ISSUE BRIEF
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The Financial Hardship Faced by Older Americans Needing Long-Term Services and Supports

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ABSTRACT

ISSUE: In addition to medical care, individuals with functional or cognitive impairment often require long-term services and supports (LTSS), which Medicare does not cover. Little is known about the additional out-of-pocket expenses that individuals and their families incur to meet these needs.

GOAL: To analyze medical and LTSS spending among older Medicare beneficiaries, particularly the costs of assistive devices and personal care and the ways those costs are met.

METHODS: Descriptive analyses of the National Health and Aging Trends Study (NHATS), 2015.

KEY FINDINGS AND CONCLUSIONS: Beneficiaries with high LTSS needs have higher Medicare and out-of-pocket spending than those without such needs and are more likely to report that medical care makes up part of their credit card debt. Those with high LTSS needs are also more likely to report trouble paying for food, rent, utilities, medical care, and prescription drugs. Many older Medicare beneficiaries using LTSS are vulnerable to incurring substantial costs. Without an affordable, sustainable financing solution, Medicare beneficiaries with LTSS needs will continue to be at greater risk of delaying necessary care, being placed in a nursing home prematurely, and having to "spend down" into the Medicaid program.

TOPLINES

- Older adults needing long-term services and supports have higher Medicare spending and higher out-of-pocket costs than those without these needs.
- Medicare beneficiaries requiring long-term services and supports are more likely than other beneficiaries to report skipping meals, being unable to afford rent, or being unable to pay for their prescription drugs.

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BACKGROUND

Two-thirds of older Medicare beneficiaries use long-term services and supports (LTSS) or have difficulty performing activities of daily living (ADLs), such as eating, bathing, dressing, transferring in and out of bed, toileting, and walking across the room.[1] There is considerable variability in the use of LTSS, from the type of service used — personal care, assistive device, home modification, among others — to the intensity of support required. One-third of Medicare beneficiaries use LTSS for two or more activities, and another one-third use assistive devices or report difficulty with just one activity.

Although there is great need for LTSS among older Medicare beneficiaries, the Medicare program does not cover these services, so individuals or their families must cover the costs. For low-income beneficiaries who qualify, state Medicaid programs provide some coverage, but the generosity and accessibility of Medicaid varies by state. Approximately one-third of Medicare beneficiaries with functional or cognitive impairment have low incomes (less than $24,000 a year for an individual) but do not qualify for Medicaid.[2] For those individuals, the out-of-pocket costs for medical services and LTSS can be especially burdensome.

For decades, researchers and policymakers have debated options to expand coverage for LTSS. The closest the United States has come to implementing a financing solution in recent years was enactment of the Community Living Assistance Services and Supports (CLASS) Act of 2010, which was signed into law with the Affordable Care Act. However, it was quickly abandoned by the U.S. Department of Health and Human Services because of financially unsustainable design features.[3]

Older Medicare beneficiaries with LTSS needs who do not qualify for Medicaid therefore shoulder the additional financial burden on their own or with their families' assistance. One-quarter of all Medicare beneficiaries spend 20 percent or more of their income on out-of-pocket health expenses and premiums.[4] Studies have shown that high out-of-pocket expenditures are associated with increased risk of Medicaid entry, particularly among those with functional or cognitive impairment who use LTSS.[5] Little is known about the full scope of financial burden experienced by these individuals, including how they pay for these services, as well as the adverse consequences of these additional expenses.

Using the National Health and Aging Trends Study (NHATS) 2015, this analysis focuses on the medical and LTSS spending among three groups of Medicare beneficiaries:

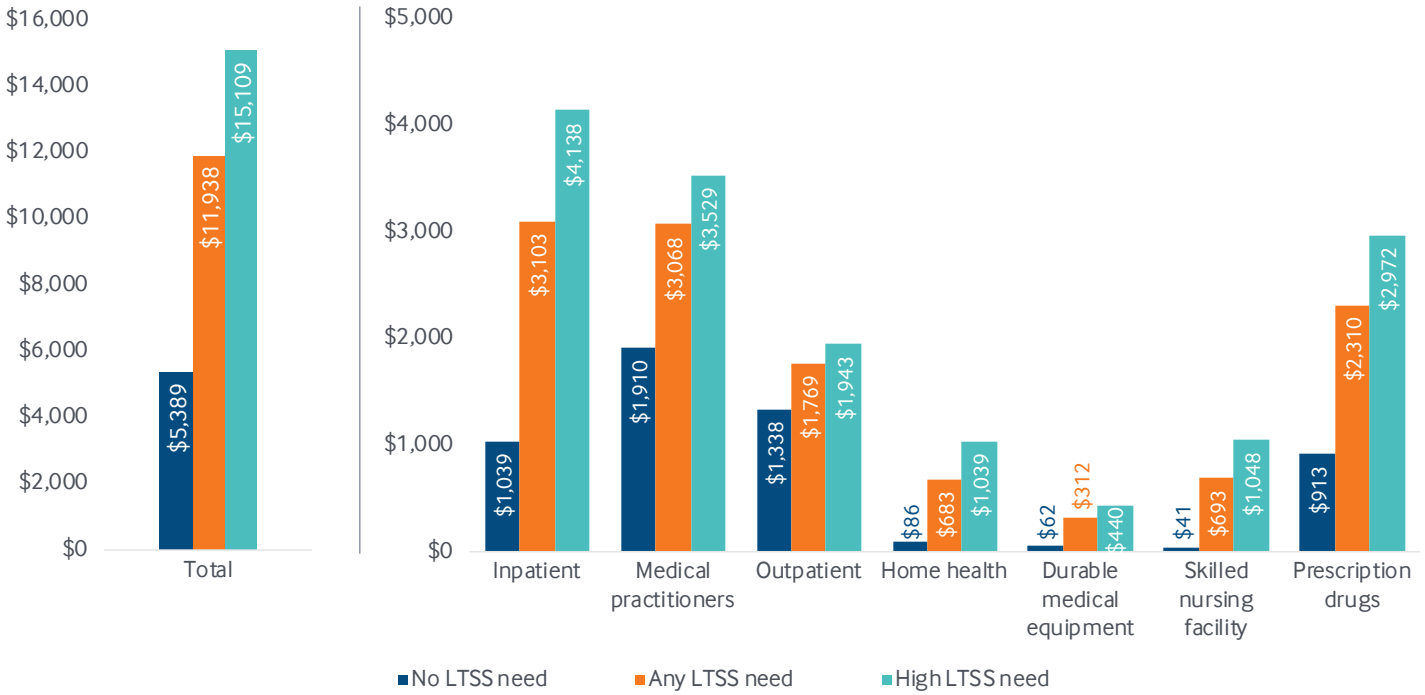
- those with **no LTSS need**
- those with **any LTSS need** (only difficulty with ADLs or use of LTSS for at least one ADL)
- those with **high LTSS need** (LTSS use plus at least two ADLs).

RESEARCH FINDINGS

Those who require any level of long-term services and supports have significantly higher average annual Medicare spending across all types of Medicare covered services (Exhibit 1). In 2015, an older, community-dwelling Medicare beneficiary with no LTSS use cost the Medicare program on average $5,389, compared with $11,938 for an individual with any LTSS need. Average annual Medicare spending increased to $15,109 for those with high LTSS need. Inpatient spending was the largest single contributor to Medicare spending among those needing any level of long-term services and supports, while physician spending was the largest single contributor for those without the need for LTSS. Compared with those who did not require long-term services and supports, inpatient spending was three times higher among those with any LTSS need and four times higher among those with high LTSS need. Additionally, prescription drug expenditures were three times higher among those with high LTSS need compared with those who had no such need.

Not surprisingly, the out-of-pocket share of Medicare covered expenses is substantially higher for older Medicare beneficiaries needing any level of long-term services and supports (Exhibit 2).[6] For medical services covered by Medicare, beneficiaries with high LTSS need have average out-of-pocket spending of $2,759, twice as high as those without such need. These out-of-pocket costs do not include the premium costs that older Medicare beneficiaries are also responsible for paying.

Exhibit 1. Average Annual Medicare Spending by Type of Service Among Older, Community-Dwelling Medicare Beneficiaries, 2015



Notes: LTSS = long-term services and supports. N = 3,975, weighted to 21.8 million fee-for-service (FFS) beneficiaries for services other than prescription drugs; N = 2,454, weighted to 13.2 million FFS beneficiaries enrolled in Part D for prescription drug spending.

Data: Authors' analysis of Medicare claims data, 2015.

Exhibit 2. Out-of-Pocket Spending for Medicare Covered Services by Older, Community-Dwelling Medicare Beneficiaries, 2015

Notes: LTSS = long-term services and supports. N = 3,975, weighted to 21.8 million fee-for-service (FFS) beneficiaries for services other than prescription drugs; N = 2,454, weighted to 13.2 million FFS beneficiaries enrolled in Part D for prescription drug spending.

