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Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

DISABILITY AND CARE NEEDS OF OLDER AMERICANS BY DEMENTIA STATUS:

AN ANALYSIS OF THE 2011 NATIONAL HEALTH AND AGING TRENDS STUDY

April 2014

Office of the Assistant Secretary for Planning and Evaluation

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**DISABILITY AND CARE NEEDS OF OLDER
AMERICANS BY DEMENTIA STATUS:
An Analysis of the 2011
National Health and Aging Trends Study**

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ACRONYMS

The following acronyms are mentioned in this report.

AD8	Alzheimer's Disease 8 Question Interview Tool
ADL	Activity of Daily Living
IADL	Instrument Activity of Daily Living
NHATS	National Health and Aging Trends Study
NSOC	National Survey of Caregiving
WHO	World Health Organization

EXECUTIVE SUMMARY

Studies of the prevalence of Alzheimer's disease and other dementia in the United States estimate that 14% of those over age 70 are affected, and that prevalence increases with age, exceeding one-quarter of persons over age 80. The implications of population aging for increases in older persons with dementia and the impact on families, which will be the mainstays in caregiving, have been recognized worldwide in a 2012 World Health Organization report on Dementia as a Public Health Priority, and in the United States by the National Alzheimer's Project Act of 2012. This report uses the National Health and Aging Trends Study, to describe late-life disability and care needs of older adults with dementia. Using a dementia classification developed previously, we examine patterns for older adults with probable, possible and no dementia in the extent of activity limitations, receipt of assistance, and caregiving resources.

Our results underscore the disabling effects of dementia and its substantial role in late-life disability and caregiving to older people. Among persons not residing in nursing homes, 78% of persons with probable dementia, compared with 42% of those with possible dementia and 18% of those with no dementia, received assistance with self-care or mobility activities or household activities for health or functioning reasons. Among persons 85 or older, 92% of those with probable dementia received assistance with at least one of these activities. Less than half (44%) of persons in this age group with no dementia received such help.

The concentration of assistance among persons with dementia means that those with probable dementia account for almost one out of three older persons not residing in nursing homes who receive help with self-care, mobility or household activities for health reasons. The impact is even more striking among those at more intense levels of assistance--persons with probable dementia account for almost half of the 2.7 million older adults receiving help with three or more self-care or mobility activities.

Among persons not in nursing homes who received assistance, those with probable dementia were more likely to live in supportive care settings (about one in five), and to be low income, non-White, and widowed, than those with no dementia. Nearly all (95%) persons receiving assistance with any activity had unpaid help, regardless of dementia status. One-third of informal caregivers were assisting someone with probable dementia and two-fifths of all hours were to persons with dementia. Persons with probable dementia were more likely to have both paid and unpaid help, and total hours of assistance (from non-staff paid help or unpaid help) were more than double that for persons who received assistance but had no dementia.

High percentages of caregivers reported positive aspects of caregiving regardless of whether the recipient had dementia. Caregivers to persons with probable dementia experienced more negative effects from caregiving, however--18% indicated a

substantial negative impact and another 31% indicated some negative impact compared to 6% and 25% respectively for caregivers to someone without dementia. Caregivers to persons with probable dementia were more likely to use some caregiver support services (respite, training, financial help) but also were more likely to be looking for support services. In general, use of formal support services was low among all caregivers.

INTRODUCTION

Studies of the prevalence of Alzheimer's disease and other dementia in the United States estimate that 14% of those over age 70 are affected, and that prevalence increases with age, exceeding one-quarter of persons over age 80 (Corrada et al. 2010; Hebert et al. 2013; Plassman et al. 2007). Alzheimer's disease accounts for close to three-quarters of persons with dementia (Plassman et al. 2007). Studies from United States and European populations find evidence for declines in the rate of cognitive impairment (Larson et al. 2013), but there is widespread agreement that the overall growth of the older population and increases in persons living into their 80s and 90s will result in more persons with dementia in the near future.

The link between cognitive functioning and disability is well-established (McGuire et al. 2006). Recent research also supports cognitive change as a precursor to physical function declines (Atkinson et al. 2010). Memory, disorientation, and other features of dementia affect a person's ability to perform everyday activities and over time often lead to complete dependence on others. The implications of population aging for increases in older persons with dementia and the impact on families, which will be the mainstays in caregiving, have elevated the need for policy-relevant information worldwide on needs for care and consequences for care providers (WHO 2012).

The purpose of this report is to describe disability and care needs, and some aspects of caregiving, for older people with dementia using 2011 data from the National Health and Aging Trends Study (NHATS) baseline and the National Survey of Caregiving (NSOC). Drawing on disability measures from NHATS (Freedman & Spillman 2013) and a measure developed for NHATS that classifies persons as probable, possible, and no dementia (Kasper et al. 2013a), we examine variation by dementia status for several topics: activity limitations and assistance; demographic characteristics and residence; caregiving resources; and support available to or sought by caregivers to individuals with dementia.

DATA OVERVIEW

NHATS has been designed to capture a detailed picture of how functioning in daily life changes with age (Freedman 2009). Below is a description of the sample and several key measures used in this report. Those taken from Freedman & Spillman (2013) are designated by an asterisk (*).

Sample. The first round of NHATS took place in 2011 with a national sample of older adults drawn from the Medicare enrollment file (Montaquila et al. 2012a). African Americans and respondents at older ages were oversampled. In all, 8245 interviews were completed. Respondents living in the community and residential care settings other than nursing homes received a two-hour in-person interview that included self-reports and performance-based measures of disability. For respondents in residential care settings including nursing homes a facility respondent provided information about services available and the type of place.

This report draws on information from respondents who completed the sample person interview (N=7609) and excludes those living in nursing homes (N=468). A large proportion of nursing home residents are known to have dementia (ranging from one-half to three-quarters; Magaziner et al. 2000; Spillman 2011). Excluding the over 1 million nursing home residents in 2011 biases our estimate of the proportion of persons with probable dementia downward by about 1.5-2 percentage points.

NSOC was conducted with caregivers to NHATS participants. Interviews with caregivers gathered information about the caregiving experience, caregiving support, and demographic, socioeconomic, and family characteristics. NSOC eligibility was a two-stage process. First NHATS respondents were eligible if they reported help with mobility, self-care or household activities for health/functioning reasons, or lived in residential care settings. Second, caregivers were eligible if they were a relative or an unpaid caregiver helping with a broad set of activities that included mobility, self-care, or household activities or other activities such as transportation or medical visits. For more details on the NSOC design see Kasper et al. (2013b) and Spillman et al. (2014).

Key Measures from NHATS for this Report. We constructed several key measures for this report including dementia status, activity limitations, assistance, the potential and actual care network, hours of care, and residence in supportive care places.

