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Authors

Polenick, Courtney A
Leggett, Amanda N
Maust, Donovan T
et al.

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Medical Care Tasks Among Spousal Dementia Caregivers: Links to Care-Related Sleep Disturbances

Courtney A. Polenick, PhD[1,2], **Amanda N. Leggett, PhD**[1,2], **Donovan T. Maust, MD, MS**[1,2,3,4], and **Helen C. Kales, MD**[1,2,3,4,5]

[1]Department of Psychiatry, University of Michigan, Ann Arbor, MI 48109

[2]Program for Positive Aging, University of Michigan, Ann Arbor, MI 48109

[3]Institute for Healthcare Policy and Innovation, University of Michigan, Ann Arbor, MI 48109

[4]Department of Veterans Affairs, HSR&D Center for Clinical Management Research (CCMR), Ann Arbor, MI 48109

[5]Geriatric Research, Education and Clinical Center (GRECC), VA Ann Arbor Healthcare System, Ann Arbor, MI 48109

Abstract

Objectives—Medical care tasks are commonly provided by spouses caring for persons living with dementia (PLWDs). These tasks reflect complex care demands that may interfere with sleep, yet their implications for caregivers' sleep outcomes are unknown. We evaluated the association between caregivers' medical/nursing tasks (keeping track of medications; managing tasks such as ostomy care, IVs, or blood testing; giving shots/injections; and caring for skin wounds/sores) and care-related sleep disturbances.

Design—A retrospective analysis of cross-sectional data from the 2011 National Health and Aging Trends Study and National Study of Caregiving was conducted.

Setting—Spousal caregivers and PLWDs/proxies were interviewed by telephone at home.

Participants—The US sample included 104 community-dwelling spousal caregivers and PLWDs.

Measurements—Caregivers reported on their sociodemographic and health characteristics, caregiving stressors, negative caregiving relationship quality, and sleep disturbances. PLWDs (or proxies) reported on their health conditions and sleep problems.

Results—Caregivers who performed a higher number of medical/nursing tasks reported significantly more frequent care-related sleep disturbances, controlling for sociodemographic and

Corresponding author: Courtney A. Polenick, Department of Psychiatry, University of Michigan, 2800 Plymouth Rd., Building 16, Room 200S, Ann Arbor, MI 48109. cpolenic@med.umich.edu.

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health characteristics, caregiving stressors, negative caregiving relationship quality, and PLWDs' sleep problems and health conditions. Post hoc tests showed that wound care was independently associated with more frequent care-related sleep disturbances after accounting for the other medical/nursing tasks and covariates.

Conclusions—Spousal caregivers of PLWDs who perform medical/nursing tasks may be at heightened risk for sleep disturbances and associated adverse health consequences. Interventions to promote the well-being of both care partners may benefit from directly addressing caregivers' needs and concerns about their provision of medical/nursing care.

Keywords

dementia care; informal caregiving; medical care; medical/nursing care

Objective

Alzheimer's disease and related dementias currently affect over 5 million US adults, with a projected impact on 7.1 million by 2025 and 13.8 million by 2050.[1] Along with cognitive and functional impairment, persons living with dementia (PLWDs) have high rates of chronic medical comorbidities (e.g., diabetes, heart disease) that complicate their long-term care.[1,2] Strikingly, one-quarter (26%) of PLWDs have five or more chronic medical conditions versus only 3.8% of other Medicare beneficiaries.[1] Spouses are a primary source of support for PLWDs, with roughly two-thirds of spousal caregivers assuming responsibility for medical tasks traditionally handled by healthcare professionals.[3] Medical/nursing tasks such as keeping track of medications, managing peripheral intravenous lines (IVs), giving injections, and caring for wounds require specialized skills in which many family caregivers lack training.[3–6] These tasks can be difficult, stressful, and time-consuming,[3–16] potentially interfering with caregivers' self-care. Yet little is known about their actual impact on key caregiver health behaviors.

Sleep disturbances are reported by approximately 50%–70% of individuals caring for PLWDs.[17] Numerous factors contribute to caregivers' sleep disturbances including older age, female gender, medical or psychiatric morbidity, negative caregiving relationship quality, and care-related stressors that are objective (e.g., PLWDs' nighttime awakenings) or subjective (e.g., caregivers' emotional caregiving difficulties).[17–20] Disturbed sleep is linked to detrimental health consequences such as weight gain, cardiovascular disease, and earlier mortality.[21–23] Caregivers' sleep interruptions may also reduce the quality of care they provide and increase the PLWD's likelihood of institutionalization, underscoring the need to gain a better understanding of everyday influences on care-related sleep disturbances.[17–19]

