

## Commentary

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# Life with Parkinson's Disease During the COVID-19 Pandemic: The Pressure Is "OFF"

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**Abstract.** People with Parkinson's disease (PwP) have been suggested to be more vulnerable to negative psychological and psycho-social effects of the COVID-19 pandemic. Our aim was to assess the potential impact of the COVID-19 pandemic in PwP. A Danish/Swedish cohort of 67 PwP was analysed. Health-related quality of life (HRQL), depression, anxiety, apathy, sleep and motor symptom-scores were included in the analysis. Additionally, the Danish participants provided free-text descriptions of life during the pandemic. Overall, the participants reported significantly better HRQL during the COVID-19 period compared with before. Reduced social pressure may be part of the explanation. Despite worsened anxiety, night sleep improved.

At the end of 2019, the novel Corona Virus Disease 2019 (COVID-19) hit the world. The disease and countermeasures to slow down its spread have had a profound impact on the way people live, how they interact and many activities of daily living [1]. Thus, there are concerns that the COVID-19 pandemic has brought a shadow pandemic of psychological and societal injuries as well as physical complications [2]. People with Parkinson's disease (PwP) have, like other risk groups, been enforced to radically change everyday life in terms of normal routines, physical training and social interactions. These factors normally help PwP to counteract and cope with the

disease and to reduce stress [3, 4]. Because normal dopaminergic functioning is important for flexible adaption to new circumstances [5, 6], PwP may be more susceptible for negative psychological and psychosocial effects of the isolation and other restrictions due to the pandemic [7, 8].

In this study, we aimed to measure the potential impact of the COVID-19 pandemic on both motor and non-motor symptoms. We report from two cohorts of PwP (the WestPORT study [9] at Sahlgrenska University Hospital, Sweden, and a study-cohort at Zealand University Hospital, Denmark). Data were available from before the pandemic and were either collected specifically for the current purpose (Danish cohort) or as part of a planned longitudinal study. All participants who had provided ratings before and during the COVID-19 pandemic were included in the analysis ( $n=67$ ; median age=70 years (range:

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43–87 years), median duration of Parkinson's disease (PD) in years = 6 years (range: 3–21 years), 47.8% females). Although the restrictions and recommendations between the two countries may have differed, the authorities in both countries, advised chronically ill persons, including PwP, to stay isolated at home during the period April to June.

We selected five variables hypothesized to become negatively affected during the COVID-19 pandemic: health-related quality of life (HRQL), depression, apathy, anxiety and sleep. Therefore, we analysed patient ratings of PDQ8 (Parkinson's disease Questionnaire, ranging from 0 = highest HRQL to 32 = lowest HRQL) [10]. From the Swedish cohort, EQ-VAS (EuroQol visual analogue scale for general health status, 0 = worst possible and 100 = best imaginable), and relevant items of PRO-PD (Patient Reported Outcome in Parkinson's disease, each item score from 0 = no problem to 100 = most severe problem) [11]. From the Danish cohort, we used PDQ-39 (Parkinson's disease Questionnaire, ranging from 0 = Highest HRQL to 156 = Lowest HRQL) [12], BD I-II (Beck Depression Scale, ranging from 0 = no depression to 63 = most severe depression) [13] and LARS (Lille Apathy Rating Scale, ranging from -36 = no apathy to 36 = highest degree of apathy) [14]. To compare the longitudinal changes in HRQL in the two cohorts, PDQ-8 was extracted from PDQ-39 ratings of the Danish cohort. The Swedish study had also collected baseline data approximately 16

months before the pre-COVID survey and this information was used to describe historical symptom development in that cohort (Table 1).

In the Swedish cohort, change in motor symptoms from baseline, before and during COVID-19 were also objectively assessed using the Parkinson KinetiGraph™ (PKG) bradykinesia median score (BK50) [15]. Patient-rated motor symptoms were calculated using a total score of the PRO-PD items bradykinesia, gait and tremor [11] reported by the Swedish cohort.

The Danish participants were also asked to provide free-text descriptions on how the COVID-19 had influenced their everyday life. These descriptions originated from two questions:

1. *How does the COVID-19 situation influence your social activities and how do you experience this?*
2. *Have your usual routines/habits changed during the COVID-19 period, and how does this affect your everyday life?*

The descriptions were not included in a content analysis with the aim to derive themes [16], but to provide subjective illustrations of life with PD during the COVID-19 pandemic as an informal inspiration to a qualitative understanding of the scores.

The pooled mean (SD) PDQ8-scores from both cohorts improved from 10.6 (5.5) before to 7.9 (4.8) during the COVID-19 pandemic ( $p = 0.003$ ,  $n = 67$ ). Other results of the analysis are displayed in Table 1.

