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# The Impact of the COVID-19 Pandemic on Care Partners of People with Parkinson's Disease

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**Abstract:** Background: Since the onset of the coronavirus disease 2019 pandemic, the caregiving routine for care partners of people with Parkinson's disease (PwPD) changed substantially.

Objectives: To understand the nature and severity of burden in care partners of PwPD during the ongoing pandemic. We also sought to describe care partners' perceived change in burden and factors associated with increased burden.

Methods: Cross-sectional online questionnaire-based study among care partners of PwPD, registered in the Fox Insight study. The questionnaire consisted of the Modified Caregiver Strain Index, whether an aspect of strain had changed over the course of the pandemic and additional pandemic-specific infection and lifestyle-related items.

Results: Two hundred seventy-three non-paid primary care partners responded to the questionnaire, 73% female with a median age at enrollment of 64 years, 56% reporting a household income greater than 75,000 USD per year, and 61% retired. An increase in burden compared to before the pandemic was prevalent, ranging from 33% to 63% for individual items. Emotional strain increased most frequently (63%). Decreases in burden were uncommon; work adjustments (7%) and time demands (6%) decreased most frequently. PD-related factors and care partner roles in personal care of the PwPD were the factors that were associated with strain in multivariable analysis, whereas social and pandemic-related factors were not.

Conclusion: In this affluent and mostly retired cohort, increases in emotional strain during the pandemic were prevalent. Despite this, caregiving roles in personal care and severity of symptoms in the PwPD were more strongly associated with strain than social and pandemic-related factors.

Care partners are of immense importance for people with Parkinson's disease (PwPD).<sup>1</sup> Since the onset of the coronavirus disease 2019 (COVID-19) pandemic, the caregiving routine for many care partners of PwPD has changed substantially.<sup>2</sup> The pandemic has directly disrupted healthcare provision. Because of pandemic restrictions, medical appointments are less frequent or canceled, switched to online or telephone format, all to reduce possible COVID-19 exposure.<sup>3</sup> Albeit a valid alternative given

the pandemic-imposed limitations, patients experienced limitations using telemedicine<sup>4</sup> and interest to pursue telemedicine varies, including among PwPD.<sup>5</sup> Additional measures to reduce exposure might prevent paid care partners to assist or non-paid care partners to visit the PwPD. Discontinuation of such services or assistance has increased the demand of help by care partners and family members.<sup>3</sup> Furthermore, non-medical care activities (eg, exercise programs) outside the home have been curtailed.<sup>6</sup>

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**Keywords:** Parkinson's disease, care partner, caregiver, burden, Covid-19. Relevant disclosures and conflict of interest are listed at the end of this article.

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In contrast, the pandemic and related measures may have created a surplus in time available for interpersonal relations and increased communication through online platforms or telephone with more distant family and friends. In all cases, PwPD and their care partners have had to adapt to changing circumstances.

Improving our understanding of the effects of the COVID-19 pandemic on care partner burden in Parkinson's disease (PD) presents a unique opportunity to identify factors that adversely impact care partners. A recent study reported on the negative impacts of the COVID-19 pandemic on both PwPD and their care partners, with both mental and physical health-related quality of life being significantly lower than national standards. However, they did not report burden or factors that influenced care partner burden.<sup>7</sup> A telephone interview study found heightened levels of stress for care partners to be related to non-motor symptoms in the PwPD, particularly anxiety.<sup>8</sup>

In the general population, the pandemic has been associated with increased levels of psychological distress<sup>9,10</sup> and these times of crisis may have an additional effect on burden while caregiving. A study in dementia informed us that the COVID-19 pandemic has changed care partner needs; they identified a lack of consultation with a specialist, a lack of access to medicine and care partners needed help engaging the person with dementia at home.<sup>11</sup>

Previous studies have identified factors influencing PD care partner burden before the global crisis. They concluded among others that greater care partner burden was associated with lower patient quality of life, longer disease duration, and higher degrees of disease severity and subsequently, higher care partner burden was associated with higher utilization of social and mental health services.<sup>12,13</sup> Lack of information on the current caregiving landscape in PD hampers our ability to support care partners effectively.

Therefore, we explored the aspects and severity of burden in care partners of PwPD during the ongoing pandemic. We sought to describe care partners' perceived change in burden and factors associated with increased care partner burden. These factors were categorized by PwPD-related, care partner related, and pandemic related factors.