Dementia status. Three types of information collected by NHATS were used to create a classification indicating probable dementia, possible dementia, and no dementia: (1) a report that a doctor told the sample person he/she had dementia or Alzheimer's disease; (2) a score indicating probable dementia on a screening

instrument (the AD8; Galvin 2005, 2006) administered to all proxy respondents; and (3) results from cognitive tests that evaluate memory, orientation and executive function.

Details on construction of this classification and results of sensitivity and specificity of the NHATS measure in a sample of persons clinically assessed for dementia are available elsewhere (Kasper et al. 2013a). Using this classification approach, NHATS estimates 14.8% of persons 71 and older have probable dementia (11.2% of persons ages 65 and older). This estimate aligns well with others. The Aging, Memory and Demographic Study, found 13.9% of persons 71 or older had dementia (Plassman et al. 2007). A recent study using the Health and Retirement Survey, gave an estimate of 14.7% for persons 70 and older (Hurd et al. 2013).

This report focuses on the non-nursing home population ages 65 and older, 9.7% of whom have probable dementia.

*Activity limitations.** We constructed a three-category measure reflecting limitations in self-care, mobility, or household-related activities. Self-care activities include bathing, dressing, eating, and toileting. Mobility-related activities include getting out of bed, getting around inside one's home or building, and leaving one's home or building. Taken together, self-care and mobility activities correspond to activities of daily living (ADLs). Household activities are laundry, hot meals, shopping for personal items, paying bills/banking, and handling medications, corresponding to instrumental activities of daily living (IADLs). Three hierarchical categories were created summarizing how activities are carried out: (1) without difficulty and without assistance from another person; (2) with difficulty when carried out alone and with whatever accommodations the individual has made; and (3) with assistance from another person, which for household activities must be for health-related or functioning-related reasons. See Freedman & Spillman (2013) Appendix I for further details.

*Assistance.** Individuals receiving assistance with 3+ self-care or mobility activities are considered separately from those receiving assistance with 1-2 self-care or mobility activities. The third category consists of individuals who receive assistance with household activities for health or functioning reasons but do not receive help with self-care or mobility. Combined, these three groups form the non-nursing home population receiving help with any self-care, mobility or household activities (analogous to any ADL or IADL assistance).

*Actual care network.** Actual networks include persons who helped in the last month with self-care or mobility tasks, household tasks, or selected other tasks (driving, seeing the doctor, less common money matters, and health insurance matters). If the respondent lived in a residential care setting, staff members were not included in counts of network members, but were considered a source of paid help in prevalence estimates. Other non-staff paid and unpaid persons assisting respondents in residential care were counted individually. In this report we focus on actual networks for sample persons who received help in the last month with any self-care or mobility task or any household task for health or functioning reasons.

*Supportive care environments.** NHATS distinguishes among care settings that are nursing homes, supportive care settings other than nursing homes, and all other community settings. Nursing homes and other supportive care places were confirmed through an interview with a facility staff member. Such an interview was triggered by questions in the sample person interview about whether the place where they lived offered group meals, bathing and dressing care, or had different levels of care the sample person could move to if he/she needed care.¹ In cases where an interviewer conducted the facility interview first, the type of setting was first confirmed through the facility interview, and a sample person interview attempted if the respondent was found to be in a residential care setting other than a nursing home. Supportive care included the following place types (as reported by the facility respondent): adult family care homes, group homes, board and care homes, personal care homes, assisted part of a multi-level place, and enriched housing (housing with services).

*Hours of unpaid and paid care.** For older adults living outside the nursing home, NHATS provides estimates of hours of unpaid and paid care in the last month provided by each caregiver, excepting hours provided by staff at residential care settings.

Hours were missing for one or more caregivers for 12% of sample persons receiving help. We imputed missing paid and/or unpaid hours for each caregiver based on the NHATS respondent's age, sex, level of assistance, and, for informal caregivers, the caregiver's relationship to the sample person. We then summed hours across all caregivers for each sample person to create total hours. See Freedman & Spillman (2013) Appendix II for details.

We include all hours provided by an individual identified as a (non-staff) caregiver for the activities identified earlier, including self-care, mobility, household tasks, driving, seeing the doctor, and help with insurance matters and other less common financial tasks. NHATS respondents report only total hours provided by each caregiver identified, so that hours cannot be parsed into those devoted to particular activities.

Key Measures from NSOC Constructed for this Report. Measures from NSOC that were taken from Spillman, Wolff, Freedman and Kasper (2014) are designated by two asterisks (**).

*Types and amount of help.*** Each NSOC respondent reported the total hours of care they provided in the month prior to interview. NSOC respondents also reported whether they helped with activities in five domains of care:

- self-care and mobility activities;
- household activities;

¹ The services trigger was used for people living in multi-unit buildings; people living in other structures (e.g., free standing or attached homes or mobile homes) were instead handed a list of places asked if the place they lived was a private residence or one of the other places on the card (e.g., board and care facility, assisted living facility, continuing care retirement community, or religious group quarters).

- transportation;
- health or medical care activities; and
- interactions relating to the health care system and providers.

*Work and family.*** Each caregiver's age, relationship to the care-recipient, gender, and whether they worked for pay was collected in NSOC. For employed caregivers, hours worked in the last week was obtained. For those who were employed but did not work in the last week, hours were assessed for the most recent week when they did work.

*Positive and negative aspects of caregiving.*** The primary measures used to characterize positive and negative aspects of caregiving draw on four items assessing perceived gains from caregiving and four items assessing perceived negative aspects of caregiving (Pearlin et al. 1990, Lawton et al. 1989). Each item has three response categories: very much, somewhat, or not so much. Both sets of questions were preceded by a neutral introduction in which the interviewer asked the respondent to listen to the statements and "answer whether this describes your situation...". Values were rescaled so that each item was valued from 0 (not so much) to 2 (very much). Factor analysis indicated that the two sets of items represented two factors, one positive with loadings of 0.52 or higher ($\alpha=0.70$) and the other negative with loadings of 0.58 or higher ($\alpha=0.75$). Each set of items was then combined to create positive and negative scales valued 0-8. We also examined three items in which respondents were asked where they experienced financial, emotional, and physical "difficulty," and if so, to rate the level of difficulty of each type on a scale of 1-5. Only 94 (<5%) of the 1996 respondents in the analysis sample was missing any of the 11 items. Missing values were imputed separately for positive, negative, and difficulty items using a vector approach that matched donors and recipients by residential setting, the reported values for the vector of positive (negative, or difficulty) items, relationship to care-recipient, gender, and age. Donors were respondents with the respective vectors fully reported.

