The Association of Caregiver Characteristics and Caregivers' Perceived Difficulty in Medication Management Tasks

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Abstract

Background: Medication management tasks are commonly performed by family caregivers caring for patients with dementia, but caregivers also reported difficulties in performing these tasks.

Objectives: Using the 2017 National Study of Caregiving (NSOC) and the 2017 National Health and Aging Trends Study (NHATS), this study examined the association between caregiver characteristics and caregiver difficulty in performing medication management tasks (e.g., ordering medications, keeping track of medications, giving shots).

Methods: The main independent variable was the number of medication management tasks performed by the caregivers. The dependent variable was difficulty in performing medication management tasks. Other variables of interest included caregiver age, sex, education, co-residence with the care recipient, and use of support services. This study used the Pearlin's Stress and Coping Model to select other control variables from hundreds of variables contained in the NSOC. A lasso logistic regression model was used to account for the large amount of other control variables.

Results: Caregiver difficulty was found mainly in keeping track of medications or giving shots (42.4%). More medication management tasks were significantly related to caregiver difficulty [OR=2.71; 95% CI (1.84 - 3.99)]. A significant association linking support service use with task difficulty was also observed [OR=1.82; 95% CI (1.06 - 3.13)], which warrants additional research.

Conclusions: Caregiver difficulty was found mainly in keeping track of medications or giving shots. More medication management tasks were significantly related to caregiver difficulty. Since patients with dementia are often on multiple medications, it is crucial to ensure medication management is done correctly to avoid adverse health consequences.

Keywords: caregiving, medication management, dementia

More than 16 million family and unpaid caregivers provide care to people with Alzheimer's or other dementias in the United States.[1] Patients with dementia are often unable to take their medications as prescribed due to cognitive and physical constraints. The responsibility of managing medications for patients with dementia often falls on family caregivers.[2,3] Medication management is defined as: "the entire way that medicines are selected, procured, delivered, prescribed, administered and reviewed to optimize the contribution that medicines make to producing informed and desired outcomes of patient care".[4] This outlines the full scope of medication management tasks that caregivers perform, including aspects of acquisition, storage, adherence, and monitoring of safety and efficacy.[5]

Medication management has been reported in several studies as the most common health care-related task performed by caregivers.[6–9] Decades ago, when IADLs (instrumental activities of daily living) were created to measure patient's dependency, "help with medications" was categorized as one of the IADLs.[6] With the increasing complicated medication regimen prescribed to patients with dementia, researchers have singled out assistance with medications and other health care-related

tasks as a group, because these tasks have become increasingly prevalent, and they require complex medical knowledge and skills.[8,10,11]

Managing medications is challenging for caregivers. More than 60% of caregivers who manage medications reported this task was emotionally difficult and frightening,[11] and 29% of caregivers who performed medication management tasks experienced anxieties about making mistakes and causing harms to the patients.[6] Caregivers have reported making medication errors, commonly occurring in the storage and administration of medications, such as losing pills, administering the medications at the wrong time, missing a dose, etc.[12] A study showed that one in eight caregivers who helped with medication management reported that they were aware of making mistakes in medication administration.[13] Medication errors can lead to adverse drug events that affect patient health profoundly. A study using the National Electronic Injury Surveillance System in the United States from 2007 to 2009 revealed the number of hospital emergency admissions caused by adverse drug events was 99,628 annually among older adults.[14] Since the volume and scope of health care services has expanded dramatically over the years, this number is very likely an underestimate.

A number of studies have demonstrated the difficulties of and barriers to medication management faced by caregivers. First, caregivers need to deal with the complex medication regimens prescribed to patients with dementia.[7] Patients with dementia

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take an average of 10 medications,[12] which may vary in dosage forms and need to be administered at different times during the day.[2] Administering inhalers, injections, or adjusting doses add extra complexity to the medication management tasks.[2] Second, caregivers need to help administer medications while handling care recipients' behavioral changes. As care recipients no longer understand the importance of taking medications, this could result in resistance.[16] For other patients, to prevent them from taking more medications by mistake, caregivers have to lock up medications or store them out of the patient's sight.[3] Patients with dementia in advanced stages often have difficulty swallowing, so caregivers may need to split or cut pills without realizing this can affect the therapeutic outcome of the medications.[3,17] Third, caregivers lack knowledge in medication management tasks and training. A study reported 92.3% of the patient-caregiver dyads identified at least one deficiency in medication knowledge, in how to take medications, and in how to procure medications properly.[12] Caregivers also find it difficult to interpret medical jargon in prescriptions, such as "Pro Re Nata (PRN)", meaning taken as needed.[18] Despite the lack of knowledge in medication management, caregivers receive limited training. More than 60% of the caregivers learn managing medications on their own, with almost half never receiving training from anyone.[6]

