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

Authors:

Marlena van Munster[1], Marcel R. Prinz[1], Eric Crighton[2], Tiago A. Mestre[3], David J. Pedrosa[1,4,*] and iCARE-PD consortium

[1] Department of Neurology, Philipps University Marburg, Baldingerstraße, 35043 Marburg, Germany

[2] Department of Geography, Environment and Geomatics, University of Ottawa. Simard Hall, 60 University Private, Ottawa, Ontario, Canada

[3] Parkinson's Disease and Movement Disorders Clinic, Division of Neurology. Department of Medicine. The Ottawa Hospital Research Institute, The University of Ottawa Brain and Mind Research Institute, Ottawa, ON, Canada

[4] Centre of Mind, Brain and Behaviour, Philipps University Marburg, Hans Meerwein Straße 6, 35032 Marburg, Germany

* correspondence: Department of Neurology, Philipps University Marburg, Baldingerstraße, 35043 Marburg, Germany - david.pedrosa@staff.uni-marburg.de

Abstract

Background

Due to the heterogeneous clinical presentation, people with Parkinson's disease (PwPD) develop individual health care needs as their disease progresses. However, as a result of limited health resources during the COVID-19 pandemic, many patients were put at risk of inadequate care. All this occured in the context of inequitable health care provision within societies, especially for such vulnerable populations.

Objective

This study aimed to investigate factors influencing satisfaction and unmet need for health care among PwPD during the COVID-19 pandemic in Germany.

Methods

Analyses relied on an anonymous online survey with a 49-item questionnaire. We aimed at describing access to health services before and during early stages of the pandemic. To this end, a Generalized Linear Model (GLM) was used to derive significant predictors and a stepwise regression to subsummarise the main factors of perceived inadequate care.

Results

In total, 551 questionnaires showed that satisfaction for PD-related care decreased significantly during the pandemic ($p < .001$). Especially, factors such as lower educational level, lower perceived expertise of healthcare providers, less confidence in remote care, difficulties in obtaining healthcare and restricted access to care prior to the pandemic but also lower densites of neurologists at residence and less ability to overcome barriers were indicative of higher odds to perceive unmet needs ($p < .05$).

Conclusion

The results unveil obstacles contributing to reduced access to healthcare during the COVID-19 pandemic for PwPD. The findings may guide factors to consider in the future in order to improve healthcare provision.

Keywords

Parkinson's disease; COVID-19 pandemic; health care; impact; Germany; access

Introduction

The Covid-19 pandemic presented unprecedented challenges worldwide afflicting people economically and culturally. With rising incidences of affected subjects, public life around the world came to a standstill and access to public services, especially health care, was disrupted [1–3]. Scientific evidence suggests that health care utilization declined by about one-third during the pandemic [2]. In Germany, a decrease in the use of outpatient and inpatient services was reported during the first wave, with dental and specialist examinations being cancelled most frequently, followed by physiotherapy, occupational therapy or speech therapy. [4]. Yet, this disruption affected individuals in Germany to varying degrees and especially those with chronic diseases, such as persons with Parkinson's disease (PwPD) [5–8]. This is not too surprising in that PwPD belong to the high-risk group for severe courses or for secondary complications of Covid-19, which made them reluctant to visit medical facilities [9].

PwPD 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. PD negatively affects individual psychosocial functioning [10], often leaving those affected in need of social, financial or physical support. People suffering from chronic diseases, including PwPD, often necessitate continuous medical services outside of emergency departments, such as frequent physiotherapy, and therefore appeared at high risk of undersupply during the pandemic [1, 3, 7]. Recent studies have unveiled the impact of the Covid-19 pandemic on people suffering from PD [6, 11–14]. For the German population, Zipprich et al. interviewed PwPD about their experience of healthcare during the pandemic. About one-third indicated that they experienced a decrease in their mobility because regular therapies (e.g., physiotherapy) were cancelled [11]. Fründt et al. also showed that PwPD who received long-term care were more socially isolated during the pandemic than those who did not receive long-term care. Thus, it seems likely that PwPD were affected to varying degrees by the constraints during the pandemic, not least because other areas of public health research also suggest that health crises have a highly individualized impact on access to care for vulnerable groups [15–17].

