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DATAWATCH

Informal And Formal Home Care For Older Adults With Disabilities Increased, 2004–16

Rates of informal home care use among older adults with disabilities increased from 2004 to 2016, such that in 2016 almost three-quarters of these adults received informal home care. Informal care remains the most common source of home care, even though formal home care use grew at almost twice the rate, with a 6-percentage-point increase to 36.9 percent in 2016.

In the absence of a national system to pay for long-term services and supports for older adults with disabilities, much of the burden of providing home care falls on informal caregivers. Policy makers and advocates raise concerns about the supply and well-being of caregivers, even as many states have expanded formal home care options. Yet national estimates of informal and formal home care use are rare, do not look at changes over time, or are dated.[1–5] Using national data from the Health and Retirement Study, we found that the rate of informal home care receipt grew from 2004 to 2016, such that in 2016 almost three-quarters of older adults with disabilities received informal home care (exhibit 1).

In this article we provide national estimates of the sources and combinations of home care received by cohorts of community-dwelling older adults with disabilities in the period 2004–16. We illustrate variation by race/ethnicity in the use of formal versus informal home care services. Knowing how older adults with disabilities living in the community have, or do not have, their needs for assistance met is critical for developing informed policy.

Study Data And Methods

From the 2004, 2008, 2012, and 2016 waves of the University of Michigan Health and Retirement Study, a longitudinal nationally represen-

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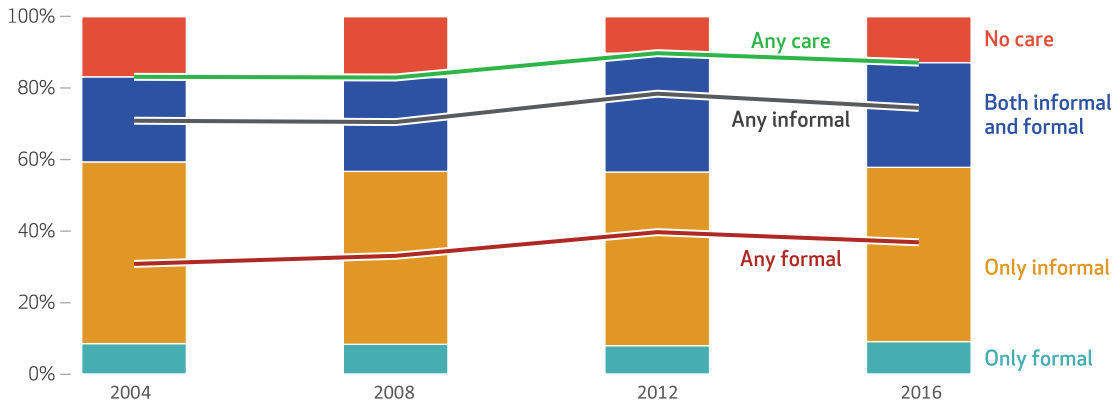
EXHIBIT 1

Use of home care among community-dwelling people ages sixty-five and older with two or more limitations in activities of daily living/instrumental activities of daily living, selected years 2004–16



SOURCE Authors' calculations using the 2004, 2008, 2012, and 2016 waves of the Health and Retirement Study. **NOTES** The weighted percent adjusts for age, sex, and number of limitations in activities of daily living/instrumental activities of daily living. Formal home care does not include transportation services and meals.

tative survey of older people in the US, we included 6,910 unique respondents who were age sixty-five or older, were community dwelling, and reported limitations in two or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs). ADLs can include walking, dressing, bathing, eating, getting into or out of bed, and using the toilet; IADLs can include preparing hot meals, shopping for groceries, making telephone calls, taking medications, and managing money. We used the need for assistance with ADLs and IADLs as a common proxy for functional impairment—the type of disability that is associated with a need for long-term services and supports, such as home care. We used repeated cross-sections and population weights from each wave to provide a nationally representative picture of the prevalence (and changes in prevalence) of formal and informal home care use among older adults with disabilities living in the community. The population weights were adjusted for response rates, which ranged from 81.0 percent to 89.1 percent between 2004 and 2016.

We focused on assessing Health and Retirement Study respondents' receipt of care in the home. Proxy respondents answered for respondents who had significant cognitive impairment, to minimize loss to follow-up. We assessed rates of formal and informal care use in the home, both overall and by race/ethnicity (non-Hispanic white, non-Hispanic black, and Hispanic). Any informal home care (sometimes referred to as family care) was defined as receiving help with ADLs or IADLs from a family member (paid or unpaid) or a nonfamily unpaid helper. Any formal home care was defined as receiving help either from a medically trained person in the home or from a paid nonrelated helper. We estimated the rate of home care receipt for each nationally representative cross-sectional cohort, using probit and multinomial logit models, adjusting for respondents' age, sex, and number of ADL and IADL limitations.

There were limitations to this work. We used the data as repeated cross-sections, so we did not adjust for some respondents being observed in multiple years. Also, proxy response, which ranged from 21.75 percent in 2004 to 14.23 percent in 2016, might not accurately represent what respondents would have answered. Finally, we present analysis from only four waves of the Health and Retirement Study. However, using seven waves yielded results that are consistent with those obtained using four waves, as shown in the online appendix.[6]

Study Results

Rates of use of informal home care and formal home care both increased over the study period, with no apparent trade-off between the two. Formal home care receipt increased at almost twice the rate of receipt of informal home care, with a 6-percentage-point increase to 36.9 percent in 2016 (exhibit 1). The rates of informal home care alone (48.3–50.8 percent) and formal home care alone (7.9–9.2 percent) appear stable. These changes in home care patterns led to a 5-percentage-point increase in receipt of both informal and formal home care (from 23.8 percent to 29.2 percent) and a 4-percentage-point decrease (from 16.9 percent to 12.9 percent) in the percentage of older adults with disabilities who reported receiving no home care.

