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Original Investigation

Disability and Care Needs Among Older Americans

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Policy Points:

- Nearly half of elderly Medicare beneficiaries have difficulty performing daily activities without assistance or receive help with such activities. This help is most often from informal caregivers.
- Substantial numbers of older adults living at home or in supportive settings other than nursing homes experience adverse consequences related to unmet need.
- With continuing care shifts away from nursing homes, strategies are needed to improve community-based long-term care services and supports to aid both older adults and the informal caregivers who provide most care.

Context: The cost of late-life dependency is projected to grow rapidly as the number of older adults in the United States increases in the coming decades. To provide a context for framing relevant policy discussions, we investigated activity limitations and assistance, care resources, and unmet need for a national sample of older adults.

Methods: We analyzed the 2011 National Health and Aging Trends Study, a new national panel study of more than 8,000 Medicare enrollees.

Findings: Nearly one-half of older adults, or 18 million people, had difficulty or received help in the last month with daily activities. Altogether, 1 in 4 older adults receiving help lived in either a supportive care (15%) or a nursing home (10%) setting. Nearly 3 million received assistance with 3 or more self-care or mobility activities in settings other than nursing homes, and a disproportionate share of persons at this level had low incomes. Nearly all older adults in settings other than nursing homes had at least 1 potential informal care network member (family or household member or close friend), and the average number of network members was 4. Levels of informal assistance, primarily from family

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caregivers, were substantial for older adults receiving help in the community (164 hours/month) and living in supportive care settings (50 hours/month). Nearly all of those getting help received informal care, and about 3 in 10 received paid care. Of those who had difficulty or received help in settings other than nursing homes, 32% had an adverse consequence in the last month related to an unmet need; for community residents with a paid caregiver, the figure was nearly 60%.

Conclusions: The older population—especially those with few economic resources—has substantial late-life care needs. Policies to improve long-term services and supports and reduce unmet need could benefit both older adults and those who care for them.

Keywords: disability, long-term care, aging.

By 2030 the number of Americans aged 65 or older will exceed 70 million, or 20% of the population,[1] and the vast majority of these individuals will be living with multiple chronic conditions.[2] The economic costs of dependency and underlying medical conditions at older ages are large and projected to grow rapidly as the number of older adults in the United States continues to increase in the coming decades.[3] Reduced well-being for individuals facing loss of functioning and concern for families, who provide the bulk of uncompensated care, also are important societal issues.[4-6]

A number of ongoing national trends make improving understanding of late-life disability and care arrangements especially valuable. First, in recent decades, trends in late-life disability have been dynamic. During the 1980s and 1990s, the percentage of older adults with activity limitations fell,[7,8] but more recent studies suggest that this trend has leveled off and may reverse in the coming years as the baby boom generation enters its peak retirement years.[9-11] Some researchers point to increases in obesity and a slowdown in gains from education as reasons to be pessimistic about a continued downward trajectory.[12,13] At the same time, the use of assistive devices in later life has risen, potentially extending independent functioning and reducing the need for assistance for some older adults.[14-17]

A second set of trends relates to the families of older adults. Although the family continues to be the major provider of care for older adults, the number of potential family caregivers has been declining. In addition, societal trends toward delayed childbearing and women's greater participation in the labor force have placed competing demands

on potential family caregivers' time. One study found that both increasing demands on family caregivers and increasing needs of those receiving care contributed to a growing reliance on paid caregivers between 1984 and 1994.[4] A later analysis found, however, that the use of paid care fell dramatically between 1994 and 1999, after the transition to prospective payment for Medicare home health, whereas family caregiving remained stable.[5] As a result, the proportion of older adults relying only on informal caregivers rose. Certainly, the state of current and potential caregiving, including the distribution of paid and informal caregiving arrangements and the ways in which families respond to declining health and functioning, is important to track as the baby boom generation enters late life.

A third important development is the shift in the types of places in which older adults are receiving care. Many states are trying to redistribute Medicaid-based care away from nursing homes and toward community-based settings, and the number of people living in residential care settings other than nursing homes is growing. The 2010 National Survey of Residential Care Facilities (NSRCF), a provider-based survey of state-regulated residential care facilities with 4 or more beds, reported that there were nearly 1 million beds in the United States serving about 650,000 residents aged 65 or older.[18,19] This number excludes older adults who receive care in unregulated residential settings. We know relatively little about the service package available to and used by older adults in either regulated or unregulated settings or the extent to which their informal and formal caregivers provide supplemental assistance.

Finally, although concerns about meeting the needs of older adults with limitations are not new, they have intensified as care settings diversify and uncertainty continues about the availability of family caregivers. Today, about 1 in 5 older people with limitations in activities of daily living report needing more help than is received.[20,21] Among the adverse consequences of reported unmet need are falls, burns, inadequate nutrition, incontinence, missed physician's appointments, depression, hospitalization, and emergency room visits.[22-24] Uncertainty about future disability trends and care availability makes tracking how well older adults' care needs are being met even more essential.

In 2011, the National Health and Aging Trends Study (NHATS), supported by the National Institute on Aging as the successor to the 1982-2004 National Long Term Care Survey, began collecting data to improve understanding of late-life disability and its consequences. NHATS

includes older persons in all settings—in the community, residential care, and nursing homes—and obtains detailed information about their disability, long-term care use, and unmet need. Annual interviews with updated content areas and reengineered measures of functioning allow the NHATS to capture a more complete picture of late-life disability and care in cross section and over time.

