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

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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.

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.

INTRODUCTION

Parkinsonism reflects a group of neurological disorders with similar neurological and movement-related symptoms,[1] and encompasses two main subtypes (neurodegenerative 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 night[16]) 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 ≤49% 'weak', 50%–70% 'moderate' and ≥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-SLEEP[30] and NHP-Sleep[29] 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 study[33] 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 Covidence[35] (see figure 1). Following duplicate removal and title and abstract screening, a total of 83 records remained for full-text screening. Following

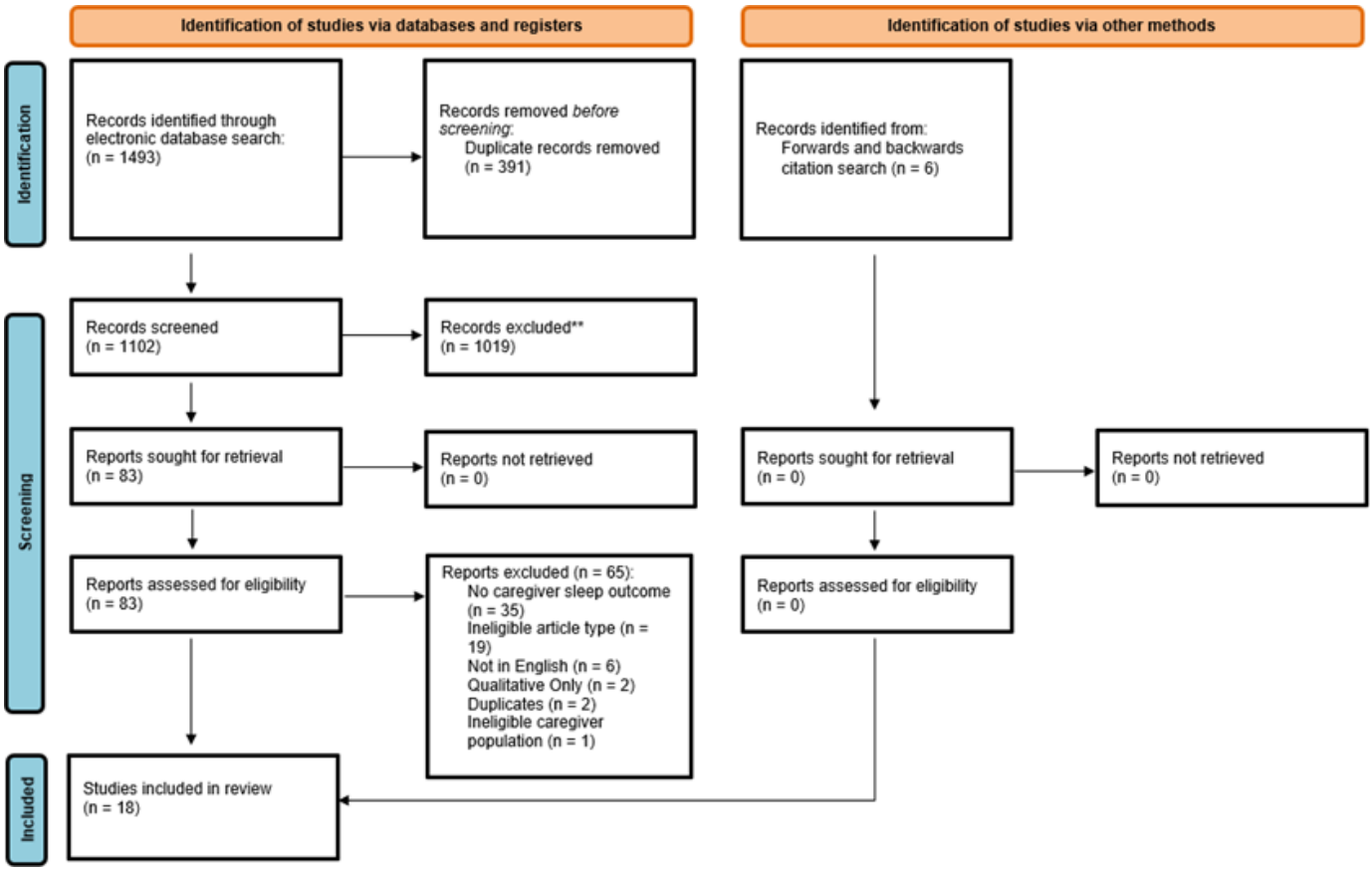

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart for selection of studies included in this review.

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 hours[29] 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 PSQI[31] was the most commonly used measure, being used in 28% (n=5) of studies.[33 40 44 47 48] One study used both the PSQI[44] and the validated General Sleep Questionnaire.[51] Other validated sleep measures used were: MOSS-SLEEP[52] (n=1),[30] NHP-Sleep[53] (n=1),[29] Scale for Outcomes in Parkinson's Disease-Sleep[54] (n=1),[37] and Verran and Snyder-Halpern Sleep Scale[55] (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 Life[56] (n=1),[43] Patient Health Questionnaire[57] and Family Needs Questionnaire[58] (n=1).[45] One study[41] 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 study[36] 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)	% female	Caregiver mean age (SD)	Relationship to care recipient *N*	Care recipients' condition	Frequency of caregiving	Duration of caregiving: mean (SD)
Bartolomei, 2018[30]	Italy	55	64	62.0 (12.0)	Spouse (n=47) Offspring (n=8)	Parkinson's disease	Not reported	Not reported
Cifu, 2006[36]	USA	49	98	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	40	70	64.2 (9.4)	Spouse (n=36) Offspring (n=4)	Parkinson's disease	Not reported	Not reported
Hand, 2021[37]	UK	115	66	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	101	63	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	357	Not reported	Not reported	Not reported	Parkinson's disease	Not reported	Not reported
Hicks, 2019[40]	USA	18	50	62.2 (10.4)	Spouse (n=16) Friend (n=2)	Parkinson's disease	Not reported	Not reported
Lee, 2020[41]	Taiwan	162	67	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	36	67	61.3 (11.1)	Spouse (n=21) Offspring (n=15)	Dementia with Lewy bodies	Not reported	Not reported
Lökk, 2008[42]	Sweden	404	62	68.5 (9.4)	Spouse (n=396) Not reported (n=8)	Parkinson's disease	Not reported	Not reported
Olsson, 2016[29]	Sweden	66	70	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)
Ozdilek, 2012[43]	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, 2004[44]	Not reported	23	65	65.2 (11.3)	Spouse (n=23)	Parkinson's disease	Not reported	Not reported
Perez, 2020[45]	USA & Mexico	253	73	59.9 (14.7)	Not reported	Parkinson's disease	87.9 hours (weekly)	50.1 months
Smith, 1997[49]	Germany	153	78	64.0 (11.0)	Spouse (n=153)	Parkinson's disease	Not reported	Not reported
Teel, 1999[50]	USA	29	52	73.0 (not reported)	Spouse (n=29)	Parkinson's disease	10.1 hours (daily)	5.1 years
Thommessen, 2002 [46]	Norway	58	Not reported	Not reported	Spouse (n=58)	Parkinson's disease	Not reported	Not reported
Wade, 2020[47]	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.

