

BMJ Open Sleep disturbance in caregivers of individuals with Parkinsonism: a systematic review and meta-analysis

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To cite: Sprajcer M, Owen PJ, Crowther ME, *et al.* Sleep disturbance in caregivers of individuals with Parkinsonism: a systematic review and meta-analysis. *BMJ Open* 2022;**12**:e062089. doi:10.1136/bmjopen-2022-062089

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-062089>).

Received 17 February 2022
Accepted 24 October 2022



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ABSTRACT

Objectives The global prevalence of Parkinsonism continues to rise given ageing populations. Individuals with Parkinsonism who have moderate or severe symptoms typically require a high level of care, including assistance with activities of daily living. This care is often provided across the 24-hour period by a family member or friend. It is likely that providing care significantly impacts the sleep duration and quality of the caregiver given overnight caring responsibilities, in addition to worry and stress associated with the caregiving role. The aim of this systematic review and meta-analysis was to investigate whether providing care to an individual with Parkinsonism was associated with disturbed caregiver sleep, and to identify associated factors that may contribute to disturbed sleep in this population.

Setting Five databases were electronically searched on 30 June 2021 including CINAHL, PubMed, PsycINFO, CENTRAL and EMBASE.

Participants Eligibility criteria included a population of caregivers whose care recipient has a form of Parkinsonism.

Primary and secondary outcome measures To be included in this systematic review, outcome measures of caregiver sleep (eg, sleep duration, sleep quality) were required.

Results Eighteen studies (n=1998) were included. Findings indicated that caregivers of individuals with Parkinsonism typically experience poor sleep quality (mean (95% CI): 5.6 (4.8 to 6.4) points on the Pittsburgh Sleep Quality Index), increased sleep latency and poor sleep efficiency.

Conclusions The degree of poor sleep quality was clinically significant. However, further investigation of sleep outcomes is required using sleep measurement tools tailored for this population (eg, measures that capture overnight sleep disruption by care recipient(s)). Additionally, there is a need for appropriate individual and societal-level interventions to improve caregiver sleep.

PROSPERO registration number CRD42021274529.

INTRODUCTION

Parkinsonism reflects a group of neurological disorders with similar neurological and movement-related symptoms,¹ and encompasses two main subtypes (neurodegenerative

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This systematic review and meta-analysis presents evidence on the impact of caring for an individual with Parkinsonism on caregiver sleep.
- ⇒ Clinically meaningful differences in sleep quality were identified when caregivers of individuals with Parkinsonism were compared with non-caregivers.
- ⇒ A rigorous systematic review methodology was used, in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline.
- ⇒ Many included studies used methods of measuring sleep that are not tailored to a caregiver population, and as such may underestimate the negative impacts of the caring role on sleep.
- ⇒ Potential factors associated with poor sleep in this population are identified, though casual relationships were not established.

and secondary Parkinsonism).^{2,3} Typical symptoms consist of rest tremor, rigidity, bradykinesia and stooping posture, with frequent comorbidities including cognitive impairment and poor mental health (eg, depression and anxiety).⁴ Parkinson's disease (PD) is the most common form of Parkinsonism,⁴ with up to 1500 individuals per 100 000 experiencing this disease worldwide.⁵ Furthermore, the prevalence of PD is expected to rise in coming years due to ageing populations.⁶ Individuals with moderate to severe symptoms of Parkinsonism typically require a high level of care, including both social support and assistance to complete activities of daily living.⁷ Furthermore, the amount of care required is likely to increase as PD progresses.⁸ This type of informal care represents a significant monetary cost. In Australia, productivity losses cost an estimated \$A184.4 million each year based on the inability of caregivers to work full time (or at all), and reflect the provision of 19 million hours of care annually.⁹ For many individuals with Parkinsonism, this care is

typically provided informally by a family member or close friend.⁷

Caregivers of individuals with Parkinsonism may be required to undertake a variety of tasks to support daily living and optimise the quality of life experienced by their care recipient. Caregiver activities may include assisting with eating, dressing, personal hygiene, visits to the bathroom overnight or turning over in bed.⁷ For some, the caregiving role may also involve making medical or financial decisions on behalf of the individual with Parkinsonism.¹⁰ The responsibilities of this group of caregivers can be demanding and associated with reduced caregiver quality of life,⁷ in addition to poor physical health (eg, poor cardiovascular health, obesity) and mental health (eg, depression, anxiety).¹¹ Moreover, caring responsibilities often require a significant time investment from caregivers, due to the high level of care required as the disease state progresses.¹²

Within other caregiving populations, evidence suggests that sleep duration and quality are also likely to be impacted by the caring role.^{13–15} For example, a recent systematic review of sleep in caregivers of children with medical needs concluded caring is associated with longer sleep latency, short sleep duration (below the recommended duration of 7–9 hours per night¹⁶) and poor quality sleep (eg, increased wake after sleep onset, poor sleep efficiency).¹⁴ Similarly, a systematic review of sleep in caregivers of individuals with dementia found caregivers typically obtained 2.4–3.5 fewer hours of sleep per week than non-caregiving controls, in addition to poorer sleep quality.¹⁵ While these reviews suggest that caregiving responsibilities are likely to impact sleep, to date no systematic synthesis has been performed on sleep in caregivers of individuals with Parkinsonism. It is likely that caregivers of individuals with Parkinsonism have similar experiences to other caregiving groups (eg, tasks undertaken, time required to perform caregiving duties, emotional impact of caring for a close family member or friend). As such, these individuals may experience similarly poor sleep outcomes (eg, sleep latency, sleep quality, sleep duration, sleep efficiency) to other types of caregivers. However, individuals with PD often experience significant sleep disturbances (eg, overnight wakings, increased sleep latency and early awakenings),¹⁷ and are up to eight times more likely than healthy individuals to experience rapid eye movement (REM) sleep behaviour disorder (RBD).¹⁸ As such, it is likely that caregivers of individuals with Parkinsonism experience unique challenges when providing care. The aim of this systematic review and meta-analysis is therefore to investigate whether providing care to an individual with Parkinsonism was associated with disturbed caregiver sleep. Furthermore, we aim to identify associated factors that may contribute to disturbed sleep in this population. By identifying the extent to which caring responsibilities result in disturbed sleep in this population, and what factors may be associated with poor sleep, we will be able to provide evidence to underpin the provision of

additional, targeted support to caregivers of individuals with Parkinsonism.

