

Commissioned Research Report

# Sleep deficits in Australian carers

Understanding and helping the  
sleep deficits of Australian carers

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Report

# Sleep deficits in Australian carers

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### Executive Summary

Caring responsibilities place unique demands on the carer. Increasingly, the impact on the caring individual is recognised and growing efforts are made to support their needs. A recent systematic review commissioned by Carers Australia through the Sleep Health Foundation identified that the sleep of carers is poorly understood. Carers who may be vulnerable to poor sleep are not well characterised, and the aspects of caring duties which contribute to poor sleep have not been well established.

This report details findings from an online survey of Australian carers, conducted in early 2020. These findings highlight the prevalence of poor sleep for Australian carers, with sleep duration well below the recommended hours per night for healthy teenagers and adults. Caring requirements are diverse, and have varied impacts on individuals.

We see here that sleep disturbance in carers often relates to concern, worry, or attention to the needs of the care recipients. However, carers themselves who reported health conditions of their own had particularly poor sleep and are a subgroup of Australian carers who may require individualised support to improve sleep health. Young Australian carers are sleeping substantially less than the recommended durations which is concerning.

Carers who were caring for individuals with multiple complex needs were also vulnerable to poor sleep. Many indicated that their sleeping arrangements were not ideal; and while bed or bedroom sharing was preferred by some it was not the best approach for all.

These findings highlight a pressing need to support the sleep health and wellbeing of Australian carers, and particularly in vulnerable sub-groups including young carers, carers with their own health concerns, and carers supporting recipients with multiple complex needs.

**Carers experience significant disturbances to sleep, and impairments to both sleep quantity and quality, across all caring contexts**

## Introduction



**In 2018, 12% of Australians were unpaid carers, equating to 2.65 million people nationwide.**

Carers are individuals who provide care and support to those members of our community who have a disability, mental illness, chronic condition, palliative illness, drug or alcohol issues, or are frail aged(1). These recipients of care are typically, but not always, family members of the carer. Carers are the foundation of community care systems, including aged, disability, and palliative care, making carers an integral part of Australia's overall healthcare system.

In 2018, 12% of Australians are unpaid carers, making up 2.65 million people nationwide(2). They represent every Australian demographically, however some groups are more likely to be carers. 70% of carers are women, and the average age of carers is 54 years old, although 9% of carers are under the age of 25(2). It is also significant to note that 30% of carers are themselves living with a disability(2).

Unpaid carers do not operate within normal working hours or schedules. They care as they are needed, and each does so in a unique manner, dependent on the needs of the care recipient, and potentially also catering to the needs of the wider family in addition to the care recipient, often 24 hours a day, 7 days a week. Therefore, research in this area must be tailored to this distinctive group, to understand the experience of carers and how to provide them assistance.

One-third of carers provide 40 hours or more per week of unpaid care, the equivalent of full-time work. This is then linked to the 42% on average lower income per week when compared with non-carers(2). The replacement value of unpaid care was \$60.3 billion, equating to over \$1 billion per week(1). However, provision of care 24 hours a day, 7 days a week has obvious repercussions for the carer themselves(3). Sleep disruption is one such repercussion.

## Sleep in carers

Adequate and quality sleep on a regular basis is critical to both the acute and long-term health and wellbeing of Australians(4). The Federal Government's Parliamentary Inquiry into Sleep Health Awareness in Australia (2018-2019)(5) demonstrates that on a national level sleep is recognised as important aspect of health and wellbeing.

The Reducing Sleep Disruption in Carers Report(6) noted that based on the known number of carers and the cost of inadequate sleep identified by Deloitte in Asleep on the Job(1), "the costs of inadequate sleep in carers could be as high as \$12.15 billion per annum in Australia". Carers Australia has identified that inadequate sleep for many carers is a major factor affecting their health and wellbeing(5).



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## How bad is sleep in carers?

Overall, it is clear carers experience significant disturbances to sleep, and impairments to both sleep quantity and quality, across all caring contexts. Due to the lack of high-quality research in this area the proportions are varied. Some studies reported 75% of carers reported sleep disturbance(7), whereas others are lower at 20%(8). The Pittsburgh Sleep Quality Index (PSQI) was the main tool utilised to assess subjective sleep quality, with large variability in scores across studies.

A PSQI global score greater than 5 is indicative of 'poor quality' sleep, and in some studies 95% of carers' scores over this number (9, 10).

Very little research has employed objective sleep measures, such as polysomnography to determine carers sleep quantity and quality. However, one study that did utilise polysomnography showed that some carers obtained as low as 4.4h of sleep per night(11), with an average of 7.0h. which is equivalent to non-carer Australian population(4, 11, 12).

Sleep efficiency (the proportion of time spent asleep compared to time in bed) was also reported to be significantly lower than the non-carer population (typical sleep efficiency in the population = >85%), with some studies recording sleep efficiency as low as 77% in carers (10, 13). Furthermore, sleep disturbance increased with higher burden of caring duties (i.e., the more frequent the care, the poorer the sleep)(14).

Carers have also indicated that non-carer family members experience sleep disturbance attributed to care recipient/s, such as noise, overnight care needs, or worry for their wellbeing (15, 16). Together, this snapshot highlights the poor sleep commonly experienced by carers.



**Previous research shows up to 75% of carers report poor sleep**



**Previous research reports some carers get as little as 4.4 hours sleep per night**

## Why do carers get poor sleep?



Care recipient needs to go to the bathroom



Care recipient requires resettling



Ongoing worry



Care recipient has medical needs



Noise

There are several reasons why carers may experience poor sleep, which depend on the individual circumstances of each carer and care recipient. However, some common causes of poor sleep have been identified. In the research to date, the major factor contributing to carer sleep disruption was directly caused by the overnight needs of their care recipient(16-19). Care recipients needing to go to the bathroom, requiring medical assistance (e.g. turning)(20), needing to be re-settled, or making noise during the night(16) were commonly reported causes of sleep disturbance(15, 21, 22).

The number of times carers awaken during the night is very high (range of 2.2-17.5 awakenings per night), with some studies reporting that 90% of carers regularly woke at least once per night(21). Ongoing stresses related to caring, such as vigilance, rumination, and worry, were also frequently reported as causing sleep disturbance(23, 24).

There is some evidence that different populations of carers are impacted in different ways. For example, younger caregivers (<65 years) have significantly shorter sleep durations than older caregivers (>65 years)(25); partner caregivers have poorer sleep quality than other family member carers(25); and female carers report more sleep disturbance than male caregivers(15, 26), reflecting interventions addressing sleep must be individualised to each carer demographic.

While this evidence indicates that there are some broad groups of carers whose sleep may be impacted to a greater degree than others (i.e. gender, age), we do not currently have an understanding of more specific groups of carers who may be either at risk (i.e. combined demographic factors), or who could be in need of tailored interventions. This requires further investigation.

## How does poor sleep affect carers?

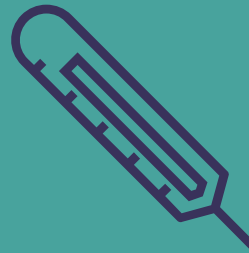
There is evidence sleep disturbances are likely to impact carers' lives and health in numerous ways. Previous small overseas studies in carer groups show that sleep disturbances are associated with decreased quality of life(26, 27); increased depressive symptoms(10, 28, 29); increased physiological stress(10, 30, 31); and poorer self-reported health status(10, 15) .

Disrupted sleep is also a safety concern, as up to 20% of serious road accidents in the general population are associated with poor sleep(32). Further, individuals with poor sleep are eleven times more likely to make a workplace error(33), and twice as likely to die in an industrial accident(34). While the negative health, safety and performance outcomes have not been explored in detail in caring populations, it is likely that poor sleep may pose potential risks to both the carer and care recipient.

## Poor sleep in the community is associated with:



Increased depressive symptoms



Poorer health status



Increased stress levels



Increased risk of road accidents





## Sleep in Australian Carers

There have been only three studies to our knowledge specifically looking into Australian carers' sleep, all of which focused on carers of child disability. However, all found sleep outcomes are comparable to the findings from overseas. In a study performed with carers in Victoria(35), 50% of mothers of children with developmental disabilities reported waking during the night every night as a result of their caring duties. Similarly, two other survey-based studies from Victoria(36, 37) found over 50% of carers of children with disabilities had had poor sleep. Poor sleep was also associated with poorer wellbeing and higher rates of depression and anxiety within these populations(36, 37). Additionally, 60% of parents reported their sleep as a significant problem that negatively impacted their daily commitments(36).

These studies suggest that Australian carers' sleep is typically poor and is likely to negatively impact the lives of carers themselves. However, there is a need for additional research considering those who are caring for adults and older children to gain a better understanding of the negative impacts of caring roles on sleep, the common and recurring causes of sleep disturbances, and how to effectively address these issues.



**60% of parents of Australian children with development disabilities reported poor sleep had a significant negative impact on their daily lives**

# Context of 2020 commissioned report

In 2019 Carers Australia partnered with the Sleep Health Foundation to undertake a systematic review of the literature regarding the extent, causes, and consequences of sleep disruption in carers worldwide, and any identified strategies and interventions to address these issues. This work was conducted by a team from CQUniversity Australia's Appleton Institute, and collaborators from the University of South Australia. The evidence base indicated carers experience significant disturbances to sleep and impairments to both sleep quantity and sleep quality, across all caring contexts. Following recommendations in the 2019 report, the Sleep Health Foundation commissioned a research team led by CQUniversity Australia's Appleton Institute in collaboration with the University of South Australia and Massey University to better identify the causes of sub-optimal sleep in Australian carers, understand the best ways to tackle poor sleep within the carer context, and widely disseminate this information via fact sheets and publications.



To achieve this, a survey was conducted to gather information about the sleep of Australian carers, addressing the aims listed below.

The intent of the survey and subsequent report was to inform development of carer specific factsheets and other resources for carers to access, with a view of helping carers improve their own sleep.

# Study Aims

1

Examine the self-reported causes of sleep disruption in this cohort of Australian carers, which may include

- practical needs of the care recipient
- vigilance, rumination and worry related to the care recipient
- poor sleep hygiene

2

Examine whether there are sub-groups of carers who are more dissatisfied with their sleep and who may be particularly at risk of the different types of sleep disruption, as above (e.g. young adult carers, older carers of those with dementia)

3

Identify the extent to which a range of sleep disruption mitigation strategies are used within this group of carers (e.g. respite care, napping, assistive technologies)

4

Explore the self-reported efficacy of a range of sleep management strategies in use across this cohort of carers (i.e. which strategies work a lot, a bit or not at all)

5

Examine the help-seeking strategies that this group of carers have pursued in relation to their sub-optimal sleep and the self-reported outcomes of these strategies

Any individual who provides care for another was invited to participate.

### Survey design and recruitment

The survey designed was required to be completed within a ~15 minute window, and broadly needed to identify sleep behaviours, source quality of sleep, and strategies carers currently use to manage their sleep. Given the limited existing data in this population, numerous open text options were provided to allow carers opportunity to provide input and feedback as desired.

To ensure the survey met the brief of Carers Australia, a consultative approach was taken to developing the survey materials. This comprised multiple feedback opportunities between the research team, the Chair of the Sleep Health Foundation, and Carers Australia representatives. The research team was overall responsible for developing the survey.

This resulted in a final survey which met the needs of Carers Australia, using appropriately validated and reliable survey measures. Recruitment was facilitated through Carers Australia and Sleep Health Foundation networks.

Data were collected in early 2020, via the Qualtrics platform, with data collection ceasing in mid-March 2020.



Online advertisement content provided by Carers Australia.



#### **DOES BEING A CARER IMPACT YOUR SLEEP?**

**Do you struggle with sleep?**

**Does your caring role mean late nights and early starts with broken sleep in-between?**

**We want to hear from you about your experiences!**

Carers Australia has commissioned the Sleep Health Foundation and Central Queensland University to conduct a study into how being a carer impacts sleep. The study will look at what strategies are currently being used by carers to help them sleep and provide recommendations for how carers can improve their sleep.

[CLICK NOW](#) to contribute to the study by completing a short survey.

