# THE NATIONAL HEALTH AND AGING TRENDS STUDY

### **2021 RESEARCH BRIEF**

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### WHAT IS NHATS?



### **Background**

The National Health and Aging Trends Study (NHATS) was launched in recognition of the shifting landscape of late-life and the need for data to support the scientific study of how daily life changes as we age. Funded by the National Institute on Aging, NHATS began conducting annual interviews with a nationally representative sample of Medicare beneficiaries ages 65 or older in 2011. Periodically caregivers to NHATS participants also are interviewed in the National Study of Caregiving (NSOC) to provide the perspective of family and friends who help older adults experiencing limitations in daily life. Intended as a platform for research to guide efforts to reduce disability, maximize functioning, and enhance quality of life, NHATS and NSOC data are available at <a href="https://www.nhats.org">www.nhats.org</a>.



### Study Design Overview

NHATS gathers information from a nationally representative sample of Medicare beneficiaries ages 65 and older. Annual, in-person interviews collect detailed information on the disablement process and its consequences. The sample is refreshed periodically, allowing researchers to study national-level disability trends as well as individual trajectories. The NHATS interview is guided by a conceptual framework that recognizes individual-level physical and cognitive capacity is distinct from the environments in which activities take place and the accommodations made in response to limitations. Among the specific content areas included are: the physical, social, technological and service environment; tests and self-reports of physical and cognitive capacity; use of assistive devices and rehabilitation services; help received with daily activities (self-care, household, and medical); participation in valued activities; and wellbeing. Other topics focus on chronic conditions, symptoms, sensory impairments, transportation, subjective and economic wellbeing, and demographic factors. A last month of life interview focuses on quality of end of life care. NHATS data are supplemented by linkages to Medicare data and geographic information.

NHATS is
intended as the
primary
platform for
scientific inquiry
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Americans.







#### Study Aims

### NHATS has two primary scientific aims:

To promote scientific study of late-life disability trends and dynamics

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To advance our understanding of the social and economic impact of late-life functional changes for older people, their families, and society

### Study Design Overview

NHATS has been designed to answer a variety of late-life disability-related questions including:

- Are trends in late-life functioning and disability changing over time, and how is this affecting family caregiving?
- Who experiences gaps in needed assistance with everyday activities?
- What is the impact of Alzheimer's Disease and related dementias (ADRD) on older adults and their families?
- How is the quality of end-of-life care changing for older adults?
- What do social engagement and participation look like for older adults?
- How is medical care and health care spending changing in later life?



### **CURRENT NHATS RESEARCH**



### FAMILY AND UNPAID CAREGIVING

Researchers have taken advantage of the unique linkages between NHATS and the National Study of Caregiving (NSOC), which interviews family and other unpaid helpers of NHATS participants. NHATS-NSOC was featured in a report from the National Academies on Families Caring for an Aging America (NASEM 2016) and has provided unique insights on end of life caregiving (Ornstein 2017); the disproportionate share of care provided to individuals with dementia (Kasper 2015); caregiver involvement in health care activities (Wolff 2016); adequacy of training (Burgdorf 2019, 2021); and race-based differences in caregiving (Fabius 2020).

### UNMET NEED FOR ASSISTANCE

NHATS provides innovative measures of unmet need that reflect consequences of not receiving adequate care, such as having to stay inside or in bed because no one was there to help. The prevalence of these types of adverse consequences due to unmet need is substantial. Among communitydwelling older adults who have difficulty or receive help, 32% had an adverse consequence in the last month related to an unmet need (Freedman 2014). Investigators have found that adverse consequences are more prevalent among Black older adults (Berridge 2018), those with elevated depressive symptoms (Xiang 2016), and high-need/highcost older adults (Beach 2018).

### ALZHEIMER'S DISEASE AND DEMENTIA

NHATS has become an important national resource for studying disability and care needs related to Alzheimer's Disease and Related Dementias (ADRD) and consequences for families. NHATS offers researchers an annual dementia classification measure (Kasper 2013). Drawing on this measure, researchers have found that a substantial majority of older adults with probable dementia in the United States have never been professionally diagnosed or are unaware that they have been (Amjad 2018). Researchers have used NHATS to examine safety and quality of life considerations (Amjad 2016; Reckrey 2020) and trends in dementia incidence (Freedman 2018).