## Method

### Study Design

We conducted a cross sectional, online, questionnaire-based study among care partners of PwPD, registered in the Fox Insight study.<sup>14</sup> Sponsored by The Michael J. Fox Foundation, the Fox Insight study gathers longitudinal data from PwPD as well as people without through online questionnaires. Additional one-time surveys are added periodically to address new research questions. Fox Insight participants were invited to complete a questionnaire concerning COVID-19 pandemic-related experiences (COVID-19 questionnaire) starting June 23, 2021. The questionnaire included a section specifically for primary, unpaid caregivers of PwPD. We limited analyses to COVID-19

questionnaires completed between June 23, 2021 and September 23, 2021. Data used in preparation of this manuscript were downloaded from the Fox Insight database on October 24, 2021. All survey questions and data are made available to investigators through registration at <https://foxden.michaeljfox.org>.<sup>15</sup> For up-to-date information on the study, visit <https://foxinsight-info.michaeljfox.org/insight/explore/insight.jsp>. For purposes of this analysis, self-identified care partners were excluded from the COVID-19 questionnaire if they reported a diagnosis of PD or endorsed being paid for their caregiving.

The Fox Insight study and the COVID-19 questionnaire were approved by New England Institutional Review Board (IRB) and informed consent was obtained online from all participants. Approval of the use of Fox Insight data for the analyses reported here was obtained by the ethics board of the University Health Network, Toronto, Canada.

### Care Partner COVID-19 Questionnaire

Our research group, composed of clinicians (experienced in PD), epidemiologists, social workers, and a care partner in PD, developed the questionnaire based on personal knowledge and experience. Burden was assessed cross-sectionally through a one-time survey using the Modified Caregiver Strain Index (MCSI), a validated 13 item index spanning multiple domains.<sup>16</sup> The total score ranges from 0 to 26, with higher total scores representing a higher degree of burden. There are no established cutoff scores for elevated burden. In addition to the original index, if the participant indicated an item as contributing to their burden, they were subsequently asked whether this specific aspect had (1) increased, (2) decreased, or (3) stayed the same compared to before the COVID-19 pandemic. Additional items were formulated through group discussion and addressed disruption in daily needs and services, social isolation, concern over their own (care partner) health, and the health of the person with PD and reduced help and care. We collected additional data on PwPD symptoms and care partner responsibilities. The questionnaire is provided in the Table S1.

### Analyses

Factors investigated for association with burden were categorized as PwPD or care recipient characteristics (years since diagnosis, symptoms in past month, and problems in past week), care partner characteristics (gender, age, race, yearly income, employment status, education level, and care partner responsibilities), and pandemic related factors (self-reported COVID-19 diagnosis, disruption in daily needs or services, factors contributing to care partner burden).

### Statistical Methods

Statistical analyses were performed using R-statistics (version 4.1.0). To assess the degree of respondent bias in our sample, baseline demographic values of the respondents to the COVID-19

survey are compared to the care partners in the total Fox Insight cohort (self-identified at time of registration, paid and non-paid) using Welch's *t* test and Fisher's exact test.

Univariable regression analyses with the total score of the MCSI being the dependent variable were used to investigate associations between MCSI score and PwPD-related factors, care partner related factors, and social support and pandemic related factors. Subsequently, a single multivariable negative binomial regression analysis including all variables was performed. The coefficients were converted into rate ratios. Spearman's correlation and the phi coefficient were used to assess concordance between categorical and dichotomous variables, respectively. Highly concordant variables (correlation coefficient >0.7) were considered for exclusion from the analysis.

To adjust for multiple testing in the univariable analysis, we used the Bonferroni correction: with 45 variables to be included, a significance cutoff value of  $\alpha = 0.001$  was used.

## Results

### Care Partner Characteristics

As of the October 24, 2021, 1234 individuals were enrolled in Fox Insight as self-identified care partners of PwPD (paid or unpaid; this attribute is not distinguished in the Fox Insight registration questionnaire). A total of 372 self-identified care partners responded to the COVID-19 questionnaire, of which 347 identified as non-paid care partners and 273 identified as non-paid primary care partners. Assuming a similar proportion of paid and unpaid care partners in the respondents and the total Fox Insight cohort, we estimate a response rate of 30%.

The study participants' average age at enrollment in the Fox Insight cohort was 64 years, with 73% being female and the vast majority being Caucasian (99%). A total of 56% of respondents had a yearly household income higher than 75,000 USD, a substantial proportion was retired (61%), and the respondents were highly educated with 47% having a master's degree or higher. Table 1 shows the characteristics of the participants in detail.

