Caring for Older Adults with Vision Impairment and Dementia

Varshini Varadaraj, MD, MPH¹, Shang-En Chung, ScM², Kayla S. Swiatek, BA³, Orla C. Sheehan, MD, PhD³,⁴, Ashley Deemer, OD⁵, Joshua R. Ehrlich, MD, MPH⁶,⁷, Jennifer L. Wolff, PhD⁴,⁷, Lama Assi, MD¹, David L. Roth, PhD², Bonnielin K. Swenor PhD, MPH¹

¹Dana Center for Preventive Ophthalmology, Johns Hopkins Wilmer Eye Institute, Baltimore, Maryland
²Johns Hopkins University Center on Aging and Health, Baltimore, Maryland
³University of Kentucky College of Medicine, Lexington, Kentucky
⁴Division of Geriatric Medicine and Gerontology, Johns Hopkins University School of Medicine, Baltimore, Maryland
⁵Lions Vision Research and Rehabilitation Center, Wilmer Eye Institute, Johns Hopkins University School of Medicine, Baltimore, Maryland
⁶Department of Ophthalmology and Visual Sciences, Center for Eye Policy and Innovation, University of Michigan, Ann Arbor, Michigan
⁷Institute for Health Care Policy and Innovation, University of Michigan, Ann Arbor, Michigan

Address correspondence to:
Bonnielin K. Swenor, PhD, MPH, 600 N. Wolfe Street, Wilmer 116, Wilmer Eye Institute, Johns Hopkins Hospital, Baltimore, MD 21287. E-mail: bswenor@jhmi.edu

Funding: This work was supported by the National Institutes of Health [grant numbers K01AG052640 to B.S. and K23EY027848 to J.R.E].

Conflict of Interest: None
ABSTRACT

Background and Objectives: Dementia and vision impairment (VI) are common among older adults but little is known about caregiving in this context.

Research Design and Methods: We used data from the 2011 National Health and Aging Trends Study, a nationally representative survey of Medicare beneficiaries, linked to their family/unpaid helpers from the National Study of Caregiving. VI was defined as self-reported blindness or difficulty with distance/near vision. Probable dementia was based on survey-report, interviews, and cognitive tests. Our outcomes included: hours of care provided, and number of valued activities (scored 0-4) affected by caregiving, per month.

Results: Among 1,776 caregivers, 898 (55.1%, weighted) assisted older adults without dementia or VI, 450 (21.9%) with dementia only, 224 (13.0%) with VI only, and 204 (10.0%) with dementia and VI. In fully-adjusted negative binomial regression analyses, caregivers of individuals with dementia and VI spent 1.7-times as many hours (95% CI=1.4-2.2) providing care than caregivers of those without either impairment; however, caregivers of individuals with dementia only (95% CI=1.1-1.6) and VI only (95% CI=1.1-1.6) spent 1.3-times more hours. Additionally, caregivers of individuals with dementia and VI had 3.2-times as many valued activities affected (95%CI=2.2-4.6), while caregivers of dementia only and VI only reported 1.9-times (95% CI=1.4-2.6) and 1.3-times (95% CI=0.9-1.8) more activities affected, respectively.

Discussion and Implications: Our results suggest that caring for older adults with VI involves similar time demands as caring for older adults with dementia, but that participation impacts are greater when caring for older adults with both dementia and VI.

Translational Significance: As compared to caring for older adults with either dementia or vision impairment, caring for older adults with both dementia and vision impairment involves more hours of caregiving per month and further limits caregivers’ ability to participate in social activities. Low vision rehabilitation and integration of low vision services into the care of older adults with dementia and vision impairment may reduce caregiver burden.

Keywords: Caregiving - Informal, Caregivers stress, Vision Loss
Background and Objectives

For many older adults, vision impairment and dementia are salient features of aging. As in most parts of the world, with the aging of the population in the United States (US), the number of older adults with these often co-occurring impairments is set to rise. With an increasing number of older adults, not only do concerns arise about appropriately meeting the care needs of individuals in late-life, but also about the impact that providing care may have on caregivers. There has been considerable research describing the experience of caregivers of people with dementia, and it has been noted that these caregivers provide more help with daily activities and encounter more conflicts with their social activity than caregivers of people without dementia.

The caregiving experience of those caring for adults with vision impairment, has also been explored, albeit to a lesser extent. This literature has largely focused on the impact of caregiving on psychosocial health. One study using a clinical sample found about one-third of caregivers assisting a relative with vision impairment had symptomatology indicating high risk of depression. Other studies conducted in visually impaired populations, reported an increased risk of depression among caregivers who provided greater hours of care.

