

Measuring the Effect of Caregiving: *Perspectives from the National Health and Aging Trends Study and the National Study of Caregiving*

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**National Health &
Aging Trends Study**

how daily life changes as we age

Overview for talk

- Focus on 3 aspects of measurement:
 - How do we define “caregiving”?
 - What do we learn from the perspectives of care recipients & caregivers?
 - What effects of caregiving should we be measuring (with a focus on caregiver wellbeing)?

Drawing on design and measurement related to caregiving from two linked Data Sources

Nationally representative of older adults and their caregivers and funded by NIA:

- **National Health and Aging Trends Study (NHATS)** focuses on disability in later life and provides data from in-person interviews with 8,000+ persons (conducted annually 2011 to 2023)
- **National Study of Caregiving (NSOC)** interviews caregivers to persons in NHATS about their caregiving experience (2011*, 2015*, 2017; 2020 to 2023)

*Funded by ASPE DHHS

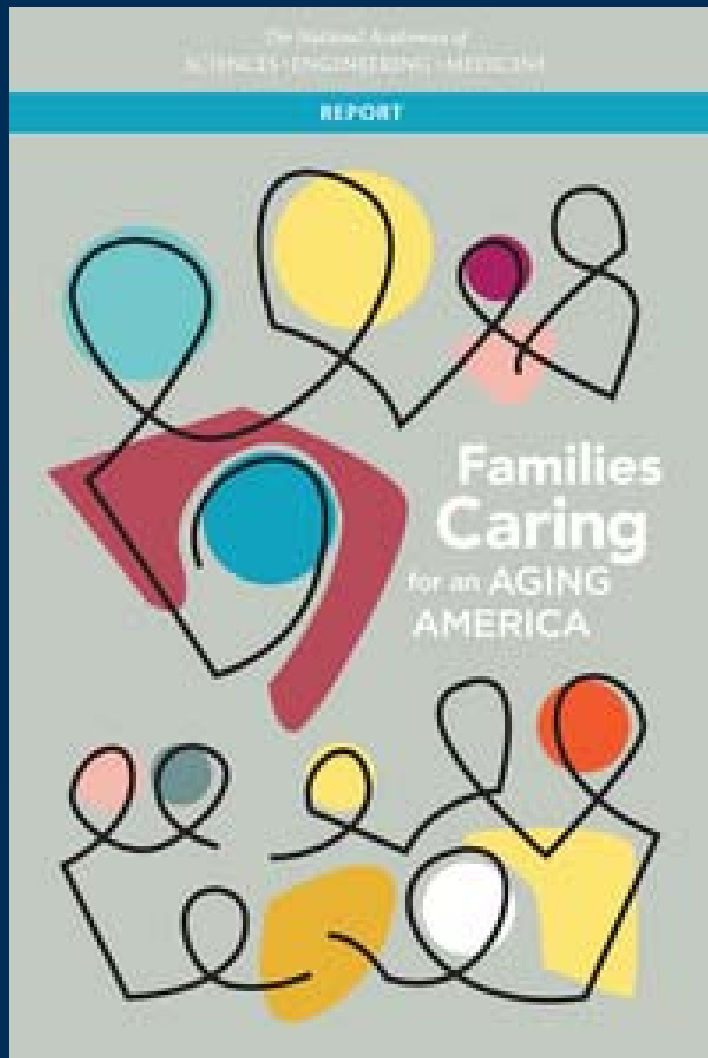
Data to define caregiving & caregiving for persons with dementia

- NHATS identifies activities for which an older person is receiving help and asks who is helping
- Activities include:
 - Self-care, mobility, household activities for health/functioning reasons (classic ADL/IADL)
 - But also– transportation, help in medical activities (insurance, interacting with providers)
- Helpers with each activity are identified (relationship to older adult, gender)
- Extensive information from NHATS on physical & cognitive functioning of NHATS participant (e.g. dementia status) to characterize care recipients

NHATS approach allows:

