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Impact of COVID-19 Pandemic on Perceived Access and Quality of Care in German People with Parkinson's Disease

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Abstract

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Keywords: Parkinson's disease; COVID-19 pandemic; health care; impact; influence; Germany; iCARE-PD

Background

The COVID-19 pandemic has presented societies with unprecedented challenges. The uncontrolled spread of a virus causing potential fatal side effects despite intensive care and the consecutive necessity to reduce everyday life has afflicted societies economically and culturally. Yet, the impact on healthcare systems was particularly drastic. With rising incidences, public life around the world came to a standstill and access to public services, including healthcare, were limited to the most basic needs. This standstill has affected individuals in societies differently: vulnerable groups, such as people with chronic illnesses, were particularly affected by the restrictions [**?**, **?**, **?**]. This is not overly surprising insofar as that chronic illnesses affect individual psychosocial functioning negatively [**?**], thus people with chronic illnesses are often dependent on social, financial or physical support. Additionally, people with chronical illnesses often require continous non-emergency medical services and seemed therefore at high risk of undersupply during the pandemic.

The group of the chronically ill also includes people with Parkinson's Disease (PD). Person´s living with PD show a progressive condition characterized by motor but also non-motor symptoms. A plethora of different clinical signs may emerge during the course of PD, which is why continuous therapy adjustments and needs assessments by healthcare professionals are required. Several studies have unveiled the impact of the COVID-19 pandemic on person´s with PD [**?**, 1, 2, 3, **?**]. What remains unclear, however, is whether all patients were equally affected by the COVID-19 crisis.

Studies from other areas of public health research indicate very indicidual affection of public health crisis [4, 5]. With regard to PD-patients individual symptoms may play an important role, but more generally, this inequality can also be explained by so-called Social determinants of health (SDH). SDH are non-medical factors that influence, among other things, peoples access to healthcare, these factors can be

present at both individual and societal level [6]. The link between SDH and individuals access to healthcare is observable with regard to the COVID-19 pandemic, which means that some population groups experienced greater impacts than others based on their SDH [7]. People with PD in particular are dependent on a good social support network, which raises the question of whether patients with poorer SDH were affected more severly by the COVID-19 crisis.

What may be considered as relevant SDH is by no means universal. Rather, a context-specific consideration is required [6]. For PD, Zaman et al. proposed a model summarising structural and individual factors potentially influencing patients access to healthcare [8]. Structural SDH may thereby be encompass barriers, that PD-patients meet on a system-level when accessing healthcare, such as a lack of care coordination, limited communication between healthcare providers, disparities in health services or the unavailability of specialised services [8]. Personal barriers, influencing PD-patients abilities to seek help, engage with care providers, reach important care services or pay for them [8] may, in turn, pose individual SDH.

To our knowledge, it has not yet been investigated how SDH may relate to the COVID-19 pandemic on PD-patients access to healthcare. Therefore, we examined the impact of a multitude of factors on people suffering from PD with special emphasis on their access to healthcare during the pandemic in Germany.

Methods

Analyses rely on an anonymous survey carried out as part of the abbreviation iCARE PD missing (iCARE-PD)-project (`https://icare-pd.ca/`). Witin the scope of the project, a 49-items questionnaire was developed which aimed at characterising the access of PD-patients to healthcare services prior and during the pandemic. The initial questions in English were translated to German and were structured in four sections: A) questions describing patients' health status (in terms of PD but also of concomitant diseases), B) questions regarding experiences with healthcare services within twelve months before the pandemic, C) questions addressing experiences with healthcare services during the COVID-19 pandemic with special emphasis on telemedicine services, and, D) questions devoted to ascertain demographic backgrounds of participants. There were single, multiple choice questions or open-ended quesions, some of which depended upon the specific answers on previous ones. A full version of the questionnaire is included in the supplementary material.

The questionnaire was distributed nationwide using the members' e-mail newsletter of the German Parkinson Association (Deutsche Parkinson Vereinigung (DPV)) between November 2020 to January 2021. The e-mail included a short inivtation as well as a link to an online survey, which patients could access using a personal computer, a tablet or a smart phone. In Germany, SoSci Survey [**?**] served as database for hosting the survey. Throughout the data inout, the database was supervised and manually checked for plausibility.