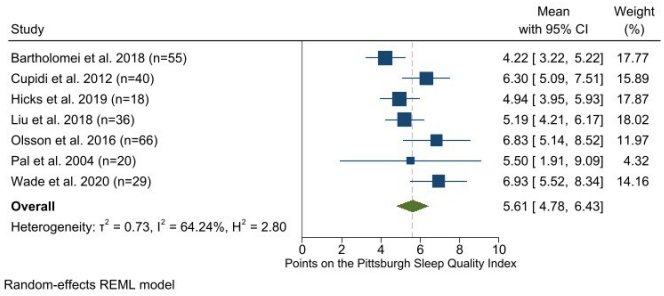

Figure 2 Forest plot for the meta-analysis of sleep quality (Pittsburgh Sleep Quality Index) point estimates in caregivers of individuals with Parkinsonism. REML, Restricted Maximum Likelihood.

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

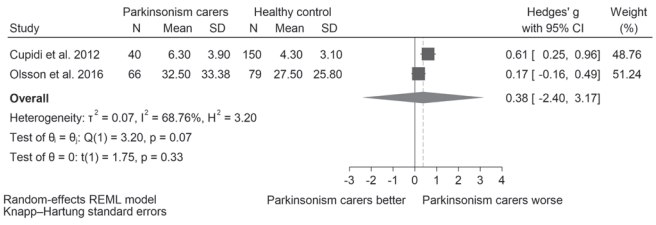

Figure 3 Forest plot for the meta-analysis of sleep quality (Pittsburgh Sleep Quality Index) in caregivers of individuals with Parkinsonism compared with healthy controls. REML, Restricted Maximum Likelihood.

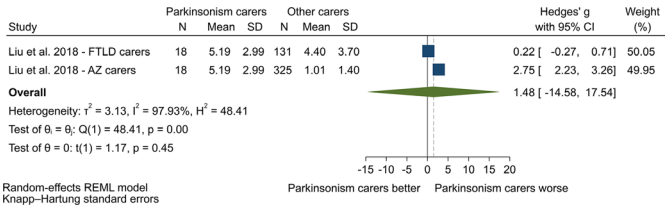

Figure 4 Forest plot for the meta-analysis of sleep quality (Pittsburgh Sleep Quality Index) in caregivers of individuals with Parkinsonism compared with other carers. AZ, Alzheimer's disease; FTLD, frontotemporal lobar degeneration. REML, Restricted Maximum Likelihood.

disturbance[47] 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-being[47] 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 conditions[61] 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 adults[16]) 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 needs[14] 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 controls[18]). 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 adults[78]—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 health[86] 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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Supplementary Material 1

PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	4-5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	5
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary Material 2
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	7
Data	9	Specify the methods used to collect data from reports, including how many reviewers	7

Section and Topic	Item #	Checklist item	Location where item is reported
collection process		collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	7
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	7
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	7
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	8
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	8
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	8
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	8
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	8
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g., subgroup analysis, meta-regression).	8

Section and Topic	Item #	Checklist item	Location where item is reported
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	8
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	8
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	8
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	8-9
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Supplementary Material 4
Study characteristics	17	Cite each included study and present its characteristics.	Table 3
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 1 and Table 2
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 3
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	10-12
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	10-12

Section and Topic	Item #	Checklist item	Location where item is reported
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	10-12
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	10-12
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	10-12
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	13
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	14
	23b	Discuss any limitations of the evidence included in the review.	16-17
	23c	Discuss any limitations of the review processes used.	18
	23d	Discuss implications of the results for practice, policy, and future research.	14-15
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	19
Competing interests	26	Declare any competing interests of review authors.	19
Availability	27	Report which of the following are publicly available and where they can be found:	Supplementary

Section and Topic	Item #	Checklist item	Location where item is reported
of data, code and other materials		template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Material 3

Supplementary Material 2

Search Terms

Data bases searched: PubMed, CINAHL, PsycInfo, EMBASE, and CENTRAL.

