



This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International license (<http://creativecommons.org/licenses/by-nc/4.0/>).

research article

Balancing sleeping with guardianship: narratives of sleep during informal dementia care

Rosemary Gibson, r.gibson@massey.ac.nz
Amy Helm, amy@tenpoint.co.nz
Isabelle Ross, ies.ross2000@gmail.com
Philippa Gander, p.h.gander@massey.ac.nz
Massey University, New Zealand

Mary Breheny, mary.breheny@vuw.ac.nz
Victoria University of Wellington, New Zealand

Sleep has been recognised as compromised in dementia care. This study aims to represent the experiences and needs of informal carers via sleep-related accounts. Retrospective interviews were conducted with 20 carers concerning sleep changes across the trajectory of dementia care. Key interactive narratives were around: 'sleep as my sacrifice'; tensions between identities of being a 'sleeper' versus 'guardian'; and 'sleep as a luxury'. Maintaining healthy sleep and preferable sleep practices is challenging while balancing the responsibilities of dementia-related care. Acknowledging sleep as a sociological practice enables a greater understanding of carers' nuanced experience and support needs.

Key words dementia care • narrative analysis • sleep • transitions

To cite this article: Gibson, R., Helm, A., Ross, I., Gander, P. and Breheny, M. (2024) Balancing sleeping with guardianship: narratives of sleep during informal dementia care, *International Journal of Care and Caring*, 8(1): 114–129, DOI: 10.1332/239788221X16613777827869

Introduction

There are strong social drivers for 'ageing well' and to support families 'living well with dementia' (Ministry of Health, 2013, 2016). The meaning of these concepts depends upon the preferences of the care recipient and their family as regards the living situation (typically the family home), the availability of appropriate support, and the ability to maintain a valued position in society for both the care recipient and carer. The role of 'carer' is often taken up by one key family member, particularly in Western society. This responsibility is often informed by gender, geographical and vocational convenience, as well as pre-existing relationships. Considerations and practices of caring are guided by family expectations and shared social understandings, as well as individual beliefs,

emotions and resources (Breheny and Stephens, 2012; Horrell et al, 2015). For example, common discourses of wanting to 'be there' as an independent carer have been identified. These are informed by feelings of virtue and obligation related to family duties or feelings of affection (Breheny and Stephens, 2012).

While different types of carer identities are apparent, a common narrative of providing 'good care' prevails (Breheny et al, 2020). Therefore, when accidents happen or help is required, this may be interpreted as signs of failing to fulfil the caring role and can trigger processes towards aged residential care, which, in turn, connotes a loss of independence (Jorgensen et al, 2009; Ng et al, 2021). Furthermore, care provided by others or within institutional settings is often considered of poorer quality, which contributes to refusal of external assistance (Edwards et al, 2003). These kinds of drivers have been identified as contributing to some of the difficulties carers experience, including: long hours required to support the care recipient, alongside other domestic, vocational or social responsibilities; feeling overwhelmed; and increased risks of health problems (Alpass et al, 2013; Fekete et al, 2019).

Carers report round-the-clock responsibilities and feelings of stress, fatigue and burnout (Adelman et al, 2014; Chiao et al, 2015; Gibson et al, 2015; Reynolds et al, 2020). Such outcomes are akin to chronic shift work, yet carers are not necessarily trained to manage such routines, remunerated for undertaking them or given access to support networks. Furthermore, carers experience an array of emotional changes that come with supporting someone they are close to with the symptoms of their illness (Fekete et al, 2019). Those supporting people living with dementia are often of older age, with their own health challenges to manage, alongside those of the care recipient. Together, these factors test the dimensions of sleep health in a particular way, compared both to general populations and to other carers (Gibson et al, 2021).

Sleep disturbances are common among people with dementia, with many reporting less regular sleep timing and an increase in symptoms of insomnia, night-time agitation or confused behaviours, as well as nightmares and daytime sleepiness (McCurry and Ancoli-Israel, 2003; Bliwise, 2004; Gibson et al, 2014; Gibson and Gander, 2020). Carers often have sleep disturbances too, commonly related to the sleep patterns of the care recipient, though also associated with the full-time nature of caring or with stress related to the situation (McCurry et al, 2015; Maun et al, 2018; Gibson and Gander, 2020; Reynolds et al, 2020). Previous research using a postal survey addressing the prevalence and types of sleep disturbances among dementia carers using the Insomnia Severity Index (Morin et al, 2011) indicated that approximately 65 per cent of carers have poor sleep (a third of whom would be classed as having moderate to severe sleep disturbance) (Gibson and Gander, 2020). The nature of such sleep disruptions is influenced by the waking situation and responsibilities, as well as by changes during the trajectory of care. Routine factors, such as witnessing and supporting confused behaviours at night, or keeping a watchful eye throughout the day, reduce the carer's opportunities for sleep at night or for 'catch-up' sleep during the day. Significant transitions, such as facilitating a move to residential aged care (RAC) or providing end-of-life care, can also create stressors that can exacerbate sleep disruptions for both the carer and the care recipient. Such sleep-related changes can have implications for carers' long-term health and well-being (Gibson and Gander, 2020; Gibson et al, 2021).

Sleep is acknowledged as a pillar of physical and mental health, as well as a facilitator of 'ageing well' (Foley et al, 2004; Gibson et al, 2020). Across the lifespan, chronic sleep

loss and sleep disorders are associated with poorer waking function, mood disorders, increased disease and medication use, and accidents. With ageing and dementia, sleep problems have implications for frailty, exacerbated cognitive impairment, falls and hospital admittance (McCurry and Ancoli-Israel, 2003; Gibson et al, 2020).

Typical guidance for improving sleep health includes behavioural interventions to improve ‘sleep hygiene’, therapeutic napping and chrono-therapeutics. While these techniques show promise for treating sleep disturbances in this population, it is also vital to consider the context of the dementia care circumstances. The feasibility and successes of sleep-related interventions can be challenged by the overall caring situation (McCurry and Ancoli-Israel, 2003; McCurry et al, 2007; David et al, 2010; Gibson et al, 2017). Furthermore, sleep is often simplified by quantified categories, such as ‘disordered’, ‘short’ or ‘unsatisfactory’, though these do not necessarily capture the sleep experience.

