

# BMJ Open Exploring older care recipients' sleep status as a predictor for informal carer distress: evidence from New Zealand's interRAI home care assessment data

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## ABSTRACT

**Objectives** Understanding factors affecting informal carers' well-being is important to support healthy ageing at home. Sleep disturbances of care recipients are increasingly recognised as affecting the well-being of both parties. This research assesses the relationship between indicators of care recipients' sleep status and carer distress, as well as carer distress with subsequent admission to residential aged care, using prospectively collected Home Care International Residential Assessment Instrument (interRAI-HC) assessment data.

**Participants** Data were sourced from 127 832 assessments conducted between 2012 and 2019 for people aged 55 years or older who had support from at least one informal carer. The majority (59.4%) of care recipients were female and 59.1% were defined as having cognitive impairment or dementia (CloD).

**Setting** New Zealand.

**Design** Logistic regression modelling was used to assess the independent relationships between indicators of care recipients' sleep status (difficulty sleeping and fatigue) and primary caregivers' distress (feeling overwhelmed or distressed). Kaplan meier curves illustrated the subsequent relationship between caregiver distress and care recipients' transitions to aged residential care.

**Results** Care recipients' sleeping difficulty (32.4%) and moderate–severe fatigue (46.6%) were independently associated with caregiver distress after controlling for key demographic and health factors included in the assessment. Distress was reported by 39.9% of informal caregivers and was three times more likely among those supporting someone with a CloD. Caregiver distress was significantly associated with care recipients' earlier admission into aged residential care.

**Conclusions** Indicators of sleep disturbance among care recipients are associated with increased likelihood of carer distress. This has implications for managing the overall home-care situation and long-term care needs, as well as the well-being of both parties. Findings will inform research and development of measures, services and interventions to improve the sleep and waking health of older people, including those with CloD and family caregivers.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study utilised a large sample of data from >125 000 formal Home Care International Residential Assessment Instrument (interRAI-HC) assessments reflective of New Zealand healthcare setting to explore the relationship between indicators of older care recipients' sleep disturbance with primary informal carer distress.
- ⇒ Results are based on cross-sectional comparisons rather than longitudinal analyses, however indicate the importance of sleep status.
- ⇒ The interRAI-HC assessment data focuses primarily on the care recipient, so lacking comprehensive data concerning primary carer's situation and health.
- ⇒ Sleep is not a key focus of the interRAI-HC assessment and the questions pertaining to sleep disturbances and fatigue are short and not standardised measures for identifying disordered sleep.
- ⇒ Despite the large sample size, Māori and Pacific Peoples are under-represent in the data, reducing statistical power for understanding differences by ethnicity or culture.

## INTRODUCTION

With increasing life expectancy, there is a growing population of older adults.<sup>1</sup> This has been met with strong social drivers for 'ageing well in place'.<sup>1–3</sup> The meaning of this depends on the preferences of the individual and their familial context. However, preferences typically err on living within the family home for as long as possible, rather than utilising institutionalised care.<sup>1</sup> With advancing age and frailty, conditions such as dementia, depression and anxiety increase alongside somatic diseases.<sup>4</sup> Ageing well in place is therefore dependent on the availability of appropriate support. Such support is typically provided informally, by those who live with the older person and are not formally trained in healthcare. This is often a family member who's caregiving role may be informed by

gender, geographical and vocational convenience, as well as pre-existing relationship quality rather than healthcare skills.<sup>2 5 6</sup>

In New Zealand, approximately 480 000 people (almost 10% of the population) are estimated to be providing informal care on a regular basis for someone who is ill or disabled.<sup>7</sup> Studies from elsewhere indicate this prevalence could be higher, particularly where the formal health systems are changing or failing (eg among those disadvantaged geographically, culturally or socioeconomically<sup>1 8</sup>). Therefore, informal caregivers represent billions of dollars' worth of support every year and provide a vital role in aged healthcare.<sup>7</sup> Understanding and supporting informal caregivers as well as care recipients is an important step in ageing well in place.

Caring for someone with chronic or complex needs can result in caregiver distress (ie, anxiety and stress associated with the caring role), or 'burden'. Such terms are used to encompass the impact of different dimensions of caregiving. For example, in relation to emotional toll, time dependency, developmental changes, as well as the physical tasks and social issues.<sup>9</sup> The well-being of caregivers has been associated with the health and emotional status of the care recipient as well as the severity of their symptoms and the amount of time and type of care that is required.<sup>10-12</sup> For example, Quinn *et al*<sup>13</sup> found that the poorer quality of life of care recipients with dementia was associated with increased carer stress and challenges. Others have indicated that older carers and those who live with their care recipients, particularly spousal carers have greater likelihood of carer distress, as opposed to those who live elsewhere or are younger family members.<sup>14</sup> With a growing population of informal caregivers, greater attention is required to understand, prevent and moderate such impacts.

