Validating the Parkinson's disease caregiver burden questionnaire (PDCB) in German caregivers of advanced Parkinson's disease patients

M. Klietz,* L. Rippena,* F. Lange, A. Tulke, L. Paracka, D. Dressler and F. Wegner

Department of Neurology, Hannover Medical School, Hannover, Germany

ABSTRACT

Background: Advanced Parkinson's disease (PD) may place a high burden on patients and their caregivers. Understanding the determinants of caregiver burden is of critical importance. This understanding requires the availability of adequate assessment tools. Recently, the Parkinson's disease caregiver burden questionnaire (PDCB) has been developed as a PD-specific measure of caregiver burden. However, the PDCB has only been evaluated in a sample of Australian caregivers of patients at a less advanced stage of the disease.

Objective: We tested whether a German translation of the PDCB qualifies as an adequate measure of caregiver burden in a German sample of caregivers of advanced patients with PD.

Methods: We collected PDCB data from 65 caregivers of advanced patients with PD. Reliability of the scale was assessed and compared against the original version. To validate the German version of the PDCB, we examined the correlations with the caregiver burden inventory (CBI), the short form 36 health survey (SF-36), the Parkinson's disease quality of life questionnaire 39 (PDQ-39), disease duration, and the amount of caregiving time.

Results: The total PDCB score proved to be reliable and to be significantly related to CBI and SF-36 scores. PDCB scores also increased with increasing amounts of caregiving time.

Conclusions: The German version of the PDCB appears to be an adequate measure of caregiver burden in caregivers of advanced PD patients.

Key words: advanced Parkinson's disease, caregiver burden, PDCB questionnaire, health-related quality of life, big five personality factors

Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease worldwide (Nussbaum and Ellis, 2003) with an estimated increase of patients in the future due to demographic change (Bach *et al.*, 2011). In advanced stages of PD most patients are in need of help because both motor and non-motor symptoms (Higginson *et al.*, 2012) as well as frequent adjustments of treatment create high levels of distress for the patients and result in loss of autonomy (Klietz *et al.*, 2018).

The concept of caregiver burden can be explained as a multidimensional construct that summarizes the adverse effects of giving care for a person on functioning of the caregiver (Zarit *et al.*, 1986). Caregiver burden can affect the caregiver in multiple dimensions (e.g. financial, emotional, social, spiritual and physical) (Zarit *et al.*, 1986). Factors influencing caregiver burden in PD are recently reviewed by Mosley *et al.* (2017). Briefly, patient factors as motor impairment and non-motor symptoms like cognitive impairment, psychosis, depression, anxiety, impulse control disorders and sleep are associated with caregiver burden (Martinez-Martin *et al.*, 2015a; Mosley *et al.*, 2017; Santos-García and de la Fuente-Fernández, 2014; Torny *et al.*, 2018; Vatter *et al.*, 2018). Caregiver factors interacting with burden in a caregiving situation were psychiatric symptoms of the caregiver, coping and adaption to the caregiving situation and finally social support (Mosley *et al.*, 2017). Early identification and treatment of caregiver burden is crucial to help the caregiver avoid burnout.

To this date there is little known about the caregiving situation of advanced PD patients in Germany and the degree of burden to which their

caregivers are exposed (Schmotz *et al.*, 2017). Caregiver burden and burnout represent a limit to the health care of PD patients at home (Bruno *et al.*, 2016) and may also be considered relevant under health economic aspects because indirect costs rise with caregivers' increasing lack of time for their regular work (Arno *et al.*, 1999; Huse *et al.*, 2005; Martinez-Martin *et al.*, 2019).

Hence, understanding the determinants of caregiver burden associated with advanced PD is of critical importance for patients, caregivers, and society. An adequate understanding of caregiver burden necessitates that this construct can be accurately assessed. Multiple measures of caregiver burden have been developed, the most widespread and accepted is the caregiver burden inventory (CBI) (Grün *et al.*, 2016; Hagell *et al.*, 2017; Jones *et al.*, 2017; Martinez-Martin *et al.*, 2008, 2015; Mosley *et al.*, 2017; Schmotz *et al.*, 2017; Trapp *et al.*, 2018; Zarit *et al.*, 1980). However, the CBI is not specific to PD; that is, many issues that might particularly affect caregivers of patients with PD are not reflected by the items of the inventory. For this reason, the Parkinson's disease caregiver burden questionnaire (PDCB) was developed as a PD-specific measure of caregiver burden. In an Australian sample of caregivers of patients with PD, Zhong and colleagues found this scale to have adequate reliability and validity (as indicated by a strong correlation with the CBI) (2013).

Here, we examine whether the PDCB retains these favorable psychometric properties in a German sample of caregivers of more advanced patients with PD. In comparison to Zhong and colleagues, we included a larger number of possible correlates of caregiver burden in our study which allowed us to generate new insights into the validity of the PDCB.