Sleep is multifaceted. While individual biology and behaviours are important, sleep is also shaped by social expectations. When we consider sleep within a broader ecological model, the role of wider society becomes clearer. For example, schedules of work, responsibilities and social engagements shape sleep practices. This includes the ability to maintain regular exposure to time cues necessary for robust cycles of sleep and wake, alongside being able to sleep within personal schedule preferences. Such factors are also influenced by individual health status and mediated by the sleeping and waking contexts and needs of others (Grandner, 2017; 2019). Thus, when the patterns of daily life are interrupted by change or crisis, sleep is affected.

The practice of how, when and with whom we sleep is increasingly recognised as sociological (Williams, 2005; Meadows, 2005; 2016). Common discourses of sleep in Western society include the drive to achieve eight hours of uninterrupted sleep at night, bed sharing as a marker of relationship status, and connotations of sleeping in the day as a marker of laziness. With an increasingly busy modern society, time devoted to sleeping serves as a marker for availability and productivity (Williams et al, 2013; Hsu, 2014). With ageing and retirement from work, the pressure for productivity may decrease. Furthermore, sleep is commonly presented with expectations that quality will decline with ageing. Similarly, daytime napping becomes a more contentious behaviour, viewed as a tool to support well-being, while also being resisted due to negative connotations of ageing and inactivity (Venn and Arber, 2011). Home-based dementia care is a situation in which the norms of time use, including sleep practices, may be challenged (Moore et al, 2001; Gibson et al, 2021). This has implications for both people with dementia and carers.

While the importance of sleep disturbance is increasingly being recognised in dementia-care situations, its role has yet to be represented in relation to the overall narratives of caring across the trajectory of care, including transitions to formal care and beyond. The present research aims to understand and represent the experiences and needs of those providing support to someone they live with who has dementia through their accounts of sleep expectations, needs and practices, and how these change across the trajectory of care.

Methods

Narrative psychology provides a framework to represent carers’ experiences across the dementia-care journey, while including relational contexts (McAdams, 2001; Wong and Breheny, 2018). This research uses a social-constructionist approach to narrative analysis, which considers participants’ personal stories as co-created in the interview context, as well as reflecting wider narratives that are structured socially (Murray, 2000). Analysis of

narratives involves the formulation of a person's subjective experience within relational contexts (Efran et al, 2014). Using a narrative analysis allows for an in-depth exploration that represents the individual's subjective experience and relational content, as well as the social and moral expectations that shape the stories told (Stephens and Breheny, 2013).

Participants and data collection

A total of 20 participants were recruited from an optional mailing list compiled from a previous postal survey concerning sleep and dementia-related care among 525 carers across New Zealand (Gibson and Gander, 2020). Invitations were sent to 93 potential participants who lived either within the lower North Island or rurally, with the intention of representing both urban and rural carers. In order to gain perspectives across the trajectory of caring, participants were eligible if the person they supported had transitioned into RAC since taking part in the postal survey approximately two years earlier. The median age of participants was 75.5 years (range = 24–87); 14 were female, and the majority (18) identified as New Zealand European ethnicity. A total of 17 had provided dementia-related care for their spouse (other care recipients were a friend, parent and grandparent). Eight care recipients had died since their transition into residential care.

Interviews were semi-structured and explored: the experience of caring for someone with dementia; how sleep changed for both parties as the disease progressed; how sleep problems were negotiated; the role of sleep disturbances in the decisions about transitions to RAC; and how carers were sleeping after the transition (and, if applicable, following the death of the care recipient). Thirteen interviews took place in participants' homes in urban centres in New Zealand's lower North Island. The remaining seven were conducted by telephone with those living in rural locations to provide greater breadth to the data set.

Analysis

Interview recordings ranged from 28 to 103 minutes (median = 55 minutes) and were transcribed verbatim. The names of participants, family members, key places and care providers were excluded or changed to ensure anonymity. The data-analysis process involved immersion with the data via listening to the audio recordings of the interviews and detailed reading and rereading of the transcripts. Further checking and cleaning of transcripts took place before coding using NVivo12 software. Codes were collated and constructed into themes that recurred across the participant interviews. Carer narratives relevant to the experience of negotiating sleep and caring were identified. These were cross-checked against case studies written up for each participant, which summarised their care experience. Common narratives were then workshopped with the wider team, and illustrative extracts were selected. Final examination identified the social constructions of sleep within the context of dementia caring, including the shared social and moral context in which the stories were told.

Findings

Three key narratives constructed from the data were: 'sleep as my sacrifice'; carers' negotiation of 'sleeper versus guardian'; and 'sleep as a luxury'. These narratives were used in interaction with each other to represent the challenge of maintaining healthy sleep while balancing the responsibilities and satisfactions of dementia-related care.

Sleep as my sacrifice

Many carers presented themselves as being socially expected to make sacrifices and to be able to cope throughout the stages of dementia. They spoke of the care recipient as coming first; their own needs or life priorities were described as ‘on hold’ or as minor considerations. Some described their care situation as an obligation or an arrangement, with responsibilities and schedules not of their choice. Carers represented themselves as working ‘on autopilot’ and as constantly trying new ways to support the care recipient and manage their dementia symptoms.

Participants told stories about forgoing their own sleep. The practices of sleep, including schedules and environments, were often affected by responsibilities within their roles. For example, some described going to bed earlier than they would prefer or sleeping with lights on or in a different room to facilitate the sleep and support needs of the care recipient. Carers’ routines and sleep practices were described as dictated by the person with dementia, which often meant altering sleep patterns in response to the care recipient’s symptoms and desires, and, in turn, the carer becoming ‘out of sync’ with their own sleep preferences. Here, Sally describes the sacrifices she made in her sleep to align with her husband Roy’s requests, as he typically wanted her close by:

‘Not long after we moved here, he started sleepwalking, which meant that every time he moved in the night, it woke me. Then, it sort of got worse during the years that followed, till there came a time when, oh, some nights, I would be awake every hour ... and it’d take a while to go back to sleep. There were nights where I’d just get a book and read, and then he’d suddenly wake up to go to the bathroom and he’d say, “What are you reading for? What are the lights on for?”, you know, “Turn the light off”. He always liked to be in charge, in a nice way, but now it’s almost a manic trait of him now.... One night, he wouldn’t want to go to bed till really late and wouldn’t let me go to bed and leave him here; another night, he’d be agitating to go from about seven o’clock. It was really, oh, a bit bizarre. I’d make him stay up though if he wanted to go earlier. But when he went into care, I was going to bed about eight to half past eight each night and catching up on sleep. I’d sleep right through the night ... I was just exhausted.’