Community pharmacists are uniquely positioned to help caregivers during pharmacy encounters.[19] Community pharmacists are the most accessible primary care health professionals, and they interact with patients with dementia and caregivers frequently.[20] This study aims to examine the association between caregiver characteristics and difficulties in medication management tasks. The study findings can help guide pharmacists and other providers to support caregivers in medication administration and adherence.

Data
This study used two linked nationally representative surveys, the 2017 National Study of Caregiving (NSOC) and the 2017 National Health and Aging Trends Study (NHATS).[21] The NSOC is a study of family and other unpaid caregivers who helped older adults living with physical and cognitive limitations in daily activities. The NSOC has been conducted three times in conjunction with the NHATS in 2011, 2015, and 2017. NHATS participants were Medicare enrollees who were 65 years and older. NHATS participants were eligible for NSOC if they received assistance in the past month with self-care or mobility activities or household activities, the latter for health or functioning reasons.

Once eligible NHATS participants were identified, they were asked to nominate up to five caregivers to contact for interviews. For older adults with more than five eligible caregivers, five caregivers were randomly selected. Caregivers were eligible for NSOC if they were family members or unpaid non-relatives who provided assistance to the NHATS participants in the past month with mobility, self-care, household tasks, or transportation, or in the past year with

money matters (other than bills, banking), or provided assistance with medical activities such as handling health insurance. Upon obtaining oral consent, a telephone interview was conducted with the caregivers. Of 6,312 participants in NHATS, 2,214 were eligible for NSOC. These individuals nominated 4,676 caregivers to be interviewed by NSOC. Non-response could be due to NHATS participants not providing contact information for their caregivers, or if caregivers refused to be interviewed or could not be located. The final 2017 NSOC study sample consisted of 2,652 caregivers to 1,697 care recipients. This yields 92.4% and 61.9% first-stage and second-stage response rates, respectively.[22]

Method
Study population
The study population was 2,652 caregivers caring for older adults with dementia. Dementia in NHATS and NSOC refers to probable dementia, which the NHATS determined either by self-report of dementia diagnosis, a score indicating dementia on the AD8 Dementia Screening Interview, or performance on cognitive tests of memory, orientation, and executive function.[23] This study first excluded 328 caregivers who did not help in the last month or whose care recipients died, and then, this study further excluded 312 caregivers who were helping older adults living in residential care, 96 older adults living in nursing facilities, and 1,296 caregivers whose care recipients were patients with possible or no dementia.

Variables
The main independent variable was the number of medication management tasks performed by the caregivers. Following Noureldin and Plake,[9] items related to medication management tasks included: ordering medications, keeping track of medications, and giving shots/injections. The item on keeping track of medications was defined as making sure the correct medication is taken at the correct time.[24] Caregivers were asked if they had helped with each of these medication management tasks in the last month. Answers to these questions were in yes/no format. The summed number of medication management tasks ranged from 0 to 3. A detailed description of the items is in Table 1.

The dependent variable was difficulty in performing medication management tasks. Caregivers that helped with medication management tasks were asked the level of difficulty for each task. Two types of difficulty were assessed in the survey: difficulty ordering prescribed medicines, and difficulty managing medications or giving shots or injections. A description of the difficulty items is in Table 1. Answers to the questions ranged from very difficult, somewhat difficult, a little difficult, and not at all difficult. Very difficult was coded as 4, and not at all difficult was coded as 1. Following previous studies, those who had not performed the tasks in the past year were coded as 1.[25,26] A summed score for the two types of difficulties ranged from 2 to 8. Given the positive skew in the data, the median (=2) was used to split the sample for analysis. This study grouped caregivers whose score was 2 as "no

difficulty", and anyone with a summed score above 2 as "any difficulty".

