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Permalink

https://escholarship.org/uc/item/2wg3c36c

Journal

Movement Disorders Clinical Practice, 8(4)

ISSN

2330-1619

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Publication Date

2021-05-01

DOI

10.1002/mdc3.13201

Movement Disorders
CLINICAL PRACTICE

REVIEW

Current Knowledge on the Evolution of Care Partner Burden, Needs, and Coping in Parkinson's Disease

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ABSTRACT: Background: Care partners support people with Parkinson's disease through a long journey ranging from independence to dependence for many daily tasks. Longitudinal studies are important to understand the evolution of this process and predictors of future needs of care partners.
Methods: A scoping review was conducted, searching PubMed for longitudinal studies examining care partner burden, needs or coping in Parkinson's disease published through May 2020.
Results: Eight observational studies and 19 interventional studies met the eligibility criteria. Longitudinal observation ranged from 7 weeks to 10 years, involving between six and 8515 care partners. All studies addressed care partner burden, while two and three studies respectively addressed needs and coping. Only one study related burden to specific stages or duration of disease. Results from identified studies show that care partners in Parkinson's disease are at risk for increasing burden over time. Multiple predictors of future burden have been identified related to the person with Parkinson's disease, the care partner, or an intervention. No studies examined the evolution of needs and coping in caregiving in Parkinson's disease.
Conclusion: The scarcity of longer term, observational research on the temporal evolution of burden and particularly needs and coping in caregiving for someone with PD is a main identified gap. Even within these observational studies, the impact of caregiving is not often reported. Longitudinal studies on these topics are needed to help understand their change over time and relation to each other, which can inform support planning for care partners.

Parkinson's disease (PD) is a progressive and chronic disease with a broad spectrum of motor and non-motor manifestations.[1] With a median age of 71 years at onset of PD and a median survival of 10.3 years after diagnosis, many patients are in a vulnerable age category.[2] As the disease slowly progresses over time, the patient will become more dependent on care,[3] which is to a great extent carried out by informal care partners (i.e. spouse, family members).[4,5] This is challenging and their role may cause social, psychological, and economic burden, leading to negative impact on their own physical and emotional health.[6–8]

Given the long duration and progressive nature of disease in many patients these effects evolve and cannot be fully summarized in a cross-sectional way.

Research on this topic of longitudinal design would be particularly important as it would help us understand the care partner experience throughout the disease journey. Furthermore, it is only through longitudinal studies that predictors of future burden can be discovered. Understanding the temporal evolution of these burdens and resulting needs is important to enable health care providers and support organizations to anticipate needs and

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Keywords: Parkinson's disease, care partner, burden, needs, coping.
Received 16 November 2020; revised 1 March 2021; accepted 7 March 2021.

provide opportunities to help care partners in their role as a care partner at any given time.

Burden and needs arise from caregiving in Parkinson's, and these are dealt with by coping mechanisms (see Fig. 1). The objective of this scoping review is to present (1) what is known about burden, needs, and coping in caregiving for someone with PD from longitudinal studies; and (2) and to identify research gaps in the existing literature on the evolution of care partner burden, needs, and coping through the disease course to guide future research.

Methods

Methods and results reporting are based on the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) criteria.[9]

Literature Search

We performed a broad search on caregiving in PD in order not to miss any papers related to this topic. A preliminary literature scan on PubMed was performed to identify search terms and to set up eligibility criteria. The following search strategy was used to identify studies on PubMed, published until the end of May 2020:

(parkinson disease [MesH Terms] OR Parkinson* [tiab]) AND (Caregivers [MesH Terms] OR Spouse [MesH Terms] OR caretaker* [tiab] OR care partner* [tiab] OR caregiv* [tiab] OR partner* [tiab] OR spouse* [tiab] OR caregiver* [tiab])

Inclusion Criteria

(1) Reporting caregiver outcomes related to burden, needs, or coping; (2) Published in English; and (3) Longitudinal design. Studies examining interventions without care partner involvement in the intervention and studies that involved paid care partners were excluded. Review papers were excluded, although their reference lists were scanned to capture additional relevant papers.

Data Collection

Titles and abstracts were screened by the first author (MJH) to identify studies potentially meeting the eligibility criteria. To ensure the accuracy of inclusion of abstracts, three other authors (CM, EB, ND) carried out the same procedure for separate samples of studies. Differences in included studies were solved through discussion. Potentially eligible studies were reviewed full text. Data extraction was performed by the first author (MJH). To ensure accuracy of data extraction, one independent author (CM) carried out the same procedure for data input for a subset of studies. Differences were again solved by discussion. Independent data extraction was performed on successive subsets until complete agreement was achieved.