PubMed		
Search	**Query**	**Hits**
#1	"caregivers"[MeSH Terms] OR "caregiver burden"[MeSH Terms] OR "family"[MeSH Terms] OR "home nursing"[MeSH Terms] OR "caregiv*"[Title/Abstract] OR "care giv*"[Title/Abstract] OR "carer*"[Title/Abstract] OR (("family"[Title/Abstract] OR "families"[Title/Abstract] OR "spouse*"[Title/Abstract] OR "partner*"[Title/Abstract] OR "parent*"[Title/Abstract] OR "grandparent*"[Title/Abstract] OR "sibling*"[Title/Abstract] OR "relative*"[Title/Abstract] OR "friend*"[Title/Abstract] OR "husband*"[Title/Abstract] OR "wife"[Title/Abstract] OR "wives"[Title/Abstract] OR "close person*"[Title/Abstract] OR "significant other*"[Title/Abstract] OR "child"[Title/Abstract] OR "children"[Title/Abstract]) AND ("care*"[Title/Abstract] OR "caring"[Title/Abstract]))	765024
#2	"parkinsonian disorders"[MeSH Terms] OR "basal ganglia diseases"[MeSH Terms] OR "hydrocephalus, normal pressure"[MeSH Terms] OR "parkinson*"[Title/Abstract]	172007
#3	"sleep"[MeSH Terms] OR "sleep initiation and maintenance disorders"[MeSH Terms] OR "sleep*"[All Fields] OR "insomnia"[All Fields] OR "nap"[All Fields] OR "naps"[All Fields] OR "napping"[All Fields]	267167
#4	animals[MeSH Terms] NOT humans[MeSH Terms]	4853683
#5	#1 AND #2 AND #3 NOT #4	281
CINAHL		
Search	**Query**	**Hits**
#1	MH "caregivers+" OR MH "caregiver burden+" OR MH "family+" OR MH "home nursing+" OR TI ("caregiv*" OR "care giv*" OR "carer*" OR ("family" OR "families" OR "spouse*" OR "partner*" OR "parent*" OR "grandparent*" OR "sibling*" OR "relative*" OR "friend*" OR "husband*" OR "wife" OR "wives" OR "close person*" OR "significant other*" OR "child" OR "children") AND ("care*" OR "caring")) OR AB ("caregiv*" OR "care giv*" OR "carer*" OR ("family" OR "families" OR "spouse*" OR "partner*" OR "parent*" OR "grandparent*" OR "sibling*" OR "relative*" OR "friend*" OR "husband*" OR "wife" OR "wives" OR "close person*" OR	461760

	"significant other*" OR "child" OR "children") AND ("care*" OR "caring"))	
#2	MH "parkinsonian disorders+" OR MH "basal ganglia diseases+" OR MH "hydrocephalus, normal pressure+" OR TI ("parkinson*") OR AB ("parkinson*")	73416
#3	MH "sleep+" OR MH "sleep initiation and maintenance disorders+" OR "sleep*" OR "insomnia" OR "nap" OR "naps" OR "napping"	87988
#4	MH "animals+" NOT MH "humans+"	97487
#5	#1 AND #2 AND #3 NOT #4	244

PsychInfo

Search	**Query**	
#1	MA "caregivers+" OR MA "caregiver burden+" OR MA "family+" OR MA "home nursing+" OR TI ("caregiv*" OR "care giv*" OR "carer*" OR ("family" OR "families" OR "spouse*" OR "partner*" OR "parent*" OR "grandparent*" OR "sibling*" OR "relative*" OR "friend*" OR "husband*" OR "wife" OR "wives" OR "close person*" OR "significant other*" OR "child" OR "children") AND ("care*" OR "caring")) OR AB ("caregiv*" OR "care giv*" OR "carer*" OR ("family" OR "families" OR "spouse*" OR "partner*" OR "parent*" OR "grandparent*" OR "sibling*" OR "relative*" OR "friend*" OR "husband*" OR "wife" OR "wives" OR "close person*" OR "significant other*" OR "child" OR "children") AND ("care*" OR "caring"))	214536
#2	MA "parkinsonian disorders+" OR MA "basal ganglia diseases+" OR MA "hydrocephalus, normal pressure+" OR TI ("parkinson*") OR AB ("parkinson*")	35030
#3	MA "sleep+" OR MA "sleep initiation and maintenance disorders+" OR "sleep*" OR "insomnia" OR "nap" OR "naps" OR "napping"	81093
#4	MA "animals+" NOT MA "human+"	68662
#5	#1 AND #2 AND #3 NOT #4	123

EMBASE

Search	**Query**	**Hits**
#1	'cargivers'/exp OR 'caregiver burden'/exp OR 'family'/exp OR 'home nursing'/exp OR 'caregiv*':ab,ti OR 'care giv*':ab,ti OR 'carer*':ab,ti OR (('family':ab,ti OR 'families':ab,ti OR 'spouse*':ab,ti OR 'partner*':ab,ti OR 'parent*':ab,ti OR 'grandparent*':ab,ti OR 'sibling*':ab,ti OR 'relative*':ab,ti OR 'friend*':ab,ti OR 'husband*':ab,ti OR 'wife':ab,ti OR 'wives':ab,ti OR 'close person*':ab,ti OR 'significant other*':ab,ti OR 'child':ab,ti OR 'children':ab,ti) AND ('care*':ab,ti OR 'caring':ab,ti))	1174208
#2	'parkinsonian disorders'/exp OR 'basal ganglia diseases'/exp OR 'hydrocephalus, normal pressure'/exp OR 'parkinson*':ab,ti	303342
#3	'sleep'/exp OR 'sleep*' OR 'insomnia' OR 'nap' OR 'naps' OR 'napping'	496276
#4	'animal'/exp NOT 'human'/exp	5630303

#5	#1 AND #2 AND #3 NOT #4	1300
#6	#5 NOT [conference abstract]/lim	811

CENTRAL

Search	**Query**	**Hits**
#1	(MeSH descriptor: [Caregivers] explode all trees) OR (MeSH descriptor: [Caregiver Burden] explode all trees) OR (MeSH descriptor: [Family] explode all trees) OR (MeSH descriptor: [Home Nursing] explode all trees) OR ("caregiv*" OR "care giv*" OR "carer*"):ti,ab,kw OR (("family" OR "families" OR "spouse*" OR "partner*" OR "parent*" OR "grandparent*" OR "sibling*" OR "relative*" OR "friend*" OR "husband*" OR "wife" OR "wives" OR "close person*" OR "significant other*" OR "child" OR "children"):ti,ab,kw AND ("care*" OR "caring"):ti,ab,kw)	60720
#2	(MeSH descriptor: [Parkinsonian Disorders] explode all trees) OR (MeSH descriptor: [Basal Ganglia Diseases] explode all trees) OR (MeSH descriptor: [Hydrocephalus, Normal Pressure] explode all trees) OR ("parkinson*"):ti,ab,kw	12233
#3	(MeSH descriptor: [Sleep] explode all trees) OR (MeSH descriptor: [Sleep Initiation and Maintenance Disorders] explode all trees) OR "sleep*" OR "insomnia" OR "nap" OR "naps" OR "napping"	47662
#4	(MeSH descriptor: [Animals] explode all trees) NOT (MeSH descriptor: [Humans] explode all trees)	59
#5	#1 AND #2 AND #3 NOT #4	36
#6	#5 AND Limit: Trials	34

