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Clinical perception and management of Parkinson's disease during the COVID-19 pandemic: A Canadian experience

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ABSTRACT

Background: The COVID-19 pandemic has necessitated the social isolation of the population and the rapid implementation of remote care for patients with neurodegenerative diseases. The objective of this study was to explore the perceived impact of confinement in patients with Parkinson's disease and document the effects of gender and living environment.

Methods: We recruited two cohorts from the Canadian provinces of Québec and Alberta, which differed in the dynamics of COVID-19 spreading at the time of the study, and administered a questionnaire on the perceived effects of confinement on daily living and disease management.

Results: The data reveals that approximately half of the patients experienced a change in one or more clinical symptoms, with differences observed between gender (e.g. day-to-day changes in slowness in men, aggravated headaches in women) and geographic location (e.g. increased depression in Alberta but reduced sleep quality in Québec). Furthermore, participants identifying as women or living in Alberta implemented more frequently home or online exercise. Lastly, high levels of satisfaction with phone or video consultations did not translate into a sustained interest to pursue this mode of healthcare.

Conclusions: This study suggests that COVID-19-related confinement affected Parkinson's disease manifestation and management. Patients also reported varying levels of interest to continue remote care. A number of differences reported in our study were seemingly related to gender and living environment.

1. Introduction

The unforeseen COVID-19 pandemic has imposed the confinement of the global population. This sudden disruption of lifestyle and daily activities has raised concerns regarding the wellbeing of patients affected by chronic diseases such as neurodegenerative disorders [1–4]. However, these unprecedented circumstances offered an opportunity to evaluate several important factors which contribute to the welfare and comfort of patients with Parkinson's disease (PD). These include social interactions and daily routines, ability to manage life-disrupting motor and non-motor symptoms and continuity of healthcare. Recent reports from a number of countries have shown that confinement due to COVID-19 has aggravated motor and non-motor symptoms in patients diagnosed with PD [5–9]. Accumulating evidence from past outbreaks

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and the current pandemic also revealed gender disparities [10-12] such as differences in disease burden and response to health risk [13,14]. These observations suggest that women's overall health status and quality of life during the COVID-19 pandemic may deteriorate more significantly compared to men and need to be monitored closely to appropriately address health disparities in the population. In addition, clinical studies have previously reported that PD-related symptoms can manifest differently in men and women patients [15–18]. As such, the existence of a gender effect in response to confinement in patients with PD has yet to be characterized and understanding gender-based differences is essential to implement adequate PD-related public health responses. Furthermore, regional differences in the perception of COVID-19-related risk and impact on chronic disease management have emerged in the United States and appear to reflect COVID-19 burden in these communities [19]. In Canada, the number of diagnosed COVID-19 cases reported during the first wave of contaminations (March-July 2020) also differed dramatically between provinces, which provided a unique opportunity to compare how PD patients living in regions with fast or slow COVID-19 spread perceived the confinement. The objective of this study was to expand on previous findings and explore different variables that may impact self-reported changes in motor and non-motor symptoms, such as gender (i.e. self-identification as man, woman or other gender identity) or living in geographic areas with different rates of COVID-19 community transmission. In parallel, we assessed the level of satisfaction of PD patients with remote consultations and their interest in pursuing this alternative mode of care in the future.

2. Methods

The Canadian Open Parkinson Network (C-OPN) [20], the Quebec Parkinson Network (QPN) [21] and the Calgary Parkinson Research Initiative (CaPRI) [22] collaborated to collect the responses of 417 PD patients to an online questionnaire. These networks or initiatives were created with the goal to accelerate PD research and each have a registry component whereby potential patients are recruited. Patients may be referred by a neurologist or an investigator conducting other research studies at local Movement Disorders Clinics, or recruited via advertisements displayed in these clinics or on their Facebook page. Patients can also join the various initiatives via self-referral through the websites.

Participants were invited to fill out the online survey if they were actively enrolled in the networks and had consented to be contacted for future research. To ensure a research outcome that is inclusive and representative of all participants, patients were asked to select their gender from a list of options (man, woman, transgender, other). All participants identified as either "man" or "woman", and none of the patients selected the "transgender" or "other" option. The questionnaire, which was available between May 20th and September 16th 2020, assessed the impact of the COVID-19 confinement on perceived wellbeing, management of symptoms and continuity of health care. Sarah Bogard (QPN) and Catherine Normandeau (C-OPN) designed and submitted the questions to a panel of movement disorder clinicians affiliated with C-OPN in order to evaluate adequacy and relevance. The survey was subsequently modified by changing or adding items until a consensus was reached by the panel of experts. The final survey consisted of 36 questions divided in three main sections related to physical and mental wellbeing, daily activities and PD symptoms during the COVID-19 confinement (full questionnaire available as a Supplementary Material). The beginning of confinement was defined as the date when provincial governments enforced social isolation measures and travel restrictions, which corresponded to March 13th 2020 for participants living in Québec and March 17th 2020 for those in Alberta. For the purpose of this questionnaire, the terms "virtual care" and "virtual visits" refer to both phone and videoconferences. To capture the responses of patients with PD during the early stages of confinement, we did not test the survey in a pilot group.

The online questionnaire was administered through REDCap electronic data capture tool software [23] or the Longitudinal Online Research and Imaging System (LORIS) [24] to all enrolled parkinsonian patients via C-OPN, CaPRI and QPN that consented to be contacted for future research. Responses from patients diagnosed with atypical parkinsonism syndromes (e.g. progressive supranuclear palsy or multiple system atrophy) were excluded from the analysis presented here. (REB19-1688, REB16-0545, Ethical approval Pro00091716, MUHC-15-944) and informed consent (either electronically, verbally, or implicitly) were obtained in accordance with appropriate institutional policies. Implied consent consists in providing a written explanation, at the beginning of the questionnaire, stating that participants accepting to complete the survey also give their consent to take part in the study. It is an abbreviated version of all relevant material normally included in a consent form, including that participation is voluntary, but does not require a signature and informs that participation is voluntary (see Questionnaire, Supplementary Material). This procedure is approved by local Research Ethics Boards and is commonly used for de-identified questionnaires that present minimal risk or harm to participants. Eligible patients (patients with PD older than 18 years of age) were invited to complete the online questionnaire either via email or over the phone with trained research personnel (coordinator or research assistant) based on their preference. Overall, 89% (383/430) of questionnaires were self-administered by patients.

Categorical data between groups were analyzed using a Pearson exact Chi-square test with Monte Carlo estimation when appropriate and continuous data were analyzed using a Student's t-test. The interest in future virtual care was modeled using univariate and multivariate logbinomial regression models with and without interaction to analyze the relationships between the variables *province* and *education* or *living environment*. Statistical analysis was performed using the SPSS statistics software (version 27.0 of the IBM SPSS Statistics for Windows, IBM Corp., Armonk, NY, USA) and the SAS® software (version 9.4 of the SAS system for Windows, SAS Institute Inc., Cary, NC, USA) with significance level set at $p \leq 0.05$.