In New Zealand, anyone seeking publicly funded home care services (such as support with household duties, activities of daily living (ADL) or caregiver support) must undergo an assessment. The home care international residential assessment instrument (interRAI-HC) is a formal part of the process for assessing New Zealand residents with regard to what care and support are required and can be provided by government-funded services, or whether they are eligible for entry into aged residential care<sup>15 16</sup>). The interRAI-HC has been mandatory for those seeking such services since 2012. It helps assess levels of need and is repeated as required. It includes a range of questions including those concerning the care recipient's individual and social position and context, their health and functioning, as well as a measure of informal carer distress. Recent research has analysed interRAI-HC assessment data to identify variables significantly associated with caregiver distress.<sup>14</sup> These include relationship to their care recipient, time spent providing care as well as care recipient's mood, cognition and health status. However, sleep has often been overlooked in assessments of healthy ageing as well as of caregiver stress. This is an important consideration as sleep occupies approximately a third of our time.

Sleep is increasingly recognised as a vital aspect of health and well-being across the lifespan, important for waking function and mood, as well as long-term mental and physical health.<sup>17 18</sup> Sleep has been shown to change with ageing, disease, and with increased roles and responsibilities. Older research participants often report sleep as becoming more fragmented, occurring earlier each night or being less satisfying compared with younger adults or their former selves.<sup>19 20</sup> Furthermore, sleep disorders such as insomnia and sleep apnoea become more prevalent with ageing and diseases such as depression, cardiovascular disease and cognitive impairment.<sup>17 21 22</sup> Such changes in sleep can lead to daytime sleepiness or fatigue and exacerbate the waking symptoms of disease, such as reduced mental attention, working memory and immune functioning. For example, within a cohort of adults aged over 80 years, 29% self-reported sleep problems. Furthermore, those with sleep problems in this cohort were significantly more likely to also have indicators of frailty, cognitive impairment, pain, falls, as well as increased hospital admissions.<sup>23 24</sup>

Poor sleep health (eg, having a primary sleep disorder or atypical quantity, timing or quality of sleep) is associated with individual-level factors (such as genetics, health status and individual choices); social level factors (such as socioeconomic status, work, culture and family roles) and broader societal factors (such as 24/7 society, natural environment and racism).<sup>25 26</sup> In New Zealand, self-reported sleep problems (measured using various single items measures as well as validated scales) are reported by 25%–30% of the general population including older adults.<sup>23 24 27-29</sup> Socioeconomic and ethnic disparities in sleep health have consistently been found among younger adults. However, with advancing age, demographic and socioeconomic factors appear to be less predictive of poor sleep, while physical and mental health status become more so.<sup>23 24</sup>

Health conditions often exacerbate sleep problems. For example, cardiometabolic conditions, depression, arthritis and pain have all been found to contribute to issues such as sleep-disordered breathing, issues getting to sleep and staying asleep as well as excessive daytime sleepiness.<sup>30 31</sup> The number of comorbid health conditions tends to increase with ageing. Furthermore, medications prescribed for other health conditions frequently have sedating or alerting side effects and thereby reduce sufficient or satisfying sleep.<sup>32</sup> Cognitive impairment and dementia-related conditions have unique sleep-related symptoms including desynchronised sleep patterns and confused awakenings from sleep, as well as increased prevalence of sleep disorders such as obstructive sleep apnoea and insomnia.<sup>33 34</sup> These kinds of sleep disturbances can be challenging for the individual as well as informal carers supporting them at home.<sup>34 35</sup> Therefore, to better understand carer distress, factors relating to sleep require greater consideration.

Informal carers have been identified as having considerable sleep disturbances associated with the weight of

their responsibilities, the sleep of the person they support and degrees of external support.<sup>36</sup> For example, in a New Zealand based survey, Gibson and Gander<sup>35</sup> found that 65% of those caring for someone with dementia at home reported trouble sleeping themselves. Moderate-to-severe sleep problems were more likely among carers with poorer self-related health and living standards as well as when the care recipient required support at night or had sleep problems themselves.<sup>35</sup> Most importantly, sleep problems were significantly associated with considering residential care requirements more imminently for the person with dementia.<sup>35</sup> Follow-up interviews with a subsample of these survey participants suggest that sleep is among the most challenging issues among those caring for someone with dementia, having implications for carers mood, health and ability to cope with the overall situation.<sup>37</sup> However, the relationship between care recipients sleep and carer distress has yet to be explored in broader samples of New Zealand carers or using large-scale population data.