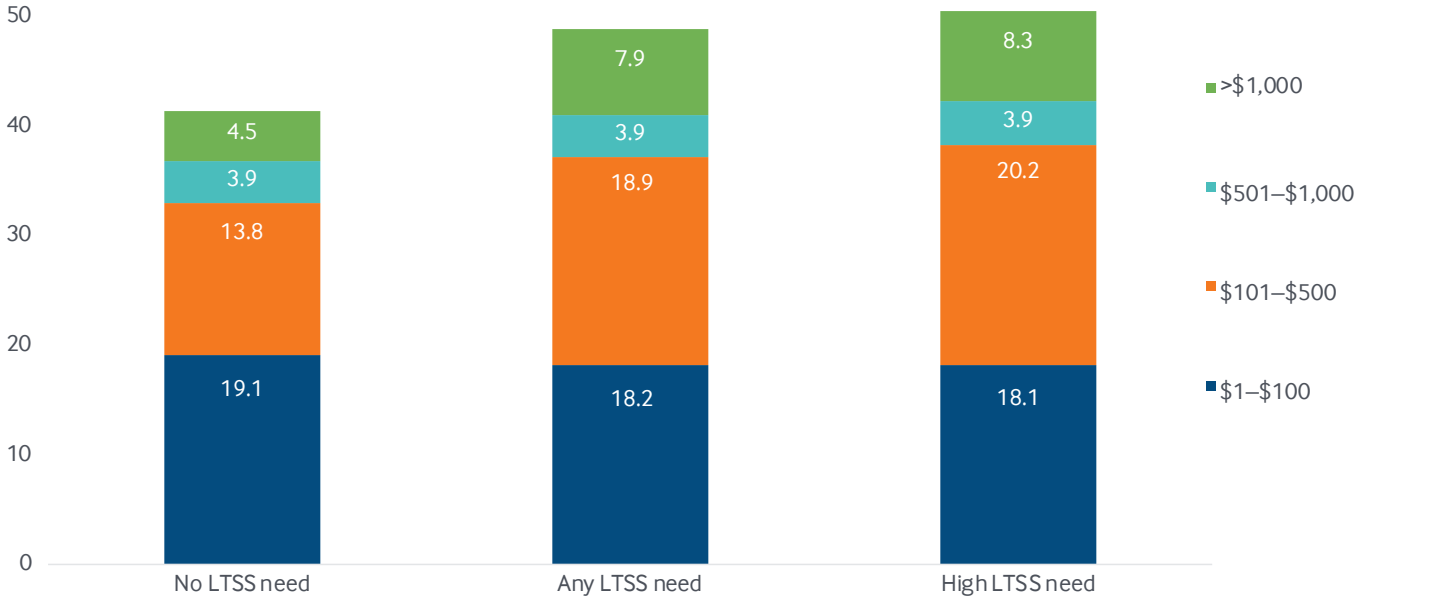
Data: Authors' analysis of Medicare claims data, 2015.

Beyond medical spending, older, community-dwelling Medicare beneficiaries often incur additional out-of-pocket costs for paid personal care, assistive devices, environmental modifications, meal delivery services, transportation, and other services. As depicted in Exhibit 3, half of beneficiaries with high LTSS need spent money on assistive devices in 2015. Within this group, spending per person was mostly below $500, although one in 12 reported spending more than $1,000 on assistive devices in 2015. Interestingly, more than 40 percent of those with no LTSS need also spent money on assistive devices in 2015. This may reflect assistive devices used as a safety precaution (e.g., installation of grab bars) or for activities not included in the six ADLs used for this analysis. Among those who reported receiving paid help (3.6% of those with high LTSS need), the average monthly spending on this service was $764 per person, or $9,168 annually (data not shown).

Credit cards are one way that older Medicare beneficiaries may pay for medical care and LTSS. Although those with high LTSS need have the highest out-of-pocket spending on these services, they are less likely to have a credit card than individuals without such needs (Exhibit 4). Among those who do own credit cards, beneficiaries with high LTSS need take longer to pay off their balance, and more of the balance represents medical costs, compared with beneficiaries without such need (Exhibit 5). As dependency on these services increases, so does the reliance on credit card debt for covering expenses.

Older Medicare beneficiaries with LTSS needs are more likely to receive support in the way of financial gifts or through public programs providing food stamps or payment assistance for utilities such as electricity or gas. Nearly one in 10 older adults with high LTSS needs receives financial gifts, most commonly from family members. Exhibit 6 shows that a greater proportion of beneficiaries needing any level of long-term services and supports depends on food stamps or other public programs for food and housing support than those without such needs.

