Reliance on Informal Caregiving for Near the End of Life in Medicare Advantage versus Traditional Medicare

Background: 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.

Methods: We used 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 estimated 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.

Results: On average, MA decedents were less likely to die in a nursing home and averaged fewer days of nursing home care near the end-of-life. While there were no differences in total 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 ($p < 0.05$), with those with at least 1 ADL/IADL limitation averaging 12.2 fewer hours/month ($p < 0.05$). This was offset by 24.5 additional hours/month of unpaid informal care among those with ADL/IADL limitations ($p < 0.05$). The additional informal care has an estimated value of $3,780 - $4,320 per decedent, or $7.23 to $8.26 billion in additional payments to MA plans.

Conclusion: Decedents in Medicare Advantage received more care from informal caregivers near the end-of-life and less professional care in the last 3 months of life. Whether this is driven by patient preferences or insurer decisions, this additional effort from friends and family members represents a transfer to health insurance companies. Additional compensation for family caregivers may be appropriate.