The InterRAI-HC assessment includes assessments of care recipients sleep disturbance as well as fatigue and primary carer distress.<sup>38</sup> Given that these assessments are mandatory and the high acceptance rate from clients of data usage for research purposes (over 90%<sup>14</sup>), the Inter-RAI-HC provide a unique national data set to assess the relationship between the sleep status of those with complex needs and carer stress on a much larger scale than previous research considering sleep and caregiving. While sleep elements within the assessment have been explored with regard to depression and loneliness,<sup>39 40</sup> the relationship to carer stress still needs consideration to inform future research and interventions within the context of family-based aged care. Therefore, the present research had the following aims: to evaluate whether indicators of care recipient's sleep disturbance are independently associated with carer distress; and to identify relationships between carer distress and admission of care recipients into aged residential care.

## METHODS

### Study design and participants

We conducted a retrospective cohort study of older adults and their primary informal carers, who were living in a home-based setting. All InterRAI-HC assessment data collected between 1 July 2013 and 30 June 2019 with consent for use for research purposes were included. Where multiple home care assessments were available, only the most recent assessment was used. Data pertaining to care recipients aged less than 55 years were excluded, as were those who did not have a primary informal caregiver. This was to facilitate a sample of 'older' adults requiring care, acknowledging the lower life expectancies among some ethnic groups living in New Zealand<sup>41</sup> and the complex health needs of the ageing population requiring home-care.<sup>1</sup>

### Instruments/variables

The interRAI-HC includes questions across a range of domains including physical health, disease diagnoses, cognition, informal care supports and mood and behaviour.<sup>38</sup> In New Zealand, the interRAI-HC assessment is undertaken for all individuals who require publicly funded home care services. Assessments are conducted by trained clinical assessors and answers are recorded following an interview with the care recipient and (when relevant) their primary carer. Medical records are also used to complete the assessments.

In the present study, caregiver distress was defined as the assessor coding 'yes' to one or both of the items: 'primary informal helper expresses feelings of distress, anger or depression' and/or 'family or close friends report feeling overwhelmed by person's illness' at the time of the assessment. Variables explored as potential predictors of caregiver distress were based on questions relating to the context of care as well as the demographic and health status of the care recipient (who is the focus of the interRAI-HC assessment).

The question relating to sleep asked whether the care recipient has 'difficulty falling asleep or staying asleep; waking up too early; restlessness or non-restful sleep', with response options: 'not present', 'present but not exhibited in last 3 days'; 'exhibited on 1 of last 3 days'; 'exhibited on 2 of last 3 days' or 'exhibited daily in last 3 days'. Responses were dichotomised to 'none' (ie, defined as 'not present') and 'difficulty with sleep' (defined as present within any of the frequency options). The fatigue question had response options 'none', 'minimal', 'moderate', 'severe' and 'unable to commence any day-to-day activities'. These were dichotomised as 'none-minimal fatigue' and 'moderate-severe fatigue'. The interRAI-HC assessment also includes an item measuring if the care recipient has 'too much sleep—excessive amount of sleep that interferes with person's normal functioning', however less than 10% of care recipients had a positive response on this item and it was not analysed further here.

Confounding variables included in the models were identified from previous literature on caregiver stress<sup>14 42</sup> namely: urban or rural living, being a spousal carer and informal care time; demographics of the care recipient—age, sex and ethnicity; and the care recipient's health status including: presence of cognitive impairment or dementia (CIoD), bladder continence, bowel continence, depression, wandering or pain, presence of Parkinson's disease, congestive heart failure or chronic obstructive pulmonary disease. An ADL hierarchy was also included. This is a scale used to identify stages of the disablement process, with a lower ADL score reflecting that an individual is more able to independently undertake ADL than someone with a higher ADL score.<sup>43</sup>

In addition, hospital admission information from the Ministry of Health's National Minimum Data set<sup>44</sup> was used to identify if the care recipient had been admitted to hospital or visited the emergency department in the last 90 days. Medication information was obtained from



the Ministry of Health's pharmaceutical collection data set<sup>45</sup> to identify polypharmacy, defined as having five or more medications prescribed per month. Information about aged residential care entry dates was provided by Technical Advisory Services (TAS).

### Statistical analysis

Data from 217 663 assessments collected between 2013 and 2019 were considered. The preparation process included the exclusion of any repeat assessments (79 953), any assessments from people aged less than age 55 years (2172) and those who did not have an informal caregiver (7706). Data from the remaining 127 832 assessments were used. Ministry of Health data were matched to the interRAI data set using each individual's National Health Index (NHI) number (allocated to all individuals who receive healthcare in New Zealand).