In addition to Germany, the iCARE-PD questionnaire was also shared with patient associations in Canada, Spain, Portugal and the Czech Republic with the respective translations. In this study, we limit ourselves to data collected from German patients.

Statistical analyses

All analyses were conducted in R (R Core Team (2021), [**?**]). After estimation of descriptive statistics, satisfaction with overall PD-related care was compared before and during the pandemic using a non-parametric *sign-test* (rstatix package, `https://github.com/kassambara/rstatix/`). The two questions that were used were: "In the 12 months prior to the COVID-19 pandemic, overall, how satisfied are you with the way healthcare services related to Parkinson's disease were provided?" (B17) vs. "Since the beginning of the COVID-19 pandemic, overall, how satisfied are you with the way healthcare services related to Parkinson's disease are provided?" (C6).

Furthermore, using a Generalised Linear Model (GLM) we estimated the odds for worse satisfaction with PD-related care. After establishing the full model with a total of 32 predictors, we conducted a stepwise logistic regression in order to reduce the complexity leaving the most meaningful predictors for the question: "Since the beginning of the COVID19 pandemic, how often did you feel you needed healthcare for Parkinson's disease but did not receive it?" (C4). For that purpose, first missing data was imputed taking advantage of a multivariate imputation scheme using the MICE-package [**?**]. We thereby assumed data missing at random and used the Predictive Mean Matching Method (PMM). After missing data imputation, stepwise reduction using a GLM with Stepwise Feature Selection (*glmStepAIC*) in both directions from the *caret*-package aimed at minimising the Akaike Information Criterion (AIC). For that, we first split all data into 80% of training and 20 % of

test data and performed the stepwise regression after centering and rescaling values and applying a 10-fold cross-validation. The predictions of the two models were compared with the test data using Accuracy, Area Under The Curve (AUC) and LogLoss as metrics. All data for the analyses and all analyses can be followed under `https://github.com/dpedrosac/covidPD/`

Additional data

Within the last section of the survey, participants were asked to disclose the first three of five numbers of their German postal code, which allowed for regional data containment. We concatenated resulting data with publicly available population densities[1] and those for family doctors and neurologists[2]. Merging the available data with the maps for postal codes[3] resulted in maps (cf. Figure 1). Densities were stratified into five equal quantiles to allow for analyses. Moreover, the provided information of concomitant diseases (besides PD) was collated to a score – the Elixhäuser Comorbitiy Score with its modification introduced by van Walraven et al. [9]; here, higher values indicate more severe disease burden. Finally, all questions were assigned to barriers to accessing health services regarding PD as described by [8] (cf. Table **??** supplementary data).

[1] `https://www.bbsr.bund.de/BBSR/DE/forschung/raumbeobachtung/Raumabgrenzungen/deutschland/regionen/Raumordnungsregionen/raumordnungsregionen-2017.xlsx?\_\_blob=publicationFile\&v=3`

[2] `https://gesundheitsdaten.kbv.de/cms/html/16402.php`

[3] `https://www.suche-postleitzahl.org/downloads`

Results

In total, 551 questionnaires were filled out with 252 different postal codes from all 17 German regions (Bundesländer, cf. Figure 1A). Of all participants, 388 (70.4%) returned a complete questionnaire (for demographics from parts A and D of the questionnaire cf. Table 1).

Satisfaction for PD-related care significantly decreased during the pandemic. Hence, the *sign-test* for the question: "Overall, how satisfied are you with the way healthcare services related to Parkinson's Disease are provided?" indicated lower values during the pandemic (Mdn = 1) compared to before (Mdn = 3, $p = 10^{-73}$). More than 90% of all participants stating to be rather unsatisfied or very unsatisfied with their PD-related care during the pandemic (cf. Figure 2).

To ascertain underlying reasons for dramatic declines of satisfaction, logistic regressions on question C4 ('Since the beginning of the COVID-19 pandemic, how often did you feel you needed healthcare for Parkinson's Disease but did not receive it?") was performed unveiling different factors which contributed to this perception of unmet neets during the pandemic (cf. Figure 3). Thus odds to affirm this question were highly significant ($p < .001$) for those patients inferring lower levels of competence for their neurologist, with a lower ability to access PD-care before the pandemic, for patients with higher degrees of stigmatisation in healthcare and for those who did not receive healthcare services before the pandemic. A significant contribution – albeit lower with significance values $p < .05$ – were encountered for PD-patients with increasing levels of comorbidity, with perceived lower expertise of the General practitioner (GP), with higher quality of life scores retrospectively, for people with higher financial burden due to PD or who rescheduled healthcare due to financial burden before the pandemic. Finally, lack of availability of remote healthcare during the pandemic and geographical or in general more numerous barriers before start of the pandemic were also indicative of higher odds to perceive unmet needs. For an illustration on significant predictors cf. Figure 3 and for the entire list of results cf. Table **??** in the supplementary material.

