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Original Report

Decision Making for Patients With Severe Dementia Versus Normal Cognition Near the End of Life

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Abstract

Background and Objectives: The clinical progression of severe dementia frequently leads to situations where surrogate decision makers must quickly make choices about potentially burdensome treatments that offer limited clinical benefit. We examined whether the number of decision makers and their access to advance directives were related to treatment choice for patients with severe dementia in comparison to those with normal cognition.

Research Design and Methods: We retrospectively linked survey responses about end-of-life treatment decisions to Medicare claims for Health and Retirement Study respondents dying between 2002 and 2015 whose next-of-kin reported a need for surrogate decision making. We estimated multivariable logistic regression models to study measures of aggressive care in the last 6 months of life; in-hospital death, burdensome transfers, and burdensome treatments.

Results: Compared to patients who were cognitively normal near the end of life (n = 1 198), patients with severe dementia (n = 722) were less likely to experience burdensome treatments (18% [95% confidence interval {CI} 14–21] vs 32% [95% CI 29–35]), burdensome transfers (20% [95% CI 17–24] vs 30% [95% CI 27–33]), and in-hospital death (24% [95% CI 20–28] vs 30% [95% CI 26–33]) when surrogates were involved. Rates of burdensome treatments, transfers, or in-hospital death for decedents with severe dementia did not vary with single versus multiple decision makers or when decision makers were informed by advance directives. However, among decedents with normal cognition, a single decision maker informed by an advance directive was associated with the lowest rates of burdensome treatments and in-hospital death.

Discussion and Implications: Surrogate decision makers made similar choices around end-of-life care for patients with severe dementia regardless of the number of decision makers and availability of advance directives. However, both advance directives and single decision makers were associated with less aggressive care for cognitively normal decedents.

Translational Significance: Family and friends must frequently make end-of-life decisions for older adults with serious illness, yet little is known about the importance of the composition of the decision-maker team. We studied the receipt of medical treatments that may be painful or burdensome to patients during the last 6 months of life. Our results suggest that written documents describing treatment preferences and having 1 person make decisions were associated with less aggressive care for cognitively normal decedents, but neither was associated with treatment differences for dementia patients. Patients may want to select single decision maker if they prefer less aggressive care.

Keywords: Advance care planning, Cognitive impairment, Family caregivers

Health care for older Americans near the end of life (EOL) can be characterized by aggressive and invasive medical care that is at odds with patients' stated preferences. Serious illness can impede patients' abilities to make decisions about their care, creating a need for surrogate decisions to be made, usually by family or friends. This is particularly salient for the 22% of older adults who develop severe dementia prior to death (1). Severe dementia often co-occurs with physical health conditions that can lead to frequent hospitalizations and situations requiring decisions about aggressive and potentially

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burdensome treatments that are unlikely to improve the survival or quality of life for these patients (2–4).

Surrogate decision makers must often make decisions quickly and with limited information about their loved ones' preferences in the context of emergency hospitalizations and other acute health events where dementia or temporary impairment limits patient participation (4–6). Surrogates report difficulties making these decisions, and studies suggest that surrogate decisions do not necessarily reflect patient preferences (3, 7–9). Surrogates frequently rely on several sources of information when making EOL decisions including written and oral direction from patients, their own experiences and preferences, and guidance from others, who may not have a relationship with the patient (3, 7, 9, 10).

A growing body of nationally representative studies in the United States find that advance directives are associated with less aggressive EOL care on some, but not all metrics, though nontrivial shares of patients with care-limiting preferences receive aggressive care (1, 11–14). Recommendations to engage in advance care planning, ideally prior to the onset of cognitive impairment, are often posited as strategies to improve the quality of EOL care, yet recent studies find that relatively few patients are engaging in activities such as preparing written advance directives, given legal authority to surrogate decision makers, and discussing treatment preferences, even when serious, life-limiting illness such as cancer or dementia presents (15, 16).