Supplementary Material 3

Supplementary Material 3A: Stata code

```
*****************************************
//point estimate (sleep quality)
*****************************************
clear
input str50 study n m sd
"Bartholomei et al. 2018 (n=55)" 55 4.22 3.8
"Cupidi et al. 2012 (n=40)" 40 6.30 3.90
"Hicks et al. 2019 (n=18)" 18 4.94 2.15
"Liu et al. 2018 (n=36)" 36 5.19 2.99
"Olsson et al. 2016 (n=66)" 66 6.83 7.01
"Pal et al. 2004 (n=20)" 20 5.5 8.2
"Wade et al. 2020 (n=29)" 29 6.93 3.87
end

gen se = sd/sqrt(n)

meta set m se, studylabel(study) eslabel(Mean)
meta summarize
return list
local ES = r(theta)
meta forestplot, xline(`ES', lcolor(gs12) lpattern(dash)) noohom noosig xlabel(0(2)10) xline(0,
lcolor(gs7) lpattern(solid))

meta summarize, leaveoneout

*****************************************
//point estimate (sensitivity analysis: omit non-PSQI)
*****************************************
clear
input str50 study n m sd
"Cupidi et al. 2012 (n=40)" 40 6.30 3.90
"Hicks et al. 2019 (n=18)" 18 4.94 2.15
"Liu et al. 2018 (n=36)" 36 5.19 2.99
"Pal et al. 2004 (n=20)" 20 5.5 8.2
"Wade et al. 2020 (n=29)" 29 6.93 3.87
end

gen se = sd/sqrt(n)

meta set m se, studylabel(study) eslabel(Mean)
meta summarize
return list
```

```
local ES = r(theta)

meta forestplot, xline(`ES', lcolor(gs12) lpattern(dash)) noohom noosig xlabel(0(2)10) xline(0,
lcolor(gs7) lpattern(solid))

meta summarize, leaveoneout

*****************************************
//point estimate (sensitivity analysis: omit data transposed to mean[SD])
*****************************************
clear
input str50 study n m sd
"Bartholomei et al. 2018 (n=55)" 55 4.22 3.8
"Cupidi et al. 2012 (n=40)" 40 6.30 3.90
"Hicks et al. 2019 (n=18)" 18 4.94 2.15
"Liu et al. 2018 (n=36)" 36 5.19 2.99
"Pal et al. 2004 (n=20)" 20 5.5 8.2
"Wade et al. 2020 (n=29)" 29 6.93 3.87
end

gen se = sd/sqrt(n)

meta set m se, studylabel(study) eslabel(Mean)
meta summarize
return list
local ES = r(theta)

meta forestplot, xline(`ES', lcolor(gs12) lpattern(dash)) noohom noosig xlabel(0(2)10) xline(0,
lcolor(gs7) lpattern(solid))

meta summarize, leaveoneout

*****************************************
//Parkinsonism carers vs healthy control
*****************************************
clear
input str50 study n1 m1 s1 n2 m2 s2
"Cupidi et al. 2012" 40 6.30 3.90 150 4.3 3.1
"Olsson et al. 2016" 66 32.5 33.38 79 27.5 25.80
end

format %9.2f m1
format %9.2f s1
format %9.2f m2
format %9.2f s2
```

```
meta esize n1 m1 s1 n2 m2 s2, studylabel(study) eslabel(Hedges' g)
meta summarize, se(khartung)
return list
local ES = r(theta)

meta forestplot, xline(`ES', lcolor(gs12) lpattern(dash)) xlabel(-3(1)4)
nullrefline(favorsleft("Parkinsonism carers better ", al(baseline) height(45)) favorsright("
Parkinsonism carers worse", al(baseline) height(45))) columnopts(_data1,
supertitle(Parkinsonism carers)) columnopts(_data2, supertitle(Healthy control)) xline(0,
lcolor(gs7) lpattern(solid)) se(khartung)

****************************************
//Parkinsonism carers vs other carers
****************************************
clear
input str50 study n1 m1 s1 n2 m2 s2
"Liu et al. 2018 - FTLD carers" 18 5.19 2.99 131 4.4 3.70
"Liu et al. 2018 - AZ carers" 18 5.19 2.99 325 1.01 1.40
end

format %9.2f m1
format %9.2f s1
format %9.2f m2
format %9.2f s2

meta esize n1 m1 s1 n2 m2 s2, studylabel(study) eslabel(Hedges' g)
meta summarize, se(khartung)
return list
local ES = r(theta)

meta forestplot, xline(`ES', lcolor(gs12) lpattern(dash)) xlabel(-15(5)20)
nullrefline(favorsleft("Parkinsonism carers better ", al(baseline) height(45)) favorsright("
Parkinsonism carers worse", al(baseline) height(45))) columnopts(_data1,
supertitle(Parkinsonism carers)) columnopts(_data2, supertitle(Other carers)) xline(0,
lcolor(gs7) lpattern(solid)) se(khartung)
```

Supplementary Material 3B: point estimate (sleep quality; leave one out)

Omitted study	Mean	Lower 95%CI	Upper 95%CI
Bartholomei et al. 2018 (n=55)	5.871	5.097	6.645
Cupidi et al. 2012 (n=40)	5.484	4.550	6.418
Hicks et al. 2019 (n=18)	5.763	4.794	6.733
Liu et al. 2018 (n=36)	5.717	4.718	6.716
Olsson et al. 2016 (n=66)	5.435	4.580	6.289
Pal et al. 2004 (n=20)	5.617	4.747	6.488
Wade et al. 2020 (n=29)	5.365	4.563	6.166

Supplementary Material 3C: point estimate (sensitivity analysis: omit non-PSQI)

[INSERT SUPPLEMENTARY MATERIAL 3C FIGURE]

Supplementary Material 3D: point estimate (sensitivity analysis: omit non-PSQI; leave one out)

