

Parkinson's Disease and Subjective Prospects for the Future in Different Life Domains. Findings of a Nationally Representative Sample

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Purpose: To analyze the link between Parkinson's disease and perceived prospects for the future.

Patients and Methods: Data were taken from the German Ageing Survey (year 2021; n=4296 individuals, thereof 33 individuals with Parkinson's disease) were used. This is a nationally representative sample of community-dwelling individuals ≥ 40 years in Germany. Perceived prospects for the future in different life domains (ie, living standard, health and general optimism) were used as outcomes. Physician-diagnosed Parkinson's disease served as key independent variable. It was adjusted for several covariates.

Results: Individuals with Parkinson's disease had a markedly worse (Cohen's d=0.65) general optimism compared to individuals without Parkinson's disease. After adjusting for various factors, these differences disappeared in multiple linear regressions ($\beta=-0.04$, $p=0.72$). Moreover, multiple ordered logistic regressions showed that individuals with Parkinson's disease had a worse future self-rated health (OR: 4.10, 95% CI: 1.99–8.47, $p<0.001$) compared to individuals without Parkinson's disease.

Conclusion: Our study first showed that general optimism may be lower among individuals with Parkinson's disease (bivariate analysis). However, this association disappeared when it was adjusted for health-related factors in regression analysis. In sum, our findings indicate that more general future-related factors did not significantly differ between individuals with and without Parkinson's disease. However, there were significant differences in future self-rated health.

Keywords: perceived longevity, outlook, optimism, health, living standard, Parkinson, Parkinson's disease

Introduction

Parkinson's disease is a progressive neurodegenerative disorder which is mainly characterized by, among other things, multisystem involvement and non-motor symptoms (eg, sleep disorder, constipation or hyposmia).¹ As also outlined by Schapira et al¹

The diagnosis of PD is currently dependent on the presence of motor deficits including bradykinesia, rigidity and tremor, usually manifesting unilaterally or at least asymmetrically. (p. 435)

A lot of studies have shown that Parkinson's disease is associated with worse physical functioning² or depressive symptoms³ – or more generally with lower health-related quality of life.⁴ However, only very few studies examined less clinically-oriented outcomes such as general optimism or life satisfaction. For example, a former longitudinal study showed that the incidence of Parkinson's disease can lead to lower satisfaction with life.⁵ Moreover, another recent study⁶ reported a strong bivariate association between Parkinson's disease and lower general optimism which, however, vanished in multiple linear regression analysis, after adjusting for various covariates.

Due to the limited knowledge, particularly related to perceived prospects for the future in different life domains, our aim was to examine the association between Parkinson's disease and the aforementioned perceived prospects for the future in different life domains – based on nationally representative data of middle-aged and older community-dwelling adults. Such knowledge may help to underline the relevance of Parkinson's disease for future-oriented psychological outcomes. Such outcomes are of great importance. We assume that outcomes such as poor future self-rated health may also (at least partly) reflect a potential powerlessness in the face of Parkinson's disease. Moreover, we assume that individuals may therefore feel helpless and may think that Parkinson's disease is progressing inevitably, regardless of their behavior regarding the disease. This may lead to a self-fulfilling prophecy where individuals may develop bad lifestyle habits (eg, start smoking, increase alcohol intake or drug use or sedentary behavior) and ultimately bad health.^{7–10} Moreover, this is important because favorable lifestyle habits can have a positive impact on physical capacities among individuals with Parkinson's disease.¹¹ Moreover, we assume that adherence to treatment (ie, behavior of the person with medical or health advice) may also change among individuals with Parkinson's disease when the future is perceived as hopeless and without prospects. For these reasons, we think that it is important to examine the associations of interest.

With regard to government restrictions during the time of data collection: In mid-March 2020, a series of nationwide actions were taken to address the spread of COVID-19 in Germany, which involved, among other things, temporarily shutting down schools. Subsequently, in mid-April 2020, certain limitations were eased, enabling schools to resume operations in May 2020. Nevertheless, as infection rates started to surge once more during the autumn of 2020, additional measures were enforced. Finally, in May 2021, specific restrictions were lifted to facilitate a phased transition towards resuming normal activities.

Materials and Methods

Sample

We employed data from wave 7 of the German Ageing Survey (DEAS, “Deutscher Alterssurvey”) – a representative sample of community-dwelling middle-aged and older adults in Germany. We have focused on the most recent data collection in order to get as up-to-date a picture as possible of the associations of interest. The German Ageing Survey is funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ). Fieldwork was done by the infas Institute for Applied Social Sciences from November 2020 to March 2021. A CAPI-per-phone survey (with accompanying written drop-off questionnaire for self-completion which included sensitive questions such as well-being) was used. The average interview duration was about 75 minutes in wave 7. The DEAS study covers main topics in later life such as labor force participation, retirement, media consumption, well-being, health or ageism.