Support available to and sought by caregivers. NSOC interviewed persons named as helpers (unpaid or relatives) to NHATS participants receiving assistance with mobility, self-care or household activities for health or functioning reasons. Details on NSOC eligibility, content, and data are available in the NSOC User Guide (2013) at <http://www.nhats.org>. The items used in this report asked caregivers about: having friends or family to help care for the NHATS participant; whether in the last year they went to a support group for people who give care; whether in the last year they used a service that took care of the NHATS participant so the caregiver could take some time away; whether in the last year they received any training to help them take care of the NHATS participant; whether in the last year they found financial help for the sample person including helping apply for Medicaid; and whether in the last year they looked for any of the support services they did not report using.

Weighted Percentages and Population Estimates. For all estimates we use analytic weights that take into account differential probabilities of selection and non-

response (Montaquila et al. 2012). For population estimates, we further adjust totals to the age distribution of the sample frame.

Activity Limitations and Assistance by Dementia Status

Table 1 shows the percentage and number of adults 65 and older living outside of nursing homes with self-care or mobility limitations, with household activity limitations, and with any limitations by dementia status. Overall, we estimate that 9.7% (3.6 million) have probable dementia, 10.8% have possible dementia (4 million), and 79.5% have no dementia (29.4 million).

TABLE 1. Self-Care, Mobility, and Household Activity Limitations by Dementia Status in the Non-Nursing Home Population Ages 65 and Older (%)			
	Probable Dementia	Possible Dementia	No Dementia
Total %	9.7	10.8	79.5
Population estimates (in millions)	3.6	4.0	29.4
Self-care or mobility limitations^{a*}			
No difficulty and no help	25.0	49.9	69.6
Difficulty, but no help	15.7	23.3	18.8
Help	59.3	26.8	11.6
Household activity limitations^{b*}			
No difficulty and no help	18.1	51.6	71.8
Difficulty, but no help	7.4	11.2	13.7
Help for health or functioning reasons	74.5	37.2	14.5
Any limitations*			
No difficulty and no help	12.8	37.9	60.0
Difficulty, but no help	9.1	20.3	21.6
Help	78.1	41.8	18.4
SOURCE: 2011 NHATS; N=7069.			
NOTES:			
a. Bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.			
b. Laundry, hot meals, shopping for personal items, paying bills/banking, or handling medications.			
* Levels of limitations differ by dementia status at p<0.001.			

Activity limitations differed significantly by dementia status. Among persons with probable dementia, 59.3% received help with self-care or mobility, and only 25.0% had no help or difficulty with these activities. By contrast, among those with no dementia 11.6% received help, and 69.6% had no self-care or mobility help or difficulty. Those with possible dementia were more likely to have received self-care or mobility help than those with no dementia (26.8%) but the percentage was well below that for persons with probable dementia.

For household activities, an even higher proportion--about three-quarters--of persons with probable dementia received help. Similarly, persons with possible

dementia were more likely to have received help with household activities than with self-care or mobility (37% vs. 27% respectively). By contrast, the proportion of persons with no dementia who received help with household activities was similar (14.5%) to the proportion receiving help with self-care or mobility tasks.

Taking all limitations into account, there is a strong gradient by dementia status for help, difficulty but no help, and no difficulty or help. Among persons with probable dementia, 78% received help, compared with 42% of those with possible and 18% with no dementia. For those with probable dementia, 87% received help or had difficulty, in contrast to 62% of persons with possible dementia and 40% of those with no dementia.

Types and Levels of Assistance by Dementia Status. Table 2 provides a mutually exclusive hierarchy of assistance levels for the non-nursing home population by dementia status. Over one-third of persons with probable dementia were receiving help with three or more self-care or mobility activities. Another 23% received help with 1-2 of these types of activities, and 19% received no help with self-care or mobility activities but received help with household activities for health or functioning reasons. The percentage of those with possible dementia receiving help with three or more self-care or mobility activities was substantially lower (9%) than for persons with probable dementia although proportions receiving assistance with 1-2 activities, and household activities, were closer to levels for those with probable dementia. Only 3.4% of persons with no dementia received assistance with three or more self-care or mobility activities; another 8% received help with 1-2, and 7% received help with household activities only.

TABLE 2. Types and Levels of Assistance by Dementia Status in the Non-Nursing Home Population Ages 65 and Older						
Assistance Level	Probable Dementia		Possible Dementia		No Dementia	
	%	millions	%	millions	%	millions
3+ self-care or mobility activities ^a	36.3	1.3	8.8	0.4	3.4	1.0
1-2 self-care or mobility activities ^a	23.0	0.8	18.0	0.7	8.1	2.4
Household activities ^b	18.8	0.7	15.0	0.6	6.9	2.0
Any self-care, mobility, or household activity	78.1	2.8	41.8	1.7	18.4	5.4
No assistance^c	21.9	0.8	58.2	2.3	81.6	24.0

SOURCE: 2011 NHATS; N=7069.

NOTES:

- Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.
- Assistance for health or functioning reasons with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications and no assistance with self-care or mobility.
- No assistance with self-care, mobility or household activities for health or functioning reasons.

Among the 2.7 million older people not residing in nursing homes who received assistance with three or more self-care or mobility activities, 1.3 million or close to half were persons with probable dementia. Among all persons receiving help, those with probable dementia accounted for 28% (2.8 million out of 9.9 million) and those with probable or possible dementia comprised 45%. These estimates underscore the significant role dementia plays in who receives assistance with daily activities among older people.

Table 3 shows the mutually exclusive hierarchy of levels of assistance by age group and dementia status for those living in the community and supportive care settings other than nursing homes. As expected, percentages reporting help increased with age regardless of dementia status: for those with probable dementia from 61% in the youngest, to 92% in the oldest age group, and among persons with no dementia from 13% to 44%, respectively. Among those with probable dementia, however, levels of assistance were high at all ages, and from about one-quarter of the youngest age group to almost half of the oldest received assistance with three or more self-care or mobility activities. Among those with no dementia, only 2% of the youngest and 10% of the oldest received this level of assistance.

TABLE 3. Types and Levels of Assistance by Dementia Status and Age in the Non-Nursing Home Population Ages 65 and Older (%)				
	65-74	75-79	80-84	85 or Older
Probable dementia				
3+ self-care or mobility activities ^a	25.8	34.1	30.2	47.3
1-2 self-care or mobility activities ^a	14.9	16.9	26.0	29.0
Household activities ^b	20.5	9.6	22.5	15.2
Any self-care, mobility, or household activity	61.2	70.6	78.7	91.5
No assistance	38.8	29.4	21.3	8.5
Possible dementia				
3+ self-care or mobility activities ^a	6.9	6.5	12.0	10.9
1-2 self-care or mobility activities ^a	13.3	15.4	18.9	27.3
Household activities ^b	12.0	15.5	11.4	22.7
Any self-care, mobility, or household activity	32.2	37.4	42.3	60.9
No assistance	67.8	62.6	57.7	39.1
No dementia				
3+ self-care or mobility activities ^a	2.0	4.6	3.7	10.3
1-2 self-care or mobility activities ^a	6.9	6.5	10.5	16.4
Household activities ^b	4.1	7.5	10.8	17.5
Any self-care, mobility, or household activity	13.0	18.6	25.0	43.8
No assistance	87.0	81.4	75.0	56.2
SOURCE: 2011 NHATS; N=7609.				
NOTES:				
a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.				
b. Assistance for health or functioning reasons with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications and no assistance with self-care or mobility.				