Compared to the total Fox Insight care partner cohort (paid and unpaid), study respondents were significantly older at enrollment, were more affluent, more highly educated individuals, and more were retired. This comparison was not ideal given that we included only unpaid care partners in the current study, however, we could not distinguish paid and unpaid care partners in the total cohort. Additional comparisons to the total Fox Insight care partner cohort are displayed in Table S1.

### Care Partner Experiences

Difficulties encountered during the pandemic by the care partner are portrayed in Table 2. Fifteen participants (5.5%) reported a COVID-19 diagnosis. One person was admitted to hospital because of COVID-19, and subsequently, the intensive care unit. Few participants experienced problems getting food (6%) or household essentials (26%), but in contrast, the items social

**TABLE 1** Sociodemographic characteristics of care partners in COVID-19 questionnaire cohort

	Study cohort (n = 273)
Female gender, No. (%)	199 (72.9)
Age at enrollment mean, (SD)	63.8 (9.7)
Race, No. (%)	
American Indian/Alaska native	2 (0.7)
Asian	3 (1.1)
African American	1 (0.4)
Native Pacific Islander	1 (0.4)
Caucasian	280 (98.9)
Prefer not to answer	0 (0.0)
Yearly household income, No. (%)	
<20,000 USD	9 (3.3)
20,000 to 34,999 USD	11 (4.0)
35,000 to 49,999 USD	24 (8.8)
50,000 to 74,999 USD	41 (15.0)
75,000 to 99,999 USD	34 (12.5)
>100,000 USD	118 (43.2)
Prefer not to answer	36 (13.2)
Employment status, No. (%)	
Employed, full-time	59 (21.6)
Employed, part-time	32 (11.7)
Retired	167 (61.2)
Unemployed	13 (4.8)
Prefer not to answer	2 (0.7)
Highest completed education level, No. (%)	
Less than a high school degree	3 (1.1)
High school degree	10 (3.7)
Some college (1–4 years, no degree)	31 (11.4)
Associate's degree or higher <sup>a</sup>	229 (83.9)
Prefer not to answer	1 (0.4)

<sup>a</sup>Category includes Associate's, Bachelor's, Master's, Professional school, and Doctorate degree.

Abbreviations: COVID-19, coronavirus disease 2019; SD, standard deviation.

isolation (61%) and not being able to do things that give joy (61%) were prevalent.

A substantial proportion of care recipients (PwPD) were reported by the care partner to have cognitive difficulties (58%), anxiety (46%), or a depressed mood (41%) in the past month. In addition, problems with standing up from a bed or chair (54%), moving slowly or in need of personal care (45%), and constipation (42%), encountered in the past week were prevalent among

**TABLE 2** Pandemic related problems as reported by care partners

	Study cohort n = 273
Infection with SARS-CoV2, No. (%)	15 (5.5)
If yes, admission to hospital, No. (%)	1 (6.6)
Disruption in daily needs or services, No. (%)	
Problems getting food	16 (5.9)
Problems getting household essentials	70 (25.6)
Problems getting help with usual housekeeping	25 (9.2)
Problems getting help with personal care assistance	6 (2.2)
Factors contributing to care partner burden, No. (%)	
Social isolation	167 (61.2)
Difficulty accomplishing tasks of daily life outside the home	79 (28.9)
Concern over own health	110 (40.3)
Decline in health of person with PD	133 (48.7)
Reduced access to healthcare services	76 (27.8)
Reduced help from paid care partners	19 (7.0)
Reduced help from family and friends	52 (19.0)
Not being able to do the things that give joy	166 (60.8)
The pandemic did not contribute to my burden	45 (16.5)

Abbreviation: PD, Parkinson's disease.

care recipients. In Table 3, an overview is given of the symptoms experienced by the PwPD.