An overlooked aspect of the caregiving paradigm is the role of co-occurring dementia and vision impairment on the caregiving needs of older adults, and the impact on those caring for them. While multimorbidity or the coexistence of any two or more health conditions is a risk factor for disability in older adults, and therefore can be argued to be associated with a magnified caregiving need-profile, co-occurring vision and cognitive impairments have been shown to have an especially strong impact on functioning. Although vision and cognitive impairments impact various areas of daily functioning such as self-care, mobility, and
household activities, activity limitations are not always analogous. For example, mobility limitations are particularly relevant to adults with vision impairment while an impact on activities of daily living (ADLs) is more pertinent to cognitive impairment.\textsuperscript{9, 10}

In addition, there is much emerging literature showing that vision impairment is a risk factor for cognitive decline and dementia.\textsuperscript{11, 12} Despite evidence establishing the relationship between vision and cognition, they are often still considered as disparate elements when treating older adults. A better understanding of the interplay between vision and cognitive impairment and the impact of the resultant cumulative disability risk on caregiving needs is required. This data will provide knowledge to help plan for appropriate supportive strategies, respite care, and interventions to support caregivers while optimizing health in older people with these commonly co-existing multimorbidity.

To address this gap and build on our understanding of caregiving needs of older adults, we examined caregiving relationships for individuals with vision impairment and dementia using data from the National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC). We hypothesized that family and unpaid caregivers caring for older adults with co-occurring dementia and self-reported vision impairment may experience greater time demands, and, relatedly, a more pronounced impact on participation in valued activities, beyond that predicted by caring for an individual with vision impairment or dementia alone.
Research Design and Methods

Study Population

This study used data from the 2011 round of the NSOC linked to the corresponding 2011 NHATS, that together provide cross-sectional care-recipient and caregiver perspectives on late-life care at a national level. These data are de-identified and publicly available and therefore exempt from institutional review board approval.

NHATS

The NHATS\textsuperscript{13} is a nationally representative survey of Medicare beneficiaries aged 65 years and older. Comprehensive information on health and function, performance in daily activities in the prior month, and assistance received, are collected via in-person interviews with study participants (or proxy respondents). For NHATS participants that receive assistance, further details on the activities for which assistance is provided, the relationship to the person(s) providing assistance, and information on whether help is paid or unpaid are collected in a detailed helper roster.\textsuperscript{13}

NSOC

The NSOC\textsuperscript{14} is a nationally representative study of family and other unpaid caregivers to NHATS participants that is conducted in conjunction with NHATS. NSOC participants are identified from the NHATS helper roster on the basis of providing assistance with mobility, self-care, household activities, transportation, or medically oriented tasks to NHATS participants. Caregivers of community dwelling NHATS participants receiving help with (1) self-care, (2) mobility, or (3) household (latter for health or functioning related reasons specifically) activities, or those who lived in residential care facility with supportive services are eligible for the NSOC. NSOC data includes
information from telephone interviews conducted with up to 5 helpers (5 selected at random if >5) to these NHATS participants.

Analytic sample

The 2,423 NHATS participants who were eligible\textsuperscript{13,14} for NSOC had 4,935 caregivers that met eligibility criteria in 2011. NSOC interviews were conducted with a total of 2,007 caregivers of 1,369 older adults.\textsuperscript{15} NSOC respondents providing care to community-dwelling older adults were included (i.e., older adults in residential care facilities reliant on availability of supportive services were excluded) leaving a sample of 1,786 family and unpaid caregivers (1,684=spouse or son/daughter and 102=unpaid relative) to 1,199 NHATS participants. Finally, we limited this study to all caregivers who had assisted an NHATS participant with any activity in the last month to yield an analytic sample of 1,776 caregivers linked to 1,196 NHATS participants.

Caregiving Outcomes

Two caregiving outcomes were analyzed: the number of hours of care provided in the last month, and the number of valued activities affected by caregiving (scored 0-4). Participation restriction in valued activities refers to activities reported as being very or somewhat important to the caregiver that were limited in the prior month because of caregiving. Valued activities included: (1) visiting friends and family, (2) going out for enjoyment, (3) attending religious services, and (4) participating in club meetings or group activities. Participation restriction in each valued activity was coded as a binary variable (yes/no) and then summed to obtain the 0-4 composite score for this outcome.
Vision

In NHATS, older adults provided self-reports of visual function for distance and near tasks, while using contact lenses or glasses (if necessary). For distance vision, participants were asked if they could see well enough to “recognize someone across the street” or “watch television across the room”. For near vision, participants were asked if they could “see well enough to read newspaper print”. As in prior studies,\textsuperscript{16, 17} self-reported vision impairment was defined as participant or proxy reported blindness or difficulty with distance or near vision (i.e. answering “no” to either question).

Dementia

Participants were classified as having probable, possible, or no dementia based on previously defined criteria\textsuperscript{18, 19} including survey-report, the Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) criteria, and cognitive performance tests. NHATS respondents were classified as having probable dementia based on: (1) participant- or proxy-reported physician diagnosis of dementia or Alzheimer’s disease, or (2) an AD8 score ≥2; the AD8 is an 8-item questionnaire administered to informants to assesses memory, temporal orientation, judgment, and function of the participant,\textsuperscript{20} or (3) participant cognitive test scores ≤1.5 SDs below mean in at least 2 of the 3 cognitive domains - memory (immediate and delayed 10- word recall), orientation (date, month, year, and day of the week; naming the President and Vice President), and executive function (clock drawing test). Possible dementia was indicated by impairment (cognitive test scores ≤1.5 SDs below mean) in 1 domain in absence of meeting the physician diagnosis or AD8 criteria described above. Participants not meeting these criteria were classified as having no dementia.