Medical/nursing tasks may be linked to care-related sleep disturbances among spousal caregivers for at least three reasons. First, these tasks involve a considerable time commitment which limits activities that promote healthy sleep patterns (e.g., exercise, socializing). Caregivers commonly arrange their schedules around tasks such as preparing injections or IV bags, planning and administering multiple doses of medication, and monitoring wound care.[7,15,16] Second, during the night, caregivers may need to give medication, change bandages, or check IV tubes.[6,7,10,11,15, 24] Nighttime care activities

could be compounded by the PLWD's resistance or distress that further exacerbates caregivers' sleep disturbances.[8,12,25] Third, many caregivers have no prior medical training and concerns about the potential for serious complications might result in hypervigilance that interferes with caregivers' sleep.[18,19] Adverse events such as drug-drug interactions, infections, and medical equipment malfunctions are a major concern for caregivers that affect up to 15% of home care recipients.[10,13,26] The tendency to stay awake and monitor medical care could be especially strong among spousal caregivers because they typically share a bedroom with the PLWD. In the extreme, medical/nursing tasks may evoke rumination or intrusive thoughts that lead to sleep disturbances. Many spousal caregivers worry, for example, that they will make a life-threatening mistake.[3] Spousal caregivers also worry that these tasks are upsetting to their partner,[3] perhaps even more so when he or she has dementia and may not understand the reason for the task or any associated discomfort. Taken together, previous work highlights the importance of evaluating the links between spousal caregivers' medical/nursing tasks and sleep in the dementia care context.

We examined how medical/nursing tasks and care-related sleep disturbances are associated among spousal caregivers of a PLWD using data from a nationally representative US sample. The four tasks considered in this study (keeping track of medications; managing tasks such as ostomy care, IVs, or blood testing; giving shots/injections; and caring for skin wounds/sores) were selected because they often involve both daytime and nighttime care provision that may interfere with caregivers' sleep. [6,7,10,11,15, 24] We hypothesized that a higher number of medical/nursing tasks would be significantly linked to more frequent care-related sleep disturbances, controlling for caregivers' sociodemographic and health characteristics, caregiving stressors, negative caregiving relationship quality, and PLWDs' health conditions and sleep problems.

Methods

Sample and Procedures

The sample included 104 community-dwelling adults aged 65 and older with dementia and their co-resident spousal caregivers drawn from the 2011 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC). In line with the University of Michigan's policies, internal review board approval was not required because we used publicly available secondary data with no individual identifiers.

Participants were eligible for NHATS if they were Medicare enrollees aged 65 and older, resided in the contiguous US, and received health-related assistance in the last month with mobility, personal care, and/or household chores. Participants were recruited from a Medicare enrollment database using a stratified three-stage sampling design. Of the 12,411 contacted enrollees, 8,245 (71%) were interviewed.

NHATS participants were eligible for NSOC if they had at least one family or unpaid nonfamily caregiver who provided health-related assistance with mobility, self-care, household chores, and/or medical care activities. The 2,423 eligible NHATS participants had 4,935 eligible caregivers. Of the 3,362 (68.1%) caregivers for whom contact information was given, 2,007 (59.7%) completed a 30-minute telephone interview.[27]

Of the 2,007 caregivers participating in NSOC, 368 were co-resident caregivers for community-dwelling individuals who had probable dementia, which was determined in NHATS using the following:[28] 1) a reported diagnosis by the participant or a proxy respondent; 2) meeting criteria for diagnosis based on the AD8, a widely used and validated dementia screening interview;[29] or 3) scoring at least 1.5 standard deviations below the mean in two or more domains of cognitive testing including memory, executive function, and orientation. We were interested in spousal care dyads, and so we removed 257 non-spouse caregivers who were primarily adult daughters (43.3%) or sons (21.9%) of the PLWD. Of the 111 caregiving spouses, seven were removed due to missing data on study variables, resulting in an analytic sample of 104 spousal caregivers and PLWDs. Couples were all heterosexual and had been married for 45.29 years on average (*SD* = 19.89, range = 2 – 72).

Measures

Medical/nursing tasks—Caregivers reported whether they performed four types of care tasks (1 = yes, 0 = no): keeping track of medications, managing medical tasks (e.g., ostomy care, IVs, testing blood), giving shots/injections, and skin wound/sore care. Summed scores were created (range = 0 – 4).

Care-related sleep disturbances—Caregivers reported how frequently their sleep was interrupted in the last month because of caregiving (1 = every night, 2 = most nights, 3 = some nights, 4 = rarely, 5 = never). Responses were reverse coded.