Methods

Participants

We obtained approval from the local Ethics Committee of Hannover Medical School (No. 3123-2016 and No. 3178-2016), and patients as well as their caregivers gave written informed consent. Our sample included 29 local caregivers and 38 caregivers of advanced PD patients in other regions of Germany. Thus, we collected data from a total of 67 caregivers of advanced PD patients. Two of them did not complete the PDCB, which renders a final sample of $N = 65$. Caregivers of patients with idiopathic PD were recruited from (1) our movement disorder outpatient clinic, (2) our neurological wards and (3) German Parkinson's disease support groups. The study questionnaire was handed to local caregivers and mailed to non-local caregivers. Inclusion criteria

for advanced PD patients were defined as Hoehn and Yahr stage III to V and disease duration of at least 5 years. Patients suffering from atypical Parkinsonism were excluded from this study. We only included the primary caregiver of the advanced PD patients. Professional caregivers e.g. nurses in a professional caregiving background were excluded from this study.

Measures

Caregivers were asked to complete a newly developed German version of the Parkinson's disease caregiver burden questionnaire (PDCB). The original items published by Zhong *et al.* (2013) were translated into German and back-translated to English by two independent professional translators. Comparisons between all the original, translated and back-translated items by the translators and two of the authors (MK & FW) did not reveal any meaningful differences. Finally, an expert group of six experienced neurologists and movement disorder specialists at Hannover Medical School (including MK, LP & FW) confirmed the validity of the translated PDCB items. The PDCB contains 20 items that can be answered on a five-point Likert scale ranging from 0 to 4. Participants can thus reach a maximum of 80 points on this questionnaire. In addition, respondents are asked to rate their global burden as a caregiver on a scale from 0 to 100. The total PDCB score is obtained by dividing this global burden rating by 5 and adding it to the PDCB questionnaire sum score. It can range from 0 to 100 with higher scores indicating higher caregiver burden.

PDCB scores were validated against caregivers' scores on the caregiver burden inventory (CBI), a more established, but also more general (i.e., not PD-specific) tool for the assessment of caregiver burden (Zarit *et al.*, 1980). The CBI consists of 22 items that we have had translated for the purpose of the current study according to the same procedure described above. Respondents can score a maximum of 88 points on the CBI. Scores below 20 points are taken to indicate the absence of burden, 21–40 points indicating mild, 41–60 points indicating moderate, and 61–88 points indicating severe burden (Zarit *et al.*, 1980).

In addition, caregivers completed the short form 36 health survey (SF-36) (Ware and Sherbourne, 1992). The SF-36 assesses health-related quality of life across eight dimensions. Subscale scores were percentage-transformed so that a score of 0 would indicate maximum impairment and a score of 100 would indicate the absence of any reported impairment. As subscale scores were highly correlated ($\alpha = .84$), we calculated an average score across the eight scales to analyze the relationship between

PDCB scores and overall health-related quality of life in a more parsimonious way.

Based on prior research on the relationship between disease severity and caregiver burden (Martinez-Martin *et al.*, 2008, 2014; Morley *et al.*, 2012), we reasoned that PDCB scores should be higher in caregivers of patients who are more severely affected by PD. To obtain a rough indicator of patients' PD-related impairment, caregivers were provided with a copy of the Parkinson's disease quality of life questionnaire 39 (PDQ-39) to be completed by the respective patient (Peto *et al.*, 1995). This scale assesses patients' functioning and well-being across eight domains. By averaging percentage-transformed scores across these eight subscales, one can obtain a global indicator of PD-related impairment in quality of life, the Parkinson's disease summary index (PDSI) (Jenkinson *et al.*, 1997). Higher PDSI scores indicate worse quality of life. Caregivers of patients with possible cognitive impairment were asked to assist patients in completing the PDQ-39 to ensure correct results and avoid anosognosia.

Caregivers were also asked to provide general information about their background and demographics. Among others, they reported patients' disease duration as well as the daily amount of time they dedicated to giving care to the patient. Based on prior research, we expected these variables to be positively related to scores on the PDCB (Huse *et al.*, 2005; Martinez-Martin *et al.*, 2008; Rodríguez-Violante *et al.*, 2015; Schmotz *et al.*, 2017).

To explore further possible correlates of caregiver burden, we asked caregivers to complete Beck´s depression inventory (BDI) (Beck *et al.*, 1961) as a measure of depressive symptoms as well as a short version of the Big Five Inventory (BFI-10) (Rammstedt and John, 2007), assessing the five personality dimensions extraversion, agreeableness, conscientiousness, neuroticism, and openness.