# Methods

## Demographics

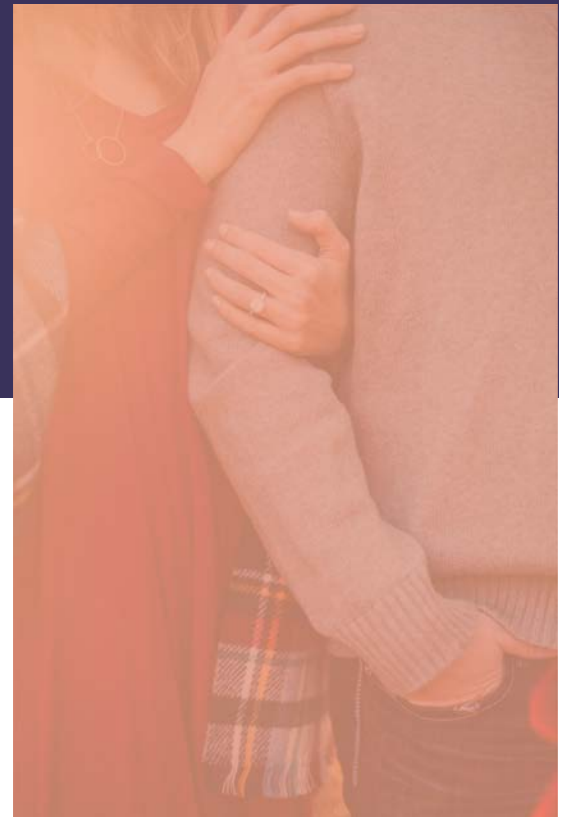
Demographic information was collected including gender, age, living location (major city, inner regional, outer regional, remote or very remote), postcode, employment status (working full-time, working part-time, a full-time student, part-time student, homemaker, unemployed, retired, unable to work due to disability, volunteer or other – please specify), whether the respondent has received any government payments in the last three months (including Carer Allowance, Newstart Allowance, Youth Allowance, Austudy, ABSTUDY, Disability Support Pension, Age Pension).

## Carer screening

Non carers were screened from the study by asking: “how many people do you currently provide assistance for (e.g. personal care, assistance with activities of daily living) because of their long-term illness, disability or frailty?”. If respondents indicated that they ‘do not provide care’ then they were taken to the end of the online survey.

## Sleep screening and management strategies

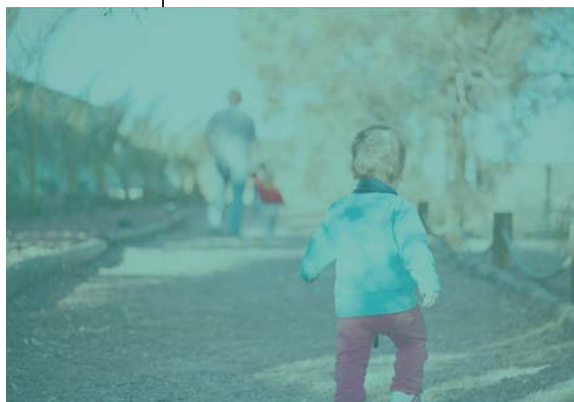
Information about participant sleep and sleep management strategies were collected. To screen their sleep, respondents indicated how satisfied/dissatisfied they are with their current sleep pattern (possible responses include ‘very satisfied’, ‘satisfied’, ‘moderately satisfied’, ‘dissatisfied’ and ‘very dissatisfied’. This question was taken from the Insomnia Severity Index (ISI). Respondents also indicated the amount of sleep in hours that they receive each night. Participants who responded that they were both satisfied with their sleep, and received >7 hours of sleep a night, were not included in final analyses, as the funding agency brief was to focus on strategies and help seeking in carers who were not achieving adequate sleep.





Carers were provided with a list of commonly used sleep management strategies and selected all that applied to them, including any they self-identified beyond the list provided. These are summarised in the box below.

Any further information about their sleep management strategies could be provided using a free text box, and where appropriate, these comments have been used to contextualise 'other' responses in the report.



For each sleep strategy indicated, respondents were then required to rate the effectiveness of that strategy using a 0-100 sliding scale, where 0 indicated that the strategy was 'not at all effective in managing their sleep', and 100 indicated that the strategy was 'extremely effective in managing their sleep'.

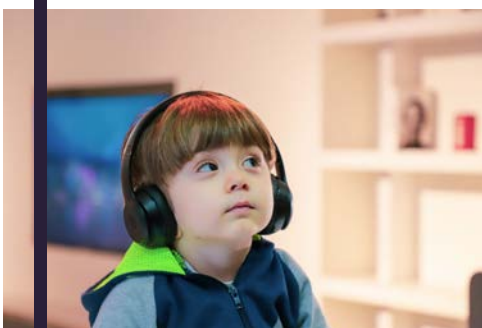
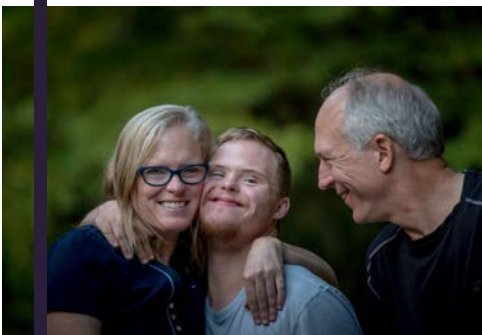


### Sleep Management Strategies

- Napping
- Going to bed early
- Over the counter sleep medication
- Prescription sleep medication
- Using sleep tracking technology
- Respite care services
- Having friends or family provide support
- Consistent pre-bed routine
- Comfortable mattress and/or bedding
- Altering eating or caffeine habits
- Exercising
- Use of sleep aids (eye masks, ear plugs)
- Meditation/relaxation/yoga
- Alcohol or other substances
- Other

## Care recipient demographics

Various aspects of the care recipients' demographics were assessed including care recipients' age and gender. To determine the care recipients' health condition, respondents selected all conditions that applied to their care recipient/s, from a list of various health conditions, which are summarised in the report (see page 23). To determine the extent of the care recipient's condition, respondents were asked "Do you believe that their condition is a lifelong condition or a condition from which they are expected to recover?" for which they could respond "lifelong" or "I expect them to recover".



## Impact of caring on sleep

The effects of caring on the carer's sleep was determined by providing carers with a list of commonly reported caring tasks which result in poor or disrupted sleep and selected all that applied to them. For each caring task indicated, respondents were then required to rate the extent that the task results in poor or disrupted sleep on a 0-100 sliding scale, where 0 indicated that the task does not result in poor sleep at all, and 100 indicated that the task results in a great deal of poor sleep.

The amount of time typically taken to provide care throughout the night was determined by asking respondents the number of times they get out of bed to provide care.

Respondents rated the extent that their caring role interferes with their sleep on a sliding scale of 0-100, where 0 indicated their caring role does not interfere at all and 100 indicated their caring role is extremely interfering. A similar rating scale was used to determine the extent that their caring role interferes with sleep through worry or rumination about the care recipient, where 0 indicated that worry or rumination does not interfere their sleep at all and 100 indicated that worry or rumination was extremely interfering to their sleep.

Finally, respondents were provided with a list of carer relevant assistive strategies or technologies and were asked to indicate which they utilised. Options included a bell, care dog, insulin pump, continuous glucose monitor, blood glucose meter, location/movement monitoring system, enuresis monitors, locks, temperature controls, fall detector, epileptic seizure alarm, video display/hands free phone, pressure mattress/bedding, personal alarm call system, other. Participants could also indicate that they do not use any assistive technologies in the household. Any further information about how their caring role impacts their sleep could be provided using a free text box.

Carers' sleep quality was determined using the Pittsburgh Sleep Quality Index (PSQI). The PSQI is a 19-item self-report questionnaire which measures sleep quality and sleep disturbance over the past month (38). Seven component scores are generated from the nineteen items including subjective sleep quality, sleep duration, sleep latency, sleep disturbances, habitual sleep efficiency, use of sleep medication and daytime dysfunction. The sum of the seven component scores make up the global PSQI score which has a range of 0-21, with higher scores indicating poorer sleep quality. The PSQI has demonstrated high internal consistency (Cronbach's  $\alpha=0.83$ ) and validity in both clinical and non-clinical populations (38, 39).

Respondents were also asked to indicate whether they shared a bed or bedroom with the care recipient, and how frequently. Responses options included not during the past month, less than once a week, once or twice a week, three or more times a week, and always.



## Sleep behaviour



## Help seeking

Help seeking behaviours related to improving carer's sleep were identified. A list of help seeking behaviours, taken from the 2019 Sleep Health Foundation Insomnia study (40), were provided and respondents indicated which they have engaged in during the past 12 months. For each help seeking behaviour, respondents were then required to rate the extent that the behaviour is effective in helping their sleep problems on a 0-100 sliding scale, where 0 indicated that the behaviour/strategy is not at all effective, and 100 indicated that the behaviour/strategy is extremely effective.

Any further information regarding the help respondents have sought or received regarding their sleep could be provided using a free text box.



Carers were asked questions related to their current personal circumstances including the use of respite care and their perceived standard of living. A list of common respite services was provided, and respondents indicated which services they currently receive. Options included: no respite service are currently used, short-term in-patient respite care (i.e. your care recipient will stay at a facility for a week or two at a time), in home care support (i.e. a nurse or carer visits the care recipient's home) for less than 5 h / week, in home care support (i.e. a nurse or carer visits the care recipient's home) for 6 - 15 h / week, in home care support (i.e. a nurse or carer visits the care recipient's home) for 16 - 30 h / week, in home care support (i.e. a nurse or carer visits the care recipient's home) for more than 30 h / week, care assistance out of home (e.g. day clubs), overnight respite in a care facility, cottage respite, house cleaning services, cooking support (e.g. Meals on Wheels, a personal chef), other (please specify), my care recipient currently lives in a residential care facility (e.g. hospital, nursing home, etc.).

If the respondent indicated any respite services other than "the care recipient current lives in a residential care facility (e.g. hospital, nursing home, etc.)", respondents were then asked "what living arrangement do you have with the person you provide care for?" (options: we live in the same household all of the time, we live in the same household some of the time, my care recipient lives with another friend or relative, or other)) and "are you considering residential care facilities for the person they provide care for" (options: not at all, possibly in the next 5 years, possibly in the next 12 months, definitely/awaiting placement).



## Personal circumstance



## Data management and analysis

### Aim 1

Prevalence as a percentage is provided for each cause of poor sleep. Means (averages) and standard deviations (an indicator of how varied responses are) were calculated for participant responses (out of 100) to indicate the extent to which carers felt each cause contributed to poor sleep. A higher score is indicative of a more negative impact on sleep.

### Aim 2

Descriptive statistics were generated for each variable to assess frequency of response items in each category. In order to determine meaningful differences between groups and identify sub-groups at risk for poor sleep quality and short sleep duration, a number of variables were recoded to allow for univariate analysis (using analysis of variance (ANOVA) for variables with >2 categories, and independent samples t-tests for variables with 2 categories). Age of carer was recoded into four categories (<18 years, 18-34 years, 35-54 years and >55 years). Age of care recipient was recoded into five categories (<10 years, 11-16 years, 19-34 years, 35-54 years and >55 years). Carer sleep or health problems which disturb sleep were grouped into yes or no, and care recipient health conditions were categorised by number (1, 2, >3). Number of caring requirements which disturb sleep were recoded into three categories (1-3, 4-6, >7). Assistive technology in the household and access to respite services were both grouped into yes/no.

Examination of the sleep duration variable revealed a small number of outliers (extreme values including both very short and very long sleep duration). Using the process of winsorizing, we retained these cases by replacing the extreme values with the next relevant case value.

## Data management and knowledge continued

### Aims 3 & 4

In a similar approach to Aim 1, prevalence as a percentage is provided for each sleep strategy. Means (averages) and standard deviations (an indicator of how varied responses are) were calculated for participant responses (out of 100) to indicate the extent to which carers felt each strategy was effective. A higher score is indicative of greater perceived effectiveness.

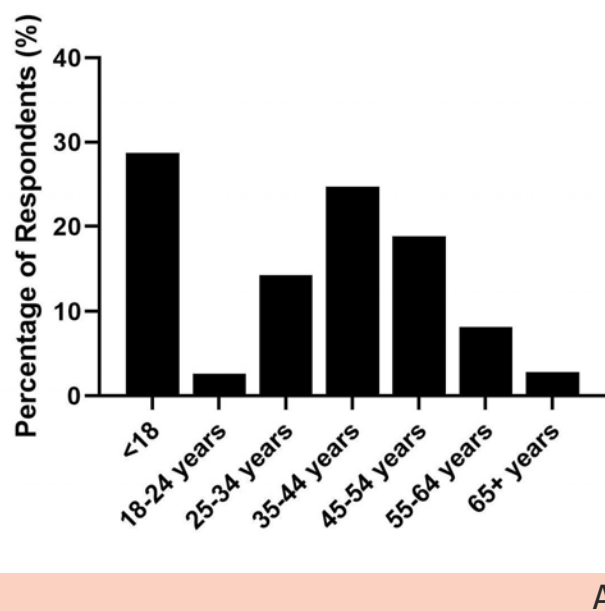
### Aim 5

Prevalence as a percentage is provided for a series of help seeking strategies. Means (averages) and standard deviations (an indicator of how varied responses are) were calculated for participant responses (out of 100) to indicate the extent to which carers felt each strategy was effective. A higher score is indicative of greater perceived effectiveness.

