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

Marlena van Munster¹, Marcel Printz¹ and David J. Pedrosa^{1,2*}

*Correspondence:

david.pedrosa@staff.uni-marburg.de

¹Department of Neurology, Philipps University, Marburg, Germany

Full list of author information is available at the end of the article

Abstract

Background: Due to a very heterogeneous clinical presentation, Parkinson's Disease (PD)-patients may develop different needs during their illness. Exceptional situations, such as the COVID-19 pandemic, have added to the scarcity of health resources, revealing some affected individuals receiving inadequate care. Meanwhile, research on the social determinants of health suggests an uneven burden during the pandemic. Therefore, this study examines the influence of individual and structural determinants on the perceived health care situation during the pandemic in Germany.

Methods: The analyses are based on an anonymous online survey that used a 49-item questionnaire. The aim of this survey was to describe access to health services by PDpatients before and during the pandemic. To this end, a Generalised Linear Model (GLM) was used to derive significant predictors, whereas a stepwise regression aimed to summarize the main factors contributing to inadequate care.

Results: All over Germany, 552 questionnaires were filled out. Satisfaction for PD-related care significantly decreased during the pandemic generally ($p < .001$). Yet, factors such as educational level, perceived expertise of healthcare providers, confidence in remote care, perceived ease of obtaining healthcare and the ability to access care prior to the pandemic, the density of neurologists within the area of living and the ability to overcome barriers were indicative of higher odds to perceive unmet needs during the pandemic ($p < .05$).

Discussion: Our results unveil both structural and individual obstacles contributing to people's reduced access to healthcare. Furthermore, we could show and that people with poorer Social determinants of health (SDH) experience a greater feeling of not having received needed health services during the COVID-19 pandemic.

Conclusion: This survey identifies common barriers that drove perceptions of limited health care during a very unique time. At the same time, some of our findings may be generalizable to all patients, so they can guide which societal and individual factors can be improved in the future to not only identify PD-patients at risk of inadequate support, but also to provide more resources to mitigate these issues in the future.

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

Background

The COVID-19 pandemic presented modern societies with unprecedented challenges. The uncontrolled spread of a virus causing potentially fatal side effects despite in-

tensive care and the resulting necessity to reduce everyday life afflicted societies economically and culturally. However, 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 health care, was disrupted [1, 2, 3]. This disruption affected individuals in societies to varying degrees. The group of particularly affected subjects included those with chronic diseases [4, 5, 6, 7]. This is not overly surprising in that people with chronic illnesses often belong to the high-risk group for a severe course of COVID-19, causing reluctance to attend medical facilities [8]. Also, chronic conditions negatively affect individual psychosocial functioning [9], often leaving affected persons in need of social, financial or physical support. People suffering from chronic diseases often necessitate continuous medical services outside of emergency departments and therefore appeared at high risk of undersupply during the pandemic [7, 1, 3].

The group of chronically-ill also includes people with Parkinson's Disease (PD). PD-patients show a progressive condition characterized by motor but also non-motor symptoms. A plethora of different clinical signs may emerge during the disease's course, requiring continuous therapy adjustments and need assessments by healthcare professionals. Recent studies have unveiled the impact of the COVID-19 pandemic on people suffering from PD [6, 10, 11, 12, 13]. However, it can hardly be assumed that all PD-patients were equally affected by the COVID-19 restrictions as other areas of public health research also indicate that health crises have very individual effects on health care access for vulnerable groups [14, 15, 16].

In addition to individual health care needs, other determinants may be inferred that influence how severely care is restricted. In recent years, the concept of so-called Social determinants of health (SDH) has emerged [17, 18] which may pose an interesting concept to answer the question of what is relevant to maintain a high level of support and well-being individually but also on a societal level.

What may be considered relevant SDH is by no means universal. Rather, a context-specific consideration is required [18]. For PD, Zaman et al. proposed a model summarising structural and individual factors potentially influencing patients' access to healthcare [19]. Structural SDH may on the one hand 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 [19], etc. Otherwise, individual barriers influencing PD-patients' abilities to seek help or to engage with care providers, to reach important care services or to pay for them [19] may likewise be of great importance. Particularly people with PD often hinge on a good support network.

