

# UCSF

## UC San Francisco Previously Published Works

### Title

Hospice Improves Care Quality For Older Adults With Dementia In Their Last Month Of Life

### Permalink

<https://escholarship.org/uc/item/9kc4j4gz>

### Journal

Health Affairs, 41(6)

### ISSN

0278-2715

### Authors

Harrison, Krista L  
Cenzer, Irena  
Ankuda, Claire K  
et al.

### Publication Date

2022-06-01

### DOI

10.1377/hlthaff.2021.01985

Peer reviewed



Published in final edited form as:

*Health Aff (Millwood)*. 2022 June ; 41(6): 821–830. doi:10.1377/hlthaff.2021.01985.

## Hospice Improves Care Quality For Older Adults With Dementia In Their Last Month Of Life

Krista L. Harrison, PhD<sup>a,b,c</sup>, Irena Cezner, PhD<sup>a</sup>, Claire K. Ankuda, MD<sup>d</sup>, Lauren J. Hunt, RN, PhD, FNP-BC<sup>c,e</sup>, Melissa D. Aldridge, PhD<sup>d</sup>

<sup>a</sup>Division of Geriatrics, Department of Medicine, University of California San Francisco, San Francisco, California, United States. 490 Illinois Street, San Francisco, CA 94143 USA

<sup>b</sup>Philip R. Lee Institute for Health Policy Studies, University of California San Francisco, San Francisco, California, United States.

<sup>c</sup>Global Brain Health Institute, University of California San Francisco

<sup>d</sup>Department of Geriatrics and Palliative Medicine, Mount Sinai

<sup>e</sup>Department of Physiological Nursing, University of California San Francisco, San Francisco, California, United States. 2 Koret Way, San Francisco, CA 94143 USA

### Abstract

The Medicare hospice benefit was originally designed around a cancer disease paradigm but increasingly serves people living with dementia. At this time, almost half of all older adults receiving hospice care have dementia. Yet there is minimal evidence as to whether hospice benefits people living with dementia outside of nursing facilities. We asked whether and how perceived quality of last-month-of-life care differed between people living with dementia and persons without dementia and whether hospice use among people living with dementia was associated with higher perceived quality of care compared with the quality of care for people living with dementia who did not use hospice. We used nationally representative data from the National Health and Aging Trends Study and Medicare claims from 2011–17 to examine the impact of hospice enrollment on proxy perceptions of last-month-of-life care quality. Proxies of people living with dementia enrolled in hospice compared with proxies of those not enrolled more often reported care to be excellent (predicted probability: 52 percent versus 41 percent), more often reported having anxiety and sadness managed (67 percent versus 46 percent), and less often reported transitions in the last three days of life (10 percent versus 25 percent). There were no differences in the impact of hospice on proxy ratings of care for people living with dementia compared with ratings of care for people without dementia. Policy makers should consider these benefits when weighing changes to hospice policy and regulations that may affect people living with dementia.

---

Alzheimer's disease and other dementia syndromes (hereafter "dementia") affect one in three older adults ages eighty-five and older.<sup>1</sup> Dementia is one of the top six causes of

death,<sup>2</sup> with the proportion of people with dementia dying in home and community-based settings increasing rapidly from 14 percent in 1999 to 28 percent in 2019.<sup>3,4</sup>

Hospice is the dominant model of care for seriously ill individuals at the end of their life, serving 50.7 percent of Medicare decedents.<sup>5</sup> Hospices support people with serious illness and their families through interprofessional care that encompasses symptom management and psychosocial, spiritual, and caregiver support with the goal of enabling individuals to remain at home at the end of life. People living with dementia now make up one of the largest growing segments of the hospice enrollees and account for almost half of all hospice enrollments.<sup>6,7</sup>

Despite the fact that the majority of people living with dementia live and die in the community,<sup>3,4</sup> evidence around dementia end-of-life experiences and impacts of hospice primarily come from nursing home and hospital settings. Studies have shown that among people living with dementia in nursing facilities, use of hospice (compared with nonuse) is associated with better caregiver ratings of care and fewer unmet needs.<sup>8–12</sup> In nursing home comparisons of hospice enrollees with any diagnosis with nonenrollees with any diagnosis, hospice is associated with fewer hospitalizations in the last thirty days of life and better assessment and treatment of pain.<sup>13–15</sup> The minimal information available regarding home- and community-dwelling people living with dementia in the United States indicates that they have similar medical acuity and symptom burden as people living with dementia in nursing homes.<sup>16–21</sup> Moreover, they are often cared for by family caregivers who lack formal training and who experience significantly more strain caring for people living with dementia who are in the last year of their life.<sup>22,23</sup> The potential of hospice to improve the end-of-life experience for people living with dementia and their families is enormous,<sup>24</sup> yet we know relatively little about how hospice affects end-of-life outcomes for people living with dementia across all settings. Understanding whether hospice care benefits people living with dementia is critical as hospice undergoes ongoing reform that might affect people with dementia.<sup>25–27</sup>

We leveraged the National Health and Aging Trends Study to examine the quality of end-of-life care at the population level. We sought to investigate whether and how perceived quality of last-month-of-life care differed between people living with dementia and persons without dementia and whether hospice use among people living with dementia was associated with higher perceived quality of care compared with perceived quality of care for people living with dementia who did not use hospice. We examined hospice enrollment for at least one day in the last month of life, as well as hospice enrollment for thirty or more days. We used the National Health and Aging Trends Study linked to Medicare claims to examine outcomes including overall quality of care; symptom management; support for personal and spiritual needs; provision of goal-consistent, respectful, patient- and family-involved coordinated care; and transitions in the last three days of life.

## Study Data And Methods

### Data Sources

Data are from the National Health and Aging Trends Study, an ongoing annual longitudinal population-based survey of Medicare enrollees linked to Medicare and hospice claims.<sup>28</sup> Assessments of last-month-of-life care for decedents are completed by proxies; weighted response rates ranged from 95 percent in 2012 to 97 percent in 2017.<sup>29</sup> The National Health and Aging Trends Study is sponsored by the National Institute on Aging (NIA U01AG32947) and is conducted by Johns Hopkins University.<sup>28</sup>

Our sample included 2,805 National Health and Aging Trends Study participants who died between 2011 and 2017 (the last available year of Centers for Medicare and Medicaid Services claims data) and who were ages seventy and older, per National Health and Aging Trends Study guidance for maintaining national representativeness when pooling data across waves.<sup>30</sup> Of these, we excluded 657 decedents who did not have a sample person interview within two years before death and eighty-nine who did not have a last-month-of-life survey or end-of-life outcomes. Online appendix exhibit A1 provides a flow chart with additional details of sample derivation.<sup>31</sup> Our final study sample was 2,059 decedents.