Differences in levels of assistance within age group by dementia status are striking. Among 65-74 year olds with no dementia, only 13% received any assistance, and only 2% were persons receiving the most intense levels of help, whereas 61% of 65-74 year olds with probable dementia received assistance, and 26% were persons who received help with three or more self-care or mobility activities. Among persons 85 or older with probable dementia, 92% received assistance compared with 44% of persons in this age group with no dementia. Persons with possible dementia fall between those with probable dementia and no dementia at each age group in terms of levels of assistance.

Demographic Characteristics. Table 4 shows demographic characteristics by dementia status for all persons living outside of nursing homes and among only those receiving assistance with any self-care, mobility or household activities for health or functioning reasons.

TABLE 4. Demographic Characteristics by Dementia Status Among Persons Receiving Any Assistance in the Non-Nursing Home Population Ages 65 and Older (%)							
	Any Self-Care, Mobility, or Household Activity Assistance^a			Total Non-Nursing Home Population			Total
	Probable	Possible	No Dementia	Probable	Possible	No Dementia	
Gender							
Male	34.4	39.0	28.2	39.5	49.3	43.1	43.4
Female	65.6	61.0	71.8	60.5	50.7	56.9	56.6
Income							
Lowest quartile	46.1	44.9	32.6	44.9	36.2	19.5	23.8
2nd quartile	28.9	27.8	29.0	29.9	25.9	23.3	24.3
3rd quartile	16.6	17.3	22.2	17.0	22.6	28.5	26.7
Highest quartile	8.4	10.1	16.2	8.2	15.3	28.7	25.2
Race/ethnicity							
White	69.8	69.1	79.7	67.6	70.0	83.6	80.5
Black	12.1	11.5	8.5	12.4	10.6	7.2	8.1
Hispanic/other	18.1	19.4	11.8	20.0	19.4	9.2	11.4
Marital status^b							
Married	37.4	39.4	48.3	39.3	48.1	60.4	57.0
Divorced/separated	9.7	10.7	12.0	10.2	12.8	12.4	12.2
Widowed	47.1	46.1	34.9	44.1	35.3	23.8	27.1
SOURCE: 2011 NHATS; N=7609.							
NOTES:							
a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building or, for health or functioning reasons, with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications.							
b. Never married not shown.							

Gender. Women were a similar proportion of persons with probable and no dementia (60% and 57% respectively). Among persons who received assistance, they were a somewhat higher percentage (72%) of those with no dementia compared to those with probable dementia (66%).

Income. Among persons with probable dementia, 45% were in the lowest income quartile and only 8% were in the highest quartile. By contrast among those with no dementia 19% were in the lowest quartile and 29% were in the highest. Among those who received assistance, this pattern held although the differences were somewhat smaller: 46% were in the lowest quartile among those with probable dementia, and 33% were in the lowest quartile among those with no dementia. Overall, among persons receiving assistance, a much higher percentage were in the lowest income quartile (from 33% to 46%) than the highest quartile (from 8% to 16%), regardless of dementia status.

Race/ethnicity. Although the proportion of persons who are White was lower among those with probable dementia (68%) than those with no dementia (84%), the majority of persons with dementia are White. The proportion of Black, Hispanic, and persons of other races was higher among persons with probable dementia and lower

among those with no dementia (e.g., 12% of persons with probable dementia were Black, and 7% of those with no dementia were Black). These patterns by dementia status held among persons who received assistance.

Marital status. Widowed persons were a higher proportion of persons with probable dementia (44%) than of persons with no dementia (24%), likely due in part to the older age of many widowed individuals. Married persons accounted for 39% of those with probable dementia and 60% of those with no dementia. Differences were narrower among persons who received help. Married persons were 37% of persons with probable dementia who received assistance and 48% of persons with no dementia who received assistance.

Demographic Characteristics by Levels of Assistance for Persons with Probable Dementia. Table 5 shows demographic characteristics by levels of assistance among persons with probable dementia. Women, persons in the lowest income quartile, White persons and those who were widowed, were a larger proportion of persons with probable dementia who were receiving help across all levels of assistance. For the most part, these patterns mirror those for persons with possible or no dementia who are receiving help.

TABLE 5. Demographic Characteristics by Levels of Assistance for Persons with Probably Dementia in the Non-Nursing Home Population Ages 65 and Older (%)				
	3+ Self-Care or Mobility Activities^a	1-2 Self-Care or Mobility Activities^a	Household Activities^b	Any Self-Care, Mobility, or Household Activities
Gender				
Male	33.4	31.5	39.7	34.4
Female	66.6	68.5	60.3	65.6
Income				
Lowest quartile	46.1	47.3	44.5	46.1
2nd quartile	31.2	27.9	25.7	28.9
3rd quartile	14.6	19.1	17.5	16.6
Highest quartile	8.0	5.7	12.3	8.4
Race/ethnicity				
White	69.9	67.7	72.2	69.8
Black	13.1	13.9	7.8	12.1
Hispanic/other	16.9	18.4	20.0	18.1
Marital Status^c				
Married	37.2	35.5	40.1	37.4
Divorced/separated	7.9	10.2	12.5	9.7
Widowed	48.8	48.3	42.4	47.1
SOURCE: 2011 NHATS; N=838.				
NOTES:				
a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.				
b. Assistance for health or functioning reasons with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care, mobility, or household activities).				
c. Never married not shown.				

Care Resources and Caregiving by Dementia Status

The next tables provide information about care resources and caregiving to older people who received assistance with self-care, mobility or household activities for health or functioning reasons. Persons in nursing homes are excluded. Additional information on caregiving is available in Spillman et al. (2014).

Residence Type by Level of Assistance and Dementia Status. Supportive care settings that provide assistance with routine activities and/or meals are one option for providing needed assistance to persons with disabilities. Among persons with probable dementia not in nursing homes, 16% were living in a supportive care setting and 84% were in the community (Table 6). By contrast, about 8% of persons with possible dementia, and 4% of those with no dementia, were in supportive care settings.