Other variables of interest included caregiver age (17-49, 50-59, 60-69, 70 and older), sex (female, male), education (less than high school, high school, some college, college and above), whether the caregiver lives with the care recipient, and use of support services. Use of support services was measured by combining the sum of the five support services items in NSOC: support group, respite care, training, financial help (including Medicaid), and paid helpers. Respondents answered "yes" or "no" to the question if they had used each of the support services in the last year. "Yes" was coded as 1 and "no" is coded as 0. The summed score of support services ranged from 0 to 5. For those whose score was zero, they were categorized as "no support service". Those with a score of larger than zero were grouped under "any support service".[27]

Analysis
Demographic characteristics of the sample caregivers, as well as characteristics of their medication management tasks and difficulty in performing these tasks were presented. Statistical differences between groups with and without difficulty were evaluated using Chi-squared tests for categorical variables and t-tests for continuous variables.

This study used the Pearlin's Stress and Coping Model to select other control variables from the rich amount of variables contained in NSOC.[28] This model has been widely used in assessing caregiver outcomes, and is recommended for use by professionals who work with family caregivers.[29] In this conceptual model, other control variables that pertained to five domains of caregiver stress were selected in the lasso logistic regression model: the background and context of stress (caregiver's sociodemographic characteristics); the primary stressors (e.g. cognitive status of the care recipient); secondary role strains (e.g. family conflict, constriction of social activities), secondary intrapsychic strains (e.g. mastery, competence), and the mediators of stress (e.g. social support, coping).

Given the large amount of other control variables drawing from the Stress Model, including them all in the regression model is likely to incur overfitting problems.[30] To reduce overfitting, this study used a lasso logistic regression model with the "dslogit" command in STATA.[31] Lasso stands for "least absolute shrinkage and selection operator". It is a penalized regression, or regularization, that introduces a penalty term to the regression model to shrink the coefficients of the unimportant variables to zero. However, lasso tends to omit covariates with small coefficients, and this can bias other coefficients.[31] To solve this, this study used dslogit, meaning double selection. Here is a simple example,

$$y = \alpha d + \beta x + \varepsilon$$

Where d is the variable of interest, x represents all the other control variables, y is the dependent variable, and ε is the error term. Double selection first runs a lasso of d on x. Next, it runs

a lasso of y on x. Let $\tilde{x}$ be the union of the selected control variables from the previous two lasso models. Finally, regress y on d and $\tilde{x}$.[31] By running double selection, dslogit is robust to the mistakes that lasso makes. The lasso inference commands do not report the estimates of the coefficients on the other control variables (β). The model for this study is:

> Difficulty in performing medication management tasks = α_1 number of medication management tasks + α_2 caregiver age + α_3 caregiver sex + α_4 caregiver education + α_5 co-residence with the care recipient + α_6 caregiver support service usage + β all other control variables + ε

All statistical analyses were performed using STATA 17 (StataCorp, College Park, Texas) and statistical significance was determined by an α level of 0.05. The complex survey design of NHATS and NSOC were not considered in this study, because the lasso inference commands in STATA do not support survey weights.[31] Regression analysis was clustered at the care recipient level. Regression results were reported using adjusted odds ratios. The extent and nature of missing data was examined. Item nonresponse was in general low (<5%), and missing values were imputed using single imputation. Following the approach by Gottschalk,[32] missing values for age, categorized as 'don't know (DK)', 'refused (RF)', and 'missing (M)' in the NSOC, were replaced by the mean. For education, missing values were replaced by the mode (some college). For co-residence, missing values were coded as 0 (not living with the care recipient). For the number of medication management tasks, and the number of support services, this study used the STATA command "rowtotal" to sum the underlying variables. This command treats missing values as zero. For the difficulty items, missing values were replaced by 1 (not at all difficult).

Results
The study sample included 620 caregivers of 357 community-dwelling older adults with dementia (Table 2). Caregivers performed an average of 1.4 medication management tasks. The caregivers were mainly females (69.8%), above 60 years old (56.7%), with some college education (39.0%), and living with the care recipient (54.4%). More than half (56.5%) of the caregivers did not use any support service.

Figure 1 shows the percentage distribution of caregiver difficulty in performing medication management tasks. More caregivers reported difficulty in keeping track of medications or giving shots. The total percentage of reporting a little difficulty and above for keeping track of medications or giving shots was 42.4%, larger than that for ordering prescribed medicines (34.0%).