Unadjusted and adjusted logistic regression models were used to assess the independent relationship between care recipient's sleep difficulty and fatigue with primary caregiver's distress while adjusting for the confounding variables noted above. Log-rank tests and Kaplan Meier curves were created to illustrate the relationship between primary caregiver distress and care recipient transitions to aged residential care.

Statistical analyses were conducted using IBM SPSS Statistics V.28 and Kaplan Meier curves were created using StataSE V.17. Missing data ranged from 0.000008% to 4.0% across the variables. Therefore, no imputation methods were deemed necessary. The reporting of the results for this study followed REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) reporting guidelines.<sup>46</sup>

### Patient and public involvement

This research was informed by previous qualitative works directly involving older people, people with dementia and informal carers in New Zealand. Surveys and interviews with carers for people living with dementia indicated that sleep of those they supported could become very disrupted and contribute to their feelings of distress and considerations for formal care. However, carers also reported that the importance of sleep in the caregiving situation was often overlooked.<sup>47–49</sup> Together, this indicated a need for a larger study, utilising large data such as this, to corroborate the reported experiences of local carers. The questions used in the research were already established by interRAI assessment committee. Team members of the community organisation responsible for overseeing the New Zealand interRAI assessments (the TAS) were consulted at the inception of the study regarding suitability of data and analysis plans. This and other works by the corresponding author have been peer reviewed by members of the Sleep/Wake Research Centre as well as Carers NZ prior to commencing. Together, such guidance informed the ultimate data request. Outcomes have also been shared at local 'knowledge exchanges' hosted by the TAS which included academics, health

professionals and service providers. Findings will also be summarised as an aspect of publicly available reports concerning sleep ageing and caregiving research in New Zealand.

### RESULTS

Caregiver distress was defined among 39.9% (n=50 954) of the primary informal caregivers. Table 1 displays the characteristics of the care context and care recipients' demographic, sleep and health status, stratified by presence or absence of carer distress. Mean care recipient age was 82.5 years (SD: 8.1) with a range of 55–110 years. Over half of the care recipients were female (59.4%). Approximately one-third of care recipients were reported as having sleeping difficulties (32.4%) and almost half as having moderate to severe levels of fatigue (46.6%).

Table 2 shows that care recipients' sleep status was independently associated with the carer distress outcome. Carer distress was 1.26 times more likely in situations where the care recipient had sleeping difficulties compared with those whose care recipients did not have any sleeping difficulties. Additionally, carer distress was 1.29 times more in situations where the care recipient had moderate-to-severe fatigue (as opposed to those care recipients had none to minimal fatigue). This is after adjusting for key variables concerning context of care as well as care recipients' demographic and health status, many of which were also associated with carer distress (eg, time providing care, presence of cognitive impairment, depression or wandering).

Caregiver distress among primary informal caregivers was significantly associated with care recipient's earlier admission into aged residential care ( $\chi^2(1) = 5299.0$ ,  $p < 0.001$ ) as shown in figure 1.

### DISCUSSION

This study demonstrates an independent association between the sleep status of older care recipients and distress among their primary informal carers, after controlling for other known factors associated with caregiver distress or burden. The prevalence of caregiver distress ('feelings of distress, anger or depression' and/or 'feeling overwhelmed' by the care recipient's illness) in this large population sample was 39%. This is similar to previous studies measuring burden, depression or stress associated with caregiving,<sup>10–12</sup> justifying the inclusion of 'feeling overwhelmed' to capture this affect.

### Sleep and fatigue of care recipients

A third of care recipients were identified as having sleeping difficulties, including difficulties falling asleep, staying asleep, waking up too early, restlessness or non-restful sleep. Such symptoms are indicative of insomnia, circadian phase disruptions and/or restlessness associated with other common sleep disorders such as sleep apnoea or restless legs syndrome.<sup>22</sup> Caring for someone who had

**Table 1** Characteristics of caregiving context, and care recipients' demographic, sleep and health status (totals and stratified by the presence or absence of caregiver distress, n=127 832)