Analyses

Following Zhong and colleagues (2013), we analyzed the descriptive distribution of caregivers' responses to the 20 PDCB items, the reliability of the PDCB questionnaire score (Cronbach's α), and the item-total correlations. We also computed the correlation between the PDCB questionnaire score and the PDCB global burden rating to test whether combining them into a total score is sensible and whether the global burden rating might qualify as brief measure of caregiver burden.

To examine the validity of the German version of the PDCB in advanced patients with PD, Spearman correlations were computed for the relationships of total PDCB scores with CBI sum scores, average SF-36 scores, PDSI scores, disease duration, and

Table 1. Patient and caregiver characteristics ($n = 65$)

	MEAN	SD	MIN	MAX
PD patients				
Age (years)	74.8	5.7	58	88
Disease duration (years)	16.3	6.7	5	34
PDSI	49.2	12.7	22.4	83.6
Caregivers				
Age (years)	70.9	9.1	45	86
Sex			male 29.2%	female 70.8%
Caregiving hours per day	7.1	6.7	0.1	24
PDCB	39.8	14.9	9	80
CBI	34.4	14.6	8	68
SF-36	56.2	20.0	18.4	91.4
BDI	12.9	6.0	2	28

Abbreviations: PD = Parkinson's disease; PDSI = Parkinson's disease summary index; PDCB = Parkinson's disease caregiver burden inventory; CBI = caregiver burden inventory; SF-36 = short form 36 health survey; BDI = Beck depression inventory; SD = standard deviation.

caregiving time. Non-parametric correlation coefficients were used to obtain results that are comparable to the ones reported by Zhong and colleagues (2013). All correlations were expected to be positive, with the exception of the correlation with SF-36 scores (where higher scores indicate better functioning), which was expected to be negative. For these correlational analyses, the level of significance was set to .05/5 = .01 to adjust for the number of examined correlations. Regarding the remaining study variables (BFI-10 and BDI scores, demographic data), relationships with the PDCB were analyzed in an exploratory manner. Analyses were carried out using SPSS 25.0 (IBM, Armonk, NY) and Graphpad Prism 5.00 (San Diego, California, USA).

Results

Patient characteristics

On average, PD patients were 74.8 years old (SD 5.7, min 58, max 88). Mean disease duration was 16.3 years (SD 6.7, min 5, max 34). Patients scored an average of 82.9 points on the PDQ-39 and the associated average PDSI score was 49.2 (SD 12.7, min 22.4, max 83.6). All PD patient characteristics are summarized in Table 1.

Caregiver characteristics

Mean age of recruited PD caregivers was 70.9 years (SD 9.1, min 45, max 86), 70.8% of the caregivers were female, and 91% were spouses of the related

PD patient. On average, caregivers were 3.9 years younger than their corresponding patients (SD 8.5, range: 43 yrs younger to 7 yrs older). Caregivers reported to spend an average of 7.1 hours a day (SD 6.7h) with caregiving activities. Note, however, that many caregivers expressed having difficulties in determining the amount of daily caregiving time and 12 caregivers did not provide an answer to this question. Mean PDCB scores were 30.0 (SD 11.3, min 9, max 60) for the 20 questionnaire items, 49.2 (SD 26.2, min 0, max 100) for the global burden rating, and 39.8 (SD 14.9, min 9, max 80) for the aggregated total score. Caregivers scored an average of 34.4 (SD 14.6, min 8, max 68) on the CBI and an average of 56.2 (SD 20.6, min 18.4, max 91.4) on the SF-36. All these aggregate scores are close to the midpoint of the respective scales. On the BDI, caregivers scored an average of 12.9 points (SD 6.0, min 2, max 28). All caregiver characteristics are summarized in Table 1.

Reliability of the Parkinson's disease caregiver burden questionnaire (PDCB)

Cronbach's α of the 20 items contributing to the PDCB questionnaire score was .80. All items were positively related to the total score, but some of these item-total correlations must be considered to be rather low (Table 2). Especially item 10 was only weakly correlated with the PDCB questionnaire score and removing this item would result in a slight increase in reliability. The PDCB questionnaire score was correlated with the PDCB global burden rating, r = .55, p < .001. Based on this result, we considered aggregating the two measures into a PDCB total score (as proposed by Zhong *et al.*) to be appropriate. Distribution characteristics of the PDCB total score are displayed in Figure 1. This total score was used for the following correlation analyses.

Validity of the Parkinson's disease caregiver burden questionnaire (PDCB)

Table 3 displays the correlations between PDCB total scores and those variables that we expected to be related to them. It can be seen that the correlations with CBI sum scores (r = .71, p < .001), average SF-36 scores (r = −.40, p = .001), and caregiving hours per day (r = .36, p = .008) were significant at the corrected significance level of .01.

In addition, PDCB scores increased with increasing PDSI scores (r = .30), but the associated p-value (p = .015) did not fall below the corrected significance level. PDCB scores were not related to disease duration (r = −.09, p = .500).