Study results were reported by method (observational/interventional) and domain (burden/needs/coping). Data on the interventional and control arms from interventional studies were analyzed separately. The interventional arms identify interventions associated with care partner outcomes and the control arms portray the natural longitudinal evolution of care partner outcomes. Where possible, statistical significance of change scores was reported. Reporting the significance of changes when results were reported as baseline and end of follow-up means or medians was not possible due to the absence of raw data.

Identification of Gaps in Literature

Gaps in literature were identified by comparing results from our review with concepts arising from group discussions, taking advantage of the combined clinical expertise.

Results

Search Results and Characteristics

Thirty-one studies of longitudinal design were identified by our search. Four studies were excluded from the review resulting in

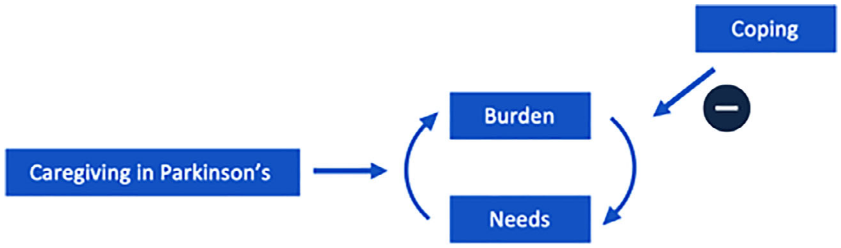

FIG. 1. Conceptual image of the interrelation of burden, needs, and coping in caregiving. Both burden and needs arise from caregiving. Burden and needs are closely related concepts as unaddressed needs may result in burden and burden causes needs.

27 eligible studies (Fig. 2). All studies concerned burden and respectively two and three longitudinal studies additionally reported on care partner needs or coping strategies.

Studies were published from 2004 to 2020. Six studies were from the UK and the US each, five studies were from the Netherlands, two studies were from Australia, and one study was from each Denmark, Italy, and Sweden. Five studies were multicenter, three from centers in North America, and two from centers within Canada, the Netherlands, Israel or the US.

The duration of observation among the studies included ranged from 7 weeks to 10 years. Most studies recruited carepartners of people with idiopathic PD and included a broad range of disease severity and/or duration. The largest study included 8515 care partners and had a mean follow-up of 9.4 years. Five observational studies reported follow-up of 5 years or more. One study reported care partner economic burden related to disease duration. No studies reported care partner needs or coping strategies related to specific ranges of disease severity or duration. Further details on study characteristics are described in Table 1.

Longitudinal Outcomes in Care Partners from Observational Studies

Caregiving Tasks and Costs

The number of direct care tasks performed by care partners increased over a 10-year period. Care partners were asked which of 50 direct care tasks they performed at each timepoint of the follow-up, which was 27% at baseline, 31% at year 2, and 48% at year 10.[17] Women with PD made earlier use of a paid care partner. However, higher reported burden in unpaid care partners for men with PD did not correlate with faster time to a paid care partner in 5 years of follow-up.[12] Care partners of persons with PD were matched 1:5 to policyholders with a non-Parkinson's dependent on sex, age, region, and index year in one study to compare their direct and indirect economic burden. PD care partners faced both higher direct and indirect costs and had an almost twofold greater income loss over 5 years.[11]

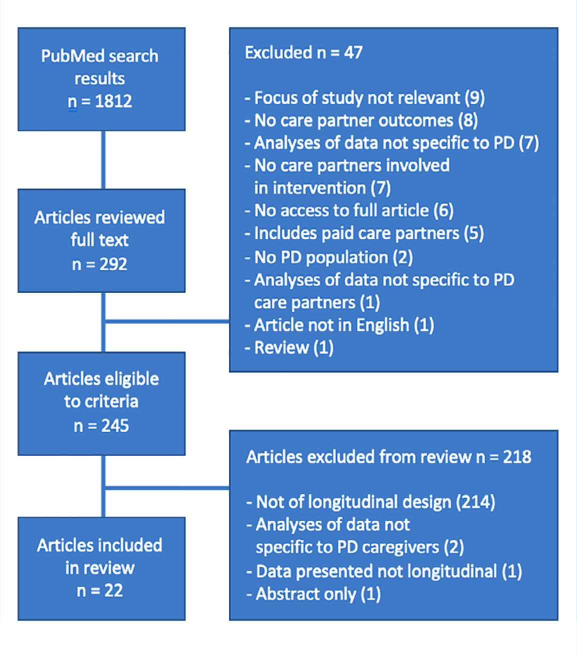

FIG. 2. Studies selected for the scoping review.