Starting with the entirety of 32 questions that might be predictors of affirming question "C4" (see above), using a two-way stepwise regression model these could be reduced to 7 which were: Educational level, Perceived GP's experience, Confidence in assessing necessary services remotely, Ease obtaining healthcare prior to the pandemic, Ability to assess care prior to the pandemic, the density of neurologists and the ability to overcome bassiers (cf. Table 2). Markers for model comparison were indicative of similar performances in the "full model" with 32 predictors compared to the reduced one (cf. Figure 4)

Discussion

In this study we seeked to investigate factors contributing to insecurity and the feeling of not having received health services during the COVID-19 pandemic. To the best of our knowledge, this has been the first time that SDH have been related to the the pandemic on access to healthcare in PD-patients. With this questionnaire, we could demonstrate that the COVID-19 pandemic did not affect all patients equally but that structural, as well as, individual determinants massively infer on people´s access to healthcare. Our results may thus enable a deeper understanding of obstacles not only during the pandemic, but in general for patients suffering from PD.

It remains undisputed that the COVID-19 pandemic has been the defining event in recent years. At a relatively early stage of the pandemic and before and the availability and knowledge of the benefits of vaccination provided some relief for people, our data reflect people's unbiased and acute concerns. Interestingly, a good overall performance of the German healthcare system was certified during the COVID-19 pandemic, [10], which is transferable on healthcare data in person´s with PD[2]. At the same time, it would fall short to consider the subjectively perceived but objectively nonexistent inadequacy as the cause of the results, as some of the aspects are found in the literature to be prominent factors of inadequate care.

Absatz über generelle Probleme bei der Versorgung/dem Zugang zu Leistungen...

However, a look at other countries confirms that not every person with PD was equally affected by the pandemic and so it seems necessary to include personal background in the question of satisfaction with health care. Survey data from 9762 participants including 5429 person´s with PD in the United States demonstrated that a disruption of daily activity was more common in those who lived alone, that person´s with lower income were less likely to report alternative means of exercise or social activities, and that older person´s were less likely to use alternative ways to exercise [**?**]. Further investigations into the effect of these, as Zaman et al. defined, individual and structural influences on measures of healthcare experiences during the COVID-19 pandemic in the German population are needed.

The role of telehealth in increasing access to care for person´s with PD has been recognized [**?**, **?**]. Based on our data, the access to telehealth decreased the likelyhood of experiencing unmeet care needs during the pandemic. However, there is still a long way to go in Germany [**?**]. Further investigation on how to increase patients confidence in telemedicine and how to overcome technological limitations (ie. lack of high speed internet), is needed. An important factor to be mindful of is that the application of telemedice may cause unintended negative effects on health equity [**?**]. Poverty and barriers to digital health literacy are some factors which may contribute to discrepancies in the future, if not addressed appropriately [**?**].

Therefore, it seems essential for a future-oriented Parkinson's health care to look more closely at who experiences which barriers in access to health care and how these barriers can be overcome in a crisis-proof manner.

Limitations

Despite revealing problems that patients encountered during the pandemic, the interpretation of our results requires some caution. This, the survey was an anonymous

online survey so that representativeness for the German PD population is not warranted. No only is it possible that patient's filling out the questionnaire are highly selected from one of the biggest support groups in Germany, the online tool also suggests that it is more likely to be tech-savvy and therefore possibly less affected patients. In this context, it was yet surprising that the mean age of participants was almost 67 years, so that young-onset PD-patients cannot be inferred from this. Finally a limitation is also the fact that there was no way to control for misdiagnosis or the correctness of data, so that these results await confirmation in observational studies with more meticulous information on demographics.

