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Canadian Healthcare Access in Parkinson's Disease and COVID-19: A Cross-Sectional Survey

Monica D. McKeown[1] , Eric Crighton[2], Tiago A. Mestre[3] and iCARE-PD consortium

[1]Division of Neurology, Department of Medicine, University of Ottawa, Ottawa, Canada, [2]Department of Geography, Environment and Geomatics, University of Ottawa, Ottawa, Canada and [3]Division of Neurology, Department of Medicine, Parkinson's Disease and Movement Disorders Center, The Ottawa Hospital Research Institute, University of Ottawa Brain and Mind Institute, Ottawa, Canada

ABSTRACT: *Background:* Parkinson's disease (PD) is a common chronic neurodegenerative condition. As a result of the COVID-19 pandemic, healthcare provision faced challenges worldwide. We aimed to explore how the COVID-19 pandemic changed healthcare experiences for people living with Parkinson's disease (PwP) in Canada. *Methods:* We conducted a national cross-sectional online survey about healthcare access for PwP in 2020. Participants (n = 298) were recruited through Parkinson Canada, the national patient association and its provincial partners, that advertised the study in a monthly newsletter. We used descriptive statistics and multivariate regression modelling to test associations of interest. A P < 0.05 was deemed statistically significant. *Results:* During the COVID-19 pandemic, PwP reported greater difficulty obtaining PD-related healthcare services and lesser satisfaction with healthcare provision compared to pre-pandemic experiences. Dissatisfaction with care was associated with the presence of barriers to access services, a lack of confidence in accessing services remotely, pre-pandemic care dissatisfaction, and difficulty in obtaining care during the COVID-19 pandemic. Unmet care needs were associated with a lack of confidence in accessing services remotely, dissatisfaction with pre-pandemic care, difficulty obtaining pre-pandemic care, and communication challenges. *Conclusion:* Our results suggest that healthcare experiences for PwP significantly changed during the COVID-19 pandemic, with challenges in access to virtual care. Poorer pre-pandemic care experiences were amplified during the pandemic.

RÉSUMÉ : **Accès aux soins de santé au Canada dans le cas de la maladie de Parkinson et pendant la pandémie de COVID-19 : une étude transversale.** *Contexte :* La maladie de Parkinson (MP) est une affection neurodégénérative chronique courante. À la suite de la pandémie de COVID-19, la prestation de soins de santé a été confrontée à de grands défis dans le monde entier. Nous avons ainsi cherché à explorer de quelle façon la pandémie de COVID-19 a modifié, en matière de soins de santé, l'expérience des personnes vivant au Canada avec la MP. *Méthodes :* Nous avons mené une étude nationale transversale en ligne portant en 2020 sur l'accès aux soins de santé des personnes atteintes de la MP. Les participants (*n* = 298) ont été recrutés par Parkinson Canada, l'association nationale de patients et ses partenaires provinciaux, qui ont annoncé l'étude dans un bulletin mensuel de liaison. Nous avons utilisé des statistiques descriptives et des modèles de régression multivariés pour tester des associations pertinentes. Une valeur *p* < 0,05 a été considérée comme statistiquement significative. *Résultats :* Au cours de la pandémie de COVID-19, les patients atteints de la MP ont déclaré avoir plus de difficultés à obtenir des soins de santé liés à leur affection et être moins satisfaits de la prestation de soins de santé par rapport à leur expérience prépandémique. L'insatisfaction à l'égard des soins de santé était liée à la présence d'obstacles rendant difficile l'accès aux services, à un manque de confiance dans l'accès aux soins à distance, à une insatisfaction à l'égard des soins avant la pandémie et à la difficulté d'obtenir des soins pendant la pandémie de COVID-19. Les besoins non satisfaits en matière de soins de santé ont été associés à un manque de confiance dans l'accès aux soins à distance, à une insatisfaction à l'égard des soins prépandémiques, à la difficulté d'obtenir des soins prépandémiques et à des problèmes de communication. *Conclusion :* Nos résultats suggèrent en somme que l'expérience en matière de soins de santé pour les personnes vivant avec la MP a changé de manière notable pendant la pandémie de COVID-19, des difficultés d'accès aux soins virtuels se manifestant. De plus, une mauvaise expérience en matière de soins de santé avant la pandémie a été amplifiée pendant celle-ci.