Impact on Care Partner Health

Two studies reported on caregiver health over a period of 10 years. Significant negative changes in both depressive symptoms and physical health were found and are partners were at risk for increasing global strain, strain from worry, strain from feelings of being manipulated, and strain from increased tension.[16,17] The relationship between mortality and being the spouse of a person with PD was assessed in a single study. Higher all-cause mortality risk was found for husbands of persons with PD compared to husbands of non-PD controls, but not for wives. Additionally, husbands of persons with PD (but not wives) were at higher risk of dying due to external causes compared with controls matched by age and sex and without PD, including a nearly two-fold higher risk of suicide.[14] Spouses of both sexes living with their partners 5 years after the first hospitalization due to PD had higher mortality risks.

Detailed results of five observational studies describing longitudinal changes in the impact of caregiving are shown in Table 2.

Control Arms of Interventional Studies on Burden

Thirteen interventional studies provided control arms with data on care partner outcomes from baseline to end of follow-up (see Table S1 for detailed quantitative results).[37] Here we summarize the reported changes in burden whether statistically significant or not; the statistical significance of most data is unknown, as most studies did not perform statistical tests to compare differences on the mean differences in baseline results versus follow-up results. Data of known and unknown significance are reported together to present a complete overview.

The time of follow-up ranged from 7 weeks to 12 months. Even studies lasting only 7 weeks saw worsening outcomes of depression, health and fatigue in care partners.[19,21] Burden as measured by the Zarit Burden Inventory, distress, positive interaction and negative strain as dimensions of the Dyadic Relationship Scale (DRS), anxiety, depression, resilience, quality of life, relationship quality, mental and physical health all worsened in studies with final assessments at 3 months.[22,29,32] Care minutes per day increased from 22.2 to 92.4 over 6 months.[30]

TABLE 1 Study characteristics of observational and interventional studies

Study	Intervention	PD eligibility criteria	Mean (SD) disease duration or time since diagnosis at baseline	Longitudinal sample size of care partners
Observational studies				
Dlay JK (2020)[10]	N/A	Idiopathic PD without cognitive impairment	6.1 mo (5.4)	n = 162
Martinez-Martin P (2019)[11]	N/A	PD, not further specified	Not provided	n = 378
Dahodwala N (2018)[12]	N/A	Idiopathic PD	Men 8.8 yrs (6.1), women 8.7 yrs (6.6)	n = 7209
Oguh O (2014)[13]	N/A	PD, not further specified	5.5 yrs (2.0–10.0)	n = 2252
Nielsen N (2014)[14]	N/A	PD not hospitalized with dementia or PD	Not provided	n = 8515
O'Connor EJ (2011)[15]	N/A	PD, not further specified	Not provided	n = 60
Lyons KS (2009)[16]	N/A	PD, not further specified	6 yrs (1.9)	n = 157
Lyons KS (2004)[17]	N/A	PD, not further specified	6 yrs (1.9)	n = 157
Interventional studies				
Kluger BM (2020)[18]	Integrated outpatient palliative care	Degenerative parkinsonism with moderate to high palliative care needs	INT: 116.5 mo (83.7) CON: 114.3 mo (79.2)	At baseline: n (INT) = 88, n (CON) = 87
Lyons KS (2020)[19]	Psychoeducation	PD, not further specified	114.3 mo (79.2)	n (INT) = 19, n (CON) = 20
Mosley PE (2020)[20]	Cognitive behavioral therapy	PD who had undertaken deep brain stimulation of the subthalamic nucleus	Not provided	n = 10
Hellqvist C (2020)[21]	Self-management education program	PD without cognitive impairment	INT: 5 yrs (2–7) CON: 7 yrs (3–8)	n (INT) = 30, n (CON) = 25
Leroi I (2019)[22]	Cognitive stimulation therapy	PD mild cognitive impairment, PD dementia and Dementia with Lewy Bodies without severe neuropsychiatric complications	INT: 4 yrs (0.5–24), CON: 5.5 yrs (0–33)	n (INT) = 24, n (CON) = 32
Dobkin RD (2018)[23]	Cognitive behavioral therapy	PD and a primary depressive disorder	5.49 yrs (4.99)	n = 26
Hindle JV (2018)[24]	Cognitive rehabilitation	PD dementia or Lewy Body Dementia without other psychiatric disorders, depression or neurological diseases	Not provided	n (INT) = 8, n (CON) = 8
Beck CA (2017)[25]	Virtual remote specialist visits	PD without a condition that would preclude participation	INT: 8.3 yrs (6.15), CON: 7.6 yrs (4.9)	n (INT) = 63, n (CON) = 69