METHODS

Registration and protocol

This systematic review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline.¹⁹ The PRISMA checklist can be found in online supplemental material 1. The protocol for this systematic review and meta-analyses was registered with PROSPERO on 28 September 2021 (CRD42021274529).

Patient and public involvement

No patient involved.

Eligibility criteria

Inclusion criteria for this review were: (a) population of paid (in the form of a carer's allowance or similar stipend only) or unpaid, non-professional caregivers (≥ 15 years of age) of a person with any form of Parkinsonism (eg, PD, drug-induced Parkinsonism, vascular Parkinsonism, multiple systems atrophy, progressive supranuclear palsy and corticobasal degeneration); (b) having a caregiver's sleep outcome as measured by an objective (eg, polysomnography, electroencephalogram or actigraphy) or subjective measure, including: validated questionnaires or survey/interview questions on any aspect of sleep (eg, sleep latency, sleep quality); (c) being an original published peer-reviewed article (ie, not a review of literature or conference abstract); (d) availability in English, as the exclusion of non-English publications does not significantly impact direction or size of estimates.²⁰ All types of study designs were included, but although studies that include both quantitative and qualitative data were included, only quantitative data were extracted.

Search strategy

The development of the search strategy began by using Medical Subject Headings to identify appropriate keywords, and a search of six systematic reviews was conducted to identify appropriate keywords.^{5 21–25} Key search terms in the field of caregiving, sleep and Parkinsonism were used for the search. For full search terms, see online supplemental material 2. The following limiters were employed: EMBASE (conference abstract), CENTRAL (trials).

Information sources

Five online databases (CINAHL, PubMed, PsycINFO, CENTRAL and EMBASE) were searched for this review, on 30 June 2021 (see online supplemental material 2). Backward and forward citation tracking was conducted on the included articles. Additional searches via Google Scholar (search terms: 'Parkinson', 'sleep', 'systematic review'; limiters: previous 10 years) and Cochrane Database of Systematic Reviews (search terms: 'Parkinson', 'sleep'; limiters: none) were also conducted to identify

Table 1 JBI risk of bias assessment of case-control studies

First author (year)	1	2	3	4	5	6	7	8	9	10	Score out of 10
Smith ⁴⁹ (1997)	Unclear	Unclear	Unclear	Y	Unclear	N	N	Y	Unclear	Y	3
Teel ⁵⁰ (1999)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Cupidi ⁴⁸ (2012)	Unclear	Unclear	N	Y	Unclear	Y	Y	Y	Unclear	Y	5
Olsson ²⁹ (2016)	Y	Y	Y	Y	Y	N	N	Y	Unclear	Y	7

Cut-offs 1–3 'weak', 4–7 'moderate' and 8–10 'strong'.
JBI, Joanna Briggs Institute.

previous systematic reviews on the topic. No additional articles were identified following backward citation tracking of any identified systematic reviews via these additional searches.

Selection process

Prior to screening, an inclusion/criteria pilot was undertaken by all authors using 100 randomly selected articles from the search outcomes. Following pilot testing, two authors (KH and CCG) independently completed title/abstract screening, with disagreement adjudicated by a third author (GEV). A pilot was also conducted for full-text screening (10 articles) by KG and CCG, to ensure the two reviewers were congruent in their methods and reasons for exclusion. Full-text screening was conducted by two authors (KG and CCG) and disagreements were adjudicated by a third author (GEV).

Data extraction

Data were independently extracted by two reviewers (KH and MEC) for completeness and accuracy. Data extraction was checked by a third reviewer (CCG) and any disagreements were settled via discussion. The following

variables were extracted: (a) author and year, (b) article title, (c) study design, (d), country, (e) sample size and caregiver demographics, (f) control group sample size and demographics, (g) measures/questionnaires used, (h) sleep outcomes, and (i) reported relationships between caregiver factors and sleep. The data extraction table was created based on the Cochrane Consumers and Communication Review Group's data extraction template.²⁶ Certainty of evidence was assessed according to the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) approach,²⁷ which included assessment of publication bias via visual inspection of funnel plots.

Risk of bias assessment

The Joanna Briggs Institute (JBI) standardised critical appraisal checklists were used to assess the quality of evidence in each of the 18 included studies.²⁸ Quality of evidence assessments were conducted by one author (CCG) and checked by a second author (KH). In table 1 of the JBI checklist for case-control studies, the questions are answered with the following: N=no, Y=yes and

Table 2 JBI risk of bias assessment of cross-sectional studies

First author (year)	1	2	3	4	5	6	7	8	Score %
Cifu ³⁶ (2006)	N	Y	Y	NA	N	N	N	Y	42.9
Hermanowicz ³⁹ (2019)	Y	Y	Y	NA	N	N	N	Y	57.1
Pal ⁴⁴ (2004)	Y	Y	Y	NA	N	N	Y	N	57.1
Liu ³³ (2018)	N	Y	Y	NA	N	N	Y	Y	57.1
Hicks ⁴⁰ (2019)	Y	Y	Y	NA	Y	Y	Y	Y	100.0
Happe ³⁸ (2002)	N	Y	Y	NA	N	N	N	Y	42.9
Bartolomei ³⁰ (2018)	Y	Y	Y	NA	N	N	Y	Y	71.4
Hand ³⁷ (2021)	Y	Y	Y	NA	N	N	Y	Y	71.4
Lee ⁴¹ (2020)	Y	Y	Y	NA	N	N	Y	Y	71.4
Lökk ⁴² (2008)	N	Y	Y	NA	N	N	N	Y	42.9
Perez ⁴⁵ (2020)	Y	Y	Y	NA	N	N	Y	Y	71.4
Wade ⁴⁷ (2020)	N	Y	Y	NA	N	N	Y	Y	57.1
Ozdilek ⁴³ (2012)	Y	Y	Y	NA	N	N	Y	Y	71.4
Thommessen ⁴⁶ (2002)	N	Y	Y	NA	N	N	Y	Y	57.1