Table 2 reports the characteristics of caregivers by levels of medication management task difficulty. Caregivers who reported difficulty in performing medication management tasks had on average a larger number of tasks than caregivers who reported no difficulty (1.85 vs. 1.07). Caregivers reporting more difficulty tended to be female (52.4% vs. 47.6%), with a college

degree and above (55.1% vs. 44.8%), living with the care recipient (53.7% vs. 49.3%), and having used a support service (55.6% vs. 44.4%).

Table 3 shows the odds ratios and the 95% confidence intervals from the double selection lasso logit regression. An additional medication management task was significantly associated with increased odds of reporting difficulty in performing these tasks [OR=2.71; 95% CI (1.84 - 3.99)]. Relative to those who did not use support services, the odds of reporting difficulty among caregivers who had used support services was higher [OR=1.82; 95% CI (1.06 - 3.13)]. Compared to younger caregivers (aged between 17 and 49), caregivers of older age were less likely to report difficulty, except for those aged between 60 and 69, but this was not statistically significant across older age groups. The odds of reporting difficulty among the female caregivers was 3.55 times higher compared to the male counterparts [OR=3.55; 95% CI (1.866 - 6.746)]. Relative to those with less than high school education, caregivers of higher education levels were more likely to report difficulty. The odds of reporting difficulty among caregivers with a college degree and above was 2.56 times higher than the caregivers with less than high school [OR=2.56; 95% CI (0.905 - 7.226)], but this relationship was not significant for caregivers with a high school degree, and caregivers with some college education.

Discussion

This study examined the relationship between caregiver characteristics and their difficulty in performing health care interaction tasks. To our knowledge, this is the first study focusing on caregivers' difficulty in medication management tasks. Caregivers reported difficulty more often in keeping track of medications or giving shots than ordering prescribed medications. Since the tasks of keeping track of medications and giving shots belonged to the same difficulty question, this study was unable to disentangle the relative difficulty of each task. It is unclear what "ordering prescribed medications" entails, but in the fragmented US health care system prescriptions come from multiple providers and multiple sites,[7] which may include filling and refilling prescriptions from different places at different time, and making sure medications are in stock. These specific activities were reported by caregivers as burdensome and easy to miss.[33] It is also noteworthy that in some cities, there are "pharmacy deserts" in low-access communities where people living in these communities have limited or no access to pharmacies.[34,35] As a result, people living in low-access communities need to travel far to fill their prescriptions.[34,35] Future research should also examine the burden related to filling prescriptions in low-access communities for caregivers.

Similar to previous research on health care interaction tasks,[25] caregiver involvement in more medication management tasks was associated with higher self-reported difficulty. However, since this study coded caregivers who did not perform medication management tasks as no difficulty, the results might

be an underestimation, because caregivers who did not perform these tasks might have difficulty managing medications, or avoid performing these tasks due to previous difficult experiences.[36]

Similar to previous research on health care interaction tasks,[37,38] we found that caregivers who had used support services were significantly more likely to report difficulty in medication management tasks. It is possible that caregivers who experienced difficulty actively sought out support services or were referred to these resources by others. However, this study is not able provide the causal direction of this finding due to the use of cross-sectional data. Also consistent with previous research, older caregivers were less likely to report difficulty,[25] although the association was not significant. A possible explanation is older adults consider illness a natural part of aging, so they accommodate these changes more easily.[39] Similar to previous research on health care interaction tasks,[37] caregivers with higher levels of education were also more likely to report difficulty in medication management tasks. Research on the relationship between caregiver education and task difficulty is scant, so more longitudinal research is needed to better understand why caregiver education and task difficulty is positively associated.

This study sheds light on how pharmacists could support caregivers. There have been interventions in the Unites States and internationally that used pharmacist-physician collaboration team for detecting dementia in community pharmacies,[40] and detecting inappropriate medications.[41] The close proximity of community pharmacists makes them uniquely positioned to support caregivers in performing medication management tasks. About 40% of caregivers stated that one strategy to support them was to have health professionals demonstrate medical or nursing tasks (including medication management) to them.[42] Future research should examine how pharmacists in outpatient practice settings could use pharmacy encounters as opportunities to help caregivers with medication management.