### END OF LIFE CARE

With its annual design and last month of life interview, NHATS is well-suited for studying quality of end-of-life care. Teno (2015) finds that respondents are more likely in 2011 to report unmet need for pain management and that the overall rating of quality of care has decreased since 2000. NHATS can also be used to examine the effect of transitions at the very end of life (i.e. "late" transitions; see Makaroun 2018). Several NHATS papers have examined the role of advanced care planning (ACP) on the quality of end of life care (Cudjoe 2020; Grace Yi 2019; Harrison 2016; Kale 2016). NHATS and NSOC are also valuable resources for exploring the role of family caregivers in end-oflife care. Ornstein (2017) reports that nearly 9 in 10 end-of-life caregivers are family members and other unpaid caregivers. Additional papers look at the role of caregiving strain in end of life care (Vick 2019; Pristavec 2020).

## SOCIAL ENGAGEMENT & PARTICIPATION

NHATS provides new estimates of social engagement and participation in valued activities. Cudjoe (2020) finds that 24% of older adults can be characterized as socially isolated. Several studies have identified risk factors for social engagement and/or isolation, including driving cessation (Qin 2020), fall worry (Choi 2020), and neighborhood disorder and perceived social cohesion (Latham 2018). Szanton (2015) used NHATS' open-ended question to describe older adults' favorite activities. Other studies indicate that older adults' participation in valued activities is adversely affected by limitations in cognitive and physical capacity (Parisi 2017), poor self-rated health (Choi 2016), and symptoms of insomnia (Endeshaw 2016; Spira 2014). Older individuals who are unable to leave their home are an especially vulnerable group. Ornstein (2015) published a groundbreaking paper on the epidemiology of the elderly homebound population (see also Xiang 2017; Soones 2017).

### MEDICAL CARE & HEALTH CARE SPENDING

Because NHATS participants are drawn from the Medicare enrollment file, survey data may be linked to Medicare claims and assessment files. Using Medicare claims, Wolff (2019) quantifies differences in total Medicare spending among older adults with disability by whether they have unmet needs in their daily activities. Other studies have merged survey and claims data in order to evaluate claims-based algorithms of frailty (Segal 2017; Wu 2020). In addition, NHATS has developed and implemented the first module on use of rehabilitation services to be included in a national study of older adults. Freedman (2018) examined the accuracy of rehabilitation service use reports by comparing self-reports with Medicare claims and found that survey-based measures of rehabilitation accurately captured actual use over the past year. Other researchers have used NHATS to investigate deprescribing (Reeve 2018), frailty (Bandeen-Roche 2015), and stroke (Skolarus 2016).