In primary analyses, we considered only those with probable dementia (comparison group: possible dementia and no dementia), a narrower and more specific definition.\textsuperscript{19} In a sensitivity analysis, we combined probable and possible dementia to indicate any dementia (comparison group: no dementia), a broader and more sensitive definition.
Other covariates

Socio-demographic and health characteristics of older adults were drawn from NHATS (age, race/ethnicity, sex, marital status, income, comorbidities, and diabetes) and of caregivers were drawn from NSOC (age, sex, education, self-reported health status, relationship to the older adult, cohabiting status/travel time to older adults’ residence, duration of caregiving, activities for which assistance was provided including help with instrumental activities of daily living, health system interactions, and specific health management tasks). Older adults’ comorbidities included hypertension, arthritis, osteoporosis, lung disease, stroke, heart disease, cancer, depression, and fracture, and was categorized as 0-1, 2-3, and ≥4 conditions. Diabetes (survey-reported physician diagnosis) was adjusted for separately as it is expected to be a strong confounder of the vision-caregiving relationship; diabetes is a driver of vision impairment and diabetics may require more caregiving.

Statistical Analysis

Sociodemographic and health characteristics were summarized across the four NHATS participant groups with and without vision impairment and dementia. Unweighted frequencies and weighted percentages for categorical variables and means (standard error [SE]) for continuous variables are reported. Multinomial logistic regression models were constructed to assess the differences in sociodemographic and health characteristics across the four NHATS participant groups (participants with and without vision impairment and dementia). Similarly, NSOC caregiver characteristics, were summarized across these four groups (those caring for participants with and without vision impairment and dementia).
The nature and intensity of care provided by each group as expressed by hours of care per month, types of activities for which help is provided, health system interactions, and health management tasks are described. Caregiving-related participation effects in valued activities and the use of supportive services, stratified by the four NHATS participant groups with and without vision impairment and dementia, is also described.

Weighted (using NSOC weights) negative binomial regression models, clustered by NHATS participants (to account for correlation between multiple caregivers for an NHATS older adult), were constructed to examine how vision impairment and dementia status is associated with intensity of caregiving (hours of caregiving in the last month) and the impact on participation in valued activities (number of valued activities affected by caregiving in the last month). This approach was chosen as caregiving hours and number of valued activities affected by caregiving are both count data, and the expected value was not equal to the variance. Finally, models were constructed to test for interactions between impairment categories (i.e. vision impairment x dementia) to examine if co-occurring vision impairment and dementia affect caregiving outcomes in a non-additive manner. All models were adjusted for NHATS participant age, race/ethnicity, sex, marital status, income, comorbidities, diabetes, and NSOC caregiver age, caregiver sex, caregiver education, caregiver’s self-reported health, caregiver relationship to the older adult, and cohabiting status. Covariates were included based on clinical relevance and/or previous demonstration of impact on vision impairment or dementia and caregiving needs.

Analyses were conducted in SAS 9.4 (SAS Institute, Cary, North Carolina, USA) and STATA 15 (StataCorp LLC, College Station, TX, USA).
Results

Caregiver Characteristics

Among caregivers to older adults in 2011, 55.1% (95% CI=50.1-60.2) assisted older adults without dementia or vision impairment, 21.9% (95% CI=18.1-25.6) with dementia only, 13.0% (95% CI=10.7-15.3) with vision impairment only, and 10.0% (95% CI=7.2-12.9) with dementia and vision impairment, (Table 1). The majority 68.5% of older adults had a single caregiver included from the NSOC sample, while 31.5% had more than one caregiver.

As compared to NHATS participants receiving care without dementia or vision impairment, those with dementia and vision impairment were older, less likely to be white or married, and more likely to have diabetes and a lower income (Supplementary Table 1). As compared to caregivers of older adults without either impairment, caregivers of participants with dementia and vision impairment were less likely to be a spouse, more likely to be an adult child, and more likely to have been providing care for longer than 4 years (Table 1).

Caregiving Circumstances and Activities

Caregivers of persons with dementia and vision impairment were more likely to assist with mobility, banking and selfcare-related activities, as well as with activities pertaining to navigating health system logistics and health management than caregivers of persons without either impairment (Table 1).
Caregiving Related Difficulties

Caregivers of older adults with dementia and vision impairment were more likely to report reduced participation in each of the following activities: visiting friends and family, going out for enjoyment, attending religious services, and participating in club meetings or group activities (Table 2).

Caregivers of persons with dementia and vision impairment were more likely to use one or more supportive services than caregivers of persons without either impairment.