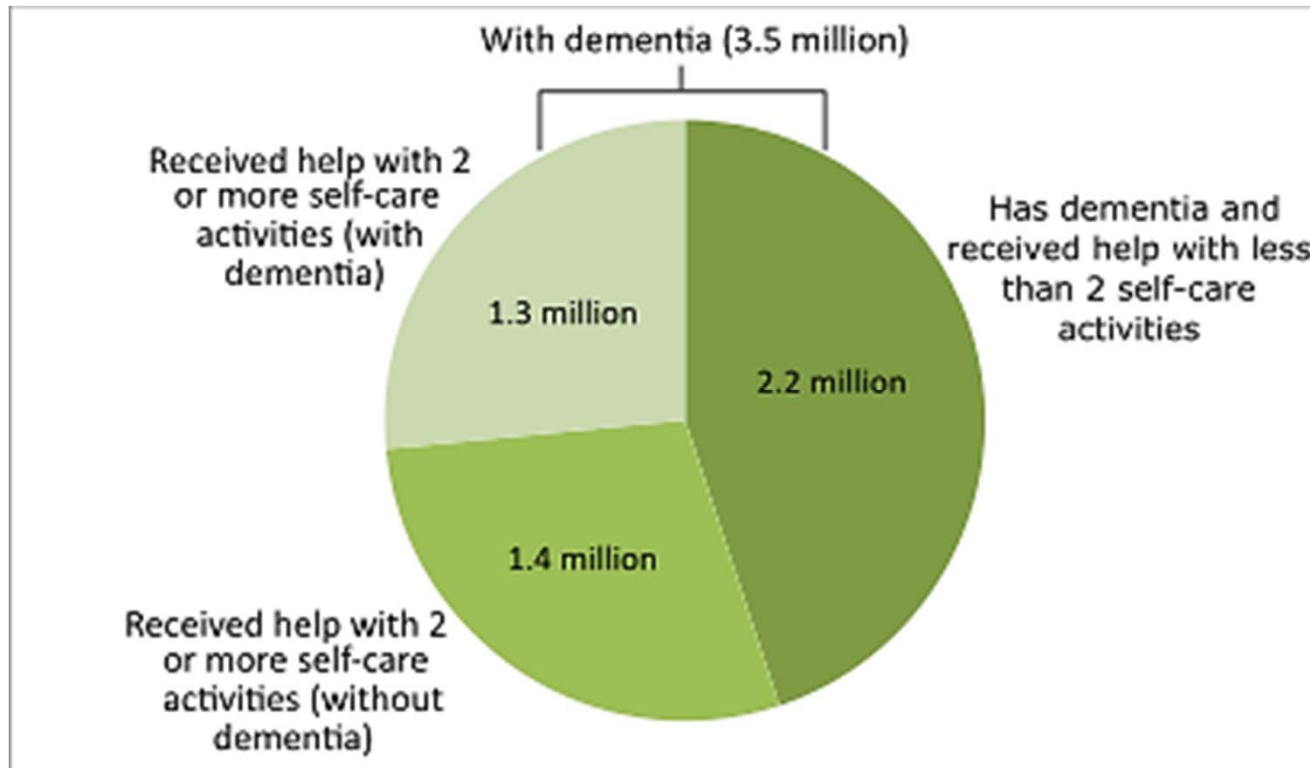
- Defining care recipient populations
 - Using a common set of activities (e.g. all persons receiving self-care help)
 - By levels and combinations of help received
- Defining caregivers
 - By activities they help with
 - By characteristics of caregiver
 - By characteristics of the care recipient, such as dementia status

National Academies of Science Report on Family Caregiving (2016)



NAS report drew on NHATS to develop estimates of caregivers to older adults:

- Nearly 18 million caregivers to older adults with disability
- 8.5 million caregivers assist 5 million high need older adults



8.5 million caregivers provide help to 4.9 million high-need older adults (persons with dementia and/or 2 or more self-care needs), 2011

NOTES: As reported by Medicare beneficiaries age 65 and older (or their proxy) for the prior month. Self-care activities include bathing, dressing, eating, toileting, or getting in and out of bed. “Probable dementia” includes individuals whose doctor said they had dementia or Alzheimer’s disease and individuals classified as having probable dementia based on results from a proxy screening instrument and several cognitive tests. Excludes nursing home residents.