### **SELECT NHATS PUBLICATIONS**

- Amjad H, Roth DL, Samus QM, Yasar S, Wolff JL. (2016). <u>Potentially Unsafe Activities and Living Conditions of Older Adults with Dementia</u>. Journal of the American Geriatric Society, 64(6), 1223-32. PMCID: PMC4914464
- Amjad H, Roth DL, Sheehan OC, Lyketsos CG, Wolff JL & Samus QM. (2018). <u>Underdiagnosis of Dementia</u>: An Observational Study of Patterns in Diagnosis and Awareness in US Older Adults. Journal of General Internal Medicine, 33(7), 1131-1138. PMCID: PMC6025653.
- Bandeen-Roche K, Seplaki CL, Huang J, Buta B, Kalyani RR, Varadhan R, Xue QL, Walston JD, Kasper JD. (2015). <u>Frailty in Older Adults: A Nationally Representative Profile in the United States</u>. J Gerontol A Biol Sci Med Sci. 70(11): 1427-34. PMCID: PMC4723664
- Choi NG, Bruce ML, DiNitto DM, Marti CN, Kunik ME. (2020). <u>Fall Worry Restricts Social Engagement in Older Adults</u>. J Aging Health. 32(5-6):422-431.
- Choi NG, DiNitto DM, Marti CN. (2016). <u>Social Participation and Self-rated Health Among Older</u>
  Male Veterans and Non-veterans. Geriatr Gerontol Int. 16(8):920-7
- Cudjoe TKM, Boyd CM, Wolff JL, Roth DL. (2020). <u>Advance Care Planning: Social Isolation Matters</u>. J Am Geriatr Soc. 68(4):841-846.
- Cudjoe TKM, Roth DL, Szanton SL, Wolff JL, Boyd CM, Thorpe RJ Jr. (2020). <u>The Epidemiology of Social Isolation: National Health & Aging Trends Study</u>. J Gerontol B Psychol Sci Soc Sci. 75(1):107-113. PMCID: PMC7179802
- Endeshaw YW, Yoo W. (2016). <u>Association Between Social and Physical Activities and Insomnia Symptoms Among Community-Dwelling Older Adults</u>. J Aging Health. 28(6): 1073-89. PMCID: PMC4914473
- Fabius CD, Wolff JL, Kasper JD. (2020). <u>Race Differences in Characteristics and Experiences of Black and White Caregivers of Older Americans</u>. Gerontologist. 60(7):1244-1253. PMCID: PMC7491434
- Freedm in VA, Kasper JD, Jette A. (2018). <u>Can Older Adults Accurately Report their Use of Physical Rehabil tation Services</u>? Arch Phys Med Rehabil. 99(8):1507-1513. PMCID: PMC6064388
- Freedman VA, Kasper JD, Spillman BC, Plassman BL. (2018). <u>Short-term Changes in the Prevalence of Probable Dementia</u>: <u>An Analysis of the 2011-2015 National Health and Aging Trends Study</u>. The Journals of Gerontology: Series B, 73(suppl\_1), S48-S56. PMCID: PMC6018980
- Freedman VA, Spillman BC. (2014). <u>Disability and Care Needs Among Older Americans</u>. Milbank Quarterly 92(3):509-41. PMCID: PMC4221755.
- Grace Yi EH. (2019). <u>Does Acculturation Matter? End-of-Life Care Planning and Preference of Foreign-born Older Immigrants in the United States</u>. Innovation in Aging. 3(2): igz012. PMCID: PMC6561643
- Harrison KL, Adrion ER, Ritchie CS, Sudore RL, Smith AK. (2016). <u>Low Completion and Disparities</u> <u>in Advance Care Planning Activities Among Older Medicare Beneficiaries</u>. JAMA Internal Medicine. PMCID: PMC5304942
- Kale MS, Ornstein KA, Smith CB, Kelley AS. (2016). <u>End-of-Life Discussions with Older Adults</u>. J Am Geriatr Soc. 64(10): 1962-1967. PMCID: PMC5072996
- Kasper JD, Freedman VA, Spillman BC. (2013). <u>Classification of Persons by Dementia Status in the National Health and Aging Trends Study</u>. NHATS Technical Paper #5. Baltimore: Johns Hopkins University School of Public Health. Available at www.NHATS.org.
- Kasper JD, Freedman VA, Spillman BC, Wolff JL. (2015). <u>The Disproportionate Impact of Dementia on Family and Unpaid Caregiving to Older Adults</u>. Health Affairs 34(10): 1642-1649. PMCID: PMC4635557
- Latham K, Clarke PJ. (2018). <u>Neighborhood Disorder, Perceived Social Cohesion, and Social Participation Among Older Americans: Findings from the National Health and Aging Trends Study</u>. J Aging Health. 30(1): 3-26
- Makaroun LK, Teno JM, Freedman V, Kasper JD, Gozalo P, Mor V. (2018). <u>Late Transitions and Bereaved Family Member Perceptions of Quality of End-of-Life Care</u>. JAGS. 66(9):1730-1736. PMCID: PMC6156998
- National Academies of Sciences, Engineering, and Medicine (NASEM). 2016. <u>Families caring for an aging America</u>. Washington, DC: The National Academies Press.
- Ornstein KA, Kelley AS, Bollens-Lund E, Wolff JL. (2017). <u>A National Profile of End-Of-Life Caregiving In The United States</u>. Health Aff (Millwood). 36(7):1184-1192. PMCID: PMC5612447