Limitations

This study has several limitations. First, the data used in this study do not contain the number of medications or the types of medications taken by the care recipients.[9] It has been reported that number of medications is associated with more caregiver medication errors.[12] Thus, it might be possible that the number of medications is also positively associated with difficulty in medication management. Future research could also explore how difficulty varies across different types of medications. Second, the available items on medication management difficulties were on acquisition and adherence, but important aspects such as monitoring side effects were missing.[9] A literature review of caregiver assistance with medication management also revealed that the existing studies had a narrow focus on adherence.[2] Assistance with other medication management tasks warrants more future research. A timely

example is the recent drug approved by the US Food and Drug Administration, aducanumab, for treating Alzheimer's disease. Aducanumab can cause serious side effects including swelling in areas of the brain, headache, and falls.[43] In addition, although the clinical trial data did not reveal harmful interactions between aducanumab and other drugs,[44] if aducanumab is used on a wider patient population who are commonly on multiple medications, monitoring drug-drug interactions is critical to protect patient health. The approval of aducanumab has profound implications to caregivers as they need to monitor side effects closely. Third, keeping track of medications and giving shots are two different aspects of medication management, but the difficulty of performing these two tasks was measured using the same item.

Fourth, this study followed the standard approach in the literature on caregiving tasks by summing the tasks,[45] but a sum scale assumes that each task is equally difficult, and performing one more task adds the same amount of difficulty.[11] Moorman and Macdonald's study on nursing caregiving tasks addressed this issue by asking nurse practitioners to rank the difficulty of each task in four domains: technical complexity, diagnostic work required, exposure to bodily fluids, and risk to care recipient. [11] A similar approach could be used in future research to explore the relative difficulty in each medication management tasks. Fifth, each NHATs participant can nominate up to five caregivers for interview in NSOC. The number of caregivers per care recipient ranged from one to five in NSOC, because some caregivers refused to be interviewed. When there was only one caregiver for the care recipient, this study was not able to identify whether this caregiver was the primary caregiver. Finally, the cross-sectional data in this study cannot determine causality; thus, longitudinal studies are warranted.

Conclusions

This study examined caregiver characteristics and caregiver difficulty in performing medication management tasks. Caregiver difficulty was found mainly in keeping track of medications or giving shots. More medication management tasks were significantly related to caregiver difficulty. This study showed significant association linking support service use with task difficulty, which warrants more future research. This study also identified several issues in the operationalization and measurement of medication management tasks in the survey. It is crucial to ensure medication management is done correctly to avoid adverse health consequences. Pharmacists are well suited to help caregivers with medication management, so future research should examine how pharmacy encounters in outpatient practice settings could be utilized to support caregivers.

References

1. Alzheimer's Association. 2019 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2019;15(3):321-387. doi:10.1016/j.jalz.2019.01.010
2. 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. doi:10.1111/jocn.12519
3. Look KA, Stone JA. Medication management activities performed by informal caregivers of older adults. *Res Soc Adm Pharm*. 2018;14(5):418-426. doi:10.1016/j.sapharm.2017.05.005
4. The Audit Commission. *A Spoonful of Sugar. Medicines Management in NHS Hospitals.* Audit Commission Publications.; 2002.
5. Wagle KC, Skopelja EN, Campbell NL. Caregiver-Based Interventions to Optimize Medication Safety in Vulnerable Elderly Adults: A Systematic Evidence-Based Review. *J Am Geriatr Soc*. 2018;66(11):2128-2135. doi:10.1111/jgs.15556
6. Reinhard SC, Levine C, Samis S. *Home Alone: Family Caregivers Providing Complex Chronic Care*. AARP Public Policy Institute; 2012:50.
7. Lee M, Ryoo JH, Campbell C, Hollen PJ, Williams IC. Exploring the challenges of medical/nursing tasks in home care experienced by caregivers of older adults with dementia: An integrative review. *J Clin Nurs*. 2019;28(23-24):4177-4189. doi:10.1111/jocn.15007
8. Riffin C, Ness PHV, Wolff JL, Fried T. Family and Other Unpaid Caregivers and Older Adults with and without Dementia and Disability. *J Am Geriatr Soc*. 2017;65(8):1821-1828. doi:10.1111/jgs.14910
9. Noureldin M, Plake KS. Correlates of caregivers' involvement in the management of older adults' medications. *Res Soc Adm Pharm*. 2017;13(4):840-848. doi:10.1016/j.sapharm.2016.09.009
10. Wolff JL, Spillman BC, Freedman VA, Kasper JD. A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Intern Med*. 2016;176(3):372-379. doi:10.1001/jamainternmed.2015.7664