Conclusion

In order to learn from the pandemic in the long term, difficulties in access to healthcare must be uncovered and addressed. The results of this analysis showed that the COVID-19 pandemic did not affect all PD-patients equally, but that people who experienced individual and structural barriers to accessing healthcare before the COVID-19 pandemic were more affected by the COVID-19 pandemic. Therefore, it is important to examine these determinants more closely and to address them in future-oriented, resilient healthcare models.

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Abbreviations

Availability of data and materials
The iCARE-PD-project, which poses the umbrella for this study, was registered under DRKS00025764 in the German Clinical Trial Register (`https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00025764`).Data from all participants and all analyses are available under `https://github.com/dpedrosac/covidPD`

Ethics approval and consent to participate
The study was approved by the local Ethics committee (reference number: AZ 164/19) and carried out in accordance with the Declaration of Helsinki. All patients gave informed written consent prior to participating.

Competing interests
The authors declare that they have no competing interests.

Consent for publication
All authors have written and agreed the final version of the manuscript.

Authors' contributions

Conceptualization, D.P., M.vM.; methodology, D.P.; software, D.P.; formal analysis, D.P., M.vM., M.R.P.; provision of resources, D.P.; writing—original draft preparation, D.P., M.vM., M.R.P.; writing—review and editing, D.P., M.vM.; visualization, D.P.; supervision, D.P.. All authors have read and agreed to the published version of the manuscript.

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Figures

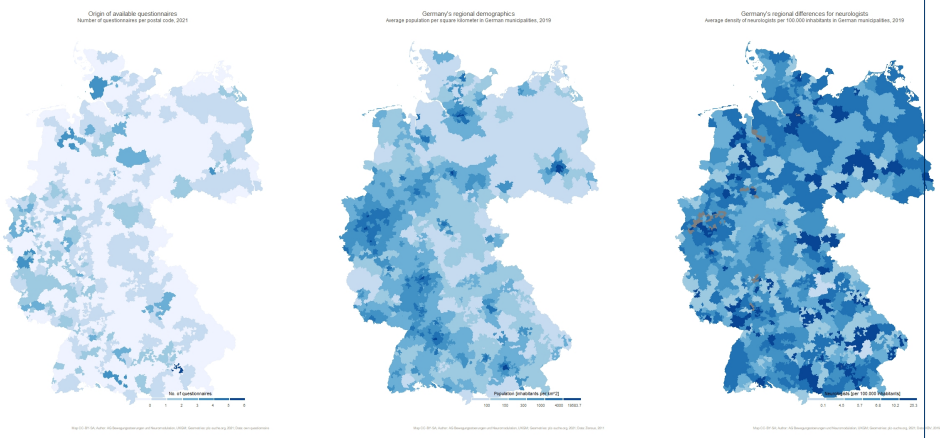

Figure 1: Demographic data for Germany and additional regional data for the obtained questionnaires. A) Number of received questionnaires within our survey for the distinct three digit postal codes. B) Illustration of inhabitants per square kilometer for Germany. C) Density of neurologists in all parts of Germany according to the German Statutory Health Insurance Association (*Kassenärztliche Bundesvereinigung*)