## Burden and Change during the Pandemic

The median total score of the MCSI was eight of a maximum possible score of 26 (interquartile range, 4–14). Figure 1 shows the distribution of MCSI scores. The issues most frequently perceived to be difficult were a change from the care recipient's former self (36%) and sleep disturbance (27%), whereas financial strain (7%), work adjustments (12%), and caregiving being inconvenient (12%) were selected least frequently. An increase in burden compared to before the pandemic was prevalent, ranging from 33%–63% for individual items (Fig. 2). The items that increased most frequently over the course of the pandemic were emotional strain (63%), confinement (50%), and upsetting behavior on the part of the care recipient (50%). The items that increased least frequently were financial strain (33%), family

**TABLE 3** Person with PD (care recipient) characteristics, symptoms, and problems as reported by care partner

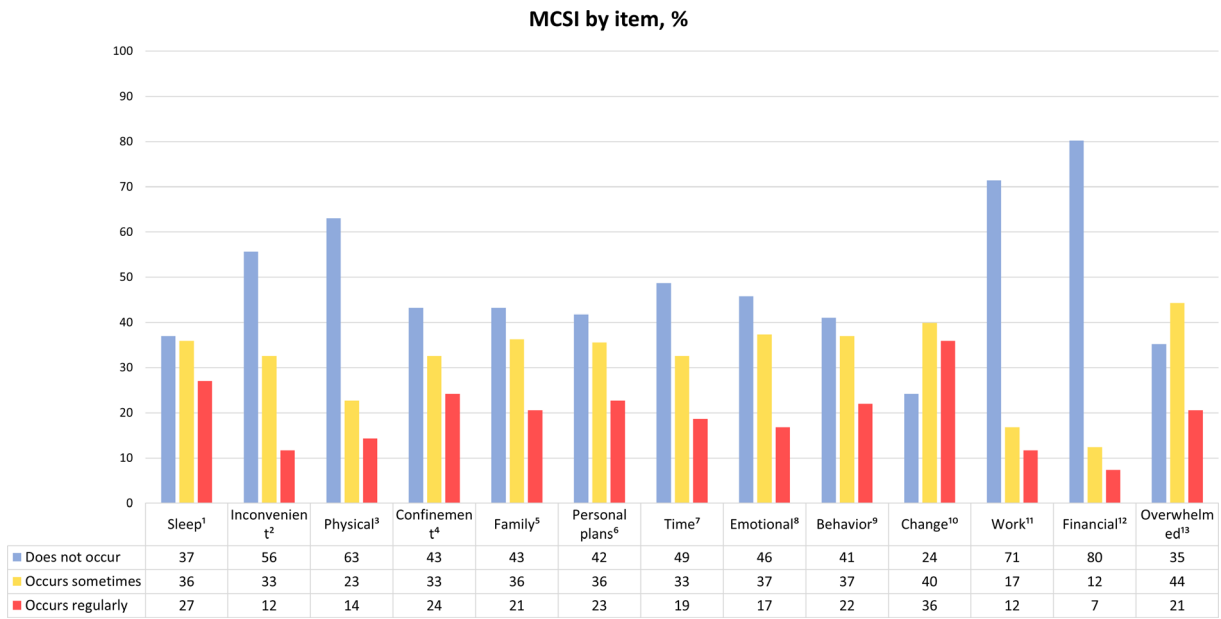
	Study cohort n = 273
Years since diagnosis median (IQ range)	8 (5.0–12.0)
Symptoms in past month, No. (%)	
Falls	103 (37.7)
Depressed mood	113 (41.4)
Anxious mood	126 (46.2)
Apathy or a loss of motivation	112 (41.0)
Difficulty with memory or thinking	157 (57.5)
Hallucinations/psychosis	46 (16.8)
None of the above	52 (19.0)
Problems in past week, No. (%)	
Difficulty swallowing	79 (28.9)
Difficulty handling food and utensils	68 (24.9)
In need of aid during dressing	91 (33.3)
Moving slowly or in need of aid during personal care	124 (45.4)
Difficulty standing up from bed or chair	147 (53.8)
Suffering from diminished control of urine	102 (37.4)
Suffering from constipation	89 (42.4)
None of the above	45 (16.5)

Abbreviations: PD, Parkinson's disease; IQ range, interquartile range.