3. Results

3.1. Population characteristics

A total of 417 patients with PD were recruited, with an average age of 68.2 ± 9.7 years, disease duration of 8 ± 5.4 years, disease onset at 60.9 \pm 11.4 years and 61.3% were men. The cohorts recruited from Québec (n = 240) and Alberta (n = 177) had a similar demographic profile (Québec: men, 63.7%; age, 68.5 \pm 9.5; PD duration, 8.6 \pm 6.4 years. Alberta: men, 58.8%; age, 67.9 \pm 9.5; PD duration, 7.8 \pm 4.9 years) with comparable distribution of gender (p = 0.31), age (p = 0.495), duration of PD (p = 0.256), presence of comorbidities (p = 0.650), and only a small proportion of patients was diagnosed with dementia (Québec, 0%; Alberta, 2.9%; men, 1.5%; women, 1.6%) (Supplementary Table 1, Fig. 1A). Men and women participants also had a similar distribution of age (p = 0.885), duration of PD (p = 0.941) and presence of comorbidities (p = 0.664). The median Hoehn and Yahr (H&Y) stage was 2 (scale of 1-5) for the Alberta and Québec cohorts and remained unchanged when the participants were stratified between men and women (Supplementary Table 1). H&Y scores were available for 91% of patients in Alberta and for 56% in Québec. The number of patients with a University degree was equivalent in both provinces (~45%), but people without such degree more frequently held a high school diploma in Québec or a non-university diploma (e.g. trade certificate) in Alberta (p = 0.005). In addition, more participants in Alberta reported living in urban areas, i.e. where the total population count exceeded 10,000 people (78.1%, Québec; 86.9%, Alberta; *p* = 0.026) (Table 1).



Fig. 1. Changes to daily routines and PD-related symptoms during COVID-19 confinement. (A) Map depicting the geographic location of the two provinces included in the study (yellow). The size of the circles is proportional to the number of participants in each province. Information in the yellow squares summarizes the characteristics of the cohorts recruited in Alberta and Québec. (B) Graph showing the cumulative mortality associated with COVID-19 infection in the global population in Alberta (red line) and Québec (blue line) during the survey period (March to September 2020). Census data obtained from provincial sources [46], COVID-19 mortality data obtained from the COVID-19 Canada Open Data Working Group [47]. (C,D) The timeline provides key dates related to COVID-19 confinement in Alberta (C) and Québec (D) and the histograms depict the number of responses to the surveys during the duration of the study with each bar of the histogram corresponding to a specific week. (E,F) Radar chart showing the percentage of self-reported worsening (E) or daily fluctuations (F) in motor and non-motor symptoms in men (blue line) and women (orange line) since COVID-19-related confinement. Each grey line of the axis corresponds to a percentage value. Data analyzed using a Pearson exact Chi-square test with Monte Carlo estimation when necessary, *p \leq 0.05. Abbreviations: n, number; PD, Parkinson's disease; Sept., September.

Table 1

Impact of COVID-19 confinement on daily living.

	•				•	
COVID-19	Total					
Positive COVID-19 diagnosis, yes % (n)	0.5 (2)					
	Men	Women	P value*	Québec	Alberta	P value*
Concern about contracting	, COVID-19, %					
Major	18.9 (48)	19.5 (31)	0.075	15.1 (36)	24.7 (43) ^a	<0.0001
Minor	49.6 (126)	59.1 (94)		48.1 (115)	60.3 (105)ª	
None	31.5 (80) ^a	21.4 (34)		36.8 (88) ^a	14.9 (26)	
Social isolation						
	Men	Women	P value*	Québec	Alberta	P value*
Living environment ^b , % (r	ו)					
Urban	79.8 (194)	85.3 (133)	0.184	78.1 (175)	86.9 (152)ª	0.026
Rural	20.2 (49)	14.7 (23)		22.4 (52) ^a	12.8 (23)	
Biggest impact of confiner	ment on daily	living, % (n))			
Mood	15 (38)	21.5 (34)	0.139	20.1 (47)	14.1 (25)	<0.001
Physical activities	34.4 (87)	25.3 (40)		26.9 (63)	36.2 (64) ^a	
Medical appointments	6.7 (17)	11.4 (18)		6.8 (16)	10.7 (19)	
Work	4.3 (11)	1.9 (3)		4.3 (10)	2.3 (4)	
Family	29.6 (75)	31 (49)		29.1 (68)	31.6 (56)	
Other	8.7 (22)	8.2 (13)		12.8 (30) ^a	2.8 (5)	
Modes of communication	with family, %	6 (n)				
Phone call	86 (221)	88.1 (141)	0.531	85 (204)	89.3 (158)	0.203
Videoconference	51.8 (133)	65.6 (105) ^a	0.005	56.3 (135)	58.2 (103)	0.692
Email	47.9 (123)	50 (80)	0.671	40.8 (98)	59.3 (105) ^a	<0.001
Postal mail	3.5 (9)	8.1 (13) ª	0.04	5 (12)	5.6 (10)	0.769
Other	11.7 (30)	14.4 (23)	0.421	10 (24)	16.4 (29) ^a	0.053
Before confinement, frequ	ency leaving	home, % (n)				
1-2 times per week	8.9 (23)	11.3 (18)	0.760	11.7 (28)	7.3 (13)	0.143
3-4 times per week	17.5 (45)	18.2 (29)		16.7 (40)	19.2 (34)	
5-6 times per week	27.6 (71)	27.7 (44)		25.5 (61)	30.5 (54)	
7 or more times per week	43.2 (111)	39.6 (63)		42.7 (102)	40.7 (72)	
Does not leave household	1.9 (5)	3.1 (5)		3.3 (8)	1.1 (2)	
During confinement, frequ		, ,				
1-2 times per week	38.1 (98)	42.8 (68)	0.021	37.2 (89)	43.5 (77)	0.117
3-4 times per week	21 (54)	15.7 (25)		18 (43)	20.3 (36)	
5-6 times per week	8.6 (22)	11.3 (18)		8.4 (20)	11.3 (20)	
7 or more times per week	14.4 (37) ^a	5.7 (9)		12.6 (30)	9 (16)	
Does not leave household	17.5 (45)	24.5 (39)		23.8 (57)	15.3 (27)	
During confinement, reaso	-			FA 0 (400)	00 5 (400)-	0.000
Groceries, pharmacy	63.4 (163)	56.3 (90)	0.145	54.2 (130)	69.5 (123) ^a	0.002
Walk, physical exercise Visit family or friends	58 (149) 11.3 (29)	53.8 (86) 11.3 (18)	0.397 1	55.8 (134) 6.3 (15)	57.1 (101) 18.1 (32)ª	0.842 <0.001
Talk to neighbors	11.3 (29) 10.5 (27)	910 (16)	1	0.3 (15) 10.4 (25)	10.1 (32) ² 10.2 (18)	<0.001 1
Work or volunteer	7.8 (20)	5.6 (9)	0.436	4.6 (11)	10.2 (18)ª	0.032
Other	4.3 (11)	4.4 (7)	1	4.2 (10)	4.5 (8)	1
Did you leave by yourself I	· · /	. ,		x · - /	x-7	
Dia you leave by yoursell I	15.2 (39)	25.6 (41) ^a	0.025	21.8 (52)	15.8 (28)	0.124
Did this situation change of	. ,	nfinement, ve	es % (n)			

