Report: Reducing Sleep Disruption in Carers

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EXECUTIVE SUMMARY

Background

Carers are those who provide unpaid care to one or more people (usually but not always a relative) with a disability, chronic illness, mental health condition, terminal illness, or who are frail aged. The value of support and assistance provided by Australia's 2.7 million informal or family carers is significant from both an economic and quality of life perspective for care recipients. However, provision of care 24 hours a day, 7 days a week has obvious repercussions for the carer themselves. Sleep disruption is one of the repercussions.

Adequate sleep on a regular basis is critical to both the acute and long-term health and wellbeing of Australians. The Federal Government's Parliamentary Inquiry into Sleep Health Awareness in Australia (2018-2019) demonstrates that the importance of sleep is recognised at a national level. Carers Australia has identified that inadequate sleep for many carers is a major factor affecting their health and wellbeing and their submission as part of the parliamentary inquiry outlined specific challenges for carers in Australia in terms of sleep. The submission emphasised that these challenges should be treated as co-occurring with, but distinct from, those challenges faced by care recipients and that the supports needed to cope with sleep disruption are distinct.

Specifically, carers can be on-call 24/7 to provide care and while these non-standard hours are similar to that of other populations such as doctors, emergency services personnel or even new mothers, the carer context is unique for a number of reasons. In terms of sleep, one of the biggest challenges that carers face is the fact that they are required to provide round-the-clock care, including overnight, in an essentially unregulated 'workplace'. Even when sleep is regularly disturbed or restricted, carers do not necessarily have access to the equivalent of regular 'in-shift' or between shift breaks.

One purpose of this commissioned research is to inform the advice provided to carers on sleep issues. The aim of this report was to systematically gather and review the evidence-based literature on a) the extent, causes and consequences of sleep disruption among carers and b) the interventions, strategies and services and prevention of sleep loss required to help carers better manage sleep. In accordance with these aims, this report comprises a literature review which includes information about;

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- the extent of carers' sleep disruption and/or sleep loss;
- the contributing factors and consequences of sleep disruption
- the nature and diversity of sleep disruption

Further, specific summaries and recommendations have been made on the following points;
- the role of replacement care and how it can most effectively be provided;
- economic costs of the sleep loss arising from caring;
- the known extent of increased accidents among carers due to their sleep disruption
- recommendations to reduce sleep disruption that could be implemented at the government, community, family/friend and carer level;
- targeted areas for future research in the carers' context

Literature Review

Literature (162 peer reviewed articles) was summarised by care recipient condition (e.g. Cancer, Dementia), and it was found that sleep outcomes were similar across all groups. There was considerable variability across studies in terms of the proportions of carers experiencing sleep disturbance, poor sleep and/or the degree of this disturbance. Overall however, **the literature indicated that carers experience significant disturbances to sleep and impairments to both sleep quantity and sleep quality, across all caring contexts.** Importantly, while the presence of sleep disturbance in carers in various contexts was well established, the majority of studies did not report on the causes and/or consequences of such sleep disturbance and did not generally explore the nature of the sleep disruption in detail (e.g. fragmentation, sleep timing, sleep strategies).

Where reported, causes of sleep disturbance could be related to a) practical needs of the care recipient (assistance with toileting, administering medications or other assistance e.g. turning the care recipient) and/or b) vigilance, rumination and worry related to care recipient, and/or their care giving duties. In terms of consequences, the more common consequences of sleep disruption in this population were: decreased quality of life, increased physiological stress and increased depression. Evidence regarding sleep timing and sleep strategies was very limited but it was reported that carers' sleep opportunity was shorter than their care recipient because they often went to bed later but had to wake up earlier to commence caring duties. In some cases, carers tried to offset night time sleep disturbances with day time naps.

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Recommendations

A series of specific recommendations have been made, in line with the report aims and deliverables. These recommendations are based on the available carers' literature but also draw upon the research team's collective expertise in the field of sleep, non-standard working hours, health and safety.

- *The role of replacement care (paid or informal) and how it could be most effectively provided*

Recommendation: Models of replacement care need to be designed, developed and trialled in consultation with carers. Where models of replacement care are currently in use, evaluations of outcomes for carers should be conducted.

- *The economic costs of sleep loss arising from caring.*

Recommendation: Recent estimates of the cost of inadequate sleep per person per annum suggest substantial sums, however, more specific estimates of the costs of sleep loss associated with caring responsibilities in this unique group of workers are urgently needed in Australia to meaningfully establish the economic impact beyond broad sleep loss estimations.

- *The known extent of increased accidents among carers due to their sleep disruption and if possible any valid estimates of the national cost*

Recommendation: Data specifically in the carers' context does not exist, however, increasing carers' awareness of their heightened levels of risk due to sleep disruption across all daily tasks is a critical area for intervention. Awareness should focus on importance of sleep, strategies to improve the overall amount of sleep obtained day-to-day (e.g. sleep hygiene practices, use of opportunities) as well as increasing understanding of the impact of sleep restriction on daily performance (e.g. driving, administration of medications).

- *Recommendations that could be implemented at the government, community, family/friend and carer level to reduce sleep disruption*

Government level: Decision-makers need to recognise that funding of initiatives is required to explicitly address the chronic challenges that family or informal caregivers in Australia face in terms of sleep. Sleep disruption can be minimised in carers, at least acutely, with the provision

of resources for overnight respite care. At the Government level, support for this recommendation may be through carer-specific funding, as opposed to being folded into the care recipient's NDIS funds.

Community level: Funding by the federal or state governments is recommended for 'on-the-ground' support persons to provide a range of services. Such support individuals may be recruited from those already engaged with the caregiving systems e.g., NDIS, Child and Youth Health or similar and they will have up-to-date knowledge about sleep. This includes training on screening tools to help detect undiagnosed sleep disorders as well as knowledge of what services (e.g., respite care) are available to carers and their families plus an ability to provide assistance with day-to-day practicalities of running a household and caregiving with a view to providing breaks for primary caregivers for rest.

Family-Friend level: The role family and friends could play in supporting the primary caregivers relates to both overnight 'coverage' of night-time caregiving but also reduction in the worry, rumination and stress that is reported by carers, all of which are known to negatively impact sleep. If the caregiving needs are complicated or the primary caregiver finds it difficult to relinquish their role even for a short period, picking up other, non-caring duties to ease both the mental and physical load is another way family and friends can assist. Education of family and friends about such needs is required.

Carer level: The needs of the care recipient and the way this impacts sleep opportunity is often beyond the carer's control and so carers need to optimise or improve the sleep that they do get. One of the main ways that carers can help themselves in terms of sleep is to understand and adopt good 'sleep hygiene'. The term sleep hygiene describes a series of known behaviours and environmental factors that facilitate sleep such as the regularity of sleep timing/ patterns, restricting use of stimulants (e.g., caffeine, nicotine), improving the sleeping environment (e.g., light, temperature, noise), facilitating bedtime activities and promoting routine, diet and exercise.

Other issues highlighted in the literature

In addition to the required recommendations, the following were identified as topics of interest from the review of literature.

Use of sleep medications

The use of sleep medications was not commonly reported in the literature. However, those that did identify this issue reported either frequent usage or deliberate avoidance, with the latter being the result of how the medications might impact the carer's ability to provide care overnight. Future research should consider capture of information around sleep medication usage (or indeed any medication that may interact with sleep) in carers. Specifically, whether these have been prescribed, whether they use them (and with what sort of regularity) and if they think this may impair their ability to do their carer and other activities effectively and safely.

Interventions, strategies to improve sleep in carers

In general, carers have not been the focus of intervention studies and where they have been, the vast majority were not sleep-based interventions or did not have a primary aim of improving sleep. Results from the limited available data suggest promising results for a sleep specific intervention in caregivers. Importantly, two of four studies specifically focused on maximising the quality of sleep that carers are able to obtain rather than changing aspects of the care recipients' sleep, condition or disease – factors that are often beyond the control of the carer.

Assistive Technologies

Assistive technologies are a rapidly growing area comprising a number of different categories of technology, for example, diagnosis and monitoring. The majority of assistive technologies are designed for the benefit of the care recipient and are not focused on carer well-being directly. Research and development of assistive technologies should include assessment of the impact they have (positive or negative) for the carer as well. Only a few studies have done this to date.

Future research in the sleep and carer context

Based on the information presented in the report, and the limitations of the current, available literature, future research should consider;

- consistent use of the same, validated sleep questionnaires across research studies to enable collation of small data sets for more meaningful analyses;
- use of sleep measures that are multi- rather than one-dimensional to assess the different elements of sleep disruption and facilitate nuanced interventions or strategies;

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- data collection that captures changes to sleep over time to identify whether there are patterns of (somewhat) predictable changes for carers' sleep as illnesses progress in care recipients;

- deliberate inquiry into the reasons for sleep disturbance (including break-down of terms such as 'worry', 'rumination' and 'stress') with the aim of developing individual, family or system-level positive coping strategies and evaluating their effectiveness;

- expansion of current data to include information about lesser-known or underrepresented (in the literature) carer groups or scenarios to ensure all groups benefit from evidence-based decisions.

Conclusion

The informal carers workforce is critically understudied in terms of impacts for sleep and the consequences of sleep disturbance. The report has highlighted the breadth of issues in terms of sleep disturbance for carers, **with some degree of poor sleep reported nearly without exception in the available literature.** Moving forward, there is an urgent need for more resources to improve carer sleep, as well as a need for a more detailed understanding of the causes and adverse consequences of sleep disruption in the many and varied carer contexts.

INTRODUCTION

According to a 2015 survey, 2.7 million Australians are informal carers for a family member or friend and 10% of carers in Australia are under the age of 25 years (Australian Bureau of Statistics, 2015). The care of individuals with a disability, chronic illness, mental health condition or terminal illness, or persons who are frail and/or aged, commonly rests with a relative or family friend and is often referred to as informal or family care. Many carers live with the care recipient (although not all) and all take on significant responsibility for the care recipient's wellbeing, providing assistance with core activities of mobility, self-care and communication. Informal care arrangements span chronic conditions in both adults and children including:

- Dementia and Alzheimer's disease,
- Parkinson's disease,
- Cancer,
- Mental health conditions,
- Physical Disability (e.g., spinal cord injury, Multiple Sclerosis) and,
- Cognitive disability (e.g., developmental delay, brain injury)

The value of support and assistance provided by informal or family carers is significant from an economic and quality of life perspective. However, the benefits to individuals and the community come at a personal cost to carers themselves (Schulz and Sherwood, 2008). Carers report emotional stress, social isolation and negative impacts on health related to the burden of care they are providing (Kim and Rose, 2011). The physical, emotional and psychological impacts of caring for a friend or family member are significant. Provision of 24/7 care has obvious repercussions for the ability of a carer to engage in external employment, devote time to other family members, or to participate in social, leisure or other self-care activities. In addition, the stage of life of the carer and the relationship (e.g., degree of kin-ship) with the care recipient will also influence these outcomes. For example, caring for a spouse is associated with different challenges than caring for a child with complex needs. Challenges for male versus female, or younger versus older carers may vary, although evidence is currently lacking in this regard. In addition, according to the Australian Bureau of Statistics, more than one-third of primary carers in Australia are also living with a disability themselves (Australian Bureau of Statistics, 2015).Optimising the quality of life for carers is therefore a significant concern.

In addition to the impacts already noted, an obvious consequence of 24/7 caring responsibilities is sleep disruption. Sleep, together with diet and physical activity, is one of the pillars of a healthy lifestyle. Good quality and quantity sleep is essential for optimal performance and well-being and yet alarmingly, sleep disruption is a regular occurrence for much of the Australian population (Adams et al., 2017). Many of us experience brief periods of sleep disturbance, for example from a late night or disruptions from unexpected noise. Such transient disruptions generally have minimal impacts on waking function. However, when sleep disruption is chronic, the impacts on mental and physical well-being (Rajaratnam and Arendt, 2001, Reynolds and Banks, 2010, Hillman and Lack, 2013), as well as safety (Lombardi et al., 2010, Banks and Dinges, 2007, Reynolds and Banks, 2010), can be significant. Given that carers are engaged in informal care in Australia for an average 38 years (Australian Bureau of Statistics, 2015), the chronic impacts of sleep disruption particularly relevant. In line with this, the recent Bedtime Reading report (2019) - the outcome of Federal Government's recent Parliamentary Inquiry into Sleep Health Awareness in Australia - specifically notes not only the significant safety risks associated with sleep deprivation, but also highlights this in relation to shift workers in safety-critical occupations including disability carers and the health industry.

To date, the impacts of an informal, unpaid caring role for sleep and any subsequent consequences for carers has not received rigorous research attention. Of course, sleep disruption is not unique to carers and knowledge about the impact of working arrangements for sleep from other groups (e.g. on-call workers, volunteer fire and emergency services personnel new parents), can be used to form a general understanding of the implications of the carer role for sleep and any related consequences. However, carers have a 'unique work environment' (Bedtime Reading Report, 2019, p55) firstly because it is essentially unregulated and as such there is no equivalent to rostered in-shift breaks, or time off for recovery and recuperation. Further, while it may appear as such, their work is not voluntary, caring for a family member is carried out usually without question but not necessarily by choice and this may, especially over time, contribute to the burden of the role.

The disability care workforce is 'critically understudied from a sleep loss perspective' (Bedtime Reading Report, 2019, p55). Understanding the specific impact of caring responsibilities on sleep may provide some avenues for supporting health, wellness and resilience in this unique population and is a crucial first step in providing meaningful guidance for carers relating to sleep.

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DELIVERABLES:

We reviewed the current literature relating to sleep of carers (*Deliverables 1a*) to determine the state of knowledge about (first three dot points of *Deliverable 1b*) :

- the extent of carers' sleep disruption and/or sleep loss;
- the contributing factors and consequences of sleep disruption;
- the nature and diversity of sleep disruption, for example sleep fragmentation, body clock implications.

This information will be used to inform the evidence base upon which the fact sheets will be developed (*Deliverable 2*).

Deliverable 1b) (dot point 4) The role of replacement care (paid or informal) is the topic of very little peer reviewed literature and as such, is addressed as a separate discussion point. We have drawn upon available, albeit limited peer-reviewed literature, as well as other relevant literature and resources.

Deliverable 1c) published documentation, if any is available, of the economic costs of the sleep loss arising from caring (If valid extrapolations can be made, for example, from the Sleep Health Foundation 'Asleep on the Job' report, these should be included);

Deliverable 1d) the known extent of increased accidents among carers due to their sleep disruption, and, if possible, any valid estimates of the national cost;

Deliverable 1e) recommendations that could be implemented at the government, community, family/friend and carer level to reduce sleep disruption;

Deliverable 1f) what specific areas of research about carers and sleep would be important for future research studies;

Deliverable 1g) other issues as informed by the literature.

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METHOD

Search strategy

This review was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Liberati et al., 2009). A systematic search of the electronic database PubMed was used to identify relevant peer-reviewed studies published between January 1960 and February 2019, the search was conducted in February 2019. The key words used for the search were: *carer, caregiver,* and *caregiving* searched together with *sleep,* and *family, informal, unpaid, spouse.* Reference lists from retrieved articles were examined to identify any additional relevant articles and conference papers that were not discovered in the original search. Identification of relevant grey literature (e.g., conference abstracts) resulted in follow up searches to locate related full-text articles via GoogleScholar and ResearchGate.

Eligibility criteria

To be included in this systematic review, studies were required to have investigated the sleep of unpaid carers in their caring role. Outcome variables of interest were objective measures of sleep, such as polysomnography or activity monitors, and subjective measures of sleep collected from sleep diaries or surveys.

Titles and abstracts of search results were screened for relevance to sleep and carers. Potentially relevant articles were accessed to review the full text. Articles were restricted to studies where sleep was an outcome measure. Screening, data extraction and quality assessment was performed independently by two authors (SJ and KK) with discrepancies resolved through discussion between authors. If no agreement could be reached, differences were resolved by discussion and consensus with a third author (GV).

Data extraction

A data extraction spreadsheet was developed based on the Cochrane Consumers and Communication Review Group's data extraction template. Extracted information included: 1) Carer characteristics, including age, sex and occupation; 2) Caring context/scenario 3) Sleep outcome measure(s); 4) Sleep outcome; and 5) Reported reasons for sleep disturbance.

Quality assessment

The methodological quality of each study in the review was assessed using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (Thomas, 2003). Based on the quality assessment, a global quality score was assigned to each study. The

global score of a study was determined by the number of strong, moderate and weak scores in the subsections of the assessment tool (selection bias, study design, confounders, blinding, data collection method, withdrawal and dropout). To obtain a 'strong' global score a study needed to obtain four or more strong ratings and no weak ratings, a 'moderate' global score required less than four strong ratings and no more than one weak rating, and a 'weak' global score occurred when a study had two or more weak ratings.
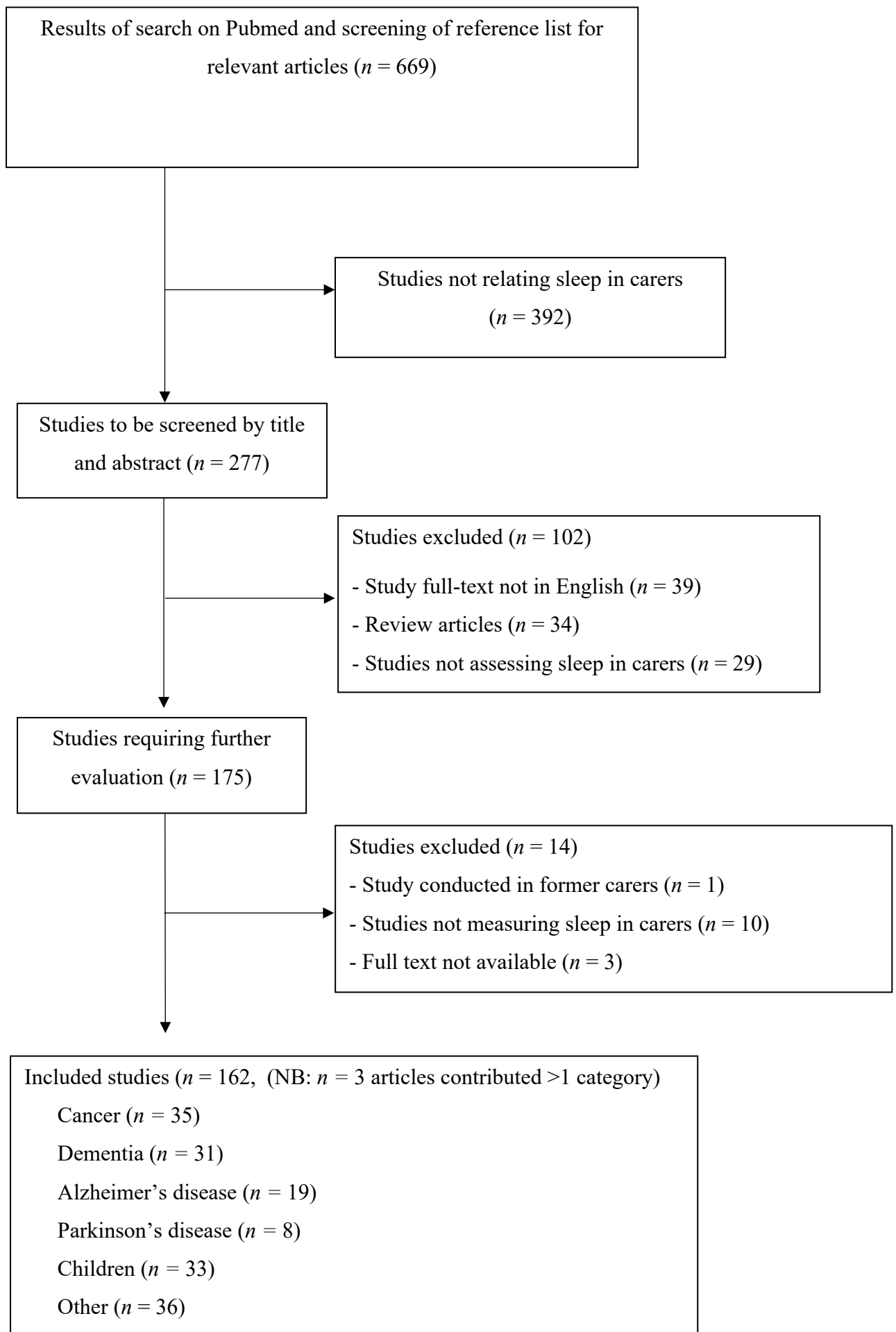
RESULTS

Literature Selection Overview

A flow diagram summarising the selection process is shown in Figure 1. The original search yielded 695 English-language articles. Of these, 392 were rejected during initial screening as they did not relate to carers and sleep. Of the remaining 303 articles, 39 were excluded as the full-text of the article was not in English (even though the abstract was), 34 were review articles and 29 were rejected for not reporting relevant outcomes. Finally, 10 studies were rejected as they did not measure sleep in carers, 3 studies had no corresponding full-text versions and 1 study was conducted in former carers. Consequently, the final number of studies included in this systematic review was 162.

Study characteristics

Study characteristics and key findings of the 162 studies are summarised in Appendix 1.

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┌─────────────────────────────────────────────────────────┐
│   Results of search on Pubmed and screening of reference │
│   list for                                                │
│             relevant articles (n = 669)                   │
└─────────────────────────────────────────────────────────┘
                        │
                        │          ┌──────────────────────────────┐
                        ├─────────▶│ Studies not relating sleep    │
                        │          │ in carers                     │
                        │          │        (n = 392)              │
                        │          └──────────────────────────────┘
                        ▼
┌─────────────────────────────────┐
│   Studies to be screened by title│
│   and abstract (n = 277)         │
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Studies excluded (*n* = 102)

- Study full-text not in English (*n* = 39)

- Review articles (*n* = 34)

- Studies not assessing sleep in carers (*n* = 29)

Studies requiring further evaluation (*n* = 175)

Studies excluded (*n* = 14)

- Study conducted in former carers (*n* = 1)

- Studies not measuring sleep in carers (*n* = 10)

- Full text not available (*n* = 3)

Included studies (*n* = 162, (NB: *n* = 3 articles contributed >1 category)

    Cancer (*n* = 35)

    Dementia (*n* = 31)

    Alzheimer's disease (*n* = 19)

    Parkinson's disease (*n* = 8)

    Children (*n* = 33)

    Other (*n* = 36)

Causes and consequences of sleep disruption among carers

This section begins with a summary of the main findings of the literature review. Information about the various sleep measures used across the literature is then described. More detailed results divided by the care recipient's condition then follows. An annotated bibliography of findings can be found in Appendix 1.

Relevant Deliverable
A) *the evidence base from which the fact sheet information will be drawn;* B) *information about:* - *the extent of carers' sleep disruption and/or sleep loss;* - *the contributing factors and consequences of sleep disruption, for example hypervigilance, stress, physical demands, poor mental health, grieving, family impact, workforce participation;* - *the nature and diversity of sleep disruption, for example sleep fragmentation, body clock implications.*

Executive summary of literature

Quantity and quality of the available evidence

A large number of studies investigated carers' sleep disturbances, with the largest number of studies examining the sleep of carers whose care recipients were adults with cancer (34 studies) or children with various care-needs (32 studies). The majority of studies utilised subjective measures of sleep, either through semi-structured interviews, questions related to sleep as part of a health questionnaire, or subjective sleep assessment tools (e.g., Pittsburgh Sleep Quality Index). Studies were generally of high quality, for example many studies compared carers to a group of non-carer control participants (Cora et al., 2012, Painter et al., 2014). Very few studies were conducted in Australia ($n = 3$).

The extent of carers' sleep disruption and/or sleep loss

Overall, the literature indicates that carers experience significant disturbances to sleep and impairments to both sleep quantity and sleep quality, across all caring contexts. The proportion of carers that subjectively reported sleep disturbances varied. For example, some studies reported that ~75% of carers reported sleep disturbances (Bergman-Evans, 1994) whereas some studies reported that the proportion of sleep disturbance was ~20% (Zverova, 2012). The

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Pittsburgh Sleep Quality Index (PSQI) was the main tool utilised to assess sleep quality, with again large variability in scores across studies. A PSQI global score > 5 is indicative of 'poor quality' sleep, and in some cases the prevalence of carers' scores over this number was as high as 95% (Carter, 2006). Very few studies objectively measured sleep (either by actigraphy or polysomnography). Of those that utilised these measures, total sleep time was as low as 4.4 h per night (Lee et al., 2015). Sleep efficiency (the amount of sleep obtained within the sleep period) was also reported to be significantly lower than normal (>85%), in some cases as low as 77% (von Kanel et al., 2006). The number of awakenings during the night was also very high (range 2.2-17.5 awakenings), with some studies reporting that 90% of carers regularly woke during the night (Gibbins et al., 2009).