Introduction

Parkinson's disease (PD) is a chronic neurodegenerative condition affecting over 60,000 Canadians.[1] PD often requires a multidisciplinary care team, including neurologists (most commonly those with specialized training in movement disorders), specialized nurses, physiotherapists, occupational therapists, social workers, and speech-language pathologists. Access to these services is critical for optimizing the functioning of people living with Parkinson's (PwP) as they experience a wide range of symptoms impacting quality of life.[2] Despite Canada's universal healthcare system, PwP often face significant access barriers to care due to various factors such as individual's physical limitations and limited availability of services.[3]

The COVID-19 pandemic had significant impacts on healthcare systems around the world. The strain the COVID-19 pandemic placed on healthcare systems exacerbated existing barriers to care access and created new ones, including disruption in specific therapeutic options such as deep brain stimulation, limited infrastructure in place to provide effective virtual care, difficulty in obtaining regular medications, and disruptions in clinical trials.[4–6] From the patient's perspective, the COVID-19 pandemic led to disruptions in healthcare delivery and self-reported worsening of motor and non-motor PD symptoms, particularly mental health symptoms.[7,8] A scoping review on the psychological and social impacts of the COVID-19 pandemic for PwP identified discontinuation of regular healthcare appointments, decreased physiotherapy appointments, loss of daily activities and social support, and reduction in physical activity as key changes in PD care.[8] There was increased adoption of virtual care strategies, such as video-based appointments and smartphone symptom monitoring, during the COVID-19 pandemic to enable continuity of care.[9,10] The impact of the COVID-19 pandemic on PwP has not been explored in the Canadian population, with unique geographical and healthcare system level factors at play.

To improve our understanding of the impact of the COVID-19 pandemic on access to healthcare for PwP in the Canadian context, this study was conducted with the following objectives: (1) examine experiences with PD-related healthcare and their access and (2) identify factors that were associated with experiences with PD-related healthcare and their access during the COVID-19 pandemic.

This study is part of a larger international study investigating access to healthcare and factors affecting accessibility of healthcare for PwP in Canada and Europe (https://www.icare-pd.ca).

Methods

We conducted a cross-sectional national survey of PwP in Canada. Data were collected using Qualtrics encrypted online survey tool (https://www.qualtrics.com/) between July and September 2020, during the first year of the pandemic. Participants were recruited through Parkinson Canada, the national Parkinson's patient association (https://www.parkinson.ca/) and its provincial partners that advertised the study in a monthly newsletter. The inclusion criterion was a self-reported clinical diagnosis of Parkinson's disease by PwP or a spouse/caregiver answering on their behalf.

The questionnaire (see Appendix A) used for data collection was divided into four sections: (1) current health condition, Hoehn & Yahr stage of PD as reported by patients, and a standardized quality of life measure for PwP (PDQ-8, score ranging from 0 to 100 with 100 being lowest quality of life,[11]); (2) experiences with PD-related care and associated access barriers (i.e., availability, affordability, accessibility, adequacy, and appropriateness) prior to the COVID-19 pandemic; (3) experiences with care since the COVID-19 pandemic; and, (4) socioeconomic characteristics. This paper focuses on the experiences with care during the COVID-19 pandemic. Before the questionnaire was distributed, it was pilot tested for comprehensibility and response burden by 10 PwP. The survey was available in both French and English.

We conducted descriptive statistics for each survey question. For responses to open-ended questions, we first grouped responses into categories. We evaluated changes in outcomes of interest (*ease of obtaining healthcare, dissatisfaction with care, and unmet care needs*) with COVID-19 pandemic using a Wilcoxon signed-rank test. We also sought to understand which factors were associated with worse care experiences. We employed multivariate logistic regression techniques, using a forward stepwise selection process, retaining independent variables with a significance level<0.05 (Wald inclusion test statistic). Owing to its a priori relevance, the variable "Stage of Parkinson's disease"[12] was forced into the final models. We analysed the data using SPSS (v.28).

Ethics approval for this study was obtained from the Ottawa Health Research Institute Research.

Results

We collected data from a total of 298 PwP. Approximately half of the participants were male (53.7%), and 90.9% were Caucasian. Over two-thirds of respondents reported having a post-secondary (44.0%) or graduate degree (22.8%), and 15% reported making less than $40,000 annually. With regard to the living situation, 14.8% live alone, most live in urban areas (big cities = 50.7%; towns or small cities = 36.2%), in particular Ontario (67.1%) and Quebec (27.5%). Regarding disease status, respondents most commonly reported to be at early stages of PD (stage 1 = 34.9%, stage 2 = 38.6%). Approximately half (52%) had been diagnosed in the prior five years, and 54.7% reported no medical co-morbidities. The mean PDQ-8 score was 26.46 ± 17.23 (Table 1 for demographic and clinical characteristics).