Caregiving Intensity and Impact on Valued Activities

In unadjusted analyses examining group differences, caregivers assisting older adults without either impairment provided a mean of 64.9 (SE=3.9) hours in the past month, 91.5 (SE=5.8) hours for those with dementia only, 100.3 (SE=13.7) hours for those with vision impairment only, and 125.1 (SE=16.1) hours for those with co-occurring impairments. In regard to impact on valued activities, caregivers assisting older adults without dementia or vision impairment, and with dementia only, vision impairment only, and co-occurring impairments, reported that participation in a mean of 0.30 (SE=0.03), 0.59 (SE=0.06), 0.42 (SE=0.05), 0.97 (SE=0.10) valued activities were affected in the last month due to providing care, respectively.

In weighted, fully adjusted negative binomial models, in the last month, caregivers of older adults with dementia and vision impairment spent 1.7-times more hours on caregiving (IRR=1.7; 95% CI=1.4-2.2), and caregivers of adults with dementia only (95% CI=1.1-1.6) and vision impairment only (95% CI=1.05-1.61) spent 1.3-times more hours, as compared to caregivers of older adults without either impairment (Table 3). Additionally, caregivers of older adults with dementia and vision impairment reported 3.2-times as many valued activities were affected per month (95% CI=2.2-4.6) as compared to caregivers of older adults without dementia and vision impairment, while caregivers
of those with dementia only reported 1.9-times (95% CI=1.4-2.6) more activities per month were affected. Although not statistically significant, the caregivers of older adults with vision impairment had 1.3-times (95% CI=0.9-1.8) more activities affected per month.

In other models testing for interactions between each impairment category, the interaction terms were not statistically significant (p>0.05 for both models of caregiving outcomes), Supplementary Table 2. In additional sensitivity analysis reclassifying dementia to include probable and possible dementia, the results were similar.

Discussion and Implications

In a nationally representative sample of family and unpaid caregivers who assist older adults with mobility, self-care, household activities, transportation, and medical care, we found that caregivers of individuals with dementia and self-reported vision impairment spent almost twice as many hours providing care than caregivers of older adults without dementia or self-reported vision impairment, and they had 3-times as many valued activities affected. Caregivers of individuals with either dementia or self-reported vision impairment still spent 1.3-times more hours and had about 1.9- to 1.3-times as many valued activities affected as compared to caregivers of older adults without these impairments. These results indicate that caring for older adults with self-reported vision impairment places similar demands on family and relatives as does caring for older adults with dementia and suggests that these implications are additive when caring for older adults with both dementia and vision impairment.
Vision and cognitive impairments share common risk factors\textsuperscript{23, 24} and vision impairment itself is a risk factor for cognitive decline.\textsuperscript{11} Prior research has shown that older adults with dementia have a higher prevalence of age-related vision problems than the general population.\textsuperscript{25} Alzheimer’s disease, the most common cause of dementia in older adults, progressively impairs cognition. Associated memory loss, disorientation, emotional disturbances, and impairment of judgment\textsuperscript{26} may necessitate assistance from family and other caregivers to perform daily tasks. In combination with the diminution in visual function, which commonly accompanies Alzheimer’s and includes contrast sensitivity loss,\textsuperscript{27} visual field defects,\textsuperscript{28} delayed eye saccades,\textsuperscript{29} and impaired object recognition,\textsuperscript{30} difficulties faced with activities of daily living may be exacerbated.\textsuperscript{9, 31} As a corollary, our results confirm that older adults with co-occurring vision impairment and dementia require greater intensity of caregiving and caring for them places more demands on family caregivers.

The caregiving effects of dementia have been well documented. Collectively, this research shows that caring for persons with dementia takes up more time, requires help across a wider range of daily activities and has a greater impact on family caregivers’ social life, physical health and mental well-being.\textsuperscript{15, 32–34} However, our results show that caring for older adults with self-reported vision impairment imposes consequential caregiving demands.

The few studies examining caregiving needs among older adults with vision loss have been largely comprised of small clinic-based cohorts. Bambara et al. found that among 96 caregivers of patients attending a low vision rehabilitation clinic, 35% were identified at risk for depression.\textsuperscript{6} Caregivers at risk for depression were younger, more likely to be female, caring for a relatively younger person with vision loss and providing assistance for a loved one with worse visual acuity compared with non-depressed caregivers. Braich et al. conducted a study on 522 individuals in India providing care
to legally blind (visual acuity varied from 20/200 to no light perception) relatives. Using The Burden Index of Caregivers (BIC), a questionnaire that measures the time, emotional, physical and existential demands of caregiving, they ascertained that more severe forms of blindness were associated with requiring more help with activities of daily living and additional hours of close supervision per day, both of which increased risk of caregiver depression. Another clinic-based study in Canada of 236 caregivers found worse BIC scores among those caring for persons with poorer vision (20/200 or worse) than compared to those caring for persons with better vision (visual acuity 20/60 to 20/200). Taking together these two streams of caregiving data on cognitive and vision impairments, it follows that individuals caring for older adults with co-occurring dementia and vision impairment are most likely to provide more intense care and experience greater restriction of their social activities. Care activities for older adults with vision impairment are likely different from those of older adults with dementia, and therefore, demands may be “additive” for adults with both types of impairments. For example, older adults with vision impairment may require greater assistance with mobility-related activities while dementia may necessitate more help with activities of daily living and self-care.