The contributing factors and consequences of sleep disruption, for example hypervigilance, stress, physical demands, poor mental health, grieving, family impact, workforce participation. The majority of studies did not report causes and/or consequences of sleep disturbances. A summary of the contributing causes and consequences of sleep disruption from the available literature is presented below:

Causes: The major factor contributing to sleep disruption in the carer was sleep disruption caused by the care recipient (Pal et al., 2004, Smith et al., 1997, Wright, 2011). Further, sleep disturbance increased with increased burden of caring duties (i.e., the more frequent the care, the poorer the sleep) (Happe and Berger, 2002). Vigilance, rumination and worry were other frequently reported causes related to sleep disturbance (Simpson and Carter, 2013, Meltzer and Mindell, 2006). Further, the care recipient needing to go to the bathroom or requiring medical assistance (e.g., turning the care recipient) (Heaton et al., 2005) during the night was also regularly reported as a major cause of sleep disturbance (Gibbins et al., 2009, Klassen et al., 2012).

Consequences: The major consequences of sleep disruption in this population were: decreased quality of life (Cupidi et al., 2012, Pawl et al., 2013), increased inflammation or physiological stress (von Kanel et al., 2012, Mills et al., 2009) and increased depression (Rowe et al., 2008, Peng et al., 2019, Carter, 2006). Some research indicated that sleeping in the same room as the care recipient made it easier to monitor the care recipient's condition, but that this also impacted the carer's sleep (Klassen et al., 2012). In some cases, disturbances to carer's sleep meant the carer slept in another room from the care recipient (Halliday et al., 2017).

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The nature and diversity of sleep disruption, for example sleep fragmentation, body clock implications

Carers' sleep quantity and quality was impacted by their caring duties. For example, carers often went to bed later than the care recipient, but were also required to wake up earlier to commence caring duties (Gibson et al., 2014). Once carers were asleep, their sleep was often disturbed multiple times during the night. In some cases, carers tried to offset night time sleep disturbances with day time naps (Lee et al., 2015).

Sleep measures

Interviews: Qualitative methods, such as interviews, are often used, sometimes in conjunction with quantitative methods such as surveys, to provide more detail and context. Interviews are typically semi-structured, including open-ended (e.g., "Could you tell me about your sleep?"), rather than closed (e.g., "Is your sleep quality bad?") questions, often followed by a series of open-prompts to elicit further detail (e.g., "Could you tell me more about what that was like?"). As opposed to quantitative methods, which are more often focused on measurement, statistics, and generalisability, qualitative methods tend to focus on phenomenology, or lived experience (Ng et al., 2013, Illing, 2010).

Questionnaire Measures: Sleep can also be measured by questionnaire. This has frequently been done through the inclusion of one or more items relating to sleep, disturbances or disorders, as part of a larger questionnaire about health more broadly (Bergman-Evans, 1994). There are also a number of specific, validated questionnaires that are commonly used to measure sleep disturbances. Two of the most common are the Pittsburgh Sleep Quality Index (PSQI, (Buysse et al., 1988)) and the General Sleep Disturbance Scale (GSDS, (Lee, 1992a)).

- The PSQI assesses sleep during the previous month, and includes 19 self-rated items (and can also include five items that may be answered by a bed partner). Questions form seven component scales (scored from 0 to 3), which include sleep quality, latency, duration, disturbance, medication, and daytime dysfunction. These are summed to produce an overall sleep disturbance score (range 0-21), where higher scores indicate higher disturbance. A cut-off of 5 is typically used to indicate poor sleep.
- The GSDS also focuses on sleep during the previous week, and includes a total of 21 items concerning difficulties getting to sleep, waking up during sleep, waking too early, sleep quality, sleeping poorly, not feeling rested, not feeling satisfied, having too little

or too much sleep, fatigue and alertness at work, and use of sleep aids. Responses are provided on 10-point scales (anchored from "never" to "all the time"), and scores are summed such that higher scores indicate higher sleep disturbance.

Sleep Diaries: These are typically structured with daily entries recording the times that the person: (a) got into bed; (b) turned the lights out; (c) fell asleep; (d) woke up during the sleep period e.g., to visit the bathroom); (e) awoke for the final time; and (f) got out of bed. This allows calculation of a number of variables to describe sleep, including subjective sleep onset latency (the time between lights out and fall asleep), sleep period time (the period between lights out and wake up), and total sleep time (the time in bed actually spent sleeping). Sleep diaries also typically include a subjective sleep quality scale (e.g., How refreshing was your sleep? 1=not at all, 5=extremely), and may also ask questions about sleep location, and sleep aid use.

Actigraphy: The actigraph, typically worn on the wrist, is a small device resembling a wrist-watch that incorporates an accelerometer, which detects body movement or lack of movement. The actigraph data is collected in concert with information from sleep diaries that identifies periods when the person is in bed. A computer algorithm is then used to infer the timing, duration, and quality of sleep based on the absence of recorded movement.

Polysomnography: The primary signals used to determine sleep are measured by electrodes applied to the face and scalp to record brain waves (electroencephalogram, EEG), eye movement (electrooculogram, EOG), and muscle activation (electromyogram, EMG). From patterns in EEG, EOG, and EMG, two distinct sleep patterns may be discerned; Rapid Eye Movement (REM) and Non Rapid Eye Movement (NREM) sleep (Carskadon and Dement, 2011).

REM sleep is characterised by prominent rapid eye movements, fast, desynchronised, low amplitude EEG wave forms and loss of muscle tone. Thus, while there is a high level of brain activation, the body is in a state of paralysis. For this reason, it is also referred to as paradoxical sleep. REM is associated with irregularities in temperature, heart rate and respiration, and intermittent muscle twitches. A large proportion of dreaming is thought to occur in REM sleep, since individuals awoken during this stage report story-like dreams (Carskadon and Dement, 2011, Pelayo and Dement, 2017).

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NREM sleep has been divided into four stages. Stage 1 (N1) is considered to be a transitional stage, somewhere between sleep and wakefulness, only occurring for a short time. It is characterised by low amplitude EEG activity, slow rolling eye movements and a low arousal threshold. Stage 2 (N2) is generally recognised as the onset of true sleep, and is the most prevalent sleep stage. It is associated with specific EEG wave forms (referred to as Spindles and K-Complexes). Stages 3 and 4 (recently labelled N3) are commonly known as slow wave sleep (SWS). This stage is marked by the occurrence of high amplitude, slow wave activity. The arousal threshold is high and individuals tend to be unable to recall awakenings, which are often very brief (Carskadon and Dement, 2011, Pelayo and Dement, 2017).

REM and NREM sleep alternate in periodic cycles. A normal, healthy individual will experience approximately four alternating NREM/REM cycles of approximately 90 minutes duration during a nocturnal sleep period. With each cycle, the amount of REM sleep increases, and the amount of NREM sleep decreases (Carskadon and Dement, 2011, Pelayo and Dement, 2017). This pattern in wake, NREM, and REM sleep across a sleep period is often referred to as sleep "architecture." When considering sleep disruption, it is important to consider sleep quantity and quality (length, awakenings, and architecture).

Polysomographic techniques including EEG, EOG, and EMG, are the gold standard in sleep measurement. However, such techniques are relatively obtrusive and labour intensive, not only in terms of data collection, but also in terms of data processing and scoring. As such, alternative methods of measurement are commonly used. These include sleep diaries and actigraphy.

A summary of each of the common measurement approaches and typical outcome measures, with acronyms, is provided in Table 1.

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Table 1. Common subjective sleep measures used in the studies reviewed.

Instrument	Measure components	Scoring and interpretation
Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1989)	Nineteen individual items about sleep and sleep habits in the previous month from which seven "component" scores are generated. Component scores combine to give a Global score (range 0-21).	Scores range from 0-21 with a score >5 indicative of poor sleep.
Anxiety-insomnia scale (part of Goldberg General Health Questionnaire (GHQ-28)) (Goldberg, 1979)	Anxiety-insomnia is one of four subscales in the 28-item questionnaire which assesses aspects of health 'over the past few weeks'	Scores range from 0-84 with higher scores indicate greater deviation from typical/usual
Centre for Epidemiological Studies Depression (CED-D) scale (Radloff, 1977)	Sleep disturbance "my sleep was restless" is one of 20 items to measure depressive symptoms. Asked to rate how often sleep was restless in the past week on a scale of 1 (none/rarely) – 4 (most/all of the time)	Higher score indicates greater degree of disturbance. No cut offs for sleep item.
Functional Outcomes of Sleep Questionnaire (FOSQ) (Weaver, 1997)	74 item scale that assess difficulties with behaviours due to tiredness; difficulties being active at different times of the day; impact of sleepiness on sexual activity; frequency of certain activities	The lower the score, the greater the impact of sleepiness on the daily activities assessed
Sleep Disorders Questionnaire I (Douglass et al., 1994)	Asks questions regarding 6 diagnostic domains (Insomnia: Psychiatric Disorders: Circadian Rhythm Disorder: Movement disorders: Parasomnias and suspected sleep apnoea (seek clinical evaluation)	Specific scoring criteria for each domain but higher scores indicate more sleep difficulties
Medical Outcomes Study-Sleep Scale (MOS-SS) (Hays, 1992)	12-items assessing six dimensions of sleep in past 4 weeks. Dimensions; sleep maintenance, respiratory problems, perceived adequacy, daytime somnolence, time to fall asleep and hours of sleep.	Higher scores indicate poorer sleep outcomes No clinical cut offs.
Sleep hygiene index (SHI) (Mastin et al., 2006)	13-item questionnaire to detect presence of behaviours thought to comprise sleep hygiene. For each behaviour, rate (0-5) how frequently they engage in it (always, frequently, sometimes, rarely, never).	Scores range from 0-52 with higher scores indicate more maladaptive sleep hygiene status
General Sleep Disorders Scale	A 21-item scale measuring sleep disturbance in the past week including problems initiating sleep, wake during sleep, waking too	Higher scores indicate greater 'disturbance' (max score 147)

(Lee, 1992a)	early, quality of sleep, sleep quality as well as daytime function and use of substances to induce sleep.	43 and above is considered to be indicative of clinical levels of sleep disturbance
Morin Daily Sleep Diary (Morin, 1993)	A daily sleep diary. For each sleep, individual asked to rate timing, duration, quality, interruptions, use of medications and alcohol in relation to sleep	N/A

Sleep disturbances in carers reported by care recipients' condition.

This section is divided by the care recipients' condition. Based on available literature, care recipient conditions with >5 studies were summarised together. This resulted in literature summaries for Cancer, Parkinson's disease, Dementia and Azheimer's disease. Alzheimer's disease, while a form of Dementia was summarised separately from 'all-cause' Dementia as there were significant number of studies that specifically focused on care recipients with an Alzheimer's disease diagnosis. Finally, the literature presented in the final category - 'Children' - contains several care recipient conditions with the common factor of individuals being children. A further 44 studies investigated care recipient conditions but with 5 or fewer studies focused on each condition.

For each condition, the number of studies is first described and then the findings are discussed by sleep measure used. Please note that some studies may have used participants from multiple caring contexts (e.g., Parkinson's disease and Alzheimer's) or multiple sleep measures (e.g., sleep diary and actigraphy), and so may be described in more than one section.

1) Cancer

Thirty-four studies investigated the sleep of carers of care recipients with cancer (all references – see Appendix 1). Of these studies, seven assessed sleep using qualitative measures (e.g., semi structured interviews), eight assessed sleep as a measure included as part of a health questionnaire, 18 used a subjective measure of sleep and five used actigraphy. No studies used polysomnography.

Qualitative: Very few studies used qualitative measures to assess carers' sleep where the care recipient had cancer. Of note, one study found that all carers reported negative changes to sleep since the care recipient was diagnosed (Carter, 2002). In some cases, this resulted in a change in sleep arrangements, for example in one study carers reported moving to another room to sleep so as to not be disturbed by the care recipient (Halliday et al., 2017). Severe fluctuations in sleep quantity and quality, and moderate to severe sleep problems were regularly self-reported in the literature (Cora et al., 2012, Carter, 2002).

Sleep included as part of a health questionnaire:
The General Sleep Disturbance Scale has been used extensively to study carers' sleep where the care recipient has cancer. All studies have reported high scores, with average scores ranging

from 37-43 (Fletcher et al., 2008, Stenberg et al., 2014, Aouizerat et al., 2009, Miaskowski et al., 2012, Willette-Murphy et al., 2009, Dhruva et al., 2012). Of concern, one study found that nearly 23% of carers reported that they got enough sleep to feel rested 'a little or none of the time' (Litzelman et al., 2018). This study found that problem-focused coping was associated with less sleep, possibly due to rumination making it harder to fall asleep (Litzelman et al., 2018). Other studies found that carers reported significant disturbances to sleep (24-45%) (Pellegrino et al., 2010, Carney et al., 2011).

Subjective sleep measure: The PSQI has been used quite extensively to study carers' sleep where the care recipient has cancer. All studies have shown that the average global PSQI score of the carers sits above the clinical cut off score for poor sleep (i.e. >5) with average scores ranging from 5.7 to 11.5 (Al-Daken and Ahmad, 2018, Carter, 2002, Carter and Acton, 2006, Cuthbert et al., 2017, Dhruva et al., 2012, Lee et al., 2015, Chang et al., 2007). More specifically high numbers of the carers studied scored above the clinical cut off, with the percentage of carers' global ratings >5 ranging from 59% to 95% (Dhruva et al., 2012, Aslan et al., 2009, Carter, 2006). Large fluctuations in sleep outcome measures over time were reported in one study (Carter, 2003). Many carers (85.6%) reported using at least one non-pharmacological strategy to manage their sleep disturbance (e.g., behavioural changes, lifestyle practices, biological treatments) (Aslan et al., 2009), while PSQI scores were lowest in those that used sleep medication (Carter, 2002). Interestingly, if responsibility of the care recipient was 'shared' then average PSQI score was lower (but still >5) (Chang et al., 2007). In studies that utilised other subjective sleep measures (e.g., sleep diaries) carers reported trouble falling asleep (46-50%), restless sleep (82%), staying asleep (76%), and waking during the night (90%) (Flaskerud et al., 2000, Gibbins et al., 2009). Another study found that 32% of carers reported poor quality sleep, and 68% of carers reported some sleep disturbance (Pawl et al., 2013).

Actigraphy: A small number of studies have used actigraphy to study carers' sleep where the care recipient has cancer. Many studies reported long sleep onset latencies (i.e., the time taken to get to sleep), with averages ranging from 26 to 35 min (Pawl et al., 2013, Carter and Acton, 2006). Most studies report average total sleep time below the recommended 7-9 h for a healthy adult, with average duration from 3.5-6.8 h (Carter and Acton, 2006, Carney et al., 2011, Dhruva et al., 2012, Pawl et al., 2013, Lee et al., 2018b, Lee et al., 2015). One study however, did report that carers' total sleep time was 7.8 h, with a sleep efficiency of >90%, indicating

good sleep quantity and quality (Gibbins et al., 2009). The amount of sleep obtained in the sleep period (i.e., sleep efficiency) was also low, ranging from 70-85% (Carter, 2003, Carter and Acton, 2006, Carney et al., 2011). Of concern, a number of studies reported a significant number of wakings during the night, ranging from 8.3-17.5 (Dhruva et al., 2012, Pawl et al., 2013). In one study, total sleep time over a 24-h period was 6.3 h, despite the overnight sleep duration of 4.6 h, indicating that participants were utilising daytime naps to supplement sleep (Lee et al., 2015).

Causes of sleep disturbance: Very few studies investigated the causes contributing to carers' sleep disturbance in circumstances where the care recipient had cancer. Carer burden was highlighted as a significant factor influencing sleep in some (Al-Daken and Ahmad, 2018), but not all studies (Lee et al., 2018b). An explanation for the latter finding was strategies that reduce carer burden, also reduced carers' ability to monitor the care recipients' condition, which created a higher level of worry. Other causes of sleep disturbance included: the patient's illness (83.3%), the care recipient needing to go to the toilet (42.0%), financial problems (36.6%), inadequate support system (34.4%), anxiety from exposure to adverse effects of the therapy on patient (26.6%), fatigue (30.0%), worry (26.0%), family issues (20%) and poor sleep routine (6%) (Aslan et al., 2009, Zhang et al., 2014, Gibbins et al., 2009).

Consequences of sleep disturbance: A small number of studies reported on the consequences of carers' sleep disturbance where the care recipient had cancer. Associations between sleep disturbance and depressive symptoms were most frequently reported (Fletcher et al., 2008, Carter, 2002, Carter and Acton, 2006, Paek et al., 2018). Strong relationships between sleep disturbance and reduced quality of life were also prevalent in the literature (Zhu et al., 2014, Chang et al., 2007). Disturbances to sleep were also associated with negative changes to inflammatory markers (Aouizerat et al., 2009), fatigue (Pawl et al., 2013), irritability and anger towards the care recipient (Carter, 2002), anxiety (Fletcher et al., 2008, Paek et al., 2018) and pain (Fletcher et al., 2008).

2) Dementia

Twenty-seven studies investigated the sleep of carers of care recipients with Dementia (all references – see Appendix 1). Of these studies, four assessed sleep using qualitative measures (e.g., semi structured interviews), five assessed sleep with a measure included as part of a health

questionnaire, 16 used a subjective measure of sleep, nine used actigraphy and two used polysomnography.

Qualitative: Interview data revealed that both sleep opportunity and the quality of sleep within that opportunity were impacted by carer duties. For example, in one study caregivers went to bed later than the care recipient, as they took this opportunity to 'relax' or 'do other jobs', but then had to wake early to provide morning care (Gibson et al., 2015). Causes of sleep disturbance were directly associated with the care-recipient's sleep problems, or by association e.g., stress impacting ability return to sleep (Ali and Bokharey, 2015, Gibson et al., 2014).

Sleep included as part of a health questionnaire: There are inherent difficulties in providing a cohesive summary given the differing types of questions and questionnaires used. That said, consistent across all studies was the significant proportion of carers reporting some degree or type of sleep disturbance or dissatisfaction (Chiu et al., 2014, Naruse et al., 2012, Koyama et al., 2017, Moon and Dilworth-Anderson, 2015). The proportion of carers reporting disturbed sleep (as indicated by 'dissatisfaction' 'interruptions', 'disturbance' 'waking during the night', 'difficulty falling asleep') ranged from a quarter (27%), to nearly the entire sample studied (99%) (Koyama et al., 2017, Chiu et al., 2014). Two studies made comparisons between carers and non-carers and found that non-carers reported less interrupted sleep compared to carers (Moon and Dilworth-Anderson, 2015) and that when care recipients moved into formal care, carers had a reduction (over time) in their anxiety-insomnia score (Matsuda et al., 1997).

Subjective sleep measures: Of the eight studies that reported global PSQI score, 100% reported carers having an average global PSQI score >5 - widely considered the cut-off for clinically poor sleep (Brummett et al., 2007, Eleuteri et al., 2018, Fonareva and Oken, 2014, Merrilees et al., 2014, Peng et al., 2019, Simpson and Carter, 2013, Wilcox and King, 1999). Within the PSQI is a question on sleep medication and again, where reported more than half the sample reported taking sleep medication in the month prior (Merrilees et al., 2014, Peng et al., 2019).

Usefully, two studies had non-carer groups with which to make direct comparisons of global PSQI scores, with carer groups in both studies having poorer sleep as indicated by the PSQI e.g., 7.3 *vs.* 5.5 (Brummett et al., 2007), 8.3 *vs.* 4.4 (Fonareva et al., 2011). Comparisons were also made within carer cohorts and interestingly showed PSQI differences depending on characteristics of either the carers (e.g., 8.5 *vs.* 5.4 for those 'high' *vs.* 'low' depressive

symptoms) (Eleuteri et al., 2018) or the caring scenario (7.8 *vs* 4.9 for carers of individuals with severe *vs.* sematic dementia) (Merrilees et al., 2014). The comparative studies highlight not only the differences in sleep between carers and non-carers but also the need to understand carer characteristics and contexts in order to predict how sleep might be impacted.

Actigraphy and Polysomnography: All studies using objective measures - actigraphy and polysomnography - reported total sleep time. Not surprisingly, there was significant variation between studies with average total sleep ranging from 5.8 h (D'Aoust et al., 2015, Beaudreau et al., 2008) up to 8.1 h in carers of individuals with a diagnosis of frontotemporal dementia (Merrilees et al., 2014). In line with the subjective reports, the majority of studies reported average sleep at <7 h (Rowe et al., 2008, D'Aoust et al., 2015, Beaudreau et al., 2008, Fonareva et al., 2011, Spira et al., 2010, Smagula et al., 2017). Similarly, there was substantial variability in the amount of time spent awake after falling sleep with average times ranging from 8 min (Sakurai et al., 2015) to 112 min (Beaudreau et al., 2008) - most studies reported wake times between 30 and 60 minutes (Rowe et al., 2008, D'Aoust et al., 2015, Fonareva et al., 2011, Smagula et al., 2017, Peng et al., 2019). The other commonly reported measure was how long carers took to fall asleep, with average duration across studies 20 – 30 minutes (Rowe et al., 2008, D'Aoust et al., 2015, Smagula et al., 2017, Peng et al., 2019, Beaudreau et al., 2008).

While the overall picture from the objective data indicate poor sleep, there were some exceptions. For example, in one study carers' total sleep ranged from 7.7-8.1 h (Merrilees et al., 2014) – higher than the national average (Adams et al., 2017). Measures of sleep efficiency in this same study also suggest sleep in general was within what would be considered a normal, even 'good' range - approximately 86% for the two carer groups (Merrilees et al., 2014). By way of comparison, two studies reported much poorer sleep outcomes, with total sleep at <6 h and sleep efficiency <73% in both studies (Beaudreau et al., 2008, D'Aoust et al., 2015). While not all findings were as severe as this, these studies highlight the both the substantial variability and severity of the sleep disruption in some caring contexts.

Causes of sleep disturbance: The use of different methodologies and measures makes it difficult to directly compare results from the studies. However, some consistent themes did emerge with the first being related to the practicalities of caregiving. Physical disturbance at night e.g., being kicked, touched, nightmares, (Gibson et al., 2014) and the sleep difficulties of the care recipient disturbed carers' sleep (Ali and Bokharey, 2015, Simpson and Carter, 2013).

Performing over-night care duties (postural change, toileting support and diaper changing) (Naruse et al., 2012, Wilcox and King, 1999) and managing night-time wanderings of the care recipient (Flaskerud et al., 2000) were also cited as causes of sleep disturbance.

Another theme was that of 'vigilance' (Simpson and Carter, 2013, Gibson et al., 2014, Flaskerud et al., 2000). Only one study provided detail on the need to be 'vigilant' - to safeguard the care recipient at night (Simpson and Carter, 2013) – but anecdotally, vigilance is likely related to unpredictable night time activities of the care recipient – and the need of the carer to have to respond. Along the same lines as being vigilant was 'worry', (Rowe et al., 2010, Simpson and Carter, 2013). Again, there was a lack of detail regarding the source of worry but one study specifically stated that worry was related to 'current or future events' (Simpson and Carter, 2013). Finally there was a link between sleep disturbance and the symptoms or status of the care recipient's condition (Ali and Bokharey, 2015, Simpson and Carter, 2013, Chiu et al., 2014) highlighting that sleep disturbance is likely to vary not only between carers but also within the same carers depending on the care recipient's health and needs at a particular time.

Finally, only one study reported not only on the causes of sleep disturbance and also the detailed strategies carers had developed in order to minimise sleep disturbance (Gibson et al., 2014). Carers in this study worried about the care recipient tripping in the night when going to the bathroom. In response they often left lights on, kept doors and windows locked to reduce overnight worry, maintained regular bedtime routines and slept in separate beds or bedrooms to reduce sleep disturbance. Sharing of information on specific, practical yet simple strategies for coping is likely to be of value to all carers, but especially to those newer to their carer roles.

Consequences of sleep disturbance: Not all studies discussed the specific consequences of the reported sleep disturbance. Nonetheless, some broad consequences that were associated with (not necessarily caused by) sleep outcomes were evident. There was a consistent association between sleep and aspects of mental health, including depressive symptoms (Eleuteri et al., 2018, Chiu et al., 2014, Beaudreau et al., 2008, Rowe et al., 2008), low mood (Ali and Bokharey, 2015), anger (Liu et al., 2015) and distress (Wilcox and King, 1999).

Finally, one study reported that poor carer sleep could be one of the reasons why carers admit care recipients to care services (Lee et al., 1997). Other consequences were less extreme with poor sleep and/or sleep disturbance associated with general daytime dysfunction (Peng et al.,

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2019, Chiu et al., 2014), impairment to physical functioning (Chiu et al., 2014, Spira et al., 2010), daytime dozing (Chiu et al., 2014), sleep medication usage (Peng et al., 2019) and increased physiological arousal and stress (Sakurai et al., 2015, Fonareva et al., 2011).