Using data from the first round (2011) of NHATS, we analyzed the current context and implications of disability for older Americans. In this paper, we first present estimates of the number of older adults with activity limitations using measures that recognize behavioral adaptations to functional loss. We then focus on older adults receiving assistance, examining the distribution of the population by level of assistance and the demographic profile of those receiving assistance. Next we describe the size and composition of the potential and actual care networks of older adults and hours of care received by level of assistance. We also present estimates of the availability and use of various services for older adults living in residential care settings, including nonstaff paid and unpaid help. Finally, we provide estimates of unmet need, overall and by level of assistance, by composition of the care network, and by residential setting.

Data and Methods

Data

NHATS was designed to capture a detailed picture of how functioning in daily life changes with age.[25] The validated disability protocol explores whether and how activities were performed in the month before the interview, gathering information about the types of help received for personal activities and mobility, household activities, and other common activities, such as driving places and going to medical appointments.[26] NHATS also collects detailed data on the service environments in which older adults live and measures adverse consequences related to unmet need.

Sample

The first round of NHATS took place in 2011 with a national sample of older adults drawn from the Medicare enrollment file.[27] African

Americans and older respondents were oversampled. In all, 8,245 interviews were completed. Respondents (or proxies) living in the community and in residential care settings other than nursing homes participated in a 2-hour in-person interview that included self-reports and performance-based measures of disability. For those living in nursing homes and other residential care settings, an interview was conducted with a member of the facility staff to learn about the respondent's service environment. Our estimates of the prevalence of disability and characteristics of the population with and without disability were based on the 8,077 participants who either completed an in-person interview ($n = 7{,}609$, including 583 completed with a proxy respondent) or lived in a nursing home ($n = 468$). Our analyses of care arrangements and unmet need exclude nursing home residents because they were not eligible for an in-person interview.

Measures

We constructed several summary measures reflecting activity limitations, level of assistance, the potential and actual care network, residential setting and services, hours of care, and adverse consequences related to unmet needs.

Activity Limitations. NHATS included the following self-care and mobility-related activities: bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, and leaving one's home or building. Together, these self-care and mobility activities correspond to activities of daily living. For each activity, respondents were asked if and how often in the last month they used specific assistive devices for the task, how often they received help with the task, how difficult the task was for them to carry out by themselves (with any devices they previously had reported using), and whether they carried out the activity more often, less often, or about the same as a year ago.

NHATS also measured limitations in selected household activities, specifically doing laundry, preparing hot meals, shopping for personal items, paying bills/banking, and handling medications, which are common instrumental activities of daily living. For each of these activities, respondents were asked whether in the last month someone else carried out the activity with them or for them for health or functioning-related reasons, whether they ever performed the activity by themselves, and,

if so, whether they had difficulty doing so. They also were asked about frequency of carrying out the activities compared with a year ago.

From this information, we constructed a 4-category, hierarchical measure of limitations in self-care, mobility, or household-related activities: (1) has no limitation in the ability to carry out activities (that is, performs without devices, without reduced frequency, without difficulty, and without help); (2) accommodates ability limitations by using devices (for self-care and mobility activities) or by performing the activities less frequently (for self-care, mobility, and household activities) but does not experience difficulty or receive help from another person; (3) has difficulty carrying out activities alone even with accommodations but receives no help from another person; and (4) receives assistance from another person, which for household activities must be for health- or functioning-related reasons, or lives in a nursing home setting.

Assistance. We also grouped all respondents receiving personal help with self-care, mobility, or household activities into 4 mutually exclusive assistance levels: (1) all residents of nursing homes, who were assumed to be receiving assistance; (2) individuals receiving assistance with 3 or more self-care or mobility activities; (3) individuals receiving assistance with 1 or 2 self-care or mobility activities; and (4) individuals receiving assistance solely with household activities (for health or functioning reasons).

Potential and Actual Care Networks. We counted as potential informal care network members all living children (inside and outside the household), spouses/partners, other household members, and up to 5 social network members that the respondent identified as persons that he or she could talk to about important things.

For the actual care network, we counted unpaid and paid caregivers who had helped in the last month with self-care or mobility tasks, household tasks, or selected other tasks (driving, seeing the doctor, and taking care of less common money matters and health insurance matters). For respondents receiving assistance in residential care settings, we did not count individual staff members, but we did include paid caregivers who were not staff members as well as unpaid persons. In addition to counting the number of caregivers, we also classified the network by the type of providers that it included (any paid, any unpaid); for this purpose, respondents living in residential care settings were classified as having paid providers. We also created categories reflecting combinations of provider types (only unpaid, only paid, both).

Supportive Care Environments. NHATS distinguishes among nursing homes, supportive care settings other than nursing homes (that is, places that provide group meals or assistance with personal care or medications or that offer multiple levels of care, such as continuing-care retirement communities), and all other community settings.[28] For respondents living in nursing homes and other supportive care settings, the type of place and availability of services for the respondent's level of care were ascertained during an interview with a facility staff member. For respondents living in supportive care settings other than nursing homes, the use of services in the last month was ascertained during the in-person interview with the respondent (or proxy). NHATS included the following services: meals, help with medications, help with bathing and dressing, laundry services, housekeeping services, transportation to medical care providers, transportation for shopping or leisure activities, recreational facilities, and organized social events/activities.