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

Methods

Questionnaire

Analyses relied on an anonymous survey carried out as part of the abbreviation iCARE PD missing (iCARE-PD)-project (<https://icare-pd.ca/>). Within the scope of this project, a 49-items questionnaire was developed which aimed at characterising the access of PD-patients to healthcare services before 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 ascertaining demographic backgrounds of participants. There were single, multiple-choice questions or open-ended questions, some of which depended upon the specific answers to previous ones. A full version of the questionnaire is included in the supplementary data.

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 invitation as well as a link to an online survey, which patients could access using a personal computer, a tablet or a smartphone. In Germany, SoSci Survey [20] served as a database for hosting the survey. Throughout the data input, 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.

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 regional distributions (cf. Figure 1). Population densities and those for neurologists were stratified into five equal quantiles for further analyses. Moreover, the provided information of concomitant diseases (besides PD) was collated to a score – the Elixhäuser Comorbidity Score with its modification introduced by van Walraven *et al.* [21] with higher values indicating more severe disease burden. Finally, all questions were assigned to barriers to accessing health services regarding PD as described by [19] (cf. Table 3 in the 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>

Statistical analyses

All analyses were conducted in R[22]. 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 were 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 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 COVID-19 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 were imputed by taking advantage of a multivariate imputation scheme using the MICE-package [23]. 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 [24] 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 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/>

Results

In total, 552 questionnaires were filled out with 252 different postal codes from all 16 German regions (Bundesländer, cf. Figure 1A). Of all participants, 388 (70.4%) returned a complete questionnaire (for demographics from parts A and D, 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 in 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 needs during the pandemic (see 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 $p < .05$ – was 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, the lack of availability of remote healthcare during the pandemic and geographical or in general more numerous barriers in access to healthcare before the start of the pandemic were also indicative of higher odds to perceive unmet needs. For an illustration of significant predictors see Figure 3 and for the entire list of results cf. Table 4 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 seven (cf. Table 2), namely:

- educational level
- perceived expertise of the general practitioner
- confidence in the ability to access required health care services remotely
- perceived ease of obtaining healthcare before the pandemic
- perceived availability of specialist care before the pandemic
- density of neurologists within the area of living
- availability of structural support to overcome geographical barriers

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 sought to investigate factors contributing to insecurity and the feeling of not having received health services during the COVID-19 pandemic among German person's with PD. To the best of our knowledge, this is the first time that SDH were related to German PD-patients' perceived access to healthcare during this extraordinary crisis. With our study, we demonstrate that not all individuals were affected equally but that structural as well as individual determinants massively infer perceived access to healthcare. Viewing the pandemic through the focal lens of an ongoing demographic change in Western societies, our findings may render a deeper insight into how future care of people with PD may be improved.

It remains undisputed that the COVID-19 pandemic has been a defining event in recent years. At a relatively early stage and before the availability of vaccination provided some relief, our data reflect people's unbiased and acute concerns regarding their own healthcare. Interestingly, a good overall performance has been attested to the German healthcare system during the pandemic [25], which is transferable to person's with PD [11]. However, a good testimony for a healthcare system should not be equated with an adequate range of services, especially when it comes to very specific needs of PD-patients. In the recent literature, care deficits on a structural level have been reported insinuating a rather partial insufficiency [26, 27, 28, 29] of this heterogeneous population.

One of the major challenges physicians face in PD is its diverse manifestation. Multimodal therapeutic approaches could be a potential remedy [26], yet limited availability of such services cause long journeys from people from some regions of Germany [26] as Regionally coordinated care approaches for people with PD remain rare [27]. Furthermore, staff providing specialised, structured and cooperative care services are lacking especially in outpatient care and in nursing homes [28], despite being advisable [30, 29]. Our results substantiate that structural challenges for individuals with PD reinforce perceived insecurity and a feeling of not obtaining the needed health care. The majority of predictors from the reduced model and eight predictors from the full model may be projected to system-level barriers as per Zaman *et al.*