Important questions about the optimal nature of advance care planning remain, along with concerns that focusing on written documents prepared at a point in time may not be applicable to decisions that ultimately need to be made or may not accurately characterize preferences if these evolve over the course of illness (17–19). Even when surrogates are informed about the patient's preferences, there are many potential barriers to decision making. Evidence from behavioral economics indicates that decision making is affected by framing and other contextual clues (20, 21). Inclusion of a larger number of decision makers could complicate the process by requiring additional time to deliberate and introduce the potential for conflict. Life-extending treatments could be required to enable multiple decision makers to travel in for a last visit or to gather for a meeting with the care team, or be delivered while a surrogate team assessed conflicting information about patient preferences that may have been revealed to different members of the team, especially if no written document is available. To the best of our knowledge, studies of advance directive efficacy have not explored the potential role of the number of decision makers, though the need to reach a consensus among group members suggests that decisions could vary even when participants can draw on written advance directives.

To address this gap, we use linked survey and claims data to compare decisions that surrogates make for patients with severe dementia, where potentially burdensome treatments are known to offer little benefit, to decisions made for cognitively normal decedents who might experience greater therapeutic benefit. We assess whether decisions vary when decision makers are informed by advance directives and decide alone or in groups.

Method

We studied in-hospital death and receipt of potentially burdensome medical treatments made for a sample of decedents who were part of a nationally representative panel study of older Americans and required surrogate decision making near the EOL.

Data

The Health and Retirement Study (HRS) is a large, nationally representative, longitudinal study of adults aged 51 and older and their spouses that has been collected since 1992 (22). HRS respondents provide considerable detail about health and economic well-being through biennial interviews. HRS also conducts posthumous exit interviews with proxy informants, who are typically the same individuals named as power of attorney and/or who were involved with EOL decision making (1). We included HRS respondents who died between 2002 and 2015, had a complete exit interview with a proxy respondent, required surrogate decision making near the EOL, and had linked Medicare claims. Sample composition is shown in Figure 1 and described later.

Surrogate Interviews

Next-of-kin proxy respondents reported whether the decedent required surrogate decision making near the EOL, information about the people involved in the decision, and whether there was a written advance directive that indicated a desire to limit treatment in some circumstances in the HRS Exit Interviews. We used these data to focus on the subset of decedents whose proxy informants reported that the decedent required surrogate decision making near the EOL in response to the survey question "Did any decisions have to be made about the care and treatment of [First Name] during the final days of [his/her] life?" If decisions were required, respondents were also asked about who participated in these decisions, which allowed us to identify deaths with single versus multiple decision makers. Deaths, where proxies reported that decisions were necessary, were characterized by a larger number of situations where decisions could be necessary, such as hospitalizations near the EOL.

Cognitive Status

We classified respondents' cognitive functioning as cognitively normal, mild dementia, or severe dementia during their last interview prior to death using a previously validated algorithm that crosswalks respondents' cognitive performance on the Telephone Interview for Cognitive Status or proxy reports about memory and cognition during their last core interview to clinical categories (normal cognition, mild cognitive impairment, and dementia). Survey measures of cognitive functioning were crosswalked to clinically meaningful designations based on the survey results of a set of respondents who also underwent a full clinical examination through the Aging, Demographics, and Memory Study using methods that have been described previously (23, 24). Use of survey-based measures allows us to identify dementia patients even if they do not receive Medicare-reimbursed care for their dementia. We classified decedents as having severe dementia if their cognitive performance was consistent with dementia and they had 3 or more activities of daily living limitations following other HRS papers (1). We compare decedents with severe dementia to those who were cognitively normal.