Exploratory analyses

Total PDCB scores were negatively related to caregivers' age (r = −.33, p = .009) and positively related to the age difference between patient and caregiver (r = .31, p = .011). Female caregivers reported higher PDCB scores (M = 42.8, SD = 14.7) than male caregivers (M = 32.4, SD = 13.0, t = 2.68, p = .009). Higher PDCB scores were related to higher BDI scores (r = .48, p < .001), higher neuroticism scores (r = .34, p = .006), lower conscientiousness scores (r = −.28, p = .029), and lower agreeableness scores (r = −.30, p = .019) on the BFI-10. No substantial correlations were found with extraversion (r = .09, p = .484) and openness (r = −.09, p = .476).

Discussion

In the present study, we evaluated the psychometric characteristics of the PDCB in a sample of caregivers of advanced patients with PD in Germany. We found the scale to be reliable and to relate to an established measure of caregiver burden (i.e., the CBI). In addition, PDCB scores were correlated to variables that are conceptually associated with the burden experienced by caregivers (e.g., their health-related quality of life and the amount of time that they spend giving care). These results indicate that the PDCB retains large parts of its psychometric quality when being translated into German and being administered to caregivers of patients in a more advanced state of PD.

Comparison with the original version of scale

In comparison to the study by Zhong and colleagues, we examined caregivers of patients who were in a substantially more advanced stage of the disease. Patients were five years older and the average disease duration was more than twice as long in our study. Nonetheless, the internal consistency of the PDCB was similar across studies (α = .80 vs. α = .86). Likewise, we found a strong correlation between PDCB and CBI scores (r = .71), which had also been reported by Zhong and colleagues (r = .77 - .80). As in our study, Zhong and colleagues found the PDCB questionnaire score to be correlated with the PDCB global burden rating, but the size of this correlation was substantially larger in their sample (r = .84) than in ours (r = .55). The difference between these correlation coefficients is significant (z = 3.12, p = .002, http://vassarstats.net/rdiff.html), and might indicate that the global burden rating is less representative of the PDCB questionnaire in German caregivers of advanced PD patients than in Australian caregivers of less advanced patients.

Table 2. Item characteristics of the German version of the Parkinson's disease caregiver burden questionnaire (PDCB)

ITEM	ENGLISH ORIGINAL	GERMAN TRANSLATION	MEAN	SD	CORRECTED ITEM–TOTAL CORRELATION	A IF ITEM DELETED
1	I have been injured as a result of caring for him/her, e.g. back strain as a result of lifting.	Ich habe mir infolge seiner/ihrer Betreuung eine Verletzung zugezogen, z. B. meinen Rücken durch schweres Heben überlastet.	1.58	1.45	.24	.80
2	I feel physically capable to help him/her with activities of daily living such as toileting, dressing, showering, bathing, and lifting.	Ich fühle mich körperlich in der Lage, ihm/ihr bei Alltagstätigkeiten zu helfen, z. B. beim Toilettengang, Anziehen, Duschen, Baden und Heben.	0.97	1.19	.30	.80
3	I feel annoyed or frustrated because my sleep is disturbed by him/her at night.	Ich bin verärgert oder fühle mich frustriert, weil mein Nachtschlaf durch ihn/sie unterbrochen wird.	1.88	1.26	.59	.78
4	I think I get enough sleep at night, and I feel awake during the day.	Ich denke, ich schlafe nachts ausreichend und ich fühle mich tagsüber wach.	2.06	1.16	.56	.78
5	Dealing with the day-to-day unpredictability of symptoms makes it frustrating and difficult.	Es ist frustrierend und schwierig, mit der täglichen Unberechenbarkeit von Symptomen zurechtzukommen.	2.43	1.33	.33	.80
6	I am fine with how slowly he/she moves and does things.	Ich habe kein Problem damit, wie langsam er/sie sich bewegt und Dinge erledigt.	1.66	1.14	.34	.80
7	He/she has trouble with urinary urgency, and helping with toileting is very difficult for me.	Er/sie hat Probleme mit dem Harndrang und es ist für mich sehr schwierig, beim Toilettengang zu helfen.	1.55	1.31	.48	.79
8	I have had trouble coping with his/her compulsive behaviors (such as gambling, sexual hyperactivity, hobbies, and hoarding).	Ich hatte schon einmal Probleme, mit seinen/ihren zwanghaften Verhaltensweisen (wie z. B. Glücksspielen, sexueller Hyperaktivität, Hobbies und zwanghaftem Horten) zurechtzukommen.	1.42	1.54	.49	.79
9	I feel anxious or confused because I am unsure whether he/she is suffering from depression.	Ich fühle mich verunsichert oder verwirrt, weil ich nicht sicher bin, ob er/sie an einer Depression leidet.	1.75	1.13	.44	.79
10	I am okay with having to take care of our responsibilities, such as decision making, chores and appointments.	Ich habe kein Problem damit, die Verantwortung für unsere Angelegenheiten (z. B. Entscheidungen, häusliche Pflichten und Termine) zu übernehmen.	0.82	1.17	.08	.81
11	I get upset because it seems he/she can't be bothered to take responsibility of his/her health.	Es regt mich auf, weil es ihm/ihr anscheinend egal ist, die Verantwortung für seine/ihre Gesundheit zu übernehmen.	1.40	1.38	.38	.79

