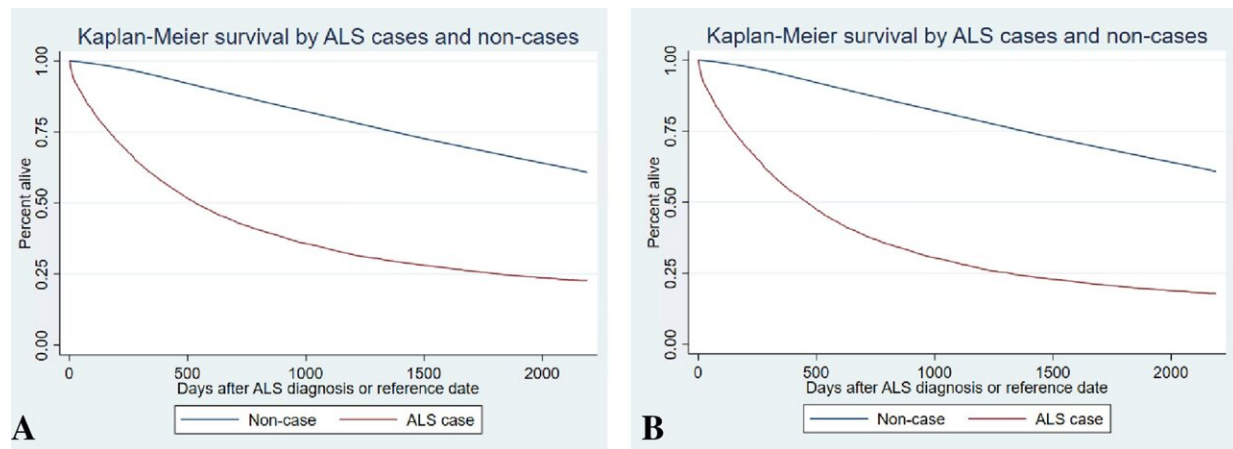


Study finds ALS patients treated by neurologists received better care

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Kaplan-Meier Estimates of Survival among Individuals with and without an ALS Code (ICD-9-CM ALS code [335.20]), U.S. Medicare 2009. Credit: *PLOS ONE* (2024). DOI: 10.1371/journal.pone.0304083

Amyotrophic lateral sclerosis (ALS) patients received better care if they were treated by a neurologist, a new [study](#) published in *PLOS One* has found.

But researchers found that Black, older and socially disadvantaged ALS patients were less likely to see a [neurologist](#), raising concerns about equity in treating the deadly disease.

Patients who were treated by neurologists were more likely to receive interventions endorsed by the American Academy of Neurology.

"This study highlights the importance of neurologist care for ALS patients and the need to overcome barriers and provide care that is more equitable for ALS patients," said Brad Racette, MD, FAAN, Chair of Neurology at Phoenix's Barrow Neurological Institute and senior author of the study.

"Life expectancy in ALS is short, with average survival two years after diagnosis and only 10% survival after five years. Interventions that improve survival and [quality of life](#) are critical for the care of these patients."

Barrow Neurological Institute joined the study with Washington University School of Medicine in St. Louis and the University of the Witwatersrand in Johannesburg.

In 2009, the American Academy of Neurology (AAN) published practice parameters for ALS ([amyotrophic lateral sclerosis](#)) [patient care](#) with evidence-based interventions that improve ALS patients' survival and quality of life. These recommended interventions include prescription of riluzole, early [feeding tube](#) placement and non-invasive ventilation.

Using Medicare claims, the study reviewed 8,575 ALS cases between 2009 and 2014—and only 3,676 (42.9%) saw a neurologist during the five-year follow-up period. The cohort was composed primarily of non-Hispanic White beneficiaries (86.7%) with an average age of 68.1 years. Slightly more than half (54.5%) were male.

The study found that those patients who saw neurologists after their diagnosis were more likely to receive care consistent with the AAN

practice parameters than those who did not. The study found that of all Medicare beneficiaries with ALS, 26.7% received a feeding tube, 19.2% received non-invasive ventilation and 15.3 filled a riluzole prescription between diagnosis and death or end of follow-up. Patients with ALS who saw a neurologist were much more likely to receive each of these interventions than patients who never saw a neurologist.

Black beneficiaries were less likely to receive care from a neurologist than non-Hispanic White beneficiaries. Beneficiaries in a disadvantaged area were less likely to receive care from a neurologist compared to beneficiaries in an advantaged area.

Neurologists provided care that was consistent with evidence-based guidelines far more often than non-neurologists, the study determined.

Dr. Racette said that as interventions are likely more effective in the early stages of the disease, and utilization of non-invasive ventilation and feeding tubes can lead to improved survival and quality of life, it is critical for providers who take care of ALS patients to be aware of evidence-based ALS practice parameters.

"The difference between the care received by ALS patients who were treated by a neurologist and those who did not see a neurologist was dramatic," Dr. Racette said. "Our study highlights the importance of receiving specialist care for ALS patients and provides evidence that may guide health policies and education efforts in the U.S.

"This is of critical importance as the aged population continues to increase; the treatment disparities presented here may continue to worsen without efforts to mitigate them, in particular for Black and disadvantaged beneficiaries," Dr. Racette said.

More information: Osvaldo J. Laurido-Soto et al, Adherence to

practice parameters in Medicare beneficiaries with amyotrophic lateral sclerosis, *PLOS ONE* (2024). DOI: [10.1371/journal.pone.0304083](https://doi.org/10.1371/journal.pone.0304083)

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