Healthcare experiences and accessibility during the COVID-19 pandemic

When compared to individual experiences pre-pandemic, PwP had greater difficulty obtaining PD-related healthcare services during the COVID-19 pandemic (p < 0.01), were less satisfied with healthcare provision for PD during the COVID-19 pandemic (p < 0.005), and did not endorse a change in the ability to receive care for PD when needed (p > 0.05, Fig. 1).

Table 2 shows the increase in virtual care usage during the COVID-19 pandemic (70.2% of respondents) compared with before the COVID-19 pandemic (26.8% of respondents). Fifty-one per cent of respondents had used telephone, and 20.8% had used video conferencing for virtual care. Most PwP (85.9%) indicated comfort with the technology used, 93.0% had access to the required technology, and 85.6% of respondents had indicated to have access to technical assistance if required. While over two-thirds (69.1%) reported being confident in the remote assessment of appropriate treatment, a smaller proportion reported being confident in the remote assessment of their condition (58.4%) or their ability to access services remotely (54.6%).

Over a third of respondents (39.7%) indicated that ease of obtaining care was somewhat to very difficult (Table 2), and 29.3%

Table 1: Characteristics of study participants (n = 298)

Characteristics	% (n)*
Age, years	
<65	24.2 (72)
65 - 79	59.9 (178)
80 +	15.8 (47)
Gender	
Male	54.8 (160)
Female	45.2 (132)
Primary language	
English	68.8 (205)
French	27.5 (82)
Other	3.4 (10)
Marital status	
Not married or living in common law relationship	23.2 (69)
Married	76.8 (228)
Education level	
High school diploma or less	14.5 (43)
Some post-secondary education	18.2 (54)
Post-secondary degree	44.03(131)
Graduate degree	23.0 (68)
Household income	
< $40,000	17.7 (45)
$40,000 to < $70,000	30.7 (78)
$70,000 to < $130,000	37.4 (95)
≥ $130,000	14.2 (36)
Living situation	
Live alone	15.9 (44)
With family, friend, or in retirement home	84.1 (233)
Type of community of residence	
Big city (> 300,000 people)	51.0 (151)
Town or small city	36.5 (108)
Country village, village, farm, or countryside	12.5 (37)
Province or territory of residence	
Ontario	67.8 (200)
Quebec	21.7 (64)
Other province or territory	10.5 (31)
**Stage of Parkinson's disease **	
Stage One (early stage)	35.0 (104)
Stage Two (early to mid-stage)	38.7 (115)
Stage Three (mid-stage)	14.8 (44)
Stage Four or Five (mid to advanced stage)	11.5 (34)
Time Since Diagnosis	
0-5 years	52.0 (155)
6-10 years	26.5 (79)
11 + years	21.5 (64)
PDQ-8, mean (SD)	26.5 (17.2)

*n for each variable may differ from survey n due to missing data.
**adapted from Hoehn & Yahr Stage.[12]

indicated their care needs were unmet sometimes or often. The most reported reasons for unmet care needs were lack of available appointments with a neurologist (20%), cancellation of non-essential medical services and community resources (16.8%), limitations of remote assessments (14.8%), and decreased communication between patient and physician/clinic (7.4%).

## Factors associated with negative healthcare experiences during the COVID-19 pandemic

We pursued these analyses for the following outcomes of interest: *Unmet care needs* and *dissatisfaction with care*. PwP were more likely to report *Unmet care needs during the pandemic*, if they lacked confidence in accessing services remotely (OR 2.71, 95% CI 1.36–5.41), were dissatisfied with pre-pandemic care (OR 3.17, 95% CI 1.23–8.18), experienced communication challenges (OR 3.38, 95% CI 1.25–9.14), and had difficulty in obtaining pre-pandemic care (OR 5.20, 95% CI 2.59–10.46). In addition, PwP were more likely to report *dissatisfaction with care* if they reported barriers to services (OR 3.28, 95% CI 1.35–8.02), lacked confidence in being able to access services remotely (OR 3.36, 95% CI 1.35–8.40), had difficulty in obtaining care during the COVID-19 pandemic (OR 5.58, 95% CI 1.97–15.79), or were dissatisfied with care pre-pandemic (OR 6.09, 95% CI 2.23–16.66). The stage of Parkinson's disease was not found to be significant in any of the models. (Table 3 for results of multivariate logistic regression models).