Exhibit 3. Out-of-Pocket Spending on Assistive Devices, 2015

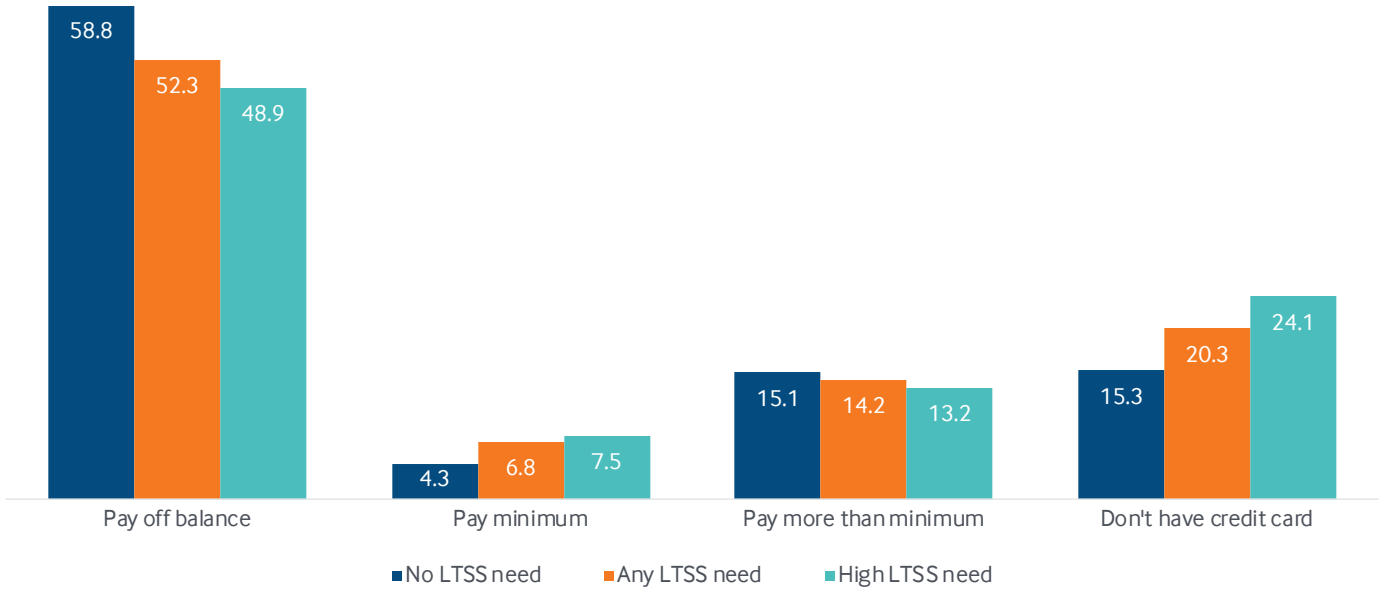


Notes: LTSS = long-term services and supports. N = 7,070, weighted to 38.8 million Medicare beneficiaries; excludes nursing home and non-nursing home residential care residents.

Data: Authors' analysis of National Health and Aging Trends Study (NHATS) 2015 data.

Exhibit 4. Credit Card Ownership and Payments in 2015 by LTSS Need Status

Percent

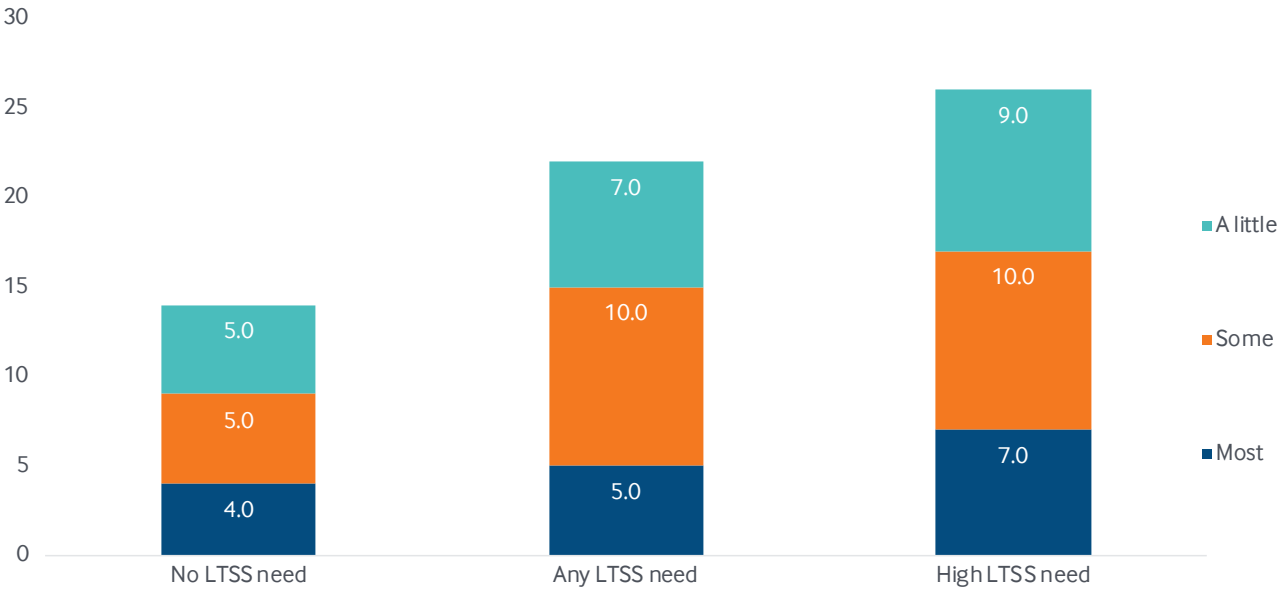


Notes: LTSS = long-term services and supports. N = 7,070, weighted to 38.8 million Medicare beneficiaries; excludes nursing home and non-nursing home residential care residents; totals do not add to 100%, as 6.4% of the weighted community refused this question.

Data: Authors' analysis of National Health and Aging Trends Study (NHATS) 2015 data.