11. Moorman SM, Macdonald C. Medically Complex Home Care and Caregiver Strain. *The Gerontologist*. 2013;53(3):407-417. doi:10.1093/geront/gns067

12. Erlen JA, Lingler J, Sereika SM, Tamres LK, Happ MB, Tang F. Characterizing Caregiver-Mediated Medication Management in Patients with Memory Loss. *J Gerontol Nurs*. 2013;39(4):30-39. doi:10.3928/00989134-20130220-91

13. Donelan K, Hill CA, Hoffman C, et al. Challenged To Care: Informal Caregivers In A Changing Health System. *Health Aff (Millwood)*. 2002;21(4):222-231. doi:10.1377/hlthaff.21.4.222

14. Budnitz DS, Lovegrove MC, Shehab N, Richards CL. Emergency Hospitalizations for Adverse Drug Events in Older Americans. *N Engl J Med*. 2011;365(21):2002-2012. doi:10.1056/NEJMsa1103053

15. Phillips DP, Christenfeld N, Glynn LM. Increase in US medication-error deaths between 1983 and 1993. *Lancet Lond Engl*. 1998;351(9103):643-644. doi:10.1016/S0140-6736(98)24009-8

16. Aston L, Hilton A, Moutela T, Shaw R, Maidment I. Exploring the evidence base for how people with dementia and their informal carers manage their medication in the community: a mixed studies review. *BMC Geriatr*. 2017;17(1):242. doi:10.1186/s12877-017-0638-6

17. Gillespie RJ, Harrison L, Mullan J. Medication management concerns of ethnic minority family caregivers of people living with dementia. *Dementia*. 2015;14(1):47-62. doi:10.1177/1471301213488900

18. Poland F, Mapes S, Pinnock H, et al. Perspectives of carers on medication management in dementia: lessons from collaboratively developing a research proposal. *BMC Res Notes*. 2014;7(1):463. doi:10.1186/1756-0500-7-463

19. Noureldin M, Murawski MM, Mason HL, Hyner GC, Plake KS. The association between family caregivers' involvement in managing older adults' medications and caregivers' information-seeking behavior. *J Am Pharm Assoc*. 2017;57(2):170-177.e1. doi:10.1016/j.japh.2016.12.061

20. Barry HE, Parsons C, Passmore AP, Hughes CM. Community pharmacists and people with dementia: a cross-sectional survey exploring experiences, attitudes, and knowledge of pain and its management. *Int J Geriatr Psychiatry*. 2013;28(10):1077-1085. doi:10.1002/gps.3931

21. National Health and Aging Trends Study: National Study of Caregiving (NSOC). Published 2020. Accessed February 26, 2020. https://www.nhats.org/scripts/QuickLinkNSOC.htm

22. Freedman VA, Skehan ME, Wolff J, Kasper JD. *National Study of Caregiving I-III User Guide*.; 2019. Accessed February 26, 2020. https://nhats.org/scripts/documents/NSOCII_USER_GUIDE.pdf

23. Kasper J, Freedman V, Spillman B. *Classification of Persons by Dementia Status in the National Health and Aging Trends Study. Technical Paper #5*. Baltimore: Johns Hopkins University School of Public Health; 2013. Accessed October 19, 2020. https://www.nhats.org/sites/default/files/inline-files/DementiaTechnicalPaperJuly_2_4_2013_10_23_15.pdf

24. Wolff JL, Spillman B. Older Adults Receiving Assistance With Physician Visits and Prescribed Medications and Their Family Caregivers: Prevalence, Characteristics, and Hours of Care. *J Gerontol Ser B*. 2014;69(Suppl_1):S65-S72. doi:10.1093/geronb/gbu119

25. Giovannetti ER, Wolff JL, Xue QL, et al. Difficulty Assisting with Health Care Tasks Among Caregivers of Multimorbid Older Adults. *J Gen Intern Med*. 2012;27(1):37-44. doi:10.1007/s11606-011-1831-5

26. 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 Off J Am Assoc Geriatr Psychiatry*. 2017;25(10):1085-1093. doi:10.1016/j.jagp.2017.05.001