*Data are analyzed using a Pearson exact Chi-square test with Monte Carlo estimation when necessary. Significant values are in red ($p \le 0.05$).

^a Significantly different from the other gender or province, $p \le 0.05$

^b Defined as follows: rural < 10 000 people, urban > 10 000 people

Abbreviations: n, number

3.2. Impact of COVID-19 on daily living

The data were collected in an epidemiological context where COVID-19 cumulative mortality in Québec totaled 5,834 (68 per 100,000) people by the end of September 2020, compared to 267 (6 per 100,000) in Alberta (illustrated in Fig. 1B) and at a time where provinces had implemented different policies and timeline/schedule of restrictions (illustrated in Fig. 1C and D). A majority of responses were collected in May and June for both Alberta and Québec, suggesting that the responses to the survey are concentrated at the beginning of the study period (Fig. 1C and D). Our survey only reported 2 cases officially diagnosed with COVID-19 and no participants were hospitalized during the study for PD or COVID-19-related health reasons (Supplementary Table 1). Physical activities, family and changes in mood were the three categories most impacted by the confinement, regardless of the province or gender.

Environment. Participants in both provinces expressed concerns about contracting COVID-19, but those living in Alberta reported significantly greater concerns (p < 0.001). Differences in the preferred mode of communication were observed, with participants in Alberta communicating more frequently by email compared to those living in Québec (p < 0.001) (Table 1).

Gender. Phone calls were the most utilized mode of communication with family members but women engaged more frequently in video-conferences (p = 0.005) and postal mail (p = 0.04) compared to men. It should also be noted that a greater number of women reported living alone compared to men (p = 0.025) and this living situation changed for 7.4% of all participants during confinement. Before the implementation of social isolation measures, there were no differences in the frequency at which participants left their home, but during the confinement, 14.4% of men reported going out at least seven times a week compared to only 5.7% of women (p = 0.021) (Table 1).

3.3. Self-reported aggravation of motor and non-motor symptoms in PD patients

We then investigated the impact of the confinement on PD-related symptoms and questioned whether changes in motor and non-motor symptoms would vary as a result of geographic location or gender (Table 2).

Environment. Across all provinces, participants reported experiencing changes in motor symptoms during the confinement, including tremor (group average: 26.6%), rigidity (group average: 31.6%), slowness (group average: 26.8%) and balance (group average: 24.1%). A general worsening of symptoms was most frequent regardless of the province, but patients also reported day-to-day changes (Table 2, Fig. 1E and F). Furthermore, changes in depression were more common in Alberta (p = 0.051) while participants in Québec observed a diminution in their quality of sleep (p = 0.035).

Gender. We found gender-based differences in the evolution of slowness (p = 0.045), with men experiencing daily fluctuations (15.4%) women, 32.9% men), while women more often experienced a persistent aggravation of this symptom (82.1% women, 67.1% men). There was a trend towards differences in the evolution of tremor between men and women (p = 0.06), with men frequently reporting day-to-day changes (18.2% women, 37.7% men) while women noted a worsening (77.3% women, 60.9% men). In addition, women described the worsening of headaches compared to men (p = 0.002) (Table 2). We found that there were more women participants living alone than men and this situation could have exacerbated the social isolation already imposed on them during confinement. An analysis of the perceived changes in symptoms according to gender and living arrangements revealed that women living alone before and during the confinement experienced significantly greater changes in balance (p = 0.028) and "other" symptoms (p= 0.034) compared to women not living alone (Table 2, Section B). The "other" category allowed participant to detail unlisted symptoms which

included fatigue, lower endurance and insomnia. However, analysis did not unveil an effect of the living situation in the perception of symptoms by men participants.

3.4. Disease management and telemedicine

As part of the questionnaire, we inquired about changes in physical activity, as regular exercise is essential to manage PD symptoms, but a majority of participants reported a decrease in their level of physical activity as a result of confinement. However, most participants implemented home or online exercise during this period (men, 48.6%; women, 61.6%) and we found a greater interest in home-based exercise in Alberta compared to Québec (p < 0.0001) and in women compared to men (p = 0.016) (Table 3). During the study period, scheduled appointments were largely carried out by phone and approximately 30% of patients who communicated with their neurologist adjusted their PD medication, without significant differences by province or gender. When asked about their remote care experience, patients admitted to high levels of satisfaction regardless of province or gender and \sim 45% of the participants in Québec showed an interest in pursuing remote consultations (i.e. phone or videoconference), compared to 26% in Alberta (p < 0.001) (Table 3). These varying levels of interest could depend on a person's education, as shown in other studies [25], or on the living environment, with rural patients facing transportation challenges or having to travel longer distances to visit their providers. Given the findings that the Alberta and Québec cohorts significantly differed in living environments and educational profiles, we assessed the influence of these variables on the participant's interest in future remote care. Log-binomial regression models revealed the absence of statistically significant interactions between provinces and education, or provinces and living environment, suggesting that these variables do not account for the different interest in future phone- or videoconference-based care between provinces. However, some trends were observed and participants with a University degree or living in an urban area were more likely to express an interest in future remote care if they were located in Québec compared to Alberta (positive responses increased by 65% [95% CL: 17%; 134%] with a University degree, or 56% [95% CL:18%; 106%] with urban living).