3) Alzeihmer's disease

Eighteen studies investigated carers' sleep where care recipients had Alzheimer's disease (all references – see Appendix 1). Of these studies, seven assessed sleep as a measure included as part of a health questionnaire, seven used a subjective measure of sleep, four utilised actigraphy and four used polysomnography. There were no qualitative investigations (e.g., semi-structured interviews) identified by our broad search criteria.

Sleep included as part of a health questionnaire: Sleep questions as part of health questionnaires have been used to study carers' sleep where the care recipient has Alzheimer's disease. A large proportion of carers regularly reported disturbances to sleep (Zverova, 2012, Caswell et al., 2003), with disturbed sleep recognised as a common health-related complaint amongst carers (Bergman-Evans, 1994). For example, 74.4% of carers reported sleep related health problems, 65% reported restless sleep most of the time, and 14% reported restless sleep all of the time (Bergman-Evans, 1994, Cupidi et al., 2012, Mannion, 2008). Interestingly, one study found immediate family members of a care recipient were significantly more likely to report higher scores on the anxiety-insomnia scale, compared to 'other' family members (Ruiz Fernandez and Ortega Galan, 2019). Further, carers who had cared for ≤ 2 years reported higher ratings of insomnia compared to longer periods of care time (Ruiz Fernandez and Ortega Galan, 2019).

Subjective sleep measure: The PSQI has been used quite extensively to study carers' sleep where the care recipient has Alzheimer's disease. All studies have shown that the average global PSQI score of the carers sits above the clinical cut off score for poor sleep (i.e. >5) with average scores ranging from 5.8 to 9.1 (von Kanel et al., 2012, Roepke et al., 2012, von Kanel et al., 2014, Cupidi et al., 2012, Liu et al., 2017). More specifically high numbers of the carers studied scored above the clinical cut off, with the percentage of carers' global ratings >5 as high as 85% (Liu et al., 2017). In one study, 58% of carers reported 'poor' or 'fair' quality sleep in the previous month and 47% reported being disturbed during sleep ≥3 times a week (Creese et al., 2008). In another study, carers self-reported low total sleep times (5.9-6.4 h) and

sleep efficiency (72.1-78.5%), a high number of awakenings (1.9-3.0), and frequent wake after sleep onset (48.3-73.1 min) (Willette-Murphy et al., 2006).

Actigraphy and Polysomonography: A small number of studies have used actigraphy to study carers' sleep where the care recipient had Alzheimer's disease. Most studies report average total sleep time at the lower end of the recommended 7-9 h for a healthy adult. In most studies carers slept on average between 7.0-7.3 h each night (McCurry et al., 2008, von Kanel et al., 2014, Schwartz et al., 2013, von Kanel et al., 2012). One of these studies also found that placement of the spouse into formal care did not impact sleep but that death of the spouse exacerbated sleep disturbances (von Kanel et al., 2014). Of concern, wake after sleep onset averaged 1-h, indicating significant impacts to sleep quality (McCurry et al., 2008, von Kanel et al., 2014). Carers' sleep also varied considerably across a week (McCurry et al., 2008).

Polysomnography was used in a small number of studies investigating carers' sleep of care recipients with Alzheimer's disease. Total sleep time and sleep efficiencies were below recommended ranges for healthy adults, e.g., average total sleep time ranged from 5.9-6.5 h (Mausbach et al., 2006, von Kanel et al., 2006) and sleep efficiency averaged 77-89% (von Kanel et al., 2006, Mills et al., 2009). In one study, carers slept 51 minutes less than non-carers (McKibbin et al., 2005). In another study, wake after sleep onset averaged 84 minutes (Mausbach et al., 2006).

Causes of sleep disturbance: Only one study specifically reported causes of sleep disturbance in carers of Alzheimer's disease care recipients (Creese et al., 2008). A majority of carers (63%) cited the care recipient's behaviour as the major cause of sleep disturbances (Creese et al., 2008). Specific causes included: the care recipient needing to go to the bathroom, restlessness, wandering, requests for attention/help, sleep talking, nightmares, wanting to get dressed. Of these factors, the recipient needing to go to the bathroom and wanderings were significantly associated with poorer carers' sleep quality (Creese et al., 2008).

Consequences of sleep disturbance: Very few studies reported on the consequences of carers' sleep where the care recipient had Alzheimer's disease. Where this was investigated, depressive symptoms and stress as a consequence of sleep disturbances were the most frequently reported (Mausbach et al., 2006, von Kanel et al., 2012, Mannion, 2008). Other

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studies reported that sleep disturbances were associated with poor health (Mannion, 2008), inflammation (Mills et al. 2009, Von Kanel et al. 2012), quality of life (Cupidi et al. 2012), carer role burden (Creese et al. 2008) and negative mood (Von Kanel et al. 2014). One study found no association between sleep variables (total sleep time, sleep efficiency, napping behaviour) and the prevalence of diabetes, dyslipidemia or hypertension (Schwartz et al. 2013).

4) Parkinson's disease

Six studies investigated the sleep of carers of care recipients with Parkinson's disease (all references – see Appendix 1). Of these studies, five assessed sleep using a general health questionnaire, and one used the PSQI. None of the studies utilised qualitative measures (e.g., semi-structured interviews), sleep diaries, actigraphy or polysomnography.

Sleep included as part of a health questionnaire: Studies found that carers self-reported significant sleep problems and regularly experienced disturbed sleep (Bartolomei et al., 2018, Grun et al., 2016, Smith et al., 1997). Specifically, two studies found that 41% of carers reported 'bad' or disturbed sleep (Grun et al., 2016, Happe, 2003). Further, 26% of carers reported excessive levels of tiredness and 18% reported insufficient sleep duration. Self-reported total sleep time was also low, averaging 6.4 h, but showing signficiant night-to-night variability (range 3-8 h) (Cifu et al., 2006).

Subjective sleep measure: Only one study used the PSQI to assess carers' sleep where the care recipient had Parkinson's disease. In this study, carers reported an average global PSQI score of 5.5 and 60% had a score >5.0. Of concern, 20% of carers had a score ≥ 10 (Pal et al., 2004).

Causes of sleep disturbance: Studies reported that the major causes of carers' sleep disturbance where the care recipient had Parkinson's disease were carer burden (Cifu et al., 2006), coping ability (Cifu et al., 2006), the need to provide adequate care to the care recipient (Grun et al., 2016), regular caring duties (Happe, 2003) and the severity of the care recipients' disease state (Smith et al., 1997). One study also reported that there was a significant relationship between the sleep of the carer and the sleep of the care recipient (Pal et al., 2004).

Consequences of sleep disturbance: Only one study reported causes of sleep disturbance in carers of Parkinson's disease care recipients. In this study, 27% of carers reported that they felt

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burdened by tiredness (Happe and Berger, 2002). No other studies that investigated the sleep of carers of care recipients with Parkinson's disease discussed consequences.

5) Children

Thirty-two studies investigated the sleep of carers of child care recipients (all references – see Appendix 1). Of these studies, seven assessed sleep using qualitative measures (e.g., semi structured interviews), six assessed sleep as a measure included as part of a health questionnaire, 19 used a subjective measure of sleep, two used actigraphy and one used polysomnography.

Qualitative: Qualitative assessments of sleep through interviews reveal that sleep disruption is common for carers of children dependent on technology (Heaton et al., 2005). Interviews also revealed that sleep disruption occurs in carers of children with cancer (Klassen et al., 2012) and diabetes (Sullivan-Bolyai et al., 2003) and it is worst immediately following diagnosis.

Sleep included as part of a health questionnaire: Sleep questions included as part of general health questionnaires revealed that approximately half of carers experience sleep disruption (up to 56% of carers). Carers of children with dermatitis (Al Shobaili, 2010), cancer (Boman et al., 2003), a disability (Dykens et al., 2014), atopic eczema (Moore et al., 2006), and Smith Magenic Syndrome (Foster et al., 2010) experienced sleep disruption measured by a range of different self-reported measures. Total sleep time was reported to be 6.4 h in mothers and 4.8 h in fathers of children with Smith Magenic Syndrome (Foster et al., 2010). While these questions do shed light on the degree to which carers' sleep is impacted, there was no additional information related to causes of sleep disturbance.

Subjective sleep measure: Subjective sleep measures have been used in several studies, providing a breadth of findings. The range of tools applied, and the specific variables reported from each tool, make it difficult to provide an integrated summary of findings. However, some broad conclusions can be drawn. Measures of total sleep time and sleep quality are globally worse for carers of children with illness or disability when compared to non-carer controls (Gallagher et al., 2010, Meltzer and Mindell, 2006, Nozoe et al., 2016, Pollock et al., 2013, Wright, 2011). Only one published study reported no difference in sleep of carers (of asthmatic children) and non-carer controls (Yuksel et al., 2007). In addition, inadequate sleep measured by total sleep time, degree of disruption, or sleep quality is reported in carers of children with

physical or developmental disabilities (Chu and Richdale, 2009, Lee et al., 2018a, Wayte et al., 2012), chronic illnesses (Cottrell and Khan, 2005, Feeley et al., 2014, Jaser et al., 2017, Wood et al., 2008, Yilmaz et al., 2008) and cancer (Matthews et al., 2014). Total sleep time is reported to be less than 5 hours for some carers with the majority less than 7 hours per night. Scores on the PSQI are reported to be above 5 and up to 10 in carers of ventilated children suggesting clinically significant sleep disruption. Sleep was one hour longer per night for carers who had access to night nursing than those who did not have night nursing (6.3 h v 7.3 h) (Meltzer and Booster, 2016).

Actigraphy and Polysomnography: Objective measures of sleep, actigraphy and polysomnography, have been used less frequently in published literature but provide useful insights in terms of structure of sleep. In particular, objective measures of sleep provide an indication of sleep disturbance from measures such as wake after sleep onset and number of arousals. Parents of ventilator-assisted children had shorter total sleep time, longer wake after sleep onset, and lower sleep efficiency than non-carers as measured by actigraphy (Meltzer et al., 2015). Also using actigraphy, one study reported parents of children with Angelman Syndrome slept an average of 6.3 h and had 63 min wake after sleep onset suggesting inadequate quality and quantity of sleep (Goldman et al., 2012). A single study using polysomnography found a higher proportion of Stage 3 sleep in carers of children with Duchenne muscular dystrophy (Nozoe et al., 2017). This is indicative of carers carrying a sleep debt.

Causes of sleep disturbance: Where children are dependent on technology (e.g. ventilators, oxygen, pumps, dialysis) the main causes of sleep disruption include responding to alarms, turning the child and attending to children in pain or vomiting (Heaton et al., 2005). Parents of children with cancer, diabetes and epilepsy reported that worry associated with the diagnosis and the need to be constantly vigilant were main causal factors for disrupted sleep, in addition to direct caring activities (Sullivan-Bolyai et al., 2003, Klassen et al., 2012, Wright, 2011). Stress is also reported as a factor impacting carers' sleep (Gallagher et al., 2010, Meltzer and Mindell, 2006).

The greater the sleep and behavioural problems in the child, the greater the sleep disruption reported by carers (Chu and Richdale, 2009, Goldman et al., 2012, Jaser et al., 2017, Lee et al., 2018a) suggesting direct impacts on sleep. Similarly, the severity of a child's asthma,

Duchenne muscular dystrophy, or eczema (Nozoe et al., 2017, Yuksel et al., 2007, Wayte et al., 2012) were all related to sleep disruption in carers. One study reported no difference in sleep between carers whose children were on sleep or behavioural medication and those who were not suggesting no improvements were seen in carers' sleep when children were medicated (Gallagher et al., 2010).

Broadly, the causes of sleep disturbance in carers of children fall into three categories - direct impacts associated with monitoring and responding to immediate needs, direct impacts associated with the child not sleeping, and indirect impacts associated with stress and worry. Strategies supporting the sleep of carers could focus on any or all of these causes.

Consequences of sleep disturbance: Many studies reported on the consequences of carers' sleep. Associations of sleep disturbances with depression (Cottrell and Khan, 2005, Feeley et al., 2014, Wayte et al., 2012, Matthews et al., 2014, Yilmaz et al., 2008), psychological well-being (Chu and Richdale, 2009) and quality of life (Feeley et al., 2014, Meltzer et al., 2015) were regularly reported. Interestingly, one study found that parents of children with a disability (autism or cerebral palsy) who did not experience sleep disruption participated more regularly in health promoting activities, than parents who experienced regular sleep disruption (Bourke-Taylor et al., 2013). Other consequences of sleep disturbance included reduced marital satisfaction (Cottrell and Khan, 2005), emotional distress (Klassen et al., 2012), stress and anxiety (Matthews et al., 2014, Yilmaz et al., 2008).

6) Other

There were 44 studies on "other" care-recipient conditions with some studies investigating multiple care-recipient conditions. Number of studies related to these conditions are below.

These included: mental disorder (1), heart failure (1), elderly (5), disability (2), spinal cord injury (5), renal disease (3), chronic pulmonary disease (1), stroke (3), palliative (5), intensive care unit survivors (3), Prader-Willi Syndrome (1) hematopoietic stem cell transplant (1), multiple sclerosis (1), osteoporosis (1) neurologic condition (1), ventilator dependent (1), sickle cell anaemia (1), cardiovascular disease (1), neuromuscular disorders (1), brain injury (1), neurosurgical patients (1), diabetes (1), cerebral infarction (1), cerebral haemorrhage (1) and undefined care-recipient conditions (4).

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Further details on these care-recipient conditions and the sleep- related issues researched can be found in the annotated bibliography (see Appendix 1).

DISCUSSION

The review of existing literature has consistently demonstrated a relationship between the demands placed on carers and negative outcomes on sleep and, where measured, on general health and well-being. Overall, the review has highlighted the need to consider a range of recommendations to address these impacts on sleep and avenues to address the remaining knowledge gaps.

Relevant Deliverable
B) *(dot point 4) The role of replacement care (paid or informal) and how it could be most effectively provided*

An obvious potential intervention to address negative impacts on sleep is to provide for replacement care to enable respite and recovery for carers. Intuitively, the role of replacement care in supporting sleep of carers is common sense. Sleep research in laboratory and field settings has demonstrated that 'recovery' sleeps after periods of complete sleep loss or repeated nights of insufficient sleep are associated with reduced sleepiness and improved performance (Jay et al., 2007, Belenky et al., 2003). Recovery sleeps are generally defined (or designed) as longer sleeps at the end of a period of consecutive nights of disrupted or restricted sleep. Much of our understanding about the benefit of recovery sleep is drawn from laboratory studies of human sleep, or from occupational settings – both contexts differ markedly from the experience of carers but can provide a base for assessing options.

A seminal study restricted the sleep opportunity of participants in the laboratory for seven nights to either 3, 5, 7 or 9 hours time in bed (Belenky et al., 2003). Performance declined in a dose-dependent manner across the week such that less sleep was associated with poorer performance and more negative mood. Following the sleep restriction period, participants were provided three consecutive nights of 8 hours time in bed. Performance measures improved following the recovery nights (albeit not to baseline levels). A subsequent study, also in the laboratory demonstrated that a week of extended sleep prior to a period of sleep restriction provided some 'protection' against the effects of sleep deprivation (Rupp et al., 2010). A more

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recent study similarly reports performance improvements with recovery sleep but notes that the same benefits are not seen for physical health and well-being as for cognitive function (Depner et al., 2019). This suggests that recovery sleep (facilitated by replacement care) may be part of the answer but other strategies for coping and ongoing support are also necessary.

A naturalistic study of commercial vehicle drivers examined the impact of forced breaks from the weekly driving activity on performance (Van Dongen et al., 2011). Drivers had 'restart breaks' as part of their schedule which involved either one or two consecutive nights without driving. The restart breaks were associated with higher total sleep time and better performance during the following drive. These studies and others clearly demonstrate the value in scheduling 'recovery' sleep opportunities. However, laboratory designs, and studies in occupational environments where work is scheduled, are very different to the complex situation faced by carers.

Changes to carers' sleep based on respite or replacement care was the focus of very few studies identified in this review. In two separate studies investigating sleep outcomes for parental carers of young children, impacts of replacement care or overnight nursing were positive. Specifically, one study found that carers of ventilator-assisted children with less night time nursing coverage had significantly shorter sleep onset latency (an indicator of increased sleepiness) than caregivers with night nursing (Meltzer and Booster, 2016). A comparison of their sleep found a one-hour difference in total sleep time; sleep with no nursing help totalled 5.9 h compared to sleep time with nursing help of 6.8 h. Similarly, positive outcomes were reported, (albeit no direct sleep measures) in a study which found that when medical technology-dependent children had short-term care away from home, the families caring for them cited getting a good night's sleep as a major benefit (Heaton et al., 2005).

In one study, researchers aimed to investigate the relationship between sleep duration and cortisol in carers on days that care recipients remained in the home, and days that care recipients went to an Adult Day Service (ADS) (Leggett et al., 2016). The naturalistic design allowed a comparison of sleep on ADS days and non-ADS days. Sleep was shorter and carers woke earlier on ADS days than non-ADS days, presumably due to the need to get organised for the ADS day although this was not specified (Leggett et al., 2016). While a break from providing care was found to be beneficial for physiological markers of stress, the authors make no comment on the impacts on sleep, other than to suggest sleep hygiene programs may be beneficial for both carer and care recipient (Leggett et al., 2016). Another study reported minor

improvements in the sleep of individuals with dementia associated with days at ADS (Zarit et al., 2011). It is difficult to know whether improvement in the care recipient's sleep correlates with carer sleep improvement. For example, some carer groups report being more anxious when there is less disruption, and in some patient groups there is ongoing vigilance/monitoring even if the patient is sleeping well (Monaghan et al., 2012). Therefore, there are likely to be differences between conditions and carer type (spouse, parent, bed sharing arrangements) in terms of the impact on carer's sleep quality.

A retrospective investigation of carer experience compared a group of carers who were caring for a family member at home and a group of carers who no longer cared for a family member as they had been moved into a nursing home. Carers no longer caring for their family member reported improved sleep following the move (Lee et al., 1997) but there were other negative outcomes such as changed relationships. Using a similar design, one study used the General Health Questionnaire to examine changes in carers over time following the care recipient moving to a home or facility (or not) (Matsuda et al., 1997). The anxiety-insomnia scores did reduce over time following the move. It is difficult to draw definitive conclusions from these studies given the small sample and specifics of the settings. In addition, given the different caring contexts (relationship, health status etc), costs and benefits will vary significantly between carers.

Finally, there may be factors associated with respite or replacement care that need to be further investigated so that the burden and worry associated with 'handing over' does not override any potential benefit of the respite care itself. For example, in a study of mothers caring for their child with type 1 diabetes, it was reported that carers worried about how others would manage the care of their child (Sullivan-Bolyai et al., 2003) and another study reported the need for respite care to be 'tailored' in order for it to be beneficial (Kayadjanian et al., 2018).

While there is currently insufficient evidence in the literature to derive definitive recommendations for replacement care to improve sleep, benefits of replacement care are likely in situations where: the care recipient sleeps well during the night of replacement care; the carer can handover care without associated feelings of worry or guilt that then impact their sleep; the carer is able to use the time of replacement care for sleep, or for activities that support good sleep health (e.g., self-care, physical activity, completing tasks that are otherwise taking time away from sleep). Situations in which replacement care may NOT be beneficial may

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include: replacement care that masks systemic issues that impact the carer's sleep which are thus not dealt with appropriately; replacement care that increases feelings of worry or guilt; carers not being provided with replacement care on which they can rely.

Recommendation 1: Models of replacement care need to be designed, developed and trialled in consultation with carers. Where models of replacement care are currently in use, evaluations of outcomes for carers should be conducted.

Relevant Deliverable
C) The economic costs of sleep loss arising from caring

The economic costs related to caring include actual health care costs for the care recipient and lost productivity on the part of the carer (absenteeism, presenteeism, or carer not being able to engage in work). Knowledge about the economic costs of sleep loss associated with caring responsibilities is lacking, and no Australian-specific information exists. According to a recent parliamentary inquiry submission into Sleep Health Awareness in Australia (Carer's Australia, #113) the estimated "replacement cost of unpaid family and friend carers is over $60 billion". It is reasonable to infer from the existing data that the costs are substantial, but presently unknown.

In the absence of carer specific literature, we are limited to literature and economic estimates from existing and recent studies on sleep loss more broadly, which may not take into consideration the specific and unique needs of carers. Deloittes Access Economics estimated the total cost of inadequate sleep in Australia to be $66.3 billion a year – or $8968 per person affected (Sleep Health Foundation, 2017). Given there are 2.7 million carers and 49% report experiencing sleep disruption, the costs of **inadequate sleep in carers** could be as high as $12.15[1] billion per annum in Australia. This statistic should be interpreted with caution, as it does not take into consideration the potentially unique circumstances of carers in Australia, and (for example) the specific costs related to respite and other services which may be required to support sleep in this cohort.

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[1] Based on the cost of inadequate sleep at $8968 per person (Sleep Health Foundation, 2017) multiplied by approximately 1.35 million persons (representing the 49% of the 2.7 millions carers reporting disturbed sleep)

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Recommendation 2: While the recent Deloittes' estimate relating to the cost of inadequate sleep per person per annum is substantial, it is not possible to discern the degree to which this estimate is relevant to carers. For example, sleep deprivation as a cause of excessive daytime sleepiness in the Deloittes' estimate is comprised of 'behavioural, circadian rhythm sleep disorders, altered sleep phase, and jet lag'. How carers perceive, and report, their sleep and contributors to inadequate sleep, may be specific to their circumstances. Consequently, more specific estimates of the costs of sleep loss associated with caring responsibilities in this unique group of workers are urgently needed in Australia to meaningfully establish the economic impact beyond broader sleep loss estimations. Specifically, these estimates need to consider unique factors (and combinations of factors) including replacement costs to facilitate sufficient sleep, actual health care costs for the care recipient, lost productivity, and the relative costs associated with (for example) maintaining paid employment whilst also maintaining a caring role which compromises sleep. The potential safety costs of insufficient sleep in terms of carer error in their caring arrangement and on the road should also be considered relative to the unique environment of this workforce to fully appreciate the impact of sleep loss for safety and wellbeing.

Relevant Deliverable
D) The known extent of increased accidents among carers due to their sleep disruption and if possible any valid estimates of the national cost

It is known that inadequate sleep (in the form of sleep deprivation or disturbed sleep) negatively impacts cognitive and physical abilities and not surprisingly impacts for performance and safety (e.g. errors) have the potential to be significant (Rajaratnam and Arendt, 2001, Lombardi et al., 2010, Reynolds and Banks, 2010, Hillman and Lack, 2013). The Bedtime Reading Report (2019) also acknowledges these known impacts of sleep deprivation and, with direct relevance to carers, specifically notes the determinantal impact sleep deprivation can have on patient care (p55). No direct evidence was found as part of this review quantifying the increased risk of accidents and other health and safety outcomes posed by the negative sleep outcomes for carers. In one study however, parental carers of children with cancer reported that sleep disturbances impaired their daily activities (e.g., dangerous driving) (Klassen et al., 2012). Given the consistent findings of sub-optimal sleep across carer groups, the lack of evidence in the research should not be taken as the absence of a problem. Further, given the findings in relation

to consistently poor sleep and daily total sleep times well below recommended amounts, it is likely that carers carry a significant burden of sleep debt day-to-day and accordingly are at considerably heightened risk of adverse safety and health outcomes as a consequence of their role as carers.

The negative sleep outcomes reported across the studies in this review would place the average carer within high risk zones for occupational accidents and adverse health outcomes (Thomas and Ferguson, 2010, Folkard and Tucker, 2003, Nachreiner et al., 2000). Accordingly, given the increased known risk associated with the forms of sub-optimal sleep outcomes across all types of carers, there is a need to develop risk mitigation strategies that both decrease the degree of sub-optimal sleep outcomes and also reduce the likelihood of accident and negative health outcomes.

Recommendation 3: Increasing the awareness of carers of their heightened levels of risk due to sleep disruption across all daily tasks is a critical area for intervention. Such awareness should focus on strategies to improve the overall amount of sleep obtained day-to-day, as well as increasing understanding of the impact of sleep restriction on performance, especially in day-to-day high-risk activities such as driving. Such awareness programs should focus on practical strategies to reduce risk by: 1) improving sleep outcomes; and 2) strategic risk reduction strategies in day-to-day tasks.

Relevant Deliverable
E) Recommendations that could be implemented at the government, community, family/friend and carer level to reduce sleep disruption

Recommendations to reduce sleep disruption in carers at the government, community, family/friend and/or carer level must begin with the knowledge that inadequate sleep in any population is a significant health and safety concern. Existing evidence indicates that for family or informal carers in Australia, disturbed and/or inadequate sleep is common. Inadequate sleep is reported by caregivers for individuals with a diverse range of chronic conditions – it seems that poor sleep is often intrinsic in caring roles. This has implications for both the carers and care recipients in terms of health, well-being and safety.

A critical first step in any of the following recommendations is education that explicitly informs decision makers, at each of these levels of:

a) the importance of regular, adequate sleep for human health and well-being, and

b) the evidence surrounding the unique and often prolonged/chronic challenges that family or informal caregivers in Australia face in terms of sleep.