### Measures

We identified participants' dementia status in the National Health and Aging Trends Study round before death, based on the algorithm validated for use in surveys<sup>32</sup>: report of physician diagnosis, proxy responses to the AD8 dementia screening interview,<sup>33</sup> or cognitive testing. We drew sociodemographic, health, and functional characteristics from the last National Health and Aging Trends Study interview before death (mean: 10.5 months before death; standard deviation: 10.0 months): age, gender, race and ethnicity, educational attainment, partnership status, income, number of children, living alone, census region, metropolitan area type, health conditions (self-report of whether a doctor told them they had cancer, heart disease, lung disease, stroke, or diabetes), and receiving help with or not doing activities of daily living (ADLs: bathing, eating, dressing, toileting, transferring, walking inside). Missingness was less than 5 percent and was not imputed.

We examined setting based on National Health and Aging Trends Study residence categorizations in the round before death, at hospice admission, and at death. The National Health and Aging Trends Study uses interviewer observations and questions of the sample person or facility staff person to categorize residences as nursing homes, community-based residential care settings, or private homes. This aligns with prior work in other large data sets.<sup>34</sup> Community-based residential settings include group homes, board and care homes, assisted living, or continuing care retirement communities.

We drew age at death and characteristics of hospice use from the Medicare claims data. We measured hospice use in two ways: at least one day in the last month of life and for thirty continuous days before death. Appendix exhibit A2 details the definition of hospice use.<sup>31</sup>

Our outcome measures for proxy ratings of last-month-of-life care quality included eleven ratings of care and one clinical indicator of care quality. To build off prior literature,<sup>35–37</sup>

we dichotomized variables with Likert scales to compare the most positive rating with any less-positive rating for adjusted analyses. Appendix A3 provides details on outcome measure definitions and dichotomization.<sup>31</sup> We added a commonly used clinical indicator of care quality: late transitions (those in the last three days of life).<sup>38</sup> Mean time to completion of proxy interview after death was about six months (mean: 188.5 days; SD: 131.6 days), and 71 percent of proxies were spouses or children.

## Analyses

We described the characteristics of participants overall, comparing people living with dementia with participants without dementia, and examined differences in proxy ratings of care between people living with dementia and those without dementia, using chi-square tests to determine differences.

We then examined whether having received hospice in the last month of life affected ratings of care quality. We estimated covariate balancing propensity scores<sup>35</sup> for each decedent's likelihood of hospice enrollment, conditional on variables known to affect hospice use: age; sex; race and ethnicity; education; marital status; number of children; income; presence of cancer, heart disease, lung disease, stroke, or diabetes; metropolitan area; census region; and year of death. We used the product of the inverse probability of treatment weights<sup>39</sup> and the National Health and Aging Trends Study survey weights in all analytic comparisons. Appendix A4 and exhibits A5–7 provide details on covariate balancing propensity score specification and standardized differences.<sup>31</sup> We tested the interaction between hospice use and dementia status to assess whether the impact of hospice was greater for people living with dementia compared with the impact for those without dementia. We repeated the above analyses for thirty continuous days of hospice before death compared with no hospice.

Analyses were conducted using SAS, version 9.4, and Stata, version 17.0. All analyses account for the National Health and Aging Trends Study survey weights.

## Limitations

This study has some limitations. It examines whether participants had dementia, but not whether dementia was the cause of death. It is likely that many persons with dementia died of other conditions, and we cannot assess how their experience was shaped by the presence of dementia versus other serious illnesses. Also, we were unable to adjust for unmeasured characteristics of older adults who do and do not enroll in hospice, such as preferences for end-of-life care or market-based variation in the availability of hospice care. Although imperfect, the inverse probability of treatment weight is among the most rigorous methodologic tools available outside of a randomized trial and has been used in a wide range of studies to investigate policy-relevant questions using observational survey data. Finally, this study does not represent the national population of nursing home residents ages seventy and older, as the National Health and Aging Trends Study does not capture information about demographics and dementia status for those living in nursing homes at the time of the first National Health and Aging Trends Study interview.

## Study Results

### Sample Characteristics

Among 2,059 decedents ages seventy and older, participants had a mean age at death of 84.6 (SD: 7.1), 54 percent of participants were women, the majority identified as White non-Hispanic, and a third had less than high school education attainment and annual incomes in the bottom tercile (exhibit 1). At the last interview before death, 80 percent of participants lived in home settings (data not shown); 52 percent of those who used hospice in the last month of life began receiving it at home. For a table that includes additional data, see appendix exhibit A8.<sup>31</sup> Overall, 36 percent died at home and 32 percent in the hospital.

Comparing the 40 percent ( $n = 951$ ) of people living with dementia within the study population with the 60 percent ( $n = 1,108$ ) with no dementia, people living with dementia had greater prevalence of social and functional vulnerabilities: older mean age at death (87 versus 83 years;  $p < 0.001$ ), lower annual incomes (35 percent versus 25 percent had incomes of \$0–\$15,000;  $p < 0.001$ ), higher prevalence of stroke (15 percent versus 6 percent;  $p < 0.001$ ), and significantly higher levels of all measures of ADL impairment. A higher proportion of people living with dementia used hospice (59 percent versus 43 percent;  $p < 0.001$ ) and had a longer median length of stay (median, fifteen days for people living with dementia for the enrollment ending in death versus ten days for those with no dementia). Among people living with dementia, the most common location of death was at home (37 percent), followed by 23 percent at hospital and 24 percent in nursing homes; in comparison, 39 percent of those with no dementia died in the hospital and 35 percent died at home, with only 13 percent dying in a nursing home ( $p < 0.001$ ) (appendix exhibit A8).

### Last-Month-Of-Care Quality Is Similar For People Living With Dementia And People Without Dementia

In unadjusted ratings of last-month-of-life care in the overall study sample, 48 percent of proxies reported excellent care quality and more than three-quarters of proxies rated personal care always managed, care goal-consistent, and care coordinated; other measures left greater room for improvement (exhibit 2). For a table that includes additional data, see appendix exhibit A9.<sup>31</sup> In unadjusted comparative analyses, meaningful differences in proxy ratings of last-month-of-life care included higher prevalence of personal care always managed, family kept informed, and care coordination among people living with dementia compared with care coordination among those without dementia. People living with dementia also had fewer late transitions. Only two differences were observed in adjusted analyses: people living with dementia (compared with those with no dementia) had anxiety more often managed, and they had less goal-consistent care (not shown).