4. Discussion

4.1. Effects of confinement on PD-related symptoms

Two distinct cohorts of patients were recruited in Québec and Alberta, provinces with different dynamics of COVID-19 transmission at the time of the study. Access to this large dataset enabled a stratification based on gender and/or geographic location, complementing existing studies and offering a unique insight into the susceptibility or resilience of different sub-populations of PD patients to the COVID-19 confinement. Approximately half of the participants noted changes in motor and non-motor symptoms, in accordance with previous studies reporting an aggravation of behavioral and psychological symptoms, a worsening of sleep disorders, depression and anxiety as well as reduced physical activity of patients with PD as a result of confinement or loneliness [5-7, 26-32]. Patients also reported increased anxiety and worsened cognitive abilities (30.9% and 17.9% positive responses, respectively) during confinement, without significant differences between gender and living environment. Changes in clinical presentation and decreased low intensity exercise have also been reported for patients with neuromuscular diseases [33]. This suggests that patients affected by chronic disorders experience similar detrimental effects of COVID-19 confinement on wellbeing and disease management strategies. However, the influence of inherent and extrinsic factors on these observations remained unclear and our study found that at least five PD-related symptoms were differentially perceived as a result of province or gender. For example, our data highlight a strong association between living alone and

Table 2

Self-reported evolution of motor and non-motor symptoms in PD patients during COVID-19 confinement.

SECTION A: Evolution of clinic	cal symptoms					
Perceived changes in motor sy	ymptoms					
	<i>Men</i> (n = 257)	<i>Women</i> (n = 160)	P value*	<i>Québec</i> (n = 240)	<i>Alberta</i> (n = 177)	P value *
Tremor, yes % (n)	24.9 (64)	27.5 (44)	0.556	27.9 (67)	23.2 (41)	0.274
Rigidity, yes % (n)	30 (77)	33.1 (53)	0.535	30.8 (74)	31.6 (56)	0.861
Slowness, yes % (n)	29.2 (75)	24.4 (39)	0.284	28.7 (69)	25.4 (45)	0.451
Balance, yes % (n)	26.8 (69)	21.3 (34)	0.197	22.9 (55)	27.1 (48)	0.325
No change in the above symptoms, % (n)	44.7 (115)	45.6 (73)	0.861	43.8 (105)	46.9 (83)	0.524
Other, yes % (n)	3.5 (9)	6.3 (10)	0.191	5.4 (13)	3.4 (6)	0.327
Perceived severity of change i	n motor symp	otoms			•	-
	Men	Women	P value*	Québec	Alberta	P value*
Tremor, % (n)		/_ /.				
Increase	60.9 (42)	77.3 (34)	0.060	70.8 (51)	61 (25)	0.435
Decrease	1.4 (1)	4.5 (2)		1.4 (1)	4.9 (2)	
Day to day change	37.7 (26) ^a	18.2 (8)		27.8 (20)	34.1 (14)	
Rigidity, % (n) Increase	70 (56)	69.8 (37)	1	72.7 (56)	66.1 (37)	0.574
Decrease	2.5 (2)	1.9 (1)	1	1.3 (1)	3.6 (2)	0.374
Day to day changes	2.5 (2) 27.5 (22)	28.3 (15)		26 (20)	30.4 (17)	
	21.3 (22)	20.3 (13)		20 (20)	30.4 (17)	
Slowness, % (n) Increase	67.1 (53)	82.1 (32)	0.045	74 (54)	68.9 (31)	0.500
Decrease	0	2.6 (1)	0.040	0	2.2 (1)	0.000
Day to day changes	32.9 (26) ^a	15.4 (6)		26 (19)	28.9 (13)	
Impaired balance, % (n)						
Increase	75 (54)	67.6 (23)	0.671	74.6 (44)	68.8 (33)	0.464
Decrease	2.7 (2)	5.9 (2)		1.7 (1)	6.3 (3)	
Day to day change	23.3 (17)	26.5 (9)		23.7 (14)	25 (12)	
Perceived changes in non-mot						-
•	Men	Women	P value*	Québec	Alberta	P value*
Depression, yes % (n)	11.7 (30)	15.6 (25)	0.246	10.4 (25)	16.9 (30) ^a	0.051
Anxiety, yes % (n)	28 (72)	33.8 (54)	0.215	30.8 (74)	29.4 (52)	0.749
Cognitive difficulties, yes % (n)	19.5 (50)	16.3 (26)	0.410	15.8 (38)	21.5 (38)	0.141
Perceived severity of change i	n non-motor s	symptoms				-
	Men	Women	P value*	Québec	Alberta	P value*
Depression, % (n)						
Increase	61.3 (19)	76 (19)	0.241	65.4 (17)	70 (21)	0.712
Decrease	0	0		0	0	
Day to day change	38.7 (12)	24 (6)		34.6 (9)	30 (9)	
Anxiety, % (n)	75 (54)	75 5 (40)	1	74 (54)	76.0 (40)	0 042
Increase Decrease	75 (54) 1.2 (1)	75.5 (40) 0.8 (1)	1	74 (54) 1.4 (1)	76.9 (40) 1.9 (1)	0.843
	1.2 (1)	0.0(1)		1.4(1)	1.3(1)	

Day to day change	23.6 (17)	22.6 (12)		24.7 (18)	21.2 (11)	
Cognitive impairment, % (n)						
Increase	68.6 (35)	50 (13)	0.317	61.5 (24)	63.2 (24)	0.280
Decrease	5.9 (3)	7.7 (2)		2.6 (1)	10.5 (4)	
Day to day change	25.5 (13)	42.3 (11)		35.9 (14)	26.3 (10)	
Sleep quality, % (n)						
Improved	8.6 (23)	7.5 (12)	0.625	6.7 (16)	10.7 (19)	0.035
Worsened	28.8 (74)	26.9 (43)		32.1 (77) ^a	22.6 (40)	
No change	61.5 (158)	65.6 (105)		61.3 (147)	65.5 (116)	
Headaches, % (n)						
Got better	0.8 (2)	1.3 (2)	0.002	1.2 (3)	0.6 (1)	0.012
Got worse	5.1 (13)	15.7 (25) ^a		8.5 (21)	9.4 (17)	
No change	38.5 (99)	37.7 (60)		32 (78)	46.1 (81)ª	
Not applicable	54.9 (141)	45.3 (72)		57.3 (137) ^a	42.9 (76)	

SECTION B: Perceived changes according to the patient's living situation

Perceived changes in motor symptoms

	М	en	Women			
	Living with others (n = 211)	Living alone (n = 30)	P value*	<i>Living with</i> others (n = 115)	Living alone (n = 30)	P value*
Tremor, % (n)	25.1 (53)	23.3 (7)	1	27 (31)	30 (9)	0.819
Rigidity, % (n)	28.9 (61)	36.7 (11)	0.399	33 (38)	40 (12)	0.521
Slowness, % (n)	29.9 (63)	30 (9)	1	23.5 (27)	33.3 (10)	0.347
Balance, % (n)	25.6 (54)	33.3 (10)	0.381	17.4 (20)	36.7 (11)	0.028
Other, % (n)	2.8 (6)	3.3 (1)	1	2.6 (3)	13.3 (4)	0.034
Perceived changes in non-n	notor symptoms	•		•		
	Men			Women		
	Not living alone (n = 217)	Living alone (n = 30)	P value*	<i>Not living alone</i> (n =115)	<i>Living alone</i> (n =30)	P value*
Depression, % (n)	11.4 (24)	13.3 (4)	0.761	16.5 (19)	16.7 (5)	1.000
Anxiety, % (n)	28.9 (61)	23.3 (7)	0.666	33 (38)	30 (9)	1.000
Cognitive difficulties, % (n)	20.9 (44)	13.3 (4)	0.465	16.5 (19)	20 (6)	0.785

*Data are analyzed using a Pearson exact Chi-square test with Monte Carlo estimation when necessary. Significant values are in red ($p \le 0.05$).