SOURCE: Data from the 2011 NHATS.

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Receiving assistance with activities by dementia status of care recipient and types and levels of help

	Dementia	No Dementia
All older adults		
Number (millions)	3.6	33.4
Percent	9.7%	90.3%
Type of assistance		
Any self-care activities	53.1%	10.7% *
Any household activities	73.9	17.0 *
Self-care or household activities	77.2	20.3*
Older adults receiving help		
Number (millions)	2.8	6.9
Percent	28.9%	71.1%
Level of assistance for people receiving help		
3 or more self-care activities	39.8%	14.4%*
1–2 self-care activities	29	38
Household activities only	31.2	47.5

*p<0.01 NHATS, 2011. Excludes Nursing home residents.

Source: Kasper, Freedman, Spillman & Wolff. *The disproportionate impact of Dementia on family and unpaid caregiving to older adults. Health Affairs 2015*



Numbers/types of caregivers and relationship to older adult care recipient by dementia status

Number of family & unpaid caregivers & any paid care	Dementia	No Dementia
0	2.2%	4.4%*
1	32.5	39.3
2	35.8	33.3
3 or more	29.5	23.0
Paid caregivers	30.1	20.5 *
Relationship to care recipient		
Spouse	17.2%	26.1% **
Daughter	35.2	26.4
Son	17	17.3
Other family or unpaid caregiver	30.6	30.2

*p<0.01**p<0.05 NHATS, 2011. Community resident only; excludes nursing home residents.

Source: Kasper, Freedman, Spillman & Wolff, Health Affairs 2015



What do we learn from perspectives of both the care recipient and caregiver ?

- NHATS provides care recipient perspective on help received, for what and by whom; extensive information on care recipient's physical & cognitive function, demographics, well-being and more
- NSOC provides caregiver perspective on help being provided (and related matters e.g. hours and duration of caregiving) and their caregiving experience—how caregiving affects well-being and other aspects of their lives
- NHATS and NSOC have overlap but NSOC is key to providing insight into effects of caregiving on the caregiver

What effects of caregiving should we be measuring?

Key questions in broad terms are:

- What are the activities undertaken in the caregiving role?
- What is the level of effort involved in caregiving – usually measured in time (often hours)?
- What is the effect of caregiving on other activities such as work, family responsibilities, valued activities – usually measured in terms of “interference” (restrictions in participation; work productivity)
- What is the effect of caregiving on person’s wellbeing (overall subjective & caregiving-related emotional, financial, physical health)?

Is there anything different for caregivers to persons with dementia ? (all of the same questions apply)

Overview of NSOC Content Areas

- Care activities
- Intensity & duration of care
- Positive & negative aspects of caregiving
- Caregiver health & wellbeing
- Services & support environment for caregiver
- Participation
- Household composition and demographics
- Employment and caregiving
- Insurance, income, OOP costs, transfers
- Added 2017: content for last month of life caregivers; caregiver interaction with health care providers & involvement in medical care

Assessing wellbeing from caregiver's perspective

- Measures of wellbeing specific to caregiving role:
 - Positive aspects of caregiving
 - Negative aspects of caregiving
 - Areas of Difficulty (“how difficult is helping XXX: physically, financially, emotionally)
- Overall wellbeing of persons who are caregivers:
 - Depression/anxiety
 - Subjective wellbeing – hedonic (pleasure/pain in the moment) and eudaimonic (self-realization/meaning)

Caregiving wellbeing is both an outcome and a contributing factor

- How is caregiver wellbeing affected by:
 - Restrictions on participation in other valued activities/ work
 - How time is spent
 - Caregiving circumstances: person with dementia, intensity of help (hours)
- How does caregiver wellbeing influence:
 - Depression/anxiety
 - Overall subjective wellbeing