On the level of individual SDH, our data may also have some implications. We identified low educational attainment as a predictor for the perception of inadequate health care, which according to Zaman [19] relates to two dimensions: health literacy and self-efficacy. The former thereby inversely correlates with the ability to express healthcare needs [33, 34] – another significant predictor in our data – and with lower educational levels of PD-patients [35]. This is in good accordance with higher rates of hospitalisations and a higher caregiver burden [35] as well as higher disease severity [35] in PD-patients with lower health literacy. With regards to higher self-efficacy, this correlates the level of education [36] and, at the same time, with quality of life [37, 36]. Hence, our model suggests that people with PD who have received more education and who present with higher quality of life scores show the greatest probability to absorb healthcare disruptions in healthcare. Our data advocates for greater attention to individuals with lower levels of education, but particularly those with a diminished quality of life from professionals involved in PD-patient care.

Unsurprisingly, PD-patients deemed the expertise of physicians, that is neurologists and GP alike, important on the perception in adequate care. It is well-known

that patients' trust in care professionals may foster healthcare utilization [38, 39]. This warrants special emphasis since training appears at first glance accessible. The extent to which a trained Parkinson nurse could facilitate special services and therefore complement medical expertise remains a question to be answered (van Munster 2022). Yet, one might infer that they could catalyze tailored offerings such as legal or economic counselling. Hence, economic problems were highlighted in our results and are consistently cited as a reason for not seeking care services [19], although being often neglected by physicians. Barring direct costs, e.g. those services spared from health insurance, many patients also claim indirect expenses like those resulting from the inability to work [40]. This may gain importance with increases in the employment of women nowadays. In general, however, a rather surprising result is that women are at higher risk of perceived undersupply. The reasons are unclear, but abundant literature indicates that women have fewer caregivers compared with their spouses [41] especially, as they are less likely to receive care from their male partners [19]. A higher vulnerability to disruptions of healthcare because of the pandemic is therefore feasible and awaits future confirmation. In general, one might posit that to strengthen the resilience of PD health care, strategies are needed that recognize and address both structural and individual barriers in access to healthcare.

In addition to investments, reorganization and policy reforms on the structural level [45, 46], suitable assessments are also required to make the individual requirements of patients tangible for the treatment team [47, 46]. One possible solution for subjects lacking access to healthcare services or who may not be able to ask for assistance due to insufficient health literacy could be telehealth services. Telehealth services are effective means to facilitate access to care for persons with PD [42, ?]. In this questionnaire, we could corroborate these results as patients with access to these services before the pandemic reported a reduced likelihood of unmet care needs. Nevertheless, some caution is advised when interpreting these findings as this cohort must be deemed rather technology-savvy according to the nature of the questionnaire. Therefore, this process may not be generalisable for all German patients [43]. Further investigations are warranted, e.g., on how to increase the confidence in telemedicine or how to overcome technological limitations such as high-speed internet availability. Another possible caveat to consider are putative unintended negative effects on health equity, so that PD-patients with low incomes or with other barriers to accessing technology could be left behind and thus underserved [44].

General Limitations:

Despite revealing problems patients encountered during the COVID-19 pandemic, the interpretation of our results requires some caution. Hence, it was an anonymous online survey, so that the representativeness for the German PD population is not warranted. As abovementioned, not only patients filling out the questionnaire may be highly selected from a major support group in Germany but especially the online tool also suggests that it is more likely to be filled out by tech-savvy patients. In this context, the mean age of almost 67 years was surprising, so that young-onset PD-patients cannot be inferred from this. Finally, a limitation is also the fact that there was no way to ascertain misdiagnosis or the correctness of data, so that these results await confirmation in observational studies with controlled 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 pandemic were more affected. Therefore, it is important to examine these determinants more closely and to address them in future-oriented, resilient healthcare models. Further investigations into the effect of individual and structural influences as by Zaman *et al.* defined on measures of healthcare experiences should be object of further scrutiny.