^a Significantly different from the other gender or province, $p \le 0.05$

Abbreviations: n, number

perceived changes in motor symptoms in women, but not men participants. Living alone had previously been identified as a factor aggravating the effects of the COVID-19 pandemic in patients with PD [27], supporting our observation that lifestyle and social interactions could explain the gender effect observed. Our results relative to the fluctuation or continuous aggravation of motor symptoms observed in men vs. women is not readily accounted for by treatment changes, as men and women equally modified their medication after a visit with their care provider. In further support of our observations, previous studies suggested that women were more likely to perceive COVID-19 as a significant health risk [14], which could in turn influence their physical and psychological responses to confinement. In contrast to other studies [15–18], pre-confinement motor symptom assessment of the patients included in our cohorts did not identify statistically significant gender differences. This may explain the relatively small number of symptoms perceived differently between men and women during confinement. However, the reported aggravation of slowness, headaches and balance (Table 2) in women vs. men warrants further investigation of post-COVID-19 changes to PD-related symptoms in a larger cohort.

The observed differences between provinces suggest an association between the sociocultural environment, local COVID-19 transmission dynamics and the response to confinement, corroborating previous findings on the role of social contexts to risk perception [34–36]. For example, three independent studies carried out in the spring of 2020 found varying levels of COVID-19-related risk perception in distinct populations of PD patients. In these reports, 42% of surveyed Spanish

Table 3

Changes in physical activity and medical care during COVID-19 confinement.

Physical activity						
	Men	Women	P value*	Québec	Alberta	P value*
Changes in physical activity,	• •					
Increase	8.6 (22)	5.6 (9)	0.186	7.9 (19)	6.8 (12)	0.451
Decrease	61.9 (159)	71.3 (114)		63.3 (152)	68.4 (121)	
No change	29.3 (75)	23.1 (32)		28.7 (69)	24.3 (43)	
Home or online exercise, % (r	ו)					
No	51 (130)ª	38.4 (61)	0.016	57.8 (137) ^a	30.5 (54)	<0.0001
Yes	48.6 (124)	61.6 (98) ^a		42.2 (100)	68.9 (122)ª	
Remote care			-			
	Men	Women	P value*	Québec	Alberta	P value*
Visits with neurologist, % (n)						
In person	4.7 (12)	3.8 (6)	0.069	5.4 (13)	2.8 (5)	0.426
Phone call	46.3 (119)ª	33.8 (54)		40.4 (97)	42.9 (76)	
Video	1.9 (5)	0.6 (1)		0.8 (2)	2.3 (4)	
Not applicable	45.1 (116)	57.5 (92) ^a		50.4 (121)	49.2 (87)	
Other	1.6 (4)	3.1 (5)		2.1 (5)	2.3 (4)	
Changes in medication by mo	de of commu	nication, yes	s, % within ca	tegory (n)		
In person	8.3 (1)	0	1	7.7 (1)	0	1
Phone call	30.3 (36)	35.2 (19)	0.719	32 (31)	31.6 (24)	0.727
Video	20 (1)	0	1	0	25 (1)	1
Other	25 (1)	40 (2)	1	20 (1)	50 (2)	0.524
Self-decided	6.1 (7)	11 (10)	0.308	6.7 (8)	10.3 (9)	0.444
Satisfaction with phone or vic	leo consultati	ons, % (n)				
Extremely satisfied	8.7 (22)	7.5 (12)	0.067	10.2 (24)	5.6 (10)	0.148
Satisfied	27.3 (69)	23.3 (37)		24.3 (57)	27.7 (49)	
Neutral	12.3 (31)	8.2 (13)		9.8 (23)	11.9 (21)	
Dissatisfied	5.5 (14)	1.3 (2)		2.6 (6)	5.6 (10)	
Extremely dissatisfied	0.4 (1)	0.6 (1)		0.9 (2)	0	
Not applicable	45.5 (115)	59.1 (94) ^a		52.3 (123)	48.6 (86)	
Interest in future phone or vir	tual consultat	ions, % (n)				
No	34.1 (86)	32.7 (52)	0.259	28.2 (66)	40.7 (72) ^a	<0.001
Yes	39.3 (99)	32.1 (51)		44.4 (104) ^a	26 (46)	
Unsure	25.8 (65)	34.6 (55)		27.4 (64)	31.6 (56)	

*Data are analyzed using a Pearson exact Chi-square test with Monte Carlo estimation when necessary. Significant values are in red ($p \le 0.05$).

^a Significantly different from the other gender or province, $p \le 0.05$

Abbreviations: n, number

patients reported high concerns about contracting COVID-19 [8], compared to 8% in India [4] and 59% of patients reporting fear/worries in Germany [37]. These observations indicate that geographical location, such as Alberta vs. Québec in our study, along with different sociocultural backgrounds could affect a patient's perceived risk to contract the virus. Lastly, a recent study assessed the association between worsening of motor or non-motor features during the COVID-19 pandemic and four variables related to lifestyle or medical support namely (1) "available home support during lockdown", (2) "duration of home confinement", (3) "duration of Parkinson's disease" and (4) "difficulty seeking formal neurologist's opinion and/or medicines for Parkinson's disease" [28]. It was found that some – but not all – clinical features are affected by these variables, emphasizing that clinical manifestations of PD are complex and can be influenced by more than one external factor. Overall, our data indicate that patients may have different susceptibilities to COVID-19 confinement, and could inform on measures relative to disease management in these different populations.

