

A study of how Americans die may improve their end of life

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A Rutgers Health analysis of millions of Medicare records has laid the groundwork for improving end-of-life care by demonstrating that nearly all older Americans follow one of nine trajectories in their last three



years of life.

"Identifying which paths people actually take is a necessary precursor to identifying which factors send different people down different paths and designing interventions that send more people down whatever path is right for them," said Olga Jarrín, the Hunterdon Professor of Nursing Research at Rutgers and corresponding author of the study published in *BMC Geriatrics*.

The team pulled the final three years of clinical records from a randomly selected 10% of all 2 million Medicare beneficiaries who died in 2018. Analysis of how much personal care each patient received and where they received care revealed three major care clusters—home, skilled home care and institutional care. Each cluster contains three distinct trajectories.

Roughly 59% of patients fell into the "home" cluster, meaning they spent most of their last three years at home while friends and family helped them with any tasks they couldn't do for themselves. Such patients typically received little professional care, either in their own homes or in nursing homes, until the last year of life.

Another 27% of patients fell into the "skilled home care" cluster, meaning nurses and other skilled professionals helped friends and family care for them inside their own homes for most of their final three years.

The final 14% of patients fell in the "institutional care" cluster and spent most of their final three years either in hospitals or (more commonly) nursing homes, receiving nearly all necessary care from paid professionals.

The researchers used a group-based trajectory modeling approach, evaluating associations between care trajectories and both



sociodemographic and health-related metrics. Patients in both the skilled home care and institutional care clusters were more likely than patients in the home cluster to be female, Black, enrolled in Medicaid or suffering from <u>dementia</u>. Extensive use of skilled <u>home care</u> was more prevalent in Southern states, while extensive use of institutional care was more common in Midwestern states.

"Our study not only identifies different patterns of care but also sheds light on the clinical and policy factors that dictate where and when patients receive care," said Haiqun Lin, lead author of the study and a professor of biostatistics who is also co-director of the Center for Health Equity and Systems Research within Rutgers School of Nursing.

"Understanding these patterns is crucial for advance care planning, and ultimately, for achieving the triple aim of improving care experiences, reducing care costs, and improving care quality."

The study is the first of several the researchers plan to base on their analysis of the Medicare data. Now that they have identified the trajectories that people actually follow in their last years of life, they will look for the key factors that direct people down each path and interventions that will help more people stick to the path they prefer.

For most but not all people, that means one of the paths in the home <u>cluster</u>.

"Most people want to stay at home with minimal professional help," said Jarrín, who also is the director of the Community Health and Aging Outcomes Laboratory within Rutgers Institute for Health, Health Care Policy, and Aging Research. "However, the goal for a significant minority of people is to avoid being a burden to family and friends, and such people tend to want professional care."

Jarrín added, "Our goal isn't forcing people toward any particular type of



care. It's helping them to plan for and get the care that's right for them."

More information: Place of Care in the Last Three Years of Life for Medicare Beneficiaries, *BMC Geriatrics* (2024). DOI: 10.1186/s12877-023-04610-w

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