(Continues)

TABLE 1 *Continued*

Study	Intervention	PD eligibility criteria	Mean (SD) disease duration or time since diagnosis at baseline	Longitudinal sample size of care partners
Pomponi M (2016)[26]	Self-management education program	PD without clinically significant cognitive disorders or neurological/ psychiatric disorders	8.4 yrs (4.6)	n = 28
Cash TV (2015)[27]	Expressive writing	PD without dementia or a severe mental illness	Not provided	n (INT) = 6, n (CON) = 4
Shah SP (2015)[28]	Tele-support group	PD, not further specified	7 yrs (4.3)	n = 6
Daley DJ (2014)[29]	Adherence therapy	Idiopathic PD without dementia	INT: 8.7 yrs (6.4), CON: 7.8 yrs (4.2)	n (INT) = 25, n (CON) = 23
Sturkenboom IH (2014)[30]	Occupational therapy	Idiopathic PD, problems with ADL, without a predominant disabling comorbidity or cognitive impairment	INT: 6.0 yrs (4.0–10.0), CON: 6.0 yrs (3.0–11.0)	n (INT) = 113, n (CON) = 53
van der Marck MA (2013)[31]	Integrated multidisciplinary care	Idiopathic PD, <80 yrs, no severe cognitive impairment or severe comorbidity, no other neurological conditions, H&Y < 5	INT: 5.8 yrs (4.2), CON: 6.8 yrs (4.8)	n (INT) = 94, n (CON) = 90
Sturkenboom IH (2013)[32]	Occupational therapy	Idiopathic PD, problems with ADL	INT: 7.5 yrs (7.1), CON: 6.9 yrs (4.3)	n (INT) = 26, n (CON) = 13
A'Campo LE (2011)[33]	Coping strategies training	PD, not further specified	INT: 5.95 yrs (5.33) [0.2–20], CON: 5.46 yrs (4.45) [0.2–14]	n = 40
Leroi I (2010)[34]	Sleep therapy	Idiopathic PD and sleep disturbances without severe psychiatric disturbances or dementia, severe unstable medical conditions	75 mo (15.4)	n (INT) = 8, n (CON) = 7
A'Campo LE (2010)[35]	Coping strategies training	Idiopathic PD, without severe psychiatric problems (psychotic symptoms or personality disorders)	5.46 yrs (4.45) [0.2–14]	n (INT) = 25, n (CON) = 19
Secker DL (2005)[36]	Cognitive behavioral therapy	PD, not further specified	INT: 10.0 yrs (7.5), CON: 8.5 yrs (4.0)	n (INT) = 15, n (CON) = 15

INT, interventional arm; CON, control arm.

TABLE 2 Longitudinal impact of caregiving in observational studies

Study	Follow-up	Results	Association ↑ = Increasing ↓ = Decreasing
Martinez-Martin P (2019)[11]	5 yrs	Compared to policy holders with a non-PD dependent, PD care partners had significantly higher mean total out-of-pocket costs (range years 1–5, \$1259–1585 vs \$902–\$1192, respectively; all $P < 0.01$) over 5 yrs. The rate of income loss was more than twice that in the controls (annually approximately \$1200 vs \$520, and cumulatively \$5967 vs \$2634 by year 5; $P = 0.03$).	Out-of-pocket costs ↑ Cumulative income loss ↑
Nielsen N (2014)[14]	9.4 yrs (mean)	Male carepartner spouses had a higher risk of all-cause mortality (HR = 1.06 [95% CI = 1.00–1.11]), suicide (1.89 [1.05–3.42]) and death from undefined symptoms/abnormal findings (1.25 [1.07–1.47]). 5 yrs after first PD hospitalization both husbands and wives had higher risk of all-cause mortality (1.15 [1.07–1.23] and 1.11 [1.04–1.17]).	
Dahodwala N (2018)[12]	60 mo	Care partners of women (vs men) with PD had a faster time to using a paid caregiver (HR 1.76, 95%CI 1.35–2.28, $P < 0.001$).	
Lyons KS (2009)[16]	10 yrs	The yearly linear slope for global strain (FCI) was $\beta = 0.007$ ($P < 0.001$).	Strain ↑
Lyons KS (2004)[17]	10 yrs	Direct care tasks increased from 27% of 50 tasks at baseline, 31% at yr 2, to 48% at yr 10. The intercept ($\beta = 7.98$, $P < 0.001$) and linear slope per year ($\beta = 0.39$, $P < 0.001$) of depressive symptoms (CES-D) were both significant in a linear model. SF-36 physical health worsened significantly (intercept ($\beta = 83.38$, $P < 0.001$, linear slope per year ($\beta = 1.34$, $P < 0.001$)	Direct care tasks ↑ Depression ↑ Physical health ↑

CES-D, Center for Epidemiological Studies – Depression scale; FCI, Family Caregiving Inventory; LOT, Life Orientation Test; MCSI, Multidimensional Caregiver Strain Index; SF-36, Short Form Health Survey (36 items).