Cut-offs ≤49% 'weak', 50%–70% 'moderate' and ≥71% 'strong'.
JBI, Joanna Briggs Institute; NA, not applicable.

unclear. JBI case-control checklist cut-offs were set at 1–3 'weak', 4–7 'moderate' and 8–10 'strong'. In table 2 of the JBI checklist for cross-sectional studies, the questions are answered with the following: N=no, Y=yes and NA=not applicable. JBI cross-sectional checklist cut-offs were set at $\leq 49\%$ 'weak', 50%–70% 'moderate' and $\geq 71\%$ 'strong'.

Statistical analysis

Due to data paucity, meta-analysis was only feasible for sleep quality outcomes (ie, Pittsburgh Sleep Quality Index (PSQI), Medical Outcomes Study-Sleep Problems Scale Index II (MOSS-SLEEP), Nottingham Health Profile-Sleep (NHP-Sleep)). Seven studies were included in this meta-analysis. Data extracted were mean and SD. All analyses were conducted using Stata V.17 (StataCorp, College Station, Texas, USA). Random-effects meta-analysis determined a point estimate for sleep quality of caregivers of individuals with Parkinsonism. Data presented as median (IQR, min–max)²⁹ were transformed to mean (SD) using established formulae. Data from the MOSS-SLEEP³⁰ and NHP-Sleep²⁹ scales were transposed to a 21-point scale given the PSQI (a 21-point scale) was the most commonly implemented tool. The PSQI assesses seven separate sleep components (sleep quality, sleep onset latency, sleep duration, sleep efficiency, sleep disturbances, use of sleep medication and daytime dysfunction) and higher scores indicate poorer sleep.³¹ Point estimate sensitivity analyses

included: (1) omitting each individual study from the main analysis, (2) omitting studies that did not use PSQI, (3) omitting the study that used transposed mean (SD) data.

Pairwise random-effects meta-analysis estimated the standardised mean difference (Hedges' g) in sleep quality between caregivers of individuals with Parkinsonism and: (1) healthy controls and (2) other carers. Both of these additional analyses included just two studies. As such, these pairwise meta-analyses implemented the Hartung-Knapp-Sidik-Jonkman method per prior recommendations for meta-analysis of less than five studies.³² In one study³³ that presented two comparator groups, the sample size of the group of caregivers of individuals with Parkinsonism was adjusted according to Cochrane guidelines.³⁴ Code for all analyses is supplied in online supplemental material 3A.

RESULTS

Study selection

Searches of the five databases yielded 1493 results. Of these results, 391 duplicates were electronically removed via Covidence³⁵ (see figure 1). Following duplicate removal and title and abstract screening, a total of 83 records remained for full-text screening. Following