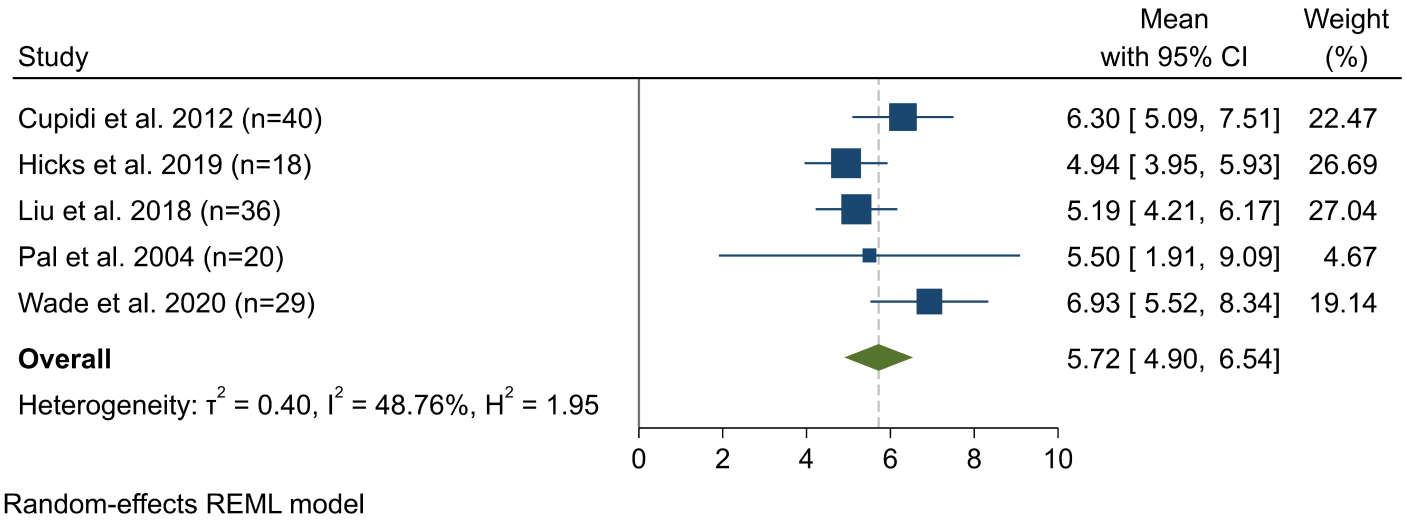
Omitted study	Mean	Lower 95%CI	Upper 95%CI
Cupidi et al. 2012 (n=40)	5.565	4.571	6.559
Hicks et al. 2019 (n=18)	6.000	5.064	6.937
Liu et al. 2018 (n=36)	5.931	4.870	6.993
Pal et al. 2004 (n=20)	5.739	4.861	6.618
Wade et al. 2020 (n=29)	5.402	4.708	6.097

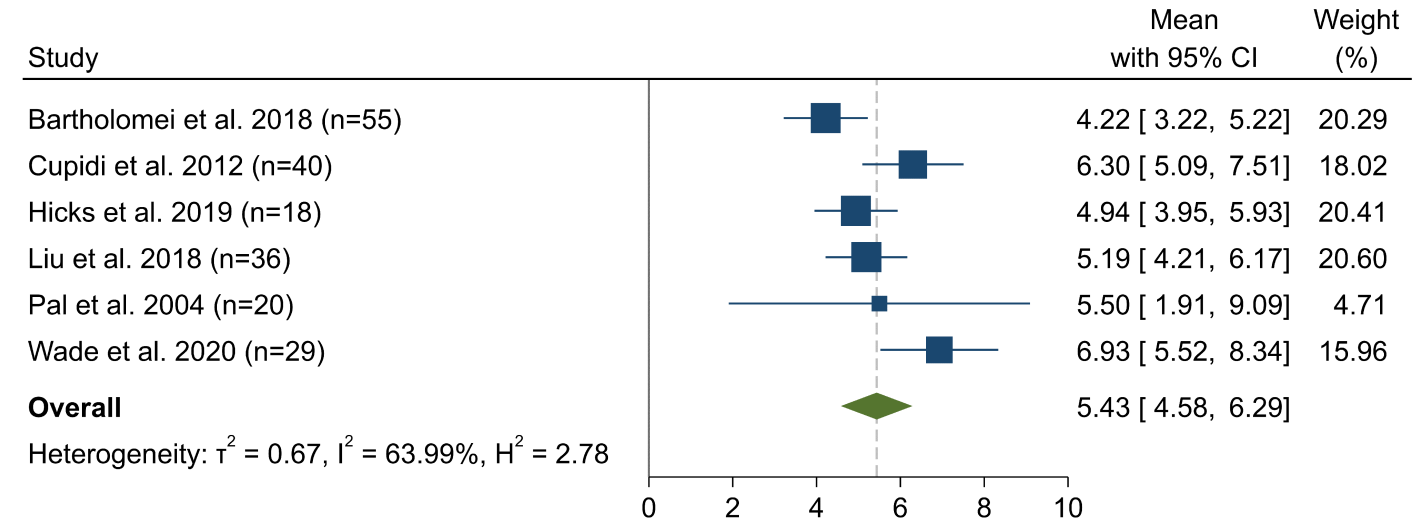
Supplementary Material 3E: point estimate (sensitivity analysis: omit data transposed to mean[SD])

[INSERT SUPPLEMENTARY MATERIAL 3E FIGURE]

Supplementary Material 3F: point estimate (sensitivity analysis: omit data transposed to mean[SD]; leave one out)

Omitted study	Mean	Lower 95%CI	Upper 95%CI
Bartholomei et al. 2018 (n=55)	5.720	4.899	6.542
Cupidi et al. 2012 (n=40)	5.244	4.303	6.185
Hicks et al. 2019 (n=18)	5.577	4.517	6.636
Liu et al. 2018 (n=36)	5.519	4.430	6.607
Pal et al. 2004 (n=20)	5.437	4.528	6.346
Wade et al. 2020 (n=29)	5.129	4.378	5.879


Study
Mean with 95% CI
Weight (%)
Cupidi et al. 2012 (n=40)
6.30 [5.09, 7.51]
22.47
Hicks et al. 2019 (n=18)
4.94 [3.95, 5.93]
26.69
Liu et al. 2018 (n=36)
5.19 [4.21, 6.17]
27.04
Pal et al. 2004 (n=20)
5.50 [1.91, 9.09]
4.67
Wade et al. 2020 (n=29)
6.93 [5.52, 8.34]
19.14
Overall
5.72 [4.90, 6.54]
Heterogeneity: τ² = 0.40, I² = 48.76%, H² = 1.95
0
2
4
6
8
10
Random-effects REML model