Predictors of Future Burden

Twenty-four studies assessed factors predicting burden in care partners for persons with PD. Multiple interventional and non-interventional factors have been identified to either heighten or lower care partner burden and these are described quantitatively in Table S2. A qualitative summary is provided here.

Non-Interventional Predictors of Future Burden

Lower income, worse mood in the care partner as measured by the short form of the Profile of Mood States of the care partner, and increased motor severity of the person with PD have been identified as predictors of poorer care partner quality of life in a follow-up of 12 months, while economic pressure, relationship satisfaction, and social support were not identified as such.[10,15] Physical activity of the person with PD at baseline was found to be associated with less future care partner burden at the time-point of 3 years.[13]

Female sex and higher pessimism in care partners have been found to be predictors of higher future strain in over 10 years of follow-up. Female care partners were more at risk, as wives experienced higher role strain and a faster increase in strain than husbands. Higher optimism and mutuality in the spousal relationship predicted lower future strain.[16,17]

Interventions Associated with Future Burden

Nineteen interventional studies (11 randomized controlled trials, three non-randomized controlled trials, five uncontrolled trials) examined the effect of interventions on care partner outcomes. Taken together, improvements were achieved in care partner burden, quality of life, anxiety and strain depression, general health, relationship quality and stress. Care partners were involved in all interventions, although in only two studies were the interventions aimed primarily at the care partner.[20,36]

Burden was the most assessed care partner outcome in interventional studies. Care partner burden improved after 6 months in one[26] of two studies[21] assessing PD management education for the person with PD and the care partner. Burden improved at 12 months after an intervention of palliative care services and greater benefit was associated with higher palliative care needs, worse grief, and lower cognitive function of the person with PD.[18] Care partner burden reduced after cognitive behavioral therapy, and this was maintained for either 10 weeks or 3 months following the intervention.[20,23,36] Burden also improved after cognitive stimulation therapy at 12 weeks.[22]

Paradoxically, burden worsened after 8 months in a study providing multidisciplinary care.[31] Virtual house calls did not change care partner burden[25] and tele-support did not significantly improve care partner outcomes,[28] just as expressive writing,[27] sleep therapy,[34] and adherence therapy did not improve care partner burden.[29] Occupational therapy did not result in improved care partner outcomes.[30]

Emotional health benefits of interventions were demonstrated in multiple studies. Care partner anxiety improved at 12 months after receiving palliative care and cognitive behavioral therapy.[18,20,23,36] Care partners had fewer depressive symptoms at 7 weeks when receiving psychoeducation to improve self-management, health, self-efficacy, and reduce stress.[19] Unfortunately, cognitive behavioral therapy[20,36] and sleep therapy[34] did not achieve this effect.

At last, quality of life was studies in several studies. Cognitive behavioral therapy improved strain at 6 months[36] and psychoeducation had minimal effect at 7 weeks.[19] Quality of life improved in two studies examining either cognitive stimulation therapy or cognitive rehabilitation for both the person with PD and the care partner at 12 weeks and 6 months,[22,24] but quality of life did not improve after cognitive behavioral therapy,[20] PD management education,[21] or sleep therapy.[34] Better overall health was found at six months after an intervention of cognitive rehabilitation.[24]

Needs and Coping

Two studies were identified with outcomes related to needs and three studies were identified with outcomes related to coping in caregiving for a person with PD. These studies were all of interventional design.

Need for help scores improved after 8 weeks of an education program to learn coping strategies for both the person with PD and the care partner, while need for help scores worsened in the control group. Need for help in the areas of “achievement capability/physical symptoms,” “emotional functioning” and “social functioning” was significantly reduced, as measured by subscales on the Belastungsfragebogen Parkinson angehörigen–kurzversion (BELA-A-k).[35] This effect was not maintained at 6 months in another study examining the same intervention in clinical practice.[28]

Coping was measured as self-efficacy in two studies. In one study, cognitive rehabilitation therapy did not improve self-efficacy significantly at 6 months[24] and in the other study it did improve at 7 weeks after an educational intervention.[19] Coping did not improve at 6 months in a study examining the effect of occupational therapy.[30]