This study has some limitations. First, our estimates of vision impairment from NHATS participants/proxies and data on caregiving hours and impacted activities from NSOC caregivers were based on self-reported data that may be subject to recall bias. However, self-reported vision still provides valuable information that captures individuals’ perspectives on their disability and function, and has been previously used in NHATS. To define dementia, the use of multiple criteria that have been previously employed, including self-report of a diagnosis, use of the AD8 instrument, and cognitive performance tests, is a strength of the study. Regardless, this definition is subject to measurement error, since we relied on interviewer-reported diagnosis and a non-clinical assessment. Finally, causal associations cannot be determined from this cross-sectional study, and
longitudinal research is needed to determine causal processes underlying the observed effects.

Relatively, because vision impairment and dementia are both progressive in nature, these observed associations will likely change over time.

Despite these limitations, this study is among the first to provide insight into the caregiving needs and relationships of older adults at the crossroads of vision impairment and dementia. Our results show that caring for older adults with vision loss places similar time demands on caregivers as compared to caring for older adults with dementia. However, caring for older adults with co-occurring dementia and vision loss is associated with enhanced caregiving demands as evidenced by greater intensity of providing care as well a greater restriction of participation in caregiver valued personal/social activities. Given that older adults with these commonly co-occurring impairments have more complex caregiving needs and require greater intensity and breadth of assistance, their family and unpaid caregivers need to be better engaged and supported by stakeholders in the health care system. Outreach programs that focus on caregiving training and support services could help educate caregivers on caring for these older adults at increased risk of functional decline as well as provide respite services to reduce the strain experienced by them. In addition, better utilization of low vision rehabilitation and integration of low vision services into the overall care of older adults may be needed. Future research should also examine how caregiver support may be useful in improving caregiver quality of life and the quality of care provided.
References

1. Older People Projected to Outnumber Children for First Time in U.S. History. US Census Bureau. https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html. Published March 13, 2018. Accessed April 7, 2020.

2. Alzheimer’s Association. 2018 Alzheimer’s disease facts and figures. *Alzheimer’s & Dementia*. 2018;14(3):367-429. doi:10.1016/j.jalz.2018.02.001

3. Chan T, Friedman DS, Bradley C, Massof R. Estimates of incidence and prevalence of visual impairment, low vision, and blindness in the United States. *JAMA Ophthalmol*. 2018;136(1):12-19. doi:10.1001/jamaophthalmol.2017.4655

4. Moon H, Dilworth-Anderson P. Baby boomer caregiver and dementia caregiving: Findings from the National Study of Caregiving. *Age Ageing*. 2015;44(2):300-306. doi:10.1093/ageing/afu119

5. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff*. 2015;34(10):1642-1649. doi:10.1377/hlthaff.2015.0536

6. Bambara JK, Owsley C, Wadley V, Martin R, Porter C, Dreer LE. Family caregiver social problem-solving abilities and adjustment to caring for a relative with vision loss. *Invest Ophthalmol Vis Sci*. 2009;50(4):1585-1592. doi:10.1167/iovs.08-2744

7. Braich PS, Lal V, Hollands S, Almeida DR. Burden and depression in the caregivers of blind patients in India. *Ophthalmology*. 2012;119(2):221-226. doi:10.1016/j.ophtha.2011.07.038

8. Khan Z, Braich PS, Rahim K, et al. Burden and depression among caregivers of visually impaired patients in a Canadian population. *Adv Med*. 2016;2016. doi:10.1155/2016/4683427

9. Whitson HE, Cousins SW, Burchett BM, Hybels CF, Pieper CF, Cohen HJ. The combined effect of visual impairment and cognitive impairment on disability in older people. *J Am Geriatr Soc*. 2007;55(6):885-891. doi:10.1111/j.1532-5415.2007.01093.x

10. Patel N, Stagg BC, Swenor BK, Zhou Y, Talwar N, Ehrlich JR. Association of co-occurring dementia and self-reported visual impairment with activity limitations in older adults. *JAMA Ophthalmol*. 2020. doi:10.1001/jamaophthalmol.2020.1562

11. Swenor BK, Wang J, Varadaraj V, et al. Vision impairment and cognitive outcomes in older adults: the health ABC study. *J Gerontol A Biol Sci Med Sci*. 2019;74(9):1454-1460. doi:10.1093/gerona/gly244

12. Davies-Kershaw HR, Hackett RA, Cadar D, Herbert A, Orrell M, Steptoe A. Vision impairment and risk of dementia: findings from the English longitudinal study of ageing. *J Am Geriatr Soc*. 2018;66(9):1823-1829. doi:10.1111/jgs.15456

13. Kasper, JD, Freedman VA. 2020. National Health and Aging Trends Study User Guide: Rounds 1-9 Beta Release. Baltimore: Johns Hopkins University School of Public Health.
14. Freedman VA., Skehan ME, Wolff J, Kasper JD. 2019. National Study of Caregiving I-III User Guide. Baltimore: Johns Hopkins Bloomberg School of Public Health. https://www.nhats.org/sites/default/files/inline-files/NSOC_I_III_USER_GUIDE_Version4_0.pdf. Accessed July 28, 2020.