Caregiver covariates—We controlled for caregivers' age, gender (1 = female, 0 = male), and educational attainment (1 = no schooling completed to 9 = masters, professional, or doctoral degree). We also controlled for two caregiver health factors linked to sleep outcomes: physical impairments and multimorbidity.[30,31] Physical impairments were determined from caregivers' reports of whether they had the following health problems that limited their activities in the last month: pain, breathing difficulties (e.g., shortness of breath), limited strength/movement in shoulders/arms/hands, limited strength/movement in hips/leg/knees/feet, and low energy or exhaustion. Each problem was considered an impairment if caregivers rated it as interfering with their activities on some days, most days, or every day. Summed scores were calculated (range = 0 – 5). Caregivers' multimorbidity (1 = two or more chronic conditions, 0 = one or no chronic conditions) was determined from their reports of being diagnosed with six health conditions: arthritis, diabetes, heart disease, hypertension, lung disease, and osteoporosis. To account for sleep problems that are not specific to caregiving, we controlled for caregivers' nighttime awakenings. Caregivers were asked how often in the last month they had trouble falling back asleep when they awoke during the night (1 = every night, 2 = most nights, 3 = some nights, 4 = rarely, 5 = never). Responses were reverse coded.

Care-related covariates—Additionally, we controlled for care-related stressors that are associated with caregiver sleep outcomes.[17–20] Caregivers' ADL assistance indicates the severity of dementia care and included helping the PLWD with bathing, dressing, eating, toileting, getting in/out of bed, and mobility inside/outside the house. Summed scores were

created (range = 0 – 7). Caregivers reported whether they experienced emotional caregiving difficulties (1 = yes, 0 = no) along with the extent of these difficulties from 1 (a little difficult) to 5 (very difficult). We combined the two items so that caregivers with no difficulties were assigned a zero and those reporting difficulties received a score based on their degree (0 = no difficulty to 5 = high difficulty).[14,20] Role overload was measured with three items assessing how much caregivers feel they a) are exhausted when they go to bed at night; b) have more things to do than they can handle; and c) do not have time for themselves (1 = very much, 2 = somewhat, 3 = not so much).[32] Items were reverse coded and averaged (range = 1 – 3, α = .76). Negative caregiving relationship quality was ascertained from caregivers' reports of how much the care recipient a) argues with them; and b) gets on their nerves from 1 (a lot) to 4 (not at all). Items were reverse coded and averaged (range = 1 – 4), and the Spearman-Brown reliability estimate (recommended for two-item scales[33]) was .62.

PLWD covariates—PLWDs (n = 61) or their proxies (n = 41 spouses; n = 1 adult daughter; n = 1 adult son) reported whether they had been diagnosed with eight health conditions: arthritis, cancer, diabetes, heart disease, hypertension, lung disease, osteoporosis, and stroke. Summed scores were calculated (range = 0 – 8). PLWDs' sleep problems were assessed with two separate items. The frequency of difficulty with falling asleep (i.e., taking more than 30 minutes to fall asleep) and nighttime awakenings (i.e., trouble falling back asleep after waking in the night) in the last month were reported by PLWDs or their proxies (1 = every night, 2 = most nights, 3 = some nights, 4 = rarely, 5 = never). Items were reverse coded.

Statistical Analysis

We conducted hierarchical regressions to allow for examination of the variance in care-related sleep disturbances that is explained with each model step. In the first step, we entered the covariates. Medical/nursing tasks were added in the second step to evaluate their independent associations with care-related sleep disturbances. Continuous predictors and covariates were mean centered. Models were estimated in SAS Version 9.4 (SAS Institute, Inc., Cary, NC) using the NSOC analytic weight with statistical procedures to account for the complex survey design and produce nationally representative estimates.[34]

Results

Bivariate associations between caregivers' care related sleep disturbances and study covariates were examined in preliminary analyses. Significant positive correlations were found for ADL assistance (r = .24, p = .01), emotional caregiving difficulties (r = .36, p < .001), role overload (r = .20, p = .05), and negative caregiving relationship quality (r = .27, p = .01), showing that spouses' care-related sleep disturbances are linked to more intense caregiving stressors. More frequent care-related sleep disturbances were also significantly correlated with caregivers' greater nighttime awakenings (r = .20, p = .04), which suggests that care-related sleep problems are associated with trouble falling back asleep after waking in the night.

Figure 1 depicts the percentage of spousal caregivers who performed each medical/nursing task. Caregivers most commonly reported keeping track of medications (82.4%), followed by caring for skin wounds/sores (46.6%), managing medical tasks such as ostomy care, IVs, or blood testing (21.9%), and giving shots/injections (15.3%). Over half of caregivers (52.3%) assisted with two or more medical/nursing tasks. Roughly one in five caregivers (17.6%) reported performing three or more medical/nursing tasks and about one in twenty (5.7%) provided all four tasks.

Table 1 shows background characteristics for caregivers and PLWDs, along with scores on key variables. On average, caregivers reported that they rarely experienced care-related sleep disturbances; however preliminary analyses revealed that more than a quarter of caregivers (27.8%) had these disturbances on some nights, most nights, or every night in the last month (not shown in table). This suggests that a considerable proportion of spousal care dyads may be at risk of poor health and caregiving outcomes from caregivers' care-related sleep disturbances.