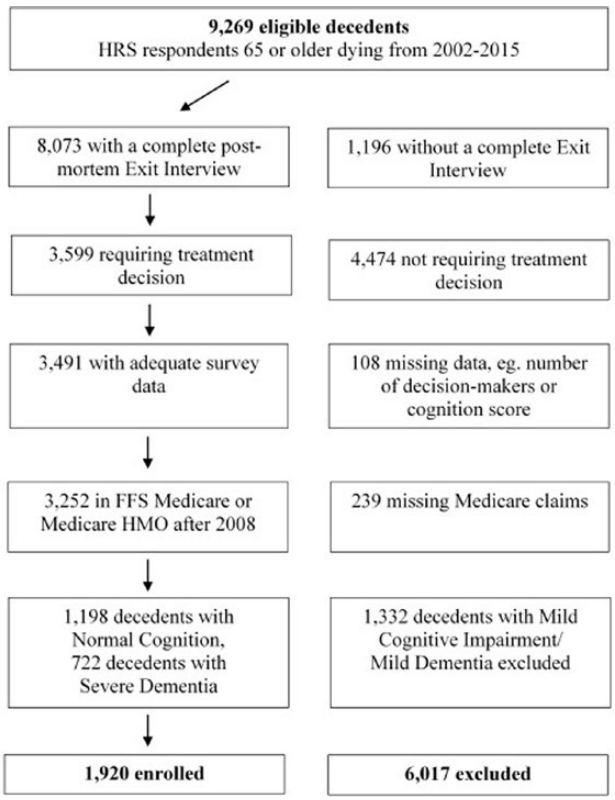

Figure 1. Sample construction process. HRS = Health and Retirement Study; HMO = Health Maintenance Organization.

Medicare Claims Characterize Potentially Burdensome End-of-Life Care

Most HRS respondents consent to a Medicare linkage, providing administrative claims data detailing treatments received for more than 93% of our potential sample (Figure 1). We used MedPAR inpatient hospitalization claims data to identify 3 dependent variables commonly used to assess the aggressiveness of EOL care. Burdensome treatments include feeding tube placement, dialysis, cardiopulmonary resuscitation, mechanical ventilation, and tracheostomy in the last 6 months of patients' lives (25). Burdensome transfers include any transfer between sites of care in the last 3 days of life, more than 2 hospitalizations in the last 90 days of life, and multiple admissions for dehydration, pneumonia, sepsis, or urinary tract infection in the last 120 days of life (26). Because we only observe Medicare-reimbursed care, we may understate the total number of burdensome transfers, for example, if there are private-pay nursing home stays or moves across facility types in a continuing care community. In-hospital death was assessed using the final disposition of hospitalizations ending on the date of death. We excluded the small number of decedents who were enrolled in Medicare managed care plans and died before 2008, because claims data were not collected on managed care enrollees during this period. After that time, MedPAR reported necessary utilization data for those in Medicare Advantage and Fee-for-Service Medicare.

Statistical Analysis

We estimated multivariable logistic regression models to study in-hospital death, burdensome transfers, and burdensome treatments during the last 6 months of life using Stata 15. We first compared differences in these outcomes among decedents with severe dementia versus normal cognition in their last core interview, because these treatments are recognized as unlikely to provide therapeutic or quality-of-life benefits to patients with severe dementia. We then assessed whether the presence of multiple decision makers and treatment-limiting advance directives were associated with differential rates of in-hospital death, burdensome treatments, and transfers for either group of patients. Our regression models included controls for self-reported age, sex, race, Hispanic ethnicity, educational attainment, veteran status, and proxy reports of whether the decedent lived in a nursing home at the time of death, the number of living children and children living nearby, and comorbid health conditions. Our de-identified secondary data analysis was exempt from review by a local university Institutional Review Board (blinded for review).

Although we primarily identified the need for treatment decisions from proxy reports in the HRS exit interviews, this approach may not capture decedents with critical treatment needs requiring surrogate decision making near the EOL. The MedPAR data provided an alternative way to focus on these decedents. As a robustness check, we also included decedents with hospitalization during the last month of life that began with an emergency department visit in the surrogate decision-making cohort.