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Abbreviations

AIC	Akaike Information Criterion	4
AUC	Area Under The Curve	4
DPV	Deutsche Parkinson Vereinigung	8
GLM	Generalised Linear Model	1
GP	general practitioner	5
iCARE-PD	abbreviation iCARE PD missing	3
PD	Parkinson's Disease	1
PMM	Predictive Mean Matching Method	4
SDH	Social determinants of health	1

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..

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Author details

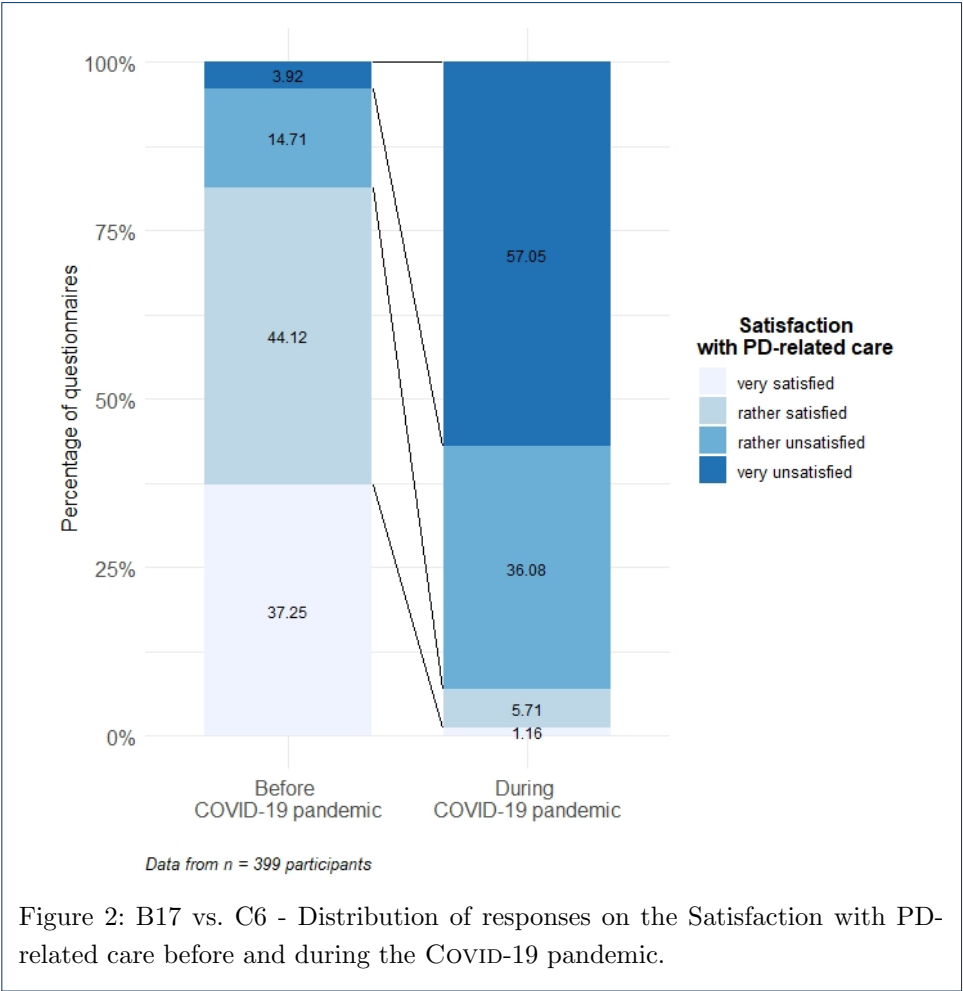
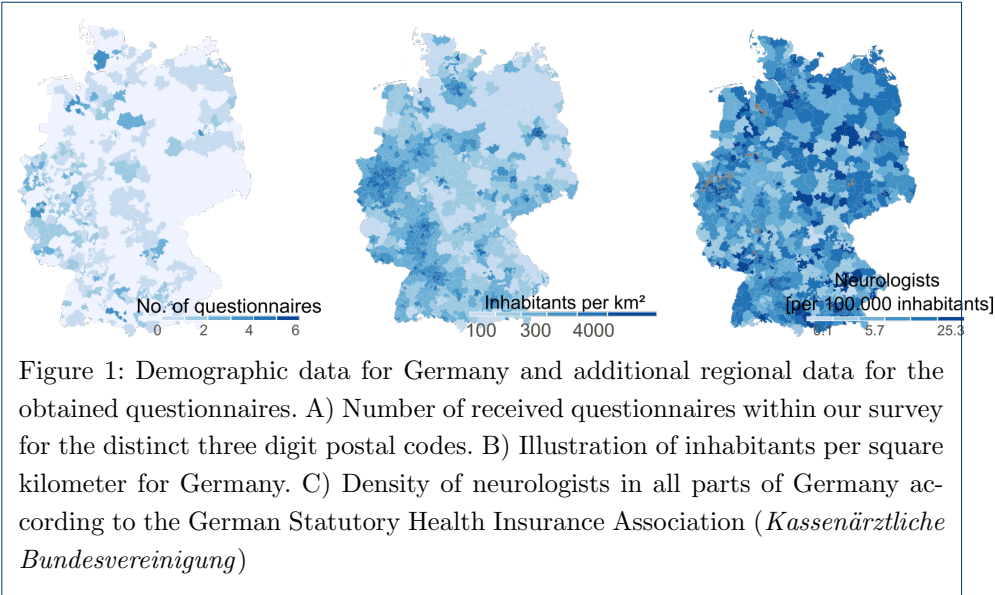
¹Department of Neurology, Philipps University, Marburg, Germany. ²Centre of Mind, Brain and Behaviour, Philipps University, Marburg, Germany.