Recommendation 4: At the Government level, sleep knowledge, education and training should be accessible at community, family/friend and carer level. The role the government can play in this initiative could be in terms of funding and advocacy of these initiatives and resources for execution and coordination, which would likely happen at a local government or community level. As discussed (p.26 replacement care discussion), one of the most obvious initiatives through which sleep reduction can be minimised in carers, at least acutely, is the provision of overnight respite care. The benefits of regular, adequate sleep for health, and performance are well known and moreover will afford benefits not only to carers but also to care recipients. At the Government level, support of this recommendation may be through **carer specific funding** as opposed to being folded into the care recipient's NDIS funds.

For appropriate funding and subsidies to be implemented, governments need to understand the challenges faced by carers in terms of sleep, including an understanding that the impacts are both acute and chronic. The Federal Government's parliamentary inquiry into Sleep Health Awareness in Australia (2018-2019) and the economic and social consequences of sleep loss demonstrate that the federal government has an awareness of this as a national issue. The submission by Carers Australia as part of this parliamentary inquiry was an important step in ensuring that the specific challenges for carers in Australia are known and should be treated as co-occurring but distinct from challenges (and subsequent supports needed) faced by care recipients.

Recommendation 5: Funded or subsidised by the government, recommendations at the community level relate to having 'on-the-ground' support persons. For example individuals, perhaps those already engaged with the caregiving systems e.g., NDIS, Child and Youth Health or similar that have;

- up-to-date sleep knowledge about the benefits of sleep <u>however it comes</u> – as a nap, a single full night's sleep amongst many poorer nights, split sleep schedules etc;

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- practical tips outlining ways sleep can be improved;

- screening tools to help detect undiagnosed sleep disorders;

- knowledge of what services (e.g., respite care) are available to carers and their families

- tips to make best use of respite care and other services in terms of sleep;

- assistance with day-to-day practicalities of running a household and caregiving with a view to providing breaks for primary caregivers for rest.

Recommendation 6: With a focus on recommendations to reduce sleep loss, the first steps with family and friends is education, previously discussed. The role family and friends could play in supporting the primary caregivers relates to both overnight 'coverage' of night-time caregiving but also reduction in the worry, rumination and stress that is reported by carers, all of which are known to negatively impact sleep. For example, having family members take turns to be 'on-call' over-night, or for a portion of the night, to give the primary caregiver some protected sleep is one way family and friends can help. If the caregiving needs are complicated or the primary caregiver finds it difficult to relinquish their role even for a short period, taking it in turns to be 'on-call' for the primary caregiver (who is on-call essentially to the care recipient), to pick up any non-caring duties to ease both the mental and physical load is another way family and friends can assist.

Recommendation 7: One of the main ways that carers can help themselves in terms of sleep is to adopt good 'sleep hygiene'. The term sleep hygiene describes a series of known behaviours and environmental factors that facilitate sleep (Yang et al., 2010). Sleep hygiene incorporates factors such as regularity of sleep timing/ patterns, use of stimulants (e.g., caffeine, nicotine), sleeping environment (e.g., light, temperature, noise), bedtime activities or routine, diet and exercise (Yang et al., 2010). As a set of sleep promoting behaviours they are simple and easy to adhere to and importantly for carers, they are usually within their individual control. Therefore, while the needs of the care recipient and the way this impacts sleep opportunity is often beyond the carer's control there are simple ways for carers to optimise or improve the sleep that they do get.

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Relevant Deliverable
G) Other issues as informed by the literature

Use of sleep medications

Despite the volume of research, very few studies report whether carers are seeking pharmaceutical treatment for their inadequate sleep and/or sleep disturbance (hypnotics etc). Further, of the research that does address use of sleep medications specifically (albeit not as a main focus), findings are mixed. For example, two studies (Gibbins et al., 2009, Cupidi et al., 2012) reported that use of sleep medications was low among the carers investigated (e.g., 10%). In contrast, other research discusses how some of the carers were regularly using sleep medications (Merrilees et al., 2014, Koyama et al., 2017). For example, 54% of female carers were taking sleeping medication and 41% were doing so > 3 times a week (Merrilees et al., 2014). Findings such as these, however rare, need careful consideration given not only the adverse consequences of regular use of sleeping medications but also what usage might mean in terms of provision of overnight care. In line with this, one study found that while carers were prescribed medications, some did not use them specifically because of how it might impair the care they gave overnight (Carter, 2006).

Recommendation 8: Future research should consider capture of information around sleep medication usage (or indeed medication that may interact with sleep) in carers (e.g., as a stand-alone question or part of other questionnaires – e.g., it is asked specifically in the PSQI). Specifically, whether these have been prescribed, whether they use them (and with what sort of regularity) and if they think this may impair their ability to do their carer and other activities effectively and safely.

Interventions, strategies to improve sleep in carers

In general, carers have not been the focus of intervention studies and where they have been, the vast majority are not sleep-based interventions or with a primary aim of improving sleep. To date, intervention studies involving carers are aimed at broadly addressing stress, well-being, health and/or 'needs' e.g., (Acton and Carter, 2006, Akkerman and Ostwald, 2004, Jain et al., 2014, Mackereth et al., 2005, Rose et al., 2009). Only two studies from the initial PubMed search were identified as assessing an intervention related specifically to sleep (Carter, 2006, Simpson and Carter, 2010), with a further two identified from the reference lists of relevant

studies (McCurry et al., 1996, McCurry et al., 1998). The focus of all four studies was assessment of brief (5-6 week) behavioural interventions for sleep of carers.

Two studies assessed the efficacy of a brief (6 week) behavioural sleep intervention program (McCurry et al., 1996, McCurry et al., 1998). The intervention comprised weekly sessions for 6 weeks covering topics including sleep hygiene, stimulus control, sleep compression, and relaxation techniques. In a pilot study (n = 4 caregivers) of this program, sleep outcomes, namely sleep duration, sleep efficiency, sleep latency and wake after sleep onset all improved with the program and improvements were generally maintained at 3-month post follow up. In a follow-up study (McCurry et al., 1998), sleep outcomes were measured using the PSQI and were found to significantly increase (indicating improvements to sleep quality) immediately following intervention and 3 months post (compared to baseline). Self-reported sleep efficiency also showed improvement during the intervention period. This work, provides small albeit promising results for a sleep specific intervention in caregivers.

Two other studies investigated the efficacy of the Caregiver Sleep Intervention (CASI) behavioural sleep program to primary carers of individuals with cancer and dementia (Carter, 2006, Simpson and Carter, 2010). The CASI program was 5 weeks and had components related to stimulus control, relaxation, cognitive therapy, sleep hygiene and goal-setting in relation to the care components. In addition to self-reported sleep outcomes, based on responses to the widely used PSQI questionnaire, actigraphs were also used in both studies to quantify sleep latency, duration and efficiency objectively at 3 follow-up periods. Baseline PSQI scores prior to intervention were 9.9 and 9.3 for the intervention and control groups respectively – indicating poor sleep in both groups. At 4 months post intervention the intervention group saw improvement to PSQI score with a reduction to 5.4 (compared to the control group 10.3). In terms of objective data, differences between groups were only detected in terms of sleep onset latency, where at week 5 of the intervention, the intervention group had a sleep onset latency of 14 mins (compared to 24 min in the control group). PSQI scores also improved following the intervention (7.0) compared to pre-intervention (10.4). Importantly, the CASI Intervention was delivered with appreciation of the caregiving burden – i.e. at the convenience of the caregiver and in the 2010 study caregivers reported that the program was no additional burden. Further, the intervention was tailored for the carer context, that is, the CASI was developed and content/education delivered specifically with the burden of caregiving in mind.

Recommendation 9: While very few intervention studies have focused specifically on improving carers' sleep, results are promising. In line with this existing research, future interventions should focus not on changing aspects of the care recipients' sleep, condition or disease, but rather maximising the quality of sleep that carers are able to obtain.

Assistive Technologies and Sleep

A definition of assistive technologies, used in the dementia care context, are technologies that '*increase, maintain or improve capabilities of individuals with cognitive, physical or communication disabilities*' (Marshall, 2000), and while there are categories of assistive technologies that are specifically carer 'centric' the majority are designed for benefit to the care recipient. However, given the known burden of caring for an individual with a chronic disease or illness and the burden these carers remove from public health services, it makes practical and ethical sense to protect the health and well-being of carers. Therefore, any assessment of the efficacy of assistive technologies should include the impact they have (positive or negative) for the carer as well. Examples of this approach with regards to sleep are detailed below.

One study assessed the impact of diabetes-related technology on broad aspects of daily living, frequency and severity of hypoglycemia, and diabetes-related distress – importantly this impact was evaluated by both care recipients and carers (Barnard et al., 2016). More than 80% of both carers and care recipients reported that the technologies made it easier to manage diabetes related symptoms. In terms of negatives, carers reported sleep disturbance associated with alarms as well as more negative emotions and diabetes related distress (e.g., fear of hypoglycaemia). The study highlights not only the pros and cons of the technology but how the impact of the condition (e.g., diabetes) itself is different for carer and care recipient – the perceived benefits of any technology are also likely to be different.

In the dementia context, no significant differences were found between two groups of carers, one that used a night-time monitoring device for the care-recipient and a control group who did not use the device (Rowe et al., 2010). Qualitatively however, reports from semi-structured interviews were much more positive in terms of helpful impacts, albeit not directly related to sleep (Spring et al., 2009). The assistive technology included reliable alerts to inform the carer of the whereabouts of the care recipient – this gave them 'peace of mind' and importantly some needed personal space while still being vigilant to care recipient location. As with the diabetes

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example, above, the alarms during the night were also noted as a negative to the in-home night-time monitoring system.

Assistive technologies associated with Alzheimer's disease and other Dementias have been the focus of recent reviews (Ienca et al., 2017, Livingston et al., 2017) while specific to these disease states, findings could broadly be applied to many other caring contexts. A main message from these reviews is that assistive technologies are a rapidly growing area comprising a number of different categories of technology, for example, diagnosis, monitoring, therapeutic and while most are not focused on carer well-being directly, technologies that monitor symptoms, or assist the care recipient with daily tasks may, in turn, reduce the burden for carers. There were also carer-specific technologies identified, although again these are not solely focused on sleep and minimising sleep disturbance but, rather, broadly focused on 'caring for carers' through education and support.

Recommendation 10: Assistive technologies are a rapidly growing area and while few are focused specifically on carer health and wellbeing, they have the potential to do so indirectly. In terms of education and support technologies inclusion of sleep considerations, such as sleep education could reasonably be made a part of such programs/technical supports for carers.

Relevant Deliverable
F) Sleep and carer: important areas for future research

The current literature is diverse and covers a broad range of caregiver contexts. Importantly, the peer reviewed literature paints an unequivocal picture in terms of caregiving and poor sleep. When measured, negative consequences to sleep (quantity and quality) are consistently reported amongst carers. While this is the take-home message from the literature, there are limitations to our current understanding of carers' sleep which should guide the direction of future research and inquiry.

In brief, recommendations regarding the direction of future research, in light of these gaps and limitations are;

- consistent use of the same, validated sleep questionnaires across research studies to enable collation of small data sets for more meaningful analyses;

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- use of sleep measures that are multi- rather than one-dimensional to assess the different elements of sleep disruption and facilitate nuanced interventions or strategies;

- data collection that captures changes to sleep over time to identify similarities associated with demographics of carers or predictable changes for sleep as illnesses progress in care recipients;

- deliberate inquiry into the reasons for sleep disturbance (including break-down of terms such as 'worry', 'rumination' and 'stress') with the aim of developing individual, family or system-level positive coping strategies and evaluating their effectiveness;

- expansion of current data to include information about lesser-known or underrepresented (in the literature) carer groups or scenarios to ensure all groups benefit from evidence-based decisions.

These suggested guidelines for future research have been expanded below.

Recommendation 11: Consistent use of validated sleep questionnaires across research studies

The current literature would benefit from future research that consistently used the same, well-validated measures to capture sleep (e.g., Pittsburgh-Sleep Quality Index (PSQI) and General Sleep Disturbance Scale (GSDS)). Streamlining the measures used would also allow meaningful comparison between different caregiving groups or the same groups across time (pre and post intervention for example) and other populations. An advantage of the PSQI and GSDS in particular, (and others) is the known cut-off scores to indicate clinically significant sleep disturbance.

Notwithstanding the benefits of self-report measures (efficient in terms of time and cost, participant burden), objective measures, for example actigraphy or polysomnography (see p.10 for a description of these) can add multiple dimensions to sleep measurement (the benefits of which are discussed below) which provide valuable detail and context to sleep in certain scenarios that subjective measures cannot. Importantly, objective data is free from response bias. Given, however, the time and cost involved in collection and analysis of objective sleep data, future research studies should employ objective measures once subjective data (interviews, focus groups, questionnaires) have already provided context and guided more specific research questions. Actigraphy is relatively cost-effective option under these circumstances.

Recommendation 12: Multi-dimensional measures of sleep

A limitation if the current literature base is the use of what we have termed, 'one-dimensional' sleep measures. Examples of one-dimensional measures include;

- sleep quality ratings (1=poor - 5=excellent)

- frequency of sleep interruption (1=never-5=every night)

- being able to get a good night sleep would make life better for caregiver (Yes/No)

This type of questioning is limited because the current literature (peer reviewed and grey), and particularly anecdotal reports, infer that sleep disturbance in the caregiving context is multi-dimensional. For example, there are aspects of the role that impact overnight sleep opportunity such as administering medications, turning, assistance with toileting, routine monitoring and observations, tending to alarms on technical assistance devices. There is also the known rumination, worry and stress either directly or indirectly related to the caregiving role which are likely to impact the quality of any sleep obtained. Addressing each aspect would require a different approach.

In terms of advocating for caregivers, understanding the depth of the sleep challenges they face and determining what sort of support is required (or is most pertinent) requires an understanding of the specific aspects of sleep that are being impacted. To address this, future research should consider measures of sleep that are multi-dimensional such as the PSQI (Buysse et al., 1988) or GSDS (Lee, 1992b) which break down dimensions of sleep into quantity, timing, nature of interruptions, napping and even impact/consequences. This additional information will allow identification of the aspects of sleep most greatly impacted which will contribute to a better understanding of the depth/significance of the problem and potential ways to address it. Inclusion of objective measures of sleep (which by nature capture multiple aspects of sleep), for example, at the very least timing, and simultaneous capture of quantity and multiple quality metrics will also facilitate a more in-depth understanding.

A dimension of sleep that is particularly lacking in the current literature is sleep timing (bedtime, get up time, timing and duration of day sleeps). Interestingly this information is captured as part of numerous questionnaires, including the PSQI, and all objective data, but it is rarely reported as individual outcomes. Future research should consider capture and analysis

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(or even retrospective analysis if possible)) of this information particularly as a way to inform whether current sleep/activity patterns differ between or for certain carers, whether current sleep timing strategies are helpful and where improvements (if any) can be made.

Another dimension of sleep that is lacking in the current literature is the application of sleep hygiene principles (refer to section above). There are many aspects to caregiving that are out of the carer's direct control, making it even more crucial for carers to 'control the controllable' and optimise the sleep opportunities they do have. In order to do this, there needs to be data collected about both sleep hygiene knowledge and practices. Asking individuals directly about their sleep habits or getting them to describe their sleep routines (e.g. bedroom set up, alcohol, caffeine use etc) would provide valuable insight into their sleep hygiene practices as would the use of a validated questionnaire such as The Sleep Hygeine Index (Mastin et al., 2006). This information would add value to future research and education agendas as it can then inform the development of tailored intervention and/or education programs for carers. Importantly this information can be collected simultaneously with other sleep related outcomes.

Recommendation 13: Diversification from cross-sectional study designs

The majority of the studies reviewed as part of this report are cross-sectional. Cross-sectional study designs are a particularly valuable starting point in a research agenda, when determining the existence and estimated prevalence of a problem such as sleep disturbance or deprivation, and capturing data from a large number of people in a time- and resource-efficient manner (e.g., a one-off questionnaire or survey). What cross sectional studies do not capture however are changes to sleep outcomes over time. The next steps therefore, could be to employ longitudinal study designs to capture changes to sleep as disease state or condition of the care recipient progresses.

We know that significant changes occur in sleep over time in the caregiving role. For example, one study found that one third of their sample (n=60) reported a negative change to sleep in the past year (Creese et al., 2008). More longitudinal studies in this context would provide a greater understanding of how carers' sleep may change across the time course or particular phases of the care recipient's condition. Information about changes to sleep over time could be used to manage expectations of carers with regards to their sleep at certain times or to identify times where increased or different support is reasonably required. In addition, longitudinal data are required to determine whether there are relationships between the extent of sleep disturbance

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and the likelihood of carers relinquishing their caring role (or wishing to do so) and/or the development of other mental and physical health issues.

Diversification of study design beyond cross-sectional data is also required if efficacious interventions for sleep are to be designed, tested and implemented. As noted previously (respite care p.26), there are clear benefits to overnight respite care – where carers' sleep is, in essence, protected for a night/s while someone else takes on caregiving duties. There is evidence in the broader sleep literature that supports this (namely 'recovery sleep' literature) as well as practical and anecdotal evidence. There is relatively little in caregiving settings. Therefore, future research to investigate and quantify the benefits of respite and replacement care would be worthwhile, including measurement of the abovementioned issues (worry, guilt and logistical issues) that may negate some of the benefit of respite care for sleep.

While summary of general (i.e. not sleep-related) intervention studies was beyond the scope of this report, studies have specifically investigated the impact of interventions such as mindfulness, stress management, exercise and health promotion (Akkerman and Ostwald, 2004, Borek et al., 2018, Cullen and Barlow, 2004, King et al., 2002, Paller et al., 2015, Secker and Brown, 2005) which may all have positive benefits for sleep as well as other mental and physical health outcomes. Very few studies have systematically investigated sleep interventions for carers (Carter, 2006, Simpson and Carter, 2010, McCurry et al., 1996, McCurry et al., 1998) (discussed further, below) and this should be a focus of future research.

Recommendation 14: Research inquiry into the reasons for sleep disturbance (including break-down of terms such as 'worry', 'rumination' and 'stress') and its consequences
While the presence of sleep loss and/or sleep disturbance is clear from the current literature, the specific reasons for sleep disruption and consequences of the disruption are less frequently reported. As a result, the reasons for, and consequences of, sleep disturbance have to be inferred from what is known about care recipient needs and the more general sleep literature, running the risk of important factors being missed. While some causes of sleep disruption are highly visible (e.g., turning the care recipient, help with toileting, administering medications overnight), general worries or stress or impacts on other aspects of carers' lives are less obvious. Further, future research needs to capture not only sleep outcome metrics and associated reasons for sleep disturbance, but also data on its consequences (e.g., daytime

sleepiness, inattention, mood disturbance, impaired decision making) to meaningfully establish the causal relationship between poor sleep, health and performance in persons providing care.

Recommendation 15: Expansion of current data to include information about lesser-known or underrepresented (in the literature) carer groups or scenarios

The impact of the caregiving scenario on sleep and other outcomes is complex and may vary depending on how long someone has been a caregiver, the needs of care recipient, relationship to the care recipient and health of the caregiver themselves. Targeted research that specifically aims to understand these differences for as many scenarios as possible is crucial to our understanding and assistance with the issues. For example, a large portion of the studies excluded carers with certain medical conditions that would adversely impact their health and/or sleep independent of their caregiving role. Not all carers are in good health however, with an estimated 30% of carers having a disability themselves (Australian Bureau of Statistics, 2015). Therefore, it would be valuable to understand if the demands of the role impact them differentially and to establish whether there are any synergistic impacts of poor sleep due to non-caring related factors, e.g., sleep-breathing disorder, medications, other health complications.

Another underrepresented group in the literature are younger carers. We know that 10% are under the age of 25 years (Australian Bureau of Statistics, 2015), yet as shown in Table 1, the average age of the carer cohorts studied across all care recipient conditions was typically in the range of 55-70 years - the studies on children were an exception, where carers were generally younger (30-40 yrs), as to be expected. While some studies did break-down the carer demographics by, for example gender, kinship to care recipient and age, it was not common to report on study outcomes by the different age groups (or any of the other demographic characteristics). As such we do not have a clear picture of whether impacts in terms of sleep are different in younger carers compared to the overall picture that has been pained by the literature presented in this report. As outlined by sleep health organisations worldwide (including Sleep Health Foundation and the National Sleep Foundation, sleep need (the average amount of sleep required per 24h) varies across the lifespan and the minimum sleep recommended for adolescents is 8-10h - at least an hour more than that recommended for adults (>18) and possibly an hour more again compared to adults >65 years. While carers under the age of 18 are in the minority, given their age (and sleep need) the impacts of sleep and the subsequent impacts on health and well-being have the potential to extend for many years.

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Future research should therefore look to reporting on the data of younger carers, even if they do represent a minority, so any sleep issues unique to this younger cohort can be identified.

CONCLUSION

The systematic review of literature investigating carers' sleep disturbance clearly demonstrates that, despite considerable variability in care giving scenarios, carers report poor and/or disturbed sleep. Importantly, this finding was consistent across a variety of contexts and carers caring for individuals with a range of disease/conditions. While limited objective data were collected, available results show that carers regularly obtain less (often by more than an hour) than the recommended 7h of sleep per night. Objective quality indicators also suggest poor/er sleep than is the ideal.

Despite the large variability in caring contexts, the general finding of poor sleep can be broadly applied across this unique workforce, but with the knowledge that the findings are weighted towards the most common (most studied) carer contexts and those carers with the most prevalent demographic groups. For example, a majority of data comes from carers who are female, the spouse of the care recipient, age >60 years and providing care for an individual with cancer, dementia (including Alzheimer's disease) or Parkinson's disease. While these data may in fact be representative, there is dire need to expanded our knowledge, particularly for the smaller groups and the less common scenarios – e.g. younger carers, or carers who are not a spouse, or who do not live with care recipient. We know much less about the impacts of sleep for these people and therefore our ability to provide valuable, targeted interventions and assistance is limited also.

Our recommendations, detailed from page 32, highlight the importance of respite care but the current lack of knowledge regarding how best to use this care and its limited availability; the lack of carer specific knowledge in being able to estimate economic costs associated with carer sleep loss and associated accidents as well as ideas for practical interventions and strategies at the government, community, family/friend and carer level to improve carers' sleep. These are independent of current initiatives which are typically focused on the care recipient. Overall because this unique and invaluable workforce is understudied in terms of sleep, research that focuses specifically on sleep disruption and its consequences for carers is a critical first step in improving not only carer sleep health but also their general health and wellbeing.