Results

Our sample included 1 920 decedents who required EOL decision making, including 722 with severe dementia (37.6%; Table 1). Deaths where proxies reported a need for decision making were characterized by more hospitalizations in the last 6 months of life, higher risk of emergency admission in the last month of life, and less use of hospice care than those without decision making (Supplementary Table 1), suggesting that proxy reports accurately identified patients who experienced clinical situations more likely to require decision making. Decedents with severe dementia were older and more likely to be female, Black, and Hispanic than cognitively normal decedents. Cognitively normal decedents were more likely to experience burdensome treatments, burdensome transfers, and in-hospital death prior to adjusting for demographic characteristics and comorbidities. Multiple decision makers were more common for cognitively normal patients (45.2% vs 17.6%) and slightly more of the multiple decision-maker teams had advance directives when decedents were cognitively normal (54.8% vs 49.3).

After adjusting for demographics, family characteristics and comorbid health conditions, patients with severe dementia remained less likely to experience burdensome treatments (18% [95% confidence interval {CI} 14–21] vs 32% [95% CI 29–35]; Figure 2; Supplementary Table 2), burdensome transfers (20% [95% CI 17–24] vs 30% [95% CI 27–33]), and in-hospital death (24% [95% CI 20–28] vs 30% [95% CI 26–33]) compared to those with normal cognition.

Having an advance directive and a single decision maker was associated with the lowest rate of potentially burdensome treatment for cognitively normal decedents (27% [95% CI 22–33] vs 35% [95% CI 22–33] for no advance directive, multiple participants; Figure 3; Supplementary Table 3), whereas advance directives and multiple participants (12% [95% CI 7–18] vs 23% [95% CI 16–29]) were associated

Table 1. Summary Statistics

Variable	Cognitively Normal		Severe Dementia*	
	Multiple Participants	Single Participant	Multiple Participants	Single Participant
	n = 666	*n* = 532	*n* = 357	*n* = 365
Died in hospital, *n* (%)	301 (45.2)	195 (36.7)	63 (17.6)	76 (20.8)
Burdensome transfer, *n* (%)	213 (32.0)	160 (30.1)	65 (18.2)	76 (20.8)
Burdensome treatment, *n* (%)	230 (34.5)	180 (33.8)	57 (16.0)	58 (15.9)
Advance directive, *n* (%)	365 (54.8)	281 (52.8)	176 (49.3)	161 (44.1)
In nursing home, *n* (%)	231 (34.7)	231 (43.4)	266 (74.5)	276 (75.6)
Age, years, mean (*SD*)	80.3 (7.9)	79.6 (8.5)	85.5 (8.0)	86.6 (8.4)
Female, *n* (%)	353 (53.0)	292 (54.9)	244 (68.3)	236 (64.7)
Veteran, *n* (%)	226 (33.9)	162 (30.5)	70 (19.6)	76 (20.8)
Hispanic, *n* (%)	28 (4.2)	17 (3.2)	22 (6.2)	43 (11.8)
Black, *n* (%)	41 (6.2)	46 (8.6)	55 (15.4)	62 (17.0)
<High school, *n* (%)	153 (23.0)	133 (25.0)	170 (47.6)	189 (51.8)
High school, *n* (%)	227 (34.1)	173 (32.5)	92 (25.8)	89 (24.4)
>High school, *n* (%)	286 (42.9)	226 (42.5)	95 (26.6)	87 (23.8)
Married, *n* (%)	335 (50.3)	247 (46.4)	104 (29.1)	96 (26.3)
Living children, mean (*SD*)	3.3 (2.0)	2.9 (2.4)	3.5 (2.3)	2.9 (2.5)
Children within 10 miles, mean (*SD*)	0.2 (0.4)	0.1 (0.4)	0.2 (0.4)	0.1 (0.3)
Medicare HMO, *n* (%)	152 (22.8)	105 (19.7)	53 (14.8)	55 (15.1)
Years dementia, mean (*SD*)			8.8 (4.6)	8.7 (4.4)
Cancer, *n* (%)	217 (32.6)	180 (33.8)	71 (19.9)	69 (18.9)
Lung condition, *n* (%)	159 (23.9)	149 (28.0)	63 (17.6)	41 (11.2)
Diabetes, *n* (%)	206 (30.9)	160 (30.1)	103 (28.9)	113 (31.0)
Heart condition, *n* (%)	334 (50.2)	260 (48.9)	173 (48.5)	167 (45.8)
Stroke, *n* (%)	105 (15.8)	115 (21.6)	163 (45.7)	171 (46.8)
Psychological problems, *n* (%)	110 (16.5)	92 (17.3)	144 (40.3)	134 (36.7)
ED visit, last month, *n* (%)	411 (61.7)	312 (58.6)	154 (43.1)	160 (43.8)
Years from last core interview to death, mean (*SD*)	1.6 (1.1)	1.5 (1.6)	1.0 (0.9)	1.0 (0.8)