Suggestions for care improvement from PwP

PwP suggested improving accessibility of PD-related care during the COVID-19 pandemic broadly grouped into three areas: i. healthcare system and clinic services, ii. virtual care, and iii. education/communication. For healthcare system and clinic services, suggestions included providing home visits by someone knowledgeable in PD and increasing the frequency of follow-up visits. Suggestions for improving virtual care included focusing on video conferencing to the detriment of telephone modalities, providing resources to improve technological literacy, and increasing the virtual provision of non-medical services such as exercise classes and support groups. Education and communication suggestions included increasing knowledge of available resources (e.g., Parkinson Canada) and timely communication between the care team and patient.

Discussion

This study uniquely portrays how the COVID-19 pandemic changed healthcare experiences for PwP in Canada. Overall, we found that experiences with care significantly deteriorated during the COVID-19 pandemic for PwP. Participants were less satisfied and had greater difficulty obtaining healthcare compared to the pre-COVID-19 pandemic. Those with barriers to accessing care pre-COVID-19 pandemic and/or difficulty obtaining pre-pandemic carte were more likely to experience dissatisfaction, increased difficulty obtaining healthcare, and unmet care needs during the COVID-19 pandemic. Thus, focusing on reducing barriers to accessing care will be important moving forward in a post-COVID-19 pandemic era. The most cited barriers to accessing care were difficulty getting an appointment, increased wait times between referral and appointment, and difficulty in getting a referral. Prolonged wait times are an unfortunate reality of
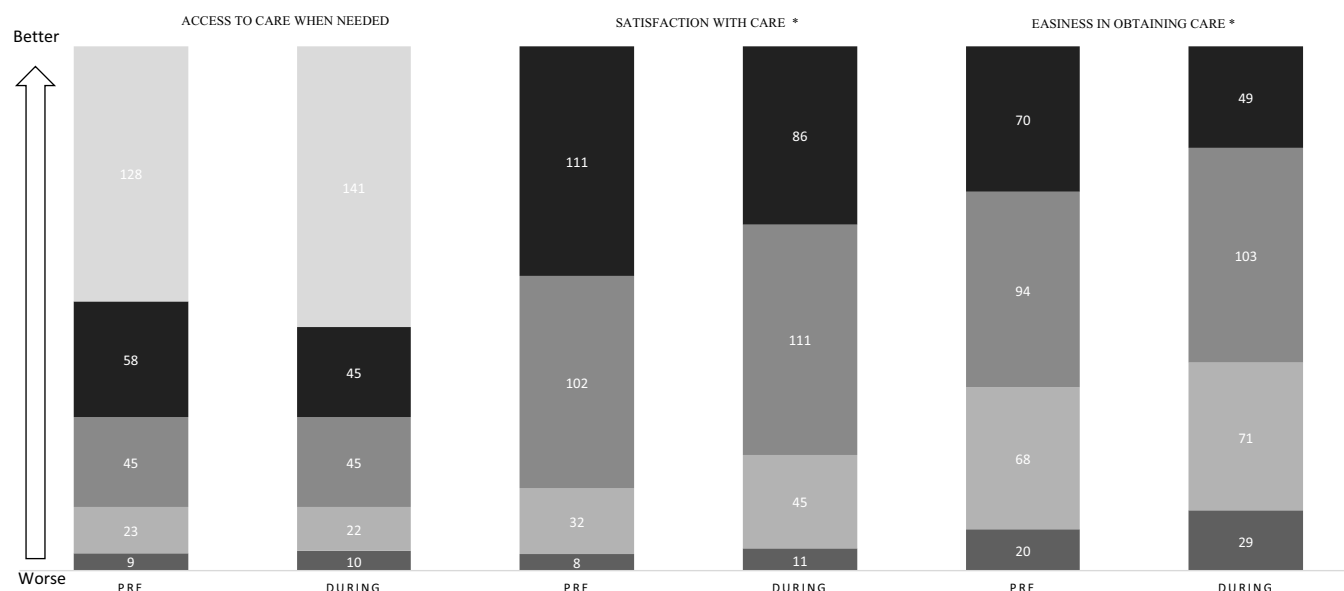
Figure 1: Changes in healthcare experiences for PwP during the COVID-19 pandemic. * statistically significant differences pre- and during COVID-19 pandemic. Ease of obtaining care = p < 0.01, satisfaction with care, p < 0.005. Wilcoxon signed-rank test. Response options: satisfaction with care and ease of obtaining care – Likert-like scale with four categories, 1 being very dissatisfied / very difficult and 4 being very satisfied / very easy, access to care when needed – Likert-like scale with five categories, 1 never and 5 being always. Absolute values for responses are provided.