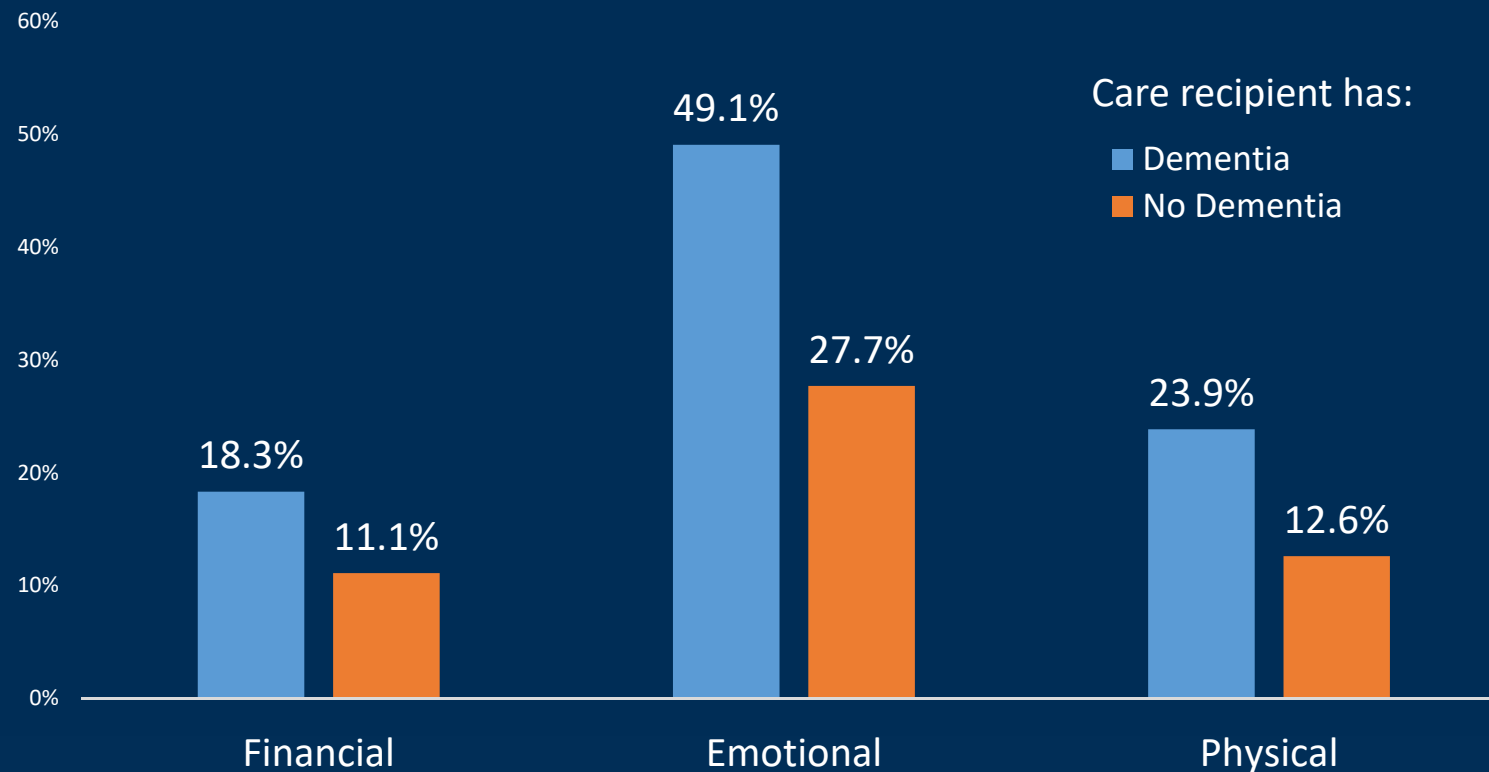
Items reflecting positive & negative aspects of caregiving: Gains & negative aspects by dementia status*