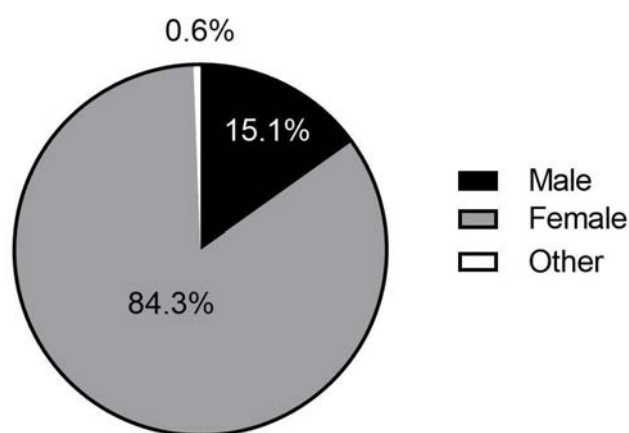


# Findings

## A snap shot of Australian Carers



In total, 500 participants provided responses about age and gender. However, 124 either did not complete subsequent information about the number of care recipients ( $n=107$ ), or specifically indicated they do not provide care to a care recipient ( $n=17$ ). For these analyses, sleep screening questions were used to filter out participants who indicated that they were either satisfied with their sleep, or achieving at or above the recommended duration to ensure no undue burden was placed on carers to respond to questions about poor sleep. This accounted for only 4.8% ( $n=24$ ) of carers who commenced the study, leaving a sample of 352 care providers for inclusion in subsequent analyses.

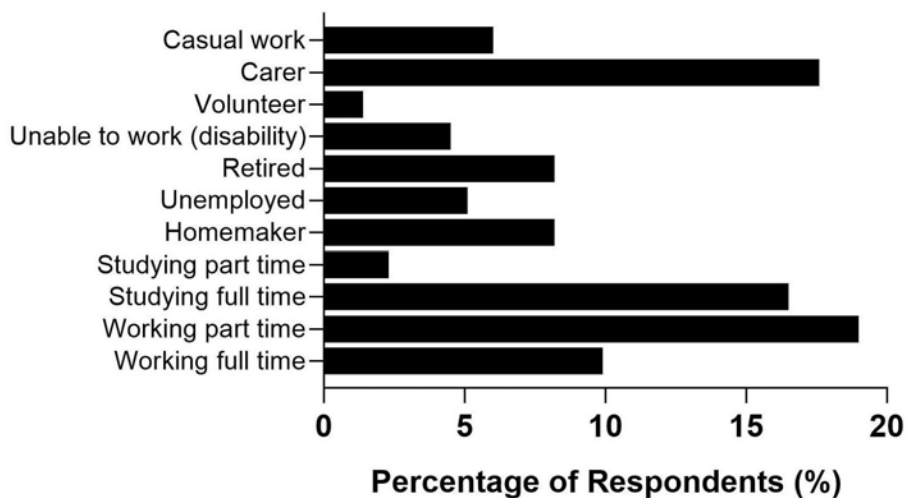


The distribution of carer age was noticeably bimodal, with the highest frequency of participating carers in either the under 18 (28.7%), or 35-50 (35.5%) year age brackets (as pictured). It is possible that the online only nature of recruitment with this study facilitated greater engagement with younger, rather than older, carers and the findings should be interpreted with this consideration in mind. Survey participants were predominantly female (84.3%).

Gender



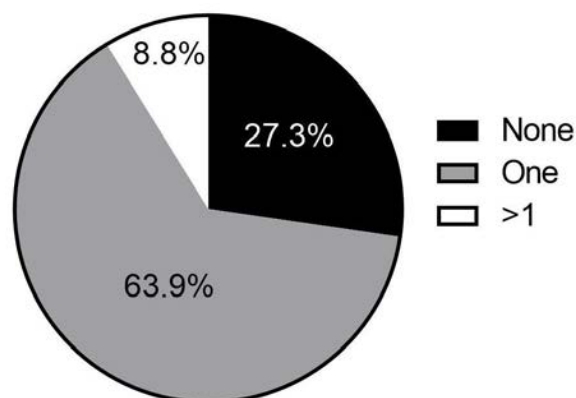
# Findings

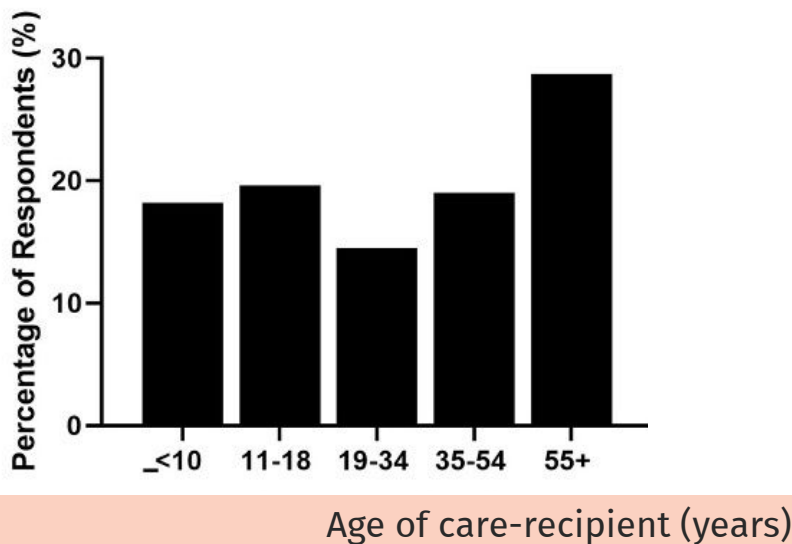


## Characteristics of participating Australian carers

When asked about employment status over the preceding 3 months, the most common responses were working part time (19.3%), primarily caring (17.8%) or studying full time (16.7%). The majority of participants indicated they reside in a major city (40.9%). More than 70% of respondents indicated they received one (63.9%) or more (8.3%) government payments; with carer's payment/support the most common source of government support (59.9%).

### Government Payments



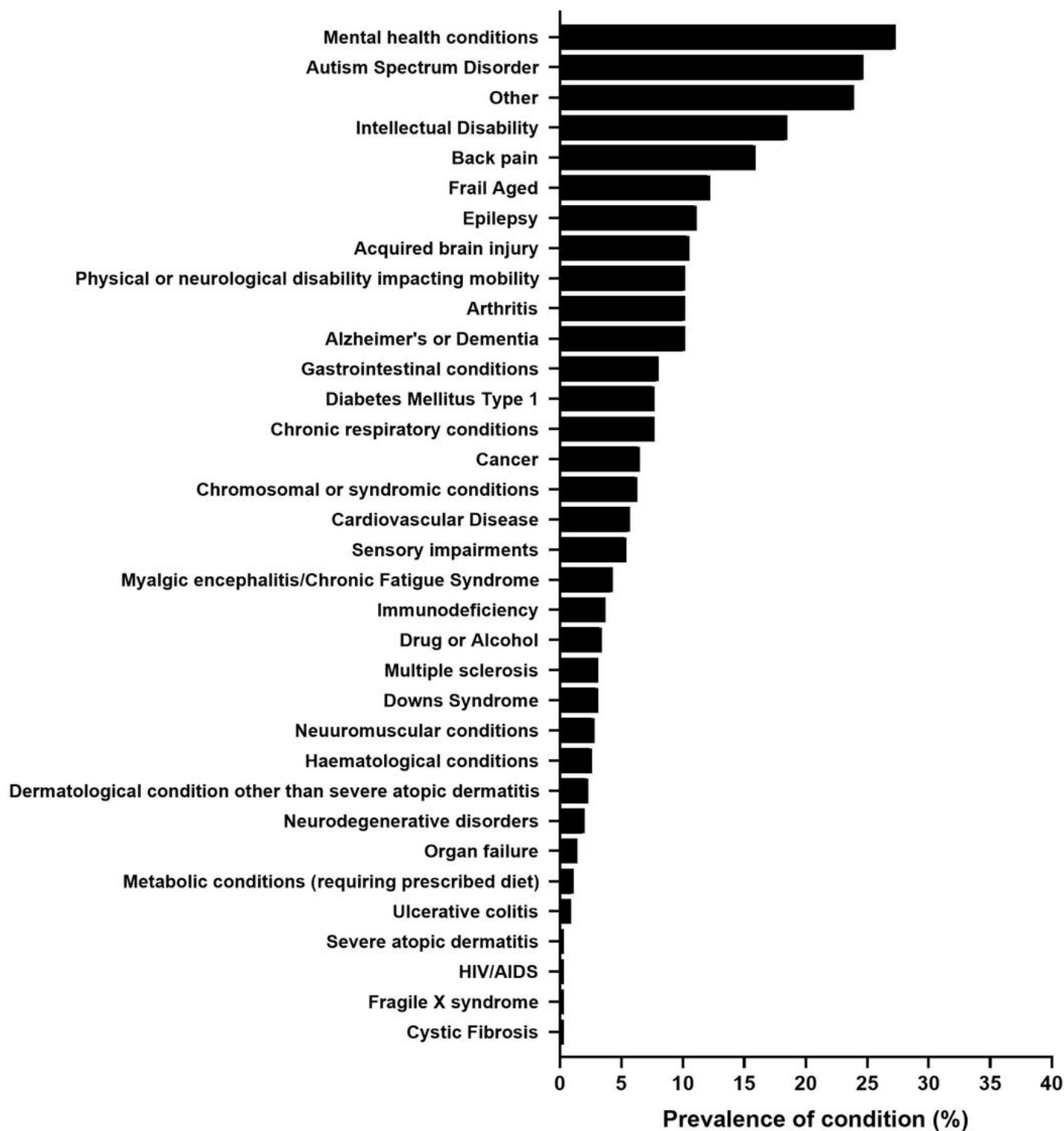


The majority of carers indicated they provide care for one recipient (72.4%), and that they live predominantly in the same household as their care recipient/s all (92.0%) or some (3.7%) of the time. Almost all carers who responded to the survey (97.2%) indicated they believed the condition of their care recipient was a lifelong condition. A quarter of respondents (24.6%) indicated they were currently considering residential care facilities for their care recipient; the remainder indicated this was not an option at all.

Care recipients were diverse in terms of age and reason for care. Care recipients were predominantly under 18 (37.8%) or over 65 years (18.8%). An overview of the spread of age is provided in the figure above.

## Care recipients and the caring environment

# Findings

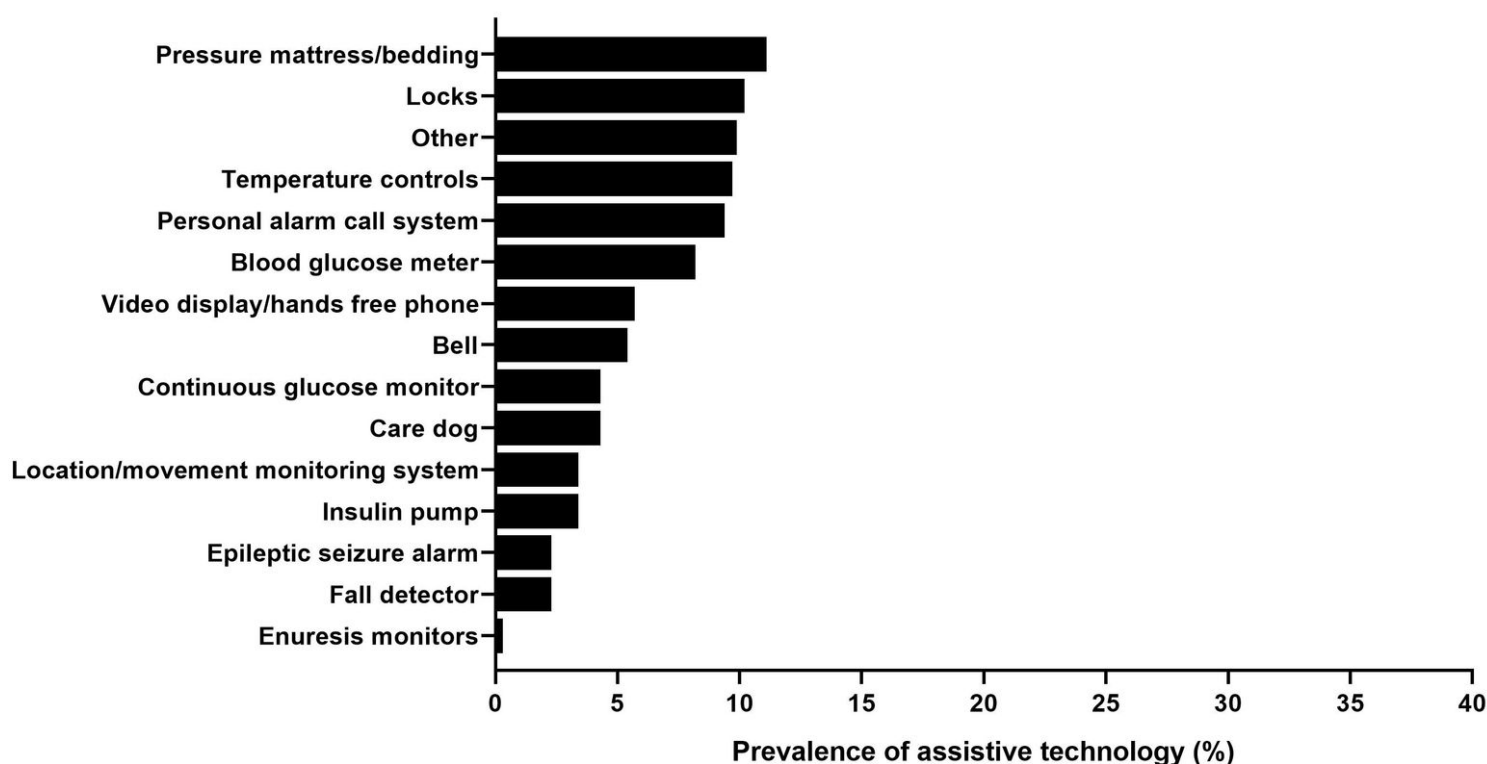


*Note: prevalence will not total to 100% as carers could answer multiple conditions.*