### Hospice Improves Last-Month-Of-Life Care For People Living With Dementia

Among people living with dementia, 59 percent ( $n = 555$ ) used hospice for at least one day in the last month of life (appendix exhibit A8). Hospice enrollment was associated with better proxy-reported perceptions of last-month-of-life care on some domains compared with the reported perceptions of people living with dementia with no hospice (exhibit 3).

Findings from the adjusted propensity score models indicate that proxies of hospice-enrolled people living with dementia more often rated care as excellent compared with people living with dementia who were not enrolled in hospice (predicted probability: 52.0 percent versus 41.4 percent;  $p = 0.012$ ) (exhibit 3). A higher percentage of proxies of people living with dementia in hospice versus not in hospice rated sadness and anxiety managed (predicted probability: 66.9 percent versus 45.7 percent;  $p = 0.009$ ) and rated enough spiritual support (predicted probability: 51.1 percent versus 30 percent;  $p < 0.001$ ). A smaller percentage of people living with dementia in hospice had late transitions compared with people living with dementia who were not in hospice (predicted probability: 9.8 percent versus 24.6 percent;  $p < 0.001$ ) (exhibit 3).

We observed no differences in the impact of hospice on people living with dementia compared with its impact on people without dementia (interaction terms not shown). In sensitivity analyses, we found no major differences in outcome measures by proxy type or by proxy self-reported familiarity with the daily routine of the sample person.

### **Longer Hospice May Improve Last-Month-Of-Life Care Even More For People Living With Dementia**

Finally, we observed a potential dose response of hospice care. Even though all confidence intervals overlapped, the effect of people living with dementia receiving thirty continuous days of hospice in the last month of life compared with receiving no hospice tended to be higher than the effect of people living with dementia receiving hospice of one or more days in the last month of life compared with receiving no hospice (exhibit 4).

## **Discussion**

Our novel study uses data from a national sample of Medicare beneficiaries to address the questions of whether hospice benefits people living with dementia, and whether it affects people living with dementia differently than it affects those without dementia. The vast majority of our study sample lived in the community a year before death, and more than half enrolled with hospice, including almost two-thirds of those with dementia. We found that proxies of hospice-enrolled people living with dementia were more likely to rate last-month-of-life care as excellent compared with proxies of people living with dementia who did not enroll with hospice. We observed no differences in the impact of hospice on ratings of last-month-of-life care for persons with versus without dementia. These findings suggest that hospice benefits people living with dementia just as well as it benefits people without dementia.

Disease-specific differences in time lines for disease progression, need for help, and caregiving needs may have implications for measuring care quality. Although the last-month-of-life care quality measures are the best available, there is need for improvement.<sup>40,41</sup> These measures do not tell the full picture of the experience of end of life for people with dementia and their care communities. The duration of dementia is long and unpredictable and is often not recognized as terminal.<sup>42</sup> The last month of life for people living with dementia may look similar to the last three or even six months of life because people living with dementia often die from conditions that deteriorate in the last forty-eight

hours, such as infection. The responsibilities and burden of caregiving for people living with dementia<sup>43</sup> occurs over a much longer period of time and with a different intensity than, say, caregiving for persons dying of cancer, and may differentially affect proxy appreciation for the involvement of hospice. A year before death, people living with dementia have higher symptom burden and functional impairments than those without dementia,<sup>21</sup> and people living with dementia at home need more support for functional and medical needs than those in facility settings.<sup>20</sup> Future work should examine the impact of care settings on proxy perceptions of last month of life among people living with dementia. The Consumer Assessment of Healthcare Providers and Systems Hospice Survey<sup>44</sup> and its predecessor, the Family Evaluation of Hospice Care,<sup>45</sup> indicate that proxies rate home-based hospice care more highly than hospice care in nursing facilities.

Although we found that care quality for hospice-enrolled people living with dementia was as good as it was for hospice-enrolled individuals without dementia, there is room for improvement: only half of proxies rated overall quality at the highest level. This finding, coupled with the high prevalence of dementia among hospice enrollees,<sup>6,46</sup> underscores the need for dementia care to be a core competency of hospice teams.<sup>47</sup> Other potential recommendations include adding more support for caregivers, including anticipatory guidance<sup>48,49</sup>; providing additional home health aides for functional needs; and removing medications from standard hospice medication order sets that could exacerbate behavioral symptoms of dementia (for example, psychotropics, anticholinergics, and aggressive use of opioids that are renally metabolized).<sup>50–52</sup>

Our findings inform an ongoing debate about whether hospice in the United States adequately serves people living with dementia and their families, given that the Medicare hospice benefit evolved to primarily serve end-stage cancer.<sup>53</sup> Prior research indicates that hospice employees perceive demand for hospice care among people living with dementia to be increasing at the same time that changes to hospice policy and regulations make it more difficult to meet this need.<sup>25</sup> Concerns about lack of access to care for people living with dementia come from two sources: difficulties people have in being admitted to hospice and the experiences of hospice enrollees who are disenrolled alive.

First, eligibility for the Medicare hospice benefit requires that physicians attest to a six-month prognosis if the disease runs its expected course, but our ability to identify a six-month prognosis for most dementia syndromes is no better than a coin flip.<sup>54</sup> This means some people living with dementia may not receive the full benefit of hospice care because they are enrolled too close to death or not at all.

Second, people with dementia are known to have long duration of hospice use, which has been found to be profitable to hospice organizations; for-profit hospices are more likely to care for those with dementia.<sup>46,55,56</sup> Given concerns about long duration of hospice use and the influx of for-profit hospices and private equity funding,<sup>27,57</sup> Medicare has responded by implementing policies to curb long hospice enrollment.<sup>26</sup> People living with dementia are disproportionately discharged alive from hospice<sup>46,56,58</sup> because their decline has stabilized or because hospices are concerned that they will not be reimbursed for care if they cannot adequately document decline. Being disenrolled for extended prognosis or being expelled

from hospice negatively affects both seriously ill people and families because there is no simple replacement for hospice care.<sup>59–63</sup>

Our finding that hospice significantly benefits those with dementia and their families underscores the need to ensure access to high-quality end-of-life care for this growing population. Future policies and regulations should focus on hospice agencies with unusually high rates of long stays and live discharge rather than current population-based approaches that may have unintended consequences of broadly reducing access to care for people living with dementia. Demonstration studies can test how removing prognostic requirements from hospice eligibility for people living with dementia affects timely access, care quality, and costs. In addition, we need robust, accessible, and affordable systems of home and community-based care tailored to the needs of people living with dementia and their care communities, which facilitate the transition to hospice.