Beyond the variable degree of disability due to PD and the resulting and highly individual needs other determinants influencing how severely care is restricted may be inferred. Thus, determinants of access to healthcare 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 can be considered a relevant determinant, however, is by no means universal and rather context-specific considerations are required [18]. For PD, Zaman et al. proposed a model summarising structural and individual factors potentially influencing patients' access to healthcare [19]. Structural determinants 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 determinants of access to healthcare may relate to the perceived healthcare situation during the COVID-19 pandemic of PwPD in Germany. Therefore, we examined the impact of a multitude of factors on this population with special emphasis on their access to healthcare.

Methods

We conducted a cross-sectional survey of PwPD in Germany (or their caregivers). All stages of the disease were eligible to participate in the survey which consisted of a anonymous questionnaire. This questionnaire was distributed nationwide using the members' e-mail newsletter of the German Parkinson Association (Deutsche Parkinson Vereinigung e.V., dPV) between November 2020 to January 2021. The e-mail included a short invitation with 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. 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.

Questionnaire

This work carried out as part of the multinational iCARE-PD-project (https://icare-pd.ca/). Within the scope of this project, a 49-item questionnaire was developed which aimed at characterising the access of PwPD to healthcare services before and during the pandemic. 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. Fur that purpose, the initial questions in English were translated to German and were structured in four sections: A) patients' health status in terms of PD, operationalized by [21] and [22], but also concomitant diseases, B) experiences with healthcare services within twelve months before the pandemic, C) experiences with healthcare services during the COVID-19 pandemic with special emphasis on telemedicine services, and, D) demographic and socioeconomic characteristics of participants. There were single and multiple-choice questions along with 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.

Statistical analyses

All analyses were conducted in R [23]. Publicly available data on population densities [1] and those for neurologists[2] could be added to the analyses for regional data containment. For that purpose, we used the first three numbers of their German postal code, which were disclosed in the last section of the survey. Merging the available data with the maps for postal codes[3] resulted in regional distributions (cf. Figure 1). Population and neurologist densities were stratified into five equal quantiles for further analyses. Moreover, the provided information of concomitant diseases

---

[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

(besides PD) was collated to a score – the Elixhäuser Comorbitiy Score with its modification introduced by van Walraven et al. [24] 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).
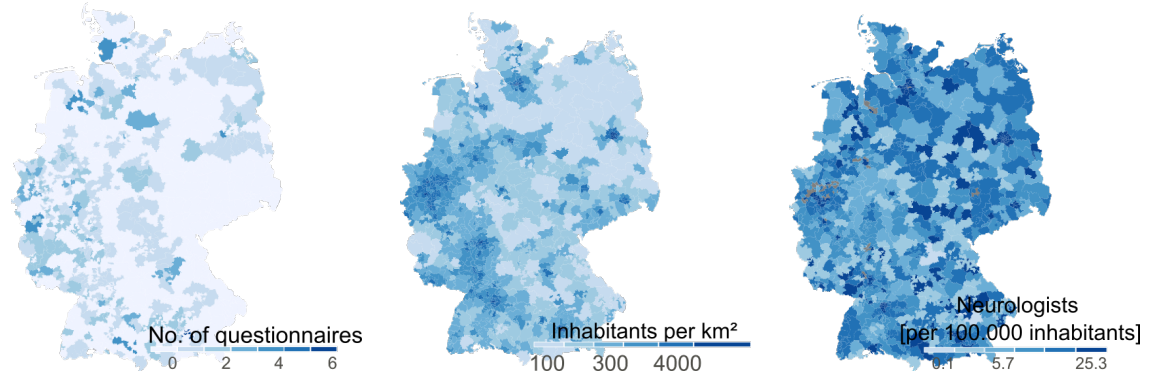

Figure 1: Demographic data for Germany and additional regional data for the obtained questionnaires. A) Number of received questionnaires within our survey for the distinct three digit postal codes. B) Illustration of inhabitants per square kilometer for Germany. C) Density of neurologists in all parts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

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 PD were provided?" (B17) vs.

- "Since the beginning of the COVID-19 pandemic, overall, how satisfied are you with the way healthcare services related to PD are provided?" (C6).

Furthermore, using a Generalized Linear Model (GLM) with a binomial link function, we estimated Odds ratios 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 PD but did not receive it?" (C4). For that, first missing data were imputed by taking advantage of a multivariate imputation scheme using the MICE-package [25]. We thereby assumed data missing at random and used the Predictive Mean Matching Method. Consecutively, stepwise reduction using a GLM with Stepwise Feature Selection (*glmStepAIC*) in both directions from the *caret*-package [26] aimed at minimising the Akaike Information Criterion (*AIC*). We first split all available data into 80% of training and 20% of test data and performed the stepwise regression after centering

and rescaling values and by 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 and analyses are available at https://github.com/dpedrosac/covidPD/

Results

In total, 551 questionnaires (response rate about 3%) were filled out with 252 different postal codes from all 16 German regions (Bundesländer, cf. Figure 1). Of all participants, 388 (70.4%) returned a complete questionnaire (for demographics from parts A and D, cf. Table 1).