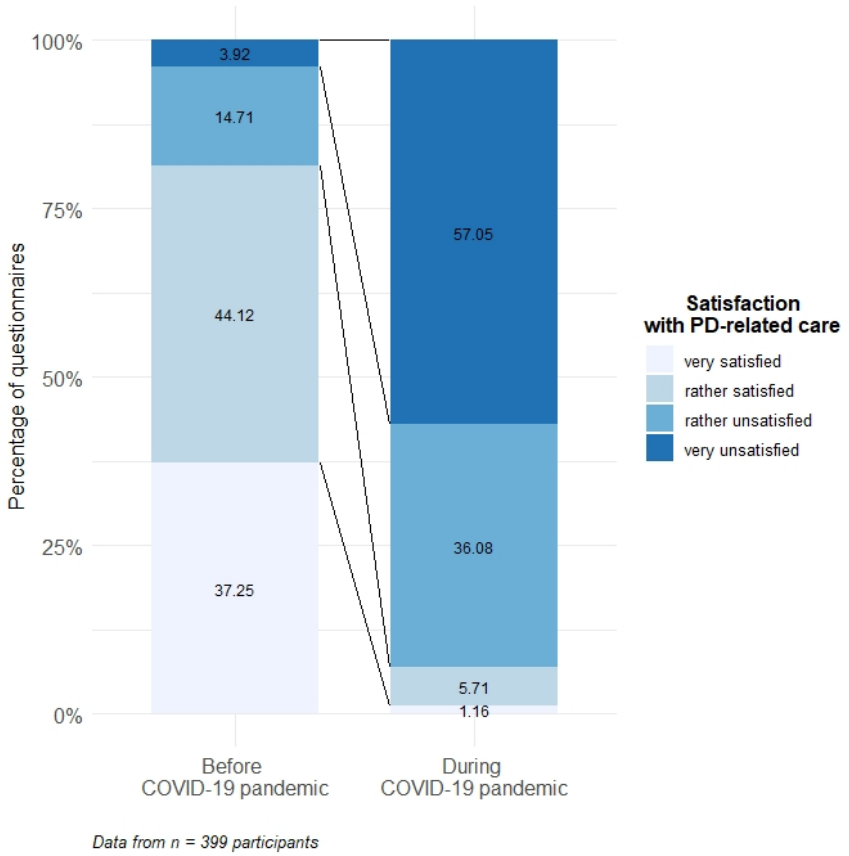

Figure 2: B17 vs. C6 - Distribution of responses on the Satisfaction with PD-related care before and during the COVID-19 pandemic.

Tables
Additional Files

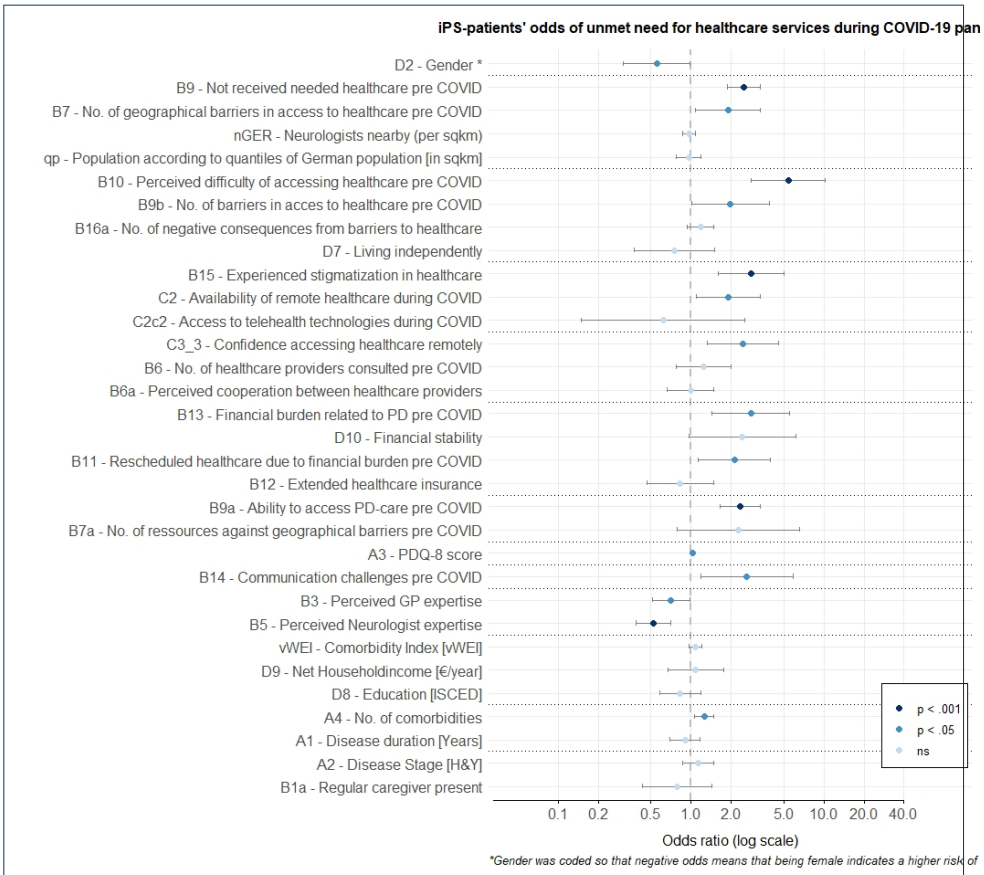

Figure 3: Unadjusted Odds ratios according to the GLM for all 32 questions. Odds were determined so that higher values indicate affirmation to the question that healthcare was needed but this need remianed unmet during the COVID-19 pandemic. The dashed lines indicate the distinct domains according to Zaman et al. [8], whereas significance is illustrated as color of the dot, with two distinct levels of significance.