Exhibit 5. Proportion of Credit Card Debt for Medical Care Among Those with Credit Card Debt in 2015

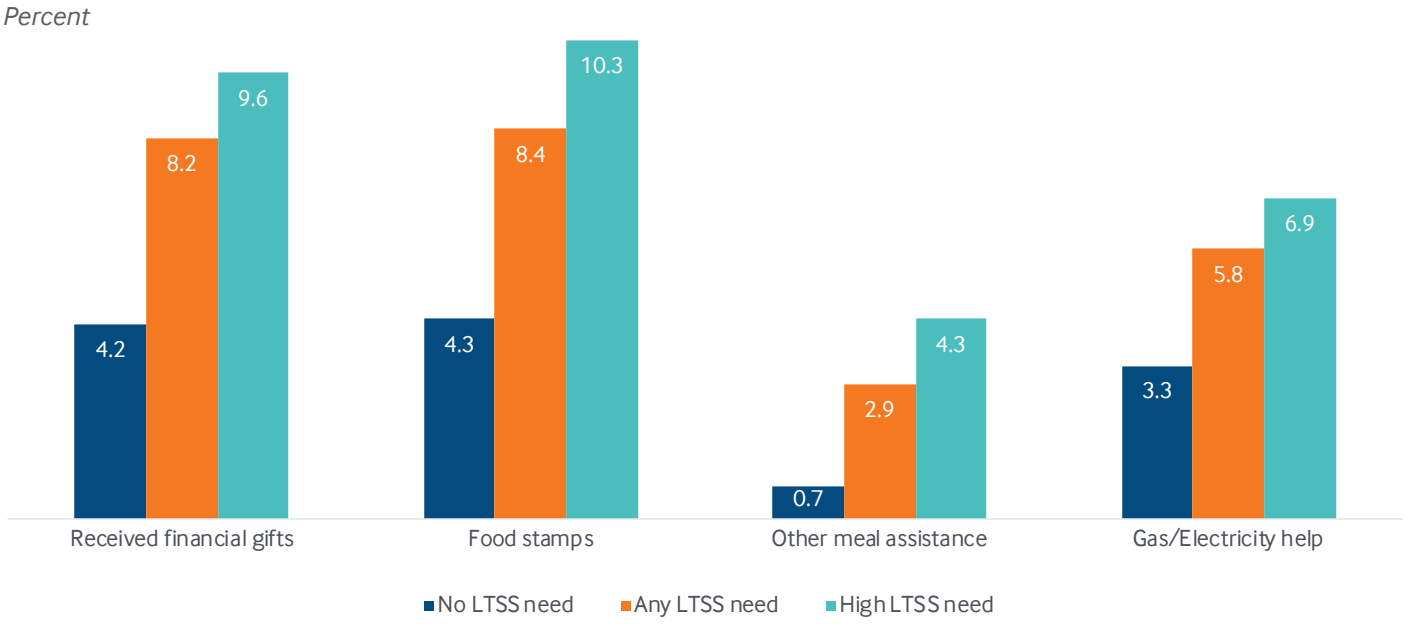
Percent



Notes: LTSS = long-term services and supports. N = 7,070, weighted to 38.8 million Medicare beneficiaries; excludes nursing home and non-nursing home residential care residents.

Data: Authors' analysis of National Health and Aging Trends Study (NHATS) 2015 data.

Exhibit 6. Proportion of Older Medicare Beneficiaries Receiving Financial Assistance or Other Public Support



Notes: LTSS = long-term services and supports. N = 7,070, weighted to 38.8 million Medicare beneficiaries; excludes nursing home and non-nursing home residential care residents.

Data: Authors' analysis of National Health and Aging Trends Study (NHATS) 2015 data.