Table 1: Demographics and clinical characteristics of survey respondents

	Overall (n = 551)
Age (mean (SD))	66.76 (9.25)
Gender = Female (%)	148 (41.6)
Time since PD diagnosis (%)	
<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)

Satisfaction for PD-related care significantly decreased during the pandemic (pre-pandemic, Mdn = 3 vs. post-pandemic, Mdn = 1; $p = 10^{-73}$). More than 90% of all participants stated to be somewhat unsatisfied or very unsatisfied with their PD-related care during the pandemic (cf. Figure 2).

To ascertain factors associated with 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 PD but did not receive it?") was performed, unveiling factors which contributing 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
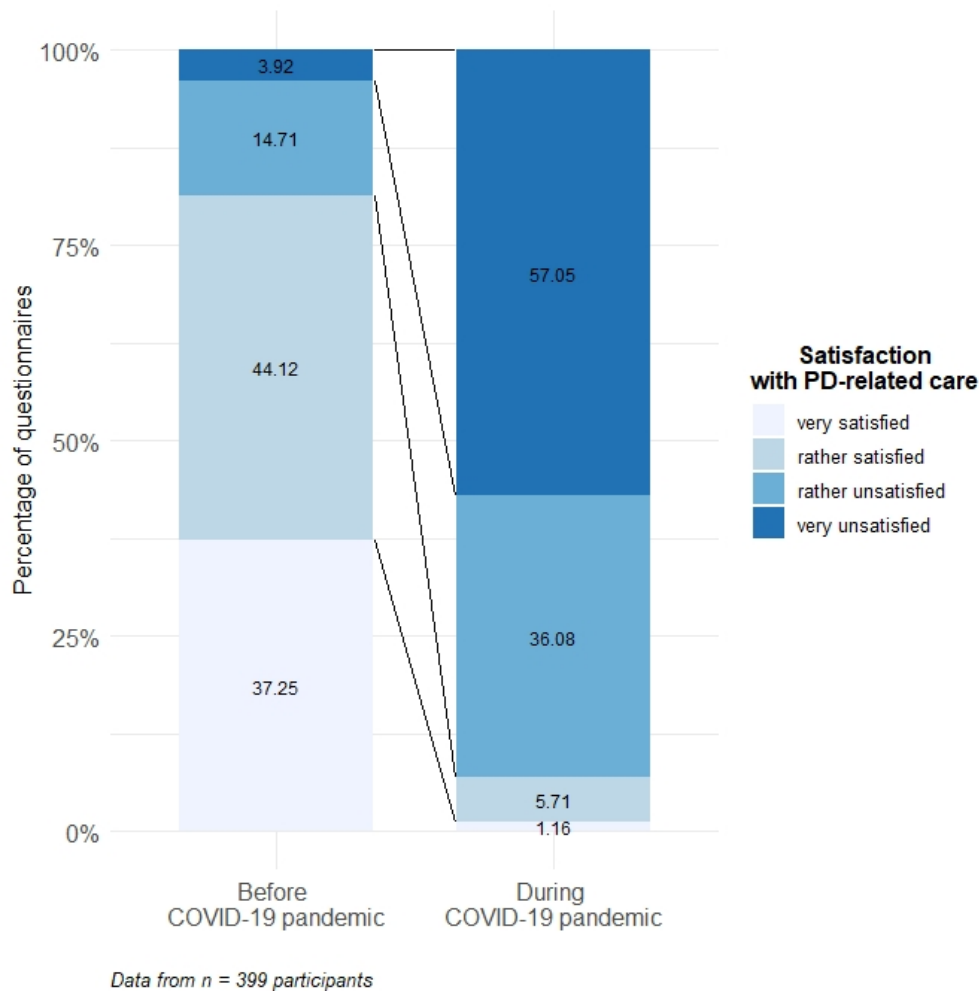
Figure 2: B17 vs. C6 - Distribution of responses on the Satisfaction with PD-related care before and during the COVID-19 pandemic.