Notes: ED = Emergency Department; HMO = Health Maintenance Organization; IP = inpatient; *SD* = standard deviation. Respondents to the Health and Retirement Study (HRS) age 65+ with linked Medicare claims who died from 2002 to 2015 and required a treatment decision near the end of life.
*Severe dementia is determined using an algorithm from (1), which incorporates cognitive assessment scores with proxy assessments and limitations on Activities of Daily Living (ADLs).

with the lowest rates of burdensome treatment for severe dementia patients in comparison to those who lacked an advance directive and had multiple decision makers.

Neither the number of decision makers nor the presence of an advance directive was associated with lower rates of burdensome transfers for either cognitively impaired or cognitively normal decedents (Figure 3; Supplementary Table 4).

Rates of in-hospital death were consistently lower for severe dementia patients than those with normal cognition. However, there were no significant differences across advance directive use or number of decision makers for those with severe dementia (Figure 3; Supplementary Table 5). Among the cognitively normal decedents, having a single decision maker was associated with lower rates of in-hospital death regardless of whether an advance directive had been prepared.

We assessed the robustness of our findings to a number of alternative specifications, including restricting the sample to decedents who had an emergency department visit in the last month of life, adding controls for the decedent's Hospital Referral Region quartile of EOL Medicare spending, derived from the Dartmouth Atlas of Healthcare, to capture the average aggressiveness of a decedent's health care environment, and focusing on deaths since 2008 in case care patterns were changing over time and to avoid any bias resulting from the lack of Medicare managed care claims in the early years of our sample. In the last month of life alone, between 43% and 62% of decedents were admitted to the hospital through the emergency department (Table 1), suggesting that proxy-reported need for surrogate decision making tracked well with situations where patients would have required acute medical care near the EOL. The robustness analyses indicated that advance directives were associated with lower burdensome treatment and in-hospital death in models that did not account for the number of decision makers, and found mixed evidence of differences between single and multiple decision makers (Supplementary Figures 1–4).

Discussion and Limitations

Older adults with and without prior cognitive impairment frequently require surrogate decision making near the EOL. Our results concur with other studies reporting lower rates of aggressive care for patients with severe dementia in comparison to those with normal cognition (15, 26–28). Although

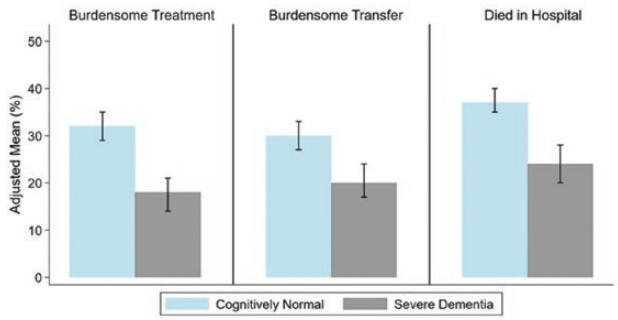

Figure 2. End-of-life treatments among patients requiring surrogate decision-making. Respondents to the Health and Retirement Study age 65+ with linked Medicare claims who died from 2002 to 2015 and required a treatment decision near the end of life. Severe dementia is determined using an algorithm from (1), which incorporates cognitive assessment scores with proxy assessments and limitations on activities of daily living. Means (95% CIs) are adjusted for decedent demographics, family characteristics, nursing home residence, receiving health care through a Health Maintenance Organization, years with mild cognitive impairment/dementia, and comorbid health conditions. CI = confidence interval.

