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

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Abstract

Background: the context and purpose of the study.

Methods: how the study was performed and statistical tests used

Results: the main findings.

Conclusions: brief summary and potential implications.

Trial Registration: If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be in stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'.

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

Background

The COVID-19 pandemic is an unprecedented event for people within the last few generations. The uncontrolled spread of a virus causing potential fatal side effects despite intensive care and the consecutive necessity to reduce everyday life has afflicted Western societies economically, culturally but obviously also within healthcare systems. In an attempt to spare societies from far worse, with rising incidences everyday world almost ceased and public access to services was limited to the most basic needs. All the measures taken to prevent worse, left those particularly exposed who may not be vitally at harm but whose well-being rely heavily on intact social functioning.

People with chronical illnesses attain more freqently to non-emergency medical services and seemed therefore at high risk of undersupply during the pandemic. Numerous studies have unveiled the impact of the COVID-19 pandemic on chronically-ill patients [?, ?], who remained homebound to avoid innecessary exposure and thus hinged upon their surroundings' solidarity. At the same time this pandemic has not least shown the janus-headed nature of remote medical solutions: On the one hand, because we healthcare providers in Western societies have had to get used to making diagnoses and discussing therapies from afar in a hurry. Otherwise, because it has revealed our hitherto inadequate means for safe, stable but especially widely available remote solutions. In neurology, one may have inferred that subjects particularly prone for undersupply would be those suffering from neurodegenerative

diseases according to the chronical nature of the diseases but also due to mobility restrictions.

Patients suffering from Parkinson's Disease (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 and may require continuous therapy adjustments and needs assessments by healthcare professionals. There is no solid evidence on whether restrictions of offered services may have striken PD-patients more profundly, according to the limited number of studies conducted so far [?, ?, ?]. However, studies from other areas of public health research indicate very indicidual affection of public health crisis [?, ?]. 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. The link between them 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 [?].

The is no universal conceptualisation of what SDH imply. In a broadest sense, they comprise contextual, structural and individual factors [?] associated with health. The word *contextual* is of utmost importance here: what may be considered as relevant SDH is by no means universal. For PD, Zaman et al. proposed a model summarising structural and individual factors potentially influencing affected patients' access to healthcare [?]. Structural SDH may thereby be reflected by barrieres, 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 [?]. Individual SDH, in turn, may be reflected by personal barriers in this model, influencing PD-patients' abilities to seek help, engage with care providers, reach important care services or pay for them [?].

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. This analysis relies on an anonymous survey carried out as part of the abbreviation iCARE PD missing (iCARE-PD)-project (https://icare-pd.ca/).

Methods

The study was approved by the local Ethics committee (AZ??) and carried out in accordance with the Declaration of Helsinki. All patients gave informed written consent prior to participating. 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).

A questionnaire with 49 items was developed within the iCARE-PD-project and aimed at characterising the access of PD-patients to healthcare services but also at identifying barriers to be addressed prior and during the pandemic. The questionnaire was developed in English and consisted of four different parts: 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. In addition to Germany, the questionnaire was also delivered in Canada, Spain, Portugal and the Czech Republic with the respective translations. In this study, we limit ourselves to data collected from German patients.

The invitation to participate in the German survey was disseminated via the e-mail list of the German Parkinson's Association Deutsche Parkinson Vereinigung (DPV). All participants were asked to fill out the questionnaire anonymously from November 2020 to January 2021 via the online platform SoSci Survey (Leiner, D. J. (2019). SoSci Survey (Version 3.1.06) [Computer software] using a personal computer, a tablet or a smart phone.

Additional data

Since Participants were asked to disclose the first three of five numbers of their German postal code, it allowed us for regional data containment. We concatenated resulting data with publicly available population densities (https://www.bbsr.bund.de/BBSR/DE/forschung/raumbeobachtung/Raumabgrenzungen/deutschland/regionen/Raumordnungsregionen/raumordnungsregionen-2017.xlsx?__blob=publicationFile&v=3) and those for family doctors and neurologists (https://gesundheitsdaten.kbv.de/cms/html/16402.php). Merging the available data with the maps for postal codes ((https://www.suche-postleitzahl.org/downloads)) resulted in maps (cf. Figure 3) from which data for population densities and number of neurologists per 100.000 could be extracted and fed into further analyses. This data was stratified into five equal quantiles. Moreover, the provided information of concomitant diseases (besides PD) was collated to a score, the Elixhäuser Comorbitiy Score, modified by van Walraven [**?**]; here higher values indicate more severe disease burden. Finally, all questions were assigned to barriers to accessing health services regarding PD as described by zaman2021barriers (cf. Table in the supplementary data).