4.2. Post-COVID-19 care and telemedicine

This survey reports that scheduled consultations were carried out most frequently via phone calls, suggesting that videoconference-related technologies may have been inaccessible to most patients and/or care providers at the time of the study. However, caution is warranted as this proportion may only reflect clinical practices at early stages of the pandemic and could be specific to the selected subset of clinics. The cohort living in Québec appeared more inclined to continue remote neurological care (i.e. phone or videoconference) compared to Alberta. A recent study found that 46% of PD patients in the United States expressed the desire to pursue telehealth even after the end of the pandemic [38], which is similar to the level of interest observed in the Québec cohort. Furthermore, a study carried out shortly before the COVID-19 pandemic questioned 18 patients with PD located in rural British Columbia (Canada) and found that living in a large urban center was largely perceived as an advantage to receive the best PD care, and more than 70% of the participants would consider using videoconferencing for follow-up appointments with their neurologist [39]. The different interest in future remote care observed between patients living in Québec or Alberta is not readily explained by the rural or urban living environment, but future studies could (i) recruit a larger cohort and (ii) collect data on travel burden, as published before [39]. We can, however, propose that the basis for inter-regional differences could involve a combination of culture and comfort with digital tools, but also reflect the structure of care in different clinics across provinces. For example, patients in some centers can conveniently access multiple services (e.g. dieticians, physical therapists) on the same day for in-person visits, while these may be more difficult to schedule during a single telemedicine appointment. The varying levels of expressed interest in telemedicine suggest a potential for a more personalized approach to healthcare delivery, by offering patients the choice between remote or in-person consultations. North American clinicians reported patient resistance to videoconferencing in the early COVID-19 crisis as the second barrier to its implementation, after the lack of access to technology [40]. It will therefore be critical to ensure that deploying video-based consultations does not create disparities between patients from different socioeconomic backgrounds, not only for their medical care but also for their inclusion into research studies [41]. Lastly, clinical studies have suggested that telemedicine for PD patients is as effective as in-person care [42-44]. These promising findings would benefit from additional studies designed to evaluate the differences between in-person vs. virtual visits in a neurologist's ability to adjust medication [45].

5. Conclusions

Our findings have been collected from a brief observational survey, which presents with strengths and limitations. For instance, the documentation of perceived consequences of the confinement is not accompanied by clinical assessments by movement disorder specialists and the data is not controlled for socioeconomic status. Strengths include the fact that this is an inclusive study that compares two cohorts recruited from provinces with very different dynamics of COVID-19 progression. We also surveyed a large number of participants, which further enabled a gender-based analysis. Our study showed that slowness, depression, sleep quality, headache and balance were differently perceived as a result of gender and/or localization, suggesting that patients with PD can be segregated into sub-populations with different sensitivities to confinement and related changes to their routine and living conditions. The impact of the environment on the observed differences between provinces is complex and likely to be attributed to more than one factor among which are the rate of COVID-19 community transmission in each province and the sociocultural environment. To draw firm conclusions on how gender and/or geographical location affect clinical symptoms during COVID-19-related social isolation, the findings presented in this article will need to be validated by a follow-up study that includes a

larger sample size, or re-analyzed as part of a global meta-analysis of published literature. Additional survey will also be critical to understand the long-term impact of the COVID-19-related restrictions on mental and physical resilience of both patients and their caregivers, as well as the consequences of this rapid shift from in-person to virtual care from the perspective of neurologists and caretakers.

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Ethical compliance statement

Ethical approval and informed consent (either electronically, verbally or implicitly) were obtained in accordance with appropriate institutional policies: (i) University of Calgary Conjoint Health Research Ethics Board (CHREB), REB19-1688, REB16-0545; (ii) University of Alberta Health Research Ethics Board, Pro00091716; (iii) McGill University Health Centre Research Ethics Board, MUHC-15-944. Implied consent consists in providing a written explanation, at the beginning of the questionnaire, stating that participants accepting to complete the survey also give their consent to take part in the study (see Questionnaire, Supplementary Material).

Author contributions

Manuscript: A. Study design and data collection, B. Data and statistical analysis, C. Writing of the First Draft, D. Review and Critique, E. Editing, F. Final Edits.

A.d.R.J.: B, C, F. S.B.: A, D, E. C.N.: A, B, D, E. C.D.: A. R.B.P.: D, E. N.D.: D, E. O.M.: A, D, E. J.M.: A, D, E. D.M.: A, D, E.

E.F.: A.

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Appendix A. Supplementary data

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References

- R.C. Helmich, B.R. Bloem, The impact of the COVID-19 pandemic on Parkinson's disease: hidden sorrows and emerging opportunities, J. Parkinsons Dis. 10 (2) (2020) 351–354.
- [2] A.J. Stoessl, K.P. Bhatia, M. Merello, Movement disorders in the world of COVID-19, Mov. Disord. 35 (5) (2020) 709–710.
- [3] S.M. Papa, P. Brundin, V.S.C. Fung, U.J. Kang, D.J. Burn, C. Colosimo, H.L. Chiang, R.N. Alcalay, C. Trenkwalder, M.D.-S.I. Committee, Impact of the COVID-19 pandemic on Parkinson's disease and movement disorders, Mov. Disord. 35 (5) (2020) 711–715.
- [4] S. Prasad, V.V. Holla, K. Neeraja, B.K. Surisetti, N. Kamble, R. Yadav, P.K. Pal, Parkinson's disease and COVID-19: perceptions and implications in patients and caregivers, Mov. Disord. 35 (6) (2020) 912–914.
- [5] M. Salari, A. Zali, F. Ashrafi, M. Etemadifar, S. Sharma, N. Hajizadeh, H. Ashourizadeh, Incidence of anxiety in Parkinson's disease during the coronavirus disease (COVID-19) pandemic, Mov. Disord. 35 (7) (2020) 1095–1096.
- [6] A. Shalash, T. Roushdy, M. Essam, M. Fathy, N.L. Dawood, E.M. Abushady, H. Elrassas, A. Helmi, E. Hamid, Mental Health, Physical activity, and quality of life in Parkinson's disease during COVID-19 pandemic, Mov. Disord. 35 (7) (2020) 1097–1099.
- [7] N. Kumar, R. Gupta, H. Kumar, S. Mehta, R. Rajan, D. Kumar, R.M. Kandadai, S. Desai, P. Wadia, P. Basu, B. Mondal, S. Juneja, A. Rawat, S.S. Meka, B. Mishal, L. K. Prashanth, A.K. Srivastava, V. Goyal, Impact of home confinement during COVID-19 pandemic on sleep parameters in Parkinson's disease, Sleep Med. 77 (2021) 15–22.
- [8] D. Santos-Garcia, M. Oreiro, P. Perez, G. Fanjul, J.M. Paz Gonzalez, M.J. Feal Painceiras, C. Cores Bartolome, L. Valdes Aymerich, C. Garcia Sancho, M.D. M. Castellanos Rodrigo, Impact of coronavirus disease 2019 pandemic on Parkinson's disease: a cross-sectional survey of 568 Spanish patients, Mov. Disord. 35 (10) (2020) 1712–1716.