Table 2 presents the hierarchical regressions. Including medical/nursing tasks in Step 2 explained 3% of the variance in care-related sleep disturbances with a total of 41% accounted variance. Adjusting for the covariates, performing a higher total number of medical/nursing tasks was significantly linked to more frequent care-related sleep disturbances ($B = .26$, $\beta = .21$, $t = 2.63$, $df = 56$, $p = .01$, 95% CI [.06, .45]). In other words, each additional medical/nursing task was associated with 0.26 greater care-related sleep disturbances (on a scale from 1 to 5).

To consider whether particular types of medical/nursing tasks are independently linked to care-related sleep disturbances, we estimated a model in *post hoc* tests with all covariates from the main analysis and each medical/nursing task as a separate variable (not shown in table). Caring for wounds/sores was significantly associated with more care-related sleep disturbances ($B = .49$, $\beta = .20$, $t = 2.61$, $df = 56$, $p = .01$, 95% CI [.11, .86]). Thus, caregivers performing wound care reported 0.49 greater care-related sleep disturbances (on a scale from 1 to 5) than those who did not perform this task. The three other tasks were not independently associated with care-related sleep disturbances.

Finally, we conducted *post hoc* models to evaluate whether the above associations were found among 244 co-resident non-spouse caregivers of a PLWD with complete data on study variables. The total number of medical/nursing tasks was not significantly linked to non-spouse caregivers' care-related sleep disturbances ($B = .05$, $\beta = .05$, $t = 0.76$, $df = 56$, $p = .45$, 95% CI [−.08, .17]) and no significant associations were found for the four separate medical/nursing tasks when they were examined as independent predictors.

Conclusions

This study demonstrates that medical/nursing tasks have adverse implications for sleep patterns among spouses caring for PLWDs. Consistent with the hypothesis, performing a higher number of medical/nursing tasks was linked to more frequent care-related sleep disturbances among caregivers, over and above sociodemographic and health factors,

caregiving stressors, negative caregiving relationship quality, and the PLWD's health conditions and sleep problems. Providing wound care was also found to be independently linked to greater care-related sleep disturbances, beyond characteristics of the care situation and other medical/nursing tasks. These findings show that medical/nursing tasks have robust links to care-related sleep disturbances among spousal caregivers after accounting for an array of possible confounding variables that explained over one-third of the variance in such difficulties. *Post hoc* tests showed that these associations were not found for non-spouse caregivers (e.g., adult children), indicating that medical/nursing tasks have unique implications for spouses' care-related sleep problems.

Spousal caregivers who perform a higher number of medical/nursing tasks likely encounter more care-related challenges that impair their sleep compared with those who provide less frequent medical caregiving. The four medical/nursing tasks examined in this study each hold the potential for nighttime interruptions, [6,7,10,11,15, 24] which could happen more frequently for caregivers engaged in multiple care activities. Caregivers' sleep may be more disturbed, for example, when they both give pain medication and monitor IVs relative to managing either task alone. Providing a higher number of medical/nursing tasks reflects greater care complexity and burden,[9,14] perhaps leading to more opportunities for care-related sleep disturbances. Moreover, most caregivers lack training in medical/nursing tasks, [3–6] and so a higher number of tasks may intensify related caregiving burden and worries that interfere with sleep. Aside from the direct provision of care, spousal caregivers performing multiple medical/nursing tasks could develop maladaptive strategies to cope with sleep disruptions that ultimately perpetuate their occurrence. Caregivers may, for instance, nap for longer than 30 minutes during the day, drink caffeinated beverages to stay alert, and/or consume alcohol in the evening to help them fall asleep, all of which can maintain their sleep disturbances.[18,19] The impact of these compensatory behaviors could be magnified by worries about medical caregiving. Bolstering this possibility, prior work has found that almost one-third (32%) of caregivers providing medical/nursing care believe they need to constantly monitor for complications, and their worries become more prevalent with a higher number of these care tasks.[6]

Wound care may be particularly linked to care-related sleep disturbances for several reasons. This type of medical caregiving involves preparing and applying bandages, ointments, and prescription drugs for skin care, as well as treating pressure sores or postsurgical wounds. [6,15] These highly specialized tasks require frequent monitoring to prevent complications and are commonly accompanied by fears of harming the care recipient, both of which could disrupt caregivers' sleep patterns.[6] In addition, caring for wounds requires regular contact with bodily fluids that may be emotionally difficult and unpleasant for many caregivers.[6,15] Furthermore, dementia likely presents distinct obstacles in wound care that interfere with caregivers' sleep. PLWDs may, for example, attempt to remove bandages during the night due to forgetting or not fully comprehending their purpose. Receiving wound care could also be distressing and painful for PLWDs, potentially contributing to behavioral and psychological symptoms of dementia that amplify care-related sleep problems among spousal caregivers.[17–19]