Statistical analyses

All analyses were conducted in R (R Core Team (2021), [**?**]). After descriptive statistics were estimated, satisfaction with overall PD-related care was compared before (Question B6:) and during the pandemic (Question ??:) using a nonparametric *sign-test* (rstatix packages Quelle??). 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 question C4 (Fur that purpose, first missing data was imputed taking advantage of a multivariate imputation scheme using the MICE-package (Quelle??). We thereby assumed data missing at random and used the

Predictive Mean Matching Method (PMM). After finishing imputation, stepwise reduction using a Generalized Linear Model with Stepwise Feature Selection (*glm-StepAIC*) 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 data and applying a 10-fold cross-validation. The predictions of the two models were compared with the test data using accuracy, **auc!** (auc!) and LogLoss as metrics. The data for the analyses and all performed analyses can be found under https://github.com/dpedrosac/covidPD/

Results

In total, 551 questionnaires were filled out with 252 different postal codes from all 17 German regions (Bundesländer, cf. Figure 3A). Of all participants, 388 (70,4%) returned a complete questionnaire (for demographics from parts A and D of the questionnaire cf. Table 1).

There was a significant decrease in satisfaction with PD-related care during the pandemic. Hence, the sign-test for the question: indicated significantly lower values during the pandemic (Mdn = 1) compared to before (Mdn = 3, $p = 10^{-73}$) with more than 90% of all participants stating to be "rather unsatisfied" or "very unsatisfied" with their PD-related care during the pandemic (cf. Figure 1). To ascertain underlying reasons for this dramatic decline of satisfaction, we conducted logistic regressions on question C4 ("Did you need healthcare but did not receive it?"). Thereby, different factors could be identified contributing to the perception of an unmet neet for services during the pandemic (cf. Figure 2). Thus odds to affirm this question were highly significant higher ($p < .001$) 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. Significantly higher, albeit lowers, odds were encountered for PD-patients' with increasing levels of comorbidity, with perceived lower expertise of the General practitioner (GP), with higher PDQ-8 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 (all $p<.05$). For an illustration on significant predictors cf. Figure 2 and for the entire list of results cf. Supplementary material.
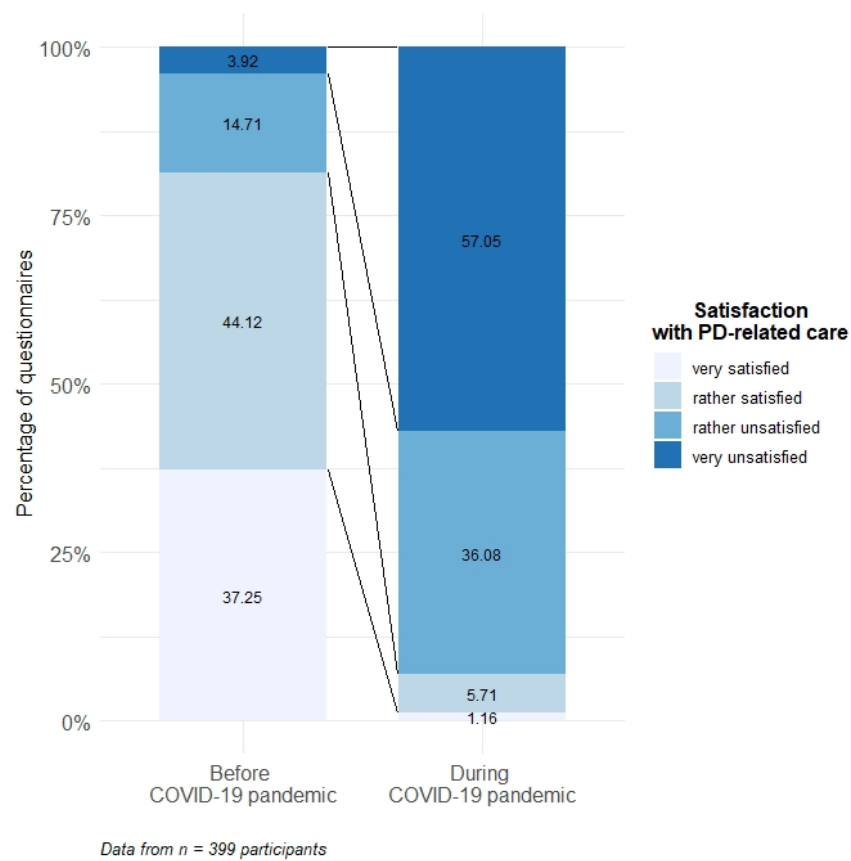
Figure 1: Distribution of responses on the Satisfaction with PD-related care before and during the COVID-19 pandemic.
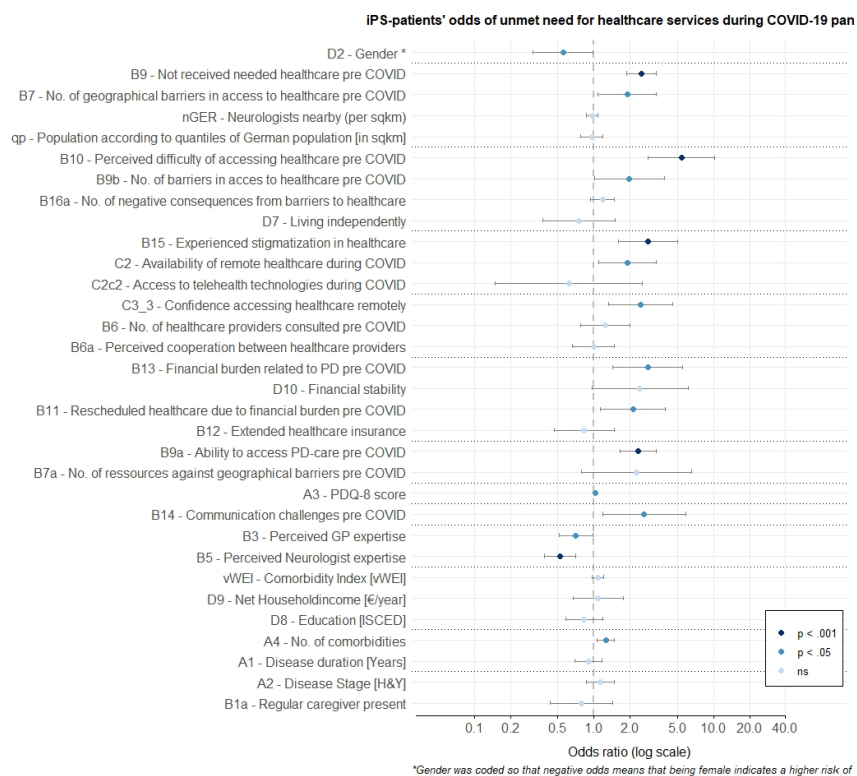
Figure 2: Unadjusted Odds ratios according to the GLM for all 32 questions. Odds were determined so that higher values indicate affirmation to the question that healthcare was needed but this need remianed unmet during the COVID-19 pandemic. The dashed lines indicate the distinct domains according to ??, whereas significance is illustrated as color of the dot, with two distinct levels of significance.