Hours of Unpaid and Paid Care. For all respondents living in settings other than nursing homes, NHATS asked about the number of hours of care provided over the last month by each caregiver (other than staff members of residential care settings) and whether each caregiver was paid. The number of hours was missing for 12% of respondents receiving assistance. For these cases, we imputed the number of hours for each caregiver based on the respondent's age, sex, and reported level of assistance, and, for unpaid caregivers, their relationship to the respondent. The amount of care over the last month was very similar for the reported and imputed cases; weighted means totaled 105.7 hours for only reported cases and 107.6 hours for reported and imputed cases together.

Adverse Consequences Associated With Unmet Need. Finally, NHATS asked about the adverse consequences associated with unmet need for assistance for those respondents who reported having difficulty or receiving help with self-care, mobility, and household activities.[21,23] Respondents who reported difficulty performing an activity by themselves were asked whether at any time in the last month they had experienced a particular consequence because the activity was too difficult to carry out by themselves. Respondents who reported getting help with an activity every time they performed it were asked whether the consequence occurred because they had no one there to help. Respondents were asked about the following consequences: having to stay in bed, not being able to go places in their home or building, not being able to leave their home or building,

going without eating, going without showering/bathing/washing up, accidentally wetting or soiling their clothes, going without getting dressed, going without clean clothes, going without groceries or personal items, going without a hot meal, going without handling bills and banking matters, and making a mistake in taking their medications. We created 3 summary measures indicating an adverse consequence for (1) mobility/self-care activities, (2) household activities, and (3) either type of activity.

Demographic Characteristics. NHATS confirmed each participant's age and gender and obtained a current address, which was used to identify the major census division (New England, mid-Atlantic, west north central, mountain) in which the respondent lived. Respondents were asked to report their race (with those giving multiple responses asked to identify a primary race) and whether they considered themselves Hispanic or Latino. We classified their responses as white non-Hispanic, black non-Hispanic, Hispanic, and all others. Data were also collected on the main sources of income for respondents and their spouses/partners and on total income in the prior year from all sources, with a bracketed range offered as needed. Altogether, 13% of respondents reported a bracketed range of total income and 31% were missing a value. We used the imputed total income value provided by NHATS for these respondents.[29] For our analyses, we constructed total income quartiles with cutoff points at $15,000, $30,000, and $60,000. Results were similar in a sensitivity analysis using separate quartile cutoff points for married and unmarried respondents.

Weighted Percentages, Means, and Population Estimates. For all percentages and means, we used analytic weights that take into account the differential probabilities of selection and nonresponse.[30] For population estimates, we applied the age-specific prevalences from NHATS to the age distribution of the Medicare enrollment file (sample frame), so that the estimates sum to a total population of 38.2 million older adults.

Results

Activity Limitations

In all, 18 million older adults—nearly half—reported having difficulty (19.6%) or receiving help (28.7%) from another person with self-care/

mobility or household activities (see Table 1). Another 11.5 million older adults (30%) reported fully accommodating their limitations by using devices or reducing the frequency of the activity. About 20% of those younger than age 85 reported having difficulty but not receiving help. The proportion was lower for older age groups for whom receipt of help was more common. The proportion who reported fully accommodating their limitations ranged from about one-third of those aged 65 to 69 to about 12% among those aged 90 and older.

These distributions differed by type of limitation. For instance, difficulty was more commonly reported for self-care or mobility activities than for household activities (18% vs 12%), and help was more commonly reported for household activities than for self-care or mobility activities (25% vs 20%). Age patterns with respect to help, however, were similar across the type of limitation, with the respondents in each successive age bracket more likely to say that they received help.

Assistance With Activities

Of the 10.9 million older adults who reported receiving help with daily activities in the last month, 1.1 million lived in nursing homes (see Table 2). Of the remaining 9.8 million receiving help, 1.6 million (16.2%) lived in supportive care, and 8.2 million lived in community settings (83.8%). Thus, in all, 1 in 4 older adults receiving help lived in either a supportive care (15%) or a nursing home (10%) setting (not shown). Among those receiving assistance in settings other than nursing homes, nearly 3 million had help with 3 or more self-care or mobility activities, about 4 million had help with 1 to 2 such activities, and slightly more than 3 million had help with only household activities.

Women and widowed individuals made up a disproportionately large share of those receiving each level of assistance in the community (including supportive care settings other than nursing homes). Blacks and Hispanics were overrepresented in the self-care or mobility assistance categories, and women and blacks were overrepresented among nursing home residents. Income was negatively associated with assistance, with those in the bottom income quartile overrepresented across all levels of assistance, particularly among those receiving help with 3 or more self-care or mobility activities.