In general, the DEAS study has a cohort-sequential design. However, a new baseline sample could not be introduced in the most recent wave because a survey under the conditions of the COVID-19 pandemic could not be conducted in a face-to-face interview and only address data, but no telephone numbers, were available for the baseline sample.

Thus, in wave 7, the sample was based on all participants of the baseline samples 1996 to 2014 who were still available and who were willing to participate in the panel. The gross sample equaled 8379 individuals. In total, valid interviews were available for 5402 individuals aged 46 to 100. Moreover, about 82% (4419 individuals) of the participants filled out the additional written drop-off questionnaire. Due to a few missing values, the analytical sample equaled $n=4296$ individuals.

In wave 7, the response rate equaled approximately 65%. One main reason for non-participation was the fundamental refusal to take part, and thus the accompanying withdrawal of willingness to participate in the panel. The probability of participation was positively associated with younger age, higher educational level and good health status, whereas it was mostly not associated with income category, marital status, living situation or community size.¹² Klaus et al¹³ gave further details about the DEAS study.

Before the interview, each participant signed a formal waiver of informed consent. An ethical statement was not required because the criteria for such a statement were not met (eg, examination of patients, risk to respondents, lack of information about the aims of the study, or use of invasive methods). This is in accordance with the guidelines of the German Research Foundation. The DEAS study is organized by the German Center for Gerontology (DZA), which

decided that an ethical statement was not needed. The DEAS study has a standing advisory board that received detailed information about the sampling procedure, consent to participate, and instruments used in the DEAS study before each wave of data collection. This standing advisory board concluded that the DEAS study does not require approval by an ethics committee. The procedure described is in accordance with local guidelines. The study also follows the recommendations of the Declaration of Helsinki on Ethical Principles.

Dependent Variables

Different future-related outcomes were used: standard of living in the future, health prospects for the future and general optimism.

To quantify the living standard in the future, individuals were asked: “And if you think about the future, how do you expect your standard of living to change in the future?” [“will improve greatly”; “will improve somewhat”; “will remain the same”; “will worsen somewhat”; “will get much worse”].

To quantify health prospects for the future, individuals were asked: “How often do you deal with the topic death and dying?” [never; seldom; sometimes; often; very often]. Additionally, individuals were asked: “How do you expect your state of health to change in the future?” [“will improve greatly”; “will improve somewhat”; “will remain the same”; “will worsen somewhat”; “will get much worse”]. Furthermore, individuals were asked: “What age do you think you will live to?” [years]. With regard to perceived longevity, we removed four (quite) implausible values (two times: expected longevity was lower than their actual current chronological age; two times: expected longevity was 200 years).

Lastly, general optimism was quantified using a tool developed by Brandtstädter and Wentura.¹⁴ This tool has five items (each ranging from 1 = strongly agree to 4 = strongly disagree). An example is: “I am looking forward to the life ahead of me”. Four items were recoded. Subsequently, a final score was built by averaging the items. The final score ranges from 1 to 4 with higher values corresponding to higher optimism.

Key Independent Variable: Parkinson's Disease

From a list of various chronic conditions, individuals were asked to identify which chronic conditions they had been formally diagnosed with by their doctor. One of these chronic conditions was Parkinson's disease (no; yes). This item served as key independent variable. Such an assessment was also used in former studies^{5,6} and is a common way of quantifying Parkinson's disease in large cohort studies such as the Survey of Health, Ageing, Retirement in Europe (SHARE) – or the DEAS study. It should be noted that the age of diagnosis and the severity of Parkinson's disease was not quantified in the DEAS study (please see the limitations section for further details).

Covariates

Following prior research and based on theoretical considerations,^{15,16} several covariates were included in regression analysis: With regard to sociodemographic factors, age, sex (men; women), marital situation (married, living together with spouse; married, living separated from spouse; divorced; widowed; single), and educational level (which distinguished between low (0–2), medium (3–4), and high (5–6) education according to the ISCED-classification¹⁷) were included. With regard to lifestyle factors, we included: Current smoker status (daily; sometimes; not anymore; never been smoker), frequency of sports activities and alcohol intake (in both cases: six categories from daily to never).