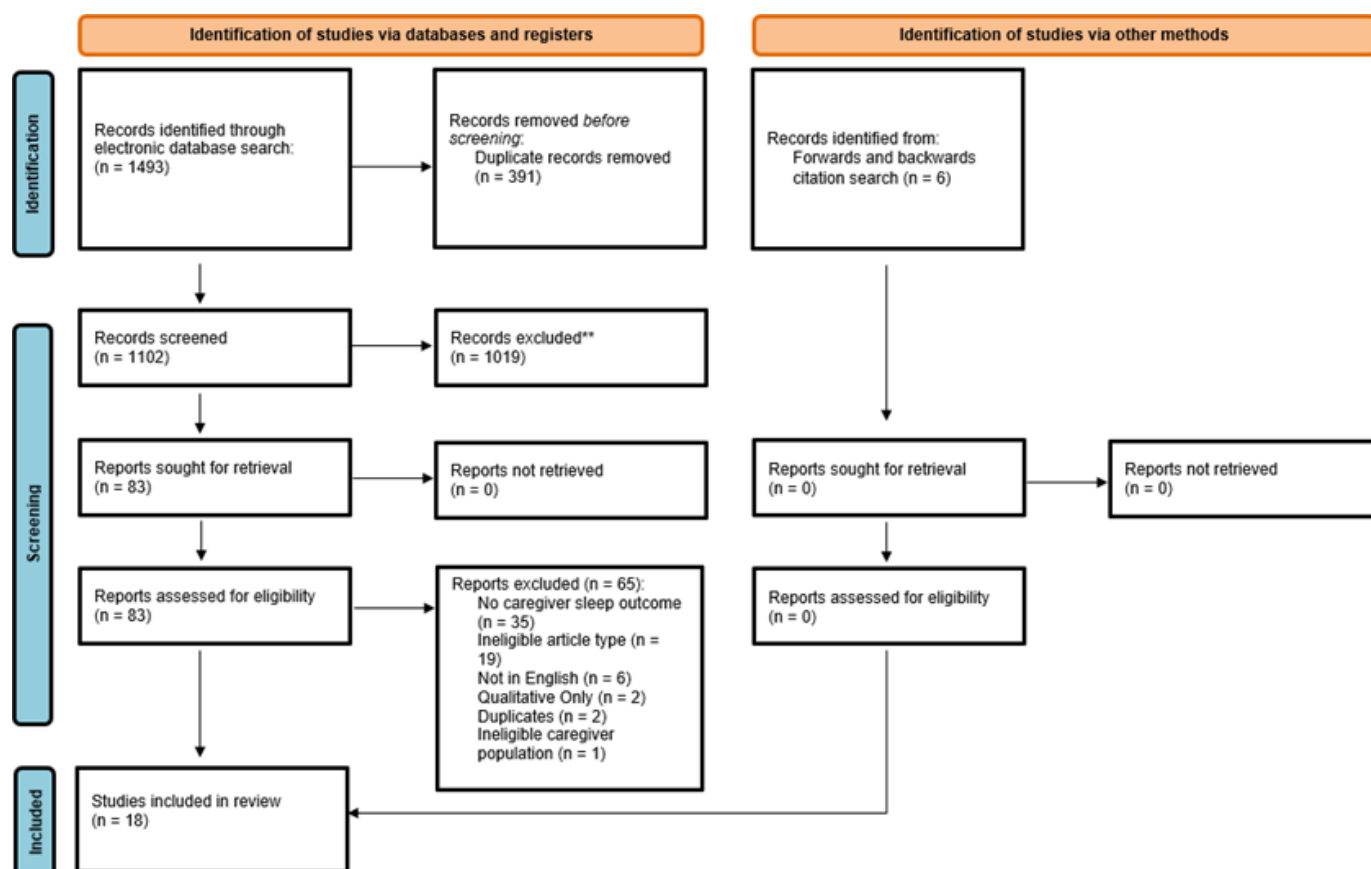


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart for selection of studies included in this review.

full-text review, 65 studies did not meet inclusion criteria and were excluded (see online supplemental material 4). The majority of studies were excluded as they did not measure caregivers' sleep (n=35) or due to an ineligible type of article (eg, review, conference paper, trial registry) (n=19). An overview of records excluded at each stage is presented in [figure 1](#). The total number of eligible studies for inclusion was 18.

Study characteristics

The average time since publication for included studies was 8.7 years, with a range of 0–24 years. The majority of studies (78%, n=14) were of cross-sectional design,^{30 33 36–47} with the remaining 22% (n=4) using a case–control design with healthy, non-caregiving controls.^{29 48–50} [Table 3](#) summarises key sample characteristics of included studies.

Participant characteristics

The included studies represented a total of 1998 participants. Individual study sample sizes ranged from 18 to 404 participants. Overall, most caregivers were female (~54%), compared with 25% male, while two studies did not report caregiver gender. The average age of caregivers within the included studies ranged between 57 and 73 years, with 33% (n=6) of studies reporting average caregiver age of >65 years. The majority of the participants (64%, n=1272) were spouses or significant others of the care recipient, 4% (n=86) were the care recipient's offspring or offspring's spouse, 1% (n=22) were the care recipient's sibling, parent or friend, while the relationship of 31% (n=618) of caregivers was not reported.

Caregiving characteristics

Of the included studies, 28% (n=5) measured caregiving frequency.^{29 38 43 45 50} As shown in online supplemental material 5, over a quarter of studies (28%, n=5) examined duration of caregiving with the average time providing care varying between 26 months and 7.7 years.^{29 41 43 45 50}

One study reported that 53% of caregivers provided daily care, while 16% provided regular, but not daily care.³⁸ Furthermore, average weekly caregiving was reported to range from 22 hours²⁹ to 88 hours,⁴⁵ while some studies reported average daily caregiving as approximately 10 hours of care per day.^{43 50}

Measurement of caregiver sleep

A summary of outcome measures used and results of included studies are provided in online supplemental material 5. All studies used subjective measures of caregiver sleep and none measured caregiver sleep objectively (eg, actigraphy, polysomnography). The PSQI³¹ was the most commonly used measure, being used in 28% (n=5) of studies.^{33 40 44 47 48} One study used both the PSQI⁴⁴ and the validated General Sleep Questionnaire.⁵¹ Other validated sleep measures used were: MOSS-SLEEP⁵² (n=1),³⁰ NHP-Sleep⁵³ (n=1),²⁹ Scale for Outcomes in Parkinson's Disease-Sleep⁵⁴ (n=1),³⁷ and Verran and Snyder-Halpern Sleep Scale⁵⁵ (n=1).⁵⁰ A proportion of studies used sleep

items from larger validated measures, such as measures of quality of life or depression, WHO Quality of Life⁵⁶ (n=1),⁴³ Patient Health Questionnaire⁵⁷ and Family Needs Questionnaire⁵⁸ (n=1).⁴⁵ One study⁴¹ used the Mini International Neuropsychiatric Interview,⁵⁹ which indicates a diagnosis of psychiatric disorders including insomnia related to depression. Two studies examined sleep disruption attributable to care recipient needs.^{46 49} Further, one of the studies that examined sleep disruption attributable to care recipient also examined a single non-validated measure of sleep quality ('I cannot sleep well at night').⁴⁹ Two studies used non-validated single measures of sleep, namely self-report sleep duration (average hours per night)³⁶ and sleep disturbance (sleep disturbance last 4 weeks: Yes/No).⁴²

Caregiver sleep

The studies that examined sleep quality using the PSQI report average global sleep quality scores between 4.9 and 6.9 points. The majority of the studies using the PSQI (80%, n=4) reported average PSQI scores above the clinically significant poor sleep quality score ≥ 5 points.^{33 44 48 60} Of the studies that used control groups and PSQI outcomes, PD caregivers had poorer average global sleep quality scores (ie, higher score) than healthy controls (PD carers: 6.3 ± 3.9 points; control: 4.1 ± 3.1 points)⁴⁸ and both frontotemporal lobar degeneration (FTLD) and Alzheimer's (AZ) caregivers (PD carers: 5.2 ± 3.0 points; FTLD carers: 4.4 ± 3.7 points; AZ carers: 1.0 ± 1.4 points).³³ These findings are consistent with another case–control study, using the Verran and Snyder-Halpern Sleep Scale, which found sleep disturbance scores were significantly higher among caregivers (3.88 points) compared with controls (3.02 points).⁵⁰ Further, this study also found caregivers had significantly lower sleep effectiveness (6.68 points) compared with non-caregiving controls (8.02 points).⁵⁰ It should be noted that spread (eg, SD) in this study was not reported. Poor sleep, as measured by the 4-point scale 'I cannot sleep well at night', was reported to be significantly higher among PD carers (2.3 ± 1.0 points) compared with healthy controls (1.8 ± 0.9 points).⁴⁹ These findings differ from another case–control study using the Nottingham Health Profile sleep survey, which found no significant difference in sleep scores between PD caregivers and controls.²⁹ When considering single-use non-validated sleep outcome measures, 27% of caregivers reported poor sleep in the previous week.³⁸ Furthermore, another study found 46% of caregivers reported sleep disturbance in the previous 4 weeks.⁴² Only one study³⁶ examined caregiver sleep duration. The study found that caregivers reported an average sleep duration of 6.4 ± 1.5 hours per night, which is below adult healthy sleep guidelines of 7–9 hours.¹⁶