As a whole, the present findings reveal that a large proportion of spouses caring for a PLWD may be vulnerable to care-related sleep disturbances. Notably, approximately one in five caregivers performed three or more medical/nursing tasks and about half provided wound care. Sleep disturbances among spouses who are responsible for such complicated caregiving are of substantial clinical and public health concern. Along with harmful consequences for their own health, caregivers' sleep problems may hinder their daily functioning in ways that increase risk for poor quality of medical caregiving. This could lead to preventable hospitalizations or even fatal mistakes in the PLWD's care.[4,6,35–37] Given the potential for costly and devastating consequences, we propose that clinicians should take a proactive role in assessing practical and psychological aspects of medical/nursing tasks that may impede spousal caregivers' sleep. Training in the safe and appropriate provision of these tasks has been shown to attenuate caregiving burden[5] and may help minimize worries or nighttime complications that disrupt caregivers' sleep. Guiding caregivers in developing and evaluating strategies to combat sleep disturbances (e.g., finding a friend or family member to help with medical/nursing tasks or using assistive technology to signal problems during the night) could be especially beneficial. Such strategies should adapt across time to the evolving needs of PLWDs (e.g., medication changes) and their spousal caregivers. Of note, over two-thirds of caregivers in this sample reported multiple chronic conditions, highlighting the importance of addressing how spouses' own health problems may complicate medical/nursing tasks and their relation to sleep disturbances.

We acknowledge six main limitations. First, cross-sectional analyses preclude the examination of causal associations. Second, on average, spouses reported low levels of care-related sleep disturbances. Consequently, the findings may not generalize to spousal caregivers who experience these disturbances more frequently. Third, the NSOC does not include measures of caregivers' preexisting sleep problems (e.g., insomnia, apnea) or objective indicators of sleep. Fourth, the sample was universally heterosexual and predominantly caregiving wives, limiting generalizability. Fifth, data on care-related sleep disturbances are not available among caregivers who did not reside with the PLWD. The associations found in this study may be different for non-resident caregivers because they have limited exposure to nighttime caregiving. Last, overall effect sizes were small. Confidence intervals, however, included upper ranges of .45 for total medical/nursing tasks and .86 for wound/sore care in post hoc tests, suggesting that larger effects may occur for some caregivers. Nevertheless, even small effects may have a significant clinical and public health impact.[38] One might argue, for instance, that any increase in care-related sleep disturbances compromises well-being among spousal caregivers, many of whom are faced with their own health problems that can make caregiving and self-care more challenging.[3,39] Indeed, care-related sleep disturbances in this sample were significantly correlated with more intense caregiving stressors and greater difficulty falling back asleep upon waking in the night. These links are likely bidirectional such that care-related sleep disturbances may both aggravate and be worsened by caregiving stress in addition to sleep problems that are not specific to the care role. Future research should further explore the clinical significance of the current findings, including the assessment of spousal caregivers' perceptions of how medical caregiving and care-related sleep disturbances impact their well-being and functioning.

In summary, this study shows that medical/nursing tasks are common among spouses caring for PLWDs and are associated with greater care-related sleep disturbances. The rapidly growing number of individuals with Alzheimer's disease or related dementias in the US and worldwide ensures that the prevention and treatment of spousal caregivers' sleep disturbances will become an increasingly vital public health issue.[1,40] In light of findings indicating that medically challenging dementia caregiving situations place spousal caregivers at risk for disrupted sleep, clinicians should proactively address the ongoing needs of spouses providing medical/nursing care to PLWDs. Routine clinical visits and interventions to preserve the optimal well-being of both care partners may benefit from recognizing and supporting the complex medical care needs of this highly vulnerable caregiving subgroup.