the pandemic, for patients with higher degrees of stigmatisation in healthcare but also for those who did not receive healthcare services before the pandemic. A significant contribution – albeit lower with significance values $p < .05$ – was encountered for PwPD with increasing levels of comorbidity, with perceived lower expertise of the general practitioner, with higher quality of life scores retrospectively, for people with higher financial burden due to PD or who needed to reschedule healthcare appointments due to financial problems 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. In assumption of an overfitted model, we performed a two-way stepwise regression for question "C4" (see above)
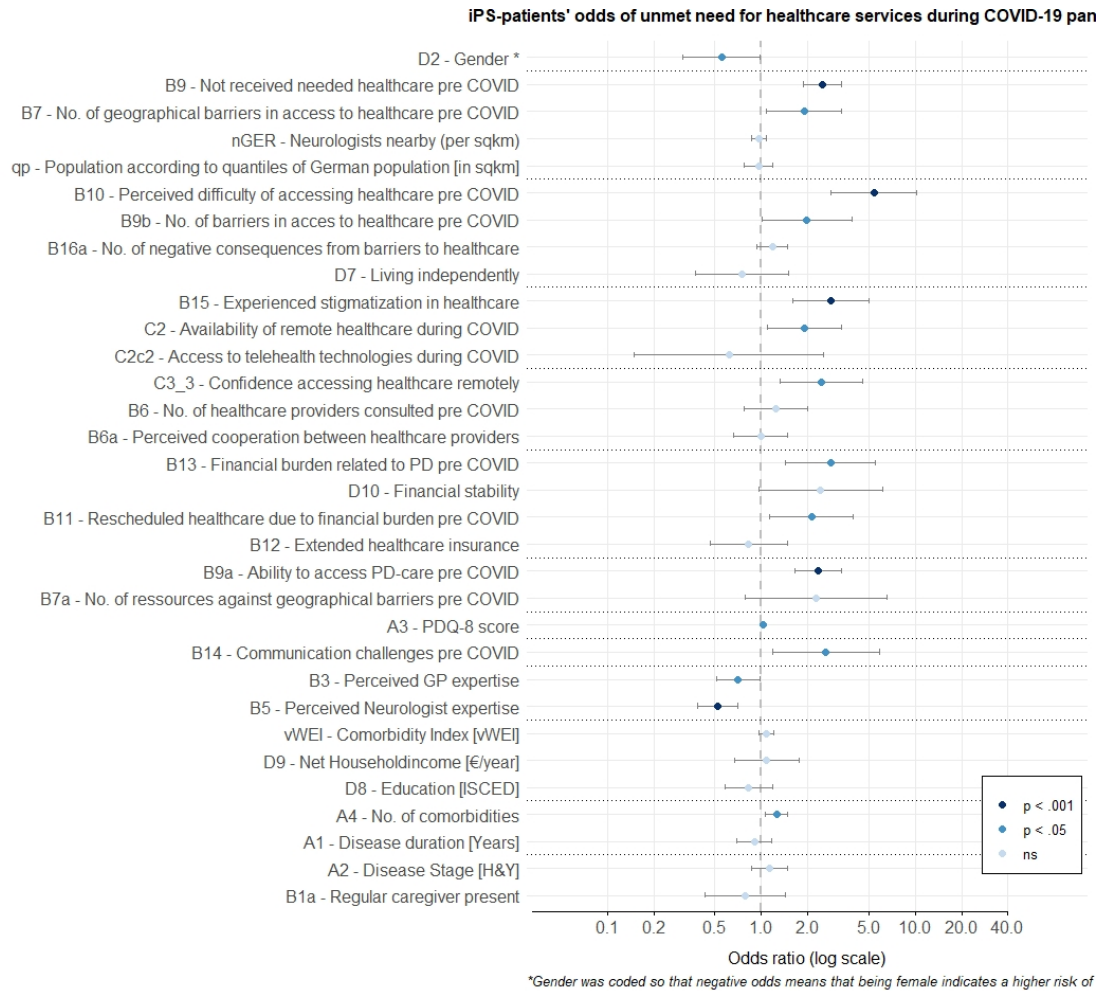
Figure 3: Odds ratios for all items in terms of perceived inadequate healthcare during pandemic. Odds were determined via GLM and coded so that higher values indicate affirmation to the question that healthcare was needed but this need remianed unmet during the COVID-19 pandemic. The dashed lines indicate the distinct domains according to Zaman et al. [19], whereas significance is illustrated as color of the dot, with two distinct levels of significance.

so that the intitial 32 items could be reduced to seven significant predictors of unmet needs for healthcare services (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

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

Predictor	Estimate	SE	z-value	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

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 identified factors such as lower educational levels, a lack of perceived expertise in the treating physicians and structural obstacles or lack of support offerings as important factors contributing to insecurity and the feeling of not having received adequate health services during the COVID-19 pandemic among German PwPD. To the best of our knowledge, this is the first time that determinants of PD-patients' perceived access to healthcare were investigated. With our study, we demonstrate that not all individuals were affected equally but that structural as well as individual determinants 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 PwPD may be improved.

