



Factum

People with Parkinson's face gaps in the availability of health services

Caregivers under significant emotional burden

Toronto, ON, March 28, 2018 — Ipsos recently conducted a stakeholder survey on behalf of Parkinson Canada to better understand the challenges faced by three stakeholder groups:

- Individuals diagnosed with Parkinson's disease
- Those who personally provide care to someone living with Parkinson's
- Health care providers and those who work with people with Parkinson's or with care partners

People living with Parkinson's, caregivers and health care providers (HCPs) perceive significant issues with access and wait times for treatments for Parkinson's disease. This, along with mental health issues, caregiver burden and financial burden, are discussed in more detail below.

Access and Wait Times

Two in 10 (18%) of those with Parkinson's or their caregivers say they/their loved one waited over a year to receive a formal Parkinson's disease diagnosis after first reporting their symptoms to a medical professional. One in 4 people living with Parkinson's disease rate access to medical specialists as poor or very poor (24%) and greater numbers also find access to movement disorder clinics (28%) and Parkinson's nurse specialists (27%) poor or very poor. Only half of those diagnosed with Parkinson's disease report being a patient of a movement disorder clinic (53%) either currently (43%) or in the past (10%).

People living with Parkinson's rate physical activity programs (73%) and regular appointments with specialists (49%), as services that would be most helpful to them. These two services are ranked highly among caregivers as well, however, caregivers are significantly more likely to indicate home care would help (49% compared to 16% among those living with Parkinson's).

Four in 10 people living with Parkinson's rate access to long-term care facilities poor or very poor (40%). On the other end of the access spectrum, nearly 9 in 10 rated access to oral medication good, very good or excellent (89%) and 8 in 10 also rated access to a family doctor as good, very good or excellent (81%).

Among caregivers, almost half rated access to long-term care facilities poor or very poor (45%). About 3 in 10 caregivers also rate access to movement disorder clinics (29%) and Parkinson's nurse specialists (32%) as poor or very poor. Three in 10 caregivers also rate access to mental health services as poor or very poor (29%), with even more rating wait times for mental health services as poor or very poor (37%). Similar to responses from those they care for, most care givers find access to oral medication (86%) and their family doctor (79%) good, very good or excellent.

In general, health care providers (HCPs) rated access to services and treatments more critically than those living with Parkinson's and their caregivers. In particular, half rate access to movement disorder clinics as poor or very poor (52%) and over 4 in 10 rate access to



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Parkinson's nurse specialists as poor or very poor (45%). Access to speech language and swallowing therapy, was also rated poor or very poor by 3 in 10 HCPs (29%).

Wait times for services and treatments were rated even more negatively than access by HCPs. At least half rated wait times as poor or very poor for long-term care facilities (53%), medical specialists (59%), Parkinson's nurse specialists (52%), and movement disorder clinics (56%).

One in 5 HCPs surveyed cited a lack of medical specialists as one of the biggest barriers to people living with Parkinson's getting the care they needed (20%). Other barriers noted include: more information and a better understanding of Parkinson's (32%), the availability of education resources (30%) and a lack of support groups or counselling (20%).

Mental Health and Caregiver Burden

People living with Parkinson's report experiencing anxiety (55%), stress (52%), loss of confidence (52%), sadness (45%) and depression (33%). Caregivers report often feeling stressed (41%), exhausted (35%) and guilty they aren't doing enough (31%), with one in four working full-time (25%). Additionally, six in 10 or more report feeling frustration towards the person with Parkinson's (72%), anxious (66%) and helpless (59%) and at least some of the time, with 2 in 10 feeling this way often.

Financial Burden

Medication (90%), exercise (76%) and physiotherapy (45%) are the most common services/treatments used by people living with Parkinson's, with additional services added as the disease progresses, such as speech language and swallowing therapy (23%), occupational therapy (21%) and consultations with dieticians (16%).

Three quarters of people living with Parkinson's and their care partners report paying out of pocket for exercise programs (74%), 4 in 10 pay for physiotherapy themselves (44%) and 1 in 3 pay for some medication out of pocket (34%). Without reimbursement by insurers (public or private) 4 in 10 would find paying for medication a major financial burden (45%) and almost the same number would find paying for other treatments a major burden (39%).

Compared to those with Parkinson's and caregivers, HCPs were more likely to see medication and other treatments for Parkinson's as a financial burden if they were not reimbursed by private insurance, or covered by provincial health programs. Three in 4 thought the costs of treatments such as physiotherapy, occupational therapy, counselling, speech and other therapies, would be a major financial burden for patients if not covered (76%) and 3 in 5 think medication costs would be a major burden (59%).



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About the Study

A 30-minute online survey was conducted among Parkinson Canada's members between September 29 and October 24, 2017. A link provided by Ipsos to the survey was sent out to 25,853 stakeholders by Parkinson Canada with two reminder invites. The margin of error for the total sample of 1,478 is plus or minus 2.5 percentage points, 95 per cent of the time.

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