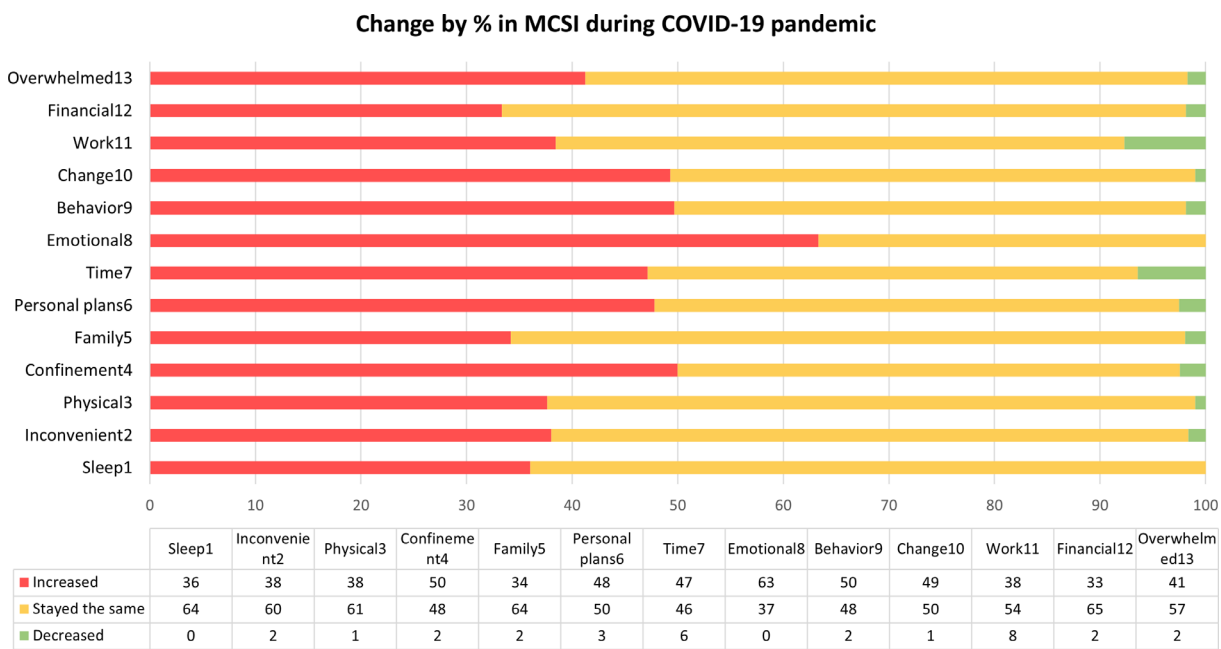
adjustments (34%), and sleep disturbances (36%). Few issues decreased during the pandemic (Fig. 2).

## Factors Associated with Care Partner Burden

No variables were excluded from regression analyses on the basis of high concordance with other variables. Table 4 shows the relationship between PD-related symptoms and functional difficulties and the MCSI. All PD-related factors investigated, except for constipation, remained significantly associated with total MCSI score in univariable analysis after correcting for multiple testing. In multivariable analysis, the following PD-related factors remained significantly associated with care partner burden, independent of other variables: depressed mood, difficulty with thinking or memory, trouble standing up from car seat or bed, and trouble with control over urine, with a rate ratio of 1.2 for each factor.



**FIG. 1.** Modified Caregiver Strain Index (MCSI) scores by individual item. Items in the MCSI. 1. My sleep is disturbed; 2. Caregiving is inconvenient; Caregiving is a physical strain; 4. Caregiving is confining; 5. There have been family adjustments; 6. There have been changes in my personal plans; 7. There have been other demands on my time; 8. There have been emotional adjustments; 9. Some behavior is upsetting; 10. It is upsetting to find the person I care for has changed so much from his/her former self; 11. There have been work adjustments; 12. Caregiving is a financial strain; 13. I feel completely overwhelmed.



**FIG. 2.** Change in Modified Caregiver Strain Index (MCSI) scores per individual item. Items in the MCSI. 1. My sleep is disturbed; 2. Caregiving is inconvenient; 3. Caregiving is a physical strain; 4. Caregiving is confining; 5. There have been family adjustments; 6. There have been changes in my personal plans; 7. There have been other demands on my time; 8. There have been emotional adjustments; 9. Some behavior is upsetting; 10. It is upsetting to find the person I care for has changed so much from his/her former self; 11. There have been work adjustments; 12. Caregiving is a financial strain; 13. I feel completely overwhelmed.

**TABLE 4** Rate ratios for MCSI score and PD-related factors as reported by care partner

	Univariable analysis	Multivariable analysis
Years since diagnosis	1.0**	1
Symptoms occurring in past month		
Occurrence of falls	1.5*	1
Depressed mood	1.7*	1.2*
Anxious mood	1.7*	1.2
Apathy	1.7*	1.1
Difficulty with thinking/memory	2.0*	1.2***
Hallucinations	2.1*	1.2
Problems encountered in past week		
Difficulty swallowing	1.5*	1
Using utensils	2.0*	1.1
Needs help dressing	2.0*	0.9
Slow moving or needs help with personal care	2.0*	1.1
Trouble standing up	2.1*	1.2***
Trouble controlling urine	2.0*	1.2***
Experiencing constipation	1.3	0.9

Note: Presented are rate ratios for each item indicating a multiplication factor in total MCSI score for the item present vs. not present.

