The Impact of Hospice Care on the Wellbeing of Alzheimer's Disease Patients and Their Family Members

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Specific Aims and Significance

With the rapidly rising prevalence of people with Alzheimer's Disease (AD), there are substantial concerns with how best to care for AD patients near the end of life. While two decades ago, relatively few were admitted to hospice, by 2019 **over two-thirds of Medicare decedents with AD died in hospice.** Family members of AD patients, often aptly named "the invisible second patients," bear a significant burden in the care of their loved ones.

Although AD patients increasingly rely on hospice care, it is not known whether this trend has led to improvements in the well-being of AD patients at the end of life or the well-being of their family members. Existing evidence on the effects of hospice care for AD patients has primarily relied on cross-sectional comparisons between patients who elect hospice vs. those who do not; this methodology is limited by selection bias, as patients who choose hospice care (and their family members) may differ in unobservable ways from those who do not. Furthermore, existing studies of family members have mostly relied on survey data with small samples, which may suffer from response bias and limited generalizability.

In this project, we will estimate the impact of hospice use on the well-being of AD patients and the family members who live with them. This project makes two main contributions. First, we will overcome selection bias in hospice utilization by leveraging natural experiments arising from the opening of new hospice facilities, which generates shocks to the availability of hospice services in a local health care market. Second, we will analyze caregiver outcomes in large administrative data, using a novel linked-address dataset for the universe of Medicare beneficiaries that allows us to identify family members who reside at the same address as the AD patient.

In particular, we plan to use **20 years of Medicare claims and patient assessment data on both AD patients and their family members** to analyze how hospice care affects their physical and psychological well-being. Between 1999 and 2019, the number of hospice facilities increased from about 2000 to 4500. Our preliminary analyses show that each new entrant increases county-level hospice utilization by 10%. Using hospice openings as an instrumental variable for hospice use, we will estimate the impact of hospice use by comparing observably identical AD patients and family members in areas with increased availability of hospice care to those in areas that did not experience changes in availability. Our specific aims are:

Aim 1: To assess how hospice care affects the cognitive and functional well-being of AD patients

We will assess how the greater availability of hospice affects patients' well-being through a) changes in utilization of health care services and b) changes in assessed outcomes. We will analyze Medicare claims data to identify changes in AD patients' health care service use following hospice enrollment. We will focus on services that are associated with reduced comfort and lower quality of life, such as days spent in inpatient, intensive care unit, or other institutional settings. We will also analyze changes in the use of services targeted at co-morbid conditions (e.g., diabetes, heart disease), mental health services, psychiatric medications, and pain medications.

We will examine whether hospice use leads to changes in AD patients' cognitive and functional well-being by analyzing the rich outcomes in the CMS-mandated health assessments in the Minimum Data Set (MDS) and the Home Health Outcome and Assessment Information Set (OASIS). These assessments are collected by health care professionals in regular intervals for all nursing home residents and home health patients, each of which cover approximately half of all hospice patients. We will test whether electing hospice affects measures of pain management, depression, and ability to carry out activities of daily living.

Aim 2: Measuring how hospice care affects the physical and psychological well-being of family members living with AD patients

We will identify individuals living with AD patients using the linked-address data and analyze changes in their physical and psychological well-being using the same data described above, focusing on outpatient visits, physician services, and prescription drugs. On the one hand, if hospice care improves the comfort of AD patients, it could ease the physical and psychological burden on family caregivers. On the other hand, since patients must forgo curative care when electing hospice, family members could experience increased burden in informal caregiving and adverse health outcomes. We will explore heterogeneity by beneficiary characteristics, including conducting stratified analysis for Black and Hispanic beneficiaries, who on average are less likely to use hospice than White patients.

We plan to advance research in this field by creating a comprehensive linked database for AD patients and their caretakers. We will publish the database aggregated at the county-year level to facilitate further research and policymaking. Through this R03 project, we plan to build the groundwork for a future R01 where we will expand our analysis to include the Medicare Advantage population.