TABLE 6. Residence Type by Dementia Status Among Persons Receiving Assistance in the Non-Nursing Home Population Ages 65 and Older (%)			
	Any Self-Care, Mobility, or Household Activity Assistance^{a,b}	3+ Self-Care or Mobility Limitations	Total Non-Nursing Home Population
Probable dementia			
Community residence	80.3	79.4	84.0
Supportive care residence	19.7	20.6	16.0
Possible dementia			
Community residence	81.3	89.9	91.5
Supportive care residence	18.7	10.1	8.5
No dementia			
Community residence	86.5	86.1	96.2
Supportive care residence	13.5	13.9	3.8
SOURCE: 2011 NHATS; N=7609.			
NOTES:			
a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.			
b. Assistance for health or functioning reasons with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care, mobility, or household activities).			

Among persons with probable dementia, about one-fifth of those who received any assistance (self-care, mobility or household activity) or assistance at more intensive levels (self-care or mobility), were in supportive care environments. The percentage of persons with no dementia who lived in supportive care settings increased from 4% among those who received no assistance with self-care, mobility or household activities to 13%, among persons receiving any help or help at more intensive levels. Despite their higher representation in supportive care settings, four out of five persons with probable dementia in the non-nursing home population who received assistance lived in community settings.

Number of Informal Caregivers and Hours of Help. As shown earlier, persons with probable dementia represent nearly half of those receiving assistance with 3+ self-care or mobility activities, and close to one in three persons receiving any assistance

with self-care, mobility or household activities. Table 7 shows that one-third of informal caregivers to older people are assisting someone with probable dementia (not in a nursing home) and about half of informal caregivers are assisting someone with probable or possible dementia. Two-fifths (40.0%) of all informal caregiving hours are to persons with probable dementia.

TABLE 7. Number of Informal Caregivers and Hours of Help Provided in the Last Month by Dementia Status in the Non-Nursing Home Population Ages 65 and Older

	Number of Caregivers (000s)	Percent of Caregivers	Mean Hours of Care Provided	Aggregate Monthly Hours Provided (000s)	Percent of Aggregate Hours of Help
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
SOURCES: NHATS and NSOC; N=1996.					

Care Network Size. Table 8 shows mean caregiver network size and the proportion of persons with 1-3 or more caregivers by dementia status and level of assistance. Among persons who received assistance with any activity, mean network size was slightly larger for persons with probable dementia (2.4) than for others (2.1). Regardless of dementia status, mean care networks were larger for persons who received help with three or more self-care or mobility activities than for those receiving assistance with household activities only.

The distribution of number of caregivers varies by both dementia status and level of assistance. About three-quarters of persons who received help with three or more self-care or mobility activities had more than one caregiver regardless of dementia status. There were differences by dementia status for other levels of assistance, however. For persons who received help with 1-2 self-care or mobility activities, 70% of persons with probable dementia compared to 61% of those with no dementia had more than one caregiver. For household help only, the differences were similar: 67% of persons with probable dementia had more than one caregiver, compared to 58% among those with no dementia.

The proportion relying on one caregiver was roughly similar among those who had help with three or more self-care or mobility activities regardless of dementia status. However, reliance on one caregiver was less common for persons with probable dementia at other levels of assistance: for help with 1-2 self-care activities, 30% for those with probable and 39% for those with no dementia; for help with household activities only, 33% for those with probable and 42% for those with no dementia.

Help from three or more caregivers was more common among persons who received help with three or more self-care or mobility activities, and was similar for recipients with probable and no dementia.

TABLE 8. Actual Informal Care Network Size by Level of Assistance and Dementia Status of Care Recipients in the Non-Nursing Home Population Ages 65 and Older				
	3+ Self-Care or Mobility Activities^a	1-2 Self-Care or Mobility Activities^a	Household Activities^b	Any Self-Care, Mobility, or Household Activities
Probable dementia				
Network Size (mean) ^c	2.7	2.3	2.0	2.4
% with:				
1 Caregiver	23.2	30.1	33.3	27.6
2 Caregivers	30.5	33.0	40.7	33.7
3+ Caregivers	46.3	36.9	26.0	38.7
Possible dementia				
Network Size (mean)	2.6	2.1	1.8	2.1
% with:				
1 Caregiver	23.7	35.3	43.4	35.7
2 Caregivers	38.0	26.8	40.1	33.8
3+ Caregivers	38.3	37.9	16.5	30.5
No dementia				
Network Size (mean)	2.6	2.1	1.9	2.1
% with:				
1 Caregiver	26.7	39.0	42.5	37.9
2 Caregivers	28.1	31.2	35.4	32.2
3+ Caregivers	45.2	29.8	22.1	29.9
SOURCE: 2011 NHATS; n=2457.				
NOTES:				
a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.				
b. Assistance related to health or functioning with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care or mobility activities).				
c. Network size and distribution by number of caregivers excludes a small number of persons reporting 0 caregivers (N=42). These are primarily persons in residential care who received assistance from staff members only. Staff in residential care are excluded from counts of caregivers.				

Paid and Unpaid Help and Hours of Help. As expected, about 95% of persons who received any assistance with self-care, mobility or household activities had unpaid help and these high levels were observed at all levels of assistance and regardless of dementia status (Table 9). In contrast, there was variation across groups with regard to paid help, which includes help from staff for those in non-nursing home supportive care settings: 42% among those with probable dementia had paid help in comparison to 34% among those with possible and 30% among those with no dementia.

Most people who received any assistance had unpaid help only, from 58% for those with probable dementia to 69% of those with no dementia. Receiving only paid help was rare--about 5% among those who received any help--and did not differ by dementia status. Persons with probable dementia were more likely than others, however, to have both paid and unpaid help (37% vs. 29% of those with possible dementia and 25% of those with no dementia).

Among those who received any help, mean hours of assistance provided in the last month were substantially higher for persons with probable dementia compared to others for paid, unpaid, and total hours. Paid hours does not include hours of help from

staff for those in non-nursing home supportive care settings. Overall mean hours of help in the last month with any activity were 267 hours for those with probable dementia, 152 hours for those with possible dementia and 123 hours for those with no dementia.

TABLE 9. Paid and Unpaid Help in the Last Month and Mean Hours of Help by Dementia Status of Care Recipients in the Non-Nursing Home Population Ages 65 and Older (%)				
	Probable	Possible	No Dementia	Total
Any Paid Help ^a	42.3	33.6	30.5	34.5
Any Unpaid Help	94.9	95.8	95.0	95.0
Paid Help Only ^a	5.1	4.3	5.1	5.0
Unpaid Help Only	57.7	66.4	69.5	65.5
Botha	37.2	29.3	25.4	29.5
Paid Non-Staff Hours (mean) ^b	46.0	16.9	17.9	25.9
Unpaid Hours (mean)	220.8	135.4	105.0	143.8
Total Hours (mean) ^b	266.8	152.3	123.0	169.7
SOURCE: 2011 NHATS; N=2499.				
NOTES:				
a. Help from staff for those in non-nursing home supportive care settings is included as paid help.				
b. Hours of help does not include staff in non-nursing home supportive care settings.				