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References

1. Alzheimer's Association. 2017 Alzheimer's disease facts and figures. Alzheimers Dement. 2017; 13:325–373.
2. Claque F, Mercer SW, McLean G, et al. Comorbidity and polypharmacy in people with dementia: insights from a large, population-based cross-sectional analysis of primary care data. Age Ageing. 2017; 46(1):33–39. [PubMed: 28181629]
3. Reinhard, SC., Levine, C., Samis, S. Family caregivers providing complex chronic care to their spouses. Washington, DC: AARP Public Policy Institute and United Hospital Fund; 2014. Available at: https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2014/family-caregivers-providing-complex-chronic-care-spouses-AARP-ppi-health.pdf. Accessed November 21, 2017
4. Donelan K, Hill CA, Hoffman C, et al. Challenged to care: informal caregivers in a changing health system. Health Aff. 2002; 21(4):222–231.
5. Mollica MA, Litzelman K, Rowland JH, et al. The role of medical/nursing skills training in caregiver confidence and burden: a CanCORS study. Cancer. 2017; 123(22):4481–4487. [PubMed: 28727147]
6. Reinhard, SC., Levine, C., Samis, S. Home alone: family caregivers providing complex chronic care. Washington, DC: AARP Public Policy Institute; 2012. Available at: https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf. Accessed October 10, 2017
7. Francis S, Smith F, Gray N, et al. The roles of informal carers in the management of medication for older care-recipients. Int J Pharma Pract. 2002; 10(1):1–8.
8. Gillespie R, Mullan J, Harrison L. Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature. J Clin Nurs. 2014; 23(23–24): 3296–3308. [PubMed: 24354583]
9. Giovannetti ER, Wolff JL, Xue Q-L, et al. Difficulty assisting with health care tasks among caregivers of multimorbid older adults. J Gen Intern Med. 2012; 271:37–44.
10. Guberman N, Gagnon E, Côté D, et al. How the trivialization of the demands of high-tech care in the home is turning family members into para-medical personnel. J Fam Issues. 2005; 26:247–272.
11. Israel F, Reymond L, Slade G, Menadue S, et al. Lay caregivers' perspectives on injecting subcutaneous medications at home. Int J Palliat Nurs. 2008; 14(8):390–395. [PubMed: 19023955]
12. Look KA, Stone JA. Medication management activities performed by informal caregivers of older adults. Res Social Adm Pharm. 2017 [Epub ahead of print].

13. Moorman SM, MacDonald C. Medically complex home care and caregiver strain. Gerontol. 2012; 53:407–417.
14. Polenick CA, Leggett AN, Kales HC. Medical care activities among spouses of older adults with functional disability: implications for caregiving difficulties and gains. Am J Geriatr Psychiatry. 2017; 25(10):1085–1093. [PubMed: 28652082]
15. Rodrigues AM, Ferreira PL, Ferré-Grau C. Providing informal home care for pressure ulcer patients: how it affects carers' quality of life and burden. J Clin Nurs. 2016; 25:3026–3035. [PubMed: 27577533]
16. Travis SS, Bethea LS, Winn P. Medication administration hassles reported by family caregivers of dependent elderly persons. J Gerontol A Biol Sci Med Sci. 2000; 55(7):M412–M417. [PubMed: 10898259]
17. Peng H, Chang Y. Sleep disturbance in family caregivers of individuals with dementia: a review of the literature. Perspect Psychiatr Care. 2013; 49:135–146. [PubMed: 23557457]
18. McCurry SM, Logsdon RG, Teri L, et al. Sleep disturbances in caregivers of persons with dementia: contributing factors and treatment implications. Sleep Med Rev. 2007; 11:143–153. [PubMed: 17287134]
19. McCurry SM, Song Y, Martin JL. Sleep in caregivers: what we know and what we need to learn. Curr Opin Psychiatry. 2015; 28(6):497–503. [PubMed: 26397027]
20. Leggett AN, Polenick CA, Maust DT, et al. "What hath night to do with sleep?": the caregiving context and dementia caregivers' nighttime awakenings. Clin Gerontol. 2017 [Epub ahead of print].
21. Depner CM, Stothard ER, Wright KP. Metabolic consequences of sleep and circadian disorders. Curr Diab Rep. 2014; 14:507. [PubMed: 24816752]
22. Li Y, Zhang X, Winkelman JW, et al. Association between insomnia symptoms and mortality: a prospective study of US men. Circulation. 2014; 129:737–746. [PubMed: 24226807]
23. Sofi F, Cesari F, Casini A, et al. Insomnia and risk of cardiovascular disease: a meta-analysis. Eur J Prev Cardiol. 2014; 21:57–64. [PubMed: 22942213]
24. McDonald J, McKinlay E, Keeling S, et al. How family carers engage with technical health procedures in the home: a grounded theory study. BMJ Open. 2015; 5:e007761.
25. Smith F, Grijseels MS, Ryan P, et al. Assisting people with dementia with their medicines: experiences of family caregivers. Int J Pharm Practice. 2015; 23:44–51.
26. Masotti P, McColl MA, Green M. Adverse events experienced by homecare patients: a scoping review of the literature. Int J Qual Health Care. 2010; 22:115–125. [PubMed: 20147333]
27. Montaquila, J., Freedman, VA., Edwards, B., et al. National Health and Aging Trends Study round 1 sample design and selection. Technical Paper 1. Baltimore, MD: Johns Hopkins University School of Public Health; 2012. Available at: https://www.nhats.org/scripts/sampling/NHATS%20Round%201%20Sample%20Design%2005_10_12.pdf. Accessed October 12, 2017
28. Kasper, JD., Freedman, VA., Spillman, BC. Classification of persons by dementia status in the National Health and Aging Trends Study. Technical Paper 5. Baltimore, MD: Johns Hopkins University School of Public Health; 2013. Available at: https://www.nhats.org/scripts/documents/NHATS_Dementia_Technical_Paper_5_Jul2013.pdf. Accessed October 12, 2017
29. Galvin JE, Roe CM, Xiong C, et al. Validity and reliability of the AD8 informant interview in dementia. Neurology. 2006; 67(11):1942–1948. [PubMed: 17159098]
30. Chien M-Y, Chen HC. Poor sleep quality is independently associated with physical disability in older adults. J Clin Sleep Med. 2015; 11(3):225–232. [PubMed: 25515275]
31. Helbig AK, Stöckl D, Heier M, et al. Relationship between sleep disturbances and multimorbidity among community-dwelling men and women aged 65–93 years: results from the KORA Age Study. Sleep Med. 2017; 33:151–159. [PubMed: 28449896]
32. Pearlin LI, Mullan JT, Semple SJ, et al. Caregiving and the stress process: an overview of concepts and their measures. Gerontol. 1990; 30(5):583–594.
33. Eisinga R, Grotenhuis M, Pelzer B. The reliability of a two-item scale: Pearson, Cronbach, or Spearman-Brown? Int J Public Health. 2013; 58:637–642. [PubMed: 23089674]
34. Kasper, JD., Freedman, VA., Spillman, B. National Study of Caregiving user guide. Baltimore, MD: Johns Hopkins University School of Public Health; 2013. Available at: https://