Discussion

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Conclusion

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In this section we examine the growth rate of the mean of Z_0, Z_1 and Z_2. In addition, we examine a common modeling assumption and note the importance of considering the tails of the extinction time T_x in studies of escape dynamics. We will first consider the expected resistant population at vT_x for some $v > 0$, (and temporarily assume $\alpha = 0$)

$$E\big[Z_1(vT_x)\big] = \int_0^{v \wedge 1} Z_0(uT_x) \exp(\lambda_1)\, du.$$

If we assume that sensitive cells follow a deterministic decay $Z_0(t) = xe^{\lambda_0 t}$ and approximate their extinction time as $T_x \approx -\frac{1}{\lambda_0} \log x$, then we can heuristically estimate the expected value as

$$E\big[Z_1(vT_x)\big]$$
$$= \frac{\mu}{r} \log x \int_0^{v \wedge 1} x^{1-u} x^{(\lambda_1/r)(v-u)}\, du. \tag{1}$$

Appendix

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Abbreviations

AIC	Akaike Information Criterion	4
DPV	Deutsche Parkinson Vereinigung	3
GLM	Generalised Linear Model	3
GP	General practitioner	4
iCARE-PD	abbreviation iCARE PD missing	2
PD	Parkinson's Disease	2
PMM	Predictive Mean Matching Method	4
SDH	Social determinants of health	2

Availability of data and materials
All analyses are available on https://github.com/dpedrosac/covidPD

Ethics approval and consent to participate
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Competing interests
The authors declare that they have no competing interests.

Consent for publication
Text for this section. . .