## Conclusion

In this national sample of Medicare beneficiaries, hospice-enrolled people living with dementia had higher-quality last-month-of-life care compared with people living with dementia who were not enrolled in hospice. Hospice-enrolled people living with dementia had similar ratings of last-month-of-life care as hospice enrollees with no dementia. Given the benefits of hospice to people living with dementia, efforts to enable access are warranted.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgment

This study was originally presented as an oral presentation at the American Academy of Hospice and Palliative Medicine Virtual State of the Science, February 12, 2022, and at AcademyHealth on June 5, 2022 in Washington, DC. Krista Harrison received funding from the National Institute on Aging (Grant No. P01AG066605, K01AG059831). Claire Ankuda received funding from the National Institute on Aging (Grant No. P01AG066605, K76AG064427). Lauren Hunt received funding from the National Institute on Aging (Grant No. P01AG066605, K76 AG074924). Melissa Aldridge received funding from the National Institute on Aging (Grant No. P01AG066605, K07 AG060270).

## BIOS for 2021–01985 (Harrison)

Bio1: Krista L. Harrison (krista.harrison@ucsf.edu), University of California San Francisco.

Bio2: Irena Cenzer, University of California San Francisco.

Bio3: Claire K. Ankuda, Icahn School of Medicine at Mount Sinai, New York City.

Bio4: Lauren J. Hunt, University of California San Francisco.

Bio5: Melissa D. Aldridge, Icahn School of Medicine at Mount Sinai; and the James J. Peters Bronx Veterans Affairs Medical Center, Bronx, New York.

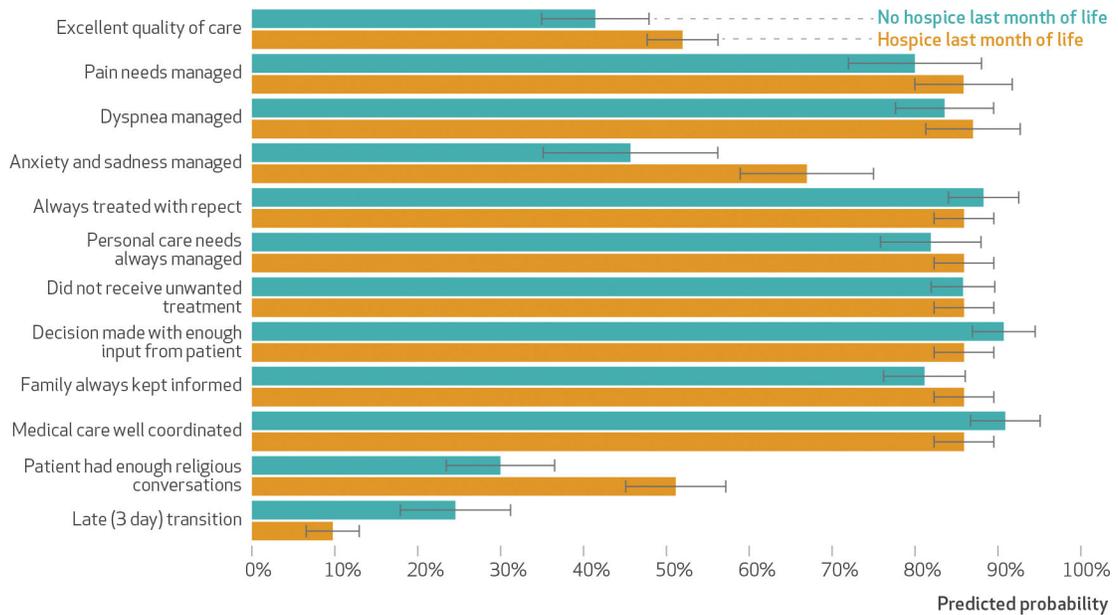
## Notes

1. Alzheimer's Association. 2022 Alzheimer's disease facts and figures [Internet]. Chicago (IL): Alzheimer's Association; [cited 2022 Apr 7]. Available from: <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>
2. Kochanek KD, Xu J, Arias E. Mortality in the United States, 2019 [Internet]. Hyattsville (MD): National Center for Health Statistics; 2020 Dec [cited 2022 Apr 7]. (NCHS Data brief No. 395). Available from: <https://www.cdc.gov/nchs/products/databriefs/db395.htm>
3. Aldridge MD, Bradley EH. Epidemiology and patterns of care at the end of life: rising complexity, shifts in care patterns and sites of death. *Health Aff (Millwood)*. 2017;36(7):1175–83. [PubMed: 28679803]
4. Authors' analysis of data from: Centers for Disease Control and Prevention. CDC WONDER [Internet]. Atlanta (GA): CDC; [cited 2022 Apr 7]. Available from: <https://wonder.cdc.gov>
5. National Hospice and Palliative Care Organization. NHPCO facts and figures: 2020 edition [Internet]. Alexandria (VA): NHPCO; 2020 Aug 20 [cited 2022 Apr 7]. Available for download from: <https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2020-edition.pdf>
6. Aldridge MD, Hunt L, Husain M, Li L, Kelley A. Impact of comorbid dementia on patterns of hospice use. *J Palliat Med*. 2022;25(3):396–404. [PubMed: 34665050]
7. Carlson MDA, Morrison RS, Bradley EH. Improving access to hospice care: informing the debate. *J Palliat Med*. 2008;11(3):438–43. [PubMed: 18363486]
8. Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Patients dying with dementia: experience at the end of life and impact of hospice care. *J Pain Symptom Manage*. 2008;35(5):499–507. [PubMed: 18261878]
9. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc*. 2010;58(12):2284–91. [PubMed: 21143437]
10. Ernecoff NC, Lin F-C, Wessell KL, Hanson LC. Quality of life with late-stage dementia: exploring opportunities to intervene. *J Am Geriatr Soc*. 2019;67(6):1189–96. [PubMed: 30801671]
11. Mitchell SL, Black BS, Ersek M, Hanson LC, Miller SC, Sachs GA, et al. Advanced dementia: state of the art and priorities for the next decade. *Ann Intern Med*. 2012;156(1 Pt 1):45–51. [PubMed: 22213494]
12. Miller SC, Lima JC, Mitchell SL. Influence of hospice on nursing home residents with advanced dementia who received Medicare-skilled nursing facility care near the end of life. *J Am Geriatr Soc*. 2012;60(11):2035–41. [PubMed: 23110337]
13. Miller SC, Mor V, Wu N, Gozalo P, Lapane K. Does receipt of hospice care in nursing homes improve the management of pain at the end of life? *J Am Geriatr Soc*. 2002;50(3):507–15. [PubMed: 11943048]
14. Miller SC, Mor V, Teno J. Hospice enrollment and pain assessment and management in nursing homes. *J Pain Symptom Manage*. 2003;26(3):791–9. [PubMed: 12967728]
15. Gozalo PL, Miller SC. Hospice enrollment and evaluation of its causal effect on hospitalization of dying nursing home patients. *Health Serv Res*. 2007;42(2):587–610. [PubMed: 17362208]
16. Callahan CM, Tu W, Unroe KT, LaMantia MA, Stump TE, Clark DO. Transitions in care in a nationally representative sample of older Americans with dementia. *J Am Geriatr Soc*. 2015;63(8):1495–502. [PubMed: 26200764]
17. Mitchell SL, Morris JN, Park PS, Fries BE. Terminal care for persons with advanced dementia in the nursing home and home care settings. *J Palliat Med*. 2004;7(6):808–16. [PubMed: 15684848]
18. Taylor CA, Greenlund SF, McGuire LC, Lu H, Croft JB. Deaths from Alzheimer's disease—United States, 1999–2014. *MMWR Morb Mortal Wkly Rep*. 2017;66(20):521–6. [PubMed: 28542120]
19. Nicholas LH, Bynum JPW, Iwashyna TJ, Weir DR, Langa KM. Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Aff (Millwood)*. 2014;33(4):667–74. [PubMed: 24711329]