As Roy’s dementia progressed, Sally described being put into a “lockdown” each afternoon. Roy obstinately closed curtains and locked doors from mid-afternoon, limiting Sally’s social and light exposures, adding to implications for sleep scheduling. Across this story, Sally detailed her struggles between allowing Roy to dictate their sleep habits and holding out for a more familiar pattern of late-evening sleep timing. This negotiation is fraught for them as a couple; Sally describes Roy being “in charge” as a familiar part of their relationship, which alters from a nice trait to a manic one as the dementia progresses. Accommodating these changes in their shared sleep timing is part of being a self-sacrificing carer.

Many used this narrative of sleep as a sacrifice to link dementia-care experiences to sleep changes as a new parent: “Now I know why, how mothers feel who’ve got tearaway toddlers or, you know, how on earth they get through those child-rearing years with so little sleep, just amazes me!” (Daniel). This extended to the sense of complete dedication across the day. For example, Nathalie, who had not had children herself, reflected: “I never had children, and I think, often think, ‘I think, I’ve got

what I want now. I've got a two-year-old. And he's got all these people caring for him twenty-four hours a day." Although Nathalie described dementia care as akin to parenting, with the sense of necessity and unconditional love, she also mused that it should not be "quite like this" because the sacrifices were untimely, coming with different ramifications for the household than with child rearing.

Despite being tired, carers described a tendency to prioritise other activities, rather than ensure their own sleep. This included prioritising other care-related or domestic chores or work over daytime napping. This enabled them to maintain a sense of coping with the situation as a whole and supported a common goal of allowing them to care at home for as long as possible. This narrative of sacrifice was often told through stories of having little choice in how they managed due to the situation. Here, Pamela describes the challenge of looking after her own sleep while caring:

'I do know that not having sleep has a huge impact on your, on your life, on your day-to-day living, and especially when you're caring for somebody. You know, you do have to be aware. So, many people would say to me, "Oh, you do have to be careful Pamela." And I used to think, "Well, how do you be careful?", you know? I feel all right. And I'm aware that, yes, I do need to be careful. I know that I need sleep and, you know, but how does it happen, you know? Tell me how it happens. Tell me how I have to care for myself! You know, you've got to care for yourself; well how do you care for yourself when you're looking after someone? You do – you do care for yourself as well as you can. But you definitely need that sleep!'

Pamela's story of care demonstrates how sacrificing sleep occurs in a caring context. People recognise the need for carers to be well to function as carers, but this advice is framed in terms of the carer 'being careful' or the carer 'caring for themselves'. Pamela's story is one of puzzlement: what is she to do with this advice? It contradicts the caring imperative to prioritise looking after someone else and the physiological need for sleep. The advice Pamela is given is empty of any practical support or service provision, and, as such, makes this self-care another responsibility for her to manage. At the intersection of these tensions, Pamela's solution is to report: "I feel all right."

Although sleep disruptions were often part of the situation, few carers in the study had sought formal guidance on sleep. However, many had accessed or attempted to access formal in-home support services or external respite care. These could be interpreted as the kinds of strategies for self-care that carers are encouraged to take up to manage the overall situation. For some, having a period of respite allowed them rest and recovery, as well as a feeling that they could "get a handle on it", but as Nathalie commented, it could often take several days to wind down and be able to relax, and this progressed alongside the increasing severity of dementia:

'I needed like – and I realised even a week, after a while, when I did manage to get him in for respite care, which again was terribly difficult and harrowing. He would, I would pay for it when I came back 'cos he'd be so angry ... 'cos he would, he thought that I was going to leave him, and leave him there. So, yeah. But, like, I realised even a week wasn't enough. It just wasn't enough ... for me to recover. To get, to just get that – 'cos it took me a few nights to be able to sleep. You know? Like even for five hours at

a stretch so ... I think just on alert, just hyped or ... and I – that's when I realised too, is that when I look back over my life, I, I'm very good at.... People used to say, "Oh, you look really calm" and everything. Oh my God, like the turmoil underneath was huge. And I've never, I've never been able to relax. So, of course, it just was, everything came out. It was heightened. My non-relaxation became even worse.'

Nathalie's story shows that there were ongoing implications to engaging with the strategies designed to address sleep debt. Her husband resented the respite care she organised to recharge, and the emotional exhaustion of dementia care meant that she needed nights of respite to recover sleep patterns. Such struggle was described as well hidden, as Nathalie focused on maintaining an outward appearance of calm. Others described issues of respite associated with a rapid return to pre-respite sleeplessness, or return from respite exacerbating dementia symptoms, or respite-related events leaving the carer more exhausted. After describing many experiences of her husband not receiving the level of care she expected in respite facilities, Emma commented on the issues faced when he returned home: "Every time he went in, I reckon it took me the six weeks I had to get him back to where he was when he went into those rest homes, and then they wondered why I didn't want him going in a rest home!"

Sleeper versus guardian

This narrative highlighted the importance of protection within dementia caring and the implications that sleeping has on achieving safety and guardianship. Vulnerability was described as exacerbated at night. Carers described the complicated balance of satisfying their needs as a 'sleeper' with maintaining their requirements as an active 'guardian'. Many carers reported a desire to maintain a sense of routine and structure in their waking and sleeping life. However, dementia-related sleep disturbances often meant the care recipient sleeping at socially abnormal times of day or experiencing some confused awakenings or behaviours on waking, which could be challenging for carers. For example, some care recipients put themselves in danger or behaved unusually in the times around and during sleep by, for example, checking the property or surrounding land. With many of the care recipients having fragmented sleep across the 24-hour period, carers described a sense of needing to be on continuous duty: "I think that was the biggest impediment: that you're locked in, on that care cycle all the time. Even if you're not physically caring at the moment, you're on red alert the whole time" (Joe). Here, Joe refers to the nature of being in the guardian role at all times due to the potential of support being required. The need to be observant does not cease, regardless of direct needs in any given moment. The feeling of being on 'red alert' was common, and despite feeling tired, carers also identified this heightened alertness as impeding their ability to sleep when the care recipient did. They described a sense of duty to maintain vigil in observing, protecting and supporting their more vulnerable care recipient while they slept.