Table 1. Percentage and Number (in Millions) of the 65 and Older Population With Self-Care, Mobility, and Household Activity Limitations, and Percentage by 5-Year Age Groups[a]

	Among 65+		Among 5-Year Age Groups (%)					
	%	Millions	65–69	70–74	75–79	80–84	85–89	90+
Any Limitation								
Fully able on all activities	21.7	8.3	30.1	27.7	19.2	13.9	6.3	2.4
Device used less often but no difficulty	30.0	11.5	34.4	32.8	32.2	26.7	18.7	12.3
Difficulty but no help	19.6	7.5	19.6	20.7	21.0	21.2	16.5	9.3
Help	28.7	10.9	15.8	18.8	27.5	38.2	58.5	76.0
Self-Care or Mobility Limitation[b]								
Fully able	31.5	12.0	44.6	39.0	27.4	19.7	10.2	3.9
Device used less often but no difficulty	30.0	11.4	27.1	30.4	35.4	32.4	28.8	19.7
Difficulty but no help	18.3	7.0	17.1	17.7	19.1	21.8	19.1	14.6
Help	20.1	7.7	11.0	12.9	18.1	26.1	41.8	61.7
Household Activity Limitation[c]								
Fully able	47.5	18.1	54.9	55.2	49.7	40.4	26.2	16.5
Less often but no difficulty	15.3	5.8	20.6	16.5	12.8	12.9	8.9	4.6
Difficulty but no help	12.4	4.7	12.2	13.6	13.6	12.5	10.8	5.7
Help for health or functioning reasons	24.8	9.5	12.3	14.6	23.9	34.2	54.1	73.1
Population (in millions)		38.2	11.6	8.9	6.9	5.4	3.4	1.9
Unweighted *n*		8,077	1,417	1,610	1,569	1,590	1,067	824

n = 8,077

[a]Data from the 2011 National Health and Aging Trends Study.

[b]Bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, leaving one's home or building.

[c]Laundry, hot meals, shopping for personal items, paying bills/banking, handling medications.

Table 2. Size and Characteristics of the Population Aged 65 and Older Receiving Personal Assistance, by Level of Assistance (%)[a]

		Non–Nursing Home Population					
	Nursing Home Population	3+ Self-Care or Mobility Activities[b]	1 to 2 Self-Care or Mobility Activities[b]	Only Household Activities[c]	Any Self-Care, Mobility, or Household Activity	No Assistance[d]	Total, Non–Nursing Home
Size: % (Millions)	2.9 (1.1)	7.0 (2.7)	10.3 (3.9)	8.5 (3.3)	25.8 (9.8)	71.3 (27.2)	97.1 (37.0)
Gender							
Male	27.0	31.1	31.9	32.3	31.8	47.7	43.4
Female	73.0	68.9	68.1	67.7	68.2	52.3	56.6
Race							
White, non-Hispanic	79.6	71.0	74.9	78.4	75.0	82.6	80.5
Black, non-Hispanic	12.0	11.6	10.2	8.7	10.1	7.4	8.1
Other, non-Hispanic	4.0	5.0	3.9	4.0	4.2	4.8	4.6
Hispanic	4.4	12.4	11.1	8.9	10.7	5.3	6.7
Marital Status							
Married/living with partner	—	42.1	47.0	40.7	43.6	61.9	57.0
Separated/divorced	—	8.7	11.4	12.9	11.1	12.7	12.2
Widowed	—	44.0	37.1	41.3	40.3	22.1	27.1
Never married	—	5.2	4.6	5.1	4.9	3.3	3.7

Continued

Table 2. *Continued*

		Non–Nursing Home Population					
	Nursing Home Population	3+ Self-Care or Mobility Activities[b]	1 to 2 Self-Care or Mobility Activities[b]	Only Household Activities[c]	Any Self-Care, Mobility, or Household Activity	No Assistance[d]	Total, Non–Nursing Home
Income Quartiles							
1st < $15,000	—	43.6	37.1	36.2	38.6	18.4	23.8
2nd $15,000–< $30,000	—	29.6	28.7	28.3	28.8	22.6	24.3
3rd $30,000–< $60,000	—	17.1	20.3	21.2	19.7	29.3	26.7
4th ≥ $60,000	—	9.7	13.9	14.3	12.9	29.7	25.2
Residence Type							
Community	0.0	83.2	86.6	81.0	83.8	98.4	94.5
Supportive care setting other than nursing home	0.0	16.8	13.4	19.0	16.2	1.6	5.5
Nursing home	100.0	NA	NA	NA	NA	NA	NA
Unweighted *n*	468	749	968	782	2,499	5,110	7,609

[a]Data from the 2011 National Health and Aging Trends Study.
[b]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.
[c]Assistance for health or functioning reasons with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care or mobility activities).
[d]No assistance and assistance with household activities for reasons other than health or functioning or with transportation, seeing the doctor, and/or less frequent money or health insurance matters (but not self-care or mobility activities or household activities for health or functioning reasons).

Nearly 1 in 5 older adults who received help with only household activities lived in supportive care settings other than nursing homes, compared with 13.4% of those receiving help with 1 to 2 self-care or mobility activities and 16.8% of those receiving assistance with 3 or more such activities.

Potential and Actual Care Networks

Very few older adults had no potential informal network members (see Table 3). The mean size of the potential network was relatively stable across levels of care, at about 4 members, and was only slightly smaller in supportive care settings than in the community (2.9 vs 4.2). Excluding friends, the average potential network size was about 3, with about 5% having no potential network members (not shown). Among those receiving assistance, the percentage with no potential informal caregivers was larger in supportive care settings than in the community (8.7% vs 1.3%).