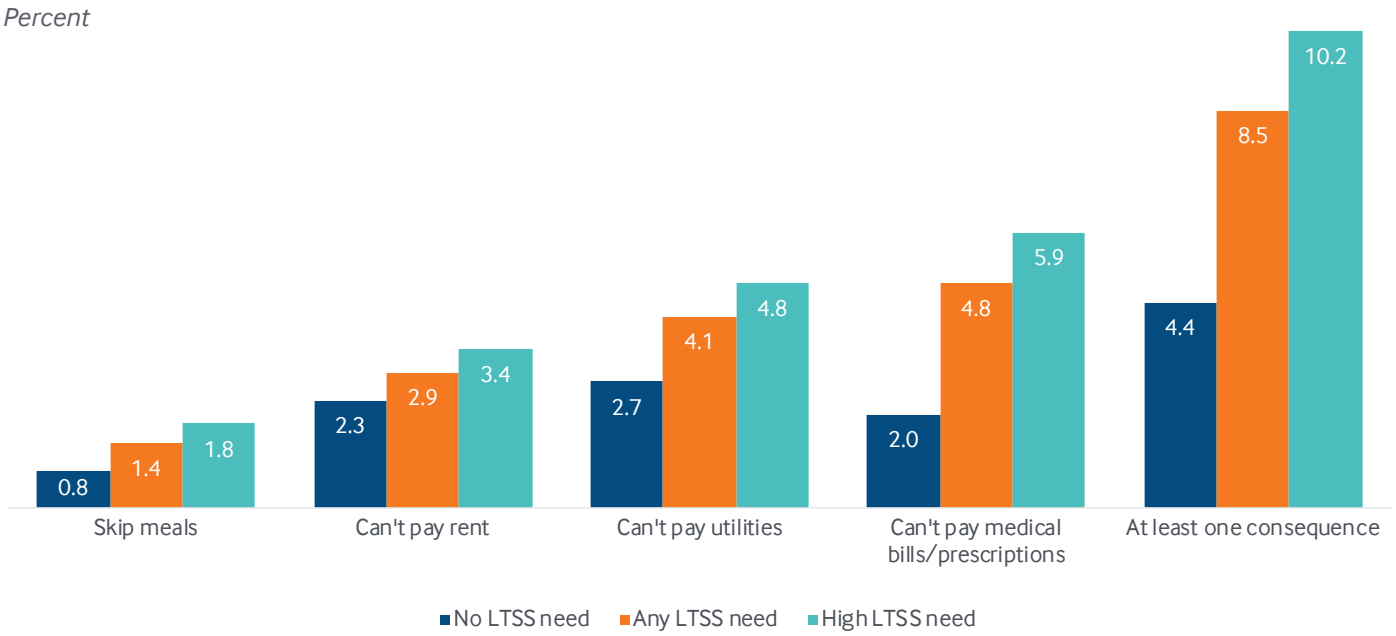
Not receiving assistance may lead to severe adverse consequences for older adults, including an inability to pay for food, rent, or utilities that provide light, heat, or warm running water. Exhibit 7 shows that older Medicare beneficiaries with the greatest LTSS needs are more likely to experience these adverse consequences than those without such needs. Although the absolute percentage of older adults who experience adverse consequences because of unmet needs is small, the relative differences between these groups is concerning. Older Medicare beneficiaries with high LTSS need are twice as likely as those with no LTSS need to skip meals. They are also more likely to not be able to pay rent (3.4% vs. 2.3%) or their utilities (4.8% vs. 2.7%). And compared with those who have no LTSS need, these older adults are nearly three times more likely to be unable to pay their medical bill or prescription copayments, impeding their ability to follow through with care plans.

DISCUSSION

With concerns of growing health care costs and a diminishing Medicare trust fund, there is continued scrutiny on the small proportion of the population that accounts for a significant proportion of health care expenses. Consistent with other studies,[7] we find that Medicare beneficiaries with functional or cognitive impairment that need LTSS incur significant expense to Medicare. The dominant concern of policymakers has been the sustainability of the program, but little attention has been paid to beneficiaries' out-of-pocket burden for the costs of medical care and long-term services.

A recent report by the Commonwealth Fund[8] found that two-thirds of older Medicare beneficiaries required LTSS for at least one ADL in 2015. More than half of beneficiaries with high LTSS need spent money on assistive devices in 2015, with one in 12 beneficiaries spending more than $1,000. Although widely used, assistive devices are only one type of LTSS that individuals with ADL limitations

Exhibit 7. Adverse Consequences Associated with Not Having Enough Money by LTSS Need



Notes: LTSS = long-term services and supports. N = 7,070, weighted to 38.8 million Medicare beneficiaries; excludes nursing home and non-nursing home residential care residents.

Data: Authors' analysis of National Health and Aging Trends Study (NHATS) 2015 data.

might rely on, and therefore represent only a portion of the cost burden. Other needs may include personal care, transportation services, meal delivery and preparation, and environmental modifications.

Many older Medicare beneficiaries have limited means to meet these costs. In 2010, 60 percent of Medicare beneficiaries with high LTSS need had incomes below 200 percent of the federal poverty level — approximately $22,000 in 2010 — and less than half were "dual eligibles" who also qualify for Medicaid.[9] One-quarter of beneficiaries with high LTSS need do not have a credit card; those who do have one are more likely to use it for medical costs and pay only the minimum every month. Older Medicare beneficiaries with high LTSS need were almost three times more likely to be unable to pay for medical care or prescription medications, compared with those with no LTSS need. These adverse consequences are more common among older Americans than they are among older adults in other high-income countries.[10]

If they are not able to access the care they need, carry out their medical care plan, or safely perform ADLs, older adults are likely to experience worse outcomes and become even more costly to the health care system. Additionally, not being able to pay for housing costs or nutritional needs places older Medicare beneficiaries at risk of expensive nursing home placement. (In 2017, a semiprivate room in a nursing home cost $85,775 per year on average.[11]) Nursing homes are intended to provide advanced care for those with complex or severe care needs that cannot be safely provided in the community. They are not meant to be the default option for older Medicare beneficiaries needing long-term services and supports because the financial burden of these costs results in an inability to pay for rent or utilities.