Any gains from caregiving			
	Care Recipient has Dementia	Care Recipient No Dementia	p-value
Endorsed at least one item	99.6%	99.5%	
More confident about your abilities	81.4%	80.1%	
Taught you to deal with difficult situations	90.8%	84.1%	<.05
Brought you closer to care recipient	93.4%	86.0%	<.01
Gives you satisfaction that recipient is well cared for	99.1%	98.2%	
Any negative aspects of caregiving			
Endorsed at least one item	70.2%	58.8%	<.01
Exhausted when you go to bed at night	53.4%	41.1%	<.01
Have more things to do than you can handle	46.9%	35.6%	<.01
Don't have time for yourself	50.2%	38.9%	<.01
When you get a routine going, recipient's needs change	33.5%	21.9%	<.01

*Care recipient is 70 or older. % reporting “very much” or “some” vs. “not so much”

Source: NSOC 2017

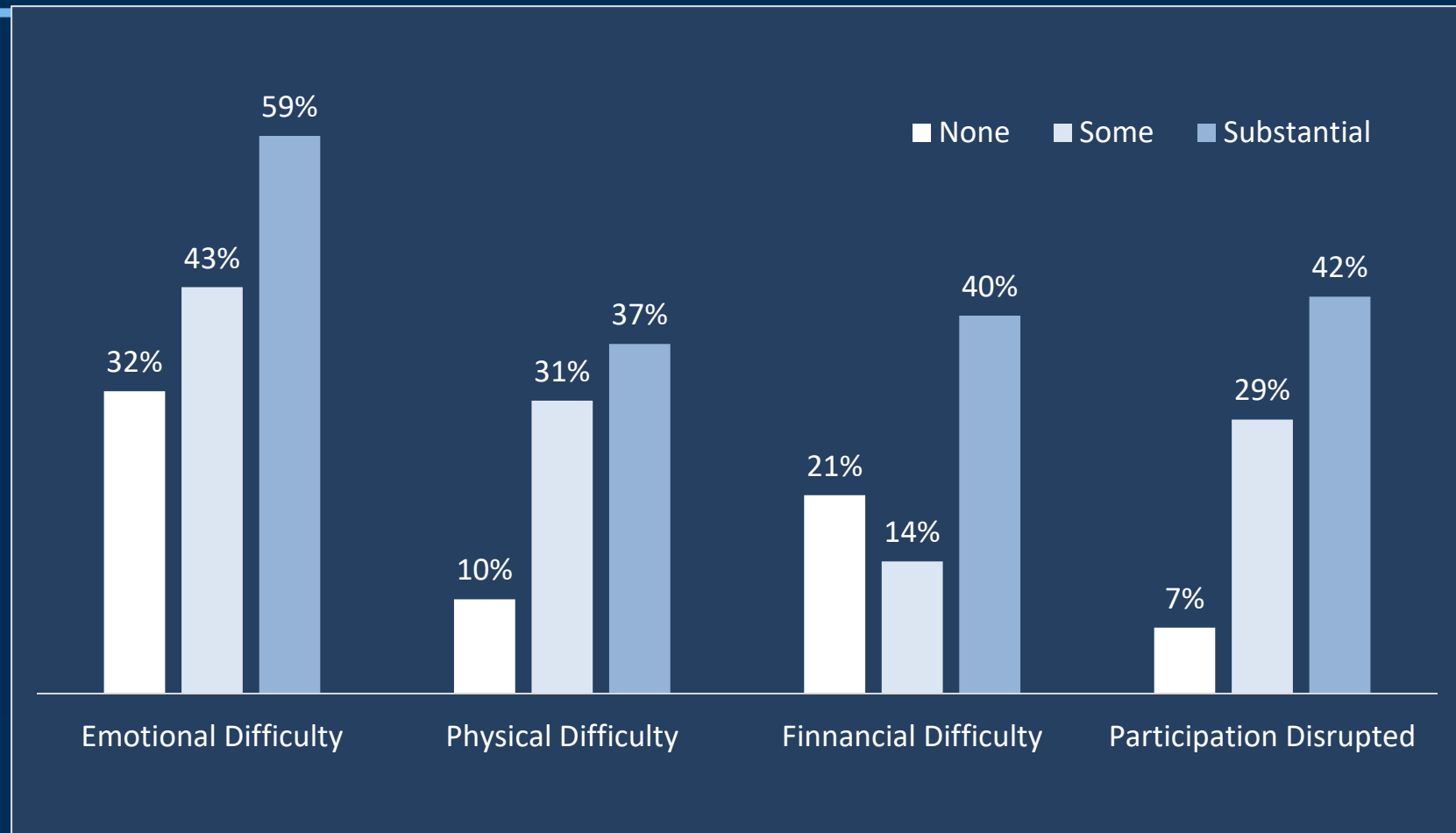
Difficulties with Caregiving by Care Recipient Dementia Status*