the Canadian healthcare system.[13] Strategies to enhance well-being during prolonged wait times have been studied in migraine, and an educational intervention was shown to be associated with less migraine associate disability, decreased emergency department visits, and reduced medication and narcotic overuse.[14] Thus, focusing on patient education in PD may be helpful moving forward as patients wait for their specialist appointments, which was suggested in our study, with participants recommending easier access to available educational resources (e.g., Parkinson Canada). Additionally, increased education on PD for primary care providers (PCPs) might increase the ease of referral to a movement disorders specialist or general neurologist and optimize the initiation of initial management strategies by PCPs.

Data from other countries looking at healthcare experiences of PwP during the COVID-19 pandemic have found disruptions of care, worsening of PD symptoms, and/or reduced quality of life.[7,15,16] Survey data from 9762 participants, including 5429 PwP in the United States, demonstrated that, for all comers, 62% had experienced disruption in healthcare, including cancelled appointments, reduced in-home care, or difficulty obtaining medications during the pandemic.[7] Compared to our study, their data showed an effect of demographic factors: race and lower income were independently associated with difficulty obtaining PD medications.[7] Thirty-five per cent of PwP had at least one daily activity disrupted, which was more common in those living alone. Additionally, 21% had cancelled exercise classes, and 57% had cancelled social activities; PwP with lower income were less likely to report alternative means of exercise or social activities, and older PWP were less likely to use alternative ways to exercise.[7] Further investigations into the effect of these demographic factors on other measures of healthcare experiences during the COVID-19 pandemic in the Canadian population are needed.

The use of virtual care in the management of Parkinson's disease is promising. The beneficial role of virtual care in increasing access to care for PwP residing in British Columbia has been recognized in a patient survey, namely for accessing mental health resources.[17] In addition, it was found that an interest in virtual care utilization correlated with perceived barriers such as lack of community services and healthcare providers' insensitivity to PD-related issues.[18] Furthermore, it was shown that motivation to access specialty services would be increased if patients could access them from the comfort of their own homes.[18] Additionally, there has been increasing interest in virtual assessment of motor features of PD allowing for more frequency and accurate assessment of motor function, including use of wearable technology such as smart watches.[19] Finally, a recent meta-analysis has shown that with respect to PD severity, compared with usual care, telehealth intervention was beneficial in lowing motor impairment significantly.[20] Based on our data, most patients used virtual care during the COVID-19 pandemic, endorsing access to the required technology and technical support when needed. A focus on improving patient confidence in the remote assessment of a condition and its treatment will be important.[10] Additionally, addressing technological limitations (i.e., lack of high-speed internet), validating remote assessment of PD, and addressing privacy concerns should be a focus moving forward. An important factor to be mindful of is that while virtual care has been rapidly implemented to provide unique healthcare solutions to address the challenges with healthcare delivery during the COVID-19 pandemic, there may be unintended negative effects on health equity (19).[19] Poverty, lack of access to digital health, poor engagement with digital health for some communities, and barriers to digital health literacy are some factors which may have contributed to discrepancies in health outcomes during the COVID-19 pandemic[20] and will require further scrutiny in a post-COVID-19 era of increased uptake of digital health for care delivery. In keeping with this, survey data from the United States showed telemedicine were used by 39% of PwP during the COVID-19 pandemic; however, those with lower household income were less likely to attend appointments through virtual care.[7]

As a cross-sectional online survey, a few study limitations should be mentioned. First, participation in this online survey

Table 2: Use and perceptions of care during the COVID-19 pandemic (n = 298)