Discussion

When examining the natural evolution of care partner burden, needs, and coping in PD, studies of longitudinal design are preferable over cross-sectional studies of cross-sectional as the design allows follow-up on the change in outcomes at the individual level. Cross-sectional studies that attempt to infer relationships to disease severity or duration can be misleading as the same individuals are not represented at the different points in the disease course. Burden, needs, and coping of care partners in PD are very specific to time and person, as they are directly related to factors associated with the individual with PD or the care partner. Therefore, following a cohort of individuals over time allows more firm conclusions on the evolution of burden than cross-sectional designs. The aim of this review was to understand this natural evolution, yet published longitudinal studies did not accomplish this completely. Important gaps in literature have been identified.

Most of the longitudinal literature on care partner burden, needs or coping consists of interventional studies aimed primarily at the person with PD. The observation period is usually less than 6 months and ranging from 7 weeks to 1 year. The scarcity of longer term, observational research on the temporal evolution of burden in caregiving for someone with PD is a critical gap. Only five studies were identified within this category. Even within these observational studies, the impact of caregiving is rarely reported at specific disease stages or durations, (only one study did this),[11] making it difficult to generate a portrait of caregiving in PD throughout the disease journey.

The longitudinal studies reviewed demonstrate that care partners play an important role in the health care system for persons with PD, contributing more as the disease progresses over time, but their role is associated with negative outcomes, namely higher costs, a slightly higher mortality risk and negative changes in strain, depressive symptoms, and physical health over time.[11,14,16,17] Care partner burden in PD is multidimensional, as is clear from the diversity of outcomes by which burden is assessed in identified studies (see Table 3).

Nevertheless, burden encompasses more components than these outcomes of identified observational studies on the impact of caregiving in PD and more aspects are yet to be addressed. Psychosocial burden, such as sleep disturbances or restrictions in social life, particularly have not been assessed in these studies, while these are common problems in care partners.[38] Another missing aspect of care partner burden is the long-term risk of

TABLE 3 Longitudinal predictors of burden from observational and interventional studies

Care partner outcome	Instrument	Association	↑ = Increasing ↓ = Decreasing	Follow-up
Anxiety	GAI	Cognitive behavioral therapy	↓	3 mo[20]
	HADS	Cognitive stimulation therapy	↑	12 weeks[22]
Burden	ZBI	Integrated outpatient palliative care	↓	12 mo[18]
	MCSI	Physical activity of the person with PD	↑	12 mo[13]
	CBI	Cognitive behavioral therapy		6 mo[36]
	ZBI	Self-management education program		6 mo[26]
	ZBI, CDS	Cognitive behavioral therapy		3 mo[20], 14 weeks[23]
	ZBI	Occupational therapy		3 mo[32]
	ZBI	Cognitive stimulation therapy		12 weeks[22]
	BELA-A-k	Education program to learn coping strategies		9 weeks[35]
	BELA-A-k	Integrated multidisciplinary care		8 mo[31]
Depression	CES-D	Psychoeducation	↓	7 weeks[19]
	CES-D	Female gender of care partner	↑	10 yrs[17]
General health	GHQ-28	Cognitive behavioral therapy	↓	6 mo[36]
Needs	BELA-A-k	Education program to learn coping strategies	↓	9 weeks[35]
Physical health	SF-36	Higher age of care partner	↑	10 yrs[17]
	SF-36	Higher pessimism of care partner		10 yrs[17]
Quality of life	WHOQOL	Income	↓	12 mo[15]
	WHOQOL	Mood		12 mo[15]
	WHOQOL	Cognitive rehabilitation		6 mo[24]
	EQ5D	Cognitive stimulation therapy		12 weeks[22]
Relationship quality	RSS	Cognitive stimulation therapy	↓	12 weeks[22]
Strain	FCI	Higher mutuality	↓	10 yrs[16]
	FCI	Higher optimism of care partner	↑	10 yrs[16]
	CSI	Cognitive behavioral therapy		6 mo[36]
	MCSI	Psychoeducation		7 weeks[19]
	FCI	Female gender of care partner		10 yrs[16]
	FCI	Higher pessimism of care partner		10 yrs[16]
Stress	Rel.SS	Cognitive stimulation therapy	↓	12 weeks[22]
	NPI	Greater motor severity	↑	36 mo[10]
No effect		Virtual remote specialist visits		12 mo[25]
		Expressive writing		10 mo[27]
		Education program to learn coping strategies		6 mo[33]
		Occupational therapy		6 mo[30]
		Adherence therapy		12 weeks[29]
		Sleep therapy		8 weeks[34]
		Tele-support group		8 weeks[28]
		Self-management education program		7 weeks[21]