Study
Mean with 95% CI
Weight (%)
Bartholomei et al. 2018 (n=55)
4.22 [3.22, 5.22]
20.29
Cupidi et al. 2012 (n=40)
6.30 [5.09, 7.51]
18.02
Hicks et al. 2019 (n=18)
4.94 [3.95, 5.93]
20.41
Liu et al. 2018 (n=36)
5.19 [4.21, 6.17]
20.60
Pal et al. 2004 (n=20)
5.50 [1.91, 9.09]
4.71
Wade et al. 2020 (n=29)
6.93 [5.52, 8.34]
15.96
Overall
5.43 [4.58, 6.29]
Heterogeneity: τ² = 0.67, I² = 63.99%, H² = 2.78
0
2
4
6
8
10
Random-effects REML model

Supplementary Material 4

Full texts excluded with reasons

Full text	Reason
Aarsland D, Mills R, Williams H, Chi-Burris K, Karistedt M, Ballard C (2015) Decreased burden among caregivers of patients with Parkinson's disease psychosis (PDP) treated with Pimavanserin, a selective 5-HT2A inverse agonist. *Neurol* **84**.	**Publication Type**
Australian New Zealand Clinical Trials Registry, Clinical Trial Details: ACTRN12616000764437, https://www.australianclinicaltrials.gov.au/anzctr/trial/ACTRN12616000764437, Last updated 27th June 2017, Accessed on December 11th, 2021.	**Publication Type**
Anderson KE (2004) Dementia in Parkinson's disease. *Curr Treat Options Neurol* **6**(3), 201-207.	**Publication Type**
Bhidayasiri R, Trenkwalder C (2018) Getting a good night sleep? The importance of recognizing and treating nocturnal hypokinesia in Parkinson's disease. *Parkinsonism Relat Disord* **50**, 10-18.	**Publication Type**
Boersma I, Jones J, Coughlan C, Carter J, Bekelman D, Miyasaki J, Kutner J, Kluger B (2017) Palliative care and Parkinson's disease: Caregiver perspectives. *J Palliat Med* **20**(9), 930-938.	**Design**
Cagnin A, Di Lorenzo R, Marra C, Bonanni L, Cupidi C, Lagana V, Rubino E, Vacca A, Provero P, Isella V, Vanacore N, Agosta F, Appollonio I, Caffarra P, Pettenuzzo I, Sambati R, Quaranta D, Gugliemi V, Logroscino G, Filippi M, Tedeschi G, Ferrarese C, Rainero I, Bruni AC (2020) Behavioral and psychological effects of Coronavirus disease-19 quarantine in patients with dementia. *Front Psychiatry* **11**.	**Outcome**
Carod-Artal FJ, Mesquita HM, Ziomkowski S, Martinez-Martin P (2013) Burden and health-related quality of life among caregivers of Brazilian Parkinson's disease patients. *Parkinsonism Relat Disord* **19**(11), 943-948.	**Outcome**

Catalan MJ, Molina-Arjona JA, Mir P, Cubo E, Arbelo JM, Martinez-Martin P (2018) Improvement of impulse control disorders associated with levodopa-carbidopa intestinal gel treatment in advanced Parkinson's disease. *J Neurol* **265**(6), 1279-1287.	**Outcome**
Chang A, Fox SH (2016) Psychosis in Parkinson's disease: Epidemiology, pathophysiology, and management. *Drugs* **76**(11), 1093-1118.	**Publication type**
Charlesworth G (2005) Cognitive behavioral therapy reduced psychological distress in carers of people with Parkinson's disease. *Evid Based Ment Health* **8**(4), 103.	**Publication Type**
Chen JP, Han Y, Ou ZJ, Mao CJ, Liu CF (2020) Effects of sleep quality and mood of patients with Parkinson's disease on their caregivers. *Zhonghua Yi Xue Za Zhi* **100**(43), 3414-3418.	**Language**
Chong R, Albor L, Wakade C, Morgan J (2018) The dimensionality of fatigue in Parkinson's disease. *J Transl Med* **16**(1), 192.	**Outcome**
Crabb L (2001) Sleep disorders in Parkinson's disease: The nursing role. *Br J Nurs* **10**(1), 42-47.	**Publication Type**
De Oliviera FF, Machado FC, Sampaio G, Marin SMC, Naffah-Mazzacoratti MDG, Bertolucci PHF (2020) Neuropsychiatric feature profiles of patients with Lewy body dementia. *Clin Neurol Neurosurg* **194**.	**Outcome**
Devos D, Moreau C, Maltete D, Lefaucheur R, Kreisler A, Eusebio A, Defer G, Ouk T, Azulay JP, Krystkowiak P, Witjas T, Delliaux M, Destee A, Duhamel A, Bordet R, Defebvre L, Dujardin K (2013) Rivastigmine in apathetic but dementia and depression-free patients with Parkinson's disease: A double-blind, placebo-controlled, randomised clinical trial. *J Neurol Neurosurg Psychiatry* **85**(6), 668-674.	**Outcome**
Dobkin RD, Interian A, Durland JL, Gara MA, Menza MA (2018) Personalized telemedicine for depression in Parkinson's disease: A pilot trial. *J Geriatr Psychiatry Neurol* **31**(4), 171-176.	**Outcome**
Ellgring JH (1999) Depression, psychosis, and dementia: Impact on the family. *Neurology* **52**(7), 17-20.	**Publication Type**
Emre M, Tsolaki M, Bonuccelli U, Destee A, Tolosa E, Kutzelnigg A, Ceballos-Baumann A, Zdravkovic S, Bladstrom A, Jones R (2010) Memantine for patients	**Outcome**

