

Dementia and Informal Caregiving

Analyses of the National Survey of Caregiving

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Presentation aims

- Brief overview of National Health and Aging Trends Study (NHATS) and National Survey of Caregiving (NSOC)
- Present new estimates of
 - The number of informal caregivers helping elders with daily activities in 2011 and how many hours of care they provided
 - How the type and amount of care differs across caregiver characteristics and by recipient dementia status
 - The distribution and balance of positive and negative aspects of caregiving by caregiver and recipient dementia status
 - How support received and sought by caregivers differs by dementia status



Overview of NHATS and NSOC

- National Health and Aging Trends Study (NHATS) is an annual survey of Medicare beneficiaries age 65+, first fielded in 2011
- Designed to support multi-disciplinary studies
 - Trends and trajectories of health, functioning
 - Consequences for older population, families, and society
- National Survey of Caregiving (NSOC) was a supplement to the first round of NHATS to examine caregiving from the caregiver perspective

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Why conduct NSOC?

- Informal caregiving is an important consequence of declining health and functioning
- Informal caregivers play a critical role in care for the older population with disabilities
 - Administration for Community Living and the National Plan to Address Alzheimer's Disease recognize need to support informal caregivers
 - National data on caregiving experience needed to inform policy design
- National Survey of Caregiving (NSOC) is a resource for national estimates
 - Provides information from the caregiver perspective for a well-defined sample of care recipients
 - Interviews all informal caregivers to NHATS respondents
 - Collects information to identify the time they spend on a broad range of supports beyond traditional daily activities
 - Examines objective and subjective measures of demands on caregivers

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NSOC sample overview

- NSOC sample (n~2,000) based on NHATS respondent identification of those helping with each daily activity
- Two-stage NSOC eligibility process
 - NHATS respondents
 - Living outside nursing homes and reporting help with mobility/self-care, household activities for health/functioning related reasons, or living in supportive residential settings.
 - Eligible caregivers
 - Family members or an unrelated unpaid caregiver
 - Helped with any activity identified in the NHATS interview: mobility, self-care, household activities, transportation and medical care activities
- Up to 5 caregivers selected (5 randomly if > 5)

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Recipient dementia measure

- Dementia status
 - No dementia
 - Possible dementia
 - Probable dementia
- Based on
 - a report that a doctor told the sample person he/she had dementia or Alzheimer's disease
 - score on a screening instrument (the AD8; Galvin 2005, 2006) administered to proxy respondents
 - results from cognitive tests evaluating memory, orientation and executive function.

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Caregiver characteristics

- Relationship to recipient
- Age
- Labor force participation

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Amount and type of care provided

- Monthly hours of care reported by caregiver
 - (e.g. 90 hours= \sim 3 hours per day, 20 hours per week)
- Individual activities performed
- Domains of care
 - Self-care/mobility
 - Household activities (shopping, housework, bills/money, medications)
 - Transportation
 - Health system interactions (make appointments, speak to health care providers, order medications, insurance issues)
 - Health/medical care (e.g. diet, exercise, foot or skin care, medical tasks such as ostomy care, injections)

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Positive and negative aspects of caregiving scales

- Gains and negative aspects measured on separate scales of 0-8
 - Categorized: little or none=0-2; some=3-5; substantial=6-8
- Gains from caregiving
 - More confident about your abilities.
 - Taught you to deal with difficult situations.
 - Brought you closer to care recipient.
 - Gives you satisfaction that recipient is well cared for
- Negative aspects of caregiving
 - Exhausted when you go to bed at night.
 - Have more things to do than you can handle.
 - Don't have time for yourself.
 - When you get a routine going, recipient's needs change.

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Results

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Dementia caregivers provide a disproportionate share of aggregate monthly informal care hours

	Number of caregivers (000s)	Percent of caregivers	Mean hours of care	Aggregate monthly hours (000s)	Percent of aggregate hours
All caregivers	17,949	100.0	74.8	1,342,520	100.0
Recipient dementia status					
No dementia	9,369	52.2	64.9	608,435	45.3
Possible dementia	2,741	15.3	71.9	197,236	14.7
Probable dementia	5,838	32.5	91.9	536,849	40.0