*Care recipient is 70 or older

Source: NSOC 2017

Caregiver wellbeing among those helping with health care activities for persons with dementia



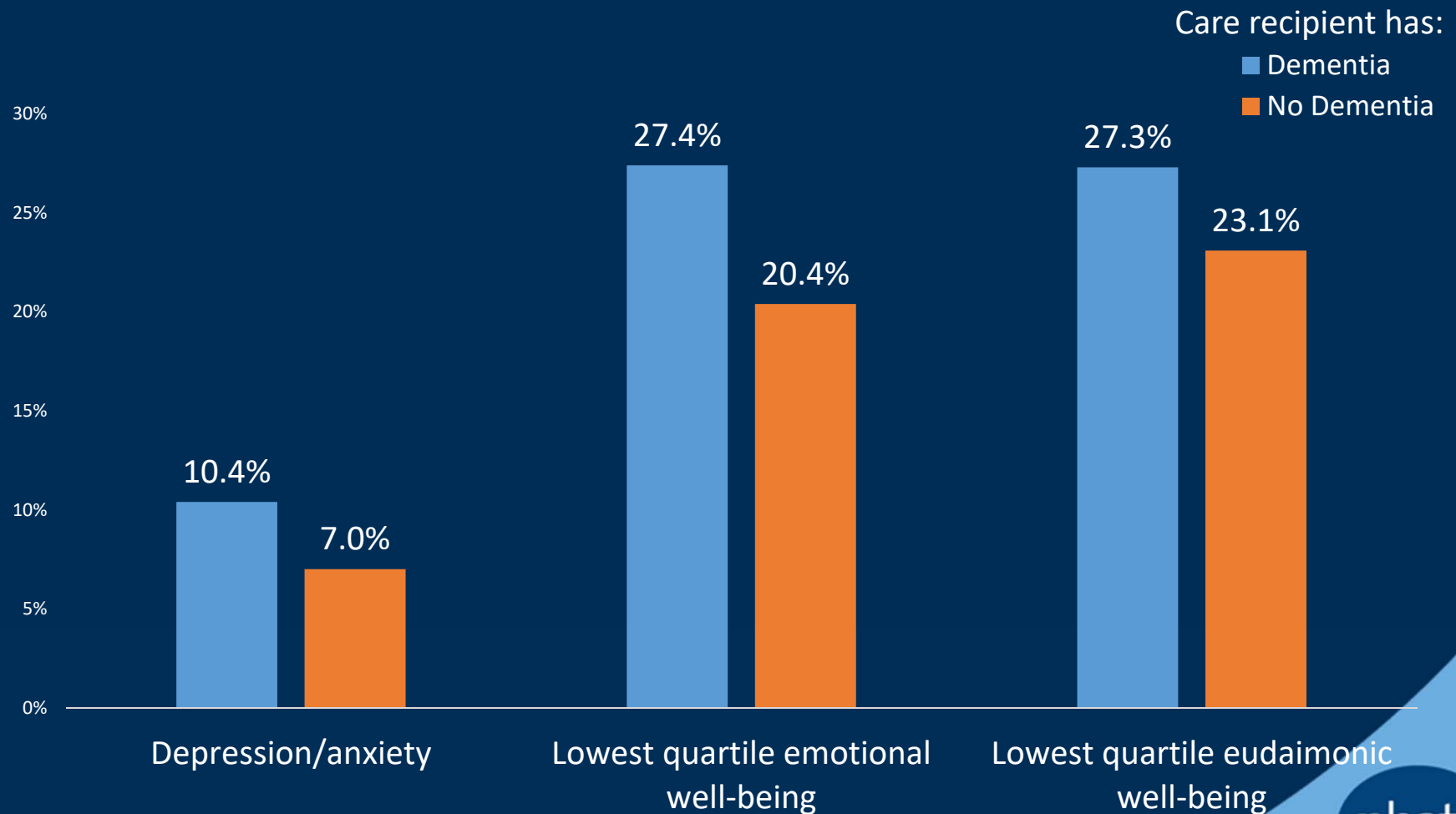
NSOC 2015; health care activities = medication management; accompanying on physician visits.