\*P value of <0.0001.

\*\*P value of <0.0005.

\*\*\*P value of <0.05.

Abbreviations: MCSI, Modified Caregiver Strain Index; PD, Parkinson's disease.

Relations between care partner related factors (ie, demographics and regular responsibilities in their care partner role) and MCSI are shown in Table 5. In univariate analysis, assisting with personal care, feeding, and mobility assistance were significantly associated with increased burden. Assisting in personal care was the only significant care partner related factor that remained significant in the multivariable analysis, with a rate ratio of 1.5.

In Table 6, the rate ratios of social support and pandemic-related factors are presented. Household finances and disruption in services were not significantly associated with higher burden, however, most psychological, disruption in care, and severe acute respiratory syndrome coronavirus 2 (SARS-CoV2) health (not including SARS-CoV2 infection) related factors were associated with higher burden in univariate analysis. In multivariate analysis, no social or pandemic related factors were significantly associated with higher burden.

**TABLE 5** Rate ratios for MCSI scores and care partner related factors

	Univariable analysis	Multivariable analysis
Demographics		
Gender <sup>a</sup>	1.0	1.1
Age	1.0	1.0
Low income <sup>b</sup>	1.4	1.0
Region of residence <sup>c</sup>	1.1	1.0
Responsibilities as a care partner		
Assisting with personal care	2.2*	1.5**
Feeding	2.1*	1.2
Mobility assistance	1.8*	1.0

Note: Presented are rate ratios indicating a multiplication factor in total MCSI score for the item present vs. not present.

<sup>a</sup>Female compared to male;

<sup>b</sup>Defined: below 20,000 USD/year;

<sup>c</sup>Urban regions compared to rural regions.

\*P value of <0.0001.

\*\*P value of <0.05.

Abbreviations: MCSI, Modified Caregiver Strain Index.

## Discussion

This study demonstrates a substantial proportion of care partners describing increases in burden during the pandemic, and emphasizes the need to look out for care partners at risk of experiencing higher burden. As assessed through the MCSI, the items being most frequently perceived to be difficult were change in personality of the PwPD and sleep impairment. A change in personality is a well-known feature of PD.<sup>17</sup> These findings raise the question whether the pandemic and its implications influence this change in personality, possibly through home confinement and less social interaction. Our results support this, in that almost half of care partners felt that difficulties related to changes in personality had increased over the course of the pandemic. Regarding sleep, the COVID-19 pandemic has been found to be associated with new onset or worsening of sleep disturbances in PwPD,<sup>18</sup> which can equally disturb the sleep of the care partner. This aligns with our results in which over a third of care partners reported more sleep disturbance over the course of the pandemic. Particular attention to these issues in routine clinical care could be helpful to both the care partner and the PwPD.<sup>19</sup>

Of all 13 original items of the MCSI, emotional adjustments were the most frequently increased item over the course of the pandemic. This result highlights the importance of direct inquiry regarding the care partner's emotional health, and particularly in these challenging times. Financial strain showed the least increase in burden, which might be explained by the relatively high income of the cohort.

**TABLE 6** Rate ratios for MCSI scores, social support and pandemic related factors

	Univariable analysis	Multivariable analysis
Health and SARS-CoV2		
Infection with SARS-CoV2	1.0	1.1
Concern over own health	1.6*	1.1
Decline in health of person with PD	1.9*	1.2
Disruption in care		
Inability to attend PD support group	1.2	1.0
Reduced access to health care services	1.6*	1.1
Reduced help from paid care partners	1.8**	1.1
Reduced help from family and friends	1.9*	1.1
Psychological		
Social isolation	1.6*	1.0
Not being able to do the things that give joy	1.6*	1.1
Pandemic did not contribute to burden	0.5*	0.9
Disruption in services		
Problems getting food	1.4	0.8
Problems getting household essentials	1.3	1.0
Help with usual homecare	1.3	1.3
Help with usual personal care	1.9	0.9
No issue	0.8	–
Household finances affected***		
Income declined	1.3	–
Savings/retirement declined	1.5	–
Difficulty paying rent	1.9	–
Difficulty paying other bills	1.8	–
Other	1.3	–
No issue	1.7	–

Note: Presented are rate ratios indicating a multiplication factor in total MCSI score for the item present vs. not present.