with Parkinson's disease dementia or dementia with Lewy bodies: A randomised, double-blind, placebo-controlled trial. *Lancet Neurol* **9**(10), 969-977.	
Fernandez HH, Tabamo RE, David RR, Friedman JH (2001) Predictors of depressive symptoms among spouse caregivers in Parkinson's disease. *Mov Disord* **16**(6), 1123-1125.	**Outcome**
Fredman L, Gordon SA, Heeren T, Stuver SO (2014) Positive affect is associated with fewer sleep problems in older caregivers but not noncaregivers. *Gerontologist* **54**(4), 559-569.	**Population**
Giminez-Roldan S, Navarro E, Mateo D (2003) Effects of quetiapine at low doses on psychosis motor disability and stress of the caregiver in patients with Parkinson's disease. *Rev Neurol* **36**(5), 401-404.	**Language**
Grun D, Pieri V, Valliant M, Diedrich NJ (2016) Contributory factors to caregiver burden in Parkinson disease. *J Am Med Dir Assoc* **17**(7), 626-632.	**Outcome**
Hacksell U, Burstein ES, McFarland K, mills RG, Williams H (2014) On the discovery and development of Pimavanserin: A novel drug candidate for Parkinson's psychosis. *Neurochem Res* **39**(10) 2008-2017.	**Outcome**
Hand A, Oates LL, Gray WK, Walker RW (2018) Understanding the care needs and profile of people living at home with moderate to advanced stage Parkinson disease. *J Geriatr Psychiatry Neurol* **31**(5), 237-247.	**Outcome**
Hand A, Oates LL, Gray WK, Walker RW (2019) The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease. *Aging Ment Health* **23**(3), 337-344.	**Outcome**
Hulshoff MJ, Book E, Dahodwala N, Tanner CM, Robertson C, Marras C (2021) Current knowledge on the evolution of care partner burdern, needs, and coping in Parkinson's disease. *Mov Disord Clin Pract* **8**(4), 510-520.	**Publication Type**
Hwynn N, Haq IU, Malaty IA, Resnick AS, Okus MS, Carew DS, Oayama G, Dai Y, Wu SS, Rodriguez RL, Jacobson CE, Fernandez HH (2011) The frequency of nonmotor symptoms among advanced Parkinson patients may depend on instrument used for assessment. *Parkinsons Dis* **2011**.	**Outcome**

International Clinical Trials Registry Platform: ISRCTN11720842, https://trialsearch.who.int/?TrialID=ISRCTN11720842, Last updated January 13th 2015, Accessed on December 11th 2021.	**Publication Type**
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Machado FC, De Oliviera FF, Marin SDC, Sampaio G, Bertolucci PHF (2020) Correlates of neuropsychiatric and motor tests with language assessment in patients with Lewy body dementia. *Archiv Clin Psychiatr* **47**(3), 75-81.	**Outcome**
Mahale M, Behal P, Bewal N, Aggarwal V, Singhal A, Yadav AK, Vasdev V (2021) Study of prevalence of neuropsychiatric symptoms in elderly dementia patients. *J Clin Diagnost Res* **15**(2), 14-17.	**Outcome**
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Mosley PE, Moodie R, Dissanayaka N (2017) Caregiver burden in Parkinson disease: A critical review of recent literature. *J Geriatr Psychiatry Neurol* **30**(5), 235-252.	**Publication Type**
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Norton J, Aarsland D, Chi-Burris K, Ballard C (2016) Caregivers of PDP patients have an increased risk of developing emotional and social distress that is decreased when PDP is treated with Pimavanserin. *J Parkinson Dis* **6**, 257.	**Publication Type**
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Song Y, Jung L, Richards KC (2012) Dementia and sleep disturbances. *Aging Health* **8**(1).	**Publication Type**
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Teel CS, Press AN, Lindgren CL, Nichols EG (1999) Fatigue among elders in caregiving and noncaregiving roles. *Western J Nurs Res* **21**(4), 498-520.	**Publication Type**
Teofilo LLC (2005) Part XVI: Sleep in Special Patient Groups, Sleep: A Comprehensive Handbook. Wiley-Liss, New York.	**Publication Type**
Vats A, Amit A, Doshi P (2019) A comparative study of bilateral subthalamic nucleus DBS in Parkinson's disease in young versus old: A single institutional study. *J Clin Neurosci* **70**, 85-91.	**Outcome**
Viwattanakulvanid P, Kaewwilai L, Jitkritsadakul O, Brenden NR, Setthawatcharawanich S, Boonrod N, Mekawichai P, Bhidayasiri R (2014) The impact of the nocturnal disabilities of Parkinson's disease on caregivers' burden: Implications for intervention. *J Neural Transm* **121** (1), 15-24.	**Duplicate**
Wade R, Pachana NA, Dissanayaka N (2020) Management of sleep disturbances in Parkinson's disease patients, carers and the patient and carer dyadic relationship: A scoping review. *Clin Gerontol* **43**(5), 499-507.	**Publication Type**
Zhu J, Zhong M, Yan J, Wu Z, Pan Y, Shen B, Dong J, Zhang L (2020) Depressive symptoms effect subjective sleep quality in Chinese patients with Parkinson's disease. *Clin Neurol Neurosurg* **195**.	**Outcome**

Supplementary Material 5

Relevant outcomes of included studies

First author, Year	Study design	Control group (type, *n* and % female, age(SD) years)	Sleep outcome	Carer burden measure	Sleep Results Mean (SD)	Carer Burden Results Mean (SD)
Bartolomei, 2018 [30]	Cross-sectional	-	MOSS-SS Index	CBI	MOSS-SS: 20.1 (18.1)	CBI: 9.0 (13.4)
Cifu, 2006 [35]	Cross-sectional	-	Self-report sleep duration (hours/per night)	ZBI CDS	Sleep duration: 6.4 (1.5)	ZBI: Not reported CDS: Not reported
Cupidi, 2012 [47]	Case-control	Healthy controls, *n* = 150, F = 35%, 66.7 (5.1)	PSQI	CBI	**Carer**; Global PSQI: 6.3 (3.9) Disturbance: 1.3 (0.5) Quality: 1.3 (0.9) Duration: 1.1 (1.0) Latency: 1.1 (0.9) Daytime dysfunction: 0.6 (0.7) Sleep efficiency: 0.8 (1.1) **Control;** Global PSQI: 4.3 (3.1) Disturbance: 1.0 (0.5) Quality: 0.9 (0.8) Duration: 0.7 (0.7) Latency: 0.7 (0.7) Daytime dysfunction: 0.8 (0.9) Sleep efficiency: 0.4 (0.6)	CBI: 13.4 (13.4)
Hand, 2021 [36]	Cross-sectional	-	SCOPA-Sleep	CBI	Not reported	CBI: 62.9% ≥ 24, 32.7% ≥ 36
Happe, 2002 [37]	Cross-sectional	-	Self-report poor sleep in last week	CBI	Self-report poor sleep: 27% of carers	Not reported