Source: Updated and stratified by dementia status based on Wolff, Spillman, Freedman, Kasper. A

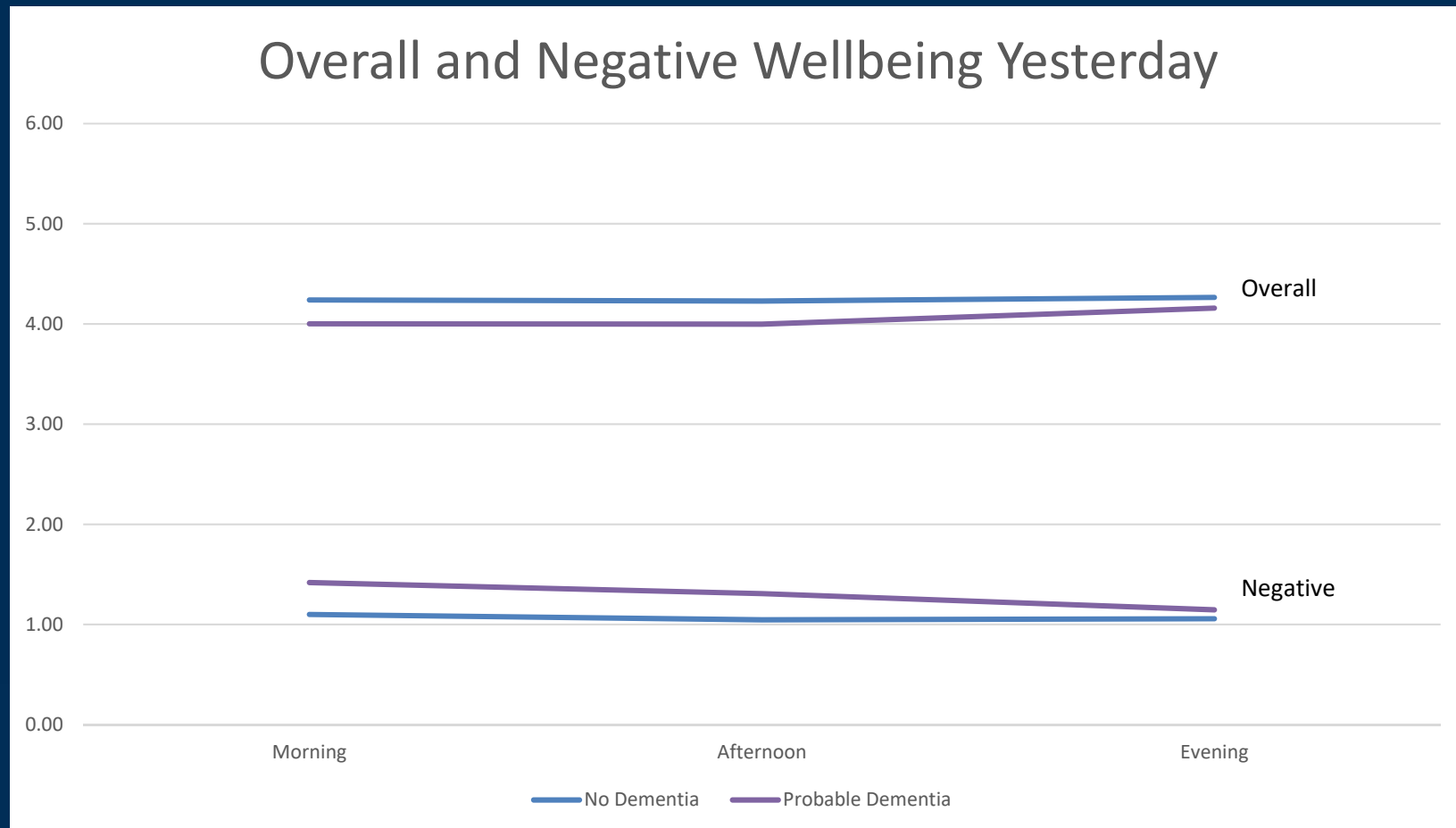
17 national profile of family and unpaid caregivers who assist other adults in health care activities. JAMA Internal Medicine, 2016.