Our results substantiate that structural challenges for individuals with PD reinforce perceived insecurity and a feeling of not obtaining the needed healthcare. The majority of predictors from the reduced model and eight predictors from the full model may be projected to system-level "barrier" put forward by Zaman et al. Interestingly, a good overall performance has been attested to the German healthcare system during the pandemic [27], which is transferable to PwPD [12]. 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 [28–31] for this heterogeneous population. One of the major challenges physicians face when treating PD is its diverse clinical manifestation. Multimodal complex treatments could be a potential remedy [28], yet limited availability of such services cause long journeys for people from some regions [28] as coordinated care approaches for PwPD remain rare in some parts of Germany [29]. Furthermore, staff providing specialised, structured and cooperative care services are lacking especially in outpatient care and in nursing homes [30] despite being advisable [31, 32].

On the level of individual determinants, our data may also have some implications. We identified low educational attainment as a predictor for the perception of inadequate healthcare, which according to Zaman [19] relates to two dimensions: health literacy and self-efficacy. The former inversely correlates with the ability to express healthcare needs [33, 34] and with educational levels of PwPD [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 PwPD with lower health literacy. With regards to higher self-efficacy, this correlates with the level of education[36] and, at the same time, with quality of life [36, 37]. Hence, our model suggests that PwPD who have received more education and who present with higher quality of life scores show the greatest probability to absorb disruptions in healthcare. Contrarily, our data hence advocates for greater attention tp PD-patients with lower levels of education, but particularly those with quality of life restrictions.

Unsurprisingly, PwPD deemed the expertise of neurologists important on the perception in adequate care. It is well-known that patients' trust in care professionals may foster healthcare utilisation [38, 39]. This warrants special emphasis since training appears at first glance accessi-

ble. The extent to which a trained Parkinson nurse could facilitate special services and therefore complement medical expertise remains a question to be answered [40]. Yet, one might infer that they could catalyst 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]. 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 [41]. This may gain importance with increases in the employment of women nowadays. In general, however, a somewhat surprising result is that women are at higher risk of perceived undersupply. The reasons are unclear, but literature indicates that women have fewer caregivers compared with their spouses [42] 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 [43, 44], suitable assessments may also help to make the individual needs of patients tangible [44, 45]. One possible solution for subjects lacking access to healthcare services or who may not be able to ask for assistance due insufficient health literacy could be telehealth services. These services are effective means to facilitate access to care. In this questionnaire, we could corroborate this [46, 47] as PD-patients familiar with telemedicine services before the pandemic reported a reduced likelyhood of unmet care needs. Nevertheless, some caution is advised when interpreting these findings as this cohort must be deemed rather technology-savy according to the nature of the questionnaire. Therefore, this process may not generalisable for all patients [48]. 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 PwPD with low incomes or with other barriers to accessing technology could be left behind [49].

General Limitations:

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. 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. The response rate of 3% of this study was slightly lower than a comparable questionnaire study of PD-clientele [12]. As abovementioned, not only patients filling out the questionnaire may be highly selected from a major support group in Germany. 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 as Zaman et al. defined on measures of healthcare experiences should be object of further scrutiny.

References

[1] A. Núñez, S. Sreeganga, and A. Ramaprasad (2021): "Access to Healthcare during COVID-19": *International journal of environmental research and public health*, **18**.

[2] R. Moynihan, S. Sanders, Z. A. Michaleff, et al. (2021): "Impact of COVID-19 pandemic on utilisation of healthcare services: a systematic review": *BMJ open*, **11**.

[3] W. H. Organization et al. (2020): "The impact of the COVID-19 pandemic on noncommunicable disease resources and services: results of a rapid assessment".

[4] C. Heidemann, L. Reitzle, C. Schmidt, et al. (2022): "Non-utilisation of health care services during the COVID-19 pandemic: Results of the CoMoLo study": *Journal of Health Monitoring*.

[5] K. S. Kasar and E. Karaman (2021): "Life in lockdown: Social isolation, loneliness and quality of life in the elderly during the COVİD-19 pandemic: A scoping review": *Geriatric Nursing*, **42**.