Prevalence of conditions of care recipient as reported by carers

# Findings

## Assistive technologies



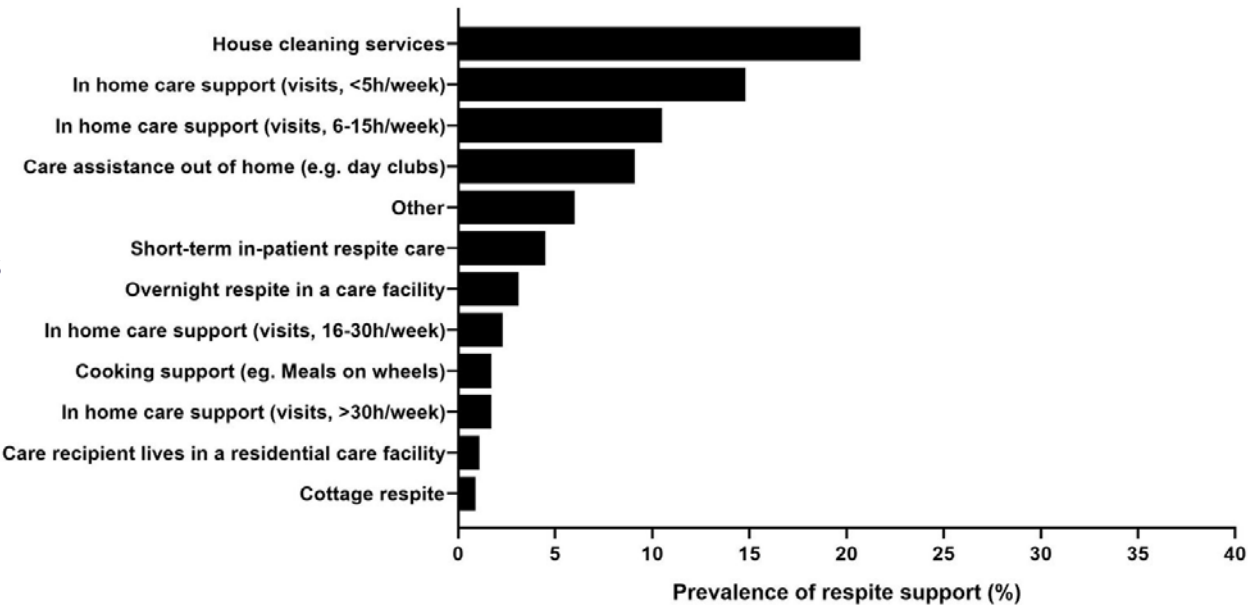
Prevalence of different assistive technologies reported by carers.

Just under half of the carers surveyed (45.5%) indicated that they use assistive technology in the household. A summary of assistive technologies reported by the sample is provided. 'Other' assistive technologies included a variety of open text responses such as oximeters and heart rate monitoring, modified or specialised beds, continuous positive airway pressure (CPAP) machines, iPads with speech and walkie talkies.



# Findings

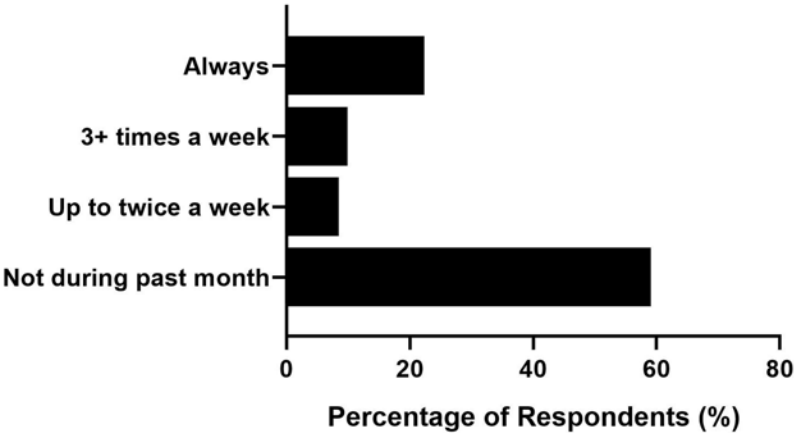
Use of any respite services was reported by 50.9% of carers in the sample. The types of respite varied, and are summarised to the right.



Prevalence of use of different respite services



## Bed sharing



Frequency of bed sharing with care recipient

Almost a quarter (22.4%) of carers indicated that during the past month, they always shared a bed or bedroom with their care recipient, while over half (59.1%) had not shared a bed or bedroom at all. The remaining one-fifth of participants (18.4%) shared a bed or bedroom with their care recipient a few nights a week.

# Aim 1

## *key messages*

Examine the self-reported causes of sleep disruption in this cohort of carers

- 1** The top three causes of sleep disruption in carers relate to concern and needs of the care recipient, rather than the carer's own health and wellbeing
- 2** Worry and rumination about the health and wellbeing of the care recipient is the most prevalent cause of sleep disruption in this sample of carers, affecting almost 80% of carers surveyed
- 3** More than 60% of carers are aware that they are awake and listening for disturbance from their care recipient, which is disturbing their sleep



# Findings

Carers were asked about a variety of potential causes of sleep disruption related to their caring responsibilities, including two questions about caring for themselves (i.e. their own health problems or sleep problems disturbing their sleep opportunity). This question was framed as *“Which of the following aspects of your caring role or your personal circumstances results in poor sleep/sleep interruptions during the night?”*

Participants were able to select as many disruptions as applied to their personal circumstances. When individuals indicated a cause of sleep disruption, they were also asked to score on scale of 0-100 the extent to which they felt each cause contributed to their own poor sleep or sleep interruption. Participants were provided with a list of 11 possible causes of sleep disruption relating to care for their recipient or for their own health/sleep health, and the option to provide a summary of ‘other’ causes.

Multiple causes of sleep disruption were common for carers. Only 10.5% of respondents indicated one cause of sleep disruption; almost half of the sample indicating they experience 4-6 of the causes of sleep disruption listed. The causes of sleep disruption, and their perceived impact on sleep are summarised on page 29.

# Findings

## The prevalent causes of carer sleep disruption were:



Worrying about care recipient



Listening for care recipient needs



Care recipient is distressed



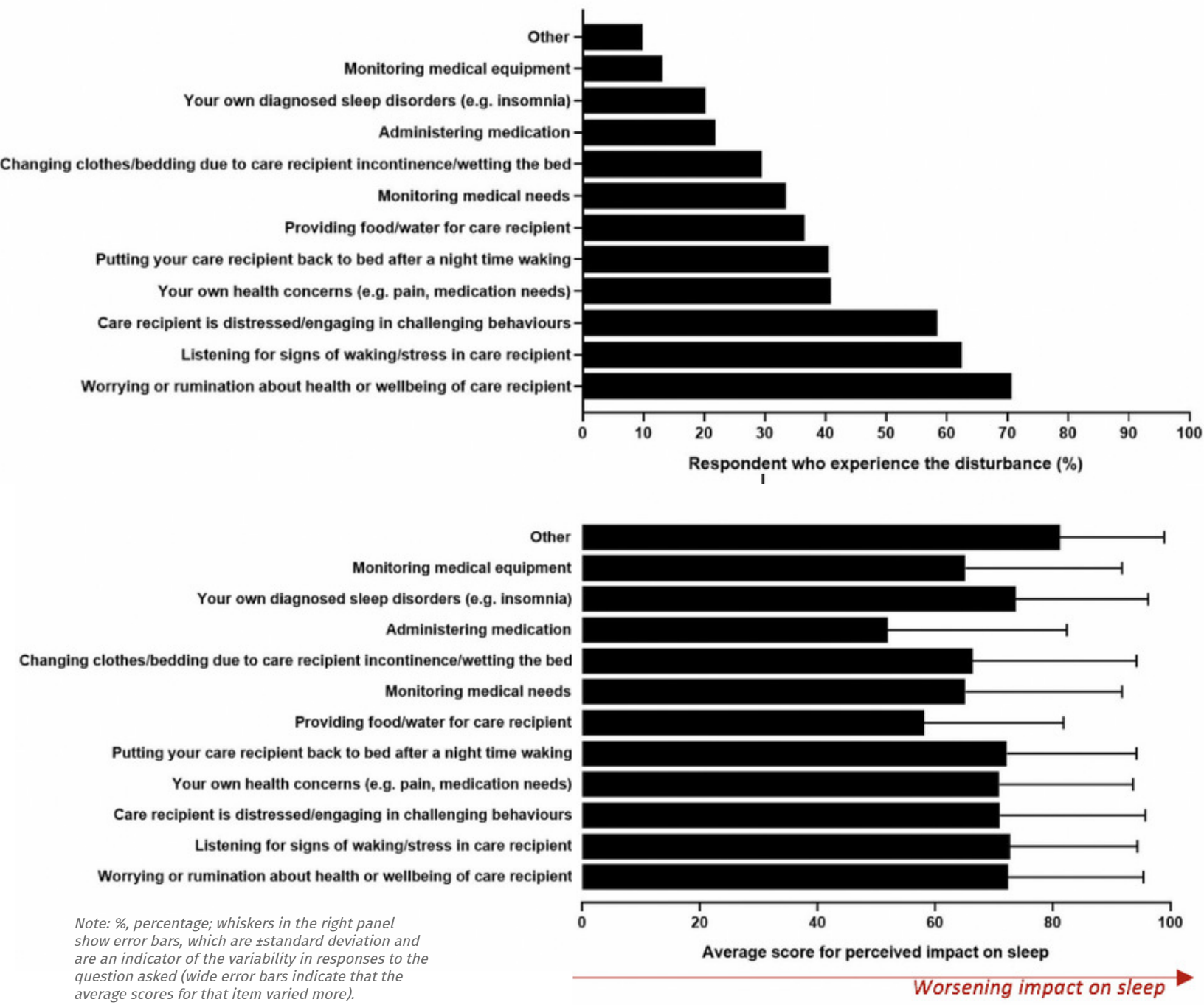
Carers' own health concerns

## Prevalence of care requirements which disturb sleep at night, and their perceived impact on sleep

These findings highlighted that worry or rumination related to the health and wellbeing of the care recipient was the most prevalent cause of sleep disruption amongst carers. The extent to which worry or rumination impact on sleep was comparable to the impact reported by participants who were actively waking to attend to care recipients in distress, exhibiting challenging behaviours, or putting care recipients back to bed after waking. Administering medication, providing food or water to a care recipient, and monitoring medical equipment were the three causes of sleep disruption with the lowest perceived impact on carer sleep.

Thirty-six carers indicated 'other' caring responsibilities contributed to sleep disruption. As the average score for impact on sleep was high for these responsibilities, we examined the free-text responses provided by these 36 respondents to better understand causes of sleep disruption. Financial worries, toileting (for themselves or for the care recipient) and the need to fit in other domestic, study or work responsibilities, or have time for themselves at night were identified as contributors to poor sleep or sleep interruption.