Whereas about 75% of older adults at all assistance levels had 3 or more potential informal network members, about two-thirds of all who had help relied on only 1 or 2 actual caregivers. The size of the actual care network, which ranged from 1.8 to 2.6 caregivers, increased with level of assistance. Nearly 80% of older adults with no activity limitations reported receiving assistance with household and other activities (for reasons other than health or functioning), although the average for this group was low, at 1 person. Excluding residential care staff, the average actual network sizes were similar for those living in supportive care settings and in the community (1.7 vs 2.3), but 12.5% of those in supportive care settings had only staff helpers (no nonstaff helpers) in their networks.

Most of the actual helpers were members of the potential informal network (not shown), including children inside and outside the household (42%), spouses/partners (18%), other household members (8%), and other social network members (6%). The remaining 26% of helpers came from outside the potential network, with 10% paid and 16% unpaid. The most common type of "other" unpaid helpers were friends, followed by granddaughters, other nonrelatives, and daughters-in-law.

Table 3. Potential and Actual Care Networks for the Population Aged 65 and Older, by Level of Assistance and Residential Setting[a,b]

	Level of Assistance					Assistance With Any Self-Care, Mobility, or Household Activity by Residential Setting	
	3+ Self-Care or Mobility Activities[c]	1 to 2 Self-Care or Mobility Activities[c]	Only Household Activities[d]	Any Self-Care, Mobility, or Household Activity	No Assistance[e]	Supportive Care Setting	Community
Potential Informal Care Network							
Mean	4.1	4.1	4.0	4.0	4.0	2.9	4.2
% with none	2.7	2.9	1.9	2.5	1.2	8.7	1.3
1	7.9	5.8	7.5	6.9	6.7	12.4	5.9
2	13.4	16.7	15.7	15.5	12.2	22.7	14.1
3	19.6	19.5	20.4	19.8	22.2	20.5	19.7
4+	56.4	55.1	54.5	55.3	57.7	35.7	59.0
Actual Network[f]							
Mean	2.6	2.1	1.8	2.2	1.1	1.7	2.3
% with none	1.7	1.7	3.9	2.4	20.6	12.5	0.5
1	24.2	35.3	39.1	33.7	53.9	37.7	32.1

Continued

Table 3. *Continued*

	Level of Assistance					Assistance With Any Self-Care, Mobility, or Household Activity by Residential Setting	
	3+ Self-Care or Mobility Activities[c]	1 to 2 Self-Care or Mobility Activities[c]	Only Household Activities[d]	Any Self-Care, Mobility, or Household Activity	No Assistance[e]	Supportive Care Setting	Community
2	30.1	30.3	35.9	32.1	18.9	31.2	33.1
3	20.9	18.5	15.3	18.1	5.0	9.9	19.9
4+	23.2	13.8	5.8	13.7	1.7	8.7	14.9
Unweighted *n*	749	968	782	2,499	5,110	316	2,183

$n = 7{,}609$

[a]Data from the 2011 National Health and Aging Trends Study.

[b]Excludes nursing home residents.

[c]Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, leaving one's home or building.

[d]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).

[e]No Assistance and assistance with household activities for reasons other than health or functioning or with transportation, seeing the doctor, and/or less frequent money or health insurance matters (but not self-care or mobility activities or household activities for health or functioning reasons).

[f]Actual network in supportive care settings counts only nonstaff paid helpers and unpaid helpers. Staff members in supportive care settings are excluded from the counts.

Composition of Actual Network and Hours Received

Of those getting help in the last month and living in settings other than nursing homes, about one-third received paid help (including help from staff), nearly all (95%) received unpaid help, and about 30% received both types of assistance (see Table 4). The prevalence of paid help increased with the level of assistance, but the receipt of unpaid help was nearly universal across all levels of assistance. Consequently, sole reliance on unpaid help was much higher for those in the 2 lower-assistance groups (70%–72%) than for those in the highest assistance group (50%). Similarly, about 1 in 4 of those in the 2 lower-assistance groups received a combination of paid and unpaid care, compared with nearly half of those in the highest assistance group.

The average number of paid (nonstaff), unpaid, and total hours of help received in the last month rose sharply with the level of assistance. The number of hours of unpaid help ranged from 85 for the household activities–only group to 3 times that amount (253 hours) for the group receiving assistance with 3 or more self-care or mobility activities, and the average number of paid nonstaff hours rose from fewer than 5 to about 70 across the 3 assistance levels.

Although nearly all persons living in supportive care settings and in the community had some unpaid help, both the percentage receiving any nonstaff paid help and the fraction receiving a combination of paid and unpaid help were smaller in supportive care settings than in the community (see Table 5). The average number of hours of nonstaff paid help in supportive care settings was about half that in community settings, and the average number of unpaid hours (50) was less than one-third of those in community settings (164).

In addition to nonstaff assistance, those living in supportive care settings other than nursing homes got staff-provided help with a variety of activities (Table 6). The most commonly available services were social activities (92%), meals (87%), and housekeeping (79%), while the most commonly used services were meals (77%), housekeeping (68%), and social activities (62%). Although available to most older adults in supportive care settings, fewer than half reported using transportation, laundry, medication, personal care services, or recreational facilities in the last month.