Mean unpaid hours of help to persons with probable dementia were double (221) those to persons with no dementia (105).

Characteristics of Informal Caregivers and Hours of Help. The distribution of caregivers by relationship to the recipient differs by dementia status (Table 10). Spouses and daughters each are about one-quarter of caregivers to persons with no dementia. Daughters, as a proportion of caregivers, increase to 29% for recipients with possible dementia and 35% of caregivers to recipients with probable dementia. Spouses on the other hand decrease to 15% of caregivers to recipients with possible or probable dementia. Otherwise, caregiver differences are relatively small with regard to age, gender, and employment of caregivers by dementia status of the care-recipient. Women are 60% of caregivers to persons with no dementia and 64% of caregivers to persons with probable dementia, for example. The proportion of caregivers who work for pay is 43% if care-recipients have no dementia and 45% if care-recipients have probable dementia.

Mean hours per month of care are substantially different depending on the dementia status of the care-recipient. Mean hours provided by informal caregivers to persons with no dementia were 65 hours per month, compared to 92 hours for persons with probable dementia, a 41% increase. Hours provided by spouse caregivers averaged 90 per month for care-recipients with no dementia and 145 hours per month for care-recipients with probable dementia, a 60% increase. Average hours provided by daughters was 60 per month if the recipient had no dementia and 102 hours for recipients with probable dementia, a 70% increase.

TABLE 10. Characteristics of Informal Caregivers and Mean Hours of Care Provided in the Last Month by Dementia Status of Care Recipients in the Non-Nursing Home Population Ages 65 and Older

	No Dementia			Possible Dementia			Probable Dementia		
	Number (000s)	Percent	Mean Hours of Help	Number (000s)	Percent	Mean Hours of Help	Number (000s)	Percent	Mean Hours of Help
All Caregivers	9369	100.0%	65	2741	100.0%	72	5838	100.0%	92
Relationship to recipient									
Spouse	2479	26.5	90	424	15.5	150	899	15.4	145
Daughter	2415	25.8	60	807	29.4	72	2041	35.0	102
Son	1604	17.1	51	535	19.5	76	1149	19.7	80
Other	2871	30.6	56	976	35.6	35	1750	30.0	61
Caregiver age									
<45	1608	17.4	95	468	17.4	54	872	15.5	82
45-54	2131	23.0	53	701	26.0	74	1358	24.2	97
55-64	2172	23.4	51	786	29.2	69	1803	32.1	85
65-74	2016	21.8	58	414	15.4	67	862	15.4	93
75+	1337	14.4	81	324	12.0	106	713	12.7	124
Caregiver gender									
Male	3749	40.0	53	1023	37.3	67	2082	35.7	86
Female	5621	60.0	73	1718	62.7	75	3757	64.3	95
Caregiver works for pay									
No	5312	57.4	78	1444	53.3	99	3151	54.5	115
Yes	3944	42.6	48	1265	46.7	42	2628	45.5	65
SOURCES: 2011 NHATS and NSOC; N=1966.									

These large increases in hours of care provided to recipients with dementia are further indication of the challenges of caring for older individuals with dementia and where the burden falls. Spouse caregivers of persons with dementia provided the highest mean hours of help, 145 on average per month. Daughters, however, provided the largest share--over a third of hours--among caregivers to persons with dementia.

Types of Assistance Provided by Informal Caregivers. Informal caregivers assist with a broad range of activities, grouped here into five areas: self-care or mobility, household activities, transportation, health system interactions, and health or medical care.

Mobility assistance is provided by 78% of caregivers to persons with probable dementia versus 67% of those with no dementia. Differences are greater for self-care, where 63% of helpers to persons with probable dementia provide this type of help in contrast to 40% of helpers to those with no dementia. Help with household activities for health or functioning reasons is almost universal--96% of caregivers provide this type of assistance regardless of the dementia status of the recipient. The largest difference in types of household help provided is for keeping track of medicines, where 63% of helpers to an older person with dementia assist, compared with 38% of helpers to someone with no dementia.

TABLE 11. Types of Help Provided by Informal Caregivers in the Last Month by Dementia Status of Care Recipients in the Non-Nursing Home Population Ages 65 and Older						
	No Dementia		Possible Dementia		Probably Dementia	
	Number (000s)	Percent	Number (000s)	Percent	Number (000s)	Percent
Self-care or mobility	6626	70.7	2227	81.2	4931	84.5
Mobility	6272	67.1	2000	73.0	4554	78.1
Self-care	3706	39.7	1403	51.2	3697	63.4
Household activities	9040	96.5	2640	96.3	5640	96.6
Shopping	8513	90.9	2388	88.4	5122	87.9
Laundry, housework, meals	7315	78.1	2175	79.7	4722	80.9
Help with bills, managing money	5132	54.8	1607	58.6	3731	63.9
Keep track of medicines	3583	38.3	1451	52.9	3692	63.2
Transportation	8294	88.5	2397	87.4	4812	82.4
Health system interactions	6723	71.8	2122	77.4	5003	85.7
Make appointments ^a	4793	51.2	1701	62.1	4366	74.8
Speak to doctor ^a	4378	46.8	1473	53.7	4008	68.6
Order medicine	3835	41.0	1483	54.1	3335	57.1
Other insurance issues ^a	2138	22.8	631	23.0	1754	30.1
Add or change insurance ^a	2755	29.5	814	29.7	2464	42.3
Health/medical care	4878	52.1	1715	62.6	3650	62.5
Diet	2500	26.7	764	27.9	1651	28.3
Foot care	2104	22.5	954	34.9	1799	30.8
Skin care	2018	21.5	630	23.2	1510	25.9
Exercises	1619	17.3	649	23.7	1540	26.4
Dental care	771	8.2	431	15.7	1473	25.2
Manage medical tasks	817	8.7	226	8.2	856	14.7
Shots or injections	630	6.7	233	8.5	528	9.0

SOURCES: 2011 NHATS and NSOC; N=1996.
NOTE:
a. The reference period is "in the last year" for these activities, which may be performed less frequently.

Four out of five caregivers provide assistance with transportation, ranging from 88% for those who help someone with no dementia, to 82% of those who are helping someone with probable dementia.

