Does Informal Care Substitute for Formal End-of-Life Care in Medicare Advantage?*

Lauren Hersch Nicholas, Dan Polsky, Cathy Bradley

Abstract

The end of life represents an expensive period of service use for many older Americans, especially those with dementia. Historically, these treatments have been poorly coordinated, with expensive transitions across sites of care. Nearly half of Medicare beneficiaries are now enrolled in Medicare Advantage (MA), the managed care alternative to Traditional, fee-for-service Medicare (TM), near the end-of-life. MA plans are incentivized to reduce healthcare spending, which could be done by encouraging enrollment in hospice care, improving care coordination, or skimping on necessary but expensive services. It is unknown whether the reductions in formal care observed in Medicare Advantage increase reliance on informal caregiving near the end of life.

We use nationally representative Health and Retirement Study survey data linked to Medicare claims for 2,742 survey respondents who died between 2016 – 2021 to assess the differences in rates of informal and formal caregiving near the end-of-life for those in MA versus TM. We estimate general linear models to compare average hours of unpaid informal, insurance paid and out-of-pocket paid home care in the last 3 months of life for HRS respondents dying between 2016 - 2021.

On average, MA decedents were less likely to die in a nursing home and receive fewer days of nursing home care in the last 3 months of life if admitted. While there were no differences in total (paid + unpaid) hours of assistance with ADLs and IADLs among those remaining in the community at death, MA enrollees received 14.4 fewer hours/month of insurance-covered care ($p < 0.05$). This was offset by 24.5 additional hours/month of unpaid informal care from friends and family ($p < 0.05$). While we cannot determine whether the additional informal care represents patient or family preferences versus barriers accessing formal care, we find no differences in use of advance directives or preferences for aggressive end-of-life care in MA vs. TM and receipt of hospice care does not explain the elevated rates of informal caregiving in MA.

The additional informal care provided by MA enrollee's families in the last 3 months of life alone has an estimated value of $3,780 - $4,320 per decedent, a $7.23 to $8.26 billion transfer to MA plans.

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