Healthcare Costs and Utilization Patterns Before and After Dementia Onset With and Without Timely Clinical Recognition by the Healthcare System

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Despite increasing advocacy for early detection of Alzheimer's disease and related dementias (ADRD), most individuals are not diagnosed in a timely fashion. Because there is currently no cure, the economic benefits and costs of timely diagnosis remain largely theoretical and empirically untested. We analyzed healthcare utilization and cost patterns for a cohort of patients before and after clinical recognition of dementia to determine the empirical impact of a timely diagnosis.

We linked participant data from five longitudinal cohort studies at the Rush Alzheimer's Disease Center (RADC) with Medicare Fee-For-Service claims. This study design allowed us to compare two distinct data points: the date of dementia onset determined by annual RADC cognitive assessments (which are not routinely disclosed to participants) versus the date of clinical recognition identified through the first Medicare claim containing ICD-9 or ICD-10 diagnosis codes for dementia. Based on these timepoints, we defined a "timely diagnosis" as the presence of a clinical diagnosis within a window spanning three years prior to one year after the research-determined onset. The comparator "underdiagnosed" group consisted of individuals who were either diagnosed late or never received a clinical diagnosis prior to death. We examined Medicare Part A and B costs, emergency department visits, hospitalizations, and outpatient interactions. We adjust for an extensive set of fixed effects and patients' characteristics (demographics, cognitive function, health status).

Our study offers several key takeaways. First, nearly half of the patients with dementia are not diagnosed in a timely manner in the healthcare setting. Second, while healthcare utilization and costs are generally higher among patients with clinically recognized dementia, this is primarily driven by differences in patient and clinical characteristics across groups. Third, for most outcomes—specifically total costs, emergency department visits, and hospitalizations—utilization increased during the three years leading up to dementia onset, peaked around the time of onset, and then declined regardless of whether dementia was clinically recognized. However, outpatient provider interactions followed a distinct pattern; the timely diagnosis group had a significantly higher number of interactions before onset which then experienced a sharp decline after onset, eventually leading to fewer interactions compared to the underdiagnosed group.

These findings imply that the post-onset decline in general healthcare costs is not driven by the receipt of a diagnosis, as previously hypothesized, but happens universally at the onset of dementia regardless of whether a healthcare provider diagnoses it. Furthermore, the higher costs associated with diagnosed dementia are attributable to underlying health characteristics. Our

findings highlight the need for clearer guidelines on appropriate care for patients with dementia, including specific factors that should be considered when evaluating different treatment options.