15. 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

16. Xiang X, Freedman VA, Shah K, Hu RX, Stagg BC, Ehrlich JR. Self-reported vision impairment and subjective well-being in older adults: a longitudinal mediation analysis. J Gerontol A Biol Sci Med Sci. 2020;75(3):589-595. doi:10.1093/gerona/glz148

17. Ehrlich JR, Hassan SE, Stagg BC. Prevalence of falls and fall-related outcomes in older adults with self-reported vision impairment. J Am Geriatr Soc. 2019;67(2):239-245. doi:10.1111/jgs.15628

18. Ho SC, Donnan SPB, Sham A. Psychosomatic symptoms, social support and self worth among the elderly in Hong Kong. J Epidemiol Comm Health. 1988;42:377-382. doi:10.1136/jech.42.4.377

19. Kasper JD, Freedman VA, Spillman B. Classification of Persons by Dementia Status in the National Health and Aging Trends Study- Technical Paper #5. https://www.nhats.org/scripts/documents/DementiaTechnicalPaperJuly_2_4_2013_10_23_15.pdf. Accessed March 16, 2020.

20. Galvin JE, Roe CM, Xiong C, Morris JC. Validity and reliability of the AD8 informant interview in dementia. Neurology. 2006;67(11):1942-1948. doi:10.1212/01.wnl.0000247042.15547.eb

21. Lee R, Wong TY, Sabanayagam C. Epidemiology of diabetic retinopathy, diabetic macular edema and related vision loss. Eye Vis. 2015;2(1). doi:10.1186/s40662-015-0026-2

22. Langa KM, Vian S, Hayward RA, et al. Informal caregiving for diabetes and diabetic complications among elderly Americans. J Gerontol B Psychol Sci Soc Sci. 2002;57(3):S177-S186. doi:10.1093/geronb/57.3.S177

23. Uhlmann RF, Larson EB, Koepell TD, Rees TS, Duckert LG. Visual impairment and cognitive dysfunction in Alzheimer's disease. J Gen Intern Med. 1991;6(2):126-132. doi:10.1007/BF02598307

24. Klaver CC, Ott A, Hofman A, Assink JJ, Breteler MM, de Jong PT. Is age-related maculopathy associated with Alzheimer's disease?: The Rotterdam Study. Am J Epidemiol. 1999;150(9):963-968. doi:10.1093/oxfordjournals.aje.a010105

25. Bowen M, Edgar DF, Hancock B, et al. The Prevalence of Visual Impairment in People with Dementia (the PrOVIDe study): a cross-sectional study of people aged 60-89 years with dementia and qualitative exploration of individual, carer and professional perspectives. Health Services and Delivery Research. 2016. doi:10.3310/hsdr04210
26. Bature F, Guinn B-a, Pang D, Pappas Y. Signs and symptoms preceding the diagnosis of Alzheimer's disease: a systematic scoping review of literature from 1937 to 2016. *BMJ Open*. 2017;7(8):e015746. doi:10.1136/bmjopen-2016-015746

27. Nissen MJ, Corkin S, Buonanno FS, Growdon JH, Wray SH, Bauer J. Spatial vision in Alzheimer's disease: general findings and a case report. *Arch Neurol*. 1985;42(7):667-671. doi:10.1001/archneur.1985.04060070057015

28. Trick GL, Trick LR, Morris P, Wolf M. Visual field loss in senile dementia of the Alzheimer's type. *Neurology*. 1995;45(1):68-74. doi:10.1212/WNL.45.1.68

29. Fletcher WA, Sharpe JA. Smooth pursuit dysfunction in Alzheimer's disease. *Neurology*. 1988;38(2):272-272. doi:10.1212/WNL.38.2.272

30. Alegret M, Boada-Rovira M, Vinyes-Junqué G, et al. Detection of visuoperceptual deficits in preclinical and mild Alzheimer's disease. *J Clin Exp Neuropsychol*. 2009;31(7):860-867. doi:10.1080/1380390802595568

31. Lawrence V, Murray J, Banerjee S. "Out of sight, out of mind": a qualitative study of visual impairment and dementia from three perspectives. *Int Psychogeriatr*. 2009;21(3):511-518. doi:10.1017/S1017510909008424

32. Schulz R, O'Brien AT, Bookwalta J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist*. 1995;35(6):771-791. doi:10.1093/geront/35.6.771

33. Haley WE, West CA, Wadley VG, et al. Psychological, social, and health impact of caregiving: A comparison of Black and White dementia family caregivers and noncaregivers. *Psychol Aging*. 1995;10(4):540. doi:10.1037/0882-7974.10.4.540