www.nhats.org/scripts/documents%5CNSOC_Round_1_User_Guide.pdf. Accessed October 12, 2017

35. Classen DC, Jaser L, Budnitz DS. Adverse drug events among hospitalized Medicare patients: epidemiology and national estimates. Jt Comm J Qual Patient Saf. 2010; 36(1):12–21. [PubMed: 20112660]
36. Piazza G, Nguyen TN, Cios D, et al. Anticoagulation-associated adverse drug events. Am J Med. 2011; 124:1136–42. [PubMed: 22114827]
37. Sadak T, Foster Zdon S, Ishado E, et al. Potentially preventable hospitalizations in dementia: family caregiver experiences. Int Psychogeriatr. 2017; 29(7):1201–1211. [PubMed: 28349858]
38. Rutledge T, Loh C. Effect sizes and statistical testing in the determination of clinical significance in behavioral medicine research. Ann Beh Med. 2004; 27:138–145.
39. Polenick CA, Leggett AN, Webster NJ, et al. Multiple chronic conditions in spousal caregivers of older adults with functional disability: associations with caregiving difficulties and gains. J Gerontol B Psychol Sci Soc Sci. 2017 [Epub ahead of print].
40. Prince, MJ., Wimo, A., Guerchet, M., et al. World Alzheimer Report 2015: The global impact of dementia: an analysis of prevalence, incidence, cost and trends, 2015. Available at: https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf. Accessed November 27, 2017

Highlights

- We examined the links between medical/nursing tasks and care-related sleep disturbances among spousal dementia caregivers drawn from a nationally representative US sample.
- Over half of spousal dementia caregivers (52.3%) perform two or more medical/nursing tasks, with roughly one in five (17.6%) engaged in at least three of these care tasks.
- This study extends the literature by showing that caregivers report more frequent care-related sleep disturbances when they perform a higher number of medical/nursing tasks.
- Wound care is independently linked to more frequent care-related sleep disturbances, controlling for characteristics of the care situation and other medical/nursing tasks.
- Interventions to preserve both care partners' health and well-being may benefit from addressing the ongoing needs of spouses providing complex medical care.