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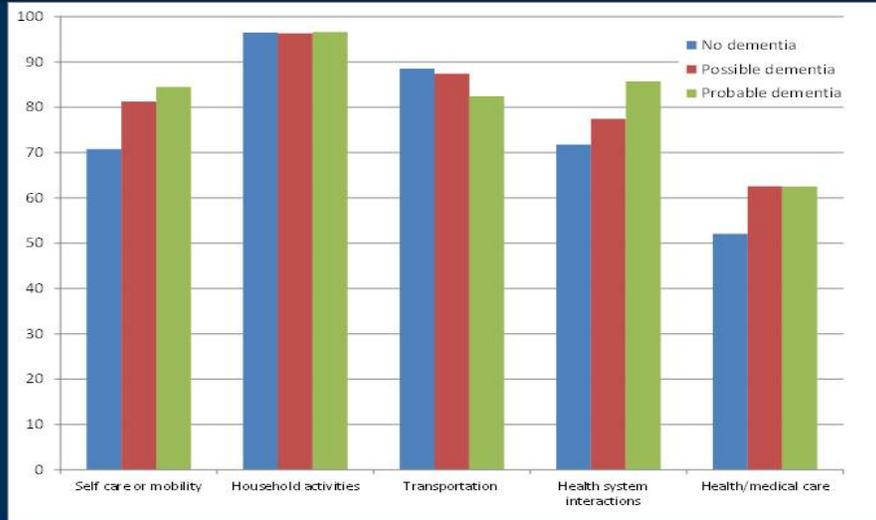
Dementia caregivers are less likely to be spouses, more likely to be daughters, and provide significantly higher mean monthly hours

Informal Caregiver characteristic	Recipient dementia status					
	No dementia		Possible dementia		Probable dementia	
	%	Mean hours of help	%	Mean hours of help	%	Mean hours of help
Spouse	26.5	90	15.5	150	15.4	145
Daughter	25.8	60	29.4	72	35.0	102
Son	17.1	51	19.5	76	19.7	80
Other	30.6	56	35.6	35	30.0	61
<45	17.4	95	17.4	54	15.5	82
45-54	23.0	53	26.0	75	24.2	97
55-64	23.4	51	29.2	69	32.1	85
65-74	21.8	58	15.4	67	15.4	93
75 +	14.4	81	12.0	106	12.7	124
Not working	57.4	78	53.3	99	54.5	115
Working	42.6	48	46.7	42	45.5	65

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Dementia caregivers are more likely to help with self care/mobility, navigating the health care system, and medical tasks



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Little/no gains and substantial negative aspects of caregiving are more than twice as common for dementia caregivers

Care recipient dementia status	All caregivers		Self care or mobility caregivers	
	Little or no gains	Substantial negative aspects	Little or no gains	Substantial negative aspects
No dementia	5.7	6.3	4.1	7.5
Possible dementia	5.7	6.5	5.4	7.8
Probable dementia	7.0	17.8 **	8.1 †	19.9 **

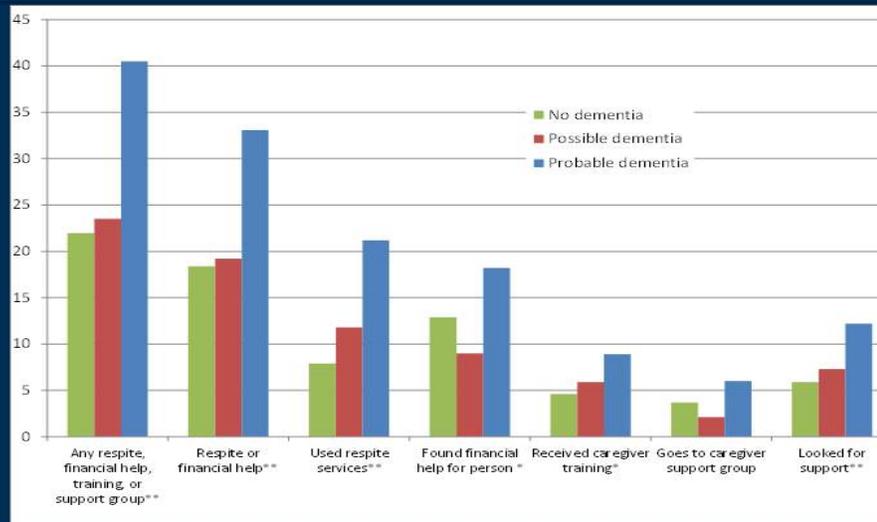
**(*) significantly different from previous value at the 5%(10%) level in a two-tailed test.

††(†) significantly different from the value for No dementia at the 5%(10%) level in a two-tailed test.

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Dementia caregivers are twice as likely to have used outside supports, most often respite or financial help for the recipient



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**(*) Receiving or seeking support differs by dementia status at $p \leq 0.05$ ($p \leq 0.10$).

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Conclusion

- Nearly 1 in 3 of 18 million informal caregivers to 9 million older Americans, are assisting persons with probable dementia and account for 40 percent of aggregate care hours
- Relative to those caring for persons with no dementia, they
 - provide higher mean hours of care
 - are more likely to assist with self-care or mobility and with health system navigation and health/medical tasks
 - are twice as likely to report little or no gains from caregiving and more than twice as likely to report substantial negative aspects
 - are far more likely to receive or seek outside support

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References

- Kasper, JD, VA Freedman, and BC Spillman. "Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study." Report to the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, April 2014.
- Spillman, BC, J Wolff, VA Freedman, and JD Kasper. "Informal Caregiving for Older Americans: An Analysis of the 2011 National Survey of Caregiving." Report to the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, April 2014.
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