- [9] D. Guo, B. Han, Y. Lu, C. Lv, X. Fang, Z. Zhang, Z. Liu, X. Wang, Influence of the COVID-19 pandemic on quality of life of patients with Parkinson's disease, Parkinsons Dis. 2020 (2020) 1216568.
- [10] H. Simba, S. Ngcobo, Are pandemics gender neutral? Women's health and COVID-19, Front. Glob. Womens Health 1 (2020) 570666.
- [11] C. Wenham, J. Smith, R. Morgan, Gender, C.-W. Group, COVID-19: the gendered impacts of the outbreak, Lancet 395 (10227) (2020) 846–848.
- [12] J. Connor, S. Madhavan, M. Mokashi, H. Amanuel, N.R. Johnson, L.E. Pace, D. Bartz, Health risks and outcomes that disproportionately affect women during the Covid-19 pandemic: a review, Soc. Sci. Med. 266 (2020) 113364.
- [13] C. Gonzalez-Sanguino, B. Ausin, M.A. Castellanos, J. Saiz, A. Lopez-Gomez, C. Ugidos, M. Munoz, Mental health consequences during the initial stage of the 2020 Coronavirus pandemic (COVID-19) in Spain, Brain Behav. Immun. 87 (2020) 172–176.
- [14] V. Galasso, V. Pons, P. Profeta, M. Becher, S. Brouard, M. Foucault, Gender differences in COVID-19 attitudes and behavior: panel evidence from eight countries, PNAS 117 (44) (2020) 27285–27291.
- [15] E. Stefanova, L. Ziropadja, M. Petrovic, T. Stojkovic, V. Kostic, Screening for anxiety symptoms in Parkinson disease: a cross-sectional study, J. Geriatr. Psychiatr. Neurol. 26 (1) (2013) 34–40.
- [16] J.E. Yoon, J.S. Kim, W. Jang, J. Park, E. Oh, J. Youn, S. Park, J.W. Cho, Gender differences of nonmotor symptoms affecting quality of life in Parkinson disease, Neurodegener. Dis. 17 (6) (2017) 276–280.
- [17] K. Szewczyk-Krolikowski, P. Tomlinson, K. Nithi, R. Wade-Martins, K. Talbot, Y. Ben-Shlomo, M.T. Hu, The influence of age and gender on motor and non-motor features of early Parkinson's disease: initial findings from the Oxford Parkinson Disease Center (OPDC) discovery cohort, Park. Relat. Disord. 20 (1) (2014) 99–105.
- [18] B. Scott, A. Borgman, H. Engler, B. Johnels, S.M. Aquilonius, Gender differences in Parkinson's disease symptom profile, Acta Neurol. Scand. 102 (1) (2000) 37–43.
- [19] B. Mehta, D. Jannat-Khah, C.A. Mancuso, A.R. Bass, C.J. Moezinia, A. Gibofsky, S. M. Goodman, S. Ibrahim, Geographical variations in COVID-19 perceptions and patient management: a national survey of rheumatologists, Semin. Arthritis Rheum. 50 (5) (2020) 1049–1054.
- [20] Canadian Open Parkinson Network. https://copn-rpco.ca/ accessed online December 21 2020.
- [21] Z. Gan-Or, T. Rao, E. Leveille, C. Degroot, S. Chouinard, F. Cicchetti, A. Dagher, S. Das, A. Desautels, J. Drouin-Ouellet, T. Durcan, J.F. Gagnon, A. Genge, J. Karamchandani, A.L. Lafontaine, S.L.W. Sun, M. Langlois, M. Levesque, C. Melmed, M. Panisset, M. Parent, J.B. Poline, R.B. Postuma, E. Pourcher, G. A. Rouleau, M. Sharp, O. Monchi, N. Dupre, E.A. Fon, The Quebec Parkinson network: a researcher-patient matching platform and multimodal biorepository, J. Parkinsons Dis. 10 (1) (2020) 301–313.
- [22] Calgary Parkinson research initiative. https://capriresearch.org/ accessed online December 20 2020.
- [23] P.A. Harris, R. Taylor, B.L. Minor, V. Elliott, M. Fernandez, L. O'Neal, L. McLeod, G. Delacqua, F. Delacqua, J. Kirby, S.N. Duda, R.E. Consortium, The REDCap consortium: building an international community of software platform partners, J. Biomed. Inf. 95 (2019) 103208.
- [24] S. Das, A.P. Zijdenbos, J. Harlap, D. Vins, A.C. Evans, LORIS: a web-based data management system for multi-center studies, Front. Neuroinf. 5 (37) (2012).
- [25] B.R. Viers, S. Pruthi, M.E. Rivera, D.A. O'Neil, M.R. Gardner, S.M. Jenkins, D. J. Lightner, M.T. Gettman, Are patients willing to engage in telemedicine for their care: a survey of preuse perceptions and acceptance of remote video visits in a urological patient population, Urology 85 (6) (2015) 1233–1239.
- [26] I. Subramanian, J. Farahnik, L.K. Mischley, Synergy of pandemics-social isolation is associated with worsened Parkinson severity and quality of life, NPJ Parkinsons Dis. 6 (2020) 28.
- [27] E.G. Brown, L.M. Chahine, S.M. Goldman, M. Korell, E. Mann, D.R. Kinel, V. Arnedo, K.L. Marek, C.M. Tanner, The effect of the COVID-19 pandemic on people with Parkinson's disease, J. Parkinsons Dis. 10 (4) (2020) 1365–1377.
- [28] N. Kumar, R. Gupta, H. Kumar, S. Mehta, R. Rajan, D. Kumar, R.M. Kandadai, S. Desai, P. Wadia, P. Basu, B. Mondal, Sanchita, A. Rawat, S.S. Meka, B. Mishal, L. K. Prashanth, A.K. Srivastava, V. Goyal, Impact of home confinement during COVID-19 pandemic on Parkinson's disease, Park. Relat. Disord. 80 (2020) 32–34.
- [29] A. van der Heide, M.J. Meinders, B.R. Bloem, R.C. Helmich, The impact of the COVID-19 pandemic on psychological distress, physical activity, and symptom severity in Parkinson's disease, J. Parkinsons Dis. 10 (4) (2020) 1355–1364.
- [30] V. Oppo, G. Serra, G. Fenu, D. Murgia, L. Ricciardi, M. Melis, F. Morgante, G. Cossu, Parkinson's disease symptoms have a distinct impact on caregivers' and patients' stress: a study assessing the consequences of the COVID-19 lockdown, Mov. Disord. Clin. Pract. 7 (7) (2020) 865–867.
- [31] P. Rábano-Suárez, R. Martínez-Fernández, E. Natera-Villalba, I. Pareés, J. C. Martínez-Castrillo, A. Alonso-Canovas, Impulse control disorders in Parkinson's disease: has COVID-19 related lockdown been a trigger? Mov. Disord. Clin. Pract. 8 (2021) 940–943.
- [32] E. Del Prete, A. Francesconi, G. Palermo, S. Mazzucchi, D. Frosini, R. Morganti, P. Coleschi, L.M. Raglione, P. Vanni, S. Ramat, A. Novelli, A. Napolitano, C. Battisti, M. Giuntini, C. Rossi, C. Menichetti, M. Ulivelli, V. De Franco, S. Rossi, U. Bonuccelli, R. Ceravolo, C.-P. Tuscany Parkinson, Prevalence and impact of COVID-19 in Parkinson's disease: evidence from a multi-center survey in Tuscany region, J. Neurol. 268 (4) (2021) 1179–1187.
- [33] V. Di Stefano, G. Battaglia, V. Giustino, A. Gagliardo, M. D'Aleo, O. Giannini, A. Palma, F. Brighina, Significant reduction of physical activity in patients with neuromuscular disease during COVID-19 pandemic: the long-term consequences of quarantine, J. Neurol. 268 (1) (2021) 20–26.