Meta-analysis of caregiver sleep

A total of seven studies that included sufficiently similar global sleep scores were eligible for inclusion in meta-analysis. Meta-analysis of seven studies (participants:

Table 3 Characteristics of included studies

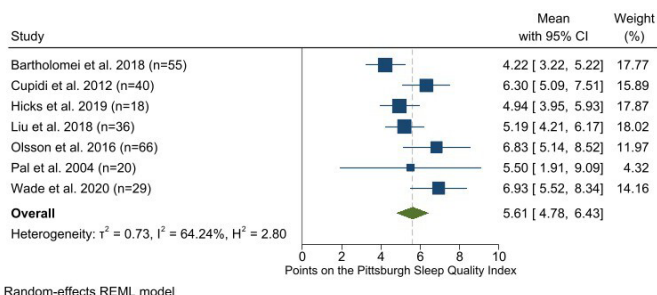
First author, year	Country	Sample size (caregivers of individuals with Parkinsonism)			Caregiver mean age (SD)	Relationship to care recipient N	Care recipients' condition	Frequency of caregiving	Duration of caregiving: mean (SD)
		% female	n	SD					
Bartolomei, 2018 ³⁰	Italy	64	55	62.0 (12.0)	Spouse (n=47) Offspring (n=8)	Parkinson's disease	Not reported	Not reported	
Cifu, 2006 ³⁶	USA	98	49	70.0 (9.9)	Wife (n=40) Offspring (n=4) Daughter-in-law (n=1) Significant other (n=3) Friend (n=1)	Parkinsonism	Not reported	Not reported	
Cupidi, 2012 ⁴⁸	Italy	70	40	64.2 (9.4)	Spouse (n=36) Offspring (n=4)	Parkinson's disease	Not reported	Not reported	
Hand, 2021 ³⁷	UK	66	115	70.7 (9.7)	Spouse (n=98) Offspring/daughter-in-law (n=12) Sister (n=3) Friend (n=2)	IPD PDD HY stage II-V CBD MSA PSP	Not reported	Not reported	
Happe, 2002 ³⁸	Germany	63	101	62.3 (10.0)	Partner/spouse (n=101)	Parkinson's disease	Never/not necessary: 53%, regularly, not daily: 16%, daily: 53%	Not reported	
Hermanowicz, 2019 ³⁹	USA	Not reported	357	Not reported	Not reported	Parkinson's disease	Not reported	Not reported	
Hicks, 2019 ⁴⁰	USA	50	18	62.2 (10.4)	Spouse (n=16) Friend (n=2)	Parkinson's disease	Not reported	Not reported	
Lee, 2020 ⁴¹	Taiwan	67	162	59.1 (12.5)	Spouse (n=122) Offspring (n=30) Parent/sibling/friend (n=10)	Parkinson's disease	Not reported	7.7 years	
Liu, 2018 ³³	China	67	96	61.3 (11.1)	Spouse (n=21) Offspring (n=15)	Dementia with Lewy bodies	Not reported	Not reported	
Löök, 2008 ⁴²	Sweden	62	404	68.5 (9.4)	Spouse (n=396) Not reported (n=8)	Parkinson's disease	Not reported	Not reported	
Olsson, 2016 ²⁹	Sweden	70	66	69.9 (8.2)	Spouse (n=63) Offspring (n=1) Other (n=2)	Parkinson's disease	22.5 hours (weekly)	3.0 years (median)	

Continued

Table 3 Continued

First author, year	Country	Sample size (caregivers of individuals with Parkinsonism)	% female	Caregiver mean age (SD)	Relationship to care recipient N	Care recipients' condition	Frequency of caregiving	Duration of caregiving: mean (SD)
Ozdemir, ⁴³ 2012	Turkey	50	78	56.6 (13.2)	Spouse (n=37) Offspring (n=11) Sibling (n=2)	Parkinson's disease	10.0 hours (daily)	26.0 months
Pal, ⁴⁴ 2004	Not reported	23	65	65.2 (11.3)	Spouse (n=23)	Parkinson's disease	Not reported	Not reported
Perez, ⁴⁵ 2020	USA & Mexico	253	73	59.9 (14.7)	Not reported	Parkinson's disease	87.9 hours (weekly)	50.1 months
Smith, ⁴⁹ 1997	Germany	153	78	64.0 (11.0)	Spouse (n=153)	Parkinson's disease	Not reported	Not reported
Teel, ⁵⁰ 1999	USA	29	52	73.0 (not reported)	Spouse (n=29)	Parkinson's disease	10.1 hours (daily)	5.1 years
Thommessen, ⁴⁶ 2002	Norway	58	Not reported	Not reported	Spouse (n=58)	Parkinson's disease	Not reported	Not reported
Wade, ⁴⁷ 2020	Australia	29	62	69.0 (5.9)	Spouse (n=29)	Parkinson's disease	Not reported	Not reported

CBD, corticobasal degeneration; HY, Hoehn and Yahr; IPD, idiopathic Parkinson's disease; MSA, multiple systems atrophy; PDD, Parkinson's disease dementia; PSP, progressive supranuclear palsy.