Table 1

Health-related quality of life, depression, apathy, anxiety and sleep in patients with Parkinson's disease before and during the COVID-19 pandemic. Low scores indicate less problem in all scales except EQ-VAS. NA, not applicable

Cohorts	Instrument	Baseline-data (April–August 2017) ( $n = 30$ ) Mean (SD)	Pre-COVID-19 (August–November 2018) Mean (SD)/ $p$ for difference compared to baseline scores	COVID-19 (April–June 2020) Mean (SD)/ $p$ for difference compared to the Pre-COVID- 19 scores
SE ( $n = 30$ for baseline scores and $n = 33$ for others)	HRQL, <b>PDQ8</b> (0–32)	8.6 (4.2)	10.4(5.7)/0.163	7.6 (4.8)/0.027*
	HRQL, <b>EQ-VAS</b> (0–100)	73.7 (8.6)	71.6(9.2)/0.247	75.9 (9.1)/0.086
	<b>PRO-PD</b> (0–100, low-better)			
	Depression	17.2 (15.3)	18.7 (16.2)/0.647	25.0 (16.6)/0.129
	Apathy	28.3 (22.8)	26.7 (22.5)/0.286	32.3 (23.6)/0.145
	Anxiety	10.5 (11.4)	12.4 (13.6)/0.089	22.6 (21.2)/0.035*
	Sleep	36.7 (27.6)	38.2 (30.7)/0.243	31.6 (24.8)/0.039*
DK ( $n = 34$ )	Total motor score (Gait, balance, tremor, 0– 300)	111.5 (60.2)	117.5 (57.8)/0.083	118.9 (52.9)/0.631
	<b>PKG</b> Bradykinesia score (BK50)	29.5(6.9)	30.6 (8.4)/0.686	31.7 (10.8)/0.676
	HRQL, <b>PDQ-39</b> (0–156)		29.6 (14.6)/NA	22.1 (9.8)/0.018*
	Depression, <b>BDI-II</b> (0–63)		9.7 (4.2)/NA	9.6 (5.3)/0.981
	Apathy, <b>LARS</b> (-36 to 36)		-15.8 (6.4)/NA	-13.2 (5.4)/0.346
	Anxiety, <b>BDI-II</b> (Item 16, 0–4)		0.9 (0.6)/NA	1.6 (0.9)/0.001*
	Sleep, <b>PDQ-39</b> (Item 21, 0–3)		1.7 (0.8)/NA	1.5 (0.7)/0.253

We used the Holm-Bonferroni test to adjust for the multiple comparisons within the questionnaires. The significant differences are marked with an asterisk.

Despite the expected impairment in PDQ8 over time in PwP, the participants reported significantly better HRQL during the peak COVID-19 in the spring 2020 compared with before the COVID-19 period (Table 1). The improvement in PDQ8 score exceeded 2 points, the minimal clinically important difference [17]. Further, in a similar time interval before the COVID-19 pandemic the PDQ8 from the Swedish cohort worsened by >2 points, suggesting that PDQ8 improved by >4 points during the pandemic compared to the expected outcome. The PDQ8-instrument may, however, have exaggerated improvement because the impact of two of the items assessed (“Had difficulty getting around in public places” and “Felt embarrassed by having PD”), may be reduced by self-isolation during the pandemic. However, the activity independent EQ-VAS also suggested improvement, although this did not reach significance. Also, the separate eight items in

the PDQ8 scale showed that there were significant improvements in “Problems with concentration” and “Difficulty getting around in public places”, whereas “Close relationships” and “Felt depressed”, worsened (Supplementary Table 1). Therefore, a possibly artificial positive effect of isolation due to not having to move in public places is balanced by a possibly artificial negative effect of stressing close relationships. The largest improvement in any PDQ8 item was found for the ability to concentrate, which could be a result of reducing interactions and life demands during isolation.

The participants’ free-text descriptions of life during the COVID-19 pandemic provide other possible explanations for the improvements in HRQL, for example in terms of equalization of external demands, expressed like: “*I have not experienced a big change, I kind of like the “slow” life*” (Man, 75 years) and “*I think the pressure is gone . . . I do not have to commit socially, and there is no pressure on how I look or appear to others*” (Woman, 62 years). Other examples of free-text descriptions are