34. Tremont G. Family caregiving in dementia. *Med Health R I*. 2011;94(2):36.

35. Kasper JD, Freedman VA, Spillman B. National study of caregiving user guide. Baltimore: Johns Hopkins University School of Public Health. 2013.
Table 1. Characteristics of NSOC Caregivers Linked to NHATS and Caregiving Activities.

| Caregiver Characteristics                      | No vision impairment or dementia (n=898, 55.1%) | Dementia only (n=450, 21.9%) | Vision impairment only (n=224, 13.0%) | Vision impairment and dementia (n=204, 10.0%) | p-value |
|------------------------------------------------|-----------------------------------------------|-------------------------------|--------------------------------------|----------------------------------------------|---------|
| Age, mean (SE)                                 | 57.0 (0.7)                                    | 57.8 (0.7)                    | 57.4 (1.1)                           | 54.2 (1.6)                                   | 55.4 (1.2) | 0.117 |
| Female, %                                      | 62.3                                          | 60.4                          | 66.3                                 | 61.1                                         | 65.8     | 0.230 |
| Education, %                                   |                                               |                               |                                      |                                              |          | 0.596 |
| ≥High school                                   | 42.9                                          | 419                           | 41.0                                 | 45.5                                         | 49.3     |       |
| Some college                                   | 33.1                                          | 32.1                          | 37.2                                 | 32.6                                         | 30.6     |       |
| ≥College                                       | 24.0                                          | 26.0                          | 21.8                                 | 21.9                                         | 20.1     |       |
| Self-rated health status, %                    |                                               |                               |                                      |                                              |          | 0.254 |
| Excellent or very good                         | 50.5                                          | 53.3                          | 46.9                                 | 47.8                                         | 46.5     |       |
| Good                                           | 28.5                                          | 26.5                          | 31.9                                 | 32.7                                         | 27.5     |       |
| Fair or poor                                   | 21.0                                          | 20.3                          | 21.2                                 | 19.5                                         | 26.1     |       |
| Relationship to the older adult, %             |                                               |                               |                                      |                                              | <.001    |       |
| Spouse                                         | 23.0                                          | 28.2                          | 18.6                                 | 15.3                                         | 13.6     |       |
| Daughter or son                                | 53.0                                          | 48.3                          | 60.8                                 | 56.0                                         | 58.0     |       |
| Other relative                                 | 16.4                                          | 14.6                          | 15.5                                 | 21.2                                         | 22.0     |       |
| Nonrelative                                    | 7.7                                           | 9.0                           | 5.1                                  | 7.5                                          | 6.4      |       |
| Travel time to older adults’ residence, %      |                                               |                               |                                      |                                              | 0.072    |       |
| Co-reside                                      | 51.7                                          | 50.9                          | 50.9                                 | 55.1                                         | 53.3     |       |
| ≤10 min                                        | 25.5                                          | 26.8                          | 26.0                                 | 24.1                                         | 18.6     |       |
| 11-30 min                                      | 16.2                                          | 15.9                          | 15.2                                 | 13.1                                         | 24.2     |       |
| ≥31 min                                        | 6.7                                           | 6.5                           | 7.9                                  | 7.7                                          | 3.9      |       |
| Duration of caregiving in years, %             |                                               |                               |                                      |                                              | 0.031    |       |
| <1                                             | 16.6                                          | 18.5                          | 16.2                                 | 12.7                                         | 11.7     |       |
| 1-4                                            | 39.6                                          | 37.7                          | 46.3                                 | 38.7                                         | 36.3     |       |
| >4                                             | 43.9                                          | 43.8                          | 37.5                                 | 48.6                                         | 51.9     |       |
| Providing assistance for, %                    |                                               |                               |                                      |                                              |          | 0.822 |
| Shopping                                       | 90.8                                          | 91.3                          | 89.2                                 | 91.4                                         | 91.1     |       |
| Transportation                                 | 87.3                                          | 88.4                          | 85.5                                 | 90.0                                         | 81.7     | 0.201 |
| Housework                                      | 84.9                                          | 83.6                          | 89.5                                 | 83.7                                         | 83.5     | 0.303 |
| Mobility                                       | 72.0                                          | 67.4                          | 73.4                                 | 78.7                                         | 85.1     | <.001 |
| Banking                                        | 58.4                                          | 54.4                          | 65.9                                 | 62.1                                         | 59.0     | 0.047 |
| Self-care                                      | 51.4                                          | 43.6                          | 60.5                                 | 50.4                                         | 75.7     | <.001 |
| Health system logistics, %                     |                                               |                               |                                      |                                              |          |       |
| Make appointments                              | 59.6                                          | 52.2                          | 75.1                                 | 59.0                                         | 67.0     | <.001 |
| Order medicines                                | 52.0                                          | 45.1                          | 63.8                                 | 52.4                                         | 64.1     | <.001 |
| Handle insurance issue                         | 39.9                                          | 36.5                          | 43.9                                 | 40.0                                         | 50.0     | 0.048 |
| Health management, %                           |                                               |                               |                                      |                                              |          |       |
| Diet                                           | 30.6                                          | 30.4                          | 31.1                                 | 30.0                                         | 31.4     | 0.994 |
| Foot care                                      | 29.7                                          | 25.8                          | 29.9                                 | 34.4                                         | 44.2     | <.001 |
| Skin care                                      | 25.6                                          | 22.8                          | 25.2                                 | 26.0                                         | 41.1     | <.001 |
| Exercise                                       | 23.1                                          | 20.1                          | 28.5                                 | 19.3                                         | 32.6     | 0.012 |
| Dental care                                    | 15.7                                          | 9.7                           | 23.1                                 | 11.8                                         | 37.9     | <.001 |
Table 2. Caregiving Related Difficulties Among Caregivers.