Random-effects REML model

Figure 2 Forest plot for the meta-analysis of sleep quality (Pittsburgh Sleep Quality Index) point estimates in caregivers of individuals with Parkinsonism. REML, Restricted Maximum Likelihood.

n=264)^{29 30 33 40 44 48 60} revealed a point estimate (95% CI) of 5.61 (4.78 to 6.43) points on the PSQI (figure 2). Following omission of each individual study, point estimate (95% CI) ranged 5.44–5.87 (4.55 to 5.10, 6.17 to 6.73) points (online supplemental material 3B). Sensitivity analysis of only PSQI data (ie, omission of other tools transposed to a 21-point scale) yielded a point estimate (95% CI) of 5.72 (4.90 to 6.54) points (online supplemental material 3C,D), whereas omission of data transposed to mean (SD) resulted in a point estimate (95% CI) of 5.43 (4.58 to 6.29) points (online supplemental material 3E,F). Caregivers of individuals with Parkinsonism had lower sleep quality compared with non-caregiver healthy controls (standardised mean difference (95% CI): 0.38 (–2.40 to 3.17), $p=0.331$, $I^2=68.8\%$, studies: n=2, participants: n=335, GRADE: very low; figure 3) and other carers (1.48 (–14.58 to 17.54), $p=0.450$, $I^2=97.9\%$, studies: n=1, participants: n=492, GRADE: very low; figure 4; note: group split for multiple comparators).

Factors associated with sleep in caregivers

The studies included in the present review indicate several caregiving factors which are associated with caregiver sleep, such as care recipient sleep quality and depression, caregiving burden, and frequency and length of caregiving. Four studies found that caregiver sleep quality was associated with care recipient sleep quality.^{30 38 44 45} In addition, two of these studies found that caregiver sleep quality was also associated with care recipient depression scores.^{30 44} When considering caregiver burden, greater levels of burden and caregiver distress are associated with decreased self-report sleep duration,³⁶ increased sleep

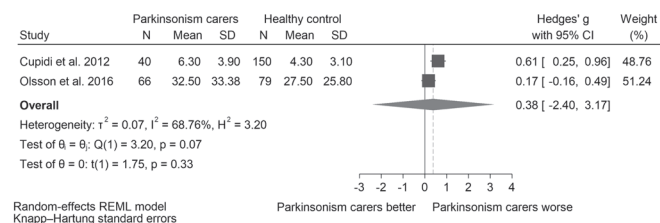


Figure 3 Forest plot for the meta-analysis of sleep quality (Pittsburgh Sleep Quality Index) in caregivers of individuals with Parkinsonism compared with healthy controls. REML, Restricted Maximum Likelihood.

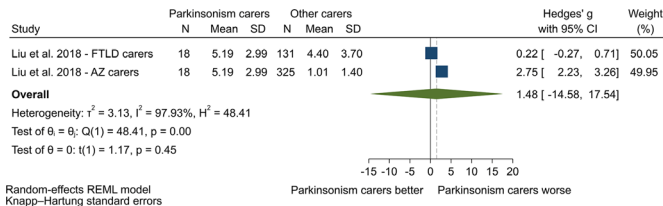


Figure 4 Forest plot for the meta-analysis of sleep quality (Pittsburgh Sleep Quality Index) in caregivers of individuals with Parkinsonism compared with other carers. AZ, Alzheimer's disease; FTLD, frontotemporal lobar degeneration. REML, Restricted Maximum Likelihood.

disturbance⁴⁷ and sleep problems.⁴⁵ This may also be true for sleep quality, in which increased caregiver burden and higher severity of motor symptoms in Parkinson's care recipient was associated with an increased odds of poor sleep.³⁸

In examining frequency of caregiving, the prevalence of sleep disturbance was shown to increase with regular caregiving, in a dose–response pattern.³⁸ Furthermore, greater patient sleep problems were associated with greater caregiver sleep problems.⁴⁵ Caregivers also reported that they experienced sleep disruption due to care recipients' night-time sleep symptoms such as hallucinations, delusions, agitation and unsettled behaviours.³⁷ These findings are consistent with a study that reported 93% of caregivers report sleep disturbance, with the most common reason for disturbance being the care recipient Parkinson's symptoms.⁴⁷ In addition, another study found a statistically significant difference in caregiver sleep disturbances between caregivers who had sufficient health/social access and those who did not.²⁹

Few studies reported associations between caregiver characteristics and sleep. Two studies found that female caregivers experienced higher levels of sleep disturbances compared with men.^{42 49} Poorer sleep was associated with greater caregiver depressive symptoms,^{40 44 47 48} lower subjective well-being⁴⁷ and lower quality of life scores.^{40 48} In contrast, one study that used diagnostic interviewing found that depression was less common in caregivers with insomnia, compared with those caregivers without insomnia.⁴¹ One study found an association between caregiver sleep disturbances, but not overall sleep quality and caregiver anxiety symptoms.⁴⁴

Critical appraisal of included studies

Of the 18 included studies, 4 were case–control with quality assessment scores ranging from 3 to 10 (see table 1). Of the case–control studies, one article was classed as 'weak',⁴⁹ two were classed as 'moderate',^{29 48} and one was classed as 'strong'.⁵⁰ Common weaknesses of case–control studies included a lack of clarity as to whether case groups (ie, carers of individuals with Parkinsonism) were comparable with, and matched appropriately with, control groups (aside from the caring role). Furthermore, few studies reported the length of time in the caregiving role, which resulted in an 'unclear' classification for the assessment item 'Was the exposure period

of interest long enough to be meaningful?’ for 75% of case-control studies. Case-control studies in this area should, in future, provide more information regarding both the matching of controls with cases, and the duration of caregiving.