With regard to health-related covariates, we included: Self-rated health (single item, from 1 (very good) to 5 (very bad)), physical functioning (SF-36 subscale “physical functioning”, ranging from 0 (worst) to 100 (best)),¹⁸ depressive symptoms (Center for Epidemiologic Studies Depression Scale;¹⁹ 15-item version, ranging from 0 (no depressive symptoms) to 45 (severe depressive symptoms)) and a sum score for chronic conditions (0 to 11 chronic conditions; for example: cardiac and circulatory disorders, cancer or diabetes).

Statistical Analysis

For our analytical sample, sample characteristics stratified by Parkinson's disease (ie, absence or presence of Parkinson's disease) are shown. The effect sizes between Parkinson's disease and the outcomes (Cramer's V or Cohen's d, as appropriate) are also given. Then, we conducted ordered logistic or linear regressions (as appropriate) to examine the

association between Parkinson's disease and the outcomes. A full-information maximum likelihood (FIML) approach was used to address missing values in sensitivity analyses for linear regressions.²⁰ For example, when general optimism served as outcome measure, the average variance inflation factor (VIF) was 2.21, with most VIFs being very low. This suggests that multicollinearity is not a threat. To deal with serial correlation, cluster-robust standard errors were calculated.

$P < 0.05$ was used to define the statistical significance level. The analyses were done with Stata 16.1 (StataCorp, College Station, TX, USA).

Results

Sample Characteristics and Bivariate Analysis

Sample characteristics for our analytical sample (additionally stratified by Parkinson's disease) are shown in Table 1. In the total sample, average age was 68.8 years (SD: 10.2 years), ranging from 46 to 98 years. About 51% of the individuals

Table 1 Sample Characteristics

Variables	Absence of Parkinson's Disease N=4263	Presence of Parkinson's Disease N=33	Total Sample N=4296	P-value
	Mean (SD) / n (%)			
Sex				0.09
Men	2083 (48.9)	21 (63.6)	2104 (49.0)	
Women	2180 (51.1)	12 (36.4)	2192 (51.0)	
Age	68.8 (10.2)	75.5 (9.0)	68.8 (10.2)	<0.001
Educational level				0.21
Low education	166 (3.9)	3 (9.1)	169 (3.9)	
Medium education	1971 (46.2)	12 (36.4)	1983 (46.2)	
High education	2126 (49.9)	18 (54.5)	2144 (49.9)	
Marital status				0.64
Married, living together with spouse	2967 (69.6)	25 (75.8)	2992 (69.6)	
Married, living separated from spouse	48 (1.1)	0 (0.0)	48 (1.1)	
Divorced	405 (9.5)	1 (3.0)	406 (9.5)	
Widowed	584 (13.7)	4 (12.1)	588 (13.7)	
Single	259 (6.1)	3 (9.1)	262 (6.1)	
Smoking behavior				0.88
Yes, daily	440 (10.3)	2 (6.1)	442 (10.3)	
Yes, sometimes	135 (3.2)	1 (3.0)	136 (3.2)	
No, not anymore	1620 (38.0)	13 (39.4)	1633 (38.0)	
No, never	2068 (48.5)	17 (51.5)	2085 (48.5)	
Alcohol intake				0.16
Daily	552 (12.9)	4 (12.1)	556 (12.9)	
Several times a week	1122 (26.3)	12 (36.4)	1134 (26.4)	
Once a week	653 (15.3)	0 (0.0)	653 (15.2)	
1–3x a month	495 (11.6)	3 (9.1)	498 (11.6)	
Less often	1000 (23.5)	11 (33.3)	1011 (23.5)	
Never	441 (10.3)	3 (9.1)	444 (10.3)	
Frequency of sports activities				0.31
Daily	477 (11.2)	2 (6.1)	479 (11.1)	
Several times a week	1206 (28.3)	8 (24.2)	1214 (28.3)	
Once a week	667 (15.6)	7 (21.2)	674 (15.7)	
1–3x a month	242 (5.7)	1 (3.0)	243 (5.7)	
Less often	451 (10.6)	1 (3.0)	452 (10.5)	
Daily	1220 (28.6)	14 (42.4)	1234 (28.7)	

(Continued)

Table 1 (Continued).