# Causes of sleep disruption



Causes of sleep disruption in Australian carers, and the perceived impact of these disturbances on sleep

# Aim 2

## *key messages*

Examine whether there are sub-groups of carers who are more dissatisfied with their sleep and who may be particularly at risk of the different types of sleep disruption, as above (e.g. young adult carers, older carers of those with dementia)

- 1** Sleep quality and sleep duration are poor across carers of all ages, and irrespective of the age of the care recipient
- 2** Sleep quality and sleep duration are particularly concerning in young carers, with average sleep duration in this sub-group well below the recommended 8–10 hours a night for teenagers.
- 3** Carers with health and/or sleep problems themselves report poorer sleep quality, and are a sub-group of carers who likely require additional support and intervention
- 4** Carers with bed and bedroom sharing arrangements which differ from night-to-night (i.e. sharing a few nights a week) reported poorer sleep quality than those who never or always shared a bed or bedroom with their care recipient.

# Aim 2

## *key messages*

(cont)

Examine whether there are sub-groups of carers who are more dissatisfied with their sleep and who may be particularly at risk of the different types of sleep disruption, as above (e.g. young adult carers, older carers of those with dementia)

- 5** Increasing numbers of night wakings to provide care is linked with poorer sleep quality and shorter sleep durations
- 6** Access to respite services was not associated with better sleep quality and duration. This may be as respite does not include nights, or provokes anxiety and worry which further impacts sleep. The relationship between respite services and sleep requires further attention.
- 7** Carers of individuals with multiple complex needs are a sub-group particularly vulnerable to sleep disruption.

# Findings

## Aim 2 findings

In order to address Aim 2 and identify sub groups of carers who may be more dissatisfied with their sleep and more at risk of sleep disruption, we explored problems with sleep using two outcomes:

- Sleep quality (global score from the Pittsburgh Sleep Quality Index, or PSQI)
- Self-reported sleep duration (self-reported average sleep duration)

In total, 204 carers provided complete responses to the PSQI which allowed for interpretation of self-reported habitual sleep duration, and calculation of the global PSQI sleep quality score.

Scores on the PSQI in the sample of carers were indicative of poor sleep quality across all carers. Higher PSQI scores are indicative of poorer sleep quality; with 21 the maximum score.

Sleep durations in the sample ranged from three to nine hours over the preceding month, after accounting for extreme outliers.



**Some carers reported as little as 3 hours sleep per night over the preceding month**





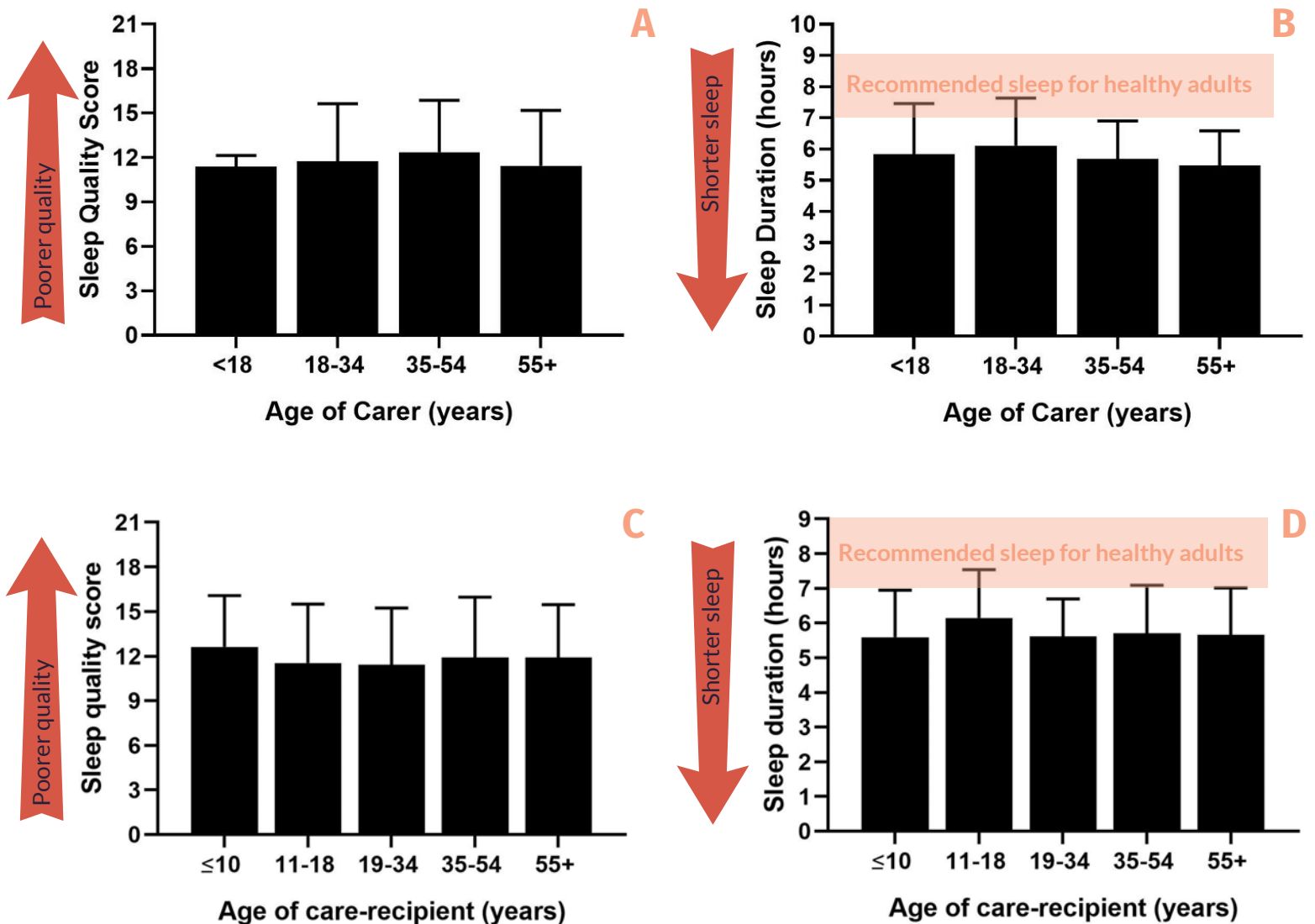
## Aim 2 analysis overview

Potential sub groups of carers were considered in terms of individual factors (e.g. age of carer, age of care recipient, health/sleep needs of the carer themselves, and sleeping arrangements), demands on carers (e.g. number of health conditions and volume of night time caring commitments which intrude on sleep), and access to resources (e.g. assistive technology and respite).

It is important to note here that the small sample size and under-representation of groups (e.g. older carers and care recipients, and carers of people with dementia) meant we were unable to conduct further sub group analyses, and control for factors like age, gender and type of illness.

## Carer and care recipient age

Sleep quality (A)<sup>1</sup> and duration (B)<sup>2</sup> did not differ by **age of the care provider** or **age of the care recipient**<sup>3</sup> (C and D), with values in the “poor” range across carers and recipients of all ages. These values are lower than National Sleep Foundation recommendations and comparison samples of ‘good’ sleepers, and similar to samples of people experiencing sleep disorders. Average sleep durations for young carers, in particular, fell well below recommended healthy sleep durations.



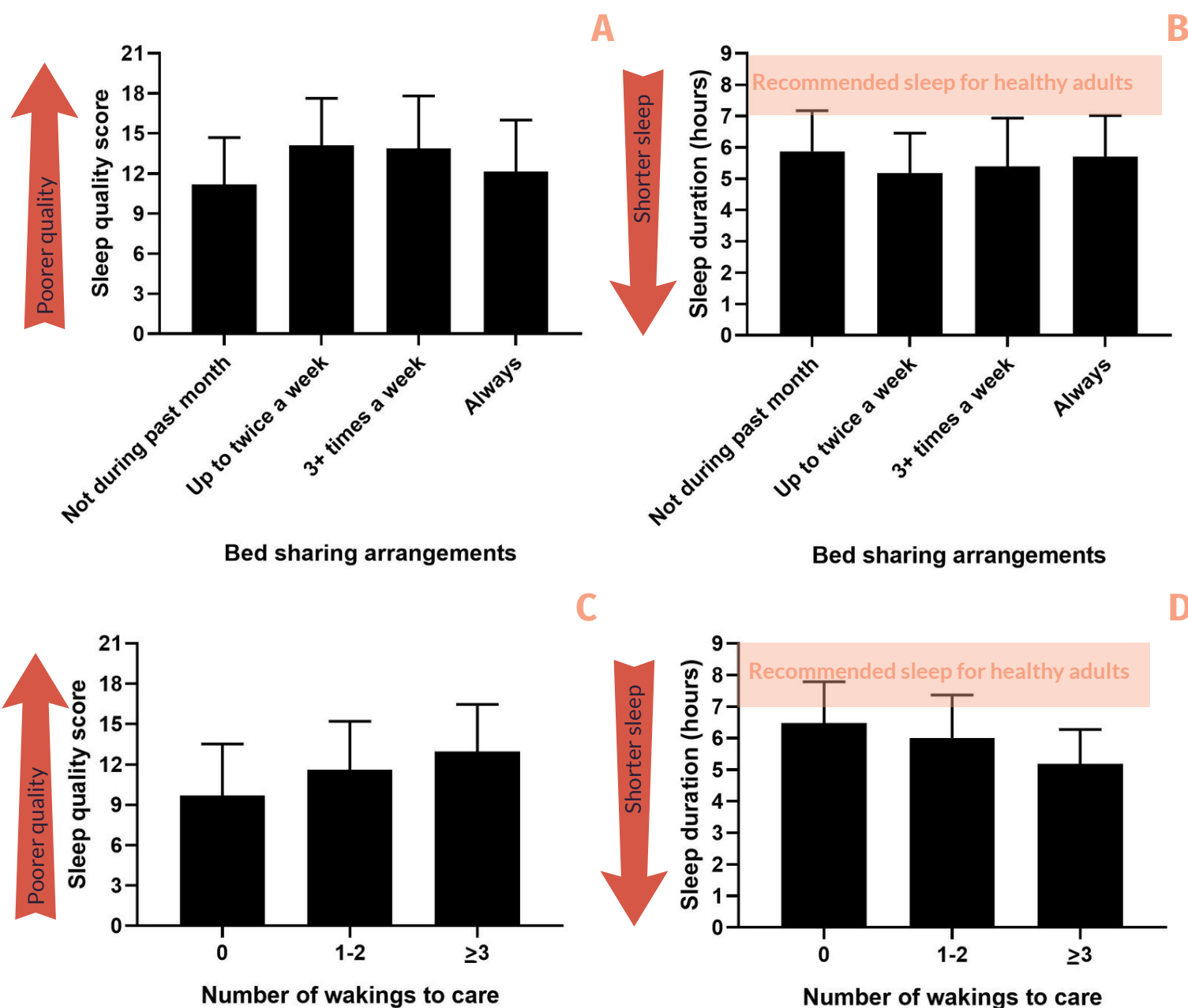
Average sleep quality and sleep duration scores by carers' and care recipients' age

1. Difference in sleep quality by age of care provider was not significant ( $F_{3,83.77}=0.94$ ,  $p=0.423$ )
2. Difference in sleep duration by age of care provider was not significant ( $F_{3,80.58}=1.62$ ,  $p=0.192$ )
3. Differences in sleep quality ( $F_{4,91.11}=0.56$ ,  $p=0.690$ ) and sleep duration ( $F_{4,92.80}=1.05$ ,  $p=0.388$ ) by age of care recipient were not significant

## Sleeping arrangements and number of night wakings to provide care

Sleep quality (A) was poorer in **those who shared sleep space (either bed or bedroom)** with the care recipient a few times a week compared to those who shared 3 or more times a week<sup>4</sup>. Sleep duration (B) did not differ according to sleeping arrangements<sup>5</sup>. Those who always shared a sleep space with their care recipient had a higher sleep quality score, than those who inconsistently did. However, this was not significantly different to those who had not shared a sleep space in the past month. This suggests that inconsistency and change in sleep routine has a more significant impact on carers' sleep quality, rather than the sleeping arrangements themselves.

Sleep quality (C) worsened<sup>6</sup>, and sleep duration (D) shortened<sup>7</sup> with **higher numbers of night wakings** on a typical night. Of note, even in carers who indicated no waking overnight to provide care, sleep quality was still poor and sleep duration shorter than recommended for healthy adult sleep.