27. Potter AJ. Factors Associated With Caregivers' Use of Support Services and Caregivers' Nonuse of Services Sought. *J Aging Soc Policy*. 2018;30(2):155-172. doi:10.1080/08959420.2017.1414539

28. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the Stress Process: An Overview of Concepts and Their Measures. *The Gerontologist*. 1990;30(5):583-594. doi:10.1093/geront/30.5.583

29. Family Caregiver Alliance. *Caregiver Assessment: Voices and Views from the Field. Report from a National Consensus Development Conference (Vol. 2)*. Author; 2006. Accessed June 29, 2021. https://www.caregiver.org/uploads/legacy/pdfs/v1_consensus.pdf

30. McNeish DM. Using Lasso for Predictor Selection and to Assuage Overfitting: A Method Long Overlooked in Behavioral Sciences. *Multivar Behav Res*. 2015;50(5):471-484. doi:10.1080/00273171.2015.1036965

31. StataCorp. STATA Lasso Reference Manual Release 17. Published online 2021. Accessed July 14, 2021. https://www.stata.com/manuals/lasso.pdf

32. Gottschalk S. Depression and Emotional Difficulty in Informal Caregivers by Employment Status: An Analysis based on data of the National Study of Caregiving (NSOC). Published online January 8, 2020. Accessed February 3, 2021. https://reposit.haw-hamburg.de/handle/20.500.12738/9258

33. Travis SS, Bethea LS, Winn P. Medication Administration Hassles Reported by Family Caregivers of Dependent Elderly Persons. *J Gerontol Ser A*. 2000;55(7):M412-M417. doi:10.1093/gerona/55.7.M412

34. Qato DM, Zenk S, Wilder J, Harrington R, Gaskin D, Alexander GC. The availability of pharmacies in the United States: 2007–2015. *PLOS ONE*. 2017;12(8):e0183172. doi:10.1371/journal.pone.0183172

35. Look KA, Dekeyser C, Conjurske S, et al. Illustrating access to community pharmacies in Wisconsin. *J Am Pharm Assoc*. 2021;61(4):492-499. doi:10.1016/j.japh.2021.02.004

36. Wolff JL, Freedman VA, Mulcahy JF, Kasper JD. Family Caregivers' Experiences With Health Care Workers in the Care of Older Adults With Activity Limitations. *JAMA Netw Open*. 2020;3(1):e1919866-e1919866. doi:10.1001/jamanetworkopen.2019.19866

37. Fields B, Rodakowski J, James AE, Beach S. Caregiver health literacy predicting healthcare communication and system navigation difficulty. *Fam Syst Health*. 2018;36(4):482-492. doi:10.1037/fsh0000368

38. Fabius CD, Wolff JL, Kasper JD. Race Differences in Characteristics and Experiences of Black and White Caregivers of Older Americans. *The Gerontologist*. 2020;60(7):1244-1253. doi:10.1093/geront/gnaa042

39. Keller ML, Leventhal H, Prohaska TR, Leventhal EA. Beliefs about aging and illness in a community sample. *Res Nurs Health*. 1989;12(4):247-255. doi:10.1002/nur.4770120407

40. Ramos H, Pardo J, Sánchez R, et al. Pharmacist-Physician Interprofessional Collaboration to Promote Early Detection of Cognitive Impairment: Increasing Diagnosis Rate. *Front Pharmacol*. 2021;12:579489. doi:10.3389/fphar.2021.579489

41. Moga DC, Abner EL, Rigsby DN, et al. Optimizing medication appropriateness in older adults: a randomized clinical interventional trial to decrease anticholinergic burden. *Alzheimers Res Ther*. 2017;9(1):36. doi:10.1186/s13195-017-0263-9

42. National Alliance for Caregiving (NAC) and American Association for Retired Persons. Caregiving in the US 2015.https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf. Published 2015. Accessed July 26, 2021.