Table 2. Continued

ITEM	ENGLISH ORIGINAL	GERMAN TRANSLATION	MEAN	SD	CORRECTED ITEM-TOTAL CORRELATION	A IF ITEM DELETED
12	I feel anxious because I need to be aware of what he/she is doing all the time.	Es beängstigt mich, dass ich ständig Bescheid wissen muss, was er/sie gerade macht.	2.00	1.33	.45	.79
13	I am worried when he/she wants to take more Parkinson's medicine than the doctor prescribed.	Ich mache mir Sorgen, wenn er/sie mehr Parkinson-Medikamente einnehmen will, als der Arzt verordnet hat.	0.88	1.32	.39	.79
14	I find it very easy to deal with his/her medications.	Ich finde es sehr einfach, mich um seine/ihre Medikamente zu kümmern.	1.08	1.33	.35	.80
15	I feel embarrassed because of his/her behaviours or comments.	Seine/ihre Verhaltensweisen oder Kommentare bringen mich in Verlegenheit.	0.82	1.01	.58	.79
16	I am comfortable going out with him/her.	Ich fühle mich wohl dabei, mit ihm/ihr auszugehen.	1.14	1.13	.34	.80
17	I don't like it when people notice his/her tremor or dyskinesia (abnormal involuntary movements).	Ich mag es nicht, wenn andere sein/ihr Zittern oder seine/ihre Dyskinesie (anormale unwillkürliche Bewegungen) bemerken.	0.83	1.04	.33	.80
18	I feel that he/she is still my friend.	Ich habe das Gefühl, dass er/sie immer noch mein Freund/meine Freundin ist.	0.42	0.81	.32	.80
19	I miss the good times we used to have together.	Ich vermisse die guten Zeiten, die wir einmal miteinander hatten.	2.98	1.15	.18	.80
20	I am still able to make plans for the future, or to pursue my dreams.	Ich kann immer noch Zukunftspläne machen oder meine Träume verfolgen.	2.29	1.23	.25	.80

Note. Scores of inverted items have been recoded. Higher values indicate higher caregiver burden.
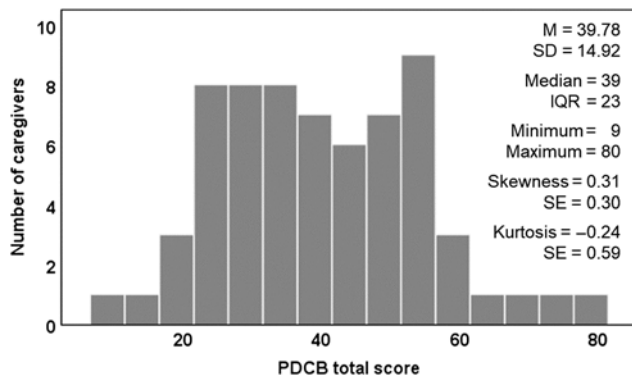
Figure 1. Distribution characteristics of the Parkinson's disease caregiver burden inventory (PDCB) total score. M = mean, SD = standard deviation, IQR = interquartile range, SE = standard error.

Similarly to Zhong and colleagues, we found the item-total correlations involving the first two PDCB items (referring to caregivers' physical condition) not to be very strong. Moreover, we identified a few additional items that might be problematic to use in a German population and/or in caregivers of advanced patients with PD. Further research involving caregivers of patients in diverse stages of the disease is required to determine whether this is due to our translation or whether these items are not sensitive indicators of caregiver burden in the target population. In the long run, it might prove beneficial to delete or replace the items in question. Yet, given the good reliability of the scale in our study, we see no reason to discourage the use of the German version of the PDCB in advanced patients with PD.

New evidence for the validity of the Parkinson's disease caregiver burden questionnaire (PDCB)

In addition to the replication of the PDCB-CBI link reported by Zhong and colleagues, our study revealed a substantial correlation between the PDCB and the SF-36. This correlation is likely reflective of the fact that both scales aim to assess how impaired respondents feel in their daily functioning. In contrast to the SF-36, the PDCB is more specific with regard to the source and nature of this impairment. Hence, it is not surprising that the correlation is smaller than, for example, the correlation between PDCB and CBI (where impairment is assessed at comparable levels of specificity).