For the 14 cross-sectional studies included, the quality assessment scores ranged from 42.9% to 100% (see table 2). Of the cross-sectional studies, three were classed as ‘weak’,^{36 38 42} five were classed as ‘moderate’,^{39 44 46 47} and six were classed as ‘strong’.^{30 37 40 41 43 45} Of note, all cross-sectional studies were classified as ‘NA’ for the item ‘Were objective, standard criteria used for measurement of the condition?’, given that there are no existing standardised criteria used to identify individuals as carers. Additionally, all but one cross-sectional study did not identify or manage confounding factors. Future cross-sectional research in this area would benefit for the identification of potentially confounding factors, given that carers may have, for example, personal health conditions⁶¹ or other traits that may impact their experience.⁶²

DISCUSSION

The aims of this systematic review and meta-analysis were to investigate whether providing care to an individual with Parkinsonism was associated with disturbed caregiver sleep, and to identify associated factors that may contribute to disturbed sleep in this population. The included studies indicated that caregivers of individuals with Parkinsonism experience poor sleep quality, increased sleep latency and poor sleep efficiency,^{33 36 38 40 42 44 46–50} in addition to daytime sleepiness, daytime dysfunction and excessive tiredness.^{39 42–45 47 48} Reported sleep quality was generally worse than the clinical cut-off scores for poor sleep, as measured by the PSQI.^{33 40 44 47 48} Meta-analyses indicated that caregivers of individuals with Parkinsonism experienced poor sleep over this clinical cut-off point.^{29 30 33 40 44 48 60}

For many included studies, the duration and quality of sleep obtained was sufficiently poor to be considered clinically meaningful.^{33 36 44 47 48} For one study,³⁶ this reflected shortened sleep duration (ie, fewer hours than the 7–9 hours per night typically recommended for adults¹⁶) though generally clinical significance was determined via the use of validated sleep quality scales.^{33 44 47 48} It should be noted that while clinically significant poor sleep was identified based on our meta-analysis (with a mean global PSQI score of 5.6 (95% CI: 4.8 to 6.4)), there is some debate about the standard clinical cut-off point of >5 points.^{63–65} There is some evidence to suggest that a cut-off score of 8 points may be more appropriate, particularly in populations who are likely to experience disrupted sleep.^{63 66} As such, sleep quality in caregivers of individuals with Parkinsonism may be classified as moderately poor, rather than severely poor. Despite this, the degree of poor sleep reported by this caregiver population is likely to have a range of implications for alertness, cognition, performance and long-term health.⁶⁷ Furthermore,

the findings of our meta-analysis are similar to outcomes seen in some other caregiver populations.^{14 15 68 69} Several reviews have been published in recent years on sleep in caregivers, including caregivers of individuals with dementia,¹⁵ children with either medical needs¹⁴ or who depend on medical technology,⁶⁸ and individuals with a brain tumour.⁶⁹ As in the present systematic review, these reviews suggest that caregiver sleep is likely poorer than that of the general population, to a clinically significant, but not consistently, severe degree.

For caregivers of individuals with medical needs (including, but not limited to, individuals with Parkinsonism), sleep can be disrupted by a range of factors.⁷⁰ Aspects of the carer experience that impact sleep may differ depending on the individual needs of the care recipient, but include waking overnight to assist with tasks (eg, visiting the bathroom), providing medical assistance (eg, turning over in bed, administering medication) or helping to resettle their care recipient.^{70–72} Additionally, sleep is often disrupted by the carer listening out for their care recipient in case they are needed.^{70 73} Worry and rumination about their care recipient is also a common cause of poor or disrupted sleep in carers,^{14 74} as is the carer’s own mental health.^{70 75}

The present review highlights the unique challenges faced by caregivers of individuals with Parkinsonism as compared with caregivers of other populations (eg, dementia, children with medical needs). Several studies highlighted certain factors associated with Parkinsonism which may be associated with sleep in the caregiver population. For example, the relationship between the severity of care recipient motor symptoms and caregiver sleep,^{37 38} though this finding was not consistent across all studies.³⁰ Motor symptoms are characteristic of Parkinsonism, and as such may result in unique challenges for this population of caregivers (eg, the degree of physical assistance required to perform the activities of daily living).⁷⁶ Furthermore, PD is often associated with significant impacts on patient sleep, including increased sleep latency, sleep fragmentation, early awakenings and subsequent excessive daytime sleepiness.¹⁷ Sleep disturbances in the care recipient tended to be associated with poor sleep among caregivers due to being woken, or due to worry and alertness (ie, ‘listening out’ for their care recipient overnight). In addition, individuals with PD are far more likely than the general population to experience RBD (24% of individuals with PD experience RBD compared with 3% of healthy controls¹⁸). RBD is characterised by abnormal behaviours during REM sleep (enactments of dreams) associated with a loss of muscle atonia.⁷⁷ The presence of RBD is likely to be a unique challenge faced by some caregivers of individuals with Parkinsonism, as a high level of overnight awareness is likely required to prevent injury in their care recipient. The presence of these characteristic motor or sleep-related symptoms may therefore make caregivers of individuals with Parkinsonism particularly vulnerable to poor sleep.

All studies in this review included subjective measures of sleep, with no studies using objective measures



(eg, actigraphy, polysomnography). While subjective measures are useful (particularly validated measures such as the PSQI) to assess perceived sleep outcomes, there are known discrepancies between these measures and objectively measured sleep.^{78 79} Problematically, the discrepancy between subjective and objective measures of sleep does not follow a clear trend (which could otherwise be used to 'correct' subjective data). Evidence typically shows both overestimation and underestimation of sleep outcomes (eg, total sleep time, sleep efficiency) in older adults⁷⁸—the group most likely to act in the caregiving role for individuals with Parkinsonism.⁸ Furthermore, there is evidence to suggest that reports of poor sleep in older adults, as measured by the PSQI, show no predictive validity for determining objectively measured sleep quality.⁷⁹ As such, it is possible that caregiver sleep duration and quality may differ significantly from the self-reported sleep included in this review.