Emma illustrated this in her descriptions of her husband Matthew's unpredictable sleep patterns, which limited her ability to achieve other errands or rest herself:

'He started obsessing actually about silly things, like it getting dark. But he walked non-stop, and unfortunately, our house has got stairs in it between the lounge. He may sleep for five or ten minutes, and I'd have the – down here it's X [local assessment team] who come and work out how much help you need: "Oh well, I guess you sleep when he goes down?" I didn't sleep when he went down, I had to do everything that I couldn't do because I was on constant watch of Matthew, you know, like I had to help on the stairs because he was likely to fall, but I had these people saying, "Well, obviously you put him down and then –" but I mean you couldn't guarantee... You'd put him down and he may sleep for two hours, he may sleep for ten minutes and then leap out of bed. So, the lack of understanding of the people that I dealt with was just unbelievable. I mean, by the same token, I chose to have Matthew here; I could have put him in care at any stage, but at the beginning, I made a commitment that I would care for him.'

Matthew's unpredictable sleep meant that Emma had to be constantly alert to maintain his safety. The support services provided advice around 'sleeping when he sleeps', advice familiar to parents of infants. However, Matthew is not an infant safely contained; rather, he could wake at any time and struggle to negotiate hazards in their home. As in Pamela's example earlier, the advice given to Emma profoundly misunderstood the dementia-care situation and focused on what Emma can do to deal with the situation. Emma resisted this advice as impractical in the context of dementia care but also took up an identity as a self-sacrificing carer in her story. She concluded that guarding Matthew was part of the commitment she had made to care for him; losing sleep becomes part of this caring commitment.

Carers were not only concerned about vigilance; rather, they were also concerned to maintain the care recipients' safety in case they became unwell or died first. For example, John shared a concern that he might die before his wife Linda and had systems in place within his family and the retirement village to protect her should this happen. These systems also allowed them both to sleep:

'I mustn't die before Linda, and I said, "What happens if I do die in the middle of the night?," 'cos Linda wouldn't be able to use the telephone, she wouldn't be able to open the door, she wouldn't be able to communicate with anybody and she'd be wandering around in a terrible mess eventually. And chatting to X [daughter] about this, who's in X [overseas], and this is one thing that I can do. We've got alarm systems by the bedroom and the toilet. There's a little lamp up there; it triggers every time a person walks past it, and if it doesn't receive a trigger to reset within twenty-four hours, it sets off an alarm over the office, and then they'll come and check. But Linda would be walking around and resetting the alarm... She could be here three or four days... Well, they might never come, you know, who knows? But anyway, arrangements were made with X [daughter], she'd ring from X [overseas] every morning before she goes to work and just to make sure I was still alive. And that closed the last door that I need to make sure Linda was protected. Yeah, I'm ok. I survived the night, everything's all right. Now, if I didn't answer the phone, she would then probably have a couple of tries, maybe try the cell phone, she would ring the office and let them know that

there's no response. It was great. Everything was tight, yeah.... 'Cos I'm eighty-three, but with the atrial fibrillation, who knows, you know, it could happen suddenly, heart failure.' (John)

John described the need to make contingency plans for an unknown future to ensure Linda's care. The potential of dying in his sleep creates unique vulnerabilities for the care recipient, and John had developed complex strategies to overcome his concerns, making him feel more comfortable going to sleep as his wife's care needs were safeguarded should he be rendered unavailable as guardian.

The identity of continuous guardian was pronounced across the interviews, regardless of how constrained the carer's days and nights actually were. For example, Nicole used sleep medications for herself at night, and was subsequently able to manage her needs as a 'sleeper'. Yet, she still considered herself to be responsible as 'guardian' for the majority of the time:

'So, my sleep patterns when Derek was actually deteriorating, I wasn't aware quite often of how he was because the zopiclone would take the edge off my alertness, and so it was only the last few nights that he was at home – and he had deteriorated very unexpectedly and very, very quickly – that I was aware that he was getting up during the night and doing some very bizarre things. So, the zopiclone has been an absolute lifesaver for me, in that it's given me a decent night's sleep. If I didn't take it, I wouldn't be able to get to sleep until, oh, three or four in the morning, and no matter how tired I was, I would lie there, and I just couldn't actually get off.' (Nicole)

In prioritising her sleep, Nicole was also able to maintain her paid work in the day and achieve naps:

'Well, I would have a dozy nanny nap in my chair while he was asleep because I basically work in the mornings and I've only got a little bit of work in the afternoon, so I was home. He would stay in bed or the person would get him up and shower him while I was at work, and then from there on, we would do things together.'

However, she still defined herself as "his caregiver for twenty-three-and-a-half hours a day" because other than the "half an hour someone would come in and help him have a shower", she felt that sense of responsibility.

Ruby was unusual compared to others, in that she detailed being less aware of her husband's symptoms and decline. With this, she was able to keep up with her hobbies and social activities with reduced anxiety and subsequently reasonable sleep:

'It didn't really dawn on me that he was in a sad state. Whether I wasn't quick enough on the uptake or whether the kids noticed it and didn't tell me that that's what they thought, I don't know. But I've been discussing the matter with them at different times, and it was the case of, "Mum, you looked after him so well, you didn't even realise that he was, you know" ... I was too close to it.' (Ruby)

With this, Ruby summarised her interview with, “if I sleep well, I feel good. If I don’t [feel good], I sleep”, which, contrary to the common narrative, indicates a sense of control over her sleep, prioritising sleep needs and recognition of its importance in maintaining well-being.