The amount of time that individuals spend giving care to patients with PD can be conceived of as a predictor or component of experienced caregiver burden and, thus, a valid measure of caregiver burden should correlate with the daily number of caregiving hours. Our study shows, for the first time, that the PDCB fulfills this criterion. This finding is comparable to the results present in prior research

using alternative measures of caregiver burden (Corallo *et al.*, 2017; Grün *et al.*, 2016; Martinez-Martin *et al.*, 2015; Morley *et al.*, 2012; Sanyal *et al.*, 2015; Zhong *et al.*, 2016). Similarly, one could expect that caregiver burden increases with increasing disease duration (Martinez-Martin *et al.*, 2012). However, we did not find a corresponding correlation between PDCB scores and disease duration in our study. In advanced patients with PD, disease duration might not be a very good indicator of disease-related impairment anymore. In our sample, all patients were at an advanced Hoehn and Yahr stage, but the number of years that had passed until they reached that stadium varied substantially (Klietz *et al.*, 2018). Hence, disease duration and disease severity (or disease-related impairment) might have been partially decoupled in our sample. Consistent with this notion, the correlation between disease duration and PDSI scores was only medium in size in our study. Alternatively, it is possible that increasing disease duration is not only associated with increasing disease severity, but also with improving coping skills on the part of the caregiver. These skills might help caregivers to compensate the disease-duration-related increase in caregiving demands. Finally, we observed that caregivers of patients who rated their disease to decrease quality of life on the PDQ-39 tended to report more caregiver burden on the PDCB (although this correlation did not reach the corrected level of significance). This finding can be taken as tentative evidence for a link between disease-related impairment and PDCB scores. However, it should be noted that this indicator of disease-related impairment relied exclusively on self-reports and might have even been affected by the personal judgement of the caregiver that helped completing the scale.

Exploratory findings

The correlations we presented between PDCB scores, demographics, and personality traits might be of interest to future studies or meta-analytic research on the predictors of caregiver burden. The correlations of the PDCB with neuroticism and conscientiousness in our study seem comparable to those obtained by Tew and colleagues (2013) who used the same personality assessment, but a different measure of caregiver burden. These authors did not find the correlation between caregiver burden and agreeableness that we observed in our study. Further research is required to evaluate the reliability and relevance of these associations.

Clinical significance

Our results suggest that the PDCB can play a useful role in the assessment of burden in caregivers of

Table 3. Spearman correlations between total PDCB scores and validation measures

	1	N	2	3	5	6	7
1. PDCB total score	–						
2. CBI	.71**	65	–				
3. SF36	− .40**	63	− .34	–			
5. PDSI (PDQ-39)	.31*	63	.40	.05	–		
6. Disease duration	− .09	64	.06	.10	.31	–	
7. Caregiver hours	.36**	53	.38	− .10	.43	.14	–

Note. Correlations of interest for hypothesis testing are highlighted in bold. The number of cases available for these correlations are displayed next to them (n). The remaining correlations were not compared against a significance threshold. CBI = caregiver burden inventory, PDCB = Parkinson's disease caregiver burden inventory, PDQ-39 = Parkinson's disease quality of life questionnaire 39; PDSI = Parkinson's disease summary index, SF-36 = short form 36 health survey.

* significant at p < .05.
** significant at the corrected p < .01.

patients with advanced PD. The scale can provide valuable information for general physicians, neurologists, and movement disorder specialists to identify caregivers in need for support. Early support and tailored interventions may prevent a drastic decline of caregivers' health-related quality of life. Caregiver functioning and disability can be viewed as a complex interaction between individual and contextual factors. To decrease caregiver burden it is important to find the optimal treatment for PD patients' motor and non-motor symptoms with a focus on dementia, depression, and anxiety (Martinez-Martin *et al.*, 2015; Morley *et al.*, 2012). In addition, implementation of outpatient care, daytime care, or even palliative care might be helpful to reduce caregiving time per day and caregiver burden. Finally, psychotherapy and behavioral interventions could be used to equip caregivers with the skills necessary to cope with the caregiving situation (Lyons *et al.*, 2004). Validated assessment tools such as the PDCB should be used to evaluate the isolated and combined effectiveness of these components in alleviating caregiver burden.

Limitations

In comparison to other studies on caregiver burden in PD, the size of our sample might seem rather small. It should be noted that the size of our sample was larger than the one in the study by Zhong and colleagues who examined very similar research questions. Moreover, given the size of the correlations between PDCB scores and validation measures that could have been expected based on the results by Zhong and colleagues, our sample size has likely been sufficient to allow for adequately powered tests of these correlations. Nevertheless, larger replication studies are required to obtain more

stable estimates of the size of these correlations and to be able to detect more subtle relationships between PDCB scores and possible determinants of caregiver burden. In addition, future longitudinal studies are required to examine further psychometric characteristics (including test-retest reliability and predictive validity) of the PDCB.

