canada has partnered with the Ontario Brain Institute and the Ontario Neurodegenerative Disease Research Initiative (ONDRI). ONDRI is a research program designed to investigate similarities and differences of dementia among five diseases that will improve the diagnosis

and treatment of neurodegeneration. The focus is on diseases that are associated with dementia: Alzheimer's disease/mild cognitive impairment, Parkinson's disease, amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease), frontotemporal lobar degeneration, and vascular cognitive impairment (resulting from stroke).

ONDRI is a long-term observational study that is seeking out the common early indicators and risk factors of the five diseases.

The mandate is to ensure that the findings from the data collected are transformed into new diagnostic methods that will help detect diseases earlier, improved clinical practice that puts patients first, and eventually new effective treatments that will slow the diseases from progressing or even prevent the disease so people can continue to enjoy the later years of their lives.

ONDRI is one example of a scientific approach to looking at the commonalities between neurodegenerative diseases. This type of exploration will lead to an enhanced understanding of dementia and how it can be managed, treated, and hopefully cured.

In closing, Parkinson Canada respectfully submits the following recommendations:

1. Greater awareness and understanding of dementia in Parkinson's disease, which is critically important for people with the disease and their families, health care providers and the public.
2. Increased investment in brain research, like that of the Ontario Brain Institute and "Mapping Connections" (research partnership between Neurological Health Charities Canada and the Government of Canada), which looks at the commonalities across neurological diseases.
3. Investment in a brain action plan that can tackle issues related to dementia across several diseases, as well as the common issues experienced by Canadians with neurological diseases in areas such as access to treatment and care, caregiver support, income security, mental health services, health provider education, prevention and risk reduction.

Parkinson Canada is the national voice of Canadians living with Parkinson's. We provide education, advocacy and support services in communities coast to coast to individuals and the health care professionals that treat them, since 1965. The National Research Program funds innovative research to search for better treatments and a cure. Parkinson Canada is an Imagine Canada accredited organization.