BDI, Beck Depression Inventory; BELA-A-k, Belastungsfragebogen Parkinson angehörigen–kurzversion; CBI, Caregiver Burden Inventory; CSI, Caregiver Strain Index; CDS, Caregiver Distress Scale; CES-D, Center for Epidemiological Studies - Depression scale; EQ5D, EuroQoL-5D; FCI, Family Caregiving Inventory; GAI, Geriatric Anxiety Inventory; GHQ-28, General Health Questionnaire; HADS, Hospital Anxiety and Depression Scale; MCSI, Multidimensional Caregiver Strain Index; NPI, Neuropsychiatric Inventory; Rel.SS, Relatives Stress Scale; RSS, Relationship Satisfaction Scale; SF-36, Short Form Health Survey (36 items); WHOQOL-BREF, World Health Organization Quality of Life Scale – Brief version; ZBI, Zarit Burden Interview.

poorer quality of life. One study did use the SF-36 to assess care partner health-related quality of life, but different aspects of quality of life as environment quality and social status have not been specifically assessed.[17]

Results addressing these outcomes can help healthcare practitioners and thereby care partners, to understand the evolution of burden and prepare them for or mitigate possible future burden.

A main advantage of longitudinal studies is the opportunity to identify predictors of future burden, which informs targeted monitoring to identify care partners needs at their earliest stages, or informs targeting interventions to prevent problems. Predictors of future burden identified in the published literature were either related to the person with PD, care partner-related, or healthcare-related. Due to their association with greater burden

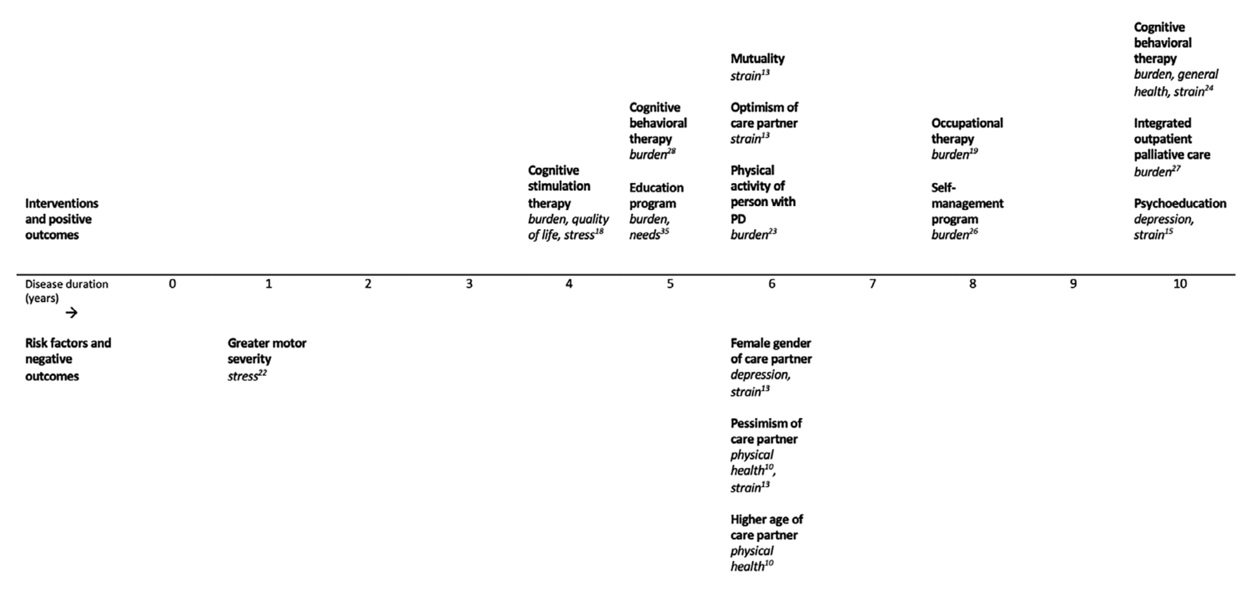

FIG. 3. Opportunities for intervention from longitudinal studies. Timeline definition: Mean disease duration reported in paper. Papers that did not report a disease duration are not presented in this figure.

or strain over time, risk factors warranting intervention or close monitoring would include greater motor severity of the person with PD; female sex, less physical activity, lower income and depressed mood of the care partner. Other findings related to interventions and although several potentially beneficial interventions were identified, the duration of benefit is unknown for most. At most 6 months follow-up was undertaken, with no evidence for sustained benefit.