Conclusion

The German version of the PDCB appears to be an adequate measure of caregiver burden in caregivers of advanced patients with PD. Given the rather modest correlation with the questionnaire part of the scale, we cannot unconditionally recommend using the PDCB global burden rating as a standalone measure. Future studies might focus on the development and evaluation of a brief version of the scale, which can then be used for the assessment of caregiver burden in the clinical routine.

Description of author's roles

MK, LR and FW designed the study with assistance of FL; MK, LR, LP and AT carried out the study. FL performed the statistical analysis. FL, MK, LR, DD and FW analyzed the data and wrote the manuscript. AT, DD and LP revised it critically for important intellectual content.

Authors' note

The sponsors had no influence on the carrying out of the study or the writing of the manuscript.

References

Arno, P. S., Levine, C. and Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs (Millwood)*, 18, 182–188. doi: 10.1377/hlthaff.18.2.182.

Bach, J.-P., Ziegler, U., Deuschl, G., Dodel, R. and Doblhammer-Reiter, G. (2011). Projected numbers of people with movement disorders in the years 2030 and 2050. *Movement Disorders*, 26, 2286–2290. doi: 10.1002/mds.23878.

Beck, A. T., Ward, C. H., Mendelson, M., Mock, J. and Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561–571.

Bruno, V., Mancini, D., Ghoche, R., Arshinoff, R. and Miyasaki, J. M. (2016). High prevalence of physical and sexual aggression to caregivers in advanced Parkinson's disease. Experience in the Palliative Care Program. *Parkinsonism & Related Disorders*, 24, 141–142. doi: 10.1016/j.parkreldis.2016.01.010.

Corallo, F., De Cola, M. C., Lo Buono, V., Di Lorenzo, G., Bramanti, P. and Marino, S. (2017). Observational study of quality of life of Parkinson's patients and their caregivers. *Psychogeriatrics*, 17, 97–102. doi: 10.1111/psyg.12196.

Grün, D., Pieri, V., Vaillant, M. and Diederich, N. J. (2016). Contributory factors to caregiver burden in Parkinson disease. *Journal of the American Medical Directors Association*, 17, 626–632. doi: 10.1016/j.jamda.2016.03.004.

Hagell, P., Alvariza, A., Westergren, A. and Årestedt, K. (2017). Assessment of burden among family caregivers of people with Parkinson's disease using the Zarit Burden Interview. *Journal of Pain and Symptom Management*, 53, 272–278. doi: 10.1016/j.jpainsymman.2016.09.007.

Higginson, I. J. et al. (2012). Symptoms and quality of life in late stage Parkinson syndromes: a longitudinal community study of predictive factors. *PLoS ONE*. Edited by M. Toft. Public Library of Science, 7, e46327. doi: 10.1371/journal.pone.0046327.

Huse, D. M., Schulman, K., Orsini, L., Castelli-Haley, J., Kennedy, S. and Lenhart, G. (2005). Burden of illness in Parkinson's disease. *Movement Disorders*, 20, 1449–1454. doi: 10.1002/mds.20609.

Jenkinson, C., Fitzpatrick, R., Peto, V., Greenhall, R. and Hyman, N. (1997). The Parkinson's Disease Questionnaire (PDQ-39): development and validation of a Parkinson's disease summary index score. *Age and Ageing*, 26, 353–357.

Jones, A. J. et al. (2017). Caregiver burden is increased in Parkinson's disease with mild cognitive impairment (PD-MCI). *Translational Neurodegeneration*, 6, 17. doi: 10.1186/s40035-017-0085-5.

Klietz, M. et al. (2018). Impaired quality of life and need for Palliative care in a German cohort of advanced Parkinson's Disease Patients. *Frontiers in Neurology*, 9, 120. doi: 10.3389/fneur.2018.00120.

Lyons, K. S., Stewart, B. J., Archbold, P. G., Carter, J. H. and Perrin, N. A. (2004). Pessimism and optimism as early warning signs for compromised health for caregivers of patients with Parkinson's disease. *Nursing Research*, 53, 354–362.

Martinez-Martin, P., Arroyo, S., Rojo-Abuin, J. M., Rodriguez-Blazquez, C., Frades, B. and de Pedro Cuesta, J. (2008). Burden, perceived health status, and mood among caregivers of Parkinson's disease patients. *Movement Disorders*, 23, 1673–1680. doi: 10.1002/mds.22106.

Martinez-Martin, P., Rodriguez-Blazquez, C. and Forjaz, M. J. (2012). Quality of life and burden in caregivers for patients with Parkinson's disease: concepts, assessment and related factors. *Expert Review of Pharmacoeconomics & Outcomes Research*, 12, 221–230. doi: 10.1586/erp.11.106.