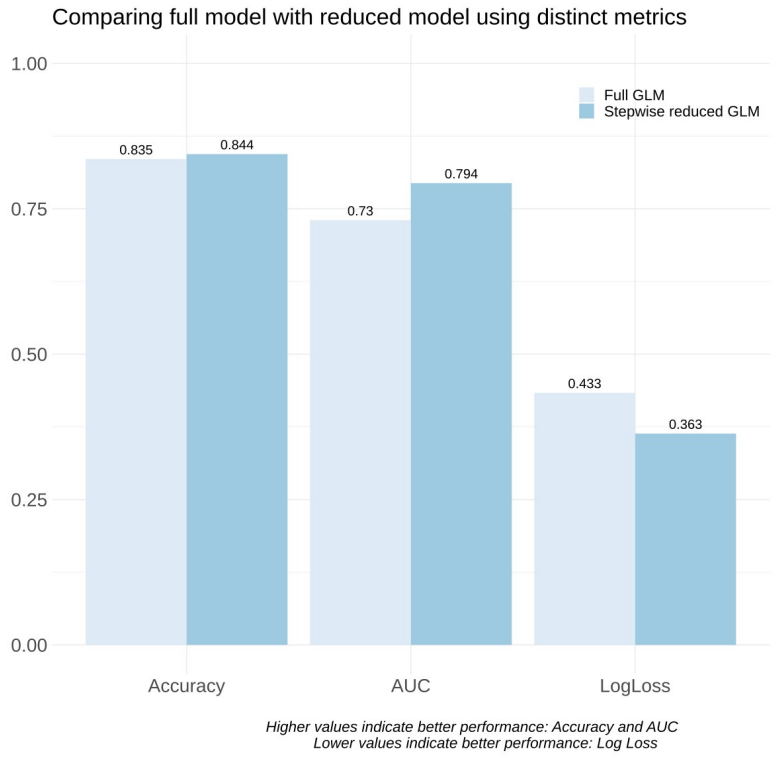

Figure 4: Comparison of the models. The full model including all 32 predictors was compatred in terms of accuracy to the reduced model resulting from the stepwise GLM regression. Values between both models are comparable although only 7 predictors remained in the model compared to the full model. For further details of the multilevel regression cf. Table 2

Table 1: Demographics of subjects filling out questionnaire:

	Overall (n = 552)
Age (mean (SD))	66.76 (9.25)
Gender = female (%)	148 (41.6)
Disease duration (%)	
<2 years	62 (13.1)
2–5 years	154 (32.6)
5–10 years	157 (33.2)
10–15 years	69 (14.6)
>15 years	31 (6.6)
Disease stage (%)	
Hoehn & Yahr I	189 (40.3)
Hoehn & Yahr II	156 (33.3)
Hoehn & Yahr III	77 (16.4)
Hoehn & Yahr IV	41 (8.7)
Hoehn & Yahr V	6 (1.3)
Education level according to ISCED (%)	
primary education	20 (5.0)
secondary education	234 (58.4)
post secondary education	69 (17.2)
highest education level possible	78 (19.5)
PDQ-8 scores (mean (SD))	41.30 (14.23)
Van-Walraven-Elixhauser Comorbidity Index (mean (SD))	6.55 (1.95)

Table 2: Significant factors contibuting to unmet care needs during COVID-19 pandemic according to the reduced GLM:

Predictor	Estimate	Std.Error	zvalue	*p*
(Intercept)	-2.65	0.29	-9.24	<.0001
Educational level (D8)	-0.73	0.24	-3.01	0.003
Perceived GP's expertise (B3)	0.34	0.17	2.07	0.038
Confidence in accessing necessary services remotely (C3)	0.64	0.22	2.90	0.004
Ease obtaining healthcare prior to the pandemic (B10)	-0.47	0.22	-2.15	0.031
Ability to access care prior to the pandemic (B9)	0.41	0.20	2.07	0.038
Density of Neurologists	0.47	0.21	2.22	0.027
Overcoming barriers (B7a)	-0.51	0.22	-2.38	0.017