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APPENDIX 1 – ANNOTATED BIBLIOGRAPHY

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Cancer										
Aouizerat et al. (2009) (1)	1	Longitudinal	USA	- N=85 (28%) family carers	- 63 ± 11	- General Sleep Disturbance Scale	N	- General Sleep Disturbance 37.0 ± 14.7.	1. -	-
Al-Daken and Ahmad (2018) (2)	2	Cross-sectional	Jordan	- N=111 (73%) family carers	- 36 ± 11 [18-67]	- PSQI	N	- Global PSQI 9.1 ± 4.3. - Clinically significant scores 85.6%.	2. -	Poor quality of sleep strongly positively correlated with carer burden.
Aslan et al. (2009) (3)	2	Cross-sectional	Turkey	- N=90 (53%) carers	- 41 ± 11 [15-70]	- PSQI	N	- 72% Global PSQI >5. - Global PSQI 8.2 ± 0.4. - Sleep quality 1.4 ± 0.8. - Sleep latency 1.6 ± 1.1. - Habitual Sleep Efficiency 0.9 ± 1.2. - Sleep disturbances 1.4 ± 0.7. - Use of sleeping medication 0.0 ±0.3. - Daytime dysfunction 1.7 ± 1.2.	Cancer related - 83% emotional distress. - 37% financial problems. - 34% inadequate support system. - 27% anxiety from exposure to adverse effect of the therapy on patient. Non cancer related - 34% fatigue. - 22% familial issues. - 20% illness. - 14% daily events. - 8% job stress. 3. 6% poor sleep routine.	-
Carney et al. (2011) (4)	2	Cross-sectional	USA	- N=102 (71%) patient/carer dyads	- 62 ± 10	- PSQI - General Sleep Disturbance Scale - Actigraphy	Y	Subjective - Clinically significant PSQI score 45%. - Clinically significant General Sleep Disturbance Scale score 40%. - Clinically significant total sleep time amount 50%. Objective - Sleep onset latency 13.1 ± 10.7. - Wake after sleep onset 12.5 ± 10.0. - Number of awakenings 17.6 ± 9.5. - Awake duration 3.4 ±2.2. - Total sleep time 408.5 ± 78.7. - Time in bed 485.9 ± 78.5. - Sleep efficiency 84.2 ± 10.9.	-	-
Carter (2006) (5)	2	Intervention	USA	- N=30 (63%) total carers - N=15 (60%) intervention - N=15 (66%) control	- 53 ± 17 [21-85] - 52 ± 16 [21-84] - 55 ± 18 [23-85]	- PSQI - Actigraphy	Y	*Baseline data* Subjective - Global PSQI 9.9 ± 4.6 intervention *vs* 9.3 ± 5.5 control. - Sleep onset latency 27.0 ± 36.0min intervention *vs* 26.0 ± 17.0min control. - Total sleep time 5.7 ± 1.8h intervention *vs* 6.0 ± 1.7h control. - Sleep efficiency 79.0 ± 13.7% intervention *vs* 76.0 ± 16.0 control. Objective	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- Sleep onset latency 12.4 ± 14.0min intervention *vs* 11.1 ± 9.0 control. - Total sleep time 6.4 ± 1.7h intervention *vs* 5.5 ± 2.1 control. - Sleep Efficiency 89.0 ± 8.0% intervention *vs* 84.0 ± 9.0min control. - Wake after sleep onset 30 ± 21 intervention *vs* 45.0 ± 28.0 control.		
Carter (2002) (6)	2	Cross-sectional	USA	- N=47 (87%) family carers	- 54 [26-75]	- PSQI - Interviews	N	- Global PSQI 11.4 ± 4.4 - Sleep quality 1.7 ± 0.8 - Sleep onset latency 1.6 ± 1.2 - Sleep duration 2.1 ± 1.0 - Sleep efficiency 1.3 ± 1.0 - Use of medications 0.9 ± 1.2 - Daytime dysfunction 1.5 ± 0.8	Care-recipients sleeping difficulties.	Carers linked their depressive symptoms to their perceived chronic sleep loss.
Carter (2003) (7)	2	Longitudinal	USA	- N=10 (80%) family carers	- 61 [39-81]	- PSQI - Actigraphy	Y	- Large fluctuations in sleep outcome and measures over time. - Subjective sleep latency 33 ± 29min week 1, 28 ± 19min week , 30 ± 25min week 10. - Objective sleep latency 42 ± 38min week 1, 45 ± 61min week 5, 40 ± 42min week 10. - Subjective sleep duration 6.0 ± 1.3h week 1, 6.2 ± 1.1h week 5, 6.3 ± 1.4h week 10. - Objective sleep duration 4.8 ± 1.6h week 1, 5.3 ± 1.4h week 5, 5.5 ± 1.2h week 10. - Subjective sleep efficiency 80 ± 11% week 1, 84 ± 16% week 5, 80 ± 16% week 10. - Objective sleep efficiency 73 ± 17% week 1, 80 ± 13% week 5, 76 ± 14% week 10.	-	-
Carter and Acton (2006) (8)	2	Cross-sectional	USA	- N=52 (80%) family carers	- 54 [26-75]	- PSQI	N	- Global PSQI 11.3. - Carers had moderate – severe sleep problems in 6/7 subscales on the PSQI (see Carter and Chang, 2000).	Carers who used less functional coping strategies reported more sleep difficulties.	Carers who reported more sleep problems also reported more depression.
Carter and Chang (2000) (9)	2	Cross-sectional	USA	- N=51 (50%) carers	- 54 ± 14 [26-75]	- PSQI	N	- 95% of carer reported severe overall sleep problems. - Total sleep time 11.3 ± 4.4. - Sleep quality 1.7 ± 0.8. - Sleep latency 1.6 ± 1.2. - Sleep duration 2.6 ± 1.0. - Habitual sleep efficiency 1.3 ± 1.0. - Sleep disturbance 2.4 ± 0.7. - Sleep medication 0.9 ± 1.2. - Daytime dysfunction 1.4 ± 0.8.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Chang et al. (2007) (10)	2	Cross-sectional	Taiwan	- N=51 (80%) carers	- 45 ± 11 [24-67]	- Chinese PSQI	N	- Compared PSQI scores between shared and non-shared caring responsibility groups. - 88% carers reported sleep problems. - Global PSQI 7.0 ± 2.8 for shared vs 8.4 ± 3.4 for non-shared. - Subjective sleep quality 1.2 ± 0.7 for shared vs 1.59 ± 0.7 for non-shared. - Sleep latency 1.2 ± 0.9 for shared vs 1.6 ± 1.0 for non-shared. - Sleep duration 1.3 ± 0.8 for shared vs 1.6 ± 0.9 for non-shared. - Habitual sleep efficiency 0.5 ± 0.9 for shared vs 0.5 ± 0.9 for non-shared. - Sleep disturbance 1.2 ± 0.6 for shared vs 1.5 ± 0.5 for non-shared. - Use of sleep medication 0.26 ± 0.79 for shared vs 0.1 ± 0.3 for non-shared. - Daytime dysfunction 1.4 ± 0.5 for shared vs 1.5 ± 0.5 for non-shared. -	-	Sleep problems were correlated with poor quality of life in the physical health, psychological, social relationship and environmental domains.
Cora et al. (2012) (11)	1	Cross-sectional	Italy	- N=20 (90%) carers - N=20 (90%) non-carers	50 ± 12 [25-70] carers 51 ± 12 [25-69] non-carers -	- Sleep questions as part of interview.	N	- Carers reported more sleep dysfunctions compared to controls.	-	-
Cuthbert et al. (2017) (12)	2	Cross-sectional	Canada	- N=130 (72%) family carers	- 70.09 ± 6.55 [60-84] males 70.29 ± 6.88 [60-86] females	- PSQI	N	- Global PSQI 6.9 ± 4.5.	-	-
Dhruva et al. (2012) (13)	2	Cross-sectional	USA	- N=103 (72%) family carers	- 61 ± 10 [94-86]	- Actigraphy - PSQI - General Sleep Disturbance Scale -	Y	- *Measures taken prior to care-recipients commencement of radiotherapy.* Objective - Sleep onset latency 13.0 ± 10.5min. - Percent wake 12.7 ± 10.1%. - Number of awakenings 17.6 ± 9.4. - Wake duration 3.4 ± 2.1. - Total sleep time 6.8 ± 1.3h. - Sleep period time 8.1 ± 1.3h. - Sleep efficiency 84.0 ± 10.9%. Subjective - Global PSQI 5.7 ± 3.2 - Sleep quality 0.9 ± 0.7 - Sleep latency 0.9 ± 0.9 - Sleep duration 0.9 ± 0.8 - Habitual sleep efficiency 0.6 ± 0.9 - Sleep disturbances 1.3 ± 0.5	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- Use of sleep medications 0.5 ± 0.9 - Daytime dysfunction 0.7 ± 0.6 - General Sleep Disturbance 39.1 ± 16.0 - Quality of sleep 2.6 ± 1.7 - Quantity of sleep 4.6 ± 1.3 - Sleep onset latency 1.5 ± 1.9 - Mid-sleep awakenings 4.1 ± 2.4 - Early awakening 2.3 ± 2.2 - Medications for sleep 0.2 ± 0.5 - Excessive daytime sleepiness 1.8 ± 1.2		
Flaskerud et al. (2000) (14)	2	Cross-sectional	USA	- N=117 (100%) total carers - N=36 AIDS - N=40 dementia - N=41% cancer	- 46 ± 17 [23-75] AIDS - 70 ± 6 [51-82] dementia - 52 ± 14 [26-74] cancer	- Interviews - PSQI	N	- Trouble falling asleep 61% in AIDS carers *vs* 60% in dementia carers *vs* 46% in cancer carers. - Restless sleep 75% in AIDS carers *vs* 44% in dementia carers *vs* 82% in cancer carers. - Trouble staying asleep 53% in AIDS carers *vs* 61% in dementia carers *vs* 76% in cancer carers.	Vigilance of patient getting up, wandering or being in pain in dementia and AIDS carers.	-
Fletcher et al. (2008) (15)	2	Cross-sectional	USA	- N=60 (100%) family carers	- 64 ± 9	- General Sleep Disturbance Scale	N	- *Sample was divided into high level and low level symptom groups. Symptoms were depression, anxiety, pain, sleep disturbance and fatigue.* - General Sleep Disturbance 39.9 ± 16.2 in total sample, 30.0 ± 7.9 in low symptom group *vs* 56.8 ± 12.1 in high symptom group.	-	Sleep disturbance severity was positively correlated with depression, trait and state anxiety and pain.
Frambes et al. (2017) (16)	1	Intervention	USA	- N=180 (43%) total carers - N=94 (43%) reflexology intervention - N=86 (43%) control	- 56 ± 15 reflexology - 53 ± 15 control	- Sleep disruption items on a physical health questionnaire. Larger values indicate better sleep quality, possible range 32-75.	N	- No significant differences between control and reflexology group on sleep disturbances. - Sleep disturbance at 5 weeks 45.0 ± 0.9 in reflexology group *vs* 45.7 ± 0.9 in control group. - Sleep disturbance at 11 weeks 44.0 ± 0.9 in the reflexology group *vs* 45.0 ± 0.9 in control group.	-	-
Gibbins et al. (2009) (17)	2	Cross-sectional	UK	- N=60 (45%) family carers	- 66 [27-80]	- Actigraphy - Standardized sleep history - Epworth Sleepiness Scale	Y	Objective - Sleep Efficiency >90%. - Time awake 8.3-9.4%. - Fragmentation and movement 35.4-41.4 min. Subjective - 42% of carers did not usually sleep well. - 42% had problems getting to sleep. - 10% take medications to help them sleep. - Epworth sleepiness scale 5.0 [0-13]	- 42% going to the toilet. - 28% disturbed by the patient. 26% worry.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Halliday et al. (2017) (18)	2	Cross-sectional	USA	- N=8 (100%) family carers -	- Not reported	- Interviews	N	Carers sleep was impacted by the patients Jejunostomy feeding tubes.	- Jejunostomy feeding tube impacted carers sleep in terms of noise (alarms).	-
Kotronoulas et al. (2016) (19)	2	Longitudinal	Scotland	- N=48 (83%) carers	- 55 ± 9 [38-74]	- PSQI - Sleep-wake assessments	N	*Baseline data* - PSQI 5.5 ± 3.5. - Perceived sleep quality 2.1 ± 1.6. - Daily disturbances 2.0 ± 1.1. - Sleep efficiency 81.9 ± 12.8%. - Sleep onset latency 50.5 ± 13.0. - Total sleep times 6.7 ± 1.4h. - Wake after sleep onset 68.6 ± 50.9. - Nocturnal awakenings 1.5 ± 0.9. Early morning awakenings 1.2 ± 1.3.	-	-
Lee et al. (2018) (20)	2	Longitudinal	Taiwan	- N=95 (68%) carers	- 50.9 ± 12.7	- PSQI - Actigraphy	Y	- Global PSQI ~9.5 >151 days prior to care-recipients death *vs* ~10.7 between 1-30 days prior to care-recipients death. - Total sleep time mean range 3.6-5.4h. - Sleep onset-latency 35.0min. - Sleep efficiency 92%. - Wake after sleep onset 11%. Duration awake due to patient needs 32.6min.	- Depression, fatigue and longer survival periods after care-recipients diagnosis were predictive for sleep disturbance.	-
Lee at al. (2015) (21)	2	Cross-sectional	Taiwan	- N=172 (79%) carers	- 46 ± 12 [20-78]	- PSQI - Actigraphy	Y	Subjective - Global PSQI 8.58 ± 3.96. - Sleep quality 1.58 ± 0.81. - Sleep latency 1.48 ± 1.05. - Sleep duration 1.5 ± 1.01. - Sleep efficiency 1.45 ± 1.21. - Sleep disturbance 1.02 ± 0.40. - Use of sleep medicine ± 0.36 ± 0.86. - Daytime function 1.68 ± 0.98. Objective - Sleep onset latency 10.51 ± 10.7. - Sleep duration 4.4 ± 2.3h. - Wake after sleep onset latency (epoch) 4.0 ± 2.9. - Sleep efficiency 90.5 ± 7.03.	- Fatigue, caregiving burden and depressive symptoms were all predictors of sleep disturbances. - Females and carers who spent more hours providing care had more sleep disturbances.	-
Lee et al. (2015b) (22)	2	Cross-sectional	Taiwan	- N=176 (76%) carers	- 46 ± 12 [20-78]	- PSQI - Actigraphy	Y	49% reported dissatisfaction with sleep quality 72% experienced clinically significant levels of sleep disturbance Global PSQI 9.1 ± 4.1. - Sleep quality 1.6 ± 0.8. - Sleep latency 1.5 ± 1.0. - Sleep duration 4.6 ± 2.5h. - Sleep efficiency 1.5 ± 1.2. - Sleep disturbance 1.0 ± 0.4. - Use of sleep medicine 0.4 ± 0.9.	- 47% of the time carers woke up to care for the care-recipient. - Higher levels of sleep disturbances were found in carers with a care-recipient with a recent diagnosis and also carers with high self-esteem. -	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- Daytime function 1.6 ± 0.8. - Sleep satisfaction 2.6 ± 1.1. Objective - Total sleep time 6.3 ± 4.0h. - Sleep latency 10.4 ± 10.6. - Number of awakenings 3.9 ± 2.8 - Ratio of wake after sleep onset 19.6 ± 18.3%. - Sleep efficiency 90.6 ± 7.0%.		
Litzelman et al. (2018) (23)	2	Cross-sectional	USA	- N=1482 (75%) carers	- 27% 20-50 years - 28% 51-60 years - 24% 61-70 years - 20% ≥ 71 years	- Sleep question in survey "extent of getting enough sleep".	N	- 23% felt rested "a little/none of the time". - 40% felt rested "some of the time". - 37% felt rested "all/most of the time".	-	-
Miaskowski et al. (2010) (24)	1	Cross-sectional	USA	- N=185 (% not reported) carers	- 62.5 ± 10.5	- General Sleep Disturbance Scale	N	- General Sleep Disturbance Scale 37.0 ± 14.7.	-	-
Miaskowski et al. (2012) (25)	2	Cross-sectional	USA	- N=85 (% not reported) carers	- 62.5 ± 10.5	- PSQI - General Sleep Disturbance Scale - Actigraphy	Y	*Data identified as carers only is reported.* - -General Sleep Disturbance 38.7.	- Carers who were younger and had a lower physical ability to perform activities, work or self-care were more likely to be in the higher sleep disturbance class.	-
Paek et al. (2018) (26)	2	Cross-sectional	USA	- N=33 (82%) carers	- 60.0 ± 11.2	- Single question about night sleep duration		42.4% of carers reported to have <7h sleep/night.	- Short night-time sleep was significantly related to caregivers depression, anxiety, higher caregiver burden and <3 days of physical activity.	-
Passik and Kirsch (2005) (27)	2	Longitudinal	USA	- N=25 (16%) spousal carers	- 55 ± 12	- Caregiver Numeric Rating Scale of Insomnia and Energy Levels (0=no insomnia – 10=worst possible insomnia over last week)	N	- Baseline insomnia rating 2.6 ± 2.9. Follow up (one month since baseline) insomnia rating 3.2 ±2.9.	-	-
Pawl et al. (2013) (28)	2	Cross-sectional	USA	- N=133 (69%) carers	- 52 ± 12 [21-77]	- PSQI - Accelerometer	Y	- Global PSQI 1.3 ± 0.9. - Total Sleep time 5.9 ± 1.4h. - Wake after sleep onset 15.1 ± 9.2min.	-	Quality of life was positively associated with sleep quality and negatively associated with TST.
Pawl et al. (2013b) (29)	2	Cross-sectional	USA	- N=133 (69%) carers	- 52 ± 12 [21-77]	- PSQI - Accelerometer	Y	Objective - Sleep latency 35.4 ± 34.5. - Total sleep time 5.9h ± 84.6. - Wake after sleep onset 15.1 ± 9.2%. - Number of awakenings 8.3 ± 3.5. - 48% napped at least once a day for 16.4 ± 23.5min.	- Anxiety predicted carer sleep quality, sleep duration and nocturnal arousals. - Lower care-recipient physical functioning was associated with greater carer wake after sleep onset.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								Subjective - Sleep latency 24.9 ± 26.8min. - Wake after sleep onset 11%. - 61% reported good sleep quality. - 32% reported fairly poor-very poor sleep quality.		
Pellegrino et al. (2010) (30)	2	Cross-sectional	Italy	- N=104 (57%) carers	- 45 ± 15	- Sleep questions part of physical and functional components of a quality of life questionnaire.	N	24% reported >2 episodes of sleep disruption per week since care-recipients diagnosis.	-	-
Stenberg et al. (2014) (31)	1	Longitudinal	Norway	- N=278 (60%) carers	- 56 [21-85]	- General Sleep Disturbance Scale	N	*Baseline data* General Sleep Disturbance Scale 39.8 ± 21.8.	-	-
Teel and Press (1999)	2	Cross-sectional	USA	- N= 32(53%) carers of patients with Alzheimers - N= 29 (52%) Parkinson's carers - N= 33(52%) cancer carers - N=33 (49%) non-carers.	- 72 Alzheimer's carers - 73 Parkinson's carers - 70 cancer carers - 74 non-carers	- Verran and Snyder-Halperon Sleep Scale (15 items scale on a 10 point rating scale).	N	- Sleep behaviours among all carers were similar. - Sleep behaviours between carers and non-carers were significantly different. - Sleep disturbance 4.48 in Alzheimers carers *vs* 3.88 in Parkinson's carers *vs* 3.88 in Cancer carers *vs* 3.02 in non-carers Sleep effectiveness 6.92 in Alzheimers cares *vs* 6.68 in Parkinson's carers *vs* 6.88 in cancer carers *vs* 8.02 in non-carers.	-	
Willette-Murphy et al. (2009) (32)	2	Cross-sectional	USA	- N=68 (100%) total carers - N=38 physically inactive - N=30 physically active	- 66 ± 8 physically inactive - 63 ± 9 physically active	- PSQI - General Sleep Disturbance Scale - Sleep diary - Actigraphy	Y	- Subjective total sleep time was significantly lower and subjective onset latency significantly higher in inactive carers than active carers. Subjective - Global PSQI 5.8 ± 3.0 for inactive vs 6.0 ± 3.9 for active. - General Sleep Disturbance 38.4 ± 17.5 for inactive vs 41.5 ± 14.7 for active. - Feel rested (1=very rested, 4=not at all rested) 2.2 ± 0.6 for inactive vs 2.4 ± 0.7 for active. - Total sleep time 7.1 ± 1.4h for inactive vs 7.9 ± 1.2 for active. - Sleep onset latency 23.3 ± 27.5 for inactive vs 11.7 ± 9.3 for active. Objective - Total sleep time 6.9 ± 1.2h for inactive vs 7.1 ± 1.2h for active.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- Sleep onset latency 13.3 ± 12.0min for inactive vs 12.9 ± 8.8min for active. - Sleep efficiency 84.1 ± 12.5% for inactive vs 84.7 ± 9.4% for active. - Number of awakenings 16.1 ± 8.3 for inactive vs 16.5 ± 9.3 for active. Wake after sleep onset 12.5 ± 11.4 for inactive vs 12.3 ± 9.2 for inactive.		
Zhang et al. (2014) (33)	1	Cross-sectional	China	- N=900 total sample - N=600 (52%) spousal carers - N=300 (50%) non-carers	Spousal carers - 17% 31-40 - 34% 41-50 - 34% 51-60 - 15% ≥ 61 Non-carers - 26% 31-40 - 32% 41-50 - 19% 51-60 - 23% ≥ 61 -	- Sleep subscale in the Symptom Checklist (possible score 1-35)	N	- Spousal carers reported significantly more sleep disturbances than the non-carer group. - Sleep subscale 7.3 ± 1.3 for spousal carer's vs 4.8 ± 2.2 for non-carers.	- Poor carer health. - Care-recipients with greater needs. - Financial burden. - Job stress.	-
Zhu et al. (2014) (34)	2	Cross-sectional	China	- N=243 (0%) spousal carers	50 ± 9	- Self-report measure of sleeping time	N	- 10.3% slept <6h. - 73.3% slept 6-8h. - 16% slept >8h.	-	- More sleep predicted better quality of life scores.
Dementia										
Ali and Bokharey (2015) (35)	2	Qualitative Cross-sectional	Pakistan	- N=8 (38%) carers	60 [51-69]	- Semi-structured Interviews	N	- Main theme was that sleep disturbance were a result of the care-recipients sleep problems. - Stress related sleep disturbances depended on the duration and severity of the stressful situation. -	Care recipient's difficulties in sleeping, as a result of the Dementia, kept caregivers awake as well.	-
Beaudreau et al. (2008) (36)	2	Cross-sectional	USA	- N=60 (% not reported)	65 ± 13 [27-85]	- Actigraphy	Y	- Number of awakenings 17.2 ± 5.6 - Sleep efficiency 70.3 ± 13.7% - Time in bed 7.7 ± 1.3 h - Total sleep time 5.3 ± 1.6 h - Sleep onset latency 24.5 ± 33.3 min - Wake after sleep onset 112.0 ± 53.2 min -	Worse self-rated health and older age was related to more time in bed.	-
Brummet et al. (2006) (37)	1	Cross-sectional	USA	- N=175 (% not reported) carers - N=169 (% not reported) non-carers	- 61 ± 13 carers 56 ± 14 non=carers	- PSQI	N	- Global PSQI 7.3 ± 3.8 in carers vs 5.5 ± 3.4 in non-carers	Negative affect mediates the association between caregiving and poor sleep quality.	-
Chiu (2014) (38)	2	Cross-sectional	Taiwan	- N=117 (65%) carers	- 56 ± 13	- General Sleep Disturbance Scale.	N	- 26% indicated that sleep disturbances interfered with their daily life. - 99% reported issues with sleep quality.	- Sleep disturbance positively correlated with care-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
						- Interference with Daily Life Scale.		- 60% reported difficulty falling asleep. - 67% reported waking up during their sleep. - 97% reported dozing in the daytime.	recipient's neuropsychiatric symptoms scores. 50% of sleep disturbance explained by carers physical fatigue and depressive symptoms and their interaction.	
D'Auoust et al. (2015) (39)	2	Cross-sectional	USA	- N=53 (79%) carers	- 63 ± 12 [38-86]	- Actigraphy - Sleep Diaries - Epworth Sleepiness Scale	Y	*Subjective* - Total sleep time 6.3 ± 1.0 h - Sleep Efficiency 78.1 ± 11.4 % - Sleep onset latency 30.2 ± 21.3 min - Wake after sleep onset 45.9 ± 34.2 min - Sleep quality 3.0 ± 0.6 - Epworth Sleepiness Scale 8.2 ± 4.0 *Objective* - Total sleep time 5.8 ± 0.8 h - Sleep efficiency 72.1 ± 6.0 % - Sleep onset latency 24.3 ± 18.5 min - Wake after sleep onset 43.8 ± 19.6 min	- Depressed carers reported greater wake time than objective evidence. - Note: only care-recipients with evidence of night-time caring activity were recruited.	-
Ducharme et al. (2014) (40)	2	Cross-sectional	Canada	- N=32(75%)	- 54 ± 11	- Family Caregivers Support Agreement tool. - Semi-structured interviews. - 1 item about sleep "to be able to get a good night sleep" (would make life better).	N	47% of carers reported that getting a good night's sleep would make life better for them.	-	-
Flaskerud et al. (2000) (14)	2	Cross-sectional	USA	- N=117 (100%) total carers - N=36 AIDS - N=40 dementia - N=41% cancer	- 46 ± 17 [23-75] AIDS - 70 ± 6 [51-82] dementia - 52 ± 14 [26-74] cancer	- Interviews - PSQI	N	- Trouble falling asleep 61% in AIDS carers *vs* 60% in dementia carers *vs* 46% in cancer carers. - Restless sleep 75% in AIDS carers *vs* 44% in dementia carers *vs* 82% in cancer carers. Trouble staying asleep 53% in AIDS carers *vs* 61% in dementia carers *vs* 76% in cancer carers.	- Vigilance of patient getting up, wandering or being in pain in dementia and AIDS carers.	-
Eleuteri et al. (2018) (41)	2	Cross-sectional	Italy	- N=117 (73%) carers -	- 54 ± 6	- PSQI	N	- Data were analysed stratified by low and high depressive symptoms. - Global PSQI 5.4 ± 4.1 for carers with low depressive symptoms - Global PSQI 8.5 ± 3.7 for carers with high depressive symptoms	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Fonareva et al. (2011) (42)	1	Cross-sectional	USA	- N=20 (90%) carers - N=20 (90%) non-carers	- 65 ± 7 [50-76] carers - 66 ± 8 [55-76] non-carers	- PSQI - Epworth Sleepiness Scale - PSG	Y	- Global PSQI 8.3 ± 3.4 in carers *vs* 4.4 ± 2.3 in non-carers. - Epworth Sleepiness Scale 6.6 ± 4.4 in carer's *vs* 5.1 ± 3.2 in non-carers. - Total sleep time 6.8 ± 1.7 h in carers *vs* 7.1 ± 1.6 h - Sleep efficiency 85.3 ± 12.5% in carers *vs* 91.0 ± 4.0% in non-carers - Wake after sleep onset 53.9 ± 65.0 min in carers *vs* 35.9 ± 28.1 in non-carers - Number of arousals 51.3 ± 24.7 in carers *vs* 41.0 ± 13.2 in non-carers.	-	-
Gibson et al. (2014)(43)	2	Qualitative Cross-sectional	New Zealand	- N=12 (75%) family carers	- 11 >65 years - 1<65 years	- Focus Groups	N	- Carers would go to bed later than care-recipients but had to wake early to provide morning care. - Carers would often be woken by the care recipient and would then find it harder to get back to sleep.	- Sleep disruptions often due to confused awakenings of care-recipient. - Worry and depression were also sometimes raised by carers – in two instances this affected their sleep.	-
Koyama et al. (2017) (44)	1	Cross-sectional	Japan	- N=104 (58%) carers - N=104 non-carers	- 65 ± 12 carers - Not reported for non-carers. -	- Neuropsychiatric Inventory	N	- Data were analysed stratified by younger and older caregivers. - 39% of younger carers reported sleep problems *vs* 13% in younger non-carers - 28% of older carers reported sleep problems *vs* 17.2 in older non-carers. - Note: sleep problems may be underestimated in this sample as some carers reported no sleep problems however, took sleeping medication.	-	-
Lee et al. (1997) (45)	3	Cross-sectional	Korea	- N=30 (73%) home carers - N=24 (87%) previous home carers (care-recipient now in nursing home)	- 57 ± 15 home carers - 48 ± 11 previous carers	- Perceived Difficulties and Satisfaction checklist.	N	- Disrupted sleep on the Perceived Difficulties and Satisfaction list was 2.3 ± 1.4 in home carers *vs* 3.8 ± 1.5 for previous carers (score based on when care-recipient was still at home).	-	-
Leggett et al. (2016) (46)	3	Cross-sectional	USA	- N=158 (87%) carers who utilize adult day services for care-recipient.	- 62 ± 11 [39-87]	- Subjective sleep duration.	N	-	-	-
Liu et al (2015) (47)	2	Cross-sectional	USA	- N=173 (87%)	- 62 ± 11 [39-89]	- Assessment of sleep quality	N	- Better sleep quality associated with less fluctuations in daily anger but not depression.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Lorenzo-Lopez et al. (2017) (48)	3	Cross-sectional	Spain	- Total N=72 (71%) carer-dyads - N=33 (78%) formal carers - N=39 (64%) informal carers	- 83 ± 8 carers - 84 ± 8 formal carers - 83 ± 8 informal carers	- Neuropsychiatric Inventory	N	- Prevalence of sleep and night-time behaviour disorders was 17% in all carers, 21% in formal carers and 12% in informal carers.	-	-
Matsuda et al. (1997) (49)	2	Longitudinal	Japan	- Total N=103 - Group A N=44 home care - Group B N=18 home care then institution <6months - Group CN=41 home care then institution for >6 months - (% female not reported)	- 57 ± 11 Home care - 51 ± 7 Institution<6 - 55 ± 10 Institution >6	- General Health Questionnaire - Anxiety-Insomnia scale	N	- Anxiety-insomnia score did not differ significantly among the groups at initial survey but did at the follow up survey. - At follow up, the anxiety-insomnia score for the institution >6months group was significantly lower than the home care group. - 3.0 ± 2.3 for institution >6 months *vs* 4.6 ± 2.1 for home care.	-	-
McCurry et al. (1998)	1	Intervention	USA	- N=36 (78%) carers	- 68.7 ± 10.6 total	- PSQI	N	- Global PSQI pre-treatment 10.8 ± 3.4 for active *vs* 11.9 ± 4.5 for control. - Global PSQI post-treatment 7.8 ± 3.3 for active *vs* 10.6 ± 4.4 for control. - Global PSQI 3-month 6.2 ± 3.6 for active *vs* 10.2 ± 4.2 control.	-	
McCurry et al. (1996)	2	Intervention	USA	- N=4 (75%) carers	- [61-72]	- PSQI - Sleep Diary	N	- Results are reported for each participant as changes between baseline and final week of intervention. - Participant 1: 24% increase in total sleep time and 12% increase in sleep efficiency. - Participant 2: 48% improvement in total sleep time and sleep efficiency and 84% decrease in wake after sleep onset. - Participant 3: 51% decrease in wake after sleep onset and 16% increase in sleep efficiency. - Participant 4: 43% improvement in total sleep time, 38% reduction in wake after sleep onset and 91% decrease in sleep latency.	-	-
Merrilees et al. (2014) (50)	2	Cross-sectional	USA	- Total N=22 (63%) care-recipient-carer dyad	- 59 ± 9 FTD carer - 63 ± 11 Semantic carer	- PSQI - Actigraphy	Y	- Global PSQI 7.8 ± 4.2 for FTD carer *vs* 4.9 ± 2.5 for Semantic carer. - Global PSQI 9.7 ± 3.9 for female FTD carer *vs* 4.0 ± 0.0 for male FTD carers	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
				- N=13 (31%) carer of care-recipient with Frontotemporal Dementia (FTD) - N=9 (44%) carer of care recipient with Semantic Dementia				- Global PSQI 5.8 ± 2.8 for female Semantic carer *vs* 3.67 ± 2.1 for male Semantic carer. - Time in bed 8.7 ± 1.0 for FTD carer *vs* 8.3 ± 0.7 Semantic carer - Total sleep time 8.1 ± 0.8 for FTD carer *vs* 7.7 ± 0.73 for Semantic carer - Sleep efficiency 86.8 ± 4.8% for FTD carer *vs* 86.2 ± 5.0 for Semantic carer - Wake after sleep onset 64.0 ± 23.0min for FTD carer *vs* 65.2 ± 25.3 for Semantic carer - Number of awakenings 27.0 ± 10.3 for FTD carer *vs* 27.6 ± 6.8 for Semantic carer - Wake bouts (duration) 2.2 ± 0.7 in FTD carer *vs* 27.6 ± 0.6 in Semantic carer.		
Moon and Dilworth Anderson (2015) (51)	2	Cross-sectional	USA	Total N=650 (70%) Baby boomer carers of people with Dementia and people without Dementia. N=138 (73%) carers of people with Dementia N=512 (69%) carers of people without Dementia	- 57 ± 5 total - 57 ± 6 carers of people with Dementia - 57 ± 5 carers of people without Dementia -	- Subjective single question regarding sleep interruption 1=never – 5= every night.	N	- Interrupted sleep score 1.9 ± 1.1 for total, 2.3 ± 1.3 for Dementia carer and 1.8 ± 1.1 for non-Dementia carer.	-	-
Naruse et al. (2012) (52)	3	Cross-sectional	Japan	N=280 (77%) carers	- 64 (SD and range not reported) - 18 < 65 years - 262 ≥ 65 years -	- Classified as either being satisfied or dissatisfied with their sleep based on rating responses to three questions based on mood, amount of sleep and quality of sleep.	N	- 68% of the sample were dissatisfied with their sleep. - Sleep dissatisfaction higher in carers whose care-recipient were unstable and bed-ridden. -	Care needs: - Suction - Postural change - Toileting assistance - Diaper change	-
Peng et al. (2019) (53)	2	Cross-sectional	USA	N=43 (93%) family carers	- 65 ± 10	- PSQI - Sleep Hygiene Index - Sleep diary - Actigraphy	Y	*Subjective* - Global PSQI score 10.4 ± 4.0; >5 92% - Sleep onset latency 30.3 ± 24.5 min - Total sleep time 5.9 ± 1.2 h - Sleep efficiency 79 ± 12%	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
					-			- Sleep disturbances 1.8 ± 0.6 - Sleep quality 2.0 ± 0.6 - Taking sleep medication 68% *Objective* - Sleep onset latency 40.1 ± 24.7min; ≥ 20min (76% of sample) - Total sleep time 7.5 ± 1.2 h - Sleep efficiency 80.8 ± 11.9 %; ≤85% (65.7% of sample) - Wake after sleep onset 30.8 ± 11.9 - Number of awakenings 33.4 ± 11.4		
Rowe et al. (2010) (54)	1	Intervention	USA	N=53 (82%) carers N=26 (74%) carers in experimental group N=27 (88%) carers in control group	- 62 ± 12 [38-86]	- Sleep Diaries - Actigraphy	Y	- Sleep variables were compared between an experimental group who used a night-time monitoring device for the care-recipient and a control group who did not use a night-time monitoring device. No significant differences on any sleep variables between the experimental group and the control group.	Worry	-
Rowe et al. (2008) (55)	1	Cross-sectional	USA	N=31 (64%) carers N=102 (74%) non-carers	- 71 ± 8 [61-86] carers - 73 ± 7 [60-89] non-carers	- Sleep Diaries - Actigraphy	Y	- Total sleep time, sleep efficiency, wake after sleep onset and sleep quality were significantly different between carers and non-carers. *Objective* - Total sleep time 6.6 ± 0.3 in carers *vs* 7.1 ± 0.2 in non-carers. - Sleep efficiency 80.4 ± 9.3 in carers *vs* 87.3 in non-carers. - Sleep onset latency 22.8 ± 89.1 in carers *vs* 12.5 ± 102.2 in non-carers. - Wake after sleep onset 48.6 ± 43.8 in carers *vs* 40.7 ± 37.0 in non-carers. *Subjective* - Total sleep time 6.4 ± 0.4 in carers *vs* 6.9 ± 0.2 in non-carers - Sleep efficiency 77.4 ± 15.4% in carers *vs* 85.2 ± 9.5% in non-carers - Sleep onset latency 30.6 ± 58.5 in carers *vs* 24.4 ± 65.7 min in non-carers - Wake after sleep onset 52.8 ± 74.1 in carers *vs* 29.0 ± 87.9 in non-carers - Sleep quality 3.1 ± 25.4 in carers *vs* 3.5 ± 21.2 in non-carers	Depression was a significant covariate predicting sleep onset latency, total sleep time and wake after sleep onset.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Sakurai et al. (2015) (56)	1	Cross-sectional	Japan	N=20 (80%) carers N=20 (80%) non-carers	- 60 [56-66] 25th-75th percentile - 65 [59-69] 25th-75th percentile	- PSQI - Actigraphy	Y	- Note: in brackets is 25th-75th percentile - Global PSQI 5.0 (3.3-6.8) for carers *vs* 3.0 (3.0-4.0) for non-carers - Total sleep time 6.0 (4.7-6.8) in carers *vs* 6.1h (4.7-7.3) in non-carers - Sleep efficiency 97.9% (96.2-99.5) in carers *vs* 76.9% (94.3-99.3) in non-carers - Sleep latency 6.5 min (1.8-21.3) in carers *vs* 5.0 min (0.0-5.8) in non-carers - Wake after sleep onset 8.0 min (1.6-34.0) in carers *vs* 12.5 min (1.3-20.5) in non-carers	Stress - Carers exhibited significant increase in sympathetic nervous system activity throughout sleep *vs* non carers.	-
Simpson and Carter (2010)	1	Intervention	USA	N=10 carers	- 63 ± 14.9	- PSQI - Actigraphy	Y	- Global PSQI 7.8 ± 5.0 at baseline *vs* 5.2 ± 3.9 at week 5. - Sleep efficiency 86.5 ± 3.8% at baseline *vs* 80.5 ± 14.5 at week 5. - Sleep duration 7.1 ± 1.2h at baseline *vs* 6.9 ± 1.4h at week 5. - Sleep latency 17.4 ± 11.5 at baseline *vs* 24.9 ± 20.4 at week 5. - Wake after sleep onset 45.0 ± 16.7 at baseline *vs* 64.6 ± 56.7 at week 5.		
Simpson and Carter (2013) (57)	2	Qualitative Cross-sectional	USA	N=15 (66%) carers	- 58 ± 14 [27-81]	- PSQI - Focus groups	N	- Global PSQI 6.8 ± 3.3	- Care-recipients poor sleep - Vigilance - Worry	-
Simpson and Carter (2015) (58)	2	Cross-sectional	USA	N=59 (90%) Cohabitating carers N=21 (86%) Distal carers	- 65 ± 13 Cohabitating carers - 58 ± 11 Distal carers	- PSQI	N	- Global PSQI did not differ between cohabitating and distal carers. - Global PSQI 7.4 ± 3.4 for cohabitating carers *vs* 7.8 ± 4.5 for distal carers. - Cohabitating carers experiences significantly more sleep disruptions than distal carers 1.6 ± 1.3 for cohabitating carers *vs* 0.3 ± 0.8 for distal carers. - 59% cohabitating carers experienced sleep disruptions at least once a week and 36% ≥3 a week. - Total sleep time 6.4 ± 1.3 h for cohabitating carers *vs* 6.4 ± 1.7 h for distal carers. - Sleep percentage 80.2 ± 13.2% for cohabitating carers *vs* 81.3 ± 15.2% for distal carers. - Sleep latency 21.9 ± 23.9 min for cohabitating carers *vs* 24.1 ± 28.0 min for distal carers.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Smagula et al. (2017) (59)	2	Cross-sectional	USA	N=57 (77) carers	- 74 ± 7	PSG Actigraphy - Sleep Diaries	Y	- Sleep latency 24.5 ± 26.4 min - Total sleep time 6.4 ± 1.0 h - Wake after sleep onset 55 ± 23.6 min	-	-
Spira et al. (2010) (60)	2	Cross-sectional	USA	N=45 (67%) carers	- 69 ± 13	Actigraphy	Y	- Total sleep time 6.3 ± 1.5 h. - Wake after sleep onset 87.5 ± 72.6 min. -	- Shorter total sleep time was associated with poorer self-reported physical function in carers. - Each 30-min increase in total sleep time was associated with a 2.2 increase on the physical function scale. - Every 10-min increase in wake after sleep onset was accompanied by a 0.5 point decrease on the physical function subscale. -	
Wilcox and King (1999) (61)	1	Cross-sectional	USA	N=90 (100%) carers N=52 healthy adults N=29 sleep impaired older women N=62 depressed individuals	63 ± 9 [49-82] carers 60 [24-83] healthy adults 62 [50-73] sleep impaired older women 60 [21-82] depressed individuals -	PSQI	N	- Global PSQI 7.7 ± 3.8 in carers *vs* 2.7 ± 1.7 in non-carers *vs* 9.0 ± 4.3 in sleep impaired older women, *vs* 9.8 ± 3.3 in depressed individuals - Sleep quality 1.2 ± 0.7 in carers *vs* 0.4 ± .05 in non-carers *vs* 1.7 ± 0.7 in sleep impaired older women *vs* 1.6 ± 0.7 in depressed individuals. - Sleep latency 1.2 ± 10.6 in carers *vs* 0.6 ± 0.7 in non-carers *vs* 1.6 ± 0.8 in sleep impaired older women *vs* 1.5 ± 0.9 in depressed individuals. - Sleep duration 0.8 ± 0.9 in carers *vs* 0.3 ± 0.5 in non-carers *vs* 1.1 ± 1.1 in sleep impaired older women *vs* 1.6 ± 0.9 in depressed individuals. - Sleep efficiency 1.1 ± 1.1 in carers *vs* 0.1 ± 0.3 in non-carers *vs* 1.3 ± 1.2 in sleep impaired older women *vs* 1.4 ± 0.9 in depressed individuals. - Sleep disturbances 1.5 ± 0.5 in carers *vs* 1.0 ± 0.4 in non-carers *vs* 1.4 ± 0.6 in sleep impaired older women *vs* 1.4 ± 0.4 in depressed individuals.	- 30% of carers cited disruptions from the care-recipient as a reason for sleep disturbances. - Of these carers 60% reported that this occurred ≥3 times a week. - Carers reporting more psychological distress also reported more overall sleep problems.	-
Alzheimer's										
Bergman-Evans et al. (1994) (62)	3	Cross-sectional	USA	- N=47 (77%) home carers	- 70 ± 8 [55-86] home carers	Measure of sleep disturbance as part of a physical health	N	- 74% of home carers and 70% of nursing home carers reported sleep related health problems.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
				N=47 (62%) nursing home carers	75 ± 8 [55-90] nursing home carers	characteristics questionnaire		- Sleep problems were the most frequently reported health related complaint in both groups.		
Caswell et al. (2003) (63)	1	Cross-sectional	USA	- N=44 (52%) carers - N=66 (68%) non carers	- 74 ± 8 [58-92] carers - 71 ± 6 [55-85] non-carers	Sleep Problems Questionnaire derived from Sleep Disorders Questionnaire I.	N	- Sleep problems scores significantly differed between carers and non-carers. - Sleep problems score 25.3 ± 6.7 for carers. - Sleep problems score 22.4 ± 5.0 for non-carers.	-	-
Creese et al. (2008) (64)	2	Cross-sectional	Canada	- N=60 (68%) spousal carers	- 74 ± 9 [49-93]	Quality of sleep using 5 survey items (3 items modified from the PSQI).	N	- 58% reported 'poor' or 'fair' quality sleep in previous month. - 33% reported a negative change in sleep quality over past year. - 47% reported disturbed sleep 3≥ times per week. -	- 63% cited the care recipient as the cause for disturbance: - Bathroom; Restlessness; Wanderings; Requests for attention/help; Sleep talking; Nightmares; Wanting to get dressed; Bathroom and wanderings were significantly associated with poorer carers sleep quality.	-
Cupidi et al. (2012) (65)	1	Cross-sectional	Italy	- N=40 (57%) Alzheimer's carers - N=40 (70%) Parkinson's carers - N=150 (37%) non-carers	- 68 ± 14 Alzheimer's carers - 64 ± 9 Parkinson's carers - 67 ± 5 non carers -	PSQI	N	- Global PSQI = 5.8 ± 3.5 for Alzheimer's carers *vs* 6.2 ± 3.9 for Parkinson's carers *vs* 4.3 ± 3.1 for non-carers. - 80% of Parkinson's carers reported reduced sleep quality. - 73% of Alzheimer's carers reported difficulties falling asleep. - 55% of Parkinson's carers were 'poor' sleepers *vs* 30% of non-carers. - 45% of Alzheimer's carers reported poor sleep but not significantly different to Parkinson's carers or non-carers.	-	-
Fernandez and Galan. (2019) (66)	2	Cross-sectional	Spain	- N=255 (86%) family carers	- 55 ± 12	Goldberg General Health Questionnaire (GHQ-28).	N	- Spouses and children (biological or in-law) had more severe insomnia symptoms compared to 'other' family members. - Carers who cared for ≤2 years had higher average scores on anxiety-insomnia scale (although not significantly different to other lengths of care time).	-	-