TABLE 12. Gains from and Negative Aspects of Caregiving Reported by Informal Caregivers by Dementia Status of Care Recipient in the Non-Nursing Home Population Ages 65 and Older (%)			
	Little or None	Some	Substantial
No Dementia			
Gains from caregiving ^a	5.7	27.3	67.0
More confident about your abilities	20.1	33.9	46.0
Taught you to deal with difficult situations	14.4	35.6	50.0
Brought you closer to care-recipient	9.4	20.0	70.6
Gives you satisfaction that recipient is well cared for	1.3	12.2	86.5
Negative aspects of caregiving ^a	68.7	25.0	6.3
Exhausted when you go to bed at night	62.2	24.2	13.6
Have more things to do than you can handle	60.8	26.1	13.2
Don't have time for yourself	65.3	24.7	10.0
When you get a routine going, recipient's needs change	72.9	19.5	7.5
Difficulties with caregiving ^b			
Financial	85.2	9.7	5.1
Emotional	67.5	22.5	10.0
Physical	84.6	10.4	5.0
Possible Dementia			
Gains from caregiving ^a	5.7	26.9	67.4
More confident about your abilities	17.0	36.9	46.1
Taught you to deal with difficult situations	17.4	32.9	49.7
Brought you closer to care-recipient	10.8	21.7	67.4
Gives you satisfaction that recipient is well cared for	2.1	10.8	87.1
Negative aspects of caregiving ^a	65.1	28.4	6.5
Exhausted when you go to bed at night	58.3	28.3	13.4
Have more things to do than you can handle	61.4	25.9	12.7
Don't have time for yourself	61.2	24.7	14.1
When you get a routine going, recipient's needs change	76.2	16.5	7.4
Difficulties with caregiving ^b			
Financial	87.7	7.5	4.9
Emotional	64.7	24.0	11.4
Physical	88.2	8.1	3.7
Probable Dementia			
Gains from caregiving ^a	7.0	24.7	68.4
More confident about your abilities	20.3	35.4	44.3
Taught you to deal with difficult situations	12.2	31.4	56.5
Brought you closer to care-recipient	11.0	22.9	66.1
Gives you satisfaction that recipient is well cared for	0.6	13.7	85.7
Negative aspects of caregiving ^a	51.4	30.8	17.8
Exhausted when you go to bed at night	49.3	29.9	20.8
Have more things to do than you can handle	48.1	26.8	25.1
Don't have time for yourself	46.3	30.0	23.7
When you get a routine going, recipient's needs change	62.3	23.6	14.1
Difficulties with caregiving ^b			
Financial	74.0	16.0	10.0
Emotional	54.2	25.6	20.2
Physical	74.8	15.6	9.6
SOURCES: 2011 NHATS and NSOC; N=1966.			
NOTES:			
a. Based on a scale from 0-8 summing individual items for gains or negative aspects after recoding each item to 0-2. Categories for scales are 0-2: little or none; 3-5: some; 6-8: substantial.			
b. For difficulty items, respondents are asked whether they have any difficulty. If yes, scores from 1 (a little difficulty) to 5 (a lot of difficulty) are obtained. Categories are 0: none; 1-2: some, and 3-5: substantial.			

Involvement by caregivers to older persons in health system interactions is also common. However, a higher percentage of helpers are involved for care-recipients with probable dementia compared to those with no dementia, respectively: 69% versus 47% speak to the doctor for the person, 57% versus 41% order medicine, and 42% versus 29% help add or change insurance.

Over half of informal caregivers help with various health and medical tasks. Differences by dementia status of the care-recipient are greatest for dental care, where 25% of helpers to persons with probable dementia assist versus 8% of helpers to persons with no dementia, followed by exercises and foot care.

Positive and Negative Aspects of Caregiving. Caregivers were asked about both positive and negative aspects of caregiving. In addition, they were asked about financial, emotional, and physical difficulties with caregiving. Table 12 shows results by dementia status for individual positive and negative items, as well as summary scales that characterize gains from caregiving (summing all positive items) and negative aspects of caregiving (summing all negative items).

Among the positive items, there was no difference by dementia status. High percentages (86%) of caregivers felt substantial satisfaction that the recipient was well cared for as a result of providing care. Half or more of caregivers indicated substantial agreement that caregiving taught them to deal with difficult situations and brought them closer to the care-recipient. Overall, the summary measure shows that two-thirds of caregivers--whether caring for someone with dementia or someone without--felt gains from caregiving were substantial.

In general, across the negative items, the percentages of caregivers who indicated a substantial impact were low. However there were differences between caregivers to someone with dementia, who were more likely to report substantial negative effects from caregiving, and caregivers to someone with no dementia. From 20% to 25% of caregivers to persons with dementia said that being exhausted when they went to bed at night, having more things to do than they can handle, and not having time for themselves, were substantial issues. By comparison, percentages for caregivers to someone with no dementia ranged from 10% to 14% on these items. Overall, the summary measure shows that 18% of caregivers to an older person with dementia indicated a substantial negative impact of caregiving and another 31% indicated some negative impact, in contrast to 6% (substantial) and 25% (some) of caregivers to a recipient with no dementia.

A higher percentage of caregivers indicated some or substantial emotional difficulties, compared with financial or physical difficulties, associated with caregiving. Among caregivers to someone with probable dementia, 20% indicated substantial emotional difficulties and another 26% indicated some emotional difficulties. About 10% indicated substantial financial or physical difficulties (16% indicated some). Among caregivers to a recipient with no dementia, 10% had substantial emotional difficulties

and 22% had some. Only 5% of caregivers to someone with no dementia indicated substantial financial or physical difficulties.

Table 13 focuses on reports of little/no gains from caregiving and substantial negative aspects. Differences in finding little or no gains from caregiving do not differ by dementia status of the care-recipient, consistent with the more detailed information in Table 12, which suggests no differences across the items on gains from caregiving by dementia status. Differences in experiencing substantial negative gains were significant across dementia status however, with caregivers to persons with probable dementia being more likely to indicate substantial negative effects of caregiving.

TABLE 13. Little or No Gains and Substantial Negative Aspects of Caregiving Reported by Informal Caregivers by Dementia Status of Care Recipient in the Non-Nursing Home Population Ages 65 and Older				
	All Caregivers		Self-Care or Mobility Caregivers	
	Little or No Gains	Substantial Negative Aspects	Little or No Gains	Substantial Negative Aspects
Care-recipient dementia status				
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**
SOURCES: 2011 NHATS and NSOC; N=1966.				
**(*) 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.				

Support Services Received or Sought by Informal Caregivers. Table 14 shows sources of support used and sought by caregivers to older adults by dementia status of the care-recipient. Over half of informal caregivers indicated friends or family were available to help care for the older adult, regardless of dementia status. While participation in support groups was low across the board, persons caring for someone with probable dementia were more likely to have used services so they could take time away, to have received training to help care for the recipient, and to have found financial help for the recipient. Caregivers to someone with probable dementia also were more likely to have sought these types of support--respite services, training, financial help for the recipient--although support-seeking was low among all caregivers ranging from a high of 12% (caregivers to those with probable dementia) to a low of 6% (caregivers to those with no dementia).