Variable	Total	Caregiver distressed 50 954 (39.9%)	Caregiver not distressed 76 828 (60.1%)
	Number (%)	Number (%)	Number (%)
<b>Caregiving context</b>			
Spousal caregiver*			
Yes	37 718 (29.5)	20 742 (40.7)	16 976 (22.1)
No	90 109 (70.5)	30 212 (59.3)	59 897 (77.9)
Informal care time†			
<18 hours	109 196 (85.4)	40 076 (78.7)	69 120 (89.9)
18–35 hours	11 758 (9.2)	63,57 (12.5)	5401 (7.7)
36+ hours	6872 (5.4)	4521 (8.9)	2351 (3.1)
Living environment‡			
Urban	107 829 (87.9)	42 925 (84.2)	64 904 (84.4)
Rural/other	14 851 (12.1)	8029 (15.8)	11 924 (15.6)
<b>Care recipient</b>			
Sex§			
Male	51 768 (40.5)	23 156 (45.5)	28 612 (37.2)
Female	75 975 (59.4)	27 754 (54.5)	48 221 (62.8)
Ethnicity			
Māori	8854 (6.9)	3214 (6.3)	5640 (7.3)
Pacific Peoples	4386 (3.4)	1550 (3.0)	2836 (3.7)
Asian	2343 (1.8)	1140 (2.2)	1203 (1.6)
Other	112 249 (87.8)	45 050 (88.4)	67 199 (87.4)
Sleep difficulty¶			
None	86 402 (67.6)	32 955 (64.7)	53 473 (69.6)
Difficulty present	41 402 (32.4)	17 999 (35.3)	23 403 (30.4)
Fatigue¶			
None–minimal	68 300 (53.4)	24 530 (48.1)	43 770 (56.9)
Moderate–severe	59 530 (46.6)	26 424 (51.9)	33 106 (43.1)
CloD**			
Not present	52 237 (40.9)	13 095 (25.7)	39 142 (50.9)
Present	75 592 (59.1)	37 857 (74.3)	37 735 (49.1)
Bladder incontinence††			
Not present	69 119 (54.1)	24 988 (49.1)	44 131 (57.5)
Present	58 609 (45.9)	25 932 (50.9)	32 677 (42.5)
Bowel incontinence‡‡			
Not present	97 285 (76.4)	35 478 (70.0)	61 807 (80.7)
Present	30 009 (23.6)	15 200 (29.8)	14 809 (19.3)
Depression§§			
Not present	110 684 (86.6)	43 402 (85.2)	67 282 (87.5)
Present	17 174 (13.4)	7552 (14.8)	9595 (12.5)
Wandering			
Not present	123 610 (96.8)	48 038 (94.3)	75 572 (98.3)
Present	4149 (3.2)	2882 (5.7)	1267 (1.6)
Pain¶			
Not present	71 749 (56.1)	29 152 (57.2)	42 579 (55.4)
Present	56 081 (43.9)	21 802 (42.8)	34 279 (44.6)
ADL hierarchy			
0	41 613 (32.6)	10 646 (20.9)	30 967 (40.3)
1	14 035 (11.0)	4760 (9.3)	9275 (12.1)

Continued

Table 1 Continued

Variable	Total	Caregiver distressed 50 954 (39.9%)	Caregiver not distressed 76 828 (60.1%)
	Number (%)	Number (%)	Number (%)
2	20 781 (16.3)	10 192 (20.0)	10 589 (13.8)
3	22 986 (18.0)	11 157 (21.9)	11 829 (15.4)
4	17 057 (13.3)	8574 (16.8)	8483 (11.0)
5	9908 (7.8)	4918 (9.7)	4990 (6.5)
6	1452 (1.1)	707 (1.4)	745 (1.0)
Parkinson's§§			
Not present	122 754 (96.0)	48 479 (95.1)	74 275 (96.6)
Present	5077 (4.0)	2475 (4.9)	2602 (3.4)
CHF§§§			
Not present	104 441 (81.7)	41 896 (82.2)	62 545 (81.4)
Present	23 390 (18.3)	9058 (17.8)	14 332 (18.6)
COPD§§§			
Not present	106 500 (83.3)	42 969 (84.3)	63 531 (82.6)
Present	21 331 (16.7)	7985 (15.7)	13 346 (17.4)
Admitted to hospital			
No	83 147 (65.0)	35 155 (65.1)	49 992 (65.0)
Yes	44 685 (35.0)	17 799 (34.9)	26 886 (35.0)
Visited ED			
No	112 771 (88.2)	44 978 (88.3)	67 793 (88.2)
Yes	15 061 (11.8)	5976 (11.7)	9085 (11.8)
Polypharmacy§§			
Not present	83 380 (65.2)	33 235 (65.2)	50 145 (65.2)
Present	44 452 (34.8)	17 719 (24.8)	26 733 (34.8)
*5 values missing †6 values missing ‡5152 values missing §89 values missing ¶12 variables missing **3 values missing ††104 values missing ‡‡538 values §§value missing ADL, activities of daily living; CHF, congestive heart failure; ClOD, cognitive impairment or dementia; COPD, chronic obstructive pulmonary disease; ED, emergency department.			

sleep difficulties was associated with a 26% increased likelihood of reporting distress. Previous research has also identified that caring for someone whose symptoms include sleep problems significantly increases the likelihood of the caregiver also having sleep disturbances, which can subsequently affect their waking mood, function and ability to cope with the overall situation.<sup>35–37 49 50</sup>