Liu et al. (2017) (67)	2	Cross-sectional	China	- N=309 (60.8%) carers	- 53 ± 12	PSQI	N	- Global PSQI score was 8.0 ± 2.8. - 85% of carers had a global PSQI score >5. - 78% reported poor sleep quality.	-	-
Mannion et al. (2008) (68)	3	Cross-sectional	Ireland	- N=43 (79%) carers	- [49-63]	Self-administered questionnaire including sleep items in Short Form 36-item Health Survey	N	- 65% of carers reported restless sleep most of the time and 14% all of the time.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
						measure and the Centre for Epidemiological Studies Depression (CED-D) scale.				
Mausbach et al. (2006) (69)	2	Cross-sectional	USA	- N=40 (65%) spousal carers	- 73 ± 8	PSG	Y	- Average total sleep time 5.9 ± 1.4h. - After wake after sleep onset 84 ± 48.4 min.	-	-
McCurry et al. (2008) (70)	2	Cross-sectional	USA	- N=44 (66%) carers	- 65 ± 15 [21-87]	Actigraphy	Y	- Total sleep time 7.1h ± 1.2h. - Wake after sleep onset 1.0h ± 1.2. - Number of night awakenings 6.5 ± 2.2. - Considerable variability in carers sleep over the week.	-	-
McKibbin et al. (2005) (71)	1	Cross-sectional	USA	- N=33 (66.7%) spousal carers of care recipients with moderate to severe Alzheimer's - N=40 (75%) carers of care recipients with mild Alzheimer's - N=40 (71.2%) non-carers -	- 74 ± 9 (moderate-severe Alzheimer's) - 71 ± 8 (mild Alzheimer's - 68 ± 10 non-carers	- PSQI - Functional Outcomes of Sleep Questionnaire PSG	Y	- Data was stratified by clinical dementia rating of patient and carers age (younger =<71years, older = >71years). - Global PSQI 9.1 ± 5.4 for younger moderate-severe carers *vs* 2.2 ± 5.4 for older moderate-severe carers. - Global PSQI 4.4 ± 3.4 for younger mild-moderate carers *vs* 4.4 ± 4.7 for older mild-moderate carers. - Global PSQI 2.2 ± 4.4 for younger non-carers *vs* 5.6 ± 3.8 for older non-carers. - Older carers in the moderate-severe group slept 51min less than older healthy non-carers. - The moderate-severe carer group reported significantly greater sleep impairments than non-carers.	-	-
Mills et al. (2009) (72)	2	Cross-sectional	USA	- N=81 (72%) carers - N=41 (73%) non-carers	Males - 77 ± 9 High Clinical Dementia Rating - 78 ± 4 Low Clinical Dementia Rating - 71 ± 9 non carers Females - 71 ± 9 High Clinical Dementia Rating - 69 ± 8 low Clinical Dementia Rating - 66 ± 6 non-carers	- PSG	Y	- Males caring for spouses with more severe dementia experienced more disturbed sleep. - All carers had sleep efficiencies <85% with all males ≤80%. -	- Males caring for those with moderate-severe dementia slept nearly an hours less than females caring for spouses with a similar disease state.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Roepke et al. (2012) (73)	2	Cross-sectional	USA	- N=110 (69%) spousal carers	74± 8	- PSQI	N	- Global PSQI score 6.6 ± 3.5.	-	-
Schwartz et al. (2013) (74)	2	Cross-sectional	USA	- N=126 (71%) carers	74 ± 8	- Actigraphy	Y	- Total sleep time 7.3 ± 1.1 h. - Daytime sleep duration 0.8 ± 0.7 h. - Percent sleep at night 87.3 ± 5.4 % -	-	-
Teel and Press (1999)	2	Cross-sectional	USA	- N= 32(53%) carers of patients with Alzheimers - N= 29 (52%) Parkinson's carers - N= 33(52%) cancer carers - N=33 (49%) non-carers.	- 72 Alzheimer's carers - 73 Parkinson's carers - 70 cancer carers 74 non-carers	- Verran and Snyder-Halperon Sleep Scale (15 items scale on a 10 point rating scale).	N	- Sleep behaviours among all carers were similar. - Sleep behaviours between carers and non-carers were significantly different. - Sleep disturbance 4.48 in Alzheimers carers *vs* 3.88 in Parkinson's carers *vs* 3.88 in Cancer carers *vs* 3.02 in non-carers - Sleep effectiveness 6.92 in Alzheimers cares *vs* 6.68 in Parkinson's carers *vs* 6.88 in cancer carers *vs* 8.02 in non-carers.	-	-
Von Kanel et al. (2006) (75)	2	Cross sectional	USA	- N=64 (69%) spousal carers - N=36 (72%) non-carers	- 72 ± 9 spousal carers 69 ± 7 non-carers	- PSG	Y	- Total sleep time 6.1 ± 1 h in carers *vs* 6.5h ±1 h in non-carers. - Sleep Efficiency 76.9% ± 11.2% in carers *vs* 81.7% ± 9.2% in healthy non-carers. - Note that carers were significantly older than non-carers.	-	-
Von Kanel et al. (2012) (76)	1	Longitudinal (assessments once a year for up to four years)	USA	- N=109 (70%) spousal carers - N=48 (66%) non-carers	- 74 ± 8 spousal carers - 75 ± 6 non-carers	- PSQI - Actigraphy	Y	- Global PSQI score 6.1 ± 0.43 for carers *vs* 5.8 ± 0.7 for non-carers. - Objective sleep measures did not significantly differ between carers and non-carers over time. - Placement of spouse into formal care did not positively or negatively impact sleep outcomes for carers.	- Death of spouse exacerbated sleep disturbances for carers. This may represent a vulnerable group and/or period in this population.	-
Von Kanel et al. (2014) (77)	2	Longitudinal (assessments once a year for up to four years)	USA	- N=126 (71%) carers	- 74 ± 8	- Actigraphy	Y	- Global PSQI Score was ~ 6 for each time point. - Actigraphic total sleep time was >7 h for each time point. - Wake after sleep onset was ~1 h for each time point. -	-	-
Willette-Murphy et al. (2006) (78)	2	Cross-sectional	USA	- N=37 (100%) spousal carers - N=37 (100%) non-carers	- 74 ± 8 wife carers - 75 ± 7 non-carers	- Morin Daily Sleep Diary	N	- Sleep efficiency, total sleep time, sleep onset latency, number of awakenings, wake after sleep onset, sleep quality and feelings upon waking were significantly worse in carers than non-carers. - Subjective sleep efficiency range 72.1-78.6 for carers *vs* 86.7-90.5 for non-carers.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- Total sleep time range 5.9-6.4 for carers *vs* 6.9-7.4 in non-carers. - Sleep onset latency range 11.6-36.4 for carers *vs* 12.8-20.3 for non-carers. - Number of awakenings range 1.9-3.0 for carers *vs* 0.9-1.9 for non-carers. - Wake after sleep onset range 48.3-73.1 for carers *vs* 11.9-22.8 for non-carers. - Sleep quality range 2.6-3.2 for carers *vs* 3.8-4.1 for non-carers. - Feelings upon waking range 2.5-3.0 for carers *vs* 3.7-4.0 for non-carers.		
Zverova (2012) (79)	3	Cross-sectional	Prague	- N=73 (83%)	- Not reported	- Subjective questionnaire: Carers rated their sleep disturbance as never/seldom/sometimes/often.	N	- 33% of women and 22% of men reported that they experienced sleep disturbances 'often'. - 33% of women and 54% of men reported that they experienced sleep disturbances 'sometimes'. - Note that only 16% of sample were men.	-	-
Parkinson's										
Bartolomei et al. (2018) (80)	2	Cross-sectional	Italy	- N=55 (65%)	- 62 ± 9	- Medical Outcomes Study-Sleep Scale (MOS-SS)	N	- No severe sleep disorders were found in the carers sample. - Score on sleep problems subscale 20.1 ± 18.1.	-	-
Cifu et al. (2006) (81)	2	Cross-sectional	USA	- N=49 (98%)	- 70 ± 9 [48-83]	- Caregiver survey - One sleep question measuring hours of sleep	N	- Average nightly sleep was 6.4 ± 1.5h.	- Caregiver burden was negatively associated with caregiver's self-reported sleep and coping ability.	-
Cupidi et al. (2012) (65)	2	Cross-sectional	Italy	- N=40 (57%) Alzheimer's carers - N=40 (70%) Parkinson's carers - N=150 (37%) non-carers	- 68 ± 14 Alzheimer's carers - 64 ± 9 Parkinson's carers - 67 ± 5 non carers -	- PSQI	N	- Global PSQI = 5.8 ± 3.5 for Alzheimer's carers *vs* 6.2 ± 3.9 for Parkinson's carers *vs* 4.3 ± 3.1 for non-carers. - 80% of Parkinson's carers reported reduced sleep quality. - 73% of Alzheimer's carers reported difficulties falling asleep. - 55% of Parkinson's carers were 'poor' sleepers *vs* 30% of non-carers. - 45% of Alzheimer's carers reported poor sleep but not significantly different to Parkinson's carers or non-carers.	-	-
Grun et al. (2016) (82)	2	Cross-sectional	Luxembourg	- N=59 (majority females % not reported)	- 63 ± 11	- Single question asking about whether the patient requires night care or not.	N	- 41% of carers experienced nocturnal sleep disruption.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Happe and Berger (2002) (83)	2	Cross-sectional	Germany	- N=106 (63%) spousal carers	- 62 ± 10	- - Sleep questions analysed as part of a caregiver inventory	N	- 41% of daily carers reported bad sleep. - 18% of daily carers reported insufficient sleep duration. - 26% of daily caregivers reported excessive tiredness	- The more frequent the care the poorer the carers sleep.	-
Pal et al. (2004) (84)	2	Cross-sectional	Canada	- N=23 (65%) spousal carers	- 65 ± 11 [42-83]	- PSQI - Sleep Questionnaire -	N	- Global PSQI 5.5 ± 3.8. - 60% had PSQI scores >5 and 20% >10. -	- Carers sleep was affected by care-recipients' sleep disruption.	-
Smith et al. (1997) (85)	2	Cross-sectional	Germany	- N=153 (77%) spousal carers - N=103 (42%) non-carers	- 71 men carers - 62 women carers - 63 men non-carers - 63 women non-carers	- Questionnaire with sleep questions from - Zung Self-Rating Depression Scale	N	- Poor sleep 2.3 ± 1.0 in spouse carers *vs* 1.8 ± 1.0 in non-carers. - Disturbed sleep rating 2.3 ± 0.9 in women *vs* 1.9 ± 0.9 in men. - 26.5% of men carers and 47.9% of women carers reported to experience poor sleep 'often' or 'always' *vs* 13.8% of men non-carers and 20.5% of women non-carers. -	- Most of the variance in poor sleep was predicted by gender. Whereas predictors of disturbed sleep were largely explained by care-recipient's disease severity.	-
Teel and Press (1999)	2	Cross-sectional	USA	- N= 32(53%) carers of patients with Alzheimers - N= 29 (52%) Parkinson's carers - N= 33(52%) cancer carers - N=33 (49%) non-carers.	- 72 Alzheimer's carers - 73 Parkinson's carers - 70 cancer carers - 74 non-carers	- Verran and Snyder-Halperon Sleep Scale (15 items scale on a 10 point rating scale).	N	- Sleep behaviours among all carers were similar. - Sleep behaviours between carers and non-carers were significantly different. - Sleep disturbance 4.48 in Alzheimers carers *vs* 3.88 in Parkinson's carers *vs* 3.88 in Cancer carers *vs* 3.02 in non-carers - Sleep effectiveness 6.92 in Alzheimers cares *vs* 6.68 in Parkinson's carers *vs* 6.88 in cancer carers *vs* 8.02 in non-carers.	-	-
Children										
Ali Shobali (2010) (86)	2	Cross-sectional	Saudi Arabia	- N=447 (50%) parents of children with atopic dermatis.	- 65.9 ± 32.9	- Sleep question on the Dermatitis Family Impact Questionnaire	N	- ~55% of parents reported that the family's sleep was impacted either "very much" or "a lot".	- Symptoms of the care-recipients disease.	-
Boman et al. (2003) (87)	2	Cross-sectional	Sweden	- N=268 (% not reported) parents of children with cancer.	- Not reported	- Multidimensional questionnaire – 5 items on sleep disturbances rated on 2 point likert scale.	N	- Sleep disturbances 1.47. - 46% of parents reported difficulty in sleeping, early awakenings and/or during sleep re-experiencing situations associated with the child's illness.	-	-
Bourke-Taylor et al. (2013) (88)	2	Cross-sectional	Australia	- N=152 (100%) mothers of children with disabilities.	- 41.7 ± 5.4	- Questions regarding sleep interruptions to address needs of child.	N	- 49% of mothers were woken >4 times per week. - ~50% were woken once per night - 15% were awoken twice per night - 9% were awoken ≥3 times per night.	- Higher child care needs.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
Chu and Richdale (2009) (89)	3	Cross-sectional	Australia	- N=46 (100%) mothers of children with disabilities.	- 40.2 ± 6.2 [28-57]	- PSQI	N	- Global PSQI 8.6 ± 3.6. - 78% had clinically significant disturbed sleep.	- Sleep problems of child. - Behaviour problems of child	-
Cottrell and Khan (2005) (90)	2	Cross-sectional	USA	- N=50 (% not reported) parents of children with epilepsy.	- 32.3 [21-39]	- PSQI	N	- Global PSQI not reported. - Subjective total sleep time 4.5h. - Parents woke 3 time per night. - 59% parents reported their sleep to be a significant problem related to their ability to attend daily household tasks and their own health.	- Number of seizures - Parents perception of the seizure severity	-
Dykens et al. (2014) (91)	1	Intervention	USA	- N= 243 (100%) mothers of children with autism and other disabilities.	- 40.87 ± 8.92 [23-76]	- Insomnia Severity Index.	N	- Insomnia Severity Index 12.33 ± 6.43 indicating sub-threshold insomnia in mother carers.	-	-
Feeley et al. (2014) (92)	2	Cross-sectional	USA	- N=61 (100%) family carers of children with bronchopulmonary dysplasia.	- 29.59 [17-50]	- PSQI	N	- Global PSQI 7.6 ± 3.7. - 78.7% had clinically significant sleep disturbances (PSQI >5). - Carers reported sleeping 5.8h a night. - 68.8% reported ≤6h of sleep per night. - 42.6% reported <5h per night. - 23.3% reported ≤4h per night. - 31.1% reported sleep quality as bad with 1.6% reporting sleep quality as very bad. - Sleep onset latency 37.8 ± 41.06.	-	-
Foster et al. (2010) (93)	2	Cross-sectional	USA	- N=112 (86%) parents of children with Smith-Magenis syndrome.	- 41.36 ± 9.6 mothers - 42.07 ± 9.9 fathers	- Sleep questions in online questionnaire. Included hours of sleep obtained per night and desired hours of sleep per night.	N	- Sleep was disrupted 5 night per week in both maternal and paternal carers. - Maternal carers reported 6.4h sleep per night but needed 6.9h to function adequately and desired 7.3h per night. - Paternal carers reported 4.8h sleep per night but needed 6.3h to function adequately and desired 6.5h per night.	-	-
Gallagher et al. (2010) (94)	3	Cross-sectional	UK	- N=67 (79%) parents of children with developmental disabilities. - N=42 (71%) parents of typically functioning children.	- 42.7 ± 6.4 [29-58] parent carers. - 10.0 ± 4.8 [29-58] parents of typically functioning child.	- PSQI	N	- Global PSQI 9.9 ± 3.5 in carer parents *vs* 4.9 parents. - 72% carer parents had significantly poor sleep quality *vs* 22% in non-carer parents. - Sleep quality 1.6 ± 0.9 in carer parents *vs* 0.9 ± 0.7 in non-carer parents. - Sleep latency 1.3 ± 0.9 in carer parents *vs* 0.7 ± 0.7 in non-carer parents. - Sleep duration 1.6 ± 1.0 in carer parents *vs* 0.5 ± 0.7 in non-carer parents. - Sleep efficiency 1.7 ± 1.3 in carer parents *vs* 0.9 ± 1.0 non-carer in parents.	- Parent stress was a predictor of poor sleep quality.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- Sleep disturbance 1.2 ± 0.5 in carer parents *vs* 0.9 ± 0.3 in non-carer parents. - Sleep medication 0.9 ± 1.09 in carer parents *vs* 0.2 ± 0.43 in non-carer parents. - Daytime dysfunction 1.5 ± 0.8 in carer parents *vs* 0.7 ± 0.4 in non-carer parents.		
Goldman et al. (2012) (95)	2	Cross-sectional	USA	- N=16 (% not reported) parent of children with Angelman syndrome.	- Not reported	- Insomnia Severity Index - Epworth Sleepiness Scale 4. Actigraphy -	Y	- Sleep onset latency 31.7 ± 22.5min - Total sleep time 6.3 ± 0.8h - Wake after sleep onset 63.8 ± 30.0min - Fragmentation index 35.0 ± 11.9 - Time in bed 7.3 ± 1.1h.	- Childs poor sleep.	-
Heaton et al. (2005) (96)	2	Cross-sectional	UK	- N=46 (74%) parents of children with technology dependent children.	- 37.3 [22-52]	- Interviews	N	- 61% reported regular sleep disruption (waking 2 nights per week). - Families whose child had short term care away from home reported getting a good night's sleep as a major benefit.	- The need to use and oversee the use of medical technologies at night. - Alarms for turning the child. Attending to the needs of the child.	-
Jaser et al. (2017) (97)	3	Cross-sectional	USA	- N=515 (% not reported) parents of children with type 1 diabetes.	- Not reported	- PSQI	N	- Global PSQI 6.6 ± 3.4. 5. 53% had significantly poor sleep quality (PSQI >5). -	- Parents with more fear of hypoglycaemia had worse sleep quality.	-
Kayadjanian et al. (2018)	2	Cross-sectional	USA	- N=142 (~ 83%) carers of children with Prader-Willi syndrome.	- 20-29 6% - 30-39 27% - 40-49 (25%) - 50-59 (27%) - 60-69 (11%) - 70-79 (2%) - 80+ (1%) - Unknown (1%)	- Caregiver survey – included one question asking "I get less sleep because of my child with Prader-Willi Syndrome Yes/No?"	N	- 61% of carer reported getting less sleep because of the care-recipient.	-	Carers who reported getting less sleep, also reported a higher level of carer burden.
Klassen et al. (2012) (98)	2	Cross-sectional (qualitative)	Canada	- N=50 (74%) immigrant parent carers of children with cancer. - N=29 (81%) single carer parents of children with cancer.	- 41.3 [29-52] immigrant parents - 41.7 [22-61] single parent	- Interviews	N	- 60% of immigrant parent carers and 82% of single carer parents reported sleep disturbances and poor quality sleep and provided illustrative quotes.	- Cancer related worries. - Caring for child (toileting, tending to feeding tube, comforting child) - Being woken by child. 6. Sleeping in the same room. -	-
Lee et al. (2018) (20)	3	Cross-sectional	USA	- N=40 (100%) mothers of children with	- 42.1 ± 5.3	- PSQI - Sleep Diary	N	- Global PSQI 7.9 ± 4.8 - 61% reported significantly poor quality sleep (PSQI >5)	- Approximately 30% of mothers' sleep disruption was related to their child.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
				developmental disabilities.				- 33% reported waking during the night at least once per week. - Sleep quality 1.5 ± 0.8 - Sleep latency 1.4 ± 10.3 - Sleep duration 1.1 ± 1.0 - Sleep efficiency 0.5 ± 0.9 - Sleep disruptions 1.6 ± 0.6 - Use of sleep medication 0.7 ± 1.1 - Daytime dysfunction 1.3 ± 0.9 - Minutes to fall sleep 27.7 ± 28.0 - Sleep efficiency 88.9 ± 16.1% Sleep Diary - Total sleep time 7.1 ± 0.8h - Sleep onset latency 23.13 ± 55.54min - Sleep disruptions 2.2 ± 1.7 - Sleep disruptions due to child 0.6 ± 0.7 - Wake after sleep onset 40.2 ± 47.6min - Daytime napping 75.8 ± 60.32min - Sleep quality 2.5 ±0.5 - Sleep efficiency 90.31 ± 6.95%	- 60% cited other reasons such as use of bathroom, joint pain, disturbed by partners snoring or work schedule, stress or nightmares.	
Lee et al. (2017) (99)	2	Cross-sectional	USA	- N= 10,035 total sample. - N=1436 (58%) family carers of children with disabilities. - N=8599 (55%) non-carers.	- 39.4 ± 0.44 family carers - 38.3 ± 0.18 non-carers	- National survey identifying unhealthy risk behaviours including unhealthy sleep (reporting to have <7h sleep in a 24h period).	N	- The carer group had a higher prevalence of unhealthy sleep behaviours than the non-carer group (47.7% of carers *vs* 41.1% of non-carers).	-	-
Matthews et al. (2014) (100)	2	Cross-sectional	USA	- N=26 (100%) mothers of children with cancer. - N=26 (100%) non-carer mothers.	- 32.4 ± 6.8 mother carers - 36.0 ± 6.0 non-carer mothers	- Insomnia Severity Index - Morin Sleep Diary - Actigraphy	Y	- Insomnia Severity Index 7.8 ± 5.7 mother carers *vs* 4.92 ± 4.2 in non-carer mothers. Indicative of sub-threshold insomnia in carers and no insomnia in non-carers. Sleep diary - Total sleep time 7.2 ± 1.1h in mother carers *vs* 6.6 ± 0.8h in non-carers - Sleep latency 7.3 ± 4.2min in carers *vs* 10.2 ± 7.8min in non-carers - Sleep efficiency 87.1 ± 3% in carers *vs* 84.9 ± 6.38% in non-carers - Wake after sleep onset 49.2 ± 15.1min in carers *vs* 61.4 ± 43.2min in non-carers. - Awakenings 24.2 ± 6.05 in carers *vs* 24.0 ± 7.0 in non-carers.	- There was a correlation between the child's total sleep time and the mothers total sleep time and number of awakenings for the carer mothers.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								Actigraphy - Total sleep time 7.2 ± 1.8h in mother carers *vs* 6.9 ± 1.3h in non-carers - Sleep latency 7.1 ± 4.1min in carers *vs* 10.6 ± 7.4min in non-carers - Sleep efficiency 79.0 ± 9.8% in carers *vs* 78.8 ± 9.3% in non-carers - Wake after sleep onset 97.8 ± 63.7min in carers *vs* 92.3 ± 47.2min in non-carers - Awakenings 23.7 ± 7.3 in carers *vs* 23.2 ± 6.7 in non-carers.		
Meltzer and Booster (2016) (101)	2	Cross-sectional	USA	- N= 180 total sample. - N=35 (83%) carers of children with atopic dermatitis (AD). - N=27 (96%) carers of children with asthma (AS) - N=57 (75%) carers of children with atopic dermatitis and asthma (AD+AS). - N=61 (75%) carer of children with ventilator assistance (VENT). - N=63(79%) parents of healthy children (HEALTHY).	- 34.63 ± 5.76 AD carers - 41.07 ± 8.02 AS carers - 38.53 ± 8.36 AD+AS carers - 43.2 ± 7.52 VENT carers 7. 41.55 ± 6.40 HEALTHY non-carers	- PSQI 8. Insomnia Severity Index -	N	- Global PSQI 9.1 ± 0.7 AD *vs* 9.3 ± 0.7 AS *vs* 9.5 ± 0.5 AD+AS *vs* 10.9 ± 0.8 VENT *vs* 6.2 HEALTHY. - Insomnia Severity Index 11.6 ± 1.1 in AD *vs* 11.3 ± 1.1 in AS *vs* 12.1 ± 0.8 in AD+AS *vs* 10.9 ± 0.8 in VENT *vs* 6.3 ± 0.8 in HEALTHY. - Total sleep time 5.9 ± 0.2 for AD *vs* 6.5 ± 0.2 for AS *vs* 6.0 ± 0.2 for AD+AS *vs* 6.0 ± 0.2 for VENT *vs* 6.8 ± 0.2 in HEALTHY.	- Sleep disturbances greater in parents with children with chronic illness compared with parents of healthy children.	-
Meltzer et al. (2010) (102)	2	Cross-sectional	USA	- N=36 (81%) family carers of children with	- 38.2 ± 6.2 [27-48]	9. 24-Hour Sleep Patterns Interview -	N	- Carers were divided into analysed by day-time or night-time nursing coverage and hours per week (<80 or >80)	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
				respiratory atopic disease.				- Sleep onset latency 21.9 ± 18.0 for daytime nursing <80h *vs* 25.0 ± 17.13 for daytime nursing >80h *vs* 36.3 ± 18.3 for night-time nursing 0h *vs* 15.9 ± 10.5 for night-time nursing 16-48h *vs* night-time nursing 21.7 ± 18.3 for night-time nursing >48h. - Total sleep time 6.6 ± 1.2h for daytime nursing <80h *vs* 5.9 ± 1.3h for daytime nursing >80h *vs* 5.9 ± 1.3h for night-time nursing 0h *vs* 6.0 ± 1.6h for night-time nursing 16-48h *vs* 6.9 ± 0.8h for night-time nursing >48h.		
Meltzer and Mindell (2006) (103)	2	Cross-sectional	USA	- N=118 (100%) mothers. - N=29 (100%) mothers of ventilator dependent children. - N=42 (100%) mothers of children with cystic fibrosis. - N=47 (100%) mother of healthy children.	- 37.9 ± 6.5 ventilator dependent - 38.5 ± 6.1 cystic fibrosis - 38.4 ± 4.7 healthy	- PSQI 10. 24-Hour Sleep Patterns Interview 11.	N	- Global PSQI 10.1 ± 3.7 for VENT *vs* 7.4 ± 3.6 for CF *vs* 5.9 ± 3.2 for HEALTHY - Sleep onset latency 24.9 ± 18.7 for VENT *vs* 17.7 ± 18.0 for CF *vs* 17.6 ± 12.9 for HEALTHY. - Total sleep time 6.3 ± 1.2 for VENT *vs* 7.28 ± 0.9 in CF *vs* 7.3 ± 0.9 in HEALTHY. - Night waking frequency 1.4 ± 0.9 in VENT *vs* 1.1 ± 0.9 in CF *vs* 0.9 ± 0.9 in HEALTHY. - Sleep Quality 3.3 ± 0.7 in VENT *vs* 3.7 in CF *vs* 3.8 in HEALTHY.	-	-
Meltzer et al. (2015) (104)	2	Cross-sectional	USA	- N=56 (75%) parents of ventilator dependent children. - N=56 (66%) parent non-carers.	- 42.8 ± 7.6 mother carers - 45.1 ± 7.4 father carers - 41.7 ± 6.3 mother non-carers - 40.9 ± 6.9 father non-carers	- Actigraphy	Y	- Total sleep time 6.5 ± 1.5h in carers *vs* 7.4 ± 1.3h in non-carers - Wake after sleep onset 32.0 ± 21.1min in carers *vs* 20.3 ± 15.6min in non-carers. - Sleep efficiency 88.9 ± 5.7% in carers *vs* 92.6 ± 4.3% in non-carers.	-	-
Moore et al. (2006) (105)	3	Cross-sectional	UK	12. N=92 (60%) parent carers of children with asthma and eczema. -	- Not reported	- Sleep questions in questionnaire.	N	- Data based on 2 nights and quoted as medians [interquartile range]. - Number of times sleep was disturbed by the child 4 [2-6] in eczema mothers and 4 [0-5] in eczema fathers *vs* 2 [0-3] in the asthma mothers and 1 [0-1] in the asthma fathers. - Number of times parent got up to attend to the child 4 [2-5] in eczema mothers and 2[0-5] in eczema fathers *vs* 1 [0-3] in	- Mothers of younger children had their sleep disrupted more than mothers of older children. - There was a strong correlation between the number and amount of times the mother was up with the child and the severity of the child's eczema.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- asthma mothers and 0 [0-1] in asthma fathers. - Time (min) parent was up with the child 78 [19-216] in eczema mothers and 90 [10-252] in eczema fathers *vs* 0 [0-35] in asthma mothers and 0[0-10] in asthma fathers.		
Nozoe et al. (2017) (106)	2	Cross-sectional	Brazil	- N=119 (100%) total sample. - N=74 mothers of children with Duchenne muscular dystrophy. 13. N=45 mothers of healthy children. 14.	- 46.3 ± 1.3 carer mothers. - 45.8 ± 1.3 non-carer mothers.	- PSQI - Epworth Sleepiness Scale - Sleep Diary - PSG	Y	- PSQI not reported. - Epworth Sleepiness Scale 9.8 ± 1.4 in carer mothers *vs* - 8.5 ± 1.3 in non-carer mothers. Sleep Diary - Total sleep time 8.1 ± 0.5 in carer mothers *vs* 7.5 ± 0.3 in non-carer mothers. - Arousals 11.0 ± 2.1 in carer mothers *vs* 6.1 ± 1.0 in non-carer mothers. - Naps 2.0 ± 0.3 in carers mothers *vs* 1.0 ± 0.5 in non-carer mothers. PSG - Total sleep time 6.1 ± 0.1h in carer mothers *vs* 6.1 ± 0.1h in non-carer mothers. - Sleep latency 22.5 ± 2.9min in mother carers *vs* 12.6 ± 2.9min in non-carer mothers. - Wake after sleep onset 46.8 ± 5.5min in carer mothers *vs* 59.6 ± 5.4min in non-carer mothers.	- Severity of disruption in mothers sleep proportional to the degree of severity in their son's disease.	-
Nozoe et al. (2016) (107)	2	Cross-sectional	Brazil	- N=32 mothers of children with Duchenne muscular dystrophy. - N=32 mothers of sons without any neuromuscular or chronic disease.	- 46.2 ± 8.1 Duchenne muscular dystrophy carers - 46.0 ± 7.1 non-carers	- PSQI	N	- 61% of carer mothers had impairment to their sleep *vs* 21% of non-carer mothers. - Global PSQI 7.2 ± 2.3 in carer mothers *vs* 4.6 ± 3.9 in non-carer mothers. - Subjective sleep quality 1.7 ± 1.1 in carer mothers *vs* 0.7 ± 0.7 in non-carer mothers. - Sleep latency 1.3 ± 1.1 in carer mothers *vs* 0.7 ± 0.6 in non-carer mothers. - Sleep duration 1.2 ± 0.9 in carer mothers vs 1.1 ± 0.9 in non-carer mothers. - Sleep efficiency 1.0 ± 1.2 in carer mothers *vs* 0.5 ± 0.9 in non-carer mothers. - Sleep disturbances 1.4 ± 0.5 in carer mothers *vs* 1.32 ± 0.5 in non-carer mothers. - Use of sleeping medications 0.40 ± 0.9 in carer mothers *vs* 0.1 ± 0.4 in non-carer mothers.	- Length of time using a non-invasive ventilation treatment was considered a protective factor for good sleep in carer mothers.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- Daytime dysfunction 0.4 ± 0.7 in carer mothers *vs* 0.3 ± 0.6 in non-carer mothers.		
Painter et al. (2014) (108)	1	Longitudinal	USA	- N=30 (87%) parent carers of children with new-onset epilepsy. - N=29 (100%) non-carers.	- Not reported	- Sleep question in a Daily Phone Diary -interview to record activity in last 24h period.	N	- Sleep was similar between carers of children with new-onset epilepsy and non-carers. - Sleep duration 8.3h in control weekday *vs* 8.1h in epilepsy weekday.	-	-
Pollock et al. (2013) (109)	1	Cross-sectional	USA	- N=73 (92%) parent carers of children with cancer. - N=133 (88%) non-carer parents with healthy children.	- 41.0 ± 6.5 carer parents. - 42.8 ± 5.9 non-carer parents.	- PSQI	N	- Global PSQI >5 53.4% in carer parents *vs* 22.6% in non-carer parents.	-	-
Ricci et al. (2007) (110)	3	Cross-sectional	Italy	- N= 45 (% not reported) parents of children with atopic dermatitis. - N=(% not reported) 20 non-carer parents.	- Not reported.	- Dermatitis Family Impact Questionnaire	N	- Carer parents reported that their biggest problems in terms of quality of life was disturbed sleep of the family members.	-	-
Sullivan-Bolyai et al. (2003) (111)	2	Cross-sectional (qualitative)	USA	- N= 28 (100%) mothers of children with diabetes.	- 33.0 ± 5.2	- Open-ended interviews.	N	- Mother reported sleep deprivation especially in the 6 months after the child's diagnosis with diabetes. - They also reported to experience chronic sleep deprivation thereafter.	- Constant vigilance	-
Wayte et al. (2012) (112)	2	Cross-sectional	UK	- N= 40 (100%) mothers of children with cerebral palsy.	- Not reported.	- PSQI	N	- Global PSQI >5 = 40% indicating poor sleep quality in carer mothers.	Sleep disturbance in children were significantly correlated with sleep disturbance scores in their mothers.	-
Wood et al. (2008) (113)	3	Cross-sectional	Canada	- N=52 (100%) carer mothers of children with epilepsy.	- Not reported.	- PSQI	N	- Global PSQI 7.7 ± 3.9. - Global PSQI >5 67% indicating poor quality sleep in carer mothers.	-	-
Wright (2011) (114)	2	Cross-sectional	Canada	- N= 34 (% not reported) parents carer of children with cancer.	- Not reported.	- Semi-structured interviews. Specific sleep questions included.	N	- Week-day total sleep time 6.8 ± 1.3 carer's *vs* 7.2± 1.0 non-carers. - Weekend total sleep time 7.0 ± 1.2 carers *vs* 7.8 ± 1.1 non-carers.	62% of carers felt that their sleep was negatively impacted by their child's sleep *vs* 39% of non-carers.	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
				- N=64 (% not reported) parents of healthy children.				- 32% of carers had trouble falling asleep *vs* 8% of non-carers. - 29% of carers used sleep medication *vs* 7% of non-carers.		
Yilmaz et al. (2008) (115)	2	Cross-sectional	Turkey	- N=62 (100%) mothers of children with asthma. - N= 21 (100%) mothers of children with cystic fibrosis. - N=35 (100%) mothers of healthy children.	- Not reported.	- PSQI	N	- Global PSQI 4.6 ± 2.4 in cystic fibrosis carers *vs* 4.7 ± 2.8 in asthma carers *vs* 3.2 ± 1.6 in non-carers.	-	-
Yuksel et al. (2007) (116)	2	Cross-sectional	Turkey	- N=75 (100%) mothers of children with asthma. - N=46 (100%) mothers of healthy children.	- Not reported.	- PSQI	N	- Global PSQI 5.0 ± 3.1 in carers *vs* 3.9 ± 2.9 in non-carers. - Sleep Quality 1.0 ± 0.9 in carers *vs* 0.7 ± 0.8 in non-carers. - 34% of asthma carers had "bad sleep" *vs* 6.7% in non-carers.	Total PSQI score of mother carers was negatively associated with asthma severity in children.	-
Other Conditions										
Ae-Ngibise et al. (2015)	2	Qualitative Cross-sectional	Ghana	- N=75 (56%) carers of people living with serious mental disorders.	- Mean age not reported - 20% 16-34 - 60% 35-64 - 20% 65≥	- Interviews	N	- Carers reported difficulties in sleeping because of the behaviour (e.g. crying, talking) of the care-recipient.	- Talking - Crying - Fear of the care-recipients behaviour	-
Al-Rawashdeh et al. (2017)	2	Cross-sectional	USA	- N=78 (58%) spousal carers of heart failure patients.	- 59.5 ± 12.3	- Patient Health Questionnaire-9. - Scores ranged from 0-100 with higher scores indicated higher level of sleep disturbance.	N	- Sleep disturbance score 36.2 ± 23.8.	-	- Higher sleep disturbance predicted poorer physical well-being and poorer mental well-being.
Alrashed (2017)	2	Cross-sectional	Saudi Arabia	- N=341 (100%) carers of people with disabilities, elderly or	- Mean age not reported - 0.8% <20 - 23.8% 20-29 - 43.7% 30-39 - 18.5% 40-43	- Self-administered questionnaire including an item on sleep quality.	N	- 36.4% reported poor sleep quality. - 38.0% reported moderate sleep quality. - Poorest level of sleep was for carers of individuals with a disability, carers of the elderly followed by carers of children aged 5 or younger.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
				children under the age of 5.	- 12.3 % 50-59 - 0.9% 60>					
Arango-Lasprilla et al. (2010)	2	Cross-sectional	Colombia	- N=37 (86.5%) carers of people with spinal cord injury.	- 44.9 ± 16.4	- Caregiver Needs Questionnaire (CNQ) including an item on sleep (likert scale 1-5 where 1 is strongly disagree and 5 is strongly agree)	N	- Sleep needs was ranked number 7 out of 9 needs of the carer (indicating less frequent need). - Sleep needs score 2.9 ± 1.1.		- Greater sleep needs were positively correlated with depression and burden and negatively correlated with satisfaction with life.
Avsar et al. (2013)	2	Cross-sectional	USA	- N= 113 total carers of people with end stage renal failure. - N= 53 (49%) carers of people with renal transplants - N= 60 (45%) Carers of people with peritoneal dialysis	- 40.7 ± 13.6	- PSQI	N	- Frequency of poor quality sleep was significantly higher in the peritoneal dialysis group (38%) than the transplant group (11%).	-	-
Borg and Hallberg (2006)	2	Cross-sectional	Sweden	- 543 (51.2%) total carers. N=151 (49.7%) frequent carers. - N= 392 (51.8%) less frequent carers. - 1258 (49.4%) non-carers.	- Mean age not reported - 5.17% 49-64 - 22.5% 65-74 - 16.2% 75-84 - 4.2% 85≥	- Older Americans' Resources Schedule (OARS) includes a dimension on physical health including sleeping pattern.	N	- 29.1% of frequent carers did not feel refreshed after a night's sleep *vs* 24.91 in less frequent carers *vs* 18.7% in non-carers. - 34.2% of frequent carers had difficulty falling asleep *vs* 20.7% in less frequent carers *vs* 19.8% in non-carers.	-	- Not feeling refreshed after a night's sleep was a risk factor for low life satisfaction.
Carlsson (2012)	2	Cross-sectional	Sweden	- N=75 (72%) relative carers of palliative patients.	- 64.0 [26.0-90.0]	- Insomnia Severity Index - Epworth Sleepiness Scale - Richard-Campbell Sleep Questionnaire (questions on sleep depth, falling asleep, awakenings, returning to sleep and quality of	N	- Insomnia severity index 9.6 ± 6.3. - 23% of carers reported moderate or severe clinical insomnia. - 49.3% had insomnia problems ≥3 times a week. - Perceived sleep duration 6.5h. - Perceived sleep need 8h. - Epworth Sleepiness Scale 5.6 ± 4.0. - Richard Campell Sleep Questionnaire 64 ± 23.4.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
						sleep (range 0= worst possible sleep – 100= best possible sleep.				
Celik et al. (2012)	2	Cross-sectional	Turkey	- N=142 (67%) carers of hemodialysis patients.	- 46.1 ± 10.9 [20-64]	- PSQI	N	- 88% of carers had poor quality sleep (PSQI >5). - Global PSQI 11.69 ± 3.0 - Subjective sleep quality 2.2 ± 0.8 - Sleep latency 1.8 ± 0.7 - Sleep duration 0.7 ± 0.5 - Sleep efficiency 2.2 ± 1.3 - Sleep disturbance 2.4 ± 0.6 - Use of sleep medication 1.3 ± 0.8 - Daytime dysfunction 1.7 ± 0.8	-	-
Charlifue et al. (2016)	2	Cross-sectional	USA	- N=73 (85%) family carers of people with spinal cord injuries.	- 52.5	- Focus groups	N	- Lack of sleep was a common problem reported in the focus groups. -	-	-
Choi et al. (2016)	1	Repeated measures (Measured at enrolment, within two weeks post discharge and two months post discharge)	USA	- N=28 (79%) carers of intensive care unit survivors.	- 49.8 ± 12.8	- PSQI - Accelerometer	Y	- PSQI ≥ 5 64.3% at admission *vs* 53.6% ≤ 2 weeks post discharge *vs* 53.6% 2 months post discharge. - Total sleep time 5.4 ± 1.2h at admission *vs* 6.1 ± 1.9h ≤ 2 weeks post discharge *vs* 5.9 ± 1.8h 2 months post discharge. - Sleep efficiency 81 ± 11% at admission *vs* 79 ± 11% at ≤ 2 weeks post discharge *vs* 80 ± 12% at 2 months post discharge. - Wake after sleep onset 54 ± 36min at admission *vs* 67 ± 45min at ≤ 2 weeks post admission *vs* 66 ± 60min at 2 months post discharge.	- Worsening trends in subjective and objective sleep were found in carers whose patients did not return home by two months post ICU discharge.	-
Choi et al. (2014)	1	Repeated measures (measures at enrolment, within two week post ICU discharge, two months post	USA	- N=47 (75%) carers of intensive care unit survivors.	- 52.3	- PSQI	N	- Global PSQI 8.3 for carers at admission *vs* 10.0 at ≤ 2 weeks post ICU discharge *vs* 7.9 at 2 months post ICU discharge *vs* 8.5 at 4 months post ICU discharge.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
		discharge and four months post discharge)								
Das et al. (2010)	2	Cross-sectional	India	- N= 199 (76%) carers of stroke survivors.	- 42.5 ± 14.6	- 20-item Burden Assessment Schedule	N	- 43% of carers reported sleep disturbances.	- Presence of dementia and depression in stroke survivors caused significant deterioration in carers sleep.	-
Fekete et al. (2017)	2	Cross-sectional	Switzerland	- N=118 (72.9%) partner carers of people with spinal cord injuries.	- 50.7 ± 10.0	- 36-Item Short Form Health Survey. Three items used to assess the frequency of different types of sleep problems.	N	- 54% of carers had at least one or more sleep problems.	-	-
Gibson et al. (2015)	1	Cross-sectional	New Zealand	- 177 (55%) home based carers. - 257 (68%) other carers. - - 1747 non-carers.	- 64 [56-72] home carers. - 62 [56-72] other carers. - Not reported for non-carers.	- 2008 Health Work and Retirement Survey.	N	- Worn out (some or all of the time) 44.7% in home cares vs 43% in other carers vs 36.9% in non-carers. - Tired (some or all of the time) 64.7% in home carers vs 57.2% in other carers vs 52.7% in non-carers. - Dissatisfied- very dissatisfied with sleep 24.4% in home carers vs 23.7 in other carer vs 19.5% in non-carers. - Diagnosed sleep disorder 11.9% in home carers vs 8.2% in other carers vs 7.7% in non-carers.	-	-
Harding et al. (2012)	2	Qualitative cross-sectional	UK	- 20 (55%) carers of palliative cancer patients.	- 55.5 ± 16.9	- Interviews	N	- Sleep deprivation was reported as a challenge faced by carers.	- Constant vigilance - Taking care-recipient to the toilet	-
Hearson et al. (2011)	2	Cross-sectional	Canada	- 13 (77%) family carers of advanced cancer patients.	- Mean age not reported. - 15.4% 40-49 - 46.2% 50-59 - 23.1% 60-69 - 15.4% 70-79	- Epworth Sleepiness Scale - PSQI - Interviews	N	- Epworth Sleepiness Scale 8.7. - 38.5% had scores indicative of excessive daytime sleepiness. - Global PSQI 10.0. - 100% had scores indicative of a moderate to severe sleep problem.	Psychological - Busy mind. - Emotions. - Thoughts related to patients changing condition. Environmental factors - Noise. - Light levels from baby monitors. - Sleeping on the couch. Patient related factors - Pain.	- Physical consequences: Exhaustion, stomach upsets, headaches, increased daytime sleepiness. - Psychological Grouchy, impatient, irritable, teary, angry, sad, crazy. Cognitive changes such as forgetfulness.