43. US Food and Drug Administration. ADUHELM label. Published online June 2021. Accessed July 19, 2021. https://www.accessdata.fda.gov/drugsatfda_docs/label/2021/761178s000lbl.pdf

44. Penn Memory Center. Aduhelm (aducanumab) Q+A. Penn Memory Center. Published 2021. Accessed July 19, 2021. https://pennmemorycenter.org/aduhelm/

45. Reinhard SC. The Work of Caregiving: What Do ADLs and IADLs Tell Us? In: *Family Caregivers on the Job : Moving beyond ADLs and IADLs*. United Hospital Fund; 2004:37-65.
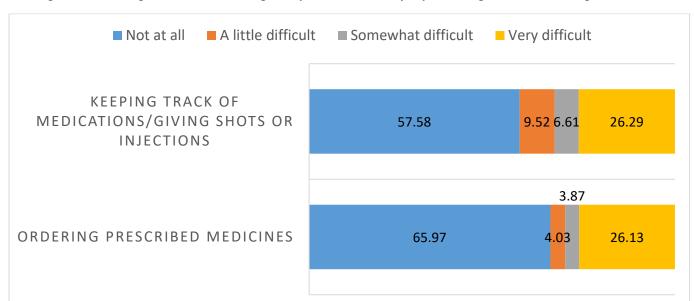
Figure 1. Percentage distribution of caregiver's perceived difficulty in performing medication management tasks.

Table 1. Description of items related to medication management tasks, and difficulties in performing medication management tasks in 2017 NSOC Round 7.

Items related to medication management tasks	Items related to difficulties in performing medication management tasks
In the last month {of {his/her} life}, did you ever help {SP} order {his/her} prescribed medicines or order these for him/her}?	Was if very, somewhat, a little or not at all difficult for you: ordering {his/her} prescribed medicines?
In the last month {of {his/her} life}, did you ever help {SP} keep track of {his/her} medications?	Was if very, somewhat, a little or not at all difficult for you: managing {his/her} {medications} {shots or injections}?
In the last month {of {his/her} life}, did you ever help {SP} take shots or injections?	

Note:
NSOC: National Study of Caregiving.
SP: sample person, refering to the care recipient.

Table 2: Caregiver Characteristics by Medication Management Task Perceived Difficulty Group

		Difficulty groups		
	Total (N=620)	No difficulty (N = 336)	Any difficulty (N = 284)	P-value
Sum of medication management tasks				<0.001
Mean (SD)	1.42 (0.94)	1.07 (0.99)	1.85 (0.67)	
Age				0.617
17-49	98 (15.8%)	57 (58.2%)	41 (41.8%)	
50-59	170 (27.4%)	93 (54.7%)	77 (45.3%)	
60-69	198 (31.9%)	109 (55.1%)	89 (44.9%)	
≥70	154 (24.8%)	77 (50.0%)	77 (50.0%)	
Sex				<0.001
Male	187 (30.2%)	130 (69.5%)	57 (30.5%)	
Female	433 (69.8%)	206 (47.6%)	227 (52.4%)	
Education				0.030
≥ College degree	136 (21.9%)	61 (44.8%)	75 (55.1%)	
Some college	242 (39.0%)	135 (55.8%)	107 (44.2%)	
High school	164 (26.5%)	89 (54.3%)	75 (45.7%)	
< High school	78 (12.6%)	51 (15.2%)	27 (9.5%)	
Co-residence with care recipient				<0.001
No	283 (45.6%)	180 (63.6%)	103 (36.4%)	
Yes	337 (54.4%)	156 (49.3%)	181 (53.7%)	
Use of support services				<0.001
No support service	350 (56.5%)	216 (61.7%)	134 (38.3%)	
Any support service	270 (43.5%)	120 (44.4%)	150 (55.6%)	

**Table 3. Associations of Caregiver Characteristics and Caregiver's
Perceived Difficulty in Medication Management Tasks. (N = 620)**

Independent variables	Adjusted OR (95% Confidence Intervals)
Number of medication management tasks	2.706*** (1.835 - 3.993)
Use of support services (Reference: no use of support services)	1.822** (1.061 - 3.127)
Age (Reference: 17-49)	
50-59	0.962 (0.382 - 2.425)
60-69	1.121 (0.383 - 3.285)
≥70	0.774 (0.215 - 2.790)
Sex (Reference: male)	3.548*** (1.866 - 6.746)
Education (Reference: <high school)	
Some college	1.847 (0.756 - 4.511)
High school degree	1.398 (0.585 - 3.338)
≥College degree	2.558 (0.905 - 7.226)
Co-residence with the care recipient	1.343 (0.790 - 2.284)

Note:
*** $p<0.01$, ** $p<0.05$