20. Harrison KL, Ritchie CS, Patel K, Hunt LJ, Covinsky KE, Yaffe K, et al. Care settings and clinical characteristics of older adults with moderately severe dementia. *J Am Geriatr Soc*. 2019;67(9):1907–12. [PubMed: 31389002]
21. Amjad H, Snyder SH, Wolff JL, Oh E, Samus QM. Before hospice: symptom burden, dementia, and social participation in the last year of life. *J Palliat Med*. 2019;22(9):1106–14. [PubMed: 31058566]
22. Vick JB, Ornstein KA, Szanton SL, Dy SM, Wolff JL. Does caregiving strain increase as patients with and without dementia approach the end of life? *J Pain Symptom Manage*. 2019;57(2):199–208.e2. [PubMed: 30453054]
23. Chiao C-Y, Wu H-S, Hsiao C-Y. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int Nurs Rev*. 2015;62(3):340–50. [PubMed: 26058542]
24. Samus QM, Black BS, Bovenkamp D, Buckley M, Callahan C, Davis K, et al. Home is where the future is: the BrightFocus Foundation consensus panel on dementia care. *Alzheimers Dement*. 2018;14(1):104–14. [PubMed: 29161539]
25. Harrison KL, Allison TA, Garrett SB, Thompson N, Sudore RL, Ritchie CS. Hospice staff perspectives on caring for people with dementia: a multisite, multistakeholder study. *J Palliat Med*. 2020;23(8):1013–20. [PubMed: 32130076]
26. Medicare Payment Advisory Commission. Report to the Congress: Medicare payment policy. Chapter 11: hospice services [Internet]. Washington (DC): MedPAC; 2021 Mar [cited 2022 Apr 7]. Available from: [https://www.medpac.gov/wp-content/uploads/2021/10/mar21\\_medpac\\_report\\_ch11\\_sec.pdf](https://www.medpac.gov/wp-content/uploads/2021/10/mar21_medpac_report_ch11_sec.pdf)
27. Aldridge MD. Hospice tax status and ownership matters for patients and families. *JAMA Intern Med*. 2021;181(8):1114–5. [PubMed: 33938916]
28. National Health and Aging Trends Study [home page on the Internet]. Rockville (MD): NHATS; [cited 2022 Apr 7]. Available from: <https://www.nhats.org/>
29. Kasper JD, Freedman VA. National Health and Aging Trends Study (NHATS) user guide: rounds 1–10 final release [Internet]. Baltimore (MD): Johns Hopkins University School of Public Health; 2021 Jul 8 [cited 2022 Apr 7]. Available from: [https://www.nhats.org/sites/default/files/2021-07/NHATS\\_User\\_Guide\\_R10\\_Final\\_Release.pdf](https://www.nhats.org/sites/default/files/2021-07/NHATS_User_Guide_R10_Final_Release.pdf)
30. Freedman VA, Hu M, DeMatteis J, Kasper J. Accounting for sample design in NHATS and NSOC analyses: frequently asked questions [Internet]. Baltimore (MD): Johns Hopkins Bloomberg School of Public Health; 2020 [cited 2022 Apr 7]. Available from: [https://www.nhats.org/sites/default/files/2021-01/Accounting\\_for\\_the\\_NHATS\\_NSOC\\_Design\\_in\\_Analyses\\_FAQ\\_0.pdf](https://www.nhats.org/sites/default/files/2021-01/Accounting_for_the_NHATS_NSOC_Design_in_Analyses_FAQ_0.pdf)
31. To access the appendix, click on the Details tab of the article online.
32. Kasper JD, Freedman VA, Spillman BC. Classification of persons by dementia status in the National Health and Aging Trends Study [Internet]. Baltimore (MD): Johns Hopkins University School of Public Health; 2013 Jul [cited 2022 Apr 7]. (Technical Paper No. 5). Available from: [https://www.nhats.org/sites/default/files/inline-files/DementiaTechnicalPaperJuly\\_2\\_4\\_2013\\_10\\_23\\_15.pdf](https://www.nhats.org/sites/default/files/inline-files/DementiaTechnicalPaperJuly_2_4_2013_10_23_15.pdf)
33. Galvin JE, Roe CM, Xiong C, Morris JC. Validity and reliability of the AD8 informant interview in dementia. *Neurology*. 2006;67(11):1942–8. [PubMed: 17159098]
34. Aldridge MD, Ornstein KA, McKendrick K, Moreno J, Reckrey JM, Li L. Trends in residential setting and hospice use at the end of life for Medicare decedents. *Health Aff (Millwood)*. 2020;39(6):1060–4. [PubMed: 32479223]
35. Kumar V, Ankuda CK, Aldridge MD, Husain M, Ornstein KA. Family caregiving at the end of life and hospice use: a national study of Medicare beneficiaries. *J Am Geriatr Soc*. 2020;68(10):2288–96. [PubMed: 32602571]
36. Ankuda CK, Kelley AS, Morrison RS, Freedman VA, Teno JM. Family and friend perceptions of quality of end-of-life care in Medicare Advantage vs traditional Medicare. *JAMA Netw Open*. 2020;3(10):e2020345. [PubMed: 33048130]
37. Luth EA, Prigerson HG. Associations between race and dementia status and the quality of end-of-life care. *J Palliat Med*. 2018;21(7):970–7. [PubMed: 29620949]