Sleep disturbances are typically associated with decreased daytime alertness and functioning.<sup>18 22</sup> In the present study, 47% of the care recipients reportedly had moderate-to-severe fatigue, defined as 'diminished energy' affecting their ability to complete 'normal day-to-day activities'. Supporting someone with moderate–severe fatigue was associated with a 29% increased likelihood of caregiver distress. Fatigue can negatively affect being able to plan and complete activities both in and outside the house. This has implications for the regulation of sleep and wake because routine physical and social activities, coupled with bright light exposure, are important time cues for the circadian system.<sup>51</sup> Fatigue

and increased daytime sleeping of care recipients does not necessarily reflect more restful days for informal caregivers. In previous research, carers identified that their opportunities to rest or nap are reduced due to the physical and mental workload of informal caring, including being on 'high alert' across the 24 hour day and anxiety preventing caregivers' ability to relax. This is often related to feeling a need to uphold societal expectation and/or family preference for supporting an older member with frailty or illness at home.<sup>35 37 49</sup>

Fatigue can also negatively affect being able to plan and complete activities both in and outside the house. Routine physical and social activities, coupled with bright light exposure, are important time cues for the circadian system which regulates the timing of sleep and wake.<sup>51</sup> Fatigue and increased daytime sleeping of care recipients does not necessarily reflect more restful days for informal caregivers. In previous research, carers identified that their opportunities to rest or nap are reduced due to the physical and mental workload of informal caring,

**Table 2** Unadjusted and adjusted ORs for caregiver distress variables (n=127 832)

Variable	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Sleep difficulty present	1.24 (1.21 to 1.27)	1.26 (1.22 to 1.29)
Moderate–severe fatigue	1.52 (1.49 to 1.56)	1.29 (1.26 to 1.33)
Rural/other living environment	1.24 (1.19 to 1.28)	1.14 (1.10 to 1.19)
Spousal caregiver	2.68 (2.61 to 2.75)	2.41 (2.34 to 2.48)
Informal care time		
<18 hours	1 Reference	1 Reference
18–35 hours	1.84 (1.77 to 1.92)	1.31 (1.26 to 1.37)
36+ hours	3.04 (2.89 to 3.21)	1.83 (1.73 to 1.95)
Age	1.00 (0.99 to 1.00)	1.00 (0.99 to 1.00)
Female	0.67 (0.66 to 0.69)	0.89 (0.86 to 0.91)
Ethnicity		
Māori	1 Reference	1 Reference
Pacific Peoples	0.89 (0.83 to 0.96)	0.80 (0.74 to 0.87)
Asian	1.62 (1.47 to 1.77)	1.37 (1.24 to 1.53)
Other	1.19 (1.14 to 1.24)	1.17 (1.11 to 1.23)
CloD present	2.82 (2.76 to 2.90)	2.30 (2.24 to 2.36)
Bladder incontinence present	1.41 (1.38 to 1.44)	1.01 (0.98 to 1.04)
Bowel incontinence present	1.86 (1.81 to 1.92)	1.15 (1.11 to 1.19)
Depression present	1.21 (1.17 to 1.25)	1.15 (1.10 to 1.19)
Wandering present	3.93 (3.64 to 4.24)	2.25 (2.07 to 2.44)
Pain present	0.96 (0.94 to 0.98)	1.05 (1.02 to 1.08)
ADL hierarchy	1.30 (1.29 to 1.31)	1.17 (1.16 to 1.18)
Parkinson's present	1.48 (1.40 to 1.57)	0.97 (0.90 to 1.03)
CHF present	0.96 (0.93 to 0.99)	0.97 (0.94 to 1.01)
COPD present	0.90 (0.87 to 0.93)	0.99 (0.96 to 1.03)
Admitted to hospital	0.78 (0.76 to 0.80)	0.85 (0.82 to 0.87)
Visited ED	0.90 (0.87 to 0.92)	1.04 (1.00 to 1.07)
Polypharmacy present	0.96 (0.94 to 0.99)	1.13 (1.09 to 1.16)

Unless otherwise stated, reference groups are as per [table 1](#). Statistical significance ( $p < 0.005$ ) is indicated by 95% CIs that do not include the null value of 1.00.