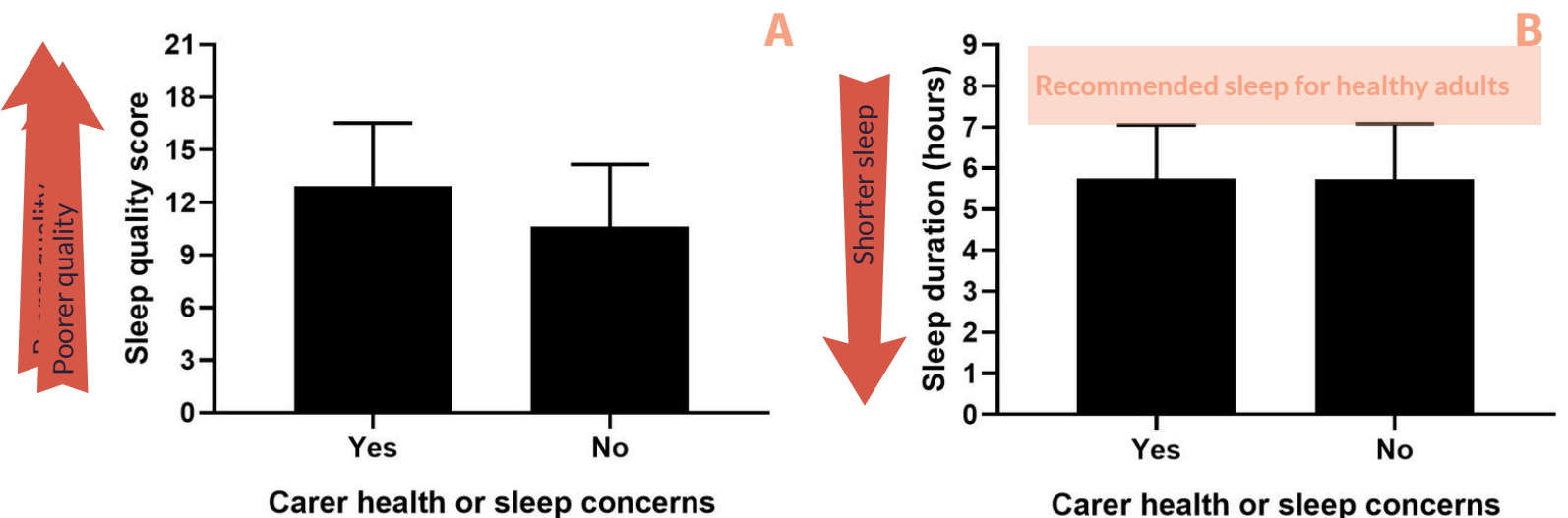
Average sleep quality and sleep duration scores by sleeping arrangements and volume of night wakings

- Significant difference in sleep quality according to sleeping arrangements ( $F(3,41.03)=5.32$ ,  $p=0.003$ ).
- No significant difference in sleep duration according to sleeping arrangements ( $F(3,40.97)=1.85$ ,  $p=0.154$ ).
- Significant difference in sleep quality with volume of night wakings to provide care ( $F(2,84.40)=9.40$ ,  $p<0.001$ ).
- Significant difference in sleep duration with volume of night wakings to provide care ( $F(2,83.20)=17.05$ ,  $p<0.001$ ).

# Findings

## Care provider has own sleep and health problems which they identify impact sleep

Sleep quality scores (A) were lower for carers who reported that their own health problems impacted their sleep<sup>8</sup>, but sleep duration (B) was consistent and short irrespective of whether the carer reported their own sleep and health problems were impacting sleep<sup>9</sup>.



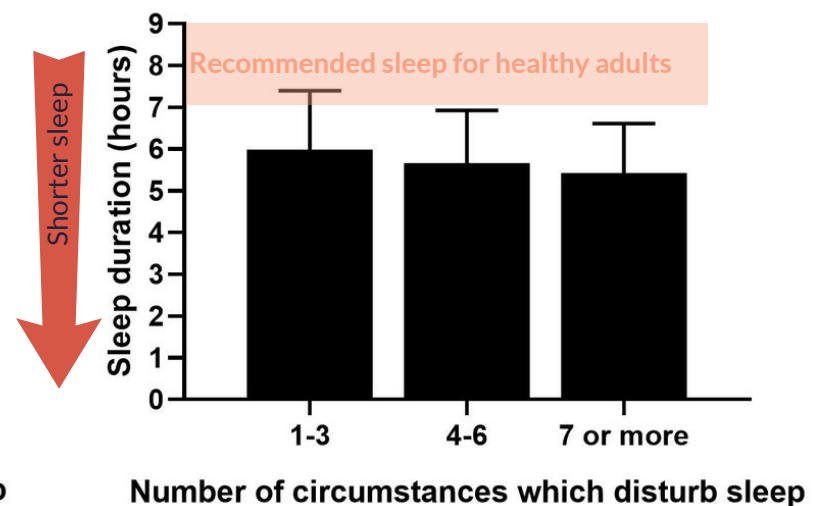
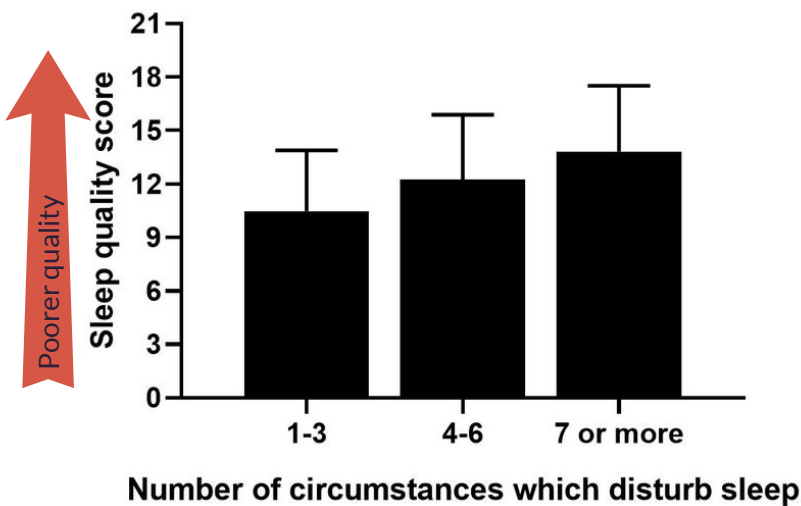
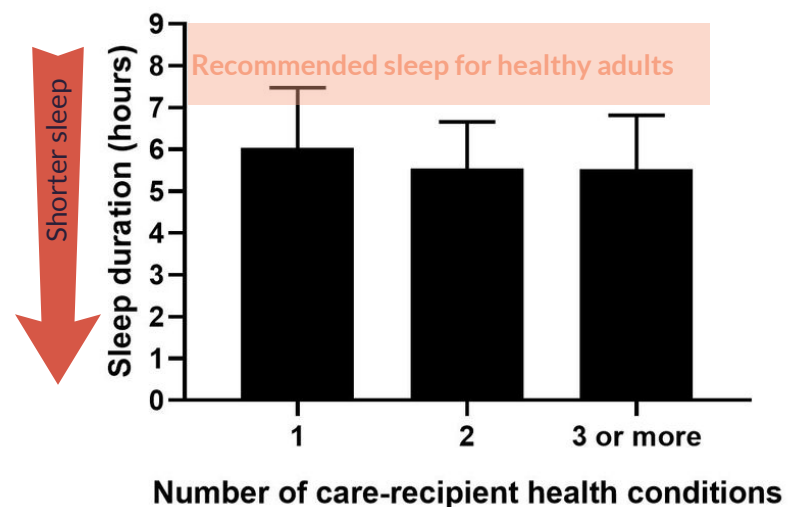
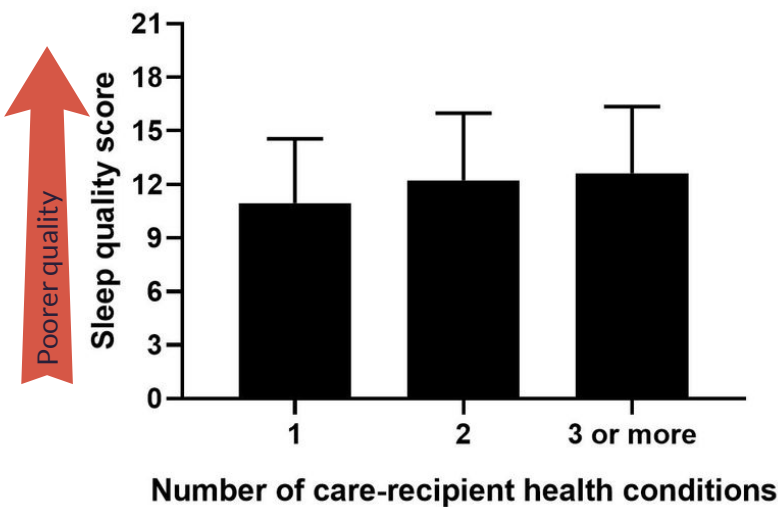
Average sleep quality and sleep duration scores according to the carer having health or sleep problems

8. Significant difference in sleep quality in carers who reported their own sleep and health problems ( $t(202)=0.09$ ,  $p=0.929$ )
9. No significant difference in sleep duration in carers who reported their own sleep and health problems ( $t(202)=0.09$ ,  $p=0.929$ )



## Number of health problems experienced by care recipient, and number of circumstances which disturb sleep

Poorer sleep quality (A)<sup>10</sup> and shorter sleep duration (B)<sup>11</sup> were found when carers reported that their care recipient lived with **multiple health problems** as compared to a singular health problem. Carers who identified a higher volume of **caring circumstances which disturb sleep** reported significantly poorer sleep quality (C)<sup>12</sup>, particularly when seven or more requirements were identified which disrupted sleep. Sleep duration did not differ significantly based on caring requirements at night (D)<sup>13</sup>. However, sleep duration was consistently low across all volumes of caring circumstances which disturb sleep.



Average sleep quality and sleep duration scores by care-recipient conditions and number of night time caring circumstances disturbing sleep

10. Significant difference in sleep quality by number of health problems experienced by the care recipient ( $F(2,114.89)=4.42$ ,  $p=0.014$ ).
11. Significant difference in sleep duration by number of health problems experienced by the care recipient duration ( $F(2,122.96)=3.49$ ,  $p=0.034$ ).
12. Significant difference in sleep quality by number of circumstances disturbing sleep ( $F(2,99.09)=12.22$ ,  $p<0.001$ ).
13. No significant difference in sleep duration by number of caring requirements at night ( $F(2,104.18)=2.62$ ,  $p=0.077$ ).