	% (n)*
Virtual care used pre-pandemic	
Yes	26.3 (78)
No	73.7 (219)
Virtual care used during pandemic	
Yes	69.9 (207)
No	30.1 (89)
Comfortable with communication technology used (n = 206 of 209)	85.9 (177)
Confidence in remote treatment	69.1 (192)
Confidence in remote assessment	58.4 (163)
Confidence in remote access	54.6 (147)
Ease of obtaining care	
Somewhat to very difficult	39.7 (100)
Somewhat to very easy	60.3 (152)
Unmet care during pandemic	
Never	53.6 (141)
Rarely	17.1 (45)
Sometimes	17.1 (45)
Often or always	12.2 (32)
Specified reasons for unmet care (n = 96)	
Lack of available appointments with neurologist	19.8 (19)
Cancellation of non-essential medical services and community resources	16.7 (16)
Limitations of remote assessments	14.6 (14)
Decreased communication between patient and physician/clinic	7.3 (7)
Challenges with contacting/booking services	4.2(4)
Lack of knowledge of how to access services	3.2(3)
Other**	34.3 (33)

*n for each variable may differ due to missing data.
**"Other" responses include progression of PD symptoms, perceived lack of knowledge of neurologist, lack of equipment at home to be able to participate in remote visits, isolation, physical distancing practices, neurologist time constraints during appointment.

Table 3: Factors associated with unmet care needs and dissatisfaction with care during the COVID-19 pandemic using multivariate logistic regression analyses

Variables	Unmet care needs OR (95% CI)	Dissatisfaction with care OR (95% CI)
Stage of Parkinson's disease[1]		
Stage 1–2	1.0	1.0
Stage 3–5	1.36 (0.64–2.90)	1.14 (0.45–2.85)
Barriers to services (pre-pandemic)		
No barriers		1.0
1 or more barriers		3.28 (1.35–8.02)
Satisfaction with care (pre-pandemic)		
Very to somewhat satisfied	1.0	1.0
Very to somewhat dissatisfied	3.17 (1.23–8.18)	6.09 (2.23–16.66)
Ease of obtaining care (pre-pandemic)		
Very to somewhat easy	1.0	
Very to somewhat difficult	5.20 (2.59–10.46)	
Communication challenges (pre-pandemic)		
No	1.0	
Yes	3.38 (1.25–9.14)	
Confidence in all services accessible remotely (during pandemic)		
Confident	1.0	1.0
Not confident	2.71 (1.36–5.41)	3.36 (1.35–8.40)
Ease of obtaining care (during pandemic)		
Very to somewhat easy		1.0
Very to somewhat difficult		5.58 (1.97–15.79)
Observations (n)[2]	237	228
Pseudo R² (Nagelkerke)	0.374	0.507

OR = odds ratio, 95% CI = 95% confidence interval.
[1]Hoehn M, Yahr D. Parkinsonism: Onset, progression, and mortality. *Neurology*. 17:427. 1967.
[2]Observations (n) vary from total study sample of n = 298 due to participants who reported not seeking care during the COVID-19 pandemic and missing data for the variables involved.

required that PwP or their caregivers had access to and a reasonable understanding of the internet, which is more common in younger populations. We suspect that individuals with later-stage PD (and thus those later in the disease course) have greater accrued disability which may limit access to the Internet and thus knowledge of and participation in our survey. For this reason, our sample is likely skewed towards younger and less advanced stage PwP compared to the Canadian PwP population, consistent with our collected demographic data indicating that the majority of participants were in early stages of PD.[21,22] This limits the applicability of our findings to PwP who have more advanced disease. Second, although recruitment was conducted through Parkinson's Canada, a national organization which provided excellent access to its membership, membership and involvement are likely not equally strong in all regions. This is reflected in the regional distribution of the sample with a greater representation of the provinces of Ontario and Quebec. Finally, we had less representation from non-Caucasian populations.

Conclusion

Our results suggest that healthcare experiences for PwP significantly changed during the COVID-19 pandemic. Access to healthcare was more difficult, and satisfaction with PD-related healthcare decreased during the COVID-19 pandemic in Canada, despite virtual care measures implemented nationwide. We identified factors associated with worse care experiences, namely unmet care needs and decreased satisfaction with healthcare during the COVID-19 pandemic. In addition, while there is higher access to the technology required for virtual care, there is less confidence in the effectiveness of remote clinical assessment. Overall, our findings and patient-centred suggestions on improving care experience in Canada for PwP may inform policy and practice changes in a post-COVID-19 era, as digital health and virtual care are expected to be further explored.

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