A. de Rus Jacquet et al.

- [34] A. Bish, S. Michie, Demographic and attitudinal determinants of protective behaviours during a pandemic: a review, Br. J. Health Psychol. 15 (4) (2010) 797–824.
- [35] J.J.V. Bavel, K. Baicker, P.S. Boggio, V. Capraro, A. Cichocka, M. Cikara, M. J. Crockett, A.J. Crum, K.M. Douglas, J.N. Druckman, J. Drury, O. Dube, N. Ellemers, E.J. Finkel, J.H. Fowler, M. Gelfand, S. Han, S.A. Haslam, J. Jetten, S. Kitayama, D. Mobbs, L.E. Napper, D.J. Packer, G. Pennycook, E. Peters, R. E. Petty, D.G. Rand, S.D. Reicher, S. Schnall, A. Shariff, L.J. Skitka, S.S. Smith, C. R. Sunstein, N. Tabri, J.A. Tucker, S.V. Linden, P.V. Lange, K.A. Weeden, M.J. A. Wohl, J. Zaki, S.R. Zion, R. Willer, Using social and behavioural science to support COVID-19 pandemic response, Nat. Hum Behav. 4 (5) (2020) 460–471.
- [36] S. Dryhurst, C.R. Schneider, J. Kerr, A.L.J. Freeman, G. Recchia, A.M. van der Bles, D. Spiegelhalter, S. van der Linden, Risk perceptions of COVID-19 around the world, J. Risk Res. 23 (7–8) (2020).
- [37] H.M. Zipprich, U. Teschner, O.W. Witte, A. Schonenberg, T. Prell, Knowledge, attitudes, practices, and burden during the COVID-19 pandemic in people with Parkinson's disease in Germany, J. Clin. Med. 9 (6) (2020), 1643.
- [38] M.P. Feeney, Y. Xu, M. Surface, H. Shah, N. Vanegas-Arroyave, A.K. Chan, E. Delaney, S. Przedborski, J.C. Beck, R.N. Alcalay, The impact of COVID-19 and social distancing on people with Parkinson's disease: a survey study, NPJ Parkinsons Dis. 7 (2021), 10.
- [39] D. Peacock, P. Baumeister, A. Monaghan, J. Siever, J. Yoneda, D. Wile, Perception of healthcare access and utility of telehealth among Parkinson's disease patients, Can. J. Neurol. Sci. 47 (5) (2020) 700–704.
- [40] V. Shivkumar, T. Subramanian, P. Agarwal, Z. Mari, T.A. Mestre, G. Parkinson Study, Uptake of telehealth in Parkinson's disease clinical care and research during the COVID-19 pandemic, Park. Relat. Disord. 86 (2021) 97–100.
- [41] A. Naito, A.M. Wills, T.F. Tropea, A. Ramirez-Zamora, R.A. Hauser, D. Martino, T. H. Turner, M.R. Rafferty, M. Afshari, K.L. Williams, O. Vaou, M.J. McKeown, L. Ginsburg, A. Ezra, R. Iansek, K. Wallock, C. Evers, K. Schroeder, R. DeLeon,

N. Yarab, R.N. Alcalay, J.C. Beck, Expediting telehealth use in clinical research studies: recommendations for overcoming barriers in North America, NPJ Parkinsons Dis. 7 (2021), 34.

- [42] C.A. Beck, D.B. Beran, K.M. Biglan, C.M. Boyd, E.R. Dorsey, P.N. Schmidt, R. Simone, A.W. Willis, N.B. Galifianakis, M. Katz, C.M. Tanner, K. Dodenhoff, J. Aldred, J. Carter, A. Fraser, J. Jimenez-Shahed, C. Hunter, M. Spindler, S. Reichwein, Z. Mari, B. Dunlop, J.C. Morgan, D. McLane, P. Hickey, L. Gauger, I. H. Richard, N.I. Mejia, G. Bwala, M. Nance, L.C. Shih, C. Singer, S. Vargas-Parra, C. Zadikoff, N. Okon, A. Feigin, J. Ayan, C. Vaughan, R. Pahwa, R. Dhall, A. Hassan, S. DeMello, S.S. Riggare, P. Wicks, M.A. Achey, M.J. Elson, S. Goldenthal, H.T. Keenan, R. Korn, H. Schwarz, S. Sharma, E.A. Stevenson, W. Zhu, I. Connect. Parkinson, National randomized controlled trial of virtual house calls for Parkinson disease, Neurology 89 (11) (2017) 1152–1161.
- [43] E. Cubo, J.M. Gabriel-Galan, J.S. Martinez, C.R. Alcubilla, C. Yang, O.F. Arconada, N.M. Perez, Comparison of office-based versus home Web-based clinical assessments for Parkinson's disease, Mov. Disord. 27 (2) (2012) 308–311.
- [44] R.E. Korn, A. Wagle Shukla, M. Katz, H.T. Keenan, S. Goldenthal, P. Auinger, W. Zhu, M. Dodge, K. Rizer, M.A. Achey, E. Byrd, R. Barbano, I. Richard, K. L. Andrzejewski, H.B. Schwarz, E.R. Dorsey, K.M. Biglan, G. Kang, S. Kanchana, R. Rodriguez, C.M. Tanner, N.B. Galifianakis, Virtual visits for Parkinson disease: a multicenter noncontrolled cohort, Neurol. Clin. Pract. 7 (4) (2017) 283–295.
- [45] E. Mulroy, E. Menozzi, A.J. Lees, T. Lynch, A.E. Lang, K.P. Bhatia, Telemedicine in Movement Disorders: lecons du COVID-19, Mov. Disord. 35 (11) (2020) 1893–1896.
- [46] Government of Alberta, Population statistics. https://www.alberta.ca/populat ion-statistics.aspx. Accessed online December 22 2020.
- [47] I. Berry, J.P.R. Soucy, A. Tuite, D. Fisman, Open access epidemiologic data and an interactive dashboard to monitor the COVID-19 outbreak in Canada, CMAJ 192 (15) (2020), E420.