38. Makaroun LK, Teno JM, Freedman VA, Kasper JD, Gozalo P, Mor V. Late transitions and bereaved family member perceptions of quality of end-of-life care. *J Am Geriatr Soc.* 2018;66(9):1730–6. [PubMed: 29972587]
39. Austin PC, Stuart EA. Moving towards best practice when using inverse probability of treatment weighting (IPTW) using the propensity score to estimate causal treatment effects in observational studies. *Stat Med.* 2015;34(28):3661–79. [PubMed: 26238958]
40. Lendon JP, Ahluwalia SC, Walling AM, Lorenz KA, Oluwatola OA, Price RA, et al. Measuring experience with end-of-life care: a systematic literature review. *J Pain Symptom Manage.* 2015;49(5):904–15. [PubMed: 25543110]
41. Quigley DD, McCleskey SG. Improving care experiences for patients and caregivers at end of life: a systematic review. *Am J Hosp Palliat Care.* 2021;38(1):84–93. [PubMed: 32551966]
42. Harrison KL, Hunt LJ, Ritchie CS, Yaffe K. Dying with dementia: underrecognized and stigmatized. *J Am Geriatr Soc.* 2019;67(8):1548–51. [PubMed: 30908605]
43. Harrison KL, Bull JH, Garrett SB, Bonsignore L, Bice T, Hanson LC, et al. Community-based palliative care consultations: comparing dementia to nondementia serious illnesses. *J Palliat Med.* 2020;23(8):1021–9. [PubMed: 31971857]
44. Quigley DD, Parast L, Haas A, Elliott MN, Teno JM, Anhang Price R. Differences in caregiver reports of the quality of hospice care across settings. *J Am Geriatr Soc.* 2020;68(6):1218–25. [PubMed: 32039474]
45. Unroe KT, Stump TE, Effler S, Tu W, Callahan CM. Quality of hospice care at home versus in an assisted living facility or nursing home. *J Am Geriatr Soc.* 2018;66(4):687–92. [PubMed: 29427519]
46. De Vleminck A, Morrison RS, Meier DE, Aldridge MD. Hospice care for patients with dementia in the United States: a longitudinal cohort study. *J Am Med Dir Assoc.* 2018;19(7):633–8. [PubMed: 29153752]
47. Schneider CE, Bristol A, Ford A, Lin S-Y, Palmieri J, Meier MR, et al. , HAS-QOL Trial Investigators. The impact of Aliviado dementia care-hospice edition training program on hospice staff's dementia symptom knowledge. *J Pain Symptom Manage.* 2020;60(2):e7–13.
48. Yeh JC, Newman J, Main R, Hunt LJ. Improving end-of-life care for persons living with dementia: bereaved caregivers' observations and recommendations. *J Pain Symptom Manage.* 2021;62(3):579–86. [PubMed: 33556499]
49. Shafir A, Ritchie CS, Garrett SB, Bernstein Sideman A, Naasan G, Merrilees J, et al. “Captive by the uncertainty”-experiences with anticipatory guidance for people living with dementia and their caregivers at a specialty dementia clinic. *J Alzheimers Dis.* 2022;86(2):787–800. [PubMed: 35124641]
50. Brickner L, Scannell K, Marquet S, Ackerson L. Barriers to hospice care and referrals: survey of physicians' knowledge, attitudes, and perceptions in a health maintenance organization. *J Palliat Med.* 2004;7(3):411–8. [PubMed: 15265350]
51. Holmes HM, Sachs GA, Shega JW, Hougham GW, Cox Hayley D, Dale W. Integrating palliative medicine into the care of persons with advanced dementia: identifying appropriate medication use. *J Am Geriatr Soc.* 2008;56(7):1306–11. [PubMed: 18482301]
52. Peacock SC. The experience of providing end-of-life care to a relative with advanced dementia: an integrative literature review. *Palliat Support Care.* 2013;11(2):155–68. [PubMed: 23088769]
53. Harrison KL, Connor SR. First Medicare demonstration of concurrent provision of curative and hospice services for end-of-life care. *Am J Public Health.* 2016;106(8):1405–8. [PubMed: 27310352]
54. Mitchell SL, Miller SC, Teno JM, Kiely DK, Davis RB, Shaffer ML. Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. *JAMA.* 2010;304(17):1929–35. [PubMed: 21045099]
55. Wachterman MW, Marcantonio ER, Davis RB, McCarthy EP. Association of hospice agency profit status with patient diagnosis, location of care, and length of stay. *JAMA.* 2011;305(5):472–9. [PubMed: 21285424]