Self-rated health (from 1 = very good to 5 = very bad)	2.4 (0.8)	3.4 (0.9)	2.4 (0.8)	<0.001
Physical functioning (from 0 = worst to 100 = best)	82.2 (22.0)	53.3 (34.6)	82.0 (22.2)	<0.001
Number of chronic conditions	2.8 (2.1)	3.1 (2.0)	2.8 (2.1)	0.48
Depressive symptoms (from 0 to 45, higher values reflecting more depressive symptoms)	6.2 (5.8)	11.3 (8.9)	6.2 (5.8)	<0.001
Living standard in the future				0.69
Will improve greatly	15 (0.4)	0 (0.0)	15 (0.4)	
Will improve somewhat	170 (4.0)	2 (6.1)	172 (4.0)	
Will remain the same	3272 (77.5)	23 (69.7)	3295 (77.4)	
Will worsen somewhat	709 (16.8)	8 (24.2)	717 (16.8)	
Will get much worse	58 (1.4)	0 (0.0)	58 (1.4)	
Frequency of dealing with death and dying				0.61
Never	120 (2.8)	1 (3.0)	121 (2.8)	
Seldom	1170 (27.6)	5 (15.2)	1175 (27.5)	
Somewhat	2045 (48.2)	18 (54.5)	2063 (48.2)	
Often	731 (17.2)	7 (21.2)	738 (17.3)	
Very often	179 (4.2)	2 (6.1)	181 (4.2)	
Future self-rated health				<0.001
Will improve greatly	51 (1.2)	0 (0.0)	51 (1.2)	
Will improve somewhat	418 (10.1)	2 (6.1)	420 (10.1)	
Will remain the same	2491 (60.5)	10 (30.3)	2501 (60.2)	
Will worsen somewhat	1108 (26.9)	18 (54.5)	1126 (27.1)	
Will get much worse	52 (1.3)	3 (9.1)	55 (1.3)	
Perceived longevity	85.5 (7.3)	85.5 (6.7)	85.5 (7.3)	0.996
Optimism (from 1 to 4, higher values reflecting more optimism)	3.0 (0.6)	2.6 (0.6)	3.0 (0.6)	<0.001

were female and about 78% of the individuals thought that the living standard will remain the same in the future. Moreover, 48% of the individuals “somewhat” dealt with death and dying, and 60% of the individuals thought that their future self-rated health will remain the same. The average perceived longevity equaled 85.5 years (SD: 7.3) and average general optimism was 3.0 (SD: 0.6).

Parkinson’s disease was significantly associated with age, self-rated health, physical functioning, depressive symptoms, future self-rated health and general optimism (with the expected signs). Further details are shown in [Table 1](#).

Cohen’s *d* for the association between Parkinson’s disease and general optimism equaled 0.65. Moreover, Cohen’s *d* for the association between Parkinson’s disease and perceived longevity equaled -0.07 .

We also calculated Cramer’s *V* (link between Parkinson’s disease and standard of living in the future). It was 0.02. Furthermore, Cramer’s *V* for the association between Parkinson’s disease and future self-rated health was 0.10. Moreover, Cramer’s *V* for the association between Parkinson’s disease and frequency of dealing with death and dying was 0.02.

Regression Analysis

Findings of regression analyses are shown in [Table 2](#). It was adjusted for sex, age, family status, education, smoking behavior, alcohol intake, physical activity, depressive symptoms, physical functioning, self-rated health, and chronic diseases in all regressions (a full model displaying all covariates is shown in [Supplementary Table 1](#)).

Multiple ordered logistic regressions showed that individuals with Parkinson’s disease had a worse future self-rated health (OR: 4.10, 95% CI: 1.99–8.47, $p < 0.001$) compared to individuals without Parkinson’s disease. However, the presence of Parkinson’s disease was not significantly associated with the other outcomes after adjusting for covariates.

Table 2 Parkinson's Disease and Perceived Prospects for the Future in Different Life Domains. Findings of Multiple Linear and Ordered Logistic Regressions (as Appropriate)

Independent Variables	Ordered Logistic Regression			Linear Regression	
	Outcome: Standard of Living in the Future	Outcome: Frequency of Dealing with Death and Dying	Outcome: Future Self- Rated Health	Outcome: Perceived Longevity	Outcome: General Optimism
	OR (SE)			Beta-Coefficient (SE)	
Presence of Parkinson's disease (Ref.: Absence of Parkinson's disease)	1.10 (0.45)	1.11 (0.37)	4.10 (1.52)***	0.02 (1.12)	−0.04 (0.10)
Covariates [†]	✓	✓	✓	✓	✓
Observations	4261	4281	4157	4005	4296
(Pseudo-) R^2	0.02	0.05	0.02	0.17	0.29

Notes: Beta coefficients or Odds Ratios (OR) are displayed, as appropriate. Standard errors (SE) in parentheses. *** $p < 0.001$. [†]Covariates cover: sex, age, family status, education, smoking behaviour, alcohol intake, physical activity, depressive symptoms, physical functioning, self-rated health, and chronic diseases.

Our robustness checks with FIML (in case of linear regressions) to address missing data also showed that the presence of Parkinson's disease is neither significantly associated with perceived longevity ($\beta = 0.66$, $p = 0.59$) nor with general optimism ($\beta = 0.03$, $p = 0.79$).