\*P value of <0.0001.

\*\*P value of 0.0009.

\*\*\*Not included in multivariable analysis because of ambiguous results—both declining income and lack of any income issues associated with a point estimate suggesting association with increased burden.

Abbreviations: MCSI, Modified Caregiver Strain Index; SARS-CoV2, severe acute respiratory syndrome coronavirus 2; PD, Parkinson's disease.

We found that cognitive, emotional, and physical manifestations of PD are all independent sources of burden for care partners in the multivariable analysis. This finding is consistent with prior research,<sup>20</sup> including a multi-center study of 2476 care partners of PwPD reporting that disease severity, a higher frequency of falls, lower performance on cognitive test, and antidepressant use were associated with higher care partner burden.<sup>13</sup> A previous systematic review noted that non-motor symptoms tend to outweigh motor symptoms as contributors to burden when examined concurrently.<sup>20</sup> In our results, the magnitude of associations were similar across the two domains. Other studies have found psychosis to be associated with care partner burden,<sup>21</sup> yet this did not remain significant when adjusting for other factors in our analyses. It is possible that this is because of low power, being one of the most infrequently reported symptoms in our cohort (in 17% of care recipients). Specifically with respect to the COVID-19 pandemic, one study investigating associations between care partner burden and pre-lockdown patient characteristics concluded that among other factors, disease severity, attention and memory deficits, and depressive symptoms were significantly associated with higher care partner burden during the pandemic.<sup>22</sup>

The only care partner related factor significantly associated with care partner burden in the multivariable analysis was a role in assisting with personal care. It is interesting in this context that neither reduced help from paid care partners and family and friends nor social isolation were significantly associated with burden when adjusting for other factors. This suggests that another aspect of assisting with personal care, besides the often perceived lonesome role in this, specifically increases burden for care partners.

No care partner socio-demographic characteristic (age, gender, income, and region of residence) was significantly associated with care partner burden. Conflicting results were found previously, with female gender inconsistently being associated with greater burden.<sup>20,23,24</sup> Contrary to our study, low income was previously found to be associated with higher burden.<sup>20</sup> Our study is underpowered to evaluate this because only nine respondents (3%) would be considered to have low income by US standards.

Finally, we investigated pandemic related factors. Although some associations were found in univariate analysis, when adjusting for other factors, no pandemic related factors remained significantly associated with higher burden. This might suggest an adequate adaptation of the care partner and surrounding care system to the ongoing pandemic. The generalizability of this finding to a less affluent population would need to be explored. In addition, the fact that a substantial proportion of care partners reported an increase in burden over the course of the pandemic suggests that the main factors driving these increases remain to be uncovered and deserve further study.

Our study identifies care partners taking care of people with PD experiencing selected symptoms (including a depressed mood, cognitive impairment, trouble standing up, and trouble with control over urine) as well as care partners having responsibilities in aiding in personal care as being particularly at risk. Although exploratory in nature, one goal of this study was to



identify modifiable factors associated with higher burden. From this perspective, screening for these symptoms and having a low threshold for treatment would likely help reduce care partner burden. A recent study in PwPD concluded that reduced access to physical therapy and medication are important themes for the patients themselves during the pandemic.<sup>25</sup> Lack of access to therapists and specialists may compromise symptom control in PD, which according to our results would magnify care partner burden. One study using a self-help workbook, aimed at addressing depression in the PwPD and based on cognitive behavioral therapy, showed improvement in both depressive symptoms as well as care partner burden and may overcome challenges accessing health care providers.<sup>26</sup> Multi-pronged approaches may be most effective; another study found that multi-component interventions (ie, both educating about coping strategies and providing emotional support) were particularly effective at reducing burden in care partners for persons with dementia.<sup>27</sup> Explicitly inquiring about needs is an approach to understanding ways to modify burden; a study in dementia identified greater access to consultation with a specialist and medicines as care partner needs during the pandemic.<sup>12</sup> This is congruent with our findings of the relevance of symptom burden in the PwPD to care partner burden. Further research on care partner needs in PD during the COVID-19 pandemic should be conducted.