Of all 19 interventional studies, just two studies examined interventions that were primary focused on care partners.[20,36] More studies examining an intervention specifically aimed at the care partner are needed to help care partners in PD.

Findings in other neurological diseases can provide insights into useful avenues of research in PD caregiving. Observational studies of longitudinal design in dementia and amyotrophic lateral sclerosis with a follow up ranging from approximately 1 year up to 3 years did study the evolution of burden and identified factors associated with increased care partner burden.[39–41]

Similar studies in PD are needed to examine longitudinal associations. For instance, the relationship between severity of PD and care partner burden has been examined cross-sectionally,[42] but not longitudinally. Factors of interest related to the person with PD that have not yet been evaluated in longitudinal literature in PD, but have been identified as potentially relevant in cross-sectional studies or longitudinally in other chronic neurological diseases are motor severity, disease-related symptoms (psychosis, cognitive impairment, apathy, impulse control disorders, etc.), functional deficits in basic or instrumental activities or daily living, gender, and available health care services. Care partner-related factors of importance would include age, gender, ethnicity, health, mobility, economic situation, work, social situation, level of education, and health care access.[39–45] As this review only focused on interventions that included care partner involvement, one should keep in mind that interventions focused on the person with PD (for example reducing OFF-time) while likely to reduce caregiving burden were not the focus of this review.

Identifying these factors and their relationship and contribution to care partner burden can enable healthcare practitioners can help care partners to anticipate and prepare for future burden and they can function as key points for future research (see Fig. 3).

Needs and coping have been studied in the fewest longitudinal studies. We identified no studies have demonstrated persistence of benefit of an intervention for carepartners at 6 months or beyond. There is a major unmet need for evidence-based interventions to address needs and improve coping strategies in PD care partners. Observational cross-sectional studies provide some guidance: needs such as stress management, services for symptom management, coping with relationships and coping with their new lifestyle have been identified and could be the subject of future interventional studies.[46,47] When these needs arise in the course of PD and their predictors is not known.

Burden, needs, and coping are concepts very closely related to each other. Needs are a consequence of burden, and both can be dealt by with coping. Consequently, when burden changes throughout PD, so do needs and coping (see Fig. 2). Their changes throughout the temporal evolution of PD are as important as the evolution of burden and has not yet been studied.

The relationship between unmet care partner needs and disease symptoms has been studied longitudinally in dementia and amyotrophic lateral sclerosis, and the relationship between care partner coping and burden has been studied longitudinally in dementia.[48–50] Their findings suggest some strategies for improvement of caregiver burden and emotional health that may also apply in PD. Emotion-focused coping strategies instead of problem-focused coping strategies (as measured by the BRIEF-Cope) was associated with less anxiety at 1 year follow-up in a dementia care partner population.[48] Similar associations might be of interest to study in PD and could guide as reference for potential interventions.

Limitations of this review are that it is limited to English literature and to a single online database (PubMed). Another limitation of this review is that studies addressing interventions solely aimed at the person with PD are not included. The quality of included studies has not been assessed, as our primary aim was to identify gaps in the literature, however doing so could identify specific areas for future methodologic improvement.

This scoping demonstrates that further research is needed regarding the evolution of burden, needs, and coping in caregiving in PD. Longitudinal studies on these topics are needed to help understand their change over time and their relationship to each other. This will give direction to care partner-centered PD care and can better guide the design of interventional studies focused on care partners.

Acknowledgment

We acknowledge Monica Korell, an epidemiologist and project manager from the University of California, for coordinating the project and online meetings.

Author Roles

(1) Research Project: A. Conception; B. Coordination; C. Planning; (2) Data: A. Collection; B. Analysis; C. Review; (3) Manuscript: A. Writing of the first draft; B. Review and Approval.

M.J.H.: 1A, 1B, 1C, 2A, 2B, 2C, 3A
E.B.: 1A, 2B, 3B
N.D.: 1A, 2B, 3B
C.M.T.: 1A, 3B
C.R.: 1A, 3B
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Disclosures

Ethical Compliance Statement: We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines. The authors confirm that neither the approval of an institutional review board nor patient consent were required for this work.

Funding Sources and Conflict of Interest: No specific funding was received for this work and the authors declare that there are no conflicts of interest relevant to this work.

Financial Disclosures for the Previous 12 Months: The authors declare that there are no additional disclosures to report. ■

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Supporting Information

Supporting information may be found in the online version of this article.

Table S1. Longitudinal impact of caregiving in control arms of interventional studies.

Table S2. Longitudinal predictors of burden from observational and interventional studies, quantitative results.