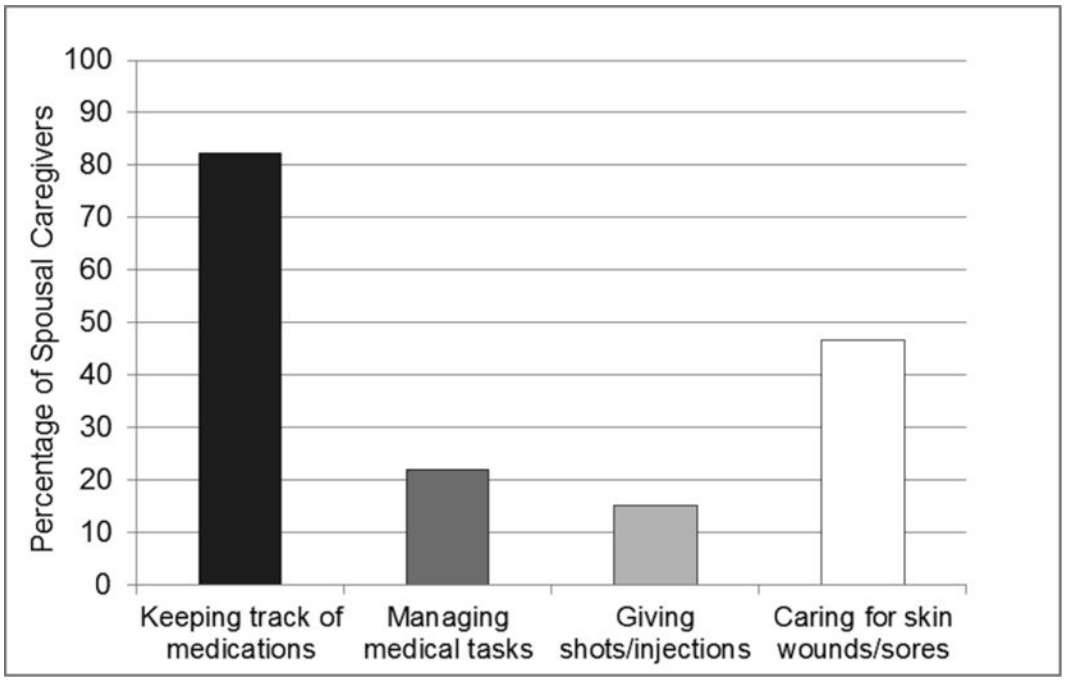

Figure 1.

Percentage of spousal caregivers who performed each of the four medical/nursing tasks using weighted, nationally representative estimates. Managing medical tasks included activities such as ostomy care, IVs, or blood testing.

Table 1

Background Characteristics and Scores on Major Variables for Spousal Caregivers of a Person Living With Dementia

Variable	*M*	*SE*
CG Age in years (range = 47 – 95)	75.57	1.15
CG Physical impairments[a]	1.73	0.21
CG Nighttime awakenings[b]	2.65	0.16
CG ADL assistance[c]	2.27	0.25
CG Emotional caregiving difficulties[d]	1.77	0.24
CG Role overload[e]	1.78	0.09
CG Negative caregiving relationship quality[f]	2.33	0.10
CG Total medical/nursing tasks[g]	1.66	0.11
CG Care-related sleep disturbances[b]	2.02	0.16
PLWD Chronic conditions[h]	2.70	0.17
PLWD Difficulty falling asleep[b]	2.34	0.15
PLWD Nighttime awakenings[b]	2.14	0.12
	(%)	
CG Gender (female)	59.0	
CG Multimorbidity (two or more chronic conditions)	71.9	
CG Educational attainment		
High school graduate	26.7	
College graduate	11.7	
Post graduate	3.2	

Note. Values are weighted to produce nationally representative estimates. ADL = activities of daily living. CG = caregiver. PLWD = person living with dementia.

[a] Range = 0 – 5.

[b] Rated from 1 (never) to 5 (every night).

[c] Range = 0 – 7.

[d] Rated from 0 (no difficulty) to 5 (high difficulty).

[e] Mean of three items rated from 1 (not so much) to 3 (very much).

[f] Mean of two items rated from 1 (not at all) to 4 (a lot).

[g] Range = 0 – 4.

[h] Range = 0 – 8.

N = 104 spousal caregivers.

Table 2

Associations Between Medical/Nursing Tasks and Care-Related Sleep Disturbances Among Spousal Caregivers of a Person Living With Dementia

	Spousal Caregivers' Care-Related Sleep Disturbances[†]					
Predictor	***B***	***SE***	**β**	***t***	***df***	**ΔR^2**
Step 1						.38
CG Age in years	.02	.01	.12	1.40	56	
CG Gender (female)	−.79**	.18	−.32	−4.29	56	
CG Educational attainment	.08	.05	.13	1.58	56	
CG Physical impairments	.09	.07	.12	1.22	56	
CG Multimorbidity (two or more chronic conditions)	.14	.27	.05	0.51	56	
CG Nighttime awakenings	.10	.08	.11	1.20	56	
CG ADL assistance	.13	.07	.25	1.95	56	
CG Emotional caregiving difficulties	.14	.07	.21	1.88	56	
CG Role overload	−.10	.19	−.06	−0.56	56	
CG Negative caregiving relationship quality	.36*	.14	.24	2.64	56	
PLWD Chronic conditions	.06	.09	.07	0.71	56	
PLWD Difficulty falling asleep	.04	.13	.04	0.28	56	
PLWD Nighttime awakenings	−.16	.12	−.15	−1.29	56	
Step 2						
CG Total medical/nursing tasks	.26*	.10	.21	2.63	56	.03
Total R^2	.41					

Note. Estimates are presented from Step 2. Degrees of freedom accounted for the sampling design. ADL = activities of daily living. CG = caregiver. PLWD = person living with dementia.

[†]Rated from 1 (never) to 5 (every night).

N = 104 spousal caregivers.

*$p \leq .01$.

**$p \leq .001$.