POLICY IMPLICATIONS

The high out-of-pocket costs associated with LTSS place older Medicare beneficiaries requiring these services at increased risk of Medicaid enrollment.[12] This has immediate and long-term cost implications for state and federal Medicaid budgets. By addressing the needs of beneficiaries requiring LTSS, we can also lower Medicare spending for this group by reducing avoidable hospitalizations and emergency department visits.[13]

There have been many financing solutions proposed to support Medicare beneficiaries with limitations in ADLs, from comprehensive support to catastrophic spending coverage only,[14] but little broad progress. Incremental steps were made in the Bipartisan Budget Act of 2018, which gave Medicare Advantage (MA) plans flexibility to provide nonmedical services and to tailor benefits to the needs of beneficiaries.[15] As a result, the 30 percent of the Medicare population enrolled in MA plans can now receive some LTSS coverage.[16]

Many plans and providers participating in alternative payment models are also testing the effectiveness of addressing social determinants of health like housing instability and food insecurity. This study shows that such concerns are of particular concern to beneficiaries with the greatest need for long-term service and supports. Research shows that the help provided by the Supplemental Nutrition Assistance Program (SNAP) and the Low-Income Home Energy Assistance Program (LIHEAP) for low-income beneficiaries is associated with reduced health care spending and nursing home entry.[17] Yet the availability of such services and programs is highly location-dependent, with eligibility for public programs varying across states. Meanwhile, the expansion of health care providers into nonmedical services is still in its infancy.

Our findings also point to the importance of Medicare coverage of personal care services to enhance access to needed care, reduce the financial burden of out-of-pocket expenses, and prevent or delay entry into long-term nursing home care. This analysis shows that the average expenditure on personal care services for those with high LTSS need receiving paid help is nearly $10,000 a year. Adding to Medicare coverage a targeted personal care benefit that provides up to $400 a week would substantially alleviate this financial burden while also helping people live independently.[18]

In the past 50 years, the needs of Medicare beneficiaries have evolved beyond what the program covers to encompass both health and LTSS needs. Without significant updates to the program, many beneficiaries will continue to face significant financial burden, delay necessary care, and experience avoidable adverse outcomes.

HOW WE CONDUCTED THIS STUDY

The National Health and Aging Trends Study (NHATS) is a nationally representative, longitudinal study of Medicare beneficiaries age 65 and older that provides in-depth information on functional and cognitive impairment and how older adults are coping and accommodating with daily life and activities. The NHATS applies a multistage sampling design using the Medicare enrollment file as a sampling frame. It oversamples Medicare beneficiaries at older ages, as well as African Americans. Survey weights are applied to all analyses to account for the sampling design.

This analysis draws on the 2015 wave of the survey to describe levels of long-term services and supports (LTSS) among community-dwelling older adults (persons in nursing home and residential care settings are excluded). The study sample was 7,070, which, when weighted, corresponds to 38.8 million Medicare beneficiaries. Analyses of Medicare spending relied on a sample of 3,975 (weighted to 21.8 million) fee-for-service (FFS) beneficiaries, and prescription drug spending relied on 2,454 (weighted to 13.2 million) FFS beneficiaries enrolled in Medicare Part D.

LTSS need is defined as difficulty in carrying out one or more activities of daily living (ADLs), not doing an activity because of health reasons, using assistive devices to perform activities, or receiving paid or unpaid help for at least one activity. ADLs include eating, bathing, dressing, toileting, transferring in and out of bed, or walking across the room. This analysis focuses on three groups: the first with “no LTSS need” nor difficulty with ADLs (N=1,930); the second with “any LTSS need” that uses LTSS for at least one ADL or reports only difficulty with ADLs (N=5,140); and the third with “high LTSS need,” which refers to using LTSS for two or more ADLs (N=3,503). High LTSS need represents a subcomponent of any LTSS need with greater dependency on support, while no LTSS need and any LTSS need are mutually exclusive.

NOTES

1. Amber Willink et al., *Are Older Americans Getting the Long-Term Services and Supports They Need?* (Commonwealth Fund, Jan. 2019).

2. Karen Davis, Amber Willink, and Cathy Schoen, "Medicare Help at Home," *Health Affairs Blog,* Apr. 13, 2016.

3. Howard Gleckman, "Requiem for the CLASS Act," *Health Affairs* 30, no. 12, (Dec. 2011): 2231–34.

4. Cathy Schoen, Karen Davis, and Amber Willink, *Medicare Beneficiaries' High Out-of-Pocket Costs: Cost Burdens by Income and Health Status* (Commonwealth Fund, May 2017).

5. Amber Willink et al., "Physical and/or Cognitive Impairment, Out-of-Pocket Spending, and Medicaid Entry Among Older Adults," *Journal of Urban Health* 93, no. 5 (Oct. 2016): 840–50; and Amber Willink, Karen Davis, and Cathy Schoen, *Risks for Nursing Home Placement and Medicaid Entry Among Older Medicare Beneficiaries with Physical or Cognitive Impairment* (Commonwealth Fund, Oct. 2016).