Moreover, in another robustness check, physical functioning was removed as a covariate because Parkinson's disease manifests itself primarily through a loss of function. However, compared with our main results presented in Table 2, our results remained nearly the same (ie, only the association with future self-rated health was significant: OR: 3.96, 95% CI: 1.95–8.05, $p < 0.001$).

Discussion

The objective was to analyze the association between Parkinson's disease and perceived prospects for the future in different life domains. In bivariate analysis, particularly individuals with Parkinson's disease had a markedly lower general optimism compared to individuals without Parkinson's disease. After adjusting for sociodemographic, lifestyle- and health-related factors, these differences disappeared in multiple linear regressions. Moreover, multiple ordered logistic regressions showed that individuals with Parkinson's disease had a worse future self-rated health compared to individuals without Parkinson's disease. Our findings are difficult to compare with previous studies due to the lack of studies examining the association between Parkinson's disease and perceived prospects for the future in different life domains. Thus, our study adds very first evidence in this research field and may serve as a basis for upcoming studies.

At first glance, it was surprising to see that Parkinson's disease was not significantly associated with four out of five outcomes. It seems that community-dwelling individuals having Parkinson's disease are not generally pessimistic (general and in terms of perceived longevity, thoughts about death and in terms of living standard) about their future life. Particularly the perception of the standard of living in the future may partly reflect confidence in the German long-term care insurance. As discussed in a recent study,⁶ the general optimism of individuals with Parkinson's disease may reflect a general trust in the treatment of Parkinson's disease. Furthermore, they may have developed strong coping skills to face their diagnosis of Parkinson's disease.²¹ These factors may also explain why individuals with Parkinson's disease had no significant differences in the outcomes “frequency of dealing with death and dying” and general “perceived longevity” - compared to individuals without Parkinson's disease. Other possible explanations for the aforementioned results may be the wide array of (health-related) covariates included and the potential lack of statistical power – which clearly highlights the need for upcoming research in this field using data from very large, representative samples.

In contrast, individuals with Parkinson's disease reported a worse future self-rated health compared to individuals without Parkinson's disease. Looking at the other results (and their possible explanations), this may sound contradictory at first. However, future self-rated health may more strongly reflect emerging functional limitations – or factors such as

the perception of low mental energy, tremor or feeling dependent on others in the future (compared with the older general population without Parkinson's disease). A former qualitative study also showed that individuals with Parkinson's disease often fear further losses of functioning.²¹

With regard to strengths and limitations of our current study: Data were taken from a large, population-based sample. For example, a valid tool was used to quantify general optimism – and the other outcomes had a high face validity. Various covariates were included in regression analysis and FIML was used in sensitivity analysis (in case of linear regressions). However, we cannot rule out the possibility that other factors may affect the outcomes (such as other family-related factors). Moreover, it should be noted that our study was limited to community-dwelling individuals (which may explain the small number of individuals with Parkinson's disease). It may be the case that the effect sizes are more pronounced among individuals living in institutionalized settings. Future research in this area is therefore needed. Additionally, the actual severity of the disease and the time of diagnosis remain unknown. If data are available in future studies, these factors should be incorporated in upcoming studies. Lastly, some sample selection bias of the DEAS study in general should be taken into consideration.¹³ For example, it may be the case, that individuals scoring lower in optimism may have a higher likelihood of non-participation.

Individuals were asked if they had received a formal diagnosis of Parkinson's disease from their doctor. This was not additionally backed up by an official diagnosis on the part of the doctors. In this respect, we cannot completely exclude the possibility that the information provided by the participants is incorrect. However, we assume that the participants can correctly remember an official diagnosis by the doctors and also state this as such. Additionally, factors which may be important for Parkinson's disease such as anxiety symptoms or dementia were not quantified in the DEAS study.

Conclusion and Future Research

In conclusion, our study first showed that particularly general optimism may be markedly lower among individuals with Parkinson's disease (bivariate analysis). However, this association disappeared when it was adjusted for health-related factors in regression analysis. In sum, our findings indicate that more general future-related factors did not significantly differ between individuals with and without Parkinson's disease. However, there were significant differences in future self-rated health between individuals with and without Parkinson's disease.

With regard to future research: Exploring this association in different countries could yield intriguing results and shed light on how geographical location and the availability of health facilities in different settings affect outcomes. For example, a comparison between the UK and the US, for example, where access to healthcare is very different, would also provide potentially valuable insights.

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Disclosure

The authors report no conflicts of interest in this work.

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