### **SELECT NHATS PUBLICATIONS**

- Ornstein KA, Leff B, Covinsky KE, Ritchie CS, Federman AD, Roberts L, Kelley AS, Siu AL, Szanton SL. (2015). <u>Epidemiology of the Homebound Population in the United States</u>. JAMA Intern Med. 175(7): 1180-1186. PMCID: PMC4749137
- Parisi JM, Roberts L, Szanton SL, Hodgson NA, Gitlin LN. (2017). <u>Valued Activities Among Individuals</u> with and without <u>Cognitive Impairments: Findings from the National Health and Aging Trends Study</u>. Gerontologist. 57(2):309-318. PMCID: PMC6074869
- Pristavec T, Luth EA. (2020). <u>Informal caregiver burden and benefits and older adult mortality: A survival analysis</u>. J Gerontol B Psychol Sci Soc Sci. 75(10):2193-2206. PMCID: PMC7664316
- Qin W, Xiang X, Taylor H. (2019). <u>Driving Cessation and Social Isolation in Older Adults. Journal of Aging and Health</u>. 32(9):962-971. PMCID: PMC7901288
- Reckrey JM, Morrison RS, Boerner K, Szanton SL, Bollens-Lund E, Leff B, Ornstein KA. (2020). <u>Living in the Community With Dementia: Who Receives Paid Care?</u> Journal of the American Geriatrics Society, 68(1), 186-191. PMCID: PMC6957088
- Reeve E, Wolff JL, Skehan M, Bayliss EA, Hilmer SN, Boyd CM. (2018). <u>Assessment of Attitudes</u>
  <u>Toward Deprescribing in Older Medicare Beneficiaries in the United States</u>. JAMA Internal Medicine.
  178(12):1673-1680. PMCID: PMC6583614
- Segal JB, Huang J, Roth DL, Varadhan R. (2017). <u>External Validation of the Claims-Based Frailty Index in the National Health and Aging Trends Study Cohort</u>. American Journal of Epidemiology. 186(6):745-747. PMCID: PMC5860423
- Skolarus LE, Freedman VA, Feng C, Wing JJ, Burke JF. (2016). <u>Care Received by Elderly US Stroke Survivors May Be Underestimated</u>. Stroke 47(8): 2090-5. PMCID: PMC4961527
- Soones T, Federman A, Leff B, Siu AL, Ornstein K. (2017). <u>Two-Year Mortality in Homebound Older Adults: An Analysis of the National Health and Aging Trends Study</u>. J Am Geriatr Soc. 65(1):123-129. PMCID: PMC5258674
- Spira AP, Kaufmann CN, Kasper JD, Ohayon MM, Rebok GW, Skidmore E, Parisi JM & Reynolds CF, III. (2014). <u>Association Between Insomnia Symptoms and Functional Status in U.S. Older Adults.</u> J Gerontol B Psychol Sci Soc Sci. 69 (Suppl 1): S35-41. PMCID: PMC4303068
- Szanton SL, Walker RA, Roberts L, Thorpe RJ, Wolff J, Agree E, Roth DL, Gitlin, LN, Seplaki CS. (2015). Older adults' favorite activities are resoundingly active: the NHATS study. Geriatric Nursing 36(2): 131-5. PMCID: PMC4775165
- Teno JM, Freedman VA, Kasper JD, Gozalo P, Mor V. (2015). <u>Is Care for the Dying Improving in the United States</u>? Journal of Palliative Medicine 18(18): 662-6. PMCID: PMC4532900
- Vick JB, Ornstein KA, Szanton SL, Dy SM, Wolff JL. (2019). <u>Does Caregiving Strain Increase as Patients With and Without Dementia Approach the End of Life?</u> Journal of Pain and Symptom Management. 57(2):199-208.e2. PMCID: PMC6348024
- Wolff JL, Nicholas LH, Willink A, Mulcahy J, Davis K, Kasper JD. (2019). <u>Medicare Spending and the Adequacy of Support With Daily Activities in Community-Living Older Adults With Disability: An Observational Study</u>. Ann Intern Med. 170(12):837-844. PMCID: PMC6736697
- Wolff JL, Spillman BC, Freedman VA, Kasper JD. (2016). <u>A National Profile of Family and Unpaid Caregivers Who Assist Older Adults with Health Care Activities</u>. JAMA Intern Med. 176(3): 372-9. PMCID: PMC4802361
- Wu S, Mulcahy J, Kasper JD, Kan HJ, Weiner JP. (2020). <u>Comparing Survey-Based Frailty Assessment to Medicare Claims in Predicting Health Outcomes and Utilization in Medicare Beneficiaries</u>. J Aging Health. 32(7-8):764-777. PMCID: PMC6885102
- Xiang X, Brooks J. (2017). <u>Correlates of Depressive Symptoms Among Homebound and Semihomebound Older Adults</u>. J Gerontol Soc Work. 60(3):201-214. PMCID: PMC5845464

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