Although disruption of services and material needs seem to be relatively uncommon in our cohort, negative social effects (eg, social isolation) are prevalent and on multiple fronts. A qualitative study conducted before the pandemic showed the effectiveness of online-based support groups in spousal care partners experiencing isolation based on geographical distance, enabling care partners to attend social activities they would otherwise not be able to physically attend.<sup>28</sup> Creative solutions, such as virtual memory cafes (virtual social engagement with peers) for people with dementia and their care partners<sup>29</sup> have been developed and the results of our study suggest that they may also be relevant in PD. Additionally, modern solutions through the use of personal phone devices (and more advanced, VR-devices) are ways to facilitate rehabilitation and therapy at a distance for PwPD struggling with physical mobility, speech impairment, and cognitive problems.<sup>30</sup>

In times of uncertainty, opportunities are provided to learn new mechanisms and interactions. Aside from all negative aspects of this pandemic to learn from, there are certain positive developments we should consider implementing in our usual care system. Reductions in burden related to reduced demands on time and reduced need to make adjustments in work because of caregiving, albeit reported by a minority of our participants, indicate the value of these aspects to some care partners. Ideally, time-saving solutions for care partners of PwPD could be considered as a coping strategy beyond the pandemic.

This study does come with limitations. First, using an online platform, there is selection bias in care partners who are both familiar with and have access to technology. It seems reasonable that during a confining global pandemic modern technological solutions will mitigate some challenges and therefore, it is

possible that the findings underestimate the overall increase in burden in the general population, being less technologically savvy. Furthermore, the study cohort was remarkably well-educated, has a substantial proportion of people with a high income, and the majority is retired. All of these attributes will increase access to resources that may help with coping and/or reduce the stressors related to life during the pandemic in general and limit the generalizability of these results. For instance, time-saving solutions like hiring household help may very well not be possible for many less affluent care partners, and work and time constraints may be greater in a cohort with less retired care partners. Given this, it is noteworthy that despite this selection bias a substantial proportion of care partners reported increased strain during the pandemic in multiple domains. Such changes are likely even more prevalent in less advantaged populations. Second, Fox Insight participants are self-identified care partners of PwPD, with no confirmation of diagnosis by the research team. However, a validation study of self-reported diagnosis compared to an expert diagnosis determined through a telemedicine evaluation found a 95% concordance for diagnosis (or not) of PD in Fox Insight. Although not directly validating the care partner's report of diagnosis in the care recipient, it suggests a likely high accuracy.<sup>31</sup> Third, the MCSI does not provide benchmarks of burden (ie, low, mild, and high), making it difficult to interpret without a comparison group. Fourth, because of the design of the questionnaire, it is possible that we underestimated instances of improvement in burden related to the pandemic. Individuals reporting that a specific burden did not occur did not have the opportunity to report if it had improved relative to before the pandemic. This source of bias could be hypothesized for burdens such as "a demand on time" or "work adjustments to free up time for caregiving." Similarly, the questionnaire contained an extensive battery of questions regarding the negative consequences of both the pandemic, as well as caregiving in general. It would be interesting to also explore potential positive effects, such as developing a more intimate bond as the result of more spare time. Interestingly, a recent study suggested a reduction of apathy in PwPD during the pandemic compared to before, possibly explained by the increased time at hand by the care partner.<sup>32</sup>

In conclusion, our findings provide direction for investigating the effects of interventions to alleviate care partner burden. Hopefully these findings can aid in alleviating burden for care partners encountered during and beyond these stressful times.

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## Author Roles

(1) Research project: A. Conception, B. Organization, C. Execution; (2) Statistical Analysis: A. Design, B. Execution, C. Review and Critique; (3) Manuscript Preparation: A. Writing of the First Draft, B. Review and Critique.

D. H. B. S.: 1B, 1C, 2A, 2B, 3A, 3B.

M.J.H.: 1A, 1B, 1C, 2A, 2C, 3A, 3B.

E.B.: 1A, 2A, 2C, 3B.

N.D.: 1A, 2A, 2C, 3B.

M.K.: 1A, 2A, 2B, 2C, 3B.

C.M.T.: 1A, 2C, 3B.

C.M.: 1A, 1B, 1C, 2A, 2B, 2C, 3A, 3B.

## Disclosures

**Ethical Compliance Statement:** The Fox Insight study and the COVID-19 questionnaire were approved by New England IRB and informed consent was obtained online from all participants. Approval of the use of Fox Insight data for the analyses reported here was obtained by the ethics board of the University Health Network, Toronto, Canada. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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## Supporting Information

Supporting information may be found in the online version of this article.

**Table S1.** Sociodemographic characteristics of care partners, total FI cohort compared to study cohort.