[6] G. Yogev-Seligmann and M. Kafri (2021): "COVID-19 social distancing: negative effects on people with Parkinson disease and their associations with confidence for self-management": *BMC neurology*, **21**.

[7] C. Scheidt-Nave, B. Barnes, A.-K. Beyer, et al. (2021): "Care for the chronically ill in Germany–The challenges during the COVID-19 pandemic": *Journal of Health Monitoring*, **5**.

[8] W. Sepúlveda-Loyola, I. Rodrıguez-Sánchez, P. Pérez-Rodrıguez, et al. (2020): "Impact of social isolation due to COVID-19 on health in older people: mental and physical effects and recommendations": *The journal of nutrition, health & aging*, **24**.

[9] A.-L. Feral-Pierssens, P.-G. Claret, and T. Chouihed (2020): "Collateral damage of the COVID-19 outbreak: expression of concern": *European Journal of Emergency Medicine*.

[10] D. Demirtepe-Saygili, "Psychosocial Effects of the COVID-19 Pandemic on Adults With Chronic Illnesses", *The Impact of the COVID-19 Pandemic on Child, Adolescent, and Adult Development*, IGI Global, 2022, pp. 1–20.

[11] H. M. Zipprich, U. Teschner, O. W. Witte, A. Schönenberg, and T. Prell (2020): "Knowledge, attitudes, practices, and burden during the COVID-19 pandemic in people with Parkinson's disease in Germany": *Journal of clinical medicine*, **9**.

[12] O. Fründt, A.-M. Hanff, T. Mai, et al. (2022): "Impact of COVID-19 Pandemic on (Health) Care Situation of People with Parkinson's Disease in Germany (Care4PD)": *Brain sciences*, **12**.

[13] D. Richter, R. Scherbaum, D. Bartig, et al. (2021): "Analysis of nationwide multimodal complex treatment and drug pump therapy in Parkinson's disease in times of COVID-19 pandemic in Germany": *Parkinsonism & related disorders*, **85**.

[14] S. K. Brooks, D. Weston, and N. Greenberg (2021): "Social and psychological impact of the COVID-19 pandemic on people with Parkinson's disease: a scoping review": *Public Health*, **199**.

[15] T. Huijts, P. Stornes, T. A. Eikemo, C. Bambra, and H. Consortium (2017): "Prevalence of physical and mental non-communicable diseases in Europe: findings from the European Social Survey (2014) special module on the social determinants of health": *The European Journal of Public Health*, **27**.

[16] E. C. Lowcock, L. C. Rosella, J. Foisy, A. McGeer, and N. Crowcroft (2012): "The social determinants of health and pandemic H1N1 2009 influenza severity": *American journal of public health*, **102**.

[17] W. H. Organization, *COVID-19 and the social determinants of health and health equity: evidence brief*, World Health Organization, 2021, pp. i–22.

[18] W. H. Organization et al. (2010): "A conceptual framework for action on the social determinants of health".

[19] M. S. Zaman, S. Ghahari, and M. A. McColl (2021): "Barriers to Accessing Healthcare Services for People with Parkinson's Disease: A Scoping Review": *Journal of Parkinson's Disease*.

[20] D. J. Leiner, *SoSci survey (version 3.1. 06)[computer software]*, 2019.

[21] M. Hoehn and M. Yahr (1967): "Parkinsonism: onset, progressive and mortality": *Neurology*, **17**.

[22] C. Jenkinson, R. Fitzpatrick, V. Peto, R. Greenhall, and N. Hyman (1997): "The PDQ-8: development and validation of a short-form Parkinson's disease questionnaire": *Psychology and Health*, **12**.

[23] R Core Team, *R: A Language and Environment for Statistical Computing*, R Foundation for Statistical Computing, Vienna, Austria, 2021, URL: https://www.R-project.org/.

[24] C. van Walraven, P. C. Austin, A. Jennings, H. Quan, and A. J. Forster (2009): "A modification of the Elixhauser comorbidity measures into a point system for hospital death using administrative data": *Medical care*.

[25] S. van Buuren and K. Groothuis-Oudshoorn (2011): "mice: Multivariate Imputation by Chained Equations in R": *Journal of Statistical Software*, **45**.

[26] M. Kuhn (2008): "Building Predictive Models in R Using the caret Package": *Journal of Statistical Software, Articles*, **28**.