6. Schoen, Davis, and Willink, *Medicare Beneficiaries' High Out-of-Pocket Costs,* 2017.

7. Jose F. Figueroa et al., "Concentration of Potentially Preventable Spending Among High-Cost Medicare Subpopulations: An Observational Study," *Annals of Internal Medicine* 167, no. 10 (Nov. 21, 2017): 706–13; Jennifer Windh et al., *Medicare Spending on Older Adults Who Need Long-Term Services and Supports* (Long-Term Quality Alliance, 2017); and Harriet L. Komisar and Judy Feder, *Transforming Care for Medicare Beneficiaries with Chronic Conditions and Long-Term Care Needs: Coordinating Care Across All Services* (SCAN Foundation, Oct. 2011).

8. Amber Willink et al., *Are Older Americans Getting the Long-Term Services and Supports They Need?* (Commonwealth Fund, Jan. 2019).

9. Davis, Willink, and Schoen, "Medicare Help at Home," 2016.

10. Robin Osborn et al., "Older Adults Were Sicker and Faced More Financial Barriers to Health Care than Counterparts in Other Countries," *Health Affairs* 36, no. 12 (Dec. 2017): 2123–32.

11. "Compare Long-Term Care Costs Across the United States 2017" (Genworth, 2017).

12. Willink et al., "Physical and/or Cognitive Impairment," 2016; and Joshua M. Wiener et al., *Medicaid Spend Down: New Estimates and Implications for Long-Term Services and Supports Financing Reform* (RTI International, Mar. 2013).

13. Sarah Ruiz et al., "Innovative Home Visit Models Associated with Reductions in Costs, Hospitalizations, and Emergency Department Use," *Health Affairs* 36, no. 3 (Mar. 2017): 425–32.

14. Davis, Willink, and Schoen, "Medicare Help at Home," 2016; Melissa M. Favreault, Howard Gleckman, and Richard W. Johnson, "Financing Long-Term Services and Supports: Options Reflect Trade-Offs for Older Americans and Federal Spending," *Health Affairs* 34, no. 12 (Dec. 2015): 2181–91; Marc Cohen, Judith Feder, and Melissa M. Favreault, *A New Public–Private Partnership: Catastrophic Public and Front-End Private LTC Insurance* (Urban Institute, Feb. 2018); Long-Term Care Financing Collaborative, *A Consensus Framework for Long-Term Care Financing Reform* (LTC Financing Collaborative, Feb. 2016); and Bipartisan Policy Center, *Initial Recommendations to Improve the Financing of Long-Term Care* (BPC, Feb. 1, 2016).

15. Bipartisan Budget Act of 2018, Congress, 115–119 Sess. (2018).

16. Amber Willink and Eva H. DuGoff, "Integrating Medical and Nonmedical Services — The Promise and Pitfalls of the CHRONIC Care Act," *New England Journal of Medicine* 378, no. 23 (June 7, 2018): 2153–55.

17. Kali S. Thomas and Vincent Mor, "Providing More Home-Delivered Meals Is One Way to Keep Older Adults with Low Care Needs Out of Nursing Homes," *Health Affairs* 32, no. 10 (Oct. 2013): 1796–802; Seth A. Berkowitz et al., "Supplemental Nutrition Assistance Program (SNAP) Participation and Health Care Expenditures Among Low-Income Adults," *JAMA Internal Medicine* 177, no. 11 (Nov. 2017): 1642–49; Seth A. Berkowitz et al., "Meal Delivery Programs Reduce the Use of Costly Health Care in Dually Eligible Medicare and Medicaid Beneficiaries," *Health Affairs* 37, no. 4 (Apr. 2018): 535–42; Laura J. Samuel et al., "Does the Supplemental Nutrition Assistance Program Affect Hospital Utilization Among Older Adults? The Case of Maryland," *Population Health Management* 21, no. 2 (Apr. 2018): 88–95; Sarah L. Szanton et al., "Access to Public Benefits to Reduce Risk for Nursing Home Entry Among Maryland's Dual Eligible Older Adults," Presentation, AcademyHealth, June 2015; and Sarah L. Szanton et al., "Food Assistance Is Associated with Decreased Nursing Home Admissions for Maryland's Dually Eligible Older Adults," *BMC Geriatrics* 17, no. 1 (July 24, 2017): 162.

18. Davis, Willink, and Schoen, "Medicare Help at Home," 2016.

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Judith Kasper, Ph.D., is professor of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health. Dr. Kasper's research and teaching focuses on health policy in disability and long-term care; assessment of needs for care and service provision to physically and mentally disabled people; health care financing and access for vulnerable populations; and the development and application of data sources — national surveys in particular — for health policy analysis and health services research. She is principal investigator of the National Health and Aging Trends Study funded by the National Institute on Aging to support research on disability trends and dynamics among older people.

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