Authors' contributions
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Authors' information
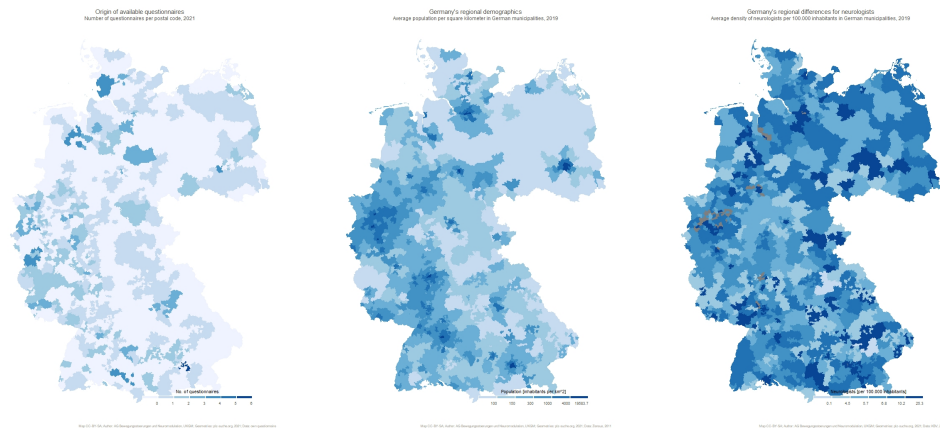Text for this section. . .

References

Figures

Figure 3: 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 (source: https://www.destatis.de) C) Density of neurologists in all parts of Germany according to the German Statutory Health Insurance Association (Kassenärztliche Bundesvereinigung, https://www.kbv.de/html/)
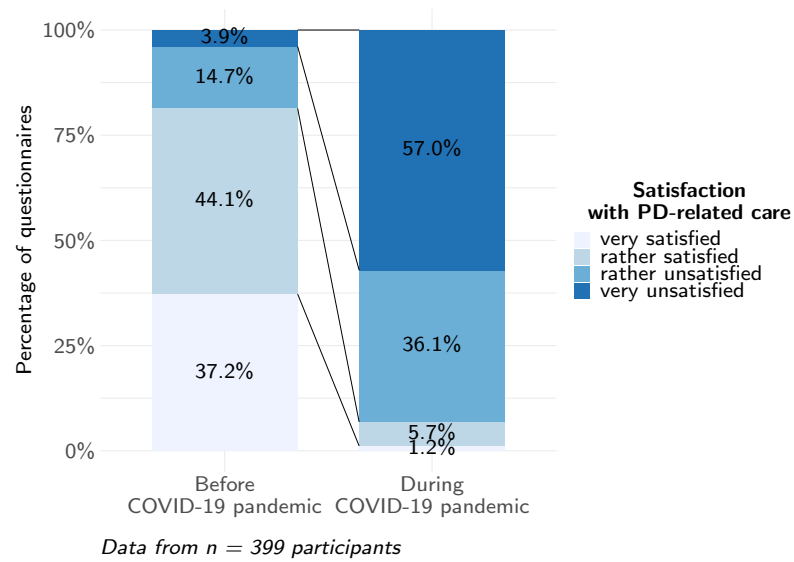
Figure 4: Distribution of responses on the Satisfaction with PD-related care before and during the Covid-19 pandemic.