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Figures



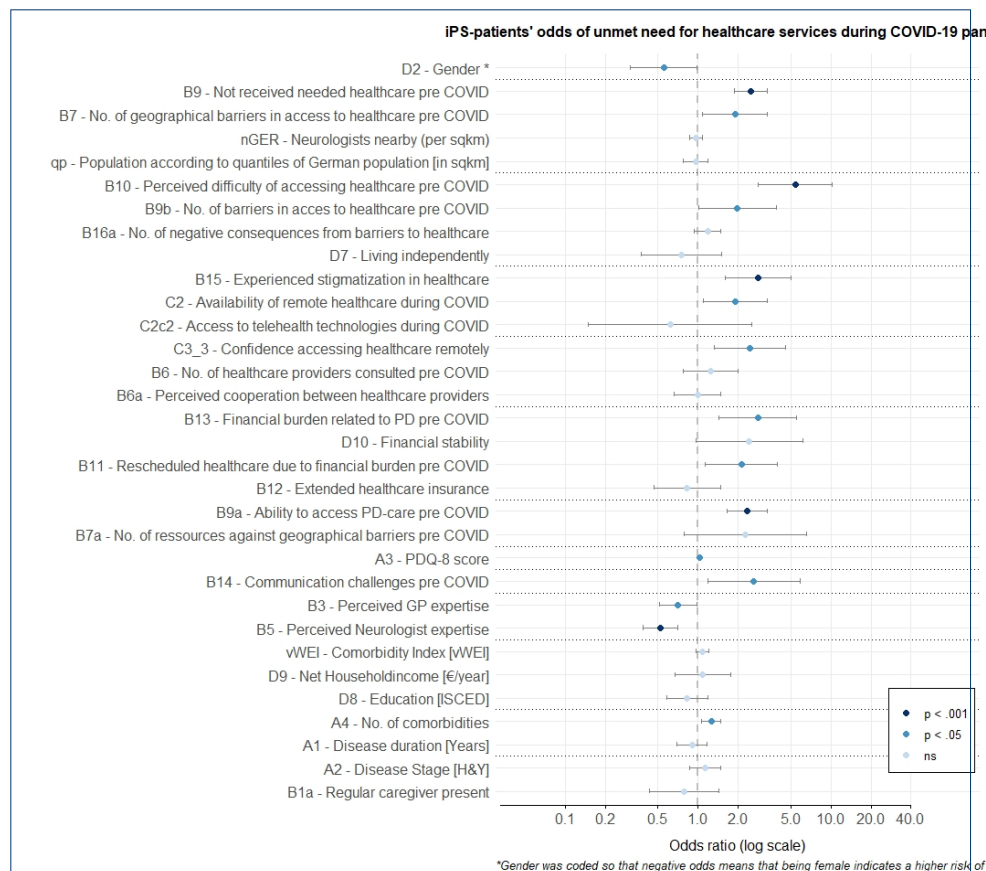


Figure 3: Unadjusted Odds ratios according to the GLM for all 32 questions. Odds were determined so that higher values indicate affirmation to the question that healthcare was needed but this need remained unmet during the COVID-19 pandemic. The dashed lines indicate the distinct domains according to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