| Caregiver Characteristics                                      | Total (n=1776) | No vision impairment or dementia (n=898, 55.1%) | Dementia only (n=450, 21.9%) | Vision impairment only (n=224, 13.0%) | Vision impairment and dementia (n=204, 10.0%) |
|----------------------------------------------------------------|----------------|-----------------------------------------------|-------------------------------|--------------------------------------|--------------------------------------------|
| Impact on valued activities<sup>b</sup>, %                     |                |                                               |                               |                                      |                                            |
| Visiting friends and family                                    | 17.6           | 12.6                                          | 21.3                         | 17.9                                 | 36.5                                       | <.001                                      |
| Going out for enjoyment                                        | 12.1           | 7.3                                           | 15.5                         | 11.4                                 | 31.3                                       | <.001                                      |
| Attending religious services                                   | 8.1            | 5.4                                           | 11.6                         | 8.6                                  | 14.5                                       | <.001                                      |
| Participating in club meetings or group activities             | 7.5            | 5.2                                           | 11.8                         | 4.5                                  | 15.3                                       | <.001                                      |
| Works for pay, %                                               | 39.5           | 37.4                                          | 41.8                         | 43.5                                 | 41.3                                       | 0.436                                      |
| Impact on work (among those who work), %                       |                |                                               |                               |                                      |                                            |
| Missed work in past month<sup>c</sup>                        | 10.2           | 9.4                                           | 12.3                         | 9.8                                  | 10.2                                       | 0.859                                      |
| Missed hours<sup>d</sup>                                       | 10.5           | 10.0                                          | 13.5                         | 7.7                                  | 10.2                                       | 0.647                                      |
| Reduced productivity                                           | 14.0           | 11.9                                          | 18.7                         | 12.8                                 | 15.5                                       | 0.348                                      |
| Supportive services or assistance directed to caregiver, %     |                |                                               |                               |                                      |                                            |
| Respite care                                                   | 10.6           | 7.2                                           | 16.3                         | 9.6                                  | 18.6                                       | <.001                                      |
| Received training on how to assist                            | 6.8            | 4.9                                           | 9.4                          | 6.4                                  | 12.0                                       | 0.004                                      |
| Support group participation                                    | 4.6            | 3.9                                           | 7.9                          | 2.3                                  | 4.0                                        | 0.306                                      |
| Use of ≥1 supportive service                                  | 18.4           | 13.1                                          | 27.8                         | 16.5                                 | 29.5                                       | <.001                                      |

<sup>a</sup> Responses of no difficulty are categorized as little or none, rated levels of difficulty of 1 to 2 are categorized as some, and rated levels of difficulty of 3 to 5 are categorized as substantial.

<sup>b</sup> Reduced participation in the past month because of caregiving for activities identified as being somewhat or very important.

<sup>c</sup> Missed work refers to any missed time from work in the past month because of caregiving. Missed hours reflects hours of work missed because of caregiving in relation to all hours typically worked.

<sup>d</sup> Missed hours.
Table 3. Regression Analysis: Caregiving Outcomes for Caregivers of Older Adults by Vision Impairment and Probable Dementia, Accounting for Clustering by Care Recipient.

| Group                                      | Model 1. Caregiving hours per month | Model 2. Number of valued activities affected due to providing care |
|--------------------------------------------|--------------------------------------|---------------------------------------------------------------|
|                                            | N=1,776                              |                                                               |
| No vision impairment or dementia           | Reference                            | Reference                                                     |
| Dementia only                              | 1.3 (1.1, 1.6)                       | 1.9 (1.4, 2.6)                                               |
| Vision impairment only                     | 1.3 (1.1, 1.6)                       | 1.3 (0.9, 1.8)                                               |
| Vision impairment and dementia             | 1.7 (1.4, 2.2)                       | 3.2 (2.2, 4.6)                                               |

Note: IRR=incident rate ratio; CI=confidence intervals.

Models adjusted for NHATS participant age, race/ethnicity, sex, marital status, income, comorbidities, and diabetes, and NSOC caregiver age, caregiver sex, caregiver education, caregiver self-reported health, caregiver relationship to the older adult, and cohabiting status.