Sleep as a luxury

For most participants, descriptions of sleep across the trajectory of care illustrated an implicit narrative that sleep is a luxury rather than a need while caring. Sleep was storied as something that can be aspired to or recouped when able to reprioritise their own needs or preferences. For example, Steven described losing his regular daytime nap due to needing to be extra vigilant for his wife Karen after lunch:

‘Ever since, I suppose for thirty years, I’ve always tried to have a sleep for half an hour in the afternoon, three quarters of an hour at the most. It’s a luxury, I love it, it’s just gorgeous. Well that all went because I couldn’t go have a sleep because I couldn’t leave her. God knows what would happen. She couldn’t find, she couldn’t cook, she couldn’t do anything, ’cos she couldn’t find where things were and she couldn’t understand.... So, I lost my afternoon sleep, which doesn’t sound much, but it was something which, you know, forty-five minutes of the day was great, as a total amount of sleep.’

Here, Steven described his nap as a lifelong pattern, established luxury and personal pleasure. He lost this luxury in order to prioritise ongoing presence for his wife. Although he minimised this loss – “doesn’t sound like much” – it clearly was incredibly personally meaningful to Steven, well beyond attaining a forty-five-minute nap.

After their intensive role as carer ended (that is, once the care recipient moved to RAC or had died), carers revelled in the luxury of being able to sleep within their own time, which included returning to sleep preferences, having lie-ins, napping during the day and enjoying dream experiences. For example, Sally, who had described her husband’s obsession with closing the house up, did not close the curtains for two months after his transition to residential care. Others, like Nathalie, celebrated their control over their sleep by buying new bedding or nap chairs:

‘Here I am ... I’m on my own. I’m not disturbing anybody... I’m so grateful for all of this.... This is a new acquisition, this chair. And I thought I need to be able to have a somewhere where I can comfortably ... put my feet up and just have a little nap in the afternoons.’

The regaining of a sense of place and personal autonomy is illustrated with the purchase of a chair as a place to sit undisturbed and nap on her own terms. This narrative of sleep as luxury illustrates considerations around forgoing personal sleep while being an active carer. Sleep is viewed as a luxury, rather than a necessity. Once the role reduces or ends, sleep is embraced and treated as an indulgence that has been regained.

Discussion

This study has explored how carers balanced sleep with dementia caring. A narrative analysis was used to identify common stories carers told about their experiences and practices of sleep over the trajectory of dementia care. Sleep was storied as a sacrifice that carers can make, a challenge for managing to be an active ‘guardian’ for their care recipient and a luxury commodity. These narratives functioned in interaction with each other to represent the nuanced challenge of maintaining sufficient sleep while balancing the responsibilities of dementia-related care. Use of time and sleep was narrated as dependent on the carer’s needs or preferences, in interaction with the support required and sleep patterns of the care recipient, as well as how they felt they should be behaving while in a caring role. Since these narratives worked together, they are discussed as a set, rather than separately.

An overarching issue, clear throughout, was a limitation that being asleep posed on carers’ ability to be ‘on duty’. Falling into sleep allows for ‘offline’ recovery and processing. However, with caring, and for many being the sole carer, sleep also renders them ‘off guard’ and less responsive to their care recipient’s immediate needs. Sleep also poses a risk to carers’ own (ageing) bodies, which may mean that they are not easily woken or, indeed, may not wake at all. Carers experienced these concerns alongside feelings of needing to maintain vigilance as a carer (often presented as a twenty-four-seven commitment). A further, paradoxical, tension was apparent regarding carers’ innate position and desires as a ‘sleeper’, which is recognised as necessary for optimal functioning, including being healthy and feeling like ‘their own person’. These tensions led to a situation where carers’ sleep loss was narrated as a sense of self-sacrifice, in which the guardianship of the care recipient was prioritised and achieving quality sleep was a luxury that could be forgone when necessary and indulged in later.

These narratives align with sociological theories of sleep that acknowledge sleeping as a behavioural practice requiring negotiation with factors related to the self, as well as to those with whom we live and sleep, and the impositions of external society (Meadows, 2005; Williams, 2005; Grandner, 2019). Furthermore, when we sleep, our brain disengages from the outside world and we become vulnerable to occurrences in the active world. When sleeping in a routine and safe environment, this is seldom considered. However, in vulnerable situations such as unstable or crowded housing, living and sleeping in areas of high crime, or when a person, or a household member, has a health condition (such as presented here), the risks of what could occur while sleeping become a realistic concern (Williams, 2002; 2007).

The narratives presented can be understood in terms of the prevailing imperative of caring that values the self-sacrificing carer who places the needs of the care recipient above their own needs. This is informed by high moral obligations around performing care well and maintaining a sense of coping with the overall situation (Breheny et al, 2020). Self-care of the carer is acknowledged as important, but in the context of limited support, often forgone. How this is presented and managed likely varies by carers’ situations, experiences and relationships with care recipients (Breheny et al, 2020). The present research adds to this, presenting examples of self-sacrifice and negotiation through the lens of carers’ sleep status and practices.

Many related their caring experience as akin to caring for young children. However, unlike parenting, these carers were less likely to sleep while the care recipient did. When carers had external support to relieve them, they did not typically use that

care respite for sleep. The concept of napping was presented as one of luxury, either recognised as a lucky opportunity to be able to achieve it or relished as an experience after home-based care had ceased. Such accounts were examples of how carers' schedules were reallocated after caring. This narrative identifies a marked shift, symbolic of new-found freedom, through relinquishing the identity of self-sacrificing carer.

These findings add examples of practices of sleeping. How, when, where and with whom we sleep, and the behaviours around this, are personal. Therefore, we are often protective of routines, including sleep preferences, having established and adjusted them across the life course (Meadows et al, 2018; Staton et al, 2019). When the practice of sleep is compromised (such as during care), it has an impact not only on sleep health, but also on the maintenance of self-identity at the personal, interpersonal and social levels (Meadows, 2005). The loss of sleep practices was narrated as bound up in the sacrifices related to the caring role and was later luxuriously reclaimed once full-time guardianship was relieved after the care recipient had transitioned into residential care or beyond. The interpersonal nature of sleep was clear in the presentation of sleep debt as an aspect of this stage of life, akin to parenting, which was expected to pass. Furthermore, interconnections between the sleep practices of carer and care recipient were strong, with carers often having to adjust (or sacrifice) their sleep timing to prioritise the care recipient and constant availability. This indicates the sensitivity of sleep being required to occur in a compatible manner during such situations as caring.