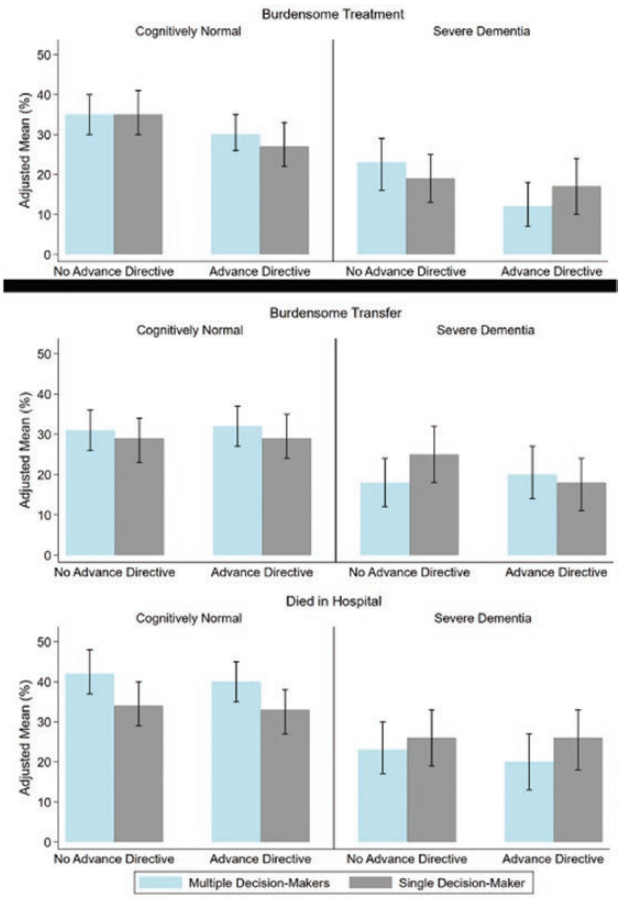

Figure 3. End-of-life treatments with single versus multiple decision makers* advance directives. Predicted probabilities of treatment receipt and 95% confidence intervals. Respondents to the Health and Retirement Study age 65+ with linked Medicare claims who died from 2002 to 2015 and required a treatment decision near the end of life. Severe dementia is determined using an algorithm from (1), which incorporates cognitive assessment scores with proxy assessments and limitations on activities of daily living. Advance directives are written documents specifying a preference for limited care. Means (95% CIs) are adjusted for decedent demographics, family characteristics, nursing home residence, receiving health care through a Health Maintenance Organization years with mild cognitive impairment/dementia, and comorbid health conditions. CI = confidence interval.

rates of burdensome treatment were lowest for severe dementia patients with advance directives and multiple decision makers, we did not find consistent relationships between either the number of decision makers or their access to preference information through written advance directives and receipt of potentially burdensome care for severe dementia care patients. Having a single decision maker was associated with lower rates of in-hospital death for cognitively normal decedents, whereas advance directives but not number of decision makers were predictive of lower rates of burdensome treatment for these patients.

Our results also imply that additional advance care planning is unlikely to be sufficient to change the quality of care provided to severe dementia patients near the EOL. Even when patients had written advance directives, patients with severe dementia who required EOL decision making experienced nontrivial rates of burdensome treatment, transfers, and in-hospital death, suggesting further room for improvement (4, 10, 26, 28–30). Nearly half of patients with severe dementia and normal cognition admitted to the hospital for emergency care in the last month of life experienced burdensome transfers and similar shares died in the hospital. It is unknown whether surrogate decision makers for severe dementia patients considered advance directives completed prior to dementia onset relevant to decisions after cognitive decline. It is also possible that the care team did not have access to appropriate information until after transfers or treatments had been initiated, suggesting that steps such as electronic medical record integration could be helpful.