The national results mask considerable heterogeneity. Although there was an overall reduction in the percentage of older adults with disabilities receiving no home care between the 2004 and 2016 cohorts, the trends differ by race/ethnicity (exhibit 2). Rates of no home care receipt were cut nearly in half among Hispanics during this time as a result of increases in both formal and informal home care receipt. Non-Hispanic whites also saw decreases in rates of no home care receipt, along with a 5.5-percentage-point increase in formal home care receipt (from 30.2 percent to 35.7 percent). Non-Hispanic blacks also experienced an increase in formal home care receipt but had the smallest change in receipt of no home care.

Discussion

For years, informal home care has been the main source of support for older adults with disabilities. Increases in female labor-force participation, declines in fertility, and geographic mobility among adult children have raised concerns about a contraction in the informal home care supply.[7] At the same time, policy and payment reforms such as Medicaid home and community-based services waivers have expanded formal home care options in the past decade. Although older adults overwhelmingly prefer to remain at home, the majority state that they would prefer formal home care over informal home care if they need care in the future.[1] Changing policies, constrained caregiver availability, and individual preferences all may have contributed to the changes in the mix of home care observed during the past decade.

This inquiry shows that although rates of formal home care use increased substantially during the past twelve years, this trend was not accompanied by a decrease in informal home care receipt. In fact, a higher proportion of older

EXHIBIT 2

Type of home care among respondents ages sixty-five and older with two or more limitations in activities of daily living/instrumental activities of daily living, by race/ethnicity, 2004 and 2016

	Any informal home care	Any formal home care	Informal home care only	Formal home care only	Both	No home care
2004	(*n* = 1,361)	(*n* = 657)	(*n* = 855)	(*n* = 151)	(*n* = 506)	(*n* = 524)
White, non-Hispanic	69.9%	30.2%	50.5%	8.6%	22.9%	18.1%
Black, non-Hispanic	74.9	35.1	50.6	8.1	28.6	12.6
Hispanic	72.3	31.2	52.2	8.0	24.9	14.9
2016	(*n* = 1,295)	(*n* = 700)	(*n* = 733)	(*n* = 138)	(*n* = 562)	(*n* = 337)
White, non-Hispanic	72.4%	35.7%	48.4%	9.6%	27.6%	14.5%
Black, non-Hispanic	76.1	38.3	48.9	9.0	30.9	11.2
Hispanic	81.7	42.0	49.0	7.5	35.8	7.7

SOURCE Authors' calculations using the 2004 and 2016 waves of the Health and Retirement Study. **NOTES** *n* is number of observations; the exhibit shows weighted and adjusted row percentages. Adjusted for age, sex, and number of limitations in activities of daily living/instrumental activities of daily living. Formal home care does not include transportation services and meals. The percentages of columns 3, 4, 5, and 6 might not add to 100% because of rounding.

adults with disabilities had two sources of home care in 2016—both informal and formal—than in 2004. That the rate of informal home care receipt has increased is a counterpoint to the worry that the increasingly constrained caregiver supply would not keep pace with demand. This could be interpreted favorably, given that fewer older adults with disabilities are going without care; in contrast, an increase in the rate of informal home care receipt despite the constrained supply could lead to an exacerbation of well-established consequences to caregivers,[8] such as poor health, reduced labor force participation, and strained finances.[9–13]

The increasing prevalence of receipt of both informal and formal home care is noteworthy. Although research has shown that informal home care may substitute for formal home care,[14–16] the two also may be complementary.[5,17,18] Formal home care may allow informal caregivers to focus on different tasks that need attention as the care recipients' needs change.

Importantly, informal home care has been largely left out of policy decisions about formal home care. Policy makers need to consider the availability of informal home care and the role of caregivers when expanding formal home care,[19,20] and clinicians making referrals for formal home health care need to consider the impact on informal care providers, including impacts on their own health and work.

This study was unable to speak to informal home care supply, the intensity of home care received, or who is financing the formal home care (for example, out of pocket versus Medicaid). Recent data efforts, including the National Health and Aging Trends Study; its companion survey, the National Study of Caregiving; and a recent module of the Behavioral Risk Factor Surveillance System (2015–17), can help fill some of these gaps, although none have the same time horizon. Future work should examine the individual financial implications of the increase in formal home care sources, as well as whether this care sustains community living over nursing home entry. However, we know of no data sources that allow for comparisons of informal and formal home care use among nonelderly care recipients. Thus, for policy makers to understand the experiences and spillovers to younger caregivers and the supports used by younger adults with disabilities, new data sources are needed. ■

This article has been corrected online. Exhibits 3 and 4, which had been included in the original version of the article, were deleted. Those exhibits presented state-level data on rates of older adults with limitations in activities of daily living/instrumental activities of daily living who received formal or informal home care. The exhibits were removed as a result of author violations of the data use agreement between the authors and the Health and Retirement Study. Text referring to these exhibits has also been deleted. The remainder of the article, including the results and conclusions, is not affected by these omissions. This research was supported by the National Institutes of Health's National Institute on Aging (Grant No. R01AG057501). This content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health's National Institute on Aging.

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