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								- Sleep problems. - Restlessness. - Delirium. - Decreases in functional status. Health care system related factors - Lack of assessment of carers sleep status by health care team. - Carers knowledge and use of services (e.g. respite). - Quality of care provided in the home by outside agencies.		- Consequences for care-recipient – reduced quality of care of the recipient.
Kesselring et al. (2001)	2	Cross-sectional	Switzerland	- N=129 (73%) carers of elderly patients.	- 69 ± 12.4 12.4 [36-97]	- Demographic data - Burden Scale	N	- 53% of carers reported to suffer from sleep disturbances. - 55% of the carers reported that rest and sleep was negatively impacted by caring.	-	-
Khan et al. (2007)	2	Cross-sectional	Australia	- 62 (40.3%) carers of people with multiple sclerosis	- 54 [37-62]	- Caregiver Strain Index (includes items on sleep)	N	- 51.6% of carers reported that their sleep was disturbed by the care recipient. - 40.4% of carers reported that the severity of their sleep disturbance was at least moderate or more severe.	-	-
Kochar et al. (2007)	1	Cross-sectional	USA	- N=375 (100%) carers of people with osteoporotic fractures. - N=694 (100%) non-carers.	- 81.0 ± 3.6 carers - 81.4 ± 3.7 non carers	- Self-reported frequency of sleep problems in previous month (trouble falling asleep, trouble staying asleep and waking early and having trouble falling back asleep).	N	- Carers with low depressive symptoms had similar levels of sleep problems as non-carers. - Carers with high depressive symptoms were twice as likely to report trouble staying asleep and trouble waking early than non-carers.	-	-
Koyanagi et al. (2018)	2	Cross-sectional	Worldwide	- N=(51%) total sample, carers made up 20% -	- 39.0 ± 16.4 (total sample)	- World Health Survey (included an item on sleep problems)	N	- Caregiving was associated with significantly higher odds for sleep problems.	A greater number of caregiving activities/responsibilities were associated with significantly increased odds of sleep problems.	-
LaVela et al. (2013)	2	Cross-sectional		- N=73 (100%) veteran women carers. - N=3629 (100%) non-veteran women carers.	- 51.6 ± 16.6 [18.00-99.00] veteran carers - 55.3 ± 13.8 [18-99] non veteran carers. -	- Poor sleep measured as number of days with not enough sleep in the past month and frequent	N	- Number of days not getting enough sleep in past month 11.84 ± 11.24 in veteran carers vs 9.35 ± 10.33 in non-veteran carers. - 41% of veteran carers reported frequent insufficient sleep vs 30% of non-veteran carers.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
						insufficient sleep, defined as 14 or more days having experienced not getting enough rest or sleep in the past 30 days.				
LaVela et al. (2015)	2	Cross-sectional	USA	- N= 51(68%) carers of adult with spinal cord injuries. - N= 1016 (72%) carers of adults with other neurological conditions.	- 53.0 ± 14.6 [21-83] spinal cord injuries - 56.9 ± 13.5 [19-94] other neurological conditions. -	- Behavioral Risk Factor Surveillance System survey. - Poor sleep measured as number of days with not enough sleep in the past month and frequent insufficient sleep, defined as 14 or more days having experienced not getting enough rest or sleep in the past 30 days.	N	- 47% of carers of adults with spinal cord injuries experienced insufficient sleep *vs* 30% of carers of adults with other neurological conditions. - Carers of adults with spinal cord injuries experienced 13 days without enough sleep in the past months *vs* 9 days for carers of adults with other neurological conditions.	-	-
						-				
Lerdal et al. (2014)	2	Cross-sectional	Norway	- N=20 (75%) carers of patients in palliative care	- 58.6 ± 14.5 [50-83]	- PSQI - Actigraphy - Sleep Diaries -	Y	Subjective - Global PSQI 6.8 ± 2.9 - 65% of carer had PSQI score >5. - Sleep onset latency 22.9 ± 19.0min - Sleep duration 6.71m ± 1.01h - Sleep efficiency 84 ± 12.0% Objective - Total sleep time (night sleep) 7.53 ± 1.01h - Number of awakening 8.97 ± 5.39 - Wake after sleep onset 112.4 ± 74.8min -	-	-
Lerdal et al. (2016)	2	Longitudinal Measures taken	Norway	- N=16 (91%) partner and other family carers of patients in palliative care	- 58.6 ± 13.8 [36-77]	- PSQI - Actigraphy	Y	Reporting hospice data only. Subjective - Global PSQI 6.56 ± 3.10 Objective - Total sleep time 8.3 ± 1.3 - Number of awakenings 7.1 ± 4.4	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
		while care-recipient is in hospice, 6 months post care-recipient death and 12 months post care-recipient death.						- Wake after sleep onset 105 ± 80min Partner carers reported worse sleep quality with a global PSQI of 7.1 vs 5.2 for other family carers.		
Liu et al. (2017)	2	Cross-sectional	Taiwan	- N=80 (58%) carers of patients admitted to a respiratory care ward. - N= 80 (73%) home carers of ventilator dependent patients.	- 53.6 ± 9.7 carers of patient admitted to respiratory care ward. - 50.6 ± 14.9 home carers of ventilator dependent patients.	- Burden assessment scale (includes measure of sleep problems, rated on a 5-point Likert scale where higher scores indicate greater burden).	N	- Lack of sleep was a greater burden in the home carers vs the carers whose care-recipients were admitted to a respiratory ward (3.3 ± 1.0 vs 2.8 ± 1.2).	Insufficient sleep was a factor attributing to physical burden in carers.	-
Madani et al. (2018)	2	Cross-sectional	Saudi Arabia	- N=63 (86%) carers of patients with sickle cell disease	- 39.5 ± 9.8 [21-71]	- Interviewed using the Questionnaire for Adult's Health Related Quality of Life (sleep item included with a range of 0-100 with higher scores indicating better quality of life).	N	- Sleep quality score 59.5 ± 33.0.	-	- Sleep quality, as a dimension of quality of life, was significantly affected by caring.
Mochari-Greenberger and Mosca (2012)	2	Cross-sectional	USA	- N=423 (67%) carers of patients with cardiovascular disease	- 49	- Caregiver Strain Questionnaire	N	- 30% of carers reported that sleep disturbance contributed to caregiver burden.	-	-
Read et al (2010)	3	Cross-sectional	UK	- N=10 (80%) carers of young men with neuromuscular disorders receiving non-	- 50 ± 6.7	- PSQI	N	- Global PSQI 7.4 ± 4.7	-	- Poor sleep quality in carers was with poorer emotional well-being.