Table 4. Percentage of Older Adults Receiving Paid and Unpaid Help in the Last Month and Mean Nonstaff Hours for Those Receiving Assistance, by Level of Assistance[a,b]

	3+ Self-Care or Mobility Activities[c]	1 to 2 Self-Care or Mobility Activities[c]	Only Household Activities[d]	Any Self-Care, Mobility, or Household Activity
Any paid help	50.0	28.0	29.4	34.5
Any unpaid help	94.7	95.6	94.6	95.0
Paid help only	5.3	4.4	5.3	5.0
Unpaid help only	50.0	72.0	70.5	65.5
Both	44.7	23.6	24.1	29.5
Paid nonstaff hours (mean)	69.9	13.7	4.5	25.9
Unpaid hours (mean)	252.8	118.1	85.0	143.8
Total hours (mean)	322.6	131.8	89.6	169.7
Unweighted *n*	749	968	782	2,499

n = 2,499

[a]Data from the 2011 National Health and Aging Trends Study.

[b]Excludes nursing home residents.

[c]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.

[d]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).

Table 5. Percentage of Older Adults Receiving Nonstaff Paid and Unpaid Help in the Last Month and Mean Hours for Those Receiving Assistance, by Residential Setting[a,b]

	Supportive Care Setting[c] (%)	Community (%)
Any nonstaff paid help	14.5	21.2
Any unpaid help	96.1	97.6
Nonstaff paid help only	3.9	2.4
Unpaid help only	85.5	78.8
Both	10.6	18.8
Paid nonstaff hours (mean)	14.2	28.7
Unpaid hours (mean)	49.6	164.0
Total hours (mean)	63.7	192.6
Unweighted *n*	283	2,174

$n = 2{,}457$
[a]Data from the 2011 National Health and Aging Trends Study.
[b]Excludes 42 cases receiving only staff care.
[c]Excludes nursing home residents.

Table 6. Support Services Available to and Used by Older Adults in Supportive Care Settings[a,b,c]

Support Services	Available (%)	Used in the Last Month (%)
Social activities	91.6	61.7
Meals	86.5	76.7
Housekeeping services	79.1	68.0
Van service to shopping	75.4	26.0
Van service to doctor	72.8	27.9
Laundry services	72.3	47.8
Help with medications	64.3	41.6
Recreational facilities	64.0	29.5
Help with bathing or dressing	62.6	30.2

$n = 412$
[a]Data from the 2011 National Health and Aging Trends Study.
[b]Includes 96 persons living in supportive care settings but not reporting assistance with self-care, mobility, or household activities.
[c]Excludes nursing home residents.

Adverse Consequences by Activity and Demographic Group

Overall, 15.0% of older adults reported having an adverse consequence related to unmet need in the last month (Table 7). The proportion was more than twice as high (nearly 32%) for the subset of older adults at risk for a consequence, that is, who reported either having difficulty or receiving help with an activity in the last month. The most common adverse consequences were wetting or soiling clothes, staying inside, not going places inside one's home or building, and making mistakes with medicine.

The percentage reporting an adverse consequence varied substantially by demographic group and level of need (see Table 8). Within the group with reported care needs (right column), minorities, widowed or never-married adults, and those in the lowest income quartile had the highest prevalence of adverse consequences. Level of disability also was an important factor. Only about 15% of those saying they had difficulty but did not use personal assistance reported that they had experienced an adverse consequence, compared with 44% of those receiving some assistance. The rate of adverse consequences also rose significantly with assistance level—from about one-quarter of those at the lowest to three-quarters of older adults at the highest level. Although the extent of unmet need was similar for those in the community and in residential care, those receiving paid help in the community had an especially high prevalence, nearly 60%.

Discussion

Our analyses of nationally representative data indicate that older adults in the United States have substantial late-life disability and care needs. Nearly half the population aged 65 years and older, about 18 million Americans, reported receiving help related to their health or functioning or having difficulty carrying out self-care, mobility, or household activities alone with whatever supports they had put in place. In all, nearly 11 million older Americans received assistance. About 1 million resided in nursing homes, and the remaining almost 10 million received care in the community or in alternative supportive care settings, typically from 1 or 2 caregivers. Of those receiving assistance in settings other than

Table 7. Percentage of 65 and Older Population with Adverse Consequences in the Last Month Related to Unmet Need, by Activity[a,b]

Activity	Consequence	With Difficulty or Receiving Help (%)	With Adverse Consequence (%)	With Adverse Consequence Among Those With Difficulty or Receiving Help (%)
Toileting	Wet or soiled clothes	8.7	3.8	43.4
Getting outside	Stayed inside	19.5	5.8	29.6
Getting around inside	Did not go places in home/building	18.2	4.8	26.0
Managing medication	Made mistake taking medicine	16.4	3.3	19.9
Bathing/showering/cleaning up	Went without bathing/showering/cleaning up	15.5	2.0	12.9
Getting out of bed	Had to stay in bed	19.5	2.3	11.5
Making hot meals	Went without a hot meal	19.9	1.9	9.5
Getting dressed	Went without getting dressed	17.7	1.3	7.5
Shopping for food or personal items	Went without groceries	22.9	1.4	6.3
Paying bills or banking	Went without paying bills	15.7	0.9	5.7
Doing laundry	Went without clean laundry	17.4	0.9	4.9
Eating	Went without eating	6.9	0.3	3.7
Any activity	Any consequence	47.1	15.0	31.8

$n = 7{,}609$

[a]Data from the 2011 National Health and Aging Trends Study.

[b]Excludes nursing home residents.