Tables

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	6.55 (1.05)

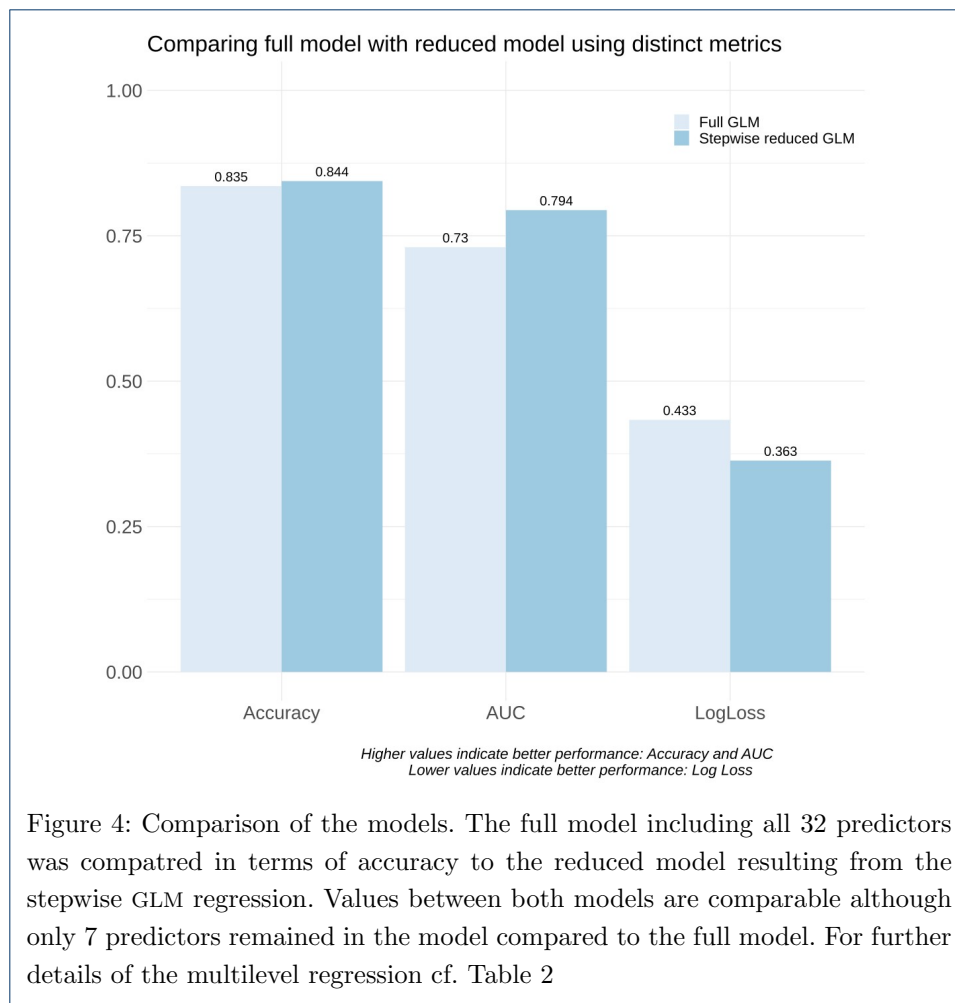


Table 2: Significant factors contributing to unmet care needs during COVID-19 pandemic according to the reduced GLM:

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

Additional Files

Table 3: Matching of items in the questionnaire to the categories from the work of Zaman et al. [19]