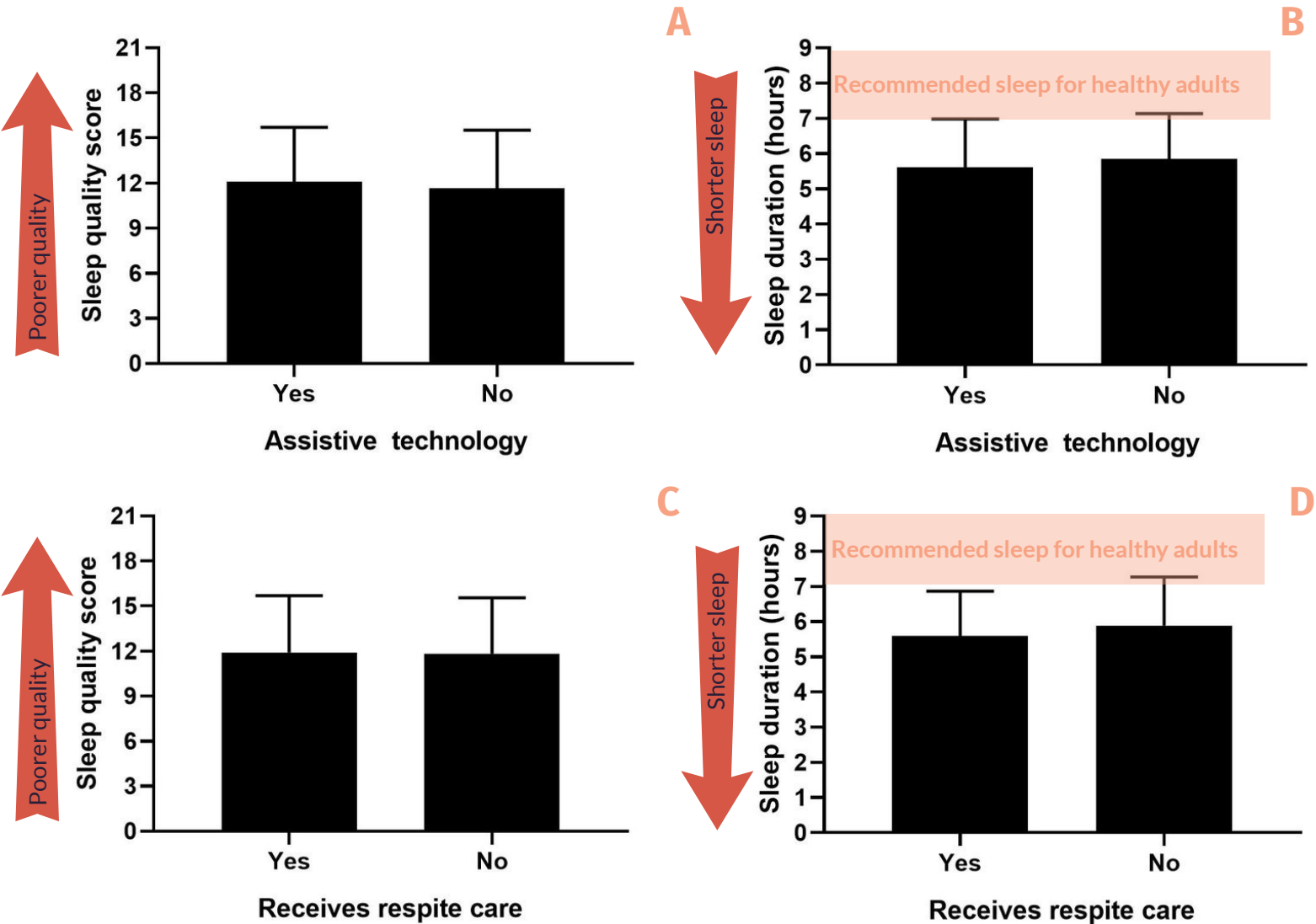


**Access to resources  
(respite and assistive technologies)**

Presence of any assistive technology in the household was not associated with sleep quality (A)<sup>14</sup> or sleep duration (B)<sup>15</sup>. Similarly, access to any respite services was not associated with sleep quality (C)<sup>16</sup> or sleep duration (D)<sup>17</sup>. However, it is important to note that while no significant differences were observed in access to respite services and sleep duration, when given the opportunity to comment about their caring arrangements many carers expressed a need/desire for extra support and respite. It should be noted that the most common reported respites were short-duration day-time services (e.g. <5-hour cleaning/cooking support), and not overnight or replacement care. Analysis of what respite services improve carers sleep should be investigated in the future.

***"I'm tired. There is no help available...I've looked and I've asked. We don't qualify or something. I don't know. Maybe help just doesn't exist..."***

**female, 53 years, caring for one recipient**



**Average sleep quality and sleep duration scores by use of assistive technology and respite services**

14. No significant difference in sleep quality scores by presence of assistive technology in the household ( $t(202)=0.84$ ,  $p=0.402$ )  
15. No significant difference in sleep duration by presence of assistive technology in the household ( $t(202)=1.33$ ,  $p=0.186$ )  
16. No significant difference in sleep quality scores by respite services in the household ( $t(202)=0.17$ ,  $p=0.865$ )  
17. No significant difference in sleep duration by respite services in the household ( $t(202)=1.56$ ,  $p=0.121$ )



# Aim 3 & 4

## *key messages*

Identify the extent to which a range of sleep management strategies are used within this group of carers (e.g. respite care, napping, assistive technologies) and explore the self-reported efficacy of a range of sleep management strategies in use across this cohort of carers (ie which strategies work a lot, a bit or not at all)

1

Carers in this sample reported varied, and often multiple, strategies attempted in an attempt to achieve sufficient sleep. Given the perceived efficacy of these strategies, and the poor sleep quality and duration in the sample, it is evident that there is a need to develop and support sleep strategies specifically for carers in the community

2

In light of the causes of sleep disruption identified as part of Aim 1, cognitive and behavioural strategies (such as cognitive behavioural therapy for insomnia [CBTi]) may be a good strategy to support carers in the community

3

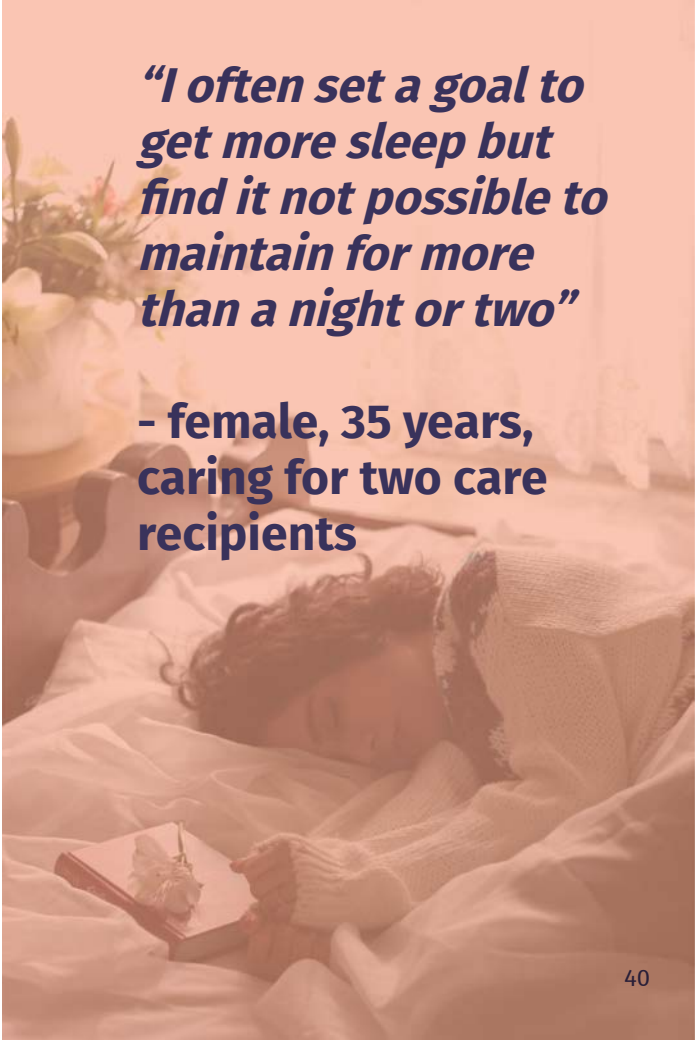
There remains a reasonable percentage of carers who have not tried any strategies. Increasing communication and support for all carers about healthy sleep strategies, and particularly amongst support groups and networks, may be a positive step.

## Aims 3 & 4

To address Aims 3 and 4, participants were provided with a series of sleep management strategies and asked “Which of the following do you currently use to manage your own sleep?”. Carers were able to select as many strategies as applied to their personal circumstances. When a strategy was identified, carers were asked to score on scale of 0-100 the extent to which they felt the strategy assisted with their sleep. There was also an option for carers to indicate that they do not use any sleep strategies.

Participants were provided with a list of 14 sleep strategies, and the option to provide a summary of ‘other’ strategies they currently use. Other options included use of illicit substances (cannabis, cannabis oil), lock up routines to keep house occupants safe, prayer, and essential oils. Prevalence and perceived efficacy of the strategy for assisting sleep are summarised on page 42.

A number of carers do not currently use any sleep strategies to improve their sleep (13.6%). This is important to note, as all participants included in the analysis either reported dissatisfaction with their sleep, or a habitual sleep duration below the recommended duration for healthy adults which is indicative of a need for intervention or support to improve sleep.

A photograph of a woman with dark hair sleeping peacefully in a bed. She is wearing a white long-sleeved top. A book is open on the bed near her, and a vase with white flowers is visible in the background. The image has a warm, orange-toned overlay.

***“I often set a goal to get more sleep but find it not possible to maintain for more than a night or two”***

**- female, 35 years, caring for two care recipients**



## Aims 3 & 4



40%

### Napping

was the most commonly reported sleep strategy but had the lowest efficacy, used by 40% of respondents

In contrast to napping, respite services were used as a sleep strategy by <10% of respondents, but **scored as one of the more effective strategies** in terms of managing sleep.

Importantly, some participants indicated in their free text responses that they felt their caring responsibilities impacted too significantly to implement any management strategies.

Further, there often were financial or contextual constraints on the ability to manage their sleep disruption, particularly for young carers. Some open text examples are provided below for context.

"I have to work it around study, part time job, and caring for mum."

female, 19 years, caring for one recipient

"Sometimes due to the demands of my caring role and current mood of my care recipient - I am unable to employ these strategies. This ends up damaging the quality of my sleep and thereby makes it more difficult to perform my daily functions as a carer and young student"

male, 19 years, caring for one recipient

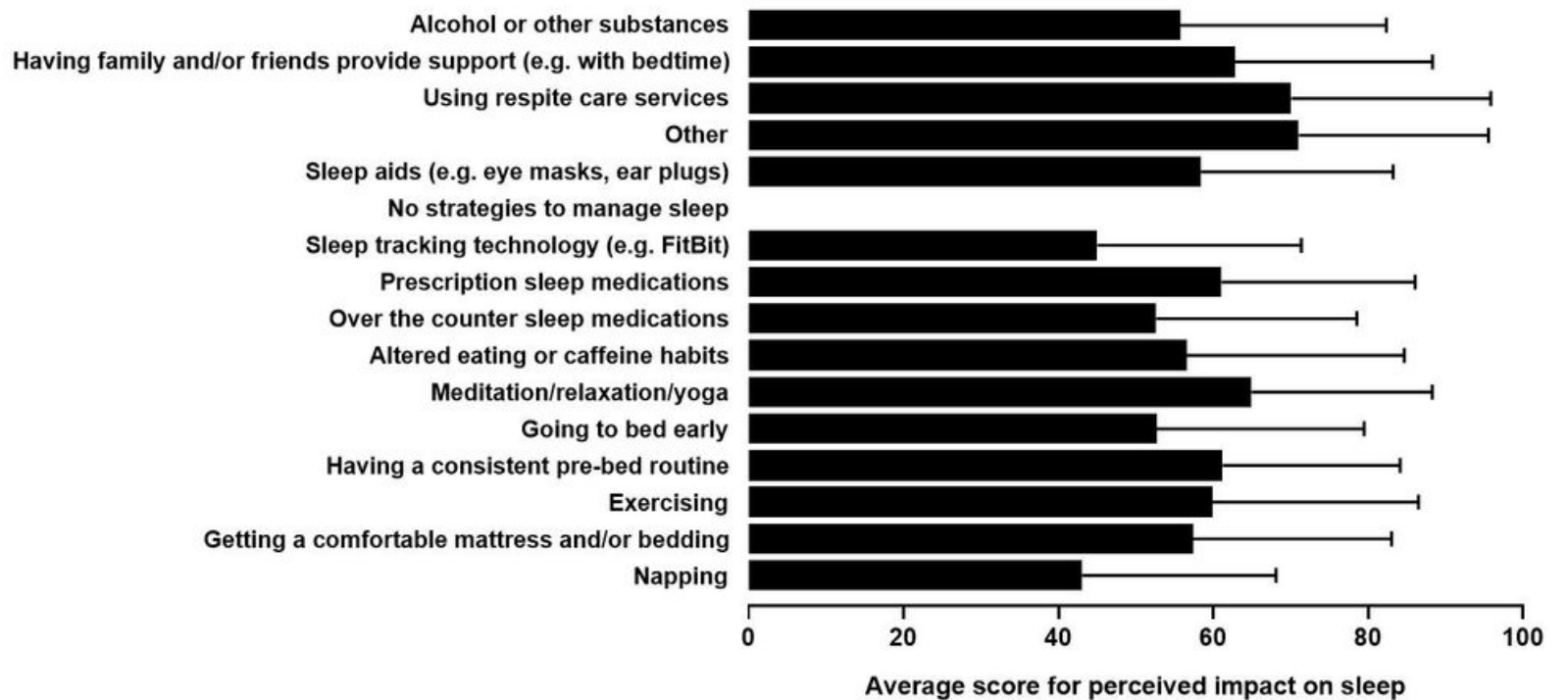
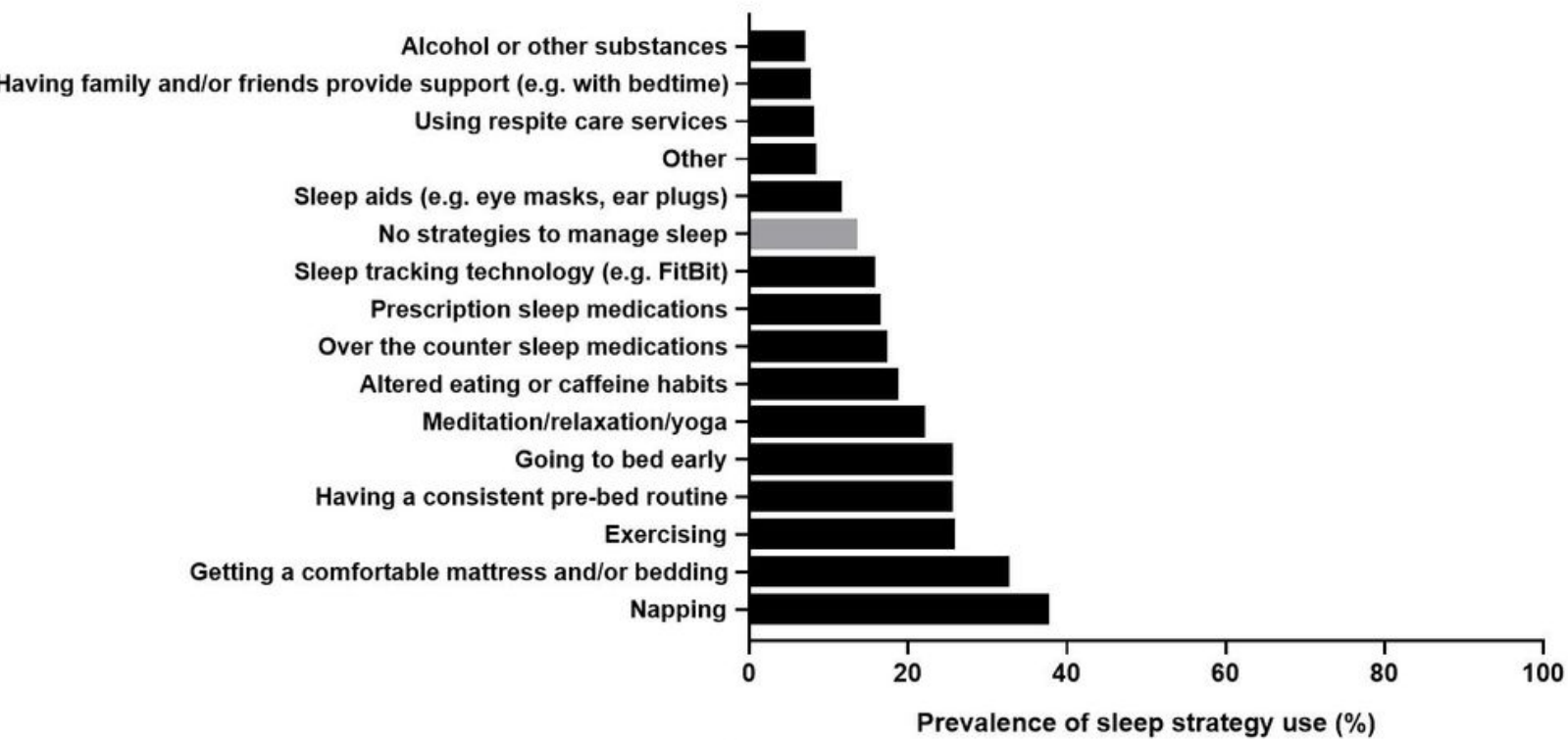
"I need a new mattress but can't afford one. I use sleeping tablets to get 7-8 hrs of sleep but would prefer to get to sleep naturally"