Table 8. Percentage of 65 and Older Population With Any Adverse Consequence in the Last Month Related to Unmet Need, by Demographic Group[a,b]

	With Adverse Consequence (%)			
Demographic Group	All	*p*-value[c]	Among Those With Difficulty or Receiving Help	*p*-value[c]
All	15.0		31.8	
Gender		0.00		0.21
Male	12.3		30.4	
Female	17.1		32.6	
Race		0.02		0.00
White, non-Hispanic	13.8		30.2	
Black, non-Hispanic	19.1		34.9	
Other, non-Hispanic	15.5		33.8	
Hispanic	24.3		41.4	
Census Division		0.02		0.24
New England	13.5		26.4	
Mid-Atlantic	14.8		30.5	
East north central	12.1		28.2	
West north central	14.1		31.7	
South Atlantic	14.8		32.5	
East south central	19.4		39.2	
West south central	17.4		32.7	

Continued

Table 8. *Continued*

Demographic Group	With Adverse Consequence (%)			
	All	*p*-value[c]	Among Those With Difficulty or Receiving Help	*p*-value[c]
Mountain	12.9		32.4	
Pacific	15.9		32.8	
Marital Status		0.00		0.01
Married/living with partner	11.6		28.8	
Separated/divorced	15.4		32.6	
Widowed	21.1		35.3	
Never married	21.5		34.5	
Income Quartiles		0.00		0.00
1st (lowest)	24.5		39.7	
2nd	17.8		32.0	
3rd	10.9		26.2	
4th (highest)	7.6		24.5	
Residence Type		0.00		0.21
Community	14.1		31.4	
Supportive care setting	31.1		35.0	
Difficulty vs Assistance				0.00
Difficulty but no assistance	—		14.8	
Any assistance	—		44.4	

Continued

Table 8. *Continued*

Demographic Group	With Adverse Consequence (%)			
	All	*p*-value[c]	Among Those With Difficulty or Receiving Help	*p*-value[c]
Assistance Level				0.00
Household activities only	—		24.8	
1-2 self-care or mobility activities	—		40.7	
3+ self-care or mobility activities	—		73.7	
Type of Assistance by Residence				0.00
Any paid help community	—		57.4	
Any paid help residential care	—		36.3	
Only unpaid help (community and residential care)	—		42.4	

[a]Data from the 2011 National Health and Aging Trends Study.
[b]Excludes nursing home residents.
[c]*p*-value is for X^2 test for group differences.

nursing homes, 6.6 million—nearly 1 in 5 older adults—received help with the most basic self-care or mobility activities.

This last figure is substantially larger than previous estimates, which range from 7% to nearly 9% for the mid-2000s.[9,31-33] Several measurement-related issues likely contributed to the higher estimate reported here. For instance, NHATS captured functioning and accommodations for the last month rather than for the shorter reference periods (previous week or currently) used in other studies. In addition, we included leaving one's home or building, which is not consistently included with self-care and mobility measures in other studies but is arguably a critical activity for maintaining social ties and well-being. Finally, other surveys use screening or skip patterns that exclude some study participants from questions about assistance based on whether they acknowledge or perceive having difficulty. Notwithstanding these differences, other studies suggest that the population-level declines in the prevalence of disability during the 1980s and 1990s leveled off during the 2000s and may reverse course as a greater share of the baby boom generation reach old age.[9,10] Our estimates thus offer a new baseline for monitoring national trends as these large cohorts reach the ages at highest risk for disability and need for long-term care.

With respect to care availability, very few older adults had no potential informal caregivers (only 2% to 5%, depending on the definition), and the average was about 4 per person when counting spouses/partners, children, household members, and close friends. Actual care networks were most often composed of 1 or 2 caregivers, typically children or spouses/partners. About 3 in 10 older adults who received assistance supplemented this informal care with paid help. The 3 million older adults receiving the highest levels of care had more varied networks—in the mixture of paid and unpaid helpers and the number of providers—and the number of hours of care rose sharply with the level of assistance.

We also found that of those older adults receiving assistance, a large share—15%—lived in supportive care environments other than nursing homes. This group, numbering approximately 1.6 million older adults, outnumbered the population in nursing homes. Other studies that focus on regulated facilities providing meals, 24-hour supervision, and help with personal care or health-related services suggest a lower figure, closer to 650,000, for this age group.[18,19] Our estimate included individuals receiving assistance who lived in places that offered meals, personal care

or medication services, or multiple levels of care, irrespective of licensure, and, as such, covered a broader range of settings.

Relative to older adults living in the community, those living in supportive care settings had, on average, fewer potential network members (3 rather than 4) and slightly smaller actual (nonstaff) care networks. But nearly all received unpaid help (95%, amounting, on average, to nearly 50 hours a month), and nearly 15% also received paid help from outside the facility. Such findings suggest that although residential care may substitute for both paid and unpaid sources of help, supplemental sources of care remain. The details regarding the hours of informal care we presented are from the recipients' viewpoint, so a valuable future approach would be to examine the details of care from the informal caregivers' viewpoint. In any case, our findings regarding the extent of informal care and, to a lesser degree, paid nonstaff care in supportive settings are new and warrant further study, given the increasing numbers of older adults living in these settings. In particular, residence in supportive care settings may be a way of making caregiving more sustainable as needs for care or oversight increase. Future research should investigate the relationship between supportive care settings and care networks outside the residence and whether the involvement of supplemental care in this setting helps keep the level of unmet need on par with that in the community.