How sleep is fitted in between waking responsibilities can be viewed as an indicator of individual processes, the pace of life and broader social acceleration. Context is important, and the pressures of waking life vary across the life course (Hsu, 2014; Staton et al, 2019). Here, socially engrained practices of sleep were apparent in carers' resistance to sleep outside of social norms or resting when respite was presented. Instead, domestic productivity was upheld. This may reflect high energy levels stimulated via the busy or emotive caring role, or possibly upholding appearances of capacity, coping and vitality, bound up with moral obligations of family care (Nussbaum, 2000; Horrell et al, 2015).

Considerations

The present findings reflect carers' retrospective stories after transitioning the care recipient into RAC (and for some, after the care recipient had died). It is accepted that memories, knowledge and meanings may have shifted with the passing of time (Wong and Breheny, 2018; Breheny et al, 2020). The memory and impact of positive versus negative events are also expected to differ depending on emotional distress (Berntsen et al, 2011). However, this narrative approach also provides strength in gaining retrospective perspectives of the complete caring experience (McAdams, 2001). This is important given that accounts of potentially stressful or sleep-deprived experiences can be challenging to comprehend with regard to their impact on affect when actively caring.

The narratives constructed here relate to the dementia care situation and offer a novel lens for considering the sociology of sleep. However, findings reflect the situations of this sample of carers with shared characteristics. Recruitment took place through opting into a mailing list from a survey originally distributed via regional dementia organisations (Gibson and Gander, 2020). Families with limited access to diagnostic services (for geographical or financial reasons), of Māori or Pacific Island ethnicity, with poorer

physical and mental health, and that do not identify with the ‘dementia’ and/or ‘carer’ terminology are less likely to engage with dementia-related organisations, services or research activities (Dyall, 2014; Beattie et al, 2018; Dudley et al, 2019). A total of 18 of the 20 participants in this study identified as of New Zealand European ethnicity. Greater attention and engagement are recommended to provide a platform for the stories of Māori and Pacific Island carers. This is important because indigenous cultures have been identified as having a younger onset of dementia, higher incidence of sleep problems and different approaches to sleeping, family practices and dementia (Paine et al, 2004; 2005; Dyall, 2014; Dudley et al, 2019). Sleep, a key pillar of well-being practised by all, requires further consideration through the various lenses of society to inform the goals of healthy ageing and living well with dementia under the guardianship of carers.

Summary

Sleep represents approximately a third of our recommended time use (or intended time), and there is strong evidence for sleep’s importance for waking function and health. Supporting sleep is increasingly recognised as key for ageing well, including for carers. However, sleep is also a behavioural practice deeply entrenched in individual and social norms. This data set highlights the narratives of carers’ experiences of balancing sleep while supporting someone with dementia at home. Here, tensions are highlighted between: recognising the desire to sleep in order to maintain a sense of self; the requirement of sleep in order to function and support care recipients; and the need to sacrifice sleep in order to maintain the key role as guardian carer. The findings allude to common social beliefs and expectations around sleep and sleepiness, which would benefit from being addressed with regard to wider social discourses of ageing and dementia. This will guide external support frameworks where the facilitation, rather than sacrifice, of sleep could be promoted, providing a means of supporting waking function, vigilance and coping with the overall situation.

Funding

This work was supported by the Health Research Council of New Zealand (Grant 18/621) and Lottery Health Research (Grant 72086).

Acknowledgements

The authors would like to acknowledge the participants for their time sharing their stories and colleagues at Alzheimer’s New Zealand and Dementia New Zealand for their support.

Ethics

This work was approved by the New Zealand Health and Disability Ethics Committee (16/CEN/101).

Conflict of interest

The authors declare that there is no conflict of interest.

References

Adelman, R.D., Tmanova, L.L., Delgado, D., Dion, S. and Lachs, M.S. (2014) Caregiver burden: a clinical review, *Journal of the American Medical Association*, 311(10): 1052–9. doi: [10.1001/jama.2014.304](https://doi.org/10.1001/jama.2014.304)