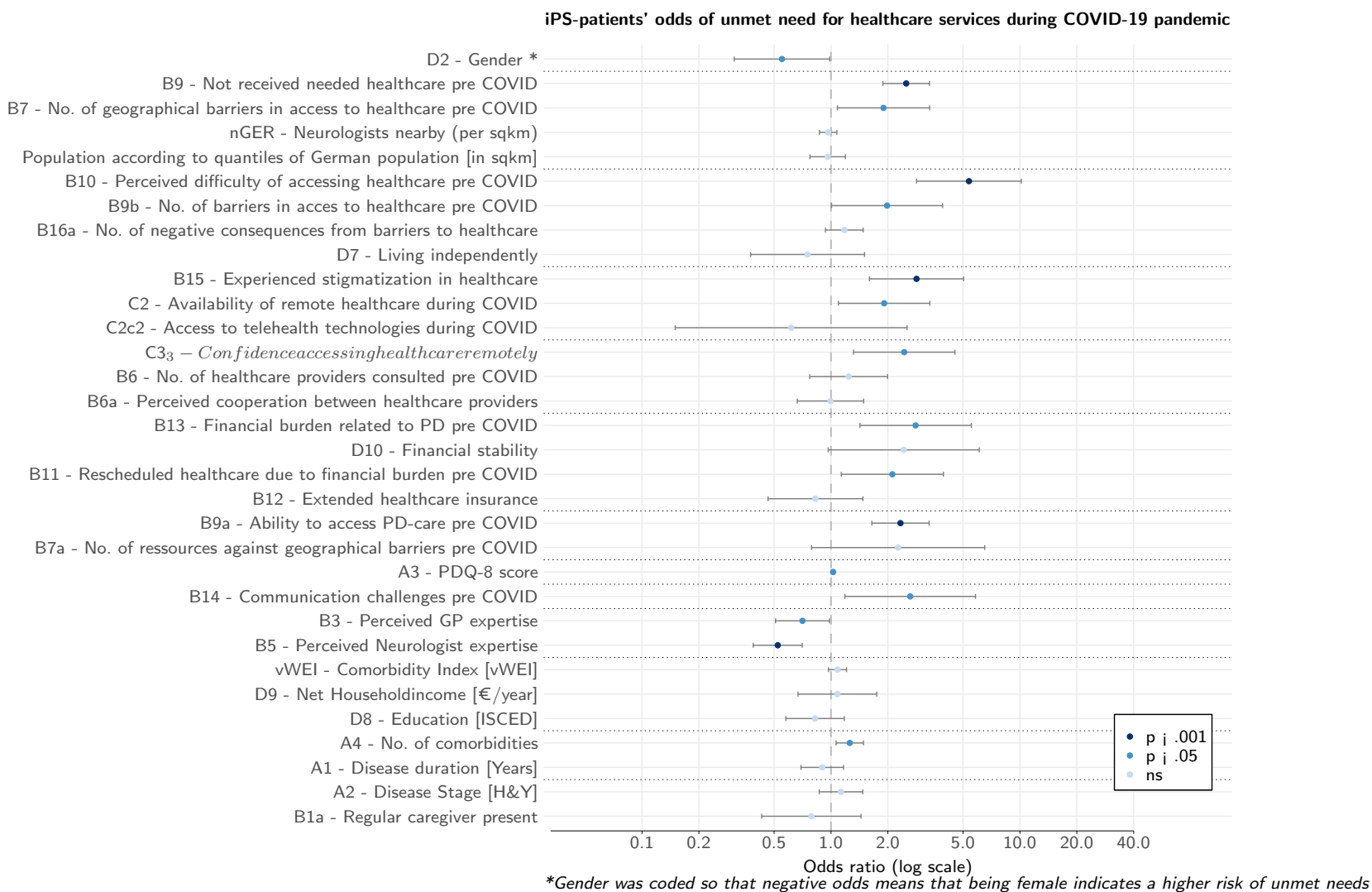**iPS-patients' odds of unmet need for healthcare services during COVID-19 pandemic**

Figure 5: Logistic regression for distinct predictors. A GLM with a binomial logit function was used to estimate the odds for different questions and data from the questionnaires for affirding that ??. All odds are displayed on a logarithmic scale and significance level is color coded. For additional information cf. supplementary material.
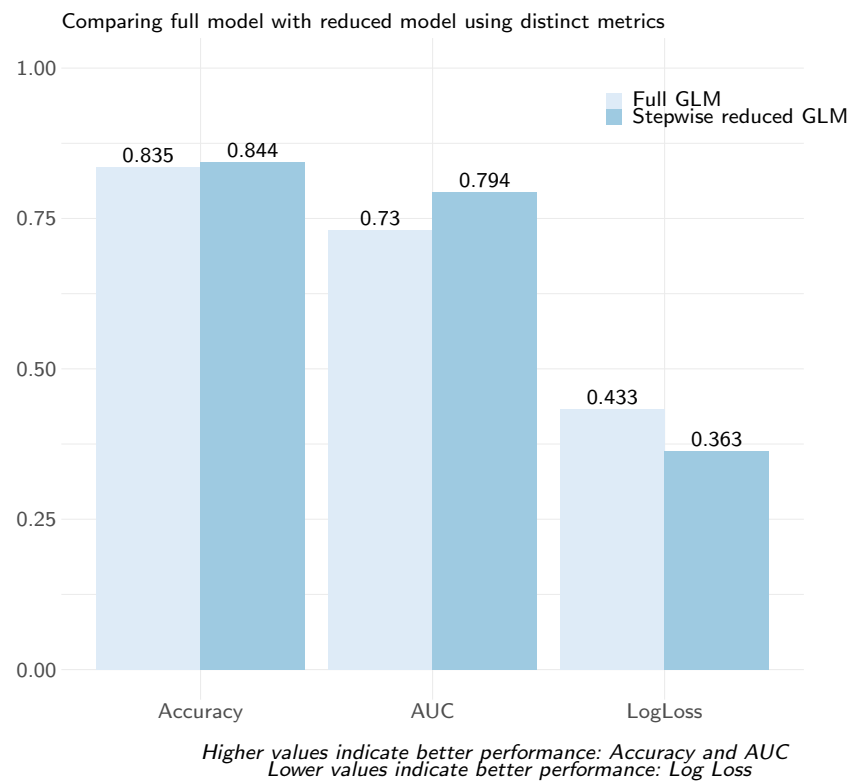
Comparing full model with reduced model using distinct metrics