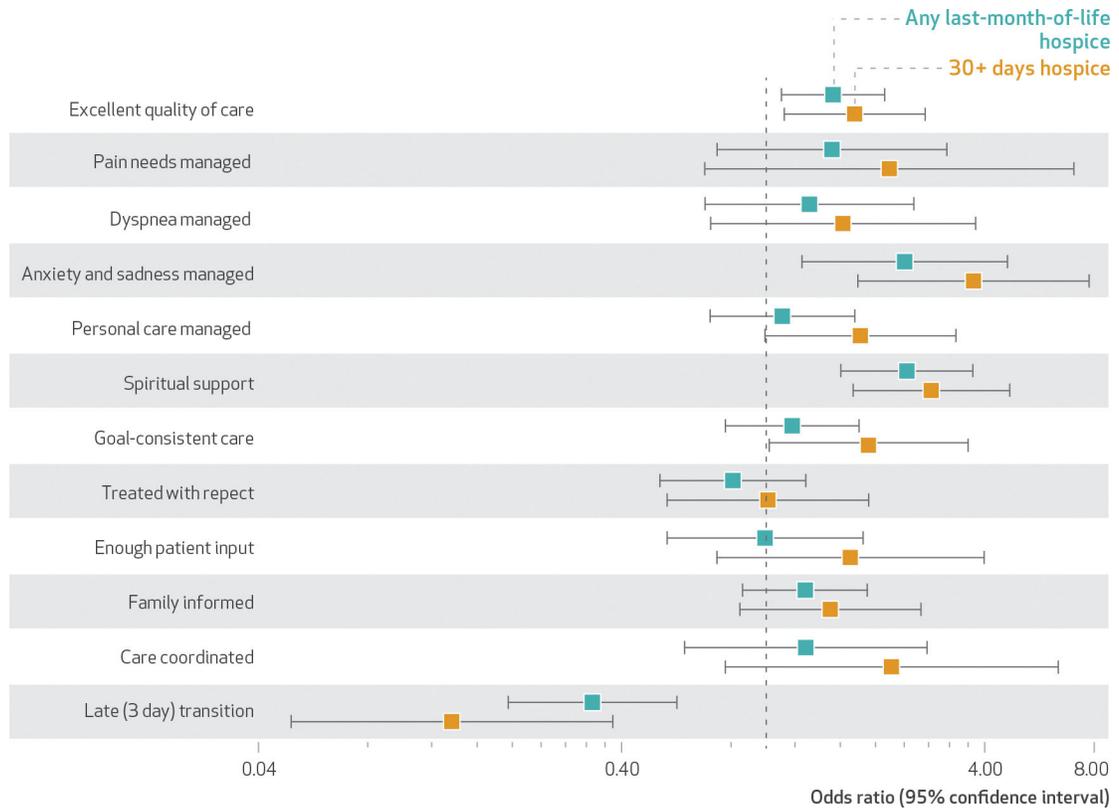
56. Luth EA, Russell DJ, Brody AA, Dignam R, Czaja SJ, Ryvicker M, et al. Race, ethnicity, and other risks for live discharge among hospice patients with dementia. *J Am Geriatr Soc.* 2020;68(3):551–8. [PubMed: 31750935]
57. Braun RT, Stevenson DG, Unruh MA. Acquisitions of hospice agencies by private equity firms and publicly traded corporations. *JAMA Intern Med.* 2021;181(8):1113–4. [PubMed: 33938919]
58. Albrecht JS, Gruber-Baldini AL, Fromme EK, McGregor JC, Lee DSH, Furuno JP. Quality of hospice care for individuals with dementia. *J Am Geriatr Soc.* 2013;61(7):1060–5. [PubMed: 23710597]
59. Hunt LJ, Harrison KL. Live discharge from hospice for people living with dementia isn't "graduating"—It's getting expelled. *J Am Geriatr Soc.* 2021;69(6):1457–60. [PubMed: 33855701]
60. Luth EA, Russell DJ, Xu JC, Lauder B, Ryvicker MB, Dignam RR, et al. Survival in hospice patients with dementia: the effect of home hospice and nurse visits. *J Am Geriatr Soc.* 2021;69(6):1529–38. [PubMed: 33608869]
61. Wladkowski SP. Live discharge from hospice and the grief experience of dementia caregivers. *J Soc Work End Life Palliat Care.* 2016;12(1–2):47–62. [PubMed: 27143573]
62. Wladkowski SP. Dementia caregivers and live discharge from hospice: what happens when hospice leaves? *J Gerontol Soc Work.* 2017;60(2):138–54. [PubMed: 27997295]
63. Harrison KL. The hidden curriculum of hospice: die fast, not slow. *Health Aff (Millwood).* 2021;40(5):844–7. [PubMed: 33939517]



**Exhibit 3:**

Comparing associations of last-month-of-life care quality outcomes among Medicare beneficiaries ages 70 and older, 2011–17, by use of hospice for at least 1 day in the last month of life

**Source/Notes:** SOURCE Authors’ analysis of the data from participants in the National Health and Aging Trends Study ages 70 and older who had a sample person interview and who died between 2011 and 2017. NOTES Analyses used covariate balancing propensity score methods to estimate the propensity for enrolling in hospice at least 1 day in the last month of life, estimated with variables known to affect hospice use: age; sex; race and ethnicity; education; marital status; number of children; income; comorbidities of cancer, heart disease, stroke, or diabetes; metropolitan area; census region; and year of death. From the propensity score model, we estimated normalized inverse probability of treatment weights. For each outcome measure we used postestimation commands to present the adjusted predicted probabilities. All analyses account for National Health and Aging Trends Study survey weights. Late transitions were defined as care setting changes in the last 3 days of life.



**Exhibit 4:**

Comparing associations of last-month-of-life care quality outcomes among Medicare beneficiaries ages 70 and older, 2011–17, by use of hospice for 30 continuous days in the last month of life (versus no hospice) and with hospice use of at least 1 day in the last month of life (versus no hospice)

**Source/Notes:** SOURCE Authors’ analysis of the data from participants in the National Health and Aging Trends Study ages 70 and older who had a sample person interview and who died between 2011 and 2017. NOTES Analyses used covariate balancing propensity score methods to estimate the propensity for enrolling in hospice 30 continuous days in the last month of life and propensity for enrolling at least 1 day in the last month of life, estimated with variables known to affect hospice use: age; sex; race and ethnicity; education; marital status; number of children; income; comorbidities of cancer, heart disease, stroke, or diabetes; metropolitan area; census region; and year of death. From the propensity score model, we estimated normalized inverse probability of treatment weights. All analyses account for National Health and Aging Trends Study survey weights. We present the odds ratio of quality outcomes for use of hospice for 30 continuous days in the last month of life (versus no hospice) and at least 1 day in the last month of life (versus no hospice). Late transitions were defined as care setting changes in the last 3 days of life.

**Exhibit 1:**

Characteristics of decedent study sample among Medicare beneficiaries ages 70 and older by dementia status, 2011–17

|                                                               | Overall (N = 2,059) | Without dementia (N = 1,108) | With dementia <sup>a</sup> (N = 951) |
|---------------------------------------------------------------|---------------------|------------------------------|--------------------------------------|
| <b>Demographics<sup>b</sup></b>                               |                     |                              |                                      |
| Age at death (median, SD), years <sup>c</sup>                 | 84.5 (7.1)          | 83.0 (6.3)                   | 86.8 (7.5)                           |
| Women (versus men), %                                         | 54                  | 52                           | 56                                   |
| Black, %                                                      | 9                   | 8                            | 11                                   |
| Hispanic or Latino/a/e/x, %                                   | 6                   | 5                            | 8                                    |
| White, %                                                      | 80                  | 82                           | 76                                   |
| Less than high school education versus high school or more, % | 31                  | 28                           | 37                                   |
| Single, divorced, widowed (versus married or partnered), %    | 61                  | 59                           | 64                                   |
| Annual income, %                                              |                     |                              |                                      |
| \$0–14,600                                                    | 29                  | 25                           | 35                                   |
| \$14,601–30,000                                               | 35                  | 34                           | 37                                   |
| \$30,001–1,000,000                                            | 36                  | 40                           | 29                                   |
| <b>Family and residence<sup>b</sup>, %</b>                    |                     |                              |                                      |
| 4+ children (versus fewer or none)                            | 32                  | 32                           | 32                                   |
| Metropolitan area type (versus nonmetro)                      | 81                  | 82                           | 80                                   |
| Northeast census region                                       | 21                  | 22                           | 18                                   |
| Midwest census region                                         | 23                  | 25                           | 20                                   |
| South census region                                           | 36                  | 34                           | 39                                   |
| West census region                                            | 21                  | 19                           | 23                                   |
| <b>Health conditions<sup>b</sup>, %</b>                       |                     |                              |                                      |
| Cancer                                                        | 19                  | 20                           | 16                                   |
| Heart disease                                                 | 40                  | 39                           | 41                                   |
| Lung disease                                                  | 28                  | 30                           | 25                                   |
| Stroke                                                        | 10                  | 6                            | 15                                   |
| Diabetes                                                      | 31                  | 32                           | 29                                   |
| <b>Functional impairment<sup>b,d</sup>, %</b>                 |                     |                              |                                      |
| Bathing                                                       | 42                  | 22                           | 72                                   |
| Eating                                                        | 26                  | 10                           | 50                                   |
| Dressing                                                      | 43                  | 24                           | 72                                   |
| Toileting                                                     | 23                  | 8                            | 45                                   |
| Transferring                                                  | 27                  | 11                           | 52                                   |
| Walking inside                                                | 35                  | 16                           | 64                                   |