[27] E. O. on Health Systems, Policies, B. M, et al., *Germany: health system review*, Health Systems in Transition; Vol. 22 (6), World Health Organization. Regional Office for Europe, 2020, pp. i–273.

[28] D. Richter, D. Bartig, S. Muhlack, et al. (2019): "Dynamics of Parkinson's disease multimodal complex treatment in Germany from 2010–2016: Patient characteristics, access to treatment, and formation of regional centers": *Cells*, **8**.

[29] M. van Munster, L. Tönges, K. F. Loewenbrück, T. Warnecke, and C. Eggers (2020): "Building a Parkinson-Network–Experiences from Germany": *Journal of clinical medicine*, **9**.

[30] T. Prell, F. Siebecker, M. Lorrain, et al. (2020): "Specialized staff for the care of people with Parkinson's disease in Germany: an overview": *Journal of Clinical Medicine*, **9**.

[31] G. Deuschl, W. Oertel, and H. Reichmann (2016): "S3-Leitlinie Idiopathisches Parkinson-Syndrom": *Leitlinie der Deutschen Gesellschaft für Neurologie (DGN). AWMF-Register-Nummer*.

[32] D. L. Radder, J. Nonnekes, M. Van Nimwegen, et al. (2020): "Recommendations for the organization of multidisciplinary clinical care teams in Parkinson's disease": *Journal of Parkinson's disease*, **10**.

[33] J. T. Davis, A. Ehrhart, B. H. Trzcinski, S. Kille, and J. Mount (2003): "Variability of experiences for individuals living with Parkinson disease": *Journal of Neurologic Physical Therapy*, **27**.

[34] C. S. Hurt, L. Rixon, K. R. Chaudhuri, et al. (2019): "Barriers to reporting non-motor symptoms to health-care providers in people with Parkinson's": *Parkinsonism & Related Disorders*, **64**.

[35] J. E. Fleisher, K. Shah, W. Fitts, and N. A. Dahodwala (2016): "Associations and implications of low health literacy in Parkinson's Disease": *Movement disorders clinical practice*, **3**.

[36] K. E. Lim, S. R. Kim, Y. H. Sung, et al. (2020): "Factors influencing self-management in Parkinson's disease: a cross-sectional study": *Geriatric Nursing*, **41**.

[37] O. M. Rostagni and L. A. Stutts (2022): "Gratitude, self-efficacy, and health-related quality of life in individuals with Parkinson's Disease": *Psychology, Health & Medicine.*

[38] J. L. Bainbridge and J. M. Ruscin (2009): "Challenges of treatment adherence in older patients with Parkinson's disease": *Drugs & aging*, **26**.

[39] J. Y. Shin and B. Habermann (2016): "Initiation of medications for Parkinson's disease: a qualitative description": *Journal of Clinical Nursing*, **25**.

[40] M. van Munster, J. Stümpel, F. Thieken, et al. (2022): "The Role of Parkinson Nurses for Personalizing Care in Parkinson's Disease: A Systematic Review and Meta-Analysis": *Journal of Parkinson's Disease.*

[41] A. E. Spottke, M. Reuter, O. Machat, et al. (2005): "Cost of illness and its predictors for Parkinson's disease in Germany": *Pharmacoeconomics*, **23**.

[42] N. Dahodwala, K. Shah, Y. He, et al. (2018): "Sex disparities in access to caregiving in Parkinson disease": *Neurology*, **90**.

[43] L. A. Taylor, A. X. Tan, C. E. Coyle, et al. (2016): "Leveraging the social determinants of health: what works?": *PloS one*, **11**.

[44] L. Gottlieb, C. Fichtenberg, H. Alderwick, and N. Adler (2019): "Social determinants of health: what'sa healthcare system to do?": *Journal of Healthcare Management*, **64**.

[45] N. L. Friedman and M. P. Banegas (2018): "Toward addressing social determinants of health: a health care system strategy": *The Permanente Journal*, **22**.

[46] M. Achey, J. L. Aldred, N. Aljehani, et al. (2014): "The past, present, and future of telemedicine for Parkinson's disease": *Movement disorders*, **29**.

[47] M. van Munster, J. Stümpel, F. Thieken, et al. (2021): "Moving towards Integrated and Personalized Care in Parkinson's Disease: A Framework Proposal for Training Parkinson Nurses": *Journal of personalized medicine*, **11**.