Higher values indicate better performance: Accuracy and AUC
Lower values indicate better performance: Log Loss

Figure 6: Comparison of the models. The full model including all predictors was compatred in terms of accuracy to the reduced model resulting from the stepwise GLMregression. Values between both models are comparable although only ?? predictors remained in the model compared to the full model with ?? predictors. For further details of the multilevel regression cf. Table ??

Tables
Additional Files
Additional file 1 — Sample additional file title
Additional file descriptions text (including details of how to view the file, if it is in a non-standard format or the file extension). This might refer to a multi-page table or a figure.

Additional file 2 — Sample additional file title

Additional file descriptions text.

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. [?]

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

"Factors"	"Domain"	"Odds Ratio"	"CI.05"
"A2 - Disease Stage [H&Y]"	"Autonomy"	1.13	0.87
"B1a - Regular caregiver present"	"Autonomy"	0.79	0.43
"A1 - Disease duration [Years]"	"Health Status"	0.9	0.69
"A4 - No. of comorbidities"	"Health Status"	1.26	1.06
"vWEI - Comorbidity Index [vWEI]"	"Health Belief"	1.08	0.97
"D8 - Education [ISCED]"	"Health Belief"	0.82	0.58
"D9 - Net Householdincome [per/year]"	"Health Belief"	1.08	0.67
"B3 - Perceived GP expertise"	"Health Literacy"	0.71	0.51
"B5 - Perceived Neurologist expertise"	"Health Literacy"	0.52	0.39
"B14 - Communication challenges pre COVID"	"Communication (personal)"	2.63	1.18
"A3 - PDQ-8 score"	"Self-efficacy"	1.03	1.01
"B7a - No. of ressources against geographical barriers pre COVID"	"Transportation"	2.27	0.79
"B9a - Ability to access PD-care pre COVID"	"Transportation"	2.33	1.65
"B11 - Rescheduled healthcare due to financial burden pre COVID"	"Cost of care"	2.11	1.13
"B12 - Extended healthcare insurance"	"Cost of care"	0.83	0.46
"B13 - Financial burden related to PD pre COVID"	"Cost of care"	2.81	1.42
"D10 - Financial stability"	"Cost of care"	2.43	0.97
"C3_3 - Confidence accessing healthcare remotely"	"Difficulties of Diagnosis"	2.44	1.32
"B6a - Perceived cooperation between healthcare providers"	"Difficulties of Diagnosis"	0.99	0.66
"B6 - No. of healthcare providers consulted pre COVID"	"Difficulties of Diagnosis"	1.24	0.77
"B15 - Experienced stigmatization in healthcare"	"Coordination in care"	2.84	1.6
"C2 - Availability of remote healthcare during COVID"	"Coordination in care"	1.91	1.09
"C2c2 - Access to telehealth technologies during COVID"	"Coordination in care"	0.62	0.15
"B16a - No. of negative consequences from barriers to healthcare"	"Communication (system)"	1.18	0.93
"D7 - Living independently"	"Communication (system)"	0.75	0.38
"B9b - No. of barriers in acces to healthcare pre COVID"	"Communication (system)"	1.98	1.01
"B10 - Perceived difficulty of accessing healthcare pre COVID"	"Communication (system)"	5.37	2.84
"B7 - No. of geographical barriers in access to healthcare pre COVID"	"Disparty in Health Services"	1.9	1.08
" Population according to quantiles of German population [in sqkm]"	"Disparty in Health Services"	0.96	0.77
"B9 - Not received needed healthcare pre COVID"	"Disparty in Health Services"	2.5	1.88
"nGER - Neurologists nearby (per sqkm)"	"Disparty in Health Services"	0.97	0.87
"D2 - Gender *"	"Unavailability of Specalist Services"	0.55	0.31