Table 2  
Descriptions of life with PD during the COVID-19 time period

	Examples of subjective descriptions provided by PwP
Question 1:  <i>How do the Covid-19 situation influence your social activities and how do you experience this?</i>	<p>“It is such a relief not having to ‘perform’, neither to my relatives nor to my physiotherapist” (Woman, 68 years)</p> <p>“I miss the normal life, and I have lost the control. In some way I have to create a new reality” (Woman, 65 years)</p> <p>“We are living more ‘slowly’ and it is nice . . . the pressure of being active like my husband is gone. Somehow we are being more equal in a way” (Woman, 71 years)</p> <p>“I think that my physical condition may has worsened . . . my training partners provided me with so much energy . . . now I am being more rigid and I do not have the same energy as before” (Man, 70 years)</p> <p>“I miss my training, my daily exercises but in a way, I feel more relaxed, and I can get in touch with my ‘disease-fellows’ anyway in our ‘virtual space’ – this aspect is the most important thing for me” (Man, 73 years)</p> <p>“Before COVID-19, I constantly had to ask my relatives to drive me around to everything and help me with different things. In a way, life has become simpler and I am not feeling so dependent on others” (Man, 76 years)</p> <p>“This situation makes me lonely . . . I have nothing more to say about that . . . I look forward to a more stable world” (Woman, 74 years)</p>
Question 2:  <i>Have your usual routines/habits changed during the COVID-19 period, and how does this impact your everyday life?</i>	<p>“Sometimes I feel sad that that everything has changed but it has also opened up for new possibilities” (Woman, 69 years)</p> <p>“The new routines will continue after COVID-19. For a long time, my work pace has been too much. More focus has been drawn to what I am capable of and the possibilities herein” (Man 61 years)</p> <p>“The routines have not changed radically, but mentally in relation to the lack of freedom” (Man, 72 years)</p> <p>“I is difficult to me to concentrate, I am more indifferent . . . but I love my home and to be here, simplicity is what counts” (Man, 71 years)</p> <p>“Without the usual routines, I have become more passive, because I have a hard time knowing what to do. So, I am a little stuck. Sometimes I feel lonely and without hope for things to be normal” (Woman, 74 years)</p> <p>“In a way you have to change your ‘mindset’ until the new habits and structures have become the ‘new normal’ . . . until then I lack the sense of control” (Man, 75 years).</p>

presented in Table 2. Only a small proportion of the statements were purely negative.

Almost all participants (59/67 individuals) had experienced less sleep disturbances during the COVID-19 compared to pre-COVID-19 period. This may be due to the decrease in “pressure” and activity level as the transition into “slow life” may be a relief to persons that constantly have to relate to disease-related changes and be evaluated due to their physical appearance [18]. Thus, a change in lifestyle and reduction in external demands may have reduced the stress-level in PwP. However, PRO-PD motor scores as well as BK50 were similar before and during the COVID-19 period. A recent study showed that the COVID-19 pandemic led to a worsening of PD-symptoms due to psychological distress as well as decreased physical activity [19]. Our findings contrast to the common hypothesis that COVID-19 related changes in lifestyle circumstances will be mostly negative to PwP [7, 8, 20], and they may not correlate with QoL outcome measures.

However, an increased level of anxiety is reflected in the data. Anxiety is a common problem in PD due to the pathophysiology of this disease and the expected gradual increase of neuro-psychiatric symptoms [20]. However, the participants’ descriptions indicate that the anxiety could be of existential character, as existential anxiety can be associated with symptoms of anxiety and depression as well as psychological distress related to identity problems [21]. These components are expressed in several of the free-text replies like *“I miss my “normal” life ... It creates anxiety in me, which in a way always is “awake”, because I am dependent of my normal habits to manage the disease”* (Man, 71 years). Existential anxiety is probably not unique to PwP but could affect people of all walks of life during a situation like the COVID-19 [2]. Interestingly, anxiety seems in the previous quote, like in other quotes (Table 2), to be associated to the re-construction of normal life and normal structures/routines. Therefore, anxiety in PwP may not only be due to a progression of PD and the pathophysiology behind. It may be a combination of environmental vulnerability due to changes, coping strategies and personality traits [4], factors likely to be influenced during a crisis like the COVID-19 pandemic.

Understanding the way PwP cope with changing situations is important as the ability to maintain or quickly recover mental health during and after times of adversity may serve as a prognostic factor [22, 23]. Recent studies have shown that mindfulness and other

psycho-educational interventions can reduce depression and anxiety, and even improve motor symptoms [24]. Consequently, activities like home-based exercise programs, mindfulness, or establishment of social support groups to diminish social isolation in PwP during COVID-19 have been created, but perhaps PwP can gain a better HRQL with a more “mindful living” that is invoked by the reduced tempo and expectations during life in the pandemic. These findings may be valuable for the empowerment of PwP as they indicate that some demands and expectation of modern life that we have come to view as normal may inadvertently reduce quality of life in PD.

This study made pragmatic use of ongoing studies, where data happened to be collected before and during the first COVID-19 period in Sweden and Denmark, two countries with somewhat different strategies to limit spread of infection. Consequently, the study is small and contains heterogenous outcome variables, which is a limitation. However, unlike other studies addressing similar questions [8, 26], we had access to previous baseline data, which was used to describe the historic evolution of symptoms in the Swedish cohort during a similar time period before the advent of the COVID-19 pandemic. Although, one can argue that some changes in PDQ8 could be artefacts of the isolation as such, other variables including PDQ39 and EQ-VAS support general improvements in some health-related aspects of quality of life during the COVID-19 pandemic.

In conclusion, the immediate negative consequences of the COVID-19-period for PwP may not be as severe as expected. Conversely, patient ratings and free-text descriptions suggest that, despite increased anxiety, the pandemic and related changes in society are associated with improvement in HRQL, better night sleep and an overall feeling that the “pressure” is gone.

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## CONFLICT OF INTEREST

The authors have no conflicts of interest to report.

## SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <https://dx.doi.org/10.3233/JPD-202342>.

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