SOURCE Authors' analysis of the data from participants in the National Health and Aging Trends Study ages 70 and older who had a sample person interview and who died between 2011 and 2017. Weighted percentages (or medians) are shown. For a table that includes additional data, see online appendix exhibit A8 (see note 31 in text).

<sup>a</sup> Dementia status was determined at cohort entry based on the National Health and Aging Trends Study algorithm using: report of diagnosis, proxy responses to the AD8 dementia screening, or cognitive testing.

<sup>b</sup> Assessed at cohort entry, which was a mean 10.5 (standard deviation [SD]: 10.0) months before death.

<sup>c</sup> Assessed at time of death via National Health and Aging Trends Study last-month-of-life survey or via claims data.

<sup>d</sup> Impairments indicates the percentage of participants who received help or did not do this activity of daily living.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Exhibit 2:**

Outcomes of last-month-of-life care quality, overall and comparing people living with dementia and those without dementia among Medicare beneficiaries ages 70 and older by dementia status, 2011–17

| Measure                               | Overall            | Without dementia | With dementia | P-value <sup>a</sup> |
|---------------------------------------|--------------------|------------------|---------------|----------------------|
| <b>Quality of care (no.)</b>          | 1,987 <sup>b</sup> | 1,051            | 936           | 0.832                |
| Excellent (%)                         | 48.3               | 48.5             | 48.0          |                      |
| Very good to poor (%)                 | 51.7               | 51.5             | 52.0          |                      |
| <b>Pain (no.)</b>                     | 1,857              | 1,012            | 845           | 0.0527               |
| No pain (%)                           | 30.3               | 30.8             | 29.4          |                      |
| Pain not managed (%)                  | 16.0               | 17.8             | 13.2          |                      |
| Pain managed (%)                      | 53.8               | 51.4             | 57.3          |                      |
| <b>Trouble breathing (no.)</b>        | 1,901              | 1,033            | 868           | 0.054                |
| No trouble breathing                  | 44.0               | 42.0             | 46.8          |                      |
| Breathing not managed (%)             | 11.1               | 12.6             | 8.9           |                      |
| Breathing managed (%)                 | 44.9               | 45.3             | 44.3          |                      |
| <b>Anxiety or sadness (no.)</b>       | 1,782              | 988              | 794           | 0.0903               |
| No anxiety (%)                        | 41.7               | 43.2             | 39.5          |                      |
| Anxiety not managed (%)               | 27.1               | 27.7             | 26.2          |                      |
| Anxiety managed (%)                   | 31.1               | 29.1             | 34.3          |                      |
| <b>Personal care managed (no.)</b>    | 1,973              | 1,036            | 937           | 0.0173               |
| Always (%)                            | 81.0               | 79.0             | 83.7          |                      |
| Usually to never (%)                  | 19.0               | 21.0             | 16.3          |                      |
| <b>Enough spiritual support (no.)</b> | 1,543              | 806              | 737           | 0.714                |
| No (%)                                | 57                 | 56.5             | 57.6          |                      |
| Yes (%)                               | 43                 | 43.5             | 42.4          |                      |
| <b>Goal-consistent care (no.)</b>     | 1,936              | 1,026            | 910           | 0.2786               |
| No (%)                                | 11.7               | 11.0             | 12.8          |                      |
| Yes (%)                               | 88.3               | 89.1             | 87.3          |                      |
| <b>Treated with respect (no.)</b>     | 1,972              | 1,033            | 939           | 0.717                |
| Always (%)                            | 87.2               | 87.3             | 87.0          |                      |
| Usually to never (%)                  | 12.8               | 12.7             | 13.0          |                      |
| <b>Patient or family input (no.)</b>  | 1,934              | 1,024            | 910           | 0.4052               |
| No (%)                                | 9.3                | 9.8              | 8.5           |                      |
| Yes (%)                               | 90.7               | 90.2             | 91.5          |                      |
| <b>Family informed (no.)</b>          | 1,973              | 1,040            | 933           | 0.032                |
| Always (%)                            | 80.6               | 78.9             | 83.1          |                      |
| Usually to never (%)                  | 19.4               | 21.2             | 16.9          |                      |
| <b>Care coordinated (no.)</b>         | 1,879              | 986              | 893           | <0.001               |
| No (%)                                | 13.4               | 16.9             | 8.6           |                      |

| Measure                                  | Overall | Without dementia | With dementia | P-value <sup>a</sup> |
|------------------------------------------|---------|------------------|---------------|----------------------|
| Yes (%)                                  | 86.6    | 83.1             | 91.4          |                      |
| <b>Late transition<sup>c</sup> (no.)</b> | 1,957   | 1,056            | 901           | 0.0197               |
| No (%)                                   | 81.5    | 79.7             | 84.2          |                      |
| Yes (%)                                  | 18.5    | 20.3             | 15.8          |                      |

SOURCE Authors' analysis of the data from participants in the National Health and Aging Trends Study ages 70 and older who had a sample person interview and who died between 2011 and 2017. Outcome measures are presented as weighted numbers and percents and are drawn from the last-month-of-life survey were completed by a proxy (71 percent of respondents were spouses or children); mean time to completion after decedent death was approximately 6 months (mean: 188.5 days; standard deviation: 131.6 days). For a table that includes additional data, see online appendix exhibit A9 (see note 31 in text).

<sup>a</sup>P values are the result of unadjusted bivariate analyses including chi-square tests for categorical variables to determine statistically significant differences between those with and without dementia.

<sup>b</sup>As response rates varied by outcome, the first row of each outcome includes the *N* for each population.

<sup>c</sup>Late transitions were defined as care setting changes in the last 3 days of life.