Overall Subjective Well-being of Caregivers by Care Recipient Dementia Status



24 hour Time-Diary Based Measures of Wellbeing



Source: NSOC Time Diary data, 2017.

Summary regarding factors needed to measure effects of caregiving

- Ability to define caregiving activities and characteristics of recipients (e.g. dementia) and caregivers
- Perspective of caregivers to assess effect of caregiving on their lives and well-being
- Ability to characterize effects of caregiving on key outcomes: well-being, health, participation in other activities, work

Future NHATS/NSOC data to measure effects of caregiving

- Longitudinal data on caregivers 2020 – 2023 to understand changes over time in caregiving
 - new vs. long-term caregivers
 - how caregiving activities grow/change
- Inclusion of caregivers at end of life (perspective on caregiving in last month of life of recipient)

Auxilliary Slides

- Overview of NHATS Design
- Overview of NHATS Content
- Overview of NSOC Design
- Overview of NSOC Content

Go to www.nhats.org

to register for data and obtain User Guides, other documentation such as technical papers (e.g. sample design, dementia classification; caregiving hours and work productivity), and procedures for access to

Restricted data (e.g. geography; Medicare linkages)



Overview of NHATS Sample Design & Data Collection

- Study population: Medicare beneficiaries ages 65 years or older
- Design:
 - Age-stratified: 5-year age groups, including oversample of 90+
 - Oversampling of Black persons
- Fieldwork
 - Annual in-person interviews (May – October)
 - Round 1 (2011) – Round 8 (2018) available
 - Round 9 (2019) in progress
 - Round 10 (2020) – 13 (2023) funded
 - Replenishment in Round 5 (2015) and Round 10 (2020)

Overview of NHATS Content Areas

- Mobility, self-care and household activities (done by self, help from others, use of devices, environmental accommodations)
- Physical and cognitive capacity assessments
- Household, family and social context
- Health conditions and sensory impairments
- Socioeconomic status (income sources, assets, work, home ownership, insurance plans)
- Wellbeing (hedonic, eudomonic, anxiety, depression)
- Demographics and early life circumstances

For details go to www.nhats.org

Overview of NSOC Design

- Helpers to NHATS participants who receive help with self care/mobility or household activities(for health & functioning reason)
- 30-minute telephone (web starting 2020) interview completed within 4 weeks of NHATS interview
- 2011 and 2015 cross-sectional
- 2017 cross-sectional and longitudinal (2015 NSOC participants); last month of life caregivers added; 24 hour time diary
- 2020 through 2023 cross-sectional & longitudinal; last month of life caregivers added

Overview of NSOC Content Areas

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Caregiver Time Diaries (2017)

- ~30-minute telephone survey
- Modeled after American Time Use Study and Disability and Use of Time supplement to PSID
- Ask caregivers on randomly selected day of the week (all 7 days), what they were doing, with whom, where, and how they felt
 - For care activities ask “who for”
 - Captures multi-tasking, and standby care