TABLE 14. Whether Informal Caregivers^a Received or Sought Help by Dementia Status of Care Recipient in the Non-Nursing Home Population Ages 65 and Older (%)			
	Care Recipient Status		
	Probable Dementia	Possible Dementia	No Dementia
Total caregivers (%)	32.6	15.3	52.2
Estimate (in millions)	5.8	2.7	9.4
Friends or family to help care for person	56.3	58.2	58.0
Goes to support group for people who give care	6.0	2.1	3.7
Used services so could take time away**	21.2	11.8	7.9
Received training to help care for person*	8.9	5.9	4.6
Found financial help for person*	18.2	9.0	12.9
Looked for one or more types of support**	12.2	7.3	5.9

SOURCE: 2011 NSOC; N=1966.

NOTE:

a. Caregivers who provided help to NHATS participants with self-care, mobility or household activity limitations (for health or functioning reasons); excludes paid non-relatives.

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

SUMMARY AND IMPLICATIONS

This report uses NHATS to describe the relationship between dementia status and late-life disability and care needs of older adults. We group older adults as probable, possible or no dementia based on a dementia classification developed earlier (Kasper et al. 2013). As a progressive disabling condition that increases in prevalence with age, dementia is a concern for its effects on functioning and quality of life of older people as well as on family and friends who become sources of support as capabilities to live independently decline.

Our results underscore the substantial role of dementia in late-life disability and in caregiving to older people. Most persons with probable dementia not in nursing homes received assistance from others with self-care, mobility, or with household activities for health or functioning reasons (78%). The proportion receiving help is far higher than for persons with possible dementia (42%) or those with no dementia (18%).

The concentration of assistance among persons with dementia means that those with probable dementia account for close to one in three (28%) of the 9.9 million people not in nursing homes who received help with these activities (persons with probable or possible dementia account for 45%). The impact is even more striking for those at more intense levels of assistance--persons with probable dementia account for nearly half of the 2.7 million older adults receiving help with three or more self-care or mobility activities. Three-quarters of persons with probable dementia also receive assistance with household activities. These activities require higher level cognitive functioning, and these results are consistent with numerous studies that have found a relationship between diminished cognition and difficulty or need for assistance with activities such as meal preparation, shopping, and banking (Farias et al. 2009; Peres et al. 2006; Purser et al. 2005).

Although dementia is highly prevalent among nursing home residents--estimates range from 50% to 75%--little information has been available concerning residence in other supportive living environments by dementia status. Our findings show that living in non-nursing home supportive care settings is more common among those with probable dementia--about one in five did so among those not in nursing homes. While the majority of persons with dementia were cared for in community settings, these results suggest the importance of recognizing supportive care settings other than nursing homes as environments where many residents have dementia-related disability and care needs.

Prevalence of dementia varies by characteristics such as income (higher in the lowest income quartile), race/ethnicity (lower among White individuals although Whites account for over two-thirds of all non-nursing home persons with probable or possible dementia), and marital status (higher among widowed persons who together with

married persons account for three-quarters of persons with probable or possible dementia). Perhaps most striking, although not surprising, is the high proportion of low income persons among those who received assistance with any activity, but even here 46% of those with probable dementia are in the lowest income quartile, compared with 33% of persons with no dementia.

While it is generally accepted that dementia caregiving is particularly burdensome (Shultz & Martire 2004), our findings reveal differences in caregiving networks and levels of support at the national level by dementia status. About three-quarters of persons receiving the highest levels of assistance had more than one caregiver regardless of dementia status (73%-77%), but persons with probable dementia more often had more than one caregiver at other levels of assistance. Almost all (95%) persons receiving assistance had unpaid help. One-third of informal caregivers are assisting someone with probable dementia and two-fifths of all hours were to persons with dementia. In addition, one-third of caregivers to persons with probable dementia were daughters. While only 15% of caregivers to persons with probable dementia were spouse caregivers, they provided on average 145 hours of help. High percentages of caregivers reported positive aspects of caregiving regardless of whether the recipient had dementia. Caregivers to persons with probable dementia experienced more negative effects from caregiving, however--18% indicated a substantial negative impact and another 31% indicated some negative impact compared to 6% and 25% respectively for caregivers to someone without dementia.

Persons with probable dementia were more likely to have paid help in addition to unpaid help for self-care or mobility assistance in particular. Total hours of assistance with any activity in the last month to persons with probable dementia was more than double that for persons who received assistance but had no dementia. Hours of both paid and unpaid assistance were substantially higher for persons with probable dementia compared to others, but despite the additional paid help, the proportion of all hours from unpaid helpers was similar for persons with probable (83%) and no dementia (85%). Caregivers to persons with probable dementia were more likely than other caregivers to use some caregiver support services (respite, training, financial help) but also were more likely to be looking for support services. In general, use of formal support services was low among all caregivers.

There are several limitations to this analysis. Our dementia classification cannot be equated with a clinical diagnosis. Nonetheless, our estimates of dementia are in line with others from large population-based studies and our classification measure showed good sensitivity and specificity in a diagnosed sample (Kasper et al. 2013). We were unable to include nursing home residents in this analysis since these individuals were not interviewed in the first round of NHATS and, as a result, we cannot assign dementia status. Nursing home residents are a small percentage of the 65+ population (2.9%; Freedman & Spillman 2013), but from 50% to 75% of older persons living in nursing homes are thought to have dementia. Excluding these individuals likely understates by a small amount the role of dementia in receipt of help with self-care and other activities of daily life. Because NHATS included older adults in all other supportive care settings,

however, this important and growing group is included in our analyses of disability and caregiving. Our findings suggest many differences in late-life disability and caregiving by dementia status. While dementia is likely a major contributor, other comorbid conditions may also be important in explaining differences between those with persons with and without dementia. Finally, these analyses are cross-sectional and further research is needed to clarify how disability and caregiving change with dementia status transitions.

In conclusion, this report provides a national picture of the role of dementia in late-life disability and care for older adults. Disability in a range of activities that are part and parcel of independent living among persons with dementia in turn translates to substantial caregiving support that is being provided by family and friends, as illustrated by the findings on hours of assistance provided by unpaid helpers to those with probable dementia. The National Alzheimer's Project Act of 2012 represents a new national plan to address the challenges of dementia on many fronts. The data in this report provide new and important information documenting the impact of this disease on older people and their families and the basis for further investigation into how policies and programs can meet the needs of the millions of Americans affected by dementia.

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