More generally, the risks of adverse consequences suggestive of unmet need are high in later life, particularly for those needing greater levels of care. For those living at home or in supportive care settings other than nursing homes and reporting having difficulty or receiving help with daily activities, 32% reported having at least 1 adverse consequence in the last month indicative of unmet need, and this percentage rose with the level of assistance. Those receiving paid care in the community and those with low incomes had especially high levels of unmet need. Komisar and colleagues found similarly high levels of unmet need among older beneficiaries eligible for both Medicare and Medicaid in 6 states in 1999.[23] Past research also has established that unmet need leads to other negative outcomes, such as falls, hospitalizations, and emergency room use.[21-24] In light of the focus on shifting public benefits from nursing homes to community settings,[34] further investigation is needed to better understand how care networks and settings affect unmet need and what policies might be proposed to address such risks.

Although the findings presented here are cross-sectional, other research has distinguished among various late-life disability pathways, some gradual and others precipitous.[35-37] Previous studies also identified numerous modifiable factors linked to the onset and progression of disabilities, many of which may be influenced by public health policy: depressive symptoms, limited physical and social activity, lack of assistive devices and environmental modifications such as grab bars, and a constellation of factors that increase the risk of falling (eg, cognitive impairment, lower body strength and coordination limitations, and sensory impairment).[38-40] A comparison of several potentially high-impact intervention strategies suggests that fall prevention programs may be an especially effective way of reducing disability rates in the population.[36]

Studies also have shown that older adults with disabilities often have multiple, complex chronic diseases.[41] Dementia, too, affects a large number of older adults in the United States as well as the families who care for them, and the condition is responsible for substantial societal costs in the form of paid and unpaid long-term care.[42,43] The lack of coordination between acute and supportive service providers has been identified as problematic for these individuals with high medical and supportive care needs, especially those who are economically disadvantaged.[44] This issue is particularly relevant in light of our finding that older Americans in the lowest income quartile are more likely to be receiving the highest level of assistance and also are more likely than those with higher incomes to experience adverse consequences related to unmet need.

Initiatives such as the Program of All-Inclusive Care for the Elderly (PACE), the SCAN foundation's person-centered care models, new Medicare and Medicaid care integration initiatives included in the Affordable Care Act, and emerging dementia care models all attempt to better match services to needs by taking a whole-person approach to integrating supportive and medical services for older adults with complex medical and functional needs.[45-49] Because these models have not been widely implemented, there is no evidence yet of population-level effects. Nevertheless, the implementation of such care innovations should be closely monitored because of their potential for improving health outcomes and quality of life and for reducing or deferring functional decline through improved care coordination and disease management.

Our analyses suggest another, related area for further research to inform policies to support increased independence in the face of declining function. Although their needs are great, a sizable share of the older

population—30%—is managing to accommodate their limitations independently. A significant portion of this group uses assistive devices or environmental modifications, although others cut back on their activities, which may signal a preclinical disability leading to social isolation, depression, and other negative consequences.[6,50] We also found that African Americans and those of Hispanic origin were disproportionately represented at higher levels of assistance and were more likely to report adverse consequences linked to unmet need. Other research suggests that these groups and low-income older Americans may be the most important to target with programs promoting home modification and identification of assistive devices suited to the individual's needs and capacities.[6] More research is needed to increase our understanding of the various behavioral accommodations and their role in delaying the need for personal assistance and mitigating activity difficulty and consequences for well-being in later life, particularly for minority and economically disadvantaged groups.

Finally, the nearly 10 million older Americans receiving assistance in settings other than nursing homes have an average of 2.2 caregivers, for a total of 21 million persons providing assistance. Most (90%) are unpaid informal caregivers who provide on average 144 hours of help per month, with far more hours for those with the greatest care needs. About 6 in 10 are spouses, partners, or children, who bear the greatest burden of caregiving and are susceptible to levels of stress that can result in the cessation of caregiving and the institutionalization of the care recipient.[51,52] Besides forming the foundation of the personal care workforce, these family caregivers often perform medically oriented tasks, help the care recipient navigate the health care system, and oversee transitions between care settings.[53-57] Informal caregivers' involvement in these activities can be critical to the recipient's health and functional trajectory. Thus, supporting informal caregivers through multiple pathways, including training, information, and direct assistance, is an explicit policy goal, notably through Administration for Community Living initiatives, such as the National Family Caregiving Support Program and Aging and Disability Resource Centers, and, more recently, through the US Department of Health and Human Services National Plan to Address Alzheimer's Disease.[58]

This article documents substantial late-life disability and care needs for older adults in the United States. Although nearly all older adults have potential care networks and the amount of informal assistance is

considerable in both community and residential care settings, the extent of unmet need is high. Notable is the finding that nearly 3 million older adults receive assistance with 3 or more self-care or mobility activities, a level of need associated with a high rate of unmet need, a high risk of institutionalization, and eligibility for private insurance or public program benefits. A disproportionate share of older persons at this level of assistance is in the lowest income quartile. Although publicly and privately paid care continues to be an important source of assistance to older adults with extensive needs, the higher chances of experiencing unmet need for those receiving paid care is cause for concern. As individual preferences and public programs continue to support shifting the locus of long-term care from nursing homes to the community and to alternative residential care settings, policies to improve long-term services and support and to reduce unmet need could benefit both older adults and those who care for them.

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