Data and Approach

We will use administrative data from the Centers for Medicare and Medicaid Services (CMS) between 1999 to 2019. Specifically, we use data from the Provider of Services (POS) file to identify facility openings in each geographic region (counties) during the study period. We use these data to identify a set of "experiments" that consist of one county with a new hospice facility entering the market at a particular time point, plus a set of control counties without new hospice entry. We will then merge the hospice facility entry experiments with the Medicare Master Beneficiary Summary File (MBSF) and the Chronic Conditions Segment to identify Medicare beneficiaries with AD who reside in each of the treated or control counties in each experiment.

We will use the 100% Medicare hospice claims data to measure hospice utilization. We will use the Medicare inpatient, outpatient, skilled nursing facility, home health, and Part D claims data to measure care intensity via total spending. For example, prior studies have found a negative association between electing hospice and inpatient hospitalizations and intensive care unit use. We will use the claims data to assess whether electing hospice *causes* a lower intensity of non-hospice care. Table 1 shows categories and examples of outcome variables measuring AD patient well-being. We will extract these from the universe of CMS patient assessment data, which consists of the minimum data set (MDS), available from 1999 to 2019, for nursing home patients and the outcome and assessment information set (OASIS), available from 2006 to 2019 for patients receiving home health.

Table 1. Key measures of patient well-being, by data source

OASIS [Variable name in Version B1; Version C1]	**MDS** [Variable name in MDS 2; MDS 3]
Pain: frequency of pain (none, some days, daily, constant) [m0420; m1242]	**Pain**: presence, frequency (rarely—almost constantly), intensity (mild—very severe) [J2A, J2B; J0400, J0600A, J0600B] indicator for pain affecting sleep*, indicator for pain affecting day-to-day activity* [J0500A, J0500B]
Depression: any depression, depression score on PHQ-2 screening* [m0590; m1730]	**Depression and Anxiety**: whether and how frequently verbal and non-verbal expressions of distress were observed [E1A-E1P]** depression score on PHQ-9 screening* [D0200A-D0200I]
Anxiety: from "never" to "constant"^ [m0580; m1720]	
Activities of Daily Living (ADL) from fully independent to fully dependent: dress, bathe, toilet, transfer, locomotion [m0650-m0700; m1810-m1860]	**Activities of Daily Living** (ADL) from fully independent to fully dependent: bed mobility, bathe, toilet, transfer, locomotion, walk, eat [G1AA-G2B; G0110A1-G0120B]
Pressure and Stasis Ulcers: presence and stage [m0460, m0470; m1324, m1332]	**Pressure and Stasis Ulcers**: presence and stage [M1A-M1D, M2A-M2B; M0100A-M0900D]
Confusion: from "never" to "constant"^ [m0570; m1710]	**Medications**: antipsychotics, anxiolytics, antidepressants [O4A-O4C; N0400A-N0400C]

*Only available starting 2010. **Only available prior to 2010. ^Only available at admission.

Our analysis of family member well-being will use the same databases described above. However, despite the analogous empirical strategies, the results of our **Aim 2, which looks at caregiver outcomes, are independent and do not rely on our results from Aim 1**. Ex ante, the effects of hospice on caregivers may be smaller *or larger* than the direct effects of hospice on AD patients.

A key novel dataset for this analysis is a linked-address crosswalk that links each Medicare beneficiary to all other Medicare beneficiaries by residential address (including street and apartment numbers). Due to privacy concerns, it is not possible to observe a beneficiary's exact address at a level finer than the 9-digit zip code. The novel crosswalk that we use does not reveal address information, but rather **allows us to know which beneficiaries were living together at a given point in time** between 2006 and 2017. We will henceforth infer that beneficiaries linked to an AD patient are family members and thus likely to be caregivers. We will filter out cases where a large number of beneficiaries are linked together, as these likely represent group living situations such as nursing homes. Because this unique crosswalk is updated at the yearly level, we can capture cases where AD patients previously lived at home but later moved into a nursing or group home.

After restricting to individuals with a matched family member with AD, we will apply our empirical framework to family member outcome variables, focusing on the Medicare outpatient, physician, drug claims data. AD patients' caregivers are less to be receiving nursing home care themselves, which rules out the MDS as a source of outcomes. For family members who also receive home health care, we will additionally draw on OASIS for psychological measures (e.g., depression, anxiety). We hypothesize that an AD patient's hospice election might affect their caregiver's ability to seek outpatient and preventive care themselves.