[48] C. Eggers, I. Wellach, S. Groppa, M. Strothjohann, and J. Klucken (2020): "Care of patients with Parkinson's disease in Germany: status quo and perspectives as reflected in the digital transition": *Der Nervenarzt.*

[49] M. Samuels-Kalow, T. Jaffe, and K. Zachrison (2021): "Digital disparities: designing telemedicine systems with a health equity aim": *Emergency Medicine Journal*, **38**.

Supplementary Material

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	
1. A2, B1a, D7	Autonomy	
2. A1, A4, vWEI, B16a	Health Status	
3. D8	Health Literacy	Person-level Barriers
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	
10. NA	Difficulties of Diagnosis	
11. B6a	Coordination in care	System-level barriers
12. B15, C2c2	Communication (system)	
13. B7, B9b, B10, C3_3, nPop, nGer	Disparty in Health Services	
14. B6, B7a, B9, B9a, C2, C2c2	Unavailability of Specalist Services	

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

Factors	Domain	OR	CIlow	CIup	p
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 Specialitsts 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	Disparty in Health Services	1.9	1.08	3.33	0.026
B7a - No. of structural and transportation ressources 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 Specialits Services	2.5	1.88	3.32	p < .001
B9a - Availability of PD-specific community ressources	Unavailability of Specialists Services/ Transportation	2.33	1.65	3.31	p < .001
B9b - No. of structural and transportation barriers in acces to healthcare pre COVID	Disparatiey in Healthcare Services/ Transportation	1.98	1.01	3.89	0.048
B10 - Perceived difficulty of accessing healthcare pre COVID	Disparatiey 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

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

Factors	Domain	OR	CIlow	CIup	p
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 Specialitsts Services	1.91	1.09	3.34	0.023
C2c2 - Access to telehealth technologies during COVID	Unavailability of Specialitsts 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 Householdincome [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]	Disparty in Health Services	0.96	0.77	1.19	0.714
nGER - Neurologists nearby (per sqkm)	Disparty 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

Comparing full model with reduced model using distinct metrics

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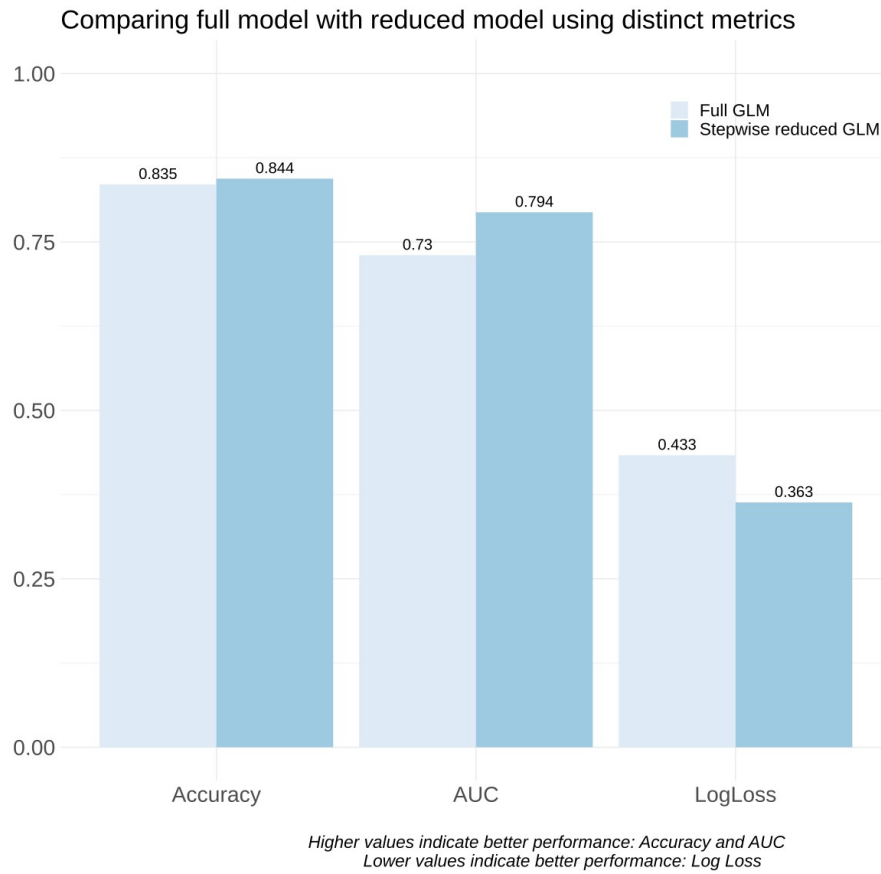*Lower values indicate better performance: Log Loss*

Figure 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