Table 3: Matching of items in the questionnaire to the categories from the work of Zaman et al. [8]

tab3:matchingzaman)

Question from Covid-Survey	**Representative for what barrierer**
1. A2, B1	Autonomy
2. A1, A4, vWEI	Health Status
3. D8, D9	Health Literacy
4. B3, B5	Health Belief
5. B14a	Communication (personal)
6. PDQ-sum score	Self-efficacy
7. B7a, B9a/b	Transportation
8. B11, B12, B13, D10	Cost of care
9. NA	Difficulties of Diagnosis
10. C3, B6a, B6	Coordination in care
11. B15, B14, C2c	Communication (system)
12. B16, B16c, D6, D7, B9b, B10	Disparty in Health Services
13. B7, B8, B9,	Unavailability of Specalist Services
14. D2	Other

Table 4: Odds ratios for the distinct items of the questionnaire
tab4:resultsall)

Factors	Domain	Odds Ratio	CIlower	CIupper	p-value
A2 - Disease Stage [H&Y]	Autonomy	1.13	0.87	1.47	0.367
B1a - Regular caregiver present	Autonomy	0.79	0.43	1.44	0.438
A1 - Disease duration [Years]	Health Status	0.9	0.69	1.16	0.419
A4 - No. of comorbidities	Health Status	1.26	1.06	1.49	0.007
vWEI - Comorbidity Index [vWEI]	Health Belief	1.08	0.97	1.21	0.155
D8 - Education [ISCED]	Health Belief	0.82	0.58	1.18	0.284
D9 - Net Householdincome [per/year]	Health Belief	1.08	0.67	1.75	0.75
B3 - Perceived GP expertise	Health Literacy	0.71	0.51	0.98	0.038
B5 - Perceived Neurologist expertise	Health Literacy	0.52	0.39	0.7	$p < .001$
B14 - Communication challenges pre COVID	Communication (personal)	2.63	1.18	5.82	0.017
A3 - PDQ-8 score	Self-efficacy	1.03	1.01	1.05	0.011
B7a - No. of ressources against geographical barriers pre COVID	Transportation	2.27	0.79	6.51	0.129
B9a - Ability to access PD-care pre COVID	Transportation	2.33	1.65	3.31	$p < .001$
B11 - Rescheduled healthcare due to financial burden pre COVID	Cost of care	2.11	1.13	3.93	0.019
B12 - Extended healthcare insurance	Cost of care	0.83	0.46	1.48	0.521
B13 - Financial burden related to PD pre COVID	Cost of care	2.81	1.42	5.53	0.003
D10 - Financial stability	Cost of care	2.43	0.97	6.09	0.059
C3_3 - Confidence accessing healthcare remotely	Difficulties of Diagnosis	2.44	1.32	4.53	0.005
B6a - Perceived cooperation between healthcare providers	Difficulties of Diagnosis	0.99	0.66	1.49	0.975
B6 - No. of healthcare providers consulted pre COVID	Difficulties of Diagnosis	1.24	0.77	1.99	0.374
B15 - Experienced stigmatization in healthcare	Coordination in care	2.84	1.6	5.03	$p < .001$
C2 - Availability of remote healthcare during COVID	Coordination in care	1.91	1.09	3.34	0.023
C2c2 - Access to telehealth technologies during COVID	Coordination in care	0.62	0.15	2.53	0.5
B16a - No. of negative consequences from barriers to healthcare	Communication (system)	1.18	0.93	1.48	0.166
D7 - Living independently	Communication (system)	0.75	0.38	1.51	0.421
B9b - No. of barriers in acces to healthcare pre COVID	Communication (system)	1.98	1.01	3.89	0.048
B10 - Perceived difficulty of accessing healthcare pre COVID	Communication (system)	5.37	2.84	10.17	$p < .001$
B7 - No. of geographical barriers in access to healthcare pre COVID	Disparty in Health Services	1.9	1.08	3.33	0.026
Population according to quantiles of German population [in sqkm]	Disparty in Health Services	0.96	0.77	1.19	0.714
B9 - Not received needed healthcare pre COVID	Disparty in Health Services	2.5	1.88	3.32	$p < .001$
nGER - Neurologists nearby (per sqkm)	Disparty in Health Services	0.97	0.87	1.07	0.527
D2 - Gender *	Unavailability of Specalist Services	0.55	0.31	0.98	0.044