female, 48 years, caring for one recipient

"I need to sleep in the same room as my husband but haven't found a suitable bed that will fit in the space so I sleep in a recliner"

female, 60 years, caring for one recipient

# Sleep Management Strategies



Sleep management strategies used in Australian carers, and the perceived efficacy of these strategies

# Aim 5

## *key messages*

Examine the help-seeking strategies that this group of carers have pursued in relation to their sub-optimal sleep and the self-reported outcomes of these strategies.

- 1** Given the poor sleep quality and duration across this sample, the rates of help seeking are low, with only half of carers in the sample indicating they have sought help for sleep in the last 12 months
- 2** Perceived efficacy of these sources of help is low overall, and highlights that existing print and online media may not be accessible, relevant, or sufficiently targeted to support sleep problems in this unique subgroup of the population
- 3** Promoting the importance of carer sleep, and conversations with healthcare practitioners in this regard, should be a priority to improve engagement with relevant sources of help for sleep.

## Access to resources



**“GP wasn't interested in my lack of sleep, anxiety, depression. GP only interested in BGLs.”**

**female, 54 years, caring for five recipients**

Napping was the most prevalent sleep strategy used in this sample of carers, with almost 40% of respondents indicating they nap. Interestingly, however, ratings of efficacy were lowest for napping of all of the strategies.

In contrast, respite services were used as a sleep strategy by <10% of respondents, but scored as one of the more effective strategies in terms of managing sleep.

To address Aim 5, participants were asked a series of questions about help seeking for sleep problems, framed as “During the last 12 months, have you sought help with your sleep problems from any of the following?”. Carers were able to select as many sources of help for sleep problems, both formal and informal, as were relevant to their circumstances. There was an option to select ‘other’, and specify. When a source of help was identified, carers were also asked to score on scale of 0-100 the extent to which they felt the source of help assisted with their sleep. Participants could also respond that they had not sought help for their sleep problems in the last 12 months.

Almost half of carers who participated indicated they had not sought help for their sleep problems in the last 12 months. This included informal help such as internet searches, books, and family or friends. Of those who did seek help, the most common sources of assistance reported were general practitioners and mental health professionals.

Comments about help seeking were not always negative. One carer's insight provided an example of benefits gained from seeking help:

***“Talking about strategies with both friend and GP was helpful. Each has a different perspective and ideas, so often gained some benefit. I think brainstorming re own issues has been the greatest help. Sleep inducing and duration lengthening has really been of little help”***

female, 60 years, caring for one recipient

Strategies shared by other carers were perceived to be beneficial, due to lived experience, and may offer insight into a pathway towards supporting more carers with help for sleep. This is likely due to the perception that carers share experiences and may have awareness and ideas to improve sleep which are relevant to the unique situations faced by many carers.

*“Carers have particular issues most none(sic) Carers don't understand. I truly believe that's why help from other Carers is more effective than none(sic) carers”*

female, 53 years, caring for one recipient



It is important to note that some respondents identified that the feeling of poor sleep had become normalised,

*“Haven’t really had time to delve into it. It feels ‘normal’”*

female, 45 years, caring for one recipient

and the perception that help seeking strategies cannot help the problem

*“There is nothing any of them can do to stop the person I care for from waking me up”*

female, 45 years, caring for two recipients



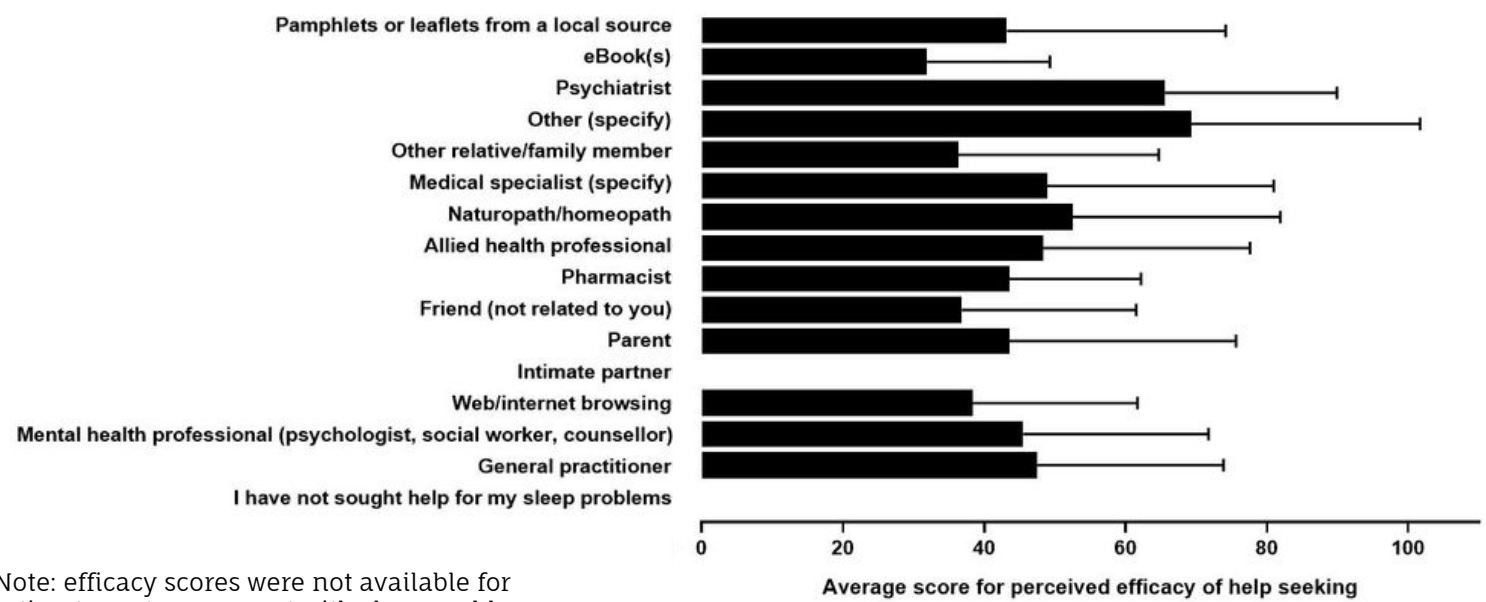
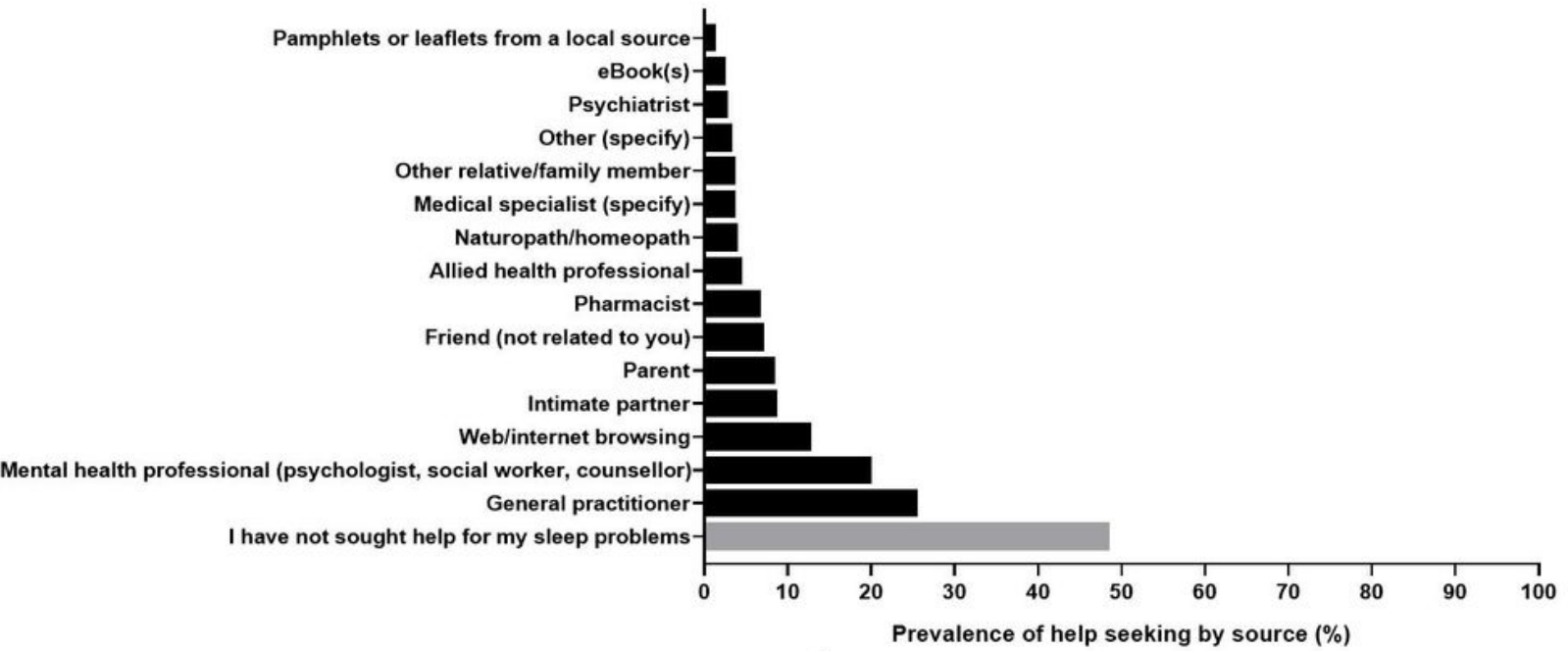
Feeling unseen or overlooked in regards to their own sleep and wellbeing was also reported on more than one occasion:

*“I feel I get left behind sometimes in health. Due to having caring duties and other kids very demanding.”*

female, 45 years, caring for three recipients



# Prevalence of seeking help



Note: efficacy scores were not available for intimate partner support with sleep problems and are not included in the figure.

Prevalence of help seeking by source, and perceived effectiveness of each source

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***“This is a place that most people do not want to know about.***

***Thank you for listening to the less known part of a carers life.”***

female, 69 years, caring  
for one recipient.

The impact of these perceptions related to seeking help for sleep problems will require further attention in future studies.