- Alpass, F., Pond, R., Stephens, C., Stevenson, B., Keeling, S. and Towers, A. (2013) The influence of ethnicity and gender on caregiver health in older New Zealanders, *Journals of Gerontology – Series B: Psychological Sciences and Social Sciences*, 68(5): 783–93. doi: [10.1093/geronb/gbt060](https://doi.org/10.1093/geronb/gbt060)
- Beattie, E., Fielding, E., O’Reilly, M., Brooks, D., MacAndrew, M. and McCrow, J. (2018) Recruitment of individuals with dementia and their carers for social research: lessons learned from nine studies, *Research in Gerontological Nursing*, 11(3): 119–28. doi: [10.3928/19404921-20180308-01](https://doi.org/10.3928/19404921-20180308-01)
- Berntsen, D., Rubin, D.C. and Siegler, I.C. (2011) Two versions of life: emotionally negative and positive life events have different roles in the organization of life story and identity, *Emotion*, 11(5): 1190–201. doi: [10.1037/a0024940](https://doi.org/10.1037/a0024940)
- Bliwise, D.L. (2004) Sleep disorders in Alzheimer’s disease and other dementias, *Clinical Cornerstone*, 6(1): 16–28. doi: [10.1016/S1098-3597\(04\)90014-2](https://doi.org/10.1016/S1098-3597(04)90014-2)
- Breheny, M. and Stephens, C. (2012) Negotiating a moral identity in the context of later life care, *Journal of Aging Studies*, 26(4): 438–47. doi: [10.1016/j.jaging.2012.06.003](https://doi.org/10.1016/j.jaging.2012.06.003)
- Breheny, M., Horrell, B. and Stephens, C. (2020) Caring for older people: relational narratives of attentiveness, commitment and acceptance, *International Journal of Care and Caring*, 4(2): 201–14. doi: [10.1332/239788219X15730452705345](https://doi.org/10.1332/239788219X15730452705345)
- Chiao, C.Y., Wu, H.S. and Hsiao, C.Y. (2015) Caregiver burden for informal caregivers of patients with dementia: a systematic review, *International Nursing Review*, 62(3): 340–50. doi: [10.1111/inr.12194](https://doi.org/10.1111/inr.12194)
- David, R., Zeitzer, J., Friedman, L., Noda, A., O’Hara, R., Robert, P. and Yesavage, J.A. (2010) Non-pharmacologic management of sleep disturbance in Alzheimer’s disease, *Journal of Nutrition, Health and Aging*, 14(3): 203–6. doi: [10.1007/s12603-010-0050-9](https://doi.org/10.1007/s12603-010-0050-9)
- Dudley, M., Menzies, O., Elder, H., Nathan, L., Garrett, N. and Wilson, D. (2019) Mate wareware: understanding ‘dementia’ from a Māori perspective, *The New Zealand Medical Journal*, 132(1503): 66–74.
- Dyall, L. (2014) Dementia: continuation of health and ethnic inequalities in New Zealand, *New Zealand Medical Journal*, 127(1389): 68–81.
- Edwards, H., Courtney, M. and Spencer, L. (2003) Consumer expectations of residential aged care: reflections on the literature, *International Journal of Nursing Practice*, 9(2): 70–7. doi: [10.1046/j.1322-7114.2003.00415.x](https://doi.org/10.1046/j.1322-7114.2003.00415.x)
- Efran, J.S., McNamee, S., Warren, B. and Raskin, J.D. (2014) Personal construct psychology, radical constructivism, and social constructionism: a dialogue, *Journal of Constructivist Psychology*, 27(1): 1–13. doi: [10.1080/10720537.2014.850367](https://doi.org/10.1080/10720537.2014.850367)
- Fekete, M., Szabo, A., Stephens, C. and Alpass, F. (2019) Older New Zealanders in caregiving roles: psychological functioning of caregivers of people living with dementia, *Dementia*, 18(5): 1663–78. doi: [10.1177/1471301217725897](https://doi.org/10.1177/1471301217725897)
- Foley, D.J., Ancoli-Israel, S., Britz, P. and Walsh, J. (2004) Sleep disturbances and chronic disease in older adults: results of the 2003 National Sleep Foundation sleep in America survey, *Journal of Psychosomatic Research*, 56(5): 497–502. doi: [10.1016/j.jpsychores.2004.02.010](https://doi.org/10.1016/j.jpsychores.2004.02.010)
- Gibson, R.H. and Gander, P.H. (2020) Factors associated with the sleep of carers: a survey of New Zealanders supporting a family member with cognitive impairment or dementia, *Dementia*, 20(3): 919–35. doi: [10.1177/1471301220915071](https://doi.org/10.1177/1471301220915071)
- Gibson, R.H., Gander, P.H. and Jones, L.M. (2014) Understanding the sleep problems of people with dementia and their family caregivers, *Dementia: The International Journal of Social Research and Practice*, 13(3): 348–63.

- Gibson, R.H., Gander, P.H., Alpass, F. and Stephens, C. (2015) The effect of caregiving status on the sleep of older New Zealanders, *Australasian Journal on Ageing*, 34(3): 155–9. doi: [10.1111/ajag.12161](https://doi.org/10.1111/ajag.12161)
- Gibson, R.H., Gander, P.H., Jones, L.M. and Dowell, A.C. (2017) Non-pharmacological interventions for managing dementia-related sleep problems within community dwelling pairs: a mixed-method approach, *Dementia*, 16(8): 967–84. doi: [10.1177/1471301215625821](https://doi.org/10.1177/1471301215625821)
- Gibson, R.H., Gander, P., Kepa, M., Moyes, S. and Kerse, N. (2020) Self-reported sleep problems and their relationship to life and living of Māori and non-Māori in advanced age, *Sleep Health*, 6(4): 522–8. doi: [10.1016/j.sleh.2019.11.002](https://doi.org/10.1016/j.sleh.2019.11.002)
- Gibson, R.H., Helm, A., Breheny, M. and Gander, P. (2021) ‘My quiet times’: themes of sleep health among people caring for a family member with dementia, *Dementia*, (6): 2024–40. doi: [10.1177/1471301220980247](https://doi.org/10.1177/1471301220980247)
- Grandner, M.A. (2017) Sleep, health and society, *Sleep Medicine Clinics*, 12(1): 1–22. doi: [10.1016/j.jsmc.2016.10.012](https://doi.org/10.1016/j.jsmc.2016.10.012)
- Grandner, M.A. (2019) Social-ecological model of sleep health, in M.A Grandner (ed) *Sleep and Health*, Cambridge, MA: Academic Press, pp 45–53.
- Horrell, B., Stephens, C. and Breheny, M. (2015) Capability to care: supporting the health of informal caregivers for older people, *Health Psychology*, 34(4): 339–48. doi: [10.1037/hea0000144](https://doi.org/10.1037/hea0000144)
- Hsu, E.L. (2014) The sociology of sleep and the measure of social acceleration, *Time & Society*, 23(2): 212–34. doi: [10.1177/0961463X13486729](https://doi.org/10.1177/0961463X13486729)
- Jorgensen, D., Arksey, H., Parsons, M., Senior, H. and Thomas, D. (2009) Why do older people in New Zealand enter residential care rather than choosing to remain at home, and who makes that decision?, *Ageing International*, 34(1): 15–32. doi: [10.1007/s12126-009-9034-7](https://doi.org/10.1007/s12126-009-9034-7)
- Maun, E., Glaser, K. and Corna, L. (2018) Co-resident care-giving and problematic sleep among older people: evidence from the UK Household Longitudinal Study, *Ageing and Society*, 40(6): 1195–222. doi: [10.1017/S0144686X1800168X](https://doi.org/10.1017/S0144686X1800168X)
- McAdams, D.P. (2001) The psychology of life stories, *Review of General Psychology*, 5(2): 100–22. doi: [10.1037/1089-2680.5.2.100](https://doi.org/10.1037/1089-2680.5.2.100)
- McCurry, S.M. and Ancoli-Israel, S. (2003) Sleep dysfunction in Alzheimer’s disease and other dementias, *Current Treatment Options in Neurology*, 5(3): 261–72. doi: [10.1007/s11940-003-0017-9](https://doi.org/10.1007/s11940-003-0017-9)
- McCurry, S.M., Logsdon, R.G., Teri, L. and Vitiello, M.V. (2007) Sleep disturbances in caregivers of persons with dementia: contributing factors and treatment implications, *Sleep Medicine Reviews*, 11(2): 143–53. doi: [10.1016/j.smrv.2006.09.002](https://doi.org/10.1016/j.smrv.2006.09.002)
- McCurry, S.M., Song, Y. and Martin, J.L. (2015) Sleep in caregivers: what we know and what we need to learn, *Current Opinion in Psychiatry*, 28(6): 497–503. doi: [10.1097/YCO.0000000000000205](https://doi.org/10.1097/YCO.0000000000000205)
- Meadows, R. (2005) The ‘negotiated night’: an embodied conceptual framework for the sociological study of sleep, *Sociological Review*, 53(2): 240–54. doi: [10.1111/j.1467-954X.2005.00512.x](https://doi.org/10.1111/j.1467-954X.2005.00512.x)
- Meadows, R. (2016) The importance of viewing sleep as a ‘practice’, *Addiction*, 111(6): 1094–5. doi: [10.1111/add.13358](https://doi.org/10.1111/add.13358)
- Meadows, R., Williams, S.J., Gabe, J., Coveney, C. and Arber, S. (2018) The sociology of sleep, in F.P. Cappuccio, M.A. Miller and S.W. Lockley (eds) *Sleep, Health and Society: From Aetiology to Public Health*, 2nd edn, Oxford: Oxford University Press, pp 171–8.