A further potential limitation of the data collected by many of the included studies is the generalisability of standard validated sleep measures to a population faced with atypical challenges. The applicability of standard sleep measures (eg, PSQI) to caregivers (both of individuals with Parkinsonism and other diagnoses) may be limited by the scope of questions in these tools. For example, the PSQI asks the individual to rate the degree to which they have trouble sleeping based on a range of standard factors (eg, being too hot or cold, snoring, finding it difficult to fall asleep).³¹ However, as this scale (and others) are not tailored to a caregiving population, there are no specific questions asking about sleep disruption experienced as a result of caring responsibilities (eg, worry or rumination, overnight caring, being woken by their care recipient, etc). Similar issues with the application of standard validated scales for caregiving populations have been noted in caregivers of individuals with dementia, with additional factors such as 'sleeping with one ear open' noted, but not captured by standard scales.⁸⁰ Furthermore, there is evidence to suggest that older adults tend to adjust their expectations of good sleep (or health), resulting in a potential under-reporting of sleep-related complaints.⁸¹ Rather than reporting their sleep as being of poor quality, some evidence suggests that older adults may attribute poor sleep quality or short sleep duration to 'ageing'—and may therefore under-report negative outcomes.⁸² As a result of both the demographic characteristics of caregivers of individuals with Parkinsonism and the potential lack of suitability of current subjective sleep measures, it is likely that sleep duration and/or quality may be consistently overestimated in this population.

Despite consistent reports of poor sleep in caregivers of individuals with Parkinsonism, just one study addressed potential interventions to improve their sleep.⁴⁰ This study suggested that mindfulness may be associated with better sleep quality in caregivers.⁴⁰ There is some evidence of the impact of interventions on sleep in other caregiver populations, which suggests that strategies such as cognitive-behavioural sleep interventions,

health interventions, exercise and relaxation may have positive outcomes—though findings are mixed.⁸³ These interventions may also be effective in caregivers of individuals with Parkinsonism—though further evidence is required to support tailored recommendations. However, these caregiver-level sleep interventions generally do not consider the potential for interventions to be implemented with a broader scope. That is, interventions are generally targeted at the caregiver themselves (eg, exercise, relaxation), rather than through the lens of improving the underlying causes of poor sleep. Critically, it is generally more than the immediate needs of the care recipient (and an associated lack of exercise, relaxation, positive cognition, etc) that negatively impact caregiver sleep. Evidence indicates that caregivers (of individuals with a range of diagnoses) report a low level of social and practical support, which are also associated with poor sleep outcomes.⁸⁴ The toll associated with a lack of social and practical support (including at the governmental level), in addition to the difficulty associated with accessing support that is available, is immense.⁸⁵ Not only this, but there are significant emotional factors associated with the caregiving role (eg, worry/rumination, stress) and a simple lack of time for sleep.⁸⁴ As such, broader interventions designed to consider caregiver sleep should be considered for this caregiving population in future research. Strategies may include subsidised respite care, in-home practical support and support with negotiating government systems—designed with consideration given to the impact on caregiver sleep.⁸⁴ For example, short-term out-of-home care could be provided during overnight periods in addition to as part of 'day clubs'⁷⁰—with a view to improving caregiver sleep.

There are several apparent limitations of the current body of evidence available on sleep in caregivers of individuals with Parkinsonism. While all studies presented measures of sleep quality, just one study included a measure of sleep duration (ie, total sleep time).³⁶ It may be useful for future research to measure the amount of sleep obtained by this caregiving population, given the potentially detrimental impacts of insufficient sleep duration on both health⁸⁶ and performance outcomes.⁸⁷ Similarly, few studies included information on sleep disturbances (eg, number of overnight wakings), which are likely a component of poor sleep in this population. As discussed, the lack of objectively measured sleep and the use of standardised subjective measures are also significant limitations in this regard. As such, future research would ideally include measures of total sleep time and other sleep variables—measured by either actigraphy (or other wearables), or at-home polysomnographic options. Additionally, the development of tailored subjective measures for use within caregiving populations may be appropriate.

In addition to the limitations of the body of evidence, there are several limitations of this review. First, the decision was made to include carers aged ≥ 15 years only which may limit the applicability of findings to younger

caregivers. However, this decision was made in line with previous research undertaken on caring populations,⁸⁸ and was chosen given the type of caring responsibilities addressed by this study (eg, attending to medical needs, managing these needs in consultation with a healthcare team) would be less likely to be undertaken by children. For younger children who live with a family member who requires care, caring activities may instead involve, for example, a greater burden of household chores or childcare for younger siblings.⁸⁹ Additionally, studies published in languages other than English were excluded from this review, which may limit generalisability to non-English-speaking countries. The present review also included studies that employed cross-sectional designs, which limits the capacity to infer causality. Furthermore, due to data paucity, meta-regressions investigating factors that influence sleep quality (eg, age, gender) were not conducted.

This systematic review demonstrates that caring for individuals with Parkinsonism was associated with poor sleep quality, increased sleep latency and poor sleep efficiency. Meta-analysis also indicated that clinically meaningful differences were also seen between caregivers of individuals with Parkinsonism and non-caregivers. Care recipient sleep quality and motor symptoms, as well as caregiver burden and mental health status, emerged as potential factors associated with sleep in caregivers of individuals with Parkinsonism. Future studies should implement targeted subjective measures (eg, interviews), in addition to objective sleep outcomes (eg, actigraphy) to allow for further evaluation of sleep in this susceptible population group.

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Contributors GEV, RHG, SF, MS and CCG conceptualised the study. Paper screening, data extraction and qualitative evaluation were performed by KH and MEC. Data collation and analyses were performed by PJO and MEC. MS is the guarantor. The manuscript was written by MS and KH with significant contributions from PJO, MEC, CCG, SF, RHG and GEV. PJO, MEC, CCG, SF, RHG and GEV also contributed to interpretation of findings and revision of the manuscript.

Funding MEC is supported by an Australian Government Research Training Programme (RTP) Scholarship.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

Ethics approval No ethics approval number is provided as this is a systematic review and as such no new data were collected.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study.

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