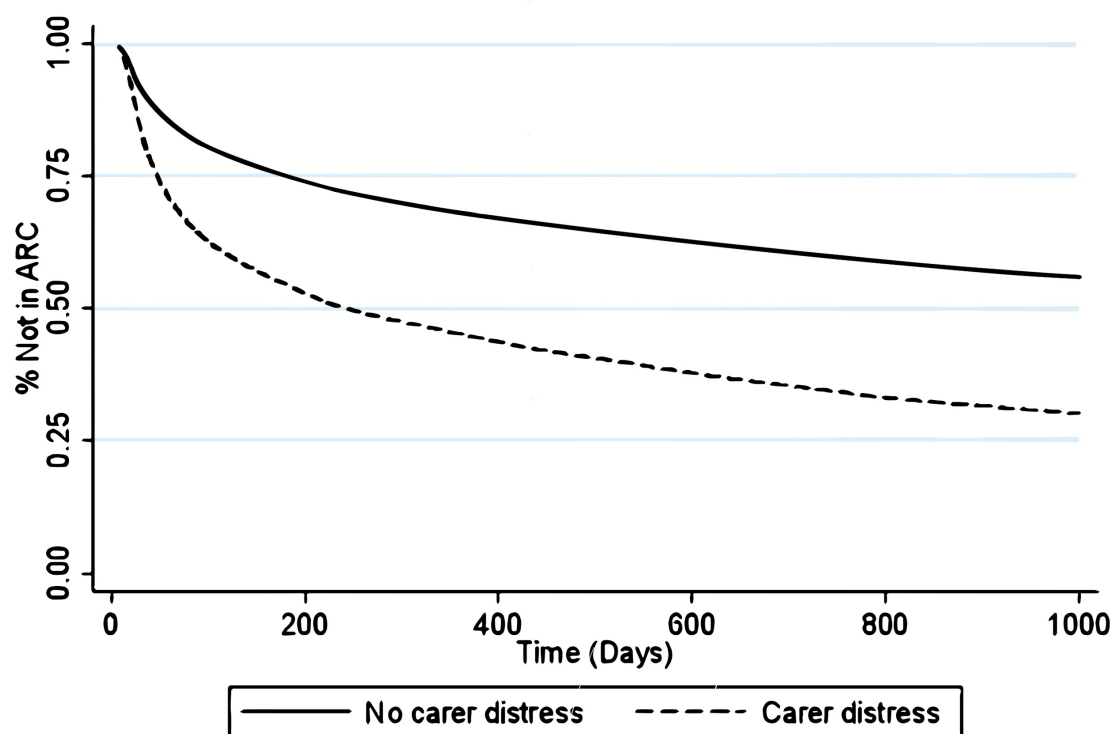
ADL, activities of daily living; CHF, congestive heart failure; CloD, cognitive impairment or dementia; COPD, chronic obstructive pulmonary disease; ED, emergency department.

including being on 'high alert' across the 24 hour day and anxiety preventing caregivers' ability to relax. This is often related to feeling a need to uphold societal expectation and/or family preference for supporting an older member with frailty or illness at home.<sup>35 37 49</sup>

The sleep patterns of carers has been identified as more likely determined by the routines and sleep of the care recipient rather than their own preferences. This is more common among spousal carers, possibly as they are accustomed to sharing living and sleeping spaces with the care recipient and the mediating influence that the sleep of others can have.<sup>35 52</sup> While the sleep status of carers is not represented in the present study, caregiver distress was identified as more common among spousal caregivers than non-spousal as well as with more hours of care provision.

### Sleep and comorbidities of care recipients

Caring for someone with a CloD was the greatest independent predictor of caregiver distress, with 2.3 higher odds compared with those caring for someone with other conditions. Unique sleep-related symptoms have been associated with the physiological and psychosocial changes of dementia, as well as with associated medications.<sup>33</sup> Such symptoms include seemingly confused or automated behaviours around or during bedtime (traditionally termed as 'sundowning') such as 'wandering' (defined in the interRAI assessments as 'moving with no rational purpose, seemingly oblivious to needs or safety'). While just 3% of the care recipients were reported to exhibited wandering-type behaviours, this was also associated with a 2.3-fold increase in the likelihood of caregiver distress.



**Figure 1** Kaplan Meier curve of caregiver distress and aged residential care entry.

This research has implications for informing resources and interventions in the space of sleep, ageing and caregiving. Previous research has trialled non-pharmacological interventions for addressing sleep-related disturbances in dyads of care recipients and their informal caregivers. Findings are particularly promising for addressing sleep symptoms associated with sundowning or circadian dysregulation. For example, tailored routines, including timed bright light therapy together with physical activity and sleep education, are feasible and have positive impacts on the sleep and waking symptoms of people with dementia as well as the sleep and well-being of family caregivers.<sup>53 54</sup> Despite this, sleep is still typically overlooked in aged and dementia care. The present findings contribute to the justification of including such assessment and intervention.