- Ministry of Health (2013) New Zealand framework for dementia care, www.health.govt.nz/system/files/documents/publications/new-zealand-framework-for-dementia-care-nov13.pdf.
- Ministry of Health (2016) *Healthy Ageing Strategy*, Wellington: Ministry of Health.
- Moore, M.J., Zhu, C.W. and Clipp, E.C. (2001) Informal costs of dementia care: estimates from the National Longitudinal Caregiver Study, *Journals of Gerontology – Series B: Psychological Sciences and Social Sciences*, 56(4): S219–28. doi: [10.1093/geronb/56.4.S219](https://doi.org/10.1093/geronb/56.4.S219)
- Morin, C.M., Belleville, G., Bélanger, L. and Ivers, H. (2011) The Insomnia Severity Index: psychometric indicators to detect insomnia cases and evaluate treatment response, *Sleep*, 34(5): 601–8. doi: [10.1093/sleep/34.5.601](https://doi.org/10.1093/sleep/34.5.601)
- Murray, M. (2000) Levels of narrative analysis in health psychology, *Journal of Health Psychology*, 5(3): 337–47. doi: [10.1177/135910530000500305](https://doi.org/10.1177/135910530000500305)
- Ng, C.K.M., Leung, D.K.Y., Cai, X. and Wong, G.H.Y. (2021) Perceived help-seeking difficulty, barriers, delay, and burden in carers of people with suspected dementia, *International Journal of Environmental Research and Public Health*, 18(6): 1–11.
- Nussbaum, M. (2000) Women’s capabilities and social justice, *Journal of Human Development*, 1(2): 219–47. doi: [10.1080/713678045](https://doi.org/10.1080/713678045)
- Paine, S.J., Gander, P.H., Harris, R. and Reid, P. (2004) Who reports insomnia? Relationships with age, sex, ethnicity, and socioeconomic deprivation, *Sleep*, 27(6): 1163–9. doi: [10.1093/sleep/27.6.1163](https://doi.org/10.1093/sleep/27.6.1163)
- Paine, S.J., Gander, P.H., Harris, R.B. and Reid, P. (2005) Prevalence and consequences of insomnia in New Zealand: disparities between Maori and non-Maori, *Australian and New Zealand Journal of Public Health*, 29(1): 22–8. doi: [10.1111/j.1467-842X.2005.tb00743.x](https://doi.org/10.1111/j.1467-842X.2005.tb00743.x)
- Reynolds, A., Sprajcer, M., Vincent, G., Gibson, R., Kovac, K., Adams, L., Dorrain, J., Gupta, C., Paterson, J., Thomas, M. and Ferguson, S.A. (2020) *Sleep Deficits in Australian Carers: Report Prepared for Sleep Health Foundation and Carers Australia*, Adelaide: CQ University Appleton Institute.
- Staton, S. et al. (2019) *Sleep and Society: Continuity and Chaos across the Life Course*, Brisbane, QLD: University of Queensland, https://issr.uq.edu.au/files/12817/113245%20ISSR_Sleep%20Study_FINAL.pdf.
- Stephens, C. and Breheny, M. (2013) Narrative analysis in psychological research: an integrated approach to interpreting stories, *Qualitative Research in Psychology*, 10(1): 14–27. doi: [10.1080/14780887.2011.586103](https://doi.org/10.1080/14780887.2011.586103)
- Venn, S. and Arber, S. (2011) Day-time sleep and active ageing in later life, *Ageing and Society*, 31(2): 197–216. doi: [10.1017/S0144686X10000954](https://doi.org/10.1017/S0144686X10000954)
- Williams, S.J. (2002) Sleep and health: sociological reflections on the dormant society, *Health*, 6(2): 173–200. doi: [10.1177/136345930200600203](https://doi.org/10.1177/136345930200600203)
- Williams, S.J. (2005) *Sleep and Society: Sociological Ventures into the Un(Known)*, London: Routledge.
- Williams, S.J. (2007) Vulnerable/dangerous bodies? The trials and tribulations of sleep, *Sociological Review*, 55(Suppl 1): 142–55. doi: [10.1111/j.1467-954X.2007.00698.x](https://doi.org/10.1111/j.1467-954X.2007.00698.x)
- Williams, S.J., Coveney, C.M. and Gabe, J. (2013) Medicalisation or customisation? Sleep, enterprise and enhancement in the 24/7 society, *Social Science and Medicine*, 79(1): 40–7. doi: [10.1016/j.socscimed.2012.07.017](https://doi.org/10.1016/j.socscimed.2012.07.017)
- Wong, G. and Breheny, M. (2018) Narrative analysis in health psychology: a guide for analysis, *Health Psychology and Behavioral Medicine*, 6(1): 245–61. doi: [10.1080/21642850.2018.1515017](https://doi.org/10.1080/21642850.2018.1515017)