Our study is the first to our knowledge to consider the role of multiple decision makers. Although we did not see consistent differences when patients with severe dementia had 1 versus multiple decision makers involved in their care, we found that having a single decision maker was associated with less aggressive care for those with normal cognition. It is possible that friends and family members were more prepared for the possibility of surrogate decision making when they were assisting a cognitively impaired patient, whereas those who were involved in care for someone with normal cognitive functioning may have required more time to reach a consensus or simply took more time to gather at the hospital. Although there is potential for decisions to further vary based on the quality of relationships between decision makers and patients and even across members of decision-making teams, the HRS does not collect any data on relationship quality. Other research has found no consistent differences in EOL care for dementia patients when decisions were made by children, spouses, or children and spouses together (31).

We studied average differences across those with and without advance directives and with single versus multiple decision makers. However, these average effects may mask important differences across subgroups. Prior research has found that advance care planning was more likely to be associated with preference-concordant care, such as not providing aggressive interventions for patients with do not resuscitate orders, for White patients, but not for Black patients (32). Although we controlled for race, ethnicity, and educational attainment (to proxy for socioeconomic status), our sample was predominantly non-Hispanic White, leaving us underpowered to test

for differences in the associations between advance directive use, decision-maker involvement, and receipt of potentially burdensome EOL care across racial and ethnic groups. Black and Hispanic decedents with dementia were less likely to receive hospice care and more likely to use emergency care in the last 6 months of life in descriptive comparisons that did not adjust for potential confounders (27). Future research should consider whether single versus multiple decision-maker teams are associated with different outcomes across a broader range of clinical scenarios and expected versus unexpected deaths to determine whether there are heterogeneous effects of decision makers.

We also relied on proxy reports of advance care planning and decision-maker involvement. These posthumous reports are frequently used to study EOL care, but may introduce measurement error if proxy informants incorrectly remember details. However, most proxy respondents in our sample were involved in the decision-making process. If these decision makers were not aware of an advance directive, for example, it is unlikely that the document influenced decisions. Three percent of respondents preparing advance directives reported a desire to receive all care possible and were included in the no treatment-limiting advance directive group. We did not observe patient preferences for EOL care if no advance directive was written, so we do not know whether their outcomes reflect preference-concordant care to remain alive as long as possible. Because the advance directive group had indicated a desire to limit treatment in certain settings, it is concerning to see similar rates of burdensome transfers for all decedents.

Conclusion

In this retrospective analysis of nationally representative data from patients who required surrogate decision making near the EOL, we considered the potential contributions of written advance directives describing treatment preferences and the involvement of single versus multiple decision makers. Aggressive EOL treatment was frequently provided to Medicare beneficiaries who required surrogate decision making in their last 6 months of life, even when patients had severe dementia, a counter-indication for such treatments. While multiple decision makers informed by advance directives were associated with the lowest rates of burdensome treatments for patients with severe dementia, we did not find consistent decision maker or advance directive patterns for these patients. Surrogate decision makers were least likely to choose aggressive EOL for patients with normal cognition when a single decision maker was involved. Even under these circumstances, more than one-fifth of patients with severe dementia and more than one third of cognitively normal patients died in the hospital, with many of those individuals also experiencing potentially burdensome treatments or transfers. Our results provide modest support for patients with preferences for less aggressive care preparing written advance directives and designating primary decision makers, preferably as part of a larger strategy including discussing preferences with surrogates and participating in programs that offer electronic access to advance directives, do not resuscitate forms, and other relevant documents. System-level strategies, such as reducing the financial incentives for nursing home-to-hospital transfers, earlier access to palliative care, or engaging care teams in regular goals-of-care conversations, may be needed to reduce rates of potentially burdensome treatments and transfers for patients who prefer less aggressive care near the EOL .

Supplementary Material

Supplementary data are available at *Innovation in Aging* online.

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Conflict of Interest

None.

Author Contributions

This study was conducted at the University of Colorado and the Johns Hopkins University using data collected by the University of Michigan. The Principal Investigator, L.H.N., led the study, had full access to all study data, and made the final decision to submit the paper. L.H.N., K.M.L., D.R.W., and S.D.H. designed the study; M.Y.B. and L.H.N. made analytic decisions and analyzed study data; and all authors contributed to interpretation of results, placing results in context of the broader literature, and critical review and approval of the final report.

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