Caregivers of people with dementia are losing sleep

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WACO—Caregivers of people with dementia lose between 2.5 to 3.5 hours of sleep weekly due to difficulty falling asleep and staying asleep—a negative for themselves and potentially for those who receive their care, Baylor University researchers say.

But the good news is that simple, low-cost interventions can improve caregivers' sleep and functioning.

The researchers' analysis of 35 studies with data from 3,268 caregivers—"Sleep Duration and Sleep Quality in Caregivers of Patients with Dementia"—is published in *JAMA Network Open*, a publication of the American Medical Association.

Informal caregiving for a person with dementia is akin to adding a part-time but unpaid job to one's life, with family members averaging 21.9 hours of caregiving, according to estimates by the Alzheimer's Association.

Cumulative impact noted

"Losing 3.5 hours of sleep per week does not seem much, but caregivers often experience accumulation of sleep loss over years," said lead author Chenlu Gao, a doctoral candidate of psychology and neuroscience at Baylor.

"Losing 3.5 hours of sleep weekly on top of all the stress, grief and sadness can have a really strong impact on caregivers' cognition and mental and physical health. But improving caregivers' sleep quality through low-cost behavioral interventions can significantly improve their functions and quality of life."

Chronic stress is associated with short sleep and poor-quality sleep. And nighttime awakenings by a patient with dementia also can contribute to disturbed sleep in caregivers, researchers said.

"With that extra bit of sleep loss every night, maybe a caregiver now forgets some medication doses or reacts more emotionally than he or she otherwise would," said co-author Michael Scullin, director of Baylor's Sleep Neuroscience and Cognition Laboratory and assistant professor of psychology and neuroscience.

"Caregivers are some of the most inspiring and hardest-working people in the world, but sleep loss eventually accumulates to a level that diminishes one's vigilance and multi-tasking."

Self-care makes a difference

Notably better sleep was observed in caregivers after such simple behaviors as getting more morning sunlight, establishing a regular and relaxing bedtime routine and taking part in moderate physical exercise.

In the United States, 16 million family caregivers give long-term care for dementia patients. Dementia affects some 50 million adults globally and is expected to increase to 131 million by 2050, according to the World Alzheimer Report. The global annual cost is nearing $1 trillion, largely due to patients' loss of independence because of problems with eating, bathing and grooming, incontinence and memory loss.

For the analysis, researchers searched articles in peer-reviewed journals and books addressing caregivers, sleep, dementia and Alzheimer's disease, published through June 2018. Those studies measured sleep quality and quantity by monitoring brain electrical activity, body movements and self-reporting by caregivers.

The difference in time and quality of sleep was significant when compared to non-caregivers in the same age range and with the recommended minimum of sleep: seven hours nightly for adults. Researchers also analyzed intervention-related changes in sleep quality, such as daytime exercise, not drinking coffee or tea past late afternoon, not drinking alcohol at night and getting more sunlight in the morning.

Different theories have emerged

Researchers noted that four theories about sleep in dementia caregivers have emerged in studies:

- The controversial “sleep need” view asserts older adults need less sleep than younger ones. If so, caregivers should report less sleep time but without changes in perceived sleep quality.
- The “empowerment view” argues that caregiving is a positive, enriching experience, and so sleep quality should be unchanged or even improved.
- The “environmental stressor view” holds that the caregiving is so stressful and unpredictable, caregivers would be unable to change their routine in such a way to benefit their sleep.
- The “coping” view says health problems may be driven by unhealthy responses to stress, such as increased alcohol use and less exercise, while interventions should be associated with better sleep.

Baylor researchers’ analysis found caregivers slept less and perceived their sleep quality to be worsening. That means that they were not simply adapting—or not “needing”—sleep. Importantly, caregivers could improve their sleep through behavioral changes, as expected by the “coping” view of caregiving.

“Given the long-term, potentially cumulative health consequences of poor-quality sleep, as well as the rising need for dementia caregivers worldwide, clinicians should consider sleep interventions not only for the patient but also for the spouse, child or friend who will be providing care,” Gao said.