Incontinence is more common with advancing age and dementia and has consistently been associated with caregiver stress, including here.<sup>55</sup> Increased toileting needs and incontinence-related events are typically more common during sleep, creating increased tasks for informal caregivers needing to support care recipients with wayfinding, personal hygiene and laundering bedding,<sup>56</sup> so this factor also has implications for the sleeping and waking life of both care recipients and caregivers, which warrants further exploration.

In the present sample, 44% of care recipients reported pain, 13% had depression, 18% chronic heart failure and 59% CIoD. Such conditions have all been identified as exacerbating sleep difficulties.<sup>22 30</sup> The association of these factors with sleep problems is currently being

explored in the interRAI-HC as well as long-term care data (to be reported elsewhere).

#### Sleep of care recipients and transition to institutional care

Distress among primary informal carers was found to be independently associated with the care recipient having an earlier transition into aged residential care. Together, the study findings reinforce the importance of the relationship between sleep and stress in informal caregiving situations. They demonstrate that sleep, and strategies to maintain or improve sleep health need to be taken more seriously in the context of healthy ageing and supporting informal caregivers.

#### Study limitations

It is important to consider that the present findings are based on cross-sectional comparisons. However, that an independent relationship remained between care recipients' sleep and carers' distress, after controlling for other factors known to affect caregiver stress, is key. Sleep's role with health, particularly mental health, has been recognised as bidirectional with issues such as feelings of depression or anxiety being a predictor for as well as an outcome of problem sleep.<sup>57</sup> Future studies may consider a longitudinal approach with structural equation modelling to better ascertain which aspects of sleep and mental health are impacted and when.

Another limitation is that the interRAI-HC focuses primarily on the care recipient and only provides information on the familial relationship and hours of care provision required of the carer. Previous research has identified individual and social factors as related to



self-reported carer burden or distress.<sup>11 12</sup> While some items were included in the present analyses (eg, time spent providing care, rural or urban living environment), it is recommended that future research and healthcare assessments should consider a more dyadic or familial approach to better understand the role of carer's demographic status and health situation (including their own sleep health) with regard to feelings of burden or distress.

A third limitation is that sleep is not a key focus of the interRAI-HC assessment. The questions pertaining to sleep disturbances and fatigue are not standardised measures and use just the last three days as a timeframe. While sleep difficulties and fatigue are indicative of sleep disorders,<sup>22</sup> it is recommended that future studies include validated measures considering various dimensions of sleep across a longer time frame. For example, a better understanding of care recipients (and carers) sleep duration, timing and quality; as well as symptoms of sleep disorders would better inform tailored interventions to improve sleep health within these populations.

Finally, this study was based on a New Zealand interRAI-HC cohort and cannot necessarily be generalised elsewhere. The analyses are limited to the data provided by those consenting for use for research purposes. Less than 10% tend to opt out of this; therefore, the data are still considered reflective of the New Zealand healthcare setting. Despite the large sample size, Māori and Pacific Peoples are under-represented in the interRAI-HC assessment data. This reduces statistical power for reliably understanding differences by ethnicity or culture. Possible contributing factors include a shorter life expectancy and reduced likelihood of Māori and Pacific Peoples seeking formal care and living in aged care facilities, as well as older Māori being less likely to be represented in such contexts.<sup>2 6 15</sup> To accommodate for the disparities in life expectancy, the age of participant inclusion was set lower than previous studies concerning aged care. In this sample, non-Māori and non-Pacific People were more likely to report caregiver distress. This may be associated with differing approaches to informal care and ageing between cultures.<sup>6</sup> Similarly, differences in perceptions and management of sleep problems have been noted between cultures.<sup>19 58</sup> Further research with samples more representative of New Zealand's diverse population are warranted to inform more meaningful and appropriate assessments, resources, and interventions for families seeking support with aged care.

## Conclusion

This study highlights the importance of considering the status of sleep and fatigue among the key factors associated with caregiver stress, which is subsequently related to care recipients' earlier transitions into aged residential care. Such findings are important for understanding the complexity of informal care situations and provision of support and respite where able. Further work is needed to explore whether caregiver distress and health outcomes

can be relieved by promoting sleep health among care recipients, their informal caregivers, and families.

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**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Consent obtained directly from patient(s).

**Ethics approval** This research involves human participants but relies on the analysis of extant assessment data. During the interRAI assessments, informed consent was obtained from the care recipient (or person entitled to consent on their behalf) to have their anonymised assessment information for research purposes. This research proposal was approved by the Technical Advisory Service who are responsible for the interRAI assessment data, and independent ethical approval was obtained from the Central Health and Disability Ethics Committee (19/NTA/152).

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**Data availability statement** Data may be obtained from a third party and are not publicly available. Applications can be made to New Zealand's Technical Advisory Services, Statistics NZ and Ministry of Health to source interRAI assessment data and matched healthcare records.

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