Martinez-Martin, P. et al. (2015). Neuropsychiatric symptoms and caregiver's burden in Parkinson's disease. *Parkinsonism & Related Disorders*, 21, 629–634. doi: 10.1016/j.parkreldis.2015.03.024.

Martinez-Martin, P. et al. (2019). The long-term direct and indirect economic burden among Parkinson's disease caregivers in the United States. *Movement Disorders*, 34, 236–245. doi: 10.1002/mds.27579.

Morley, D. et al. (2012). Factors influencing quality of life in caregivers of people with Parkinson's disease and implications for clinical guidelines. *Parkinson's Disease*, 2012, 1–6. doi: 10.1155/2012/190901.

Mosley, P. E., Moodie, R. and Dissanayaka, N. (2017). Caregiver burden in Parkinson disease: a critical review of recent literature. *Journal of Geriatric Psychiatry and Neurology*, 30, 235–252. doi: 10.1177/0891988717720302.

Nussbaum, R. L. and Ellis, C. E. (2003). Alzheimer's disease and Parkinson's disease. *The New England Journal of Medicine*, 348, 1356–1364. doi: 10.1056/NEJM2003ra020003.

Peto, V., Jenkinson, C., Fitzpatrick, R. and Greenhall, R. (1995). The development and validation of a short measure of functioning and well being for individuals with Parkinson's disease. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 4, 241–248.

Rammstedt, B. and John, O. P. (2007). Measuring personality in one minute or less: a 10-item short version of the Big Five Inventory in English and German. *Journal of Research in Personality*, 41, 203–212. doi: 10.1016/j.jrp.2006.02.001.

Rodríguez-Violante, M., Camacho-Ordoñez, A., Cervantes-Arriaga, A., González-Latapí, P. and Velázquez-Osuna, S. (2015). Factors associated with the quality of life of subjects with Parkinson's disease and burden on their caregivers. *Neurología (English Edition)*, 30, 257–263. doi: 10.1016/j.nrleng.2014.01.002.

Santos-García, D. and de la Fuente-Fernández, R. (2014). Factors contributing to caregivers' stress and burden in Parkinson's disease, *Acta Neurologica Scandinavica*, 131, 203–210. doi: 10.1111/ane.12305.

Sanyal, J., Das, S., Ghosh, E., Banerjee, T. K., Bhaskar, L. V. K. S. and Rao, V. R. (2015). Burden among Parkinson's disease care givers for a community based study from India. *Journal of the Neurological Sciences*, 358, 276–281. doi: 10.1016/j.jns.2015.09.009.

Schmotz, C., Richinger, C. and Lorenzl, S. (2017). High burden and depression among late-stage idiopathic Parkinson disease and progressive supranuclear palsy caregivers. *Journal of Geriatric Psychiatry and Neurology*, 30, 267–272. doi: 10.1177/0891988717720300.

Tew, E. H., Naismith, S. L., Pereira, M. and Lewis, S. J. G. (2013). Quality of life in Parkinson's disease caregivers: the contribution of personality traits. *BioMed Research International*, 2013, 151872. doi: 10.1155/2013/151872.

Torny, F., Videaud, H., Chatainier, P., Tarrade, C., Meissner, W. G. and Couratier, P. (2018). Factors associated with spousal burden in Parkinson's disease. *Revue Neurologique*, 174, 711–715. doi: 10.1016/j.neurol.2018.01.372.

Trapp, S. K., Ertl, M. M., Gonzalez-Arredondo, S., Rodriguez-Agudelo, Y. and Arango-Lasprilla, J. C. (2018). Family cohesion, burden, and health-related quality of life among Parkinson's disease caregivers in Mexico. *International Psychogeriatrics*, 1–7. doi: 10.1017/S1041610218001515.

Vatter, S., McDonald, K. R., Stanmore, E., Clare, L. and Leroi, I. (2018). Multidimensional care burden in Parkinson-related dementia. *Journal of Geriatric Psychiatry and Neurology*, 31, 319–328. doi: 10.1177/0891988718802104.

Ware, J. E. and Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care*, 30, 473–483.

Zarit, S. H., Reever, K. E. and Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20, 649–655.

Zarit, S. H., Todd, P. A. and Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *The Gerontologist*, 26, 260–266.

Zhong, M., Evans, A., Peppard, R. and Velakoulis, D. (2013). Validity and reliability of the PDCB: a tool for the assessment of caregiver burden in Parkinson's disease. *International Psychogeriatrics*, 25, 1437–1441. doi: 10.1017/S1041610213000586.

Zhong, M., Peppard, R., Velakoulis, D. and Evans, A. H. (2016). The relationship between specific cognitive defects and burden of care in Parkinson's disease. *International Psychogeriatrics*, 28, 275–281. doi: 10.1017/S1041610215001593.