Question from Covid-Survey	Representative for...
Person-level Barriers	
1. A2, B1a, D7	Autonomy
2. A1, A4, vWEI, B16a	Health Status
3. D8	Health Literacy
4. B3, B5	Health Belief
5. B14	Communication (personal)
6. PDQ-8	Self-efficacy
7. B7a, B9a/b	Transportation
8. B11, B12, B13, D9, D10	Cost of care
9. D2	Other
System-level Barriers	
10. NA	Difficulties of Diagnosis
11. B6a	Coordination in care
12. B15, C2c2	Communication (system)
13. B7, B9b, B10, C3_3, nPop, nGer	Disparity in Health Services
14. B6, B7a, B9, B9a, C2, C2c2	Unavailability of Specialist Services

Table 4: Odds ratios for the distinct items of the questionnaire

Factors	Domain	Odds Ratio	CI lower	CI upper	p-value
A1 - Disease duration [Years]	Health Status	0.9	0.69	1.16	0.419
A2 - Disease Stage [H&Y]	Autonomy	1.13	0.87	1.47	0.367
A4 - Presence of comorbidities	Health Status	1.26	1.06	1.49	0.007
B1a - Regular caregiver present	Autonomy	0.79	0.43	1.44	0.438
B3 - Perceived GP expertise	Health Belief	0.71	0.51	0.98	0.038
B5 - Perceived Neurologist expertise	Health Belief	0.52	0.39	0.7	p < .001
B6 - No. of healthcare providers consulted pre COVID	Unavailability of Specialists Services	1.24	0.77	1.99	0.374
B6a - Perceived cooperation between healthcare providers	Coordination in Care	0.99	0.66	1.49	0.975
B7 - Presence of geographical barriers in access to healthcare pre COVID	Disparity in Health Services	1.9	1.08	3.33	0.026
B7a - No. of structural and transportation resources against geographical barriers pre COVID	Unavailability of Specialists Services/ Transportation	2.27	0.79	6.51	0.129
B9 - Not received needed healthcare pre COVID	Unavailability of Specialists Services	2.5	1.88	3.32	p < .001
B9a - Availability of PD-specific community resources	Unavailability of Specialists Services/ Transportation	2.33	1.65	3.31	p < .001
B9b - No. of structural and transportation barriers in access to healthcare pre COVID	Disparity in Healthcare Services/ Transportation	1.98	1.01	3.89	0.048
B10 - Perceived difficulty of accessing healthcare pre COVID	Disparity in Healthcare Services	5.37	2.84	10.17	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
B14 - Communication challenges pre COVID	Communication (personal)	2.63	1.18	5.82	0.017
B15 - Experienced stigmatization in healthcare	Communication (system)	2.84	1.6	5.03	p < .001
B16a - No. of negative health consequences from barriers to healthcare	Health Status	1.18	0.93	1.48	0.166
C2 - Availability of remote healthcare during COVID	Unavailability of Specialists Services	1.91	1.09	3.34	0.023
C2c2 - Access to telehealth technologies during COVID	Unavailability of Specialists Services/ Communication (system)	0.62	0.15	2.53	0.5
C3.3 - Confidence accessing healthcare remotely	Disparities in Healthcare Services	2.44	1.32	4.53	0.005
D2 - Gender *	Other	0.55	0.31	0.98	0.044
D7 - Living independently	Autonomy	0.75	0.38	1.51	0.421
D8 - Education [ISCED]	Health Literacy	0.82	0.58	1.18	0.284
D9 - Net Household income [per/year]	Cost of Care	1.08	0.67	1.75	0.75
D10 - Financial stability	Cost of care	2.43	0.97	6.09	0.059
PDQ-8 - PDQ-8 score	Self-Efficacy	1.03	1.01	1.05	0.011
nPop - Population according to quantiles of German population [in sqkm]	Disparity in Health Services	0.96	0.77	1.19	0.714
nGER - Neurologists nearby (per sqkm)	Disparity in Health Services	0.97	0.87	1.07	0.527
vWEI - Comorbidity Index [vWEI]	Health Status	1.08	0.97	1.21	0.155