First author, Year	Study design	Control group (type, *n* and % female, age(SD) years)	Sleep outcome	Carer burden measure	Sleep Results Mean (SD)	Carer Burden Results Mean (SD)
Hermanowicz, 2019 [38]	Cross-sectional	-	PMDAlliance survey	-	Excessive tiredness carer: 84% of carers	-
Hicks, 2019 [39]	Cross-sectional	-	PSQI	-	Global PSQI: 4.9 (2.6)	-
Lee, 2020 [40]	Cross-sectional	-	MINI - Insomnia	-	Insomnia: 7.4% of carers	-
Liu, 2018 [32]	Cross-sectional	i) FTLD carers, *n* = 131, F = 37%, 58.3 (13.5) ii) AZ carers, *n* =325, F = 46%, 60.6 (12.7)	PSQI	ZBI	**PD Carers;** Global PSQI: 5.2 (3.0) **FTLD Carers;** Global PSQI: 4.4 (3.7) **AZ Carers;** Global PSQI: 1.01 (1.4)	**PD Carers;** ZBI: 22.6 (16.5) **FTLD Carers;** ZBI: 23.6 (15.9) **AZ Carers;** ZBI: 12.3 (9.7)
Lökk, 2008 [41]	Cross-sectional	-	Sleep disturbance is last four weeks (yes/no)	-	Sleep disturbance: 46%	-
Olsson, 2016 [29]	Case-control	Healthy controls, *n* = 79, F = 59%, 71.9 (9.0)	NHP - Sleep	-	**Carer Sleep;** md(q1-q3; min-max) 20 (0-60; 0-100) **Control Sleep;** 20 (0-40; 0-100)	-
Ozdilek, 2012 [42]	Cross-sectional	-	WHOQOL-BREF - Sleep	ZBI	Not reported	ZBI: 27.6 (15.1)
Pal, 2004 [43]	Cross-sectional	-	PSQI GSQ	-	PSQI; Global Score: 5.5 (3.8) Disturbance: 1.1 (0.5) Quality: 0.8 (0.6) Duration: 0.7 (1.0) Latency: 1.0 (1.1)	-

First author, Year	Study design	Control group (type, *n* and % female, age(SD) years)	Sleep outcome	Carer burden measure	Sleep Results Mean (SD)	Carer Burden Results Mean (SD)
					Daytime dysfunction: 0.9 (0.6) Sleep efficiency: 0.8 (1.1) GSQ; Excessive daytime sleepiness (17.4% of carers) Excessive dreams (4.3% of carers) Hallucinations (0% of carers)	
Perez, 2020 [44]	Cross-sectional	-	PHQ-9 Sleep questions: Trouble falling to sleep or staying asleep, or sleeping to much" "Feeling tired or having little energy" FNQ “I need to get enough rest or sleep"	ZBI	Not reported	Not reported
Smith, 1997 [48]	Case-control	Healthy controls, *n* = 103, F = 43%, 63.0 (14.0)	Self-report sleep quality: 'I cannot sleep well at night' Disrupted sleep: “I can no longer sleep through the night because my partner needs help (e.g., to turn over, to be covered by a blanket, to go to the toilet)”	-	**Carers;** Sleep quality: 2.3 (1.0) Sleep disturbance Female: 2.3 (1.0) Males: 1.9 (0.9) **Control;** Sleep quality: 1.8 (0.9)	-

First author, Year	Study design	Control group (type, *n* and % female, age(SD) years)	Sleep outcome	Carer burden measure	Sleep Results Mean (SD)	Carer Burden Results Mean (SD)
Teel, 1999 [49]	Case-control	i) Healthy controls, *n* = 33, F = 49%, 74 ii) AZ Carers *n* = 30, F = 53%, 72 iii) Cancer, *n* = 33, F = 52%, 70	Sleep disturbance: VSH Sleep effectiveness: VSH	-	**PD Carers;** Sleep disturbance: 3.9 Sleep effectiveness: 6.7 **AZ Carers;** Sleep disturbance: 4.5 Sleep effectiveness: 6.9 **Cancer Carers;** Sleep disturbance: 3.9 Sleep effectiveness: 6.9 **Control:** Sleep disturbance: 3.0 Sleep effectiveness: 8.0	-
Thommessen, 2002 [45]	Cross-sectional	-	Sleep disturbance: Is your sleep interrupted by your relative?	-	Sleep disturbance: 17% of carers	-
Wade, 2020 [46]	Cross-sectional	-	PSQI	ZBI	Global PSQI: 6.9 (3.9) Disturbance: 1.3 (0.5) Quality: 0.8 (0.6) Duration: 0.8 (0.9) Latency: 1.0 (1.0) Daytime dysfunction: 1.1 (1.0) Sleep efficiency: 1.1 (1.1)	ZBI: 18.5 (14.2)

Notes: PD; Parkinson's Disease, CES-D, Centre for Epidemiologic Studies Depression Scale-10 item; CBI, Caregiver Burden Inventory; MOS-SS index II, Medical Outcomes Study-Sleep Scale Index II; FNQ, Family Needs Questionnaire; PSQI, Pittsburgh Sleep Quality Index; GSQ, General Sleep Questionnaire, PADRECC, Parkinson's disease research, education and clinical centre; ZBI, Zarit burden interview; HADS, Hospital anxiety and depression scale; GQS, General questionnaire for sleep; SII, Sleep intervention index; SCOPA-sleep, Scale for outcomes in Parkinson's disease – sleep; VSH, Verran and Snyder-Halpern sleep scale; RSS, Relative stress scale; WHOQOL-BREF, World health organisation quality of life assessment-brief; NHP – sleep section, Nottingham health profile survey – sleep section; FTLD, Frontotemporal Lobar Degeneration; AZ, Alzheimer's disease; PMDA, Parkinson and Movement Disorder Alliance survey.