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
				invasive ventilation.						
Rittman et al. (2009)	2	Cross-sectional	USA	- N=276 (90%) carers of veterans post-stroke.	- 60.7 ± 12.8 [18-88]	- PSQI	N	- 20.5% of carers reported receiving 1-5h of sleep. - 26.5% took ≥30 min to fall asleep. - 87% rated that sleep was important to their caregiving role. - 15.4% reported using sleep medications ≥ 3 times per week. - 15.7% reported that their sleep quality was either "fairly bad" or "very bad".	- Assisting care-recipient Worry	-
Saban et al. (2016)	2	Cross-sectional	USA	- N=40 (100%) spousal carers of veterans with traumatic brain injury.	- 43.1 ± 15.3	- Patient Health Questionnaire (sleep item included)	N	- 40% of carers reported trouble sleeping.	-	-
Sato et al. (2002)	3	Cross-sectional	Japan	- N=9 (100%) family carers of elderly relatives. - N=9 (100%) non-carers.	- 65.2 ± 4.8 [57-73] carers. - 66.9 ± 4.2 [61-74] non-carers	- PSG - Sleep Evaluation Questionnaire (each item scored on range of 0-100 where higher scores represent more positive evaluation).	Y	Objective - Total sleep time 6.5 ± 1.0h in carers *vs* 6.6 ± 1.2h in non-carers. - Sleep latency 28.5 ± 15.3min in carers *vs* 26.1 ± 13.3min in non-carers. - Wake after sleep onset 48.2 ± 24.7min in carers *vs* 42.6 ± 24.6min in non-carers. - Sleep efficiency 81.1 ± 6.7% in carers *vs* 82.3 ± 4.6% in non-carers. - Number of awakenings 27.0 ± 10.5 in carers *vs* 29.7 ± 9.0 in non-carers. - Number of times out of bed 2.1 ± 1.9 in carers *vs* 0.6 ± 0.9 in non-carers. - Out of bed duration 20.8 ± 13.0min in carers *vs* 2.8 ± 5.1min in non-carers. Subjective - Ease/difficulty getting to sleep 63.3 ± 23.1 for carers *vs* 76.6 ± 15.1 for non-carers. - Slow/quick getting to sleep 60.7 ± 23.0 for carers *vs* 57.4 ± 30.0 for non-carers. - Sleep restlessness 59.1 ± 29.2 for carers *vs* 91.7 ± 5.8 for non-carers - Period of wakefulness 48.7 ± 14.8 for carers *vs* 79.6 ± 11.1 for non-carers.	-	-
Sharma et al. (2014).	2	Cross-sectional	India	- N=100 (24%) family carers of neurosurgical inpatients.	- 3% <20 - 66% 20-40 - 26% 40-60 - 5% >60	- Modified Caregiver Strain Index - Interviews	N	- 41% of carers reported that the duration of sleep they were getting was not sufficient. - 55% of carers reported to receive <4 hours of sleep. - 41% reported to received 4-7 hours of sleep.	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
								90% of carers mentioned disturbed sleep patterns with 43% reporting that their sleep is disturbed on a regular basis.		
Trivedi et al. (2014)	2	Cross-sectional	USA	- N=111,156 (57%) carers to friends/family members with health problems, long-term illness or disability	- 55.0 ± 14.8	- National survey (sleep module administered to a subset of participants).	N	- 56% of carers received the recommended amount of sleep. - 59.4% did not fall asleep unintentionally. - Carers were less likely than non-carer to receive the recommended amount of sleep.	-	-
Tsukasaki et al. (2006)	2	Cross-sectional	Japan	- N=35 (100%) carers to the elderly (spouses or relatives)	- 58.7 ± 6.6 carers with no sleep disruptions. - 65.8 ± 11.5 carers who wake up to use the toilet. - 57.3 ± 12.2 carers scheduled voluntary awakening for care. - 58.4 ± 8.6 involuntary awakening for care.	- Actigraphy -	Y	- Number of sleep interruptions 0 for no sleep disruptions *vs* 1.3 ± 0.7 for toilet disruptions *vs* 2.0 ± 1.1 for voluntary care disruptions *vs* 2.3 ± 1.3 for involuntary care disruptions. - Duration of sleep 6.6 ± 1.3h for no sleep disruptions *vs* 6.6 ± 1.5h for toilet disruptions *vs* 6.3 ± 0.9h for voluntary care disruptions *vs* 6.7 ± 1.1h for involuntary care disruptions.	-	-
Tsukasaki et al. (2008)	2	Cross-sectional	Japan	- N=78 (100%) elderly carers of relatives or spouses	- 62.5 ± 9.6	- Actigraphy - Interviews - Questionnaires	Y	- Total sleep time 6.1 ± 1.4h. - Number of times leaving the bed 1.3 ± 1.3. - 26% reported not getting a deep sleep. - 8% reported taking hypnotics within the preceding month. - 40% provided night-time care to care-recipients.	-	- Hours of sleep at night were inversely associated with the mean systolic blood pressure.
Washington et al. (2018)	2	Cross-sectional	USA	- N=395 (82%) carers of hospice patients.	- 60.6 ± 12.6	- 9-item Patient Health Questionnaire (Includes a sleep item measuring trouble falling or staying asleep or sleeping too much in prior 2 weeks. Range of 0 = not at all – 3 = nearly every day).	N	- 17% reported trouble falling asleep or sleeping too much nearly every day. - 13% reported trouble falling asleep or sleeping too much more than half the days. - 33% reported trouble falling asleep or sleeping too much several days.	-	- Sleep problems and anxiety were highly positively correlated.
			-	-	-	-		-	-	-

Authors	Quality Assessment	Study Design	Country	N (% female)	Mean age ± SD [range] (years)	Measures	Objective measure (Y/N)	Sleep outcome	Reason for disturbance	Impact/Consequence
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